

## **PRIVACY POLICY/NOTICE**

### **GENERAL PRIVACY NOTICE EU General Data Protection Regulation Date: 2025**

#### **Data Controllers**

##### **Who is the Data Controller?**

Real World Genetics Oy performs scientific activities which may use social and health data that are made available through Findata, the Finnish Social and Health Data Permit Authority.

Findata is a separate public authority that grants permits and provides secure access to Finnish social and health data for research and statistics. Your information may be included in data that is obtained through Findata. When data are combined and processed under a Findata permit for secondary use, Findata acts as the data controller for that processing.

Some of our research projects may instead use data from other sources, such as biobanks or hospitals. In those cases, the organization that provides the data remains the data controller for that dataset.

Real World Genetics Oy is, in most cases, also a data controller of your data, which means that it must ensure protection of your data with the same, or agreed, level of security as the organization providing your data. However, Real World Genetics Oy receives only pseudonymous data from the data sources, and therefore it has limited possibility in responding to data subject right requests. It will always refer you to the relevant data controller.

Nevertheless, if you are unsure about who to contact, you may contact us via the information below and we will help you where we can.

**Real World Genetics Oy**  
ag@realworldgenetics.com

#### **Purposes of Processing Health Data for Scientific Study**

Real World Genetics Oy carries out their scientific research activities under the legal basis for public interest, to improve scientific and health knowledge. Every study can only be performed under a limited data permit that is provided by the applicable organization where the data is applied for and obtained from (e.g. Findata, biobank or hospital, etc.) Data

cannot ever be used for another project, study, sold, shared, used, or processed for any other purpose than stated and permitted by the applicable data permit.

Unless collaborators have obtained access permission by the organization providing the data, Real World Genetics Oy only the allowed summary statistics are shared with companies. See below on more information on this.

## **Type of Personal Data Processed**

Real World Genetics Oy research activities include pseudonymous health and genetic data in order to find patterns in large groups of people to understand how genes, lifestyle, and health factors are linked. Data is analysed statistically, and the outcomes can be, for example, risk estimates or group-level associations. Our summary findings are then shared with companies to support development of new medicines, medical devices, or innovations.

The data that we obtain from secure data providers, such as Findata or biobanks, can include information like age, sex, health conditions, treatments, and genetic markers, but certainly no names, social security numbers, or addresses. Real World Genetics has no way of identifying the individual behind the data.

## **Parties and Responsibilities**

Real World Genetics Oy is responsible for the study design, analysis and is the main applicant for any data access. Real World Genetics Oy will be responsible for the data management and fulfillment of data controller's duties, as agreed with the specific organization providing the data. Real World Genetics Oy shall handle data subject right requests and information obligations when agreed with the data provider authorities and organisations.

Real World Genetics Oy is also responsible for any collaborator that is needed for their expertise to access the data. Such access must be approved individually via the data permit from the data provider, including if such access involves a data transfer. Any applicable data transfer must be, and shall be, secured via the transfer tools from Chapter V of the GDPR.

The data provider authorities and/or relevant organizations are responsible for approval of Real World Genetics Oy data applications to obtain data for a specific purpose. Furthermore, the authorities must approve or agree on the secure environment for processing the data by Real World Genetics and approve every individual that should access the data. The authorities are also responsible for secure pseudonymization of the data and handling data breach notifications and data subject information and notifications.

If studies are sponsored by pharmaceutical companies, such companies have no access to the data, unless approved and permitted in writing by the applicable data provider. Sponsors shall have access to aggregated results which are free to share as no individual profile or status can be derived from this information.

## **Storing, Retention and Duration of the study**

All studies are obtained under a limited data permit that includes an end date. No data can be processed for longer than the allowed end date. After the study, and except for approved result data, the obtained data must be deleted.

## **Security of Processing**

Your data is protected with strong technical and organizational safeguards. All research using health or genetic information is carried out inside a secure environment, provided by the official data authority where possible, or other environment that is agreed with the data authority.

The data is pseudonymized, which means that any direct identifiers (such as your name, ID number or other identifier) has been removed or replaced with random codes before we receive access.

All access in secure environments is logged and limited to authorized individuals that are named in the permit. Any result or data sharing is first checked and approved by the data authority to ensure that no individual can be identified, or confidential information is shared.

## **Automated decisions and Artificial Intelligence (AI)**

Concerning Real World Genetics Oy research activities where Real World Genetics is the Data Controller, no data subject is subject to any decision that is based on solely automated processing, including profiling, which produces any legal effect concerning the data subject or similarly significantly affect them.

That said, it may be possible that Real World Genetics Oy is involved in artificial intelligence (AI) or machine-learning methods to find patterns in large amount of health or genetic data. Such a method helps us train computer models to recognize connections.

