

REALTIME FILE

Association of University Centers on Disability
WEBINAR: NIH ALL OF US RESEARCH PROGRAM
JUNE 21, 2018

REMOTE CART CAPTIONING PROVIDED BY:
HOME TEAM CAPTIONS
www.captionfamily.com

* * * * *

Communication Access Realtime Translation (CART) captioning is provided in order to facilitate communication accessibility. CART captioning and this realtime file may not be a totally verbatim record of the proceedings.

* * * * *

>> Roberta Karlin: Ok. All righty. Good afternoon, everybody. I am Roberta Karlin, the Executive Director of the Association on Health and Disability. On behalf of the Executive Committee of the Friends of NCBDDD, I would like to welcome you to this webinar on the NIH research program All of Us.

The All of Us program has the overall goal of helping researchers understand more about why people get sick or stay healthy. All of Us is expanded to include populations that have been underrepresented in biomedical research and they are now including people with disabilities in the All of Us Research Program which we are all really excited about.

Our two speakers today are Ronnie Tepp and Karl Cooper. Ronnie Tepp will provide an overview of the All of Us Research Program and Karl Cooper will provide an overview of AAHD's outreach role to the disability community.

Ronnie is a principle at HCM Strategists located here in Washington , DC. HCM is a nationally recognized advocacy and public policy firm specializing in health and education. She is the principal investigator for the Engagement Awarding Team for the NIH All of Us Research Program and leads an overseas team charged with building a national network of trusted intermediaries to reach populations that have been historically not well represented in biomedical research. And AAHD is one of those trusted intermediaries.

Karl Cooper is an attorney and a disability advocate and a person with his own disabilities. He spent most of his professional career addressing the needs of individuals with

disabilities and currently serves as the Director of Public Health programs at AAHD where he oversees a number of projects which conduct outreach in the disability community.

Before we begin a few logistical details. We apologize --

>> Audio recording for this meeting has begun.

>> Roberta Karlin: Because of the number of participants, your audio lines will be muted throughout the call. However, we will unmute your phones, microphones, at the end of the Q&A portion. So I don't think that's actually true anymore. Those are just my prepared remarks since there was some audio difficulties with the microphones.

I believe, and Anna, please correct me if I'm wrong, that you can still submit questions at any point during the presentation via chat box on the webinar counsel and you may send a chat either to the audience, the entire audience, or to the presenters only. And then we will compile the questions throughout the webinar and address them at the end.

>> Anna Costalas: Can I interject one thing? If folks press star pound, they'll mute themselves. We're having technical difficulties and I cannot access the dashboard. So if you press star and pound, you'll mute yourself. Thank you.

>> Roberta Karlin: Thank you, Anna. We'll try to get to all of the questions but if not, Karl and Ronnie are available after the webinar. You can send them e-mails and they would certainly respond to your questions in a timely fashion.

The webinar is being recorded and it will be available on the Friends of NCBDDD website following this event. And there's a short five-question evaluation survey that we would really appreciate if you could fill out.

The Friends would like to thank AUCD for hosting this webinar and also our guest speakers for taking the time out of their busy schedules to participate in this webinar. So thank you. And we hope you enjoy the webinar. Again, Ronnie and Karl are available via e-mail after the webinar if there's questions that aren't answered.

So, Ronnie, take it away.

>> Ronnie Tepp: Great. Thank you, Roberta, and thanks to everybody on the call for making time to learn a little bit about All of Us.

Anna, show me again -- I'm happy to advance my own slides but the little arrow you showed me went away. There it is. Ok. Great.

Ok. So I'm going to back up for a minute, a brief minute, from where Roberta started which was talking about the All of Us Research Program. I just want to say a few words about precision medicine. I know we have different levels of understanding on the phone and just to level-set everybody, just to start here in terms of the concept of precision medicine which acknowledges that each of us is unique and that the interaction of biology environment and lifestyle all work together to greatly impact our health and our health outcomes. And what that means is that a treatment that works for one person may not work for another. And what precision medicine will enable us to do is to have the ability to look at things through the lens of a social construct with the focus on lifestyle and environment in addition to biology.

