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Description

This case discusses issues of research subjects' informed and voluntary consent, specifically whether participants must be recontacted and provide a second consent specific to the new study or whether the case author simply assumes that is an implication of the previously stated elements of the agreement.

Body

Jim is a graduate student in the department of genetics. For his thesis research, he is mapping a gene involved in blood sugar homeostasis. His work is part of a larger multi-center study of the genetics of obesity. The larger study involves several thousand patients and includes information such as socioeconomic class, self-identified ethnicity, activity level, weight and other medical data. Blood and DNA samples are maintained in Jim's lab along with a database that links unique identifiers -- but not patient names -- with the data. The study coordinator at each site has access to the encryption key; however, the students and other researchers working on the project do not. Researchers may use the database to retrieve and enter data pertaining to the samples, but they cannot learn the identity of the individuals in the study.

The subjects/patients involved in the study were recruited at various study sites. On first contact with a potential participant, a genetic counselor explains the study and arranges for a meeting to begin the informed consent process. During this meeting,

participants learn about the aims of the project, their role as subjects, and the risks and benefits involved in participation. The consent forms state that blood and DNA samples and the resulting data will be anonymized, that subjects may withdraw at any time and that samples will be used exclusively for this study. If their samples are to be used in unrelated research, the individual participants must be recontacted and go through a second consent process, specific to the new study.

Jim's project involves a subset of several hundred samples from the obesity study. One day, Renee, one of the other graduate students in the lab, approaches Jim and starts asking questions about the samples he's working with. She explains that for her work on sickle cell anemia and mutations in a hemoglobin gene in African Americans, she needs 50 ethnicity-matched control samples. Since Jim has access to such a large collection of samples, Renee asks if she can take small aliquots of some of his samples from the obesity study. She tells Jim that she will not be looking at disease in these patients, or really doing a "study" on them; she just needs them as controls, and she doesn't even need that much DNA. "Which box are they in?" Renee asks, as she heads for the freezer.

Renee was standing at the freezer with the door open when Jim said, "I'd be happy to tell you more about our samples, Renee, but you had better talk to Jane, the study coordinator, about getting consent from the obesity study participants if you really want to use them for your study. Another option," he suggested, "which might be faster, is to just order a set of anonymous samples from a commercial DNA bank. It would really be a pain to recontact all of those people just for a set of controls."

Discussion Questions

1. As Renee said, she does not intend to really "study" the obesity samples; she just needs ethnicity-matched anonymous controls for her work. Should the aim of her study affect Jim's response?
2. Does the fact that she and Jim are in the same lab make a difference?
3. If the consent forms were not explicit regarding the use of samples, would that change Jim's responsibilities?
4. If you were the study coordinator, and Renee approached you about using these samples, what would you do?

Notes

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Contributor(s)

Brian Schrag

Editor(s)

Brian Schrag

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