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The Story of Henrietta Lacks: Medical Ethics and Systemic Racism



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In 1951, doctors took a sample of Henrietta Lacks’s cells without her knowledge and consent. While this cell sample led to many advances in medicine and science, many people have since criticized the ethics of how they were acquired. In this text, we explore the ethical implications of researchers acquiring Lacks’s cells without her consent in the social context of the time.

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Published April 11, 2024 | Updated July 9, 2024

INTRODUCTION

The immortal HeLa cell line that Henrietta Lacks unknowingly provided to the scientific research community has advanced the treatment and study of polio, tuberculosis, salmonella, cancer, and many other conditions. But that’s only part of the story.

In this text, we address how **systemic racism** and the norms surrounding medical ethics impacted Henrietta Lacks's life and experience with the US health-care system as both a Black woman in the 1950s and an involuntary research participant. We will also consider what has changed (and what hasn't) since Henrietta Lacks’s cells were taken and used without her knowledge or consent.

HOW WERE THE HELA CELLS OBTAINED?

The story of the HeLa cell line begins on January 29, 1951, when Henrietta Lacks, at the age of 31, went to Johns Hopkins Hospital to treat what she described as a “knot” in her womb and vaginal bleeding. While she underwent treatment, doctors took tissue samples from her cervix without her knowledge or consent and gave them to Johns Hopkins physician and cancer researcher Dr. George Otto Gey (Skloot, 2011).

At the time, medical research was limited by the fact that human cells could only stay alive for short periods of time once removed from the body, which made it difficult to conduct extensive studies. In a scientific breakthrough, Gey was able to use the cells from Lacks’s tissue sample to create the first human **immortal cell line**. These cells, which Gey named HeLa cells by abbreviating Henrietta Lacks’s first and last names, have the extraordinary property of being able to grow and divide indefinitely in a laboratory environment (Skloot, 2011).

