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Defining the Subject of Consent in DNA Research

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The advent of population-specific genomic research has prompted calls for invention of informed consent protocols that would treat entire social groups as research subjects as well as endow such groups with authority as agents of consent. Critics of such an unconventional ethical norm of "group consent" fear the rhetorical effects of approaching social groups with offers to participate in dialogues about informed consent. Addressing a specific population as the collective subject of genomic research, on this logic, adds currency to the potentially dangerous public opinion that such a group is bound by genetic ties. The paper considers the problem of group and individual identity within the rhetorical dynamics of the discourse and politics of consent.

KEY WORDS: Rhetoric; informed consent; genetics; African Burial Ground Project.

Each human cell contains roughly six billion base pairs of DNA. One of the most significant conclusions that emerged from the early returns of the Human Genome Project (HGP) is that most genetic differences between humans are determined by variations in just one out of 1000 of these base pairs. Moreover, these are not differences that distinguish between different populations, as they are more likely to show up *within* traditionally defined socio-cultural groups than *between* such groups. "At this fundamental level of molecular definition," suggests HGP co-director Ari Patrinos (1997, p.1), "it should be obvious to all of us that what unites us dwarfs anything that separates us." President Bill Clinton (2000) echoed these sentiments recently, celebrating the HGP with the observation that "one of the great truths to emerge from this triumphant expedition inside the human genome is that in genetic terms, all human beings, regardless of race, are more than 99.9% the same."

While it may be true that 99.9% of the human genome is the same in all humans, regardless of their ethnic classification, the .1% difference is what drives the

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science and industry of genomics. Information generated from the HGP is shaping the practice of medicine in such a way that individual variations will constitute the object of diagnosis and treatment. To get the necessary information, widespread genetic testing seems "virtually inevitable" (Jackson, 1997a, p. 951). There is a growing sense that these scientific findings have the potential to shake the foundations of political traditions, laws and institutions forged in previous eras. After the recent announcement by HGP co-director Francis Collins and Celera CEO Craig Venter that the mammoth job of sequencing the entire human genome was nearly complete, the *New Republic* was not out of the mainstream in opining that our politics are already "falling behind" ("The Big Test," 2000, p. 9). Surely one major challenge facing a post-HGP society will be invention of social norms, political institutions and cultural presumptions that can "catch up" with the explosion of genomic knowledge, and help guide us through the myriad challenges presented by newfound human agency to predict and change the future. Already, proposals are circulating for a constitutional amendment that would protect medical privacy. New regimes of intellectual property rights are being drawn up. Social movements and cultural groups struggle increasingly to redefine notions of collective identity as genetic research shakes up prevailing conceptions of shared history and biology.

The time-honored ethical norm of informed consent in medicine holding that the decision to conduct research should be based on mutual agreement reached between medical practitioners and patients or research subjects normally assumes such agreements are forged in individualized dialogues focusing on the specific needs and concerns of single subjects. However, the overlap between individual and group concerns brought about by the advent of advanced DNA testing has complicated this ethical framework, since the informed decision of lone subjects to participate in DNA research potentially impacts other persons not directly involved in the research, such as siblings or members of a particular ethnic group. So, for example, knowledge that someone has an hereditary disease produces inferences (scientifically legitimate or not) about the probability that biologically related persons will get the same disease. This dilemma highlights a vexing ethical challenge facing medical practitioners seeking to conduct DNA research in a post-HGP world: Who should be asked for consent in such cases?

A complete "map" of the human genome is likely to spur an exponential increase in targeted research projects designed to link specific diseases and traits with discrete genetic patterns (see Holtzman & Marteau, 2000, pp. 141–142). While this research has the potential to alleviate much human suffering and disease by improving health care options, the use of genetic maps to mark off specific populations targeted for medical interventions carries with it a host of significant social and ethical ramifications. These ramifications stem from the ways in which the findings of genetic science as well as the discourse framing such findings can bear on notions of group and individual identity. Experience with genetic screening in the cases of sickle cell anemia, breast cancer, and toxic vulnerability

research sheds some light on this matter, as does a landmark case in the use of genetic identification of the dead. Each provides some insight into the ways that the identity of research subjects can be construed for scientific, social, and political reasons.

