

**An Online Curriculum for Ethical, Social, and Legal Issues Related to Genetic
Research on Racial and Ethnic Groups**

(Draft: Not for Duplication)

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Over the past decade, genetic research on disease susceptibility, drug response, and evolutionary history, has increasingly involved racial and ethnic groups, even as racial and ethnic categories in biomedical research have 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 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.

This syllabus offers a comprehensive overview of the issues that scientists face in communicating and collaborating with racial and ethnic groups in genetic research. The information provided originates in interviews with genetic researchers and community organizations, along with supplemental research, which were part of an NIH-funded study conducted by the Center for the Study of Society and Medicine at the Columbia University College of Physicians and Surgeons.

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Section 1: Introduction to Genetic Research on Racial and Ethnic Groups

I. The History of Race/Ethnicity in Medical Research

Pre-World War II: Throughout the 19th and early 20th centuries scientists widely understood race to represent objective biological divisions of humanity. (Ethnic groups were viewed either as racial groups in and of themselves or as racial sub-groups). Race was both essentialist and hierarchical with racial groups believed to display measurable physiological, behavioral, and intellectual differences. Seen in this manner, racial differences had obvious implications for health and many physician researchers of the era sought associations between racial groups and disease susceptibility, occupational injuries, and hygiene. When federal and state health departments began to collect health statistics in the early 1900s it went unquestioned that data should be divided by racial categories. The use of race in early medical research often drew heavily on social assumptions of racial superiority and fears of immigrant populations, and many prominent physicians used such research to provide scientific support for segregation and eugenics policies, both in the United States and abroad.

Byrd and Clayton 1992 (pp. 189-200) and Haller 1970 (pp. 154-167) provide an overview of 19th and early 20th century scientists' views and use of race.

Krieger and Fee 1996 (pp. 391-418) discuss the ways in which racial and ethnic categories were applied in the efforts to collect health data.

McBride 1991 (pp. 9-68) writes on how early 20th century physicians linked race and disease contagion in order to facilitate segregation.

Provine 1973 (pp. 790-796) and Sofair and Kaldjian 2000 (pp. 312-319) provide an overview of the effect of early 20th century views of race on the development of eugenics policies.

The Rise of Population Genetics: In the years following World War II, leading scientists from the fields of evolutionary biology, population genetics, and physical anthropology publicly disavowed the biological validity of race as previously understood. In its place they advanced the concept of the population as a more accurate representation of how genetic diversity was structured within the human population. However, the degree to which human populations might themselves constitute taxonomic races or how closely they overlapped with traditional racial categories remained contested. During the same period, the concept of ethnicity emerged as an increasingly popular alternative to race, especially among social scientists, because of its emphasis on cultural criteria. In medical research, however, race, as well as ethnicity, continued to be used largely as biological variables and the premise that racial and ethnic groups displayed meaningful biological differences in terms of disease susceptibility, hormone production, and drug response remained the subject of substantial research. Growing research in the 1960s and 1970s on hereditary genetic diseases, such as sickle cell disease and Tay-Sachs disease, occurring in specific racial and ethnic groups, further supported the medical importance of race and ethnicity.

Dobzhansky 1951 (pp. 264-266) and Cavalli-Sforza 1966 (pp. 362-379) provide representative scientific arguments for the replacement of race with population.

Reardon 2005 (pp. 17-73) and Marks 2000 (pp. 241-249) provide an overview of the emergence of population genetics and the new discipline's claims about race and human genetic diversity.

Montagu 1962 (pp. 919-928) presents an early call for the use of ethnicity instead of race in science.

Oppenheimer 2001 (pp. 1049-1055) examines current debates surrounding the use of ethnicity versus race in medical research.
 Damon 1969 (pp. 69-80) argues for a continued biological view of race and ethnicity in medical research.

II. Racial and Ethnic Groups and Human Genetic Variation

In-Group Variation is Greater than Between-Group Variation: In a 1972 paper, the geneticist Richard Lewontin reported that the majority of human genetic variation (~85%) occurred within a given population opposed to between populations. In line with these findings, Lewontin and others have argued that racial categories have little biological validity as 1) between group genetic variation represents little of the total genetic variation between any two individuals and 2) racial categories correspond poorly to underlying patterns of human genetic diversity. This position was bolstered in 1999 when the Human Genome Project published findings that 99.9% of all genetic material is shared among all individuals. However, recently some geneticists have argued against Lewontin's conclusions, claiming that his methodology misconstrued genetic differences that do exist along racial classifications.

Lewontin 1972 (pp. 381-398) presents findings on human genetic variation.
 Cooper 1984 (pp. 715-722) and Condit 2001 (pp. 85-108) argue that Lewontin's findings support the claim that racial categories have little biological validity.
 IHGSC 2001 (pp. 860-921) and Collins and Mansoura 2000 (pp. 221-225) introduce findings on shared genetic material from the Human Genome Project.
 Edwards 2003 (pp. 798-801) argues that Lewontin's conclusions about human genetic classification are incorrect and based on fallacious statistical reasoning.

Are Race and Ethnicity Suitable Proxies for Meaningful Genetic Differences?: Over the past decade an increasing number of scientists have challenged the position that race and ethnicity are genetically meaningless. While acknowledging that 99.9% of genetic material is shared between individuals, they argue that the remaining 0.1%, approximately 3 million base pairs, can, through statistical analysis, be shown to congregate in clusters that correlate significantly with racial categories. Other geneticists have responded that the statistical analysis used to produce such clusters is often biased by its selection criteria and that while genetic differences between geographically distinct population groups do exist, the overall structure of human genetic diversity is better characterized by a genetic continuum or cline, in which genetic variation changes incrementally over geographic distance.

Bamshad 2004 (pp. 598-609) and Fausto-Sterling 2004 (pp. 1-37) provide an overview of recent research on whether human genetic diversity is aligned with racial categories.
 Risch 2002 (pp. 1-12), Rosenberg 2002 (pp. 2381-2385), and Jorde and Wooding 2004 (pp. S28-S33) argue that human genetic diversity is organized in genetic clusters that approximate racial categories.
 Kaufman and Cooper 2001 (pp. 291-298), Kittles and Weiss 2003 (pp. 33-67), and Serre and Paabo 2004 (pp. 1679-1685) argue that human genetic diversity is best represented by clines.

