Am. J. Hum. Genet. 63:696–702, 1998

A Model Agreement for Genetic Research in Socially Identifiable Populations

Morris W. Foster,[1] Deborah Bernsten,[1] and Thomas H. Carter[2]

[1]Department of Anthropology, University of Oklahoma, Norman; and [2]William K. Warren Medical Research Institute, Department of Medicine, University of Oklahoma Health Sciences Center, Oklahoma City

Summary

Genetic research increasingly focuses on population-specific human genetic diversity. However, the naming of a human population in public databases and scientific publications entails collective risks for its members. Those collective risks can be evaluated and protections can be put in place by the establishment of a dialogue with the subject population, before a research study is initiated. Here we describe an agreement to undertake genetic research with a Native American tribe. We identified the culturally appropriate public and private social units within which community members are accustomed to make decisions about health. We then engaged those units in a process of communal discourse. In their discourses about our proposed study, community members expressed most concern about culturally specific implications. We also found that, in this population, private social units were more influential in communal decision making than were public authorities. An agreement was reached that defined the scope of research, provided options for naming the population in publications (including anonymity), and addressed the distribution of royalties from intellectual property, the future use of archival samples, and specific cultural concerns. We found that informed consent by individuals could not fully address these collective issues. This approach may serve as a general model for the undertaking of population-specific genetic studies.

Received March 3, 1998; accepted for publication June 22, 1998; electronically published August 7, 1998.

Address for correspondence and reprints: Dr. Morris W. Foster, Department of Anthropology, University of Oklahoma, 455 West Lindsey Avenue, Room 515, Norman, OK 73019. E-mail: Morris.W.Foster-1@ou.edu

0002-9297/98/6303-0007$02.00

Introduction

Population-specific studies have a growing role in genetic research. Reports on gene localization for common diseases often vary when populations are compared (Ober et al. 1992; Kerem et al. 1995; Devgan et al. 1997; Szabo and King 1997), in part because the genetic factors contributing to a particular phenotype may vary with population histories. Plans are underway to catalog that diversity for single-nucleotide polymorphisms (Collins et al. 1997) and for polymorphisms linking environmental hazards with disease susceptibility (Brown and Hartwell 1998). Currently, it is standard practice to name ethnically, geographically, and linguistically identifiable populations in public databases and scientific publications. That practice, however, may entail collective risks that are shared by all members of those populations, not just those who choose to participate in research studies.

The primary risk is that laypersons may misuse scientific findings. There is a long history of the popular or political use of scientific findings about heredity to support racism and other varieties of discrimination (Kevles 1985; King 1992; Caplan 1994; Wolf 1995). A recent National Research Council (NRC) report on the study of human genetic diversity (Committee on Human Genome Diversity, National Research Council 1997) recognized the possibility that members of socially identifiable populations may be adversely affected if associated with a particular genetic predisposition. For example, discrimination occurred when African Americans publicly were associated with sickle cell trait during the early 1970s (Phoenix et al. 1995). More-recent examples of employment and insurance discrimination based on genetic information also have been noted (Andrews et al. 1994). Most recently, members of the American Ashkenazi community have expressed concerns about the collective risks of the numerous genetic studies that have focused on their population (Stolberg 1998).

Little consideration has been given, though, to how to address the collective implications that genetic studies may have for the populations that they name. Even the recent NRC recommendations for the study of genetic diversity rely primarily on existing human-subject protections for individuals, rather than suggesting new protections against collective risks to identifiable populations. Nonetheless, there is an emerging bioethical literature that has begun to raise questions about collective issues: What research ethics are appropriate in culturally diverse situations (Christakis 1992; Pelligrino 1992; Angell 1997)? How can the autonomy of both communal and individual decision making be respected in the recruitment of study participants (Gostin 1995; Glick 1997; Lyttle 1997*a*)? How can researchers minimize the risks of stigmatizing entire categories of people (King 1992; Caplan 1994; Wolf 1995)? How can individual privacy be protected in small populations (Powers 1993)? Who should profit from valuable information derived from a unique population (Pompidou 1995; Friedlander 1996; Lyttle 1997*b*)? Under what conditions can DNA collected for one project later be used for other research (Clayton et al. 1995; Weir and Horton 1995)?

