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Keynote Address: "Research with Communities to Improve Health and Reduce Health Disparities"

Elmer R. Freeman

Center for Community Health Education Research and Service

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Research with Communities to Improve Health and Reduce Health Disparities

**Elmer R. Freeman, MSW
Executive Director**

Center for Community Health Education Research and Service

**University of Massachusetts
Center for Clinical & Translational Science**

“Challenging Issues in Community Health: The Role of Research”

Friday, November 30, 2012



CCHERS Mission

The mission of CCHERS is to promote the development of “**academic community health centers**” that integrate service, education and research to influence and change health professions education, improve health care delivery, and promote health systems change, *to eliminate racial and ethnic disparities in health.*



Institutional Partners

- Boston Medical Center
- Boston Public Health Commission
- Boston University School of Medicine
- Northeastern University Bouve College of Health Sciences



Community Health Center Partners

- Bowdoin Street
- Brookside
- Codman Square
- Dimock
- Dorchester House
- East Boston
- Gieger/Gibson
- Harvard Street
- Mattapan
- Neponset
- Roslindale
- South Boston
- Southern Jamaica Plain
- Uphams Corner
- Whittier Street

Certified as a ***primary care practice-based research network*** by the Agency for Healthcare Research and Quality and recognized as a ***minority serving institution*** by the National Institutes of Health



CCHERS' Research Goals

- To establish a sustainable practice based research network of **“academic community health centers”**.
- To become recognized as a credible center for initiating and conducting community-based health services and clinical research.
- To increase interest and reward of university faculty to engage in and conduct community-based research.
- To increase the interest and capacity of the community to engage in and conduct academic research.
- To develop common research agendas derived through consensus between academic and community partners.





Community Placed vs. Community-Based

Levels of Community Involvement

- Community **notification** - inform the community of the intentions of the research risks and benefits relating to the individuals and communities involved.
- Community **consent** - obtaining some expression of community approval.
- Community **endorsement** - community representatives are asked to formally support the research activities.
- Community **participation** - seeking and obtaining community advice in planning, development, execution, and dissemination of the research.
- Community **origination** - research purpose and goals set by expressed community needs.

Jenkins, B. "Health Disparities: Why we have not solved the problem, Why we need new approaches." The Research Center on Health Disparities, Morehouse College, April 2004.



Continuum of Research Relationships



Unilateral

Collaborative

Participatory

Democratic

- Unilateral – Single researcher sets the agenda and maintains control over all aspects of the study.
- Collaborative – Idea comes from the researcher who decides to include the community in some stages of the study.
- Participatory – Driven by the convergence of community need and researcher interest/expertise.
- Democratic – A partnership arising out of a CBPR project and uses a participatory decision making process with designated representatives.



Challenges of Community Partnered Research

- Tenuous nature of university and community relationships
- Understanding the academic research enterprise
- Building research capacity and infrastructure
- Building relationships based on trust
- Coping with differentials in power and issues of control
- Being seen as credible partners with “expertise”
- Establishing a structure and process for inclusion, communication and decision making
- Allocation of financial resources and fiscal control
- Coping with the dynamic and fluid process of community engagement

Freeman, E.R., Brugge, D., Bennett-Bradley, W.M., Levy, J.I., and Carrasco, E. (2006). “Challenges of Conducting Community-Based Participatory Research in Boston’s Neighborhoods to Reduce Disparities in Asthma.” *Journal of Urban Health*, November/December, 4(6) pp. 1013-1021



University – Community Expectations

- Scholarly publications
- Funded research grants
- Professional supervision of applied grants
- Supervision of student research
- University/collegiate service
- Membership in professional associations
- Manuals & policy papers
- Funded service projects
- Project development and evaluation
- Social action research and strategic planning
- Civic and community participation
- Professional and leadership development

Sullivan and Kelly, *Collaborative Research: University and Community Partnership*, APHA, 2002.



