**2017 Online KT Conference:**

**Knowledge Translation Outcome Measurement**

Commitment Issues: How to get my community organization to

say yes to an integrated KT project.

Chris McBride, Spinal Cord Injury British Columbia (SCI BC)

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>> JOANN STARKS: So we're going to go ahead and get started with our first presentation today. This presentation is from Dr. Chris McBride, executive director of the organization SCI BC or Spinal Cord Injury of British Columbia. His presentation is Commitment Issues: How to get my community organization to say yes to an integrated KT project. If you have any questions during the presentation, please ask them in the chat box and we will address them as we can, or we may hold them to the end depending on how things progress and what your question is. Chris, are you ready to get started?

>> CHRIS MCBRIDE: I am indeed.

>> JOANN STARKS: Okay, let's go. Thank you.

>> CHRIS MCBRIDE: Okay. Well, first let me start out by thanking the center of knowledge translation for disability and rehab research for this great opportunity to present at this online conference. This talk that I'm about to give really just started with a knowledge translation specialist here in Vancouver, British Columbia, who knew some of the challenges I faced in terms of dealing with the academic community and engaging in knowledge translation-related research. And I did a small presentation to their community of practice that seemed to get the attention of a few folks that wanted me to do more on this topic and really am pleased to continue to do that here today.

As mentioned, the title of my talk is commitment issues, how to get my community organization to say yes to an integrated KT project. And I hope some of the things you take away from today include a little bit better appreciation of the role that community organizations like mine as research users can play in the integrated knowledge translation process. Understand what can prevent organizations like mine from engaging in these types of projects but more importantly understand what it takes for me to -- and organizations like mine to actually commit to an iKT partnership. IKT integrated knowledge translation is a term I learned recently from one of my great collaborators who I will mention a little bit later. It is really involving the research users in all stages of the KT process. As equally respected and valued partners.

Just a brief overview of what I'll be talking about today. Part one will be background on my organization and myself to provide context for the next part which is the barriers that I've seen many times in my work. Part three about what can we do to get to yes and in the last part I'll give some examples some good and some bad, and I will avoid the ugly.

So before I actually start, I thought I would just read and email I received probably 8 to 10 times a month and this comes from keen researchers looking to engage me in their research and their knowledge translation activities. Usually starts like this. Hello, and there is a lack of total lack of personalization there. I'm conducting an important study on spinal cord injury. To recruit participants for this study we're reaching out to organizations working with the SIC population. We hope to -- to their respective members. We're also happy to have our invitation for participation in your newsletter to reach the maximum number of participants. Interested organizations can contact our research coordinator for further information. I believe the results of this study will be useful for participants as well as for the organizations that initiate work toward improving the health status of the spinal cord injury population. Thank you in advance for your support. Now, I do hope this email doesn't sound too familiar to you. If it does, don't feel bad. I've received it even from good friends of mine who I've known for many years. Really this type of email to me is spam and it won't get me to say yes to an iKT partnership. That's kind of the overriding context I guess for the talk.

So just to get started a little bit about Spinal Cord Injury BC and mean. Spoiler alert. This is the first step to getting me to say yes. So first, what is Spinal Cord Injury BC all about? I try not to use acronyms as much as possible, SIC means spinal cord injury and SCI BC is spinal cord injury organization of British Columbia. We're a nonprofit organization that has been operating in the province for over 60 years now. And we serve about 2,000 people through our peer support programs and more through our info services that we provide. So I always think that my members best describe the work we do. This is from a member from a couple of years ago who said Spinal Cord Injury BC is the go to place for information and support for people who know what you are going through and how to help you get back into real living. They also -- I thought also words are one thing but maybe we could watch one video. I'll queue that up in a second. Here it comes now.

>> What are the feelings you have when you are first injured?

>> What a hard question to ask.

>> Disbelief. Fear, anger.

>> Misunderstood and dark.

>> You begin to realize what condition you are really in.

>> It's the unknown.

>> You lose the use of your legs and you feel like you aren't whole. You're not normal. That no one is going to accept you anymore.

>> You think your life is over, and then you think well, maybe I can make something of it.

