Informed Consent After the Human Genome Project

Gordon R. Mitchell and Kelly Happe

Human genome research destabilizes established notions of the "consenting research subject," because individuals who donate DNA samples for research studies necessarily reveal sensitive information not only about themselves, but also about others genetically linked to them. An ethical quandary arises from the fact that as virtual research subjects, these genetically linked others may be harmed by research, yet traditional informed consent protocols give them no say about whether proposed projects should be approved. Proliferation of population-specific genetic research in the wake of the Human Genome Project's completion could magnify this ethical quandary on a vast scale. Such concerns have motivated recent proposals in medical ethics to collectivize the norm of informed consent and require investigators to secure group-based approval for genomic research. Controversy over the wisdom and workability of "communal dialogue" protocols for informed group consent pivots around quintessentially rhetorical issues and highlights the myriad challenges involved in reconciling medical benefits with ethical concerns in the post–Human Genome Project milieu.

On June 26, 2000, Francis Collins, Director of the National Human Genome Research Institute, and J. Craig Venter, President of Celera Genomics, Inc. announced triumphantly that a draft of the human genome sequence had been assembled. With an end to the Human Genome Project (HGP) in sight, Collins and Venter joined President Bill Clinton in heralding completion of "the most wondrous map ever produced by mankind," produced in this "greatest age of discovery ever known," when scientists are helping us learn "the language in which God created life."[1]

Such buoyant rhetoric anticipates a post-HGP golden age, with genomic scientists unlocking the mysteries of human life and improving living conditions for all. However, this sanguine optimism should be tempered by the realization that

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a person's class status, ethnicity, and/or gender may very well determine the degree to which they reap the fruits of the genomic "revolution." Indeed, with the ability to diagnose genetic susceptibility to disease far outpacing available treatments, vulnerable groups may come to experience the "book of life" as a recipe for social exclusion and discrimination. This caveat points to the importance of informed consent as an ethical norm in genomic research. Given the weighty ethical, legal, and social implications of post-HGP research, consent protocols used to gain approval for such research deserve careful scrutiny.

In medical ethics, rules governing this process of gaining consent have evolved into a communicative norm requiring that research subjects and patients be informed during consent conversations with researchers and doctors. However, genomic research poses challenging ethical and social issues that overshoot traditional models of informed consent based on the idea that consent is constituted in a communicative act between single subjects and medical practitioners. Sometimes pulling one card from a house of cards causes the entire structure to collapse. The individual and collective stakes imbricated in genetic research intertwine similarly, because disclosure of genetic information by individual DNA donors also exposes information about others with similar genetic profiles. As a team of researchers based at the University of Oklahoma points out,"[a]ll members of a socially identifiable population may be placed at risk by the identification of genetic features linked with their common identity."[2]

The ramifications of genomic research can ripple quickly throughout human populations, with potentially dire consequences for social groups linked to the individual human research subjects who donate tissue samples. As Morris Foster, Ann Eisenbraun, and Thomas Carter explain, "[g]enetic analyses provide information that may trigger stigmatization, discrimination or pyschosocial problems for an entire category of persons defined by common ancestry, even though most members may not have been informed of or consented to the analyses."[3] This phenomenon, a kind of genetic domino effect, has prompted ethicists, scientists, and policymakers to rethink the basic categories undergirding traditional informed consent norms.On one level, Morris Foster, Deborah Bernsten,and Thomas Carter suggest that such revision entails reconceptualization of the very idea of a research subject: "To the extent that genetic research addresses questions that are population specific, the population is the subject."[4] As virtual research subjects, entire groups of people can have their autonomy and privacy compromised by the decision of a solitary individual to participate in genetic research.[5]

One-on-one models of informed consent give these genetic bystanders no say in decisions about whether to proceed with potentially harmful research, since such normative frameworks invest individual research subjects with sole power as agents of consent. Several scholars have recently proposed adoption of "group consent" as a normative rule governing genomic research to alleviate this ethical blind spot in

traditional informed consent doctrines. Such a group consent norm would oblige researchers to secure approval for their work not only from individual research subjects such as DNA donors, but also from relevant populations who share the donor's genetic profile, or who might be adversely affected by proposed projects. By shifting the focus of informed consent from an individual to a group concern, the proposal for group consent in genomic research converts what was previously a private matter into a public affair.

The proposed conversion of informed consent from an ethical norm governing private relationships between doctors and patients to one governing public dialogues between medical researchers and entire population groups raises important issues of special concern to scholars of rhetoric and public affairs. Deciding which audiences should be brought into group consent discussions, determining how researchers should interact with such audiences, and developing criteria for assessing the meaning of audience feedback are all issues shot through with rhetorical significance. Rhetoric, the practical art of vetting viewpoints through deliberation in contingent moments of public decision, here becomes the medium used to negotiate ethical questions and settle on prudent courses of action.

Collective deliberation is complicated here by the fact that in genetic research settings, lines separating individual from group participation blur together. The resulting ambiguity presents vexing rhetorical challenges to those pondering difficult issues regarding appropriate protocols for public deliberation and the proper range of community involvement. The multifaceted nature of these issues is dramatized by the fact that language choices made during the course of dialogue on such subjects exert powerful "framing effects" that tilt the trajectory of deliberation in substantial respects. In the wake of the HGP's completion, scholars, scientists, and citizens will be challenged to fashion novel ethical frameworks suitable for the new world created by genomic technology, as well as to develop reflexive awareness of how framing effects enable and constrain deliberation within such frameworks. This essay engages such challenges by exploring rhetorical dimensions of informed consent in the genomic research context.

Part 1 introduces the problem by considering aspects of genomic research that pose risks to vulnerable populations. This sets the stage for consideration of proposed group consent protocols in part 2, where such proposals are situated contextually within informed consent's historical evolution, then examined in light of the controversy that has ensued after publication of proposed protocols. Part 3 reflects on the value of a rhetorical approach to negotiating the vexing ethical dilemmas involved in group consent dialogues where approval for proposed human subject research is sought. With collective deliberation emerging as an important aspect of the consent process in genomic research, stakeholders will increasingly struggle with many of the same issues that have been perennial themes of analysis in intellectual projects such as rhetoric of science and public understanding of science.

This conceptual convergence presents an opportunity for those involved to pursue reciprocal exchange of ideas to mutual benefit.

POST-HGP RESEARCH: "GRAPESHOT FOR THE GUNS OF PREJUDICE"?

In official informed consent guidelines, HGP co-directors Francis Collins and Aristides Patrinos anticipate that "the DNA sequence information produced by the Human Genome Project will be used in the future for types of research which cannot now be predicted and the risks of which cannot be assessed or disclosed."[6] This level of uncertainty regarding the future course of genomic research seems troubling in light of the possibility that genomic data could become what Philip Reilly, of the Shriver Center for Mental Retardation, calls "grapeshot for the guns of prejudice."[7] Since such findings could impact not only individuals, but entire groups of people linked by a common genetic identity (whether real or imagined), it would seem prudent to consider the extent to which genomic research poses unique risks to entire population groups. Geneticist Jon Beckwith provides one rationale for such a focus with the observation that "in a society that has been torn during the last 40 years over the civil rights movement,school integration, affirmative action, etc., academic arguments for irremedial genetic differences in capabilities between groups may be used to reinforce and support existing discrimination and to oppose policies that attempt to remedy past injustices."[8] Beckwith's reminder punctuates the fact that post-HGP research products will not be introduced into a social vacuum, but will rather be refracted through the prisms of prevailing social norms. Representative Cliff Stearns's (R-FL) comment that "genetic discrimination may be the civil rights battle of the next century"[9] signals that the task of reconciling individual and group interests in the genomic research context will not be an easy chore. It is possible to anticipate the potential harm that unbridled genomic research might pose to particular population groups by considering how historical patterns of prejudice and discrimination could shape the development and application of genomic technologies. We pursue this task in the following section, exploring how prevailing race, class, and gender norms might expose members of vulnerable populations to harmful effects of genomic research.

Race, Class, and Gender as Fault Lines for Genetic Discrimination

Genetic testing is a unique medical intervention, because a patient's or research subject's decision to permit collection of data about his or her genomic profile can have far-reaching consequences that may not be immediately apparent. It is particularly difficult to envision such consequences when doctors propose genetic interventions as sources of information that any concerned patient would want to have. The benign veneer of such proposals typically masks the impact of marking bodies with immutable evidence of genetic "defect."

This dynamic is exacerbated by the fact that rapidly developing technologies are creating a large gap in medicine between the ability to diagnose and the capacity for treatment. Historically, similar gaps have given rise to discriminatory social practices designed by institutions to "cope" with the "inherent defects" of persons afflicted by physical and mental "disorders."[10] For example, in the 1970s, federal and state governments sponsored screening programs for sickle-cell anemia (SCA) that targeted African Americans and identified gene carriers, even when symptoms were not present in research subjects. While the program may have been well intentioned, it nevertheless resulted in general stigmatization and employment discrimination based on race. One influential study concluded that those with sickle-cell trait (people carrying a copy of the SCA gene, but not having SCA) were rendered "hypersusceptible" to chemicals present in almost all industrial environments.[11] With such information in wide circulation, "almost all of the major airlines grounded or fired their employees with the sickle-cell trait."[12] DuPont used SCA screening data to exclude African Americans from well-paying industrial jobs (African Americans were found to be 83 times more likely than whites to carry the SCA gene).[13] The U.S. Air Force Academy excluded sickle-cell carriers from their applicant pool. As it turns out, these exclusionary policies were motivated more by unfounded fear than sound science. For Ruth Hubbard and Elijah Wald, the historical record of such overreaction in this case is very instructive: "As the failure of the sickle-cell screening programs shows, any program that raises doubts about people's genes must be handled very delicately."[14]

Possibilities for similar types of discrimination grow as the range of testable "disorders" expands and equivocal genetic screening data proliferate. For instance, consider breast cancer. After years of demands that more medical attention be given to breast cancer, researchers have responded by isolating genetic mutations that predispose women to develop the disease. In the long run, this research promises to yield important advances in the prevention, detection, and treatment of breast cancer (knowledge of BRCA1's function, for example, may enable development of new pharmaceuticals for women with mutations of this gene).

