



**The Assessment of Quality of Life
(AQoL) II Instrument**

**Derivation of the Scaling Weights Using a
Multiplicative Model and Econometric
Second Stage Correction**

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Economic evaluation of health and health care related activities must quantify the *importance* of the quality of life of the outcome. This is done through the use of the Quality Adjusted Life Year (QALY) as a unit of outcome. As QALYs are defined as the product of life years and an index of the quality of life, this latter quantity requires measurement. This task is carried out by measuring the *strength of preference* for a health state relative to full health and death.

A number of utility instruments presently exist but the utility scores produced by them differ very significantly (Hawthorne et al 2001). The AQoL project was a response to the implied challenge. It was undertaken in an attempt to improve the methodology of MAU instrument construction and, hopefully to produce utility scores which had greater reliability and validity.

Innovations include the following:

(i) The descriptive system.

- use of the correct psychometric procedures for instrument construction;
- a description based upon ‘handicap’—problems in a social context—as distinct from a ‘within the skin’ descriptive system;
- a multi level descriptive system which permitted redundancy—double counting—within dimensions in order to achieve instrument sensitivity but structural independence between the dimensions;
- an increase in the sensitivity of the descriptive system in the region of full health and specifically a system which permits the evaluation of health promotional activities.

(ii) Tariffs (Scaling/Calibration)

- The creation of at least two scaling systems based upon the time trade-off (as with AQoL 1) and the person trade-off (PTO) scaling methodologies. The appropriate choice of scaling instrument has not been determined in the literature;
- A reworking of the utility scores employing techniques to eliminate one possible source of bias in previous methodologies (including AQoL 1), viz a ‘focusing effect’;
- The testing and use of ‘deliberative weights’ which permit and encourage the contemplation of the health states over a significant period time;
- The use of a more flexible two stage modelling methodology to combine disaggregated dimension scores into an overall utility score for a multi attribute health state.

Results from the AQoL 2 project are published in four reports. These are:

- (i) Conceptualising the Assessment of Quality of Life Instrument Mark 2 (AQoL 2), Methodological Innovations and the Development of the AQoL Descriptive System;
- (ii) The Assessment of Quality of Life (AQoL) II Instrument: Derivation of the scaling weights using a multiplicative model and econometric second stage correction;
- (iii) The Assessment of Quality of Life (AQoL) II Instrument: The effective deliberation and alternative utility weights in a multi attribute utility instrument;
- (iv) Overview of the Assessment of Quality of Life Mark 2 Project.

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The Assessment of Quality of Life (AQoL) II Instrument. Derivation of the Scaling Weights Using a Multiplicative Model and Econometric Second Stage Correction

1 Introduction

1.1 Genesis of AQoL 2

The Assessment of Quality of Life (AQoL) Project was undertaken for two reasons. First, there is a need for a valid and reliable instrument for the measurement of the quality of life in the context of an economic evaluation of health promotional activities as well as curative therapies. This implies the need for an instrument which is sensitive to changes in the quality of life in the vicinity of normal and better than normal health. The case for using a multi attribute utility (MAU) instrument rather than a series of holistic utility studies is largely pragmatic. Holistic studies (which evaluate single disease specific health states) are costly and the number of health states requiring assessment is exceedingly large. In principle, an MAU instrument, once created, may be used to cheaply and quickly evaluate the utility of different health states. An additional and related advantage is that an MAU instrument may be ‘validated’—tested against other instruments or subjected to alternative forms of evaluation. In contrast, holistic health states are usually used only in the study for which they were created. This does not permit independent validation of the description or the utility weights¹.

The second reason for the AQoL 2 is that there does not, at present, appear to be an instrument which is demonstrably better than alternative instruments. In particular, in the author’s five instrument study it was found that different instruments produce very different scores (Hawthorne et al, 2000). There has been almost no attempt to demonstrate the existence of a ‘strong interval property’; viz, the validity of the quality of life—length of life trade-off implied by the utility scores produced by the various instruments (Richardson 1994). Existing instruments have quite different coverage of the various dimensions of health, that is, the level and detail of the description of health states is highly variable. Likewise, the methods used to measure utilities and the models used to combine item scores into the multi attribute health state utility differ significantly between the existing instruments. Unsurprisingly, utility scores from different instruments obtained from the same individuals have varied enormously. In the authors’ 900-person comparison of five instruments (EQ5D, SF36, 15D, HUI3 and AQoL1) the correlation between instruments varied from 0.82 (AQoL, 15D) to 0.65 and 0.66 (HUI3 and EQ5D; HUI3 and SF36) (Hawthorne et al 2000). This applies that in the latter two cases only 42 and 43 percent respectively of the variation in one instrument would be explained by variation in the second.

