

2023 KT Online Conference: Rehabilitation Research Knowledge Translation

Presenter:

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Transcript for audio/video file on YouTube:

<https://youtu.be/Tdb6Um2webg>

FELICE TRIROGOFF: I'm happy to introduce our first panel from the Shirley Ryan AbilityLab. First, we have Linda Ehrlich-Jones, who is the Associate Director of the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab, formerly RIC, where she oversees the rehabilitation measures database, a compendium of summaries of instruments used by rehabilitation professionals.

She's joined by Jenny Burns, who is a Project Manager in the Center for Rehabilitation Outcomes Research and John Abbate, a research assistant also at the center. He supports research in the Rehabilitation Research and Training Center on home and community based services. Linda, are you ready?

LINDA EHRLICH JONES: I am. Thank you, Felice.

FELICE TRIROGOFF: Great, thank you.

LINDA EHRLICH JONES: All right. I am Linda Ehrlich-Jones. And I am a White woman with short dark hair wearing glasses and a white turtleneck and a flowery blue shirt as well. As far as disclosures, Our. Funding comes for the Rehabilitation Measures Database from NIDILRR through the Knowledge Translation Disability Rehabilitation Research project on Promoting Patient-Centered Care through Use of Standardized Assessments. We also receive funding from the Shirley Ryan AbilityLab.

Our learning objectives for today include what is the Rehabilitation Measures Database? Why produce infographics? What does the RMD Advisory Committee do? And what goes into making an infographic? And how have these infographics been received?

So what is the Rehabilitation Measures Database? It's a free online database with over 550 rehabilitation measures, summaries that provide psychometric properties and links to the actual measures if they are available. The Center for Rehabilitation Outcomes Research collaborates with universities and volunteers across the country to produce these summaries.

Who uses the Rehabilitation Measures Database? Our users include the Allied Health therapists, such as occupational therapists, physical therapists, and speech language pathologists, but also nurses and physicians who work in physical medicine and rehabilitation settings with disability populations. Our measures are related to stroke, spinal cord injury, brain injury, vestibular disorders, cancer, older adults,

arthritis, and more. And we know it's a valuable resource because it gets more than 4.5 million page views annually by people from 195 countries.

So what else does the database have to offer? Included on the database is rehabilitation measurement statistics. So there's a statistics guide to explain the different psychometric properties. We also have modules or videos on selecting and using rehabilitation measures. We also have an online LinkedIn Rehabilitation Measures Networking Group that you can join at the link that you see on the slide. That is a group that can ask questions about measures or questions about the RMD.

We also have an Advisory Committee for this grant, and who are they? They include educators, clinicians, researchers, people with lived experience, and members of organizations that support people with disabilities. So what do they advise us on? Including the infographics, development of focus group questions, input on our RMD social media, and other dissemination efforts.

Our Advisory Committee suggested focus groups to provide feedback on how information about measures could reach patients and their care partners. Our focus group participants said, "I'd like to know which assessments they're using. Why they're using them, what they mean, how they can be helpful to the patient and the family, and how we're going to use them to evaluate or as a tool moving forward."

Another participants told us, "I don't feel like the communication between perhaps the professional and the family is always clear and consistent. And often that information, perhaps is shared among the professional team and not relative relayed effectively to the family member and how it's used and what it means." So why infographics? We wanted to create something that would improve patients' and care partners' understanding of these standardized assessments.

They use plain language that describes the measure and how and why it is used and what the patient will need to do for that measure and what the score actually means. There are graphics that support the text and increase readability. They can be easily printed and handed out and patients and care partners can follow their rehabilitation progress by keeping track of their scores on these infographics.

Making the infographic, we selected measures that are commonly used. We keep Google Analytics of the measures on the database and have a list of about 25 of the top used instruments. And then we started with a template that was created in software called Canva. And the sections for the infographic include what is the purpose? What do I have to do? And what does my score mean?

And we wanted them to be consistent, so as patients receive different infographics for different measures, they would have an understanding of what the information would be there. So following the template, we describe the measure using plain language, we aim for an eighth grade reading level. We select relevant graphics, and then we drop text and graphics into the template.

So here are a couple of the examples of the infographics that we have currently created. The one on the left is the Berg Balance Scale. It is a test to measure balance. And you can see here there's a short paragraph explaining what the purpose of the test is, what are the different things that the patient will have to do during that test, and what does their score mean? We do want to highlight that we do have a

disclaimer that asks them to have a conversation with their health care provider about what the results actually mean for them as an individual.

The infographic on the right is the dynamic gait index. And that is a test to evaluate risk of falling. And again, it has a short paragraph about the purpose, what the patient will have to do for that test, and then what the score will mean. Two of our newer examples of infographics include on the left, the nine hole peg test. This is a test to evaluate finger dexterity, so again, what the purpose is, what I have to do. And there's a graphic that shows exactly what the person will have to do in terms of moving the pegs into the holes and then back into the stand. And at the bottom again, what does my score mean?

