2016 KT Conference:

Communication Tools for Moving Research to Practice

Day 1 - Discussion

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>> KATHLEEN MURPHY: So say hello, I’m going to introduce you in order. We have Carmen Capo-Lugo, Feinberg School of Medicine. Carmen, can you say hey?

>> CARMEN CAPO-LUGO: Hello. Great to be here.

>> KATHLEEN MURPHY: Thanks so much for joining us. And she is here with Judith Gross from the Beach Center on Disability at the University of Kansas. Judith?

>> JUDITH GROSS: Hi! Great to be here. It's been a great presentation so far.

>> KATHLEEN MURPHY: Teresa Grossi from the Indiana Institute on Disability and Community at Indiana University.

>> TERESA GROSSI: Hi, I'm here and it's been a great afternoon. Thanks for having me.

>> KATHLEEN MURPHY: Oh we’re thrilled you could join us. And last but not least, there’s John Kramer from the Institute for Community Inclusion and the University of Massachusetts Boston and Children's Hospital Boston. John do you want to say hi?

>> JOHN KRAMER: Good afternoon, everyone. It's great to be here.

>> KATHLEEN MURPHY: So thanks everyone. So, as I mentioned, before we turn to the discussion questions, I am going to take a tip from our presenters. We are going to get a better sense of who’s in the room by letting you respond to a couple of quick polls.

So we are going to pull one of those up and I'm going to stop talking for a couple minutes while you all get a chance to submit your response. The question is have you attended one of our KT conferences in the past? No, this is my first time. Yes, once or twice. Yes, every year!

[Reading]

Okay it looks like the responses are pretty stable. Of those who responded, about 2/3. This is the first time joining us. So that’s great, that is reflecting the new outreach. And about a quarter might have attended in the past. And we’ve got our core 15 percent – 8 responders – saying yes, every year. Okay, so that’s good to know. Moving on to the next poll, getting a sense as far as who is in the room given the international context you’re working in: which of the following settings is most relevant to your work? On this poll we of course included the US since our funding agency is domestic, and the target audience is grantees of our funding agency the National Institute on Disability, Independent Living, and Rehabilitation Research. But we recognize the great leadership that Canada – particularly the Canadian Institutes for Health Research – have played in the knowledge translation field, and we welcome our friends in the north. And we really love it when we get participation from other countries. I think we have had some register and maybe they're just shy and not participating in the polls, cause I see we have 90 participants still online and only about half of you are doing the polls, but that’s okay. So, good vocal representation from Canada, but most still from the US, in case that helps form the discussion as well. Okay.

So let's go ahead and pull that poll down and we are going to look at another one in case it is helpful. What are your reasons for attending this conference? Do you want to learn about knowledge translation, and learn about communication science and social media, learn specific tools for creating infographics, hear about what others in the field are doing, improve your organization’s capacity to communicate using social media and/or other innovative technology? Or if there’s something we didn’t think of, we’d love it if you’d let us know in the chat. Again, if you are struggling between two answers, go ahead and let us know, you put one down but you wish you would have included something else. Good to know, Jeff – I can only select one but I want to select all of them. Okay. I appreciate Melissa pointing out she is not sure she can answer on her mobile device. We appreciate that feedback because a lot of this conference does assume people are on the desktop computer. We have a doctoral student working on translational health sciences. I think that is enough there with the polls. We can see that most of us generally want to learn about knowledge translation.

Let's move on to to the meat of our time together and take a look at the questions. We really appreciate, a lot of you did submit questions. And as a staff, we definitely take them seriously and have looked at all of them. Here are some more questions we have tried -- not everybody is able to pose this. Some of the questions were specific. We tried to come up with themes, almost do like a content analysis of the questions. So one discussion that has come up in the chat and that is obviously really important and that is obviously really important to this conference is the emphasis not only on presenting things visually and thinking through knowledge translation, but making sure that whatever we're doing is accessible. Alberto I don’t know maybe if you could respond…

>> ALBERTO CAIRO: Yeah, I can reply to that. Yes.

>> KATHLEEN MURPHY: I'm going to reread the question unless you want to do that--

>> ALBERTO CAIRO: What are ways to ensure that the growing emphasis on visual displays of information and use of images doesn’t leave out of the picture people who visual impairments? This is an ongoing discussion in visualization. I mean visualization is about visuals, obviously, right, so it’s about using the visual areas of the brain to decode information. The thing is that the visual areas of the brain can be accessed through your eyes, but there are also opportunities to use sound to basically envision the data inside your brainor to communicate the data inside your brain. This is an area that is still to be explored. It's a completely unexplored area. And I'm really excited about the possibilities in the future for this. But not only that, but not using just sound, also using tactile displays. So basically using 3D printers, for example, you create your graphic on the computer in a 3D environment for instance. And instead of just exporting it as an image or video, you import it in 3D so people who are visually impaired can actually use their fingers -- or their hands to decode the information. So I don't have an answer to the question of how we ensure that we don't leave these people out of the picture. But I’m certainly interested in exploring this area in the future and I do believe it is one of the areas of growth in the future for sure.

