**2017 KT Conference:**

**Knowledge Translation Outcome Measurement**

The Rehabilitation Measures Database: A Tool for Promoting Adoption of Standardized Outcome Measures

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ANN OUTLAW: Let's move on to our next presentation. Now we'll hear from doctors Allen Heinemann and Linda Ehrlich-Jones from the Shirley Ryan AbilityLab. Allen Heinemann is from Northwestern University's Feinberg School of Medicine and Anne is the director of the Center for Rehabilitation Outcomes Research. Linda is a research associate professor in the Department of physical medicine and rehabilitation at Northwestern University Feinberg School of Medicine and assistant direct Fore the center for rehabilitation outcomes research. In 2012 doctors Heinemann and others received the knowledge translation activity award for the contribution of their Rehabilitation Measures Database and today we'll hear more about the database. Dr. Heinemann, are you ready to begin?

ALLEN HEINEMANN: Yes, I am. Can you hear me okay?

ANN OUTLAW: Perfectly. Thank you.

ALLEN HEINEMANN: Thank you to AIR and to the knowledge translation for disability and rehabilitation research center for the invitation to participate in this webinar. It's an honor to be included. We were very surprised that we received the award five years ago. Boy how those five years have flown. By way of background, this knowledge translation resource was initially funded by NIDILRR as part of a rehabilitation, research and training center on improving measurement of rehabilitation outcomes. Trudy Malinson was the inspiration for this project. She became aware that Jennifer Moore, who I believe is on the call today, was leading efforts at the rehabilitation Institute of Chicago to develop for allied health and nursing clinicians internally a repository of standardized assessment instruments, descriptions of them and identified best of breed that would help guide rehabilitation practice. Trudy became aware of that resource and thought the field would benefit from it more broadly and the rest is history. We developed the database as part of that now completed RTC but its legacy lives on thanks to the generosity of the Shirley Ryan AbilityLab. We moved to our new facility about eight years ago. And we moved to a new website as of one week ago.

ANN OUTLAW: Excuse me, Dr. Heinemann. It sounds like we're getting background noise coming from your computer. Could you make sure that your computer speakers are off and that maybe your cell phones might be on as well so if you could turn those off or on airplane mode?

ALLEN HEINEMANN: I have the speakers muted and I will put my cell phone onto airplane mode. We do have a couple of microphones adjacent to the projector we're using so we can see the presentation. If the problem continues after I go onto airplane mode which I've done right now we may need to turn off the projector if that problem persists, does it?

ANN OUTLAW: I can't hear it right now. I'm waiting for our tech folks to let me know. We're not hearing it now. I think we're good to go.

ALLEN HEINEMANN: We also moved the microphone away from the projector and hopefully that will help. The inspiration for the project was recognized by Jennifer Moore and her colleagues who realized that having a freely available searchable web-based database of outcome measures would be helpful for clinicians when they wanted to select appropriate instruments for screening to monitor patient progress and to assess the outcomes in rehabilitation care. Our primary focus was inpatient rehabilitation but subsequently the outpatient rehabilitation application to these instruments is also pretty evident.

The RMD helps clinicians by providing concise descriptions of instruments, how to use them at the point of care with patients. The goal is to help clinicians implement and modify a plan of care and ultimately improve their patients' outcomes by being able to monitor their outcomes closely. Large and growing literature on the clinical utilization of standardized instruments in rehabilitation. Here are a sample of articles, documenting the infrequent rate at which in the case of physical therapists not using the standardized assessments, the issues also problem with mental health practitioners. As -- monitoring patients progress, the same is true in oncology as well as nursing. We have company with other specialties not relying on standardized assessments.

Frequently clinicians are using experience to monitor progress. The problems with that is that it can lead to inaccurate identification of when patients plateau and when it is time to be discharged from therapy and limits achievement of maximal patient outcomes.

Background here, again Diane jetty has contributed to this as well as Schreiber and others, much focuses on physical therapy practice. APTA has been a real leader in promoting use of standardized assessments. For example, 93% agree that understanding research evidence is essential for providing patient care but 80% indicate they value research contributions. 80% agree that empirical evidence improves the quality of care and overall they understand they are expected to incorporate research -- in treatments that they provide to patients.