In the short term, tests are available enabling women to find out if they have inherited one of hundreds of genetic mutations known to increase breast cancer risk. Yet informed consent is crucial here, given that testing's value may be outweighed by the potential harm that testing inflicts.[15] For example, while tests exist for many of the mutations discovered (there are hundreds of mutations of the BRCA1 gene alone), the clinical significance of a positive result is often ambiguous. Some mutations are known to carry an 80 percent lifetime risk of breast cancer, and for women with these mutations, preventive measures like mastectomy can be lifesaving. The problem with widespread testing is that the amount of risk that each mutation confers differs—one survey of research found that risk can vary anywhere from 60 to 80 percent during the course of a woman's lifetime.[16] However, a separate study of three

mutations of the BRCA1 and BRCA2 genes in Ashkenazi Jews showed that a woman who tests positive for a mutation has a 50 percent chance of getting breast cancer by age 70.[17] Putting this discrepancy in perspective, genetic epidemiologist Margaret A. Tucker says, "[a]t this time, we cannot predict an individual's risk based on genetic testing alone. . . . That risk is modified by other genes, environmental exposures or lifestyle factors that we don't have information on yet."[18] Indeed, as research on inherited breast cancer accumulates, it is becoming clear that the disease is produced by a profoundly complex interplay of genetic predispositions and environmental variables.[19]

This causal uncertainty presents problems when one considers that, presently, breast cancer prevention strategies are far from flawless. According to Nina Hallowell, of the Centre for Family Research, "the geneticisation of breast/ovarian cancer has meant that many healthy women have adopted risk management practices which may have iatrogenetic consequences."[20] Women who test positive for a mutation can begin aggressive screening measures, can elect to undergo experimental procedures like Tamoxifen therapy, or can opt for prophylactic mastectomy. Tamoxifen, a drug typically given to some women with a personal history of breast cancer, is associated with several side effects, including but not limited to cardiovascular death, stroke, and uterine cancer.[21] There are also limits to prophylactic mastectomy. Such a procedure cannot guarantee that a woman will avoid getting breast cancer, since whatever breast tissue remains after the mastectomy could be potentially cancerous.[22] Moreover, not all women have access to surgeons with the experience and technical expertise necessary to maximize the prophylactic value of mastectomies.[23] Responding to the increasing frequency with which prophylactic mastectomy is publicly discussed as a surgical solution to breast cancer risk, the Massachusetts Breast Cancer Coalition concludes: "The fact that removal of so many healthy breasts is being hailed as 'prevention' should shock us into understanding how little we really know about what actually causes breast cancer. Many women who develop breast cancer have few if any of the risk factors, and many women with risk factors never develop the disease. While for a select few women prophylactic bilateral mastectomy may be a lifesaving decision, we must keep in mind that removing the causes of breast cancer, not the breast, should remain our real goal."[24]

When the additional risks of employment and health insurance discrimination connected with BRCA screening are considered, one can appreciate why there were initial reservations expressed about widespread commercial testing. The Council for Responsible Genetics argues that since approximately 90 to 95 percent of breast cancer is caused by factors other than inherited risk, and since researchers are far from understanding the complex genetic basis of inherited and somatic breast cancer, prevention strategies such as removal of carcinogenic substances from occupational, residential, and ambient environments should be the top priority of public

health officials.[25] According to Harvard biologist Ruth Hubbard, "[f]ocussing the public's attention on our individual risk factors by hyping gene tests will benefit the scientists and companies that develop and market the tests, but those tests are not likely to protect us from damage to our genes or to other parts of our bodies."[26]

The organizing logic behind the SCA and BRCA screening programs, as well as many other genetic testing regimens, is that use of genetic technology can isolate defects and diseases that might be removed or ameliorated with preventive interventions. However, this logic is complicated by the fact that "defect" and "disease" are inherently plastic concepts. This dynamic is illustrated dramatically in the case of prenatal screening, where an ever-expanding notion of genetic defect animates a testing regime that increasingly poses a threat to the reproductive autonomy of women. Out of the 4,000 genetic traits that are known, more than 300 are identifiable through prenatal genetic testing.[27] Much attention has been focused on the expanding prenatal screening net, through which prospective mothers are at risk of being denied the right to procreate, and pregnant women are given diagnostic information that tells little about whether certain genetic predisposition will result in disease, how serious the symptoms will be, or if treatment is available.[28] As geneticist Richard C. Lewontin explains,"[w]hen a woman is told that the fetus she is carrying has a 50 percent chance of contracting cystic fybrosis . . . she does not gain additional power just by having that knowledge, but is only forced by it to decide and to act within the confines of her relation to the state and her family."[29] According to epidemiologist Abby Lippman, pressures brought to bear in this context raise the specter of eugenics, although such terminology is deliberately eschewed in official reports.

> Though the word "eugenics" is scrupulously avoided in most biomedical reports about prenatal diagnosis, except when it is strongly disclaimed as a motive for intervention, this is disingenuous. Prenatal diagnosis presupposes that certain fetal conditions are intrinsically not "bearable." Increasing diagnostic capability means that such conditions,as well as a host of variations that can be detected *in utero* are proliferating, necessarily broadening the range of what is not "bearable" and restricting concepts of what is "normal." It is, perhaps,not unreasonable to ask ifthe "imperfect" will become anything we can diagnose.[30]

We do not mean to suggest that the screening of serious prenatal defects is an inherently unworthy practice. However, Lippman's analysis shows how the complex entwinements of individual and collective interests in the genetic screening context raise thorny ethical issues deserving careful attention. As the Council for Responsible Genetics points out, "[m]uch of this testing is administered without the informed consent of pregnant women, and the contexts in which these services are being used are far from favorable to women."[31]

Risks posed by widespread circulation of genomic information extend well beyond medical and clinical contexts. For African Americans, the tendency of social phenomena to be "biologized" in genetic research poses unique risks of racial discrimination. Research programs such as former President George H. W. Bush's "Violence Initiative" purport to find the biological basis of violent, criminal behavior, enabling researchers to zero in on inner city youth as those most "susceptible" to this kind of behavior.[32] According to law professor Alfreda Sellers-Diamond, the Violence Initiative is emblematic of a variety of eugenic policies that are likely if HGP research projects are introduced into the prevailing social climate with impunity.

> If indeed, as has been suggested, the gene pool in the United States is deteriorating, and there is a causative relationship between race, IQ, and criminal behavior, then national anti-crime policy might come to reflect measures involving early detection, identification, and preventative treatment of individuals who might later demonstrate violent behavior. All African-Americans might be subject to such treatment irrespective of actual behavior. Policy might also come to reflect "rational" decisions to provide disincentives to the reproductive capacity of genetically disadvantaged people in order to "protect" their offspring from "genetic enslavement" and might reflect also a reevaluation or special commitment of societal resources for genetically superior groups. If the social, educational, and health problems of Black people of the inner city are found to be caused by genetic deficiencies and defects, then society would be imprudent in allocating resources to solve problems which are virtually unsolvable. Indeed, society would be equally imprudent to allocate extraordinary resources to individuals who are genetically destined to succeed.[33]

A similar pattern of triage thinking appears in policy debates dealing with the regulation and cleanup of environmental toxins in the food chain, in workplaces, and in public spaces. Public discussion of how best to allocate public health dollars for environmental cleanup is preempted here by efforts to isolate genetic markers that indicate human vulnerability to toxic exposure. The blame for disease is shifted from environmental conditions long known to be epidemiological risk factors to the presence of susceptibility markers in individual genomes. Polluters stand to gain from the weakened environmental cleanup regime made possible by this shift, whereas biotechnology firms take advantage of new opportunities to explore the genetic basis of disease (which becomes the focus of public health research in light of the government's lack of willingness to prevent toxins from being released in the first place). Unfortunately, the financial windfalls touted as part of this new bioeconomy mask the economic harms perpetuated by such an arrangement—most basic cost-benefit analyses show that it is more efficient to practice prevention than to fund genetic susceptibility research and screen large populations.[34]

Employment discrimination may also increase as employers use blame-shifting to duck out of costly environmental cleanup efforts. Corporations can decide to hire only those individuals who test positively for resistance to toxins, or they can shift the blame for environmental hazards by blaming workers with "defective genes" that make them susceptible to illness.[35] There are several documented attempts by corporations to dodge culpability in lead exposure cases by claiming that exposed children had genetic susceptibility to low IQ scores.[36] As Hubbard observed, "at a time when many employers are resisting compliance with even the most basic industrial hygiene regulations aimed at reducing the risks of documented industrial diseases, genetic screening serves to deflect attention from serious occupational health hazards that threaten all workers."[37] Prevailing political momentum to scale back environmental regulations threatens to intensify the trend Hubbard identified several years ago.

The current structure of the U.S. health-care delivery system only reinforces these trends by shifting extensive risks to the uninsured and underinsured. In this light, George J. Annas and Sherman Elias anticipate that the distribution of HGP's benefits and costs is likely to cut across class lines: "As with all new, expensive medical technology, the fruits of the Human Genome Project are likely to go primarily to the wealthy. Its stigma potential is likely to be used primarily against the poor."[38] Those who test positive for genetic "defects" risk losing their health insurance and face the prospect of fewer social welfare benefits, a trend that is sure to have a disproportionate impact on poor and working-class persons. There are few institutional safeguards currently in place to prevent such class-based discrimination. There are no federal laws banning health insurance discrimination based on genetic profiles, and while a majority of states have enacted protections,many state laws are not thorough enough.[39]

THE DEBATE OVER GROUP CONSENT

Previous discussion of the potential risks posed by the genetic screening and testing made possible by the HGP highlights the fact that computerized genomic research represents a new sort of science so powerful that its capability to transform society invites comparisons to the Manhattan Project, another government-sponsored megascience initiative that altered the course of history dramatically.[40] This analogy not only foregrounds the potential of genomic research to trigger sweeping changes in medicine, politics, and culture; it also signals ominously the potential harm to human subjects posed by acceleration and proliferation of such research. According to a summary of Annas's recent presentation to a Human Subjects Conference, "informed consent, justice, and fairness are not being taken seriously enough in the area of genetic research. Neither the Nuremberg Code nor current Federal regulations address genetic research directly; therefore,new safeguards are needed."[41] It is

useful to contextualize Annas's prescription for new informed consent safeguards by considering briefly how prevailing informed consent norms have evolved, especially since such a history reflects the emergence of effective communication as a constitutive component of medical ethics, a trend that may be of particular interest to rhetorical scholars.

