

MSU engages public on using newborn blood spots for research

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With millions of newborns' blood samples stored in a Michigan bio-bank, researchers are working to determine public attitudes toward the practice of using the blood spots for medical research.

The Michigan State University study will help drive [public](#) policy decisions and develop an improved consent process for the state's bio-bank, known as the Michigan BioTrust, said Ann Mongoven, an assistant professor in MSU's Center for Ethics and the Humanities in the Life Sciences.

The project is funded by a five-year, \$1.1 million grant from the National Institutes of Health. The MSU grant is part of a larger research project led by Sharon Kardia at the University of Michigan. The Michigan BioTrust's Community Values Advisory Board is collaborating with researchers.

Michigan's bio-bank is a tissue repository of bloodspots left over from Michigan's newborn screening program, which tests all babies for genetic and [metabolic abnormalities](#). While the bio-bank offers public health research opportunities, it also presents ethical challenges, said Mongoven, who also has an appointment with the Department of Pediatrics and Human Development.

The new study aims to develop, implement and evaluate a new model of community engagement to help guide the ethical and policy questions that arise when using [blood](#) stored in the bio-bank for research.

"The Michigan Biotrust initiative raises serious issues for both individual research participants and for communities," she said.

Those include: Is it acceptable to use someone's blood in research without that person's knowledge and consent? If research is done on de-identified [human tissue](#), should the donor be considered a research subject? How can one truly 'consent' for as yet unknown future research? What should be done if research reveals information that could be clinically useful to a specific research subject? Could groups as well as individuals be affected by population research? How should resource priorities be determined when the use of precious community resources is at stake?

"These issues have drawn much public attention to the ethics of public health biobanking," Mongoven said, "without the proper research into [public attitudes](#)."

Lawsuits and citizen campaigns have limited research on neonatal bloodspots in both Minnesota and Texas after parents learned the state had saved children's bloodspots and were using them for research. [Public health](#) officials express concern that such negative attention could decrease support for clinical newborn screening as well as for research, putting newborns with serious medical conditions at risk.

While Michigan's state government has fostered greater transparency by creating a Community Values Board to develop ethical guidelines, Mongoven said, many in the public do not know the state saves bloodspots.

"The state faces challenging questions about how to notify the public of the blood samples' existence and of citizens' option to 'opt out' of having their blood used in research," she said. "There are tensions between treating the blood as a community resource or as private property. What

the MSU research reveals will inform efforts to meet those challenges."

Mongoven is working on the project with Stephen Lovejoy, associate director with MSU Extension. Across the state, educators from MSU Extension will facilitate regional conversations with the public, helping to connect with communities and to collect data and input.

In addition to Mongoven's study, MSU's Tom Tomlinson, director of the Center for Ethics and the Humanities in the Life Sciences, is leading a bio-banking project that will help define the nature and strength of public attitudes regarding the state bio-bank and its research uses. The study also will consider the best ways to protect the public's interest.

Provided by Michigan State University

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