



National Community Partner Forum
December 6 -7, 2011
240 Egan Research Center
Boston, MA

**Achieving the Promise of Community-Engaged Health Disparities Research:
A National Community Partner Forum
Dec 6-7, 2011 in Boston, MA**

Community engagement in research is central to understanding and addressing racial, ethnic and socioeconomic disparities in health. Research funding agencies are supporting faculty members and institutions to engage communities as partners in conducting research. As more community organizations enter into research partnerships with institutions as well as initiate and conduct research, it is clear that we need our own networks for professional development, mentoring and advocacy in order to advance the social change through knowledge and power sharing that must happen if we are to achieve health equity in this country.

Forum Goals

- To share knowledge, provide mentorship and make recommendations around community review of proposed research, governance structures for research, community engagement in the research process, and funding the community infrastructure needed to conduct research.
- To disseminate knowledge shared and generated at the forum through accessible products that participants jointly co-author. These products might include, for example, a set of key questions that community groups should ask at the start of a research partnership, and a template memorandum of understanding for community-institutional research partnerships.
- To establish national and regional networks to facilitate shared learning, professional development and advocacy.

Forum Guiding Questions

- How do we ensure that communities most affected by health disparities have a voice at the tables that decide what research gets conducted, how and by whom?
- How do we support communities most affected by health disparities to conduct and manage their own research?
- How do we ensure that communities work as equal partners with universities and other institutions to make sure that community research interests are met?
- How do we ensure that social justice is central to community-engaged research?
- How do we form effective networks for furthering dialogue and action around community knowledge development and equitable community-academic partnerships?

Forum Participants

Experienced and novice community partners involved in research who are committed to social justice, willing to share their challenges and successes, and eager to both enhance their impact at a local level and contribute to a broader research and advocacy agenda.

Forum Premises

- The forum seeks to arm communities with the knowledge and the supportive network to be able to challenge the status quo, avoid the pitfalls and maximize the benefits of research.
- We are concerned that community-based participatory research could just become a methodology that simply replaces the conventional research methodology without embracing social change, policy change, paradigm shifts and power sharing.
- Community partners should be adequately supported for their roles in research, whether conducted on their own or with academic partners,
- Community partners and their allies should be at the decision making tables that shape research (e.g., research ethics boards, grant review panels) and able to rapidly respond to opportunities to influence research policy (e.g., NIH requests for public comment).

ABOUT THE FORUM CO-SPONSORING ORGANIZATIONS

COMMUNITY-CAMPUS PARTNERSHIPS FOR HEALTH (CCPH)

A national non-profit organization founded in 1996, CCPH promotes health through partnerships between communities and academic institutions. We view health broadly as physical, mental, social and spiritual well-being and emphasize partnership approaches to health that focus on changing the conditions and environments in which people live, work and play. Our strategic goals are to:

- Leverage the knowledge, wisdom and experience in communities and in academic institutions to solve pressing health, social, environmental and economic challenges
- Ensure that community-driven social change is central to the work of community-academic partnerships
- Build the capacity of communities and academic institutions to engage each other in partnerships that balance power, share resources, and work towards systems change

Our members – a diverse group of over 2,000 individuals affiliated with community organizations, colleges and universities, health care delivery systems, student service organizations, foundations and government – are advancing these goals in their work on a daily basis. CCPH is governed by a 12-member board of directors who reflect the diverse constituencies we serve. What ties us together is our commitment to social justice and our passion for the power of partnerships to transform communities and academe. Learn more about CCPH at <http://ccph.info>

CENTER FOR COMMUNITY HEALTH EDUCATION RESEARCH AND SERVICE (CCHERS)

CCHERS is a community-based organization that is a community/academic partnership established in 1991 with a \$6 million grant from the W.K. Kellogg Foundation's Community Partnerships in Health Professions Education initiative. The partnership is comprised of Boston Medical Center, the Boston Public Health Commission, Boston University School of Medicine, Northeastern University Bouvé College of Health Sciences and an established network of fifteen community health centers (FQHC) serving the racially and ethnically diverse populations of the City. Northeastern University serves as its host institution and sustaining partner.

