

Community Leaders from Across the U.S. Call for Health Research Equity & Impact

Highlights from the 2nd National Community Partner Forum • December 5-7, 2012 • Washington DC

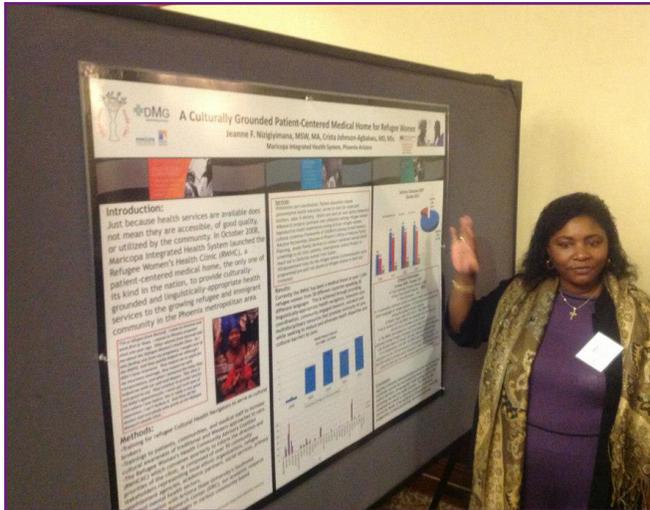


Community engagement in research is essential to understanding and addressing racial, ethnic, linguistic and socioeconomic disparities in health. Research funding agencies are supporting faculty members and academic institutions to engage communities as partners in conducting research. Often missing from these investments, however, is the support for research capacity and infrastructure that is vitally needed *in communities*. As more community organizations enter into research partnerships with institutions as well as initiate and conduct research, it is clear they need funding and research resources as well as supportive networks for professional development, mentoring and advocacy. Toward that end, Community-Campus Partnerships for Health (CCPH) and the Center for Community Health Education Research and Service (CCHERS) obtained funding from the National Institute of Minority Health and Health Disparities (NIMHD) for the first National Community Partner Forum on Community-Engaged Health Disparities Research, held December 7-9, 2011 in Boston, MA.

There is an enormous amount of power and knowledge in the community.

Designed “by and for” leaders of community organizations engaged in research, the inaugural forum drew over 100 participants from across the U.S. who quickly came together around an agenda for change. For research to have any hope of moving the needle on health disparities, communities of color and low-income communities need to have:

- *Power* in decisions made about research
- *Capacity and infrastructure* to engage as equal research partners with institutions and conduct their own research
- *Significant roles* in building the capacity of academic institutions to engage and partner with communities



Building on the inaugural forum, the 2nd National Community Partner Forum, held December 5-7, 2012 in Washington DC sought to:

- *Deepen the knowledge and skills* needed by community partners to successfully conduct community-engaged research, negotiate community-academic research partnerships and serve in national leadership roles
- *Disseminate the innovative work* of community partners
- *Engage in constructive dialogue* between community partners and key stakeholders in the academic, government and philanthropic sectors
- *Grow and deepen* a national network of community partners that has a significant voice in decisions about research practice and policy

Yes, we want a seat at the table, but we also want to create a new table...a new paradigm for research.

The Eunice Kennedy Shriver National Institute of Child Health & Human Development and the National Institute of Environmental Health Sciences joined NIMHD in funding the 2nd forum. Generous scholarship support was provided by the University of Maryland School of Public Health,

Maryland Institute for Applied Environmental Health, Program on Community Engagement, Environmental Justice, and Health; the Connecticut Health Foundation; and Community-Campus Partnerships for Health's Bobby Gottlieb Scholarship Fund.

Over 100 community partners from 27 states and the District of Columbia attended the 2nd forum; 87% people of color and over 80% involved in federally funded research. The agenda was designed for community partners to learn and strategize together as peers for a day and a half before their academic partners and invited leaders from the government, philanthropic and non-profit sectors joined the conversation for an evening poster reception and report-out on

There's a lot of rhetoric about CBPR – but is it really happening on the ground?

the final day. Skill-building workshops led by planning committee members covered the basics of community-based participatory research (CBPR), applying for and managing research grants, developing positions of leadership, establishing a community IRB or research review board, and ensuring that research findings are disseminated and used.

Breakout groups were organized around topics identified as priorities at the first forum: training and mentoring; institutional accountability; ethical issues and ethics review; funding, policy and advocacy; and leadership development. During the breakouts, participants shared their experiences, addressed common challenges and identified promising practices. Each group reported out recommendations that were shaped into a collective agenda for action that was presented on the last day. The audience included academic partners and invited senior staff from the National Center for Advancing Translational

Sciences, National Institute of Minority Health and Health Disparities, National Institute of Drug Abuse, Environmental Protection Agency, Connecticut Health Foundation, Susan G. Komen for the Cure, National Association of Community Health Centers, Association of American Medical Colleges and the Genetic Alliance. The facilitated discussion that followed sought feedback on the action agenda and strategies for moving it forward. A spontaneous workgroup formed to explore ways in which academic partners could be supportive.



