**2015 KT Conference: KT Solutions for Overcoming**

**Barriers to Research Use**

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Session: Engaging Stakeholders in Rehabilitation Research: Literature vs. Reality

Presenters: Chantal Camden, Sherbrooke University   
Keiko Shikako-Thomas, McGill University

Kathleen Murphy: Our first presenters for today are Chantal Camden from Sherbrooke University, and Keiko Shikako-Thomas from McGill University. Their talk is titled “Engaging Stakeholders in Rehabilitation Research, Literature, versus Reality”. Chantal and Keiko, are you ready?

Chantal Camden: We are.

Keiko Shikako-Thomas: We are.

Kathleen Murphy: Alright.

Chantal Camden: Thanks so much for the introduction. Hi, everyone. I'm Chantal Camden. I'm an assistant professor at Sherbrooke University in Quebec.

Keiko Shikako-Thomas: Hi, I'm Keiko Shikako‑Thomas, an occupational therapist is my background and I’m an assistant professor at McGill University in Montreal. It's a pleasure being with you today.

Chantal Camden: To let you know we are physically in two locations. Keiko is in Montreal and I'm in Sherbrooke. We will try our best to make sure that everything goes smoothly but if we jump on the conversation at the same time, please excuse us.

Now we will go quickly to the first slide which is a disclaimer to let you know that our views in this presentation are only our views, and to let you know Keiko and I met when we were both post-doc fellows at CanChild and we published an article around engaging stakeholders in rehabilitation research and we have the reference at the bottom of the slide. But we also wanted to share with you that there is a free article online at CanChild’s website, if you are interested to hear more about integrated knowledge translation too.

To let you know my expertise around engaging with stakeholders is mostly with regards to certain developing, implementing, and evaluating new service models for children with disabilities, and Keiko has been working mostly with decision makers and policymakers but also community organizations, families and other stakeholders around policymaking and improving policies to foster participation for children with disabilities.

We thought before actually getting started, we would have funny slides to share with you. In the early days of knowledge translation, we would see, we realize there were gaps between the evidence that we had and the knowledge that was used in clinic.

The knowledge translation process was mostly unidirectional from research to clinic. It was around using lay language to actually transfer the knowledge to apply in clinic. Over time, we realized that actually, there was a whole universe around the clinicians, so it is like some funny images to illustrate that there are many factors influencing the clinicians and their ability to use evidence. But also knowledge translation or implementation science is not only about focusing on clinicians but also engaging with families and policymakers, but also many other stakeholders to ensuring that we use the evidence that we have in clinic. Not only in clinic but all sorts of programs and activities, like policies. And in fact, knowledge translation process is a bidirectional and relationship philosophy with the double-sided arrows. The organization of services is one of the factors influencing, where the ability to use the evidence. And this is how I became over time, interested in implementing new service models.

Keiko Shikako-Thomas: In trying to understand better our audience, which is the topic of the day, it is an understanding that people come from different mindsets and also different universes. In trying to communicate this to exemplify and putting in the mind‑set for talking to different stakeholders, here we come.

If you try to understand who is up there, so this person is saying, where am I? You are saying you are 30 meters above the ground in a balloon. You must be a researcher. Yes, how did you know? Because what you told me is absolutely correct, but completely useless.

Well, you must be a policymaker. Yes, how did you know? Because you don't know where you are, you don't know where you are going, and now you are blaming me.

So that's a funny example to give an idea of how different audiences and different clients, different groups have different needs, and understanding the needs is crucial into getting the product that we want out of our research interaction, and making successful interactions, interactions that can result into better research outcomes, which is what we aim at discussing today, giving the full credit from the slides to Jonathan Lomas, and that was presented at the workshop for large screen, so using double permission. So just to illustrate what we want to bring to you today.

To give you a quick overview of what we are going to talk, we want to first get to know our audience today, and this is a very new for me all on‑line conference for all of us. It's interesting to have different interactions with our audience. But in the next slide, we want to get to know you better. Then, we are going to give a quick overview of what is integrated KT, and that is integrated knowledge translation that the concept we are trying to present here and try to make a scoping review of the article we will talk about.

A little bit of theory regarding the findings for knowledge scoping review, so why engage stakeholders in research, how to do it so that method we identified from the research what has been done, what are facilitators and barriers and expected outcomes of engaging with different stakeholders. Also we are going the share a few stories of engagement for knowledge research programs. We have had different experiences with different stakeholder groups. We would like to share what we have done, what has worked and what has not worked, and to potentially generate some discussion with you.

