# how we work together

**THE INTEGRATED KNOWLEDGE TRANSLATION RESEARCH NETWORK CASEBOOK**

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# FOREWORD

Jessica Reszel

The Integrated Knowledge Translation Research Network (IKTRN) is delighted to present the sixth volume of our casebook series, which focuses on integrated knowledge translation (IKT) projects with and for children and youth.

The creation of a casebook focused on research partnerships related to children and youth is timely. At the time of writing this foreword, our child health-care system is experiencing an unprecedented demand. This extraordinary need for pediatric services has brought an already fragile system to a crisis. While administrators, care providers, policy-makers, and patients and families work quickly to manage the current "perfect storm" in child and youth care, it is clear that systemic changes are needed to create a stronger and more sustainable system that better meets the needs of children, youth and their families. This casebook showcases examples of existing partnerships in child and youth health and social care that are working to do just that.

The cases cover a variety of topics focused on young people in diverse settings, including the intersection of environment and community health (Kennedy *et al.*), rehabilitation for children and youth with disabilities (Mitchell *et al.*; Yamaguchi *et al.*), shared decision-making in juvenile idiopathic arthritis (Proulx *et al.*), children with rare diseases (Smith *et al.*), trauma-informed care in inpatient mental health (Stokes *et al.*), speech-language pathology in school settings (Vollebregt *et al.*) and health and social science research more broadly (Woodgate *et al.*). These partnerships took different forms, ranging from national networks to partnerships with single organizations.

This casebook's focus on IKT in child and youth settings also makes important contributions to the science and practice of IKT by expanding our understanding of who can (and should) be a research partner and the roles that these partners can take on the team. While in IKT the term "knowledge user" is commonly used to describe the non-researcher members of the partnership, the cases illustrate the diverse terms being used in practice (e.g., knowledge holders, knowledge-exchange partners, patient partners, parent partners, youth advisors). In some cases, the language has been deliberately chosen to challenge the notion that the non-researcher partners are only "users" of knowledge, and to acknowledge their roles as creators and contributors of knowledge in the partnership.

The cases describe these diverse knowledge users and illustrate how these partners were meaningfully engaged in the process. Authors describe partnering with diverse team members including patients, children and youth, parents, health-care providers, policy-makers, educators, administrators and researchers. In several cases, authors described how knowledge users contributed to designing the partnership itself through co-creating guiding principles and terms of reference, and co-designing partnership frameworks. These teams highlight the importance and benefits of creating and supporting leadership opportunities for knowledge users, with knowledge users taking on roles as co-leaders of advisory committees, serving as mentors, leading project teams, co-hosting events and taking on champion roles. These knowledge-user leadership roles resulted in positive outcomes such as capacity

building, increased project engagement and commitment, improved recruitment and dissemination, and more relevant and innovative outputs.

One of the most unique contributions of this casebook is the insight into using an IKT approach with young people specifically. To initiate partnerships with young people, authors described the importance of understanding their interests and motivators to engage in research and leveraging team members' current relationships and pre-existing committees. Teams applied developmentally appropriate methods to maintain partnerships with youth, including tailoring their communication methods, meeting formats and timing, and engaging with social media. Although not without challenges, these intergenerational partnerships were described as beneficial for both the young people and adults. For instance, young people experienced new opportunities for mentorship, skill development and leadership, which in some cases contributed to education and career advancement for youth. In addition, the experience of a collective voice and supportive team was perceived as a positive experience for youth, building their confidence and motivation. For the adults, partnering with youth brought hope, energy and creativity to the team, and inspired the team to persevere as they tackled complex topics.

The authors were asked to reflect on what they learned from their projects and share their most important recommendations for other teams using an IKT approach. For example, authors advised teams to be flexible on multiple fronts—in communication methods, in letting team member roles and the project evolve, and in remaining open to different types of knowledge and lenses. The recommendations also highlighted the importance of creating structures for a meaningful and successful partnership, both at a team level (e.g., application of frameworks and guiding principles) and at a broader organizational/network level (e.g., leadership support). Finally, cases identified the need to create safe spaces for mutual learning, including working to understand different perspectives and acknowledging and learning from errors.

This casebook provides learnings for IKT partnerships in general, and for those working with and for children and youth. We hope that you enjoy reading these cases that show how current research partnerships are not only working to improve care and outcomes for young people, but also learning from and developing an upcoming generation with the knowledge, skills and mindset to work in meaningful partnerships.

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# Learning with and from youth: Reflections of intersectoral researcher-knowledge user partnerships in the Environment, Community, Health Observatory (ECHO) Network

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**Keywords:** youth; intersectoral; environment; health; integrated knowledge translation

## INTRODUCTION

In 2017, the Environment, Community, Health Observatory (ECHO) Network, a research program co-led by researchers and knowledge users, was formed to strengthen intersectoral capacity to understand and respond to the health impacts of resource extraction, particularly in rural, remote and Indigenous communities.[1,2] Youth collaboration has been a core interest throughout the ECHO Network and central to developing connections within and across various sectors. In ECHO's third year, an "ECHO & Youth" team emerged, with youth and educators serving an increasingly important role as both knowledge providers and knowledge users. Working as trainees, researchers, principal applicants and knowledge users for the ECHO Network, we provide reflections from the ECHO & Youth team's engagements as an instructive glimpse into how the ECHO Network has approached relationship-building and collaboration between adult researchers and youth.

## INITIATING THE PARTNERSHIP

While the ECHO Network was largely founded on established and ongoing relationships between researchers and community organizations (e.g., health authority, non-governmental organizations, non-profit organizations), youth predominantly became involved in the ECHO Network as university trainees of ECHO researchers or through existing partnerships within the regional cases.[2] Often, youth engagement was facilitated through an adult involved in the ECHO Network that the youth already had a relationship with (e.g., existing teacher-student relationships, employee-supervisor relationships).

In the ECHO Network, youth are seen as knowledge holders, research partners and collaborators in the dynamic process of knowledge production, mobilization and sharing. In this way, youth have become an increasingly valued type of knowledge-exchange partner. This framing challenges the tendency for youth to be considered one-way knowledge "users" and "learners" and instead honours and appreciates youth as reciprocal knowledge "holders" and "sharers," along with other ECHO Learning Community members. Indeed, youth partnerships were facilitated through the ECHO Network being designed as a "Learning Community"—a structure that reflects ongoing commitment to exchange among different kinds of knowledge holders. As a Canadian Institutes of Health Research (CIHR) funded Team Grant, the overall research design for the ECHO Network prioritized creating a dynamic learning environment, where researchers and members across the Learning Community could share

knowledge and learn from each other in conversations and events.[2] Through this larger engagement, regional cases, community partners and ECHO researchers could invite educators and the youth they work with to these events, providing a welcoming environment for new youth partnerships to form.

The Learning Community structure expanded the types of youth engagement that the ECHO Network was able to support by leveraging collaborations with existing projects. For example, a partnership between School District 91 and ECHO Network members at the University of Northern British Columbia helped inform the design of the "Koh-learning in our Watersheds" project. Additionally, connections between the ECHO Network and the Health Arts Research Centre created opportunities for ECHO researchers, trainees and youth to participate in a science and health camp designed to support Indigenous youth pursuing higher education.

Youth involvement in the ECHO Network was designed to respond to diverse interests among different types of youth. For example, in response to the youths' desire to have spaces to work together independent of later career-stage researchers, youth who wanted to lead a trainee team were encouraged to self-organize meetings and set their own agendas, which included supporting each other through academic endeavors, co-publishing and building research capacity. Further, youth who wanted to develop their facilitation skills were invited to co-host ECHO knowledge-exchange events, while others who wanted to engage younger youth across the network were encouraged to design cross-network events to achieve this. Invitations were emailed to the ECHO Network Learning Community with an explicit note to extend the invitation to the youth they work with.

Timelines and styles of engagement were determined by the youth themselves, informed by insights into what skills they wanted to acquire and in what capacity they wanted to be involved in the network. Youth engagement was further facilitated at ECHO events by asking youth to share their experiences and knowledge of environment-community-health connections. By rooting their involvement in the network in their own lived experiences, we received feedback from youth that they felt comfortable, confident and eager to be involved in ECHO activities, and they did not find participating to be onerous or intimidating.

## MANAGING THE PARTNERSHIP

The ECHO & Youth Team provided opportunities to both strengthen connections between adult and youth researchers and leveraged the success of established projects through the sharing of integrative tools and processes. One example is a collaboration between Université de Moncton Groupe de développement durable du Pays de Cocagne and École Grande-Digue in the ECHO New Brunswick regional case. Together, they led a Watershed Exploration Walk in 2018 and 2021, the second time enhancing the activity by using the phone-based geospatial SMASH app,[3] a tool trialed and facilitated by youth-based ECHO work in British Columbia.

The ECHO Network demonstrated its commitment to prioritizing youth leadership through a range of strategies. For instance, Grade 11 and 12 students and their teacher (School District 91, northern British Columbia) traveled to the ECHO Network team meetings in 2018 (Camrose, Alberta), 2019 (Moncton, New Brunswick) and 2022 (Cowichan Lake, British Columbia). Youth attendees at these meetings participated actively alongside other Learning Community members and were empowered to present feedback and recommendations to inform future youth inclusion

throughout the network.[4] These engagements guided the direction of various ECHO events including youth-led and youth-centred sessions in the knowledge exchange-focused [ECHO Pulse series](#).[5] Commitments to using age- and stage-appropriate methodologies as well as equity-centred participation were also demonstrated by our development of youth social media channels such as the Alberta Regional Case's [ECHO Tik Tok](#).

