Is a Biobank a Home?
Heather Dewey-Hagborg

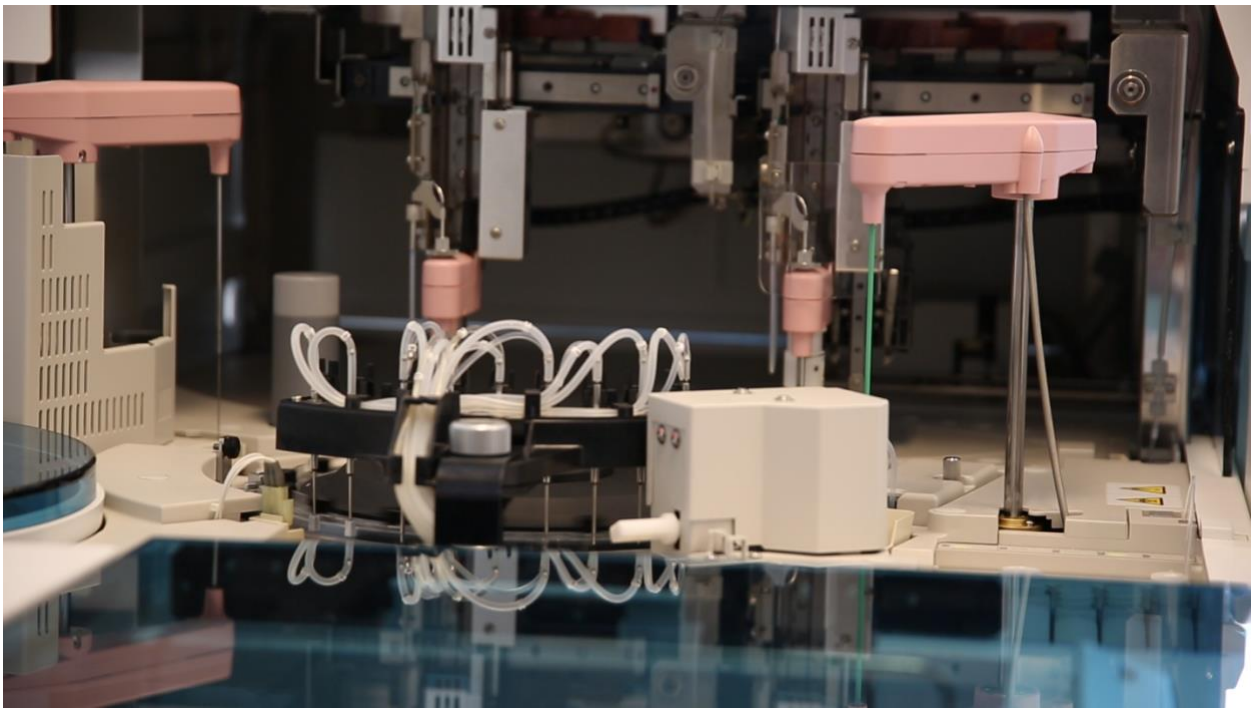
Home is, of course, not necessarily where our bodies are. We travel, we migrate, we leave or lose places we once considered home. But what does it mean when our genetic material is splintered and partially distributed among various sites? Is a freezer or tank of liquid nitrogen that stores our cells and bodily fluids a home? Or a computer that archives our data? Are we "at home" in these places? Or are we ill at ease? Do we even know which of these sites house and protect our bodily materials? Perhaps most importantly, what would make us feel at home in this physically fractured situation?

Many people are unaware that every time you have blood drawn, have a biopsy performed, urinate in a cup, or have your nose or cheeks swabbed, these fluids, cells, and data can have a long afterlife. They can live on in a deep freeze, submerged in vats of liquid nitrogen, or as data, with the potential to be used in scientific research indefinitely. In some cases, they can be bought and sold for profit and turned into commercial products.

