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“BIOETHICS IN ACTION” AND HUMAN POPULATION GENETICS RESEARCH

ABSTRACT. Recent disputes about human population genetics research have been provoked by the field’s political vulnerability (the historic imbalance of power between the geneticists and the people they study) and conceptual vulnerability (the mismatch between scientific and popular understandings of the genetic basis of collective identity). The small, isolated groups often studied by this science are now mobilizing themselves as political subjects, pressing sovereignty claims, and demanding control over the direction and interpretation of research. Negotiations between the geneticists and the people asked to donate DNA have resulted not only in explicit bioethics protocols but also in diffuse anxiety over the incommensurability between expert and non-expert views about genetic evidence for identity claims. This article compares two disputes over genetics research: the Human Genome Diversity Project and the use of genetics to prove identity claims among the Melungeons of Tennessee. The case studies illustrate “bioethics in action”: how particular controversies and interests drive the production of bioethics discourses and techniques (such as informed consent protocols). They also illustrate some limits on the usual apparatus of bioethics in overcoming this science’s multiple vulnerabilities. **A1**

KEY WORDS: bioethics, identity politics, population genetics, group consent, Human Genome Diversity Project, Melungeons

INTRODUCTION

This article explores some key social conflicts affecting recent research in human population genetics as well as the reasons why geneticists turned (or did not turn) to the language and procedures of contemporary American bioethics to resolve them. Human population genetics studies the distribution of inherited traits in diverse populations (as measured though underlying frequencies of genotypes and alleles) as well as the mechanisms of genetic change at the population level (Mange and Mange 1990). Although geneticists have carried out population-based research for nearly a century, in the past decade they faced unprecedented challenges to the conduct of their studies and the interpretation of findings. The challenges have come from non-scientists, particularly the individuals and groups who provide DNA material and, on that basis, demand a role in setting the agenda of research and interpreting the facts produced by genetics laboratories.

By comparing two separate disputes between the geneticists and groups providing DNA, the article exemplifies the study of “bioethics in action” or “bioethics in the making.” The phrases borrow explicitly from Bruno Latour’s (1987) agenda for

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the study of science, technology, and society. Latour laid out two ways of construing facts and machines (i.e., scientific truth claims and material technologies) as objects of critical investigation. The first approach privileges ready-made science: the final products of scientific work such as a computer, a cosmological theory, or a model of the economy (Latour 1987: 21). In classic Mertonian sociology of science (as in the ordinary routines of most scientists), these are "black boxes" whose stabilization over time and internal complexity is typically disregarded (see also Hess 1997). The second approach attends to science in action: the messy daily activities, the mobilizing of social networks, and the rhetorical practices by which scientists try to create (what later appear as) final products. Studying science in action means examining controversies before they are settled and competing interpretations before any single contender finally holds true. Latour's work abandons preconceptions about what actually constitutes knowledge, and instead documents how scientists and engineers construct facts in particular locales using the social resources at hand.

By analogy, studying bioethics in action means tracing the early stages of controversies over professional obligations, virtues, or the rights of patients and research participants before consensus is reached even about defining such terms. Although bioethics is a relatively young discipline in the United States, it has already transformed the practice of clinical research (Rothman 1991), and a similar change is well underway in the life sciences, notably genetics (see Evans 2002). Its regulatory apparatus (model protocols for informed consent, institutional review boards, etc.) already form the background realities for the conduct of much medical and social science research. They are the ready-made bioethics that professionals must master and incorporate into the design of research involving human subjects (another ready-made term). But the discourses and apparatus of today's conventional bioethics require the same analysis as the facts and machines of technoscience. Employed as a black box in daily professional work, they demand a critical and relativist analysis that shows how they were produced and stabilized in the first place.

The first case study below discusses why a group of eminent geneticists turned to informed consent protocols to answer open political conflict about their work. This case analyzes a particular network of people, events, and institutions that helped produce today's conventional wisdom about the need for "group consent" in population genetics research. The second case discusses a geneticist who did not craft a formal protocol but improvised his responses to conflicts as they arose. He was left with a nagging anxiety about the gap between his scientific commitments and popular claims about cultural identity instead of a stable ethics procedure that would allow similar research to proceed in the future. These differently scaled cases reveal how vulnerabilities in the practice of population genetics have occasionally broken out into explicitly ethical disputes between experts and non-experts (with long-term repercussions for the moral sensibility of this research community), but at other times created chiefly private frustration on the part of individual scientists.

The case studies also take us into terrain, well mapped by both celebratory and critical scholarship about the growth of American bioethics in general. According to the insiders' celebratory account, bioethics emerged as an enlightened response to the dilemmas of new technologies (e.g., dialysis, organ transplantation, mechanical ventilation, and genetic screening) and it advanced wider struggles for civil and political rights (Jonsen 1998). By subjecting routine professional practice to the scrutiny of fair and careful judgment, the story goes, bioethics discourse safeguards patients' autonomy and advances moral deliberation (Callahan 1999: 277).[1] The critical narrative (advanced mostly by social scientists) agrees that bioethics movement began as a vehicle of broader rights claims and a struggle to end the abuse of professional power (see Bosk 1999; DeVries and Subedi 1998; Weisz 1990). But as an institutionalized enterprise, it came to fit quite well with medicine's dominant style and self-image. One long-time commentator compares bioethics to the American arms control establishment during the Cold War (Fox 1993; see also Stevens 2000). The nuclear weapons race generated tense debates over expert versus civilian control, and a new class of arms control intellectuals mediated between military experts and their most radical critics. Similarly, according to these critics, bioethics encompasses and blunts stronger critiques of medicine's power. Instead of demanding the redistribution of health resources, it aims to balance competing claims in particular bedside dilemmas. Instead of limiting medical dominance, it helps physicians avoid legal liability. Bioethics now represents medicine's humane and benevolent self-image, both to the public and to the profession itself. It helps "perpetuate a system often in conflict with that idealized identity" (Rosenberg 1999: 38) but explains its rapid growth and wide acceptance.

Of course, neither of these polarized narratives adequately describes the ordinary work of most bioethics experts as they craft policy papers, informed consent protocols, or practice guidelines. The critique, in particular, ignores bioethics in action: the welter of competing agendas, social networks, and representations (among doctors, scientists, patients, and research participants) in which influence such documents get produced. As noted even by Albert Jonsen—a consummate insider to American bioethics—these are documents of compromise, which have marginal but real effects (Jonsen 2001). The first case study below describes the emergence of one such showpiece: a protocol for group consent in population genetics research. Because of the popular opposition to the Human Genome Diversity Project (HGDP) in the early 1990s, a project committee wrote an ethics protocol to answer critics and keep the research on track (North American Regional Committee 1997). In the second case, by contrast, the popular use of genetics to certify personal and group identity led to a different sort of conflict, and the main actors never considered trying to resolve it through explicit ethics protocols. The emergence of a stable object of bioethics in the first case, and its absence in the second, shows some of the ways that population geneticists respond to open conflict about their work. The case studies show how demands for collective recognition transform the context and substance of population genetics research (see Taylor 1992). Groups' claims to sovereignty and identity help define what the "principled conduct of research" might mean in practice. Moreover, tracking the groups' claims and the geneticists' response provides an alternative to both the celebratory and critical accounts of bioethics. This article aims, therefore, neither to glorify nor unmask the artifacts of bioethics but to show how people construct them and why they find them useful or, indeed, useless (compare Rabinow 1996: 17).

HUMAN POPULATION GENETICS AND ITS POLITICAL VULNERABILITY

The field of population genetics extends accepted Mendelian principles to the study of inter- and intragroup variation (see Gillespie 1998; Lewontin 1985; Mange and **A2** Mange 1990: 405–478). At the population level, genetic variation arises from four factors: not only mutation and natural selection (the engines of individual variation) but also particular patterns of mating and migration. For these reasons, the separate populations of a given species do not have the same genetic makeup (i.e., they have different percentages of specific alleles). Comparing groups in terms of their allele frequencies thus makes possible the scientific study of evolutionary processes, such as large-scale migration, catastrophic population declines, and the branching of species into separate breeding populations. Population genetics analyzes such events through experiments with laboratory animals as well as formal statistical models.

Several topics recur in general population genetics textbooks over the past few decades (e.g., Hartl and Clark 1997; Jacquard 1974). The classic case of inbreeding allows investigation of genetic drift (changes in allele frequencies due to the randomness of normal genetic inheritance exacerbated by differential fertility in small populations). Data about the rate of genetic mutation drive fundamental debates in Darwinian theory, about why and how genetic variability is maintained within a species. Simply describing the genetic distance between individuals and groups demands much scholarly attention in the wake of molecular genetics and newly precise DNA typing. Human population genetics takes up the same themes, with the same language and quantitative approach, as its parent field. For example, it explores such topics as village fission, as measured by gene frequencies and selective forces (Neel 1984) and large-scale migrations, as measured through patterns of mitochondrial mutation (Cavalli-Sforza et al. 1994). A vast literature uses genetically controlled traits such as blood groups and surface antigens to determine human population histories and environment–gene–culture interactions (e.g., Molnar 1998; Mourant 1983).

