

Parents don't fully understand biobank research, study finds

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Researchers who collect genetic samples from children for medical research need to explain the process more clearly to parents, according to a new study that suggests many parents don't fully understand the finer details about how these samples will be used and stored. The study was published in June in *Genetics in Medicine*.

Kim McBride, MD, MS, principal investigator in the Center for Cardiovascular and Pulmonary Research in The Research Institute at Nationwide Children's Hospital, and colleagues followed up with families enrolled in a genetic biobank—a storage facility for DNA, [genetic data](#), and [tissue samples](#)—after their initial consent, to find out whether they were fully aware of the nature of their agreement. The results were alarming: more than half of all parents misunderstood key concepts of the study.

Ensuring parental understanding of the consent process is a crucial element of ethical [genetics research](#), says Dr. McBride. For the study, he and his colleagues collected anonymous questionnaires from families that had consented between 2004 and 2008 to the storage and analysis of their children's DNA samples in a genetic biobank. The biobank was created to study the genetics of [congenital malformations](#) of the heart's left ventricular [outflow tract](#).

The researchers found that, while parents had a good grasp of some consent concepts, other important information was poorly understood. For example, parents understood that their consent was voluntary and the

samples would be used for research on the causes of [heart defects](#). However, they overestimated how the research might benefit their child and undervalued the risks of enrolling in the study.

"Although the primary purpose of the study was to obtain biologic samples for future testing, parents did not understand that their child's samples would be stored indefinitely," Dr. McBride says. When both parents were involved in the decision, they displayed a better overall understanding of the true nature of the consent agreement than parents making the decision alone.

Most families participating in research are involved with clinical trials, which involve a different set of expectations and agreements during the consent process than genetic sampling. "Participants in a clinical trial are enrolled in a treatment and are followed over time with the expectation that they may receive a new and better therapy," Dr. McBride says. In a biobank study, however, participants cannot typically expect any personal benefit or even any follow-up.

This is starting to change, however. Some new models for [biobank](#) studies are more inclusive of the research subject, offering on-going contact and return of results that may impact their health, says Dr. McBride, who also is an assistant professor in pediatrics at The Ohio State University College of Medicine. "To provide individuals and families with adequate knowledge to participate in genetic research, informed consent delivery must evolve, especially as the demand for genomic data increases."

Interventions to improve understanding—often incorporating visual aids and video consenting—provide promising results, but few studies demonstrate their effectiveness for biobanking consent. Furthermore, there is currently no movement to adopt these techniques widely, something Dr. McBride says warrants consideration. "The focus of

researchers should shift to how to improve the informed consent process through alternative methods of consent delivery, so that consenting families are truly informed partners in genetic research."

Provided by Nationwide Children's Hospital

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