

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

COPR Work Day

**Presentation to the NIH Director
April 21, 2006**

Presented by
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Agenda Work Group Co-Chairs

Tracking COPR Impact

- Recommend that COPR adopt planning and tracking tools developed by the COPR Performance Review Work Group:
 - COPR Planning Table
 - COPR Post-Report Evaluation Tracking Table

Add a Fourth “P”: Participation!

- NIH might consider adding a fourth “P” to its overall vision—participation
 - Supports trans-NIH vision of inclusion

Knowledge Management (OPASI)

- COPR affirms the development of the strategic communication plan for “interested publics”
- COPR liaison
- Public input in the developmental stages of the thesaurus

Role of the Public in the Research Process

- COPR affirms current NIH support for public involvement in research, such as the Public Trust Initiative activities.

Role of the Public in the Research Process

- Collaborate with OER to identify opportunities for public involvement in the research continuum
 - Role in clinical research peer review (support of Trans-NIH Dialogue: Public Members in Peer Review)
 - Role in IRBs
 - Diverse best practices

Role of the Public in the Research Process

- Establish recognition/award program
 - Internal award program—using Plain Language Awards as a model
 - Future external award program

Role of the Public in the Research Process

- COPR wants to initiate an effort to raise awareness among researchers of the importance of public input.
 - Educating researchers on public involvement in the research process is critical
 - Urge public involvement in medical research by making it a possible grant criterion

Role of the Public in the Research Process

- Develop a work group to help NIH educate researchers:
 - Pursue idea and consider framework for curriculum for researchers
 - Enhance NRSA awards—training to include public participation

Collaborative Research

- Concern at the grassroots level that small community research entities (For example, 2-year institutions) are still minor players in the larger academic medical research arena
 - Find out what NIH is doing to promote and affirm community research (that people have begun referring to as community-based participatory research)

Collaborative Research

- Promote greater collaboration between smaller community research entities and large academic institutions
 - Immediate opportunities using existing NIH resources and programs
 - Innovative ways to bridge the gap
 - Creative ways to build capacity for smaller research institutions

Collaborative Research

- Actively pursue partnerships with voluntary groups, clinics, community organizations, etc.

Collaborative Research

- Address feasibility of community/academic summit
- Provide technical assistance opportunities for CTSA applicants (to make community engagement happen)

Agenda Work Group Tasks

- Develop agenda topics for fall 2006 COPR meeting
- Create Agenda Work Group subgroup to gather information on collection of quantitative data for various patient and health categories
 - Emphasize underserved and under-recognized populations

Other Thoughts

- COPR as a model for other HHS agencies

Next Steps

- Prioritize topics and select new work group focus areas
- Organize new work groups or subgroups
- Identify topics for fall 2006 COPR meeting