

---

# Hawai'i's Role to Increase Public Participation in Health Research

Marjorie K. Mau MD, MS; and Douglas Yee

(on behalf of all Council of Public Representatives members and alumni)

## Introduction

The idea of public participation in the biomedical, behavioral and clinical research enterprise has gained new recognition throughout the United States and is most visibly evident at the National Institutes of Health (NIH) through the Council of Public Representatives (COPR). The COPR has been in existence since 1999 and was established to serve as an advisory council to the Director of NIH on the public's perspective on health research and its contributions to improving the public's health. As such, the COPR has had a significant role in advising the Director of NIH, Dr. Elias Zerhouni, on engaging the public and to develop and foster the public's trust in NIH's mission and vision. The COPR is comprised of a diverse group of individuals from across the United States and its affiliated territories that are charged with bringing to light the perspectives and concerns from this diverse public to bear on NIH's research enterprise.

The State of Hawai'i is fortunate to have had two members appointed to the COPR, Mr. Douglas Yee (1999-2003) and Dr. Marjorie Mau (2005-2008). Both Hawai'i residents have served on the COPR under the directorship of Dr. Elias Zerhouni, who is credited with transforming NIH's long term mission into a stronger integration of its 27 Institutes and Centers via the NIH Roadmap. Hawai'i representation on COPR allowed for heightened awareness of the public health and scientific research needs of the Pacific region on a national level. It is this unique contribution to NIH and to the relevant needs of the collective communities in Hawai'i and the Pacific region that provided insight to many NIH leaders and policy makers. Over time, the changes at NIH that have included COPR's input and recommendations have provided for a new concept of how public participation is not only relevant but necessary to advance scientific research to eliminate health disparities and other emerging health issues in the native populations of the Pacific region.

The purpose of this article is to share the collective wisdom of the Council of Public Representatives and to stimulate others in the community to be participatory in the United State's premier health research institution, the National Institutes of Health.

## The Future is Now: Enhancing the Role of the Public in Medical Research

The National Institutes of Health is a demonstrated leader of medical research in the United States. Over the past half-century, the NIH's sustained efforts have produced remarkable gains for Americans. This publicly funded research has led to significant declines in heart disease, reduced incidence of many types of cancer, and numerous advances to combat infectious diseases like HIV/AIDS, tuberculosis,

and many others. Coupled with better living conditions, education, and nutritional quality, along with improved hygiene, these research activities have nearly doubled the human lifespan since the turn of the 20th century.

This success, however, has brought challenges. With the precipitous drop in acute disease has come a rise in chronic, long-term illness that strains the populace and economy. Even more troubling is that the nation's chronic disease burden is not uniformly distributed, and health disparities remain a vexing problem. The entire health care community recognizes that new and continued efforts are needed to correct this imbalance. Now, more than ever, it is important that the public play an active role in medical research. At this time, stronger, not weaker connections between the public and medical research are vital to progress.

## COPR: NIH's Public Voice

The NIH Council of Public Representatives (COPR) was established following the 1998 Institute of Medicine report *Scientific Opportunities and Public Needs*.<sup>1</sup> COPR was created to provide a vehicle for greater interaction among the NIH, its leadership, and the general public. As America's voice to and from the NIH, COPR members play a key role in engaging the public in research.

COPR is a diverse group of 25 people from across the country who have been chosen, through an open application process, to represent the public. They are patients, family members of patients, science and health professionals, communicators, and educators. Representatives advise the NIH Director on an ongoing basis by bringing important matters of public interest to NIH leadership, helping to increase public participation in NIH activities and initiatives, and working to advance public understanding of the NIH and its programs.

The COPR is attuned to current realities: escalating health care costs, an aging population, and many other complexities of modern society that create challenges to preserving the health of the nation. Dr. Elias Zerhouni, Director of the NIH, has posited that a more "*predictive, personalized, and preemptive*" form of medicine offers the best chance to alter the current practice of intervening very late in the course of a disease, when it is most expensive in financial and human costs. COPR endorsed this approach, but suggested a fourth "*p*:" *participatory*. Dr. Zerhouni has incorporated this concept into his vision for transforming medicine.

