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The descriptive system of the EuroQol Instrument

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2.1 OBJECTIVES

In determining the coverage and structure of the EuroQol descriptive system, it was important to keep in mind the objectives of the instrument itself. Thus the EuroQol was to be a generic instrument for describing and valuing health-related quality of life (HRQoL), providing both a descriptive profile and an overall index for HRQoL. While it should be capable of identifying differences between populations and population groups, it was not intended to be a comprehensive measure of HRQoL, but as a standardised tool to facilitate the collection of a common data set. The instrument was also intended to be self-completed, and to be acceptable for use in postal surveys.

The concept of HRQoL used was broadly in line with the definition later suggested by Patrick and Erickson, 1993 - 'the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy'. The dimensions chosen should aim to capture physical, mental and social functioning, as the basic elements of relevance to a generic measure (Brooks, 1995). It should be noted that the development of the EuroQol took place mainly in northern Europe, with an inevitable bias towards cultural concepts appropriate to that part of the world. However, a recent population survey conducted in Spain suggests that the descriptive system is applicable there (Badia *et al*, 1995). No formal testing has been conducted in non-western cultures, although experimental studies in eastern Europe, Thailand, and among Bangladeshis living in England have been successful.

The objectives of the EuroQol enterprise led to certain requirements for the descriptive system. Firstly, in order to generate a generic instrument, the dimensions should be relevant to patients across the spectrum of health care, as well as to members of the general population. Thus there would be no mention of specific diagnoses, diseases or treatments, while disease-specific items, such as symptoms, would not be included. Such a demarcation is not always clear, in that a feeling of depression can be a symptom or a diagnosis in itself. However, the criterion for a dimension was that, even though it may figure largely in a particular illness or disease, it should also be of relevance to a wide range of patients and to the general population.

Secondly, the descriptive system should be fairly simple in order to generate a feasible number of potential health states for valuation purposes. In this respect the EuroQol Group has been motivated by an important strategic consideration. Within the

field of HRQoL measurement, there are two different, and to some extent opposing, schools of thought. While both agree that HRQoL is a multidimensional phenomenon, the first believes that this should be preserved at all costs and that HRQoL can only be represented as a profile of scores across discrete dimensions. The EuroQol Group is, however, grounded in the second school, which believes that health status can be modelled on a unidimensional continuum that permits point observations to be represented by a single index score. Furthermore, rather than weighting each dimension separately and then using some sort of additive or multiplicative process to combine them, it was desired to value whole health states so that the resulting valuations would incorporate interactions between dimensions. Thus, not only could changes in 1 dimension be detected (as with a profile measure), but when there was an improvement on 1 dimension and a deterioration on another, this information could be reconciled to produce a measure of net subjective change across all dimensions.

This valuation approach requires respondents to value whole health states and, ideally, for each respondent to value as many states as possible, if not all potential health states. The descriptive system therefore needs to be simple, using as few dimensions as possible, and as few items as possible within each dimension. The number of potential health states grows rapidly with an increase in the number of items or dimensions e.g. an instrument with 2 items in each of 3 dimensions generates 8 (2^3) health states, while one with 6 dimensions, each with 4 items, generates 4096 (4^6) states. As a further consideration, the description of a health state needs to be fairly short and sufficiently clear so that the respondent can identify differences between the states, particularly those that may differ by only 1 item. It was therefore considered preferable to present the items within each health state as bullet points rather than in a more narrative style.

The final requirement was that the instrument should be amenable to self-completion in a range of settings e.g. in a busy hospital clinic or in the respondent's own home. The instrument should be simple enough not to require detailed instructions, and the descriptive page should only take a couple of minutes to complete. A small number of dimensions and items, with an easy response form was therefore desirable. It was considered that placing a tick or a cross in the appropriate boxes was the most usual and straightforward way for respondents to answer.

2.2 SELECTION OF DIMENSIONS

It was evident from the beginning that a compromise had to be made between the desire to have a comprehensive instrument covering all the dimensions that other HRQoL instruments had used, and the need for a simple instrument that would be feasible in practice. A selection process was needed to choose from the large number of potential dimensions. The Group discussed various alternatives, including a survey of patients and the general population to identify common dimensions of relevance to

all groups. From the large amount of data produced, it would then be possible to identify such dimensions, although the ultimate choice would be heavily influenced by the expectations and biases of the researchers - there would still need to be some value judgement about which of the many 'important' dimensions should be included. In acknowledging this subjectivity in the choice of descriptive dimensions, the EuroQol Group decided to take an alternative strategy, by drawing on their own expertise to select the dimensions.

