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Organizer 1:  (Accent renders audio hard to understand regarding specific words and context).

Organizer 2:  We have four topics or issues that we thought would be fun to discuss with everyone, and for each issue or topic, we have one or two questions.  So, we have about an hour, so I think we will ask everyone to talk at your tables for about six or seven minutes and then come back and share with the larger group, and then we will tell you what we have learned and the challenges that we still face around each issue.  We are talking about our CTSA-wide community engagement advisory board, but I think these questions and issues are faced whether you are making a CAB or some kind of \_\_\_\_\_\_, and we were sort of chatting at the beginning that all advisory boards around community-engaged research all have similarities and differences.  So, whether you are doing something similar to what we are doing, or thinking about that, we are thinking more about community advisory boards in the traditional sense, which I am not even sure I know what that means.  I think we can help each other find answers to the questions.  So, the first topic we want to talk about is how you find good members. That is always a challenge.  So, what do you do to find board members, or what ideas might you have to find board members, and then what challenges do you have in finding board members?  So, if everybody could just have a note-taker and appoint a leader at each group, we will talk amongst ourselves for a little bit and then we will come back and share.

(GROUPS TALKING)

Organizer 2:  Alright.  I hate to make people stop talking when I hear such good conversations, and I am also guessing with this first question, you might have gone beyond the scope of the question and spent some time introducing yourselves and then moved on to the questions, but I do want to come back and focus on these questions and talk a little bit about what we have done at UIC, and then move on to the next question.  So, you all will get to talk again.  Let's start with that table in the back.  What do you do to find board members and then what sort of challenges did you raise?

Participant:  So, ideas to find members - they said have other members give recommendations, so whoever you know, try and invite them in, think about the area of expertise that you are looking for to form this board so that you have some kind of flavor to start with, also ... (inaudible) ... so, other people that you work with, anybody that you know in organizations, and also talk to your family members.

Organizer 2:  They love hearing about our work, right?  What about challenges?

Participant:  (Far from microphone).  Yes.  So, if you have people who have a specific area of expertise, they might be biased.  If you don't have the funds for compensation, that may be a challenge.  You are going to have to dedicate staff, which could be a challenge.  Time constraints - people are busy.  It may be difficult being consistent ... (inaudible).  It may be challenging to be flexible because every person is going to have different issues.  (Inaudible).

Organizer 2:  What about the other back table?  What do you have to add to this?

Participant:  (Fire truck in background).  I think one of the themes that we came up with was diversity of people from organizations, so having an Executive Director can be good, but also having a community organizer or someone with that experience of working directly with people, not just at an administrative level.  Then, also, doing an assessment of the various stakeholders and what kind of knowledge they have and what they can bring to the table, so sort of doing your homework before you actually do the outreach itself.  Challenges - ditto what they said.

Organizer 2:  Flexibility, yeah ... being consistent, but also flexible.  Alright.  What about this table here?

Participant:  One thing with challenges we didn't specifically mention, but what I am hearing is geographical challenges, whether you are just local or statewide, can be a big challenge as far as organizing.

Participant:  Especially in a major metropolitan area, sometimes it takes half an hour to go to my office.

Participant:  Someone was just saying at our table that with that time, what can they contribute, and how do you keep them engaged?

Participant:  And keeping them motivated in between meetings.

Participant:  The last one is - what happens if \_\_\_\_\_\_ has a great idea, but the Board doesn't agree with it?  Do you go ahead and go with it or just stop there?

Organizer 2:  So, last table?  Do you guys have anything to add?

Participant:  (Far from microphone).

Participant:  It is the other typical CTSA, like an external advisory board or cabinet, or internal leadership within the CTSA, but he is adding the CAB under his office.  Then, he also has a translational research council ... (inaudible).  So, that includes folks outside of the medical school.

Participant:  So, the participation of the advisory board comes from community members or organizations?

Participant:  Right.  So far, it is only five ... (inaudible).  We have drafted a "bringing them on-board process" for them to come and start ... like a board - how do you operate, how do you determine membership, what is the compensation, what is the decision-making process.  So, we presented a series of options on that for them to get started with.  Then, also, for recruitment, we use the design team to identify basically a recruitment list of people to recommend individuals through a survey, so it ended up being around 100 or so around the state.  We sent that out and got about 50 recommendations ... (inaudible).  From those five, he is going to work with them to try and identify an additional seven for the CAB.  That way there is some community input.  (Inaudible).