Realizing this vision calls for a coordinated effort from the government, the scientific community, the private sector, and the American public. To reach the goal of personalized, pre-emptive health,

Program	Features	More Information
Be Smart About Your Heart	NIH-ADA partnership promotes heart health for diabetics	www.ndep.nih.gov
Back to Sleep	Health campaign reduced sudden-infant deaths by more than 50 percent	www.nichd.nih.gov/sids/
CityLab Mobile Bus	Engages 7,000 students/year in hands-on biomedical research	www.bumc.bu.edu/citylab
NIDA Community-Based Centers	Educates new doctors to identify and treat addiction and substance abuse	www.drugabuse.gov/
Heart Truth	Health awareness campaign created the “Red Dress” national symbol	www.nhlbi.nih.gov/health/hearttruth/

*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

### Many Roles for the Public in Research

Public engagement in the research process can lead to beneficial outcomes in several ways. For one, an enhanced dialogue between patients, health-care providers, and researchers can help enable people to take charge of their own health: preventing illness, preserving quality of life, and conserving costs. Second, public involvement at many levels provides underrepresented populations a voice to inform priority-setting endeavors relevant to the broader health research agenda. Third, the public can enrich scientific endeavors by helping to bridge disciplines that do not typically interact and identify cultural and environmental variables that impact research results. Finally, public involvement in research is a critical link in the dissemination of research findings to policy and practice.

Because of creative and effective NIH-sponsored educational campaigns and outreach programs on health trends and diseases, Americans are better informed and empowered to make healthy choices. Successful integration of these programs into communities is a direct result of sustained public involvement (Table 1). Yet, more of these models of success are needed across a broader and more diverse American population to effectively eliminate health disparities.

As a society, Americans cannot rely on a simplistic strategy that assumes that if you tell people something is good for them, they will do it. Public engagement is more than “educating the public”, it is also empowering. Complex arrays of cultural and other influences contribute to views about research that go beyond understanding science. Public trust in research depends not only upon knowledge, but also on value systems.

Authentic public engagement requires a solid foundation of public trust, and it needs to be earned and nurtured. Any erosion of public trust can have untoward, multidimensional consequences that impact not only the advancement of health, but also society at large.

With careful planning, public involvement in research can be very successful (Table 2). One common thread for success is open communication between researchers, health care providers, patients, and public participants.

Program	Features	More Information
Healthy Vision Community Award Program	Gives seed money for community-based health education programs	www.healthyvision2010.org/
NIAMS Health Partnership Program	Fully engages community in rheumatology research planning and implementation	www.niams.nih.gov/hi/outreach/hpp/chcfact.htm
African American Hereditary Prostate Cancer Study Network	Involves collaborative recruitment centers in seven major urban areas	www.genome.gov/10002040
HIV Vaccination Trial Network	International collaboration of scientists and educators searching for an effective and safe HIV vaccine	www.hvtn.org/
We Can!	Partnership of 154 community sites helping children achieve a healthy weight	wecan.nhlbi.nih.gov
Example of Community Engagement in Hawai'i		
Center of Native and Pacific Health Disparities Research at UH-JABSOM	Partnership of 22 community organizations at 50 sites (Ulu Network) throughout the State of Hawaii, new partnerships (2007) with Anchorage, AK and Los Angeles, CA to conduct research studies, research training and community dissemination aimed at eliminating health disparities in Native Hawaiian, Alaska Native, Pacific Islander and other health disparate communities in the Pacific.	www.hawaiiexportcenter.hawaii.edu

quicker, more reliable ways are needed for discoveries to become practical and effective prevention strategies and treatments in children and adults. For that, the role of the public in medical research is paramount. Better understanding and increased involvement also enhances the public’s trust in research.

However, 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 endorses this position and highly values public involvement in research. Their current efforts aim to increase awareness and promote action.

## A Voice for Change

The COPR believes a fundamental change in the current medical research paradigm is needed to more firmly conceptualize the public as a true partner in the continuum of research. The benefits of broader community involvement can be far-reaching, providing opportunities for co-leadership, greater availability of resources, enhancement of recruitment, and the development of culturally relevant research instruments. Over time, effective public-researcher partnerships can promote and sustain increased understanding about the context of science in society for all parties.

