



EQ-5D

How to obtain EQ-5D

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EQ-5D: an introduction

- **EQ-5D** is a standardised measure of HrQOL for use in clinical and economic appraisal and population health surveys, developed by the **EuroQol Group**
- EQ-5D assesses health status in terms of five dimensions of health and is considered a 'generic' questionnaire because these dimensions are not specific to any one patient group or health condition. EQ-5D includes a 6th question, the EQ-VAS, that allows patients to rate their own health
- EQ-5D can be referred to as a patient-reported outcome measure (PROM), because patients can complete the questionnaire themselves to provide information about their current health status and how this changes over time.
- 'EQ-5D' is not an abbreviation and is the correct term to use when referring to the instrument in general

EuroQol

- EQ-5D was developed by the EuroQol Group, and its distribution and licensing are managed by the EuroQol Research Foundation
- The **EuroQol group** consists of a large global network of experts (members) who are committed to ongoing research and donate time to support EuroQol
- The **Foundation** manages the distribution and licensing of the EQ-5D.
- Provides EQ-5D for **free to non-commercial organisations**, after they register to use it; commercial users are charged a fee
- The Foundation is a **non-profit-making** organisation that invests all income into research, education, and user support (EuroQol Research Foundation)
- The Office staff is employed by the Foundation



How to obtain EQ-5D?

- The Foundation is the single point of distribution of EuroQol instruments, prominent among these: the family of EQ-5D instruments
- To obtain EQ-5D, you need to register. This takes about 10 minutes.
- After registration, the EuroQol Office will contact you by e-mail and inform you about the terms and conditions which apply within 5 days
- Our license policy will apply →



Scan me for details!

License Policy: non-commercial use

- Majority of EQ-5D registrations are simple non-commercial requests (90%) and these users will receive EQ-5D without charge.
- The license gives user the right to use EQ-5D in the registered study
- For most requests, you will only need to agree to our Terms of Use in order to obtain EQ-5D
 - automated & fast
- A license agreement and/or a digital cost recovery fee is required when
 - the user wants to modify EQ-5D;
 - EQ-5D data is collected digitally on a non-supported platform (*to be abandoned in 2022*);
 - the sample size is higher than 5000



License policy: commercial

- A **license fee** will be charged for commercial use of the EQ-5D. For example when EQ-5D is used by or on behalf of a pharmaceutical company, medical device manufacturer, or any other for-profit company.
- License agreements are provided per EQ-5D version (e.g. EQ-5D-5L), mode of administration (e.g. paper) and language. License fees are calculated accordingly.
- A license will be valid for 3 years and is not restricted to a single study.
- Commercial requests will be handled with priority. The response time for commercial requests is 5 business days.
- No license fee for studies on **covid**

Registration steps: summary

1. Choose your route, commercial or non-commercial
2. Enter your contact details, how you intend to use EQ-5D, and key study facts
3. Select the instrument that you require from a list of 2000+ available versions, considering version (EQ-5D-5L, EQ-5D-3L, or EQ-5D-Y), mode of administration, and language
4. You receive a confirmation email with **Terms of Use** or a Draft **License Agreement**. After signing it, you are directed to a web portal where your EQ-5D versions are ready to be downloaded.

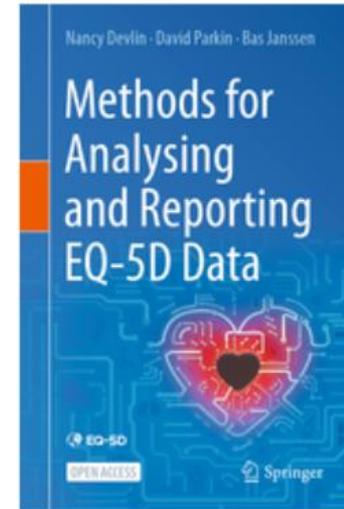
Registering a study does not obligate the purchase of an EQ-5D licence

Research, education and user support

- Not for profit: minus EQ office cost, all revenues are used to fund new research; currently 282 projects ongoing world-wide)
- Recent collaborations included the development of Belgian value sets for EQ-5D-5L and for EQ-5D-Y-3L
- Research to further our field in a broad sense, for instance to learn about psychometrics, child health, instrument comparisons, valuation methods, response heterogeneity, user dashboards, inequality measurement, covid impacts etc

Research, **education** and **user support**

- How to analyse EQ-5D data?
- EQ-5D provides three pieces of information (descriptive data; social values; EQ-VAS scores); each piece offers added value
- An open access book describes a wide array of analysis that can be done with EQ-5D data and explains relevance in different context
- Analytical tools are provided where possible (e.g algorithms to attach Belgian values to EQ-5D scores)



Next steps ..

- We believe that the efforts made by KCE and others to produce a value set for the EQ-5D-5L will be an important push for health related quality of life research in Belgium.
- Hopefully resulting in increased collaboration between EuroQol and Belgian researchers that use EQ-5D.
- If you have any questions, please contact me at stolk@euroqol.org

Greetings from EuroQol in Brussels (2019)!