Learning from and with youth as knowledge-exchange partners in the ECHO Network was particularly valuable when working at the complex nexus of environment-community-health issues. We found that youth were proactive and positive about addressing complexity, and that their hope and energy helped to move other (adult) researchers beyond feelings of "stuckness" when grappling with these topics. The active involvement of youth in the ECHO Network also provided an additional influence on the adult researchers' sense of accountability in grappling with environment-community-health issues, given that the younger generations are being born into, and already having to deal with, these intersecting challenges. Learning Community members consistently noted that engaging with youth increased their own willingness to "stay with the trouble."[2 (p 14)]

Despite the evident benefits, it is important to be aware of the challenges that can arise when engaging youth in these intergenerational contexts. One such challenge occurs when youth are encouraged to creatively express and address equity issues in ways that cross traditional silos of sectors and disciplines and then encounter organizations and institutions that are not necessarily attuned to these integrative perspectives. In response, the ECHO Network is learning about how best to (a) equip youth to be prepared to encounter the siloed approaches that characterize many environment, community and health institutions; and (b) further enable youth to

navigate these settings with the tools needed to encourage more integrative approaches when this is possible and desired.

## IMPACT OF THE PARTNERSHIP

Providing youth with meaningful opportunities to engage as knowledge holders in the ECHO Network and benefit from mentorship are key outcomes that led to capacity-building and opportunities for career and education advancements. Several youth who engaged with ECHO while at grade school are now studying health or environmental sciences at university and taking on leadership roles in conservation initiatives fuelled by involvement in the ECHO Network. Further, one of the youth members who previously held the ECHO project assistant role was mentored by the research manager to then co-fill the role of network coordinator. The Watershed Exploration activity integrated curriculum spanning science, physical education, language arts and technology, which shifted educators' pedagogical approaches to thinking about health and environment connections in contexts ranging from New Brunswick to northern British Columbia.

## LESSONS LEARNED

At the centre of the ECHO Network's approach are the highly valued relationships formed across the Learning Community. By intentionally engaging youth as knowledge-exchange partners, the ECHO Network has supported intergenerational connections, enabling opportunities for reciprocal growth among Learning Community members. The ECHO Network has provided a valuable space to explore complexity, tap into collective wisdom when grappling with complex issues and engage in supportive cross-generational spaces of mutual learning when issues feel overwhelming. Through initiating, developing and navigating partnerships, we have come to understand that responses to issues are context specific. Therefore, we suggest a series of questions, rooted in the lessons we

have learned, which can be used to critically reflect on how to manage intergenerational partnerships:

**1** **Be flexible.** How can you integrate flexibility in your partnerships to allow new interests and diverse knowledge sources to emerge? What steps are you taking to ensure your partnership allows for youth-responsive pathways for this type of emergence to happen?

**2** **Be aware of ethical dilemmas.** How can you include youth in research in ways that are mutually beneficial,[6] and respond to the ethical dilemmas we encounter when youth are changing the ways we think through these complex issues while also being faced with siloed systems that cannot implement their suggestions without upstream system-level changes?

**3** **Create safe, equitable spaces.** How will you challenge dominant narratives and paradigms while working to the best of your ability to provide a safe, equitable and productive space for all your members and partners?

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# Using a learning collaborative as a knowledge translation approach to create youth apprenticeship programs in rural communities

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**Keywords:** rural; apprenticeship; youth; learning collaborative; integrated knowledge translation

## INTRODUCTION

The Rural Youth Apprenticeship Development (RYAD) project uses an integrated knowledge translation (IKT) approach to partner researchers with state vocational rehabilitation agencies (referred to as VR agencies henceforth) to develop apprenticeship programs for working-age youth with disabilities living in underserved rural communities in the United States. This apprenticeship implementation project included VR agencies, youth with disabilities, the workforce system and businesses as knowledge co-producers and partners. This article focuses on the primary partners—VR agencies—and the Learning Collaborative Model, which serves as the infrastructure for the collaboration.

## INITIATING THE PARTNERSHIP

The RYAD project staff have a long-standing history working with VR agencies on several federally funded grants that focus on improving employment outcomes for individuals with disabilities. The nexus for this project began as part of a former grant initiative in 2016 when our institute hosted a think tank and invited 23 VR agencies to explore strategies to increase the participation of people with disabilities in apprenticeship and paid work experience programs. During the meeting, it became clear that while the employment landscape for people with disabilities had improved nationally, there are fewer opportunities for working-age youth with disabilities to access apprenticeship programs in rural communities.

After the think tank, there was interest in continuing the dialogue, and this led to the establishment of a community of practice to identify promising practices and knowledge gaps about apprenticeship programs. The community of practice met monthly for one year and identified the following questions:

- How can we develop apprenticeships when there are limited community partners and employers?
- How can we address skills gaps in the rural workforce where there are limited training and education opportunities?
- How can we strategically address the lack of youth support services, such as access to technology, transportation and other resources?
- What tools and resources can VR agencies access and use to educate stakeholders on what constitutes apprenticeship programs and the opportunities and benefits to creating them in rural settings?

In 2020, we sought to further study these questions, applied for funding and were awarded the RYAD grant to identify rural-specific needs, challenges and effective strategies to develop youth apprenticeship programs in rural

communities across states. We engaged with VR agencies that were just beginning to explore and learn about apprenticeship programs. We also partnered with Arkansas Rehabilitation Services and Career Development Center, who presented at the aforementioned think tank we hosted in 2016, to serve as the mentors in the learning collaborative to share their knowledge of creating successful youth apprenticeship programs in rural communities in their state. Their experience was valuable to other agencies that joined the learning collaborative from Wyoming, Vermont and Maine, three of the most rural states in the United States, as they began to think about developing programs.[1]

## MANAGING THE PARTNERSHIP

The RYAD project uses the Learning Collaborative Model to foster ongoing dialogue between the partners to support implementation of apprenticeship programs for youth with disabilities in rural communities.[2] The Learning Collaborative Model is a knowledge translation approach for implementation and evaluation studies that has successfully been used with over 40 VR agencies across numerous national research and implementation projects. This knowledge translation strategy aligns with the project's broader IKT approach of involving the key stakeholders in all the knowledge development phases. The key tenets of the model are facilitation and guidance by researchers and peer-to-peer exchange. All partners have a stake in the success of the project and are fully engaged from research question development through implementation. The focus is the operational level to support the agencies as they navigate through geographic contexts, youth-specific considerations and procedural and bureaucratic factors that play a significant role in the success of implementation. For example, a core component of apprenticeship programs is the education or instruction leading to occupational credentials. With youth being the target group, the participating VR agencies

explored different approaches for partnering with secondary, post-secondary and other training providers. The group used the learning collaborative forum to explore possible strategies they could propose to their education partners. The identified strategies included offering high school or college credit, providing flexible schedules to fit the apprenticeship classes and providing on-the-job training during school hours.

The research and vocational rehabilitation partners attend quarterly learning collaborative meetings with a co-developed agenda that includes implementation updates and accomplishments, brainstorming on challenges and topical discussions on emerging themes. This provides a forum for problem-based learning and ongoing collaboration to assist the agencies with apprenticeship program development, continuous improvement and strategic planning for sustainability. Commenting on his experience as a mentor member of the learning collaborative, Jonathan Bibb of Arkansas stated:

*"It's been very eye-opening to me because I see a lot of the similarities in the struggles we face in rural communities across states. For example, transportation, especially for people with disabilities, is a real barrier and a recurring issue. So how do you address it? How do you know how to work together to find solutions to these problems? That's one of the things we spent a lot of time brainstorming together in the learning collaborative."*

The goal of these interactions is to move beyond disseminating research findings to fostering dialogue about challenges, barriers and solutions to implementing rural apprenticeship programs. In between learning collaborative meetings, the VR agencies receive ongoing individualized support on implementation and evaluation through regular check-ins with the research team, on-demand consultations with the mentor, guidance from

experts on the advisory council and adjunct meetings with other agencies that have created and implemented apprenticeship programs.

The model helps with system-wide capacity building through documentation and development of a wide range of tools designed to be adapted for agency use. The partners are involved in all stages of content development, from determining what resources and tools are needed, to designing, testing, using and disseminating products. While there is no "one-size-fits-all" approach, the learning collaborative creates a meaningful feedback loop that helps reach consensus on joint initiatives while allowing flexibility for findings to be contextualized based on agencies' unique rural settings and the populations they serve.

## IMPACT OF THE PARTNERSHIP

The VR system varies from one service delivery area to the next.[3] Partnership between agencies and researchers in the learning collaborative led to increased awareness and understanding of the unique needs, barriers and opportunities for developing youth apprenticeship programs in rural areas. One of the most striking barriers that arose in our work together is the lack of understanding of apprenticeship programs and the value they can add to the rural workforce. The knowledge exchanged about VR staff's working and lived experience within rural communities provided insight that led to the collaborative development and dissemination of outreach materials that fit rural community contexts and informed program design.

The project researchers partnered with the agencies to co-create outreach materials and explore dissemination methods that are most appropriate and relevant to each rural community. The agencies in the learning collaborative shared a variety of ways their offices connect with community stakeholders and helped identify three main target groups to receive outreach materials: vocational rehabilitation counselors, local businesses and youth. Project partners then recommended further changes for overall readability, plain language use, preferred messaging per audience, design and format. The format of materials was heavily influenced by how the agencies communicate and connect with youth and businesses in each of their rural areas.

