

**RECOVER January Listening Session:
Understanding Long COVID Across Communities of Color**
January 21, 2022

Speaker 1: Thank you all for joining today's listening session, hosted by the NIH Researching COVID to Enhance Recovery Initiative, also known as RECOVER. This event is being recorded and all participants have been muted. Before we begin, we'll share a few housekeeping notes. As a participant in today's session, you will have the ability to unmute [00:00:30] yourself, turn on your camera, view participants, and participate in the chat. When we get to the discussion portion of today's agenda, we will encourage you to turn your camera on to engage in the discussion. And if you prefer, you are also welcome to type in the chat panel. During the Q&A and discussion, we will ask that you virtually raise your hand to speak. You can do so by clicking on the reactions button [00:01:00] and then raise hand, and one of the hosts will then invite you to unmute yourself.

Finally, we encourage everyone to change your name as it appears in zoom, in order to add your organization and location. To change your name, you can click on participants, then more, rename, and then from there you can change your name. Thank you all. And now I will turn [00:01:30] it over to Dr. Natasha Williams to introduce today's speakers.

Dr. Natasha Wil...: Good afternoon. Thank you for joining us for today's listening session for the NIH Researching COVID to Enhance Recovery Initiative, also called NIH RECOVER. My name is Natasha Williams. I am an associate professor at NYU Grossman School of Medicine, Department of Population Health, Institute for Excellence in Health Equity. I am also the lead for the community [00:02:00] engagement for clinical science core. I am really happy to be here with you all today. And I am one of the co-hosts for our session. Today's session is the second in a series of discussions to hear from patient, community and others affected by post-acute sequelae of SARS-CoV-2 or PASC, including Long COVID.

In this case, we are specifically interested in how long COVID is affecting black and indigenous [00:02:30] communities of color. Recognizing that communities of color are disproportionately affected by COVID-19, it is likely that they similarly might experience a disproportionate burden of Long COVID. Historically, what we know is that misinformation and structural factors such as access to healthcare may pose as barriers to health seeking for racial and ethnic communities. It is also likely that these barriers exist when [00:03:00] addressing Long COVID. As we seek to better understand the needs and priorities of patients who are most affected by Long COVID, your organization's voice is a valuable part of this conversation. I will now turn it over to my co-host, Dr. Andrea Lerner to introduce herself. So over to you, Dr. Lerner.

Dr. Andrea Lern...: Thanks Dr. Williams. Good afternoon everyone and thank you for joining [00:03:30] today. My name is Andrea Lerner. I'm an infectious diseases

physician and medical officer in the office of the director at the National Institute of Allergy and Infectious Diseases, part of the National Institutes of Health. Back to you, Dr. Williams.

Dr. Natasha Wil...: Thank you, Dr. Lerner. Now, I'm going to introduce today's discussion moderator. We are delighted to have Dr. James Hildreth with us today. Dr. James Hildreth [00:04:00] is the president and chief executive officer of Meharry Medical College, the nation's largest, private, independent, historically black academic health sciences center. He is also a temporary voting member of the Vaccines and Related Biological Products Advisory Committee, a member of the advisory committee to the NIH director, and he's served on the president's COVID-19 task force. We are honored to have him join us today. [00:04:30] Next slide, please. Now that we've finished our introductions, we will begin with a brief overview of the RECOVER Initiative, and then the remaining session will focus on discussion. Next slide. I'll hand it over to you, Dr. Lerner.

Dr. Andrea Lerner...: Great. Thank you very much. So I'll just take a few moments to talk about the purpose of today's listening [00:05:00] session. As Dr. Williams mentioned, today we hope to engage with patients and organizations representing communities of color, including those hardest hit by COVID to better understand the levels of awareness of Long COVID, and also discuss opportunities to promote diverse and inclusive participation in the RECOVER Initiative studies. Next slide, please.

So now I'll just give a brief overview [00:05:30] of the RECOVER Initiative and actually what the RECOVER Initiative is studying. So I'd like to just clarify some terminology. So the RECOVER initiative is studying the post-acute sequelae of SARS-CoV-2 infection. This is abbreviated P-A-S-C, PASC, as you can see here. This term refers to the effects that COVID-19 has on the body after [00:06:00] the initial parts of the illness. So, the later term effects of COVID-19 and SARS-CoV-2 infection, which is the virus that causes COVID-19.

Under this umbrella is also what is often referred to as Long COVID. So the term PASC is meant to refer to a broad variety of effects. What is often referred to as Long COVID, you may have heard people describing ongoing [00:06:30] symptoms, waxing and waning symptoms that impact quality of life after the initial periods of COVID-19. So patients vary in the timing and extent of their recovery. People report symptoms ranging from mild to truly incapacitating, and these symptoms can involve multiple parts of the body and really affect overall quality of life.

Symptoms reported due to Long COVID [00:07:00] can range from things like fatigue, shortness of breath, brain fog or difficulty thinking or concentrating, sleep disorders, fevers, gastrointestinal symptoms, anxiety and depression, and sometimes these can persist for quite a long time. People may have ongoing symptoms similar to the symptoms they had earlier with COVID-19 that persist, or people can develop [00:07:30] new symptoms and these can wax and wane. And while we don't fully

understand the public health impact of post-acute sequelae of SARS-CoV-2 and long COVID, we know that given this scope of COVID-19, this is likely a large public health impact and it's important to acknowledge that. Next slide, please.

So now I'll just pause [00:08:00] to see if there are any questions about PASC or Long COVID that I've just discussed. Okay. I'm not seeing hands raised, I'm not seeing anything in the chat. All right. So next slide, please.

So next... I told you a little bit about what RECOVER is studying. [00:08:30] Next, I'll talk about actually the goals and structure of the RECOVER Initiative studies. So the goal of RECOVER is to improve rapidly, our understanding of, and also the ability to predict, treat and prevent PASC and under that umbrella, including Long COVID. So the key scientific aims, we would like to understand the full clinical spectrum. [00:09:00] So all of the different manifestations of PASC and the biology that underlies the recovery from COVID-19. We'd like to define the risk factors, the incidence and prevalence and different subtypes of PASC because we're likely dealing... We're calling everything by one name now, but as we learn more about it, this is likely multiple different conditions.

We aim to study [00:09:30] the pathogenesis of PASC and Long COVID over time. And this may be able to be related to other known disorders and inform our knowledge about other disorders. And ultimately we'd like to identify interventions to treat and prevent PASC. Next slide, please. So how will these aims be accomplished? What is the RECOVER research approach? [00:10:00] So, as I've mentioned, the goals of the initiative are to understand PASC including Long COVID advanced towards clinical trials and informed treatment and preventative strategies for PASC. So this will be accomplished by multiple different types of studies. So at the heart of the RECOVER Initiative, is what we are calling the recovery cohort. This is... I'll deep get into this a little bit more on the next slide, but [00:10:30] this is a cohort of individuals with COVID-19 and PASC and they'll be followed over time to understand the progression of their recovery.

Complimenting and in addition to their recovery cohort and part of the RECOVER Initiative, will be studies of electronic health records, studies of real world data, and included in that are things like mobile health [00:11:00] and wearable technologies that can record data as people recover, and also studies of human tissue. And some features underpinning all of these different types of studies are that they involve hundreds of researchers and sites around the country, across the whole country, we aim for inclusive and diverse participation in these studies, they will enroll children, adults, and [00:11:30] pregnant individuals. Community engagement is a central tenant under underpinning the RECOVER Initiative and the studies are multi-disciplinary. So multiple researchers with multiple different types of expertise are involved. Next

slide, please. And now I'll turn it back over to Dr. Williams to talk about the national scope of the RECOVER Initiative.