SICKLE CELL ANEMIA SCREENING

In the early 1970s, the medical community began to take great interest in sickle cell anemia as knowledge of sickle cell genetic structure was emerging quickly. Yet little was done to detect or prevent the disease until President Richard Nixon established a $6 million screening program designed to test African Americans for the sickle cell gene. This specific population group was chosen in part because reports were circulating that the odd death of four army recruits during routine training exercises was due to the fact that they were African Americans who carried the sickle cell gene (see Murray 1997, p. 144). Because this screening program lurched ahead without a comprehensive public education campaign, it risked reinforcing misconceptions about the meaning of test results, as well as the nature of the disease itself. Mass testing of African Americans surely did not help the employment prospects of that group, although the social impact of the testing is unclear. Given the perception of risk, however, the major airlines are reported to have grounded or fired employees who tested positive as sickle cell trait carriers (Duster, 1990, p. 26). The DuPont Corporation screened African Americans for the sickle cell gene and restricted the workloads of those who tested positive (Hubbard & Henifin, 1985, p. 244).

In time, it became apparent that sickle cell anemia affected many different ethnic and racial groups and that carriers of the sickle gene were not likely to fall ill or even develop the disease. Although screening for the sickle gene has evolved into an important medical tool available to improve health care, African Americans still shoulder the lingering social stigma.

BREAST CANCER

After the BRCA1 gene was initially isolated and cloned, researchers began the arduous process of identifying the hundreds of mutations suspected of being the cause of increased breast cancer risk. Although researchers expected mutations to correlate with specific families, they were surprised to find a mutation in women who were not in the same family, but were of Ashkenazi descent (Struewing et al., 1995). This was welcome news for geneticists working from the assumption that the discovery of prevalent mutations would facilitate development of a genetic test and the implementation of screening programs targeting large populations of women. Following this “ethnic turn” in the research findings, geneticists analyzed

tissue samples gathered from archives of donations provided by Jewish persons participating in a screening program for Tay-Sachs disease and published the finding that as many as 1% of all Ashkenazi Jews carried this BRCA1 mutation (Struewing et al., 1995).

The Ashkenazi community was not asked to participate in genetic research on breast cancer until after the initial 1% rate of the BRCA1 mutation was published. In the interest of promoting understanding of breast cancer risk, thousands of Ashkenazi Jews in the Washington D.C. area volunteered for a subsequent study (Struewing et al., 1997), and part of the research plan called for community forums and educational campaigns concerning the risk of breast cancer among women of Ashkenazi descent.

There is little doubt that Ashkenazi women benefit from the research that is being done on the population-specific BRCA1 mutation. Yet the initial research on the existence and rate of mutations produced some public misunderstanding. Some science writers reported that the mutations found in the Ashkenazi population indicated increased risk of breast cancer, despite the fact that no epidemiological studies had yet been completed. Such speculation may have exposed Ashkenazi women to discrimination in the employment and insurance markets, with prospective employers and insurers tempted to make decisions based on premature assumptions about the shared biological characteristics of Ashkenazi Jews.

Since the tissue samples used by researchers to draw conclusions about the frequency of BRCA1 mutations in Ashkenazi populations were drawn from research subjects participating in an entirely different study dealing with Tay-Sachs disease, we do not know how the original DNA donors would have felt about their tissue samples being used for a research project to which they had not explicitly consented (see Reilly & Goldgar, 1995). This should be cause for reflection, given that "the individual subject as well as other group members may be harmed by the accumulation of group data, such as the prevalence of a specific mutation in the breast cancer 1 (BCRA1) gene in Ashkenazic Jewish women" (Rothstein, 1997, p. 466).

