PROGRAM BRIEF

AHRQ Activities Using Community-Based Participatory Research to Address Health Care Disparities

AHRQ's mission is to improve the quality, safety, efficiency, and effectiveness of health care by:

- Using evidence to improve health care.
- Improving health care outcomes through research.
- Transforming research into practice.

Introduction

Community-based participatory research (CBPR) is an approach to health and environmental research meant to increase the value of studies for both researchers and the communities participating in a study. In 2001, the Agency for Healthcare Research and Quality (AHRQ) collaborated with several Federal agencies and the W.K. Kellogg Foundation to convene a 2-day conference designed to address three key barriers to CBPR: (1) insufficient community incentives (i.e., staffing and resources) to play a partnership role in CBPR projects, (2) insufficient academic resources (i.e., staffing and resources) for researchers to play a partnership role in CBPR projects, and (3) inadequate funding and funding mechanisms that are not sensitive to community involvement. The conference recommended that AHRQ commission one of its Evidence-based Practice Centers (EPC) to study existing evidence on the conduct and evaluation of CBPR. As a result, in 2004, AHRQ published the RTI International–University of North Carolina EPC's systematic review and synthesis of the scientific literature regarding CBPR and its role in improving community health.*

A formal definition of CBPR was developed for this EPC Report:

> **"Community-based participatory research** is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change."

The CBPR approach is particularly attractive for academics and public health professionals struggling to

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* See p.4, under "AHRQ Reports on CBPR."

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address the persistent problems of health care disparities in populations that the U.S. Department of Health and Human Services has designated as priority populations. These populations include historically underrepresented populations, such as racial and ethnic minorities; low-income, rural, and inner-city populations; women; and children.

Benefits

When conducted properly, CBPR benefits community participants, health care practitioners, and researchers alike. It creates bridges between scientists and the communities that participate in the study through the use of shared knowledge and valuable experiences. By involving members of the community in the research design, the collaboration lends itself to:

- The selection of a relevant research question.
- Development of culturally appropriate measurement instruments.
- A deeper understanding of the community's unique circumstances.

Community involvement helps recruit subjects and reduces possible distrust of researchers and public health professionals as "outsiders." In many cases, community involvement helps build its capacity to participate in future research. Community involvement helps researchers develop ways of communicating and implementing their findings within the community and to academic and clinical peers. Finally, participatory research collaborations can help bring in needed funding, assist in developing proposals for new programs, and aid in developing comprehensive evaluations of community needs. Community groups often cannot do these things on their own. In many instances, community members' involvement in research has had a profound impact on environmental health issues and social determinants of health.

Approaches

In one approach to CBPR, community-based organizations or community groups partner with academic researchers to ensure that selected research topics are relevant and responsive to their identified needs. These groups may be churches, church members, neighborhood organizations, community residents, or other social organizations. These groups play a direct role in the design and conduct of the research study by:

- Bringing community members into the study as partners, not just subjects.
- Using the knowledge of the community to understand health problems and to design activities that improve health care.
- Connecting community members directly with how the research is done and its results.
- Providing the immediate benefits of the research results to the community that participated in the study.

In CBPR, community members are also involved in dissemination of research and findings. This involvement can help improve the quality of life and health care in the community by putting new knowledge in the hands of those who need to make changes.

Practice-based research networks (PBRNs), consisting of community-based practices that come together to conduct health care research, can be another partner in working with the community. AHRQ funds a number of PBRNs for health services research, and the members of these networks are often closer than academic researchers to the local geographic area, and have more direct involvement with priority populations. A number of AHRQ-funded studies that PBRNs conduct use CBPR as the research model (see "AHRQ Grants Involving CBPR," below).

Challenges

The 2004 EPC Report noted a number of challenges facing the growth of CBPR. These include:

- Improving research quality by researchers selecting the strongest possible study design, measurement approach, data collection plan, and analysis strategy that provides some benefit to all participants from the community.
- Ensuring that capacity-building in collaborative research occurs for both the community and the research team.
- Educating funding organizations to develop Requests for Applications that adhere to CBPR principles.
- Improving the quality of reports on CBPR studies published in the peer-reviewed literature.