The last example on the right is the Oswestry Disability Index. And is how much does low back pain limit daily activity? Again, what's the purpose? What do I have to do, and then a little bit more about what that specific score means to that individual. So we're trying to highlight different instruments that are performance-based or patient reported outcomes or observational types of measures.

We have an Advisory Committee that I spoke about earlier that reviews approximately three infographics at their quarterly meetings. We get wonderful feedback from them, and we incorporate that feedback. And the final draft is scanned for accessibility using Adobe Accessibility Checker. The images are described, and the sections are labeled by reading order and color contrast is checked.

And then the final infographic is posted with their particular measure on the database. And they're usually posted right at the top of the specific instrument. So as you can see here, the Dynamic Gait Index, that blue box has a download feature where they can print the infographic and hand it to the patient as they're leaving their therapy or session.

Other aspects of dissemination that we have in relation to this grant include our CROR Outcomes newsletter, for which we have approximately 4,000 subscribers. The information is also shared at conferences, webinars, and presentations. Our infographics are shared on our Facebook page, where we have about 3,000 followers and Twitter followers, about 1,600, and our LinkedIn group, where we have 315 members.

The Functional Gait Assessment infographic was posted on Facebook and was seen by over 1,000 people, where usually, our posts are only seen by 30 to 100 people. And our infographics were downloaded about 7,500 times between February and June of this year, 2023. So today, we have eight infographics, nine 9 hole peg test, the Dynamic Gait Index, the Timed Up and Go, the Modified ashworth Scale, the Oswestry Disability Index, the Functional Gait Assessment, the Berg Balance Scale and Disabilities of the Arm, Shoulder, and Hand Questionnaires. And we have more infographics that we're getting ready to post as well.

We did do a survey regarding the rehabilitation measures database in 2023. We found that clinicians, rehabilitation patients, as well as their care partners were asked if they would like to view the infographics, and 70% said yes. Patients and care partners were asked if the Berg Balance Scale infographic that was shown in the survey would be useful if the measure were used during rehabilitation. And 55% of respondents said yes, which was a similar response for the Dynamic Gait Index.

Clinicians were asked if they thought the infographic that was shown in the survey would be useful for communicating with patients and care partners about the assessment. And 60% of respondents said yes. Some comments that we received in the survey, they felt that the infographics were useful, practical, and easy to read. I really appreciate this idea of creating resources to help patients understand measures.

Another respondent said, "I am someone who likes to use several different forms of communication for my clients, and I do like these options." And lastly, "I love this idea. And I would like to see it for more assessments. I always discuss test results with clients. But I know I've had students and colleagues who don't always feel comfortable. And a tool like this would make those conversations more accessible." And I will leave questions till the end of our presentation. Thank you.

FELICE TRIROGOFF: Great, thank you so much. Jenny, would you like to come on camera? Great. Jenny, you're up, and feel free to self-describe.

JENNY BURNS: Thank you. Hi, my name is Jenny Burns. I'm a white woman with dark blonde hair pulled back wearing a gray sweater. And I will be talking about the MRSCICS Matters Newsletter and how we use it to keep in touch with participants enrolled in the National Spinal Cord Injury Database. And I'm about to copy the links that I'll be referring to in the chat so you have them.

All right, so first, this presentation and the newsletter will be talking about is supported by the Midwest Regional Spinal Cord Injury Care System Project funded by NIDILRR, the National Institute of Disability Independent Living and Rehabilitation Research. And we have five objectives for this part of our presentation. First, what is the National Spinal Cord Injury Database? Second, how is Shirley Ryan AbilityLab involved with the database?

Third, I'll describe the enrollment process and how we collect follow up data. Fourth, why do we need to keep up with enrollees as a center? And fifth, I'll talk about our MRSCICS Matters Newsletter, one of our dissemination resources.

So what does it mean to be a model system? This designation is awarded to high quality treatment facilities. It is a facility with an acute care and an inpatient rehabilitation program or multiple facilities that group together to form that. So the clinical care is the top priority. It's also the second priority, contribute data to the National SCIMS database. So that's the research component.

And the third is dissemination to other researchers and professionals and knowledge translation to those populations and to people living with spinal cord injuries and their loved ones, so three components. And Shirley Ryan AbilityLab is a spinal cord injury model system. So what is the National Spinal Cord Injury Database? This is the research data component of the Spinal Cord Injury Model System Project. We'll go over the actual data collection in more detail later.

But the National Spinal Cord Injury Database was established in 1970 to study the long-term outcomes of traumatic spinal cord injury and factors that affect that course. So we collect information about demographics, spinal cord injury characteristics, and then medical, psychosocial, employment outcomes.