III. Genetic Research and Health Disparities

Social Explanations for Health Disparities: Beginning with the civil rights movement significant attention has been given to discrepancies between the health of minorities and

the white population in the United States. In the 1985 the Department of Health and Human Services published the first comprehensive report on health disparities and under the Clinton administration the elimination health disparities became a major health care objective. Much of the public health research undertaken on the roots of health disparities has focused on social factors, either the socioeconomic status of minority communities or personal and structural biases within the health care system.

Mayberry 2000 (pp. 108-145) , Clayton and Byrd 2001 (pp. 35S-54S) and Smith 2005 (pp. 317-324) provide historical overviews of health disparities as a political issue and a focus of public health research.

Nickens 1986 (pp. 577-580) and McCord and Freeman 1990 (pp. 173-177) summarize early influential reports on health disparities.

Smedley 2003 (pp.) Williams and Jackson 2005 (pp. 325-334) , and Kawachi 2005 (pp. 343-352) review recent research on health disparities.

Genes and Health Disparities: Over the past decade there has emerged significant debate over the degree to which genetic differences between racial and ethnic groups might contribute to health disparities. In the 1990s epidemiological studies on a number of diseases concluded that racial/ethnic differences in health outcomes could not be explained solely by social factors, leading to the hypothesis that genetic differences that exist between racial and ethnic groups are likely to explain some percentage of health disparities. Since the completion of the Human Genome Project research has accelerated on identifying genes that disproportionately predispose particular racial and ethnic groups to specific diseases or decrease the effectiveness of drug treatments in such groups. However, some researchers have argued that available evidence suggests that social factors remain the primary cause of health disparities and that research seeking genetic explanations for health disparities is an inefficient means of addressing the problem.

Fine 2005 (pp. 2125-2128) summarizes the debate over whether genetic differences contribute to health disparities.

Burchard 2003 (pp. 1170-1175) , Collins 2003 (pp. 835-847) , and Mountain and Risch 2004 (pp. S48-S53) argue for a genetic role in health disparities.

Cooper 2003 (pp. 1166-1170) , Lee 2001 (pp. 33-75) , and Sankar 2004 (pp. 2985-2989) argue against a genetic role in health disparities.

Pharmacogenetics as a Solution to Health Disparities: The undertaking of the Human Genome Project produced much discussion regarding the prospect of “personalized medicine” or pharmacogenetics, whereby in order to produce optimal efficacy and safety, an individual’s drug therapy would be determined by their genotype. This vision of “personalized medicine” has yet to be realized. However, some researchers have argued that by identifying genes that disproportionately affect drug metabolism or toxicity in particular racial and ethnic groups, more effective drugs can be designed for specific use in those groups. In 2005, the FDA approved the first race-specific drug, BiDil, as a treatment for heart failure in African-Americans. Supporters of the decision have heralded it as “a step towards the promise of personalized medicine,” and have argued that it will assist in eliminating mortality differences between black and white individuals with heart failure. Opponents have countered that the decision was based on flawed research and represents more a marketing coup than a medical advancement.

Nebert and Menon 2001 (pp. 19-22) and Tate and Goldstein 2004 (pp. S34-S42) review the use of race and ethnicity in pharmacogenetic research.
 Wilson 2001 (pp. 265-269) examines the affect of population genetic structure on drug response.
 Taylor 2004 (pp. 2049-2057) provides study data used to support BiDil.
 Carlson 2005 (pp. 464-468) and Daar and Singer 2005 (pp. 241-246) argue in favor of BiDil and race/ethnicity-specific drugs.
 Kahn 2004 (pp. 1-46) and Lee 2005 (pp. 2133-2138) argue against the approval of BiDil.

IV. Case Study: African Americans and Prostate Cancer

That African American men in the United States have the highest incidence and mortality rates for prostate cancer in the world, and that these rates diverge significantly from those of white men in the United States, has been a central feature of prostate cancer epidemiology research from the 1960s onward. Through the early 1990s most such research focused on environmental or behavioral risk factors thought to be responsible for these differences, most prominently diet and sexual activity. Prostate cancer also received attention in the 1980s within early reports on health disparities, which attributed the racial differences in disease largely to the socioeconomic differences between African Americans and whites. In the 1990s these disparities began to draw the attention of genetic researchers. A 1996 study by researchers from the National Human Genome Research Institute and Johns Hopkins University examined 91 families at high risk for prostate cancer and found that one-third of these families, including the two African American families participating in the study, manifested a linkage to an area on chromosome 1q labeled HPC1. This finding was buttressed by a second, smaller confirmatory study that included six African American families. The second study substantiated the idea of a susceptibility gene at this locus and “hint[ed] that mutations in the HPC1 gene are more prevalent in African Americans than in Caucasian Americans.”

To explore this gene and others possibly involved in hereditary prostate cancer in African American men, Howard University received funding in 1997 from the NIH to initiate the African American Hereditary Prostate Cancer (AAHPC) Study Network. The study represented a collaboration of seven medical centers across the United States seeking to recruit at least 100 African American families at high risk for prostate cancer. It was advertised as not simply an effort to identify prostate cancer genes, but as an initiative designed and carried out by African American scientists to investigate a serious, but neglected, African American health problem. Despite the efforts of the AAPHPC study, however, a prostate cancer gene that explains the racial differences in the disease has yet to be identified. Many researchers have continued to maintain that genetic factors play a large role in the high incidence and mortality of the disease in African Americans, but that probably a number of weaker genes instead of one powerful gene are responsible. Some critics have suggested, however, that in focusing on African Americans as a single group researchers failed to account for the genetic heterogeneity of the group, and that future research must be designed to better reflect the genetic diversity present in African Americans.