The Group undertook a detailed review of other generic HRQoL measures available at the time. These included the Quality of Well-Being (Patrick *et al*, 1973), the Sickness Impact Profile (Bergner *et al*, 1976), the Nottingham Health Profile (Hunt and McEwen, 1980), the Rosser Index (Rosser and Kind, 1978), the Health Measurement Questionnaire (Kind and Gudex, 1991) and the 15-D (Sintonen, 1981).

Contrary to expectations, the dimensions suggested for inclusion by the various members of the Group were broadly similar, with differences relating more to the names of dimensions rather than to their contents. There was general agreement that the following dimensions should be included in a basic HRQoL tool: mobility, daily activities and self-care, psychological functioning, social and role performance, and pain or other health problems.

2.3 SELECTION OF ITEMS

Items were chosen so as to be of ordinal character within each dimension, and to cover a wide range of severity within each dimension. Thus there should be scope for application in many different settings and populations, from healthy people living in their own homes and going about their usual activities, to severely ill patients in hospital. Thus the first item was always 'no problem', while the last item was the most extreme possible answer e.g. 'extreme pain, unable to do'. Where there was a third level, this was intended to be roughly in the middle of the continuum between 'no problem' and 'extreme problem'.

A consequence of developing the instrument within a multidisciplinary and multi-lingual group was that considerable importance was placed on identifying words that conveyed a similar meaning to people with different backgrounds and from different cultures. Indeed, there were many words suggested in one language that could not be translated sufficiently closely into another language. The great benefit of this exercise taking place round a table was that the meaning and wording of each dimension could be discussed, and we were able to reach a general consensus over the interpretation of the dimension. Simultaneous translation ensured that both the dimension and its items were likely to be readily understood in the national setting.

Care was also taken to avoid medical or technical terminology, preferring everyday usual language. Where uncertainties remained, it was possible to conduct a short survey to test the effects of using different words e.g. the use of ‘strong pain’ rather than ‘extreme pain’ in the Norwegian version.

2.4 THE EUROQOL 6D DESCRIPTIVE SYSTEM

The descriptive system that emerged in 1988 from the review of other generic measures consisted of 6 dimensions, each with either 2 or 3 items (Table 2.1). A person’s health state was described as a 6-figure number, by selecting one item (coded 1, 2 or 3) from each dimension e.g. state 212221 meant problems in walking but no problems with self-care, inability to perform work or leisure activities, moderate pain or discomfort but no anxiety or depression. Theoretically, this set of dimensions and items generated 216 ($2^3 \times 3^3$) permutations. Physical functioning was encompassed in the ‘mobility’ and ‘self-care’ dimensions, social functioning in the ‘social relationships’ dimension, and mental functioning in the ‘anxiety/depression’ dimension.

Table 2.1 Original 6D EuroQol descriptive system

Mobility

1. No problems walking about
2. Unable to walk about without a stick, crutch or walking frame
3. Confined to bed

Self-care

1. No problems with self-care
2. Unable to dress self
3. Unable to feed self

Main activity

1. Able to perform main activity (e.g. work, study, housework)
2. Unable to perform usual activity

Social relationships

1. Able to pursue family and leisure activities
2. Unable to pursue family and leisure activities

Pain

1. No pain or discomfort
2. Moderate pain or discomfort
3. Extreme pain or discomfort

Mood

1. Not anxious or depressed
 2. Anxious or depressed
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There was considerable discussion of the implications of having a dichotomous dimension, such as pain/discomfort or anxiety/depression. It was acknowledged that this might cause ambiguity for respondents, but the alternative of making each dimension separate had too large an implication for the potential number of health states.

Following a large national survey of lay concepts of health (van Dalen *et al*, 1994), an investigation was conducted as to whether an additional dimension of energy/tiredness should be incorporated into the EuroQol classification. The results of the survey had suggested that the EuroQol descriptive system sufficiently covered the dimensions of particular importance to people, except for the frequently mentioned one of energy/vitality. However, the inclusion of an energy/tiredness dimension into the 6D schema was found to have no significant effects either on self-reported health or on the valuation of other health states, and regression analysis showed no clear contribution from an energy dimension (Gudex, 1992). The extra dimension was thus not incorporated into the EuroQol descriptive system.

2.5 THE EUROQOL 5D DESCRIPTIVE SYSTEM

In the light of initial experiments with the 6D version, a number of changes were made, resulting in a descriptive system with 5 dimensions, each with 3 items (Table 2.2). This version was formally ratified by the Group in 1990.