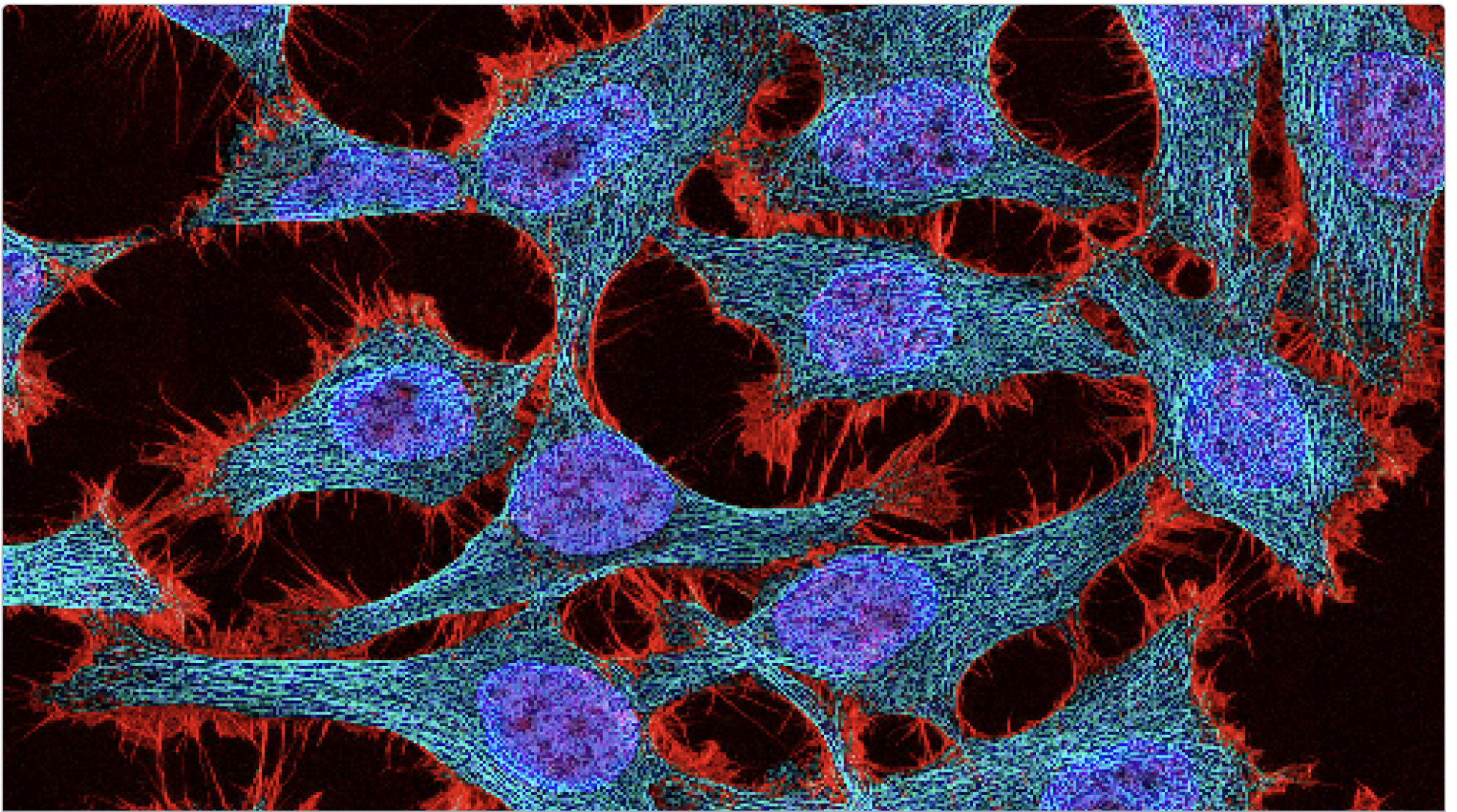


Figure 1: A high resolution image of HeLa cells that have been stained to show their structural features. This image was captured using [fluorescence microscopy](#)—which captures longer wavelength light emitted by the cell. (*HeLa-II* is labeled as Public Domain under [CC-PD-Mark](#).)

HOW DID HELA CELLS HELP TO ADVANCE MEDICAL RESEARCH?

As the first human immortal cell line, HeLa cells became invaluable to scientific and medical research. For more information on the significance of HeLa cells and their contribution to science, please visit [The Story of Henrietta Lacks: The Medical Contributions of HeLa Cells](#).

WAS COLLECTING LACKS’S TISSUE CELLS ETHICAL?

It is important to note that taking Henrietta Lacks’s cells without her consent or knowledge was not considered unethical at the time. It didn’t violate the **ethical norms** (or acceptable standards of behavior) that guided medical research in the 1950s. The hospital that collected Lacks’s cells had agreed many years earlier to send cell samples from any patient diagnosed with cervical cancer to the laboratory for testing in order to try to learn more about the disease (Johns Hopkins Medicine, n.d.).

However, it is critical to think about Lacks’s case within the larger context of society at the time. While the physicians who collected and studied Lacks’s cells may not have violated any of the norms of that period, can we really consider those norms ethical to begin with? If we take into account the deeply unequal society in which they were set, we need to question whether harvesting Lacks’s cells without her consent was ever justifiable.

SYSTEMIC RACISM IN HEALTH CARE

Throughout Lacks’s lifetime, Black people faced **systemic racism** across US society, including in its health-care system (Yearby et al., 2022). For example, Black people’s access to health care was severely limited due to **racial segregation**.

“This was the era of Jim Crow—when black people showed up at white-only hospitals, the staff was likely to send them away, even if it meant they might die in the parking lot. Even Hopkins, which did treat black patients, segregated them in colored wards, and had colored-only fountains.”
- Rebecca Skloot, author of *The Immortal Life of Henrietta Lacks*

Lacks had to travel almost 20 miles to John Hopkins Hospital for each visit, as it was the only major hospital in the area that treated Black patients (Skloot, 2011). She was repeatedly sent home when she asked for additional medical attention and was finally hospitalized when her pain became unbearable (Gross, 2010).