¹ It is sometimes argued that greater validity is achieved if the same instrument is used to assess both the before and after health states. However this advantage may or may not occur. There is little advantage in using an invalid instrument both before and after an intervention. Further, it is possible that an instrument may satisfactorily measure HRQoL before an intervention but that the intervention improves a dimension of health whether the instrument is insensitive. Use of a single instrument both before and after the intervention does not overcome this problem.

The construction of AQoL1 was motivated by the need to overcome these problems². By March 2003 the instrument had been used in 53 projects in 4 countries. It has performed well in conventional tests of validity.³ Nevertheless, the authors have had two concerns with the instrument. First, like other MAU instruments, the descriptive system lacks sensitivity in the good—excellent range of the scale. This limits the instrument’s usefulness in the context of health promotion⁴. Secondly, despite a construction methodology explicitly designed to minimise the effect of redundancy⁵ (a problem particularly effecting multiplicative methods) the AQoL generally produces the lower utility scores than the EQ5D, SF36 (Brazier 1 weights) and the 15D. Only the HUI3—the other multiplicative instrument—produces comparable scores. But in both cases the utilities assigned to very poor health states are unexpectedly low which suggests that the ‘strong interval property’ has not been achieved. If confirmed, this would imply that quality of life comparisons using these instruments would be valid (that is, achieve what they ought to achieve) but that the trade-off between quality and quantity of life would exaggerate the importance of quality⁶.

Other strengths and weaknesses of the AQoL 1 are summarised in Richardson et al in 2003.

1.2 Constructing the AQoL 2 Descriptive System

Construction of the AQoL 2 descriptive system was described in an earlier report (Richardson et al 2003). The major tasks this involved are listed in Box 1.

The construction process differed from the approach taken in other instruments in order to overcome apparent weaknesses in previous methodologies. Eight such differences are notable. First, the descriptive system was based, as far as possible, upon the concept of handicap; that is upon the effect of illness upon individuals functioning in a social environment. This contrasts with the more common ‘within the skin’ approach which attempts to describe health related quality of life with reference to disability or impairment of the person’s physical and psychological functioning. The AQoL descriptive system is therefore based upon the hypothesis that quality of life is most efficiently described by reference to handicap—that wellbeing is dependent upon social context as well as intrinsic health status. Secondly the AQoL system was, to our knowledge, the first—and to date only—descriptive system based upon the correct psychometric procedures for instrument construction. These are described in Box 1.

Third the AQoL has pioneered the use of multi level modelling. Health states consist of broad dimensions (social relationships, independent living, etc) which are combined using a multiplicative model. Each of these dimensions is, in turn, constructed from individual items and a dimension specific multiplicative model.

² Construction of the AQoL1 is described in Hawthorne et al 1995, 1996, 1997, 2001

³ These consist of the comparison of AQoL results with results from other MAU or disease specific instruments

⁴ The five instrument comparison reported in Hawthorne et al 2000 AQoL proved to be more sensitive in this health domain than the other instruments included in the study.

