**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

Quantitative Measures to Assess Community Engagement in Research

Deborah Bowen and Melody Goodman

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>> DONNA MITRANI: Our next presenters are Deborah Bowen and Melody Goodman. Dr. Bowen is Professor in the Department of Bioethics at the University of Washington, working on studies applying technologies to improve people's understanding of their risk for disease and interactions with healthcare and health promotion. Dr. Goodman is an Associate Professor of Biostatistics in the College of Global Public Health at New York University, an expert methodologist with a large toolbox that includes knowledge of a broad array of analysis techniques.

Their presentation, Quantitative Measures to Assess Community Engagement in Research, will highlight the results of a systematic review of stakeholder measures, and results in developing a better method of engagement. As a reminder, if you have questions during the presentation, please ask them in the chat box. After the presentation, I will lead an interactive discussion with reactors and conference participants. That said, Deborah, are you ready to begin?

>> DEBORAH BOWEN: We're ready.

>> DONNA MITRANI: Thank you.

>> DEBORAH BOWEN: Good morning, or good afternoon by now. Thank you for asking us to present. I think the morning ‑‑ early afternoon's presentation allows us to follow quite nicely, because we're going to talk about our efforts to develop specific quantitative measures of how engaged stakeholders are in the process of working together with academic folks on research projects. So we're going to talk you through our steps. And we're going to show you data and findings that allow us to be able to develop a strong instrument that would be able to be used across projects and would inform how engaged people really feel, and where their engagement processes lie.

So, first, here are some colleagues that have actively participated in this research, and partly this is a good slide to have because if you need to get in contact with me or with Melody for any follow-up activities like I'd like to use your instrument, can you send me a copy, or I'd like to get a copy of your paper, please go ahead and email us and stay in contact with us and use these emails to do so. So the earlier presenter has done a great job of introducing this topic. We started this plan several years ago when we first sat down to define how we'd like to measure community engagement, meaning how engaged people are, how involved, and how excited and how much they're willing and ready to play with us in the academic community partnership realm as full partners.

So we pulled this definition from the various definitions that are out there. This is a field that as you know, if you've read any of this stuff, is defined in multiple ways. And some of them are contradictory a little bit. So we had to choose a definition that we thought best encompassed what we defined as community engagement. A key element of this definition includes the words collaboratively, groups of people. The affiliation, what is a stakeholder really is an entirely separate question. Where do stakeholders come from, how do we find them, how do we work with them, who should they be when you sit down to design a project in increasing use to decide about cesarean section, who are the stakeholders in such an effort, who should they be, who might they be, who wants to play a role as a stakeholder is a very complicated question.

But most of us believe that community engagement is a powerful tool for doing better research. And that's the fundamental reason for doing community engagement, as I think the earlier presenter has spoken about. Community engagement takes time. Gosh, it would be so much easier if I could sit in my little windowless office and plow out through research activities all alone. It's mostly very easy and potentially very wrong. What community engagement does for an academic person like myself is to ensure that some of these good things happen, or help them to happen.

We ask better questions. We hope that we create better sustainability interventions. We increase the relevance of the project as stakeholders if we understand it. And I'm speaking about “we” meaning we, the academics, but certainly all of us together. That trust‑building activity is key, as we've heard several times already today. There are resources that community members and stakeholders have that academic folks don't have. And so combining together with us is often a really great strategy for getting the work done that you want to get done.

Underlying community engagement is a sense of reciprocity. I think in the way that we define it. And so we've struggled over the past several years to understand what reciprocity really means and to apply it. Not always easy, not always fun, but certainly I'm ultimately hopeful, rewarding. Here are the kinds of things we decided early on that we wanted to know. What happens when you initiate a community‑based project? How does engagement develop? And then does engagement change our outcomes?

In other words, if we're doing a project to change cesarean rates, if we work together with community members to effect that change, will the outcomes be better? We hope that they will. We believe that they will. But mostly scientists like to look at data about whether or not they are. (Chuckling) So being able to evaluate that ‑‑ in other words, measure it and relate it to some other measure of outcome ‑‑ is a key for us. We needed to find tools to measure community engagement in our stakeholder groups and better understand the engagement process through that measurement.

Here are the activities that we've been working on this topic over the past four‑five years. We first ‑‑ like any good scholarly effort, we sat down and did a review. We wanted to understand what the tools were that were out there published now. We then sat down to develop a new measurement, because we didn't see the tools that we wanted. We wanted a more specific tool that measured the quality and quantity of engagement, and the stage of engagement, as well as whether or not someone was with the program. And then finally, in order to advocate for the use of this measurement around other projects, our projects and other people's projects, we felt that we had to understand how the measurement was performing.

