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Experts Call For Federal Regulation Of Genetic Ancestry Testing

ScienceDaily (July 3, 2009) — Imagine donating a sample of your DNA to help researchers study the genetics of diabetes. The disease is common among your friends and family, and you're proud of your role in finding out why. Now, imagine that some time later, you learn that your DNA has been used for other studies on topics you never expected — schizophrenia, human migration, inbreeding. Although your name isn't attached to the sample anymore, scientists are using your DNA to draw conclusions about your community and your ancestors. Some of these studies violate your cultural beliefs.

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That's what happened to the Havasupai Tribe of Arizona. In 2004, they sued Arizona State University, the institution that originally collected the DNA, for failing to provide ethical oversight on the use of the samples. The case is still working its way through the courts.

The lack of federal regulation in this and other instances of DNA use will be addressed in the Policy Forum section in the July 3 issue of Science by Sandra Soo-Jin Lee, PhD, of the Stanford Center for Biomedical Ethics, and colleagues from four other universities. The need for a clear set of rules governing genetic ancestry testing is becoming more urgent, Lee said, given the proliferation of private corporations that promise consumers insight into their genetic origins.

"Direct-to-consumer genetic ancestry tests fall into an unregulated no-man's land," Lee and her colleagues wrote, "with little oversight and few industry guidelines to ensure the quality, validity and interpretation of information sold."

Genetic ancestry tests, which can cost just a few hundred dollars and require only a simple cheek swab, are gaining popularity among genealogy hobbyists and curiosity-seekers. But without clear rules and regulations, consumers may not be getting what they were promised. (Lee wrote specifically about the challenges posed by the direct-to-consumer genetic testing industry in the June 5 issue of *The American Journal of Bioethics*.)

In this new piece, Lee and her co-authors respond to recent testing guidelines issued by the American Society of Human Genetics to discuss more broadly how policies that govern ancestry testing, including genetics research, are insufficient. While the federal Office of Human Research Protections requires researchers to obtain consent from donors of DNA, the rules aren't clear about how scientists can then use these samples. In the Havasupai case, for instance, samples weren't tagged with individuals' names, so scientists believed they were free to use them for later studies. The problem is that, because scientists can now identify the ancestry behind the DNA, such samples can be used to draw conclusions about small, possibly vulnerable groups of people.

According to Lee and her colleagues, developing a set of rules is challenging because of the diverse interests of the different groups involved in genetic testing: for-profit companies, academic scientists, casual consumers, Native American tribes and specific ethnic or racial subsets of the population. Oftentimes, conversations among these players can be muddled by unclear terminology and disagreements about the nature of concepts such as "origin." To geneticists, that word might conjure visions of genetic markers, the authors wrote. But to Native Americans, "origin" might mean a location or landscape important to the tribe's cultural identity.

To bring the sides together, the authors call for stronger federal oversight. "We encourage regulatory agencies such as the Federal Trade Commission, the Food and Drug Administration, and the Centers for Disease Control to help set industry standards for responsible and accountable practices in genetic ancestry testing," said co-author Kimberly TallBear, PhD, assistant professor of science, technology and environmental policy at UC-Berkeley. Such leadership will be necessary, the authors wrote. In managing conflicts between groups that have

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