>> Maureen Johnson: Hello and welcome to the Community Engagement Science webinar in Autism spectrum disorders.   Part of the webinar series sponsored by the Autism Special Interest Group.   I'm Maureen Johnson, program specialist at AUCD.   Thank you for joining us today.   Before we begin, I would like to address a few logistical details.   Because of the number of participants, your audio line will be muted throughout the presentation.   However, we will unmute your audio line one at a time during the Q and A time at the end.

You can also submit questions at any point during the presentation via the chat box on your webinar console.   You may send a chat to the whole audience or to the presenters only.   We will compile -- we will compile your questions throughout the webinar and address them at the end.   Please note that we may not be able to address every question and may combine some questions.

This webinar is being recorded and will be available on AUCD's webinar library.   There will also be an evaluation survey at the close of the webinar.   We invite you to provide feedback on the webinar and also to provide suggestions for future topics.   Please join me in welcoming today's presenters.

Brian Be is an artist, performs and writes songs and does photos and videos.   Being on the autism spectrum, he lives with ongoing challenges/blessings.   Brian is a self-advocacy coordinator for the JFK partners, taking arts into community wellness.   He served the community in many ways, most notably an

appointment to the Colorado behavioral health planning and advisory council for 10 years and two years as co-chair of JFK partners community adviser council.   Brian is also one of the co-chairs for the autism special enter group.

Dr. Richard Boles is the pediatric psychologist with a specialization in child behavior and nutrition. He earned his doctorate degree in clinical child psychology from the University of Kansas and completed his residency at the children's hospital center.   He's the associate professor at the University of Colorado medical campus.   I will now pass the microphone over to Brian Be.

>> Brian Be: Thank you very much, Maureen. Hello, folks, Dr. Boles, welcome.

>> Richard Boles: Thank you.

>> Brian Be: Thank you for joining the Autism Special Interest Group few AUCD for today's webinar. You're going to see an overview slide there of what we're gonna cover today.   You'll see that Dr. Richard Boles and myself will talk a bit.   And then the second part of the webinar is a chance for you to participate. Because we're gonna do here today community engagement science.   We want you to connect with each other and with us.

Dr. Boles, would you like to say anything for hello before we get started?

>> Richard Boles: Oh, yes.   Just a quick hello to everyone.   I appreciate all those who have joined us and look forward to the next hour and talking more about community engagement.

>> Brian Be: Indeed.   Hey, may I call you Richard?

>> Richard Boles: Sure.

>> Brian Be: Okay.   Thank you.   I noticed that there's just a lot going on in the world these days and it gets to affecting me sometimes.   Could we do a grounding exercise together before we get started?

>> Richard Boles: Sounds good.

>> Brian Be: Yeah?   Do you have one that you enjoy that you would like to facilitate, or would you like me to?

>> Richard Boles: I'll let you choose, actually.

>> Brian Be: Okay.   So, naturally I'm just doing a stretch right now.   So, we invite all of you to

do the same during this webinar.   Keep your water handy.   And let's just do three breaths together.   So, if you've logged on and you can sit back.   Let's just do a grounding exercise of three breaths.   We'll go in.   Gentle pause and out.   You may want to stand up.   Gentle in.   Gentle pause and out.   And in.   Ah!   And out.   Thank you, everyone, for taking the time to be with us today.

These are crazy times.   You know?   But we appreciate your time and your interest in community engagement.   And with that, let's get started.

>> Richard Boles: Okay.   Thank you, Brian.

>> Brian Be: Before we do, I just remembered, if you did the grounding exercise with us, please say so in the chat box.   I notice folks are already doing great and saying, hi, I'm from Virginia and Commonwealth and so on.   Just say in the chat box, did you do the grounding exercise, yes or no.   If you don't do ours, hopefully you did your own.

>> Richard Boles: Thank you, Brian.   It helps, especially at the noon hour, to take a moment and slow down for a second.   So, why don't we go ahead and get started.   As Brian mentioned, our objectives are listed here.   And we're gonna begin right off the bat with a demonstration of community engagement conversation.   From there, we'll talk about community engagement?   Why do we do it?   And just briefly, how might we do it?   And then we reserved the rest of our time, as mentioned, about talking with each of you about some of the challenges and ways that you've addressed it.   We hope that we can learn from each other in this process.

What I would like to first, though, do is begin with a couple of polling questions.   So, let's begin with polling question number one, please.   And I would like to ask for each of you to select, maybe one or more, that you think are true for you.   A, I represent academia or a university as a researcher or as a clinician or as a support service provider.   Or B, I represent a person with lived experience such as a patient, a family member, an underserved or underrepresented population.   Someone with a disability and/or on the autism spectrum.

