Community Organization Booklet

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I. Introduction

Over the past decade genetic research on disease susceptibility, drug response, and evolutionary history, has increasingly involved racial and ethnic groups, even as the use of racial and ethnic categories in biomedical research has become more controversial. These developments have led the National Institutes of Health (NIH) and other medical and scientific organizations to call for better communication between investigators and racial and ethnic communities so as to enable them 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. In its “Points to Consider When Planning a Genetic Study That Involves Members of Named Populations” the NIH recommends that investigators planning research on racial and ethnic populations conduct community consultations prior to initiating their studies.

Community organizations have an important role to play in facilitating communication between investigators and racial and ethnic communities. Community organizations hold in-depth knowledge about the needs, values, and concerns of the communities they represent. Because of this knowledge, community organizations offer genetic researchers a valuable partner in consulting with community members, recruiting participants, and designing genetic studies. Because of their expertise and their respected standing, community organizations are also well positioned to assist the communities they represent to better understand the goals and risks of genetic studies, as well as manage the impact of new genetic knowledge that may result.

This online booklet provides information about the methods, goals, risks, and benefits of genetic research as well as the procedures and information relevant to
participating in studies and managing their outcomes. The information provided in this booklet is informed by interviews with genetic researchers and community organizations as well as supplemental research, all of which were part of a study funded by the Ethical, Legal and Social Implications (ELSI) Research Program at the National Human Genome Research Institute and conducted by the Center for the Study of Society and Medicine at the Columbia University College of Physicians and Surgeons. Each unit in the booklet is accompanied by a list of relevant readings. Where appropriate, further readings are listed as well. In general, the readings are directed toward a lay audience while the further readings are written for those with more than a basic understanding of human genetics.