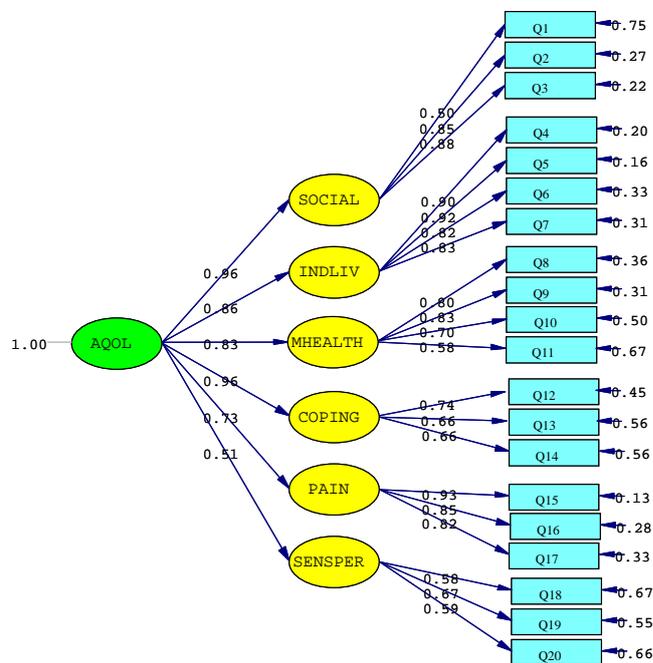
⁵ This occurs when a particular element of a health state affects more than one item response and, consequently, results in the ‘double counting’ of the importance of this element.

⁶ For example, consider an intervention which restored an individual to full health from a health state with a true utility score of 0.9, but a measured utility of 0.8. The true utility score implies an increase in utility of 0.1 when individuals are cured and that 10 individuals obtaining this increment would be equivalent to saving 1 life ($10 \times 0.1 = 1.00$). In contrast, measured utility would wrongly imply that a return to full health increased utility by $1.0 - 0.8 = 0.2$ and that only 5 individual would need this improvement to be equivalent to saving a life: that is the relative value of the improved quality would be inflated by 100%.

importance. Likewise suicidal depression cannot reduce a person to near suicide through the depression dimension alone.⁷ The properties of the multiplicative model are discussed below.

Despite the advantages of the multiplicative model, there is no logical or empirical reason for believing that the structure of health states is a simple multiplicative function of the decomposed elements; that is, the multiplicative model may be a first approximation only to the true structure which is more flexible than suggested by the multiplicative model. The fifth innovation in the AQoL 2 protocol is the use of a two stage scaling procedure. A multiplicative model is used in the first stage to obtain the first approximation. This is then employed in a second stage to explain the TTO values obtained from survey responses to a number of multi attribute health states. Other independent variables are employed to increase the explanatory power. In the present study these include dimension dummies, dimension scores, age and sex of the respondent. In principle there is no reason why this list could not be increased if this improved predictive power.

Figure 1 Structure of AQoL 2



Chi-Square = 460.73, df = 164, P-value = 0.00000, RMSEA = 0.054, CFI = 0.99, CFI = 0.99

There is no consensus in the literature concerning the choice of a scaling instrument. Some have argued that the standard gamble should represent a gold standard (Torrance 1986). Others have rejected this argument and proposed the time trade-off (Richardson 1994). More recently the person trade-off has been advocated (Nord 1999). Recognising that different instruments may capture different values Nord et al (1999) have suggested the use of a combination of the time trade-off (TTO) to capture patient preferences and the person trade-off (PTO) to capture social values.

⁷ It is possible that the person with suicidal depression will have sufficiently low scores for other items that the overall utility is close to zero-death. But this result would be coincidental and not a result of instrument construction and would suggest the likelihood of redundancy if the implied correlation between items was unwanted in other health states.

The sixth innovation in the scaling protocol explicitly recognises the unresolved nature of this debate and, for the first time, employed three separate scaling instruments. The present paper only discussed the TTO based valuations.

Two final innovations in the construction of AQoL 2 were the use of ‘deliberative weights’ and a visual aid designed to minimise error arising from a ‘focussing effect’—the tendency for survey respondents to focus upon the elements of poor health in a health state description and to disregard positive elements. These two innovations are discussed later.

The structure of the final AQoL is shown in Figure 1.

The two columns of numbers superimposed on the arrows from the AQoL latent variable to each of the dimensions and from the dimensions to the items represent LAMDA coefficients which in the left hand and middle columns are the correlation coefficients between the two levels of variables. The final right hand column represents unexplained variants or error. The CFI coefficient of 0.99 indicates that the hypothesised structure of the latent variable explains 99 percent of the systematic variation in the pattern of responses from the 20 items.

2 Modelling Utilities

The major steps and decisions in the scaling of an MA instrument are summarised in Box 2.

