

# **EUROQOL RESEARCH FOUNDATION JULY 2024-JUNE 2025**

## **Executive summary**

The Annual Report presents the EuroQol Research Foundation's activities and achievements during the financial year (FY) 2024/25.

In FY 2024/25, EuroQol\* took important steps to advance the implementation of its Strategic Plan for 2024–2028. Key milestones were the research and advancement of experimental instruments – the EQ-TIPS (EQ Toddler and Infant Populations) and the EQ-HWB (EQ Health and Wellbeing) – and the creation of a set of supplementary dimensions for EQ-5D-5L (the EQ-5D Bolt-on Toolbox) that expand and extend measurement scope in specific populations. These initiatives were complemented by strengthened global stakeholder engagement and increased support for early career researchers (ECRs) worldwide via funding for research studies, (individual) grants, and attendance at regional meetings, all to serve the public benefit objectives of the EuroQol Research Foundation.

A major milestone was the official launch of the EQ-5D-Y-5L in September 2024. Designed as a new generic measure of health-related quality of life (HRQoL) for children and

adolescents, the EQ-5D-Y-5L represents the culmination of a decade-long development programme. The instrument was developed with extensive input from children and adolescents, and has been validated through international studies across diverse clinical populations. Its successful launch was enabled by the close collaboration of the Younger Populations Working Group (YPWG), international study teams, the Version Management Committee (VMC), and the EuroQol Office.

Globally, the Foundation is supported by the EuroQol Group Association, a multidisciplinary scientific network of 122 researchers from 29 countries, who contribute to advancing the Foundation's strategic goals. This year, we welcomed three new members to the Association.

In FY 2024/25, EuroQol granted 6973 requests for EQ-5D instruments. These were provided free of charge in 92%

of cases. Most (92%) of the Foundation's total income of €12,076,687 was invested in activities directly achieving our Vision and Mission, while 8% covered overhead costs. Research and educational grants totalling €6,078,962 were awarded to research teams in six continents, representing an 8% increase compared with FY 2023/24. In addition, we continued to support 240 ongoing research projects, with 90 newly funded this year.

To strengthen knowledge-sharing and collaboration, EuroQol hosted several webinars and international meetings, including the EuroQol Plenary Meeting in Noordwijk (September 2024) and the EuroQol Academy and Early Career Researcher Meetings in Barcelona (March 2025). These meetings and webinars provided important platforms for transferring knowledge and disseminating new research findings, fostering networking opportunities, and supporting the next generation of researchers.

<sup>\*</sup>EuroQol consists of the EuroQol Research Foundation and EuroQol Group Association.

## Foreword

The EuroQol Research Foundation is a not-for profit-organisation with a mission to serve the public benefit: we provide tools for measuring and valuing health that aim to improve decisions about health and health care around the world.

Achieving these goals underpins all the work of the Foundation. It is therefore with great pleasure that we present the 2024/25 Annual Report of the EuroQol Research Foundation, highlighting the achievements of the past year.

We support public benefit by making our instruments available completely free of charge to all non-commercial users, including government and charitable health organisations, healthcare providers and academic researchers: in 2024/25, 92% of licences were for non-commercial use, contributing significantly to the production of evidence on health outcomes across health systems internationally.

The Foundation is also a major funder of research on measuring and valuing health outcomes, awarding over €6 million in grants in 2024/25. These research grants are open to researchers in countries across the world. This research aligns with our public benefit objectives and produces new

evidence on population and patient health, advancing scientific methods that benefit the field of health economics and outcomes research.

Users of EuroQol instruments benefit from the support and wide range of resources we provide to promote good practice in analysing and reporting data. We actively build research capacity by funding PhD scholarships and travel grants, fostering an international community of researchers via our scientific meetings, and through education and outreach activities.

EuroQol is unique among developers of patient-reported outcome instruments for two reasons. First, our commitment to providing instruments tailored to local users and decision-makers. For example, the EQ-5D-5L, available in over 190 languages, is accompanied by over 40 value sets, ensuring that its use in decision-making reflects

local preferences. Second, our dedication to ongoing research means we continue to expand the measurement tools and value sets provided to users.



A key example, in 2024/25, is the launch of a new instrument, the EQ-5D-Y-5L, further adding to the tools we provide to measure health in children and adolescents and providing an important complement to the adult EQ-5D-5L. Methodological work now underway will inform a valuation protocol and future value sets to support its use in health technology assessment (HTA).

Other instruments currently in development include the EQ-TIPS for measurement and valuation of health in toddlers and infants (0–4 years), and the EQ-HWB-9, aimed at measuring wellbeing and health in contexts and populations where both are relevant to decision-making. In addition, EuroQol is developing the EQ-5D Bolt-on Toolbox, a carefully selected and tested set of additional dimensions of HRQoL to supplement the EQ-5D-5L in specific patient populations.

This exciting progress is made possible by the research undertaken by our members and collaborators internationally. Support for this programme of research has been enhanced in 2024/25 by the establishment of a Programme Director role to work alongside the Scientific Director and our exceptional team in the EuroQol Office, to all of whom we express our thanks.



Nancy Devlin Board Chair



Rosalie Viney
Executive Committee Chair



A key example, in 2024/25, is the launch of a new instrument, the EQ-5D-Y-5L, further adding to the tools we provide to measure health in children and adolescents and providing an important complement to the adult EQ-5D-5L.



## Introduction to EuroQol

EuroQol consists of a Research Foundation and the Group Association (see organisational structure on page 7).

The Foundation is based in the Netherlands and is a Dutch not-for-profit organisation (ANBI) that aims 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 Foundation manages the worldwide distribution and licensing of EuroQol instruments. The Association, which develops and owns those instruments, is an international member-based organisation connecting multidisciplinary researchers active in the field of measurement and valuation of health.

