

Building a multidisciplinary research collaboration to study engagement in pediatric rehabilitation: Experiences, strategies, and lessons learned

Transcript of pre-recorded session for Children's Healthcare Canada 2020 Conference
Delivered by Dr. Kate Einarson and Ms. Emily Chan

[Section 1: Introduction]

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[00:00] **Kate:** Thank you for joining us today. This is the presentation entitled 'Building a multidisciplinary research collaboration to study engagement in pediatric rehabilitation: Experiences, strategies, and lessons learned'.

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[00:19] **Kate:** My name is Kate Einarson. I'm a knowledge translation specialist at the Bloorview Research Institute.

[00:26] **Emily:** And my name is Emily Chan. I'm currently a Master's of Social Work student at the University of Toronto. I'm also a former Holland Bloorview client and a current Youth Leader.

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[00:39] **Kate:** We'll be talking to you today about a project we're both part of. It's called 'Engagement in the Pediatric Rehabilitation Intervention Process: Its Nature, Measurement, and Role in the Determination of Outcomes'. This work was funded by CIHR from 2014 to 2019, and has been extended for 2020 and 2021. Preparatory work for this grant and collaboration began in 2011 so this project has been ongoing for almost a decade now.

It's a multidisciplinary collaboration composed of researchers, clinicians in a variety of disciplines including occupational therapy, physical therapy, speech therapy, therapeutic recreation, life skills, and other areas, as well as trainees in both research and clinical disciplines. Our team also has two lived experience partners who contribute to our work. We are composed of investigators from across Canada, the United States, and Australia.

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[01:40] **Kate:** Right now we have research team members, as I said, across North America and Australia. The lead site is in Toronto, with investigators at McMaster University in Hamilton, Mount Royal University in Calgary, Drexel University in Philadelphia, George Washington University in Washington, and the University of Queensland in Brisbane.

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[02:07] **Kate:** Since 2011, forty contributors have been part of this team from all of those various sites, as I mentioned. Some of them are still active now. Others, for example trainees who have finished their work, graduated, and moved on, are no longer part of the team. But we thank all of these collaborators for their roles past and present.

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[02:29] **Kate:** Specifically today, Emily and I are going to be speaking to you about the lead investigator site, which is in Toronto, Ontario at Holland Bloorview Kids Rehabilitation Hospital. We'll be telling you about our PRIME team based out of Holland Bloorview.

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[02:46] **Kate:** The PRIME team at Holland Bloorview Kids Rehab Hospital is led by Dr. Gillian King, the lead investigator, a senior scientist at the Bloorview Research Institute, and Canada Research Chair in Optimal Care for Children with Disabilities. The team is also composed of a number of scientists and clinicians from a variety of disciplines, several members of the research staff at the Bloorview Research Institute, as well as family leaders including Emily, who you've met, a former Holland Bloorview client, and Jan Magee, who is the parent of a former Holland Bloorview client. A number of team members have moved on from their roles, either within Holland Bloorview or to other institutions. Some of them remain involved with the team to this day.

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[03:32] **Kate:** Today we'll be talking you through two sections about the PRIME team. First, we'll give a brief overview of the PRIME research and our results, to talk to you about 1) what is engagement in pediatric rehabilitation and why it matters, and then, 2) how do you assess engagement and measure it?

Then we'll move on to a discussion of our diverse PRIME team and the processes the team has been using for the past decade, including some of the strengths and challenges we've navigated, strategies and lessons we've taken away from that work, and we'll showcase a number of personal perspectives and reflections from various members of our team.

[Section 2: PRIME Research and Results]

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[04:07] **Kate:** Engagement is fundamental to therapy, and engagement of children and their parents is generally considered to be a critical building block to the success and the achievement of therapeutic goals. Some might say the lack of engagement is the Achilles heel of healthcare delivery, so it can be a barrier to success.

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[04:32] **Kate:** Despite this importance, though, there is a lack of clarity around exactly what we mean when we say 'engagement in therapy'. Engagement for our team's purposes is defined as a multi-faceted state of affective, cognitive, and behavioural involvement and investment in therapy. One service provider in some of our work told us "If you don't engage them, if you don't get a parent involved, if you don't get the child involved, all the therapy in the world is not going to do anything".

