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31 December 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,

Nancy J Devlin
Board Chair

Rotterdam, 31 December 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 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.

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. The EuroQol Research Foundation closely monitors the quality of the translation process and the valid application of digital versions 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

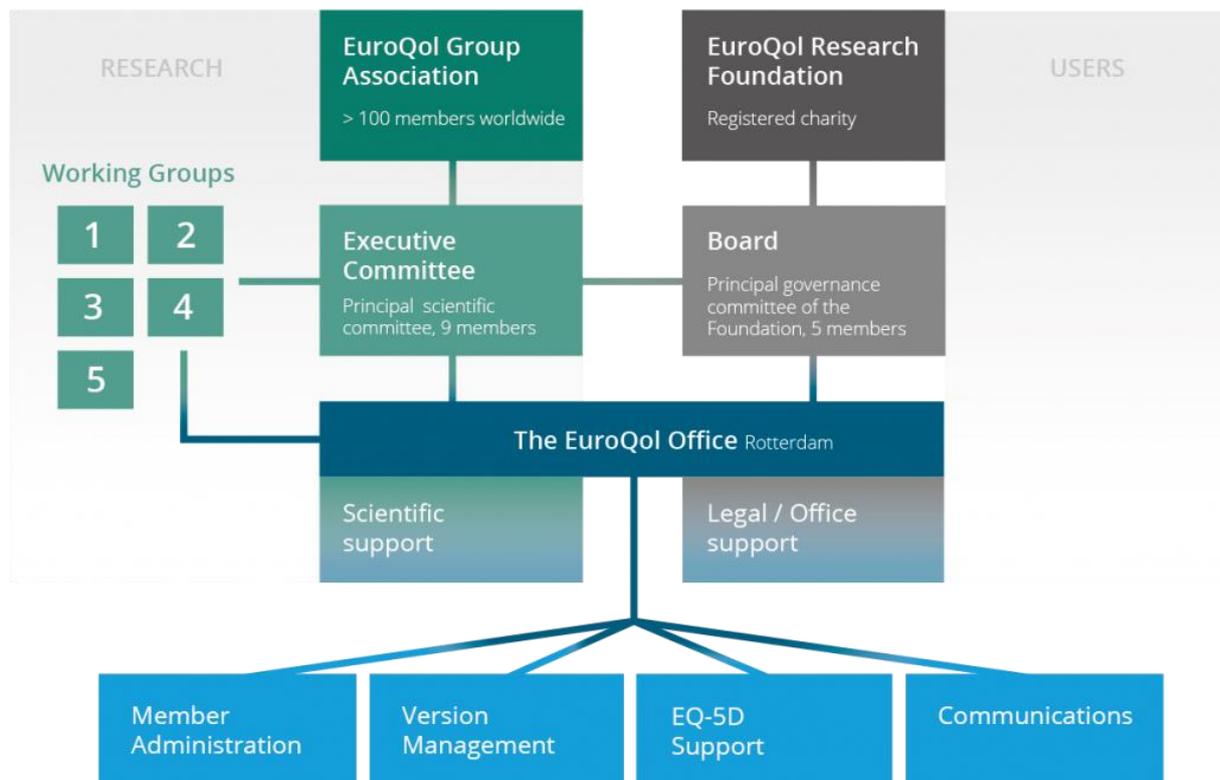
The Foundation strives to realize its objectives by working closely with the members of the EuroQol Group Association.

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 and future projects

In order to achieve its stated objectives, the Foundation invests in a substantial programme 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 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 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 national value sets have been published 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.

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.

In the financial year 2020-2021 the Foundation funded a total of 76 scientific studies, with a total value of 6,025.548 euros. 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 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 of the EuroQol Research Foundation has a responsibility for:

- (i) strategic thinking about the Foundation's activities, and in particular ensuring the long-term sustainability of the Foundation;
- (ii) ensuring that the overall activities of the Foundation satisfy the requirements of the Foundation’s designation as a Public Benefit Organisation (Dutch: Algemeen Nut Beogende Instelling, ANBI). i.e., at least 90% of the efforts of the Foundation are to be focused on the Public Good, consistent with the Foundation's stated [Mission & Vision](#);
- (iii) 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 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 18th January 2019 no sponsorship/license fees are charged for any non-commercial use of EQ-5D, small or country-wide. 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 2020-2021 the Foundation received 6433 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, Germany, Australia, Japan, the Netherlands, Canada, France, Thailand and China. All these requests resulted in 665 paid sponsorship agreements with commercial companies. This means that vast majority of EQ-5D use is for free. In the past financial year 4126 non-commercial customers received 12,997 EQ-5D versions for free. If commercial license fees would have been charged, this use would have generated more than 50 million Euro. 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 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 the past financial year 2020-2021 the number of registrations grew by 15% while income grew by 34%.

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 would 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 (2021-2022), the Foundation expects to obtain at least the same level of sponsorship income as in 2020-2021. 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 increasingly also 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 funded more frequently, next to educational- and travel grants. In financial year 2020-2021 8 PhD projects were funded. These educational activities may be expanded in future.

Lastly, in line with our Aims, the Foundation funded scientific meetings for a total cost of €431,938 in the past financial year 2020-2021. These were mostly virtual/ digital meetings due to COVID-19. Both the annual Plenary scientific meeting and the Academy meeting were held as virtual meetings, which were well attended by both members and non-members of the EuroQol Group Association. In addition, educational webinars and workshops are now offered to the broader scientific community throughout the year. When the COVID-19 situation permits it, face-to-face meetings will be organised again, both for local audiences and for the larger community.

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

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