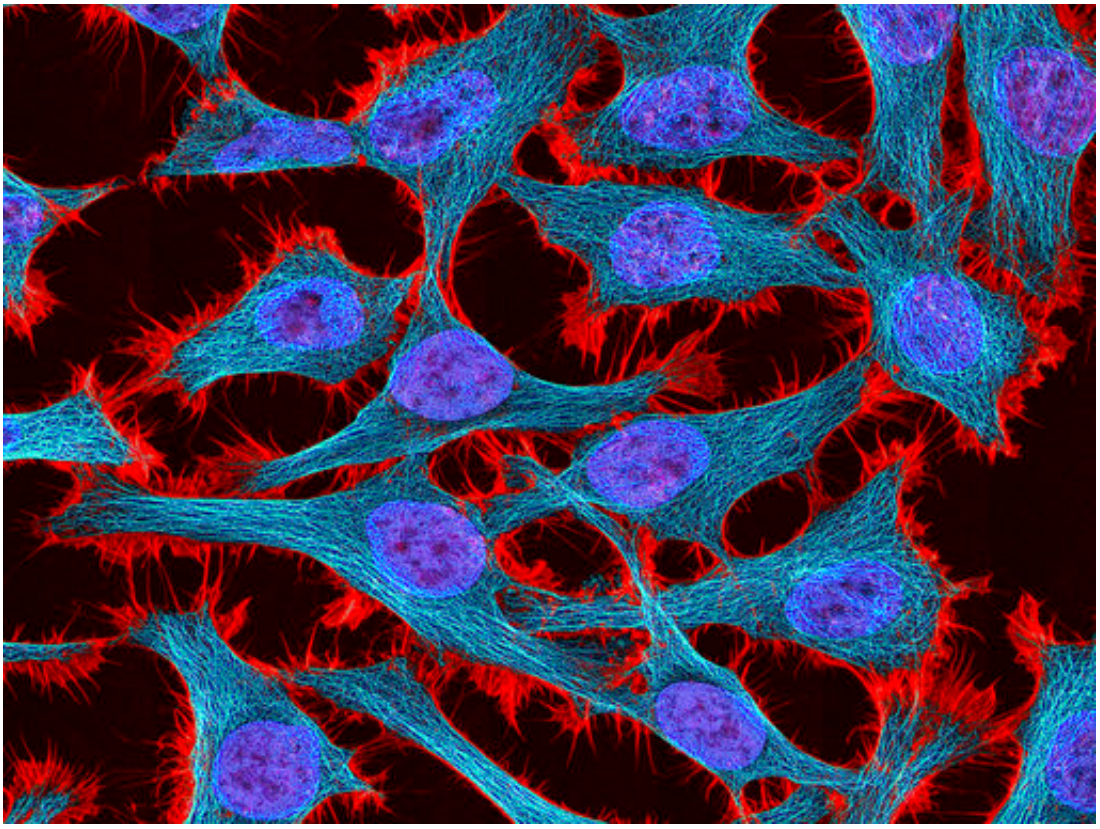
Q&A: Could the Henrietta Lacks case happen today?

April 20 2017, by Malcolm Ritter



This undated microscope image made available by the National Center for Microscopy and Imaging Research shows HeLa cells. Until these cells came along, whenever human cells were put in a lab dish, they would die immediately or reproduce only a few times. Henrietta Lacks' cells, by contrast, grew indefinitely. They were "perpetual, everlasting, death-defying, or whatever other word you want to use to describe immortal," says Dr. Francis Collins, director of the U.S. National Institutes of Health. (National Center for Microscopy and Imaging Research via AP)

What happened in the 1951 case of Henrietta Lacks, and could it happen again today?

The story of the woman who unwittingly spurred a scientific bonanza made for a best-selling book in 2010. On Saturday, it returns in an HBO film with Oprah Winfrey portraying Lacks' daughter Deborah. Cells taken from Henrietta Lacks have been widely used in biomedical research. They came from a tumor sample taken from Lacks—who never gave permission for their use.

A look at the case:

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HOW DID DOCTORS GET THE CELLS?

As the book relates, Lacks was under anesthesia on an operating table at Johns Hopkins Hospital in Baltimore one day in 1951, undergoing treatment for cervical cancer. A hospital researcher had been collecting cervical cancer cells to see if they would grow continuously in the laboratory. So the surgeon treating Lacks shaved a dime-sized piece of tissue from her tumor for that project. Nobody had asked Lacks if she wanted to provide cells for the research. She died later that year.