It also serves as a public research database. It's a centralized web based database that's managed by the National Spinal Cord Injury Statistical Center at the University of Alabama in Birmingham.

There is a link to their site in the chat. And currently, there are 18 spinal cord injury model system centers around the United States that contribute data to this centralized research database. And the data is available to the public by request. So the team at the University of Alabama Birmingham help researchers around the country and around the world pull the data that they would need to do research and the de-identified data is available.

So as I mentioned briefly, there are currently 18 active spinal cord injury model systems of care. And the place that I work Shirley Ryan AbilityLab, formerly the Rehabilitation Institute of Chicago serves as the Midwest regional model system. And we have been involved in the project contributing data since 1973. And centers are funded for five year cycles. We're currently in our 2021 to 2026 cycle.

So just to highlight the importance and the usefulness of the National Spinal Cord Injury Database, they have information publicly available using the data that's been entered into the database to provide information about spinal cord injury, etiology, prevalence, and occurrence throughout the United States. And then this research is used to evaluate and improve spinal cord injury treatments, improve available resources, and sometimes change public policy.

So we can see here that just some of the things that we know from the National Spinal Cord Injury Database, over the 50 plus years it's been active, there have been 36,275 participants enrolled in the database across 31 total centers. It's estimated that there's around 300,000 people living with traumatic spinal cord injury in the United States with about 18,000 new injuries per year.

The injuries are primarily occur in males, 79% men and only 21% females, also 56% in non-Hispanic White people, 24% in non-Hispanic Black, 14% Hispanic, 2.6% Asian, 1.7% other or mixed race, and 0.5% Native. We can also see these average trends over time because the database has been collecting data for so long, which is something that makes it a unique research project.

So we can see that in the 1970s, the average age at injury was 29 years old, and that's gone up significantly to 43 years old in 2015. And acute hospital lengths of stay has decreased from 24 days to 12 days. And then the rehabilitation length of stay, so inpatient rehabilitation has decreased significantly from 98 days in the 1970s to 31 days since 2015.

And then finally, the cause of spinal cord injury is something that is important to outcomes and policy. So we can see that the majority of spinal cord injuries result from vehicular accidents and falls and then about 15% from violence, just over 8% sports, 4% medical problems or medical complications, and then 4% something else.

So just to briefly review our data collection and how the study kind of works at our center. So at Shirley Ryan AbilityLab, we enroll about 90 new participants each year. So these are people who just sustained a traumatic spinal cord injury and are currently staying in our inpatient rehabilitation facility. And we approach patients to be enrolled while they complete inpatient rehabilitation.

So after we obtain informed consent, our research assistants collect information during a brief, about 15 minute interview right before the patient is discharged from rehabilitation. And this quick interview asks some questions about their medical history, their demographics, including demographics prior to injury like employment and marital status, and their ability to move and feel sensation, so kind of like our baseline survey. And we also extract information from the medical record.

Then the major component of the data collection for the SCIMS database is the long-term follow-up data collection. So each participant is contacted by phone or email. We also do texting now at these designated time points, so one year after their injury, five years after their injury, 10 years after their injury, 15, every five years thereafter.

And we're actually currently interviewing people for the first time at our site who are 50 years post spinal cord injury. So that's pretty exciting. And our team completes about 200 follow up surveys per year. So that's information that goes into the national database. And this interview or survey is a little longer. We ask more detailed information about their socioeconomic status, medical complications, just general health, pain, and then psychosocial well-being and functional abilities.

So because this is such a long-term study, and the long term data collection is so important to seeing trends and things like that, participant retention strategies are really important for us to make contact in between these five year gaps in data collection. So people are always moving, changing their phone numbers or emails. People get married or divorced, go to jail, maybe have to go back to the hospital, pass away. There's all sorts of things that can happen over 50 years. So I will talk about some of the strategies that we use to stay in touch.

So first, every year, a participant gets a personalized birthday card during their birthday month. And we also send holiday cards annually. And that's really just to first of all, let the participants know that we are thinking about them, and second of all, confirm addresses and give people a reminder, an opportunity to reach out to us if they have any updates with contact information or their status.

And then we added in 2014 the MRSCICS Matters Newsletter. So again, MRSCICS stands for Midwest Regional Spinal Cord Injury Care System. And MRSCICS Matters is the name we came up with. So it started as another way to stay in touch with people in the database in hopes that they'd be more likely to complete the follow-up interviews, kind give us a more personal touch. And we send it out twice per year.

So it used to be all print for the first few years. We would mail out hard copies of the newsletter. Now, we've switched to completely electronic or email newsletters. And then there were a few years around COVID when we did both print newsletters and email newsletters. So we have about 1,000 subscribers. It's mostly participants enrolled in the MRSCICS database, so people living with spinal cord injury plus some of our research and clinical collaborators.

