



## **16<sup>th</sup> Joint Call EuroQol Working Groups September 2023**

Prepared by Laura Pickering (Grants Manager), EuroQol Research Foundation, in collaboration with the Working Groups, with approval from the Executive Committee.

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## 1. Introduction

The EuroQol Research Foundation (henceforth “Foundation” is inviting applications for funding of research. Applications will be assessed on merit through a competitive process. The Foundation aims to serve the public interest by supporting scientific, not-for-profit research and development of instruments which describe and valued health. The Foundation intends to fund high quality research that is of scientific and strategic interest to the EuroQol Group and its members. WGs have been set up to support the research agenda outlined by the Executive Committee (“Exec”), primarily focused on the measurement and valuation of health. The WGs are appointed by the Exec to foster research within their remit, which can be found in the Working Groups document (Appendix 1).

Proposals that seek to address one or more specific aims of the WGs will be considered for funding, but strategic priorities will influence decisions. For this call, the WGs have reviewed coverage of their aims by the current research portfolio and identified priority areas. The targeted calls below result from that priority check.

Please note:

- The provisional funding available for the current call stands at approximately €1-1.5M. Therefore, the Exec is still willing to consider a range of funding opportunities of benefit to the Group. This includes activities to support research collaboration and dissemination.
- Appendix 4 provides a summary of the types of grants available, ranging from small-scale travel grants to large-scale PhD grants.
- Any time sensitive funding proposals can still be fast tracked using an offline procedure. If you plan to submit a time sensitive proposal, please contact Laura Pickering, Grants Manager ([pickering@euroqol.org](mailto:pickering@euroqol.org)) or Elly Stolk, Scientific Director ([stolk@euroqol.org](mailto:stolk@euroqol.org)).

Submissions beyond the listed themes are also welcome, however for the best chance to have a funding proposal accepted applicants are encouraged to primarily focus on the priority research areas identified by the Working Groups, as funding in this area will be prioritised. If you have an excellent idea for a research project, we invite you to seek funding for it is through the current call. If you are interested to undertake other activities that have merit to the EuroQol Group, but you are uncertain whether this is in scope, you are invited to contact Elly Stolk ([stolk@euroqol.org](mailto:stolk@euroqol.org)) and Laura Pickering ([pickering@euroqol.org](mailto:pickering@euroqol.org)) for advice and guidance.

This call for proposals introduces the SAVED initiative. In light of changing demands on managing research data and the transition to Open Science, EuroQol seeks to further increase added value for its members by making selected data available for secondary use. This implies that selected funded proposals may be required to transfer the resulting data and data management to EuroQol and its SAVED Archive. If SAVED status has been or is being considered for a project or funded proposal, this will be specified in the Grant Offer Letter and preparations for data transfer and secondary use need to be made. Further details on SAVED and can be found in Appendix 5.

The deadline for submissions is **Sunday 22 October 2023 at 23:59 CEST**. Good luck with your applications!

## 2. Scope of this call

### 2.1 Descriptive Systems Working Group

The Descriptive System Working Group (DSWG) calls for proposals contributing to three research areas that will support the group in developing methodological knowledge and furthering evidence about existing and emerging EuroQol instruments. The three areas are:

- Development of psychometric knowledge to inform standardised protocol(s)
- Production of evidence to assess bolt-ons and other modifications to descriptive systems
- Exploration of the 'Deep Dive' approach to measuring health related quality of life

#### 2.1.1 Development of psychometric knowledge to inform standardised protocol(s)

There are many psychometric methods available for testing preference-based instruments at the descriptive and value set level. These include, but are not limited to, classical test theory, factor analysis, structural equation modelling, and various forms of item response theory. The majority of evidence produced is based on classical test theory, but the DSWG has recently supported work extending this.

Evidence is required to understand which psychometric methods are most appropriate for the EQ family of instruments, or the extent to which different psychometric methods are appropriate to assess the potential and performance of EuroQol instruments. To date, little research is available on the way these methods can and should be used.

The DSWG invites proposals to investigate and compare psychometric methods with a focus on issues relevant to preference-based measures. This will ultimately support the development of a protocol (or set of protocols) for the development and assessment of EQ instruments (e.g., EQ-HWB, EQ-5D-Y, EQ-TIPS, and bolt-ons).

We encourage all applied proposals psychometrically testing the EQ family of instruments to include a methodological angle, and we are collaborating with the EQHWB WG to develop the protocol, and therefore encourage proposals exploring the EQ-HWB instruments to include a methodological element. If you require advice on this, please contact the DSWG (details at end of this section).

Examples of proposals relating to this theme include, but are not limited to:

- Reviews of psychometric methods used for the assessment of EQ instruments (including summaries of methodological choices and observed results of common psychometric tests)
- Use of primary and secondary data sources to explore psychometric methods, and/or develop and test novel approaches
- Comparison of psychometric methods across EuroQol and other preference and non-preference-based instruments
- Use of psychometric methods to understand and compare instruments across proxy and self-completion, administration modes and languages
- Exploring methods for developing non preference-based scoring approaches for EQ instruments (an area of interest to the DSWG and PHSWG).

During recent rounds a number of proposals were funded under this theme. Therefore, interested members are encouraged to contact a DSWG representative to ensure alignment of new proposals with ongoing work (contact details at the end of this section).

The DSWG is also invites proposals to investigate and compare qualitative methods which focus on content validity of preference-based measures in terms of comprehensibility, relevance and comprehensiveness (completeness). Methodological work may explore:

- How to apply content validity qualitative methods and evidence to a generic measure context
- Establishing best practice in qualitative work in the context of international preference-based measures
- How to combine and weight qualitative content validity (and other validity) evidence from different sources including different countries and different patient groups.

### **2.1.2 Production of evidence to assess bolt-ons and other modifications to descriptive systems**

#### ***IP status of bolt-ons***

The DSWG has been tasked with examining the IP status of the suite of EuroQol bolt-ons and to establish a clear framework for managing, developing and using bolt-ons. In this round we are focusing on the following bolt-ons: cognition, vision, hearing, sleep, tiredness/fatigue/energy/vitality, social relationships and breathing. We are also interested in work into bolt-on sets including multiple dimensions. These include the EQ-PSO (skin irritation and self-confidence) and psycho-social bolt-on set (Chen and Olsen, 2023<sup>1</sup>). Recent review work (Rencz et al, in development) has found multiple descriptors for many bolt-ons, and work is required to test the various descriptors, with the aim of harmonising one version. Another research area of interest is around the use of global (e.g. cognition) vs. subcategory (e.g. memory, learning, concentration) bolt-on descriptors.

Research in this area may include:

- Qualitative evidence on the content and face validity of the different wordings of bolt-ons in various relevant patient populations
- Stakeholder consultations to elicit the views of HTA representatives regarding the use of bolt-ons in decision making
- Qualitative evidence of the content validity of the bolt-ons for other users (e.g., clinicians).
- Production of quantitative psychometric evidence of the performance of the different wordings of bolt-ons as well as global vs. subcategory bolt-on descriptors alongside the EQ-5D-5L, condition-specific HRQoL measures and clinical measures in a range of patient populations
- Testing of bolt-ons in diverse languages and cultural contexts.

Multi-country qualitative and/or quantitative primary data collections are recommended, but secondary analysis of existing observational or clinical trial data will also be considered as part of this research programme.

#### ***Exploratory work on bolt-ons and other modifications***

There are a number of exploratory research areas where further evidence could support both the bolt-on programme, and the wider programme of the DSWG (given methodological approaches used). These include:

- Non-preference-based scoring of bolt-ons: As evidence suggests that bolt-ons increase measurement sensitivity, but result in many challenges for valuation, the DSWG calls for work exploring the non preference-based scoring of single or multiple bolt-ons alongside the core descriptive system.

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<sup>1</sup> Chen G, Olsen JA. (2023). Extending the EQ-5D: the case for a complementary set of 4 psycho-social dimensions. Quality of Life Research, 32(2): 494-505.

- Exploring the use and adaptation of constructs and items from other instruments as EQ-5D bolt-ons
- Exploring the use of and potential challenges associated with using the EQ-HWB items as bolt-ons
- The investigation of possible double counting across existing bolt-ons and the core descriptive system.
- Exploratory research related to other modifications of EuroQol instruments, such as recall period, item wordings and pictorial versions.

### **2.1.3 Exploration of the ‘Deep Dive’ approach to measuring health related quality of life**

At the 2022 plenary meeting in Chicago, the DSWG presented a paper introducing an approach that conceptualises the EQ-5D as a multi layered measure of health-related quality of life (Mulhern et al 2022, available from the authors on request<sup>2</sup>). The approach retains the EQ-5D descriptive system, while enabling a ‘deep dive’ into each of the five dimensions using the Dimension Specific Modules (DSM). It is a concept that could increase the sensitivity and information provided by the EQ-5D and underpin future evolvments of the instruments. Since the Plenary Meeting, further work testing potential methods for developing a multi layered instrument based on existing data has been conducted, and a consultation with the group membership is underway.

So far, this pilot exploratory work has been led by working group members, and our aim is to involve the wider membership in this initiative. Therefore, we call for proposals from the membership to inform the development of this potential research programme. Fundamental research exploring the basis of the approach is welcomed. This could be theoretical, and/or qualitative work exploring the development framework, the strengths and challenges of the approach, and the requirements of such an instrument. Work understanding what key stakeholders (for example end users including decision makers and clinicians) would require from such an instrument is also encouraged.

We also call for exploratory empirical work to understand how DSMs could be formulated and developed. At this point the DSWG is focusing efforts on a single dimension (Mobility) whilst acknowledging unique challenges across the five dimensions. This could include consideration of how items for a DSM focusing on Mobility could be developed and tested qualitatively and quantitatively. This will inform the next stages of the research programme.

Consultation with the DSWG about proposals in this area is strongly encouraged.

#### **General information**

Please contact Brendan Mulhern (Brendan.mulhern@uts.edu.au) to discuss potential proposal submissions and/or for further information about any of the research areas described.

We encourage members to discuss their ideas for innovative descriptive system related research with the chair of the working group (contact details below). Ideas should be considered within the updated aims of the DSWG (see Appendix 1). Members of the working group are available to provide advice on your ideas for research and support the development of proposals.

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<sup>2</sup> Mulhern B, Finch A, Janssen MF, Oppe M. (2022). A multi layered “Deep Dive” measure of health-related quality of life based on the EQ-5D: Introducing the approach. EuroQol Plenary, Chicago.

## 2.2 Education and Outreach Working Group

As part of its mission, the EuroQol Group supports activities designed to develop and support its membership, as well as disseminate knowledge to the wider scientific community. The Group also supports outward-facing activities designed to enhance the understanding of EuroQol technologies across an expanding range of end-users. The Education and Outreach Working Group (EOWG) has a role in supporting initiatives to achieve these objectives.

The EuroQol Research Foundation funds a variety of initiatives to support dissemination and knowledge transfer, these include:

- Education and outreach activities
- Travel grants
- Journals Open Access fee reimbursement

### 2.2.1. Education and outreach activities

With the increasing volume of research funded by EuroQol Research Foundation, we seek proposals to better disseminate and transfer generated knowledge. We also invite members to submit proposals for education and/or outreach activities that support the mission of the EuroQol Group (<https://euroqol.org/euroqol/vision-and-mission/>). For example, funding may be requested for developing and teaching courses, or conference visits to support dissemination of new research findings, or organization of workshops or webinars. We invited you to think about your event considering the following aspects:

Characteristics	Options
Event type	Meeting, workshop, roundtable discussions etc.
Event purpose	Strategic outreach and networking, training, education, scientific meeting etc.
Event format	Face to face, virtual, hybrid
Target audience	EuroQol members, end-users, early career researchers, policy makers etc.
Audience's location	International, regional (e.g., Asian), country specific etc.
Piggy-back to other meetings	ISPOR, ISQOL, HTAi etc.
Event program	Abstracts driven, invited speakers etc.
Collaboration with EuroQol WGs	Valuation, youth population, population and health systems, descriptive systems
Other funding source	Yes, no

If you have ideas for other activities that you would like feedback on, please feel free to send an email to Zhihao Yang ([zhihao\\_yang\\_cn@outlook.com](mailto:zhihao_yang_cn@outlook.com)). If you have other ideas to promote knowledge dissemination and transfer, the EOWG welcomes your suggestions.

### 2.2.2. EuroQol Travel Grants

*EuroQol travel grants* have been made available to students and researchers to provide funding for international travel and subsistence to undertake EQ-5D related research at a university or a recognized academic or policy center/institute under the supervision of a EuroQol member. The travel grants support short term visits abroad as well as long term partner institution residency. The scope of these travel grants is wide and could serve different aims, as discussed below.

### Short term EuroQol travel grants

The short-term travel grants support members who wish to meet physically to conduct EuroQol-related activities, mostly for specific projects, to travel abroad for a short period of time. These grants may also be requested with the purpose of meeting to develop projects/proposals, rather than working on existing projects. The period abroad can vary between a couple of days to 2 months. Please note: To receive funding for meetings or collaboration efforts of smaller teams, a deliverable should be clearly defined, such as a research proposal or a publication.

