

## INside the OUTcomes: A Rehabilitation Research Podcast

### Episode 3: The Rehabilitation Measures Database

#### **SHARON PARMET, HOST:**

Welcome to INside the OUTcomes: A Rehabilitation Research Podcast from the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. I'm your host, Sharon Parmet.

Today we're going to be talking with two very special guests about the Rehabilitation Measures Database, an online resource managed by the Center for Rehabilitation Outcomes Research and hosted by Shirley Ryan AbilityLab. This database contains more than 500 rehabilitation measures used by clinicians and practitioners across the world. But as we will see in this episode, it is much more than just a collection of rehabilitation measures.

I want to welcome my guest to the podcast now. Dr. Linda Ehrlich-Jones is Associate Director of the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab and a research associate professor in the Department of Physical Medicine and Rehabilitation at Northwestern University's Feinberg School of Medicine. She holds a PhD in nursing science from the University of Illinois at Chicago. Dr. Ehrlich-Jones oversees the rehabilitation measures database. Dr. Namrata Grampurohit is Associate Professor in the Department of Occupational Therapy at Thomas Jefferson University in Philadelphia, and a member of the Jefferson Center for Outcomes Measurement. She earned her PhD in Rehabilitation Science from the University of Washington, Seattle, and was trained in occupational therapy at the University of Mumbai in India. Dr. Grampurohit contributes to the summaries of the Rehabilitation Measures Database. Welcome Dr. Ehrlich-Jones and Dr. Grampurohit.

#### **DR. EHRLICH-JONES:**

Thank you.

#### **DR. GRAMPUROHIT:**

Thank you.

#### **SHARON:**

I want to start with a really simple question before we get into what the database is. Can you tell me what is a rehabilitation measure?

#### **DR. GRAMPUROHIT:**

I can get this started. So hi, everyone. And so in the field of rehabilitation, we train and work with people with all sorts of conditions that affect them, either neurologically, orthopedically, or psychologically. So to be able to track these different motor or sensory or psychological abilities, and to chart their change over time, we need measures that can be used in rehab. And hence we call them rehabilitation measures or rehab measures for short. And we use different names for them. We call them measures, we call them skills tests, questionnaires, surveys, assessments. But rehab measures is what we call them here at the Shirley Ryan AbilityLab, where we have the database.

#### **SHARON:**

Can you give me an example of what a measure might be? What's a popular measure that people use all the time?

#### **DR. GRAMPUROHIT:**

Yeah, the Berg Balance Scale is a popular one among physical therapists, occupational therapists, and that one looks more like a test, you ask the person to do something, you ask them to walk, and you ask them to turn. And that one looks more like a physical performance test. And then some other measures look like questionnaires or surveys. So they take all different forms from mechanical gauges to measure strength to questionnaires and surveys. So there's a

big variety and Berg Balance is one of the popular ones that I think patients and therapists and doctors would all be quite familiar with.

**SHARON:**

And so when you're using measures in practice, are you using them to gauge where a patient is when you start working with them or to show how they're progressing or maybe not progressing in their physical therapy?

**DR. GRAMPUROHIT:**

Yeah, all of those, in order to even identify if there is a problem, if the problem is getting better, it's getting worse. So all of the various ways that you just mentioned, a measure can be used. A metric can also be used to show people how they are doing for themselves. So some of the items in a test can help people understand the different aspects of say their motor performance or their sensory performance.

**SHARON:**

So when a practitioner is looking for a particular measure, we all know that the Rehabilitation Measures Database is the place to go. Can you describe what exactly is the Rehabilitation Measures Database? What does it look like? What does it contain? What are some of its functionalities?

**DR. EHRLICH-JONES:**

So the Rehabilitation Measures Database sits on the website of Shirley Ryan AbilityLab. It's a compilation of over 500 measures. Currently, we're at 535 of these rehabilitation measures. It gives us information about the psychometric properties of the instruments. So such things as validity or reliability, their ability to help us understand the different aspects of somebody's ability to do things or not do things such as Dr. Grampurohit told us about. It's something that has been there since 2011 and has been steadily growing over the last 12 years.

**SHARON:**

So the database is more than just these measures, it also serves as a teaching tool for students, is that right?

