Conference on Community-Based Participatory Research

**Sponsored by the Agency for Healthcare Research and Quality
in collaboration with
The W.K. Kellogg Foundation
The Office of Minority Health, U.S. Department of Health and Human Services
The Office of Behavioral and Social Sciences Research, National Institutes of Health**

**November 27–28, 2001
Rockville, Maryland**

Conference on Community-Based Participatory Research
November 27–28, 2001
Rockville, Maryland

Background

Growing Interest in Community-Based Participatory Research: There is increased interest in research that aims to improve the health of disadvantaged (minority, low-income, rural, central city, and other) populations. However, conventional research in these communities has a contentious history and offers limited opportunities to improve the health and well being of these communities.

Three additional factors compel us to look toward participatory research to improve the health of disadvantaged communities. First, local community knowledge increases our understanding of the complex interactions among economic, social, and behavioral factors that contribute to disparities and, therefore, should inform the design of interventions aimed at reducing these disparities. In addition, there is a gap between the knowledge produced in research and practiced in these communities. Finally, members of these communities are increasingly reluctant to participate in research and are organizing to monitor and/or prevent such activities.

Definition: Community-based participatory research (CBPR) is a collaborative process of research involving researchers and community representatives; it engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community members in the processes and products of research. In addition, community members are invested in the dissemination and use of research findings and ultimately in the reduction of health disparities.

Barriers: Participatory research in disadvantaged communities has a long and successful history in the social sciences and international and rural development. There is a growing recognition of the importance and promise of this type of research within health services and public health institutions and funding organizations. However, in spite of the increased interest expressed by communities, universities, and funders, CBPR is underutilized. Practitioners of CBPR have identified several barriers to CBPR. These barriers include:

- Poor community incentives and capacity to conduct CBPR;
- Lack of academic incentives and the need to develop capacity for researchers and community-based organizations (CBOs) to partner in CBPR projects; and
- Inadequate funding and insensitive funding mechanisms.

Purpose of the Meeting

The Agency for Healthcare Research and Quality (AHRQ), in collaboration with the W.K. Kellogg Foundation, the Office of Minority Health in the United States Department

of Health and Human Services (DHHS), and the Office of Behavioral and Social Sciences Research at the National Institutes of Health (NIH), convened a diverse group of participants for the Conference on Community-Based Participatory Research. Academic researchers, community representatives, private and government funding agencies, and others gathered on November 27–28, 2001, at the AHRQ Conference Center in Rockville, Maryland. The purpose of the meeting was to promote and support the use of CBPR, to explore the use of CBPR as a resource for policy-makers to help guide their program development, and to develop strategies to advance CBPR. The two-day meeting brought together representatives from the private and public funding community, CBPR practitioners, community organizations, AHRQ grantees, and other stakeholders to develop strategies that support CBPR within the community, academy, and funding organizations and encourage the use of community knowledge in program development and administration. Participants addressed barriers in the three key areas identified above.

Conference Objectives:

- To convene participants to raise awareness about and the relevance of CBPR;
- To bring together diverse groups to discuss CBPR and provide an opportunity for participants to form new partnerships;
- To identify opportunities and strategies to promote and foster CBPR that focus on addressing the institutional and other barriers to CBPR; and
- To explore CBPR as a strategy for funding agencies to obtain input from disadvantaged communities to develop their programs.

Conference Sessions and Activities: On the first day of the conference, the keynote speaker addressed the value of CBPR and subsequent speakers presented papers on community incentives and capacity building for CBPR, academic incentives and capacity-building for CBPR, and funding and funding priorities. Reactor panels composed of representatives of funding organizations, researchers, community representatives and advocacy groups, and professional organization journal representatives responded to the papers presented. All participants engaged in a facilitated and open discussion on the papers.

On the second day of the conference, participants divided into breakout groups and worked on the three topics to develop recommendations and strategies. The groups reconvened to share their findings and engage in open discussion.

Conference Products: In an effort to disseminate conference work, AHRQ will develop a supplement in the *Journal of General Internal Medicine* that summarizes the proceedings and presents original CBPR work and findings. AHRQ will also prepare a meeting summary for community-based organizations.

Welcome and Overview

Ms. Robin Tucker has spent 14 years working in health care and has focused recently on culturally competent care and health disparities. As the facilitator for the meeting, she saw her role as brining people with different backgrounds and perspectives together to find common ground and work toward a common goal. She remarked that she would listen, guide discussion, and provoke thoughtful dialogue. Her goal was for all participants to leave with a valuable experience.

The AHRQ Context: Ms. Tucker introduced Dr. Carolyn Clancy, Director of the Center of Outcomes and Effectiveness Research at AHRQ. Dr. Clancy was impressed with the incredible response to the meeting. The meeting would help AHRQ further focus its work with priority populations. She provided a context for the meeting by describing the health-related research continuum, which extends from biomedical research (basic science and controlled clinical trials) to health services research. AHRQ focuses on health services research including cost and effectiveness trials, quality and outcomes research, syntheses and meta-analysis, and organization, financing, and delivery research. Congress established the Agency 1989 in response to the need for research that would improve the health of populations. AHRQ's three goals are to support research to improve health outcomes, strengthen quality, and improve cost, use and access to health care. The Agency's target audiences include clinical decision-makers, health system decision-makers, and public policy decision-makers. AHRQ works in partnership with communities so it can reach its key audiences.

One can think of the research that AHRQ supports as a "pipeline of investment" in the following three connected components:

- New knowledge on priority health issues;
- New tools and talent; and
- Translating research into practice.

AHRQ emphasizes translating research into practice because this component facilitates the development of effective tools for clinicians to use in practice. This component also involves discovering what is needed to sustain changes in practice. AHRQ's research investment results in improved health care outcomes, better quality, greater access, and appropriate cost and use.

AHRQ's 1999 reauthorization reaffirmed the Agency's core research mission to improve quality, outcomes, costs, and utilization of health care. The reauthorization also focused on improving patient safety and charged the Agency with producing annual reports on trends in health care quality and disparities in health care. She emphasized that the latter report concentrates on disparities in health care rather than disparities in health, although the extent to which disparities in health are caused by disparities in care is a critical question. It is clear that non-clinical factors such as patient income and practitioner characteristics affect health outcomes. For example, receipt of a vaccine for preventable pneumonia among those over age 65 years is profoundly higher in those with higher

incomes. Sources of disparities include health insurance access and affordability, available providers and services, primary care accessibility, available specialists and referral services, and quality of care received. AHRQ's reauthorization indicated clearly the following priority populations: rural, inner-city, low-income, racial and ethnic minority populations, women, children, individuals with special health care needs, and elderly individuals. Although these groups often overlap, ARHQ faces a huge challenge in addressing health care disparities.

Health Care Disparities—An AHRQ Priority: Dr. Clancy reviewed current AHRQ initiatives to address health care disparities. The Agency established training programs to build capacity for research on priority populations to address leading issues in minority health. Training programs are located in research centers that focus on improving outcomes of care for minority populations and training minority researchers. AHRQ established the Minority Research Infrastructure Support Program (M-RISP) to increase the number of minority health services researchers and to build capacity for institutions to conduct health services research intended to improve health for Hispanics and African Americans. AHRQ grantees may apply for Minority Supplements to extend their research to these populations.

AHRQ has ongoing activities at historically black colleges and universities (HCBUs), Hispanic institutions, and Native American internship programs for students from Tribal colleges. The Agency increased its investments in these activities in 2000. AHRQ established Excellence Centers to Eliminate Ethnic/Racial Disparities (EXCEED) sites to advance the state-of-knowledge beyond mere documentation of disparities. EXCEED researchers hope to improve understanding of underlying etiologies and identify strategies to reduce inequities. They are working to develop capacity and infrastructure for minority health services research. EXCEED focuses on causes that are amenable to improvements in health services, including access, financing, bias, organizational factors, preferences, interactions with the medical system, and health literacy. Researchers in the program are working to develop sustainable relationships between investigators and communities.

Dr. Clancy stressed the important role communities have to play in health services research focusing on minority individuals. Communities might partner in conducting and disseminating research to improve care and identify research priorities on an ongoing basis. A key challenge involves linking communities with researchers in a true partnership rather than "colonization." Communities and researchers must also identify critical success factors for partnership. She thanked conference organizers and remarked that the meeting was a great opportunity to advance partnership among communities, researchers, and funding agencies.

Conference Origins: Dr. Dan Stryer welcomed participants and thanked them for traveling under difficult circumstances. He mentioned that the meeting began as a small gathering of EXCEED investigators to promote collaboration. Dr. Henrie Treadwell offered support from the W.K. Kellogg Foundation. Once people heard about the opportunity to gather, meeting participation grew rapidly because of the tremendous

interest in this timely topic. Dr. Stryer focused on the need to act on the information learned at the conference. He asked participants to identify specific steps to advance CBPR, reduce barriers, and facilitate this promising research model. CBPR undoubtedly strengthens the impact of health services research.

Dr. Stryer thanked Dr. Kaytura Felix-Aaron for leading the effort and Dr. Robin Weinick for her contributions to planning. He noted that AHRQ staff had tremendous support as they organized the conference. He acknowledged conference departmental collaborators and representatives from these organizations: The W.K. Kellogg Foundation (Dr. Henrie Treadwell); Office of Minority Health (Mr. Guadalupe Pacheco); and Office of Behavioral and Social Sciences Research (Drs. Raynard Kington and Virginia Cain).

Dr. Henrie Treadwell greeted participants on behalf of the W.K. Kellogg foundation. She thought the conference would facilitate continued partnership for this important work. Although the Kellogg Foundation has limited resources, they hope to bring synergy to CBPR efforts. Dr. Treadwell noted the appropriateness of AHRQ's focus on priority populations. These groups are majority populations in many areas and will soon become majority populations throughout the country. They need services, yet the health care system is ill equipped to serve them appropriately. Research on priority populations is needed to inform policy. Dr. Treadwell was pleased to see a diverse group at the conference, and she challenged each participant to become a "committee of one" to advance the dialogue on CBPR and health services research funding.

Participants introduced themselves and described briefly their interest in CBPR.

Conference Overview: Dr. Kaytura Felix-Aaron greeted participants and provided an overview of the meeting. CBPR is a collaborative process of research that involves researchers and community representatives in *all* phases of research. Also known as Participatory Action Research, this research model emphasizes participation of groups under study. She stressed the importance of distinguishing participation from involvement. Participation connotes true partnership and a decision-making role for the community, which is an essential principle for CBPR.

CBPR is not new, but DHHS and private foundations demonstrate increasing interest in this model. AHRQ staff assessed the "CBPR landscape"—i.e., the current environment for CBPR. They observed high interest and commitment to CBPR in some areas or "islands of CBPR." Despite growing interest in CBPR, there is skepticism about its value and a lack of information about this research model. Those familiar with CBPR have identified many challenges to its advancement. In response to the current context, AHRQ decided to convene a diverse group of stakeholders to identify needs and strategies to advance CBPR.

Conference Objectives, Products, and Goals: Dr. Felix-Aaron reviewed the meeting objectives, agenda, and products. She stressed that organizers allocated more than half of the conference time for open discussion and that participants would develop an action plan on the second day. Dr. Felix-Aaron remarked that the conference summary,

commissioned papers, and original research findings would be published in a special issue of the *Journal of General Internal Medicine* next year. A conference summary written for community-based organizations would also be available in a community-oriented publication. She requested that participants volunteer to serve as reviewers on the publications. Dr. Felix-Aaron noted that the indicators of conference success would be the development of an action plan that advances CBPR and the identification of three actions that participants would take after leaving the meeting.

Ms. Tucker also focused on the need for action as a conference product. She mentioned that meeting organizers made several tools available for this purpose. She requested that participants use the four index cards at their stations to raise questions and suggest action steps. The cards were color-coded to identify questions related to community, academic, and funding issues. Participants also received cards to suggest action steps to advance CPBR. The index cards would be collected, synthesized, and redistributed to encourage discussion and solutions. Ms. Tucker referred participants to the two color-coded post-it notes in their materials packet. They should write their greatest hope and biggest fear on separate notes and post these on the designated wall. Participant questions, hopes, and fears are listed in Appendices A and B.

The overall goal of the conference was to open dialogue, so these tools and the open discussion time provided many opportunities. She encouraged participants to be honest and to provide the "gift of feedback" to let others know of offensive comments. Ms. Tucker emphasized that participants should be authentic and share their experiences, but she acknowledged the challenges of doing so in such a diverse group.

On the first day of the conference, the keynote speaker addressed the value of CBPR and subsequent speakers presented papers on community incentives and capacity building for CBPR, academic incentives and capacity-building for CBPR, and funding and funding priorities. Reactor panels composed of representatives of funding organizations, researchers, community representatives and advocacy groups, and professional organization journal representatives responded to the papers presented. All participants engaged in a facilitated and open discussion on the papers.

Keynote Address: The Value of Community-Based Participatory Research
Barbara Israel, Dr.P.H., M.P.H., University of Michigan

A Context for CBPR: Dr. Barbara Israel remarked that the conference was a very exciting event and acknowledged her research partners in the Detroit community. She explained that an increasing amount of evidence indicates a disproportionate burden of morbidity and mortality within communities of few economic and social resources and communities of color. Inequities in health status are associated with social, structural, and physical environmental factors such as poverty and economic divestment.

The current disparities in health status have implications for research and practice. Addressing these disparities in health status is a major challenge for researchers,

practitioners, and the affected communities. Historically, within such communities, research has rarely directly benefited and sometimes actually harmed the communities involved. Research has tended to exclude these communities from influence over the research process.

