

GENETIC  
TESTING  
AND THE USE OF  
INFORMATION



Edited by  
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## THREE

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# The Social Implications of the Use of Stored Tissue Samples: Context, Control, and Community

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David Korn sets up some presumptions, assumptions, and paradigms that need to be challenged. The debate, concern, and angst surrounding genetic privacy forces us to ask, Are patient groups, researchers, and privacy advocates all talking a different language? Are we all approaching privacy from different perspectives? How can we get to a point where we can really listen to what others are saying?

My husband always tells me that I worry too much about the privacy of genetic information and the uses to which it is put, and that most people walking down the street do not think about the issues at all. I got a reality check when my mother said, "I read in the newspaper about a cancer gene—the so-called Jewish cancer gene for colon cancer. A few months ago, I read about another gene for breast and ovarian cancer. Why," she asked, "are all those studies looking only at the Jews?"

I explained to her that genetic researchers were studying many different gene pools and ethnic groups, such as the Finnish and the Amish. I also told her that

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researchers are particularly interested in populations characterized by “founder’s effect.”<sup>1</sup>

She said, “I really don’t understand any of that. I see in this newspaper article that the researchers used some samples from people who had undergone testing for Tay-Sachs syndrome. Didn’t you get a Tay-Sachs test before you were pregnant with Andrea?” When I said yes, she asked, “Did they use your sample?”

I said, “I have no idea. The samples are anonymized.” She asked, “How could they use anonymized samples?”

I thought this was a good reality check. Most of us have been in the hospital, or we have had a relative in the hospital. The first time I heard that my tissue sample was being used for research, when I had not given it to anybody for that purpose, I questioned the propriety of that. Would I have agreed to submit a tissue sample if I had known that it was going to be used in research? Probably, although I am more cautious now than I was a few years ago. In fact, the little empirical data we have indicates that most of us, if asked, would consent to allow our tissue samples to be used in research.

The key question for us is, What if we are not asked? What implications does that have for a public backlash against science? How much of the public’s trust and support for science is going to be further eroded if consent procedures are not clear? Patients should know that when

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1. The genetic composition of any particular population is known as its gene pool. When a few individuals leave a large population and start their own new isolated population, a gene that is relatively rare in the large gene pool can become common in the new gene pool. Founder’s effect occurs when a particular gene becomes disproportionately represented in a population because many of its members can trace their lineage back to a few individuals.

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they have a blood or tissue sample taken in the course of a clinical visit, a portion of it is stored for their benefit. After all, tissue samples are stored primarily for the patient's protection, for accreditation, and for liability reasons.

Research is a public benefit that Dr. Korn, and indeed many of us, want to support. But how do we communicate that value without creating a public backlash? The first question we have to examine then becomes, Why do we even care about genetic privacy? Some of us are afraid that the information will be misused. That concern causes us to commingle concerns about genetic discrimination and genetic privacy. It is hard, as a public policy matter, to separate genetic discrimination and privacy because an individual who believes that he has been discriminated against has the difficult task of proving it; a person may not even know that his information was actually used. Therefore, it becomes important to protect access to the information, not just to erect safeguards against discrimination. We create a false dichotomy when we separate privacy issues from discrimination protections; the two have to be taken together as a package.

A second reason that we care about genetic privacy is that it encourages research. If we cannot assure patients that their genetic information will be kept private or at least that physicians will do the best they can to keep it confidential, patients will not want to be research subjects, at least in situations in which we require informed consent. If that indeed is the rationale for why we care about genetic privacy, then why have Dr. Korn and many other scholars set up a paradigm that balances concern for privacy with public benefit and research? I do not like that paradigm. It does not encourage broad-based community support for biomedical research. In-

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stead, I would like to see a paradigm that actively builds up public trust so that patients can support our research agenda. We should make the public a partner in biomedical research, rather than create a dichotomy between private rights and public benefit and then try to maintain a precarious balance.

There are three Cs to think about when discussing genetic privacy. The first is context. The most important reason we care about genetic privacy is that it is a social value. Independent of caring about misuse and independent of caring about our agenda for research, it is just something we, as a community, want to encourage and promote. Genetic privacy is a value that is the basis of being an individual. It is a value that we care about in the context of our family, and it is a value that we care about for our community. Therefore, context matters. It matters whether samples are collected in a clinical context or in a research context. There is a lot of gray-ing around the edges, particularly with genetic testing, but we need to ask, first, what the expectation of the individual is at the time his tissue sample is collected—whether in the clinical context or the research context. How do we recognize what the patient's expectation is and deal with the patient's knowledge needs?

The second C is control. If we want patients to support the research establishment, we have to give patients some sense of control. That is what my mother's phone call was about: Who gave the researchers permission to use the Tay-Sachs test results? Did the subjects consent to the use of their tissue samples?

The third C is a sense of community. Supporting research in a partnership is a communitarian effort, but that does not mean only recognizing the benefits to the community. It also requires recognizing that there are risks to a community. That was my mother's

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final point, when she asked why they were picking on us. Nobody is "picking on us." We need to put the "picking on us" in context with the science and the needs of our community.

We should think about the themes of context, control, and community when we reexamine the paradigm that requires us to balance concern for private rights with public benefit and research.