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Observations on one hundred students filling in the EuroQol questionnaire

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7.1 INTRODUCTION

The EuroQol Instrument measures HRQoL (EuroQol, 1990). The questionnaire was developed by the EuroQol Group, an international group of scientists working together in the field of measuring HRQoL. In developing the EuroQol, one of the ambitions was to make the questionnaire suitable for postal distribution. Hence, almost all research carried out using the EuroQol Instrument is by means of postal surveys. A disadvantage of this is that the researcher does not know how the subjects fill in the questionnaire. Of course, the investigator can ask some simple written questions and he/she can analyze the remarks in the margin, but observations and more complex questions are impossible. In order to address this issue, 100 students filled in the questionnaire while the first author was present, enabling him to make observations and asked questions afterwards.

Some of the specific research questions for this investigation were based on the regular scientific literature about the EuroQol Instrument (The EuroQol Group, 1990, 1991, 1992; Nord, 1991; Brooks, 1991; Carr-Hill, 1992; Essink-Bot, 1990). However, most of the questions were inspired by the Scientific Meetings of the EuroQol Group and the reports of the pilot studies that have been circulated within the Group. Some of these reports have been printed in scientific series published by research centres. An example of this literature is the EuroQol proceedings from Lund, Sweden edited by Björk (1992). However, most of the knowledge is still circulating in hard copy and is not publicly known. An attempt to collect this body of knowledge was undertaken by Nord in 1991. He gathered the findings and comments on the pilot studies and brought them together in the Index EuroQolus. Many of the research questions in this investigation are mentioned in EuroQolus, so it will serve as a reference for this chapter.

In the past, there has only been one attempt to carry out an observed administration of the EuroQol. This was undertaken by Ashby, Rushby and O'Hanlon in 1988. It was a small pilot study, in which the EuroQol questionaire was filled in by 16 members of the university staff at Brunel University, UK. The report of the pilot study is referenced in EuroQolus as Brunel 1, and contains one and a half pages of observations and comments by the subjects. Although the number of subjects was low and the reporting limited, the pilot study raised a number of important hypotheses about the way subjects fill in the questionnaire.

P. Kind et al. (eds.), EQ-5D concepts and methods, 81–90.

Because this investigation does not test just one hypothesis but a number of research questions, the structure of this chapter was adjusted. The methods section describes only the EuroQol Instrument itself and the general structure of the experiment. The hypotheses, method of testing, and the results are grouped by research question.

7.2 METHOD

The EuroQol Instrument.

The first description of the EuroQol Instrument was published in 1990 (EuroQol Group, 1990). Since this first article, the questionnaire has been changed. The version used in this investigation conforms to the modifications made at the EuroQol Conference in Lund, Sweden in 1991. The first page of the EuroQol contains general information about the purpose of the questionnaire. After the introduction, the subjects were asked which EuroQol health state they were in. The EuroQol health states are described according to 5 dimensions, each with 3 levels. The dimensions and levels are listed in Table 7.1.

Table 7.1 Dimensions, levels and the codes of the health states

Digit Place	Dimension	Code	Category
I	Mobility	1	No problems in walking about.
		2	Some problems in walking about.
		3	Confined to bed.
II	Self-Care	1	No problems with washing or dressing self
		2	Some problems with washing or dressing self
		3	Unable to wash or dress self
III	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 (e.g. work, study, housework, family or leisure activities).
		3	Unable to perform usual activities (e.g. work, study, housework, family or leisure activities).
IV	Pain / Discomfort	1	No pain or discomfort
		2	Moderate pain or discomfort
		3	Extreme pain or discomfort
V	Anxiety / Depression	1	Not anxious or depressed
		2	Moderately anxious or depressed
		3	Extremely anxious or depressed

A EuroQol health state can be described as a 5 digit code. The first digit represents the category of mobility, the second self-care, etc. For instance, the health state in figure 7.1 can be represented by the number 33321.

