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The National Institutes of Health Announces Online Availability of "Points to Consider When Planning a Genetic Study That Involves Members of Named Populations"

To the Editor:

The National Institutes of Health (NIH) has developed a guide for researchers, called "Points to Consider When Planning a Genetic Study That Involves Members of Named Populations." The NIH supports and encourages the concept and process of community consultation in many research areas and believes that investigators who are planning genetic-research projects involving members of named populations should consider whether and how those communities should be consulted. The new "Points to Consider" document describes what is meant by "community consultation"; presents situations in which community consultation should be considered; identifies potential benefits, both for researchers and for communities, that engagement in this process offers; and provides practical examples of how to plan a community consultation. The "Points to Consider" document is posted on the NIH Web site, at the URL given below.

It is increasingly important for researchers to realize that nonscientists may not be well versed in the scientific benefits resulting from genetics research. Individuals and the communities to which they belong may fear that participation in genetic studies involving named populations may end up stereotyping that particular named population, potentially putting the entire community at risk of discrimination by insurers or other third parties. In creating the "Points to Consider" document, the NIH aims to assist scientists in the design of studies that operate in variable social and cultural contexts and that yield meaningful data while they work with communities.

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Electronic-Database Information

The URL for data in this letter is as follows:

Points to Consider When Planning a Genetic Study That Involves Members of Named Populations, http://www.nih.gov/sigs/bioethics/named_populations.html

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