According to the gynecologist who treated her, Lacks received the standard treatment for cervical cancer at the time, which included undergoing a biopsy to diagnose her cancer and receiving radium treatment. However, we can’t ignore the societal inequalities that were present during her diagnosis and treatment. Studies examining this period of US history have shown that Black people were generally admitted to hospital at more advanced stages of illness compared to white people and experienced higher mortality rates once hospitalized (Skloot, 2011).

RACIAL HEALTH DISPARITIES TODAY

Differences in standards of care or mortality rates between groups of people are examples of **health disparities**. Unfortunately, the systemic inequalities Lacks experienced as a Black person have yet to be resolved. Black Americans continue to face significant disparities in access to and use of health-care facilities (Artiga et al., 2021). When they do access health-care facilities, Black people receive lower standards of care on average than white people (AMA, 2020).

The fact that the same issues of systemic racism in health care exist for many Black Americans today is a critical reminder that we need to focus our energies on addressing racial health disparities. Learn more: [What are Health Disparities?](#)

WHAT DOES LACKS’S CASE MEAN FOR CONSENT TODAY?

Understanding the larger medical landscape in the 1950s in the US raises ethical questions about the quality of care that Lacks received as a Black woman. But what questions does Lacks’s case raise about ethical norms in medical research today?

Ethical considerations for biospecimen research

Henrietta Lacks’s case calls into question modern ethical considerations around **biospecimen** research. The ethical practice guidelines for obtaining biospecimens (samples of biological materials such as blood, tissue, or DNA) still do not require **informed consent** from a donor, as long as the specimen is de-identified to ensure the donor’s anonymity (Wolinetz & Collins, 2020).

The lack of informed consent in biospecimen research allows researchers wider access to samples, which can provide valuable information regarding how the human body reacts to certain medicines, treatments, and diseases. However, this practice also erases the contributions of the people who provided those samples—as we’ve seen in the case of Henrietta Lacks. In order to conduct their research more ethically and build public confidence, the scientific community should more intentionally seek permission from participants wherever possible (Wolinetz & Collins, 2020).

Engaging Black research participants

Lacks’s case also raises questions regarding the scientific community’s approach to engaging Black research participants. Throughout the history of scientific and medical research, many researchers have taken advantage of Black research participants to source data and biological material, without providing adequate information about the purpose of their research or how it could affect them (Scharff et al., 2010).

HOW HAVE RESEARCHERS TAKEN ADVANTAGE OF THE BLACK COMMUNITY IN THE PAST?

One of the most damaging experiments for the Black community in the history of medical research was the Tuskegee Syphilis Study, in which the US Public Health Services conducted research on Black participants without their informed consent and did not offer participants treatment for their disease when it became available. To learn more about the study and its effects on the Black community in the US, please visit [A Timeline of the Tuskegee Syphilis Study](#).

Today, unlike the standards for biospecimen research, all modern research that includes human participants—such as clinical trials or medical surveys—requires obtaining informed consent. This involves fully explaining the details of a research study to potential participants, including how it could affect them, before they agree to participate.



Figure 2: Building public confidence among human research participants requires informed consent. (Image by LabXchange @ The President and Fellows of Harvard College.)

However, there are some cases in medical research in which patients are unable to give consent because of their condition, or because there is not enough time to follow the proper channels of obtaining informed consent. These instances usually relate to emergency, end-of-life situations, such as cardiac arrest. For cases such as these, the FDA introduced the exemption from informed consent (EFIC) process that allows researchers to pursue vital research on emergency conditions without obtaining informed consent (Brown, 2020).

In these cases where informed consent is not required, the overrepresentation of Black research participants is still a concern. Recent research shows that Black participants make up 29% of all participants in studies that have been exempted from informed consent, even though they represent a much smaller portion (13%) of the overall US population (Kemet, 2019). In contrast, only 5% of participants in clinical trials are Black (Brown, 2020). In other words, the percentage of Black participants in voluntary research studies such as clinical trials is far lower than the percentage of Black participants in involuntary research studies. Why is this concerning?

