Descriptive systems RFP – Sept 2020

For this round of funding, the Descriptive System Working Group (DSWG) calls for proposals contributing to five broad research themes:

- Testing the coverage and validity of the existing EQ-5D instruments in different populations.
- Assessing the recall period in clinical populations and the use of innovative methods for measuring health fluctuations over time.
- Producing evidence on the international acceptability, relevance, and face validity of existing bolt-ons
- Comparing methodological approaches for the psychometric assessment of existing EQ-5D instruments.
- Investigating questions of relevance to both the DSWG and the Version Management Committee (VMC)

Research teams are encouraged to suggest novel methodological approaches to use for these studies. Further information is provided below:

Testing the coverage and validity of existing EQ-5D Instruments in different populations

We call for proposals in two main areas, namely coverage and validity. All types of validity (e.g., face, content, and construct) are of interest. Examples of populations include, but are not limited to, different cultural, demographic, and disease groups. Proposals conducting literature reviews, and using both qualitative and quantitative methods are welcome.

Reviews of instrument coverage and validity

There has been a significant amount of DSWG research focused on testing the coverage and validity of EQ-5D instruments internationally. This has been done by investigating the relevance of the five items, as well as the areas of QoL that are important to people. There is also work in this area conducted outside of the EuroQol Research Foundation.

We are therefore calling for proposals conducting syntheses or reviews of current findings from the studies in different populations investigating instrument coverage and validity, to draw conclusions and establish where further development is required. This will include EuroQol funded work and wider publications. Projects in this area can involve collaboration with the DSWG to identify studies and provide syntheses of findings to inform future research calls.

Generating new evidence investigating instrument coverage and validity:

We are interested in proposals investigating the validity and appropriateness of EQ-5D instruments in different populations. This includes, but is not limited to, research on different cultural, demographic, and disease groups. We call for proposals:

- Assessing the cultural appropriateness of the EQ-5D and its validity for use as a common measure across demographic and disease groups. This work could involve primary or secondary data collection and could employ quantitative and/or qualitative methods. There is also the opportunity to work with the VMC on this issue, in particular using the cognitive debriefing reports they have available (see Section 5).
- Conducting further primary research to assess the validity and psychometric performance of the EQ-5D across populations and disease-specific groups in comparison to other measures. This includes assessing the performance of the instruments in measuring multi-morbidities.
- The validity and relevance of the descriptive system as a measure for use in health crises in comparison to other measures. This could include, for example, measuring health and broader quality of life relating to the COVID-19 pandemic.

Note: In proposals submitted under this theme, it is essential to delineate whether the objective is to assess domains, items, or attributes in different populations. A domain refers to the concept that you wish to measure or describe. An item is a measure of a domain (e.g., a question, a cognitive task). An attribute is a description of a domain (e.g., adjectival statement, vignette). A domain may be measured using multiple items and described using various attributes; however, each of the five EQ-5D-5L domains has one item and one attribute. Any assessment of domains, items, or attributes must account for context, such the disease, language, and setting. A domain/item/attribute may be appropriate and validated in one setting or population, but inappropriate and invalid in another.

Assessing recall period in clinical populations and the use of innovative methods for measuring health fluctuations over time

Many acute diseases and conditions cause fluctuations in health over time. Some conditions, such as infectious diseases (e.g., flu, episodic conditions), epilepsy, and 'event' like conditions (e.g., stroke), have a severe impact for a short time and different illness progressions after. Even chronic conditions, which may be progressive or stable over time (e.g., angina) show substantial fluctuations. This poses challenges for the measurement of quality of life and computation of QALYs.

Currently, there are few ongoing methodological studies investigating how the recall period of EQ-5D instruments might be modified using different recall periods. These studies have been conducted in respiratory, infective and autoimmune diseases, but other clinical conditions may benefit from modified time frames, such as cancer, diabetes, cardiovascular diseases, etc. The selection of a candidate set of appropriate recall periods relies on the availability of comparative evidence across clinical populations. For this reason, research investigating the most relevant recall period in different clinical populations is invited.

Moreover, using a modified recall period represents only one option for measuring fluctuations over time. One alternative may be to experiment with repeated measurements (e.g., longitudinal data, diaries) using qualitative methods to investigate how patients experience their illness and how they respond to the EQ-5D instruments. Another may be to modify instructions to improve the instrument self-completion. The DSWG calls for research that may address these gaps using innovative methods.

Proposals in this area should consider the ongoing work previously funded and suggest extensions to this in populations not yet tested. Please contact Brendan Mulhern (Brendan.mulhern@chere.uts.edu.au) or Aureliano Finch (finch@euroqol.org) to discuss this theme further.

Producing evidence on the international acceptability, relevance, and face validity of existing bolt-ons

The DSWG is currently overseeing a program of research aimed at developing bolt-on dimensions, items, and attributes. The majority of the developmental work has been conducted in a small set of countries. Yet, questions remain on the relevance and applicability

of the bolt-ons internationally. The question of relevance and applicability is threefold. First, it is necessary to understand whether existing candidate bolt-ons domains are relevant in different cultures and contexts. Second, it is important to understand whether the way bolt-ons are phrased and translated (for example in the wording used and the examples provided) are applicable around the world. Finally, we need to understand the psychometric properties of the bolt-ons internationally (see also Section 4).

