

# *Doing Bioethics: Challenges for Anthropology*

Margaret Everett

Anthropological participation in bioethics, especially in the area of policy-making, has been limited for a number of reasons. This paper explores the anthropological critique of bioethics and considers reasons why anthropologists are not more visible in bioethics debates. Reflections on the author's own participation on two ethics boards illustrate both the potential contributions of the anthropological perspective to bioethics and the challenges for a more effective engagement.

**Key words:** bioethics, research, policy-making

## Introduction

The field of bioethics emerged in the twentieth century from an apparent paradox—enthusiasm, on the one hand, for new developments in science and medicine, including new treatments for disease, and on the other hand deep concerns for the moral dilemmas raised by those same technologies. Grounded in moral philosophy, the field has grown since the 1960s to become a full-fledged academic discipline, with a distinct set of concepts, principles and theories, professional organizations and career paths (Kleinman, Fox, Brandt 1999). The field has also “gone public,” with bioethicists quoted in the media and called to testify in courts and legislatures. Bioethics has become even more prominent in the past decade as a result of the Human Genome Project, which earmarked a percentage of its funding for the study of “ethical, legal and social issues” (ELSI). Broad changes in health care delivery, medical insurance, and the rise of genetic medicine all play a role in the growing perception of risk posed by expanding genetic information.

The term “bioethics” has been applied broadly to refer to a wide range of activities and perspectives in both clinical and policy settings. However, anthropologists and sociologists have often criticized “mainstream bioethics”—for its use of abstract principles, its inattention to cultural, social and political context, and for its failure to consider equity as an area for ethical deliberation. Writing about bioethics, anthropologist and psychiatrist Arthur Kleinman makes the following assessment: “The experience of illness is made over, through the application of ethical abstractions...into a contextless philosophical construct that is every bit as professionally centered and divorced from patients suffering as is the biomedical construction of disease pathology” (1995a: 1669). What is often called “mainstream bioethics,” seems to hold a similarly dim view of anthropologists who

argue for a kind of ethical relativism, an attention to ethical dilemmas as they present themselves in specific social, cultural, and political contexts (see, for example, Macklin 1998).

This mutual distrust may explain, in part, the relative paucity of anthropological contributions to the field of bioethics, and the limited participation of anthropologists in the cottage industry of ethics panels that have cropped up in the wake of the Human Genome Project. What are the challenges for anthropologists who seek to engage bioethics on its own turf? This article reviews the anthropological literature on bioethics and uses the author's own experiences on two bioethics committees to reflect on the challenges and opportunities for anthropologists seeking to have a voice in policy making.

From 1999 to 2004, I served on two committees charged with overseeing and revising Oregon's landmark Genetic Privacy Act. With the explosion of genetic knowledge and the growing use of genetic testing in clinical and research settings, concern over possible discrimination, especially the potential loss of health insurance, sparked the passage of such laws in a majority of states between 1995 and 2000. I was asked to serve on Oregon's Genetic Research Advisory Committee (GRAC) as a “health care consumer” representative after writing in the local newspaper about my own family's experience with a rare disorder and genetic testing. Because I did not serve officially as an anthropologist, my experience may admittedly not be generalizable to the question of anthropologists working in bioethics. Still, my position as a participant observer gave me the opportunity to see how such committees work, how policies are shaped and who the key stakeholders are. I could not help thinking as both a “consumer” of genetic services and an anthropologist, and I had ample opportunity to reflect on the possible contributions and limitations of anthropological perspectives in such a setting.

## Finding a Seat at the Bioethics Table

If anthropologists have found it difficult to find a seat, and a voice, at the policy table, they have found it especially difficult to find a place within bioethics debates. Already dominated

---

Margaret Everett is Associate Professor of anthropology at Portland State University.

by academics in another discipline, namely philosophy, and imbued with the discourses of law and biomedicine, anthropologists have struggled to be heard in such debates, and have struggled as well with the ethics of their own participation in bioethics decision-making. A number of anthropologists have dedicated themselves to engagement with bioethics, even as they acknowledge both its limitations and the challenges for anthropologists entering the field (see, for example, Marshall and Koenig 1996). While producing a number of studies about areas of ethical and moral debate in biomedicine—organ transplant, physician disclosure, reproductive technologies, euthanasia—anthropologists have had a much less visible role in the application of bioethics to health care policy and practice. Before describing my own experience on a bioethics committee, I will first discuss some of the anthropological critiques of bioethics.

Chief among anthropologists' critiques of bioethics is its focus on individualism and dedication to a set of abstract principles, such as autonomy and beneficence, over an attention to empirical study and contextual analysis. Rapp, for example, notes that bioethicists have "produced a field of discourse that is quite consonant with its American cultural roots, and self-confidently unaware of its own sociocultural context" (2000: 44). If bioethics is unaware of its own cultural context, many anthropologists have argued, it is equally reluctant to examine the social context of ethical dilemmas.

