

New legal model proposed to counter red tape, boost participation in DNA sample research

April 18 2011

Healthy people who contribute DNA samples for medical research see their relationship with researchers as sharing a trade secret, rather than participation in traditional medical research, according to a new study.

Legal and medical experts from the University of North Carolina at Chapel Hill and Duke University studied interviews with research participants. They discovered that even though subjects had read informed consent documents which explicitly stated that their DNA contribution was not a commercial transaction, participants still perceived the exchange in that light.

The experts believe that using trade secrets as a paradigm for the contribution of DNA to research would solve several current problems that are stymieing [scientific advances](#) and deterring people from taking part in research studies.

Their findings appear in a policy paper, “Genomics, Biobanks and the Trade-Secret Model,” published in the April 15, 2011, issue of the journal Science.

“If you listen to what DNA sample contributors – research subjects – say about their participation, they understand it more than anything else as a commercial transaction,” said John Conley, William Rand Kenan Jr. Professor of Law in the UNC School of Law.

Conley said the policy paper is intended to start a debate about the nature of informed consent in DNA-related research. Traditionally, informed consent for the purposes of [medical research](#) tries to make it explicitly clear that research subjects are not entering into a commercial exchange that would in some way reward their participation.

“Why not do it differently for DNA research? DNA contributed by healthy donors is quite different from giving a liver, for example,” Conley said.

The people interviewed expressed a range of views about research using contributed DNA. About half had contributed DNA, while the other half had been asked to contribute but declined.

“Some said ‘just give me the money and I’m done.’ Others would have taken less money but with conditions such as being able to opt out of a future research project or being told if researchers find something that has a bearing on their personal health,” said Conley. He argued in favor of a tiered consent, which would give more or less control over the use of their DNA depending on their preferences.

Conley said that using [trade secrets](#) as a paradigm for the contribution of DNA to research would solve several current problems, such as how to handle DNA and tissues stored in banks for research purposes. Getting informed consent from donors for each new research application also is burdensome, said Conley; with a trade secret approach, however, individuals could give blanket consent or could retain the right to opt out of future research programs.

“We are trying to fit old models onto new technologies, such as biobanking,” said paper coauthor Ryan Gladden, second-year law student and Conley’s research assistant. “This is one solution.”

Provided by University of North Carolina at Chapel Hill

Citation: New legal model proposed to counter red tape, boost participation in DNA sample research (2011, April 18) retrieved 27 April 2024 from

<https://medicalxpress.com/news/2011-04-legal-counter-red-tape-boost.html>

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