Appendix 1 Description of the VAS (rating scale)

The text and figures below are an edited extract from the online questionnaire. The visual aid and question for only one of the two illnesses is reproduced. The second visual aid and question differed only with respect to the health state descriptors.

Introduction to the Rating Scale

Now we would like you to evaluate the health states that have been used (in the survey) on a rating scale such as the one shown in Box A.1. This is a way of measuring how strongly people feel about different things.

On this scale, 0 represents Death and 100 represents Full Health.

There are no right or wrong numbers for a health state. Rather the distance between points on the scale shows how strongly you would feel about these health states.

For example if you gave three health states, A, B and C a score of 50, 60 and 70 it would mean that you felt the improvement from A to B was about as much – or as important for you – as a move from B to C.

Similarly a move from death to A (score 50) would be about as important for you as a move from A to full health.
Box A.1 Evaluating Mobility and Self Care

Question:
On our scale ‘Full Health’ does not mean perfect health but ‘no problems with walking, self care or usual activities: it is good, not perfect health’.
Please indicate using the scale how good or bad these health states are, in your opinion. On this scale 0 represents death and 100 represents full health.
Write your answers in the highlighted boxes beside each health state.

| Health state 1 | I have slight problems with • Walking and self-care |
|----------------|--------------------------------------------------|
| Health state 2 | I have moderate problems with • Walking and self-care |
| Health state 3 | I have severe problems with • Walking and self-care |
| Health state 4 | I am unable to • Walk about or self-care |

| Full Health |
|-------------|
| 100         |
| 90          |
| 80          |
| 70          |
| 60          |
| 50          |
| 40          |
| 30          |
| 20          |
| 10          |
| 0           |

Death
Appendix 2 Transforming VAS values to TTO utilities

The transformation from VAS values to TTO utility used a relationship derived during the construction of the AQoL-8D utility algorithm [1]. A total of 162 health states describing the 8 dimensions of the AQoL-8D were evaluated during an interview using both a VAS and a TTO. The sample of 670 individuals interviewed included 323 patients undergoing treatment and 347 demographically representative members of the Australian public. On average each was asked to rate 5.5 health states giving a total 3,714 observations or an average of 23 observations per health state. The 162 average results were used to estimate a number of regression models. The most successful of these was equation A 2.1 below.

\[ U = 1 - (1 - V)^{1.62} \]  …equation A 2.1

By comparison, in the construction of the HUI 2 Torrance et al. [2] used 4 points derived from average data to fit the transformation function A 2.2.

\[ U = 1 - (1 - V)^{2.29} \]  …equation A 2.2

where U was estimated using a standard gamble and V employed a VAS.

For the construction of HUI 3 Feeny et al. [3] employed three marker states between full health and death. Two functions were estimated; one for those where the worst health state was worse than death and one for when it was better than death. His selected transformation for the larger, latter group is given by A 2.3.

\[ U = VAS^{0.559} \]  …equation A 2.3

where U was measured as a standard gamble and VAS on a ‘feeling thermometer’.
The difference in predicted utilities from these functions is illustrated below. They imply
similar results but with a greater concentration of utilities using the Torrance formula at the
top of the scale and a greater inflation of utilities using the Feeny formula at the bottom of the
scale. Differences may be explained, to an unknown extent, by the different survey
methodologies employed and by the use of a standard gamble rather than the time trade-off as
in the estimation of utilities for the AQoL-8D.

Table A2.1 Comparisons of 3 VAS-Utility transformations

| VAS | Utility |
|-----|---------|
| 0.0 | Torrance$^{(2)}$ | 0.0 | 0.21 | 0.40 | 0.69 | 0.88 | 0.97 | 0.99 | 1.0 |
| 0.1 | Feeny$^{(3)}$ | 0.0 | 0.28 | 0.41 | 0.60 | 0.75 | 0.88 | 0.94 | 1.0 |
| 0.2 | Richardson$^{(1)}$ | 0.0 | 0.16 | 0.30 | 0.56 | 0.77 | 0.93 | 0.98 | 1.0 |

1. Richardson J, Sinha K, Iezzi A, Khan MA. Modelling utility weights for the Assessment of Quality of Life (AQoL) 8D. Quality of Life Research. 2014;23(8):2395-404. 10.1007/s11136-014-0686-8.
2. Torrance G, Feeny D, Furlong W, Barr R, Zhang Y, Wang Q. Multiattribute utility function for a comprehensive health status classification system: Health Utilities Index Mark II. Medical Care. 1996;34(7):702-22.
3. Feeny D, Furlong W, Torrance G, Goldsmith C, Zhu Z, DePauw S, et al. Multi attribute and single attribute utility functions for the Health Utilities Index Mark 3 System. Medical Care. 2002;40(2):113-28.
Appendix 3 An illustrative decision algorithm