The exclusion of communities from the research process has implications for research and practice. Interventions have often not been as effective as they could be because communities were not involved. Because communities were not included in all aspects of intervention design, implementation, and evaluation, interventions have not been tailored to participant concerns and cultures. There have been increasing calls for more participatory and comprehensive approaches to research and practice in order to reduce disparities in health. She acknowledged that CBPR is not the only viable research model, but noted that it is one effective approach to advancing more equitable health services research.

Definition and Key Principles of CBPR: Dr. Israel defined CBPR as follows:

> *CBPR in public health is a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process; with all partners contributing their expertise and sharing responsibility and ownership to enhance understanding of a given phenomenon, and to integrate the knowledge gained with action to improve the health and well-being of community members.*

Participants follow key principles when conducting CBPR. Dr. Israel emphasized that those involved should not impose principles on a partnership, but need to discover and establish principles as a partnership. Dr. Israel shared the CBPR principles that she and her colleagues have developed in working together in Detroit. (1) CBPR recognizes the community as a unit of identity. A community may be a geographic area, but it could also be a shared ethnic/racial or other identity. Cities are usually not a single community, rather they are made up of multiple communities of identity. (2) CBPR builds on the strengths and resources within the community. All communities have skills, assets, networks of trusting relationships, and mediating structures (e.g., CBOs, faith-based organizations). Those involved in CBPR support and expand existing social processes to address community needs. (3) CBPR facilitates collaborative, equitable partnership in all phases of the research and involves an empowering process. In a true collaborative research process, investigators and communities work together to define the problem, collect data, and interpret results.

(4) CBPR promotes co-learning and capacity building among all partners. This approach recognizes that researchers need to enhance their capacity and have a great deal to learn from the process. (5) The CBPR research model integrates knowledge generation and intervention for the mutual benefit of all partners. Therefore, all involved need to determine the mutual benefit of the process. Not all CBRP projects must include intervention implementation. It could be of mutual benefit to develop an intervention or guide policy. (6) CBPR emphasizes the local relevance of public health problems and the

multiple determinants of health and disease including biomedical, social, economic, and physical environmental factors. CBPR builds on problems identified by the community, which are often corroborated by additional sources of data (e.g., epidemiological surveys). (7) The CBPR process is cyclical and iterative, and research goals are not always known at the beginning of work with a community. This often challenges funders and researchers. (8) Individuals engaged in CBPR disseminate findings and knowledge gained to all partners and involve them in the dissemination process. Community members co-author reports and publications that reach and are useful to the community. CBPR involves a long-term process and commitment. Dr. Israel emphasized that it is critical for researchers to continue working with the community when they are no longer funded to do so.

An Illustration of CBPR: Dr. Israel acknowledged the Detroit Community-Academic Urban Research Center (URC) partner organizations that include community-based organizations, an academic institution, the local health department, and an integrated care system. The Centers for Disease Control and Prevention (CDC) funded the Detroit URC in 1995 through a co-operative agreement. The overall mission of the Detroit URC is to establish an effective community-based participatory research partnership to jointly identify factors affecting the health and well-being of residents on the east and southwest sides of Detroit. The Detroit URC strives to implement and evaluate interventions and policies to address these factors in ways that recognize, build upon and enhance the resources and strengths of the communities involved.

The Detroit URC is currently conducting 11 funded CBPR projects addressing a wide scope of issues. For example, projects address access to healthy foods and safe places to exercise, the environmental triggers of childhood asthma, and the relationship between socioeconomic status, physical environment, and risk for cardiovascular disease. Each project has a steering committee with representatives from URC partner organizations and additional organizations depending on the needs of the project. The Detroit URC has received over $23.5 million in Federal and foundation funding, involved 20 University of Michigan faculty and over 50 graduate and post-doctoral students, hired over 70 community members, and has built new relationships between researchers and community members, and between the African American and Latino communities within Detroit.

Benefits of CBPR: Dr. Israel described the benefits of using a CBPR approach and the contributions of this approach to communities and science. CBPR enhances the relevance and use of data, increases the quality and validity of research, improves intervention design and implementation by facilitating participant recruitment and retention, and benefits the community through the knowledge gained and actions taken. CBPR also provides resources for the communities involved, joins partners with diverse expertise to address complex public health problems, increases trust and bridges cultural gaps between partners, and has the potential to translate research findings to guide the development of further interventions and policy change.

General Recommendations: In conclusion, Dr. Israel remarked that there is a need for greater awareness and recognition of the meaning and value of community-based participatory research. Communities that experience a disproportionate burden of health disparities need funding support from public and private institutions to advance CBPR. Funders should emphasize capacity building and training of all partners to enhance the skills needed to conduct CBPR. Institutions should increase the benefits and reward structures for involvement in CBPR. Finally, multiple case study evaluations are needed to assess the context, process, and outcomes of CBPR efforts.

Open Discussion

Participants discussed issues experienced in their CBPR work. They focused on achieving mutual respect among the different players in CBPR as a necessary condition for advancing this approach.

Question Asked: How faculty involved in CBPR might gain respect from the academic community: Dr. Israel remarked that supportive deans assist faculty members who conduct CBPR. Obtaining funding for CBPR work provides legitimacy and infrastructure. It is absolutely necessary to publish, so one might conduct research in other areas with a quicker publication turnaround while also conducting CBPR.

Question Asked: Interacting with Institutional Review Boards (IRBs): Dr. Israel commented that her team worked very closely with their IRB and communicated changes in the research protocol in an ongoing fashion. They provided the rationale for and obtained approval from the IRB to use a verbal consent procedure for group and individual interviews, as appropriate.

Question Asked: Involving community outreach workers and community members as interviewers: Some researchers may be threatened by the involvement of community outreach workers in CBPR. Dr. Israel suggested involving these workers in interventions, which does not tend to threaten researchers. When involving community members with interviews, one will need to convince researchers that community members can collect high quality data. She recommended showing researchers mock interviews and demonstrating an extensive training process for community members. Her team spends 10 to 40 hours training interviewers and provides extensive practice with feedback. They partner students with community members, which results in improved data quality and benefit to students. She used some standard procedures that enhance data quality, for example, field office staff review interview responses immediately after collection to obtain missing data and provide feedback to the interviewers. Staff call participants at random to check on interview quality. She noted that her team has dismissed interviewers when follow-up showed that they were not doing a good job. Once researchers are convinced that community members are well trained and that quality checks are in place, their hesitation to include them as interviewers usually diminishes.

Question Asked: Protecting client confidentiality when community members are involved in data collection: When those living in the community interview their fellow community

members, confidentiality and data quality might be jeopardized. One way to address this concern is to check interviewer-participant assignments and substitute interviewers as necessary to ensure that no one interviews someone they know. All CBPR interviewers should sign an agreement to protect participant confidentiality.

Community Incentives and Capacity Building for CBPR: Successfully Promoting Community Interests through Research
Rebeca Ramos, M.A., M.P.H., US-Mexico Border Health Association

The Importance of the Community as An Equal Partner: Ms. Ramos remarked that community-based organizations (CBOs) want to ensure that investigators transfer knowledge generated by CBPR back to the community and integrate it into practical programs as directly and immediately as possible. CBPR can be a powerful approach to advance practice, support CBO sustainability, and build community capacity at every level. However, the power of CBPR depends on the extent to which the community is intimately integrated in the planning, implementation and utilization of the research. That is, the community must be an equal partner at all stages of CBPR. One must operate from the premise that the community and CBOs implement strategies. Therefore, those involved in CBPR must consider how research coincides with the interests of the community.

Barriers to Community Participation: Ms. Ramos identified the following impediments to the full participation of the CBO:

- The community does not own or have rights to data;
- The community perspective was secondary to scientific methods and theories;
- Antagonism between academics and seasoned community-organizing practitioners;
- Inter-organizational competition for limited resources;
- Lack of consensus on goals;
- Inadequate resources to advance identified goals; and
- An overemphasis on high-level policymakers, rather than mid-level implementers.

Conditions for Community Capacity Building: Ms. Ramos identified the following necessary conditions for successful community capacity building:

- Participation must extend beyond the CBO executive level;
- Traditional and non-technology transfer mechanisms to enhance learning of community members;
- Augmentation of the response to specific community needs;
- Respecting, valuing, and working with all groups in the community; and
- Expansion of data collection possibilities and inclusion of new methods and settings.

Overcoming Barriers: She listed the following specific mechanisms that facilitate the full participation of CBOs:

- The ability of the CBO to choose research partners (this is a very powerful motivator);
- Establishing ground rules and formal contracts with clear descriptions of roles and expectations;
- Establishing a method for decision-making; and
- Building a climate of mutual trust and respect and recognizing the different skills of team members.

She emphasized that the research-to-action approach involves close collaboration of researchers with the community and focuses on gaining and sustaining positive outcomes in the community. This approach strengthens the community with the intervention design, implementation, evaluation, and resource acquisition. In the research-to-action approach, community-based workers are offered professional development opportunities as part of the project. Both the academic and the community at large receive the project findings, and the team acknowledges the contributions of all stakeholders. The team applies the principles of parity, inclusion, and representation in project planning and implementation to achieve full participation by clients, academics, casework managers, and clinicians. The team shares data collection responsibilities, which facilitates understanding of the community perspective. Stakeholders validate findings and indicate whether the project recommendations would actually work in the community.

Two Examples of Initiatives with Full Community Participation: Ms. Ramos provided two examples of community-driven initiatives with full community participation. Taking the research-to action approach, the initiatives resulted in the transfer of programmatic innovations (programs, interventions, services, and practices) to minority communities.

The first example, Programa Companeros, illustrates capacity building within a community-based organization (CBO) through research. This is a CBO-based program in Ciudad Juarez on the United States-Mexico border, near El Paso, Texas. Companeros has collaborated with Federal, state, and academic institutions for over 15 years to gain knowledge and skills to better deliver services to the community. The CBO has gained knowledge and improved practice by the successive implementation of research projects. Programa Companeros exhibited characteristics that facilitated research-to-action. The CBO selected researchers interested in drug use and HIV prevention so that those involved had a desire to work as part of a team. Researchers committed to working with the CBO on the project for as long as possible. The research process provided technical assistance to improve existing interventions and professional development opportunities for the CBO staff. These critical facilitators of community participation were negotiated at the beginning of the project.

The second example, the AIDS Behavioral and Epidemiological Study Training Program (AIDS BEST-Program), used a community-oriented process for building capacity among community-based researchers. AIDS BEST-Program was a collaboration of the

University of New Mexico, University of Texas School of Public Health, and United States-Mexico Border Health Association funded by the World AIDS Foundation and the John E. Fogarty International Center for Advanced Study in the Health Sciences. Its primary goal was to involve minority community-based researchers in the conduct of prevention studies in their communities. AIDS BEST had an epidemiological research training track focused on the principles of modern epidemiology, study design considerations, data management, data analysis, and program quality assurance. The behavioral research training track focused on the principles of individual and community behavioral theories in HIV prevention, and the design and evaluation of behavioral intervention research projects.

The AIDS BEST project emphasized capacity building goals. It involved community-based researchers to conduct effective community prevention studies. The program supported community-based researchers to implement projects in their own localities independently or in cooperation with academic institutions. Research projects often do not transfer adequate resources to support the community as it collects data, even though data collection is often a heavy burden to communities. However, the AIDS BEST project augmented local resources to carry out effective and creative studies that responded to community need. Ms. Ramos emphasized that augmenting community resources is a critical aspect of CBPR.

Capacity building activities (CBAs) consisted of problem-based learning tutorials, workshops, and a follow-up consultation by faculty via telephone and electronic mail. Working in small groups with a faculty mentor, trainees were presented with a learning challenge and sought a solution to that problem in these small groups. Other sessions consisted of faculty presentations followed by active involvement by the trainees in exploring a topic of relevance to their communities. CBAs were successful because the training program provided a foundation to address issues that were relevant to particular communities. The activities made new and cost-effective tools available to meet the challenges faced by local-level researchers. There are now a few community-friendly outlets for the results of capacity building activities and community-based projects.

Reasons Underlying Full Community Participation: Ms. Ramos emphasized that these initiatives were successful for the following reasons:

- The community had full ownership and participation in the research process.
- There were mechanisms and systems (policies, staff development, and service delivery design) in place to ensure participation.
- Stakeholders had a specified role in the design, execution, and utilization of research findings. CBOs mandated the role of stakeholders.
- These projects involved an explicit and previously negotiated transfer of technology, a process of learning and adapting the different conceptualizations of research, and research outcomes (data) linked to the sustainability of CBO programs.
- There was a consensus that the community collaboration was as important as the findings.

Summary and Conclusion: CBPR builds capacity for all partners. To build capacity one must identify a genuine concern across multiple communities, select partners working in non-academic institutions, and provide training to researchers on rules for working with communities. Because capacity building is a process rather than an event, there must be incentives for all participants throughout the process. From the community perspective, incentives for participation in the research-to-action-approach include access to state-of-the-art interventions, the possibility of obtaining funding or employing stakeholders through research grants, and enhancing organizational skills and status through work with research institutions.

Panel Discussion: Community Incentives and Capacity Building for CBPR
Barbara Major, St. Thomas Health Services
Mary Northridge, Ph.D., M.P.H., American Journal of Public Health and Harlem Health Promotion Center
Clifton Poodrey, Ph.D., National Institute of General Medical Sciences, National Institutes of Health

Ms. Barbara Major commented that CBOs have to reconsider their mission. CBOs tend to become very involved in service provision, but they should also work for change in institutions and a health care system that was not designed to serve communities of color. In her community race is an independent health risk, and people face systemic, institutional racism. Health care research and evaluation is not race neutral. She wondered if participants meant building capacity for service provision or institutional change when they spoke of "building capacity for communities." She stressed the need for communities to hold CBOs accountable for advancing institutional change.

