



NIH Public Trust Initiative Update

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Initiative Co-Chairs

Dr. Patricia A. Grady

Director, National Institute of Nursing Research

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NIH Public Trust Initiative

NIH cannot control the public's perceptions in the area of research...

...but we at NIH can improve how we communicate and interact with the public.





NIH Public Trust Initiative

The Public Trust Initiative is based on the following assumptions:

- Public trust is a top priority for the NIH
- The NIH has a long-term commitment to public trust
- Public input with NIH decision-making and research planning leads to better research
- Quality research is necessary for optimal health





NIH Public Trust Initiative

Mission Statement

The mission of the NIH Public Trust Initiative (PTI) is to enable the public to understand and to have full confidence in the research that NIH conducts and supports across the country and throughout the world.





NIH Public Trust Initiative

SPECIFICALLY, the Public Trust Initiative seeks to provide the public:

- Information about how NIH conducts and supports research
- Opportunities to participate in priority setting and other NIH activities
- Opportunities to participate in clinical research
- Access to, and understanding of, research results





NIH Public Trust Initiative Steering Committee

Patricia Grady
Yvonne Maddox

Co-Chair, Director, NINR
Co-Chair, Deputy Director, NICHD

Lauren Aaronson
Barbara Alving
John Burklow
Michaele Christian
Lisa Colpe
Zeke Emanuel
Sharon Hrynkow
Lisa Kaeser
Raynard Kington
Dushanka Kleinman
Cliff Lane
Amy Patterson
Cliff Poodry
Joan Schwartz
Nicole Johnson Baker

Senior Advisor, NIH NINR
Acting Director NCRR—*Clinical, women's health*
Assoc. Director for Comm., NIH OD—*Communications & education*
Assoc. Director, Div. Cancer Treatment, NCI—*Clinical trials, oncology*
Acting Asst. Director for Roadmap Coordination, NIH OD
Chair, NIH Department of Bioethics—*Ethics*
Acting Director, FIC—*International*
Senior Program Analyst, NIH NICHD
Deputy Director, NIH—*Health disparities, BSSR*
Deputy Director, NIDCR
Clinical Director, NIAID—*Clinical trials, patient advocacy*
Director, Office of Biotechnology Activities, NIH OD
Director, Div. Minority Opp. & Res., NIH NIGMS—*Special populations*
Asst. Director, OIR—*Women's health, intramural*
COPR Member—*Public, patient advocacy*





NIH Public Trust Initiative Liaison Group

Representatives from

- Institutes
- Centers
- Offices of the Director





NIH Public Trust Initiative

Public Trust Initiative Inventory

- Inventory of current NIH activities
- Tremendous response from all the ICs
- Over 100 pages of abbreviated info
- Categorized by types of activity
- Reviewing for target “publics”
- Identifying ‘exportable’ programs





NIH Public Trust Initiative

Types of Activity

- Involving and Protecting Human Participants in Clinical Research
- Including the Public in IC Activities
- Promoting the Visibility of NIH Information for the Public
- Teaching and Developing Course Materials for Science Education
- Education and Outreach Programs for Extramural and Intramural Clinical and Research Communities





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Target “Publics”

- The General Public/Community
- The Research Participants
- The Research Advocacy Community
- The Extramural Scientific Community
- The Intramural Scientific Community





Examples of Exportable Activities for the Extramural Science Community

- Outreach Notebook for the Inclusion, Recruitment, and Retention of Women and Minority Subjects in Clinical Research (ORWH)
- Short courses and Summer courses (e.g., NINR Summer Genetics Institute, NIGMS summer program for college students)
- Training for PIs and IRB members (NIEHS)
- Improved Informed Consent documents/procedures (e.g., NIDDK, NEI, NIDCD, NIAID/video)





Examples of Exportable Activities for Research Participants

- Consumer Advocates in Research and Related Activities (CARRA) program (NCI)
- Research Subject Advocacy Programs (e.g., NCRR, NIAMS health liaisons, NIDCR pt advocates forum, NHLBI's Baby Hug trial)
- Educational Materials (e.g., ClinicalTrials.gov)





Examples of Exportable Activities for the General Public

- Public Education Campaigns (e.g., NIMH/Real Men Real Depression, NHGRI/DNA Day, NICHD/Milk Matters, NINDS/Know Stroke, NIA/SeniorHealth)
- Health Fairs/Screenings/Traveling Exhibits (e.g., NEI's The Eye Site, NHLBI's The Heart Truth, NIMH's Brain)
- Medicine for the Public (CC lecture series since 1978)





NIH Public Trust Initiative

RFA-RM-06-002 Institutional Clinical and Translational Science Award

“The importance of overcoming the barriers to and enhancing the opportunities for public trust and participation in clinical and translational research cannot be overemphasized. The NIH's Council of Public Representatives recently explored ways to foster community involvement in clinical research and reported their recommendations

http://copr.nih.gov/reports/October_2004_COPR_WORKSHOP_Proceedings.pdf.”