The mission of CCHERS is to promote 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. Learn more about CCHERS at <http://cchers.org>

NATIONAL INSTITUTE OF MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD)

The NIMHD envisions an America in which all populations will have an equal opportunity to live long, healthy and productive lives. The agency's mission is to promote minority health and to lead, coordinate, support, and assess the National Institutes of Health's effort to reduce and ultimately eliminate health disparities. In this effort NIMHD conducts and supports basic, clinical, social, and behavioral research, promote research infrastructure and training, fosters emerging programs, disseminates information, and reaches out to minority and other health disparity communities. Learn more about NIMHD at <http://www.nimhd.nih.gov>

Funding for this conference is being made possible in part by 1R13MD006705-01 from the National Institute on Minority Health and Health Disparities, awarded to Community-Campus Partnerships for Health and the Center for Community Health Education Research and Service. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention by trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

MONDAY DECEMBER 5, 2011

Location:

Boston Marriott Copley Place
110 Huntington Avenue, Boston, MA 02116
617-236-5800

6 pm – 8 pm Welcome Reception – Room: Saint Botolph Room on the 2nd Floor

TUESDAY DECEMBER 6, 2011

Location:

240 Egan Research Center
Forsyth Street
Northeastern University
Boston, MA 02120

Room: Unless otherwise specified, forum sessions take place in the Raytheon Amphitheatre

7:30 am – 8:30 am Continental Breakfast

7:30 am – 1 pm Forum Registration

8:30 am - 9:00 am Forum Opening Session: Setting the Stage

Speakers: Susan Gust, Immediate Past Board Chair, Community-Campus Partnerships for Health (CCPH), Minneapolis, MN, and Elmer Freeman, Executive Director, Center for Community Health Education Research and Service (CCHERS) & Past CCPH Board Chair, Boston, MA

9:00 am - 9:30 am Table Discussions

9:30 am – 10:00 am Break

10:00 am – 11:30 am Case Studies as a Springboard for Sharing Learning & Action

Participants will choose among concurrent sessions that feature case studies of promising practices that correspond to each of the forum priority topics areas. Presenters will take about 25 minutes to share their case study, with the remaining time for participants to ask questions, share their own experiences and make recommendations for what actions, resources and products are needed to move forward.

A. Community review of proposed research

Room: 206 Egan Research Center

The Special Service for Groups Community IRB

Eric Wat, Director, Research and Evaluation Unit, Special Service for Groups (SSG), Los Angeles, CA

This case study will focus on the establishment and development of the SSG Institution Review Board, a community IRB based in Los Angeles. It will discuss the reason for establishing a community IRB as an alternative to institution-based IRB, how the community IRB is structured and supported, and common issues addressed by a community IRB. The case study highlights unique issues presented by community-based participatory action research projects, such as ethical issues of experimental design, role conflict for researchers who are also providers, and the additional oversight of community protections as well as human participant protections.

The Memorandum of Understanding (MOU) as a Tool for Equitable Governance of Partnerships
Loretta Jones, Founder & CEO, Healthy African American Families, Los Angeles, CA

An MOU is a document describing a bilateral or multilateral agreement between parties. It expresses a convergence of will between the parties, indicating an intended common line of action. It is often used in cases where parties either do not imply a legal commitment or in situations where the parties cannot create a legally enforceable agreement. It is a more formal alternative to a gentlemen's agreement. The purpose of a MOU is to remove confusion from the configuration of community/university partnerships. This case study will look at and determine what the explicit requirements are that need to be addressed in these community/university partnerships from a community perspective, using examples from partnerships between Healthy African American Families and universities and other research institutions in Los Angeles.

C. Community engagement in all phases of the research process

Harlem Community & Academic Partnership Strategies for Community Engagement, Research & Policy Change

Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership and CCPH board member, New York, NY

This case study will present 1) the model of the Harlem Community & Academic Partnership (HCAP) and the use of its Intervention Work Group (IWG) approach to ensure community participation throughout the research process; and 2) the work of the HCAP Policy Work Group as example of an IWG that has conducted policy research using a CBPR approach and is currently using its research findings to prioritize policy advocacy goals and strategies.

The Harlem Community & Academic Partnership is a coalition of community residents, community-based organizations and service providers, academics, and public health institutions. HCAP seeks to improve the health of East and Central Harlem by using a CBPR framework to identify “what works” in addressing the social determinants of health in these communities. HCAP therefore supports projects that gather and utilize community knowledge to promote better health. Since 1999, HCAP has worked to build and strengthen trust, to establish credibility in the East and Central Harlem communities, to demonstrate a true commitment to improving the health of our residents, and to create a platform from which to address local urban health issues. The Policy Work Group (PWG) is an intervention work group of the HCAP, originally charged with examining policy barriers to substance use treatment in East and Central Harlem. Policy Work Group (PWG) Report #2 examines the knowledge, attitudes, and beliefs of New York City public housing residents about community reintegration of formerly incarcerated individuals. This report describes the approach and implementation of a qualitative research project by community activist leaders using the principles of Community-Based Participatory Research (CBPR). A research approach was used as a way to document and generate local evidence and data to validate what we as community leaders and advocates anecdotally and experientially knew about the experiences of public housing residents and community members returning home from prison and jail in East and Central Harlem. A series of policy-oriented recommendations and strategies for effective and successful community reintegration are presented. The expectation is that the recommendations and action steps provided are considered and acted upon by a cross-section of stakeholders including community members living in communities with high recidivism rates, community-based service providers, government elected and appointed officials, the reentry advocacy community, law enforcement and correction officials, federal and city housing officials, and formerly incarcerated individuals.

