

## Community-Based Participatory Research: Lessons for Stakeholder Engagement in Patient-Centered Outcomes Research

### Transcript

MS. PENNY MOHR: Good afternoon. This is Penny Mohr, and I'm the senior vice president of program development at the Center for Medical Technology Policy. It's my pleasure today to welcome you to the webcast sponsored by the Agency for Healthcare Research and Quality Effective Health Care Program that's titled Community Based Participatory Research Lessons for Stakeholder Engagement in Patient Centered Outcomes Research. We have a wonderful turnout today with over 260 people participating by phone. Just a brief word about our sponsorship for our webcast today, it was funded as part of the AHRQ's Community Forum Project for which I am a subcontractor. The Community Forum is charged with working with AHRQ's Effective Health Care Program components to expand stakeholder involvement in research processes and activities.

By stakeholder we mean the broad array of groups with a vested interest in outcomes of comparative effectiveness research or patient centered outcomes research such as patients, clinicians, payers, policy makers, and healthcare administrators. They are also developing and testing methods for gathering public input on value based healthcare questions. That said the presentation and panel discussion that we're going to have today does not represent the official policy of either AHRQ or the U.S. Department of Health and Human Services. I also want to note today that we're recording the webcast and it will be made available on the Effective Health Care Program website for your review for you to pass on to those who are not able to attend today.

Before we begin I'd like to set the stage for why we felt this was an important webcast to host. Community Based Participatory Research or CBPR has a rich history of community engagement that reaches back almost a half a century. Meanwhile a fundamental feature of Patient Centered Outcomes Research or PCOR, which has only recently entered our lexicon, is the engagement of users of research in research in helping to select priorities, designing and implementing research and translating and communicating the findings. Given that researchers involved in both fields interact infrequently we thought it would be terrific to host a dialog between experts in both fields to talk about some of the relevant lessons.

Today we're hoping to bring together experts to discuss some of the lessons from CBPR and how can it enhance stakeholder engagement in PCOR, and to encourage a greater dialog and resource sharing between the CBPR and PCOR research communities going forward. I'm thrilled today to introduce our panelists. We have an absolutely expert and excellent panel joining us today. Ms. Pat Deverka is a senior research director from the Center for Medical Technology Policy and she has led CMTP's efforts to develop and test robust methods for involving stakeholders across a variety of PCOR applications and has published extensively in that area. She oversees CMTP's Patient and Consumer Advisory Committee which provides ongoing advice about how to more effectively engage patients and consumers in CER, and they have contributed to the development of principles in stakeholder engagement in PCOR in a conceptual framework which she is going to be sharing today.

Another of our PCOR experts is Dr. Dan Mullins. He is a professor in the Pharmaceutical Health Services Research Department at the University of Maryland School of Pharmacy. His research has used both aspects of CBPR and PCOR. He is serving as the principle investigator for a PCOR contract to enhance methods for engaging hard to reach populations in PCOR, and as a recipient of one of six NHCER methods development grants examining ways to improve the efficiency of clinical trials. In addition to his research as PI Daniel has been responsible for the evaluation of components of a number of community based interventions for other PI grants including an NHLDI grant aimed at reducing hypertension among black males and a current state of Maryland grant to create a health enterprise zone in west Baltimore to reduce cardiovascular health disparities.

Ms. Dwyane Monroe brings the patient perspectives to this dialog. She is living with diabetes and hypertension both and she's also a community outreach trainer and advocate and facilitates the Community Health Action Team in Baltimore. She has experience with CBPR directly with working with Johns Hopkins University in chronic disease management, and also has been a community advisor for Dr. Mullins grant which I mentioned previously for PCOR. Our experts in CBPR include Dr. Madeleine Shalowitz who is the director of health services research and section head for child and family health studies for NorthShore Research Institute, which is an affiliate of NorthShore University Health Systems, and integrated health system serving the Chicago area. She's an experienced health services research specifically in reducing health disparities in pediatric and maternal health and she also brings a perspective of working through NorthShore's Community Health Hospital Community Benefits program to improve public health in the community. She's also the lead author of an AHRQ's funded review of the literature on strategies for community engagement with CPDR.

Dr. Nina Wallerstein is professor in the department of family and community medicine at the University of New Mexico School of Medicine and director of the university's Center for Participatory Research and director of the community engagement and research component of the clinical translational science center. She has 25 years of CBPR research experience and her work is focused on developing culturally centered research in tribal communities.

Our agenda for today's webcast will be a little bit innovative and highly interactive. We are engaging people in a dialog and have set this up as a conversation among the panelists. We're going to begin with a short didactic presentation from our CBPR experts Dr. Nina Wallerstein and Dr. Shalowitz giving us an idea about an overview of CBPR and it's use in health system settings, and Dr. Pat Deverka will provide an introduction to stakeholder engagement in PCOR. Next we're going to move into an open dialog across our panelists about some of the similarities and dissimilarities between CBPR and stakeholder engagement in PCOR, and some of the lessons that we might learn. We've reserved a portion of the webinar at the end to focus on the specific issue of how to engage under represented populations, and I'll be calling on two of our panelists, specifically Dr. Mullins and also Dr. Shalowitz, Dr. Wallerstein to discuss the issue of how to engage under represented populations, and we will also be asking for Dwyane to provide a patient perspective throughout and we'll ask her to be a reactant through the different discussions that we will be having today.

I would like to point out that there is also a 15 minute Q&A period at the end of the webinar. If you could we would like to make sure that this is interactive so if you could use the chat feature you could type in and submit your questions as we go through this webinar and then the webinar facilitator will share your question with the audience and ask the speakers to respond at the end. We'll do our best to respond to everyone but our time is limited and we'll follow up with any questions that we're unable to address after the webinar has concluded. Without further adieu it's my pleasure to turn this over to Dr. Nina Wallerstein to provide you with an introduction to CBPR. Nina?

## Community Based Participatory Research: Principles and Conceptual Framework

DR. NINA WALLERSTEIN: Thank you so much. I was asked to basically set the stage of the principles and framework for CBPR so I want to start with the definition. As we all know W.K. Kellogg Foundation CBPR definition has been highly used as a collaborative approach equitably involving all partners using and benefiting from community partners strength and starting with a research topic of importance to the community with the goal of improving community health and improving health equity as a key action orientation to this research process. It's based on looking at CBPR as part of the continuum engagement. Often we do research which is on communities or sometimes in community settings in clinical practice settings for example, but to move towards the CBPR perspective we have to ask the question how much are we involving our community members in a with perspective? How much are we working with community members, with community agencies, with community providers rather than on them with our own determined agenda?