Brawley 1998 (pp. 184-186) reviews past and current research on African Americans and prostate cancer.
 Henschke 1973 (pp. 763-768) , Schuman and Mandel 1980 (pp. 630-649) , and Nomura and Kolonel 1991 (pp. 200-227) provide examples of early research investigating the high rates of prostate cancer in African Americans.

Whittemore 1995 (pp. 732-740) , Smith 1996 (pp. 1371-1374) , and Cooney 1997 (pp. 955-959) present key genetic prostate cancer studies in African Americans.

Powell 2001 (pp. 120-123) and Ahaghotu 2004 (pp. 165-169) describe and present data from the AAPHC study.

Freedland and Isaacs 2005 (pp. 243-252) address the inability of recent studies to identify a prostate cancer gene in African Americans and outline new approaches to research on the group.

Section 2: Conducting Genetic Research on Racial and Ethnic Groups

I. Differing Views of Genetic Research

Past Experiences with Medical Research: In conducting genetic research on racial and ethnic groups researchers must be highly attentive to the groups' preexisting views of medical research and of the health care system as a whole. The willingness of racial and ethnic groups to undertake genetic research is in part contingent on the groups' past experiences with medical research and the manner in which such experiences are interpreted by current members of the group. For instance, reported difficulties in recruiting African Americans into genetic studies have been attributed to mistrust based in past abuses of medical research (such as the Tuskegee Syphilis Study) and historical disenfranchisement from the health care system.

Shavers 2002 (pp. 248-256) and Roberson 1994 (pp. 2687-2691) summarize the effect of past medical experience on minority recruitment within medical research in general.

Baker 1999 (pp. 212-222) examines levels of distrust for medical research among different minority groups.

Duran 1998 (pp. 183-189) discusses obstacles to the recruitment of Hispanics into medical research.

White 2000 (pp. 585-598) reviews the Tuskegee Syphilis Study.

Gamble 1997 (pp. 1773-1778), Fouad 2000b (pp. S35-S40), and Shavers 2000 (pp. 563-572) examine the legacy of Tuskegee among African Americans and its effect on research participation.

Cultural Understandings of Genetics: Racial and ethnic groups often view genetics, and medical science more generally, from within a different cultural framework than do researchers. In some cases such differences may impact the willingness of group members to participate in genetic research. A group's understanding of genetics is often shaped by pre-existing beliefs about the composition and origins of the body, as well as by the access that its members have to science education. In cases where pre-existing beliefs about the body conflict with a study's use of genetics, a high degree of cultural sensitivity may be required on the part of researchers to insure that the study is both acceptable to group members and unlikely to cause cultural harm. The task is to present a genetic study in a culturally sensitive manner, while maintaining an accurate and complete description of the scientific goals of research.

Richards and Ponder 1996 (pp. 1032-1036), Catz 2005 (pp. 161-172), and Furr 2002 (pp. 23-30) examine how different racial and ethnic groups in the US understand genetics and genetic research.

Lin-Fu 1998 (pp. 124-129) discusses the views of Asian Americans and Pacific Islanders on genetics.

Romero 2001 (pp. 1-10) discusses the views of Native Americans on genetics.

Phan 1995 (pp. 237-246) examines views of genetics within different religious denominations in the US.

Campbell 1998 (pp. 275-305) and Palmer and Tano 2004 (pp. 1-10) discuss cultural views of the body and their effect on research participation.

Baty 2003 (pp. 146-155) provides a guide for culturally sensitive genetic research and education in African Americans.

Burhansstipanov 2002 (pp. 149-157) provides a guide for culturally sensitive genetic research and education in Native Americans.

II. Recruitment of Participants for Genetic Studies

Genetic researchers have employed different recruitment strategies towards the aim of more effectively enrolling study participants from racial and ethnic groups. Commonly researchers have centered on working closely with political, religious or community

institutions that represent or are influential among members of the group. Such institutions have assisted researchers by dispensing information about a study, alleviating distrust of researchers, and identifying eligible participants. A number of studies have also employed advertisement campaigns targeted at racial or ethnic communities. However, the success of these types of strategies often depends on their appropriate adaptation to the characteristics of a specific group, as recruitment strategies that prove successful for one group, disease, or study type may not prove successful for others. Many genetic studies attempting to recruit racial and ethnic minorities have sought to employ researchers from the same racial or ethnic group. Others have looked to involve community leaders in planning and conducting research. Proponents of this strategy contend that it increases trust between group members and researchers and results in research that is more aligned with the health needs of the group. Some researchers, however, maintain that the racial or ethnic concordance of researchers is less important for recruitment than strong community or clinical relationships.

Blumenthal 1995 (pp. 197-205) and Swanson and Ward 1995 (pp. 1747-1759) summarize strategies for recruiting members of minority groups into medical research generally.

Royal 2000 (pp. S68-S77) , Hughes 2004 (pp. 1146-1155) , and Patterson 2005 (pp. 79-82) provide examples of recruitment strategies used in cancer genetics studies.

Williams 2000 (pp. 527-538) provides an example of recruitment strategies used in a hypertension genetics study.

Marcer 2003 (pp. 125-127) and International HapMap Consortium 2004 (pp. 467-475) discuss the recruitment strategies used in the International HapMap Study.

Stevens 2003 (pp. 105-112) , Cooper-Patrick 1999 (pp. 583-589) and Brach and Fraser 2000 (pp. 181-217) examine the effect of racial/ethnic concordance in health care generally.

Fouad 2000a (pp. S35-S40) discusses the importance of racial/ethnic concordance for the recruitment of African Americans into medical research.

Hughes 2004 (pp. 1146-1155) discusses the significance of racial/ethnic concordance in recruitment for hereditary breast cancer research.