Specific answers to these questions will vary with the cultural frameworks shared by members of each socially identifiable population approached for participation in research projects. Although federally funded U.S. researchers are bound by the doctrine of informed consent for individuals, there is considerable variation in how persons with differing cultural and ethnic identities decide to participate in research studies or make treatment choices (Blackhall et al. 1995; Gostin 1995). In particular, one should not expect to find everywhere the highly individualistic decision-making process idealized in Euro-American culture and enshrined in Western medical ethics (Christakis 1992). Indeed, researchers should be aware of the possibility of unintentionally imposing a foreign social structure on members of other cultures. Thus, ascertaining and engaging population-specific decision-making processes is a general problem for research in human genetic diversity. Our approach to negotiating an agreement with a Native American tribe may serve as a model for how genetic researchers can collaborate with diverse, socially identifiable populations and take appropriate account of both biomedical and indigenous ethics.

Communal Discourse

We used a process of communal discourse (Foster et al. 1997) to engage the participation of the Apache Tribe of Oklahoma. We began by conducting a health survey through 150 ethnographic interviews (~20% of the adult population). The interviews included questions about who was consulted in making health-care decisions. We used the answers to those questions to identify public and private social units that Apaches were accustomed to consult about their well-being. These units were considered by community members to be the most appropriate entities to consult about the collective implications of genetic research. Our definition of "appropriate" is derived from the population's preexisting processes for reaching a communal consensus. Although such processes vary among populations, our procedure for identifying culturally appropriate decision-making units is generally applicable. Anthropology has well-defined methods for the study of collective decision making (Vincent 1990).

A related problem was the inclusion of a cross-section of appropriate social units sufficient to represent all segments of the Apache population. Here, we relied on a combination of information from the health-survey interviews and advice from Apache elders. Members of the Apache community were themselves very aware of the question of representativeness—a necessary element in reaching any communal consensus—and were able to guide us in including specific social units. In the Apache community, the major public unit is a five-person Apache Business Committee that is elected by tribal members. It is recognized as having public authority to make formal decisions about matters affecting the well-being of the community as a whole. Everyday private life, however, is ordered by five major extended families, which are the private units within which information about such matters as individual health status is confidential. The Apache Business Committee takes care to appoint members from each of the major families to any community panel.

We requested that the Apache Business Committee sponsor a series of public meetings, open to all tribal members, in which we explained our research goals. As a result of this initial dialogue, we modified our goals to take account of communal priorities. We then sought grant support for our research, as well as to support the collaboration of the Apache Business Committee, which appointed a committee to evaluate the research proposal and to negotiate a subcontract with the University of Oklahoma.

The Apache Business Committee designated this committee as a "tribal institutional review board" (IRB) but that designation may be somewhat misleading. What the Apaches called a "tribal IRB" functioned in a dual role that is not standard in bioethical practice; that is, it both evaluated the research project for its implications for the Apache community and then explained those implications to and negotiated them with researchers. Typically, an IRB undertakes only the first of these tasks, whereas inclusion of the second might be considered—according to Euro-American ethics—as creating a conflict of interest for the IRB. In the case of the Apache community, however, such a separation of responsibilities was seen by members as impractical. Those persons who were judged most knowledgeable in evaluating the cultural implications of the proposed research also were considered the most appropriate persons to negotiate community-specific concerns with researchers. The same qualities of personal and cultural authority were deemed necessary for both tasks. To avoid confusion with more typical IRBs, we will use the term "community review board," or "CRB," to refer to the Apache committee.

The Apache CRB functioned as the public arena for a dialogue in which investigators provided information and answered questions in eight formal meetings over the course of 6 mo. Members of the CRB, in turn, related specific features of the proposed agreement to their extended families. Questions or concerns that arose out of those discourses in private social units were brought up by the CRB when we met.