>> A community like Spinal Cord Injury BC is essential.

>> Essential in the sense that the essence of hop

>> Openness.

>> It feels like I'm in a safe place.

>> You get a feeling of warmth, of value.

>> SCI BC and the staff and peers have given me reason.

>> It makes me feel stronger in myself because I know somebody else is going through what I'm going through.

>> To get back to employment, to get back to life and to get back to relationships. There are all these questions that can't necessarily be answered by the experts because the experts are the people living it.

>> It wasn't until I participated in Spinal Cord Injury BC is that I do belong.

>> I think magic is what keeps us wanting to get up and see what's going on and a new day.

>> A reason to continue.

>> Something happening that you can't explain but it was exactly what you needed.

>> CHRIS MCBRIDE: Okay. So that wasn't just a cheap employ to get you to donate. You can ignore the last little bit there. Why I thought it was important to share gives you some context for one of the important services that we provide. It is actually the area in which we're doing a lot of integrated knowledge translation research with some really good academic partners and we'll talk a little bit about that later, too. So from our sort of corporate speak, what Spinal Cord Injury BC does is help people adapt and strive as they deal with a new injury or struggle with the challenges of living and aging with disability. We do it with peer support services and resource center which has an online component but also a 1-800 toll free info line number and lots of great resources people can access in person or online. Then there is our communications piece which is really important through the iKT process as well as we provide a lot of great content that we share with our membership in a number of different ways. Woven throughout all of our services is that core and that magic of peer support. It is actually that magic that we're working with the researchers to kind of tease out and figure out how we can provide our service better.

So when you are dealing with Spinal Cord Injury BC you are dealing with 30 of us throughout the province of British Columbia here in Canada. 17 years -- in the last couple of weeks we've hired 19 people that work for Spinal Cord Injury BC have themselves spinal cord injury or other disability. That's the part of people knowing what you're going through and helping you get back into real living. We have some physical centers and an online presence throughout the province.

When it comes to the KT process, our information resource center is really important as well and as I mentioned info line and a number of different specialty websites that we provide direct services through and also print. Our spin magazine here that goes out to 4,000 addresses in British Columbia every quarter is our most valued communication asset and a really great way to share information and disseminate information and activate people to make changes in their lives.

Just really quickly about me. I only present this history here just to emphasize that I'm sympathetic from the challenges of engaging community in the KT process on the research side and probably spent more of my life in the research world than I have in community service world. But yes, throughout my life I've been a spinal cord injury researcher and then moved on to managing the ICord research center in Vancouver, one of the world's largest spinal cord injury research centers that really integrates a broad range of researchers from cellular work to clinical work to engineering and to now behavior change, which is very exciting. Through my work at the disability health research network funded by the Michael Smith foundation for health research in British Columbia we had a mandate to build capacity in research capacity within research organizations which was a challenging and rewarding process. Through my roles with the Rick Hanson institute, also did a lot of national network building and partnership development with community organization. I'm very excited to be moving forward with others on that.

So partnerships are important to us so why do we value them and why do we bother engaging in them? Really, we need partnerships to advance our mission to help people with spinal cord injuries and their families. These types of partnerships take many forms. There is formal partnerships, plenty of collaborations and then there is the other sponsorships, grant funding partnerships we hold with many different organizations and groups.

Key partnerships include other disability focused community service providers, private sector. We have lots of really great private sector partners we work with here. Health authorities are important to the work we do and very proud of our relationship with Vancouver health and academic research institutions which include the University of British Columbia and McGill University, LaVal and University of Toronto just to name a few.

One of the interesting things about engaging with a community partner like Spinal Cord Injury BC you take advantage of working with a community organization that taps into a broader network of community stakeholders. This is just one example where we're one of five members of what's called the BC spinal cord industry services network, five strong and innovative community service organizations here in BC that do everything from employment to technology supports to wheelchair supports of various varieties and recently we were just awarded $5 million from the provincial government to extend and build our network out so that we can reach more British Columbians with disabilities and improve their lives and their families' lives.