Box 2 Steps in the calculation of utility scores

- | |
|---|
| <ol style="list-style-type: none">1. Select a model for recombination of items2. Select a scaling instrument3. Conduct scaling surveys4. Convert positive and negative scores into disutilities5. Combine item scores into a health state utility using the selected model6. Obtain the ‘bridge’—the transformation between the (0-1) index of disutility and the (0-1) disutility scale (multiplicative models)7. Convert disutilities into utilities8. Validate of initial utility scores and adjustment of the initial importance weights |
|---|

There are three levels of decisions to be made in order to attach utility weights to the various health states described by a multi attribute descriptive system. These are, first, the type of model to be used (additive, multiplicative, or econometric). Secondly, the appropriate method of scaling—calibrating—the items must be selected (standard gamble, time trade-off, person trade-off). Thirdly, and most neglected in the literature, a set of techniques must be selected for describing and eliciting scores from respondents (interview or postal survey; visual aids; internal consistency checks, etc).

The need for modelling arises from the immense number of health states which, as noted above, may be described by even relatively small descriptive systems. It is impossible to evaluate every health state separately. To overcome this problem the construction of an MAU instrument requires, first, the decomposition of the construct, ‘health’, the scaling of the constituent parts and

then the recombination of these parts into full health states. It is this latter step which requires a decision with respect to the type of model to be used.

The final multi-level structure of the AQL 2, is reproduced in Figure 1. It has two advantages as compared with the single level instruments that have been constructed to date. First, the procedure allows 6 sets of dimensional scores to be produced which may be used to measure or track changes in the constituent parts of a patient's overall utility through time, that is, it may be used to profile health states. Secondly, the structure attempts to overcome one of the problems inherent in MAU modelling. The concept of an overall health related quality of life is highly complex and it is difficult to disaggregate the concept into its constituent parts without encountering redundancy—one element of a poor health state may be reflected in several items (ie there is double counting of this element). For example, a person who is deaf may encounter difficulties with communication and this element may influence the scores of both the items measuring communication and those measuring hearing. However elimination of one set of such elements to eliminate double counting (for example deafness) may result in the omission of another element of deafness apart from communication (for example, the intrinsic enjoyment of hearing). For this reason AQL 1 and AQL 2 permit redundancy within a dimension in order to obtain a full and accurate description of the dimension. However the disutility of the dimension worst health state is independently measured and the combined influence of items cannot exceed the value of the dimension worst health state. Redundancy in the item scores cannot, therefore result in a dimension score which exceeds the dimension worst score.

As discussed above there is a compelling logical reason for the adoption of a multiplicative model. However there are no grounds for believing that there is a simple multiplicative relationship between items, dimensions, and the construct health. Consequently the AQL 2 adopted a two-stage scaling strategy in which the initial stage 1 estimates of utility derived from a simple multiplicative model are subject to econometric analysis of a sort which permits the modification of the simple model.

2.2 Estimation of utilities from survey data

Utility scores were estimated from data collected on three separate occasions from survey respondents. During the first two contacts interviewers elicited, *inter alia*, time trade-off data. During the second interview data reliability were tested by collecting TTO scores a second time, for the major parameters. Person trade-off, self TTO, and socio-economic data were also collected. The former two data sets are to be analysed in a later report. In both of the two interviews additional data was collected relating to multi attribute health states including the AQL all worst health state. These values were used, subsequently, in the second stage of the model construction.

'Values' relating to the rating scale response categories and the rating scale worst health state were collected from a mail survey of the same respondents. This approach was adopted for three reasons. First, rating scales are simpler than the TTO to administer and, despite repeated efforts, we were unable to validate a postal form of the TTO. Secondly, understanding item responses and item worst health states is a comparatively simple task which has repeatedly been used in postal surveys. Thirdly, respondents were already very familiar with the health states and the principle of scaling. During the second interview all respondents had been given a limited number of rating scale questions in order to allow the estimation of a transformation function between the rating scale and TTO scores. This function is described later.