Apaches discussed implications for the community as issues separate from those for individuals. They recognized that risks of stigmatization and discrimination would apply to all tribal members, not just to those who might volunteer as study participants. They asserted a communal interest even for biological specimens that would be individually anonymous, because of the use of the collective name "Apache." This communal interest was no less for stored materials subject to studies in the future. Nevertheless, despite potential collective risks, Apaches were strongly motivated to participate in research on diabetes mellitus, which they perceived as a major health problem.

A tentative agreement was reached, and a written draft prepared by the university counsel. The tribal CRB approved it unanimously. However, final approval by the Apache Business Committee was not given for several months, while private discourses continued in the extended families. Only after a consensus in these private social units became apparent did the Apache Business Committee approve the contract. The agreement includes funds to compensate the tribe for expenses of maintaining a CRB and helping to recruit volunteers. It does not obligate members to participate in the research. Nor does it supplant standard informed consent by individual participants.

Provisions

Scope of Research

Community members expected the research questions to be specific and to be relevant to communal concerns. Our agreement specifies that the research will investigate genetic factors in diabetes mellitus and prostate cancer. If additional questions arise, the researchers must return to the Apache CRB for approval.

Publications

All manuscripts that report project findings will be reviewed by the Apache CRB, which will have 60 d to raise objections to use of the tribal name. In that event, investigators either could revise the manuscript to satisfy Apaches' concerns or could publish the results without naming the Apache tribe. Although study populations traditionally have been named in scientific publications, keeping their identities confidential would not necessarily invalidate analyses of genetic factors for disease susceptibility and resistance.

Intellectual Property

According to long-established practice, as well as limited legal precedent, individuals who donate biological materials do not have legal claim on the intellectual property derived from them (Knoppers et al. 1996). In our agreement, the owner of any intellectual property is the university, the sponsoring institution. The subcontract, however, recognizes the unique contribution of the participating community in the creation of that intellectual property. The university will deduct 10% of royalties for legal and administrative costs. Of the remainder, the university will retain 30%, the tribe will receive 30%, and investigators will receive 30%. The unassigned 10% will be retained in a reserve fund for liability or litigation. The Apache CRB resolved that any royalties to the tribe be earmarked for the promotion of the health and education of tribal members.

Archival Storage and Study

At the conclusion of our project, we will negotiate with the tribal CRB the issue of long-term storage of biological specimens. If we are unable to reach an agreement, those materials will be disposed of in a culturally appropriate manner. However, if the tribal CRB permits storage of samples, explicit provisions will be negotiated to define how future research projects would receive community approval.

Cultural Concerns

We encountered some concerns that are culturally specific to the study population. Apaches have restrictions about physical contact that are specific to gender, family, and age. Thus, the tribal CRB decided that blood samples should be drawn by a non-Apache. Apaches also expressed an interest in what is done with biological materials that are not consumed by laboratory analyses. Those materials still are considered part of the body, so investigators and the tribal CRB will review procedures to ensure that the proper respect is accorded. More generally, each of the other provisions negotiated with the tribe was interpreted from a uniquely Apache cultural perspective. For instance, concerns about adverse affects from the publication of scientific findings focused on stigmatization of families with a history of diabetes within the community, rather than on discrimination from outside. Similarly, the primary concern about the use of archival specimens was in potential studies comparing the Apache genome with those of other Native peoples. Results from such comparative studies could contradict Apache origin narratives. Both these risks are based on how Apaches culturally construct their own sense of shared identity, not on how others view them.

Discussion

Researchers cannot assume that collective issues can be addressed fully by the informed consent of individuals. Indeed, as we found among Apaches, individuals may be prohibited from discussing community-specific issues outside the public and private social units in which collective decision-making processes are situated. We found that Apaches expressed most concern about the culturally specific implications of more-general aspects of genetic research. Our findings also indicate that, in some populations, private social units may have a larger role in communal decision making than do public authorities. Thus, the existence of readily identifiable public social units and leaders does not mean that informed communal consensus can be assured simply by seeking approval from a public authority. These findings suggest that researchers may need to investigate the sociocultural organization of a human population before analyzing its genetic architecture.

