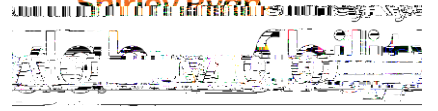
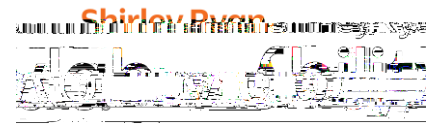


Shirley Ryan





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:

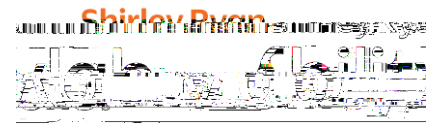
So we spoke about the database itself, and the students that helped contribute to it and you have an advisory council, is that right?

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



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.

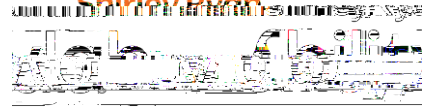
DR. GRAMPUROHIT:

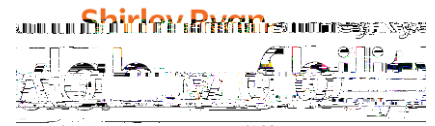
There are funders who might be looking at this information, as well as the funding agencies, who want to know what all is out there, in terms of measuring some of these important aspects of function.

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?

Shirley Ryan





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](http://SRAlab.org/rehabilitation-dash-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](http://SRAlab.org/research-forward-slash-labs-forward-slash-CRO). 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.