Dr. Clifton Poodrey remarked that like many participants, he feels connected to at least two communities. He wondered what people mean when they use the term "community." He challenged participants to reach out to a broad range of communities with vastly different interests, awareness levels, problems, and issues. It would be especially challenging to reach communities that are not looking for information. He focused participants on training individuals to conduct CBPR and stressed the need to find alternative, cost-effective training models. He mentioned the need to examine NIH review criteria for applications submitted by CBOs, the impact of not getting funded on CBOs, and characteristics of CBOs that obtain funding. He thought it would be a challenge to balance provision of long-term funding and offering opportunities to many researchers.

Dr. Mary Northridge encouraged participants to contribute to CBPR from their own expertise and experiences of effective practices. She stressed the importance of adding committed experts to a CBPR team. Often, one can train committed individuals to have the necessary skills for CBPR. She also encouraged participants to use a variety of existing mechanisms for dissemination.

Open Discussion

Participants discussed community issues and capacity building. They stressed the overall cultural context of racism and discrimination that exists in institutions and systems. Until this context shifts toward an equitable state, it will be challenging to create CBPR that reflects balanced power and a true partnership. Some community members remember inequitable relationships with researchers, which seemed to be established only for the benefit of the investigator or a large institution. They noted some progress, and these participants looked forward to better relationships with investigators and using research to bring positive changes to their communities. Participants from many communities emphasized capacity building—enhancing the economic and human resources present in communities so they can further develop their resources—as a key action that will promote greater equity. Participants called for those in positions of power to share that power and build long-term relationships and truly get to know the community. To community members, part of power sharing involves co-ownership of data from the community, publishing, and working with researchers to obtain funding from large institutions.

The importance of true power sharing among CBPR partners:

Participants stressed the importance of power sharing to eliminate racism and other forms of discrimination. Before they implement strategies to facilitate capacity building in a specific community, CBPR partners should have frank discussions about racism and power and the need for investigators to relinquish power. Researchers often rush to the outcome stage before they fully understand CBPR process. CBOs have to ensure that the CBPR process fulfills their needs. To build capacity, CBOs need people who serve as liaisons between the community and research environments.

A good model of power sharing between the community and academics exists—the Native American Research Centers on Health Initiative. Primary grant applicants are Tribal or Tribally-sanctioned communities, but secondary partners can be research institutions. Grant applications are reviewed for scientific merit and relevance to the community. Other sponsors might find this different approach interesting or useful for building new models. For more information on this initiative, contact Dr. Spero Manson.

Training on systemic racism and the development of a culturally competent curriculum for clinicians have tremendous impact. It is critical to make changes in institutions that permit sustained improvements in racism and discrimination.

Funding for capacity building:

Perhaps there should be three funding venues—academic, community-based; and a mix of community and academic.

Communities struggle with obtaining funds through the complicated procedures in place at large institutions. They often perceive a cultural gap between their communities and

these institutions. For example, institutions require applicants to explicitly define terms that community members understand intuitively (e.g., accountability and equity). Community representatives expressed a need for cultural translation so they can better understand how large institutions approach funding.

CBPR products and dissemination:

Publishing by community partners is an essential adjunct to CBPR. Once community partners have published work, the relationship or dynamic with researchers and other partners changes. Individuals involved in CBPR should develop a process for authorship and convene a scientific writer's workshop to build capacity of community partners to publish. The need to recognize that submitting for publication involves understanding the language and culture of publishing. Community members have not been trained in this language and culture, but could learn.

The importance of knowing the community:

The relationship with the community is critical and determines the outcome of the work.

Even after one has worked with a community for many years, there is still a need to continually evaluate their needs. The community often enters a project with new interests and needs.

Individuals who work in both the academic and community settings are often not fully accepted in either environment, so they feel like outsiders in two communities. Both contexts have room for growth in terms of accepting these individuals and increasing their understanding of the other group.

Working with NIH:

Researchers seek funding from NIH because of the high prestige and other advantages that NIH funding provides. However, grant reviewers with a purely academic background might not value research with community organizations as much as basic science.

Researchers seeking funding must recognize that funding agencies have agendas and try to find common ground to advance the project.

Participants perceived that the CBOs successful at obtaining NIH support might "speak the loudest." They were concerned that other groups with valuable contributions and good community representation do not attract attention and win funding. Dr. Poodry responded that NIH recognizes the need to hear from a variety of community voices. NIH convenes a series of focus and advisory groups to obtain good community representation. He acknowledged that it would be a challenge to establish targeted initiatives for CBPR at NIH.

Academic Incentives and Capacity Building for CBPR

Two speakers summarized two different CBPR models. The models reflect experiences of researchers engaged in CBPR at three different types of academic institutions—a small, private university, a large, public institution, and a private, research-focused institution—with wide CBPR experience. Dr. Phil Nyden emphasized that CBPR's main strength is that it produces knowledge for consumption rather than storage and has guaranteed impact. Mr. Toby Citrin focused on building academic capacity for the conduct of CBPR and indicated potential facilitators.

Incentives for Faculty Participation in Community-Based Participatory Research
Phil Nyden, Ph.D., Loyola University Chicago

<u>*Barriers to CBPR Participation from the Academic Perspective*</u>: Dr. Phil Nyden described some of the barriers to CBPR from the academic perspective. In the academic setting, the discipline defines research priorities. This is a barrier because university-based research focuses on furthering knowledge in the discipline rather than social change. Theoretical knowledge is favored over practical knowledge. As a result, applied research is not valued as highly as theoretical research and ideas tend to be kept within the academic setting. The academic community views CBPR as biased because it involves "representatives" of the population to be studied in the research process, which raises potential bias in data collection. Academic researchers perceive that the data analysis might be manipulated to serve political ends because CBPR does not only involve unbiased, "outside" researchers. Academic researchers perceive CBPR as parochial because it is limited in scope and less powerful in its general application. Members of the academic community value "global" research and regional or national quantitative summary data, while CBPR offers highly-textured, local, and qualitative data. Finally, tenure and promotion guidelines impede academic participation in CBPR. Tenure and promotion is not usually based on "demonstrated contributions to the improved quality of life in society"—a key principle of CBPR. Academic researchers often show indifference or even hostility to community engagement. A key aspect of this barrier is the emphasis that tenure and promotion committees place on publications and contributions to the field. Work with an impact on society does not tend to be valued as highly as contributions to the discipline.

<u>*Overcoming Barriers*</u>: Dr. Nyden stressed that academic researchers can break through these barriers by emphasizing CBPR's strengths. CBPR can help universities establish and foster interdisciplinary initiatives. In theory, academic institutions value interdisciplinary approaches and recognize that "cutting-edge" work brings different disciplines/perspectives together. Because social problems are holistic and complex, they require an interdisciplinary approach. He stressed that academic institutions are under considerable pressure to establish their relevance to general society. This has been called the "age of engagement" in higher education, and advocates of CBPR could take advantage of this climate to form partnerships with universities. Advocates of CBPR could also engage students seeking practical experience during the course of their training. Since service learning and community-engagement are now recognized aspects

of academic mission statements, CBPR could fit into these goals. Increasingly, people recognize that universities are not the only setting that generates and communicates knowledge. Academic institutions are therefore seeking partners in the non-academic world. CBOs are increasingly sophisticated centers of knowledge and have much to offer academic partners.

Motivating Investigators to Participation in CBPR: In terms of motivating faculty at a personal level to engage in CBPR, one can argue that CBPR is "traditional research plus"—i.e., it is knowledge for consumption rather than storage and has a guaranteed impact. Individual researchers might respond positively to CBPR's team approach because it connects faculty, other researchers, and practitioners with similar interests. They might be persuaded by the common tendency of faculty and CBOs to question the status quo. Faculty members would certainly be motivated by the opportunities that CBPR provides for significant new research avenues, funding sources, and publication outlets. The interactive, passionate nature of CBPR and the way that CBPR energizes teaching might motivate some faculty to participate in this approach.

Facilitators of Academic Participation: Dr. Nyden commented that changing the hiring and tenure and promotion procedures might be a slow or difficult process. However, he was optimistic that the academic community could encourage faculty to conduct CBPR by reducing the discipline-bound control of faculty personnel policies. They might increase university-wide incentives to promote engaged scholarship by setting aside interdisciplinary positions with an emphasis on community engagement and favoring community-engaged faculty departmental hires. The academic community might create a national network of peers to judge CBPR faculty. Finally, academics could make service a primary, not residual, evaluation category for tenure and promotion.

Models for Academic Participation in CBPR: Dr. Nyden described Portland State University as a working model that rewards community-engaged teaching and research. This institution emphasizes that research is an activity and views scholarship as discovery, integration, interpretation, and application. Portland State defines service in a way that supports CBPR—i.e., service is faculty engagement that solves social problems, facilitates organizational development, improves existing practices/programs, or enriches the cultural life of the community.

The Loyola University of Chicago Center for Urban Research and Learning (CURL) follows the CPBR model. In this model, projects are seen as research *with* the community not research *on* the community. The model recognizes the knowledge in the community and offers research opportunities to members who have traditionally been excluded. The community is a partner at all stages of research, from conceptualization to dissemination of results. CURL engages in team-based research and action projects involving faculty, graduate students, undergraduate students, community organization leaders /staff/members, and CURL staff. All team members are supported by the university's endowment and engage in co-learning.

These collaborative centers could serve multiple functions including institutional advocacy for CBPR, coordination of CBPR efforts, and as a repository of information and resources. Collaborative centers could also serve as technical assistance centers for CBPR projects, organizers of collaborative research meetings for discussion of ongoing projects, and alternative socialization venues for faculty and graduate students.

Conclusion and Broad Recommendations: In conclusion, Dr. Nyden suggested that funders and government organizations might support and promote CBPR through specific funding for CBPR initiatives, encouraging CBPR in all funding contexts, funding comprehensive CBPR centers, and financially supporting grassroots-based national policy-making. Although gains have been made in CBPR, substantial work remains.

Capacity Building for CBPR
Toby Citrin, J.D., and Lee R. Bone, M.P.H.

Mr. Toby Citrin acknowledged that his presentation was based on his experience with the Community Health Scholars Program at the University of Michigan (www.sph.umich.edu/chsp). He also recognized his collaborator, Ms. Lee Bone.

Definition of Academic Capacity for CBPR: Mr. Citrin described some reasons why academic institutions should support CBPR. CBPR furthers the ultimate missions of both the institution and schools of public health, strengthens research and teaching, relates research to community needs, strengthens the impact on community, and improves community support for the institutions. To support CBPR, academic institutions require faculty with a set of CBPR competencies. These faculty members understand the values and mission of community-based pubic health, the social and economic determinants of health, and have the knowledge and skills to apply CBPR principles. They especially understand that community-based public health is best practiced in a partnership mode. Faculty members with CBPR competencies are able to transfer these skills to the community and other scholars and are able to work effectively in and with diverse communities. A key characteristic of these individuals is that they enhance the capacity of the community to conduct CBPR. Faculty members who are successful at obtaining funding for CBPR must inform funders of the importance and relevance of this research model. Faculty members with CBPR competencies also understand the policy implications of CBPR and work with communities to translate CBPR into policy to sustain their work. These individuals balance academic tasks and CBPR work and are familiar with community-based teaching and learning approaches. They write grants that express CBPR principles and negotiate across community-academic groups.

An academic institution with CBPR capacity must have both academic and community mentors/advisors to coach students at various levels. CBPR mentors understand and have experience with CBPR, act as role models of academic or community success, and advocate on behalf of scholars conducting CBPR. Mentors offer advising on academic professional and career development and act as role models of success at combining community competency, CBPR and successful academic career development. Academic mentors advise students on the academic institution's culture, writing for publication and

presentation, and techniques of community-service learning. Community mentors offer expertise in community leadership and the community's perspective on and prioritization of health issues and other challenges to community well-being. They advise scholars on community assets related to addressing health issues of interest, provide the community's insights on the culture of the community organization and the population it serves. Institutional capacity also includes having strong CBO partners with experience conducting CBPR, willingness to work with academics, potential CBPR projects, and leaders who can serve as mentors.

Barriers: Academic institutions must overcome barriers to enhance their capacity to conduct CBPR. One barrier is the extra time and expense needed to build trust and conduct CBPR. CBPR often involves travel and communication issues. The CBPR model is impeded by a lack of performance measures and the lack of credibility for research methods among some funders. Mr. Citrin emphasized the need to develop measures to hold organizations accountable and to distinguish credible and non-credible CPBR. Individuals conducting CPBR also have to face concerns about exploitation among some CBOs and confusion about terminology.

Solutions: Mr. Citrin described factors that facilitate academic capacity building for CBPR. Developing institutional capacity results in the ability to further enhance institutional capacity (e.g., those with a track record of success in CBPR have a greater chance of obtaining more resources to further CBPR work). Funding and institutional administration support for CBPR facilitates capacity building. Developing a support network within the institution and across other institutions enhances capacity. He stressed the importance of developing _long-term_ community-academic partnerships because they strengthen research and teaching. Such relationships cannot be dependent on time-limited, individual grants. Institutions with support from their recruiting/admissions offices (i.e., those who mention CBPR opportunities to potential students and staff) can build capacity by attracting talented individuals. Postdoctoral training programs promote training and career development among scholars with an interest in CBPR. Finally, institutions that have strong relationships with national organizations that promote CBPR (e.g., the Loka Institute and the Community-Based Public Health Caucus) build capacity by sharing expertise and disseminating CBPR principles and methods.

