

PHILANTHROPY AND RESEARCH BIOBANKS: THE MODEL OF BIOTRUST

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Biobanks: Definition, Birth, Typology

The necessity of cataloguing information is apparent in different fields of human activity. In the healthcare sector and the medical field, the need to assemble data on a population appears historically at the beginning of the modern state (ca. the nineteenth century) not merely for statistical reasons but also for the state's need to control resources which could be found in the surrounding territory (Hacking 1982).

In the twentieth century, the human body has been studied more deeply in terms of each of its components (molecules, cells, tissues, blood, etc.). This has stimulated the establishment of “biobanks” (Loft and Poulsen 1996) that represent a new way “of organizing life, of collecting, storing, and assembling life in the form of human materials” (Gottweis 2008, 24).

There are many typologies of biobanks (Sallée and Knoppers 2005), and the different terms used to describe them “reflect not only their diversity, but also demonstrate a lack of consensus on what exactly is a biobank” (Bovenberg 2006, 23).

On the basis of the *contents*, biobanks can be classified into DNA banks, tissue banks, cells banks, blood banks, stem cell banks, egg and sperm banks, etc. Classified according to the *aim*, they are distinguished into research biobanks, pathology biobanks (having diagnostic or therapeutic purposes), forensic banks used in crime prevention and detection, and biobanks for transplants. Taking as criterion the *target of reference*, biobanks can collect data belonging to small groups of people, or they can be useful for studies of entire populations (for example, in the case of population genetics).

This paper focuses on biobanks that store human tissues and are established for research purposes, the value of which has gained them the appellation of “encyclopedia of tomorrow” (Lyotard 1984). Our specific focus is on the role of

philanthropy in building a reasonable model of research biobank and the complex legal issues entailed in donative activity involving human tissue.

Legal and Ethical Status of Body Parts

In order to know how best to establish and maintain research biobanks, we must understand the *status* of body parts and, as a consequence, who should be allowed to handle them.

According to international legal and ethical instruments, human beings and their bodies are not reducible to objects of experimentation without the subject's permission: the Nuremberg Code of Ethics, Oviedo Convention, and Helsinki Declaration all stress the importance of informed consent as a fundamental requirement for every kind of medical activity upon humankind. Also accorded wide acceptance around the world are the respect for human dignity and a disdain for the commodification of the human body, which cannot be sold freely on the market (see Radin 1987).

If this is the view about bodies as a whole, what about body parts? Are we owners of our own body components? What legal relationship do we have with them?

Questioning whether the individual is the owner of his or her body means asking whether one can exercise property rights over it and its components. A clarification of the concept of "property rights" is useful. When we make reference to "owning" the body, we adopt a clear property pattern. The notion of property here considered is the one that starts from the Roman Law tradition, the right *utendi et abutendi*¹ (of use and abuse), and ultimately arrives at modern property law, understood as "a bundle of rights with four key attributes: use, possession, exclusion, and disposition" (see Feldman 2011, 8). In modern framework, which includes attention to disposition, the concept of property has a close link with commercialization.

The human body is presently a highly contested area in the evolution of the laws of property. Whereas the commodification of the whole body is internationally recognized as wrong and prohibited, about the body's components there are at present at least two different positions commonly held. According to some scholars (e.g., Andrews and Nelkin 2001), body parts are nothing different from other chattels, and thus can be objects of trade and assigned at the owner's will. It is a matter of "self-dominion," "self-determination," and "autonomy" to be able to manage and handle our body parts in line with our own interests and preferences (see Morgan 2001). Others, by contrast, think that body parts must not

be considered as property in this way in any case, because to do so would be to reduce human beings to commodities (see Kant 1963; Munzer 1993). There is a moral repugnance at the idea of people selling their body parts, and it is viewed as a violation of human dignity. In addition, it is believed that the consequent commercialization of body parts could bring on inequalities of protection and result in exploitation of poor people.

Questions about the application of property rights to parts of the human body necessitate further typological distinctions. Trying to categorize body parts, we can suggest the following classification: (a) inert, renewable parts; (b) parts having independent functionality, and (c) stored human tissues.

