



**Achieving the Promise of Community-Engaged Health Disparities Research:  
A National Community Partner Forum  
*January 2, 2012 Evaluation Report***

Ninety community leaders from across the U.S. convened from December 5-7, 2011 in Boston for “Achieving the Promise of Community-Engaged Health Disparities Research: A National Community Partner Forum.” Co-sponsored by Community-Campus Partnerships for Health (CCPH) & the Center for Community Health Education, Research & Service (CCHERS) with funding from the National Institute of Minority Health & Health Disparities, the forum focused on four priority areas for action: community review of proposed research, governance structures for research, community engagement in all phases of the research process & funding community infrastructure needed to conduct research. The forum ended on a high note with recommendations made, workgroups formed, relationships deepened & a pledge to re-convene. Learn more about the forum at <http://bit.ly/uCu3r5>

This evaluation report contains information collected through handwritten evaluations turned in by participants at the end of the forum and an online evaluation emailed out to participants the next day. Please note open-ended responses are verbatim and only edited to remove identifying information. When responses have been grouped together by a category, the category appears in *italics*.

Funding for the forum was made possible in part by 1R13MD006705-01 from the National Institute on Minority Health and Health Disparities, awarded to CCPH and CCHERS. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention by trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

These acronyms are used in this report:

CBO Community-Based Organization  
CBPR Community-Based Participatory Research  
CCPH Community-Campus Partnerships for Health  
CDC Centers for Disease Control and Prevention  
CTSA Clinical and Translational Science Award  
FBO Faith-Based Organization  
IRB Institutional Review Board  
MOU Memorandum of Understanding  
NCC National Community Committee (of the CDC Prevention Research Centers program)  
NIH National Institutes of Health  
PRC Prevention Research Center

**PART I: Online evaluation completed by 51 participants after the forum (57% response rate)**

**(1) What was your overall impression of the forum?**

Excellent	28	55%
Very Good	17	33%
Good	5	10%
Poor	1	2%

**(2) To what extent did the forum meet its stated objective: to share knowledge & provide mentorship around community review of proposed research, governance structures for research, community engagement in the research process & funding community research infrastructure?**

Objective met	41	80%
Objective met somewhat	10	20%
Objective not met	0	0%

**(3) To what extent did the forum meet its stated objective: to make recommendations around community review of proposed research, governance structures for research, community engagement in the research process & funding community research infrastructure?**

Objective met	42	82%
Objective met somewhat	7	14%
Objective not met	2	4%

**(4) To what extent did the forum meet its stated objective: to establish networks to facilitate shared learning, professional development and advocacy?**

Objective met	47	92%
Objective met somewhat	4	8%
Objective not met	0	0%

**(5) To what extent did the forum meet YOUR objectives in attending?**

Objectives met	40	78%
Objectives met somewhat	10	20%
Objectives not met	1	2%

**(6) Indicate if you agree with the statement:**

- 84% (42) indicated the forum provided sufficient opportunity for interaction among participants
- 94% (47) indicated the forum created a safe space in which to share issues and challenges
- 90% (45) indicated the forum was a worthwhile use of my
- 96% (47) plan to share what they learned from the forum with peers
- 88% (43) plan to share what they learned from the forum with academic partners
- 80% (39) plan to participate in one or more workgroups
- 60% (29) are interested in helping to plan a similar type forum on a city or state level

**(7) Do you plan to attend CCPH conference, April 18-21, 2012 in Houston?**

Yes	12	24%
No	6	11%
Not sure	33	65%

**(8) How will you describe the forum to others?**

I wish you could have been there. It was a gathering of diverse people passionate about the wellness of their communities. This is a group of people strongly committed to action-with, that respects the communal wisdom and experience at the heart of each community. A refreshing change.

The forum was a powerful and inspiring process of collective reflection towards planning an agenda for positioning and capacitating community based research organizations to investigate their community problems and develop solutions to these problems, both independently and in partnership.

The forum was an energizing mobilization process during which community partners recognized the need to change systems and the capacity they have to collectively make this happen.

I learned the difference between a community IRB, community advisory board and IRB.

This was time well spent. There were concrete outcomes established. This movement can be a part of a collective effort better network CBOs and FBOs.

Attending the national forum allowed me to understand the integral part of engaging with the community and using research methods to provide sustainable efforts for program development.

I learned what CBPR is, how to leverage universities for partnerships, and what kind of infrastructure is needed for research development.

I learned what resources provide federal funding.

I will stay connected with participants to obtain toolkits for using CBPR, to build on the action items, and to reach out for support when needed.

We discussed potential pitfalls that were shared by others in their projects and programs. This was a good opportunity to learn from others mistakes/mis-steps.

Highly informative. Ground-breaking.

It was a gathering of 100 community activists who came together to share best practices of working with universities and to help guide people new to the field of community-based research. It was also a gathering to develop plans and actions on how to move forward to help community-based organizations conducting research to thrive.

I would say that the forum was just the shot in the arm that I needed. Without a doubt, I benefited from the exposure to the experience represented at that forum.

I have and will continue to say that this was one of the best opportunities for community leaders to come together to share information as well as learn from each other. My comment always ends with ...I have not attended a poorly organized, non-beneficial CCPH sponsored forum/conference yet... and I don't expect it to happen.

That it was great to be with Community partners to start thinking about how to push back on Academia to really be participatory in the research and not just a name on the project.

One of the most inspiring conferences . The forum was really down to earth and about relationships with academic partners.... Who often don't understand us.... Great forum...

It was informative and inspirational.

It raised a lot of issues for me - both positive and negative - in regard to community participation in research, and in particular in the potential setup for communities to begin acting like academics in order to be perceived as credible and worthy of direct funding.

I want more time with those people.....they taught me so much in the little time we had together.

That it was a remarkable gathering of community organizations of all types, constituencies and backgrounds, doing research with others including university partners, or desiring to do so; that it is a politicized group that would like to have a voice in scientific decision making at all levels and that it is committed to research for social justice, that addresses structural inequities as well as disparities.

It's a catalyst for change.

The forum was informative; considerate of non-profit organizations (community-based organizations - CBOs); gave exposure of industry practices; and provided case studies from well-organized and respected national non-profit entities.

The forum was very informative, engaging, and participatory. The forum really modeled what we must do to effectively engage communities in CBPR. We must help communities realize and mobilize this power (efficacy).