And so in terms of confession, my background is as a psychologist. Melody's a biostatistician. Together those backgrounds allow us to understand the psychometric, performance properties of a measurement. We will hope at the end of this effort we will be able to claim the tool that we're developing as a good, solid, reliable, valid tool. And that goes a long way with researchers. It goes a long way in getting your PCORI or NIH grant, or Canadian federal grant, or any grant that must be reviewed by a peer review process.

It says we have a hammer we trust, and we're going to use that to measure something that is important to the project. So that's our mission, encapsulated in these three elements. First, we conducted a systematic review. So a systematic review is a review of the existing published and publicly available, and otherwise available if you want, literature on what tools are available. We knew that tools existed. We knew that people were using methods of evaluating their partnerships. We didn't know what they were. And we realized as we sat down with colleagues and discussed this that people had different views, kind of like the elephant joke, right?

Where people who can't see put their hands out and feel different parts of an elephant and feeling the trunk is completely different than feeling the tail. You'd believe that you had your hands on a different animal if you felt the trunk, tail, or leg of an elephant. In the same way, we found everybody had their favorite measure but nobody understood which one was better or which one we would choose, one over the other. Or why one would choose measure A versus measure B. When you find yourself in that setting, for me, you have to do a systematic review.

Everybody measures something, but we had to figure ‑‑ directly head‑on compare these measures to see which one was the strongest methodologically, which one had the most data behind it. Maybe the work had already been done. Maybe we didn't need to develop a new measure. That would be great because we could go ahead and use the hammer that had been developed and found reliable and valid. Well, here is what we found. And I'll give you the reference to this or send it to you if you want to email it. It's published in a journal but I can send you the PDF.

We found basically, the measures that existed in 2015 sorted themselves into two camps. One camp were counts. People counted things. People love to count things. And I think the previous presenter has alluded to those measurements. Counting people who show up at meetings, counting attendance, counting the numbers of people who do things, who participate in events or who try to have input is one way that engagement has been measured. And there are, as you might imagine, pros and cons to that count methodology.

A second way is to try to measure some construct that is related to or that is seen to measure engagement. And I'll give you some examples of those. So we might measure perceived involvement, for example. We might give people a scale and ask all the stakeholders in a project to rate how involved they feel on a scale of 1‑9 using six questions that measure different kinds of involvement. Do you feel like you're involved in this project design and evaluation, and interpretation, and publication, and use of tools, etc., etc.

There were several of those projects and papers that evaluated measurement tools that measured a construct or two that are relevant. What we found in a nutshell is that the measurement properties of any of these measurements were very poor. In other words, in our PCORI grant, we couldn't claim that any of them in the years that we evaluated previous to 2015 had any sort of ‑‑ what I would call psychometric data associated with them. People rarely reported inter‑rater reliability. In other words, if I measured something today and I measure it tomorrow and I measure it among different kinds of people, would I expect to find the measurements similar or different?

And what did I find? Well, nobody had really looked. Nobody's really evaluated that. Nobody's published it, anyway. Similarly, in terms of validity, how do I know that the construct of perceived involvement ‑‑ how do I know that that's the key construct? Well, one way one does that is to look at its relationship to another measurement that is actually a measure of engagement. Nobody's really reported that as well by the time of our review. Mostly nobody looks at the relative impact of engagement on outcomes, which was really our key question, our essential question.

Does engaging stakeholders in a research project make it a better research project? Certainly these were not tracked over time. Often they were single measures, basically stuck into ‑‑ it looked like to us they were stuck into a paper to say yeah yeah yeah, we measured that stuff. People are into this project. Let's move on. And we didn't really get a sense of how engaged they were, whether or not that engagement continued over time, or whether it was relevant to the choices that got made in the project. And these were all questions that we felt like we wanted to answer.

Specifically, here are some examples of the counting method. These are in our review and you can take that review paper and take a look at it and get a sense of whether you like these measures. We felt like they were very unsatisfactory. They're certainly part of the answer. If people don't show up at your party you're pretty much not having a party. So we thought that some of these counting measures were useful, but they didn't tell us the whole story.

Similarly, here are some of the construct method examples. And we felt the same way about these. They are certainly telling us part of the story, but they're not giving us a measurement of engagement. And besides, for most of these measures we have no full understanding of whether they measure what they say they're measuring or whether they're measuring it in a reliable fashion. We simply didn't know because people didn't report it. And again, being scientists and being people who write grants for a living and generate research dollars for a living, we felt like it was both our job and responsibility to be able to answer some of these questions about a measurement tool, a hammer we would get behind and use repeatedly in all of our different projects and advocate for use among our colleagues.

We felt like the literature from our systematic review was inadequate. That's usefulness of a systematic review for figuring this out. We had to start somewhere. We had to understand where we were starting. So, we sat down. And from here I'm going to ask Melody to take over. We began to think about well, okay, if the literature is inadequate and doesn't give us what we need, what would we want to see in a measurement tool? What would we want to measure? How would we phrase that measurement tool and then what would we do to develop it? Melody?

