



DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

September 23, 1998 Meeting Minutes

COPR PLANNING MEETING SUMMARY: ENHANCING PUBLIC PARTICIPATION IN NIH ACTIVITIES

Prepared October 8, 1998

On September 23, 1998, Dr. Harold Varmus, NIH Director, held a special meeting on enhancing public participation in NIH activities. Dr. Varmus began the meeting by welcoming the invited participants and those watching. He gave a brief introduction to the NIH—the agency's history, mission, and role. The participants then introduced themselves and explained their interests in NIH and in attending the meeting. Dr. Varmus commented on several issues that arose during the participant introductions, including the notion of what "public" means to NIH, the role of the Office of the Director vis-a-vis the Institutes and Centers (IC), and accountability in funding. To provide context for the discussions to come, Dr. Varmus made a presentation on how NIH works, particularly the functions of the Office of the Director in such areas as budget formulation, management of the enterprise, and research coordination.

After additional brief presentations that provided background information as to how the agency currently communicates with the public, and some of its current opportunities for public involvement, the participants broadly discussed the future activities and responsibilities of the proposed NIH Director's Council of Public Representatives and the NIH Offices of Public Liaison. These initiatives were recommendations number seven and eight of the IOM report, *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health*. Twenty-three individuals that were invited by Dr. Varmus—selected to represent a broad spectrum of NIH's constituencies—attended the meeting to express their views on matters relating to the topics below.

Director's Council of Public Representatives (COPR)

- What should be the responsibilities and activities of the COPR?
- What is the role of this COPR as compared to the role of other NIH Advisory Councils?
- Describe some activities that could be undertaken by the COPR to strengthen public participation.
- What processes, mechanisms, and criteria should be used for identifying appropriate candidates to serve on the COPR?

The issue of NIH's accountability to the public was a central focus of the discussion. The ideas of what that term encompasses ranged from accountability as to how resources are being used to accountability for getting information to, and communicating with, the public on health matters. Aside from the question of whether two councils for the NIH Director (the COPR and the Advisory Council to the Director) might overlap, thus diminishing the credibility of both, these ideas of accountability seemed to lead to two separate concepts for the COPR.

The first concept is that of an advisory council that would bring information to NIH through information gathering. In this model the advisory council would review NIH priorities, IC responses to public input, and help NIH gather public input to bring the voice of the public to NIH decision-making. The second concept is that of an advisory council that would help bring information from NIH to the public by helping to communicate NIH procedures, making research and the role of NIH more understandable to the public. The advisory council would help the NIH communicate what research has been done, in the historical sense, and what can be done in the future.

These models can also be seen as reflecting the extremes of the dual relationship/role that the participants saw as being inherent in the COPR—serving the needs of the NIH Director and serving the needs of the public it represents. The discussion raised a central question which remained open: is the COPR one thing or many things?

The participants noted that the criteria for choosing members of the COPR would depend on the model chosen, or a hybrid of the two. The submission of applications and nominations was discussed as the means of creating a pool of individuals from which to select members. Suggested criteria included: diversity; geographic representation; broad representation of NIH constituencies, including the media; analytic ability; an understanding of science; the ability to think broadly; an understanding of the public view; an interest or stake in the issue; experience in community education/outreach; sufficient knowledge of science or research related experience; the ability to disseminate information. Whatever criteria were chosen, both the individuals making up the pool and the individuals selecting them should have high credibility.

It was agreed that there be no more than 20 members on the COPR to ensure that it operates effectively. The participants noted that the final selection of the members should be carried out by the NIH Director, and that the Director should reserve the right to reach out to individuals to serve on the COPR as necessary.

The NIH Offices of Public Liaison (OPLs)

- What should be the responsibilities and activities of the OPLs?
- Should all Institute-level OPLs perform the same activities?

- How should the activities of the Office of the Director's (OD) OPL differ from those of the IC-level OPLs?
- How should NIH make the existence of the OPLs known and to whom?
- How should the OPLs draw in the public?
- What programs and activities should the OPLs consider that have been particularly successful in providing public viewpoints to the NIH?

The discussion started by using the functions suggested in the IOM report as a base for all OPLs: serving as a contact point for the public; serving as a place Congress can refer its constituents; conducting outreach to constituency groups. The participants noted that referrals from Congress could be difficult for IC OPLs to handle as these contacts are usually requests for detailed information on specific diseases—such information may cut across several ICs.

While the participants had some difficulties in suggesting additional activities, there were several. These included using the OPLs as educational tools, using the OPLs to conduct the outreach function of the COPR, and using the OPLs to identify issues of concern to public and bring them to the COPR. In addition, the OD OPL would share important basic cross-cutting information and best practices among the ICs. The OD OPL would staff the COPR and evaluate NIH performance in outreach/liaison.

Dr. Varmus ended the meeting by thanking the participants for providing their recommendations to the NIH. He noted that the discussion would continue and that NIH would accept additional comments from the invited participants and other members of the public.

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