Wonderful opportunity to meet and network with experts and individuals committed to advancing community progress and health research with social justice.

I learned about a number of priority areas that my community organizations needs to address to become even more effective especially related to how we structure the organization and partner with degreed researchers.

It was a unique opportunity to share the challenges and successes of CBPR in diverse communities and neighborhoods across the country. The forum was an excellent way to create a learning community, to network and to bring best practice ideas back to my area.

I finally felt validated when I heard other advocates/activists share their experiences about the work that we do, and the objectives we hope to achieve.

I learned so much! I became knowledgeable about Community IRBs and independent IRBs. Knowledge was provided about community engagement in research processes and funding community research. I met the people that I have been receiving emails from in CCPH!

Forum members brainstormed ideas to improve equitability in the relationship between research institutions and community-based organizations when engaging in community based participatory research.

The forum acted as a mirror for me to see where my community-campus partnerships are on the continuum. Attending the forum help me to be more focused on what I need to be doing as a community partner to aide other partners in becoming more educated about practicing CBPR.

That I thought that it was only our group that was in this situation.

I learned about community member perspectives from the NIH research world, and as someone from the CDC PRC world, it is clear to me that we need to join forces.

A rich experience.

It was a lot of useful information that I will use in the very near future.

This was a passionate and dedicated group of community activists who came together to create a new more just paradigm of research that empowers and benefits community and raises the consciousness of academicians.

Community partners across the country gathered to discuss how to advance community engaged research for health. We developed recommendations, got to know one another, and learned important information relevant to our work. Prior to the conference, my relationships with other community partners outside my geographic area were minimal. I now have a resource from the bios document to refer to.

Lots of good conversations, and no University researchers were there.

Felt validated, felt welcome to Boston, and excited to tell people about CCPH and working projects.

Very poor attempt at getting meaningful dialogue and action.

The opportunity to share with peers was unparalleled, the openness and honesty in raising successes and failures, grievances and collaborative triumphs was outstanding, and the chance to spend time and think/learn with people committed, deeply committed, to the health of their communities combined to make this a forum to remember - self and world changing.

Good Question! I would tell them about all the community based participatory research that is happening in conjunction with higher ed institutions in various areas, I would talk about the benefits of community based IRBs and the ability to become gatekeepers to communities of color and how communities are involved in research project from beginning to end, how IRBs should have communities (residents) as members. How research is improved and guided with community input and participation.

It was an excellent opportunity to network with like-minded individuals. It was inspirational to learn about what others are doing and to see their passion and commitment to improving CBPR. I learned a lot about the broad issues that need to be addressed to improve communities' experiences and outcomes of CBPR.

I was impressed with all the work being done around the country by CBOs with academic partners. The forum gave me the opportunity to meet peers, learn about what is being done around the country, the struggles that we all go through in the collaborations with academic institutions as well as ideas on new projects and strategies to overcome barriers to have effective relationships with our partners.

People that attended the forum were exceptional. A lot of motivation and energy. The forum was well organized. I liked the way it was broken down into main topics. It was a great opportunity to network and brainstorm actions with others.

The "themes" pertaining to the relationships between community organizations and universities are consistent Nationwide

It was good for networking and getting a sense of who is involved in CBPR.

It was a great forum. I learned a lot about what non profits go through and about community IRBs.

The fact that it was a national forum with CBO leaders from various states, it was very informative. The information shared and goals set were important to CBOs. The workshops were excellent and discussions were very helpful to our work as a CBO. Best of all is the networking opportunity for the CBOs especially in research area.

The people were amazing, the networking fantastic, and the content really helped me....

It seemed a lot of people were having issues with collaborators. I didn't like how the leadership was wanting to be aggressive towards them. It seemed when individuals pointed out there were a lot of good collaborators, it was pushed under the rug as that was not what organizers wanted to get out of the group.

It was well done, and I met individuals who I will connect with in the future.

That it was very interesting and people attending have a lot passion for community work.

**(9) What were your objectives in attending the forum?**

To be a part of the creation of a community partners network and to learn how to create this type of network locally.

To know more about what research CBOs do.

I wanted to understand how to strengthen foundations of community based research in providing programs in my CBO. I also wanted to understand all that this entails and how to strengthen our collaborations to turn them into partnerships.

1. As a planning committee member, to facilitate discussion during several forum sessions/components.
2. As a researcher from a community based research organization, to present a case study of my organization in order to prompt discussion about infrastructure needs and strategies for securing them.
3. To learn from planning committee members and other forum participants about their successes and challenges as community based researchers.
4. To network and become part of this emerging national network that is building a shared agenda for advocacy and resource sharing.

To meet potential partners and learn about how other small non-profits built up their research departments with or without academic partners; and to find possible ways to better incorporate community involvement in research.

1. To learn from the network and get support for [our] CBPR project.
2. To share our experiences as well as provide input into the CBPR movement.

To learn how to approach partnerships with universities as a community-based organization doing research.

To connect with people how are doing this kind of work who can act as a mentor to me through this process.

My main objective was to come and network with as many people as possible that do community research to glean perspectives and possibly help shape future projects for my board.

My objectives were to:

1. Connect with like-minded community leaders.
2. Share/learn from experiences.
3. Discuss/develop next steps to strengthen current community engagement for better outcomes and improved health.

To network with community partners and gain insight on governance and research regulation from the community point of view.

To establish new relationships with other community partners around the country... To broaden our organizations reach and scope of community participatory research.....

Share ideas and experience and learn what others are doing, and build networks with other community folks doing similar work.

To help me sort out where I want to go next as a grassroots activist of 35 years, where do I want to take my stand on the issue of research? To meet people in a similar place and from different perspectives to mine.

My objectives were to find out more about community partnerships and how to be effective as a community partner.

To share with others with common limitations and goals.

Join our voices to present a joined front to the federal organizations.

Find expertise and model to learn about how to charge for our community services within the CBPR partnerships.

As a relatively new CAB member at [name] university, I wanted to learn more about the role of the CAB and how to ask the right questions of the academic researchers, and to help ensure that the process was truly community based and engaged. I also wanted to learn more about funding for the sustainability of CBPR projects.

To share with other participants, the challenges my advisory committee has had to address while "informing" university researchers about respect for the local culture and expectations of the community.