- Confined to bed.
- Unable to wash or dress self.
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Moderate pain or discomfort.
- Not anxious or depressed

Figure 7.1 EuroQol health state 33321

After the subjects classified themselves according to the EuroQol health state descriptive system, they indicated their own health on a vertical, calibrated scale, numbered from 0-100. The bottom of the scale was labelled 'the worse imaginable health state' and the top was labelled 'best imaginable health state'. After the instructions, the main task started. Two pages each with 8 health states were presented either side of the calibrated scale. On both pages, states 11111 and 33333 were repeated. The subjects were asked to draw lines from the health states to points on the scale which indicated how good or how bad the health states were, in their view.

Following this task, the subjects answered some written questions about their socio-economic status.

The subjects were not allowed to ask any questions about the questionnaire when they filled it in, but were told to follow the written instructions. Only when a student could not continue or the subject's responses indicated that the task was unclear, were additional spoken instructions given. After the students filled in the questionnaire, they were asked some verbal questions about the task. For example, one of the questions was: 'What would you have answered if the health state which was labelled unconscious had been labelled death?'.

Posters introducing the investigation were hung in the university's cafeteria at Erasmus University, The Netherlands. The poster advertised a 25 Guilder (US $17.00, September 1992) payment for participating in an interview concerning 'the assessment of health states', which would last for one and a half hours.

7.3 RESULTS

The subjects.

First a pilot study was set up with 10 subjects. A total of 105 students cooperated in the main investigation. The students had an average age of 22.70 years (SD 3.77) and 39% were female. Almost half of the students (48.6%) came from the faculty of Law, 16.2% from the faculty of Public Administration, 14.3% from the faculty of Economics, 11.4% from the faculty of Sociology and 9.5% from various other faculties. Every subject finished the questionnaire.

Table 7.2 The means and standard deviations of the health states

Health States	Mean	SD	Health States	Mean	SD
11111[a]	0.92	0.08	22233	0.26	0.13
11111[b]	0.91	0.09	33321	0.24	0.14
11211	0.75	0.13	22323	0.23	0.12
11121	0.70	0.13	Unconscious[c]	0.20	0.20
21111	0.69	0.14	Death[d]	0.12	0.22
11112	0.67	0.15	33333[b]	0.10	0.10
12111	0.61	0.16	33333[a]	0.09	0.10
11221	0.55	0.12	21232	0.35	0.13
32211	0.43	0.16	22233	0.26	0.13
21232	0.35	0.13			

a. State appearing at the first page of the EuroQol Visual Analogue Scale.
b. State appearing at the second page of the EuroQol Visual Analogue Scale.
c. Values between 0 and 100, N = 102.
d. Values between 0 and 100, N = 75.

The difficulty of the main valuation task

After the valuation of the EuroQol health states, the EuroQol Instrument asks the subject how difficult it was to fill in the questionnaire. One percent of the students said that it was very difficult, 36% fairly difficult, 65% fairly easy and 5% very easy. From these results it can be concluded that most of the subjects (70%) found it to be fairly easy to very easy to fill in the questionnaire. Similar results were found for the general public. For example in the investigation of Essink-Bot (1990), 57% of the general public found the postal questionnaire to be fairly easy to very easy to fill in. However, almost all authors reported that many mistakes were made. For example, in the investigation of Essink-Bot study, only 81 out of 112 questionnaires (72.3%) con-

tained usable valuations of the health states on pages 5 and 6. From their observations in 1988, Ashby and her colleagues concluded that when respondents said that the questionnaire was rather easy, they referred to the whole questionnaire, including the easy questions at the beginning and end (EuroQolus, 7.4; Brunel, 1). In order to test this hypothesis, subjects were asked to indicate how difficult it was to value the health states, after reading the instructions. Only 41% answered that the task was fairly easy or very easy, so it appears that Ashby and her colleagues were correct.

The remarks that the subjects made after they finished the EuroQol gave further indications that the main task was difficult. In fact, most remarks made were about the valuation task. Sixteen of the 105 respondents said that it was hard to compare the 8 health states on 5 dimensions simultaneously. Ten subjects said almost the same by indicating that it was hard to be consistent. Fifteen students found it hard to picture the health states. In addition 6 students found the calibration of the scale too fine for such a complex task. It has been suggested that the task might be difficult because valuing health states causes emotional stress. This did not seem to be the case in the current study, because only one student made a remark about emotional stress.

