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Organizer 1:  Welcome, welcome.  What I was saying is we are basically showing y'all how we started our Community Scientist Academy.  So, "Pair and Share."  Find one person, preferably someone you don't already know, and let's see ... y'all can be three.  Let me ask you this.  Is this better (ringing bell) or this (clapping) to signal to stop?  So, when you hear the bell, stop and listen.  We want you to introduce yourself to your partner and tell why you came here.  What is your interest in learning about a Community Scientist Academy, and then we are going to have you join with another pair, and we will tell you what to do.  Go!

(INTRODUCTIONS)

Organizer 1:  Alright.  So, now what I want you to do - you each have a flip chart and I want you to identify what is your common theme in your group that you talked about.  We are going to have two or three minutes to do this.  Share with each other what you came up with.

(GROUP WORK)

Organizer 1:  So, now we are going to have one person from each group share.  This group is going to go first.

Participant:  So, I think there were a lot of commonalities.  We use different language for a lot of commonalities about why we are here today.  One is ... (inaudible).

Organizer 1:  Excellent.  Thank you.  Let's give them a hand.  That was great.  Let's hear from this table.  What did y'all come up with?

Participant:  (Inaudible), so before we try to really get someone interested in research, we've got to deal with the healing.  We've got heal from that pain.  That was 40 years.  So, my work is to first, get people to be part of research, because they don't want nothing to do with it.  (Inaudible) ... by giving them the courage to speak out.  We have a historical truth and we have to have a healing transformation and racial healing transformation.  Then, we have to make sure we work with researchers, know them, and trust them, because your research project is going to be only as good as the people you trust with your information.  So, we have all this healing process.  The way you think determines how you feel.  How you feel determines your beliefs.  Your beliefs determine your habits, and your habits determine your actions.  So, if you have fear, it is flight or fight.  It is hard to build trust from people ... when you oppress us for so long.  So, we thought of a healing program for that, and with historical truth ... that means we go back to world history, because if you say African history, they are going to shut down ... (inaudible).  So, we could say - "No research on us without us."  So, they will have to get us another planet and then we can become involved in that research.

Organizer 1:  Did you have something?

Participant:  Candace is here to increase community participation and help people be proactive with their health, and I came from the other side.  I need to learn how to educate researchers and have them understand that what the community has to say has validity, and it will impact their research.  I get a lot of push-back.

Participant:  And I think what she is saying is we need bidirectional learning.  Researchers have to learn also.

Participant:  (Inaudible).  When you talk about that history, the bad news ... until you learn the good news, then you can combine that.  So, the learning is the healing part.  Many people stay there with the hurt, and never open the door to say, "That did happen, but ... (inaudible)."

Participant:  And that is one of the things we try to do.  We want to acknowledge that history has happened, but we also want to acknowledge life has \_\_\_\_\_\_\_ as well.  There is a lot of misinformation that millennials have tapped onto without actually knowing, and without having actually read about what happened, but because we have heard our ancestors talk about it, we have held on to that.  When I ask them do they actually know what happened, they go, "Well, no, but my grandma said it."  Well, how can you be resistant to something you don't really know about?  You don't know the history and you don't know the future, but you are resisting to what is happening now.  So, until you know both sides, how can you say no, because you still not informed.

Participant:  That is because we are not healed.

Participant:  It is that healing aspect.  (Inaudible).

Organizer 1:  Well, this was great.  I wish we could just talk like this.  We will go on and have more conversation as we go.  Do you want to tell them how we got started?

