The Valuation of Health Outcomes Data from Clinical Trials for Use in Economic Evaluation

Volume 3

A thesis presented for the degree of PhD at the School of Health and Related Research, the University of Sheffield
by

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APPENDIX 1

UNIVERSITY OF SHEFFIELD

FACULTY OF MEDICINE

School of Health and Related Research

We are trying to find out how people value health. Please answer every question as best you can, but don't take too long over each one.

BACKGROUND INFORMATION

1) How old are you?

_____ years

2) How would you describe your occupation (*e.g.* accountant, housewife, teacher)?

_____

3) How old were you when you completed your full-time education?

_____ years

4) In general, would you say your health is

excellent ☐

very good ☐

good ☐

fair ☐

poor ☐

5) How long have you suffered from irritable bowel syndrome?

_____

Please tick one box in each group to show which statements best describe you state of health over the past seven days.

Pain and discomfort related to irritable bowel syndrome

In the past seven days, have you had adequate relief of your abdominal pain and discomfort?

Yes ☐

No ☐

Urgency

Do you feel a sense of urgency more than three days per week?

Yes ☐

No ☐

Constipation

Do you experience constipation (to the extent that you would wish to seek relief)?

Yes ☐

No ☐

These symptoms are commonly experienced by irritable bowel syndrome sufferers. They will be used to describe states of health in the following questionnaire.

Ranking exercise

When you have ranked these health states, please list them below in order of severity, starting with the best at the top. You may rank two or more health states equally.

_____

_____

_____

_____

_____

_____

_____

Standard gamble exercises

You are going to be asked to make choices between the states of health you have just ranked. One choice will involve a risk and the other will be a certainty.

In the following exercises, the states of health in the upper boxes show the CERTAIN outcome of NOT having treatment (Choice A), but differ in every exercise.

The states of health in the lower two boxes show the UNCERTAIN outcomes of having treatment (Choice B). One of these boxes shows the outcome for success, and the other shows the outcome for failure. These differ between exercises.

For each choice there are a range of chances of a successful outcome and corresponding chances of failure. These are shown on the left hand side of the facing page.

From now on, imagine that you yourself are in these states, and that they would last for the rest of your life without change.

Question 1

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

✓	You have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

OR

Failure

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

Question 2

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X	You do not have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

OR

Failure

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

REMINDER

Please note that the health state description in the lowest box has changed.

Question 3

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X You do not have adequate relief of abdominal **pain and discomfort**.

X You feel a sense of **urgency** more than three days per week.

Choice B

Success

✓ You have adequate relief of abdominal **pain and discomfort**.

✓ You do not feel a sense of **urgency** more than three days per week.

OR

Failure

Immediate death

REMINDER

Please note that constipation has now been added to the health states.

Question 4

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X	You do not have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.
X	You experience **constipation**.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.
✓	You do not experience **constipation**.

OR

Failure

Immediate death

Question 5

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.
X	You experience **constipation**.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.
✓	You do not experience **constipation**.

OR

Failure

Immediate death

Health scenarios

In the following pages we describe combinations of the previous states of health occurring over time (health scenarios). You would be in these states for different proportions of a 12 week period. This period will be followed by another period of 12 weeks with these health states, and so on for the rest of your life. Please note that the health states will not come in blocks, but will be scattered throughout the 12 week period.

Ranking exercise

When you have ranked the health scenarios, please list them in order of severity, starting with the best at the top. You may rank two or more health scenarios equally.

_____

_____

_____

_____

Question 6

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Week out of
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 wee
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 wee
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 wee
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	6 wee
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Week out of 1
✓	You have adequate relief of abdominal **pain and** discomfort.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Week out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

Question 7

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	4 week
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 week
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	4 week
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Week out of 1
✓	You have adequate relief of abdominal **pain and discomfort**.	12 wee
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Week out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

Question 8

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Week out o 12
X	You do not have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	6 wee
X	You do not have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	2 weel
✓	You have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	2 weel
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	2 weel

Choice B

Success

		Weeks out of 12
✓	You have adequate relief of abdominal **pain and discomfort**.	12 weeks
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

REMINDER

Please note that the health state description in the lowest box has changed.

Question 9

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Wee out of
X	You do not have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	2 wee
X	You do not have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	2 wee
✓	You have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	2 wee
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	6 wee
X	You experience **constipation**, which may occur at any time over the 12 week period.	2 wee

Choice B

Success

		Week out of 1
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	12 wee

OR

Failure

Immediate death

COMMENTS

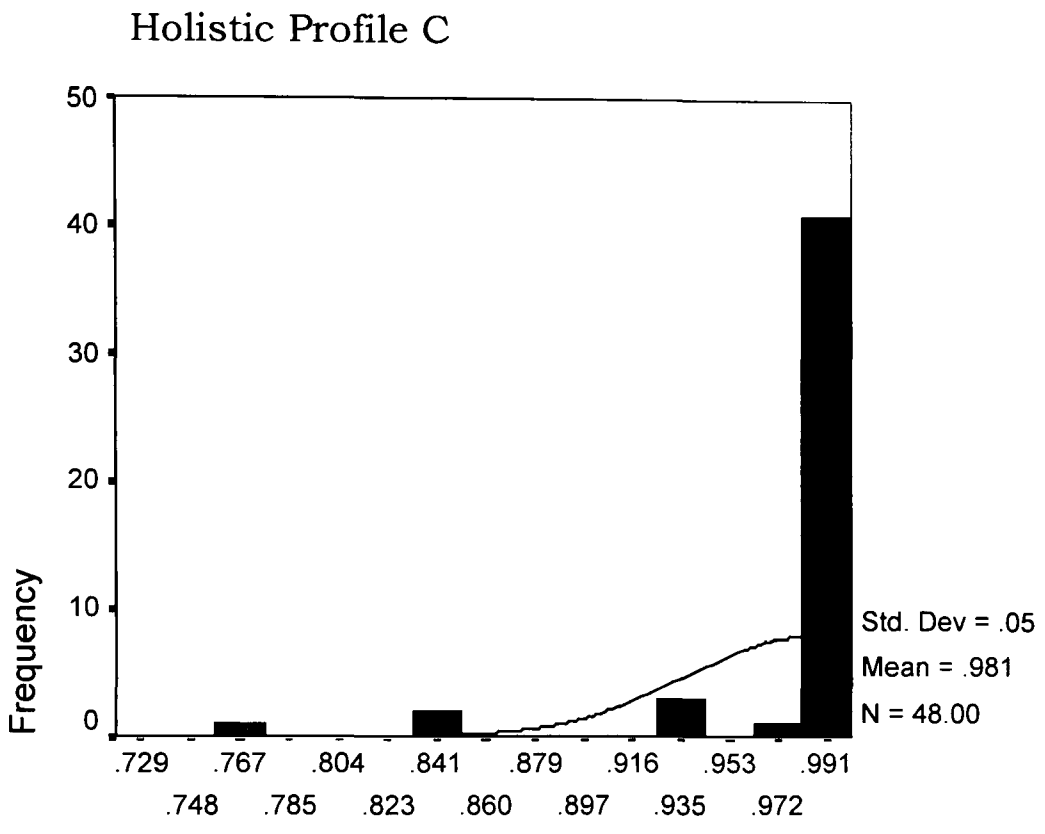
We would be very interested to know what you think of the issues addressed in this questionnaire and the way they were presented. We would be particularly interested to know your thoughts on the following:

a) the gamble approach used in the questions
b) the descriptions of the health states, *e.g.* how well you feel they reflect your experiences.
c) the health scenarios used in the second part of the questionnaire
d) any other aspects you feel to be important

If you have any comments, please use the space below.

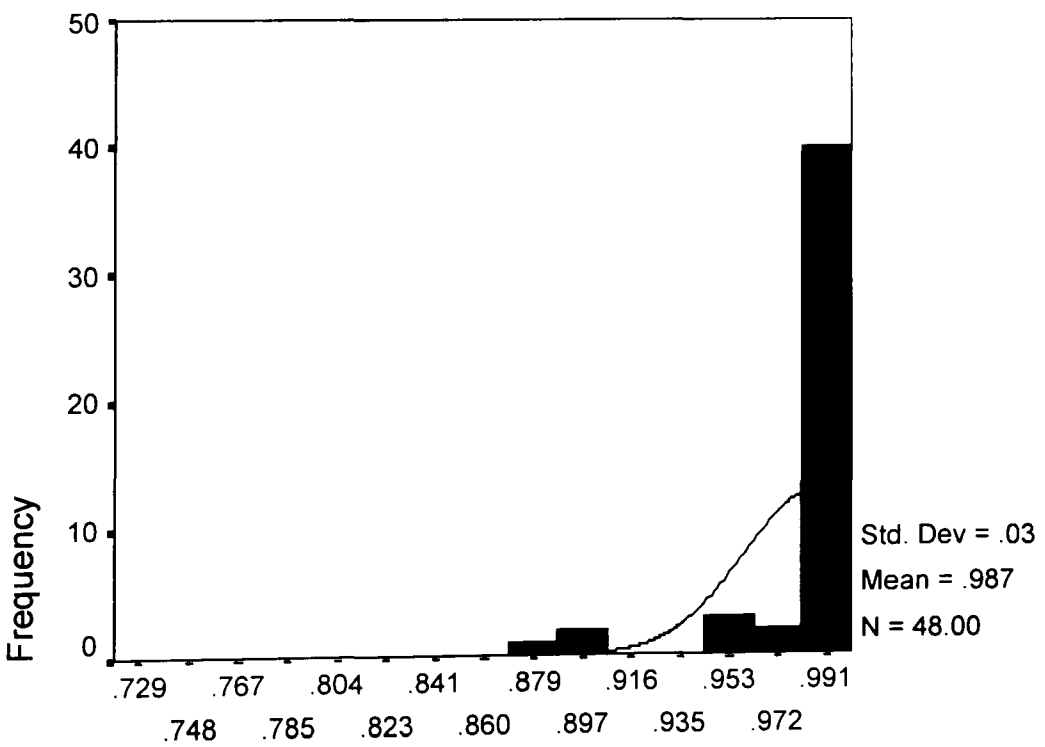
We would like to take this opportunity to thank you for participating in this survey.

