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Organizer 1:  Thank you guys for joining us.  My name is Gaye Thomas, and I am here with my wonderful colleague, Betty Kaiser.  McKenzie is handing out a packet that we will be referring to today, and we've got some extras up here.  So, Betty and I are absolutely passionate about this work of stakeholder engagement, and we are just delighted for this opportunity to be here with you guys to share just a few tips and tools that we have learned over the last seven years of consulting with researchers and working on nine studies funded by PCORI, which you all know is the Patient-Centered Outcomes Research Institute and such a driver in this whole world of stakeholder engagement.  So, we have about 90 minutes with you today, and we are going to start by getting to know each other a little bit, and then we are going to examine two common problems that we have seen in stakeholder engagement, and then share some of the tips and tools that we have found help deal with those issues.  And then last, we are going to discuss some strategies to keep stakeholders engaged across the whole lifespan of your project.  So, we are focusing today on what happens after you have recruited stakeholders, after you have gotten them to join your project, and we know that not everybody may be at that point or may actually be worried about recruiting stakeholders, but don't worry, because at the end of the presentation, we are going to share the link for a free tool kit that we have developed that focuses almost exclusively on recruiting stakeholders.  So, there are more tips and tools available - we just won't cover them today.  So, who are we?  Why are we here?  Betty and I are the Co-Directors of WNRS, which is the Wisconsin Network for Research Support and that is a base at the University of Wisconsin-Madison School of Nursing. Our focus is helping researchers effectively engage stakeholders or study participants.  We started WNRS in 2010 with an NIH grant to develop a community-based infrastructure to support health sciences research and with an idea that if we could develop an infrastructure that actually allowed people to have a direct voice into the research enterprise, that it might actually maybe budge the needle a bit on health disparities.  So, since 2010, we have worked with about 100 research teams at multiple universities on projects funded by any number of organizations.  And since 2010, we have also been running two unique Community Advisory Boards, the Community Advisors of Research Design and Strategies.  The CRDS are Madison-based groups of Lai community members from diverse backgrounds.  They meet monthly with researchers to give feedback on a wide range of public-facing materials, such as surveys, recruitment letters, smartphone apps and websites.  Gaye and I have planned over 140 meetings between researchers and the CRDS, and our stakeholder engagement work on PCORI grants is based on what we have learned during our long relationship with these groups.  We know what it takes to prepare people to give effective advice to researchers, and we know what it takes to plan and run an effective meeting that works for everyone involved.  So, let's get started with introductions.  We know that you may be familiar with the people at your table, but make sure that you are.  Please go around the table, share your name, where you are from, and one thing you love to do for fun.  Talk amongst yourselves.  Alright.  Thank you guys for sharing so much at your tables.  It is wonderful to hear people talking and getting to know each other a little bit.  I learned that McKenzie is an architectural photographer, so you never what skills and interests are lurking in the people right around you.  Some of you may recognize this seven-piece framework of stakeholders, developed by \_\_\_\_\_\_ and Colleagues.  So, just take a minute to scan the different stakeholders listed here.  As I think I mentioned earlier, today, Betty and I are really going to focus on patient and public stakeholders because that is our particular passion, but we know that other people have a lot of different experience.  So, just to get a sense of who is here in the room, we wondered if you would just raise your hand if you have experience working with patient or public stakeholders on a research project.  Okay.  Has anybody worked with the provider/purchaser/payor part?  Alright.  And anyone over here worked with policy makers?  Oh, this is great.  This is wonderful.  We've got a lot of different experience and will have a lot of opportunities to share as we go along.  One thing that we have found is that most people can pretty easily identify the kind of stakeholders that they would like to get involved in their project, and many people can even recruit them and find that fairly straightforward to do.  So, once you have your stakeholders, then what?  You've gotten through the rough part, right, and now it is just smooth sailing.  As many of you know, that is not quite what happens.  That is really when the real work begins, and this is exactly where we have seen this point where you've got your stakeholders on board and this is exactly where we see projects falter.

Organizer 2:  So, in our consulting, we've noticed two consistent problems - uncertainty about patient stakeholder roles and responsibilities, so, there is confusion on all sides about what to expect and who is doing what, and incomplete planning for stakeholder meetings, which leads to a frustrating experience for patient stakeholders and means that researchers don't get the outcomes that they want.  So, let's start here - uncertainty about roles and responsibilities. So, first, let's all put ourselves in the shoes of a patient stakeholder.  Let's say I've been invited to join a Patient Advisory Committee on a research project.  Someone on the project team has told me a little bit about the project and they've explained that they will meet with researchers to advise them.  I know when and where meetings will happen, I know how often they will happen, and I know how much I'll be paid, but I really don't know what to expect at these meetings, and I am wondering - what am I actually going to do sitting around a table with researchers.  What are they going to ask me?  Will people use language that I don't understand?  How will people treat me?  Am I going to feel comfortable sharing my ideas with researchers.  You answer those questions with a fun, focused, friendly orientation.  We have delivered orientations to over 175 different stakeholders, including patients, family members and research staff, and from our perspective, a successful orientation is not about pathing knowledge into people.  It is about preparing stakeholders for the actual work that they will do at a meeting.  So, we focus on three main outcomes for stakeholder orientation.  We want stakeholders to understand the overall goal of the project and their responsibilities, we want them to feel confident that they can do their job as a stakeholder, and we want them to feel like they are respected members of a team.  We want stakeholders to leave the orientation feeling positive.  They know what their work will involve, they know they can do the work, and they feel like they are part of a community where they are going to be treated well.  So, let's look at the first template in your packet, as Ms. Gaye is showing here.  This is a 90-minute agenda for a patient advisory committee orientation, and throughout this presentation, we are going to use the acronym PAC for Patient Advisory Committee.  We have helped research teams develop tailored orientations as long as six hours, but this 90-minute template is more typical, and you would use this orientation at your very first meeting with a patient advisory committee.  So, please take a few minutes to read this template at your table, and then we would like you to discuss these questions with your whole table or in groups of two or three.  So, take about five minutes all together, and then we are going to get back together and hear some responses from each table.  So, go ahead and read the template and talk about the discussion questions at your table.  Alright, could people wrap it up and let's share our comments and ideas about this agenda?  So, let's start with the first question - just some initial reactions and impressions.  Let's get a comment or two from each table.  Can we start with this table over here, just initial reactions and overall impressions of this template for a Patient Advisory Committee orientation?