To learn all that I could so that I can take it back to my community. To get a clearer understanding of where I "fit". To network with others in the field.

To increase my knowledge of the scope of community based participatory research, to share my experiences with regard to the 4 forum priority topic areas and to contribute in identifying "best practices" toward improving the relationship between research institutions and CBOs.

To learn from others and share my experiences.

To get at real challenges in CBPR and solutions for community engagement.

As a CCPH board member, I wanted to hear and learn more about IRB.

I wanted to expand my exposure to community engagement models and how they are working.

Learning about other work going on in CBPR.

Meet and begin to set up opportunities for collaboration with stakeholders that I would not have previously identified.

Deepen my knowledge and networking.

To learn and take back ideas to our community academic partnership. To inform the national conversation and work on CBPR and its application in the field.

To learn more about community based research and to learn about IRBs.

Learn what others are doing nationally. Meet folk, sit back, reflect, absorb, and plan internally how to proceed on some of my work.

Learning from others about their experiences as we plan for our partnerships.

Learn what is going on in CBPR, meet some people I have been emailing, get good definitions and some language to take back to other stakeholders, learn best strategies to deal with researchers/donors.

Member of the planning committee, so the objectives for me were to make it work and to support the unique and hard work of the CCPH leadership and staff!

To understand as a CBO how to implement community based research that is recognized and accepted as standard, to understand the interworking of IRB and review process, to learn how to partner with a higher ed facility to accomplish CBPR, and understanding the dynamics of the relationship between CBO and Universities.

Meet individuals engaged in CBPR and learn from their experiences. Share my ideas of how community-based research could be enhanced. Plug into an advocacy effort.

To establish a network to share information and ideas.

To learn about the do's and don'ts of developing a Community Review board.

Learn about CBOs interface with academia. Their status regarding research knowledge and capacity.

To learn more about CCPH, to learn more about how to have effective community partnerships, and to network.

To share information about our community research ethics review board and to network with other CBOs involved in research.

To network and find out what it's all about!

To learn and to network.

To learn, and to gain a larger perspective on what we do.

To learn more about CBPR around the country and learn how individuals worked better with groups.

To continue to learn about community based research, and what others are doing around the country.

To share my experience conducting research in the community and learn from others. I was also interested in becoming part of this group.

I was open to possibilities. I was very naive about the organization. I had little knowledge of the acronym used to define the organization and it was an 'aha' moment when I realized the grounding was 'community-CAMPUS partnerships' and that campus referred to universities. I am still wondering how authentic/true CBPR will be realized as long as the funding goes to the university system. From my narrow lens, ways of seeing, being, knowing, and doing are often very diverse.

### **(10) What were the most important new things you learned?**

#### *Allies & the power of the collective*

- The degree of collective experiences that could be brought together around these issues.
- Learned that there were other people who believed in the premise that Research is Ceremony offered by Shawn Wilson.
- I learned about the existence of an incredible network of community-based research organizations that have complementary research strengths and needs and tremendous capacity for enhancing infrastructure through collective resource sharing and advocacy.
- That there are a growing number of communities redefining the rules of engagement in research.
- The most important thing that I learned from this forum was that the climate is changing in which we do our community research and if we are to be taken seriously and remain viable we (the community) are going to have to effect that change.
- That our organization is not alone...
- That it's not only the Latinos in [my city] who are faced with the problem of dealing with the academics.
- That the problem that we are facing is not only us.
- We have lots of allies.
- We need to connect to share our collective power.
- That there are a lot of people with similar goals who are as eager as I am to overcome the isolation.
- That we need to follow their lead (as expressed in the take charge spirit of the final table discussion) to continue to help overcome obstacles - and the personal corollary that I am not alone.
- It helped me reassess what we are doing and how to take things to the next level.
- That there were people out there who have trodden our path and that we can look up to them for assistance and guidance...and that they are willing to share information.
- I learned that many of my issues are shared concerns. I learned about new solutions and information that will help me.
- There is much coordination and organizing left to be done to implement CBPR.

#### *Affirmation*

- Renewed affirmation of the importance of honoring diverse ways of knowing and being – that perspective is very marginalized in my research/academic conversations. I continually challenge randomized clinical trials and pre-test/post-test designs as the gold standard in intervention research.
- I didn't learn this, but was reminded that there are extraordinarily brilliant and courageous people in the world making great sacrifices for what they believe in.
- I also learned that I know a lot about community engagement, which was affirming.

#### *Key terms, issues & concepts*

- Learned the term 'white ally' which sent me on a soul-searching journey.
- That the time is ripe to introduce the concept of social enterprise for community-based programs.
- The rights CBOs have in negotiating terms of partnerships with universities.

- Positioning CBOs to be better-equipped partners with academia.
- We can call the research question.
- That not all CBOs have a MOU in place for universities that do community based research.
- A CBO could ask for indirect expenses.
- That there are ways to negotiate the indirect cost rates.
- The difficulties in partnering with universities.
- The idea of creating social enterprise opportunities.
- Issues related to CTSA.
- How to start thinking about collective outcomes evaluation.
- That all grant funding does not require applications be submitted by Principal Investigators who have PhDs.
- A community member can be a principal investigator.
- That I have a sidewalk PhD!
- That there is indigenous wisdom that requires honoring, respect and presence of the elders that should be instilled in all research.
- That the NCMHD had become the NIMHD. I believe this agency can provide support for CBOs that are addressing the many health disparities that exist in urban and rural communities.
- All university and community partnerships are not at the same place and that there is room for improvement in all areas of the partnership.
- The current obstacles that create inequity in the relationship between research institutions and community-based organizations and potential solutions to creating more equitability in this relationship.
- Infrastructure needed as a CBO to be effective community partner.
- Good governance!
- The process of community engagement is happening on many fronts.
- Creating bodies of knowledge as a context for talking about the valuable knowledge that we all create and sometimes don't value as much as we should.
- Shortchanging and devaluing the community and its members is the norm, funders have narrow and mechanistic definitions of science and knowledge, and money is scooped up by the big fish and is supposed to trickle down to us.
- There's a big divergence in knowledge and resources between community partners. This is very frustrating because it's a form of disparity.
- Characteristics that CBOs need to have in place in order to have an equal level relationship with the academic sector
- The most important thing I learned is to even the playing field (whether I'm working with a CBO or university) for all members (and include all members) of CBPR.
- That there is a deeper piece about how community knowledge is formed and preserved that I need to think a lot more about. That 'respect' and 'trust' are terms that come up over and over and the lack thereof (on both sides of the research equation) needs to be addressed.
- That there are always new things to learn (my head is stuffed)!
- The "themes" pertaining to the relationships between Community Organizations and Universities are consistent Nationwide.

