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Organizer 1:  I just completed my postdoc with the Meharry-Vanderbilt Community Engaged Research Core, and Dr. Murray is an Associate Director for the Meharry-Vanderbilt Community Engaged Research Core, so she served on my mentoring team.  Much of the impetus behind the practice strategies for engaging community stakeholders and patients as partners in research came out of some of the research that we did throughout my postdoc and, I think, a year prior to my postdoc.  So, we are going to get right into it, but I am hoping that you all can actually go ahead and get into some of the objectives.  What we hope to do for you today is provide academic and community partners (so, hopefully there are both in the room) with strategies for engaging community stakeholders as research partners, provide a forum for discussions on challenges and facilitators for successfully partnering with community stakeholders, and finally, we will discuss strategies for implementing and sustaining partnerships for conducting community-engaged research.  So, throughout this conference, you all have learned that community engagement is important, and you probably felt that way before you got here.  So, part of what we wanted to do is not focus really on the importance of community-engaged research, because we believe you are already there, but for those of you who have never actually engaged in community-engaged research, or started a project on your own, but are thinking about it, or want to figure out how to do it better, we felt the need to discuss some of the challenges, some of the pitfalls, and really some of the expectations you can have for conducting this type of research.  I actually spent two years in the postdoc trying to learn how to conduct community-engaged research and how to conduct it effectively.  So, in terms of coming to conferences and showing up to workshops, there is just not enough information out there to really go out there and be able to successfully conduct it.  So, we figured we could focus on some very specific things that could possibly help you go out and conduct effective community-engaged research by engaging community members and by engaging patients.  The impetus behind the learning lab, the transition from traditional research models where the academic partners dictate the direction of a project, so an approach where academic and community partners are viewed as equal can be a challenge, and I say that both as a researcher and through some of my experience working with PCORI on the patient perspective.  So, I am also a part of the patient population.  So, when I do conduct my research, it is also through the perspective of a caregiver.  So, my husband actually has sickle cell disease.  My research is on community-engaged strategies with patients with sickle cell disease.  So, when I talk about sickle cell research, people always say, "You sound so passionate," and I think to myself - I am very good at compartmentalizing, but it is very difficult to not think about the last 13 years of communicating with physicians and communicating with my husband, and trying to get him to do things that would improve his health overall.  So, that is some of the perspective that I bring into my research, and one of the approaches that we did in our project, which we will get into a little bit later.  Some of the things that we hope to accomplish together, so not just us as the researchers, are learning the benefits of engaging community stakeholders and patients as partners, learning the benefits of community academic partnerships (so this idea of partnerships between academic institutions and community organizations is a big interest of mine), and sharing what you already know about making partnerships work with each other and learning more (so, we are going to do a couple of activities as the tables and then as a group).  We are going to discuss some of the challenges associated with community academic partnerships and then learn some of the strategies for developing, and finally, sustaining these partnerships.  The process of transition from outreach to shared leadership is a challenge.  So, the idea is we are increasing the level of community involvement, which impacts trust and communication, but we usually start here with this idea of outreach.  So, a lot of you, on top of being familiar with community-engaged research, may also be familiar with community-based research.  I go through this discussion consistently with other faculty members who say they do community-based research, and when I say I do community-engaged research, there is this discussion surrounding - well, what is the difference?  I always ask them - well, did you start out with your research question from your perspective or from the community's perspective?  Was the community sitting at the table with you, or were they engaged at the table with you?  That is a big thing that comes up a lot with PCORI merit review - what is the patient or the community stakeholder doing when they come to the table?  A lot of times it ends up being just a checkmark where you can say they were at the table, and I always bring that question up - well, what are they going to be doing?  I don't want a patient or community member sitting at the table feeling like their voice isn't being heard or that they are not allowed to express their voice.  You had a comment?

Participant:  What is a community, because when they say they are doing community research, your community agency represents a lot of members in the community, but how much more effective can that voice be?