We have an average open rate of 30% and an average click rate of 4%. Some of our goals with the content is to make sure it's written in plain language. So we do a reading level check and make sure it's accessible to people with physical, visual impairments. And third, make sure it's interesting and relevant

to people living with spinal cord injuries. So we try to produce content that will actually be helpful and interesting.

And then I mention this again later, but we have an archive of all of our past editions of the MRSCICS Matters Newsletter if you are curious. And that includes both the print and email PDFs. So some examples of the type of content we like to highlight in our newsletters, first, research team member profiles, so again, kind of making the research more personal and matching a face to a name for people who have interviewed with data collectors over the phone, and we also like to share new research findings, especially if it is something that came from the Spinal Cord Injury Model System Database.

We like to highlight MSKTC fact sheets, which are fact sheets produced by the Model Systems Knowledge Translation Center. And we also like to highlight any spinal cord injury research opportunities, current events, educational resources, really anything that is forwarded to us from our network of collaborators or something that we see and think would be relevant to people with spinal cord injury or participants.

All right, so just to highlight this one part of our newsletter that we include in every edition, we summarize an MSKTC fact sheet. So the Model Systems Knowledge Translation Center is kind of the centralized group that coordinates all of the knowledge translation efforts for all of the model systems, so spinal cord injury, burn, and traumatic brain injury. There are spinal cord injury fact sheets are plain language documents.

They're written by clinicians and researchers and then edited and revised by plain language experts to summarize important topics that are relevant to people living with spinal cord injury. Some of the topics include depression, pain, bladder management, driving, wheelchair management, opioids, aging, employment. Their topics really run the gamut from medical to daily activities to end of life stuff and pain. So that's just one resource. We always highlight, we do a little summary in our newsletters and then link out to the fact sheet were referencing and the link to that is also in the chat.

Whoops. So here is just the front page of what our print newsletter used to look like. And those are available as PDFs on our archives. You can access all past editions of the newsletter on that archives page. And feel free to contact me with any questions, and I'll be available for questions at the end. Thank you.

PRESENTER: Thanks. Thanks, Jenny. I really enjoyed the reading level. That's something to keep in mind when developing content for newsletters. John, can you join me on camera?

JOHN ABBATE: Hi, my name is John. I have a Black and gray hair, glasses and a beard. I'm a White male. And I'll go into the presentation. I'm going to be talking about turning an accessible document, or one version, I guess is easy read, so next slide, please, or I'm controlling those. Thank you. OK, so let me move you, so I can read. This screen isn't the way. I'm sorry about that. OK, so why is an easy read important?

Then we're going to talk about the different components of an easy read, our easy read document the components of the one that was made through Schiller on AbilityLab, strengths and challenges and takeaways and resources. I'll try to push you on the link later, or the chat, I mean. OK, so the CROR policy brief, Center for Rehabilitation Outcomes Research Policy Brief, so the first one back last year was The Influence of Disability Models on Person-Centeredness in HCBS, Home and Community-based Services.

But we found basically to get something out of that, the reader needs to be pretty well versed in concepts like the [INAUDIBLE] disability model types, HCBS, which many people surprisingly don't know, a person-centeredness, and different laws or policies affecting HCBS. So why make a policy brief accessible? It's really the best way to translate knowledge to people whom the research is supposed to impact first off.

I mean, equity, hearing and seeing things in basic terms, this is good for people with varying disabilities. It's pretty much for everyone. It's actually a good thing.

So what is an easy read document? Easy read document's format is a format that is accessible and uses easy to understand language, pictures, or icons, which I'll show a few examples of. The main components of an accessible document or easy read glossary or a word stanovich, some people don't put that by feel. It's pretty important to have something to refer back to the reading level, third and fourth grader easy read, five to eight for a plain language, which most people are used to.

Active voice, it's much better than passive. And I have an example, which is totally not sure right now. The Chicago Bears are winning the game that would be an example of active voice. Passive would be the game is being won by Chicago Bears, so yeah, emphasis on one.

OK, so continuing on the main components of an easy read. You want to do a large font, 14 at minimum. Bullet points, try to keep it condensed, one idea per line. You're going to usually want icons and pictures. I've seen some people not use these. But I mean, they're pretty good to use icon wise. The reading level, I went over, third and fourth grade, low idea density, but doesn't change definition, which is actually pretty challenging.

Your active voice versus passive voice, again, playing the language, what we're all used to mostly is fifth to eighth grade. So this is just example of icon, just the universal sign for disability or wheelchair users. Keep it clean and clear. There's a resource I have this non non-project for icons, free icons. Some of the free icons leave a lot to be desired. But they're free, so yeah.

Accessible document, summary statement of what was originally made back in 2022 that found wasn't really the best hard to understand the resource, but the models of disability and how they influence home and community-based services and supports people get our research. There's a few different parts, but the first part that it's referring to is just a mainly talking. We're creating measures or different ways testing, HCBS choice and control if it's person-centered.