>> KATHLEEN MURPHY: Thanks Alberto.

>> TIFFANY LOHWATER: Can I answer as well? This is Tiffany. I have an idea on this too that’s a bit more, especially as you talk about audio data. I think this is where some radio and podcast news presentations could be really helpful where they provide data and information audibly and I think that is a really interesting way for you to get some sense as to how to do that and I don't want to go into the specifics now, I'm just thinking of a couple specific examples. There was a Radiolab recently – I believe it was over the summer – that had a crisper, and I believe it actually had the sound of what a repeat would sound like. You know, I thought it was really interesting the way that was done.

The person who is asking the question, it would be good to listen to some really good media displays of audio information and how they get that across. That might give you some ideas.

>> CARMEN CAPO-LUGO: This is Carmen. I would like to say a couple of things. I think this question is how do we merge the information that we got in the first presentation? And the information that we had here. One idea is -- you know, communication is language. If you can see it in a table and understanding -- understand it, we should be able to use language to communicate what we have in a graph.

And also, I want to mention, too, that there are some researchers that are also using vibration to communicate not only data visualization, but also other data. Right now, the thing they're doing is trying to communicate things we are not able to send. That would also be another way to visualize data through vibration.

And I think that NIDILRR has a role in this and that maybe a call for proposals that are trying to focus and developing more research in this area would be a great way to support this endeavor.

>> KATHLEEN MURPHY: That is really fascinating, Carmen. I mean it would really address people with multiple disabilities using vibrations, not only visual. I know the other reactors, you’re all NIDILRR grantees. Have you all been grappling with visual displays of data and trying to make sure that it is as successful as possible. John, I know you're with ICI. How do you -- and I know -- I get your newsletter where you have really great visuals.

>>JOHN KRAMER: Sorry. I was on mute. So one of the things -- I mean, I'm not sure that what we do -- I mean, I think it's been pretty well-represented in what is talked about today. I mean I think the key point is maybe underscoring that idea around taking a multi-modal approach and really thinking about what the story behind the data that you're trying to present and to -- you know, to use the design elements that are clean and visually appealing which I think definitely is part art as well. But to also think about different modalities in describing the data both -- kind of a tag for a screen reader, but also to complement what you're calling out in the figures -- in the text itself. You know, to really be able to kind of refer back to those things seem mostly to make that story.

>> KATHLEEN MURPHY: Yeah. Multi-platform has definitely helped us at KTDRR as well.

>> TERESA GROSSI: Yes, this is Teresa. I am not -- I agree with John. It got me thinking how we really all have to continue to be very purposeful and deliberate and keep it on the radar. I know we do here in many ways for some of the work we do, but sometimes you know as a researcher you get so excited about the data that this is a very nice reminder about how we presented in the multi-formats and modes to make sure everyone has access to it. So it is a really great point.

>> JUDITH GROSS: This is Judith. I can't say that I really have anything earth shattering to add, but we try to be conscientious about the images we use and make sure they are contributing and ensure that our documents follow accessibility guidelines and there's some nice resources out there. Let me look real fast and I can put it in the chat box, but there's a resource with downloadable guidelines to make sure your word documents and your PowerPoints are all accessible for screen readers.

>> KATHLEEN MURPHY: Great. Thanks. I'm sure everybody would appreciate that.

>> TERESA GROSSI: Actually, this is Teresa. I'm looking for ours, too. We have a huge list from our office of Accessibility and Technology. So once I find it, I will put it up as well or send it to one of you all.

>> KATHLEEN MURPHY: Jess from the National Association – NARIC, all these acronyms you get used to the acronyms, so NARIC.com – is pointing out that Touch Graphics has developed tools this area, so that’s Touchgraphic.com. Lina is noting that they have been required to provide written descriptions for all graphs. So those who are visually impaired -- as we've been discussing --

>> ALBERTO CAIRO: Mm-hmm.

>> KATHLEEN MURPHY: And Joanne is asking Tiffany, do you have any comments about getting your research across the digital divide?

>> TIFFANY LOHWATER: This is Tiffany. I'm assuming by digital divide you mean people who have ready access to digital and those who do not.

