Whose body is it anyway? Disputes over body tissue in a biotechnology age

Lori Andrews, Dorothy Nelkin

The collection and use of human body tissue—from 18th century practices of dissection to 20th century organ transplantation—have evoked concerns about the use of body parts without consent; the psychological, social, and religious impact of breaking down the integrity of the body; and, especially, the potential exploitation of the individuals who are the sources of organs and tissues. Physicians and scientists have been accused of profiteering, insensitivity to the emotions of patients or family members, and secrecy about unseemly practices as they sought out cadavers and body parts.

Recent disputes—over the taking,1 use,2 and distribution3 of body tissue; the genetic testing of previously collected samples;4,5 and the patentability of human genes6—are taking place in an increasingly commercial context. They are often viewed in terms of a narrow practical question: are individuals entitled to know about, and have a say in, the uses that are made of their body tissue? But the proliferation and diversity of disputes over body tissue are symptomatic of a much larger problem—a growing divide between scientific and social views of the body in the commercial context of the biotechnology age. This gap is the focus of our analysis.

The growth of interest in human tissue
Human tissue has always provided clues to health status. But the body in the biotechnology age is speaking in new ways. DNA analysis of waste tissue such as hair, blood, or saliva can reveal intimate and detailed information about a person. Genetic testing of tissue can indicate an individual’s future health, information that may open beneficial therapeutic or remedial options, but also the possibility of employment or insurance discrimination.7

And, according to recent scientific claims, human tissue can reveal information about behavioural traits,8 race,9 or sexual preference.10

Human tissue has also become a source of raw material for products (such as cell lines and diagnostic tests). The market for skin, blood, placenta, gametes, biopsied tissue, and genetic material is expanding,11 driven partly by commercial incentives fostered by legal developments in the 1980s. A 1980 US federal law allowed universities and commercial incentives fostered by legal developments in the 1980s. A 1980 US federal law allowed universities and commercial incentives to companies investing in academic research.12 Another law encouraged government researchers to enter into joint ventures with for-profit companies.13 At the same time, a landmark US Supreme Court case in 1980 granted a patent on a life-form (a bacterium) setting the stage for the patenting of human genes.14

The scientific view of the body
In 1772, Robert Boyle expressed a view of the body that has characterised much of medical practice: “I think the physician is to look upon the patient’s body as an engine that is out of order, but yet so constituted that, by his concurrence with . . . the parts of the automaton itself, it may be brought to a better state”.15 This mechanical view of the body as a set of parts that can be manipulated, analysed, and enhanced has reached the ultimate in genetics in which the very object manipulated, assessed, turned into a product, and enhanced, is the DNA itself. In particular, the science of genetics focuses on the smallest units of the body, studied in isolation. As Steven Rose observes: “The core issue is reducibility, which . . . comes not as second but as first nature to natural scientists”.16

Anthropologist Margaret Lock has described the scientific view of the body as “refined, isolated, decontextualized, and abstracted from real time, actual location and social space”.17 This decontextualised view is strategically useful for certain aspects of medical practice. Physicians must do things to patients that would be considered unlawful in other contexts. The clinical detachment that defines the patient less as a person than as an anatomical object with certain diseased parts helps the physician adjust to this unsettling role.

In this changing context, developments in the removal, storage, and transformation of human tissue have created new opportunities for medical research and biotechnological applications that have increased demands for tissue. Body tissue has become a part of an international market. For example, a company has obtained American and European patents on the process of extracting stem cells from cord blood; and pharmaceutical companies are searching the world for disease genes and sometimes patenting them.

As the market for human tissue has increased, so have disputes in which scientific and commercial ideas about the proper uses of tissue confront social and personal understandings about the body. Whereas scientists seek greater access to bodily materials, others defend their cultural values and individual rights. Scientists need to pay greater heed to such social claims, for they reflect legitimate interests and further other important social values and activities. Indeed, courts and other policy-making bodies are struggling to develop systems to accommodate productive use of bodily materials while respecting cultural associations and individual rights. And they are increasingly incorporating social meanings of the body into their decisions.