AHRQ Grants Involving CBPR

Stroke Telemedicine Access Recovery Project (HS17956). Principal Investigator (PI): Patricia C. Gregory, M.D.; University of North Carolina, Chapel Hill. This career-development award provides training and mentoring in CBPR to a clinician-scientist providing pilot data for a study of barriers to successful implementation of a rural hospital's community-based Stroke Telemedicine Access Recovery, or STAR, project. (Ends 2014)

Building Health Services Research Capacity for Tribes in Montana and Wyoming (HS14034). PI: Gordon Belcourt, M.A., M.P.H.; Montana-Wyoming Tribal Leaders Council. This grant provides funding for the Montana-Wyoming Tribal Leaders Council to continue to build capacity to address priority health issues identified by the tribes; build capacity and infrastructure for tribal participatory research focused on health promotion, prevention, and management of chronic diseases; and increase support for culturally appropriate health programs and for the role of traditional medicine practitioners. (Ends 2011)

Communities as Partners in Cancer Clinical Trials (HS16471). PI: Sarena D. Seifer, M.D., Community-Campus Partnerships for Health. This grant supports a three-part conference series to create a conceptual framework for communities as partners in cancer clinical trials and explores the application of CBPR principles and approaches to key areas of cancer research. (Ends 2009)

Exploring the Role of Secondary Conditions in Nursing Home Transitions (HS16166). PI: Tom W. Seekins, Ph.D.; University of Montana. This study uses CBPR principles to understand the role of secondary conditions in transition from the nursing home to the community and uses this understanding to modify a previously demonstrated intervention project. (Ends 2009)

We Will Not Be Moved: The Black Church Health Movement, 1900–1935 (HS10294). PI: Jacqueline M. Brooks Carthon, Ph.D.; University of Pennsylvania School of Nursing. This study explored the role of black churches in Philadelphia in providing services to congregants and others during a period when health care organizations were less accessible to members of the black community. The lessons learned are of critical importance to health disparities researchers. (10/1/2007 to 10/31/2008)

A National Assisted Living CBPR Partnership to Improve Medication Management (HS16171). PI: Sheryl Zimmerman, Ph.D.; University of North Carolina, Chapel Hill. This grant provided support to a national partnership of 10 research organizations concerned with improvement of assisted living through application of CBPR principles. Initial efforts were to improve medication management in assisted living facilities. (9/1/2006 to 8/31/2008).

The Creation of PBRN to Study Health Care Delivery to a Transitioning Community (HS16023). PI: Michael Dulin; Carolinas Medical Center/University of North Carolina, Charlotte. This study used a collaboration between academics, primary care ambulatory clinics, and community health organizations to understand the underuse of health care resources by the growing Hispanic community in Charlotte. (6/1/2006 to 5/31/2008)

Community Integration After Spinal Cord Injury: Using Photovoice to Identify Barriers (HS16941). PI: Susan D. Newman, Ph.D.; Medical University of South Carolina. This study applied participatory methodology to focus research on issues of greatest relevance to individuals with spinal cord injuries. It trained the subjects in the use of cameras to document the barriers and facilitators they encounter in the community, using semistructured individual interviews to provide additional information. (6/1/2007 to 5/31/2008)

Making Chronic Kidney Disease Guidelines Work in Underserved Practices (HS16031). PI: Chester H. Fox, M.D.; State University of New York at Buffalo. Chronic kidney disease, a worldwide public health issue, is four times more likely to burden minority populations. This study sought to use participatory research methods to assess provider- and staff-identified barriers to implementing evidence-based guidelines for chronic kidney disease in minority populations. (6/1/2006 to 5/31/2008)

International Meeting on Indigenous Child Health (HS16753). PI: Sunnah Kim, B.S.N., M.S.; American Academy of Pediatrics. This grant provided funding for an international meeting involving U.S. and Canadian organizations. One of the conference's objectives was to describe CBPR findings about the health and health care of indigenous populations. (12/1/2006 to 11/30/2007)

National Conference: Quality Health Care for Diverse Populations (HS15499). PI: Dennis Andrulis, Ph.D., M.P.H.; State University of New York Downstate Medical Center. This grant funded the fourth National Conference on Quality Health Care for Culturally Diverse Populations, which highlighted the best of culturally competent health care to national health organizations and leaders, including communities. (9/1/2004 to 8/31/2005)

Overcoming Health Racial Disparities (HS10861). PI: Timothy S. Carey, M.D., M.P.H.; University of North Carolina, Chapel Hill. A partnership between the University of North Carolina and two historically black North Carolina universities (North Carolina Central and Shaw Universities), the goal of the project was to understand and eliminate health disparities for adult cancer and other chronic illness among black adults, particularly rural black populations. (9/1/2003 to 8/31/2006)

Adult Health and Disabilities in Three Housing Conditions (HS13977). PI: Pei-Shu Ho; Medstar Research Institute. The project supported the National Rehabilitation Hospital's Center for Health and Disability Research in partnering with a community-centered disability group to carry out a CBPR study on the health status and health care needs of low-income or impoverished working-age people with physical impairments living in the District of Columbia. (6/1/2004 to 11/30/2006)