Organizer 1:  I don't think, at least in my experience with PCORI, it is about having the agency there, because the definition of community is going to vary, right?  So, I started out doing community-based research where I work with a community-based organization where I went to talk about my ideas, but I really wasn't there to learn about the needs of that particular community.  So, sometimes I find myself going back and forth between using the term "community" and using the term "patient," and I often use the term "patient" when I am looking at a specific disease and the patients want me to use that term, and sometimes I work with them and they don't like the term "patient," because we are all patients at some point in our lives.  But in terms of what you are referring to with having the community agency either listed on the grant, or you are saying they are there and actively participating, it is really about the objective of your grant.  So, if you are looking at an agency with sickle cell disease, we work with the Sickle Cell Foundation of Tennessee, but they are not just an agent.  We were actually referred to them as a conduit, so they are actually spearheading the project, meaning they are not just someone we are working with, but they are actually considered to be a research partner.  So, when we apply for the grant, they are a PI on the grant.  Everything that we have to do in terms of getting approved to do research at the academic institution, our community partner has to do, whether it is a representative from the community organization or a group of individuals from that organization.  Another example - right now I have a grant with another faculty member at Meharry Medical College on research dissemination.  So, we have a group of community partners.  So, when we say "community" in our grant, we are actually talking about three groups of communities ... so, the deaf and hard of hearing, the Latino and Spanish-speaking and then low-income community.  So, we use the term "community," but we are actually defining in the grant that they are very specific communities.  So, we can be very specific, which is what I like to do, especially when I am talking to faculty members, or it can be as broad as talking about community organizations.  Then, finally, I just want to set some ground rules before we really get into it.  Number one - we hope there is discretion so that everyone is open to expressing their concerns, some of the experiences they have had in terms of challenges and barriers to doing research, and to be able to do that without judgment.  I also want this to be an all-inclusive space.  So, when I talk to my students, I want this to be sort of like their living room.  So, a living room is a place where you feel comfortable, and if there is someone walking in, you feel like you can talk to them.  So, in this space, I like for this to be our community-engagement living room where we can all come together and talk about what community engagement means to us, why we want to put forth this work, why we feel it is important, and how can we effectively do it.  Then, finally, just be respectful of others' opinions.  Some of us are researchers.  Some of us are community members.  Because we come from separate groups, and some of us have different levels of experience working with those groups, our opinions may differ.  And quite frankly, in my opinion, scientists sometimes like to have differences in opinion, and that is okay - we can all have our differences as long as we are respectful of everyone.  I am actually going to hand it over to Dr. Murray right now.

Organizer 2:  I am delighted to be here and be co-presenting with this incredible young scholar, who just launched her professional track at Georgia Southern this fall.  So, she has moved out of that training role to training others.  So, kudos to Telecia.  I always like to know who is here.  So, I am going to start out before I talk about this to ask your name and your role in this conference.

(INTRODUCTIONS)