Inert, renewable parts: In determining whether property rights could apply or not, it is important to distinguish among different types of body parts. Inert, renewable body parts are those—such as hair or mammal milk—that can be reproduced by the body and the loss of which does not affect the body’s physical integrity in a permanent way. When we consider such parts, it does not seem problematic to adopt a proprietary model. Indeed, it is commonly accepted that such parts, or products, after leaving a person, do not belong to him or her anymore and can be treated according to property rights.

Parts having independent functionality: A second category of body parts comprises those that have autonomous functionality (such as blood or bone marrow), which are commonly objects of transplant. In this case the preferred logic governing rights of dispensation has been the one of “gift” or “donation,” based on the principle of gratuity: once a donor has given consent to donation, he or she loses the control over that blood or bone marrow, which goes to “enrich” another person and becomes part of the other’s body. In this case, the property right over blood or bone marrow is transferred by the gratuity; profit is excluded, and the individual has the “management” of that part of his or her body until he or she transfers the right to it according to a spirit of gift. This is the application of a “weak” principle of gratuity which allows the exercise of a property right upon a good (from which the power of giving blood or bone marrow derives) but doesn’t permit a profitable gain from the transfer.² This perspective, based on Titmuss’ view of blood donation (1970), finds a confirmation within the Oviedo Convention, where the ban on obtaining profit by the sale of the body or its parts is mentioned (art. 21). We should note here, however, that legal regime governing blood and plasma transactions differs among the countries. The main adopted framework is the one of donation, according to Titmuss’ view (for solidarity and moral reasons),

but the notion of property seems not to be excluded in particular with reference to plasma. For example, in the United States the purchase of plasma is admitted, while in Europe the regime of donation is preferred for the whole blood components (see, for example, the Recommendation (95) 15 of the Council of Europe).

Stored human tissues: A third category of body parts comprises human tissues assembled in research biobanks. They do not have independent functionality, cannot be reproduced by the body, and have three facets: the *material* one (the physical structure); the *informational* facet, as those goods carry information about the individual, his/her family and biological group, his/her identity, diseases, and state of health; and the *ethical* dimension, as they could be considered inherently part of the personhood which is the carrier of human dignity (in a Kantian meaning of having an intrinsic value and not being reducible to “chattel”).

With these delineations of different categories of body parts in mind, we can now turn to consider more in depth the applicability of property rights in the case of human tissues.

Property Rights and Human Tissues

If property rights could be exercised over human tissues, who would be the hypothetical owners? We will examine three possibilities.

Does the person who provided the tissue retain property rights over it?

The most common and “natural” idea is to confer such a right to each individual for his or her samples, but some relevant judicial cases indicate weaknesses in this position.

The plaintiff in *Moore vs. Regents of University of California*, John Moore, was an American citizen who was diagnosed with a rare form of leukemia and whose spleen was removed for therapeutic purposes. When doctors discovered the unique potential his spleen possessed, they asked for a patent on his spleen’s cells. After obtaining the patent, they granted the license for commercial exploitation of it to two different pharmaceutical companies. When he found out about this, Moore filed a lawsuit against the hospital where the doctors worked, claiming ownership of his biological samples and the right to participate in the gains achieved by the hospital and university.

The California Supreme Court did not find conclusively that Moore either did or did not possess property rights over all of his body and its parts, demonstrating “the confusion in the various philosophical principles operating in this area”

(George 2001, 25). It did find that whatever rights Moore might have had, he could not have claims upon his samples after donation. The court ruled that the doctors and researchers could exploit Moore's body parts because through their labor they had transformed them into their own property.

A similar situation occurred in *Greenberg v. Miami Child Research Institute*, regarding a claim of ownership of biological material from a single donor. The United States District Court for the Southern District of Florida ruled that individuals do not possess property rights over biological material gifted for research purposes, and that participants in research projects do not have a right to benefits arising from the commercialization of such discoveries.

Do researchers have property rights over human tissues?

Important to the discussion of whether researchers have property rights over human tissues they collect is the ruling in *Washington University v. William J. Catalona* which deals with the conflict between a researcher at Washington University (who had collected and catalogued more than 250,000 tissue samples, removed from 3,600 patients) and the university which employed him (considered as the repository owner of those biological materials) (see Andrews 2006).