Participant:  What we were just talking about is we don't know how many people might be at this meeting, but the timeframes may be so short for accomplishing the goal, but we also talked about just having a chance for a feedback loop, so being able to get feedback from the group about the process, but also setting parameters and limitations within the context of what they are supposed to be doing so that it is not just sort of, "Tell us how to do this better," but it's more, "Help us ... (inaudible) ... we can change."

Organizer 2:  So, that's a great comment.  We haven't given you much context for the development of this, but this has been in development since 2012, and that was the first time we delivered an orientation to the CRDS, and they did exactly the feedback process that you are talking about.  As we have redone various iterations, we have always gone back to the CRDS and said, "Okay, what do you think of this?"  So, this has been embedded in our Patient Advisory.  How about this big table back here?  Any first impressions, reactions.  Anything at all will be helpful.

Participant:  Mentorship ... (inaudible - too far from microphone).

Organizer 1:  And what is the goal of that?

Participant:  To prepare them to ... (inaudible).

Organizer 2:  Yeah.  So, once again, we have provided insufficient context.  People have joined this group.  At this point, people would have signed on, so they would have some basic understanding of what the project is about.  But the orientation is to really flush it out and give them the opportunity to experience what is it going to be like in this group, and then at the end of the meeting, if it is not what they want, to step back.  That is part of the purpose of an orientation, to really give people a flavor of what it will be like to work in this group, and then be able to gracefully exit at the end and say, "No, that is just not what I am looking for right now."  Thank you for that comment.  How about this table?

Participant:  Also without that context, so take this with a grain of salt, but we talked a lot about what kind of rapport we thought was necessarily to build ... (inaudible), but relationship-building and trust-building is critical to get to this point.  Also, toward the end, we talked about the need also around dissemination and closing that feedback loop to ensure that the relationships move on over time and these are sustained relationships and not just for the purposes of the meeting.  Also, we had a conversation about, I guess, the language seemed to imply that there was an inherent one-way arrow kind of feedback to those decision-makers as opposed to this committee being kind of a governance role with the decision-making power.

Organizer 2:  Okay, great feedback.  And how about this table, just an initial comment or impression on the agenda?  Usefulness?  Anyone?

Participant:  I was wanting to know how often would it meet because you don't want to have such a lag between the meetings that you lose the momentum, but also these are volunteers, so you don't want to ask too much of them.

Organizer 2:  So, down there in the bottom, you see there is a #6, "PAC Meeting Process."  This is a template, so it is intentionally rather generic, because as we all know, research projects run the breadth of one year, five years, an eight-person committee, multiple committees, and so we tried to make this generic so it could be useful and adaptable for those kinds of situations.  In our work, groups can meet from monthly to every three or four months over the course of a project.  So, that is something you would explain to people here.  This is what you can expect for the frequency of our meetings, how long they will last, whether there will be homework involved.  That PAC meeting process is where you would give people all of those details that they will need to make the decision about joining or not.

Participant:  We were also trying to get to the bottom of how you distinguish effective feedback versus ineffective.

Organizer 2:  We actually have a demonstration of that later on.  Yes?  Go ahead.

Participant:  Outside of the meeting, what are the other processes for communication?

Organizer 2:  Okay.  Did you get that, Gaye?  So, did anything in the Objectives surprise you?  Anything you don't understand or doesn't look right for a Patient Advisory Committee?

Participant:  Are the researchers independent?  (Inaudible).

Organizer 2:  The answer is - it all depends.  The context in which we are working at the University of Wisconsin-Madison, is that we are usually consulting on projects, voted projects, where researchers are building their own Community Advisory Board.  So, these are often not CBPR projects.  The researchers are not embedded in the community.  They are putting together a patient stakeholder board for the purpose of informing their work and helping with one specific project over a limited time period.  So, sometimes, the way that plays out is that the research team might have a designate, often a staff member, project staff, but we work with many teams where the PI, the Principle Investigator, does attend these meetings.  So, there is usually one research team member present that may not always be the lead investigator, but sometimes is.

Participant:  The reason I asked that is ... (inaudible) researchers, preparing them to receive the information.

Organizer 2:  Yes.  That was outside the scope of this presentation, but that is part of our consultation work as well - is helping researchers as far as what is needed to welcome patient voices into a project.  Any other comments?  Go ahead.

Participant:  (Inaudible).

Organizer 2:  So, that is a great comment.  Gaye is going to actually talk in a few minutes about one of those constraints, and explain how we would address it in orientation, but another thing we would do is typically not front-load people with too much technicality, and frankly "un-fun stuff" in a first meeting.  We want people to get a flavor of actually being in a meeting.  When you need to pull out, when you need to say to people, "That would not get through IRB," for example, we think there are really graceful ways to do that and that you do it at the point in which it is needed rather than trying to front-load people with a lot of minutia that frankly is not going to make sense to people until you have a very specific example for them.  Any other comments or suggestions about this agenda?  Yeah?

