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NIH SEEKS MORE PUBLIC INPUT

Newly established Council of Public Representatives will advise agency on priority setting, other issues

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The National Institutes of Health [Council of Public Representatives](#) (COPR) met for the first time recently on NIH's Bethesda, Md., campus. The council was established by NIH Director Harold E. Varmus as a forum for discussing issues affecting the development of NIH policy and research programs. It was created to provide advice and recommendations to the NIH director regarding matters related to research, NIH policies, and public participation in agency activities.

COPR (pronounced "copper") was set up in response to a July 1998 report from the [Institute of Medicine](#) (IOM), called "Scientific Opportunities and Public Needs," that said NIH should seek broader public input on decisions about how to spend its nearly \$14 billion budget (in fiscal 1998) (C&EN, July 13, 1998, page 13). Its 20 members were selected from a pool of about 250 applicants. Most of those not selected will be "COPR associates" and may be called on to serve on the council in the future. They also may serve on other NIH advisory committees.

**Varmus**

At the meeting, Varmus, who chairs the council, gave COPR members some history behind the need to share details about NIH priority setting with the public. "About two or three years ago," he said, "as NIH budgetary fortunes began to accrue, especially in contrast to other government agencies that were seeing their budgets flat line or even decrease . . . there was increased interest in how NIH--the lucky guys--were spending their money." A series of appropriations hearings outlined the complex process, and NIH put together a priority-setting handbook. In 1998, the Labor, Health & Human Services, and Education appropriations bill--which provides NIH's funds--requested the IOM study.

After the study was completed, a group of advisers to NIH convened last September to help Varmus determine how to set up the public council, and a notice was published in the *Federal Register*, calling for members.

According to Varmus, the role of COPR is twofold: to bring NIH to the public by transmitting the agency's views and aspirations, and to bring public views to NIH by advising the agency on actions and activities. He said some of the goals of the council are to describe the virtues and deficiencies of NIH, to look at how the individual institutes and centers oversee research, and to help with accountability. COPR members will serve three-year terms, and about one-third of the members will be new to the council each year.

The COPR members represent a range of cultural, geographic, age, and professional diversity. Most have had experience with disease conditions and NIH research and clinical trials either through family connections, work with advocacy groups, professional roles, or personal experiences. Included on the panel are a doctor who works as a television journalist, a neuroscience researcher who is involved in community outreach health programs, a champion tandem bicycle racer who lost her vision as a result of diabetes, and a graduate student in law and public health who has cystic fibrosis.

Varmus said several criteria were set for selecting COPR members. These were an interest in NIH, the ability to communicate effectively, the ability to consider broad issues and go beyond personal interests, the ability to contribute to a group process, leadership skills, the ability to express the public view, and analytical skills.

At the meeting, directors of four institutes talked about what the individual centers at NIH are doing to bring word of their activities to the public. The directors represented the National Institute on Deafness & Other Communication Disorders, the National Institute of Neurological Disorders & Stroke, the National Institute of Arthritis & Musculoskeletal & Skin Diseases, and the National Heart, Lung & Blood Institute. Varmus said he'd like the directors of all 25 institutes and centers to speak at COPR meetings on a rotating basis so that over their three-year terms, the members will hear the "complete repertoire" of what the institutes do.

The meeting covered several topics of interest to COPR members and the public as a whole. Considerable time was devoted to discussion of clinical trials and the establishment of the NIH Clinical Trials Database, which will be available on the Internet and through a toll-free telephone number. According to Alexa McCray, director for the [Lister Hill National Center for Biomedical Communications](#) at the National Library of Medicine, a prototype system will be ready for focused testing by summer and the first public version should be available by the end of the year. The database will be enhanced throughout 2000 with the addition of information from other agencies and the private sector.

The database is required by the [Food & Drug Modernization Act of 1997](#) and applies to all new drug applications and experimental trials. One of its roles will be to link patients with information about what trials are going on, the requirements for participating in those trials, and contact information to learn more. Varmus pointed out that clinical trials are an important point of public interface for NIH, because they allow people to get involved in and learn about the types of research that the agency is doing.

Another topic discussed at the meeting was health disparities--the differences in the quality of health care for different socioeconomic groups. Varmus said that although most issues of disparities concern minorities, education levels, age, and living in urban versus rural areas also are important factors. Concentrating on health disparities is a major focus of Department of Health & Human Services Secretary Donna E. Shalala.

Sidebar: [Offices of Public Liaison help NIH reach constituents](#)

Varmus said he wants COPR members to evaluate NIH programs and judge whether appropriate actions to address this issue are being taken.

In addition to the twice-a-year COPR meetings, council members will be getting involved in myriad other activities at NIH. These additional roles could include serving on review committees for intramural research programs, being involved in retreats for planning of future agency budgets, participating in town meetings, and helping with reviews of individual institute directors and reviews required by the Government Performance & Results Act.

Varmus mentioned several areas that he'd like to cover at the next COPR meeting, which likely will be held in October. These include discussions of training and recruitment of NIH researchers, issues related to informed consent and patient protection, complementary and alternative medicine, and topics related to the Human Genome Project. He also said he would like COPR members who participate in other roles at NIH to follow up with the group on the activities with which they have been involved. ▶

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