Just quickly about the research and academic institutions we're involved with. ICord here in Vancouver is a really great place and we have multiple levels of partnership with them, their resource center and accessible fitness center and spinal cord center. We partner up on scholarships and many research projects that we're involved in as a co-applicant or community partner. Many translation -- knowledge translation activities including cafe scientifique which we promote and engage with researchers in an informal center. We host those webcasts and post them later. We have a partnership that involves us directly supporting recruitment for research participation. Just quickly about UBC Okanagan and the growing wealth of talent that's there involved in many research projects as a community partner and many knowledge translation activities.

So the question is, if spinal cord industry BC needs partnerships why is it so hard for us to commit to them? I'll start off with just a thought question for you. When I first hear from research partners or potential partners, can you maybe guess what my favorite question from them is? Can you help me recruit participants for your study? Can you feature my research in your magazine and newsletter? How can I help? Can I put your name on my grant application? And would you like to be an author on this project's paper? These are questions I get all the time. Incentives you could look at them. There is one that really stands out for me and there is one -- only one that really matters here and my favorite question is, how can I help? This is an actual quote from the first time I met integrated KT expert and research partner Heather gain forth at the behavior change lab Okanagan. Our relationship started online. For the record, though, I will be really clear it was via Twitter and totally only about research. But what Heather did when we connected and it's led to a phone call and after a little bit of exploration about what spinal cord injury did and what her research focus was Heather led with a question, how can I help? And that stimulated some really great conversation about what was -- what were really good research questions that would benefit both my organization and would be of interest to her research interests? So this spawned a lot of really productive research that we're engaged in today. Including one that I'm excited about, developing some guiding principles for knowledge translation activities in spinal cord injury research. That work has just been underway.

Just extending the dating piece here a little bit meeting online or whatever, so I sort of feel like developing academic community, knowledge translation partnerships is a bit like dating. Like any dating scenario the first date is the critical date. And like so many dates, the first one can be a challenge. And if unsuccessful it is really going to be a turn-off for committing to a future engagement. So what are some of the common pitfalls of that first date? Well, I'll go through each of these in detail in a minute here but as an overview, false assumptions. Sort of the overly optimistic that assumes they're far more interesting than they are to the other partner. Expecting something for nothing. This I describe as a cheap date. And it is important to remember that we both need to get something out of a partnership. One-sided engagement is a very common turn-off where it's really all about either the academic partner for maybe all about the community partner. All this can result in tokenism which maybe is a bit like the arrogant date.

When it comes to false assumptions, I've been a researcher and worked with them for decades and know how passionate they are about their work and they love to talk about it and they assume everybody else is also interested in it. While their projects may be of really great academic interest. Studies aren't always as interesting and valuable to organizations like minor or members that researchers think they might be. All too often the academic partner will expect something for nothing and assume that I'll be really willing to dedicate a lot of my human resources and infrastructure to help with their project for free and to be honest I rarely am because probably the project isn't as valuable to me as they think it is as well. And so like most nonprofits, Spinal Cord Injury BC can't afford to be a cheap date.

In terms of one-sided engagement, when the balance of power is held by the academic partner and the scope of my participation or my organization's participation is too trivial I'm probably not going to be all that interested in partnering. If we don't have an opportunity to shape the products the findings probably aren't as relevant as they should be and the project is more than likely to either be delayed or to fail all together.

In tokenism. That's a word I know many of you are aware of. It's a dirty word. And it's where the role of the organization -- community organization is diminished to one of triviality. Merely being a conduit for recruitment notices or newsletter story about a research project is not really enough. As we've heard -- as you know, many of the granting applications require community partnership knowledge translation plan. If we just become a check box to say you've included a community partner in this without engaging us in a meaningful way and shaping the project that's tokenism and demeans the value of my organization and I'm probably not going to be all that interested in partnering.

So those are the pitfalls. How do we get to yes? So here are six tips on getting Spinal Cord Injury BC to commit to an integrated knowledge translation partnership. The first is arrive early and get to know me and my organization. This will set up everything else that's on the list here which includes listening carefully. It is important that we end up speaking the same language. The relevancy of the project is really important and it's important for each partner to understand the value to the project and important to note anyway both parties must be respectful of each other and the role that they can play in the project.