I have examples of precision medicine in practice today that many of you will be familiar with. Some examples are up here on the slide. So if you think about prescription eyeglasses, there's no one standard pair of eye glass that corrects vision for everybody who needs glasses to see. And likewise, hearing aids are customized to meet individual needs.

When we think about precision medicine, we think about not just the promise of precision medicine but we think about the cost of what we practice today which you can refer to as imprecise medicine. And there are costs for patients. There are costs for providers. And

there are costs for researchers. Some of which are listed here on the slide.

For patients, we have a system where healthcare is targeted to the average patient, not to the individual. For providers we don't have enough research and data to draw on to have clinical evidence in diverse populations, medical records are scattered, and it's hard for providers to access them in one place.

And for researchers, we have a system where data is siloed. And there are challenges, as you are all well aware, of acquiring large sample sizes to conduct certain types of research.

So with that super quick introduction to precision medicine, I want to share information about All of Us Research Program and how it seeks to accelerate the pathway to precision medicine.

President Obama first talked about the All of Us Research Program in his State of the Union address in 2015. And as Roberta mentioned in her introduction, it is an effort to bring together a million or more volunteers that reflect the rich diversity of our country -- and I'm going to talk about diversity in a moment -- who are willing to share their health data over a decade or more. And this is really important. We are looking for volunteers not just today but for the long run. The program is open to people, healthy and sick.

And this is another important point. Unlike a single research study that's focused on a particular disease or a particular population, the All of Us Research Program will serve as a national resource to inform many studies covering a wide variety of conditions.

There are three primary objectives to support this mission. And, again, you can see them up here on the slide. Building and nurturing relationships with participant partners. We don't call them subjects we don't call them members of a cohort. We call them participants in a community that we're seeking to build. Second, to deliver a rich resource of data that is easy, safe, and free to access. And third to catalyze a robust ecosystem of researchers who want to use it.

The program began with a set of core values that have guided the development and design of the program from day one. And, again, in the interest of time I won't read through them but that's not to take away from the importance. I would encourage you all to go back and take a look at these. It's quite unusual, I would say, to have a research study that starts with core values. And every decision that's made comes back to whether or not it is true to these core values.

I want to spend the next couple of minutes talking about how the All of Us Research Program is different, different in many different ways. When we think about diversity and when we talk about diversity, oftentimes people are talking about race and ethnicity. When we talk about and think about diversity in terms of the All of Us Research Program and the diversity of the participant community we are seeking to build, we think about quadruple diversity, diversity of people from all walks of life, diversity of health status, healthy and sick, diversity in terms of geography, rural, urban, and diversity of data types. We think about clinical, social, and environmental. You put that altogether and that's what we think of when we think of a very rich, diverse dataset.

The program is also different in terms of the transformational approach it takes to thinking about participation and really approaching individuals. Again, not as subjects but as real partners. We have participant partners that have been over the last few months integrated into governance of the program who are helping us to grow and shape the program now that we are about a month and a half after national launch.

And data access, this is something that comes up a lot when I talk to organizations and individuals who are thinking about getting involved. The dataset that will be created will be available to researchers, to providers to citizens, scientists, with appropriate safeguards to help accelerate scientific breakthroughs. And the data that will be available will grow over time.

So how do we do this? You know, we, my team and the program, have placed a high priority on reaching and educating and hopefully motivating populations and individuals that have been historically underrepresented in biomedical research and there are many reasons why that is. But what we know is that the barriers to participation for some is quite high. So really understanding what are the barriers that we have to overcome or work through and how do we do that.

And this is where my team, as the Engagement Team, sort of an extension of the program where we spend our time. We spend our time trying to identify who the right intermediaries are, the trusted messengers, as Roberta said. Who are the individuals and the organizations that serve and/or represent the population that we are seeking to educate and engage.

And in building this network, that I'll get to in a few slides, and in talking to these individuals and communities, it's really listening a lot and working to understand what the promise is and what the value proposition is. And it's not just potential participants but it's researchers and providers as well.

