



*Proposed Working Groups – Version March 11 2015*

**Revised Working Group (WG)s for 2015-17**

**Guided by Scientific Priorities**

**2015 Executive Committee**

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## *Proposed Working Groups – Version March 11 2015*

*The purpose of this section is to explain why and how the Working Group (WG) structure has been revised, what their new objectives are, and how they will work. Over the coming months the WGs will each 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.*

### **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.
- A few years ago the Executive Committee decided to introduce a new structure, by introducing six WGs, each to be charged with clearly defined, specific objectives relating to the scientific agenda of the EuroQol Group.
- 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.
- When the WGs were put into place the intention was to evaluate the performance on a periodic basis (e.g., every 6 months). Overall, the WG structure has proved to be an effective and productive source of research deliverables for the EuroQol organization. However, the overall effectiveness of the WGs has varied somewhat.
- In March 2014, a joint Board-Executive meeting took place in which the long-term strategy of the EuroQol Group was defined. At the September 2014 Plenary meeting, the Strategic Research Priorities document was introduced to the EuroQol membership, and feedback provided to the Executive and Board.
- In this document, informed by the Strategic Research Priorities and WGs Review documents, we describe the proposed scope of each WG.
- The WG structure has been revised to be able to match the research priorities the Executive Committee and the Board have jointly defined in the Strategic Research Priorities. New WGs are proposed, some existing WGs have revised objectives, or have been discontinued.
- Once this document is signed off, a call for nominations for WG membership will be sent out. Current WG members and Chairs are strongly encouraged to nominate themselves.
- The Executive Committee will appoint the WG Chairs. Although Chairs may independently reach out and contact a potential member directly to nominate him/herself for a WG position, all EuroQol members are cordially invited 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



### *Proposed Working Groups – Version March 11 2015*

teams. Membership in more than one WG is permissible. WG Chairs will report progress towards the stated aims of a WG annually to the Executive. 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 Younger Populations WG.
- From time to time, a Project Team will be initiated. The Project Team differs from a 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 Project Team 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 Project Team reports to, and works in close cooperation with, the WG. A Project Team is time-limited and will be dissolved once the objectives have been achieved. A WG can send out nomination calls for Project Team membership. A recent example of an Project Team was the team (MAT) that conducted a series of studies to improve the TTO module of EQ-VT, under supervision of the Valuation 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.

#### **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 if they are wondering which WG would be best aligned with a research idea or proposal. If in doubt, please contact the Chair of the Executive Committee, Simon Pickard (aspickard11@gmail.com), or the Executive Director Bernhard Slaap (slaap@euroqol.org), for guidance or feedback.



**2. Summary of WGs for 2015-17**

Six WGs (WG) are being established:

2012-14	Proposed 2015-2017	Comment
	Descriptive Systems WG	This new WG will focus on exploring the conceptual basis for generic preference-based HRQL measures.
Value Sets WG	Merged	The activities of this WG will be incorporated into the Valuation WG.
Valuation Methodology WG	Valuation WG	Continues to 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.
EuroQol Data Archive WG	Integrated with business office activities	The activities will be integrated with business office under the supervision of a senior scientist, and the existing DAWG members will be asked to serve as an advisory board to provide guidance to the office.
EQ-5D in Children	EQ-5D in Younger Populations WG	Continues
EQ-5D in large scale health applications	Large Scale Applications WG	Continues; modify aims to support clinical and population based initiatives
EQ-5D beyond health care	Discontinued	Future initiatives will be considered as innovative research.
	Interface Development WG	New WG; will focus on new applications of existing instruments, ways to collect data, social media (the D in R&D; more development than research); potential for commercialization and commodification will be considered
	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.



### **3. WG Principles**

- The WGs are intended to be relatively small, **focused** groups (4-6 members), with specific objectives to be agreed with the Executive Committee.
- The WGs vary in terms of scope, timelines and budgets.
- 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 **actively create opportunities to involve others with relevant expertise in the EuroQol Group wherever possible**. Members of WGs can also apply, but the WG is not expected to lead the research as a team.
- A PA encourages research on a given topic but is largely generic, such as new methods to value health or the development of apps for the EQ-5D, where the specific aims are composed by the investigator. In contrast, an RFP is directive, eliciting “proposal bids” from members for a proposal on a specific topic where the aim is stated in the RFP, e.g. to develop a EQ-Y instrument for children <5 years of age (this example is strictly illustrative).
- 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.
- Unless otherwise stated, the WGs will provide a progress report and future plans every 6 months, 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.
- In the periodic review of WG performance, the Exec will review output by using metrics such as, but not limited to: number of RFPs or PAs sent out, the number of research proposals submitted, allocated budgets etc.
- In the remainder of this document, we provide details on the remit of each WG, provide justification as it relates to the 2015 strategic research priorities, and list ideas about the scope of activities of each WG. These aims may be revised by the WGs over time with approval from the Executive Committee as time progresses.



