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O1: We are really excited to spend the next hour and a half with all of you. My name is Lisa Goldman (?). This is my first time having the wonderful privilege of coming to this meeting, and I have wanted to come for so long. So, just being here with all of you, I have kind of met my goal. I think I can speak on behalf of the four of us. We are pretty excited about this next 90 minutes that we get to spend with you, and we very much want to learn as much from you as you will be able to learn from us. Can you flip back to the first slide since I can’t remember our title? The title of our learning lab today is “Engaging Diverse Communities to Understand How \_\_\_\_\_\_\_ Health Research Can Address Health Disparities.” You may notice the subtle language difference between “precision medicine” and “precision health.” Referring back to our wonderful keynote this morning, that is along the lines of “Language Does Matter,” and we will talk a little bit about that as we continue through the presentation. I am also very privileged to be here with these three wonderful people, and we will get a chance to introduce ourselves in just a second. In addition to four of us who are here today, we are part of a large team who could not have done this work alone. So, we very much have relied on each other. We are a group of researchers, community leaders, students and community members who have been working on this project for just about the last year. So, we are going to use some text polling today because I think it is fun. I am about to start teaching this quarter, and my students taught me how to do text polling. So, if you can get out your phone, this is just a warm \_\_\_\_\_\_\_\_ poll. So, what you need to first do is go to your text messaging app and put in the number “22333,” like a phone number, and you can just look up here once you’ve done that, and then I want you to text the letters “cphs,” because we are from the Center for Population Health Sciences. That is what that stands for. And then you should get a little automatic text back that you have joined the text polling, and you know you’ve done it right. If you are like me, it might take three tries to put the number in correctly, so have patience with yourself. Then, the first question is – what is your current mood? You can text the letters A, B, C, D, E and F to let us know your mood. You did it! I’m from the West Coast, so I would definitely be a C.

P: I couldn’t sleep last night, so I’m feeling a little “F” due to sleeplessness, of course.

O2: And as the rest of you are doing it, just so you know, we are going to be doing polling throughout the session, and each time we poll, you are going to have to put in the “cphs” before you do your answer each time, even though you will already have “22333” available to you.

O1: And once you have texted your answer, just kind of look up so we know that you are ready to roll. So, while we would very much love to go around the room and learn exactly who each of you are, at the very beginning before we start working in small groups, we will just share a little bit about who we are up here, and I think I will let Jill go first.

O2: I’m Jill Evans. I am with Stanford in the Center for Population Health Sciences, and I am the Program Director for “SPHERE,” which you will learn more about. It is the name of our … (inaudible) … in precision health. I oversee the project and track the goals and objectives for the project.

O1: And I forgot to ask if you can just say a brief word about what excites you about working on precision health and maybe a little about what challenges you.

O2: So, those are probably the same thing as what excites me about it is the topic is very interesting, it is new, we are learning from each other … and what is challenging about it is it is new and I didn’t know a lot about it going in. I am learning a lot as we go along. But going into the communities is a little bit challenging. One of the speakers mentioned today that there is not always comfort around genetics in different populations, so it has been a challenge, but we have learned from the community.

O1: And you don’t see Isabelle’s name on your program because she was a late addition.

O2: She was one of the 20!

O1: So, we will let her introduce herself as well, and also say a little word about what excites you and what challenges you.

O3: I may have to have you ask each question so that I remember them. I am Isabelle Durana (?). I am the CEO and Founder of Latinas Contra Cancer for about two more weeks, and then I am transitioning. We have new leadership, thank God. We are based in San Jose, California, and we provide across the cancer continuum services to Spanish-speaking Latinos, so we work with the undocumented, the immigrant and the low-income community. So, after 14 years, we have a lot of experience in this space. I, myself, am moving on to develop a national organization called the Latino Cancer Institute, in which we hope to coalesce and amplify our voices around this issue. So, not one Latina contra cancer, but a multiplicity of us around the country. I am a journalist by trade, 43 years in the biz, and one of the things I believe in is data, information and context. As we heard this morning, words are crucial and key. I have always loved the idea of working with researchers, so Latinas Contra Cancer, as a rule, has been working with researchers off and on since 2008 or so, because I believe that the community needs not to be afraid of science. They need to understand it, embrace it and be able to come to the table feeling equally armed to work with science. So, we have convened since 2008, at the National Latino Cancer Summit, and that is when science meets service, where we bring the two together to learn to collaborate and network. So, when Stanford came along with this program, it felt very right. It felt like an extension of everything we need to do. Now, I am also a cancer survivor. So, in the year 1999, I actually did a three-part series on my cancer, and I don’t know if I said this to you guys, but one of the things we looked at was the future of research and addressing cancer. We went to Stanford, and they were already talking about immunotherapy back in 1999. So, I’ve never forgotten that. So, as I’ve watched precision medicine develop out, like Jill said, the challenges and whatever, I came to learn more and more and more. I went to a lot of precision medicine conferences, and the challenge is understanding most of it because the science is so hot. But I was determined. Like I say to all of my communities – let’s not be afraid of it; let’s embrace it, learn it and see how we apply it. The excitement for me was that we were now bringing it down to community, and this was following President Obama’s initiative. I said, “We’ve got to get Latinos engaged.” I think one of our issues is trying to understand the subpopulation of Latinos and how they think about genetics, because not all of us think alike. We have had different kinds of experiences that will color how we approach genetics and genetic testing, and the population that was here from San Jose that was engaged with this project were mostly Mexican. So, they do have a different point of view, I think, than Puerto Ricans, Cubans, Dominicans. So, we shouldn’t take it that this is a heterogenous community, and that one size fits all. So, it becomes even more complex for us to begin to address these issues inside our community. Did I answer all the questions?