Many bioethicists, on the other hand, consider excessive attention to social and cultural context to be a dangerous kind of relativism, one that may diminish rather than enhance patient rights (Macklin 1998). Beauchamp and Childress begin their popular textbook, for example, by making the distinction between "normative" and "empirical" moral claims. The practice of bioethics, the authors tell us, is about "the common morality," that is, normative moral claims based on abstract principles. While culture or community-specific moral claims may sometimes appear to contradict these abstract principles, they do not form part of the common morality (2001: 4-5). Anthropologists, not surprisingly, have wondered where they, or other social scientists for that matter, might fit into such an approach. According to Hoffmaster, "Social scientists...engage in descriptive ethics when they investigate and interpret the actual moral beliefs, codes, or practices of a society or culture" (2001: 1). Insisting on a separation between descriptive and normative ethics, between what "is" and what "ought" to be the case, is untenable, according to Hoffmaster (see also Marshall and Koenig 1996: 353). Bioethics problems are themselves the products of specific cultural, political and social environments. "Yoked to the abstractions of reason and theory," and ignorant of context, Hoffmaster charges that "[Bioethics] prescind[s] the messy details and attachments that give our lives meaning and vigor, the nagging contradictions that make us squirm and struggle, and the social, political, and economic arrangements that simultaneously create and constrain us" (2001: 1).

Of her own experiences researching amniocentesis, Rapp writes, "I have been struck by both the respectful curiosity and philosophical dismissal that met my insistence on recognizing the

diversity of problems that prenatal diagnosis poses for different sociocultural groups" (Rapp 2000: 45). Marshall and Koenig argue that medical ethics must deal with the "cultural construction of morality" (1996: 350). Anthropologists, in fact, have coined the term "medical ethnethics" to refer to "the moral tenets and problems of health care as they are conceived and reacted to by members of a society" (Joralemon 1999: 103). From this perspective, bioethics is just one more ethnethical system, one rooted in a particular culture and a particular ethnomedical system, that of biomedicine. Fabrega (1990), for example, has described the way 'ethics' has been deployed across cultures to legitimize certain healers and healing practices and exclude others.

Kleinman has been sharply critical of bioethics, even as bioethicists have taken steps to engage multiculturalism: "Culture, it would seem, is appropriated in ethical discourse largely in an outmoded manner aimed at creating a caricature—cultural relativism—that is meant to act as a foil for continuation of a business of moral philosophy as usual" (1995b: 42). He distinguishes the ethical and the moral. The ethical refers to the abstract knowledge of experts, while "moral accounts are the commitments of social participants in a local world about what is at stake in everyday experience" (1995b: 45). Kleinman argues that one of the chief contributions of anthropology to bioethics is the possibility of engaging, and bridging, the ethical discourse of experts and the moral discourse of patients, victims, and families (1999). When ethnographic materials are granted a place in bioethics, however, it is "a separate and unequal place" (1999: 84).

Criticism, and a growing number of alternative approaches to bioethics, has emerged from within and outside the field. For many years, there has been a healthy debate within the profession about whether bioethics has become an objective critic or handmaiden of biomedicine (see, for example, Rothman 1991). Feminist contributors have also challenged the field's orthodox approach (see Donchin and Purdy 1999). Narrative ethics has raised the importance of attending to patient's stories and lived experiences (see Hunter 1991). The many contributions of transcultural nursing have broadened the view of medical ethics and encouraged a more multi-cultural perspective (see Doswell and Erlen 1998; Lutzen 1997; Ray 1994). Many authors advocate a social justice framework, challenging bioethics to shift its focus to the health care system and questions of health equity. Sociologists and others argue that too many bioethicists focus on the wrong problems -- exotic new technologies, rare conditions and scenarios—rather than broader concerns about access and equity. Churchill argues that "energy and talent are deflected from major social problems toward issues that affect only a few affluent individuals" (1999: 266). Similarly, some argue that bioethics narrow focus on the doctor-patient interactions and the ethics of individual transactions precludes serious attention to questions of justice (Daniels, Kennedy, Kawachi 1999). More recently, anthropologists and others have applied a Foucauldian approach to bioethics, viewing bioethics as a discourse and a set of practices embedded in relations of power (Frank and Jones 2003; Hoyer 2002). Rather than the

neutral application of abstract principles, a more critical approach would question why and how certain dilemmas get cast, and then managed, as “ethical” problems (Hoyer 2002).

