EQ-5D: a measure of health status from the EuroQol Group

Rosalind Rabin and Frank de Charro

Established in 1987, the EuroQol Group initially comprised a network of international, multilingual and multidisciplinary researchers from seven centres in Finland, the Netherlands, Norway, Sweden, and the UK. Nowadays, the Group comprises researchers from Canada, Denmark, Germany, Greece, Japan, New Zealand, Slovenia, Spain, the USA and Zimbabwe. The process of shared development and local experimentation resulted in EQ-5D, a generic measure of health status that provides a simple descriptive profile and a single index value that can be used in the clinical and economic evaluation of health care and in population health surveys. Currently, EQ-5D is being widely used in different countries by clinical researchers in a variety of clinical areas. EQ-5D is also being used by eight out of the first 10 of the top 50 pharmaceutical companies listed in the annual report of Pharma Business (November/December 1999). Furthermore, EQ-5D is one of the handful of measures recommended for use in cost-effectiveness analyses by the Washington Panel on Cost Effectiveness in Health and Medicine. EQ-5D has now been translated into most major languages with the EuroQol Group closely monitoring the process.

Keywords: application; EQ-5D; EuroQol Group; health status measurement; translation; valuation.


The EuroQol Group

EQ-5D is a generic measure of health status developed by an international research group, the EuroQol Group. Established in 1987, the EuroQol Group initially comprised a network of international, multilingual and multidisciplinary research teams from seven centres in Finland, the Netherlands, Norway, Sweden, and the UK (1, 2). As the composition of these teams changed, so did the membership of the Group. After 1995, it was agreed that membership would be determined on an individual basis so that nowadays the EuroQol Group comprises researchers from Canada, Denmark, Germany, Greece, Japan, New Zealand, Slovenia, Spain, the USA and Zimbabwe. In 1994, the EuroQol Group reconstituted itself into an Association with an Executive Committee, a formal Board of Management and a growing Business Management Office in the Netherlands.

Aim

The principal aims of the EuroQol Group were (and remain) the development of a standardized, non-disease-specific instrument for describing and valuing health-related quality of life that would complement, rather than replace, other health-related quality of life measures. The required characteristics of the instrument were that it would be: 1) an easy 'add-on' to studies using existing instruments; 2) capable of being disseminated as a postal questionnaire for self-completion; 3) relatively undemanding – taking only a few minutes to complete; 4) relevant to all respondents: healthy or severely ill; at home or in hospital; of all ages; 5) capable of producing a single index value; 6) consistent with health states ‘worse than dead’.

EQ-5D

The descriptive system

From the outset, the EuroQol Group has always focused on the capacity of the instrument to generate cross-national comparisons, and the Group has invested considerable effort in both the development and valuation aspects of health status measurement. Issues such as language variants, layout experimentation, timeframe, choice of dimensions and levels, etc, were exhaustively researched in the first year of the EuroQol Group’s formation. In choosing the
descriptive system for EQ-5D, the EuroQol Group was conscious from the outset of the potential trade-off between multidimensionality and simplicity. The Group has firmly opted for the latter but has also aimed in its choice of descriptors, for full coverage over the health spectrum from best to worst, while also addressing the issue of death. After intense discussion within the Group and a review of the general health-related quality of life literature, six dimensions were originally identified, but these were later reduced to the current five so that nowadays EQ-5D defines health in terms of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is divided into three levels: no problem/some or moderate problems/extreme problems. According to this classification 243 potential health states are thus defined. In addition to these two further states have been specified, ‘dead’ and ‘unconscious’, giving a total of 245 health states.

Valuing health states

Once the descriptive system had been agreed upon, the EuroQol Group turned its attention to valuation aspects of health status measurement. Several research projects in different countries were carried out to elicit valuations (primarily by means of postal surveys) from general population and patient samples for EQ-5D health states derived from the descriptive system. First, respondents were asked to describe their own health according to the five dimensions and also provide a self-rating on a 20-cm vertical scale with endpoints of ‘best imaginable health state’ set at 100 and ‘worst imaginable health state’ set at 0. They were then asked to hypothetically value a subset of EQ-5D health states (known as the ‘common core’) as well as ‘unconsciousness’. The respondents were then asked to draw a line to indicate the position of the state ‘dead’ in comparison to the other states. In a final section, respondents were asked a series of sociodemographic questions including those relating to age, gender, education, occupation, experience of illness and smoking behaviour.

