



A Rising Tide: New Integrated Knowledge Translation Guiding Principles for Conducting and Disseminating Spinal Cord Injury Research in Partnership

Webinar transcript – March 12, 10:00am (PDT)

BACKGROUND

In this webinar, our panel of SCI researchers, research users, and funders will introduce and discuss the co-development of new Integrated Knowledge Translation (IKT) Guiding Principles for Conducting and Disseminating Spinal Cord Injury (SCI) Research in Partnership. We will outline our efforts to support the use of the principles and discuss the potential of the principles to combat tokenism and improve the relevance and impact of SCI research.

The eight principles are designed to help SCI researchers and research users engage more meaningfully in research that is relevant, useful, and/or useable. The principles represent the first rigorously co-developed, consensus-based guidance to support meaningful SCI partnerships.

The principles were co-developed by a multidisciplinary group of SCI researchers, clinicians, people with SCI, representatives from SCI community organizations, and funding agencies and are published in [Archives of Physical Medicine and Rehabilitation](#).

Panelists: Dr. Chris McBride, John Chernesky, Gayle Scarrow, and Dr. Heather Gainforth

Moderator: Dr. Kathleen Martin Ginis

Visit the IKT Guiding Principles website for more information and to download the principles: www.iktprinciples.com

TRANSCRIPT

Kathleen Martin Ginis: So we will get started then - good morning, good afternoon, good evening - I know we have people from across the globe joining us in a variety of time zones. I'm Kathleen Martin Ginis. I'm a professor at the University of British Columbia on the Okanagan campus and also a member of the IKT integrated knowledge translation principles team.

I wanted to begin by letting you know that this session is being recorded and it will be made publicly available on our website. We will also be using a live auto transcription for this meeting, please note that since the transcript is automatically generated it may not be entirely accurate. So we will also be translating the transcript into French after the meeting, and the video recording and the English and French transcripts will be made available on our website in the coming weeks.

Throughout the webinar we want to hear from you please put your questions or comments in the chat Rhyann McKay will be monitoring the chat. If you have any questions in English or French please contact her or put your question in the chat and Shane Sweet is on hand and he will be translating any French questions to the group, if you have any technical difficulties, please contact Stephanie Masina via the chat.

Today, our speakers are located in the cities of Kelowna and Vancouver and British Columbia Canada. Kelowna is located on the traditional ancestral and unceded territory of the Syilx Okanagan Nation and their peoples. The City of Vancouver is located on the traditional ancestral and unceded territory of the Musqueam, Squamish, and Tsleil-Waututh peoples. Together, we respectfully acknowledge that we are uninvited guests in these territories. We would also like to acknowledge that you are joining us today from many different places near and far and acknowledge the traditional owners and caretakers of those lands.

We will be hearing from four panelists today - full bios of our speakers are available on IKTprinciples.com.

A brief introduction for each of our speakers – Dr. Chris McBride is the Executive Director of Spinal Cord Injury British Columbia and has over 25 years experience as an SCI researcher, research centre executive, volunteer, and now community service leader in the SCI sector.

John Chernesky has over 25 years of lived experience of spinal cord injury and has participated in dozens of research studies and, in addition to being a coordinator on a – sorry – co-investigator on a number of research projects. As the Consumer Engagement Manager at the Praxis Spinal Cord Institute he works closely with individuals with lived experience of SCI, including their family and friends and community organizations and advocacy groups to ensure research is addressing their priorities.

Gayle Scarrow is the Director, Knowledge Translation at the Michael Smith Foundation for Health Research. She leads the development, implementation, evaluation and ongoing management of Michael Smith’s knowledge translation plan for the purpose of fostering and accelerating the impact of health research in British Columbia and beyond.

Dr. Heather Gainforth is an Associate Professor at the University of British Columbia in Kelowna, British Columbia, Canada, Michael Smith Foundation for Health Research Scholar and an ICORD Principal Investigator. Dr. Gainforth has led the partnership that co-developed the IKT Guiding Principles and with that I’m going to turn things over to Heather who is going to introduce the IKT Guiding Principles.

Heather Gainforth: Good morning, and welcome everyone. I’m so grateful to you, for spending your time with us this morning, we are very excited to share the IKT Guiding Principles for spinal cord injury research with you today.

I know that there are a number of individuals that have just joined us, and so a few reminders as I’m going through this presentation. In terms of some general housekeeping - so if you have any questions that come up, Rhyann McKay is going to moderate our chat. You're welcome to contact her through there. As well as at the end of my presentation we're going to have a large discussion. You can raise your hand and ask a question and our panel will be speaking as well at that point. Stephanie Masina can help you with any technical difficulties that you have so if there's anything you need from her, please reach out. I’m hoping that everyone can see my slides at this point and that they’re all in front of you. Get a little nod - yep - alright so with that will get going.

I would like to begin by thanking the impressive panel that helped to co-develop the IKT Guiding Principles, and that has been extremely motivated and dedicated to this project, so thank you and thank you all for being here today.