### **Anthropological Contributions: Research and Policy**

Anthropology’s traditional reluctance to pass judgement may inhibit the participation of anthropologists in bioethics (Marshall and Koenig 1996), but not all anthropologists are reluctant to weigh in on policy decisions. Donald Joralemon (2000), for example, has been an outspoken opponent of proposals to allow the sale of organs for transplantation. Using cross-cultural and historical evidence about the treatment of the dead, Joralemon has argued that the free market approach to organ procurement negates the social functions of treating the dead body with respect and ritual. Joralemon has not only presented his arguments in academic journals and books, but has participated in policy debates through medical conferences and as a commentator in the press. Scheper-Hughes has similarly taken an advocacy role by investigating the global traffic in human organs. In addition to academic publications (see Scheper-Hughes 2000), she has also launched a website devoted to widely disseminating the results of a wealth of research on the organ trade and promoting a human rights approach to the commodification of the body (see *Organs Watch*). Many anthropologists now work in the United States and Europe, in hospitals, clinics, and research laboratories, following new developments in biotechnology and biomedicine from development to implementation (Rabinow 1996; Heath 1998, Rapp 2000), and the image of anthropologists as students of exotic others with simple technologies must surely be fading. Anthropology’s attention to collectivities can and should be presented as an *asset* rather than a hindrance to participation in bioethics discussions. For example, mainstream bioethics is paying increasing attention to the potential harm of genetic research for racial and ethnic groups, and searching for ways to include a discussion of such potential harms in the consent process (Clayton 1995).

Anthropologists have participated in bioethics in both clinical and policy settings. However, the few accounts of anthropologists who have served on ethics panels suggest both the narrow focus and limited participation of bioethics committees. McBurney (2001), for example, looks at an Institutional Ethics Committee (IEC) in a Canadian hospital, which was created to deal with ethical problems arising in clinical practice, especially around resuscitation issues. Her own study supports previous work suggesting that such committees reinforce existing power structures and hierarchies within the hospital rather than facilitating a broadly inclusive discussion of ethics. Asking the question “who is not being invited to the ethics enterprise?” McBurney found that the structure, authority and membership of the IEC excluded key players, especially nurses, who after all dealt most intimately with patients and families. She concluded that the committee functioned more to deal with risk management (legal risk) and public relations than with the internal evaluation of ethical dilemmas (2001: 195).

In her critique of cancer screening programs, Kaufert (2000b) notes that she came to the subject as a result of having served on a Canadian provincial government committee charged with planning breast and cervical cancer screening programs. Though she does not say how she came to participate on the committee as an anthropologist, she does say that the committee was made up primarily of radiologists, oncologists, epidemiologists and bureaucrats, and her article highlights the way her own perspective as an anthropologist varies from that represented by the committee’s deliberations. The conversation, she says, focused on a “calculation of risks, mortality and cost-effectiveness” (2000b: 166), while she questions what effect screening programs have on women, and the fear and mistrust in their bodies they may engender. Kaufert also argues that discussions of patient compliance with screening were imbued with themes of guilt, fear, morality, and personal responsibility:

Listening to these conversations, I came to see screening not simply as a public health measure or an expression of corporate medicine, but as a philosophical and historical construct reflecting a very particular view of health and disease, and a very particular perspective on women and their bodies. I became increasingly interested in the implications for women of a definition of the female body as an object in constant need of monitoring, evaluation and surveillance, a body for screening. (2000b: 166-7)

Unfortunately for the present discussion, Kaufert does not describe how such misgivings found their way into the committee’s deliberations, if at all. Can such critiques influence public policy and bioethics debates? Or are they just interesting fodder for anthropological debates? My own experience on several ethics and genetic services advisory boards has caused me to ask similar questions about my own participation in bioethics.

Several anthropologists have used ethnographic tools to explore moral problems. Lock (2001) describes the “situated ethics” of organ transplantation, demonstrating how profoundly culture, religion and historical context shape the debates in Japan and North America. Rapp’s (2000) research on prenatal genetic counseling shows how deeply “informed consent” and “autonomous decision making” can be influenced by class, gender, culture, and religion. Rapp’s ethnography of genetic counseling and testing in action demonstrates that the principles of non-directive genetic counseling, in which patients are presented with supposedly neutral “facts” and allowed to make decisions consistent with their own values and beliefs, is significantly more complicated than the abstract principles on which it is based.

Justice and social context figure prominently in the contributions of anthropologists to the study of organ transplant in India. Das stresses the importance of justice and ethnography when considering the application of bioethics in low-income countries: “[U]nless we can come to grips with the everyday life within which moral and ethical questions may be grounded for clinicians, patients, and policy-makers,

there is little use in debating the relevance of bioethics for low-income countries" (1999: 100). Cohen (1999), in investigating organ selling in India raises the question of how to judge autonomy and informed consent in a context of severe poverty, chronic indebtedness and gender inequality. Anthropologists have often demonstrated the influence of context, political economy, and existing social hierarchies, on ethical deliberations. Yet we have struggled to infuse policy-making with these factors.

## Legislating Genetic Privacy

Oregon was one of the first states to pass a statute specifically regulating the use and disclosure of genetic test results, and it drew national attention when it became one of only a few states to declare that a person's genetic information was their private property (see Everett 2003). The 1995 law has been revised several times since it was initially passed. One of the most significant changes to the law has been the removal of *property* language in place of *privacy* assurances and specific penalties for the improper use and/or disclosure of genetic information. The 1995 Oregon Genetic Privacy Act states that "An individual's genetic information is the *property* of the individual," whereas the modifications to the law passed in 2001 replace that clause with the statement: "Genetic information is uniquely *private and personal* information that generally should not be collected, retained or disclosed without the individual's authorization." That change was primarily driven by the medical school (Oregon Health and Sciences University) and the pharmaceutical industry (represented by the Pharmaceutical Researchers and Manufacturers of America—PhRMA), who were concerned that property rights would complicate research and cloud intellectual property rights, especially gene patents.