Two Case Studies: Mr. Citrin described two case studies that illustrate the development of high capacity for the CBPR model. The University of Michigan School of Public Health (UM-SPH) used the principles of community organizing to mobilize efforts, facilitate projects, overcome barriers, and provide mentorship and encouragement in support of CBPR. UM-SPH built infrastructure that facilitates CBPR. For example, they created a staff position for a liaison to match academic and community partners based on research interest and established a CBPR resource room to support students working on these projects. UM-SPH developed long-term partnerships with multiple funding sources and established academic training programs from the masters to junior faculty levels.

The Johns Hopkins University Bloomberg School of Public Health is another example of an institution that built CBPR capacity. Key leaders, the president and governing board,

were committed to community-based public health. They integrated this commitment into the University's strategic plan through the Urban Health Initiative. The Bloomberg School plans to create a concentration in CBPR and offer courses in CBPR competencies, thus integrating this research model into educational programs. A consortium of faculty members that interact and share information, advocates, and promotes CBPR across the public health school. The university offers incentives to support CBPR including seed funding and infrastructure to help faculty obtain external funding for CBPR projects.

Although these and other institutions have developed capacity for CBPR, many challenges remain. The field must develop a clear description of CBPR methods and establish a base of evidence demonstrating the impact of CBPR on institutions, CBOs, scholars, policy-making, and community health status. Mr. Citrin suggested that the ultimate goal for CBPR would be to strive for "excellence in scholarship through engagement." To achieve this goal, CBPR might fit into several existing frameworks including the Boyer Model of Higher Education, the "Engaged Institution," and "Demonstrating Excellence in Academic Public Health Practice" (a document from the Practice Coordinators of Schools of Public Health). He stressed that CBPR is a promising model, but that it is not suited for all researchers. Such investigators might find a better fit with other valid research models.

Panel Discussion: Academic Incentives and Capacity Building for CBPR
Eric Bass, M.D., M.P.H., Journal of General Internal Medicine and Johns Hopkins School of Medicine
David Korn, M.D., Association of American Medical Colleges
Tony Whitehead, Ph.D., University of Maryland

Dr. Eric Bass, editor of the *Journal of General Internal Medicine*, shared from his perspective as a general internist in a traditional academic medical center. CBPR and other types of "non-traditional" research approaches face the same barriers—i.e., the perception that the science is "soft" and difficulties in obtaining funding and publication. He focused on specific actions that could facilitate funding and publishing and bring attention to CBPR successes.

Overcoming Funding Barriers: To overcome funding barriers, Dr. Bass recommended that the field do the following:

- Develop, maintain, and publicize a directory of agencies that are willing to fund CBPR;
- Convene workshops in grant writing for researchers who use the CBPR approach;
- Identify opportunities to direct institutional resources to CBPR (e.g., advocate for community health indicators in the academic plan of your institution; support the career development of CBPR investigators; recruit and train people interested in CBPR taking advantage of existing fellowships); and
- Identify opportunities to influence policy-makers to direct money to CBPR.

Overcoming Publication Barriers: To overcome publication barriers, Dr. Bass recommended that the field do the following:

- Identify clinical and public health journals interested in publishing CBPR, especially qualitative research;
- Take advantage of opportunities for CBPR experts to serve on journal editorial boards;
- Convene workshops to help researchers write better papers with community partners and to inform them of the different types of scholarly articles;
- Submit original research to the special issue of the _Journal of General Internal Medicine_ that will emerge from this conference; and
- Develop and disseminate better methods of measuring CBPR's impact.

He emphasized that actions that enhance the ability to obtain funding and publish will help faculty who conduct CBPR gain promotion and tenure. He encouraged participants to expand CBPR networks to share information and facilitate dissemination.

A Perspective from Academic Medical Centers: Dr. David Korn shared the perspective of medical schools and centers. His goal was to make observations that might assist strategy and planning efforts. Participants should keep in mind that academic medical centers represent a diverse set of social institutions, so it is not useful to make generalizations about "medical schools" as if they were all similar. Various medical schools have very different missions, prestige levels, histories, and relationships with communities. Some institutions have a mission to advance local/regional concerns, while others see the world as their community. There are some common themes, however. All institutions of higher education expect faculty to demonstrate excellence in some combination of teaching and research, and some require service to community. Dr. Korn emphasized that in the academic setting, evaluation is paramount. The focus of academic evaluation is the individual, so the system has difficulty assessing achievement for individuals involved in interdisciplinary research. This problem has to be solved before CBPR and other types of interdisciplinary research can fully establish themselves in academic institutions. Fortunately, there is increasing recognition that most scientific problems are so complex that they require interdisciplinary research. Unfortunately, a well-established value hierarchy exists in academic institutions. That is, academic institutions place higher value on some types of research and journals. Most research universities rely heavily on external funding as their fluid pool of resources since institutional resources are limited and allocated for specific purposes. Therefore, investigators must persuade institutional leaders to allocate resources to their research program or win external funding from an organization that has integrity and rigorous selection criteria. He thought it would be productive for CBPR to train investigators to conduct rigorous research and champion the work. A focus on patient empowerment as part of CBPR might be of interest to academic medical centers.

A Perspective from Anthropology: As an anthropologist, Dr. Tony Whitehead shared from the cultural framework perspective. When there is tension between two communities, it is necessary to address the unconscious paradigms that individuals carry

into situations. All cultures, including academic disciplines, socialize and influence the views and values of their members. Academics are trained to view issues with a high degree of precision and reduce phenomena to a small set of variables. In contrast, communities emphasize context, process, appropriateness, and relevancy. Science is a language and tends to be the language of those in power. Community members can see that researchers have been socialized to see themselves as more important than others so tension results. Community-researcher relations are complicated when the community involved is diverse and complex. In developing such relationships, cultural translation is necessary for the communities to have a better understanding of each other. Community partners can provide a translation of the culture/community, yet researchers have to be open to the emergent characteristics of cultures and relationships. Overall, understanding the community enhances the meaningfulness of the research and positive relationships with the community facilitates the research process. Often the community struggles with the same questions as researchers. He encouraged those involved with CBPR to develop a "project culture" and establish common objectives and goals from the beginning. Relationship monitoring and process and formative evaluation can help researchers develop a project culture.

Open Discussion

Participants discussed academic incentives and capacity building. They focused on academic culture, which values rigorous research methods, analysis and reduction of phenomena to a small set of variables, and the language of science. In contrast, the community perspective values context, process, appropriateness and relevancy. Because of the unbalanced power dynamic and differing cultures and languages, tension results when the two cultures meet. Academics who want to work with the community and understand the culture sometimes feel that they are "caught between two worlds, but part of neither." These investigators, as well as others from non-traditional research approaches, perceive a disadvantage in terms of how their institutions assess their work. Community members focused on the need for academic institutions, which have been traditionally isolated, to reach out to communities and build external relationships. Dr. Korn appreciated the issues identified by participants, but he advocated action rather than discussion of differences and perceptions held by one group about another. He encouraged participants to take specific steps that would advance the necessary changes that they have identified.

The need to increase the number of faculty members conducting CBPR:

Although CBPR is not the only valid research approach and is not suitable for all researchers, the CBPR approach needs more investigators.

Benchtop science and CBPR can be connected. Researchers should be creative and open minded about this possibility.

Funding initiatives:

Requests for Applications/Proposals should ask for projects that join benchtop science and CBPR, thereby targeting and facilitating collaboration.

Federal funding allocation and research agenda should be accountable to taxpayers.

Since the amount of commercial research and development funding is threefold the Federal research budget, investigators using the CBPR approach should apply for private sector funds.

Academic-community relationship:

CBPR projects should include CBOs in their budgets.

Once a relationship with an academic institution is established, the community should leverage university resources (e.g., priority tuition reimbursement for students who are community partners and positions that are half time community and half time academic.

Students could pressure the university administration to improve the CBPR curriculum.

To foster a good academic-community relationship, partners need to discuss and agree upon intellectual property rights from the beginning. Universities have not typically dealt with intellectual property issues in the context of collaboration, but there is a great need for them to do so.

The value of CBPR:

CBPR offers a fresh approach to engaging disadvantaged populations in clinical research.

The methods for developing evidence-based guidelines could be applied to synthesizing evidence on the value of CBPR. Scholars should compile evidence on interventions that are only effective when implemented at the community level.

In communicating the value of CBPR, proponents need to balance the emphasis on process and products.

Funding and Funding Priorities for CBPR
Angela Glover Blackwell, J.D., PolicyLink

Ms. Angela Glover Blackwell commented that she learned a great deal today. She has used CBPR in her own work, although she did not use this term. She noted that others had pointed out the funding challenges, so she would try to elaborate on the deeper issues of CBPR funding.

An Example of Community-Based Work: She described her experience with several community-based projects. In one situation, the city of Oakland, California, supported the Urban Strategies Council to bring various organizations together to prepare an application for empowerment zone funding. The team enacted the principles of CBPR and developed an excellent application. However, the project was not funded. She stressed that the organizations continued to work together for community change. The city demonstrated deep understanding of community needs by trusting community organizations with the application rather than automatically delegating it to an academic institution.

Community-Building Participatory Research: Ms. Blackwell expressed a strong preference for *community-building* participatory research because it advances solutions that improve quality of life for individuals and communities. She defined community-building participatory research as:

> Continuous, self-renewing efforts by residents and professionals to engage in collective actions aimed at problem solving initiatives to make life in the community better. This work improves lives and equity and creates new relationships, assets, standards, and expectations of life in the community.

The community-building perspective understands that historical racism has put individuals at an extreme disadvantage. This perspective also understands that racism continues every day because it permeates institutions regardless of leadership.

Recommendations for Funding Organizations: Funding for community-building participatory research must focus on achieving equitable outcomes and examining the process to reverse power dynamics. Funders must understand the following:

- The goal of community-building;
- The process of community-building;
- Power is concentrated in organizations and institutions;
- Communities need flexible mechanisms to solve complex problems;
- Evaluation of community-building is critical and many struggle with this issue; and
- Funding/incentives must be connected to measures of authentic, deserving work.

Panel Discussion: Funding and Funding Priorities for CBPR
Carolyn Clancy, M.D., Agency for Healthcare Research and Quality
Iris Farabee-Lewis, D.D., Centennial Caroline Street United Methodist Church
Raynard Kington, M.D., Ph.D., Office of Behavioral and Social Sciences Research,
National Institutes of Health
Henrie Treadwell, Ph.D., W.K. Kellogg Foundation

Community Members Emphasize Infrastructure Development Needs: Dr. Iris Farabee-Lewis stressed that communities require financial support to develop infrastructure. They need technical assistance to sustain research projects. Funders could support the development of long-term relationships among diverse groups. Dr. Farabee-Lewis emphasized that there must be follow-up programs/interventions to address community problems identified by research. The community would like to see funding initiatives to train their own people to do research. Finally, communities deserve access to data collected by CBPR projects.

Increasing Acceptance of CBPR Among Funders: Dr. Raynard Kington commented that he is optimistic about CBPR's future based on recent indications and events. The National Academy of Sciences/Institute of Medicine released several reports relating to this type of research. Because such reports have tremendous influence on the scientific process, there is good reason to expect that funders will respond. These reports identified research questions that can only be addressed through community-based research. The Federal initiative to eliminate health disparities elevated the profile of these research questions. Therefore, research topics that are best addressed by the CBPR are now at the forefront.

There is also increasing acceptance that the interdisciplinary approach is the only effective way to address complex problems. Although it can be difficult to effectively implement interdisciplinary teams, biomedicine provides a successful model. There is also an increasing interest in the social determinants of health, a topic very suitable for CBPR. With increasing interest in social determinants of health and health disparities, investigators need to make explicit to funders how CBPR will solve important health problems. Dr. Kington noted that there are multiple valid definitions of community. He suggested that CBPR investigators adopt the broadest definition possible to engage the maximum number of people.

Funders Require Education on CBPR: Dr. Kington spoke of the need to improve the grant review process. CBPR is not well understood by reviewers. Therefore, the field must define excellent CBPR and create specific criteria that reviewers can use in their assessment of grants. To educate funders and scientists about CBPR, members of the community should volunteer to be on IRBs or community advisory committees (for a university or NIH Institutes).

Dr. Carolyn Clancy commented on the current high interest in CBPR as a means of enrolling participants in large clinical trials. Although this interest is pragmatic, individuals invested in CBPR could build on this momentum to advance CBPR as a

research model. She encouraged participants to define critical CBPR elements for funders. Funders need specific information on the following questions:

- What should funders expect from CBPR?
- How should funders evaluate CBPR?
- What are the characteristics of excellent CBPR?
- What are the predictors of CBPR success?
- What resource-sharing formula is most appropriate for CBPR partners?

Funders have resources that can act as a catalyst, but are challenged to build capacity in communities with multiple needs and few assets. They struggle with the need to balance unique insights into one community and knowledge that can be transferred to other communities. Funders need benchmarks for CBPR success and guidance as to suggestions to researchers when these benchmarks are not achieved. CBPR must demonstrate its value through clear metrics and clarify the types of research questions for which CBPR has the most value. The field must develop methods, especially for interaction assessment.

Dr. Clancy commented that community members might improve the grant review process by suggesting panelists and advising funders about the characteristics of a balanced CBPR portfolio.

Challenges: Dr. Henrie Treadwell noted the enormous challenges faced by those attempting to eliminate health and other disparities. Given the current policy and resource allocation, health status is declining. Change is clearly needed, and she hoped that the victims of inequities would not be blamed.

She stressed that taxpayer communities should have a voice in determining the Federal research agenda. Communities must discuss and clearly identify a worthwhile research agenda. Effective CBPR includes a policy component and community organization to inform policy and mobilize public funds.