There are multiple benefits to integrating standardized assessments into routine care. Recommended for use in various clinical guidelines. Pretty clear evidence that implementing standardized assessments leads to improved patient outcomes as well as satisfaction and clinical decision making to help determine whether treatment plans are appropriate. Identifying weather patients are making meaningful progress and determine if a patient is at risk for adverse outcomes such as falls, impairment levels that don't improve and reduced prognosis. Also helps with clarifying diagnoses and when referrals are appropriate. Fundamentally patients like to see outcomes when it can be put in numerical terms. That compliments the I'm doing better but I can't see the results in very consistent manner. Certainly, as a physical therapy patient myself and having returned several times for shoulder and low back issues, when I'm asked to demonstrate range of motion or manual muscle testing is completed I'm left wondering how are they quantifying and how reliable are the numbers and I would have appreciated more specific quantification.

Well, if standardized assessments are so good how come they aren't used more often? A number of areas we attempted to address by the development of Rehabilitation Measures Database. Primary amongst those barriers is clinician-limited access to research. Not everyone works at a university setting or a larger hospital where access to public medical and other online resources is accessible. The curriculum that many clinicians have completed doesn't include thorough training on how to read and critique articles describing development of standardized assessments or treatment trials. Probably the biggest constraint has to do with time. Patients are expected to bill for services, expected to provide direct services, and digging through the literature synthesizing it is prohibitively time consuming. A resource that does that homework for them would seem to be of great benefit.

A number of ways to overcome these barriers have been described in the literature. Noted by these citations. We will give you the references at the end of the lecture today. Providing research that's summarized in an understandable manner was a recommendation from more than 20 years ago. Summarizing research evidence concisely for clinicians, the recommendation from more than 10 years ago and providing online resources that are accessible and available at the point of care that are not behind a cache barrier point also recommended.

We were guided by those considerations as we started to develop the Rehabilitation Measures Database. We organized focus groups to get input on what people wanted to see in such a resource. We included the usual suspects in medical rehabilitation, PTs, OTs, speech language, psychologists, nurses, among others. What they told us is they wanted psychometric information to help guide service delivery. So that meant knowing information about reliability and validity. Normative values, indexes of change related to sensitivity. Whether there were ceiling and floor he effects and the utility of the instruments are. They wanted the information about how to administer the tests on how to score and interpret them and if at all possible access to the actual test or score form or if it was proprietary, a link so they could acquire it.

Hits to the Rehabilitation Measures Database continues to grow. We have over 100,000 monthly site visits. Users live all around the world. And with the move to the new website last week we now have more than 400 instrument summaries that are available to users.

Our mission in delivering information to clinicians now is to facilitate evidence-based practice throughout the world. We'll do that by providing clinicians with high quality to assist in identify using the best instrument to assess and monitor patients who undergo rehabilitation that addresses physical and cognitive issues. Collaborators pay a critical role in this resource. We've engaged faculty and students in a number of rehabilitation science and nursing programs. Faculty use writing instrument sum reels at class projects. They're often very collaborative in nature. Students are invited to develop and update instrument summaries. Faculty serves as mentors. Provides an opportunity to learn psychometric terminology and learn skills in literature reviews and how to analyze them. Several have gone on to public reviews as well as taking advantage of the opportunities to provide brief summaries in several journals. Students also gain visibility professionally in so doing. They can have a publication that they be cite and include in their resume.

Linda, have I veered into your content here? She is signaling I can keep on rolling here. One more slide. This slide lists the programs with which we collaborate at the University of Illinois at Chicago just down the street. We're involved with PT and OT graduate programs, University of Indianapolis, as well as Duke university where PT collaborators are based. University of North Carolina, DePaul University in Chicago has a nursing program that works with us. Buffalo in rehabilitation counseling.

George Washington university. Occupational therapy and the University of north Texas we engage physical therapists and faculty.

LINDA EHRLICH-JONES: All right, thank you, Allen. I'll continue on talking about our professional organization collaborators. So, we've had association with the American physical therapy association, the evaluation database to guide effectiveness or edge groups. We've worked with the neurology group, the vestibular group, Parkinson's disease, multiple sclerosis, stroke, spinal cord injury and PT now. We've also worked with the American occupational therapy Association and the American Congress of Rehabilitation Measurement as part of the measurement networking group we've developed an RMD task force which that group we just met last week in Atlanta and will be having them to help us with our work as we go forward.