Organizer 2:  So, basically, what we are going to do today is give you an insight on how we created this, what I would call a "workshop."  We don't really like to call it a workshop, because I don't like workshops, but we have put together interactive activities whereby we can talk about patients and communities engaged in research, and being a partner, and learning about research.  We have two objectives.  What we are going to do today is articulate at least three key concepts covered in our Community Scientist Academy.  That is what we have created.  We are going to talk about how we came to that.  I hear somebody saying something about \_\_\_\_\_\_\_.  We are going to tell you why we came up with the terminology "Community Scientist Academy."  We are going to describe at least two interactive exercises used to engage participants in the CSA.  Our plan is to go over the overview of the Community Scientist Academy.  Sine we are over-schedule, Bonnie is telling me we need to speed up.  We are going to do something called "Shift and Share," we are going to have a \_\_\_\_\_\_\_ exercise, and then we are going to debrief with some Q&A and some discussion, and we want some feedback on how we can improve this particular activity.  This is a pilot, and we want to know - is this effect?  Is it ineffective?  Is it something you could use, or do you think we need to discard it and start over?  Our objectives today are to increase community members' and patients' understanding about the research process and to increase access to opportunities for them to influence and participate in research.  So, we are talking about preparing community people to serve as grant reviewers, advising research projects, serving on patient and family advisory councils, joining registries that we have out ... so, we are talking about preparing community people to actually engage, not so much to be a patient or a subject (as sometimes we have heard people refer to).  We want people to know how to actively become a part of the research process.  This particular activity or this workshop was created BY community people FOR community people, and we are wanting to make sure community people are engaged in the delivery of this workshop.  So, everything we do in our academic institution ... and I must say that as a community member who is partnering with an academic institution, I have had the opportunity and my community colleagues have had the opportunity to really be a voice in how things are set up, how they are operated.  I am so thrilled.  Now, everything is not hunky-dory.  Let me tell you that.  There are still things that we need to do, but we know that we are heard when we speak, and that is because of something I heard Mr. Long (?) say earlier.  We have a relationship with the folks at our academic institution.  I have been working, and my community has been working with the University of Arkansas for Medical Sciences now for about 15 years.  So, we have had our ups and downs, and we are going to have some more ups and downs, but we have developed a relationship, and there is a level of trust there where I know if I go in the room and something is not right, they know we are going to say something.  They know community folks are going to say something.  They also know if we feel like we have been mistreated, or if things are going well, we are going to say something as well.  And I can get on a soapbox about this.  Three \_\_\_\_\_\_ members with the Community Engagement Core were essential in developing this particular workshop and one of those CAB members was a mature lady (and I don't say "old" anymore, because I am hitting that mark, so I come up with all these other terms to describe myself), but she was "seasoned."  She had participated in the Citizen's Policy Academy, and she was so fascinated with how that was operated that she brought it to our CAB, our advisory council, and that is where this particular framework came from.  We reviewed some existing trainings that had been conducted, and the police academy was one.  We chose to focus on some basics.  We have community-based information sessions.  Before we even started delivery or disseminating the workshop, we did some community information sessions, and we will have some pictures later that you will see about those, where we went to community people and shared with them what we wanted to do, and received some input from them as far as what should happen.  Some of the key concepts we cover in the CSA is we do an introduction of research basics, we go over the definition of research, the research process, the different types of research, research partnership, how research questions are formed, and that thing that a lot of community members aren't familiar with - IRB.  We talk about study design.  We talk about research funding and the grant review process, because with our TRI, and I'm sure with some of your TRI's, we have grants that the academic folks apply for, and we have community people that serve as reviewers for those grants.  We also address study implementation and dissemination, which I heard somebody say something yesterday about how dissemination doesn't happen sometimes, and sometimes it happens in a way that it is not community-friendly, so we talk about that and deal with that.  We also talk about ways to be involved in the research process as I said earlier, as a grant reviewer, as a community advisory board member.  Whatever is going on with that research, community should be a part of it.  In our information session, these are some pictures.  We have had the planning committee be five to our one-time community-based info sessions.  Basic intro to research was provided, introduction to the TRI and to the Community Scientist Academy.  We also had researchers there who were sharing the research they do, and we ended up with feedback from 38 participants, who felt that there was sufficient interest in proceeding with the Community Scientist Academy.  So, after we did the initial information sessions and we informed them as to what we were proposing to do, and sort of game them an outline, they thought we should proceed with this particular activity.  So, that is how we got to where we are now with the actual Community Scientist Academy.

Participant:  How did you submit ... (inaudible)?  How were they selected?

Organizer 2:  We created a flyer.  We created some tools that we used to disseminate the information that we were going to have this information session, and we provided those tools to community folks so that they could share that information in their respective communities.  Now, one thing we dealt with - our academic center is in the capital of Arkansas, which is Little Rock.  Most of our community partners are outside that capital city.  For instance, I live 103 miles east of my academic center that I partner with.  There are some partners within the city itself.  So, initially we held some information sessions in the city limits, in Little Rock proper.  Then, we provided the information to communities outside of Little Rock to recruit people to attend the information sessions.  So, we conducted two pilots.  They are always co-led by an academic person and a community person.  We had one that dealt with community research and then one that dealt with clinical research.  I know some of you were wondering if we did anything along the clinical side.  We did.

