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Organizer 2:  Alexis?

Participant:  My name is Alexis Gordon.  I serve on the Sickle Cell Foundation on Tennessee's Board, and I represent the Nashville, Tennessee area.

Participant:  I am \_\_\_\_\_\_.  I work for Yvonne.  She is my boss.  I manage the community engagement studio model at Vanderbilt.  I am the \_\_\_\_\_ Navigator.

Organizer 1:  I just want to say a little bit more about my colleague.  Alexis has been involved in a lot.  She is one of our great community partners.  She has been involved in a lot of different research projects.  She has been in I don't know how many of our community engagement studios as an expert.  She has worked on several research projects around sickle cell disease, and she is the member of a stakeholder engagement board for our Mid-South Clinical Data Research Network.  Tiffany is a social worker by training and has a community organizer background, which has been really valuable in the services that we have developed over the years.  The combination of having people in other disciplines and having our community partners has really helped us in the work we do.  So, today, we are going to talk about how to help community members and patients claim their power when they are in these consultative and advisory roles in research.  We are going to talk about institutional barriers, how do I identify and recruit people to serve in these roles, preparing people for the research roles, and then we are going to have a little exercise breakout group.  So, we are going to talk a little bit about our experiences, but I know that probably for everyone in this room, things are going to sound familiar.  You have your own experiences and we want to tap into that experience and the wisdom in this room as well so that we can share some of the things we have learned.  I am going to give a little overview about institutional barriers.  Thinking about the speakers we heard this morning, it is fair to say that a lot of these barriers are rooted in institutional or structural racism and sexism.  That is part of the culture.  It is part of the institutional culture in an academic institution in the majority of institutions.  The Hopkins and Vanderbilts were not created to serve people of color and were not created to serve women, and we have a lot of that structure still with us.  I want to start out with some words that one of our colleagues shared.  We have a community member that serves on a scientific review committee for CTSA.  So, this is a committee of researchers.  It is frankly mostly older white men.  You have seen those groups of people, right?  And we have two African American women who are not researchers who sit on that.  What they have shared with me ... and we have spent about nine months, literally, preparing them to serve in this role.  We have said things to them like, "When you go into this committee, you may feel marginalized, patronized, like people are speaking down to you, and are you okay with that, because you have an important voice here?"  We wanted them to understand that was going to happen to them, and they were like, "Bring it on - we know it is going to happen and we have been here before."  Most of the proposals they read are not necessarily community-engaged research proposals, so why are there, and that is what the other people at the table are thinking - why do we have non-scientists at the table?  But she says, "When I read those proposals, I think about the people that I represent, and I think about what they would say, because I am their voice at the table."  So, that empowers her.  She has a purpose there.  What often happens, and this happened last week, and you have all seen this happen ... she asked a question about compensation on this particular study, and I won't go into details about the study, but the researcher said, "It is not really important - we feel like we can recruit adequately without compensation."  And of course, her point was, "Then a lot of people are not going to be able to participate in your study."  Then, the conversation moved on, and the older white man sitting next to her said to the researcher, "Well, what about compensation?"  All of the sudden, there was a discussion among the rest of the committee members.  There is a word for that.  I don't know what it is ... I think it is "man-storming."  If you all have a better name for it, please let me know.  This is part of the culture.  The men at the table are the experts.

Participant:  Perceived experts.

Organizer 1:  We need to empower our community partners to perceive themselves as experts, and we need to help our academic colleagues to understand that there is an expertise there that they need.  There is actually a growing body of research that says this.  In the Institute of Medicine, it says this.  PCORI is saying this.  There is research that says it.  So, that is one of our tools.  We are going to have to educate our leaders because we don't necessarily have buy-in from institutional leaders to support integrating community members in this way.  Cultural humility - that is something that is not easy to come by.  We find that when we have a meeting, and we use our community engagement studios in this way, where clearly the community member is coming with experts, and the role of the researcher is to listen.  For most of them, it is an "ah-ha" moment.  It is like, "Oh, they have something of value that is going to make me a better researcher, that is going to help me be more successful in my research."  If they can't hear that or see the value, then they lack that particular humility.  Compensation is a barrier.  When I first started with our CTSA and I put money in my budget to pay my CAB members, the PI said, "But they are volunteers; why would pay them?"  I said, "Well, they have something we value, and how do we show we value something?"  We pay for it.  You get paid $300 for walking into the room, so yes, we pay for what we value.  That is how it works.  Setting up processing for compensation that is not burdensome ... maybe it is gift cards.  Maybe you find a way with your finance and legal department to not collect their social security numbers, because that can be very burdensome or intimidating for certain populations.  Work schedules - most people work during the day and they can't just go off to meetings, so you need to think about meetings at night, meetings on the weekend and meeting in the community.  Get those researchers off the campus and into the real world.  I talked a little bit about the institutional culture, developing and training for researchers, but also engaging the community members in the development and actually implementing that training because they have a very important perspective to bring to the table.  And we can talk a little bit more about institutional barriers.  I'm sure you all have a long list of them.  Then, I think on the other side, there are barriers of perception on the community side, but I am going to let Tiffany talk about recruiting.