CBPR has a set of principles that will be useful to looking at PCOR research recognizing the community's idea of identity, a long term commitment approach, balancing research and action. In my own experience with tribal communities I recognize the importance of working under tribal sovereignty where tribal governments have the authority to approve you being on the...to work with that community and also to approve any kind of data that will be published. They own the data and although most communities may not most people on this telephone call or conference may not be actually working with tribal communities. These ethical principles of working with community members as colleagues and co-publishers and co-sharing those kind of data in a very genuine way I think has applicability for all communities these tribal principles. I wanted to share with you today mostly this conceptual model that colleagues and I in a three part partnership have been developing. It's an NIH study from the last we're on our fourth year. That is a collegial partnership with ourselves at the University of New Mexico, the University of Washington, and the National Congress of American Indian Policy Research Center in developing this model that I think would be useful not just for CBPR but for PCOR processes as well, and let me just walk you through it. It starts at the left side, looks complicated but it's very straightforward. We all live and do our research in a context whether it's the social economic context, a historic collaboration context of the relationship between the clinical setting and the health setting or the university and the community setting and the university, the capacity of the community, even the university capacity to engage in CBPR or community engaged research.

That context sets the stage for whatever partnership is developed whether there are agency members involved, community members, CBOs, clinical providers, academics, and those partnering processes are both based on decision making and relationships and how you work well together, the trust that evolves but also the structure. What are the guidelines, the norms, the memory [phonetic] end of the agreement? The essence of this model is if you have community partnership of some sort it will change and inform the research, which moves you to the next oval. It will change the intervention. It will change the understanding of how this fits within the culture and organizational context and climate, a lot of the implementation science agenda comes right in here of the context, and that change will then inform a set of outcomes that might be not just only improved research outcomes but also greater capacity of the clinical setting or the community setting, policies that may improve health at a larger level capacity, et cetera.

This model of engagement we expect and hope could be useful in thinking about PCOR. Let me just take you through a few more examples of how we use this model to set up metrics and measures of partnering asking the question of how do you know if you have an effective partnership that's going to make a change in our outcome. This as I said is a research for improved health study. We've been testing the model. We've developed a literature review of existing measurement tools, but we developed our own instruments bringing together the best skills we could of the country that we found and develop new ones to do a data collection of close to 300 partnerships in an internet survey and some in depth case studies, and I want to share with you just a few metrics and measures out of our research and we'll be able to get these access to these instruments, et cetera, through these websites when you get off this webinar.

Just some examples, we have examples of community capacity context. You can see the number is the number of questions within scales. We have found that through our beginning analysis of our data over the partnerships that we've collected data from that alignment with the principles that if the partners are aligned with their values and principles it actually is associated with better outcomes, power dynamics, how much that's shared, the process of dialog and listening, how much the partners involved in different aspects of the research, not just the design and the research design or the questions but in the data collection, in the data analysis which of course you have different roles of partners but most importantly the data interpretation and the usefulness of this back to the community as well as to the clinical setting, and then of course trust is a major element of how partnerships work together so those are some skills that should be available to you.

We also have found that if those partnership dynamics are working well then there will be impact on set of proximal outcomes of partnership synergy and cultural centeredness of the work itself as well as some more distal outcomes of improved personal and professional levels outcomes of the partners themselves, and then concrete changes in community policy level outcomes, improved services and health improvement. We have measures as well of these outcomes. Finally I just want to give you two examples of what these very important measures mean. This is an example of cultural centeredness which says in this case this is a billboard on the Navajo nation. Have you noticed a change in your harmony, breath, energy? It may be TB

shows that you need cultural sensitiveness. This is not a billboard you would find in New York City. This could only be a billboard for the Navajo nation and that's for any of our interventions. How to think about what does it mean to be doing it within this context, this clinical context or even this community context, and finally just a short showing you of our metrics of trust. We've developed this hipology that goes from no trust up through what we call critical reflective trust, and we've been looking at how trust both can be nurtured and can grow within a partnership and just to finish these metrics we suggest and measures could be used with all members of a partnership to be able to assess how much they're in alignment with each other, what's the level of trust in this partnership now, where do you want to be in the future, and how for example can you get there, best get there, and given that trust of course we consider an important partnership dynamic for them reaching the kind of outcome that might be important not just in a community setting but again through PCOR in the clinical settings as well. With that I'll end and look forward to the dialog. Thank you.

MS. MOHR: Great, thank you very much Nina and I think that it's specifically great that you have these links to resources that are embedded in your slides so that participants will be able to go back on to the AHRQ website and find this material. I'd like to move now to Madeleine Shalowitz who's going to be talking about her specific experience working within an integrated health system and using CBPR. Thank you, Madeleine.

## **CBPR Value System for Program Development, Evaluation and Information Sharing in a Health System Environment**

DR. MADELEINE SHALOWITZ: The purpose of this transition is to move from the community setting to a healthcare setting and harness community wisdom in a somewhat different way to the academic rigor of the medical environment, and in that regard I'd like to acknowledge my academic partner and affiliation in this which is the University of Chicago because the CTSA at the University of Chicago has been really supportive of the work that I'm going to be showing you, and the health services research background that I bring to this is now being applied in the Center for Clinical Research Informatics at NorthShore. What Nina presented to you is a very balanced view of community and researchers, but really in a health system the balance is very different. The health system is very concerned about it's patients and also about those who pay the bills, the payers, but family and cultural in society is rarely if ever considered in traditional medicine, traditional medicine meaning the U.S. healthcare system, not tribal medicine, and perhaps will need to be incorporated more as we look to more integration of health outcomes across sites and services.

I do want to point out to you that more in line with Nina's presentation is that the perspective or the patient or on the pediatrician so you're seeing the perspective of the parent with regards to the child is really about they're alive outside the treatment setting and you'll see that the health system is located at the periphery of their life. Whereas the health system sees itself as the center to the family their lives outside the treatment setting is primary. The program I would like to describe to you is Be Well Lake County which is NorthShore University HealthSystem's signature community program. It is a direct donation from the hospital and various other funders to the Lake County Health Department and it provides comprehensive

diabetes management for adult medically underserved Type 2 diabetics in one of the northern counties of Illinois. It's a partnership between NorthShore University Health System and the Lake County Health Department, which operates five community health centers in Lake County. The purpose of presenting this to you is to show how patient input and provider input has changed the clinical programs that are provided and also change the questions we ask in the evaluation. Clinical program was in fact a collaborative development among NorthShore Community Health Department Service Provider input and data in an iterative process over time. What NorthShore brought to the table was funding for comprehensive primary care visits, medication and testing supply systems because community health systems have so much difficulty with subspecialty care access the NorthShore physicians were provided subspecialty care to the health center patients as part of the proposal, and thirdly in medical nutrition therapy and diabetes education. With patient input—which I'll show you a little bit more about in a minute—over time and through philanthropic funding we've added fitness programs, a community garden and retinal screenings.

One of the concerns of the community is that this diabetes program is housed in a food desert, and so based on provider and patient input we added a food security measure to the standard care, and what we learned was almost 57% of the patients with Type 2 diabetes in Lake County in fact did not have adequate access to food. We asked the question do patients who don't have enough food have worst diabetes control because that certainly makes a whole lot of sense since diabetes involves substantial lifestyle management. I'm showing this to you as a pilot data analysis because I think it's very important to understand that medical care is in a larger context and in fact the community context may influence the outcomes of Cadillac care. In affect this program brought all of these resources to families and essentially eliminated most of the access issues. At the beginning of the program the patients had pretty similar hemoglobin A1Cs but by nine months in the program you can see a diverging difference between those who are food secure and those who are food insecure, insecure is the top curve, and secure is the bottom curve.