#### *Community IRBs, institutional IRBs & community review boards*

- All about IRBs.
- CAB members can directly interact with the IRBs.
- Community IRBs.
- The concept of Community IRBs/Advisory Boards
- I did not know that there are independent IRBs.
- That in forming a Community Review Board is imperative to include the academic partners in the process.

- That it is possible to have community based IRBs, the structure of IRB through a workshop I attended, other resources available to help in the design of community based IRBs.
- University and independent IRBs.
- Community IRBs - I was not aware of them and found out there is one where I live.

#### *Tools & resources*

- Where to go to find federal funding.
- How to network to gain tools.
- Standards for community advisory boards.
- How to write a good MOU.
- Funding options and sustaining the work.
- I learned about some of the funding structures and considerations for securing grants to perform CBPR.
- How a community/academic partnership were able to build infrastructure through a major health disparities grant.
- Framework perspectives on research and partnership from one of the presenters who is doing fabulous work.

#### *CBPR*

- What CBPR is.
- Case studies of successful research methodology.
- That CBPR provides opportunities for the voiceless communities to articulate their needs and be acted upon. It was important to hear the challenge and push back from one of the participants on the importance of CBPR if for no other reason than to help close that gap.
- The "language" of CBPR as our agency is on the "greener side" of CBPR.
- Benefits of educating other community partners about CBPR.
- The focus groups and photo voice projects we have done are research!  
What others are doing world wide about community based research.

#### *Other*

- I learned more about what CCPH is and its aims.
- I learned different experiences from different groups.
- Nothing.

### **(11) What questions do you have that remain unanswered?**

#### *Questions re: forum next steps, products, staying connected as a network*

- How information will be implemented?
- What is the plan for next steps?
- What is the timeline for moving the recommendations forward and how will we be kept in the loop?
- What is the "product" that will be created that will inform others doing CBPR on "best practices"? And how will this "product" be disseminated?
- Maintaining our new found family of partners, especially our relationship with CCPH...? We certainly would like to become members...
- Can we expand? Is this really a movement? Can we shift the science agenda at the national level? How much do we need to know to do it?
- How are we going to sustain and nurture the energy that was present at the forum? How will we avoid the pitfall of recreating the hierarchical knowledge control structure that we acknowledge as a deficit on the academic side.
- When and how will I be able to participate in the proposed Policy Issues conference proposed for this spring? I hope to make a contribution on some level.

- Does CCPH have a "tool kit" or "shared learnings" information link for community organizations who are partnered with Universities to access for them to obtain documents, MOU templates and other tools that would guide them through the process of partnering with Universities? If not, it may be worth thinking about.
- Will this continue with the same CBOs that were invited this year? And will there be more joining?
- The infrastructure needed to achieve some of the identified strategies is significant and securing the infrastructure takes time/resource. I hope that participants who committed to working groups have the time to build these processes as needed - including participation in grant proposal development for some of them.
- Lots of acronyms... missed out on some of the understanding due to that.

*Questions re: implementation back home*

- How do I start a IRB?
- How do I train my CBO to use CBPR?
- How do CBOs in their research infancy affect change through CBPR?
- How do I make recommendations for necessary research infrastructure?
- How to support and build internal staffing for small non-profits wishing to engage in research and evaluation projects.
- How exactly to negotiate the indirect cost rates.
- Where do I go from here, and how do I do it in a way that is effective in a big way without compromising what I believe to be ethical, moral and true.
- My remaining questions will be directed towards our institutional partners and will also be developed from the established working groups at the forum.
- Cost models for fair/equal partnerships.
- Need more information and coaching about establishing a CBO that has the capacity to effectively partner with the university.
- How do I as a volunteer get the monies that I deserve. How do I become a paid volunteer. I also want to become a paid person for my local CBO.
- How can I get involved in a real CBPR project?
- How can I change the narrative of my institution and even many community members?
- Only question is around how to achieve the objectives without losing sight of the main focus, which is for me conducting research the will lead to benefit our communities.
- I am a member of a Community Advisory Committee that supports the work of an African American (AA) individual who acquired her PhD approx. 3 years ago, but has had a lengthy relationship with the academic institution that performs most of the research in our area. Sometimes, we have proven to be the "conscience" of the proposed research efforts in our community, and respond only because of the efforts of the AA associate professor who originally solicited our input and guidance. How do we get the research institution to understand this and succeed in preventing the research institutions from attempting to circumvent our position regarding AAs as research subjects?
- Where am I going to find another day in the week?!

*Questions re: affecting change in research & funding*

- Identifying the research agenda that is directly defined by the community vs. research agenda designed by a faculty or RFPs (requests for proposals) released by the Feds.
- Current trends in funding CBPR.
- I'd like to know more about the academic structures, priorities and issues faced when engaging communities in research. I'd also like to know more about the federal funding structure and the politics of funding and performing CBPR.

*Questions re: specific entities*

- What are the CTSA's doing to engage community in a meaningful way?
- How do the prevention research centers work to address health disparities?
- Does the CDC understand what community engagement is?
- Why does community do so much for free when there is so much comparatively speaking money available for a research project?

*Other*

- None at this time (5)  
At this point I am still processing all the information acquired during this two day conference, I am sure that questions in my mind will arise in a day or two, but for now I am sorting and processing learned information to apply to start up a think tank we are proposing to implement in 2012.
- I don't know if participants understood the importance of research and program evaluation.

**(12) What will you do differently as a result of the forum?**

*Share information*

- Share this information with other community partners.
- Had a great conversation with my colleague about working together and her response to "white ally."
- I will inform and educate my community partners.
- I will share this information with the Community Action Board at my PRC and the NCC.