And this is just kind of a good primer or like a little bit of pre-work to familiarize people with how services can affect if it's based on a social model or the medical model, how people, how it impacts services. But

anyways, accessible documents sections, we talked about disability and how it's defined, social, medical, other models. Those are the main known ones. How disability definitions of policies and laws, which I was talking about a little, what person-centered supports are, how definitions of disability affect person-centered supports, and ways to improve person-centered supports.

This is an example of the definitions, which I kind of like glossary. I mean not just-- and I mean, it's good for anyone. You have something to refer back to. This is an example of breakdown of using text. Icons, some of the icons that are free, you have to get creative with like here with the different models use the Venn diagram with a guy in a wheelchair, the accessible, the universal wheelchair user accessible ability sign.

Yeah, so you get creative if they're free, or if you have the budget to pay more, probably would do that, but not always possible. So we have great reception and response, received a lot of informal or positive feedback. It's download 65 times. Facebook wise, there were 600 impressions. Twitter post got more than 400 impressions. And reception continued. More than 1,000 subscribers of our quarterly HCBS Quality Matters newsletter, which I'll put in the chat.

And a little here on that email had a close to 40% open rate and 22% click rate. Most content has 28% open rate and 2% to 3% click rate. So yeah, that's I mean by positive reception. Challenges, takeaways, which are quite a few, reading level, being used to plain language reading level, and part of life and in school, we're taught to be a little wordy. Vocabulary wise, too, you want to use higher level words. So bring it back down to what you used to do is not easy.

It's easy by name, but it's definitely not easy at all. So you got to be really patient with changing a lot of the words and sentences around. Once again, don't take away the meaning, but emphasis just easy read. It's easy by name, but it's definitely not. And different resources, which I'll put in the chat, Hemingway app is the way to-- It's a good, I forget the exact word. They use the word. But basically what it does is just checks your reading level or grade level and the words you're using, and you can kind of play around with it that way.

Noun Project is a free app website I mentioned a few times. So Advocacy Resource and Tech Center, SARTAC is a really good resource for things of that nature, easy reading just disability in general or accessibility. The Autistic Self Advocacy, let people know about them, or ASAN, Up-GOER Five, which I find very helpful. It's the most common-- one good feature, it's the most commonly used 1,000 words, and it's nice to try to stick to that. And it's definitely challenging, to say the least.

But a lot of this stuff isn't set in stone but good guidelines to follow. And I think that's it. Thank you, everyone. And yeah, I'll put things in the chat. And we're doing questions when we're done, correct?

PRESENTER: Thanks, John. What a great click rate and open rate as a communication person. You love to see it. I'd like to invite your colleagues, Jenny and Linda back on camera as well as KTDRR's Director, Dr. Kathleen Murphy, who will be moderating Q&A.

KATHLEEN MURPHY: Thank you, Felice. And thank you Shirley Ryan AbilityLab. Yes, I'm Kathleen Murphy, and I'm a white woman with shoulder length blonde hair. I often put on these blue frame plastic reading glasses that are the necklace I wear every day is what I say. I'm actually also wearing a real necklace, which has a little blue diamond kind of pendant thing. And that's over a maroon colored long sleeve t-shirt, and that's under a blue jacket with a notched collar. So that's me.

And we do have questions and great links in the chat. Thank you John. Before we go to the Q&A, since we do have a little bit of extra time, some of what's going on in the chat is questions about evaluation. Because we do offer CRC credit for this conference. And some of our attendees are interested in that. And they might be a little bit confused about what we're doing with the evaluation this year.

So to give some context, we love it when we get hundreds of people registering and coming to our conference, of course, right? And our funder, same funder as these projects we've heard now does love it when we can get lots of evaluations from those hundreds of registrations. And it can be hard. People are busy. Everyone has respondent burden kind of done with surveys. So we're offering this link many, many times to try to catch people who are coming in and out of the conference.

So you will notice that it's the same form. Except on day one, we had questions about day one presentations open yesterday. We had questions about day two. And today, we just turned off the day two, and we have the day three questions open. So I know that may be getting tiresome, but we do want to be able. The other questions are about your experience with the platform or what did you think of the art? Those do vary every day. So even though it's the same questions, you're reporting on a different experience.

So if you are wondering, wait, oh you know, I came, and I didn't get a chance, and you've turned off the day two and day three, absolutely no worries. We will be sending the whole thing out with all of the questions opened up again next week so that you will be able to get your full credit. And what we'll do to kind of figure out gosh, how many hours, we'll look because Zoom is documenting, right, as people attend. So we'll just see if you wanted CRC credit, well, how many hours were you here, and there you go. That will be the number of hours that you get.

