This document was submitted on June 2, 2008 in response to
NOT-RM-08-014, Request for Information: To Solicit Ideas for Common Fund / Roadmap Trans-NIH Strategic Initiatives
http://grants.nih.gov/grants/guide/notice-files/NOT-RM-08-014.html

Short Project Title: Realizing the Promise of Community Engagement in Research

Problem/Opportunity: Increasingly, the NIH is identifying community engagement in research as central to increasing public trust in and support for research, overcoming the barriers of translating research from "bench to bedside to community" and addressing our nation's most pressing health concerns. *For example:*
- Dr. Zerhouni recently added "participatory" to his set of guiding principles to transform the clinical research enterprise.
- The Clinical and Translational Science Awards include a community engagement core.
- A growing number of NIH funding announcements – some from individual ICs and some that cut across multiple ICs – explicitly require community-academic partnerships or community-based participatory research approaches.
- A growing number of NIH institutes are explicitly seeking to involve community members as peer reviewers.
- The NIH Director's Council of Public Representatives has established the Role of the Public in Research Workgroup to encourage researchers to involve the public in research.

NIH makes substantial investments that support faculty members and academic institutions to engage communities and to conduct research in and with communities, but almost no such investment is made in the parallel infrastructure needed in *communities.*

Approach: Below we outline a multi-pronged approach to building the capacity of community-based organizations (CBOs) to develop authentic partnerships with academic institutions and to develop their knowledge and skills to conduct research.
- *Develop an aggressive and robust outreach and engagement program to ensure that CBOs provide input on NIH policy and strategic directions, access NIH funding and serve as peer reviewers.* Unless one is deeply entrenched in the NIH process, NIH is difficult to navigate and understand. A clear and succinct communications strategy to reach CBOs is needed, including technical assistance workshops specifically designed for them that cover such topics as demystifying NIH and the research funding process, explaining NIH grant applications instructions (to make them more accessible), navigating the IRB process and obtaining a federally negotiated indirect cost rate.
- *Develop community partner mentoring & training programs.* Programs are needed that enable CBOs with research experience and expertise to mentor and train less experienced peers, as well as cross-mentoring programs between institution-based researchers and community partners.
- *Provide community partners with structures and mechanisms to have a voice within NIH initiatives that fund community-engaged research.* Giving communities their own space to connect and serve as resources for each other, and to have a direct communications link to NIH staff, is crucial to the long-term success of these initiatives.
- *Facilitate the ability of CBOs to be principal investigators (PIs) and directly funded organizations.* Very few NIH grants support individuals without doctoral or medical degrees as PIs. It is not enough to point to eligibility criteria on paper that indicate that community and faith-based organizations can apply. The reality is that few apply and even fewer are funded. Mechanisms and metrics are needed to document and assess relevant life and work experiences of community partners. The above-mentioned technical assistance workshops, mentoring and training programs would also help address this issue.
- *Align the array and duration of grant mechanisms with community-engaged research.* Just as having funding for requisite lab space and supplies is crucial to successful basic science research, funding is needed to support the relationship-building and partnership infrastructure that is essential to successful community-engaged research.
- *Ensure fair and equitable peer review of community-engaged research.* When communities are partners in research, they need to be included as peers in the peer review process. The few NIH review panels that include community-based reviewers are still dominated by academics and a culture that may prevent community members from speaking freely. A standing study section to review these applications is needed, comprised of an equal number of academics and community members with community-engaged research experience and facilitated by community and academic co-chairs. Similarly, the NIH advisory councils must also have community members serving on them.
- *Develop review criteria and scoring procedures that are appropriate for community-engaged research.* Standard NIH review criteria overlook key aspects of community engagement in research. Reviewers are asked to assess "scientific and technical merit," but in community-engaged research, for example, these must include the nature and extent of community participation and the authenticity of the partnership.
- *Evaluate community engagement efforts and disseminate findings and best practices.* An evaluation is needed of the nature, extent and impact of community engagement in NIH funded programs and at NIH as a whole. The substantial public investment in NIH demands this level of accountability, not to mention the important role the findings will have in informing "the field" and future practice and policy. NIH grantees that involve community-engaged research should be convened for the purpose of building collective knowledge, sharing experiences and lessons learned, and providing feedback to NIH for how to best support these efforts. These meetings should involve academic and community partners and can serve as one setting where cross-mentorship to take place.
- *Invest in NIH staff that have knowledge, experience and expertise in community engagement and community-engaged research.* This proposal will only be successful if NIH has internal capacity in these areas among its staff.

Terms: Community engagement**,** community-based research, community-academic partnerships, community-NIH partnerships

Submitted by: Community-Campus Partnerships for Health (CCPH), on behalf of the organizations listed in alphabetical order below. Citations for supporting literature and model programs that could inform this effort will be provided by CCPH upon request to CCPH executive director Sarena Seifer at sarena@u.washington.edu

Asian & Pacific Islander American Health Forum, http://www.apiahf.org
Asian Pacific Islander Caucus of the American Public Health Association, http://www.apicaucus.org/
Association of Asian Pacific Community Health Organizations, http://www.aapcho.org
Community-Campus Partnerships for Health, http://www.ccph.info
Education Network to Advance Cancer Clinical Trials, http://www.enacct.org
Harlem Community & Academic Partnership, http://www.harlemresourceguide.org/aboutus.htm
Health Research for Action Center at the University of California at Berkeley, http://healthresearchforaction.org/
National Association of Community Health Centers, http://www.nachc.org/
Urban Indian Health Institute, Seattle Indian Health Board, http://www.uihi.org/