III. Racial and Ethnic Identification of Participants

Racial and Ethnic Categories in Genetic Research: The NIH has stipulated that all studies it funds must use racial and ethnic categories that correspond to those used in the United States census, as set by the Office of Management and Budget. However, these are minimum requirements, and researchers are permitted to select more specific categories. Thus, one of the difficulties researchers face in conducting genetic studies on racial and ethnic groups is determining what racial or ethnic categories to use. While racial and ethnic designations may appear self-evident, they are constructed in complex and often contradicting ways. Racial and ethnic identities often overlap ambiguously or contain distinct sub-identities. Individuals may claim to belong to multiple racial and ethnic groups and a consensus of who “belongs” in a group may not be present even among members of the group itself. In selecting a broad category, such as “Asians,” researchers risk missing significant distinctions among sub-groups within the category, while by choosing a more limited category, such as “Japanese-Americans,” they risk attributing results too narrowly of and inhibiting the comparison of data. Furthermore, for the results of a study to be meaningful for fellow researchers and the public alike, the racial and ethnic categories used must both be consistent with other similar studies and be in common public usage.

National Institutes of Health 2001a outlines NIH guidelines on the use of race in medical research. Office of Management and Budget 2000 provides OMB definitions of racial and ethnic categories. Bennett 1997 (pp. 477-480, Sondik 2000 (pp. 1709-1713) review and provide criticism of the use of OMB set racial and ethnic categories in medical research. Burhansstipanov and Satter 2000 (pp. 1720-1723) discuss how OMB classifications affect research on Native Americans. Anand 1999 (pp. 241-244) , Bhopal and Donaldson 1998 (pp. 1303-1307) , and Waters 2000 (pp. 1735-1737) discuss the problems inherent in selecting racial and ethnic categories for medical research.. Hahn 1992 (pp. 268-271) , Aspinall 1998 (pp. 1797-1808) , and Williams 1999 (pp. 121-137) examine the methodological issues implicit in selecting racial and ethnic categories for medical research.

Methods for Identifying the Race and Ethnicity of Research Participants: Another difficulty researchers face in conducting genetic studies on racial and ethnic groups is determining how to identify the race or ethnicity of study participants. Since there is no objective or unequivocal means of identifying an individual's race or ethnicity, researchers have traditionally relied on one of several subjective methods. These include identification by the researcher, identification by a second party, such as a physician or a community leader, participant self-identification, identification based on a participant's reported ancestors, and identification by birthplace or last name. However, none of these options constitutes a genetically precise method, as all rely on individuals' social criteria for group membership based on the *a priori* designation of racial and ethnic categories. Of these options, participant self-identification has in recent years become increasingly popular, with the NIH stipulating in 1993 that, except under extraordinary conditions, all studies funded by it must rely on that method. Participant self-identification is not without shortcomings, however, and can be problematic when participants respond with multiple racial or ethnic identities or racial or ethnic identities different from those selected for a study, or do not have sufficient knowledge of their racial or ethnic ancestry to meet study requirements. Recently, some researchers have advanced the use of genetic analysis to place study participants into categories not associated with socially defined race or ethnicity.

Hahn 1996 (pp. 75-80) , Moscou 2003 (pp. 1084-1086) , Hammerschmidt 1999 (pp. 10-12) , and Boehmer 2002 (pp. 1471-1472) summarize the different methods employed by researchers to identify race and ethnicity. National Institutes of Health 2001a provides NIH guidelines for the identification of race and ethnicity. Kaufman 1999 (pp. 101-103) argues that self-identification is the only acceptable method of identification. Fuchs 2002 (pp. 1-5) and Hahn 1992 (pp. 268-271) discuss potential shortcomings with self-identification. Shields 2005 (pp. 77-103) argues for the development of genetic methods of participant identification.

A Need for Clarity: A prevailing criticism of the use of race and ethnicity in medical research has been the inconsistency with which different studies have used and reported racial and ethnic categories. Because there are no objective and unequivocal means of identifying an individual's race or ethnicity researchers have selected differing methods of identifying participants. This inconsistent treatment of race and ethnicity has led to difficulties in comparing results from different studies and in evaluating whether racial and ethnic categories represent accurate measurements of risk. It has also been suggested that by not making explicit in publications which methods were used, studies often communicate a biological notion of race and ethnicity. To this end, a number of major

medical journal have stipulated that studies clearly state the methods through which researchers ascertain racial or ethnic identity of participants.

Kaplan and Bennett 2003 (pp. 2709-2916) review the issues involved in the use and assignment of racial and ethnic categories.

Huth 1995 (pp. 619-621) , LaVeist 1994 (pp. 1-16) , and Comstock 2004 (pp. 611-619) examine the methodological issues that arise from the inconsistent use of race/ethnicity in published studies.

Wang 2005 (pp. 37-45) examines the methodological issues that arise from the inconsistent use of race/ethnicity in genetic research.

International Committee of Medical Journal Editors 2003 , Nature Genetics 2000 (pp. 97-98) , and British Medical Journal 1996 (pp. 1094) are representative of recent journal requirements for the publication of studies using racial and ethnic categories.

Is Self-identified Race/Ethnicity an Effective Proxy for Genetic Clusters?: In discussing the appropriateness of using racial and ethnic categories in medical research, there exists significant disagreement over the degree to which existing methods of identifying race and ethnicity, particularly participant self-identification, can yield biologically meaningful results. Critics cite historical and sociological research on the complex and fluid ways in which race and ethnicity are socially constructed and point to genetic studies that have found little association between individuals' genotype and their self-identified race. Proponents cite genetic research that has found an association between individuals' self-reported continental ancestry and genetic clusters produced by the statistical analysis of selected single nucleotide polymorphisms (SNPs).

Winker 2004 (pp. 1612-1614) summarizes the debate over whether self-identified racial and ethnic categories correspond to genetic clusters.

Barnholtz-Sloan 2005 (pp. 1545-1551) and Wilson 2001 (pp. 265-269) present findings showing only a weak association between self-identified race/ethnicity and genetic clusters.

Tang 2005 (pp. 268-275) and Burchard 2003 (pp. 1170-1175) present findings showing a strong association between self-identified race/ethnicity and genetic clusters.

IV. Using Stored DNA Samples

Researchers may sometimes use stored DNA samples to conduct genetic research on racial and ethnic groups. Some groups have voiced concern that the use of stored samples with racial and ethnic labels may result in discrimination or stigmatization. The use of stored DNA samples also presents researchers with additional challenges for accurately ascertaining the racial or ethnic identity of the donor. While different DNA and tissue banks have different guidelines for the labeling of race and ethnicity, this information, if available, may be attached to the sample with no explanation of how it was determined.