Participant:  One thing we have heard from stakeholders in similar committees is that they want to have an opportunity to share where they have expertise or experience ... (inaudible).

Organizer 2:  Okay.  That is great.  Yes?

Participant:  We have a Community Advisory Board at Wake Forrest.  One thing that they made very clear to us is that they want to see and learn the results.  Once something is done, it is like, okay, this is why we did that.  So, I think we all need to be careful to include that.

Organizer 2:  We have a very specific example of that later on in our slides.  We completely agree with you that closing the loop ... if you ask for input, then you have to come back to people and tell them how you have used that input.  So, just to close this discussion, was there anything that seemed to be missing from this?  Was there anything that you looked at and thought, well, wow, why isn't this in a patient orientation?

Participant:  I don't necessarily think this is missing.  I think this is just what we have experienced.  After serving on many, many advisory boards and being a part of the folks that have been recruited and also part of the groups that have gone out and recruited, this is heavy-handedly toward the institutions.  It is not a level playing field from the beginning.  We tell the stakeholder what our project is about more than we listen to the stakeholder about what their concerns around this issue is about, and until we are able to be more level in our approach and able to slow down the wheel at the beginning, and allow the voice of the stakeholders to develop and develop its own strength, to be a part of the engine that is driving the research, we are always going to run off the \_\_\_\_\_\_.  We met you.  You were nice ladies.  We are so grateful you are here.  You are great gentleman.  You express very well.

Organizer 2:  That comment is so interesting, because we know that a lot of people in this audience are embedded in CBPR, Community-based participatory research.  Many of the people that we work with are not embedded in that tradition.  They are researchers who are very new to this field, and why are they doing it?  Because there is funding for it, because there is a Patient-Centered Outcomes Research Institute that is saying - you must do comparative effectiveness research to get these funds and you have to have patients involved.  So, I completely agree with that perspective, and the reality is that there are many people who are getting funded for this work who are not embedded in that tradition or that thought process.  So, how can we make the best of that situation?

Participant:  I think what we have found that has been so beautiful about this work is we do start with a lot of researchers who are, at best, uncomfortable with this, and at worse, maybe a little resistant to the whole idea.  You know, what can people tell me about my research?  I'm the expert.  I've been doing this my whole career.  But funders tell me I need to do this, so here I am.  I think, by the end of the project, these researchers who are not community-engaged researchers will say, "I am never doing a project again without patients," or, "I am never doing a project again without listening to the community."  So, it is an evolution.  PCORI has jump started what I hope will be a revolution.  We are just at the beginning of that thought.

Organizer 2:  Go ahead.

Participant:  (Inaudible - far from microphone).  I feel like it is getting to know researchers and stakeholders as people and not necessarily about the grounds for the study ... (inaudible).

Organizer 2:  We completely agree with you.  Everyone in this room knows it is relational.  Yes?  One last comment.

Participant:  One exercise that Glenda and I have done in a couple of different settings is - start off with, what are the priorities, and what are the reward systems in place, because I think oftentimes when we start, a research committee is focused on grant-writing, funding, \_\_\_\_\_\_, and at the same time, those are really important.  So, I think part of the development of the rapport ... (inaudible).

Organizer 2:  Thank you.  And just recognizing those commonalities of everyone around the table, we try to build that in in various ways to orientation.  You are not going to level the playing field entirely, but what can we do throughout the orientation to level that playing field and identify commonalities for people?  Well, thanks, everyone.  We hope that template is useful to you.  We hope you take it back to your workplace and think about adapting it, improving it, building on it.  So, thanks for all of your thoughtful comments.

Organizer 1:  Great.  So, let's move on.  We do have some tips and tools for each one of these agenda items, and as I mentioned earlier, we will explain later where you can find these resources online.  But this morning, we are going to focus on four items on this agenda, and we would like to start with the Project Goal and Stakeholder Roles.  So, to help people get oriented to a project goal and their role, we often use what we call an elevator speech activity, and we developed that activity because we found that the stakeholders are often actually quite confused about the point of the group they have joined.  Is it a support group?  Or some kind of group therapy?  Is it a health education class?  Or is the stakeholder group kind of a gatekeeper?  Do they actually have the final say on decisions for the projects?  So, please look at Page 3 on your handout.  It is called the "Elevator Speech Example."  If you could just turn to that page, during an orientation for patient stakeholders, we talk about getting comfortable, describing the point of the advisory group and the project itself.  We would ask PAC members to pair up with somebody next to them and take turns reading the questions and the answer aloud.  So, just take a minute to scan this example, and we've got a couple of questions.  So, it is very short.  So, again, just to provide the context, most of our consulting is again with people who are in the position of saying, "We've got the project; our train has left the station, but along the road there are going to be switches in the train track, and we need your advice to know if we go this way or that way."  But they are not deciding WHAT the train is.  They are already on the train.  So, this, obviously you would adapt for your own individual project.  I don't want people to get caught up on that one-way-ness of it.  But just stepping back from that piece, do you have any comments on - does this seem useful just as a start to help orient patient stakeholders to their role and the goal of the project?

Participant:  I like the idea that it is in language that anyone can read.  I was surprised when you get to the last sentence ... (inaudible).  The first few sentences explain who we are, and I guess I wanted one more sentence about why this is important.

Organizer 1:  Okay.  What do we hope will be different?

Participant:  (Inaudible).

Organizer 1:  That is a good point.