**DR. EHRLICH-JONES:**

That's correct. We have a lot of different things that are on the website, like educational resources. So there's right now a bunch of webinars that we've done in the past that people can listen to that are measurement related. We are currently working on some more webinars or some more teaching tools that are a little bit shorter, that can give information about the psychometric properties. Actually, we're working on what reliability is at the current time. There's also information about statistics and some of the different aspects of the psychometric tools, or the psychometric data so that people have a better understanding of that when they're reading literature, or when they're trying to create a summary for the database.

**SHARON:**

Can you talk a little bit about how the students work with the Rehabilitation Measures Database?

**DR. EHRLICH-JONES:**

Sure. So we work with the faculty at a variety of institutions and in a variety of disciplines. And I'm sure that Dr. Grampurohit is going to tell us a little bit more because she's one of our favorites, that works with us quite often. But the assignment is basically for the students either to create a new summary for a new instrument that is not currently in the database, or an update. So if there's one in there, maybe that's very popular and needs to have updates from some new data that's out in the literature, that they would add that information to the current summary that is in there.

**DR. GRAMPUROHIT:**

Yeah. And I can add to that. So Dr. Ehrlich-Jones is kind enough to say that I'm her favorite. So thank you. But the reason I'm her favorite is because I learned from her.

So there's a lot of opportunity for students to learn, and come learn about the measures and the measurement properties as they develop these summaries. So there's a lot of growth opportunity for students to understand the measures to learn about the properties and to showcase their work on the website. So this is a public-facing website. So students can actually use the work that they publish for from these measures, on their CVs on their resumes. And it's a great opportunity for us in educational institutions to showcase our students' excellent work in parallel with some contributions towards literature that the Rehabilitation Measures Database makes.

**SHARON:**

So what you're saying is that for each measure, it may have been out there for a while being used. But there's a whole array of literature published on each measure that talks about did the measure work for this particular purpose, things like that. And so the students are asked to go into the literature, review what has been written, and then update these measures with that additional information. So it's not just you print out the Berg Balance Scale and that's it, you can also see how it's been used, what situations it's valid in and how people have been using it in the past, right?

**DR. GRAMPUROHIT:**

Yeah, exactly. Especially the different types of conditions for which that test is used. So for example, in stroke, in spinal cord injury, and multiple sclerosis, so the different conditions in which these measures have been used, you can go on the database and look at that. So that's a great educational tool.

**SHARON:**

So we spoke about the database itself, and the students that helped contribute to it and you have an advisory council, is that right?

**DR. EHRLICH-JONES:**

So we have a couple of groups that are helping us. So as part of one of our grants from the National Institute on Disability, Independent Living and Rehabilitation Research. We do have an advisory committee for that grant that helps us with information that we're putting onto the database. But we also have through the ACRM American Congress of Rehabilitation Medicine, a taskforce that works with us and helps us to decide about different areas that need to be bolstered in the database and who we should be looking to and who we should be collaborating with.

**DR. GRAMPUROHIT:**

And if I can add to that one of the really excellent features of having such an advisory council is it actually has people with disabilities and their care partners. And so having the database cater to what's important to people with disabilities, I think is a real strength and something that has really, given this team that has brought in grants from NIDILRR and such agencies the ability to cater to what people who have disabilities and the clinical community both want.

**SHARON:**

In addition to all that, I know that there is a whole host of other resources on the Rehabilitation Measures Database page that can help you get the most out of the measures when you go to select one. Can you talk a little bit about the educational materials that people can find there?

**DR. EHRLICH-JONES:**

So in addition to some of the videos that you can find there, there's also some resources to other types of databases that might also have some information that might be helpful things such as COMBI, or SCIRE, so some of the ones that are more focused on his particular disease entity or diagnosis, such as spinal cord injury or brain injury. We talked a little bit before in terms of information about these statistics, and can get a better understanding of that, and to look at some of the other places for people to look. So there's information about different journals and things like that which you can look for more information if they're looking for certain areas, such as physical therapy types of measures, or occupational therapy types of measures.

**SHARON:**

So when you go to the database, and I know this because I've been contributing in my own small way through developing infographics for some of the more commonly used measures, what you see when you land on that page is a search feature. And then there are kind of topic areas where you can look and see what's in there, can you describe the different topics that the measures typically fall under?