Development of an Enabling Services Database at Community Health Centers (HS13401). PI: Heidi Park; New York Academy of Medicine. This grant funded a pilot CBPR research project to work with the Association of Asian Pacific Islander Community Health Organizations and their member health centers to collect data on services that these centers provide to improve access to care for Asian American/Pacific Islander patients. (9/1/2003 to 8/31/2005)

AHRQ Reports on CBPR

Viswanathan M, Ammerman A, Eng E, et al. *Community-based Participatory Research: Assessing the Evidence*. Evidence Report/Technology Assessment No. 99 (Prepared by RTI-University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication No. 04-E022. Rockville, MD: Agency for Healthcare Research and Quality. August 2004.

Ford JG, Howerton MW, Bolen S, et al. *Knowledge and Access to Information on Recruitment of Underrepresented Populations to Cancer Clinical Trials*. Evidence Report/Technology Assessment No. 122 (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 290-02-0018.) AHRQ Publication No. 05-E019-2. Rockville, MD: Agency for Healthcare Research and Quality. June 2005.

AHRQ-Funded CBPR Publications

Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation* 2009 May 19; 119(19): 263—2642.

Kim MT, Kim EY, Han HR, et al. Mail education is as effective as in-class education in hypertensive Korean patients. *J Clin Hypertens* (Greenwich) 2008 Mar; 10(3):176-184.

Ancker JS, Kukafka R. A combined qualitative method for testing an interactive risk communication tool. AMIA Annu Symp Proc 2007; 16-20. [Electronic publication.]

Noe TD, Manson SM, Croy C, et al. The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. *Ethn Dis* 2007 Winter; 17(1 Suppl 1):S1-6-14.

Van Voorst RF, Araya-Guerra R, Felzien M, et al. Rural community members' perceptions of harm from medical mistakes: a High Plains Research Network (HPRN) Study. *J Am Board Fam Med* 2007 Mar-Apr; 20(2): 135-143.

Leonhardt KK, Deborah B, Pagel P. Partners in safety: implementing a community-based patient safety advisory council. *WMJ* 2006 Dec; 105(8):54-59.

Anderko L, Lundeen S, Bartz C. The Midwest Nursing Centers Consortium Research Network: translating research into practice. *Policy Polit Nurs Pract* 2006 May; 7(2):101-109.

Love MM, Pearce KA, Williamson, MA, et al. Patients, practices, and relationships: challenges and lessons learned from the Kentucky Ambulatory Network. *J Am Board Fam Med* 2006 Jan-Feb; 19(1):75-84.

Carey TS, Howard DL, Goldmon M, et al. Developing effective interuniversity partnerships and community-based research to address health disparities. *Acad Med* 2005 Nov; 80(11):1039-1045.

Anderko L, Bartz C Lundeen S. Practice-based research networks: nursing centers and communities working collaboratively to reduce health disparities. *Nurs Clin North Am* 2005 Dec; 40(4):747-758, xi–xii.

Anderson SR, Belcourt GM, Langwell KM. Building healthy tribal nations in Montana and Wyoming through collaborative research and development. *Am J Public Health* 2005 May; 95(5):784-789.

Manson SM, Garroutte E, Goins RT, et al. Access, relevance, and control in the research process: lessons from Indian country. *J Aging Health* 2004 Nov; 16(5 Suppl.);58S-77S.

External Resources

Community-Campus Partnerships for Health

A national nonprofit organization that supports CBPR partnerships, Community-Campus Partnerships for Health (CCPH) maintains a Web site of CBPR resources, including definitions, principles, tools, reports, presentations, journal articles, syllabuses and course materials, Web links, and electronic discussion groups. It can be found on the Web at http://www.ccph.info. CCPH's biweekly e-newsletter, *Partnership Matters*, compiles timely announcements about CBPR grants, conferences, and publications. To subscribe, send an e-mail to ccphuw@u.washington.edu or visit http://depts.washington.edu/ccph/enews.html.

Community-Based Public Health Caucus

This group, affiliated with the American Public Health Association, is guided by the belief that "community lies at the heart of public health, and that interventions work best when they are rooted in the values, knowledge, expertise, and interests of the community itself," according to its Web site, http://www.sph.umich.edu/cbphcaucus/. The caucus can be reached by e-mailing cbphcaucus@umich.edu.

Additional Information

For further information about AHRQ's involvement in community-based participatory research, contact:

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