

Interagency Working Group for Community-based Participatory Research

Meeting summary

April 26, 2002

National Institutes of Health

Neuroscience Center, Room C

Meeting began at 10:05 a.m.

Mr. O'Fallon welcomed everyone to the second meeting of the Federal Interagency Working Group for Community-based Participatory Research (IWG). After some quick housekeeping items, Mr. O'Fallon briefly read through the agenda and stated what the anticipated goals were of the meeting. Then, participants quickly introduced themselves. There were 20 participants around the table and 2 individuals participating via conference call.

Definition of Community-based Participatory Research

This discussion centered on the several definitions that representatives submitted. The primary themes that people raised regarding the definition included:

- ❑ **Approach/Framework:** participants believe that CBPR is best expressed as an approach or framework rather than a methodology.
- ❑ **Collaboration:** the definition must have some terminology that indicates the approach/framework involves active interactions between all parties involved
- ❑ **Equity:** that no one party has greater voice/decision-making authority than the other
- ❑ **Types of research:** depending on the audience the IWG is trying to reach, it is important to demonstrate that CBPR can be applied to the spectrum of research
- ❑ **Levels of research:** that CBPR can be applied to research affects individuals as well as social structures
- ❑ **Phases of research:** from question identification to evaluation and translation of project results
- ❑ **Stakeholders:** IWG participants believe that "community" might be too vague of a term and that "affected stakeholders" might be better suited.

The definition currently reads:

CBPR is a framework that promotes collaborative partnerships between researchers and those affected in all types (from x to y), levels (from x to y), and phases (from x to y) of research.

Time ran out before the IWG could come to an agreed upon definition. Therefore, the IWG decided to form a sub-group to continue working on the definition. Participants on this sub-group are: Fred Tyson (NIEHS), Carolyn Beeker (CDC), Jon Kerner (NCI), Deborah Frisch (NSF), Hal Zenick (EPA), and Kay Felix-Aaron (AHRQ). This sub-group will address the issues raised at the meeting, and further refine the definition begun by the IWG. The IWG will revisit the definition at the next meeting.

Objectives of the IWG

The purpose of this discussion was to define a set of objectives for the IWG. Mr. O'Fallon organized suggested objectives into "General" and "Specific" categories. General objectives were more encompassing, whereas the specific objectives would likely result in a deliverable.

General Objectives discussed at the meeting:

- Serve as a focal point to identify and develop new, coordinated activities to increase awareness, understanding and use of CBPR;
- Critically evaluate the strengths and weaknesses of the CBPR approach/framework;
- Identify challenges and opportunities for supporting CBPR;
- Encourage research training and career development opportunities for CBPR researchers and practitioners; and
- Serve as a network through which information can be shared regarding community-based participatory research activities.

Participants expressed the importance for the IWG to evaluate the strengths and weaknesses of CBPR. The rationale is that if the IWG is to promote CBPR effectively, the IWG must have analyzed the approach fully.

Participants recognize that more specific objectives may fall under the broader headings of these general objectives.

The final general objective does not mean that the IWG will create a central repository/clearinghouse of all CBPR-related materials, though that may be something for the IWG to consider at a later time.

Specific Objectives discussed at the meeting:

- Identify locations where multiple studies are taking place and determine (1) if work can be coordinated so it more efficient and less burdensome (2) if wider conclusions can be drawn from work across fields based on the same study population (or if this results in increasing confounding factors in individual studies).
- Produce an evidence report on the value of CBPR
- Produce a policy analysis report
- Elucidate funding processes and challenges for CBPR projects
- As a large group, confirm IWG intention to participate in the National Leadership Summit and develop a workplan.
- Identify smaller working groups to:
 - map the CBPR terrain: who's doing what, where, with whom? The workgroup would describe the CBPR continuum (identifying exemplars of different points on that continuum) and conduct an inventory of CBPR activities in US-based public health, including published and unpublished studies, completed and in-progress.
 - conduct critical analysis of CBPR: through systematic review of electronic databases and expert interviews, assess state of the science of CBPR on such dimensions as theory and measurement, feasibility (cost-effectiveness, availability of noncategorical dollars, range of applications), and short/intermediate/long-term impacts. Even if we conclude that there is insufficient evidence re its impacts on traditional health outcomes, the review should help us identify where the gaps are. We may also conclude that this approach is "desirable," for reasons other than its currently measurable impacts on health.
 - catalogue/compile/devise strategies for building more inclusive partnerships, especially business, labor, and agencies (e.g., HUD) positioned to address social/economic/structural influences on health

Report on OBSSR work with Community-Campus Partnerships for Health

"Developing and Sustaining Community-University Partnerships for Health Research: Infrastructure Requirements"

Dr. Lawrence Fine disseminated a factsheet about this effort and provided the IWG with background information as well as anticipated outcomes. A copy of the factsheet may be obtained from the IWG website <http://www.niehs.nih.gov/dert/programs/translat/IWG/iwghome.htm>.

He said that a report would be released later this summer, but that he was uncertain as to how it would be disseminated.

CDC Program Announcement on Community-Based Participatory Prevention Research <http://www.cdc.gov/od/pgo/funding/02003.htm>

Ms. Cheryl Coble provided IWG participants with background information on this program and she informed them of the amazing response rate they have received. To date her office has received over 560 letters of intent. Funding will begin August/September 2002. Due to the incredible response rate and the number of questions received regarding this announcement, her office has developed a "Q&A" page.

Ms. Coble shared an article written by Dr. Lawrence Green and Dr. Shawna Mercer titled "*Can Public Health Researchers and Agencies Reconcile the Push from Funding Bodies and the Pull from Communities?*" (*Am. Journ. Public Health, December 2001, Vol. 91, No. 12 pp 1926-1929*).

Upcoming CBPR-related Events

- AHRQ. At the last meeting, Dr. Kay Felix Aaron mentioned that her office had sent forth a proposal to develop an evaluation document of CBPR. She recently received approval to write this report. She invites interested IWG members to participate in this effort.
- AHRQ. Summer intern will do a research project on CBPR.
- AHRQ. Issue on CBPR in the Journal of General Internal Medicine. The focus of this issue is on research findings and data. Dr. Kay Felix Aaron is the editor of this issue and Dr. Fred Tyson (NIEHS) is an associate editor.
- CDC. Dr. Carolyn Beeker announced that her office has organized a session at APHA (November 2002) on the lessons learned from their Urban Research Centers (<http://www.niehs.nih.gov/dert/programs/translat/IWG/URC-factsheet.pdf>). Of particular importance is that the community partners will give the presentations.
- NIEHS. Dr. Fred Tyson mentioned that NIEHS will organize a roundtable meeting on CBPR this Fall and requested input from the IWG members. This roundtable meeting will involve the participation of 8-10 invited experts, to identify the state of the science in CBPR. It was noted that this activity will complement the ARQH activity discussed by Dr. Felix Aaron. Mr. O'Fallon suggested that the roundtable could be convened in concert with an IWG meeting.

Next meeting

No meeting date was set. Mr. O'Fallon will send out a series of dates to the IWG and try to find a date that is amenable to most people's schedule.

Assignments

1. CBPR Definition sub-group. Refine the definition and share with the larger IWG prior to the next meeting. Fred Tyson will coordinate these efforts.

Meeting adjourned at 12:45 p.m.