I'll give you a few seconds to finish answering that.   Thanks to all of those who have responded so far.

>> Brian Be: Indeed. And let me just invite you to join this webinar series for the month. April is Autism Acceptance Month. This is the first of four webinars that AUCD Autism Special Interest Group will be rolling out for this month. The next one is this coming Wednesday. You'll see that in the follow-up survey after our webinar today.

>> Richard Boles: Excellent. Let's go ahead and move to our second poll question. Which is, again, just select the statements that are true for you, please. The first one being, A, as a researcher or a prouder, I participated in community engagement projects. Or B, as a person with lived experience, I have participated in community engagement experiences.

>> Brian Be: If you're not sure, just take a guess. And we'll talk more about it shortly. As of right now, you get to decide what is community engagement for you and your projects. Soon Richard and I will share our experience and then we will all process some more together.

>> Richard Boles: Okay. I think let's go ahead and close the poll. Thank you for all of you who participated in that. That gives us a sense of really who we have on the webinar with us today. So, thank you for that.

What I'd like to do now is actually demonstrate with Brian a bit of a conversation of community engagement and we'll then move forward and reflect on that and talk more specifically. So, again, now I'm just gonna present as a role as a researcher in talking with Brian about a project that you have. And we're hopefully going to illustrate some major points about community engagement science. Brian, thanks again for the chance to talk more about our project.

As I mentioned in the email, I'm forming a community steering committee. This will help us prepare a PCORI grant submission next year. And I wanted to share details about the projects and answer any questions.

>> Brian Be: Sounds great. I would love to hear about it.

>> Richard Boles: No problem. For our project, we have a community engagement plan. That includes a community steering committee that

we're forming.   This is going to include community partners, stakeholders, researchers like myself and the idea that we're gonna learn what our project goals are and develop a partnership.   Now, you might be more familiar with a community advisory board or sometimes called a C AB for short, but this is a but the different.   The way I would like to illustrate it, I'll use the CAB car as an analogy.   If you're joining a community advisory board or a CAB, it's like taking a cab to go somewhere.   The driver decides where to go and you sit passively in the backseat.

What we have here is a community steering committee.   Each passenger gets to share the driver responsibility.   Actively making decisions about which direction and how you're going to get to the destination.   So, in short, Brian, a community steering committee provides an opportunity to go beyond consulting with more collaboration.

>> Brian Be: Okay.   Wait, I think I've done this before.   Is this the game where you pull over somewhere safe and you all get around and run around and change drivers?

>> Richard Boles: Yeah.   I think it's something like that.   We just to want make sure that everyone gets a chance to actually have a participation in leading the ideas in what we're gonna be doing for this project.   It's not just me telling you, hey, here is what we're going to do, do you mind listening and giving your thoughts at some point?   We're going to drive together and how we're going to get there.

>> Brian Be: Okay.   Off done a community advisory board before.   This sounds more engaging. I'm excited.   I have a question, though.

>> Richard Boles: Yeah.

>> Brian Be: So, you're talking about engaging the autism spectrum, did I hear that correct?

>> Richard Boles: Yes.

>> Brian Be: Amy on the autism spectrum. That's been my only experience from birth.   But as an advocate in getting to know a lot of friends and family and community, I found that I do not represent the whole autism community.   There is a vast amount of folks -- folks that do touch for talk.   Folks that sometimes are called non-verbal.   But in fact, they make noises and they communicate and gesture.

And then family members.   Are we -- are we engaging just the so-called "Verbal end," kind of the Asperger's kind of end or more than that?

>> Richard Boles: Great answer.   Let me tell you details about the project and hopefully can address what you've raised.   Because the idea of the diversity within the autism community is really important.   And it's part of the reason why we do this community engagement process so that we really do represent all of those that might be involved.   So, I'll give you a brief introduction to the project itself.   As you know, I've worked with kids and how they grow. Including kids that may be diagnosed with autism. And one of the things that we've learned is they can be at higher risk for high weight development.   Both early on and that it persists into adulthood.

And this is something that we have really struggled in the past to try to understand from a prevention and treatment standpoint.   And so, what we're trying to do in this project is to really involve community partners from the very beginning to better understand what we can do to tailor our project, to tailor our intervention to make it more relevant for those involved.   And so, with that, I want to address the point that you raised that, you know, kids with autism may be quite diverse in their functioning.   On the high to end those that may have limited abilities in terms of communication, or they communicate in ways that aren't similar to others.

