

My name is Elizabeth Wynn, I'm the Equality and Diversity Manager at the Babraham Institute, and today I'm going to be talking about the history and ethics of HeLa cells. I'm going to give a quick, brief history of Henrietta Lacks and HeLa cells and then talk much more about the ethical issues that surround them, because HeLa cells are incredibly important but they are also still very controversial. I know that some of the people here have worked or continue to work with HeLa cells, I've actually worked with them in the past, so I'm hoping at the end of this we can have a really interesting discussion.

Starting with the woman herself: Henrietta Lacks. She was born August 1, 1920 – so one reason this talk is titled HeLa100 is because it's the centenary of her birth. And you might see the hashtag HeLa100 on Twitter, for example, information about this – she was born in 1920 and died October 4, 1951. She was born in Virginia and her name at birth was Loretta Pleasant and no one knows how she went from Loretta to Henrietta or when that happened really.

She worked as a tobacco farmer from a young age. She didn't go to high school and she and many of her family members worked on the tobacco farm at the plantation that their ancestors had been enslaved at. She married in 1941 and moved to Connecticut with her husband so he could work in a steel mill and she raised their five children.

In 1951, in January, she went to John Hopkins Hospital due to a knot in her womb. This was the only hospital in the area that accepted Black patients. And in fact, it was the same hospital that she had given birth to her youngest child at just four months prior.

At John Hopkins she was diagnosed with cervical cancer and, despite receiving the standard care at the time, she died less than a year after getting her diagnosis. So passed away in October of that year at the age of just 31. While she was receiving treatment her doctor took tumour samples without her knowledge or consent, which went on to become the HeLa cell line.

So let's talk about that cell line next. It was developed by George Otto Gey and his lab assistant Mary Kubicek. George Gey was a cell biologist doing research at John Hopkins and he was trying, developing different techniques for culturing human cells *in vitro* for the purpose of research. The thing is, most cells would die within a couple of days after being taken out of the body, until they got the HeLa cells, which proved to be extremely robust and prolific. They would double about every 20 to 24 hours and would continue growing forever. So the HeLa cells, which were named after the first two letters of Henrietta Lacks' names, became the first immortal human cell line.

George Gey and John Hopkins Hospital and University didn't profit from this development at all. They provided the cells for research purposes to anyone who would ask to these were widely distributed to aid in research and in the past 70 years they have contributed to so many different areas of research.

One of the first things that the HeLa cells were used for was testing Jonas Salk's polio vaccine.

The link between human papilloma virus and cervical cancer was discovered with research on HeLa cells, and that led to a Nobel Prize.

HeLa cells were used to discover effective techniques for counting chromosomes. From the 1920s to the 1950s, it was commonly known that humans had 48 chromosomes. It wasn't until some researchers used HeLa cells to develop methods for effectively counting chromosomes that it was proved that humans actually have 46 chromosomes. And it's sort of ironic that they used HeLa cells to develop these techniques because HeLa cells, being hugely mutated as cancer cells, actually have, depending on the strain, between 76 and 80 chromosomes.

HeLa cells were taken into space with some of the first space missions in the 1960s to study the effects of zero gravity on cells.

And then there are numerous studies on fields as varying as cancer, infection, the effects of toxins, and ageing, of course, that have been done with HeLa cells. Work that was done on telomeres in HeLa cells also led to a Nobel Prize.

So HeLa cells have proved incredibly useful and the impact that they have had on research cannot be understated. Currently it's estimated that there are over 11,000 patents and 110,000 papers that reference HeLa cells.

That was the abridged story of Henrietta Lacks and HeLa cells and now I'm going to spend most of the time talking about the ethical issues that surround using HeLa cells.

The first one is informed consent. As I said, when Henrietta Lacks was undergoing cancer treatment at John Hopkins without her knowledge and consent her cells were taken to be used for research. That was completely legal and ethical at the time.

There are definitely questions, discussions that we need to have about, just because something was legal at the time and ethical at the time, now it isn't, so what does that mean in terms of us using these cells? Certainly if cells were obtained in this way now it would be completely illegal and unethical and no one would use them. But I'm actually going to talk about how and why that change happened, that change in how we perceive collecting tissue from individuals.

Tissue culture techniques started being developed in 1910 though it didn't actually become a very useful and valuable tool until technological advances in the 40s and 50s. But between 1910 and 70ish researchers would regularly obtain tissue samples from surgeons. You didn't need permission from the individual or the family, all you needed as a researcher was a good working relationship with a surgeon.

And consent for the use of tissue samples wasn't considered necessary by researchers or by the public. People definitely, the public definitely had worries about this strange new technology, but it was things like 'chemical babies' or tissue culture growing out of control and a wave of cells taking over the world.

No one raised issues of consent for taking and using the tissue. I think mostly because these were viewed as waste products. You know, cells taken from you, they're no use to you, if they're of use to researchers, why not use them? Here is a line from a *Guardian* article in 1961: "Human embryos ending their existence at London hospitals are providing scientists with the means of making a vaccine against the common cold." So there's no judgment there. There was no suggestion that doing this research was unethical. I think another reason for this is because this new technology tissue culture had immediately proved to be beneficial. Like the polio vaccine which saved and improved the lives of so many people.