Participant:  Could you make the distinction between community research and clinical research?

Organizer 1:  Yeah, so the first one was focused on community-engaged research and the other one was more clinical trials and more patient-focused.  The first pilot was a Community Scientist Academy.  The second one was the Patient Scientist Academy.  A lot of it had to do with where we recruited.  Now, we have combined them and we are not differentiating between them after we went through the whole process.

Participant:  Yeah.  I think that was my whole point - that clinical research is supposed to be community-engaged research, so that's why I wanted the distinction.

Organizer 1:  We will get more into how we do it, and I think it'll be clear ... who we invite.

Organizer 2:  Also, think about it like this.  If you are not a scientist, and you are being introduced to this process ... when you went to medical school or to get your Ph.D., were you taught about both community-engaged and clinical research processes in one lump?  It is easier to digest and understand ... (inaudible).

Organizer 1:  I think part it is that we were ... this is from our perspective ... who we were trying to recruit, the researchers that we engaged to present about their research, and it wasn't necessarily visible to the people who were participating.

Organizer 2:  As a community person, I would like for it to go hand-in-hand, but it doesn't, because that is not the traditional way we do it.  So, we try to accommodate that by going in the same modality, but then we want to combine them now because we see what we have done, and now we think we can integrate the two.  So, it took us a moment to realize that it may be possible.  But initially, we knew there may be some push-back anyway.

Organizer 1:  One other thing that is interesting is that the people who participated in the second pilot were patients who were actively struggling with disease.  They were having to leave the session to go have their appointment in a wheelchair.  So, the first one was more people in the community.  We are all patients.  I mean, in some ways, there is no distinction.  We have all, in most cases, been to the doctor, but some of us are more actively dealing with treatment or undergoing a lot of interaction with the healthcare system, and I think that was the other distinction, which turned out not to be as important.

Participant:  (Inaudible) ... bidirectional learning.

Organizer 2:  So, we had our sessions and then we had graduation.  We had a total of 24 participants.  We collected baseline data and then we did pre and post session evaluations, and we received feedback from the Community Scientist Academy participants.  Then, we also did an interest form, and we will talk a little bit more about that.  So, how was this set up?  We had an open-room setup to facilitate discussions.  We don't believe in tables, most of the time.  We did a pre and a post session knowledge survey.  We started out calling it something else, but somebody said, "No, let's call it a Knowledge Survey."  So, as we were going on, we gathered information from the participants themselves to incorporate.

Organizer 1:  Yeah, because they felt like they were taking a test.

Organizer 2:  We did introductions and you had a taste of how we do introductions.  We don't do introductions in a normal way.  We always have some other techniques that we use.  There is always a brief slide presentation and discussion of the new concepts that are going to be discussed.  We use educational videos, and down below you see where we will have a link in the PowerPoint where we will have a video that we used during the presentation.  After the first week, we have interactive exercises to review the previous material.  So, each week we have a review so that people don't forget the materials that we previously discussed.

Organizer 1:  And that is where a lot of the interaction ... people getting into groups and having real structured interactions ... but it is not a test, and they have fun with it.  They have their materials from the week before.

Organizer 2:  And we tried to get away from a lot of didactic presentations that you normally get in a workshop.  We have guest researchers that come in and discuss their studies, focusing on the key concept.  So, each week we would have a key concept, and we would have researchers come in that had conducted some research on that particular concept, and they would actually come in and discuss or present their research around that concept.

Organizer 1:  So, this is Dr. Hutchins, who is a cancer researcher.  She was in the second pilot, talking about her experience implementing clinical trials.  There were a lot of questions and a lot of interaction that day.  This is Karen Yuri, and she does community-based research.  I think she was talking about developing partnerships.  (Inaudible).  So, each day, if we were talking about study design, they would focus on how they designed their study regarding that concept for the day.  But the main point we wanted to get across here is it is sitting around the table with the researcher.  They wouldn't have that opportunity ... exactly what you were saying - it is that relationship beginning to develop.

Organizer 2:  And a lot of community folks don't know who the researchers are who are going to conduct the research, so that was really valuable.