The study of small, isolated groups has an enduring appeal for human population genetics, but it also creates the field's political vulnerability to charges of unethical conduct. Such "genetic isolates" offer a natural laboratory for many key topics because they are relatively homogeneous, migration is negligible, and their small size leads to faster changes in genetic structure and allows more accurate genealogical records. Such naturally occurring isolated gene pools thus replicate the same conditions among *Homo sapiens* that geneticists would normally create for other species through laboratory work or mathematical modeling (see Jacquard 1974: 494). Of course, members of such small-scale, isolated groups are also politically weaker than the typical academic geneticist. From the standpoint of these groups, routine research practices can appear to repeat and reinforce their historic subordination to more powerful interests. Indeed, the critics of the HGDP targeted precisely the desire of population geneticists for data from isolated, indigenous groups. According to the critics, treating human community groups as gene pools appropriate for scientific comparison fundamentally undercuts their political sovereignty, and hence, it stands as an ethical indictment of the entire project.

SOVEREIGNTY CLAIMS AND THE HUMAN GENOME DIVERSITY PROJECT

The HGDP called for the globally organized collection of DNA material (in the form of blood, hair, and human tissue samples) from diverse populations of special interest to geneticists, according to the letter in *Genomics* that sparked the project (Cavalli-Sforza et al. 1991). The project aimed to "illuminate the variation, selection, population structure, migration, mutation frequency, mechanisms of mutation, and other genetic events of our past" (Cavalli-Sforza et al. 1991). These standard tasks of human population genetics would be undertaken with the powerful new tools of molecular genetics (instead of older technologies involving blood groups and HLA-typing; Bowman 1999). Research would also establish systematic procedures for storing bodily substances, amplifying DNA, comparing specific alleles and other loci, and creating a publicly accessible database of genetic variation. In accordance with standard research practice, the units for sampling would be simultaneously biological populations and social groups, although disagreements about how to determine them continued throughout the project's planning stages (Human Genome Diversity Committee 1993). Reardon (2001) carefully traces the competing proposals to categorize populations by language, geographic boundaries, endogamy, rural residence, or indigenous status (i.e., groups that presumably descend from those existing before European colonialism). In the end, the organizers did not settle on a single definition of a "population," hence they did not have an overarching rationale for deciding whom to sample. From the standpoint of project planners, however, this was not a problem. The HGDP meant to coordinate the ongoing work of numerous laboratories, not to impose on them a single agenda for research (other than to test diverse samples for the same set of generic markers, see Greely 2001). Since each laboratory worked with its own set of problems, it needed a separate sampling strategy. The project planners ultimately created a tentative list of populations, including many small-scale indigenous societies, based on geographic, historical, sociological, linguistic, and medical criteria. According to the plan, researchers would approach these populations and request 25–150 individuals to contribute DNA material.

Indigenous rights groups launched a vehement attack on the HGDP in 1993, which lasted for several years. Critics denounced it on multiple grounds: as a prelude to "bioprospecting" and gene patenting, the exploitation of politically weak communities by profit-driven biotechnology firms, a resurgence of racism which labels certain groups as genetically inferior (due to their disease susceptibility), a violation of the rights of indigenous peoples, and a threat to their origin stories and indigenous beliefs (see Mead 1996; Rural Advancement Foundation International [RAFI] 1993, 1994). Bioethicists affiliated with the project have written widely on the controversy (see below), and it has drawn the attention of anthropologists (Cunningham 1998; Lock 1994), science studies scholars (Gannett 2001; Reardon 2001), and geneticists (Kidd and Kidd 1999). The US-based National Academy of Sciences (Committee on Human Genome Diversity 1997), the United Nations Bioethics Commission, and the international Human Genome Organization have reviewed the ethics of the HGDP project and issued recommendations.[2]

Out of all the separate issues involved in this controversy, I focus here narrowly on one particular object of bioethics that emerged from it: the protocol for group consent written by Henry Greely et al. For that reason, I want to expose in documentary fashion (via verbatim quotes, all from public domain sources) the original rationale for the project (especially its sampling strategy), the original criticism, and the successive steps taken by the project personnel to answer the critics. In keeping with the theme of "bioethics in the making," I am interested in the very way the word "ethical" was used, when it was introduced, how people filled the semantic space opened by that word, and what they accomplished—politically and professionally—by talking about the rightness or wrongness of this research.

The list of populations for sampling exposed the political vulnerability of its parent science. Despite the heterogeneous criteria for groups, small-scale indigenous populations, which planners also termed "isolates of historic interest," remained a priority. According to a 1993 planning document, "the human species is moving towards increasingly intensive amalgamation. . . This leads to an interest in sampling those of the ‘native’ or ‘aboriginal’ populations in each region—descendants of peoples present at the time of major incursions from other continents—who seem likely to have been least affected by admixture with the incoming populations” (Human Genome Diversity Committee 1993: 8). Critics directly challenged this rationale:

> The project’s emphasis on preservation and its insensitivity to indigenous people is best exhibited by the term they use to describe indigenous communities that have been targeted for human DNA sampling: “isolates of historic interest” (IHIs). In this Year of Indigenous People [1993] and at the time of the UN Conference on Human Rights, we find such initiatives emerging from the West totally unethical and a moral outrage. We call on all groups and individuals concerned with indigenous people’s rights to mobilize public opinion against the case of human communities as material for scientific experimentation and patenting. Indigenous communities are not just ‘isolates of historical interest.’ They have a right to be recognized as fully human communities with full human rights which include decisions about how other countries will relate to them. (Third World Network 1993)

Rejecting the term “isolates of historic interest” was the leading edge of a broader critique of the way the HGDP constitutes its object of study. The above statement, distributed by the Third World Network International Secretariat in Penang, Malaysia, opposed the practice of analyzing human communities as biological populations: a core method of human population genetics. The challenge concerned not its scientific merits but rather its presumed political effect: stripping communities of their rights and objectifying them as passive objects of research.

Calls to respect the sovereignty of indigenous groups permeated the opposition to the HGDP (over 30 advocacy groups issued formal declarations of opposition to the HGDP, according to Resnick 1999). “The fact is that from beginning to end, the very people from whom the [DNA] samples are being taken are not being consulted during any stage of the process,” according to an “Urgent Human Rights Alert” issued by the South and Meso-American Indian Information Center (SAIIC 1993). The alert requested people to write to the National Institutes of Health (NIH) and demand the end of “this insidious project . . . until all parties **A3** have been properly consulted.” However, exactly who constituted these parties and how to respect their sovereignty remained in question. Roy Pat Mooney, the director of the RAFI, who led the early opposition, demanded that the HGDP gain the explicit approval of indigenous people’s organizations and function under the auspices of the United Nations (Mooney 1993). As a model, he pointed to the Guaymi General Congress, the organized legislative representative of the Guaymi people of Panama. The Congress successfully challenged a patent claim brought by the US government over a cell line developed from a Guaymi woman, and then demanded the cell line’s repatriation to Panama. Its actions demonstrated, according to Mooney, precisely the sort of sovereignty that the HGDP ignored.

The SAIIC director urged project personnel to contact any of the "myriad indigenous organizations that represent hundreds of communities and thousands of Native peoples," and he recommended in particular the Continental Commission of Indigenous Nations (CONIC; Cayuqueo 1993). Another candidate was the World Council of Indigenous Peoples (WCIP), which issued a proclamation "to categorically reject and condemn" the HGDP and vowed to seek international legal recourse if the project proceeded (WCIP 1994). Both WCIP and CONIC are non-governmental organizations, founded in 1975 and 1991, respectively, which advocate their members' perspectives to policymakers and lobby in international forums.[3] Several coalitions also emerged specifically to denounce the project, such as the groups that issued the 1993 Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous People (International Association of the Mataatua Declaration 1996). The declaration demanded an immediate halt to the HGDP and called for the international community (specifically, the United Nations) to protect the fundamental right of indigenous peoples to define and control their property, including their genes. The directors of RAFI, although instrumental in organizing the opposition, disavowed representing any or all indigenous groups. They identified themselves simply as an ally, and their opposition to the HGDP as yet another front in their battle against all schemes to patent life (plants as well as human cell lines) (Mooney and Hammond 1995).