I'd like to argue to you that we have been stuck on repeat. As researchers, we have been taught to write the research grant, get the money, do the research, publish the results, and repeat. And the problem with this approach is that the end point in this cartoon is publishing the results, and it's not application. When the end point isn't application, what we end up doing is sacrificing real world impact. The gap between discovery and application of research is a particular concern for people living with spinal cord injuries, whose needs and voices are often not reflected in our research process and whose lives could be enhanced by the research discoveries.

So, establishing research partnerships between researchers, someone whose job it is to carry out research activities, and research users, individuals or groups that can use or benefit from the research, is one knowledge translation approach that is gaining attention for its potential to close the gap between research and practice. When I'm talking about knowledge translation, I'm talking about the idea of getting research into the hands of real world users. Increasingly, we are seeing research funders, SCI organizations, and people with lived experience of spinal cord injury encouraging and sometimes requiring or mandating that researchers partner with research users on grants. And this approach aligns with disability communities' calls for there to be "nothing about us without us", yet only a small minority of spinal cord injury research and knowledge translation activities are planned and implemented in partnership with people with spinal cord injury and research users. So what's the solution here?

Our team has proposed the idea of integrated knowledge translation. This isn't a new idea just within spinal cord injury, a term that emerged from a research funder in Canada, but this idea of partnering together. So integrated knowledge translation refers to the meaningful engagement of the right research users at the right time throughout the research process. That means that we are partnering together when we're planning the research, that we're partnering together when we're conducting the research, that we're partnering when we're disseminating it, and we're trying to get it applied in the real world. And what do we mean when we say meaningful engagement? So meaningful engagement means that we're contributing to and that we're influencing a personal or socially meaningful research dissemination and/or implementation goal. And that we feel that we have a sense of responsibility to others. Meaningful engagement, I would argue, is the opposite of tokenism.

So tokenism is something that we hear about in SCI research and in research outside of spinal cord injury. And that happens when a partner is asked to endorse and therefore legitimize research programs over which they have little real influence or control. So that means that they haven't been meaningfully engaged. This could happen when a research user is asked to sign off as a partner on a grant or be involved in a project without actually having any decision-making power over those research activities, and often can happen when things are done in a rush and quickly - we've got a grant due, could you sign on X - it doesn't allow for meaningful engagement.

In my own research, what does integrated knowledge translation look like? So for me, I asked organizations like Spinal Cord Injury British Columbia, where Chris McBride is the Executive Director. I go to that organization, and I say how can I help? And then at every step in the research process, we continue to ask how can I help? What research questions matter to you? When we're answering that question, what methods makes sense, how can we decide on this together? When we're disseminating that research, what tools and resources should we create together and when we're applying that research, how do we make sure it has an impact? Notably, the Integrated Knowledge Translation Guiding Principles were also developed using an IKT approach. So in 2016 I intended the Praxis conference that was led by the Rick Hansen Institute at the time - now the Praxis Spinal Cord Institute -

and I asked how can I help? At that conference, we were addressing the gap between spinal cord injury research and practice, and some of you, I know were at that conference. And a group of us met together, and the answer to this question was that we need to change the spinal cord injury research system. We need to think about helping researchers and research users engage more meaningfully in research that avoids tokenism, and that is relevant, useful, and usable.

So that meant that we needed to think about how could we rigorously co-develop, co-implement, and co-evaluate Integrated Knowledge Translation Guiding Principles for conducting and disseminating spinal cord injury research in partnership. And it was really important to this group, that we really thought about the SCI system. We defined that as funders, researchers, and research users. Everyone in this system needed to be committed to making sure that we fostered meaningful engagement and research. If any one of these groups doesn't commit and promote the guiding principles or adopt them, it becomes much harder for us to make a change. And you're here today because we've actually been able to create the guiding principles, and now we're thinking about what does it mean to implement them and what does it mean to evaluate them, so we can have impact.

So who was this team that came together over time? So we're a strong North American group of spinal cord injury researchers, research organizations, people with lived experience, health professionals, and research funders, and as you'll see from our panel today, many of these individuals wear multiple hats. So they might be a person with lived experience, who also works in a spinal cord injury organization, who also does research, and we really sought out people with that diverse experience.

The team includes individuals who all are also associated with several organizations in the research system so that we could make change with decision makers in the system throughout. And together we created eight principles - so what do I mean when I say eight principles of integrated knowledge translation. So principles are those fundamental norms, rules, or beliefs that represent what is desirable or positive for a person or group, organization, community, and really what they're helping you do is think about the rightfulness or the wrongfulness of your actions. So they are really about the idea of guiding the heart of your research and so that that can guide your head to do and practice those principles in everything you do.