Organizer 2:  Okay.  So, why did I do that?  Well, I think it is important, first, that we acknowledge you as part of the process and then I wanted to know how many people we had representing these two constituents that we are talking about developing these partnerships with.  So, one of the things that we know is when people are thinking about developing partnerships with either academicians doing it with community partners, or community partners facilitating the process, we come to the table with different expectations.  We want to talk about those expectations because once we know what they are, then as informed members of this partnership, we can begin to talk about clearing out what these expectations are and articulating them in a way that it doesn't create barriers in trying to develop this partnership.  So, what do community partners come to the table with?  Well, you come to the table with access to community settings or facilities and a direct link with patients or individuals whom the researcher wants to have access to.  So, as the pastor and clinician mentioned earlier, Duke sought this person out because they are interested in reaching a particular population.  So, he comes to the table at Duke University with some resources that Duke should garner from because he can give those back to Duke.  Facilitate introductions to staff, clients and stakeholders is something else that the community partner can give, and community partners come with historical knowledge about what has transpired in that community that the researcher may not have any idea about that may be either facilitating or creating barriers to the work getting done.  So, that information is needed as the researcher begins to develop their research project, and then they can help set up schedules for the timeline that researchers have to use to govern their particular research project, and they can help set up that schedule because they know what is feasible in the communities.  So, what does the researcher give?  The academician comes with shared knowledge about how to do community assessment.  One of the speakers this morning talked about ways in which she utilized services from Northwestern University to help them understand how to look at their data so the researcher can give that back to the community.  They also have time and effort.  Anytime we get a grant, there is effort allocated to that particular grant, which means if we want to facilitate work in the community, we have "x" percent of our time, 20%, to devote to this project.  They also bring talent and expertise as students and faculty, and oftentimes it is work where you don't have to necessarily pay them for learning on the job.  So, they can come to the community, giving that capital back to the community, reliable information that will be beneficial to clients.  Then, they have some information about what are the best practices in order to be able to do the work.  So, what are the benefits one should expect to get in this partnership?  The community partner gets a way to meet a mission that you may have in your community.  If you are focused on trying to increase screenings for cancer, researchers can help you meet that mission.  You can also find a way to empower, which is a word that we loosely use, but really become advocates for your own health in terms of what you can get from this process, which was clearly illustrated this morning, and information about health curriculum and then ways in which you can begin to assess the needs of your communities and develop strategies for addressing those needs.  What can the academic partner hope to get from the partnership?  Successful and sustainable partners.  I view partnerships with community partners and academicians as a relationship.  So, you come to the table first like a date.  You want to find out whether or not you want to be in a relationship with this person.  So, it all depends on the way things work at that first date as to whether or not you are going to call them back and say, "Let's do this again."  Then, over time, you realize that you really dance to the same music, that things are feeling really good, that you argue, but you also make up.  So, for that part of the process, you can end up as a colleague mentioned earlier - having long-term sustainable relationships with each other, achieving goals you may have with regard to the partnership and the opportunity for students to learn and cut their teeth in your communities where they learn how to do this and do it in an ethical way.  There is access to evidence-based preventative interventions, which communities may not know exist, but there are people who have spent tons of money (the federal government) to develop these evidence-based programs that we are trying to find a way to get off the ivory tower shelves into the communities.  We have access to that, and you can expect to get that through this partnership.  Lastly, it is an opportunity for students to engage in communities apart from their own cultural training, and to become culturally sensitive to communities that they have never had access to.  So, it is a give-and-take process.  What we want you to think about is - where do you lie in your expectations, what you want to get if you develop a relationship either as an academician coming to a community partner or vice versa?  What is it that you want, and what can you give?  So, you negotiate that in this process of partnership develop.  I think I'm finished ... or probably over my mark.

Organizer 1:  A little over.  I didn't want to stop you.  So, the next thing we are going to do is an activity.  I am going to ask you two ladies if you can join this table over here.  Now that you have introduced yourselves and talked a little bit about whether you are a researcher or a community member, I would like you to talk to each other at your table about some of the benefits of engaging an academic partner, if you are a community partner, and engaging a community partner, if you are a research partner, whether that be a community organization, if it is a group of patients with a specific \_\_\_\_\_\_, or if it is individuals who represents a certain demographic population.  We are going to spend about five minutes doing this.

(GROUPS TALKING)

Organizer 1:  So, Jacquie has made her way up to the front of the room and she is going to write down some of your wonderful ideas about the benefits of working with a community or research partner.  We are going to start right here in the middle.  What did you say about some of the benefits?

Participant:  I think two highlights that we talked about were the impact beyond project ... (inaudible).

