HOW HISTORICAL MEDICAL WRONGDOINGS CONNECT TO CURRENT INEQUITIES

Learning Outcomes and Intended Impact

To better understand the current inequities within clinical trials, it is imperative we examine the racialized experiences marginalized groups have faced throughout the history of modern medicine in the United States. Deepening our understanding of these traumas, experiences, and lasting impacts will help shape community relations and understanding for clinical trials moving forward. While clinical trials and other medical research have been leveraged to better understand methods of disease and infection prevention, they have not come without the toll of many who unknowingly sacrificed their wellbeing, often without ever receiving the benefit in which they were sacrificed.

HISTORICAL CONTEXTS

The most known example of this that is studied in most medical ethics classes is the Tuskegee Syphilis study. In summary, the United States Public Health Service, the precursor to the Centers for Disease Control and Prevention, recruited 600 Black men from Tuskegee, Alabama in 1932. These participants were told they were being studied for untreated syphilis in Black men. Treatment was withheld from the participants even though penicillin had become the standard of care for syphilis by 1940. The study only ended in 1972 once a whistleblower leaked information about the research project (Chen et al., 2024). Concurrently, American physicians were also deliberately infecting hundreds of Guatemalans with syphilis and gonorrhea in the 1940s without their knowledge or consent. Under brutal conditions, incarcerated men, soldiers, and children in the national orphanage were infected to research the effects and the modes of

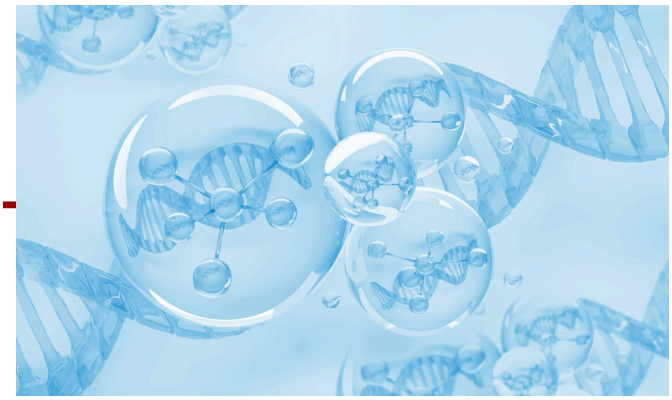
infection transmission (Tobin, 2022). Women have also been the subject of nonconsensual research that stripped them of body autonomy to fuel medical research and profits.

Disproportional Impact on Black Women

In the 1950s, cervix tissue cells were taken from a Black woman named Henrietta Lacks without her consent or knowledge. These cells were used for medical research and development including drugs for herpes, cancer treatment, and spinal muscular atrophy therapy (Brittain, 2024). Lacks herself passed away at 31 from cervical cancer.

While these examples from the 20th century are nowhere near exhaustive, they represent American medicine's lust for knowledge and breakthrough at any expense. And as medicine and medical research become driven more and more by profit, the exploitation becomes more egregious.

In the case of Henrietta Lacks, while Johns Hopkins distributed her cells for free, the companies on the receiving end have made large sums of money from products that have originated from her cells. Biotech firm Thermo Fisher developed several products using the cells from Henrietta Lacks to the tune of $40 billion in annual revenue (Merelli, 2023). While the company reached a settlement with Lacks' descendants, it does not fill the void created by the unethical acquisition of her cells nor the lack of accountability from the medical community. There is also a larger philosophical debate surounding the millions of people who have beem positively impacted by this unethical harvesting of cells; in addition to the treatments that have been discovered through the HeLa cells, this case of Henrietta Lacks sparked policy change in the United States with regulatory overhauls regarding patient informed consent (Beskow, 2016). There is no denying some of the positives to come out of the HeLa cells but the larger discussion remains surrounding the disproportionate cases of Black women and Black families being on the short end of these discoveries and benefits. Many of the advances in modern medicine are a result of inhumane practices on Black women.



> "The field of gynecology still relies on and utilizes procedures and best practices that were a result of testing on enslaved Black women."