That brings us to our first question. The poll is already there. We would like to know who you are, and interesting, looking at the chat box, we see, when we ask to introduce everybody where you are from but nobody said who you are, so which group you are representing, researcher, clinician, individual with disability, family member of someone with disability, community worker, teacher, coach, some other professional, program manager, decision‑maker, policymaker, other, in which case we ask you to enter in the chat box. I see already a librarian that is great.

I apologize for not being listed. We are learning that. That is good. The next time we will have librarian as an option. That is great. Many of you are typing. We will give it a minute. We have a communicator, knowledge broker. That is great. Scientific coordinator, KT associate, another librarian research fellow, program support assistant. Can you choose more than one? Yes, you can, if I'm not mistaken. I think you can.

Yes, if you fit in more than one category, yes I think you can mark two categories. Try that. I'm not too familiar with the question option, but I think you can. Oh in fact you can't? Sorry.

Just pick one that represents you the best, I guess, the one that you devote most of your time, let's try that. We have KT specialist. We just learned that we can't. I know. We are learning how to go.

Choose the one that you think represents you the best. That is okay. That is just for us to get a bit of feeling who is out there. We have master’s students, graduate students, KT coordinators and associates. That is great. Good to know that these positions are out there.

Entering specialist, we do have majority of researchers, looking at our poll, we have a few community workers. That is great. Program managers and other, which are the many different people who are typing their answers in the chat box. That is great. Thank you for participating in that. That is good to know, who we are talking to. And feel free to at any time enter questions in the chat box and interact as we go.

Let's move on to the next one. Move on to Chantal.

Chantal Camden: So what we like to know is which strategy has the most impact on your academic career? So again, there is only one option, choose the one you think has the most impact. If you saw other, please use the chat box to indicate which strategy you think has the most impact in your academic area. I notice a question, apply more for researchers, although because it says academic area for non-researcher, select the one you think has the most impact on your career.

We see that academic journals is the top choice so far. We have face‑to‑face meetings with stakeholders. Unfortunately we cannot see who is saying what. But I would suspect, academic journal is probably the one that is mostly selected by researchers, while the other group of stakeholders maybe have different other options. We have some people who have selected press release. Now two persons, policy briefs. E‑mail alerts, academic conferences, seminars or workshops. Many interviews haven’t been selected by anyone so far. Under other, we have academic journals, both face‑to‑face meetings. These are options being selected. Thank you for participating in this question. Back again to Keiko.

Keiko Shikako-Thomas: We wanted to do a very interactive as much as possible in an on‑line environment. We want you to be active in thinking about it. We asked before what is the strategy that has most impact on your academic career. But now if you think of what strategy do you think has the most impact on clinical practice, here we have academic journals, press release, policy briefs, E‑mail alerts, academic conferences, seminars, workshops, face‑to‑face meeting with stakeholders, media interviews, others, in which case you can type in the chat box.

Let's give you time to respond to that one. Of course, this is to set up the model, what are the different things that you have to respond to, so we all have to respond, the majority of us being researchers, we know that we have to respond to progress in academic career, those are some traditional standard dissemination means. But when we think of impact on clinical practices, chances are, so in your answers we are seeing that your beliefs and experiences show a different reality.

The majority of participants have chosen seminars or workshops as the principal, the main form to change clinical practice, so that is interesting followed by face‑to‑face meeting with stakeholders and a few policy briefs, and when you are talking about clinical practice, so it's interesting. I'm seeing other options in the chat box, management support, changing employment culture. That is really great. You are all participating. That is great. What a huge disconnect between researchers and clinicians, yes.

It is interesting, in that is exactly the point that we want to make throughout the presentation, that the forms that we use to engage stakeholders and the formats also that we choose can be significantly different.

That is very interesting to know and that is what we are going to bring next.

Chantal Camden: Now we would like to switch to integrated knowledge translation. We would like to know how much do you feel you know about integrated knowledge translation. We have again only one option. That changed from not at all to a lot. Just to get started, and know a little bit how people feel, their knowledge regarding integrated knowledge translation. Many people do actually, quite a lot, some people, and some people a fair bit, a little bit ‑‑ okay, that is great. That is good for us to know that there is hopefully things that we can share with you today. You will probably realize too that there is probably much more around integrated knowledge translation, as you know often different words are used for the same things as synonyms.

