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Organizer 1:  Good morning, everyone.  This is the "Strategies for Engaging the Community and Creating Patient-Centered Research Questions."  I'm Courtney Clyde (?).  I am a Program Officer with the Patient-Centered Outcomes Research Institute, PCORI.  I manage or run the Pipeline to Proposal Awards program where we basically provide capacity-building strategies and funding for people to come together in communities to develop research questions that are important to that community, and there are no specific health issues that they have to have identified by the time of their application, but we do want them to ensure that whatever the topic is that they are going to be doing is something that matters to the community.  So, often, folks will do things along the lines of town halls to gather community information and things of that sort.  So, we will be talking you through some of that as we progress on.  This is my colleague, Dr. Shavaun Laird (?).  So, just a few logistics - welcome to our session.  The restrooms are straight down this corridor here and then to the right.  The trash receptacle and the recycling bin are right over there.  They are kind of hidden in a drawer.  The session is being digitally recorded.  We have adhesive tear sheets that we made and posted around the room.  We are going to engage you in conversation.  We want this to be as interactive as possible.  So, I will be noting some of the things that you share as we come back from our breakout activities.  We are due to stop at noon.  We will be going, then, to the networking lunch from noon to 1 o'clock.  I think that might be it.

Organizer 2:  We want to make sure we have our housekeeping done correctly.  As Courtney said, I am Shavaun Laird, and I am with the Eugene Washington PCORI Engagement Awards program, which we call "Engagement Awards Program" for short.  We are also a capacity-building program.  We will talk a little bit more about that, what we at PCORI mean by that, in a minute.  Before we get started, how many of you are researchers?  I just wanted to get a sense of people's knowledge base and where we should be headed.  I am going to say a good 80% of you are researchers, and being at this meeting, I am going to say that a lot of you probably do community-engaged research already.  For the Engagement Awards Program, people call us all the time and ask us - "What kinds of projects will fit within the program?"  So, I get to have a lot of conversations with people about the engagement processes they have and what they are doing to increase engagement in their own research portfolio.  Sometimes, what I find, or what I have found in the past is that even folks who are very experienced in involving the community and involving patients in their research tend to do it after the research question had already been created.  I get a lot of "ah-ha" moments talking to people about where they could get their ideas for engaging the community in research even before that, like, "Oh, have you thought about using this data you already have to create a research question?"  They are like, "Oh, I never would have thought of that."  So, that was kind of the impetus for this session.  So, as far as, if it is a little bit too basic for you, I wanted you to kind of know where I was coming from.  On the flip side of that, we also fund patient groups, community groups, non-researchers, to build capacity within their own communities for engaged research ... so, the session also for the non-researcher, to understand that you, too, have a valuable role in determining someone's research question and contributing to that process.  So, we wanted to kind of give a hands-on learning lab to walk people through some of the data sources, how data can be transformed and what kind of data they can be looking for in non-traditional setting, if that makes sense.  We definitely want this to be interactive.  We are not standing here as experts lecturing to you, but we want to spark a conversation and kind of get people's minds going about how they move their engaged research portfolio forward, and starting with an engaged research question.

Participant:  I am \_\_\_\_\_\_ and I am a recipient of a Eugene Washington ... (inaudible).

Organizer 2:  Great, yay!

Participant:  So, if anybody has questions about that ...

Organizer 2:  Yes.  We have engagement awardees in the room if you have any questions about the program.  I am not sure if we have any Pipeline awardees.  Yes, we have Pipeline awardees in the room, as well, if you have questions about that program.  So, again, we are going to talk a little bit about the importance of a patient-centered research question, specifically.  We are going to talk about what kinds of information can be used to inform a research question, understand what makes a good patient-centered research question and discuss, as we talked about earlier, this idea that anyone can really create a research question.  You would be surprised, as researchers, how many organizations are creating research questions and not really realizing that is what they are doing.  They are just collecting information and not knowing what to do with it, and then it just sits.  Researchers are always looking for data sources, and it is sitting there, and you have no idea because they are not making that connection that this connection would be useful.  Just so that we are all on the same page, I wanted to be clear that we are talking about research, which is a very broad term, right?  At PCORI, we define it as clinical comparative effectiveness research, which is a very specific type.  There is research into social determinants of health, which is a little bit different, CVPR, which is a little different.  When we are talking about research as a term, we are just talking about a systematic way of answering a very specific question, and that systematic approach is really key.  Forming the question the right way helps to point you in the direction of what that approach should look like.  So, the better question you create, the easier it is to create a research protocol.  So, again, kind of preaching to the choir of why engagement is important, why is it important to engage the community and patients in a research project in the first place, making sure that the question is relevant and useful to the target population at the end of the day, so that you are not just doing research for the sake of research, and that research doesn't just sit in journals and end up in the ivory tower somewhere?  We also want to make sure that the results are taken up by the target community as quickly as possible, and one of the best ways to do that, we feel at PCORI, is to make sure it was information they wanted to know in the first place.  That is one of the reasons you want to make sure that you involve the target community in the creation of a research question.  The type of research that we fund has to be patient-centered, and by that, we mean that the questions and the outcomes reflect what is important to patients and caregivers.  Then, there is this idea of patient and stakeholder engagement, which is kind of the means to the end, involving patients not just as research subjects, but as true partners in the entire scope of the research project.  I am sorry if I am moving a little bit quickly, but I know a lot of you already know this, and our time has been shortened a little bit.