Participant:  How did you get the community to come out and hear somebody they didn't know, or how did you get your participation and how did you maintain it?

Organizer 2:  Let's back up a little bit.  When people signed up for the session, they actually made a commitment that they were going to come to all the sessions.

Organizer 1:  Which they weren't always able to do.

Organizer 2:  Right, but they did make that commitment on the front end.  They didn't know who the presenters were going to be, or who the researchers were going to be, but they were open-minded enough that whoever came and presented, they were willing to listen.  And it turned out really well, because they were very fascinated with what the subject matter was.  I was excited.

Organizer 1:  One thing that was interesting in terms of how people heard about the CSA ... we did those information sessions.  One of the reasons we did those was because we thought we could recruit from them.  We had 38 people and we only ended up with two people in the actual ... the people who came, a lot of them learned about it on Facebook.  We had our community-engagement program manager go on the news at 5:00 in the morning and did a little talk about it, and we had some articles in the newspaper about it.  But most people heard about it through mass media rather than being people that we knew ahead of time, which was encouraging, because we engaged new people that way.

Participant:  Did you think the information sessions were also helpful ... (inaudible)?

Organizer 1:  Oh, it absolutely was important.

Participant:  So, how did you invite the people to the information sessions?

Organizer 1:  Same way.  We had flyers and a press release.

Participant:  So, did you disseminate them throughout the communities or churches?

Organizer 2:  In whatever respective community we were going in, we provided a flyer specific for that particular community, and we had a contact in that community who was willing to host that particular information session.  We provided food.

Organizer 1:  Actually, we did not pay people.  They got dinner at the information sessions, but at the training sessions, we just had snacks.  At the celebration, we had a meal.

Participant:  How do colleges or universities feel about incentivizing communities?

Organizer 1:  We definitely do it for our CAB members, absolutely.  We would have done it for this, but we didn't have a budget for this academy.  This project came out of our CAB.  The head of our CTSA came to our CAB meeting and said, "How can we get more people in the community to influence what we are going in the CTSA," and their response was, "People in the community need to understand it better."  We said, "How do we make that happen," and they said, "You need to have an academy, like the police academy!"

Organizer 2:  But the graduation celebration is the culminating experience where people are awarded a certificate.  We decorate and have music and a nice meal.  It is really nice.  So, that is basically what the CSA is, and we are developing a toolkit that is going to have all of this information and it is going to be online.  It is in progress right now, so we will be letting you know when it is available.  We will get the background and overview, and all of this information will be in that toolkit if you are interested in conducting a Community Scientist Academy.

Participant:  (Inaudible) ... Is it something that the Program Manager or Director of the Community Engagement Core has to fund out of the regular budget they have, or do they apply for funding?  A lot of what we do comes out of the blood, sweat and tears and ideas of our community members with no funding.

Organizer 1:  I am over our community engagement core and our CTSA.  Anna is actually an employee of the university, but that is only because her organization doesn't have enough employees to pay health insurance.  She is a community person.  She is on our CAB.  She is a community co-ambassador.  She has 20 years of experience partnering with us.  But our other CAB members are not like that.  So, what we have done with this is we have two Community Program Managers, Nicki and Camille, and myself, that are sort of the staff for the CAB, and the way we tried to do this is - the research of looking at other training and putting together the materials, we did a lot of that load of work and brought to the community members every week.  We met every week with ... there were three CAB members who volunteered to be on the planning committee, Anna, Mr. Charles Moore, and Ms. Sarah \_\_\_\_\_\_.  So, most of those meetings were about an hour a week, and they would give their feedback.  They were the reason we did the information sessions, because even though the CAB said they really wanted to do it, once we started planning it, we were like, "Are people in the community really going to be interested in hearing about the IRB and study design?"  We decided this information session would be a quicker, cheaper way to test the level of interest, and that is why we decided to go forward with everything.

Participant:  Did you build a formal curriculum?

Organizer 1:  Yeah.  We have a curriculum.  That is what is going to be on our toolkit.

Organizer 2:  They are four weeks, two hours a week, and that fifth week is the graduation celebration.  But let me just share with you - when we did the Patient Scientist Academy, they requested an additional week, because they felt they needed some additional information.  So, we are going to add a week.  So, people are committed enough that they want to know more.

