

Community Partner Policy Workgroup
Meeting Minutes
Wednesday, January 16, 2008

Participants:

Jennifer Hawes-Dawson, Community Liaison, RAND Center – Prevention Research Center (at UCLA), Los Angeles, CA

Loretta Heuer, Migrant Clinicians Network, Collaborative Coordinator, Grand Forks, ND

Ilda Montoya, Research Manager, Mt. Auburn Hospital, Cambridge, MA

Molly White, Univ. of Michigan, Community Engagement Program Manager, Ann Arbor, MI

Kristine Wong, Program Director, Community-Campus Partnerships for Health, Seattle, WA

Meeting

Each person introduced herself by giving some background into what projects they are working on, as well as their interest in joining the workgroup.

Ilda Montoya is working at a small community-based hospital (Mt. Auburn) that is part of the Clinical and Translational Science Award (CTSA) consortium organized by Harvard Medical School. They are working on the community engagement piece, but she has found that the community-based part of the consortium is looking to engage with the academic end of the consortium on how they will implement the community engagement piece.

Jennifer Hawes-Dawson works with the RAND Center's Prevention Research Center at UCLA. They have a community advisory board. Jennifer's role is to facilitate partnerships with local groups.

Molly White is also working on community engagement as part of the University of Michigan's CTSA. They are working on developing relationships with groups around the Ann Arbor area. She also serves on the national Community Engagement Steering Committee for all CTSA's.

Loretta Heuer is the Collaborative Coordinator for the Migrant Clinicians Network, is involved with their IRB, and also works with Latino farmworkers.

Kristine gave the group background information on how the Community Partner Workgroups got started [through the Community Partner Summit (CPS) that was held in April 2006], and gave a history on what the Mentoring and Policy workgroup has been doing to date. She reemphasized that the group is open only to community partners and community-academic liaisons. Kristine also referred folks to the CPS report for a general overview of what was discussed, as well as recommendations and next steps. The link to this report is: <http://depts.washington.edu/ccph/cps-summit.html#Products>

Some of the work that the Policy group has been doing includes:

-Determining who federal agency funding contacts are, and talking to them about some of the challenges community groups face when responding to requests for proposals, as well as proposals that are not designed appropriately for community partners. The workgroup first decided to try to interview funders, but when they found resistance, they felt that it was better to take a more proactive approach and start developing some of the things they felt were needed (e.g., a training for reviewers of CBPR grants).

-Most recently, the workgroup has responded to a number of national calls for feedback in regards to the National Institutes of Health (NIH)'s Peer Review Process, and the NIH's National Center for Research Resources (NCRR)' Strategic Plan. The workgroup's comments focused on the need for NIH to structure their funding and review mechanisms in a way that was more conducive for equal community partner support, as well as building infrastructure for these groups in CBPR. After submitting their comments, they have not had a response back to date, and were disappointed to see that when NCRR posted a summary of comments about feedback that was given to the Strategic Plan, the community engagement concerns were not mentioned.

CCPH has also met with several people at NIH and NCRR, and feel that their CTSA funding program is a great opportunity to make change in the community engagement area in a large scale – precisely because there is a mandate for all CTSA's to implement community engagement. However, there is no formal guidance on how to interpret the community engagement piece. CCPH realized that there is broad interest from CTSA's nationwide in this area when several representatives from different CTSA's started contacting CCPH in regards to the IRB/REB training workgroup they were developing (to teach IRB's/REB's about CBPR and how to review CBPR protocols).

Kristine asked the group to speak about some of the issues they were facing, and how this workgroup might be able to address those issues in a policy framework that would directly meet the needs of community partners/liasons. In response, the group talked about their experiences in working with local communities in the area of research. They have found that the trust is not there, due to the fact that these institutions have not engaged with communities in the past. To address this, they feel that there needs to be some way to introduce communities to what research is, as well as what the challenges are, and how to develop a two-way dialogue from that point. Community members have shared with them that part of this barrier with the university is that they do not know how to approach the institution, because they do not know who to contact in regards to their concerns. For those who are working with CTSA's, they feel that it would help to be able to have some tool or model of support to go about doing community engagement in regards to research.

Additionally, someone mentioned that institutions don't always see the connection on how research results can be used to improve community health, and do not welcome the

results when it means there needs to be a change in policy/process. Someone else mentioned that there needs to be more of a focus on translating research results to policy.

The group agreed that working on developing some sort of guidance or tool for the CTSA's would be a good place to start, but that they needed to learn more about these programs. The group agreed that we needed to be working with the NIH CTSA staff people on a national level to see if there is buy-in and interest to actually develop such a guidance. Kristine added that she felt that it was important that this guidance come from from the NCRP itself, otherwise there was no way to be sure that the guidance or model the group devised would have any teeth. If there was interest on behalf of folks at NCRP, we could work with them to develop the guidance or model. Jennifer Hawes-Dawson also said that the CDC Prevention Research Center's National Comm. Committee (33 members across the country) might also be interested in being a part of this (i.e., working with them to develop a guidance for the Prevention Research Centers). Kristine mentioned that two people on that committee did attend the Community Partner Summit (Ella Green-Moton and Yvonne Lewis), and that we could talk with them to get their feedback and flesh out this plan further.

To get everyone up to speed on these issues, Kristine suggested that people take a look at the CTSA website (www.ctsaweb.org), and that people involved in the CTSA's and the PRCs could forward any informational material to workgroup members (of course, only information that is permissible to share with others).

Kristine mentioned that at the end of the month, she will be meeting with the NIH's Clinical Research Ethics Workgroup Coordinator for the CTSA's, and will bring up this workgroup's interest (as well as the interest on behalf of the IRB/REB training/curriculum workgroup that CCPH and the Tuskegee Bioethics Center are co-facilitating). He will be briefing the NIH Community Engagement Steering Committee Coordinator about our meeting as well, since she cannot attend. Kristine will also get more background information about what the Workgroup and Steering Committee has been doing in this area, and what they are planning to do in the future. Hopefully, there will be some ways that the groups can work together. Molly also mentioned that she could serve as a liaison to the CTSA Community Engagement National Steering Committee as well, as we move forward.

Kristine asked each person to evaluate how the meeting went for them, and whether or not they would return for the February meeting. Each person responded positively, and that they would look forward to participating in the next call. Minutes will be sent out via the Policy listserv, and in February, CCPH will develop a password-protected area for the Community Partner Workgroup, where members can access minutes and documents.

The next call is: Wednesday, Feb. 13, at 1:30 pm PST/4:30 pm EST. Access codes will be sent out before the call.