Vocational rehabilitation agencies have reported several benefits garnered from their participation in the learning collaborative, including research to practice guidance, access to promising practices and assistance in tailoring the strategies to their agencies. The Learning Collaborative Model provided the space and opportunity for consistent knowledge exchange among partners that built clear lines of communication and trust. Partners formed both formal relationships within the project and externally within their own workforce development system networks. The impact of the learning collaborative is predicted to support continued efforts among partners working to build, maintain and sustain rural youth apprenticeship programs.[2]

## LESSONS LEARNED

1 **Each rural community has a unique context and benefits from customized knowledge translation strategies.** RYAD's approaches to dissemination and outreach were tailored based on how the VR agencies communicate and connect with youth and businesses in each of their rural areas. Engaging with those who live within the rural communities is key to reaching youth with disabilities in the most underserved, rural areas.

**2** **Rural community partners are co-producers of knowledge and key to maximizing implementation efforts.** The RYAD project team worked collaboratively with VR agencies to develop implementation plans that define partners' roles and determine outcome measures. These plans were living documents that were revised as the project progressed and included detailed steps and lessons learned.

**3** **Providing an infrastructure for ongoing dialogue specific to rural communities and the challenges they face maximizes knowledge translation relevance, reach and impact.** RYAD's Learning Collaborative Model provided the infrastructure for VR agencies to collaboratively form partnerships, build trust, leverage resources and break barriers to ultimately improve employment outcomes for rural youth with disabilities.

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# Engaging young people with juvenile idiopathic arthritis in shared decision-making research

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**Keywords:** patient engagement; engagement with young people; shared decision-making, lived experience; integrated knowledge translation

## INTRODUCTION

Juvenile idiopathic arthritis (JIA) is a chronic inflammatory disease primarily affecting the joints that can cause significant pain and adversely impact the quality of life of young people and their families.[1-5] Young people with JIA must regularly manage pain, which can be complex because of the wide variety of available treatment options, each carrying potential benefits and risks.[6] It is important for young people to participate in decision-making[7] with health-care providers to identify the most appropriate pain management strategies for them.[8] Shared decision-making, a process that involves the exchange of evidence-based information on treatment options and discussion of youth and families' values and preferences, is well-suited to making personalized pain management decisions. Our team designed a research program in 2015 that aimed to develop and evaluate a patient decision aid[9] for pain management in JIA. This interactive web-based patient decision aid, the "JIA Option Map," was evaluated for acceptability and usability to help young people with JIA choose among pain management options. We are now expanding the

JIA Option Map to manage other JIA symptoms and functional activities.

This research program uses an integrated knowledge translation (IKT) approach[10] and involves patient partners[11] with lived JIA experience, pediatric rheumatology health-care providers and researchers. This paper describes our process for engaging young people with JIA as partners in this research program, the impact of patient partner participation and lessons learned. Young people with JIA participated in different ways throughout the research program, consistent with the "Involve," "Collaborate" and "Empower" levels noted in the International Association for Public Participation (IAP2) Spectrum of Participation.[12] The level of engagement varied depending on the tasks and evolved over time with a more formalized participation since 2020.

## INITIATING THE PARTNERSHIP

The partnership between the principal investigator (PI) (Dr. Karine Toupin April) and knowledge broker (Laurie Proulx) developed over a period of fifteen years, prior to the current research

program when the PI and knowledge broker first met at a Canadian Arthritis Network meeting in 2006. Proulx met other people with JIA through her involvement in the Canadian Arthritis Patient Alliance and recruited individuals (Alex Sirois, Emily Sirotich) for the research program, while the PI met additional individuals (Natasha Trehan, Naomi Abrahams) who wished to join the team. The role of the patient partner (Proulx) evolved over time and was eventually formally acknowledged as a knowledge broker[13] in 2020, acting as a facilitator between the patient partners and the PI and other research team members. The knowledge broker took on a paid leadership role, which includes managing and coordinating patient engagement activities for the research program, as well as developing and implementing a knowledge translation plan focused on the public, patients, health-care providers and policymakers.

## MANAGING THE PARTNERSHIP

In the past two years of the research program, patient partners contributed to several activities including developing protocols and funding applications, helping to adapt study procedures and recruiting participants via social media, and developing various knowledge translation activities and products. We used a variety of approaches to support young people with JIA, such as support from a knowledge broker, agreed-upon terms of reference, training, and flexibility in engagement approaches allowing patient partners to take on tasks based on their interests and availability. Patient partners were acknowledged in publications and compensated to mitigate any negative financial impacts.

The knowledge broker role aimed to facilitate communication between patient partners and the research team and reduce power imbalances with researchers and health-care providers. The role also involved communicating and collaborating with patient organizations and other stakeholders to help support the research and disseminate and implement findings. The individual's past experience as a patient partner and communication skills helped them identify barriers to participation and create a safe environment where patient partners could speak for themselves.

The knowledge broker and PI drafted the terms of reference, which described patient partners' roles and responsibilities, methods to resolve conflicts, training and compensation based on prior recommendations.[14] The terms of reference were updated based on the patient partners' (Sirois, Sirotich, Abrahams, Trehan) feedback. The knowledge broker and PI provided the patient partners with training resources about health research[15] and opportunities to build research skills through hands-on activities (e.g., abstract writing, poster presentations, video creation, networking events, publication writing).

Bi-monthly meetings between patient partners and the PI were facilitated by the knowledge broker with an agenda established in advance with input from patient partners. We solicited availability well in advance to respect their other commitments. One-on-one meetings were offered if meeting times were not convenient. The knowledge broker and PI used active listening and questions to solicit group feedback. Minutes were recorded and shared. Meetings occurred with the full study team every three to four months. The knowledge broker actively participated in study team meetings and solicited participation of patient partners to support equitable participation. Patient partners chose Slack for regular communication and contributed to documents on a shared drive.

The team regularly evaluated patient engagement practices to ensure they met the patient partners' needs. Based on a review of patient engagement

measurement tools,[16] the team selected the Public and Patient Engagement Evaluation Tool (PPEET)[17] to evaluate patient engagement using an anonymous online survey. Results of the first evaluation indicated that:

- The terms of reference were clear and reflected the roles of patient partners
- Patient partners had enough information and support available to share their expertise
- The communication tools were useful in facilitating engagement
- Patient partners were able to express themselves and felt that their views were heard
- The knowledge broker role was helpful since it identified support needed, made it easier to share patient partners' perspectives and decreased power imbalances with other team members

## IMPACT OF THE PARTNERSHIP

Patient partners had an impact on various aspects of the research. For example, patient partner perspectives widened potential users of the JIA Option Map from youth to young adults with JIA. Patient partners also identified the need to expand the JIA Option Map to include mental health symptoms. Patient partner feedback had a significant impact on the study design and outcome measures to expand and evaluate the JIA Option Map and facilitated participant recruitment through social media. In terms of outputs, the JIA Option Map was improved based on patient partner feedback.

Patient partner perspectives showed the importance of increasing patients' and the public's awareness of this work, which led to the co-creation of a website (over 1,000 views) including a section for plain language summaries and logos created by a patient partner (Trehan) and research promotion through Twitter, Instagram and YouTube. There was a 10-fold increase in use of social media and dissemination of findings at

scientific conferences and through webinars, videos, blog posts and podcasts including a podcast with Take a Pain Check, a not-for-profit organization founded by a patient partner (Trehan) for youth with rheumatic diseases.[18]

The knowledge broker facilitated communication with patient organizations, which supported participant recruitment through social media. The knowledge broker also helped disseminate findings to policy-makers, including writing a policy submission for the Canadian Pain Taskforce consultations. Finally, the impact was profound on the PI, who chose health research as a career based on her experiences with chronic illness. It prompted further self-reflection on the power imbalance between researchers/clinicians and patients in health research and how to ensure that the entire research team facilitates patient engagement and IKT. Patient partners benefited personally by having their perspectives recognized and valued, influencing JIA health research, developing new skills and meeting other people with JIA.

## LESSONS LEARNED

Although our IKT approach has many strengths, the PPEET evaluations and analysis identified some areas for improvement in our partnership, including:

- actively agreeing on tasks and timelines in advance
- providing more training opportunities for patient partners according to their needs
- recruiting diverse patient partners reflecting socioeconomic and cultural diversity, as well as parents and caregivers

The PI and the knowledge broker experienced several difficulties with paying patient partners, stemming from administrative barriers at the academic institution. Our challenges led to a publication[19] focused on identifying barriers and solutions to patient partner compensation.

We have several recommendations for research teams:

**1** **Make expectations transparent and routinely check in with partners.** Co-develop terms of reference to manage expectations related to the patient partnerships. Assess and evaluate patient engagement throughout the research process to identify gaps and areas for improvement.

**2** **Provide flexibility in engagement and communication approaches.** For instance, book meetings to accommodate school commitments and use different communication tools to enable young people to be involved in research. Regularly communicate tasks and timelines using preferred communication channels.

**3** **Consider engaging a knowledge broker with lived experience** in a support role to facilitate communication with patient partners.

Our case study shows that young people with JIA, led by a knowledge broker with lived experience, and following agreed-upon but flexible terms of reference, can participate effectively and provide valuable perspectives in research on shared decision-making. Future work will explore communication between patient partners and the entire research team in more depth.

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# Patient partnership in a pediatric rare disease research network: Mutual learning for meaningful research

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## INTRODUCTION

INFORM RARE is a Canadian research network, established in April 2020 with funding from a Canadian Institutes of Health Research Strategy for Patient-Oriented Research (SPOR) Innovative Clinical Trial Multi-Year Grant. The network is co-designed and co-led by patients and families, health-care providers, policymakers, methodologists and research ethicists. Working together, we generate evidence to improve clinical care, outcomes and health policy for children with rare diseases. Patient partnership and engagement is embedded in all aspects of INFORM RARE. We believe that with our integrated knowledge translation (IKT) approach we can co-produce research that is more relevant and actionable. Although our IKT approach includes the engagement of multiple stakeholders, for this case study we concentrate on partnerships with patients and families.