The EuroQol Group's core instrument, the EQ-5D, is one of the most widely used concise, generic measures of health around the world. In the vast majority of cases, it can be used free of charge; a license fee is only charged for commercial use (8% of users in the past financial year). As the primary source of income for the Foundation, licensing funds the research that has been instrumental to

achieving the objectives of the Foundation and has helped to develop EuroQol into a thriving network of scientists advancing the field of health measurement and valuation.

With 30 professionals across various disciplines, the Foundation's Office Team handles requests for the use of EuroQol instruments, manages the maintenance and development of EuroQol instruments and their many translations, oversees the research funding programme, and disseminates research findings (see page 7). The team works within the governance structures of the Association and its members to ensure that the Foundation makes the best use of available funds.

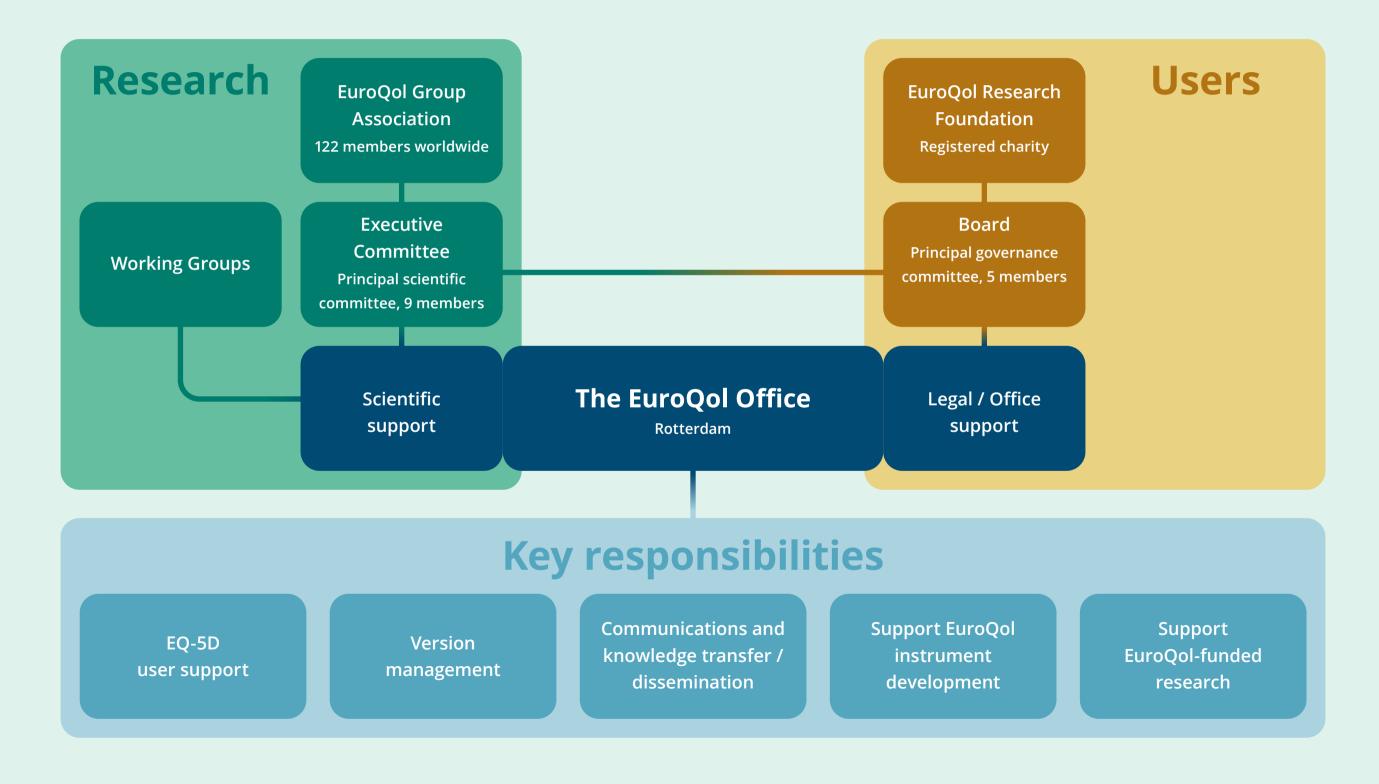
Globally, the Association's members support the Foundation to reach its goals. Currently, six Working Groups (WGs) are charged with clearly defined, specific objectives relating to the scientific agenda of the Foundation and the Association. To support users and advance research, there are further key EuroQol bodies such as the Version Management Committee (VMC),

and the Industry Consultation Group (ICG). Our members contribute not only through their research, but also by actively supporting the Foundation's mission in a variety of ways. One of their most important roles is liaison between the Foundation and the global community. Through our members, we stay closely connected to global developments and the scientific needs driving progress in our field. In turn, members play a vital role in sharing and amplifying the Foundation's work within their own networks and regions.



**Bernhard Slaap**Executive Director

## Our organisational structure



## Our vision and mission statement

The EuroQol Research Foundation has updated its Vision and Mission and set six strategic goals for 2024–2028 to drive its mission forward.



To serve the public benefit, and without an aim for profit, the EuroQol Research Foundation and Association aim 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.



**To achieve social good** by making available and supporting the use of EuroQol's instruments to improve healthcare decision-making and health outcomes across the world.

**To provide leadership and innovation** in the development of EuroQol's instruments and methods for measuring, valuing and reporting health.

**To actively transfer knowledge** and best practice in the use of EuroQol's instruments.

**To build research capacity** by fostering an international community of researchers to sustain and advance the development and application of EuroQol's instruments.



## Strategic goals 2024-2028

Provide an integrated suite of instruments for measuring and valuing health across the lifespan



2

Lead research,
development and
innovation to advance
the measurement
of health



3

Foster and promote research excellence in health valuation methods



4

Ensure all users of our instruments receive timely professional support



Maintain, expand and demonstrate our contributions to the achievement of social good



Increase our international reach and relevance

## Our EuroQol instruments

#### EuroQol is aiming to ensure that the whole lifespan of a person can be covered using different instruments within the EuroQol family.

