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The Immortal Life of Henrietta Lacks, the Sequel

By REBECCA SKLOOT

LAST week, scientists sequenced the genome of cells taken without consent from a woman named Henrietta Lacks. She was a black tobacco farmer and mother of five, and though she died in 1951, her cells, code-named HeLa, live on. They were used to help develop our most important vaccines and cancer medications, in vitro fertilization, gene mapping, cloning. Now they may finally help create laws to protect her family's privacy — and yours.

The family has been through a lot with HeLa: they didn't learn of the cells until 20 years after Lacks's death, when scientists began using her children in research without their knowledge. Later their medical records were released to the press and published without consent. Because I wrote a book about Henrietta Lacks and her family, my in-box exploded when news of the genome broke. People wanted to know: did scientists get the family's permission to publish her genetic information? The answer is no.

Imagine if someone secretly sent samples of your DNA to one of many companies that promise to tell you what your genes say about you. That report would list the good news (you'll probably live to be 100) and the not-so-good news (you'll most likely develop Alzheimer's, bipolar disorder and maybe alcoholism). Now imagine they posted your genetic information online, with your name on it. Some people may not mind. But I assure you, many do: genetic information can be stigmatizing, and while it's illegal for employers or health insurance providers to discriminate based on that information, this is not true for life insurance, disability coverage or long-term care.

"That is private family information," said Jeri Lacks-Whye, Lacks's granddaughter. "It shouldn't have been published without our consent."

Some scientists agree: [Jonathan Eisen](#), a genomics researcher at the University of California, Davis, [tweeted](#), "A bit stunned that the people publishing the HeLa genome appear to not have gotten consent from the family." Another said this was going to further damage public trust in science. A few argued that the cells had changed so much over time, they couldn't accurately tell us anything about Lacks (to which a geneticist replied, "Your claim is so wrong that I don't know where to start"). Several noted that consent wasn't required to publish the HeLa genome (true). But over all, the scientific

community was surprisingly silent on the issue.

On its own, the HeLa genome doesn't say anything specific about Lacks: it's a string of billions of letters that detail the genetic information that makes up a HeLa cell, which is useful for science. A news release from the [European Molecular Biology Laboratory](#), where the HeLa genome was sequenced, said, "We cannot infer anything about Henrietta Lacks's genome, or of her descendants, from the data generated in this study."

But that's not true. And a few scientists decided to prove it. One uploaded HeLa's genome to a public Web site called [SNPedia](#), a Wikipedia-like site for translating genetic information. Minutes later, it produced a report full of personal information about Henrietta Lacks, and her family. (The scientist kept that report confidential, sharing it only with me.) Until recently, few people had the ability to process raw genome data like this. Now anyone who can send an e-mail can do it. No one knows what we may someday learn about Lacks's great-grandchildren from her genome, but we know this: the view we have today of genomes is like a world map, but Google Street View is coming very soon.

Scientifically speaking, that's good news. There's a lot of hope for using technology like this for affordable "personalized medicine." But legally and ethically speaking, we're not ready for it.

As Francis S. Collins, director of the National Institutes of Health, says: "This latest HeLa situation really shows us that our policy is lagging years and maybe decades behind the science. It's time to catch up." The regulations governing this sort of research were written in the 1970s, long before anyone imagined what you could learn from a bit of DNA. They are largely based on the now outdated belief that if samples are "anonymized" (i.e., your name is removed), there's no need to get consent before using them in research.

The problem, says [Yaniv Erlich](#), a fellow at the Whitehead Institute for Biomedical Research, is that anonymity vanishes when it comes to DNA: "People don't realize it's impossible to hide genetic information once it's out there." He and his colleagues recently proved that it's possible to use online public databases to find the identities of people whose anonymous DNA samples had been sequenced and published online. Yet researchers aren't required to tell you that there is no guarantee that a genome, once sequenced, will stay private or anonymous.

More than a year and a half ago, the N.I.H. and several government organizations proposed changing current regulations to require consent for tissue research, genome sequencing and sharing private data. The proposal generated public comment but nothing changed, and science continues to move forward with speed, potential and

outdated regulation.

The Lackses' experiences over the last 60 years foretold nearly every major ethical issue raised by research on human tissues and genetic material. Now they're raising a new round of ethical questions for science: though their consent is not (yet) required for publishing private genetic information from HeLa, should it be? Should we require consent before anyone's genome is sequenced and published? And what control should gene-sharing family members have?

The Lacks family is proud of HeLa's contributions to society, and they don't want to stop HeLa research. But they do want to learn about the HeLa genome — how it can be used for the good of science while still protecting the family's privacy — so they can decide whether to consent to its publication. And they want researchers to acknowledge that HeLa cells are not anonymous and should be treated accordingly.

After hearing from the Lacks family, the European team apologized, revised the news release and quietly took the data off-line. (At least 15 people had already downloaded it.) They also pointed to other databases that had published portions of Henrietta Lacks's genetic data (also without consent). They hope to talk with the Lacks family to determine how to handle the HeLa genome while working toward creating international standards for handling these issues.

The publication of the HeLa genome without consent isn't an example of a few researchers making a mistake. The whole system allowed it. Everyone involved followed standard practices. They presented their research at conferences and in a peer-reviewed journal. No one raised questions about consent.

In the three years since my book about HeLa was published, the Lacks family and I have spoken to audiences by the thousands about these issues. Public response is overwhelmingly consistent and in line with several studies: the public supports the science and wants to help it move forward. But that support is dependent on consent and trust.

Rebecca Skloot is the author of "The Immortal Life of Henrietta Lacks."