

Americans want a say in what happens to their donated blood and tissue in biobanks

July 14 2016, by Raymond G. De Vries And Tom Tomlinson, University Of Michigan

The last time you went to a hospital, you probably had to fill out forms listing the medications you are taking and updating your emergency contacts. You also might have been asked a question about what is to be done with "excess tissues or specimens" that may be removed during diagnosis or treatment. Are you willing to donate these leftover bits of yourself (stripped of your name, of course) for medical research?

If you are inclined to answer, "Sure, why not?" [you will join the majority of Americans who would agree to donate](#), allowing your leftovers, such as blood or unused bits from biopsies or even embryos, to be sent to a "biobank" that collects specimens and related medical information from donors.

But what, exactly, will be done with your donation? Can the biobank guarantee that information about your genetic destiny will not find its way to insurance companies or future employers? Could, for example, a pharmaceutical company use it to develop and patent a new drug that will be sold back to you at an exorbitant price?

These questions may soon become a lot more real for many of us.

Precision medicine, a promising new approach to treating and preventing disease, will require thousands, or even millions, of us to provide samples for genetic [research](#). So how much privacy are we willing to give up in the name of cutting-edge science? And do we care about the

kinds of research that will be done with our donations?

Precision medicine needs you

In January 2015, [President Obama announced](#) his "Precision Medicine Initiative" (PMI), asking for [US\\$215 million](#) to move medical care from a "one size fits all" approach to one that tailors treatments to each person's genetic makeup. In [his words](#), [precision medicine](#) is "one of the greatest opportunities for new medical breakthroughs that we have ever seen," allowing doctors to provide "the right treatments at the right time, every time, to the right person."

The PMI is [now being implemented](#), and a critical part of the initiative is the creation of a "[voluntary national research cohort](#)" of one million people who will provide the "data" researchers need to make this big jump in medical care. And yes, those "data" will include blood, urine and information from your [electronic health records](#), all of which will help scientists find the link between genes, illness and treatments.

Recognizing that there may be some reluctance to donate, the drafters of the initiative bent over backwards to assure future donors that their privacy will be "rigorously protected." But privacy is not the only thing donors are worrying about.

Together with our colleagues at the [Center for Bioethics and Social Sciences in Medicine](#) at the University of Michigan and the [Center for Ethics and Humanities in the Life Sciences](#) at Michigan State University, we asked the American public about their willingness to donate blood and tissue to researchers.

Data from our national survey – published in the [Journal of the American Medical Association](#) – reveal that while most Americans are willing to donate to biobanks, they have serious concerns about how we

ask for their consent and about how their donations may be used in future research.

What are you consenting to?

We asked our respondents – a sample representative of the U.S. population – if they would be willing to donate to a biobank using the current method of "blanket consent" where donors are asked to agree that their tissue can be used for any research study approved by the biobank, "without further consent from me."

A healthy majority – 68 percent – agreed. But when we asked if they would still be willing to give blanket consent if their specimens might be used "to develop patents and earn profits for commercial companies," that number dropped to 55 percent. Only 57 percent agreed to donate if there was a possibility their donation would be used to develop vaccines against biological weapons, research that might first require *creating* biological weapons. And less than 50 percent of our sample agreed to donate if told their specimen may be used "to develop more safe and effective abortion methods."

You may think that some of these scenarios are far-fetched, but we consulted with a biobank researcher who reviewed all of our scenarios and confirmed that such research could be done with donations to biobanks, or associated data. And some scenarios are real. For instance, biobanked [human embryos have been used](#) to confirm how [mifepristone](#), a drug which is used to induce miscarriages, works.

Trust in science is important

Should we take these moral concerns about biobank research seriously? Yes, because progress in science and medicine depends on public trust in

the research enterprise. If scientists violate that trust they risk losing public support – including funding – for their work.

Witness the story of the [Havasupai tribe of Arizona](#). Researchers collected DNA from members of the tribe in an effort to better understand their high rate of diabetes. That DNA was then used, without informing those who donated, for a study tracing the migration of Havasupai ancestors. The findings of that research undermined the tribal story of its origins. The result? The tribe banished all researchers.

Rebecca Skloot's best-seller, ["The Immortal Life of Henrietta Lacks,"](#) revealed the way tissues and blood taken for clinical uses can be used for purposes unknown to the donors.

In the early 1950s, [Ms. Lacks](#) was unsuccessfully treated for cervical cancer. Researchers harvested her cells without her knowledge, and after her death they used these cells to develop the HeLa cell line. Because of their unique properties, HeLa cells have become critical to [medical research](#). They have been used to secure more than 17,000 patents, but neither she nor her family members were compensated.

In a similar case, [blood cells from the spleen of a man named John Moore](#), taken as part of his treatment for leukemia, were used to create a patented cell line for fighting infection. Moore sued for his share of the profits generated by the patent, but his suit was dismissed by local, state and federal courts. As a result of these and similar cases, nearly all biobank consent forms now include a clause indicating that donations might be used to develop commercial products and that the donor has no claim on the proceeds.

Researchers can ill afford to undermine [public trust](#) in their work. In our sample we found that [lack of trust](#) in scientists and scientific research was the strongest predictor of unwillingness to donate to a biobank.

Those who ask you to donate some of yourself must remember that it is important not only to protect your privacy but also to ensure that your decision to do good for others does not violate your sense of what is good.

The "[Proposed Privacy and Trust Principles](#)" issued by the PMI in 2015 are a hopeful sign. They call for transparency about "how [participant] data will be used, accessed, and shared," including "the types of studies for which the individual's data may be used." The PMI soon will be asking us to [donate bits of ourselves](#), and if these principles are honored, they will go a long way toward building the trust that biobanks – and precision medicine – need to succeed.

This article was originally published on [The Conversation](#). Read the [original article](#).

Source: The Conversation

Citation: Americans want a say in what happens to their donated blood and tissue in biobanks (2016, July 14) retrieved 6 May 2024 from <https://medicalxpress.com/news/2016-07-americans-donated-blood-tissue-biobanks.html>

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