The 2nd forum ended with a clear path for moving forward. The planning committee pledged to continue serving as leaders for the growing network, with immediate plans to prepare a forum report, sponsor a webinar to present the forum agenda for action more broadly, and conduct “coaching” conference calls for community partners seeking timely advice and feedback on their research partnerships. Follow-up meetings with key stakeholders in the academic, government and philanthropic sectors are focusing on strategic actions they can take to advance the forum agenda for action. Four workgroups – training and mentoring, leadership development, community centers of excellence in CBPR and academic partners as allies – are continuing to meet. Planning has begun for regional forums in Massachusetts, Michigan and North Carolina, modeled after a regional forum in New York City held in March 2012 in follow-up to the first national forum.

We need to acknowledge and honor multiple ways of knowing.

During its debriefing on the 2nd forum, the planning committee revisited the term “community partner” and felt it did not adequately convey the leadership, assets and goals of community members and community-based organizations that undertake research to advance health equity and social justice. The committee therefore adopted the terms “community leader” and “community-based organization” and named the network that has emerged from the two forums as the *Community Network for Research Equity and Impact*.

Agenda for Action

Communities want a shared, balanced, and equal ownership stake in the decision-making system for the research enterprise at the federal, state, local and academic levels. Research funding agencies must make meaningful financial investments to ensure that community leaders participate on national advisory councils, grant review panels and policy-making bodies related to research and that their voices are heard.

It’s a no-brainer: funds for community research infrastructure should come to communities.



Research institutions must be held accountable for equitable partnerships through clearly articulated memoranda of understanding with community-based organizations that describe the principles that will be followed and a plan for how these will be monitored and evaluated.

Public research funding agencies should establish a minimum set of standards when making grants to research institutions for community-engaged research. These would include, for example:

- Community leaders and community-based organizations will not primarily serve as recruiters for research participants
- Community leaders and community-based organizations will be compensated at the same rate of pay for their time and expertise as academic partners
- Community leaders and community-based organizations will have equal say in how data is presented, published and used
- Investments must be made in the training and mentoring of community leaders and community-based organizations

Funding is needed to support the start-up and continued operations of community IRBs and community-based research review boards. These entities – accountable to the communities they serve and represent – play critical roles in ensuring that community risks, benefits and feasibility of proposed research are carefully considered.

Community leaders, community-based organizations and their allies must advocate for supportive changes in research funding and policy that lead to:

- Increased investments in community-based participatory research
- Direct funding to community-based organizations for research capacity-building and infrastructure
- Support for training and mentoring
- Proposal review panels that include community leaders as full reviewers

The successful integration of communities into CBPR requires an organized network of seasoned community leaders and community-based organizations to convene and coordinate peer training and support. The national network that has emerged from the two forums, with support from Community-Campus Partnerships for Health, is poised to serve in that role.

We must join forces with other like-minded networks to strengthen our collective voice to advance research equity and impact.

We need to move beyond documentation and work together in a truly engaged way to drive evidence-based solutions to health disparities.

Get Involved



We invite community leaders and community-based organizations to participate in the **Community Network for Research Equity and Impact** by completing this [form](#).

Visit the forum [webpage](#) for forum agendas, presentations, handouts and reports.

Email us at programs@ccph.info with any questions, comments and suggestions. Let us know how you are advancing the agenda for action!

Stay informed by subscribing to the [Community-Based Participatory Research listserv](#).

We need to arm ourselves with the knowledge and skills to not only engage in research, but to inform what research gets funded and how it's carried out and used. The health of our communities is at stake.

Forum Planning Committee

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Forum Cosponsoring Organizations



Community-Campus Partnerships for Health

Promoting Health Equity & Social Justice

A national non-profit membership organization founded in 1996, **Community-Campus**

Partnerships for Health promotes health equity and

social justice through partnerships between communities and academic institutions. Only by leveraging the knowledge, wisdom and experience in communities and in institutions will we solve pressing health, social, environmental and economic challenges.



The **Center for Community Health Education Research and Service** in Boston is a community-based organization and community/academic partnership established in 1991 that promotes the development of “academic community health centers,” that integrate education, research, and service, to influence and change health professions education; improve health care delivery; and promote health systems change to eliminate racial and ethnic disparities in health.

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