So when it comes to arriving early and getting to know us, the most successful partnerships happen when engagement starts really at the planning stage of the project. Preferably before the grants are written or in the process of the writing of the grants. What happens all too often is that the request to partner comes far too late in the process. Popped in just a couple of days before grant deadline or even after a project has been funded and ethics approvals have been granted and then the academic partner is trying to figure out how they will implement their project and come to me and say hey, can you partner on this project that I've got going? Probably won't align as well as it could and be too challenging for us to undertake at that point. Really what's happening when an academic partner comes to us late in the game, they're coming to us with a take it or leave it offer. In most cases my response is going to be to leave it.

Listening carefully is really important and Heather demonstrated that to me in the first time that we had a conversation. It's really what spurred a lot of creative thought around research projects that we have subsequently engaged in. It allows the partners to share what's important. What are the important questions about the area of interest? What is the most relevant and importantly what is feasible? By listening to the community organization, the researchers can develop a whole bunch of great ideas and options for research questions. They may not all be the ones that are ultimately decided on, that's a joint production to come up with the actual research project, but creating I guess a menu of options is really exciting for both parties. By listening to the researchers, community partners can co-development plans. The motivation piece is important and when listening and great conversation happens, both parties can be equally motivated to achieve success through the project.

Now, I know that having been in the academic world and now being in the community world, I think I'm somewhat bilingual because I know that the two worlds speak very different languages and often use very different words to describe the same things. So it's really important that specific attention be paid to ensuring that all partners are using a common language. Otherwise there will be all sorts of different assumptions made and things can go off the rails fairly quickly. I would like to emphasize that this is not a matter of academic partners dumbing things down. I hear that all the time. It's rather insulting. My staff, for example, are really smart people. They just use different words to describe things. It is not a matter of dumbing things down, just a matter of using a common language.

The relevancy piece is very large in our decision-making process. This is where the early engagement and the listening and using the right language do pay off. Taking time up front to understand what the community organization does, which is why I gave you a little snapshot of what Spinal Cord Injury BC does and what it or its members' priorities are will help to ensure the research questions and the approach align with the organization's vision mission. That's really important. We won't do things that are too tans gentle to our vision and mission. The project can align or enhance operational capacity. The more closely a project relates to our standard operations, the easier it is for us to engage in that project. And also when there is a great potential to enhance outcomes of our services, to be realized through the partnership and this is an example with our peer support that a number of researchers are engaged in with us, we're excited because the work that -- the questions they're asking from the research perspective are directly related to the peer support services we provide and we believe there is a potential for us to enhance the outcomes of our services through this partnership that we have. Which gets to the value.

It's important that all parties do understand the value proposition relating to their investment in this partnership and I guess the one thing I like to emphasize is people often maybe don't realize running a nonprofit doesn't mean we aren't running a business. Maybe we don't go after profit but we do go after revenue. We need revenue to keep ourselves going, which means we can't really afford to do things for free. But I also like to emphasize that value isn't always in money. Value can come in many different ways. If a project involves something that will lead to an increased competency of my staff that's a huge value. If the partnership results in enhancing the outcomes and impacts of our services, that's also a huge value. Often the evidence developed through the partnership will help build a case that will support our operational sustainability, of huge value to us. Then providing direct benefits to our members is really something that we will consider as well. But I do like to emphasize that if money can be brought to the table that always does help. But I also should say we don't chase money. If it's not relevant and if it's not aligning with our vision and mission we aren't just going to go after and chase money because that ends up being more work and costly than it might appear.

So finally here, being respectful. Obviously respecting the value and unique strengths of each partner and what they can bring to a partnership but also to understand the challenges and the barriers that the partners face in doing -- in participating in the project is essential for the success of the project. This -- all this -- ensuring the co-responsibility for the project development and decision making, this idea of co-production of the knowledge is really a part of the respect that we expect when we enter into these types of partnerships. And when you combine the respect -- being respectful with the previous five tips, to us this is really the antidote to the issue of tokenism.