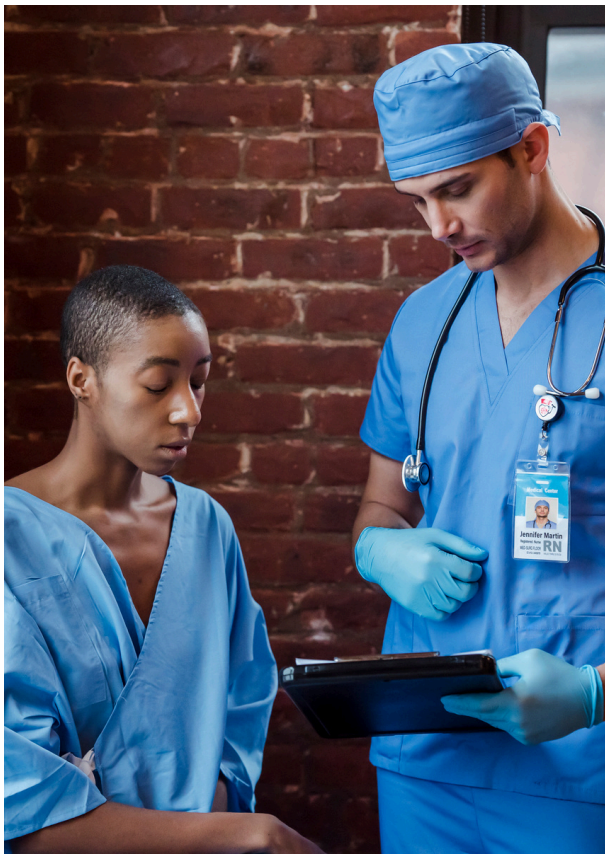
The field of gynecology still relies on and utilizes procedures and best practices that were a result of testing on enslaved Black women. Dr. James Sims, a white physician from South Carolina, is notorious for introducing many techniques and treatments still in use today. Sims is credited with inventing a version of the modern speculum as well as pioneering a surgical technique used to repair vaginal fistulas (Tumin, 2018). He experimented his techniques on enslaved women in 1845 without any form of anesthesia (Lerner, 2003). Sims was not the only physician to make medical breakthroughs at the expense of enslaved Black women. French surgeon Dr. François Marie Prevost traveled to former French colonies to perform experimental cesarean sections on enslaved Black women (Benia & Owens, 2017).

COMMUNITY IMPACT

While it can be argued that thousands of people have benefitted from these sorts of exploitations, it is important to understand these sorts of actions have longstanding impacts on the communities harmed and can create mistrust between marginalized communities and healthcare.

HEALTHCARE FOR SOME

There are many negative consequences that arise from medical mistrust, including low utilization of healthcare resources and poor management of health conditions (Halkitis & Jaiswal, 2019). This mistrust derives from the belief that healthcare and medicine in the United States is acting against one's best interest or well-being. And with the myriad of examples provided in this brief, along with the hundreds of additional cases, it is understandable as to why marginalized communities would not have faith in the medical information provided to them and the intended benefits truly being in their best interest. Clinical trials face an uphill battle of erasing over 100 years of neglect, misleading information, and intentional harm. When engaging with marginalized communities, intentional care must be placed on overcoming the history of abuse and dehumanization medical research and clinical trials have caused, many times without any sort of reparation or requital. There has never been a systematic lookback at the harm caused with an intentional effort at financially compensating those most impacted. Coupled with the inequities in healthcare access and treatment, long-term benefits do not accrue to the communities disproportionally bearing the sacrifices of discovery and development.



Healthcare in the United States is unique because it is not an innate right for all, but a privilege that must be acquired. Most healthcare access in the United States is provided through one's full-time work profession. Other access points include Medicare for those who are 65 or older and Medicaid, a joint state and federal program

that provides coverage for people with limited income and resources. Because of these limitations, and the aggressive pursuit of profit from insurance companies and hospitals, many are left being underinsured, having no insurance, or not receiving adequate care due to circumstances out of their control. These differences in access and experience in the healthcare system has led to health disparities across various groups. These disparities are differences or gaps in the quality of health and healthcare across, racial, ethnic, and socio-economic groups (Riley, 2012). Environmental characteristics such as education, employment, income, food insecurity, and housing insecurity all play into reasons why marginalized groups will have different experiences within the healthcare system compared to those with more privilege. When these systemic factors are then coupled with personal bias, therein lies the throughline between the historical wrongdoings with the current barriers to healthcare access in the United States.

DEI CONSIDERATIONS

As clinical trial looks look towards the future of creating inclusive and just sites, they must ground themselves in the history of how many people have been treated within the healthcare system. Medicine in the United States, much like all other systems, was intentionally designed to care for those deemed most worthy and prey on those who were thought to be disposable and interchangeable. The intentional mistreatment by physicians and healthcare staff towards marginalized communities was meant to dehumanize them as part of the overall marginalization that has been present throughout the history of the United States.

