

Duration

One class session of about 45 minutes (excluding take-home assignment)

Resource

1. Student Handout

**Objectives of Lesson**

- Learn of two historic examples of violations to Americans
- Explore civil and legal ethical violations and protections
- Identify the importance of codes of ethics in research and study
- Create their own code of ethics which should include civil and legal protections

- Students should be able to:
 - identify ethical violations in research studies (both in and outside of Psychology)
 - think critically about research study practices and methods

College Board Objectives from the 2019–20 CED

- **Topic 1.6:** Ethical Guidelines in Psychology (p. 39)
- **1.N:** Identify how ethical issues inform and constrain research practices.
- **1.O:** Describe how ethical and legal guidelines protect research participants and promote sound ethical practice.

Student Activities

- Read and discuss “When research Lacks compassion”
- Read and discuss “Now, You’ve Got Bad Blood”
- Create a code of ethics

How to Use This Lesson

Use this lesson as an introduction to Topic 1.6 Ethical Guidelines in Psychology. The lesson topics are highly illustrative and seek to diversify the curriculum. You may choose to do the entire lesson in-class, or complete activities 1 and 2 in-class, and assign activity 3 as an at-home assignment.

PSYCHOLOGY AND EXPERIMENTS

As we dive into the curious world of Psychology and experimentation, we have to ask ourselves is anything okay to study in the name of science? History has proven that the answer is no.

A researcher should not be able to conduct a harmful experiment on humans with no consequence. Even when animals are the subject, there must be certain rules and regulations in place for protection. But how do researchers determine what is ethical and what isn't? An Institutional Review Board is designed to protect the rights of human participants involved in research studies. In an example where research is conducted at a college or university, the **Institutional Review Board (IRB)** for that school will determine if a study should be conducted and must approve of the methods for the execution of the study.

What happens without the protection of laws (National Research Act of 1974 and the Nuremberg Code of 1947) and IRBs? The answers lie in our history of unfortunate experiments.

KEY TERMS

- Ethical: moral principles
- Unethical: a violation of moral principles
- Biopsy: removing a sample of tissue from the body in order to learn more about a disease or affliction
- Propagating: breeding plant or animal material from an original parent sample
- Non-compliance: to not follow the directions of an authority figure

When research Lacks compassion

By 1951, researchers were desperate to find effective treatments and cures for cancer and other lethal diseases. For 30 years, doctors and scientists had tried to unsuccessfully keep tissue cells alive outside of the human body for use in research that is unethical to conduct on living human subjects.

At the time, Johns Hopkins Hospital was the home of physicians treating patients with such ailments as cancer. As fate would have it, this is where Biologist George Otto Gey and cervical cancer patient Henrietta Lacks would cross paths, and our lives are immeasurably impacted by their overlap today. Together, they would change the world.

In these days, cancer treatment was just as toxic and lethal as the disease itself, if not more so. Henrietta didn't know about her cancer until after the birth of her fifth child. By then, her cancer was so aggressive and advanced that it was only a matter of time before she expired. Henrietta (or Hennie, as her friends and family fondly called her), continued to visit John Hopkins Hospital for treatments and observation from 1950–51. During one such visit, an unconscious Henrietta received a routine biopsy. Two samples were taken: healthy tissue and cancerous tissue. The samples were given to Dr. Gey who propagated the cells and quickly discovered that these cells were unlike any he'd ever worked with before. While others died quickly once removed from the body, Henrietta's cells doubled every 20 to 24 hours—making these cells immortal!

Since that fateful day, Henrietta's cells have produced over 800 billion times. At first, vials of her cells were given away to laboratories all over the world. Finally, researchers had access to cells that could be used for drug and treatment experiments without the need for human experimentation. In 1954, microbiologist associates began selling HeLa cells. As of 2017, they could be purchased through biomedical suppliers at a price of \$10,000 per vial. These miraculous HeLa cells (as they became known) are at the forefront of every major medical breakthrough, saving millions of lives and generating billions of dollars.

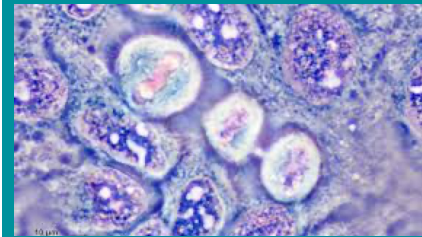
Permission was never obtained from Henrietta Lacks nor her family for the use of her body tissue in experimentation or



Henrietta Lacks

Mother of modern medicine

HELA CELLS



HeLa cells gave birth to the biomedical industry! Here are treatments and studies in which HeLa helped develop and advance:

- Polio vaccine
- Tuberculosis
- Cancer research
- Leukemia treatment
- Herpes treatment
- In vitro fertilization
- Influenza
- AIDs treatment
- Parkinson's disease
- Chemotherapy drugs
- HPV research
- Hemophilia
- Ebola
- Gene mapping
- Stem cell research
- Cornea regeneration

Henrietta's cells were even put into space and placed into nuclear bombs for research.

in sale. In fact, the family was never formally notified that Henrietta's cells had been used at all. The family was lied to and even asked to give blood under false pretenses so they could perform research on Henrietta's children. The family may never have found out had fate not intervened yet again, when a relative of a Lacks family friend informed her children that his coworkers had been doing research at the National Cancer Institute using Henrietta's cells. The family has never received compensation and only recently received recognition.