The amount of funding is limited to €15,000 per grant and this should be used for travel, training course fees, accommodation and subsistence only. An application form has been developed for the applicant to complete; it should also be signed by the member in the host organization who will host the applicant. The support from EuroQol is limited to the travel grant; all other support should be provided by the host institute.

### Long term travel grants

The long term travel grant allows researchers interested in getting more deeply involved with specific types of EuroQol work to get residency at an institute abroad for a specific period (2 months to a year) and be embedded in the team. The grant supports various types of residencies at a partner institute, e.g., work placements, internships, trainee ships, and research specialization visits. If you want to apply for a travel grant of this type, you will need to identify a EuroQol member at a partner institution as the host. Any EuroQol member who has demonstrated expertise related to your planned work may act as a host.

An alternative to partner institution residency could be similar arrangements with the EuroQol Office allowing researchers interested in the general scope of EuroQol activities to come to Rotterdam and be embedded in the office scientific team. The amount of funding is context specific.

### **2.2.3 Open Access (OA) fee reimbursement**

The EuroQol Group has a new **OA fee policy** that the foundation will refund all costs of publishing articles in open access journals, either for manuscripts related to funded projects or for manuscripts on EQ related works led by members and relevant to EuroQol in another way. To apply for the OA reimbursement, a request needs to be submitted in the grant submission portal.

### Open Access publishing - avoid predatory journals

The EuroQol Research Foundation stimulates the Open Access publication of manuscripts in general. However we are concerned about predatory journals that charge Article Processing Costs for publication without providing proper editorial services and peer review. Publishing in these kind of journals can cause reputational damage for academics and by extension for the Foundation. We therefore ask you to avoid publishing in predatory journals. While there is no universally accepted white or black list of journals, we kindly ask you to verify the status of the journal that you are targeting, for instance by checking whether it is included in the Directory of Open Access Journals (a whitelist) or predatoryreports.org (a blacklist). Open Access fee reimbursement requests for journals with a questionable reputation may be denied.

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## 2.3 EQ-HWB Working Group

The EQ-HWB WG calls for proposals contributing to four areas that will support the group in furthering evidence about the EQ-HWB and EQ-HWB-S. These areas draw on feedback received by the Executive Committee, which highlighted gaps that need addressing to move the instruments IP status forward, and are:

- Production of evidence for the EQ-HWB and EQ-HWB-S psychometric performance
- Scoring of the EQ-HWB
- Conceptual work investigating the positioning of the EQ-HWB measures relative to health, social care and carer related quality of life measures
- Engagement with international stakeholders and dissemination activities

### 2.3.1 *Production of evidence on the EQ-HWB and EQ-HWB-S psychometric performance*

To strengthen the evidence base, we are calling for research examining the EQ-HWB and EQ-HWB-S. For the **EQ-HWB-S**, we are particularly interested in addressing three gaps:

- The content, construct and known group validity of the EQ-HWB-S in informal carers.
- The responsiveness of the EQ-HWB-S in comparison to external indicators and competitor instruments, in assessing health and social care interventions. These may vary by jurisdiction but include common preference-based health measures such as the SF-6D, AQL-8D, HUI, measures developed for or recommended for use in social care such as the ASCOT (social care and informal care versions) and the ICECAP measures, and informal care measures such as the CarerQoL-7D.
- Exploration of the use of a visual analogue scale (VAS) for the EQ-HWB-S. Research in this area could investigate the use of different anchors (for example wellbeing and health), comparability with the EQ-VAS, or the inclusion of multiple VAS (for example a health VAS and a wellbeing VAS)

For the **EQ-HWB**, the WG welcomes a broader program of work examining the psychometric characteristics (i.e., validity, reliability, and responsiveness) of the instrument, including:

- Investigations of the use and validity of the EQ-HWB in social care users or people living with disabilities.
- Investigations of the responsiveness of the EQ-HWB to change in comparison to external indicators of change especially in the context of long-term health conditions, social care and for informal carers.
- Comparisons of the EQ-HWB responses across different modes of administration (e.g., Self-complete paper and electronic version comparisons) especially where different modes of administration may be considered applicable e.g. in the elderly.
- Investigations of differential item functioning of the instrument based on different language versions

In addition, studies investigating the psychometric comparative performance of the EQ-HWB and EQ-HWB-S are also welcome.

### **2.3.2 Scoring of the EQ-HWB**

The EQ-HWB WG welcomes research examining approaches to scoring the profile measure. Examples of possible approaches include, but are not limited to, applications of item response theory, Rasch analysis, mapping and comparative work on possible alternative scoring algorithms.

### **2.3.3 Conceptual work investigating the positioning of EQ-HWB measures relative to health, social care and carer related quality of life measures**

The EQ-HWB welcomes theoretical and conceptual research on the distinction, usefulness and applicability of measures of health, well-being and social care. This could be theoretical, and/or qualitative work exploring the EQ-HWB instruments and their possible uses and applications.

### **2.3.4 Engagement with international stakeholders and dissemination activities**

A key requirement for promoting the EQ-HWB-S and the EQ-HWB is to engage with external and international stakeholders. Examples of these stakeholders include health technology assessment bodies, national departments of health and social care, public and patient engagement groups, clinicians and others. Qualitative research investigating the requirements, views and perception of relevance of the new instruments in these groups, and that highlight possible gaps that the instrument can cover, is welcome.

The EQ-HWB also welcomes initiatives aimed at promoting the dissemination and knowledge transfer for the instruments. These include organization of round tables, of conference panels and other forms of outreach.

## **2.4 Populations and Health Systems (PHS) Working Group**

The Populations and Health Systems Working Group (PHSWG) aims to promote and enhance the use of EuroQol (EQ) instruments in health system applications (e.g. for measuring health systems performance, enhancing patient-centred care, evaluating and improving quality of care, and evaluating health policy ), and for the measurement and valuation of population health. The PHSWG is interested in innovative proposals for both methodological and applied research that contributes towards these aims. Applicants are encouraged to review the WG's full stated research interests and priorities (appendix 1) and to contact co-chairs of the WG to establish that their proposal is within scope prior to application.

For this round of funding, the PHSWG is particularly interested in submissions that address the following topics:

### ***2.4.1 Methods to present, report, and interpret EQ data***

There has been an increased use of EQ data in various non-HTA applications including routine outcomes measurement within health systems, population health assessment and surveillance, and commissioning of value-based care. In these applications, EQ data needs to be presented to, reported, and interpreted for various stakeholders and audiences. As such, we encourage research that addresses the following sub-topics:

- Methods and approaches to summarize and present EQ data (especially dimension level data and EQ VAS scores) to various stakeholders (including patients, clinicians, administrators/managers, policy makers) to establish their preferences over different presentational formats, or to develop new ways of presenting data e.g., in the form of clinical dashboards
- Methods for developing a non-preference-based scoring for EQ instruments
- Methods for interpreting various data elements of the EQ-5D (dimension level data, values and EQ VAS scores), such as the MID

### ***2.4.2 Use of PROMs data in routine care***

The PHS WG seeks to understand uses of PROMs in routine care, and what role the EQ instruments already play or could play in the future. We know that some health systems already collect PROMs data at national (e.g., in England, Wales, Sweden) or sub-national levels (e.g., in some provinces of Canada, New South Wales) but our understanding is incomplete. We encourage research that examines the following sub-topics using appropriate methods (e.g. scoping reviews incl. grey literature; qualitative analysis):

- Where is routine collection of PROMs taking place, how are PROMs data used to inform patient, clinical, managerial or commissioning decisions, and how and why are the EQ instruments used in this context (or not).
- What are potential barriers and facilitators for the uptake of EQ instruments in routine care?

Please note that research to investigate the use of PROMs in clinical studies or in the context of health technology assessment is likely to be out of scope.

### ***2.4.3 Assessing the usefulness of EQ instruments to characterize major societal or natural events***

This topic is aimed at assessing whether EQ instruments are sensitive and useful to capture the impact of major events such as disasters (natural or human-caused), crises or wars. This may also include the impact of an economic or energy crisis. Apart from capturing the overall impact of any major event, ideally EQ instruments would also be sensitive enough to capture various degrees of resilience across (groups of) respondents. The actual impact of any major event on population health will of course also be of interest to report. Although ideally data prior to the event would be available to assess the impact of the event, in many cases one will have to rely on recall methods to assess the health or HRQoL status prior to the event. As recall bias may affect outcomes, methodological studies studying recall bias using EQ instruments are also welcomed. Note that this topic is considered to fall under innovative research. As there might be conceptual and methodological challenges, a proposal involving large scale primary data collection is not sought at this point.

### ***2.4.4 Using EQ instruments in studying health inequalities***

As the EuroQol instruments are being implemented more often in large epidemiological studies and routine data collection, standardizing equity stratifiers can facilitate and encourage comparisons across studies and countries. We encourage research projects that focus on the following sub-topics:

- Examination of equity stratifiers, either foundational work on a set of stratifiers which can be uniformly applied across studies and/or empirical work on the measurement properties of stratifiers.
- Investigating measures of inequalities (e.g., the concentration index, slope measure of inequality), including proposals focusing on inequality decomposition, i.e., where health inequalities are decomposed into various contributing explanatory factors.

## 2.5 Valuation Working Group

The EuroQol Valuation Working Group (VWG) has a broad remit, reflecting the importance of valuation methodology to all our instruments. The VWG is charged with multiple aims across a variety of areas that include:

- investigating how our existing valuation methods may be further refined;
- investigating new approaches to valuing health;
- investigating the most appropriate methods for valuing new EQ instruments;
- exploring normative issues related to valuation, for instance, in the context of value sets being constructed for and by different populations (e.g., patient groups or children/adolescents);
- collaborating with working groups or other approved groups (e.g., special interest groups, task forces, and squads) on conceptual and practical issues related to the valuation of EQ instruments.

More specifically, in the context of the above aims, for the present call we identified the following priority areas. First, we encourage proposals focused on methodology to support discrete choice experiments (DCEs) as a stand-alone approach to valuation. Specific areas of interest are approaches to generating design updates, methods to identify respondents with poor quality data especially in the presence of non-linear time preferences, and proposals that make rigorous analyses of DCE data accessible to analysts with a good working knowledge of regression modelling.

Second, we are interested in proposals that aim to explore methods that can be used for the valuation of bolt-ons. The proposals should consider the issue of comparability between bolt-on and core-dimensions value sets, the methodological soundness of the methods, and the pragmatic considerations (such as the possibility that a significant number of bolt-ons might be valued in the future). The proposals can either relate to new ideas for bolt-on valuation or scrutinizing the existing approaches (for instance, the shrinking factor model). Proposals could focus on formulating and testing the assumptions of the valuation methods (for instance, the additivity of utility between the core dimensions and bolt-ons) or on proposing how to efficiently conduct bolt-on valuations (for instance, how to efficiently use the existing core-dimension value set).

Please note that the VWG and EQ-5D in Younger Populations Working Group (YPWG) are jointly planning a programme of methodological work in preparation for a future protocol for the valuation of the EQ-5D-Y-5L. The specifics of this call will be announced in the YPWG section of the Request For Proposals and they are not included here, to avoid duplication.

Proposals not directly related to the above areas are still welcome if they can demonstrate a clear practical relevance for the EuroQol Group and the valuation of EQ instruments.

For any doubts regarding the priorities in the present call, please contact the VWG Office liaison ([roudijk@euroqol.org](mailto:roudijk@euroqol.org)) or the VWG chair ([michal.jakubczyk@gmail.com](mailto:michal.jakubczyk@gmail.com)).

## 2.6 Younger Populations Working Group

*Contribution from the Y-5L valuation squad on behalf of YPWG*

### Preparing for Y-5L valuation

The EQ-5D-Y-5L is planned to be launched in Q2 2024. A joint VWG/YPWG group has been established to consider the methods work which is required to prepare for valuation of the Y-5L. The group held a workshop with a range of experts in valuation of pediatric health in March 2023 to consider what has already been learned from valuation of Y-3L, what evidence gaps remain, and what further options for the valuation of Y-5L might be explored. A number of research priorities which have been identified for which proposals are now welcome:

#### **2.6.1 Exploring a response mapping between the Y-5L and the adult EQ-5D-5L instruments, to establish whether it is feasible to establish a robust crosswalk between the two.**

Research into methods to elicit preferences for Y-based health states has generally focused on approaches which produce values that are specific to the age(s) of children covered by Y instruments (Y-3L and Y-5L). For instance, when valuing Y-3L health states, we ask respondents to think about the health states in the context of a 10-year-old child. An alternative to the generation of such 'age specific' values is to link the Y-5L to the adult 5L instrument, i.e. to establish a crosswalk which means that Y-5L profile data can be preference weighted using existing adult 5L value sets. Such an approach would have the advantage of smoothing the transition between Y-5L and adult 5L instruments and make the results obtained in, for example, CUA studies more comparable. Whether such a mapping is possible, what the characteristics of the response mapping and mapped values would be, and what the advantages and limitations of such an approach would be (e.g. from a user perspective), have yet to be explored. We welcome proposals to investigate these questions, particularly from those who already have access to Y-5L and adult 5L profile data, or are able to collect such data, from relevant samples.