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[05:05] **Kate:** Pediatric rehabilitation is additionally complex because it involves not just engaging the client (a child or a youth); the parent is generally also presumed to be fundamentally important to achieving therapy goals and outcomes. Parent engagement, for many clinicians, is considered to be essential because it has consequences for participation and also potentially for outcomes.

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[05:33] **Kate:** Part of the reason engagement remains poorly understood is that it's both a process but also an outcome of therapy. So, little is known about the links between engagement and potential positive outcomes for a number of reasons. One is that we lack a good understanding of engagement as both a process, and a state. We also don't have a good understanding of how engagement can be enhanced or facilitated by service providers and therapists in a session. Finally, there are no reliable, valid ways to measure engagement of clients, parents, or service providers.

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[06:19] **Kate:** This lack of understanding means that engagement is rarely measured in clinical practice and is rarely studied in research. To address this the team set out to answer a number of questions. In the first stage of our research program we wanted to describe the components of engagement, including defining what it is and characterizing what it looks like, then to explore strategies that can be used to enhance engagement over the course of the session. Subsequently, we set out to develop reliable and valid measures of engagement that can be used for children, youth, parents, and service providers who are part of therapeutic rehabilitation.

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[07:04] **Kate:** The team's conceptual model of engagement has three components that are important to understand. The first is affective engagement, which is how you feel. So for example, we might assess: is the client hopeful about outcomes? Are they receptive to the therapy? Do they trust the therapist they're working with? Secondly is the cognitive component of engagement, and this is what you think. So does the client believe that the intervention will work? And does it make sense to the client? The third component is behavioural, and this one is the most observable. It's what you do. So, is the client participating in activities and do they feel confident they will achieve their goals? All of these components together compose engagement in therapy, but some of them are easier to observe than others. I said previously that engagement is both a state and also a process. So the research team subsequently worked to unpack these ideas.

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[08:12] **Kate:** Engagement can be a state of being engaged in therapy, and there are several components to being engaged in the therapy session. One is feeling hopeful, and that's related to affective involvement and trust. It's how you feel. Conviction is related to what you think and to the commitment you have to the intervention. Confidence is related to your behavioural involvement in the tasks at hand.

One parent in our interview studies told us about their hopeful stance and their confidence by saying "Overall I usually am positive when I leave there 'cause my kids are getting the help they need, and I'm leaving there with the knowledge to help them at home".

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[09:03] **Kate:** Additionally though, engagement is a process. It's a complex, dynamic process that's co-created between the client, the service provider, and the parent in any session, and it can change from moment to moment. So it's related to 1) how receptive the client is to the therapy, how much they believe in the therapist and the therapy, 2) their willingness and their belief in the intervention, and 3) their own self efficacy, so the belief that the intervention is workable for them.

A client told us: "I was feeling confidence that I could actually do what I was supposed to do. And actually get to that certain point where I could maintain the strength."

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[09:45] **Kate:** Taken together, all this means that engagement is complex and dynamic. It's co-created between the client and their therapist or the service provider, and there's a number of characteristics that are important.

One is the engagement is multifaceted. So, for example, you can't infer the level of engagement based on behaviour alone. Someone can have negative emotion or affect but still be behaviourally compliant in a therapy session. Or they might be behaviourally very passive, but very cognitively engaged.

Additionally, engagement is a desired state. So that might vary by person, depending on how much they want to be involved, or how much they find engaging. One parent told us: "I feel like I'm already as involved as I want and need to be". So it varies by person.

Engagement and being engaged can be motivation enhancing. So a service provider told us: "If the client isn't interested in what you're doing, there's no point in doing it".

Engagement is multi-determined, and by that we mean that many factors can influence engagement before, during, and after a session; in the therapeutic context and setting; as well as personal factors for each of the people involved.

Engagement is changeable, over time and in the moment. So one service provider told us: "I can see a shift in buy-in or engagement over the course of the session because they might see the potential of something we're doing."