After some disagreements with the university, Catalona decided to leave the research center and move to Northwestern University near Chicago. Before leaving, he asked patients to sign a statement in which they said that the samples had been entrusted by them to Dr. Catalona for his research purposes. Washington University did not accept these statements, and it claimed to be the sole owner of those donated human tissues. The clash between patients, a university researcher, and the custodian of the samples (the Washington University biobank) was resolved by the U.S. Supreme Court, which recognized Washington University as the owner of any biological material. The Court stressed that medical research can progress only if the scientific community's access to biological materials is unhindered by the interference (and whims) of private individuals. Declaring these materials as an individual's property, the Court stated, would render them—as the District Court had earlier affirmed—mere “chattels going to the highest bidder” (*Washington University v. Catalona (Catalona I)*, 437 F. Supp. 2d 985 (E.D. Mo. 2006), at 1002).

In sum, American courts have generally ruled against individuals claiming property rights over biological materials, tending instead to assign contested rights to research institutions.

Allowing researchers to assert property rights over human tissues taken from other people raises logical problems. In particular it would seem strange to refuse property rights to the person who provided the tissue but then allow another individual to assert the very rights that were ruled not to have existed in the first place. Another thorny issue is how to ensure that the needs of research are met without allowing researchers to use samples for their own purposes or economic exploitation. A grant of property rights to researchers would put the matter on a slippery slope into a pure business model potentially ruled by greedy people more interested in gain and in what is economically advantageous than what is ethically and scientifically justifiable and useful for society. As Dickenson has stated, if body parts are gifted but then exploited by researchers, could not this be considered ultimately as commodification of the body (2002, 55-63)?

Do property rights work for human tissues?

The above-noted flaws in recognizing property rights over human tissues for individuals who donated them or to researchers who received them show the limits of property rights in this field. In either case, problems arise. In addition, such a proprietary model could lead to the well-known “tragedy of the Anti-Commons” (Heller 1998),³ the overutilization of privatization and exclusive property rights (with limited access to data), thus blocking innovation and research.

In conclusion, the examples given here strongly suggest that the proprietary model does not work for human tissues.

Can the “commons” model apply?

Because of the difficulties associated with delineating clear property rights to body parts, some scholars have suggested considering human tissues as “common goods” (see Knoppers and Fecteau 2003; Widdows 2009).

The main instrument supporting this view is “anonymization”: if human tissues are rendered anonymous—by deleting each reference to personal data that might identify the donor—they may be considered as goods to be freely used by anybody without prejudice and exempted from prior property rights as a result of consent from the person to whom they originally belonged.⁴ But if the quality of “commons” were really attributed to the goods (and thus they were the community’s common estate), there still would remain the problem of deciding who controls and manages the data. There would remain the danger of falling into the “Tragedy of the Commons” (Hardin 1968, 1243-1248), the situation that occurs

where different people use the same resource, which is commonly accessible, for their private interests, and thus risk overexploiting the resource in such a way that fails to realize the optimal use and can result in depletion of the resource. It is likely that such problems would arise with reference to body parts, if they were considered as “commons.” Consequently, the model of commons cannot work, and another perspective is needed (see Macilotti 2008).

Philanthropy in the Context of Research Biobanks

In the search for a new, justifiable foundation for research biobanks, the role of philanthropy appears significant.

Etymologically, “philanthropy” is intended to signify “love toward human beings, as an attitude of the soul and an operative individual’s and social groups’ effort to promote the others’ happiness and wealth” (translated from *Treccani.it Enciclopedia Italiana*).

A notion of philanthropy that is clearly relevant to biobanks is Richard Gunderman’s definition of “liberal philanthropy,” in which the aim “is not merely, or even primarily, to reduce, prevent, or eliminate need. The ultimate goal of philanthropy is to promote sharing,” transforming receivers into givers and developing people’s full potential (Gunderman 2005, 5).

In considerations of “property” or “ownership,” the “core conception is the notion of absolute control; ownership is the ability to do what you like with your own, without having to account to anyone else for your actions” (Singer 2000, 29). In contrast, the concept of philanthropy “connotes a form of cooperative human relations with respect to shared conditions and aims” (Winickoff 2007, 443). Philanthropy, in other words, shifts attention from property rights and the extraction of gains therefrom to “partnerships” in which there is shared participation in creating broader social value.

Applied to biobanks, a philanthropic conceptual framework may help us (a) better define the legal status of human tissues, (b) shape the relationship between the participants in research projects (whose biomaterials are placed in the biobank) and the community, (c) more clearly establish the role and responsibilities of scientists; and (d) indicate the appropriate structure of biobanks.