**DR. EHRLICH-JONES:**

So I think Dr. Grampurohit talked a little bit about that in terms of the type of measure. So whether it's an observational measure, it's a performance measure, patient-reported measure, if we happen to have the ability to post the actual measure itself, if it's out in the public domain, there is a link there on the summary, that's called instrument details. If we aren't able to do that there usually is information about how to get it by talking with the person who actually created that measure.

There's also information as we talked about earlier about the different populations. So it's kind of nice to know that this measure has been used in spinal cord injury has been used in people with amputation, as opposed to where I wish I knew whether it's ever been used before for a particular diagnosis. So that's helpful. It also talks about the age ranges, some, you know, measures are better for people who are younger pediatric people. If it's people that are older, they are older adults. So it'll give you that kind of information. It also will tell you, if you need any kind of special equipment that is needed to actually do that particular test, such as the Berg Balance Scale, do you need something to pick up off the floor? What do you have available when you're getting ready to do the test? So I think there's a lot of information right there upfront at the beginning of the measure, as you scroll through the measure some of the psychometric properties.

**DR. GRAMPUROHIT:**

Yeah, if I can add to that. There's also really good information on how to interpret scores for some of the measures. So every measure gives you a score. So what do you do once you get that score is always a question in the minds of clinicians and students and researchers and patients, as well. So what to do with the scores can kind of become an important aspect. And some of our really popular measures also have different languages in which these measures are available. So that's another important aspect where all the different languages in which that tool is available are listed. So those are some additional ones beyond what Dr. Ehrlich-Jones mentioned.

**SHARON:**

So it sounds to me like this database not only has the measures and they're backed up by research, and they serve as projects for students to continue to back them up and to continue to review them. You've got collaborators at different universities across the country. And there are all these other educational resources built right into the website about how to interpret the statistics and how to get the most out of the measures and some definitions of keywords used in the measures. So this resource, who looks at it? How, how popular is it? Really? I mean, we think it's the best. But tell me about it. Is it backed up? Is that a valid claim?

**DR. EHRLICH-JONES:**

Well, we actually do look at our Google analytics to see who was looking at it, we can see that people from over 160 different countries around the world look at it. I think last year, we had about 4 million hits on the site, we know from our colleagues that it's not only the students that find it useful and clinicians, but also our researcher colleagues, when you get ready to write a grant, you've got the information that you need to put into the grant about the different instruments you would like to use to collect your data and have the references right there for them. So we many times get a quick email from somebody saying, I just wrote a grant, thank you, because I had all the information I needed right at my fingertips.

**DR. GRAMPUROHIT:**

There are funders who might be looking at this information, as well as the funding agencies, who want to know what all is out there, in terms of measuring some of these important aspects of function.

**SHARON:**

So I know that a new feature of the database or the infographics, which I myself work on a little bit, can you talk a little bit about the infographics and what was the what was the thinking behind moving into that?

**DR. EHRLICH-JONES:**

So we had, so Dr. Allen Heinemann, who is the director of our department, and I had a conversation as we were putting together this grant that is funded by NIDILRR. And one of the things we were concerned about is that we really hadn't focused the database on the consumer on patients and people that take care of them as their care partners. And one of the things that we thought would be helpful is to provide them with information and language that they could understand about what that measure was, why their therapist or their doctor might be doing that particular measure the purpose of it, and then what the score actually meant, so that when the therapist told them, their score was a certain number, whatever it would have meaning to them. And we know that when people come to the hospital, or they come to therapy, the first thing that happens when they walk in the door is what happens, right what happened at that session, and they'll be able to then share that information with their family so that they know what happened and what the issues were and what the therapists or doctors were concerned with, and kind of keep track then from that day forward, as they re-measure them over time, how they're improving, with the treatments that they're receiving.

**SHARON:**

We take the measures and boil them down to just the basic information. What are why are you measuring this? What do I have to do? Do I have to walk? Do I have to bend? Do I have to do something else? And then what is my score mean? So that that person can like you said, Go home, tell their caregiver, this was my score, this is what I did. We're going to be retested later. And to follow that progress. I know that some of the measures vary, but some of them are a little denser and a little more sciencey. So the infographics are a great way to kind of boil it down and make it patient-friendly, so that they can get the most out of that, that therapy appointment and know what was being measured.