*Proposed Working Groups – Version March 11 2015*

Linkage between the Strategic Research Priorities and the new WGs:

	Strategic Research Priorities	New WGs
1.	Explore the conceptual basis for generic preference-based HRQL measures	1. Descriptive Systems WG
2.	Investigate new approaches to valuing health (not necessarily associated with the conventional QALY paradigm).	2. Valuation WG
3.	Examine large scale health systems applications for EQ products (e.g., in Routine Outcome Measurement)	3. EQ-5D Large Scale Applications WG
4.a	Support the development and dissemination of EQ-5D-5L value sets in key regions.	2. Valuation WG
4.b	Explore valuation research in specific patient groups	2. Valuation WG
5.	EQ-5D-Y: refine descriptive systems, valuation studies	4. EQ-5D in Younger Populations WG
	(Broader Strategic Priority: related to Mission statement)	5. Interface Development WG
	(Broader Strategic Priority: related to Mission statement)	6. Education and Outreach WG

**4. Details of each proposed Working Group.**

**A. WG 1: Descriptive Systems Working Group**

- i. Aim 1: to explore the conceptual basis for generic preference-based HRQL measures (i.e., descriptive and measurement work)
- ii. Aim 2: Investigate the conceptual basis and develop a framework to rationalize the development of various bolt-ons and bolt-offs

*Rationale:* At the Strategic meeting in March 2014 it was decided by the joint Board and Executive Committee that a top priority for the EuroQol Group is the explore the conceptual basis for generic preference-based HRQL measures. Although the need for another generic preference-based measure of HRQL is not self-evident, the expertise and interest within the group is well-suited to support an initiative guided by scientific frameworks that explores whether a new initiative should be pursued, such as an entirely reconceptualised generic health state classifier system. Much progress has been made in the field in the 25 years since the EuroQol Group was initiated, and there was consensus among the Executive and Board that there was opportunity to explore and evaluate the conceptual basis for generic measures of health, including the EQ-5D. There is also a need for conceptual clarity on future work related to bolt-on initiatives, such as a conceptual basis to guide decision-making related to extensions of the descriptive system. However, it is also conceivable that the EQ-5D is a well-designed and validated measure suited for many different applications and will remain viable and widely used in the far future. This WG will promote research that explores the current and future needs for generic preference-based HRQL measures, and help to evaluate whether alternative descriptive systems should be pursued. The WG will use PAs to encourage EQ



*Proposed Working Groups – Version March 11 2015*

members to think about proposing topical research *program* proposals, besides regular research *project* proposals, as their primary objective requires both broader and deeper work, which typically takes more than 1 year.

**B. WG 2: Valuation Working Group**

- i. Aim 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).
- ii. Aim 2: Support the development and dissemination of EQ-5D-5L value sets in key countries. To stimulate interest in producing EQ-5D (3L and 5L) value sets in key countries across the world and assist the Executive in prioritising value sets requesting support.
- iii. Aim 3: To support methodological research examining the basis/rationale for value sets for patient groups.
- iv. Aim 4: To provide scientific guidance and support for existing protocols related to valuation studies.
- v. Aim 5: To collaborate with other WGs or approved groups that work on conceptual and practical issues concerned with valuation of EQ-5D technologies.
- vi. Aim 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.
- vii. Aim 7: To provide scientific guidance and support for valuation of bolt-on studies.

*Rationale:* This WG has one of the most challenging and broad remits, 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. We would expect this team to work closely with the **EQ-5D in Younger Populations WG**. Work on this team also continues on improving our standard valuation protocol EQ-VT.

It is possible that a wide range of countries will be interested in developing value sets for the EQ-5D-5L (and also the 3L) in the future. One task of this WG is to identify countries where HTA systems are sufficiently allowed and/or where there may be a need for a 5L value set 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





*Proposed Working Groups – Version March 11 2015*

was followed. 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 3L and 5L valuation protocols and 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.

**C. WG 3: Large Scale Applications Working Group**

- i. Aim 1: To initiate RFPs and PAs that promote and examine large-scale health systems applications for EQ products.
- ii. Aim 2: To stimulate methodological and applied research relating to the use of EQ-5D in measuring local and system-wide performance, as well as its use in assessing population health. For example:
  1. Methodological research in applications including, but not limited to, measurement properties, data collection, presentation formats, communication strategies.
  2. Applied research including, but not limited to, evaluation of specific interventions or programs, case-mix adjustment, evaluation in population level interventions, assessment of disparities across population subgroups.
- iii. Aim 3: To focus on applications inside healthcare systems, as well as in other non-health sectors.
- iv. Aim 4: To explore the development and use of new and existing EQ-5D products for large-scale applications in conjunction with the Business Office and Interface Development WG.