>> KATHLEEN MURPHY: Yes. Or even as we have noted in the conference, some people are moving to mobile, too. No platform versus platform and then various platforms.

>> TIFFANY LOHWATER: Right. Yeah. So I think those are two different questions. I guess part of it is understanding the audiences that you're trying to reach and being aware of all different issues that may stand in your way of getting to them. So obviously if there's an access issue, trying to find other ways to communicate in addition to online is really important.

I think that is where a lot of the in-person stuff -- doing things in the community where you're trying to reach is important. For example libraries, where people are able to acces the computers, trying to reach the demographics where they are instead of assuming they will come to you.

And then I think the other about platform -- it is a good question in terms of how much is now being done on mobile as opposed to on actual devices, full computers, I think that is going to increase in the future. In most places, many others who are doing online work with moving in the direction towards being a mobile-first actually, and desktop second.

I think you will continue to see that. So a lot of that is about simplifying what you place online and making sure things are readable and you know, the different standings that you need to do that.

So I think that will be interesting to watch as that develops, but I do feel like that is a huge issue in terms of people accessing content, especially in many countries where people are only using phones to get internet access, for example, instead of using a laptop or desktop computers.

>> KATHLEEN MURPHY: Great. Thanks, Tiffany. So I'm looking at our list of audiences are and we don't have rural communities up there. And since those are sometimes communities that do not have access to good, fast internet. For any of the NIDILRR grantees that are on the line, do you have large constituencies for your projects that are rural? Have you tried to figure out ways to reach them in multiplatform ways, or however?

>> TERESA GROSSI: This is Teresa Grossi and I was just saying that our project is working with the schools and adult providers in a variety of areas and we have to think so much about with schools the firewalls of what they can get access to and what they can’t, and some of our community and rural areas, getting access to high-speed internet, or how we display it and how long it will take it up. Just with a recent survey, we just found out that individuals -- well, a lot of individuals -- the intellectual disability individuals that don't have access to technology, so it's about how do we think about the variety of audiences and then how are we going to tell the story in the variety of messages that have to go out?

So it has become a constant charge of thinking about who are the audiences? Where are they? What is the message? But then, how do we get the information to them?

>> ALBERTO CAIRO: This is Alberto. I would like to add to something that was mentioned before. It is all related -- accessibility -- about the mobile-first approach. This is certainly something that is happening in the news industry. You ask any department and news publications that does visualization or data journalism or infographics, they are all going mobile first.

In some cases, they don't think about creating the same project for the desktop computer. They create just for mobile platforms. If they have time, as an afterthought, they do it for the computer screen. But in most cases, they do it just for the mobile platform.

>> JOHN KRAMER: This is John Kramer. One of the things I've been thinking about a lot is kind of what the role of open access is in all of this and -- referring to the open-access movement. I've been looking a little bit at -- you know, how can you disseminate work to be more universally accessible behind paywalls -- not just locating on the project websites, you know, not kind of branching out a little bit, how do you feed your work in a broader sense, maybe to universities or local colleges that don't necessarily have a lot of resources or a lot of journal subscriptions and so I know a lot of the universities that we belong to have institutional repositories that use -- that all link together. I think it is called the open-access network.

I'm going to post the link here. But you know, everything I've been reading about that is it increases your readership over the work, the life of the work. There are some questions obviously around intellectual property and copyright stuff that we should all be aware of anyway in the work that we -- in the work that we produce, but if your goal is to really drive readership and to read the harder-to-access populations, it seems like a good low-cost high-benefit way of exposing your work.

>> KATHLEEN MURPHY: Okay. I know Alberto, you have noted that you're going to need to leave in a couple of minutes. So --

>> ALBERTO CAIRO: I have time. I can wait until the very end. I was just checking the schedule it says until 5:00 p.m., I can stay.

>> KATHLEEN MURPHY: Okay. Thank you.

>> ALBERTO CAIRO: Mm-hmm.

>> KATHLEEN MURPHY: So we've been talking about, you know, sort of different audiences with respect to rural or not or whatever their practices are with respect to the kind of technology they use or can't use. But again, thinking back to what a lot of you wrote when you registered and submitted your questions, a lot of the questions pertained to try to go meet the needs of either a specific audience -- especially policy makers and clinics a lot of you asked about, or trying to think through how can something be designed to meet more than one audience? So for the grantees on the phone, John, Judith, Theresa, and Carmen: do any of you have experience working, trying to reach policy makers specifically?

>> CARMEN CAPO-LUGO: No.