Now we will switch from integrated knowledge translation to actually engaging. Thank you. To actually engaging with stakeholders, we would like if you use the chat box to respond how in only one word describe what you know about stakeholders engagement.

When you hear stakeholder engagement, what does it mean to you? (overlapping speakers).

Keiko Shikako-Thomas: There was some conversation going on that you are missing, strategist, like social media apps which is interesting and it's true that those are more recent interaction, that should be good to consider from the previous question.

Chantal Camden: That is a very good point. This is emerging KT strategies and we should probably act on the next presentations and options. Now with regards to one word that describes stakeholder engagement, we have different things around communication, collaboration, understanding, dialogue, a lot of things around communication, teamwork, collaboration comes up quite often, being heard, participation, foundational, power sharing. That is all very good words that we will come back to in our discussion.

To let you know, integrated knowledge translation is about stakeholder engagement, throughout the research process. Integrated knowledge translation is about power sharing, communication, collaboration, participation and so on, so all words that you already listed in the chat box. So thanks so much for that.

Now because we are talking about engaging with stakeholders, we would like to invite you to respond again to another poll question. We would like to know with whom you have engaged in research previously, and for this one you do have the option to check more than one box. Please check all that apply. Many people have engaged with researchers, research teams and nowadays every day we have more researchers involved in research projects. Individuals with disabilities, actually that is good, we have 68 percent so far, people have already engaged in research with individuals with disabilities.

Finally, the individual, service providers, community leaders, teacher, coaches, librarians, we would include there too, healthcare program managers, decision‑makers and other. Let me see. Many different people I guess, policymakers, people from the industry too, very good to know.

We have actually; have been engaged with lots of people in the knowledge translation, so it's great to know. You do have lots of experience, and are looking forward for your input as we go through the presentation. Please do use the chat box to share your ideas, stories or ask questions as we go through the slides.

Now, I promise that is the last poll question for a little while. We would like to know how much time you think it takes to move research from basic science to clinic or to clinical practice. We have five different options, from 0 to 2 years, 3 to 5, 6 to 10, 11 to 20 or more than 20 years.

We have the majority are saying 11 to 20 years and some that are saying six to ten, three to five. Actually that is probably the only one that we ‑‑ oops, sorry. If you can maybe remove the poll question. The actual good response if there is one, there are others talking about 17 years, because it's the time that has been found in median over a systematic review to see and evaluate the time it takes from basic science to clinical practice. The study is a couple years ago. But exactly, someone said it depends, obviously, right? So there’s some recent experiences, where the stars align, main driver was having legislative support and dollars. Exactly, there’s not just the contextual factors, but will influence how fast the XXX move into the practice. In general, there is a huge time line between the time where basic science knowledge is produced and the final is applied to clinical practice. Some other suggests that we engage with stakeholders in the research process to fasten the application of the basic science knowledge into the clinical practice.

Keiko Shikako-Thomas: Right. That brings us to the next, to the topic, so that is a lot of participation, thank you all very much for engaging so far.

We have the question, why should we engage with stakeholders? I'm sure that all of you who are attending here are, preaching to the converted. But there are pragmatic reasons. It's easier to, it facilitates the research process, facilitates recruitment, if you have your stakeholders engaged from the beginning. As mentioned in the chat box, if you have, when everything is aligned, one of the main drivers are involved and committed and fund‑wise and action‑wise, if they are committed that makes the research process easier.

That is a practical reason to engage with stakeholders. There are also theoretical reasons. If you have to justify as a given framework, if you are saying you are using a participatory action, research approach, or if you need qualitative design, where you want different stakeholders' input crucial responding to your question, so that might be why you would engage with them from the beginning.

Sometimes and in some places, it's already mandatory to. We know in Canada, there is for sure a trend to engage or to have knowledge users listed in grant applications, and I know it's by age and in the U.S. it's a similar requirement to have stakeholders as part of your research team, and list it as such, and actually saying how they are going to be involved.

But most importantly, from a perspective viewpoint it's that by having stakeholders engaged, we can identify what are the relevant research questions. We can link the results that we are looking for with creating the knowledge that is already needed, and then as it's ready to be used, it will be readily transferable as well. It will be relevant for the group, and it will be used to solve real life problems, and real world problems, as opposed to problems that are only relevant in the research setting.

