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Case - HeLa Cells

Description

A case study that is part of unit 7 of the Course on Genomics, Ethics and Society. This case provides a synopsis of the case of Henretta Lacks and and issues of intellectual property and consent around the use of genetic material for research.

Body

Many scientists and doctors have claimed that the biggest challenge to using genomic data for advanced medical therapy and research is limited access to genetic information (Kohane, 2011; Presidential Commission for the Study of Bioethics, 2012). Accurate diagnosis and treatment of diseases requires tremendous amounts of data, especially for rare cases. Ready access to this information also allows for quicker diagnoses (e.g., days instead of weeks), which can mean the difference between life and death for some patients.

However, many experts have argued that current management of genetic information puts privacy at risk, and have thus advocated for greater limitations on access to genetic information (Ahmed, 2013; Gutmann & Wagner, 2013; Presidential Commission for the Study of Bioethics, 2012). Though genetic data can provide many benefits, both for individuals whose data it is and for public health, the release of genetic information can also cause great harm. For example, revealing genetic evidence for the presence of mental illness could lead to social stigma or cause psychological harm. It could also be used against individuals in legal contexts, such as custody battles. This is especially worrisome given how easy it is to obtain a sample for DNA testing (e.g., from a toothbrush).

Another cause for concern is that learning about an individual's genome also reveals information about family members, many who will not have offered consent for their data to be revealed. Genetic information can be used to make diagnoses, to assign medications, and to identify potential risks based on demographic information. But some people might not want to know these things about themselves, and consent from one family member does not constitute consent for all.

Nonetheless, many doctors and researchers have argued that gene research and therapy cannot be successful without changing the way we manage privacy and consent (Green et al., 2011; Jensen, Jensen, & Brunak, 2012; Kohane, 2011). One major issue is the lack of accessibility for different databases and connection between databases. Many patients' data are released only to specific databases and for specific purposes, a practice that is thought to protect privacy (Presidential Commission for the Study of Bioethics, 2012). For instance, a bill being considered in California would require researchers to request permission for each different study or potentially to discard genetic data after it has been used for its specified purpose (Shen, 2012). However, this seriously limits the use of genetic information for therapy and research. Since patients' data is usually anonymized, they cannot be contacted again in the future in order to obtain consent for additional research, nor can their previous results be compared to later results.

Another problem is the lack of standardized consent that would make participation in genetic studies easier. The default format, particularly in the U.S., is for patients to "opt-in" to genetic research programs in order for their genetic data to be retained. This usually results in decreased participation, compared to a default where patients must opt-out in order to have their data excluded. Opt-in defaults are also used in order for patients to have their data marked with identifiable information, so doctors and researchers can track them over time. Anonymizing data ensures a level of privacy, but some argue that patients should be encouraged more strongly to consider making they and their data identifiable for future research.

Currently, in the U.S., the Genetic Information Nondiscrimination Act of 2008 (GINA) is the primary federal legislation in place to protect against the misuse of genetic testing (Presidential Commission for the Study of Bioethics, 2012). However, GINA primarily prohibits discrimination in the context of employment and health insurance based on the results of genetic tests. It does not provide any protection against violations of privacy, nor does it prescribe rules for obtaining consent for genetic research. The Presidential Commission for the Study of Bioethics has argued that

what is needed are restrictions that go beyond GINA, and ensure privacy, but do so while still facilitating good research.

Consider the case of Henrietta Lacks (“Privacy and protection,” 2013; Skloot, 2013). In 1951, she was diagnosed with cervical cancer and died soon after. However, cells from her tumor were taken and stored, without her or her family’s consent, and subsequently became the source for numerous scientific studies, including various cancer medications. Recently, her genetic information—based on what are now known as HeLa cells—was made widely available and partially released to the public. Lacks’ family objected to this as an invasion of privacy and the National Institute of Health (NIH) assigned a task force to protect and limit access to HeLa cell information.

- ***Imagine you are a member of the NIH task force. What level of access would you allow for researchers and doctors wishing to use the HeLa genome? Would you anonymize this data for future studies? You are told that any recommendations you make will be applied to other cases of access to genetic data. What general recommendations would you make, given some commitment (you can argue about how much) to the goals both of allowing for progress in genomic medical research, and for protecting the privacy of individuals' genomic data?***

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