And even when we're thinking about participants, the value proposition will vary from person to person. So when -- when we think about the promise for participants what we've heard from the conversations we've had over the last two years, for some people the motivation is going to be an opportunity to help fight disease. For others, a chance to learn about their own health. And for others, the ability to choose and access your own data. And for many, and this comes up in almost every conversation when people learn about this opportunity, it's an opportunity to ensure that your community is included in the studies that will lead to new understanding and new treatment.

For researchers, we spend a lot of time talking to the research community. And, again, a number of issues and motivations have come up. These are the top: access to a rich resource of data, the creation of a longitudinal dataset that will follow participants as they move, as they age, as they get sick, and as they try new treatments; and also access to a dataset that is richer and more diverse than anything that currently exists.

For providers we have heard the interest in better tools for them to treat their patients better information, a better way to connect information that is now scattered across multiple records, sitting in multiple different places and new knowledge to help address health disparities.

So the next couple of slides I'll walk you through really briefly. At the end when we get to questions and answers, we can come back to any piece of this I would say any of these sections in and of itself is probably an entire webinar but I'm trying to provide a holistic overview, very high level.

So I want to talk about what the program looks like, what has been built in terms of the infrastructure over the last two years.

So here are the six main components of the All of Us Research Program consortia. There's the data and research center. This is housed at Vanderbilt University. This is where the data is spent and where it's curated, de-identified and where it lives in a secure environment.

There is the Biobank that has been built at the Mayo Clinic that will receive and store the bio specimens that volunteers will provide. Blood and urine.

There is the Participant Technology Systems Center being built by Vibrant Health. And that's the website, the phone-based apps for participants to enroll and to learn more about the program.

The Participant Center and Direct Volunteer Pathway. I'll get to that in a second. That is a pathway through which individuals can enroll and that's run out of the Scripps Research Institute in California with multiple corporate partners.

There's the Healthcare Provider, HPO, Network. These Are the on-the-ground enrollment sites. I'll show you a map as to where they are located. And these awards have grown and this is continuing to be built out.

And then there's the Communications & Community Network. And this is where HCM, my firm, sits along with Wondros which has helped with the branding and communications for the program.

So this is a map. I recognize it's really hard to read. We have to figure out a better way to show this. It gives you a sense of the consortia. So in the dark blue you have the national partners like Mayo Clinic, Scripps, the groups I just talked about. In the red you have the health provider organizations and those are the large systems that are doing on-the-ground enrollment. And the map doesn't accurately show where they are. It shows where they're headquartered but some of these consortium that span multiple states, that's not reflected really that well on this map. And then there are a handful of federally qualified health centers that are part of this HPO network that are also doing enrollment.

Again, this is hard to read but you'll have to look back on. This is another way of showing the map. This doesn't work so well either. These are the logos of the health provider organizations, the corporate partners are on top, groups like Walgreens, Blue Cross/Blue Shield, WebMD. Again, if people are interested, that's almost a separate webinar where we can talk about what these different corporate partners are doing as it relates to the program. And down on the bottom you have the other partners that are working on the technology, the communications and engagement platforms.

This slide here shows the community and provider partner network. This gets to what Roberta was talking about and what I mentioned earlier in terms of as a program building out a national network of trusted intermediary and validators and individuals that represent and/or serve priority populations we are so excited that AAHD has recently join joined. They're one of our newer partners in this network and they've already been quite busy. And Karl, I know, will talk in a few minutes to share about what they've been doing as it relates to outreach and education for all of us.

This network has grown. We are about nine months into the network. And groups have joined on at different times. And each of them, depending on who they are and who they serve or represent, are engaging in a number of different activities.

So how does somebody enroll? There are two ways a person can enroll. So if you receive your healthcare through one of the health provider organizations, the ones that were depicted in red in the map a few slides back, you -- everybody starts with the website you go to the website, join allofus.org. You create an account. You go through the consent document that is a combination of text and video. You then fill out some initial survey modules. And then the technology will pair you with the closest enrollment center and you will be invited to make an appointment to go in and provide blood and urine samples.

