

**Consultation with the National Community Committee
November 18, 2009
Summary of the Conversation**

CCPH-CTSA Member Interest Group participants (and their CTSA affiliations)

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NCC participants (and their PRC affiliations)

Katie Barnes, North Carolina PRC
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Ella Greene-Moton, Michigan PRC
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History behind this call: The CCPH-CTSA member interest group, comprised of Community-Campus Partnerships for Health (CCPH) members affiliated with Clinical and Translational Science Awards (CTSAs), has been meeting regularly by phone since March 2009 to share information, address common challenges, and support each other as a force for change re: community engagement and community-engaged research within the CTSA program and beyond. The National Community Committee (NCC) of the Centers for Disease Control and Prevention (CDC) Prevention Research Center (PRC) program has been mentioned on the calls a number of times as a local and national model of community engagement in research. This consultation call was scheduled to provide an opportunity for CCPH-CTSA interest group members to ask questions of the NCC and explore its relevance to the CTSA program. The call was preceded by a 90 minute public presentation by NCC members about the history, accomplishments, lessons learned and future directions of the NCC. The audiofile and handouts from the presentation are available at <http://depts.washington.edu/ccph/pastpresentations.html>

Who represents “community” on the NCC? One of the challenges that NCC had early on was clarifying who the NCC representatives from each PRC should be. As explained by NCC reps on the call: We are still working through some of those issues but we’re pretty much on the right track in understanding that NCC is a place for community reps (and most often we mean grassroots community members and representatives of grassroots community-based organizations) to come together and network and be able to experience opportunities for capacity building. What we found early on, when we did not prescribe who needed to be at the table, was that not all PRCs were as engaged with their communities as they should have been. When we first formed the NCC, we had to recognize the fact that when the PRC program first started there was no requirement for a community committee or community reps, so PRCs that were part of the initial round of funding didn’t have grassroots community partners. We have evolved over time and now one of our stronger points is that if a PRC has

a community-academic liaison at its rep to the NCC – even if that person is housed at the academic institution – we don't fight as much against that person being a member of the NCC but we ask that they bring a grassroots community person with them to help ensure that community perspectives are heard at the NCC and to help strengthen the work that's being done at the local level. There are community-academic liaisons who are representing their PRC on the NCC, but we ask that they bring the community's perspective and to share the voice of the community. They understand that they are there as a representative of the community.

PRCs take different approaches to determining who their NCC reps will be. For example the Community Action Council of the North Carolina PRC elects two NCC representatives, and these can include community-academic liaisons who are employed by the academic partner. In Michigan, a practice partner or community-academic liaison would not be able to serve on the NCC because they have by-laws re: who the community reps can be and they must be from grassroots community-based organizations (CBOs).

What is the difference between comprehensive PRCs and developmental PRCs? Developmental PRCs were established to acknowledge the time it takes to develop the trusting relationships and partnerships that are essential to the PRC model. In the last funding cycle, CDC funded 30 PRCs at the comprehensive level. These had to show that they already had partnerships in place and were ready to hit the ground running with a research project. Five PRCs were funded at the developmental level, to help them develop the structure for a “full blown PRC” and to develop community partnerships. They developmental PRCs are required to complete a pilot research project, but the focus is more on developing partnerships and infrastructure than research.

What are the expectations for community involvement in the CTSA program? How are community partners involved now? CTSA reps on the call made these comments:

- There are different levels of community involvement at CTSA's across the country. Some CTSA's have very strong community engagement cores, with strong community boards or other mechanisms for community involvement in guiding their direction and decision making.
- It is important to remember that the community engagement core of a given CTSA represents only about 2-3% of that CTSA's budget.
- There are very small slices of support for the community. Health disparities are getting worse every year and the current system – totally controlled by the academic and medical establishment – is not working.
- Community is sometimes defined broadly by CTSA's and this can cause conflicts. One example given was for a community education program that community partners wanted focused on grassroots community members, but the CTSA was pushing to also include educating community physicians.
- At the national level, there hasn't been clear communication or explanation as to the role and responsibility of community partners in the CTSA program. The National Center for Research Resources (NCRP) at the National Institutes of Health (NIH) and the CE KFC are trying to figure out how best to include community partner perspectives and representation at the national level. Unlike the development of the NCC, which was initiated and driven by community partners, these efforts are being driven by NCRP/NIH and academics involved in the CTSA program. What seems to be being proposed by NCRP/NIH is a community advisory body to the national CTSA CE KFC, but no community participation on the CE KFC itself or other CTSA KFCs. When the idea was brought up on the last KFC CE call, there were a lot of concerns raised by CE KFC members about the apparent lack of support for community representatives to

participate (e.g., no funding for their time or travel, no dedicated staff support within NCR/NIH). There was a lot of push back about the idea.

