

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 public website

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:

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

Custom value:
IP addresses, Date and time of a visit to the service website, Operating system, Amount of data transmitted, Browser

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

None

3. For what purposes do we process your personal data

Your personal data will be processed for the following purposes:

Service Delivery:
Technical support and maintenance

Compliance & Security:
Security monitoring
Terms of service enforcement

The GeneticScores.org website (<https://geneticscores.org>) provides information and documentation about polygenic risk scores, a method of estimating genetic predisposition to disease. Personal data are processed to ensure the service remains available and secure, to better understand the needs of the users and guide future improvements of the service, to check that the Terms of Use of the service are followed, to conduct and monitor data protection activities, to create anonymous usage statistics, to conduct and monitor security activities.

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 Analytics

ER Entity Names:
Google

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

Countries outside EEA:
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 until the end of the project/process

Retention period rational:
Personally identifiable data are kept to ensure legal compliance and to facilitate internal and external audits if they arise.

7. How do we protect your personal data

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

1. Risk Management & Controls: Regular risk assessments of information assets, Implementation of control measures, Periodic review of access rights
2. Training & Access: Mandatory security awareness and data protection training, Access granted based on job roles, Strict management of privileged accounts, Cryptographic key management
3. Incident Response & Recovery: Cyber security incident management process, Regular penetration testing, Disaster recovery planning, Business continuity measures
4. Compliance & Privacy: Protection of personal data in adherence with IP68 and other contractual obligations, Biometric data security, Rigorous due diligence of third party data hosting such as cloud services, Regular compliance monitoring

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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