Developing and Sustaining Research Infrastructure in a Community-Based Organization

Grace Damio, Director of Research and Service Initiatives & Deputy Director, (NIH Export) Center for Eliminating Health Disparities Among Latinos, Hispanic Health Council (HHC), Hartford, CT
Sofia Segura-Pérez, Associate Director, Community Nutrition Unit, HHC
Luis Bedregal, Research Scientist, HHC

This case study will highlight: a) successes, challenges and lessons learned in building and sustaining community based research infrastructure; and b) structure, process and results of the NIH EXPORT CT Center for Eliminating Health Disparities Among Latinos (CEHDL), a model community-campus-hospital partnership in which the Hispanic Health Council (HHC) has played a major role.

HHC is a nationally recognized, private non-profit, community based organization located in Hartford, CT, whose mission is to improve the health and well-being of Latinos and other diverse communities. Towards achieving this mission, HHC utilizes three core strategies: community based participatory research, evidence-based direct services and policy advocacy. HHC was founded by group of medical anthropologists, health providers and faculty and community activists. For 33 years, HHC has conducted research for the purposes of: assessing community need and better understanding inequities in health experienced by underserved communities; developing, testing and disseminating methodologies of community engagement in participatory research, and interventions in health promotion and chronic disease management; and applying research findings toward influencing policy decisions affecting the health and well-being of its target/partner communities. Since its inception, HHC has been distinguished by: 1) the strength of its partnerships; 2) the cultural relevance of its methods and products; 3) the social justice orientation of its work; and 4) the impact of its work on health and social policy and service systems. Since its inception, HHC built its own research infrastructure and successfully applied for and led NIH and other research grants. HHC has also partnered extensively and effectively with many higher education institutions.

11:30 am – 1:00 pm Lunch & Table Discussions

“Table tents” will identify discussion topics that participants can choose from.

1:00 pm – 2:30 pm Case Studies as a Springboard for Shared Learning & Action

Participants will choose among concurrent sessions that feature case studies of promising practices that correspond to each of the forum priority topics areas. Presenters will take about 25 minutes to share their case study, with the remaining time for participants to ask questions, share their own experiences and make recommendations for what actions, resources and products are needed to move forward.

A. Community review of proposed research

Room: 206 Egan Research Center

The Bronx Community Research Review Board

Joann Casado, Executive Director, The Bronx Health Link, Bronx, NY
Francisco Martin del Campo, Health Educator, The Bronx Health Link, Bronx NY
Rosalind McMullin, CRAB Member
Lucy Pagan, CRAB members
Moderated by: Peggy Shepard, Executive Director, WE-ACT for Environmental Justice and CCPH board member, New York, NY

The case study will focus on the establishment and development of the Bronx Community Research Review Board (known as the Bronx CRAB), a partnership between the Albert Einstein College of Medicine and the Bronx Health Link, a community-based agency in the South Bronx.

The case study will explore these topics:

- The foundation for development of the CRAB
- The recruitment process for CRAB members
- The training process for CRAB members and its unique application of Freirian principles
- The actual review process and outcomes
- Evaluation
- Challenges to the model, lessons learned and next steps

B. Governance structures for research

Room: 306 Egan Research Center

The Importance of Developing Good Governance Models to Guide the Research

Susan Gust, Community Activist and Immediate Past CPH Board Chair, Minneapolis, MN

While CBPR or research may be central to our work with other organizations, agencies or academic institutions, the governance structure that holds this work is arguably just as important in order for deep and systemic change to occur. Models of shared power and governance are built through recognizing factors such as: self-interest, who defines the benefits, is leadership and capacity being built on all sides, etc. The Community Impact Statement Process was developed looking back through a “20-20 lens” on the decade-long existence of The Phillips Neighborhood Healthy Housing Collaborative which conducted over 2 million dollars of federally-funded research on childhood lead poisoning.