Dr. Natasha Wil...: Thank you so much Dr. [00:12:00] Lerner. So as you can imagine, a study of this magnitude really will take place across the country. The RECOVER cohort anticipates enrolling adults, children and their caregivers, and pregnant participants and their newborn infants. They will encompass hundreds of clinical sites across the nation, really to reflect the ethnic and racial diversity across the human lifecycle and reaching all geographic regions. It [00:12:30] is designed to address the fundamental questions in the first 12 months, provide longitudinal follow up and really lay the foundation for studies of pathobiology and clinical interventions. There will be analysis of electronic health records of more than 36 million adult and pediatric patients. Next slide, please.

The RECOVER consortium includes a main protocol development. Developing [00:13:00] these main protocols including collaboration with over 200 investigators, 33 patients with input from NIH subject matter experts, provided phase one awards to 30 clinical cohorts and three large scale electronic health record studies. It is essential for harmonizing these studies and that involves standardizing scientific aims, tests and procedures, a unified entry criteria based [00:13:30] on the World Health Organization for all cohorts. We make consistent data structure across all cohorts and a harmonized data management and data analysis plan. We will create tiered phenotyping approach for adults in pediatric cohorts and planned adaptive designs really based on continuing analysis and the evolving science as we continue to learn about COVID. In some, the RECOVER Initiative has [00:14:00] ensured that all cohort and site studies are harmonized under a main protocol. Next slide, please.

As we mentioned, the RECOVER Initiative is patient-focused. And some of these features really involve including over 400 attendees of discussion on the patient experience, over 30 patients participated in this main protocol development. There's representation across the government structure [00:14:30] where patients, caregivers and other community representatives will be included. As we shared, community engagement really adds value to every element of the initiative. Next slide. We'll take a brief pause to see if there are any questions at this point.

Speaker 2: So I do have one question, if I may ask, it seems like you are [00:15:00] going to be using the electronic health records. I know that Cerner and Epic are the major two electronic health systems that are utilized. If there are providers that aren't on those systems, whether there'll be alternative ways that they can participate if they don't have access to those systems.

Dr. Natasha Wil...: So we would be happy to work with any of those sites that are doing recruitment [00:15:30] to better understand their needs. But many of these sites are a part of the electronic health records, but certainly welcome discussions to better understand those needs. Thank you for your question. Okay. Next slide. So now I will [00:16:00] just like to

remind us again about our moderator for today's listening session, Dr. James Hildreth. And I'll just share, in addition to his position, Dr. Hildreth graduated from Oxford University with a PhD in immunology and obtained his MD from Johns Hopkins University. He later became the first African American in the 125 year history of Johns Hopkins School of Medicine, to earn [00:16:30] full professorship and tenure in the basic sciences. He also served as the first African American dean of the College of Biological Sciences at University of California, Davis.

In October 2008, he was honored for his contributions to medical science by election to the Institute of Medicine, part of the National Academy of Sciences. And he also earned an honorary doctorate from the University of Arkansas, the Garrett-Evangelical [00:17:00] Theological Seminary and induction into the Arkansas Black Hall of Fame. We are honored to have Dr. James Hildreth join us today. And I'll hand it over to you, Dr. Hildreth.

Dr. James Hildr...: Thank you, Dr. Williams. I first want to thank Dr. Gary Gibbons, the NHLBI director, for inviting me to take part in this very important conversation. As you heard, I was part of the president [00:17:30] Biden's Health Equity Task Force, and we spent a considerable amount of time thinking about Long COVID and its impact on minoritized communities. And I would invite you to go to the HHS website, I think a copy of the final report is posted there for anyone who wants to see it. As you've heard, it is very likely, in fact we are sure that Long COVID, like COVID-19, is going to disproportionately impact communities of color, minoritized communities. [00:18:00] And from my perspective, being a physician scientist, we know that there's a long history for women and minorities. Women present with conditions that readily diagnosed by objective measures such as tests or procedures, often times are not taken very seriously by the providers and chronic fatigue syndrome is a great example of that.

And as you've heard from my colleague, Long COVID encompasses conditions that impact multiple [00:18:30] systems in our bodies, which means that teams of investigators and physicians across multiple specialties, neurologists, pulmonologists, et cetera will be involved in finding the answers and taking care of patients. Minoritized communities and those without insurance, don't usually have access to primary care physicians and they certainly won't have access to specialists.

So I think it's very, very important, and this is one of the recommendations that came under the task force, that we make sure that [00:19:00] uninsured persons in our country have access to the kind of treatment they will need. And very importantly as well, that the appropriate disability considerations be given to those individuals to make sure that the impact on Long COVID is not a disproportionate burden on that. And those are just a few of the things that we talked about and recommended in our report to the president. But I would invite you to go to the website there and look at the report and all the recommendations that we've made.

So [00:19:30] if go to the next slide, I want to go through some guidelines as we have our discussion today, just to make sure that all voices can be heard and that we can have some order in this important conversation. First, I would advise you to use the raise hand function if you'd like to speak. And you had a demonstration on how to do that when we first began. But I ask you to wait until called upon before you unmute yourselves and talk. And if you would like to, [00:20:00] certainly turn on your video when you ask your question, if you'd like to be seen by the community. And please introduce yourself by name and tell us whose organization that you are from in order to make sure that as many voices can be heard as possible, we ask that you make only one comment or ask only one question and that you limit your time to two minutes. In that way, all of us can take part in this, again, this very important conversation today.

So if I can [00:20:30] have a next slide, please. We've come up with some questions to organize our conversation today. And the first question is a really important one, it relates to our perceptions of this. And so the question is, what is your perception of the level of awareness around Long COVID and its symptoms in your community? And we all know that as we've talked about before, many people don't recognize [00:21:00] Long COVID for what it is. So there's a great need to make sure we have an understanding of the level of understanding of our communities about this. And some of the things we might ask as a part of that question is, are there specific groups or individuals that we might focus on that we might want to reach as we're doing this work? And from your understanding, what have people heard about RECOVER, and what have they heard about Long COVID and the studies that we're doing?

[00:21:30] And then recognizing that all of us may not recognize the labels and symptoms as Long COVID. What, if anything, have you heard in your community that people talk about in getting over COVID? Because often times in that recovery, there's actually Long COVID happening, but people are not aware that there's a name for it, that this is an actual phenomenon. And then, so based on all of that and your knowledge of what is happening, [00:22:00] what would you think are the best modalities for getting the word out, delivering information around Long COVID to the communities that you are here representing? So with that, I will open it up for comments and questions. So you can either enter your question in the chat or... Oh, I see. [00:22:30] Dr. Mumtaz, I believe from NIH CEAL.

Dr. Mumtaz: Yes. I'm one of the four co-chairs of the steering committee of NIH CEAL, thank you. And my question is, do we have any estimates of the proportion of people who have suffered from COVID who then go on to suffer from Long COVID?

Dr. James Hildr...: My understanding of this is that somewhere between [00:23:00] 20% and 30% of individuals who get COVID-19 will go on to suffer from Long COVID. But I believe that one of my colleagues might have some

additional information to share. So I would welcome them to respond as well.

Dr. Mumtaz: Thank you.

Dr. Andrea Lern...: Yes. So estimates for the incidents [00:23:30] and prevalence of Long COVID, many studies fall around the range that Dr. Hildreth mentioned. It's important to also recognize very widely ranging in the literature and it depends on specifically what the studies are looking at, which symptoms, which effects and in which population. Some studies have shown that people with more severe [00:24:00] underlying, or more severe initial disease, such as hospitalized patient-

Dr. Andrea Lern...: ... lying, or more severe initial disease, such as hospitalized patients have a greater burden of lingering effects. So it's very variable.

Dr. James Hildr...: Thank you. I see Wanda Altman. I can't... I'm sorry.

Wanda Altman: Yes. It's Wanda Altman.

Dr. James Hildr...: Yes, please [00:24:30] come in. Can you...

Wanda Altman: I had a comment, not a question so much.

Dr. James Hildr...: Please.