If you live outside of one of these health provider networks, which is a lot of people, then you still go through the same process up until you get to the point of pairing. And then you stop. And depending on who you are and where you live and who is enrolling, the program may send you an invitation to leverage one of the corporate partners. So, for example, there are certain Walgreens that have sites that are the intake centers for participants where you can donate your blood and urine and provide a bio sample and they will send you there.

And I should say the program launched -- some of you may have heard the program launched nationally on May 6 at seven sites across the country. There were events on the same Sunday. So we're about a month and a half into doors open, if you will, nationally. We have about 70,000 people that have enrolled to date and have begun the process of creating accounts, filling out surveys, and providing bio specimens. And we're learning as we go. And changes will occur as we learn and as more people join.

This here is a screen shot of the website, joinallofus.org. I would encourage you to go there to learn more about the program. There are frequently asked questions you can browse. You can set up an account and actually go through the enrollment process.

I will say that at the moment you have to be 18 years old or older. You have to live in the United States. And you have to be able to go through consent. The program is working on child enrollment. The program has a goal of opening up enrollment, beginning to open up enrollment, to children starting in 2019.

As I said, the information collected from participants will evolve over time with the science, with the technology, and, frankly, with the trust that we will build hopefully with participants. This slide here shows what will initially be asked of a participant. When you enroll, you'll provide consent. You'll authorize the transfer of your EHR. There are three basic survey modules that you'll be asked to complete. If you are paired with a site or invited to go in to donate your bio specimen, they will also do physical measurements you will provide blood and urine as a donation. And there are also some pilot studies that are starting and being run through the Scripps Research Institute. The first one is a Fitbit pilot. So what they will do is select individuals from the pool of participants and offer up the opportunity to them to be part of the study.

This just pulls out, again, the initial survey modules. And then numbers four, five, six, personal health history, family history, healthcare access and utilization are the next steps being developed. And then there are steps below that and then below that.

The approach will be once you enroll and you fill out your surveys, you will, over time, continue to receive surveys so that over time the program can continue to collect information and learn from you.

So this slide I want to sit on for a minute. There are a number of issues related to the disability community broadly that the program is working on. I know you all will likely be interested to understand.

There are issues related to data collection in the surveys there is a task force that has recently -- well, the program has announced they will be creating a task force. The members haven't been decided yet but it will be staffed by members within the consortia but there will be a mechanism and the ability for expertise outside of the consortium. And that's something we'll be working on with AAHD and hopefully many of you on the phone to make sure as a program we're asking the right questions and we're capturing the right data.

There are also issues, as you're well aware, related to enrollment and to consent. There are efforts underway right now. They're finishing up -- working to finish up children. And

then sort of next on their list is going to develop a plan and recommendations for enrollment for individuals who require proxy consent.

And I should mention for those of you who are familiar with the IRB process, the program at the very beginning set up its own IRB. So there is an IRB that was created at the beginning of this program to just work with all -- work with the All of Us Research Program.

And then -- it's not on this slide but it's important, and I should revise the slide to reflect this, but there are also issues around access broadly as it relates to the program. And that's something that Karl and the team at AAHD have already begun to help us with: Access to materials, access to things like the mobile unit that we have, that is traveling around the country, to bring information about All of Us literally to where people live. So that's another important area that we're working on as well.

Privacy and security. This comes up in every conversation we have. You know, this is the program's most important responsibility, to make sure that we are safeguarding a participant's identity and data. So this is part of the reason why the launch date kept getting moved, because they wanted to make sure that they had done their due diligence and have systems in place to safeguard this data.

So I'm going to end here. I'd like to end -- before I turn it over you, Karl -- with just a note. My e-mail and contact information is here on the next slide. I would encourage any of you who are interested in learning more to reach out. I know I went through that quite quickly. And also, I didn't have slides on this but if your organization -- if you're on representing an organization and you might be interested in learning more about how you as an organization can get involved, our team has developed a whole menu of opportunities. And we've also developed tools and resources to help organizations engage in some of these opportunities.

And I'm happy, offline, one-on-one, to talk you through what those are and how to access them. So I would encourage anyone who is interested to reach out.

With that, Karl, I will turn it over you.