Following World War II, an international war crimes tribunal established the Nuremberg Code as the standard for judging the behavior of Nazi medical doctors who performed involuntary experiments on human subjects as part of Germany's "Final Solution." The Nuremberg Code begins with the statement "[t]he voluntary consent of the human subject is absolutely essential," and goes on to outline ten ethical guidelines for medical research conducted on human subjects. In the United States, subsequent evolution of the informed consent doctrine during the 1950s and 1960s was shaped significantly by national security imperatives.[42] With health effects research identified by the Pentagon as a crucial component of the U.S. military readiness program,the job of translating ethical norms of the Nuremberg Code into practical guidelines for research fell primarily to "bureaucratic sources with legal, insurance, and public relations responsibilities, rather than from the fraternity of medical researchers."[43] It was not until 1953 that the U.S. military chain of command recognized the Nuremberg Code as a formal and binding standard governing medical research on human subjects. This policy was handed down in a memorandum signed by Secretary of Defense Charles Wilson,[44] but because the memorandum was classified Top Secret, "there were problems in the dissemination" of the memo throughout the military research community.[45]

During the 1970s, scandals such as disclosure of the Tuskegee Syphilis Study galvanized concern about informed consent among members of the medical community and ultimately led to promulgation of research codes by the Department of Health, Education, and Welfare as well as congressional passage of the National Research Act. Litigation growing out of such codes drew from precedents in contract and negligence law to inform judgments regarding the legality of particular research protocols in military and civilian contexts.

Later, the doctrine of informed consent took a communicative turn, as heightened concern for vulnerable research subjects prompted ethicists to refashion the norm from a legal "duty to warn" into a mandate for "actively shared decision-making" between doctor and patient. In 1981, the U.S. Congress commissioned a President's Commission report on the subject of informed consent, entitled *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*.[46] This report concluded that the courts had not fulfilled their obligation to fashion a sufficiently robust doctrine of informed consent, and that the failings of the judiciary could be explained mainly by the fact that in focusing so intently on the jurisprudence addressing doctors' "duty to warn," judges had become blind to the real essence of informed consent, "actively shared

decision-making."[47] In making the procedural quality of doctor-patient interaction a key criterion on which informed consent rests, the President's Commission extended legal requirements for consent in several respects.

First, by placing the burden of initiating and facilitating dialogue on physicians, the procedural account of informed consent acknowledged the privileged power position held by doctors and shed light on the potentially distorting effects of such power on the quality of clinical dialogue. Thus, the President's Commission noted that a physician's privileged status also carried with it the mantle of leadership in patient-physician conversation: "[T]he health professional's expert knowledge, focused through the particular diagnosis and prognosis for the patient,usually confers on that person the natural role of leader and initiator in building any shared understanding."[48] This prescription called on health professionals to translate technical concepts into everyday language, inform patients about all relevant alternatives to proposed treatments, and be aware of "framing effects," since "the way information is presented can powerfully affect the recipient's response to it."[49]

Second, the joint decision-making model highlighted the importance of reflexive, critical deliberation. Through disclosure and dialogue, the aim here was that doctors and patients would have the opportunity to refine and improve their own viewpoints as they became increasingly cognizant of different perspectives during conversational give-and-take. According to ethicist Jay Katz, this communicative reflexivity is a vital ingredient in medical decision making, since it is necessary to cope with the inherently bounded rationality of difficult judgments about risk.[50]

Third, the shared decision-making model represented a decentering of the locus of legitimate physician authority. Under the duty-to-warn framework of informed consent, doctors secured *de facto* legitimacy vis-à-vis patients by virtue of their authoritative status as scientific experts. But by refiguring informed consent as a dialogic process instead of a fixed legal hurdle, the shared decision-making model prioritized trust growing out of genuine mutual doctor-patient conversation as a crucial component of medical ethics.

The commission's recommendations still stand as important milestones in the evolutionary history of informed consent standards, because in 1991, the U.S. federal government codified many of these recommendations in the "Common Rule," a general set of regulatory provisions governing human subjects research.[51] Today, the Common Rule and the Nuremberg Code are acknowledged explicitly as controlling guidelines for informed consent in official HGP documents.[52] However, the historical record of official disregard for the Nuremberg Code in U.S. government-sponsored research,[53] the spotty track record of translating official policy into medical practice in the area of informed consent, and recent disclosures of ethical abuses in gene therapy experiments,[54] warrant careful review of contemporary claims certifying the ethical soundness of current medical experiments involving human subjects.

The unique challenge posed by prescriptions for new safeguards for informed group consent in the genomic context is that such a task requires creation of normative frameworks surpassing previous individualized frameworks fashioned to govern one-on-one doctor-patient encounters. These individualized frameworks currently govern the consent process in genomic research, but approval given by individuals in such one-on-one settings may not satisfy fully the ethical norm of informed consent in this context, since one person's decision to participate in such research necessarily transforms family members and other genetically related persons into virtual research subjects. Foster, Bernsten, and Carter note that since the study of a single person's genetic tissue necessarily reveals potentially sensitive information about all persons genetically linked to that lone research subject,"in an identifiable population, nonparticipants share the same collective risks as do persons who volunteer for research."[55] Extending this line of analysis, law professor Henry Greely suggests that the guarantee of autonomy undergirding individualized norms of informed consent may actually *compromise* the collective autonomy of groups affected by genomic research.

> Looking at this as an issue of *individual* autonomy, however, seems somewhat artificial. The research inevitably provides information about a group, as well as the individuals who constitute it. The group—whether one family, a set of families in a genetic disease organization, or an ethnic group—is really the research subject. It is the group's collective autonomy that is challenged if researchers, with the informed consent of only a few individuals in the group, can probe for information about the whole group.[56]

Policymakers and opinion leaders are still coming to grips with the ethical and logistical challenges presented by the fact that genomic research impacts whole population groups as research subjects, even when just a few individual DNA donors contribute tissue samples for analysis. Some commentators have focused on how this trend has implicated ethical issues in research subject recruitment.[57] Others have examined how research findings shape broad social norms regarding entire population groups.[58] A related line of research has taken up the challenge of developing concrete models and protocols for "group based consent" in the context of genomic research.[59] The following discussion explores concrete models and specific proposals for group consent, then considers reservations expressed about the utility and appropriateness of the group consent norm.

Model Protocols for Group Consent

A team of anthropologists at the University of Oklahoma recently created a protocol for group consent of genomic research and tested it in "communal discourses"

with Native American populations.[60] The team's decision to pursue a targeted, population-specific DNA sampling procedure led the team to approach two culturally discrete population groups with their proposal. Initially, the researchers conducted a survey of the potential study participants, in order to "identify formal and informal decision-making processes" regarding health in the respective Native American communities.[61] Researchers then convened a series of public meetings (open to all tribal members) where they explained their research goals, namely to improve understanding of diabetes mellitus and prostate cancer, illnesses perceived to be major health problems by the Native American research subjects.

Ultimately, the public meetings resulted in both communities granting consent for the proposed research projects. However, such agreements were reached only after the researchers responded to important concerns raised by prospective research subjects. These concerns were met with commitments by the research team to adhere to certain experimental procedures and share decision-making authority with tribal authorities. Specifically, researchers agreed to modify techniques for drawing and storing blood samples, so that laboratory treatment of such samples would be harmonized with Native American religious beliefs. Community review boards were created to establish channels of dialogue between the research team and community members. These boards were given authority to review manuscripts that reported project findings and to provide general feedback to the research team as the project unfolded.[62] The overall *telos* organizing these projects was an emphasis on group involvement and community consensus. "When specific concerns were expressed," members of the research team explained, "these issues were re-negotiated."[63]

It will be instructive to explore further the issue of group-based informed consent by examining the Human Genome Diversity Project (HGDP), since another model for group consent has been proposed specifically to govern HGDP research. The HGDP is an independent genetic research initiative formally launched in 1994 and funded by multiple agencies of the U.S. government.[64] Instead of pursuing the HGP goal of mapping and sequencing the three billion nucleotide pairs of DNA making up "the" human genome,[65] the HGDP is designed to study genetic variations across distinct cultural and ethnic groups. The fact that HGDP research actually targets specific social groups as "donor populations" has raised ethical concerns.

Responding to these concerns in 1997, a large group of doctors, scientists, and citizens comprising the North American Regional Committee (hereafter NamC) drafted a "Proposed Model Ethical Protocol for Collecting DNA Samples." Because the NamC embraces openly group-based informed consent as an ethical imperative in the context of DNA research, the "Proposed Model Ethical Protocol" bears directly on some of the main themes highlighted in this essay. First and foremost, the "Proposed Model Ethical Protocol" acknowledges that "the population-based nature of this research requires population-based consent" and that "it cannot be

ethically appropriate to sample some members of a group when the group itself has not agreed to participate in the HGDP."[66] The "Proposed Model Ethical Protocol" stipulates further that "community consent can only be given after the researchers have fully explained their proposed activities." Dimensions of explanation must include "the nature,the goals, and the method" of the research, and in order to render such explanations understandable to community members, "researchers will have to educate the population about genetics."[67]

The University of Oklahoma's framework for "communal discourse" and the NamC's "Proposed Model Ethical Protocol" exhibit concrete ways in which the group consent norm for genomic research can be expressed in practice. These two examples are similar in that they are both attempts to pursue group consent in research projects targeting distinct sociocultural populations as collective research subjects. The Native American tribes approached by the University of Oklahoma team and the various indigenous populations solicited to participate in the HGDP have relatively well-defined social structures, group histories, and customs of collective decision making. However, there are unique challenges involved in replicating this type of population-specific protocol for mass sequencing projects such as the HGP, where the sociocultural heterogeneity of the DNA donor population makes it difficult to isolate appropriate audiences for communal dialogues focusing on group consent. In the next section, these difficulties will be put in high relief when we explore the controversy over group consent protocols and focus on arguments advanced against norms for group consent. Such a dialectical perspective on this emergent scientific controversy takes sociologist Trevor Pinch's observation as a point of departure: "It has been argued persuasively that scientific controversies form a strategic research site for studying science. During a controversy, social processes not normally visible within science can become unusually explicit. . . . Under the lens of a scientific controversy, the good, the bad and the ugly within science come into focus as never before."[68]

Controversy Over the Group Consent Norm

Publication of the research protocols for group consent just described has stimulated lively controversy covering a rich variety of topics, including the proper role of participatory decision making in human genetics research, the limits of research protocols unique to Anglo-American science, and other political concerns that might fall under the rubric of "identity politics." Skeptics of the group consent norm have argued that difficulties in isolating appropriate audiences for group consent undermine the utility of communal discourse models, that resource limitations complicate widespread implementation of the group consent norm, and that the norm introduces a harmful element of paternalism into the scientific research setting.