What are the eight guiding principles? I'll tell you what they are and then I will tell you more about how we created them. So to engage more meaningfully in research that is relevant, useful, or usable, the IKT guiding principles are: (1) Partners, develop and maintain relationships based on trust, respect, dignity, and transparency. This principle recognizes that research is inherently relational and that you need to spend time building that partnership and building that trust. (2) Partners share in decision-making. So that means that there is not one person on the partnership that gets to make all of the decisions. Everybody has decision-making power, so they're not on the panel just to tick a box. They're there because they are there to make a decision with you. (3) Partners foster open, honest, and responsive communication. You can't do the other principles really without communication. (4) Partners recognize, value, and share their diverse expertise and knowledge. This means that all knowledge doesn't come with a PhD. Knowledge comes from lived experience, it comes from our day-to-day work in research or outside of research, and all of that is valuable when we're coming to the table. (5) Partners are flexible and receptive in tailoring the research approach to match the aims and the context of the project. So this means that you need to understand everybody's needs around the table so that you can be flexible and understanding in that process. (6) Partners can meaningfully benefit by participating in the partnership. And we talked about what meaningful engagement means earlier, but that I shouldn't be on a project if it's not meaningful to me, and this relates to both

researchers and research users. (7) Partners address ethical considerations. Whether that's the ethics of how your partnership is working or the ethics of your actual project. (8) And partners respect the practical considerations and financial constraints of all partners. So you think about the ideas of how does someone get to that meeting - is someone being paid, how do the finances work, can we do that in an equitable way.

It's important to note with these principles that we use the term "partners" and not "researchers" or "research users". All of us on the partnership need to be held accountable to holding these principles, and this isn't just something that the principal investigator should do, or the research users should do. We all need to be adopting and valuing the principles.

There are three components in the principles to support you. The principles start with a preamble, they give a little bit of a background of how to use them and why they exist. Then there are the eight principles that I just showed you and then finally on the back page there are all the definitions that will help you to be able to understand the principles, and the one pager associated with these three pieces are available on our website for you.

So, how did we develop these principles and how did we come up with them together? It wasn't just picking and choosing; we aimed to use a very rigorous process. So the entire process was guided by the appraisal of guidelines for research and evaluation (AGREE) II instrument which is a rigorous internationally-accepted consensus approach to transparently evaluate the development of clinical practice. It's important that we use a rigorous process because we wanted to make sure that we were able to support researchers and research users with evidence when they're trying to also create evidence.

In 2017, we were lucky enough to receive an ICORD Seed Grant. So ICORD is a research organization, a spinal cord injury research organization based in Vancouver BC. And we used the funds to start an initial meeting with a core panel. At that meeting, we aimed to address the first three domains of the AGREE II instrument. The first three domains ask you to think about the scope and the purpose of your, in our case, guiding principle. They ask you to think about stakeholder involvement, who needs to be involved in order for this to have impact, and that is how we really started to think about - we need funders, we need researchers, and we need research users. And then, very importantly, the rigor of the process used to synthesize the evidence and develop the guidance needs to be thought about but also transparently outlined. So that's what I'm going to do for you right now.

So, what was the first thing we thought about doing, was that we actually went to the literature and looked at three key data sources. The first was a review of reviews. We looked at 86 different reviews on research partnership principles - I'm going to tell you a little bit more about that review - and we also did a scoping review looking at 13 different papers specific to spinal cord injury research partnership principles. And then we did interviews with spinal cord injury researchers and research users who were identified as champions of taking a partnered approach. And we aimed to understand what kind of principles they used in their research. After removing all of the different pieces with similar meanings and redundancies, we had a list of 125 different research principles that could be used to potentially guide the spinal cord injury research process. That wasn't necessarily useful to us at that point, so I'll tell you a little bit about how we cut that down, but before I do that, I do want to highlight our review of reviews paper.

For anyone that's joining us today that is wanting to learn about principles within and outside of spinal cord injury research, I think that this article is really important for you, because what we aimed to do was look at the principles, the strategies, the outcomes, and the impacts of different research partnership approaches within health and beyond health. This was a huge undertaking led by Dr. Femke Hoekstra, but it required us to take a coordinated multicenter team approach. What that means is that we got several teams across Canada to help us to be able to get through these 86 different reviews and there are a number of other reviews that are building off of this work. The reason that I want you to look at this paper if you're interested in partnerships, though, is that we do provide some initial guidance for use of the findings in partnerships overall and there's a bit more information around strategies, outcomes, impacts that I think might help you if you're very interested in this work.

I told you that we got to this list of over 125 principles that should be potentially considered for guiding spinal cord injury research. But from there, what we did is we wanted to get that down to a useful list. So we did a Delphi consensus study. And it was conducted with SCI researchers and research users that had been involved in at least one partnered research project. We did it in three rounds and broadly we asked people which principles should be used to guide research partnerships? And at the end of the third round - so everyone rates the different principles and then eventually we get to an idea of what's desirable, or what should be used - we had a list of 37 principles. That list of 37 principles then came to an expanded multidisciplinary panel of 17 individuals that represented funders, researchers, and research users at a two-day meeting in Vancouver held at Spinal Cord Injury BC, and after two days of deliberation, we came down to these eight key principles that I presented to you today. That includes the preamble, the glossary, and the principles. Notably all of the panel members that are involved in today's webinar were at that meeting, so if you have deep questions about what that process was like, we're happy to talk to you about it.

Lastly, the IKT guiding principles were then reviewed by panel members as well as 35 potential end users with experience working in research partnerships, both within and outside of spinal cord injury research. And mean ratings indicated that the potential end users agree or strongly agree that the preamble, the principles, and the glossary were clear, useful, and appropriate.

So that gets us to this publication that you're learning about today that transparently outlines how the IKT guiding principles were developed so that they were guided by the AGREE II framework. They are designed to be used by researchers, funders, and research users and, importantly, this document is open access, so you can access it even if you're not in an institution. And it includes supplementary files, where you can really look and see our decision-making process and see the transparency around that.