The critics all aimed to establish indigenous groups as legitimate political entities with a legally mandated sphere of authority, who are fully capable of defending their interests through accepted channels. They pursued their goal by urging other indigenous groups to refuse to cooperate with the project and by presenting their objections to the UNESCO International Bioethics Committee. The critics thus politicized the relationship between scientists and the populations they wished to sample (see Mooney 1993). They reinterpreted the relationship of scientists to their subjects as one between two self-conscious and organized groups, in which the latter must strive especially hard to defend its sovereignty and interests.

Critics also advanced their cause by historicizing the researcher–subject relationship. From their perspective, gathering DNA from isolated groups in developing societies continued long-standing relations of extractive colonialism. Human population genetics research involves, minimally, obtaining DNA samples in the form of blood, saliva, cheek scrapings, or hair. Critics interpreted such methods not as routine scientific practice but as the latest phase of imperialism. They took great offense at the absence of a similar historical consciousness among HGDP planners. In an early version of the Mataatua Declaration, eventually submitted to the UNESCO bioethics commission, the director of the Maori Congress of

New Zealand wrote:

> Nowhere in the HGDP literature, or in the UNESCO draft documents, have I ever sighted acknowledgement of the extent and effects of the first wave of colonization—of the energies being expended now just to encourage indigenous peoples to be proud of who they are, to regain the use of their languages and cultural and spiritual traditions, nor is there acknowledgement of indigenous struggles to regain their confiscated lands. This is not an issue of DNA, it is a very real issue of colonization, assimilation, oppression and human rights abuses. (Mead 1995)

In the same spirit, Nilo Cayuqueo (director of SAIIC) continually invoked the history of the past 500 years in his objections to the project. Given the centuries of colonial dependence, he asked, could indigenous groups genuinely choose not to participate? Given the record of Western oppression and genocide, could the HGDP successfully prevent profit-minded biotechnology companies from abusing the scientific findings? Could reciprocity between researcher and subjects ever truly be achieved? (Cayuqueo 1993). The weight of history thus joined claims of sovereignty in the widespread objections to the HGDP.

The opposition took HGDP planners by surprise, but it represented the achievement of two decades of growth in indigenous rights activism. The groups leading the protest emerged in the wake of ethnic politics of the 1960s and 1970s. In 1975, a coalition of Canadian First Nations formed the WCIP, inspired by the earlier efforts of the American Indian Movement to create links with indigenous organizations outside the West. The WCIP soon acquired observer status as an NGO at the United Nations, and by 1990, it included representatives of groups from South and Central America, Australia, New Zealand, the former USSR, and Scandinavia (Wilmer 1993). The SAIIC was founded in 1983 at a pan-Indian conference in Bolivia. The first UN-sponsored conference of indigenous NGOs took place in 1981 and led eventually to the writing of the Draft United Nations Declaration on the Rights of Indigenous Peoples. From the start, such groups have transmitted news quickly to their dispersed members, captured media attention, and coordinated political pressure to advance indigenous self-determination. They advocate the rights of indigenous people to control their own land and resources, both traditional commodities (lumber or minerals) and biotechnological resources (such as pharmaceutics developed from rainforest species; Barsh 1993: 206). Moreover, since most nation states do not recognize the sovereignty of indigenous groups, the groups typically demand UN adjudication of important disputes. Mobilizing opposition to the HGDP and bringing grievances to international bodies perfectly fit the technical capacities and long-standing mission of the global indigenous rights movement.

GROUP CONSENT: THE ETHICAL RESPONSE TO POLITICAL CRITIQUES

In what terms did the HGDP personnel respond to critics and defend the ethical integrity of the project? Henry Greely, professor at Stanford Law School, served as the project's most public and energetic defender; a health law expert and member of the North American Regional Committee of the HGDP, he answered the letters and communiqués from RAFI and SAIIC in the days or even hours after they appeared on the Internet. (On at least one occasion, he met personally with critics at the WCIP conference in Guatemala; see Greely 1994.) He countered some of the opposition simply by restating the project's organization and goals. Against the charge of seeking to develop profitable drugs, he stated that the project refuses to support gene patents and "expressly reject[s] unfair and exploitative 'gene-hunting'... The Project, in fact, sees its open, international, non-commercial and non-governmental structure as a solution to biopiracy" (Greely 1995). Against the charge of targeting disappearing indigenous groups, thereby exploiting their oppression for the sake of scientific curiosity, Greely countered that the project aimed at inclusion. It will ensure, he wrote, that "the genetic diversity of ALL of humanity, not just the North Americans and Western Europeans currently being analyzed by various genome projects will enter the final genome map" (Greely 1995; Greely reiterates this defense in his 2001 review article).

Direct responses to particular objections, however, were not enough to maintain the legitimacy of a global scientific project involving potentially thousands of individuals. Even before the controversy broke out, HGDP planners had issued internal working papers and protocols based on accepted principles of scientific conduct in American bioethics: gaining informed consent and protecting the privacy and intellectual property of sampled individuals (Greely 1997).[4] As the protests grew, however, Henry Greely took another step as chair of the subcommittee on ethics within the North American Regional Committee of the HGDP. Supported by the MacArthur Foundation in 1994–1995, he led a working group in drafting a Model Ethical Protocol (MEP), which was posted on the project web site and published in 1997 (North American Regional Committee 1997).[5] Although neither the North American Regional Committee nor its parent organization, the HGDP, officially adopted the proposed protocol, it nonetheless represents the most sustained effort to answer the project's many critics.

If the object of bioethics analyzed here is the MEP, the driver or core mechanism of this object is the novel notion of group consent. Recall that for HGDP critics, collecting DNA material reinforces longer term inequities between developed and indigenous societies (see Cunningham 1998: 207, 221). The MEP engages, but only briefly, with this critique. It reminds researchers that many populations to be sampled have historically faced "discrimination, oppression and even genocide" (p. 1443). Such passages acknowledge the historical grievances of HGDP critics, but the protocol quickly moves to the immediate and practical details of research. It emphasizes respect for populations (parallel to the foundational bioethics principle of respect for persons). It defines respect partially as a matter of logistics: learning about the culture and politics of a given population before approaching it, using knowledgeable translators, and following the appropriate etiquette in making the initial contact (p. 1438 ff). The core ethical procedure, however, is a transformed version of informed consent. The potential risks and benefits of the HGDP affect entire groups, not individuals (notably, the collective financial benefits from commercial uses of genetic material and the collective risk of stigma, if the certain groups are shown to have a greater genetic propensity for certain diseases). Expanding the approach of informed consent, the protocol requires that researchers obtain the consent of both individuals and groups via their "culturally appropriate authorities" before sampling a given population (pp. 1443–1444).

To follow the mandate of group consent, Greely et al. must determine what counts as a population and its relevant authorities. To this end, they invent new social categories, tailor-made to guide them in their core ethical task. Their ad hoc sociology specifies two levels of organization for any sampled population. The first level is the immediate, local community, for example, the village, parish, or portion thereof where the sampled individuals reside. The community may have obvious authorities (such as a headman), or a general consensus may constitute the only practical means of group consent. The second level consists of the supra-local organization with which sampled individuals identify. The MEP thus directs researchers to obtain consent of individuals, their local community, and their supra-local group. For example, researchers wishing to sample a Navajo population must obtain the consent of the individuals, the village where they live, and the Navajo tribe through its tribal council. Researchers wishing to sample Lubavitcher Jews need the consent of the individuals, the relevant local community, and the group's recognized religious leaders (pp. 1445–1446).

Greely et al. recognize the difficulties in following the "chain of consent." In practice, how does one identify the culturally appropriate supra-local authorities? To guide researchers, they provide a legalistic two-pronged test: supra-local authorities must be consulted if (1) the population believes that it meaningfully belongs to a higher level group; and (2) there exist individuals or organizations at the higher level whose authority the given population accepts. For example, even though the Navajo belong to the larger group of Na-Dene language speakers, the latter does not constitute a culturally appropriate authority. Determining whom to ask for consent is explored through several other short examples (Maori, Cree, and Irish Americans). In the end, the protocol states that only the sampled population itself can determine which higher level groups must give their consent (p. 1445). Even with such information in hand, actually obtaining their consent may require that researchers spend "a year or more of contact, explanation, and service to the community." (p. 1447). Despite such ambiguities, Greely et al. make group consent the centerpiece of the protocol. They rely on it to determine how to approach groups, what information to provide to them, how to provide reciprocal benefits and medical services, and how to solve the problems of patenting human genes and cell lines (see Greely 1997).