Participant:  Are these going to be uploaded on the app?

Organizer 2:  I don't know.  Vickie, are they?  I believe they can be uploaded somewhere.  I have a sign-in sheet.

Organizer 1:  There is a sign-in sheet that should be circulating, and I can make sure that it continues to circulate, and we can make sure that you get the slides following this session.

Organizer 2:  So, the type of research that PCORI funds ... I wanted to highlight this idea - we want to make sure the patients' needs and preferences and outcomes that are most important to them are considered when creating a research protocol for PCORI.  So, when we talk about engagement, we are really talking about engagement in all aspects of the research process.  So, this is kind of a full cycle of the research process from a PCORI point of view, and what we are focusing on today is this "Topic Selection and Research Prioritization" piece of it.  So, the creation of the research question kind of comes out of that process.  So, this is just a sample of some of those traditional sources of ideas for research.  So, traditionally, I spent only a couple of years in academia, so if you feel that I am misrepresenting the academic experience ... but I was always taught that you look for gaps in the literature.  You go through the literature.  You look at something that you are interested in.  You go through literature to look at it, and you see where the gaps are, where there are unanswered questions.  For those of you who aren't academics, at the end of a research paper, you will see this kind of discussion section where the researcher is saying something like, "This is what has been found in the past, and this is where my findings fit in, and this is where there are no findings, where there is no information available."  As a researcher, I have been trained to focus on that area.  That is where I should create my research question.  That would be kind of the heart and soul of my research portfolio moving forward.  Sometimes it is previous research.  You are doing research and you have these other side outcomes that you have included in a survey and data collection, or something comes up that was unexpected, and you kind of spark off a research project from there.  Sometimes it is something you have always been interested in, or you are kind of talking with someone, and an idea comes to you.  Sometimes, especially as a junior faculty member, from colleagues or mentors is where my research questions are "volun-told," as my friends say.  I was "volun-told" to research something.  Sometimes it has to do with the availability of information or of money.  So, a funding opportunity comes out, and you say, "I need a research question for that," because you need funding in order to keep your job ... so, funding being the heart and soul of a researcher's bread and butter.  So, sometimes there are questions you want to answer, but there is no data available to answer it.  So, then you have to kind of abandon that or move on to something else, or tweak your focus based on what kind of data is available to you.  Sometimes it is just kind of random information, that inspiration, that just kind of hits you out of nowhere.  So, I thought that we could talk a little bit in these small kind of table groups about the type of information or data that can be used to inform patient-centered research questions.  So, I know that I kind of talked about some of these sample sources, but I want to make sure that, in our discussion, we flush out the type of data that we can get from those sources that we can use to create specifically the questions ... so, not things that we can collect after we ask the question, but what information are we using to create the question itself?  Some researchers may feel like this is kind of a redundant activity, but for non-researchers, this is something they may not know already.  So, I would like to really just get some of that information down so that we are all starting on the same page.  You can just take some notes.  We will do this for like 5 or 10 minutes, and then we will collaborate on answers, and Courtney is going to make sure we get everything recorded.  Does everybody understand the exercise?

(TABLE GROUPS TALKING)

Organizer 2:  Alright, why don't we get started talking as a larger group?  Do you guys want to start off?  Everyone?  For the type of information or data that can be used to inform a patient-centered research question.

Participant:  Sure.  So, in adding on to the list that you had already started, some additional ideas that were thrown around here - hospital records, clinical chart data, discharge information, but also hospital quality metrics, so looking at patient satisfaction surveys, \_\_\_\_\_\_ measures, caps, and other quality reports that are already being generated for different accreditation standards.  There might be information there that could be helpful.

Organizer 2:  So, we are talking about kind of the information that the hospital uses to improve the way it runs, and repurposing that for the purpose of health services research.  What about you guys?

