

New public attitudes about access to medical information, bio tissue for research

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In this age of surveillance cameras, computer algorithms for tracking website visits, and GPS-imbedded cell phones, many people feel their right to privacy is slipping away. This perception extends into the medical realm as well where information gleaned from Electronic Health Records and clinical tissues are being used for medical research purposes with and without patient consent in some situations, though compliant with federal regulations.

With the continued development and importance of the University of Utah's biobank of tissues acquired through [research](#) projects and through residual clinical specimens, lead investigator Jeff Botkin, M.D., MPH, and his colleagues initiated a study to better understand public attitudes regarding these practices. "There are many technical and financial challenges to establishing a biobank, but we think the largest risk to the enterprise is a loss of public trust if the public is surprised and alarmed by how research is conducted at institutions like ours," says Botkin, associate vice president for research integrity at the University.

The results of the study, published this month in the *Journal of Community Genetics*, reveal that when the general public is educated about the intricacies involved in collecting and using this information in population-based research—particularly the safeguards and confidentiality measures in place to maintain anonymity—that they support it.

To educate the study's 131 participants, they were shown a [12-minute](#)

[video on electronic medical records initiative and access to residual biospecimens research](#). Then they engaged in lengthy focus group discussions revealing their opinions about how the research was handled. Questions included: Did they feel it was ethical? Did they feel like there should be [informed consent](#)? How long should people have to give their consent, after all they could be in the hospital? What are your thoughts about conducting this type of study without written consent from people whose records are reviewed?

"The general support we heard for research was consistent with other surveys from around the country. What was surprising is the public is generally not aware of the safeguards in place to assure that research is done in an ethically appropriate fashion," points out Botkin, professor of pediatrics and chief of [medical ethics](#) at the School of Medicine. "It was heartening to see that people are reassured when they learn about how the safeguards work."

"The video explained that individual identifiers are not relevant; rather it is information like one's age, ethnicity, or areas they live that is the information researchers want from [medical records](#)," explains co-investigator, Erin Rothwell, Ph.D., research associate professor in the College of Nursing and Division of Medical Ethics and Humanities.

"The most important finding from this study was that people, when educated about the safeguards, were fine with their information or tissue being used for research without their signed consent. They were okay with it as long as they had the option to opt out if they wanted," explains Rothwell. She points out that many people who do sign consent forms often don't understand the details it involves anyway. "Our current approach to informed consent is flawed due to lengthy consent forms and increased complexity."

The study indicates that once the general public is educated and

understands that the risk to their privacy is low, and the option to say "no" (an opt-out) is available, then they are onboard with contributing to the research. "Figuring out how to inform patients about these issues in a routine fashion is the next big challenge," adds Botkin, heartened though that participants do see the light, that this work will ultimately benefit people worldwide.

Provided by University of Utah Health Sciences

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