The model that we have described here is a logical extension of the current scope of ethical review of protections for human subjects in research projects. IRBs already are required to evaluate special kinds of risks to what are defined as "vulnerable" populations or categories of potential subjects. Subjects of genetic research may be most vulnerable through socially identifiable, population-specific identities. In the end, it is the researcher's responsibility to demonstrate that human subjects who share socially recognizable identities are protected from collective risks. Some of those issues' resolutions that we devised in collaboration with the Apache Tribe of Oklahoma may be controversial and require some additional discussion.

Anonymity

The option of making a research population anonymous may strike some researchers as an infringement on the freedom of scientific inquiry. Restrictions on free speech, however, generally are permitted when a potential harm to others may result. In particular, protections for human subjects are accepted as necessary and reasonable limits on research projects. Existing ethical standards, for instance, already recognize the collective risks entailed in the publication of family or kindred names in pedigree studies, and they usually prohibit the use of such names (Powers 1993). Even anonymous pedigrees, however, may constitute risks for family members (Botkin et al. 1998). We consider limitations on the use of the Apache tribal name to be an extension of established protections from and continuing concerns about such collective risks.

Agreements about the conduct of research freely entered into by all parties should not be considered unreasonable restrictions on free speech. Researchers often agree to restrictions on publication when using information controlled or owned by other parties. By agreeing to allow Apaches to review manuscripts prior to publication—and to request that the population be made anonymous in some instances—we obtained a communal consensus that will allow us to recruit a sufficient number of Apaches to our study. Arguably, without that agreement we would not have a similar degree of access to Apache genetic information.

Not naming a population still would permit publication of research findings about genetic factors of disease susceptibility. The primary impediments would be in relating our results to those of other researchers for the same population. A comparable restriction, however, has not seriously compromised disease-susceptibility studies in which family or kindred names are kept anonymous. Thus, we do not anticipate significant problems if socially identifiable populations choose to be anonymous. We do not propose a blanket prohibition on the naming of identifiable populations. Instead, we propose that a study population be given the opportunity to exercise control over the public use of its name, because of the collective risks that publication may entail.

Although a knowledgeable reader may infer the identity of a population that is made anonymous in scientific publications, we believe that collective risks are greatest from laypersons. Unless scientists have a compelling reason to do so, they are unlikely to publish speculations about the identity of a population in an anonymous study. If there were a scientifically compelling reason to know, researchers could consult the authors to find ethical ways to handle the population's identity without increasing the collective risk to its members. Similar practices have been followed when researchers share confidential information about family or kindred studies.

Commercialization

The sharing of royalties with a subject population has not been a standard practice. Financial incentives often are offered to individual subjects and are not, in themselves, considered unethical recruiting devices. To the extent that genetic research addresses questions that are population specific, the population is the subject. As we have noted, members of socially identifiable populations

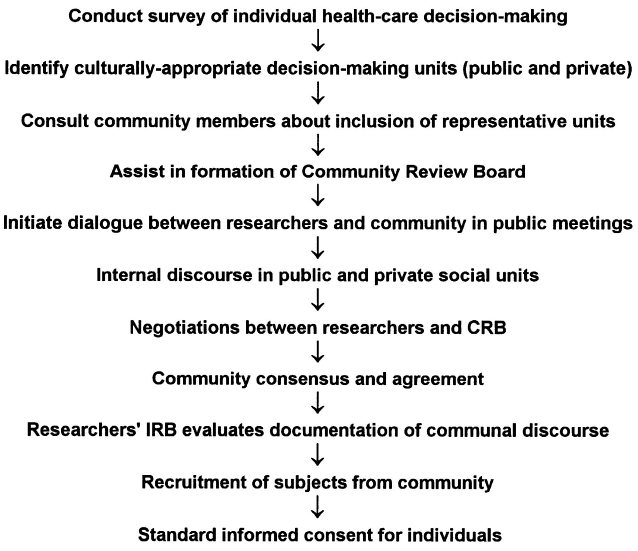

Figure 1 General model for communal discourse with socially identifiable populations.