*Rationale:* Recent years have seen the introduction of routine collection of EQ-5D data across the whole health care systems, via ‘PROMs’-type programmes (eg. the English NHS; Alberta Health Services) and in large patient registries (eg in Sweden). In terms of sheer numbers of observations, these sorts of uses of EQ-5D probably now dominate the use of the instrument.

We need to ensure that these uses of our instrument are supported by the appropriate business practices, relevant scientific developments and ensure we capitalize on the opportunities these uses





*Proposed Working Groups – Version March 11 2015*

of the instrument present as ‘laboratories’ for research. Interested EuroQol Group members can send a request for invitation to participate in the SIG to the WG Chair.

Additionally, the EuroQol WG will investigate how a generic instrument could be used in beyond health care applications.

**D. WG 4: EQ-5D in Younger Populations Working Group**

- i. Aim 1: To develop EQ-5D instruments suitable for use in younger populations of various age ranges. This includes the validation of the EQ-5D-Y in younger age groups (using the proxy version).
- ii. Aim 2: To promote research to explore the validity of the EQ-5D-Y as a measure of health status in younger populations.
- iii. Aim 3: To work closely with WG on Valuation in developing a work programme for the valuation of EQ-5D-Y states.
- iv. Aim 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 .
- v. Aim 5: To update the user guide for the 5-level Youth version.

*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 younger populations 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 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.

**E. WG 5: Interface development Working Group**

- i. Aim 1: To support different end users of the EQ-5D instruments who wish to use electronic or internet based methods of data collection. The WG would broaden our support of end users beyond just clinical trial applications into many other areas of routine data collection.
- ii. Aim 2: To develop RFA and PAs for technology-related opportunities for EQ-5D related applications, such as integration into social media and online surveys. This may include developments to diversify/enhance future revenue streams, but also much of the work of the WG will be not-for-profit.



*Proposed Working Groups – Version March 11 2015*

*Rationale:* This proposed new WG represents a novel departure from the basis for past WGs in that the focus is on the D of R&D, development rather than more fundamental research into the development of new instruments. The DNA of this working group can be traced back to the Digital Task Force which aimed to engage with ePRO vendors and end users in order to develop and validate electronic representations of the EQ-5D instruments. Here we want to take this work forward beyond the arena of the clinical trial.

This WG spans mandate of the Executive, the Board, and Business Office and is intended to initiate and facilitate the development of novel ways of capturing EQ-5D data through electronic and internet based applications. This may include apps, social networks, handheld and BYOD data collection and other approaches. We will work with different providers to develop new mechanism to support data collection. This could be a software package to facilitate EQ-5D data collection in routine outcome measurement, an EQ-5D app to support health promotion based software or a smartphone version of EQ-5D to support very cheap data collection for studies in the developing world. Some of this work will bring new income for the group, but much of it will be designed to support the work of clinicians and researchers in the field interested in outcomes measurement. This WG could also have huge potential to support the work of other groups such as the **Large Scale Applications WG**.

The objective of this WG would include: (1) develop new ways to collect data for EQ-related products and find uses and potential markets for that data/information that could include development of an online app which can be incorporated with other methods of data collection; (2) develop mechanisms for providing greater access to web/ tablet versions of EQ-5D for public sector users.

**F. WG 6: Education and Outreach Working Group**

- i. Aim 1: Organize regular educational meetings for interested EuroQol members on specific topics related to research and application of EQ-5D.
- ii. Aim 2: Organize and promote regional meetings of researchers, decision makers and users interested in EQ-5D outside Europe and North America.
- iii. Aim 3: Propose educational and uptake initiatives to the Executive Committee that could be supported by the Foundation.

This new WG will have a mandate that supports part of the EuroQol mission unrelated to R&D but which is vital to sustaining the membership and its goal: i.e education and outreach. Two initiatives are proposed: for members, regular meetings with an educational focus would be initiated, perhaps staggered 6 months from the scientific plenary. The focus would be on providing educational sessions and workshops that help members gain a greater understanding of the EQ Group's ongoing research agenda and which encourage involvement in research initiatives.

A second initiative, related to outreach, would be to set up regional meetings of researchers and others interested in EQ-5D outside Europe and North America. There appears to be an increasing mass of researchers using EQ-5D in Asia, and to a lesser extent in South America. Given the costs involved and the limited access to the yearly Plenary Meeting, there would appear to be a justification for setting up regional meetings to facilitate exchange of ideas, experiences and results



*Proposed Working Groups – Version March 11 2015*

between researchers and those with an interest in using the instrument (government, insurers, etc) from the same region. Involvement of core EQ members from that region would be encouraged.

Finally, additional educational and outreach initiatives could be proposed by the WG for consideration by the Executive Committee.

**If you would like more information on any aspect of the WGs, please contact:**

**Bernhard Slaap, Executive Director: [slaap@euroqol.org](mailto:slaap@euroqol.org)**

**Simon Pickard, Chair of the Executive Committee: [aspickard11@gmail.com](mailto:aspickard11@gmail.com)**

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