The W.K. Kellogg Foundation supports pre- and post-doctoral training programs to increase the pool of CBPR investigators, especially those from minority and disadvantaged communities.

Open Discussion

Participants discussed funding and funding priorities for CBPR. Community members identified specific needs related to developing infrastructure and sustaining research projects. They stressed that it is not enough to identify problems in the community and conduct research studies examining such problems. Communities require follow-up programs to achieve social gains and improve overall health. Participants expressed a desire to be a part of the solution for identified problems, and they committed to being part of the solution by presenting various proposals to facilitate community advances.

Dealing with finite resources:

Participants acknowledged limited funding for all research and discussed how to address this problem. Ms. Blackwell suggested that CBPR focus on influencing policy to obtain limited Federal resources. Community members could convince policymakers to address issues of interest to CBPR. Individuals engaged in CBPR should work with the media and political scientists, as this would help mobilize public opinion and reach policymakers. To engage the media and policymakers on an issue, CBPR investigators should provide rich, qualitative data (i.e., stories that put a "human face" on CBPR and show the positive effects of this approach). CBPR should also stress that the approach yields rich data and knowledge that can facilitate quality of life improvement. Policymakers tend to focus on practical outcomes, which CBPR has the potential to provide. It is critical for CBPR to be explicit about how evidence could be translated into policies and to indicate the worthiest research topics.

Dr. Kington suggested that CBPR investigators argue that the approach increases understanding of basic health processes and could be extended to all disadvantaged populations. He thought funders would respond favorably to the broadest possible impact of CBPR.

Community health indicators:

Most community health indicators are deficit- and disease-oriented. Community members prefer to emphasize their assets and strengths. CBPR should define the attribute of a healthy community.

The funding process:

The scientific paradigm dominates the grant review process. Reviewers require training on the CBPR approach. Funders should develop truly interdisciplinary review panels.

The CBPR field must find a way to reach funding organizations that have no interest in this research model.

Investigators should identify agencies whose interests are aligned with CBPR and support efforts by these organizations to enhance and better allocate resources.

Sustaining gains in the community:

Communities must organize to sustain gains in equity.

Breakout Group Reports

Conference organizers divided participants into three breakout groups to develop strategies to overcome barriers identified for communities, academics, and funding organizations and to discuss community, academic, and funder incentives and capacity building. Breakout groups consisted of participants from diverse experiences, but each focused on incentives and capacity building from one perspective. Conference organizers provided a set of ground rules and specific questions for each breakout group. Questions for each group are presented prior to each group's report. Facilitators and notetakers were present in each group to help it formulate a report to the larger body when participants reconvened.

Participants recommended numerous action steps. Conference organizers highlighted the following 13 recommendations in order to focus attention on those that had greatest consensus and presented opportunities for immediate action:

1. CBPR projects should enter the communities through appropriate gatekeepers/links within the communities.

2. Academic institutions should develop educational programs to train academicians to conduct CBPR.

3. Federal agencies should work together to advance and foster CBPR.

4. Funders should develop funding aimed specifically at enhancing community research capacity.

5. Funders should develop and expand funding mechanisms that will support CBPR as well as enhance capacity to conduct CBPR. Funders need to focus on three issues: who defines the research question, who conducts the research, and who oversees the funds.

6. Funders should train reviewers to understand CBPR grant applications (i.e., include panelists who have CBPR experience, provide a criteria list, and train reviewers to evaluate community inclusion).

7. Researchers and community members should develop an advocacy strategy for sharing the benefits of this work (e.g., through the media and targeting legislators).

8. Researchers should learn to communicate effectively with the community using appropriate languages and literacy levels and grassroots venues and to enhance the community members' ability to communicate.

9. A national organization with interest and experience in CBPR should build a national network for information on CBPR.

10. The field should develop CBPR curricula.

11. The field should develop guidelines/principles for the conduct of CBPR.

12. An Evidence-based Practice Center should synthesize evidence on the conduct and evaluation of CBPR in order to provide funders and others with criteria to assess the quality of CBPR.

13. Funders should change the scope of activities under funding support (e.g., translational activities and sustainability of partnerships).

These highlighted recommendations are also listed throughout this summary as they occurred in the discussion.

Community Group Report

Participants of the community breakout group spent time explaining and clarifying their perspectives. They discussed systemic discrimination and the need for those engaging in CBPR to have this difficult conversation. From the community perspective, it is critical for researchers to "walk the walk" and establish mechanisms in the research project that integrate community members as equal partners.

Conference organizers focused community breakout group participants on the following questions:

- What are the community barriers to conducting CBPR? What community factors facilitate CBPR? How can these factors be influenced in order to support CBPR?
- What accountability mechanisms and systems within CBOs are required to facilitate their full participation in research?
- What activities and resources are needed to facilitate the development of community capacity to engage in CBPR, including improving community capacity to initiate projects and to obtain grant funding?
- What is community consent for research and how do CBOs assess and support community consent?

Barriers: The group identified the following barriers to conducting CBPR from the community perspective:

- The reality of racism;
- The history of institutions using and abusing communities;
- Severe under-representation of people of color and low-income individuals in health professions and research;
- Perceptions that motives for conducting CBPR may be self-serving (e.g., to get funding or enroll minority populations) so that the work does not benefit the community; and

- CBOs and "community gatekeepers" do not always represent the entire community.

These are difficult and sensitive issues, but the must be discussed among CBPR partnerships from the beginning.

Facilitators: The group identified the following facilitators to conducting CBPR from the community perspective:

- Recognizing and emphasizing community assets and strengths (e.g., viewing community members as mentors and experts);
- Provide real service to assist communities—i.e., understand and try to meet their needs;
- Be willing to face the reality of negative history in working with communities;
- Conduct research while understanding the complex, interconnected context of people's lives;
- Building and maintaining a good relationship within/across the community;
- Building and maintaining good relationships outside a formal research context;
- Include multiple communities in the planning process;
- Welcome new participants into the dialogue;
- Build on community assets;
- Develop relationships with community gatekeepers;
- Develop relationships with powerful individuals to create change;
- Establishing and sustaining respecting, trusting relationships;
- Acknowledging and incorporating existing community structures (e.g., powerful CBOs and grass-roots groups); and
- Sharing the realities partners face in a non-defensive manner to enhance understanding.

Recommendations: The group suggested that CBPR projects incorporate the following:

- Opportunities to exchange perspectives;
- Those engaged in CBPR need to educate IRB panelists and ensure that panelists understanding this approach to research (i.e., in term of research content and review panel representation);
- IRBs should have community members;
- Understand specific communities;
- CBPR projects should hire from within the community; and
- Entering the community through appropriate gatekeepers/links within communities.

Action Items: All CBPR partners need to build capacity, not just communities. The group suggested the following activities and resources to build the capacity of *all* partners:

- Academic institutions should build power sharing procedures into institutional procedures concerning externally conducted research projects;
- Academic institutions should develop educational programs to train academicians to conduct CBPR;
- Academic institutions should create a "brain train" rather than a "brain drain"— i.e., build pipelines to have wider representation among health professions and positions of power;
- Academic institutions must educate IRBs about CBPR and work to increase representation of community members;
- Academic institutions should provide information to funders (and others) about CBPR and when it is an appropriate approach;
- Academic institutions should provide indirect costs to community members and CBOs;
- Community members should serve on IRBs;
- CBOs with successful, funded projects should mentor CBOs at earlier stages of readiness in CBPR;
- Federal agencies should work together to advance and foster CBPR;
- Funders should develop funding specifically aimed at enhancing community research capacity;
- Funders should publicize programs available for institutions, faculty members, and communities that are interested in engaging in CBPR;
- Funders should share specific funding mechanisms and processes to enhance the number of investigators engaged in CBPR;
- Funders should build power sharing procedures among partners into the request for applications;
- Funders should ensure that funds reach a variety of academic institutions (not just large research institutions) and different research models and increase the inclusion of researchers of color;
- Funders should adapt the PHS 398 forms for this type of research (evaluation criteria include: community members on boards, capacity sharing, dissemination to the community, specific training program, and demonstration that the projects responds to the community's priority issues);
- Funders should train reviewers to understand CBPR grant applications (i.e., include panelists who have CBPR experience, provide a criteria list, and train reviewers to evaluate community inclusion);
- Researchers (with their academic institutions) should examine different educational processes/models so community members obtain skills and educational credit;
- Researchers should increase academic capacity to engage in this work by extending it to more institutions;
- Researchers should increase training of community members to conduct programs, research, and evaluation;

- Researchers and community members should create a strategy to obtain broader community input regarding resource allocation;
- Researchers and community members should develop an advocacy strategy for sharing the benefits of this work (e.g., through the media and targeting legislators);
- Researchers should conduct qualitative research to understand the community and its assets;
- Researchers should learn to communicate effectively with the community using appropriate languages and literacy levels and grassroots venues and to enhance the community members' ability to communicate; and
- Researchers should share information from evaluation and research with communities.

The group described how researchers and funders might begin and sustain a dialogue with communities about their priorities. It is critical to include community members as project staff members and for faculty to reflect the characteristics of the community. These actions help researchers develop trust and a good relationship with the community. Researchers must acknowledge that the project involves multiple communities and that there are differences within communities. Power sharing among partners must be built into the institutions. Academic partners should provide community members with some authority to direct financial resources.

Members of the group did not like the term "community consent" because CBPR does not involve a single community. They generally agreed that a consenting community stays with a project. Perhaps "community participation" is a more appropriate term. Participants stressed the researchers need to obtain community and CBO consent. They should recognize that not all CBOs represent the community, that there are multiple levels of community, and that the extent to which a CBO represents a community can change. Perhaps a model of community consent is provided by a Tribal council resolution to grant access and authority to conduct research with their community. Community advisory boards help define projects and ensure regular community inclusion. Researchers should discuss the definition of consent and the mechanisms that they want to use to obtain consent with the community. Sometimes consultation allows researchers to ignore the community voice, so the community must specify their requirements for consent. To engage a community in a project, investigators should conduct qualitative research to assess the community's view on the conduct of research. Researchers should also engage CBOs to encourage and assess community consent for programs. Finally, the community consent process must be fluid and dynamic. Communities and academicians must share an ongoing dialogue to identify what action should occur and whether actions should continue.

Academic Group Report

Participants in the academic breakout group discussed the academic culture and its effect on researchers interested in CBPR. As CBPR is a non-traditional type of research, those who work in this field must educate their colleagues about this approach and convince

funders and promotion/tenure committees of its value. Participants identified barriers, but they dedicated considerable energy to generating solutions and developing recommendations that will enhance academic capacity to engage in CBPR.

Conference organizers focused academic breakout group participants on the following questions:

- What are the academic barriers to conducting CBPR? Which academic factors facilitate CBPR?
- How can these factors be influenced in order to support CBPR? Examples of barriers include publication, teaching responsibility, and tenure/promotion requirements.
- Which academic models have successfully overcome these barriers? Which elements do these models share? Examples of models include centers like CURL and science shops.
- What opportunities exist for inter-funding organization collaboration to develop methodologies and/or databases to advance the field?
- How might academic institutions develop institutional and faculty capacity to conduct CBPR?
- How much of this capacity development needs to occur at the individual faculty member level versus the organizational level?
- What organizational changes can be instituted to facilitate CBPR and what institutional resources in additional to financial support are needed for this type of research?
- What is the future need for CBPR researchers and how will this need be met?

Barriers: Participants identified the following barriers to academic participation in CBPR:

- The faculty members who choose to do CBPR are less valued than those who engage in traditional research;
- High competition for funds;
- Universities are not sensitized to community building as a civil rights issue;
- Engaging in non-traditional research has an impact on tenure prospects;
- The field needs performance measures to legitimize CBPR;
- The field needs to build faculty capacity in terms of increasing the number of CBPR investigators and enhancing their skills;
- Competition for funding, scarce faculty positions, and promotion creates disincentives for collaboration;
- The power inequality between researchers and the community.

Participants focused on this last barrier and generated the following suggestions for improving investigator-community relationships:

- Investigators should demystify research for community members (educate them about the problem and foster joint ownership of the issue).

- The community should be part of the grant application and award process.
- Communities need resources to build capacity. Workshops could help community-based research organizations build capacity, especially scientific writing workshops.
- The academic sector has to make a commitment to partnership including:
  - ✓ Community reciprocity in initiating research questions;
  - ✓ Some CBOs can receive money and contract with university as a collaborator; and
  - ✓ Lessons to be learned in partnering with HBCUs and Tribal Colleges.

- The research should always have a positive impact on the community involved.
  - ✓ Different communities may perceive benefit in different ways.
  - ✓ Does research design incorporate community needs and wants?
  - ✓ Is the intent of the project to help bring about structural change?
- Benefit of research participation for the community could include more or better information and employment or skill development.
- Some research should not be conducted as CBPR.
- The community must have a broad interest in research beyond acquiring resources.

Facilitators and Solutions: Participants noted that some academic models have overcome these barriers. These models are characterized by the following <u>facilitating factors</u>:

- Community advocates sit with academic representatives and create a relationship;
- CBPR partners contribute to mutual education efforts;
- Faculty members are committed and are supported of community organizations to prevent burnout; and
- Researchers understand how to work with the community and have access to community leaders.

Participants identified the following <u>general solutions</u> to promote CBPR:

- Community organizations should proactively create a dialog with universities and discuss the mutual benefit of CBPR. However, sometimes CBOs/community representatives do not represent the entire community.
- CBPR investigators should look for support in multi-disciplinary departments (medicine, public health, nursing, anthropology, and sociology).
- Student advocacy could be a vehicle for advancing CBPR (students could advocate for CBPR inclusion in conferences; faculty could partner with student organizations).
- The field should develop strategies to increase CBPR publication output.
- Journals and funders should provide awards for excellent CBPR faculty.
- Awards are also needed to recognize community participants, but a standard for community participation should be developed.