have demonstrably greater risk for participating in genetic research, as compared with members of the general population. The nature of discrimination and stigmatization is such that smaller populations tend to be more vulnerable and more often targeted. In addition, in an identifiable population, nonparticipants share the same collective risks as do persons who volunteer for research. As a matter of equity, we believe that it is reasonable that such populations should have the opportunity to share in any financial benefits that come from commercial development of a population's unique genetic resources. Currently, universities, researchers, and corporations all take financial interest in the outcome of research studies. There is reason to believe that socially identifiable populations may feel exploited unless they are offered a similar financial interest for their participation (Macilwain 1996). In our presentations to Apache community members, we emphasized that the actual chance of any commercial reward is very small. On the basis of their dialogues with us, we believe that the commercial potential of the project that we proposed had little to do with the Apache community's interest in participation.

Future Studies of Archival Samples

Questions of appropriate approval for genetic research on archival samples constitute a growing debate. Typically, the informed-consent document signed at the time of donation is considered to define permissible future uses of biological specimens. We found, however, that members of the Apache community expressed a desire to see how the research project actually was performed and to hear reports from researchers on its preliminary results before agreeing to archiving samples. As part of our agreement, we will make periodic reports to the Apache community on our findings. Only afterward will they consider entering into a longer-term agreement that might include maintaining a collection for future research. We believe that this caution is entirely reasonable. If community members feel that researchers performed the initial blood collection and research in ways considered inappropriate or offensive, then there would be some means to opt out of archival storage. We also think that the community should continue to be treated as an interested party in research designed after samples have been collected. All the collective risks that we outlined for our initial research project also apply to future uses of archival specimens. Thus, in subsequent projects undertaken with archival material, communal discourse and contractual provisions can provide important human-subjects protections. For that to be assured, some community control over the use of archival samples must be retained—unless samples are rendered anonymous as to population identity. Population-anonymous samples in publicly available collections may be further protected by user agreements that explicitly state the conditions under which samples were donated—including prohibitions on research that may attempt to reveal population identity.

Coercion

Throughout our negotiations, we emphasized that our study would be based on individual volunteers. We tried to make a clear distinction between communal deliberations on this research project and individual choices to participate. A communal consensus in support of a research project constitutes a collective willingness to promote the research, not a commitment of individual participation. Apache culture makes a strong distinction between communal and individual action. Although some other communities may place greater weight on communal decision making, existing human-subjects regulations in the United States require that researchers provide individuals the opportunity to decide about participation on their own. Communal pressures to participate can be minimized by being explicit about the distinction between community consensus and individual consent. One safeguard for individual autonomy is to provide opportunities for privacy in collection procedures. Donors may be given the option of declining to participate when they are alone with the phlebotomist—after they have given the outward impression, to the community, that they are taking part in the study. Our university IRB asked us to strengthen protections for individuals by allowing donors to have their samples withdrawn at any time during the first 60 d after do-

- **Scope of Research**
- **Use of the Population Name in Publications**
- **Distribution of Royalties from Intellectual Property**
- **Specimen Archiving and Conditions for Future Study**
- **Population-specific Socio-cultural Concerns**

Figure 2 Collective issues for negotiation with socially identifiable populations.

nation. Clearly, traditional IRB oversight should continue to safeguard individual autonomy.

Generalizability

The process of reaching a communal consensus about genetic research and the kinds of issues raised can be stated as a general model, the generalizable aspects of which are summarized in figures 1 and 2. That general model may be suitable as a standard for evaluation of the collective risks for human subjects in genetic research. By means of a process of communal discourse, even socially identifiable populations that lack an overarching public unit (such as the Apache Business Committee) can reach a consensus about a genetic-research project, through the preexisting decision-making process of private social units. Although not formally organized into a shared polity, private social units may be united by a shared cultural framework that makes consensus possible.