National Bioethics Advisory Commission 1999 (pp. 1-26) provides recommendations for the use of stored samples in medical research, including that on racial and ethnic groups.

National Bioethics Advisory Commission 1999 (pp. 77-80) , Kaiser 2003 (pp. 1485) , and Meslin and Quaid 2004 (pp. 229-234) discuss groups concerns over the use of stored samples.

Eiseman 2003 (pp. 27-83) overviews the policies, including those related to racial and ethnic labeling, of human tissue repositories in the US.

V. Case Study: Ashkenazi Jews and BRCA1/2 Research

In July 1995, less than a year after the initial identification of the breast cancer susceptibility gene BRCA1, researchers unexpectedly discovered a shared gene mutation in Ashkenazi Jewish families. Over the subsequent year two additional mutations, one in the BRCA1 gene and one in the BRCA2 gene, were also linked to Ashkenazi Jews. The studies upon which this linkage was based, as well as subsequent research required researchers to develop strategies for acquiring DNA samples from the group. Initially these samples came from cancer families with whom researchers had long worked and whom, through close and prolonged contact, researchers came to know well. As researchers expanded BRCA studies to the broader Jewish population, they relied both on stored DNA samples from past screening programs for Tay-Sachs disease, and on samples taken for the research from individuals in the community. In recruiting Jewish participants for BRCA research, researchers relied on the experience generated from those earlier Tay-Sachs screening programs in which they contacted and worked through Jewish community institutions. In both cases, rabbis and other community leaders lent the research credibility, advertised it among community members and, in some studies, helped researchers identify eligible participants.

Researchers were also faced with how to determine whether a potential participant or sample donor was specifically of Ashkenazi Jewish descent. Most studies relied on either self-identification by participants or identification by rabbis or other community leaders. Some studies, especially those relying on stored samples, assumed that because an overwhelming percentage of Jews in the United States were Ashkenazi (~90%), a high percentage of the samples would be as well. Other studies established Ashkenazi descent by asking participants about the nationality of their ancestors or by selecting participants with common Ashkenazi surnames.

In response to the research some Jewish organizations and community members voiced concern about the effects on the group of being publicly linked to a deadly disease. Most frequently these concerns focused on the possibility of stigmatization and discrimination, especially by insurance companies. Overall, however, the Jewish community responded favorably to the research. Researchers had little difficulty in recruiting participants, with many individuals viewing participation as both beneficial to the group and society at large. This enthusiasm came in the face of the negative history of genetic research and stigmatization that Jews faced under the Nazis. However, despite this history, the Jewish community has been found to have a high degree of trust for biomedical research in the United States. It has been posited that this trust is in large part a product of frequent use of the health care system, high levels of ethnic concordance between researchers and the community, and the past success of research-community collaborations, most notably in the case of Tay-Sachs screening.

Brandt-Rauf 2006 (pp. 1-35) provides an overview of BRCA1/2 research on Ashkenazi Jews.

Struewing 1995 (pp. 1-7) , Tonin 1996 (pp. 1179-1183) , Levy-Lahd 1997 (pp. 1059-1067) , and

King 2003 (pp. 643-646) represent key studies leading to the linkage of Ashkenazi Jews to BRCA1/2.

Struewing 1995 (pp. 198-200) and Oddoux 1996 (pp. 185-190) present studies that used stored samples from Tay-Sachs screening programs.

Kaback 2001 (pp. 253-265) reviews the development and success of Tay-Sachs screening programs in

the Jewish community.
Rothenberg and Rutkin 1998 (pp. 148-153) and Dorff 1997 (pp. 65-96) discuss the response of the Jewish community to being the focus of BRCA1/2 research.
Schwartz 2001 (pp. 336-342) discusses the response of the Jewish community to the use of stored samples.

Section 3: Involving Racial and Ethnic Groups in Genetic Research

I. Community Consultation and Consent

Differing Characteristics of Racial and Ethnic Groups: To better facilitate cooperation between racial and ethnic groups and genetic researchers, many community leaders and researchers alike have advocated for the increased involvement of group members in designing, appraising, conducting, and disseminating studies that involve the group. However, in determining how best to involve group members in the research process researchers must consider the fact that groups differ widely in their political and social characteristics. While some racial and ethnic groups, such as Native Americans, have centralized political or religious institutions with the authority to represent the groups, others, such as African Americans, have largely decentralized political and community organizations. Furthermore, while some racial and ethnic groups may be culturally homogenous, with members sharing similar language, beliefs, and education, other groups are highly heterogeneous. In working with racial and ethnic groups researchers must be particularly aware of the potential for disparities within groups. Political or community institutions that claim to speak for all members of a group may in fact only represent a small segment of the group and in some cases may seek to cooperate with researchers in order to maintain or acquire power over other segments of the group.

UNESCO 1995 (pp. 1-25) provides an overview and recommendations for involving different racial and ethnic groups in genetic research.

Galarneau 2002 (pp. 33-40) examines how the characteristics of different groups affect their health care priorities.

Kone 2000 (pp. 243-248) reviews different community-research collaborations in the in the Seattle area. Davis 2000 (pp. 38-45) compares efforts to involve different racial and ethnic groups in genetic research. Sude and Hager 2003 discuss how community structure affected community involvement in the International HapMap Study.

Brunger 2003 (pp. 245-255) and Nicholas 2001 (pp. 45-63) discuss the ethical considerations of class and gender inequalities in community-researcher collaborations.

Consent vs. Consultation: Genetic research on racial and ethnic groups pose risks to the groups involved, as well as to individual research participants. Because individuals belonging to a racial or ethnic group cannot easily distance themselves from that group, risks that accompany a genetic study, such as stigmatization and discrimination, are born by all members of the group regardless of whether or not they participated in the study. This has led some advocates within racial and ethnic groups to call for the establishment of group consent protocols, whereby a panel of political, religious, and community leaders from within the group would be required to consent to any study conducting genetic research on members of the group. Where this has occurred, most notably in several Native American tribes, it has taken the form of community institutional review boards. However, critics of group consent have pointed out that except in cases where a racial or ethnic group has a clear and representative governing body, it is difficult if not impossible to select a representative panel to speak on behalf of the whole group, especially when the negative decision of such a panel would supersede the decision of any individual member of the group to participate in research. In its place they have proposed a model of group consultation, whereby researchers would introduce proposed

research to group members in public forums and elicit feedback, but would not seek to attain the consent of the group as a whole.

