



Version 7.0  
31 January 2021

Stichting EuroQol Research Foundation

**POLICY PLAN**

## 1. Introduction

This is the Policy Plan of the Stichting EuroQol Research Foundation (the “Foundation”).

This Policy Plan gives an overview of:

- 1) The background and objectives of the Foundation;
- 2) Its activities and policy;
- 3) Its current projects;
- 4) The organization;
- 5) The source, management and destination of its funds;
- 6) Testimonials, and
- 7) Contact details.

The Stichting EuroQol Research Foundation has been granted the status of Charitable Institution, in Dutch *Algemeen Nut Beogende Instelling (ANBI)*, since January 1st, 2014, RSIN: 804679101.

On behalf of the Stichting EuroQol Research Foundation,

Kristina Secnik Boye  
Board Chair

Rotterdam, 31 January 2021

## 2. Background and objectives of the Foundation;

The Stichting 'EuroQol Research Foundation' was established in 1995. The aim of the Foundation is to serve the public interest by supporting/instigating/performing scientific research and development of instruments that describe and value health without an aim for profit.

The Foundation is charged with governing the intellectual property rights of the EQ-5D questionnaire and related instruments. Furthermore, its aim is to promote the scientific and other interests of the 'EuroQol Group Association'.

The EuroQol Group Association comprises of a network of international, multilingual, multidisciplinary researchers, originally from seven centres in England, Finland, the Netherlands, Norway and Sweden. Currently there about 100 members worldwide. The process of shared developments, local experimentation and a lively scientific discussion resulted in EQ-5D questionnaire, a measure generating a single index value for a health status, which is used in health care evaluation and as well as in patient-reported outcome measurement.

EQ-5D was initially developed simultaneously in Dutch, English, Finnish, Norwegian and Swedish. It is now widely used in many countries around the world and has been translated into most major languages with the EuroQol Research Foundation closely monitoring the quality of that translation process and it monitors a valid application of the questionnaire in practice.

The Mission of the Foundation is to, on a non-profit basis:

1. Provide leadership in the research and development of instruments that describe and value health;
2. Promote the use of instruments developed by the EuroQol Group and to support individuals and organization across the world seeking to use those instruments;
3. Foster and support an international community of researchers whose activity informs the development and application of instruments that describe and value health;
4. Ensure access to the accumulated research expertise of the EuroQol Group and to actively promote the transfer of knowledge and evidence regarding the use, analysis, and interpretation of the developed measures;
5. Support promising early career researchers in the field of health and quality of life research through involvement in research activities.

### 3. Activities and policy

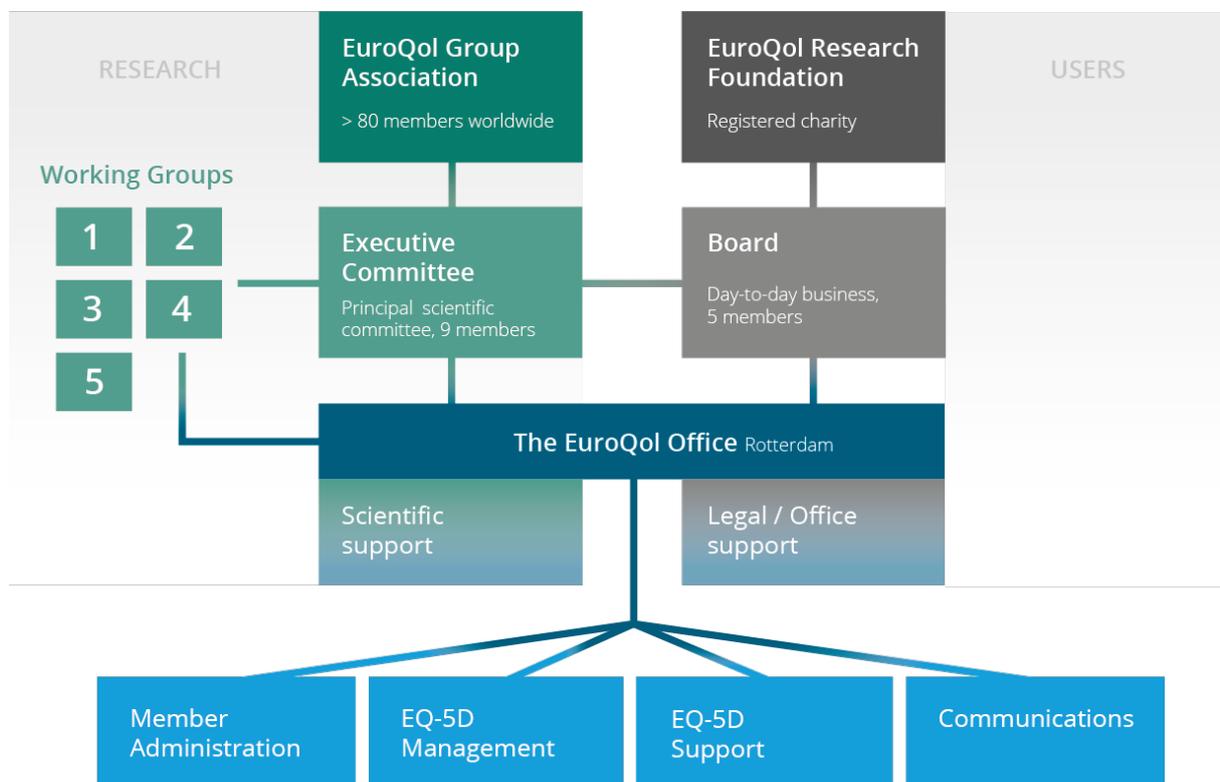
The Foundation strives to realize its objectives by working closely together with the members of the EuroQol Group Association.