>> MELODY GOODMAN: Yes. So, as Deb mentioned, this stemmed from our own work trying to evaluate some research that we were doing as part of a center to address cancer disparities. And the center used community engagement approaches. We had lots of great anecdotal evidence about how engagement worked. When our funder asked us to show how engagement impacted the science, we didn't have a measure of engagement. There was no way to show an association with that. So we worked with our Disparities Evaluation Advisory Committee, which we call DEAC, and we looked for engagement principles.

We found the principles of community‑based participatory research, and for patient‑centered outcomes research, and some that have been developed by community campus partnerships for health. There was a lot of overlap. We ended up, with the help of our community partners, agreeing on the 11 engagement principles that you see on the screen. And I wanted to note we were looking for things that we could measure, not just all aspects of engagement. There may be things missing, but these are the ones our community partners felt were important to think about when you're measuring the impact of engagement.

Focus on relevance and determinants of health, acknowledge the community, disseminate findings and knowledge to partners, seek and use the input of community partners, involve an iterative process, foster co‑learning capacity building and co‑benefit, build on strengths and resources within the community, facilitate collaborative partnerships, integrate and achieve a balance of all partners, involve all partners in the process, and plan for a long‑term process and commitment.

We also were thinking about how do we classify the levels of engagement seen. And this figure is from a commentary written by myself and Dr. Thompson thinking about how do you classify the levels of engagement. We put them in three bins ‑‑ nonparticipation is really where we do more outreach and education. You're not really engaging the stakeholders in the process. What we call symbolic participation where sometimes you bring people to the able but don't let them say anything. And what we hoped for, engaged participation where people come to the table and are active participants in what's going on.

So, Deb mentioned that we have a PCORI grant, Patient‑Centered Outcomes Research Substitute. PCORI has been interested in methodology around engagement and trying to assess the science of stakeholder engagement. And our grant was really to take that measure that we had developed and to validate it but also to shorten it and make sure it was feasible for people to implement in other studies. Our grant has four specific aims. We wanted to examine the validity of each principle.

We're trying to measure on two scales, one that measures quantity and one that measures quality. From our community stakeholders, people talked a lot about you can do something poorly really often, or you could do something well and not so often. They felt we needed to assess both quantity and quality. We used the standardized process for expert validation from advocacy groups, patients, families, and other key stakeholders in the process. We also wanted to examine the psychometric properties, specifically reliability and sensitivity to change, and validity with other key measures that were out there.

That could help us determine cutoff for levels of community engagement. Our third aim was to really create a shorter version of the measure that could be used in studies. And then our fourth aim was more an implementation setting where we're going to work to implement our measure in current patient‑centered outcomes research to really see how it works in practice. So, our first aim was really to do content validation. So we used a Delphi process with a group of experts.

We used web‑based surveys and round four was a two‑day‑in‑person meeting. And our final round was another web‑based survey to reach consensus. We also are going to talk a little bit about, sort of, the participant surveys that we're using to get some data for psychometric analysis. And throughout this process we wanted to make sure that engagement was key. So we report quarterly back to the disparities elimination advisory committee, our board that's been working with us for several years as we've worked to develop a measure.

And then we just recently finished doing cognitive interviews, which is people using the measure and making sure things read right and people understand what we're trying to ask them and can respond accordingly. So, the Delphi technique, for those of you who don't know, is a method for collecting and organizing informed opinions from a group of experts. We used an iterative process often used in survey instrument development. The approach is appropriate to ensure feedback is obtained from all stakeholders, with all experts being treated equal.

This was really important because we do have academic researchers and community health stakeholders as experts on our panel. We wanted to make sure that the voices of academics didn't appear louder than the voices of some of the community health stakeholders. (Clearing throat) When we did the in‑person meeting we also used some live pollings that we could really see where things were in real time. And we really think the use of the Delphi technique afforded us to user a stakeholder‑engaged approach, which really had not been done before.

The responses to each of the Delphi surveys were analyzed by the project team. And then we returned it back to the Delphi panelists for further consideration and their response. Even though the goal of the Delphi process is to reach consensus, we did not want to force consensus. So it was important for us to figure out if there were spaces where consensus could not be reached. So once we reached consensus, subsequent iterations of items are shown back to the panelists until we get to a version where we think we are final.

Panelists are encouraged to reconsider their responses. When they get their Delphi report, it shows them their responses and an aggregate response from other panelists. They can change their response or they can decide to hold firm and think that they really disagree with where the consensus is going. Our outcome was to reach 80% consensus among experts. We did not force consensus. For items where consensus could not be reached, we discussed those at the in‑person meeting to get a sense of what those nuances were. If it was worth missing, or other things that wouldn't allow us to reach consensus on some of these ideas.