*Effect change locally*

- Be more involved in my local CBO.
- Help create more research ready community partners.
- Evaluate offering of programs to our community.
- Find a way to use CBPR with our next community assessments.
- I will try to engage the community into an honest discussion on what are the "real" needs of the community vs. needs identified by academicians based on secondary data.
- Negotiate terms with university partners - and utilize MOUs to ensure my organization gets its fair share of funding and acknowledgment from a study.
- I will look at and attack my work with my board from a different perspective. One that includes policy & advocacy as well as leadership development.
- Continue to push the importance of community being at the table from partners to decision makers.
- Will be more involved in our process for IRB and community partnerships with academia.
- Exploring ways to create "community centers of excellence" that can conduct research and contract with universities.
- Interact with my academic partner feeling empowered.
- Be a more assertive CAB member; seek new opportunities for engaging community in ways that are different than what I have been accustomed to,
- Be sure to support the work of the community advisory committee in its efforts to make our University partners even more accountable in their proposed relationships with research subjects in the community, and seek to work with other CBOs in their efforts to address specialty health
- I can now communicate with others more intelligently.
- I will continue to increase my knowledge as well as my agency's knowledge of CBPR, including its value in our day-to-day work.
- I will advocate for more CBPR trainings among all partners.

- I will work to establish my CBO to have the capacity to effectively partner with my university partners.
- I will invite more people to the discussion. I will no longer say that I am a partner in research but rather that I do research.
- I will think more purposefully about my engagement with students
- Think about the wisdom in the community and value it more.
- Here forward will be deeper.
- Very carefully consider before entering into an academic community partnership.
- Perhaps I will call a research question!
- Get paid what I deserve.
- Refer to recommendations as I move forward with my work.
- Always keep the communities best interest in mind and realize that it is our right to be apart of each discussion at every level.
- Be more outspoken since I know the general view of community members
- Be more rigorous in initial discussions with academic partners about the parameters of our work together.
- Give more serious thought to the idea of story, qualitative analysis, and how communities seem to almost organically understand that medical research is largely stuck in a linear paradigm and that models from other fields, dynamic systems analysis for example, are equally valid and more appropriate to research in the health /medical area.
- Be more aggressive about pursuing research questions raised by community.
- Everything as it pertain to community based research, next time we are approached to be a community partner in a research project, we want MOUs, contracts, and to be part of the process from the start or we will not participate.
- I have already initiated conversations with people about an initiative that I want to accomplish.
- Refine the MOU before starting a new joint proposal with an academic partner. Up to now the MOU has been developed after the funding is granted.
- Make sure that academia recognizes the value that CBOs have,
- Have more informed conversations with institutional partners when federal funding and community-based health research is a consideration.
- I will ask the right questions when consider future CBPR and will seek to educate members of my community as to what true CBPR looks like.
- Look at my own organization way of doing culturally based research and how we can start writing about it.
- Do more teaching.
- Be mindful that all interaction and requests and research are for the mutual achievable benefit, rewards and advancement of progress.
- I will be talking with our university partner to explore how we might institutionalize CBPR as an ongoing approach so that it isn't dropped after the current university CBPR champion leaves or retires.
- Develop a community concept development fund.

#### *Get more involved nationally*

- Become more active with CCPH.
- Become a member of CCPH.
- I will continue to serve on the planning committee and to support the work of the training and mentoring working group.
- Not sure yet, but will definitely continue to network, and to do so with a new group of amazing people throughout the country.

- I was glad to be part of the "accountability" discussion group that took its role as a work group seriously. We are already sending emails back and forth, a tangible outcome worth my time. I will probably be more involved with this group or groups resulting from this effort.
- Try to stay connected to a committee and/or the planning council efforts.
- Continue with working groups to continue the progress made at the conference.

#### *Leverage opportunities for greater impact*

- Leverage public health officials to consult in our community engaged readiness for research.
- Already, I was invited to review a manuscript article that used CBPR. I am given an opportunity to effectively change what and how CBPR is published or at least invite the authors to consider how they engaged with community in CBPR.
- Speak at more conferences to try to change the way science is "done" and who defines it.
- Write more about CBPR in high impact journals.

#### *Continue learning & networking*

- Familiarize myself with all the different acronyms.
- I will read the materials I brought back to share.
- Take more trainings
- Try to educate myself more on IRBs.
- Follow up with some of the contacts I made.
- Work hard to stay in touch
- Access the "smarts" of CBO and research leaders that have information.
- Utilize the experience and knowledge of my colleagues

#### *Other*

- I plan to do more of what I have been doing over the past fifteen (+) years.
- I am still digesting it, my thoughts and conversations.
- Not sure.
- Nothing.

### **(13) What topics would you like to see covered in future forums?**

#### *Build on what we started at the forum*

- Build on the issues that we identified.
- Not necessarily more topics, but having an opportunity to attend all topics as part of the conference. Although the slides will be available, I would have loved to be a participant in a few other workshops which was held at the same time of other workshops.
- More small group discussion for special populations (Native American/Alaska Native, immigrants, rural, etc.) to share lessons for adaptation and to create a technical assistance pipeline.
- Even more opportunity for focusing on social justice and its link to the ethical and moral questions that arise when we even consider developing, implementing, participating in, enabling research within our communities (however we define them).
- More attention to recapturing cultural heritage and local knowledge as major contributors to health.
- More attention to structural determinants of health in relation to what type of research we need.

#### *Research & CBPR*

- CBPR 101, 201, 301 workshops depending on one's level of engagement and knowledge.
- I would like to learn more about which academic community partnerships who are building a better CBPR world.

- I raised the thought of CBPR being considered on a continuum. I would like to include this thought/option in our discussions...
- Research methods workshops the CBPR way(s) - engaging, interactive, user friendly yet rigorous.
- A "mapping" of the history of research.
- What is real CBPR.
- Examples of grounding CBPR projects in participants' lived experiences.
- Examples of CBPR occurring In GLBTQ communities.
- Building CBO capacity to engage in CBPR – 'nuts and bolts.'
- Examples of CBPR outcomes, i.e. study findings that translated into action
- Seminars/overview regarding importance of research and program evaluation.
- Outcomes evaluation
- Cultural based research
- What are approaches to research?
- Working with diverse groups/indigenous traditional knowledge sharing
- A workshop that would assist in giving directions on start up procedures and would familiarize us with all those abbreviations.
- Translating alternative research methodologies into the linear language of funders.
- Addressing the huge disconnect between academic research and CBPR.
- Network weaving: a tool in sustaining CBPR models.
- How to disseminate CBPR results/best practices.