Figure 5.A.1



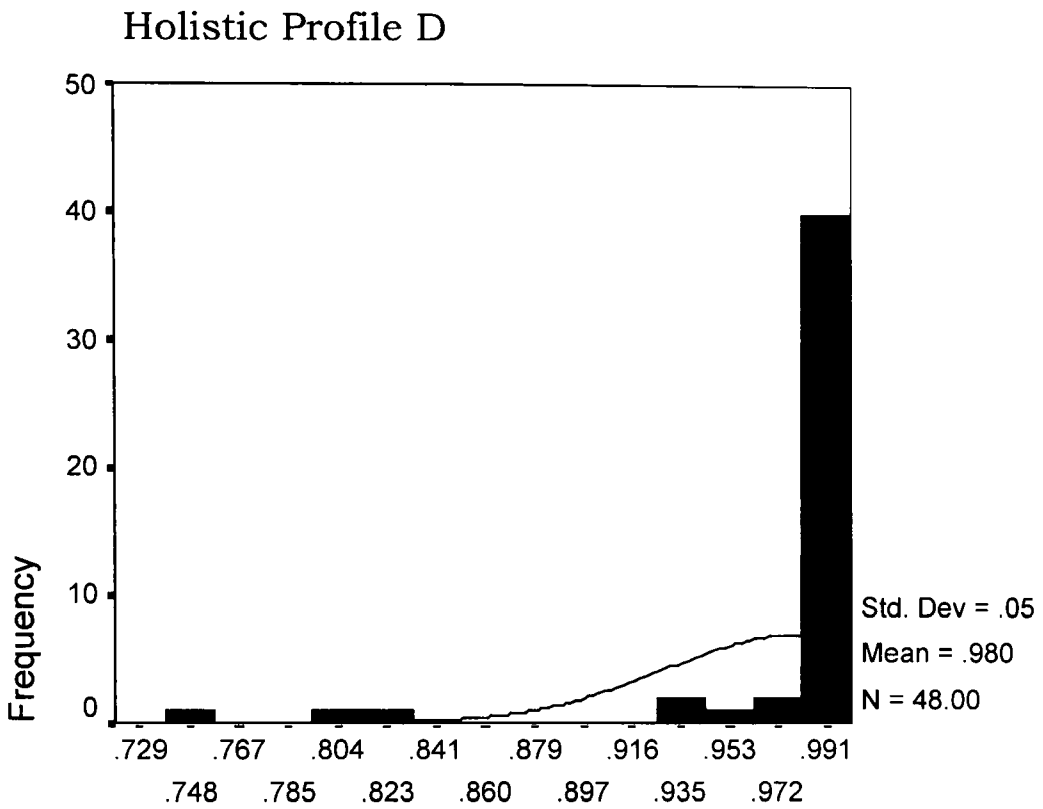
Holistic Profile C

Figure 5.A.2



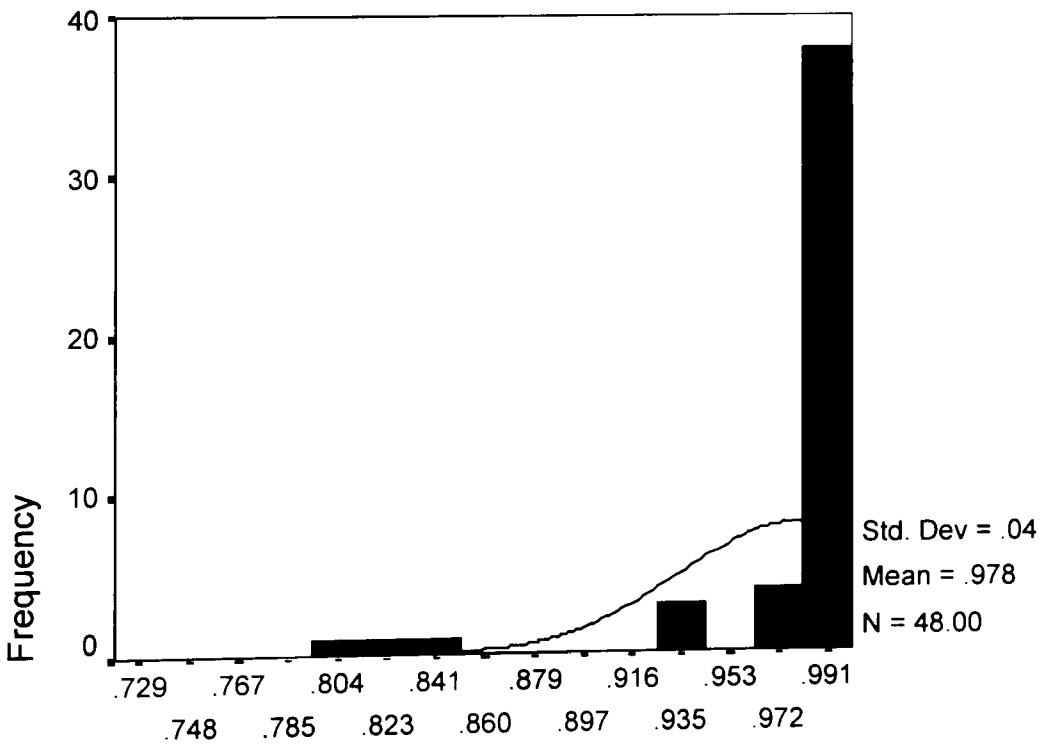
QALY Profile C

Figure 5.A.3



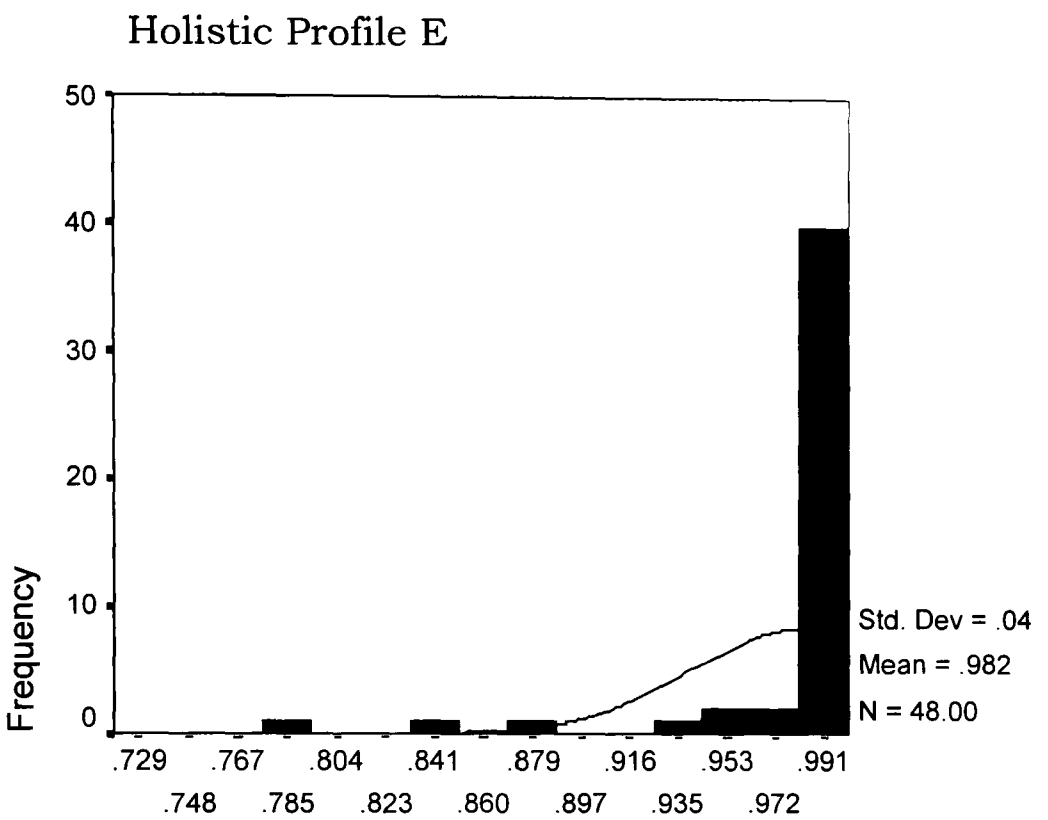
Holistic Profile D

Figure 5.A.4



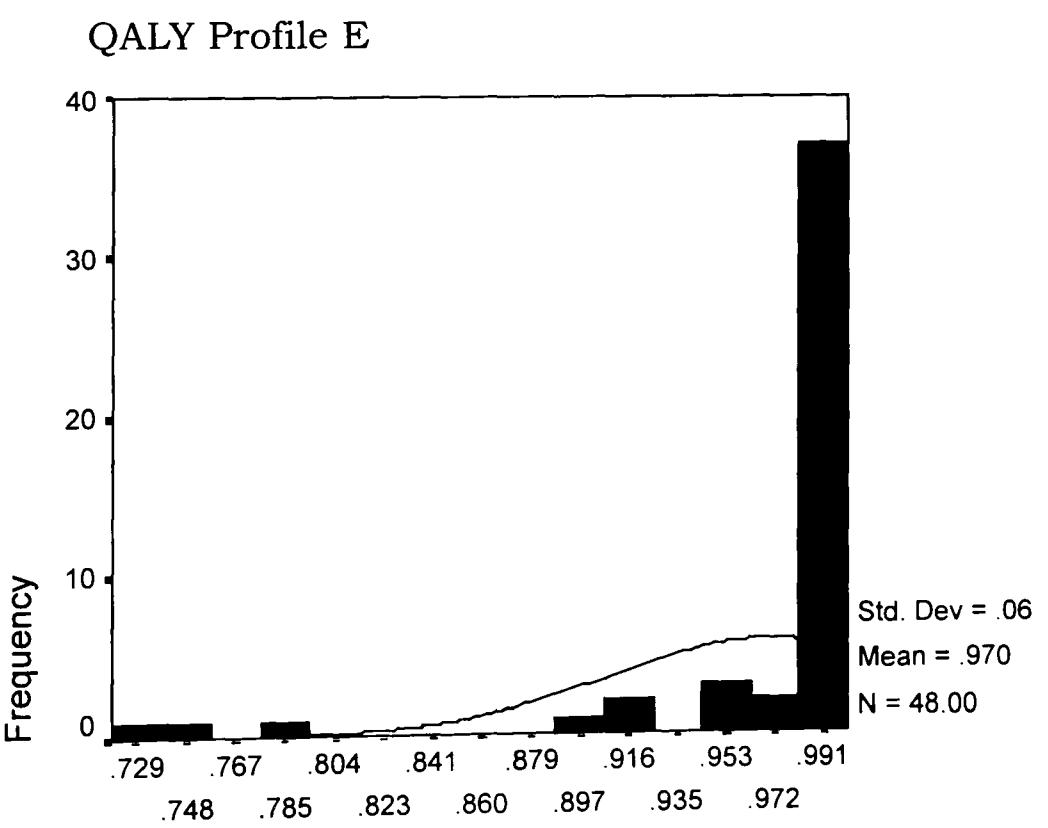
QALY Profile D

Figure 5.A.5



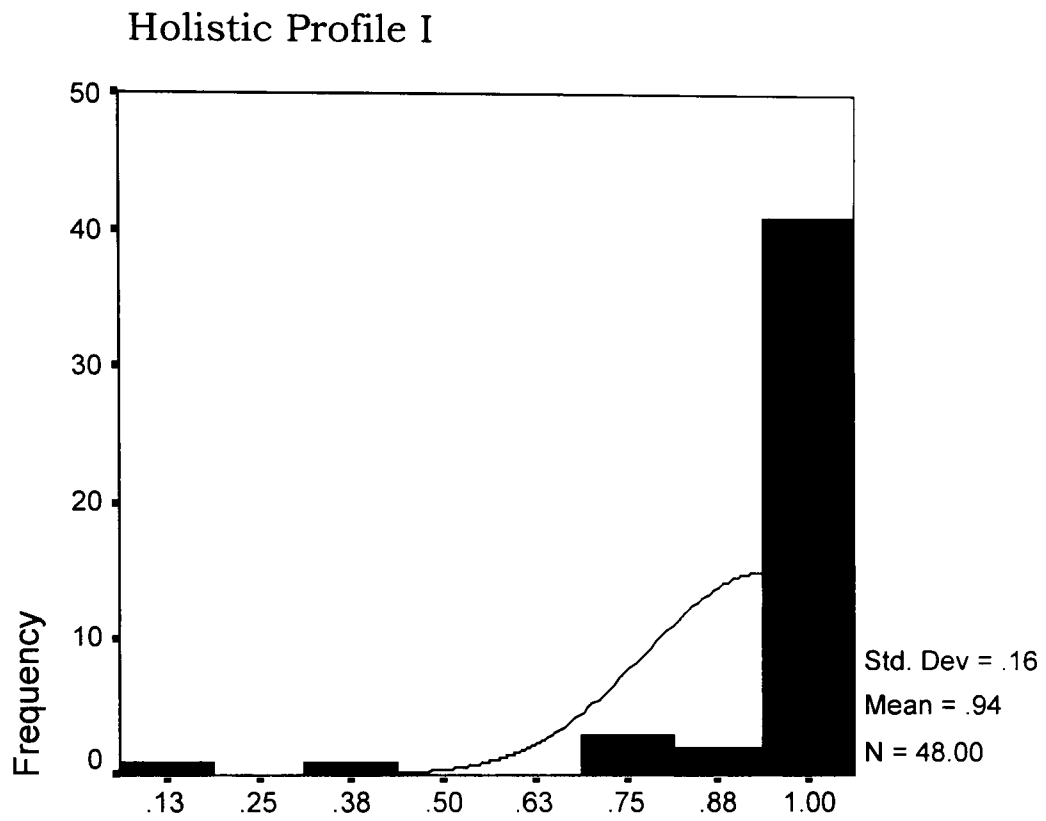
Holistic Profile E

Figure 5.A.6



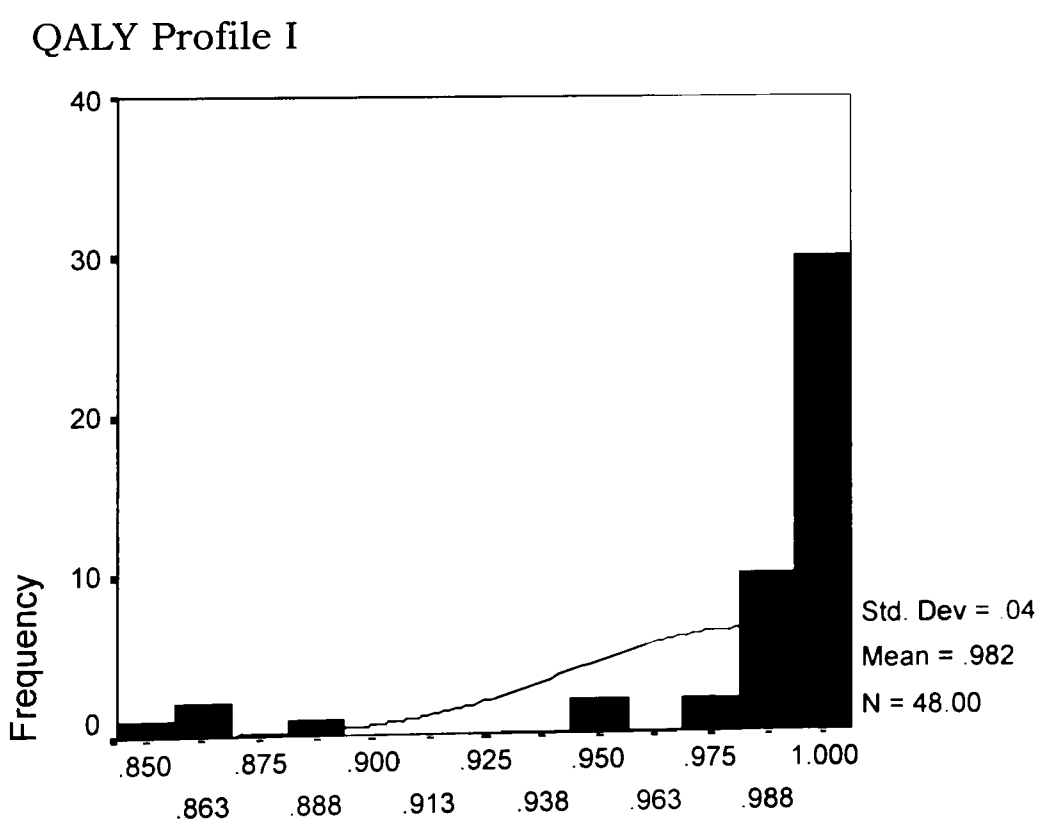
QALY Profile E

Figure 5.A.7



Holistic Profile I

Figure 5.A.8



QALY Profile I

Figure 5.A.9

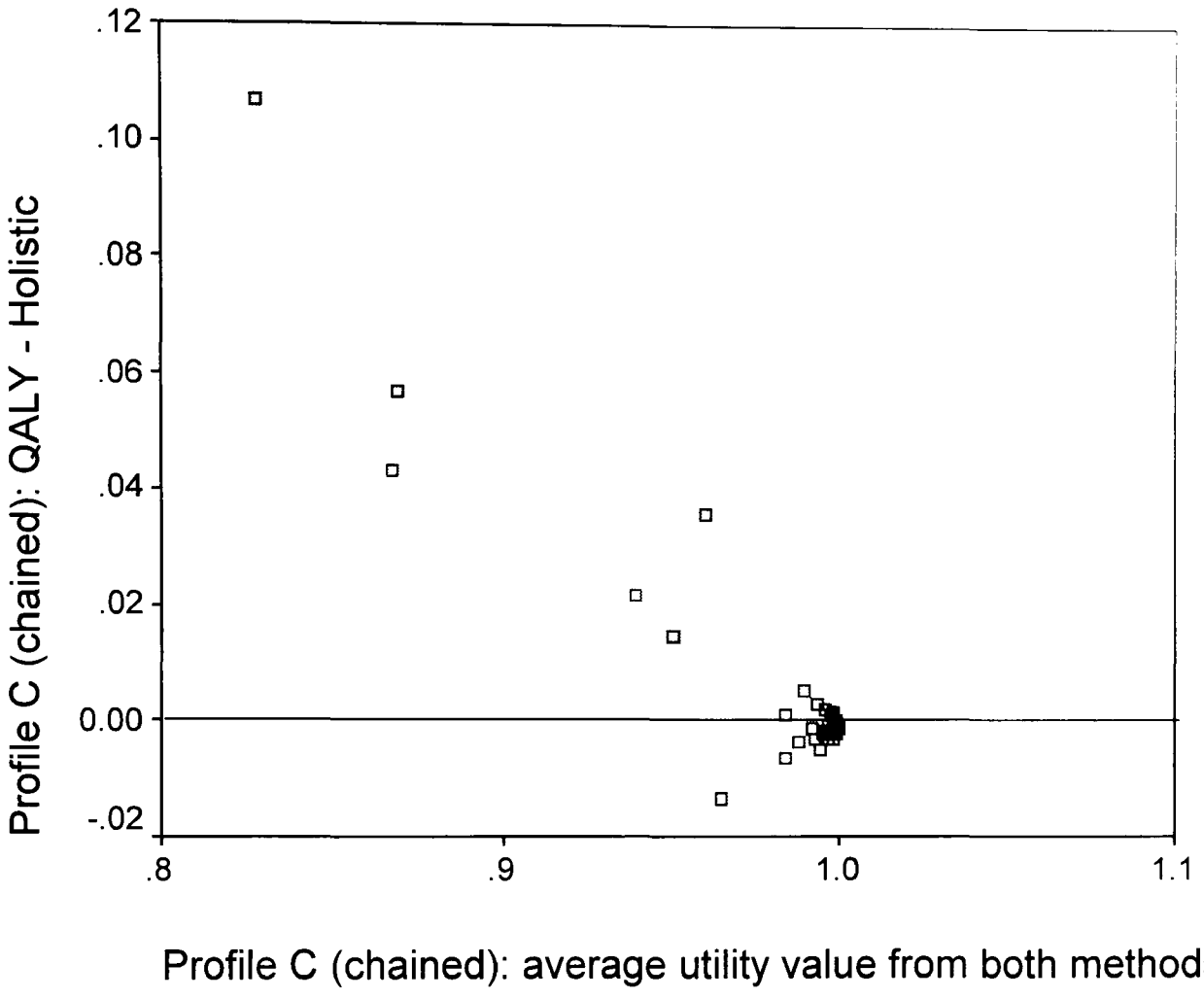


Figure 5.A.10

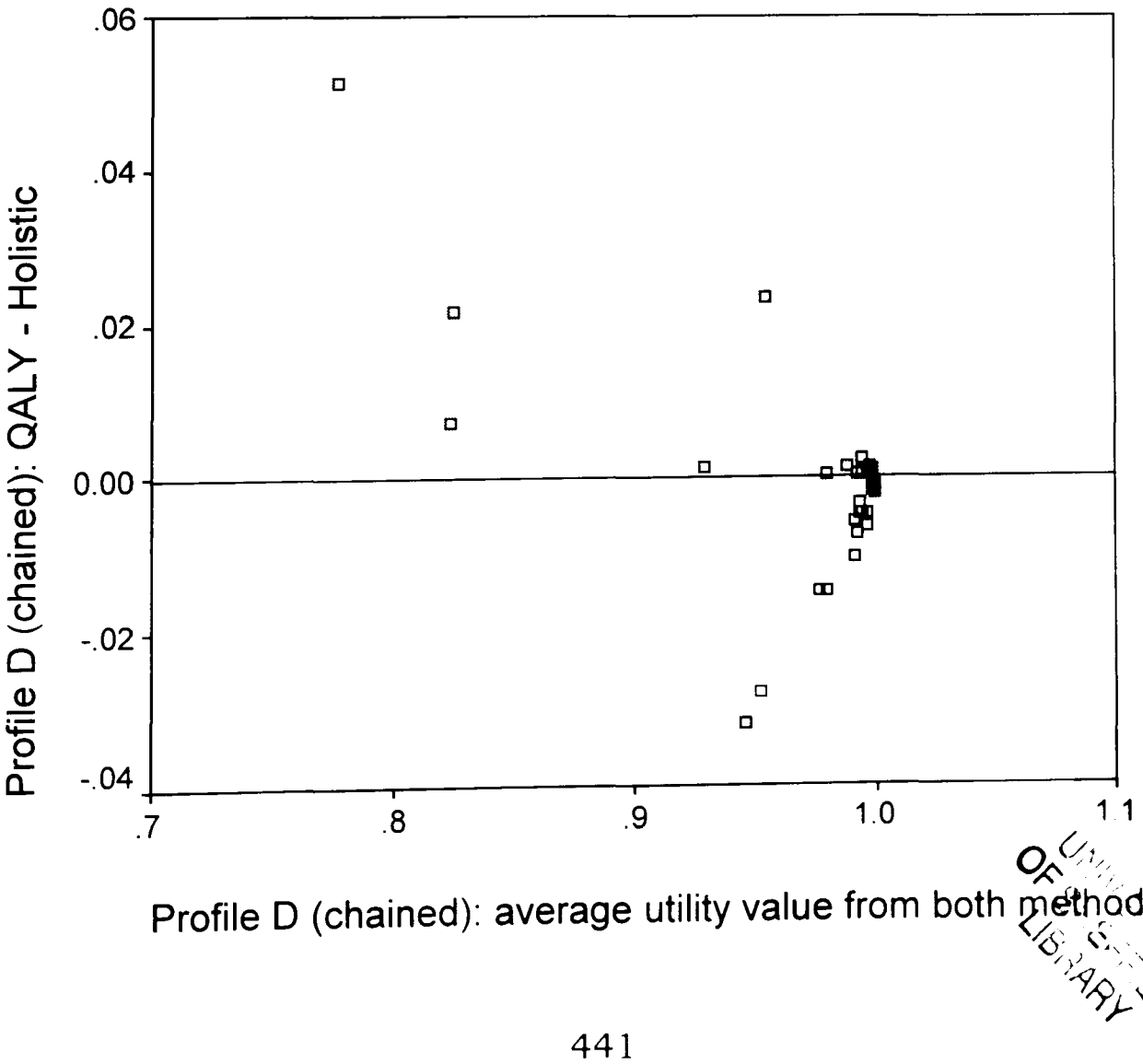


Figure 5.A.11

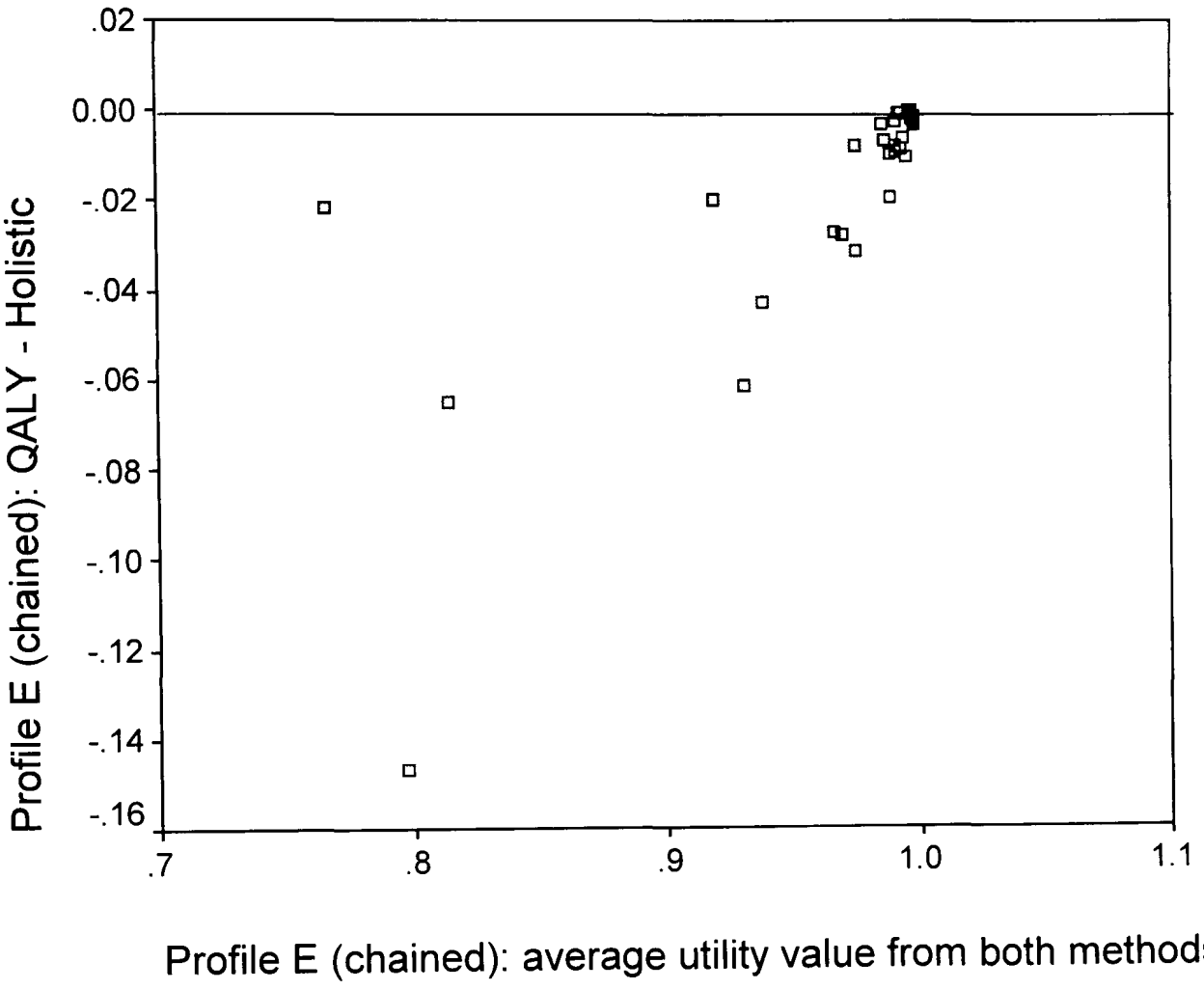


Figure 5.A.12

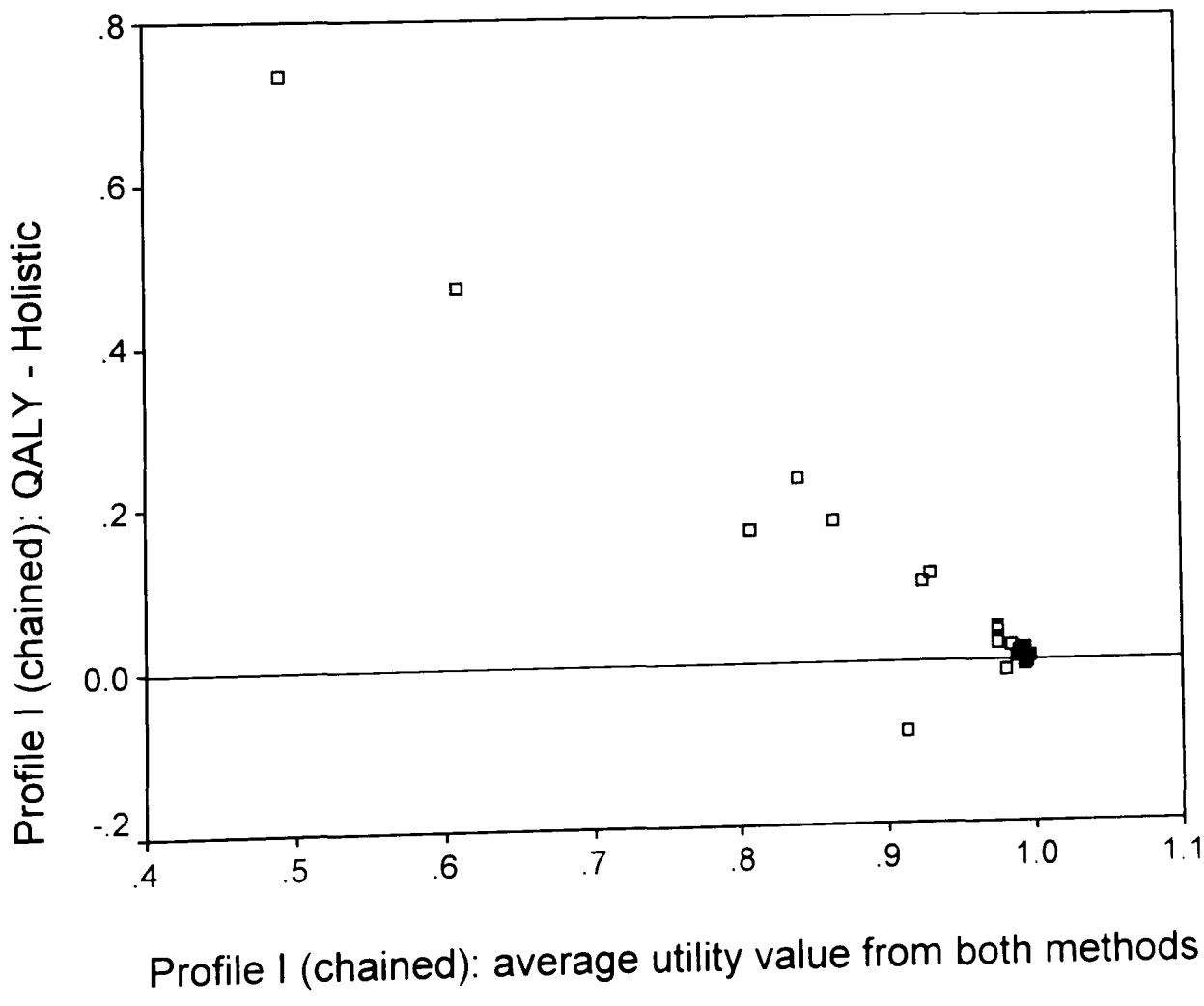


Table 5.A.1 Background characteristics of the sample, including age (n=49), length of time with IBS (n=42*), age at completion of full-time education (n=48†), and occupational status.

	Mean	SD	Median	IQR	Min	Max
Age (years)	46.6	11.7	48.0	38.0-54.5	20.0	69.0
Duration of IBS (years)	12.1	9.9	10.0	4.0-18.5	2.0	51.0
Age at end of full-time education	16.6	2.2	16.0	15.0-18.0	12.0	23.0

* A total of seven respondents gave inexact values for duration with IBS, and these values were approximated. One respondent had suffered IBS for two to three years, one for five to six years, three for over 10 years, one for over 20 years, and one for over 30 years. These were given values of 2.5, 5.5, 10, 20, and 30 respectively.

† One respondent was still in full-time education, leaving 48 to be included in the summary statistics.

Table 5.A.2 Occupational status of respondents.

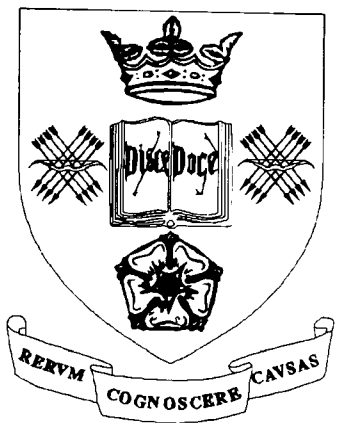
Occupation type	N (49)	%
Managerial	5	10.2
Health professionals	6	12.2
Education	5	10.2
Civil servant	2	4.1
Laboratory analyst	1	2.0
Not highly trained	18	36.7
Not in paid employment	12	24.5

Table 5.A.3 Patients' comments for Study 1.

Patient	Comments
106	The risk of whether a person would risk immediate death could be influenced by so many other factors e.g. commitments, severity of IBS, age, religion, morals, state of mind. I am not convinced it is a useful measure. The other measures of risk are good and I can understand the sense of these and how they can be usefully used.
110	These are all true to the symptoms of I.B.S. and sometimes death might be an alternative to everlasting suffering.
111	Rather extreme for death as alternative. Would be better to give an intermediate state as well of "deterioration X twice of present health state"! Otherwise does male you think of risks of medication. "Enough to put you off!"
113	It depends on your state of health at the time how you answer the questions. If you have had a very bad week one would be prepared to take more risks. b) Yes it does reflect my experiences. They do vary each day, making life very difficult planning ones life and job. What you can eat, and where you can have a meal out.
114	I do not think that anyone would risk immediate death with more than 1% if they actually had to make the choice and not answer on a bit of paper. These questions really make you think about what is worst in your own case and what you can live with and without. I think that this questionnaire is a good idea as it makes you think about your condition and out things into perspective.
115	a) Immediate death is extreme and I think unrealistic even if the suffering is excrutiating! b) In my case, I suffer much more of constipation than urgency and it is not reflected in this survey. c) Health scenarios in 2nd part are good because IBS is very unpredictable and the patterns vary from day to day. d) Medicines are not the only relief of IBS.
116	a) I think it depends on your own symptoms as to how much you are prepared to gamble with your life. b) Good. c) Good. d) Life style can also be a factor, and can affect the symptoms.
219	a) How desperate you are. Some take more risks than others.
301	a) Good. b) V. good. c) Good.
302	I would not choose to go along with immediate death thinking from a Christian approach I feel it would be like committing suicide.
303	Presented clearly but I found the gamble approach difficult to understand.

304	It makes you think about how much risk you will take depending on how ill you feel, and what you have tried with treatments. The more treatments that have been unsuccessful the more risk you will take as you become more desperate.
305	It would be hard to totally understand what was being asked just by reading the questions as they all seem to read very similar. It was quite helpful to have someone with us to help and guide us.
306	Last table taken was excellent.

APPENDIX 2



UNIVERSITY OF SHEFFIELD

FACULTY OF MEDICINE

School of Health and Related Research

We are trying to find out how people value health. Please answer every question as best you can, but don't take too long over each one.

BACKGROUND INFORMATION

1) How old are you?
_____ years

2) Are you

male ☐

female ☐

3) How would you describe your occupation (*e.g.* accountant, housewife, teacher)?

_____

4) What is your highest level of education?

primary ☐

secondary ☐

A level ☐

university ☐

other (please specify below) ☐

_____

5) In general, would you say your health is

excellent ☐

very good ☐

good ☐

fair ☐

poor ☐

1) How long have you suffered from irritable bowel syndrome?

_____

EUROQOL© HEALTH QUESTIONNAIRE

Here are some simple questions about your health in general. By ticking one answer in each group below, please indicate which statements best describe your own health state TODAY.

Please tick one

1. Mobility

I have no problems in walking about ○

I have some problems in walking about ○

I am confined to bed ○

2. 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 ○

3. Usual Activities

I have no problems with performing my usual activities
(e.g. work, study, housework, family or leisure activities) ○

I have some problems with performing my usual activities ○

I am unable to perform my usual activities ○

4. Pain/Discomfort

I have no pain or discomfort ○

I have moderate pain or discomfort ○

I have extreme pain or discomfort ○

5. Anxiety/Depression

I am not anxious or depressed ○

I am moderately anxious or depressed ○

I am extremely anxious or depressed ○

Please tick one box in each group to show which statements best describe your state of health over the past seven days.

Pain and discomfort related to irritable bowel syndrome
In the past seven days, have you had adequate relief of your abdominal pain and discomfort?

Yes ☐

No ☐

Urgency
Do you feel a sense of urgency more than three days per week?

Yes ☐

No ☐

Constipation
Do you experience constipation (to the extent that you would wish to seek relief)?

Yes ☐

No ☐

These symptoms are commonly experienced by irritable bowel syndrome sufferers. They will be used to describe states of health in the following questionnaire.

Ranking exercise

When you have ranked these health states, please list them below in order of severity, starting with the best at the top. You may rank two or more health states equally.

_____

_____

_____

_____

_____

_____

_____

Standard gamble exercises

You are going to be asked to make choices between the states of health you have just ranked. One choice will involve a risk and the other will be a certainty.

In the following exercises, the states of health in the upper boxes show the CERTAIN outcome of NOT having treatment (Choice A), but differ in every exercise.

The states of health in the lower two boxes show the UNCERTAIN outcomes of having treatment (Choice B). One of these boxes shows the outcome for success, and the other shows the outcome for failure. These differ between exercises.

For each choice there are a range of chances of a successful outcome and corresponding chances of failure. These are shown on the left hand side of the facing page.

From now on, imagine that you yourself are in these states, and that they would last for the rest of your life without change.

Question 1

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

✓	You have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

OR

Failure

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

Question 2

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X	You do not have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

OR

Failure

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

REMINDER

Please note that the health state description in the lowest box has changed.

Question 3

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

X	You do not have adequate relief of abdominal **pain and discomfort**.
X	You feel a sense of **urgency** more than three days per week.

Choice B

Success

✓	You have adequate relief of abdominal **pain and discomfort**.
✓	You do not feel a sense of **urgency** more than three days per week.

OR

Failure

Immediate death

Health scenarios

In the following pages we describe combinations of the previous states of health occurring over time (health scenarios). You would be in these states for different proportions of a 12 week period. This period will be followed by another period of 12 weeks with these health states, and so on for the rest of your life. Please note that the health states will not come in blocks, but will be scattered throughout the 12 week period.

Ranking exercise

When you have ranked the health scenarios, please list them in order of severity, starting with the best at the top. You may rank two or more health scenarios equally.

_____

_____

_____

_____

_____

_____

_____

_____

_____

Question 4

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	0 weeks
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	1 weeks
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	1 weeks
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	10 week
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Week out of 1
✓	You have adequate relief of abdominal **pain and discomfort**.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Week out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

Question 5

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	0 week
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 week
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	8 week
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Weeks out of 1
✓	You have adequate relief of abdominal **pain and** discomfort.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

Question 6

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 week
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 week
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	6 week
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Weeks out of 12
✓	You have adequate relief of abdominal **pain and** discomfort.	12 weeks
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Weeks out of 12
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 weeks
X	You feel a sense of **urgency** more than three days per week.	

Question 7

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Week *out of 1*
X X	You do not have adequate relief of abdominal **pain and discomfort**. You feel a sense of **urgency** more than three days per week.	4 week
X ✓	You do not have adequate relief of abdominal **pain and discomfort**. You do not feel a sense of **urgency** more than three days per week.	2 week
✓ X	You have adequate relief of abdominal **pain and discomfort**. You feel a sense of **urgency** more than three days per week.	2 week
✓ ✓	You have adequate relief of abdominal **pain and discomfort**. You do not feel a sense of **urgency** more than three days per week.	4 week

Choice B

Success

		Week *out of 1*
✓ ✓	You have adequate relief of abdominal **pain and discomfort**. You do not feel a sense of **urgency** more than three days per week.	12 wee

OR

Failure

		Week *out of 1*
X X	You do not have adequate relief of abdominal **pain and discomfort**. You feel a sense of **urgency** more than three days per week.	12 week

Question 8

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Week out o 12
X	You do not have adequate relief of abdominal **pain and discomfort**.	6 week
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	2 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 week
X	You feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	2 week
✓	You do not feel a sense of **urgency** more than three days per week.	

Choice B

Success

		Weeks out of 1
✓	You have adequate relief of abdominal **pain and discomfort**.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Weeks out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 week
X	You feel a sense of **urgency** more than three days per week.	

Question 9

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Wee out of
X	You do not have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	8 weel
X	You do not have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	2 weel
✓	You have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	2 weel
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	0 weel

Choice B

Success

		Week out of 1
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	12 week

OR

Failure

		Week out of 1
X	You do not have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	12 wee

Question 10

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Wee *out of*
X	You do not have adequate relief of abdominal **pain and discomfort**.	10 wee
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	1 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	1 week
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	0 week

Choice B

Success

		Week *out of 1*
✓	You have adequate relief of abdominal **pain and discomfort**.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Week *out of 1*
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 wee
X	You feel a sense of **urgency** more than three days per week.	

Question 11

Please put a ✓ against all cases where you are CONFIDENT that you would CHOOSE the risky treatment (Choice B).
Please put a X against all cases where you are CONFIDENT that you would REJECT the treatment (Choice B) and accept the certain health state (Choice A).

Outcome of treatment

Chances of success		Chances of failure
100 in 100*		0 in 100*
99 in 100*		1 in 100*
98 in 100		2 in 100
97 in 100		3 in 100
96 in 100		4 in 100
95 in 100		5 in 100
90 in 100		10 in 100
85 in 100		15 in 100
80 in 100		20 in 100
75 in 100		25 in 100
70 in 100		30 in 100
65 in 100		35 in 100
60 in 100		40 in 100
55 in 100		45 in 100
50 in 100		50 in 100
45 in 100		55 in 100
40 in 100		60 in 100
35 in 100		65 in 100
30 in 100		70 in 100
25 in 100		75 in 100
20 in 100		80 in 100
15 in 100		85 in 100
10 in 100		90 in 100
5 in 100		95 in 100
0 in 100		100 in 100

* You may be willing to accept the treatment but *only* if it has a chance of success of *higher* than 99 in 100 (*i.e.* a chance of failure which is less than 1 in 100). If so, at what level of success would you accept treatment?

_____

Choice A

		Wee *out of*
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 wee
X	You feel a sense of **urgency** more than three days per week.	
X	You do not have adequate relief of abdominal **pain and discomfort**.	0 week
✓	You do not feel a sense of **urgency** more than three days per week.	
✓	You have adequate relief of abdominal **pain and discomfort**.	
X	You feel a sense of **urgency** more than three days per week.	0 week
✓	You have adequate relief of abdominal **pain and discomfort**.	
✓	You do not feel a sense of **urgency** more than three days per week.	0 week

Choice B

Success

		Week *out of 1*
✓	You have adequate relief of abdominal **pain and discomfort**.	12 week
✓	You do not feel a sense of **urgency** more than three days per week.	

OR

Failure

		Week *out of 1*
X	You do not have adequate relief of abdominal **pain and discomfort**.	12 wee
X	You feel a sense of **urgency** more than three days per week.	

COMMENTS

We would be very interested to know what you think of the issues addressed in this questionnaire and the way they were presented. We would be particularly interested to know your thoughts on the following:

a) the gamble approach used in the questions
b) the descriptions of the health states, *e.g.* how well you feel they reflect your experiences.
c) the health scenarios used in the second part of the questionnaire
d) any other aspects you feel to be important

If you have any comments, please use the space below.

We would like to take this opportunity to thank you for participating in this survey.

Invitation material

Dear

Re: Interview study of people with irritable bowel syndrome (IBS)

I am writing to you on behalf of researchers at the University of Sheffield, who are doing a study of people with irritable bowel syndrome. They have approached this practice and asked us to contact the irritable bowel syndrome patients on our list. We have given our approval to this study as long as patients are willing to take part. They need a total of 70 irritable bowel syndrome patients to take part in the study. It will involve coming to the GP surgery and completing a questionnaire. Details of the study are provided in the attached patient information sheet.

Please read the attached information sheet carefully. If you are willing to take part in the study, please complete the enclosed consent form and send it in the stamped addressed envelope to:

Miss Isabel Taylor
ScHARR
Freepost SF1314

Sheffield
S1 1AY

Miss Taylor will only contact you if you return the consent form.

You are under no obligation to take part in this study. Should you wish to decline, your present and future care will not be affected in any way.

Yours sincerely,

on behalf of the partnership

PATIENT INFORMATION SHEET (SEPTEMBER 2001)

INVESTIGATING THE RELATIONSHIP BETWEEN DURATION AND UTILITY: A STUDY OF PATIENTS WITH IRRITABLE BOWEL SYNDROME

A study to determine how patients with irritable bowel syndrome (IBS) feel about increases or decreases in the frequency of symptoms

You are invited to participate in a questionnaire study to explore how increases or decreases in symptoms of irritable bowel syndrome (IBS) effect the way people with IBS feel.

"What is the purpose of this study?"
These days new treatments have to undergo rigorous tests before being funded by the NHS. One thing that is required is for treatments to be tested to make sure they give a reasonable quality of life. Thus it is necessary to be able to make accurate estimations of quality of life. There are several theories about what is the best way to measure quality of life. It is important that the best method is used, so that only the best new treatments are used. When an illness has symptoms that vary a lot in frequency and duration, it makes quality of life measurements more complicated. Irritable bowel syndrome is one such condition. This study tests two methods of measuring quality of life by asking irritable bowel syndrome sufferers to make choices between various different possible health states.

"How long will the study last?"
This will be a one-off interview lasting 1 to 1½ hours.

"Why have I been chosen?"
Your doctor has agreed for irritable bowel syndrome sufferers on his/her lists to be contacted and invited to participate in this study. A total of 70 irritable bowel syndrome sufferers will be invited.

"What will it involve?"
If you agree to participate in this study you will be asked to join a group of 3 to 10 other patients at the GP surgery named on the accompanying letter. Each person in the group will be handed a questionnaire to complete, which will contain various sets of tasks. The questionnaire will ask you to consider health scenarios in ways which you will probably not have thought about before. Because of this, you may need to take your time to understand and reflect on each task. However, there will be a trained interviewer present throughout the exercise, and she will explain all the tasks thoroughly before you are asked to complete them. The questions in the questionnaire will not relate to you specifically, or to your individual condition.

"What if I do not wish to take part?"
This will in no way affect your present or future treatment. However, if you do decide to take part you will be given a copy of this information sheet and a signed consent form to keep.

