

NATIONAL INSTITUTES OF HEALTH

COPR Mission

The COPR shall consult with and advise and make recommendations to the Director, NIH, on issues and concerns that are important to the broad development of NIH programmatic and research priorities. The COPR shall also assist the NIH in enhancing the participation of the public in NIH activities that have an impact upon the public, in increasing public understanding of the NIH and its programs, and in bringing important matters of public interest forward for discussion in public settings.

Source: COPR Handbook 2007

COPR Roles and Responsibilities

- Provide the NIH with public-oriented viewpoints and perspectives
- Identify and address issues of importance to the NIH in relation to the public
- Increase awareness of outreach activities and programs conducted by the NIH
- Provide a sounding board for major issues faced by the NIH
- Bring major new issues of public importance or interest to the attention of the NIH
- Enhance understanding and awareness of the NIH among constituency groups and the general public
- Identify how the NIH might broaden its base of public input, enhance existing mechanisms for obtaining public input, or develop new mechanisms for obtaining public input

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Human Research Protections in Clinical Trials: A Public Perspective

October 2001

“If it is to fulfill its promises, clinical research must lead not only with the high tech of cutting-edge science, but also with the high touch of human interactions that value and empower patients as full partners in the research process.”

Made recommendations related to:

- Informed consent
- Availability and transparency of information
- Conflicts of interest
- Confidentiality and privacy
- Enhanced public education and training

Informed NIH policy by elucidating the issues and helping to inform the NIH’s clinical trial Web sites and materials for patients, professionals, and researchers.

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Report on the Organizational Structure and Management of the NIH

December 2002

Recommendations included:

- Encourage additional funding trans-NIH research
- Make expenditures in specific disease areas more transparent

Recent NIH progress: A common fund for some trans-NIH research projects and an Office of Portfolio Analysis and Strategic Initiatives.

Enhancing Public Input and Transparency in the NIH Research Priority-Setting Process

April 2004

Recommendations included:

- Encourage going beyond the NIH campus
- Partner with communities
- Use proactive outreach, including low- and high-technology approaches
- Increase trans-Institute communication
- Promote bidirectional communication
- Make sure public input reaches decision makers
- Fully utilize advisory councils and their public members

Progress can be seen in the following expanded NIH communications efforts:

- **Web Sites:** *Get Involved at NIH, Research Results for the Public*
- **Constituency Outreach Newsletters/Updates:** *NIH Director's Update, NIH Public Bulletin, The NIH Nexus, The NIH News In Health*
- **Collaborations with Media:** Discovery Channel, NBC 4—*News for Your Health*, outreach to mainstream health magazines, *Parade Magazine* cover
- **NIH Director Requests for COPR Member Participation:** NIH Roadmap 1.5 meetings (10), Institute/Center Director selection and review panels (~ 6), NIH-COPR Public Trust Workshop (21 COPR Members plus about 80 public participants with NIH staff)
- **Bidirectional Communication:** Exchanges between the COPR and NIH leadership that include the COPR meeting agenda-setting process and the meeting discussion format

These are a sampling of the many ways the COPR helps to shape NIH interactions with the public.

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Report and Recommendations on Public Trust in Clinical Research