Participant:  When I read it, I had a huge problem with, "And her research project team."  There is no buy-in from the stakeholder right there.  This is all about Dr. Jones (?) and her project.  If the stakeholder is giving this explanation to another perspective stakeholder, that is going to be a problem.  So, this is Dr. Jones' project?  That's all I could hear.  This is Dr. Jones' project and you are part of her team instead of being part of "the" team.

Organizer 1:  I see where you are going with this.  We are part of her extended research team and we are trying to help move this whole thing forward in a way that is responsive to perspective people like us.  That is a really good catch.  Thank you.  That's a good point.  Any other thoughts?  Let me just move on.  We also like to help stakeholders recognize all of the stakeholders connected to a project and show the unique role of each group.  This, I think, gets back to a question that was raised earlier about who has the final say and is this group a gatekeeper group.  So, we show a diagram like this one so stakeholders can actually visualize where they fit into the project and they can see that their input is just one of several voices that the lead researcher at the center has to take into account.  And it really does help clarify that, again, on the projects we have worked on, the buck really stops with the lead researcher.  He or she has to make final decisions for the project.  Are there any comments or questions about what you think about using this diagram, or could you imagine using something like this?

Participant:  (Inaudible).

Participant:  I have a question.  What about the idea of having the arrows both ways, so it is two-way communication?  It is not just input coming into the researcher ... (inaudible).  A lot of times there is not feedback about why certain decisions have to be made.  So, the community understands and feels respected that their input was used in some way ... (inaudible).

Participant:  So, I will criticize myself first.  (Inaudible).

Organizer 2:  Well, to be fair, we actually had to resize that bubble in order to get the lead researcher all on one thing so we didn't end up with ... and actually, we tailored this for a particular project.  So, depending on who it is, and their outlook and their values and their personality and their project, we have done a hundred iterations of this.  Actually, our favorite one is a wheel, so there is a sense that nothing really moves forward unless all three of these (or however many ... some people have 8 to 10 circles around them, depending on how many multi-sites they have or whatever), but the idea is that this doesn't work unless everything is working together and we are all communicating and it is moving forward.  You point is sort of - what is at the heart of it?

Participant:  Yeah.  The funder doesn't answer to the researcher.  The researcher answers to the funder.

Organizer 2:  Okay.  Well, this is just something to tweak.  The idea for us is that we have encountered the experience where patient stakeholders think because they have been recruited as patient advisors, that they get the last say.  There is a lot of disillusionment and real disappointment, and then back to that whole trust issue, when people find out somewhere along in the game - uh-oh, no, actually our voice isn't the only voice, or the most important voice, or the final voice.  So, we actually think it is kind of important to be up front so that people's expectations can be accurate and people don't have that crushing sense that, oh my gosh, I've been suckered in again.

Participant:  We just completed an Alzheimer's research project with University of Illinois, and when we started, we used the word "Alzheimer" as a project title.  Well, we got a lot of push-back from it because of the stigmatism.  We did not know that when we first started.  The lead researcher had to go back to NIH and say, "Can we change the name because the stakeholders do have a big voice in it."  If the stakeholders don't agree, you will not have a project.

Organizer 1:  That's a great example.

Organizer 2:  We have another example of that exact example a few slides later.

Participant:  The stakeholders can have a big say-so.

Organizer 1:  No.  They certainly can, and you want that.  But whatever the reality is for your project, just be transparent.  Don't bring people in and not be transparent.  Transparency is just really important in our book.

Participant:  I was just wondering why we wouldn't use the same organizational chart that would be used for the professionals in the study ... (inaudible) ... like institutionally, and have the stakeholder advisory committee represented there.

Organizer 2:  In our experience, our community-based groups were recruited by staff at community centers.  So, the people on our CRDS groups are people that use the parenting programs, who use the senior meal programs, who use women’s support groups.  In our experience, if we presented an organizational chart to a lot of our constituents, people would not have a context for what they are looking at.

Participant:  I mean for the studies ... (inaudible).

Organizer 1:  It is totally a choice, and I think, for us, it is the idea that this seems a little less hierarchical, and it seems to imply, and in our experience, this is our value, but we are all in this together.  Now, somebody has to make a final decision.  That is just a reality.  This is not a communist project.  Somebody has to make the final decision.  That is just the way it is.  But the hierarchical chart to me just feels a little bit top-heavy, but that is a choice.

Organizer 2:  These comments are really helpful about some possibly misleading things in the diagram, ways to change it, ways to make it look like it is more of a level playing field.

Organizer 1:  We will take one more and then we should move on.

Participant:  (Inaudible).

Organizer 1:  Alright.  So, let's move on to Item 4 in your agenda, The Effective Feedback.  I think we mentioned this earlier.  As all of you know, it is not enough to just get a group of people together say, "Please give us effective feedback."  What does that mean?  That is what we talked about earlier.  What does that even look like?  So, in our experience, we found that a short skit can help people hear what effective feedback on a research material actually sounds like.  So, in the next few minutes, we would like you to put yourselves in the shoes of a patient stakeholder at an orientation with the two of us.  So, we are going to put on our facilitator hats, and don't worry - we don't actually wear these.  We are at an orientation now.  We have our facilitator hats on.  You are the stakeholders at the orientation.  So, this is what we might do.  At our future PAC meetings with this group, Betty and I are going to be asking for your feedback on materials, like this recruitment letter.  So, let's just read the main paragraph together.  Two researchers at the UW-Madison, Dr. Jackson and Gomez, are studying the impact of heart failure on cognitive function.  We are recruiting individuals over age 65 who have a diagnosis of heart failure.  Research participants will undergo annual neuropsychological testing and brain MRI.  The total time of participation will be three hours.  So, now Betty and I are going to play members of the PAC who are going to give feedback on this letter, because you may wonder - what are we looking for from you guys?  So, as you listen and watch this skit, just think about the different ways that Betty and I give feedback on this letter, and after the skit, we will talk about how effective you think our feedback was and how it made you feel.  Well, here is my first thought - if I opened this at home, I would probably throw it out before I read it, because without any kind of logo to tell me that this project is connected with the University, I think I would just think it was a scam.