So now I'll just go into a few examples. A couple where -- one where we say no and a couple we ended up saying yes. I start with this and as I've given this example a couple times to a broader and broader audience, I will emphasize that in doing so, in providing this example of a case where I said no I'm not trying to chastise the academic partners in this process, it just is a really good example of something that could have been so much better and we could have done something better if the process had been right. What came to me and my organization was a finished product basically that was spinal cord injury manifesto for change. That's pretty provocative. That's some pretty strong rhetoric and sounds kind of awesome. Really, who wouldn't want to support a manifesto for change when it came to spinal cord injury? SBIBC didn't want to support that and lots of reasons for why. You can probably guess based on what I've gone through before. But the timing was a fail. So there was no involvement of my organization or even some of my partners -- counterparts from across the country in different provinces in the development of the document or the project itself. That meant that our role at this point was really only in dissemination. That was exactly the request that came to us. Can you help us get this piece of -- which is an advocacy piece out? Well, if we weren't involved, we weren't going to -- it wasn't probably going to be as relevant because although the three conditions that they were advocating for improved health services and were all important, they weren't the top priorities for our members. And if we're going to burn some political capital on an advocacy piece like this, we really need to make sure we're doing so on the highest priority issues. In this case, they weren't the highest priority issues. So getting involved actually presented some degree of reputational risk for us. Really, there was very little value in what was being presented. I mean potentially for our members there could have been some improved health services if it was going to be successful but it wasn't clear that there would be any success through this piece. So the value probably wasn't there. Just based on all those first eight fails I would say it was really not enough respect for the role that we could play in this process. So in this case we declined the opportunity to be a partner.

This is a case of where we said yes. The image here isn't showing up, but what it is is a wallet card that was developed in partnership with researchers, clinicians here at our rehabilitation center and our members here at SBIBC. It's a life threatening condition that many people with spinal cord injury face but it is very odd set of symptoms that most emergency room doctors or even general practitioners won't recognize and might not respond in a way that -- a timely or appropriate way for the patient's health. So we co-developed this card that our members could present to the clinician should they be experiencing this condition in a clinical setting. All the partners got together very early in the process and we worked hard to make sure that the information was presented in language that was appropriate for our members and B, appropriate for the clinicians that would be receiving the information. It was important that the information presented on it also be valid and that would be trusted based on who was involved in the partnership. We as Spinal Cord Injury BC helped with the design and delivery and we give these out to all of our members as they go through the rehab process and as they return to the community and we keep reminding them about it. The value here is that -- there was no money in it for Spinal Cord Injury BC and we actually cost us a little bit in printing costs, but this is something that can save the lives of our members and we feel that that's enough value for us to invest in this piece.

Here is another example of somewhere we said partnership that we said yes to. This is not just the Canadian disability participation project itself, a national project led by Dr. Kathleen Martin Guinness at the University of British Columbia which involves almost 50 academic and community partners across not only Canada but with some international partners as well to enhance community participation amongst people with physical disabilities. So the big project itself we're very proud to be a partner of and it is also all of the projects -- a number of the projects that will being undertaken through the disabilities project that we're participating in. Why we're involved is because we were involved early in the project's development phase and we had influence and an opportunity to help co-develop the project itself and some of the sub projects that are going on today. We spent a lot of time up front ensuring a common language was used. It was particularly relevant to our peer support work. There are a number of different terms used by different groups to describe care mentorship and peer support and all these things. Had we not done that there would have been great confusion and the validity of the results would have been greatly compromised had we not agreed upon a common lexicon. The research partner here insured the priorities of community groups and partners were well understood and included. Many of the projects that we're engaged in take advantage of our existing services. This really minimizes the impact of our participation and builds in a lot of value for our participation. There was thoughtful remuneration for our involvement. There was a monetary component. Very small but thoughtful and we take advantage of many other great opportunities such as getting to go to meetings where we can network and meet our colleagues and network and this is always very hard for a nonprofit organization to afford to do, to go to conferences, to go to meeting with their professional peers throughout the country or internationally. Lots of ways value was brought to this project and lots of ways that respect is built in throughout the whole process. So this is another example and I will also add that the project that has been -- was funded in part by the Rick Hanson institute as well. SBIBC and ICord enjoy a unique partnership in terms of the level of connection we have and participation we have together in knowledge translation activities be it for a specific project or for more higher level initiatives as well. And this is an example of a series of videos we created to help encourage our members to participate in research. We know there is a high demand by researchers who are engaged in human-based research activities for people to participate in their studies. But we also know there is a relatively low demand by our members to engage in those researches and participating in studies is a rate limiting step. What I'm pleased to hear the feedback from our research partners who have -- who we have helped recruit for studies that through our partnership with ICord we've reduced the time for recruitment by half in many of their projects. We feel like that's a really valuable piece for both sides and so just maybe watch this fun video here of stop watch sessions that we created to encourage participation.