Participant: So, when they sign up, they commit to the four weeks?

Organizer 2:  We let them know how many weeks it is going to be, that it is going to four weeks, and then the fifth is going to be graduation, but after they went through it, they wanted an additional week because they felt they needed some additional information.

Organizer 1:  They actually wanted it longer.

Organizer 2:  Yeah, they wanted it more than two hours.  There is so much you can share.  And then you get into these discussions, and they want to talk longer, and we only had the two hours and we tried to make sure we didn't exceed the time limit that we had set, because when you tell somebody you are going to do something or have them there for two hours, you want it to be two hours.  They wanted to stay longer.  They wanted more and more, and I was just ecstatic because I was wondering initially - are they even going to participate?  And then when they came, they wanted more, and I thought, oh, my God, this is amazing, because I want everybody in my community to know what I know about research.  There are pitfalls, but there are also benefits to research, and we want to make sure our communities don't get that false information, or they just don't have the feeling that ... you can dictate how the research goes if you are a part of the conversation, but if you are not a part of the conversation, you don't have anything to say!

Participant:  So, it looks like you all did evaluation \_\_\_\_\_\_.  So, those were the knowledge assessments, right?

Organizer 1:  Right.

Participant:  Were there other assessments?

Organizer 1:  We did not assess trust.  It is a very difficult concept to measure.  In retrospect, we might have done it if we had thought more fully about it, because we just wrote a paper about this, and of course, in the objectives we were saying, "We are trying to increase trust," and I was like, "We can't say that because we didn't measure that!"  I think we did, but we don't have a measure of that.  And we also did a lot of feedback, and in the interest form at the end, where we list all the different ways that people can be involved in research at our institution and have them indicate what they are interested in ... and then we follow up with them, like the review committee for the pilot grant.

Participant:  (Inaudible)?

Organizer 2:  During that last session, we will bring people in who have actually served in some of those capacities, as an Advisory Board Member, as a CAB member, as a grant reviewer, and they will sit on the panel and they share that with the participants as well so they will get a sense of - this is something that I can do or this may be something I might be interested in.

Organizer 1:  I'm glad you brought that up, because that is where the interest comes in learning more.

Organizer 2:  And we asked, "What role would you like to play?"  I think somebody asked where it is budgeted.

Organizer 1:  Yeah.  It is just out of our community engagement sweat, and then the volunteers from the community who are on the CAB.  So, how many of y'all have heard Liberating Structures?  It is just a resource I wanted to make sure you all are aware of.  I am in Little Rock, and we are in the same location as our Clinton School, public service.  Our Presidential Library is there, and they had someone there who came and did workshops with us on how you can use these.  You can look them up online.  It is nothing fancy.  Basically, these are structures that you can use ... it is basically structured group interaction, and the whole purpose is to avoid doing what I am doing right now, which is me talking to you, and I am not hearing what you are thinking and saying.  It is also avoiding just unstructured mass chaos.  So, there are about 33 different structures on this website.  So, we use this a lot to liberate everyone to participate so that we hear everyone's voice.  They are fun to do.  Some of them are just things you do all the time, the "Pair and Share" thing.  The other one that we use ... I think we are kind of doing it now.  It is called "Shift and Share."  When we would have the researchers come, we would usually have two.  So, we would break people into two groups and they were like the expert that was going to talk about that topic for the day, and we are sitting here.  Anna might be one of the research experts that day talking about being a community member, how that partnership that she has with \_\_\_\_\_\_ and with the TRI was formed, or it might be Dr. McSweeney talking about how she implemented qualitative research on heart disease in women in the community.  So, it is about 10 minutes in each session, and then we "Shift and Share," and that is all it is.  It is an opportunity for smaller groups to really meet someone and feel more comfortable, like, oh, can I ask you about this, and can I ask you about my cousin who has the same problem, or now, I was asked to participate in a study one time, but I didn't feel comfortable.  So, they get more one-on-one interaction with the researchers.  One of the things that was really exciting to us is this is a way to grab researchers.  Because we did it on campus, which has its pros and cons, it is not a big investment for them, and at first, they didn't realize what they were getting into and sometimes they were like, "Oh, I don't have time."  But we just keep asking, and then finally they come and they realize that they are excited and interested, and most of the researchers, once they do it, they want to come back.  So, that was something we learned that was really important.