O1: Yeah, beautiful.

O4: Good morning. My name is Rhonda McClinton Brown. I am the Executive Director of the Office of Community Engagement within Stanford’s Center for Population Health Sciences, and for this initiative, I chaired the Consortium Core, which is the community advisory group, with Lisa, and we have joined forces and collaborated on our work because we felt like it was so closely aligned. Let’s see – what excites me? Well, just a little bit more … I have a longstanding relationship working in the community, mostly with community health centers. I spent most of my career as a community partner, and then I’ve been at Stanford for the last nine years. What excites me about precision health, I think, is the promise. What scared me initially was I think I didn’t have a real strong understanding of precision health and what that would mean for communities, and I think working so many years in the community and understanding the complexities and the challenges that everybody is facing on a day-to-day basis, I struggled initially with where precision health would be on the hierarchy of needs and issues that everybody is dealing with, and how can we partner with organizations that are dealing with day-to-day house, living conditions, food insecurities, healthcare access, and where does precision health fit into that. I initially fell short in my vision of seeing how that could happen and how that could help disparities. I think this year, having this wonderful team that we just showed you on the slide, and having Isabelle with all of her knowledge, I have learned a great deal through this process of working on precision health, that it excites me about the promise of really how it could really actually impact health disparities. I am excited about the critical role that community partners can play in helping us with precision health and just the possibilities. So, it has been a wonderful transformation for me, personally.

O1: Well, I’m glad I get to go last, because I think the excitement and challenges have really been summarized by the three of them. So, I’m a faculty member at Stanford and I work in the Office of Community Engagement with Rhonda, and have been charged with developing and implementing the community engagement implementation science part of this Precision Health Initiative to address health disparities, and like my colleagues, I was a little nervous at the beginning. I am an epidemiologist that focuses on chronic disease prevention, primarily in the Latinos and American Indians, and precision medicine felt a little bit tangential to my work. Nevertheless, I was really committed to the idea of ensuring that groups that are traditionally underrepresented are at the table and influencing this movement as it goes forward. So, I kind of viewed it as a social justice charge that I was taking on, even though specifically it was maybe a little bit outside of my realm of expertise. I will just add one other challenge. For me, on campus, working with other faculty members to incorporate community engagement and CVPR into their work is always an exciting part of my research, and this meant that I was going to work with a whole other set of researchers that I don’t traditionally have contact with – so, the genetic scientists and the lab-based kind of researchers that we don’t get an opportunity to work with very often. So, that was part of the excitement and a challenge for me, as well, kind of moving into a new research community that I hadn’t been in before. So, let me just give you a little roadmap of what we are going to do today. So, I promise we are not going to be up here talking the whole time. It is not our style. First, we are going to do a debate, a short debate, but I am hoping it will start to generate some of the ideas that will get us started for our small group work, and then after the debate, we are going to move into three different groups that are defined by the particular challenges that recognize as we have moved through this research project. Then, at the end, we will do a lot of report back and then do our conclusion. So, back to the polling, we have talked a little bit about precision health already. We haven’t defined it yet. So, what I am asking for the people in the room, if you are familiar with the term “precision health” … oh, good, the letters came up. I don’t know which is yes and which is no. So, text “a” for “yes” or “b” for “no.”

P: Do we have to do “cphs” again?

O2: Yes. You have to do “cphs” each time, yeah. You are rejoining the poll for that question? Oh, no? I’ve been doing it every time. Oh, look at that. You are absolutely right. Okay.