Nobody has asked yet today, but other common questions are whether or not we are going to archive these presentations. And absolutely, we archive this conference every year we host it this is actually the 10th year we've done it, not in a row. We had a little hiatus last year. But it's our 10th, I guess, sort of anniversary. So just like all the other times, we will post 508 PDFs and transcripts of all of these presentations. So you are welcome, Andrew, for that information because I know it's a little bit confusing what we're doing, but there's a method in our madness, OK?

So that's that. Again, if there's any more CRC people who need more information, just go ahead and put your questions in the chat, and I'll probably answer them offline because it's a little bit boring to talk about. OK, so let's move on to something more interesting. So we did get questions. We have a representative from another NIDILRR funded Knowledge Translation Center and those of you who were here on day one heard Dr. Michelle Zorrilla from the IMPACT Center.

So her colleague Mary Goldberg is here with us. And we are so happy to have you, Mary. And you did have a couple of questions. So let's go ahead and get to them. So you were wondering why Linda Ehrlich Jones was presenting. You said, this is great. Do you accept recommendations for tools to be added as infographics? So that's for you, Linda.

LINDA EHRLICH JONES: Great, thank you, Kathleen. Absolutely, people can email us and let us know if there's something of interest. Because we know that there's some instruments that are much more popular than others. But there are certainly some that could be of benefit. So yes, please just let us know, and we'll be happy to work on it. There is some problem with some instruments that don't take well to or don't translate well into an infographic. But if there's a way to do that, we'll be happy to try.

KATHLEEN MURPHY: Great, thanks. And could you just go over again for me the primary audience for the database?

LINDA EHRLICH JONES: So the rehabilitation measures database, it's for originally was put together for clinicians. Clinicians don't have time to be scouring the internet looking for instruments or looking for data that says the instrument is helpful for what it is that they're looking for. But then we found it was also very helpful for students. And we collaborate with different universities, graduate programs that have an interest in helping students to learn about different psychometric properties like reliability, validity, things along those lines.

So the database itself was not really something we would want to promote with people with disabilities or their care partners or whatever. So this was a way by adding the infographics was to put in something that would be of benefit. It is really data focused. So you see the statistics related to the use of different instruments. So whoever feels comfortable with that information, certainly welcome to use that. But that, primarily the infographics were created to then provide information to people that weren't familiar with statistics.

KATHLEEN MURPHY: OK, yeah, I wanted to call that out because I love that. Because, the whole conference theme is thinking through when you have something right, how can you tailor it maybe to another audience that you weren't originally thinking about when you designed it? So it's just like the perfect example of the heart of the conference. We do have some more questions about it. Amanda is saying this question is for Linda.

Thanks for sharing information about the rehabilitation measures database. For the database, are the measures in other languages, such as in American Sign Language? If so, would it be possible to include it as a search or filter for it so you're tagging the measures by their language?

LINDA EHRLICH JONES: So we do identify when there is another language used. We have not done sign language. So I appreciate that comment because that's something for us to think about for the future. And but yes, thank you very much. At this point, we don't always know all of the different languages that instruments have been translated to, but we do try to provide what it is that we do know.

Unfortunately, we don't have a list that you could go to and say I want to something in Spanish, and you find it that way. You actually have to go to the instruments. But we are definitely working on trying to make that a little bit more accessible.

KATHLEEN MURPHY: Awesome. And Roberto Sandoval is wondering how often the infographics or the rehab measures database is updated and who updates the measures if so?

LINDA EHRLICH JONES: Sure. So the instruments, because we work with students, a lot of times, it depends on the faculty and the students themselves as to which instruments they would like to work on, whether it's an update or whether it's a new instrument to add to the database. We are now trying, because we have so many measures, we're trying to work on updating. There are some that have been there since the inception, which was around 2011, 2012.

Also, we get information from people in the community that tell us, this instrument hasn't been updated for a while. It could be for a couple of reasons. One is we haven't gotten it updated. But the other reason could be that there's not a lot of data that has come about since it was actually put on the database. So if people have suggestions about instruments that they would like to see an update, again, if they could contact us, we'd be happy to put that on our list as we work with more students and volunteers.

We're also open to having people that would like to work with us on an individual basis if they have an instrument that they're interested in and would like to update it on the database. Again, please let us know. We'd be more than happy to work with you. We have a specific author toolkit that is available that will help people in how to put together. There's a template that is in Word, so it's a relatively easy thing to put the information into. And then the staff that works with me, Jenny and our other staff person, Kevin then actually load it into the database onto the website.

KATHLEEN MURPHY: OK, because KTDRR also has various databases, and we are kind of use a similar process to yours. So it's an important thing for the audience to be aware if you're thinking about oh, yeah, a database, that would be a great KT product to keep in mind. It's really a constant project to keep it updated, right? It's not just one and done. Yeah, there's a lot of maintenance.

Yeah, and so I know my understanding is if I'm remembering right, so NIDILRR, our funding agency has a dedicated funding stream for rehabilitation research to practice projects. And hasn't this database been awarded one of those?