Organizer 2:  Okay, thanks.  I am going to go out on a limb and say that all of you have, at some point in time, probably have had to identify and recruit individuals for a project, right?  And do you get that phone call in the eleventh hour where they say, "Hey, I really need an African American male who knows this, this and this to sign off on this project.  Can you find a pastor for me that lives in this neighborhood that will sign a letter of support?"  Yeah, okay, like we have people living in our drawers and file cabinets that we can just call up.  I always tell Yvonne, and she totally agrees because she has a history of working in the community as well, that I always feel uncomfortable with that and basically won't do it because I feel like that is our social capital.  I am not going to lend my social capital to any researcher to just kind of do with what they want, because they don't understand the value of it.  So, part of our role is educating them about the value of building relationships and sustaining relationships, having genuine relationships.  I always try to say, "I am so excited that you want to partner with the community.  I can help you work through that process, but unfortunately I am probably not going to be able to locate someone for you on this short timeline."  It is okay to say no.  A gentleman said earlier, "How do we have that conversation without offending people?"  Sometimes you've got to offend people.  That is the just the nature of the corner they put us into occasionally, but I feel like that is more on them than us, because it is our role to help educate them about social norms and what is appropriate and what is not, and not to take advantage of the community.  On the flip side of that, which is what we are talking about today, is how we can help community members claim their power.  I always hate the word empowerment, because that acts like people don't have power and we are giving it to them.  They have plenty of power.  We are just helping them find a seat at the table, claiming their power.  I wanted to start a presentation with Maxine Waters - "Reclaiming my time."  I thought that typified academic culture for me, because how many times have you been in meetings ... just like if I gave the example, and people will talk over them ... they will wait and come back around like it was their idea.  They kind of pacify, in a way, things that get mentioned and don't have value to it, even though if they knew what they were doing, they would be way more successful in the research world at recruiting individuals into their studies.  The majority of NIH studies don't meet the recruitment goals ... don't even come close to recruiting enough underserved population.  So, I feel like what you all have in this room is golden, and if you can convince the research world, academicians, that what you have is going to add value, then you are going to be rock stars, if you are not already.  So, reclaim your time.  When you are identifying and recruiting, I tried to come up with four bullets, essentially, that can help prioritize your very limited time.  So, when I am recruiting for community engagement studios, essentially a one-time meeting where I pull together consultants for the community, just average folks who don't necessarily have to know anything about research to be our consultant.  They can talk about potential barriers, how to improve implementation, how to message, how to recruit.  They basically improve the research project by giving feedback from their own perspective.  Right now, we are recruiting for about 12 studios, one of which is an entirely different city.  We do that all the time as well.  These are the steps we take.  So, the first is - Narrow your focus of the expertise you need.  So, for instance, you need individuals that have that "lived" experience, so because they are living with diabetes they have experienced homelessness.  That "lived" experience is going to inform the project.  That is one piece.  The second piece could be that the expertise that they need might have to be ... for instance, with Alexis, who is our rock star (Alexis is on every studio that I have on sickle cell and she will share that in a minute), but also, I have an increasing number of requests that are looking at IT applications, patient decision-making tools, pain management, etc.  She is an IT developer.  So, I have her in every IT meeting that I ever need a consultant in.  I have other individuals, though ... for instance, the one she came to was a pain management app.  It was individuals who were experiencing treatment for cancer or had chronic pain conditions.  So, think about what is the expertise you need around the table.  I have other community experts who have experience now because they have grown in their roles of being able to analyze data from a community perspective, because the researcher, who is analyzing data, will see it very differently from someone who lives in that community.  A researcher might say, "People said this because of A," and a community member might say, "Huh-uh - they said it because of B, and you are not seeing it from their perspective."  So, it is really valuable.  Next - The Specifics of Demographics.  I cannot say this enough.  All African Americans are not the same.  I have so many researchers say, "I need to get African American feedback on the project."  I am like, "Okay, well, let's talk a little bit about the project.  Do you want a diversity of folks in the room?  Would you like a diversity of educational attainment?  Urban or rural?  Do you want to put the diversity of age in?  Talk to me a little bit.  Or are you specifically saying you are nervous you are not going to get enough African Americans who live in this urban area to participate for a specific reason?"  Then we could narrow in on that particular group of folks and say, "Hey, they want your feedback, and they know they don't know how to reach out to you or message you for you to tell them if this is a good project, and if so, great, and if not, how would you fix it?"  Sometimes we have studios where people say, "I would not participate in this ever," and we have had researchers go, "Well, I should start over."  So, think about that and educate academicians and researchers about that.  There are no homogenous groups.  Everyone is not the same.  So, you may have a need for individuals across the spectrum of folks, or you may want to narrow in your focus on the project.  The next is - Defining Roles and Expectations, and this is really important for us.  For me, when I am recruiting individuals who are new to the research world of acronyms and blah, blah, blah, I try to make everybody feel at ease and let them know, we call you a "community expert" because you are an expert in your own right.  You are bringing an expertise to the table that they do not have, and that is why we compensate you for your time.  And we also make sure that they are the majority of the people in the room.  So, when academicians want to fill the room or facilitate, we don't let them.  We always have more community members in the room than academicians, and that is really important, so that they can claim their power.  And those are like baby steps, right?  Then, once people start to feel comfortable and they have gone to a few meetings or they have consulted on a few projects, then we try to move them into roles like maybe facilitation.  Then, after that, they may contract with us to even help with some recruitment and orientation.  Then, after that, they may become research team members, or they may become a co-PI on a national project.  So, there are these opportunities for growth that you have to be very mindful in defining what the roles are, defining expectations on the front end, and you sometimes have to push that envelope with researchers.  So, if they come to you and there is no job description, or no MOU, or no compensation plan set, then I would say, "If you can get me these things, then I can probably recruit someone for you."  That also helps kind of push them along as well.  Then, the last piece is the recruitment plan.  So, those are all the things that I have been talking about that needs to be put to paper.  All of those things, what is the focus of expertise, let's hash out demographics of folks that need to be involved, what are the roles and expectations, and did you check off job description, compensation, MOUs, all these things we are talking about today?  That is your recruitment plan.  Then, for us, we use a lot of \_\_\_\_\_\_ tools.  I am not recruiting for research.  I am recruiting consultants.  I use LinkedIn.  I use Twitter.  I use Facebook.  I have my biggest success with established social networks.  If I need a group of moms who used opiates during their pregnancy, there are organizations in Davidson County that serve moms who used opiates when they were pregnant, and my job is to have good relationships with all the people who work there, because they trust me, they know they'll be compensated, they know we are very respectful, they know we will treat it as a learning opportunity, and then the researcher can get their feedback.  Youth who are transgender - we have a national model in our city who works with LGBTQU.  I know the organizer.  I call him up.  I have known him for 15 years.  He says, "Let me present this to the youth and see if they are interested."  We had 12 youth that showed up for a meeting to be consultants on a project.  So, it is about building those relationships with the community using your social capital, your honesty, your integrity, and then building those groups through those networks.  All jokes aside, when we have those that say we have to recruit for studios out of Nashville in Boston or University of Alabama, etc., they go, "How do you know people here?"  We start with Google.  We do a quick listing of the major social service organizations and social networks and clubs and groups.  We find out who the key leaders are and then we just genuinely reach out to them.  We introduce ourselves.  We tell them what we are doing and why, why we love to have community input, if this is something that would be of interest, and once we establish a rapport and a relationship, they are usually really open in coming to the table.  So, don't be afraid to ask.  I am going to let Alexis speak to these points for her perspective.