#### **2.6.2 Mixed methods research to explore ways of obtaining stated preferences from children and young people.**

The Y-3L valuation protocol focused largely on collecting stated preferences for Y-3L states from adult members of the general public. However, consultation with HTA bodies in Canada, Australia and the US has shown that there is considerable interest from decision makers in learning more about children's health state preferences with the view to, potentially, incorporating them in the assessment of health technologies for pediatric populations. Research has been undertaken to obtain stated preferences from children (e.g using latent scale DCE), but in general these have used tasks designed for use in adults. To date there has been little attempt to design tasks to be acceptable and feasible for use in children, or to establish the lower age bounds for preference elicitation. We call for research focusing on eliciting children's stated preferences. A useful starting point would be a review of the existing literature on stated preference research performed to date in children and adolescents. We also welcome proposals which employ innovative mixed methods (i.e. qualitative and quantitative) research to develop and test preference-elicitation (valuation) methods for use in children and adolescents and particularly welcome proposals that actively include consumers (children and young people) in the planning, design and implementation of those methods, following good practice in co-design.

### 2.6.3 Use of DCE with duration as a 'standalone' approach for valuing Y-5L.

In the current Y-3L valuation protocol (and indeed in the EQ-VT protocol for valuing adult states), the role of DCE is restricted to obtaining preference information concerning the relative importance of levels and dimensions i.e latent scale DCE. However, there is increasing interest (e.g. in valuing adult health states) in the potential for using variants of DCE that include duration (in particular, methods that incorporate non-linear designs) as a standalone method for valuing HRQoL in a manner that is anchored at 1 and 0 as required for QALY estimation. To date, there have been *no* studies undertaken to explore the use of non-linear DCE with duration approaches in the valuation of child health states by either adult respondents or adolescents. We welcome proposals to investigate the use of these methods in valuing Y-5L, with a view to exploring issues of particular relevance to valuing pediatric health states (e.g. unwillingness to trade off life years for quality of life in children; the role and relevance of time preference) into account in valuation.

### 2.6.4 Addressing issues in the use of TTO to value the Y-5L.

While, as we note above, a priority is to explore the potential for use of DCE with duration as a method for valuing Y-5L, we also recognise that TTO methods continue to have strong appeal to HTA bodies (e.g., the new UK 5L value set is based on TTO only). For this reason, we also call for methods research to address remaining issues identified with the use of TTO in valuing Y-3L that are also relevant to valuation of Y-5L. This includes:

- Addressing the issue that arises in the current protocol's use of cTTO in obtaining values  $> 0$  and  $< 0$  i.e. for values  $> 0$ , the state being evaluated occurs in a 10-20 year old, whereas for values  $< 0$ , the use of the lead time means the state to be evaluated occurs at 20-30 years of age.
- Ways of mitigating adults' unwillingness to trade off child life years
- Exploring the feasibility and acceptability of the use of TTO-based approaches to elicit children's preferences from an 'own health' perspective.



### **3 Submission Guidelines**

#### **3.1 Available budget**

For the current call a budget of up to €1-1.5M can be made available, but the Foundation reserves the right not to distribute all the funds available for this round depending on the number and quality of proposals received.

#### **3.2 What we fund**

This call invites applications for various types of research grants: proposals for small projects, regular research applications, proposals for educational or regional meetings, topical research applications for larger projects or programmes of work, and proposals for funding of PhD research.

**Low cost proposals:** Low cost proposals (max budget €25,000) qualify for a lighter review procedure. These proposals will be reviewed by WGs and based on these reviews a decision will be made by the Executive Committee.

**Topical research program proposals:** Members are invited to submit proposals for larger projects, possibly of a longer duration (i.e. 2-4 years), either as a coherent series of studies, or one very large study, to an intended maximum of €150K. Requests for larger budget can be made, but a strong motivation would be needed and it is recommend to look for co-funding from another organization instead. Interested members are encouraged to contact the relevant WG Chair to ensure alignment with ongoing- and planned research. For grants that fall within this category, the Executive Committee will provide feedback on a first-stage application before a full grant proposal can be applied for.

**PhD proposals:** The current call also invites applications for PhD scholarships/fellowships. The Executive Committee has prepared a practical guidance document for applicants seeking funding for PhD proposals from EuroQol (Appendix 2).

The attached budget guidelines specify how the budgets should be presented. The budget guidelines are the same for all proposals.

For more detailed information on the types of grants that EuroQol offers, please refer to Chapter 2 of this call and appendix 2, guidance for applicants.

#### **3.3 Who can submit?**

In this round, the EuroQol Research Foundation accepts proposals that are submitted by research teams or individual researchers affiliated to different institutions/organisations (Universities, NGOs, companies, etc.). The Principal investigator does not need to be a member, but at least one EuroQol member has to be involved in the project as co-investigator.

All researchers are strongly encouraged to contact the relevant WG Chair to discuss plans for proposals, to ensure alignment with ongoing and planned research, and alignment with the research objectives of the WG and this Call for Proposals. If you would like input or have questions about the preparation of your proposal, please email the relevant WG contact below, or for general questions, contact Laura Pickering, Grants Manager at [pickering@euroqol.org](mailto:pickering@euroqol.org).

### 3.4 Submission procedure

All proposals reports will need to be submitted via the EuroQol Projects Submission Portal: <https://euroqol-proposals.grantplatform.com/>. You will first need to register to create a personal account. Then you can start working on your submission. Progress will be saved, and you update your submission right until the submission deadline (even if you have submitted it already). The deadline for submissions is **Sunday 22 October 2023 at 23:59 CEST**.

At registration, please make sure to accept receiving broadcast emails, and notifications from the system to facilitate communication.

### 3.5 Timelines

After the deadline:

- the Scientific team leader will check whether your proposal meets the call's eligibility criteria.
- experts will review all the eligible proposals in November 2023
- your proposal will be discussed by the Exec in December 2023
- applicants will normally receive further information about the decision of the Exec within three weeks after the Exec meetings (by mid-January, taking into account the Christmas break).

### 3.6 Further information

For further information, you can contact Elly Stolk (EuroQol Scientific Director), Laura Pickering (Grants Manager), the relevant working group chairs and Office scientist(s) who support that WG, or any other members of that WG. The primary contacts of each WG for questions about this call are:

Descriptive Systems	Brendan Mulhern	<a href="mailto:Brendan.Mulhern@chere.uts.edu.au">Brendan.Mulhern@chere.uts.edu.au</a>
	Fanni Rencz	<a href="mailto:rencz@euroqol.org">rencz@euroqol.org</a>
Education and Outreach	Zhihao Yang	<a href="mailto:zhihao_yang_cn@126.com">zhihao_yang_cn@126.com</a>
	Mandy van Reenen	<a href="mailto:vanreenen@euroqol.org">vanreenen@euroqol.org</a>
EQ-HWB	Clara Mukuria	<a href="mailto:c.mukuria@sheffield.ac.uk">c.mukuria@sheffield.ac.uk</a>
	Aureliano Finch	<a href="mailto:finch@euroqol.org">finch@euroqol.org</a>
Populations and Health Systems	Juanita Haagsma	<a href="mailto:j.haagsma@erasmusmc.nl">j.haagsma@erasmusmc.nl</a>
	Bas Janssen	<a href="mailto:janssen@euroqol.org">janssen@euroqol.org</a>
Valuation	Michal Jakubczyk	<a href="mailto:michal.jakubczyk@gmail.com">michal.jakubczyk@gmail.com</a>
	Bram Roudijk	<a href="mailto:roudijk@euroqol.org">roudijk@euroqol.org</a>
Younger Populations	Mike Herdman	<a href="mailto:mikeherdman.insight@gmail.com">mikeherdman.insight@gmail.com</a>
	Bram Roudijk	<a href="mailto:roudijk@euroqol.org">roudijk@euroqol.org</a>

If you are interested to seek collaboration or get access to the data which may become available as part of the agreements with researchers/authorities in Sweden and Alberta, Canada, please contact the local contact persons (copying the WG chair):

Emelie Heintz (Sweden)	<a href="mailto:emelie.heintz@ki.se">emelie.heintz@ki.se</a>
Fatima Al Sayah (Alberta)	<a href="mailto:falsayah@ualberta.ca">falsayah@ualberta.ca</a>

#### **4 Appendices**

1. Working Group (WG) aims
2. Guidance for applicants
3. Budget guidelines
4. Grants offered by EuroQol
5. SAVED information for applicants

## **Working Group (WG) aims**

*By the EuroQol Executive Committee*

*Last update: August 2023*

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## 1. Introduction

In this document, informed by the Strategic Research Priorities and WGs Review documents, we describe the current scope of each WG. It is to explain why and how the Working Group (WG) structure has been introduced, what the current objectives are, and how WGs will work. The WGs will be generating Requests for Proposals (RFP), which will be calls for targeted research, to which any EuroQol Group members may respond. These will represent important new opportunities for members of the EuroQol Group to obtain funding for research.

## 2. General information about the WG policy

### 2.1. Background to Working Groups as an Initiative

- The continued success of the EuroQol Group and non-profit status requires that our revenues and the substantial reserves be invested in research and development.
- The Executive Committee has a responsibility for establishing the scientific direction of the EuroQol Group, and in promoting and funding a research programme consistent with the overall scientific strategy.
- The WGs were set up to represent the principal means by which we channel ideas and proposals to the Executive Committee for consideration for research funding.
- Working Groups (WGs) are charged with clearly defined, specific objectives relating to the scientific agenda of the EuroQol Group, as defined by the Executive Committee.
- WG Chairs will report progress towards the stated aims of a WG annually to the Executive. Informed by progress towards stated aims and strategic priorities, the WG structure or objectives states for WGs can be revised by the Executive Committee.
- The performance of WGs will be reviewed on a periodic basis (e.g., every 2 years).
- Overall, the WG structure has proved to be an effective and productive source of research deliverables for the EuroQol organization.

### 2.2. Implementation of the WG structure

- WGs Chairs and members will be selected by the Executive Committee. An appeal for nominations from the membership be made for WG Membership can be part of the selection procedure.
- Although WG Chairs may independently reach out and contact a potential member directly to nominate him/herself for a WG position, EuroQol members are encouraged to nominate themselves. Those EuroQol members who are interested in working on a particular WG should express their interest through the Business Office. Subsequently, the WG Chairs will submit a list with the proposed WG members from the list of nominees to the Executive Committee for their feedback and to finalize the Work Group teams. Membership in more than one WG is permissible.
- The membership of each WG will be revisited at least annually to ensure a collaborative and productive team-based approach. EuroQol members may express their interest to join a WG at any time to the Business Office.

- Our goal is to engage all members of the EuroQol Group in the research activities being coordinated by the WGs. Note that the mandate of each WG is not to conduct research, but to coordinate and facilitate it. The WGs are encouraged, but not required to, establish a Special Interest Group (SIG), which comprises EuroQol Group members with a demonstrable research interest in the relevant area. The SIGs will provide a wider network of researchers with which the WG can liaise, seek input from and keep informed about the RFPs being developed. SIG members will be able to share with the WG any information or topic that has relevance for its research agenda. EuroQol Group members who are interested in being a member of a given SIG should contact the relevant WG Chair, explaining their expertise and research activities in the area of work. For reasons of efficiency, the number of persons participating in a SIG may be limited. A current example of a SIG lies within the Children WG.
- From time to time, a Taskforce of Program Team (PT) will be initiated, charged with a specific aim. The PT differs from the SIG by the fact that it is an ad-hoc team to conduct specific studies that generate evidence on strategically important research questions in a short period of time. If considered necessary to realise their objectives, a WG can propose the need for an PT to the Executive Committee. This approach has proven to be very effective in getting a lot of work done in a short period of time. A taskforce or PT reports to, and works in close cooperation with, the WG. The taskforce or PT will be dissolved once the objectives have been achieved. A WG can send out nomination calls for Taskforce or PT membership. After receiving a proposal by the WG the Executive Committee will formally appoint the members. Recent examples of a Taskforce was the 3L/5L Taskforce charged with investigating the consequences of transitioning from 3L to 5L. An older example was the team that conducted a series of studies to improve the TTO module of EQ-VT, under supervision of the Valuation Methodology WG.
- Lastly, we consider it essential to promote and support novel, innovative research, whether it is covered by the Strategic Research Priorities or not. Proposals for innovative research are welcome and can be submitted at any time. They will be reviewed directly by the Executive Committee.

### 2.3. How can members of the EuroQol Group find out more about the activities of the WGs?

Information about the progress of each WG and calls for proposals will be posted on the members’ area of the website and updates will be emailed to all EuroQol group members.

EuroQol Group members are encouraged to email the WG chairs and liaisons if they are wondering which WG would be best aligned with a research idea or proposal. If in doubt, please contact the Scientific Director Elly Stolk (stolk@euroqol.org), or the Executive Director Bernhard Slaap (slaap@euroqol.org), for guidance or feedback.