As Allen briefly mentioned, we do have collaborations with three specific journals. The archives of physical medicine and rehabilitation, rehabilitation psychology, and the American journal of occupational therapy. For the archives and rehabilitation psychology we have what we call a tear sheet. Meaning that it could be something that the clinician could actually tear out of the journal and take with them to their clinical site and use that information there. The front page of that tear sheet is a brief abstract of what the instrument is about, including one particular patient population. The second page contains the psychometric information and the administration information and any other information that might be of help to the person using that instrument. The American journal of occupation al therapy and nursing journal we've got a different type of tear sheet. Four pages in length and contains a case study. So, the most recent one that we have for American journal of occupational therapy is on the my vocational -- and contains a case study and goes through the use of this particular instrument and also talks about the interpretation of the results of that instrument.

We were going to do a little bit of a demonstration but it was a little bit on edge as to what would happen since we hadn't actually gone onto our new site until about Wednesday evening late into the night. But this is the new site that you will need to go to. Currently if you go to rehab measures.org you will be automatically redirected to the Shirley Ryan AbilityLab website. We have some screen shots here and we did create a couple of videos and we will be putting them on the actual database website so you'll be able to go through them for those of you who aren't familiar with how to use our website. But this is the site that will come up when you go to the URL that we just gave. The Rehabilitation Measures Database. You would click on the top bar where it says research and it would take you down to the bottom of the page where you would actually hit on searching the Rehabilitation Measures Database. If you know the instrument that you are interested in looking for, you would put that in that search bar that is listed there and for purposes of this demonstration we'll say the Berg balance scale and you hit the little magnifying glass. If you happen to know that you don't know the instrument but you happen to know which particular population you are interested in, you could actually click on one of these populations that could take you to the search feature as well.

So, when you get to the actual instrument, there are several things that you want to note here. There is the one bar in there that says instrument details. That's where you'll find either a link to an instrument or to -- actually find a PDF of the instrument if that's available for us to give to you. You can actually scroll down and see the different psychometrics underneath here on this particular instrument. And if you want to save this, there is a way that you can have your own personal dashboard and you can see that there are -- there is a link there for you to save.

We haven't lost any of the important information that we had on the old website so we still have the statistical terms and their use. In particular for students that are working with us, we do have the information there that talks about the different definitions of reliability, validity, etc. So that is still available. In addition, there is information about the people that have contributed to the rehab measures database. In addition, there is also a link to our educational resources that we had on the old website. So, these were videos that are available to use in your classroom that talks about the different aspects and psychometric properties and that's where we will put our additional videos about using the new website. This is just a graphic of the Google analytics so we can keep track of all of the hits that we get on this website. This happened to be over the life of the website so as you can see 6,373,000 in terms of sessions. We've had quite the few people come to visit us at this site. We did want to highlight the funding that has become available to help with keeping this -- creating this website and keeping this website maintained. As Allen mentioned originally, this was funded by the national institutes on disability and independent living and rehabilitation research through a rehabilitation research and training center. That focused primarily on the populations of stroke, spinal cord injury and traumatic brain injury. Since that initial funding we received additional funding from the retirement research foundation that Jenny Moore helped us with. This was to highlight different areas that were important to the older adult. So, things such as osteoarthritis, Parkinson's disease, urinary incontinence. Balance deficits and falls, and the paralyzed veterans of America educational foundation that we could add psycho social things and add more instruments related to occupational therapy and nursing by way of that grant.

Our future directions. Most importantly as I mentioned we do have a task force now that is part of the American congress on rehabilitation medicine measurement networking group that anyone can participate. It is an opportunity to help shape what is RMD is going to look like in the future. We've made some changes in the way that it's presented on the new website but we are always looking for more information and more help from our users as to what would make using this site easier. We're also looking for additional academic and professional collaborators. For those of you involved in professional or academic universities that would be interested in using the RMD as an assignment for a research or statistical course, to please let us know. And we're always looking for additional collaborators for us to public the journal tear sheet. Currently there are 42 tear sheets that are available through archives, rehabilitation psychology and the American occupational therapy journal and looking for more opportunities.