Organizer 3:  So, my organization has been working with Tiffany and Yvonne probably three or four years now.  So, the way we recruited individuals is obvious with the Sickle Cell Foundation of Tennessee, so obviously if you have some connection to sickle cell disease, whether it is you that has the disease, or whether you are a caregiver, mostly parents of individuals living with sickle cell disease.  So, we have a database of probably 600 to 700 individuals in Tennessee that are living with sickle cell disease or that have sickle cell disease in their family, either the beta thal trait or just the trait itself.  So, there are a lot of different technical terms and medical terms for the disease.  If you want to know more about them, just get me to the side and I can tell you more about them.  But if you have any of those different things in your family, we welcome you to be a part of the Sickle Cell Foundation of Tennessee.  What we do basically have a yearly calendar.  We basically run our calendar in conjunction with the school calendar.  May is when we typically meet.  We meet once a month in the Nashville area, whether it is on the institutional campus or in a medical facility or religious facility.  Wherever we go, we meet with families.  We usually have anywhere from 20 to 30 participants at each meeting.  At each monthly meeting, we try to empower our families and the patients living with sickle cell disease on a variety of subjects or variety of topics.  So, usually if we follow the school year, we will typically do something in August and September around back to school or how to create 504 plans for your children who have sickle cell disease, or IEPs, if you are familiar with those, so that the schools are aware that you have this disease and how to help you live with this disease and what your children should do.  So, we have a variety of subjects that we talk about with our families and patients throughout the year.  It could be health.  It could be how to stay warm in climates that are cold climates because that is important for sickle cell patients ... how to make sure your water intake level is where it needs to be, because that is also important to sickle cell patients as well.  So, everything we do is basically to empower the patients and the caregivers.  So, when Tiffany or Yvonne calls and says they need someone who has this disease, we can always just give them a family or 10 to 15 individuals that can consult on a project for them.  We give them whatever advice they need.  We go in and critique proposals.  We read proposals.  We dissect proposals.  We put big red "x's" on proposals, and we give thumbs up to proposals as well.  That is basically what we do.  One of my biggest pet peeves about research is the dissemination of information, and one of the things I talk about at every single research forum I go is that we don't want to just participate, but what are you going to do with the information you gather from us?  We appreciate you engaging us and wanting our information, but now what do you do?  Is this going to be in a journal somewhere on a shelf in the library, or is this actually going to reach the community within which we serve?  So, most of the time, I am giving two thumbs up to anyone who has a dissemination plan on their research proposal, especially if it is going back into the community, and what you are looking to do and what you are looking to gain.  But that is basically what we do.  We empower them to be consultants on projects.  We empower them to own their knowledge, kind of own their experience, own their expertise.  Although I am not an M.D., I have lived with sickle cell disease all of my life, and you just studied it for four years in medical school, so there is a lot that I know that you don't.  I am just saying.  So, that is how we try to empower participants and patients as well, just owning our expertise and being a part.

