Regeneron Genetics Center (RGC) Data Privacy Statement



Regeneron Genetics Center (RGC) is committed to respecting every individual's privacy by protecting and properly handling the personal data with which we are entrusted. We strive to maintain the trust of our employees, collaborators research participants, and vendors. This is especially important as we believe that human genetics provides an unparalleled resource for understanding the underlying biology and the mechanisms that cause and prevent disease. RGC works with health systems, academic institutions, and biobanks ("collaborators") around the world, who provide de-identified biological samples for research use, together with the de-identified health data. RGC maintains this data for continued research, and protects it in accordance with global data privacy laws to prevent any inappropriate use or re-identification of the research participant. As part of our work to advance the global scientific understanding of the genetics of human health and wellness, we take our responsibility as ethical stewards of personal data very seriously. It is our mission to advance science and research while also engaging in the responsible handling of personal data. Just as the Regeneron Data Privacy Philosophy enumerates: we believe in being transparent, acting with integrity, and safeguarding the data we handle.

1 Doing what's right.

The research conducted at RGC starts with people who volunteer and trust that all entities utilizing their data in the research continuum are trustworthy and will preserve their data privacy. The data at RGC originates from our collaborators, who engage volunteers to become study participants. RGC establishes agreements with these collaborators that require compliance with applicable data protection laws and RGC takes affirmative steps to ensure that appropriate consent or other legal mechanisms are in place to permit the intended sharing and use by RGC. RGC understands that it is a privilege to receive and be able to conduct important science with the valuable personal data and associated materials provided by the study participant.

2 Acting with integrity.

Acting with integrity and respecting the contributions and actions of our team, our collaborators and the study participants is fundamental to RGC's activities. We engage with each of our collaborators in good faith, with transparency and with a commitment to good ethical behavior. The research we pursue follows industry practices within the fields of life sciences and medical research. Ethical research practice includes privacy compliance by ensuring the individual's privacy is protected throughout the research process. RGC takes responsibility of personal data seriously. We are dedicated to using transparent and up-to-date practices for utilizing personal data in research.

Oata protected is data respected.

We are committed to acting responsibly and safeguarding the data with which we are entrusted. This requires protecting personal data throughout its lifecycle in alignment with industry standards. To prevent unauthorized access to personal data, we use robust authentication measures, oversee access and use, employ data encryption, limit storage to secure environments, and utilize secure data erasure and destruction measures. We also obligate our vendors to process personal data with similar protections.

How do we protect an individual's personal data?



RGC uses technical, physical and administrative controls to guard against unauthorized access to, or disclosure of, personal data. Our team regularly reviews and improves our security practices to help ensure the integrity of our systems and personal data. In fact, we have dedicated staff for Data Privacy and Information Security.



RGC maintains human samples, genetic data, and de-identified health data on individual study participants in a secure environment. Any attempt to re-identify a data subject is prohibited.



We conduct third party risk assessments and other due diligence with our vendors and collaborators to verify that their processes and practices comply with applicable data privacy laws and ethical guidelines.