### 2.4. Summary of WGs

The WG structure currently includes six WGs:

Working Group	Aim
Descriptive Systems WG	The aims of the DSWG are framed around the generation of knowledge for, and development of, existing instruments, instruments currently under development, and future instruments. .
Education and Outreach WG	As part of the broader mission of the EuroQol group, this WG leads initiatives to educate members, and the broader scientific community/ policy maker to promote better understanding of the uses of EQ-5D and its underlying science.
EQ-Health & Wellbeing WG	To produce evidence and knowledge on the EuroQol Group’s portfolio of measures that include broader wellbeing aspects beyond health.
Population and Health Systems WG	The purpose of the PHS WG is to promote and enhance the use of EuroQol instruments in health care system applications, and for the measurement and valuation of population health.
Valuation WG	Focus on valuation methods. However, the activities have been extended to include international initiatives related to prospective valuation studies and international initiatives using data collected from valuation studies.
Younger Populations WG	Validation and valuation of the EQ-5D-Y versions



## 2.5. WG Principles

- The WGs are intended to be relatively small, **focused** groups, with specific objectives to be agreed with the Executive Committee.
- Unless otherwise stated, the WGs will provide a progress report and future plans on an annual basis, and will undergo a formal review after 2 years, but the Executive Committee reserves the right to revise the terms, membership, and viability of each WG at any time.
- The WGs will be responsible for leading and driving forward research and development that falls within scope of their mandate. Through Requests for Proposals (RFPs) and Program Announcements (PAs) developed by the WG with input from the Executive Committee, each WG will present aims for the grant round and provide information about current research priorities. Members of WGs can also apply, but the WG is not expected to lead the research as a team.
- The WGs are accountable to the Executive Committee. Each WG Chair will keep the Executive periodically updated regarding the team's status and progress. Additionally, a EuroQol Office scientist will serve as 'liaison' to facilitate communication between the EuroQol office and the WG. The Office scientists are not automatically considered as WG members but can nominate themselves to become a formal WG Member in a manner consistent with other members.
- To further ensure good communication, the Executive Director and Chair of the Executive Committee, or their designee, should in principle have access to WG meetings as needed.
- In the remainder of this document, we provide details on the remit of each WG, and the aims they are charged with.

### 3. Current remit of each working group

#### 3.1. Descriptive System Working Group

*(last updated: August 2021)*

##### 3.1.1. Aims of the DSWG:

The three aims of the DSWG are framed around the generation of knowledge for, and development of, existing instruments, instruments currently under development, and future instruments. The aims are as follows:

1. To generate further knowledge and understanding of existing EuroQol instruments
2. To further develop the descriptive systems of EuroQol instruments (including existing instruments, instruments under development, and bolt-ons) scientifically and strategically.
3. To explore the development of future instruments, descriptive systems and bolt ons, scientifically and strategically.

These aims position the DSWG as central to the life cycle management of EuroQol instruments (current, those under development, and future). They enable the DSWG to develop research activities and programmes, and work on priority areas, as guided by the Executive Committee over the short and long term. They lead to the production of knowledge and outcomes with relevance to the entire EuroQol group.

##### 3.1.2. Broad research programmes and activities

Within the three suggested aims, research programmes and activities will be developed and coordinated by the DSWG. A broad set of programmes and activities are outlined below. These will be refined and prioritised by the DSWG in consultation with the Executive Committee and EQ office, and can be subdivided into smaller programmes of work as needed. This list is not exhaustive, meaning that the DSWG can be responsive to changes in the research landscape, and add programmes and activities as and when needed. The DSWG is interested in the use of mixed methods approaches (including literature reviewing, and qualitative and quantitative work) across its research activities.

##### a) Programme of research to evaluate current and future EuroQol instruments

*(Aims 1-3)*

This programme will:

- Generate knowledge about existing EuroQol instruments in different populations and settings. This can be done using mixed methods approaches in primary and secondary data, and literature reviews.
- Further develop group expertise in psychometric methods by testing approaches for the evaluation of existing EuroQol instruments.
- Assess the cross cultural validity of EuroQol instruments

Within this broad programme, there are specific areas related to the instruments that can be investigated. For example, these include, but are not limited to:

- Assessing consistency across the same versions of instruments (e.g. issues around mode of administration, language versions, interviewer administered versions, proxy and self-complete)

- Investigating descriptive system issues (for example, investigating the composite dimensions (PD and AD) building on other recent work in this area)
- EQ VAS-specific research
- Testing the influence of recall periods (current and alternative)
- Supporting the VMC with their research needed

*b) Programme of research to test methods for the development of instruments and descriptive systems (Aims 2-3)*

This programme will:

- Further develop group expertise in psychometric and measure development methods by testing approaches for the development of new instruments and descriptive systems. This can be done using mixed methods approaches in primary and secondary data, and literature reviews.
- Testing methods to promote the cross cultural validity of future EuroQol instruments and descriptive systems
- Test the use of innovative methods (e.g. multidimensional IRT) in the development and assessment of new items or attributes

*c) Moving towards a psychometric protocol for the development and testing of EQ instruments (Aims 1-3)*

- The output of Programmes 1 and 2 could further develop a psychometric evidence knowledge base to inform the broader work of the group, and support the DSWG in generating a psychometric protocol for the development and testing of all current and future EuroQol instruments

*d) Research programmes to explore the development of items, attributes or versions linked to the core measure (Aims 2 and 3)*

- These long term initiatives may include research to explore extensions to the core measure, including, for example, the development of a deep dive instrument, and a pictorial version of the descriptive system.

*e) Further production of evidence on bolt-ons (Aims 1 – 3)*

The DSWG will develop their existing bolt on research programme to:

- Conduct conceptual work based on current and future bolt-ons
- Extend bolt-on development strategically (e.g. where bolt-ons may be required)
- Test the performance of existing bolt-ons in different settings in relation to the five dimensions, the dimensions included in other instruments, and other bolt-ons (this also links with Programmes 1 - 3)

*f) Exploration of conceptual frameworks for existing instruments, additional instruments and descriptive systems (Aims 1 – 3)*

Conceptual framework research is at the core of the development and understanding of instruments, and our work in this area can:

- Outline the conceptual framework for developing additional health instruments (e.g. deep dive instruments and item banks).

- Outlining the conceptual framework for developing extended health instruments (e.g. PREMS, quality of care, wellbeing and end of life instruments)
- Understand and describe what is meant by the concepts and terminologies used in the field and test the appropriateness of EuroQol instruments to measure these

*g) Collaborate with other WGs to support instrument development*

Collaborate with the EQ-HWB WG to support the further development of the EQ-HWB instruments in research areas fitting with the remit of the DSWG. For example:

- Validation of the EQ-HWB-S and EQ-HWB
- Translatability and adaptation to other cultures and languages
- Comparisons to other measures
- Longitudinal performance

Collaborate with the YPWG on further development of experimental instruments and modifications, including the EQ-TIPS.

*h) Involvement in the development of a framework and process for moving instruments through IP stages (experimental, beta and approved).*

The work of the DSWG is central to the process required to progress instruments and bolt-ons through the IP stages. The DSWG is leading the development of the documentation outlining this process, and the work led by the group will be central in producing the evidence required to make decisions about instrument status.

The programmes and activities are broadly described within the aims, and can be further developed prioritised by the DSWG in consultation with the Executive Committee. It will be possible for the DSWG and Exec to seek 'alignment' over the short and long term objectives and priorities of the DSWG. This could be via semi-regular discussions (for example twice a year) between DSWG, Executive and EQ office stakeholders.

### *3.1.3. Other initiatives:*

To maximise the potential of the aims and research themes outlined above is planning a number of related initiatives:

- Explore the potential to set up a DSWG specific SIG, or project specific taskforce. For example, this could be a general SIG around DS specific issues, or targeting a particular part of the research programme (the development of the approval guidelines, or the development of a pictorial version).
- Explore the potential to develop a data repository for use in DSWG specific projects (in collaboration with the office as potential coordinators of the process)
- Build further collaboration with other WGs and committees. This will include close coordination with the VMC (building on a recent joint call for proposals), and possible coordination of the valuation of bolt-ons with the VWG. The development of criteria for moving instruments forward in status is also relevant to the YWG and HWB, and we will build links with them for involvement in that process. The development of the research activities above would benefit from consultation with the PHSWG.

## 3.2. Education and Outreach Working Group

### 3.2.1. Aims of the Education and Outreach Working Group

The aim of the EOWG is to support the EuroQol Group to achieve its mission by:

- Enabling/facilitating the widest possible access to the accumulated research expertise of the EuroQol Group and promoting the transfer of knowledge and evidence regarding the use, analysis, and interpretation of measures developed by the EuroQol Group;
- Enhancing networking and collaborations amongst EuroQol Group members;
- Fostering and supporting an international community of researchers whose activity informs the development and application of EuroQol instruments;
- Supporting early career researchers in the field of health and quality of life research through involvement in EuroQol Group activities.

### 3.2.2. Rationale

The EuroQol Group is recognized having an important role as a key driver of methodological development in the area of measurement and valuation of health, we are aiming at effective communication and dissemination of our research output and generated knowledge among the EuroQol Group members, as well as the wider scientific community and users of EuroQol instruments.

### 3.2.3. Activities

In support of its aims, the EOWG undertakes a variety of activities:

- Meetings: there are three kinds of meetings that are directly organized or supported by the EOWG, including the Academy meeting, Early Career Researcher (ECR) meeting and regional meetings. These meetings serve different purposes and engage different audiences. Academy meetings provide a space for EuroQol members and external researchers to have in-depth discussions and deliberations on specific topics of interest related to research and application of EuroQol instruments and other elements of the EuroQol Research Foundation mission. The ECR Meeting provides structured opportunities of involvement, research, networking, training and mentorship for younger and relatively inexperienced researchers in EuroQol-related research. Regional meetings provide an opportunity to engage researchers and key stakeholders in certain geographic regions around the world (determined by regional interest and relevance) and to support EuroQol related research and application in those regions.
- Online events: current online events include the (co-)organization of the EuroQol webinar series, workshops, and PhD roundtable discussions. Webinars are often a one-hour event disseminating recent research project results. Workshops are often hosted by other WGs to discuss large research projects. PhD roundtable discussions are organized for EuroQol PhD network members on various topics relevant to the PhD Network.
- Funding short- and long-term travel grants for EuroQol members and Early Career Researchers (ECRs).
- Supporting the EuroQol PhD network.
- Collaborating with the communication team and disseminate EuroQol related information.
- Reviewing proposals to produce educational events or materials to be funded by the EuroQol Research Foundation.

### 3.3. EQ-HWB Working Group

*(Last updated: July 2023)*

The EQ Health and Wellbeing Working Group (EQ-HWB WG) was formed in December 2022 to produce evidence and knowledge on the EuroQol Group's portfolio of measures that include broader wellbeing aspects beyond health. These aspects may be relevant to the needs of specific populations, such as carers and those living with long-term conditions. Currently, the portfolio consists of two instruments, the profile EQ-HWB and the classifier EQ-HWB-S.

#### 3.3.1. Aims of the EQ-HWB Working Group

The EQ-HWB WG's primary aim is to support developmental activities to advance the EQ-HWB and EQ-HWB-S measures from experimental to beta status and ultimately to approved versions. This will be achieved by engaging with both internal (Executive Committee, other WGs, EQ researchers) and external (non-EQ researchers, reimbursement agencies, pharmaceutical developers, social care and public health policy-makers, public and patient engagement groups) stakeholders and strengthening the evidence base for the EQ-HWB and EQ-HWB-S.

As the type and amount of evidence required may differ between instruments for different stages of their development, the research program and objectives below represent broad categories that may apply to the profile, classifier or both. This flexible approach allows the WG to adapt its strategies and methods to meet the specific requirements of each instrument at any given stage of development.

#### 3.3.2. Rationale

The EQ-HWB WG aims to support research aims/questions and consolidate evidence arising from EuroQol and non-EuroQol researchers in order to establish the validity of the classifier and the profile measure before they move to beta status. The development of the EQ-HWB and EQ-HWB-S is summarised in various publications (see Brazier et al, 2022; Mukuria et al, 2022; Peasgood et al 2022; Carlton et al 2022) which focus on the item identification (UK) and qualitative and quantitative testing of the items undertaken internationally across six countries (Argentina, Australia, China, Germany, UK and USA).

Efforts initiated by the SIG under the DSWG are currently underway to test the measure rather than items which were previously tested alongside a long-list of candidate items but often as a subset drawn from specific domains as not all the candidate items could be tested in the same individual (Carlton et al 2022). This will generate evidence to support a change in the instruments IP status from experimental to beta. A feasibility valuation study has been completed (Mukuria et al 2023), and other work has also been initiated under the Valuation WG. Separately, the VMC has undertaken work to support development of appropriate translations. Research objectives 1 to 3 continue to be the immediate priority areas. Each vein of research generates evidence that is important for supporting movement towards beta (and approved) status, and it is important for there to be a systematic approach to collate and incorporate this evidence into any changes to the EQ-HWB measures.

EuroQol members and external stakeholders are interested in the performance of the EQ-HWB and EQ-HWB-S relative to other measures: for example, other carer and social care measures. Identifying where the gaps in evidence exist and initiating research in these areas is crucial in order to support uptake of the measures. The EQ-HWB WG will encourage engagement with stakeholders to determine their requirements and facilitate research efforts to identify any gaps in evidence.