Organizer 2:  I don't know.  To me, a letter is a letter.

Organizer 1:  Well, if I can just say, I really don't understand that first sentence.  "Cognition" is not a word that I normally use, and it really doesn't help me understand what this study is about.  Repeating the words "heart failure," that is a little scary.  Just reading that twice makes me feel like my heart is failing.  I just wonder - could you say "heart disease" or something like that instead?

Organizer 2:  Well, I don't think that sounds scary at all.  I am interested in science and took a lot of science classes in college and did really well in those subjects.  I thought about going on in a mental profession at one point, so science just comes naturally to me.

Organizer 1:  Okay.  Well, maybe the letter could just explain what "cognition" is.  Again, maybe it is just me, but I actually don't know what neuropsychological testing means.

Organizer 2:  Well, my mom was a nurse, so I am used to hearing a lot of medical words and I grew up around a lot of medical people, so I am totally comfortable in a medical setting.

Organizer 1:  Well, I think that's cool that you are so comfortable with that kind of language.  I wish I was, too, but those technical words, they honestly put me off, and I don't think I am alone.  I think that medical jargon can be scary and it can turn people off.

Organizer 2:  Well, I don't think you should dumb down research.

Organizer 1:  Okay.  Well, I did wonder about something else.  The letter says that the total time is three hours.  I don't get that.  Does it mean it is three hours for one visit?  Does it mean you have to go to a bunch of shorter visits that add up to three hours?  I have heard that research projects can take a lot more time than you expect, so I think it would be helpful to give more details about the actual time the study requires.

Organizer 2:  I don't think that information about total time is confusing at all.  Three hours is three hours.  I think people are interested in medical research or they are not.

Organizer 1:  Okay.  Stay in the mind of a PAC member.  You are at the orientation.  You just observed this skit.  So, what stood out to you about the feedback that they gave on this letter?

Participant:  (Inaudible) ... reflected real life.  It was tangible and specific.  It was practical advice.

Participant:  It is truly reflective of perspective of somebody who would be on the other side of that.

Organizer 1:  Other comments?  What did you think about the way she presented her comments?

Participant:  (Inaudible).

Organizer 1:  So, eager interest.  On the dark side, what did you think of my feedback?

Participant:  You were a blow-hard.

Organizer 1:  I was a blow-hard.  It comes naturally.  What else?

Participant:  Dismissive.

Participant:  You were vague.

Organizer 1:  I was vague in contrast to Gaye, who had these specific comments.

Participant:  (Inaudible).

Organizer 1:  Exactly.  One of the big contrasts here is that Gaye used her personal experience in a really effective way.  It was specific.  I "blew hard" about my background, but in a way, that was completely irrelevant for the project.

Participant:  This is a comment.  Most of the PACs that I have served on, there has been one ... I don't like to use the word "blow-hard," but coming from a psychological perspective, you've got to understand that the letter made the person feel good about what they knew already.  That doesn't mean to discount what they knew, but just understand that is the framework that they come to the PAC, but it doesn't frame the PAC for everybody.

Organizer 1:  Our hats are off now, and you can step out of the shoes of the person who just witnessed this skit.  What do you think about this activity for an orientation activity?  Any other comments on its usefulness for orienting patient stakeholders to their goals on a research project?

Participant:  I'm not so sure about how I feel about ... (inaudible).

Organizer 1:  You are raising a big issue for doing any of this work, which is the skills and attitude of the facilitator.  We are not really addressing that today, but it is a huge point.

Participant:  (Inaudible).  I wonder if I were a part of the PAC and I saw myself being reflected in one of those ... (inaudible) ... how I would feel.  So, that's why I caution.

Organizer 1:  Ohhh.  Well, what I can tell you is this is one of the pieces of our orientation that routinely evokes laughter because people see that I am a stereotype and they seem to automatically recognize that she is trying, but she is taking things too far.  This is something that always evokes laughter, and people have a lot of comments afterward.  The exact same thing that you just did plays out ... what really worked well with Gaye, what didn't work so well with me - it really seems to resonate with people.

Organizer 2:  Can I just say something?  We have been doing this a lot, and I have never heard Betty say before "the dark side."  We would actually never say that.  In an actual orientation, we would just say, "What did you think of this?  What did you think of that?"  The fact is that sometimes they will say, "I loved it how Betty just told it like it is."  You want to know that.  You want to affirm that.  As you said, sometimes people either identify with it, or there may be times that you may have people like that, and you don't want them to feel ashamed or bad that it is their style.  In fact, it is kind of good for a facilitator to get that queue up front, like, "Okay, now I have a sense of what we have going on here."  It is actually very helpful.  Did you have a comment?

Participant:  I like the idea of this exercise.  I also have found that we, as facilitators, don't have a good sense of how we want feedback or what the full expectations are around feedback.  So, it is helpful to think about how to address that at the beginning.  It still feels maybe a little "top-down" to me.  I wonder if we would envision a way to allow the stakeholders, or the patients, to share how feedback should be provided and how they want to influence the project.