The group recommended the following four initiatives that will help overcome the challenges of building academic capacity to conduct CBPR:

1. *Build a national network for information on CBPR*—The network would serve as a support system for all parties and a repository for models. The network's structure would include academics, CBOs, funders, and students and would be accessible to the community. Finding a home and the necessary infrastructure funding for the network might be challenging, but possibilities include the Loka Institute, the APHA Caucus, or Community-Campus Partnerships for Health (CCPH). Specific network functions include the following:

   - Provide information on CBPR methods, skills, tools, and strategies;
   - Support junior faculty, student advocacy, and award developments;
   - Disseminate funding information and enhance opportunities for collaboration.

2. *Develop CBPR curricula*—In these efforts, developers must recognize that one size does not fit all. Teaching and learning must be reciprocal, so communities teach academics and academics demystify research for communities. The curricula should include workshops and courses on scientific writing. To develop CBPR curricula, the field could work with foundations to obtain support. Foundations might also support the development of distance learning. Special training modules might be developed for people in positions of power (e.g., politicians and deans of academic institutions. Such modules would describe how CBPR overlaps with their interests and agendas. The curricula should encourage discussion of social justice and include results of CBPR work.

3. *Develop guidelines/principles for the conduct of CBPR in order to provide funders and others with criteria to assess the quality of CBPR*—CBPR needs a community-driven "gold standard" to describe high quality research using this approach. An AHRQ Evidence-based Practice Center (see recommendation below) might review the evidence and write a report describing the conduct and evaluation of CBPR. The report would form the basis of guidelines for conducting CBPR, including standards for publication, funding, and community group participation. Guidelines might advise those entering CBPR agreements. Case studies of CBPR work by schools of public health would also be helpful. These should describe the impact of CBPR and include the principles and values connected with this approach.

4. *Request that an Evidence-based Practice Center synthesize evidence on the conduct and evaluation of CBPR*—Such a review would be used as the basis for guidelines/principles for CBPR developed by a nationally recognizable entity. The guidelines might be disseminated through professional associations (e.g., APHA Caucus). The group noted that developing CBPR guidelines/principles would have the following benefits:

   - Guidance to groups entering CBPR;
   - Standards for peer-reviewed journals;

- An improved tenure and promotion process by providing metrics of quality;
- Enhanced stature for CBPR;
- Improved assessment capacity for funders; and
- Enhanced curriculum development.

Funding Group Report

The group focused on making general recommendations with specific action steps for funders. They talked about the lack of resources among those interested in CBPR and the frustrations that result when funding and personnel are "spread thinly" across many projects. However, the group committed itself to identifying positive actions that funders might take to promote CBPR.

Conference organizers focused funding breakout group participants on the following questions:

- What are the elements of a successful partnership and how do funders identify and evaluation these partnerships and their output? (Output includes research findings, dissemination of results, and translation into practice and programs).
- How should funders evaluate the feasibility, merit, and sustainability of CBPR projects? Given the long time horizon needed for developing CBPR projects, how should funders evaluate accountability throughout the life of these projects?
- How can funders use the knowledge generated from these partnerships and research projects to guide program development?

Participants made the following recommendations for funders and specified action steps for each recommendation:

1. *Facilitate partnership building and community capacity development*—Funders need to facilitate partnerships and increase community capacity to do research. They can take the following actions to do so:

- Provide seed money to CBOs for infrastructure building to build research capacity.
- Fund activities that develop partnerships over an extended period of time. These activities should be funded both in the context of specific research projects and as separate partnership-development activities. Funding should be available directly to communities, rather than the traditional model of providing funding through research institutions.
- Fund training to enable communities and researchers to work together. Place an emphasis on creative models for working together, on developing communication skills that enable communication from different perspectives, and on consensus building. Work to build the capacity of academic researchers to talk to and work with communities.
- Develop a balanced portfolio that both supports existing partnerships and enables the development of new partnerships.

- Recommend particular partnerships to other funders. If a funder has worked with a successful partnership, they could vouch for grantees to other funders. This is particularly helpful for grantees working with private funders.
- Provide funding for community partners to attend national academic meetings with researchers and conduct joint presentations on their research. Also require joint presentations to the community.
- Place equal value on the contributions of researchers and of community members in the research process. Recognizing that each bring a unique set of skills and knowledge to the process.
- Develop a set of templates to assist community organizations in the grant writing process. These templates would provide more specific guidance and sample language for completing grant applications.

2. *Explore new funding mechanisms*—Funders need to focus on three issues: who defines the research question, who conducts the research, and who oversees the funds. They can develop new funding mechanisms that will enhance the capacity to conduct CBPR:

- Use a variety of alternate funding mechanisms to help build partnerships and facilitate the conduct of CBPR, including (1) microgrants; (2) phased funding to enable partnership building before applying for research funding; and (3) partnership/research long-term funding.
- Investigate alternative ways to dispense funds, ensuring that funding gets to community organizations at the beginning of a project. Actively seek to provide funds directly to communities, rather than solely through researchers.
- Establish and fund an inter-agency/inter-foundation group charged with promoting CBPR.
- Create and fund community-based research centers which would serve as coordinating and technical assistance centers for community based grantees, and which could themselves receive grant money (similar to an office of sponsored research, but located in the community rather than in the university). Initially fund one per region, then one per state, then ideally one per community. Consider both physical centers and virtual centers – the structure of the center needs to be responsive to community needs.
- Develop new funding mechanisms that develop skills within multiple communities. Communicate these opportunities directly to communities, rather than working through researchers.

3. *Require changes to grant applications and change the scope of activities under funding support*—Funders can enhance CBPR by changing the information required in grant applications and changing the activities funded under their grants (e.g., translational activities and sustainability of partnerships). Specific actions include:

- Require CBPR grantees to translate research into practice and policy and to disseminate their research and translation in the community and to the media.

- Require budgets for CBPR research activities to include a set aside for translation and dissemination activities.
- Require CBPR projects to have a final presentation to the community on the grant activities and findings, in addition to the final written report to the funder.
- Emphasize grants that build the sustainability of partnerships and the sustainability of the interventions developed in CBPR.
- Require community involvement in data acquisition and analysis. Insist on joint researcher-community ownership of the data and joint responsibility for analysis, moving away from the more traditional notion that researchers own and analyze the data.
- Require grantees to document intended community benefits in their application. These benefits go beyond the findings of the research to focus on the benefits of participating in the research process, including increasing community capacity and well-being (e.g., number of jobs to be created by the project, increased community capacity to conduct research).
- Change the requirements for documenting a partnership in a grant application. The current use of letters of support and memoranda of understanding is meaningless, as these are often drafted by the researcher and then signed by the community members. Develop a checklist of items to be addressed in describing the partnership, including issues such as:
  - ✓ How long has the relationship existed?
  - ✓ What activities has the partnership done together?
  - ✓ How often do the partnerships meet?
  - ✓ Who comes to the meetings?
  - ✓ How are decisions made?
  - ✓ Does the grant application include funding for community partners to attend national meetings and conduct joint presentations on their research?
  - ✓ Does the grant application include plans to make a community presentation in addition to a final report to funders?
  - ✓ Does the grant application include plans to translate research into policy and practice, and to disseminate research findings and their translation within the community?
  - ✓ Does the grant application demonstrate a plan for joint researcher/community ownership of data and joint analysis?
  - ✓ What is the proposed distribution of grant funds between researchers and community organizations?
- Require documentation that the community organization actively participated in writing the grant application and reviewed the final application before it submission.
- Require a certain dollar or proportion of grant funding to go directly to the community, rather than leaving it to the researcher's discretion.
- Seek to fund grants that incorporate multi-method research.

4. *Change the grant review process*—There are a number of changes to the peer review process that funders could make which would enhance CBPR, including the following:

- Allow a longer timeframe for responses to RFAs. Researchers and community organizations working in partnership requires time.
- Have peer reviewers examine the list of research and community partners and the assets they will contribute to the project.
- Have a structured method for peer reviewers to use when assessing partnerships. This could include guidelines for interpreting the checklist described above. Peer reviewers need to understand the criteria for good researcher-community partnerships.
- Consider "reverse site visits" when evaluating applications. Such visits would involve contacting community partners and asking them structured questions to determine the extent of their involvement in the project and the nature of the partnership.
- Include peer reviewers who have a clear understanding of CBPR in study sections.
- "Re-view" the review process to examine ways to make CBPR more competitive in study section review.

5. *Develop and implement new evaluation tools*—Funders need to be able to evaluate both the usefulness of CBPR and the quality of research partnerships with community organizations. They can:

- Fund research to help define what constitutes good CBPR in the U.S.
- Develop process evaluations for partnerships:
- Define the elements of success in ongoing partnerships.
- Require evaluations to take place throughout the partnership process, not solely at the end.
- Build partnership evaluation into RFAs.
- Funders could ask communities how they would like accountability and health outcomes to be evaluated.
- Focus on a process of mutual accountability, in which community organizations and researchers are accountable to one another, and are jointly accountable to the funding organization.

6. *Other*—Several additional suggestions for funders include:

- Allow time and funding for translation of research materials into other languages, going beyond translation and back-translation to ensure that all materials are meaningful to the community members participating in the research.
- Think strategically about community needs when making funding decisions about CBPR.
- Use CBPR as an opportunity to think about building public health infrastructure within communities.
- Create an interactive web-based electronic site for CBPR researchers and community leaders to use to discuss issues and share experiences.

Apart from the above six recommendations, participants suggested action items for funders in specific areas.

Regarding <u>funding policies and priorities</u>, the group suggested the following action steps:

- Change RFA requirements and targets;
- Shift priorities about funded topics and funding allocation (this is a long-term goal);
- Create new funding mechanisms, including community research centers (e.g., phased funding); and
- Work together (funders and public agencies) to develop funding mechanisms and research agendas.

Regarding <u>responding to RFAs</u>, the group suggested the following action steps:

- Promote true partnership in the responding entity (i.e., joint responses to RFAs between community and academics);
- Convene more pre-planning/discussion meetings around RFAs and target these to community organizations;
- Provide capacity building and technical assistance to both academic and community organizations (include training funds and technical assistance provided directly to communities); and
- Require that grant applicants demonstrate the project's benefit to the community.

Regarding the <u>peer review process</u>, the group suggested the following action steps:

- Review the review process;
- Determine peers for CBPR peer review;
- Clarify expectations and criteria for good partnerships for the benefit of grant applicants and reviewers; and
- Increase community representation on IRBs and include requirements for disseminating results to the community in institutional research policies.

Regarding <u>funding decisions</u>, the group suggested the following action steps:

- Apply the same concepts used in peer review to making funding decisions (changes need to move beyond study section to where the funding decision are made);
- Include a new criterion in funding decisions: what benefits and serviced are provided to the community?

Regarding the <u>execution of research</u>, the group suggested the following action steps:

- Use multiple methods for conducting research;
- Have the community be full partners in designing project evaluations;
- Conduct an ongoing *process* evaluation of partners, with a feedback loop throughout the research project; and
- Evaluate how projects increase community capacity as it progresses.

Regarding <u>post-research activities</u>, the group suggested the following action steps:

- Funders should partner directly with communities to work on translation and dissemination;
- Focus on sustaining projects, partnerships, and environments conducive to partnerships and community building;
- Determine data ownership and sharing mechanisms; and
- Create a working group for funders on CBPR to encourage collaboration and raise the conversation to a national level.

Conclusion

Participants identified three activities that they would personally undertake to advance CPBR in their organizations. Ms. Tucker also requested that participants make a commitment to contact a fellow participant about CBPR. She summarized three key principles from the conference as follows:

- True partnership with an equitable structure is fundamental to CBPR;
- Multiple training opportunities are needed by the community, academic researchers, and funders to enhance capacity building; and
- A CBPR network is needed to encourage collaboration and information sharing and CBPR guidelines must be created to strengthen and advance this research model.

Throughout the conference, participants submitted comments on the ideas and discussions. They also submitted their greatest hopes and fears regarding CBPR. Summaries of comments and greatest hopes and fears are presented in Appendix A and B respectively. Unedited participant comments can be obtained from conference organizers.

Dr. Stryer thanked participants for their enthusiasm, passion, energy and commitment. He appreciated the frustrations expressed, but thought the discussion raised awareness. He remarked that the conference would be successful if participants could translate ideas into actions. Committing to three activities would be participants' last action of the conference, but the beginning of translating ideas into actions. AHRQ staff will recommend changing solicitations for research to include language targeting CBPR and research on health disparities. He encouraged participants to evaluate the conference using the forms provided or other means. The evaluation would help AHRQ improve the

process of obtaining input. He thanked conference co-sponsors, conference center staff, Cygnus staff, and participants for sharing their wisdom and passion.

Appendix A

Summary of Comments Submitted by Participants

Conference organizers distributed color-coded index cards to participants. Throughout the conference, participants submitted the cards with questions relating to the community, academic, and funding sessions. Unedited participant remarks can be obtained from conference organizers.

The following section summarizes participant comments.

Community Session

- Racism and discrimination continues. Historical and current discrimination has resulted in an imbalance of power. How do we change institutions, transfer power to communities, and address these issues up front?

- How do we alleviate CBO concerns about being used as research study recruitment agencies?

- How can communities ensure full representation in CBPR given that CBOs, high-visibility gatekeepers, and community activists do not necessarily represent the entire community?

- How do we train communities in: research skills, technology use, grant writing, and publishing?