Participant:  I have a question.  In your empowerment process, or helping people reclaim their power, do you have an official class or curriculum that you take your parents or patients through in order to reclaim the power?

Organizer 3:  Yeah.  So, one of the things we do specifically for sickle cell disease is we talk to our patients and our families about how to go in and tell the doctor what is wrong with you.  If you are familiar with sickle cell disease at all, you know it is a rare disease and not many medical doctors really know how to treat it, to be honest with you.  We have used our experiences over the years to say, "When you go into the E.R., this is what you say."  If you don't already have a medical plan that you travel with from your doctor that is written on actual letterhead from your doctor, this is what you go in and say.  I was blessed to have a mom who was a nurse, who, when I grew up in the 70s, had friends that were doctors.  So, I was a bit privileged because they could tell me how to go in and talk to the E.R. at the University in the city I went to that had no idea what sickle cell disease was, and thought I was just a drug-seeker.  So, we talk to them about what to say, how to say it, and give them specific information about how to treat you.  So, we talk about that all the time at our meetings.

Participant:  Then, I guess I wanted to know more about how you prepare them for research.

Organizer 3:  Yeah, training.  We have different training sessions depending on what research project they are going to, where they are going to participate.  It depends also on the duration of the project.  So, there are a lot of variables based on the project.  So, we just finished up a PCORI one that was about two years or so that we needed to recruit patients for, document, and create a database for, but that database needed to be available for over a three-year period.  So, we needed to go in and specifically ask those questions about - how long have you been at this address and will you be at this address for the next three years, or is this contact information accurate?  So, it is really specific to the research project that they are going to participate in, and we have one-on-ones with them if they are looking to participate in that project.  We will read the proposal.  We will see what their role will be on the project, if they are expected to create any deliverables on the project, or if they are looking to participate in the study, or exactly what their role is, and we focus our training specifically on the project they are going to participate in.