Complexity of Research Relationships

- Work “in” the community
- Discipline driven
- Supported by descriptions in the literature
- Question is hypothesis based
- Separate and unique roles
- Power differential
- Community assets go unrecognized
- Limited selection of community voices
- Learning is scholarly of individual expertise
- Culture of academia
- Work “with” the community
- Multi discipline driven
- Supported by real life experiences
- Question to find solution
- Multiple roles
- Shared power
- Community assets are identified
- Multiplicity of community voices
- Group co-learning and capacity building
- Politics of the community

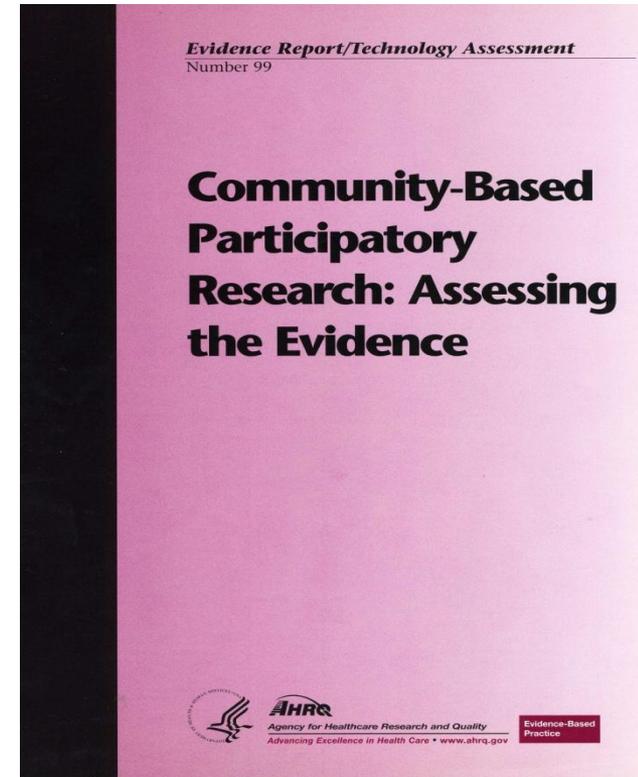


Community Based Participatory Research

Improving Research Quality, Enhancing Community Capacity,
and Improving Health Outcomes

CBPR is a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and translation of this research into interventions and policies to improve health.

Israel, et al 2003



Viswanathan, Ammerman, Eng, et al. *Community-Based Participatory Research: Assessing the Evidence*, Evidence Report/Technology Assessment No. 99, RTI-University of North Carolina, Rockville, MD: Agency for Healthcare Research and Quality, July 2004.



Council of Public Representatives

- Prompted by 1998 report issued by the Institute of Medicine: ***Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the NIH***
- Federal Advisory Committee of 21 diverse members of the public provide input and feedback from the public's perspective on emerging health issues and research priorities as identified by the COPR and/or the NIH Director
- Increase public awareness of NIH outreach activities, programs, and resources, including trustworthy health information
- Research for policy ... Policy for research
- The 4 P's ... predictive, pre-emptive, ... personal ... and **participatory**

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

Council of Public Representatives

www.copr.nih.gov



What We Do

The COPR facilitates dynamic and interactive communications between NIH and the public by

- Serving as the public's voice on issues relating to NIH's mission;
- Informing the public of the research and health benefits gained through the public's investment in NIH; and
- Helping NIH understand the public perspective and engage the public in NIH activities.

Who We Are

As members of the Council of Public Representatives (COPR), we serve the NIH Director. We represent a wide range of cultural, geographic, and professional backgrounds and perspectives, and we share a deep interest in public health and a commitment to the public's views and needs. The COPR is the formal mechanism at NIH for public input into the research decision-making and priority-setting process. The Council advises the Director on issues of importance for the broad development of NIH programs. The COPR is one of two external advisory committees chaired by the NIH Director.

Our Activities

We meet twice a year in public session to discuss topics identified by the Director and by COPR members. At the request of the NIH Director and the Directors of the Institutes and Centers, we also sit on NIH committees, including research review committees for strategic planning, current research issues, health education campaigns and outreach efforts. COPR members work on special trans-NIH issues, such as building public trust in clinical research and enhancing public input and transparency in the NIH research priority-setting process.

