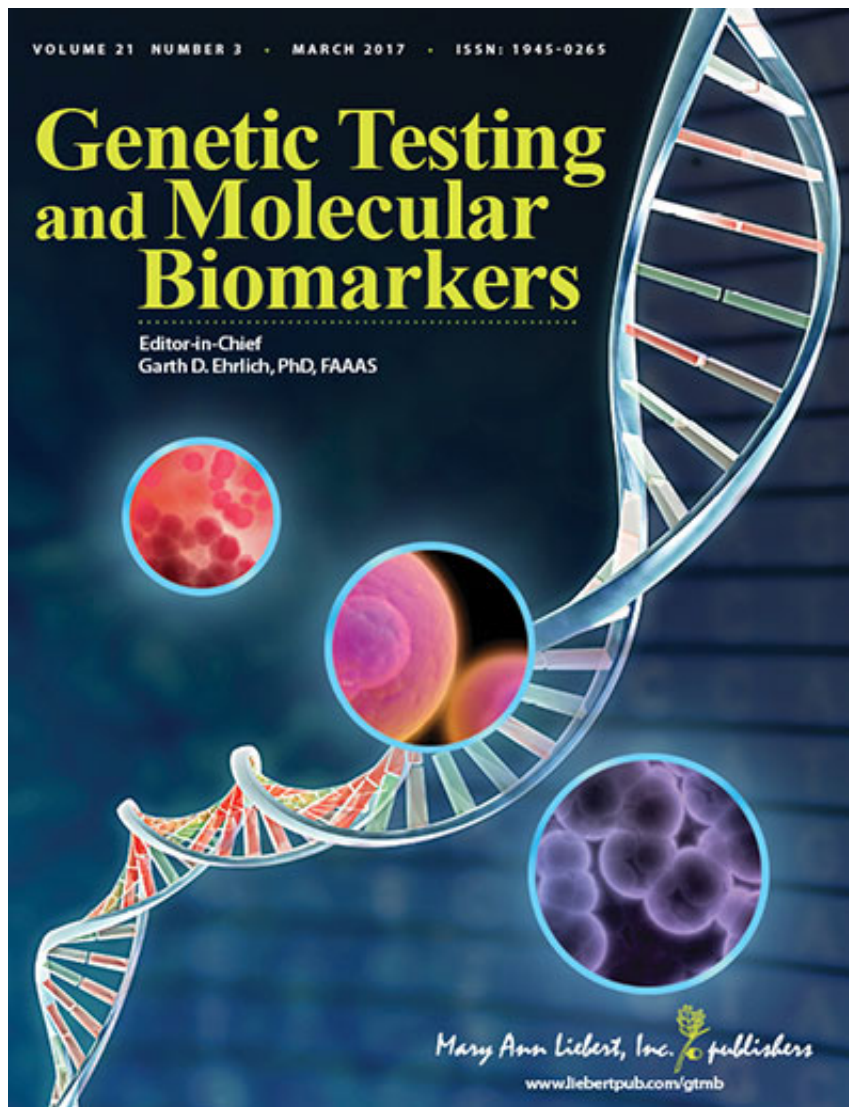


# Are biobank donor families worried about a confidentiality breach?

April 5 2017

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Credit: Mary Ann Liebert, Inc., publishers

A new study examines how well families that donate tissue to a biobank—or decide not to donate—understand the risk and implications of a potential confidentiality breach. The technology to acquire genome sequence data from biobanked samples has outpaced the ability to protect large databases from security breaches, raising the issue of whether loss of confidentiality risk should be discussed with donor families during the consent process, as discussed in an article published in *Genetic Testing and Molecular Biomarkers*.

The article entitled "Confidentiality in Biobanking Research: A Comparison of Donor and Nondonor Families' Understanding of Risks," is coauthored by Laura Siminoff, PhD, Heather Traino, PhD, MPH, Temple University (Philadelphia, PA) and colleagues from Temple and Virginia Commonwealth University (Richmond, VA), representing the GTEx Consortium. The researchers explore the knowledge and opinions of family decision-makers regarding the risks associated with participating in biobanking research, such as the Genotype-Tissue Expression (GTEx) Project. Concern levels differed between donor families and those that refused donation. Families were often willing to trade access to research results for absolute confidentiality associated with participation.

"The knowledge dichotomy separating those who choose to participate in genetic studies versus those that do not suggests that perhaps better health and medical education of the populace would be warranted," says *Genetic Testing and Molecular Biomarkers* Editor-in-Chief Garth D. Ehrlich, PhD, FAAAS, Center for Genomic Sciences and Center for Advanced Microbial Processing, Institute for Molecular Medicine and Infectious Disease, Drexel College of Medicine (Philadelphia, PA).

**More information:** Laura A. Siminoff et al, Confidentiality in Biobanking Research: A Comparison of Donor and Nondonor Families' Understanding of Risks, *Genetic Testing and Molecular Biomarkers*

(2017). [DOI: 10.1089/gtmb.2016.0407](https://doi.org/10.1089/gtmb.2016.0407)

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