Using this method, valuations for the common core health states were elicited in Finland and the USA (3), Canada, Germany, the Netherlands (4, 5), Spain (6), Sweden (7) and the UK (8). In addition, the choice-based method of time trade-off (TTO) was also used to elicit values for EQ-5D health states in the UK (9), Spain, Germany and Japan.

The results of these studies have shown that the central tendency measures for these common core states may be similar for European countries, and, for the past 3 years, EuroQol Group effort has concentrated on harmonizing and integrating the results of the various European valuation projects with a view to exploring the possibility of producing a standardized set of European valuation data. The EQ-5D health states were included in a meta-analysis of the various European studies that enabled the respondent to classify his/her health according to five dimensions (EQ-5D self-classifier) and unconsciousness. Scoring algorithms required to estimate the score for any health state are available on request.

Key messages

- Outcome measures need to encompass a broad range of different disease areas, specialities and types of care.
- Many of the currently existing disease-specific measures are not adequate, and generic health-related quality of life profiles do not provide a single index that can be linked to cost.
- The EQ-5D developed by the EuroQol Group has been developed to address these issues.
EQ-SD from the EuroQol Group

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

### Mobility
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

### Self-Care
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

### Usual activities (e.g. work, study, housework, family or leisure activities)
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

### Pain/discomfort
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

### Anxiety/depression
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Figure 2. EQ-5D self-classifier and visual analogue scale.**

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care, usual activities, pain/discomfort and anxiety/depression. Each dimension is divided into three levels, i.e., no problem/some or moderate problems/extreme problems. The resulting health state can therefore be defined by a 5-digit number by combining one level from each of the five dimensions. For example, state 21133 would indicate some problems with mobility, no problems with self-care or usual activities and extreme problems with pain/discomfort and anxiety/depression. Potentially 243 health states can be defined according to this classification, and the information gathered can be used in a variety of ways.
One example is to use the data as a profile of health status based on information about the level of self-reported problems. Figure 3 shows data from general population postal surveys carried out in the UK and the Netherlands. Each of the five dimensions on the EQ-5D self-classifier is shown as a percentage of respondents indicating any problem (10).

A study by Hurst and co-workers (11) measured health-related quality of life in more than 200 patients with rheumatoid arthritis with the EQ-5D self-classifier. Figure 4 shows the generated health profiles classified by functional class (recognized therapeutic criteria that classifies patients in terms of disease severity). As can be seen from Figure 4, the percentage of respondents reporting no problems diminishes, while the percentage with some problems or extreme problems increases in each EQ-5D dimension with increasing functional class.

EQ-5D_index. The information derived from the EQ-5D self-classifier can also be converted into a single summary index (EQ-5D_index) by applying scores from one of the European valuation sets, referred to previously, that are generated as part of the EuroQol enterprise. Does the choice of value set depend on the purpose of the research? For example, for a cost-utility analysis where quality-adjusted life years (QALYs) or QALY-type calculations are being computed, it would be wise to use a value set generated by the choice-based TTO method. For analyses other than cost-utility, however, the choice of which set to use is wider.

Table 1 shows a comparison of the EQ VAS scores and the EQ-5D_index scores from the same Hurst study (11). The value set used to generate the EQ-5D_index was derived by using the TTO methodology as part of the Measurement and Valuation of Health (MVH).

![Figure 3. Self-reported health states (postal survey results from the UK and the Netherlands). (Reproduced from (10) with permission.)](image-url)

![Figure 4. Patients with rheumatoid arthritis by functional class. All values are percentages. (Reproduced from (11) with permission.)](image-url)
EQ-5D FROM THE EUROQOL GROUP

Table 1. Mean (o) and median (interquartile range) EQ-5Dutility and EQ-5Dvast and HAQ scores classified by functional class.