Participant:  Sure.  So, we talked about basically infusing some qualitative research, maybe having interviews with patient staff or community organizations about patient experiences, or actually with patients themselves.  Some other qualitative methods were focus groups in town hall meetings.  We also noted about the electronic medical records or electronic health records.

Organizer 2:  For non-researchers, when we talk about qualitative versus quantitative, we are just talking about data that is kind of number-based versus data that is more narrative, or story-based, or discussion-based.  Go ahead.

Participant:  I don't actually recall if you mentioned it already, but another one was to utilize the emphasis on collecting health insurance information.  That is something that is commonly asked using diagnostic codes, so repurposing that data that has already been collected.

Participant:  We also mentioned Photovoice software, and I think another interesting one was Google searches, like if you could actually look by county see the kinds of things people are searching to get a sense of the information they are looking for.

Participant:  Photovoice?

Organizer 2:  Are you guys familiar with Photovoice?  Can you describe Photovoice?

Participant:  I believe it is basically like blogging.  You go around with a camera and narrate.  It is video-based.

Organizer 2:  The way I have seen it used, too, is there are some people who aren't good at articulating their experience in writing or verbally, but they do it better in picture.  So, they use pictures of their neighborhood to kind of talk about their experience, for example.  I have seen it done in different ways, but it is basically a visual way of expressing yourself versus kind of writing it out or speaking it.  What did you guys come up with?

Participant:  So, we talked about gathering whatever existing data was available or information, and then translating that for communities to review.  One case was a representative from a health department that shared their rendering about what they knew about data in the area, and then getting feedback from the community.  That could include stories that the community had, maybe focus groups, town halls.  It also included physician anecdotes from their interactions with patients.  Maybe they are not seeing that as data, but including that in kind of a qualitative way to understand what it happening.  So, thinking outside of ... pushing people to look broader than just quantitative data and to think of multiple sources of qualitative data, I guess.

Participant:  So, our PCORI project is funded to create a community-based research academy, so we focus a lot on the ... (inaudible).  We have created a space where the people from the Department of Health can interact with \_\_\_\_\_\_, \_\_\_\_\_\_ and caregivers, but then the actual academy is teaching regular folks every single public health research method that you can imagine in order to build their capacity to have comfort with those research methods, but also to develop their own studies.  So, one session that we had with \_\_\_\_\_\_, who was a Post-Doc at Johns Hopkins University and had done a lot of work on \_\_\_\_\_\_ analysis, how you locate health in the body.  So, she led us in a session where there is like a stick figure of a person and we talked about how we locate ill health and tools at work, in our community.  So, like Photovoice, it was using different methods to tell a story, but marrying that always with a specific ... (inaudible).

Participant:  Our example was kind of similar where we were trying to understand why people had departed from drinking water as a primary beverage.  So, it was looking at the statistics of what we knew in the community, and then asking elders what was happening when they were young, just incorporating those stories to help us understand what the questions might be.

Organizer 2:  Okay.  This is all kind of building on what people already know to be true, and kind of repurposing it.  So, in one sense, we are talking about data that is collected by hospitals, by insurance companies, and then in another sense, we are talking about the data that people are collecting in their everyday lives, things that people just inherently know that they don't realize could be used as data for research questions.  And last but definitely not least, the table in the back?

Participant:  I will say a few things and the rest of the table can chime in.  (Inaudible) ... involve your community partners, your health department, and other large groups within the community participating in that.  So, that was one of the first ones.

Organizer 2:  And when you say "needs assessment," I just want to make sure everybody is on the same page with the terminology.  What kind of information are we talking about?

Participant:  You have income-per-household, whether they are a two-parent household, how many children are in the household, and with the breakdown of the households, you have health information - do they have insurance, are they uninsured?  It actually gives you a breakdown of the makeup of your community and the area, maybe what hospitals they actually go to as their primary to get their health services.  It is important that the hospitals, the health department, other health agencies and major community partners participate to actually do that assessment of the whole community so you will know who you are working with in that community.

Organizer 1:  Are you talking about doing a needs assessment related to ... (inaudible), or the ones that non-profit hospitals already do every three years?

Participant:  It is ones that are already being done, but out of the data, there are certain questions that pop up, because you are able to determine some of the disparities that are going on in your community.  Another thing - just looking at outcome data, all hospitals and medical organizations note the patients that are actually coming in.  You know when they are first diagnosed based on the treatment you are giving them, and you know the outcomes.  We are able to look at that broad data and see what some of the disparities are for different racial groups.  So, you are able to generate questions from that.  We already talked about electronic medical records, which already have a lot of that data.  Really importantly ... (inaudible) ... it was obvious when we started looking at when patients come into the hospital, the very first people they interact with are the schedulers, and we noticed that we had to have patients self-report on ethnicity and your racial background because a lot of assumptions were being made.  We had not honed down a system.  Then we had to re-train all of that front staff and have the patients self-report.