"What if I change my mind during the study?"
You are free to withdraw from the study at any time without affecting your treatment in any way.

"What will happen to the information from the study?"
All information will be entirely confidential. You will be informed of the results of the study if you wish in December 2001.

"Who is funding the study?"
The study is being funded by the Medical Research Council. Your GP is not receiving any payment for the study other than for the hire of the premises where the interviews will take place.

"What if I have further questions?"
You should contact: Miss Isabel Taylor on 0114 222 0722, or Mrs Maria Platts on 0114 271 5923

CONSENT FORM

Title of Project: Investigating the Relationship Between Duration and Utility: A Study of Patients with Irritable
Bowel Syndrome

Name of Researcher: Isabel Taylor

Please initial box

1. I confirm that I have read and understand the information sheet dated September 2001. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Name of Patient	Date	Signature

Table 6.A.1 Background characteristics of the sample.

	Mean	SD	Median	IQR	Min	Max
Age (years)	49.0	12.0	50.0	39.3-60.0	21	67
Duration of IBS (years)	13.9	9.2	11.0	7.0-20.0	2	40

Table 6.A.2 Occupational status of respondents.

Occupational type	*N = 56*	*%*
Managerial	3	5.4
Health professional	4	7.1
Social work	2	3.6
Miscellaneous professional	1	1.8
Education	2	3.6
Civil servant	2	3.6
Not highly trained	19	33.9
Not in paid employment	23	41.1

Table 6.A.3 Exclusions.

ID	**Reason for exclusion**
209	Responses to Questions 4 – 11 missing.
211	Responses to Questions 7 – 11 missing.
305	Response to Question 3 missing.
306	Responses to Questions 4 – 11 missing.
218	Response to Question 2 missing.
503	Responses to Questions 1 – 3 missing.
415	Responses to Questions 2 – 11 missing.

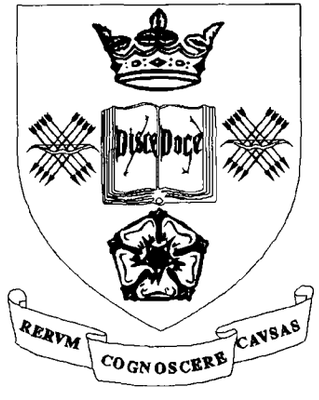
Table 6.A.4 Patients' comments.

Patient	Comments
104	The questions should state if it's medication and surgery.
105	I would be willing to take tablets. I would only have operation if it had a good chance of success.
106	If you could define tablet or operation as this would alter some of the answers.
107	I am very grateful for taking part. I would like to keep in contact and follow any developments on IB. Has it helps to understand it.
201	b – not sufficient explanations of all IBS symptoms.
112	The gamble approach used really made me think about what risks I would take for treatment. I suppose my reply may be different depending on how ill I felt at the time. I hope my answers have been of some value. Good luck with your project.
202	A) Gamble – lifes a gamble. I would prefer a straight approach.
208	When the symptoms are at their worst, you will practically agree to anything. Rational choices are only possible when the discomfort subsides and then subject to a variety of external influences (i.e. the need to "go to work" regardless).
209	Feels very analytical. Would be easier if related more directly to my own symptoms + a range of treatment approaches that I had a choice between. Implied question is "how bad is it?" and that depends a lot on context/timing. Also have to work very hard to concentrate at this time of day (possibly a symptom that's related). In terms of gambling, I'm slow to decide things. I worry over the possibilities/options for a long time. I tend not to leap into risky ventures but procastrinate.
211	I am sorry I have not answered the final questions as I am completely confused by them and do not want to give misleading information. I find the wording confusing. Far too much repetition. I find that a 'sense of urgency' for me sometimes would be a positive thing.
212	a) very difficult to "get your head around"! b) closely reflect my experience c) closely – as above d) basicalluy – I'd do/take anything to get rid of the urgency. Will live with pain/discomfort. Urgenc anxiety = urgency! Difficult for me to know how to answer. I will put up with abdominal pain as long as there is no urgency! "Urgency" brought on by anxiety of urgency coming on – so if I thought I could just get pain instead I'd be happy! Sounds weird, I know!
213	Descriptions of the state of health did reflect very well as regard to myself. I thought some of the questionnaire was unnecessarily complicated.
214	a) Very much a reflection of individual personality. b) Reflect very well my experiences.

	c) The health scenarios are typical of the way that symptoms change from week to week or month to month. d) The questionnaire seems to take into account mainly the pain and constipation aspects but the bloating, wind and need to pass urine more frequently when constipated are also debilitating.
215	I feel quite differently about pain and urgency and the decisions I would make regarding one or the other are quite different. I felt I had to categorise them together a lot. My symptom is mainly pain, so I don't often think about urgency. It's very hard to decide what risk you would take with your health! I think IBS is more personal + less generalized than doctors often think. (I have different symptoms to some I know to have IBS)
216	a) The gamble approach is a good way of assessing how much I am prepared to put up with symptoms that are unpredictable and differ in length of time suffered when faced with a risk element in treatment. This reflects how desperate a person is and how severe the problem. b) Descriptions seem fairly typical though some may not be experienced by all. c) A bit complicated – particularly after a day at work!
303	The issues addressed are obviously the main difficulties people experience with IBS but are not the only problems – will there be other studies addressing the less serious difficulties i.e. flatulence, bloating?
401	Thank God you were there other wise would not have know where to start on filling this form in.
403	Very good.
404	a) need a little more clarification. b) The health states could be more varied. c) Too limited d) More emphasis needed on the overall wellbeing a person feels when these symptoms take place.
408	Had a dental appointment, so was in a hurry and didn't feel she gave it enough attention.
412	a) obviously depends on the individual and how severe their symptoms have been or are having at present time. b) very well presented regarding health states. c) good. d) Presented adequately.
113	I feel the questionnaire helps a lot in finding out exactly how people suffer and just how much risk people will take to get better which also helps you to find out just how badly people do suffer and how much a cure is needed.
501	Well thought out and thought provoking questions.
502	a) interesting – I've been placed in this type of situation before over an unrelated health problem. The gamble is very much related to personal

	priorities e.g. family ties etc. and I don't know if this is reflected in the answers.
503	If I were to fill in the questionnaire when my symptoms were very bad, my answers would be very different.
415	Have chemical in the cleaning of domestic water been stupid?

APPENDIX 3



UNIVERSITY OF SHEFFIELD

FACULTY OF MEDICINE

School of Health and Related Research

We are trying to find out how you value different health states. Please answer every question as best you can, but don't take too long over each one.

BACKGROUND INFORMATION

1) How old are you?_____ years

2) Are you male ☐
female ☐

3) How would you describe your occupation (*e.g.* accountant, housewife, teacher)?

_____

4) What is your highest level of education?

primary ☐
secondary ☐
A level ☐
university ☐
other (please specify below) ☐

_____

5) In general, would you say your health is

excellent ☐
very good ☐
good ☐
fair ☐
poor ☐

6) How long have you been diagnosed as having varicose veins?

_____

7) Have you received treatment for your varicose veins?

yes ☐ no ☐

8) If you have not yet received treatment, you may not have any particular opinion about which treatment you think would be best for your varicose veins. If this is the case, we do not ask you to consider it now. However, if you have already decided which treatment you think would be best for *you* then please complete the space below:

I think that my varicose veins should be treated by _____

Because:_____

_____

Your current symptoms

1) Your veins are **noticeable**			Yes ☐ N
2) Your veins **stick up** and look **lumpy** and **unsightly**			Yes ☐ N
3) Your legs or ankles become **swollen**, making it difficult to put your shoes on			Yes ☐ N
4) Your veins **sometimes become swollen**			Yes ☐ N
5) Your veins **often become very swollen**			Yes ☐ N
6) Elasticated socks and stockings are **uncomfortable**, because the leg swells up around the elastic			Yes ☐ N
7) Your legs **ache** or feel **painful**	Often ☐	Sometimes ☐	N
8) You get **cramp** in your legs	Often ☐	Sometimes ☐	N
9) You have to keep **moving around** to avoid **cramps** and **aches**			Yes ☐ N
10) You get **irritation** and **itching** on your legs	A lot ☐	Some ☐	N
11) You have to keep your **weight** down to avoid problems with your legs			Yes ☐
12) You **worry** about the possibility of getting an **ulcer**			Yes ☐
13) You find that you are **organising your life around your symptoms**			Yes ☐

Ranking exercise

You will be handed some varicose vein health states. When you have ranked these health states, please list them below in order of severity, starting with the best at the top. You may rank them equally.

_____

_____

_____

_____

_____

_____

Valuing health states

You are going to be asked to make a choice between different states of health relating to varicose veins.

For Choice A we would like you to imagine that you will live for 20 years in the health state described in the left-hand box, and then you will die.

For Choice B we would like you to imagine that you will live in the health state described in the right-hand box, and then you will die.

We would like you to consider how many years in Choice B would be equivalent to 20 years in Choice A. Please use the table at the bottom of the page overleaf.

Practice question

Choice A	**Choice B**
☹ Your veins are **noticeable**. Your legs or ankles do not become **swollen**, so it is not difficult to put your shoes on. ☹ Your legs **sometimes ache** or feel **painful**. You **sometimes get cramp** in your legs. You have to keep **moving around** to avoid **cramps** and **aches**. You do not get **irritation** and **itching** on your legs. You do not have to keep your **weight** down to avoid problems with your legs. ☹ You may **worry** about the possibility of getting an **ulcer**. ☹ You may find that you are **organising your life around your symptoms**.	Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 1

Choice A

Severe varicose veins

- ☹ You have **big** veins, which **stick up** and look **lumpy** and **unsightly**. Your veins are **noticeable**.
- ☹ Your legs or ankles **often become very swollen**, so it's difficult to put your shoes on. Elasticated socks and stockings are **uncomfortable**, because the leg swells up around the elastic.
- ☹ Your legs **often ache** and feel **painful**. You **often get cramp** in your legs. You have to keep **moving around** to avoid **cramps** and **aches**.
- ☹ You get a lot of **irritation** and **itching** on your legs.
- ☹ You have to keep your **weight** down to avoid problems with your legs.
- ☹ You may **worry** about the possibility of getting an **ulcer**.
- ☹ You may find that you are **organising your life around your symptoms**.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 2

Choice A

Moderate varicose veins

☹ Your veins are **noticeable**.

☹ Your legs or ankles **sometimes become swollen**, so it is difficult to put your shoes on.

☹ Your legs **sometimes ache** or feel **painful**. You **sometimes get cramp** in your legs. You have to keep **moving around** to avoid **cramps** and **aches**.

☹ You get some **irritation** and **itching** on your legs.

You do not have to keep your **weight** down to avoid problems with your legs.

☹ You may **worry** about the possibility of getting an **ulcer**.

You do not find that you are **organising your life around your symptoms**.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 3

Choice A

Mild varicose veins

☹ Your veins are **noticeable**.

Your legs or ankles do not become **swollen**, so it is not difficult to put your shoes on.

Your legs do not **ache** or feel **painful**. You do not get **cramp** in your legs. You do not have to keep **moving around** to avoid **cramps** and **aches**.

You do not get **irritation** and **itching** on your legs.

You do not have to keep your **weight** down to avoid problems with your legs.

☹ You may **worry** about the possibility of getting an **ulcer**.

You do not find that you are **organising your life around your symptoms**.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 4

Choice A

Your current health state

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Comparing health processes

You are going to be asked to make a comparison between two processes of health care.

In the following exercise we would like you to imagine experiencing the health processes described. Then indicate on the scale how good or bad the processes are in your opinion.

Question 5

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

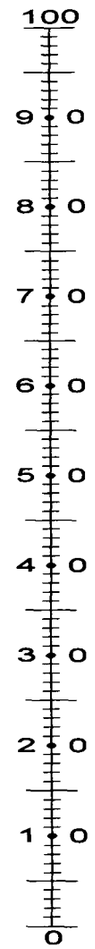
To help people say how good or bad the above process are, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100 and death is marked by 0.

We would like you to indicate on this scale how good or bad the above processes are in your opinion. Please do this by drawing a line from the boxes beside the scale to whichever point on the scale indicates how good or bad the process is.

If you consider one or both of the above processes to be worse than death, please draw the line to the "worse than death" point at the bottom of the scale.

Surgery

Full health



Death

Worse than death

Sclerotherapy

Valuing health profiles

In the following exercises, the left-hand boxes show the process and outcomes of having treatment (Choice A).

The box on the right-hand side describes full health (Choice B).

We would like you to consider how many years in Choice B would be equivalent to the events described in the Choice A.

Practice question

Choice A

Severe varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 6

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

Choice B

Full health

↓

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 7

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 8 **Choice A** **Choice B**

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Mild varicose veins for 19 years and 6 months

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 9

Choice A

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 10

Choice A

Severe varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Please Note That The Next Question Contains Some Risk In Choice A

Question 11

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

↓

Mild varicose veins for 19 years and 6 months.

But you have a 75% chance of your veins returning to the moderate state in the next 19 years and 6 months.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 12

Choice A

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. **You have a 1 in 10,000 chance of dying under the anaesthetic. (This is similar to the risk of having a fatal road accident in a year.)** If successful, you will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Mild varicose veins for 19 years and 6 months.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

COMMENTS

We would be very interested to know what you think of the issues addressed in this questionnaire and the way they were presented. We would be particularly interested in whether consideration of these issues has altered the way you feel about which is the best treatment for you.
If you have any comments, please use the space below.

We would like to take this opportunity to thank you for participating in this survey.

Table 7.A.1 EQ-5D values before treatment and one month after treatment.								
			95% C.I. of difference					
	Mean	N	Lower	Upper	t	2-tailed sig.	Z	2-tailed sig.
Utility pre-treatment	0.779	79	-0.028	-0.015	-0.580	0.564	-0.690	0.490
Utility post-treatment	0.786							

Letter and questionnaire sent to health professionals

Mr J.A. Michaels, MChir FRCS

Consultant Vascular Surgeon

Dear Colleague

We are currently undertaking a research project into the treatment of varicose veins. As part of this project we are undertaking a study of the issues that patients find important in making their decisions regarding the relative values of the different treatments and outcomes for this condition. Part of this process involves carrying out focus groups with patients to identify the issues that concern them in reaching their decisions.

We are also keen to seek professional views about this issues which they consider may be of importance to patients, and that patients may wish to know about. We would be grateful if you could complete the enclosed questionnaire, and return it in the prepaid envelope to:

Miss Isabel Taylor
PhD Student
ScHARR
Regent Court
30 Regent Street
SHEFFIELD
S1 4DA

Yours sincerely

Mr J A Michaels

Consultant Vascular Surgeon

Questionnaire

We are using information from health professionals to construct scenarios to describe the various states of health relating to varicose veins. This is in order for patients and members of the general public to be able to give their views about the relative merits of different potential conditions.

We would be grateful if you could provide comments below as to the various issues in relation to symptoms, treatment, processes and outcomes and prognosis that you feel would be relevant to be included in such a scenario. You may wish to group your comments under the subheadings below.

Symptoms

Treatment Processes

Outcomes

Prognosis

Other

Table 7.A.2 Comments returned by health professionals.	
Symptoms	Pain/discomfort
	Cosmetic (*e.g.* bulging, unsightly)
	Recurrent ulceration
	Heavy legs
	Swelling in legs at end of day
	Prominent veins, heamosclerin deposition, lipodermatoscherosis
	Varicose events and previous Hx DVTs
Treatment processes	Injection
	Longterm use of compression hosiery with no significant risk
	Surgery and associated risks
	Topical steroids and emollients for eczema
	Compression stockings
	Compression bandaging (4 layer if possible) if dopplers OK
Outcomes	Prevention of recurrence (ulceration)
	Better cosmetic appearance
Prognosis	Prevent recurrent varicose veins and cure varicose veins!
	Heal an ulcer
	Improve skin condition.
	No improvement in skin changes.
	Longterm problems high likely *i.e.* recurrent varicose events and ulcers.
Other	Do patients understand treatment may not ???? symptoms before ???? it? Once they are in clinic, they're committed.
	How high does cosmetics rate with us compared to other functional outcomes?
	Do patients understand surgery has risks and complications?
	What are patients beliefs about VV surgery for prevention of ulcer/CVI?
	How can we detect if there was exaggeration of symptoms in order to obtain NHS or priority treatment?
	What is the effect of knowledge that symptoms will get you treatment by no symptoms won't?
	Do patients understand high recurrence rates even with state of the art procedures?

Miss Isabel Taylor,
Ph.D. student,
ScHARR, Regent Court,
30 Regent Street,
Sheffield, S1 4DA.

October 2000

Dear patient,

Re: Testing Different Methods Of Valuing Health Profiles In Patients With Varicose Veins

I am a Ph.D. student at the University of Sheffield, conducting research into different methods of valuing quality of life. This includes valuing different health states in terms of quality of life. I am particularly interested in how varicose veins affect quality of life.

I have developed a questionnaire, which I will be using to interview varicose veins patients. However, I need information from people with varicose veins in order to put together descriptions of varicose veins health states for the questionnaire. This is why I am writing to you.

I should like to invite you to attend a focus group meeting at the Northern General Hospital. We will meet in a small group of up to eight, containing myself, another researcher, and six varicose vein patients. We will discuss patients' perspectives of varicose veins. The discussion may be tape recorded, so that it can be transcribed into written form after the meeting. However, all information will be kept confidential, and you will remain anonymous. The tape will be destroyed once the project is completed. All travel expenses will be reimbursed.

If you decide to come along, please fill in the attendance confirmation slip accompanying this letter.

I will draw up a list of topics relating to varicose veins, which I will hand out to everyone in the group. I enclose a brief questionnaire with this letter, asking if there are any relevant topics you would like to discuss in the group. Please fill this in and return it with the attendance slip if you would like to add any topics to the list.

If you would like any further information about the focus group, please call me on:

0114 222 0722

Thank you for your time. I look forward to meeting you.

Yours faithfully,

Miss Isabel Taylor.

QUESTIONNAIRE

We wish to use focus groups to discuss the important issues for people with varicose veins. You will be able to raise any issue you feel is relevant when the group meets. However, it would be helpful if you would list any issues you can think of at this time which you feel are important. These will then be used to produce a list of topics to discuss at the meeting.
The questions below are designed to help you consider these issues. However, if there are other topics you would like to discuss, please feel free to write your comments overleaf or on a separate sheet of paper.

1) What issues would you like to discuss relating to treatment of your varicose veins?

2) What issues would you like to discuss relating to your varicose vein symptoms?

3) What issues would you like to discuss relating to the effect your varicose veins have on your life in general?

Thank you for your comments. Please use the prepaid envelope to return this questionnaire and the confirmation of attendance slip to:

Miss Isabel Taylor,
Ph.D. student,
ScHARR, Regent Court,
30 Regent Street,
Sheffield S1 4DA

I will be attending the focus group meeting to discuss issues relating to varicose veins.

PRINT NAME.....

SIGNATURE.....

Statement of informed consent

I agree to participate in this focus group, which is part of the research project "Testing Different Methods Of Valuing Health Profiles In Patients With Varicose Veins" being conducted by Miss Isabel Taylor of the University of Sheffield.

I understand that this focus group will last up to an hour and a half, and it will be audiotaped. I understand that the tape(s) will be destroyed upon completion of the study.

I understand that the purpose of the focus group is to find out about topics relating to varicose veins.

I understand that my participation in this focus group is entirely voluntary, and that if I wish to withdraw, I may do so at any time, and that I do not need to give any reasons or explanations for doing so. If I do withdraw from the focus group, I understand that this will have no effect on my treatment.

I understand that I have an obligation to respect the privacy of the other members of the focus group by not disclosing any personal information that they share during our discussion.

I understand that all the information I give will be kept confidential to the extent permitted by law, and that the names of all the people in the study will be kept confidential.

I have read and understand this information and I agree to take part in the focus group.

_____ _____

Today's date Your signature

LETTER TO PATIENTS

<Name>
<Address>

<Date>

Dear <Name>,

Re: Interview study of people with varicose veins

The consultant vascular surgeons at the Northern General Hospital are interested in finding out patients' views on alternative treatments for varicose veins. To do this, researchers from the University of Sheffield would like to interview you.

The interview will be done at a location that is convenient to you. It will involve you completing a questionnaire. Details of the study are provided in the attached patient information sheet.

Please read the attached information sheet carefully. If you are willing to take part in the study, please complete the enclosed consent form and send it in the stamped addressed envelope to:

Miss Isabel Taylor
School of Health and Related Research
University of Sheffield
Regent Court
30 Regent Street
Sheffield
S1 4DA

Miss Taylor will only contact you if you return the consent form.

You are under no obligation to take part in this study. Should you wish to decline, your present and future care will not be affected in any way.

Yours sincerely,

Mr J Michaels Mr J Beard Mr M Armon
Mr J Rochester

Mr R Lonsdale Mr P Chan Mr R Nair Prof
R Wood

CONSENT FORM (to be returned by patient)

Title of Project: Testing Different Methods of Valuing Health Profiles in Patients with Varicose Veins

Name of Researcher: Isabel Taylor

Please initial box

1. I confirm that I have read and understand the information sheet dated ..... (version .....). ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Please give your contact details so that you can be contacted:

Address:

_____

_____

Phone number: _____

_____	_____	_____
Name of Patient	Date	Signature

PATIENT INFORMATION SHEET

TESTING DIFFERENT METHODS OF VALUING HEALTH PROFILES IN PATIENTS WITH VARICOSE VEINS

A study to determine how patients with varicose veins feel about different varicose symptoms and treatments

You are invited to participate in a questionnaire study to explore how different varicose veins symptoms affect the way people with varicose veins feel.

"Why has my doctor asked me to take part in this study?"
Clinical studies are going on at the moment, aiming to discover which of several treatment options for varicose veins is the most appropriate. These studies will of course take into account the usual clinical outcomes, such as how well the varicose veins respond after each type of treatment and possible side effects. However, the attitudes of patients towards treatments are becoming increasingly important in clinical studies. Treatments for varicose veins have different effects on quality of life. It is important to know how patients feel about these different effects. Your participation in this study will aid our understanding of how patients feel about different treatments, and will therefore add to the research to find the most appropriate treatment.

"How long will the study last?"
This is a one-off interview, which will last 1 to 1½ hours.

"What will it involve?"
If you agree to participate in this study you will be asked to join a group of 4 to 10 other patients at the School of Health and Related Research at the University of Sheffield. A small remuneration will be given to you upon arrival, which will cover travel expenses. Each person in the group will be handed a questionnaire to complete, which will contain various sets of tasks. The questionnaire will ask you to consider your condition in ways which you will probably not have thought about before. Because of this, you may need to take your time to understand and reflect on each task. However, there will be a trained interviewer in the room throughout the interview, and she will explain all the tasks thoroughly before you are asked to complete them. The questions in the questionnaire will not relate to you specifically, or to your individual condition.

"What if I do not wish to take part?"
This will in no way affect your present or future treatment. However, if you do decide to take part you will be given a copy of this information sheet and a signed consent form to keep.

"What if I change my mind during the study?"
You are free to withdraw from the study at any time without affecting your present or future treatment.

"What will happen to the information from the study?"
All information will be entirely confidential. You will be informed of the results of the study if you wish in December 2001.

"Who is funding the study?"
The study is being funded by the Medical Research Council. Your doctor is not receiving any payment for the study other than for the hire of the premises where the interviews will take place.

"What if I have further questions?"
You should contact: Miss Isabel Taylor on 0114 222 0722, or Mr Jonathan Michaels on 0114 271 4968.

Table 7.A.3 Age of respondents and number of years they suffered from varicose veins.						
	Mean	SD	Median	IQR	Min	Max
Age (years)	48.4	13.2	50.0	36.9-58.3	23	78
Duration of varicose veins	13.3	10.8	10.0	4.0-22.5	1	40

Table 7.A.4 Occupational status of respondents.		
Occupational status	*N=67*	*%*
Managerial	1	1.5
Health professional	6	9.0
Education	4	6.0
Civil servant	2	3.0
Not highly trained	18	26.9
Miscellaneous	6	9.0
Not in paid employment	27	40.3

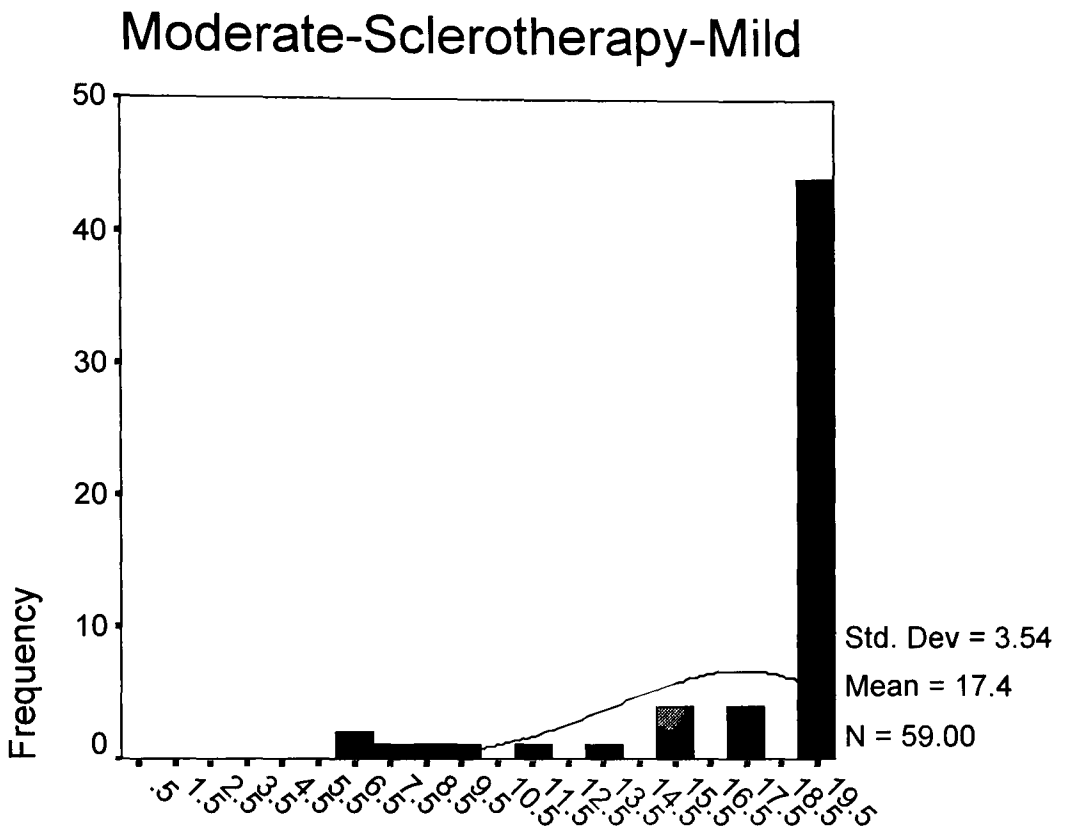
Table 7.A.5 Highest levels of education, n (%).	
Primary	1 (1.49)
Secondary	41 (61.19)
A level	5 (7.46)
University	7 (10.45)
S.R.N. O.N.C. (nursing)	1 (1.49)
Secondary & college for secretarial	1 (1.49)
Secondary & professional (nursing)	1 (1.49)
College – national diploma in agriculture	1 (1.49)
Grammar	1 (1.49)
Teachers' training college	1 (1.49)
NVQ child care	1 (1.49)
College	4 (5.97)
A-level & professional qualification	1 (1.49)
A-level & cert. educ: teacher training	1 (1.49)

