



DATE: May 14, 2025

TO: Taunton Paine, MA
Director, Division of Scientific Data Sharing Policy
Office of Science Policy, NIH

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: "Genetic Testing Registry (Office of the Director)"

The purpose of the Genetic Testing Registry (GTR) is to provide detailed information about the availability and scientific basis of genetic tests in a centralized resource as well as to facilitate data sharing for research and new scientific discoveries. The GTR provides information about clinical and research tests for heritable variants, biochemical and pharmacogenomic tests, tests for somatic variants, and tests for chromosomal aberrations and copy number variants as well as information about the laboratory offering the test, such as contact information and credentials of the laboratory (e.g., certification and licensure). Test information includes the purpose of the test and its limitations, whether it is a clinical or research test, the test methodology and analytes that are interrogated, performance characteristics such as analytic validity and clinical validity, information on clinical utility, and whether manufactured tests have been cleared or approved by the Food and Drug Administration.

The GTR collects the following personally identifiable information (PII): name, email addresses, phone numbers, and mailing addresses. I have determined that the Privacy Act does apply based on the system retrieving information about users by a unique identifier.

The following Privacy Act System of Records Notice covers this collection and use of the PII:

- 09-25-0200, Clinical, Basic, and Population-based Research Studies of the National Institutes of Health (NIH)

If you have questions, please contact me at (301) 402-6469.

Dustin Close
NIH Privacy Act Officer