- How do we resolve data ownership, intellectual property, and authorship issues given an imbalance of power between academic institutions and communities?

- How does CBPR deal with difficulties developing consensus within stakeholder groups, competition and conflicts of interest within communities, and power imbalances among community constituents?

- How do we bridge the culture gap between science and the community given exclusionary language and structures?

- How do we best publicize CBPR, disseminate CBPR results, and convince funders of CBPR's value?

- How can communities sustain gains and capacity? Can this only be accomplished if CBPR advances economic development and social justice?

Academic Session

- How can academic institutions change their culture to be more flexible, extend CBPR to health professional schools, and learn from the community?

- How can we increase the acceptance (perceived value and rigor) of CBPR among academicians?

- How can academic institutions encourage and mentor faculty who conduct CBPR?

- How can academic institutions educate IRB panelists and increase community membership on IRBs?

- How can the academic community help identify benchmarks for CBPR excellence and use these in tenure and promotion decisions?

- How can the academic community increase the number of minority researchers conducting CBPR?

- How can traditional universities and smaller academic institutions sustain CBPR?

- How can academic institutions address the special needs of female faculty?

Funding Session

- How can we persuade NIH of CBPR's value?

- How can we disseminate information about CBPR funding opportunities and models for various approaches?

- How can the grant making process be changed so that it is more open to comprehensive approaches such as CPBR? How can we communicate CBPR review criteria to funders?

- How can communities obtain funding for infrastructure needs?

- How can Federal agencies increase collaboration and communication regarding their CBPR projects?

- How can the CBPR approach compete for funding with the medical-industrial complex?

- What structural changes could be made within funding organizations that might facilitate acceptance of CBPR?

Appendix B

Summary of Greatest Hopes and Fears

Each participant posted his or her greatest hope and fear regarding CBPR and conference outcomes. Appendix B presents these as participants wrote them.

The following section summarizes participant hopes and fears.

Greatest Hopes

- To develop measures for its effectiveness, partnerships, and social determinants of health

- To make network connections, begin collaborations, and share information

- To advance recognition and understanding of the community perspective within CBPR

- To obtain funding or information on funding

- To change the Federal research agenda/priorities so as to eliminate disparities

- To obtain knowledge about good CBPR models

- To develop a successful journal supplement from the conference

Greatest Fears

- All talk and no action resulting in maintaining the status quo

- Failure to address inequitable/oppressive structural/institutional systems

- No follow-up or sustained action after the conference

- No funding support for CBPR

- "Bashing" of other perspectives

- Lack of focus on outcomes and building capacity

- Large academic institutions seen as only viable organizations to conduct CBPR

- Lack of specific multicultural CBPR initiatives

Appendix C

The final participant list for the meeting follows.

Conference on Community-Based Participatory Research

Sponsored by the Agency for Healthcare Research and Quality
in collaboration with
The W. K. Kellogg Foundation
Office of Minority Health, U.S. Department of Health and Human Services
Office of Behavioral and Social Sciences Research, National Institutes of Health

November 27 28, 2001   *Participants List as of November 26, 2001*
6010 Executive Boulevard, 4th Floor
Rockville, Maryland

Syed M. Ahmed, M.D., M.P.H., Dr.P.H.
Associate Professor
Department of Family and Community
  Medicine
Center for Health Communities
Medical College of Wisconsin
8701 Watertown Plank Road
Milwaukee, WI 53226
Phone: 414-456-8291
Fax: 414-456-6524
E-mail: smahmed@mcw.edu

Lynda A. Anderson, Ph.D.
Acting Program Director
Prevention Research Center
Centers for Disease Control and Prevention
4770 Buford Highway, MS K45
Atlanta, GA 30341
Phone: 770-488-5395
E-mail: landerson4@cdc.gov

Carol M. Ashton, M.D., M.P.H.
Director
Houston Center for Quality of Care and
  Utilization Studies (HCQCUS)
Health Services Research & Development
VA Medical Center (152)
2002 Holcombe Boulevard
Houston, TX 77030
Phone: 713-558-4554
Fax: 713-794-7103
E-mail: cashton@bmc.tmc.edu

Eric Bailey, Ph.D., M.P.H.
National Center on Minority Health and
  Health Disparities
National Institutes of Health
6707 Democracy Boulevard, Suite 800
Bethesda, MD 20892-5465
Phone: 301-402-1366
E-mail: baileye@od.nih.gov

Beth Baker, Ph.D., M.P.H.
Associate Professor
School of Public Health
Saint Louis University
3545 Lafayette Avenue, Suite 465
St. Louis, MO 63104
Phone: 314-977-3218
Fax: 314-977-1658
E-mail: bakerpa@slu.edu

Eric B. Bass, M.D., M.P.H.
Editor
Journal of General Internal Medicine
1830 E. Monument Street, Room 8068
Baltimore, MD 21205
Phone: 410-955-9871
Fax: 410-995-0825
E-mail: ebass@jhmi.edu

Carolyn Beeker, Ph.D.
Chief, CBPARA/Director
Urban Research Centers
Epidemiology Program Office
Division of Prevention Research and Analytic
  Methods
Centers for Disease Control and Prevention
4770 Buford Highway, MS K73
Atlanta, GA 30341
Phone: 770-488-8213
Fax: 770-488-8488
E-mail: cgb3@cdc.gov

Marlene Berg
Associate Director for Training Research and
  Development
Institute for Community Research
2 Hartford Square West, Suite 100
Hartford, CT 06106
Phone: 860-278-2044, ext. 226
Fax: 860-278-2141
E-mail: mberg_84@yahoo.com

Kassahun Bisrat
Executive Director
Alliance for Multicultural Community
  Services
6440 Hillcroft Street, Suite 411
Houston, TX 77081
Phone: 713-776-4700
Fax: 713-776-4730
E-mail: kbisrat@wt.net

Angela Glover Blackwell, J.D.
President
PolicyLink
101 Broadway
Oakland, CA 94607
Phone: 510-663-2333
E-mail: ablackwell@policylink.org

Lee R. Bone, M.P.H.
Associate Public Health Professor
Bloomberg School of Public Health
Johns Hopkins University
615 North Wolfe Street
Baltimore, MD 21205
Phone: 410-955-6887
E-mail: lbone@jhsph.edu

Beth Bowers, M.Div., M.S.W.
Social Science Analyst
Division of Services & Intervention Research
National Institute of Mental Health
6001 Executive Boulevard, Suite 1117
Bethesda, MD 20892-9629
Phone: 301-443-3776
E-mail: bbowers@mail.nih.gov

Pauline E. Brooks, Ph.D.
Manager of Evaluation
California Endowment Foundation
21650 Oxnard Street, Suite 1200
Woodland Hills, CA 91367
Phone: 818-932-3270
Fax: 818-703-4193
E-mail: pbrooks@calendow.org

Helen Burstin, M.D., M.P.H.
Director
Center for Primary Care Research
Agency for Healthcare Research and Quality
6010 Executive Boulevard, Suite 201
Rockville, MD 20852
Phone: 301-594-4078
Fax: 301-594-3721
E-mail: hburstin@ahrq.gov

Timothy S. Carey, M.D., M.P.H.
Professor of Medicine
Director, Cecil G. Sheps Center for Health
  Services Research
University of North Carolina at Chapel Hill
725 Airport Road, CB#7590
Chapel Hill, NC 27599 7590
Phone: 919-966-7100
Fax: 919-966-8918
E-mail: carey@med.unc.edu

Marshall H. Chin, M.D., M.P.H.
Associate Professor of Medicine
University of Chicago
MC 2007, Room B216
5841 South Maryland Avenue
Chicago, IL 60637
Phone: 773-702-4769
Fax: 773-834-2238
E-mail: mchin@medicine.bsd.uchicago.edu

Jill Chopyak
Executive Director
The Loka Institute
P.O. Box 355
Amherst, MA 01004
Phone: 413-559-5860
Fax: 413-559-5811
E-mail: chopyak@loka.org

Toby Citrin, J.D.
Director
Office of Community-Based Public Health
School of Public Health
University of Michigan
109 S. Observatory, Room M 4152
Ann Arbor, MI 48104 2029
Phone: 734-936-0936
Fax: 734-936-0927
E-mail: tcitrin@umich.edu

Carolyn M. Clancy, M.D.
Director
Center for Outcomes and Effectiveness
  Research
Agency for Healthcare Research and Quality
6010 Executive Boulevard, Suite 300
Rockville, MD 20852
Phone: 301-594-2829
Fax: 301-594-3211
E-mail: cclancy@ahrq.gov

William Cunningham, M.D., M.P.H.
Department of Medicine and Health Services
  Research 31-254A CHS
Division of General Internal Medicine and
  Health Services Research
UCLA School of Public Health
B-551 Factor Building
UCLA School of Medicine
10833 Le Conte Avenue
Los Angeles, CA 90095 1772
Phone: 310-206-1632
Fax: 310-825-3317
E-mail: wcunningham@mednet.ucla.edu

Cathy Deeds
Special Assistant
Center for Faith-Based and Community
  Initiatives
U.S. Department of Health and Human
  Services
200 Independence Avenue, S.W., Room 118-F
Washington, DC 20201
Phone: 202-358-3595
Fax: 202-401-3463
E-mail: cdeeds@osaspe.dhhs.gov

Kay W. Eilbert
President
Metropolitan Washington Public Health
  Association
6113 Holly Tree Drive
Alexandria, VA 22310
Phone: 703-329-1970
E-mail: kk81@cox.rr.com

Iris Farabee-Lewis, D.D.
Centennial Caroline Street United Methodist
  Church
Baltimore, MD 21202
Phone: 410-276-3079
E-mail: centennial@2prodigy.net

Kaytura Felix-Aaron, M.D.
Center for Primary Care Research
Agency for Healthcare Research and Quality
6010 Executive Boulevard, Suite 201
Rockville, MD 20852
Phone: 301-594-6198
Fax: 301-594-3721
E-mail: kaaron@ahrq.gov

Benjamin Fraticelli
Executive Director
Community Health Academy
2648 International Boulevard, Suite 500
Oakland, CA 94601
Phone: 510-532-6802
Fax: 510-532-9490
E-mail: ocbphi@igc.org

Ann Wilson Frederick
Exceed Community Partnership
Rosebud Field Office
P.O. Box 815
Mission, SD 57555
Phone: 605-856-2899
E-mail: annwilson@gwtc.net

William L. Freeman, M.D., M.P.H.
Director
Indian Health Service Research Program
Chair, Headquarters Albuquerque Area
  Combined Indian Health Service IRB
12300 Twinbrook Parkway, Suite 450
Rockville, MD 20852 1750
Phone: 301-443-0578
Fax: 301-443-1522
E-mail: wfreeman@hqe.ihs.gov

Vanessa Northington Gamble, M.D., Ph.D.
Vice President
Division of Community and Minority
  Programs
Association of American Medical Colleges
2450 N. Street, N.W.
Washington, DC 20037
Phone: 202-828-0572
Fax: 202-828-1125
E-mail: vngamble@aamc.org

Aida L. Giachello, Ph.D.
Center Director and Associate Professor
Midwest Latino Health Research, Training,
  and Policy Center
Jane Addams College of Social Work
1640 W. Roosevelt Road, #626 M/C 625
Chicago, IL 60608
Phone: 312-413-1952
Fax: 312-996-3212
E-mail: aida@uic.edu

Junius J. Gonzales, M.D.
Chief, Services Research & Clinical
  Epidemiology Branch
6001 Executive Boulevard, MSC 9631
Rockville, MD   20852
Phone: 301-443-3364
E-mail: jgonzale@mail.nih.gov

Lawrence W. Green, Dr.P.H.
Director
Office of Extramural Prevention Research
Public Health Practice Program Office
Centers for Disease Control and Prevention
4770 Buford Highway, MS K36
Atlanta, GA 30341 3724
Phone: 770-488-2458
E-mail: lgreen@cdc.gov

Barbara J. Hatcher, Ph.D., M.P.H., R.N.
Director, Scientific and Professional Affairs
American Public Health Association
800 I Street, N.W.
Washington, DC 20001-3710
Phone: 202-777-2490
Fax: 202-777-2534
E-mail: barbara.hatcher@apha.org

Corliss Heath, M.P.H.
Program Coordinator
Program for Healthcare Effectiveness
  Research
Morehouse School of Medicine
720 Westview Drive, S.W.
Atlanta, GA 30310 1495
Phone: 404-752-1873
Fax: 404-752-1154
E-mail: cheath@msm.edu

W. David Helms, Ph.D.
President and CEO
Academy for Health Services Research and
  Health Policy
1801 K Street, N.W., Suite 701-L
Washington, DC 20006
Phone: 202-292-6700
Fax: 202-292-6800
E-mail: helms@ahsrhp.org

Carol Horowitz, M.D., M.P.H.
Exceed Grantee
Department of Health Policy
Mount Sinai School of Medicine
One Gustave L. Levy Place
New York, NY 10029
Phone: 212-659-9567
Fax: 212-432-2998
E-mail: carol.horowitz@mssm.edu

Dan Hoskins, M.A.
Department of Biometry and Epidemiology
Medical University of South Carolina
135 Rutledge Avenue
P.O. Box 250551
Charleston, SC 29425
Phone: 843-876-1947
Fax: 843-876-1126
E-mail: hoskinsd@musc.edu

Barbara Israel, Dr.P.H.
Professor
Department of Health Behavior and Health
  Education
School of Public Health
University of Michigan
1420 Washington Heights
Ann Arbor, MI 48109 2029
Phone: 734-647-3184
Fax: 734-763-7979
E-mail: shatto@umich.edu

