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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:

- 2) Background, Mission and Vision of the Foundation;
- 3) Activities, organisation and policy;
- 4) Current projects;
- 5) The source, management and use of its funds;
- 6) Testimonials, and
- 7) Contact details.

The 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 Foundation,

Nancy J Devlin
Board Chair

Rotterdam, 24 February 2024

2. Background and objectives of the Foundation

The Foundation was established in 1995. The aim of the Foundation is to serve the public benefit 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**”).

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

Reflecting decades of funding research and development by the Euroqol Research Foundation, the EQ-5D questionnaire is now part of a wider family of instruments developed by the Euroqol Research Foundation for measuring health (EQ-5D-3L, EQ-5D-5L) and wellbeing (EQ-HWB, EQ-HWB-S) in adults; and in children (EQ-5D-Y-3L, EQ-5D-Y-5L and EQ-TIPS). These instruments are widely used in many countries around the world – the EQ-5D is the most widely recommended- and in some countries even required instrument for use in Health Technology Appraisal by health care systems around the world. The instruments are available in multiple modes of administration and have been translated into most major languages. Our instruments are accompanied by social preference weights that allow quality adjusted life years (QALYs) to be calculated for use in economic evaluation of health care.

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

1. To achieve social good by supporting the use of EuroQol’s instruments to improve health care decision-making and health outcomes across the world;
2. To provide leadership and innovation in the development of EuroQol’s instruments and methods for measuring, valuing, and reporting health;
3. To actively transfer knowledge and best practice in the use of EuroQol’s instruments;
4. To build research capacity by fostering an international community of researchers to sustain and advance the development and application of EuroQol’s instruments.

3. Activities, organisation and policy

The Foundation and the EuroQol Group are the two arms of the EuroQol organization. The Foundation exists to serve the public benefit by supporting, instigating and performing scientific research. As mentioned above, the EuroQol Group is comprised of an international network of multidisciplinary researchers and has more than 100 members.

The Board of the Foundation has a responsibility for topics such as:

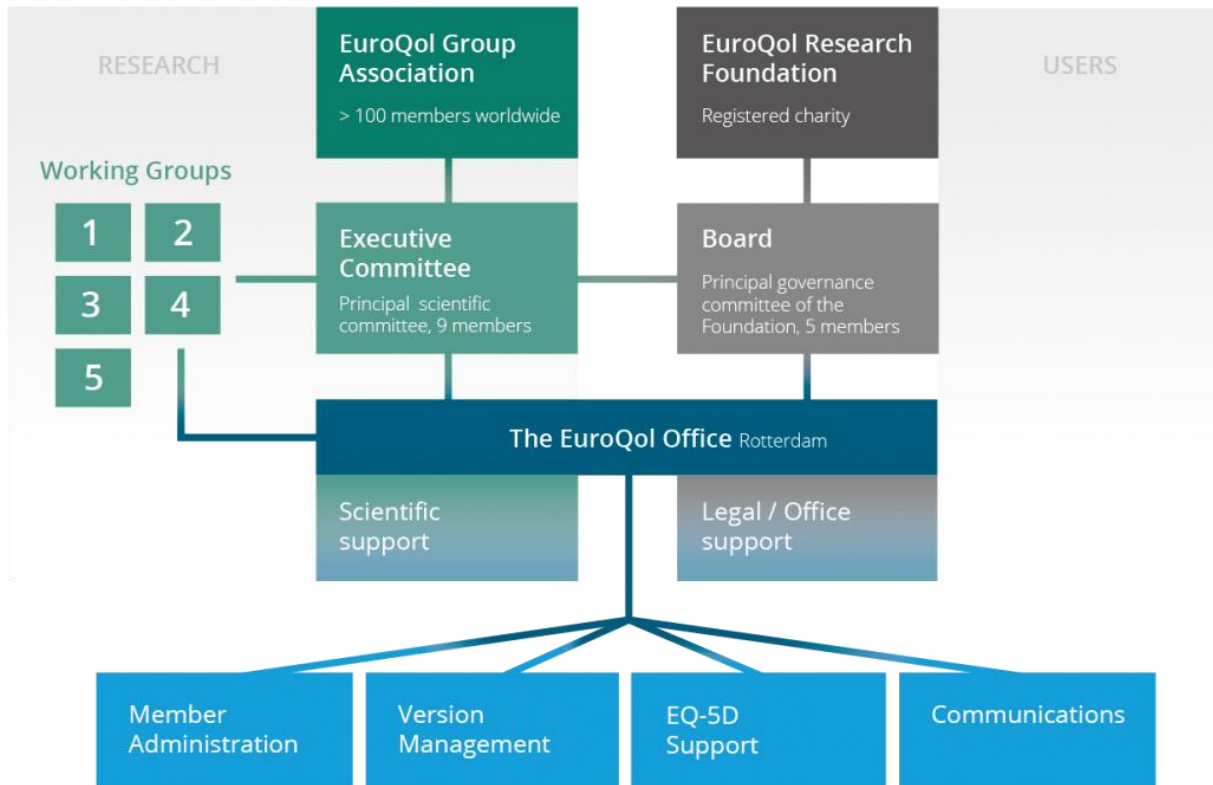
- Strategic thinking about the Foundation's activities, and in particular ensuring the long-term sustainability of the Foundation;
- Ensuring that the overall activities of the Foundation satisfy the requirements of the Foundation's designation as Charitable Institution, in Dutch *Algemeen Nut Beogende Instelling (ANBI)*, e.g., at least 90% of the efforts of the Foundation are to be focused on the public benefit, consistent with the Foundation's stated mission/vision;
- Ensuring the effective and efficient management of all aspects of the Foundation's operations, including governance of the intellectual property rights that include, but are not limited to, EQ-5D. The Board is the employer of the staff in the EuroQol office, including the Executive Director.

