Survey: Ask permission to use newborn data, parents say

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More than three-quarters of parents would be willing to permit the use of their children's newborn screening samples for research purposes if their permission were obtained beforehand, a University of Michigan survey shows.

But permission is crucial: More than half of the parents surveyed said they would be "very unwilling" to permit use of their child's newborn screening sample for future research unless they were allowed a chance to grant or deny permission.

This national survey was conducted as part of the University of Michigan C. S. Mott Children's Hospital National Poll on Children's Health to shed light on the emerging issue of how to square parents' concerns about privacy with medical researchers' desire to use the amazing array of health data available in newborn blood samples. These are routinely collected from infants in all 50 states at birth via a tiny needle-prick in the heel.

These state-required samples, taken to alert doctors to rare, serious inherited diseases that can be corrected if treated early, are stored by health agencies for years. Most parents are unaware the samples still exist, unless a sample proves useful for identification or to shed light on a child's health condition. Realizing the samples' collective value, researchers are beginning to use them to study the origins of childhood leukemia and toxin exposures in utero, and see potential for other beneficial research as well.

"Prior to this study, there was some debate about whether or not parents supported the idea of using the data for research, and whether they wanted their permission to be asked. We did the study to inform policy makers and others involved in the issue," says Beth A. Tarini, M.D., M.S., assistant professor of pediatrics at the University of Michigan Medical School.

"Clearly, most parents want to be involved in this process," says Tarini, who is a researcher at the Child Health Evaluation and Research (CHEAR) Unit in the U-M Division of General Pediatrics. "Asking parents' permission to use their children's blood samples for future research looks like a critical issue."

The survey results appear online the journal *Public Health Genomics*. The survey was conducted using an Internet-based survey of a nationally representative sample of parents.

Context

Researchers see the large existing database of newborn screening records as a rich resource for exploring a variety of diseases, but privacy advocates have raised concerns that have led to a lengthy legislative and court battle in Minnesota over whether the state's newborn screening program violates privacy by storing and making samples available to researchers without formal consent from parents. In Texas, a group sued the state earlier this year, arguing that storage of the samples without obtaining informed consent is unconstitutional.

Parents in most states are not asked to give informed consent for storing or allowing use of the samples for research when private health information has been removed from the samples.

Several states, most notably Michigan, are now evaluating more comprehensive policies for how the data are stored and used. The Michigan BioTrust for Health, established by the Michigan Department of Community Health, is seeking input from state residents on how best to store samples and under what conditions they should be studied.

Implications

Public policy that would allow use of newborn screening bloodspots for anonymized or de-identified research purposes without obtaining some form of permission from parents does not appear to be palatable to the public, says Tarini.

"If policy makers fail to engage in a discussion with parents and the public about using the screening results for research, that could create a public backlash and threaten the viability of a potentially valuable public health resource."

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