## INITIATING THE PARTNERSHIP

We used a variety of approaches to establish partnerships with patients, families and patient group representatives. Maureen Smith joined the team as the principal knowledge user (patient partner co-principal investigator (co-PI)) after Dr. Beth Potter, the nominated principal investigator, invited her to an "I have an idea" meeting. Smith, an experienced patient partner who was actively involved with the rare disease community as a

board member of the Canadian Organization for Rare Disorders and had lived experience with a rare pediatric disease, had already partnered on two studies with Potter over three years, and they agreed that ideally the collaboration would begin at the incubation stage. From this point onward, Smith was involved as an equal partner, co-leading the patient engagement aspects of the grant application. Furthermore, we were interested in exploring whether a model that entrusts the co-leadership of the patient engagement strategy to a patient partner co-PI could mitigate the power imbalances inherent to partnerships with researchers. Feedback thus far indicates that the patient partner co-PI and researchers enjoy a mutually beneficial relationship. Power imbalances are mitigated by shared decision-making and openness to the value of lived experience and patient engagement expertise.

With the help of patient organizations and clinicians, six patient partners were recruited as co-investigators, two from each of the three disease areas that are the focus of INFORM RARE's initial studies: mucopolysaccharidoses (MPS), phenylketonuria (PKU) and spinal muscular atrophy (SMA). They joined the study at the grant application stage. Four of the six patient partners were parents of children with these conditions and two were leaders of national patient organizations. With the exception of one partner who had already

collaborated with Potter and Smith, we forged new relationships with these knowledge users. It took several months to create the team and settle on research questions of mutual interest. For example, our early meetings and correspondence took place within each disease area to co-develop research priorities. Once we were funded, we initiated meetings with the full group of patient partners to build relationships and create opportunities for co-design across the network.

Once collaboration was established with our patient partners, the MPS, PKU and SMA patient groups helped us recruit members for a parent and caregiver advisory group (nine members) and a youth advisory group (11 members, aged 12-18 years). Advisors partner with us at key points during our studies (e.g., recruitment materials and survey questions). Our team also grew to include a youth facilitator and a "special youth advisor," a role created to accommodate the needs of a young adult.

## MANAGING THE PARTNERSHIP

From the onset, we invested time, energy and resources into nurturing the co-leadership of our patient partner co-PI and our firm commitment to patient partnerships based on continuous, mutual learning, as we believed it would be fundamental to the success of our IKT approach. Additionally, we took into consideration the realities of pediatric rare disease research: clinician-researchers collaborating with their own patients and families; the small pool of potential partners; partnering with people who live with the uncertainties of their health journeys; and the demands of complex care on youth and their families. We also acknowledged the unique strengths families of children with rare diseases often have, such as in-depth knowledge of their child's health and the health-care system, longstanding relationships with health-care providers and commitments to advocacy. Our

patient engagement strategy was designed with flexibility to accommodate different levels of engagement and adapt to changing needs.

To ensure that partnership roles were clearly defined, we use a published framework describing six levels of engagement: learn/inform, participate, consult, involve, collaborate and lead/support.[1] We initially envisaged the patient partner co-PI to be at the "lead/support" level, the six co-investigators at the "collaborate" level and the advisors at the "involve" level. We soon discovered that the needs of a large network carrying out multiple projects necessitates fluid levels of engagement where patient partners can move in and out of the various levels depending on the activity. For example, one of our projects is the co-development of patient registries in partnership with CanPKU and the Canadian MPS Society. The two co-investigators who are leaders within these organizations have taken on a "lead/support" role for this project and our patient partner co-PI has taken on a "consultant" role. As a further example of the need to adapt processes to our needs, although INFORM RARE adheres to the SPOR Guiding Principles[2] for patient engagement in research, we invited our patient partners to co-design our own guiding principles that fully reflect our partnership.[3] An example of a new principle is "impact," which reflects our commitment to identify, evaluate and share the differences that patient engagement makes. A unique aspect of working in pediatrics is the opportunity to work with youth advisors. We quickly realized that although we could effectively use both virtual meetings and email requests for feedback from parent advisors, the best approach with youth advisors was virtual meetings, as they are learning how to engage in research and value connecting with one another directly. Thus far, we have adapted meeting materials and methods, checked in with short surveys and welcomed a young teacher with a rare disease as a youth facilitator.

In spite of the best intentions and a firm commitment to patient partnered research, ensuring equitable participation of researchers and knowledge users in a large network is challenging when it involves embedding them in smaller working groups. As co-investigators, our patient partners were invited to join INFORM RARE's working groups (e.g., ethics, trial methods, health economics, disease-specific groups). This required training and support for other working group members (e.g., clinicians, methodologists) and their research staff.

## IMPACT OF THE PARTNERSHIP

After two years, we can report on several positive approaches to and impacts of patient partnership and engagement. We track all activities and feedback received from our advisors and report back to them on the changes that were made. When warranted, we also explain why certain changes were not made. Although this is time consuming, we see it as important for developing a trusted relationship that values the expertise of lived experience. Patient partners are fully integrated as members of working groups: they co-lead the development of two patient registries and are offered co-authorship on publications and opportunities to present at conferences. All patient partners and advisors are offered compensation. Thus far, informal surveys and interviews revealed that patient partners and advisors were overwhelmingly satisfied with their engagement experiences, see the impacts of their collaboration and appreciate opportunities for capacity building (e.g., participation in related projects or grant applications). In individual interviews, partners and advisors also shared constructive criticism, for example, suggesting that they would appreciate additional communication about how each activity fits into the greater research vision. We see this openness to providing feedback as an indication that partners and advisors are both comfortable on the team and invested in making things better.

Now that our research is established, we look forward to assessing the strength of our partnerships and their short-, medium- and long-term impacts. We are in the process of co-designing a comprehensive evaluation plan with a multi-stakeholder group, including patient partners.

## LESSONS LEARNED

We have the following recommendations for researchers who wish to partner with patients:

1 **Initiate the partnership as early as you can in your research process.** Don't worry about getting everything right at the onset. The first step is starting the conversation, listening to people with lived experience and appreciating how your perspectives can differ. Next, initiate discussions with potential partners to determine how they would like to be involved. Allow for flexibility once the partnership is underway.

2 **Build training and support into your IKT plan.** Carefully consider your context and co-design an IKT plan that meets your needs. Consider the characteristics of both knowledge users and others on your team (e.g., age group, experience in patient partnered research, sensitivity to sharing lived experience, interests) and plan for training and support.

3 **Embrace the spirit of mutual learning and let it guide you every step of the way.** Be aware of transactional behaviours where only researchers benefit from the interactions with patient partners and remember that patient partners bring their lives into this. Acknowledging errors and learning from them is essential.

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# Planning the implementation of a trauma-informed care program at a pediatric hospital: A trainee's experience using an integrated knowledge translation process

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## INTRODUCTION

"Trauma-informed care" (TIC) is a philosophy that involves addressing the needs of individuals with histories of trauma.[1] Interest in TIC continues to expand, with attempts in Canada to integrate TIC into best practice guidelines,[2] toolkits[3] and practice guides.[4] Generally agreed upon principles of TIC include four "R"s: (1) realizing the prevalence of trauma, (2) recognizing manifestations of trauma, (3) responding appropriately to trauma and (4) resisting re-traumatization, as well as the six principles of safety, trustworthiness and transparency, support, collaboration, empowerment, and cultural and gender considerations.[1,5]

## INITIATING THE PARTNERSHIP

The Children's Hospital of Eastern Ontario (CHEO) is an acute care pediatric hospital, a child and youth mental health agency and a research institute. I (the first author, a PhD candidate) began working at CHEO Research Institute in 2013 and at CHEO as a Registered Nurse in 2014. In spring 2019, given my interests in TIC, I was hired as a research assistant to co-lead a needs assessment across the mental health departments with CHEO knowledge users (Child Psychiatrist and Research Associate). As a result of this assessment, CHEO mental health leadership identified a priority of re-

modelling the inpatient mental health unit within an overarching program of TIC, and I took this opportunity to contribute to CHEO's goal through my doctoral research. In partnership with mental health leadership, in summer 2019, I developed a research proposal to facilitate the selection and implementation of a TIC program. In fall 2019, I initiated meetings with leaders, clinicians and researchers from the mental health department to refine and narrow the scope of this proposal. The clinicians included physicians, psychologists, nurses, an occupational therapist, a social worker and a child and youth counsellor, each of whom either played a leadership role in developing the model of care for the inpatient mental health unit or demonstrated a particular interest in TIC. This group expanded over time as they identified other important stakeholders (leaders across the acute mental health pathway) and became the CHEO mental health TIC advisory committee. By the winter of 2020, the researchers (myself and my thesis advisory committee) and the TIC advisory committee identified our shared research aims, parts of which are components of my thesis:

- To systematically identify TIC interventions used in pediatric inpatient and residential treatment mental health settings, the implementation strategies used with these TIC interventions, the measures used to evaluate

the TIC interventions and the effectiveness of these interventions, through scoping and systematic reviews of the literature and an environmental scan.

- To facilitate the selection of a TIC intervention for the inpatient mental health unit through triangulation of the results from the reviews and through discussions with the TIC advisory committee.