National Institutes of Health 2001b provides NIH guidelines for protecting racial and ethnic populations in genetic research.

Davis 2000 (pp. 38-45) provides an overview of the debate over group consent for genetic research.

Chadwick 2003 (pp. 209-218) discusses group consent in the context of DNA banks.

Knoppers 1996 (pp. 272-282) , Weijer and Emanuel 2000 (pp. 1142-1144) , and Piquemal 2001 (pp. 65-79) support the idea of group consent protocols.

Burhansstipanov 2005 (pp. 52-57) and Anonymous 2003 (pp.) provide examples of community IRBs in Native American tribes.

Greely 2001 (pp. 785-800) and Juengst 1998 (pp. 183-200) argue against the feasibility of group consent and propose the development of community consultation protocols in its place.

Quinn 2004 (pp. 918-922) discusses the functioning of community advisory boards.

Foster 1998 (pp. 696-702) provides examples of community consultation on genetic research in Native American tribes.

II. Inclusion of Racial and Ethnic Groups in Research

Increasingly many racial and ethnic groups have demanded an active role in planning and carrying out research conducted on their members. For groups, increased involvement in genetic studies is often viewed as a means of ensuring that research adequately benefits the group, either by directly addressing its health care needs or by providing other benefits, such as employment, education, or infrastructure development. Many racial and ethnic groups also have expressed concern that by participating in genetic research they risk being financially exploited. These concerns are based in part on past examples of “sample and run” research where researchers or corporations profited from patents or technologies obtained through research in racial or ethnic groups without compensating the group involved. As a result, some racial and ethnic groups have chosen to limit their research involvement to studies strictly investigating health issues and have voiced opposition to large population genetics projects, such as the Human Genome Diversity Project.

One way for researchers to deal with such issues is by involving the community in the design and conduct of the study. Community involvement can result in greater trust and participation among members of the group and improve the collection of data by providing researchers with insight into the organization and demographics of the group and facilitating better communication. A range of different participatory strategies have been used by researchers to bring members of targeted groups into the planning and operational stages of research. These range from top-down strategies where researchers elicit feedback from community leaders or organizations regarding an established study proposal, to bottom-up strategies, such as Community-Based Participatory Research (CBPR), where community members are surveyed regarding their health priorities and employed to help carry out the research. However, while a bottom-up approach may result in the highest level of community input, it is highly time intensive and requires extensive cooperation between researchers, community leaders, and funding agencies. Furthermore, the degree to which groups members have the capacity to assist in designing a study will vary significantly depending on their level of education and the technical complexity of the study.

National Institutes of Health 2001b provides recommendations for involving racial and ethnic

communities in genetic research.

Knottnerus 2003 (pp. 601-606) , Gaudet 2000 (pp. 134-140) , and Jackson 1999 (pp. 181-191) discuss different strategies for involving communities in setting research objectives.

Cornwall and Jewkes 1995 (pp. 1667-1676) and Fong 2003 (pp. 136-148) provide examples of CBPR. Burhansstipanov 2005 (pp. 70-76) provides examples of CBPR in Native American tribes.

Jackson 1997 (pp. 951-970) suggests the need for increased community involvement in genetic research on African Americans.

Dukepoo 1998 (pp. 130-133) and Foster 1999 (pp. 1719-1727) provide examples of community involvement among Native American tribes.

Brodwin 2005 (pp. 145-178) reviews community involvement in population genetics research.

Zion 2003 and Marks 2005 (pp. 29-44) summarize concerns held by racial and ethnic groups regarding financial exploitation.

Barsch 2001 (pp. 1-28) examines the possibility for financial exploitation within pharmacogenetic research.

Moore 1996 (pp. 60-63) and Liloqula 1996 (pp. 42-45) discuss opposition among some racial and ethnic groups to the Human Genome Diversity Project.

III. Intellectual Property and Economic and Legal Issues

Some racial and ethnic groups have expressed concerns that their DNA may be patented by scientists or corporations. These concerns are grounded in past experiences, both in medical and agricultural research, where scientists have patented materials or techniques uncovered while working on or with such groups. In some of these cases, groups found such patents particularly offensive because the groups attributed sacred status to the materials involved. Concerns over patenting may also reflect the fear that in acquiescing to genetic research groups risk losing control of their biological heritage and with it the ability to make claims about their identity and culture. They also reflect the view held by many racial and ethnic groups that their genetic material is a collective possession, the ownership of which is not relinquished through participation in research. However, many researchers argue that the ability to acquire a patent is an important component in securing funding for research as well as in developing new medical therapies. In recent years a number of groups participating in genetic research have sought benefit-sharing arrangements with researchers whereby the groups retain some portion of the intellectual property rights over information or products resulting from research.

Davis 2004 (pp. 430-440) overviews concerns held by racial and ethnic groups regarding gene patenting.

Greely 1996 (pp. 54-59) , Friedlaender 1996 (pp. 22-25) , Bhat 1996 (pp. 29-33) discuss past examples where groups believed genetic material was improperly patented.

Stephenson 2001 (pp. 1-18) and Zion 2001 (pp. 1-23) provide examples of alternative mechanisms used by groups to retain intellectual property rights.

Dickenson 2004 (pp. 109-124) , Weijer 2000 (pp. 367-368) , and Knoppers 2000 (pp. 212-214) review different community implemented benefit-sharing arrangements.