>> Does anyone understand pain? Kip, I hear you have a study on pain.

>> I do.

>> So I am about to give you 45 seconds to tell me why someone would want to be in your study. Ready?

>> Ready. We don't know a lot about pain and therefore we can't treat it very well so what we're doing to learn more about pain is image. We image the spinal cord and the brain do it using MRIs. People get into the small tunnel thing which is very claustrophobic and can be uncomfortable for some people. Not all people. In the end you get to see a picture of your spinal cord and brain. Pretty amazingly complex structure that you don't get to see every day and we have this beautiful picture you get to take home. Am I out of time?

>> Almost. Tell us is there an honorium?

>> There is for a small honorarium that we try to reimburse your time and for parking and stuff like that.

>> Pain is just a major problem for people with spinal cord injury. I have learned a ton just from talking with people with spinal cord injury about pain and hopefully we can find out what's causing it and give them better treatment. Really they have nothing that ultimately helps them. When people are in pain there are a couple of pills they can take but they're mostly ineffective. That's going to look bad.

>> Awesome.

>> Ph.D. in English apparently.

>> CHRIS MCBRIDE: Okay, that gives you a little flavor of a series of videos that we did and kip, you may be watching but kip and the other researchers were really good sports there. We wanted to humanize our research partners a little bit and get our members excited about participating in research and think about the value that participating could bring beyond just advancing the field itself.

So I'll end on this thought here. You know, it's obviously a lot of work to develop a partnership with a community organization. So is it really worth all that bother? When you could just really have a patient or consumer representative be involved instead? The question I get quite a bit and something I feel strongly about and I'll say right up front that the best scenario is both. Have both if you can. If you can only have one, I advocate strongly for having the community organization involved. I'll describe that why here a little bit. Here is a table that you have some pros and cons of -- some reasons why you would have a community patient or consumer representative versus a community organization. If you can have both that's where the most power comes in but with a patient or consumer representative, you get the really important power of the personal impact story. This can really be hugely beneficial to a project in understanding what's important to an individual. And be highly motivating for people. The problem is you are only getting the one viewpoint with that individual. Whereas when you deal with a community organization, you get the advantage of perspectives reflecting really diverse set of experiences and the priorities of a very large membership. And for a group like Spinal Cord Injury BC that has the history of thousands of people and their stories, we can reflect a much broader set of experiences and priorities. With a patient or consumer representative there is a risk of attrition during the process. Where the community organization can actually bring a pool of representation that was more likely to ensure some level of continuity throughout the research or KT process.

With an individual representative, there is a limited ability to amplify knowledge translation related communications, dissemination and implementation. Facebook and stuff is great and everybody have their networks of support. With a community organization, which typically has a large contact list and communication channels, there is a much greater opportunity to amplify KT communications. It is true that dealing with an individual representative comes with probably fewer bureaucratic channels. There are higher transaction costs when you are dealing with a community organization. But I think those transaction costs are really far worth it and as I said I'm a strong advocate for including the voice of organizations and which really means including the voice of their memberships as opposed to a member in the KT process.