- To facilitate the tailoring of the TIC intervention to the inpatient mental health unit setting and to co-develop an implementation and evaluation plan, through focus groups with patients, caregivers and staff and through discussions with the TIC advisory committee.
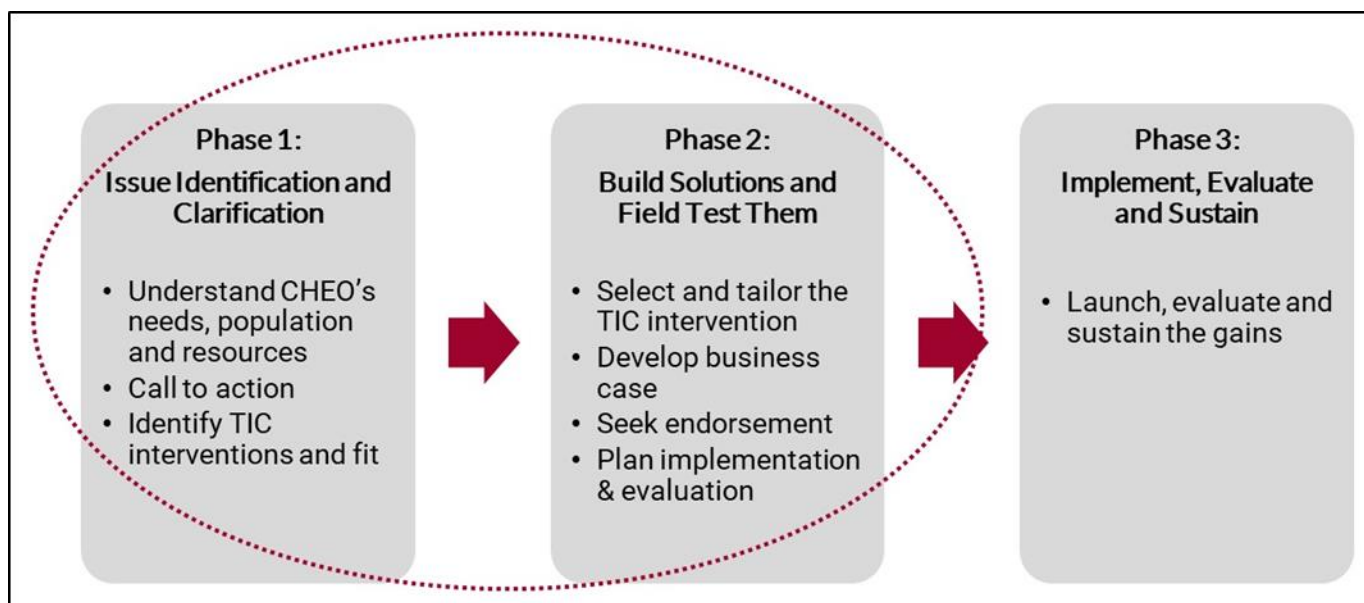
## MANAGING THE PARTNERSHIP

The partnership included researchers and knowledge users (the TIC advisory committee). Throughout 2021, I met with the TIC advisory committee (n= 17) monthly to consult and review project updates, with additional weekly ad hoc meetings with members with specific interests and areas of expertise. Members of my thesis advisory

committee also met on a weekly or biweekly basis to support the progression of the thesis research. In the spring of 2021, when decisions were being made about the selection of a TIC intervention, two knowledge users (psychiatrist and social worker) became co-chairs of the TIC advisory committee. This transition was critical to allow the TIC advisory committee to take agency over the implementation process. It also allowed me to focus on providing evidence-based information to the TIC advisory committee and facilitating the process that aligned with my thesis aims. The TIC advisory committee demonstrated their commitment to this project through regular meetings and through dedicating funds for research assistants and for compensation of focus group participants.

Our implementation partnership followed a fluid process based on the Implementation Roadmap (Figure 1).[6] This roadmap identifies three phases of implementation: (1) issue identification and clarification; (2) build solutions and field test them; and (3) implement, evaluate and sustain. Our current project encompasses the first two phases, broken down into six steps.

**Figure 1.** The Roadmap to Implementation



Phase 1:
Issue Identification and Clarification

- Understand CHEO's needs, population and resources
- Call to action
- Identify TIC interventions and fit

Phase 2:
Build Solutions and Field Test Them

- Select and tailor the TIC intervention
- Develop business case
- Seek endorsement
- Plan implementation & evaluation

Phase 3:
Implement, Evaluate and Sustain

- Launch, evaluate and sustain the gains

In Step 1, we assembled evidence related to the CHEO context. I reviewed the results of the 2019 needs assessment with the TIC advisory committee to contextualize and refine this project and discussed current practices taking place on the target unit.

Step 2 involved a call to action, which was already completed through the formation of the TIC advisory committee. We continued to discuss whether the initial implementation should be limited to the inpatient mental health unit or expand beyond and what stakeholders should be involved in planning. I identified potential best practices by leading a scoping review of TIC interventions and their implementation strategies used in pediatric mental health settings. I also conducted an environmental scan of Canadian agencies that used these TIC interventions, including TIC advisory committee members in the interviews, to explore their feasibility and fit for CHEO.

Step 3 involved customizing the best practices to the local context. The TIC advisory committee identified important criteria to consider in selecting an intervention: cost, limiting redundancy in what already exists, generalizability to other areas at CHEO beyond mental health, Canadian experiences with the TIC intervention, availability of implementation support and flexibility within implementation. Based on these priorities, I presented the TIC advisory committee a narrowed list of three candidate options identified from the scoping and systematic reviews, of which the advisory committee selected one to recommend to leadership. We discussed and determined potential indicators of success for the TIC program at CHEO based on measures used in the literature and based on consultations with CHEO knowledge users (patients, caregivers, staff). The Director of Mental Health approved funding to compensate staff to participate in the focus group consultations and protected time for a CHEO project manager to support the creation of a

business case. A subgroup formalized a business case to submit to the CHEO Foundation to request funds for the training costs associated with the TIC program and two full-time contract staff for 18-months to lead the implementation process.

At present, we are tailoring the selected TIC intervention to the inpatient mental health unit setting while incorporating feedback from consultations with knowledge users (staff, former patients, caregivers). In Step 4, we will assess barriers and facilitators of delivering the TIC intervention. We will conduct a second set of focus groups with unit staff,[7-9] and as part of Step 5, we will identify strategies to overcome identified barriers, based on the TIC and implementation science literature. Once the implementation plan is complete, Step 6 will include a detailed plan for piloting and field testing the TIC intervention on the inpatient mental health unit to inform an eventual hospital-wide launch.

## IMPACT OF THE PARTNERSHIP

To the partnership, I brought expertise in TIC and implementation. I also identified, synthesized and analyzed the evidence, and served as an implementation facilitator. The TIC advisory committee contributed knowledge and expertise of the CHEO context on various levels, provided feedback on what evidence is useful from clinician and leadership perspectives, and offered research support and funding. Through this partnership, the TIC advisory committee increasingly recognized the value of incorporating an evidence-informed process for selecting and implementing a TIC intervention, an approach that will guide CHEO's spread of the TIC program beyond the inpatient mental health unit. Partway through the project, it became clear that a designated person would be required to see through the implementation and evaluation processes, which led to the request for two staff in the business case. Implementation of this project remains ongoing and the outcomes related to the adoption of the TIC intervention are still to come. As a trainee, I gained valuable

experience facilitating this process under the supervision of experts in implementation science and collaborating with stakeholders carrying many levels of expertise on the TIC advisory committee.

## LESSONS LEARNED

**1** **Leadership involvement and support is critical to provide foundational resources for the project.** Having the Operations Director of Mental Health on board from the very beginning, supporting this project conceptually and financially, was critical to progression of this work.

**2** **Knowledge users' development of responsibility for decision-making is essential for progression of the project.** From the outset there were CHEO knowledge users guiding and contributing their research funds to this project. While I was the facilitator of the shared research aims, it became apparent that we still required formal knowledge user leadership on the TIC advisory committee. Once this was established, progress increased.

**3** **Organizational and knowledge-user enthusiasm and perseverance is essential for implementing and sustaining the project.** By the time we established the CHEO TIC advisory committee, there was already a great deal of interest among knowledge users to proceed with the initiative. From a knowledge-user perspective, it is important to be prepared for challenges in keeping the project "on the radar" as other priority projects and unforeseen delays will arise.

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# Establishing practice-based research partnerships with educational speech-language pathologists

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**Keywords:** practice-based research; speech-language pathology; school-based services; integrated knowledge translation

## INTRODUCTION

The way in which speech-language pathology services are delivered within school boards varies depending on a variety of contextual and resource constraints. Over years of presentations and advocacy work in school boards, Dr. Lisa Archibald, who considers herself to be a "clinically-minded researcher," developed relationships with speech-language pathologists (SLPs) whom she describes as "research-minded SLPs." Often, these SLPs had established evidence-informed practices and were interested in partnering with researchers to examine these practices. Given the focus on clinical questions and clinical-research partnerships to answer these questions, a practice-based research approach was adopted.[1] In practice-based research, clinical questions that emerge from practice are answered using research inspired principles, and data is collected in the clinical context. Clinicians and researchers work together throughout the identification of clinical concerns, collection of data and implementation of findings. Practice-based research is a form of integrated knowledge translation, where collaborative partnerships answer questions that specifically emerge from practice. Over the past five years, our team has established collaborative partnerships with SLPs across three school boards in southern Ontario. The goal of these partnerships is to support SLPs in examining their services and integrating the findings.

## INITIATING THE PARTNERSHIP

School boards can be a challenging context in which to conduct research because of the complexity of the organization as well as the need to prioritize instructional time for students. As our team connected with research-minded SLPs, we noticed overlapping interests and considered that by merging our efforts, we could conduct relevant research more efficiently by working in partnership. This practice-based initiative was supported through a Social Sciences and Humanities Research Council (SSHRC) Partnership Development Grant. Our aim was to establish a well-functioning team of clinically-minded researchers who could work flexibly with research-minded SLPs in school boards on an ongoing basis. The team included Archibald, doctoral and post-doctoral researchers, research assistants and school-based SLPs and educators.