The idea is engaging stakeholders, is based on the idea of making research relevant and making that from the beginning truly in all different steps.

Going back to the question that we asked you before, this research article by Brownson and group showed that how practitioners learned about research findings, it's talking about the difference between the two worlds we saw in your answers.

Practitioners learn more when they respond to survey; they said most of them learn about research findings through their professional associations. That is the first option. Then through seminars and workshops, e‑mail alerts and journal articles. However, researchers they perceive that the most effective way to, and again this is not thinking to XX except for emails, but not many of new technologies. These are‑‑ this article is 2013. I'm sure it could be different now.

How researchers perceive they most effectively reach practitioners, journal articles are still researchers will perceive this as an effective means to have the research out. Then face‑to‑face meetings and media interviews and press release. We see there are two different worlds and priorities are not aligned at all in that sense.

When you see then the researchers raise their efforts to disseminate research findings to non-research audience, that is not to other researchers, the majority feel that their efforts are poor. So a third of the respondents said that their efforts are very poor, to adequate, good to 22 percent but the minority is received as efficient or excellent, dissemination of findings to non-research audience. That’s what we are often talking here, when that’s what we are trying to emphasize is to engage with non-research audience. Yes, stakeholders could be other researchers and other research groups, but we want to focus on what are the needs of non-researchers.

The Canadian Institute of Health Research has proposed that this research to practice continuum, so understanding what are the differences that come, the different valleys of knowledge. I'm sure most of you are familiar with it but from basic biomedical research there is the first valley where knowledge has to move from basic research to clinical science and knowledge, and then from clinical science and knowledge to the second valley is health decision‑making, clinical practice.

For us, what we like to emphasize is engaging stakeholders is what will help you, if one of the factors that will probably help research navigate through this valleys and into final action and changes in decision‑making, and clinical practice at the very end of the research to continue.

Chantal?

Chantal Camden: If you want to see on the slides examples of KT strategies, there are different steps that we often talk about in dissemination and profusion or application of research knowledge. Some examples with regards to implementation, for instance, tool development, clinical practice guidelines, best practice recommendations and decision support tools, that is examples will continue to be around for implementation, so different KT strategies more with regards to implementation.

With regards to dissemination which is more like pushing or giving the knowledge, so it's around workshops, articles, briefs, YouTube videos, so as you can see there is a different type of traditional KT strategies that can be used that relate to diffusion, dissemination or application or implementation of the research knowledge.

Keiko Shikako-Thomas: When we are talking about the difference, talking about engaging with stakeholders, the integrated, the difference between traditional KT approaches and integrated KT approaches, is really to understand what are the stakeholders, why do they have an interest in the research, who are the knowledge users that could be engaged throughout the whole research process as opposed to just receiving the knowledge that is produced or using the research that has been produced at the end.

What is proposed in this IKT is approach is work together to shape the agenda. Not only coming up with agenda that you have thought of as a researcher but understanding what are the needs that are identified by the public, by the different people before you actually start and apply for a grant even.

Also, being involved as stakeholders, involved in decisions about methods, data collection and tool development and interpretation of findings and dissemination of results including choosing the best strategies to disseminate results, which resolves the problem that we discussed in the question before, which is if we don't know, if we are not understanding exactly what the public wants, they can help you if they are engaged in the process.

A few examples, moving towards integrated KT, in Canada we have the strategic patient oriented research, and in the U.S., patient centered outcomes research initiative, PCORI. Both of them are putting stakeholders' patients in that case, at the center of research teams and delineating clear engagement rules and plans.

Also, the NHS in the UK, equivalent of the Involve framework, is proposes a new research approach where research is being carried with and by the public as opposed to or about or for the public. That makes a whole difference in understanding how you are developing your research proposal and how you are applying at the very end.

Also the Involve framework proposes very interesting values for engaging stakeholders, which I think are crucial and important for us to incorporate into our values here as well. So those are respect, support, responsiveness, transparency, diversity, and accountability. . The values should be part of each of the steps when you have people involved, so they respond to the needs, you are transparent about the process, there is no magic happening in the middle that people don't know how the research finding went from this to that. A diversity of stakeholders represented and being accountable to the needs that are identified by the public.

These values are very important and the references are there if you want to know more information about the Involve framework.