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teeth, hair, skeletons and so on. Parts extracted were sold to those who could use them, such as dentists and wigmakers, and to those who assisted medical research and study, such as articulators of bones for medical skeletons and medical specimen makers. Profits were to be made at every stage. Today with the increase in commercial value of human tissue, researchers have sought unobstructed access to this resource. Pathologists routinely analyse tissue samples without obtaining consent. Researchers try to commercialise tissue without sharing profits with sources. Objectifying the body enables scientists to extract, use, and patent body tissue without reference to the person involved.

Researchers often refer to the body as a "project" or "subject" — a system that can be divided and dissected down to the molecular level. But this reductionist language is increasingly permeated with commercial metaphors. Body parts are extracted like a mineral, harvested like a crop, or mined like a resource. Tissue can be "procured" — a term that is more commonly used to refer to land, goods, or the prostitutes provided for a client. Cells, embryos, or tissue can be frozen, banked, placed in libraries or repositories, marketed, patented, bought, or sold. The physician who patented the cell line from his California patient referred to his patient's body as a "gold mine". And pathologists called a collection of 50,000 blood samples at the Centers for Disease Control and Prevention a "treasure trove".

In her study of the availability of body parts for transplantation, Renée Fox observed a similar economic language of supply and demand, contracts, exchange, and compensation — a language that is "rooted in a homo economics conception of the human person . . . the body is a commodifiable, thing-like entity". She and Judith Swazey describe the biomedical researcher's "almost predatory obliviousness" to the person who provided the body part; rather, the focus is on the organ itself, the receptivity of the recipient, or the questions of supply and demand.

Expanding commercial interests in the biotechnology age have reinforced this trend, but not without costs. Biologist Ernest Chargaff warns that the growth of human tissue research can be a slippery slope to social disaster, "an Auschwitz in which valuable enzymes, hormones, and so on will be extracted instead of gold teeth". Others see the search for human tissue as a modern-day form of body snatching. The body is clearly more than an abstract object, a project, a resource to be mined. It is also a means to establish identity and convey values to others. But body tissue has social importance beyond the individual. Social conceptions of the body establish community identification, encourage socially responsible behaviours, and set acceptable priorities for group activities.

Developmental psychologists have written a lot about the formation of body image. Reviewing this complex literature, psychologist Daniel Stern found a consistent theme — the critical importance of coherence and body integrity to a person's development and sense of self. To be healthy psychologically, an individual needs to experience self-agency (the ability to control what is done to one's body) and self-coherence (the ability to maintain the body as a non-fragmented, integrated whole). Taking or using tissue without the individual’s knowledge or consent can compromise psychological development and emotional well-being. In each of the cases shown in panel 1 the taking of tissue impinged on the plaintiff's sense of agency and coherence.

Because the body is also a means to express personal values, some people want to place limits on the use of their body parts. Some men who donate sperm only want it used by married couples. Some women will serve as a surrogate mother for women with infertility problems, but not for those who want to avoid pregnancy for career reasons. During the Nazi occupation of the Netherlands, many citizens, as a form of social protest, refused to take part in blood transfusions for Nazi soldiers. Some African-American women, recalling past research abuses, refuse to allow amniotic tissue to be sold or research abuses, refuse to allow amniotic tissue to be sold or research abuses, refuse to allow amniotic tissue to be sold or research abuses, refuse to allow amniotic tissue to be sold or research abuses, refuse to allow amniotic tissue to be sold or research abuses, refuse to allow amniotic tissue to be sold.

Body tissue also has important social meaning. In some developing world societies, blood, hair, and placenta are important in social rituals, defining community identification and reinforcing the values and rules that govern accepted behaviour. But even in contemporary western societies, the treatment of body parts can define community and reinforce social values. People signal their identification with their community by the way they display and manipulate their body. Sensitive questions emerge when genetic analysis of body tissue is used to reveal community identity. Through tissue analysis, a person may (whether that person wishes to or not) be identified according to particular genetic criteria as a member of a certain family, a certain race, a certain culture, or a certain sex. Some patients do not want their tissue used (even without their names attached) for research on race and intelligence, race and crime, or sex and mathematical ability because the findings of the research could label and stigmatise their group.
Without consent