O1: So, we asked our community members that same question. You see that this comes from 115 participants in a focus group project that actually the four of us did together with our other colleagues. You can see the darker red is the \_\_\_\_\_\_\_, familiarity with the term “precision medicine,” and “yes” is the pink, and the five different groups are American Indians … these are urban American Indians in San Jose, African Americans, Chinese, Latinos and Vietnamese, all in the San Francisco Bay area. So, you can see, we were about 50/50 in this room. I think among the four of us – we were probably Isabelle “yes” and the rest of us “no.”

O3: Also, you should remind them we have multiple languages.

O1: Chinese, Latino and Vietnamese.

O2: This was a complex project. I had five racial ethnic groups, providers who serve those groups, several community partners recruiting each group, and then multiple languages for obviously Vietnamese, Latino and Chinese. It was complex just to get to this answer.

O1: Let’s get to our definition of “precision health.” So, “precision health” is a term that we chose to use on our campus as opposed to “precision medicine,” because we felt like it encompassed, in a better, way, the idea that we are not just thinking about diagnosis and treatment, but we are really thinking about health along the continuum, from wellness to disease. And I think you heard from the four of us that one of the reasons we got involved in working in the area of precision health is just the enormous potential it has for revolutionizing health and healthcare, primarily by helping us to understand that complex interplay, not just between genetics and health, but between lifestyle, behavior, social factors, structural factors like we heard this morning. We very much view a very holistic definition of precision health and try not to distill it just to that genetic health relationship. So, at the same time that it holds great potential, I think the reason we also got involved was because of the risk of widening health disparities if those that are traditionally not represented are not at the table. So, our goal for our precision health initiative was ensuring that those underrepresented groups to the extent possible, lots of different ones, would be at the table to shape this precision health movement. So, they would be included in research and then be able to benefit from the approaches that result from that research. So, that is what brings us to our project, which we call “SPHERE,” which stands for the Stanford Precision Health for Ethnic and Racial Equity Center. This is a grant from the National Institute of Minority Health and Health Disparities, and it has three large research projects and five cores. These are our specific aims, but I think if you move to the next slide, I can explain it a little bit better. So, we have three different projects that focus on and work with different racial ethnic groups. We have one that works in an American Indian reservation in South Dakota, a second one that focuses on childhood obesity among Latinos in our local area, and a third one that works with multi-ethnic population in California, I think southern California and northern California, around the issue of communicating cancer risk information. Then, as Rhonda eluded to, we have five different cores. One is our consortium core that is charged with engaging our community partners in this research. The second is our Analytics and Modeling Core. The third is Implementation Core, another one that Rhonda and I lead, that focuses on translating research findings into practical strategies in community-based settings – kind of our most difficult charge, if you ask me. The last is our Laboratory Core. Obviously, that is processing all of the many, many samples that we are collecting. Okay. So, now, the next question for you is – to what extent do you feel that precision health can address health disparities?

O2: On a scale of 1 to 5.

O1: So, on a scale of 1 to 5, with 1 being “not at all” and 5 being “a lot,” right? That’s what we will do. So, 1 is – you don’t feel like precision health holds great potential for addressing health disparities, and 5 is – you believe it has great potential, or you call somewhere in the middle.

P: (Inaudible).

O1: Okay. So, let’s go A, B, C, D, E. A will be you least feel like it can, and E would be you feel like it holds great potential. A is 1 and E is 5.

P: It is not registering.

O3: Okay. We are going to raise hands, maybe.

O1: Okay. Raise hands if you are a 1 or a 2 – you don’t think it has great potential. How about a 3, or not so sure? Okay, 4 or 5 – you drank the Kool-Aid and you’re ready because you think it’s definitely going to work. Okay, very good. As I mentioned, for our Consortium Core, we have a large and diverse group of community partners, both from our local area as well as the reservation in South Dakota where we are working. It was definitely a challenge to bring these partners together. I would say one, because of the timing … our wonderful colleagues at NINHD, as wonderful as it is that they are funding this type of work, the timeline between releasing that RFA and asking for the proposal was a little bit shorter than it takes to develop community partnerships. Isabelle can attest to that. And the second one was it was challenging for us to knock on doors of community partners who may not have precision health as a priority and ask them to pivot so quickly and trust us. So, we will talk a little bit more about that as the day goes on. So, this is just to give you an idea of the diverse partners that we are working with on this project, and I am very gratified a year later to say as cheeky as I thought it was at the beginning when we were developing the partnerships, how it has evolved over the last year and how now I can stand here very proudly and be gratified that we have very engaged partners.

