

**The NIH Director's  
Council of *Public Representatives* (COPR)**

**Role of the Public in Research  
Work Group**

**Presentation to the NIH Director  
April 18, 2008**

Presented by Ann-Gel Palermo and Beth Furlong

# Purpose of the Role of the Public in Research Work Group

Identify ways to encourage researchers to involve the public in research, with an emphasis on community engagement

# Work Group Deliverables

1. Definitions for community engagement and public participation
2. Criteria and/or guidance that peer-review panels can use to gauge community engagement
3. Guidelines for educating researchers and the public about community engagement

# Work Group Members

- Syed Ahmed, Co-Chair
- Ann-Gel Palermo, Co-Chair
- Christina Clark, Agenda Co-Chair Liaison
- Naomi Cottoms
- Elmer Freeman
- Beth Furlong
- Marjorie Mau
- Valda Boyd Ford

## COPR Conditional Appointee Work Group Participants

- Micah Berman
- Lora Church
- Carlos Pavão
- John Walsh

# Deliverable 1: Process

- Review published and unpublished literature on definitions of community engagement and public participation
- Matrix of definitions
- Regular Work Group calls to craft definitions
- Results

# Definition of Community

**Community** refers to populations that may be defined by geography; race; ethnicity; gender; sexual orientation; disability, illness or other health condition; or to groups that have a common interest or cause, such as health or service agencies and organizations, health care or public health practitioners or providers, policy makers, or lay public groups with public health concerns.

*Source:* Community Participation in Research, PA Number PAR-05026.

# Definition of Community Engagement

**Community engagement** in research is a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus.

It is a process that requires power sharing, maintenance of equity, and flexibility in pursuing goals, methods, and time frames to fit the priorities, needs, and capacities within the cultural context of communities.

Community engagement in research is often operationalized in the form of partnerships, collaboratives, and coalitions that help mobilize resources and influence systems; change relationships among partners; and serve as catalysts for changing policies, programs, and practices.

# Definition of Community Engagement (continued)

Community engagement is a core element of any research effort involving communities. It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment before, during, and after the research.

## *Adapted from:*

Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA* 2007;297:407–410. p. 408.

Fawcett SB, Paine-Andrews A, Francisco VT, Schultz JA, Richter KP, Lewis RK, Williams EL, Harris KJ, Berkley JY, Fisher JL, Lopez CM. Using empowerment theory in collaborative partnership for community health and development. *Am J Community Psychol* 1995;23:677–697.



# Definition of Public Participation

**Public participation** is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process. Public participation is the process by which an organization consults with interested or affected individuals, organizations, and government entities before making a decision. Public participation is two-way communication and collaborative problem solving with the goal of achieving better and more acceptable decisions.

## *Sources:*

International Association of Public Participation. IAP2 Core Values.  
<http://www.iap2.org/displaycommon.cfm?an=4>.

Creighton and Creighton, Inc. What is...?  
<http://www.creightonandcreighton.com/whatis.html#6>.

# Deliverable 1: Action Item

- COPR approval definitions of community engagement and public participation

# Deliverables 2 and 3: Process

- Met with a panel of experts on community-academic partnered research, community engagement, and peer review
- Work Group discussion to identify next steps

# Invited Experts

- **Dr. Amy Bany Adams, *Special Assistant to the NIH Director, Office of the Director, NIH***
- **Dr. David Armstrong, *Chief, Scientific Review Branch, National Institute of Mental Health, NIH***
- **Dr. Jared Jobe, *Program Director, Clinical Applications and Prevention Branch, Division of Prevention and Population Sciences, National Heart, Lung, and Blood Institute, NIH***
- **Ms. Loretta Jones, *Founder and Executive Director, Healthy African American Families II***
- **Dr. Donna Jo McCloskey, *Health Scientist Administrator, Division for Clinical Research Resources, National Center for Research Resources, NIH***
- **Dr. Walter Schaffer, *Senior Advisor, Office of Extramural Research, NIH***
- **Dr. Vivian Ota Wang, *Executive Office of the President, National Nanotechnology Coordination Office, National Science and Technology Council***

# Deliverable 2: Guidelines for Educating Researchers and the Public

- Developed template for developing guidelines:
  - Values
  - Strategies and recommendations
  - Outcomes

# Deliverable 2: Guidelines for Educating Researchers and the Public

- Next steps:
  - Complete template of values, strategies/recommendations, and outcomes
  - Develop recommended implementation steps to use the template information for education

# Deliverable 3: Guidance for Peer-Review Panels

- Next steps:
  - Identify promising models and practices within and outside NIH
  - Review work done to address Deliverable 2
  - Develop recommended guidance for peer-review panels in gauging community engagement

## Deliverables 2 and 3: Work Plan

- Timeline: April 2008 to October 2008
- Monthly Work Group conference calls
- Continue to collect information on community engagement in research and peer review
- Present deliverables 2 and 3 at October 2008 meeting