>> Karl Cooper: Thanks, Ronnie. I want to just talk briefly, for those of you who weren't familiar with our organization, just who we are and what role we play in this project. The American Association on Health and Disabilities, our stated mission is to promote health and wellness initiatives for people with disabilities. We do that through forming objectives, to reduce health disparities, advocate for community inclusion, work to promote full accessibility within the healthcare set, and we also work to integrate disability into the public health agenda. And that's really where that last objective is really where this project comes in.

One of the things we like to say that we do is we look for the cracks in public health initiatives where people with disabilities may be falling through. This particular project is a great example of that in the sense that it really goes to show an area where we want to make sure that people with disabilities are fully being included that they are being considered for this and that people with disabilities are engaging with this to make sure that they really can tap into this great opportunity to make sure that they can -- make sure that their information is included so that people with disabilities are represented in the groups.

Ronnie talked about the fact that we want to make sure this is a representative sample and we want to make sure that that's done in a way that's going really reflect the disability community and make sure that their data is included in this set as well.

So AAHD's role in this organization, there's a number of things we're working to do. First was we were going to identify and fund three trusted intermediaries which I'll be talking about in a moment. The groups that we're working with. As a national organization, we don't

always have the local connections to do an outreach project like this. And we wanted to make sure we had some state and local organizations that were really going to be able to help us do that grassroots outreach to make sure that we're reaching people with disabilities at the ground level.

We're also helping work on developing a disability-focused rationale for involvement in the All of Us project. One of the things that has come up is we've looked at this project, the presentation that Ronnie just went through, as where there's so many areas where there is sort of an intersect -- the intersect of what all of us is trying to do and where the disability community has been for years.

So when they're talking about the All of Us project really having participation, making sure that they are actively involved in the project, and discussing what research questions are looked at and those types of basic issues, that really feeds into the whole idea of nothing about us without us; that we're trying to make sure that people with disabilities are included in these decisions and that as we're looking at, you know, exactly what this project is going to be used for, that we are making sure that we get the input from the disability community.

The other thing that really ties into this as well is, you know, looking at -- many NIH studies are very focused on the medical model of the way that healthcare is practiced. And the disability community we have been very much, you know, for years talking about the fact that things go beyond the medical model for disability that we can't completely determine health and health outcomes based on, you know, what is happening from a medical standpoint that successes for people with disabilities also have to do with how their environment is being changed, and what we're doing to transform that environment and their lifestyle.

So in a study like that NIH is putting out is looking at those issues, really looking at issues that are dealing with lifestyle that are dealing with environment, they're really talking about things that the disability community has been looking at for years in terms of what we can do to improve those areas to improve people's health.

So it really goes hand in hand with a lot of what the disability community is doing. And we're excited to be a part of that. And we're going to be developing a lot of that rationale to really help educate the disability community about that and really engage them in this project.

We're also, as Ronnie said, reviewing the All of Us Research Program materials and messages to make sure materials are fully accessible, making sure that they are able to completely engage in this.

We've had a lot of discussions in terms of making sure that some of the materials that we have are available in alternative formats. And as Ronnie said, the mobile asset that is going around the country, I had the opportunity to visit that in May. As a wheelchair user myself, I was able to make sure that I was able to fully engage with that and we were able to help them understand some disability issues a little bit better so that those people could completely be engage in the that activity.

We also are working to conduct national education and outreach on All of Us to the disability community, and doing that through webinars like today to make sure we are doing some of the national outreach as well as to what we're going to be doing at the local and state level with our trusted partners.

And we have three partner sites, the three that we are working with. We wanted to make sure we were getting a varying view of exactly what we're doing and who we're working with and sort of the geography that we're working with as well. So the three partner groups

we're working with is the Lakeshore Foundation, Birmingham, Alabama. And they have really a cross of all the different types of geography there, you know, Birmingham is a city but it also has a lot of rural areas around it. So it has a very sort of cross-sectional approach in terms of what they're going to be looking at from a geographical stand point and the makeup of their population.