<table>
<thead>
<tr>
<th>Functional class</th>
<th>n</th>
<th>Mean (o)</th>
<th>Median (IR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5Dutility</td>
<td>1</td>
<td>60</td>
<td>0.73 (0.14)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>63</td>
<td>0.47 (0.26)*</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>60</td>
<td>0.24 (0.31)*</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>50</td>
<td>0.02 (0.31)*</td>
</tr>
<tr>
<td>EQ-5Dvast</td>
<td>1</td>
<td>60</td>
<td>76.8 (14.7)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>63</td>
<td>58.3 (19.2)*</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>60</td>
<td>43.6 (17.5)*</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>50</td>
<td>45.0 (23.2) NS</td>
</tr>
<tr>
<td>HAQ score</td>
<td>1</td>
<td>59</td>
<td>0.49 (0.45)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>62</td>
<td>1.22 (0.42)*</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>58</td>
<td>1.93 (0.33)*</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>50</td>
<td>2.45 (0.33)*</td>
</tr>
</tbody>
</table>

*pUnpaired t-test: P < 0.001; NS = not significant.
*Mann-Whitney U-test: P < 0.000; NS = not significant. (Reproduced from (11) with permission.)

HAQ, Health Assessment Questionnaire.

project at the Centre for Health Economics, York University UK (9). Hurst reported that the EQ-5Dindex discriminated well between each functional class; patients in class IV had mean EQ-5Dindex scores close to zero with many patients having health states rated 'worse than death' in terms of the population-based values. The EQ-5Dindex (and the EQ VAS) was found to be more responsive, as measured by the standardized response mean, than most of the condition-specific measures. Regression models confirmed that change in EQ-5Dindex was predicted by change in disability, mood, pain, patient-assessed disease activity and self-reported drug side-effects, providing further evidence that EQ-5D is measuring clinically relevant change.

EQ VAS. EQ-5D also captures a self-rating of health status on a 20-cm vertical VAS, anchored at 100 (best imaginable health state) at the top and 0 (worst imaginable health state) at the bottom (EQ VAS). As shown in Figure 5, EQ VAS ratings are a quantitative measure, and differences in this scale can be used as a measure of outcome, as judged by the individual respondents (12).

How and where is EQ-5D being used? The EQ-5D self-classifier and the EQ VAS (together with the sociodemographic questions if required) are being used increasingly in a variety of ways including the following: 1) monitoring the health status of patient groups at different moments in time; 2) assessing the seriousness of conditions at different moments in time; 3) providing evidence about medical effective-ness of drugs or processes to obtain approval; 4) in economic studies, eg, to provide relevant information for resource allocation at a variety of levels; and 5) establishing levels of population health status both locally and nationally (eg, the Catalan health survey interview (13), the UK Department of Health Omnibus Sample Survey 1996, the Health Survey for England (14) and the US current Medical Expenditure Panel Survey by the Agency for Healthcare Research and Quality).

Figure 5. EQ-5D as a self-rated index (using EQ VAS scores). A UK population sample by age/social class. Social class: I: professional, managerial and technical occupations; III NM/III M: skilled nonmanual and manual occupations; IV/ V: partly skilled and unskilled occupations. (Reproduced from (12) with permission.)

To date, there are approximately 500 registered studies in the EQ-5D database. Figure 6 shows more specifically the clinical areas where EQ-5D is being used based on this data. EQ-5D is most used in the UK and Continental Europe, although its use is increasing in the US and Canada (currently approximately 15% of the registered studies). EQ-5D is mostly used in clinical observational studies and in randomized clinical trials (RCTs), reflecting the growing enthusiasm of the pharmaceutical industry to include EQ-5D in their clinical research forms (CRFs) (Fig 7). Health surveys account for 10% of the use of EQ-5D.

Currently, eight out of the first 10 of the top 50 pharmaceutical companies listed in the annual report of Pharma Business (November/December 1999) are using EQ-5D. The instrument is also one of the handful of measures recommended for use in cost-effectiveness analyses by the Washington Panel on Cost Effectiveness in Health and Medicine (15), while in the UK a National Health Service Task Group has been set up to coordinate the testing of EQ-5D as an outcome measure for use by clinicians and managers. At a national level, the institutions involved are country-specific, and the use of EQ-5D in the demand and supply areas of health care is widespread and

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Initially developed simultaneously in Dutch, English, Finnish, Norwegian and Swedish, EQ-5D is now available in most major languages and cultural adaptations (Table 2). This provides the potential for researchers setting up international clinical trials to measure differences in outcome across borders. The translation and adaptation process is set out in the translation guidelines of the EuroQol Group that follow those proposed in the international literature. This involves a process of forward translation of the English source version by two qualified translators, native in the target language, and back translation of the resulting consensus version by two qualified translators, native in English but fluent in the target language. The results are then tested on a lay sample of the target population in a cognitive debriefing exercise. EuroQol Group members closely monitor the process.