Bioethicist Eric Juengst argues that models of communal discourse would not adequately protect the populations they are designed to serve, because difficulties with "group demarcation" undermine efforts to locate the proper audiences that need to be engaged in consent dialogues.[69] According to Juengst, a serious problem arises from the fact that groups linked by genetic ties ("demes") do not match up with the social groups privileged by the Foster et al.model as proper agents of group consent.[70] Genetically linked persons who share a common stake in the outcome of a particular research project may not live near each other, or share overlapping moral, social, and deliberative ties that would be important ingredients of any meaningful group consent discussion. According to skeptics, this problem becomes more acute when larger group consent audiences are contemplated. "Their [Foster et al.] model of community participation and approval seems workable only with small groups that have a well-defined leadership structure," argues Reilly. "The challenge of seeking community approval within a tribe of a few hundred is imaginable; the challenge of seeking consensus among larger groups is not."[71] Reilly's concerns raise important theoretical issues for rhetorical scholars, since the slippery notion of a "public" may be defined genetically, geographically, socially, economically, or with other boundary markers.

Skeptics of the group consent norm have advanced other arguments based on sheer utility. For example, Reilly contends that if the Foster et al. model is generalized, it could "create a significant new cost to gene-mapping studies,"[72] and that "[e]fforts to proceed in a similar fashion elsewhere could lead to great expense and long delays and could, possibly, chill some research."[73] Writing with David C. Page of the Howard Hughes Medical Institute, Reilly speculates that pursuit of the group consent norm in research focusing on "'Jewish' genetic diseases" could "lead to research being blocked due to intangible (and largely undocumented) fears."[74]

Additionally, skeptics of the group consent norm suggest that communal dialogues designed to secure collective consent endow researchers with paternalistic authority to preempt the moral agency exercised by individual members of affected groups.[75] In a world where consensus is often elusive, some members of a population may want to participate in proposed projects, even though group leaders may not sanction such activities. As groups being studied become larger and more dispersed, conflicts of this sort seem unavoidable. This argument is reinforced by Reilly's claim that under group consent frameworks, researchers will have an incentive to engage in "forum shopping, as investigators try to determine which population would be easiest to work with."[76]

RHETORICAL DIMENSIONS OF GROUP CONSENT

The advent of genetic research has destabilized the ethical norm of informed consent by presenting the problem that harms to whole groups of persons could follow

from isolated decisions by individual research subjects to donate DNA samples. The remedial call for an expanded ethical norm of group consent represents a new twist in the history of informed consent, a rhetorical turn that foregrounds the importance of collective deliberation as a central dimension of research ethics. In this section, we explore rhetorical dimensions of the new turn toward collective deliberation and decision making in informed consent protocols. Such exploration has heuristic value for those negotiating the complex challenges posed by genomic research, as well as theoretical relevance for the public understanding of science and the rhetoric of science projects.

Public Deliberation in Group Consent Protocols

The study of rhetoric steers attention to the importance of collective deliberation as a mode of social learning and decision making. The desirability, viability, and workability of deliberative frameworks are key points of *stasis* in the controversy over proposed norms for genomic research.[77] Advocates of group consent argue that the advent of genomic research undermines the traditional assumption that legitimate consent can be granted by individual research subjects. Because an individual's participation in genomic research necessarily implicates others who share similar genetic profiles, according to the NamC and Foster et al., such genetic bystanders deserve a say about whether such research should be approved. Skeptics such as Juengst and Reilly counter that the logistical difficulties involved in isolating the proper boundary lines demarcating appropriate audiences for group consent dialogues preclude widespread application of group consent norms in genomic research. These difficulties are exacerbated, according to Juengst and Reilly, when genomic research projects solicit participation of wider audiences of research groups drawn from heterogeneous sociocultural backgrounds. If a heterogeneous donor population has genetic links to virtually all major social groups, then it would seem to follow that for informed group consent to be achieved, approval by all members of society would be required. Such a conclusion points to an inherent tension between ethical imperatives and practical logistics in genomic research projects, since a universal referendum on every proposed project hardly seems workable.

While the concerns raised by Juengst and Reilly are legitimate, such reservations should not eclipse the potential that communal discourse models have to involve discrete populations in deliberations about the appropriate trajectory of genomic research. Even when political or religious leaders are not readily identifiable in larger, dispersed, or at-risk populations, the case studies conducted by Foster's team demonstrate the feasibility of working with social units of varying sizes within an overall population. When different views between distinct populations undermine uniformity of research, Foster et al. argue that researchers have the burden of tailoring research questions, protocol, and decision making to each localized context. For

example, women identify as mothers, caregivers, survivors of disease,and members of a race, ethnicity, and class. Although it may be impossible to enlist the entire population of women in group consent dialogues to consider proposed genomic research focusing on women's health, it is still possible to craft appropriate audiences for consent dialogues based on the overlapping levels of social identity comprising this loosely defined population.

Breast cancer research offers a telling case in point. Discrete populations that could serve as audiences in group consent dialogues here might be identified with "cancer maps"[78] that demarcate groups of women who suffer from or are at risk to develop breast cancer. Using such data, researchers could engage in dialogue with women living in geographically distinct areas, discuss the relevancy of genetic research ,n egotiate guidelines for genetic screening (if such screening is desired), and work out broader arrangements for compensation of research subjects that might include, for example, cooperative plans for ameliorating carcinogenic conditions in the local environment. This opening of deliberative space may also clear the way for more widespread reflection on the dangers posed by mass marketing of genetic tests.

The breast cancer research example illustrates how multifaceted aspects of group identity relate to the logistical challenges involved in executing protocols for group consent. One insight that emerges in light of this discussion is that *contra* Juengst's suggestion, lines demarcating group consent audiences do not necessarily have to mirror the genetic boundaries marking off discrete demes. For example, a group of women living in a residential area designated as high risk on a "cancer map" may or may not share common genetic profiles. However, the group members living within this geographical boundary would share common interests stemming from their shared environmental conditions, and such overlapping interests could serve as important reference points for collective decision making regarding the appropriateness of large-scale genomic research that would involve them as research subjects.

The variegated layers of discrete subgroups embedded within larger populations pose unique challenges for researchers seeking to strike the right balance between ethical rigor and practical expediency. These challenges come to the fore when researchers face the task of drawing boundary lines demarcating selected audiences for group consent dialogues in particular research settings. On the one hand, the interest in squaring research with informed consent norms may create motivations to draw such boundaries expansively, thus bringing a wide array of subgroups into conversation. On the other hand, resource limitations and logistical concerns present countervailing incentives to isolate narrow, tightly defined subgroups as consent audiences. Since group consent is still an emergent norm in medical ethics, there are presently few guidelines available to help researchers negotiate these hurdles. However, the explosion of genomic research likely to take place after completion of the HGP is sure to intensify the need for ongoing discussion and refinement of strategies and guidelines for navigating such dilemmas.

Framing Effects in Group Consent Discussions

One bedrock principle of informed consent doctrines that has held fast through the years is the notion that the two components of the norm ("informed" and "consent") operate in tandem as an interlocking pair. Thus, no consent can be given where it is impossible for subjects to be informed, or where coercion makes it difficult for subjects to exercise consent competently. Mapped onto proposals for group consent, the interlocking nature of the informed consent norm highlights the importance that participants in "community dialogues" possess sufficient knowledge to allow for truly informed discussions. Absent such knowledge, it is easy to imagine researchers engaging in paternalist "forum shopping" of the sort predicted by Reilly. The collective consent flowing from audiences selected on the basis of their ignorance would rest on a dubious ethical foundation. Many commentators stress the importance of this principle when they call for heightened general understanding of genetics and greater public involvement in scientific agenda setting. For example, Annas and Elias suggest that "both the scientists and the public must get involved in open and intense discussions . . . if human rights and human dignity are to survive the genetic revolution."[79] Similar calls have been made for more vigorous public participation in decision making on genomic research in Australia[80] and the United Kingdom.[81]

Scholars working on the unfortunately abbreviated "public understanding of science" (PUS) problem have grappled with the theoretical and political aspects of similar calls, examining how popular attitudes toward the scientific enterprise are formed and exploring the role of such attitudes in the formulation of science policy. In a review of PUS scholarship, sociologist Brian Wynne traces the roots of such studies back to "large-scale public attitude surveys" about science that began in the 1950s.[82] These studies, conducted by organizations such as the U.S. National Science Writers Association (NSWA), were symbiotic with existing scientific institutions and helped scientists craft their rhetorical appeals to general audiences, thereby leveraging research funding requests.

Recently, PUS research has taken a more critical turn, with scholars exploring public uptake of science from a theoretical horizon that interrogates prevailing assumptions about the very nature of terms like "science" and "public understanding." Wynne explains that such an approach steers attention to issues such as "how particular scientific constructions incorporate tacit, closed models of social relationships that are or should be open to negotiation."[83] From this vantage point, Steve Fuller notes that "programmes of science literacy that promise no new political outlets ultimately serve those who dominate the scientific enterprise, by breaking down the cognitive barriers that prevent the citizenry from being completely comfortable with the 'scientific' way of thinking."[84] Approaching the controversy over group consent from such a critical perspective highlights the fact that "community discussions"

linking scientists and members of the general public in deliberations about the proper direction of genomic research are unlikely to mirror Habermasian "ideal speech situations."[85] Perhaps the most basic factor complicating such discussions involves the way in which discourse is shaped by so-called framing effects produced by the rhetorical choices of interlocutors.