Organizer 2:  So, did anybody have anybody they want to add to this list before \_\_\_\_\_\_\_ shares what we are doing at UIC?  I think we covered a lot.

Organizer 1:  We have pretty much inherited some of the concepts that have been guiding the work.  So, we actually identify members mostly by referrals from members of our advisory board.  Sometimes when we have specific issues presented by researchers, we notice that our board may not be fully prepared to address those issues, and when that happens and we know of someone else who can do it, we invite that person to come for an individual consultation to be temporarily part of the board.  We also have membership renewal every three years, and we do this with letters.  When we notice that there may be more diversity in a particular area, we make sure we have a list of candidates for those things.  We seek members that have had prior exposure to certain health conditions.  When the questions are related to particular diseases, we look at the membership and find out who would be the person who would have close experience, personal or professional, and invite them to be a part of that meeting when the discussion is going to be about that particular topic.  We favor intersectionality.  What it means is LGBTQ that are also African-American ... so, we have a member that meets two or three of these particular unique features for minority groups.  Another thing is we do want people who are willing to share their experiences and can really communicate their opinion.  Sometimes that makes for very lively discussions, and that is exactly what we want to accomplish.  We want people to express their opinions while at the same time respecting a different opinion that may be expressed by somebody else.  This represents a list of all the organizations that have been affiliated currently or in the past.  These are organizations that we also ask for support or replace membership when necessary.  I can say this is not the only group.  We keep expanding and looking for opportunities or connections elsewhere as well.

Organizer 2:  Can I make a comment about a couple of things that you didn't highlight?

Organizer 1:  Sure.

Organizer 2:  I am always putting in a plug for this, and especially with this board, which is advising researchers on a range of topics and advising them about community engagement.  UIC has so many amazing staff people who have been working on clinical research projects, community-engaged research projects, and they are also people who live in the communities of Chicago.  Some of them have health conditions.  Some of them volunteer with community organizations.  Some of them are from some of these communities.  I think we have done a decent job in engaging some staff people outside of their normal day-to-day research roles to come and be part of this and provide their wealth of expertise.  I think a lot of times we forget about that and how they really understand on-the-ground issues of research.  We could probably do a better job, but I am always putting in a plug for those people.  We also, on our CAB, have one of the community members from one of our IRBs come and provide her perspective.  She has a really unique perspective.  We are lucky to have a member who has been a community IRB member for about 10 years.  She has been on a bunch of different IRBs and she is really involved in her local community around policing and crime issues.  So, to have that perspective in the mix is also really interesting.  So, we have kind of gone outside the box of CBOs and all of that, and I think those are just some examples of ways that we have done some cool things.  So, the next topic that we wanted to focus on, which really came up in the last discussion, is processes.  So, what strategies do you use to make meetings efficient and effective?  Some of it is prep work that we have been talking about.  Then, a separate but related question - how do you get academic community researchers to engage your board?  So, in our case, we have this resource that is available to researchers and we are trying to get researchers who maybe aren't thinking about community engagement to engage, and to use our board as their first stop when they are thinking about that, so that they don't go out and embarrass us (I am a faculty member - I can say it).  So, talk amongst yourselves about these two issues and then we will reconvene.

(GROUPS TALKING)

Organizer 2:  Can we start with your table?  What suggestions do you have for having meetings run smoothly ... (inaudible)?

Participant:  Okay.  So, at Stanford University, it is very structured.  Members eat dinner while we are reviewing researcher materials.  Researchers present them as opposed to evaluation.

Organizer 2:  What about this table?

Participant:  (Voice muffled - far from microphone).

Organizer 2:  What about you guys back there?  Anything to add?

Participant:  So, to have efficient time for open discussion, make sure the speakers are brief and concise.  (Inaudible).  Schedule far out enough ... like a month or two in advance.  (Inaudible).

Organizer 2:  And what about the table in the back?  Anything to add?

