2. Scope of this call

2.1. Descriptive System Working Group

For this round of funding, the Descriptive System Working Group is calling for proposals contributing to five research themes. The remit of the working group has recently been updated (see Appendix 1), and these research themes fit within the new aims of the DSWG:

1. Psychometric assessment and further development of psychometric knowledge
2. Production of evidence to assess the IP status of bolt-ons
3. Conceptual work to understand what EuroQol instruments are measuring and describing
4. Investigation of the EQ-5D ceiling effect
5. Member driven descriptive system related projects.

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

2.1.1. Psychometric assessment and further development of psychometric knowledge

EQ-5D in rare diseases

There is a growing body of literature investigating the empirical validity and responsiveness of the EQ-5D in different disease areas, conditions and populations, and a growing number of studies summarizing this evidence in reviews and overviews of the literature. Yet, there is a paucity of evidence regarding the performance of the EQ-5D as a measure of the health impacts of rare diseases. The DS WG invites proposals investigating the validity and responsiveness of EQ-5D in rare diseases.

Further development of psychometric knowledge with a focus on issues relevant to preference-based instruments

There are a wealth of psychometric methods available for testing preference-based instruments. These include, but are not limited to, classical test theory, factor analysis, structural equation modelling, and various forms of item response theory, and the majority of evidence produced is based on classical test theory.

It is unclear 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 particular characteristics of the EQ family of preference-based instruments. However,

little research is available on the way these methods can and should be used to develop and assess preference-based measures.

The DSWG invites proposals to investigate the use of psychometric methods with a focus on issues relevant to preference-based measures. The aim of this area of work is to further develop a psychometric evidence knowledge base to inform the broader work of the providing support for the further generation of a psychometric protocol. This is important given the need to generate evidence to support the further development of the family of EQ instruments e.g. EQ-HWB, EQ-5D-Y, bolt-ons.

Examples of proposals relating to this theme include, but are not limited to, reviews of methods for conducting psychometric studies, and the use of primary and secondary data sources to explore psychometric methods, and/or develop and test new approaches. We are also interested in comparing psychometric methods across EuroQol and other preference and non preference based instruments. Instruments of strategic interest include the PROMIS, EQ-HWB and other generic preference based measures.

2.1.2. Production of evidence to examine the IP status of bolt-ons

The DSWG has recently been involved in the development of a EuroQol document to outline the process required to assess the current IP status of EuroQol Instruments (i.e. experimental, beta and approved instruments), and generate further evidence to support the transition of instruments between IP stages.

One set of experimental instruments are bolt-ons, and the DSWG is currently overseeing a program of research aimed at developing bolt-on dimensions and items in health and quality of life areas where there is a case for doing so (e.g. vision, cognition and hearing).

We call for work assessing existing bolt-ons, with a view to informing their current IP status. Work will focus on highlighting deficits in the existing evidence for a particular bolt-on(s), and using this to generate further qualitative and/or quantitative evidence to support the group in decision making about the status of bolt-ons. Further qualitative evidence could include international face validity work to understand the extent to which candidate bolt-ons are relevant in different cultures and contexts, and whether the way bolt-ons are phrased and translated (for example in the wording used and the examples provided) are applicable around the world. Quantitative evidence could include examining the psychometric properties of the selected bolt-on(s) internationally and comparatively between each other, and the performance of bolt-ons in different settings in relation to the five dimensions, the dimensions included in other instruments, and other bolt-ons

There is also interest in the conceptual basis for bolt-ons, including understanding when and how we would expect bolt-ons to be used, and developing a conceptual basis for establishing the need for current and future bolt-ons. We also call for work in this area.

Applicants are encouraged to discuss the contents of the IP document and work relating to understanding bolt-on IP status with the chair of the DSWG, Brendan Mulhern (Brendan.mulhern@chere.uts.edu.au). Given the focus of this research, applicants could consider building collaborations with other members internationally to allow for comparisons between countries and languages. The DSWG can help facilitate this.

2.1.3. Conceptual work to understand what EQ instruments are measuring and describing

The DSWG is interested in mapping out and defining the concepts and terminologies used in the measurement and description of health and quality of life, and understanding the appropriateness of EuroQol instruments to measure and describe these. This will help understand what EQ instruments measure, inform where other instruments may play a role, and support the further development and assessment of EQ instruments. We call for proposals in this area. Potential methodological approaches include, but are not limited to, use of systematic literature reviews, the development of conceptual frameworks, and use of consensus based techniques.

2.1.4. Investigation of the EQ-5D ceiling effect

Research investigating response patterns to the EQ-5D has established that the 3L, and to a lesser extent the 5L, display evidence of a 'ceiling effect' (defined as a high proportion of respondents reporting no problems on all dimensions, or 11111). This can limit the sensitivity of the descriptive system as well as the index score to mild health problems, and change in mild health problems over time. We invite research examining the ceiling effect phenomenon. In particular we are interested in reasons why it occurs across different populations, and also how response patterns to EQ-5D that result in a ceiling effect compare to responses to other generic preference and non-preference based instruments that don't exhibit a ceiling effect. Proposals could use primary or secondary data analysis to map between response patterns across instruments or use qualitative methods to explore the possible reasons behind this phenomenon.

2.1.5. Member driven descriptive system related projects

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.

General information

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