We Want *Health Research* Equity
"Communities need to be prepared for the avalanche of health research that's coming down the pike. We need to arm ourselves with the knowledge and skills to not only engage as partners in research, but to inform what research gets funded, how it is carried out and how it is used...The health of our communities is at stake."

~ Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership & Member, Forum Planning Committee
Achieving the Promise of Community-Engaged Health Disparities Research:
A National Community Partner Forum
December 5-7, 2011 ~ Boston, MA

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Why a National Community Partner Forum?

Community engagement in research is central to understanding and addressing disparities in health. Research funding agencies are supporting faculty and institutions to engage communities as partners in conducting research. There are few supports for communities to engage faculty and institutions as partners, or to conduct our own research.

As more community organizations engage in research, it is clear that they need their own networks for professional development, mentoring and advocacy.
Forum Planning Committee

Willie Mae Bennett-Fripp, Executive Director, Committee for Boston Public Housing, Boston, MA
Grace Damio, Director of Research and Service Initiatives, Hispanic Health Council, Hartford, CT
Elmer Freeman, Executive Director, CCHERS, Boston, MA
Susan Gust, Community Activist, Minneapolis, MN
Loretta Jones, Founder & CEO, Healthy African American Families, Los Angeles, CA
Alma Knows His Gun McCormick, Executive Director, Messengers for Health, Hardin, MT
Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership, New York, NY
Forum Planning Committee

Fernando Pineda-Reyes, Executive Director, Community, Research, Education & Awareness (CREA) Results, Denver, CO
Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, c/o Somerville Community Corporation, Somerville, MA
Jean Schensul, Senior Scientist & Founding Director, Institute for Community Research, Hartford, CT
Peggy Shepard, Executive Director, WE-ACT for Environmental Justice, New York, NY
Eric Wat, Director, Research and Evaluation Unit, Special Service for Groups, Los Angeles, CA
Forum Participants

Location: 27 states and DC

Setting: 80% urban, 11% rural, 3% frontier, 6% Native Nation

Race/ethnicity*: 47% African-American, 23% Caucasian, 20% Hispanic, 10% Mixed, 8% Asian, 4% Pacific Islander, 3% American Indian/Alaska Native

Gender: 60% women, 40% men

Research experience: 57% involved in community-engaged health disparities research for over 5 years, 24% for 3-5 years, 16% for 1-3 years, 3% for less than one year

Research roles*: 70% research team member, 36% principal investigator (PI), 50% co-PI, 67% community advisory committee member, 9% Institutional Review Board member

*multiple choices could be selected
Over 80% of participants are involved in federally funded community-engaged research, including*:
30% NIH Clinical and Translational Science Awards (CTSA)
23% CDC Prevention Research Centers
20% National Institute of Minority Health and Health Disparities
17% NIH Partners in Research Program
15% National Cancer Institute
8% National Institute of Environmental Health Sciences
8% Native American Research Centers for Health
5% Environmental Protection Agency
*multiple choices could be selected
Premises Reinforced at the Forum

1. CBPR could simply replace the conventional research methodology without embracing social change, policy change, paradigm shifts and power sharing.

2. Community partners must have the knowledge and the supportive network to be able to challenge the status quo, avoid the pitfalls and maximize the benefits of research.

3. Community partners need to be adequately supported for their roles in research

4. Community partners need to be at the decision making tables that shape research and be able to rapidly respond to opportunities to influence research policy.
Federal Policy Recommendations

Fund authentic community-based participatory research

Fund community based organizations (CBOs) for research capacity-building & infrastructure

Require authentic community engagement in Clinical & Translational Science Awards (CTSAs)

Establish ombudsman for community-academic disputes

Conduct audits of federal research funding

Applicants, grantees/sub-grantees & reviewers: # and % of CBOs

NIH funding: $ for CBPR and health disparities research; $ to CBOs

Indirect rates: rates used for CBPR, % applied to the funded research project, % applied to communities/CBOs
For More Information

Email us at programs@ccph.info