- A new Community Partner Integration Committee (CPIC) of the national CE KFC has been formed and has met several times by phone. The CPIC was formed by NCR/NIH and started out with members from CTSA institutions, but the committee is also inviting community participation to ensure that the discussions are informed by community perspectives. The CPIC is trying to get clarification from NCR/NIH staff as to what role if any the CPIC will have in the development of the advisory body referred to above. It is unclear what if any role the CPIC will be in determining the proposed body's purpose, composition, etc.
- Few community partners participate on the CE KFC calls and there is no explicit invitation for them to participate. They may coincidentally be on the calls because of specific roles they play in their CTSA's community engagement core, but they are not invited to participate as community reps from each CTSA. They are allowed to participate, but each CTSA has only one voting member of the CE KFC and these are all academics. The way the CE KFC calls are structured, they are incredibly unwieldy with dozens of people on the call and no work really gets done on them. It's in the smaller committees that there is more opportunity for substantive conversations and work to get done. All this being said, it can be challenging to engage community partner participation on national CTSA calls. They are already giving a lot of their time and expertise – they are busy people and for the most part are not being compensated.
- It's a delicate situation. We are at the beginning of a very long evolution. The efforts to involve community partners in the national CTSA program have largely been directed by NCR/NIH. For community reps to be more fully involved, this is going to take a long time.

NCC reps on the call explained that support for community partner involvement in the PRC program was an evolution over time. NCC is a partner within the PRC program and works with the PRC program as a whole. NCC is one of 7 committees that help to shape PRC (others include research, communications, policy, etc.). Each committee is represented on an overall PRC steering committee. It took several years to get NCC recognized as a committee. Now, NCC reps serve on every committee, not just the NCC and steering committee. This helps to ensure community participation in all of the PRC committees and a direct feedback loop between the committees and the NCC.

When the NCC first started, there was no support for community members to come together other than what was voluntarily provided by local PRCs. In the last two funding cycles, the PRC program has built in support for community partner participation within the Funding Opportunity Announcements (FOA). In the last FOA, each PRC had to identify reps to be on the NCC. In the current FOA, funds must be included in the budget to support NCC reps attendance at PRC and NCC meetings. The PRC program office provides additional support to the PRC that hosts the NCC annual planning meeting. Sharrice's position as community liaison to the NCC was created in 2002, and she now spends the majority of her time on the NCC. These supports built into the structure of the program were viewed as critically important.

Strategies for increasing community partner involvement in the CTSA program: The group on the call discussed a number of strategies for increasing community partner involvement in the CTSA program:

Identify advocates or champions within NCR/NIH and among CTSA

Several NCC reps observed that “it sounds like you have a challenge with the funding agency” and that “you need to have frank discussions about how you're supposed to be including community but

community is not included in the program's structure." They recommended identifying an advocate or champion within NCRR/NIH and working with them to find a way to have a forum for community voice to come forward. This was instrumental to the development of the NCC. The PRC program director at CDC at the time articulated a priority for community engagement and identified that CDC "needed to walk the walk," thereby opening the door for new mechanisms for community engagement in the PRC program. It wasn't welcomed by all the PRC directors. Some embraced it, others had an interest but were concerned that they didn't know how to do it, and others did not support it at all. Three PRC directors stepped forward to say this was really important and we need to help support it.

View your role as community advocates for community partners

What's so powerful about the NCC is that it was formed and led by community partners. This process can't be controlled by NCRR/NIH staff or the academics. CTSA community partners and institution-based leaders of the CE core function within CTSA need to instigate change and to help create spaces for conversations. Political advocacy is also an option that needs to be considered. NIH is funded by Congress and listens to Congress. Strategically timed inquiries from members of Congress to NIH can be influential, for example.

