

## Descriptive systems

For this round of applications, the DSWG is calling for proposals on 3 distinct research topics (that were also included in the last RFP). These are:

- The performance of EQ-5D in conditions with different durations
- EQALY related projects
- Extending the EQ-5D with bolt-ons

Each research topic is detailed below.

### Performance of EQ-5D in conditions with different durations

Many diseases and conditions show variations in health over time with varying consequences for the measurement of health-related quality of life (HRQL). Some acute conditions last for a short time, and may have different illness progressions and resulting effects on HRQL. For example, various infectious diseases, or 'event' like conditions with a recovery time such as a stroke or an injury. There are many variants of episodic conditions where the timing of reoccurrence might be uncertain (epilepsy). Chronic conditions may be progressive or may be relatively stable over time but the severity may fluctuate.

There is relatively little known about how EQ-5D performs in these various conditions with regard to duration and fluctuations, and we welcome research in this area. One may think of using multiple measurements over time (e.g. intensive longitudinal data), cognitive debriefing or qualitative studies (e.g. on how patients experience their illness; how they use EQ-5D; how HRQL measurement or the instructions may be improved), using different modes of administration, varying the instructions (other timeframes than "your health today"), or comparisons with other instruments. Any innovative approach is welcomed.

## EQALY

### a) Validity of the new measure

In order to test the performance of the new E-QALY measure, it is important to test its performance in comparison to other measures especially in evaluations (for example adding the measure to currently planned studies to allow assessment of its validity), and we welcome proposals in this area

### b) Translation and face validation of the final classification in other countries

Selection of the items to take forward in the measure will be undertaken in early 2019 based on evidence from the face validation in different countries and the psychometric survey.

Face validation, including translation where necessary, of the classification system would provide additional evidence on performance of the measure in different contexts. Proposals in this area are of interest to the DSWG, taking into account other similar work being conducted

internationally (for further information about this work please contact John Brazier (details below))

For more information on the eQALY project see: <https://scharr.dept.shef.ac.uk/e-qaly/>

## **Bolt-ons**

### *a) Development and psychometric testing of a bolt-on for “hearing”.*

Further research is required to develop the item and labels for the hearing bolt-on. For the hearing bolt-on, candidate items already exist; however, their development did not involve patients. Therefore, applicants are invited to submit proposals to develop and test item(s) on hearing involving patients in the process. In addition, applicants are invited to submit proposals on establishing the psychometric properties of candidate bolt-on item for hearing in relevant patient groups.

### *b) Investigating the relation between the EQ-5D’s “pain/discomfort” item and bolt-ons targeting physical discomfort, such as “itching” or “nausea”.*

In the EQ-5D physical discomfort is captured by the “pain/discomfort item”. While pain is obviously a very important aspect of physical discomfort, other aspects such as itching or nausea are not explicitly mentioned, which could lead to underreporting of discomfort, if it is not clear that “discomfort” includes these types of issues patients can suffer from. Therefore the DS-WG is interested in research using bolt-ons for physical discomfort (such as the “skin irritation (itching)” item from the EQ-5D psoriasis bolt-on). In particular the DSWG is interested in comparing the standard EQ-5D item “pain/discomfort” to the addition of bolt-on items relating to physical discomfort (e.g. a “pain” item, an “itching” item, and a “nausea” item), and investigate the related psychometric properties. Research could also include different operationalisations of a compound item with explicit “examples” to make more explicit what is meant with discomfort (e.g. “physical discomfort (e.g. pain, nausea, itching)”).

## **Requirements for proposals**

This research will form part of a broader research agenda being coordinated by the DSWG. Applicants are advised to approach the DS-WG for advice and to work closely with the DSWG within their proposals. For general and project proposal based queries please contact Brendan Mulhern ([Brendan.mulhern@chere.uts.edu](mailto:Brendan.mulhern@chere.uts.edu)). If you have a query about an EQALY proposal please contact John Brazier ([j.e.brazier@sheffield.ac.uk](mailto:j.e.brazier@sheffield.ac.uk)).

Researchers must also indicate a willingness for the EuroQol Research Foundation to hold the IP rights to any bolt-on developed through this initiative.