IV. Benefits and Risks of Participating in Genetic Research Involving Racial and Ethnic Groups

Participating in genetic research can offer a range of medical and non-medical benefits to individual participants, their families, and the group as a whole. For individual participants studies may provide therapeutic treatments as well as more general health care services. Some studies may also provide participants with genetic information, such as the presence of a gene mutation. However, this will not always be possible. Some genetic studies require that DNA samples be stripped of all corresponding personal information or that results be kept from participants. Where genetic information is provided, studies often employ personnel to assist participants and their families in understanding the medical and psychological implications of this information.

For a racial or ethnic community more broadly, participation in genetic research can lead to improved health for all of its members. Research that identifies a disease gene or a disease-susceptibility gene or produces findings about the characteristics of such genes may provide the basis for future diagnostic and therapeutic advancements. Genetic tests for recessive single-gene disorders, such as sickle cell disease, can be used either prenatally or postnatally to identify individuals with the disorder and help prospective parents make informed decisions about childbearing. For adult onset diseases, such as breast cancer, genetic tests can be used to identify high risk individuals within a population so that those individuals can make appropriate lifestyle and medical changes to lower their risk. In some cases, knowledge of genetic risk may also enable individuals to undergo preventative treatments, such as surgery and drug therapy. For
instance, both mastectomy and the use of the drug Tamoxifen have been shown in studies to reduce the risk of breast cancer in women who carry a genetic mutation. In cases where a racial or ethnic group is found to carry only certain specific mutations in a disease-susceptibility gene, diagnostic tests may be developed that are more effective and less expensive than those available for the general population. For instance, because the majority of Ashkenazi Jewish women with a BRCA1 or BRCA2 gene mutation carry one of three mutations common in the group, researchers have been able to develop a diagnostic test specifically for those three mutations which is significantly less expensive than other BRCA1/2 tests. Some genetic studies may also offer communities more general medical benefits. For instance, as part of a long-term genetic project on diabetes in the Pima Indians of Arizona the National Institutes of Health has established a series of comprehensive health clinics on the Pima reservation. Opportunities for local employment and education may also accompany genetic studies. In fact, some Native American tribes have begun to require that researchers, when feasible, hire tribe members for supporting positions.

Genetic research does not always lead to timely benefits, however. Many studies yield basic knowledge that cannot be directly translated into therapeutic advancements. Such advancements often require the alignment of new knowledge and technology from a number of different scientific fields. Furthermore, it often takes multiple studies to confirm the accuracy of a genetic finding. It is not uncommon for genes linked to a disease in one study to be found in subsequent studies to have a lesser effect or none at all. A recent review of past association studies found that a low percentage (33%) of
genes initially linked to a disease were subsequently confirmed to affect risk for the
disease.

Participation in genetic research can also pose certain risks to both individual
participants and to racial and ethnic groups as a whole. In rare instances, there may be a
risk of physical harm to participants. In addition, some genetic studies can pose
psychological or psychosocial risks to participants. Research may yield personal
information regarding disease and disability risks, susceptibility to toxins, paternity, and
ancestry. Especially given the familial nature of this information, it may create anxiety,
depression, and guilt, as well as disrupt family and community relationships. This
genetic information also may be of interest to a wide range of individuals and
organizations, including family members, employers, insurers, courts, and the
government. If the information is disseminated, discrimination or other harm to research
participants might result. While reported cases of genetic discrimination have been
limited, they evince a willingness on the part of some employers and insurers to act upon
genetic information, often attributing to particular alleles a higher level of risk of disease
than might a scientist. Some commentators have stated that the perceived risk of genetic
discrimination among the public is significantly greater than the actual risk.

Nevertheless, the perceived risk of discrimination has its own effects and has been shown
to discourage individuals from seeking predictive genetic testing, as well as from
participating in genetic research. Several studies have found that members of racial and
ethnic groups with a history of exploitation by medical researchers are particularly
concerned about the risk of genetic discrimination.
Because both race/ethnicity and genetics are often imbued with exaggerated degrees of absolutism by the public, genetic findings that link a racial or ethnic population to a disease or disorder may stigmatize the group involved. Oversimplified presentations of genetic findings by the media can lead to incorrect understandings about a group’s overall fitness, intelligence, or behavior. Stigmatization can be particularly powerful when the presentation of genetic findings aligns with traditional stereotypes about a group. Research linking racial or ethnic groups to a disease or disorder may also result in discrimination against the group. Where genetic findings communicate the notion that a particular racial or ethnic group is at higher risk for a disease, an occupational injury, or a mental or behavioral disorder, there exists the possibility that insurers, employers or health care providers may decide it is in their best interests to implement policies pertaining to the group generally. Genetic research that offers conclusions about a group’s origins, ancestral composition, or genetic relation to other groups may also lead to cultural harm if those conclusions differ from those held by the group.

Federal regulations exist to help protect research participants. Researchers collecting genetic information may be subject to the confidentiality requirements of the Common Rule, which applies to federally funded research and to research under the auspices of institutions that have adopted the rule more broadly. In addition, some research projects are covered by privacy regulations issued under the Health Insurance Portability and Accountability Act (HIPAA). However, the Common Rule provides only a loose framework for regulation of confidentiality: “When appropriate, there are [to be] adequate provisions to protect the privacy of subjects and to maintain the confidentiality
of data.” In addition, the HIPAA regulations only cover researchers when they are seeking information from a health care provider or plan or when they themselves are providing health care. Most states have taken steps to provide enhanced protections for genetic information. However, states differ greatly in the amount of protection they provide. As a result, a number of racial and ethnic groups have expressed concern about the confidentiality of genetic information, advocating the implementation of additional protections including prohibiting the secondary use of genetic information and destroying samples at the conclusion of a study. Stored DNA samples present particular problems in that they are often attached to personal information, such as race and ethnicity. As a result, even if samples are stripped of personal identifiers, their use may still enable researchers to link findings to particular racial or ethnic groups.

Readings

The New Atlantis editorial (2003) discusses the promises and controversies of the Human Genome Project’s new “HapMap” endeavor, including its implications for the scientific validity of race.

The New Atlantis editorial (2005) looks at the use of DNA databases in law enforcement in terms of privacy, civil liberties, and racial profiling.

UNESCO (1995) provides an overview and recommendations for involving different racial and ethnic groups in genetic research.


Further Readings

Brunger (2003) and Nicholas (2001) discuss the ethical considerations of class and gender inequalities in community-researcher collaborations.

Davis (2000) compares efforts to involve different racial and ethnic groups in genetic research.

Galarneau (2002) examines how the characteristics of different groups affect their health care priorities.

Kone et al (2000) review different community-research collaborations in the Seattle area.

Sude and Hager (2003) discuss how community structure affected community involvement in the International HapMap Study.