The plaintiffs in body tissue disputes talk of “violations”. John Moore, the patient whose cell line was patented without his knowledge or consent, said he felt like he had been “raped”. Lance Corporal John C Mayfield III, one of the Marines who refused to provide DNA for the US Department of Defence bank, said, “I have a spiritual belief that your body is one of the few things you have control over”. In a suit against Los Alamos Laboratory, a widow claimed severe mental and emotional distress because the laboratory, for research purposes, had removed 3 kg of organs, bone, and tissue from her husband’s dead body without her consent.31

In an analysis of debates over the repatriation to Japan of body parts from victims of the atomic bomb, Susan Lindee shows that the characterisation and handling of body parts is important to nations as well as individuals. The body fragments are not only a source of scientific information but also “a diplomatic commodity, a classified secret, a spoil of war, and an instantiation of the effectiveness of American democracy and American Science”.25

Control over the use of body tissue is also critical for establishing religious identity and demonstrating religious beliefs. Navajo Indians believe that placenta should be buried, rather than regarded as “waste” that is available for research. Voicing opposition to the patenting of genes, some religious leaders insist that the body be valued as a fulfilment of divine purpose: the body belongs to God.29 The issue, said a representative from the Southern Baptist Convention, “is going to dwarf the pro-life debate within a few years”.30

The norms that guide the disposition of body tissue reflect community ideals; the highest priorities for body use in a social sense are not always the same as those advocated by scientists. Giving blood and body tissue rather than selling it, for example, is a way to encourage altruism and to affirm social cohesion by linking donors to strangers and donations to the public good. A dispute over the development of private cord-blood banks and the patenting of the cord-blood stem-cell extraction technique resulted from a conflict between community ideals and the encouragement of commerce. Those who believe that cord-blood should be a public resource, freely available to those in need of therapy, have challenged commercial interests that see patenting and privatisation as essential for investment in research.

The wide range of social meanings placed upon the body—in defining community, reinforcing acceptable behaviour, and establishing priorities—have converged in disputes surrounding the Human Genome Diversity Project (HGDP). In some cases, the opposition to the Project’s collection of blood and tissue for DNA analysis reflects ritual beliefs in the communal importance of body tissue. But the opposition also follows from historically informed resentment of exploitation.

HGDP scientists insist that blood is replenishable, that taking it does no harm. But indigenous groups with little reason to trust western science have other priorities that can be expressed through controlling the use of their bodies: the major threat to their health is not genetic disease, but disorders such as diarrhoea.31 They see the harvesting of genes from people from developing countries as “biocolonialism”, providing cures for diseases in the developed world and products affordable only in wealthy countries. They believe that the project might threaten their future. Scientists want to “immortalize” the cell lines of groups that are going to become extinct.32 But members of indigenous groups fear that preservation of their DNA could eliminate the incentives to improve social conditions that would ensure their survival. They derive little comfort from the reductionist idea that their DNA lives on while their descendants vanish. In 1995, the World Council of Indigenous Peoples unanimously voted to “categorically reject and condemn the Human Genome Diversity Project as it applies to our rights, lives and dignity”.33

Scientists’ responses

The gap between scientific and social perspectives on the body has been exacerbated by the often dismissive or defensive reactions of scientists. In 1912, the Strangeways Laboratory was created in Cambridge, England, as the first laboratory devoted to tissue culture. Collecting thousands of tissue specimens, the laboratory was unnoticed by the public until the mid-1930s when the work of Honor Fell on tissue cultivation attracted media attention. But Fell put off the press: “We are studying the culture of tissues. People would not understand. I don’t think the World should know yet”. A journalist argued: “It was right that the World should know”. But Fell “only smiled”.34

Modern scientists often respond to public concerns, as did Fell, by dismissing them as misunderstanding scientific research, as anti-science, or as simply naïve. In a recent debate over patenting human genetic material, a researcher dismissed objections by referring to “ethics and other irrelevant concerns”.35 A representative of a pharmaceutical company misled indigenous people into giving blood for the HGDP by telling them it was just being taken for diabetes testing. She did not get informed consent because, she said, the individuals “would not understand HLA typing”.36

