Privacy Statement

EuroQol Research Foundation

This policy is effective from 18 December 2024



Article 1. Introduction

This document (hereinafter: 'Privacy Statement') sets out how the **EuroQol Research Foundation** (hereinafter: "**EuroQol"**) uses and protects personal data given to **EuroQol**.

EuroQol is committed to ensuring that your privacy is protected. Should we ask you to provide certain information by which you can be identified, you can be assured that it will only be used in accordance with the rules of the EU General Data Protection Regulation (GDPR).

EuroQol may change this privacy policy from time to time by updating this document. We recommend to check this document once in a while to ensure that you are aware of the most recently updated policy.

2. Legal basis for processing personal data

We process personal data based on the following legal basis:

- Your consent: EuroQol will ask your permission to process your personal data for a specified purpose. At any moment you can withdraw this consent by contacting EuroQol at: privacy@euroqol.org.
- The performance of a contract: to perform our obligation under a contract, EuroQol can process personal data. For example, for the use/delivery of EuroQol instruments, it is necessarry to use personal data to enter into a contract as well as to provide access to the User Portal.
- Legitimate interests pursued by EuroQol: EuroQol will only collect and process personal data on the basis of the legitimate interest of EuroQol when necessary. For example, to inform you about updated versions.

3. Purpose of collecting personal data

- We process personal data from users for the following purposes: to arrange
 permission to use EuroQol instruments. This includes collecting mobile phone
 numbers for the multifactor authentication to access to the User Portal, to provide
 user support and to conduct user satisfaction research.
- We process personal data from members for the following purposes: to provide member support and to facilitate hybrid meetings and to provide sources of information for scientific research purposes, meetings can be recorded.



4. What kind of personal data do we collect

For the purposes as described in point 3, we may require you to provide certain personally identifiable information such as the following:

Users:

- IP-address
- Profession
- First and last name
- (Work) address
- Gender: Mr., Mrs., Dr., Ms., Other
- Place of residence
- Phone number
- Mobile phone number
- E-mail address

EuroQol members/attendees meetings:

- IP-address
- First and last name
- (Work) address
- Gender: Mr., Mrs., Dr., Ms., Other
- Place of residence
- Phone number
- Mobile phone number
- E-mail address
- Profession
- Bank details for reimbursement
- Recordings and/or images from EuroQol's virtual meetings (which can be shared with other members)
- Login details (applicable for EuroQol's members only)

5. Study information

Although **study related information** is not 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.



6. How do we protect personal data

EuroQol has taken appropriate technical and organizational measures to protect your 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.

7. Processors

We do not share personal data with external parties unless necessary for execution of our services.

Hired processors will secure received personal data in accordance with this Privacy Policy. EuroQol ensures that the collected personal data is used in accordance with a legal basis (explained under point 2) for processing personal data.

8. Retention periods

• Registration form & member support

Personal data processed for user/member support will be stored as long as is legally required and as long as is necessary to complete the services to the user/member, unless a user/member 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.

9. Your rights

- **Right to rectification**: you have the right to have any inaccurate personal data about you rectified and, to have any incomplete personal data about you completed.
- **Right to withdraw consent**: to the extent that the legal basis for processing your personal data is <u>consent</u>, you have the right to withdraw that consent at any time.
- Right to erasure: we will delete personal data upon request, except in case of legal obligations.
- Right of inspection: on request, we can provide you with an easy understandable and verifiable summary of the collected personal data and the reasons why we collected the information.

10. 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 our website.



- We use traffic log cookies to identify which pages are being used. This helps us analyze data about webpage traffic and improve our website in order to tailor it to user needs. We only use this information for statistical analysis purposes before removing such from the system.
- Overall, cookies help us to provide you with a state of art website by enabling us to monitor which pages are useful. A cookie in no way gives us access to your device or any personal data, other than the data you choose to share with us.
- 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 the website.

Contact

If you have any questions regarding this Privacy Statement or if you want to make use of you rights, please contact EuroQol by using the following e-mail address: privacy@euroqol.org

We will respond to your request within 10 business days.

(Version 2.2, 18th December 2024)