So how and when did this change? In the 1970s, there started to be backlash against abortion legalisation, and also a lot of unethical research came to light.

Anti-abortion campaigners started saying that doing research on aborted or miscarried embryos or foetuses was the same as doing research on a baby and that changed the public discourse. Even if that wasn't accepted by a lot of people, it was still part of the public conversation.

And also a lot of unethical medical research entered the public consciousness. So one of the most famous examples of this is the Tuskegee Syphilis Study, which I'm going to talk about a bit more later, but here's another example using HeLa cells. In the 1950s and 60s, Chester Southam injected HeLa cells into patients without their informed consent. He wanted to see whether people would fight off the cells or whether they would develop cancer which is such an unethical procedure it's hard to describe it as an experiment. And one other complicating factor of this is a lot of the patients he used were prisoners.

So this type of unethical medical research that came to the published, public consciousness meant that medical research became under, came under more scrutiny and there was much more focus on how to make it ethical. In fact, it was in the 70s that the field of bioethics really came into its own, became a thing.

And though there wasn't a lot of focus yet on the ethics of informed consent when it came to tissue culture, like there wasn't the same outcry against it, the fact that medical research as a whole was under so much scrutiny and there was so much focus on informed consent, using tissues from people also came under that umbrella. So informed consent for research using tissue also became standard.

I think that there are two other things which really changed how we view tissues taken from our body. They're no longer viewed as waste materials, instead they're viewed as valuable. There are two reasons for that.

Increased genetic understanding. As technology has changed, we now have more ability to quickly and cheaply sequence cells and also understand the implications of genetic sequences. So now your cells aren't waste products, they contain highly personal information.

And also commercialisation of cells. Producing cell lines and producing products research on cell lines has become hugely profitable industry and when people started learning about this, then they thought, well, why am I giving these away for free. There is the legal precedent: *Moore v the Regents of the University of California*. A cell line was developed from cancer cells taken from Robert Moore¹ and he thought that he should get some of the profits of this. This was a pretty protracted legal case in California, lots of appeals and things, but in 1990 it did finally come down to a legal ruling that individuals aren't entitled to financial compensation for their cells or things taken or things produced from their cells. But now we do understand that by giving cells for research that could be profitable for someone. So I think that has again changed our conception of them. They're no longer waste products.

The next ethical issue I want to talk about involves ethnicity. It's a big question: how much impact, what is the role of Henrietta Lacks' ethnicity in the whole situation, her cells being taken and developed into this line. And that's a really hard thing to judge. In some ways you can say, well, George Gey was taking cells from every single cancer patient who came from, who came through John Hopkins so it's just coincidence. Surely it could have come from any individual of any ethnicity that was there. However, John Hopkins was a charity hospital and, as I mentioned earlier, one of the only hospitals in the area that accepted Black patients.

Medical research has unfortunately a long history of taking advantage of vulnerable and marginalised people. For instance, looking at Southam's research, he used prisoners. Again, a really vulnerable population.

¹ The plaintiff's name was actually John Moore.

So when we talk about Henrietta Lacks' situation, the development of HeLa cells, we really need to consider it in the context of the long history of racism in medical research, which is the next thing I'm going to talk about. So this is going to be just some of the sort of greatest hits of racism in medical research.

J. Marion Sims, regarded as the father of modern gynaecology. He developed a lot of very important surgical techniques, but he developed these by operating on enslaved Black women without anaesthesia in the 1840s. One woman he operated on 30 times.

The Tuskegee Syphilis Study I referenced earlier. For those who don't know, it was a 40 year study lasting from the 1930s to the 1970s on the progression of syphilis in 600 Black men. They didn't tell the men what their diagnosis was, in fact they told them that they were studying 'bad blood'. They didn't make any effort to prevent the spread of syphilis in the communities and they didn't offer them any treatment, even though from the 1940s it became clear that penicillin was a really effective treatment for syphilis.

Forced sterilisation. Back in the sort of, again 20s to 50s, when eugenics was viewed as a positive thing, a lot of countries had a programs which would sterilise people who were unfit. This is an example that we have, I mean a particularly stark example that we have numbers for. So over the 45 year period that the North Carolina Eugenics Board was active it oversaw sterilisations of about 7,600 women, 5,000 of whom were Black. This is despite the fact that the population of North Carolina was only 25% Black. So an extremely disproportionate number of Black women were targeted.

Clinical trials. As we all know, as I mentioned earlier, informed consent is an incredibly important part of clinical trials now. However, and this is work in the USA, there are some trials that are allowed exception from informed consent, there are certain criteria for that. And an analysis of 41 of such trials in the 2000s in the US, showed that 29% of participants were Black. The total population of America is about 13% Black and Black people have much lower rates of participation in clinical trials. In fact by ethnic group, they're the group with the lowest rate of participation. So the fact that such a disproportionate number of Black people ended up in trials that were exempt from informed consent is deeply disturbing.