The MEP is an object of ready-made bioethics. It enunciates a stable set of principles and technical guidelines for decision-making but was born from the attempts to reform, and thereby keep in operation, a particular research project. Tracing its production illustrates one way that population geneticists tried to deploy the apparatus of contemporary bioethics to manage the open conflict about their work caused by claims of political sovereignty from potential DNA donors. In this instance, however, the object did not work. It did not resolve the conflict or allow the scientific work to proceed. The HGDP, as a named and coordinated undertaking, was shut down by the late 1990s.

According to Henry Greely, the protocol has a mixed record. He believes that it succeeds on its own terms, but also that it is simply ignored by most critics and scholars (Greely 1999). Critics regard the HGDP as a whole as the archetypal villain in pre-existing narratives about racist exploitation and creeping eugenics. Once they label the project as the enemy, they can easily ignore disconfirming evidence such as the MEP. As a result, "[t]he HGDP is accused, without proof, of things that it is committed to avoiding, and . . . is urged to address issues about which it already had detailed, innovative, and progressive positions" (Greely 1999: 299). According to its chief author, therefore, the protocol has failed to satisfy critics or alter the course of debate because culturally embedded narratives are simply very hard to overcome.

Greely is correct that many of the project's opponents ignore the protocol. The sociologist Hilary Rose, for example, does not mention the MEP, but she would probably dismiss it because it attempts merely to add ethical guidelines after the fact, that is, after the scientific project was already conceived (Rose 1999). She supports a markedly different core ethical procedure for the life sciences: not ensuring informed consent, but rather explicitly building in beneficence through the design of research. Rose illustrates her ethical ideal with the vignette of an African-American geneticist who has lost a parent to prostate cancer asking for a tissue sample from another African-American man dying of the same disease. Such a case assures beneficence and respect for autonomy, and thus transcends the need for ethics protocols because "both the asking and the giving [of DNA material] are part of a shared, deeply altruistic act" (p. 329). Her critique is couched entirely in terms of other ready-made concepts—the canonical principles—within conventional bioethics. Similarly, Debra Harry (an indigenous rights activist) and Jonathan Marks (an anthropologist) (1999) oppose the HGDP because the people asked to contribute DNA had no role in defining the project's priorities (see also

Cunningham 1998). In the ideal research relation, according to these scholar–activists, indigenous people themselves would decide which genetic issues to research and which problems (such as diabetes or alcoholism) have a significant genetic component in the first place. Although Harry and Marks do not mention the MEP, they also would probably judge it as fatally misdirected. It establishes formal equality between scientists and study populations, but long after the former group has unilaterally made the truly consequential decisions about research priorities. The HGDP thus perpetuates historically unjust power relations, even if researchers perfectly follow procedures for group consent. All these authors implicitly reject the MEP because they regard informed consent—group or individual—as an insufficient ethical procedure, given persistent Western domination over indigenous societies.

Addressing a scholarly audience, Reardon (2001) and Juengst (1998) do engage with the MEP, but they criticize group consent because of the contradictory way it defines groups. Only after researchers decide which population to ask for permission to sample, do members of that population define the appropriate chain of consent. In other words, geneticists first aggregate individuals into a group that is relevant to a particular scientific hypothesis (a “biological population”). That group then becomes the moral agent specified by the MEP—the “local community” that is the source for the first level of consent. The protocol vests this group with the power to determine the proper supra-local authorities, but the power does not amount to much. After all, project scientists were in charge of identifying the lower–level group as a collective entity in the first place (Reardon 2001: 374–378). Juengst articulates the problem in philosophical terms. The unit of analysis in population genetics is the deme: a group of individuals with a significant level of genetic similarity. To assume that demes have moral standing and can grant or withhold permission for research is to commit a category error. Nonetheless, the MEP takes precisely this step by regarding self-identified social groups as surrogates for demes (Juengst 1998: 189). Group consent necessarily operates in the context of politically visible social units, while discoveries about demes concern populations which potentially have an entirely different makeup, and the MEP ignores the slippage.

However, the dissatisfaction of activists and their allies was inevitable, given who wrote the protocol and for what reasons. Critics voiced their opposition in terms of the centuries-long relations between Western and indigenous societies. The authors of the MEP, although aware of this history, chiefly aimed to hold together a specific assemblage of practices, personnel, and scientific objects as the political landscape shifted beneath it. Critics judged the project as ethically compromised because scientists did not collaborate with participants to formulate research priorities. The protocol simply relocated the prime ethical choice-point later in the research process. It is possible, Greely et al. say, to conduct population genetics research without repeating the history of oppression and here are the ready-made principles and technical procedures to be followed.

The mismatch of motives between the critics and defenders of the HGDP virtually guaranteed that the conflict would not be settled by the MEP. Superficially, the exchanges between the two sides about the MEP resembled a dialogue about the same basic questions: What counts as an indigenous group, and what are its legitimate structures of authority? What is the proper way to respect their sovereignty? Can research activities successfully detach themselves from historic relations of domination? However, each side advanced its own definition of key terms, and thereby guaranteed the impasse at the end. The definitions adopted by each side resulted directly from their interests as historical actors. The authors of the protocol were mostly HGDP members: that is, leading figures in contemporary human population genetics and molecular anthropology. Their interests lay in keeping the project viable by establishing clear boundaries between acceptable and unacceptable research activities. As a document meant to reform the behavior of scientists, defend the HGDP in front of various audiences, and thereby keep the scientific work moving along, the MEP testifies to the immediate pragmatic goals of its authors. The critics were leaders of indigenous rights activist organizations engaged in a decades-old attempt to gain political sovereignty, and hence control over resources targeted by more powerful nation states and multinational corporations. Their struggle to halt the HGDP was yet another arena to demand recognition and political legitimacy.

Calling attention to the project's ethical problems was an opportunity for indigenous rights leaders and devising a systematic defense became a necessity for HGDP planners. Not surprisingly, the two sides' motives for speaking to each other never converged. Claims of sovereignty aim at something fundamentally different (a change in historical memory, large-scale political reform) from the stricter regulation of research. Therefore, a research ethics protocol such as the MEP could not satisfy their goal. Moreover, population genetics research is impossible without the notion of biological populations, but this construct differs in kind from the model of politically equal sovereign communities. Human population genetics—like any science involving human research participants—is vulnerable to political critique because of the power imbalance between experts and non-experts. The technical vocabulary and regulatory apparatus of group consent could not resolve this vulnerability in the case of the HGDP. At most, the MEP could have helped this particular project muddle through, despite competing definitions of populations. But because an ethics protocol cannot finally settle how gene pools have political standing, it cannot remove the political vulnerability and automatically usher in a period of placid normal science.

My analysis of the dispute over the HGDP illustrates one way to study bioethics in action. It takes the published final product of a high-profile committee and explores the "upstream" events and contingencies surrounding its origin. This account ratifies neither the celebratory nor the critical narratives about American bioethics. Greely et al. needed to write the MEP chiefly because their opponents had begun to shut the project down, not because they wanted to advance ethical theory about group rights. But the protocol does not demonstrate the co-optation of bioethics, since following it would actually have made geneticists' work more difficult and in certain cases impossible.

Compared to these polarized narratives, the account here better captures the short-term logics and negotiations typical of the everyday work for people professionally involved in the bioethics enterprise. Yet this case study of bioethics in action also has limitations. It is a historic account, and the moment it describes has already passed. Group consent is now stabilized both as a technique and as a conceptual category in the ethics of population genetics research, as evidenced by other model protocols (e.g., Beskow et al. 2001; Foster et al. 1998; NIGMS 1999), which cite each other as well as the broader literature about the ethical use of human biological materials. Group consent is nearing the status of a black box of ethics, routinely employed by researchers as well as NIH peer review committees. Does the mismatch of motives and interests evident during the production of the MEP afflict the current use of group consent protocols? Or is the black box finally closed? The answer cannot be predicted from my analysis here.

THE REINVENTION OF MELUNGEON ETHNICITY

The conflict between the agendas of scientific genetics and popular movements for recognition and sovereignty does not always implicate chiefly differences in power. Geneticists, of course, do not always end up as the enemies of people providing DNA. In the case described below, members of a small, once-isolated group requested DNA analysis to validate their claims of collective ancestry. They were happy to find a geneticist willing to take on their project, but he eventually had serious misgivings about the entire enterprise. People asked him to provide evidence about cultural identity and descent, but he knows his science is irrelevant to their most pressing questions.