Look for opportunities to integrate community partners within the CTSA structure and build from there
Right now the NCRR/NIH is talking about a community advisory body to the CE KFC. This may not be as influential or wide-reaching a structure as the NCC, but it's a viable place to start. If successful, it could begin to open the door to community involvement in other parts of the CTSA program nationally.

Forge connections between CTSA and PRCs

Some CTSA are located in geographic proximity to PRCs, and some involve the same academic institutions. These connections at the local level need to be made. We should also share the audiofile and handouts from today's NCC presentation with NIH/NCRR staff and CE KFC members. It was recommended that Sharrice have a conversation with NIH/NCRR staff about the NCC and the ways that the CDC PRC program office supports it. Sharrice indicated that she is going to talk with Eduardo Simoes, director of the PRC program at CDC, about today's conversation. He has presented to the CTSA several times and has mentioned the NCC in his remarks. He is a champion of the NCC and can help to contribute to the development of mechanisms for meaningful community involvement in the CTSA program.

Increase community partner participation in the CCPH-CTSA member interest group.

The CCPH-CTSA member interest group presents an opportunity for CTSA community partners to connect with each other. A few CTSA community partners who are CCPH members have been participating in the CCPH-CTSA member interest groups calls. CCPH will go back to the original survey that identified CCPH members involved in CTSA and remind everyone about the interest group calls. Institution-based members of the interest group will be encouraged to identify and invite community partners who are interested in being involved in the interest group calls to join the calls.

Take advantage of Spring 2010 regional conferences on community-engaged research

A series of regional conferences on community-engaged research are taking place in March and April 2010 (see list below) that are opportunities for CTSA community partners to organize and voice support for greater community partner participation in the CTSA program. These are being funded by the CDC through a cooperative agreement with the Association of Prevention Teaching and Research. They are being designed for CTSA participation, but anyone can register for them. The group discussed the merits of having a consistent message that could be shared at each of the regional conferences. The

NCC reps on the call offered to publicize the conferences among NCC members and encourage their participation.

Conferences marked with * are being co-sponsored by CCPH. Conferences marked with + feature CCPH presenters.

*+March 11 – “Partners for Health: Communities and Researchers Working Together” – Loma Linda, CA – http://www.atpm.org/prof_dev/community10_loma_linda.html

March 18 – “Partnering with American Indian Communities in Health Research” – Omaha, NE – http://www.atpm.org/prof_dev/community10_nebraska.html

*+April 6 – “Taking it to the Curbside: Engaging Communities to Create Sustainable Change for Health” – Boston, MA – http://www.atpm.org/prof_dev/community10_harvard.html

April 15 – “Outcomes that Matter: Translating Community-Engaged Research into Improved Health” – Durham, NC – http://www.atpm.org/prof_dev/community10_duke.html

+April 20 – “Researchers and their Communities: Rewarding the ‘Meaning’ in Meaningful Community Engagement” – Albuquerque, NM – http://www.atpm.org/prof_dev/community10_new_mexico.html

*+April 23 – “Improving Children’s Health through Community-Engaged Research” – Ann Arbor, MI – http://www.michr.umich.edu/news&events/children_health.html

Link with organizations that represent CBOs that are involved in community-engaged research
In addition to CCPH and the NCC, the National Community-Based Organization Network affiliated with the Community-Based Public Health Caucus of the American Public Health Association conference was also mentioned.

Be explicit about the definition of community

Each CTSA needs to develop its definition of “community.” That definition can drive answers to questions like “who represents community” and “who should represent community on a national CTSA committee?” For example, the Michigan PRC talks defines community as “the folk being researched.”

Other topics and action items: Fran asked about resources that might be helpful in her work with community partners to translate research into policy change. Suggestions included 10 case studies of CBPR partnerships that have led to policy changes (see: http://depts.washington.edu/ccph/pdf_files/CBPR_final.pdf) and the audiofile and handouts from CCPH’s October 21 educational conference call on participatory policy analysis (see: <http://depts.washington.edu/ccph/pastpresentations.html>)

Jen indicated she would keep CTSA reps on the call informed about upcoming CPIC calls. Call agendas and meeting summaries are posted on the CTSA website at http://www.ctsaweb.org/index.cfm?fuseaction=committee.viewCommittee&com_ID=1041&abbr=