In our initial meetings with each school board (n=3), Archibald and one doctoral or post-doctoral researcher met with the SLPs (ranging between two to eight SLPs per board) to discuss the targeted project. This small group of researchers and SLPs formed the lead team. The lead team included the key contacts for each project and was responsible for maintaining communication, sending regular progress updates and making decisions throughout the partnership. At the initial meeting, the SLPs described the current service

delivery model at the school board and the component of the service delivery model that they were interested in evaluating. Through this discussion, we identified the specific research questions that each partnership would investigate, decided how we were going to answer these questions and established each other's roles in the project. Specifically, the SLPs, researchers and trained research assistants were responsible for collecting the data, the researchers analyzed the data, and together the researchers and SLPs interpreted the findings and discussed implementation. In addition to establishing our lead team, a working group of SLPs from each school board was identified to support the partnership and were consulted as needed.

After the initial meeting, the researchers began the procedures for formal review by the ethics review board at the university and the school board's research department. At the same time, we planned a research study to examine the evolution of these partnerships and completed the ethics review process for that project as well. Depending on the school board, the SLPs were involved in the ethics procedures to varying degrees; however, the researchers often worked directly with other school board personnel during this time, which helped the research team to better understand the school board context. For example, researchers worked with an education officer from the accountability and assessment department to support ethics submissions.

Establishing a strong partnership from the outset was important. In our partnerships, there were specific, often unplanned, moments and activities that fostered the development of a strong initial partnership and played a large role in establishing a secure foundation. For example, in one partnership, a doctoral student completed her clinical placement with the school board, which strengthened perceived commitment to the project and enhanced our understanding of the school

board context. In a second project, a doctoral student assisted the SLPs with a current project in their department prior to beginning the planned partnership project, once again demonstrating commitment to the partnership. These rapport building activities strengthened the initial partnership and were important for developing trust amongst the partners.[2] Our analysis found other important themes in the initiation phase including establishing shared goals and mutual respect,[3] formalization of the partnership and roles within the partnership[2] and transparency of the goals of the partnership. Factors that supported the establishment of a formal partnership included involvement from SLP partners in securing grant support and a memorandum of understanding.

## MANAGING THE PARTNERSHIP

Given the practice-based nature of these projects, the research questions were related to clinical concerns that were of interest to both the researchers and SLPs. This common interest supported equal participation from both partners, and as practice-based researchers, our goal was to support the SLPs in answering their questions. At any point where the project changed direction or new research questions were being determined, the SLPs' questions and interests remained the priority. We used several ongoing strategies to encourage and maintain engagement including open communication via email, in-person meetings, presentations, and the identification and support of an internal champion amongst the SLPs. The role of our champion was to communicate the value of the partnership to the group, be available to answer questions regarding the project, maintain communication with the research team and share updates from the research team with the SLPs. We strongly feel that without our champions the engagement and commitment to the projects would have suffered.

Through open communication, our team was able to address workload concerns, manage

hesitancies surrounding outcomes of the partnership and reduce faulty assumptions. Considering the busy caseloads that SLPs already face in school boards, it was important for us to manage the amount of time and work that SLPs were contributing to the project. This workload management was specific to the school board and project; however, workload also varied throughout the span of each partnership. As an example, in one partnership the SLPs were involved in data collection beyond their normal workload in year one of the project, which they reported to be unsustainable in the year-end report. In year two, research assistants were hired to collect these data. In our experience, finding a sustainable workload is not only important for partnership maintenance but also to support SLPs feeling involved and invested in the project without feeling overburdened. To manage hesitancies relating to the outcomes of the projects, we focused on ensuring transparency in the partnership (i.e., our focus was to support the SLPs, not identify practice concerns). Another meaningful consideration for partnership maintenance was having explicit discussions around all aspects of the research protocol and any deviations that occurred. Although we established a strong partnership with each school board, on occasion we failed to acknowledge the gap between our understanding of the research process and theirs, or our lack of understanding of specifics related to their clinical context. We came to use the term "assumed knowledge" for these moments when, for example, we assumed the SLPs understood the limits on variance from our ethics protocols (e.g., adding a questionnaire requires an amendment), or when we hired research assistants and it became clear that a partnered approach to hiring and onboarding would have been better. In one project, the researchers hired and trained research assistants to collect data; however, by not involving the SLPs in the training, the research assistants did not receive school board specific information that could have been helpful for them.

When differences arose or there were moments of assumed knowledge, we took accountability for errors on our part, an action we felt was important to maintain trust in the partnership. Additionally, these moments created an opportunity for the team to work together to decide what needed to be put into place to prevent similar moments in the future.

We believe, largely due to the goal of practice-based research and its focus on clinical questions, differences surrounding the direction or goals of the partnership were limited. If differences emerged, they were dealt with through discussions with the lead team. Other factors we found to facilitate partnership maintenance included showing our dedication to the partnership (e.g., travelling to visit with SLPs), showing our appreciation for their efforts (e.g., providing lunch during meetings), maintaining our flexibility related to clinical changes and celebrating all successes. Finally, we intentionally considered the role that professional pride, disciplinary centrism or biases might be playing when we were engaging in our partnership[4] and worked to reduce negative impacts.

## IMPACT OF THE PARTNERSHIP

The strength of our partnerships contributed to the success of our research collaborations. Prior to the formal initiation of the partnerships, the SLPs involved in our partnerships respected Archibald, her research and her advocacy work, laying the foundation for respect in the partnership. Similarly, our genuine interest in the clinical practices at the school board and our practice-based research approach showcased our intention to keep their clinical questions as our priority. This commitment to practice-based research remained the focus of our partnerships and the direction of each partnership was guided by this commitment (e.g., surveying clinicians to identify the most important clinical question). The SLPs expressed that

knowing of other school boards engaged in this practice-based research process demonstrated our credibility in this work, and they expressed interest in connecting with other SLPs to hear about their partnerships. We consider the strong initial partnership to be most impactful to the success of these partnerships. We feel that these strong initial partnerships helped to negate some of the barriers due to physical distance between partners. The partnerships also helped to increase the research capacity at the school boards. For example, one SLP closely involved with a project began a PhD program to further her knowledge in the area, and one school board expressed their gratitude for finding researchers who share their interest in evaluating their own clinical practices and the researchers' commitment to supporting them.

## LESSONS LEARNED

**1** **Create a plan to reduce assumed knowledge.** In our partnerships, assumed knowledge led to communication breakdowns (e.g., SLPs adding a questionnaire to the study or researchers not providing research assistants with school board specific information). Consider building a plan to reduce the likelihood that assumed knowledge will exist in your partnership.

**2** **Ensure transparency amongst partners.** Transparency is important for establishing trust, respect and investment in the initial phases of the partnership and for maintaining these key factors throughout the partnership. A successful strategy for promoting this amongst our partnerships was clearly outlining our motivations and expectations for the project in the initial partnership-building phase and asking the SLPs to do the same.

**3** **Plan partnership evolution and evaluation.** While discussions concerning project evolution and evaluation are expected, discussions of partnership evolution and evaluation may help ensure partners are satisfied and benefitting from the partnership.

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# Co-producing and applying a framework to guide researchers partnering with young people in health and social sciences research

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## INTRODUCTION

Young people have a right to be engaged and a right to be heard in research. The IN·GAUGE™ research program aims to improve the lives of children, youth and families by adopting a partnership approach to researching the topics that matter most to them. Established by Dr. Roberta L Woodgate and headquartered at the University of Manitoba in Winnipeg, Canada, the IN·GAUGE research program creatively engages children, youth and families as partners, advisors and co-investigators in an integrated knowledge translation (IKT) process.

## INITIATING THE PARTNERSHIP

The IN·GAUGE research program uses an IKT approach that seeks to distribute power among young people and their families (who we call "research partners") and encourages their creativity throughout the research process. Research partnerships with knowledge users at IN·GAUGE may begin in any of four ways: (1) the research program lead (Woodgate) initiates a discussion with a group of young people and/or their families to identify research areas of interest, and then procures research funding; (2) the research program lead secures research funding for a specific topic, and then recruits young people and/or their families to engage throughout the study; (3) young people and/or their families

submit their ideas to IN·GAUGE using various online platforms (e.g., website, social media); or (4) as IKT partnerships beget more research, the researchers and partners jointly initiate new research projects and pursue funding together. For example, young people and families engaged in the IN·GAUGE research program have explored a wide range of issues related to their experiences with health and social inequities, such as chronic illness and disabilities, respite care, mental health, youth employment, young newcomers and social connectedness.

However, over the course of these studies, IN·GAUGE research partners expressed concerns to the research program lead about the way health and social sciences research is being done, with and without them. This recurring feedback led to a new research initiative where IN·GAUGE research partners were asked to share their experience of being a partner in research and advise on how researchers can better partner with young people in health and social sciences research. The remainder of this article describes the framework that resulted from this project and its application.

## MANAGING THE PARTNERSHIP

To amplify the voices of young people in research, IN·GAUGE research partners were recruited to co-develop a tool to guide health and social sciences

researchers working in partnership with youth. The *Youth Engagement in Research Framework* (Figure 1) illustrates youths' perspectives on how to create a culturally inclusive research environment, how to meaningfully engage youth in health and social sciences research, which conditions should be met throughout the research process and what youth hope to get out of the experience. This framework can be used to inform how research partnerships with youth are initiated and managed.