Organizer 2:  So, this has been really eye-opening, even for me.

Participant:  I have been looking at this list and am thinking about accessibility to these pieces of data.

Organizer 2:  We are going to move on to that, like where we find that information.

Participant:  If you are just the average community member who is thinking about doing a research project, who would you even go to at a hospital?

Participant:  We have a couple more, too, that we didn't add at the beginning that I would like to just share.  (Inaudible) ... looking at that evaluation from those events, and working with a safety net system, the one thing that we have done is ask the NCOs (?) what their challenges are with their members, and then designing health systems research around that to try and resolve those issues.  Some of the things I thought that were pretty innovative were looking at social media, Google trends to look at the trending hashtags around different issues, and then also someone mentioned just questions that might come up - increase in popular interest into current events and media coverage.  How do we generate some questions regarding increased media coverage?  Then, I think in terms of access to data, Departments of Health put out a lot of reports that sometimes just sit there or don't get picked up by the media ... (inaudible).

Organizer 2:  So, I wanted to definitely emphasize the fact that what we have talked about is repurposing a lot of information that is already out there, be it technical information or information that we feel is inherent to our everyday lives, and that information can all be translated into research questions.  So, of course, at PCORI, we focus on comparative effectiveness research questions, which is all about the comparison, comparing Approach A to Approach B, or Treatment A to Treatment B.  So, at the end of the day, that is the kind of research that we focus on.  So, that is why these questions are set up the way they are set up.  But sometimes there are just questions that patients or community members have in their everyday lives that can be translated into a research question format.  So, for example, "Am I taking the right blood pressure medication?"  It is a fairly straight patient question that needs to be answered, and then the research question could be, "What are the side effects and benefits of different blood pressure medications," because from a researcher's perspective, that is the real question being asked here, right?  Is the blood pressure medication I am taking better or worse than another one, and when I say "better" or "worse," what do I mean by that?  Oh, go ahead.

Participant:  Yeah.  I didn't want to interrupt your train of thought there, but something hit me when you talked about that.  From my personal experience before I started volunteering with PCORI, I didn't realize that I had a choice and there were options out there.  I didn't know that.  I have arthritis, and I was like, "I guess I've got to use this cane."  I finally got to the point where, oh, you know what?  I've got choices and treatments where I can have, not only a better health outcome, but really a quality of life, and it helps me make decisions, not only on medication and treatment, but really, where to live and what to do with these next 50 years.  As an African American female, who is also a senior citizen on a fixed income, with arthritis and a couple of other autoimmune diseases, I understand now that I have a choice, and in order to find out what my options were, I had to partner with or find people who could answer some of these questions I had, which I didn't realize were research questions.

Organizer 1:  And that is the thing.  The data sources, the types of information we were just talking about, some of it is just kind of factual information, and you are kind of just taking it as a fact, like, "This is what my doctor told me I needed to do."  So, there really isn't, for you, a question there, but that is why you need to have kind of this multi-stakeholder approach.  So, you need to have researcher and patients and providers and community members and health department.  Once you partner all of those people together, they can each take a look at what you are saying and what information is there with a different lens.  Once you start looking at things from a different lens, these questions start to emerge.  So, my doctor told me I needed to start taking this blood pressure medication, so I am taking "Medication X."  It doesn't make me feel great, so sometimes I don't take it.  But then a researcher might say, "Why were you not taking your medication?"  A physician might say to you, "There are other medications that you could take that wouldn't make you feel this way."  So, everybody is coming at it through a different lens, so these facts or this data that we are talking about, can be viewed in so many different ways, and that is how you can kind of get to the point where you have a question.  In the next example here, it talks about my mother being an 81-year-old woman with dementia - should I place her in a nursing home?  So, that is the person's real question, but then the CER question becomes - what are comparative benefits and risks of nursing homes, assisted living and home-based care for older adult patients with dementia?  So, it is when you bring the perspective that Shavaun just shared of the researcher, other community members, clinicians, as well as that patient or caregiver, then you realize that there are actually other options than the one that has been presented to you, and it is almost like that group is stronger in developing a research question in the end because there are various perspectives that have contributed to the development of that research question.

Organizer 2:  So, as a non-researcher, what you should take away from this is that there are research questions sitting inside of you.  They are in your brain.  You just need to talk things out with other people to help tease them out.  So, you have a lot to offer, even though you may not have the training that a researcher or a Ph.D. or an M.D. has.