It was considered that each dimension should have the same number of items, providing a more balanced structure to the descriptive system, and giving equal importance to each item in the resulting composite health states. In addition, semantic changes were made in order to create the same structure within each dimension i.e. 'no' problems, 'some or moderate' problems, and 'unable or extreme' problems. Under the mobility dimension, the second level was further changed so as to not exclude people who used other types of walking aid, or people who had problems walking but did not use an aid.

Table 2.2 5D EuroQol descriptive system**Mobility**

1. No problems in walking about
2. Some problems in walking about
3. Confined to bed

Self-care

1. No problems with self-care
2. Some problems washing or dressing self
3. Unable to wash or dress self

Usual activities

1. No problems with performing usual activities
(e.g. work, study, housework, family or leisure activities)
2. Some problems with performing usual activities
3. Unable to perform usual activities

Pain/Discomfort

1. No pain or discomfort
2. Moderate pain or discomfort
3. Extreme pain or discomfort

Anxiety/Depression

1. Not anxious or depressed
2. Moderately anxious or depressed
3. Extremely anxious or depressed

Note: For convenience each composite health state has a 5 digit code number relating to the relevant level of each dimension, with the dimensions always listed in the order given above. Thus 11232 means:

- 1 *No problems walking about*
- 1 *No problems with self-care*
- 2 *Some problems with performing usual activities*
- 3 *Extreme pain or discomfort*
- 2 *Moderately anxious or depressed*

A major change was made to the dimension of self-care. The third item, relating to inability to feed oneself, was marked by very few respondents and was felt to be too specific for use in most patient groups. The ability to wash oneself was agreed to be more relevant, and was thus included along with dressing oneself.

Adding an extra dimension to 3 of the dimensions (main activity, social relationships and mood) had severe consequences for the number of potential health states described by the system. A total of 729 (3⁶) states were then described, and this was

felt to be too large a number for the later valuation task. It was finally agreed to take out 'social relationships' as a separate dimension as it had been shown to contribute little to the valuation of health states. It was subsumed under what was previously the 'main activity' dimension, which was changed to explicitly mention family and leisure activities alongside work, study and housework.

2.6 VALIDITY OF THE DESCRIPTIVE SYSTEM

The descriptive system is presented to respondents on page 2 of the EuroQol Instrument. It can be used to indicate whether a respondent has a problem on any of the dimensions, and, if so, how severe this problem is. The same data from a number of individuals can be aggregated to obtain a descriptive HRQoL profile for a particular patient or population group. As a further step, a score can be given to each health state so described, either by asking respondents themselves to rate their own health, or by applying a score from a social tariff (see later chapters).

In view of the objectives of the EuroQol Instrument, the performance of the descriptive system can be assessed in a variety of ways. Does it include all the necessary dimensions for a generic, common core instrument of HRQoL i.e. does it have content validity? Does it produce results concordant with those from other HRQoL instruments or related measures i.e. does it have convergent validity? For example does a respondent scoring poorly on mobility on the EuroQol also score poorly on physical mobility on the SF-36? Is a relationship between status and age identified, where older respondents might be expected to report more problems with mobility and self-care than younger respondents? Does it identify differences that would be expected between respondent groups i.e. does it have discriminant validity? For example, patients with arthritis would be expected to indicate more problems on mobility and greater pain than others of a similar age in the general population, while people with acute asthma might be expected to report more problems with performing usual activities and a greater degree of anxiety or depression. Does the descriptive system identify changes across time i.e. does it show sensitivity to change? Being a simple generic system, it is unlikely to identify small differences across time (these may instead be identified through the use of self-rated own health on page 3 of the instrument), but it should still be capable of recognising clinically important changes - particularly as the descriptive system is intended as the basis for applying scores from a social tariff.

2.7 SUMMARY

The EuroQol descriptive system has developed within the context of a generic, index measure of HRQoL. Dimensions have been chosen based on a conceptual process rather than by statistical means such as factor analysis, and have been identified through a review of other generic health status measures. Emphasis has been placed on identifying a common core set of dimensions rather than attempting comprehensive coverage of all those possible, allowing the instrument to be used alongside both other generic measures as well as disease-specific instruments. Another strategic consideration was the requirement to generate a feasible number of health states for later valuation.

The result is a 5-dimensional system covering mobility, self-care, usual activities, pain/discomfort and anxiety/depression. With 3 levels within each dimension, a total of 243 different health states are described. This system can be used to generate a profile of HRQoL for a single individual, a group of patients, or a whole population, and can also be used to assess changes in HRQoL across time.

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2.8 REFERENCES

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