In the communicative model of informed consent developed by the President's Commission in the early 1980s, framing effects were acknowledged as key elements of doctor-patient dialogues having real potential to compromise the integrity of "actively shared decision-making." Under this ethical framework, doctors were obliged to anticipate framing effects of their own discourse and adjust their contributions to informed consent dialogues so as to minimize confusion and avoid unnecessary consolidation of their own decision-making power. Such an ethical burden becomes especially weighty when mapped onto "communal dialogues" designed to secure group consent for genomic research.[86] The public nature of such dialogues magnifies the potential impact of framing effects and heightens the need for scientists to engage in reflexive critique about their own languaging strategies.[87]

One of the most powerful framing effects in public discourse about genomic research materializes when proponents of such research invoke the argumentative *topos* of "genetic essentialism" to bolster their positions.[88] It is not difficult to locate examples where prominent advocates of genomic research have advanced claims that inflate the causal determinism of genetic factors in accounting for disease or explaining the essence of human nature. As Dorothy Nelkin and M. Susan Lindee point out, "in presenting their research to the public, scientists have been active players in constructing the powers of the gene."[89] This same phenomenon is noted by Jon Beckwith and Joseph Alper, who observe that "genetic essentialist thinking" has been reinforced by the "hyperbole surrounding the HGP."[90] In addition to HGP founder James D. Watson's famous claim that "our fate is in our genes,"[91] there is also his statement that the HGP, "the Holy Grail" of life, promises to reveal "ultimate answers to the chemical underpinnings of human existence."[92] While such episodes of hyperbole could be discounted as benign instances of megascience boosterism, this sort of discourse tends to circulate widely in public spheres and crystallize into rhetorical frames that structure popular understanding about genetic science.[93]

This essentialist hyperbole has important framing effects on general public understanding and communal discussions of genomic research. According to Nelkin and Lindee, "[t]he popularity of the Human Genome Project, with its almost weekly discovery of new genes and promises of new cures, encourages the institutional use of genetic information and, at the same time, discourages serious public scrutiny."[94] In public spheres where the predictive power of genomic research is oversold, collective judgments regarding the appropriateness of research are likely to be clouded by the mirage of gene therapy miracles. Likewise, inflated popular perceptions of the causal efficacy of genes as foolproof predictors of health

and behavioral trends tend to work as recipes for social discrimination in areas such as health insurance,[95] employment,[96] education, adoption, and crime control.[97] "Even though genomic information can be unreliable or extraordinarily complicated to decipher," law professor Larry Gostin explains that "public perceptions attribute great weight to genetic findings and simply aggravate the potential stigma and discrimination."[98]

Traditional notions of a scientific "detached observer" are rendered obsolete in this context, since the way scientists *communicate* about their genomic research products produces material effects that can have substantial bearing on whether such products are used for good or ill. In one-on-one clinical settings, doctors encounter similar situations when they make choices about how to frame patient prognoses and treatment options. Noting this phenomenon, the President's Commission concluded that an important component of the doctor's burden in consent conversations involves the obligation to adopt a reflexive posture that heightens awareness of the potential framing effects of their own professional discourse. According to the President's Commission, such a burden also entails the obligation to counter proactively any framing effects that might flatten consent conversations or endow professionals with stultifying power monopolies.

The North American Regional Committee's formulation of researcher responsibilities in group consent discussions regarding the HGDP contains a parallel call for self-limiting rhetoric. In its "Proposed Model Ethical Protocol," NamC stipulates that "researchers must ensure that the population understands both the limits of disease-related research and the limits of their own work."[99] Celeste Michelle Condit's notion of a "biological version of the Heisenberg uncertainty principle" offers one possible expression of such a rhetorical norm:"[J]ust because it becomes increasingly easy to intervene in biological systems does not mean that it will be proportionately easy to control the outcomes of those interventions."[100] By framing "communal discussions" of genomic research in the self-limiting language of such a "biological version of the Heisenberg uncertainty principle," researchers might equip audiences with the resources to make more informed decisions regarding genomic research agendas, softening overdetermined notions of genetic essentialism and lessening risks of genetic stigma and discrimination in the process.

Notably, the "Proposed Model Ethical Protocol" goes beyond prescribing an affirmative pedagogical responsibility for researchers to explain the limits of their projects in informed consent dialogues, making a further requirement that researchers take initiative to counteract any abuse of genetic information produced by the HGDP.

> But, whatever the scientific reading of HGDP data, it seems likely that racists or nationalists will try to misuse it for their own purposes. Bosnian Serbs might well try to use any relevant HGDP data to claim genetic superiority to Bosnian Muslims. To

> prevent harm to participating populations, the Model Protocol recognizes that the HGDP must *react to*, and *counteract*, that kind of abuse.[101]

This remarkable normative principle suggests that genomic scientists have ethical responsibility not only for the part of the research process they control directly, but also for any possible *spin-off uses* of their genetic research products. A strong interpretation of this ethical responsibility would yield an imperative on the part of scientists to intervene affirmatively in the political sphere to counter misuse of their research.[102] Such an expectation represents a dramatic break from traditional models of scientific inquiry that presuppose a clear bifurcation between laboratory science and public affairs. However, such a break is not wholly foreign to science. As historian Lawrence Badash explains, after World War II, "social responsibility became a stronger and stronger force among American scientists. . . . One by one, and not without resistance, scientific societies adopted bylaws or policy statements that affirmed their duty, as they saw it, to try to influence national policy."[103] It took two devastating nuclear explosions to spark this political consciousness on the part of nuclear scientists; it remains to be seen whether genomic scientists reach comparable awareness absent a similar catastrophic catalyst.

CONCLUSION

Recently, philosopher Peter Sloterdijk gave a provocative lecture entitled "Rules for the Human Zoo: An Answer to the Letter on Humanism" at the Elmau Castle in Bavaria. In his talk, Sloterdijk ruminated on the value of "selection," "breeding," and "biotechnological optimization" as viable options for social improvement in an age when traditional means of humanist advancement (e.g., reading, education) have, according to him, exhausted much of their potential.[104] Apparently, Sloterdijk's intervention was motivated less by a desire to advocate eugenics, and more by the hope that through provocation, German publics could be prodded to debate more frankly the implications of modern genetics. The firestorm of controversy that ensued following Sloterdijk's speech serves as a reminder of how the rapid acceleration of genetic science portends wrenching upheaval in public forums where the implications of such technical advances are contemplated. What are the prospects for society to deal effectively with the profound social challenges posed by genetics in light of what Sloterdijk darkly calls "today's tendency toward barbarism"? Given the historical patterns of prejudice and discrimination in the United States, can the fruits of genetic technology be realized in a way that avoids ushering in a new era of social oppression? Proponents of "communal dialogue" protocols for informed consent in genomic research express faith in the value of public discourse as a steering mechanism in this regard. Whether such forms of public participation blossom and fulfill their potential remains to be seen. However, when one considers the role

of public input during the original debates on the HGP itself, it becomes clear that such a flowering of public participation would represent a significant break from the past.

The HGP grew out of an insider lobbying effort where officials at the Department of Energy's Office of Health and Environmental Research (DOE's OHER) pitched the project to official Beltway audiences and capitalized on the intersection of powerful interests lined up behind the proposal in the mid-1980s.[105] To garner support from the scientific community, OHER chief Charles DeLisi drew up a memo in 1986 outlining several preliminary phases of HGP work.[106] In DOE hearings held shortly thereafter, three sympathetic DOE witnesses addressed the nascent HGP, and no testimony from independent scientists critical of the project was taken.[107] Then, in 1990, Senator Pete Domenici (R-NM) convened congressional hearings to consider budget appropriations for the HGP. While many viewed the hearings as a formality given the bureaucratic inertia that had already gathered behind the project, two vocal critics were invited as witnesses. However, after all of the proponents had testified, only one of the two critics was finally called to address the committee, long after eleven of the twelve journalists had left. As historian Michael Fortun explains,"it was indeed evident that Domenici (nor for that matter any of the other senators who had shown up for the hearing that day) was not particularly interested in hearing and considering criticism of what had been a favored project of his for several years."[108] The insider campaign to launch the HGP hardly stands out as an exemplar of participatory decision making conducted to assert democratic control over science and technology. In retrospect, such a high-powered,low-profile lobbying effort seems highly questionable as a method of securing approval for a megascience initiative with the potential to transform society so fundamentally.

More than a decade after the HGP's initial approval, such concerns have taken on new salience, since a complete "map" of the human genome is likely to spur a dramatic increase in targeted research projects designed to link specific diseases and traits with discrete genetic patterns found in social groups. The far-reaching potential of genomic research to touch the lives of those who do not even participate directly as DNA donors signals a need for opinion leaders, researchers, and citizens alike to develop heightened awareness of the medical, cultural, and political ripple effects posed by this line of research. For scientists, such heightened awareness is not just politically expedient; it may be ethically imperative, in light of recent trends in the informed consent process emphasizing the importance of collective participation in consent protocols. For citizens, there is similar urgency, since "[a]s research on disease susceptibility and resistance increasingly focuses on population-specific genetic diversity," Foster, Bernsten, and Carter point out that such research "may affect an increasingly larger proportion of research subjects, including some who are now treated as being members of the 'general population.'" In this scenario, the

fact that "everyone is a member of one or more socially identifiable populations"[109] will come into high relief, with the issue of group consent taking on larger ethical relevance for all members of society.

Population-specific DNA research projects proposed in the wake of the HGP promise to produce rhetorical exigencies that call for collective deliberation and shared decision making as necessary responses to complex contingencies. There are many logistical challenges raised by this development, and the process of integrating public input into proposed research initiatives places novel demands on scientists, some of whom are likely to view participatory decision making as a cumbersome constraint on free-wheeling inquiry. But as sociologist Marque-Luisa Miringoff points out, "[s]cientists can no longer insulate themselves from the demands of public involvement."[110] In our age of what physicist John Ziman calls "post-academic science," where "scientists are inevitably drawn into the sphere of politics,"[111] the tidy boundaries that used to separate laboratories from deliberative forums are becoming much muddier.