The Council reports to the Director in a variety of ways, depending upon the topic. In serving as the NIH voice to the public, we give presentations at various events, including professional meetings, nonprofit organization forums, local town hall and chamber of commerce meetings, and health fairs. We use these opportunities to seek additional input.





A Research Paradigm Shift: From Traditional to Participatory

| Traditional | Participatory |
|-----------------------------|-----------------------------|
| Randomized Controlled Trial | Natural Experiment |
| Biomedical Scientists | Experimenting Practitioners |
| In the Community | With the Community |
| Research on Subjects | Research with Participants |
| Hypothesis Driven | Solution Driven |
| I Wonder If | I Wonder How |
| Academic Impact | Societal Impact |
| Evidence Based Practice | Practice Based Evidence |
| | |



COMMUNITY ACADEMIC RESEARCH PARTNERSHIPS: THE GOOD, THE BAD AND THE UGLY

Elmer R. Freeman, Executive Director
Center for Community Health Education Research and Service, Inc.



HISTORY, MISSION AND GOALS

CCHERS was established in 1991 with a \$6 million grant from the WK Kellogg Foundation's initiative, Community Partnerships in Health Professions Education.

The mission of CCHERS is to promote the development of "academic community health centers" that integrate service, education and research to influence and change health professions education, improve health care delivery, and promote health systems change, to eliminate racial and ethnic disparities in health.

- Promote community based, primary care oriented **education** for a range of health professions students, from high school through graduate and professional school, to improve community health services provided to underserved populations.
- Promote community derived and directed health services and clinical **research**, in partnerships with academic medical center, government, and university researchers, that focuses on health problems that impact diverse urban populations.
- Promote coordination of **services** and interagency collaboration among universities, health services providers, community based organizations, and community residents to create healthier communities.
- Promote public and marketplace policy **change** in health professions education, community health, and health care access to create an equitable health care system for diverse urban populations and communities.

THE PARTNERSHIP

Institutional

Boston Medical Center
Boston Public Health Commission
Boston University School of Medicine
Northeastern University Bouve College of Health Sciences

Community Health Centers

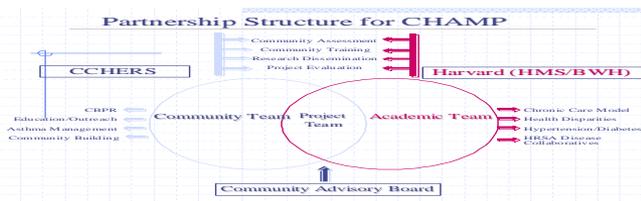
Bowdoin Street Mattapan
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Dimock South Boston
Dorchester House Southern JP
East Boston Upham's Corner
Gieger/Gibson Whittier Street
Harvard Street

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THE MODEL

Community Health and Academic Medicine Partnership (CHAMP)

- Harvard Medical School/Brigham and Women's Hospital & CCHERS.
- R21 funded by NHLBI to determine the quality of chronic disease management for diabetic and hypertensive patients in 7 community health centers through site visits, focus groups with patients, chart reviews, and interviews with physician and other primary care providers.
- Larger research team, mentoring of the PI, limited resources.
- Co-investigators, health center liaison, focus groups, organize/facilitate advisory board.
- Residency training at B&WH, credibility of CCHERS as a research partner, new funding for program interventions at health centers.



Challenges of Community Partnered Research

- Tenuous nature of university and community relationships
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Lessons Learned

- Roles** – Everyone must understand and appreciate the role, responsibilities and what each individual partner contributes.
- Structure** – Successful partnerships are structured to ensure sharing of power, resources, control and decision-making.
- Communication** – Successful partnerships are built on open and honest communication.
- Relationships** – The personal relationships that develop between the individual representatives of the partner organizations is critical.
- Trust** – Successful partnerships are built on trust that comes from taking the time to learn the culture, values, principles and processes of the individual partners.
- Vigilance** – Pay attention to the details ... the Devil's in them. Do not let the small things become deal breakers.
- Time** – Building partnerships takes time. It is a process ... not an event.
- Commitment** – Promises must be kept. Representatives should caution not to promise more than they can deliver.
- Leadership** – Successful partnerships require "boundaryless" leaders that can be effective in multiple arenas.
- Outcomes** – The process is just as important, if not more important, than the product.
- Benefits** – Partners must recognize, establish and work toward mutual benefit in order to maintain interest and commitment.