Wanda Altman: That I was stricken with COVID in July of 2020, and anything of long COVID of long haulers until one night I was having insomnia and turned the TV to full court press. And there was a young woman on there, speaking to long haulers [00:25:00] and the work she had done around long COVID and talked about the symptoms, which were many of the symptoms that I experienced now. So I would say in the community, there is not a high level of awareness around long COVID and its symptoms because I've spoken with persons that will say, "Oh, I still have this cough. I can't get rid of this cough. I'm still not able to [00:25:30] taste or smell," but they don't have any idea. And I couldn't tell them what it was other than it's just something that lingers around after COVID, because I was not aware of long COVID until I was invited to... I mean, the recovery. I was aware of long COVID, like I said, when I turned to the TV program, but RECOVER, I was only aware of it when I was invited to participate in the listening session.

Dr. James Hildr...: Thank you. And you [00:26:00] raised a really important point that we are dealing with, which is how to get the word out to communities that are not aware of this phenomena. That is a real thing that we need to be focused on. So your point is definitely well taken. I see Dr. Bryan Heckman and then Dr. Abigail Echo-Hawk, please go ahead. Dr. Heckman, did we lose Dr. Heckman? So Abigail, would you like to go while we get [00:26:30] Dr. Heckman back?

Dr. Abigail Ech...:

Sure. Thank you so much. I'm Abigail Echo-Hawk. I'm the director of the Urban Indian Health Institute, the only national tribal epidemiology center, focusing on urban dwelling, American Indians and Alaska natives, along with being the executive vice president, the Seattle Indian health board of federal qualified health center in Seattle Washington, serving American Indians and Alaska natives. And I just want to start my comments by first talking a little bit about my concerns around the methods of the study that definitely raised some awareness for [00:27:00] me of thinking about how this study may have some limitations, particularly when it looks at the information related to American Indians and Alaska natives. I'm co-author on several different papers regarding the rates of COVID-19 in American Indian and Alaska native communities nationwide. And what we found was an incredible lack of data. And as a direct result of that, we have found racial misclassification and non collection of race and ethnicity of American Indians, Alaskan natives, along with other BIPOC communities.

And as a direct result of that, when [00:27:30] you look in the EHR records and you're trying to track whether or not they had a COVID infection and then long COVID after that is a direct result of that, those limitations in the data are going to skew and not properly represent the American Indian and Alaska native experience. And so there is definitely some work that needs to be done on looking at the racial misclassification possible linkages to correct for racial misclassification in order to make those studies relevant to a population [00:28:00] that has been one of the most impacted by COVID-19. In addition, the recruitment strategies that may be using hospital records in which to send letters out to folks to engage, or however you're looking to engage participants is that we find when people are using hospital records, American Indians, Alaskan natives often go off reservation lands in order to receive treatment, particularly if they ended up in the hospital.

When you send letters out, you are actively recruiting on tribal lands without tribal permission, which is active and active act against [00:28:30] tribal sovereignty in which they have the ability to limit, to engage in and to regulate any research happening on tribal land. So I would definitely suggest you take a look at your methods to ensure that you're not impinging on tribal sovereignty and conducting unethical research. In regards to the question there is an absolute lack of understanding of long COVID within our community. We are still in the midst of an incredible crises and people are trying to just overcome that crises. [00:29:00] And we haven't been able to engage in what long COVID impacts can look like, but yet within my own clinical population and my work I do across the nation, we are seeing long COVID. And when our folks go into non-indigenous hospitals and clinics, nobody's believing them.

And so we're seeing the impact of implicit bias, racism and prejudice, and the non-belief of those who are experiencing symptoms. One of the things we have found is that the mainstream [00:29:30] strategies, particularly around COVID vaccinations and information around COVID 19, since the

beginning of the pandemic from the mainstream perspective did not reach our community.

My organization put out and did the only a survey on COVID-19 vaccine hesitancy's and perceptions. And in that we found the complete opposite of the strategy that was being used by mainstream strategies around engaging people in COVID-19 vaccines. And so when we think about the best modalities for delivering information [00:30:00] has to be community driven. There are specific communities in which we're not going to have just one unified message, and it's going to have to be not only adaptable, but sometimes just completely different. And the way that the information is gathered, it has to be done through true community engagement and for tribal communities, that means tribe to tribe. And in addition to national indigenous organizations like the National Congress of American Indians, the National Indian Health Board, the Urban Indian Health Institute, my own organization, we [00:30:30] are the trusted messengers within our community. They are going to BRING others. So thank you.

Dr. James Hildr...: Sorry, Abigail. I do want to point out that all those things that you raised as concerns were addressed in the health equity task force. Disaggregated data is very important. In fact, almost half of the work that we did related to data and how to get the best data to find the solutions that we need. So all the points that you raise are certainly valid. And I would certainly invite you as I did earlier to get a copy of the full report [00:31:00] to the president, because I assure you that those considerations you raised were all work that we did to try to find some recommendations and solutions, but thank you. And the trusted messenger piece is certainly critical. And I think that the folks at NIH and in HHS understand that. So thank you very much, Abigail. Dr. Heckman, you're back, please. Sorry.

Dr. Bryan Heckm...: All right. Can you hear me?

Dr. James Hildr...: Yes. We can hear you.

Dr. Bryan Heckm...: Wonderful. Well, starting with a thank you for [00:31:30] organizing all of this and taking into account everyone's perspectives to try to make the best effort moving forward and tackling what's a very large issue, so not to further complicate it, but I'm worried about the direct and indirect benefits and the complex cycles that would happen from a multi-level perspective. So if there's some of these biological systems being disrupted which reduce access to care, perhaps, or access to mental health services, [00:32:00] or in even just disproportional impact of deaths amongst different communities might relate to higher levels of trauma, which then could then cycle into higher depression, anxiety, and less likelihood of being able to work or being able to be physically healthy, which then can further the gap, the equity gap in terms the social determinants of health. I'm coming from that as the director for the Center for the Study of Social Determinants of Health at Meharry, and also as a clinical psychologist.

[00:32:30] So I guess I'm curious is that outside the scope of RECOVER, because it's not directly the biological aspect or are thinking about these multi-level complex systems, which provide these feedback loops that keep the problem going part of this or not. And then further thinking through potential buffers that might be different in addition to the differential pathways for the disease itself, but similar to [00:33:00] what others have mentioned here. So I won't go in greater depth and I'd be remiss to that. Also think about this as an opportunity to enhance capacity building and workforce development through unique strategic partnerships between minority serving institutes, as well as primarily wide institutes and the leading R ones so that the pairing up will allow for that stronger connection with the community and allow for a much more community engaged, holistic approach more broadly. So I'll leave it there. Thank you.

Dr. James Hildr...: Thank you, [00:33:30] Dr. Heckman. And certainly I know for sure that behavioral health and the... I don't know, the behavioral... The health consequences of all this is certainly part of what NIH is looking to address. And I don't know if Dr. Lerner wants to say anything about that or Dr. Williams, but I do believe that's clearly part of the strategies to address that aspect of all this.

Dr. Natasha Wil...: Yes, absolutely. Thank you for that question Dr. Heckman, I will just add that we certainly included the social determinants [00:34:00] of health because we recognized that this was really beyond the biological mechanisms of recovery and dealing with long COVID. So we have addressed those issues. So thank you for that question.

Dr. James Hildr...: Well, thank you. Next, we had Emma [Merabi 00:34:19], I believe. Emma, I apologize if I... Was just your name, but please take it away.

Emma Merabi: Thank you, doctor. No, it's okay. It's Merabi, echoing what many have said, [00:34:30] and thanks for this really helpful briefing. And also just want to lift up what Abigail said earlier about American Indians and everything. I was taking copious notes, but I can mean what she said.