The most powerful arguments made by scientists seeking unimpeded access to human tissue have to do with contributions to scientific and medical progress. They argue that restraints on their ability to gain access, manipulate, and commercialise tissue will impede the progress of research and deprive society of useful medical benefits. But that argument is wearing thin. The “advances” in genetic diagnosis of late-onset disorders have meant that many currently healthy people live under the sword of Damocles—of knowing they are at enhanced risk for later illnesses, such as breast cancer or Alzheimer’s disease. Current “treatments” such as prophylactic oophorectomy for women who learn they are at higher-than-average genetic risk for ovarian cancer may not only be risky, disruptive, and unnecessary, they may also be ineffective since some women still develop cancer in the remaining tissue.

Moreover, claims about the potential benefits from unrestricted access to patient-tissue have been exaggerated. A federally appointed committee investigating gene therapy found that, even though 567 Americans had undergone gene therapy, in about 100 different experiments, “there is still little or no evidence of therapeutic benefit [of gene therapy] in patients or even animal models”. The panel condemned most of the efforts as “pure hype” and expressed concern that in the rush to undertake gene therapy, the development of other easier-to-achieve conventional treatments for the same disease was likely to be ignored.37

Integrated cultural meaning into policy

The potential contribution of unfettered research to scientific and medical progress has had significant
influence on legal and policy decisions. For example, in Moore v Regents of the University of California, a patient sued his physician and a biotechnology company for using his biopsied tissue without his consent and transforming it into a patented cell line, and the court sided with the interests of the defendants. Its reasoning was that giving the patient a property right to his tissue would impede progress and "destroy the economic incentive to conduct important medical research".

However, in recent decisions, the federal government, professional societies, institutional review boards, and courts have begun to apply values other than mere scientific progress. Some institutional review boards, for example, have integrated cultural values into the protocols for tissue retrieval and use, giving patients increased rights to control the uses made of their body material. When researchers sought to analyse previously collected tissue samples at the Centers for Disease Control and Prevention, an advisory group pointed out that "retaining tissue samples or immortalizing cell lines may violate cultural or religious beliefs". Because of the risks of research-uses of even anonymised tissue, the American Society of Human Genetics and the American College of Medical Genetics recommend that individuals be asked whether or not they wish to allow its anonymous use before tissue is taken from them.

The personal feelings of individuals about maintaining body integrity are increasingly recognised by the courts. In one case, a man with a strong fear of fire had his leg amputated. 4 weeks later, he inquired about the disposal of the leg. When he learned that it had been incinerated, he suffered psychological "shock". The court did not allow him to sue the hospital for shock because he did not voice his concerns in a timely manner. But the court did indicate that patients have the right to make specific reservations about demands on, or objections to, a hospital's normal procedures for disposal of tissue.

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Even in the Moore case, the California Supreme Court held that the physician had violated his fiduciary duty by not telling the patient in advance of surgery that the physician had a commercial interest in the tissue: "A physician who treats a patient in whom he also has a research interest has potentially conflicting loyalties". And in a dispute between a couple and their physician over whether they could take their embryo to another facility for implantation, the Court held that the embryo was the couple’s property, even though it resided in the physician’s laboratory. The doctor was the mere custodian of their tissue.

Cultural norms, too, are beginning to influence the treatment of body tissue. The North American Advisory Group to the H G D P has emphasised the importance of sensitivity to community values in the collection of tissue from indigenous groups. They would require that the current process be handled in a culturally appropriate way, including the need for consent from a representative or the leader of the group or tribe, not only from the individuals being sampled.

Legislative actions about historical remains show how the social meaning of the body can take precedence over its potential scientific use. The Native American Graves Protection and Repatriation Act redefined Native American remains as the personal or tribal property of descendants and required their repatriation. Similarly, when researchers in Australia insisted they should be able to keep Aboriginal ancestral remains to undertake research, Aboriginal communities successfully convinced courts that the spirits would not be at peace until the bones were returned.