As I mentioned, engagement is co-constructed between the people who are involved. So one service provider told us: "To me, engagement means having the client, or the parents, on board with what you're working on and you're working on things that are meaningful for them."

And finally, engagement is highly contextualized. So for example, the way an engaged child looks might be different than the way an engaged youth looks in a session. So it's a contextual factor.

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[11:51] **Kate:** The last part of his research program was to explore ways that service providers can facilitate engagement of clients and parents in their sessions. In interviews, service providers told us a number of things. Many of their strategies were collaborative and relationship-building. They had to do with therapeutic rapport, and also about listening to the client and the family. This included communicating, enabling, individualizing and tailoring their strategies, and relationship building. Some other factors that were mentioned as part of this work were directive strategies, so prompting and guiding, and other directive

behaviours. And also that some intervention formats suited certain types of engagement better than others. For example, group programming was mentioned as often being engaging.

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[12:45] **Kate:** The PRIME team has published a number of peer-reviewed articles on various parts of this work to date. There are also a number of other publications that were shared in preparation for this work, including literature reviews and conceptual models, and more recent work related to the topic engagement by trainees and other members of the study team. So for example, in addition to this core program of research about the engagement of clients, families, and service providers, members of the Holland Bloorview team, including trainees and clinicians, have also used the PRIME measures to study engagement in life skills programs, engagement in friendship programs, and engagement in solution-focussed coaching.

If anyone is interested in a more comprehensive list of the publications associated with this work, they are available on the PRIME website at

PrimeResearchTeam.com

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[13:41] **Kate:** Having done this exploratory work to characterize the nature of engagement and strategies that can encourage it, that brings us to the question of how you can measure engagement. If it's something changeable that can be co-created and can fluctuate over time, how can we try and measure it? From session to session, or within the context of a session. To answer that question the PRIME team is developing a suite of tools that will allow evaluation of client, service provider, and intervention characteristics that might contribute to engagement in therapeutic rehab.

These are designed for use by clients, by parents, by service providers, and even by others, such as research observers who might be contributing to research studies. And they're all being developed with input from researchers, clinicians, parents, clients, and others, including a psychometrician, knowledge translation staff like myself, and graphic design.

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[14:45] **Kate:** This collection of measures but I'm talking about we've entitled the Pediatric Rehabilitation Intervention Measure of Engagement (or PRIME) suite of tools.

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[14:55] **Kate:** At present there are six tools in the suite. Three of the tools are designed for use by the parent, one is designed for use by the client (a child or youth from ages 8 to 18), one is designed for use by the service provider, and the last one, as I mentioned, is for use by an external observer such as a research staff member.

Three of these are self-report measures where the person reflects on their own engagement; three of them are reports by others about the engagement they are seeing from somebody else, such as a parent reporting on the engagement level of their child.

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[15:34] **Kate:** These measures are being developed carefully over time as part of this research process and there's a number of stages involved. Each has been developed by the research collaborative team based on theoretical models and conceptual models, to develop questions that they think will capture important aspects of engagement, and then pilot tested with the intended audiences.

Subsequently, research versions of the tools are used in data collection and there are a number of data collection sites involved in this work. Some of them are at primary investigator sites; for example much of the data collection for this work has taken place at Holland Bloorview hospital, but there are other data collection sites as well, including [in Ontario], [in Australia], a few in the Greater Philadelphia area, and some in Chicago.

Once we have ample data on a research version of a measure, each one goes through a psychometric assessment to assure test-retest reliability and to explore validity and responsiveness of the measures. Based on those data tools of revised and refined. So for example, a factor analysis might show that some of the items are more informative than others and questions that don't hang together are removed from the tool.

As a final stage the tools go through usability testing and design, where they are again brought back to their intended audience and structured in ways that make some more useful and easier to navigate for the intended users. They also received accessibility treatment. So for example, PDF versions of documents are accessible by screen readers. I'll show you an example now of one tool in this suite. It's the PRIME-P measure designed for parents to rate their own engagement in a session. This tool is one that has recently gone through all five stages of this process, but I will point out that each tool is at a different stage of development.