Consensus may be defined as a common understanding about some issue within a population. Although consensus may be expressed formally as an explicit approval or disapproval, such as in the case of the Apache Business Committee, it represents a more fundamental, underlying process of collective decision making among the private social units that constitute the population. Thus, consensus should not be characterized as communal consent. The latter implies a discrete, monolithic communal choice that is not, in our experience, the usual way in which members of a socially identifiable population reach broadly based, shared conclusions about collective issues.

Geographic dispersion poses special problems for approaching socially identifiable populations for genetic research. In the case of geographic dispersion, we suggest that communal discourse be conducted in locales in which subjects will be recruited. This allows a reasonable chance that potential volunteers will have the benefit of discourse about collective risks in their own private social units (a discourse in one location would not be adequate to inform subjects who live elsewhere). Provisions that take account of those risks as well as unique sociocultural concerns can be reviewed by the researchers' sponsoring institution and can be implemented by whatever legal instrument is locally appropriate.

In the evaluation of collective risks, the additional expense that communal discourse poses for a research project is an important consideration. We believe that those costs can be contained. Most genetic studies entail some preliminary contact with the subject population. The health surveys used to identify public and private social units could be performed as part of that preliminary research—for instance, in clinical settings. The relevant information can be obtained by asking affected and unaffected persons a series of questions about how they recognize and make decisions about illness, including questions regarding whom they asked for advice, who may have assisted them in seeking care, who may have provided care for them, and their social relationships to those persons. Social scientists with some working knowledge of the population, as well as prominent community members, could be consulted to interpret responses. If it comprises relatively unrelated community members, a sample size much smaller than the 20% that we used may be adequate. Subsequent public meetings and ongoing dialogue with communal social units require more of researchers' time than funds.

The protections that communal discourse can provide more than outweigh the costs. Everyone is a member of one or more socially identifiable populations (Parker and Majeske 1996). As research on disease susceptibility and resistance increasingly focuses on population-specific genetic diversity, the kinds of collective issues considered here will become more prominent—and may affect an increasingly larger proportion of research subjects, including some who are now treated as being members of the "general population."

Acknowledgments

This work was supported in part by National Institutes of Health grant HG010302 (to M.W.F.) and by National Science Foundation grant SBR9610336 (to M.W.F. and T.H.C.), by Presbyterian Health Foundation (support to T.H.C.), by a Leukemia Society of America fellowship (to T.H.C.), and by the William K. Warren Medical Research Institute (support to T.H.C.). The authors acknowledge the assistance of A. Chalepah, J. F. Cuccio, A. J. Eisenbraun, W. Freeman, J. H. Moore, N. Nisbett, K. Ockershauser, K. Rothenberg, and D. Strong.

References

Andrews LB, Fullarton JE, Holtman NA, Motulsky AG (1994) Assessing genetic risk: implications for health and social policy. National Academy Press, Washington, DC

Angell M (1997) The ethics of clinical research in the third world. N Engl J Med 337:847–849

Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S (1995)

Ethnicity and attitudes toward patient autonomy. JAMA 274:820–825

Botkin JR, McMahon WM, Smith KR, Nash JE (1998) Privacy and confidentiality in the publication of pedigrees: a survey of investigators and biomedical journals. JAMA 279: 1808–1812

Brown PO, Hartwell L (1998) Genomics and human disease—variations on variation. Nat Genet 18:91–93

Caplan A (1994) Handle with care: race, class and genetics. In: Murphy T, Lappe M (eds) Justice and the Human Genome Project. University of California Press, Berkeley, pp 30–45

Christakis NA (1992) Ethics are local: engaging cross-cultural variation in the ethics for clinical research. Soc Sci Med 35: 1079–1091