TOXIC VULNERABILITY IN THE WORKPLACE

The Environmental Genome Project (EGP) was launched by the National Institute of Environmental Health Science (NIEHS) in 1998. The EGP's mission is to promote understanding of "genetic susceptibility to environmental agents," in order to facilitate "more effective disease prevention and improved public health" (NIEHS, 2000). On its Internet website, the NIEHS (2000) prefaces its answer to the question "Why an environmental genome project?" with a quotation from Francis Collins: "We are all at risk for something." Each person is more or less susceptible to environmental toxins, and the EGP attempts to catalogue these risk polymorphisms. NIEHS officials (2000) argue that this will improve public health

by "allowing individuals to make better informed decisions regarding environmental exposures they allow/tolerate." Such a justification sounds reasonable when the project is assessed from an individualized perspective. It is easy to understand why any given worker might want to know more information about how toxins in the workplace interact with their own bodies.

However, the EGP becomes more problematic when assessed in a broader social context. There is already precedent for discrimination in the workplace based upon the biological susceptibility of workers. Corporate screening programs are on the rise and as "genetic tests get easier, cheaper, and more accurate, their use is likely to increase if proper guidelines are not established" (Kaufmann, 1999, p. 437). Accounts of employment discrimination resulting from screening continue to grow (Levanthal, 1997; Miller, 1998; Rachinsky, 2000). Individuals with inherited susceptibility to toxins face the possibility that they will be denied certain jobs or will be penalized when employers provide only minimal health insurance benefits. While a patchwork of state laws offers spotty protection, no federal legislation exists that safeguards people from employers and insurance companies.

All this should prompt ethicists, scientists, and policy-makers to rethink the basic assumptions undergirding traditional informed consent doctrines, and take a close look at the rhetoric of the "consenting subject." Traditional models of informed consent fashioned to govern one-on-one encounters between doctors and patients (e.g. Faden & Beauchamp, 1986; Katz, 1984) do not account for the interconnectedness of individuals and groups in the genetic context. "To the extent that genetic research addresses questions that are population specific, the population is the subject" (Foster et al., 1998, p. 699; see also National Research Council, 1999, p. 383). As 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 (see Foster & Sharp, 2000, pp. 93–94). Policy-makers 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.

RECONSIDERING THE "SUBJECT OF CONSENT"

One shift in the "rhetoric of consent" occurs in recent articulations of "group consent." A group consent norm would oblige researchers to secure informed consent not only from individual research subjects such as DNA donors, but also from relevant populations who share the donor's genetic profile, or could be adversely affected by the research. But how does a group give its consent, and on what basis? This challenge has been taken up by one team of anthropologists at the University of Oklahoma who recently created a protocol for group consent of

genomic research and tested it in "communal dialogues" with two Native American populations (see Foster, Sharp, Freeman, Chino, Bernsten & Carter, 1999; Foster et al., 1997). 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 (Foster et al., 1997, p. 278). Researchers then convened a series of public meetings (open to all tribal members) in which they explained their research goals, namely to gather tissue samples for the purpose of improving understanding and potential treatment 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 the 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 in harmony with Native American religious beliefs. Community review boards were created to establish an ongoing channel for 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 (see Foster et al., 1998, pp. 697–699). The overall organization of these projects emphasized group involvement and community consensus. "When specific concerns were expressed," members of the research team explained, "these issues were re-negotiated" (Foster et al., 1997, p. 278).

