

Interagency Working Group for Community-based Participatory Research

Meeting summary

August 2, 2009

Housing and Urban Development

Office of Healthy Homes and Lead Hazard Control

Meeting began at 10:00 a.m.

Mr. O'Fallon welcomed everyone to the third 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 23 participants in attendance.

Definition of Community-based Participatory Research: Report back from CBPR definition sub-group & discussion

The definition submitted by the sub-group (Drs. Kerner, Zenick, Beeker, Tyson, Felix-Aaron, and Frisch) reads:

"CBPR is defined as research conducted in communities in which *community members, persons affected by condition or issue under study* and other key stakeholders in the community's health have the opportunity to be full participants in all phases of the work (from conception⇒ design⇒ conduct⇒ analysis⇒ interpretation⇒ conclusions⇒ communication of results)."

For the most part, IWG members were satisfied with this definition. The major source of contention in the ensuing discussion of the working definition of CBPR was whether or not to draw the line between the process/conduct of CBPR and implementation of research findings/outcomes. The membership was unable to resolve this issue during the time allotted. Some discussion will continue electronically. However, participants recognize the need to finalize this definition. Other minor recommended changes were adopted.

At the end of the discussion, the definition read:

"**Community-based participatory research** is **scientific inquiry** conducted in communities in which *community members, persons affected by condition or issue under study* and other key stakeholders in the community's health have the opportunity to be full participants in **each phase** of the work (from conception⇒ design⇒ conduct⇒ analysis⇒ interpretation⇒ conclusions⇒ communication of results)."

**Office of Minority Health:
Report on Secretary's National Leadership Summit**

Dr. Audrey Burwell summarized the meeting. There were over 2100 participants at the summit. The feedback has been positive. Dr. Ruffin (Director, National Center on Minority Health and Health Disparities, NIH) moderated a session on CBPR. To prepare him as best possible, Olivia Carter-Pokras had asked members of CBPR IWG, among others, to submit descriptions of what their Institute/Agency/Office has done in terms of CBPR. The response rate was very good, which allowed Dr. Carter-Pokras and the Office of Minority Health to develop an initial document highlighting the efforts of HHS in the realm of CBPR.

Dr. Burwell disseminated this document to all IWG participants. Overall, the document was very impressive. IWG participants noted that some work would be required to address missing information pertaining to their Institute/Agency/Office. All participants recognized that this broad summary captures a wide range of CBPR efforts, from projects that are more "community-placed" to others that are truly participatory in nature.

Some of the presentations from the National Summit can be found on the web at <http://www.summit.omhrc.gov/>.

It should also be noted that Dr. Burwell announced that Dr. Carter-Pokras would be leaving the DHHS (and the CBPR IWG) to accept an academic appointment.

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

Dr. Lawrence Green addressed the group about the review process of the applications received in response to the solicitation. The purpose of the program is to promote cross-cutting research. The announcement referred potential applicants to two websites pertaining to CBPR (see links to these sites from the IWG website at <http://www.niehs.nih.gov/translat/IWG/iwghome.htm>).

1. Community Campus Partnerships for Health (Principles of CBPR)
2. British Columbia: Canadian Royal Society (Guidelines of CBPR)

The response to the announcement was astonishing.

Letters of Intent = 570

Applications Received = 411

Applications Reviewed = 379

This massive number of applications required 111 reviewers that were organized into 5 panels. Approximately 50% of the applications were streamlined. Of the applications reviewed, Dr. Green estimates that only 25 will be funded. There were an additional 40 in the fundable range.

Apparently there was some disappointment in the level of cross-cutting work being proposed.

Questions were asked about the possibility of other Agencies/Institutes being able to fund any of the applications that scored high, but were not funded. Dr. Green said that any interested Agencies/Institutes should follow up with him.

**Agency for Healthcare Research and Quality (AHRQ):
Community-based Participatory Research Survey**

Kay Felix-Aaron and Jennifer McNabb from AHRQ discussed their preliminary work on trying to classify the CBPR portfolio for AHRQ. They were proposing to enlarge the scope of the work to include the CBPR portfolio of all of HHS, HUD, EPA, etc. Kay emphasized that this project began as a requirement from AHRQ to document the CBPR portfolio within AHRQ.

There were some suggestions about this effort. First, it was recommended that a methodology/rules for grant selection be developed before sampling. Otherwise the project will be unfocused and projects selected may not really be community-based or participatory. Second, a clearly defined goal of the project would need to be articulated.

Meeting participants did not enthusiastically endorse this effort as a group project. However, people did see the value in developing such a document. Further discussion is warranted on this issue at subsequent meetings.

EPA: Announcement on Research to Develop Improved Methods and Approaches to Empower Communities to Participate More Effectively in Environmental Cleanups

Kevin Garrahan from the EPA's National Center for Environmental Assessment, Office of Research Development presented on the recent announcement. He highlighted the purpose, background, scope of research and the status of the award process.

The purpose of the program is to stimulate research on environmental risk communication and community involvement. A secondary purpose is to develop improved methods,

models and approaches to empower communities to participate more effectively on environmental cleanups.

This announcement originates from the NRC report, "A Risk-Management Strategy for PCB-Contaminated Sediments."

The scope of research varies. Some groups proposed tools for measuring community preferences, while others are developing methods to evaluate societal/cultural impact, and other group plan to establish methods to evaluate the effectiveness of community involvement programs.

The deadline for responding to this announcement was September 19, 2002. EPA anticipates making awards in January 2003.

National Academy of Science (NAS): Ethical Issues

Susan Cummins, NAS, gave a quick presentation regarding the development of a new committee to examine ethical issues pertaining to lead (Pb) research involving children, youth and families. The committee will write a consensus report that provides ethics guidance to protect children, youth and families during the conduct of house intervention research. The committee will also do other activities over the course of the study. For more information, please contact Susan Cummins at scummins@nas.edu.

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. None at this time.

Meeting adjourned at 1:15 p.m.