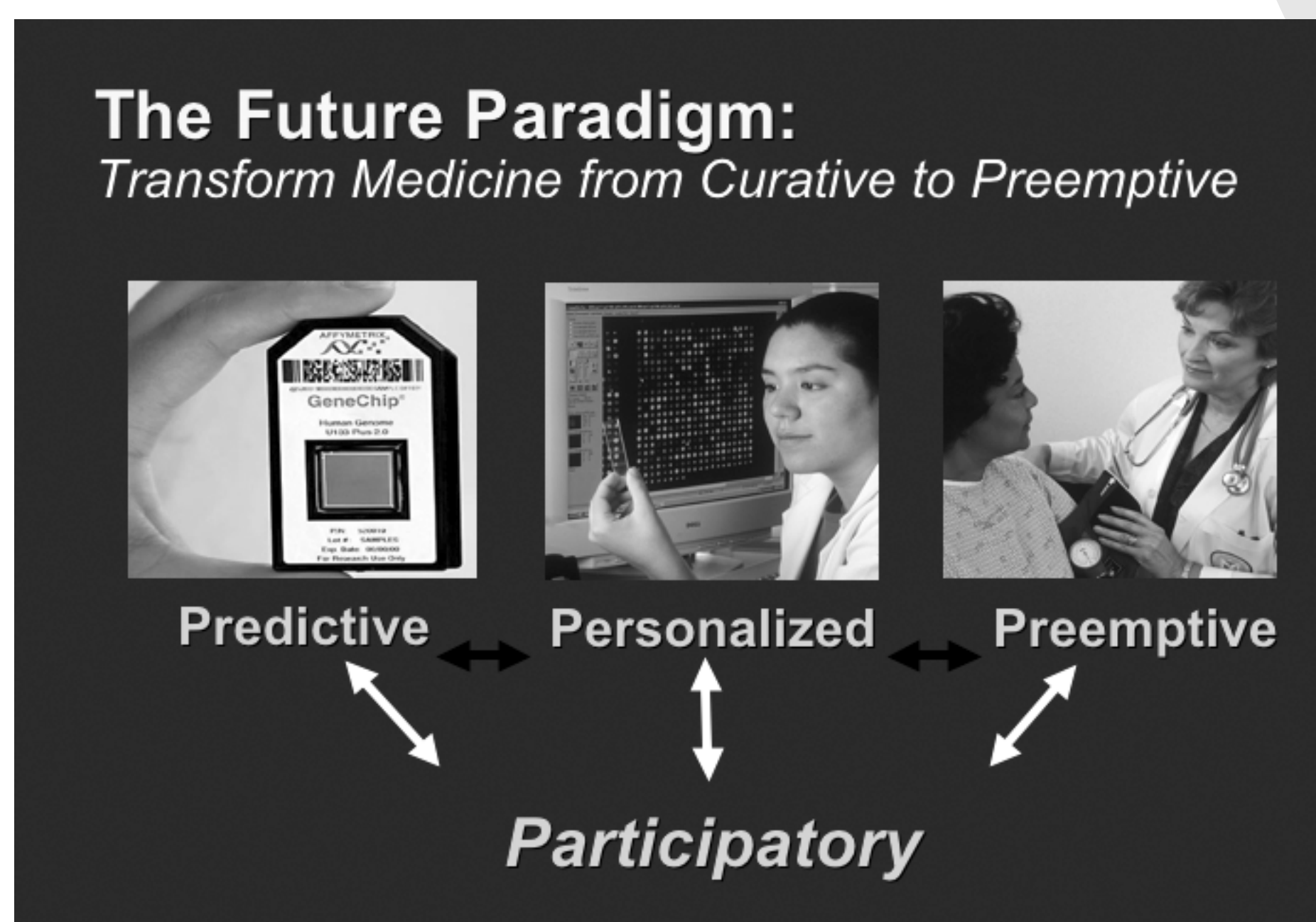
January 2005

This report encouraged a culture change in the scientific community with regard to public participation in research. Recommendations included to:

- Engage researchers, educators, and academic institutions in incorporating the public's perspective consistently at every level of training and in both the conduct of clinical research and the publication of findings from that research
- Document and publish “best practices” from efforts to reengineer the clinical research enterprise as soon as the NIH begins to see results, so that progress in improving public trust in medical research grows rapidly and steadily

This report was a direct result of the COPR-NIH Public Trust Workshop. It complemented and supported the NIH Public Trust Initiative efforts and provided input to the emerging Clinical and Translational Science Awards program designed to reengineer the clinical research enterprise through clinical centers of excellence and the collection and dissemination of “best practices.”

In addition, NIH leadership now consistently includes “Participation” as an integral part of the research paradigm—the “fourth P” in transforming medicine from curative to preemptive.



Recommendations

from the November 3, 2006, COPR Meeting

COPR: NIH's Public Voice

Effective public involvement in research is neither simple nor unidirectional. It is long-term and sometimes difficult, and it thrives on many ambassadors to advance progress and sustain momentum. COPR highly values public involvement in research, and current efforts aim to increase awareness and promote action.

Considerations for advancing the role of the public in research:

- Establish baseline of NIH community participation
- Educate researchers about potential roles for the public
- Provide guidance to applicants/grantees, enhance training programs
- Identify and disseminate best practices of community engagement
- Bridge gaps between organizations and research institutions
- Build partnerships that expand community involvement in research

Recommendations

from the November 3, 2006, COPR Meeting

A Voice for Change:

As a worldwide scientific leader, the NIH plays a pivotal role: Any steps the agency takes toward encouraging public engagement will be widely noticed. Providing incentives and developing training programs that encourage clinical researchers to involve communities in research will send a strong message on the importance of this practice within the research enterprise. Engaging communities takes time and resources, and researchers need assurance that their activities in this realm will be appreciated within the current peer-review and funding processes.

Increasing researcher appreciation for public/community engagement:

- Identify evidence-based practices to involve communities
- Develop ways to measure efficacy of public participation
- Build effective collaborations and partnerships
- Offer meaningful incentives that encourage clinical researchers to involve communities in research
- Communicate benefits of community involvement in research
- Increase public base of support for research
- Create tools to educate researchers on community involvement/engagement
- Provide guidance to applicants
- Stakeholder outreach: professional organizations, academic leadership, study sections, IRBs

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Communications Efforts of the NIH and the COPR

The Communications Work Group has contributed input to NIH outreach efforts and has worked with the NIH Office of Communications and Public Liaison for four years.

The Group's recommendations are many and have included:

- Encourage the human element ("putting a human face") in NIH communications
- Enhance public awareness and knowledge of the NIH
- Consider an "ambassadors program" that would include COPR Members, COPR alumni, advisory board members of other Institutes, and high-profile "recognizable" volunteers
- Publish COPR editorials ("COPR messages") on the value of public participation in the research process
- Highlight the value of investment in biomedical research through educational PSAs
- Consider the creation of a centralized NIH "kids" Web site, taking advantage of currently distributed sites

These recommendations can be seen through the following: an NIH brochure and overview publication, NIH Radio and podcasting programs, an award-winning Web site, NIH Hispanic Health Fairs for the public, an NIH collaboration with the Discovery Channel and exploration of other communications and educational collaborations, the consideration of an NIH Ambassador Program, and two pending COPR editorials ready for submission to a trade journal and mainstream newspaper, among many other projects in progress.

NIH: We are communicating daily with the public and reaching out with new media, in new ways, and for public education to improve the nation's health....