

## Guided Plan for a Series of Forums between Genetic Researchers and Community Organizations

This plan outlines a series of forums designed to stimulate dialogue between genetic researchers and community organizations on the benefits and risks of genetic research in racial and ethnic communities, as well as on potential strategies for consultation and collaboration between researchers and community organizations. The National Institutes of Health (NIH), in its “Points to Consider When Planning a Genetic Study That Involves Members of Named Populations,” has recognized the need for such a dialogue to enable scientists and community members to share each other’s understandings of the methods and goals of genetic research, the social risks involved, and the importance of community consultation and informed consent. This guided plan for facilitating that dialogue is part of an NIH-funded study researching how genetic researchers and community organizations conceive of and negotiate positions on genetic research within racial and ethnic communities.

Community organizations represent a crucial interface in this dialogue between genetic researchers and members of racial and ethnic communities. Because they often hold in-depth knowledge about the needs, values, and concerns of the communities they represent, community organizations offer genetic researchers a valuable partner in consulting community members, recruiting participants, and designing genetic studies. Because of their expertise and their respected standing, community organizations are also well situated to assist the communities they represent to better understand the goals and risks of genetic studies, as well as to manage the impact of new genetic knowledge that results from such studies. Genetic researchers are equally critical participants in this dialogue. They bring to the relationship a scientific expertise in genetics and disease that forms the basis for the structuring of genetic research. They design and direct genetic research, selecting and recruiting populations for study. As such, they occupy a strategic position for informing community organizations about research and for incorporating community concerns and recommendations into it. The forums aim to provide a venue for community organizations and genetic researchers to address concerns and needs related to their potential research collaborations.

Each of the four forums focuses on a specific aspect of the researcher-community organization collaboration, as outlined below. It is anticipated that each forum would last about two hours and would be conducted in roundtable fashion. The moderator would initially introduce the topic, following which all attendees would have an opportunity to make a brief presentation regarding their relevant experiences or concerns. Following this, the remainder of the forum would be dedicated to an open discussion of the topic. It is hoped that following the completion of the series attendees would participate in drafting recommendations for facilitating better researcher-community organization collaboration.

Prior to the forum all attendees should be provided with a copy of a booklet and a model curriculum prepared by the Center for the Study of Society and Medicine on genetic research in racial and ethnic communities. The booklet, directed toward community

organizations, and the curriculum, directed toward researchers, provide an overview to the topics to be discussed in the forums, as well as relevant case vignettes and readings. These materials are available to the public on the Center for the Study of Society and Medicine's website at <http://www.societyandmedicine.columbia.edu>.

## Forums

### **Forum 1: Communication of Risks and Benefits**

How do community organizations and researchers perceive the benefits and risks of genetic research? What problems have they found in communicating these perceptions to each other? What strategies have they tried? Have organizations sought to have their views of benefit and risk incorporated into the informed consent process in genetic research? How do organizations and researchers see the results of these efforts? What strategies might improve communication of benefits and risks?

### **Forum 2: Privacy and Confidentiality**

How do genetic researchers view issues relating to privacy and confidentiality? What types of concerns have they dealt with and in what ways have they dealt with them? Which privacy and confidentiality issues most concern community organizations? How have they dealt with these concerns? Do communities as a whole have a right to privacy and confidentiality? If so, what is the nature of that right and how might it be protected?

### **Forum 3: Discrimination and Stigma**

How do organizations and researchers view the implications of genetic research for engendering racial or ethnic discrimination in insurance, the workplace, or other social institutions? How might these issues be dealt with so as to minimize negative consequences to communities? Are researchers or organizations concerned about the possible consequences of genetic research for the public perceptions of communities? How do the two groups balance these concerns with the advantages they perceive of participating in genetic research?

### **Forum 4: Community Consultation**

How do organizations and researchers view the need for community involvement in population-based genetic research? Who speaks for a community? What strategies can be devised to create a researcher/community partnership that will enhance the research? How can communities contribute from the inception to the definition of a project's goals and methods? What inputs can communities have at later stages in the research process? What can communities expect in return for participation?