Mistakes and the instructions.

Fifty-five percent of the students claimed that the instructions were clear. However, 71% of the students had to go back and forth between the instructions and the valuation task, which indicated that the instructions were not completely understood after one reading. But although the task seemed complicated, only a few serious mistakes were made. One of the most striking mistakes was the interpretation of the label 'best imaginable health state' located above the calibrated scale, and the interpretation of the instruction 'Remember, we want you to indicate how good or bad each of these states would be for a person like you.' Sixteen students thought that the aim was to indicate how well one could imagine being in the health states themselves. Of the 16 students who made this mistake initially, 7 corrected themselves after valuing a few states. The other 9 subjects continued and were corrected by the investigator. The scores of the subjects who made this mistake had a typical dichotomous distribution. Since most students have never been in a bad health state, they found it most difficult to imagine the bad health states. Therefore, all the bad states had extreme low values and the good health states had extreme high values. These dichotomous scores were also noted by Brooks in 1991. In order to avoid confusion about the word 'imaginable', it would perhaps be better to eliminate the word or to replace it with 'the best health state'.

Sintonen (EuroQolus 5.1 A; Sintonen, Helsinki, 6:4) noticed that some subjects started to draw lines from the dimensions (the sentences) of the health states, instead of from the health states as a whole. In this investigation 5 students started to do this. Three students corrected themselves, but 2 others had to be corrected by the investi-

gator. When the students valued their own health states on page 3, 11 students did not draw a line from the box to the scale, but indicated the value in some other way. This mistake did not have very serious consequences, because the scores were still usable. However, it is an indication that the task is unfamiliar for many people. Afterwards, 7 subjects remarked that drawing lines was not very common and therefore caused confusion.

Students have better cognitive capacities than the general public. Hence, it is likely that the general public would have experienced more difficulties with the questionnaire than the students. On the other hand, it is reasonable to expect that problems encountered by students will also be present in the general public.

The 1 year period.

The instructions for the main valuation task read: 'When thinking about the health state imagine that it will last for 1 year. What happens after that is not known and should not be taken into account'. This instruction is important because the value of a health state is dependent on its duration. For instance, Sutherland (1982) found that the utility of a bad health state decreases after a certain duration, which she called the maximum endurable time. During Ashby's investigation in 1988, 18 of the 37 subjects forgot the instructions of the 1 year interval and thought about a chronic health state (EuroQolus 5.1 A and 5.1 E; Brunel, 1). In the present investigation, the subjects were asked which time interval they had in mind when they valued the health states. Table 7.3 gives the results.

Table 7.3 The actual time interval subjects used

Time interval	Number	%
One year	36	34.5
A chronic state	28	6.7
A period longer than 1 year, but not clearly defined	25	23.8
No time period in mind	8	7.6
Months	5	4.8
Days	2	1.9
Weeks	1	1.0

As can be seen from Table 7.3, only 34.5% of the subjects remembered the instruction about the 1 year time interval. Where the subjects forgot the instruction, they were most likely to believe that the states would be stable for a period of time longer than 1 year. Both Nord and Bonsel (EuroQolus 10.E; Bonsel/Bot, Rotterdam, EuroQolus 10:1 and 10.F; Nord, Oslo, 5:4) have suggested that the duration of 1 year would give problems with the valuation of death. Two subjects said that it was impossible to be dead for 1 year. However, there was no significant systematic rela-

tionship between the actual time interval used by the subjects and the value of death. A suggestion would be to drop the 1 year instruction and to work with chronic states.

The order of valuation.

A point that is often discussed is do the subjects employ a strategy, or do they simply fill in the questionnaire? This investigation provided an opportunity to observe the order of the valuations. Table 7.4 gives the results of these observations.