And so, by having folks on our committee represent the spectrum fully, we are able to then include some of those characteristics into our prevention and treatment intervention better than we may have done in the past which may have been narrowly focused on maybe just the higher end of the spectrum.   And so, you raise a good point.   Also, for those individuals that may not be children, but for those that are older adolescents or parents themselves.   And so, our program exactly on that point will be family-based.

And so, we don't want just kids to be talking. But we look to the parents and the relatives that might be helping to care for kids to also be a part of our committee so that we can really understand what's gonna be most relevant and important for this project.

>> Brian Be: Nice.   Nice.   Amy glad to hear

that. And I'm glad you mentioned adults. So often the tension like in research goes to kids. But kids grow up. Best as I understand.

>> Richard Boles: So, from what I've talked about so far, is this something that you want to be a part of? Are you interested in more information?

>> Brian Be: Yeah, I'm excited. Thanks for inviting me.

>> Richard Boles: All right. Well, our next step is we're going too far a workshop. This is for folks, such as yourself, that are going to be part of the committee. And we will talk about our mission and the roles and responsibilities for each person that is a part of this workshop. We're going to collaborate on developing a plan that works for everybody in meeting the goals and interests. We will pay you for your time. We know that being paid is only one way it receive a recognition. And so, if you value other incentives, please talk about that as we move forward.

>> Brian Be: Thank you. Yeah. Thank you for telling me that there's pay. And, yeah, you're right. There's -- I mean, already I value just the way that you're approaching me. It does say -- sound really ambitious for including everybody. But I certainly like the idea. So, yeah, what's the next step?

>> Richard Boles: Very good. I'm glad I have your interest. So, with that next step, we're going to go ahead and close this skit and stop and come back to this webinar. Thanks, Brian.

>> Brian Be: Thank you.

>> Richard Boles: And so, for our audience, what you would like to do now is to administer our third polling question. And so, based on what you just heard, tell us which you agree with in terms of these comments about community engagement on that conversation. A, the researcher, myself, valued a genuine collaboration with our community partner, Brian. B, that just was not realistic. Or C, the community partner will probably not have a strong role in this project.

>> Brian Be: Thank you for your honesty. Tell us what you really feel. Not just what you think we might want to hear. Especially since some of you

have written grants and done projects like these. Thank you again for being here. This is community engagement science through AUCD's special interest group for autism. We invite you to self-care. Remember to stretch. Get some water. Treat yourself, put your phone on do not disturb if you'd like.

>> Richard Boles: All right. Thank you for giving us that response on that skit. And, you know, I saw that a lot of you believed that the researcher valued the participation and the contribution by the community partner. But I also appreciate the idea that some of you thought maybe this just isn't realistic to think about that kind of process like that. And that maybe the community partner himself isn't going to have a strong role in this project. And I think those are really valid ideas about, you know, what you just heard. And real concerns around conducting community engagement science.

What I would like to do now is just take a few minutes to go over a little bit more of the nuts and bolts of community engagement. And then we'll move ahead with some discussion. Just briefly, let's talk about what it is. It's -- it's really this idea of collaboration. And you'll hear that word throughout this presentation. And it's between multiple folks, including higher education and communities, for this exchange that's beneficial and meaningful between all of those involved about the knowledge that you have and are going to get from the project, as well as the exchange of resources. And I just want to emphasize that it really has to be bidirectional across all of these groups and that it's not just one direction of receiving benefits.

And that really is what defines community engagement. It's an ideology. Not just a strategy, of what we're gonna do. And I think that that's really important to think about. Let's talk about what community means first. Who am I talking about within the community? I think this includes children or adults maybe diagnosed with autism. Could be the parents or relatives of an individual with autism. Also, maybe teachers who may be involved with kids or young adults or adults with autism. Clinician who is may serve in special clinics. Leaders of local chapters organized to support individuals with autism and, of course, advocates for autism within the

community.   I think it includes a really diverse set of folks.

When we think about community.   So, we use this word, but it really encompasses many individuals.

>> Brian Be: Right.

>> Richard Boles: And it's a term to really actually engage.   When we say, "engage," it's this idea of actively working with community members rather than on or for them.   It's with them.   And so, there's, you know, multiple areas that this can be done and so, in the figure there, you see community outreach, for example.   This could be being a part of a community class or a board membership. Community service like a food bank volunteer, for example.   Within education, you may be participating in workshops or conferences.   Of course, in clinical care, you could be at community-based care centers or free health screenings, for example.

