Large Scale Health Applications

Large Scale Applications (LSA) cover the use of large datasets that include the EQ-5D, or an application of the EQ-5D in a setting with a wide scope. Examples are so called Quality Registries (defined by various 'categories': condition, medical specialism, treatment, device, etc.), national health surveys, and large-scale multinational trials or cohort studies. Such data are often collected as part of a routine process not specifically dedicated to the EQ-5D, and aim to cover patient or regional populations.

The mission of the EuroQol Group is to improve decisions on health and in health care, using information where EQ-5D is part of, or the single most important outcome measure. This also applies to LSA projects. While LSA data sets, whether clinical registries or population health surveys, allow for research on a particular medical condition, it should be noted that research with large datasets can also have a large methodological or otherwise innovative component, in particular if the research is multi-national and if results are aimed directly at improved decision-making by any stakeholder (i.e., patients, clinicians, administrators). This is visible in countries where the EuroQol Group created opportunities for its members by large-scale contracts (APERSU in Canada, Sweden, UK, Norway and perhaps others to come).

This RFP includes two areas of interest:

Patient Reported Outcome Measures (PROMs) in quality registries

There is a growing demand for routine collection of generic health measures like the EQ-5D in the context of real time quality processes, along with routine high frequency health measurement with digital devices aiming to let the client do the right (healthy) thing. The conversion of these data into 'information' for decision-making is a challenge. Hence we encourage a shift in scientific attention to optimal data-processing and data-presentation, in response to the user's demands.

EQ-5D 'PROMs data' could be held by individual hospitals, clinics, or primary care practices, by others such as regional or national health bodies or insurance organisations, or as part of national or regional patient registries. The foci of interest for these data may be comparative performance of providers or patient decision-making. We are therefore especially interested in research proposals in the following areas:

- Specific issues in analysing and reporting of EQ-5D as PROM. So far the pre-post difference between two EQ-5D scores (with its utility) and two EQ-VAS scores has not been investigated thoroughly in the context of use as PROM. One can think of how EQ-VAS scores relate to EQ-5D dimension scores over time, and how response shift might affect both. A related methodological issue is about the choice of thresholds or MIDs, which is different in the context of benchmarking.
- Reporting behaviour, or 'response heterogeneity'. This is a systematic response tendency of a person, in terms of the scale used, unrelated to the true health level. A

commonly known tendency is to avoid extremes (e.g. elderly people, people from Asian background). As PROMs are used for quality purposes including checking of differential care performance among subgroups (e.g. by education or ethnic background), the detection and adjustment of response heterogeneity has become important.

- Another area is about presentation of EQ-5D information for different stakeholders, for different purposes. While the EuroQol Group has made progress in the technical possibilities to compare EQ-5D data, it is still not clear which presentational formats work best for the various user situations (e.g. for clinicians, decision makers, etc.).
- The conversion of registry data into decision tools for common decisions is largely uncharted territory (for EQ-5D), e.g., presenting patients for treatment A with available information on his/her relative position now, and on future information - personalized - given a decision concerning treatment A.
- A growing area is examining how PROMs are used in practice. Think of quality control at large; performance management (also at the managerial and individual provider level); and individual patient decision-making. In general this deals with comparing EQ-5D results with an estimated expectation. Here is much room for innovation, where a study should take generalizability of a tool or solution into account.

Inequalities in health / population health

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, international). If the EQ-5D is contrasted with other measures of morbidity, properties of the EQ-5D might be explored in this context. Another area of interest is population health, including changes in population health status, population risk factor models and population norms. We are interested in factors that determine population health status defined in EQ-5D terms, including demographic, cultural, epidemiological geographical and temporal factors, and disease impact/burden of disease initiatives.

This list does not exclude other research questions which may have specific merits, and can be proposed, bearing the rationale of LSA in mind. For advice or guidance in developing your research proposal, please feel free to contact the Co-chairs of the LSA WG (info listed at the end of this document).