Table 7.4 The observed order of the valuations on pages 5 and 6

Order of filling in	page 5	page 6
First the left column, then the right column.	54.3%	53.3%
From left to right, like reading a book	14.3%	14.3%
No recognizable strategy	13.3%	14.3%
Makes a ranking first	8.6%	8.6%
Seeks the best or the worst first, then no recognizable strategy.	8.6%	8.6%

Only 7.6% of the subjects changed their strategy from pages 5 to 6, and 31.4% went back and forth between pages 5 and 6, in order to compare the valuations on both pages. From these results we concluded that only a minority uses a strategy. The majority just takes the task as it comes.

The influence of the depression dimension.

It has been suggested that the dimension depression and anxiety has a relatively high influence on the value of a health state, because this dimension could be seen as an interpretation of physical health (EuroQolus 5.5 B; Nord, Oslo, 6:2 and 13.E; Brunel, 1). This view has been supported by another observation of Ashby and her colleagues (EuroQolus 8.A; Brunel, 1). Some of their subjects said that it is impossible to be in a bad physical state without feeling depressed. In order to investigate this, the subjects were asked if they saw the psychological dimension as dependent or independent of the physical dimensions. From the sample, 48.6% saw these 2 dimensions as independent, 34.7% as dependent and 16.7% did not know. However, the values obtained by the independent subjects did not differ significantly from those of the dependent subjects (tested univariatly on all health states, T-Test, $p > .05$). Therefore, the differentiation in independent and dependent subjects seems not to be relevant for the valuation of the health states.

The EuroQol visual analogue scale as a school grade.

From discussions during the pilot study, the impression was gained that subjects saw the EuroQol visual analogue scale as a way to give a school grade or school mark to a

health state. Thus, after finishing the questionnaire, the students were asked to give a mark to their own health state. In Holland, 10 is the best school grade, 0 the worst and 6 is sufficient to pass. The mean value of this mark was 8.152, with a standard deviation of 1.007. This value has a close resemblance to the value given on the visual analogue scale. On this scale, the students gave a mean value of 81.25 to their own health state, with a standard deviation of 10.22. The correlation between these 2 values was .7511. If it is true that people see the values on the EuroQol Instrument as school grades, then a value of 100 does not mean sufficient but excellent and 60 means sufficient.

The treatment of dead and unconscious.

The valuation of death has always been a point of discussion within the EuroQol Group and much research has been done on this topic. There is some evidence that the inclusion of the valuation of death may decrease the response, because it causes cognitive and emotional stress (see for instance EuroQolus topic 10). The mean value of death on the EuroQol visual analogue scale is always above 0 and has a high variance. Even values of 100 are reported (Brooks, 1991). The valuation of death also has theoretical complications (EuroQolus 10; van Hout, Rotterdam 7:11). The difficulty of valuing death was also visible in the results of this investigation. When asked what they would have done if the box labelled 'unconscious' had been labelled 'death', the students gave heterogeneous responses. These responses are listed in Table 7.5.

Table 7.5 Responses to the valuation of death on the EuroQol visual analog scale

Response	N	%
0	51	48.6
A value between 1 and 50	21	20.0
Death is not a health state (no value given)	26	24.7
A value between 50 and 1.00	3	2.9
"You can't be dead for 1 year'	2	1.9
A value below 0	1	1.0
'Don't know'	1	1.0
Total	105	100

As can be seen in Table 7.5, most subjects gave the value 0 or said that it was impossible to value death. About one quarter of the students gave a value between 0 and 100, which lifted the mean value of death above the theoretical anchor point of 0. Three students did not give a value to the state unconscious, because they felt it was not possible to do so. Many other students made spontaneous remarks or had to giggle when they valued unconscious and death. There was no doubt that the valuation of death and unconscious was a bizarre thing to do in their eyes.

The estimated time to complete the questionnaire.

It took an average of 12.85 minutes to complete the whole questionnaire and 6.92 minutes to value the health states. This last period of time did not include the reading of the instructions. At the end of the questionnaire the subjects were asked to estimate the time spent. The average estimated time was 13.42 minutes. The correlation between these two values was .568.

We concluded that the EuroQol Instrument was more easily administered compared to Standard Gamble (SG) and Time-Trade-Off (TTO). The EuroQol Instrument seems a simple way to elicit valuations for health states: these findings support its use for postal surveys.

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7.4 REFERENCES

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