

Bioethicists call for federal regulation of genetic ancestry testing

July 2 2009, By Yasmin Anwar

(PhysOrg.com) -- As the popularity of take-home DNA kits to trace ancestry or calculate the risk for serious medical conditions grows, there is an increasingly critical need for federal oversight of "direct-to-consumer" genetic testing, as well as of the use of DNA samples for research, according to researchers from the University of California, Berkeley, and several other academic institutions.

In the past year, scientists, sociologists and bioethicists, among others, have come to agree that the technology of these direct-to-consumer tests, which run between \$100 and \$1,000 apiece, is problematic and that the test results can be misleading and lead to problems including skewed ethnic data and questionable membership claims to Native American tribes.

But while organizations such as the American Society of Human Genetics have issued guidelines to curb the unintended consequences and misuses of DNA testing, federal agencies need to step in and help shape a "gold standard" in genetic ancestry testing, according to a policy paper published in the July 3 issue of the [journal Science](#) and coauthored by researchers from UC Berkeley, Stanford University, the University of Texas, University of Wisconsin and New York University.

"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 coauthor

Kimberly TallBear, assistant professor of science, technology and environmental policy at UC Berkeley.

The article in Science is a direct response to the American Society of Human Genetics guidelines, which recommend increased accountability, transparency and collaboration among consumers, scientists and the companies selling take-home genetic ancestry kits.

"We take the position that overcoming the most difficult ethical challenges of genetic ancestry testing will depend on the political will of federal agencies to prioritize values of transparency, responsibility and communication," said Sandra Soo-Jin Lee, a medical anthropologist at the Center for Biomedical Ethics at Stanford University and lead author of the policy paper.

Lee and other authors argue that voluntary collaboration and transparency are unlikely to succeed because of the proprietary nature of companies' and institutions' genetic databases; the power disparity between scientists and their research subjects; and the diverse and possibly conflicting interests of stakeholders who don't even share a common language. For example, TallBear said, "Whose definition of 'origin' will prevail?"

"To a geneticist, origin might refer to ancestral populations inferred for an individual on the basis of specific genetic markers, specific algorithms for assessing genetic similarity and specific reference populations," the article says. "To a casual consumer, 'origin' might mean 'the country where I was born' ... to a Native American, origin might also signify the landscape feature or event where his/her people emerged or acquired their identity."

According to news reports, a half million consumers have purchased genetic ancestry tests, which are sold by more than two dozen personal

genomics companies with names such as "Roots for Real," "23andMe" and "DNA Tribes." Typically, the test taker swipes the saliva inside his or her cheek and sends the swab to the lab. The DNA is extracted and compared to samples from a reference database of haplotypes (sets of inherited, linked genetic markers) to see if there's a match.

Different tests use different methods. For example, mitochondrial DNA tests trace the mother's lineage, while Y-chromosome tests track paternal ancestry. But because these tests only trace one bloodline, they exclude most ancestors. Moreover, they cannot pinpoint where these ancestors lived.

Another option is AncestryByDNA, a genealogy test that relies on markers that show genetic differences between what are assumed to be four biologically distinct populations: Africans, Europeans, East Asians and Native Americans. But some groups that don't fit neatly into these categories, such as South Asians and Middle Easterners, have received test results identifying them as Native Americans, for example, according to researchers.

Also critical to resolve, according to the article, are the ethical issues concerning the collection and use of DNA samples. For example, members of the Havasupai Tribe in Arizona allege that researchers from Arizona State University and the University of Arizona collected 400 blood samples from tribal members for diabetes research. But, according to news reports, those same samples were also used for unauthorized research on schizophrenia, [inbreeding](#), and population migration, which stigmatize tribe members. The Arizona Court of Appeals ruled late last year that the Havasupai tribe can sue the Arizona Board of Regents, which is seeking to settle the case.

"It is a scientific imperative that we enact enforceable policies that determine what constitutes responsible and accountable collection and

secondary use of [DNA samples](#)," the article says.

In addition to Lee and TallBear, coauthors of the article are Troy Duster, professor of sociology at UC Berkeley and New York University; Deborah Bolnick, assistant professor of anthropology at the University of Texas; and Pilar Ossorio, associate professor of law and bioethics at the University of Wisconsin Law School.

Provided by University of California - Berkeley ([news](#) : [web](#))

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