Utility scores were estimated from the time trade-off interviews using equations 1a and 1b. Survey respondents were asked to select the number of years, x , in full health that would be equivalent to living 'n' years in a health state with a utility score, U , which is less than full health (equation 1). This allows the calculation of utility as x/n (equation 1b). Subject to some caveats this approach has been universally used in TTO based estimation of utilities.⁸ In the AQL surveys a time period $n = 10$ was adopted.

$$n(U) = 1. x \quad \text{Equation 1a}$$

$$U = x/n \quad \text{Equation 1b}$$

Negative Utilities

Negative utilities exist. There are health states where people would prefer to be dead. The implications of this fact for utility measurement are problematical and different approaches have been employed. With TTO procedures the first step in measuring the strength of 'negative utility' is relatively simple. Survey respondents are asked whether the health state is better or worst than death. When the latter reply is given a respondent is asked a second question, viz, 'how many years, x , in this worse than death health state, followed by full health for the rest of your years of life, n , would be equivalent to death?' This statement is captured in equation 2a from which negative utility may be calculated as shown in equation 2b. For example, if death was equivalent to 9 years in the health state followed by 1 year of full health, then, from equation 2, utility would equal $-1/9$.

$$0 = x.U + (n - x).1 \quad \text{Equation 2a}$$

$$U = -(n - x)/x \quad \text{Equation 2b}$$

This latter approach is incomplete and equation 2b cannot be used directly. This is because the value of the disutility rises without the constraint which is placed upon positive utilities (or an upper limit of 0.00 on disutility). Thus, in equation 2b if $x = 5$ and $n = 10$ then $U = -1.00$ which is the same order of magnitude as full health. It is, however, highly implausible that people could experience such a terrible health state. But this is not the lower boundary. As x approaches zero—people refuse to contemplate the health state under any circumstances—utility approaches an apparent score of negative infinity. Any such response would overwhelm all other respondent's preferences and for this reason the disutility scores obtained in equations like 2b must be transformed.

The transformation of negative scores is discussed at length in Richardson and Hawthorne (2001). It was argued that the common approach of adopting -1.00 as the lower boundary in order to achieve 'symmetry' with positive utilities is not convincing. As noted above, it is inconceivable that people can experience such a health state even though the mathematics of a literal interpretation preference implies this. Richardson and Hawthorne (2001) conclude that negative utilities should be given a limiting score of -0.25 which is equivalent to a disutility score, $DU = 1.25$.

⁸ An adjustment is sometimes carried out to take time discounting into account; visual or other props may be used.

All negative scores may be transformed so that 'values' between zero and minus infinity are constrained to the range 0.00 -m. This is equivalent to constraining negative utility values to the range 1.00 to 1 + m, where m is the maximum negative utility. A function that will achieve this transformation is:

$$DU = 1 + m + \frac{m}{v-1} \quad \text{Equation 3}$$

When the score for the untransformed value of a health state (V), equals zero (death) then $DU = 1.00$. When V is equal to minus infinity, $DU = 1+m$. As demonstrated by Richardson and Hawthorne (2001) the choice of parameters here has a potentially important effect upon the magnitude of the entire scale.

The Multiplicative Model

The general form of the multiplicative disutility function used by the AQoL is given in Equations 4 to 6 (von Winterfeldt and Edwards 1986):

$$DU = \frac{1}{k} \left[\prod_{i=1}^n [1 + kw_i DU_i(x_{ij})] - 1 \right] \quad \text{Equation 4}$$

$$k = \prod_{i=1}^n (1 + kw_i) - 1 \quad \text{Equation 5}$$

$$U^* = 1 - DU^* \quad \text{Equation 6}$$

Where: k = scaling constant

w_i = weight for dimension i ; and

$DU(x_{ij})$ = dimension disutility for item responses, j on a 0.00-1.00 scale.