Publication of the research protocols for group consent just described has inaugurated a heated debate within the genetics and bioethics communities, reflecting the complex relationship between biological and social categorization and the discourse that sustains it. Eric Juengst, a prominent German bioethicist and long-standing commentator on ethical aspects of the Human Genome Project, has been on the front-lines of this debate. Juengst contends that models of communal discourse will not adequately protect the populations they are designed to serve. Since genetic links transgress the boundaries of social identity, informed consent within one community may not cover individuals who reside outside of that group, yet share the same genetic marker. For Juengst, the initial assimilation of genotype to social group characteristics (i.e. signifiers and practices) by geneticists is an arbitrary move that lacks grounding in the actual genetic makeup of human populations (for discussion, see Mitchell & Happe, forthcoming).

Juengst suggests that the mere act of initiating communal consent dialogues with research subjects is fraught with peril because the implicit messages conveyed in such conversations shape prevailing notions of group identity. According to Juengst, the Foster et al. model for informed group consent inadvertently naturalizes social difference by conflating social and genetic identity, thereby exposing

research subjects to the sorts of discrimination associated historically with the early American eugenics movement. The conflation of nature and culture by researchers, in this account, threatens to unravel decades of progressive social change that followed in the wake of eugenicist activism and legislation.

In light of these concerns, Juengst (1998, p. 677) claims that the Foster et al. protocol guides researchers to produce "hollow rhetoric" that provides illusory protection at a steep cost. Approaching self-identified, morally authoritative social communities" for consent, Juengst (1998, p. 674) reasons, would be a "dangerous gesture: by superimposing our social and biological categories, we would increase the risk of discrimination against the group members, and any protections that prior permission might afford would be undone immediately by both the modern human diaspora and the multiplicity of our group allegiances." Using genetic structure as the map for social identity amounts to "reifying the deme," which Juengst (p. 675) defines as "accepting the existence of objectively real and sharply defined biological groupings." According to Juengst (p. 675), the pernicious effect of this rhetorical transaction "makes it easier for the group and its neighbors to stereotype its members," and "will produce scientific wedges to hammer into the social cracks that already divide us" (p. 676). Merely addressing a specific population to discuss genomic research, on this logic, adds currency to public opinion that such a group is bound by genetic ties.

RHETORIC AND REIFICATION

While Juengst's concerns merit serious attention, it should also be noted that concrete experience stemming from attempts by Foster and colleagues to operationalize models of informed group consent in Native American disease research suggests that, in practice, reciprocal dialogue between researchers and research subjects has the potential to counteract the tendency of group consent dialogues to "reify the deme." In this case, Native American research subjects exercised agency over every stage of research. This participatory approach to scientific inquiry influenced the design of research questions and enabled tribal leaders to emphasize that social and environmental factors were as important as genes for the health of the tribe. Proceeds from the research were earmarked for "the promotion of the health and education of tribal members" (Foster 1998, p. 698). Researchers agreed that tribal permission would be required to conduct any future research on archived tissue samples.

This example illustrates how it is possible for a community to "seize intellectual control" (Devieux & Mathis 1996, pp. 14–15) of research projects and in the process fundamentally change the dialogue over consent. Another case involving a dispute over the identification of remains in a burial ground sheds additional light on the political dynamics and power relationships involved in "communal dialogues" over the proper purpose and course of genomic research.

In 1991, human bones were discovered during a construction dig in lower Manhattan, New York. The discovery was made during a U.S. federal government General Services Administration (GSA) project to build a 34-story office building at Foley square, an area right off Broadway and bounded by Duane, Elk, and Reade streets (see Hansen & McGowan, 1998, pp. 1–6). When local African American groups found out that the unearthed human remains were part of what eighteenth century maps labeled "Negroes Burying Grounds," they quickly mobilized to call for the GSA to stop construction at the site, in accordance with a federal law requiring a halt in such cases.

With construction on hold, the city investigated the site and hired a small contract archeology firm for the job, Historical Conservation and Interpretation (HCI). City officials initially thought that there might be about ten skeletons at the construction site, but subsequent digs uncovered over 400 skeletons, buried some sixteen feet below the bustling streets of downtown Manhattan (Turk, 1993, p. A1). The historical significance of this discovery was unexpectedly important. The sheer size of the African Burial Ground, the earliest and one of the largest such burial grounds known to exist in North America, placed in the historical context of the slave trade in seventeenth century Dutch colony of New Amsterdam, has been debunking the fable of the "free North" since 1991 ("Scientists probe," 1993).

