Restoring trust vital in public acceptance of the use of residual newborn screening specimens

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Government guidelines published today on the use of dried blood spots collected during mandatory newborn screening underemphasize the importance of getting the public on board with the practice, according to University of Michigan researcher.

Educating the public about the value of research on newborn blood as well as asking parents their preference on the storage and use of specimens would go a long way in eliminating government mistrust and opposition to the practice of using newborn blood for valuable research, says Beth A. Tarini, M.D., M.S., a faculty member with the Child Health Evaluation and Research (CHEAR) Unit at the University of Michigan, in a commentary available online today ahead of print in the journal Genetics in Medicine.

The journal is the official, peer-reviewed journal of the *American College of* Medical Genetics.

Throughout the U.S., state law mandates that newborns be tested shortly after birth for treatable, endocrinologic, metabolic and hematologic diseases.

According to the U.S. Centers for Disease Control, approximately 3,000 babies with severe disorders are identified in the United States each year using newborn screening programs.

In some states, after screening has been completed, the samples are used for research aimed at improving the health of the population – such as studying exposures to environmental toxins during pregnancy and early childhood. The majority of the general public has little understanding of the benefits of using these stored blood samples for research purposes.

The recommendations out today by the Secretary of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children recommendations come after extensive investigation and deliberation involving international and national experts in newborn screening, public health and law, and members of the general public.

The guidelines focus heavily on the legal and ethical procedures that states must follow to permit research using these specimens. But they fall short in addressing the public's increasing apprehension about residual dried blood spots storage and use – especially public concerns about privacy and potential government misuse of samples.

Especially in light of two lawsuits, claiming research use of sample specimens violated privacy laws, were filed in 2009.

Filed by families in Minnesota, the first lawsuit alleged that storage and use of DBS violated in the state's Genetic Privacy Act. It was dismissed by the court, claiming that the Act was not applicable to the NBS program. The second lawsuit, filed against the Texas State Department of Health by families who claimed storage and use of NBS for undisclosed research purposes violated their constitutional protection from unlawful search and seizure. The case was settled.

Much of the mistrust is rooted in public rhetoric that claims that samples may be used to ration healthcare or create a government DNA database for tracking citizens, says Tarini, M.D., M.S., also a pediatrician at U-M C.S. Mott Children's Hospital.

"These claims are unfounded and, in some cases, represent a co-opting of these issues for broader political agendas," Tarini explains in her commentary.

However, these claims can easily pollute public opinion when the public is not properly educated about the use of specimens and when suspicion is fueled by government mistrust, warns Tarini.

In order to prevent the spread of fear and misinformation regarding specimen use and storage, Tarini stresses that the health care community should engage the public and explain the value of the specimens as a promising resource for the public good.

"Although the value of the specimens may be forgone conclusions to those of us who work in public health…it is likely not that way for the general public," Tarini adds.

Tarini urges that educating the public on these benefits is critical. "The real challenge lies in getting the public to believe in these processes and the value of studying these specimens."

According to Tarini, the most effective way to foster trust and lessen public concern may be to give parents the ability to consent to the use of their child's specimens for research use, as the state of Michigan has done.

"Paradoxically, it is likely that allowing parents the opportunity to say no may actually get them to say yes," Tarini concludes.

Provided by University of Michigan

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