When marginalized communities are thought of as expendable, they are treated as subjects rather than patients; they are thought of as research and not as people. These attitudes are embedded in the early culture of medicine that helped shape the current culture in existence today. While regulations and governing bodies act as guardrails to prevent such atrocities from happening again, they cannot upheave centuries of power dynamics and privilege that manifest inequitable dynamics amongst healthcare professionals and the communities they intend to serve. Instead, the burden must be placed on these healthcare professionals to make certain their trials and research are intended to aid all communities and are inclusive from the beginning to ensure all opinions, thoughts, and points of view are considered. If not, society will continue to see the legacy of oppression rampant in society.

> “The intentional mistreatment by physicians and healthcare staff towards marginalized communities was meant to dehumanize them”

The actions of the past create lasting impacts that are still present. When analyzing health outcomes and research results, medical professionals must challenge themselves to understand how race and ethnicity play a proxy to disproportioned outcomes. Healthcare disparities seen in society today are not simply the result of one's individual actions; they are a result of centuries of environmental and socioeconomic factors that drive different outcomes for different people. Whether it be mistrust in clinical trials or not having the ability to see a specialist because of the cost of healthcare, these oppressive tools establish a hierarchical society where the wealthy and well-connected receive the benefits of worldclass medicine and the poor and working class hold onto whatever leftovers are made available to them.

Role of Clinical Trials

Clinical trials and medical research have a direct hand to play in this oppression and will continue to do so if advancement in medicine is driven by profit and return on investment. To break this cycle and create a new legacy in society, leaders in the medical field must rethink medicine functions and how clinical trials can offer a pathway to healthcare.

There will always be criteria on eligibility for clinical trials. For leaders in medicine, it is not about trying to change things outside of one's control. The challenge and call to action for all those in the medical field is to transform inequities within their sphere of influence. Everyone on a team has a role to play within a clinical trial or medical research. Within that role, there is an opportunity to challenge the status quo and understand how a process, procedure, or policy can be rethought and done differently. These bold and courageous leaders will create a legacy and pathway for systematic changes in healthcare and community relations with medicine. A good first step in this process is to understand how clinical trials can offer a pathway to healthcare.

Clinical trials can be so specialized that patients may have never been exposed to that sort of physician before. For an example related to the CLIN 2 trial, rural counties have a lower mean ophthalmologist density (0.58/100,000 individuals) compared to metropolitan counties (6.29/100,000 individuals) (Adleman et al., 2020). Because of this rural-metropolitan divide, many in smaller counties across the United States may never have been tested or exposed to symptoms related to the disease being studied. This example reinforces the benefits clinical trials can bring to communities who do not have the same level of access to medical specializations. These trials become the first line of defense for disease prevention.

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Clinical trials and medical research improve millions of lives and change the world. At the same time, trials and research have a history of devastating communities and creating abuse and mistrust; both can and are true at the same time. It is imperative for healthcare leaders to lead the fight for disease irradiation while also protecting the communities who continue to be the front line for discovery and medical breakthroughs. Only then can we have a society build on medical equity and inclusion for all. Clinical trials such as the CLIN 2 study aim not only to bring advancements in medicine that can positively impact the vision of millions around the world, but they intentionally focus on inclusion and equity to prevent atrocities of the past from continuing. The legacy of ethical and well-run clinical trials will be built on the shared values of making healthcare and medicine accessible for all.

About the USC Race and Equity Center

The University of Southern California is home to a dynamic research, professional learning, and organizational improvement center that serves educational institutions, corporations, government agencies, and other organizations that span a multitude of industries across the United States and in other countries. We actualize our mission through rigorous interdisciplinary research, high-quality professional learning experiences, the production and wide dissemination of useful tools, trustworthy consultations and strategy advising, and substantive partnerships. While race and ethnicity are at the epicenter of our work, we also value their intersectionality with other identities, and therefore aim to advance equity for all persons experiencing marginalization. Our rigorous approach is built on research, scalable and adaptable models of success, and continuous feedback from partners and clients.

We acknowledge that our center is on the traditional land of the Gabrielino-Tongva peoples. We also recognize the Chumash, Tataviam, Serrano, Cahuilla, Juaneño, and Luiseño People for the land that USC occupies around Southern California. We honor their past and present.

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USC Race and Equity Center

Our mission is to **ILLUMINATE**, **DISRUPT**, and **DISMANTLE** racism in all its forms.

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