While these riveting developments drew the attention of many historians, archaeologists, and New York citizens, they posed a problem for GSA officials, who wanted to get on with building their $276 million office building. In fall of 1991, GSA resumed construction and hired a larger team of anthropologists (the Metropolitan Forensic Anthropology Team—MFAT) to help expedite the process of removing the human remains. That MFAT had little experience with skeletal excavation was clear to onlookers strolling down Broadway, who could witness excavators "with toothbrushes in hand," working "amidst bulldozers rumbling around them" (Turk, 1993, p. A1). On MFAT's watch, GSA construction contractors accidentally poured concrete on up to twenty skeletons and scooped out other remains with a backhoe.

As word of these mishaps spread, members of the local descendant community organized to protest poor treatment of their ancestors' remains. Activists decried MFAT's excavation techniques and the conditions in which MFAT stored the skeletons, which were wrapped in acid corroding newspapers in an overstuffed three-room lab after they were removed from the Foley Square burial site (see Turk, 1993, p. A1). Scientists affiliated with the descendant community, including Dr. Michael Blakey of Howard University, also questioned MFAT's research objectives. MFAT scientists focused primarily on racial categorization, answering the question "were they black slaves?" (Blakey, 1998b). In Blakey's view, a research design based on such simplistic racial typing failed to explore the full historical richness of the African Burial Ground (ABG), a "spiritual, cultural, historical, and archeological treasure" (Hansen & McGowan, 1998, p. 6; see also Paterson,

1999). ABG activists objected to the GSA's research design because it used DNA analysis that would reduce their ancestors' social identity to skin color. In a "fight over how history should be written" (Cook, 1993, p. 1), waged through animated arguments at public hearings, placards at sidewalk rallies, columns in local newspapers, and signatures on petitions, activists challenged the authority and competence of the GSA and MFAT, questioned mainstream media accounts of events, and insisted upon the right of the descendant community to assert stewardship over the ABG.

In this case, activists achieved important victories in both offensive and defensive dimensions of movement protest. Initially, they wrested control over the research design for excavation and analysis of ABG remains, successfully installing Dr. Blakey as scientific director of the project and gaining authorization for the transfer of nearly 400 skeletal remains to Howard University in Washington, D.C. From this "harvest of community activism" (Brown, 1993, p. 1) came formal authority for the descendant community "in setting the research priorities, constructing hypotheses, collection and analysis of data, and the interpretation of research results" (Jackson, 1997a, p. 957).

This transfer of authority resulted in a change in the ABG research design, which shifted away from strict racial typing and toward a much broader scientific and social agenda. "Some of the priorities of the descendent community included the testing of hypotheses that reconstruct and evaluate the lifestyles of the individuals buried at the African Burial Ground (based upon a careful assessment of the osteological evidence) and hypotheses that seek to identify the likely ancestral homeland regions in Africa of buried individuals (based upon a thorough evaluation of extended haplotypes in the bone-derived DNA of the deceased and cultural analysis of any funereal artifacts)" (Jackson, 1997a, p. 957). This project has grown into "the biggest, most sophisticated, most noted bioarchaeological project in the United States," which so far has traced the ancestry of 32 individuals buried at Foley Square back to their native lands in Ghana, Nigeria, Niger, and Benin (Blakey, 1998a, p. 11). As an exemplar, the ABG project is notable for its emphasis on interdisplinary scientific collaboration, as well as its acceptance as a foundational premise that scientists configure their work within the broader framework of social communities.