#### *Support for research-ready CBOs*

- Specific mentoring for new research ready CBOs.
- CBO infrastructure building.
- More process examples: 1) how to negotiate an indirect cost rate, 2) processes for setting up a community review board.
- More about starting IRBs.
- Budgeting to benefit the community.
- Community partners as authors.
- Finances of Community partners. How to charge for our services in the CBPR budget.
- Specific skill-building sessions on advocacy and possibly some specific related topics - 101 on NIH, etc.
- How to find university partners.
- What benefits CBOs need to request in the funding as it relates to the budget.
- Infrastructure needed for CBOs.
- Training on how to be registered with the government to get a federal indirect cost rate.
- Law classes educating us of our legal rights as gatekeepers.
- Creating community faculties.
- More startup tools, development tools, and base level evaluation and assessments to help determine if starting an community level IRB is the best for a CBO or to partner with a higher ed institution.

#### *Resolving problems & conflicts with partners*

- Skills around problem-solving issues with university partners.
- Strategies to engage and improve relations and financing between academic partners and partners and community.
- Negotiating the balance of power and where it truly lies.
- Strengthening participatory research relationships.
- Perspectives from academic partners. The relationship is difficult for them as well.

### *Policy, advocacy & systems change*

- Specific policy initiatives and actions that we can plug into or develop.
- More conversations about how to develop specific strategies to engage and hold systems locally and nationally accountable. Graphs showing how the systems work, visuals are important.
- How to use social media to do advocacy.
- Something more advanced in terms of action, not unrealistic and naive like we need an institute of community engagement at NIH.
- Training in advocacy.
- What is policy?
- What are the options for leadership in research advocacy?
- How to build coalitions.
- How to establish and work with affinity groups.

### *Funding*

- Overview of grant application.
- Potential funders who promote CBPR.
- Funding mechanisms to address the needs of communities, capacity building for those that are either not affiliated with an academic institution or that are learning how to figure out the subcontracting process, etc.
- Fundraising.
- Funding for startups.
- Funding

### *IRBs & research ethics*

- More about IRBs (2)
- IRB education.
- Training the IRB member.
- Develop a CITI course like for academic partners on community issues before they can get involved in CBPR.

### *Other*

- Not sure (4)
- How can we relate our role with making health care and public health less expensive for our communities and families.
- The potential for an individual with specialized skills in provision of mental healthcare services to link with CBOs to provide guidance for the psychological needs of certain individuals seeking care who might benefit from the work being done by CBOs and University partners.
- Reframe research as a technical skill: researchers are not above it all, with an unbiased overview of the research and content landscape: they are to be hired by CBOs, like accounting and computer services.
- Social enterprise.
- If there were time and space, a 'burnout' prevention something or other. Not yoga or whatever, but a chance to talk about personal or work frictions/flops/fundlessnesses and how to avoid the temptation to alliterate! ;-)

### **(14) What programs or activities would you like to see CCPH and CCHERS sponsor in the future?**

#### *More national community partner forums*

- More of the same (4)
- More forums that will build on the expertise of community partners.

- Similar forums with a smaller group of people.
- Another community forum before the academics are invited. I think the community partners need one more meeting together before the academics can use this as another example of community engagement.
- A memorable experience all in all. Lets do it again.
- Continue to create effective community partnership forums...
- I think that next year we should include more applicants.....already there are people in my and others' networks who would like to come. There is power in national voice. I hope we can make it happen.
- More summits, definitely, where the attendees are viewed as the experts (as this one was)
- More of the same with various topics especially topics that apply to current funding opportunities.  
Fundraising for this national group to continue to come together - perhaps write a document for others to learn from.

#### *Regional and local forums*

- Regional mini-forums.
- Regional summits might help to engage people that can't afford to travel to national meetings.
- Take this work to the southern portions of the U.S. in order to link with local efforts to address/learn from the work of CBOs in those areas.
- Provide local/state/regional support like the one you are doing in NY.
- Possibly thinking about doing dialogue groups in local communities to include many more community leaders/ participants in those discussions.
- Smaller programs that allow for community members and community based service provider programs to also be included.
- Co-host local gatherings with local funders.
- Regional sub-workshops developed so that they feed into larger multi-regional convenings (this may evolve out of the work groups?)
- Shorter and closer.
- Possibly, single topic, probably local, skills/support workshops around some of the themes identified in this forum. For example, what does policy mean in terms of a local board of health or a local city government?

#### *Forums that include community and institutional partners*

- I would like to see these entities sponsor a follow-up Forum that includes representatives from community-based organizations as well as representatives from research institutions that covers the same 4 Forum priority topic areas in order to further the conversation...
- Discussion with the other half so that we can be on the same page.
- I liked what was described for a possible future meeting with community-academic partners.
- To invite representatives from funding sources as well as academic partners to the Forum.
- To invite academic partners to the forum.

#### *Products/tools/resources*

- Perhaps creating a check-list for grant review boards or manuscript review when CBPR is the stated approach.
- A clearinghouse of all CBPR research and a discussion as to where the research is headed to.
- Members/resources directory.
- Speakers' bureau.
- Develop a resource toolkit on the CCPH website to help community and academic partners to work through the process of partnering and resolving challenges.

- Please publish a glossary of terms commonly used in our work and a listing of the key national funding prospects. There were so many acronyms to learn as someone fairly new to the process. Thank you!

### *Training*

- Skill building on research topics.
- Training workshops for CBOs.
- Training for community organizations.
- Capacity training.
- Training on how to engage new partners in our work.
- Training for new CAB members.
- More advanced policy related issues related to CBPR.
- IRB trainings and literacy trainings in the language of researchers.
- Training in burn out prevention.
- Training on specific topics like qualitative analysis for dummies, fund raising issues particular to the health field, etc.
- How to mobilize a community in addressing social determinants of health.
- A research based proposal review workshop, sample scientific proposal, sample questions that IRB may ask themselves as they pertain to review of proposals.
- Training on community IRB, training on negotiating the process, resources available and how to use the resources like an MOU....
- Training for community persons as IRB members.
- Conferences that focus on best practices of CBPR (case studies).