C. Community engagement in all phases of the research process

Room: Raytheon Amphitheater

A Case Study of the Center for Community Health Education Research and Service

Elmer Freeman, Executive Director, CCHERS, Boston, MA

Andrew Taylor, Project Coordinator for Community Research, CCHERS, Boston, MA

This case study is about CCHERS and its network of 15 community health centers organized as a primary care practice based research network to increase research being conducted in partnerships with the expansive academic biomedical research enterprise of Boston. It presents the usual approach of academic researchers to health centers and/or CCHERS as well as many other CBO's in Boston seeking to use them to recruit, in this case Blacks/African-Americans, to their clinical trials. It is a classic case that is playing out in real time as we speak and the discussion will partially be used to advise CCHERS in its next steps moving forward. It also will help explicate relevant issues and discussion for participants to apply in their particular circumstances.

D. Funding the community infrastructure needed to conduct research

Room:440 Egan Rrsch Ctr

A Case Study of the Institute for Community Based Research

Jean (Jay) Schensul, Founding Director, Institute for Community Research, Hartford, CT

Peg Weeks, Executive Director, Institute for Community Research, Hartford, CT

This session will use the Institute for Community Research, a CBRO (Community based research organization) as the basis for discussing ways of building and obtaining financial support for community infrastructure required to conduct independent or partnership research. The Institute for Community Research was formed in 1987, as a way of revitalizing an existing organization that played a central role advocating for the sustainability of community based organizations in the Greater Hartford area, and that was being defunded. The mission of the organization as defined by the new director and the board who remained in the turnover was “to use research in collaboration with

community partners to promote justice and equity in a diverse multicultural world.” Two critical factors underlie the ICR mission: a) to forge research partnerships with community residents and CBOs to carry out research together as a means of improving service and democratizing social science; b) equitable cost sharing to ensure that all partners have the financial capacity to carry out and use the results of research. To fulfill its mission, ICR had to diversify its funding base, find support for its own infrastructure, forge research partnerships with other organizations and find ways to cost share. ICR has had the independent capacity to generate research funding and a mission mandate to share it equitably. And it has partnered with many different types of organizations including universities. With ICR examples, the presentation will suggest some useful strategies for equitable fundraising and fund sharing to conduct community based research; will discuss specific financial issues relating to research infrastructure that arise in partnerships with universities and how to address them, and will offer suggestions for how to build research capacity in organizations that want to grow it. The discussion following the presentation will focus on group problem solving and recommendations.

2:30 pm – 3:00 pm Break

3:00 pm – 4:30 pm What Do We Need to Say & Do?

Participants will choose a breakout discussion that corresponds to one of the forum priority topic areas. These facilitated conversations will result in identifying actions, resources and products that are needed at local, regional and national levels to advance the topic.

A. Community review of proposed research

Room: 206 Egan Research Center

Co-facilitators

Fernando Pineda-Reyes, Executive Director, Community, Research, Education & Awareness (CREA) Results, Denver, CO

Peggy Shepard, Executive Director, WE-ACT for Environmental Justice and CCPH board member, New York, NY

Eric Wat, Director, Research and Evaluation Unit, Special Service for Groups (SSG), Los Angeles, CA

B. Governance structures for research

Room: 306 Egan Research Center

Co-facilitators

Susan Gust, Community Activist and Immediate Past CCPH Board Chair, 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

C. Community engagement in all phases of the research process

Room: Raytheon Amphitheater

Co-facilitators

Willie Mae Bennett-Fripp, Executive Director, Committee for Boston Public Housing, Boston, MA

Elmer Freeman, Executive Director, Center for Community Health Education Research and Service (CCHERS), Boston, MA

Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership and CCPH board member, New York, NY

D. Funding the community infrastructure needed to conduct research

Room: 440 Egan Rrsch Ctr

Co-facilitators

Grace Damio, Director of Research and Service Initiatives & Deputy Director, (NIH Export) Center for Eliminating Health Disparities Among Latinos, Hispanic Health Council (HHC), Hartford, CT

Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, c/o Somerville Community

Corporation, Somerville, MA
Jean (Jay) Schensul, Founding Director, Institute for Community Research, Hartford, CT

4:30 pm – 5:00 pm Reflections on the Day

Comments from Dean Terry Fulmer
Bouvé College of Health Sciences
Northeastern University

Reflection led by Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership and CCPH board member, New York, NY and Fernando Pineda-Reyes, Executive Director, Community, Research, Education & Awareness (CREA) Results, Denver, CO

5:00 pm – 7:00 pm Reception

Wed December 7, 2011

Location:
240 Egan Research Center
Forsyth Street
Northeastern University
Boston, MA 02120

Room: Unless otherwise specified, forum sessions take place in the Raytheon Amphitheatre

7:30 am – 8:30 am Continental Breakfast

8:30 am – 10:30 am What Are We Saying & Who Needs to Listen?