O3: It has moved me from a 1 closer to a 5.

O1: Definitely, as we have heard this morning, it can be a transformative experience, and I think for all of us, it definitely has been. Was there a question back there?

O4: I just wanted to remind everyone – we will have a poster in the poster session that talks a little about the members and the diversity of members, so feel free to stop by the poster.

O1: Yeah. Okay, so I am going to turn it over to Jill to get our debate started.

O2: Okay. So, we are going to have a debate – half the room versus the other half of the room. This side of the room is going to say how precision health can address health disparities, and that side of the room where I saw a little more “unsuredness” over on that side, is going to talk about how precision health cannot address our health disparities. We are going to let you get up at this point. So, this group, if you can gather around the flip chart up here, and this group, I am just going to put you on the window that you can write on. What I would like you to do is just brainstorm what you think should go on the list of why precision health can address health disparities and then why it cannot. So, you are going to have 10 minutes, and during that time, appoint someone to be your spokesperson, because they are going to have to debate the person on the other side. We are going to give you two minutes to debate your side.

(GROUPS TALKING)

O1: Okay, are you ready? Who wants to go first? Okay, you go first.

P: So, I think community engagement is based on ideas of social justice. There is just such a legacy of inequality predicated on genetic differences, like this idea that one race is inferior to another. So, you have this whole backlog, a very big mountain of opposition, that there aren’t any genetic differences, and then you have all these miscommunications around what the genetic promise is – how medicine is going to deliver us through genetics. So, you have a lot of misinformation. Add that to context, and you learn more and more that we are more genetically alike than we are different, so we feel like it is too reductionistic to try to tag things just to a gene environment, because there are so many layers. We are just looking at this through a health equity lens, right? We do think there are a lot of people who are willing to divert a lot of precious and spared resources to this alluring promise, like the Fountain of Youth, or I’m going to get my genetics just right, I’m going to have optimal health. We feel like that is a missed opportunity when the people who are at the very bottom of the heap are dealing with real issues of access to healthy food. So, we did have some interesting points. It is just back-filling with community engagement. Again, we feel like it is diversion of resources. We feel like it is really hard to bring to the table the people who have been marginalized by this very issue, and ultimately, back to where I started, we feel like it is very reductionistic.

(CLAPPING).

O1: Ready?

P: Yes. So, we viewed the “yes, we can” … we are going to build on this concept of “yes, precision medicine can,” and so with this concept of “yes, we can,” thinking about precision health as an issue of social justice. So, thinking about it, it can happen, because when you are not at the table, you are not a part of the solution. So, in order for us to think about moving from this reductionist mentality, we have to say – are there treatments available that treat the most marginalized in our community? So, two issues that came up when we were saying, “Yes, we can,” were access and dissemination. So, access – thinking about those places where precision health should be, those populations who are already doing this well, like FQHCs, Federally Qualified Health Centers. Federally Qualified Health Centers have a way already of giving access to patients who don’t already have access despite insurability, right? So, one of the things precision health can do is work with the FQHC population, because that can ensure access. We need to be mindful of the risk reductionist and the stigma that comes with risk, but still thinking about risk stratification in a responsible way … so, not risk stratification that says that because you have this disease, you are now further marginalized and further stigmatized, but risk stratification that says we are responsible to respond to what we have seen through this risk stratification. So, when we address your diabetes through this precision health, and we find out that you also live in a food dessert or area of food insecurity, precision health would allow us to say, okay, we also need to connect you with the farmer’s market or connect you with some other social service support to address that holistic population. So, we see precision health as a way to address this holistically. Also, in thinking about dissemination, I think about statins when they first came out, thinking about the fact that Asian populations were not at the table. We can disseminate precision health by making sure populations are at the table that weren’t for original research.

O1: Very good.

(CLAPPING).

O1: One-minute rebuttal?

P: I’d like to concede this notion that, “If you’re not at the table, you’re on the menu.” That’s a Malcolm X quote that I think is really valid. There are too many marginalized people that aren’t at more important tables. I still think that this precision health thing is a marginal table. We need to work harder at the education table. The very things that this is reportedly going to help us fix … we need to get them at the education table, the food table, the healthcare access table – that is where they are still on the menu because they are not at the table. So, what we are saying is – when you are getting to make the call about scarce resources and opportunity, we want to make sure we are getting more and more people out of the grind of poverty so that we don’t have to worry about whether or not they are … (inaudible). They have healthy body weight. They have access to preventative care and vaccines. I mean, Federally Qualified Health Centers aren’t really doing a great job of getting access to care, so how are you going to piggyback on them when they are already over-burdened. We have a wrecked system as it is.