Engaging the Public in Clinical Research is a Priority



Enhanced access to credible health information is key to this process.





Health Disparities and the NIH Public Trust Initiative

American Indians and Alaska Natives have disproportionately high prevalence of the following conditions and risk factors:

- Mental health
- Diabetes
- Obesity
- Substance abuse
- Sudden Infant Death Syndrome (SIDS)





Native American and Alaska Native Health and the NIH Public Trust Initiative

Ten Leading Causes of Death in the U. S. for American Indians and Alaska Natives:

1. Heart disease
2. Cancer
3. Unintentional injuries
4. Diabetes
5. Stroke
6. Chronic liver disease
and cirrhosis
7. Chronic lower
respiratory disease
8. Suicide
9. Influenza and
pneumonia
10. Homicide





NIH Alaska Native Outreach Effort February 2005

- IC Directors responded to invitations from the Southcentral Foundation (major Alaska Native health care provider) and former COPR member Dr. Ted Mala, to participate in their upcoming health fair in Anchorage and to visit some villages
- A delegation of public liaison officers and others from NIH, representing nearly half the ICs participated





NIH Alaska Native Outreach Effort February 2005

Purpose

To better understand the culture and health care delivery system for Alaska Natives, and to build stronger bridges for carrying out research activities





NIH Alaska Native Outreach Effort

What we learned:

- How health care is delivered in Alaska, through meetings with hospital administrators, telehealth experts, and tribal leaders.
- The challenges of providing health care and conducting research in a largely rural, highly dispersed population.
- How traditional and complementary medicine may blend with westernized medical care.





NIH Alaska Native Outreach Effort

What we shared:

- The wide range of health careers (OSE's Lifeworks) and training opportunities available.
- Dissemination of our research-based health information through the SCF Health Fair, elementary through high school classes, and seminars for health professionals and educators.
- Tailored science education, NIH 101 and other training programs





NIH Public Trust Initiative

Next Steps

- Conduct smaller scale outreach efforts modeled after parts of the Alaska trip
- Identify incentives for ICs to adapt/adopt activities successful in other ICs
- Present to scientific directors, EPMC, clinical directors, IC Councils



NIH Public Trust Initiative

Next Steps (cont.)

- Put exhibits around campus
- Emphasize public trust issues at all NIH events for the public and festivals
- Create a set of slides for all to use when 'on the road'





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Next Steps (cont.)

- Showcase activities, including community initiated, on the website on a rotating basis
- Write articles/showcase activities for the NIH Record, Catalyst, DDIR Bulletin Board, and offer to ICs for their e-newsletters
- Further encourage inclusion of communities in grant awards





NIH Public Trust Web Site

The screenshot shows the NIH Public Trust website homepage. At the top, there is a red banner with the NIH logo on the left and the text "Public Trust" in a large, white, serif font on the right. Below the banner is a navigation menu on the left side with links: Home, Our Mission, Steering & Liaison, NIH Council of Public Reps, NIH Activities, NIH Resources (highlighted in yellow), NIH Roadmap, FOIA, and Get Involved at NIH. The main content area is white and contains a "Welcome" section. It features a small image of a person's face and a paragraph of text: "Welcome to the National Institutes of Health's Public Trust Initiative web site! We hope that this will be a dynamic site, one to which you will return often." Below this is another paragraph: "In the spring of 2004, Dr. Elias Zerhouni, Director of the NIH, announced the establishment of the NIH Public Trust Initiative. As reflected in our mission statement, he stated that his goal is to 'improve the public's health through promotion of activities and attitudes that will instill confidence in what we do as a premier biomedical and behavioral research enterprise.' We were honored that he asked us to co-chair this exciting effort." This paragraph is accompanied by a small image of a group of people. The next paragraph states: "We have already discovered that there are many activities of interest throughout NIH, and expect to publish soon an inventory of those activities. In the meantime, we are working with representatives from each of the 27 Institutes and Centers to determine which activities might successfully be replicated across the NIH, and to develop a five-year plan for enhancing and maintaining the public's trust. A key component of that planning process is the list of recommendations developed during a major meeting held in October 2004 that was convened by Dr. Zerhouni's Council of Public Representatives." This paragraph is also accompanied by a small image of a group of people. The final paragraph in the main content area reads: "As you can imagine, NIH has many 'publics.' But no matter whether you are interested for yourself or a family member, an advocate or policymaker, or a grantee or member of the scientific community, we welcome your thoughts and input. If you have any issues of concern related to the public trust that would benefit from being addressed by the Initiative, please let us know." Below this is a line of text: "We look forward to our partnership!" followed by the names "Patricia A. Grady, PhD, RN, FAAN" and "Yvonne T. Maddox, PhD" in bold. At the bottom of the main content area, there are links for "Contact Us", "Privacy Notice", "Disclaimer", and "Accessibility". The footer of the website contains three logos: the NIH logo, the Department of Health and Human Services (DHHS) logo, and the "FIRST GOV" logo with the tagline "The First Click to the U.S. Government".

<http://publictrust.nih.gov>