The ABG controversy shows that the theoretical categories, experimental designs, and very purposes of genetic research projects are, rhetorically speaking, up for grabs. It is possible for so-called vulnerable groups to rally in the process of asserting democratic control over all phases of the genomic research agenda. Such activism can transform the process of gaining "consent" in important ways (Devieux & Mathis, 1996, pp. 14–15).

Prevailing opinion that the ABG project is a "success story of descendent-community involvement in rescue archaeology and subsequent political and intellectual empowerment" (Pearson, 1999, pp. 165–66), prompted activists and

scientists to convene a 1994 meeting in Washington, D.C., where participants drafted an African American Manifesto on Genomic Studies to formalize and extend many of the demands made by the New York activists in the ABG Project controversy, and to provide a foundation for similar efforts in the future. The manifesto calls for "full inclusion" of African Americans in surveys of genomic diversity and insists that "African Americans must participate in the research design, research implementation, data collection, data analysis, data interpretation and dissemination of research results (i.e., scientific publications and policy implications of the results)" (quoted in Jackson, 1997b, p. 101).

While the African American Manifesto on Genomic Studies represents a promising breakthrough in community empowerment, it is worth noting one of the manifesto's limitations as a template for addressing the many ethical and social dilemmas introduced by genetic research. The manifesto's model of community empowerment starts from the premise that there exists a relatively well-defined and cohesive social group that is capable of asserting a collective voice in consent dialogues and research design negotiations.

CONCLUSION

Research designed to locate common genetic threads running through specific population groups can help group members understand and cope with diseases that might afflict them disproportionately, as well open windows into the past that shed new light on ancestral history. But at the same time, there is a potential cost entailed in such research based on group generalizations. History is littered with examples where the conflation of social group identity with biological sameness has been a recipe for balkanization and oppression. These dangers have become even more immediate concerns in an age of rapidly developing genomic science, where the accumulation of sensitive information about social groups is the common result of isolated decisions by individuals to contribute tissue samples for DNA research.

This state of affairs throws traditional notions of the "consenting subject" into disarray, since the individual who says "yes" to DNA research functionally speaks with a collective voice, standing in for others with similar biological characteristics. The sickle cell, breast cancer, and toxic workplace screening programs illustrate how lines separating individual from group participation in research blur together. This dynamic infuses a subject's decision to participate in genomic testing with great complexity, freighting individual health care decisions with a host of wide-ranging social implications.

Some commentators have sought to negotiate this complex terrain by collectivizing the subject of consent in genomic research, asking entire population groups to approve population-specific research in consent dialogues regarding the merits and drawbacks of such projects. It would seem that widespread acceptance

of a group consent norm could go far toward lessening the risks of social stigma and discrimination posed by the tendency of genomic research to "biologize" social identity. But this is no straightforward solution, since the very act of *defining* a collective subject of consent can have important ramifications on how the social identity of defined groups is perceived. Regardless of whether specific groups consent to genomic research, whenever researchers approach them for consent, they risk "reifying the deme" (Juengst, 1998, p. 675), creating the impression that such groups are bound by shared genetic ties. Paradoxically, this process can expose discrete ethnic and social populations to the same sort of discrimination group consent dialogues are designed to prevent.

The struggle over genomic research in the African Burial Ground Project shows that the challenge of coming to grips with this kind of research is not only an ethical conundrum; it is also part of a larger political landscape. "In African American biohistory, this is one of the very few cases where community concerns and priorities have significantly contributed to the scientific paradigm at every stage of the research. . . . The ABG Project should serve as a prototype for future genomic initiatives, particularly among groups that have historically been victimized, rather than assisted, by genetic studies" (Jackson, 1997a, p. 957). In important respects, the example of community empowerment in the ABG Project shows how collective subjects can use the power of language to influence policy stances on genomic research and shape the social meanings based on research findings. Perhaps the emergence of similar collective subjectivities in a wide variety of genomic research settings offers the best hope for society to "catch up" with its own technological creations.

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