The rest of this article examines the use of DNA evidence to assert identity claims among the Melungeons, a multiracial group from southern Appalachia. Their demand for and reception of genetic studies have generated several conflicts, but not along the familiar fault-lines. This case featured few political disagreements about whether research should proceed. Obtaining cheek swabs and hair roots, extracting the DNA, and growing cell lines did not provoke a popular outcry about imperialism or formal ethical self-scrutiny. Melungeons' demand for collective recognition proved incommensurable not with the politics of genetic research, but instead with the limits that researchers themselves place on the interpretation of their findings. This case turned on the conceptual vulnerability of human population genetics: the mismatch between scientific and popular views about the ability of genetics evidence to establish collective origins and identity. A formal protocol such as the MEP, meant to adjudicate between acceptable and unacceptable research practices, cannot particularly help geneticists who face a conflict not with potential DNA donors, but instead with their own professional and intellectual commitments. The geneticist who worked with the Melungeons was thus pushed into an even murkier ethical terrain than the HGDP defenders. He found it impossible to resolve the relevant conflicts without abandoning his fundamental dedication to his scientific craft.

For over 100 years, journalists, social scientists, and folklorists have written about the Melungeons of northeastern Tennessee and neighboring regions of Virginia and Kentucky. In a journalistic idiom, the Melungeons are a “lost tribe,” “Virginia’s mystery race,” an “almost exinct,” or “dwindling hill clan,” to cite titles of popular magazine articles over the years. However, attempts at a more accurate description quickly get caught up in the same identity politics that divide the group itself and that drive its current interest in genetic research. Until recently, most academic accounts classified Melungeons as an enclaved community of mixed black, white, and American Indian ancestry, one of several such groups living in the eastern and southern United States. The anthropologist Gilbert (1946) included Melungeons in his detailed list of “mixed-blood racial islands”—groups that are considered racially distinct by their white, black, and Native American neighbors—along with the Brass Ankles and Croatans of the Carolinas, the Red Bones of Louisiana, the Guineas of West Virginia and Maryland, and the Jackson Whites of New Jersey.[6] Gilbert characterized all these groups as backward minorities, suffering from illiteracy and poverty, difficult to classify racially, and needing assimilation to improve their condition.

Other social scientists forgo the paternalism, but offer similar accounts of Melungeon origins. Price (1951) traces the Melungeons to a fluid mixed-race society living in the 18th century in Virgina and the Carolinas. For Beale (1957), they are a “tri-racial isolate,” one of 27 such groups found throughout the South. Such groups contain “intermingled Indian, white, and Negro ancestry,” and they persist as singular, bounded communities because of their geographical isolation and the legal or customary restrictions on marriage with both whites and blacks (see also Berry 1963). Most recently, DeMarce (1992, 1993)—a professional historian and genealogist—has documented Indian–white, black–white, and black–Indian amalgamations among the historic source populations of Melungeons. She also traces the likely migration of major Melungeon families from west central Virginia into the core area of northeast Tennessee where most people who now call themselves Melungeon trace their lineage.

Until the early 1990s, these scholarly representations remained unchallenged by Melungeons themselves, simply because few people actually admitted to being one. Berry's informants told him only that he would find Melungeons "across the creek" or "in the next hollow" (Berry 1963: 17). Price learned how to identify typical Melungeon surnames and physical traits from individuals who specifically disclaimed the identity. Beale noted that in the 1950 Tennessee census, individuals locally known as Melungeon were most often marked by census workers as white, less often as Negro, and occasionally as Indian. He emphasizes that the designation of tri-racial comes from the outside investigator, not the groups themselves. In fact, "the mixed-blood individual will usually insist—with vehemence, if necessary—that there is no Negro ancestry in his family . . . but that he is partly Indian" (Beale 1957: 188). Cavender (1981) found the same situation during fieldwork in Hancock County, Tennessee, in 1979 and 1980. People identified by others as Melungeon usually denied the very existence of the group. Most whites, moreover, used the term simply as an epithet for anyone who was poor or had a suspected black ancestor. People interviewed by the above researchers presumably did not self-identify as Melungeon for several reasons: to escape the term's lower class connotations (shiftless, backwards, thieving); to avoid the danger to one's rights and status from acknowledging black ancestry (see DeMarce 1992: 6–7); or simply because the term no longer existed as a meaningful ethnic marker.

"Melungeon" during this period was an exonym, a term that outsiders used to identify the group, but that no one used to label themselves (see Puckett, 2001). The word reinforced the class hierarchy and racial boundaries of southern Appalachia. However, the meaning and uses of the term began to change in the 1960s. In 1966, two economists, professors from Jefferson City, Tennessee, conducted a regional economic study of Hancock County, at that time among the ten poorest counties in the nation. They recommended the development of tourism and, in particular, suggested "a drama featuring the mystery of the Melungeon settlement in the county . . . [t]he natural spin-off from the drama would be an outlet for handicraft items" as well as food and lodging services for tourists (quoted in Ivey 1977: 102). The play *Walk Towards the Sunset: The Melungeon Story*—a sentimental narrative about two centuries of anti-Melungeon prejudice—opened in 1969 in the Hancock County town of Sneedville (Beale 1990).

The play produced a short-lived tourism boom, but it also inaugurated a deeper change in the value and significance of Melungeon identity. In 1973, Sneedville residents began for the first time to identify themselves as Melungeon or to acknowledge Melungeon ancestry (Ivey 1977). Only a few years later, a self-labeled insider to the group complained to Cavender that some of the people "coming out of the closet" as Melungeons were actually imposters (Cavender 1981: 32). The next phase in this process of ethnic reinvention began two decades later with the publication of *The Melungeons: The Resurrection of a Proud People* (Kennedy

1997, first edition published in 1994). In his book, N. Brent Kennedy, PhD, the vice-chancellor of development at Clinch Valley College, Virginia, describes how his struggle with sarcoidosis, a chronic inflammatory disease, led him to reconstruct his family genealogy, embrace his Melungeon heritage, and explore the origin and racial makeup of the group. Now in its second edition, the book serves as the first contact for many people entering Melungeon circles. Kennedy also enlisted academic support to find the Melungeon Research Committee (now the Melungeon Heritage Association [MHA]), and he organized the growing interest in Melungeon identity into a series of yearly meetings. The "First Union," held in 1997 at Clinch Valley College with over 500 attendees, featured talks on genealogy and grantsmanship, along with Appalachian music and storytelling.[7] Subsequent meetings have been held yearly in Kentucky and Tennessee. People who consider themselves Melungeon regularly attend these meetings, and they also participate in a vast web presence of family associations and competing home pages that assert different origin theories or explore connections with African-American and Native American groups.

In the 1990s, therefore, thousands of people began to claim Melungeon identity or descent. The exonym became an autonym. Individuals who once shunned the label (or did not even know it existed) now claim it publicly and use it as an entrée into new face-to-face as well as virtual communities. As with many emerging identity movements, conflicts over authenticity and the prerogative to define the group's essence and boundaries divide today's Melungeons.[8] First of all, people living in the Appalachians who have personally suffered from the stigma of poverty and suspected black ancestry have different reasons to proclaim themselves Melungeon than do those whose ancestors left the region three or four generations ago and securely enjoy white status. Even locally, the better-educated individuals who organize the yearly gatherings inadvertently separate themselves from the poorer majority, who often cannot afford the registration fees and the time off from work. In fact, the majority of people attending the Fourth Union held in 2002 were retirees, often from out of state, with a sprinkling of white-collar professionals. Finally, certain Melungeons privilege their Indian descent and seek legal recognition as a tribe,[9] thereby alienating themselves from the MHA, which explicitly does not seek tribal status.

The revitalization of Melungeon identity also participates in broader social changes. According to Darlene Wilson, a historian and long-time MHA board member, the Melungeon movement aims to reverse the economic and racial caste system of the United States (Wilson 1998). She believes Melungeon ethnic activities hasten the long-term retreat of American racism, a viewpoint echoed on the MHA web page: "We firmly believe in the dignity of all such mixed ancestry groups of southern Appalachia and commit to preserving their rich heritage of racial harmony and diversity."[10] Kennedy's book, a touchstone for many present-day

Melungeons, adopts the common formulae of late 20th century identity politics:

> The restrictive choices of either quietly accepting our "stigma" [as Melungeon] or sweeping it under the rug in the pitiful self-delusion of "being like everyone else" were unacceptable. To me there seemed to be a third, admittedly blasphemous option: to embrace our heritage—whatever it might be—and wear it like a banner . . . . My mother, at first uneasy over my decision to come out of the Melungeon closet, quickly came to understand. (Kennedy 1997: 7)

Intentionally or not, Kennedy's self-description recalls the shame of trying to pass as white or to normalize a physical disability, as well as the ordeal of acknowledging one's homosexuality to family members. As the Melungeons' most well-known spokesman, Kennedy demands recognition in terms similar to those employed by many other groups in the national political scene. His calls to overcome internalized stigma, to make authentic contact with oneself, and to honor group distinctiveness in the face of pressures to assimilate are all standard ingredients in contemporary politics of difference (Taylor 1992: 38 and passim).

