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Stichting EuroQol Research Foundation

POLICY PLAN

Introduction

This document sets out the Policy Plan of the Stichting EuroQol Research Foundation (the “Foundation”).

This Policy Plan gives an overview of:

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

This document may be read in conjunction with the [2024-2025 Annual Report of the EuroQol Research Foundation](#).

On behalf of the Foundation,

Nancy J Devlin
Board Chair

Rotterdam, 11 December 2025

1. Background and objectives of the Foundation

The Foundation was established in 1995. The Vision of the Foundation is:

To serve the public benefit and, without an aim for profit, to improve decisions about health and health care throughout the world by developing, making available and supporting the use of instruments with the widest possible applicability for the measurement and valuation of health.

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

1. To achieve social good by making available and 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.

The Foundation is charged with governing the intellectual property rights of the EQ-5D questionnaire and related instruments. Furthermore, its aim is to dedicate at least 90% of its resources to the achievement of its public good vision and mission, including advancing scientific research on health outcomes measurement and valuation; supporting health system users to use its questionnaires to measure outcomes; and building research capacity by fostering an international community of researchers via education and outreach activities.

The EuroQol Group Association (the "EuroQol Group") comprises a network of international, multilingual, multidisciplinary researchers, originally from seven centers in England, Finland, the Netherlands, Norway and Sweden. The EuroQol Group has the same Vision as the Foundation. Currently there are 122 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 Foundation, the EQ-5D questionnaire is now part of a wider family of instruments developed for measuring health in adults (EQ-5D-3L, EQ-5D-5L) and in children (EQ-5D-Y-3L, EQ-5D-Y-5L). 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 value sets that allow quality adjusted life years (QALYs) to be calculated for use in economic evaluation of health care.

The continued development of new instruments and tools is a focus for EuroQol in the next decade, with close collaboration of researchers worldwide. Instruments in development are EQ-HWB and EQ-HWB-9 for the measurement of health and wellbeing in adults, and EQ-TIPS

for the measurement of health-related quality of life in infants and toddlers. To broaden the scope for using EQ-5D-5L, the Bolt-on Toolbox is in development, with additional dimensions for use in specific patients and populations. The first of these new instruments and tools are expected to be available to all users in a couple of years.

2. Activities, organization 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 120 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 issuing twice-yearly calls for research proposals; the appraisal of submitted research proposals; overseeing scientific working groups; the organization of the annual scientific meetings; and implementing the rules concerning membership of the EuroQol Group.

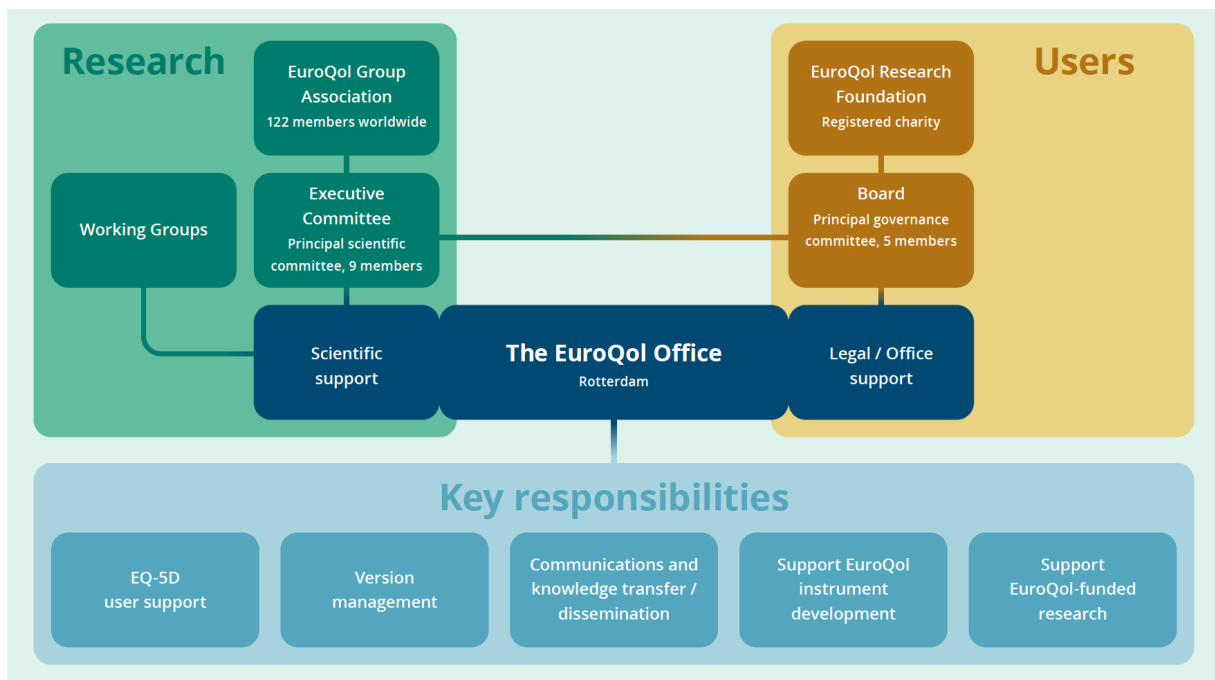
The Board is entitled to accept (and refuse) donations on behalf of the Foundation. No donations are accepted that are made under known conditions contrary to the mission of the Foundation.