Within research, part of where I tend to reside and based on the example I just gave, you could be part of a patient-centered outcomes research project or PCORI.   Or a participant-based CBPR.   Or last, involved with policy and advocacy in being an advocate for health policies.   There's a number of different areas that community engagement can exist. We talk about the research circle today, but as you see, there's many places.

>> Brian Be: Thank you.   Richard, I think of community engagement science as like a bridge. Like if you look at our illustration here with these different circles, they're each their own thing.   But there is an area of overlap.   That common area in the middle.   That's -- that's the bridge.   You've to the different groups coming to the and they've got a river to go over.   There's a reason for the bridge.   There's obstacles.   But it's about a mindset of teamwork.   I do have this question for you, Richard.   When I think of community engagement science, I think of a checklist, okay?   This is science.   So, do this, A, B, C, D, do these 24 things.   Is that community engagement science?   A checklist?

>> Richard Boles: Yeah, I would argue that it could be a part of community engagement.   But I think in and of itself, it doesn't define the whole process.   And the whole goal of community engagement science in that certainly there are

concrete steps, and we're gonna talk about some of those today.   But I want folks to think community engagement science as it's something a little bit bigger than a checklist of things that they do that it can almost seem -- almost even almost condescending, well, we have our community partner on board and they advised us and helped us disseminate our results.   It's not just a check box.   It really needs to be more than that.   And it's about really sharing the values of both the science of what we're trying to learn.

But also, the values of patients and families and community partners in what they see in relation to the project as being important and in relevance to what they hope to get out of it.   And so, again, it's really this ideology and not just a simple list of steps to take.   But really that it's this exchange of values, even, that people can share.   And I think if you it in that way, you've really bought into the spirit of community engagement as it was designed.

>> Brian Be: Got it.   Thank you.   And I know there's a LENS site in Oklahoma that developed a partnership of seven values.   We may be able to refer to that when we get to the end in our references.

>> Richard Boles: Perfect.   So, we talked a little bit about this, but I want to emphasize the point, again, of why do we do this?   It's really to create relevant outcomes that are better utilized by our patients, our families, our communities.   And it really helps us translate the science.   And that's part of the reason why community engagement science exists.   It's really that research shouldn't just end up in journals for other academics to read.

While that's a part of it, and it's important that we learn, as researchers, from what others are doing, we've missed an important part of what we can do in this whole process if we don't think about other ways that this research can be meaningfully used and engaged by the community.

And so, with that, we have a process that begins from the very beginning that includes folks from the community.   It sounds easy.   And maybe it sounds simple, I don't know.   There's a fair number of folks that have identified as already having some experience with community engagement.   So, I'm happy to hear if that's actually the case.   But I think

it's -- it's something that takes work and it has to be thoughtfully planned about from the very beginning or else we tend to do what I think is maybe more superficial and we just, again, have this, you know, minor representation of somebody maybe that's involved in the community.   But they really have a little involvement in contribution to the project.

>> Brian Be: Right.

>> Richard Boles: Yeah.

>> Brian Be: A lot of us are familiar with the dynamic of the token person with a disability.   Which is saying it's going beyond that.   In fact, I would like to reference -- thank you, Christie, for your comment.   But it's not just about higher ed.   It's not just about universities, academia.   For that matter, it's not just about autism.   Community engagement science can be first time nursing mothers.   It can be a wage, a region.   You know?   Whatever your community is.

But the engagement that we're focusing on a lot today for our presentation is a researcher and the autism spectrum disorder and those autism stakeholders.   Right might I even be so bold to say that the comments from Kristi, Jill and others I have missed demonstrate community engagement as I talk about this practice.   As talk this definition of community engagement, you yourselves who may represent other areas of involvement bring to the table this idea of, oh, wait a second.   Make sure you haven't thought too narrowly about what this might mean.   And so, even in real-time, the idea of bringing together folks to talk about this demonstrates the point itself that we learn from others and to really expand and think about what community engagement means.

Because the truth is, we sometimes come to the table with, you know, our best experience from ourselves.   And our world view is in part wrapped around our world.   And so, by engages with others that may come with other world views and other environments and backgrounds and training and experiences, it adds to the conversation.   And so, it's really helpful to have this kind of communication.