**Figure 6. Clinical areas where EQ-5D is being used.**

**Table 2. Availability of EQ-5D in different languages and cultural adaptations (December 2000).**

<table>
<thead>
<tr>
<th>EQ-5D official translations and cultural adaptations</th>
<th>EQ-5D 'best available' translations and cultural adaptations (awaiting official status)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afrikaans</td>
<td>Japanese</td>
</tr>
<tr>
<td>Argentinean Spanish</td>
<td>Mexican Spanish</td>
</tr>
<tr>
<td>Australian English</td>
<td>Norwegian</td>
</tr>
<tr>
<td>Australian German</td>
<td>Peruvian Spanish</td>
</tr>
<tr>
<td>Canadian English</td>
<td>Portuguese</td>
</tr>
<tr>
<td>Canadian French</td>
<td>South African</td>
</tr>
<tr>
<td>Catalan</td>
<td>English</td>
</tr>
<tr>
<td>Croatian</td>
<td>Spanish</td>
</tr>
<tr>
<td>Czech</td>
<td>Swedish</td>
</tr>
<tr>
<td>Danish</td>
<td>Turkish</td>
</tr>
<tr>
<td>Dutch</td>
<td>UK English</td>
</tr>
<tr>
<td>Finnish</td>
<td>US English</td>
</tr>
<tr>
<td>French</td>
<td>US Spanish</td>
</tr>
<tr>
<td>German</td>
<td>Venezuelan</td>
</tr>
<tr>
<td>Hungarian</td>
<td>Spanish</td>
</tr>
<tr>
<td>Italian</td>
<td>Ukrainian</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

**Figure 7. Types of study where EQ-5D is being used.** RCT, randomized clinical trial.

includes general practitioners, hospital specialists, nurses and remedial therapists, public health specialists and health service researchers.

**EuroQol Group annual plenary meetings**

The Group has been holding plenary meetings since 1987 at various centres in Europe. Since 1991, papers presented at the annual meetings have been published in the conference proceedings or as a set of discussion papers. The meetings are generally spread over three days and consist of an open scientific session where members of the Group (and a number of non-EuroQol Group members) are invited to submit papers on their research in which EQ-5D is used. In
2000, the plenary meeting was held at the end of September in Pamplona, Spain, hosted by The Universidad Pública de Navarra. The scientific agenda covered a number of different methodological issues relating to valuation and included new valuation data from Slovenia, Japan, Zimbabwe and New Zealand. Population studies included health-related quality of life data on people with low income and members of different minorities in the USA and health care in Hungary, while outcome studies covered the use of EQ-SD in clinical areas such as diabetes, stroke, faecal incontinence and HIV. In September 2001, the EuroQol plenary meeting will be held in Copenhagen.

**Communication**

At the end of 1999, the EuroQol Business Management mailed a newsletter and survey of usage to more than 1000 researchers worldwide on the Group’s mailing list. Further newsletters will be distributed electronically. A new web address has been registered: www.euroqol.org. The site includes current information about Group membership and useful references in addition to providing an electronic version of the EQ-SD registration form that can be completed and returned directly to the EuroQol Business Management via the Internet.

**Conclusion**

There are now nearly 300 EQ-SD references in peer-reviewed journals. These are mostly concerned with methodological developments and EQ-SD usage in clinical studies but also include references to EQ-SD use in economic studies and population health surveys. EQ-SD therefore appears to be holding its own among the plethora of available health-related quality of life instruments. Its usefulness as a simple questionnaire, complementing other health status instruments but, nevertheless, capable of yielding a rich source of data, is increasingly attracting researchers in the fields of health economics, health status measurement and population health surveys. It is hoped that this momentum can be maintained as we move into the 21st century.

**References**