In essence those who have food security who have adequate access profited from the program whereas those who are food insecure were not able to do that, the interference with glucose control increased over time. I wanted to present to you a way to bring together all the stakeholders environment and the top part of the slide shows you an organizational structure that I've in fact used and I'm still using with the Lake County Health Department partners in order to run a CBPR program and then I'd like to talk to you about the adaptation to PCOR. You'll see that all of the stakeholders interrelate to one another through two advisory committees. The balance of the advisory committees is different. On one side the community but that has representation from the academic side, and then an academic steering committee with representation from community.

In essence we operate as a complex network so that we make sure that all voices are heard all the time even though the specific agendas might be different. I propose to you that a sample PCOR adaptation might look quite similar where the health system and patients are the primary stakeholders in the center but that we bring in payers and policy makers, family and communities and two way funding and service provision side and then a community advisory

committee in a network model similarly. In summary I think the adaptations for healthcare are clear for CBPR although the overlap is not completely 100%, and with that I'd like to turn back to Penny.

MS. MOHR: Great, thank you very much Madeleine. I just wanted to remind people that we are going to sending out the slides for today's presentation. We've been getting a lot of questions about that at the conclusion of the webinar so you will be getting that everybody who's registered, and without further adieu I'd like to turn this over to Pat to give us her presentation on PCOR and stakeholder engagement.

## **Patient-Centered Outcomes Research and Stakeholder Engagement**

DR. PATRICIA DEVERKA: Thanks Penny. My cast today is to briefly describe the role of stakeholder engagement in patient centered outcomes research, which admittedly has a much shorter track record than CBPR but I believe shares some of this objective. First I'd like to ensure that we're all clear about the relationship between comparative effectiveness research which I refer to on several of my slides and in the reference materials and Patient Centered Outcomes Research or PCOR the focus of today's webinar. On the left hand side of the slide is a familiar Institute of Medicine definition of Comparative Effectiveness Research or CER which is uniquely characterized from other types of clinical research by its purpose which is to provide comparative evidence to help stakeholders make better decisions.

On the right hand side of the slide is a more detailed description of Patient Centered Outcomes Research or PCOR. PCOR I think can be viewed as a subset of CER or more specifically PCOR is comparative effectiveness research focused on and guided by the needs and concerns of patients. Just like CER PCOR requires the active involvement of stakeholders to ensure that the research will meet its stated goals. As you can see from the bullets I've listed patients and other key stakeholders should be actively engaged throughout the research process, which includes the results dissemination phase, an aspect of the research continuum that has traditionally been neglected after scientific publication but is an area of intense research currently.

I think it's important to highlight the context for involving stakeholders in PCOR. There was a great deal of initial enthusiasm I think for stakeholder engagement that was super charged in 2009 with the 1.1 million dollar RF funding for CER. These stakeholder engagement efforts will focus primarily on the areas of priority setting and identifying future research needs, but there are also some examples of involving stakeholders in designing studies. In parallel a number of researchers including our team at CMTF took a step back and evaluated what was working well with the process and what were some of the barriers which I've listed here. Many of these may sound familiar to you and many of these have begun to be systematically addressed by experts in the field but briefly the literature has allowed consistent terminology and definition to stakeholders and allow consistency and processes for stakeholder engagement. There also is a new shared understanding between stakeholders and researchers of what it means to affectively or successfully involve stakeholders in research, primarily stemming from a lack of common principles and best practices but more fundamentally because there is no agreed upon conceptual model for stakeholder engagement in CER.

Perhaps not surprisingly there's limited data regarding the impact of involving the stakeholders in research and systematic evaluation of the process such as we saw described by Nina is rare.

Researchers have an expectation that they often need stakeholder input in projects with short timelines or immediate start dates and it's difficult to coordinate schedules with all relevant stakeholders. There are also extensive training needs for all of the stakeholder's groups and I would put researchers in that category, and so you need to ensure full participation in the meaningful experience for stakeholder engagement which I'm going to define later. All of these issues translate into concerns primarily on the part of researchers and funders. The stakeholder engagement will add time and cost to projects, and without clear measures of impact and effectiveness I'd argue that there's no good way to put these concerns into the proper perspective to assess the true value of stakeholder engagement.

That's why our group of researchers at CMTA undertook an effort to help address some of these barriers as you'll see on the next slide. There's a lot of information here and if you're interested in understanding these concepts in greater detail I've provided a reference to the article that goes into the full background and development of the definitions and conceptual model. In the interest of time I'd like to highlight just a few key points. First given the identified problem of confusing terminology we worked with an advisory group of patient consumers and patient advocates to define what we mean by the term stakeholder. I'd only point out here that our definition includes the notion of communities so there appears to be overlap with the target audience for CBPR. Then after reviewing the literature on deliberative methods and other approaches for engaging stakeholders in research we took the step of defining what we mean by stakeholder engagement and you can see that definition on the lower left hand side of the slide.

Here I'd like to emphasize that after extensive discussion and debate with our advisors and project team we settled on specifying two key aspects of the process. First it actively solicits knowledge, experience, judgment and values of the people that participate therefore we really wanted to signal that each of these sources of information are seen as valuable and desirable for the process. Second that it's focused on two important outcomes that ideally require collaboration to achieve, creating a shared understanding among stakeholders and making decisions that are viewed as actionable and credible to all parties. Again there seems to be overlap with the goals of CBPR although the differences between them appear to occur in how the method for engaging stakeholders translated into practice.

Finally I want to point out that we also recognize the need for a conceptual model for engaging stakeholders so that we could begin to measure the impact at both the level of process outcomes and final or CER outcomes. This model is adapted from the literature on risk based decision making. They use both analytic methods and deliberative methods to inform choices, solve problems, and make stakeholder driven decisions. We felt it was highly relevant to the situation of CER where research experts and non-experts come together to use data, experience, and values combined through a variety of quantitative and qualitative methods to make decisions that ultimately are translated into both immediate project related outcomes or more long term health and policy related outcomes. You'll see in some of the process outcomes notions such as trust, respect, fairness, which appear comparable to some of the concepts covered by Nina. While successfully applied to one three year project this model requires further



testing on a broader range of projects and requires the robust validation of the sort that Nina shared during her remarks.

Nevertheless we feel that agreement regarding the definitions, terminology and conceptualization of stakeholder involvement is essential for understanding the contributions of stakeholders to CER and evaluating the effectiveness of engagement practices. Only then can we measure and evaluate the influence of stakeholders on particular CER projects and using through results to inform process improvements and conceptual model refinements. The next slide provides a graphical depiction of how we currently see stakeholder engagement occurring in practice. While this slide was developed as part of a white paper commissioned by PCORI to describe the international experience with methods for engaging the public and topic generation for research it's useful for describing the continuum of patient or stakeholder engagement in research as well. At the top of the slide is the traditional approach to clinical research where patient representatives are occasionally invited to meetings or asked for input. Here the information flow is primarily from the researchers to the patients. At the level of consultation the information flow is primarily from the patients to the researchers in the form of focus groups or questionnaires or even mediated conversations, but typically patients don't participate in decision making and the goal is not to have the process result in new shared understanding of the issue on the part of both the patients and the researcher.