While this trend may pose headaches for scientists who disdain navigating the turbulent currents of public discourse, it presents unique opportunities for rhetorical scholars who study such discourse.[112] Early rhetoric of science scholarship was concerned with uncovering hidden tools of persuasion buried in the most technical texts. This work sometimes had the feel of brave excavating expeditions, with rhetorical critics delving deep into the "internal" processes of natural science to unearth persuasive devices often buried underneath markers of detached objectivity. Today, it is the scientists who increasingly make a related kind of expedition, crossing into the realm of rhetoric to discuss their work in public forums. This change in the flow of intellectual traffic is in part born out of necessity—collapse of the so-called scientific social contract has forced scientists more frequently into deliberative settings where they are called upon to justify their work to non-expert audiences. But Ziman explains that the heightened role of ethics in contemporary science also plays a role here: "As their products become more tightly woven into the social fabric, scientists are having to perform new roles in which ethical considerations can no longer be swept aside."[113]

One sees scientists struggling with this rhetorical exigence in the nascent controversy over group consent in genomic research. It may be the case that some genetics research likely to be approved in one-on-one consent protocols might meet resistance in group consent dialogues, especially once potential research subjects begin to grasp more surely the nature and limits of proposed projects. However, scientists should be prepared to accept such scenarios if they take informed consent seriously as an ethical norm governing research. Will the coming era of widespread genomic research resemble the golden age of revolutionary medicine promised by HGP visionaries, or the gloomy and dystopic future dramatized in the film *Gattaca*? The future probably lies somewhere in between. Whether society veers toward one

pole or the other depends on how the trajectory of history is charted during upcoming deliberations about the proper course of post-HGP science. Watson popularized the HGP with the famous slogan "our fate is in our genes." Now, with the question of what to *do* with the avalanche of genomic data produced by Watson's project rising to the top of the agenda, the time seems ripe to embrace the idea that "our fate is in our hands."[114]

NOTES

1. "Remarks by the President, Tony Blair, Dr. Francis Collins, and Dr. Craig Venter, on the Completion of the First Survey of the Entire Human Genome Project," White House press release, June 26, 2000, Internet, White House website, online at <http://clinton3.nara.gov/WH/EOP/OSTP/html/00628_2.html>
2. Morris W. Foster, Richard R.Sharp, William L. Freeman, Michelle Chino, Deborah Bernsten, and Thomas H. Carter, "The Role of Community Review in Evaluating the Risks of Human Genetic Variation Research," *American Journal of Human Genetics* 64 (1999):1719.
3. Morris W. Foster, Ann J. Eisenbraun, and Thomas H. Carter, "Communal Discourse as a Supplement to Informed Consent for Genetic Research," *Nature Genetics* 17 (1997): 277; see also National Research Council,"Human Rights and Human Genetic Variation Research," in *Health and Human Rights: A Reader*, ed. Jonathan M. Mann, Sofia Gruskin, Michael A. Grodin,and George J. Annas (New York: Routledge,1999),383.
4. Morris W. Foster, Deborah Bernsten, and Thomas Carter, "A Model Agreement for Genetic Research in Socially Identifiable Populations," *American Journal of Human Genetics* 63 (1998):699.
5. Morris Foster and Richard Sharp propose a dichotomy between "external risks" and "intra-community risks" to elucidate the range of possible group-based harms that might result from the decision of a few individual group members to participate in genomic research. In this schema, external risks involve harms visited upon group members as a result of public release of research findings. Examples include challenges to the legal or political status of sovereign American Indian and Alaskan Native communities, employment or insurance discrimination, and difficulties adopting a child. In contrast, intra-community risks arise when genetic information "can be interpreted by members of a study population in ways that disrupt the established social order of their shared community." Such disruptions might ensue if genetic research produces findings at odds with prevailing notions of shared identity that tie communities together, or if research results undermine the moral standing of certain families within a community (see Morris W. Foster and Richard R. Sharp, "Genetic Research and Culturally Specific Risks: One Size Does Not Fit All," *Trends in Genetics* 16 [2000]: 93–94).
6. Francis S. Collins and Aristides N. Patrinos, "The Use of Human Subjects in Large-Scale DNA Sequencing," National Human Genome Research Institute statement, retrieved October 8, 1998, Internet, National Institute of Health website, online at <http://www.nhgri.nih.gov/Grant_info/Funding?statements/RFA/human_subjects.html>
7. Philip R. Reilly, "Rethinking Risks to Human Subjects in Genetic Research," *American Journal of Human Genetics* 63 (1998):684.
8. Jon Beckwith, "The Responsibilities of Scientists in the Genetics and Race Controversies," in *Plain Talk About the Human Genome Project: A Tuskegee University Conference on its Promise and Perils . . . and Matters of Race*, ed.Edward Smith and Walter Sapp (Tuskegee, Ala.: Tuskegee University, 1997), 85;see also Jonathan Beckwith, "The Human Genome Initiative:Genetics' Lightning Rod," *American*

Journal of Law and Medicine 17 (1991): 1–13; and Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers* (Boston: Beacon Press,1997).

9. Prepared statement by Rep. Cliff Stearns (R-FL), in U.S. Congress, Hearings of the House Subcommittee on Technology, House of Representatives, *Technological Advances in Genetic Testing: Implications for the Future*, 104th Cong., 2d sess. (Washington, D.C.: U.S. Government Printing Office,1996),4.
10. See Troy Duster, *Backdoor to Eugenics* (New York: Routledge, 1990); and Dorothy Nelkin and Laurence Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* (New York: Basic Books,1991).
11. Ruth Hubbard, "Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues," *International Journal of Health Services* 15 (1985): 243.
12. Duster, *Backdoor to Eugenics*, 26.
13. Hubbard, "Genetic Screening";see also David D. Phoenix,Sherrill M. Lynbrook, Ralph W. Trottier, Faye Cobb Hodgin, and Lee A. Crandall, "Sickle Cell Screening Policies as Portent: How Will the Human Genome Project Affect Public Sector Genetic Services?" *Journal of the National Medical Association* 87 (1995):807–12.
14. Hubbard and Wald, *Exploding the Gene Myth*, 35.
15. In this section, we deal only with the testing of healthy women who have not had breast cancer. With regard to the testing of women who have breast cancer, researchers are currently examining whether knowledge of a mutation can help to determine the most effective treatment and prevention strategies. For example, see Jennifer S. Lee, Sholom Wacholder, Jeffrey P. Struewing, Mary McAdams,David Pee,Lawrence C. Brody, Margaret A. Tucker, and Patricia Hartge, "Survival After Breast Cancer in Ashkenazi Jewish BRCA1 and BRCA2 Mutation Carriers," *Journal of the National Cancer Institute* 91 (1999):259–63.
16. Anne-Marie Martin and Barbara L. Weber, "Genetic and Hormonal Risk Factors in Breast Cancer," *Journal of the National Cancer Institute* 92 (2000): 1127.
17. Jeffrey P. Struewing, Patricia Hartge, Sholom Wacholder, Sonya M. Baker, Martha Berlin, Mary McAdams, Michelle M. Timmerman, Lawrence C. Brody, and Margaret A. Tucker, "The Risk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 among Ashkenazi Jews," *New England Journal of Medicine* 336 (May 15,1997):1401–8.
18. Margaret A. Tucker, quoted in Rick Weiss, "Genes' Link in Cancer Reassessed; Research Overstated Breast, Ovary Risks, New Study Concludes," *Washington Post*, May 15,1997,A1.
19. Recent studies show that BRCA1 mutations account for only 15 to 45 percent of hereditary breast cancers (see Martin and Weber, "Genetic and Hormonal," 1127).
20. Nina Hallowell, "Doing the Right Thing: Genetic Risk and Responsibility," in *Sociological Perspectives on the New Genetics*, ed. Peter Conrad and Jonathan Gabe (Oxford: Blackwell, 1999), 101.
21. Massachusetts Breast Cancer Coalition (hereafter cited as MBCC),"Beyond the Headlines," Issue Paper no. 1 (July 2000):2.
22. See Hallowell,"Doing the Right Thing," 100–101.
23. MBCC,"Beyond the Headlines," 2.
24. MBCC,"Beyond the Headlines," 2.
25. For discussion of the link between the environment and cancer, see Sandra Steingraber, *Living Downstream: A Scientist's Personal Investigation of Cancer and the Environment* (New York: Vintage

Books, 1998); and Robert N. Proctor, "Genomics and Eugenics, How Fair is the Comparison?"in *Gene Mapping: Using Law and Ethics as Guides*, ed.George J. Annas and Sherman Elias (New York: Oxford University Press,1992),64.

26. Ruth Hubbard, "A Strong, But Not Perfect, Anti-Genetic Discrimination Bill," *GeneWatch: A Bulletin of the Council for Responsible Genetics* 13 (Winter 2000):8.
27. David Morris, "Cost-Containment and Reproductive Autonomy: Prenatal Genetic Screening and the American Health Security Act of 1993," *American Journal of Law and Medicine* 20(1994): 295.
28. Genetic counselors have told interviewers they encourage poor women and women of color to abort pregnancies if, for example,their fetus tests positively for non-life-threatening diseases such as sickle-cell anemia. See Dorothy Roberts, "Biology, Justice, and Women's Fate," *University of Chicago Law Roundtable* 3 (1996):465. Rayna Rapp quotes corroborating testimony from a genetic counselor: "It is often hard for a counselor to be value free.Oh,I know I'm supposed to be value free, but when I see a welfare mother having a third baby with a man who is not gonna support her, and the fetus has sickle-cell anemia, it's hard not to steer her toward an abortion. What does she need this added problem for, I'm thinking" (Rayna Rapp, "Refusing Prenatal Diagnosis: the Meanings of Bioscience in a Multicultural World," *Science, Technology, & Human Values* 23 [1998]: 154).
29. R.C. Lewontin, *Biology as Ideology: The Doctrine of DNA* (New York: HarperCollins,1992),76.
30. Abby Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities," *American Journal of Law and Medicine* 17 (1991):24–25.
31. Council for Responsible Genetics,"Predictive Testing," in *GeneWatch: A Bulletin of the Council for Responsible Genetics* 13 (2000), Internet, Council for Responsible Genetics website, online at <http://www.gene-watch.org>. Many prenatal testing procedures (e.g.,ultrasound,amniocentesis) are already performed without the consent of women,and screening for hemoglobin disorders and sickle-cell anemia are increasingly performed without consent (see Lippman, "Prenatal Genetic Testing"). For analysis placing these trends in historical context, see Ruth Schwartz Cowan, "Women's Roles in the History of Amniocentesis and Chorionic Villi Sampling," in *Women and Prenatal Testing,* ed. Karen Rothenberg and Elizabeth Thomson (Columbus:Ohio State University Press,1994),35–48. For discussion placing the risks of genetic testing posed to women in contemporary context, see Kelly Happe, "The Political Economy of Genetics: Challenges for Feminists," *Michigan Feminist Studies* 13 (1998–99):63–88.
32. For commentary linking Bush's Violence Initiative to the contemporary milieu,see Gerald Horne, "Race Backwards: Genes, Violence, Race, and Genocide," *Covert Action Quarterly* (Winter 1992–93): 29–35; and Robert Wright, "The Biology of Violence," *New Yorker*, March 13, 1995, 68–77.A more general treatment of the ideological and historical dimensions of violence research can be found in R. C. Lewontin, Steven Rose, and Leon J. Kamin, *Not In Our Genes: Biology, Ideology, and Human Nature* (New York: Pantheon,1985), 168–73.
33. Alfreda Sellers-Diamond, "Disposable Children in Black Faces: The Violence Initiative as Inner City Containment Policy," *University of Missouri Kansas City Law Review* 62 (1994):468.
34. Proctor, "Genomics and Eugenics," 68–70.
35. Hubbard questions the wisdom of testing for "hypersusceptible" individuals in this context, given the subjective nature of standards for determining susceptibility, as well as the danger that identification of "resistant" workers may create institutional momentum to expose such workers to dangerous toxins (see Hubbard, "Genetic Screening").
36. Jennifer Wriggens, "Genetics, IQ, Determinism, and Torts: The Example of Discovery in Lead Exposure Litigation," *Boston University Law Review* 17 (1997):1025.