### *Mentoring*

- Mentoring processes for capacity and skill-building.
- Mentoring programs.
- On-site mentoring where good projects are going on: Hartford? Denver? Chicago? Bronx?
- Knowledge exchanges.

### *Leadership development*

- Leadership training programs (2).
- Leadership development retreats that are fully funded (i.e. do not require attendees to seek funds or sponsorship).
- Leadership and resource development and advocacy.

### *Continuing connections*

- Keep us connected via webinars (2)
- Periodic review and updates of what is happening in the network, the field and sharing opportunities and successful practices
- Follow up with the recommendations given in the forum.
- Opportunities for community partners to stay abreast of what is happening in the research world and what we need to do to stay on top of it.

### *Other*

- Not sure yet (4).
- Retreats for coalition building.
- Networking facilitation.
- Funding forums.
- I recommend that CCPH and the NCC explore a joint venue or session.

## **(15) Do you have additional comments?**

### *Thanks*

- I am thankful for the opportunity to attend the forum and the location (Boston) was great. My gratitude to the planning committee and organizers for this very excellent opportunity to learn, network and understand the value and import of the work and the need to stay together to realize the goals of improvement for the betterment of society.
- Thank you. I learned so much and felt empowered by the energy of the group. Very well organized, thought thru and presented.
- Thank you so much for the opportunity. Great forum!
- Great job Sarena, Elmer, Susan and the Planning Council members!
- Thank you to the organizers and presenters for a job well done. Also thank you to all the people that is doing such a great work for the communities around the country.
- I found this forum to be extremely helpful and there was an abundance of knowledge from the participants alone. Thank you!
- Thank you!
- Thank you very much for inviting me to participate. I feel blessed that I was in a position to travel to this unique gathering and very much appreciate the ways that you are engaged in meaningful work that honors and respects the wisdom within community.
- Thank you so much for allowing me to participate.
- This was a fantastic first experience for me...thank you!!!

### *Comments on the forum*

- The forum was outstanding, I learned so much that I am still processing the information. I wish that it was a bit longer, there was so much information to absorb in a short time frame, had it been an additional day there would have been more time to connect with other participants, if not all of the participants. Overall it was a very beneficial conference for my organization and myself. This will be the beginning of the long-haul work to develop practices which include local community leaders and stakeholders.
- I truly wish I would be given more opportunities to share our experiences, in particular our research efforts among the Asian/Pacific Islander communities.
- I think the first day was a bit long and it was too much information at one time.
- It was absolutely wonderful...
- We all were very impressed by the group of just about 100 participants.
- Overall it was WONDERFUL.
- I expected much more of CCPH and CCHERS. The two sessions I attended on the first day were poorly facilitated and being "talked at" rather than discussed.
- The scheduled was really packed and did not allow for enough time for the community to really chat.

### *CCPH conference in April 2012 in Houston*

- I'm hoping to attend the April conference - this depends on whether [my organization] has the resources to support my attendance. This is uncertain at this time.
- If I have travel funding available or a sponsor, I will participate in the April 18-21 conference.

### *Food*

- Both lunches were delayed by the session going over. In the future it will be important for the lunches to be on time to keep blood sugars at a sufficient level to continue to the conversation,
- I think I was not ok with the foods served in the hotel for the reception.

### *Other*

- Oh, can the next conference be within the same hotel?

**PART 2: Handwritten answers to three questions asked at the end of the forum, completed by 78 participants (87% response rate)**

**(1) What worked?**

*Forum participants*

- Good mix of people with different levels of involvement in CBPR related projects.
- Bringing together leadership from all over the country to meet and exchange ideas – getting together works – that’s why people golf.
- Energy and sense of genuine community.
- The opportunity to meet others from across the nation.
- People and relationship building.
- Gathering of people doing CBPR.
- The contacts made here are unparalleled to anything else I have ever attended. I was very impressed, motivated, and inspired by others who are so passionate and care about the well-being and health of their communities in which they are a part of and represent.
- Bringing together of like minds to improve the lives of our communities.
- Life experience that everyone brought to this event is incredible.
- Bringing together such rich, passionate minds and hearts together.
- The passion shared.
- The connections made.
- The friendship created.
- The diversity and different experiences of the attendees.
- Networking opportunities and energies/ideas generated from the forum.
- Loved meeting and having Elmer.
- Everyone coming together.
- Bringing community members together to share and learn.

*Forum format and content*

- Table discussions (4)
- This is the first time that I’ve seen a “real” shared planning process with a huge group. I’m totally impressed by the passion of all participants and ‘real’ stories shared.
- The content was most appropriate for the work done by CBOs. The critical role CBOs play in community-based research. I feel validated after hearing others share why they do this work
- The format of conference.
- The open discussion.
- Case studies and meeting format.
- Breakout sessions worked well.
- The organization of breakout sessions mixed with table conversations.
- Organizing meeting around 4 clear themes over 2 days.
- Networking and hearing/sharing what we are all doing.
- Small group discussions and informal opportunities to network.
- Case studies.
- The flow.
- Great discussion topics.
- The collaborative learning sessions allowed deep conversations.
- The structure and flow of presentation that ties it all together.
- Networking opportunities.
- Small group sessions and one-on-one discussions.
- Opportunity to network during meeting, dinner, lunch, whenever!
- I liked all the time we had to talk to other people and share ideas.

- The information provided through this networking was wonderful and provided clear steps and processes to follow to organize a tribal IRB for our state.
- It was wonderful to have the discussions and learn so much from so many great minds.
- Good amount of time to schmooze.
- The interaction and exchange.
- The discussion/working group.
- Lots of time for talk, good productivity, collective voice.
- Networking!! Sharing knowledge. Affirming each other.
- Networking, passion of others, and the information provided.
- Lot's of good ideas that we can use.
- I fully appreciated this special space. Thank you.
- Opportunity to learn very specific info on CBPR and CBO's impact and passion.
- The interaction and exchange.
- The level of the conversations.
- Initiating this type of space/forum in the first place.
- Great learning and networking.
- Lot of ideas.
- Great information, people and facility.
- Lots of energy, connection and development created.
- Sharing.
- Got us all together.
- Open forum to learn from each other.
- Solution-focused brainstorming.
- Great sharing of experiences, discussions, engagement and set-up.
- Getting out ideas.
- Shared information.
- Collaborative thinking.
- Collaborative decision-making.
- Exchange of experience and ideas.
- The group dynamics were very good.