Equation A3.1 is an alternative formulation of equation 2 in which the threshold, $T$, remains unchanged but severity, patient numbers and the level of sharing create a variable QALY weight, $w^* = w^{-1}$.

\[
\frac{\text{Cost}}{w^* \text{QALY}} \leq T \quad \text{… equation A3.1}
\]

\[
w^* = \text{Sev}^\alpha N^{-\beta} \text{Share}^\gamma \quad \text{… equation A3.2}
\]

where $\text{Sev}=$ severity=1-utility of the initial health state; $N$ is the percentage of the population with the health problem and ‘Share’ is the proportion of the population which shares the cost. Table A3.1 illustrates a hypothetical set of weights which would result from equation A3.2 with the illustrative parameters $\alpha=0.5$, $\beta=0.434$, Share =1.

Numbers derived from equation A3.2 give importance weights relative to the importance of a life saving service ($\text{Sev}=1$) which affects 1 percent of patients with costs shared across the entire population ($N=1$; Share=1). The entry for Table A3.1 for these values is shaded. As the severity of the initial health state, in row 1, decreases from 1.0 (imminent death) to 0.2 (an initial health state utility of 0.8), the severity weight for services affecting 10 percent of the population decreases from 0.37 to 0.17, moving up column 1, as the number of patients decreases from 10 to 0.001 percent of the patient population, the sharing weight increases by a factor of $20/0.37=54$. The multiplicative algorithm – $(\text{Sev}^{0.5})(N^{-0.435})(1.0)$ – implies a weighting which is $20/0.17=118$ times greater for services which affect only 1 in 100,000 patients who are facing imminent death than for services which affect 10 percent of patients who are in relatively good health.

If ‘share’, the proportion of the population sharing the cost fell below 1.0 then for $\gamma>0$ $w^*$ would fall. For $\gamma=1$ $w^*$ would fall directly with ‘share’; for $0<\gamma<1.0$ $w^*$ would fall
proportionately less implying a greater burden for persons bearing the costs. For $\gamma > 1.0$, $w^*$ would fall disproportionately reducing the burden on those meeting the cost.

Table A3.1 Hypothetical weights $w^*$ incorporating severity and sharing$^{(1)}$

| Percent of population | Initial Severity | 1.0 | 0.8 | 0.6 | 0.4 | 0.2 |
|-----------------------|------------------|-----|-----|-----|-----|-----|
| Sev $^0.5$            | 1.0              | 0.89| 0.72| 0.63| 0.45|
| N                     | $N^{-0.434}$     | $(Sev^{-0.5})(N^{-0.434})(Share)Y$ |
| 0.001                 | 20               | 20  | 17.8| 15.4| 12.6| 8   |
| 0.01                  | 7.3              | 7.3 | 6.5 | 5.6 | 4.6 | 2.9 |
| 1.0                   | 1                | 1   | 0.89| 0.72| 0.63| 0.45|
| 10                    | 0.37             | 0.37| 0.33| 0.27| 0.23| 0.17|

(1) $w^* = 1/w$, where $w$ = the threshold weight in equation 2
Appendix 4 The effect of editing

Two edit criteria were used. The first was that health states were ranked in the correct order as dictated by the construction of the EQ-5D-5L. The second was that the numerical values assigned to these health states were also in the correct order.

Table A.4.1 reports the demographic characteristics of those who failed one of the edit criteria. The failure rate is greatest at the age group 25-34 but this did not result in significant under-representation of this cohort.

From Table A.4.2 and the corresponding Figure A.4.1 the responses of those deleted followed the same pattern as the edited responses. Patients A were always allocated resources and the share declined with the price of A. However the decrement as price rose which is consistent with less discrimination by respondents and less well considered answers.

Table A4.1 Participants deleted from the final analysis n=138

|         | 18-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65+ |
|---------|-------|-------|-------|-------|-------|-----|
| Male    | 4.3%  | 10.1% | 8.0%  | 10.1% | 9.4%  | 9.4%|
| Female  | 2.2%  | 13.8% | 8.7%  | 7.2%  | 9.4%  | 7.2%|
Table A4.2 Comparison of edited, deleted and all data. Percent of full cost allocated to patient A

