

People want to be asked before sharing genetic data

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People want to be informed and asked for consent before deciding whether to let researchers share their genetic information in a federal database. This is according to a team of investigators at Group Health Research Institute and the University of Washington (UW). The team's report, called "Glad You Asked," is in the September 2010 *Journal of Empirical Research on Human Research Ethics*.

To the team's knowledge, it is the first to ask research participants' opinions about the need for informed consent for sharing their own information. The team explored participants' preferences while collaborating on the [Electronic Medical Records](#) and Genomics (eMERGE) Network. The Network involves volunteers enrolled in the joint Group Health-UW Adult Changes in Thought (ACT) study. ACT is a longitudinal [cohort study](#) that tracks aging-related changes in thousands of older Group Health patients over time.

When the team asked Group Health patients who participate in ACT whether their "de-identified" (anonymous) genetic and medical record information could be shared in the database, 86 percent said yes. Then the team surveyed 365 ACT study participants who had agreed to let their genetic information be shared, mostly because of a "desire to help others." In the survey, 90 percent of participants said they thought it was important to have been asked for this reconsent.

Reconsent means getting additional informed consent from research participants before using their information for a purpose beyond what

they agreed to originally. Alternatives to re-consent—including opting out, being notified, or neither individual permission nor notification—were unacceptable to 40 percent, 67 percent, and 70 percent of the surveyed participants, respectively.

"We were surprised that so many people felt it was important for us to ask them, even though they decided to give their consent," said lead author Evette Ludman, PhD, a senior research associate at Group Health Research Institute. "This indicates that even if most of a study's participants would agree to data sharing, it's still crucial to ask them."

Since 2008, the National Institutes of Health (NIH) has strongly encouraged many studies to submit genetic information to the federal database of Genotypes and Phenotypes (dbGaP). The reason is that genomic research on large numbers of people can yield insights that aren't possible with smaller numbers.

For new studies that will enroll participants prospectively, informed consent can—and should—address such sharing. But sharing genetic data raises ethical questions for longitudinal cohort studies, including ACT, which started long before dbGaP was established in 2006. Few existing informed consents address data sharing through this new mechanism. Ideally, Dr. Ludman suggested, research grants would include funding and time to pursue re-consent. In this study, it cost around \$50 for each participant who was asked.

"Trust is a two-way street, and human research requires lots of trust," Dr. Ludman said. "People have an understandable feeling of ownership over their bodies and medical records, including their [genetic information](#)," she added. "Researchers show we're worthy of trust when we ask research participants for permission to use their information in a way that they haven't already agreed to."

Recent high-profile legal cases have highlighted the issue of consent and trust in research, including the Havasupai tribe vs. Arizona State University and parents vs. the Texas health department over storing newborn blood samples without parental consent. So too has the bestselling book, *The Immortal Life of Henrietta Lacks*, about the history surrounding the HeLa cell line, the world's most widely grown human cells.

Provided by Group Health Research Institute

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