### 3.3.3. *Broad research programmes and activities*

The research program and objectives of the EQ-HWB WG broadly relate to generating psychometric evidence for the instruments, generating appropriate scoring approaches, and facilitating a launch plan in key markets. Psychometric evidence on the validity of the measures is used to confirm or make changes to the experimental measures. The specific objectives of the research programme are as follows:

1. To generate further knowledge and understanding of the performance and validity of the EQ-HWB and EQ-HWB-S in relevant populations, with particular emphasis on addressing gaps identified by the Executive Committee, EQ bodies and/or key stakeholders. This implies:
  - Initiating, guiding and supporting development of qualitative and mixed-methods research on the profile and classifier measures to generate evidence on validity, including cross-cultural validity in relevant populations. Specific emphasis and priority will be on content validation of the measures in relevant populations e.g., informal carers and diseases known to have significant caregiving needs, such as Alzheimer's disease, Parkinson's disease, and multiple sclerosis. This will provide evidence on the appropriateness of the instruments in these contexts.
  - Initiating, guiding and supporting development of quantitative psychometric studies, using varied methods including classical test theory and latent class analysis, to validate the profile and classifier measures in relevant groups e.g. carers, those living with long-term conditions, difficult to reach populations, and populations defined by language. This evidence is required to demonstrate the validity of the instruments to key stakeholders.
  - Collaborating with the Descriptive Systems WG (DSWG) in applying guidance for generation of qualitative and quantitative psychometric evidence, including agreement on what level of evidence is sufficient to confirm validity.
  - Engaging with the Version Management Committee (VMC) to ensure questions arising from translation work are addressed, including possible differences arising from use of language versions.
  - Initiating research on other relevant aspects, such as the impact of mode of administration, the inclusion of a visual analogue scale, recall period, etc.

2. To conduct research in support of the positioning of the EQ-HWB and EQ-HWB-S alongside currently available health and wellbeing measures. This includes:
  - Initiating theoretical and conceptual research on distinctions, usefulness and applicability of measures of health, wellbeing and social care.
  - Initiating comparative methodological research on the coverage and differences between measures of health and those addressing both health and wellbeing to identify how the EQ-HWB measures address the research gaps they were intended to fill.
  
3. To identify and engage with international stakeholders (beyond health technology assessment [HTA] bodies to include national departments of health and social care, public and patient engagement groups etc.) and promote dissemination activities. Stakeholder engagement will enable the WG to clarify evidence requirements while also sharing research findings. There is potential to collaborate on these activities with the Education and Outreach Working Group, the EQ Board, Executive Committee and the EQ-HWB Special Interest Group (SIG) to:
  - Initiate knowledge exchange activities with external users and stakeholders including roundtable discussions.
  - Collate evidence of stakeholder requirements and views on the EQ-HWB measures e.g. potential uses outside of HTA including routine data collection, potential uses of the profile measure etc.
  
4. To support methodological research, in collaboration with the Valuation WG, to aid in the development of a valuation protocol for the EQ-HWB-S and ways to score and/or value the EQ-HWB. This means:
  - Initiating a program of mixed-methods research on the valuation of the EQ-HWB-S which can inform the production of valuation protocols. A mixed-methods approach reflects the need to ensure what is valued is relevant in a valuation context e.g. participants can comprehend information provided and that they can also consider all the information presented in valuation tasks.
  - Investigating approaches to scoring the EQ-HWB profile measure, including but not limited to valuing the EQ-HWB, mapping long form responses to values, and using item response theory (IRT).
  - Investigating mapping between the EQ-HWB-S and other preference-based measures, to enable assessment of the impact of using EQ-HWB-S in cost-effectiveness analysis.



### 3.4. Population and Health Systems Working Group

*(Last updated: May 2021)*

#### 3.4.1. Aims of the Population and Health Systems Working Group

The purpose of the PHS WG is to promote and enhance the use of EuroQol instruments in health care system applications, and for the measurement and valuation of population health. The PHS WG has several objectives grouped under the following three key remits:

1. Research
  - Initiate research on the use of EuroQol instruments in population health and health care systems applications (e.g. by initiating RFPs)
  - Guide and support the development of research applications under the PHS WG remit
  - Monitor and evaluate the progress of research related to the WG
2. Implementation and support
  - Support the initiation and development of PROMs programs utilizing the EuroQol instruments (e.g. for routine outcome measurement within patient registries and health organizations)
  - Support the development of proof-of-concept applications utilizing the EuroQol instruments
  - Explore the development of new products and tools that support the use of EuroQol instruments in health systems
3. Stakeholder engagement
  - Facilitate capacity building and knowledge exchange activities with external users and stakeholders (e.g., patients, providers, system administrators, and policy makers)
  - Promote the EuroQol instruments to new user groups (e.g. for monitoring, evaluating and promoting health systems performance)
  - Foster international collaborations amongst EuroQol Group members and users of the EuroQol instruments
  - Promoting the inclusion of EuroQol instruments in national health surveys

#### 3.4.2. Broad research programmes and activities

The WG is interested in innovative research proposals for both methodological and applied research. Within the three suggested aims, research programmes and activities will be developed and coordinated by the PHSWG. A broad set of programmes and activities are outlined below. Note that research interests and priorities of the PHS WG may overlap with those of other WGs such as the DSWG and the EOWG. For advice or guidance in developing your research proposal, please feel free to contact the co-chairs or members of the PHS WG, the Health Inequalities SIG or members from the Canadian APERSU program, and the Swedish PROMs program.

##### *a) The use of EuroQol instruments in population health assessment*

This topic covers research activities that attempt to measure the health of the general population using EuroQol instruments. We encourage analysis of secondary data as well as primary data collection. These data will typically also include information on the presence of conditions and general background variables (age, gender, socio-economic characteristics).

We are especially interested in research proposals, preferably involving more than one country, in the following areas:

- *Measuring population health and examining its determinants:* This includes areas of study such as the burden of disease, changes in population health status (due to e.g., disasters or COVID-19), population risk factor models (e.g., including vulnerability), and population norms. As well as descriptive studies, we are interested in studies exploring factors that determine population health status including demographic, cultural and epidemiological factors, and how these impact on health over geographical regions and time.
- *Studying health inequalities:* We are interested in studies that measure inequalities in health and health care using EuroQol instruments, including the relationship of inequalities to social and individual determinants of health and specific policies (local, national). This includes the relation of health inequalities to healthcare access inequalities and the impact of external factors like the COVID-19 pandemic and social policies. This may also include the intended and unintended effects of health policies on health inequalities.

*b) The use of EuroQol instruments as patient reported outcome measures (PROMs) in health system applications*

Many health systems and organizations around the world are using the EQ-5D as a patient-reported outcome measure (PROM) to support various purposes such as enhancing patient-centred care; monitoring, evaluating and improving quality of care; and incorporating patient-reported outcomes into value-based purchasing arrangements. The EQ-5D is currently being used alongside disease-specific PROMs in routine outcome measurement within patient registries and health organizations in Sweden, Canada and England, respectively. Many other countries are using the EQ-5D in similar applications at a smaller scale.

The use of EQ-5D as a PROM for these purposes is under-studied. Given the growing interest in PROMs around the world, especially the work that is driven by the OECD, we seek to promote the EQ-5D as the generic PROM of choice. For that, the PHS WG supports research that examines various aspects of the use of EQ-5D as a PROM including the following:

- *Implementing systems for collecting, analysing and reporting EQ-5D as a PROM*<sup>1</sup>: This includes exploring best practice of collecting EQ-5D data in PROMs programmes, and examining issues in implementing PROMs systems, such as the challenge of measurement. What data capture approaches work best; can different instruments be implemented simultaneously; can healthcare providers do proxy measurements if needed? What is the effect of feedback information to the patient on survey compliance? How do you manage language versions or proxy support? Another challenge is reporting and communicating EQ-5D information to end users in a way that is - demonstrably - instrumental to that user (dashboard graphics, etc.). Note that different user groups (e.g. individual patients, health care providers, managers, policy makers) may require different information and presentational formats.

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<sup>1</sup> In certain cases does t EQ foundation fund the implementation of any new PROMs program including EQ-5D. A strong case for need would have to made, that could consist of a novel way of implementation. Further positive aspects could include local co-funding and/or a strong support base with local stakeholders.

- *Examining the applications of EQ-5D as a PROM:* There are many potential applications of EQ-5D as a PROM; our focus is on its use in three areas: quality control, performance management, and individual patient decision making. Questions of interest include: how can EQ-5D data be analysed and reported in comparing performance of healthcare providers or to inform quality improvement initiatives? How can EQ-5D data be used to inform clinical management or to support patient decision making around treatment options (e.g., patient-decision aids)?
- *Examining the impact of EQ-5D/PROMs systems:* There is lack of information about the overall impact of PROMs programmes, such as evidence that they have resulted in changes in, for example, clinical practice, hospital performance or the health of patient populations. Demonstrating such impact is challenging, so we are especially interested in innovative ways (e.g., pragmatic cluster RCTs) to examine the effectiveness and/or cost-effectiveness of using EQ-5D as a PROM in various clinical areas.

Please note that to be eligible for funding by the EuroQol research foundation, it is essential that the proposed research is primarily about the EQ-5D, rather than including the EQ-5D as an incidental component of a PROMs program or simply as an example.

*c) Methodological advancements*

This includes research exploring retrospective measurement<sup>2</sup>, health trajectories, the use of change variables vs. difference scores, response style measurement and adjustment (response heterogeneity, response shift), equivalence studies on related concepts (e.g., healthy days, DALYs), prospective study designs, and case-mix adjustment in the context of comparing population health or health care performance.

While many research proposals will involve some data collection by the investigators, we also support those who use existing data sources and strongly support projects which collaborate with the EuroQol Foundation's collaborative program agreements currently in Sweden and Canada.

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<sup>2</sup> Retrospective measurement of EQ-5D has been applied to create pseudo-longitudinal data, relevant when pre-data is lacking (e.g. with event like conditions such as stroke or injuries). This method may be applied but the method itself may also be methodologically studied.

### 3.5. Valuation Working Group

*(Last updated: May 2022)*

#### 3.5.1. Aims of the Valuation Working Group

1. To initiate RFPs and PAs that investigate new approaches to valuing health (including approaches within scope of the QALY framework, as well as methods not necessarily associated with the conventional QALY paradigm).
2. To support the development and dissemination of value sets for all EuroQol-related instruments in key countries.
3. To support methodological research examining the basis/rationale for value sets for patient groups.
4. To provide scientific guidance and support for existing protocols related to valuation studies.
5. To collaborate with other WGs or approved groups that work on conceptual and practical issues concerned with valuation of EQ-5D technologies, including but not limited to valuation of health in children, and the use of bolt-ons to existing EuroQol instruments.
6. To appraise the methodological reporting rigor of published value sets for approval by the Executive that the Business Office can post as guidance for users/user support.

#### 3.5.2. Rationale

This WG has a broad remit, reflecting the importance of valuation methodology to all our instruments. As a consequence, clear communication lines are needed with the other WGs involved in valuation particularly the **Descriptive Systems WG** and the **EQ-5D in Younger Populations WG**.

It is likely that a wide range of countries will become (or continue to be) interested in developing value sets for the EQ-5D-5L or 3L, the EQ-HWB, the EQ-5D-Y and the TANDI. One task of this WG is to identify countries where HTA systems are sufficiently developed and/or where there may be a need for additional value sets in the foreseeable future. The WG should aim to get value set studies started in these countries. This could be done by RFP, initially among EQ members.

With a series of 5L value sets conducted, the focus for this WG has been extended. Reporting standards of 5L value set studies have been developed through the EuroQol Research Group (Checklist for Reporting Valuation Studies of the EQ-5D: CREATE) and this WG will appraise the quality of reports of valuation studies using that checklist and indicate whether the EQ-VT protocol was followed, and the effect of any variation from that approach. This appraisal will help the Executive Committee provide guidance to the Business Office on how help users and provide user support. Another aim of this WG is to promote secondary analyses of pooled data across different 5L value set studies that facilitate insights into the protocol and methods used in those studies, such as generalizability of issues across countries.

Lastly, we want to encourage the use of our valuation protocols (including the EQ-VT), with associated technical, IT and translation issues. This WG will also promote research and collaboration on (pooled) secondary data from international value sets that could inform study design and methods related to future valuation EQ-5D studies. As an aside, undertaking value set studies is complex and costly. Coordinating these studies across different countries requires considerable logistical and technical skills. The Office EQ-VT Support Team conducts this more operational side of value set studies.

### 3.6. Younger Populations Working Group

*(Last updated: 2015)*

#### 3.6.1. Aims of the Younger Populations Working Group

1. To develop EQ-5D instruments suitable for use in children of various age ranges. This includes the validation of the EQ-5D-Y in younger age groups (using the proxy version).
2. To promote research to explore the validity of the EQ-5D-Y as a measure of health status in children.
3. To work closely with WG on Valuation Methodology in developing a work programme for the valuation of EQ-5D-Y states.
4. To promote research in the field of application studies. This might include studies comparing EQ-5D-Y to other instruments as well as doing some basic research in paediatric disease areas in need.
5. To update the user guide for the 5-level Youth version.