The Executive Committee of the EuroQol Group Association can be thought of as the principal ‘scientific committee’ of the EuroQol Group Association. The Executive Committee comprises nine members, who are elected by the members of the EuroQol Group Association. Important functions of the Executive Committee include the appraisal of research proposals, scientific working groups, the organization of the scientific annual meeting and implementing the rules concerning membership of the EuroQol Group Association.

The Foundation funds research proposals that have been approved by the Executive Committee. A team of researchers, employed by the Foundation and working at the EuroQol Office in Rotterdam, the Netherlands, assists with setting up and conducting the scientific studies.

The Foundation is responsible for the management and administration of the research funds.

In the diagram below the EuroQol organisation is shown:



#### 4. Pending & Current projects

In order to achieve the objectives, the Foundation has been committed to a number of research projects, which have been initiated by the Executive Committee. These research projects typically involve methodological research such as the following:

*Value sets:* EQ-5D is used to measure health-related quality of life in patients in relation to its societal value. A societal 'value set study' is conducted to estimate how the general population in a country values health. Health economists use such societal value sets in cost effectiveness analyses. The Foundation fully funds or co-funds many of such studies.

*Research on valuation methodology:* The methodology of how to conduct value set studies and how to analyse and model such data is a research discipline in which the Foundation funds a substantial amount of studies. These studies have value beyond the EQ-5D questionnaire as the methodology developed may apply also to other questionnaires.

*EQ-5D for children and adolescents:* For children and adolescents a special version of EQ-5D called EQ-5D-Y has been developed. Research continues on both the questionnaire itself and valuation sets in children, adolescents and their parents/caregivers. For EQ-5D-Y a valuation methodology has been published, which is currently being tested in value set studies in several countries around the world. The first publication of a national value set is expected this year.

*EQ-5D in PROMs research:* EQ-5D is used frequently in large surveys as so called Patient Reported Outcome Measure (PROM) in healthcare. It provides a quick and simple indication of a patient's health-related quality of life. The Foundation is interested in research on the performance of EQ-5D in PROMs and in research on patient norm data of EQ-5D.

In the financial year 2019-2020 the Foundation funded a total of 95 scientific studies, with a total value of 4,070,387 euro. Studies typically run for 2 to 3 years. The current number of studies ongoing is about 140.

Further information about projects and the activities of the Foundation can be found on its website: <https://euroqol.org/research/>.

## 5. Organization

The Board of directors of the Foundation (the “Board”) deals with sponsors and their contracts, financial & legal affairs and is the employer of the staff in the EuroQol Office, including the Executive Director. The Executive Committee of the EuroQol Group Association elects the members of the Board of the EuroQol Research Foundation. The Board consists of 5 members and these members can be found on the [website](#).

The Board is charged with the management of the Foundation, and more in particular with the management and administration of the means of the Foundation, the adoption of the budget of income, including distributions and funds to be made available in view of the realization of the objectives of the Foundation. The Board is entitled to accept (and refuse) donations on behalf of the Foundation. No donations are accepted that are made under known conditions contrary to the mission of the Foundation.

The Executive Director and his staff of scientists and legal/administrative people at the EuroQol office in Rotterdam, the Netherlands, assist the Foundation and the EuroQol Group Association. The scientists also provide assistance to users of EQ-5D and to scientists involved in studies funded by the Foundation. The legal/administrative team arranges the licensing of EQ-5D. More information on the activities of the Office team can be found on the [website](#).

## 6. Source, management and destination of Funds

The Foundation receives sponsorships/ license fees mostly from commercial companies that use EQ-5D. Annually, the Board reviews our licensing policy. As of 18JAN2019 no sponsorship/license fees are charged for non-commercial use of EQ-5D. This differs from the past, where a modest fee could be charged for non-commercial, non-research use of EQ-5D. Sponsorship/license fees are currently the only source of funding of the Foundation. In the past, as a research foundation, the Foundation has successfully applied for national- and EU grants, when these grants aligned with the overall research strategy determined by the Executive Committee of the EuroQol Group Association.