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[17:37] **Kate:** This is an example of the PRIME parent rating scale designed for use by parents to rate their own engagement in a therapy session with their child. You see at the top a glossary of some of the terms used in the questionnaire. The body of this page is the 11-item questionnaire that parents complete to rate their engagement. And at the bottom we have a notes section for parents to provide any other context that they would like to share.

On the front page of the tool we ask for some demographic information, including whether the parent was present or absent during the session, and provide some instructions. One example of a way that this was structured based on user input was that the glossary in the research version was on page one; based on feedback we moved it to page two because people told us that's where they needed the information. So this means that we have a tool that has robust psychometric properties and has been rigorously researched and developed, but it's also been co-designed with the intended users and we think that it will be accessible, useful, and easy for them to navigate.

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[18:46] **Kate:** So the PRIME research team is winding down our grant at this point but there are some next steps we have in mind. We're going to continue developing the tools in the suite that I've just shown you, to ensure that they're valid, robust, and have clinical utility. Additionally, we're now creating resources to inform service providers' perspectives and practice, and to give them more information about engagement in rehabilitation. And lastly, we're looking to support integration of these engagement principles into design and delivery of interventions. Improving and enhancing client engagement really has the potential to increase client satisfaction, and to enhance therapy comes in the future.

[Section 3: PRIME Team and Processes]

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[19:40] **Kate:** Having discussed all of this to give you a taste of the work has been done by this team over the past eight to ten years, we'll transition to discussing some of the unique strengths of this multidisciplinary and international team that's now been working together for almost 8 to 10 years. And we'll also look at the flip side of that, which is that the multidisciplinary, international nature of the team has had some unique challenges and some opportunities for growth with this team.

We'll go through four main areas: 1) One is the time span of this work and some of the advantages and challenges that come with that. 2) One is the logistics of

coordinating a team that's so far-flung. 3) Another is the diverse nature of this group of contributors, and lastly, 4) we'll talk specifically about the engagement of our parent and client voices in the team.

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[20:23] **Kate:** So firstly, the time span. As I mentioned work on this project began, in some cases, as early as 2011. Primary investigator Gillian King has been involved in this work with some of the members of the research team for many years. On one hand, that has given us a real opportunity to follow ideas for the long-term. On the other hand, we're going to talk about how we've had to manage data and project outputs. As I mentioned previously the team has had a number of transitions, including trainees who have come and gone and staff who have changed roles or changed institutions altogether. It's been necessary for the project goals to change and evolve over time, and over this many years it's been a challenge sometimes to maintain momentum and to make sure that there is continuity across ideas.

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[21:15] **Kate:** Some of the strategies and some of the ways that we have addressed these challenges to do with the time span are quite pragmatic and easy to use in other contexts. They include: standing meetings at regular intervals that are booked at a recurring time that is agreeable for everybody involved. Some of these meetings are booked many months in advance via calendar holds.

Additionally, we have a very detailed process of documentation. Agendas are circulated for all meetings in advance and minutes are circulated afterwards. Sometimes when discussions are really fulsome meetings are recorded to be sure that all of the discussion can be captured in the minutes. This is helpful for the people who attend, to make sure that we've got a comprehensive record of what happened in the discussions. Additionally, it's helpful for keeping members who can't join any particular meeting informed about the state of the project. With so many people, including, for example, clinicians in active practice, not everyone can attend all the time.

We maintain what we call a 'team CV' which is a living document with running records of all of the staff and contributors who been involved at any time, what their roles were, and what the time span of that involvement was; any of the publications or presentations associated with this work; any of the future project ideas people would like to explore; and other information that is helpful to have in a single document. This makes research ethics updates easier, it makes grant updates easier, and it makes sharing information amongst team members simpler.

As I mentioned, some team members remained constant. Gillian King, the PI, has been involved from Day Zero. Some of the staff have also been involved for 5 to 7 years. Others have come and gone or have changed roles. One of our staff members of Holland Bloorview is now at St Michael's Hospital and another is at McMaster University. Some new folks have joined the team, such as myself. The team has adapted as the needs have changed, so in the early days we had many more staff dedicated to tasks like data collection. As data collection has wound down and stopped completely because of COVID, the emphasis of what we've needed to do has shifted. I came on to the team just over a year ago in my role for knowledge translation, with an eye to what we'd need to do toward the end of the grant.