I was curious and maybe you don't have this because doctor, you had mentioned looking at the report on HHS, but out of the 20% to 30% who get COVID and suffer from long COVID, do we have [00:35:00] a better sense of their racial and ethnic breakdown, as you mentioned, data disaggregation, as well as the number of uninsured individuals and children who suffer from long COVID.

And I asked that because obviously part of this conversation is, and Abigail got to this about community driven strategies and trusted messengers and navigators, but part of understanding outreach and accessibility is also understanding the data and where [00:35:30] there may be gaps falling short, both because we don't have it, or as some of have mentioned, race has been misclassified. So curious if there's more information on that. And I apologize, I'm from the Children's Defense

Fund with International Office and my fantastic colleague [Aleta 00:35:49] Fitzgerald is also on the call. Thank you.

Dr. James Hildr...: Well, thank you for that. And I'll let my colleagues comment, but since there is not a level of awareness of long [00:36:00] COVID as a phenomenon, as a condition, I do think that those who presented themselves with this disorder have been predominantly non-minority because we have to raise the awareness in the minority communities for those people to come forward. But I'm going to let my colleagues speak to that, Dr. Williams and Dr. Lerner.

Dr. Natasha Wil...: Yeah, I agree. There are real gaps in the data [00:36:30] that we have about long COVID for many reasons, and really robust data is needed and RECOVER is hoping to fill some of those gaps.

Dr. James Hildr...: Thank you. I think next we had Pedro Martinez and after that, John [Kaliko 00:36:50], so please Pedro, take away.

Pedro Martinez: Good afternoon, everyone. My name is Pedro Martinez and I'm representing UnidosUS. [00:37:00] And my title here is senior strategist for public health preparedness and response. And I appreciate the opportunity to contribute and bring our perspective, the long and short of it here is that as we've been discussing, there is low awareness within the Latino community in regards to what long COVID is. And I think a lot of that stems from the earlier messaging within the pandemic that this COVID-19 virus was [00:37:30] not anymore severe than the flu. So I think just folks had a misunderstanding from the beginning. Of course the science wasn't there at that time. But that being said, the folks who potentially have been impacted the most would be essential workers. Those who have been out working in the fields, working in service industry jobs, those who are in the poultry processing plants and so forth [00:38:00] that may have been... Are those who could be most impacted by long COVID, but however, they may not even be aware of long COVID.

I think that's where that jargon comes into play. What is long COVID? What does that mean, sequela? Most folks don't understand what that means. I come from an injury and violence prevention background, so I'm very familiar with sequela, but that doesn't mean that the general public is. So that being said, finding [00:38:30] a different way to communicate what long COVID is and what those symptoms are, could potentially be helpful.

In addition to those who potentially might be identified in having long COVID are those who have access to healthcare delivery, who have healthcare insurance, who have perhaps do wellness checkups on a yearly basis. But if those individuals do not have access to healthcare or low access to healthcare, then they may not have the ability [00:39:00] to even know that this potentially an extended cough or mental health issues or challenges or whatever the long COVID symptoms might be is related

to long COVID, they just might think that it might be related to something else. So I think those are just some points that I wanted to make.

And how can we best deliver this information? Once again, reemphasize community based organization, trusted community messengers are going to be the best way to be able to [00:39:30] address long COVID and to bring these points forward to the community for their awareness, but also to address misinformation and a number of other threats to public health that will be coming down the road. So once again, I appreciate the opportunity to contribute and looking forward to providing more feedback.

Dr. James Hildr...: Thank you. Thank you, Pedro. So next we have John. John, please.

John: Hi everyone. This is John Kaliko. I'm representing APIC, the Asian [00:40:00] and Pacific Islander Caucus for public health with APHA, I also work at California bridge at the public health Institute in Oakland, but I really just wanted maybe address your last question on this slide here about modalities for delivering information. I'm thinking about yesterday. We actually just hosted a webinar where we discussed vaccine equity amongst the API community, and we focused in on two organizations based in Hawaii. And one of the big [00:40:30] takeaways that I'm thinking about is that there's a lot disparities within this broad API community amongst our Southeast Asian community, as well as our native Hawaiian and Pacific Islander communities. And the biggest things that I wanted to share was that they had recommended was, and I don't think this is anything groundbreaking, but developing materials and resources that are culturally and linguistically tailored for these communities.

And so that we means developing your resources in multiple languages, making sure they're sufficiently and adequately translated [00:41:00] and comprehensible in those languages. And then one of our colleagues shared that if you, for example, she works with the Filipino community in Hawaii. And she said, if you want to reach Filipinos, you have to send Filipinos, and so working with those individuals in those communities to reach these efforts or further the efforts of this program. And so I think that applies with vaccines and also, I think maybe what you're trying to do with information around long COVID, and reaching these communities again, [00:41:30] I don't think this is groundbreaking, but I think it's worth sharing with the team.

Dr. James Hildr...: Very good.

Speaker 3: It's Dr. [inaudible 00:41:38], just want to jump in and flag. There are a few questions in the chat that we can also turn to. One of them is from Teresa [inaudible 00:41:49]. I apologize if I have garbled your name, she writes are the instances of long COVID being tracked by variant. And are there any significant differences in the number [00:42:00] of instances of long COVID based on when people initially caught COVID.

Dr. James Hildr...: I'm not aware of any data that would suggest that the likelihood of getting long COVID varies, according which variant that you are infected with. There is some evidence that the severity of your experience with long COVID might have something buried on it, but I do not believe, and I'll let my colleagues correct me if I'm wrong, [00:42:30] that there is any evidence that depending on which variant you got, you're more likely or less likely to get long COVID. So Dr. Learner.

Dr. Andrea Lern...: No, your understanding is the same as mine. That's another knowledge gap and yes, that's a gap in our data.

Dr. Natasha Wil...: I would just add that many of the patient representatives that we've been working with were diagnosed [00:43:00] with COVID in early 2021. So there does seem to be perhaps an association with these early variants, but it's still unknown.

Dr. James Hildr...: The next question I see in the chat or comment from Edward, and it relates to whether or not persons who have had COVID-19, that was not diagnosed by PCR tests, entered into an [NHR 00:43:27], what will be [00:43:30] the way to deal with that? And as you probably know, or have heard or read for every PCR diagnosed case of COVID, there are probably others that have occurred that were not diagnosed. In fact, one of the issues we have with the at home androgen testing kits is that those cases were not being reported to the CDC necessarily.

So this is another major challenge we have just knowing that the full scope of this problem is somewhat challenging. Given [00:44:00] the point that you just raised, one of the recommendations we made in our report or recommendations to the president from the health equity task force is that whether or not the case was diagnosed with the PCR test are not, if a person has evidence of long COVID, they should be entitled to treatment and consideration for treatment. But you raised a very good point, which is that there are a lot of COVID-19 cases. They're not formally diagnosed with a PCR test. And I don't know if Dr. Williams or [00:44:30] Dr. Learn want to comment on that.

Dr. Natasha Wil...: It's an excellent point and individuals who go through these protocols will be tested, but there are also a list of symptoms that are asked as well.

Dr. James Hildr...: And the next one here, I'll just read it and invite my colleagues to comment. And this is from Dr. Heckman, continuous [00:45:00] passive data streams with strong potential for clinical validity and external validity that is acceptable, high adherence will also be highly important, e.g, minimally invasive, such as [inaudible 00:45:18]. I can't reread that.

A strongly predictive of COVID-19 positive tests, three days in advance, morbidity, and other measures that [00:45:30] can be collected via phone. So I think what you're referring to Dr. Heckman is the importance of wearables. And I think Dr. Lerner may have mention that that is going to be an important component of this work that's going to be done. So your

point is definitely well taken. So I believe... Oh, one more in the chat, how does this mirror other chronic conditions management versus, [00:46:00] or diverges and how can it be compare across the framework? I attached workload capacity model. I'm not familiar with that model, so I'm sure Dr. Williams might be so, Dr. Williams, do you want to comment on that?