Participant:  My question is ... (inaudible).

Organizer 2:  The answer is - it depends.  It depends on if you are stratifying (if we are going to get into the technical, statistical data) ... if we are going to stratify by different racial groups, or by rural versus urban ... once you start breaking those down, the risks and the benefits are different.  So, someone in a rural setting may value something that someone in an urban setting may not.  So, when you are saying "better," I have to now define that word as a researcher.  What does "better" mean?

Participant:  What is so important about comparing effectiveness research and looking at real-world situations that almost hold the data that is related to their pieces that are done in terms of discovery?  NIH-funded research often excludes a lot of commissions that people show up with.  As you were describing, you don't show up with one problem and everything else is great.  So, it is more complicated when you get out into the real world.  We are struggling when you get to the end of a drug study and then you go out and you try to use that drug when people can't be sorted by eligibility and ideal outcomes.  You want to know does this work at all.  So, you shouldn't forget that when you are looking at that example, it is not that people only have hypertension, so it is not only the data bout this person has three co-morbid conditions (diabetes, hypertension and asthma), or whatever it is, and I am taking six drugs or eight drugs or two drugs, and that makes it a more complicated issue, and that is really where I think some of these comparative effectiveness questions are most important.

Participant:  I call it sub-morbidity ... I may have one that is primary ... (inaudible).  That is what my big challenge is.  Oh, by the way, I couldn't breathe and I thought I had asthma, but it is the arthritis that really gives me the hardest time.  So, I am going to not deal with this sub-morbidity.

Participant:  What is the primary complaint you came in with?

Organizer 2:  But that's it ... the primary, for everybody, is different, so the whole idea of defining this becomes important from a research perspective, but from a non-researcher perspective, you may not realize how that works.  I want to get to one more question, and then we can move forward to the next one.

Participant:  I just want to say that the questions you raise ... I would have thought the doctors had this information.  It is so critical to try and engage communities to come up with research questions because that is such a common-sense thing to say.  I remember when I first was in evidence-based medicine, I thought I must be dumb, because I was like, "I'm not getting it - there must be more than this, right?"  Like, "What were we doing before?"  How do you frame these conversations and let people know?  Actually, medicine doesn't have a lot of answers, and so that is why we need your input even more.  So, I think that is such an important thing to keep in mind when you are having discussions.  People assume that there are answers to these questions.  Of course, if there are 20 different diabetes meds, somebody made a table, and my doctor will look at it and pick the one that is best for me, but you have to really learn a lot about how the research process works, that it is super-inefficient and random, to understand that the table doesn't exist and will never exist ... but then how do you start figuring out what the right questions are?

Organizer 2:  So, this is part of the problem, right, because the data sources are imperfect.

Participant:  (Inaudible) ... when I go to the doctor’s office, they have a lot of information about me and everybody else already, but they ask me everything, and I answer all of it, even my height.  It just always there.  (Inaudible).  They ask me my number of medicines I take.  They even ask me the doses I take for all the medications.

Organizer 2:  So, I was going to do breakout groups to talk about this question kind of leading into this.  The data sources themselves - where do you find them?  What data sources should you be using?  So, we talked about the type of data.  For example, when you were talking about Photovoice, where do we find that?  Who do we go to for that?  When we are talking about EMR data, who do we ask?  If I am a community member and I want access to all of the height information for patients in my area for the past 50 years to make sure that we are not all stunted, who do I ask?  So, let's talk a little bit about where can this information that is of interest to patients and communities be found so that we can be included in the research question.  So, we talked about the type of data already, but where can we find it - we are researchers, community members, patients ... where do we find this data and how do we access it?

Participant:  One thing that I think will be important, in answering that, is you will have to speak to some of the challenges.  Say you do identify the person who handles that information, then you will have to obtain an IRB and all of those other hurdles we put in place to obstruct going in and asking somebody to have access to the height data in the community.