I call this stakeholder engagement light as there are certainly valid methods for involving patients in the research process through this type of engagement. However, it does not reflect the type of interaction described in our definition. The third level describes two collaborations where the information flow is intended to be bidirectional, and this type of interaction would occur as part of an ongoing relationship where trust would be built over time. Under these circumstances shared understanding and effective decision making would be the result of this true partnership. The highest level of patient involvement indicates the patients actually drive the research agenda and projects and researchers only participate on the requests of the patients. These types of studies are more common in the UK but may become more prevalent over time in the U.S. given recent funding announcements from PCORI for patient powered research networks. Let me stop there and I'll turn it back over to Penny.

### **Similarities and Differences Between CBPR and PCOR**

MS. MOHR: Thank you very much, Pat. That was a lot of great information. At this point in time what I'd like to do is open this up for a little bit of reflection about the similarities and differences between CBPR and PCOR, and I'd like to specifically call on Madeleine. If you could reflect a little bit on your thinking about this question, how are they different and how are they similar?

DR. SHALOWITZ: For me the CBPR value system has the goal of equalizing power across the stakeholders including patients in a bidirectional dialog is very similar in both. It really becomes an issue of how to define community, and one can use any definition around a particular illness or a particular interest in illness in terms of family support. There are many ways that you can design a community but CBPR has traditionally done that outside a treatment setting. PCOR up until this point seems to be using mostly within the treatment setting as the area of interest. The other thing I wanted to comment on is the timeline associated with CBPR

and typically the NIH has tried to invest in these kinds of proposals but they are always surprised about how long it takes to develop the partnerships to mature the products that come out and then to assure sustainability. PCOR is operating on a three year agenda and it will be very difficult for them to adhere to CBPR in a classical sense.

MS. MOHR: Madeleine, I was actually in a discussion with you earlier and you had mentioned—which I thought was very interesting—and I think this was found up in your definition that you talked about being inside of the treatment setting versus outside of the treatment setting, but also being more sort of medical centric, that PCOR is much more medical centric and I'm wondering if you could just comment a little bit on that.

DR. SHALOWITZ: That's in fact true. The calls for proposals are centering on disease diagnoses and how to augment the outcomes and the experience for patients and families in that regard. CBPR really is looking more at the health of the community and how the health of the community can be improved overall through lifestyle or interventions that might include medical interventions but also lifestyle interventions. More typically the PCOR focus has been medicine and about medical problems specifically.

MS. MOHR: I'd like to also ask Pat this same question and Pat you've put together a very nice slide that we're going to put in the background here, if you could just talk a little bit about your perspective about the similarities and differences.

DR. DEVERKA: I'm sort of a graphical person, sort of thinking pictures and I was trying as I put the talk together to think more about the similarities and you wouldn't necessarily think about it in sort of this Venn diagram because it looks like there's not much overlap but they both start with a commonality first so I certainly think that improved health outcomes at the level of communities and Madeleine talked about sort of the emphasis on a public health mission versus maybe treating a medical condition where improved health outcomes are at different levels, but certainly that's in common, and clearly engaging the participation of individuals outside the traditional scientific paradigm that's in common, and in PCOR the focus on patients and caregivers and clinicians is clearly the focus, but I think who we say represents the community in CBPR there could be a bagged dialog about that and talked about that, but I think clearly the broader concept of participation outside of the traditional scientific paradigm is clear, and something that I think that CBPR is clearly more advanced and alluded to this but I think it's certainly the intention of PCOR is to have this participation be characterized by mutual respect and trust that's something that's built over time, and I was really intrigued about sort of all the different dimensions of trust that Nina described in her last slide, and we try to do measures of that and we'd be very interested in seeing whether that scale she mentioned could be something that we measure as part of stakeholder engagement.

I think those at that level there's certainly commonalities, but what I tried to put on this slide is I do think that at least in this point in time the goals are different. We heard Madeleine talk about that and I do think in terms of how the research is designed and maybe it's a function of the three year funding cycle but right now a lot of the interactions tend to be on the PCOR side more on the consultation side. I think they are moving toward collaboration and having these partnerships be sustained over time, but they tend to be more consultative like for brief periods, and I think in some ways it's how one measures the outcomes. I feel like in PCOR it's

defining the problem as a lack of evidence and if we had better evidence people would make more informed decisions and I feel like the outcomes are more global on the CDPR side and of course improved health outcomes informed by better evidence is certainly a piece of it but this transforming social and economic conditions and changing the system and the capacity of this system from a public health perspective is a much broader agenda. I did put a little bit of that in there because I do feel like for PCOR particularly with some of these recent funding announcements for things like patient powered research networks I think there is an interest in changing, shifting the research agenda and changing the capacity of the system to respond to the research priorities of patients and caregivers, but I think that's something that's at a very nascent stage, hopefully this picture sort of allows us to sort of think through that and to have people challenge whether they agree with my conceptualization.

MS. MOHR: That's great. Nina actually has asked to raise a point here. Nina, if you would like to do that.

DR. WALLERSTEIN: I actually think that it relates to the purpose of search that you are thinking about. All of this could fall you know with each day expecting much more patient engagement for a growing field I think the opportunity, the potential for PCOR and CBPR to actually share this, what they are doing is pretty wonderful in that with what you're saying Pat of the patient powered research networks, but the purpose of the research to me is the driving force. If the purpose is to really create shared...in the context of the shared leadership you are then looking at as you said Pat broader outcomes of not just a specific screening or medical uptake of that kind of medication or whatever the specific is but you're also looking at patients and communities taking control of their own health, and you may not do it in a one time cycle of a PCOR grant of three years but as a clinic you're geographically...you're a health system geographically situated within communities, and if you're making a commitment to that community over the 20 year, 40 year, 100 year lifetime of that community when you think your health system is going to be there and the possibility for really changing that, not just adapting or implementing a single...gaining the expertise to know that this works with patients but you're building a much bigger purpose of community engagement and community capacity as an outcome in and of itself as being typical for the health of the whole community, and then you can build a PCOR grant upon another PCOR grant upon another PCOR grant with a bigger perspective of building this partnership or even community driven idea in the continuum that you've presented where the patients are driving it just like in CBPR we have community driven research or community...try boldly driven research. That's even stronger than just shared leadership, the possibility of thinking over that 100 year lifetime of health systems commitment to a community matters, not just the specific grant itself. If we really are thinking of a larger purpose of outcomes then each grant will enable hopefully to build that incrementally. Then it does matter what process you use.

MS. MOHR: Thank you very much Nina. I'd like to actually go back to Dwyane right now and specifically as you've talked about this importance from the patient's perspective Dwyane can you just reflect a little bit on what you've heard here and then we'll go to Madeleine who's also asked to contribute to this.