Specifically, our research identified seven fluid, adaptive engagement concepts that are critical for meaningful partnerships with youth in health and social sciences research. These concepts are: (1) understanding motivations to engage; (2) discussing goals for the research process and implementation intentions; (3) supporting diverse expressions of youth identity; (4) addressing facilitators and barriers to engagement; (5) reinforcing the choice to engage in research; (6) building trusting relationships; and (7) respecting different forms of knowledge. The IN•GAUGE research program puts this research evidence into practice daily. Here we share examples of how we action these seven engagement concepts from the framework.

Young people say helping others, being heard, sharing experiences, pursuing social action and

**Figure 1.** Youth Engagement in Research Framework
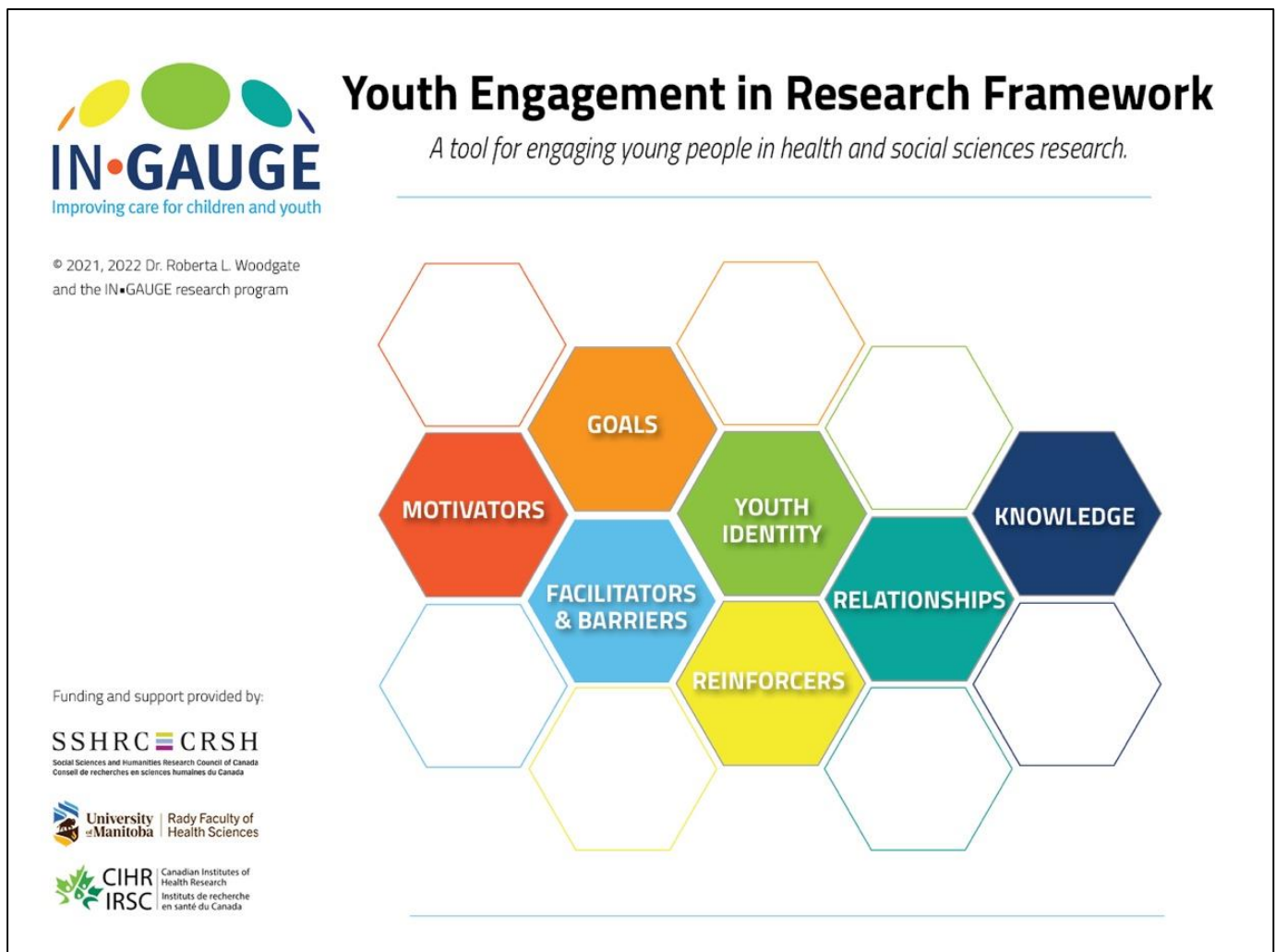
social justice, and studying the issues that matter most are their top motivators for engaging in research, and that planning to do something with the research evidence is an important part of their decision to engage in the research process.[1-3] Before an IN•GAUGE research project begins, the research team hosts either one-on-one or small group discussions with young people and their families to understand why they want to engage in research, how they would like to be involved and which research areas they would like to explore. These discussions take place at a time of the partner's choosing, and using the partner's preferred meeting method, such as telephone, online or in-person. Once an area of interest has been identified, partners may contribute to study activities (for example, developing the research question, selecting data collection methods, supporting dissemination and implementation), engaging to whatever extent they wish.

Young people describe their individual identity in relation to their social groupings, such as popular and alternative youth cultures, race, ethnicity, gender identity, sexual orientation, life experiences, living circumstances and socioeconomic status.[1-3] To accommodate individual identities and create safe spaces, IN•GAUGE research partners meet at a time and place of their choosing, and resources are allocated to cover meals, childcare, transportation, lost wages and telecommunications costs.[3] For example, a recent study included individuals who self-harm and experience severe social anxiety.[4,5] The research team provided these young research partners with telecommunications supports and data collection options that enabled them to collaborate using online meeting rooms with no cameras combined with creative writing submissions.[4,5]

To sustain engagement, young people say to demonstrate value for their time, opinions and ideas with cash and valued incentives, and to provide mentorship opportunities that develop their knowledge, skills and confidence.[3] Youth say using shared leadership is a good way to distribute power and build trusting relationships in the research setting, as is taking time to explain the research process, practicing authentic listening and providing options for acknowledging partner contributions to published research.[3] IN•GAUGE research partners choose whether and how they want to engage with other research partners and how they wish to be recognized for their work. In a recent IN•GAUGE research project that aimed to explore the reasons motivating young people to engage as partners in research (unpublished manuscript), the young partners chose an online focus group, during which they identified a strong desire to use research evidence to create positive change. On reflection, these research partners also said they felt rewarded by the IKT experience. They said they valued the opportunity to educate one another, develop empathy and learn from senior researchers who introduced them to IKT research and encouraged their involvement in decision-making.

Finally, youth say to engage them in flexible, dynamic and evolving ways throughout the research process and to embrace their imagination, creativity and communication style in the acquisition, co-creation and dissemination of knowledge.[1-3] The IN•GAUGE research program places tremendous value on alternative forms of knowledge, such as experiential knowledge. IN•GAUGE research partners select from a range of creative data collection methods for their ability to qualify experiential knowledge, including but not limited to local neighbourhood or community knowledge, cultural and traditional forms of knowledge, generational contextual knowledge, and patient and caregiver knowledge. The way data are collected in research varies from person to person based on their preferred method of self-expression, which includes interviews in conjunction with a wide range of arts-based data collection methods. The use of qualitative arts-

based data-gathering methods with young people helps them to articulate, contextualize and communicate the meaning of their lived experiences to others, which might include educators, policy-makers, health-care providers, social service providers, and even their friends, family and community. For example, in a youth-led research coproduction effort that aimed to relate the daily experience of living with anxiety, IN•GAUGE research partners chose photovoice as their data collection method and performance art to disseminate the resulting research evidence.[4,5]

## IMPACT OF THE PARTNERSHIP

Empowering young people to make contributions to the research process itself results in richer, more culturally inclusive and more usable research evidence. Researchers often investigate sensitive health and social issues without involving young people and their families to avoid perceived barriers (e.g., ethical, feasibility) to conducting research with this population. This is a trap researchers need to avoid because it has the potential to create a significant gap in what we know about the experience of being young or coming of age in today's world, which young people say further mutes their voices.

Our learnings from the IN•GAUGE research program have resulted in the *Youth Engagement in Research Framework,* which can inform strategies for partnering with young people. The framework may be used to help overcome researcher concerns related to ethics, feasibility, and even personal comfort, by providing tips on how to initiate a partnership, guidelines for early conversations and ideas on how best to allocate budget and other resources. The young people who developed this framework hope that health and social sciences researchers will choose to engage with young people in research more easily and more often.

## LESSONS LEARNED

**1** **To initiate research partnerships with young people, begin with a conversation about their areas of interest and experiential knowledge.**

**2** **Consider using a framework to guide your partnerships.** The Youth Engagement in Research Framework includes seven fluid, adaptive engagement concepts to guide how partnerships with young people are initiated and managed throughout the research process.

**3** **Partner with young people throughout the research process** to achieve richer, more culturally inclusive and more usable research evidence.

If you are interested in learning more about the *Youth Engagement in Research Framework*, please email the IN•GAUGE research team at INGAUGE@umanitoba.ca for a copy. Your feedback and experiences with using the framework are also welcomed by the IN•GAUGE research team.

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# Evolving partnerships for building communities: Experiences from the Knowledge Translation Innovation Incubator

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## INTRODUCTION

The Knowledge Translation Innovation Incubator (KTII) grant competition is an initiative of the CHILD-BRIGHT Network Knowledge Translation Program to promote and facilitate innovative knowledge translation research in childhood disability. Between 2018 and 2020, five KTII projects, led by teams of researchers and non-researcher interest groups,[1*] received funding for innovative knowledge translation projects. The application review panel consisted of researchers, parent-partners (parents or caregivers of children and youth/young adult with a neurodevelopmental condition), decision makers, clinicians, youth with disabilities, researchers and trainees.