Then we have the other ends of the spectrum with our other two groups. We're working with the University of Montana Rural Institute in Missoula, Montana, to do outreach to the rural communities and looking at exactly what that means for this project. And all the things that come along with that, like, you know, when they do -- when they are going to be involved in trying to get people to clinics to do the bio specimens and how far they have to go and making sure that that's not so much of a barrier and all of those things, things that we're looking at, and really trying to help with the messaging on so that it doesn't become a barrier for people to get involved.

And then on the other end of the spectrum, we're working with the Center for Independence of the Disabled, New York, the Center for Independent Living in New York City. They have offices in Manhattan and Queens. And they are obviously helping us with our urban focus and really looking at the messaging and how it works in the urban setting and how we can engage those individuals as well.

So in terms of what each of these groups are doing, in Birmingham, Alabama, at Lakeshore, they hosted a vendor booth at one of the launch events that was done on May 6, which was the last launch day, done in Birmingham. So Lakeshore was there. They had a vendor booth there to make sure they could highlight what they were doing for people with disabilities. They also hosted the mobile asset on May 12. And that's the picture you see that is there. That's when I went down to visit that specific location and really sort of highlight that within the local disability community there.

We're also working with local disability organizations to promote the All of Us program and the individuals you see in the picture with me are some of the folks that came out that are associated with those organizations that helped us promote that with the mobile asset that day as well.

They're also conducting a webinar for their local disability community down there to educate them about the opportunity. And, of course, all of our groups are posting -- doing social media posting to do outreach in their community through digital means as well.

The University of Montana, they're activating their local disability organizations predominantly the Centers for Independent Living that they work with in Montana. I was out there last week to do some education to the CILs to let them know what the project is all about and to answer questions they had so that they would have the buy-in among their organizations so they could truly feel like they could recommend this to the people that they serve.

And along with that, then a lot of what they do in Montana with rural outreach is trying to do things through sort of a coordinated approach that they work through a communications committee to do to make sure that they've got consistent messaging amongst the group of CILs that are there and make sure that the messaging that they are reaching the people with is going to be consistent and is really going to be able to actively meet those individuals in a variety of settings so that they can get the message out to the broadest number of people.

We're also going to be hosting exhibit booths at a lot of the local community events

happening throughout the summer. And they will be conducting a webinar for the community there as well as their social media posts as well.

And then our last group that we're going to be working with is the Center for Independence of the Disabled, New York. As an urban group, their focus is a little bit different. They're utilizing the prose outlooks that they have with a lot of outreach that they do with their disability press outlets to make sure that they're getting messaging out there to the community.

They are also -- yesterday -- the picture you see there is when I was presenting yesterday at their community workshop. They hold monthly community workshops where people can come in and learn about different things, different services, different initiatives and I was there to be able to explain the All of Us program to the group that was there and really answer questions about that. In that instance, one of the groups that Ronnie talked about was some of the clinics that are involved in this.

I was also able to partner in with Liz Cohn who works with the New York Consortium that deals with a lot of the hospitals and clinics up there that they're running to do the enrollment and the biobanks and get where they collect the bio specimens. So we were able to partner with her. She was able to answer some of the local logistical questions folks had. And it really ended up being a great event that really allowed the connection from us as a national level but also gave it that local connection as well and also promoting the All of Us at the Disability Pride Parade this summer and they will be conducting the webinar and using their social media as an outlet to reach the disability community.

So that's what we're doing with this project. We're very excited about what we're doing because we really feel like it sort of has a great intersection for what we do here at AAHD and for the disability community. And we feel like it's a great project that we really want to make sure that the disability community knows about so that they can be involved and they won't be excluded like they have been in so many clinical trials that have been done in the past.

So at this point I guess we will open it up for questions either from myself or for Ronnie.

>> Roberta Karlin: Great. Thank you so much. What a wonderful presentation.

We actually have a couple of questions already in the chat box. So I'm going to read those out you.

We have someone, the Director of the Deaf [Inaudible] at Gallaudet, people use -- information can only be done through videos, using ASL can they produce the ASL videos and associate the questions he in the All of Us survey and can those videos be easily uploaded?