#### 3.6.2. Rationale:

While we now have an EQ-5D-Y, there remains important work to be done to further develop and establish an evidence base to support the use of EQ-5D-Y as a measure of health status in children of various ages; and to develop a 5L version of the EQ-5D-Y. We would also expect this WG to liaise closely with the **Valuation Methodology WG** regarding the valuation of EQ-5D-Y. Interested EuroQol Group members can send a request for invitation to participate in the SIG to the WG Chair.

#### 4. Contact persons

If you would like more information on any aspect of the WG policies, please contact:

- Bernhard Slaap, Executive Director: [slaap@euroqol.org](mailto:slaap@euroqol.org)
- Elly Stolk, Scientific Director: [stolk@euroqol.org](mailto:stolk@euroqol.org)

## Guidance for applicants: Procedures for research funding applications

1. The EuroQol Research Foundation will fund high quality research that is of scientific and strategic interest to the EuroQol Group and its members.
2. Proposals should be submitted to the EQ Office using the EuroQol Project Submission Portal (<https://euroqol-proposals.grantplatform.com/>). Please review the [Proposal Budget Guidelines](#) before submitting a proposal.
3. For clarity, applicants should ensure that when they refer to EuroQol instruments they use the correct terms – see [EQ-5D Nomenclature](#).
4. Unless stated otherwise in a Request for Proposals, the lead applicant must be a member of the EuroQol Group, in principle, unless applying for a Seed Grant.
5. Twice a year the Executive Committee (Exec) issues a Call for Proposals, highlighting the current research priorities. These will be circulated by email and posted on the members’ area on the website. Funding will be awarded on a competitive basis.
6. Applications for funding can be submitted at any time, but are encouraged for submission when a Call for Proposals is open
7. EuroQol can offer a variety of grant types, listed below. Each Call for Proposals will outline what type of projects are invited. Please note the availability of the types of grants offered may vary from one call to the next.

Parent category	Sub category
1. Research grants	1.1 Regular research project
	1.2 Valuation study
	1.3 Seed grants
2. Individual grants	2.1 PHD grant
	2.2 Postdoctoral grant (currently not available)
	2.3 Travel grant
3. Dissemination and knowledge transfer	3.1 Education and outreach project
	3.2 Open access fee reimbursement
4. Large scale investments (XL grants)	4.1 Program of work in any strategically relevant topic area

8. Proposals are reviewed every quarter in March, June, September and December. Please note that:
  - a. For time sensitive and other high priority proposals, a fast track review procedure may be requested.
  - b. Different review and decision procedures apply for regular proposals and low cost proposals (maximum budget €25,000)

If you have any questions on the review process or submission deadlines you can send an email to Elly Stolk, Scientific Director ([Stolk@euroqol.org](mailto:Stolk@euroqol.org)) or Laura Pickering, Grants Manager ([Pickering@euroqol.org](mailto:Pickering@euroqol.org)).

9. The **regular proposal review process** is as follows:
  - a. Two Exec reviewers will independently review each proposal.
  - b. The relevant Working Group (WG) will also review each proposal. The WG Chair may delegate the reviewing task to a WG member or to another researcher with special expertise on the topic. However, the Exec wants to be assured that this review represents the considered view of the WG.
  - c. When proposals are received on a topic that falls outside the immediate remit of the WGs (e.g. 'innovative' proposals), the scientific team leader chooses the reviewers.
  - d. All reviews will be completed online using the EuroQol Project Submission Portal, where reviewers can view the proposal and rate or leave comments pertaining to the following criteria: Strategic and scientific importance; Approach/study; Design/methods: Feasibility; Budget, timelines and deliverables; Data protection and protection of human subjects. Next, the scores and/or comments are shared with all members of the Exec to decide on the proposal.
  - e. The Exec Chair may install a triage committee to facilitate the decision making process. This will be announced in the Request for proposals, together with a description of the triage process. The triage committee will consider the proposals and their reviews and make a triage decision (Fund/Conditional Fund/Revise and Resubmit/Reject/Discuss with Exec) based on the reviewer comments when a clear picture emerges from the review reports. These triage decisions need to be ratified by the full Exec. If there are important concerns raised by any member of the Exec about any triage-decision, the proposal will be deferred for discussion at the next Exec meeting. If the review reports do not provide a strong basis for a triage decision, the proposal is moved to the discussion with the full Exec.
  - f. The WG Chair may be invited to join the Exec meeting when proposals are discussed that fall within a particular WG's remit, to ensure informed decision making by the Exec.
  - g. Reviewers, WG members and Exec members will be expected to make a declaration of interest (including potential conflict of interest) for proposals they review. Any person with a conflict of interest will be excluded from being involved in any part of the reviewing and decision-making process regarding funding.
10. The **review procedure of low cost proposals** is as follows:
  - a. For low cost proposals, the relevant WG will provide 2 reviews. The Chair, or Deputy Chair of the Exec will consider the review(s) and will provide a recommendation, along with the proposal and the review, to members of the Exec. That recommendation needs to be ratified by the Exec in their quarterly decision making meeting. In case any concern is raised with the suggested decision, the proposal will be discussed by the full Exec to reach a decision.
11. The **fast track review process** is as follows:
  - a. Decisions on time sensitive or other high priority proposals can be fast tracked. The fast track procedure provides a possibility to judge funding requests in the interval between Executive Committee decision meetings. The fast track procedure invites reviews for proposals upon receipt, and the decisions are made offline.
  - b. A review will be sought from at least one member of the Executive Committee. One or more additional reviews can be requested from the Exec or Working Groups, at the discretion of the Executive Chair or Deputy Chair.



- c. The Chair, or the Deputy Chair of the Executive Committee will consider that review and will send a recommended decision via email, along with the proposal and the review, to members of the Exec with request to respond to within 48 hours in case of concerns.
  - d. If there are important concerns raised by any member of the Executive Committee about the Chair's recommended decision, the proposal will be deferred for discussion at the next Executive Committee meeting. If not, the applicant will be informed of the Exec decision to fund/ not to fund the proposal.
  - e. If you want to have your proposal reviewed by the fast track procedure, you need to contact the Scientific Director ([stolk@euroqol.org](mailto:stolk@euroqol.org)) and Grant Manager ([pickering@euroqol.org](mailto:pickering@euroqol.org)), who will discuss with the chair of the Executive Committee if your proposal qualifies for the fast track procedure.
  - f. Applicants should use the regular approach to submit their proposal, via the EuroQol Project Submission Portal, see point 2.
12. **Executive Committee decisions** on proposals will be either:
- a. Funding awarded;
  - b. Funding conditionally awarded, subject to satisfactory revisions and clarifications (confirmed by Chair's action, on the basis of reviewers' recommendations; and reported to the following Executive Committee meeting);
  - c. Invited to revise and re-submit for consideration by the Executive Committee at its next meeting;
  - d. Funding declined.
13. Applicants will normally receive feedback within three weeks after the Executive Committee meetings. Reviewers' comments will be provided anonymously to principal investigators by the EQ Office.
14. Abstracts of applications that are awarded funding will be published on the public website.
15. When funding is awarded, the Scientific Director or the Grants Manager will follow-up with a notification email, and subsequently a Grant Offer Letter confirming Executive Committee approval. The Grant Offer Letter will include a proposed payment schedule in two or more instalments, annual reporting requirements (if applicable), and will explain what is required before an invoice can be sent. The Grant Offer Letter will be accompanied by a General Terms and Conditions (GTC) document. EuroQol requests the Grant Offer Letter to be signed and returned within three months of the date on the letter.
16. If funding for a proposal is refused, the Scientific Director or Grants Manager will follow-up with a rejection notification mail that includes the reasons. To appeal a decision, you must write a letter to the Scientific Director or the Grants Manager asking to have the decision reconsidered and motivate this request.
17. **If a project has an annual or interim reporting requirement**, a notification email from Good Grants will be sent with an invitation to submit the annual/interim report within a three-month timeframe. In most cases the annual/interim report will be reviewed by a member of EuroQol's Scientific Team, and the PI will be notified if the report is approved (and therefore, in most cases, the next invoice can be submitted and/or the next phase of the project can commence if this is stated in the Grant Offer Letter). If the report is not approved, the PI will be notified of the reasons for this, and will be given an opportunity to revise and resubmit the annual/interim report.

18. **If a project is undergoing delays** and the Principal Investigator is unable to submit an annual or final report on time, they must inform EuroQol (or respond to an email from EuroQol regarding an update on a project) providing reasons for the delay and a revised timeline with a request for a budget-neutral deadline extension providing the new expected end date for the performance period. Any deadline extensions must be approved by the Grants Manager.
19. **Once a project is completed**, the process is as follows:
- a. As specified in the Executive Committee approval letter, at the completion of the project, a final report should be submitted, using the Final Report Form on the EuroQol Project Submission Portal (<https://euroqol-proposals.grantplatform.com/>), together with the original proposal, all deliverables described in the proposal and all reviewer reports, if applicable. The Principal Investigator will receive a notification email from Good Grants with an invitation to submit the final report within a three-month timeframe.
  - b. The final report will be reviewed by the relevant WG. The WG Chair may delegate the reviewing task to a WG member or to a member of the EQ Group with special expertise on the topic. However, the Exec wants to be assured that this review represents the considered view of the WG.
  - c. In case of a final report on an ‘innovative’ proposal, or any other proposal outside the scope of the WGs, the Exec Chair, together with the Scientific Director from the EQ Office, will identify a member of the EQ Group with relevant expertise and invite this member to review the report.
  - d. The final report review will be completed online using the EuroQol Project Submission Portal, where reviewers can view and rate the report and offer a recommendation (Sign-off, or Revise and Resubmit). Reviewers are asked to comment on: *Was the work completed as planned? Is the reporting up to standard? Are there strategic implications?* Next, the scores and/or comments are shared with all members of the Exec to decide whether the report can be signed off.
  - e. The final report and its review recommendation will be circulated to the Exec. Unless any issue is raised by the Exec, the final report will be approved as recommended and the PI will be notified with an invitation to submit the final invoice for the remaining budget.
  - f. An abstract of the final report will be published on the EuroQol Group’s website, unless the Exec and the project team agree otherwise.
  - g. If the applicants fail to deliver a final report of sufficient quality in a timely way, payment of the last instalment may be withheld and, in some circumstances, the first instalment may be required to be repaid. Failure to deliver a final report will be taken into account in consideration of future applications.
20. **If it is not possible to complete a project**, the process is as follows:
- a. The Principal Investigator must inform EuroQol (or respond to an email from EuroQol regarding an update on a project) as soon as possible, providing reasons for why the project cannot be completed.
  - b. The Principal Investigator must provide a summary of work completed so far, listing any completed deliverables and any failed deliverables.
  - c. The Principal Investigator should provide a proposal of how they wish to close the project, including any reporting or use of data that might be possible, a breakdown of budget already used and the remaining budget that can be returned to EuroQol.
  - d. The proposal will then be reviewed to by the Grant Manager and Scientific Director, and will be put forward for approval by the Executive Committee.

Lastly, the Executive Committee reserves the right to deviate from these guidelines when required by circumstances.

If you have any questions about applying for funding, please contact the or the [Scientific Director](#) or the [Grants Manager](#).

## Proposal Budget Guidelines (annex to 01 Guidance for applicants.pdf)

Knut Stavem & Bernhard Slaap

The Executive Committee studies budgets in applications in detail. The guidelines below are provided to ensure a smooth review process.

In the **Proposed budget area of the grant proposal form on good grants**, you are requested to provide a breakdown of the proposed budget.

Please split up your study budget in the following categories:

- Personnel costs
- Data acquisition costs
- Material costs and other preparation costs
- Dissemination costs

If you are **applying for a workshop or a symposium**, please also provide details about:

- Honoraria, including preparation time
- Venue costs and entrances fees
- Travel costs and expected costs for hotel costs and meals

### **Personnel costs**

Personnel costs are typically the largest cost constituents in proposal budgets. These can be budgeted for the preparation of the study or workshop, data acquisition and data analysis. Try to estimate the numbers of hours/days that will be spent on the project to the best of your knowledge. Please apply appropriate local hourly or daily rates when calculating personnel costs, but note that these should not exceed the EuroQol Group Foundation's 3 categories for **maximum daily rates**, i.e.:

- (1) €132.50 per hour/ €1060.00 per day, including overheads, for **senior researchers**, e.g. for investigators with leadership roles, who are at least associate professor level: experienced researchers with PhDs and a substantial publication list.
- (2) €101.00 per hour/€808.00 per day, including overheads, for **less experienced researchers**, e.g. post-docs.
- (3) €53.00 per hour/€424 per day for **students and office staff**.

Please note that the Executive Committee expects applicants to use the 3 categories for budgeting personnel costs. Applicants must provide a justification if they choose to budget research staff at higher daily rates that described above. Furthermore, a justification should be provided for any team member budgeted at the maximum daily rate. At the discretion of the Executive Committee, the budget for personnel costs will be approved, or a lower budget proposed.

EQ Office staff members can participate in EQ-funded studies. Please discuss your plans with the Scientific Director or the Executive Director prior to submitting such a proposal.