This is just one example of a partnership that included patients, consumer representatives and community organization which was Spinal Cord Injury BC. So at the initiative of an individual with spinal cord injury, who happened to be a clinician as well and a member of our organization as well, who experienced challenges in the whole pregnancy process and wanted to improve the clinical experience for other women who were going through the whole pregnancy and childbirth process with spinal cord injury. So we formed what was called, the Spinal Cord Perinatal Interest Group, which included individuals with spinal cord injury and Spinal Cord Injury BC, but also included clinicians, researchers, and KT experts, and together working with a large stakeholder group, we lead a very collaborative process that developed consensus on Caring Canada and some really great resources for people with spinal cord injury and clinicians and has stimulated further research and the development of more processes and guidelines that are currently being worked on.

We're very excited about this and it shows the power of bringing the individuals in who really help make the case through their personal impact stories. And spinal cord injury was able to provide a broader perspective of the challenges our members face not only in metro Vancouver but throughout the province, those living in rural regions and other places as well. That really brings me to the end of my presentation. Just on this slide I've provided further reading and encourage you if you are so inclined to read my blog post which basically is this presentation is a summary of and which was a two-part piece done with Dr. Heather where we explored our commitment issues to engaging in community academic KT partnerships. There is a bunch of other resources and videos that you can watch if you like the stop watch video there are a few more and you can watch more videos about what we do. Our spin magazine is a really great vehicle for knowledge translation. We love to tell research stories, human interest stories and in every story we tell we weave in the perspective of our members and we feel it's really important to present them from the interest of people's spinal cord injury and work hard to insure the relevance of these stories to them. And with that I will conclude my talk.

>> JOANN STARKS: That you have very much, Chris. That was great. A very wonderful presentation. I think your videos were excellent. We got a lot of comments on those. We did in discussing amongst ourselves we had a question of the how difficult is it to make the videos and how expensive is it to make those videos? We don't have a lot of time for questions. Did you have a professional team or video company? How did you do that?

>> CHRIS MCBRIDE: Right. Good question. We did all of those videos in-house. I'm lucky to have really incredible communications specialist and a willing group of people to participate in those videos. The videos themselves incredibly cheap to shoot. The challenge that we face with the videos is just the time to edit them and given all the other activities that we're involved in, time is always so precious. And so time is the biggest challenge if creating videos like that but we aren't expensive. It's a human resource issue.

>> JOANN STARKS: We do have a few questions but we don't have much time. One question was have Heather. How would you suggest we describe these videos for ethics applications?

>> CHRIS MCBRIDE: Well, that's probably not a question that I can answer very well. But I think what would have to be done is those videos would have to be planned out during the conception phase of the project to ensure they are built into the project plan. I guess if you have clarity about what you are presenting in those videos that you could build some ethics in and around them. I guess the ethics is always a bit of a gray area with what we do. We are not -- with the videos and recruitment things we're doing we're not part of the project and we're just taking information from a website and putting it out there. When you are involving the researchers in that video it might be a gray area. Building it in early in the project planning stage would be a smart idea.

>> JOANN STARKS: Thank you. We do have a question from Pimjai saying what happens when the contact person left the organization the collaboration fizzled. Can you comment and any strategies that might help?

>> CHRIS MCBRIDE: In terms of attrition in terms of the partnership?

>> JOANN STARKS: Yes.

>> CHRIS MCBRIDE: Yeah. So I guess when you have an individual consumer or patient representative, it is just that individual that's there. When they leave, it does become a challenge. There is really no continuity of that individual's story or perspective so you have to bring in a new one, it may be different than that individual's. If you're dealing with a community organization and we've assigned one person to be the point person on the project, that person will be bringing the perspective of the organization and its members and the priorities and so if that person from the organization is not available, we can just fill that in easily with somebody else and there will be a continuity of perspective and knowledge that will be retained within the project. So it buffers against the loss of that individual representation.

>> JOANN STARKS: Great. Thank you very much, Chris. Again, a great presentation. We're out of time right now but we did write down some of these questions and we'll hold them and we can bring them up again at the discussion session that will take place at the end of the day. We look forward to hearing more from you, Chris, when we do get back together for the interactive discussion. Thank you.

>> CHRIS MCBRIDE: Excellent, you're welcome.