**DR. GRAMPUROHIT:**

And did you say they were free, Sharon?

**SHARON:**

The entire Rehabilitation Measures Database is free to access to anyone and I will put a link to the rehab measures database in the show notes to this podcast, of course, I'm curious as to this part, the Rehab Measures Database must be around for at least a little while because we know that there are more than 500 measures in it. So I'm wondering if you can tell me about how it started.

**DR. EHRLICH-JONES:**

Sure. So as part of a grant through NIDILRR that Dr. Allen Heinemann, was the principal investigator there at the time was our Associate Director, Trudy Mallinson, who is a PhD occupational therapist who felt that clinicians really needed help and being able to learn more about standardized assessments but really didn't have the time to spend on the internet looking for things and looking, you know, this versus that and, and what have you. So she came up with this idea. And so in 2011, we were able to put together a beta test for the database where we could actually have people go in and see that information, as we've talked about the bulk of that information for a summary that they could get that information fairly quickly, and be able to review that in the short amount of time that they would have to look on the internet. So from that day forward, we've gone so this is from 2011 till today, so that's 12 years that we've worked on updating and making things, doing things that would make things better for people who use the database. So we actually currently have a survey out there asking people for their feedback about the database. But we do listen to our users and find out what it is that they find helpful, what they don't. And we're always looking for more people to help us and to work on the database, creating summaries, reviewing summaries, and helping us make it the best resource available that we can.

**SHARON:**

I heard that every time you go to a conference, and someone mentions the Rehabilitation Database, the Rehab Measures Database, I should say, everybody knows exactly what we're talking about.

**DR. GRAMPUROHIT:**

Yeah. At many conferences, I think we've been to at least in the rehabilitation world, we've been to many different conferences. And there's always been very positive feedback and a lot of interest for us to make this database even more user-friendly, and better, and more resourceful because people have all used them.

**SHARON:**

I want to end the podcast by asking each of you, which is your favorite rehab measure, and why?

**DR. EHRLICH-JONES:**

Oh, my goodness, that's so hard to pick with 535 of them. I would probably say the Timed Up and Go, or what we call the TUG. It's a great measure that can, you know, how has the person get up out of a chair, walk eight feet, turn around, come back and sit down, tells us a lot about their balance and their movement. And it's, I think, something that we've used, and or at least I've used in some of the research that I've done, and it's always been a helpful measure to me.

**SHARON:**

And how about you Dr. Grampurohit?

**DR. GRAMPUROHIT:**

So I'm gonna reflect on my own clinical practice and on my own research, because the measure of my choice is the one I helped put together the summary report and did some research with. So it's called the Cerebral Palsy Profile of Health and Function. It's short, the short form is CP Pro. It's for children with cerebral palsy to measure their health and function. And it can be completed by their caregivers, parents guardians. So that's my favorite measure. Because I've contributed to it I've seen develop, it's like, it's been a fun process to see it from research to development to now on the rehab measures database being showcased. So I think I'm going to be biased towards this measure. It's also a futuristic measure. So looking towards adopting new measurement practices, and cutting-edge statistical tools that are out there for measurement have been used in development. So I'm gonna go with that one.

**SHARON:**

I want to thank both of you for sharing about the Rehabilitation Measures Database. I will be sharing the link to it in our show notes for the podcast and thank you doctors Ehrlich-Jones and Grampurohit for being guests on the podcast.

You can find the Rehabilitation Measures Database at Shirley Ryan AbilityLab at [SRA lab dot O R G forward slash rehabilitation dash measures](https://www.sralab.org/rehabilitation-measures). This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability Independent Living and Rehabilitation Research. You can learn more about the Center for Rehabilitation Outcomes Research by visiting our website at [SRA lab dot O R G forward slash research forward slash labs forward slash C R O R](https://www.sralab.org/rehabilitation-research-labs/cror). Be sure to follow us on Facebook at [rehaboutcomes](https://www.facebook.com/rehaboutcomes) all one word or on Twitter at [rehab underscore outcomes](https://twitter.com/rehab_outcomes). This is your host Sharon Parmet signing off.