When EQ Office staff is participating in your project, please insert a line item under Personnel costs titled 'EQ Office Staff' to specify their hours, using the day rate for senior researchers. €110.00 per hour/ €880.00 per day. In **section 9, Budget requested from EuroQol**, specify this amount separately. The total amount will determine what review procedure is required (refer to guidance to applicants).

Under the category of **Data acquisition costs** it is acceptable to have the following costs as line items:

- Respondent's fees and travel costs
- Interviewer costs and their travel costs
- Office/room rent for data acquisition outside the University
- If an agency/ outside company is used, please provide a copy of their invoice/ cost proposal

As a rule, it is not acceptable to request funding for buying computer hardware or software to be used for data acquisition. Renting computer hardware for a study is acceptable.

For EQ-VT studies please add €25.000 for EQ-VT costs (software development, training, support etc.). Upon approval by the Exec this will be provided as in-kind support. In **section 9, Budget requested from EuroQol**, specify this amount separately as in-kind support.

Under the category of **Material costs and other preparation costs** it is acceptable to have the following costs as line items:

- Secretarial support, stationary, telephone costs etc. (usually not more than 5 % of total budget).
- Processing costs for human subject protection/ethics approval, if applicable

It is not acceptable to request funding for computer hardware or software to be used for data analysis or manuscript writing.

Under the category of **Dissemination costs** it is acceptable to budget for one researcher to attend an international congress to present the results of the study. Allowable costs include:

- (1) An economy class airline ticket
- (2) Meeting registration fee.

The applicant is required to seek funding from other sources for other dissemination costs, such as board and living, hours spent away the office, co-presenters of the study results etc. As a rule, costs of publishing e.g. in open access journals, are not reimbursed, although exceptions are possible for strategic important studies.

Please contact [Bernhard Slaap](#) (Executive Director) [Elly Stolk](#) (Scientific Director) or [Laura Pickering](#) (Grants Manager) if you have any comments, questions or suggestions on Research Proposal budgeting.

## Grants offered by EuroQol

Once a call has been published inviting the submission of a grant application, interested persons may put forward a proposal. The call will state what grant type applications are invited. The table below lists all EuroQol grant types and in the remainder of this document we describe the aims and scope of each grant. The procedure of applying for a grant is similar for all grant types and described in general terms in the Guide for Applicants. The procedure for specific grants may differ from this procedure to some degree due to grant specific elements. Please note that the availability of the types of grants offered may vary from one call to the next.

Parent category	Sub category
1. Research grants	1.1 Regular research project
	1.2 Valuation study
	1.3 Seed grants
2. Individual grants	2.1 PHD grant
	2.2 Postdoctoral grant (currently not available)
	2.3 Travel grant
3. Dissemination and knowledge transfer	3.1 Education and outreach project
	3.2 Open access fee reimbursement
4. Large scale investments (XL grants)	4.1 Program of work in any strategically relevant topic area

### 1. Research Grants

#### 1.1 Regular research project

A research grant is defined as a grant obtained for conducting a piece of research as described in a funding application. Research grants are the principal way of funding research for the EuroQol Research Foundation.

##### *Scope*

The Foundation aims to fund high quality research that is of scientific and strategic interest to the EuroQol Group and its members. Any proposal targeting one of the specified aims for the WGs as described in the [WG aims document](#) is consistent with the overall scientific strategy and thus will be considered for funding. Twice a year the Executive Committee (Exec) issues a Request for Proposals, highlighting the current research priorities. These will be circulated by email and posted on the members' area on the website. Funding will be awarded on a competitive basis.

##### *Funding*

Standard research projects can have a budget up to around €200,000. For requests over this threshold value, applicants would need to provide particularly convincing arguments for the need to complete all work in a single project.

##### *Eligibility*

Eligibility will be described in the request for proposals. Generally, calls are aimed at researchers with established lines of research involving EQ-5D or related instruments, many of whom are affiliated with the EuroQol Group. Some calls require that the lead applicant is a EuroQol member or that the project team includes a EuroQol member.

## 1.2 Valuation studies

Valuation studies are a specific type of research project, aimed at producing a preference based national value set for one of the EuroQol instruments. Value set development is part of the R&D process of EuroQol instruments, and EuroQol therefore wishes to collaborate closely with parties that are interested to produce a value set. This chapter describes our policy for how to set up a valuation study.

### *Scope*

The EuroQol Group and the EuroQol Research Foundation are conducting a series of value set studies globally. Value sets can be developed only for instruments that are made available to the wider public as an approved EuroQol instrument. A protocol for how to conduct the valuation studies has been published or can be obtained from the EuroQol Office. These studies are generally conducted in accordance with a protocol developed by EuroQol, which may involve conducting TTO interviews in a large sample of the general population using our standard proprietary software package called EQ-VT. Approved studies will receive in kind support of the EuroQol research foundation, but a few hurdles need to be passed before support is obtained, including assessment of case for need and available budget for the research.

### *Eligibility*

All parties interested in conducting a valuation study of one of the EuroQol instruments, are invited to contact EuroQol Office first to learn about our policy regarding valuation studies. EuroQol membership status is not required. Before a research application is invited, we want to learn about your team, your funding and your time planning. We also want to learn about the status of Health Technology Assessment (HTA) in your country, local experience with valuation research, local use of EQ-5D-3L and EQ-5D-5L and the case for need for developing a value set.

### *Funding*

Your plans for how to finance the study are also reviewed before a valuation study proposal is invited. We typically expect the country team to secure local funding to cover most of the total project cost. So, you should be aware that this will be an expensive study. Our current protocol for valuing EQ-5D-5L requires a study sample of at least 1000 respondents for an EQ-VT study. This means 1000 face-to-face interviews to be completed by a team of about 10 trained interviewers. EuroQol research foundation will support approved studies in kind, by building and testing an EQ-VT version for your country, translation costs and costs for training, quality management and support. The EuroQol Research Foundation will be taking care of these costs (around €25,000) when your studies is approved by the Executive Committee of the EuroQol Group. However, you must secure funds for the project team members, participant incentives, fieldwork, etc from local sources. Depending on how the study is conducted, an estimate for the total study budget would be €70,000 to €300,000 or more, depending on the wages in a country and the extent to which parts of the study are farmed out to commercial companies. Subject to a decision of EuroQol's Executive Committee, co-funding may be obtained from EuroQol Research Foundation to make ends meet.

Should the availability of resources be a problem, we encourage you to consider conducting a valuation study of the EQ-5D-3L instrument, which requires a smaller sample (~300) and can be completed by a smaller team. Furthermore, using the so-called 'crosswalk' approach it will be possible to create values for the 5L instrument from the 3L data.

### *Application*

The stage of drafting a valuation study proposal is entered if a team is considered capable and if it has a study design, funding and a time planning which is considered acceptable by the EQ-VT Support Team of the Valuation Working Group. In this stage the EQ-VT Support Team will work with the country team to develop a research proposal ready for review and approval by the EuroQol Executive Committee. Please note that if the EuroQol Executive Committee can also decide not to fund the study, which means that we will not provide the team with our EQ-VT software or funding.

Valuation studies have their own submission form, covering all elements required to perform a valuation study in accordance with our protocol.

### **1.3 Seed grants**

The Executive Committee announced the launch of Research Seed Grants in 2022. The main focus of the Research Seed Grants is to support innovative research that may result in providing a catalyst to, and a starting point for, launching new projects or facilitating a change in the direction of the research. The Research Seed Grant program has the following goals:

- to encourage interest among external research groups to develop new collaborations with the EuroQol group in research projects where EQ-5D or EQ-5D data play a key role, e.g. embedded in clinical practice, as a routine PROM. (see below for example areas).
- to encourage innovative research related to the [research priorities](#) of one or more EuroQoL Working groups (Descriptive system, Valuation, Youth, Population and Health Systems).

### **Scope**

Through a seed grant, short-term, exploratory research projects can be supported. The seed funds are provided to stimulate innovative use of EQ-5D or of EQ-5D data. The results will determine the potential and long-term feasibility of the research or inform the design and execution of a larger scale study. A seed grant allows researchers to explore new research initiatives, that may be high-risk projects, to start working on their research project. Examples include:

- Applications leveraging further value from existing data sets made available through Routine Outcome Monitoring
- Development and validation of risk-prediction models, diagnostic tools, or decision support models
- Studies addressing the nature of disparities in care and outcomes
- Research done in strategic framework for value-based health care research and/or implementation
- Patient profiles in health care, patient platforms, care pathways
- Methodological or applied research in the field of psychometrics, health economics, classification theory, mapping, instrument development, or information processing and presentation.

### **Funding**

Research seed grants may be requested up to €50.000. For requests over this threshold value, applicants would need to provide particularly convincing arguments for the need. The grant is for covering the direct cost of research and researcher salaries, following the usual budget guidelines. Institutional overhead expenses, indirects, material costs and travel expenses are not covered. Requested project budget should agree with project aims and scope. The maximum duration of research projects funded by a Seed Grant applications is 12 months.

### **Eligibility**

The grants are specifically aimed at researchers aiming to establish new lines of research involving EQ-5D or related instruments and who are currently not affiliated with the EuroQol Group, allowing



EuroQol to enter into new collaborations. Current members of the EuroQol group are not eligible to apply for this grant type. Collaboration with EuroQol members in the proposed research is allowed but not required, meaning that EuroQol members can join a research team as advisor or co-investigator.

The call is open to experienced researchers as well as to early career researchers, who have a proven track record, or indication of promise for early career researchers. Eligibility is subject to the requirement that the proposed research can support new collaborations or new research lines to develop. The application form will include questions about how the research is embedded in order to judge the scope for integrating results in next steps.

All domains are eligible for funding. Applicants should consider the following requirements:

- Research topic should be related to health and/or health care, to the EQ-5D or related instruments or to the Working Group themes
- Research is open to methodological as well as applied studies
- Research should be innovative in either methodology or application
- Project duration is variable but max. 12 months (see below)
- Requested project budget should be in agreement with project aims and scope

### **Application**

Each call for proposals will be disseminated to stakeholders with the intention to solicit applications. All research groups viewing this call may submit their projects. Applicants with questions about this call can contact the EuroQol Office or contact the Grants Manager ([pickering@euroqol.org](mailto:pickering@euroqol.org)) or Scientific Director ([stolk@euroqol.org](mailto:stolk@euroqol.org)). The application and review procedure are as is described in the general Guidance for Applicants. The application form invites detail about the planned research, as well as detail about the Applicant, the organisation represented, and a vision around how funding of the proposal may be a basis for building collaborations.

## 2. Individual Grants

### 2.1 PhD grants

EuroQol invites proposals for PhD research that supports EuroQol's wider goals. The grant should allow a PhD student to do original research, write it up in a thesis that meets local requirements, and defend that thesis and earn the PhD title, as well as meeting the minimum requirements of EuroQol as listed below. The student's focus will be on broadening the theoretical understanding of a theoretical subject or exploring into any unknown area and enhancing research skills. The candidate is selected by the lead-supervisor. If the application is initiated with a specific candidate in mind, a CV of the prospective candidate must be provided together with the CVs of other team members. In case of projects initiated by the applicant, and for which there is no identified candidate, the strategy and timeline for recruiting or selecting the PhD candidate needs to be described. A suitable candidate must be identified who has demonstrated interest in the area.

#### **Scope**

While the primary aim essentially is *personal* capacity building, the secondary aim is to provide opportunities to investigate in depth a particular EuroQol related *topic* or *dataset*. The most important part of the application form is the project description. The project description explains the research project or projects for the PhD, and it outlines the research strategy in some detail. It is important to present a strong rationale for the research. The background should identify gaps in the evidence base/methodological issues that will be addressed, leading to the stated aims of the PhD proposal. The significance of the research questions (1) to the field, (2) to the EuroQol community should be clearly stated. The methods of all planned projects need to be described in a level of detail. It is not necessary to provide every last detail, but the description should allow reviewers to judge what level of quality is being pursued and to consider feasibility of the proposed work and assess risk. Details of existing data sources must be provided to allow quality and suitability of the data to be assessed. If new data will be collected, a description is needed of how data will be collected, analyzed, and reported. Unlike other standard proposals, attention should be paid to interaction with the research communities addressed, including the EuroQol group (e.g. by indicating which WG will be the most natural sounding board).

#### **Funding**

There are considerable differences between countries in the approaches to doctoral education, for instance regarding qualifications, coursework requirements, time to degree, examination, and funding. . The EuroQol-Group acknowledges such variations and accepts that budgets required to fund a PHD and deliverables will vary. Applicants need to provide relevant detail about how PhD research is structured in the host institution, and list the formal requirements in terms of process and outcome. The description needs to clarify the rights and duties of a PhD student and explain whether the student will receive research training, and have tasks and duties beyond the PhD research.

The targeted amount for PhD proposals is in the range of 150.000 – 160.000 euro; higher amounts may be requested if properly motivated. A EuroQol grant may be combined with other sources of funding. A smaller budget can also be requested if EuroQol funding is requested to supplement a previously awarded project or extend the budget available for an existing PhD study. You need to provide a budget plan to explain and justify the requested budget. Please describe the total amount of funds you currently have from other sources. If decisions on other grant requests are pending, EuroQol grants may be awarded as a conditional grant that will be released as soon as the remainder of the budget has been secured.