The current family of approved instruments includes three- and five-level versions for use in adult populations (the EQ-5D-3L and EQ-5D-5L) and corresponding three- and five-level versions that employ child-friendly wording for use in paediatric populations (the EQ-5D-Y-3L and EQ-5D-Y-5L).

All EQ-5D instruments comprise a short questionnaire (the 'descriptive system') and a visual analogue scale ('EQ VAS'). The responses on the descriptive system can be

summarised using value sets, which reflect views of the general population (usually a specific country or region) about the value of each health state. These value sets can be used to calculate quality-adjusted life-years (QALYs) to inform health economic evaluations.

Efforts are currently underway to expand the family of EuroOol instruments to allow for the measurement and valuation of health across the lifespan, as well as to provide tools to extend the measurement scope of the EQ-5D beyond its core dimensions. This will allow the Group to optimise relevance for specific populations and increase measurement accuracy. For that purpose, the EQ-5D Bolton Toolbox and two experimental instruments (the EQ-TIPS and EQ-HWB) are currently in development (see page 12). A recent paper by Devlin et al. provides an overview of EuroQol's existing instruments and an update on new developments within its ongoing research programme.

#### EuroQol instruments to measure and value health across the lifespan



IA, interviewer administered; Proxy, completed by caregiver.

<sup>\*</sup>The choice of youth or adult version should be guided by the study methodology.

<sup>\*\*</sup>Still under development; accessible only to research and development (R&D) collaborators.

## One aspect of our work: R&D

#### EuroQol is committed to the continued development and refinement of its instrument portfolio to best serve its users.

Each of EuroQol's experimental instruments is developed by a dedicated WG in close collaboration with the VMC and international research teams. In March 2025, Fanni Rencz was appointed Programme Director, bringing strategic oversight, coordination, and leadership to these initiatives. EuroQol's approach to instrument development leverages its global research network: it is impressive to consider that over the past 3 years, more than 100 collaborators have contributed to the EQ-HWB, and 50 to the EQ-TIPS. The EQ-5D Bolt-on Toolbox was added to the portfolio in 2025.

The heart of instrument development lies in transforming diverse research ideas from across the EuroQol network into meaningful, practical tools. Collaboration drives this process: every idea, discussion, and insight helps shape instruments that reflect the diverse needs of our users.

Each new addition opens access to a distinct population:



The **EQ-TIPS** for toddlers and neonates



The **EQ-HWB** for caregivers and social care users



The **EQ-5D Bolt-on Toolbox** for specific patient groups

These initiatives also advance the science of measurement and valuation. We are exploring complex questions, such as how to manage transitions between instruments across age groups, and how to value bolt-ons in ways that align with existing EQ-5D-5L national value sets. At the same time, we face practical challenges – such as deciding when and how new instruments

should be used, and ensuring that our research remains grounded in real-world usage.

Looking ahead, EuroQol will continue to explore new concepts with the potential to evolve into future instruments, expanding its portfolio and driving innovation in instrument development.



It is a privilege to serve as Programme

Director and contribute to the growth of the

EuroQol family of instruments, supporting
multinational teams in developing new
instruments to improve the measurement
of health outcomes worldwide.

Fanni Rencz
Programme Director

## Our tools in development

In addition to the well-established adult and youth EQ-5D suite, we are working on several exciting new tools that will gradually become part of the EuroQol family of instruments, including two new instruments and the EQ-5D Bolt-on Toolbox. These have experimental status and are accessible only to R&D collaborators.

#### ■ EQ-TIPS (EQ Toddler and Infant Populations)

Designed for ages 0–4 years and developed with input from a wide range of stakeholders, including parents and caregivers in several countries, the EQ-TIPS' psychometric properties are currently being explored globally in Australia, Argentina, Canada, Germany, and Singapore by researchers who are collaborating on the instrument's R&D. In comparison to the EQ-5D, the EQ-TIPS includes seven dimensions relevant to this youngest age group.

#### ■ EQ-HWB (EQ Health and Wellbeing)

The EQ-HWB assesses quality of life relating to health, informal care, and social care. Designed for adults (≥18 years), this instrument is available in two versions: the EQ-HWB, and a short version to generate preference weights, the 9-item EQ-HWB-9. The EQ-HWB-9 descriptive system is currently being tested by R&D collaborators worldwide (including in Argentina, China, Germany, Hungary, Indonesia, Ireland, Slovenia, the UK, and the USA).

#### NEW in 2025

#### ■ EQ-5D Bolt-On Toolbox

A 'bolt-on' is a supplementary item, or set of items, for use in combination with the EQ-5D-5L in specific populations. Bolt-ons extend the measurement scope of the EQ-5D-5L to address HRQoL dimensions not fully captured by the original instrument. Since September 2025, the EQ-5D Bolt-on Toolbox has been added to the group of instruments under development with experimental status.





The EQ-TIPS represents an important advancement, enabling the measurement of HRQoL in the youngest age group and thereby supporting comprehensive assessment of HRQoL across the entire lifespan.



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Backed by a decade of research, the EQ-HWB is an outcome measure that provides an exciting opportunity to capture broad aspects of health relevant to informal care and social care.





The EQ-5D Bolt-on Toolbox is an innovative development that improves HRQoL measurement by expanding dimension coverage in specific (clinical) populations.



**Brendan Mulhern**Chair, Descriptive System WG

**Janine Verstraete**Chair, Younger Populations WG

Simon Pickard Chair, EQ-HWB WG



## Main achievements

EuroQol in numbers | Financial year 2024/25



**€12,076,687** 

total income

(2023/24: **€11,704,852**)

92%

of income allocated to research, education and outreach activities to meet mission objectives

(2023/24: 92%)

8%

is used for overhead costs

(2023/24: 8%)



Research

240

ongoing research projects\*

(2023/24: 247)

90

new research projects funded this year

(2023/24: 85)

\*Research is still ongoing, or the final report is still under review.