Organizer 2:  So, for those of you who are not researchers, the idea is that even if you know where the data is and you know who has it, there are administrative limitations, and I think they are going to speak to some of those in one of the learning labs tomorrow, working with the administrator.  Sometimes the IRB, the Institutional Review Board, is looking at you as an individual using that data and will tell you, you know what, maybe not, not today ... or why are you planning to use that?  So, you want the height information?  Well, why do you want it?  Then, you as a researcher, have to fill out 20 forms to inform the administrators why you want to use this height data, and then you may or may not get access to it in the end.  So, even if we have an idea of what is being collected, who is collecting it and where it sits, we may or may not have access to it.  So, you're right - that is something we have to keep in mind.  But on the flip side of that, because that is our defeatist researcher view, there is also this other information.  Number one, there is information that we can collect as a primary collector.  There is information that we can collect that we have to think outside of the box to kind of think around.  So, you may want the height data, and it feels like re-inventing the wheel, but what if you went around and collected height data?  Is it sitting in the EMR?  Yeah, it is.  But if it is really important to you, and you need to know it, there may be a community group right now, "The Height Organization of America," sitting on this data.  You guys laugh, but I interact with these organizations all the time.  They are like, "We have this rare disease, and there are 10,000 of us who are members, and we surveyed everyone and this is what they thought would be a research priority, but no one cares, so we just put that on a shelf in a report."

Participant:  Can I ask a question about your question?

Organizer 1:  You can certainly ask a question about the question.

Participant:  So, Vickie and I do have an Engagement Award.  I am the Chair.  She is the Coordinator of the only community-based "IRB" in New York City.  So, the first time I heard - it is called the "Bronx Community Research Review Board."  So, we provide community consultation to any Bronx-based researchers who are talking about doing action research, \_\_\_\_\_\_ research, community-engaged research.

Participant:  That is amazing.

Organizer 2:  How about that!?  I bet you there are community members who did know that could be done.

Participant:  It is amazing, but there is also a caveat to that, so that is why I want to ask the question, because I feel like your question is - where are the repositories of patient interests, right?

Organizer 2:  Fair enough.  That is one interpretation of it, yeah.  How can you access this information?

Participant:  Right.  So, one thing that happens to us ... It is dangerous to have such a repository is what I want to speak in the room.  We had some folks, who shall go unnamed, who were interested in pitching a precision medicine project.

Organizer 2:  Can you explain that term, "precision medicine?"

Participant:  I will say that Bronx hospitals are going to start using bio-repositories.  They are going to start collecting tissue that they ordinarily throw away and banking it to study, for research.  They came to us, because if you can imagine, as you were saying before, the public's awareness of ... (inaudible), so many egregious instances of people of color, all those things in research, are on everyone's consciousness.  So, they asked to meet with us.  They had already been approved by the IRB.  In getting this study, they needed to show that they had done some community engagement.  We ripped their IRB protocol apart.  We shared, as Bronx patients, as Bronx researchers, as lifelong Bronx residents, all of the worries that we have about the amorphous consent in the studies and that even if you found out something within my genome, you might not tell me in a timely-enough way for me to benefit from knowing anything about it.  And if you develop an innovation from something in Latino, I am not entitled to it.  Anyway, to make a long story short, we are looking at different \_\_\_\_\_\_ of how these people are saying now, "Oh, we got community consultation, because we talked to them and they okayed our study."  So, the danger of having repositories in places where people can easily say, "Oh, I understand what these patients in this area need," but feel like they don't have to do the real street community engagement work is ... (inaudible).

Organizer 2:  So, for the sake of time, I put up some possible sources, information sources, to help clarify what I was meaning, talking about and thinking of when I am talking about information sources.  Your mind immediately went to a repository, but sometimes when we are talking about a repository of qualitative information, it can sit in a non-traditional place, right?  So, somebody mentioned symposiums that are really happening where patients are talking to each other.  That, to me, is a repository of information.  I know, for example, The American Diabetes Association, the Maryland Chapter that is in the Baltimore area, they have a research symposium every year.  This year, people with diabetes got up and said, "Here are some of the decisions that I have had trouble with," and they invited other patients to come and listen so that they could learn about decision-making and learn from the decisions others have made.  But you know who wasn't there?  Researchers.  I found that to be so crazy, because here, people are telling you what they need studied - "I tried to make this decision and I didn't have the information."  They are sitting up on a stage telling this to the world, and no one was there to listen from the research community.  The research community was lecturing on the research they had done, but how many people were actually there to take in information from the patient.  So, for me, that event was a repository of information that could be accessed easily.  So, I wanted you guys to think about kind of non-traditional repositories of information.  We talked about anecdotes.  Individuals are non-traditional repositories of information.  As researchers, we are looking for power and making sure that something is statistically significant, but sometimes you just need a starting point.  If you are always waiting to collect pilot data to use that to create a larger, billion-dollar study, if you are always waiting for that, it may never come sometimes.  Think about people with rare diseases, there are only so many of them.  That is what the term "rare" means, right?  So, if you are waiting for a big repository of data on people with rare diseases, for some people, it is just never going to come.  So, you need to talk to the people you have access to and at least start somewhere ... form a partnership there and start creating a research question from there.  So, again, we will share these slides, but these are just some of the information sources we talked about.  I didn't mean to earlier bash the research literature, because there are some people who have collected information on what patients want and need, but just haven't moved forward with the "other research questions" that follow from that, for whatever reason.  Maybe it is lack of funding.  Maybe it is lack of interest.  And that information is sitting out there.  Go ahead?