IV. Case Study: Native Americans and Diabetes Research

A number of Native American tribes throughout the United States have significantly higher rates of type 1 and type 2 diabetes than the general population. This has led to interest on the part of the NIH and a number of public universities in initiating genetic studies among tribes aimed at identifying genetic risk factors for the disease. For researchers, gaining access to participants from Native American tribes has been challenging, however, and has demanded new approaches to dealing with targeted groups. Native American tribes often maintain strong cultural views of the body as a sacred and holistic entity, making many Native American individuals reluctant to provide

physical samples to researchers. These beliefs and the related belief that an individual's tribal identity is based in the body itself leads many Native Americans to be particularly protective of their genetic heritage. Distrust of biomedical research and government programs contributes to this protectiveness. Fears exist across Native American tribes that genetic material collected for research purposes will be used in ways detrimental to the tribes, either to profit researchers without compensating tribes or to undermine the sovereignty of tribes by countering claims that Native Americans are indigenous to the regions they inhabit. Many Native Americans see relevant precedents in the patenting of indigenous plant varieties by agricultural scientists and in the assertions by geneticists and physical anthropologists that the Kennewick Man, the remains of a prehistoric man found in Washington in 1996, was not genetically related to current Native American tribes and thus was not protected by the Native American Graves Protection and Repatriation Act.

In response, some tribes have begun to require researchers to demonstrate not only that studies will not endanger the physical or cultural well-being of members, but that they will provide the tribe with tangible benefits. In some cases tribal IRBs or health committees have also require researchers to work with tribe members in designing and conducting parts of the research and to submit data and conclusions for review by the tribe prior to publication. Tribes have been particularly stringent in reviewing proposals for genetic research, demanding for example that studies focus solely on identifying genetic aspects of particular diseases affecting the tribe and not on analyzing the origins or ancestral composition of the tribe. In 2001 the Navajo IRB, working under the direction of the Navajo Nation Council, placed a moratorium on all genetic research on the reservation, stating that "the ban would be maintained until the nation's human research code could be amended to speak to gene therapy and potential discrimination."

In order to gain access to Native American participants researchers investigating the genetics of diabetes in Native American tribes have had to work closely with tribal IRBs and health committees, with a range of results. Diabetes research conducted by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) on the Pima Indians, a tribe that lives in southern Arizona, has seen extensive cooperation between researchers and tribal leaders both in regard to the completion of studies and the provision of accompanying diabetes therapies for affected tribe members. On the other hand, similar research conducted by researchers at Arizona State University on the Havasupai tribe of northern Arizona has recently resulted in a lawsuit by the tribe against the university. The lawsuit alleges that along with diabetes research, researchers used blood samples from the tribe for additional studies on schizophrenia and historical patterns of consanguinity and population migration. According to the lawsuit, the Havasupai did not consent to this research and regard it as both stigmatizing and contrary to their religious traditions.

Gohdes 1995 (pp. 683-702) reviews diabetes research in Native Americans.

Naylor 2003 (pp. 363-387) , Knowler 1988 (pp. 520-526) , and Hanson 1998 (pp. 1130-1138) are representative of recent genetic diabetes studies conducted on Native Americans.

Freeman 1998 , Grounds 1996 (pp. 64-68) , and Tallbear 2000 discuss varying views held by Native American tribes on genetics and genetic research.

Pfeferbaum 1997 , Brugge and Missaghian 2002 , and McDonald 2005 discuss the organization of tribal IRBs and health committees and their actions concerning genetic research.

Stidley 2003 (pp. S139-S140) , Boyer 2005 (pp. 281-290) , and Herbert 1996 (pp. 109-112) provide

examples of research collaborations between tribes and geneticists.
NIDDK 2002 and Wheelwright 2005 review the research collaboration between the NIDDK and the Pima Indians.
Andrews 2004 (pp. 10-11) and Dalton 2004 (pp. 500-502) discuss the conflict between the Havasupai Tribe and the genetic researchers at Arizona State University.

Section 4: Risks for Racial and Ethnic Groups Participating in Genetic Research

I. Stigmatization and Discrimination

Individual Risks: Genetic research may yield personal information regarding disease and disability risks, susceptibility to toxins, paternity, and ancestry. This information 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.

Rothstein and Anderlik 2001 (pp. 354-358) review research and statements on genetic discrimination.

Hudson 1995 (pp. 391-393) discusses the potential for genetic-based insurance discrimination.

Miller 1998 (pp. 189-197) discusses the potential for genetic-based employment discrimination.

Lapham 1996 (pp. 621-624) presents data on the public's perceived risk of genetic-based discrimination.

Hall and Rich 2000 (pp. 214-221) and Peterson 2002 (pp. 79-87) discuss the effects of this perceived risk on the use of diagnostic genetic tests.

Bowman 2000 (pp. 207-212) discusses the specific concerns of African Americans about genetic-based discrimination.

Group Stigmatization and 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 risk stigmatizing 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 already held by the group. .

Wolf 1995 (pp. 345-353) and Parrott 2005 (pp. 980-990) review the risk of group discrimination and stigmatization from genetic research.

Nelkin 2002 (pp. 121-132) examines past cases of genetic stigmatization.

Davis 2004 (pp. 40-49) and Elliot and Brodwin 2002 (pp. 1469-1471) overview the issues that arise for groups when genetic research reflects on identity.

II. Privacy and Confidentiality

Researchers collecting genetic information are 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 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 identifiers, their use may still enable researchers to link findings to particular racial or ethnic groups. There has been little effort to regulate or standardize such identifiers among DNA banks.

Anderlik and Rothstein 2001 (pp. 401-433) and Fuller 1999 (pp. 1359-1361) provide reviews of recent writing and research on genetic privacy.

Common Rule, 46 C.F.R. Sec 101ff, codifies the federal rules dealing with human experimentation. Standards for Privacy of Identifiable Health Information, 45 C.F.R. Secs. 160 and 164, contains the HIPAA privacy regulations.

National Conference of State Legislatures 2006 presents a study of the ways different states treat genetic privacy.

Wang 2001 (pp. 18-26) and Wong 2004 (pp. 44-54) describe the concerns of specific racial and ethnic groups regarding genetic privacy.

Deschenes 2001 (pp. 145-178) and Anderlik 2003 (pp. 203-215) examine genetic privacy in regard to DNA banks.