O1: I’m a terrible time keeper. Oh, I’m sorry. Thank you. Okay, ready?

P: Speaking as someone who works in an FQHC, and who once got their care at an FQHC, you’re right – they are not the total solution, but they are part of the solution, and precision medicine is here. I think we have to stop talking about it like it might happen. It’s here. So, we have to talk about – since it is here, how do we get people to the table? And training is a part of that. When we talk about precision health, we don’t just talk about it from the downstream end of the patients. We also talk about who is asking the question and who is providing the care. So, part of precision health is making sure that our institutions are responsible to train people who look like the populations that we serve. It is precision engagement, precision training and precision treatment and research.

O1: Good job, both of you!

O2: Are you going to do an end handshake?

P: Still friends?

(ALL LAUGHING AND CLAPPING).

O1: Thank you for that. They did an amazing job. And as it turns out, it doesn’t seem like there are really two sides. There are challenges and there are opportunities, I think, would be a more accurate way of describing it after that. Does it seem like this group was more describing challenges and this group was more describing opportunities, but they really come from kind of the same place and the importance of getting the community at the table. So, there are no right or wrong answers. In order to address health disparities, I think we can all agree that precision health cannot be done in isolation and that we need to involve all populations from the very beginning. This still is the beginning. It hasn’t been around for that long. So, that is our challenge – getting the right people at the table. Then, engaging communities, including racial and ethnic minorities, is crucial to the success of precision health. Would anybody add anything to those? Do you think that kind of covers it?

O2: Did anybody change their mind?

O1: So, how many believe that precision health can address health disparities? Most of you. There are still some “on the fence” people, right?

P: On the fence just because the debate just highlighted the issues. (Inaudible) … but lawyers have a little bit more punch. One example is that we have a clinic at a homeless shelter, which used to be a hospital and they closed it because it was so run down and not good for patients. But people live there now, and there is a clinic embedded there where our providers give them care. There was a woman who just couldn’t get her asthma under control. It was about to send her to the emergency room and despite all the questions they asked her about her social determinants of health, she did not reveal, and they did not know until they went to her room, that in the middle of winter, 20-degree weather, instead of there being glass in her room, there was plastic and cardboard, and that provider said, “No, I’m a doctor and I will write a letter and get them to get some glass in her window.” Nothing. Tried it again and nothing. It wasn’t until she called a lawyer friend and that is when they were able to get glass. So, it is so complex. That one story is just so complex. It is the empowerment of the patient to say, “I’ve got carboard and no glass in my window,” and then empowerment of the provider to say, “Well, let me try something,” and empowerment of the provider to say, “I’ve got a girlfriend who is a lawyer, so maybe she could do something.” So, yes, identifying all the issues helps, but WHAT DO WE DO? And is that scalable? We are in a well-resourced area here, so maybe we can do that in inner cities. What does that look like? Yeah, it could help, but WILL it help?

O1: That’s a good question, and I think that’s the perfect segway to our next section.

P: Can I just say that I really do think that we can’t think about this as this huge large-scale problem or issue. We have to do it in our communities, and we have to find the best practices that are going to work to bring people to the table. So, when we get in focus groups in our different communities and … (inaudible – ambulance in background), and at the same time let the researchers hear it and put it out in larger scale, but still it is at a community level. It is not at this grand-scale level. We are never going to be able to address something that big, but we are hoping people like us are going to gather some grand-scale data that helps us apply it to our local communities. So, what you did, I think, is what is best practices. You pooled all your resources together and you addressed the issue. So, that’s what we have to think about. There is no single one big answer.

O1: So, we are moving into the “how,” and Rhonda will talk about our next process.