These are the references that Allen alluded to earlier in our presentation. And we certainly want to acknowledge again our funding sources and also to acknowledge our rehabilitation measures team, Allen, myself, Allison and Edith.

ANN OUTLAW: Excellent, thank you so much for giving us this update on the rehabilitation database. It is exciting to see all the work that you've done and continue to do with it. We have one question that has popped up and I want to encourage other participants to ask their questions in the chat box. The first question from Lisa is, is there a quality appraisal for the risk of bias process for measurement property evidence included in the RMD?

ALLEN HEINEMANN: This is a topic of some discussion last Thursday morning during the RMD test doing the ACRM meeting. There is one that's very suitable called COSMIN developed by a Dutch group that is very comprehensive. Because of its comprehensiveness it is very burdensome and labor-intensive to complete. I'm teetering on the edge of saying we ought to require use of those guidelines routinely. However, we're a little concerned about the burden it would place on students and faculty who are completing them. The reviews do undergo several levels of scrutiny. Faculty who review the assignment are reviewing it and critiquing it and grading it before we receive them. We do fact checking. Compare the numbers compiled for reliability, validity, MCIDs and the like to make sure they match up with the original source. We're limited in our resources in terms of how much interpretive fact checking that we can do. That's why additional volunteers are so critical. The hospital has generously funded part of a staff member to help with coordinating the collaborative opportunities. But we really do run on volunteer labor. We have received feedback on occasion about accuracy of some information. We've made some corrections or clarified information on rare occasion as a result of user feedback.

ANN OUTLAW: Sounds like you have a good process in place. We have a second question that has come up. First let me scroll up a little bit. I can't see it. Kathryn says congratulations and thank you for all your work on this great site. Wondering if you have looked at the usage data at all in terms of what measures, topics, etc. that users are searching? If she can see lots of fascinating opportunities from that. And also, the second part of the question is have you evaluated the impact of the site on practice behaviors or do you have any plans to?

ALLEN HEINEMANN: In terms of the instrument usage we have done a couple of things. We can look at hits to individual pages within our MD. By recollection is that the functional assessment is at the top of the list. People will get their directly but they will search for it and the search results would include the RMD entry and click through on us and appear as an outside visitor. So, we do have that information. We didn't present it today. In terms of we've also done a couple of surveys in terms of clinician usage of the information. Former project manager Jason Radd who is completing a post doctor fellowship at the University of Michigan is on the old site received several hundred respondents to a survey. He hasn't had a chance to analyze it yet but he collected data through the transition point last week. We have done a survey earlier of users. We have not submitted that for publication. We've looked at the kinds of users, purpose for which they are searching, the populations they serve and the like. That's something we hope to write up. In terms of the issue of how is this benefiting practice? I certainly hope it has but we've not undertaken an assessment of that. It's certainly a nice opportunity and we welcome the opportunity to work with anyone on the call today who would have an interest in that.

LINDA EHRLICH-JONES: It looks like someone is asking about the training for the students when they are involved in writing summaries. So, for students as well as anyone else who would be interested in writing a summary for the Rehabilitation Measures Database, we do have an author toolkit. I'm just proofing it right now. We've gone to making it look like what the new website looks like so we're trying to get that all together. But that toolkit basically explains how it is that the information needs to be gathered in order to be then put into the website. In the future, we also will be able to have a website available for each of our collaborators. So that they will have a specific username and password. So, a faculty member, hopefully who has a teaching assistant will be able to enter the student's information directly into the website and we'll go through our processes of reviewing the information, making sure all the facts are correct before it then will get sent on to being published onto the website.

ALLEN HEINEMANN: I see there are several other comments. Jenny Moore comments we've looked at traffic to specific summaries provided by the edge groups. These groups use the information in their publications as well. Kathleen Murphy asks is there anything that describes recommendations?

ALLEN HEINEMANN: Yes, the instruments reviewed by the edge groups do include a recommendation. Typically, they're fairly strong. We do not have summaries of instruments that have weak psychometric property. It's the choice between good and best depending upon the applications.

LINDA EHRLICH-JONES: Kathleen is also asking whether there needs to have some kind of requirement about a certain level of expertise on the part of the administrator of the instrument. So, we do have a training section on the website on each of the instruments. We actually are going to be expanding that area to give more information about what kinds of training and what not are needed. But there is at this particular time information about what needs to be done for that person to use that instrument, it should be available there.