The first committee on which I served, the Genetic Research Advisory Committee (GRAC), met from 1999-2000 and drafted a bill that was passed in 2001. I was asked to serve on the committee after writing an article in the local newspaper about my own family's experience with a rare genetic disorder and my opinions about the rights of human subjects in genetic research. The membership of the GRAC was made up primarily of geneticists, physicians, lawyers, and lobbyists representing a variety of health care and research interests, including the hospital association, the medical school, the Oregon Medical Association, the Oregon Biosciences Association, and PhRMA. From the beginning, I felt that anthropology was relevant to the questions the committee addressed—medical privacy, informed consent, gene patenting, and the protection of patients and research subjects. I learned firsthand, however, how challenging it can be to bring the perspective of anthropology to such a forum.

Early on in the committee's deliberations it became clear that the GRAC members were divided between those who opposed gene patenting and viewed Oregon's landmark law as a way to challenge federal policies, and those who opposed individual property rights to genetic information as

a hindrance to research and biotech expansion in the state. The debate over gene patents in Oregon roughly mirrored the national debate. In 1995, when the first genetic privacy laws were being written, there was intense national debate over the legitimacy of broad product patents for DNA sequences, especially when granted in absence of a clear identification of the function of the sequence or its potential industrial application. Scientists and bioethicists debated this issue, with clinical geneticists and their organizations cautioning against widespread patenting (arguing it would limit patient access to testing), and research geneticists and private companies (the so called "gene jockeys" in search of disease genes) arguing in favor of patents as a necessary incentive for the significant investment necessary for new medical breakthroughs. With no federal action forthcoming, some wanted to make changes to state laws in order to take a stand against gene patents.

During the deliberations of the GRAC, Oregon's only medical school announced plans to develop a new major research site that would take advantage of new developments in genetic research, and the committee was told repeatedly by patent attorneys, pharmaceutical representatives and OHSU lobbyists that the existing law was bad for business and would drive lucrative opportunities out of the state. Defenders of the "property clause" repeatedly argued that the legitimacy of federal patent policies had to be debated in order to determine the best way to protect "genetic privacy".

Eventually, a compromise bill was drafted by the committee, and subsequently passed by the legislature in 2001. That bill eliminated the property clause, clarified what might be considered "anonymous" research (and therefore exempt from specific informed consent requirements), and determined a penalty structure for unlawful disclosures of genetic information. The 2001 law also created a second committee, the Advisory Committee on Genetic Research and Privacy (ACGPR), whose charge was the continued study and oversight of genetic privacy issues. In a concession to the proponents of the property clause, the law also charged the ACGPR with the continued study of gene patenting issues and what role the state law might play in shaping those policies. Many of the members of the GRAC, including myself, have continued on as members of the ACGPR, although it should be noted that the second committee has expanded its membership to be more inclusive than the GRAC. The ACGPR, for example, includes a nationally renowned bioethicist, a genetics counselor, and a representative from the American Civil Liberties Union (ACLU).

My first challenge was finding a voice, literally, on the GRAC. My lack of background in law, medicine, or bioethics immediately put me at a disadvantage on the committee. For one thing, I lacked the knowledge of the legal and medical nomenclature, which was a source of professional authority for other members. As a "consumer representative," I lacked the professional identity of other members as well. I also was unsure of the label of "health care consumer." Other members were there to represent the interests of their employers or their profession. My label was much more vague. Was I there to

represent all people affected by genetic conditions? All health care consumers? Could my own unique experiences speak to the concerns of others? The problem of establishing my own credibility on the committee was made all the more clear to me early on, as several members of the committee openly expressed doubt that “the public” had anything of value to say on such a complex issue. If I was ever to escape what a friend of mine so aptly called my status as a “professional victim,” I was going to have to establish my legitimacy as something else. But what?

I soon was met by another challenge. It became clear early on that some members of the committee viewed me as a potential threat to their interests. What would I say about the institution where my family received medical care? Was I on the committee to seek redress for some perceived wrong? A lobbyist from a powerful research concern called me, clearly trying to “feel out” my position. Shortly thereafter, a member of the committee shared information from my medical history with another member of the committee as he questioned my motives for participating. When I confronted him about this, he apologized and assured me it would not happen again. But before I had even had a chance to raise concerns about what the committee was *not* addressing—the nature of informed consent, a critical view of how powerful business interests were shaping the debate, the lack of diversity on the committee—I felt compelled to be deferential, conciliatory, lest I be left out of the discussion altogether.