III. Reification of Race/Ethnicity

Opponents of the use of racial and ethnic categories in genetic research have voiced concern that such use results in the reification of the categories within biomedical research, the health care system, and society more broadly. Many genetic researchers have stated that the use of racial and ethnic categories represent a way station in the progression of genetic research towards personalized medicine and that once the ability exists to diagnosis and treat disease based solely upon an individual’s genotype the need to use racial and ethnic categories will disappear. However, it has also been argued that as the use of racial and ethnic categories in genetic research and the development of race-specific therapies, such as BiDil, reinforce the biological significance of race and ethnicity in certain diseases, the use of race and ethnicity in research and in clinical care will increase. Some researchers and social scientists have also voiced concern that as the public hears that race and ethnicity are biologically meaningful in regard to an ever-lengthening list of diseases, it will conclude that race and ethnicity are equally

meaningful with regard to intelligence, behavior, and morality. From this point, they suggest that it is but a small step to the support of public and private policies that discriminate on the basis of race and ethnicity. Suggestions that there may exist an intelligence-gene or a violence-gene that can explain lower test scores and higher rates of violent crime in certain racial and ethnic groups have already been made, and while most genetic researchers disclaim the existence of such genes, they are hard-pressed to counter the success of their own competing message, that genetics has the ability to explain the intricacies of the human body and mind.

Juengst 2004 (pp. 267-275) and Ossorio and Duster 2005 (pp. 115-128) overview the issue of racial/ethnic reification.

Collins 2004 (pp. S13-S15) and Rothstein and Epps 2001 (pp. 104-108) argue that the use of race/ethnicity in genetic research is a temporary step towards personalized medicine.

Lee 2005 (pp. 2133-2138) argues that commercial factors will prolong use of race in medical research.

Marks 2005 (pp. 13-16) and Schwartz 2001 (pp. 1392-1393) discuss the effect of using racial and ethnic categories in genetic research on their use in clinical care.

Duster 2005 (pp. 1050-1051) and Rotimi 2004 (pp. S43-S47) overview the possibility that the use of racial and ethnic will reify public conceptions of race.

Condit 2004 (pp. 402-408) and Nelkin 2001 (pp. 555-559) examine how the media communicates genetic findings about race and ethnicity to the public.

Newson and Williamson 1999 (pp. 327-342) overviews calls to undertake genetic research on intelligence.

Rothstein 2005 (pp. 793-798) overviews calls to undertake genetic research on behavior.

IV. Case Study: African Americans and Sickle Cell Disease

Soon after its initial description in 1910, sickle cell disease became firmly understood within the medical community as a racial disease, specifically one unique to African Americans. “Sickle cell anemia,” Thomas Cooley observed in 1928, “is distinctly racial and possibly originally limited to a small section of the negro race.” Although cases of the disease had also been documented among patients who were not identified as African American, the disease had become so closely linked to that population that physicians responded to these cases by questioning either the accuracy of the diagnosis or of the racial identity of the patient. So too, ideas about race were determinative in the 1940s when investigators distinguished the sickle cell *trait* from sickle cell *anemia*. Sickle cell trait appeared more common among Africans living in Africa than among African Americans, yet sickle cell anemia was described almost exclusively in African Americans. To explain this phenomenon, investigators hypothesized that admixture with white people had weakened the biological and genetic constitution of African Americans. “The hybrid American Negro suffering from sickle cell anemia was living proof...of the dysgenic effects of race-mixing.”

In the aftermath of the Civil Rights movement, President Richard Nixon proposed a five-fold increase in sickle cell research funding and in 1972, Congress passed the National Sickle Cell Anemia Control Act. Some groups, including the Black Panthers and the Black Athletes Foundation for Sickle Cell Anemia, quickly organized community-based screening programs. However, others, fearful that the screening programs had genocidal and/or eugenic implications, discouraged participation in them. Why, asked some community members, was the legislation entitled the “National Sickle Cell Anemia *Control* Act,” and not the “National Sickle Cell Anemia *Prevention* Act?”

The federal legislation itself, as well as some state legislation and screening programs, failed to distinguish between sickle cell *trait* and sickle cell *disease*. As a result, many participants who were carriers were erroneously informed that they had the disease. This led to gross overestimates of prevalence, which contributed to the stigmatization of carriers and promoted discrimination against them. Some carriers were charged higher insurance premiums or denied health insurance and life insurance. Others were refused jobs or fired as result of their carrier status, on the assumption that carrier status reduced a person's ability to fulfill job requirements. For example, the U.S. Air Force at times refused to accept carriers into the service and at other times, restricted the duties assigned to them.

These developments created within African American communities tensions that were, in turn, exacerbated by other errors and misrepresentations. People were erroneously informed that an individual with sickle cell disease would likely die by age twenty. Moreover, screening programs were often designed exclusively for African Americans. In order to obtain a New York state marriage license, all persons "not of the Caucasian, Indian, or Oriental races" had to undergo testing for sickle cell. Negative attitudes were reinforced when some legislation labeled sickle cell "communicable," as though it were an infectious disease. Finally, acceptance of research and screening for sickle cell was further reduced by a lack of public education and genetic counseling.

Lessin and Jensen 1974 (pp. 529-532) present the history of research on sickle cell.

Wailoo 1991 (pp. 185-208) and Tapper 1997 (pp. 263-289) examine how early researchers linked the disease to race.

Tapper 1999 (pp.) and Matarasso 1980 (pp. 650-655) examine how sickle cell became a significant social concern in the 1970s.

Manley 1984 (pp. 67-71) and Reilly 1975 (pp. 319-76) review the federal and state sickle cell legislation that was passed in the 1970s.

Pearson and O'Brien 1972 (pp. 1201-1204) , Powledge 1973 (pp. 38-47) discuss the implementation of sickle cell screening programs and the related controversy that ensued.

Severo 1980 (pp. 243-245) and Markel 1998 (pp. 161-176) discuss the cases of discrimination that occurred as a result of misinformation about sickle cell, and how these cases were viewed by the African American community.

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