| Number of patients | Budget | Sort 2 survey | n | % of full cost given to A | Max - Min |
|--------------------|--------|---------------|---|--------------------------|----------|
|                    |        |               |   | Price A                  |          |
|                    |        |               |   | 2000 | 5000 | 10000 | 15000 | 20000 |          |
| 100                | 100    | Edited        | 211 | 82.6 | 68.2 | 51    | 41.1  | 34.5  | 48.1  |
|                    |        | Deleted       | 138 | 69   | 60.7 | 51.1  | 45    | 40.7  | 28.3  |
|                    |        | All           | 349 | 77.2 | 65.3 | 51    | 42.6  | 37    | 40.2  |
| 300                | 250    | Edited        | 211 | 74.5 | 63.9 | 56.6  | 49.3  | 45.2  | 29.3  |
|                    |        | Deleted       | 138 | 65.4 | 61.3 | 55.8  | 53.8  | 50.6  | 14.8  |
|                    |        | All           | 349 | 70.9 | 62.9 | 56.3  | 51.1  | 47.3  | 23.6  |
| 600                | 500    | Edited        | 211 | 79.1 | 71   | 63.8  | 59.1  | 50.7  | 28.4  |
|                    |        | Deleted       | 138 | 66.8 | 65.5 | 60.1  | 56.7  | 55.5  | 11.3  |
|                    |        | All           | 349 | 74.2 | 68.8 | 62.3  | 58.1  | 52.6  | 21.6  |
Figure A4.1 Percent coverage of cost of A

100 Patients B

300 Patients B
### Appendix 5

**Table A5.1 Agreement with the question ‘Please indicate on the scale how you feel about each of the following statements’ (n=432)**

| Statement                                                                 | Percentages | Total |
|--------------------------------------------------------------------------|-------------|-------|
|                                                                         | Strong agree (1) | Strongly disagree (5) |   |
| It is OK to reduce services to the majority by a little to cover the cost of very expensive services needed by the few people with rare illnesses | 16.0 | 46.5 | 18.5 | 15.5 | 3.5 | 100 |
| It is OK to provide the few patients requiring very expensive services with only basic low cost care even if they are left in poor health because Medicare has a limited budget and can’t pay for everything | 2.1 | 21.5 | 27.8 | 31.7 | 16.9 | 100 |
| The Medicare levy should be increased to cover very high cost care needed by a small number of patients | 11.3 | 35.2 | 28.0 | 18.5 | 6.9 | 100 |
| The severity of illness, rather than the cost of treatment, should determine priority. If services for severe illnesses are very costly the cost should be shared across the whole community | 23.6 | 41.0 | 22.2 | 10.0 | 3.2 | 100 |
| Illnesses which are very expensive to treat should not be covered by Medicare | 3.2 | 6.3 | 13.9 | 39.6 | 37.0 | 100 |

(1) Mean, se calculated by assigning a value equal to the rank order
Table A5.2 Importance: How important were the following when you allocated the budget (n=431)

| Statement                                                                 | Percentages | Very important (5) | Not at all important (1) | Total | Mean | Std dev |
|---------------------------------------------------------------------------|-------------|--------------------|--------------------------|-------|------|---------|
| 4. The health of patients in Group A                                      |             | (5)                | (4)                      | (3)   | (2)  | (1)     |
|                                                                           |             | 24.3               | 28.9                     | 36.3  | 8.1  | 2.3     | 100    | 3.65 | 1.01    |
| 5. The total amount of health (the area shaded blue).                     |             | 43.3               | 35.2                     | 17.6  | 3.0  | 0.9     | 100    | 4.17 | 0.89    |
| 6. Fairness in the distribution of health                                 |             | 46.8               | 30.6                     | 17.6  | 4.6  | 0.5     | 100    | 4.19 | 0.92    |
| Fairness in the distribution of health                                   |             | 26.4               | 37.0                     | 29.2  | 5.1  | 2.3     | 100    | 3.80 | 0.96    |
| Fairness in the distribution of health                                   |             | 28.2               | 31.7                     | 26.6  | 9.0  | 4.4     | 100    | 3.70 | 1.10    |
| 9. Avoiding terrible health states.                                      |             | 50.0               | 26.4                     | 18.1  | 3.9  | 1.6     | 100    | 4.19 | 0.97    |
Appendix 6 Introductory Tasks

In order to focus upon the relevant health states and the tasks to be performed there was a 5 stage introduction.

1. Four health states (subsequently to be used) were described. Participants were required to rank these from best to worst.

2. The visual analogue scale (VAS) was described. Participants were asked to assess their own health state using the scale.

3. Participants were asked to rank the four health states described in (1) above.

4. The main visual aid (Box 1) was introduced and the avatar gave an example of the reasoning which might be employed. This included the following:

   Moving the handle all the way to the left creates the minimum total amount of health as shown by the tiny blue area… you’d probably think that’s a bad idea and may not agree with the distribution. So if you slide the handle all the way to the right you’ve created the maximum amount of health by giving everything to B… or do you want to share a smaller total amount of health between A and B… for instance you could allocate half ($50,000) to each group so no one dies but both groups of patients would be left with severe problems… so this illustrates the problem we’re asking you: do you maximise total health…or do you reduce total health and share it with A.

5. The participant was asked to allocate $500 between the two patients.

Data from (1) and (3) were used for editing. None of the data was used for the final results.