So, what I'd like to do is to spend just a couple of minutes about the process of how we might do this.   And I'm showing you one slide.   And so, the reality, of course, is that there is a mountain of information on

how one, you know, conducts community engagement science.   And I'm gonna give you a very high-level overview of this process.   And I don't mean for it to be all-inclusive in that there are certainly other ways to include other environments and other community partners for that matter.

        But probably transcending all of those differences is the fact that we begin forming this collaboration at the beginning of the project or the -- the study if it's a research study.   Whatever the primary goal is, you begin with this idea of creating a community engagement team.   Before the goals have been developed.   Before the process has started.   And, of course, certainly before things are being disseminated.   You want to try to identify who might be important to be at the table and to have a voice with this community engagement project.

        You might start with a certain set of ideas of who needs to be at the table.   I suspect that even in that process, you're gonna learn who you may have not thought about in the beginning that also needs to be invited to be a part of this community committee if you will.   And so, that I really think is a central part to all of what we're trying to do when it comes to community engagement.   Is to create a broad diverse team.   As much as possible.   We all have constraints of time and resources.   And so, there may be some limitations to this committee.   And that should be recognized.   But to try as best as possible to create as much diversity within your team.

        And with diversity what I mean is representation.

        >> Brian Be: Yeah.   Richard, I got to say --

        >> Richard Boles: Please do.

        >> Brian Be: I just got say that a lot of this sounds a lot like relationship-building.   And I know that takes work.   So, if I was doing a project on -- with community engagement science, I would look at sustainability.   I would look at building a pool of relationships rather than just try to build the relationship once I'm funded.

        >> Richard Boles: That's exactly right.   It's a good point, Brian.   And the truth is I think you would also to think on the back-end of how can this continue?   So, what may start with one project can

be a collaboration that continues.   And the truth is, is that continuation of collaboration really depends in part on how well you actually met the goals of community engagement on the first project itself.

And so, by really paying attention to that from the very beginning, you're likely to set up an opportunity to continue with projects down the road.   And I suspect for those that have been involved, it may have multiple experiences with similar partners and maybe new partners over those multiple experiences by how well those things were conducted.

>> Brian Be: Yeah.

>> Richard Boles: So, what I would like to then talk about is then, so, what do wow do?   You have all of these folks identified.   Well, as we demonstrated in that skit in the beginning, what really then happens is this idea to creatively come up with a plan that defines what your goals are in a way that you feel comfortable and feasible in being able to reach those goals.   And so, you know, for example, in my research proposal that I proposed to Brian, you know, it's this idea of trying to figure out how to tailor prevention and treatment programs for kids diagnosed with autism that are struggling with weight management.

Brian brought up, are we talking also about the adults that might be involved?   Are we also talking about the diversity in individuals with autism and the functioning that they may present?   And so, you know, those were two really good examples of making sure that we at least consider those goals as we start to define what our project is about.   So, it's not me just presenting, well, here are the aims that we hope to accomplish.   But rather, here are some ideas about the alms.   But let's keep this open for now. And let's talk about what all of these aims might look like.   And then we can narrow down as a group together what will be, you know, the final thing that we end up presenting to our funder, for example.

>> Brian Be: Right.   You know, Richard, I think that's part of the -- the waters, the turbulence, that we're trying to bridge over is to -- for program designers -- to come up with in advance, here's what we're gonna do.   Let's go get funding for it.   Then you get funding for it.   And yet, you have to stay open -- you have to be usually very specific to get

funding.   And yet, you've got to stay open for ideas that you haven't encountered yet.   For example, in the autism community, I've got a lot of people that I know that are not going to join a webinar like this. So, that amount of technology is just beyond them. But if you can come meet them when COVID-19 is not going on.   If you can meet them face-to-face or engage in some other ways, it could be more meaningful for them.

Yeah. really -- I really got to hand it to the program designers and the grantors and the grantees. Because its flexibility and specificity trying to play together.

>> Richard Boles: That's right.   And I can say that in my own experience in being a part of these committees, you know, for example, one of the things that we had to do was creatively create even a schedule and an environment of meeting with folks within the community that worked for them.   And so, we talked about, well, what time of day works better for you?   Is it maybe actually the later afternoon or early evening?   Do we need to think about child care for you to participate as a parent who represents our populations?   Do we need to think about including a meal to make it feasible for you to come?   You know, these are some of the logistical things that might actually be deal breakers for some because they can't feasibly make the meetings even though they want to participate.   But if we can try to accommodate as much kind of, you know, flexibility and how we meet, even.