That is our most in depth resource, I would say, for just generally working in partnerships and having something available to you, visiting us at IKTprinciples.com and downloading our one-pager is maybe the most accessible way to look at the principles. But developing and publishing that one-pager is really just the first step. Our goal was to get to guiding principles, but that's not all of our work. Principles can only have impact if they're implemented and used by funders, researchers, and research users. So that means that our next step in this process is to make sure that we understand all of the barriers and all of the facilitators that would help or stop researchers, research users, and funders from using these. Once we can understand that, then we can really dive deep and create more tools and resources.

In the meantime, that work is underway, but in the meantime, we are still committed to giving you resources, right now. So on our IKT guiding principles website, there is the one-page postcard available in both French and English. There are publications related to the development process of the principles and there are more publications on route right now to that website. So it will be updated regularly. There are resources there to promote partnered research or to support it that are available both from us as the partnership, as well as all of our partner organizations have a lot of different resources, so it becomes a one stop shop for partnered support. It also gives you information about our team profiles and, over time, we hope to have more success stories.

I do want to highlight some information around initial insights of what would maybe help the IKT guiding principles be adopted. So when we were doing the interviews with champions of partnered research, led by Femke Hoekstra as well as Lee Schaefer and Peter Athanasopoulos and our panel, we asked the question of “if there are so many barriers to doing partnered research, why is anyone doing it?” Does it make sense that they're doing it, and how are they able to do it when it can be so hard to do partnered research? So we did 10 semi-structured interviews with champions, who are either a researcher and/or research user, as we know, you can wear multiple hats. And what our insights really showed us is that if we promote an attitude shift to see the value of co-production so to really see that this is an important value in research, if we have role models to inspire other researchers and research users, if we encourage intrinsic motivation for engagement and we avoid transactional approaches, so coercing researchers or research users to be involved or incentivizing them in order to get the money, you have to do this, instead thinking about it as a value system and fostering relational research partnership skills, we can really potentially help researchers and research users be able to come to the table and do meaningful partnered research.

I really think that this quote from one participant sums it up quite beautifully. They say, “Part of [being an IKT researcher or a partner researcher] is being open to collaboration. I don't think it's a different way of thinking - or sorry - I do think it's a different way of thinking and you do have to relinquish control. A lot of researchers - for a lot of researchers, that's not the personality type they come from. I think a lot of researchers are more type A personalities. They like to bend the environment around them to their own wills. You can accomplish great things that way, but you can also become Voldemort... It's relationships that is what this type of research is all about.” And I think that's really what our partnership has highlighted is that it's about building meaningful relationships in research.

I mentioned that we're aiming to create tools and resources for researchers, research users, and funders. What we're really asking about is how do we create transformational change in the spinal cord injury research system? And I hope that today we get to talk about that more, and then we hear some of your ideas of how you're hoping we can create change as a partner. We're also looking to understand how we can evaluate and understand the impact of these guiding principles - one, so that we can show that data to help other researchers understand how they work, but also two, so that we can iterate them and improve them. So we're doing a deep dive within ICORD, the spinal cord injury research organization I mentioned to you earlier. And we're also looking across North America, how the principles are being used by researchers, research users, and funders. If you want to get involved in that work, please email us. We're keen to hear your success stories or your not so success stories. We want to understand what's working and what's not so we can better develop principles for you.

And for our discussion today, I wanted to ping some ideas and say what are important outcomes and impacts that will help us understand if the principles are working. In my own opinion I don't think these will be our traditional transactional ideas of what counts is publications and grants, etc., but more so

some transformational ideas, some relational ideas, what does it feel like to be involved in meaningful research.

And in that sense, I would say, what does it feel like to do meaningful engagement. If we think about what are the impacts of these principles. Can we ensure that when people come to the table, they feel like they are contributing to and influencing a meaningful research dissemination or implementation goal.

So while we're waiting on all of that research to come out in our last two phases of this grant, if you're sitting here today and thinking to yourself how would I actually use these principles? The first question I would say is: do you have a partner, whether it's a researcher/research user that you can talk about "what does meaningful engagement look like to you?". And then I would ask the question: "what does it look like to follow each principle for you, for a potential partner?". Have that conversation and that dialogue. Think about using the principles in that relationship to set some clear boundaries. Ask the question, what is okay in this partnership and what's not okay in this partnership. Establish processes to hold yourself and your partners accountable for supporting meaningful engagement. And when I talk about that I'm not talking about the idea of policing people and saying you're not doing this right. More so I'm thinking about the idea of progress, not perfection, and really supporting each other to say if something doesn't feel right in terms of a principle, how do we tell each other that and how do we iterate. And that requires all of us to reflect on as well as report on our process in our outcomes of our partnership. When we report and we reflect we can all learn together.

At the end of the day, I really think that the goal of the IKT guiding principles is thinking about researching and partnering with integrity, and I think this definition from Dr. Brené Brown really hits the point home. So when you're acting with integrity, she says that you're: "Choosing courage over comfort; choosing what is right over what is fun, fast, or easy; and choosing to practice our values rather than simply professing them."