Ultimately, we were able to reach consensus. So our expert review panelists come from all over the country. You'll see from St. Louis because that's where our community work started. We have people from Kentucky, North Carolina, and the like. We started with 19 members of our expert review panel. 18 of them stayed engaged throughout the entire five‑round process. Ten of those were community health stakeholders and eight of those were academic researchers who do community‑engaged or patient‑centered research.

So, one of the things that's really important to mention is that we thought because engagement principles had existed in the literature, that it would be fairly easy to reach consensus. And one of the things we realized really early on is that not only did we have to reach consensus on the engagement principles, but we had to reach consensus on definitions for the each of them, making sure that we agreed on what each of those meant.

As we moved to phase two, we are recruiting participants that are going to take four web‑based surveys over a couple of months. We're looking for people who have been community health stakeholders, who have participated in community‑engaged research studies. Participants can complete these surveys from home, from any mobile device that has an internet connection and they can start and stop as many times as they can. We're giving people Amazon gift cards for completing the surveys. Because there are so many there's basically increasing incentives the longer you stay in the study.

One and two you get $10, but $25 for both. For three and four you get $15 each or $40 for both. This has been beneficial to make sure that participants stay engaged and are completing all of the surveys across the four different ways. This slide is a little bit outdated, but it was where we were at the time we submitted the presentation. It says we have 123 people enrolled. At this point we have almost 300 people. We're getting close to our goal target of 500 participants. As you can see there's variability over the number of people who completing the surveys, but we're making sure if people completed one, they know about completing subsequent surveys.

One of the things that we are really trying to keep track of is making sure that we ‑‑ originally we thought we would only recruit participants from St. Louis and Seattle. But as we started doing this work we realized there may be geographic variability and it would be better to recruit nationally. We're mapping where our participants come from to make sure that we are targeting people in spaces where we don't have any participants yet at the moment. This is a bit outdated, but you can see most of our respondents are coming from the St. Louis area, a bit from the east and west coast areas.

So currently, which universities are represented in our survey, we have a bunch of people from Washington University in St. Louis where I used to be, and also St. Louis University, the University of Missouri. Some participants from NYU, Northwestern, University of Washington, Penn State, lots of institutions represented by one or two participants. But these are the ones that had more than five participants from a specific institution.

So really, we're interested in the psychometric properties of the measure, or the items that measure a single engagement principle, are they internally consistent with each other, measuring the same thing. We used alpha, a measure that goes from 0 to 1.7 is considered acceptable. We also looked at how well our measure is correlating with other measures that we assume that it potentially would be correlated with. There is no gold standard measure, but we have assessed some other measures of engagement to see how our measure will perform against that measure.

So when we have the 11 engagement principles there's three to five items that measure each engagement principle. We have them on a quality and quantity scale. This slide shows that all of those items are internally consistent. The four items that measure engagement principle one have a high internal consistency, meaning it looks like they're measuring the same thing, which is an important property of good scale. Now we've revised our measure based on our Delphi process. And so we went from 11 engagement principles to eight. We dropped four. Some of them are combined.

We added one engagement principle around trust. That was one of the things that our original 11 didn't have that our stakeholders felt were important. As you can see the number of items in each engagement principle is changing over time. We're in a place where we have about three to five items that assess each engagement principle. It still shows strong internal consistency. The items that are measuring our principle are related to each other and look like they're trying to get at the same construct.

Because there was no gold standard measure of community engagement, in order to evaluate, we wanted to look at how it performed against other measures. We looked at the medical trust scale. Even though it's measuring different constructs, we thought our measure should be at least associated or correlated with those measures. We also looked at the partnership assessment and community‑based research. And another measure that was proposed that looked at community partnerships particularly in HIV/AIDS trials.

And even though our sample size is still the small sample, you can see that we're already starting to see some significant results. We think once we have our full sample size we'll be able to show how our measure performs against other measures. One of the measures that we thought it was important, the community engagement research index. We're really looking at how our measures compare against that. And there's also a correlation self‑assessment measure that assesses trust.

Because we newly added that, we felt it was important to make sure we validate the trust part of the measure that we are developing. So we are still recruiting. If there's anyone on the call that would be interested in participating in our study or have community partners that you think would be great for our study, our link to complete the screener is in the PowerPoint. You complete a really short screening instrument that tells you whether or not you are eligible to participate in the study.

We're looking for people that are over 18. You have to have access to the internet to participate. We're looking for people all over the country. We ask that they have participated in some community engaged study. We're looking for a cross section. They don't have to have had a lot of engagement, just some minimal engagement in community‑engaged research. The screener will test for that. And that's where we are. So I guess we'll take questions?