Organizer 1:  That's a great idea.  If, for this 90-minute presentation, one of the things we didn't include on the 90-minute agenda is exactly what you are talking about.  It is a discussion on giving feedback.  So, we ask people to think about their life roles, their roles as a parent, as a sister or brother, their work roles.  Think about the kind of feedback that you get and what works for you?  What is the kind of feedback that is useful to you?  We actually have people do a self-reflection so that they can think - oh, how do I like feedback given to me?  Then, we can talk more about the kind of feedback that we want to support in this group so that when researchers come here, we are using the same kind of feedback and we are delivering the same kind of feedback that I, myself, would like to get if someone was giving me feedback.

Organizer 2:  Yes?  One more, and then we need to move on.

Participant:  (Inaudible).

Organizer 2:  Oh, okay.

Organizer 1:  That's really helpful.  You don't want it to feel like it is personality-driven.  So, just to close this ... we always close this activity by saying, "The most important takeaways are that effective feedback is specific, it is respectful, and it is relevant."  So, we usually have a handout that has those three.  We don't usually have quit this much conversation about usefulness as an orientation activity.  We go straight into that being the summary of that particular item.  So, let's look at Item 5 in the Orientation Agenda.  This is Giving Feedback on Research Materials.  So, at orientation, you want to give people a feel for the actual work they'll do.  We have discussed that.  And giving feedback on research materials or plans is likely what your patient stakeholders will do at every meeting.  So, at orientation, give them a chance to try it out.  So, you can talk with stakeholders about a variety of materials, and this slide displays a few examples.  One activity we think works well at orientation is the last example - Giving Project Names.  Someone raised this issue earlier.  So, let's look at an example.  Gaye and I are putting on our facilitator hats again, and you step back into the shoes of a stakeholder at orientation.  So, we would like your help with a brainstorming activity.  This is the official name of our project - "Behavioral and Neurochemical Effects of Mindfulness-Based Strategies on Intermittent Excessive Sucrose Intake."  Just a review - our project is testing some mindfulness strategies that people can use when they are traveling or attending conferences.  Researchers hope these strategies will help people avoid too many sugary foods.  So, our team wants something more straightforward that we can use when we are describing our project to the public.  We would love to come up with a name that has a catchy abbreviation, and we've got a few ideas.  We would like to hear your ideas and we would like to hear your responses to these names.  So, here are just a list of names that we have come up with:  1) "Mindfulness to Unlock Conference Health, or MUNCH," 2) "Tips for Healthy Indulging at Conferences, THINC," 3) "Travelers Resources to Access Mindfulness Practices, TRAMP."  We don't really have time to do this as a whole group, so we will take our hats off, and let's just talk about the process that Betty and I would use to get feedback from patient advisors on names like these.

Organizer 2:  So, we would go through the names one-by-one, starting with MUNCH.  What do you think of the name in short version?  Does the name make sense to you?  Does it make you want to join the study?  Is there anything that you don't like about the name or short version?  So, after we've gone through those discussion questions for every item on the list, then we would ask people if they have any new names of their own to add.  Sometimes after creating a new list with narrowed versions, then we ask people to vote.  We would go, "Do you have a favorite on this list?"  We have used this process several times to help projects come away with a more public-facing, friendly name for their project.

Participant:  What about doing it in reverse as far as having them generate lists first ... (inaudible).

Organizer 1:  That certainly is one possibility.  It kind of depends on what group you are working with.  Sometimes people need a little ... you need to kind of seed the ground, sow the seeds.  Anyway, you need to give people ideas, because sometimes just to say, "What do you think," people are like, "Well, what do you want?"  So, you don't want to give people 10 examples, but sometimes just to offer a few can get the creative juices going, like, okay, I see where we are going.

Participant:  Well, maybe give one example.

Organizer 1:  That is absolutely right, sure.  We just happened to have three that we thought were really fun.  I came up with 10, and Betty was like, "You cannot do that."

Organizer 2:  So, just to close the idea, we think it really pays for the research team to come to a meeting like this with plenty of examples, because sometimes we ask hard questions.  You don't want the conversation to dry up because you haven't provided enough stimulus for people.  So, you may need more than one, but certainly, reversing that is a good way to approach this and then have your options ready to go.  So, you are accomplishing two things with this activity.  You are giving some very useful information to the research team that they can act on promptly, and so you will be quickly closing that feedback loop, and you are giving your patient advisors a real taste of the work they'll do at meetings - how they'll work with you and how they'll work with each other.

Organizer 1:  So, this is the last orientation item that we want to highlight.  It is #6 on the agenda.  We talked a little bit about the PAC meeting process where you would cover a lot of the details, but what we want to focus on is the membership agreement.  So, in your packet, you should have a form that looks like this.  This is a template.  A membership agreement is honestly something that we didn't think about when we first started the CRDS several years ago.  We developed it because we realized that we needed something that clearly describes what stakeholders can expect from us and what expect from them.  At this point, we regularly use a form like this and we recommend it to other researchers who develop patient advisory groups.  So, what we'd like to do is if you could just take a minute to read the agreement and then we will just discuss these questions.  So, just take a minute, and then pencils down and heads up when you're done reading, and we will talk about these questions.  So, again, this is just the template.  The details are subject to personalization, tailored to your particular project.  But just in general, what do you think?  Can you see yourselves using something like this, or why, or why not?  Any thoughts?

Participant:  (Inaudible).

Organizer 1:  I don't know if you can hear what she was saying.  Even if you've known people for years, it can be helpful to actually put something down on paper.

Participant:  (Inaudible).

Organizer 1:  Okay.  So, in the part where you have "name" and "contact information," give them a chance to say, "Circle up," or how do you really want us to contact you?

Participant:  (Inaudible).

Organizer 1:  Well, there is one line - "I understand my responsibility to protect the confidentiality of PAC members."

Participant:  Those are members.  That is not about the confidentiality ... (inaudible).