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[23:47] **Kate:** At this point I'm going to hand the discussion over to Emily to talk to you about some of the other strengths and challenges we've experienced as a team.

[23:57] **Emily:** So the next category of strengths and challenges are logistics, and the first item is time zones. So the team, as we mentioned, is extremely diverse in both perspective and location, and we have team members ranging from Calgary all the way to Brisbane. Unfortunately though, this does lead to limited face-to-face relationships for our international team partners.

The next item is digital meetings. Because of our wide diverse span over many different places, digital meetings are necessary for both the larger international team due to the time zones, as well as the Holland Bloorview team. Digital participation meetings allow members of the Holland Bloorview team to join either in person or online. As mentioned earlier, we had one of our team members transition from Holland Bloorview to St Michael's and they were still able to participate online. Online participation was beneficial in two ways: one, it decreased the meeting flow disruption during the pandemic, and two, it reduced the burden of commuting to Holland Bloorview for patient partners. For people like myself commuting to Holland Bloorview is quite time-consuming, so having the option for digital meetings did really help with my involvement.

The next item is coordination of working groups and smaller teams. For both efficiency and to get different perspectives, we had subgroups of specialized experts who formed smaller working groups to work on specific subprojects. This was beneficial for productivity and momentum but it could be hard to keep track of team progress (especially for non-regular team members) despite subgroups reporting back to the larger team. Next we had to accommodate the timelines for many different stakeholders, including clinicians, families, and other people involved.

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[26:18] **Emily:** To our advantage, meeting times were agreed upon and scheduled in advance, and this was up to a year in advance. This really helped people like me with planning other commitments around team meetings and ensuring that I was still able to attend.

Video calls were combined with in-person visits and we had some people coming in internationally. This really helped with the team structure because even though some team members were unable to join us in person having a synchronous video call still made them feel like part of the team and that they were still in the room.

Such a long timeline of the project supported a very complex process of organizing and getting team members together. Despite the team seeing a change in members, something called ‘warm handoffs’ from my old team members to new were conducted to keep the workflow going. This was where an old team member would sit down and debrief with a new team member about project progress thus far. Key players were added as time went on to make sure that people who had left would still have their voice heard but their role would also be filled. Especially important was having a few constant people on our team including our PI, Gillian, as well as our research coordinator, Madhu, who kept the perspective and goals of the project at the forefront even as the team evolved and changed.

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[27:58] **Emily:** So the next bucket we wanted to talk about is our diverse team. We had a very interdisciplinary team who were comprised of: social psychology, psychometrics and statistics, physical therapy, speech therapy, occupational therapy, therapeutic recreation, life skills, and social work. Also people with lived experience of pediatric rehab (to be discussed at a later time - so, like me!) were also involved. We also had a mix of senior researchers and clinicians, mid-career clinicians, and research trainees, which resulted in varied perspectives and interests. We also had multiple different contexts: clinicians who work in inpatient and outpatient [settings], and investigators in Canada as well as the US and Australia, who are all well versed in different health systems.

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[29:10] **Emily:** We also had deliberate consensus building and inclusion. This was very helpful because lots of time was spent to develop consensus among team members, to understand and really flesh out different perspectives, and to make sure that all team members had a voice.

As you can imagine we had enormous breadth of expertise and experience which really worked to our favour. As well, the opportunity to pursue projects related to particular interests was really helpful, because several trainees did work related to the central questions but it was also tailored to their specific interests. Finally, the PI took the lead on soliciting and incorporating feedback, which was done through modalities including data analysis, interpretation, and manuscripts.

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[30:07] **Emily:** The next bucket, and my favourite bucket, is the inclusion of family leaders. Both a client and a parent are embedded into the team. At the time this project started it was not all that common to include the voices of people with lived experience on research teams. However, the PRIME team was an exception to this because we had one parent and one [client] embedded in the team for more than half a decade. This really lines up with the Holland Bloorview values and commitment of engaging with parents and clients to lead a very holistic and patient-centred research project.