Organizer 1:  So, in addition to sustainability, the whole idea of us partnering is that you want the community to benefit.  Yesterday, in one of the think tanks, we actually used the term "action-oriented," so you have a sustainable partnership, but if the whole goal is to improve health equity or health outcomes, you have to have something the community member or members are able to do at the completion of the project, and if one of those is sustainability of the partnership beyond the project, I think that is a very good value.  The second thing you said was the direction of the researcher.  That is a big one, and it is not the same at every institution, but you find that some researchers have never engaged with the community, and never really engage with their patients, but because community-engaged research and community-based research are becoming so popular and there is money for it now, you find that lots of researchers want to engage just because there is money there.  So, it is really changing this whole bias that they have had prior to about what it means to engage with patients and engage with community members.  So, it is changing the way they think about how they approach research.

Participant:  In saying that, it reminded me that it will change the power dynamics, because the money is shifting to the community, and suddenly we have value.  This is why we have always argued about having line items for your community partners that are equal, because we also add value to what they do, but what we discuss here ... (inaudible) ... for the community, what I said is that we not only gain stature when we are in a relationship with an academic institution in which they give us credibility, but it also improves our capacity to be better at what we do.  It also helps us learn how to better collect data to make sure it is clean and usable.

Organizer 1:  So, let's go to your group.  What did you say some of the benefits were?

Participant:  (Inaudible).

Organizer 1:  I want to bring up a point that Claudia mentioned.  A lot of times you think about the ability of an academic institution to provide financial capital.  So, there is also that \_\_\_\_\_\_ capital piece.  We just need more people on board, more people who truly have an interest in mental health issues.  (Inaudible) ... capacity to solve some of these problems in the community by bringing more people to the project.

Participant:  (Inaudible).

Participant:  We had a lengthy discussion.  Joanna mentioned that we need to give a voice to the community.  Orlando talked about how we use \_\_\_\_\_ relationships to start to build trust.  Orlando also talked about confronting the aims of research, but also the limitations.  It is a space where you get researchers that over-promise things.  (Inaudible).

Organizer 1:  I really like the fact that you brought out \_\_\_\_\_\_\_, because that is one of the driving pieces of my research.  I do research with a rare disease population.  So, one of the things they say throughout focus groups and interviews and just conversations is because they are a rare-disease community, there is not a lot of funding out there for this type of research, and they often feel like they are forgotten.  So, as a researcher, I feel like my best form of being a medium is to bring their voice to the table.  Now that we are doing community-engaged research, it is really an opportunity for me not to talk *for* them, but to bring them to the table so they can use their own voices.

Participant:  I was actually just going to say what she said.

Participant:  I am a \_\_\_\_\_\_\_ psychologist, so I study people in \_\_\_\_\_\_\_ and power and ethics or whatever, and I am a researcher, too, right, so I just want to argue that this whole \_\_\_\_\_\_\_ thing that we do is likely problematic.  It is likely over-inflating the importance of research.  These communities and patients are not voiceless.  They have other mediums to get their voices across - we are just not listening to them.  We are over-inflating our importance by saying we are the only conduit by which people's voices can be heard.

Participant:  I just echo your emphasis on messaging, on saying "with" instead of "to" and "on," and then "giving a voice," as though you can "grant" or "take away," so, yes - it is messaging.

Organizer 1:  And our final table?

Participant:  Sure.  The things we talked about are what has echoed throughout the room.  That is the benefit of going last.  But, I think, to summarize, one of the big over-arching benefits of engaging community stakeholders is unlocking new knowledge for researchers and communities.  So, on the researcher side, that could be new research questions, new study parameters, and on the community side, it is new knowledge about resources locally, about how a disease might impact you compared to other communities, so it creates this information loop between the people who have the information and the people who don't and who need it.

Organizer 1:  That was fantastic.

Organizer 2:  So, in two minutes, I have to talk about 20-something years of research.

