

INTERAGENCY WORKING GROUP FOR COMMUNITY-BASED PARTICIPATORY RESEARCH

Meeting summary

January 24, 2003

National Institutes of Health

National Institute of Diabetes and Digestive and Kidney Diseases.

Division of Nutrition Research Coordination

2 Democracy Plaza, 7th floor conference room (Room 701)

INTRODUCTIONS & OVERVIEW OF AGENDA

After a brief welcome and round of introductions, Fred Tyson (NIEHS) quickly went over the agenda. Three discussion points were added to the final agenda that were not on the agenda sent to IWG members. **(See Appendix 1)**

There were 20 participants in attendance, three of whom are new to the IWG. From the NIH Office of Research on Women's Health, Eleanor Hanna will be replacing Margaret Chesney as Dr. Pinn's representative. From the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), Ellen Gadbois attended. Finally, from the NIH Office of Disease Prevention, Martina Vogel-Taylor attended. Three IWG members participated by conference call. **(See Appendix 2)**

OBJECTIVES:

When the IWG was originally established, NIEHS proposed several goals and objectives of the group. At the first meeting of the IWG (2/02), members were asked to review, comment on, and suggest new objectives for the IWG. During the April IWG meeting, members reviewed and discussed the list of old and new objectives.

At the meeting today (1/03) IWG members received this list again as a basis to begin discussions on the Goals and objectives of the IWG. In addition, IWG members received a list of potential IWG activities that members had mentioned at the February 2002 meeting. These documents formed the foundation for the following discussion. **(See Appendix 3)**

In general, everyone approved of the goals and objectives listed. The major concern was how they would be operationalized, and with what resources. Objective 2, "Critically evaluate the strengths and weaknesses of the CBPR framework," received the greatest attention because of the way in which such an evaluation would take place. Following were the issues discussed:

- Gauging level of community participation in CBPR projects – people familiar with CBPR recognize that there are levels of community participation. Instruments are needed to measure the degree of community participation.
- Inventory of CBPR – it was originally suggested that an inventory of CBPR would need to precede an analysis. IWG members had considerable reservation about conducting such an inventory. Issues of time, purpose of the document, cost, process, and ultimate utility were all raised as formidable obstacles.
- Community involvement –to ensure appropriateness of evaluation.

- Breadth of such an analysis – It was proposed that if the purpose is to demonstrate the benefit of CBPR compared to traditional research methods, the evaluation should focus on a specific area such as asthma, obesity or diabetes. By focusing the scope, the size of effort would be decreased.
- Investigator presentations –to IWG to highlight critical issues of CBPR projects.
- Definition of “community.” – it was pointed out that “Community” can be defined in myriad ways (e.g., geographical, disease, demographic, etc.), and as such, it may be very difficult to analyze various CBPR projects.
- It was mentioned that there are other ways to evaluate impact of CBPR. Change in community perception of research is a measure of the impact CBPR may be having. We must not forget to consider ‘community impact’ as too often focused on ‘research impact.’
- DHHS 1% Set Aside Evaluation Program - provides money to conduct Needs Assessment, Feasibility Studies, Process Evaluations, and Outcome Evaluations. Proposals for trans-NIH evaluations receive greater attention and are eligible for up to \$100K for expedited review. The IWG could pursue this option to support an evaluation of CBPR.

IWG members were supportive of the objective that the IWG “Serve as a network through which information can be shared regarding community-based participatory research activities.” Mentioned benefit of inviting IWG members to grantee meetings that have a CBPR focus. Importance of sharing models with one another.

Other proposed goals for the IWG included:

- Hosting a symposium to spotlight CBPR and to get attention of the higher ups in HHS.
- Sharing “lessons learned” with other IWG members. In so doing, IWG members who’ve had greater experience with CBPR can share their real-life experiences with other members and perhaps obtain peer feedback.
- Compiling a list of “Case Studies” from agencies that have a history of supporting CBPR projects. Could serve as the foundation of a CBPR analysis. In addition, could serve as a means to demonstrate how CBPR adds value to conventional notions of research.

STRUCTURE/ORGANIZATION OF CBPR

Dr. Tyson and Liam O’Fallon reiterated that this discussion topic was to address the structure of this organization and consider the creation of different subcommittees.

IWG members were supportive of creating an **agenda sub-committee**. Larry Green (CDC) and Marilyn Metzler (CDC) agreed to lead this group. They will be responsible for organizing the next meeting. It was proposed that IWG meetings be thematic, that is, dedicated to one particular topic.

IWG members also agreed that an **outreach/liaison subcommittee** would be a mechanism for obtaining input from community groups. It was proposed that an existing FACA for the National Committee for Vital and Health Statistics might be interested in interfacing with the IWG. In a similar light, this subcommittee could interface with Private Foundations that are known to support community-university partnerships (e.g., WKKF, RWJ, Beldon Fund, etc.). The subcommittee could also organize a series of workshops in conjunction with IWG meetings. The workshops would involve presentations from community, researchers, and others who are involved in CBPR. No sub-committee leader was identified.

