

Case study 1

Open data in genome research

SOURCE: Callaway, E. (2013). HeLa publication brews bioethical storm. *Nature*, 1, 12689. <https://doi.org/10.1038/nature.2013.12689>

HeLa cell line is the first immortalized human cell line that is derived from the cancer cells of African American woman Henrietta Lacks (1920-1951). The cells were obtained during Lacks's treatment in 1951. It was done without her informed consent, in line with the practice that existed at that time. Neither Henrietta Lacks nor her family members were informed about the collection of cells and their use in research. The Lacks family was not aware of the cell line's existence until 1975.

In 2013, Lars Steinmetz and his group at the European Molecular Biology Laboratory in Heidelberg sequenced and published the genome of the HeLa cell line in open access. Steinmetz and his colleagues saw it as a helpful resource for their own research and for the countless other scientists studying the cell line. On the other hand, the descendants of Henrietta Lacks and many bioethicists criticized the decision to publish the genome. They pointed out that the cells were acquired without informed consent and publishing of the genome of HeLa cells may provide information about some genetic traits of surviving family members.

In reaction to the objections, Steinmetz removed the genomic data from public databases. "We were surprised, we did not expect this to happen at all," he said. "We wanted to respect the wishes of the family, and we didn't intend to cause them any anxiety by the publication of our research."

Questions for discussion:

- 1) What was wrong with the publishing of HeLa genome? Are there any conditions on which it would be right to publish the genome of the HeLa cell line? If yes, then under what conditions?
- 2) In many ways HeLa cells present a unique problem, because the donors of most other human cell lines are anonymous, but in the case of HeLa many people know that HeLa is derived from the cells of Henrietta Lacks. However, recent work has shown, that anonymized participants in large genomics projects can be identified by cross-referencing their genomes with genealogy databases. If that is the case, how worried we should be about the privacy of donors who have donated samples for other cell lines? What implications does that have for sharing genomic data of other cell lines?

Case study 2

Publication of clinical case in open access journal

SOURCE: Retraction Watch (2016). Family decries publication of child's picture in open access journal. <https://retractionwatch.com/2016/11/07/family-decries-publication-of-childs-picture-in-open-access-journal/>

In 2012 the *Indian Journal of Dermatology, Venerology and Leprology* published a paper "Delleman syndrome: Report of a case in an adolescent boy" detailing a 14-year-old boy's case. The syndrome causes cysts and malformations in the eyes, brain, and skin. The report included the boy's photo, initially with parental consent, but it was retracted later as the parents realized the open access nature of the paper.

According to Mabel Nocito who is the first and corresponding author, the parents gave oral informed consent, and it was a legally sound approach at the time: "Up until 2014 the Argentinian law allowed free publication of portrait images for scientific purposes which is no longer the case. An oral permission was enough." At the same time, Nocito explained that the parents "did not understand fully what the term open access journal meant and even as the article was written in 2011, nowadays there's a more generalized possibility of linking, liking and sharing images in different social media." Consequently, the paper was retracted. Reflecting on the consequences of the retraction, Nocito pointed out: "In the case of rare syndromes like Delleman, where case reports are the way to find out more about the disease, it is a setback but more and more we need to consider the patient's rights and feelings towards their conditions."

Questions for discussion:

- 1) Please, explain, what is at stake in this case. What are the costs and benefits of retracting and not retracting the paper?
- 2) It is mentioned in the case description, that the parents did not understand, what the term 'open access' meant and that their decision to withdraw the consent for publishing the picture was motivated by their realization that the picture is freely available. How should researchers explain open access of data or publications to research participants?
- 3) What (if anything) can be done to avoid the problem depicted in the case description?