Participant:  I think a lot of this was already covered, but having an agenda that is shared in advance, sharing the objectives that you are trying to get out of the meeting, following up between the meetings to make sure ... (inaudible).  We talked a little bit about virtual versus in-person meetings.  If it is an in-person meeting, have a virtual option if they can't physically be there.  More on the efficacy side, board members presenting their work at the board meetings to try to help board members get to know each other and build rapport.  Having a moderator be part of the group, but not be a researcher, could be really important because that gets more buy-in and more trust with the moderator.  Then, doing a Research 101 for participants, but a Community Engagement 101 for the researchers before you even get to the meeting, so that both of them, when they get to that meeting, they are kind of talking the same language.

Organizer 2:  \_\_\_\_\_\_, do you want to share a little bit about what we are doing at UIC?  I want to make a general announcement that we have a lot of tools and resources to share, particularly about evaluation, which is a topic that we wanted to discuss, but I don't think we are going to get to.  So, we are happy to share all of those materials with you.  So, if you want to write your name and email address, there is a paper at every table, and we are happy to share our abstract forms that we give to researchers and our evaluation questions and things like that.

Organizer 1:  We actually try not to demand too much of their time.  We actually have a large group of 32 people, but only 16 meet every time.  We meet four months in the spring and four months in the fall, in between the fall and spring again, to give time for vacations in the summer and a short break around Christmas.  That way we actually ensure that they attend, because vacation is very uncertain for them, as it is for everybody who has a family and a lot of expectations.  The other thing is \_\_\_\_\_ are already established.  We send them a week or two weeks in advance.  The researchers have to provide a very defined set of information.  That information is delivered to the advisory board with full descriptions of every detail about the study, and this goes to everybody on the advisory board so they know what is going to be said.  It is really important that you respect their time and elevate their contribution to something that is really important, because it is for the researchers and for us.  (Inaudible) ... consistent logistics for every meeting.  We know what is going to happen.  Make a very clear timeline.  Sometimes we have two presentations, maximum three presentations, and that is pushing the time and done with permission of the board members, and is done ahead of time.  In other words, there are no surprises.  Everyone knows who is going to be talking and how long they are going to be talking and how the meeting is going to proceed.  Protocols - usually I am the facilitator.  If I cannot do it, Susan used to do it, and then Raymond will take over.  So, the protocol of providing information in preparation for the meeting - send information in advance as much as possible.  (Inaudible) ... capacity-building.  This is very important.  It is part of our giving back.  We pay for their time, but we also want them to learn, not only about interaction, but specific sessions in which they get together because they are going to hear something that they want to learn about.  Have evaluation, feedback opportunities, performance evaluation ... as far as successes and failures, they have the chance to say they didn't like this, or they are having trouble with this or that.  Also, make sure they are always comfortable.  Sometimes we have people come just to watch and they are welcome.  If there are any personal issues, please address them directly and kindly, and most likely things are going to be okay.  We have had the complaint from the majority of the members that somebody on the team was taking too long in their contributions, and we had to talk individually with that person.

Participant:  To your point about involving staff in the discussions of your council or board or whatever, do you have any tips?  Like, I am a staff person, and it would have to come from my leadership that it would actually be acceptable.  I don't know how to, as a staff person, try to push that initiative.  Does anyone have any thoughts on doing that?

Organizer 2:  You mean for inviting other staff members?

Participant:  Well, sort of making that the culture of the board.

Organizer 2:  Yeah, the board or the institution.  I just know our culture at UIC is that we do have a lot of coordinators and on-the-ground, front-line research staff who have been there a long time, and I think our PIs are really supportive of them getting engaged and having professional development opportunities.  So, if I was a PI and I want to borrow somebody else's staff person in an advisory capacity, because I know this person is a real expert on recruitment or community engagement or training survey, I pitch it as this is a professional development opportunity for their staff person and I am recognizing their expertise.  That is how I pitch it, because if you don't offer those opportunities, you will lose good staff people.  To me, it is really a university-wide culture issue.

Participant:  Well, that is a good point.  I could probably pitch it more as professional development versus like, "You should listen to me!"

Organizer 1:  (Inaudible)?

Participant:  I am sort of meant to be a facilitator for the board meetings, but I have been there for almost seven years and I had lots of experience before that, and I have a lot to offer, certainly more than just taking notes and setting up the refreshments.