Philanthropy and the Status of Human Tissues

A philanthropic perspective can help us overcome both the proprietary view of body parts and the model of commons. In the awareness of belonging to a global

community and sharing a common genetic heritage (declared in international acts such as the UNESCO Universal Declaration on the human genome and human rights, 1997),⁵ philanthropy pushes us to conceive of each participant in biological research as a “settlor,” a custodian or steward, not an owner of his or her biological samples. Seen from this perspective, voluntarily donated human tissues become a philanthropic endowment to others, an object of “trust” managed by the settlor for the benefit both of him- or herself and the community.

Philanthropy and the Position of Research Participants

Philanthropy already shapes the role of many research participants. It reminds them of one aspect of medical research that is often underappreciated: their membership in humanity and the solidarity of their links with other human beings. In fact, in a medical field dominated by the individualistic dimension, philanthropy can contribute by drawing attention to those invisible ties that connect the individual to the rest of the community (Williams 2005) without forgetting the self. The object of individuals’ philanthropy in donating to biobanks thus becomes elastic: it could be intended as an openness to narrow groups of people (carriers of a specific disease to study), to all the people of a particular country (as in the case of genomic population repositories), or to humanity as a whole.

Furthermore, a philanthropic perspective shifts donors away from personal profit speculation, and may incentivize them to examine the profit model of the biobank to which they donate, in the belief that commercialization of their tissues would have adverse effects on the integrity of scientific research. This negation of market exploitation is counterbalanced by participants’ recognition of a right to know or not to know the results of analysis that concerns their body parts and to have access to discoveries resulting from the biobanks’ data at a reasonable cost. In a nutshell, philanthropy can be the foundation of a new participatory approach to research, founded on a renewed sense of shared participation in the human community in space and time (Knoppers and Chadwick 2005).

Philanthropy and the Role of Scientists

The temptation to engage in economic and financial speculations on bio-specimens touches scientists, too. Philanthropy, however, draws attention back to the principles of beneficence and justice that should guide scientists’ activities. Philanthropy redefines research as a means of pursuing the public and common good (according to Aristotle’s vision) and encourages researchers to look for the

improvement of people's health conditions and the benefit of future generations. Indeed, philanthropy might prevent the sort of rights claims of individual scientists such as Catalona by stressing the very nature of scientific research as a means to pursue "*external justice in avoiding a bias of interest in diseases affecting the rich rather than the poor,*" as well as "*internal justice, [in the sense that] no party involved in the biobank research process should be exploited by another*" (Oystein Ursin, 2010). Therefore, scientists are incited to mold their research for the good of human beings, to put aside any kind of profit purposes, and not to consider biomaterials as commercial goods to be valued through money.

Philanthropy and the Structure of a Research Biobank

Philanthropy can permeate the structure of research biobank by rendering it a "charitable trust" (Charo 2006; see also Macilotti et al. 2008) or "biotrust" (Winickoff and Winickoff 2003; see also Yassin et al. 2010; Winickoff and Neumann 2005). Just as the relationship of the individual settlor to the donated human tissues is one of trust (from the participants' point of view), so too can the biobank be conceived as a form of trust. As the depository of the samples, the biobank should operate as a trustee or steward which acts as a third party—impartial and equally distant—between the researcher, who signs a special agreement with the biobank, giving him access to samples for study, and the individual donor, seen as a settlor of body parts.

In this paradigm, the donor would give his or her tissues or other data (along with the right to control the use of that material) with a benefit-sharing and philanthropic intent. The researcher would be allowed access only within the limits of the license, and in the case of the production of new knowledge, the results should re-enter the scientific community, thus increasing the sum of knowledge and promoting further research. The biobank would be a system operator, called to decide among the claims of various researchers, ensure application of the principles of the trust, and spread the results of research into the community.

Most of all, the biobanks, as a philanthropic intermediary among participants and researchers, behaves as a re-distributor, promoting a culture of philanthropy within society by advancing our understanding of "what it is to be human" (McCully 2010).

