

*Disclaimer: This is a machine generated PDF of selected content from our products. This functionality is provided solely for your convenience and is in no way intended to replace original scanned PDF. Neither Cengage Learning nor its licensors make any representations or warranties with respect to the machine generated PDF. The PDF is automatically generated "AS IS" and "AS AVAILABLE" and are not retained in our systems. CENGAGE LEARNING AND ITS LICENSORS SPECIFICALLY DISCLAIM ANY AND ALL EXPRESS OR IMPLIED WARRANTIES, INCLUDING WITHOUT LIMITATION, ANY WARRANTIES FOR AVAILABILITY, ACCURACY, TIMELINESS, COMPLETENESS, NON-INFRINGEMENT, MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE. Your use of the machine generated PDF is subject to all use restrictions contained in The Cengage Learning Subscription and License Agreement and/or the Gale In Context: Opposing Viewpoints Terms and Conditions and by using the machine generated PDF functionality you agree to forgo any and all claims against Cengage Learning or its licensors for your use of the machine generated PDF functionality and any output derived therefrom.*

## Learning the wrong lesson on privacy from Henrietta Lacks

**Authors:** Christopher Robertson and Jonathan D. Loe

**Date:** Jan. 9, 2016

**From:** Washingtonpost.com

**Publisher:** The Washington Post

**Document Type:** Article

**Length:** 777 words

**Content Level:** (Level 5)

**Lexile Measure:** 1330L

Full Text:

Byline: Christopher Robertson;Jonathan D. Loe

In her acclaimed 2010 book, "The Immortal Life of Henrietta Lacks," Rebecca Skloot tells the story of a poor black woman with cervical cancer who checked into Johns Hopkins Hospital in 1951. While performing surgery to remove the cancer, Lacks's doctor also took a biopsy of her healthy cells without securing her consent. The samples were given to a researcher who cultured the cells and found that they had amazing resiliency. Over ensuing decades, these "HeLa" cells, as they came to be known, were used worldwide in biomedical science, saving millions of lives -- and making billions of dollars. Unfortunately, Lacks was not so lucky. Neither the surgery nor the later discoveries could save her life.

Now, the federal government has proposed controversial changes to the rules governing medical research using human subjects. The changes would expand regulation to cover new domains in hopes of protecting the Henrietta Lackses of today.

Americans should be wary of reforms such as this one that would expand regulatory oversight of science but, while well-intentioned, provide little real benefit to human subjects. Already, scientists report that they spend more than a third of their time on bureaucratic compliance, leaving them less time to spend in the lab. We should not slow the very science that could have saved Lacks's life in the name of paperwork that would not have helped her at all.

Current law and ethical doctrine do not require patient permission for the type of secondary use of biospecimens that occurred in Lacks's case as long as samples are not individually identified. But the proposed regulations would require consent for all research whether samples were identified or not.

While respect for people is one of the fundamental principles of bioethics, the kind of broad consent that would be required by the new rules is not the informed consent we typically demand and expect. Such general consent is not able to offer real information about the research to be performed because the aims, methods and results of future biospecimen research are often unknowable when a sample is drawn. If the new rules had applied to Lacks, Johns Hopkins would merely have asked her to sign another form referring generally to potential "research" on her specimen. Lacks, who was barely literate, likely would have complied -- her subordination is a primary theme of Skloot's book.

There really is no practical alternative to broad consent in this domain. Still, it is strange to help to advance a national reform by using a story for which the reform would have made little difference.

A different concern is that Lacks's name and information were leaked -- it was the basis for the name of the HeLa cell line, no less. However, the new reforms would do little more for privacy than what the law provides, other than recognizing that with data in the modern world there is always a risk that de-identified samples could be re-identified. Ironically, Skloot's book exacerbated this breach of Lacks's privacy far beyond the problem with the cell line's name. The HeLa label was meaningless to the majority of scientists who used it, and few others knew it existed. Still, privacy is important, and de-identified cells should remain so.

Finally, there is criticism that the Lacks family never received a share of the profits from the HeLa cell line. However, de-identification -- the primary tool for protecting the privacy of donors -- is in tension with compensation, since downstream users would have to know whom to pay. Moreover, the sheer number of samples in storage today means that paying any one subject would be difficult and that payments would be minimal in those cases where they could be made. And do we want to make the sale of human tissue legal, displacing the donation system? The new rule does not address that quandary.

If reforms fail to provide informed consent, the privacy guarantee is inherently imperfect and donations cannot be monetized, why even allow this sort of research? Another pillar of research ethics is beneficence -- maximizing benefits while minimizing risks to the

subject. With HeLa, there was no harm done to Lacks herself. And, according to Skloot, the Lacks family is rightly proud of the medical advances and millions of lives saved through use of the HeLa cells. This is the kind of balancing that scientists and review boards have long successfully undertaken.

While Henrietta Lacks's story is a cautionary tale about privacy, the government's proposed reforms are unnecessary to prevent a repeat and could unnecessarily burden researchers. We should be cautious before implementing reforms that might undermine the continued promise of medical research.

**Copyright:** COPYRIGHT 2016 The Washington Post

**Source Citation** (MLA 9th Edition)

Robertson, Christopher, and Jonathan D. Loe. "Learning the wrong lesson on privacy from Henrietta Lacks." *Washingtonpost.com*, 9 Jan. 2016. *Gale In Context: Opposing Viewpoints*, link.gale.com/apps/doc/A439343679/OVIC?u=nysl\_ro\_cmhs&sid=bookmark-OVIC&xid=0aad889b. Accessed 18 May 2023.

**Gale Document Number:** GALE|A439343679