Henrietta Lacks was an African American woman whose cervical cancer cells were taken by a doctor at Johns Hopkins Hospital in Baltimore without her permission in 1951. These cells went on to become the world's first successfully immortalized cell line. These cells, called HeLa after her first and last name, are the workhorses of in vitro medical research; every biology laboratory performing tissue culture uses them. HeLa cells were used in developing the polio and COVID-19 vaccines and have been used in studies for AIDS, leukemia, and cancer treatments. For many years, they were the only cell line used for experimentation and have become the default cells for molecular biology because they are so easy to work with. The HeLa cells genome was sequenced in 2013 and is publicly available in scientific databases.

Lacks's story became more widely known following an article by Rebecca Skloot published in the *New York Times* in 2001 and following her 2010 nonfiction publication, *The Immortal Life of Henrietta Lacks*, which was the basis for a film released in 2017. But what most people do not know is that what happened to Lacks is just the first example of what has become an increasingly common practice: making use of the scraps and detritus of medical waste as research material. Our cells and data flow in vast networks of both research and commerce, of which we are mostly unaware. Sometimes these networks are tapped for purposes we may strongly disagree with, like military research, or may even be threatened by, like police investigations.

Robot moving newborn blood cards in the automated freezer, Danish National Biobank, Copenhagen, 2018



Liquid handling robot, part of the automation of blood samples, Danish National Biobank, Copenhagen, 2018

Non-automated walk-in freezer storing fluids, Danish National Biobank, Copenhagen, 2018

I took these photographs at the Danish National Biobank in Copenhagen as part of my film project T3511 in 2018. The biobank's freezer contains blood samples taken from every baby born in a hospital setting in Denmark since 1982. It was not easy to gain access to such a facility. I asked several biobanks if I could visit and possibly film; most ignored me completely, while a few were polite enough to decline. The Danish National Biobank was remarkably open to my proposal. When I arrived, I learned that all the blood and various fluids and data they have extracted are linked to extensive medical data for research. I was shocked that such an elaborate and systematic record of the population was permitted. I had a general assumption that Europe was a place that valued and regulated privacy in a more thorough way than in the United States. I had spent a lot of time in Germany, where the laws and customs are quite different. Due to the legacy of the Holocaust, Germans are very careful not to create structures in which impulses toward eugenics could be encouraged.

For the Danish, there is a strong community orientation—the elevation of the society above the individual (famously described as *samfundssind* during the COVID-19 pandemic)—and there seems to be a great deal of trust in institutions and the government. Denmark has a strong social state and a long history of social democracy. While the country was unique in vigorously protecting its Jewish population under Nazi German occupation, it was also the first country in Europe to introduce forced sterilization laws, in 1929, a part of their history that has not been widely addressed.

My analysis therefore, is that since the public generally trusts health services, the biobank had no reason to be secretive. Drawing attention to the accumulation of biological materials and data is not considered a potential public relations problem because it is seen as a national resource. In the words of the director of the biobank, "the entire country is a cohort . . . supporting personalized medicine."[1]

The United States, by contrast, is unsurprisingly disorganized in this regard. We have a patchwork of laws and rules and customs, with much left to the states and local municipalities to navigate. Every child born in a hospital in the United States has blood drawn to be analyzed for hereditary diseases and serious medical conditions. The regulation of how these samples can otherwise be used varies by state, but, in general, there is a function creep associated with these types of data storage—they are increasingly accessed for expanding purposes (including by the police) unless explicitly forbidden. For example, police in New Jersey were recently accused of accessing newborn DNA data to investigate a sexual assault cold case, and the family has now brought a lawsuit against the department to challenge this use.[2] The point is not that newborn testing is bad—it is an enormously helpful and successful public health program. Rather, the point is that tremendous caution must be taken with this incredibly personal identifying data.

Informed consent in medicine became widespread in the wake of genocide, eugenics, and the unethical and coercive Nazi medical experimentation of World War II. While the Germans took eugenic policies the furthest, the philosophy and practice were commonplace throughout Europe and the United States.

The Nuremberg Code of 1947 outlined principles for permissible and humane medical experimentation, including explicit voluntary consent and the structuring of experiments to avoid physical and mental suffering. It was not until 1981, however, after the United States passed the National Research Act of 1974 in the wake of public outcry against the United States Public Health Service's Untreated Syphilis Study at Tuskegee, Alabama, that these guidelines became law as Title 45, Part 46 of the Code of Federal Regulations, also known as the Common Rule.[3] The United States Food and Drug Administration further requires "a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained."[4]

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[1] "When an Entire Country is a Cohort," June 5, 2021, Invest in Denmark, Ministry of Foreign Affairs of Denmark (webinar), 52:34, https://investindk.com/webinar-ondemand/webinar-series-on-personalized-medicine/unique-biobanks-supporting-personalized-medicine.

