

# **Public Participation and Community Engagement in Research**

**Reports & Recommendations from the  
NIH Council of Public Representatives**

**Community Campus Partnerships for Health Educational  
Conference Call Series. September 23, 2009**

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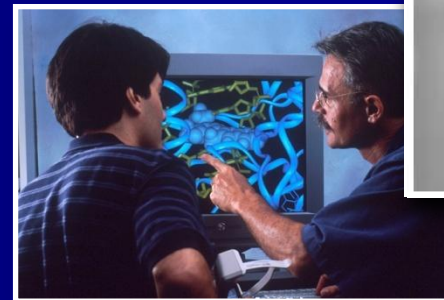
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# National Institutes of Health (NIH)

- Federal Government is the single largest sponsor of medical research in the United States, with NIH receiving the vast majority of appropriated funds
- World's preeminent medical research institution
- Steward of the nation's medical and behavioral research investment

# NIH Goal

To acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability.



# NIH Mission

***NIH is the steward of medical and behavioral research for the Nation.***

***Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.***

# Engaging the Public (examples of NIH efforts)

- Director's Council of Public Representatives (COPR)
- Community Forums
- Public and Town Hall Meetings
- Formal requests for public input (e.g., strategic plans)



- NIH Web sites (e.g., Research Results for the Public Web site)
- Public outreach campaigns
- Newsletters
- Exhibits at health fairs and community events
- Public inquiry response

# NIH Efforts to Engage the Public in Research Activities

- Outreach to public audiences,
- Clinical and Translational Science Awards,
- NIH Public Trust Initiative and RFP for Partners in Research grants (R03s),
- Public Access Policy,
- NIH Extramural Scientist Interest Group on Community-Based Participatory Research.

# Origin of COPR

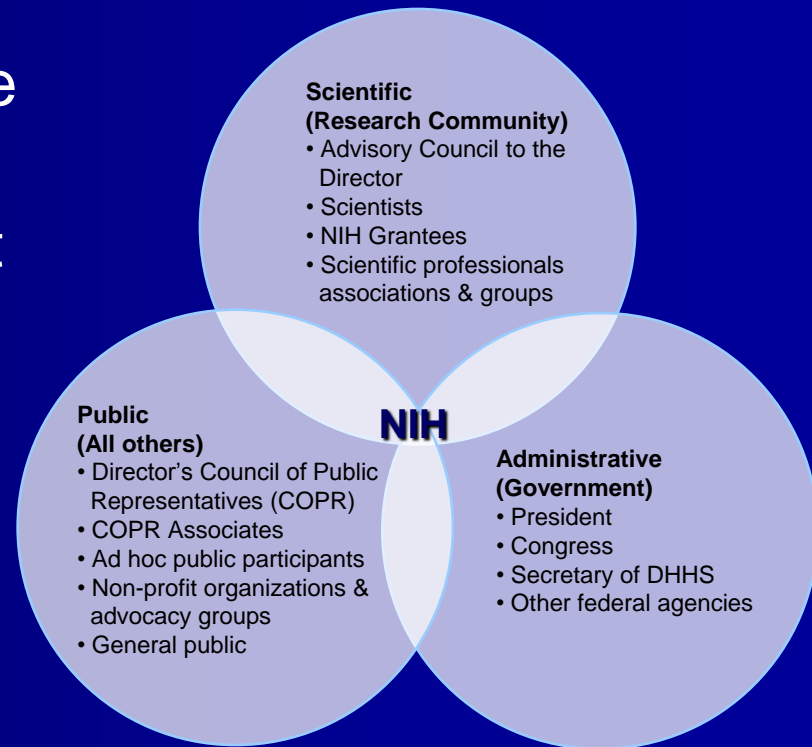
- IOM Report: **Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the NIH** –July 1998

“The director of the NIH should establish and appropriately staff a Director’s Council of Public Representatives, chaired by the NIH director, to facilitate interactions between the NIH and general public.” [Recommendation 8]

- Formed in fall 1998 by NIH Director Varmus; first meeting in 1999.

