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Organizer 1:  So, each table will address the question, and if you could try to pick the major points on the sheet, then when you rotate tables ... and we ask you not to rotate in mass - kind of mix it up, and as you have a conversation and new points come up, please add them to it.  So, you don't have to add points that have already been made.  You can extend this.  My background is working particularly with investigators in basic science who do early translational research, but because what we try to do is get them to reach across the whole spectrum, we then ask them to engage people early in translational research.  So, don't feel constrained.  You can talk about the whole spectrum, but don't avoid the end of the spectrum ... (inaudible).  So, what does engagement mean, for non-scientists, when you think about engaging in early translational research?

Organizer 2:  How many non-scientists are present in the room?  I'm Neely Williams.  I think it is important for us to think about that issue - how you view yourself, because how you view yourself will add to how you view this particular topic.  I came at it from that engagement perspective.  We want people involved early in the process of translational science.  So, the question I had is - who is going to tell us what translational science is for those people who are not from bench to T3/4 or whatever that understand that terminology.  I think it is really important for us to think about what engagement means when you are involved.  I love that last presentation - "Let's move it from engagement to involvement."  So, it's not about "inviting you to my party," but it's about, "Let's US have a party."

Organizer 3:  So, can I give a quick example of some stories that occurred from basic scientists where the engagement of patients or other stakeholders actually informed their basic science and changed their experiment.  Dr. Emiliano (?) is a basic scientist who studies metabolic syndrome, pre-diabetes and insulin resistance, and she does bariatric surgery.  So, she does bariatric surgery, sleeve gastrectomy, on mice, and she looks at the metabolic outcomes because she can't control that on humans.  She had been doing this for quite a while before she engaged in community partnership with some community physicians and bariatric surgeons, and in talking with them, she began to understand that the outcomes were not just at one month, then six months, then a year, but when people woke up from surgery, they felt different.  So, she had to redesign her mass model because she was measuring the wrong time point, and it changed her experiment.  One more example - Dr. Oren (?) is a rheumatologist who studies rheumatoid arthritis and she was looking at gene expression, so which genes are turned on and off during layers of rheumatoid arthritis.  In working with the patient population, there are sort of the difficult patients.  Their joint gets hot.  They complain they are having a flare.  You put a needle in the joint.  You get certain inflammatory markers in the blood and in the joint.  They meet the criteria for a flare.  They get their steroids bumped and they get their other medications.  But then there is this group of patients who say they are having a flare, and their blood profile doesn't match, and you tap their joint and they don't have the same inflammatory markers.  They can't get the steroids, they can't get the \_\_\_\_\_\_ and they can't get the insurance coverage because they don't meet the criteria for a flare.  She said, "Oh, my God, they are the ones who are interesting because we know what is going on with these other people who have classic information; so, I am changing my experiment - I am going to study gene expression in these unusual patients."  She couldn't possibly have known that without having a relationship with them.  So, enough for me.  I just want to empower you to think about how you might impact early science.  Don't think - well, I am not a scientist, and I don't know how to do that experiment, so I have to wait until it comes to the clinic before I can tell them how to design a clinical trial.

Organizer 1:  Is there any more preparation we need, or shall we start?

Organizer 2:  Well, I think we definitely need to hear, even if it is just out in the open, but what does engagement mean?  When you get ready to answer the questions that are on your table, you could be using different understandings of what engagement is, so you would be answering the questions from different perspectives.  So, as non-scientists as well as from scientists, what does engagement mean to you?  Those are like the core components of the question.

Participant:  So, engagement for me ... I don't have a clinical background or a science background, but I got invited to the party as a client/advocate.  So, involvement or engagement for me means I participate in my care.  That means I am informed, I am inherent and I am open to new processes or directions of my healthcare team.

Organizer 2:  So, having the appropriate information to make informed decisions about care and about what you give back to those scientists as they discuss their approaches.  What about someone else?  I just want to make sure everybody is on the same page at the table.  As long as we are working from a common definition, I think we will be good.  If you are comfortable and ready to roll to the next step ...

Participant:  From my perspective, it is not only that you are well-informed, but you are able to give back effective input, whether you have "community member" behind your name or you have letters behind your name.  It is bidirectional.  So, we all benefit.  It is not just take, take, take.

Organizer 1:  So, what I would ask you to do is turn over your colored piece of paper, which has the question for your table.  The yellow one is the main question.  Talk about your question.  Think about what you are going to say so you can be concise.  Give everyone at the table a chance to participate.  If someone would be the recorder, you have a Sharpie, and you can record your main points.  We will spend maybe 10 to 12 minutes at each table, and then you have to switch.  If everyone objects to that, and it is just too hard, then you will do just two of the questions instead of all three.  Then we will come back the last 15 minutes and put them up and have a brief discussion.

(TABLES CONVERSING)

Organizer 1:  So, the first question?  What does translational research look like without your involvement in the early stages?

