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When are your cells no longer your own?

Cell lines from human samples have historically benefitted scientific research but continue to raise questions about consent.

This month, the family of Henrietta Lacks announced that they settled their lawsuit against Thermo Fisher Scientific over the use of her cells, which were taken and placed into cell culture following her cervical cancer biopsy in 1951 and are still used today for scientific research[1]. While it was routine at the time to culture and study biopsied cells, Henrietta Lacks did not know that her cells were unique and would come to benefit scientific and pharmacological research for years to come; the cells became known as HeLa cells. She died later that year, and her family also was unaware that, unlike many other biopsied cells taken around this time, Lacks's cells could survive indefinite cell divisions, doubling every 20–24 hours. This made them invaluable as they could be easily shared.

Because of their growth and survival benefits, HeLa cells have been used to study the effects of various drugs, hormones and toxins on the growth of cancer cells, being used in over 110,000 scientific publications. HeLa cells permit the growth of large amounts of virus, which enabled the polio[2] and COVID vaccines to be produced, and they also facilitated infectivity studies that informed the development of drugs to limit the spread of viruses such as HIV[3]. HeLa cells were taken into orbit to provide information on how human cells would react to radiation.

All of this research was done without the explicit consent of Lacks, and there have been countless ethical debates and reforms surrounding patient consent since the details of the story were published. In particular, in 2013, a team of researchers posted the genome sequence of one strain of HeLa cells online[4]. This broke no rules at the time, as deposition of genetic sequence information for large-scale studies was common, but brought up issues of privacy, since Lacks's identity in relation to the cell line was known and she had not given informed consent to have her genome sequence made public. This led to an agreement by the NIH whereby sequences of HeLa cell lines should be deposited in controlled-access databases, as is the case with other private personal genomic data. It was already becoming clear that it was possible to trace supposedly de-identified genomic data back to a single individual.

A less familiar but similar story is of the 'Mo' cell line, created from spleen cells taken from John Moore during his leukemia treatment at UCLA in 1976. His spleen was dangerously swollen, so surgeons removed it, and they then found that it contained unique blood cells that produced a type of protein that stimulated white blood cell growth. UCLA researchers developed the cells into a replicating cell line to produce the protein in large quantities. Moore filed a lawsuit asking for a share of the profits when he discovered the existence of a patent based on his cells.

Moore's case similarly involves a lack of explicit consent: although he consented to have his spleen removed, he did not consent specifically for its use to develop a drug treatment. In 1991, the Supreme Court rejected Moore's claim to any drug, saying that patients should not be able to sue over their cells, as it would cause chaos for scientists using human blood or tissues in their research[5]. No one doubted that John Moore should have been informed of the intent to use his cells for financial gains, but the court found that he did not have the right to claim that his donated cells were still his property.

Similar ethical concerns have been raised over the use of the immortalized HEK293 cells, a kidney cell line that came from an electively aborted fetus in the Netherlands around 1972. Another fetal cell line, PER.C6, was developed from fetal retinal cells about a decade later. These lines came under fire from senior Catholic leaders and antiabortion activists in the United States and Canada when they were used to help research COVID-19 vaccines[6].

What is the best way forward for human cell lines, both new and existing? Today, there are updated guidelines for informed consent, and institutional review boards to oversee and approve human studies. Concurrently, there is a rise in biobank storage of de-identified human biological material for future research. Original deposition in biobanks requires informed consent, but consent is not necessary for all future work using these samples. While some biobanks and companies do ask for broad consent covering future work, it is not usually known exactly what those studies will be or who will be doing them[7]. Ordinary blood and skin cells can today be re-engineered into other tissue types. The data contained in biobanks have the potential to produce technological platforms and drugs that will be used by industry and pharma. In these cases, if financial gain were forthcoming, who would deserve the profits?

As for the cell lines that already exist, such as HeLa and HEK293, should they be removed from future research? We do have the technology to develop new cell lines, ones that have received consent to broad use or are generated from animal models instead of human. Such new cell lines, however, would require considerable time and effort to generate new protocols for their use.

Moving forward, biobanks should ensure that consent statements are clearly made and that patients depositing samples are aware that they are relinquishing their rights to future profits, or they should implement methods to contact patients for additional consent about the future use of their biospecimens. Scientists, for their part, should try to discover and work with new immortalized cell lines that have gone through updated ethics procedures. And we should continue to remember the groundbreaking work that has been done in HeLa cells over the last 70 years – and where the cells came from.

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