## Reaction From the Patient Perspective

MS. DWYAN MONROE: From the perspective of a person as a patient but also as a person who has done some work in CBPR and also focus groups working with community outreach workers and working in the community and listening to patients in clinical settings particularly also with research, a lot of what is happening here with the similarities is that piece on trust created a repoire being genuine, frequent contact being transparent and up front is the essential piece around either CBPR or PCOR. A lot of times I've noticed with studies that they don't take the time to really measure and see how important trust is so I appreciate having that trust scale up, and also looking at the fact that sometimes it looks like that PCOR to me could be like a pre-pilot for a CBPR study when you take some small clinical context and then you want to make it into a bigger, broader, type of health outcome.

MS. MOHR: That's very interesting. I'm wondering Madeleine if you had something that you wanted to raise?

DR. SHALOWITZ: I wanted to react to Pat's comment that there is no evidence. I think that both PCOR and CBPR are saying that there would be evidence if we asked better questions, and in fact that way to ask better questions is to rely on experts but the expert is not just not necessarily the health provider because in essence medical care happens within a 15, 20, or a half an hour visit but health happens outside the treatment setting and I know I've said that more than once now but the patient needs to be understood by the provider as well as being an expert in how a treatment plan will happen in their daily lives.

MS. MOHR: Do you have any suggestions for asking better questions or what specifically do you mean by that?

DR. SHALOWITZ: Asking better questions, PCOR is looking to incorporate things like preserving employment, being able to care for children, being able to function on a day to day basis as better questions to ask than just will I live longer, and that's the way they are thinking about the better questions. CBPR really extends that much further into family and community in ways that PCOR will likely think about over the course of time but right now is really focused more on the immediate impact of the disease.

MS. MOHR: Before we turn to our next question I'd like to ask Daniel if he has anything to add. Daniel Mullins?

DR. DANIEL MULLINS: I would echo I thought that Pat's diagram was very nice and showed some of the differences, and I thought that Nina's presentation was terrific at talking about bidirectional learning. In my mind I think if we could use what we know works in CBPR but apply it to health related questions that help patients and their care providers make better decisions that's the win win. I don't think that we want to suggest that everything that we've learned from CBPR is enough. Clearly we've learned how to do CBPR for other types of questions and my guess is that the methods will need to be enhanced in order to apply them to PCOR. I would draw upon the experiences from community based participatory research but recognize that we will need to adapt them as we apply them to important patient centered outcomes research questions.

MS. MOHR: Thank you very much Daniel. I actually think that what I'd like to do is ask this question about whether or not the...if there are enough similarities between CBPR to allow us to draw some lessons from PCOR and it sounds to me like the consensus among you is that there are enough similarities to be able to build on this as a platform. I think actually let's go onto the next question which I think will be building more deeply into what are the strategies for effectively equalizing the power structure between researchers and other stakeholders that allow for shared decision making? Anyone just feel free to speak up on this particular question.

DR. WALLERSTEIN: This is Nina. I think this is probably one of the essential questions so I appreciate that you are asking it or we are asking it to kind of...and I think a lot of there's no cookbook on this kind of answer. There's really only an intention to make it happen and to build the kind of relationships with partners so that this can be talked about because one of the critical strategies is actually recognizing the power differentials. You cannot equalize power unless you recognize that people are coming from different positions of power. Patients don't necessarily consider that they have power and maybe don't in cases of extreme need, but certainly all of us as patients can demand power from within our own relationships with the clinical provider, but in addition we're talking power at setting the research agenda. That's a different kind of question than power in your own medical treatment. The power to set a research question is hard to do as individuals and that's why you want to work with community organizations, associations, clinical groups of support groups of patients as a group where people are not doing it on their own.

Two things I would suggest as strategies, one is to recognize that there are power differentials as a starting point and how do you raise the question, the second is to look at both. In our model we had this idea that it's not just the relationships that you work on in building trust but it's also in the structures that you set up, and as Madeleine so nicely put in the structures of her research question establishing community advisory boards that have real authority behind them or establishing community whatever. We started calling our community advisory committees in tribes we started calling them tribal research teams so that they are actually co-researchers with us. They're not just advisory committees, and so that TRT idea tribal research team how do you create these colleagues within community partnerships of patient groups or community organizations or even with the clinical providers as partners as well so you might need to build in memorandums of agreement and guidelines for data sharing and ownership and guidelines for publication. You have to build in the structures of participation, not just the good relationships. I think those to me are important.

MS. MOHR: That's really excellent advice Nina. Dwyan actually had a question or wanted to contribute here.

MS. DWYAN MONROE: Yes, it's something really quick that sounds really...it may not sound major but listening to other patients where you have your community advisory meetings where you announce your recruitment for people to be apart of the actual research process plays a key role when you're looking at power structures. A lot of times we're asking for them to come to the university, come to the institution, come to where we are. We in public health want to do more of practicing what we preach and meeting people where they are. Having not just one or two and not just assimilating information at a community event but involving the process within

the community so utilizing the community recreation centers, faith based organizations who want to be a part of the process and conducting these processes, these meetings and these recruitments in the community along with the community and how they bring people as a part of participating in particular community events and participating through that so not just saying you need to come here, pay our parking, be a part of what we're doing here, to actually start, continue, and even end with being already in the community.

MS. MOHR: That's great and Pat you had some thoughts about this.

DR. DEVERKA: I think there are many different strategies and like what Nina said it has to be...the strategies have to be targeted to the objectives and depending on whether you're setting a research agenda or developing a specific research protocol it all needs to be tailored but things that we've tried in the past and we're learning as we go, but clearly defining the roles of all of the stakeholders is very important up front, managing expectations, having a neutral facilitatory so many times if it's the researcher that's running the meeting it's very difficult to equalize power structure so having a third party or a neutral facilitator can be very important. Having a lot of training and spending additional time with different non-experts to prepare them for the meetings because I think there's a sense that if you don't feel like you have mastery over the concepts that you can't fully engage in the discussions and dialog and we've certainly heard from researchers that don't feel like people that are not researchers can participate for example in protocol design discussions but I think we've debunked that belief by simply spending adequate time preparing all stakeholders for participation in those meetings and that could be payer participants or policy maker participants as well as patient participants. I think measuring at various time points in the project stakeholder attitudes about the process is very important and recalibrating the process based on the feedback that you get from those evaluations is very important, and then we've done things like I think Nina mentioned co-publication. I think an evaluation of the process and co-publishing with stakeholders is very important to demonstrate that their involvement was meaningful in a comparable power structure with the researchers. Those are just some top of mind strategies and again it's not a one size fits all approach to the problem.

MS. MOHR: Madeleine, I think you had some thoughts?

DR. SHALOWITZ: I just wanted to acknowledge that the goal of this is not to make patients, providers, and researchers or any in the opposite direction. The goal is to identify people for their strengths and work from strength to strength to identify synergies, and in the meantime each person needs to be a good consumer of the other's information. In writing a paper just as an example it's unlikely that a community person will be writing the statistical section, but you would hope that by working together over the course of time that the community has a solid sense of what it means to use numbers in statistics and what those numbers mean, but on the other hand if the academic strength is in the methodological rigor the community strength is in framing the problem and interpreting the results in a way that the person that understands methodology can't do without thinking about moving into the community role, and so you create a network of interaction that's greater than the sum of the individual parts. The other thing I wanted to bring up is the need for absolute accountability in the trust building process, and I would say that at least in the beginning because of all of this fear of research,

researchers, academics, doctors, all of that is initially that responsibility is on that side to show that you really are listening because the tradition is not to listen, to be very responsive to everything that you've heard, when you promise something you do it. It just like a mother and a child. You develop trust over the course of the years and then the child grows up and maybe actually is going to teach the parent, but it happens with many, many interactions over the course of time that demonstrates the respect that we have for one another.