O3: Yeah. So, now we are going to do a little bit more group work. I think we are going to have four tables, and for the sake of time, just stay in the tables you are in. So, the objective of what we are going to do now is identify strategies and best practices for engaging diverse communities in precision health research. Clearly, both sides mentioned that we need to figure out how we need to engage populations and how people at the table … clearly, the complexities of the challenges speak to the importance of having strong partnerships and people involved in the process. So, we thought we would spend the remainder of this time brainstorming some of the complexities around that, but adding a few extra components to it. So, we are going to break you up into three groups, but I think we will have two groups do the same question. So, if we could have you two join this table, and we will have this table, Table 1, we will have this middle table, Table 2, and we will have the back table, Table 3. Then, we will have this table also do Group 1, too. So, we will have two Group 1 tables. What we want you to do is those that are in group one (and we will bring you flip chart paper) … but you will be identifying initially-engaged partner organizations. So, how can we work to identify strategies and practices for … how do we identify and initially engage partner organizations? What are the strategies that we need to use? Someone in the group, the debate group over here, was saying, “This is moving so fast, but is moving too fast to effectively engage our communities.” So, what are some strategies that we can use to identify initially-engaged partner organizations? The group that is in the middle will talk about working with partners to engage community members. So, it is not just the community partner organizations, but the community members. So, what strategies and practices can we use to effectively work with partners to engage community members in this work? Then, group 3 is going to talk about strategies and practices for working with researchers from diverse disciplines and very inexperienced with community engagement. What strategies and practices can we use to really bring together the diversity and complexities of researchers that are working across the spectrum of research in precision health and have varied experience with community engagement. How do we build those strategies in working with them in partnership with our community? Then, over here, we will have Group 1 do the same thing as this group over here. So, the idea is we will bring you paper, and you can spend about 10 minutes brainstorming and prioritizing, and then we will have you report out, and we will kind of talk about our experiences and what we have had in those areas. We certainly would like to hear about your experiences as well. I think if we could brainstorm and prioritize in 10 minutes, that will put us in good shape.

(GROUPS TALKING)

O1: Okay. I hope you were able to have a rich discussion. I’m going to bring us back so we can get you to lunch on time. I think it’s a really good discussion, and that’s what we wanted to have today. So, I am going to take Group 1. I’m going to take this group first and have you report out your priorities.

P: Okay, so our topic was identifying and initially engaging partner organizations. So, first you want to think about who you are really trying to target and where you find that group in large numbers, and then within that, find that leader that you can build a trusting relationship with that they can let that trickle down to the people they work with.
Acknowledging the time it takes to engage, it could be years, so try to make it realistic as far as people trying to do that. Being present and a good listener. Asking for permission. Communication as a whole. Even that relationship that took so long to build can unravel quickly in the wrong situation. Assume that you have as much to learn from the community as they have to learn from you. Coordination of effort. Having multiple groups in the university, we have all been there. Education and social work school and nursing school, they all need to be working with community partners. The community partner might not understand why because you guys don’t talk to each other, but really, we are on separate \_\_\_\_\_\_\_ in the suburbs … so really, a coordination of those efforts is important. Going in and having cultural competency and humility, that you are not the expert, but you are willing to listen and learn and really just underline that trust.

O1: Thank you. It was a really good discussion. I was able to listen in and you had a really good dialogue going on. I am going to move back to this group. You don’t have to repeat, but is there anything in addition that you would like to add?

P: Yes, so definitely valuing the time and \_\_\_\_\_\_\_ of community partners, even if that means a monetary value. Being able to physically meet community partner organizations where they are at, so, I think, so many times I think we require people to come to us, and that creates a basic lack of trust. The last point was that trust-building takes time, and both the people investing in that research and the funders need to recognize that timeline may not fit into a three to five-year grant.

O1: Those were wonderful. Thank you.

P: (Inaudible).

O1: Say that again. I can’t hear you.

P: (Inaudible).

O1: So, I’m going to go through each group and then I’m going to share a little bit about what we’ve done with SPHERE. So, in the Group 1 topic around engaging partners – leveraging existing trusting partnerships. So, that is what we did. As Lisa mentioned, we had a very, very short turnaround time that we were charged with this responsibility and the challenge of it being a topic area that neither of us have expertise in. It was a challenge and opportunity, because I am not going to say it was just a challenge, that the focus is on multi-ethnic populations. So, that was a wonderful opportunity that we had. We started off with the trusted relationships with partners that we had. None of these partners were partners that we did anything close to precision health with, but that’s where we started. And it was wonderful. When I called Isabelle on the phone to talk about, “Wow, let me tell you about what we are doing,” she was like, “Oh, let me tell you!” I was like, “Oh, my gosh, this is going to be a huge learning experience for me!” I was so excited because we had worked together, but we had not worked together in precision health. We had worked together in other things. We had crossed paths in other ways. It was really, really nice to meld that, wow, we have a community partner that is so far advanced in this than I am. It is going to be wonderful to have her as part of this. So, we started where were at, being strategic about forming new partnerships. So, where we had gaps, and our goal, mind you, was to be very diverse. So, our goal was to be diverse geographically, to be diverse ethnically, to be diverse in gender, to be diverse in professions or topic areas … some people had experience working in diabetes, some people had experience working in cancer, some people had public policy experience, some people were community-based physicians, some people were health educators, some people were community health workers. So, we really wanted to have diversity in every respect and way. So, I created a chart and I actually mapped who our partners were and where we had gaps, and where we had gaps and we didn’t have relationships, I went out and created those relationships. We called people. We met with people. We would say, wow, we could use a national representative, we could use a statewide, we could use someone who is working on public policy around precision health. So, we built that chart that you saw earlier based on that goal of having diversity. We could use someone that has language proficiency in this area, and we really built it around that. Academic partner team members need to build capacity and communicate the potential of precision health to address health disparities. So, that speaks to – I had to go out and say, “We are doing this precision health initiative, and I would like you to join us,” but I couldn’t, myself, define what precision health was. It was really challenging for me. It was brand new. I was a little bit on this debater’s side at the moment. I was kind of way over here and I didn’t really know, because I didn’t have any experience before in what the promise was. We didn’t have the opportunity to really study and figure it out. Through this year, we have gotten better and better and better. It is really about all of the complexities of the things we have talked about today. It is important to explicitly make the connection between precision health and health disparities for potential partners. We talked about today the complexity of all the issues and the challenges that are happening at a community-based level and what people are dealing with. So, being able to make that connection – how is this going to address health disparities? What is the potential? How could it relate to the work that you are doing already? Being able to be able to make that connection was very important?