What does having the stakeholders at the center, what does that change? Is it really helps passing those values of knowledge, and then there are different ideas that have been happening engaging stakeholders within those valleys of research . For example, genetics, personalized medicine, interpreting biomedical research, engaging people to move that into clinical science, for moving from clinical science to clinical practice and healthcare decision‑making, there are several patient-oriented support units in Canada, I'm sure equivalent in other places. Also research networks that include associations, groups that are not only research groups but also stakeholder groups represented, community‑based primary healthcare and community based rehabilitation are great examples of transposing from the clinical science from the clinical practice, and finally the evidence inform healthcare which is what we all want to achieve at the very end.

Also, the consolidated framework for knowledge implementation is an interesting and another framework to understand stakeholders' involvement. There are many different interesting aspects. I encourage you to check the reference. But in understanding the outer setting and inner setting, and what are the different process that research has to pass through to adapt and transform from intervention that is adapted initially, so from intervention that came from research study to adopt in the real setting and real environment.

What’s important to understand here is that the individuals involved in the research process, they are at the very core of the whole transformation and implementation process. Individuals within the inner setting, within the outer setting, they are involved in doing and involved in understanding and adapting those needs. All those different frame works that exist for knowledge translation, integrated knowledge translation, dissemination, and implementation, the different names that are to it, it's important to understand that they have engaged in stakeholders at the very center of the discussions.

That brings us to another question. That is for to make sure that you are all still there. We would like to know how much evidence do we think we have about the outcomes of engaging with stakeholders in rehabilitation research? Engaging stakeholders in rehabilitation research, how much information do you think there is out there? Not at all, a little bit, a fair bit, quite a lot, or a lot. Or you can choose not to vote.

We have 60 percent, I was trying to give a quick peek at the chat box, and while we are responding, so I see lots of very interesting comments and questions. We can definitely try to have some time for discussion at the end of this presentation. But if not, there is a discussion time at the end of the afternoon.

So we will try to get back to your questions. You have interesting points here. Can you bring it back, the responses? I think the majority was saying ‑‑ (overlapping speakers) a little bit. Okay. I see that.

There is a little bit of information, so not a lot available. So that is what we are going to tell you about now. On to Chantal.

Chantal Camden: Yeah because this is exactly what we are wondering, how much evidence did we have around engaging stakeholders in research, more specifically with around patient research. It is how Keiko and I started to work together and concentrate on knowledge translation or engagement of stakeholders in research. There was a scoping review we conducted, already published. We want to go very quickly over the findings of the scoping review, because we decided we prefer to have more time to engage with you, either virtually through the chat or hopefully we respond to your questions at the end too.

We will go quickly over the findings and hopefully have more time at the end to discuss and share examples how we actually used some principles in our own projects.

Within a scoping review, we did a scoping review based on the principles of six different steps. Step one is define the research question. For us it was how stakeholder engagement being conceptualized in rehabilitation research. It includes who are the stakeholders, what strategies are used, what factors influence engagement and what are the impacts of engagements.

I won't go over the ‑‑ I apologize, the slide is hard to read on your screen but the scoping review process is similar to most of the different type of reviews, except we do not evaluate the quality of the studies. But as you can see, through the flow charts, it's a process of selecting the articles and extracting the information and analyzing information that comes from the article.

We actually extract and analyze the information with regards to our research questions from 19 articles. In a nutshell, the positive findings, there are two things in the slides. The first one is that there are a variety of stakeholders involved. Actually it has been already shown by one of the slides where we had a question for you, and you said as a group that you have been involved with all the different stakeholders groups, including individuals with disabilities and their families, clinicians, individuals representing community groups, decision‑makers, and program managers, (policymakers) and so on.

The second thing was that the involvement was happening at different steps of the research process, and including different actions. It was really from tying the researches questions up to disseminating results and implementing action plans. Not all of the research engaged with the stakeholders showed all the same steps but it was some steps. Most of the research process included the stakeholders in two, three or four different steps, but collectively all the articles engaged all the different steps.

With regards to actions, the stakeholders, the signs are going beyond the research steps, the stakeholders also involved in applying service users' needs to expand the experiences of various service users but also to develop new interventions evaluated.

If we go for areas of improvement, there are only one article that we found and it's not like a systematic literature review, but in the scoping review, we only found one article that clearly reports having engaged stakeholders on writing results, publishing and adding the stakeholder as a coauthor. We wonder if it is something we should do or must do. But that is certainly something that we wanted to highlight.