Our team used an integrated knowledge translation (IKT) approach to conduct a multiple case study of these five KTII-funded project teams (see Table 1). From these teams, we interviewed 13 researchers, clinicians, trainees, a designer, a youth and two parent-partners at two time points: mid-project and end of project. The multiple case study design facilitated a broader understanding of the phenomena by showing the differences and similarities between cases.[2] The aim of the case study was to understand how an IKT approach contributed to creating and fostering innovation and collaboration in research.

**Table 1.** Overview of the five KTII projects

| Project name | Innovation incubation goal |
| --- | --- |
| WeeWheel | Develop and adapt wheelchair skills training program education resources for children to address the evidence-practice gap. |
| Ready2Work | Develop and pilot an online vocational/employment readiness platform for people with autism spectrum disorders, families and vocational program professionals. |
| Making Sense of Connected-ness | Give neurodiverse children and youth and their families an opportunity to build an online hub of sensory environments in Montreal to engage the public about the impact of these sensory spaces. |
| Perspectives of Mental Health | Create digital stories of youth with neurodevelopmental disabilities that can facilitate more dialogue between youth and health-care providers in mental health discussions. |
| Child-Sized KT | Develop an interactive online platform for children and families to learn about health research. |

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* We use the term "non-researcher interest groups" to refer to individuals and/or organizations that contribute to the co-creation of knowledge under a shared research objective of social justice and equity.[1]

Here we report on the processes, outcomes and learnings from both our own research partnership (the case study team) and the five cases included in our study (the cases).

## INITIATING THE PARTNERSHIP

### The case study team

The case study team was led by three researchers and one parent-partner from the knowledge translation program, all of whom were previously part of the KTII application review panel. The broader study team included additional researchers, trainees and a parent-partner from outside the knowledge translation program recruited through word of mouth. We also used the CHILD-BRIGHT Network Citizen Engagement Matching tool (a central list of patient and parent-partners interested in engaging in research) to recruit other parent-partners for our case study team.

### The cases

All KTII project team researchers met their partners through ongoing clinical and research activities (e.g., research meetings, conferences, public events) two to five years prior to their KTII application. These connections gradually expanded by including other interested parties, resulting in a team that developed and submitted the project application together.

All five KTII projects developed partnerships by building upon existing teams with diverse backgrounds and expertise. Each project team consisted of: (1) interested stakeholders such as researchers, clinicians, community partners, youth and adults with neurodevelopmental disabilities, and family members of children with disabilities; and (2) people with specific expertise, for example, a computer programmer, a data informatics specialist, a behaviour analyst and a designer,

which added multidisciplinary perspectives to the teams. Project teams came together to address unmet needs for care and support by tapping into lived experiences.

To set a common foundation, researchers, who were the initiators in most projects, explored and identified the needs of interest groups and the optimal methods of engagement (e.g., regular meetings, focus groups) at the onset. Many interviewees stated that "there wasn't necessarily clear, concrete objectives in the early stages for what we were trying to achieve" (Project 1, Lead researcher). At this stage, many researchers challenged and shifted their own positions by disrupting the assumption that they "can pull from [their] experiences as a professional" (Project 3, Clinician). As interest groups were "coming in and saying what they think is important to them" (Project 2, Parent co-lead), a common understanding of innovation incubation gradually evolved.

## MANAGING THE PARTNERSHIP

### The case study team

Our team of researchers, parent-partners and trainees shared the various research tasks throughout the case study. For example, one parent-partner who was part of the review panel contributed to conceptualizing and designing the case study. The parent-partners were trained in qualitative analysis and paired with a research trainee. These researcher-parent dyads met regularly to inductively code data together and review the results of their partner's coding. After this iterative analysis process, a researcher consolidated the coding results and searched for emerging patterns on the factors contributing to innovation development and aspects of the IKT process leading to unique outcomes of the partnerships.[3] The interpretation of identified themes was discussed with the broader team.

We used regular meetings and e-mail communication with the case study team to keep everyone updated about the progress of the interviews and to discuss the preliminary results of the analysis.

**The cases**

In the KTII projects, researchers described how the co-development of an innovation requires a larger time investment to keep everyone connected compared to a "regular" research project. Scheduling and coordinating meetings was challenging in larger teams with conflicting schedules. Consequently, it was essential that the researchers demonstrated flexibility to ensure participation from all team members. One strategy to maintain engagement was sending a follow-up survey to parent-partners who were not able to attend a meeting. This ensured that everyone's input was heard before moving onto the next step.

Many researchers in our study believed that getting diverse perspectives would facilitate innovative thinking but also recognized that building consensus among diverse viewpoints can be challenging. Participants stressed the importance of researchers being open, listening to diverse perspectives and showing enough flexibility to adapt the research process to take a different path from what was originally planned. This openness and flexibility ultimately allowed innovative ideas to emerge.

The KTII teams described how managing the partnership involved listening and "making sure that [researchers] respect and validate the voices of the individuals" so that all participants feel part of the knowledge generation process (Project 3, Research collaborator). Researchers felt responsible for acting upon participants' expressed priorities in their projects. For instance, in response to a youth's proposal of an art exhibition, the project team was "trying to figure out how to do that to honour his work because he is one of the youth" (Project 5, Co-lead researcher). Collaborative decision-making was achieved by making sure that everyone's opinion was considered. As one researcher put it:

*"Not just I've added somebody into the process, but I'm equally working with [family partner] and [the designer] and I won't move forward until both of them respond or vice versa."* (Co-lead researcher)

Reciprocity and recognition were critical elements for maintaining partnerships because "[engagement] does not happen for free. People aren't just going to show up" (Project 1, Co-lead researcher). To maintain long-term engagement, adequate compensation such as an honorarium and opportunities for skills development are necessary and appreciated by the different parties involved.

## IMPACT OF THE PARTNERSHIP

**The case study team**

Capacity building opportunities were an important outcome of the IKT approach we used in our case study. For example, as the research staff and parent-partners worked together to collaboratively analyze the interview data, the parent-partners became interested in learning qualitative research methods. The partnership provided opportunities for the parent-partners to develop these research skills and apply them in our project.

Researchers' insights and parent-partners' perspectives were equally valued, and trust was built amongst the team to learn from each other. This partnership added richness to the analysis process by helping the researchers and trainees involved to question their assumptions during the interpretation of data, enhancing how we outlined our findings and outcomes, and increasing the rigour and applicability of the study findings.

**The cases**

The partnerships in the five KTII projects created a space where all parties "unlearned" usual ways of working by disrupting their assumed expert roles and co-developing innovations by immersing themselves in the perspectives of diverse partners. The unlearning process was well-illustrated in one project where they were creating materials to teach children how to use their wheelchair:

*"What we learned is that kids don't want to think that they're learning how to use their wheelchairs. For them, a wheelchair is just a pair of sneakers."* (Project 4, Clinician)

Building upon this new perspective, team members successfully produced a child-oriented storybook, rather than applying the traditional rehabilitation approach of "training skills." Other innovative knowledge translation products that were developed through these partnerships included an interactive online platform, a website for job seekers with autism and youth digital stories.

Beyond these tangible products, researchers working with community organizations excitedly shared how, at a project level, the partnership contributed to creating new connections with different people and institutions. For instance, research projects led to youth-nurtured friendships, as well as a new institutional collaboration between two organizations supporting youth with neurodevelopmental disabilities transitioning to adulthood. One project indicated how study products, such as bags, T-shirts and pamphlets, played a role in starting dialogue and enhancing the awareness of the sensory environment in the community, as an individual voice turned into a collective one:

*"Just as an individual, your voice isn't heard. But when you're part of a collective and you're part of something significant like this project itself…it brought so much credibility."* (Project 5, Parent co-lead)

The collective voice further led to empowering youth who "may not be able to express all things they want to say, what they want to change" (Project 5, Parent co-lead), as the feedback and support of community members made them feel stronger and motivated.

A key challenge the KTII teams experienced was how to translate the learnings and outcomes from their projects to broader social impact. For example, one project developed an interactive website for job seekers with autism. Though an innovative and highly integrated project, participants emphasized that employment is a large construct that needs to be addressed structurally through public education and policies, going beyond strengthening job search skills and resources for the autistic youth.

The innovation development experiences of the KTII teams illustrate the non-linear process of collaboration with diverse participants. As the partnerships evolved, not only did new knowledge emerge but communities of support and collaborations were also created.

## LESSONS LEARNED

Through our own IKT partnership to conduct this case study and the results of the case study itself, we have several recommendations for others forming and maintaining research partnerships.

**1** **Stay open and embrace flexibility.** Researchers need to remain open to diverse perspectives by disrupting the assumption that they are the "expert." Flexibility is needed to adapt to partners' needs and make room for other lenses. Listen, find a common language and work to understand each other's perspectives.

**2** **Ensure everyone's engagement before moving forward.** In collaborative research, partners may feel out of the loop if not regularly updated. Despite the challenges in accommodating everyone's schedule, it is important to engage and connect with all partners. Keep everyone informed through regular meetings and other follow-up strategies such as surveys and summaries of meetings before advancing.

**3** **Embody reciprocal and accountable relationships.** It is crucial to recognize the contributions made by all partners. This can be done through fair and adequate compensation of parent and patient-partners, responding to partner priorities and needs, and integrating partner input into the project. Reciprocity and accountability contribute to building trust in research partnerships, which in turn creates more space for innovation to happen.

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