

## Large Scale Applications RFP – Sept 2020

The LSA WG aims to support the use of EQ-5D as a health outcome measure in population health assessment, in studying health inequalities, and as a PROM in routine outcome measurement within health systems. LSA research topics may involve the development, implementation and use of large data sets that include the EQ-5D, but may also involve an application of the EQ-5D in a setting with a wide scope.

The WG is interested in both methodological and applied research relating to the use of EQ-5D in assessing population health, studying health inequalities, and in measuring local and system-wide performance. Note that research topics could overlap with research interest or priorities of other WGs such as the DSWG and the E&OWG. We especially welcome innovative research proposals.

### ***The use of EQ-5D in population health assessment***

This research topic covers datasets that attempt to measure the health of general population that include EQ-5D data<sup>1</sup>. These data 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 factors that determine population health status, including demographic, cultural and epidemiological factors, and how these impact on health, as measured by the EQ-5D, over geographical regions and times.

#### *Studying health inequalities*

We are interested in studies that measure inequalities in health and health care using the EQ-5D, 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 health

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<sup>1</sup> Note that these may include data resulting from valuation studies, although for some purposes these datasets may be considered not large enough

care access inequalities and the impact of external factors like the COVID-19 pandemic and social policies. This may also include unintentional and intentional policy factors for inequality reduction. If EQ-5D is contrasted with other measures of morbidity, properties of EQ-5D might be explored in this context.

### ***The use of EQ-5D as a Patient Reported Outcome Measure (PROM) in routine outcome measurement***

Many health systems and organizations around the world are using the EQ-5D as a patient-reported outcome measure (PROM), as a routine outcome measure for various purposes such as enhancing patient centred care, monitoring, evaluating and improving quality of care, and incorporating patient-reported outcomes into value-based care. The EQ-5D is currently being used alongside disease-specific PROMs in routine outcome measurement within patient registries and health organizations in Sweden and Canada, 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. Very little evidence exists on the application of the EQ-5D for these purposes and its usefulness in improving patient management, patient-clinical communication, patient-centred care, and health outcomes. Given the escalating interest in PROMs measurement around the world, especially the work that is driven by the OECD, we believe that the EQ-5D could be the generic PROM of choice that could be adopted for such usages to standardize patient-reported outcome measurement. For that, the LSAWG 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***

This includes exploring best approaches of collecting EQ-5D data in PROMs programs, and examining issues in implementing PROMs systems, such as:

- The challenges of the outcome measurement itself: what devices work best, can different instruments be implemented simultaneously, can doctors/nurses 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?
- The challenges of reporting and communicating EQ-5D information to users in a way that is - demonstrable - instrumental to that user (dashboard graphics etc.)

### *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. Our interest is in exploring ways of using EQ-5D data in each of these applications; e.g., how can EQ-5D data be analysed and reported in comparing performance of healthcare providers or to inform quality improvement initiatives? Can EQ-5D data be used to inform clinical management, and how? Can EQ-5D data be used to support patient decision making around treatment options (e.g., patient-decision aids), and how?

### *Examining the impact of EQ-5D/PROMs*

There is lack of information about the impact that EQ-5D/PROMs have on outcomes, such as evidence that they have resulted in changes in, for example, clinical practice, hospital performance and 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.

Note: It is essential that the proposed research is primarily about use of the EQ-5D, rather than including the EQ-5D as an incidental component of a PROMs program or simply as an example. We are interested in how the EQ-5D can be used in combination with other data collected within a PROMs program, including other PROMs and Patient Reported Experience Measures (PREMs).

### ***Methodological advancements***

This includes research involving retrospective measurement<sup>2</sup>, individual vs. household determinants<sup>3</sup>, health trajectories (e.g. the 'Landmark method'), the use of change variables vs. difference scores, response style measurement and adjustment, equivalence studies on related concepts (e.g. healthy days, DALYs), 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

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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.

<sup>3</sup> Specific for population data

with the EuroQol Foundation's collaborative program agreements currently in Sweden and Canada.

For advice or guidance in developing your research proposal, please feel free to contact the co-chairs of the LSA WG, the Health Inequality SIG or members from the Canadian APERSU program, and the Swedish PROMs program (info listed at the end of this document).