

# Bioethics panel urges more gene privacy protection

October 11 2012, by Lauran Neergaard

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In this image provided by the National Human Genome Research Institute, a NHGRI researcher monitors a DNA sequencing machine at the NIH in Bethesda, Md. A presidential commission says new protections to ensure the privacy of people's genetic information are critical if the nation is to realize the enormous medical potential of gene-mapping. (AP Photo/National Human Genome Research Institute, Maggie Bartlett)

It sounds like a scene from a TV show: Someone sends a discarded coffee cup to a laboratory where the unwitting drinker's DNA is decoded, predicting what diseases lurk in his or her future.

A presidential commission found that's legally possible in about half the states - and says new protections to ensure the privacy of people's [genetic information](#) are critical if the nation is to realize the enormous medical potential of gene-mapping.

Such whole [genome sequencing](#) costs too much now for that extreme coffee-cup scenario to be likely. But the report being released Thursday says the price is dropping so rapidly that the technology could become common in doctors' offices very soon - and there are lots of [ethical issues](#) surrounding how, when and with whom the results may be shared.

Without [public trust](#), people may not be as willing to allow scientists to study their genetic information, key to learning to better fight disease, the report warns.

"If this issue is left unaddressed, we could all feel the effects," said Dr. Amy Gutmann, who chairs the Presidential Commission for the Study of [Bioethical Issues](#).

Mapping entire genomes now is done primarily for research, as scientists piece together which [genetic mutations](#) play a role in various diseases. It's different than getting a lab test to see if you carry, say, a single gene known to cause [breast cancer](#).

Gutmann said her commission investigated ahead of an anticipated boom in [genome](#) sequencing as the price drops from thousands today to about \$1,000, cheaper than running a few individual gene tests.

The sheer amount of information in a whole genome increases the [privacy concerns](#). For example, people may have their genomes sequenced to study one disease that runs in the family, only to learn they're also at risk for something else - with implications for relatives who may not have wanted to know.

Thursday's report shows a patchwork of protection. A 2008 federal law prohibits employers or health insurers from discriminating on the basis of genetic information, so that people don't put off a potentially important gene test for fear of losing their job or health coverage. But

that law doesn't prevent denial of life insurance or long-term care insurance. Plus, there's little oversight of how securely genetic information is stored electronically, the report found.

Then there's the question of surreptitiously ordering genome screening from a private lab, such as during a nasty custody battle. The report didn't say that's ever happened, just that it could, and found no overarching federal or industry guidelines on how commercial testing companies should operate.

"It is not a fantasy to think about how, in the future, without clear baseline privacy protections people could use this in ways that are really detrimental," Gutmann said.

Among the commission's recommendations:

- Governments should prohibit genome sequencing without the consent of the person from whom the sample came, as part of a minimum, consistent privacy standard for every state.

- Health authorities should establish clear policies defining, in research and clinical settings, who can access someone's genomic data, allowing individuals to share it as they see fit while guarding against misuse.

- Consent forms for people enrolling in research studies should make clear how their data might be used now and in the future. Also, researchers should make clear if participants will be told about all the known disease risks spotted in their genome, including those not being expressly studied.

The Department of Health and Human Services, which oversees genetic research, called privacy an important issue and said officials looked forward to evaluating the recommendations.

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Citation: Bioethics panel urges more gene privacy protection (2012, October 11) retrieved 19 April 2024 from <https://medicalxpress.com/news/2012-10-bioethics-panel-urges-gene-privacy.html>

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