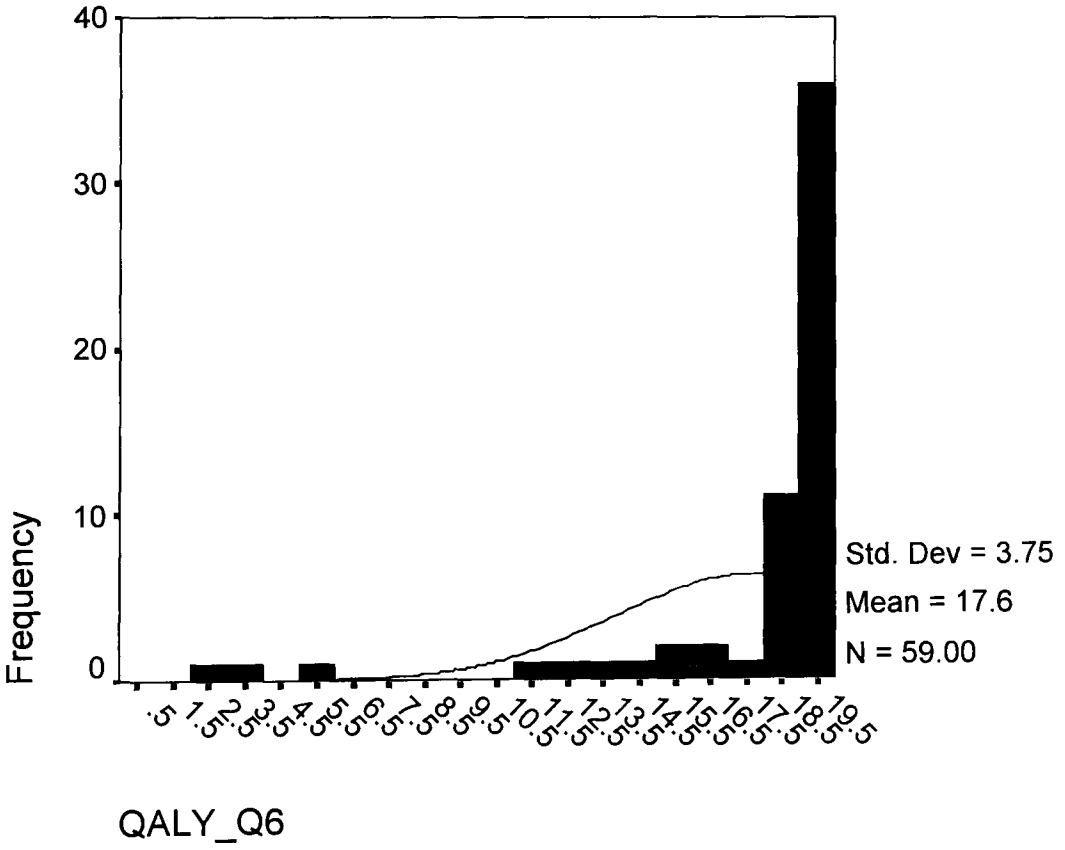
Table 7.A.6 List of choices of treatment and reasons given.
Stripping because painful
Mr Nair because leg aches sometimes but looks unsightly in summer
Nil
Stripping the veins affected and tying off in the groin area because advice from surgery
Operation because I want to get rid of them and the pain it causes
Operation because they are very painful when walking
Removal because discomfort, appearance
Stripping because they are unsightly and do cause some discomfort
Surgery because hopefully this way they will not re-occur
Surgery because I am in pain with my varicose veins
Vein stripping because that is what the hospital advised
Stripping because they look unsightly and are painful
Operation because it is large and uncomfortable and needs removing
Heat treatment because no major operation or anaesthetic is needed
Previously the offending veins were slit ??? – no operation but have since reoccurred
Previous treatment not completed so needs a further operation. But had to go through whole waiting list again
Surgery
Some doctor because they are very bad
Stripping because it affects my confidence – quality of life – I don't want to face them getting worse and worse as I'm only 32
An alternative method by inserting hot wire and shrinking vein because the regular method does not last for long and does not always help
Homeopathy and increased EFA intake and increased H_2O intake because non-intrusive – natural – horse chestnut us supposed to strengthen vein walls and I feel that *I* can help improve my veins condition without surgery (*i.e.* general anaesthetic)

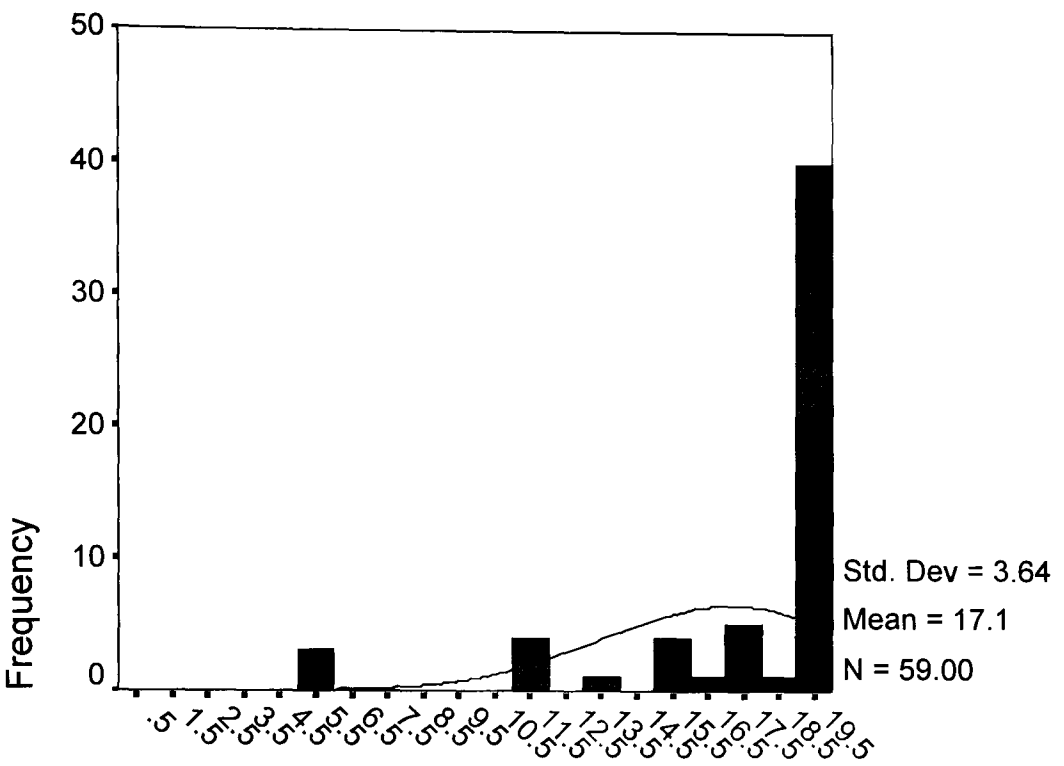
Table 7.A.7 Exclusions.	
ID 3	Missing valuation for the process of surgery
ID 7	Missing all valuation data
ID 18	Missing all valuation data
ID 19	Unclear data for valuations of moderate, mild, and current health states – "B" in lowest boxes, and then "=" all the way to the top
ID 21	Missing data for all valuations except for the severe health state
ID 22	Missing or unclear data for all valuations
ID 42	Missing data for Qs9 – 12 – health profile valuations
ID 60	Missing data for all valuations

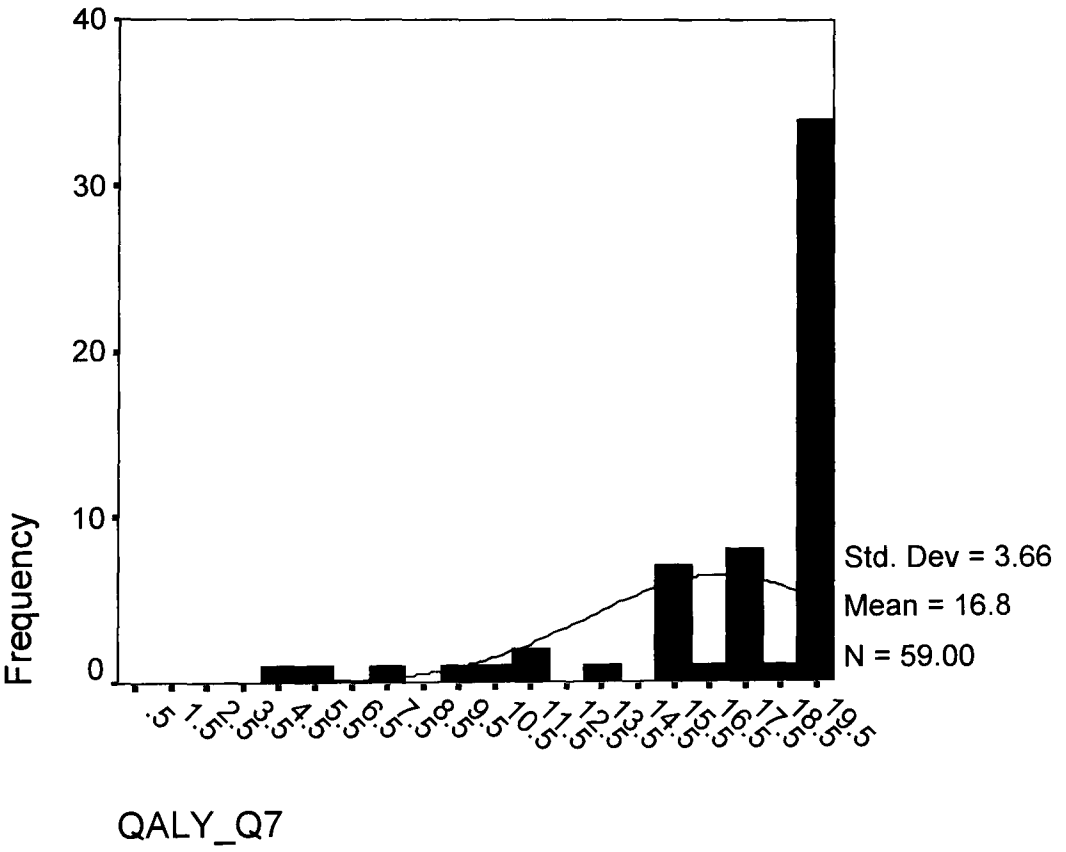
Table 7.A.8 These respondents had dubious data, but were included in further analysis.	
ID 23	Valuation of current health unclear, but this valuation is not incorporated into the health profiles
ID 33	Valuations for Q6 and Q7 health profiles had "A" and "B" the wrong way around – it was possible to use the indifferent point because it was in line with the indifferent point for the other valuations
ID 44	Valuations for severe, moderate, and mild health states were the wrong way around – it was possible to use the indifferent point because it was in line with the indifferent point for the other valuations

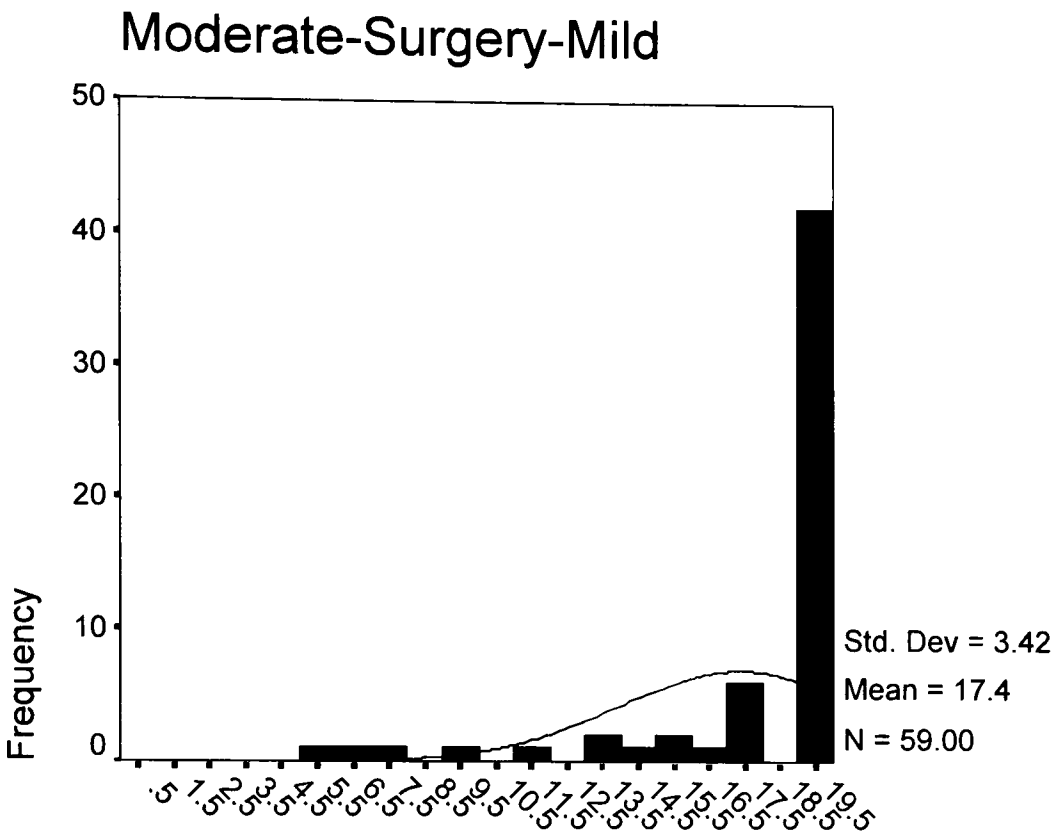
Figure 7.A.1 Histograms of direct and QALY valuations of the health profiles.

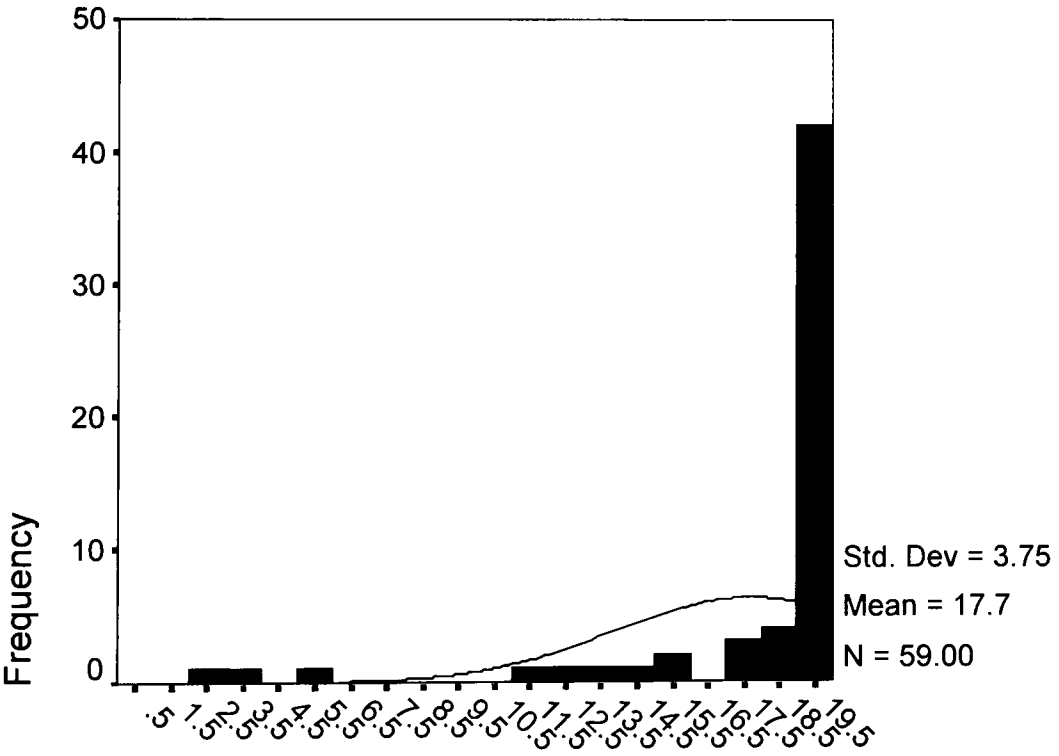


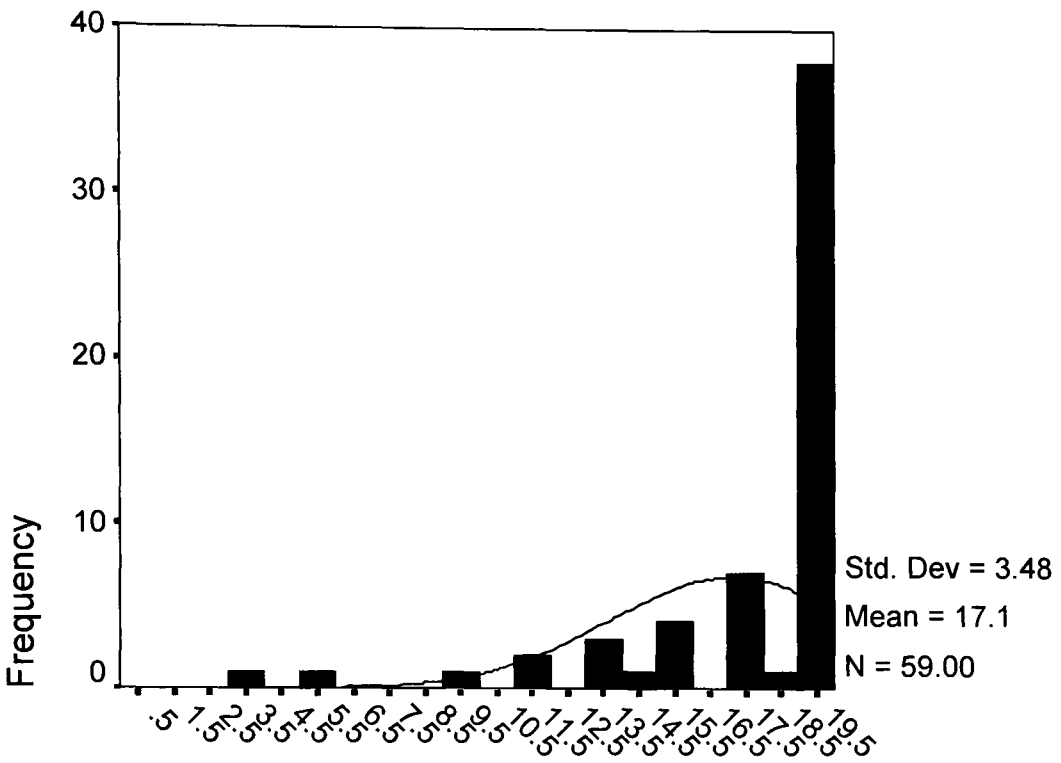


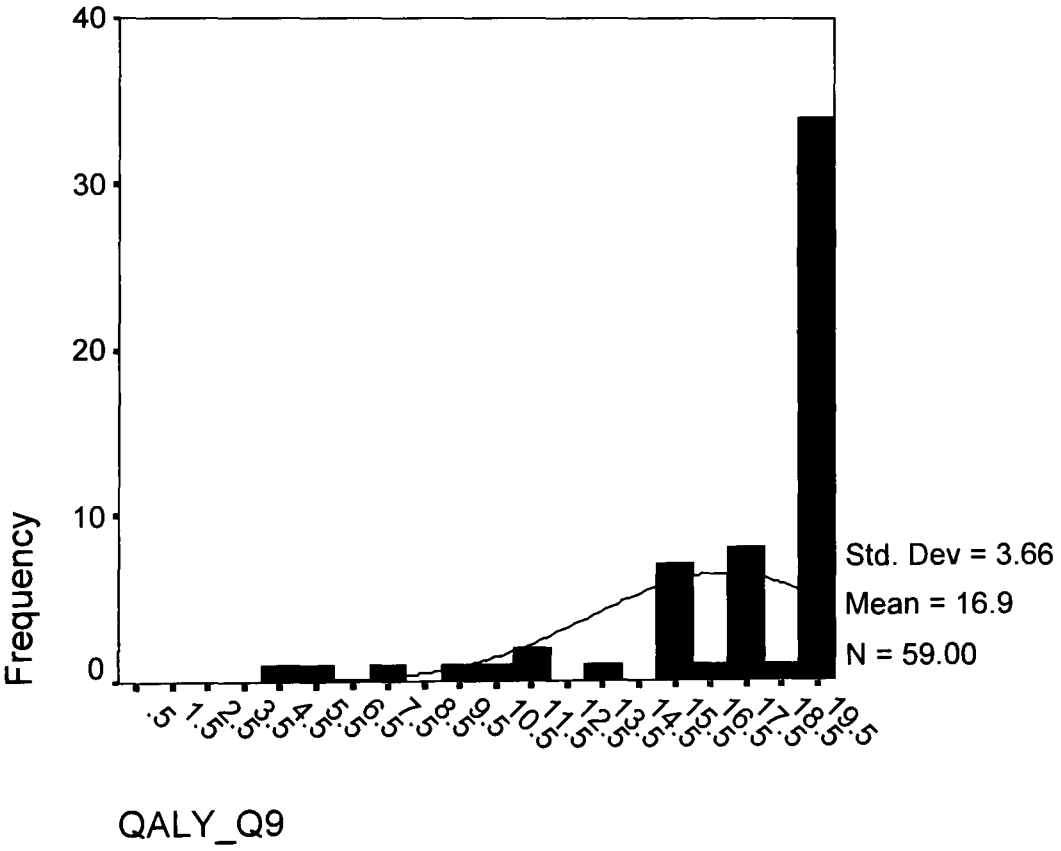

Moderate-Sclerotherapy-Moderate
Frequency
50
40
30
20
10
0
Std. Dev = 3.64
Mean = 17.1
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
12.5
13.5
14.5
15.5
16.5
17.5
18.5
19.5
Moderate-Sclerotherapy-Moderate

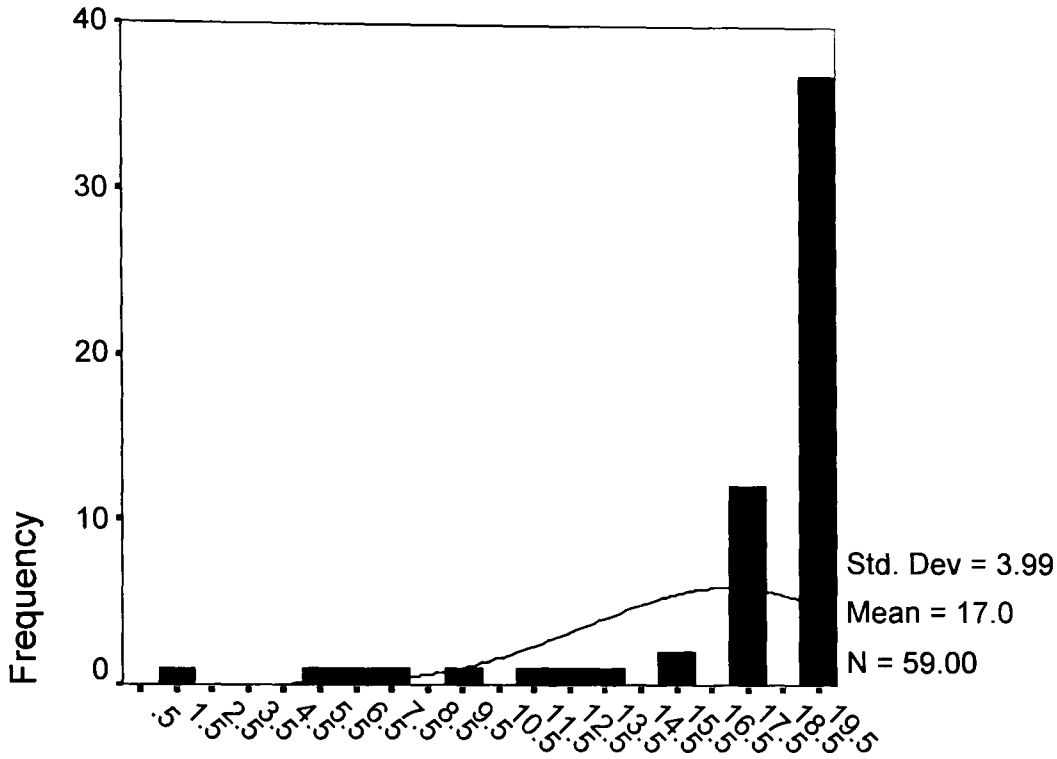

QALY_Q7
Frequency
40
30
20
10
0
Std. Dev = 3.66
Mean = 16.8
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
12.5
13.5
14.5
15.5
16.5
17.5
18.5
19.5
QALY_Q7

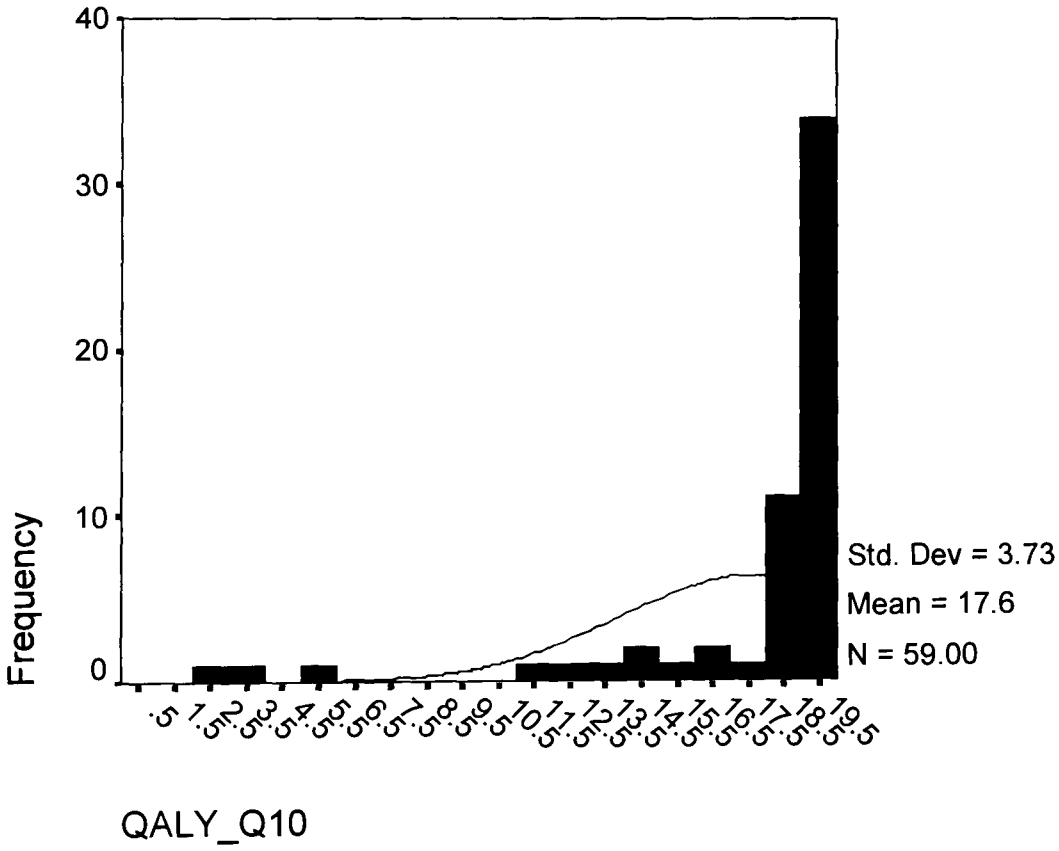

Moderate-Surgery-Mild
Frequency
50
40
30
20
10
0
Std. Dev = 3.42
Mean = 17.4
N = 59.00
Moderate-Surgery-Mild


QALY_Q8
Frequency
50
40
30
20
10
0
Std. Dev = 3.75
Mean = 17.7
N = 59.00
QALY_Q8


Moderate-Surgery-Moderate
Frequency
40
30
20
10
0
Std. Dev = 3.48
Mean = 17.1
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
12.5
13.5
14.5
15.5
16.5
17.5
18.5
19.5
Moderate-Surgery-Moderate


QALY_Q9
Frequency
40
30
20
10
0
Std. Dev = 3.66
Mean = 16.9
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
12.5
13.5
14.5
15.5
16.5
17.5
18.5
19.5
QALY_Q9


Severe-Surgery-Mild
Frequency
40
30
20
10
0
Std. Dev = 3.99
Mean = 17.0
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
12.5
13.5
14.5
15.5
16.5
17.5
18.5
19.5
Severe-Surgery-Mild