37. Hubbard, "Genetic Screening," 243;see also Lewontin, *Biology as Ideology*, 76–77.
38. George J. Annas and Sherman Elias, "Social Policy Research Priorities for the Human Genome Project," in *Gene Mapping*, 274.
39. See Council for Responsible Genetics,"Laws Regarding Genetic Discrimination," 1999 Legislative Materials Summary, Internet, Council for Responsible Genetics website, online at <http://www.science.doe.gov/production/ober/humansubj/win96/win9508.html>.
40. For discussion regarding the comparison between the Human Genome Project and the Manhattan Project, see George J. Annas and Sherman Elias, "The Major Social Policy Issues Raised by the Human Genome Project," in *Gene Mapping*, 4–5;and Timothy F. Murphy and Marc A.Lappé, eds., preface to *Justice and the Human Genome Project* (Berkeley: University of California Press,1994), xi.
41. Quoted in U.S. Department of Energy, "Old and Emerging Bioethical Issues in Research on Atoms and Genes," *Human Subjects Newsletter* (Winter 1996), Internet, Department of Energy website, online at <http://www.er.doe.gov/>. Further reinforcing the need for special attention to ethics in this area, Annas isolates aspects of DNA testing that pose unique challenges to prevailing models of medical ethics:"DNA testing (1) provides a future diary of a patient's health,(2) gives information on other family members, and (3) has a history of misuse" (see Karen K. Steinberg, Eric J. Sampson,Geraldine M. McQuillan,and Muin J. Khoury, "Use of Stored Tissue Samples for Genetic Research in Epidemiologic Studies," in *Stored Tissue Samples: Ethical, Legal, and Public Policy Implications*, ed. Robert Weir [Iowa City: University of Iowa Press,1998],82–88).
42. See Ruth Faden and Tom Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986); and Jay Katz, *The Silent World of Doctor and Patient* (New York: Free Press,1984).
43. Jonathan D. Moreno and Susan E. Lederer, "Revising the History of Cold War Research Ethics," *Kennedy Institute of Ethics Journal* 6 (1996): 236.One troubling aspect of this history is the way in which Department of Energy, Department of Defense, and Atomic Energy Commission (AEC) officials abused the classification system to cover up unethical radiation experiments, using the excuse of national security to provide cover from negative publicity. For example, when the Manhattan Project ended officially in 1947 and the AEC took control of the health effects research program,AEC officials decided not to disclose the details of the plutonium injection experiments conducted on hospital patients at university hospitals."It appears that this decision was based on concerns about legal liability and adverse public reaction,not national security," committee members concluded (Advisory Committee on Human Radiation Experiments [hereafter cited as Advisory Committee], *Final Report* [Washington, D.C.: U.S. Government Printing Office, 1995], 267).
44. See Advisory Committee, *Final Report*, 105.
45. Advisory Committee, *Final Report*, 108;see also George J. Annas, Leonard H.Glantz,and Barbara F. Katz, *Informed Consent to Human Experimentation: The Subject's Dilemma* (Cambridge: Ballinger, 1977).
46. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter cited as President's Commission), *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, vol. 1, *Report* (Washington, D.C.: U.S.Government Printing Office,1982).
47. President's Commission, *Making Health Care Decisions*, 69–105.
48. President's Commission, *Making Health Care Decisions*, 39.
49. President's Commission, *Making Health Care Decisions*, 89.

50. See Katz, *Silent World*, 121–29.
51. See U.S. Department of Energy, "Federal Policy for the Protection of Human Subjects (10 CFR Part 745)," *Human Subjects Newsletter* (Fall 1992), Internet, Department of Energy website, online at <www.science.doe.gov/production/ober/humsubj/fall92/fall9202.html>
52. U.S. Department of Energy, "The Informed Consent Process—The Key to Effective Protection," *Human Subjects Newsletter* (Fall 1992), Internet, Department of Energy website, online at <www.science.doe.gov/production/ober/humsubj/fall92/fall9203.html>
53. At the same time that United States war crimes lawyers were heading up prosecution of German doctors in the Nuremberg Medical Trial, American researchers were conducting medical experiments on human subjects in the United States that ran afoul of the same Nuremberg Code standards. This research was conducted on subjects in facilities associated with the Universities of Rochester, California, and Chicago, and involved injection of "eighteen human subjects with plutonium, five human subjects with polonium, and six human subjects with uranium to obtain metabolic data related to the safety of those working on the production of nuclear weapons" (Advisory Committee, *Final Report*, 264). The ultimate judgment issued by the Advisory Committee regarding these experiments is telling: "[W]e believe that these experiments were unethical. . . . In the conduct of these experiments,two basic moral principles were violated—that one ought not to use people as a mere means to the ends of others and that one ought not to deceive others . . ." (Advisory Committee, *Final Report*, 267). For further commentary, see Keith Schneider, "Nuclear Scientists Irradiated People in Secret Research," *New York Times*, December 17, 1993,A1; and Ron Grossman and Charles Leroux, "Radiation Tests: Needed or Horrid?" *Chicago Tribune*, January 9, 1994,A1. Curiously, many of these same revelations were made nearly a decade earlier in a report released by Representative Edward Markey (D-MA) (see Staff of the House Subcommittee on Energy Conservation and Power, *American Nuclear Guinea Pigs: Three Decades of Radiation Experiments on U.S. Citizens*, 99th Cong., 2d sess., Committee print [Washington, D.C.: U.S.Government Printing Office,1986]). Although this report was "carefully documented" and "cited specific published reports on the studies," it went "virtually unrecognized and unheralded primarily because the administration of Ronald Reagan dismissed it as overblown" (George J. Annas, "Questing for Grails: Duplicity, Betrayal, and Self-Deception in Postmodern Medical Research," in *Health and Human Rights: A Reader*, ed. Jonathan M. Mann, Sofia Gruskin, Michael A. Grodin, and George J. Annas [New York: Routledge,1999], 316).
54. See Sheryl Gay Stolberg, "Teenager's Death is Shaking Up Field of Human Gene Therapy," *New York Times*, January 27,2000,A1;and Sophia Kolehmainen,"The Dangerous Promise of Gene Therapy," *GeneWatch Bulletin* 13 (2000), Internet, Council for Responsible Genetics website, online at <http://www.gene-watch.org>.
55. Foster, Bernsten, and Carter, "A Model Agreement," 700; see also Mark A. Rothstein, "Genetic Secrets: A Policy Framework," in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, ed. Mark A. Rothstein (New Haven: Yale University Press, 1997),465–67.
56. Henry T. Greely, "The Control of Genetic Research: Involving the 'Groups Between,'" *Houston Law Review* 33 (1997): 1412. Foster and Sharp reach a similar conclusion, noting that "[a] research study that bypasses a population's established collective decision-making process, by relying exclusively on individual informed consent,places the moral authority of the larger community at risk" (Foster and Sharp, "Genetic Research," 94).
57. See Larry O. Gostin,"Informed Consent, Cultural Sensitivity, and Respect for Persons," *Journal of the American Medical Association* 274 (1995): 844–45; Larry O. Gostin,"Ethical Principles for the Conduct of Human Subject Research: Population-Based Research and Ethics," *Law, Medicine and Health Care* 19 (1991): 191–201; and John Lyttle, "Is Informed Consent Possible in the Rapidly Evolving World of DNA Sampling?" *Canadian Medical Association Journal* 156 (1997):257–58.

58. See Patricia A. King, "The Past as Prologue: Race, Class and Gene Discrimination," in *Gene Mapping*, 94–111; Arthur L. Caplan, "Handle with Care: Race, Class and Genetics," in Murphy and Lappé, *Justice and the Human Genome Project*, 30–45; Susan M. Wolf, "Beyond 'Genetic Discrimination': Toward the Broader Harm of Geneticism," *Journal of Law and Medical Ethics* 23 (1995): 345–53; and David Suzuki and Peter Knudtson, *Genethics: The Clash Between the New Genetics and Human Values* (Cambridge: Harvard University Press, 1990), 156–57.
59. Foster et al., "Role of Community Review," 1719–27; Fatimah Jackson, "Concerns and Priorities," 951–64; Fatimah Jackson, "Assessing the Human Genome Project: An African American and Bioanthropological Critique," in Smith and Sapp, *Plain Talk About the Human Genome Project*, 95–104; and North American Regional Committee, "Proposed Model Ethical Protocol for Collecting DNA Samples," *Houston Law Review* 33 (1997):1431–73.
60. See Foster, Eisenbraun, and Carter, "Communal Discourse"; and Foster et al., "Role of Community Review."
61. Foster, Eisenbraun, and Carter, "Communal Discourse," 278.
62. Foster, Bernsten, and Carter, "Model Agreement," 697–99.
63. Foster, Eisenbraun, and Carter, "Communal Discourse," 278.
64. See Henry T. Greely, "Informed Consent, Stored Tissue Samples, and the Human Genome Diversity Project: Protecting the Rights of Research Participants," in Weir, *Stored Tissue Samples*, 91.
65. Although "the human genome" is a phrase used frequently in the media and common parlance, it is really a misnomer, since *the* "map of the human genome" will actually be made up of the combined genomic sequences of many DNA donors. See Kenneth Weiss, "Biological Diversity is Inherent in Humanity," *Cultural Survival Quarterly* (1996):26–28.
66. North American Regional Committee, "Proposed Model Ethical Protocol," 1444, 1443.
67. North American Regional Committee, "Proposed Model Ethical Protocol," 1448, 1444.
68. Trevor Pinch, "Cold Fusion and the Sociology of Scientific Knowledge," *Technical Communication Quarterly* 3 (1994):88. See also Thomas Brante, "Reasons for Studying Scientific and Science-Based Controversies," in *Controversial Science: From Content to Contention*, ed. Thomas Brante, Steve Fuller, and William Lynch (New York: SUNY Press, 1993), 177–92; and Gordon R. Mitchell and Marcus Paroske, "Fact, Friction and Political Conviction in Science Policy Controversies," *Social Epistemology* 14 (2000):89–108.
69. Eric T. Juengst, "Group Identity and Human Diversity: Keeping Biology Straight from the Culture," *American Journal of Human Genetics* 63 (1998):674.
70. On a basic level, this problem complicates efforts to select appropriate audiences for group consent dialogues. However, Juengst presses the point to suggest that there is rhetorical harm in the very act of *asking* social groups to participate in such conversations. Merely addressing a specific population to discuss proposed genomic research, on this logic, adds currency to public opinion that such a group is bound by genetic ties, potentially exposing group members to discrimination in housing, employment, and the culture at large, especially in cases where group members do not actually share common genetic profiles (see Juengst, "Group Identity and Human Diversity," 674–76). This "reifying the deme" argument presents a number of complex rhetorical issues requiring extended commentary that cannot be given here. We pursue such commentary in a companion essay (see Gordon R. Mitchell and Kelly Happe, "Defining the Subject of Consent in DNA Research," *Journal of Medical Humanities* 22 [Spring 2001]:41–54).
71. Reilly, "Rethinking Risks," 684.
72. Reilly, "Rethinking Risks," 684.