Organizer 1:  I wanted to explain to them why you are going to do this.  When we go to conferences and we attend workshops, we are provided with strategies, and a lot of times the person who is speaking doesn't explain their experience and how they came up with these strategies and how they worked to do that.  One of the things we are going to be talking about is sustainability, and Dr. Murray has been able to sustain working with a particular group of community members for almost two decades now.

Organizer 2:  So, I started working in rural African-American communities in 1992, and what I realized, having grown up in a rural community in Tennessee, is that there are gatekeepers in those communities, as in most communities, and if you don't know who they are and how to partner with them, you are not going anywhere.  So, all the work that I have done over the past two decades has really focused on how to do work with populations by partnering with people in the community who know the history, who can keep me honest (I like what someone said earlier), and to make sure what I'm doing validates the ecology of the place where I am going to work.  So, in order to do that, I have been involved in several longitudinal studies, one of which started in 1995 (we are still following 80% of the sample), and another study was done in preventative interventions.  The Strong African-American Families Program was launched in 2000, a randomized trial of 700 families.  We have been following those individuals since the target child was 10, and they are now in their 20s.  What I write in the papers that I write is that it is not because I am so good at what I do ... it is because we have realized that a key to, not only being able to work with those families, is to work through community partnerships, but it is also that they help us in the process of making sure that we are not only honest, but how do you begin to engage these families in a way that they begin to trust that the work you are going to produce is going to be beneficial to our communities.  So, we developed what we call a "community liaison networking system," where these are trusted individuals in these communities, and in Georgia, we worked in seven counties, and in Tennessee we worked in five counties to do these two projects.  In Georgia, we are probably in 20 counties in the south-central area of Georgia, and our community liaisons ... we go into the community, and we just kind of hang out at the local store, find out who the heavy hitters are, go to churches, go to PTA meetings, wherever the people are ... that's where we go.  We ask questions about who the "keeper" is.  Who knows everything there is to know about this community?  And if we mess up, who is going to get us?  That is the person you want on your team.  So, because we really developed a way of establish rapport with these community liaisons, I have imposed that model in all of the studies I have done.  One of our studies started in 1995, and we now have intergenerational community liaisons as part of our project.  So, we started with the grandma, the first generation, back in 1995.  Then, we got the daughter of the son of the first generation.  Now, the younger generation, who were members of our research project many years ago, are part of our ambassador group.  And how do you do it?  It is all the things that you said earlier.  People need to realize that you are not in this community to take, that you come to learn, and in the process of learning, you are going to also give back whatever it is you have learned.  And they come to the seat as equal partners.  That is maybe more than two minutes, but that is my life.  That is my history.

Organizer 1:  So, I am going to bring Dr. Murray's history to the present on a PCORI study that we worked on.  So, this is a PCORI engagement-funded study.  So, there is a science side and there is the engagement side that focuses a little less on the research and more about engaging patients.  It is called the Tennessee Sickle Cell Disease Network.  We actually partnered with Sickle Cell Foundation of Tennessee throughout three regions of the state of Tennessee - west, middle and east.  What we did is work with the foundation as a conduit for developing a Community Ambassador Training Model.  So, this model is sort of an expansion of the community liaison work that Dr. Murray has been doing.  So, the Sickle Cell Foundation of Tennessee, the Director, Dr. Trevor Thompson, actually hand selected community health ambassadors who would be trained by researchers who would then go out to the sickle cell community and educate sickle cell advocates, patients with sickle cell disease, caregivers of individuals with sickle cell disease and individuals with sickle cell trait on what it means to conduct research on sickle cell disease, and then they were trained, including IRB training, CITI, and then actually a version of IRB through the Meharry-Vanderbilt Alliance.  One of the challenges that we faced throughout the project, and what has occurred through other community projects, is that they don't have the hours we have to sit down and take the CITI exam and learn the information.  So, what they have done with Meharry-Vanderbilt Community Engaged Research Core is develop a module that is specifically geared toward what community members need to know and understand about research including the Belmont principles and ethical situations.  In some cases, such as the Community Health Ambassador Model, they were working on this project for several years, so they needed continuous IRB approval, and so we actually selected specific modules out of CITI that would be appropriate for them and could be easily understood.  So, they actually got a community-based version, and then they were working on the project long enough to be able to do the same training that we did as researchers.  So, they developed a module with me on sickle cell disease that they could educate the community on.  So, that was the disease-specific portion.  Then, they educated them on what it means to participate in sickle cell clinical trials and what they could actually do as a participant.  So, a lot of times when we go out in the community and talk about participation in clinical trials, people have one idea of clinical trials in mind, and they never think about the fact that it could just a survey.  It may just be an interview.  But they don't know that, so they need people to go out and tell them that this is the way it could benefit your community.  So, there are only a handful of researchers doing research on sickle cell disease throughout the U.S.  We only have a very small community of individuals with the disease.  So, when we actually go out to do these clinical trials, we do need people to participate, but they only have just a very small concept of what it means to be a participant in a clinical trial.  So, one of the goals of what we called "Sickle Cell Research 101 Day" was for them to learn from other individuals from their community.  So, the Community Health Ambassadors were individuals who had sickle cell disease or parents of individuals with sickle cell disease or were already community advocates, and in some cases, as is the case with the Rural Health Ambassador, she just wanted to come on board because she had worked on a different project with Dr. Murray, so she knew the importance community-based and community-engaged research.