QALY_Q10
Frequency
40
30
20
10
0
Std. Dev = 3.73
Mean = 17.6
N = 59.00
.5
1.5
2.5
3.5
4.5
5.5
6.5
7.5
8.5
9.5
10.5
11.5
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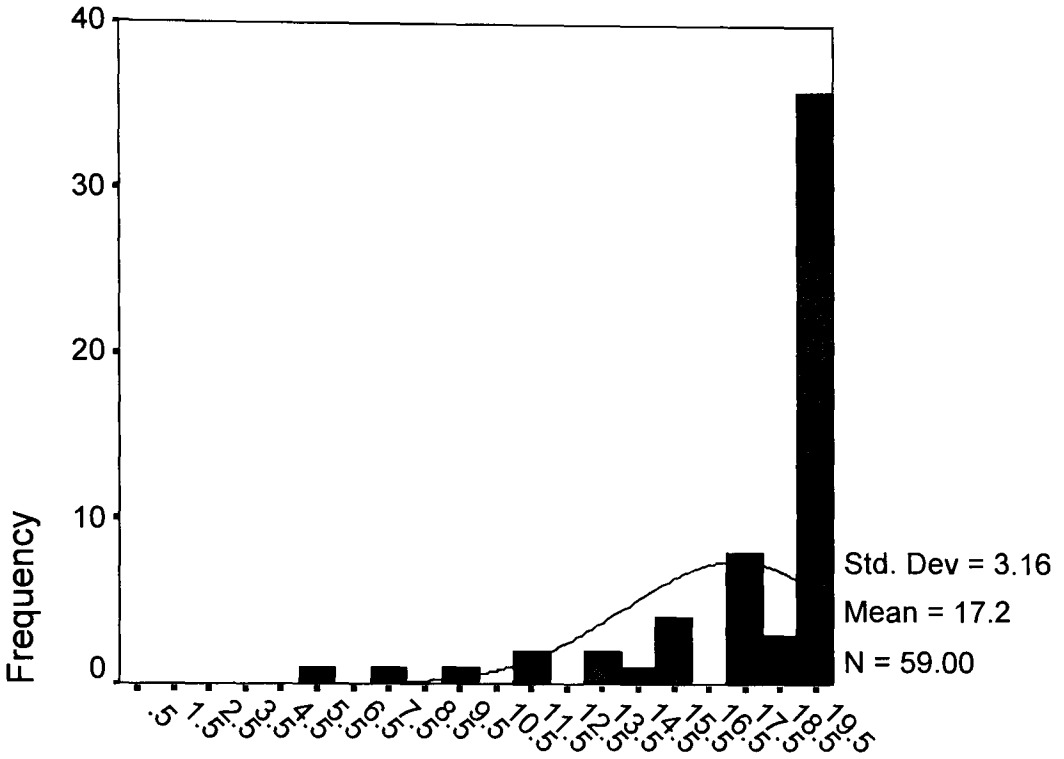
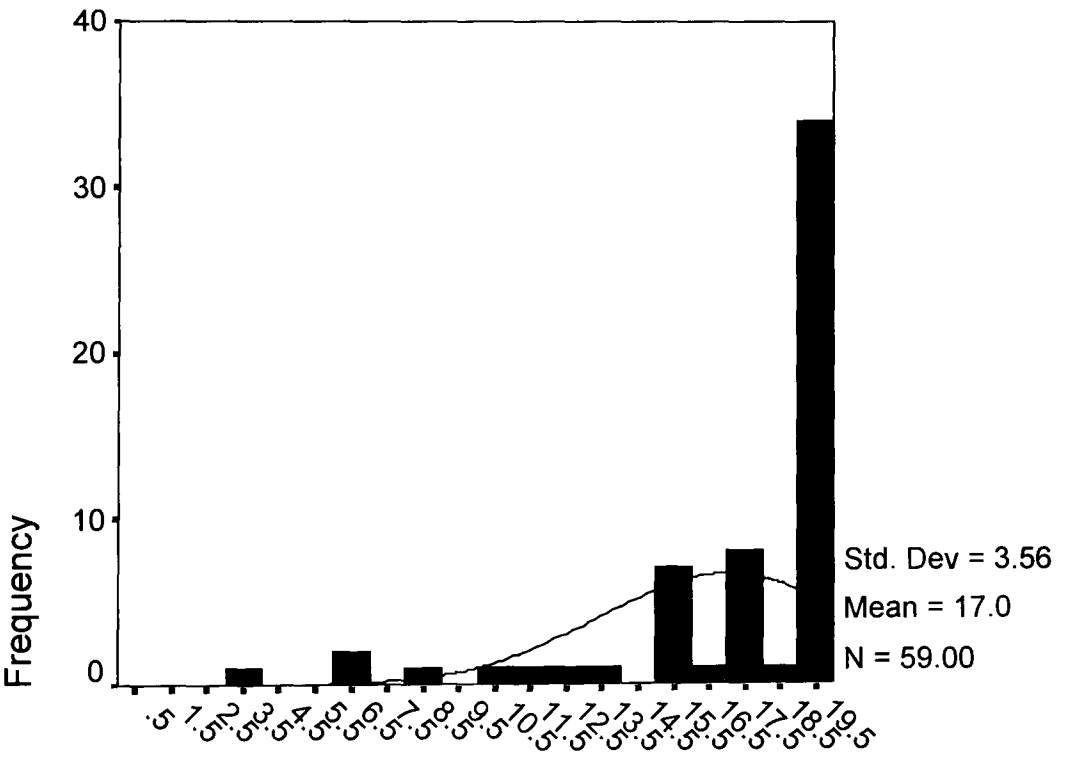
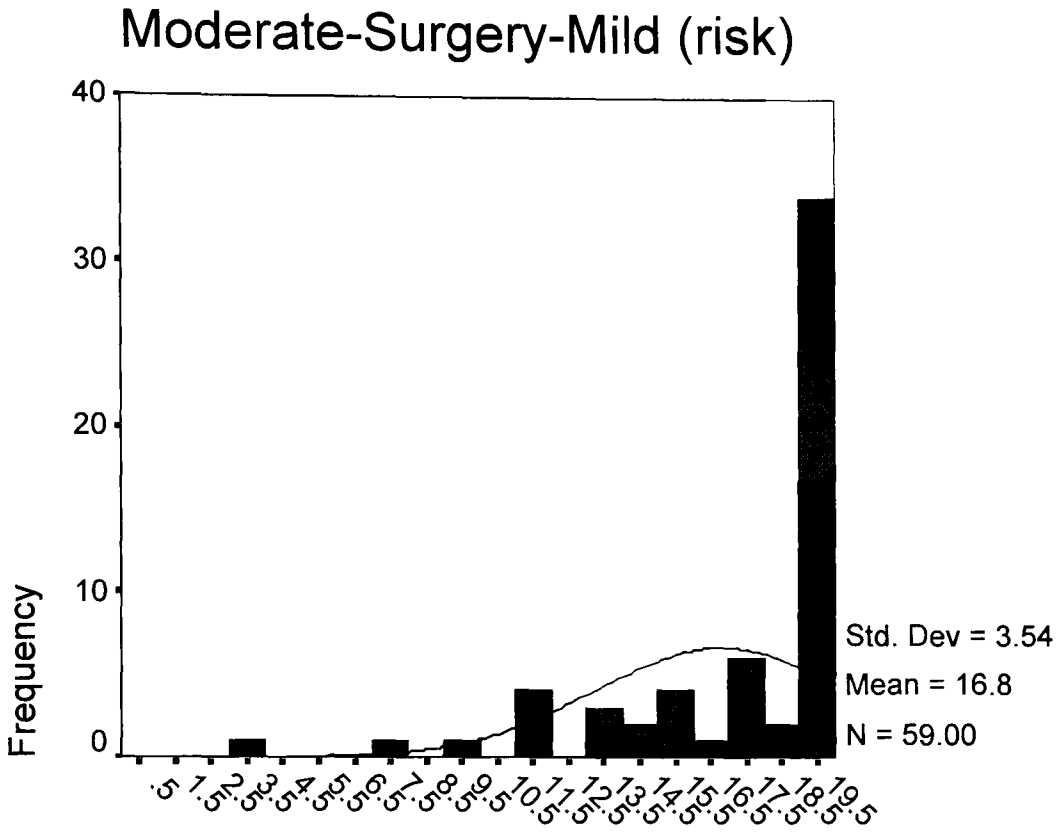
15.5
16.5
17.5
18.5
19.5
QALY_Q10


Moderate-Sclerotherapy-Mild (risk)
Frequency
40
30
20
10
0
Std. Dev = 3.16
Mean = 17.2
N = 59.00
Moderate-Sclerotherapy-Mild (risk)


QALY_Q11
Frequency
40
30
20
10
0
Std. Dev = 3.56
Mean = 17.0
N = 59.00
QALY_Q11


Moderate-Surgery-Mild (risk)
Frequency
40
30
20
10
0
Std. Dev = 3.54
Mean = 16.8
N = 59.00
Moderate-Surgery-Mild (risk)

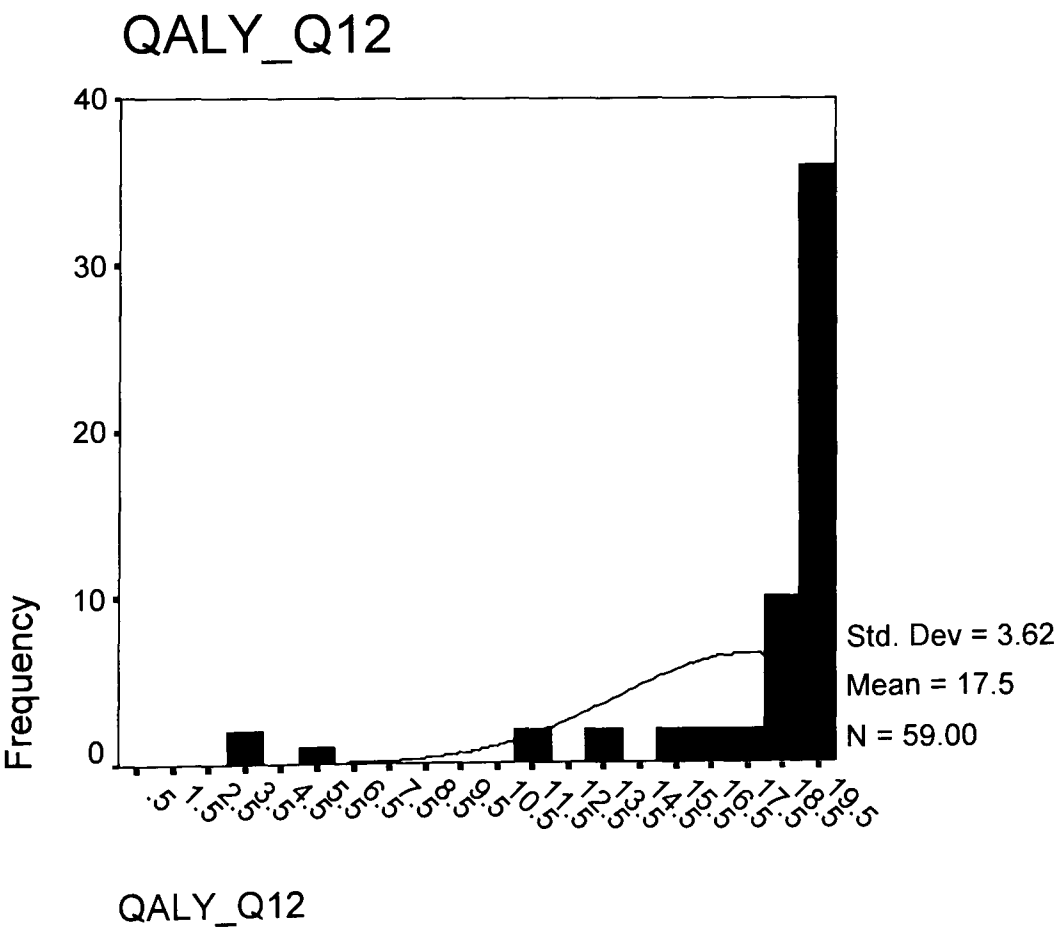
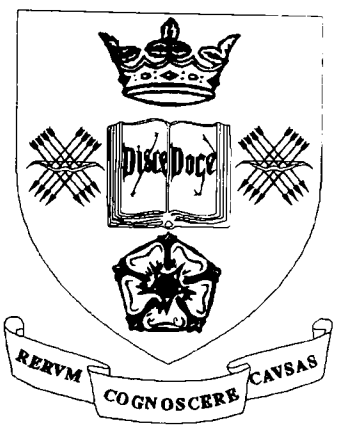

QALY_Q12
Frequency
40
30
20
10
0
Std. Dev = 3.62
Mean = 17.5
N = 59.00
QALY_Q12

Table 7.A.9 Comments made by patients.	
ID	Comments
1	I would have a focus group discussion as part of the research and I agree that lifestyle does affect the condition. Self-help and self management = very important option and one overlooked by medics.
2	At first the questions didn't sink in but when the options are considered I would go for the injection method and take a risk on the outcome. You can take a pill for pain and have a rest when you need to. No matter what occupation/life style you have. I would consider surgery as a last resort after going injections. I would like to thank you for someone giving time to listen to our views. No matter what pain/swelling/unsightly veins are my kids and family are worth fighting for.
4	Initially a very different type of questionnaire which took some understanding. However from a health point of view none of the scenarios presented was sufficiently bad to give up any years of life.
5	Presented well needed a little help. Would have thought some lifestyle questions would have helped the research.
9	Explanation very good. Great patience.
10	Very good.
11	I have been fortunate in the fact that I have not needed treatment yet other than anti-inflammatory drugs for a bout of phlebitis so I find it difficult to imagine the severity of the veins at the stage where I would need treatment.
12	I would have found it easier to answer if Choice A + B were varying degrees of symptoms e.g. severe vs. mild rather than contrasted with full health.
13	The questionnaire covers all physical problems to do with varicose veins – yet doesn't touch on the mental effects e.g. can't wear skirts, go swimming, etc.
15	You have taught me a lot about my VV. I would like to have surgery method which in my opinion is best. Thank you.
23	Having HAD both and seen the results I can only say I'd rather have surgery. I first had my veins injected at 17, then 21 then 28 and none worked. Surgery was much more effective in my situation.
25	It has been very interesting how you value the quality of life affected by having the condition, however it does not consider the problems that affect your lifestyle if the varicose vein problem causes further complications i.e. ulcers which may threaten your whole life.
26	I'm frightened of surgery but having read about the other method feel that I would choose to have surgery.
30	The major problem is understanding the severity of bad varicose veins and weighting it against reduction of life span. The other problem is one of relating your age now with your feelings in 20 years time when this might be just one problem that ????? you.
31	It was interesting to compare the surgery and sclerotherapy and the degree of the veins returning after these treatments.
32	The choice given between shorter life expectancy and suffering the veins to me was not a good option. Perhaps my veins are not severe enough at present to make these judgements as I would always choose longer life. If the option had been to have the operation or not my choices may well have been different.
33	I think the issues addressed in this questionnaire were very good and made me think a lot about it than I had. I think the that more questions could have been asked.

39	I like to have the operation to see if my leg become ant better from the pain.
41	V. complicated – left me feeling very confused – not about what course of treatment would be best for me – just the way the questionnaire is designed and worded.
43	A very interesting questionnaire. I was interested to read about the different procedures in the questions.
44	Surgery as I do not like injections.
47	I consider surgery the best option for me as I didn't realise the higher possibility of veins returning in sclerotherapy.
49	It makes you think about it.
50	I was not told about sclerotherapy. Didn't know anything about this treatment until I did this form. Now thinking about sclerotherapy instead of surgery.
53	I have not changed my opinion in relation to the issues addressed in the survey. The issue/problem with varicose veins I believe is at the minor end of the scale i.e. more important/life threatening conditions exist.
55	At the moment my varicose veins are very mild, therefore I am unable to realise how bad severe V.V. are.
56	The issues expressed make you think about your health but in my particular case, I could live with my varicose veins and enjoy full health.
65	The further problems issues stated following treatment by sclerotherapy and surgery would prompt me to ask further questions if I was to consider undertaking either option.

APPENDIX 4



UNIVERSITY OF SHEFFIELD

FACULTY OF MEDICINE

School of Health and Related Research

We are trying to find out your attitudes to risk when considering treatment. Please answer every question as best you can, but don't take too long over each one.

BACKGROUND INFORMATION

1) How old are you?
_____ years

2) Are you

male ☐

female ☐

3) How would you describe your occupation (*e.g.* accountant, housewife, teacher)?

_____

4) How old were you when you completed your full-time education?
_____ years

EUROQOL© HEALTH QUESTIONNAIRE

Here are some simple questions about your health in general. By ticking one answer in each group below, please indicate which statements best describe your own health state TODAY.

Please tick one

1. Mobility

I have no problems in walking about ○

I have some problems in walking about ○

I am confined to bed ○

2. 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 ○

3. Usual Activities

I have no problems with performing my usual activities ○
(e.g. work, study, housework, family or leisure activities)

I have some problems with performing my usual activities ○

I am unable to perform my usual activities ○

4. Pain/Discomfort

I have no pain or discomfort ○

I have moderate pain or discomfort ○

I have extreme pain or discomfort ○

5. Anxiety/Depression

I am not anxious or depressed ○

I am moderately anxious or depressed ○

I am extremely anxious or depressed ○

Valuing your current health state

You are going to be asked to make a choice regarding your future health.

For Choice A we would like you to imagine that you will live for 36 months (3 years) in your current health state, and then you will die.

Choice B is to live in the state of full health and then die.

We would like you to consider how many months in full health (Choice B) would be equivalent to 36 months in Choice A. Please use the table on the left-hand facing page.

Question 1A

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.
If Choice A is worse than death, please answer Question 1B over the page.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

Current health state

Choice B

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

Question 1B

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A			**Choice B**
State 1	*State 2*		
0 months	36 months		Immediate death
2 months	34 months		Immediate death
4 months	32 months		Immediate death
6 months	30 months		Immediate death
8 months	28 months		Immediate death
10 months	26 months		Immediate death
12 months	24 months		Immediate death
14 months	22 months		Immediate death
16 months	20 months		Immediate death
18 months	18 months		Immediate death
20 months	16 months		Immediate death
22 months	14 months		Immediate death
24 months	12 months		Immediate death
26 months	10 months		Immediate death
28 months	8 months		Immediate death
30 months	6 months		Immediate death
32 months	4 months		Immediate death
34 months	2 months		Immediate death
36 months	0 months		Immediate death

Choice A
State 1

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

FOLLOWED BY

State 2

Current health state

Choice B

Immediate death.

Question 2 Ranking exercise

You will be handed some health states. When you have ranked these states, please list them below in order of severity, starting with the best at the top. You may rank them equally.

_____

_____

_____

_____

_____

Valuation exercise

You are going to be asked to make choices between the states of health you have just ranked.

In the following exercises we would like you to imagine that you will live for 36 months (3 years) in the health state described in the upper box (Choice A), and then you will die.

Next we would like you to imagine that you will live in the health state described in the lower box (Choice B), and then you will die.

We would like you to consider how many months in Choice B would be equivalent to 36 months in Choice A. Please use the table on the left-hand facing page.

Question 3A

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.
If Choice A is worse than death, please answer Question 3B over the page.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

Chronic renal failure

You have to undergo dialysis, which means that a machine takes over the role of the kidney. This involves spending 3 hours in hospital 3 times a week.
Alternatively, you might do dialysis at home, in which case you need a large storage space in which to keep all the necessary materials. This method involves serious restrictions on your lifestyle. For example, you have to interrupt your normal daily activities to go on dialysis.
You also face restrictions on taking holidays.
You have restrictions on what you can eat and drink. For example, you are able to drink only a very moderate amount of alcohol. You are instructed to moderate your intake of certain foods, such as bananas, cheese, milk, and meat.
You feel tired and depressed for much of the time.

Choice B

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

Question 3B

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A			**Choice B**
State 1	*State 2*		
0 months	36 months		Immediate death
2 months	34 months		Immediate death
4 months	32 months		Immediate death
6 months	30 months		Immediate death
8 months	28 months		Immediate death
10 months	26 months		Immediate death
12 months	24 months		Immediate death
14 months	22 months		Immediate death
16 months	20 months		Immediate death
18 months	18 months		Immediate death
20 months	16 months		Immediate death
22 months	14 months		Immediate death
24 months	12 months		Immediate death
26 months	10 months		Immediate death
28 months	8 months		Immediate death
30 months	6 months		Immediate death
32 months	4 months		Immediate death
34 months	2 months		Immediate death
36 months	0 months		Immediate death

Choice A

State 1

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

FOLLOWED BY

State 2

Chronic renal failure

You have to undergo dialysis, which means that a machine takes over the role of the kidney. This involves spending 3 hours in hospital 3 times a week. Alternatively, you might do dialysis at home, in which case you need a large storage space in which to keep all the necessary materials. This method involves serious restrictions on your lifestyle. For example, you have to interrupt your normal daily activities to go on dialysis. You also face restrictions on taking holidays. You have restrictions on what you can eat and drink. For example, you are able to drink only a very moderate amount of alcohol. You are instructed to moderate your intake of certain foods, such as bananas, cheese, milk, and meat. You feel tired and depressed for much of the time.

Choice B

Immediate death.

Question 4A

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.
If Choice A is worse than death, please answer Question 4B over the page.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

Stroke

You have sensory loss, so that you no longer have a sense of touch.
You are also unaware of the positions of your affected limbs when you are not looking at them.
You have significant loss of the ability to speak.
Your sight is affected, so that the affected eye is no longer able to recognise familiar objects.
You have lost some control over your movements. This means that the limbs on the affected side of the body seem clumsy, and no longer do exactly what you want them to do.
You are subject to mood changes.
You are considerably more dependent on the help of others than previously.

Choice B

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

Question 4B

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A			**Choice B**
State 1	*State 2*		
0 months	36 months		Immediate death
2 months	34 months		Immediate death
4 months	32 months		Immediate death
6 months	30 months		Immediate death
8 months	28 months		Immediate death
10 months	26 months		Immediate death
12 months	24 months		Immediate death
14 months	22 months		Immediate death
16 months	20 months		Immediate death
18 months	18 months		Immediate death
20 months	16 months		Immediate death
22 months	14 months		Immediate death
24 months	12 months		Immediate death
26 months	10 months		Immediate death
28 months	8 months		Immediate death
30 months	6 months		Immediate death
32 months	4 months		Immediate death
34 months	2 months		Immediate death
36 months	0 months		Immediate death

Choice A

State 1

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

FOLLOWED BY

State 2

Stroke

You have sensory loss, so that you no longer have a sense of touch. You are also unaware of the positions of your affected limbs when you are not looking at them.
You have significant loss of the ability to speak.
Your sight is affected, so that the affected eye is no longer able to recognise familiar objects.
You have lost some control over your movements. This means that the limbs on the affected side of the body seem clumsy, and no longer do exactly what you want them to do.
You are subject to mood changes.
You are considerably more dependent on the help of others than previously.

Choice B

Immediate death.

Question 5 Ranking exercise

You will be handed some health profiles. When you have ranked these health profiles, please list them below in order of severity, starting with the best at the top. You may rank them equally.

_____

_____

_____

_____

Valuation exercise

In the following exercises, the states of health in the lowest boxes show the CERTAIN outcome of NOT having treatment (Choice B). The states of health in the upper boxes show the UNCERTAIN outcomes of having treatment (Choice A). These differ between exercises. There are a range of chances of each outcome.

On the left-hand facing page, there are a range of numbers of months. We are interested in the number of months in the certain health state in the lowest box which you feel would be equivalent to the risk described in the Choice A.

From now on, imagine that you yourself are in these states, and that they would last for the rest of your life without change.

Question 6

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.
Please put a X against all cases where you are CONFIDENT that you would choose Choice A.
Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A		Choice B
24 months		0 months
24 months		2 months
24 months		4 months
24 months		6 months
24 months		8 months
24 months		10 months
24 months		12 months
24 months		14 months
24 months		16 months
24 months		18 months
24 months		20 months
24 months		22 months
24 months		24 months

Choice A

There is a 2% chance that you will die immediately.

AND

There is a 98% chance that you will be in your current heath state for 24 months and then you will die.

Choice B

There is a 100% chance that you will be in your current health state for *x* months and then you will die.

Question 7A

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

If Choice A is worse than death, please answer Question 7B over the page.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months

Question 7B

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A			**Choice B**
State 1	*State 2*		
0 months	36 months		Immediate death
2 months	34 months		Immediate death
4 months	32 months		Immediate death
6 months	30 months		Immediate death
8 months	28 months		Immediate death
10 months	26 months		Immediate death
12 months	24 months		Immediate death
14 months	22 months		Immediate death
16 months	20 months		Immediate death
18 months	18 months		Immediate death
20 months	16 months		Immediate death
22 months	14 months		Immediate death
24 months	12 months		Immediate death
26 months	10 months		Immediate death
28 months	8 months		Immediate death
30 months	6 months		Immediate death
32 months	4 months		Immediate death
34 months	2 months		Immediate death
36 months	0 months		Immediate death

Choice A

State 1

Full health

You have no problems in walking about.

You have no problems with self-care.

You have no problems with performing usual activities.

You have no pain or discomfort.

You are not anxious or depressed.

FOLLOWED BY

There is a 20% chance that you will die immediately.

AND

There is a 10% chance that you will suffer a chronic renal failure, and this health state will last for 36 months (3 years) and then you will die.

AND

There is a 10% chance that you will suffer a stroke, and this health state will last for 36 months (3 years) and then you will die

AND

There is a 60% chance that you will be in your current heath state for 36 months (3 years) and then you will die.

State 2

Choice B

Immediate death.

Question 8

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months

Choice A

There is a 20% chance that you will die immediately.

AND

There is a 10% chance that you will suffer a chronic renal failure, and this health state will last for 36 months (3 years) and then you will die.

AND

There is a 10% chance that you will suffer a stroke, and this health state will last for 36 months (3 years) and then you will die.

AND

There is a 60% chance that you will be in your current heath state for 36 months (3 years) and then you will die.

Choice B

There is a 2% chance that you will die immediately.

AND

There is a 98% chance that you will be in your current heath state for *x* months and then you will die.

Risk attitude questions

You are going to be asked some questions to see how you feel about different levels of risk.

Choice A describes the chances that you will survive 36 months (3 years) or 0 months (*i.e.* die immediately). We ask you to consider the risks, and weigh them up in your mind.

In the bottom box (Choice B), we would like you to fill in the number of months of certain survival which you feel would be equivalent to taking the chance described in Choice A.

Question 9

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

There is a 25% chance that you will survive for 36 months (3 years) in your current state of health.

AND

There is a 75% chance that you will die immediately.

Choice B

_____ months in my current state of health

Question 10

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

There is a 50% chance that you will survive for 36 months (3 years) in your current state of health.

AND

There is a 50% chance that you will die immediately.

Choice B

_____ months in my current state of health

Question 11

Please put a ✓ against all cases where you are CONFIDENT that you would choose Choice B.

Please put a X against all cases where you are CONFIDENT that you would choose Choice A.

Please put a = against all cases where you cannot choose between Choice B and Choice A.

Choice A		Choice B
36 months		0 months
36 months		2 months
36 months		4 months
36 months		6 months
36 months		8 months
36 months		10 months
36 months		12 months
36 months		14 months
36 months		16 months
36 months		18 months
36 months		20 months
36 months		22 months
36 months		24 months
36 months		26 months
36 months		28 months
36 months		30 months
36 months		32 months
36 months		34 months
36 months		36 months

Choice A

There is a 75% chance that you will survive for 36 months (3 years) in your current state of health.

AND

There is a 25% chance that you will die immediately.

Choice B

_____ months in my current state of health

Question 12 **Time preference questions**

The following questions involve periods of ill health and excellent health occurring with certainty over 3 years, at the end of which you will die. Note that these scenarios involve periods of ill-health and of excellent health that will occur with certainty. Thus if a period of ill-health is delayed this does not influence the probability that you will suffer it. The ill-health state referred to in each scenario has the following characteristics:

> *You have some problems in walking about.*
> *You have some problems washing and dressing yourself.*
> *You have some problems with performing your usual activities.*
> *You have moderate pain or discomfort.*
> *You are moderately anxious or depressed.*

There are no right or wrong answers to the following questions. We simply want to determine your preferences. Consider scenarios A, B and C.

Scenario A

You will experience 3 months of excellent health, and then spend x days in the health state described above. This will be followed by another 33 months (2 years, 9 months) of excellent health, which will be followed by death.

Scenario B

You will experience 12 months (1 year) of excellent health, and then spend 14 days in the health state described above. This will be followed by another 24 months (2 years) of excellent health, which will be followed by death.

Scenario C

You will experience 2 years and 6 months of excellent health, and then spend y days in the health state described above. This will be followed another 6 months of excellent health, which will be followed by death.

1. How long would x have to be for you to be indifferent between scenarios A and B?

   ☐ days

2. How long would y have to be for you to be indifferent between scenarios B and C?

   ☐ days

COMMENTS

We would be very interested to know what you think of the issues addressed in this questionnaire and the way they were presented. If you have any comments, please use the space below.

We would like to take this opportunity to thank you for participating in this survey.

Proof of the equation by Miyamoto and Eraker (1985):

$U(C_{50},Q) = (0.5)U(C_{100},Q)$

$U(C_{25},Q) = (0.25)U(C_{100},Q)$

$U(C_{75},Q) = (0.75)U(C_{100},Q)$

Thus $n/100 = U(C_n,Q)/U(C_{100},Q)$

From Pliskin *et al* (1980) it follows that

$n/100 = bC_n{}^rH(Q)/bC_{100}{}^rH(Q) = (C_n/Y_{max})^r$

$(1/r)\ln(n/100) = \ln(C_n/Y_{max})$

least squares estimate of 1/r:

$Est(1/r) = (\sum X_n Z_n) / (\sum X_n{}^2)$

$r = [Est(1/r)]^{-1} = (\sum X_n{}^2) / (\sum X_n Z_n)$.

