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Privacy Flap Forces Withdrawal of DNA Data on Cancer Cell Line

by John Travis on 26 March 2013, 11:25 AM | [1 Comment](#)

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On 11 March, the European Molecular Biology Laboratory (EMBL) issued a press release proudly announcing that a research team there had deciphered much of the genetic sequence of one of the most widely used cell lines in cancer studies and had made the information available publicly. But EMBL has now withdrawn that data and apologized for a perceived ethical lapse as it seeks to allay concerns that it violated the privacy of the woman who was the original source of the cells or that of her descendants.

"We have taken the data offline until the question has been resolved of whether the family consents to the public availability of genomic information on the cell line," writes an EMBL spokesperson in an e-mail to *ScienceInsider*. "This case raises new questions, since there is no precedence for consent for cell line research, and there is no precedent for requirement of consent by relatives in genome sequencing."

The cell line in question is known as HeLa, after an African-American woman named Henrietta Lacks. As famously chronicled in science writer [Rebecca Skloot's best-selling book](#), the cell line was established, without Lacks's consent, from a cervical tumor that she was diagnosed with in 1951. (She died from cancer late that year.) Researchers have conducted so many studies with HeLa cells that they've become somewhat of a problem; scientists will periodically suffer the embarrassment of finding that HeLa cells contaminate their other cell lines.

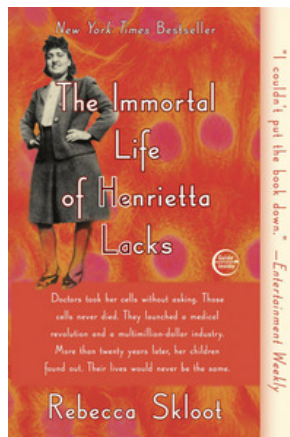
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Given the widespread use of the HeLa cell line, Lars Steinmetz and his colleagues at EMBL decided that conducting an extensive analysis of its genome could illustrate the changes caused by cancer—and also help researchers compare versions of the cell line that have evolved over decades of growth in labs around the world. The resulting paper in *G3: Genes, Genomes, Genetics* indicated that the HeLa genome was "a mess," in the words of [one media account](#).

But given the issues of consent and privacy raised by Skloot's book, many quickly wondered if the researchers had gotten permission from Lacks's family. The EMBL team hadn't—and the EMBL spokesperson acknowledges that no one thought to do so: "We did not consider this an issue exactly because of the notoriety of the cells, and the existence of so much molecular biological and genetic data on these long before our study."

Indeed, many others have published various studies on HeLa's DNA sequence—and some scientists this week suggested that the [HeLa genome is already essentially in the public domain](#). Yet, none of that previous work

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prompted the uproar generated by the EMBL team's paper. On 12 March, Yaniv Erlich, a biologist who recently [identified individuals from seemingly anonymized genetic data](#), tweeted "Nice lie EMBL!" for asserting in a press release that nothing could be inferred about Lacks or her family from the published genome sequence. (The [release has since been revised](#). Erlich noted in another message.) A few days later, geneticist Jonathan Eisen tweeted: "A bit stunned that the people publishing the #HELA genome appear to not have gotten consent from the family"; and "The sequencing of #HeLa genome w/o family consent is appalling - I literally feel like throwing up."

The issue didn't truly burst into the public light until Skloot penned a [column this weekend in *The New York Times*](#), which confirmed that there had been no green light from Lacks's descendants. "That is private family information. It shouldn't have been published without our consent," one of Lacks's granddaughters told Skloot. Skloot also noted that a scientist had taken EMBL's genome data and analyzed it to produce a "report full of personal information about Henrietta Lacks, and her family." (Skloot said she would keep that report confidential.) The writer passed on the family's concerns to EMBL, prompting the withdrawal of the data—at least for now.

The EMBL team, however, still apparently has hopes of reposting the information if they get some sort of permission. "We apologized for any distress experienced by the family as a result of our recent publication of the genome sequence of a HeLa cell line. We are very sympathetic to the hardships the family has endured over the years and we certainly had no intention to add to their concerns about the use of HeLa cells in research," EMBL's spokesperson writes to *ScienceInsider*. "We hope that the outcome of this process will be that the genomic sequence of the HeLa cell line will be publicly available for scientific research; however, our first priority are the privacy concerns of the family."

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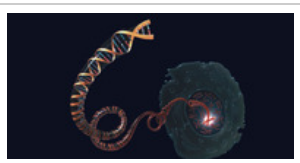
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I doubt that the Lacks descendents will want consent, in retrograde, from researchers worldwide for the colossal body of scientific research based on the HeLa cell line. However, if they did ... well ... I'll not take my imagination any further in that direction.

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