Parents Don't Fully Understand Informed Consent For Pediatric Genetic Biobanks

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Tissue samples from children are essential to modern genetic research. However, a new study suggests that parents do not fully understand the potential benefits and risks of having their children participate in pediatric biobanks.

Research for the paper Understanding of informed consent by parents of children enrolled in a genetic biobank involved a total of 252 individuals representing 188 families. Each of these parents had provided consent for their child to participate in a study examining the genetic etiology of congenital cardiovascular malformations.

by Elvert Barnes

The researchers found that the Quality of Informed Consent *best* understood by parents included:

- consent to participate in research,
- the main purpose of the study and
- the possibility of no direct benefit.

The Quality of Informed Consent items *least* understood by parents included:

- the indefinite storage of DNA,
- the possible risks of participation and
- the fact that the study was not intended to treat their child’s heart defect.

Interestingly, the researchers also found that parent age and medical decision-making by one versus both parents were frequent predictors of individual Quality of Informed Consent items.

What can biobank administrators do to ensure parents have a better understanding of the benefits and risks associated with pediatric biobanking studies?

According to Kim McBride, MD, MS, who is principal investigator in the Center for Cardiovascular and Pulmonary Research in The Research Institute at Nationwide Children’s

Hospital and one of the paper’s authors, informed consent delivery must evolve. She says 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.