CASE EXAMPLES

Lupus Awareness and Community Education (LACE) Project

- Brigham & Women's Hospital/Harvard Medical School, Massachusetts Department of Public Health & Women of Courage.
- Promote awareness of lupus and risk exposures to organic/petroleum products; conduct case finding; and determine associations.
- Power dynamics; racial/ethnic politics; and roles of the partners in project.
- Team building retreats; formative research and focus groups; community education.
- State tracking of lupus; education of primary care practitioners; environmental health policy advocacy.

Boston Area Community Health (BACH) Survey

- New England Research Institutes, CCHERS and Boston communities.
- Five year longitudinal study of urological problems in men with focus on minority males.
- Randomized sample methodology; jobs for community people; role of community advisory board (CAB); benefit/return to community.
- Introduction to community groups/organizations; organization of CAB; work with social marketing firm.
- Not sure of any implications for policy.

Asthma Center on Community Environment and Social Stress (ACCESS)

- Channing Laboratory of Brigham and Women's Hospital, Harvard School of Public Health & CCHERS.
- National center for reducing disparities in asthma with longitudinal study of 1000 pre-natal; genetic testing and assessment of environmental and community stressors and triggers of asthma.
- Organizational cultures; power differentials; and building a partnership.
- Co-investigators; qualitative community researchers; organize and convene Community Advisory Board.
- AHRQ Evidence Report No. 99; Kellogg Commission; Boston Housing Authority Healthy Homes; policy advocacy; community organizing.

Looking for *Causes* ... in all the *WRONG PLACES*

There's an old joke about a man who late one night dropped his keys in the middle of a dark parking lot. He moves some distance over to the side of the lot and begins a fruitless search for them under a bright light. When asked why he was not looking where he actually dropped them, he replied, "because this is where the light is."