Dr. Natasha Wil...: No, I not sure. Did they want to elaborate on this?

Dr. James Hildr...: So is that Bryan again?

Dr. Bryan Heckm...: [00:46:30] Yeah. I was just throwing out comments. So that seemed really highly relevant. If you have a starting framework, you can see where it deviates. And so you have a reference point or a baseline, so that's all, and there's lots of different frameworks out there. So that was just one example.

Dr. James Hildr...: We certainly can come back to this question and the sub questions, but to keep our conversation moving along, can we get to the next slide please? And this one of course was [00:47:00] what are your community's most pressing needs when it comes to communication and information regarding on COVID. And this has as its subpoints, what are the outreach approaches and interventions that you would feel would be most effective in your communities and how might RECOVER a partner with other organization like yours to better understand the impact of long COVID in your communities and better meet your most pressing related needs.

So we'll open [00:47:30] that up for common and discussion. So what are the most pressing needs when it comes to communication and getting information to those who need to have that information? So again, you can raise your hand or enter your question in the chat and we'll take it from there. I do want to make the point that in our work as a task force, we focused on something that was mentioned by one of our [00:48:00] later speakers there. That is really important...

Dr. James Hildr...: Are later speakers there. That is really important that the materials we produce be culturally and linguistically appropriate to the communities that we're going to provide them to. Because without that, that would be ineffective. So I just want to acknowledge that is something we spend a lot of time on. So to Theresa, can you introduce yourself and tell us which organization you're a part of?

Theresa: Hi, Dr. Hildreth. My name is Theresa Akentonwa. [00:48:30] I am a COVID patient and community member and founder of Black COVID-19 survivors support group. In relation to the best way to get information out. One thing I have seen is that, there's a distrust of information in general coming from the government. And if there could be [00:49:00] a cash of information of graphics, things that are appropriate for a variety of ages, for community members like myself and others who are on the grassroots level to pull from that cash to disseminate information.

I think that would reach a lot of people, particularly through social media. And that seems to be the biggest driver of [00:49:30] information as well as misinformation. When it comes to long COVID, I'm seeing some things where a lot of people may actually have long COVID, but they're attributing their problems to the vaccine. And so that's just a continuation of this distrust factor, but also misinformation and reluctance for [00:50:00] people in the black community to get their vaccination and/or their boosters.

Dr. James Hildr...: So if you don't mind Theresa, could you elaborate on that last point of conflating long COVID with the consequences of getting a vaccine? Because I think that's an important thing to all of us.

Theresa: Sure. A lot of people have... particularly for those who have had breakthrough cases of COVID after getting [00:50:30] their initial vax, whether it was the first shot or prior to getting the booster. They're not always aware that long COVID exists. And so once they've gotten the vaccine, second shot or the booster, they just become a little more conscious and a little more aware of what their own ailments and conditions are. And it's automatic for them to attribute it to having recently received that [00:51:00] second vax or having gotten the booster.

And so from what I'm seeing, just from conversations and so forth in my group, it's a strong possibility that a lot of those attributes are actually due to long COVID and not because they're suffering side effects. But that is a growing concern. People who have been vaccinated are often now not wanting to have the booster, because of [00:51:30] these side effects, which in reality just may be long COVID. And so more information about long COVID needs to be out, so that people will differentiate, side effects versus PASC.

Dr. James Hildr...: Thank you Theresa. These are really excellent points that we need to consider. So I really do appreciate your thoughts on that. I see Abigail, [00:52:00] your hand is up. Please Abigail, go ahead.

Dr. Abigail Ech...: Sure. So this is a really great question. I think one that is really important. When I think about the American Indian Alaska Native community. One of the biggest issues that we find is that, a lot of the information coming out around COVID and particularly long COVID and other aspects of COVID have been focused on internet access and we have an incredible digital divide. So when we look at some of our more rural communities, what we found is the most effective way was to actually send them letters from a trusted, tribal organization [00:52:30] versus even a pamphlet. And they just simply didn't have access to internet.

And as a result of that, they weren't getting the information that they needed in order to prevent, treat and get vaccinated against COVID. So definitely recognize that there is a digital divide within the United States, not just in rural areas, but also within urban areas and making sure that is addressed in, when looking at communication. When we think about

outreach approaches and any kinds of interventions, they need to be community driven, community informed and [00:53:00] community operated, which we means the allocation of resources needs to go to the communities.

What we found is that it really took key informant interviews, focus groups across the country, engaging with the communities. And again, recognizing that simply because for American Indians, Alaskan Natives, there's an assumption we all live on reservations, when in fact more than 70% of us live in large urban settings across the United States, but yet our health outcomes and health disparities remain almost exactly in line as those of our brothers and sisters on the reservations. And so there's also [00:53:30] a gap in information. So targeted interventions and resources and fundings were absolutely essential.

And the other thing that we have found that works really well, and I'm actually continually always searching for funding for, is peer to peer. Training outreach workers, training your sister and her auntie to go talk to their family, and to their community members. That's who they believe. There is no trustworthiness in the federal government, in our community. [00:54:00] And so when the resources come by and they say HHS down at the bottom or CDC, nobody really cares.

And so that has been a key gap and we need to be able to work and where community trustworthy organizations and also begin to build the trustworthiness of our federal scientific partners, so that we begin to do that work, to heal some of the things that are affecting whether or not information gets to us.

Dr. James Hildr...: Excellent. Thank you Abigail. Again, that was a very, very [00:54:30] important point that you raised. And I appreciate that. So, Brian, I see your hand is up again, Dr. [Heguín? 00:54:37], please.

Dr. Bryan Heckm...: Yeah. I want to just say amen to both those last two speakers. Those were wonderful. And to take a slightly different tact on it, I think they covered the messages and who, but also thinking about the modalities is really important. So even amongst social media, there's disproportionate use of which platform that different minority population [00:55:00] use relative to others. And so, maybe you want to be targeting through Instagram or Twitter versus other aspects, and maybe you want to think about a drip campaign that creates multiple avenues through which messages are coming to people, but maybe through different forms.

And the other thing I think is really important is thinking about this iteratively and through behavioral economic framework. So why would somebody want to come back for more information? It's because they're getting something positive rewarding. [00:55:30] To incentivize wanting to further engage as well. So again, coming from the SDOH perspective, if we ask what their needs and priorities are, we could actually start providing some of those, which then now they're creating a positive

relationship, which could further enhance that trust and build momentum towards longer term engagement. And that could extend to other health behaviors. So I'll leave it there. Thank you.

Dr. James Hildr...: Brian, for those of us who are not [00:56:00] the boomers, what is a drip campaign?

Dr. Bryan Heckm...: Sorry. So it's a... You give a little bit, build suspense, and so over time... You probably get them through emails where they'll be like, get ready for the unveil, but you don't know what the unveil is yet. And then they'll give a little more information. So it keeps you hooked in, but it's about that for frequency. So that, it's always in the back of your mind that you want to be engaging with the recovery initiative, but you don't quite know why because it's very subtle. So it's [00:56:30] nudging essentially and marketing.

Dr. James Hildr...: Thank you for the [inaudible 00:56:34]. I think next we have Oleta Garrett Fitzgerald. Oleta please, tell us which organization you're with. Thank you.

Oleta Garrett F...: Thank you, Dr. Hildreth. Yes. I'm with the Children's Defense Fund Southern Regional Office. And we do a lot of work in rural communities across Alabama, Georgia, and Mississippi, with a network of black women and girls. And we [00:57:00] have found that in getting information into communities, identifying people income and some people have spoken to this, identifying who those pivots are within the community to put information through, black women and mothers of any kind, are listened to when it comes to things about health black women and mothers are generally in charge of healthcare [00:57:30] arrangements around their families.