Table 8.A.1 Age and age at completion of education of respondents.

	Mean	SD	Median	IQR	Min	Max
Age (years)	38.8	10.3	38.0	31-45.5	19	70
Age at completion of education	22.2	6.0	21.5	18-23.8	15	39

Table 8.A.2 Occupations of respondents (n = 60, because this information was missing for one person).

Occupational category	*N (%)*
Manual (*e.g.* postman)	2 (3.3%)
Semi-skilled (*e.g.* secretary)	20 (32.8%)
Skilled (*e.g.* doctors, researchers)	37 (60.7%)
Other (*e.g.* retired)	1 (1.6%)

Table 8.A.3 Exclusions.	
ID 28	For the better than death question, she preferred 36 months in EVAR to just 16 months in her current health. Yet for the worse than death question she responded that she would rather die immediately than have 24 months in full health followed by 12 months of EVAR. Her EQ-5D state was 11111.
ID 29	She preferred 36 months with EVAR to 10 months in current health, but in the worse than death question she stated that she preferred immediate death to 30 months in full health followed by 6 months of EVAR.
ID 33	For the better than death questions he preferred chronic renal failure for 36 months to 34 months in full health, and 26 months with stroke to 2 months in full health. However, in the worse than death questions, he preferred immediate death to 34 months in full health followed by 2 months with chronic renal failure, and similarly for stroke.
ID 37	She stated that she would prefer 0 years in full health to 36 months with stroke, but left the worse than death question blank.
ID 40	He stated preferences for 0 months in full health to 36 months in current health, and 0 months in current health to 24 months in BMT and 36 months in EVAR. However, he did not respond to the worse than death questions. His EQ-5D health state was 11111.
ID 47	Ticks and crosses appeared to be the wrong way around for the health state valuations of current health, renal failure and stroke. There were also wide ranges of indifference, making it difficult to ascertain a score.
ID 53	The ticks and crosses were the wrong way around in the BMT valuation (Q6) and Q8 (comparison of EVAR and BMT).

Table 8.A.4 Non-convergent responses for health states.

	Ranking	TTO	Difference between greate ranking non-convergencies
ID 1	FH>CH>DD>ST>CR	FH>CH>DD>ST=CR	ST-CR = 0.000
ID 2	FH=CH>CR>DD>ST	FH>CH>CR>DD>ST	FH-CH = 0.028
ID 3	CH>FH>CR>ST>DD	FH>CH>CR=ST>DD	FH-CH = 0.028
ID 4	FH>CH>DD>CR>ST	FH>CH>DD>ST=CR	ST-CR = 0.000
ID 5	FH>CH>CR>ST=DD	FH=CH>CR>DD>ST	DD-ST = 0.972
ID 8	FH>CH>DD>ST>CR	FH>CH>DD>CR>ST	CR-ST = 0.111
ID 9	FH>CH>DD>ST>CR	FH>CH>ST>DD>CR	ST-DD = 0.194
ID 11	FH>CH>CR>ST>DD	FH>CH=CR=ST>DD	CH-ST = 0.000
ID 12	FH>CH>CR>ST>DD	FH>CH=CR>ST>DD	CH-CR = 0.000
ID 13	CH>FH>CR>DD>ST	FH>CH=CR=ST>DD	ST-DD = 0.972
ID 14	FH=CH>CR>DD>ST	FH>CH>CR>DD>ST	DD-ST = 0.917
ID 15	CH>FH>ST>CR>DD	FH=CH>DD>CR=ST	DD-ST = 0.972
ID 16	CH>FH>DD>CR>ST	FH=CH>DD>CR=ST	CR-ST = 0.000
ID 24	FH=CH>ST>CR>DD	FH=CH>CR>ST>DD	CR-ST = 0.055
ID 25	FH>CH>CR>ST>DD	FH>CH=CR>DD>ST	DD-ST = 0.694
ID 26	FH>CH>CR>ST>DD	FH>CH>CR=ST>DD	CR-ST = 0.000
ID 27	FH>CR>ST>CH>DD	FH>CR=ST>CH>DD	CR-ST = 0.000
ID 32	FH=CH>ST>CR>DD	FH>CR>CH>ST>DD	CR-ST = 0.445
ID 34	FH>CH>ST>CR>DD	FH=CH>DD>CR>ST	DD-ST = 0.972
ID 35	FH=CH>ST>CR>DD	FH>CH>CR>ST>DD	CR-ST = 0.112
ID 36	FH>CH>CR>ST>DD	FH>CH=CR>ST>DD	CH-CR = 0.000
ID 38	FH=CH>CR>ST=DD	FH=CH>CR>ST>DD	ST-DD = 0.722
ID 39	FH>CH>CR>ST>DD	FH=CH>ST>CR>DD	ST-CR = 0.166
ID 45	FH=CH>CR>ST>DD	FH>CR>ST>CH>DD	CR-CH = 0.444

ID 46	FH>CH>CR>ST=DD	FH=CH>CR>ST=DD	FH-CH = 0.000
ID 48	FH>CH>CR>ST=DD	FH>CH>CR>DD>ST	DD-ST = 0.194
ID 50	FH>CH>CR>ST>DD	FH=CH>CR>ST>DD	FH=CH = 0.000
ID 51	FH>CH>CR>ST>DD	FH=CH>CR>DD>ST	DD-ST = 0.972
ID 52	FH=CH>CR>ST>DD	FH=CH>CR>DD>ST	DD-ST = 0.861
ID 54	FH>CH>CR=ST>DD	FH=CH>CR>ST>DD	FH-CH = 0.000
ID 55	FH=CH>CR>ST>DD	FH=CH>CR=ST>DD	CR-ST = 0.000
ID 57	FH>CH>CR>ST>DD	FH=CH>ST>CR>DD	ST-CR = 0.083
ID 58	FH=CH>CR>ST>DD	FH>CH>DD>CR=ST	DD-CR = 0.972
ID 59	FH>CH>ST>CR>DD	FH=CH>ST>CR>DD	FH-CH = 0.000
ID 60	FH>CH>CR>ST>DD	FH>CH>CR=ST>DD	CR-ST = 0.000
ID 61	FH=CH>CR>ST>DD	FH=CH>CR>DD>ST	DD-ST = 0.806

Table 8.A.5 Non-convergent responses for scenarios.

	Ranking	Holistic chained	Difference between greatest ranking non-convergencies	QALY	Difference betwe greatest ranking n convergences
ID 1	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 3	FH>EVAR>BMT>DD			FH>BMT>EVAR>DD	BMT-EVAR = 0.47
ID 4	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 0.97		
ID 6	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 1.95	FH>EVAR>BMT>DD	EVAR-BMT = 0.93
ID 7	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 8	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 10	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 11	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 5.13
ID 12	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.93
ID 13	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 5.13
ID 15	FH>EVAR>BMT>DD			FH>BMT>EVAR>DD	BMT-EVAR = 8.92
ID 16	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 17	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.48
ID 18	FH>EVAR>BMT>DD	FH>BMT>EVAR>DD	BMT-EVAR = 6.00		
ID 19	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 1.00	FH>EVAR>BMT>DD	EVAR-BMT = 1.08

ID 20	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.68
ID 21	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 2.28
ID 22	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 1.18
ID 23	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.08
ID 26	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 2.73
ID 30	FH>BMT>DD>EVAR	FH>BMT>EVAR>DD	EVAR-DD = 11.00	FH>BMT>EVAR>DD	EVAR-DD = 19.80
ID 31	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 2.00
ID 32	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 2.97
ID 34	FH>BMT>DD>EVAR	FH>BMT>EVAR>DD	EVAR-DD = 16.00	FH>BMT>EVAR>DD	EVAR-DD = 16.80
ID 35	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 6.80		
ID 36	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.49
ID 38	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 3.68
ID 39	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 6.00	FH>EVAR>BMT>DD	EVAR-BMT = 0.88
ID 41	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 42	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 0.97	FH>EVAR>BMT>DD	EVAR-BMT = 3.33
ID 43	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 1.73
ID 44	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 2.00	FH>EVAR>BMT>DD	EVAR-BMT = 3.38
ID 45	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 4.84

ID 46	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 0.78
ID 48	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 2.84		
ID 49	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 0.97	FH>EVAR>BMT>DD	EVAR-BMT = 2.73
ID 50	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 3.38
ID 52	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00		
ID 54	FH>BMT=EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 5.08
ID 55	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 5.08
ID 56	FH>BMT>EVAR>DD	FH>EVAR>BMT>DD	EVAR-BMT = 4.00		
ID 57	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 2.78
ID 59	FH>BMT>EVAR>DD			FH>EVAR>BMT>DD	EVAR-BMT = 3.38
ID 60	FH>BMT>EVAR>DD	FH>BMT=EVAR>DD	BMT-EVAR = 0.00	FH>EVAR>BMT>DD	EVAR-BMT = 2.79

Table 8.A.6 Respondents' comments.

ID	Comments
11	Hard! Difficult to understand....imagine OK if you're fit and healthy – not so for people who are a bit muddled or in pain. Fun (in a way) for us to do.
12	A v. B choices 1, 3, 5, 4, 6, 7, 8, 9, 10, 11 v. hard to understand.
13	The months trade off needs a lot of mental arithmetic which I found hard to work out in my head (sorry durr!). Hard to do as a well person – may be more risk averse.
16	I would not expect anyone to complete this questionnaire – far too complex for what will probably be inaccurate outcomes...
17	The scenarios are quite clear and described well. It is very difficult to decide between Choice A and Choice B and not clear how to fill it out – it gets very confusing.
18	Examples of the choices made e.g. (A) 24 months v. 36 months (B) would have been helpful at the beginning. Cover sheet outlining the aim + objectives of the project would have given me a context for answering the qu's.
20	Quite difficult to complete. Very difficult for patients to complete.
21	Once done first few questions, became easier to answer similar questions as understood the style more.
26	Short life expectancy difficult to imagine for healthy people.
28	Difficult to answer with any degree of certainty. Increasingly, I answered in arbitrary sense – divisions seemed meaningless and I just answered quickly – as I simply couldn't make distinctions. Made my head hurt! Answered a very similar questionnaire (pilot I think) also from H.Ec. Issues – many people have a good quality of life with these conditions and would possible always choose life. Without some context to this I feel my decisions here are not 'informed'.
29	Far too complex without some kind of simple preamble + introduction to the idea of the tables, preferably face to face. Better to have instructions on the same page as the question. Health states in envelopes were user friendly.
38	The scenarios are difficult to imagine and therefore I would think that my responses would differ each time you asked me.
39	I was a little confused by the questions at times but the explanations helped. The issues are interesting to think about.
44	It was very interesting to consider the issues raised but I am not sure that it is very meaningful to a person who is in full health who has never been faced with any major health issues.

	My definition of what constitutes "some" problems will be very different to somebody who has experienced illness either directly or indirectly (e.g. caring). I am quite confident that how I would actually react if faced with any of these situations would be very different to how I think I would react. The valuation of health states is so relative that I cannot even guess how I would feel.
45	I think there is an absolutely fundamental problem with hypothetical questions like this. Although it would be much more difficult to achieve methodologically, I'd suggest that questioning people on the basis of real choices which they have made, or are making, would have much more validity. Esp. re stroke, renal failure etc. If you are interested in the risk perceptions of reasonably healthy people, then perhaps different scenarios/options would be helpful. We all calculate risk every day – food/exercise/spots/driving/substance abuse etc., as well as re health treatments… Using diary data e.g. would reflect these real choices…
47	V. difficult – too much like maths! – i.e. x, y, etc. The choice boxes could have the descriptions in column A & column B at top of box, instead of on a separate page – this could make it easier to visualize & understand.
48	Sometimes found the layout a little confusing – might have been better to have choices above month boxes.
57	I find it very difficult to imagine ill health states and death especially because I am in good health. Even when I think about ill health such as moderate anxiety and depression I always think I could alleviate the symptoms through herbal remedies.
60	Whilst I appreciate the questions, I hope it will be understood that this can at best only describe a hypothetical situation under personal circumstances that might change. In addition, personal preferences might change.

References

Abellan-Perpiñan, J., Pinto-Prades, J. (1999) "Health state after treatment: a reason for discrimination?" *Health Economics* 8, 701-7.

Adelman, L., Tolcott, M.A., Bresnick, T.A. (1993) "Examining the effect of information order on expert judgement". *Orgaizational Behavior and Human Decision Processes* 56, 348-69.

Akehurst, R.L., Brazier, J.E., Mathers, N., O'Keefe, C., Kaltenthaler, E., Morgan, A., Platts, M., Walters, S.J. (2002) "Health-related quality of life and cost impact of irritable bowel syndrome in a UK primary care setting". *Pharmacoeconomics* 20(7), 455-62.

Allais, M. (1953) "Le comportement de l'homme rationnel devant le risque, critique des postulats et axiomes de l'ecole Americaine". *Econometrica* 21, 503-46.

Allais, M. (1979) "The so-called Allais paradox and rational decisions under uncertainty". *The Expected Utility Hypothesis and the Allais Paradox.* M. Allais and O. Hagen: Dordrecht, Reidel.

Allais, M. (1984) "The foundations of the theory of utility and risk. Some central points of the discussion at the Oslo Conference". Cited in *Progress in Utility and Risk Theory.* Redel, D., Ed. Hagen, O., Wenstop, F. Dordrecht.

Altman, D.G. (1991) *Practical Statistics for Medical Research.* London, Chapman and Hall.

American Academy of Neurology (2002) "AAN Patient Information – What is Stroke?" http://www.aan.com/public/aaninfo/stroke.htm.

American Heart Association (2002) "Stroke Effects". http://www.americanheart.org/presenter.jhtml?identifier=4761.

Anonymous kidney patient (2000). Personal communication.

Ariely, D. (1998) "Combining experiences over time: the effects of duration, intensity changes and on-line measurements on retrospective pain evaluations". *Journal of Behavioral Decision Making* 11, 19-45.

Ariely, D., Carmon, Z. (2000) "Gestalt characteristics of exerpiences: the defining features of summarized events". *Journal of Behavioral Decision Making* 13, 191-201.

Ariely, D., Zauberman, G. (2000) "On the making of an experience: the effects of breaking and combining experiences on their overall evaluation". *Journal of Behavioral Decision Making* 13, 219-32.

Badia, X., Herdman, M. (2001) "Feasibility and validity of the VAS and TTO for eliciting general population values for temporary health states: a comparative study". *Journal of Health Services and Outcomes Research Methodology.* [In press.]

Bakker, C., Rutten-van Mölken, M., van Doorslaer, E., Bennett, K., van der Linden, S.J. (1995) "Feasibility of utility assessment by rating scale and standard gamble in ankylosing spondylitis or fibromyalgia". *Journal of Rheumatology* 22, 1536-43.

Bandolier 28–2 (1996) "Risk".

Baron, J. (1997) "Biases in the measurement of values for public decisions". *Psychological Bulletin* 122, 72-88.

Basili, M. (2000) "Knightian uncertainty in financial markets: an assessment" (n. 281). Università degli Studi di Siena, Dipartimento Di Economia Politica.

Bazerman, M.H., Loewenstein, G.F., Blount White, S. (1992) "Reversals of preference in allocation decisions: judging an alternative versus choosing among alternatives". *Administrative Science Quarterly* 37, 220-40.

BBC (1999) "Air travel linked to blood clots". http://news.bbc.co.uk/hi/english/health/newsid_277000/277494.stm

BBC (2000) "MP calls for long haul flight warnings". http://news.bbc.co.uk/hi/english/uk/wales/newsid_984000/984727.stm

Begg, D., Fischer, S., Dornbusch, R. (1994) *Economics.* McGraw Hill (4th ed.), London.

Bell, D., Farquhar, P. (1986) "Perspectives on utility theory". *Operational Research* 34(1), 179-83.

Bengtsson, H., Bergqvist, D. (1993) "Ruptured abdominal aortic aneurysm: a population-based study". *Journal of Vascular Surgery* 18, 74-80.

Bentham, J. (1789) *Introduction to the Principles of Morals and Legislation.*

Benzion, U., Rapoport, A., Yagil, J. (1989) "Discount rates inferred from decisions: an experimental study". *Management Science* 35, 270-84.

Bergus, G.R., Chapman, G.B., Levy, B.T., Ely, J.W., Oppliger, R.A. (1998) "Clinical diagnosis and the order of information". *Medical Decision Making* 18, 412-7.

Bernstein, L.M., Chapman, G., Christensen, C., Elstein, A.S. (1997) "Models of choice between multioutcome lotteries". *Journal of Behavioral Decision Making* 10, 93-115.

Bernstein, L.M., Chapman, G.B., Elstein, A.S. (1999) "Framing effects in choices between multioutcome life-expectancy lotteries". *Medical Decision Making* 19, 324-38.

Birch, S., Donaldson, C. (2003) "Valuing the benefits and costs of health care programmes: where's the 'extra' in extra-welfarism?" *Social Science and Medicine* 56, 1121-33.

Bleichrodt, H., Johannesson, M. (1996) "The validity of QALYs: an experimental test of constant proportional tradeoff and utility independence". *Medical Decision Making* 17, 21-32.

Bleichrodt, H. (1997) "Health utility indices and equity considerations". *Journal of Health Economics* 16, 65-91.

Bleichrodt, H., Johannesson, M. (1997) "Standard gamble, time trade-off and rating scale: experimental results on the ranking properties of QALYs" *Journal of Health Economics* 16, 155-75.

Bleichrodt, H., Wakker, P., and Johannesson, M. (1997) "Characterizing QALYs by risk neutrality", *Journal of Risk and Uncertainty* 15, 107-114.

Bleichrodt, H. (2002) "A new explanation for the difference between time trade-off utilities and standard gamble utilities". *Health Economics* 11, 447-56.

Bleichrodt, H., Herrero, C., Pinto, J.L. (2002) "A proposal to solve the comparability problem in cost-utility analysis". *Journal of Health Economics* 21, 397-403.

Bowling, A. (1997) *Measuring Health: A Review of Quality of Life Measurement Scales.* Open University Press, Milton Keynes, 2nd edition.

Boyd, N.F., Sutherland, H.J., Heasman, K.Z., Tritchler, D.L., Cummings, B.J. (1990) "Whose utilities for decision analysis?" *Medical Decision Making* 1, 58-67.

Bradbury, A., Evans, C., Allan, P., Lee, A., Ruckley, C.V., Fowkes, F.G.R. (1999) "What are the symptoms of varicose veins? Edinburgh vein study cross sectional population survey". *British Medical Journal* 318, 253-6.

Bradley, B., Singleton, M., Li Wan Po, A. (1994) "Readability of patient information leaflets on over-the-counter (OTC) medicines" *Journal of Clinical Pharmacy & Therapeutics* 19(1), 7-15.

Brazier, J.E., Harper, R., Jones, N.M.B., O'Cathain, A., Thomas, K.J., Usherwood, T., Westlake, L. (1992) "Validating the SF-36 health survey questionnaire: new outcome measure for primary care". *British Medical Journal* 305, 160-4.

Brazier, J., Dixon, S. (1995) "The use of condition specific outcome measures in economic appraisal". *Health Economics* 4 (4), 255-64.

Brazier, J.E. (1998) "Valuing health benefits: the development of a preference-based measure of health for use in the economic evaluation of health care from the SF-36 health survey" PhD thesis, University of Sheffield, Department of Economics.

Brazier, J.E., Harper, R., Thomas, K., Jones, N., Underwood, T. (1998) "Deriving a preference based single index measure from the SF-36", *J.Clinical Epidemiology* 51, 1115-1129.

Brazier, J., Deverill, M. (1999) "A checklist for judging preference-based measures of health related quality of life: learning from psychometrics". *Health Economics* 8, 41-51.

Brazier, J., Deverill, M., Green, C., Harper, R., Booth, A. (1999) "A review of the use of health status measures in economic evaluation". *Health Technology Assessment* 3 (9).

Brazier, J., Dolan, P. (2002) "Two ways to skin a cat: a comparison of two variants of standard gamble". Presented at the Health Economics Study Group meeting, 3-5 July 2002.

Brazier, J., Fitzpatrick, R. (2002) "Measures of health-related quality of life in an imperfect world: a comment on Dowie". *Health Economics* 11, 17-9.

Brazier, J., Roberts, J., Deverill, M. (2002) "The estimation of a preference-based measure of health from the SF-36". *Journal of Health Economics* 21(2), 271-92.

Brazier, J.E., Zöllner, Y.F., Platts, M., Towers, I., Schaefer, M. *"Developing a preference-based index of postmenopausal quality of life"*, a paper presented at the ISPOR conference, Barcelona November 2003.

Brooks, R. (1996), "EuroQol: the current state of play", *Health Policy* 37, 53-72.

Brookshire, D.S., Randall, A., Stoll, J.R. (1980) "Valuing increments and decrements in natural resource service flows". *American Journal of Agricultural Economics* August 1980, 478-88.

Broome, J. (2002) "Measuring the burden of disease by aggregating well-being". Chapter 3.1 in *Summary Measures of Population Health: Concepts, Ethics, Measurement and Applications.* Murray, C.J.L., Saloman, J.A., Mathers, C.D., Lopez, A.D. (eds.), World Health Organisation, Geneva.

Brouwer, W.B.F., Koopmanschap, M.A. (2000) "On the economic foundations of CEA. Ladies and gentlemen, take your positions!" *Journal of Health Economics* 19(4), 439-59.

Buckingham, K. (1993) "A note on HYE". *Journal of Health Economics* 12, 301-9.

Budd, J.S., Finch, D.R., Carter, P.G. (1989) "A study of the mortality from ruptured abdominal aortic aneurysms in a district community". *European Journal of Vascular Surgery* 3, 351-4.

Cabasés, J.M., Graminde, I., Ugalde, J.M., Pozo, F. (2000) "Social elicitation of EQ-5D health states preferences through Person Trade Off (PTO)". 17th Plenary Meeting of the Euroqol Group, Pamplona, Spain, Universidad Publica de Navarra.

Cairns, J. (1991) "Health, wealth and time preference". HERU Discussion Paper 07/91, Department of Public Health and Economics, University of Aberdeen.

Cairns, J.A. (1992) "Health, wealth and time preference". *Project Apprais* 7, 31-40.

Cairns, J.A. (1994) "Valuing future benefits". *Health Economics* 3, 221-9.

Cairns, J.A., van der Pol, M.M. (1997a) "Saving future lives: a comparison of three discounting models". *Health Economics* 6, 341-50.

Cairns, J., van der Pol, M. (1997b) "Constant and decreasing timing aversion for saving lives". *Social Science and Medicine* 45(11), 1653-9.

Cairns, J., van der Pol, M. (1999) "Do people value their own future health differently from others' future health?" *Medical Decision Making* 19, 466-72.

Cairns, J.A., van der Pol, M.M. (2000) "The estimation of marginal time preference in a UK-wide sample (TEMPUS) project: a review". *Health Technology Assessment* 4(1).

Cairns, J., van der Pol, M., Lloyd, A. (2002) "Decision making heuristics and the elicitation of preferences: being fast and frugal about the future". *Health Economics* 11. 655-8.

Callaham, M.L., Wears, R.L., Weber, E.J., Barton, C., Young, G. (1998) "Positive outcome bias and other limitations in the outcome of research abstracts submitted to a scientific meeting". *Journal of the American Medical Association* 280 (3), 254-7.

Calvert, N.W., Lloyd Jones, M., Thomas, S., Richards, R.G., Payne, J.N. (1999) "The use of endovascular stents for abdominal aortic aneurysm". Working Group on Acute Purchasing 99/08, Trent Development and Evaluation Committee (draft).

Campbell, W.B., Collin, J., Morris, P.J. (1986) "The mortality of abdominal aortic aneurysm". *Ann. R. Coll. Surg. Engl.* 68, 275-8.

Campbell, W.B., Ridler, B.M.F. (1995) "Varicose vein surgery and deep vein thrombosis". *British Journal of Surgery* 82(11), 1494-7.

Campbell, B., Bickerton, D. (1999) "Information for Patients – Injection Therapy for Varicose Veins (Sclerotherapy)". Health Information Centre, Royal Devon and Exeter Healthcare NHS Trust Barrack Road, Exeter, Devon EX2 5DW.

Carlsson, F., Johansson-Stenman, O. (2000) "Willingness to pay for improved air quality in Sweden". *Applied Economics* 32(6), 661-9.

Carr, S. (2002) *Tackling NHS Jargon: Getting the Message Across.* Radcliffe Publishing, Oxford, UK.

Cassileth, B.R., Lusk, E.J., Strouse, T.B. *et al* (1984) "Psychosocial status in chronic illness: a comparative analysis of six diagnostic groups". *New England Journal of Medicine* 311, 506-11.

Chapman , G.B., Elstein, A.S. (1995) "Valuing the future: temporal discounting of health and money". *Medical Decision Making* 15, 373-86.

Chapman, G.B. (1996) "Temporal discounting and utility for health and money". *Journal of Experimental Psychology: Learning, Memory, and Cognition* 22(3), 771-91.

Chapman, G.B., Bergus, G.R., Elstein, A.S. (1996) "Order of information affects clinical judgement". *Journal of Behavioral Decision Making* 9(3), 201-11.

Chapman, G.B., Elstein, A.S., Kuzel, T.M., Sharifi, R., Nadler, R.B., Andrews, A., Bennett, C.L. (1998) "Prostate cancer patients' utilities for health states: how it looks depends on where you stand". *Medical Decision Making* 18, 278-86.

Chapman, G.B., Coups, E.J. (1999) "Time preferences and preventative health behaviour: acceptance of the influenza vaccine" *Medical Decision Making* 19, 307-14.

Chapman, G.B., Nelson, R., Hier, D. (1999) "Familiarity and time preferences: decision making about treatments for migraine headaches and Crohn's disease". *Journal of Experimental Psychology: Applied* 5(1), 17-34.

Chapman, G.B. (2000) "Preferences for improving and declining sequences of health outcomes". *Journal of Behavioral Decision Making* 13, 203-18.

Charny, M.C., Lewis, P.A., Farrow, S.C. (1989) "Choosing who shall not be treated in the NHS". *Social Science and Medicine* 28(12), 1331-8.

Christensen-Szalanski, J.J.J. (1984) "Discount functions and the measurement of patients values: women's decisions during childbirth" *Medical Decision Making* 4, 47-58.

CNN (2001) "Deep vein thrombosis linked to most travel". http://www.cnn.com/2001/HEALTH/conditions/03/13/deep.vein.thrombosis.02/

Collin, J., Walton, J., Araujo, L., *et al* (1988) "Oxford screening programme for abdominal aortic aneurysm in men aged 65 to 74 years". *Lancet*, 2, 613-5.

Commonwealth Department of Health, Housing and Community Service (1992) *Guidelines for the pharmaceuticals industry on the submission to the Pharmaceutical Benefits Advisory Committee*. Canberra: Australian Government Publishing Service.

Commonwealth Department of Health and Ageing (2002) *Guidelines for the Pharmaceutical Industry on Preparation of Submissions to the Pharmaceutical Benefits Advisory Committee: Including Major Submissions Involving Economic Analyses.* http://www.health.gov.au/pbs/pubs/guidelines/pdfs/guidelines.pdf.

Conroy, R.M., Mulcahy, R. (1985) "Readability of literature written for cardiac patients". *Clinical Cardiology* 8(2), 104-6.

Cook, J., Richardson, J., Street, A. (1994) "A cost utility analysis of treatment options for gallstone disease: methodological issues and results". *Health Economics* 3, 157-68.

Cooper, M.G. (ed.) (1985) *Risk. Man-made Hazards to Man.* Clarendon Press.

Coursey, D.L., Hovis, J.L., Schultze, W.D. (1987) "The disparity between willingness-to-accept and willingness-to-pay measures of value". *The Quarterly Journal of Economics* 102, 679-90.

Coyle, D., Wells, G., Graham, I., Lee, K.M., Peterson, J.E., Papadimitropoulos, E. (2001) "The impact of risk on preference values: implications for evaluations of postmenopausal osteoporosis therapy". *Value in Health* 4(5), 385-91.

Crandon, A.J., Peel, K.R., Anderson, J.A., Thompson, V., McNicol, G.P. (1980) "Postoperative deep vein thrombosis: identifying high-risk patients". *British Medical Journal* 281, 343-4.

Crocker, T.D., Forster, B.A., Shogren, J.F. (1988) "An Analytical Basis for Valuing Potential and Realized Groundwater Protection Benefits in the State of Wyoming". Report to the Wyoming Water Research Center. http://library.wrds.uwyo.edu/wrp/88-11/abstract.html.