Joni Johns
Office of Information Technology
Opportunity Portal for Low Income People
  Team
Health Resources and Services
Administration
Room 10A-03, Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
Phone: 301-443-2088
E-mail: jjohns@hrsa.gov

Kit Johnston
Writer, Editor, Project Manager
Food and Wine Specialist
917 N. Irving Street
Arlington, VA 22201
Phone: 301-276-7748
E-mail: kitkit5@erols.com

Thomas Kelly, Jr.
Senior Research Associate
The Annie E. Casey Foundation
701 St. Paul Street
Baltimore, MD 21202
Phone: 410-223-2932
Fax: 410-223-2927
E-mail: tomk@aecf.org

Raynard Kington, MD
Office of Behavioral and Social Sciences
National Institutes of Health
1 Center Drive, Room 326
Bethesda, MD 20892
Phone: 301-402-1146
Fax: 301-402-1150
E-mail: kingtonr@od.nih.gov

David Korn, M.D.
Senior Vice President
Association of American Medical Colleges
2450 N Street, N.W.
Washington, DC 20037
E-mail: dkorn@aamc.org

Barbara Krimgold
Senior Project Director
Center for the Advancement of Health
2000 Florida Avenue, N.W., Suite 210
Washington, DC 20009 1231
Phone: 202-387-2829
E-mail: bkrimgold@cfah.org

Sharon M. Lee
Professor and Director, Graduate Studies
Department of Sociology
Portland State University
P.O. Box 751
Portland, OR 97207
Phone: 503-725-3962
Fax: 503-725-3957
E-mail: lees@pdx.edu

Marsha Lillie-Blanton, Dr.P.H.
Vice President in Health Policy
The Henry J. Kaiser Family Foundation
1450 G Street, N.W., Suite 250
Washington, DC 20005
Phone: 202-347-5270
Fax: 202-347-5274
E-mail: mlillie-blanton@kff.org

Barbara Major
Executive Director
St. Thomas Health Services
1020 St. Andrew Street
New Orleans, LA 70130
Phone: 504-529-5558, ext. 238
E-mail: sthsnnola@aol.com

Spero M. Manson, Ph.D.
Professor and Head
American Indian and Alaska Native
   Programs/Department of Psychiatry
University of Colorado Health Services
   Center
4455 East 12th Avenue
Denver, CO 80220
Phone: 303-315-9230
Fax: 303-315-9579
E-mail: spero.manson@uchsc.edu

Lori Minasian, M.D., F.A.C.P.
Chief
Community Oncology and Prevention Trials
   Research Group
Division of Cancer Prevention
National Cancer Institute
National Institutes of Health
6130 Executive Boulevard, MSC 7340
Bethesda, MD 20892 7340
Phone: 301-496-8541
E-mail: minasilo@mail.nih.gov

Mary E. Northridge, Ph.D., M.P.H.
Editor-in-Chief
American Journal of Public Health
Deputy Director
Harlem Health Promotion Center
Department of Sociomedical Sciences
Mailman School of Public Health of
  Columbia University
600 W. 168th Street
New York, NY 10032
Phone: 212-305-0715
Fax: 212-305-5546
E-mail: men11@columbia.edu

Phil Nyden, Ph.D.
Professor of Sociology
Director of Center for Urban Research and
  Learning
820 N. Michigan Avenue
Chicago, IL 60611
Phone: 312-915-7761
Fax: 312-915-7770
E-mail: pnyden@luc.edu

Thomas P. O'Toole, M.D.
Associate Director
Urban Health Institute
Johns Hopkins University
2024 East Monument Street, Room 2-513
Baltimore, MD 21205
Phone: 410-614-0093
E-mail: totoole@jhmi.edu

Leslie Oblak
Research Associate
Access Project
Brandeis University
Heller School, Mailstop 035
Waltham, MA 02454
Phone: 781-736-3911
E-mail: oblak@brandeis.edu

Guadalupe Pacheco, J.D.
Special Assistant to the Deputy Assistant
  Secretary for Minority Health
Office of Minority Health
5515 Security Lane, Suite 1050
Rockville, MD 20852
Phone: 301-443-3379
Fax: 301-594-0767
E-mail: gpacheco@osophs.dhhs.gov

Herminia Palacio, M.D., M.P.H.
Assistant Professor
Health Services Research & Development
VA Medical Center (152)
2002 Holcombe Boulevard
Houston, TX 77030
Phone: 713-558-4596
E-mail: hpalacio@bcm.tmc.edu

Ann-Gel S. Palermo, M.P.H.
Research Assistant
Institute for Medicare Practice
Mount Sinai School of Medicine
1200 Fifth Avenue, Suite 2A, Box 1062
New York, NY 10029
Phone: 212-241-8886
Fax: 212-876-9150
E-mail: ann-gel.palermo@msnyuhealth.org

Carol Bryant Payne. R.N.
Community Builder Fellow
Office of the State Coordinator, Senior
  Community Builder
U.S. Department of Housing and Urban
  Development
10 South Howard Street, 5th Floor
Baltimore, MD 21201
Phone: 410-962-2520, ext. 3062
Fax: 410-962-1849
E-mail: carol_b._payne@hud.gov

Delores L. Perron, Ph.D.
Scientific Advisor for Capacity Development
Office of the Director
National Institutes of Health
Building 1, Room 326
Bethesda, MD 20852
Phone: 301-496-7506
E-mail: parrond@od.nih.gov

Wendy Perry, M.P.A.
Senior Program Analyst
Agency for Healthcare Quality and Research
2021 East Jefferson Street, 6th Floor
Rockville, MD 20852
Phone: 301-594-7248
Fax: 301-443-0251
E-mail: wperry@ahrq.gov

Marj Plumb
Marj Plumb and Associates
6123 Rosalind Avenue
Richmond, CA 94805
Phone: 510-232-0360
Fax: 510-232-0359
E-mail: marjplumb@aol.com

Clifton A. Poodry, Ph.D.
Director
Minority Opportunities in Research
National Institute of General Medical
  Sciences
National Institutes of Health
45 Center Drive, MSC 6200
Bethesda, MD 20892
Phone: 301-594-3900
Fax: 301-480-2753
E-mail: poodryc@nigms.nih.gov

Rebeca Ramos, M.P.H., M.A.
Technical Director
U.S. Mexico Border Health Association
5400 Suncrest Drive, Suite C-5
El Paso, TX 79912
Phone: 915-833-6450
Fax: 915-833-7840
E-mail: rebeca@utep.edu

Donna Rathbone
National Center on Minority Health and
  Health Disparities
National Institutes of Health
6707 Democracy Boulevard, Suite 800
Bethesda, MD 20892-5465
Phone: 301-402-1366
E-mail: rathboned@od.nih.gov

LaVerne Reid, Ph.D., M.P.H.
Chair
Department of Health Education
North Carolina Central University
Miller Morgan Health Sciences Building
Durham, NC 27707
Phone: 919-530-6404
Fax: 919-530-7985
E-mail: lreid@wpo.nccu.edu

Candia Richards, M.P.H.
Director of Prevention Programs
Community Health
Bronx AIDS Services
2633 Webster Avenue
Bronx, NY 10458
Phone: 718-295-5690
Fax: 718-295-8841
E-mail: crichards@basncy.org

Patricia L. Riley, C.N.M., M.P.H.
Director CARE-CDC Health Initiative
Office of Global Health
Centers for Disease Control and Prevention
1600 Clifton Road, MS D69
Atlanta, GA 30333
Phone: 404-639-1492
Fax: 404-639-7490
E-mail: pyr0@cdc.gov

Mary C. Roary, M.H.S.
Faculty Associate, Co-Investigator and
  Project Director
Johns Hopkins University School of Nursing
525 N. Wolfe Street, Room 402
Baltimore, MD 21205
Phone: 410-614-1449
Fax: 410-614-7128
E-mail: mroary@son.jhmi.edu

Gladys Sandlin
Executive Director
Mission Neighborhood Health Center
240 Shotwell Street
San Francisco, CA 94110
Phone: 415-552-1013, ext. 201
E-mail: gladys_sandlin@mnhc.org

Sari Siegel
Staff Service Fellow
Center for Primary Care Research
Agency for Healthcare Research and Quality
6010 Executive Boulevard, Suite 201
Rockville, MD 20852
Phone: 301-594-6373
Fax: 301-594-3721
E-mail: ssiegel@ahrq.gov

Philip L. Smith, M.D., M.P.H.
Office of Program Support
Indian Health Service
12300 Twinbrook Parkway, Suite 450
Rockville, MD 20852
Phone: 301-443-6582
Fax: 301-443-1552
E-mail: psmith@hqe.ihs.gov

Selina A. Smith, Ph.D.
Scientific Director
National Black Leadership Initiative
  on Cancer II: Network Project
Morehouse School of Medicine
720 Westview Drive, S.E.
Atlanta, GA 30310
Phone: 404-756-5205
Fax: 404-756-5295
E-mail: smiths@msm.edu

Lisa Cacari Stone
4301 Paseo de las Acequias
Santa Fe, NM 87505
Phone: 505-471-4822
E-mail: lcacaristo@aol.com

Daniel Stryer, M.D.
Center for Outcomes and Effectiveness
  Research
Agency for Healthcare Research and Quality
6010 Executive Boulevard, Suite 300
Rockville, MD 20852
Phone: 301-594-4038
Fax: 301-594-3211
E-mail: dstryer@ahrq.gov

Barbara C. Tilley, Ph.D.
Professor and Chair
Department of Biometry & Epidemiology
Medical University of South Carolina
P.O. Box 250551
135 Rutledge Avenue
Charleston, SC 29425
Phone: 843-876-1327
Fax: 843-876-1127
E-mail: tilleybc@musc.edu

Anh N. Tran, M.P.H.
EXCEED Program Grant Coordinator
Houston Center for Quality of Care and
  Utilization Studies
VA Medical Center (152)
2002 Holcombe Boulevard
Houston, TX 77030
Phone: 713-558-4519
Fax: 713-748-7359
E-mail: antran@bcm.tmc.edu

Jeanette Trauth, Ph.D.
Assistant Professor
Department of Health Services
Administration Graduate School of Public
Health
University of Pittsburgh
217 Parran Hall, GSPH
Pittsburgh, PA 15261
Phone: 412-624-0968
Fax: 412-624-5510
E-mail: trauth@pitt.edu

Henrie M. Treadwell, Ph.D.
Program Director
W. K. Kellogg Foundation
One Michigan Avenue, East
Battle Creek, MI 49017
Phone: 616-969-2025
E-mail: henrie.treadwell@wkkf.org

Pattie Tucker, R.N., M.P.H.
Evaluation Coordinator
REACH 2010
Centers for Disease Control and Prevention
4770 Buford Highway, MS K30
Atlanta, GA 30341
Phone: 770-488-3445
Fax: 770-488-5974
E-mail: pjt1@cdc.gov

Robin Tucker, J.D.
Imagine Consulting
60 Edgemont Way
Oakland, CA 94605
Phone: 510-604-5806
Fax: 510-635-4362
E-mail: robinttucker@cs.com

Lorraine Valdez, B.S.N., M.P.A., C.D.E.
Nursing Consultant
Indian Health Service
National Diabetes Program
5300 Homestead Road, N.E.
Albuquerque, NM 87022
Phone: 505-248-4282
Fax: 505-248-4188
E-mail: s.lorraine.valdez@mail.ihs.gov

Carmen M. Villegas, M.A.
Community Board 11—East Harlem Area
  Council
420 East 111 Street, Suite 3102
New York, NY 10029
Phone: 212-360-3761
Fax: 212-360-3842
E-mail: cvillegas@chcsnet.org

A. Eugene Washington, M.D, M.Sc.
Director of MERC
University of California, San Francisco
3333 California Street, Suite 335
San Francisco, CA 94143 0856
Phone: 415-476-8259
Fax: 415-502-4065
E-mail: wash@obgyn.ucsf.edu

Lucille H. Webb
President
Strengthening The Black Family, Inc.
1509 Tierney Circle
Raleigh, NC 27610 1635
Phone: 919-834-8862
E-mail: webb@handtech.com

Robin M. Weinick, Ph.D.
Director
Intramural Research
Center for Primary Care Research
Agency for Healthcare Research and Quality
2101 East Jefferson Street
Rockville, MD 20852
Phone: 301-594-2010
Fax: 301-594-3721
E-mail: rweinick@ahrq.gov

Tony L. Whitehead, Ph.D.
Professor
Department of Anthropology
University of Maryland
0123 Woods Hall
College Park, MD 20742
Phone: 703-620-0515
E-mail: tonylwhitehead@home.com

Karen P. Williams, Ph.D.
Assistant Professor
Obstetrics, Gynecology and Reproductive
   Biology
Michigan State University
A210 East Fee Hall
East Lansing, MI 48824 1316
Phone: 517-432-4790
Fax: 517-432-8021
E-mail: karen.williams@ht.msu.edu

Malcolm Williams, M.P.P.
Senior Program Associate
Grantmakers In Health
1100 Connecticut Avenue, N.W., Suite 1200
Washington, DC 20036
Phone: 202-452-8331
Fax: 202-452-8340
E-mail: mwilliams@gih.org

Mattie S. Woods
Executive Director
Centers for Healthy Hearts and Souls
100 North Braddock Avenue, Suite 304
Pittsburgh, PA 15221
Phone: 412-371-3282
Fax: 412-371-6373
E-mail: centerhhs@aol.com

John Zinsser
Ombuds
Agency for Healthcare Research and Quality
6213 Executive Boulevard
Rockville, MD 20852
Phone: 301-594-1038
Fax: 301-594-0380
E-mail: jzinsser@ahrq.gov