So we would like to see a greater attention and reaching deep into communities. And then just thinking about some of the infrastructure that's been put in communities around healthcare, those organizations that were put in place to do outreach and navigation for the ACA, are already have contacts and are recognized for being connected [00:58:00] to healthcare delivery.

And then finally, as we talk about this long term, long COVID and all of the other things that we are talking about, that we are looking at this toward long term strategies for how we develop public health systems. This obviously our public health system needs a lot and it needs to be connected more into communities. So [00:58:30] those are the comments that I have.

Dr. James Hildr...: Thank you Oleta. I do want to raise one point I see in the chat, which I think is a really good one. Edward Ivy, with an organization, ABC points out, wants to know, will the initiative take into account a global perspective that is to say, how will data and information from other countries be incorporated into this project? [00:59:00] So I would just

invite Dr. Learner or Dr. Williams to address that because I think that's a very important consideration. And thank you Edward for that question.

Dr. Andrea Lern...: Yeah, thanks very much for that question. And it is a really important consideration. So while the recover initiative sites are across all 50 US states, the initiative is designed to be adaptable and nimble as we learn more [00:59:30] about long COVID and PASC, and of course that means data from around the world. So, yes, the initiative will definitely be taking into accounts data from other countries and as the science evolves, so will the recover initiative.

Dr. James Hildr...: Thank you. Pedro Martinez, I see your hand up, please, sir.

Pedro Martinez: Thank you. Once again, I'd like to provide just comments on [01:00:00] the two questions here and what comes to mind first about the outreach approaches or interventions is one of the challenges that we face within the Latino community. And also the communities of color is literacy issues, and aside from literacy. It's also health literacy, the lack of understanding of how virus is spread, symptoms to be looking out for, and just how vaccines work and what's a vaccine symptom versus a COVID symptom.

So [01:00:30] just the health literacy piece is also a way for us to elevate our community's understanding of how our bodies work and don't work to be able to combat the misinformation that is out there. That to us sounds ridiculous because we all come from a background where we have some baseline understandings of just how our bodies work. So, I believe a way to get around that is to use simplified text, easy to digest messages, and also [01:01:00] exploring communication messages of using pictures versus using texts.

I love the idea of the pamphlet and doing those mailings and so forth because not everybody that digital divide is absolutely real. The depending on what your zip code is. I wanted to provide that feedback and in terms of which partner organizations to consider, what comes to mind is our community health workers, [foreign language 01:01:27]. Those [01:01:30] folks who are on the ground, trusted messengers, who have been working with the communities for years, decades.

Those are the individuals that we could provide those pamphlets to or public health nurses. Also in those rural communities who are the frontline public health workers, where there is no health department, because those rural communities are so small. Also, thinking about what is it, escaping me, but it's [01:02:00] those wellness visits for pregnant women. I think there's also a lot of women who are pregnant or who are planning to become pregnant.

There's a lot of misinformation around COVID and I believe CDC just released a study that talks about the impact of COVID of pregnant women in also long COVID for them as well and their infants and so forth. But

going back to the point around which partnering organizations, I would say the national association of community health workers will need us, of course, [01:02:30] would be one of those, as well as the National Hispanic Medical Association and the National Alliance and Hispanic health.

These are just a couple of partnering organizations that could help carry this message forward and also help increase our community's health literacy and be able to also address literacy issues in general. Thank you.

Dr. James Hildr...: Thank you Pedro, very much. Now I see Kendrick Curry. I think your hand was up, please, sir.

Kendrick Curry: Yes, sir. Thank [01:03:00] you Dr. Hildreth. I'm Reverend Kendrick Curry. I'm with NIHCL and I'm a local pastor in Washington, D.C. One of the things that we have found very effective in terms of outreach approaches is beginning to look at integrative services. And what I mean by that is the church during this ordinary food distribution to several thousand folk on a given Saturday, we also include [01:03:30] information sessions in and around providing information with COVID.

And we do need to talk about long COVID even more because our communities really don't know much about that. At using these integrated services, we have also found that when we bring along food distribution, let's say, kidney disease screening, as well as [01:04:00] other health related matters, as noted by other speakers, then we find that it is a great way to communicate in a practical way about community health.

So, I would recommend that we do that because that is something that is helpful. When we begin to think about what the houses of worship can do, what the community based organizations can do. I will say that we should not just stop at with those integrated services, but we should also [01:04:30] look at and use things like the arts, for example, with black coalition against COVID, we've done poetry slams, we've done other things to begin to talk about COVID and vaccinations and testing, we can use the same thing as it relates to long COVID as well. Thank you.

Dr. James Hildr...: Excellent. Thank you, Reverend Curry, for those comments. Theresa from the Black COVID-19 [01:05:00] Alliance had a comment about schools, and I'm just going to invite Theresa. If you wanted to share that with the group I saw your hand.

Theresa: Sure. Schools in each community are a very, very major disseminator of information. And whether it's pamphlets or flyers postcards, whatever the case may be, I think they would be a great partner and being able to make [01:05:30] sure that information makes it to the majority of homes, through their children from schools. And so whether it's passing out, literature, or even providing some degree of curriculum that school counselors or health teachers can utilize to inform students as well as families, parents, whether it's through parent meetings, PTA, [01:06:00]

those are also some additional avenues that could have widespread effect.

Dr. James Hildr...: Thank you Theresa for that.

Dr. Natasha Wil...: Dr, may I ask a follow up question for Theresa?

Dr. James Hildr...: Sure.

Dr. Natasha Wil...: She mentioned previously about online support groups, and I was wondering if you could share any that are specific to black and indigenous and other people of color [01:06:30] that you are aware of.

Theresa: Support groups. So there are a couple on Facebook, however, as far as distraction, I'm not sure really how much traction there is, in participation. I know that in my group, we have a good amount of engagement. My group is more of a social support group, and that's something that I'm looking to [01:07:00] change. And that's why I was adding that, for all of these social support groups, having some type of vault or cash of information that, and graphics that we can utilize would really go a long way because honestly, a lot of time inside of these groups is spent in moderating, is taking down misinformation and deleting, [01:07:30] information is coming from unreliable sources.

Trying to have a lot of side conversations with people about that basic health education. As someone mentioned earlier, that there needs to be more knowledge and education about health in general, as well as what research and surveys are. When we hear [01:08:00] about research, it's an automatic, I don't want to be your Guinea pig. And so in groups like mine, that would be a perfect avenue for educating people and trying to get more participants who are willing to be a part of these cohorts and other types of research and studies that have nothing to do with forcing medications and experimental drugs on people.

Dr. Natasha Wil...: Thank you so [01:08:30] much.

Dr. James Hildr...: I would like to invite Emma Mehrabi to expound on her point that she made about conversations like this being similar to efforts around child tax credit. Emma, would you mind speaking to that to force, please?

Emma Merabi: Sure. I think other people on the call could also talked about this and I think my colleague Oleta, alluded to this a little bit and when the ACA [01:09:00] was first enacted, trying to figure out right how to get people into the system, do we use navigators? And I think there's been a lot, it's been more than 10 years of that. There's been a lot of improvements onto who are trusted messengers and how do you define navigators?

But it was more of just a comment of, to me part of this conversation is like, how is this outreach also a whole of government approach, and [01:09:30] how are we reaching people who may be in other places and

getting whether it's public benefits, like snap or going to file their taxes at a Vita Clinic, or in other local agencies or, how are we reaching people multiple ways? So we're not having to reach them in some ways in different avenues that may not be best for the communities.

I'm just commented on the [01:10:00] fact that a lot of these strategies are similar to strategies that many grassroots and direct service organizations also were implementing over the last six months, last year to get families, to sign up for their monthly child tax credit payment, if they hadn't already. And maybe there're some lessons learned in ways to strategize and implement them together.

And maybe there're some similarities and overlap and population's reached, [01:10:30] I know that you all had already discussed that there's not comprehensive data, on who has long COVID, but it's just a thought.