[2] Crystal Grant, "Police Are Using Newborn Genetic Screening to Search for Suspects, Threatening Privacy and Public Health," American Civil Liberties Union, July 26, 2022, https://www.aclu.org/news/privacy-technology/police-are-using-newborn-genetic-screening.

[3] "Federal Policy for the Protection of Human Subjects," Federal Register, National Archives, January 19, 2017, https://www.federalregister.gov/documents/2017/01/19/2017-01058/federal-policy-for-the-protection-of-human-subjects.

[4] "CFR–Code of Federal Regulations Title 21," U.S. Food and Drug Administration, updated March 22, 2024, https://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfcfr/cfrsearch.cfm?fr=50.25.

Heather Dewey-Hagborg and Toshiaki Ozawa, T3511, 2018 (film still). The film depicts a biological fluid and tissue supply company where “anonymous” donations are solicited from the public.

What has dramatically changed in the last decades is that now, if you consent to medical research, your sample and/or data may be banked and used in perpetuity by any number of researchers for any number of purposes. Furthermore, DNA data has been shown to be impossible to de-identify. Even when your name is removed, researchers have demonstrated it is possible to use algorithms to make a strong guess about who you are from DNA data alone. In my own research, I have found that by using genetic social networks like 23andMe, even an amateur can track someone down from their DNA. This has underpinned a new field in law enforcement: forensic genetic genealogy. With these tools, police traverse family trees in genetic databases, narrowing in on suspects through their relatives’ data.

While those working in hospital and medical settings are required to ask patients for consent to use their samples and/or data for medical research, this is often a cursory affair—one more piece of paper to be signed in a stack, complicated by the sense that withholding consent might impact one’s treatment. It is rare that doctors or administrators sit with patients to discuss the implications, risks, possible uses, and trajectories of medical data, tissues, or fluids that the patient consents to be used for research use. Conversations around data breaches and the potential for one’s medical record and biological data to be used against them are not standard, even when undergoing extensive genetic testing for disease. Additionally, medical privacy policies on websites are often referenced indirectly on forms. Few patients will do the extra work

of looking up a policy and reading what they are consenting to have their information used for in terms of research or tissue donation.

If one withholds consent, assuming the medical institution follows standard guidelines, there should be a reduced risk of unwanted data sharing. However, withholding consent will not protect from a direct attack on hospital databases (which are increasingly common) and it will not protect "de-identified" data and biological materials. Furthermore, opting out seems to indicate that a person is not "supporting" medical research. This is a false dichotomy. Patients should be confident in supporting research related to their own disease without worrying about their cells and data being passed around between researchers indefinitely for any purpose.

The right to informed consent is governed by the Common Rule, last updated in 2018. While there was a strong movement at that time to remove the designation of de-identified biological samples or DNA data as free from informed consent governance, industry voices prevailed, and this part of the regulation was not updated. In other words, medical institutions do not need a patient's consent to do research using their genetic materials as long as their name and contact information are removed.

What might make us comfortable, or feel "at home" in the biobanks and databases we are stored and shared from? What is clearly missing in this field is trust and the transparency upon which trust can be built. Medical research can benefit us all, but only when it is done with full participant knowledge—with consent and autonomy over personal data. The internet has shown us what happens when we let companies make the rules and govern themselves. Let us not repeat this mistake with biodata. Instead, let us re-envision biobanks as a multiplicity of homes for our cells and data, over which we have control of our presence and participation.

Dr. Heather Dewey-Hagborg is an artist and biohacker interested in art as research and technological critique. Her work appears in the collections of the Centre Pompidou, Paris; Victoria and Albert Museum, London; and San Francisco Museum of Modern Art, among others. Her art has been widely discussed in the media, including in the *New York Times*, *Artforum*, and *Wired*.