>> KATHLEEN MURPHY: Thank you so much, Melody and Deborah, that was a fantastic presentation, very interesting. At this point we're going to start a Q&A discussion. Before we begin, I wanted to remind people and encourage you if you have questions or comments for Melody and Deborah, please do not hesitate to type them into the chat pod and we'll make sure to address them at this time. To start us off, or before we begin, I want to reintroduce our reactors today.

Shauna Crane, Susan Magasi, and Rylin Rodgers. Before we turn over the discussion to them with some questions that we had from ahead of time, I want to address some questions from our chat pod. The first question comes from Rosmin. Is there a paper that describes the Delphi technique that you can share? Melody, I believe this is in comment to one of your slides. I'm wondering if you could describe any papers that are out there and how folks might access them.

>> MELODY GOODMAN: There's a lot of papers about the Delphi process. We haven't seen many papers about using the Delphi process to do stakeholder engaged measure development. We just submitted a paper on our own work. But I'm happy to share with people. There's a really good book. I can't think of the name. And some key papers on how to use the Delphi process in health research.

>> KATHLEEN MURPHY: Thank you. And another question that we wanted to bring up to both you, Melody, and Deborah. Just wondering, is there a way for folks who don't necessarily have access to an academic library to access for systematic review?

>> DEBORAH BOWEN: If you email me, I'll email the PDF. I appreciate that access to an academic library is what gets you the PDF. So I'm happy to email you the PDF if you email me using the email that's in the slide set.

>> KATHLEEN MURPHY: Thank you so much. And again, folks, if anybody has any questions or comments that they would like Melody and Deborah to address, please do not hesitate to type them into the chat pod. In the meanwhile, I want to turn over the discussion to our reactors. And our first question is for Shauna. Can you share an experience from when you participated on a stakeholder panel that fostered co‑learning, capacity‑building, and co‑benefits for all partners?

>> SHAUNA CRANE: Thank you. As before with the first presentation, my perspective is just a little different because we're not doing research here. We're training stakeholders of how to work together on advisory groups, or panels, or that sort of thing for states, for different organizations. But an activity that we do which has really fostered a co‑benefit for all partners including the sponsoring agency and the stakeholder group that's providing them feedback is to do a priority‑setting activity. And we use a method called a consensus workshop that comes out of the TOPS training program, Technology of Participation.

You use a sticky wall and cards. And there's great involvement from every single person in the room, every stakeholder, so that regardless of their role on the panel, or what capacity they're filling, whether it's a parent, or an agency member, or some other thing where all of these people come together in an advisory or stakeholder capacity, their voice is heard. And the priorities for the group to work on over a given period of time are a combined effort. And so that consensus workshop, priority‑setting, is something that really helps foster that cohesiveness as a group and a shared mission and purpose for stakeholder panels.

>> KATHLEEN MURPHY: Thank you so much, Shauna. Moving right along, our next question is for Rylin. Can you share an experience you had that excelled in having a true partnership with stakeholders, and how was that relationship built?

>> RYLIN RODGERS: So I really appreciated this presentation because of the real frame about how do we think differently, and how do we move past counting to really look at the quality and what matters. From my perspective, the richest experience in terms of having a true partnership is when stakeholders have been engaged from the very beginning, so even project design, really framing what the question is, being part of the grant application. I think those beginning contributions in a leadership/partnership way transform the work in making sure that whatever the point of inquiry matches the needs of the population that's being addressed.

And it also transforms the work in terms of some of the increased engagement over long‑term studies. I loved the question earlier about how do we maintain ‑‑ for the long haul. And I think a key part of that is making sure that the questions being asked if our research are informed from the beginning, and really in many cases, designed in partnership with the stakeholders. I think that ‑‑ in the order and the foundational premise ‑‑ in a lot of ways, I think of it as the promise of PCORI and starting to see it influence our work across the different funding models.

>> KATHLEEN MURPHY: Thank you, Rylin. I'm curious, Shauna or Susan, if either of you have an experience you could share in terms of where you formulated a partnership with stakeholders that's really excelled.

>> SUSAN MAGASI: This is Susan, and the work that I do is primarily looking at promoting healthcare justice for people with disabilities, so looking at issues of healthcare access, healthcare quality, and healthcare outcomes. And that really emerged from a long‑term partnership, all research done using a community‑based participatory approach, starting with initial conversations just like you were saying about a community‑identified need that the research partners and the community partners had a shared commitment to and passion to.

And we have used that not as part of a research study, but I would say as a line of research that we have been able to build and nurture over the course of ‑‑ I think I counted last night and it was eight different research studies, each one from a different funding organization, but that we've been able to build on, starting from some really exploratory work, just understanding what the community experiences and needs were to progressively more intervention, research, finding ways to build evidence‑informed interventions to meet and address those needs.