Participant:  Once you give them the training, when they leave, do they understand and know that their empowerment is in them ... you are trying to bring it out so they know they are empowered to do it?

Organizer 3:  Sure.  And I'm sure Tiffany can talk a little bit about our group.  We are not a shy group.  That is really important that we pick people to be on these research teams that will stay, that will be blunt to researchers and say, "These are the areas you need to focus on and this other stuff really doesn't make much sense," and have that empowerment within them.  So, yeah, we rotate our monthly meetings to allow others to speak to start to overcome speaking at the table, standing and speaking, some of those barriers that many of our community members are faced with, having the soft voice.  Some of those things are really important when you are going to sit at a table with a group of researchers and medical professionals.  But yeah, we do it.

Organizer 1: We were chatting about this and saying - is there value in saying what characteristics really are ideal for a person that you are recruiting from the community, and here is the challenge for me.  I feel like anybody can do this.  Anybody can come and sit at the table and give feedback as long as they have the right support and the proper orientation to the process so that they feel comfortable.  But it doesn't matter their educational attainment.  It doesn't matter what they live.  It doesn't matter if they have ever worked a professional job.  None of that matters, honestly, as long as it is something they want to do, that they have a desire to be at the table, that they are interested in the project, that they want to learn a little more.  They could just be curious.  We just did a studio with moms of children over the age of five, so most had to bring their kids, and I am quoting our research analyst - "To me, there were like 57 kids there.  I stepped on a \_\_\_\_\_\_\_.  I don't know what was happening."  Most of the moms there had never participated in anything like that.  The researcher and I were like ships passing in the night, as I was going out and she was coming in, and I said, "How was the studio?"  She said, "It was amazing.  I got everything I needed.  We are not going to be able to consent after delivery."  I was like, "Well, at least you know now."  She was like, "Not one woman there wanted us in the room after they had given birth."  I said, "I'm glad you know that," because that was going to be their secondary forms to complete for that project.  So, it was good that they learned that before they did that.  So, is personality important?  Yes, to the extent that someone can be brought into the conversation.  We have phenomenal facilitators.  One of them is here today.  She is my rock star facilitator.  She helps everybody on the front end.  Everyone will be expected to participate today, so don't get comfortable.  We do small groups for that reason, though, so that people aren't speaking in front of 100 people, 50 people.  It is usually a group of around 8 to 10, so there is food, we go around the table, the researcher sits, nobody is a doctor ... it is a pretty chill environment, so I think that helps.  But they do have to be willing to open up a little bit.  We have people cry in our studios because we talk about a lot of sensitive stuff, everything from a false positive on a mammogram to an ICU stay.  We have literally done a half of a dozen of ICU survivor studios.  That is emotional stuff.  It is draining to hear people share their personal traumatic stories that they are hoping will positively impact care in the future and impact research in the future.  In terms of expertise and background, as I mentioned earlier, it is all over the gamut.  It can be someone with "lived experience" that brought them to the table or it might be that they live in a zip code in north Nashville that has one of the highest rates of diabetes.  So, for our work, we are really fortunate in that the studio model that we talked about we do on weekdays, at night, on weekends, on campus, at libraries, at health centers, at schools ... we will go wherever.  We take our show on the road, which is great, because it makes researchers leave the campus.  We just tell them - you are going to have to meet us over at the Oasis Center at 6 o'clock on Thursday night, because these folks have school and that's what they need.  We will see you there!  We don't even ask, "Can you?"  We just say, "This is what you have to do."  For some projects, particularly as you get into higher levels of leadership and participation, if you are a member of a research team, and it is a national project, there may be a call at 1 o'clock on a Thursday.  Now, the hope is that they took into consideration the community members' schedules just like they did everybody else's schedule, and that is the claiming your power part, right, advocating for yourself as well.  If the community was the only one who couldn't do it at that time, maybe, but you've got to think about that - how can they advocate for themselves?  But they may have to be available during the day for a conference call.  Can they travel?  Sometimes projects have required people to travel.  Can they do that?  Are they available to do those things?  So, just like any job, because you are a consultant, they are actually working.  I want them to feel like this is a professional role that they are playing, so they have to think about those things as well, because not everyone is a perfect fit for every job.  So, depending on the requirements, the level of expertise, the duration ... you have to think about the characteristics for each individual project.

