



HeLa Cells: Grown Without Permission, For The Benefit Of Medicine

THE LEGACY OF HENRIETTA LACKS LIVES ON

A data innovation case study by **copia**

Biototechnology, as all sciences, advances step by step and builds on fortuitous and often serendipitous discoveries. In 1951, a woman named Henrietta Lacks was diagnosed with cervical cancer, and a sample of her cancerous tissue cells were taken — without her knowledge or consent — and grown in a petri dish. For decades prior, scientists had been trying to keep human cells alive under laboratory conditions without success, but the tumor cells taken from Henrietta Lacks exhibited a remarkable ability to grow and thrive. These HeLa cells became the first immortal human cells ever grown in a laboratory. Since 2001, five Nobel prizes have been awarded based on research performed with HeLa cells. Trillions of HeLa cells have been bought and sold and used in medical studies all over the world, and they continue to contribute to the advancement of medicine and biology.

HISTORY & IMPACT

It cannot be overstated how important it is for scientists to be able to experiment and replicate experiments under controlled conditions. Without a consistent supply of living human cells to test the efficacy of medicines, modern pharmacology would simply not exist. The stable growth of HeLa cells in the 1950s allowed Jonas Salk to develop the first polio vaccine — which in turn led to the first modern mass inoculations.

HeLa cells were also the first human cells ever cloned in 1955, further standardizing the cells for research purposes and making them suitable for reproducible experiments studying cancer, the toxicity of chemicals and radiation, drug efficacy, genetics and a countless number of scientific explorations. Over six decades, scientists have grown tons of HeLa cells, approximately 20 tons by some estimates. Thousands of patents have been granted based on research with HeLa cells, and over 60,000 research papers have been published.

Several strains of HeLa cells exist, having evolved over time, and an international effort to study the human genome called ENCODE has studied the HeLa genome due to its prevalence and importance in medicine and medical research. A German research team sequenced the popular 'Kyoto' version of the cell line and compared it to a reference human

genome in 2013. Other strains of HeLa cells have also been sequenced and published, and the HeLa genome has been found to have significant differences from non-cancerous human cell lines. The genetic variances have shown that HeLa cells may not be ideal models for human genetics, but this knowledge will only push biotechnology to find more suitable cell lines.

POLICY ISSUES & IMPLICATIONS

The tumor cells from Henrietta Lacks were called HeLa as an attempt to anonymize the cell line, and various pseudonyms such as Helen Lane and Helen Larson were used to conceal the identity of the original patient. The true identity of the original donor was widely known by the 1970s, as a multi-million dollar industry was already underway to becoming a multi-billion dollar industry. The genetic privacy of the Lacks family was not a consideration in the 1950s, and that attitude persisted for many years. In 1973, the surviving children of Henrietta Lacks were contacted for additional genetic samples for further studies, but the Lacks family was not informed of the impact of their genetic information.

In 2013, scientists at the European Molecular Biology Laboratory and a separate group from the National Institutes of Health (NIH) at the University of Washington had both sequenced the HeLa genome. The European researchers retracted their publication when the issue of genetic privacy was raised. The NIH came to an agreement with the Lacks family to store the HeLa genome in a database controlled by the HeLa Genome Data Access working group which has two Lacks family members as representatives for governing controlled access to the information.

In fact, the renewed interest and publicity in the story about Henrietta Lacks from the last few years resulted in a number of important discussions about both the benefits of health data and the ethics and privacy questions involving that data. It is, truly, a case where there were tremendous benefits from allowing these cells to be used, but it has caused researchers in the health space to be much more conscious of the privacy questions raised by the use of such information or material.

In the US, there is still no policy requiring consent or disclosure for the usage of materials that could be considered medical waste. In the Supreme Court of California, the case of *Moore v. Regents of the University of California* ruled that patients have no claim to monetary compensation over the commercialization of discarded body parts.

The situation with the Lacks family is also somewhat unique in that HeLa cells are one of the most well-studied cells in medicine. The original cell line was commercialized but never patented which contributed to its widespread use in research institutions. In fact, the widespread sharing and use of HeLa cells was almost certainly helped along by the lack of any attempt to use patents to restrict their usage.

Many of the breakthroughs now attributed to HeLa cells would likely not have happened (or would have been delayed) had the use and sharing of the cells been further restricted via patents.