O2: Can I interrupt you already?

O1: Yes.

O2: One of the things we’ve got to get over is that the community knows the word “disparities.” They know “inequality.” They may know “lack of access.” But they don’t know “disparities.” That is a science word. That is a research word. So, when you’re actually trying to describe it, you’ve got to use another word besides “disparities.” Your “inability to get care for your family” is a better way than “health disparities,” or the fact that you live near a garbage dump. That’s a “health inequity.” So, you’ve got to watch even how you are describing things they may not understand. I think it is very crucial, so I start to argue against the word “disparities” as though everybody knows what the hell it means.

O1: Did you have something else to add in this area of engagement and how that experience was for you?

O2: No, because we are running out of time. Otherwise, I would have a lot to say.

O1: Okay. Then, recognize and utilize the expertise of community partners. So, Isabelle came with a lot of expertise. Different partners have different levels of expertise, and really being able to ask people – let’s all together collectively define what the expertise is that we are bringing to the table, and then really appreciate that and utilize that. Then, having appropriate compensation for partners is really critical and needed. So, Group 2 – Engaging Community Members … what do you have to say? This is the middle group/

P: The first was assessing the benefits to the community partners, their needs, their assets, their priorities, and collectively working to address those issues. The other was having ongoing engagement with the community partners rather than one point in time, and having multiple funding streams to hire people to continually engage with these groups, to be “boots on the ground” and to foster and nurture relationships with these groups … and then to also provide education and training to participate in research activities and to compensate them adequately, appropriately, ethically, for their involvement. Through that training that they were provided to grow … (inaudible) … capacity. Another one is to \_\_\_\_\_\_ the fears of the community partners and the communities they represent, understanding that there is a lot more that unites us than divides us when it comes to our fears about participating in research, and then having a common language to address those issues and a narrative that partners collectively use to adequately address those issues with their community. Then, we talked about building in protections to allow for forward progress, so having community partners at the table to determine what protections are necessary to implement the research, and then have community ambassadors who help navigate and bridge relationships and have conversations about these issues … understand the color and the texture of these silos that we have and how to bridge these guys together, ensuring that the ambassadors we engage are the appropriate ambassadors for the communities and that everyone has a place at the table, and they are best able to meet the needs of their communities.

O1: We are capturing the notes today and this section is also being recorded, but we didn’t do a disclaimer. (Inaudible). I’ve been making a digital record and we are going to take all of the notes back with us … (inaudible) … to our stakeholders and supporters. It is audio recorded, not video. (Inaudible).

O1: Isabelle, as a community partner that has engaged community members, do you have something that you would like to add to this group from your experiences?

P: Absolutely not. I was in on that conversation, so she captured everything that was really, really crucial, but I did say to them that I think it is really important for us to recognize that we, as communities of color, should get out of our silos, because our communities across the country are also suffering from similar kinds of issues. When we begin to understand, as she said, that we have more in common than we have that divides us, then we can begin to address the issue as a structural issue instead of a particular racial or ethnic issue, because it is really impacting all of our communities, particularly the low income. So, we need to try to actually not just partner with a researcher, but partner with each other.

O1: So, those are all wonderful things. Recognize and utilize expertise of community members, you said that. Engage community partners early and often to optimize engagement with community members, having that longitudinal continuous engagement, is important. Make sure researchers go to the community, and don’t always ask them to always come to the university. And really, find ways to connect with people where they are. And always important to consider and require – appropriate compensation, things like gathering and food, language … (inaudible) … and incorporating traditions as much as you can, are all really important. So, Group 3?