The EuroQol Group's Executive Committee can be thought of as the principal 'scientific committee' of the EuroQol Group. The Executive Committee comprises nine members, who are elected by the members of the EuroQol Group. Important roles 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 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 are based at the EuroQol office in Rotterdam, the Netherlands. 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](#).

In the diagram on the next page the EuroQol organisation is shown:

4. Pending, Current and future projects

In order to achieve its stated objectives, the Foundation invests in a substantial programme of research projects. 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 a manner that can be summarised by a value. A societal ‘value set study’ is conducted to estimate how the general population in a given 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 regarding 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 number 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, the EQ-5D-Y-3L, has been developed. Research continues on both the questionnaire itself and value sets. For EQ-5D-Y a valuation methodology has been published, which has now been used to produce value sets in close to 20 countries around the world. A 5-level version of the Youth instrument (EQ-5D-Y-5L) is being developed. In 2024 it will be made available as an Approved version. Experimental instruments are also being developed and tested for very young infant and toddler populations (EQ-TIPS).

EQ-5D in PROMs research: EQ-5D is used frequently in large surveys as so-called Patient Reported Outcome Measures (PROMs) 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.

EQ-HWB: Several years ago, researchers from the University of Sheffield, in collaboration with an international team of researchers from the EuroQol Group and other organisations, started a research project to produce a self-reported outcome measure, suitable for use across health care and social care. The new instrument is titled EQ-HWB (EQ Health and Wellbeing instrument). EQ-HWB development work is ongoing, including exploration of value sets.

In the financial year 2022-2023 the Foundation funded a total of 75 scientific studies, with a total value of 5,290,508 euros. Studies typically run for 2 to 3 years. As of September 2023, the current number of studies actively underway is 342.

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

5. Source, management and use of Funds

The Foundation receives sponsorships/ license fees mostly from commercial companies that use EQ-5D. The Board reviews our licensing policy annually. As of 18th January 2019, no fees are charged for any non-commercial use of EQ-5D, small or country-wide. Sponsorship/license fees are currently the only source of funding of the Foundation. In the past the Foundation has successfully applied for national- and EU grants, when these grants aligned with the overall research strategy.

Non-commercial organizations, such as universities or hospitals, that want to use EQ-5D can use the instrument free of charge. In the past financial year 2022-2023 the Foundation received 6,873 requests for using EQ-5D. These requests came in from all over the world. Most requests came from the United Kingdom, the United States, Germany, Australia, Japan, the Netherlands, Canada, China, India and France. The vast majority of EQ-5D use is for free by non-commercial users, and in most cases a license agreement is not needed after registration: 4,766 users were provided with EQ-5D after agreeing to our Terms of Use. Only for very large projects or studies a licence agreement is needed: 280 non-commercial license agreements were set up for free use. For commercial companies 1097 paid license agreements were set up. 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, followed by year of stabilisation, or even decline. In the financial year 2018-2019 a strong growth was seen. In the 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, reflecting a change in the balance of license requests from non-commercial users. In financial years 2020-2021 and 2021-2022 the number of registrations grew and income grew substantially. The past financial year 2021-2022 showed an increase in income of 21%, while the number of registrations grew by 6%. In financial year 2022-2023 the number of requests for using EQ-5D stayed about the same, while income dropped by 6%.

Currently, the paid use of EQ-5D is driven primarily by the fact that EQ-5D is recommended- and in some countries even required in government guidelines on cost-effectiveness analysis in several countries. Changes in such documents would have an effect on the income of the Foundation. In January 2022 the National Institute of Health and Care Excellence (NICE) in England updated its [Methods Guide](#), which continues to state that the EQ-5D measurement method is preferred to measure health-related quality of life in adults. 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 financial year 2021/22, the Foundation funded an important large project, in collaboration with NICE, to produce UK value set for the EQ-5D-5L - which will be completed in 2024.

In the current financial year (2023-2024), the Foundation expects to obtain the same level of sponsorship income as in 2022-2023, although the current unrest in international markets does seem to negatively impact our income. 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, and non-members, can apply for research (co-)funding. There are two calls for research proposals each year, which are open to applications from both members and non-members. The Executive Committee reviews these applications. Only those applications that show scientific rigour and alignment with the overall research strategy are considered eligible for funding.

The Foundation also funds PhD projects and educational and travel grants. In financial year 2020-2021 8 PhD projects were funded. In financial year 2021-2022 3 PhD projects were funded. In 2022-2023 3 PhD projects were funded and 2 postdoc projects. These educational activities may be expanded in future.

Lastly, in line with our Vision and Mission, the Foundation funded scientific meetings for a total cost of €1,999,796. The meeting costs were substantially higher than in previous years, as for the first time post-pandemic we were able to organise well-attended face to face meetings, one of which was in Chicago, USA. Another reason for the higher meeting costs is inflation. Particularly, prices for airline tickets have almost doubled. Lastly, because these meetings were organised as hybrid in person and online meetings, higher costs were incurred for audio-visual equipment and personnel. These meetings were well attended by both members and non-members of the EuroQol Group. In addition, frequent educational webinars and workshops are now offered to the broader scientific community throughout the year.

All administrative costs are kept on a reasonable level in order that 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 EQ-5D users and other researchers by providing information on data modelling, data analyses and study conduct.

For more information on the activities of the Foundation, please see the [Annual Report](#).

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

6. 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!

7. Contact details

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Executive Director

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