>> Ronnie Tepp: Thanks. Thanks for the question. This is Ronnie with HCM. I know -- I don't know the answer to all of those pieces but what I can do is get the answers for you and make sure. One of the things we actually were having a back and forth this morning between myself and AAHD, working to facilitate a conversation with program leadership and the team that's working on the assets to make sure that, you know, when I made the point earlier about accessibility to make sure that we have multiple formats so that the program is truly accessible to all people.

So I will take this one back. Anna, I don't know the best way to get answers back. What would you suggest?

>> Anna Costalas: I will have a copy of the chat box and the question that are unanswered, I will provide you with e-mail addresses of the participants.

>> Ronnie Tepp: Perfect. Thank you for the question.

>> Anna Costalas: And for the public, I will post it on the event page, too.

>> Ronnie Tepp: Perfect. Thank you.

>> Anna Costalas: We have another question. If you could speak a little more regarding to part partners in rural areas, how they will be supported. Transportation is crucial for rural residents.

>> Ronnie Tepp: Yes. Again, thanks for that question. A couple of ways -- we know that there are barriers in terms of participation when we think about geography. Some of the partners that you saw on the map, their network extends more than just where the blue box is on the map. So some of them have reached into rural areas and they have mobile vans that they use for their health system, that they are transforming on certain days or certain months to, you know, go out on behalf of all of us and literally meet people where they are.

The other thing that our team has done, and it wasn't part of the original program design but we quickly realized that, you know, we needed to figure out how to get to people as opposed to just always asking people to get to us as a program. So our team has worked with some of the other partners. Karl mentioned it. I didn't have a slide on here. I was trying to pare down the presentation.

But we do have a mobile unit. It's called the All of Us Journey. It is a 40-something-foot trailer. It literally brings the All of Us Research Program to communities around the country. It's been on tour for 40-plus weeks. And it was just taking a bit of a break but it's back on the road. It was most recently in North Carolina. We sort of plot out three months at a time where it's going. It's only one unit at the moment. There is a mobile unit number two that is in production. That will hit the road in the fall. And that unit will have the ability to also do bio specimen collection.

So we are collecting a lot of data to make sure the interactive nature of the exhibits inside the unit are resonating with people and also, to Karl's point, that they are accessible to everybody who wants to go through the unit.

It also explains and he had indicates people about the All of Us Research Program but it also started we started and takes a few steps backwards, and makes sure the concept of precision medicine is accessible to people and understandable, and what it means to spend some time taking people through exercises to explain what it means to participate in a research study. But we've gotten great feedback from that unit. And as I said [Inaudible]. One of the corporate partners -- let me see if I can go back to this chart. Bear with me one second.

One of the corporate partners, there's Quest and EMSI, you can see at the top, corporate partner to the program. They have the ability to do bio specimen capture in people's homes. So if the program wants to pair up somebody who has joined through the website because they represent an important population or geography, then they can send EMSI to their home to do bio specimen capture there.

So it's not going to solve the entire problem but we are look looking to start with this and then we'll come up with some additional strategies, hopefully with the expertise of the community broadly as we go forward.

>> Anna Costalas: Great. We have another question -- someone just asked a question and it knocked off. Hold on.

>> Ronnie Tepp: Ok.

>> Anna Costalas: How will this not be just a medical model and of a disability model?

>> Ronnie Tepp: Sorry. Say that again?

>> Anna Costalas: Elaborate how this will not be the medical model and of a disability. You

go? If you could just elaborate. This is a little vague.

I'll go on to the next question. How to get scheduled in for a mobile unit road tour.

>> Ronnie Tepp: Great question.

>> This is Aaron to elaborate on my question. Like you asked me to.

>> Anna Costalas: Sure.

>> I'm just not a very good speller. The gentleman mentioned how he was committed to making sure that this was not just the medical model of disability but captured the other forces of disability, you know, the social and environmental forces so I was just wondering if he could elaborate how the All of Us project is going to ensure that it's not just as a person with cerebral palsy, you know, the medical community so focused on the medical model. How is it going to be different?