The Executive Director and his staff of scientists and linguistic, legal and administrative professionals are based at the EuroQol office in Rotterdam, the Netherlands. The scientists provide assistance to users of EQ-5D and to researchers involved in studies funded by the Foundation. The legal/administrative team arranges the licensing of EQ-5D to users via a Contact Centre. A Version Management Unit exists to produce language and cultural adaptations of EuroQol's instruments to make them accessible by users around the world. More information on the activities of the Office team can be found on the [website](#).

In the diagram on the next page the EuroQol organizational chart is shown:



EUROQOL



3. Pending, Current and future projects

In order to achieve its stated objectives, the Foundation supports a substantial program of research projects. These research projects typically involve methodological research.

Value sets: EQ-5D instruments, for both adults and children, aim to measure health-related quality of life in patients in a manner that can be summarized by a value. A societal ‘value set study’ is conducted to estimate how the general population in a given country values health. These values are widely used around the world in the cost effectiveness analysis of health care technologies, improving decisions about new technologies, helping governments to manage and prioritize health care spending. The Foundation fully funds or co-funds many such value set studies.

Research on valuation methodology: The methods used to conduct value set studies, including methods for eliciting stated references, and how to analyze and model such data is a research area in which the Foundation funds a substantial number of studies, and is known for its innovative work. These studies have value beyond the EQ-5D questionnaire as the methodologies developed may apply also to other questionnaires, such as EQ-HWB and EQ-TIPS.

EQ-5D for children and adolescents: For children and adolescents, adapted versions of the EQ-5D, have been developed. This includes the EQ-5D-Y-3L and a 5-level version, the EQ-5D-Y-5L, was launched in 2024. Research continues on both the questionnaire itself and value sets. For EQ-5D-Y-3L a valuation methodology has been published, which has been used to produce value sets in close to 20 countries around the world. Research is currently underway to produce a valuation protocol and value sets for the EQ-5D-Y-5L. Experimental instruments are also being developed and tested for infant and toddler populations (EQ-TIPS). Together, these questionnaires will lead to substantial improvements in the evidence available to support health care decisions in pediatrics.

EQ-5D in PROMs research: EQ-5D instruments are frequently used in large surveys and as part of routine outcome measurement in clinical settings via so-called Patient Reported Outcome Measures (PROMs) programs. 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 population and patient norm data of EQ-5D. These studies provide important information on the burden of disease and the performance of health care services in improving patient health.

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 organizations, 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). A short-form version has also been created, titled EQ-HWB-9. Development work on both instrument is ongoing, including exploration of value sets.

In the financial year 2024-2025 the Foundation funded a total of 90 scientific studies, with a total value of 6,078,962 euros. Studies typically run for 2 to 3 years. As of September 2023, the current number of studies actively underway is 240¹.

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

An overview of the research program, including instrument development initiatives, can be found in Devlin, Slaap, Xie and Stolk (2025), Measuring and Valuing Health Using EuroQol Instruments: New Developments 2025 and Beyond, Appl Health Econ Health Policy 23(6):947-960.

¹ Status 30JUN2025, at the end of the financial year.

4. Source, management and use of Funds

The Foundation receives sponsorships/ license fees only from commercial users of EQ-5D. The Board reviews the licensing policy annually. As of January 2019, the Foundation committed to no fees being charged for any non-commercial use of EQ-5D, whether small or country-wide. These non-commercial users comprise over 90% of total uses of our instruments. Sponsorship/license fees paid by commercial users 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 2024-2025 financial year the Foundation received 9,002 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. EQ-5D use is for free for all non-commercial users, and in most cases a license agreement is not needed after registration: 6,301 users were provided with EQ-5D after agreeing to our Terms of Use. Only for very large projects or studies is a license agreement needed: 95 non-commercial license agreements were set up for free use. For commercial users 577 paid license agreements were set up. In total, the Foundation fulfilled 6973 requests², of which 8% is paid use.

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 stabilization, or even decline. In financial year 2022-2023 the number of requests for using EQ-5D stayed about the same as the previous financial year, while income dropped by 6%. In financial year 2023-2024 the number of requests grew by 10%, but income dropped by 11%, reflecting increased usage by not for profit originations who are not charged a fee. In the financial year 2024-2025 the number of requests grew by 19%, while income increased by 37%.