Firstly, many clinical trials allow research participants access to new medical treatments that benefit their health, but may not be available to the general population for a long time (Brown, 2020). When a certain group of people (such as the Black community) is underrepresented in these trials, they are excluded from accessing new forms of treatment that could improve their health outcomes. Secondly, including a racially diverse participant group in clinical trials ensures that the results of these trials are more accurate and representative of the population that the US health-care system serves. A lack of diversity in clinical trials limits researchers' abilities to consider how different people's experiences and environments may influence the effectiveness of a treatment (Gray et al., 2021).

The differences in racial representations between studies that require informed consent and those that don't suggest that inequities still exist in how the medical research community involves Black research participants (Brown, 2020).

LEARN MORE ABOUT THE BENEFITS OF DIVERSE CLINICAL TRIALS

To learn more about the purpose of clinical trials and how the medical research community can increase the diversity of their participant groups, please watch [The Importance of Diversifying Clinical Trials](#).

CONCLUSION

As we reflect on Henrietta Lacks’s story, it is important to consider what lessons we have learned and what injustices remain to be remedied. Henrietta Lacks has made important contributions to medical science, not only because of the innovations her cell samples have enabled, but also because of the critical conversations about medical ethics and racial justice that her story has raised.

Despite the advancement in science and medicine that stems from Lacks’s immortal cell line, it should not detract from the systemic racism within these fields that Lacks endured as a Black woman and that continues to impact Black Americans today. It also raises important questions around the ethical treatment of research participants from racially marginalized backgrounds—especially those who have historically been overrepresented in studies that do not require informed consent, but underrepresented in voluntary studies. By engaging with these questions, medical researchers can begin to rebuild trust with these communities and address the disparities that a long history of medical exploitation has created.

KEY TERMS

- **Biospecimen:** Any biological material taken from a living organism that is used or stored for research purposes. Examples of biospecimens include samples of blood, tissue, cells, and DNA.
- **Ethical norms:** Widely accepted standards of behavior or practices within a society or community, which are based on shared values and principles.
- **Health disparities:** A higher rate of mortality (i.e., death), morbidity (i.e., disease or illness), disability, or injury experienced by one group of people relative to another. Health disparities are preventable and largely arise as a result of social or economic injustices that impact people’s health.
- **Immortal cell line:** Cells that are capable of dividing continuously and indefinitely when provided with the correct environmental conditions. Immortal cell lines are valuable in medical research, as they allow scientists to study how cells function and react to diseases and treatments. They can be obtained from naturally occurring cancerous cells (due to their ability to divide continuously), such as the HeLa cell line, or they can be obtained from cells that scientists have altered to cause them to divide continuously.
- **Informed consent:** The practice of giving the participants of a research study (medical or otherwise) full knowledge of what the study is, what will be expected of them, and how the study may affect them, before they agree to participate.
- **Racial segregation:** The systematic separation of people and communities based on socially defined race. This practice allowed for the unequal distribution of wealth and resources in a way that primarily benefited white communities.
- **Systemic racism:** Racism that is enforced in a society through its policies, institutional practices, cultural representations, and deliberately unequal balances of power.

For a comprehensive list of terms associated with the Racial Diversity, Equity, and Inclusion in Science Education project, please visit the [Glossary](#).







FOR MORE INFORMATION

- [The Story of Henrietta Lacks: Biography](#)
- [The Story of Henrietta Lacks: Uncovering the HeLa Cells](#)
- [The Story of Henrietta Lacks: A Family Legacy of Justice and Equity in Science](#)

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	Content Type	Text
	Language	English
	Subject	Ethics
	Background Knowledge	None
	Favorites	2
	Views	1,336
	Remixes	3 (2 Public , 1 Private)
	License	LabXchange Standard License

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