Requests

6973

fulfilled requests for the EQ-5D

(2023/24: 5907)

92%

EQ-5D requests provided free of charge

(2023/24: 89%)

3%

EQ-5D requests provided for a fee (for commercial use)

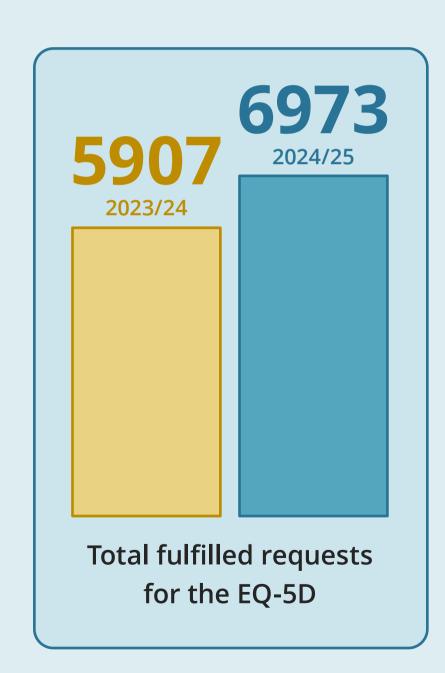
(2023/24: 11%)

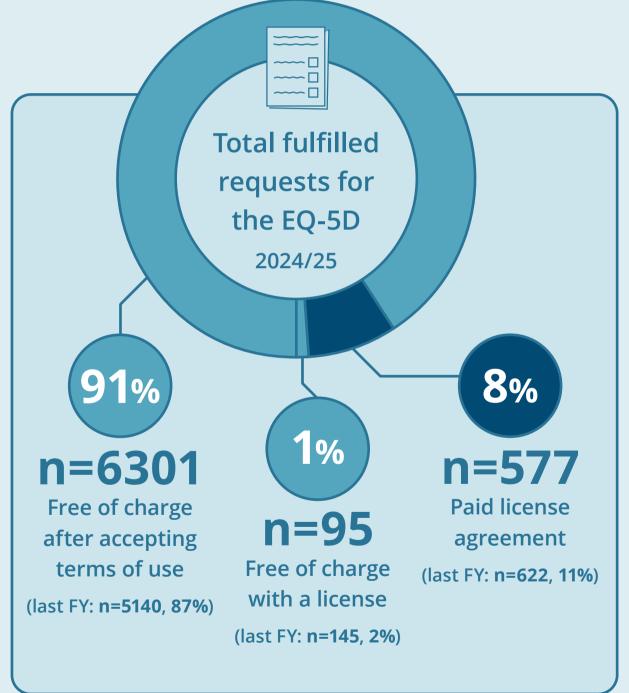
Fulfilled requests for using EQ-5D instruments

EQ-5D instruments are provided free of charge for academic, public health and other non-commercial projects, large or small. The instruments can generally be obtained within 1 business day after registration, without any license agreement.

Commercial users (e.g. pharmaceutical company, medical device manufacturer, or any other for-profit stakeholder) are asked to pay a license fee (sponsorship income). This helps support research and educational activities, as well as contributing to the development of new instruments and value sets, among other benefits.

In FY 2024/25, EuroQol granted 6973 requests for the approved EQ-5D instruments.\* Of these, 92% were free of charge. The number of fulfilled requests increased by 18% from 5907 in FY 2023/24 to 6973 in FY 2024/25.





<sup>\*</sup>This does not include experimental instruments.

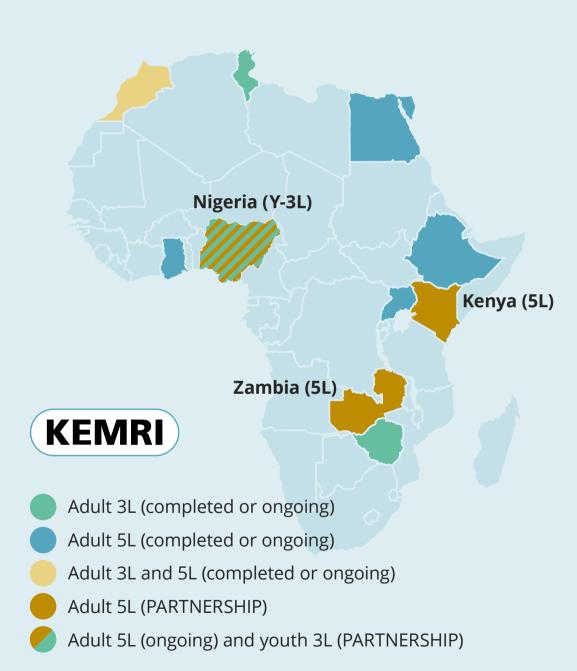
## Use of the EuroQol instruments

## **Key highlights**

## Use of EuroQol instruments in low- or middle-income countries (LMICs)

We are pleased to see increasing interest from LMICs in using EuroQol instruments. As part of our focus on stimulating research in LMICs, we funded various studies in Africa and Asia. For example, two grants currently fund psychometric testing of EQ-5D-Y-3L and EQ-5D-Y-5L in Bangladesh (Principal Investigator [PI]: Marufa Sultana) and the EQ-TIPS in Malawi (PI: Lucky Ngwira).

We are delighted to have signed an African partnership with the KEMRI-Wellcome Trust Research Programme (KWTRP) to build capacity for African researchers and policy audiences to implement the collection and use of data from EQ-5D instruments, as well as develop three EQ-5D value sets in the African region. EuroQol instruments are the only ones with value sets in Africa (to our knowledge). By the programme's end, 10 of 55 African countries will have at least one EQ-5D value set.



#### Use of EuroQol instruments in long-term care

Recent evidence demonstrates the growing use of EuroQol instruments in long-term care settings. The EQ-5D-5L has been widely used to assess HRQoL in environments such as residential care facilities, showing good psychometric properties for self-reporting and as a proxy HRQoL measure.<sup>1,2</sup>

The EQ-HWB and EQ-HWB-9 have also shown promising psychometric properties for capturing broader HRQoL outcomes among care-dependent individuals, as well as (informal) caregivers.<sup>3,4</sup> EuroQol is building stronger scientific collaborations with experts in the field of long-term care to support the development and use of the EQ-HWB in these settings.