MS. MOHR: I am cognizant of the time that we have here and we have actually three more major questions that we had talked about discussing. What I'd like to move onto is the question about successful dissemination strategies. So if we could reflect on what are some of the successful dissemination strategies for bringing the results back to the community and then we will move on to looking at engaging the underrepresented populations. I guess what I'd like to do is speaking of dissemination strategies potentially start off with Nina's perspective here about CBPR and what kind of lessons we could learn.

DR. NINA WALLERSTEIN: I guess to me this is part of a dialog that we have with our partners. The question is what would be most useful to the community is the first question that always emerges. We often think in terms of dissemination is an academic exercise of peer review journals and all of that and this question the way it's framed is not that. It's basically saying what is the benefit to the community as a key outcome, and unfortunately or B often just looks at individual cost benefit, harm benefit issues and not the idea of community benefit, and just for example when you go to the Navajo nation institutional review board there is a requirement from that IRB that you have to write as an investigator how you are going to provide training and technical assistance back to the community as part of even getting you IRB to be approved. That builds in dissemination immediately back to the community, and so the question is what's the right context within that community? In PCOR I don't know are there patient newsletters, in communities there's often community newsletters, tribal newsletters. We do executive summary reports. We do what we call community voices reports. We do meetings. We invite people back who've actually been interviewed or surveyed into a community meeting, but the question of which one you choose to me needs to be asked to the shared group or the community advisory board what to them would be most important for actually getting messages out and what are the various forms that can be used in terms of social media, et cetera.

I think that it's not that there are specific strategies but that the decision making of how those strategies are decided comes with that idea of the partnership together in this bidirectional approach of decision making. That's just sort of the thoughts of how we've thought of it.

MS. MOHR: That's great. Also I'd like to ask Daniel, you have some thoughts on this.

DR. MULLINS: I agree with what's been said so far. Certainly we know that producing Lay summaries is incredibly important. The traditional approach of having a manuscript that gets sent out and then we hope that somehow that gets disseminated is not a very good strategy so having Lay summaries, creating those in partnership as Nina said, using some individuals from the community through an integrative approach to make sure that the phrasing is culturally appropriate, recognizing that there's a need to bring information back to those who participated in a study as well as the communities from which they come so there are two

stakeholders there. There's the individual and then there's the community, and also it's important to know communities. A lot of my work has been in minority populations but I think that some of this would generalize to all people, and that is that sometimes people don't want to know just the results of your study. They want to know information about how the study's going. They want to know are they the only person or only group that's participated. They want to know if target enrollment is being met.

Sometimes it's equally important to celebrate the successful completion of a project and if the community wants to celebrate, not just learn what happened because they participate in something that actually was completed. I think many community members know that some studies don't enroll enough patients and end up terminating and no information really emerges from that study, and that's really frustrating when you have volunteered to participate and then there are no results. Providing that type of feedback I think is equally important to having lay summaries when a study does report out.

MS. MOHR: Great, and Dwyane and Madeleine have also asked to contribute and I would like you to keep it a little bit short so we can move on to the next session, but maybe we can start with Dwyane.

MS. MONROE: I just wanted to add what Dr. Mullins was saying as far as the celebration. I participated in a clinical research study with hypertension in black men and we actually did a celebration with their families and the actual PI and researchers were involved along with the community to disseminate the findings and of course the appropriate manner, but also we had an opportunity to have the actual participants in the study talk about their experiences to the audience to the community that came to be a part of it. The piece about the celebration and understanding what is the next step. I went through five years of participating in the study how is it going to affect my children? How's it going to affect my community in the long run? They want to see what's really going to happen with this besides papers and a lot of what they participated in and what was brought into the study is that going to continue or is it going to stop because the study stops. They want to know is there some sustainability, some continuity in what really happened in the study and what's really going to be the next step.

MS. MOHR: Okay, and Madeleine?

DR. SHALOWITZ: I just wanted to say for a moment certainly everything that's said thus far is critical, but I wanted to add the element of timeliness, particularly relevant for health research and particularly when we're looking for patient perspectives and we may be identifying depression or anxiety or crises in the home. It's very scary for participants to be asked questions often times, and sharing that information often has some personal costs. We absolutely have to as researchers send information back to the families in terms of resources and I know that this goes against perceived study design but it's irresponsible in my point of view to leave that information in a file for a manuscript that's going to get written several years later. If we're doing things let's say for diabetes and we're identifying people with high hemoglobin A1Cs that can't sit in a data file until the end of the study. That has to be brought back to the participant in real time with a connection to resources.

MS. MOHR: That's really terrific advice. I'd like to move on now to engaging under represented populations and specifically the question about what are some of the essential lessons for



engaging under represented populations in CBPR that would be applicable to PCOR, and I thought actually we'd just kind of flip this a little bit and start with our PCOR expert Dan Mullins who's been focusing a lot on hard to reach populations within the Baltimore area, and Dan maybe you could just say a few words about your thoughts on this.

## Engaging Underrepresented Populations

DR. MULLINS: Sure. I'll begin by saying one of the major reasons that patient centered outcomes research really has come forth as an innovative breakthrough in the way in which we conduct health sciences research is because it answers questions that are important to patients, and we haven't done that well in the past. We haven't answered questions that are important to patients and that's all patients, but it's particularly true in underrepresented populations. The challenge that researchers face is really flipping research on its head so that we engage a diversity of patients up front. We often times think of dissemination. We don't think about up front engaging individuals. Historically we conduct research even, comparative effectiveness research and then we try to translate it, but we never stop to ask the question up front about whether our question is really an important question to the patient. We think it's important. We think it's fundable but we don't bother to ask if it's important or meaningful to patients.

Last year JAMA had a CER theme issue and we published a paper on this in which we talked about the fact that patients really need to be engaged at all 10 depths of research, in particular in comparative effectiveness research. The first three steps in our framework are number one is topic solicitation, number two is prioritization of those topics and number three is framing that research question. Many of us would acknowledge that these are important. All of us on the phone would probably say yes, we should be doing that, and the reality is that we don't always do that. We sometimes skip those steps because as Pat said before we're in a hurry. We've got to get this done or we do acknowledge and we say well in the institute of medicine did those first two steps. They talked about topic solicitation and prioritization and so maybe we don't have to do that, but those are national priorities and local priorities may be different.

I believe that we need to do each of those steps and we really need to do step number three which is even if we know what we're going to study we need to figure out how to frame that question from a patient standpoint. Many of the folks on a call today have some type of professional degree and most professional schools we train students in what we call the teach back method. The teach back method is that a coalition explains to a patient some aspect of their disease or some aspect of their treatment and then the clinician asks the patient to repeat back in the patient's own words what is your understanding of your disease. How is it that you understand that you're supposed to take your medicine or how is it you're supposed to follow the treatment regimen? Why don't we have a similar teach back method for framing research questions? Why don't we explain what we want to do and ask the patients to teach back to us what that question is? I think that that will help us to produce better research. It has a side benefit of also being ethical in the sense that we are supposed to have informed consent, and how do we know if a patient is really informed if they don't really understand the question.