Non-commercial organizations, such as universities or hospitals, that want to use EQ-5D can use the instrument for free. In the past financial year 2019-2020 the Foundation received 5583 requests for using EQ-5D. These requests came in from all over the world. Most requests were coming from the United States, the United Kingdom, Australia, Germany, Japan, the Netherlands, Canada, France, Spain and India. All these requests resulted in 635 paid sponsorship agreements with commercial companies. This means that vast majority of EQ-5D use is for free. This policy is in line with mission statements 2 and 4, see Chapter 2.

It is difficult to forecast the volume of sponsorships that the Foundation will receive in future years. For several years a steady and strong growth was seen. However, in the past years the road was more bumpy. In financial year 2016-2017 a decline was evident, driven by a decrease in EQ-5D-3L use (along with an increase in EQ-5D-5L use). In financial year 2017-2018 sponsorship income was restored to previous levels. In the financial year 2018-2019 a strong growth was seen. In the past financial year 2019-2020 a 20% increase in the number of registrations for EQ-5D was noted, while there was a 13% drop in income, as compared to the previous year. Nevertheless, if the invoiced income of 2018/2019 is considered an outlier, the invoiced income in 2019/2020 is in line with the longer-term trend of continued growth.

Currently, the paid use of EQ-5D is driven primarily by the fact that EQ-5D is recommended in government guidelines on cost-effectiveness analysis in several countries. Changes in such documents will have an effect on the income of the Foundation. In October 2019 the National Institute of Health and Care Excellence (NICE) in England updated its interim [position statement](#) about the use of the 5-level version of the EQ-5D for companies, academic groups, and others preparing evidence submissions for NICE. In the position statement it is stated that the EQ-5D-3L version and value set still are the reference case for England. If data were gathered using the EQ-5D-5L version, utility values in reference-case analyses should be calculated by mapping the 5L descriptive system data onto the 3L valuation set. This and similar statements may directly affect sponsorship income.

In the current financial year, the Foundation expects to obtain at least the same level of sponsorship income as in 2019-2020. In years thereafter the Foundation expects to see a slow, gradual increase of funding, perhaps at a slower pace than the past years, unless there is a dramatic change in government guidelines documents.

The Foundation aims to channel as much income as possible towards realising its objectives, whilst maintaining sufficient reserves to guarantee the continuity of the organisation. Please see the [investment policy](#) on how reserves are managed.

Funding scientific research on instruments that describe and value health is one of the key objectives of the Foundation. Members of the EuroQol Group Association, and occasionally non-members, can apply for research (co-)funding. The Executive Committee periodically reviews these applications. Only those applications that show scientific rigour and alignment with the overall research strategy are considered eligible for funding.

Next to funding research, PhD projects are occasionally funded, next to educational- and travel grants. At the moment it is explored if these educational activities can be expanded.

All administrative costs are kept on a reasonable level in order to grant as much money as possible to be spent on research and the other aims of the Foundation. Less than 20% of the income of the Foundation is spent on personnel costs, about half of which is for researchers employed by the Foundation. These researchers support both EQ-5D users and other researchers by providing information on data modelling, data analyses and study conduct.

The Foundation invites and welcomes members of the public to make donations to support its objectives.

## 7. Testimonials

Prof. Eliza LY Wong, JC School of Public Health & Primary Care, The Chinese University of Hong Kong

We have worked very closely with the EuroQol Research Foundation over the past three years to conduct two projects on EQ-5D-5L. The Foundation has offered us an enormous support in term of staff training, technical support on quality control of data collection and expert advice on data analysis. We valued their expertise and experience. The support that we received has been great and timely. Their professional and willingness to make contribution in the area of patient's preference and quality of life made our project such a success.

Dr. Nils Gutacker, Centre for Health Economics, University of York, UK  
Member of the EuroQol Group

Prospective patients want to know if surgery will make them feel better. We developed an online tool to inform UK patients about the likely outcome of hip and knee surgery based on what previous patients had reported before (<http://www.aftermysurgery.org.uk>). This would not have been possible without the help of the EuroQol group. They gave the English NHS permission to collect the needed data using the EuroQol instrument and waived the associated fee. The intuitive format of the EuroQol instrument also makes it easy to explain the results to prospective patients. Great work!

**8. Contact details**

Stichting EuroQol Research Foundation  
Attn. Bernhard Slaap  
Executive Director

Marten Meesweg 107,  
3068 AV Rotterdam,  
The Netherlands,  
Phone number: +31 88 4400196

Website: <https://www.euroqol.org>