During this session, CCPH senior consultant Nancy Shore, CCPH board member Suzanne Cashman and students will present an analysis of Tuesday's deliberations, including emerging recommended actions, resources and products, followed by discussion. Participants will refine these further in small groups.

10:30 am – 10:45 am Break

10:45 am – 12 noon Moving from Dialogue to Action

Facilitators: Susan Gust, Immediate Past Board Chair, Community-Campus Partnerships for Health (CCPH), Minneapolis, MN, and Elmer Freeman, Executive Director, Center for Community Health Education Research and Service (CCHERS) & Past CCPH Board Chair, Boston, MA

12 noon – 12:30 pm Closing Circle

After grabbing a boxed lunch, we will close out the forum with an opportunity to hear from all of the voices in the room.

Closing led by Alma Knows His Gun McCormick, Executive Director, Messengers for Health, Hardin, MT and Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, c/o Somerville Community Corporation, Somerville, MA

12:30 pm – 2:30 pm Planning Committee Meeting

ACKNOWLEDGEMENTS

This forum simply would not be possible without the involvement of many people and organizations who generously contributed their time and other resources. We begin by thanking the National Institute for Minority Health and Health Disparities for investing in the forum, especially the encouragement and support of Director John Ruffin and Program Officer Dorothy Castille.

The forum planning committee members for their guiding vision:

Willie Mae Bennett-Fripp, Executive Director, Committee for Boston Public Housing, Boston, MA
Grace Damio, Director of Research and Service Initiatives & Deputy Director, (NIH Export) Center for Eliminating Health Disparities Among Latinos, 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
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

These individuals for ensuring that we capture the discussion, key ideas & recommendations:

Nancy Shore, CCPH Senior Consultant, Seattle, WA
Suzanne Cashman, CCPH Board Member, Worcester, MA
Franciel Dawes, Student, Friedman School of Nutrition and Policy, Tufts Medical Center
Jennifer Eastman, Student, University of New England, School of Social Work
Doug McEachern, Student, Northeastern University
Elisa Orme, Student, University of New England, School of Social Work
Davida Schiff, Student, Boston University, Medical School
Christine Simon, Student, Harvard University, School of Public Health
Bridget Thornton, Student, University of New England, School of Social Work
Jennifer Weaver, Student, Harvard University, School of Public Health

Northeastern University student volunteers for helping out throughout the forum:

Jessica Cohen	Allison Spilkia
Susanna Edens	Betsy Stanley
Raessa Singh	Katie Zheng

These staff members for their professionalism and teamwork:

Andrew Taylor, Project Coordinator, CCHERS, Boston, MA
Rahma Osman, Program Assistant, CCPH, Seattle, WA
Sarena D. Seifer, Executive Director, CCPH, Seattle, WA
Andrea Jones, Project Specialist, Healthy African American Families Phase II, Los Angeles, CA
Felica Jones, Director of Programs, Healthy African American Families Phase II, Los Angeles, CA

Northeastern University Bouvé College of Health Sciences for generously providing space for the forum. And last but not least, these organizations who helped to support travel expenses for their community partners to attend the forum:

Bad River Band of Lake Superior Ojibwe's from Wisconsin, Community Advisory Board groups, and the Lac Du Flambeau band of lake Superior Ojibwe group

Collaborative Center for Health Equity at the University of Wisconsin, Madison

Comprehensive Research Center in Health Disparities, University of California San Diego

Detroit Community-Academic Urban Research Center, University of Michigan, Ann Arbor

Galveston Island Community Research Advisory Committee

Great Lakes Inter-Tribal Council

Men on the Move: Growing Communities/Saint Louis University

North Carolina Translational and Clinical Science Institute

St. Luke's Episcopal Health Charities

University of Cincinnati's Institutional Clinical and Translational Science Award, NIH/NCRR Grant Number 5UL1RR026314-02 and Supplement Grant 3UL1RR025755-02S5

University of North Carolina-Chapel Hill Center for Health Promotion and Disease Prevention

Note: This is a partial listing as of information received by December 7, 2011. A complete listing will be included in the conference proceedings.