LINDA EHRLICH JONES: So we have, well, we did receive an award from NARRTC in terms of the database when it was first put together. We have received funding from a variety of different grants through NIDILRR. We currently have this grant that I identified in the beginning of disclosures that we have a knowledge translation, DRRP, Disability Rehabilitation Research Project. So we have a couple more years left on that grant.

So that has helped us quite a bit. Because we then can have a big focus when it's kind of little monies here a little moneys there, you kind of have to patch things together. But here, we have a grant that we've

been able to utilize to have staff and have opportunity to add things to the database. So we'll be starting to look for new resources for the future so that we can keep things going.

But we do try to use the other grant funding that we have particularly from NIDILRR as part of our knowledge translation for other areas. We're finishing up a grant on employment, Rehabilitation Research Training Center and Employment. So then we were able to actually solicit instruments that are related to employment. We were able to actually add about six or seven this year from employment based on that grant funding, so.

KATHLEEN MURPHY: Yeah, that was my understanding that over the years, you've done a good job of reframing in some ways the database to think about how it might fit into another framework and be appropriate for that project. So we did have a lot of-- we gather questions from registrants as well as looking at what attendees are doing. And there's kind of across the hundreds of questions that we get there's an interest in KT with policy makers, so this is really a question for anyone on this panel.

Do you think that what you've been discussing could be appropriate or marketed to not just clinicians and people with disabilities, but also to payers and policy makers? Would it be useful to them, or?

JOHN ABBATE: I'll go first this is John speaking. Yeah, definitely. It's something that currently working on is there was changes to what's called the access rule within ATBS and just making a plain language like I said during my presentation, making the research, translating into people that actually impacts is in my opinion, I feel like it, I mean, it needs to be done. It's a no-brainer. It just to me, it goes hand in hand. I don't see why you would not do it, so yes,

KATHLEEN MURPHY: Yeah, that makes a lot of sense, John.

LINDA EHRLICH JONES: This is Linda. We, also, as part of our newsletter, we do distribute our general newsletter to policymakers and other people that have been in contact with us to let them know what it is that we're doing in relation to this particular grant and other grants that we work on. And I think it helps to provide that opportunity for all different areas to know what it is that we're working on.

KATHLEEN MURPHY: Yeah, because you never know what is coming down the pike as far as policy is concerned. So another theme that comes up in questions, since really of course, KT is a science, right, so like we heard yesterday from the Center on Knowledge Translation for Employment Research that they were doing a study of an intervention. And you have reported the metrics on your newsletter use and the brief use.

But turning to Jenny, right, so the database that you're maintaining, you're requiring humans to enroll, and you're tracking them and all of those issues about recruitment and retention. Could you just talk a little bit about the nature of what is in the database? Are there systematic differences between patients that enroll or don't or end up dropping out of your data collection?

JENNY BURNS: Yeah, thank you. That's a really good question, and it is really important. So it's important that we try our best to make sure that certain, I guess, groups of people who are injured

maintain data collection. Because if there are large gaps in the data collection, then you can't see the trends as well. And we want to avoid any systematic biases. So for example, if somebody, or let's say our group of participants that are older adults, so 70 or 80 and maybe don't use a computer or a cell phone.

If we are only trying to contact people via text, then that entire population might get missed for that data collection window. And then that would be a huge hole in any trends would be skewed. So that's one example. And it's not just age. It's also gender, race, socioeconomic status. And I think that's part of why we collect so much information about that. So researchers can correct for things like that.

But participant retention, I think, making sure that we use a variety of different ways to contact people, like I mentioned and contacting people at a variety of different times. So even times of the day can make a big difference, like if people are working. And times of the year, we have some people with two houses, one in a warm climate, one in a cold climate. Something as simple as that can be the difference between collecting data for that person within the five year period and missing it.

KATHLEEN MURPHY: Oh, that's fascinating just thinking about the link maybe between climate change and data collection. I hadn't really thought about that like some of those trends would be shifting. Could you obviously, Joanne was pointing out, oh, great ideas to keep in touch with people, you're clearly having a ton of success if you have people that you've been tracking for 50 years.

But it does make me wonder sometimes on certain projects that NIDILRR funds, it's hard to parse out aging and disability. So how are you kind of handling that in your reporting or analyzes?

JENNY BURNS: I would think that probably goes more with the analysis portion of the data. I know that we have added this cycle a lot more questions about pain and social participation. And those are issues that definitely affect the aging population. It is also harder to collect data from people who have age related conditions, maybe partially related to their spinal cord injury or not. So even if people need to move into a nursing home, it can be much harder to contact them.

I think the MSKTC, and thank you also for mentioning it in the chat, that AIR is the center for MSKTC. But MSKTC has an aging after spinal cord injury fact sheet that goes into those sort of health related differences that I recommend checking out, and they link to resources there. Did I answer your question?