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 methods 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. Where data were gathered using the EQ-5D-5L version, utility values in reference-case analyses should be calculated by mapping the EQ-5D-5L descriptive system data onto the EQ-5D-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 has been completed in 2025. The publication of the value set is expected in 2026, after which NICE is expected to formally adopt its use for health technology assessment.

² Note that the number of received requests is higher than the number of fulfilled requests, due to the fact that commercial users are required to register each study, as multiple studies can be conducted under one license agreement. Secondly, some requesters do not respond after registering, meaning their request is not fulfilled.

In the current financial year (2025-2026), the Foundation expects to obtain the same level of sponsorship income as in 2024-2025, or a modest increase. In years thereafter the Foundation expects to see a slow, gradual increase of funding, unless there is a fundamental change in government guidelines documents.

The Foundation aims to make its instruments available (to non-commercial and commercial users) and support research projects as much as possible towards realizing its objectives, whilst maintaining sufficient reserves to guarantee the continuity of the organization. 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. 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 rigor and alignment with the overall research strategy are considered eligible for funding.

The Foundation also funds Open Access publications: in 2024-25, 28 open access fees totaling 79,717 euros, were funded) and educational and travel grants. In financial year 2024-2025 22 grants were supported, for a total of 133,920 euros. This included funding for sessions and workshops at conferences, as well as individual travel for conference participation and research visits. Given sufficient budgets, these activities may be expanded in future, and are a highly effective way of building research collaborations and expanding research capacity, and disseminating research findings to relevant audiences.

Lastly, in line with our Vision and Mission, in 2024-2025 the Foundation funded scientific meetings for a total cost of €1,478,872. These meetings were well attended by both members and non-members of the EuroQol Group. The meetings act as the principal opportunity to debate research methods and applications of the questionnaires, and the dialogue that takes place often generates important new insights and directions. In addition, frequent educational webinars and workshops are now offered to the broader scientific community throughout the year.

All administrative costs are carefully managed in order that as much money as possible is able 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 science team researchers employed by the Foundation who are actively contributing to the achievement of the mission and vision, working in collaboration with the wider research community. These researchers support EQ-5D users and other researchers by providing information on data modelling, data analyses and study conduct. In 2024-25, overhead costs are at 7.8% and consist of general expenses, depreciation of tangible fixed assets and personnel costs for staff in the overhead category, such as the executive director, office manager and the finance department.

For more information on the activities of the Foundation, please see the [2024-2025 Annual Report](#).

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

5. Testimonials

Catherine Gerard, Te Tāhū Hauora Health Quality & Safety Commission, New Zealand

The Health Quality & Safety Commission uses EuroQol's EQ-5D-5L in some of its patient population surveys, including the adult primary care patient experience survey and recently the adult hospital inpatient experience survey and the home and community support services survey. Access to a validated, generic PROM that allows for international comparison across common aspects of health has been valuable for our program. We are using PROMs to monitor self-reported health status at the population level, to understand PROMs in different patient populations, where it varies, and how it is changing over time with the intention of using this information to inform health policy, use PROMs to improve the quality of care for patients and develop actionable insights. We've appreciated EuroQol providing us with access to this valuable tool.

Prof. 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!

Dr. Eri Hoshino, Department of Health Policy, Research Institute, National Center for Child Health and Development, Japan

Working with the EuroQol Research Foundation has been an invaluable experience for our pediatric health outcomes research in Japan. The Foundation provided exceptional support throughout our development of the Japanese version of EQ-TIPS, demonstrating both deep expertise and genuine commitment to cross-cultural adaptation. The EuroQol team's responsiveness, technical knowledge, and collaborative spirit have been outstanding. Their dedication to expanding access to high-quality pediatric health-related quality of life measurement tools across different cultures and languages is truly making a global impact in child health research.

Prof. Valentina Prevolnik Rupel, Minister of Health, Slovenia
Member of the EuroQol Group

In the past two years, we have been working on reorienting the health care system from measuring inputs to measuring outcomes. Beginning with orthopedics, oncology, cardiology, and ophthalmology, the international disease-specific outcome indicators have been translated and validated, alongside EQ-5D-5L as a generic outcome measure. All instruments are currently

being digitalized and will be integrated into a national online database, making them available to all patients who wish to report their health status before and after medical procedures.

We are very pleased to have received permission to collect the necessary data using the EuroQol instrument for national use across all of the above-mentioned specialties at no charge. Based on the data analysis, the newly established independent Agency for Quality will be able to compare the results of medical procedures across providers, identify differences, and improve processes to enhance the quality of care for future patients. We hope to continue the cooperation with the EuroQol in additional areas once the current efforts are fully implemented and begin to yield results.

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.

7. Contact details

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