

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

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

**Presentation to the NIH Director  
October 31, 2008**

Presented by Ann-Gel Palermo and Syed Ahmed

# 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.

# Role of the Public in Research Work Group: Background

The Role of the Public in Research Work Group was formed to respond to the following needs:

- How to include the public in research beyond serving as research participants
- Limited researcher understanding of the value of public participation in research
- Limited researcher competency in community engagement in research

# Role of the Public in Research Work Group: Background (Cont.)

- Institutions do not always educate the community about what research is and how it can help them
- Lack of incentives for community engagement in research
- NIH requirements for training researchers to engage the community are not uniform—the quality of the training and results vary widely

# Role of the Public in Research Work Group: Background (Cont.)

- Limited guidance available for peer review panels on evaluating community engagement proposals
- How to operationalize the fourth “P” (for “participatory”) in the NIH strategic vision

# Work Group Deliverables

1. Definitions and operating principles of “community engagement” and “public participation”
2. Guidelines for educating researchers and the lay public on community engagement
3. Criteria and/or guidance that peer review panels can use to gauge community engagement

# Work Group Day Participants

- Syed Ahmed, Co-Chair
- Ann-Gel Palermo, Co-Chair
- Elmer Freeman, Agenda Co-Chair Liaison
- Micah Berman
- Lora Church
- Christina Clark
- Naomi Cottoms
- Elizabeth Furlong
- Marjorie Mau
- Carlos Pavão
- John Walsh

## Deliverable 1: Definitions

# Process

- Reviewed published and unpublished literature on definitions of public participation and community engagement
- Developed matrix of definitions
- Held regular work group calls to craft definitions of “community engagement” and “public participation”



## Deliverable 1: Definitions

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

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

## Deliverable 1: Definitions

# Definition of “Community Engagement”

**Community engagement** is a dimension of public participation. In research, community engagement 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.

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.

## Deliverable 1: Definitions

# Operating Principle for Community Engagement

Community engagement 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.

### **Sources:**

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 partnerships for community health and development. *Am J Community Psychol* 1995;23:677–697

## Deliverable 1: Definitions

### Action Item

The COPR reviewed definitions of “community engagement” and “public participation” with the NIH Director on April 18, 2008.

## Deliverable 2: Education Guidelines

# Process

- Met with experts on community-academic partnered research, community engagement, and peer review in April
- Reviewed the literature on community engagement in research
- Developed draft template for the deliverable based on literature and work group member experience
- Held frequent work group discussions by teleconference to review template

## Deliverable 2: Education Guidelines

# Guidelines for Educating Researchers and the Lay Public: Overview

- The work group developed a template for developing guidelines: *Values, Strategies, and Outcomes for Investigators Who Want to Engage the Community in Their Research*
  - 13 values
  - Strategies for achieving each value
  - Outcomes of strategies

## Deliverable 2: Education Guidelines

# Guidelines for Educating Researchers and the Lay Public: Values

### Values:

1. Investigators and communities understand community engagement in research
2. Strong community-investigator partnership
3. Communities and investigators share power and responsibility equitably
4. Equitable inclusion of diverse perspectives and populations

## Deliverable 2: Education Guidelines

# Guidelines for Educating Researchers and the Lay Public: Values (Cont.)

### Values (cont.):

5. Clear and relevant research goals
6. Mutual benefit
7. Capacity building
8. Respect and recognition
9. Continuous communications
10. Transparent monitoring and evaluation



## Deliverable 2: Education Guidelines

# Guidelines for Educating Researchers and the Lay Public: Values (Cont.)

### Values (cont.):

11. Appropriate policies regarding ownership and dissemination of results
12. Translation of research findings into policies, interventions, or programs
13. Sustained relationship
14. Sustained beneficial effects of research

## Deliverable 3: Guidance for Peer Review Panels

# Process

- Met with experts on community-academic partnered research, community engagement, and peer review in April
- Reviewed the literature on community engagement in peer review
- Developed draft template for the deliverable based on literature, work group member experience, and NIH institute and center activities
- Held frequent work group discussions by teleconference to review template

## Deliverable 3: Guidance for Peer Review Panels

# Guidance for Peer Review Panels in Gauging Community Engagement: Overview

- The work group developed a template for developing guidelines: *Peer Review Criteria for Assessing Community Engagement in Research Proposals*
  - 2 criteria for reviewers
  - 10 criteria for grant applications
  - Evidence demonstrating that each criterion has been met

### Deliverable 3: Guidance for Peer Review Panels

## Guidance for Peer Review Panels in Gauging Community Engagement: Overview (Cont.)

- *Peer Review Criteria for Assessing Community Engagement in Research Proposals* template:
  - To be used in conjunction with *Values, Strategies, and Outcomes for Investigators Who Want to Engage the Community in Their Research*

### Deliverable 3: Guidance for Peer Review Panels

## Guidance for Peer Review Panels in Gauging Community Engagement: Criteria

### Criteria for reviewers:

1. Peer reviewers understand and/or have experience in conducting research that involves community engagement as defined by the COPR
2. Peer reviewers understand the value added by public review panel members

## Deliverable 3: Guidance for Peer Review Panels

# Guidance for Peer Review Panels in Gauging Community Engagement: Criteria (Cont.)

Criteria for grant applications:

1. Evidence of equitable partnership between investigators and community partner
2. Investigators have defined relevant community or communities
3. Investigators have identified appropriate community or communities—community co-investigator has identified appropriate research partner

### Deliverable 3: Guidance for Peer Review Panels

## Guidance for Peer Review Panels in Gauging Community Engagement: Criteria (Cont.)

Criteria for grant applications (cont.):

4. Community engagement is an integral part of the research
5. Community played an appropriate and meaningful role in developing the application
6. Appropriate division of funding among partners

## Deliverable 3: Guidance for Peer Review Panels

# Guidance for Peer Review Panels in Gauging Community Engagement: Criteria (Cont.)

Criteria for grant applications (cont.):

7. Sound science
8. Training opportunities
9. Appropriate environment
10. Impact



# Recommendations

1. Seek approval by NIH Director of the three deliverables of the work group:
  - Definitions of “community engagement” and “public participation”
  - Framework for community engagement
  - Framework for peer review

## Recommendations (Cont.)

2. Request guidance from the Office of the Director (OD) on how best to explore implementation processes for these three deliverables
3. Create a new COPR work group to assist OD in exploring implementation processes
  - One co-chair of the current work group should serve as co-chair of the new work group

## Recommendations (Cont.)

4. Prepare manuscripts on community engagement education and public participation in peer review for publication in a peer-reviewed journal to share COPR's recommendations with a broader audience

Thank you, Dr. Zerhouni!