Organizer 2:  And the operational manual that she referenced is on the PCORI website for use, as well as all the deliverables.  That is huge.

Organizer 1:  The next few slides I am going to go through very quickly.  So, Dr. Murray talked about this relationship that you build between academician and community members and patients.  Sometimes the relationship is going really well.  I think she indicated that you start out with that first date, and yes, this is going to go really well, but then somewhere along the line there is a pause and you say, "Wait a minute - we are not on the same page," and that typically can occur when you have competing agendas.  So, the community partner is interested in the health needs of their community, of their target population.  The academician is interested in disseminating through manuscripts and publications that really aren't that useful to community members.  The community member is interested in improving services and increasing their program capacity and the researcher is interested in expanding opportunities for students, which may not be for the benefit of that community.  It is for the benefit of the academic institution.  The community partner is interested in documenting impact or outcomes.  The academician is interested in raising their \_\_\_\_\_\_\_, unfortunately.  The community partner is interested in documenting a need for protocol or policy change.  The academician is interested in sustaining agency partnerships and whether or not that is a good thing kind of depends on your rationale for doing so.  Then, it is not always the case that they have competing agendas, but it could be that they really do have complimentary assets, and it is really important for community members to recognize that they are not just recipients of assets or being beneficiaries from academic institutions, but they have something to offer as well.  So, community resources could be knowledge of the service population.  There is no better individual to represent their community than individuals from that community.  From an academic perspective, they have knowledge of health assessment methods.  So, we know there is information within the community, but how do we go about getting that information.  The community has access to the study population.  The academic resources access is to researchers and students ... so, again, figuring out where that human capital is.  Trust of community - this is a big component in the PCORI study that we have.  Individuals with sickle cell disease don't really like for people who don't have sickle cell disease or who don't know much about it to come in and conduct research in their community.  Academic resources are the ability to analyze the data and evidence, although now, after this conference, I am learning that is no longer an issue because community members are learning how to access and analyze big data.  They could probably teach me a thing or two.  From the community perspective, program management and fund-raising expertise - academicians have grant-writing and evaluation expertise, and grant-writing is always a benefit for local programs and local community-based organizations.  For the next 10 minutes, we are going to be working on activity #2 where you are thinking about past partnerships.  Again, if you haven't had a partnership, you are going to be thinking about some of the things that you would want out of a partnership.  So, you are going to be thinking about ways that you partner with others in your personal life or your working life.  You can choose from either.  Then, on the post-it notes that we provided on the table, you are going to use the purple to write about something that made the partnership easy, and then you are going to take that post-it note and stick it on the "Easy" post-it sheet on the wall over here.  Then, on the yellow post-it note, you are going to write down something that made the partnership challenging, and the "Challenging" post-it sheet is over here.  On the green post-it note, you are going to write out what made the partnership successful, and that is in the back to your left.  Then, finally, on the blue post-it note, you are going to write what made the partnership last over time.  So, that is the sustainable sheet, and that post-it sheet is on your right side of the wall.  So, you will do that for the next 10 minutes, and then we will come together.  When you are done, try to look at the other post-it notes and see what other people said made their partnership easy, and then we will cover easy, sustainable, challenging and successful, and then we will come back as a group and try to note some of those differences.