Cromwell, J., Mitchell, J.B. (1986) "Physician-induced demand for surgery". *Journal of Health Economics* 5, 293-313.

Cropper, M.L., Aydede, S.K., Portney, P.R. (1991) "Discounting human lives". *American Journal of Agricultural Economics* 73, 1410-5.

Cropper, M.L., Aydede, S.K., Portney, P.R. (1992) "Rates of time preference for saving lives". *American Economics Review* 82, 469-72.

Culyer, A.J. (1971) "The nature of the commodity health care and its efficient allocation". *Oxford Economic Papers* 24, 189-211.

Culyer, A. J., Simpson, H. (1980) "Externality models and health: a ruckblick over the last twenty years." *Economic Record* 219-230.

Culyer, A.J. (1989a) "The normative economics of health care finance and provision". *Oxford Review of Economic Policy* 5(1), 34-58.

Culyer, A.J. (1989b) "Commodities, characteristics of commodities, characteristics of people, utilities and the quality of life". In Baldwin, S., Godfrey, C., Propper, C. (Eds.) *The Quality of Life: Perspectives and Policies.* Routledge, London.

Culyer, A. (1991) "The normative economics of health care finance and provision". In McGuire, A., Fenn, P., Mayhew, K. (Eds.), *Providing health care: The economics of alternative systems of finance and delivery* (pps. 65-98). Oxford: Oxford University Press.

Culyer, A.J., Wagstaff, A. (1993a) "Equity and equality in health and health care". *Journal of Health Economics* 12, 431-57.

Culyer, A.J., Wagstaff, A. (1993b) "QALYs versus HYEs". *Journal of Health Economics* 12, 311-23.

Curley, S.P., Young, M.J., Kingry, M.J., Yates, J.F. (1988) "Primacy effects in clinical judgements of contingency". *Medical Decision Making* 8, 216-22.

Cuypers, P., Nevelsteen, A., Buth, J., Hamming, J., Stockx, L., Lacroix, H., Tielbeek, A. (1999) "Complications in the endovascular repair of abdominal aortic aneurysms: a risk factor analysis". *European Journal of Vascular and Endovascular Surgery* 18, 245-52.

Daly, E., Gray, A., Barlow, D., McPherson, K., Roche, M., Vessey, M. (1993) "Measuring the impact of menopausal symptoms on quality of life". *British Medical Journal* 307, 836-40.

Daniels, N. (1991) "Is the Oregon rationing plan fair?" *Journal of the American Medical Association* 265, 2232.

Dar, R., Ariely, D., Frenk, H. (1995) "The effect of past-injury on pain threshold and tolerance". *Pain* 60, 189-93.

Dekel, E. (1986) "An axiomatic characterization of preferences under uncertainty: weakening the independence axiom" *Journal of Economic Theory* 40(2), 304-18.

Department of Health and the Association of the Pharmaceutical Industry (1994) "Guidelines for the economic evaluation of pharmaceuticals". [Press release.] London: Department of Health.

Department of Health (2000). http://www.nice.org.uk.

Diamond, P.A., Hausman, J.A., Leonard, G.K., Denning, M.A. (1993) "Does contingent Valuation measure preferences? Experimental evidence". In Hausman, J.A., ed. *Contingent Valuation: A Critival Assessment.* Amsterdam: Elsevier.

Diehr, P., Psaty, B.M., Patrick, D.L. (1997) "Effect size and power for clinical trials that measure years of healthy life". *Statistics in Medicine* 16, 1211-23.

Dolan, P., Gudex, C. (1995) "Time preferences, duration and health state valuations". *Health Economics* 4, 289-99.

Dolan, P. (1996) "Modelling valuations for health states: the effect of duration". *Health Policy* 38, 189-203.

Dolan P and Kind P, (1996) "Inconsistencies and health state valuations" *Social Science and Medicine*, 42, 4, 609-615.

Dolan, P., Gudex, C., Kind, P., Williams, A., (1996a) "Valuing health states: a comparison of methods", *Journal of Health Economics*, 15, 209-231.

Dolan, P., Gudex, C., Kind, P., Williams, A. (1996b) "The time trade-off method: results from a general population study". *Health Economics* 5, 141-54.

Dolan, P. (1997) "The nature of individual preferences: a prologue to Johanesson, Jonsson and Karlsson" *Health Economics* 6, 91-3.

Dolan, P. (1998a) "The measurement of individual utility and social welfare". *Journal of Health Economics* 17, 39-52.

Dolan, P. (1998b) "Valuing health-related quality of life: issues and controversies". *Pharmacoeconomics* 15(2), 119-27.

Dolan, P. (1999) "Drawing a veil over the measurement of social welfare – a reply to Jahannesson". *Journal of Health Economics* 18, 387-90.

Dolan, P. (2000a) *The Measurement of Health-Related Quality of Life for Use in Resource Allocation Decisions in Health Care* Chapter 32 from *Handbook of Health Economics, Volume 1* edited by A.J. Culyer and J.P. Newhouse. Elsevier Science B.V.

Dolan, P. (2000b) "A note on QALYs versus HYEs: health states versus health profiles". *International Journal of Technology Assessment in Health Care* 16(4), 1220-4.

Dolan, P., Edlin, R. (2002) "Is it really possible to build a bridge between cost-benefit analysis and cost-effectiveness analysis?" *Journal of Health Economics* 21, 827-43.

Donaldson, C., Atkinson, A., Bond, J., Wright, K. (1988) "Should QALYs be programme-specific?" *Journal of Health Economics* 7, 239-57.

Donaldson, C., Gerard, K. (1993) *Economics of Health Care Financing: The Visible Hand.* Ed. Mooney, G., McGuire, A. The Macmillan Pess Ltd., Hampshire and London.

Donaldson, C. (1995) "Willingness to pay for publicly-provided health care". PhD thesis, University of Aberdeen.

Donaldson, C., Shackley, P. (1997) "Does 'process utility' exist? A case study of willingness to pay for laparoscopic cholecystectomy". *Social Science and Medicine* 44(5), 699-707.

Dreben, E.K., Fiske, S.T., Hastie, R. (1979) "The independence of evaluative and item information: impression and recall order effects in behavior-based impression formation". *Journal of Personality and Social Psychology* 37, 1758-68.

Drummond, M.F., O'Brien, B., Stoddart, G.L., Torrance, G.W. (1997) *Methods for the Economic Evaluation of Health Care Programmes.* Oxford University Press (2nd ed.). New York.

Dupuit, J. (1844) "On the measurement of utility of public works". Translated by Barback, R.H., in *International Economic Papers* 2 (1952): 83-110 from "De la Mesure de l'Utilite des Travaux Publics". *Annales des Ponts et Chaussees,* 2nd series Vol 8 (Another English version in Arrow, K.J. and Scitovsky, T. eds. *Readings in Welfare Economics,* George Allen and Unwin, London, 1969).

Duru, G., Auray, J.P., Béresniak, A., Lamure, M., Paine, A., Nicoloyannis, N. (2002) "Limitations of the methods used for calucating quality-adjusted life-year values". *Pharmacoeconomics* 20(7), 463-73.

Dyer, J.S., Sarin, R.K. (1982) "Relative risk aversion". *Management Science* 28(8), 875-86.

Easterbrook, P.J., Berlin, J.A., Gopalan, R., Matthews, D.R. (1991) "Publication bias in clinical research". *Lancet* 337 (8746), 867-72.

Ebrahim, S., Brittis, S., Wu, A. (1991) "The valuation of states of ill-health: the impact of age and disability" *Age and Ageing* 20, 37-40.

Edlin, R. (2004) "Anti-social welfare functions: a reply to Hansen *et al*". *Journal of Health Economics* 23, 899-905.

Enemark, U., Lyttkens, C.H., Troëng, T., Weibull, H., Ranstam, J. (1998) "Implicit discount rates of vascular surgeons in the managements of abdominal aortic aneurysms". *Medical Decision Making* 18, 168-77.

Eskandari, M.K., Bowles, S.A., Webster, M.V., *et al* (1998) "Ruptured abdominal aortic aneurysms in the 1990s: resource utilization, long-term survival and quality of life after repair". *Vascular Surgery* 32, 415-24.

Evans, R.G. (1974) "Supplier-induced demand: empirical evidence and implications". In Perlman, M. (Ed), *The Economics of Health and Medical Care.* New York, John Wiley and Sons.

Evans, R.G., Wolfson, A.D. (1980) "Faith, hope and charity: health care in the utility function". Unpublished paper. Department of Economics, University of British Columbia, and Department of Health Administration, University of Toronto.

Evans, R.G. (1984) *Strained Mercy: The Economics of Canadian Medical Care.* Toronto, Butterworths.

Evans, R.G. (1987) "Public health insurance: the collective purchase of individual care". *Health Policy* 7, 115-34.

Evans, R.G. (1990) "Tension, compression and shear: directions, stresses and outcomes of health care cost control". *Journal of Health Politics, Policy and Law* 15, 101-28.

Familydoctor.org (2000) "Stroke Rehabilitation". http://familydoctor.org/handouts/151/html.

Fanshel, S., Bush, J. (1970) "A health status index and its application to health services outcomes". *Operations Research* 18(6), 1021-66.

Feeny, D.H., Torrance, G.W. (1989) "Incorporating utility-based quality-of-life assessment measures in clinical trials". *Medical Care* 27, S190-204.

Feeny D., Furlong W., Boyle M., Torrance G.W. (1995) "Multi-attribute health status classification systems. Health Utilities Index". *Pharmacoeconomics* 7, 490-502.

Feeny, D. (2002) "The utility approach to assessing population health". Chapter 10.2 in *Summary Measures of Population Health: Concepts, Ethics, Measurement and Applications.* Murray, C.J.L., Saloman, J.A., Mathers, C.D., Lopez, A.D. (eds.), World Health Organisation, Geneva.

Frank, L., Kleinman, L., Farup, C., Taylor, L., Miner, P Jr (1999) "Psychometric validation of a constipation symptom assessment questionnaire". *Scandinavian Journal of Gastroenterology* 34(9), 870-7.

Fredrickson, B.L., Kahneman, D. (1993) "Duration neglect in retrospective evaluation of affective episodes". *Journal of Personaltiy and Socail Psychology* 60, 45-55.

Friedman, M., Savage, L.J. (1948) "The utility of choices involving risk". *Journal of Political Economics* 56, 279-304.

Friedman, M. (1953) "The methodology of positive economics". In *Essays in Positive Economics.* University of Chicago Press.

Friedman, L.S. (1984) *Microeconomic Policy Analysis* McGraw-Hill, Inc.

Froberg, D.G., Kane, R.L. (1989) "Methodology for measuring health state preferences III: population and context effects". *Journal of Clinical Epidemiology* 42, 345-54.

Froberg, D.G., Kane, R.L. (1989) "Methodology for measuring health state preferences III: population and context effects". *Journal of Clinical Epidemiology* 42, 585-92.

Fryback, D.G. (2003) "Whose quality of life? Or whose decisions?" *Quality of Life Research* 12, 609-10.

Furlong, W., Feeny, D., Torrance, G.W., Barr, R., Horsman, J. (1990) *Guide to design and development of health state utility instrumentation.* Centre for Health Economics and Policy Analysis, Paper 90-9, McMaster University, Hamilton, Ontario.

Gafni, A., Birch, S., Mehrez, A. (1993) "Economics, health and health economics: HYEs versus QALYs". *Journal of Health Economics* 12, 325-39.

Gafni, A. (1995) "Time in health: can we measure individuals' 'pure time preferences'?" *Medical Decision Making* 15, 31-7.

Garbacz, C., Thayer, M.A. (1983) "An experiment in valuing senior companion program services". *Journal of Human Resources* 18, 147-53.

Garber, A.M. (1999) "Advances in cost-effectiveness analysis of health interventions". Working Paper 7198, National Bureau of Economic Research, Cambridge, MA 02138. Accessible from http://www.nber.org/papers/w7198.

Garratt, A.M., Ruta, D.A., Abdalla, M.I., Buckingham, J.K., Russell, I.T. (1993) "The SF 36 health survey questionnaire: an outcome measure suitable for routine use within the NHS?" *British Medical Journal* 306:1440-4.

Gaskin, D.J., Kong, J., Meropol, N.J., Yabroff, K.R., Weaver, C., Schulman, K.A. (1998) "Treatment choices by seriously ill patients: the health stock risk adjustment model" *Medical Decision Making* 18, 84-94.

Gerard, K., Dobson, M., Hall, J. (1993) "Framing and labelling effects in health descriptions: quality adjusted life years for treatment of breast cancer". *Journal of Clinical Epidemiology* 46 (1), 77-84.

Gigerenzer, G., Todd, P., A.R. Group, eds. (1999) *Simple Heuristics That Make Us Smart*. 416 ed. Evolution and Cognition, ed. Stich, S., Oxford University Press: New York.

GMC (2003) http://www.gmc-uk.org/register/default.htm.

Gold, M., Siegel, J., Russell, L., Weinstein, M. (1996) *Cost-effectiveness in Health and Medicine*. Oxford University Press, New York.

Gordon, I.M., Knetsch, J.L. (1979) "Consumer's surplus measures and the evaluation of resources". *Land Economics* 55, 1-10.

Government Actuary's Department (2001) "Interim life tables for England, based on data for the years 1997-1999" http://www.gad.gov.uk/b2/b2div12.htm.

Gowdy, J.M. (2004) "The revolution in welfare economics and its implications for environmental valuation and policy". *Land Economics* 80(2), 239-57.

Graaf, J. (1967) *Theoretical Welfare Economics*. Cambridge University Press, Cambridge.

Gravelle, H., Rees, R. (1983) *Microeconomics*. 2nd edition. Harlow. Longman Group Limited.

Gudex, C. (1994) *Time Trade-Off User Manual: Props and Self-Completion Methods*. Centre for Health Economics, University of York, York, England, YO1 5DD.

Hall, J., Gerard, K., Salkeld, G., Richardson, J. (1992) "A cost utility analysis of mammography screening in Australia" *Social Science and Medicine* 34, 993-1004.

Hansen, B.O., Hougaard, J.L., Keiding, H., Østerdal, L.P. (2004) "On the possibility of a bridge between CBA and CEA: comments on a paper by Dolan and Edlin". *Journal of Health Economics* 23, 887-98.

Hawthorne, G., Richardson, J., Day, N., McNeil, H. (2000) "Life and death: theoretical and practical issues in using utility instruments". Centre for Health Program Evaluation, Working Paper 102.

Healey, A., Chrisholm, D. (1999) "Willingness to pay as a measure of the benefits of mental health care". *The Journal of Mental Health Policy and Economics* 2, 55-8.

Heit, J.A., Silverstein, M.D., Mohr, D.N., Petterson, T.M., O'Fallon, W.M., Melton, L.J. (2000) "Risk factors for deep vein thrombosis and pulmonary embolism: a population-based case-control study".

Herrero, C. (1996) "Capabilities and utilities". *Economic Design* 2, 69-88.

Hicks, C.M. (1990) *Research and Statistics: A Practical Introduction for Nurses.* Prentice Hall; London, New York.

Hicks, J.R., Allen, R.G.D. (1934) "A reconsideration of the theory of value". *Economica* Feb. 52-75, May 196-216.

Hicks, J.R. (1939) "The foundations of welfare economics". *Economic Journal* 49, 696-710.

Hicks, J.R. (1941) "The rehabilitation of consumer's surplus". *The Review of Economic Studies* 8, 108-16.

Hicks, J.R. (1943) "The four consumer's surpluses". *The Review of Economic Studies* 11, 31-41.

Himmelstein, D.U., Woolhandler, S. (1986) "Cost without benefit: administrative waste in U.S. health care". *New England Journal of Medicine* 314, 441-5.

HM Treasury (2003) *The Green Book: Appraisal and Evaluation in Central Government.* Treasury Guidance, London: TSO.

HMSO (1944) *A National Health Service.* Cmnd 6502. London.

HMSO (1976) *Sharing Resources for Health in England.* Report of the Resource Allocation Working Party. London.

HMSO (1992) "Mortality statistics: area". Series DH5 19.

Hogarth, R.M., Einhorn, H.J. (1992) "Order effect in belief updating: the belief-adjustment model". *Cognitive Psychology* 24, 1-55.

Horowitz, J.H., Carson, R.T. (1990) "Discounting statistical lives". *Journal of Risk and Uncertainty* 3, 403-13.

Hsee, C.K., Abelson, R.P. (1991) "The velocity relation: satisfaction as a function of the first derivative of outcome over time". *Journal of Personality and Social Psychology* 60, 341-7.

Hansen, B.O., Hougaard, J.L., Keiding, H., Østerdal, L.P. (2004) "On the possibility of a bridge between CBA and CEA: comments on a paper by Dolan and Edlin". *Journal of Health Economics* 23, 887-98.

Hawthorne, G., Richardson, J., Day, N., McNeil, H. (2000) "Life and death: theoretical and practical issues in using utility instruments". Centre for Health Program Evaluation, Working Paper 102.

Healey, A., Chrisholm, D. (1999) "Willingness to pay as a measure of the benefits of mental health care". *The Journal of Mental Health Policy and Economics* 2, 55-8.

Heit, J.A., Silverstein, M.D., Mohr, D.N., Petterson, T.M., O'Fallon, W.M., Melton, L.J. (2000) "Risk factors for deep vein thrombosis and pulmonary embolism: a population-based case-control study".

Herrero, C. (1996) "Capabilities and utilities". *Economic Design* 2, 69-88.

Hicks, C.M. (1990) *Research and Statistics: A Practical Introduction for Nurses.* Prentice Hall; London, New York.

Hicks, J.R., Allen, R.G.D. (1934) "A reconsideration of the theory of value". *Economica* Feb. 52-75, May 196-216.

Hicks, J.R. (1939) "The foundations of welfare economics". *Economic Journal* 49, 696-710.

Hicks, J.R. (1941) "The rehabilitation of consumer's surplus". *The Review of Economic Studies* 8, 108-16.

Hicks, J.R. (1943) "The four consumer's surpluses". *The Review of Economic Studies* 11, 31-41.

Himmelstein, D.U., Woolhandler, S. (1986) "Cost without benefit: administrative waste in U.S. health care". *New England Journal of Medicine* 314, 441-5.

HM Treasury (2003) *The Green Book: Appraisal and Evaluation in Central Government.* Treasury Guidance, London: TSO.

HMSO (1944) *A National Health Service.* Cmnd 6502. London.

HMSO (1976) *Sharing Resources for Health in England.* Report of the Resource Allocation Working Party. London.

HMSO (1992) "Mortality statistics: area". Series DH5 19.

Hogarth, R.M., Einhorn, H.J. (1992) "Order effect in belief updating: the belief-adjustment model". *Cognitive Psychology* 24, 1-55.

Horowitz, J.H., Carson, R.T. (1990) "Discounting statistical lives". *Journal of Risk and Uncertainty* 3, 403-13.

Hsee, C.K., Abelson, R.P. (1991) "The velocity relation: satisfaction as a function of the first derivative of outcome over time". *Journal of Personality and Social Psychology* 60, 341-7.

Hsee, C.K., Abelson, R.P., Salovey, P. (1991) "The relative weighting of position and velocity in satisfaction". *Psychological Science* 2, 263-6.

Ingoldby, C.J., Wujanto, R., Mitchell, J.E. (1986) "Impact of vascular surgery on community mortality from ruptured aortic aneurysms". *British Journal of Surgery* 73, 551-3.

International Road Traffic and Accident Database (IRTAD) (2002) http://www.bast.de/htdocs/fachthemen/irtad/english/we2.html.

Jansen, S.J.T., Stiggelbout, A.M., Wakker, P.P., Nooij, M.A., Noordijk, E.M., Kievit, J. (2000) "Unstable preferences: a shift in valuation or an effect of the elicitation procedure?" *Medical Decision Making* 20, 62-71.

Johannesson, M., Pliskin, J.S., Weinstein, M.C. (1993) "Are healthy-years equivalents an improvement over quality-adjusted life years?" *Medical Decision Making* 13, 281-6.

Johannesson, M. (1995a) "Quality-adjusted life years versus healthy-years equivalents – a comment". *Journal of Health Economics* 14, 9-16.

Johannesson, M. (1995b) "The ranking properties of healthy-years equivalents and quality-adjusted life-years under certainty and uncertainty". *International Journal of Technology Assessment in Health Care* 11(1), 40-8.

Johannesson, M., Johansson, P-O. (1996) "The discounting of lives saved in future generations – some empirical results". *Health Economics* 5, 329-32.

Johannesson, M., Johansson, P-O. (1997a) "Quality of life and the WTP for an increased life expectancy at an advanced age". *J Public Econ* 65, 219-28.

Johannesson, M., Johansson, P-O. (1997b) "The value of life extension and the marginal rate of time preference: a pilot study". *Appl Econ Lett* 4, 53-5.

Johannesson, M. (1999) "On aggregating QALYs: a comment on Dolan". *Journal of Health Economics* 18, 381-6.

Johansson, G., Swedenborg, J. (1986) "Ruptured abdominal aortic aneurysms: a study of incidence and mortality". *British Journal of Surgery* 73, 101-3.

Johnson, H.J. (1994) "Prospect theory in the commercial banking industry". *Journal of Financial and Strategic Decisions* 7(1), 73-90.

Johnson, K. (2005) "Readability and reading ages of school science text-books". http://www.timetabler.com/reading.html.

Jones-Lee, M.W. (1976) *The value of a life: an economic analysis.* University of Chicago Press, Chicago.

Jones-Lee, M., Loomes, G., O'Reilly D., Phillips, P. (1993). The value of preventing non-fatal road injuries: findings of a willingness-to-pay national sample survey. Transport Research Laboratory.

Jones-Lee, M.W., Loomes, G., Philips, P.R. (1995) "Valuing the prevention of non-fatal road injuries: contingent valuation vs. standard gambles". *Oxford Economic Papers* 47, 676-95.

Kahneman, D., Tversky, A. (1979) "Prospect theory: an analysis of decision under risk". *Econometrica* 47, 263-91.

Kahneman, D., Tversky, A. (1982) "The psychology of preferences". *Scientific American* 248(4), 161-9.

Kahneman, D., Snell, J. (1990) "Predicting utility". In Hogarth, R.A.M. (ed) *Insights in Decision Making.* Chicago, Illinois. Universiy of Chicago Press.

Kahneman, D., Knetch, J. (1992) "Valuing public goods: the purchase of moral satisfaction". *Journal of Environmental Economics and Management* 22, 57-70.

Kahneman, D., Fredrickson, B.L., Schreiber, C.A., Redelmeier, D.A. (1993) "When more pain is preferred to less: adding a better end". *Psychological Science* 4, 401-5.

Kakkor, V.V., Howe, C.T., Nicolaides, A.N., Renney, J.T.G., Clarke, M.B. (1970) "Deep vein thrombosis of the leg. Is there a high risk group?" *American Journal of Surgery* 120, 527-30.

Kaldor, N. (1939) "Welfare propositions and interpersonal comparisons of utility". *Economic Journal* 49, 542-9.

Kantonen, I., Lepantalo, M., Brommels, M, *et al* (1999) "Mortality in ruptured abdominal aortic aneurysms. The Finnvasc Study Group". *European Journal of Endovascular Surgery* 17, 208-12.

Kartman, B., Stalhammar, N.O., Johannesson, M. (1996) "Valuation of health changes with the contingent valuation method: a test of scope and question order effects". *Health Economics* 5, 531-41.

Keynes, J.N. (1917) *The Scope and Method of Political Economy.* 4th ed.

Kind, P., Dolan, P., Gudex, C., Williams, A. (1998) "Variations in population health status: results from a United Kingdom national questionnaire survey". *British Medical Journal* 316(7133), 736-41.

Kirby, K., Herrnstein, R.J. (1995) "Preference reversals due to myopic discounting of delayed reward" *Psychological Science* 6(2), 83-9.

Kirsch, J., McGuire, A. (2000) "Establishing health state valuations for disease specific states: an example from heart disease" *Health Economics* 9, 149-58.

Knetsch, J.L., Sinden, J.A. (1984) "Willingess to pay and compensation demanded: experimental evidence of an unexpected disparity in measures of value". *The Quarterly Journal of Economics* 99, 507-21.

Knetsch, J.L., Sinden, J.A. (1987) "The persistence of evaluation disparities". *Quarterly Journal of Economics* 102, 691-5.

Knetsch, J.L. (1990) "Environmental policy implications of disparities between willinges to pay and compensation demanded measures of value". *Journal of Envirmonmenta Economics and Management* 18, 227-37.

Krabbe, P.F.M., Bonsel, G.J. (1998) "Sequence effects, health profiles, and the QALY model". *Medical Decision Making* 18, 178-86.

Kuppermann, M., Shiboski, S., Feeny, D., Elkin, E.P., Washington, A.E. (1997) "Can preference scores for discrete states be used to derive preference scores for an entire path of events? An application to prenatal diagnosis" *Medical Decision Making* 17, 42-55.

Laughhunn, D.J., Payne, J.W., Crum, R.L. (1980) "Managerial risk preferences for below target returns". *Management Science* 26, 1238-49.

Laupacis, A., Bourne, R., Rorabeck, C. (1993) "The effect of elective total hip replacement on health-related quality of life". *Journal of Bone and Joint Surgery American* 75A, 1619-26.

Lenert, L.A., Cher, D.J., Goldstein, M.K. *et al* (1998) "The effect of search procedures on utility elicitations". *Medical Decision Making* 18, 76-83.

Levin, I.P. (1976) "Processing of deviant information in inference and descriptive tasks with simultaneous and serial presentation". *Organizational Behavior and Human Preferences* 15, 195-211.

Lewis, L.J.P., Traill, A. (1998) *Statistics Explained.* Harlow: Addison-Wesley.

Lipscomb, J. (1989) "Time preference for health in cost-effectiveness analysis". *Medical Care* 27, S233-53.

Llewellyn-Thomas, H., Sutherland, H.J., Tibshirani, R., Ciampi, A., Till, J.E., Boyd, N.F. (1984) "Describing health states: methodologic issues in obtaining values for health states". *Medical Care* 22, 543-52.

Llewellyn-Thomas, H.A., Arshinoff, R., Bell, M., Williams, J.I., Naylor, C.D. (2002) "Healthy-year equivalents in major joint replacement: can patients provide meaningful responses?" *International Journal of Technology Assessment in Health Care* 18(3), 467-84.

Lloyd, A.J., Hutton, J. (2002) "Do decision making heuristics distort efforts to elicit preferences?" DEEM Seminar Series, http://www.his.ox.ac.uk/herc/deem/York/Lloyd.pdf.

Loewenstein, G. (1987) "Anticipation and the valuation of delayed consumption". *Economic Journal* 97, 666-84.

Loewenstein, G. (1988) "Frames of mind in intertemporal choice". *Management Science* 34, 200-14.

Loewenstein, G., Thaler, R.H. (1989) "Anomolies: intertemporal choice". *Journal of Economic Perspectives* 3, 181-93.

Loewenstein, G., Prelec, D. (1991) "Negative time preference". *American Economic Review* 81, 347-52.

Loewenstein, G., Sicherman, N. (1991) "Do workers prefer increasing wage profiles?" *Journal of Labor Economics* 9, 67-84.

Loewenstein, G., Prelec, D. (1992) "Anomalies in intertemporal choice: evidence and an interpretation". *Quarterly Journal of Economics* 107, 573-97.

Loewenstein, G.F., Prelec, D. (1993) "Preferences for sequences of outcomes". *Psychological Review* 100(1), 91-108.

Loomes, G. (1988) *Disparities between health state measures: an explanation and some implications.* Department of Economics, University of York, York, United Kingdom.

Loomes, G., McKenzie, L. (1989) "The scope and limitations of QALY measures". *Social Science and Medicine* 28, 299-308.

Loomes, G., McKenzie, L. (1989) "The use of QALYs in health care decision making". *Social Science and Medicine* 28(4), 299-308.

Loomes, G. (1995) "The myth of the HYE". *Journal of Health Economics* 14, 1-7.

Lowry, R (1999-2005) *Concepts and Applications of Inferential Statistics.* Vassar College, New York. http://faculty.vassar.edu/lowry/webtext.html

Loyola University Health System (1999) "Aneurysm". http://www.luhs.org. Maywood, Illinois.

Machina, M. (1982) "'Expected utility' analysis without the independence axiom" *Econometrica* 50, 227-324.

Machina, M. (1987) "Choice under uncertainty: problems solved and unsolved" *Journal of Economic Perspectives* 1, 121-54.

MacKeigan, L.D., Larson, L.N., Draugalis, J.R., Bootman, J.L., Burns, L.R. (1993) "Time preference for health gains versus health losses". *Pharmacoeconomics* 3, 374-86.

