

April 4, 2025

The Honorable Brett Guthrie
House Committee on Energy and Commerce
United States House of Representatives
2161 Rayburn House Office Building
Washington, DC 20515

The Honorable John Joyce
House Committee on Energy and Commerce
United States House of Representatives
2102 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Guthrie and Vice Chairman Joyce,

The American Society of Human Genetics (ASHG) appreciates the opportunity to comment on your request for information related to considerations for the data privacy working group's priorities and next efforts. ASHG is the world's largest professional society dedicated to advancing genetics and genomics research, supporting a community of 8,000 members representing all areas of research and application in human genetics who share the common goal of encouraging people everywhere to realize the full potential and benefits of human genetics and genomics.

First and foremost, ASHG would like to thank you for your long-standing support for the larger biomedical research enterprise through your role on the House Energy and Commerce Committee. Now more than ever, the American people are benefiting from new genomic applications that are improving health, saving lives, and contributing to the U.S. economy. Genomic knowledge is transforming all aspects of biomedical research, from cancer to heart and lung disease, early child development, rare diseases, Alzheimer's disease, mental health, and more. The genetics and genomics research community is a leader in the use and stewardship of large-scale data to advance scientific knowledge and improve health. As such, ASHG recognizes the need for strong data privacy protections while ensuring continued scientific progress, and suggests that any federal data privacy and security framework should allow for continued global scientific collaboration while also establishing clear consent processes, implementing strong security measures, promoting transparency, ensuring data minimization, and developing rigorous data-sharing agreements.

Advancing Research, Data Privacy & Security

To serve the American people, it is vital that the nation prioritize both robust medical progress and national security goals and ensure that they co-exist and advance as top priorities. While data privacy is essential to national security, it is key to note that the sharing of human genetic data is vital to the advancement of biomedical research and lifesaving treatments and discoveries. Thus, there is a need for

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clear legislative frameworks that appropriately balance security with the advancement of scientific knowledge. ASHG has been engaged in national security discussions around genomic data for many years, [urging collaboration](#) between scientific and security experts in past statements, including in a 2022 [letter](#) to House and Senate leadership during consideration of the United States Innovation and Competition Act of 2021 (USICA). In 2022, ASHG 2021 President Gail Jarvik, MD, PhD, presented at the National Institute of Standards and Technology (NIST) National Cybersecurity Center of Excellence (NCCoE) virtual workshop on the Cybersecurity of Genomic Data. Dr. Jarvik spoke on the importance of broad data-sharing in conjunction with data privacy protections in order to continue scientific advancement and progress, and highlighted the importance of collaboration between scientists and national security experts to address any national security concerns arising from human genome research to ensure that new national security measures do not stall biomedical advances.

Privacy Policies, Principles, & Protections

To sustain biomedical research advances, the research community must encourage broad public participation in research, continue research investments, and promote privacy protections. Consumer privacy policies should clearly outline specific research exemptions and avoid unnecessary or duplicative regulations that slow discovery. As more genetic and genomic research is conducted in the private sector with privately collected data, ASHG [urges](#) collective recognition of, and action on, core principles that support privacy protections in both the publicly and privately funded research spheres and the potential value of harmonizing such regulations to advance research. To this end, ASHG recommends:

1. The establishment of clear consent processes
2. The implementation of robust data security measures
3. The promotion of transparency and accountability
4. Data minimization, collecting only as much data as is necessary and relevant for specific research purposes to minimize risks of data breaches and misuse
5. The development of clear data sharing agreements, including definitive guidelines on access, usage, and protection, prior to any project

As with most research fields today, large-scale data analysis is essential to advance genomic discoveries and, as with most medical information, these data must have strong protections. Not-for-profit organizations like the [Global Alliance for Genomics and Health](#) (GA4GH) have set standards and frameworks through which to expand genomic data use within a human rights framework standards that protect the privacy of genetic and personal data while allowing for the sharing of data for beneficial scientific and health purposes.

Furthermore, ASHG urges this working group to work alongside the National Institutes of Health (NIH) and other agencies to develop de-identification policies that ensure privacy for individuals while enabling all necessary scientific insight. For example, ASHG believes removal of Health Insurance Portability and Accountability Act (“HIPAA”) identifiers is important to protect research participant privacy. However, the inclusion of select HIPAA identifiers may enable further scientific insight without significantly

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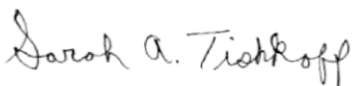
increasing the risk of re-identification. We therefore think there is value in developing alternatives to de-identification policies in conjunction with NIH while taking into account the need to consider the greater risks of re-identification for individuals within particular populations or in certain circumstances, such as within lower population-dense regions or within or near tribal reservations/land.

Global Participation in Biomedical Research

International collaboration is vital for people everywhere to realize the benefits from human genetics research. Genomics is a multinational, information-based enterprise with valued academic and industry research leadership worldwide. This includes clinical trials and research studies conducted by pharmaceutical companies and universities across the globe, which may need to report adverse events or return results to participants in countries of concern. Participation in and use of global datasets accelerates discoveries, and this broad participation helps us gain a more complete understanding of the genetics of health and disease, which can be used to develop more accurate diagnostic tests, improve treatment efficacy, and overall enhance personalized medicine. Successful international collaboration relies on scientists' common agreement on, and consistent adherence to, foundational ethical standards for public participation in research. As such, it is vital for any new data-sharing frameworks developed by this group to enable ethical cross-border research while safeguarding individual privacy.

Thanks to your leadership, Congress now has the opportunity to identify key data privacy concerns and address them in a way that bolsters collaboration and reduces any potential harm. We appreciate your ongoing support for biomedical research and data privacy, and the opportunity to respond to your request for information. We welcome the opportunity to work with you and your staff as you further consider ways to develop the working group's priorities. Please feel free to contact Karina Miller (kmiller@ashg.org) with any questions.

Sincerely,



Sarah Tishkoff, Ph.D.

President, American Society of Human Genetics