IWG members were interested in a **training subcommittee**. It was suggested that the R25 grant mechanism (education grants) could be used as a mechanism to build and nurture community-university partnerships. NIEHS is doing this successfully through its program *Environmental Justice: Partnerships for Communication*. Institutional training grants may be another mechanism to use to accomplish the same end. No sub-committee leader was identified.

IWG members expressed that rotating leadership is a good idea, but that it should be voluntary. There was no further discussion.

REPORT BACK FROM AHRQ

Kay Felix-Aaron (AHRQ) described the expert panel meeting AHRQ hosted on November 22, 2002. She outlined the process used to generate the report and the timeline for its completion. She distributed copies of the notes “Community-based Participatory Research: Notes from expert meeting on November 22, 2002.” The notes evoked many questions from IWG members.

The report highlighted the need to inform better CSR members of CBPR. Historically, CBPR projects that have gone to CSR have not fared well. Strategies to influence change in CSR discussed include:

- Invite Ellie Ehrenfeld to attend an IWG meeting.
- Interface with Research Coordinating Council (ASPE)
- Consolidate AHRQ report and use as a tool to educate CSR. [could create a website/presentation on CBPR that could be given to reviewers]

ANNOUNCEMENTS OF UPCOMING ACTIVITIES

In the final few minutes of the meeting, IWG members quickly mentioned upcoming events that may be of interest to IWG members.

- Larry Green (CDC) – Grantee mtg
- Audrey Burwell (OMH) – EJ meeting on May 28-29, 2003
- Community-Campus Partnerships for Health (Ann. Meeting) – San Diego April 26-29, 2003
- Kay Felix-Aaron(ARQH)/Fred Tyson (NIEHS) Journ. of General Internal Medicine – March/April release
- Fred Tyson– EJ/CBPR Mtg. July, 2003
- Larry Fine and Larry Green (NIH/CDC) – Methodology mtg.

ACTION ITEMS

- Larry Green and Marilyn Metzler will put together the agenda for the next meeting. If you have any topics for discussion, please send them to Larry and Marilyn.
- Initiate development of sub-committees. In light of the enthusiastic discussion of sub-committees within the IWG, it would be advantageous for us to begin forming these groups prior to the next IWG meeting. At least know who has an interest in being a part of one or more of the sub-committees. Four sub-committees received the greatest emphasis:
 - a. Evaluation
 - b. Agenda
 - c. Training
 - d. Outreach/Liaison

APPENDIX 1: FINAL MEETING AGENDA

CBPR Interagency Working Group Meeting
National Institute of Diabetes and Digestive and Kidney Diseases.
Division of Nutrition Research Coordination
2 Democracy Plaza, 7th floor conference room (Room 701)
6707 Democracy Blvd
Bethesda, Maryland

January 24, 2003

AGENDA

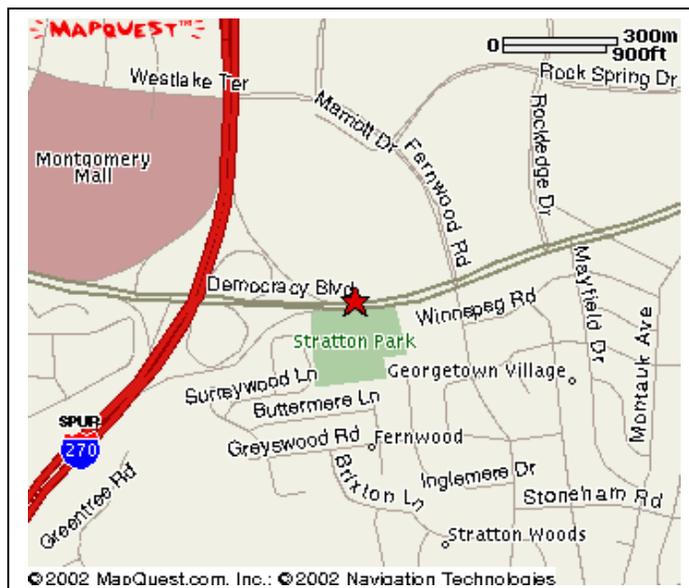
- 10:00 AM Welcome and brief introductions
- 10:15 AM Goals and objectives of the CBPR-IWG
- The purpose of this discussion is to identify and agree upon objectives for this group so that we can focus our efforts. Very important as we look to 2003.
 - The proposed goals/objectives of the CBPR-IWG can be viewed on the website. This discussion builds upon our April meeting.
- 11:15 AM Structure and organization of the CBPR-IWG.
- The purpose of this discussion is to consider ways in which to organize the working group to share leadership responsibilities among participating agencies.
 - Possibilities to consider:
 - Agenda committee
 - Rotating IWG leadership
 - Thematic subcommittees:
 - Analysis
 - Outreach/Liaison
 - Training
 - Other?
 - Others?
- 12:00 PM Report on AHRQ-convened expert panel for CBPR.
-- Kay Felix-Aaron, AHRQ
- 12:20 PM Other topics
- Analysis: Success of CBPR applications in review (solicited & unsolicited)
 - Trans-NIH Program Announcement on CBPR (proposed)
 - Washington Fax
- 12:50 PM Announcements of upcoming CBPR-related activities
- 1:00 PM Adjourn

PLEASE NOTE!