73. Reilly, "Rethinking Risks," 685.
74. Philip R. Reilly and David C. Page, "We're Off to See the Genome," *Nature Genetics* 20 (1998):15.
75. See Reilly, "Rethinking Risks," 684.
76. Reilly, "Rethinking Risks," 685.
77. For commentary on the heuristic value of using the concept of *stasis* in rhetoric of science analysis, see Alan Gross, *The Rhetoric of Science* (Cambridge: Harvard University Press, 1990), 7–9.
78. See Steingraber, *Living Downstream*.
79. Annas and Elias, "Social Policy Research Priorities," 275.
80. Loane Skene and Max Charlesworth, "The New Genetics: Legal and Ethical Implications for Medicine," *Medical Journal of Australia* 165 (1996):301–3.
81. See Jon Turney, "Signs of Life—Taking Genetic Literacy Seriously," in *Genetic Imaginations: Ethical, Legal and Social Issues in Human Genome Research*, ed. Peter Glasner and Harry Rothman (Aldershot: Ashgate, 1998), 131–40; and Nuffield Council on Bioethics, *Genetic Screening—Ethical Issues* (London: Nuffield Foundation, 1993).
82. Brian Wynne, "Public Understanding of Science," in *Handbook of Science and Technology Studies*, ed. Sheila Jasanoff, Gerald E. Markle, James C. Peterson, and Trevor Pinch (London: Sage, 1995), 365.
83. Wynne, "Public Understanding of Science," 362. See also Steven Shapin, "Why the Public Ought to Understand Science In-the-Making," *Public Understanding of Science* 1 (1992): 27–30; and Brian Wynne, "Public Uptake of Science: A Case for Institutional Reflexivity," *Public Understanding of Science* 2 (1993):321–37.
84. Steve Fuller, *The Governance of Science: Ideology and the Future of the Open Society* (Buckingham: Open University Press, 1999), 46.
85. In Jürgen Habermas's early works, the "ideal speech situation" was a utopian norm for communicative interaction completely free from the distorting effects of power and domination. See Jürgen Habermas, *A Theory of Communicative Action*, vol. 1, *Reason and the Rationalization of Society*, trans. Thomas McCarthy (Boston: Beacon Press, 1984).
86. See William L. Freeman, "The Role of Community in Research with Stored Tissue Samples," in Weir, *Stored Tissue Samples*, 281–84.
87. For commentary on the significance of rhetorical framing effects on policy discourse addressing genomic research, see Priscilla Murphy and Michael Maynard, "Framing the Genetic Testing Issue: Discourse and Cultural Clashes Among Policy Communities," *Science Communication* 22 (December 2000):133–53.
88. According to Nelkin and Lindee, genetic essentialism is a reductionist strategy of argument that "reduces the self to a molecular entity, equating human beings, in all their social historical, and moral complexity, with their genes" (Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* [New York: W. H. Freeman, 1995], 2, 41–49). *Topos* is used here in the Aristotelian sense to mean a line of argument (or "topic") deployed commonly in the service of persuasion. See Aristotle, *On Rhetoric*, trans. George A. Kennedy (New York: Oxford University Press, 1991), 51–77.
89. Nelkin and Lindee, *DNA Mystique*, 5.
90. Jon Beckwith and Joseph S. Alper, "Reconsidering Genetic Antidiscrimination Legislation," *Journal of Law, Medicine and Ethics* 26 (1998):208.
91. James D. Watson, quoted in Leon Jaroff, "The Gene Hunt," *Time*, March 20, 1989, 62–67.
92. James D. Watson, "The Human Genome Project: Past, Present, and Future," *Science* 248 (1990): 44–48.

93. See Henry Howe and John Lyne, "Gene Talk in Sociobiology," *Social Epistemology* 6 (1992):109–63.
94. Nelkin and Lindee, *DNA Mystique*, 164; see also John Lyne, "Bio-rhetorics: Moralizing the Life Sciences," in *The Rhetorical Turn: Invention and Persuasion in the Conduct of Inquiry*, ed. Herbert W. Simons (Chicago: University of Chicago Press,1990), 35–37.
95. See Mae-Wan Ho, *Genetic Engineering: Dream or Nightmare?* (Bath: Gateway Books, 1998), 186; Beckwith,"Responsibilities of Scientists";and Wolf,"Beyond 'Genetic Discrimination.'"
96. See Nelkin and Tancredi, *Dangerous Diagnostics*.
97. See Nelkin and Lindee, *DNA Mystique*, 149–68.
98. Gostin, "Genetic Privacy," 324;see also Suzuki and Knudtson, *Genethics*, 335.
99. North American Regional Committee,"Proposed Model Ethical Protocol," 1453.
100. Celeste Michelle Condit, *The Meanings of the Gene* (Madison: University of Wisconsin Press,1999), 243.
101. Greely, "The Control of Genetic Research," 1418, emphasis ours.
102. Beckwith points to one specific instance of genomic researchers exercising such an ethical "duty to respond"in his discussion of how the Working Group on Ethical, Legal and Social Implications (ELSI) of the Human Genome Project challenged the underlying genetic arguments contained in the *Bell Curve* (see Beckwith, "Scientists and the Genetics," 91). In the context of genetic testing, Condit hints at a similar duty to "restrain commercial entities from misleading advertising about their products,that is, advertising that generates disproportional or unreasonable fears and anxieties" (*Meanings of the Gene*, 223).
103. Lawrence Badash, *Scientists and the Development of Nuclear Weapons: From Fission to the Limited Test Ban Treaty 1939–1963* (New Jersey: Humanities Press,1995), 114.
104. This synopsis of Sloterdijk's speech is drawn from Andrew Piper, "Project Ubermensch: German Intellectuals Confront Genetic Engineering," *Lingua Franca* (December-January 2000): 73–77.
105. Practitioners of molecular biology, the Department of Energy's (DOE's) network of national laboratories in need of a post–Cold War mandate,and elected officials of the labs's home states all had vested interests in winning approval for HGP work. In the early stages of program advocacy, proponents argued that the DOE's long history of "health effects" research made the HGP a natural outgrowth of past work conducted by the national labs. Proctor also points out that official motivation to pursue the HGP was driven by economic desires to counter an incipient Japanese human genome project. In an interview with a DOE official, Proctor learned that the DOE was especially interested in locating radiation "repair genes" in the human genome structure,knowledge which, according to Proctor, would enable genomic science to "be used as yet another way to adapt workers to the workplace rather than vice versa" (Proctor, "Genomics and Eugenics," 65).
106. Computational genetics was DeLisi's specialty at the National Cancer Institute before joining OHER (see Robert Cook-Deegan, *The Gene Wars: Science, Politics, and the Human Genome* [New York: Norton and Co.,1994],199).
107. For analysis of the lopsided nature of the early congressional hearings on HGP, see Daniel Kevles, "Big Science and Big Politics in the United States: Reflections on the Death of the SSC and the Life of the Human Genome Project," *Studies in the History and Philosophy of Science* 27 (1997):269–97.
108. Michael Fortun, "Mapping and Making Histories: The Genomics Project in the United States, 1980–1990," Ph.D. dissertation, Harvard University, 1993,390.
109. Foster, Bernsten,and Carter, "Model Agreement," 701.
110. Marque-Luisa Miringoff, *The Social Costs of Genetic Welfare* (New Brunswick, N.J.: Rutgers University Press, 1991),145.

111. John Ziman, "Are Debatable Scientific Questions Debatable?" *Social Epistemology* 14 (April-September 2000):197.

112. Stepping into this research niche, Leah Ceccarelli and David Depew use rhetorical analysis of Theodosius Dobzhansky's *Genetics and the Origins of Species* to develop resources for countering the primacy of reductive determinism in contemporary public discourse on genetics. See David Depew, "Genetic Biotechnology and Evolutionary Theory: Some Unsolicited Advice to Rhetors," *Journal of Medical Humanities* 22 (Spring 2001): 15–28; and Leah Ceccarelli, "A Rhetoric of Interdisciplinary Scientific Discourse: Textual Criticism of Dobzhansky's *Genetics and the Origins of Species*," *Social Epistemology* 9 (1995):91–111. For more general discussion of possible avenues of research opened up by "alternative rhetorics of science" that favor active interventions into public argument as modes of scholarship, see Philip C. Wander and Dennis Jaehne, "Prospects for 'A Rhetoric of Science,'" *Social Epistemology* 14 (April-September 2000): 227–31; and Gordon R. Mitchell, *Strategic Deception: Rhetoric, Science and Politics in Missile Defense Advocacy* (East Lansing: Michigan State University Press, 2000),20–23.

113. John Ziman, "Why Must Scientists Become More Ethically Sensitive than They Used to Be?" *Science* 282 (December 4,1998):1813

114. This phrase is drawn from Abby Lippman's Human Genetics Seminar, "Orange Rice and (other) Red Herrings," University of Pittsburgh Center for Bioethics and Health Law, Pittsburgh, Pennsylvania, March 16,2001.