This trend is part of a larger legal movement around the world that is giving increased respect to the emotional impact of violations of autonomy. Kathy Laster and Pat O’M alley point to the "reassertion and recognition of the emotional and spiritual as focal concerns of law". Applied to the taking of human tissue, this trend recognises the benefits that can accrue to individuals and society from respecting the cultural meanings of the body.

Ignoring cultural values and social concerns expressed in disputes is not in the best interest of either science or society. The history of science is littered with examples of disputes that escalate when scientists neglect public concerns. The early response to animal rights protests increased the intensity of opposition and eventually the costs of doing research. Scientists’ defensive responses helped to radicalise the movement, and activists began to call not only for regulation but also for abolition of animal research. The activists escalated their tactics and broadened their constituency as they embedded the issue in broader questions such as lack of scientific accountability. Research costs increased because laboratories had to reinforce buildings and hire security guards.

Policies governing the use of patients’ tissues for genetic testing, product development, and transplantation are currently being debated. The proliferation of disputes suggest that social conceptions of the body serve important purposes for individuals and society. Ignoring them may be hazardous—to the psychological well-being of individuals, to the maintenance of important social values, and to the future of science itself.

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Improvement of social environment to improve health

Michael G Marmot

During the 19th century, advances in the health of the population mostly came from improvements in nutrition and the environments in which people lived and worked. In the 20th century, the focus shifted from the environment to the behaviour of individuals. According to this view, the great achievement of epidemiology was to nail down smoking and, to a lesser extent, cholesterol. Having done that, the epidemiologists’ job was largely complete. In the future, advances in human health will come from the revolution in molecular biology and genetic approaches to combating disease, and the role of epidemiology will, in its evidence-based, clinical form, be to support the assessment of individual risk, diagnosis, and treatment. Concern with individuals and parts of individuals has been the dominant trend in epidemiology. Ecological analysis, the correlation between the characteristics of groups, has been seen as a second-rate way to approach individual risks. Although poor sanitation and malnutrition have been solved in developed countries, the circumstances in which people live and work are still crucial determinants of disease rates and, therefore, potentially provide the place in which people live and work are still crucial determinants of disease. Why are death rates so fixed? In the U.K. there are 152 000 deaths per year from coronary heart disease. Next year, there may be fewer deaths because, happily, there is a long-term secular decline in coronary heart disease and because the ageing of the population makes little year-on-year impact. However, the death rate will not be as few as 100 000 or even 130 000; it will turn out to be close to 186 per 100 000 individuals. Similarly, next year the mortality rate in Hungary will be higher than that in the U.K., about 250 per 100 000 people.

Death rates provide a good example of the social determinants of disease. Why are death rates so fixed? In the U.K. there are 152 000 deaths per year from coronary heart disease. Next year, there may be fewer deaths because, happily, there is a long-term secular decline in coronary heart disease and because the ageing of the population makes little year-on-year impact. However, the death rate will not be as few as 100 000 or even 130 000; it will turn out to be close to 186 per 100 000 individuals. Similarly, next year the mortality rate in Hungary will be higher than that in the U.K., about 250 per 100 000 people.

Cause-specific death rates are characteristic of societies, so there must be causes of these patterns. Those of us trained in medicine, or in social psychology, tend to start with the characteristics of individuals—were the individuals who died smokers or did they have high cholesterol? But the individuals who died this year will not contribute to next year’s death rate. Thus, the characteristics of societies, over and above the characteristics of individuals, determine the death rate: “No description, however good, of particular cases will ever tell us which ones have a sociological character . . . The social rate must be taken directly as the object of analysis: progress must be from the whole to the parts” (p 148).22 Durkheim, in the late 19th century, criticised individualistic accounts of suicide and emphasised the “social element.”23 In the late 20th century, Geoffrey Rose questioned individualistic accounts of coronary heart and other diseases and pointed to the importance of population determinants.

My two great teachers in epidemiology were Leonard Syme and Geoffrey Rose. Syme started out as a Durkheimian and Rose ended as one. Rose’s Theory of preventive medicine largely developed from the study of cardiovascular disease and its risk factors, but also has

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