For many Melungeons, the right to establish their own origin story is the most public demand for recognition. Of all the speculations about origins that circulated in popular accounts, the claim of Portuguese descent has the oldest published history, dating to at least 1848.[11] Academic and popular writers have long reported that individuals classified as Melungeon (when that term was still an exonym) would call themselves Portuguese, often pronounced "Porty-ghee." Kennedy (1997) supports the Portuguese theory and adds to it ancestry claims about Turks and Moors who settled in the colonial southeastern United States. His complicated account comes wrapped in a demand to respect his Melungeon ancestors who, he says, were telling the truth when they described themselves as Portuguese. The "tri-racial isolate" theory, he writes, traces white ancestry exclusively to the British Isles. It is not only incorrect, it is also politically damaging, for it denies people "the God-given right to claim their national or specific ethnic heritages" (Kennedy 1997: 100).

For Kennedy and his supporters,[12] establishing an authoritative origin story is an a priori right of the Melungeon community. This collectivity, like all others, deserves recognition in terms of its own choosing, even (or especially) in the face of outsider experts. Many Melungeons fiercely support Kennedy's ideas about Portuguese origins. They reject the standard scholarly opinion that the group arose from an amalgam of northern Europeans, Africans, and Native Americans. They claim that calling Melungeons a "tri-racial isolate" connotes inbreeding, inferiority, and hence reproduces the elitist stereotype of Appalachian residents.

Claims of Portuguese descent generate polemics for a second and even more highly charged reason. Scholarly opinion holds that Melungeons (and other mixed-race groups) historically called themselves Portuguese to deflect suspicion of African ancestry. DeMarce (1993) and Henige (1998) both cite an 1872 Tennessee Supreme Court decision that classified a Melungeon woman as a descendent of ancient Carthagenians who long resided in Portugal, and hence not Negro. The ruling legalized her marriage to a white man and enabled her child to inherit the father's estate (DeMarce 1993: 33). In general, many people insecure about their racial identity in the antebellum and Jim Crow South tried to pass as white by claiming Portuguese or other southern European ancestry (Everett 1999: 370). According to Henige (1984), the label Portuguese is a contrived defense mechanism that reinforces one's endangered white status. Henige (1998: 280) applied this perspective to Kennedy's book, which he faults for its studied ambivalence about acknowledging black ancestry. Henige's critique as well as the long history of claims about Portuguese descent made by groups in the South raises the stakes considerably. For Brent Kennedy, proving the Portuguese origin story would not only vindicate the right of Melungeons to author their own history. It would also exonerate him and the Melungeons from charges of crypto-racism and of disguising the truth about group origins: serious matters in the current climate of identity politics.

IDENTITY CLAIMS AND POPULATION GENETICS

To convince others to accept his theory of Melungeon origins, Kennedy turned to population genetics:

> The call for DNA really came from outside the community, not within. It really came from scholars who took offense at our writings, who criticized these outlandish claims that differed from the standard tri-racial accounts. They said that these claims cannot be substantiated, given the historical records that we have here in Virginia, where we think the core Melungeon population originated. They said that the only way you can prove these theories of Mediterranean, Turkish, Portuguese, or Jewish origin, or the possible source for the illnesses that people have, is through DNA (Brent Kennedy).[13]

In the early 1990s, Kennedy had consulted several academic geneticists who told him that a proper population study—with DNA samples from both Melungeons and comparison populations in Portugal and Turkey—would cost over a million dollars. In the following years, however, advances in mapping the human genome brought the price down considerably. Thanks to PCR technology and new databases of regionally and ethnically labeled DNA, geneticists can now take DNA samples locally and make probabilistic statements about population history without collecting new samples from distant parts of the world (see Bradman and Thomas 1998, and for a popular account, Sykes 2001).

In 1998, Kennedy presented his ideas for genetics research to Kevin Jones—a British molecular biologist and newly arrived assistant professor at the University of Virginia College at Wise (the re-named Clinch Valley College). Although he had never heard of the Melungeons, Jones took on the project because he was intrigued by the patterns of unusual diseases (e.g., thalassemia and Familial Mediterranean Fever) typically associated with southern European ancestry that also occur among white, presumably Scotch–Irish, Appalachians. Brent Kennedy, however, wanted the genetics research to authenticate certain ancestry claims, not to reconstruct disease patterns, and he essentially steered the research in his direction. Kennedy oversaw the collection of DNA samples from descendents of the historic core Melungeon population, and Jones genotyped the population (by calculating the frequency of particular makers on the mitochondrial DNA (mtDNA) and the non-recombining portion of the Y chromosome), and compared Melungeon frequencies to those recorded for various world populations. (Jones has not yet published the Melungeon data, but he says his approach parallels the work by Weale et al. 2002 and Wilson et al. 2001.)

The cultural politics of self-ascribed Melungeons interacted with the technical demands of population genetics to produce the “rough edges” of Jones’s research: the zones of conflict between professional and lay expectations (see Bosk 1992). To begin with, this sort of research requires a clearly identified core population for sampling. However, the inclusion criteria for this group are essentially contested. People who now call themselves Melungeon live both in southern Appalachia and across the United States show a range of complexions and physical types, and bear a number of surnames. Conversely, many people with the same residence, appearance, and surnames do not identify as Melungeons. By necessity, Jones relied entirely on Brent Kennedy to delineate the core Melungeon group.

> I decided whom to sample. I think I know who are the original Melungeons, those who lived between 1725 and 1790. I asked myself, can we locate the descendents of those people? Hence, we chose seven or eight people on the Virginia side and ten on the Vardy, Tennessee, side. We began with these people who everyone agrees are the original Melungeons. It was very easy to find their descendents. We all know who was related to whom; we just had to find the right cousin (Brent Kennedy).[14]

At this stage, Kevin Jones’s role was to ensure that enough samples were collected, that they came from independent lineages and that the descent was traced exclusively through the female or male line, a requirement for research with mtDNA and Y chromosome markers.

In contrast to the HGDP, the process of collecting Melungeon DNA did not raise any questions about group sovereignty or informed consent. Kennedy presented his plan for sampling to the Vardy Historical Society, a local community board of self-identified Melungeons. They immediately endorsed it, as did the people approached in Virginia. In fact, Melungeons began to request DNA testing in numbers that far exceeded the needs of research and the technical capacity in

Jones's laboratory. At least a thousand people requested that their DNA be included in the analysis. Kevin Jones often received unsolicited hair samples in the mail from people who had heard of the study but were not chosen as descendents of the core Melungeon group. In the end, Jones included approximately 120 mtDNA and 30 Y chromosome samples. To preserve the anonymity of subjects, each donor received a numerical code along with their collecting kit for hair roots and cheek swabs.

The chief difficulty with DNA sampling came from people's racial anxiety. During the study, both Brent Kennedy and Kevin Jones received death threats, and Jones told me he received several anonymous warnings by telephone as well as the accusation that Kennedy was sampling the darkest people he could find. Jones told me that the people issuing these threats were simply afraid that the DNA study would find a black in their family past, and my conversations with attendees at the Fourth Union ratify his interpretation. According to one woman long active in Melungeon affairs, many more blacks had come to the first few Melungeon gatherings, but the weight of opinion soon decreed that "if you were colored, you were not going to be counted as a Melungeon." Other attendees who were researching their family lines told me bluntly that people are afraid that information about their black ancestors will become public. Their comments suggest that when participants in Melungeon activities talk about identity, they effectively portray themselves as white, despite the official rhetoric about mixed-race descent (see Pucket 2001). Even Brent Kennedy estimates that a third of self-ascribed Melungeons are afraid of the ramifications of finding black ancestry, although he says they would eventually accept the information.

Kevin Jones finished a preliminary analysis of the genetic data by early 2002. However, during the prior year, he often wondered about the wisdom of beginning work with the Melungeons.[15] First of all, he thought that the politics of identity completely overshadowed any interest in legitimate science. Each Melungeon faction wanted something different from the genetic study. Kennedy and his supporters wanted evidence of Portuguese or Turkish origins. People seeking tribal recognition, or at least affirmation of their subjective sense of Indianness, wanted to see Native American ancestry. At least a handful of individuals wanted to shut down the whole project for fear of any evidence of black ancestry. Moreover, individual DNA donors were impatient to learn about their family lines, even though Jones was conducting a population study which is unsuited for questions about individual genealogy. Finally, in his dealings with the Melungeon community, Jones encountered both a broad suspicion that scientists were secretive and insensitive and the naïve faith that his particular project would provide definitive answers about family history. He knew his research could not satisfy these contradictory expectations.