This, it seems, is the dilemma for many applied medical anthropologists working in biomedical settings, and undoubtedly for anthropologists trying to enter bioethics. Scheper-Hughes, in her critique of clinical medical anthropology, asks, “Why, as soon as anthropology enters the clinic, are the bywords suddenly negotiation, caution, tact; that is, when we are not being asked outright to ‘remain silent’ when our words might be viewed as ‘threatening’ to the powerful interests of medical practitioners?” (1990: 191) The answer, to respond to her somewhat rhetorical question, is probably that but for that caution we would not be allowed in the clinic (or the policy committee) at all. Scheper-Hughes offers an alternative to such an applied approach, which she argues seeks to tinker with a system without ever calling its fundamental assumptions into question. She suggests the role of the court jester as a model for a “critically applied medical anthropology”:

The jester, the oppositional intellectual, works at the margins and sometimes (but not necessarily) from the outside, pulling at the loose threads, deconstructing key concepts, looking at the world from a topsy-turvy position in order to reveal the contradictions, inconsistencies, and breaks in the fabric of the moral order without necessarily offering to ‘resolve’ them. (1990: 191)

Such a role requires, according to Scheper-Hughes, that the anthropologist “dis-identify with the interests of conventional biomedicine” (1990: 192).

The perspective of Critical Medical Anthropology, which “understands health issues within the context of encompass-

ing political and economic forces” (Baer, Singer, Susser 2003: 38) led me to question why the debate of the GRAC took the form that it did so quickly and with so little opposition. All sides seemed to accept that we were engaged in a balancing act between individual privacy, the common good brought by research, and economic growth (also perceived as a common good). How did all medical research and biotech growth become accepted as universally beneficial and “socially necessary”? Why should we assume that there is always a “cost” to protecting patients and research subjects? I wondered. But sitting on an ethics panel made up of “experts” and convened by a state law, I felt powerless to use this perspective to influence the deliberations. I certainly was not the court jester.

Still, I did rely on my background as an anthropologist to weigh the issues for myself. While I was troubled by the extent to which “business interests,” and not the rights of patients, were behind the move to eliminate the property clause, I was never enamored of the idea of treating DNA, or genetic information, as a kind of personal property. Both the defenders and the opponents of gene patenting seemed to accept the idea that DNA could rightly be treated as property, and that the question was to whom such property rights should accrue—the individuals who gave their tissue samples to researchers, or the researchers who “discovered” gene sequences in the lab. Didn’t both approaches treat the body, and the products derived from the body, as a commodity? (see Everett 2003) Didn’t this encourage an instrumental view of the body that conflicted with the many social meanings of the body that anthropologists have identified? (see Nettleton and Watson 1998; Lock and Scheper-Hughes 1987; Sharp 2000) In the end, I lent my support to the elimination of the property clause, even though I did not relish siding with the pharmaceutical industry on the issue.

While I felt comfortable about the short-term solution of replacing property language with privacy protections, I had deeper concerns about what I have called the “genetic privacy movement,” which were much harder to address in a policy forum. Without reference to the lived experience of people affected by genetic conditions, or for that matter much input from the geneticists and counselors who worked with them, the goals of “genetic privacy” seemed ill-conceived and sometimes contradictory. How can ethical guidelines be crafted without an understanding of who we are trying to protect, what problem we perceive to exist, and how research is likely to be understood (or not) by potential subjects? Geneforum.org, an Oregon-based organization committed to facilitating public debate about genetic issues, worked with the committee to conduct focus groups, phone surveys and interviews with key policy-makers, in order to provide a context in which to understand how “the problem” (and possible solutions) were perceived by the public and key stake-holders. For the most part, however, Geneforum’s findings were dismissed by the committee as unscientific and indicative of the public’s ignorance of the issues. When Geneforum sponsored a series of public radio programs on genetic privacy, one member of the

committee expressed doubt at the value of the series, saying "talk radio scares me." The exclusion of lay voices in such discussions was troubling. Moreover, the professional/citizen distinction on which such exclusions are based is untenable, especially because in the new era of molecular medicine, we are all potential genetic subjects.

When non-experts did have a voice, it was *not* as citizens or as potential genetic subjects, but rather as consumers of (privatized) medicine. This points not only to the commercialization of both medicine and ethics, but to the fact that deliberations over the application of emerging technologies tend to affect the wealthy and the insured more than the poor, minorities, and the uninsured. The legal debates in Oregon raised the important issue of genetic property (to whom does genetic information and material belong, and what power do states have to legislate on that question?), but not the (in my opinion) more critical question about insurance and access to health care. As anthropologist Kaufert explains, many of the privacy issues raised by the new genetics emerge directly from the American system of private health insurance and commercialized medicine (2000a).