(GROUPS TALKING)

Organizer 2:  Because we have done this before, and we haven't had people from the academic sector and community sector compare their perspectives ... so, community members said what is easy is the expectations are well-defined, there is acceptance regarding resources, trust and like-mindedness, positive attitudes (academician), paying community organizations for whatever efforts they give to the project, occupying the same space (not sure if it is physical or what that means), already having a relationship, being open to learning, previous collaborations, linking and bridging through the gatekeeper, and relationship.  So, relationship keeps coming up, like-mindedness, making sure there is equity around budget issues and being up front from the very start makes things easy.  There is a lot of commonality across the two.  Now, I am going to go to challenging.

Organizer 1:  So, on both sides, cultural differences came up and language barriers came up.  There were also a lot of issues with trust.  I am kind of curious, those of you who said "trust" from the academic members side, is it trust from the perspective of the community members and researchers?

Participant:  From the community members.  (Inaudible).

Participant:  Oh, yeah.  It's real.

Participant:  Another interesting thing about this is how ... (inaudible) ... endorsement from the community members about the challenges versus the academicians and those that kind of on both hands.  I find that interesting that the academics view this as more challenging than community partners.  And look at ease and sustainability - it is all positive.

Participant:  We kind of went rogue over here, so we didn't separate community.  The point is - we do recognize issues of trust, but that means different things.  One, can you trust that academic partner, but also the community's trust about multiple things that you have to deal with as a community leader to bridge all of those.  Part of the trust is in the language.  We are not talking about whether it is English or Spanish.  We are talking about how the research speaks with all the acronyms and all of that.  Like I said yesterday, they like to use the word "disparities."  What are the disparities?  I have many disparities.  So, it can mean multiple things.

Organizer 2:  And I want to elevate that trust to "institutional trust," because some institutions have bad reputations throughout the state, and when you work at one, you are suspect, even though you may not have been part of it.  You are suspect.

Participant:  I would say there is trust on the side of the academicians toward the community, because it is ultimately a relationship, and in a relationship, you are putting some things on the table.  You are putting your career on the table and investing a lot of time, and the community partner - are they going to hold up their end of the bargain ... (inaudible).  That comes from time spent in the relationship.

Participant:  I am from Baltimore.  Johns Hopkins has a horrendous ... (inaudible) ... with the community, and alright already!  We are correcting this stuff.  But the community doesn't believe it, because it is not transparent.