To provide two examples, 'interpersonal relationships' has been published as a culture specific bolt on in Thailand (Kangwanrattenakul et al 2018). It can be hypothesised that interpersonal relationships are relevant around the world (point 1 above), but the phrasing used in in the Thai study may not be applicable around the world (point 2). If the phrasing is not applicable, how should it be adapted for international relevance? As a second example, 'cognition' is a bolt on that has received plenty of attention (e.g. Krabbe et al, 1999), and cognitive disorders are a universal health concern. However, there is a lack of evidence about the extent to which the complex terminology and examples used to describe cognition are understood and in populations and conditions likely to report disorders of cognition.

The DSWG invites proposals investigating different aspects of the relevance, applicability and psychometric properties of bolt-ons. This work could focus on bolt-ons that have been published, or are in development. However, applicants must clearly justify why they have chosen to investigate particular bolt-on(s), and the populations, countries and/or settings included in the proposal. They should also clearly state the benefits that the group will receive from producing evidence in these areas. Given the focus of this research, applicants could consider building collaborations with other members internationally to allow for suitable comparisons between countries and languages.

Comparing methodological approaches for the psychometric assessment of existing EQ-5D instruments.

Researchers use many methodological approaches to understand the validity and psychometric performance of instruments. However, little research is available on how common methods can and should be used, individually or comparatively, such as classical test theory, factor analysis, structural equation modelling, item response theory. The influence of methodological decisions on the findings is also unclear. Without this methodological evidence, it is not possible to compare the EuroQol family of instruments and its counterparts. Conducting this research on existing instruments also provides evidence on how to assess

experimental instruments and supports the further their development (e.g., bolt-ons, EQ-HWB).

We call for proposals to investigate these issues. Examples of these proposals are and are not limited to, reviews of methods for the conduct of psychometric studies with existing EQ-5D instruments and counterpart instruments, using both primary and secondary data sources. These comparisons may also include assessments of instrument validity, as outlined in Section 1.2.

Investigating questions of relevance to both the DSWG and the Version Management Committee (VMC)

There are a range of research topics of interest to both the DSWG and VMC, and the groups are working together to build collaborative projects involving the broader membership that tackle joint aims. Members are encouraged to submit proposals investigating these issues. Please discuss your research with the chairs of the DSWG and the VMC, who can further support the development of collaborative proposals. Topic areas of interest are as follows:

Descriptive system equivalence research:
The existence of multiple modes of administration for the EQ-5D family of instruments, and the potential for multiple modes to be used in trials and other studies, raises questions of measurement equivalence, and also the appropriate mode to use in different populations. For example, an Interviewer Administered version has been recently approved and establish equivalence between versions is of interest in order to guide users as to the choice of which form of administration should be utilized.

Therefore the DSWG, in collaboration with the VMC, calls for proposals to compare the feasibility, reliability and other psychometric properties of the interviewer and self report versions of the EQ-5D. We are interested in mixed methods proposals to tackle this issue. Please also note that a similar call for equivalence research into the EQ-5D-Y instruments is highlighted by the Younger Populations Working Group. Collaborative work investigating the equivalence of both adult and child versions could be considered.

Interpretation of the descriptive system:
We are interested in proposals that investigate how the EuroQol family of instruments are interpreted by different populations. For example, are the instruments interpreted in the

context of health, health related quality of life, or general QoL? This work could use qualitative methods to understand this issue.

Analysis of cognitive debriefing reports:
The VMC has a database of cognitive debriefing reports that may be of interest in investigating descriptive system related issues, and in particular how it is interpreted in different languages and cultures (see also Section 1 above). Further work on these will be led by the VMC, with input from the DSWG. Interested parties should also review the request for proposals circulated by the VMC.

General information:
The DSWG recognizes the importance of conducting research related to COVID-19. While this RFP does not include a specific COVID-related theme, studies investigating the effect of COVID-19 on fluctuations in health, interpreting evidence from existing instruments, and using EQ-5D instruments for monitoring the pandemic, and potential future health crises, are encouraged.

To discuss potential proposal submissions or for further information about any of the research areas listed, please contact Brendan Mulhern (Brendan.mulhern@chere.uts.edu.au). For discussion of projects relating to both the DSWG and VMC, please also contact Jennifer Jelsma (Jennifer.jelsma@uct.ac.za).

References:
Kangwanrattanakul K, Gross CR, Sunantiway M, Thavorncharoensap M. (2018). Adding two culture-specific 'bolt-on' dimensions on the Thai version of EQ-5D-5L: an exploratory study in patients with diabetes. Expert Review of Pharmacoeconomics & Outcomes Research, 19(3): 321-329.
Krabbe, PF, Stouthard ME, Essink-Bot ML, Bonsel GJ. (1999). The effect of adding a cognitive dimension to the EuroQol multiattribute health-status classification system. Journal of Clinical Epidemiology, 52(4): 293-301.