I also came to find the premise of "genetic exceptionalism" troubling. That is, most members of the committee, regardless of their position, accepted uncritically that genetic information is fundamentally different from other types of medical information, and that because of its exceptional qualities, it must be guarded with special protections. The thinking goes that because genetic tests can be predictive of future health (rather than simply diagnostic of present conditions), and because they have implications for family members, genetic information is especially sensitive and revealing. However, increasingly such exceptionalism has been challenged (Green and Botkin 2003; Murray 1999; Sankar 2003). Attempting to prevent discrimination by emphasizing the presumed sensitivity and importance of genetic information may well have an unintended and contradictory effect. As Sankar argues, "If genetics determines human development to the extent that, as one supporter of genetic exceptionalism writes, 'genetic make-up is at the heart of personality'... then defects in a person's genotype appear as defects of the person, an association that explains (though it does not justify) stigmatization and discrimination" (2003: 394). Writing in the *Journal of Genetic Counseling*, I have similarly argued that genetic exceptionalism is not only misleading, but contributes dangerously to genetic determinism. In other words, by treating genetic information as our most personal and intimate information, we merely reinforce the idea that we are our DNA, an association that will more likely increase the stigma of genetic conditions rather than prevent discrimination (Everett 2004; see also Greely 1998). Reviewing the anthropological literature on genetics and identity, I argue, "anthropologists... demonstrate that the power of genetics as a basis for discrimination is overwhelmingly social. Blueprint, diary, bible, or code—these are all social constructs. How we describe and perceive DNA is important and has a real impact on individuals and families" (2004: 287).

While the GRAC was unable to grapple with this question, its successor, the Advisory Committee on Genetic Research and Privacy, has begun to question the extent to which genetic information should be distinguished from other medical information, and has spent considerable time investigating whether existing state and federal medical privacy laws might already provide adequate protection against genetic discrimination.

The ACGPR, unlike its predecessor, also took some time to consider how racial and ethnic groups might be affected by genetic research. It also has more direct involvement from genetics counselors and bioethicists than its predecessor. Its 2003 report to the Oregon legislature includes a brief summary of a pilot program designed to elicit reflections from African American faith communities on ethical issues and genetic testing (ACGPR 2003: 25-26). One member of the committee also circulated an article on 'biocolonialism' and the efforts of some tribal councils to ban DNA research in their tribes (see Sullivan 2003). While there was general agreement on the importance of these perspectives, no direct action was taken or recommended. Like the GRAC, the ACGPR had no minority representatives, nor a member representing multicultural interests. While anthropologists should not presume to represent minority interests on such ethics panels, they can point out the lack of diversity in group membership and call for more inclusive deliberations.

I recently ended my service on the ACGPR following a protracted and heated debate about further changes to Oregon's genetic privacy law. Some members of the committee, most vocally a clinical geneticist, argued for the need to expand the definition of "genetic information" to include family history. Current state law defines genetic information very narrowly as the result of a test on DNA. Proponents of this change argued that potential patients were reluctant to even discuss genetic testing for fear of losing their insurance. Although I shared some of the same concerns that insurance companies may use family history in weighing the relative risk of potential and actual customers, I had several reservations about the proposal. First, we have little evidence, especially in the state of Oregon, that such discrimination is occurring on any scale. Second, studies that have tried to determine the effect of insurance concerns on testing decisions have indicated that other factors weigh more heavily than discrimination fears (see for example Hall and Rich 2000). Third, and more fundamentally, I was skeptical that legislation of any kind can address our anxieties about medical and insurance systems that are fundamentally based on exclusions, especially when that legislation is confined to the regulation of genetic information, however broadly defined.

As a critical medical anthropologist, I have often wondered what the effect of genetic privacy laws will be. Will they prevent discrimination? Allay fears? Perhaps what they really do is pave the way for widespread genetic screening. In their Foucauldian analysis of bioethics, Frank and Jones (2003) view the field as a technology that makes certain subjectivities possible. Applied to the recent explosion of

genetic knowledge, this could mean that determining how to ethically obtain and disseminate genetic information (the task of genetic privacy laws) serves not to limit the pursuit of genetic testing, but rather enables it through the creation of new subjects (who are at once protected and subjected to new forms of surveillance) for research and clinical testing.

One can certainly find people who will say that they are afraid to be tested for fear of losing their job or their insurance, but is this the failure of legal protections, or is it rather the result of media hype, misinformation and the limits of private medicine? I suspect the latter. Without hearing from those we are trying to protect, and without looking at these questions in context, I argued, we have not identified what "problem" we are trying to solve. Moreover, Cultural anxieties around emerging technologies, however well founded, cannot simply be legislated away. I even expressed concern that further legislation could increase the public's anxiety by further reinforcing the importance of genetic information as especially revealing and potentially dangerous. It was suggested that this stance was not consistent with my role as the "consumer representative," who should be arguing for the broadest possible protections for consumer health information. I had to recognize that this was a fair criticism, and that my reservations came more from my perspective as a critical anthropologist and less from my experience as a consumer of genetic services. I decided it was time to give up my role as consumer representative, and play the role of outside anthropologist.

### **No Shirt, No Shoes, No Service: A Reality Check for the 'Barefoot Anthropologist'**

Scheper-Hughes (1995) has advocated for what she calls "barefoot anthropology," the anthropologist as activist, witness, and comrade. This is an applied anthropology infused with a moral sensibility and its feet firmly on the ground. This is easy enough to imagine (and be inspired by) in the shantytowns of Brazil and South Africa, but what does it mean for the anthropologist who finds herself in the paneled boardroom of the Oregon Medical Association? Replying to Scheper-Hughes' call for advocacy, Rabinow seems to ponder a similar question as he describes his research in a French biotech institute and the labs of Silicon Valley and concludes that "barefoot is not the only way to go" (1995: 433).