<sup>1.</sup> Engel L, et al. Validity of the EQ-5D-5L for routine assessment in residential aged care: results from a feasibility study. Value Health 2025;28:1361–1369.

<sup>2.</sup> Cheng LJ, et al. Using EQ-5D for proxy assessment of health-related quality of life in residential care facilities: a systematic review of feasibility and psychometric properties. J Am Med Dir Assoc 2024;25:104870.

<sup>3.</sup> Bailey C, et al. The validity of the EuroQol Health and Wellbeing Short Version (EQ-HWB-S) instrument in parents of children with and without health conditions. *PharmacoEconomics* 2024;42:163–179.

<sup>4.</sup> Pangestu S, et al. The psychometric properties of the EQ-HWB and EQ-HWB-S in patients with breast cancer: a comparative analysis with EQ-5D-5L, FACT-8D, and SWEMWBS. Value Health 2025;28:449–459.

# Key user service improvements

#### **New User Relationship Management tool**

In May 2025, a new User Relationship Management tool, QCIA (Quote Contract Invoice Automation), was launched to enhance the relationship with our users. The registration portal collects details direct from the user, to automate supply of a customised license. This shortens review timelines and simplifies administration.

#### **Reorganisation of Version Management**

Managing over 3000 versions of the EQ-5D presents a significant operational challenge. To address this, the Version Management has restructured its processes to ensure continuity and user focus, aligning expertise with specific user needs.

The restructuring included

- Streamlining the translation review process
- Adjusting the timing of key milestones
- Clarifying roles and collaborative processes with Language Service Providers
- Refining translation guidelines
- Exploring technical solutions to improve the efficiency and scalability of version development and management.

The team is now implementing a forward-looking strategy that fosters innovation and strengthens capacity to manage an increasing number of versions.



Operations Director Gita Varma (left), with Version Management (Left to right: Des Scott, Jennifer Jelsma, Joelle Guerin, Michael Herdman, Bianca Smit, Zhihao Yang, Claire Gudex, Sarah Derrett, Erica Lubetkin, Edvard Pilitsyn) (missing from picture: Ghada Elkholy, Julia Kleinenberg, Miriam Ruiz, Valentina Rupel and Ahsan Zafar)

# Growing stronger

### **Reflections of our Scientific Director**

EuroQol has always thrived on bringing together a global community of independent researchers united by one mission: to improve how we measure and value health outcomes. Since 1987, this collaborative spirit has driven both scientific excellence and practical innovation.

What began with the EQ-5D has evolved into something broader. Today, EuroQol is a not-for-profit instrument development organisation committed to turning research into practical tools that improve health decisions worldwide. This year alone, our research reached new heights, with 90 new projects spanning population health measurement, new valuation methods, and beyond.

Our strength lies in our diversity. With over 120 members and countless collaborators across disciplines – from medical sciences and psychology to economics and public health – we bring together a unique mix of expertise with the capacity to launch multiple projects in parallel, accelerating progress towards our goals.

But scale brings complexity. Coordinating 90 new projects across continents and disciplines is no small feat: information can fragment, priorities may overlap, and timelines often

diverge. These challenges underscored the need for greater coherence and support.

In the past year, EuroQol strengthened its internal foundations to support sustainable growth. Behind the scenes, we refined our organisational structure to ensure our expanding research network remains connected and effective. Two dedicated support units – Scientific Support and Community Management – now provide clear, tailored guidance for every collaborator. In addition, the introduction of a Programme Director role ensures projects stay aligned, on track, and strategically linked to EuroQol's broader mission. These developments, though not always visible, were essential to ensuring that we can continue to expand our reach and impact in the years ahead.

The result? A smoother, more efficient research experience: faster access to expertise, streamlined processes, and stronger support from conception to completion. More

importantly, these changes create sustainable capacity for even more ambitious collaborations in the future.

EuroQol's mission remains unchanged: turning research into tools that improve health outcomes worldwide. With renewed structures supporting our vision, we are better equipped than ever to transform discovery into delivery.



**Elly Stolk**Scientific Director

Our research and education grants in FY 2024/25

Research and education grants were provided for a total value of €6,078,962 – an increase of 8% compared with FY 2023/24.

In 2024/25, we funded 90 new research projects. The average grant size was about €56,407. Grants were provided to research projects in Asia, Africa, North America, South America, Europe, and Oceania.

EuroQol's research funding is increasingly aimed at implementing the <u>strategic goals</u> for 2024–2028 to drive its mission forward:

#### Instrument development

In FY 2024/25, a total of 47 new grants amounting to €2,666,739 were awarded to support the R&D of our experimental instruments (EQ-TIPS, EQ-HWB, and EQ-5D Bolt-on Toolbox). For example, one such grant funds the translation of the EQ-HWB-9 into the 10 most commonly requested languages (PI: Clara Mukuria).

Stakeholder involvement and engagement

We seek to strengthen our relationship with users by increasingly prioritising the involvement and engagement of stakeholders worldwide. EuroQol awarded several grants for exploring stakeholder-informed youth valuation protocols (e.g. in the UK and USA). In February 2025, the second successful EuroQol-funded meeting of EQ-5D researchers in the UK and Ireland was held in London. In addition, EuroQol allocated funding for seven regional or thematic meetings worldwide, with a total budget of €403,993. These meetings are designed to engage stakeholders in their respective regions and are scheduled to take place in the FY 2025/26.



# Key research achievements

#### **EQ-5D** value sets

EuroQol supports extensive research to produce value sets as a key feature of the EuroQol instruments.

A major milestone was the approval of the experimental valuation protocol using a stand-alone discrete choice experiment (DCE) by the Executive Committee to develop EQ-5D value sets. The DCE-based protocol is intended to reduce the cost and logistics burden of valuation studies, which improves the feasibility of conducting such studies. The DCE-based protocol will be published in 2026.