Organizer 1:  Oh, I get what you are saying.  Yeah, that again, is certainly dependent upon your project.  Often, we deal with that at more meeting-by-meeting basis, because lots of times there are things that you actually want people to go out and talk about, but then other times it is just like - this is just a draft and we really don't want you to talk about anything.  So, we say we are handing out this piece of paper to get comments, but then we are going to be collecting this at the end and asking you please not to talk about it.  So, we usually handle that more on a case-by-case, meeting-by-meeting, but if you know that applies to your whole project, then that would definitely be something you would want to put in.

Participant:  It might be helpful to have something about dissemination, so articulate the responsibilities ... (inaudible).

Organizer 1:  Okay.  So, that could be an item that you'd add, too, in terms of what an expectation might be.  We've got some ideas of things that you could change.

Participant:  I think this is wonderful.  I might add ... (inaudible) ... purpose of the PAC.

Organizer 2:  The purpose of the PAC.

Organizer 1:  Okay.  That's a great idea - add a statement right at the top or someplace kind of underscoring why we are here, what is the point of this at all, yes.

Participant:  I have a question that is somewhere relevant, but I see that one of the things is ... (inaudible).  I have a stakeholder right now who refuses to be compensated, even though she is not ... (inaudible).  I guess I am putting this off to the group, if there is a value around expectation about accepting compensation.

Organizer 2:  We wish we had time for a 90-minute on just compensation.

Participant:  I run into that all the time ... (inaudible).

Organizer 1:  I don't think you can force people, but certainly, we would totally agree with you - we have to offer.

Organizer 2:  Sometimes we encourage people - well, if you don't want it for yourself, maybe there is a charity that you'd like to donate it to.  Maybe you'd like to give it to the Food Pantry or community center to buy more meals.  Those are other thoughts.

Participant:  (Inaudible).

Organizer 1:  So, I guess just one thing I want to say about the membership agreement - in our experience, it is actually very rare that you have a serious problem with a stakeholder.  I mean, it just doesn't happen that often.  Maybe we have just been lucky.  But every once in a while, you will have somebody who just consistently misses meetings or does violate the confidentiality of somebody else in the group or maybe as what you have set up as an expectation to protect the confidentiality of materials.  And what we have found is an agreement like this can just be so helpful as a tool for reviewing the respective responsibilities that we all agreed to, and just to help frame a really respectful discussion about what is not going well.  So, we have just found that this can be so helpful in warding off those problems when they do crop up.  I just want to remind folks that we ran late on the previous session, so we have about another 14 minutes here.  You don't have to run off at 11:00.  Okay.  So, you've gotten your stakeholders through the orientation meeting, and hopefully they did all sign the membership agreement and are ready to roll.  So, this is where it is all smooth sailing, right!?  Oh, gosh no.  Remember that second problem that we mentioned - incomplete planning for stakeholder meetings.  It is time to talk a little bit about that and just as the CPPH (?) person mentioned, it is important to start with some basic principles, and these are some that Betty and I use to guide our planning for every stakeholder meeting, and you probably have others that are important to you.  But as we mentioned earlier, the unique contribution of stakeholders is their own life experience, and they bring that to every meeting.  We feel like it is our job to construct a meeting agenda so that stakeholders can use that expertise to help us.  As researchers and clinicians were trained to be impersonal and objective (that is pounded into us), stakeholders are not patients and they are not research subjects, and in our experience, we feel like effective work with stakeholders does mean allowing ourselves to get a little personal, even if it just means before or after meetings taking time to talk with people about important life events, their family, and then remembering that from meeting to meeting.  Betty and I are big fans of plain language, and I think several people have commented on that - communication that members of your target audience can understand the first time they hear or read it.  We just love that, because it puts the responsibility for communication squarely on our shoulders.  It is our job to use language that our stakeholders can understand the first time, and it also means making it 100% okay for people to call us on using confusing words, technical language, jargon, weird acronyms and all that.  Finally, we are huge believers in fun.  We don't think that meetings should be a time of endless reports and updates and constant passive listening.  So, in that spirit, please raise your hand if you have a birthday in a month that either begins with the letter "F" or "O."  Do we have any February or October birthdays?  That is alright.  Well, we are going to move on.  We brought from Madison, Wisconsin, the very best dark chocolate that exists in Madison.  Betty kept trying to say "Mebruary" or "Moctober," because her birthday is in May.  How about May?  Do we have any May birthdays?  Alright.  Do we have any July birthdays?  We've got two more.  The point of this obviously is it is okay to have fun.  You want stakeholders to feel good about coming to meetings and you want them to want to come back.  Really, the bottom line of this whole slide is just - be really explicit with your research team.  What are your principles?  What is important to you?  Make sure you check yourself.  Make sure those are what is guiding your meeting preparation.  So, raise your hand if you have been to a meeting that you thought was not the best use of your time.  So, if meetings are part of our professional responsibilities, we show up, right?  And we will continue to show up.  But for patient stakeholders, coming to meetings with you is a choice, and if meetings feel aimless or boring, people will not come.  So, it is our responsibility to make every meeting count, and doing that takes some preparation.  So, in your packet, you have an agenda template for a standard meeting.  So, we've moved past orientation, and this is a template for a standard meeting of an ongoing PAC.  So, we recommend using standard agenda like this at every meeting so the patient stakeholders come to know what to expect.  We always start with a warm welcome and a fun opening question and then a brief review of the agenda.  We are going to give you a few tips for items 3 and 5 on this agenda.  So, the third item is how the advisory group is making a difference.  This has come up earlier this morning.  We have interviewed dozens of stakeholders over the past few years about their experiences on patient advisory boards, and one thing that consistently stands out is that stakeholders want to know how the research team is using their input.  They want to know that what they do at meetings actually makes a difference. For most stakeholders, making a difference is the whole point of participating on a patient advisory committee.  So, let's look at an example of how you could show stakeholders that they are making a difference.  In your packet, you have this example with a few more details filled in.  So, this is a document that you would prepare after a patient advisory committee meeting, and then share at your next meeting with your patient advisors.  So, in the first column, the research team briefly describes one or two major topics from the meeting.  In the second column, you give a very short summary of the key feedback from your patient advisors, just a quick summary, and then in the third column, you explain the impact of that feedback - what is the research team doing with the feedback that they collected at the previous meeting.  We refer to this as "closing the loop."  I used that phrase earlier.  Anytime you ask stakeholders for input, let them know how you used it.  Does anyone have any questions about using a tool like this or using anything similar?