Still, it's no easy task to be recognized as an anthropologist with something relevant to say in bioethics, and when the opportunity to play the insider arises, we may find ourselves riddled with self doubt about "selling out" to powerful biomedicine, or wondering what we have to say that would be meaningful in such a setting. So what's an anthropologist to do?

One reading of Foucault suggests that we enter into bioethics' practices, even as we recognize in them the exercise of power. Speaking more to clinical bioethics, Frank and Jones suggest that "A Foucauldian bioethics would help people to question medicine's essentializing practices even while they

medical roles and accept medical services" (2003: 185). Applied to policy-making, we might say that anthropologists should have little faith in reforming bioethics, at least in the sense of making it less embroiled in relations of power, but neither should we retreat from its truth games, with all their benefits and burdens.

To begin with, we cannot avoid taking a moral stance on important issues. Our comparative perspective should enhance our position and argument, rather than force us to defer to an ambiguous relativism. Applied anthropologists, with their wealth of experience at encouraging "participatory" planning and policy-making, can also be a voice for a more inclusive (and less elitist) bioethics. Bioethics committees may not allow gadflies in their midst, but I believe there are ways for anthropologists to bring critical and reflective perspectives to health policy deliberations.

With our understanding of human diversity, we can continue to provide a counterpoint to biological determinism. By familiarizing ourselves and others with the cultural and biological anthropology of human genetics, we can question the assumption on which so much genetics-related policies are based, that "everything is genetic" and that DNA holds essential and immutable truths about individuals and their families.

We may indeed need to restrain the urge to launch into a lecture on anthropology while serving on ethics committees, but we can surely find other ways to deliver a critical message beyond the confines of the discipline. Through publications in interdisciplinary journals, media interviews and public testimony, and publications that reach a broad audience, anthropologists can and should find a more effective voice in public decision making. We may not always succeed at playing the court jester, but we can and should find a seat (and a voice) at the policy table.

#### **References**

- Advisory Committee on Genetic Privacy and Research  
2003 Report to the Legislature.
- Baer, Hans, Merrill Singer, and Ida Susser  
2003 *Medical Anthropology and the World System*, Second Edition. Westport, CT: Praeger.
- Beauchamp, Tom and James Childress  
2001 *Principles of Biomedical Ethics*, Fifth Edition. Oxford: Oxford University Press.
- Bosk, Charles  
1999 Professional Ethicist Available: Logical, Secular, Friendly. *Daedalus* 128(4):47-68.
- Churchill, Larry  
1999 Are We Professionals? A Critical Look at the Social Role of Bioethicists. *Daedalus* 128(4):253-274.
- Clayton, E. W.  
1995 Why the Use of Anonymous Samples for Research Matters. *Journal of Law, Medicine and Ethics* 23: 375-381.