Another notable achievement was completion of the modelling of the EQ-5D-5L valuation study in the UK. The Steering Group has approved the data quality, and the final value set is expected to be published in FY 2025/26.

Alongside the launch of the EQ-5D-Y-5L and the development of the EQ-TIPS for paediatric use, EuroQol has made extensive efforts to explore the valuation of child health and the transition between youth and adult descriptive systems and their associated value sets, with particular emphasis on stakeholder involvement throughout the process.

#### **Large population studies**

EuroQol's large-scale research infrastructure for population health data – the EQ-DAPHNIE study (Data for Assessment of Population Health Needs and Instrument Evaluation) – has begun to deliver tangible results. Initiated several years ago under the leadership of PIs Jeff Johnson and Bas Janssen, the study has completed surveys in 15 countries, reaching nearly 70,000 respondents. Early analyses have yielded two scientific publications, 17 conference presentations, and 20 data access requests, underscoring both the dataset's scientific value and growing engagement across the research community. In light of these promising developments, EuroQol has

Next steps include data collection in Indonesia,

Poland, and Singapore, including elements of the
EQ-5D Bolt-on Toolbox, and a pilot longitudinal study
in the USA that incorporates new measures of health
change and wellbeing. An Online Collection for *Quality*of Life Research is now open for submission; it will include
the introductory EQ-DAPHNIE paper,<sup>1</sup> along with 8–10

committed to continue and further the

additional articles. This collection of publications will be a useful resource, serving as core references for future work.

EuroQol members can access the datasets and infrastructure via the Data Access Review Team (DART), with opportunities to analyse existing data or use the survey platform for new data collection.



data collection.

# How we increased our impact

## Dissemination and knowledge transfer

#### Meetings

In FY 2024/25, two in-person events were hosted to disseminate new research findings and to facilitate networking and educational opportunities. Full funding for travel and accommodation was provided where required. A total of 23 ECRs and PhD students, who were not EuroQol members, were supported to attend these meetings.

- The EuroQol Plenary Meeting, held in September 2024 in Noordwijk, hosted 138 participants and 18 online attendees. The programme comprised 25 paper presentations and 20 poster presentations.
- The EuroQol Academy Meeting, held in March 2025 in Barcelona, focused on the theme of 'bolt-ons' with three sessions dedicated to exploring: (1) Development and implementation of bolt-ons; (2) Recent studies that

have developed and tested specific bolt-on dimensions; and (3) Evidence and challenges associated with valuing bolt-ons. The event was attended by 125 participants in person and 20 online, and featured three educational sessions along with 16 poster presentations.

#### **ISPOR symposium**

EuroQol funded a symposium titled 'Using HRQoL data from children and youth to strengthen HTA: What are the barriers? How can we improve current practice?' at the ISPOR Europe 2024 conference in Barcelona. Moderated by Nancy Devlin, the symposium was intended to encourage thinking and research to expand and strengthen the methods and evidence base for HTA in the paediatric space. A range of perspectives was presented, with speakers from HTA bodies, academia and industry.



Speakers at the ISPOR Europe 2024 Symposium, Barcelona, Spain >> continued from previous page



#### **Webinars**

Seven webinars were hosted by EuroQol in FY 2024/25, each helping to increase our reach and audience. These include 'EQ-5D-Y-5L psychometric properties and value preferences on health gains for children and adolescents' and 'EuroQol Data for Assessment of Population Health Needs & Instrument Evaluation (EQ DAPHNIE)'.



#### Open access fee policy

EuroQol actively promotes the dissemination of EuroQol-funded research through its open access publishing policy. In FY 2024/25, EuroQol funded the costs of 28 open access publications (11 more than in the previous year), resulting in a total expenditure of €79,717.



#### **Grants for education and outreach**

In FY 2024/25, EuroQol supported 22 grants (compared to 16 in the previous year) totalling €133,920 to support travel, visits and knowledge transfer. These initiatives serve our objective to advance knowledge in the use of EuroQol's instruments. This included funding for sessions and workshops at conferences, as well as individual travel for conference participation and research visits. EuroQol recognises the added value of offering supplementary support – particularly for ECRs – to foster professional growth. This commitment is reflected in our flexible funding approach, which accommodates most requests for knowledge-sharing opportunities that align with our mission.

As an example of a funded workshop at conferences, EuroQol supported a workshop on going beyond HRQoL for QALYs estimation, moderated by Aureliano Finch, at ISPOR Europe 2024 (Barcelona) and organised by the EQ-HWB WG. Panellists from HTA bodies, academia and industry discussed opportunities and challenges of using the EQ-HWB-9, which is intended for use across a range of health, social care and public health settings and economic evaluations.



#### **Research data management**

The EuroQol Group advances Open Science and 'FAIR' (findable, accessible, interoperable, reusable) data principles with the Storage and Access for Valuable EuroQol Datasets (SAVED) initiative, enabling access and reuse of valuable EuroQol datasets. In FY 2024/25:

- The SAVED Data Catalogue, established on the EuroQol website, was extended to over 75 valuation datasets.
- A data repository is being created, with further datasets to be added shortly. Watch this space!
- A Data Transfer Conditions document was introduced at the start of each project with SAVED status, eliminating later modifications and ensuring a more efficient process.
- A dedicated Data Manager was appointed.

Interested people can fill out the <u>application form under</u> 'Data repository' on the EuroQol website.

# Early career research support

Besides serving as a valuable forum for well-established researchers, EuroQol actively supports the development of ECRs. Through opportunities for participation, research, and networking, the Group fosters international collaboration.