Participant:  (Inaudible)?

Organizer 1:  We do an orientation.  The point about evaluation - we actually have everyone who participates fill out an evaluation to tell us if they felt like they contributed, did they influence the project, what was their experience like?  So, we can share evaluation results, at least a little bit, from some of our projects.  But they all receive an orientation.  So, I either do it on the phone or in person.  I like to go out and maybe talk to groups on the front end and say, "Hey, this is something we do if you are ever interested and want to fill out an application and put it in our database and I could reach out to you.  Here is what the studio model is.  Here is why we think it is important.  Here are the roles you would play."  We have an orientation handbook that they also get that walks them through the studio model in plain and simple English, and it also has a list of vocabulary, like commonly-used acronyms and that kind of stuff, but we try to keep it really simple.  We don't want to overwhelm folks.  We are always available for their questions and consults and things like that for community members, not just researchers.  So, it is a really basic overview and orientation of our process, basic overview of their research role, because I feel like that studio model that I talked about is almost like baby stepping into the realm of research ... like the PCORI project where we got to interview a lot of folks who had participated in studios so they could define where they felt like they were able to participate the most and also identify the areas where they felt like they needed more support and training so that they could give more detailed and fruitful feedback.  I feel like analysis is one of those areas, like, I just feel like I need more information about this data analysis thing.  So, that was one of those areas.

Participant:  I am wondering if there ever is an opportunity for \_\_\_\_\_\_ to be a part of the design, so there is no need for feedback.  Feedback would be given as it is being created.

Organizer 1:  That is our preference.  Pre-submission studios are my favorite, and luckily, I don't know if you all are familiar with PCORI, but they require it.  Then, researchers are like, "I don't even understand what this means."  So, we have a lot of pre-submission in PCORI, but we are getting more and more now that are NIH-related.  I think institutions are starting to evaluate more feedback.  I hope it is not a trend.  It makes me nervous a little bit.  I was thinking this morning, "Wouldn't it be great if all the people in that room signed a mandate on a national level and said, 'You know, we don't want this minority recruitment thing just to be a box people check and don't have to do.'"  So, yes, our preference is always ... but my doctors always say, "We meet researchers where they are, but if we just did pre-submission studios, I would be out of a job."  So, when they come to us and they are two years into their project, and they are like, "I haven't recruited one person and I don't know why," I could help get some people in a room and they could tell you all the reasons why you haven't gotten out and recruited people.  And hopefully they listen.

Participant:  When the researchers are in the room, how are they expected to act?

Organizer 1:  Well, if they are not Dr. Anyone, they are Bob, they know they are expected to listen more than they talk and we do a \_\_\_\_\_\_ with them.  They have a presentation they can do for less than 10 minutes ... (inaudible), and then we basically help them understand who the facilitator is, and they are to sit at the table and have dinner or breakfast or lunch with folks, and then if they have questions ... (inaudible).  We had a couple of incidences with researchers who were really influential who were really chatty, and it was well-intentioned, but they were so used to talking.  She said, "I am a social worker so I use body language, so he was talking to the group, and I was listening, and I walked up and just put my hand on his shoulder and said, 'If it's okay, I want to go ahead and move on real come and we can come back to that later ... I might not, though.'"  But it's a learning process.  We had one of our facilitators tell an early researcher who was really excited about work and she had tried really hard to recruit African American women into a very noninvasive study, just fill out a survey for breast cancer survivors, and she couldn't make any connections.  We were able to get with the Sisters Network in Nashville, who wouldn't return her calls, and they were like, "We will come do your \_\_\_\_\_."  So, they came and they sat down and loved her project, so much so that they said, "You can use our images for this project because we think there is a lot of value for our community in it."  But she was so excited in her planning and prep meeting with our facilitator (who was also a social worker), but some of the comments were, "You have to be quiet and stop talking.  I am really nervous that you are talking so much in our planning meeting that you won't be able to control it in the room with the women."  She said, "Okay," and she did great.  But it's all about making people feel comfortable, so somebody had to tell her - you are going to have to be quiet because you are not prepared to listen. (Inaudible).  Another researcher who does HIV work said, "I've worked with patients who have had HIV for years, and I've never had an opportunity to sit in the room and just listen, and I got to hear how it impacts them on a day-to-day basis in real life and how we can make their treatment better."  So, if you can get a researcher who can get someone to listen, it is powerful.