So, really seeing the community as those cocreators of the research questions where we bring our expertise in terms of research methods, approaches, or how do you construct an intervention. But they are driving it based on the community needs, keeping us honest for community relevance and impact.

>> KATHLEEN MURPHY: Thank you, Susan. And while we have you on the line, I'm going to turn it over to you. So the stakeholder engagement continuum includes outreach and education, consultation, cooperation, collaboration, and partnership. How would you measure stakeholder engagement in your project?

>> SUSAN MAGASI: It's a great question. And as I was listening to the presentation and even thinking about getting ready for today, realizing, you know, we probably haven't done it all that well. You know, we say we do a community‑engaged participatory approach, and I think we really do. But in terms of measuring and documenting, it's sort of our driving ethos and we've documented it qualitatively and with a shared commitment. But I know in our ‑‑ from previous, like, grant applications, we've been frustrated of like, gosh, why don't they recognize, you know, that we do this really well and that maybe some of the groups who are getting funded are newer to it, or doing –

>> And we've documented it qualitatively and with a shared commitment, but I know in some previous grant applications, we've been frustrated of like, gosh, why don't they recognize, you know, that we do this really well and that maybe some of the groups that are getting funded are newer to it or doing it in a more lip service kind of way. So I'm really intrigued by these tools that you've been developing and I've been, you know, thinking as you were presenting about, oh, we can use these tools both to better frame the fact that we do real community engagement, but then also I would like some thoughts from the presenters too on if there are ways that granting agencies or grant reviewers might be able to build off some of the tools that you're creating so that when they are evaluating proposals, that they can recognize, you know, is this true community engagement, or is it some of those other models that you presented in terms of community engagement, invite you to the table but kind of smile and talk and don't really use those. But I'm interested in what you think and how agencies might use this.

>> This is Deb Bowen, the granting agency is comprised of two kinds of chunks of people. One is the agency itself and the policies and the official line items for how they do business, and that one is a little harder, I think, because I mean, granting agencies tend not to require the use of a particular measurement, for example. That's not usually built into, say, the RFP. You know, you must use the Goodman measure of community engagement, period. Sometimes it is, but that's very rare, relatively rare, in my experience. Where I think we can make some dents in this and maybe even help you with some of your previous frustrations, is the idea that when you say something is true, right, in a grant proposal when you say something is true, my question as a scientist and as a reviewer, which is the other camp, my question to you as a reviewer would be, okay, how do I know that's true? Are you telling me this is true, or are you ‑‑ and again, not that scientists are the end all and be all, but a scientific publication gives your statements weight, and that's one of the goals here in the past few years of work on our part.

It's to be able to ‑‑ when we did the systematic review, we thought, well, certainly other people have done this, right? I mean, everybody is excited by this topic that we know, so of course they've developed measures that we can cite things and not just a web link, not just a Google search, but actually a peer reviewed publication which is the trade of the realm here, that's something we have to cite in order to say something is a true or not true statement. It helps make our case stronger if we're able to cite a peer reviewed publication.

When we found that we could in very few cases cite a great strong peer reviewed publication that looks at how well the instruments were performing, we thought, oh, oh, this means we've got to do the work ourselves in order to do that, in order to convince a molecular geneticist that we're ‑‑ I mean, that's the measure of truth in science is to be able to cite other people's work that uses the same tool. So what we're hoping for our work and for your work and for anybody's work is that the more emphasis we place on the scientific background behind these measures, the more ‑‑ the stronger they'll be and the more you can get your grants by saying, yeah, I went to the Goodman measure and I cited it and I used it, and so I know it's true because Dr. Goodman has a good tool and she's proven it and published it in a scientific journal. It sounds sort of superficial and silly, but that's actually the way the game works. So that's what we're hoping.

>> Thank you. Rylin, turning to you for a second, I'm curious, in your support of projects at your institution, have you heard how stakeholder engagement has been measured across projects there?

>> RYLIN RODGERS: So I should disclose my sort of split hats, and I was recently at an academic setting doing research around care coordination for children with medical complexity and now I've moved to AHD where, you know, our members are doing research around the country and now I'm wearing sort of a policy hat. So now that I did my disclosure, I've lost the train of the question, so could you reframe that for me?

(laughter).

>> DONNA MITRANI: Of course. Of course. I'm just asking in your experience in either of the positions you just mentioned, how have you measured stakeholder engagement in projects that either you've worked on or your organizations have worked on?

>> RYLIN RODGERS: That's a really great point and it really builds off the last response in that in some of the work that was funded through HRSA and maternal and child health, they would in fact call out measures which were required, so it builds on the piece of the real critical point in that case they were really interested in using tools that were created and funded in partnership with an organization called national family voices which works with that population of families.