Jones publicly presented his data in a much-anticipated talk at the Fourth Melungeon Union in June 2002. He first spoke about the open-ended nature of all scientific work and emphasized the anonymity of the samples and his own objectivity (as a British citizen and non-Melungeon). He described the analysis of the aggregate DNA sample into the categories of African, Native American, and Eurasian used by GenBank (the NIH database for all publicly available genetic sequences). Finally, he presented the numerical data:

> The numbers are relatively small . . . . But nevertheless, about five percent of people who claim to be Melungeon reflect a Native American ancestry on their female side, and about five percent reflect an African-American . . . . That leaves an awful lot of people who fall under the Eurasian category, and that is no real surprise . . . . Because populations have moved around Europe so much, that there are some sequences that you find anywhere in Europe. They don't tell us anything about likely origins. And when you look at those Eurasian Melungeon samples, an awful lot of them fall within that category. They are generic type sequences. They could be from England, Ireland, France, they could be from Spain, they could be from Turkey, anywhere within that Eurasian category. (Kevin Jones)[16]

He then described the few unusual (non-generic) sequences that he found: among the mtDNA samples, four sequences that matched with the Siddi (a North Indian people of East African descent) and couple of sequences that matched from Turkey; among the Y chromosomes, some matches from Anatolia and Syria.

Jones also tried to address the anxieties and expectations in his audience. He explicitly used the term "multiracial," instead of "tri-racial isolate" to describe Melungeons. He underscored the considerable genetic diversity that he found in order to dispel a common stereotype. This population, he said, is as diverse as just about any other human population, "so, if anyone has ever said, 'You inbred Melungeon!' they are lying." Finally, he emphasized that genetics does not and should not affect the sense of Melungeon identity:

> If you are hoping for a DNA sequence or a Y-chromosome type that says 'You are a Melungeon,' forget it. It doesn't exist . . . . You know what it means to be Melungeon or feel Melungeon or to be discriminated against as a Melungeon. It's a cultural identity which is real and important, but it does not reflect any genetic basis. And I hope that with the variability that exists, apparently, within this population, that's something to be proud of. Because that culture and that identity have been maintained in the face of input from all sorts of people. (Kevin Jones)

In his public performance, Kevin Jones tried to balance what people wanted to hear with what he could legitimately tell them. He knows there is no such thing as a definitional Portuguese or Turkish haplotype. He knows that the term tri-racial is just as meaningful (or meaningless) as multiracial, given the models of human variation in today's genetics. He also knows that the percentages he gave are probabilistic figures, subject to sample size, mathematical models, and the particular datasets used at GenBank and the Center for Genetic Anthropology, University College of London (which sequenced the Y chromosome data). His strategy thus involved providing enough details to please everyone without compromising himself. Speaking to a crowd of journalists (from *Smithsonian*, *Discover*, and *Wired*, as well as local media outlets) after his talk, he explained that calling the vast majority of genetic markers pan-European does not necessarily mean that Melungeon ancestors did not sail from Portugal. "All I've done is contributed data," he explained, "and people can make of that what they will. That's what I do as a scientist." Intended for the media, his remark demonstrates a benign commitment to scientific objectivity. What he did not add publicly is that his science cannot answer the questions about collective identity that set the whole project in motion.

Reflecting on his performance a few days later, Jones told me that what bothers him the most is that the Melungeon community neither understands nor cares about population genetics. People are only interested in the most exotic ancestries or their own family lines, and Jones already heard them start to weave the discovery of Siddi sequences into stories about Gypsy relatives. Indeed, people in Melungeon circles are avid customers of commercial genetic web sites such as FamilyTreeDNA.com (which sent its CEO to the Fourth Union). Founded in 1999, this company performs various types of mtDNA and Y chromosomal analysis for a few hundred dollars each, and customers purchase them to verify relatedness between cousins and also to discover if they have certain markers (SNPs, or single nucleotide polymorphisms), indicating likely Native American or Cohanim (hence, Jewish) ancestry. Jones attributes the mismatch between popular expectations and his scientific expertise to people's overwhelming devotion to genealogy through genetics. The commercial web sites cater to people's desire to turn a trivial genetic fact into an appealing identity claim, Jones said, and the Melungeons approached his own project with the same desire.

In the case of the Melungeons, a vast distance in worldview and scientific fluency separates the geneticist from the people who want him to adjudicate their identity claims. That distance constitutes the rough edge of Kevin Jones's work, where lay and expert views diverge most sharply. In his public presentation, Jones managed to avoid open hostility by carefully stating what the data could support and what it does not deny. He allowed people to pursue their quests for recognition without undue impediment. However, Jones cannot so easily resolve the professional's side of the rough edge. In our conversations, he stated the dilemma in the following terms. What is his responsibility as a scientist, when his expertise is so broadly misunderstood or ignored? Jones does not expect untrained people to master or even appreciate the complexity of population genetics. Is it more dangerous if population geneticists study a group searching for its origins, or if they do not study it? If they study the group, its members will inevitably distort the findings or get angry when they are presented in their legitimate but impenetrable complexity. If scientists do not study the group, people will use commercial genetic testing services and thereby satisfy their lust for definitive answers but not learn anything meaningful about themselves. In the end, Jones feels caught up in an impossible conflict between the role of scientist (addressing other experts) and arbiter of community origins (addressing Melungeons). By definition, fulfilling one role betrays the obligations of the other.

CONCLUSION

The HGDP and Kevin Jones's work with the Melungeons illustrate the political and conceptual vulnerabilities of human population genetics. The HGDP was a global undertaking with little direct benefit to the groups or individuals to be sampled. Indigenous rights advocates saw an opportunity to advance their sovereignty claims by opposing the HGDP in front of the highest international authorities. The HGDP personnel responded to the political firestorm by writing the MEP: a recognizable object of ready-made bioethics, produced by negotiations between professionals and their lay critics. The Melungeon case unfolded on a much smaller scale and in a different political landscape. Brent Kennedy, an ethnic insider, led a genetics project that he thought would justify his claim of Portuguese descent. Many Melungeons then eagerly requested DNA sampling as part of their battle against the widespread mis-recognition or non-recognition of their distinctive identity.

The conflicts between Kevin Jones and the Melungeons grew not from a power imbalance, but instead from incommensurable truth claims about genetics data. The struggles that preoccupied Jones for over two years do not lend themselves to the terms of formal bioethics (e.g., balancing professional prerogatives against individual or group rights). The very circumstances that made his project possible—Brent Kennedy's high profile among Melungeons and people's strong motivation to donate DNA—meant that Jones did not control the goals of research or the interpretation of findings. Realizing that he had stopped doing science as usual, Jones improvised his response to the crosscurrents of Melungeon identity politics. At times, he was baffled by people's disinterest in what genetics could legitimately say about population history. At other times, and in public, he confirmed the Melungeons' own assertion of ethnic pride. Most importantly, though, he became convinced of the incommensurability between how experts and non-experts interpret and use genetic data.

These cases suggest what drives professionals in human population genetics to turn to the vocabulary and procedures of modern bioethics. In both cases, routine scientific work was disrupted, and scientists labeled the problem as ethical as a strategy of conflict management (see Bosk 1999). Labeling a problem as ethical changes how professionals and lay-people respond to it, and inaugurates further (more or less) public negotiations. This rhetorical act does not dissolve the conflict, but nonetheless shifts how it unfolds and justifies different standards of evidence and modes of persuasion. This perspective applies chiefly to the political vulnerability of human population genetics: the unequal relation between researchers and people providing DNA samples. This inequality provoked the controversy over the HGDP, and the project planners tried to resolve it by inscribing more equal relations in their MEP. The field's political vulnerability did not affect Kevin Jones's work with the Melungeons, largely because Brent Kennedy, an ethnic insider, sponsored the project, kept control of its aims, and thereby guaranteed people's enthusiasm to donate their DNA. The political crosscurrents which did plague Jones's work were intramural concerns among different factions of Melungeons, but these typically do not drive ethical self-scrutiny among professionals.

