Author's Commentary on "Share and Share Alike?"

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In very large, multi-center studies, where the researchers have no contact with the participants, but rather only with their tissue or DNA, it can be easy to forget that "samples" come from individuals with everyday lives just like their own. These individuals have given consent for the use of their samples by specific people and in specific experiments, and they may have thought very carefully about what they do and do not want done with their samples and by whom. A researcher cannot -- and may not -- assume that the consent applies to anything except the uses explicitly described in the IRB-approved consent document. Researchers must always try to put themselves in participants' shoes and ask how they would feel if someone took such a cavalier attitude toward something so very personal as their tissue sample or genetic information. Genetic information is one of the most personal pieces of data about any individual, and it must not be treated lightly. Furthermore, researchers have a responsibility to the scientific community to treat subjects and their samples with respect to avoid harming the interests and goals of the broader community by generating mistrust of researchers and their aims and souring the public's attitude toward science.

Some scientists view consent forms and institutional review boards (IRBs) as procedural hurdles to be surmounted -- hoops to be jumped through -- rather than legitimate and necessary protections for research study participants. It is important to be aware of the origin of these protections, prompted by the Nuremberg trials, the Tuskegee syphilis study and a host of other egregious breaches of trust perpetrated by members of the scientific community. Renee's intended use of the samples is relevant only in terms of the wording of the consent: If the intended use does not fall within the definitions laid out in the consent form, then it is impermissible unless new consent is sought from the study participants. Finally, anonymous control DNAs can be purchased from commercial repositories for about

$50 per sample, making this a feasible alternative for most labs.

References

- Jones, James H. *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press, 1993.
- *The Nuremberg Code*. http://ohsr.od.nih.gov/nuremberg.php3.