Your local context will define the way in which the budget will be made available to the student (e.g. as a stipend and fees or salary). The budget will be made available in annual instalments.

In addition to stipend/fees/salary for the student, you may request:

- an individual bench fee of €5000 for the PhD student to encourage his or her scientific career. The student can freely decide whether to spend this on travel to conferences, registering for courses, etc.
- a budget up to €25.000 to cover material cost, e.g. for data collection/acquisition. This can be included in the original proposal, or applied for separately at a later stage after approval of the project while the work is ongoing.
- supporting funds for one or two supervisors. The amount is capped at €7,500 euro in case of one supervisor and at €10,000 in case of two supervisors.
- If travel is involved, this needs to be explained and justified.

Note: The cost of attending EuroQol meetings will be fully reimbursed, if applicable, and do **not** need to be included in the budget. Budgets to cover open access fees also should **not** be included in your application, but can be requested later upon acceptance of a manuscript.

It is *not* possible to request funding to cover indirect costs or overheads.

### ***Eligibility***

All EuroQol members who have approval to be a lead or co-supervisor of a PhD candidate at an institution that confers PhDs are eligible to apply. The PhD research could be undertaken at more than one institution, but the institution at which the student is enrolled will provide the lead supervisor and be the official representative of the project and budget holder. Other people involved can be co-supervisors or part of a broader advisory team.

Applicants need to ensure that the student has the necessary lead-supervisor and institutional support. The lead-supervisor must have approval to be a primary supervisor at the institution at which the student is enrolled. The lead-supervisor needs to have institutional capacity to provide the support, opportunities, and resources needed to enable effective supervision and to ensure that the candidate will qualify for the PhD according to relevant standards (this may include teaching). Qualifications of all project team members need to be clarified by including their full academic CV and intended roles in the application.

### ***Deliverables***

The required deliverables for a PhD project will be defined in part by the local context. In some countries the requirements are defined in terms of published papers, while in others it rests on a thesis presented to an exam committee. The EuroQol Group acknowledges this and accepts that the deliverables of PhD projects funded by EuroQol will vary. The lead-supervisor is responsible for ensuring that all local requirements are met, as well as the possible additional requirements defined by EuroQol. The EuroQol-Group defines as a minimum requirement from a PhD project submission of two research articles to a peer reviewed journal, and at least one of these must have been accepted for publication during the timeframe of the PhD. Furthermore, the PhD student is expected to present the research regularly at scientific conferences, including those organized by the EuroQol-Group. The EuroQol-Group expects contribution to the scientific network, e.g. if invited by a WG or the EuroQol-leadership. If applicable it also includes creating documentation/guidelines for users of the EuroQol-instrument on the topic/dataset. Generally, it is assumed that analytical tools/programs are shared with those EuroQol-members. If another organization/agency also is supplying funding to the PhD student then the EQ requirements are modified to reflect the magnitude of investment.

The timelines and important milestones of the project need to be presented (ideally on a Gantt chart), in order to allow progress to be judged. The timeline needs to include the required milestones of the

host institution and of EuroQol. The project team needs to pay appropriate attention to potential barriers for timely availability of data (including ethical approval). EuroQol requires the submission of annual progress reports to monitor if the project is on track and delivering expected results. More generally, the annual report is an important communication tool for knowledge transfer and also to document changes that become necessary or even desirable during the PhD project after its approval and require sign off by EuroQol.

## **2.2 Postdoctoral grants**

The policy for funding of postdoctoral grants is currently under review, and therefore not included in this document.

## **2.3 Travel grants**

EuroQol travel grants (EQTGs) aim to provide students and researchers funding for international travel and subsistence to study the EQ-5D at a university or a recognized academic or policy center/institute under the supervision of a EuroQol member. The travel grants support short term visits abroad as well as long term partner institution residency. The scope of these travel grants is wide and could serve different aims.

### **Scope**

- *Short term travel grants:* The short-term travel grants support members who wish to meet physically to conduct EuroQol-related activities, mostly for specific projects, to travel abroad for a short period of time. These grants may also be requested with the purpose of meeting to develop projects/proposals, rather than working on existing projects. The period abroad can vary between a couple of days to 2 months. Please note: To receive funding for meetings or collaboration efforts of smaller teams, a deliverable should be clearly defined, such as a research proposal or a publication.
- *Long term Travel grants:* The general idea is to allow researchers interested in getting more deeply involved with specific types of EuroQol work to get residency at an institute abroad for a specific period (2 months to a year) and be embedded in the team. The grant supports various types of residency at a partner institute, e.g. work placements, internships, traineeships, and research specialization visits. If you want to apply for a travel grant of this type, you will need a contact person at a partner institution in the EuroQol network: your host. Any EuroQol member who has demonstrated expertise related to your planned work may act as a host. An alternative to partner institution residency could be similar arrangements with the EuroQol Office allowing researchers interested in the general scope of EuroQol activities to come to Rotterdam and be embedded in the office scientific team.

### **Funding**

The amount of funding for short term travel grants is limited to €15,000 per grant and this should be used for travel, training course fees, accommodation and subsistence only. An application form has been developed for the applicant to complete; it should also be signed by the member who will host the student in their organization. The support from EuroQol is limited to the travel grant, all other support would be provided by the host institute. No maximum amount has been defined for long term travel grants. The amount of funding is context specific.

### **Eligibility**

Only members of the EuroQol group can apply for a travel grant, unless stated otherwise in a request for proposals.

### 3. Dissemination and knowledge transfer

#### 3.1 Education and outreach grant

This grant type invites interested persons to submit plans for any educational or outreach activity that supports the mission of EuroQol Group (<https://euroqol.org/euroqol/vision-and-mission/>). The EuroQol Group Association and EuroQol Research Foundation aim to improve decisions about health and health care throughout the world by developing, promoting and supporting the use of instruments with the widest possible applicability for the measurement and valuation of health. The Foundation is active in two roles, i.e. as distributor of instrument and as a grant making organisation in the field of measurement and valuation of health. Activities to 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 measures developed by the EuroQol Group are required to generate impact.

#### **Scope**

Funding may be requested for a range of activities. The deliverable of the funding application can be an event or a product. Some examples of events that may qualify for EuroQol funding by an educational and outreach grant are listed below. If you would like to apply for a grant to organise an event, the submission form invites you to describe the event you are planning, the target audience, the aims, etc.

- Capacity teaching of courses,
- workshops or webinars,
- conference visits to support dissemination of new research findings
- organisation of regional meetings to build capacity

Examples of product development that can be supported by a EuroQol Education and Outreach grant:

- development of teaching materials
- developments of analytical tools
- books

#### **Funding**

No maximum amount has been defined for education and outreach grants. The amount of funding is context specific.

#### **Eligibility**

Generally, calls are aimed at researchers with established lines of research involving EQ-5D or related instruments, many of whom are affiliated with the EuroQol Group. EuroQol membership status is not required.

#### 3.2 Open Access fee reimbursement

The EuroQol Group has an **Open Access fee policy** that the Foundation will refund all costs of publishing articles in open access journals, for manuscripts related to funded projects. The Open access fee reimbursement policy also covers open access publishing cost of manuscripts drafted by members and relevant to EuroQol in another way. To apply for the OA reimbursement, a request needs to be submitted in the grant submission portal: <https://euroqol-proposals.grantplatform.com/>.

#### **Eligibility**

EuroQol members and authors of manuscripts of projects that were supported by the EuroQol Research Foundation can apply for funding.

#### 4. Large scale investments (XL grants)

As a supplement to regular calls, the Executive Committee is interested in ideas for larger strategic investments in scientific programmes of work. Examples of programmes of work that have been funded as a large strategic investment include the EQ-DAPHNIE project, the programme around the TANDI, and larger investments in support around the Australian QUOKKA study. In addition, the ongoing UK valuation study can be seen as an example of large-scale spending outside the regular call structure.

##### **Scope**

The main characteristics of an application for a large-scale strategic investment programme application (XL grant) should include:

- Strategic importance: there must be compelling reasoning aligned with the EuroQol vision and mission, for the Group to take on the opportunity costs, e.g. by reaching new target groups, specific scientific milestones, or lowering user barriers.
- Scale/cost: for project ideas with budget impact up to several hundred thousand Euros, and/or with limited complexity, the regular project proposal procedure will be the default.
- Practical case: please provide reasoning for why your research idea cannot practically be implemented in the regular proposal structure.
- (Optional) membership involvement: EuroQol will consider proposals that allow the involvement of wider groups of members, ideally those who would otherwise not be highly active.

##### **Funding**

No maximum amount has been defined for education and outreach grants. The amount of funding is context specific.

##### **Eligibility**

It is not possible to start an application for an XL grant via the grants portal on your own account. Firstly the idea will need to be pitched to the Executive Committee. If the Executive Committee is interested in the idea, an invitation will be shared to submit a full proposal.

This funding option is aimed at researchers with established lines of research involving EQ-5D or related instruments, many of whom are affiliated with the EuroQol Group. The lead applicant must be a EuroQol member.

The steps to apply for an XL grant are as follows, with every next step being conditional on a positive judgement in the previous step:

1. Contact the Executive Chair and/or the Scientific Director ([stolk@euroqol.com](mailto:stolk@euroqol.com)) to briefly discuss your idea and receive confirmation that it is in scope.
2. Send a memo to the Exec that describes **what** it is that you are asking funding for, presents a **strong case** for financing the plan and **outlines the work** that will be done if the grant is awarded with an appropriate level of detail. The memo will be shared with the Exec for a go/no go decision, and to collect inputs and feedback if the Exec agrees to move forward with this idea.
3. Submit a full proposal via the grants portal. Your proposal will be assessed in the usual way. All applications will be reviewed by the Executive Committee of the EuroQol Group and by at least two other EQ members, who may be a member of the relevant Working Group(s). Applicants will be assessed on the following criteria: strategic value, scientific quality, feasibility, track record, and prospects to build on this work.

# Storage and Access for Valuable EuroQol Datasets

## The EuroQol SAVED initiative

Scientific research in the human sciences is changing: it is more data-driven, more personal data is collected, and more emphasis is put on Open Science: maximum transparency in all aspects of research, the need for second views [replicability], and the demand for valuable data to be available for secondary use. In other words: being accountable and efficient. Many research funders and publishers have made Open Science -specifically secondary data use- a prerequisite for grant allocation or accepting a paper for publishing. As such, if researchers are unable to meet the set requirements, hinderance or even barriers to continue research may occur. Open Science is well underway to becoming the new standard of conducting scientific research, and as a result of these demands, more rules and regulations emerge on Research Data Management [RDM], in particular on personal data for research. These changes cannot be ignored in the EuroQol context as well, as [personal] data collection is a at the heart of its scientific activities.

In addition to the demands arising from the Open Science paradigm and legislation on managing research data in order to facilitate its members in their scientific activities, EuroQol strives towards creating added value for its members in measurable terms by making valuable data available for secondary use, as secondary data use may lead to opportunities to pursue new or additional hypotheses on existing available data. It may open new avenues of scientific research -response heterogeneity-, enable research on rare conditions -by pooling of datasets-, and allow for retesting the primary study hypothesis with different or improved statistical methods. Secondary data use in theory has the potential to increase the scientific efficiency, or in economic terminology, higher returns on the scientific investment.

These changes have prompted EuroQol to update its professional services, facilities, and operational procedures to match the updated technical, legal, and scientific requirements of managing research data. Operationally, RDM and SAVED aim to reconcile conflicting demands and deliver fairly quickly available research data under an appropriate legal umbrella [including data adaptations to the extent needed]. Now that EuroQol has reached a considerable size -members, projects funded, datasets collected- this professionalization with parallel increase of accountability is urgently required. This makes SAVED a logical extension of EuroQol activities.

### Practical implications

Starting point for SAVED is that every EuroQol dataset is valuable and a candidate for secondary use, and arrangements to allow for secondary use must be made at onset of the research project and carried out throughout the primary data collection.

The possibilities for and desirability of making a dataset via EuroQol available for secondary use will be judged during a so-called SAVED-check, by both the applicant and reviewers. Where it is considered



desirable to grant a dataset SAVED-status, the grant offer letter will mention it and if so, a Data Transfer Agreement [DTA] will be added as an appendix. The DTA arranges the transfer and management of research data to EuroQol and the SAVED Archive, what files and metadata must be transferred, what rights and embargos remain with the primary researcher, and how the primary researcher may be involved in secondary data applications.

After signing the grant offer letter and agreeing to the terms of the DTA, the researcher is responsible for executing the research project in line with agreed terms. This includes addressing any privacy and other [local] legal requirements at onset, adhering to [local] RDM policy, and ensuring essential files and metadata are created, well-structured, updated throughout the research project, and transferred to EuroQol and the SAVED Archive as soon as they become available. This pertains to files and metadata that are typically already created or collected during the research project such as an informed consent form, raw- and cleaned dataset, codebook, syntax, and a description of e.g. methods, implying little additional effort on the part of the researcher if research is executed diligently from the start. The additional SAVED effort lies in ensuring each file is complete and comprehensible enough to allow for secondary use.

In case of any questions about SAVED, please contact the [SAVED Data Treasurer](#).