Established in 2022, the EuroQol PhD Network provides a supportive environment for doctoral students engaged in EuroQol research. In FY 2024/25, the Network welcomed Ava Hoogenboom and Jan Faller to its leadership team, joining Jia Jia Lee, Stevanus Pangestu, and Ademola Itiola, with the support of the Education and Outreach WG. As of June 2025, the Network included 41 doctoral students from Oceania, Europe, North America, Asia, and Africa. During the year, it hosted two receptions (at the EuroQol Plenary Meeting and the Academy Meeting) and organised eight webinars on topics such as 'Proxy-reported outcomes' and 'EQ-HWB: Development and current status'.

EuroQol expanded opportunities for ECRs by continuing the PhD funding programme, awarding two new grants with a total value of €264,656. We now support 14 PhD students across Oceania, Europe, North America, and Asia.

The 5th EuroQol Early Career Researcher Meeting, held in ECR prize-giving ceremony, Barcelona, Spain (Left to right: Feng Xie, March 2025 in Barcelona, was attended by 50 participants Jan Heijdra Suasnabar, and featured 9 paper and 18 poster presentations by Rosalie Viney) ECRs. The meeting provided structured opportunities for involvement, research, and networking for those interests in EuroQol-related studies. This year's ECR prize for the bestpresented paper was awarded to Jan Heijdra Suasnabar for his paper 'Utilizing large language models to enhance patient-reported outcome measures: application to the EQ-5D-5L and bolt-ons' (Leiden University Medical Center). PhD Network Reception 2025, Barcelona, P EUROGOL >> continued from previous page

At the Early Career Researcher and EuroQol Academy Meetings 2025, a Buddy Programme was continued by the ECR Committee to foster lasting connections between ECRs and the EuroQol Group. Each participating ECR was paired with an experienced EuroQol member, providing opportunities for informal meetings to exchange ideas, share experiences, and offer advice throughout the event.



# Special Focus



## Launch of the EQ-5D-Y-5L

Launched as an approved EuroQol instrument in FY 2024/25, the EQ-5D-Y-5L is a new generic measure of HRQoL for use with children and adolescents.



The EQ-5D-Y-5L covers the same five dimensions of health as the EQ-5D-Y-3L in its descriptive system questionnaire, but has five levels of response in each dimension instead of the original three. Having this wider range of response options allows respondents to describe their HRQoL more precisely. The EQ-5D-Y-5L also promotes continuity in measuring HRQoL over the lifespan, as the EQ-5D-5L is currently the most widely used instrument among adults.

The EQ-5D-Y-5L is available in digital and paper formats for self-completion (ages 8–15 years), with interviewer-administered and proxy versions (ages 4–15 years) also available. At the end of FY 2024/25, the EQ-5D-Y-5L is already available in 16 language versions, with more in development.

The EQ-5D-Y-5L is the culmination of a 10-year development programme that began in 2014. This robust research process

involved substantial input from children and adolescents to ensure relevance, acceptability, and ease of understanding. Multiple studies in several countries and clinical populations have shown that the EQ-5D-Y-5L is a valid, reliable, and responsive measure of HRQoL.<sup>1</sup>

The development and launch of the instrument were a true team effort, made possible through the close collaboration of the YPWG, international study teams, VMC and the EuroQol Office.

Michael Herdman
Past Chair, Younger Populations WG

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( EQ-5D-Y-5L

1. Cheng LJ, et al. Head-to-head comparisons of the distributional characteristics and measurement properties of the 3-level and 5-level versions of the EQ-5D-Y: a systematic review. *Value Health* 2025;28:1574–1586.

## Showcase

To support the broader use and interpretation of EQ-5D-Y-5L data, a range of new resources and educational materials are now freely available to all EQ-5D users.

As part of the launch of the new instrument, the EQ-5D-Y-5L, we have published various educational materials (all in September 2024):

- The <u>EQ-5D-Y-5L Infographic</u> was developed to briefly introduce the EQ-5D-Y-5L to the EQ-5D family of instruments and give an overview of key facts about it.
- The EQ-5D-Y-5L User Guide

  was published that includes

  details on the instrument's

  characteristics and

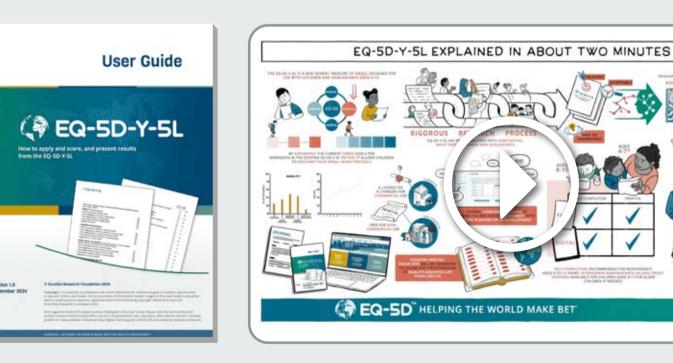
  development, and how

  to report and analyse

  EQ-5D-Y-5L data.

In September 2024, we were proud to launch a new whiteboard animation, 'EQ-5D-Y-5L explained in about 2 minutes', and an accompanying PowerPoint presentation, 'An introduction to the EQ-5D-Y-5L'.
In addition, further existing educational material was

In addition, further existing educational material was updated and expanded to include the new EuroQol instrument.





# Financial Report



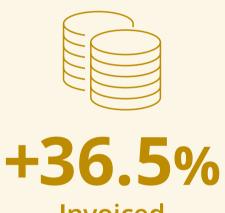
## Our financial year

Invoiced income (as defined for accounting purposes) during FY 2024/25 was €15,410,175. After 2 years of declining income, the Foundation's invoiced income in 2024/25 was 36.5% higher than the previous FY 2023/24.

Taking deferred income from the previous 2 years into consideration, total sponsorship revenue increased by 3.2%, from €11,704,852 in FY 2023/24 to €12,076,687 in FY 2024/25.

Ongoing budget control processes ensure that the Foundation uses as much of its resources as possible towards Mission and Vision activities. Consequently, the Executive Committee was able to approve research and education projects for a total value of €6,078,962 – an increase of 8% compared with FY 2023/24.