Participant:  So, we came in on the second turn, but first, we had already gone through a little bit of this.  If anyone is here who was in our first group, and I misinterpret something, please let me know.  I think the highlights were that if people are not involved early, you would get vending machine research, which the gentleman here was kind enough to explain.  The idea is it is sort of like a vending machine where you put in your money and you get your \_\_\_\_\_\_ right away.  In other words, you have someone calling saying, "I need 20 patients for this project," and then you get it right away.  You are at risk for a failing study.  You don't know what works earlier on in translational research.  You may miss full diversity.  There is a limited view of possible benefits.  You may study the right things but ask the wrong questions.  You get data but no contact, no big picture.  Another thing we talked about with data was with publishing, you may perpetuate bias.  There may be lack of interest from stakeholders.  You may prevent dissemination of results of limit dissemination of results.  (Inaudible).  Your view may be narrowed.  You may miss broader perspectives.  It may lack validity.

Organizer 1:  Would anyone like to add to the list?  So, then, the second question was - when community stakeholders are not part of the early stages, what are the costs to 1) communities and patients; 2) researchers; 3) institutions?  So, it kind of builds on the first question, but you might have come up with something different.

Participant:  The risk to communities and patients is that community and patient needs aren't met, that they have increased morbidity, mortality, quality of life ... that we wasted their time in participating in research that wasn't relevant ... that they don't have buy in, and that there is a continuing disengagement or disrespect of their voice.  They may feel like researchers or health institutions or medical providers don't care what they have to say.

Participant:  I think there is a lost opportunity for awareness.  I think that is one we haven't heard mentioned before.  The other part of that is that it impacts quality of life, so people are not getting the right intervention ... (inaudible).

Participant:  (Inaudible) ... wasting time and effort.  Also, you lose a lot of goodwill and buy-in.  There can be biases in the data collection, outcomes and results.  (Inaudible) ... Are we asking the important questions?  Are we asking the important questions to the right population?  We may have a loss of productivity because maybe it is taking a long time to run our study because we didn't engage people early enough.  We have a loss of feasibility of studies, and we lose opportunities for co-learning to grow as humans and as researchers.

Participant:  Then, it is a lot of the same things at the institutional level - if they have failed studies, they are losing money, losing time, and it can potentially impact their credibility and their reputation, especially related to that last bullet around continuing stereotypes and mistrust of the work they are doing with people that they are engaging or not engaging.  There is an opportunity cost in that they may not be having the same impact on people's lives and the community's health.  I also wanted to say that I feel like in these conversations we are using the term "early translational," meaning basic scientists, or clinical researchers, or clinical trialists ... we are missing their perspective.  Most of the researchers, if not all of the researchers here, tend to be working more in the T3/T4 or beyond phases, so we are not really following our own principles of engagement in understanding what their perspective is on this, their insights into why they would or wouldn't engage stakeholders.  I kind of feel like at this meeting next year we need to make sure that researchers themselves are here.  Just like we are not going to design research that is relevant to communities if they are not at the table, we are not going to design engagement strategies that are relevant to basic researchers if they are not at the table.

Organizer 1:  (Inaudible - too far from the microphone).

Participant:  (Inaudible - too far from the microphone).

Organizer 1:  So, I think what I heard you describe is \_\_\_\_\_\_\_ capacity-building that is bidirectional.  I think a lot of times when people talk about capacity-building, they are talking about building capacity in the community, but obviously ... (inaudible).

Participant:  (Inaudible - too far from the microphone).

Organizer 1:  (Inaudible - too far from the microphone).

Participant:  (Inaudible) ... Basically, we need to collect a lot of information to understand kidney disease.  There was no direct benefit to patients, because nobody really understood what was going on, and yet the researcher that was involved went out and talked to 360 clinicians in order to be able to recruit in Chicago.  He learned a lot from going out and spending time in practices.  So, it creates a different sense of science and how it is practiced.

Participant:  (Inaudible - paper rustling by the microphone).

Participant:  The question that we responded to was - what are the additional opportunities when stakeholders are engaged in early translational research and what can they add, and the potential impact for patients and communities.  The opportunities essentially are to refocus your research question, it humanizes the research, it provides a level of perspective you might not otherwise have, it provides the opportunity for stakeholders to reclaim power and increase balance, and can redefine the target population.  Impact includes educational growth, and we talked about that being bidirectional growth for stakeholders and researchers, it creates an environment of co-learning or opportunities for co-learning, it can actually have a positive impact on one's career ...

Participant:  We were actually talking about the patients and opening up career opportunities for them.

Participant:  Perfect.  Then raising awareness.

Participant:  So, we also talked about personal growth.  In terms of impact, we talked increased relevance, improved efficiency in research, increased accuracy of data and more meaningful outcomes for patient stakeholders that would hopefully lead to improved care and improved health, improving the ability to effectively disseminate results, and to increase the depth of understanding of perspective (again, bidirectionally).

Organizer 1:  Does anyone want to add to that?  As I listen to all of it, I know that we all believe this is important because we are here. The thing that is always lacking is evidence.  So, if you have examples of projects where you actually captured the transformation of the aim, the transformation of the outcome measure or the transformation of the project, I encourage you to disseminate it, publish it, or just send it to us if you don't know what to do with it.  Bring it forward and let this community help you disseminate it.  Data is the language of scientists ... (inaudible).  Thank you, everyone!