# NIH Director's Council of Public Representatives (COPR)

- Federal Advisory Committee
- Consists of 21 members of the public who provide input and feedback from the public's perspective on emerging health issues and research priorities as identified by the COPR and/or the NIH Director
- A diverse group with a wide range of backgrounds and perspectives



**Balancing Important Perspectives  
in the NIH Decision-Making  
Process**

# COPR Membership

COPR members include:

- Patients,
- Family members of patients,
- Health care professionals,
- Scientists,
- Communicators in health, medicine, or science
- Academicians,
- Public servants,
- Professionals from health- and science-related nonprofit agencies and professional societies.



# COPR Roles and Functions



- Provide NIH with a public perspective.
- Identify and address issues of public importance to the NIH.
- Bring NIH attention to issues of public importance.
- Increase public awareness of NIH outreach activities, programs, and resources, including trustworthy health information.

# COPR Roles and Functions



- Act as sounding board for major issues facing NIH.
- Encourage broad representation of the public on standing and ad hoc policy and program advisory bodies, including national advisory councils.
- Identify best practices for receiving public input and advocate their replication across NIH.

# COPR Nomination Process

- Members who apply or are nominated are selected from diverse communities that have an interest in NIH research, programs, and activities.
- Must be in a position to communicate regularly with the public or segments of the public on COPR and NIH activities.
- Rolling application process/public outreach.
- September deadline for each year's selection process.
- Remaining candidates invited to serve as "COPR Associates" on the COPR listserv.
- COPR Associates serve as a "resource pool" for NIH Institutes, Centers, and Offices for a variety of projects.

# The Past Decade

## COPR Recommendations and Reports

<http://www.copr.nih.gov/reports.asp>

- Frameworks for Community Engagement in Research – October 2008
- COPR Letter to the NIH Director on Communications to Enhance Awareness of NIH – March 2008
- Public Trust in Clinical Research – January 2005
- Enhancing Public Input and Transparency in the NIH Research Priority-Setting Process – April 2004
- COPR response to IOM Report on Organizational Structure and Management of the NIH – January 2004
- Public Library of Science – December 2002
- Report on the Organizational Structure and Management of NIH – December 2002
- Human Research Protections in Clinical Trials: A Public Perspective – October 2001

# Coming Soon...

## A Public Input Opportunity

### *Request for Information on Consumer Health Information-Seeking Behaviors*

- **Goal:** To obtain insight and better understanding of the health information needs and information-seeking behaviors of NIH health consumer audiences.
- **Expected Outcome:** The information gathered will assist the NIH in developing and disseminating health, medical and scientific information to a broader variety of audiences.

Visit the RFI website [in late September 2009.](http://nihhealthinfoRFI.nih.gov)

<http://nihhealthinfoRFI.nih.gov>

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

To 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:

- 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.
- There is a 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.

# Role of the Public in Research Work Group: Charge

- Identify ways to encourage researchers to involve the public in research with emphasis on community engagement.

# 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.

# Processes

- Reviewed published and unpublished literature on definitions of public participation and community engagement.
- Met with experts on community-academic partnered research, community engagement, and peer review.
- Held regular work group calls to craft and develop definitions of “community engagement”, “public participation”, and frameworks for community engagement and peer review.
- Recommendations of the COPR’s deliverables presented to and approved by the NIH Director.

## 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

# 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.

# 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

# 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

## 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.

# Next Steps

- Community Engagement in Research Implementation Trans-NIH Working Group
- COPR Member Presentations
- STEP Program: Nuts-and-Bolts of Community Engagement in Research - October, 2009
- Partners In Research (PIR) Forum - October, 2009
- CTSA Conference – May 2009
- CTSA Communications Key Function Committee
- Article: *Community Engagement in Research: Frameworks for Education and Peer Review*

# For More Information

- National Institutes of Health  
<http://www.nih.gov/>
- Directors Council of Public Representatives  
<http://copr.nih.gov>
- Research Results for the Public  
[www.nih.gov/about/researchresultsforthepublic](http://www.nih.gov/about/researchresultsforthepublic)
- Get Involved at NIH  
<http://getinvolved.nih.gov/>