P: (Inaudible – sounds really far from the microphone).

P: Another point … (inaudible – sounds really far from the microphone).

O1: That’s wonderful. Thank you. So, I’ll just wrap this up and I’ll turn it over to Lisa to close, but in this category, be mindful of varied experienced with community engagement among researchers, which she brought up. We need to be very clear and vocal about the value of community engagement with researchers. We need to be very clear and detailed about realistic budget needs. Listen carefully to researchers to understand how community engagement can benefit their specific goals. Look for small early wins. Sometimes it can be daunting. As you know, we talked about it today – just the complexities of precision health in general … but really, find some early wins. I like the idea of doing tours. I really like the idea of having some dialogue with champions. I think those strategies are all really fascinating. This was a really good discussion. I really appreciate the ideas that you’ve brought up, and I’m so glad we have captured them so we can take them back and all of us share it. We can skip this poll for the sake of time, but we want you to think about how likely you are now to use some of these strategies.

O2: For the ones that work, they can do it. So, the A, B, C is not showing up. So, highly likely is A, likely is B, and not likely is C.

O3: So, before we wrap up, we want to give an opportunity for questions and answers. So, we probably have time for one or two questions. Does anybody want to pose a question to the group or us up here?

P: I am concerned, as a new person … (inaudible) … just about the \_\_\_\_\_\_ of racial and ethnically spoken issues, the way that folks talk about … (inaudible) … like, “African Americans blah, blah, blah.” I am really concerned, working with the communities of color, how this is going to flip in a negative way when it could be such a positive thing, now that we can find out what the specific issues are affecting you as an individual or your specific community, but that could flip into a negative with people being further stigmatized and creating more access issues, etc., etc. I am just wondering if people have come up with at least a way to dialogue about it, because I feel like it is very minimizing to be like, “Oh, don’t worry about that,” because that is not the answer. But most people don’t have the capacity or the time to assert dialogues or a whole debate. Has anyone found a rhythm or any talking points about this?

O4: Well, I was thinking about the same thing. We went out and did focus groups with the five different racial ethnic communities, and trust and historical trauma and historical injustices were the main themes that came out of those focus groups. So, in my mind, we don’t have the answer to your question yet. From where I stand, I think we still have a process to go through to engage, very genuinely and sincerely engage, to ensure that is not what comes out of precision health. So, for me, personally, as a researcher, I don’t have any talking points, and I don’t feel comfortable convincing anybody yet that that’s not going to be the story. I will feel comfortable, I think, once we are truly genuinely all working together to ensure that the story is one of inclusion and one of addressing health inequities, as opposed to further perpetuating that.

O2: Can I add – that’s exactly why you need community engagement. They need to come together in these discussions and decide for themselves what the safety net looks like, how they want to build in those protections, and whether or not they are going to engage. Ultimately, they can make the choice, but if they can help engage in a community discussion, then I think there should be a lot of forums in communities around the country about this issue within the communities, whether it is across silos and groups, or whether it is within a specific arena. I think it should be held, because you will be surprised sometimes what communities come up with, how they feel, how they think.

P: I will tell you one simple example of one way in our focus group – they said that one of the most important things was to have an African American researcher being the one asking these questions. Then they would feel more trusting. So, that means we are not going to change the story tomorrow, because that is a pipeline issue that takes a long time, but it is something we should all be working toward.

P: (Inaudible) … are there principles we are all working under that address these issues, or are there rules for the initiative that guide everyone to keep to those standards?

O1: So, I think one of the charges of the Precision Health Initiative in the National Institute of Minority Health is to establish ethical guidelines. I think in the spirit of making sure we are all sitting at the table and participating in the conversations, we also need to demand that the ethics and questions and hard questions we don’t have answers to is always the agenda at the table so that we don’t forget that as we are learning and thinking this through, and these ethical issues are coming up, that it is always on the agenda, so we can begin to formulize these guidelines as we are moving forward and learning. Then, I think the other agenda item is if we always have the agenda of equity and where equity fits into this, then we are always addressing that as we are learning and bringing these things up. So, I think demanding that the ethics and equity be at the table, as high on the agenda, as all conversations, I think, will help us get there. But we all have to demand it, and we all have to invest in having that discussion. So, you bringing that up as a concern that you have, that is how we get there. We all say, “I just have this concern,” and we talk about it, and we formulize around it. So, I think that was really great.

O3: I just want to thank all of you for your participation. I learned a lot, and we hope to continue to dialogue out by our poster!