>> JUDITH GROSS: No, this is Judith. No. I don't currently, but I am -- I'm starting to actually -- to pull together some -- some products for our current research that we're finishing up here. Policy makers will be one of the people that we're trying to reach and I think what we've learned -- at least for the Beach Center – has been that stories matter. Like you can give a lot of data to policy makers, but if you couch it in somebody's actual story, you put a face to it, a name to it, what happens with them, it seems to have greater impact on their buy-in to the data, I guess.

>> TERESA LOHWATER: This is Teresa and I am fortunate that I work closely with our policy makers and quite often they request the data, not so much about the current project I'm in because they've been involved in it all along. So they are looking for policy implications. But I agree that I always have to tell a story of the person -- you know, the face behind the data and that makes a pretty powerful story for them and that is the story I want to tell, but it also shows that impact. I also sometimes think about what is the problem they're trying to solve. And quite often I could put the data from my current project or other projects that I have -- that I could pull the data to say "This may help you look at this," especially when legislators are asking a lot of questions.

I'm fortunate enough that I have an administration right now and it may not last, but it is very data driven. So I hope it continues.

>> TIFFANY LOHWATER: This is Tiffany. I was just going to weigh in. We do a lot of policy work at AAAS with national, but also state and local. But I was thinking about which policy makers are trying to reach and what types of things they're interested in. So if you're doing a state and local policy outreach, you know, giving stories and providing data relevant to the constituents they serve is going to be a useful way in.

>> ALBERTO CAIRO: And this is Alberto, I mean, I come from a completely different world – the world of journalism. So our audience is potentially anybody and everybody, right? So it’s really difficult to tailor your message when your audience is so broad. But what I have done in the past, and encouraged my students to do, is always to test their graphics. So if they’ve said they produced a visualization, an infographic, or any kind of message. And if they can, I mean they should be conducting like scientific tests with that. So actually doing experiments and analyzing how the message is received and understood. But in many cases obviously it’s not possible to do that. So the alternative would be to do non-scientific tests, just showing your graphics, your products to people who you believe may be sort of representative of the audiences that you are going to be talking to. And then asking them to read your graphics and basically record the reactions to those graphics, what they get from those graphics, what they learn from those graphics. If they struggle with a particular portion of the graphic, note that down. Because it will help you down the road to design better graphics, right, if you can learn from your own mistakes or your own wrong assumptions.

>> KATHLEEN MURPHY: Yes, definitely. And I was just typing in the chat but I’ll just say it, it’s something you may not know. Our center, KTDRR, is housed at the American Institutes for Research, and we also hold the Knowledge Translation Center for the Model Systems. And I know consistently, they do fact sheets and they do cognitive testing where they have the users read through and give feedback and also for instrumentation, you can do a meta-review where somebody reads the questions of whatever it is -- the focus group or the survey -- and thinks out loud of how they're reacting to the questions at the time. So it's not necessarily related to visualization. But it's aligned with what --

>> ALBERTO CAIRO: Yeah. Absolutely. Yes.

>> KATHLEEN MURPHY: So we’re getting some participation from the chat here. Judy Zuhula is pointing out our My Care My Call study resource guide, which rates resources and educational materials according to a consumer's level of activation. Judy, is that – what kind of care? Is it a healthcare oriented resource or, something different? So I’ll give you a chance to respond to that question. And she’s noting that they similarly have a content expert panel and consumer advisory board review and critique our graphics, as well as study and ed materials, which of course is highly encouraged by our funding agency NIDILRR. And in the disability world, for those of you who aren’t aware, when we say consumer we are talking about people with disabilities specifically. Moving on, are there any other thoughts -- there is a long list of audiences here. Whether somebody has something to say, in this instance we just started talking especially about patients, families, caregivers. Is anyone coming at this angle -- the issues of knowledge translation from the perspective of the world of healthcare?

Okay. So Judy's resource is related to self-advocacy, healthcare education. Thanks Judy.

And as far as service providers, I did want to note that someone was talking earlier about how there are firewalls – I guess it was one of our reactors – and that also can be the instance for some state vocational rehabilitation agencies, which are important NIDILRR projects. And I don’t know if some of you participating on the phone have run into that as well. So you want to do like for example Facebook or Twitter outreach, but the staff can’t participate, or YouTube or whatever. We ourselves for our Knowledge Translation for Employment Center have had to find workarounds for some of the state VR staff.