>> Karl Cooper: I'm happy to take that question. Really what I was talking about, when I was referring to that issue, is the fact that this particular study is really looking at things that go beyond biology. They're going to be studying biology for sure. They're getting the bio specimen. They're going to be checking people's DNA and getting genetic sequencing and those things. But they're also looking at issues that deal with lifestyle, dealing with issues that deal with environment, and how that all interplays into our health.

>> Can you give an example?

>> Karl Cooper: For instance, one of the things that if you -- when I enrolled -- I did the enrollment process. When I went through the enrollment process and did those initial surveys, they're asking questions about access to healthcare and, you know, what exactly you have in terms of your access. And there's going to be a lot. And there's also a lot in there on lifestyle in terms of, you know, your activity level, in terms of whether you smoke, whether you drink, and those types of things.

And they're going to be -- as they develop further surveys, they're going to be look at even more of those environmental factors. And, you know, when we talk about, you know, access to healthcare, we're talking about, you know, how often you're able to go to the doctor and what sort of barriers you reach when you have things that are -- sort of become a barriers and don't allow you fully participate in the healthcare setting.

So we're going to be looking at a lot of those different types of, you know, alternative sort of ways of looking at healthcare. And that's where we're really talking about, in those environmental factors that really play into our health that a lot of people don't think about in terms of, you know, how your community is set up and, you know what kind of access that means you have to healthcare.

Go ahead.

>> No, go ahead.

>> Karl Cooper: So you'll of those things play a factor into our health that, you know, lots of the medical providers aren't thinking about. They're only focused on the medical part of things and not looking at the broader social context to some of the medical conditions we face.

>> Well, the other thing for me and then I'll stop is, you know, they say, Oh, people with disabilities don't go to the doctor a lot. Well, with a guy with CP I don't go because I can't get on the exam table.

>> Karl Cooper: Yes.

>> Thank you.

>> Karl Cooper: Yeah. That's a problem we recognize, we talk about all the time. So I think access to healthcare is going to be one of the things they're looking at through this study from

a broader context. But then, you know, hopefully we'll be able to help them realize that they need to ask some of those more specific and point questions when they are doing some of these surveys.

That's one of the things that we've been talking with the project about, is making sure that they're really diving into exactly what we're talking about when we're talking about disabilities. Right now they have some very broad, functional questions. But they are that, very broad right now. But they're going to be doing surveys that follow-up throughout the course of this. This is a 10-year study that they want to do. So the course of those 10 years we're hoping that those surveys will get developed so that they're really asking even more specific and pointed questions on issues like that.

>> Thank you both so much.

>> [Multi-voice overlap]

>> NIH, can I follow up briefly?

>> Karl Cooper: Sure. Go ahead.

>> I'm Alison, Director of National Center for Medical Rehabilitation Center Research. I joined late. But to add to Karl's point, they are also looking at new and innovative ways to capture information. So some of the things they're looking at to potentially get to the specific example that you're talking about is how to capture the context of the person in their environment as it impacts their health. And there are health approaches like taking pictures of your environment and sending it and having that be part of your record.

So if you can't get on a table and you capture that and put a comment on it, there's some social media tools that they're going to hope to incorporate over time that will be able to capture those contextual factors that we can't get to in a regular clinical trial or regular clinical study. They're trying to turn this on its head and give the participant a little bit more power over their data and what they contribute.

So I absolutely understand that concern. And I do want you to know that that's something within NIH, something that we're starting to help this program understand that getting the context of people is very important.

>> Anna Costalas: Great. Well, it's almost 3:00 and I just want to be aware of our realtime captions. There was three or four questions that were not answered. What I'm going to do is forward them on to our presenters, and I will get them back to you, in regards to transportation and such.

I just want to thank our presenters today. Thank you for sharing this valuable information. And I thank everyone for joining us today. Thank you for putting up with our technical difficulties.

>> [Multi-voice overlap]

>> Anna Costalas: This webinar is being recorded. And will be ready at the AUCD webinar library at the end of the week, probably on Friday, tomorrow.

If you can just take a moment and fill out the survey that's going to pop up on your screen, it would be greatly appreciated. Thank you and have a great rest of your day.

>> Bye.