So when we are considering HeLa cells, even though they were taken in a way which was considered legal and ethical at the time, we need to consider them in the context of this long history of anti-Black racism in medical research. And in some ways it's not, it's more about what they represent in this context than the fact that, well, the cells could have come from anyone, they just happened to come from a Black woman.

You might, you can definitely argue that because of the circumstances of health care in the United States and, you know, the fact of segregation, that there was only one hospital which took Black people in that area, that that meant it was much more likely that the cells would come from a Black person than anyone else.

The final ethical issue I want to talk about is Henrietta's family, the Lacks family themselves.

The Lacks family have been, one could definitely say, poorly treated by researchers. So I mentioned that HeLa cells are incredibly robust and prolific and one downside of that is that they tend to contaminate other cell lines. In fact, some estimates put it as high as 20% of cells in research labs are contaminated by HeLa cells. When researchers realised this in the 1970s, they thought a useful way

of determining and figuring out the contamination would be to get blood samples from her descendants for comparison's sake.

So they reached out to her family members. The Lacks family are very underprivileged, they didn't have good levels of scientific literacy. In fact, at the time, none of the family members really understood what a cell was but they did understand what cancer was: the disease which had taken their mother, grandmother. And so when scientists came asking for blood samples they thought that they were being tested for cancer.

They gave the blood samples and then kept calling up the hospital asking when would they get the results of their cancer tests and were brushed off by researchers. And when the family eventually learned that in some way Henrietta Lacks was still alive, her cells were still alive, again the lack of communication or the, just the level that the researchers and doctors were trying to communicate and the level that the Lacks family, where their understanding was, was so different that that gap couldn't really be bridged and that led to a lot of distress for the Lacks family.

Another thing was privacy concerns. Henrietta Lacks' full name was released on George Gey's death without consulting her family. That was in the 70s and so these cells were deanonymised and her family could then be identified.

In 2013 researchers published the whole HeLa cell genome, again without asking the family. And this, they were they were really concerned about this because, as we were saying earlier, genetic information, now that we have such an ability to understand it, can give a lot of private information about not just Henrietta Lacks but her family members.

One good result of this was.

[Someone's saying something in chat. Yeah, I'm aware that, uh, I'm definitely running over.]

One good result of the genome being published, and it was quickly retracted, was the NIH came to an agreement with the Lacks family. So since 2013 anyone who wants to use HeLa cells on an NIH grant needs to have approval from a special committee which includes two members of the Lacks family.

This is something that was quite important to them. All of this huge amount of research was being done on Henrietta Lacks' cells and her family hadn't had any input into that. So now they do have input, but it is in quite a limited way. This agreement only applies to people who are on NIH grants.

A final issue is lack of compensation. As is established in law, if Henrietta Lacks were alive and, you know, for her descendants, they are not eligible to get any compensation from research done on her cells. However, it still stands, that HeLa cells are a huge industry. And it particularly rankles, I think, because many of her descendants lack access to health care because they are poor and because of the state of the American healthcare system, many of her descendants are unable to benefit from the research that has been done on her cells, on their relative's cells.

So, apart from larger abstract issues of ethics and what is right and wrong, the Lacks family have been very personally affected by the development and use of HeLa cells.

This is the final thing I'm going to talk about, and I know that it's almost half past and if anyone needs to leave absolutely do, but I hope that people will be able to stay and have a discussion because I can't give answers about what scientists should do, but I do have a few suggestions.

First one, first possibility, use alternatives. If this was a new cell line that had been developed in this way, absolutely no one would use it. There are problems with that. HeLa cells are the gold standard in a lot of ways. And if you want your research to be directly comparable to previous research, you want to keep the variables as similar as possible. So there are good reasons why people want to keep using HeLa cells.

But there are practical reasons as well for not using them. As I mentioned, there's huge issues of contamination with HeLa cells. And another thing some researchers have brought up is the fact that, because they are so mutated, you know, having up to 80 chromosomes in some cases, how good of a model are they really?

Another thing, scientists can do is compensation. Rebecca Skloot – and I can't believe I've actually gone this far without mentioning her. She's a key figure in the narrative of Henrietta Lacks. So Rebecca Skloot published a book in 2010, *The Immortal Life of Henrietta Lacks*, that really brought this story and the story of the Lacks family to the public consciousness – she has set up a foundation, the Henrietta Lacks Foundation, which offers scholarships to Lacks' descendants. And that is one place where you can donate to. Or if your concern isn't just the specific issue of the HeLa cells, but the wider problem of racism in medical science and the lack of Black researchers, then there are many other avenues for, not just financial contributions, but also your time and effort.

Another thing is acknowledgement. This is something, again, that the Lacks family is very keen on. The fact that their mother, grandmother, great-grandmother has been so influential, has been so beneficial in so many ways to so much research, so many developments in medical science. And they really just want her acknowledged. So whether that is in papers that use her cells, description of your lab bio, or by attending and promoting education around Henrietta Lacks.

That's everything I wanted to talk about. I think that the ethical issues around Henrietta Lacks can be broken down to those three main areas: informed consent, medical racism, and the Lacks family themselves. But now, if you have time to stick around, I would really love to have a discussion about this what your feelings are, what your opinions are, so I'm going to stop the recording now.