Kevin Jones faced the conceptual vulnerability of human population genetics: the mismatch between expert and non-expert views about the relevance of genetics for cultural identity (see Elliott and Brodwin 2002). He grappled with this problem when he began the research and again when he announced his findings. Taking DNA samples from Melungeons logically presupposes, one knows who counts as a Melungeon in the first place, but the science of human population genetics cannot provide the answer. Geneticists cannot decree the inclusion and exclusion criteria actually used to decide group membership, for these are irreducibly social judgments. At most, geneticists offer laboratory data which support, or do not support, judgments that are historically contingent, politically contested, and nestled in a repertoire of symbols about descent, family, kin, community, and nation. Interpreting the data produced by genetics laboratories runs into the same problem. According to Jones, his mtDNA and Y chromosome analysis say nothing about Melungeon claims to Portuguese identity, and not only for technical reasons (i.e., the probabilistic nature of population genetics data and the lack of a Portuguese haplotype). The urgency of Melungeons' claims of Portuguese (or other Mediterranean) identity unfolds against a set of background assumptions and histories: the categories of black and white in the American racial system and the elitism of outsider discourses about Appalachia. Their assumptions are not even conceivable within the terms of human population genetics. At most, a geneticist could argue that American racial categories have no scientific justification, but the conversation would effectively end there.

Population genetics data, once it leaves the laboratory, get inserted into wildly divergent interpretive schemes. When population geneticists work in partnership with community members according to their stated needs (in a noble effort to escape the field's political vulnerability), they risk running into its conceptual vulnerability. They cannot offer the stable, objective definitions of group identity that people often demand (see Brodwin 2002). Their science threatens to become irrelevant and their obligations contradictory, but this produces private anxiety for the geneticist, not politicized and public debate. The end result is a feeling of futility about crossing the expert/non-expert divide. In the case of the HGDP, its centerpiece ethics protocol managed to restate at least part of the critics' general concerns, even if it did not (and could not) fully address their political goals. However, in the case of the Melungeons, the incommensurability between scientific and popular truth claims about "genetic identity" reflects the American dilemma about race and identity, a set of concerns that runs skew to the stable representations and procedures of American bioethics. No final product of bioethics, therefore, emerged to cover over Kevin Jones's bewilderment about professional obligation and contradictory loyalties.

Finally, the two cases illustrate the ethnographic study of bioethics in action. Two main questions animate this approach. (1) Under what circumstances does explicit talk about values, rights, and obligations break out among researchers or clinicians? In general, this occurs because other social actors interrupt their work routines, question their commitments, or oppose their interests and prerogatives. The ethnographic question concerns why, in a particular context, the old routines suddenly require explicit ethical justification. (2) What practical steps do researchers and clinicians take to survive the shake-up? In particular, why do they respond to the controversy by elaborating an explicitly ethical discourse? And when does their pragmatic response get transformed, after a suitable period of time, into a ready-made product of bioethics?

Bioethics in action, therefore, is a matter of muddling through: a real-time struggle to justify one's expertise, professional mandate, and actions in the world. Occasionally, out of the struggle emerges a published text (like the Model Ethical Protocol for Group Consent), which later settles comfortably into the systematic discourse of professional bioethics, ready for future citation by researchers, clinicians, policy-makers, lawyers, and activists. A ready-made product of bioethics is thus the final stage of a particular struggle. But it tends to lose any trace of its construction at a given place and time (cf. Latour 1987). Indeed, the final products of bioethics are often self-consciously framed as a matter of transcendent principles and fundamental rights. The ethnography of bioethics in action peers below the rhetoric of moral necessity to find the earlier story of contingent moves and countermoves. It traces the complicated traffic (of professional routines and their disruption, of competing ideals, interests and agendas) that drove the original controversy as well as people's decision to frame it in ethical terms.

NOTES

1. To focus on the celebratory accounts by Jonsen and Callahan is not to reify bioethics, but to illustrate the major way the field justifies itself in recent interdisciplinary forums (e.g., Kleinman et al. 1999). Of course, people who study the ethical dimensions of medicine and life sciences carry on a lively debate about the boundaries and mission of bioethics. They argue over the relative importance of casuistry, transcendent principles, legal reasoning, narratology, feminism, empirical research, etc. Some prominent figures in the profession refuse to label themselves "bioethicists," and the field has yet to settle key questions about accreditation and the content of graduate study. Unfortunately, the diversity of opinion and approaches often fades away in the standard self-representations of the field made to social scientists as well as in the "bioethics training" offered to IRB personnel and clinician-scientists.

2. See important recent overviews by Reardon (2001) and Greely (2001), the latter defending the scientific validity of the HGDP and arguing for its revival. The HGDP generated an enormous literature in several genres: internal planning documents, reports of early meetings, activist manifestos and opinion pieces opposing it, responses by HGDP planners and supporters, critiques from other professionals (chiefly cultural anthropologists and ethicists), formal statements by bioethics commissions, and review articles about the entire controversy reflecting different disciplines and interests. From the perspective of bioethics in action, however, not all this literature is equally relevant. Reviews appearing long after the controversy died down and formal pronouncements by high-level organizations privilege stable summaries of ethical principles: the final product of earlier debates whose textual traces are more fragmentary and closely tied to immediate contexts. This paper focuses on the latter genre, especially correspondence between critics and defenders of the HGDP on Native-L, an indigenous rights list-serve (accessible at http://www.nativenet.uthscsa.edu). This is the lively and unsettled rhetorical exchange that produced, through many mediations and over several years, the Model Protocol for Group Consent, which exists as a stable artifact of today's ready-made bioethics.

3. For details about the WCIP, see http://www.cwis.org/fwdp/international/scipinfo.text; about CONIC, see nativenet.uthsca.edu/archive/nl/9309/0314.html, and about SAIIC, see saiic.nativeweb.org/brochure.html (accessed March 2002).

4. The final planning workshop (held in Sardinia in September 1993), which established the formal organization of the global HGDP, expanded and restated this list into four "areas of ethical concern." (Human Genome Diversity Committee 1993) (also known as the Alghero Document). These four areas combine straightforward restatements of accepted research ethics with the anti-racist self-image of human population genetics (see Gannett 2001). The first and most detailed area concerns respect for individuals and cultural integrity and the need for informed consent and anonymity. The second area regulates property rights in DNA; it directs any profits from pharmaceutical patents to benefit the sampled population or individual, and it endorses a single database accessible to all scientists. The remaining areas focus on the interpretation and popular uses of the project's findings, particularly the need to avoid misuse of genetic data to justify racism, xenophobia, and hypernationalism, and to publicize that genetic science does not support conventional notions of race.

5. Around the same time, at least two other organizations also prepared guidelines for ethical conduct in human population genetics research, UNESCO and the international Human Genome Organization (HUGO) (Greely 1997).

6. Gilbert used contemporary terminology in his list. The Jackson Whites now call themselves the Ramapo Mountain people; the Croatans now call themselves the Lumbee and consider themselves Indian (see Blu 1980).

7. See http://www.geocities.com/bourbonstreet/inn/1stunion.htm.

8. Information which follows about present-day Melungeons comes from interviews with Brent Kennedy, Wayne Winkler, current head of the Melungeon Heritage Association, and one other individual active in the Melungeon movement for over ten years, as well as fieldwork at the Fourth Union: A Melungeon Gathering, in Kinsgsport Tennessee, June 19–23, 2002.

9. In 1999, a group of Melungeons presented their claims to the Tennessee Commission on Indian Affairs, and they also called upon the broader Native American community to accept them as legitimate descendents of earlier tribes, even though for centuries they had hidden or denied their Indian features (Whitaker 1999).

10. See http://www.geocities.com/bourbonstreet/inn/1024/welcome.htm.

11. Other candidates for Old World source populations include Basques, ancient Carthagenians, 12th Century Welsh sailors, shipwrecked Spanish pirates, Sephardic Jews, the Lost Tribe of Israel, the lost colony of Roanoke, and Turks (Elder 1999).

12. Many people active in Melungeon circles do not agree with Kennedy's favored origin theory, but the full scope of the group's internal politics are beyond the scope of this paper.

13. Interview conducted June 23, 2002, in Kingsport, Tennessee.

14. Kevin Jones was an invited guest at two meetings of the NIH grant "Ethnicity, Citizenship, Family: Identity After the Human Genome Project" (grant 5R01-02196) in August 2001 and February 2002.

15. Transcript of public talk, Fourth Union, June 20, 2002.

16. Population geneticists who routinely recruit DNA donors and report the results in popular media have come to anticipate the incommensurability (Sloan Williams, January 2002). Through the use of informed consent protocols and formal ethics evaluation, they design studies in order to minimize potential problems. Anticipating and resolving controversies in this way, however, constitutes the terrain of ready-made bioethics. Kevin Jones, whose work with Melungeons was his first project in human population genetics, and whose college had only recently formed an IRB, illustrates the earlier stage of bioethics in action.

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A1. Au: Is the edit OK?
A2. Au: “Manges and Manges 1990” has been changed to “Mange and Mange 1990” as given in the reference list. Please check.
A3. Au: Please check the expansion of “NIH.”
A4. Au: please check the page range for reference “Cunningham 1998.”
A5. Au: Please provide page range for reference “Kleinman et al. 1999.”