Organizer 2:  I'm going to talk a little bit about preparing community members, but I want to just show you this very complicated graphic of sort of a continuum of stakeholder engagement in research.  At the lower end, we have sort of one-time engagement where you might fill out a survey or you respond to an interview one time, or you are in a community engagement studio, but as you all know, there are increasingly more engaged and sophisticated ways that community members and patients can be involved in research.  You can be a part of the governance or an advisory committee.  You can actually be a research team member, as Alexis is, and I'm sure some of you in the room here have experienced that.  Tiffany pointed out that we have one of our partners, who is the co-community investigator on a national PCORI-funded project.  So, there are lots of different ways that people, who are non-researchers, can be involved in research.  And Tiffany mentioned the orientation that we do for community engagement studio participants.  And I want to say something about facilitation also.  We use, as Tiffany mentioned, community members.  Usually they have a community organizer background, so they are really good at facilitating a meeting where they make sure that everybody's voice is in the room.  (Inaudible).  We want to shift the balance of power so that it is more equitable, so that it is more even, and having a community member in charge of the room changes the balance and the power, which is very important for us.  Not everyone who uses that model ... (inaudible), but we feel like it is really important.  In terms of preparing community members, the orientation and training will vary depending on what their role is going to be.  For someone who is actually going to be on a governance council or an advisory board, they need to know a lot more about the project they are involved in.  They probably need to know a little bit more about research.  We have a Research 101 \_\_\_\_\_\_ that we can offer.  We have training on how to build a partnership, how to work with researchers (because they have all these considerations in terms of what is required), and the people with me don't really know.  Why is it taking so long for you to be able to start?  Well, I'm awaiting IRB approval.  I can't do anything until I get IRB approval.  You know, how do you negotiate contracts?  The contracting is one of the huge institutional barriers.  We have been using MOUs for years where we sign and they sign, and it sort of spells out what everybody's role is and what we are going to give and what the community member is going to give, and one of our enterprising administrative offices, for some reason, submitted it to the legal department and the legal department goes, "Oh, this is a contract!"  And then they added like four pages of intimidating language.  We were like, "No, we are not going to have this.  This is not an organization.  This is a person."  So, the compromise was that we could have a letter of understanding, but then we sign, because we weren't going to include all of that intimidating language.  So, there is training on how to build a partnership, how to actually work with a researcher, and I think those are really important, and they can be tailored to how the academic institution ... (inaudible).

Participant:  I think there is a poster on capacity-building training here.

Organizer 2:  Yeah.  Last summer, we developed training for individuals.  (Inaudible).  City training.  Have you all done city training?  If you are not a researcher and you don't have a lot of time during the day to read a bunch of stuff that you have never been exposed to before, it is really burdensome to do the city training.  But if you are a member of a research team, even if you are a community member, and you are involved in recruiting participants, consenting people, helping collect data, or doing the intervention, you have to be getting some protection training.  It is a requirement.  We make friends with our IRB.  It is very important.  They are my best friends.  We developed an alternative to the \_\_\_\_\_\_, that our IRB is vetted and approved, and we do it face-to-face, because learning on line can be very difficult a lot of folks.  I have trouble with it.  So, we do a face-to-face training.  It takes about an hour.  We have time to ask questions and everything, and then they take a little test, and then I tell the IRB that they passed the test and the IRB will add them to ... (inaudible) ... personnel.  That has reduced this huge burden of having to go on line and do the city training, which is what most institutions would require.  I wanted to talk a little bit about meeting norms.  This is also sort of a cultural barrier.  Those of us who work in academic institutions, we go to meetings all day.  This is what we do.  We breathe meetings and dream about meetings.  But there are norms about how to act in a meeting, right?  Like, who gets to speak?  You have to raise your hand.  If you have to wait for a pause, you will never get a word in edgewise.  So, it is very intimidating for people who are not used to that culture and that way of meeting.  And that needs to be part of the orientation.  You know what?  You have every right to be at the table.  You have value.  You are an expert.  So, yes, you can interrupt.  You can be the Maxine Waters, "reclaiming my time."  I think the best part of taking the power is to understand and fully embracing the fact that if you are at the table, you have something of value to contribute, and you can speak up.  So, I think we are going to start with the exercise.