So I hope that you will join us in choosing to practice the IKT guiding principles in your research and your work. For us, we think that it's not enough for one or two groups to think about partnering in research. If we really want to make a change, we all need to work together to improve the quality and the quantity of meaningful research partnerships, so that we can think about rising the tide, lifting the boats, and closing the gap between research and practice.

I'd like to end this part of a webinar by thanking our funders as well as the team that has supported this work. I'm very excited to hear from you, as well as to hear from our panel around how we can make sure that the guiding principles have impact. Thank you.

Kathleen Martin Ginis: Thank you very much Heather for that excellent presentation. The next part of our webinar we're going to turn things over for a panel discussion, and we have some questions to get us started, but we want to hear from you. So please, if you have questions put them into the chat and I'll be checking in with Rhyann for questions.

But now turning things over to our panel, I'd like to lead with the question: "Why did you and your organization see value in creating the IKT guiding principles? What value did you see in creating those principles?"

John Chernesky: Is that directed at anybody particular on the panel, or should we all just jump in?

Kathleen Martin Ginis: Take it away John.

John Chernesky: I guess I nominated myself. Okay well, maybe I'll start by just saying that the organization that I represent, the Praxis Spinal Cord Institute, is a translational research institute. We really do work a little different than a traditional funder and we're trying to get research towards impact. For those of you that haven't heard of Praxis before, it's the process by which a theory, a lesson, or a skill is enacted, embodied, or realized. So really to simplify that it's about ideas to impact. And much like Heather said, it's about trying to create impact. Although there is value in research publication absolutely, as a person with a spinal cord injury, I want to see things that are going to change the lives of other people living with spinal cord injury. And so these IKT guiding principles really resonated with me from the moment Heather had broached the idea to me because our institute was founded by a person with a spinal cord injury, the chair of our board is a person with a spinal cord injury, and we have four key programs within our institute. We're looking to cure spinal cord injury, we're looking to advance care for persons with spinal cord injury. And supporting those two key initiatives is our commercialization program, looking to bring ideas out of the lab and into the clinic or into the marketplace, where they can impact people. And our consumer engagement program, which is really about making sure that people living with spinal cord injury are key influencers and decision makers throughout that entire process. So obviously, was a bit of a no brainer for us to get involved, because we see this as helping to support all the work that we do.

Gayle Scarrow: I'm going to jump in from the funder's point of view. Everything John says resonates for me as a funder. We want to know and help the research that we fund to have an impact. And we recognize that to do that, we need to support researchers and the people who are going to use and benefit from that research in whatever way we can. So, having something like IKT guiding principles, while specific to spinal cord injury and that development, has such broad application across health research in general, that as a no brainer this is definitely something we want to be involved in and to help to support.

Chris McBride: I'll jump in from the community partner perspective. As the leading, sort of the go-to spinal cord injury community service organization in BC - and BC is lucky to have a large number of researchers actually dedicating their research to spinal cord injury - there's a rather large demand for participation in research. And we have to make decisions about how we can, who we engage with. We just don't have the capacity to support all the projects. And so we needed to start thinking about how we made decisions about which kind of research we partnered in, and working with Gayle and Heather and others sort of refined our thinking, but we didn't have a formal process, we didn't have a set of validated guiding principles upon which to make decisions about who we partner with. And the principles are really helpful for us to go back to researchers who most often approach us from a very transactional perspective - were just really asking us to help with recruitment or whatever things like that, and it's not creating a good partnership or a good relationship. It's really just satisfying a particular need. So, we also, of course, want to engage in research that's meaningful, that we know is going to be successful and we're going to invest our time and resources in partnering. We want to do it with a partner that is in line with these guiding principles.

Kathleen Martin Ginis: That's really encouraging to hear the strong value that's been ascribed to creating these principles. So let me now shift things a little bit and ask you, "now that the principles are developed, how do you see them helping your organization achieve your organizational goals?"

Chris McBride: Well I'll jump in first, and we're very lucky to have partners like Heather and like you, Kathleen and others who really understand the whole notion of integrated knowledge translation. And I think through these types of partnerships that we've had in the research, we've really been able to participate in projects that are incredibly meaningful, not only to our membership, but also to our organization and how we operate, and the research is so directly relevant to the work that we do - it's making the efficacy of our work better, the efficiency of our work better, and I think outcomes for people with spinal cord injuries ultimately better through these partnerships.

John Chernesky: I completely agree with you, Chris. From our organization's point of view, I think we engage people living with spinal cord injury in all of the work that we do. And so, these principles are certainly hugely beneficial in the way we think about and shape the engagement activities that we undertake. But beyond that, we're also a research funder and we require that all of our grant recipients are doing so on a partnered way, that they work with all stakeholders, not just persons with spinal cord injury. Thinking about who's going to pick up that baton and that relay of translating ideas to impact and thinking about that, so using these guiding principles to help shape the way not just that we write our proposals for funding, the way that we score these grant applications that we receive, but also thinking about how we can evaluate them and evaluate the effectiveness or the meaningfulness of their partnership. So, they're brand new, but I think we've already started to adopt them in some of our work, and will continue to do so for the years to come.

