

HeLa cell controversy

- After watching the video of Rebecca Skloot and reading the Nature article you now know a limited history of amazing HeLa cells, how they transformed medicine, and made tissue engineering possible.
- Please comment on the solution that was reached between the Lack family and the NIH. Do you think this was a fair outcome for the family and for medical research?

In the end, the family decided that it wanted the data to be available under a restricted-access system similar to the NIH dbGaP database, which links individuals' genetic make-up to traits and diseases. Researchers would apply for permission to acquire the data and agree to use them for biomedical research only, and would not contact Lacks family members. A committee that includes family members will handle requests, and papers that use the data will recognize Henrietta Lacks and her kin. - Ewen Callaway, Nature 07 Aug 2013

It seems that it was a long due settlement between Henrietta Lacks descendants and the future researchers. Today there are federal laws to protect the privacy of individual health care information. HIPAA (Health Insurance Portability and Accountability Act) privacy rule not only requires that patient health information cannot be disclosed without the patient's consent but also regulates how to access this data, the circumstances in which it can be used (the data is anonymized with a variety of keys making difficult to retrieve the original records), and to whom it can be disclosed (i.e., researchers).

If we look at the whole story, it seems that even if George Gey never asked for Henrietta Lacks consent (which at that time was not required), he failed to preserve her anonymity; maybe in an awkward way to honor her, and him or Johns Hopkins never profited from the discovery or the distribution of HeLa cells. But many companies have patented products or research discoveries and made a lot of money from the HeLa cells. This is probably the less ethical part of HeLa cells story and the most disturbing, knowing that Henrietta Lacks children could not even have health insurance. Part of the controversy is about the fact these cells were and continue to be used within the scientific community raising doubts on the validity of the research. Having to obtain agreement from a committee and the family should promote peer review and better-quality control. I would think this case should take precedence and the circumstances in which an individual cells could be used for research should be explicitly defined in our laws.

Sources:

1. Bernard Lo and Lindsay Parham Ethical Research in Stem Cell Research
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2. <https://embryo.asu.edu/pages/hela-cells-50-years-good-bad-and-ugly-2002-john-r-masters>

3. <https://www.npr.org/2021/10/04/1043219867/henrietta-lacks-estate-sued-stolen-cells>