Organizer 2:  When we talk about researchers, and inviting them to come and present, that was one of our biggest challenges because they kept saying, "We don't have time," especially if we wanted them to go out into the community.  Most of them, if we had information sessions in Little Rock, they would participate, but when we talked about driving somewhere, they didn't have time.  But some of them were very much willing to go out and share their research.  Sometimes communities have no idea what research is going on, and that was a way for them to get their work out into the community.

Participant:  So, what was the timeframe?  I know you talked about the challenge with the university?  How about the challenge with the community?  So, when you have it in the university, what was that timeframe that you were getting the community to be able to commit?

Organizer 1:  The first one was in September.

Participant:  No, I mean the actual time of day.

Organizer 1:  It was in the evening, 5:30 to 7:30, and then we did the other one in the morning.  We went around to the Patient and Family Advisory Councils and tried to engage some of the patients involved, and they said, "We can't come at night - we have to come during the day," so we had it during the day, and now we have three scheduled.  That's the other thing.  We didn't have enough lead time to engage people.  Now that we know we are doing this, we are going to do it three times a year.  So, two of those will be ... I can't remember if they are both in the morning and then one at night, or the other way around, but if you can't come in the morning, you can come in the evening.

Organizer 2:  It was interesting, because the researchers couldn't come during the day, so they had to do it in the evening and most of the participants wanted to do it in the evening because they work during the day, but the patients - they wanted to come in the day because that was the best time for them.

Participant:  Because they were probably coming for their appointment.  That is interesting.

Participant:  That has been our experience, too.  We always want to offer things on weekends and nights, and I am a busy mom and I don't want to have to do things on weekends and nights if I don't have to.

Participant:  (Inaudible).

Participant:  And you get different people ... you might get retired people during the day and working people at night.

Participant:  Yeah.  You can't make any kind of assumptions around what is the best time to do it.

Organizer 1:  I will say - limitation - we don't pay for transportation give childcare.  So, I am sure that limited who participated in the pilot, and we see those as limitations that we want to address.  This is another Liberating Structure.  I don't know why it is called \_\_\_\_\_\_.  I'm sure it has some origins that are interesting to read about.  But the idea behind this is ... and I do it to my class.  I teach a Health Disparities course.  I will tell my students I want them to get in a group and talk about all the things you need to do to make sure we are not successful with this \_\_\_\_\_\_ project, and they are like, "What!?"  So, the idea here, and I tried to come up with something y'all could do ... but if you are trying to do some training for the community, or you are thinking about doing some kind of education for the community, what would be the thing you are most concerned about?  What is the biggest barrier?  What are the unwanted results?  Then, list all the things you need to do to be sure you get that unwanted result.  So, for us, one of our biggest challenge in the beginning was getting researchers to agree to come.  So, all the things we needed to do to make sure they wouldn't agree to come ... that's what I want you to do.  You can use this in your group interactions, and it might be something a little awkward to talk about.  The example they give in the training is - if you are training nurses and doctors and you are trying to overcome the problem of hand-washing (you know, nobody washes their hands), then you ask, "What do we need to do to make sure that nobody washes their hands?"  Of course, you come up with this list of all the things that people are doing, so it ends up at the end, like, "Why are we doing all those things, and how do we overcome those instead of going straight to the thing that we need to be doing?"  So, it is just kind of turning a thing on its head kind of thing.  So, do you want to do this or "Shift and Share?"  So, what is your biggest barrier and how can you make sure you don't overcome that barrier?  Planning for failure ... how do we make sure we fail?

(GROUPS TALKING)

Organizer 1:  So, it looks like y'all have lots of good ideas about how to fail!  We have seven minutes.  Anna and I are going to take prerogative here, because we need to learn from you what we need to be doing differently to improve, because we are going to keep doing this.  We want any input you have.  The other thing I wanted to say is that we are hoping to have a webinar on our toolkit.  So, one question is - do you think this is a good base to start with in terms of the information we have provided?  It would be alongside the toolkit to introduce it.  So, if you are at a CTSA, and we say we are going to do a webinar, we do our hour-long thing, we tell you what is on the toolkit, here is the link ... so, give us your feedback.  We have little notebooks at the table.  It can be good feedback or what you think we should be doing differently.  And thank you so much for coming and finding us.