Participant:  What is QI?

Organizer 2:  Quality improvement.  Again, this is the idea of repurposing information, information that is collected to improve services, to improve operations, which can also be used to move the field forward if we are talking about, for example, patient satisfaction with care.  That can be used to create a research question.  So, I didn't know if you wanted to talk about what makes a good research question.

Organizer 1:  Sure.  So, in the Pipeline Proposal Program, we fund people to get together to start making research questions, and there are times that we can't figure out what is important to this community.  So, we allow people to come together in town halls, sometimes using Twitter chat, sometimes using \_\_\_\_\_\_ depending on their location, and communicating what is relevant to them.  You've got the question of, well, you may say that you are not sure if you should take this medication or this medication, but there may be no data on it, so it may not necessarily be answerable.  So, you need to make sure that the community with whom you are working with, and whether \_\_\_\_\_\_ decision-making process that your group together identifies ... we do actually require that our awardees have a governance structure so that they can make the decisions as they are working through the question development process, and we ask them to use the PICO framework and looking at the populations with whom you will be working, what intervention it is that you'll be looking at, and as we mentioned earlier, we will be comparing interventions, right?  So, the comparison of identifying what you plan on using as a reference group ... often, people will want to use the standard of care, and while that is important, it may not be relevant for the community that you are working with, so, making sure that the community's intended outcomes are something that is included in your research question development.  Then, you are also going to have to look at how much time you have.  In some cases, we use the PICOT framework where you are also looking at the setting.  Is it a real-world setting, or is it going to be at an institution, is it going to be at a hospital, or is it going to be within a community?

Organizer 2:  This is just one or two frameworks.  We are all about creating systematic ways of doing things, so if you have done it and it works for you, I want to be able to do it in a similar way so that it works for me.  So, that framework is just kind of one way of creating a research question that is patient-centered that includes a different perspective.

Organizer 1:  And of course, there are other frameworks out there, but that is the framework we work with.  It helps them identify what their issue is, make sure they have identified their population, and kind of work through the process of then identifying the different pieces of what that research question will eventually be.

Organizer 2:  So, how do you actually use that data to create a research question?  So, there is actually data on your tables.  There is a one-pager of data that has actually been collected by an engagement \_\_\_\_\_ that has been made public, or will be made public.  It is publicly-available information.  It was collected by a project that focused on understanding the research priorities of parents who are taking care of medically-complex children, children who are at home on ventilators, who have feeding tubes, that kind of thing.  These parents have competing priorities like work that they need to do to sustain themselves and their families.  So, this information was collected online to allow them to keep caring for their kids and their households and quickly go through a survey.  So, these are a couple of the data points that were collected from them.  So, let's take maybe five minutes to create our research questions from this data.  I think it might be helpful to look at some numbers, some data, to hear other people's perspectives as to what the questions could be pulled out of that data.  It doesn't matter which sheet you use or which data point you use.

(TABLE GROUPS TALKING)

Organizer 2:  Alright, everybody.  I know we are crunched on time.  I want to make sure we talk through the data sources and how it can be applied, because I think that's the piece that people kind of miss.  We are going to start with you guys.  So, can you tell us which data point was of interest to you guys?

Participant:  We looked at both.  One question that we came up with for the home care nurses.  We saw that there is a high turnover rate with the RNs, so we were wondering if perhaps a research question would be just analyzing the factors that are contributing to the high turnover rates in the nurses.

Organizer 2:  So, from an operations standpoint, a research question to improve the operation of the service itself?

Participant:  Yes.  Then, on the flip side, the tone of what I read from all of this is that parents feel out of control in the latter aspect of this.  So, I would be interest to know, of the 13% of parents that have care teens that come to their homes, and the 77% of them that say they were satisfied, what type of satisfaction does that mean?  Satisfaction for the parent or satisfaction based on the health outcome?

Organizer 2:  Okay, cool.  Thank you.  You guys are next.

Participant:  There was a lot of information about satisfaction with the care team, and there are a lot of people who don't have a care team who want one, so why don't they have a care team?

Organizer 2:  Fair enough.  Why don't you guys go ahead?

Participant:  (Inaudible) ...

Organizer 2:  Interesting.