To accomplish more widespread knowledge and endorsement of increased public participation in research, it is important to develop robust lines of communication and keep them open. The cultural shift promoting greater data sharing and openness currently underway within the scientific community may facilitate progress, although public wariness about sharing personal information is a persistent concern requiring attention. Efforts to identify the benefits, costs, goals, and outcomes of research help non-scientists develop an awareness of and appreciation for medical studies. Thoughtful and transparent communication can also address misconceptions about research.

The scientific benefits of participatory research should be communicated widely. For example, with increased knowledge of culturally appropriate methodologies, scientific investigators may be able to increase the validity of their findings.

The COPR and others recognize that changes cannot take place overnight and that not all research studies will benefit to the same degree from active public engagement. However, an effective framework for change must be multifaceted and should target the public, government agencies, and academia. Now is the time for a philosophical paradigm shift in research towards a larger role for the public.

Academia is the linchpin of this framework. The scientific community must evolve to understand and appreciate the added value of a broader role of the public in medical research. This can only occur if institutional leadership legitimizes and rewards community engagement efforts conducted by investigators.

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 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

- Offer incentives
- Identify evidence-based practices to involve communities
- Develop ways to measure efficacy of public participation
- Build effective collaborations and partnerships
- 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
- Promote stakeholder outreach: professional organizations, academic leadership, study sections, Institutional Review Boards

## The Future is Now

The 21st century is an exciting time for medical research—one that holds the promise of achieving predictive, personalized, pre-emptive—and participatory health. Increased understanding of complex interactions between the human body, the environment, and sociological influences will identify strategies to detect disease early and help diminish health disparities. Finding genetic factors that raise chronic disease risk from exposure to environmental toxins offers an opportunity to predict disease before it strikes. In addition, a greater understanding of genetics and of behavioral influences, like stress, has the potential to further improve quality of life.

Yet research does not automatically find its way to application. Several new NIH programs that facilitate participatory research are a good start. The NIH Roadmap for Medical Research, through the Clinical and Translational Science Award initiative, encourages medical schools to team with community-based physicians.<sup>2</sup> Information technology tools currently under development promise to connect researchers, healthcare providers, and patients in unprecedented, efficient ways. It is hoped that these opportunities for connectedness will be endorsed, encouraged, and widely adopted.

Is there a meaningful role for the public in biomedical and behavioral research? As the public voice of the NIH, the COPR offers a resounding “yes.” The public and research communities will be vital partners in 21st century medicine and health. As patients, scientists, decision-makers—we are all stakeholders in our health. It is important that we get involved and work together.

<http://getinvolved.nih.gov/>

## The NIH Council of Public Representatives

Syed M. Ahmed, Wisconsin; James J. Armstrong, Ohio; Craig T. Beam, California; Ruth C. Browne, New York; Barbara D. Butler, Missouri; Wendy Chaite, New York; Christina Clark, Michigan; Naomi Cottoms, Arkansas; Linda Crew, South Carolina; Frances J. Dunston, Georgia; Valda Boyd Ford, Nebraska; Elmer R. Freeman, Massachusetts; Elizabeth Furlong, Nebraska; Robert Michael Hill, Florida; Brent Jaquet, Washington, DC; Nicole Johnson, Pennsylvania; James Kearns, California; Nicolas Linares-Orama, Puerto Rico; Cynthia A. Lindquist, North Dakota; Michael Manganiello, Washington, DC; Marjorie K. Mau, Hawaii; Matthew Margo, New York; Anne Munoz-Furlong, Virginia; Ann-Gel S. Palermo, New York; and James H. Wendorf, New Jersey.

## References

1. Institute of Medicine report, Scientific Opportunities and Public Needs. *National Academies Press* 1998. Accessed 5/10/07 at: <http://books.nap.edu/html/nih/>
2. Zerhouni EA. Translational Research: Moving Discovery to Practice. *Clin Pharmacol Ther* 2007. 81:126–8