The EuroQol Office team is active in reducing the number of outstanding old projects where final reports have not been submitted and closing outstanding finances for projects completed. In FY 2024/25, the portfolio of funded projects increased by 5.5%, rising from 401 to 423 projects, compared with an 18% increase in FY 2023/24. The total value of research expenses to be paid increased from €13,593,707 in FY 2023/24 to €14,036,845 in FY 2024/25.



Invoiced income



Total value of funded research and education projects



+5.5%
Portfolio of funded projects

### Balance sheet as of 30 June 2025

#### **ASSETS**

#### **Fixed assets**

Intangible fixed assets

Tangible fixed assets

#### **Current assets**

Receivables and prepayments

Taxes and social securities

Stocks and bonds

Cash at bank

30 June 2025		30 June 2024		
€	€	€	€	
	-		41,156	
	126,419		139,781	
2,865,287		2,724,770		
135,171		87,943		
30,280,040		25,814,975		
4,577,234		5,663,879		
	37,857,732		34,291,567	
	37,984,151		34,472,504	

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	30 June 2025		30 June 2024	
EQUITY AND LIABILITIES	€	€	€	€
Reserves				
Continuity reserve		1,375,076		1,405,721
Reserves allocated to research areas		1,132,000		1,132,000
Total reserves		2,507,076		2,537,721
Non-current liabilities (longer than 1 year)				
Pre-invoiced sponsorship	9,305,212		7,583,104	
Research expenses to be paid	8,284,686		9,531,343	
		17,589,898		17,114,447
Current liabilities, accruals and deferred income (within 1 year)				
Pre-invoiced sponsorship	10,836,834		9,225,454	
Creditors	374,613		539,105	
Taxes and social securities	51,517		81,268	
Research expenses to be paid	5,752,159		4,062,364	
Other current liabilities and accruals	872,054		912,145	
		17,887,175		14,820,336
		37,984,151		34,472,504

## Statement of income and expenditure for the year ended 30 June 2025

#### Income

Sponsorship

#### **Expenses**

Spent on research and education

Approved projects

Support of approved projects

Other core expenditures

Management and administration

Personnel costs

Depreciation, tangible fixed assets

Depreciation, intangible fixed assets

General expenses

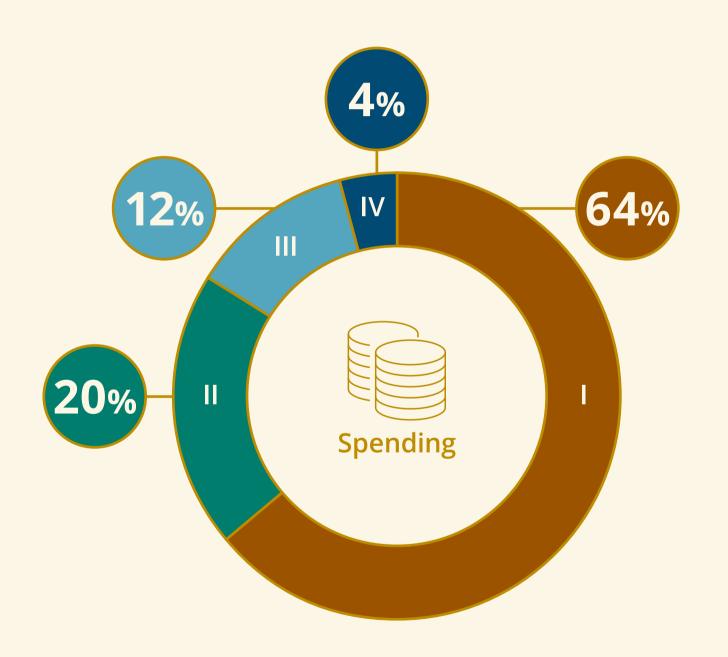
Operating result

Financial results

Result

2024/25		2023/24		
€	€	€	€	
	12,076,687		11,704,852	
5,971,708		5,649,071		
968,337		1,009,620		
3,023,338		3,292,128		
	-9,963,383		-9,950,819	
1,951,637		1,764,924		
42,262		41,843		
41,156		41,156		
591,558		473,182		
	-2,626,613		-2,321,105	
	-513,309		-567,072	
	482,664		545,585	
	-30,645		-21,487	

# Spending on mission objectives



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

**92%** of our spending is dedicated to activities directly achieving our Vision and Mission (8% is used for overhead costs)

## Acknowledgements

## Who supported our mission?



We are deeply grateful for the dedication and hard work of the Association's 122 members, representing 29 countries worldwide.

Many have supported the Foundation for years, and their continued engagement is invaluable. We take pride in our stable membership base, which reflects both the strong global interest of researchers in joining the Foundation and their meaningful commitment to collaboration. Their contributions strengthen the work of the EuroQol bodies, including the Executive Committee, Board, VMC, Communications Team, ICG, and the scientific WGs.



Academy Meeting 2025, Barcelona, Spain

## Glossary

**ANBI** Algemeen nut beogende instelling [Public benefit organisation] **DART** Data Access Review Team Discrete choice experiment Early Career Researcher **EQ-DAPHNIE** EuroQol – Data for Assessment of Population Health Needs and Instrument Evaluation **FAIR** Findable, accessible, interoperable, reusable Financial year **HRQoL** Health-related quality of life Health technology assessment Interviewer administered **Industry Consultation Group ISPOR** Professional Society for Health Economics and Outcomes Research

**KWTRP** KEMRI-Wellcome Trust Research Programme LMIC Low- or middle-income countries Principal investigator **QALY** Quality-adjusted life-year **Quote Contract Invoice Automation** QCIA R&D Research and development **SAVED** Storage and Access for Valuable EuroQol Datasets **VAS** Visual analogue scale **VMC** Version Management Committee WG Working Group

Younger Populations Working Group

**YPWG** 



The development of this Annual Report was led by Kristina Ludwig, with the support of the EuroQol Communications Team and the EuroQol Office.
Graphic design was provided by nim design.
EuroQol Research Foundation.

www.euroqol.org