- Cohen, Lawrence  
1999 Where it Hurts: Indian Material for an Ethics of Organ Transplantation. *Daedalus* 128(4):135-166.
- Daniels, Norman, Bruce Kennedy, and Ichiro Kawachi  
1999 Why Justice is Good for Our Health: The Social Determinants of Health Inequalities. *Daedalus* 128(4): 215-251.
- Das, Veena  
1999 Public Good, Ethics, and Everyday Life: Beyond the Boundaries of Bioethics. *Daedalus* 128(4): 99-133.
- Donchin, Anne and Laura Purdy, eds.  
1999 *Embodying Bioethics: Recent Feminist Advances*. Lanham: Rowman and Littlefield.
- Doswell, W.M. and J.A. Erlen  
1998 Multicultural Issues and Ethical Concerns in the Delivery of Nursing Care Interventions *Nursing Clinics of North America* 33(2):353-61.
- Everett, Margaret  
2003 The Social Life of Genes: Privacy, Property and the New Genetics. *Social Science and Medicine* 56: 53-65.  
2004 Can You Keep a (Genetic) Secret? The Genetic Privacy Movement. *Journal of Genetic Counseling* 13(4): 273-291.
- Fabrega, Horacio  
1990 An Ethnomedical Perspective on Medical Ethics. *Journal of Medical Philosophy* 15: 592-627.
- Frank, Arthur, and Therese Jones  
2003 Bioethics and the Later Foucault. *Journal of Medical Humanities* 24(3):179-186.
- Greely, Henry  
1998 Legal, Ethical and Social Issues of Human Genome Research. *Annual Review of Anthropology* 27:473-502.
- Green, M. and J. Botkin  
2003 "Genetic Exceptionalism in Medicine": Clarifying the Differences Between Genetic and Non-Genetic Tests. *Annals of Internal Medicine* 138: 571-575.
- Hall, Mark and Stephen Rich  
2000 Genetic Privacy Laws and Patients' Fears of Discrimination by Health Insurers: The View from Genetic Counselors. *Journal of Law, Medicine and Ethics* 28(3): 245-258.
- Heath, Deborah  
1998 Locating Genetic Knowledge: Picturing Marfan Syndrome and Its Traveling Constituencies. *Science, Technology and Human Values* 23(1).
- Hoffmaster, Barry  
2001 Introduction. *In Bioethics in Social Context*. Barry Hoffmaster, ed. Pp. 1-11. Philadelphia: Temple University Press.
- Hunter, Kathryn Montgomery  
1991 *Doctor's Stories: The Narrative Structure of Medical Knowledge*. Princeton: Princeton University Press.
- Joralemon, Donald  
1999 *Exploring Medical Anthropology*. Boston: Allyn and Bacon.
- 2000 The Ethics of the Organ Market: Lloyd R. Cohen and the Free Marketeers. *In Biotechnology and Culture: Bodies, Anxieties, Ethics*. Paul Brodwin, ed. Pp. 224-240. Indiana: University of Indiana Press.
- Kaufert, Patricia  
2000a Health Policy and the New Genetics. *Social Science and Medicine* 51(6):821-829.  
2000b Screening the Body: The Pap Smear and the Mammogram. *In Living and Working with the New Medical Technologies*. Margaret Lock, Allan Young and Alberto Cambrosio, eds. Pp. 165-183. Cambridge: Cambridge University Press.
- Kleinman, Arthur, Renée Fox, Allan Brandt  
1999 Introduction: Special Issue on Bioethics and Beyond. *Daedalus* 128(4): vii-x.
- Kleinman, Arthur  
1995a Anthropology of Bioethics. *In Encyclopedia of Bioethics*. Warren Reich, ed. Pp. 1667-1674. New York: Macmillan.  
1995b Writing at the Margin: Discourse Between Anthropology and Medicine. Berkeley: University of California Press.  
1999 Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for 'The New Bioethics'. *Daedalus* 128(4): 69-98.
- Lock, Margaret and Nancy Scheper-Hughes  
1987 The Mindful Body. *Medical Anthropology Quarterly* 1 (1): 6-41.
- Lock, Margaret  
2001 Situated Ethics, Culture and the Brain Death 'Problem' in Japan. *In Bioethics in Social Context*. Barry Hoffmaster, ed. Pp. 39-68. Philadelphia: Temple University Press.
- Lutzen, K  
1997 Nursing Ethics into the Next Millennium: A Context-Sensitive Approach for Nursing Ethics. *Nursing Ethics* 4(3):218-26.
- Macklin, Ruth  
1998 Ethical Relativism in a Multicultural Society. *Kennedy Institute of Ethics Journal* 8(1):1-2,4-15,17-22.
- Marshall, Patricia and Barbara Koenig  
1996 Bioethics in Anthropology. *In Medical Anthropology*. Carolyn Sargent and Thomas Johnson, eds. Pp.349-373. Westport, CT: Praeger.
- McBurney, Cate  
2001 Ethics Committees and Social Change: Plus ça change? *In Bioethics in Social Context*. Barry Hoffmaster, ed. Pp. 180-198. Philadelphia: Temple University Press.
- Murray, Thomas  
1999 Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different From Other Medical Information? *In Genetic Secrets*. Mark Rothstein, ed. Pp. 60-73. New Haven: Yale University Press.
- Nettleton, Sarah, and Johathan Watson  
1998 *The Body in Everyday Life*. London: Routledge.
- Organs Watch  
n.d. URL: <<http://sunsite.berkeley.edu/biotech/organswatch/index.html>>. (September 15, 2004)



Rabinow, Paul

- 1995 Response to Nancy Scheper-Hughes. *Current Anthropology* 36(3): 430-433.
- 1996 *Making PCR: A Story of Biotechnology*. Chicago: University of Chicago Press.

Rapp, Rayna

- 2000 *Testing Women, Testing the Fetus*. London: Routledge.

Ray, MA

- 1994 Transcultural Nursing Ethics: A Framework and Model for Transcultural Ethical Analysis. *Journal of Holistic Nursing* 12(3): 251-64.

Rothman, David

- 1991 *Strangers at the Bedside*. New York: Basic Books.

Sankar, Pamela

- 2003 Genetic Privacy. *Annual Review of Medicine* 54: 393-407.

Scheper-Hughes, Nancy

- 1990 Three Propositions for a Critically Applied Medical Anthropology. *Social Science and Medicine* 30(2): 189-198.
- 1995 The Primacy of the Ethical: Propositions for a Militant Anthropology. *Current Anthropology* 36(3):409-440.
- 2000 The Global Traffic in Human Organs. *Current Anthropology* 41(2): 191-224.

Sharp, Lesley

- 2000 The Commodification of the Body and its Parts. *Annual Review of Anthropology* 29: 287-328.

Sullivan, Tim

- 2003 American Indians Wary of DNA Tests. *The Salt Lake City Tribune*, 27 January. URL:<<http://www.sltrib.com/2003/Jan/01272003/utah/23782.asp>>. (January 30, 2003).