Equally or even more important, no studies formally evaluated strategies used. There were a lot of strategies suggested, to engage with stakeholders. But the outcome of these strategies was not evaluated, and only a few studies used data collection to evaluate the factors influencing engagement or the outcomes of engagement.

That is the reason why, on the next slide, if you have perceived impact of engagements, because we have very few evidence with regards to the real impact or definite impact of engagement. But what we believe are the impacts of engagements, is creating partnerships and building value, making knowledge more easily applicable and facilitating the research process, and empowerment of stakeholders.

Now the last one, the last thing that we want to highlight in the scoping review was how to do it, so what are the strategies that can be used to engage with stakeholders? As the image illustrates, respect is probably, building respect and it's also relating to collaboration and communication, negotiation, etcetera, power sharing, so many things related to respect, and there were six different strategies that relate to identifying stakeholders, so how to identify stakeholders, how many stakeholders are on board, which groups to design to, to report key strategies and things to pay attention around identification of stakeholders.

The second one is around adding clear and defined roles but also opening up for the approach to renegotiate roles as the processes evolves and making sure it's not six roles but you offer the stakeholders the opportunity to re-define themselves in their own roles. The committees, working committee, through different names but always adding real people into committees, that meet monthly, every three months, and that would overview the research process. Supporting stakeholder was a strategy that was mentioned. Training stakeholders formally or informally. Sometimes adding people to accompany to stakeholders. It was true for individuals with disabilities, sometimes the research group would ask someone, especially identify to combine and support the stakeholder to ease participation throughout the process.

Paying attention to communication and culture, so we already mentioned using lay term, making sure the information is clearly understood by all the groups involved, and recognizing that they might have different cultures and informs priorities. Also are able to be involved during the project. So sharing power, it's not only about adding mandatory stakeholders on board but be willing to incorporate people's suggestions throughout the process, changing some pieces of the research. And finally, to make sure to be able to do all of that in enough time, funds and resources appear to be essential.

Now it might seem to be principles and strategies to use but actually based on our experiences, when we actually tried to start doing it, sometimes it's overwhelming and there is always things that don't go as planned. Our key message for you if you have never been engaged in, involved in engaging with stakeholders, don't panic if things don't go expected. It's normal. Don't run away. Keep calm. Share with colleagues and at the end of the day it's worth engaging stakeholders.

First I'll go to a project where we worked with clinicians and the families and parent association on the project to implement knowledge tools in the centers to foster evidence‑based practice around developmental coordination disorder.

I don't know if most of you have followed along with this framework, knowledge action framework only used in Canada. The reference is on the bottom of the image. And we will go together through the different steps.

In the middle, is really around knowledge creation. The first step is to build the evidence, developmental coordination disorder we already have lots of information with regards to the chronicity of the condition, impacts on every daily functioning, the kinds of services needed. This presentation is not around the D.C.D., but just using D.C. D as an example, to say that with regards to knowledge increase, we had lots of knowledge.

Now the few next steps are around Synthesis and different tools fosters implementation of the knowledge. What we knew around DCD is that there are research to practice gaps with regards to how parents manage DCD and how clinicians manage DCD. Some resources and tools are already available, but not in French, and maybe not necessarily applicable in the context where we were in Quebec. That is the reason we decided to develop this project.

We adapted a model that was already existing and to implement it in Quebec. This is the first box in the model, which is to identify the problem. We had no access to evidence based resources, and to review and select the knowledge, we selected a website that was translated from English and adopt it for Quebec.

Now we go to the steps in the model. The first one is around identifying problem, adapting the knowledge to local context, accessing barriers and selecting different interventions, and what we have through these four first steps with the different principles that we actually identify in the scoping review, so with regards to identifying stakeholders, I was fortunate to have a long standing relationship with clinicians, and also with the parent association. Actually I knew them. We had been collaborating together but hadn't worked together in a research project. It does make a difference, as you will see.

We ask people to self‑identify their representants. We had two centers and one parent association and ask them to determine which family was going to be on the committee, and they determined themselves who was going to be on the committee, which has pros and cons.

We decided to form committees; we had a working committee meeting monthly by phone. And were the roles clear, I'm not sure because as you will see, even at the end of the project there were some people saying, I'm just starting to understand what I got myself into.