Gayle Scarrow: I can say as a funder and John a funder - he has so many multiple hats John has - that ditto for me on the whole funding section. So really, our funders want to make sure that what we're funding is going to help somebody down the line. And this is a wonderful way to help support people to do that and not just the people that we fund as researchers, but the people that they want to work with, and who want to work with them as the users and partnerships. So definitely it helps us to achieve a goal. We have so many people who come to us as researchers that we're funding say, you know this is really great, but I have no idea how to do this, and being able to point to something says well here's something you can start with then let's talk about what that looks like, and support you to be able to use these in a way that's going to be beneficial for you and your partners going forward. That's a wonderful thing to be able to do that and know that we're actually supporting the system, besides just "here's some dollars and go out and do some great stuff".

Heather Gainforth: And Kathleen if I could add on that point is - I think, when people came to me and asked this question of like, how do we change the spinal cord injury research system so that we can meaningfully engage - as a behavioral scientist when we work in designing interventions around physical activity or diet or smoking cessation, the first thing I always am looking for is, I need you to define what you want someone to do. I need to be able to understand what that looks like because otherwise I can't understand why they can't do it. So it's very hard to ask people why they can't do something if we can't have a common understanding or language around that.

And for me the guiding principles are really important for that work. So not only does it guide us to be able to act with integrity ourselves, but in terms of being able to change the system and advance the system to know if we're doing it or not, we needed a common language for that. So exactly what Gayle, John, and Chris were saying is it provides a way to say, and this is what it looks like, that I think is really important.

Kathleen Martin Ginis: So we're getting a couple of good questions in the chat. I'm going to ask a follow up question to something Heather touched on about changing the system, and I think that'll be a segue into some of our chat questions.

And that question for the panel is: "what do you think are going to be the greatest barriers to changing the system, and maybe it's something at the organizational level, at the individual level, but what do you think it's going to take, and how big are the challenges ahead of us?"

Chris McBride: It's going to take time and patience and understanding, and working through a lot of challenges, I think. It's strange to me that - I'm just going to take this chance to say - Heather used the word "real world" a few times, and I don't like that because it sort of indicates that research is not part of the real world. It absolutely is a real world process, and it just creates partition I think when we start thinking like that. I think the other thing is for some reason, a lot of this stuff is just common sense. Really it's just common sense. It's how we should all be approaching relationships, not just research-research user relationships, but somehow when research gets involved there's this strange context that gets layered on to it that sort of defaults into a more transactional type of approach for some reason. I don't know why, but to me it's like that's kind of the attitudinal shift that we need to foster over time and not freak people out that everybody has to do it this certain way. I think these principles are meant to guide, not prescribe, and I think that's sort of an important takeaway, and people will figure out what works for them in different contexts and different situations.

John Chernesky: Very much agree with you, Chris. I sometimes look at things from a slightly different lens. We think about the application or the delivery of new products or services, we think about the commercial world, we think about the business world, we think about how frequently companies and businesses consult with the end users of their products, as key informants in the development, in the creation of these new products and services. But in health research, it's often not done. It's rare how infrequently people that are going to be the end users of that product or service or are engaged, and I think this is one of those key points where we're trying to change that.

But one of the big barriers that I see is, you know for a lot of researchers, I think there's a bit of a misunderstanding of what partnered research actually is. Oftentimes I hear researchers, when I talk about engagement or partnerships or integrated knowledge translation, and oftentimes the message I'm getting back from them is talking about research participation. We're individuals with spinal cord injuries that are researchers. And sometimes they don't fully understand that what we're talking about is the primary qualification of a person with a spinal cord injury being a partner research project is that they have a spinal cord injury. It's not that they have a PhD or some other academic credential, that that lived experience is enough. But it's often what we're finding may be not enough. There's a need for people with spinal cord injuries, if they want to be active meaningful partners, to up their game to come to the table with some background knowledge and understanding of how research works, what the barriers and constraints of research are so that they can contribute in a meaningful way. So I think there's learning that's needed on all sides, not just from the research world, but also from the world of various stakeholders, but also from funders. We're seeing funders now requiring Harvard research as practices, but I think, maybe in some ways we sort of jumped the gun, because these tools haven't been created. That raising of knowledge and understanding how to work and effective partnerships has yet to be created or fully developed. So to me the barrier is that shared learning and that ability to do meaningful work in partnership and hopefully these guiding principles are the first step in creating that shared understanding. So we can create that opportunity to increase knowledge and work more meaningfully and effectively together.

Gayle Scarrow: I agree with what both Chris and John are saying. There are so many different levels here. There's the individual level, there's the barrier of what is your knowledge, what are your skills, what are your understandings, the attitudes about the competencies involved. Those are basically, how do you get along with people, and people in general like to hear themselves talk. They don't sit down and listen to the other person and inquire, who are you, and what are you about, and let's have that conversation. We're not necessarily taught to listen, so learning the competencies, actually a big one is listening, and how does that go. When you move that into the organizational level, there's organizations that do not necessarily support this, so if you're working within a university - and funders are not always supportive as well - you need time to do this work. So how do you carve out that time? Whether you're a community person, whether you're a researcher, where do you get the support to do that. And if you're being pushed because you're a researcher and you want to go for tenure and you have to have publications and funding, that doesn't give you necessarily the time to really build long term trusted relationships, which is what IKT really needs to be all about. And if you're on the side of, for example, Chris where you're on the community, you don't necessarily have time to jump into all the things that research is wanting you to be involved in. And even if you are interested, where do you find the resources to backfill you and your position to be able to participate in research as a full-time partner.