Organizer 2:  And trust is earned.  So, there has to be some way for them to realize that the institution is making it right.  I have to tell this really brief story.  So, we were launching a project in Georgia.  We were invited to a PTA meeting in a county in Georgia that is 95% African-American ... county.  So, we go to the school and when we get there the parking lot is full, and I say to my colleague, this white, Jewish guy, Jim Brody, when we are going down the road to the school (and they say black people don't care anything about schools and school involvement) ... this is what I said to him ... we walk into this cafeteria, standing room only, lined up against the wall, people were there, and we thought it was because we were telling them we were partnering with them on this project called "The Strong African-American Family."  A colleague started describing this project, and I began to see the faces of the audience, and they were not smiling.  What happened ... there had been individuals from the University of Georgia that came to this county, did an assessment of children in the school system, no parental consent, testing the academic abilities of these students, wrote an article in the local paper about the low performance of these students and the need for the school system to purchase, from the College of Education, these learning tools to extend the academic performance of the students.  We had no idea, because the University of Georgia has over 40,000 students.  We walked into this war zone.  We were "it."  We were about to get run over by grandmas and everybody else with rights.  And I said to them, "Tell me a little bit more about what happened."  So, then I had to step out of my role as a Georgia faculty member and talk to them about growing up in a rural community and the fact that they had a right to all the things they were saying.  "Give me a copy of the form you got from the school and I am going back to the University of Georgia and talking to the President, the Director of Sponsored Programs and the Director of IRB, and I am going to share with them."  That is exactly what I did.  The University President wrote an apologetic letter in a local newspaper.  Those researchers' rights to do research were revoked, which they should have been.  So, that is how you earn trust.  This word then spread throughout Hancock County, and now we can do research in Hancock County.  So, you have to be good at your word.  You just can't say it.  They have to realize that you really, really are concerned about what happens to the people in the communities where we are doing our work.  These are lived experiences that happen, and sometimes when you don't know why you are having these barriers, you need to understand why those barriers are there.  It may not have anything to do with you and your project.  It is what some person did prior to you and it is linked to Johns Hopkins.  I have great colleagues at Johns Hopkins that are doing great work, but the community needs to know.

Participant:  One of the comments under ... (inaudible) ... is "making good on your promise."

Organizer 2:  We have to wrap up.  We have five minutes.

Organizer 1:  I think we kind of touched base on the challenges.  One of the things is understanding different organizational decision-making styles.  One of the pieces of success that was specifically mentioned was communication, and sometimes that means understanding how individuals go about making their decisions.  Even if you are on the same page, if you are going about that process, but making the decision differently, that can be problematic.  Then, from our experiences, and this is one of the things that we publish through the PCORI website from our project, are some of the issues that we have run into on patient-centered studies and community-engagement studies and then studies working with patients - there are organizational challenges.  We actually got these organizational challenges from the University perspective.  So, what we do is outline some of the issues like having to hire community members.  That was a struggle.  That actually took conversations about cultural issues in terms of processing paperwork.  Understanding some of those time commitments - from the community perspective, this is not their job.  They are doing this out of service and volunteering, and working it around one, two, maybe three jobs and being a full-time parent and being an aunt who is taking kids in and being a grandma who is taking care of the kids.  So, they are working this in.  Community challenges - meaning, this was more of an issue of having access to the community.  Then, patient-driven challenges - these are issues that stem out of the patient perspective.  So, what specifically are the patient needs, and whether or not ... (inaudible) ... that have taken into consider what their needs are.  We actually went for this study out to the community and asked them - what are the burdens to disease management for you, and those are different in rural and urban communities.  Then, sustainability - now that the PCORI project is ending, we are trying to figure out how we are going to keep the Community Health Ambassador Program moving forward, and we have actually talked about expanding it to another southern state in Georgia now that I am down there and Dr. Murray has done extensive work there.  Finally, I will end it with this - what are facilitators for engaging community stakeholders and patients in research?  This is kind of our takeaway for you.  Allowing input from community stakeholders and patients is critical.  We have touched base on allowing community members to provide their own voice.  One size does not fit all.  That is kind of a personal biggie for me ... not assuming that what works for one community is going to work for another community.  Just because you have experience engaging one community doesn't mean you are going to be successful at working with another community.  Fostering positive community research and relationships, getting patients on the bandwagon early, finding ways to keep the momentum going, and then engaging researchers from multiple disciplines.  Thank you to the Meharry-Vanderbilt Community Engaged Research Core for allowing us to pull the activities out of their Building Sustainable Partnerships Module, which actually is available to communities throughout Nashville.  I really hope you guys learned a lot today and it is useful for you.