So it really speaks to the value of having a tool that has been validated and has some standing and, you know I'm frankly intrigued by the idea of a larger measure that could be used across all populations and almost have based on my previous experiences seen the nice kind of outcomes of having tools that people were using and seeing how they worked across different sites and different states and really moved the needle in terms of how far authentic voices were engaged ‑‑ were engaged, it speaks to how critical this is and what can come from it.

On the flip side, there were other projects that were funded that not only didn't call for anything, kind of weren't interested in hearing about it, so that sometimes is a challenge. I remember having the fun experience in academia of multiple submissions and edits for different journal articles and being personally challenged by some feedback to remove the stakeholder portion of why we got to that process and why certain questions were asked in terms of not being valuable, so this speaks to changing the dialogue and moving things forward, not because it's the nice thing to do, but because it's a way that we can do really great work.

>> DONNA MITRANY: Thank you. So going back for a moment to some participant‑driven questions, this question come from Eileen: How do you keep measurement tools relevant, conditions on the ground change? Melody and Debbie, I'll open that up to you first, but Shauna, Susan and Rylin, if you have anything to add, please feel free to chime in.

>> MELODY GOODMAN: This is Melody. I think we're really trying to create a generic tool that could grow a partnership over time, so our tool doesn't have a disease focus and it doesn't have a population focus, it's really just asking about things related to those principles of engagement and we am imagine that some projects will start off with minimal engagement but end with lots of engagement, maybe you'll stay at minimal engagement throughout your study, we're developing a tool that measures tool as a process if that makes sense.

>> Any thoughts?

>> I think the frame of the tool is wise, to my point about language, that how individuals and families would identify shifts over time appropriately as it evolves and we're listening to what individual preferences are and in some of the survey measures the outdated language became a barrier to engagement and appropriate sort of measurement to how people saw themselves.

So if they might see a term used around sort of a family's experience of disability or difference that wasn't reviewed in the same way that they currently were framing things, they may not answer and move forward as a consumer respondent in that way, so I like the broader perspective.

>> DONNA MITRANI: Thank you. Actually, would you mind, before we move on, would you mind clarifying what outdated language you're referring to?

>> So there's been this sort of often shift and almost ‑‑ I don't know whether controversy is the right word, but whether in the population, whether a child with a special healthcare need, with a disability, child with medical complexity, or a diagnosis‑specific category and how families and individual children or youth identify in those groups or don't, and some people have very passionate reactions has been an interesting evolution.

>> DONNA MITRANI: Thank you. And then another question I wanted to put out there for Melody and Deborah and really any our reactors is, you know, developing productive stakeholder relationships can take time, and some of the best partnerships are long‑term. So that being said, how can we balance that investment with the need to ensure that stakeholder engagement characterizes new voices in the relevant network?

>> DEBORAH BOWEN: Well, this is Deb, and one of the jokes that we used to tell ourselves when we pulled together stakeholder engagement groups around smoking cessation was that the best way to help someone quit smoking is to put them on an advisory group and say please give us advice about quitting smoking and helping other people quit smoking because usually people went, oh, I guess I should quit smoking. On in some ways, the continuing to search for new members and bring on new members, say, into a group or into a process or into the sphere of dialogue is a really good thing, and you would expect that as their engagement grows, then they would change their reporting on the measurement, and you can measure that, we hope, someday. I don't think we can quite yet, but we hope to be able to measure that and to be able to document that, that it takes a year to have someone feel very engaged and build that trust. Maybe that's a finding.

We don't know that finding yet because we haven't had the tools to measure the engagement yet, but I think continuing to just simply involve new people and maintain the old ones, I mean, people also get tired and people develop other commitments in their lives and they're able to only participate for part of the time, and that's a normal natural healthy process of working at a community level. So I guess I think that those are pretty simple ways to do it, but those are ways that we've used in our projects.

>> This is melody. I think just to add on, I think what's been really nice about creating this measure is that the team of us have all done community engaged research, I think we're really clear about a lot of these nuances, and our measure is an individual level measure. Multiple people can be talking about the same product or partnership but you're going to get an individual level measure from each person so you'll be able to tell where your partnership is overall but also if some people are not as engaged as others.

>> SUSAN MAGASI: This is Susan. I just wanted to add I think it should also be purpose driven. So reflecting on what the goals are of an individual project overall but whose perspectives and voices are needed at different phases of the research, not only do people's engagement shift, but people's capacities to engage in various phases of the research grow. So what we've been able to do as part of our work as people's knowledge, skills, confidence grows, people have been able to assume different roles within project team, and this is true of community members, you know, just as it is with other groups. So then they're able to move into other roles.