Real World Genetics Oy can only use and create AI tools or automated analyses if the data permit specifically allows for it. Each application for a data permit includes a thorough research plan and outline of methods used for the research activities. Any AI training would then take place in the secure processing environment using the pseudonymous health data (which do not include identifiable personal information).

AI models are only created for research and statistical purposes only, never to make any decision about individual people. AI models must, as well as for results, be checked and approved by authorities prior to sharing their technical information.

## **Your rights as a data subject and deviations from the rights**

You have the following data subject rights under the General Data Protection Regulation.

### Withdrawing your consent (Article 7 of the General Data Protection Regulation)

If the processing of your personal data is based on your consent, you have the right to withdraw your consent. The withdrawal of consent does not affect the lawfulness of processing based on consent before its withdrawal.

### Right of access (Article 15 of the General Data Protection Regulation)

You have the right to obtain confirmation as to whether or not personal data concerning you is processed, and, where that is the case, what data is processed. You may also request a copy of the personal data undergoing processing.

### Right to rectification (Article 16 of the General Data Protection Regulation)

You have the right to obtain rectification of inaccurate personal data.

### Right to erasure (Article 17 of the General Data Protection Regulation)

You have the right to obtain erasure of your persona data where one of the following grounds applies:

- a. the personal data are no longer necessary in relation to the purposes for which they were collected or otherwise processed
- a. you withdraw consent on which the processing is based
- a. you object to the processing pursuant to (please see 'Right to object' below) and there are no overriding legitimate grounds for the processing

- a. the personal data have been unlawfully processed
- a. the personal data have to be erased for compliance with a legal obligation in Union or Member State law to which the University is subject

However, you have no right of erasure if such erasure is likely to render impossible or seriously impair the achievement of the objectives of the processing.

#### Right to restriction of processing (Article 18 of the General Data Protection Regulation)

You have the right to obtain restriction of processing where one of the following applies:

- a. the accuracy of the personal data is contested by you, for a period enabling the controller to verify the accuracy of the personal data
- a. the processing is unlawful and you oppose the erasure of the personal data and request the restriction of their use instead
- a. the controller no longer needs the personal data for the purposes of the processing, but they are required by you for the establishment, exercise or defence of legal claims
- a. you have objected to processing pending the verification whether the legitimate grounds of the controller override those of the data subject.

#### Right to data portability (Article 20 of the General Data Protection Regulation)

Where the lawful basis of your personal data is your consent or performance of a contract to which you are party, and the processing of personal data is carried out by automated means, you have the right to receive the personal data concerning you, which you have provided to the University, in a structured, commonly used and machine-readable format and have the right to transmit those data to another controller.

In exercising this right, you have the right to have the personal data transmitted directly from one controller to another, where technically feasible.

#### Right to object (Article 21 of the General Data Protection Regulation)

You have the right to object to processing of personal data concerning you if the lawful basis of processing is the performance of a task carried out in the public interest or in the exercise of official authority or the legitimate interests pursued by the controller or by a third party. In that case, the University may no longer process the personal data unless it demonstrates compelling legitimate grounds for the processing which override the interests, rights and freedoms of the data subject or for the establishment, exercise or defence of legal claims. The University may also continue the processing of your personal data where processing is necessary for the performance of a task carried out for reasons of public interest.

#### Deviation from the rights

The rights described in this section may be deviated from in certain situations to the extent the rights would render impossible or seriously impair the achievement of the objectives of processing personal data for scientific or historical research purposes or statistical purposes.

The grounds for deviation are set forth in the General Data Protection Regulation and the Finnish Data Protection Act. The necessity of deviating from the rights will always be evaluated on a case by case basis.

In general, Real World Genetics shall refer you to the data controller (the data provider or data authority, such as Findata, Biobank or Hospital) to exercise your data subject rights. The reason for this is that Real World Genetics does not have any identifiable information on you and cannot re-identify you. This makes it hard to respond to any data subject right request. Since the data authority holds the pseudonymization keys we advise you to file your data subject right requests with the clinic, biobank, or Findata authority, where applicable. If you need assistance, you may contact us via the contact information in the first section of this notice.

## **Data Ombudsman**

You have the right to lodge a complaint with the Data Protection Ombudsman's Office if you think your personal data has been processed in violation of applicable data protection laws.

Contact details:

Data Protection Ombudsman's Office (Tietosuojavaltuutetun toimisto)

Address: Ratapihantie 9, 6th floor, 00520 Helsinki

Postal address: B.O. Box 800, 00521 Helsinki

Tel. (switchboard): 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja@om.fi

## **About this Notice**

This Notice is d.d. 2025 and serves as a general privacy notice on how Real World Genetics processes personal data. It shall remain updated and reviewed. Where applicable, a more specific privacy notice, as approved and filed with the data authority, is attached to the study information section on the website. When there is a conflict of this notice and a specific study privacy notice, the specific study notice shall always have preference.