



October 25, 2006

TO: Dr. Zerhouni and Members of the NIH Council of Public Representatives
FROM: Sarena D. Seifer, Executive Director, Community-Campus Partnerships for Health
RE: Role of the Public in the Research Process

Thank you for the opportunity to submit public comments as you deliberate on the important topic of public participation in the research process. These comments are in addition to those we submitted on October 20, 2005 regarding the preparation of public members to participate in the NIH peer review process.

Community-Campus Partnerships for Health is a nonprofit organization that promotes health through partnerships between communities and higher educational institutions. Founded in 1996, we are a growing network of communities and campuses across the US, Canada and increasingly the world, that are collaborating to promote health through community-based participatory research, service-learning, broad coalitions and other partnership strategies. We advance our mission through information dissemination, training and technical assistance, research and evaluation, policy development and advocacy, membership development and coalition building.

Community participation in research – indeed, community as *partners* in research – is central to our mission and work. We support community-based participatory research (CBPR), defined as “a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process; with all partners contributing their expertise and sharing responsibility and ownership to enhance understanding of a given phenomenon, and to integrate the knowledge gained with interventions to improve the health and well being of community members.”¹

Historically, research has rarely directly benefited and has at times harmed the communities involved, excluded them from influence over the research process, and resulted in understandable distrust of, and reluctance to participate in, research. In many communities, particularly low-income communities and communities of color, research is viewed as a “dirty word” and terms like “parachute research”, “helicopter research” and “drive-by research” are used to describe how researchers come into a community, collect their data and leave. Health interventions have often not been as effective as they could be because they are often not tailored to the concerns and cultures of participants, rarely include participants in all aspects of intervention design, implementation and evaluation, and are focused narrowly on individual behavior change with less attention to broader social and structural issues. CBPR offers many advantages over traditional approaches to research,^{1 2} because it:

- Overcomes separation of individual from culture and context
- Joins partners with diverse skills, knowledge and expertise to address complex problems
- Establishes trust between communities and researchers
- Improves research quality and validity by engaging local knowledge and theory
- Studies and addresses community-identified needs
- Enhances relevance of research questions & data
- Translates research into practice and policy change
- Increases community capacity for research
- Improves health and well-being of communities involved to effect political and social change

NIH does of course fund CBPR and in the past few years has issued a number of announcements that specifically request CBPR proposals (i.e., PAR-05-026 Community Participation in Research, RFA-MD-05-002 Community Participation in Health Disparities Intervention Research, RFA-HL-06-002 Community-Responsive Interventions to Reduce Cardiovascular Risk in American Indians and Alaska Natives). **However, its overall**

investment in CBPR has been quite modest and we believe should be substantially increased. A CRISP database search using the term CBPR yields 84 “hits” for the period 2000-2006 (by comparison, a similar search using the term RCT yields 716 “hits”). Further, NIH research funding mechanisms can undermine CBPR by placing power and control in the hands of academics: While on paper, community-based organizations are eligible to apply for NIH research funding, few apply and even fewer are funded. The Community-Level Health Promotion Study Section has no community-based peer reviewers, and while some do serve on the Special Emphasis Panels for PAR-05-026, the panels are predominantly comprised of academics. In the words of a community leader who attended a summit we recently convened on community-higher education partnerships, *“NIH is an exclusive club. The walls around it are impenetrable to community people.”*

We urge you to (a) embrace CBPR as a strategy both for engaging communities as partners in the research process and for increasing the quality and impact of research; and to (b) advocate strongly that NIH increase its support for CBPR in these tangible ways:

1. Develop funding streams to build the capacity of community-based organizations (CBOs) to conduct research and to engage as equal partners in research with academic institutions. These could support, for example, training programs that equip CBOs with knowledge and skills to conduct research and mentoring programs that enable CBOs with CBPR expertise to guide less experienced peers.
2. Develop funding streams that support the relationship-building and partnership infrastructure that is so essential to successful CBPR (RFA-MD-05-002 was a good start).
3. Form a standing study section to review CBPR proposals, comprised of an equal number of academics and community members with CBPR experience and expertise who have been properly prepared.
4. Ensure that any NIH funding announcement that includes a community engagement component have reviewers with experience in community engagement and CBPR (including community-based reviewers).
5. Align the standard NIH review criteria with CBPR approaches. For example, in CBPR, the budget and how funds are distributed is critical to assessing whether an authentic CBPR partnership is in place. The NIH review for CBPR proposals should therefore include an assessment of the budget in the scoring.
6. Develop an aggressive and robust outreach program to ensure that CBOs have opportunities to access NIH funding and provide public input on NIH policy and strategic directions. This should include regional technical assistance workshops on the NIH funding process specifically designed for CBOs that cover such topics as demystifying NIH and the research funding process, navigating the IRB process and obtaining a federally negotiated indirect cost rate.
7. Convene NIH grantees that incorporate a CBPR approach, for the purpose of building collective knowledge, sharing experiences and lessons learned, and providing feedback to NIH for how to best support CBPR. These meetings should involve principal investigators *and* community partners.
8. Convene a meeting of public and private funding agencies in the US and in Canada that have made substantial investments in CBPR, to identify and share “promising practices” and to inform NIH policy.
9. Resume leadership and staff support for the Federal Interagency Working Group on CBPR.
10. Identify and report annually on: mechanisms in place at NIH to ensure that CBOs have opportunities to access NIH funding and provide public input on policy and strategic directions, the number and dollar amount of grants that incorporate a CBPR approach, and the number and dollar amount of grants that have a CBO grantee/principal investigator.

Thank you again for this opportunity to share our perspectives. We look forward to working with you to clarify and help implement these recommendations. I can be reached at 206-616-4305 or sarena@u.washington.edu

¹ Israel BA et. al. Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health 1998. 19: 173-202.

² Viswanathan M, et al. Community-based participatory research: assessing the evidence. Summary, evidence report/technology assessment, No 99. Rockville, MD: RTI-University of North Carolina Evidence Based Practice Center & Agency for Healthcare Research and Quality (AHRQ); 2004 August 2004. AHRQ Publication 04-E022-1.