

Introduction

This document (hereinafter: '**Privacy Statement**') sets out how the **EuroQol Research Foundation** (hereinafter: '**EuroQol**') uses and protects Personal Data¹ provided to EuroQol.

- EuroQol is committed to ensuring that the privacy of the Data Subject² (e.g. website visitors, Users³ and virtual meeting attendees) is protected. We process Personal Data in accordance with the General Data Protection Regulation (GDPR⁴).
- Although **study related information** does not qualify as Personal Data in general, EuroQol is aware of the confidential nature of the information and will protect study related information with the same level of care as Personal Data.
- EuroQol may change this Privacy Statement from time to time by updating this document. It is recommended to check this document once in a while to ensure that you are aware of the most recent version of the Privacy Statement.

1. Why does EuroQol process your data?

EuroQol processes Personal Data from parties for the following purposes:

- To gather the necessary User information for (drafting and) executing the required legal agreements; to send notifications and otherwise communicate with the User, the User's contact person, the registrant, or any other individuals involved in the communication, in connection with the negotiation, performance, enforcement, or compliance with such agreements; and to make the requested EuroQol instrument(s) available for use. This includes providing access to the User Portal⁵ and therefore collect your mobile phone number for the multifactor authentication to access the User Portal. We also use your personal data to provide (User) support in order to answer inquiries and provide information about the EuroQol instruments. (*Legal basis: performance of a contract*)
- To approach User (or the User's contact person) for a scientific collaboration, where such collaboration aligns with our research objectives and contributes to scientific progress. (*Legal basis: legitimate interest*)

¹ **Personal Data** is to be understood as defined in the GDPR and means any information relating to an identified or identifiable natural person.

² **Data Subject** means the identified or identifiable person according to Article 4 under 1 of the GDPR.

³ **User** is the natural person who has [legitimate] access to EuroQol instruments considering that the required legal documents for such use have been signed.

⁴ **GDPR** means the Regulation (European Union) 2016/679 on the protection of individuals with regard to the processing of personal data.

⁵ **User Portal** is the [multifactor authentication protected] online environment where the EuroQol instruments are made accessible to the User.

- To contact User for the purpose of conducting a User satisfaction survey in order to help us measure our performance and to improve our services (*Legal basis: legitimate interest*)
- To facilitate virtual meetings. Meetings may be recorded or screenshots may be taken for scientific research purposes. Participants have the option to anonymize their name or disable their video feed. (*Legal basis: legitimate Interest*)
- To ensure the proper functioning and security of our website. We use essential cookies that are necessary for the website to function properly, such as those enabling security, network management, and accessibility. (*Legal basis: legitimate interest*)
- To enhance user experience and analyze website traffic, and provide personalized content and advertisements. We use non-essential cookies, including those for preferences, statistics, and marketing. These cookies help us understand user interactions, improve our services, and offer targeted content. (*Legal basis: consent*)

2. What data does EuroQol collect?

For the purposes as described in point 1, EuroQol may require you to provide certain Personal Data such as the following:

- Cookie identifiers and website usage data (e.g. IP-address)
- First and last name
- (Work) address
- Gender: Mr., Mrs., Dr., Ms., Other
- Phone number
- Mobile phone number
- E-mail address
- Video recordings/screenshots (if applicable)

3. How does EuroQol protect Personal Data?

EuroQol has taken appropriate technical and organizational measures to protect Personal Data against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access, and against all other unlawful forms of processing. These measures will ensure a level of security proportionate to the risks of processing, the nature of the data and the cost of the implementation.

4. With whom does EuroQol share your data?

EuroQol does not share Personal Data with external recipients unless this is necessary for the execution of the provided services. Any external Processors⁶ engaged by EuroQol are required to safeguard the Personal Data they receive in compliance with the GDPR. These Processors must ensure the confidentiality and security of the data and adhere to all applicable data protection regulations.

If personal data is processed in countries outside the EEA, this is done as minimally as possible and only when a transfer mechanism is in place and we have assessed that the transfer complies with applicable laws and regulations.

We can share your Personal Data with:

- our IT service providers for User portal access and IT support;
- our website cookie provider;
- User (satisfaction) survey providers.

5. Retention periods

- **Registration form & user support**

Personal Data processed for User support will be stored as long as legally required and as long as necessary to complete the services to the user, unless a User requests to have certain information omitted or deleted.

- **User Portal**

The User Portal account (including Personal Data) will be deleted **one (1) year**, after the last activity in the User Portal.

6. Your privacy rights

- **Right to rectification:** you have the right to correct inaccurate or incomplete Personal Data.
- **Right to withdraw consent:** to the extent that the legal basis for processing your Personal Data is consent, you have the right to withdraw that consent at any time (for future processing).
- **Right to erasure:** EuroQol will delete personal data upon request, except in case of legal obligations.
- **Right of access and data portability:** on request, we can provide you with an overview of the collected personal data in a structured format, along with the reasons for its collection.
- **Right to restriction of processing:** you have the right to limit the processing of personal data under certain circumstances.

⁶ *Processor means a natural or legal person, public authority, agency or other body which processes personal data on behalf of EuroQol, based on Article 4 under 8 of the GDPR..*

- **Rights related to automated decision-making and profiling:** EuroQol does not use automated decision-making, including profiling, that produces legal or similarly significant effects on individuals.
- **Right to submit a complaint with the Dutch Data Protection Authority (*Autoriteit Persoonsgegevens*) by means of this website:** [www.autoriteitpersoonsgegevens.nl](https://www.autoriteitpersoonsgegevens.nl/en/submitting-a-tip-off-or-a-complaint-to-the-dutch-dpa) [<https://www.autoriteitpersoonsgegevens.nl/en/submitting-a-tip-off-or-a-complaint-to-the-dutch-dpa>].

8. How do we use cookies?

A cookie is a small file which asks permission to be placed on your device's hard drive. Once you agree, the file is added, and the cookie helps to analyze web traffic or informs EuroQol when you visit the website.

- EuroQol uses traffic log cookies to identify which pages are being used. This helps to analyze data about webpage traffic and improve the website in order to tailor it to user needs. EuroQol only uses this information for statistical analysis purposes before removing such from the system.
- Overall, cookies help EuroQol to provide you with a state-of-the-art website by making it possible to monitor which pages are useful. A cookie in no way provides access to your device or any Personal Data, other than the data you choose to share.
- You can choose to accept or decline cookies. You can usually modify your browser setting to decline cookies if you prefer, however this may limit the operation of the website.

Contact

For any questions regarding this Privacy Statement or to exercise the privacy rights, please contact EuroQol by using the following e-mail address: privacy@euroqol.org

We will aim to respond to your request **within 10 business days**.