Clayton E, Steinberg KK, Khoury MJ, Thomson E, Andrews L, Kahn MJ, Kopelman LM, et al (1995) Informed consent for genetic research on stored tissue samples. JAMA 274: 1786–1792

Collins FS, Guyer MS, Chakravarti A (1997) Variations on a theme: cataloging human DNA sequence variation. Science 278:1580–1581

Committee on Human Genome Diversity, National Research Council (1997) Evaluating human genetic diversity. National Academy of Sciences, Washington, DC

Devgan SA, Henderson BE, Yu MC, Shi CY, Pike MC, Ross RK, Reichardt JK (1997) Genetic variation of 3 beta-hydroxysteroid dehydrogenase type II in three racial/ethnic groups: implications for prostate cancer risk. Prostate 33: 9–12

Foster MW, Eisenbraun AJ, Carter TH (1997) Communal discourse as a supplement to informed consent in genetic research. Nat Genet 17:277–279

Friedlander J (1996) Genes, property, and people. Cult Survival Q 20(Summer): 22–24

Glick SM (1997) Unlimited human autonomy—a cultural bias? N Engl J Med 336:954–956

Gostin LO (1995) Informed consent, cultural sensitivity, and respect for persons. JAMA 274:844–845

Kerem E, Kalman YM, Yahav Y, Shoshani T, Abeliovich D, Szeinberg, A, Rivlin J, et al (1995) Highly variable incidence of cystic fibrosis and different mutation distribution among different Jewish ethnic groups in Israel. Hum Genet 96: 193–197

Kevles DJ (1985) In the name of eugenics: genetics and the uses of human heredity. AA Knopf, New York

King PA (1992) The past as prologue: race, class, and gene discrimination. In: Annas GJ, Elias S (eds) Gene mapping: using law and ethics as guides. Oxford University Press, Oxford, pp 94–111

Knoppers BM, Hirtle M, Lormeau S (1996) Ethical issues in international collaborative research on the human genome: the HGP and the HGDP. Genomics 34:272–282

Lyttle J (1997*a*) Is informed consent possible in the rapidly evolving world of DNA sampling? CMAJ 156:257–258

Lyttle J (1997*b*) Issues concerning ethical conduct and genetic mapping raised at Montreal meeting. CMAJ 156:411–412

Macilwain C (1996) Tribal groups attack ethics of genome diversity project. Nature 383:208

Ober C, Lester LA, Mott C, Billstrand C, Lemke A, van der Ven K, Marcus S, et al (1992) Ethnic heterogeneity and cystic fibrosis transmembrane regulator (CFTR) mutation frequencies in Chicago-area CF families. Am J Hum Genet 51: 1344–1348

Parker LS, Majeske RA (1996) Standards of care and ethical concerns in genetic testing and screening. Clin Obstet Gynecol 39:873–884

Pellegrino ED (1992) Intersections of western biomedical ethics and world culture: problematic and possibility. Camb Q Healthcare Ethics 3:191–196

Phoenix DD, Lybrook SM, Trottier RW, Hodgin FC, Crandall LA (1995) Sickle cell screening policies as portent: how will the human genome project affect public sector genetic services? J Natl Med Assoc 87:801–812

Pompidou A (1995) Research on the human genome and patentability—the ethical consequences. J Med Ethics 21(2): 69–71

Powers, M (1993) Publication-related risks to privacy: ethical implications of pedigree studies. IRB 15(July–August): 7–11

Stolberg SG (1998) Concern among Jews is heightened as scientists deepen genetic studies. New York Times, April 22, sec A

Szabo CI, King MC (1997) Population genetics of BRCA1 and BRCA2. Am J Hum Genet 60:1013–1020

Vincent J (1990) Political anthropology. Columbia University Press, New York

Weir R, Horton J (1995) DNA banking and informed consent. Part 1. IRB 17(July–August): 1–4

Wolf S (1995) Beyond ‘genetic discrimination’: toward the broader harm of geneticism. J Law Med Ethics 23:345–353