It's great also to have those strong, strong relation shims, but, you know, there's this concept in sociology about the strength of loose ties as well, that there are advantages that come from not always talking to the same people about the same thing, so as a project team being reflective of when do we need to get new voices in or whose voices are not reflected as part of the current dialogue. There's a nice model, the equity focus knowledge translation model put out by Masuda and their team up in Canada that really does some of this work of looking very critically, reflectively at your team he to make sure that you have different voices, different perspectives and opportunities for those people, groups, to step forward in meaningful and important ways.

>> DEBORAH BOWEN: That's a really smart point, Susan. I think that no measure is meant to be used exactly the same way in exactly all projects with exactly the same communities, exactly in the same path, and I think that thoughtful application, I think thinking about things is generally a good idea. So applying that thought to, you know, what you're doing and what each project needs maybe, maybe there are some projects that can be handled without two or three years' worth of engagement.

Maybe the projects are much more simple than we think. So I think your idea is to just think about what you're doing is a really smart idea and not just to apply something only because it's valid and reliable. The that's a really good reason to use it, but that's not the only reason to use it. So good perspective.

>> Yeah, and similarly, I was thinking about with your work, having a tool that you can measure and use over time because people who do this kind of community‑engaged work know that it's a constant renegotiation and reinvestment in the process, and if we ever think that we're done engaging or building trust or we've got things all figured out, we just don't. And it's important, I think being able to use a tool sort of repeatedly throughout the process can help, again, foster some of that reflection.

>> DONNA MITRANI: Thank you. Melody and Deborah, it's great the that you have a measure of stakeholder engagement. I think we can all agree that this is much needed. I'm just curious, do you have any plans to use it in any projects that compare to projects or to sets of projects where one project has high level of stakeholder engagement and another does not?

>> So that's part of our psychometric testing, we plan to implement it in some of PACORI's existing projects, and like I said, we want projects across the spectrum, we want to be able to see how it performs when there's minimal engagement and when there's deep levels of engagement and I think the other thing that's important for me to mention is that our measure has no judgment in it. Like just because you may fall into the community, the outreach and education bin doesn't mean that that's not where your study should be. We're just sort of defining things, we're not saying that every study should be in a full partnership.

>> DONNA MITRANI: Thank you. Would you mind giving some examples of high levels of engagement?

>> So from some of the work that came out of our DELSI process, the department level isn't on our side, it was added in our process, high levels of engagement at least the way I understood it from our process means you've worked with these partners on multiple projects, so moving beyond one project, you have worked on multiple projects addressing an issue, so that's the highest level of engagement partnership according to our measure.

>> DONNA MITRANI: Okay. Thank you. And I know that we're getting toward the end of our time here before break, and just before we close out things, tying this discussion back to Anne Bergen's presentation earlier, I'm curious whether you, Melody and Deborah, or if any of our reactors have tied in stakeholder engagement as a measurable outcome in a logic model.

>> Well, sure. I would think that back to the earlier presentation in Anne's presentation, I would think that this measure once developed and once ready to go, once to be pulled off the shelf and used would make I think what she calls a short‑term outcome. There are maybe other places to put it, but I would think that stakeholder engagement is often an initial thing to measure, outcome to measure that you think will drive other things.

So where it belongs is somewhere in the mediational process and somewhere in the middle, I guess, and I would look at it as a short‑term outcome that you can also measure it, of course, in the long run, that would be a great idea because we hope that the engagement continues over time, but as a process outcome, I would think that we would want to work very hard in the beginning of a you project to engage all stakeholders together in the process of doing the project, and the decisions that get made out of that project will be better, we hope.

So in terms of relating it to long‑term outcomes, I would say it could be a short‑term outcome would be a very simple place to include stakeholder engagement. If you literally go back to Anne's slide that had the words "short‑term outcome," I think you could stick it there and feel pretty confident that it fits there, as well as other places.

>> DONNA MITRANI: Thank you. Any other closing thoughts from any it our reactors or from Melody or Deborah?

>> I think one thing I've learned through doing this work with Melody is that this whole process of psychometrically defining ‑‑ psychometrically defining a scale is both necessary and bewildering to me because it's very labor intensive, just as stakeholder engagement is, and what we're hoping is that for key measurements we do it and we do it and we get through that process and it turns out that the tool is useful for other people. It's not for every tool. Every tool doesn't need to be validated. We don't have the time or the resources or the grants to validate every measure of everything that we use, but for those key measures where we're making claims like community engagement is important, community engagement is happening, community engagement is truly ongoing, then maybe spending the time or grabbing colleagues like Melody that can do this kind of work and understand it and use it is essential.

So maybe that's a way to evaluate when you read about different measures, what have those people done to provide psychometric data and convince you that this is a good measure? And if they haven't convinced you, I would say that chances are that using it will be more complicated, let's say that.

>> DONNA MITRANI: Thank you very much, Deborah and Melody, and thanks again to tower reactors and for ‑‑ to our reactors and for everyone for participating in our discussion today.