It can really, I think, improve the participation by those that we really want to try to have engaged in our communities.   So, again, I want to hammer this point of, you know, active participation from the very beginning of conceptualization of what's important and to whom.   And, of course, throughout the conduct of the project.   So, once we form this committee, we define our goals and our strategies to reach those goals, we don't stop with our engagement with the community.   We continue throughout the process.   Because we may continue to learn things about how we're doing whatever it is that we're doing. If we're conducting a research study and we're having challenges with recruitment, for example, I know some things about why that might be the case.   But I

actually think I would learn a lot from community partners in helping us understand as well.

And that may give us a real opportunity to change the way that we're doing things while we're actually doing them. I think importantly, that also raises the idea of, well, what if you have conflict? What if I don't agree with what my community partner is talking about right now? What if they're raising a question or an interest that I either don't think it's important, or I think that it's not realistic to do? And vice versa. The partner may think, you're talking about something that isn't important to me. Or it's not realistic for me to be able to do that as -- as a person in the community.

Do you have a way to manage that? Do you have a process that can help individuals who are all sitting at the table feel comfortable to do that? I can again say from my own experience, it can be intimidating in some sense for a community partner member to be sitting at the table and to say to, you know, a faculty member or a researcher or somebody else, a clinician, even, I don't agree with that. That can be sometimes hard to do. And what we want to try to do is to create an environment that makes that feel safe. That they don't feel wrong in bringing that up. And that it actually can add to the conversation.

And so, you have to be deliberate in saying exactly that. That we want to hear differences. We want to know if you think we're not on the mark. And that we're actually gonna learn from you. And part of that is by explaining that that's part of what you want to do. And by modeling it yourself. And I think that's a really important part of what we do within the community is to make it feel safe and easy to have differences in what we think will be relevant for this project.

So, last point I want to make is really about the dissemination. Because oftentimes with community engagement, this may be the strongest or the only part that some folks have been involved with in the past. Well, we conducted this study. Now we have these results. How do we get it into the community? Well, if I'm only engaging the community at this stage of the project, I've really missed the mark. And I think to do community engagement science well, we, of course, started way at beginning in having the

discussion about dissemination.   Well before the project was even done.

So, again, we try to publish in our journals. But that's only one small area that might be important. Or not even at all, depending on the project.   How do we put this in the hands that's going to be most relevant and useful?   Who do we need to include? And most importantly, you know, how can we make sure that these results are trusted?   That's part of the process of community engagement is to create and establish trust of what it is that we're doing and then when we come up with our findings or our outcomes, that the community trust that these are actually useful to do.

We've all probably had experience where we've seen things in the news or that have been shared that we think, I don't know if I actually trust that.   Or is that really solid?   Is that something that was based in real, you know, strong work?   And so, it's hard I think, as consumers, as community members, to know if that's the case.   If you engage your community, though, from the beginning of the project, you've already helped establish then the trust of what it is that you found in being able to then share that with those community individuals at the end of your project.

>> Brian Be: Indeed.   In fact, Richard, dissemination, there's this growing field of knowledge translation that -- and it's about taking research that doesn't just stay for researchers.   But that it actually closes the loop, so to speak.   To come back to community.   Hopefully even the community that was a part of the study.   And help them be able to benefit from what was done.   So, dissemination is important. Thank you for sharing that.

>> Richard Boles: Excellent.   So, what I'd like to do is actually begin the last phase of our webinar here.   We've got somewhere around 15, 19 minutes, 20, depending how long you need a break, left.   I think this is a real opportunity here.   And so, before we open up for a more engaging discussion between all of our members, I would like to do one last poll. And so, this would be polling question number four, please.   So, my challenges with community engagement have been -- and please choose all that apply.   And there may be others that are not listed

here.   But A is developing a partnership before a project has been finalized or submitted for funding.

B, having my views and values reflected in the project.   And C, difficulty in resolving conflict.   You may answer all of these or none of these.   But please take a moment.

I'm seeing some say you can't choose more than one.

>> Brian Be: I invited people in the chat box to also share their project and to connect with each other that the community engagement science can be here today during this webinar.   Get other people's emails, ask them about their projects.

>> Richard Boles: I see some questions about funding as well about finding a grant or a funding source that aligns with the idea.

>> Brian Be: Right.

>> Richard Boles: That's a really great point. And while people continue to take a minute to respond, I'm going to just start with that one.   I think that's a good one.   You know, I mentioned in the skit with Brian, we're going to be writing to PCORI, the patient-centered outcome research initiative.   And that's certainly one example of an organization that really values the idea of community engagement and community partnership in many ways.   I think that oftentimes, remember, as I mentioned earlier, this is really about translating science.