So, again funders need to be looking at how do we support the full environment. And the system in general doesn't necessarily support this work. Even though we're all talking about it, we all know we need to do it, there's lots of things we know we're not supposed to do, or things that we should do, and we just have to prioritize this, and realize it's really important. We all want to make sure that we're developing research in a way that's going to be helpful and it's going to have a definite path to impact, and this is one way that we could be doing that, and we all have sort of stand up and say what's my role in helping to support that.

Kathleen Martin Ginis: Couldn't agree more with Gayle. When my students ask about IKT, I often say so much good IKT comes down to good manners and just really caring, so I think there's a lot to that.

Peter Athanasopoulos: I just also wanted to add the rigor of the outcome as well. So doing research in partnerships increases the rigor of the research. And the mobilization of so many people involved also increases the opportunity of that research coming into practice faster, and with a common understanding of what that research is going to achieve. So I think overall working in partnership actually increases, not only the capacity, but the potential to actually create a change in the research that you're trying to achieve.

Kathleen Martin Ginis: Thank you, Peter. So we're hearing a little bit about some of the barriers or challenges. I'm going to present the panel with a couple of questions that have been placed in the chat which I think get at some of the barriers or challenges that teams have been facing. So the first question comes from Jasmine Ma. She says that "One of the challenges our team faces in IKT is engaging partners from diverse educational backgrounds, different races, gender, and so on. How can we do better in ensuring we're reaching and diversifying the partners that we are engaging?"

John Chernesky: I'll jump in on this one real quick. You know, one of the things about spinal cord injury is its heterogeneity. No two injuries are the same. I've had a spinal cord injury for 27 years, and I know we're probably getting into the thousands of people living with spinal cord injury, and no two are the same. The severity of the injury, the level of the injury, the experiences of the individual, how it

presents itself. And so, whenever we're looking to engage with people, we think about those variations in the actual type of injury, and that in itself leads us towards thinking about the variety and their personal backgrounds and their experiences, whether they're living in an urban centre or rural setting, whether they have a higher education or a low education or income, what their ethnic backgrounds might be or racial diversity. So to me it's almost like just an update or an added step to the diversity that we're already looking at with the heterogeneity of the spinal cord injury.

And I don't want to put the pressure on Chris and organizations like his, but you know I do think, if you want to get brought into engagement, you need to work with community organizations. Whether it's Spinal Cord Injury BC, or Accessible Okanagan, or United Spinal, or whichever organization is in your jurisdiction. Come to them and say, I've got an idea. And that's when you want to come to them, when I have an idea, not when I've got funding or when I've got a proposal. Or you know it's when I've got an idea, and say this is what I'm thinking about - is there anybody in your network that you think would like to work with me as a partner on this project? Because very much as Chris said, they've only got a limited capacity, but they've got a huge network and they know most of the people that are members in their organization. Perhaps they can act as a facilitator to introduce you to people within their organization who can become partners on your project at that ideation stage.

Heather Gainforth: One thing I was thinking about with this too Jasmine is, one of the kind of cornerstones or key pieces of what makes something IKT is the idea that you're working with decision makers, someone with decision making power. And then, in terms of intersectionality, your spinal cord injury is not the only thing about you and that there are real barriers for different groups to have decision making power and to come to the table. And in that sense, we need to do better in terms of ensuring that lots of groups have decision making power and lots of individuals that are often not given power often don't get to come to the table. That we're doing the work to get there, and so I actually think that the IKT guiding principles are one piece of the puzzle in the equity diversity inclusion belonging this piece, that we need to do, that there's a broader bit of work that I think has always been here, but in the last year, is very clearly being asked of organizations. And I think in time, as we see more and more people coming to the table, but we have to change those systems to so that they can. And in that it's this idea of time, you can't last minute ask for people to come on to grants or to come on to projects with us. If you're looking for a diverse team, you're going to likely need to build capacity, and that means that you're going to need time to talk to organizations like SCI BC and say how do we do this because there might be some internal things that need to happen in lots of organizations before you can even think about writing the grant - is that you have to get the context right. So, a lot of work, but just because it's hard doesn't mean we don't do it.

Kathleen Martin Ginis: Thank you Heather. We've got just under five minutes left, and there are two great questions in the chat. I'm going to throw the first one to Chris McBride because I've heard him speak on this topic, many times.

This question comes from Tori Stranges who asks, "Could you make recommendations or comment on how community partners could approach researchers/funders to establish a meaningful relationship and move forward using these principles?" Chris, I've heard you speak about it the other way, so, do you want to take that one?