Participant:  We had two conversations here.  The other one was really about continuity of care.  So, there were concerns in the parents’ group about people showing up and different schedules and so on, so we were thinking you could have the same people involved, but for some families, they get consistent care and the same people show up.  You try to look at those satisfaction and outcomes versus the current state, which is it is not quite clear who is showing up at any given time ... so, not just satisfaction, but does that improve outcomes?  We deal with this every day in medicine.  How much of the clinical record do you read before you see a patient, and how well-prepared are you to go in and address an individual's needs.  So, continuity is considered an aspect of that.  If you see the same patient all the time, you don't have to review the record as extensively because you have some familiarity with them.  And you can also address preferences the longer you interact with someone.

Organizer 2:  Over here?

Participant:  We didn't get very far, but I think we were thinking along the same lines of their question about capacity.  It sounds like there is a \_\_\_\_\_\_\_ issue and the nurses are involved, and there is not enough \_\_\_\_\_\_ to go around.  So, we were thinking about a model that has the remote training of the ... (inaudible) ... because a lot of them do seem to be non-clinical, and sort of looking at a solution that removes training to increase the capacity.

Organizer 2:  So, these were all really great research questions.  Some of them had to do with operations, improvement of services, improvement of outcomes, improvement of satisfaction with care, and I think the main takeaway from that exercise is not the question itself, but the fact that this data that was collected (without regard to power and sample size and not a huge effort) was collected by a service provider who was just interested in improving the outcomes and the experiences of the people they were working with, and they felt that those people didn't get a chance to engage because their time was so taken up with taking care of these kids that they were unable to engage in other ways.  So, their engagement award was to kind of do a work-around ... figure out what was important to this community and then put that information out there so that researchers could take it and create the types of research questions that you guys created.  So, from a community perspective, the idea is that it doesn't have to be this huge undertaking of an effort to connect the things that you already know or the things that you can collect, the information that you do have access to, the repositories you do have access to, be them quantitative or qualitative.  Connecting that with research doesn't have to be perfect, flawlessly powered, and you don't have to have this huge understanding of the research process, but Jan and Carol did the best they could.  Anyone could start the process of creating a research question, and it is important that even we, as researchers, understand that this kind of pilot data doesn't have to be perfect in order to come up with a research question that is relevant to the community, that will be useful community, and whose results will be used quickly and will help to really improve the lives of the target population.  I kind of wanted to drive that point home.  We are not generalizing the data or using it to say all of the parents who take care of children with complex medical needs have these issues, but it was just a starting point, and it was one that you all were able to use to start off the research question creation process.  So, that is kind of the takeaway that I really want you guys to think about, these non-traditional sources, how anyone can start the process, how any type of data ... you know, we talked about all those non-traditional data sources and types before from Photovoice to the interviews to the symposia.  All of those can be used to create useful, relevant research questions.  I know I get caught up in the statistics of it, but again, the data doesn't have to be perfect.  That's the point.  The data doesn't have to be perfect to be useful in creating a research question.  How can community members, people off the street or patients who want to engage in research, who may have access or know the data source, connect with researchers?  A lot of you are researchers.  How would you suggest that they do that?

Participant:  Through our Pipeline project, one thing that our CAB aspires to do, our Community Advisory Board, is to be like the University of Maryland Community Research Advisory Board where the community members have sort of a public presence.  They have marketing and communication strategies so the community knows they exist.

Organizer 2:  Are we talking about the patient program?

Participant:  MD-CRAB.  Basically, communities that want to connect with researchers can go to the CRAB and say, "This is my issue - connect me with a researcher."  Then, the Community Research Advisory Board will look throughout the University of Maryland's system to try and make a match.  So, the researchers at Maryland can go to this Community Research Advisory Board to get community input on the protocols or questions at any stage, but ideally at the beginning.  But again, it works both ways, and that is kind of how our advisory board aspires to eventually be.

Organizer 2:  Any other ideas or thoughts?  That is a great model.

Participant:  We have a community research advisory council on the east campus at Bayview, and researchers who are having trouble with either recruiting or did they ask the right questions because they weren't getting the kind of responses ... they bring it to use, we review them, and we give them ideas and bounce things back and forth.  The advisory committee ranges from Doctoral, Fellows, and we have providers, researchers and community members.

Organizer 2:  Any last thoughts?

Participant:  Just making sure the connection, in terms of meeting, is where communities are as opposed to having them come to the researchers ... so, in a venue where people feel comfortable to bring people to the table that the community suggests, and listening to them about what they think is important.  Maybe people's occupation isn't as important.  Maybe the janitor is a very important spiritual leader in the community ... so, listening to the communities about whose information should be included.

Organizer 2:  Great.  Thank you all so much for coming and participating.  I hope this was helpful to all of you.