

Privacy Notice

This privacy notice explains what personal data EMBL collects, for what purposes, how it is processed, and how we keep it secure, in the context of:

GeneticScores.org analysis service

1. Who is responsible for the processing

The EMBL data controller (and joint-controller if applicable) contact details are:

EMBL-EBI Hinxton
Wellcome Genome Campus Hinxton, Cambridgeshire CB10 1SD United Kingdom
+44 (0)1223 494 444
info@ebi.ac.uk

2. What personal data do we process

The following categories of personal data may be processed:

Core Personal Information:
Basic identifiers (name, date of birth, nationality)
Contact details (email, phone, address)

Account & Technical Data:
Digital identifiers (username, IP address, ORCID)
Login credentials
Other
System access logs
Usage data and cookies

Custom value:
Browser and operating system

If applicable, the following categories of sensitive data may be processed:

Genetic data

3. For what purposes do we process your personal data

Your personal data will be processed for the following purposes:

Service Delivery:

Provide and manage service access
Technical support and maintenance
User authentication and security

Compliance & Security:

Data protection compliance
Security monitoring
Terms of service enforcement

The GeneticScores.org analysis service uses uploaded genetic data to calculate polygenic risk scores, a method of estimating genetic predisposition to disease. We also create anonymous usage statistics.

4. What is the legal basis for processing

We rely on the following legal basis(es) to process your personal data:

Your personal data is processed on the basis of Article 6(1)(d) IP68 necessary for EMBL-EBI's management, operation and functioning.

5. Who can access your personal data

The following categories of recipients may access your personal data:

EMBL internal recipients:

EMBL-EBI Hinxton:
Samples Phenotypes & Ontologies team

EMBL external recipients:

External recipient categories:
Data processors processing data on EMBL's behalf

Data Processor 1:
Google Cloud Platform

Data Processor 2:
Google Analytics

ER Entity Names:
Google

Located in:
Location of Processor, External Recipient or International Organisation:
Outside EEA

Countries outside EEA:
United Kingdom and USA

6. How long do we keep your personal data

Your personal data will be kept for the following period of time:

Retention envisaged time limits:
Personal data will be retained as long as the users use the service

Retention period rational:
Genetic data are irrevocably deleted 2 weeks after the unique encryption key is created by the user. Calculated polygenic scores are available to download for 2 weeks from successful calculation and are then irrevocably deleted. Users must agree to a Data Processing Agreement, and if they revoke their authorisation data will not be processed.

7. How do we protect your personal data

We have adopted the following measures to protect your personal data:

A virtual machine running on a platform with all security patches installed as released
Authentication and access rights are required to access the Virtual Machine and the database it contains
Encryption
Other techniques applied
Access to administrative systems and machines is restricted to a limited number of individuals
All employees are bound by confidentiality obligations
All team members involved have successfully completed the mandatory training on data protection and IT security
Data centre access is restricted to a limited number of individuals via an access card
In case of Controlled access data: specific CAD training

8. Data subjects' rights and oversight mechanism

Under Article 16 of the EMBL Internal Policy No 68, data subjects have the following rights:

- a right not to be subject to a decision made by automated means (i.e. without any human intervention)
- a right to request access to your personal data
- a right to request information on the reasoning underlying data processing
- a right to object to the processing of personal data
- a right to request erasure or rectification of your personal data.

When the legal basis to process personal data is consent, please note that you have the right to withdraw your consent at any time.

Please note that those rights can be subject to limitations, as described in Article 16 (2) of the EMBL Internal Policy No 68.

If you wish to exercise your rights or wish to contact the data controller regarding any other data protection related matters, you can contact us using, by sending an e-mail to: info@embl.de or by sending a letter to: Meyerhofstraße 1 69117 Heidelberg Germany.

Advice on data protection matters can also be obtained from the EMBL Data Protection Officer (DPO), under Article 20 (2) of the EMBL Internal Policy No 68. The DPO can be reached by email at dpo@embl.org or by letter at: EMBL Data Protection Officer, EMBL Heidelberg, Meyerhofstraße 1, 69117 Heidelberg, Germany.

If you wish to complain under Article 25(1) of the EMBL Internal Policy No 68, you may do so with the DPO by email at dpo@embl.org.

If you believe that the response of the DPO is unsatisfactory or if the DPO has failed to respond within three months from receipt of the complaint, you may complain in writing to the Data Protection Committee. It can be reached by email at dpc@embl.org or by post at: EMBL Heidelberg, Data Protection Committee, Meyerhofstraße 1, 69117 Heidelberg, Germany.

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