Chris McBride: Yeah sure. I think this actually relates to what Jasmine was asking as well and it's all about how do you make the match. And many years ago, Gayle and her community of practice roped me into giving a talk about some of this and I was trying to make a fun way to describe it and I used a

dating analogy. What kind of engagement would need to happen in order for me to commit to the relationship going forward. And I think the hardest part of this whole equation is actually that initial match, right so I'm lucky that I come from a research background, so I already had established relationships with researchers. I can imagine that if I didn't it would be very hard to figure out who to approach, but I think it's just approaching with an open-ended type of question. I think Heather and I tell the story we met on Twitter. I don't really even use Twitter anymore, but back in the day, we did, and I can't remember what the tweet was about, but she followed up and responded to me and said hey we should talk. And it was really just you know, this is my area of research, how can I help, like is there something that that you're having a problem with that my research might be able to help with. And I think just having that kind of open initial dialogue, not coming into it with like, I really need this very specific thing to be done, because the match is all about the needs on both sides, like a partnership is a two-sided equation. So, you know how you actually find the person, you can look for somebody with research expertise in a certain area and reach out to them, because I think most researchers are open to having that kind of conversation, and if they're not then they're not someone you want to partner with anyways.

Kathleen Martin Ginis: Thank you, Chris and then time for one last question from David McMillan: "I'm on board but I'm at the bottom of an institutional masthead. How do I get my leadership on board?" Not sure who to take that.

Heather Gainforth: It looks like, okay go for it, John.

John Chernesky: Sure, I was going to push Gayle to go to that, but I will say that institutional buy-in is absolutely key. If you look at IAP2, the International Association of Public Participation, they've been at this for a very long time and they look at participation in partnership well outside of just health research, but institutional buy-in is key. I would suggest to David that you know, looking at some of the evidence behind partnered research, there's evidence to show that it increases success in funding applications and securing funding, it increases participant recruitment and enrollment, and it leads to better outcome measures. Those are just three pieces of evidence, but I'm sure if you did a more fulsome scan, you'll find that there's a whole host of evidence that will show you the benefits - and you know institutions always love evidence.

Gayle Scarrow: And I will say there, depending on your sector, your organization, there might be different reasons why they are not necessarily embracing the whole idea behind partnered research and having opportunities to chat with the leadership about what it is, why it's important, showing the evidence, as John described, but then talking to them more about, so what does this look like to you, why would you not necessarily want to be supporting this within our organization. So, identifying the barrier and then working together to figure out how to get past the barrier, so what's the facilitator that's needed to get there.

Heather Gainforth: I wonder almost, David if you could use the guiding principles to guide your approach to help them. So in thinking of exactly what Gayle said is, how can I help. There's these new principles, here's the evidence around them so hopefully at least you have a document, now that maybe you can use and use that to say, what does this look like to you, and can you describe to me why you would not want to use these in our organization and why this doesn't make sense, and is there anything we can do around some of those things. What would we need to do to be able to make this work for us. Because I think engagement doesn't just have to happen in research and often having the conversation and doing that in a way that we can understand what's meaningful to them, so that

we can help them be able to make change too. They probably have some real reasons, whether they are fears or concerns or other more systemic concerns that need to be addressed, so that they can hear this message.

David McMillan: Can I follow up real quick? So, it could be, without releasing too much, it could be that maybe they think they're doing it and they're not. So is there, like a metric because one of my other questions is, am I doing this right? Because I think I'm doing it, but I'm not...

Heather Gainforth: Yes, so we're working on the metric pieces, we're working on the outcomes. But in the meantime, what I would ask you to do is have a conversation – a very open, honest conversation with anyone you're partnering with and saying, this is what meaningful engagement looks like, this is the definition, do you feel that in our partnership? Are there concerns? Here are the guiding principles. If you were just to even rate these on a 10-point scale or a yes/no, which ones are we doing well and which ones are not going so well right now? Where do you think we could improve? And then your partnership can tell you if you're doing those right because it's an experiential thing, it's a feeling, you need to feel like you belong, and that you value and that you have decision making power. And so I can't necessarily look at someone and say tick tick tick you've got it, and I think that's it, you want to avoid that, you want to do it in a dynamic conversation as much as possible. People might disagree with me but that's I think how I would use them.

John Chernesky: And I just got one last comment I want to make – that was great Heather – but David, you're not doing it wrong. I think researchers are so used to building up on previous evidence that in a new area like this, where we're still learning, we're still developing the science of partnered research, it's okay to make mistakes, as long as you're doing it with the intention to do it meaningfully and avoid tokenism, you're doing it right. And the more we do this, the more we'll learn. And another added benefit for researchers is you can publish on your research and you can also publish on your partnership and that's how we learn how we're doing it right.

Kathleen Martin Ginis: I think that's a great note to finish on John, so encouraging. We are at the top of the hour, a couple minutes over so we will be wrapping up.

I want to thank our panelists. I want to thank all of you for participating today. At one point, there were 50 people on this Zoom, which I think shows tremendous enthusiasm for the IKT guiding principles, so congratulations to Heather and your team for all the work that you've done.

Heather Gainforth: Thank you all for doing this work with us.

Kathleen Martin Ginis: If you would like to learn more about the IKT guiding principles, visit the website IKTprinciples.com. Via the website, you can join the mailing list and receive updates about next steps in the research process. And a recording of this webinar will be made available on the website as soon as possible. So thanks everyone for your time and have a great day. Bye-bye.