KATHLEEN MURPHY: Yeah, yeah, I'm just thinking, it is just something that's going to need to be parsed out. It's a little bit on my mind because actually, I have a brother who is now 65. But almost 20 years ago, he was a patient at the Rehab Institute of Chicago. Yeah, he is a stroke survivor, not FCI. But he had a wonderful experience there. And now, he just got out of having surgery because he has sciatica. So I don't think the doctors really know is this really something to do with the stroke or not? So these issues get entangled or with musculoskeletal conditions, for example.

So the other thing thinking about, so that's kind of thinking about the back end. As people come in to enroll, this is a kind of somber question, but an important one. So one of our registrants said what are the strategies to study the disability in war victims or areas in rehabilitation and KT? Are there case studies to learn lessons? Because I would imagine that you have some veterans in your database.

JENNY BURNS: Yes, so we ask about veteran status when people are enrolled, and then we confirm it at every follow-up interview. And then if they are veterans, we have connections on our advisory committee with the VA in Chicago to see if we can get those records to get more information and extract data from them or abstract or even if they have contact information that we can update. So there is a connection there.

And I think that is combat related spinal cord injury is kind of not its own thing, but its own sub section of the research related to spinal cord injury. I'm trying to think if I can remember any patient injured in active combat. But we definitely enroll veterans all the time, and the asking their veteran status and whether they've received care at veteran hospitals helps us track and then kind of isolate trends if there's something that's happening more just with the veteran population or yeah, basically looking at outcomes and how those might be different for that different population.

KATHLEEN MURPHY: And I'm assuming, of course, there's lots of ways people can get a spinal cord injury related to war. They don't have to be in combat, right? They could just be collateral. So I'm assuming, though, the database doesn't track the context of what, or does it?

JENNY BURNS: So we do--

KATHLEEN MURPHY: Context of the injury.

JENNY BURNS: Yeah, we do code the cause of the injury. So that normally happens during that first data collection point after the participant is enrolled. And we ask them how their injury happened, just kind of the general category. And then depending on the general category of their injury, we would get more information. Like for example, if it's a gunshot wound, what kind of gun. And if they want to provide more information about the context, we can use that.

There is a space for comments. And I don't know, honestly, if the analyzes get that broken down. I'm not sure if anybody's published research specifically isolating combat related spinal cord injuries using the SCIMS database. There very well may be publications out there. I know it's something that the VA does a lot of research on. I'm trying to think if there's anything else I can offer.

KATHLEEN MURPHY: That's fine. I just unfortunately, it's kind of an issue on people's minds these days.

JENNY BURNS: Definitely.

KATHLEEN MURPHY: So kind of along continuing this theme of research methods or measurement methods, John, Mary Goldberg is wondering, too, what do you attribute the great open rate when it's dependent on them clicking on the link? Do you think that the subject line makes a difference, the email text, applying the same principles, or have you been able to parse out if certain newsletters have a higher open rate because of some feature of the newsletter.

SHARON: Short answer, no.

JOHN ABBATE: I would say no. I mean, we do have someone named Sharon that does a lot with getting the message out. So it's like social media and whatnot. But I just think it's so relatable to people. So that might get their attention. It's like oh wow, research that I can actually understand and read. It's not in the clouds or pie in the sky. It's relatable to everyday, if that answers your question.

KATHLEEN MURPHY: Well, I guess if you're comparing one newsletter to another, are there things you do to try to make it even better like an even higher rate, or just kind of at this point, it just seems to be a little bit not random, but you can't-- hard to predict.

JOHN ABBATE: Yeah, it's kind of hard to predict. But Sharon's here. Sharon, what do you think? Sorry, everyone. Any thoughts?

SHARON: No, there's nothing we do.

JOHN ABBATE: No, it's kind of random right now. We don't know at this point.

KATHLEEN MURPHY: OK.

JOHN ABBATE: Thanks. What?

SHARON: Subject line.

KATHLEEN MURPHY: The subject line, yes. And I was going to say with our own newsletter, we have abandoned just saying KTFTA volume two number or whatever because that's not really that eye catching or grabbing. And if you have an action oriented subject line, it does seem to boost, at least the open rate. And yeah, just as a reminder, we are your KT center, and we were so happy to help and provide some technical assistance with that brief, and it's really exciting to see that it's up and at 'em.

JOHN ABBATE: Yeah, I understand that question more now. But honestly, just like I said, I think it's just being relatable people, like OK, let's see this. So instead of like I said, just kind of unrelatable to a lot of people.

KATHLEEN MURPHY: Right, and Bonnie is recommending personalized or subject lines as well, speak to your audience Yeah, so you can do like a little embedded experiments. You can send out the email to half your list with one subject line another with another, and we're just kind of starting to get into that.