So as you can imagine, because we are not experts in research time was needed for onboarding, orientation, and participation. Unlike the researchers, family partners are involved in a different capacity and research is not our full-time job. As you can imagine, it does take time to get oriented, to feel confident as part of the team, and to understand the project as well as the terminology used. Family and youth leaders may need a longer time to review and reply and give input as well, due to other commitments outside the research team.

Because we had a family leader and a youth leader involved we had very unique perspectives and priorities involved in the project. Often, our values and perspectives are different from researchers or clinicians, and we really got a sense of what was important and what was of interest to the entire team through the involvement of family leaders. There was also a lot of support to ensure that authentic and constructive partnerships were built.

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[32:13] **Emily:** Now, it was a significant time commitment, as was mentioned earlier. It was a multi-year project but people such as myself were able to stay on for more than half a decade, so that was really helpful in transitioning between old members and new members as well.

The need to establish and maintain mutual respect and comfort was crucial for family partners, as some of the content that we share may come from a negative experience at the hospital. Having the comfort of a safe space was crucial to our

authentic insight. Again, as mentioned earlier, orientation to and grasp of the research process did take longer for family leaders, but eventually we did get it as time went on.

Finally there was a bit of a risk of tokenism as the only family leader or youth leader on the team. And what do I mean by this? Each person speaks to our own experience or diagnosis and we are the lived experts in what we know. But only having one family member and one client puts a bit of pressure on us to be representatives for the entire disability community, when in reality we can only speak for ourselves and what we know.

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[33:40] **Emily:** So overall, the PRIME team is collaborative, highly engaged, and very resilient to change. Now we're going to jump into personal testimonials from some of our team members, starting with myself.

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[33:56] **Emily:** I joined the team initially to speak from the client and youth perspective but I really did find my role evolving throughout the duration of my project involvement. I really observed a shift from being primarily informed by my client experience to now being more informed by my clinician-in-training knowledge. As I mentioned in my introduction, I am now a second-year Master's of social work student but when I started I was still in my undergrad. So I really saw that both of these identities, as a client and as a clinician-in-training, were able to intersect to inform my perspectives and insights offered to the team. I was able to now speak from both the client perspective as well as the clinician-in-training perspective, which I think added a lot of value and nuance to the team.

Now I'm going to read a note from our family leader, Jan.

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[35:02] **Emily:** Jan says that: "Being part of the PRIME team as a parent and Family Leader is a great opportunity to be involved in a collaborative, integrated approach with researchers, clinicians, knowledge users, students, and youth. I feel like an integral part of the team, which is so important for the contribution to be authentic. By being part of the monthly meetings to contribute my perspective, the parent voice was embedded in this team approach. I know how important engagement in therapy is from my lived experience with my son. I also strongly feel that these measures will not only help to improve engagement but hopefully will inspire the client to become self-motivated around therapy as they grow into adulthood."

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[36:04] **Kate:** Our next quote is from Dr. Eric Smart, who was a PhD trainee (recently defended), as well as an occupational therapist contributing to this team. Eric said: “As someone training to become a service provider, taking the topic of client engagement for granted means you run the risk of not being able to translate all the hard work you put into learning a clinical skill into actually making a difference for families. Without client engagement, some change may happen during a session, but that change may be more meaningful to me than to the client.”

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[36:41] **Kate:** Our next contribution is from Laura Thompson, who is the lead of the Transitions Strategy team at Holland Bloorview, as well as an occupational therapist who contributed to this work. I will have the pleasure of letting Laura speak to you in her own voice:

[36:57] **Laura:** “Working with the PRIME team has been a privilege from a clinical perspective. It has allowed me to expand my knowledge of multiple factors that influence engagement and strategies to enhance this foundation of practice. The PRIME team has embraced a clinical perspective throughout, from developing the research questions, to creating and evaluating measures, to planning for knowledge translation. The team truly values relationships with key stakeholders and integrates multiple views. This enhances the clinical utility of the research and solidifies the groundwork for uptake in real-world practice.”