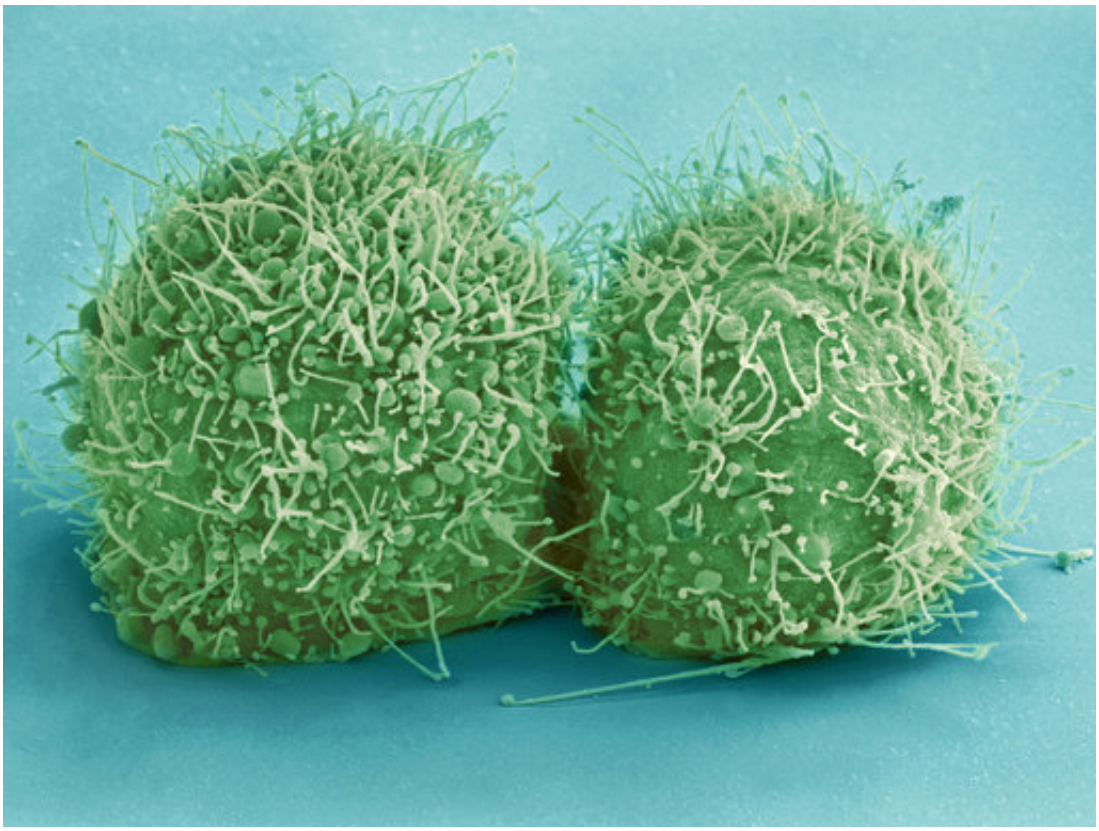
WAS IT ILLEGAL TO TAKE THE CELLS WITHOUT HER PERMISSION?

Not at that time. "What happened to Henrietta Lacks was commonly done," says bioethicist Dr. Robert Klitzman of Columbia University in New York.

WHAT ARE THE RULES NOW IN THE U.S.?

Specimens intended specifically for research can be collected only if the donor gives consent first.

If cells or tissues are instead removed for diagnosis and treatment, that is considered part of the patient's general consent for treatment.



This undated microscope image made available by the National Center for Microscopy and Imaging Research shows just-divided HeLa cells. Until these cells came along, whenever human cells were put in a lab dish, they would die immediately or reproduce only a few times. Henrietta Lacks' cells, by contrast, grew indefinitely. They were "perpetual, everlasting, death-defying, or whatever other word you want to use to describe immortal," says Dr. Francis Collins, director of the U.S. National Institutes of Health. (National Center for Microscopy and Imaging Research via AP)

But there's a twist. Once a specimen is no longer needed for treating the patient and would otherwise be discarded, scientists can use it for research. No further consent is needed, as along as information identifying the patient as the source is removed and the specimen can't be traced back to the patient, says Johns Hopkins University bioethicist Jeffrey Kahn.

IF A SPECIMEN LEADS TO A PRODUCT, DOES THE DONOR HAVE A RIGHT TO SHARE IN THE PROFITS?

Generally not, because the consent form for donation or treatment usually waives any such legal right.

WHAT WAS SO SPECIAL ABOUT LACKS' CELLS?

Until they came along, whenever human cells were put in a lab dish, they would die immediately or reproduce only a few times. Her cells, by contrast, could be grown indefinitely. They were "perpetual, everlasting, death-defying, or whatever other word you want to use to describe immortal," as Dr. Francis Collins, director of the U.S. National Institutes of Health, put it. So they provided an unprecedented stock of human cells that could be shipped worldwide for experiments. They quickly became the most popular human cells for research, and have been cited in more than 74,000 scientific publications.

HOW HAVE RESEARCHERS USED THE CELLS?

The so-called "HeLa" cells became crucial for key developments in such areas as basic biology, understanding viruses and other germs, cancer treatments, in vitro fertilization and development of vaccines, including the polio vaccine.

WHAT MAKES THEM GROW SO WELL?

Researchers proposed a possible answer in 2013. Virtually all cases of cervical cancer are caused by infection with human papillomavirus , which inserts its genetic material into a human cell's DNA. Scientists who examined the DNA of HeLa cells suggested that happened in a place that strongly activated a cancer-promoting gene. That might explain both why Lacks' cancer was so aggressive and why the cells grow so robustly in a lab dish.

DID EVERYBODY ALWAYS KNOW THE ORIGIN OF THE CELLS?

No. Lacks was named publicly only in 1971, by an article in a medical journal. Her story appeared in some magazines in the 1970s, and in a 1997 documentary on BBC. She became famous in 2010 with publication of Rebecca Skloot's best-selling book, "The Immortal Life of Henrietta Lacks."