#### *The investment in planning*

- The planning team working hard Tues night to prepare the summary.
- The planning!
- The coordination.

#### *Space & logistics*

- Accommodations.
- Food was provided.
- Great locations.
- Location was great!
- The facility.

#### *Other comments*

- After much anger with my academic partner, I feel strong and ready for continued struggle.
- Community came together.
- The national platform.
- Amazing wisdom and energy merged in the name of social change.
- Great forum.
- Will pass this info to those who are a better fit than me.
- Everyone's email was given out.

- Whew! It was good.

## **(2) What would you change?**

### *The agenda*

- Have pre-meeting workshops.
- Better introductions.
- An opportunity to meet with similar CBOs and discuss what they do
- A bit more of a story in the beginning to give context.
- Large group speak outdid not help ensure that everyone was heard from – in contrast, smaller groups worked better.
- More small groups – mentoring of new and old leaders.
- More case scenario sessions.
- Add another afternoon session to fully close out the event.
- Length of workshop and structure of afternoon session.
- Not clear about the transition from day/case study and the last discussion session.
- A lot of sitting – hard to contribute by end of the day!
- Unstructured receptions.
- More time to learn and process.
- A greater space for those of us who have just begun the work.
- Mentorship opportunities.
- Share more about the organizations involved.
- Broad themes need to be ironed out and made more concrete.
- More opportunities for new CBOs to connect with seasoned professionals to engage in dialogue around moving the needle.
- Training topics to include more strengthening of CBOs.
- Longer time and more structured small group discussions.
- Ways to break the ice and pair people with mentors and more connected/knowledgeable members.
- More strategies for dealing with academics and funding institutions.
- More structure in the summary and where do we go now session.
- An improvement in the closing sessions.
- Coming to consensus.
- More defined closing.
- Tighter ending (e.g., tables to discuss workgroups before volunteering).

### *Participants and speakers*

- Think a better job could have been done in terms of including grassroots groups.
- CBOs given opportunity to lead and facilitate sessions, not just planning members.
- Having more of my colleagues here.
- Bring more players to the table.
- Heard there were thoughts/efforts to bring power players – NIH, Institute of Medicine, elected officials, etc. to this meeting. Have us present our recommendations to them at next meeting/gathering.

### *Forum length*

- Add one more day (3).
- Longer conference.
- This needs to be at least 3 days (full).
- More time to further develop work, timelines and assignments.
- We need more time and an extra day to do the workgroups.

- Change to a longer time.
- Not enough time.

#### *Handouts*

- Provide evaluation forms (3).
- Provide writing pad (3).
- Include photos with participant bios.

#### *Meeting food & logistics*

- More snacks during breaks (6).
- Better food (2).
- Have coffee/drinks available throughout the conference.
- More heat in room.
- Different rooms – hard to hear as hearing impaired.
- Keep to agenda times.

#### *Meeting location*

- Space – keep meeting and lodging in one place (2).
- Traveling outside of hotel for actual meeting.
- Shuttles to/from hotel & Northeastern University.

#### *Other comments*

- Nothing (2)
- The propensity to want to “have” what the academics “have”---would like more slant to creating something new and to question research in general.
- What I would change would be more resources to potentially tap such as grant announcements, private foundations, and other creative ways to help begin the process of building such an infrastructure from the ground up.
- I don't know.

### **(3) What is one action step you're going to take?**

#### *Participate in workgroups*

- My group will be meeting monthly.
- I am signed up for a workgroup and will be having meetings to update the planning committee.
- Get involved in the workgroups.
- Meet with workgroup on Monday.
- Meeting with my workgroup.
- Participate on workgroup.
- Work on leadership workgroup.
- Will participate in leadership development group.
- Communication to continue among the groups that were created.
- Participate in workgroup.
- Stay connected. Join a committee.
- Be a part of a workgroup.
- Stay connected through workgroup.
- Streamlined coordination for workgroups.
- Join workgroup.

### *Share info and take action back home*

- Share info with partners and connect with networks.
- Take this info and resources back to my own community.
- This forum motivated me to send an email out and now I have a series of meetings that will be set up to possibly start a school that uses PAR (or CBPR) as a focus.
- I intend to talk to the university PI working on one project to explore how we can integrate CBPR as a continued approach to working with communities.
- Distribute info and develop letter to be sent to NIH.
- I would like to replicate this process with our network and partners.
- Bring back tools to my CBO.
- Debrief and share with academic partners.
- Taking findings and recommendations back to my CBO.
- Stand firm with our partner institution.
- Disseminate my experience in this conference.
- Meet with community partner.
- Share wisdom experienced.
- Share CBPR skills with researchers.
- Explain real CBPR to community members.
- Will identify champions of CBPR back home.
- Continue this movement forward.
- Re-engage the community!
- Engage the funders (foundations).
- Implement bringing community to more meetings.
- Use MOUs.
- Following up with training and mentoring opportunities and facilitating a structured approach to internal capacity building.
- Contact university partner regarding federally indirect cost rate.
- Will meet with other community partners and academic partners to begin developing a coalition.
- Will pass this on to colleagues who should be a part of this effort.
- Share info within my networks.
- Hope to develop community IRB board for tribes in my region.
- Continue development of CBPR/clinical trials; critical training model for communities. Plan to share in the future.
- When I arrive back home I will begin organizing a statewide tribal IRB to represent all tribes in my state.
- I want to write!
- Replicate the forum on a local level.

### *Follow-up on resources*

- Read CBPR manuals – one I have and one I'm going to order.
- Will get hold of the resources I heard about.
- Review CCPH website.
- Get resources (research is ceremony, community engagement).
- Review list/emails more intently.
- Join CCPH as an individual and as an organization.

### *Expected forum follow-up*

- Ensure that all info gets disseminated to participants as a means for taking us to the next level.
- Sending out notes – will be looking forward to the notes.
- Receive info re: specific topics.

*Other comments*

- A movement is forming!
- Energy from the group to continue this work.
- The energy I will take home with me.
- New partnerships.
- Community can be PI (principal investigator).
- Research is our knowledge and experience.
- I need leadership coaching to institutionalize shifts in education, power, money and influence.
- Thank you for the opportunity to join and participate in such an amazing form – hope to see you all soon!
- Great job.