I believe there are a lot of benefits here. I want to follow up on what some of the other speakers have said. The biggest challenge that we face in underrepresented populations is this issue of trust. It comes up first. It comes up last. It comes up every five seconds in any of these discussions and we need to establish trust with the community as well as with the individuals who might participate. Another challenge is what's been referenced before to is this issue of transparency. I heard a very nice example of this in some of our work in which some of the patients said researchers never tell us what they get out of this and I thought that was interesting. Do you guys get a raise if you complete this project? Do you get promoted, and they understand that there are incentives for researchers to do research and they want to know a little bit more about that because that might help them to understand whether they trust this research process. If a physician is getting \$500 per patient to recruit patients that might make a difference in whether the patient wants to participate.

As Penny mentioned at the beginning we did some work funded by PCORI that specifically looked at two types of what was termed hard to reach patients. The first were minority patients and the second were patients with some type of impairment whether that was visual, hearing, mobility, or cognitively impaired individuals, and we've heard loud and clear that there are some ways to address these challenges. We've heard some of them, partnering with community organizations, partnering with community leaders, being there, being there, being there. If you want to establish trust you're not just supposed to come at the kick off meetings and maybe at the end but being there not just throughout the study but you're going to be there afterwards and then if you're going to come back in two years for another study we hope that we don't just see you two years from now. We want to see you at a community event. Come to where we live. Come to where we work. Come to where we worship or where we hang out. It's well documented in the CDPR literature that hair salon's and barbershops are a good place to meet African Americans if you're trying to recruit, laundromats for many people, where people receive social services, the community health clinics. In an urban environment we learned very loud and clear that in West Baltimore every neighborhood had what they referred to as the mayor of the block, and it's not hard to find out who he or she is. That person often times is similar to a pastor in a church. They kind of run the show in there and they can help you to find patients who would be interested in your study.

We talked about media. We talked about social media, online forums. We often times don't think about cultural specific media like Mirror Reach media. A lot of minorities have a specific TV station or a specific radio that may be very local but it's where they listen to get information. A lot of people with low SES ride the bus and having information at the bus. I think that the major factor chains get that. Every time I stand by the bus stop I see an ad for a fast food chain and so obviously they're getting the attrition of people. Maybe we need to meet people while they're in transit. We need to engage at true levels. I think we often times think about engaging with the individual but first we need to engage with the community. First we need to have a sense and to explain and to discuss with the community what it would mean to partner to do your patient centered outcomes research, learn what they want out of the partnership. I think we don't often times ask the partner what is it that you want to gain from this experience.

We need to answer difficult questions like who's responsible for this. When we talk about getting patients who is recruiting the patient? Who's doing the follow up care? Simple things, if we're providing food who's buying the food? Is that coming out of my budget or is that coming out of your budget? Those are important questions to address with communities. How are we going to give back and how frequently and how often, and then after that we can begin to have conversations between the partnership and the patient. Sometimes when we're trying to recruit somebody into a study we go up to Mr. and Mrs. Jones and we say I'd like to describe a study that we're conducting and see if you'd be interested in participating? We expect that Mr. and Mrs. Jones will listen to us and then say yes or no. The reality is that the Jones family probably wants to go home and discuss this. It's not surprising that people who enroll in studies drop out. It's not surprising that sometimes the data that we get is not honest because it's true that there are some patients who show up for the \$20 gift card, and so we need to understand that if we're not addressing this need first off we may be getting people enrolled but are we really getting meaningful data?

One alternative is something that we've learned from the safety net hospital, and the research nurse there she approaches Mr. and Mrs. Jones in a different way and she says I'd like to tell you about a study that we're conducting and when you come back to clinic next week I'd like to talk to you about whether you're interested in participating. Her recruitment is much higher because she gives them the time and she builds that trust that she's not trying to rush a decision. We need to really understand kind of what's of interest to patients. I'm going to close with a great anecdote. One of the visually impaired patients who participated in our PCORI contract he said I often get asked to participate in vision studies, but I have never been asked about enrolling in a diabetes study. He said I've been blind since birth so I'm okay and I know how to manage that, but my diabetes that's a problem. I'll end with that and take any questions later on.

MS. MOHR: That's a great anecdote Daniel. Nina, I think this issue of building trust is something you've worked with for a long time and specifically your work in the tribal communities. Could you give me your thoughts about engaging underrepresented populations and CBPR and its lessons for PCOR?

DR. WALLERSTEIN: I actually have two kind of different ways of thinking about it. The first is not...is to reframe the question, not how can we better engage those folks in our studies is almost how it stands as a question, but more from let's start from the universities how we are viewed first. We come from a long trajectory of building a lot of mistrust in communities in the way that there's the research abuse in communities. We need to do our job better as university people and university structures to reframe our way of doing business so that people trust us for a reason, not trust us just because we're requesting them to trust us. I often look at what's our university policy. Are we better at recognizing the way to involve communities? Our pilot grants for example do they provide incentives for people for child care, food, travel, all those kind of things that enable a university to actually have the capacity to do this kind of work, and I think that's a really important difference is looking at our own selves first and saying how can we do better in terms of being worthy of trust?

I think that for me is really an important way of thinking and building and developing partnerships and relationships and to kind of turn the tables. The other is to think very genuinely about what a lot of people have said already, which is the importance of being respectful, being bidirectional, being reciprocal in our approach, and Pat said very early on that in stakeholder engagement this knowledge is really seen as being equally valued by the community. Other people have said this, Dwyan, Madeleine, everybody has been saying that how do we value the knowledge from patients and the knowledge from patients as being equally important, and the way we tend to think about it sometimes we think there's evidence from the academics and then there's community belief systems. Just by using these different terms evidence from the academic and community belief systems we kind of create a hierarchy. How do you transform that so that we look at that there's evidence from all different stakeholders? There's community evidence. There's practice based evidence. There's cultural based evidence. There's patient based evidence of what works for them, and how do we create and link that in positive ways to the university evidence that comes from other research design and other research studies that we've built up in our own literature, and I think if we begin to transform these hierarchies of power so that our community partners genuinely believe that they are respected and honored and that they're for working with the community association or community agency that's helping in recruitment that they are able to vouch for us because of our actions.

We often go to gatekeepers associations or places or whether they're barber shops or wherever we're going. Those become gatekeeper places but they need to vouch for us for a reason, and so I really try and think about how are we creating these mutual partnered relationships that people can vouch for us in good faith, and so the trust is built on our actions in good faith that we're showing that our university is being responsive, our university's IRB is responsive, our university funding is responsive, all of that to the demands and needs of community partners when they help us set up research projects, and lastly I do think that we have to look at the range of stakeholders that we're working with an include also policy stakeholders and leaders whether they're faith based ministers, all of those folks are really important allies for establishing partnered research projects that again can help us in bringing community members to the table. I guess I want to end with one statement that I kept in my mind every since that Mary Northridge published it. She's the editor of the American Journal of Public Health and she published this very early on an editorial about community based research and she said the three things you need to do are listen, listen, and listen again.