And so, one of the keywords that I often look for in my search for grant funding is this idea of translational science.   And that's possibly a good thing to think about if, for example, you're looking at NIH.   That within the NIH, there will certainly be requests for applications that look for the translation of science.   And I would argue that part of the translation of science is about make sure that you're translating it to the communities that are going to benefit from that.   You know, all grants require a little bit of an art on making sure that they speak to the funder in what they find is of interest in their portfolio.

But that's certainly one area.   Another area that I've had some luck in thinking about is although there are differences in the budgets are foundations. Because I think many foundations themselves recognize the importance of the community and the

families themselves in terms of the research that they are hoping to fund.   And that without a strong representation of folks themselves who benefit, you're gonna be left competitive.   So, those a couple of examples.   I wonder what other folks have learned as good areas of funding for this.

>> Brian Be: Yeah.   A lot of great conversation going on now.   Sharing projects, regions in the chat box.   Well, shall we close the poll?

>> Richard Boles: Yes.   Let's do.   And so, you know, I think that, you know, many folks identified this idea of developing a partnership as a challenge in developing that partnership before it's been submitted or funding.   And I think that part of that is really identifying who might we engage within the communities?   And that could be part of the challenge in doing that.   You know, like a lot of research, there's a lot of pilot work that goes on before the big project itself.   And so, one of the things that I've done in the past is to create very small projects where we might do qualitative work.

And this qualitative work really involves those that are gonna be benefiting from the ultimate research that we hope to do later on.   And this is one way that we have been able to identify who needs to be at the table for a community engagement project.   So, let's not go in with a pre-defined set of questions.   Let's meet with folks in the community.   Let's meet with family members of individuals that may be diagnosed with autism.   Let's ask them, who have we missed at the table here when we start to ask our questions openly?   And that's a great way that I've done in the past where we start with some qualitative work.   And with that qualitative work, it sort of snowballs in terms of, okay.   So, we've met first with families.

Well, the family members will know best about within the community of who they engage with.   So, within the community where do you go as a matter of resource or support beyond what I might be involved with at a university or a hospital.   I think there's so much more to that.   And they can then help us identify who we might also bring in as a collaboration.

But to do it small to start makes it feasible. So, you can manage this I think realistically is what I might offer as another strategy for helping to start a

project with already having a team put in place.

>> Brian Be: Right.

>> Richard Boles: So, if you're looking for a large PCORI grant, maybe take a few months of putting together an exploratory committee or a qualitative interview to identify who the committee itself might even be.

>> Brian Be: Yeah. Yeah. In fact, I've had a privilege to participate with a group that received a PCORI grant. And in doing this webinar and working with you, Richard, we have done a little bit with references and citations that has been part of the deliverables for that. But not everybody gets a PCORI grant. So, I appreciate that you said start small.

At our end slide, you're going to see references where PCORI, patient-centered outcomes institute did some very -- yes, thank you. Did some effective engagement with the autism community. But there are so many others. I heard AUCD do an interview of I think it was Stephen Shore and Benevitas with a group called Asset. There's OAR, organization for autism research.

>> Richard Boles: That's right.

>> Brian Be: But really appreciate you saying start small. That's where things can get doable. And that's how you build up to these larger projects.

>> Richard Boles: That's right. And, yeah. As you see here, we've got our -- a few references listed as well as our emails. And before we go, I just to want reiterate that we ourselves are open to having a communication if you didn't have a chance or didn't feel comfortable reaching out in this public manner. Please feel free to email us individually if you have questions or comments that you didn't feel were answered or need to chat a little bit more. We're happy to do that.

I think that, you know, another response for some of the challenges, you know. I saw some folks talking about having your views and values reflected in the project. Again, I think it really can't be overemphasized that when you -- if you start together with this idea of coming up with a committee that has this initial workshop, it's a great vehicle to use, if you will, to make sure your views and values gelt reflected

in the project.   And that they get really written down in a way that becomes formalized as a part of what this whole thing will be accomplishing.   And so, you hold everyone accountable for that.   And hopefully the folks that are, you know, participating have created an environment that makes it feel comfortable to talk about your values if they weren't mentioned in the beginning.

And I think you just have to -- I think in part you have to ask people directly that.   And you have to give them a way to communicate that in a way they feel comfortable doing.