Should Henrietta's case be used to put an end to research without consent?

NOTES

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DISCUSSION QUESTIONS

1. What is informed consent?
2. How should informed consent look in a situation like this?
3. Should samples taken from a live body be protected?
4. Do donors and their families have the right to know what their samples are used for?
5. Should donors have the right to decline certain usage?
6. Should any royalties be given to families from companies making profit?
7. Who owns the rights to samples taken?
8. How can a participant's privacy be protected?
9. How can cases like Henrietta's help form current regulations in research and experiments?

“Now, You’ve Got Bad Blood”

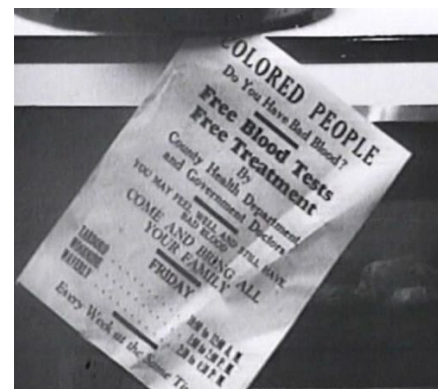
In 1932, members of the U.S. Public Health Service and Tuskegee Institute researchers embarked on a new experiment that would leave a mark on American history and research forever.

In Macon County, Alabama, 600 men were lured into participating in a study by the promise of free medical care. The participants were mainly poor sharecroppers with no access to medical care, so many flocked to screening locations to be selected. 600 men total participated: 201 of the men were the disease-free control group, and the other 399 had syphilis but did not yet exhibit symptoms.

The men were promised free meals, physicals, treatment, and burial insurance. This was all an elaborate deception for the true intentions of the experiment: observing the progression of the lethal venereal disease, syphilis, in the human body without treatment. The official name of the experiment is “Tuskegee Study of Untreated Syphilis in the Negro Male.”

The methods were extreme, and the outcomes were catastrophic. Infected patients were simply told that they had “bad blood” and given placebos, aspirin, and mineral supplements to make them believe they were being treated. Local nurses were hired to transport patients to all of their doctor’s appointments to ensure they would not receive medication, even after Penicillin was found to have successfully treated syphilis by 1945. Local public and private physicians were recruited and convinced to never tell the men their diagnosis nor to treat them. In order to track the disease’s full progression, no effective care was offered as the men went blind, insane (through infection of the brain), and died, among other horrors.

The experiment went on for 40 years and did not conclude until Peter Buxton leaked news of this atrocity to his friend with press connections. When the story was published in the *New York Times*, the public outrage forced the U.S. Public Health Service to terminate the study. By then, 128 participants perished due to syphilis or related complications, and over 40 of the men’s wives had contracted syphilis and passed the disease to 19 of their children at birth.



Flyer from the
Tuskegee Experiment



National archives—Participants of the
Tuskegee Experiment

By 1947 The Nuremberg Code (a set of 10 ethical principles for human experimentation) had been established in response to Nazi physicians' cruel experimentation on Jewish prisoners at-will during World War II. The Nuremberg Code helped to set a precedent upon which civil rights attorney Fred Gray Sr. won a \$10 million settlement along with lifetime medical benefits and burial services to the surviving participants.

This experiment annihilated the little trust African Americans held for medical institutions and the entire medical community. This legacy persists today and is key to medical non-compliance seen in Black communities.

Arguably, the only positive outcome of this experiment is the 1974 National Research Act, which established IRBs to review research involving human subjects. The act also created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, tasked with identifying ethical principles to prevent medical injustices in research and experimentation.

NOTES

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DISCUSSION QUESTIONS

1. What is informed consent?
2. How should informed consent look in a study like this?
3. Should participants and their families be aware of details of the study?
4. What is okay to keep hidden from the participants until the study concludes?
5. What is debriefing?
6. How can researchers reduce or eliminate risk to participants?
7. To what extent do we believe actions taken by researchers could be considered criminal?
8. Can you think of a useful study/experiment that might not be ethical to conduct?
9. How can cases like the Tuskegee Experiment: The Infamous Syphilis Study help protect patients and participants today?

Create your own code of ethics

After reading and discussing these two examples of unethical research practices, create your own code of ethics. Be prepared to explain why each bullet point is important and what civil or legal rights it protects.

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