Sometimes we think, I thought it was clear what I was expecting from the different stakeholders, and probably that was the case for some were involved before, but some were the first time. The key is that you need to take more time and sometimes have different strategies prior to or early to check the different points and process, to make sure the roles are still clear.

We haven't done any formal training on this project. I'm not sure if we necessarily should have done this training but certainly to accompany the stakeholders with regard to their roles, but also letting them know and especially the family representatives, the research process, different steps, what we are going to be doing through the different monthly meetings is certainly something that we could have done better.

With regard to paying attention to communication/culture, making sure to use lay terms and to ask and make sure people feel comfortable, to ask questions if they do have, I think it was clear and was pretty okay. Asking for their priorities, again, making people comfortable, saying that there are different things and priorities they would like to do. To give you an example, we are not planning certainly to engage with teachers in this project, but because it was so important for family members, we extended some of the research activities to reach out to teachers and education players, too.

Sharing power, we didn't modify the questionnaires and different strategy for recruitment. Again, having enough time, funds and resources, this was a small project but we did make sure we have money available for the participants to make sure to compensate for their participation in the project.

This is at the end of the project, next time I will know what I'm getting myself into. Again, like the experience of knowing what is really expected from the stakeholders, and to be fully honest also from the researchers when you get started, it is something that you develop the skills as you go.

I'll go quickly around, to let you know that we had a working committee that the first things they do is to really revise the new materials to make sure it was adopted to the context. We did a focus group to identify barriers and make sure like for instance, videos we have on the website were going to be available, YouTube videos were able to be displayed in the centers because it was blocked, so it was so little tiny details, but it does make a difference at the end of the day.

In the way that we developed different strategies to implement or share the website, the rehabilitation centers didn't participate so clinicians gave information to the families. The reach out or the recruitment was only little but the strategy and it's the parent association using social media, so earlier in the presentation we were talking about social media, was really what helped us reach much more families, not only for the recruitment but also for making sure parents had access to the information and this is a strategy that came from the working committee and the parent association.

Really it gave us more reach than what we were originally expecting with this project. There is maybe something missing, to relevance of engaging with stakeholders for us in research was really clear, and the fact of the strategies that gave us this reach came from the families.

The question is the method, the questionnaire that we used to follow up, it is the balance, the working committees reviewing the questionnaires, the wordings to just make sure it's clear for the parents facilitating the recruitment and interpretation of results. So what we found across three different questionnaires.

We were able to develop KT materials with the families. Stay tuned, because the next phases are coming. It was one of my experience, so having long standing relationship based on trust and transparency is something that was really helpful, and planning for each meeting is something that we need to do too, to make sure that we are able to meaningfully engage with stake holders. Otherwise there is a risk of no participation. It is not only about having stakeholders there but ensuring meaningful participation.

As a researcher, I think we really need to be trained and supportive to be able to meaningfully engage with stakeholders. There are a couple of resources listed at the bottom. I want to bring your attention to the Bloorview Research Institution where a structure has been put into place to facilitate family engagement in the research process but also support researchers who want to engage with families.

That was the example that I wanted to share with you. Now back to Keiko.

Keiko Shikako-Thomas: We got a time warning, so that is good, we make it very fast this last part. Really important, so this is our second example, I will skip through the details. But essentially, in one of the research projects that we did, we realized at the end that the findings that we had, about participation of children with disabilities in leisure activities, it was not as relevant to clinicians as we thought it would be.

It was very important for families, but clinicians felt that this was a message for policymakers, and not for the clinicians. That brought us to engaging with the whole set of different group, stakeholder group that we were not initially used to work with.

That is what I'm going to tell you about. We wanted to identify which are the policies that could then support participation, if it was not about changes in clinical practice how we could change policies and how we could communicate research results to policymakers.

In that, there are different strategies in terms of the first identify what are the policies out there, and then talking to policymakers and doing critical discourse analysis to see what were the strategies that they felt would be most effective to communicate researcher to engage them in research next time.

The difference that we saw on that, that I think are the key messages that are going to take for now, is really that the difference between what the researchers think so that goes back to the first cartoon that we used at the beginning, it's that for researchers the problem that they see is that they do not understand the policy process.

I see different policy analysts in the audience. That is an important audience to engage with. Understanding political cycles, who are the players, how that functions, what is the different timing for research versus the timing for policymaking, the ethics involved when you have to respond to policy needs through your research questions, and then the differences that exist between traditional KT approaches with clinicians or families and with policymakers can be very different.