Conclusion

The importance of bio-repositories of human tissues has grown progressively through the years, making “the design of an appropriate regulatory regime and institutional structure for genomic biobanks a novel challenge” (Winickoff and Neumann 2005, 9). In such a context, philanthropy can be very meaningful. It can shape a new relationship between the person and his or her body parts; remind us of the altruistic dimension that should connote participation in research; help prevent abuses of scientific research; recall scientists to their duties to humanity in conducting their research; and give sanction to the structure of the biobank as independent from different actors, impartial and able to balance diverse interests at stake.

NOTES

- ¹ This expression is found in Hotman, a sixteenth century jurist (in *Commentarius de verbis iuris antiquitatum*).
- ² Opposite to the “weak” notion of gratuity is the “strong” version which implies that no property right over the human body can be exercised.
- ³ The expression was used for the first time by Michael Heller, formulated as a consequence of the U.S.A. Bayh-Dole Act or University and Small Business Patent Procedures Act (Pub. L. No. 96-517, 94 Stat. 3015, 1980, codified as amended at 35 U.S.C. §§ 200-212, 2000), which dealt with the privatization of academic science and commercialization of inventions.
- ⁴ About anonymization, see Recommendation (2006) 4 by the Committee of Ministers of the Council of Europe on research using biological materials of human origin (<https://wcd.coe.int/wcd/ViewDoc.jsp?id=977859>).
- ⁵ See also Statement on Benefit-Sharing (2000) and the Statement on Human Genomic Databases (2002), enacted by HUGO Ethics Committee.

REFERENCES

- Andrews, Lori. 2006. “Two Perspectives: Rights of Donors: Who Owns Your Body? A Patient’s Perspective on *Washington University vs. Catalona*.” *Journal of Law, Medicine & Ethics* 34: 398-407.
- Andrews, Lori and Dorothy Nelkin. 2001. *The Body Bazaar: The Market for Human Tissue in the Biotechnology Age*. New York: Crown Publishers.
- Bovenberg, Jasper A. 2006. “DNA as Personal Property.” *Property Rights in Blood, Genes and Data. Naturally Yours?* Leiden: M. Nijhoff Publishers.

- Charo, R. Alta. 2006. "Body of Research—Ownership and Use of Human Tissue." *The New England Journal of Medicine* 355 (15): 1517-1519.
- Dickenson, Donna. 2002. "Commodification of human tissue: implications for feminist and development ethics." *Developing World Bioethics* 2 (1): 55-63.
- Feldman, Robin C. 2011. "Whose Body Is It Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law." *Stanford Law Review* 63: 1377.
<https://www.law.stanford.edu/sites/default/files/event/265105/media/slspublic/Whose%20Body%20Is%20It%20Anyway.pdf>.
- George, Alexandra. 2001. "Property in the Human Body and Its Parts. Reflections on Self-determination in Liberal Society." *EUI Working Papers, Law* (August 2001), Badia Fiesolana (FI).
- Gottweis, Herbert. 2008. "Biobanks in Action. New Strategies in the Governance of Life." *Biobanks: Governance in Comparative Perspective*. Herbert Gottweis and Alan Petersen, eds. London: Routledge.
- Greenberg v. Miami Child Research Institute*, 264 F Supp. 2d 1064-76 (2003).
- Gunderman, Richard. 2005. "Giving and Human Excellence: The Paradigm of Liberal Philanthropy." *Conversations on Philanthropy II*: 1-10. ©2005 DonorsTrust.
- Hacking, Ian. 1982. "Biopower and the Avalanche of Printed Numbers." *Humanities and Society* 5:279-95.
- Hardin, Garrett. 1968. "The Tragedy of the Commons." *Science* 162, no. 3859: 1243-1248.
- Heller, Michael A. 1998. "The Tragedy of the Anticommons: Property in the Transition from Marx to Markets." *Harvard Law Review* 111 (3) (January): 621-688.
- Helsinki Declaration: Ethical Principles for the medical research involving human beings, adopted by World Medical Association in 1964 and amended most recently in 2008
<http://www.wma.net/en/30publications/10policies/b3/index.html>).
- Kant, Immanuel. 1963. [1775-1801]. *Lectures on Ethics*. Indianapolis: Hackett.
- Knoppers, Bartha M. and Ruth Chadwick. 2005. "Human Genetic Research: Emerging Trends in Ethics." *Nature Reviews Genetics* 6 (January): 75-79.
- Knoppers, Bartha M. and Claudine Fecteau. 2003. "Human Genomic Databases: a Global Public Good?" *European Journal of Health Law* 10 (27).