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[37:40] **Kate:** Our next contribution is from Dr. Heidi Schwellnus, who is a Collaborative Practice Leader at Holland Bloorview, and was formerly a postdoctoral fellow on this team. She’s also an occupational therapist by training. Heidi says: “It is fantastic to have this work move forward, it can inform the nebulous area of client engagement in rehabilitation. These measures will be a great addition to areas such as program evaluation. Over the past years, my role on this project has shifted considerably; I am very entrenched in the clinical delivery of services instead of research. I see these measures as key to informing the incredible ‘art’ of engaging clients and families in pediatric rehabilitation.”

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[38:26] **Kate:** I also had a thought that I’d like to share, and that’s that researchers on this team have worked alongside clinicians, managers, trainees, and family partners from the outset of the work. Sustained collaborations help ensure the work is rigorous, relevant, and will make a difference in the lives of families. Creating a dedicated KT role like mine as part of this team is unique and field-leading. It means I can be part of multiple stages of the project, which is true integrated knowledge

translation. I can build relationships, and I can lead initiatives that take time to develop and to implement.

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[39:07] **Kate:** Finally, we'll conclude by sharing some thoughts from our lead investigator, Dr. Gillian King. Gillian says: "I have always enjoyed collaborative learning, and I value the multiple contributions of team members. I see the immense value of bringing together varied perspectives and seeing the synergies that arise when diverse teams work together. I think teams do some of their best work when they play to the strengths of each member and respect the types of contributions people feel able to make."

I think so many of the threads of the things we've been telling you about today are woven through that statement from Dr. King!

[Section 4: Conclusion]

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[39:45] **Kate:** So, to conclude, there are a number of helpful structures and strategies that our team has used for many years now. We've talked about attention to scheduling and to logistics when you're working with large groups and diverse teams. Particularly, being flexible about options for meetings and also about other ways to contribute, if it's by email, by phone, with an in-person meeting, or even with a voice note.

Ongoing documentation of the process that's taking place as well as all of the discussions really helps to manage transitions, maintain institutional memory as time goes on, and be sure that everybody has access to the information that they need. Finally, clear processes in place to manage data, particularly across multiple sites or across multiple phases of the study, is immensely helpful. And strong project coordination and oversight, especially when a project goes on for this long and in so many sites internationally.

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[40:55] **Emily:** We also found that the team climate is a key component of our success, ensuring that everyone feels included. As well, honouring the different perspectives and integrating the different perspectives really helps to build a helpful and collaborative team climate. Values of collaboration and authentic partnership, as I just said. Respect and clear communication are key. Also, ensuring that folks have enough time to respond and integrating these responses into the work that we're doing; the willingness to adapt and consider new ideas. Co-learning, co-producing, and co-using knowledge is our last guiding principle.

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[41:48] **Kate:** Thank you for your attention today. I think in summary we'd like to say that this work would not have been possible without the multidisciplinary nature of all the members of the PRIME team. In preparing this presentation, we stated that engagement is a multi-faceted state of affective, cognitive, and behavioural investment in therapy. It is co-constructed and changeable. Because engagement relies on interpersonal relationships, we think that's part of why it's so essential that research into engagement requires that the perspectives of clients, families, service providers, and others be taken into account. This research work would not have been possible without a team climate that valued collaboration, respect, and partnership across diverse teams.

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[42:42] **Kate:** If you're interested in finding out more please visit our website at PrimeResearchTeam.com, where you can see a full list of our publications to date. If you'd like to stay informed about forthcoming publications as well as be notified when new PRIME measures are made available, please sign up for the mailing list. We'll be sharing the PRIME tools as they're available for download.

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[43:06] **Kate:** In conclusion, we'd like to thank all of our contributors, including members of the Holland Bloorview team; all members of the international PRIME teams, past and present; and many of those people who participated in this research, including clients, parents, and clinicians. We thank the Canadian Institutes of Health Research for funding the last six years of this work. Thank you to the BRI and to Holland Bloorview Hospital, as well as the Holland Bloorview Foundation for their ongoing support of this work for so many years. And thank you to you, our audience today, for taking the time to listen.

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[43:42] **Kate:** We would be happy to take questions, and you're welcome to email either of us with any questions you may have.

[43:50] **Emily:** Thank you everyone for coming to our talk today, and we hope that you learned something new.