

ASHG asserts core genetic data privacy principles for all research and funding arenas

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The American Society of Human Genetics (ASHG) today affirmed the crucial role of genetic and genomic data sharing to advance medicine and health research, and asserted core principles about privacy protections that should apply to all human genetics and genomics research regardless of funding source. The Society's views appear today in *The American Journal of Human Genetics (AJHG)*.

Genetic and [genomic data](#) from research participants is helping scientists better understand the health of individuals and populations, and this new knowledge drives improved diagnosis and treatments as well as growing insight into our shared human origins. Biobanks and other growing research resources with shared data enable researchers to work at larger scale and could enable more accurate understanding of the genetic and genomic underpinnings of disease.

"To sustain these advances, it is essential to encourage broad public participation, continue research investments, and promote [privacy protections](#)," the Society stated. To realize the benefits of genetics and genomics research, the field must pursue strategies for the use and sharing of data sets and the need to protect [confidential information](#), they explained.

The Perspective comes at a time of broad global discussions about consumer data [privacy](#), and many countries are considering new broad

citizen privacy protections. Given this context, ASHG's position urges recognition of important protections already in place for federally funded research and the field's commitment to those protections. Yet it also notes that, within the United States, many genetic privacy laws apply only to federally funded research. Increasingly, researchers in the genetics and genomics community—both in academia and industry—recognize the potentially useful role of data generated by entities that are not federally funded to pursue shared health goals.

The statement outlines current laws protecting participant privacy covering federally funded research in the U.S. Most genetics and genomics research is federally funded, and is thus subject to these laws. Yet as an increasing number of private entities join the field and work directly with consumers, those research participants may not have the same privacy protections.

"Where there is appropriate consent and oversight, consumer data collected by private testing services can be a valuable resource for genetic and genomic research," the Society noted. "ASHG encourages opportunities to engage with consumer genomics companies developing customer privacy policies related to their research."

The statement articulates five essential privacy principles that the Society believes should apply to all genetics and genomics research, whether publicly or privately funded:

Individuals should have a right to maintain the confidentiality of their own genetic information and should not be compelled to disclose it.

Entities holding human genomic data must take robust measures to protect the confidentiality of individuals' medical and genetic information.

Decisions about privacy protections and data-sharing practices should be based upon an assessment of risks and benefits for both the participants and for society.

When establishing policies and practices, it is important to consider when [genetic information](#) should be treated like other health data and when it should be treated differently.

Research policies should both facilitate data-sharing and protect confidentiality in a way that both advances research and respects participants' preferences.

Looking forward, the Society will continue to engage with policymakers on measures that encourage research participation and help to advance genetics and genomics research; as well as work to ensure that new, broad data privacy policies applied outside of the research arena do not negatively affect research and medicine.

More information: American Society of Human Genetics (2019 Sept 5). ASHG Perspective: Advancing Research and Privacy: Achievements, Challenges, and Core Principles. *The American Journal of Human Genetics*. [DOI: 10.1016/j.ajhg.2019.08.005](https://doi.org/10.1016/j.ajhg.2019.08.005).

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