Mackeigan, L.D., O'Brien, B.J., Oh, P.I. (1999) "Holistic versus composite preferences for lifetime treatment sequences for type 2 diabetes". *Medical Decision Making* 19, 113-21.

Marin, A., Psacharopoulos, G. (1982) "The reward for risk in the labour market: evidence from the United Kingdom and a reconciliation with other studies". *Journal of Political Economy* 90(4), 827-53.

Marshall, A., (1890) *Principles of Economics.* Macmillan, London.

Matthews, J.N.S., Altman, D.G., Campbell, M.J., Royston, P. (1990). Analysis of serial measurements in medical research. *British Medical Journal*, 300: 230-5.

McNeil, B.J., Weichselbaum, R., Pauker, S.G. (1978) "Fallacy of the five-year survival in lung cancer". *The New England Journal of Medicine* 299, 1397-1401.

McNeil, B.J., Weichselbaum, R., Pauker, S.G. (1981) "Speech and survival: tradeoffs between quality and quantity of life in laryngeal cancer". *The New England Journal of Medicine* 305, 982-7.

McNeil, B.J., Pauker, S.G., Sox, H.C., Tversky, A. (1982) "On the elicitation of preferences for alternative therapies". *New England Journal of Medicine* 306, 1259-69.

Mehrez, A., Gafni, A. (1987) "An empirical evaluation of two assessment methods for utility measurement for life years". *Socio-Economic Planning Sciences* 21, 371-5.

Mehrez, A., Gafni, A. (1989) "Quality-adjusted life years, utility theory, and healthy-years equivalents". *Medical Decision Making* 9, 142-9.

Mehrez, A., Gafni, A. (1991) "The healthy-years equivalents: how to measure them using the standard gamble approach". *Medical Decision Making* 11:140-6.

Mehrez, A., Gafni, A. (1993) "Healthy-years equivalents versus quality-adjusted life years: in pursuit of progress". *Medical Decision Making* 13, 287-92.

Menzel, P., Dolan P., Richardson, J., Olsen, J.A. (2002) "The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis". *Social Science and Medicine* 55(12), 2149-58.

Meyerowitz, B.E. (1983) "Postmastectomy coping strategies and quality of life". *Health Psychology* 2, 117-32.

Michaels, J.A., Campbell, W.B, Shackley, P., Brazier, J., Beard, J. (1999) "Assessment of the cost effectiveness of the treatment of varicose veins". Research proposal: Form RDD 1 (94).

Michaels, J.A. (2001) Personal communication. Consultant vascular surgeon, Sheffield Vascular Institute, Northern General Hospital, Sheffield, England.

Michaels, J.A., Campbell, W.B., Rigby, K.A. (2001) "A new pragmatic classification system for varicose veins". *Phlebology* 16, 29-33.

Ministry of Health (Ontario) (1994) *Ontario Guidelines for the economic evaluation of pharmaceutical products*. Toronto: Ministry of Health.

Mishan, E.J. (1971) "Evaluation of life and limb: a theoretical approach". *Journal of Political Economy* 79, 687-706.

Mitchell, R., Carson, R. (1989) *Using Surveys to Value Public Goods: the Contingent Valuation Method*. Resources for the Future, Washington DC.

Miyamoto, J.M., Eraker, S.A. (1985) "Parameter estimates for a QALY utility model". *Medical Decision Making* 5(2), 191-213.

Miyamoto, J.M., Eraker, S.A. (1988) "A multiplicative model of the utility of survival duration and health quality". *Journal of Experimental Psychology: General* 117(1), 3-20.

Mooney, G. (1994) *Key Issues in Health Economics*. Prentice Hall/Harvester Wheatshief, Hertfordshire, UK.

Mooney, G., Jan, S. (1997) "Vertical equity: Weighting outcomes? Or establishing procedures?" *Health Policy* 39, 79-88.

Mooney, G. (1998a) "Communitarian claims as an ethical basis for allocating health care resources". *Social Science and Medicine* 47, 1171-80.

Mooney, G. (1998b) "Economics, communitarianism and health care". In Barer, M., Getzen, T., Stoddart, G. (Eds.), *Health, health care and health economics: Perspectives on distribution.* (pps.297-413). Chichester: Wiley.

Morgan, D.L. (1998) *The Focus Group Kit.* London: SAGE.

MVH Group (1995) *The Measurement and Valuation of Health: Final Report on the Modelling of Valuation Tariffs.* Centre for Health Economics, University of York.

National Institute for Clinical Excellence (1999) *Appraisal of new and existing technologies: interim guidance for manufacturers and sponsors.* London.

National Institute for Clinical Excellence (2002) *Guidance on the use of irinotecan, oxaliplatin and raltitrexed for the treatment of advanced colorectal cancer.* NICE Technology Appraisal Guidance, No. 33.

National Institute for Clinical Excellence (2004) *Guideline Development Methods: Information for National Collaborating Centres and Guideline Developers.* London: National Institute for Clinical Excellence. Available from: www.nice.org.National Institute of Diabetes & Digestive & Kidney Diseases (2002) "Kidney Failure: Choosing a Treatment that's Right for You". http://www.niddk.nih.gov/health/kidney/pubs/kidney-failure/choosing-a-treatment/choosing-a-treatment.htm.

Navarro, V. (1989) "Why some countries have national health insurance, others have national health services and the USA has neither". *Social Science and Medicine* 28(9), 887-98.

Nord, E., (1992) "Methods for quality adjustment of life years". *Social Science and Medicine* 34, 559-69.

Nord, E. (1993a) "The relevance of health state after treatment in prioritising between different patients" *Journal of Medical Ethics* 19, 37-42.

Nord, E. (1993b) "The trade-off between severity of illness and treatment effect in cost-value analysis of health care" *Health Policy* 24, 227-38.

Nord, E., Richardson, J., Street, A., Kuhse, H., Singer, P. (1995) "Maximizing health benefits vs egalitarianism: an Australian survey of health issues". *Social Science and Medicine* 41(10), 1429-37.

Nord, E. (1997) "A review of synthetic health indicators: background paper prepared for the OECD Directorate for Education, Employment, Labour, and Social Affairs". National Institute of Public Health, Oslo, Norway.

Oakley, A. (1994) "Who cares for health social relations, gender and the public health". *Journal of Epidemiology and Community Health* 48, 427-34.

O'Brien BJ and Drummond MF. (1994) "Statistical versus quantitative significance in the socioeconomic evaluation of medicines". *PharmacoEconomics*, 5, 389-398.

O'Brien, B. (1996) "Economic evaluation of pharmaceuticals: Frankenstein's monster or vampire of trials?" *Medical Care* 34(12), DS99-DS108.

Oger, E., Lacut, K., Scarabin, P.Y. (2002) "Deep venous thrombosis: epidemiology, aquired risk factors". *Annales de Cardiologie et d'Angeiologie* 51(3), 124-8.

Ohinmaa, A., Sintonen, H. (1994) "The effect of duration on the value given to the Euroqol states". In Busschbach, J. (Ed), *Euroqol Conference Proceedings*, Erasmus University, Rotterdam, pp. 51-60.

Oliver, A.J. (2000) "Testing the Allais paradox in the context of health care" Health Economics Study Group, Newcastle, January 2000.

Olsen, J.A. (1993) "Time preferences for health gains: an empirical investigation". *Health Economics* 2, 257-65.

Olsen, J.A. (1994) "Persons vs. years: two ways of eliciting implicit weights". *Health Economics* 3, 39-46.

Owens, D.K., Nease, R.F. (1992) "Occupational exposure to human immunodeficiency virus and hepatitis B virus: a comparative analysis of risk". *American Journal of Medicine* 92, 503-12.

Pain, M.D., Sharpley, C.F. (1989) "Varying the order in which positive and negative information is presented: effects on counselors' judgements of clients' mental health". *Journal of Counseling Psychology* 36, 3-7.

Pareto, V. (1909) *Manuel D'Economie Politique*.

Patrick, D.L., Bush, J.W., Chen, M.M. (1973) "Methods for measuring levels of well-being for a health status index" *Health Services Research* 8, 228-45.

Patrick, D.L., Starks, H.E., Cain, K.C., Uhlmann, R.F., Pearlman, R.A. (1994) "Measuring preferences for health states worse than death". *Medical Decision Making* 14, 9-18.

Patrick, D.L. (1997) "Finding health-related quality of life outcomes sensitive to health-care organization and delivery". *Medical Care* 35 (11) Supp, NS49-NS57.

Pauly, M.V. (1968) "The economics of moral hazard". *American Economic Review* 58, 531-57.

Pauly, M.V. (1983) "More on moral hazard". *Journal of Health Economics* 2, 81-5.

Pliskin, J.S., Shepard, D.S., Weinstein, M.C. (1980) "Utility functions for life years and health status". *Operations Research* 28(1), 206-24.

Polak, B.C.P., Wessling, H., Shut, D, *et al* (1972) "Blood dyscrasias attributed to chloramphenicol: a review of 576 publsihed and unpublished cases". *Acta Med Scand* 192, 409-14.

Propper, C. (1990) "Contingent valuation of time spent on NHS waiting lists". *The Economic Journal* 100, 193-9.

Quam, L. (1989) "Post-war American health care: the many costs of market failure". *Oxford Review of Economic Policy* 5(1), 113-23.

Rabin, M. (1997) *Psychology and economics.* Working paper, Department of Economics, University of California, Berkeley: no. 97-251.

Ratcliffe, J., Buxton, M. (1999) "Patients' preferences regarding the process and outcomes of life-saving technology. An application of conjoint analysis to liver transplantation". *International Journal of Technology Assessment in Health Care* 15(2), 340-51.

Read, J.L., Quinn, R.J., Berrick, D.M. *et al* (1984) "Preferences for health outcomes: comparison of assessment methods". *Medical Decision Making* 4(3), 315-29.

Reed, W.W., Herbers, J.E., Noel, G.L. (1993) "Cholesterol lowering therapy: what patients expect in return". *Journal of General Internal Medicine* 8, 591-6.

Redelmeier, D.A., Heller, D.N. (1993) "Time preference in medical decision making and cost-effectiveness analysis". *Medical Decision Making* 13, 212-7.

Redelmeier, D.A., Kahneman, D. (1993) "On the discrepancy between experiences and memories: patients' real-time and retrospective evaluations of the pain of colonoscopy". Working paper.

Redelmeier D.A., Rozin P., Kahneman D. (1993) "Understanding patients' decisions: cognitive and emotional perspectives". *Journal of the American Medical Association* 270(1), 72-76.

Redelmeier, D.A., Shafier, E. (1995) "Medical decision making in situations that offer multiple alternatives". *JAMA* 273, 302-6.

Redelmeier D.A., Kahneman D. (1996) "Patients' memories of painful medical treatments: real-time and retrospective evaluations of two minimally invasive procedures". *Pain* 66, 3-8.

Ressler, S. (1993) *Perspectives on Electronic Publishing: standards, solutions, and more.* Englewood Cliffs, NJ: Prentice-Hall.

Reyna, V., Brainerd, C. (1991) "Fuzzy-trace theory and framing effects in choice: gist extraction, trunctation and conversion". *Journal of Behavioral Decision Making* 4, 249-62.

Reyna, V., Brainerd, C. (1995) "Fuzzy-trace theory: an interim synthesis". *Learning and Individual Differences* 7, 1-75.

Reyna, V.F. (2004) "How people make decisions that involve risk: A dual-process approach". *Current Directions in Psychological Science* 13(2), 60-6.

Rice, T.H. (1983) "The impact of changing Meicare reimbursement rates on physician-induced demand". *Medical Care* 21, 803-15.

Richardson, J. (1987) "Ownership and regulation in the health care sector". In Abelson, P. (Ed), *Privatisation: An Australian Perspective.* Sydney, Australian Professional Publications.

Richardson, J. (1994) "Cost utility analysis: what should be measured?" *Social Science and Medicine* 39(1), 7-21.

Richardson, J., Hall, J., and Salkfeld, G. (1996) "The measurement of utility in multiphase health states". *International Journal of Technology Assessment in Health Care* 12, 151-162.

Ried W (1998) "QALYs versus HYEs – what's right and what's wrong. A review of the controversy". *Journal of Health Economics* 17, 607-25.

Rigby, K. (2001) Personal communication. Research fellow, Sheffield Vascular Institute, Northern General Hospital, Sheffield, England.

Ross, W.T., Simonson, I. (1991) "Evaluations of pairs of experiences: a preference for happy endings" *Journal of Behavioral Decision Making* 4, 273-82.

Rosser, R., Kind, P. (1978) "A scale of valuations of states of illness: is there a social consensus". *International Journal of Epidemiology* 7(4), 347-58.

Rosser, R., Watts, V. (1978) "The measurement of illness". *Journal of the Operational Research Society* 29(6), 529-40.

Rowe, R.D., D'Arge, R.C., Brookshire, D.S. (1980) "An experiment in the economic value of visibility". *Journal of Envirmonmental Economics and Management* 7, 1-19.

Rowntree, D. (1991) *Statistics Without Tears: A Primer for Non-Mathematicians.* Penguin, England.

Royal Devon and Exeter Healthcare NHS Trust (1996) "Varicose Veins & Varicose Vein Operations". Barrack Road, Exeter, Devon EX2 5DW.

Rutten-van Mölken, M., Bakker, C., van Doorslaer, E., van der Linden, S.J. (1995) "Methodological issues of patient utility measurement: experience from two clinical trials". *Medical Care* 33, 922-37.

Ryan, M., Farrar, S. (2000) "Using conjoint analysis to elicit preferences for health care". *British Medical Journal* 320, 1530-3.

Sackett, D.L. Torrance, G.W. (1978) "The utility of different health states as perceived by the general public". *Journal of Chronic Diseases* 31, 697-704.

Salomon, J.A., Murray, C.J.L. (2002) "A conceptual framework for understanding adaptation, coping and adjustment in health state valuations". Chapter 11.4, *Summary Measures of Population Health: Concepts, Ethics, Measurement and Applications.* Ed. Murray, C.J.L., Salomon, J.A., Mathers, C.D., Lopez, A.D. World Health Organization, Geneva.

Schoemaker, O.J.H. (1982) "The expected utility model: its variants, purposes, evidence and limitations". *Journal of Economic Literature* 20(2), 529-63.

Sculpher, M. (1996) "Comparing QALYs and HYEs: the case of hysterectomy versus transcervical endometrial resection". Paper presented at the Health Economics Study Group, Brunel, January 1996.

Sculpher, M., Barbieri, M. (2001) "A comparison of QALYs and health-years equivalents and their relationship with individuals' preferences". Paper presented at the Health Economics Study Group, Oxford, January 2001.

Sculpher, M., Bryan, S., Fry, P., de Winter, P., Payne, H., Emberton, M. (2004) "Patients' preferences for the management of non-metastatic prostate cancer: discrete choice experiment" *British Medical Journal* 328(7436), 382.

Sen, A. (1979a) "Utilitarianism and welfarism". *The Journal of Philosophy* 76(9), 463-89.

Sen, A.K. (1979b) "Personal utilities and public judgements: or what's wrong with welfare economics". *Economic Journal* 89, 537-58.

Sen, A.K. (1980) "Equality of what?" in *The Tanner Lectures on Human Values*. Cambridge, Cambridge University Press.

Sen, A. (1985) "Rationality and uncertainty" *Theory and Decision* 18, 109-27.

Sen, A. (1987) *On Ethics and Economics.* Basil Blackwell.

Sen, A. (1993) "Capability and well-being". In Nussbaum, M., Sen, A. (Eds) *The Quality of Life*. Clarendon Press, Oxford.

Sen, A. (1997) "Maximisation and the act of choice" *Econometrica* 65, 745-79.

Shackley, P., Cairns, J. (1996) "Evaluating the benefits of antenatal screening: an alternative approach" *Health Policy* 36: 103-15.

Shiell, A., Hawe, P., Seymour, J. (1997) "Values and preferences are not necessarily the same". *Health Economics* 6, 515-8.

Shiell, A., Seymour, J., Hawe, P., Cameron, S. (2000) "Are preferences over health states complete?" *Health Economics* 9, 47-55.

Simon, S.B., Howe, L.W., Kirschenbaum, H. (1972) *Values Clarification: A Handbook of Practical Strategies for Teachers and Students.* New York: Hart Publishing.

Singh, H. (1991) "The disparity between willingness to pay and comensation demanded". *Economics Letters* 35, 263-6.

Slovic, P. (1995) "The construction of preferences", *American Psychologist* 50(5), 364-371.

Smith, A. (1776) *An Inquiry into the Nature and Causes of the Wealth of Nations.* London, Strachan & Cadell. 1986, Harmondsworth, Penguin Classics.

Spencer, A. (2000) "Testing the additive independence assumption in the QALY model". Working Paper No. 427, Department of Economics, Queen Mary College, University of London, ISSN 1473-0278.

Spencer, A. (2003) "A test of the QALY model when health varies over time". *Social Science and Medicine* 57, 1697-1706.

Stalmeier, P.F.M., Bezembinder, T.G.G., Unic, I.J. (1996) "Proportional heuristics in time tradeoff and conjoint measurement" *Medical Decision Making* 16, 36-44.

Stalmeier, P.F.M., Bezembinder, T.G.G. (1999) "The discrepancy between risky and riskless utilities: a matter of framing?" *Medical Decision Making* 19, 435-47.

Stalmeier, P.F., Chapman, G.B., de Boer, A.G., van Lanschot, J.J. (2001) "A fallacy of the multiplicative QALY model for low-quality weights in students and patients judging hypothetical health states". *International Journal of Technology Assessment in Health Care* 17(4), 499-96.

Stalmeier, P.F. (2002) "Discrepancies between chained and classic utilities induced by anchoring with occasional adjustments". *Medical Decicion Making* 22(1), 53-64.

Stewart, R.H. (1965) "Effect of continuous responding on the order effect in personality impression formation". *Journal of Personality and Social Psychology* 1, 161-5.

Stevens, S.S. (1966) "A metric for social consensus". *Science* 151, 530-41.

Stiggelbout, A.M., Kiebert, G.M., Kievit, J., Leer, J.W.H., Stoter, G., de Haes, J.C.J.M. (1994) "Utility assessment in cancer patients: adjustment of time tradeoff scores for the utility of life years and comparison with standard gamble scores". *Medical Decision Making* 14, 82-90.

Streiner, D.L., Norman, G.R. (1989) *Health Measurement Scales: A Practical Guide to their Development and Use.* Oxford University Press.

Sugden, R. (1993) "Welfare, resources, and capabilities: A review of inequality re-examined by Amartya Sen". *Journal of Economic Literature* 31(4), 1947-62.

Sutherland, H.J., Llewellyn-Thomas, H., Boyd, N.F., Till, J.E. (1982) "Attitudes toward quality of survival – the concept of maximal endurable time". *Medical Decision Making* 2(3), 299-309.

Thaler, R.H. (1991) "Some empirical evidence on dynamic inconsistency". *Economic Letters* 8, 201-7.

Thomas, P.R., Stewart, R.D. (1988) "Abdominal aortic aneurysm". *British Journal of Surgery*, 75, 733-6.

Thomas, S.M., (1999) "Treatment of abdominal aortic aneurysms in unfit patients: an economic evaluation of endovascular repair using modelling techniques". Dissertation. MSc in Health Services Research and Technology Assessment, University of Sheffield.

Thomas, S.M. (2000). Senior Lecturer and Consultant Radiologist, Sheffield Vascular Institute, Northern General Hospital, Sheffield, UK. Personal communication.

Tibbs, D.J. (1992) *Varicose Veins and Related Disorders.* Butterworth-Heinemann Ltd. Oxford.

Torrance, G.W. (1971) "A generalized cost-effectiveness model for the evaluation of health programs". Doctoral dissertation, State University of New York at Buffalo, Buffalo, USA.

Torrance, G.W., Thomas, W., Sackett, D. (1972) "A utility maximization model for evaluation of health care programmes". *Health Services Research* 7(2), 118-33.

Torrance, G.W. (1976a) "Social preferences for health states: an empirical evaluation of three measurement techniques". *Socio-economic Planning Sciences* 10, 129-36.

Torrance, G.W. (1976b) "Health status index models: A unified mathematical view". *Management Science* 22(9), 990-1001.

Torrance, G.W. (1986) "Measurement of health state utilities for economic appraisal: a review". *Journal of Health Economics* 5, 1-30.

Treadwellm J.R. (1998) "Tests of preferential independence in the QALY model". *Medical Decision Making* 18, 418-28.

Treadwell, J.R., Lenert, L.A. (1999) "Health values and prospect theory" *Medical Decision Making* 19, 344-52.

Tsevat, J., Cook, E.F., Green, M.L. *et al* (1995) "Health values of the seiously ill" *Annals of Internal Medicine* 122, 514-20.

Tsuchiya, A. (2001) Sheffield Health Economics Group, University of Sheffield, Sheffield, England. Personal communication.

Tubbs, R.M., Gaeth, G.J., Levin, I.P., van Osdol, L.A. (1993) "Order effects in belief updaiting with consistent and inconsistent evidence". *Journal of Behavioral Decision Making* 6, 256-69.

Tversky, A., Kahneman, D. (1981) "The framing of decisions and the psychology of choice". *Science* 211, 453-8.

Tversky, A., Kahneman, D. (1986) "Rational choice and the framing of decisions". *J Bus* 58, S258-78.

Tversky, A., Kahneman, D. (1992) "Advances in prospect theory: cumulative representation of uncertainty" *Journal of Risk and Uncertainty* 5, 297-323.

Ubel, P.A. (1999) "How stable are people's preferences for giving priority to severely ill patients?" *Social Science and Medicine* 49, 895-903.

Varey, C., Kahneman, D. (1992) "Experiences extended across time: evaluation of moments and episodes". *Journal of Behavioural Decision Making* 5, 169-85.

Verhoef, L.C.G., de Haan, A.F.J., van Daal, W.A.J. (1994) "Risk attitude in gambles with years of life: empirical support for prospect theory". *Medical Decision Making* 14, 194-200.

Viner, J. (1925) "Utility concept in value theory and its critics". *Utility Theory: A Book of Readings*. Ed. Page, J. Wiley, New York.

Viney, R., Savage, E. (2003) "Modelling preferences for health care". Paper presented to the Labour Econometrics Worshop, Melbourne, August 2003. Centre for Health Economics Research and Evaluation.

Viney, R., Savage, E., Louviere, J. (2005) "Empirical investigation of experimental design properties of discrete choice experiments in health care". *Health Economics* 14(4), 349-62.

Viscusi, W.K., Magat, W.A., Huber, J. (1987) "An investigation of the rationality of consumer valuations of multiple health risks". *RAND J. Economics* 18, 465-79.

Viscusi, K.P. (1992) *Fatal trade-offs.* Oxford University Press, Oxford.

von Neumann, J., Morgenstern, O. (1944) *Theory of Games and Economic Behaviour.* Princeton University Press, Princeton, New Jersey.

Wakker, P. (1996) "A criticism of healthy years equivalents". *Medical Decision Making* 16, 207-14.

Walker, S.R., Yusuf, S.W., Wenham, P.W., Hopkinson, B.R. (1998). "Renal complications following endovascular repair of abdominal aortic aneurysms". *Journal of Endovascular Surgery* 5(4), 318-22.

Walters, S. (1999), Statistician, School of Health and Related Research, University of Sheffield, Sheffield. Personal communication.

Ware, J.E. Sherbourne, C.D. (1992). The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. *Medical Care*: 30: 473-83.

Weinstein, M., Stason, W. (1977) "Foundations of cost-effectiveness analysis for health and medical practices". *New England Journal of Medicine* 296(13), 716-21.

Weiss, R.A. (1999) "Venous symptoms are improved by venous treatment". *British Medical Journal* - Electronic responses to Bradbury *et al.*

Wells, N.E.J., Hahn, B.A., Whorwell, P.J. (1997) "Clinical economics review: irritable bowel syndrome". *Alimentary Pharmacology and Therapeutics* 11, 1019-30.

Williams, A. (1988) "Priority setting in public and private health care – A guide through the ideological jungle". *Journal of Health Economics* 7, 173-83.

Wilmink, A.B., Quick, C.R. (1998) "Epidemiology and potential for prevention of abdominal aortic aneurysm". *British Journal of Surgery* 85, 155-62.

Wolfson, A.D., Sinclair, A.J., Bombardier, C. *et al* (1982) "Preference measurements for functional status in stroke patients: inter-rater and intertechnique comparisons". In Kane, R.L., Kane, R.A., editors: *Values and Long Term Care.* Lexington (MA): Lexicon Books.

Woolhandler, S., Himmelstein, D.U. (1991) "The deteriorating administrative efficiency in the USA health care system". *New England Journal of Medicine* 324, 1253-8.

Wyatt, J.P. (1999) "Bleeding from varicose veins". *British Medical Journal* - Electronic responses to Bradbury *et al.*

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Comparing health processes

You are going to be asked to make a comparison between two processes of health care.

In the following exercise we would like you to imagine experiencing the health processes described. Then indicate on the scale how good or bad the processes are in your opinion.

Question 5

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

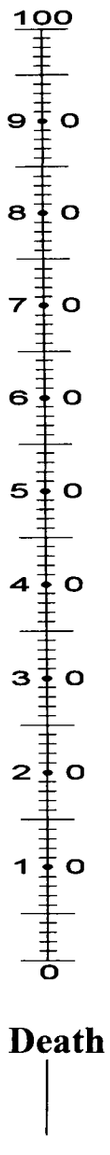
To help people say how good or bad the above process are, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100 and death is marked by 0.

We would like you to indicate on this scale how good or bad the above processes are in your opinion. Please do this by drawing a line from the boxes beside the scale to whichever point on the scale indicates how good or bad the process is.

If you consider one or both of the above processes to be worse than death, please draw the line to the "worse than death" point at the bottom of the scale.

Surgery

Full health



Death

Worse than death

Sclerotherapy

Valuing health profiles

In the following exercises, the left-hand boxes show the process and outcomes of having treatment (Choice A).

The box on the right-hand side describes full health (Choice B).

We would like you to consider how many years in Choice B would be equivalent to the events described in the Choice A.

Practice question

Choice A

Severe varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 6

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

↓

Mild varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 7

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 8

Choice A

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Mild varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 9

Choice A

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Moderate varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 10

Choice A

Severe varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. You will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Mild varicose veins for 19 years and 6 months

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Please Note That The Next Question Contains Some Risk In Choice A

Question 11

Choice A

Moderate varicose veins for 6 months

↓

Sclerotherapy

You will go to clinic and receive injections into your varicose veins. Each injected area will be covered with a pad, and a tight stocking will be put on your leg and left on for **48 hours**. During these **48 hours**, you are advised:

- to walk around regularly
- to do most of your usual activities, including light sports
- to avoid standing still or sitting with your affected foot on the floor for more than half an hour
- to avoid particularly strenuous activities which may result in the stocking or pads moving out of place
- to avoid having a bath or a shower and other activities which would get the stocking wet
- to take leave of absence from your job

Your legs may feel inflamed, swollen and painful for a week after the injections.

↓

Mild varicose veins for 19 years and 6 months.

But you have a 75% chance of your veins returning to the moderate state in the next 19 years and 6 months.

Choice B

Full health

Please put an "A" against all cases where you are CONFIDENT that you would choose Choice A.
Please put a "B" against all cases where you are CONFIDENT that you would choose Choice B.
Please put an "=" against all cases where you cannot choose between Choice A and Choice B.

Choice A		**Choice B**
20 years		0 years
20 years		2 years
20 years		4 years
20 years		6 years
20 years		8 years
20 years		10 years
20 years		12 years
20 years		14 years
20 years		16 years
20 years		18 years
20 years		20 years

Question 12

Choice A

Moderate varicose veins for 6 months

↓

Surgery

You will go into hospital for surgery. It will be done under general anaesthetic. **You have a 1 in 10,000 chance of dying under the anaesthetic. (This is similar to the risk of having a fatal road accident in a year.)** If successful, you will go home the same day. You are advised over the next **10 to 14 days**:

- to avoid standing still or sitting with your affected foot on the floor for more than half an hour, to avoid having a bath or a shower, to avoid particularly strenuous activities, and to avoid driving
- to take short walks at frequent intervals, to participate in most of your usual activities, and to wear support stockings

You may feel tired for the next week, and you may need plenty of rest for the next few days.

Your legs may have large bruises initially, and the scars may remain noticeable for a few months. Your legs may feel painful for 2 weeks after surgery.

You are advised to take leave of absence from your job for **3 to 6 weeks**

↓

Mild varicose veins for 19 years and 6 months.

But you have a 20% chance of your veins returning to the moderate state in the next 19 years and 6 months.

Choice B

Full health