>> Brian Be: Yeah.   I'm glad you mentioned that.   Thank you.   Because that first reference, which it's two pages.   It's got colors and icons.   It's pretty simple.   Seven community engagement partner values.   I really like that because, you know, earlier you said well, if there's conflict.   And I contend, there will be conflict.   If you have a pulse, there's some conflict inherent to living.   But certainly, with these projects.   That's the river that we're bridging over with community engagement science.   The seven partner values give you a chance when that conflict comes up to go and have some dialogue.   To be honest, you know?

Again, I can't -- I just -- I appreciate earlier you said that it's healthy for people to say no.   You know, healthy boundaries.   We need that in all of life.   We need it also in community engagement science.   And then you have to have a way to be able to talk about it to see if you can keep working on a project.

>> Richard Boles: That's right.   I wonder if there are any folks that would feel comfortable in talking about what felt unrealistic about that skit in the beginning?   I know there were a few folks that thought, you know, that's just not possible.   You know?   It's a nice idea.   But we can't do it that way.   And I think this is the reason why.   Does anyone want to toss out what they thought really didn't seem possible when having that kind of a dialogue between, in this case, a researcher and a community partner?

>> Brian Be: Great question.

>> Richard Boles: And feel free to send that to us privately if you feel.   I see some folks are typing.

>> Brian Be: Oh, and you know what, Richard?

I neglected to mention, for those that typing is not accessible, AUCD told me they would try to have a way where you could raise your hand.   And they may be able to activate your remote microphone.   My bad.   I just did poor community engagement science because I could have said that at the beginning, and I neglected to do so.   So, send a message if you can.   And that's the way we have to do it for the large volume.   But if for some reason you cannot, if talking is going to allow you to express your thought better.

>> Richard Boles: Perfect.   Thank you for sharing that, Brian.   I know that as I look, you know, one thing that if I had to look at it and say what's less realistic is, you know, all that takes time and resources.   And administration to put together these committees to conduct a workshop.   You know?   And all of that is outside of the actual process itself in a sense of what you're actually gonna end up doing.   But it's the preparation that takes a lot of resource.

And I think for some folks, they may say, I don't have the bandwidth.   I don't have the money, even, or the facility to manage what you just described.   And that makes it seem unrealistic.   And I think that's an important point to make because this -- this kind of process does add layers to the way that we do what we're doing.

I think that in part it's trying to be creative with your resources.   But also, trying to figure out, again, if you can do this in a smaller way to begin with addresses a little bit of that.   Fewer people need, you know, fewer resources to come together.   And that you'll learn in the next step, this is what we need to add if we were able to get more funding.   That's one way.   That's just a practical way.   But also thinking about creatively, how could you come together that's flexible.

Such as webinars, you know, coming together maybe with some people in person and others join via video.   And, you know, it's that kind of creativity that might be able to help the committee come together in the beginning when it didn't seem realistic because you don't have the resources to have everyone show up.

I'm looking again.   We're almost out of time.   Let's see here.

>> Brian Be: I would like to thank everyone for

being here today. Very likely from your home. And taking some of your time and energy to join us. Hopefully we'll get a chance to engage further on email. And hopefully you join some of the other Autism Special Interest Group webinars. There are three more coming up this month. And please remember to take the survey that we'll send out at the end of this webinar.

>> Richard Boles: Yeah. Thank you very much. I'm taking one last minute looking at some of the comments here. I think and it's -- it's really, you know, this idea of creating relationship. Thank you, Kristi, for making this comment of not cold calling. And I think that, you know, engagement is really about being genuine. As you mentioned. And that really goes a long way. It's not superficial. It's in-person if you can. It's in their community if you can. You don't bring people to the hospital or to the university if you don't have to. I like to meet with people in an environment that's easy for them and that's comfortable for them. And I think that's part of the way that you can make this engaging.

I've met with many family members at a community recreation center for example. I don't want them to necessarily come to the university. I don't like figuring out how to park there, I don't want for them to have to figure out how to park there. And so, it's little things like that that can go a long way in terms of being really respectful and thoughtful around who you're trying to engage with.

Rochelle asks if we'll be sharing our slides. Of course. These will certainly be available. We're happy to share those and the resources listed at the end for folks. Again, as we draw near now the very end of our time, I just personally would like to thank everyone who joined us for this call. Our AUCD partners and, of course, Brian for your involvement with this webinar. Thank you.

>> Brian Be: Yes, thank you, Dr. Boles. Back to our hosts at AUCD.

>> Maureen Johnson: Yes, thank you all for attending. The slides will be available on the event page. This webinar has been recorded and will be archived in the webinar library at AUCD.org. Please take a few minutes to complete our survey.