On the other hand what policymakers think is that there is a relative and small role of research‑based evidence in policymaking, and often the relevance of the research that is generating academic research is not enough, is not high enough to make the case for a policy change. Also considering that the populations that we deal with are minorities and often only one of the population that they have to take into consideration, and the priority setting ‑‑ I'm skipping to the last one ‑‑ is important to have them engaged, because that will show us what is the role of research and how we can make it about.

I'll skip, to summarize what a policy officer told us, is you have to give them ideas, policymakers are not the experts. You are the experts. The idea that you are the one that has to make the information relevant and not expect that a policymaker or politician with no background or experience in your area to take action or to do anything about information that you are generating.

It's packaging the message, can you come back with that 3 year study summarized in six bullet points in Power Point and that is often what people need to take action in the policy setting.

We developed a few alternative strategies, out of our traditional realm of research and we can discuss later as time is advancing. But developing public forums with multiple stakeholders including policymakers to present the research results and to make a difference, make a discussion of what are the next steps, what are the next research points that we can work on. Then establishing a policy dialogue where we wouldn't have all the decision‑makers, with no pressure from voting groups or other groups where they feel comfortable enough to discuss the research findings and have a deliberative dialogue on understanding how this is making ‑‑ so we are now working towards that, and generating policy dialogues in rehabilitation research, especially in childhood disabilities, is what we are trying to work on to achieve more connection with policymakers.

(voices in the background).

I realize that I lost connection within the Adobe Connect platform but I hope you can still hear me okay? (overlapping speakers).

Kathleen Murphy: We can hear you fine.

Keiko Shikako-Thomas: Sorry, I cannot move the slides for some reason. I guess the Wi-Fi went. Anyway, I would just skip to the very end. What we have identified that was important is engaging with different audiences, so it doesn't include families, so policymakers do come a lot, do rely a lot on the information that comes from families, so what families want may have a much higher and most important voice than what researchers say that is important.

If you are working with families and with policymakers at the same table, that is a double good. We can have also the voices of community organizations, which are groups that we are not often ‑‑ thank you, that is a good slide ‑‑ that are not necessarily involved in normal groups, so try to talk to associations, see who are the other groups that you traditionally didn't have, and understand the questions that policymakers are faced with are usually about cost and benefit. So that those are questions that we have to address, and that we not often address in rehab research.

That was the example, which I'm going to skip for interest of time. But think about family identified that we could provide a solution that came from research, in the case with adapted, identifying activities related to leisure for children with disabilities. We have buy in from community organizations and other groups and we get attention from policymakers, saying how we can use this information to develop better programs or to change our funding structure, how we can use this information somehow to respond to questions that we already have and then we can integrate with research.

Quick challenges, that it's important to keep in mind, it's not possible to make everyone happy, but you can be the middle ground. You can be the mediator and find what are the needs of different groups and respond as much as possible, and exactly as possible within research projects.

You have to get out of your way and you should establish ground rules before you start, so that everybody knows what they are getting into, and what they can expect to have out of it. You need to be responsive to the different group needs. You have to understand the motivation and various political cycles for instance that various community interest groups have interest on and off depending what they are working on but that is okay. Changes can occur overtime and you can develop and establish relationships even when scenarios change and political cycles change, you can still keep on going and develop a good work.

That is our final words. Chantal, you want to ‑‑ okay, so in conclusion we do know that integrated knowledge translation is a way to understand your audience and their needs. We do have to determine which are the additional audience that you are trying to reach, when not already at the table.

So who are the community groups and policymakers, who are people not traditionally involved that you can invite in and make the research more relevant?

What are the barriers that exist there, and what are the actions required overcoming the barriers? It does need to be carefully planned. It should be budgeted for, not just a quick add‑on at the very end and does require traditional solutions and untraditional solutions. But it is a very rewarding experience.

Next you will hear about the environments, formats and strategies policy outcomes. I hope that this can help you and summarize the data and get us started at the conference with having in mind the different audiences and what are their needs. I think for time we are going to have to skip to ‑‑ if you think in one word what you learned today, type in the chat box. I guess we will have questions. I have written down some of the questions but we can have that more at the end.

Keep bringing on your in one word what you learned today, that is good as a learning strategy that we can bring back to the discussion at the end for more questions.