And then I had an additional question, is the purpose of the outreach just to educate individuals and communities about long COVID, or is it also to take a further step to get folks into care who may not be already in care? And I'm just thinking of [01:11:00] if I were somebody, and I thought about this symptoms and I thought, okay, maybe I have this, what would be my next step? Particularly if I don't have a doctor, or I'm uninsured or underinsured.

Dr. James Hildr...: So that was one of the points I raised earlier that, the health equity task force that the president appointed, we were deeply concerned about those without [01:11:30] insurance and those disadvantaged communities where there's not insurance or access to providers. If you make people aware that they have a condition, aren't you ethically obliged to help them find treatment for that condition.

So we think it's imperative that as part of this effort, as we raise awareness, we also make plans to provide for the care of those individuals who might not have it. And I think very important related to that is [01:12:00] some people will not be able to go back to work.

Emma Merabi: Right.

Dr. James Hildr...: Some people will not be able to go back to work.

Emma Merabi: Right.

Dr. James Hildr...: Possibly, because of this. So there needs to be provision made for disability to make sure that the economic impact for that family is not something they cannot recover from. So your point is well taken. And it's like in the early days of the HIV efforts, when we were really pushing to get people tested before there were treatments available, and there was [01:12:30] an ethical dilemma because if you had everyone tested, but had no treatment for them, what do you do? What do you do in that situation? So I think you raise a really, really great point that we've lived

through before. And I think that was a really important consideration coming out of the task force that I was a member of. So thank you for that point.

Emma Merabi: Can we ask one quick follow up to that, Dr. Hildreth?

Dr. James Hildr...: Sure.

Emma Merabi: So just to clarify then, will the communication strategies [01:13:00] and the outreach strategies and education strategies... And again, obviously, everyone's already said this, but you have to tailor messages to the community that you're serving, so they may be somewhat different, but will that include... Is it the goal of RECOVER COVID and this initiative with NIH and others, to ensure that we include targeted messages that get people into care? Just to make sure I understand. I know you recommended that in your report, but...

Dr. James Hildr...: [01:13:30] Oh. So I think that HHS [inaudible 01:13:35], which includes, of course, NIH... NIH's role in this is to find some answers to how to deal with Long COVID. There are other agencies that are looking to ensure that people who need the care will get it. But one of the other consequences of this will be to make sure that people of color are part of the important studies [01:14:00] that need to happen to find those answers. Because as you know, there's been a historical problem of low participation of minorities in such studies. So one of the goals of RECOVER... And I'll let my colleagues who are responsible for this, speak to this, but I think that's a really important part of why is so important that these outreach efforts are happening, to ensure that the answers that we find will benefit everyone, not just a select few. So Dr. Williams, Dr. Lerner, I don't know if you want to comment about [01:14:30] that.

Dr. Natasha Wil...: Sure. But that was well said, Dr. Hildreth, absolutely right. And really at this early phase, trying to ensure diverse participation, better understand this condition with an eye towards clinical trials as well.

Dr. James Hildr...: I do want to acknowledge, in the chat a very important point was made about working with churches. I think the faith community has been pivotal to [01:15:00] getting the word out about COVID-19 and making sure people got access to vaccines and all of this. So we definitely acknowledge that the faith community will play really an important role in this effort as well. So I would like to take us to the third question, which means we can't... We're not closing the discussion on this one, but to keep things moving.

This third question that we were talking about, and we've already [01:15:30] touched on this in a couple of ways, but based on the knowledge you have of those affected by Long COVID, would the affected members of your community be willing to participate in studies, whether it's in person or digitally? Using the devices we spoke about

earlier. And some further considerations for that question are, would they be willing to share their perspective with doctors and scientists by joining a national dialogue or group? [01:16:00] Are there other ways that we may have not thought about, that we'd like to engage with those communities in terms of RECOVER? And very importantly, are there other groups that you feel should be drawn into RECOVER that we've not already reached out to or may reference to? And please raise your hands or put your comments in the chat and we'll keep the conversation going.

Some [01:16:30] of you've already made reference to the fact that unless the materials are culturally and linguistically appropriate, that that's going to create a challenge for us. But if we're able to do that, to achieve that, to make sure that we do have information and materials that meet that criteria, what do you think would be the likelihood of your community being willing to participate in those studies? Not all [01:17:00] speak at once. Dr. [Herman 01:17:08].

Dr. Bryan Heckm...: So from my experience, making sure that, yeah, the community is engaged from the very early on, from the get go and throughout, and they would be interested in participating in these larger dialogues. But particularly, with respect to black communities, making sure we acknowledge some of the atrocities that have happened been in the past. And this could potentially be a [01:17:30] way to repair some of the mistrust that has occurred and making sure that we're able to let communities know that they're able to further enhance their community by participating and helping reframe, as mentioned earlier, kind of what research is versus how that's helping shape community health and amplifying their voice for what their needs are, is a really critical message. So making sure that it is very community and patient centered. To keep that engagement high.

Dr. James Hildr...: [01:18:00] Thank you, Brian. So I see we have Abigail and then Pedro and then Edward Ivy. So please, Abigail, take it away.

Dr. Abigail Ech...: So right now, particularly, if we look at what's going on around just COVID-19 studies, in particular, the RADx studies being conducted by different investigators across from... funded by the NIH, particularly in the American Indian and Alaska native communities, when we talk about the historical missteps of research is that we talk about it in the past, like 10, 15 years ago, [01:18:30] I'm talking about yesterday. And so, as a result of that, there continues to be mistrust right now. I know there's some hesitation in tribal communities about the way that the RADx studies may be using samples collected for biospecimen research that they didn't necessarily understand was going to be part of. So you're going to have to look at the implications of current COVID-19 studies and the impact on that as you move forward with this next iteration around Long COVID.

But the answer to this question from the native perspective is yes and no. So [01:19:00] you're going to both have hesitancy and willingness to engage. One of the most important things to do is going to be engage

tribal communities, those on reservations and villages from a nation to nation, respecting their tribal sovereignty, engaging with David Wilson and his team at the NIH office for the tribal... and then the tribal advisory. Folks are going to be willing, but there is going to be hesitancy. And as a result of that, there will be limitations, so also engaging with national indigenous organizations, I said [01:19:30] some of them prior and am willing to share a list of those if you're interested, are going to be absolutely key. And we also have to acknowledge the historical missteps are yesterday and they'll probably be today. And so, it's an ongoing trust building exercise that is going to be absolutely important because the engagement of our community in these research studies is actually going to be key.

Dr. James Hildr...: Thank you, Abigail. And again, your points are well taken and we appreciate [01:20:00] those. Pedro.

Pedro Martinez: I also would like to echo that I believe that some community members would participate and some wouldn't. I think it just depends on those who... Future participants will always have that risk versus benefits calculation that they do during those consent procedure moments, right? Where they're learning about what this study is and how it's going to benefit them. [01:20:30] But also there's only so much altruism... The need to be altruistic is going to drive people to participate. So are there going to be monetary incentives per each touchpoint that this study will have with the participants? Will there be childcare coverage? Will there be transportation coverage? Those are the types of items that could factor not only participation but retention because this retention, as you know, is a major [01:21:00] issue. Also, the ability to build that rapport with those participants. So when participants do move around, when they change phone numbers, you're able to maintain communication with them is also another challenge for retention.

But also going back to that risk benefit calculation. If there is some sort of monetary benefit that could be an incentive to participate. And in terms of different methods or modalities of participation, I think it just depends on the age group and [01:21:30] also the digital divide. You have folks who will be willing to participate on a Facebook call or a Zoom call, and those who want to have something in person, face to face, and then everything in between, text messaging participation. Different ways to try to connect with different folks depending on the age groups and also access is something else that I wanted to bring forward, in addition to, having data collectors or the folks who are interfacing with the community, look [01:22:00] like the community that they're trying to connect with. So if it's a Spanish speaking participant, then of course a Spanish speaking data collector, I think that's also very important to consider. Those would be the comments I'd like to provide. And thank you again for this opportunity to contribute.