Organizer 1:  I think a couple of quick things we need to mention ... just to make sure that any training modules that you develop and you mean to implement, that you always use community members as a part of your team to develop the actual modules, and that they actually help facilitate the delivery of the training.  I think that is really, really, really key.  The second piece of it is not to put the burden on community.  The burden is also on academia.  It is not that the community is broken and that is why things aren't working.  It is that academia is broken and that is why things aren't working.  So, we talk a lot about how can we build capacity for community and community stakeholders, but in my humble opinion, I feel like we need to do a lot of training in acculturation for research in academia so that they understand their way is not the only way, and that is creating a huge barrier in why people don't come to the table and why they don't participate.  People keep saying they are not participating in clinical trials, they don't want to consult, and they are not interested.  That is not the case.  The problem is that you have created this institutional structure that doesn't allow them a seat at the table, and that is a part of the big piece.  Also, I feel like us modeling as well is really, really important.  I am borrowing a story and I do that all the time, but someone told me that we are talking about the culture of women, in particular, but then ... I mean, you could put any community that doesn't have power there, right?  But we were talking about being in a meeting and someone said, "Yeah, we just all made the agreement that if a woman makes a statement in a meeting, and we all think it is a good idea, we are just going to be like, 'That is a brilliant idea; we should talk more about that'."  Like, we are all going to speak up and support that idea.  We all just sit so quietly, like, "Lori, thank you; that was a good idea," and we don't say anything.  Then someone comes back around later, like Yvonne, and says, "Let's talk about compensation."  Well, Lori said that 20 minutes ago!  So, we kind of have to model and support each other.  So, if someone says something and you think we should talk about that, speak up and say right then.  John just had a brilliant idea.  I want to stop and talk about that.  So, just model that and create that culture, because I feel like everybody is going to have to claim power in this and make way and make room and space for everybody else.  So, everybody has a little worksheet, because I hate going to conferences and not leaving with anything new or knowledge.  It is just so boring.  So, you have a little worksheet and I hope you find a little value in them.  (Inaudible - moved away from the microphone).  The idea is that we have talked about these topics today.  We would like for you to look at this from your perspective.  You could be a huge stakeholder, but still start to identify where you think stakeholders could play a role at the university that maybe they are not already.  List the community organizations that you feel like may be potential good partners to help recruit and orient individuals to become more engaged.  The next one is - are there institutional leaders or departments, like Yvonne mentioned the IRB, that you feel like you need to build relationships with, you need to get on-board.  It could be the Scientific Review Committee.  You just have to think about it for yourself.  Then, the last piece is just ways community stakeholders can claim their power.  So, this is creating a plan of action for you, either as a community stakeholder or as an academic institution or as a medical institution.  We will be walking around and happy to answer questions.  After 10 minutes, just elect someone to give us one item that you feel like is going to bring value to everybody.  Does that make sense?

(EXERCISE BEGINS - TALKING AROUND THE ROOM)

Organizer 3:  Does anyone want to go first?  Alexis is going to lead you through our dissemination piece.  Nobody?

Organizer 2:  The roles for community stakeholders, for the Scientific Review Committee ... did you have anything to share?

Participant:  So, we thought research design, we thought dissemination was a role, and what you have been talking about all morning ... (inaudible).  We thought community organizations to partner with would be community action agencies, parent-teacher organizations and other social service organizations and faith-based organizations.  (Inaudible) ... We thought the Dean of the school.  (Inaudible) ... accounts payable.  (Inaudible).

Organizer 2:  Excellent.  Anyone from this table?  Do you have any items to share as well?

Participant:  We came up with this really cool idea that we don't know if it is a literacy consult at the university where the community can lend their voice ... (inaudible) ... so, we were just thinking about language.

Organizer 2:  Do you have any items to share that you haven't heard already?

Participant:  (Inaudible - sounds far from microphone) ... community IRB.

Participant:  I just want to say why that is going to be critical.  Many institutions are now having to go through multiple cross-institutional IRBs and the single IRB is now coming out where one institution is responsible for multiple institutions.  They are still working out what that means, but for communities, it could be a nightmare if it is not handled ... that is going to be critical for the single IRB.

Organizer 1:  Is "socialized IRB" the term?

Participant:  It's a "smart IRB."

Participant:  (Inaudible).

Participant:  (Inaudible).