1. Parking is free.
2. The "Medical Center Metro" shuttle will take you from the main NIH campus to 2 Democracy Plaza.

MAP

The red star indicates the location of the 2 Democracy Plaza.



APPENDIX 2: ATTENDEES AT THE JANUARY 24, 2003 IWG MEETING

**CBPR Interagency Working Group
Meeting Participants (1/24/03)**

Last Name	First Name	Institution/Agency	Phone	E-mail
Blakey	Carter	Office of Disease Prevention & Health Promotion, OS, OPHS, DHHS	(202) 201-0745	CBlakey@osophs.dhhs.gov
Bukoski	Bill	National Institute on Drug Abuse	(301) 402-1526	bb75h@nih.gov
Burwell	Audrey	Office of Minority Health, OS, OPHS, DHHS	(301) 443-9923	alburwell@osophs.dhhs.gov
Felix Aaron	Kay	Agency for Healthcare Research and Quality	(301) 594-6198	kfaaron@AHRQ.GOV
Green	Lawrence	Office of Extramural Prevention Research, Centers for Disease Control and Prevention	(770) 488-2458	Lgreen@cdc.gov
Hanna	Eleanor	Office of Research on Women's Health, OD, NIH	(301) 402-1770	eh43q@NIH.GOV
Hayward	Anthony	Division of Clinical Research, National Center Research Resources, NIH	(301)435-0790	Haywarda@ncrr.nih.gov
Howard	Jan	National Institute on Alcohol Abuse and Alcoholism	(301) 443-1678	jh184h@NIH.GOV
Hubbard	Van S.	National Institute for Diabetes and Digestive and Kidney Diseases	(301) 5994-8883	vh16h@nih.gov
Jackson	Morgan N.	Office of Special Populations, Division of Extramural Research & Training, National Center for Complementary & Alternative Medicine	(301) 402-1278	mj145m@nih.gov
Johnson-Taylor	Wendy	Division of Nutrition Research Coordination, National Institutes of Health	(301) 594-7440	wj50v@nih.gov
Kerner	Jon	National Cancer Institute	(301) 594-7294	jon.kerner@nih.gov
Kuczarski	Robert	National Institute for Diabetes and Digestive and Kidney Diseases	(301) 451-8354	rk191r@nih.gov
Metzler	Marilyn	Centers for Disease Control and Prevention	(770) 488-5304	mom7@cdc.gov
Nowjack-Raymer	Ruth	National Institute of Dental and Craniofacial Research	(301) 594-5394	m27e@NIH.GOV
O'Fallon	Liam	National Institute of Environmental Health Sciences	(919) 541-7733	ofallon@niehs.nih.gov
Pinn	Vivian W.	Office of Research on Women's Health, OD, NIH	(301) 402-1770	vp3w@NIH.GOV
Taggart	Virginia	National Heart, Lung and Blood Institute	(301) 435-0202	taggartv@NIH.GOV
Tyson	Frederick	National Institute of Environmental Health Sciences	(919) 541-0176	tyson2@niehs.nih.gov
Zenick	Hal	Office of Research and Development, EPA	(919) 541-2283	zenick.hal@epa.gov
Elekwachi	Oluchl	Agency for Healthcare Research and Quality	(301) 594-7886	oelekwac@ahrq.gov
Gadbois	Ellen	Office of the Assistant Secretary for Planning and Evaluation	(202) 690-7287	ellen.gadbois@hhs.gov
Vogel-Taylor	Martina	Office of Disease Prevention, OD, NIH	(301) 496-6614	martinav@nih.gov

APPENDIX 3: INTERAGENCY WORKING GROUP OBJECTIVES

Interagency Working Group for Community-based Participatory Research (IWG for CBPR)

Objectives of IWG

General objectives:

- Serve as a focal point to identify common areas for federal collaboration in CBPR, which may include development of joint initiatives;
- Develop new, coordinated activities to increase awareness and use of CBPR in health research, delivery, education, and policy;
- Identify challenges and opportunities for supporting CBPR; and
- Identify means to demonstrate the value and benefits of CBPR.
- Develop a network through which information can be shared regarding community-based activities.

Specific objectives:

- A key question from the perspective of FHWA, an agency outside the health fields, is determining if this working group plans to look at use of the community-based participatory research model applied solely within the health fields.
- A useful objective of the work group would be to 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
- As a large group, confirm our 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