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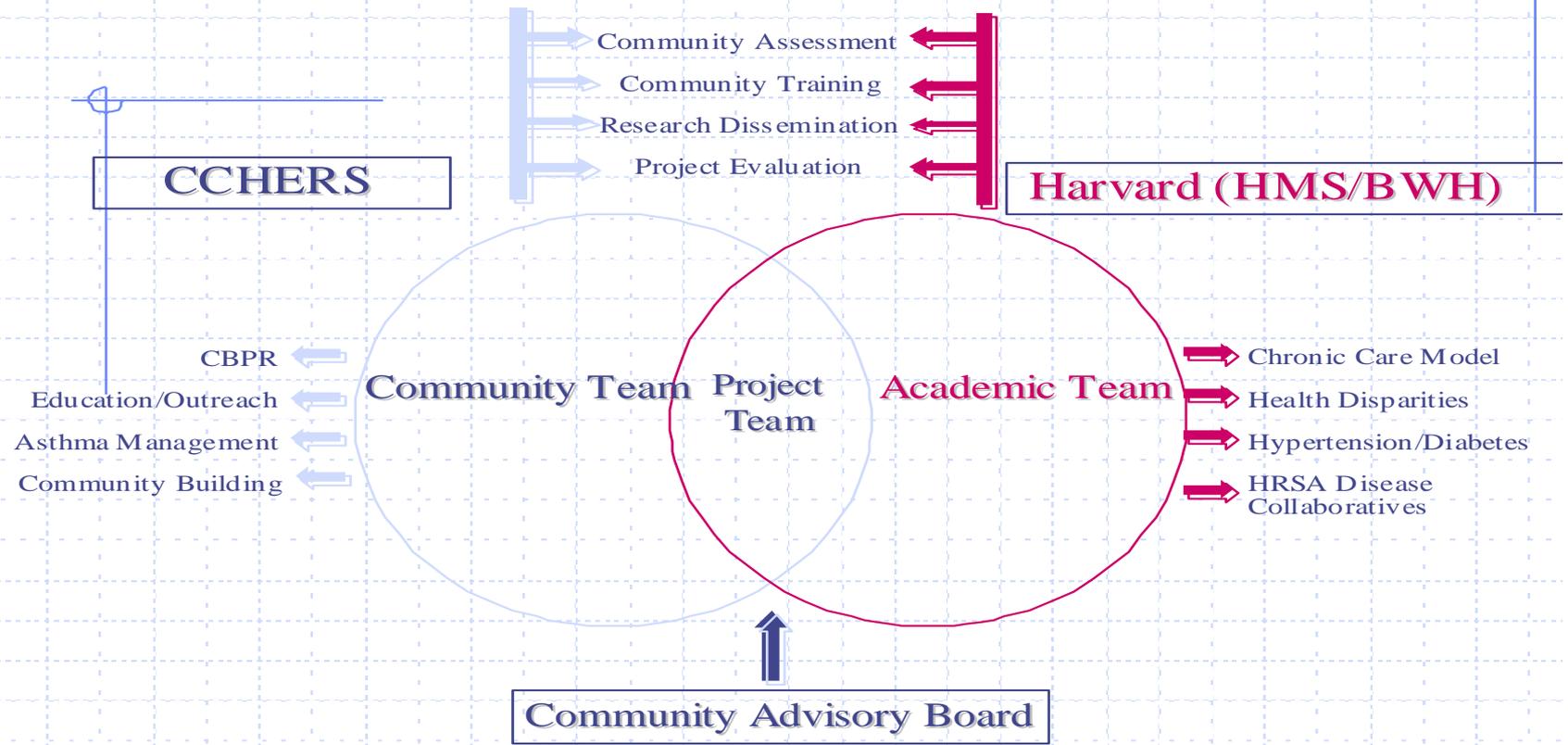
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CHAMP Partnership Structure

Partnership Structure for CHAMP





National Community Partner Forum



- Over 80% of participants are involved in federally funded community-engaged research, including*:
- 30% NIH Clinical and Translational Science Awards
- 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



National Community Partner Forum



- *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% IRB member

* Multiple choices could be selected





National Community Partner Forum



- *Re-define cultural norms and terms and coin new ones*
 - ***“We need to acknowledge and honor multiple ways of knowing”***
- *Develop research ready communities*
 - ***“As more established CBOs, we have a responsibility to mentor & train newer CBOs”***
- *Develop community ready researchers and institutions*
 - ***“We have a critical role to play in developing the capacity of our academic partners”***
- *Compensate communities for research and teaching roles*
 - ***“Our expertise is not free”***
- *Exchange existing and develop new resources*
 - ***“There’s no reason to reinvent the wheel”***



National Community Partner Forum



- *Cultivate funders*
 - ***“Social justice funders who ‘don’t fund research’ may invest in CBPR”***
- *Hold funders, institutions, and researchers accountable*
 - ***“There’s a lot of rhetoric about CBPR – but is it really happening on the ground?”***
- *Change research ethics review policies and practices*
 - ***“Ethical research is more than protecting individual study participants”***
- *Cultivate and position leaders*
 - ***“We need to position leaders for high impact positions & support them through the process”***
- *Change NIH policies and practices*
 - ***“It’s a no-brainer: funds for community research infrastructure should come to communities”***



All I Really Need to Know ... I Learned in Kindergarten

- Share everything.
- Play fair.
- Don't hit people.
- Put things back where you found them.
- Clean up your own mess.
- Don't take things that aren't yours.
- Say you're sorry when you hurt somebody.
- Wash your hands before you eat.
- Flush.
- Warm cookies and milk are good for you.
- Live a balanced life.
- Take a nap every afternoon.
- When you go out into the world, watch out for traffic, hold hands, and stick together.



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