Participant:  (Inaudible).

Organizer 1:  We also work with teams and have one internal document that might be much more detailed and have a lot more of the jargon shorthand, and then one for your group, depending on what the group is, that is maybe a little snip-snappier.  So, we should probably move on.  So, the heart of any stakeholder meeting is, of course, the feedback that your team wants on research issues or materials.  So, please look at the WNRS Tip Sheet in your packet.  It is for the end, and this outlines six of the key steps that we have learned from planning over 200 meetings between researchers and stakeholders, and it starts with picking the right material to bring.  So, what is the right material?  What does that mean?  It means only bring things that can be changed.  That is number one.  If you are not going to be able to use the input from your stakeholders, don't ask for it.  Number two, it means bring a realistic amount of work, based on the length of your meeting.  It is so much better to do less and do it more thoroughly than to try to do too much and have everyone feel rushed and frustrated.  It also means bringing material that is appropriate for the stakeholder group.  Just know your audience.  A scientific colleague can give you feedback on a scientific abstract.  A patient advisory group can give you great feedback on a Lai summary or PR for your material.  So, just know your audience.  So, the second point is - be clear about what you want to learn from the group, and make sure you've prepared, in advance, questions that will get you the information you really want.  So, these are the thoughts and questions, the followups, the prompts.  The third point is - provide context.  Set the stage so that everyone understands the context for the materials that you are asking them to review.  So, for example, if you are asking for feedback on a recruitment brochure, describe where people are actually going to be when they see the brochure.  Will they be in a clinic with their doctor?  Will it be sent to them at home where they are reading it by themselves?  That context makes such a difference, and you are going to get much more specific and useful feedback if you give people that details.  Fourth is - break the material down into bite-sized chunks.  If you have a long document for your stakeholders to review, don't just hand it out and say, "What do you think!?"  People will start jumping in with comments that are all over the document, and frankly, it is just darn confusing for everyone.  Chunk it down.  Focus on a few sentences at a time so that everyone is giving feedback on the same section.  In groups where people may have different reading speeds or abilities, which honestly, I think we can say is almost every group, we recommend that you read material aloud.  First of all, everybody hears it at the same time, but even more than that, just reading things aloud often reveals some problems and issues that just aren't obvious when our eyes skip along reading.  Last, we recommend using two facilitators at stakeholder meetings.  We think that it is helpful to have one person facilitate the discussion questions and another taking notes on the flip chart like we were here.  Betty and I just love using flip charts so that everyone can see that their comments are recorded and are heard, and if there is anything wrong, they have a chance to correct it.  You don't walk away with - oh, I heard this, and then they say, no, that's not what I said at all.  Finally, the research team actually gets a written record of the feedback.  So, these are just six major steps that we use and we know others here have lots of other experience and tips, and maybe at the end of the meeting, we can share some of those, or at the end of this session if we have some time.  So, let's move on.

Organizer 2:  So, just a few quick comments on sustaining engagement.  We've heard a lot from stakeholders over the past seven years about why they keep coming to meetings, what matters to them, and here are a few things we've learned.  People stay engaged when they feel valued.  How do you help people feel valued?  Record their comments on a flip chart.  Give them a handout like that table of how the PAC makes a difference.  People want to feel connected to each other, so have a consistent membership in your group rather than rotating people in and out all the time.  Consistency helps to build connections and relationships.  Gaye mentioned this earlier - make a conscious effort to know important personal milestones for your members and recognize them routinely.  Finally, people will stick with your project if it is easy to participate.  Pick a meeting location that is comfortable and friendly for your members.  Settings like libraries, community centers and community clinics are often much preferable to an academic setting.  And whenever possible, help people with their personal costs related to transportation or childcare.

Organizer 1:  Alright.  So, we have a few engagement resources.  We would love to follow up with you about anything we have talked about today.  So, in your packet is a WNRS Resource Page, and a good place to start is our website where you can see our toolkits.  We have two, and our articles, and we have copies of our articles with us, too, if that is of interest.  We would like to encourage you to sign up for our monthly newsletter, the WNRS Wire, and obviously it is free.  Just as a little teaser, Betty and I just got a grant this summer to develop a new and improved stakeholder orientation toolkit, and if you subscribe to WNRS Wire, you can find out when that will be available, and we like to publish a lot of other useful resources, too.

Organizer 2:  And we will be using some of your feedback to tweak that toolkit.

Organizer 1:  We would love more Twitter followers, and we would love to follow you back.  So, feel free to follow us on Twitter.  I think the last thing in the packet is - if you do plan to use or adapt any of our materials, and we really hope you will, we have included a handout about how to cite us.  Speaking of citing, we would like to cite our funders and acknowledge the people who make our work possible back in Wisconsin and we would like to thank you.

Organizer 2:  Thank you all.