Dr. James Hildr...: Thank you, Pedro. Edward. Please, sir.

Edward Ivy: Yes. So I'm Edward Ivy, with the Association of Black Cardiologists. And our organization has been working with the community [01:22:30] during this pandemic using Zoom platforms and others to educate community health advocate, training program participants and they have been very engaged, they want the knowledge. But I think it is going to take, as it was mentioned earlier... and really using those individuals on the ground in this community that understand the gaps and the challenges that exist in that community to be a part of the process.

And I think that with that, we have to include them earlier on. So engaging the [01:23:00] community like you're doing right now is very effective, but making sure that we continue to engage those individuals that are on the ground interacting directly with the community. So with our community health work or community health advocate training program participants, we've been able to get out... increase knowledge about cardiovascular disease because it is still the number one cause of death in the US. But also using our network of cardiologists who are trusted providers for our community has been a way for us to engage [01:23:30] the community and get more participation. So I do want to echo, like everyone has said, Pedro and others, that it will take engaging the community earlier on and keeping that engagement as you move forward.

Dr. James Hildr...: Thank you, Edward, very much. Jennifer [Gu 01:23:47] from APHA, please.

Jennifer Gu: Hi. I think like Pedro took everything I was going to say and said it really well, so I won't repeat too much of what he said. And I don't speak for all [01:24:00] Asian Americans and Pacific Islanders, there's over a hundred different API languages and ethnicities. And so, what we have learned from APIC is that we really need to engage communities through bilingual, bicultural nurses, community health workers, those are the people that folks are going to trust, trusted the community organizations who are on the ground, [01:24:30] like what everyone has said are the groups that Asian and Pacific Islanders are going to gravitate towards.

And yes, we will... People from our communities will join in this dialogue, will participate in your engagement efforts. And just like everyone else said, there's going to be variations because of digital literacy, health literacy, literacy in general. [01:25:00] And so, you're going to have younger folks who will engage in more social media, perhaps. And then, with the older population, I just know from my own work with community health workers you really have to have someone who speaks the language, who they see and they trust, it's going to be able to help them navigate these dialogues. I just wanted to add that piece.

Dr. James Hildr...: Thank you very much. [01:25:30] And I think we are coming close to the end of our time here. So I believe it's time for me to... Oh, Dr. Williams, please. I see her hand is raised.

Dr. Natasha Wil...: I'm sorry. I have this question or this statement, because it's come up multiple times and I really appreciate wanting documents to be in plain language, to take into consideration health literacy. And really at the CSC, [01:26:00] we spent a significant amount of time on our documents, everything from the protocol, consent forms, recruitment materials, where we spent a significant amount of time on addressing health literacy and plain language. So thank you for that comment for everyone.

Dr. James Hildr...: Thank you, Dr. Williams. Theresa, is that a new hand up or old one? Okay, go ahead.

Theresa: As far as people participating in the studies, I think they [01:26:30] need two things to really motivate them. One of them is anonymity because of the concern about unscrupulous science that has happened in the past. And also people just wanting to be assured that their information won't be held against them or put some place where in the future it can come back to be a problem with their employment or in any [01:27:00] other case. Also, incentives, which someone has also mentioned, there's kind of a feeling of right now that the medical and research community is asking, asking, asking, there's a lot of give us information, just give, give, give without a very obvious reciprocation of what the participant can expect in return.

And finally, [01:27:30] in trying to get more people to participate, just consider that the timeframe in which these in-person meetings or digital meetings would take place, because a lot of people are working class. And so missing work, midday for meetings like this, for example, is just not convenient for a lot of people. So we have to consider that, the timing, later evenings and things like that to accommodate [01:28:00] a variety of people's work and home situations, and that could help increase their desire to participate.

Finally, when you think about having a national dialogue that can feel and sound very weighty to the average person, right? "Do you want to attend a listening session with the NIH?" There's kind of a preconceived notion that there's going to be conversation that's way over our head there. This is going to be [01:28:30] a lot of pontificating from extremely educated people and that the average Joe really may not really have a place at that table. And so, being able to frame these meetings in a much more appealing way would be important in increasing participation. And also, possibly, how can these same meetings be organized in a more local aspect, whether it's [01:29:00] trained operatives and facilitators who could do community meetings at the churches or schools, so that it's a more intimate and familiar setting with people that the participants could feel more relatable to.

Dr. James Hildr...: Excellent. Thank you. Those are excellent points that you're making. Very much appreciate it. Edward, did you have your hand up or...

Edward Ivy: Yes. And I should have said this at [01:29:30] the conclusion of my previous comment. But I want to echo what someone else earlier said. That you also need to be very clear on what your ask is, on what you want the community members to do, and particularly if you're going to engage groups. So I've heard a lot say, "Hey, let's get community health advocates." But what is it that you want those advocates to do? What message do you want them to deliver to the community? And then also, it would be wonderful if there is follow-up in terms of, "Hey, I [01:30:00] think I have Long COVID, what should I do now in terms of getting care?" I think that needs to be fleshed out before you start going into communities where access may be low already. And so, they start feeling more disenfranchised because you're informing them of a situation, but you're not giving them a solution or steps to take. So I just think that you should really make sure that your ask of the community is very clear and any follow-up that needs to happen, that process is very clear as well.

Dr. James Hildr...: Right. [01:30:30] Excellent. Thank you, Edward, very much for that. I'm trying to see if there are other questions in the chat here. There's one here, I think, that Dr. Lerner might have to answer, which is, "Will the RECOVER website be a one stop shop for all information that everyone is talking about, outreach material, social media, et cetera? It would be helpful [01:31:00] to have such a one stop shop." So Dr. Williams, Dr. Lerner, do you want to comment on that?

Dr. Lerner: Yeah, I think-

Dr. Natasha Wil...: [crosstalk 01:31:11].

Dr. Lerner: Oh, sorry. If you want to... So yes, that's the idea to have the convenience, one stop shop to go for everything RECOVER. We're also going to be sharing, the close of the meeting, a way to sign up for updates about the initiative, [01:31:30] so that's another way to keep tabs on things. But yeah, we hear you about the ease of a one stop shop.

Dr. James Hildr...: So at this point, I think it might be appropriate to ask if there are any other comments or questions on any one of the three main questions or just something you think the recovery team needs to know in terms of the important work they're trying to do, related to the communities you represent. So I'll just open it up for general comments [01:32:00] before I turn it back over to Dr. Williams. Anyone have any closing thoughts, suggestions, or questions or concerns? So I want to say I'm grateful for the opportunity to be a part of this conversation. I think the work that RECOVER is going to do, and the research it's going to do is going to be really, really important, but it's [01:32:30] not going to be successful unless our communities participate. So we hope that you will engage with us to help make that happen, because it is really important.

And some people don't know this, but from the SARS pandemic of 2003, there are individuals could not go back to work for as long as two years. And so, I'm not saying that's going to be the case here, but this is going to

be a really important problem for some time to come. So this work is really important and I hope you'll be engaged [01:33:00] with us to get it done. So with that, I think I'm going to turn it back over to Dr. Williams. And so again, thank you very much for the chance to be a part of this really important conversation.

Dr. Natasha Wil...: Yes. So I'll just like to echo Dr. Hildreth comments and say thank you all so much. We really appreciate the session today and all of the feedback that you all have. We have this site [01:33:30] here where you can see other ways to be in touch and learn more about the RECOVER initiative. And also to share that we do plan to have additional listening sessions for specific communities and we welcome partnering with you as we roll out those other sessions as well. So thank you also so much and have a wonderful, wonderful afternoon.