Organizer 2:  I would be happy to talk to you about it offline because I have a lot of thoughts on using our staff members to their fullest.

Participant:  I am just curious about your evaluation and if you developed your own tool or if you use an existing tool.

Organizer 1:  We actually have both.

Participant:  I can talk to you after this.  We have \_\_\_\_\_\_\_ who does our evaluation for us and reports back to us, and I can connect you with our evaluation manager.

Organizer 1:  We also have ... (inaudible) ... focus groups.  We buy them once a year and check, okay, how is it going?  How are we doing?  What areas would you like to improve?  What areas do you need to improve?  This is an example of the materials that the researchers receive and they need to provide.  The researchers have to give us very detailed information of what they are going to say.  This information is sent to the advisory board members the week before so they are prepared and they know what is going to happen.  Like I said, there are no surprises.  Besides this, they receive the PowerPoint presentation.

Organizer 2:  We have about 10 minutes, so I say let's discuss this last topic as a large group - capacity building.  It came up in one of our previous discussions.  How do you build capacity among your members, and if you have a CAB, what kind of capacity-building have they asked for?

Participant:  We have had Research 101 training.  We use a different model than what you guys use for community members and patient stakeholders ... (inaudible).  They also want to know what other roles they could have, so we have done some sessions on things related to PCORI and additional training.  (Inaudible) ... we elude to this, but with all the information that is given to them, we have a community navigator that makes that in \_\_\_\_\_ language.  So, if you give it to them like a researcher, like if you just pull it right out of the grant, it is probably not going to be ready for the community member.  So, there is capacity-building on both sides, the researchers and the community members.

Organizer 2:  I actually asked this question.  If they don't like what a researcher says, they will send it back and tell them they need to try it again.  We need to manage that a little bit, which I think is what you have to do to respect the board.  Other cool capacity-building strategies?

Participant:  So, the way our board is set up is representatives from organizations.  We have another group called the Patient \_\_\_\_\_\_ Network, which is more of our grassroots community members, and they were the ones that recognized that where their weaknesses were could be filled in by organizations that represent key communities within our larger community.  So, what we are actually doing with them are personal site visits with each of the organizations that sit on our board and talk about ways we can build capacity within their organization and offer them support to do research within what they are already doing at their work.  Like, we had a site visit with the local pride center that represents the LGBTQ community in Buffalo last week, and we were talking about how we could match the pride center with researchers at the university that focus on LGBTQ issues and how we can work with them to do training and cultural competency trainings on collecting data on the LGBTQ community.  So, it's sort of like, we are now trying to hone in on specifically how we can be within your organization and build capacity and match you with research and researchers that are appropriate and then they are more than willing to open that door to start getting researchers in there and talking to the community.  So, it's like Researchers Match.  That is really what we are trying to do.  They also get us and resources at the university that they normally wouldn't have within their organization.  So, again, we are trying to find strengths and weaknesses.

Participant:  We invite the Chair of our community, or our Program Advisory Board ... (inaudible) ... to sit in on our program's leadership meetings, which is like our Directors and Associate Directors, because we find that it helps the Chair to actually lead the advisory board meeting as opposed to program staff having to lead and them kind of just chiming in.  It is capacity-building in terms of being more knowledgeable about community engagement programs.

Participant:  I was going to say we do training like they do back there, but for some of the longer tasks, as part of the annual evaluation every year, we have them identify capacity-building needs that they have.  So, one of the CABs that we supported this year wanted authorship training.  I learned so much.  We brought somebody in to really talk about authorship.

Organizer 1:  So, how to be part of the publications?

Participant:  Yes, and what it means.  (Inaudible).

Organizer 2:  The theme I heard on this is it is sort of balancing what you know the CAB needs and what they want, so ask them what they want, but also give them Research 101.

Organizer 1:  One very important piece here - we do capacity-building.  We basically survey our advisory board members and give them a list of topics or let them write down whatever topic is their preference.  We have seen a lot of interest in issues having to do with ethics and genetics.  So, we actually covered those by scheduling within their regular meetings ... (inaudible).  Hopefully they are members of CTSA.  For the most part, they are.

(GROUP TALKING)

Organizer 1:  Thank you very much!