That's only one of them but it's the listening as key. The second thing is show up which is what Dwyan so early talked about early on in this webinar and others have just mentioned this over and over, showing up outside our own walls, and then believe and push for and work for social justice, and again that really means mutual reciprocal respect and transforming constructions that are inequitable. I think that those three things I keep in the back of my mind as a way to engage...I don't tend to think of people in populations. I tend to think of people as community members, as family members so it's hard for me even to use this language of population because I think our language it very much influences the way we think and if we're trying to

think of mutual respect then you think of community members or family members, that also is a way to really begin to turn the tables on who's telling who what to do.

MS. MOHR: Thank you very much. We have cut into our time for questions a little bit but I would like to ask Dwyan if you have just a couple of thoughts before we turn to questions just to the point?

## Reaction From the Patient Perspective

MS. MONROE: Yes, I really appreciate the opportunity of being on a panel with researchers who get it because being a patient but also being a person who has done clinical research studies as an interventionist in the community, and working on advisory boards and supporting community health workers--which is also a caveat I'll get to in a second—I appreciate the fact that community people don't have to really kind of explain being a part of the process, and in being invited for a webinar that really listens to researchers who actually really have heard what communities are saying, and also I see the fact that if you have both people in either CBPR PCORI everybody comes from a different perspective but it's always there's that personal feel. To me PCORI feels a personal person's personal feelings when it comes to deal with an individual health issue. How am I going to manage this? How is my family going to manage this, and you have people that are clearly just focused on that in the community, but you also have people who are not just focused on that but who also are focused on how this globally looks to my community and how this is going to happen in the future.

Both I think need to continue to really bounce off each other and play a key role in partnering with each other and then move forward in getting more research and more studies in understanding how to really play this out when everybody has also mentioned and said the things that I'm constantly saying. To me the key is trust, continue to build genuine trust, to have appropriately culturally knowledge training out there so that patients can really comment with that better understanding, and making sure that once things are disseminated and that's a community driven process that there is some next steps, there are some tools, there's something tangible that they either put their hands on or that they can take back to another physician or when they go to be considered in another study that they can continue that knowledge base.

MS. MOHR: Great, thank you Dwyan. That's a really nice conclusion for the webinar. I'd like to turn it over now to Nora to facilitate some of the questions that we've gotten from participants on the phone.

NORA: Thanks Penny and we've gotten some really good questions. The first one here I think I'll target towards Nina. The question is can any of the CBPR experts elaborate on what is meant by the community as a unit of --. Nina, can you speak to that?

DR. WALLERSTEIN: I guess it's a very hard question because there are so many communities but there's geographic communities, there's...when I think communities I think of communities that have shared identity as people come together as diabetics or if they come together as lesbian, gay, transgender folks. If they come together as members of a church, if they come together as a geographic community. It is a challenge for a clinic range. You have community people who may not come together around their own geography but we all live in multiple communities, providers are communities. It is a again a question of how...it's often a question of if you're

doing research with a community that community will be defined in that way at the time. Communities are fluid in their dynamic and we live in multiple communities all of us.

NORA: Great, thank you, and I would also like to invite any of the other speakers at any time just use the raise hand function if you'd like to chime in on any of these questions. The next one is specifically for Madeleine, and the participant asks what are the benefits and costs of having two separate advisory groups, community and professional versus one multi-stakeholder group, and why do you choose two separate groups?

DR. SHALOWITZ: It's agenda driven more than anything else and there are issues that the community is less interested than the academics may be less interested in or more interested in. I think it's very important to maintain for example the relationship with the NIH for example or with PCORI or with AHRQ in the details, the production of a progress report or just the administrative tasks is not as much of interest to community members. I'm thinking of examples off the top of my head. For community how to make sure that the resources associated with any question that you ask which I told you I feel very strongly about earlier but to make sure that the mental health resources for example for somebody who might be in crisis are in fact up to date and don't have a waiting list. I just think that things naturally separate. They could separate in other ways to but that's the ones that our priority seems to work better, but the knowledge from one to the other remains important and that's why we have membership of each in both.

NORA: Thank you very much. The next question is also directed to your CBPR expert that says since it does take such a long time to develop CBPR partnerships should there be small grants available to prime the pump and help potential applicants develop the partnerships in CBPR research questions in the first place before expecting such a partnership to grow organizationally without such support? Madeleine, Nina, would either one of you like to respond--

DR. SHALOWITZ: I would say yes and in fact I've been lucky enough that I'm with the communities of Lake County to have been able to begin that way, but there is also the question of sustainability after the grant is over and to be able to continue the good work and the interaction that's the goal even after the grant ends. I would add that small grants at the end for that purpose are also important.

DR. WALLERSTEIN: I would just ask too and seed grants often in university settings provide that, and it would be great if NIH also had these small pilot grants to build partnerships as the policy change for NIH would be highly useful, and even within the PCORI structure as well.

NORA: Thank you. The next question we have is how are PCOR and CBPR the same as participatory action research?

DR. WALLERSTEIN: There are so many names for this kind of participatory research and they came from different places, participatory action research is often used in education and in some of the social sciences. It is the same. I mean there's participatory research coming out of Latin America and Africa and Asia. There are different historical legacies that we come from. There's action research. It's used more in England than Australia but there's also different emphasis whether what history it comes from, whether it's more kind of an organizational change action reflection cycle. I think you could say it's the same but we should look at the intention and

purpose of the research as kind of that's where often these similar participatory processes differ. It's not so much the name but in the overall purpose in where they sit on that continuum of involvement. That's my thoughts on it.

NORA: We have I think just time for maybe one more question and Daniel I think this one is a good one for you. The question is health information literacy should be discussed, institutions and academia speak with terms that most do not understand and this increases the divide with communities. Can you respond to that?

DR. MULLINS: Yes absolutely. I think that there's a variety of levels. There is basic literacy and then there's health literacy. I really like the question and I think that we need to address both. We have some people who may be really do understand their disease and how to manage it but they may have low literacy skills and so then we need to make sure that information that's new gets put to them in a way that they can read. We have other people who maybe can read quite well but if they don't really understand the disease that providing them with information about treatment they may not be health literate, and so we do need to make sure that we do that. Again I think working with people from the communities, having materials be developed in an ergative process with patient engagement with healthcare provider engagement will help to address that and I think we also want to think not just about those issues but translation into other languages, large print for elderly patients or individuals with visual impairment. All of those issues are critical to make sure that we're able to engage the most diverse population in our research.

MS. MOHR: Great, we're out of time. With that I would like to thank everyone for your participation and thank very much to the panelists for this excellent conversation and please join if you could we will be looking on...we will be sending out the links for the slides as well as sending out a link to everybody for an evaluation that we would like you to fill out. The webinar will be available on the AHRQ website and we recommend if you want to pass on this information to your friends and colleagues to access this webinar that it will be there in approximately a month's time. Thank you so much and we hope you learned something today.