ANN OUTLAW: Thank you so much. A little further up we had a question from Nicki that says are there tech row on the website? Like pedometers and they're increasingly used in both practice and research.

ALLEN HEINEMANN: There are a variety of different applications one could make of those devices. No, we do not have technology, solo technology kinds of applications. If one were using some sort of accelerometer to assist with measuring time up and go or other gate tests you could certainly supplement the tests with more precise measurements but that's not a focus of this database.

LINDA EHRLICH-JONES: Thank you. Some of the instruments are administered online but nothing was mentioned in terms of those two.

ANN OUTLAW: Excellent. Kathryn notes looking forward to seeing the data in the publications come out. Critical for advancing our understanding of these key interventions and impact on practice.

ALLEN HEINEMANN: We agree. Be happy to collaborate with anyone for whom it could be a professional publication. If any students are interested we would be glad to collaborate with them.

ANN OUTLAW: Excellent. The call is up. So, Joann asks if some of those technologies might be available on AbleData. Do you have any insights about that?

ALLEN HEINEMANN: Such as the instrumented tests that the other webinar viewer asked about?

ANN OUTLAW: I believe so. I think she is clarifying right now.

ALLEN HEINEMANN: It's possible they are on AbleData, a distinct area of information from what we provide.

ANN OUTLAW: Okay. Perfect. Yeah, she was talking about the pedometers and things like that. And another question that came in during our registration that -- for your presentation was once you have identified a system or organizational barriers like a change in organizational priorities or changes in funding, what are some successful strategies to address these barriers or changes? With the RMD was it difficult to -- how did you address the barriers to changing over to a new website for instance?

ALLEN HEINEMANN: Well, truth is we were originally planning to launch the new website in January. We were initially told a consultant would be transforming the data from the old site to the new website and the resources to do that did not materialize and we were left doing it on our own on an ad hoc basis. We were very careful in transferring the information to the new website, proofreading it. At the same time adding additional contents. No point putting it on the old site because that was going to go away. That work was mostly done, I think, by June. We had a number of formatting challenges which in terms of readability and font size and the like and display of information that took a bit longer to resolve. The delightful thing about the new site, it can be viewed on any platform. It recognizes whether you're on a Smartphone, tablet, or desktop computer and they display accordingly. The search function is very much improved. We are tagging instruments -- have the capacity to do that so they appear in search functions -- searches appropriately but because it's templated throughout the larger website, it is difficult to make changes just within this sub domain. So, we've had to work with others in the organization and the consultant to make those fixes. We weren't always the highest priority. So, at long last we're delighted that October 25th we finally were able to launch the new site. It was expensive. There were a lot of consulting time that went into planning, designing, implementing this. Just a little bit of off topic background. We looked at a number of mechanisms to make the website self-supporting. We were very appreciative to the TREAT center at the University of New Hampshire, I believe, that had an R24 funding for NIH to help rehabilitation investigators commercialize their products and walked us through a business development plan. That was helpful but the funding sources were very limited. We're very thankful to our employer they welcomed the opportunity to bring the website into the larger hospital fold.

ANN OUTLAW: It's a wonderful-looking website. It does seem a lot of work went into getting that up. Kathleen asked how many months and years did it take to remount the database?

LINDA EHRLICH-JONES: A little bit less than a year. Probably eight or nine months and in addition we did have some volunteers. We have routinely had volunteers that work with us. Many of them are students. Many of them have done a summary as part of a class assignment and have interest in continuing with that. So, we've had a couple of graduate students, we've even had an undergraduate student that was interested in doing this kind of work in terms of the psychometrics. But in terms of transferring the data, we had about, I think, four or five people at the same time working on it so we had multiple double checks and triple checks to make sure that all the pieces of the old website were correctly transferred. It was -- they were a very hard working group.

ANN OUTLAW: Yeah. Kathleen says I agree. That is a tremendous effort to get all of that up to speed. It looks like those are all the questions that we have. We're a little bit early for our scheduled break but we can go ahead and do that. Thank you so much, Doctors Heinemann and Ehrlich-Jones. To all the folks that are in the Adobe connect room. We'll take a break until 25 after the hour. So thank you so much and join us back at 25 past.