- Loft, Steffen and Henrik E. Poulsen. 1996. "Cancer Risk and Oxidative DNA Damage in Man." *Journal of Molecular Medicine* 74: 297-312.
- Lytard, Jean-François. 1984. *The Postmodern Condition: A Report on Knowledge*. Minneapolis: University of Minnesota Press.
- Macilotti, Matteo. 2008. "Property, Information and Interests in the Regulation of Biobanks for Research Purposes." *The New Civil Case Commentary* 7-8: 222-235.
- Macilotti, Matteo, Umberto Izzo, Giovanni Pascuzzi, and Mattia Barbareschi. 2008. "La disciplina giuridica delle biobanche." *Pathologica* 100: 86-101.
- McCully, George. 2010. "Philanthropy and Humanity." *Conversations on Philanthropy VII*: 43-48. ©2010 DonorsTrust.
- Moore vs. Regents of University of California*, 51 Cal. 3d 120 (June 9, 1990).
- Morgan, Derek. 2001. "Where Do I Own My Body and How?" *Issues in Medical Law and Ethics*. London: Cavendish.
- Munzer, Stephen R. 1993. "Kant and Property Rights in Body Parts." *Canadian Journal of Law and Jurisprudence* 6: 319-341.
- Nuremberg Code of Ethics on Medical Research, 1946, in <http://ohsr.od.nih.gov/guidelines/nuremberg.html>.
- Oviedo Convention for the protection of human rights and human dignity in reference to the applications of biology and medicine, Convention about human rights and biomedicine, signed on April 4, 1997, and made legally binding on December 1, 1999 (<http://www.conventions.coe.int/Treaty/en/Treaties/Html/164.htm>).
- Oystein Ursin, Lars. 2010. "Privacy and Property in the Biobank Context." *HEC Forum* 22 (3): 211-224.
- Radin, Margaret J. 1987. "Market-Inalienability." *Harvard Law Review* 100: 1849-1937.
- Sallée, Clémentine and Bartha M. Knoppers. 2005. *Existing Human Genetic Research Databases*, Organisation for Economic Co-operation and Development (OECD), Directorate for Science, Technology and Industry, Report on Human Genetic Databases, DSTI/STP/BIO, 14.
- Singer, Joseph W. 2000. *Entitlement: The Paradoxes of Property*. New Haven: Yale University Press.
- Titmuss, Richard M. 1970. *The Gift Relationship: From Human Blood to Social Policy*. New York: The New Press.

Treccani.it Enciclopedia Italiana Online, s.v. "Philanthropy,"

<http://www.treccani.it/enciclopedia/filantropia/> (accessed March 6, 2013).

UNESCO, Universal Declaration on the human genome and human rights. 1997.

<http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/human-genome-and-human-rights/>.

Washington University v. William J. Catalona et al., U.S. Dist. LEXIS 22969, 2006 and *Washington University v. Catalona (Catalona I)*, 437 F. Supp. 2d 985 (E.D. Mo. 2006) at 1002.

Widdows, Heather. 2009. "Between the Individual and the Community: The Impact of Genetics on Ethical Models." *New Genetics and Society* 28 (2).

Williams, Garrath. 2005. "Bioethics and Large-Scale Biobanking: Individualistic Ethics and Collective Projects." *Genomics, Society and Policy* 1: 50-66.

Winickoff, David E. 2007. "Partnership in U.K. Biobank: A Third Way for Genomic Property?" *The Journal of Law, Medicine & Ethics*: 440-456.

Winickoff, David E. and Larissa B. Neumann. 2005. "Towards a Social Contract for Genomics: Property and the Public in The 'Biotrust' Model." *Genomics, Society and Policy* 1 (3): 8-21.

Winickoff, David E. and Richard N. Winickoff. 2003. "The Charitable Trust as a Model for Genomic Biobanks." *New England Journal of Medicine* 349: 1180-1184.

Yassin, Rihab, Nicole Lockhart, Mariana González del Riego, Karen Pitt, Jeffrey W. Thomas, Linda Weiss, and Carolyn Compton. 2010. "Custodianship as an Ethical Framework for Biospecimen-based Research." *Cancer Epidemiology, Biomarkers & Prevention*. 19: 1012-1015.