>> TERESA GROSSI: This is Theresa Grossi and we’ve had to do the same thing. Our VR staff, although they’re fighting it right now pretty good, they’re not allowed access. They are using their personal accounts to be able to see some things. So we are having to do it in a variety of ways from e-mail to blogs to other social media. And actually, our director is now has a Facebook account for the agency as well as a Twitter account. But it is taking a lot of work to work through for the individual staff to get access to it. Sort of sad that our state agencies are taking so long to get on board.

>> KATHLEEN MURPHY: Well, I mean, they do have -- you know, grounds for caution, particularly anything relating to employment, and social media is pretty broad. So I can understand. From the perspective of wanting to use a tool, can be frustrating.

We have about 5 more minutes left for discussion and there's two ways we could go and I'm going to go with responding to Linda Anderson's question: What about knowledge translation for people with intellectual and developmental disabilities or IDD? It's been raised, I think earlier -- up in the comment thing. So how have -- again, John, I think this is a big constituency for your work at the ICI. How do you meet the needs of people who may have trouble reading typical scientific text? Or even -- you know --

>> JOHN KRAMER: Well --

>> KATHLEEN MURPHY: Go ahead.

>> JOHN KRAMER: Yeah, I don't know that I necessarily have like one kind of really -- piece of advice on this. I mean I think we've been more successful the more we've engaged self-advocates like -- I mean, at a fairly high level. Like self-advocates becoming empowered, for example. Working with them to provide technical assistance on some of our products, and working with them to co-author some of our products. That is kind of the first thing. And that does a couple of things: one it makes sure it is cognitively accessible and it also makes sure that it’s relevant to what they're interested in. Like I think it’s kind of both things that go hand in hand. Also you’ve just got to make sure that what you’re doing is relevant to their experience.

>> KATHLEEN MURPHY: Mhmm and I remember Tiffany, you brought that up as well. Making something interesting and one thing that I know the Canadian Insitutes for Health Research has really promoted is stakeholder engagement in designing products and research studies. So that in the end whatever is going to be translated is developed in conjunction with audience members as active participants in shaping –

>> JOHN KRAMER: Right, right in the whole research process – I mean from the generation of research questions to the final product.

>> TIFFANY LOHWATER: I believe there is a term called co-production of knowledge. And absolutely, if you're able to do that -- that is the best way to make sure your audience will be a recipient, obviously.

>> KATHLEEN MURPHY: Yes. CIHR -- the Canadian Institutes for Health Research – I know they call that, integrated KT as opposed to end of project KT. So we do have – let me just see what’s been going on over here in the chat people are leaving pointing out that plain language is a key element for cognitive access. Sometimes that’s easier said than done, so we welcome anybody’s ideas for plain language – particularly if you know of any glossaries that help readers understand terms that often come up in scientific studies like intervention, or even population. Tiffany was pointing out in her presentation that sometimes words that are just regular old nouns get put together and they mean something quite specific in the scientific context.

Okay so some people are needing to sign off and there are a few housekeeping things we need to do before the top of the hour.

I wanted to let any of the reactors a chance -- if there's some thought -- you took the time to prepare and we appreciate that. So is there something that has not come up that you wanted to be able to share with the group? I know we didn't get to the last question about fast, cheap, or good. You can usually only get 2 out of 3 is a project management aphorism.

>> TIFFANY LOHWATER: So this is Tiffany, and I just want to get to the last point about cost, time, and quality and that’s a huge issue. One of the things I like to remind scientists though that want to have everything perfect is that perfect can be the enemy of good. And that sometimes in order to make good communication, you have to be fast and cheap. So making sure that you get the training and you use it as well as you can and you practice I think is really the best opportunity. Practice and learn from your mistakes and keep going.

>> JOHN KRAMER: I just want to say one quick thing. I think part of it is learning how to seed your work where people are likely to find it in the future. I think, I mean, open access would be one example, I think also making sure that using grant resources and kind of affiliated institutions that are mandated to promote work like this. You know to really use those things, because people in the future will try to look up stuff on the internet and be more likely to find what you're doing.

>> CARMEN CAPO-LUGO This is Carmen. I also wanted to say that I feel that these two topics -- communication and visualization -- like we need to start integrating more actual training within the teaching we do and within the training of Ph.D students and post-docs because practice is needed. But if we start too late, there is a lot of things we miss. I think right now, trying to integrate Twitter, Facebook within the things that we teach will be great to really hone in those communication skills with students and teacher researchers.

>> KATHLEEN MURPHY: Yes, and there's definitely -- KTDRR regularly collects data from the grantees to find out what kinds of trainings do you want? This kind of nuts and bolts training -- when you know -- people are interested in the theories, but they also really appreciate when there's the how-to aspect of our training. So that is obviously consistent with what you're hearing from your students and what they can benefit from as well.