

Case study 1

Privacy in genomic research

From: Callaway, E. HeLa publication brews bioethical storm. Nature (2013).
<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 from Lacks's treatment without her consent, according to the practice that existed then. Neither Lacks nor her family members were compensated for the extractions of the cells or their use in research. The Lacks's family was not made aware of the line's existence until 1975. In 2013, Lars Steinmetz and his group in at the European Molecular Biology Laboratory in Heidelberg published the genome of the HeLa cell line. Steinmetz and his colleagues saw it as a helpful resource for their own research and for the countless other scientists studying the cell line. The descendants of Henrietta Lacks and many bioethicists on the other hand criticized the decision. They pointed out that the cells were acquired without consent and publishing of the genome may disclose genetic traits borne by surviving family members.

In reaction to the objections, Steinmetz removed the data from public databases. We were surprised, we did not expect this to happen at all," Steinmetz says. "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. Please, explain, what is wrong with Steinmetz's publishing of the data? 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 dilemma - 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 anonymity of other cell line genomes? What implications does that have for sharing genomic data of other cell lines?

Case study 2

Publication of clinical case in open access journal

From “Family decries publication of child’s picture in open access journal”, Retraction Watch. <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 (IJDVL)* published a paper “Delleman syndrome: Report of a case in an adolescent boy”. The paper described a case of a 14 years old boy with Delleman syndrome, a condition that often results in the development of cysts within the cavities of the skull, leading to malformations in the eyes, brain, and skin. The paper also included the boy’s picture. The picture was published with the consent of the boy’s parents. However, as the parents realised that the paper was freely accessible, they withdrew their consent. According to Mabel Nocito the study’s first and corresponding author, 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.” As a consequence, the paper was retracted. Nocito pointed out that “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? Can you add anything to the concerns mentioned by the author of the study?
2. It is mentioned in the case description, that the parents did not understand, what the term open access journal meant and that their decision to withdraw the consent for publishing the picture was motivated by their realization that the picture will be freely available. Is this problem faced by the researchers inherent in the concept of open access? Would it make any difference if the paper would be published behind the paywall? What (if anything) can be done to avoid the problem depicted in the case description?