This model is significantly more flexible than the simple additive model employed in some MAU instruments. When a disutility score of $DU(x_{ij}) = 0$ for all dimensions, i , Equation 6 reduces to:

$$DU = \frac{1}{k} (1 - 1) = 0 \quad \text{Equation 7}$$

When $DU(x_{ij}) = 1$ the equation reduces to:

$$DU = \frac{1}{k} \left[\prod_{i=1}^n (1 + kw_i) - 1 \right] \quad \text{Equation 8}$$

This is turn, from Equation 5, reduces to:

$$\frac{1}{k} (k) = 1.00 \quad \text{Equation 9}$$

Despite the apparent complexity of Equations 4 and 5 the multiplicative model imposes a very simple and specific structure upon preferences. This may be seen by setting all disutility scores, $DU_i(x_{ij}) = 1.00$. If global disutility, DU , is calibrated so that it assumes a score of 1.00 when dimension scores each have a score of 1.00 then the left hand side of Equation 4 equals 1.00 and Equation 4 becomes Equation 5. Thus Equation 5 simply states that a value of k must be selected such that DU is calibrated to equal 1.00 for the model all-worst score.

The structure of Equation 4 can be readily understood by setting $k = -1.00$. This occurs if any dimension has a disutility on the life-death scale equal to the instrument all-worst utility score. Large dimension disutilities approach this score. With this value Equation 6 reduces to:

$$DU = -\prod_{i=1}^n (1 - w_i DU_{ij}) + 1$$

As w_i is the maximum disutility of the dimension on the life death scale (LD), $w_i(DU_{ij})$ is dimension disutility on the life death scale.

$$DU = 1 - \prod_{i=1}^n (1 - DU_i) = 1 - \prod_{i=1}^n (U_i')$$

where U_i and DU_i are dimension i utility and disutility on the LD scale respectively.

As $U = 1.00 - DU$,

$$U = 1 - \{1 - \prod_i (U_i)\}$$

$$U = U_1 U_2 U_3 U_4 U_5$$

This final expression illustrates the simplicity of the model which essentially cross multiplies utility scores on each of the dimensions.

Choice of Parameters

A simple multiplicative model requires two sets of data for its scaling. First, utility scores must be obtained for each item and, secondly, a set of item importance W_i is needed. In an additive model these weights must be rescaled so their sum is equal to 1.00. The equivalent constraint in the multiplicative model is that the scaling constant, k , must satisfy the following equation.

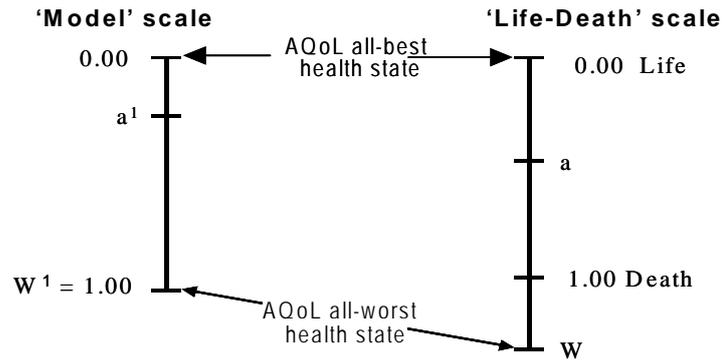
$$\frac{1}{k} \left[\prod_i (1 + kw_i) - 1 \right] = 1$$

Note that solving this equation for k requires no additional empirical data. The scaling constant is determined only by the importance weights. These in turn may be obtained a number of ways. The simplest approach is to use item worst disutilities measured on a dimension best to dimension worst scale. Dimension importance weights are measured by the disutility of the dimension worst health state on an instrument best to death scale.

Mapping Model Utility into the Life Death Scale

The multiplicative model is constructed so that predicted utilities lie in the range (0.00, 1.00). As the best health state is not necessarily death, it is necessary to map 'model disutility' onto a second scale in which 0.00 and 1.00 represent full health and death respectively. The transformation is illustrated in Figure 2.

Figure 2 Mapping 'model' onto 'life-death' utilities



$$DU(LD) = n.DU(Model)$$

In principle this task is straightforward when the model involves disutilities (and it is partly for this reason that modelling is conducted in terms of disutility scores). Establishing a single 'bridge' or equivalence between any two corresponding points and a^1 and a on the 'model' and 'life-death' scales respectively will permit the recalibration of the model utility values using the equation:

$$U(LD) = \left(\frac{a}{a^1}\right)U(Model) \quad \text{Equation 10}$$

The AQoL all-worst health state, W , is an obvious choice for calculating the bridge. It has the advantage that W , as an extremely poor health state, and will be in the vicinity of death for most people. Hence,

$$DU(LD) = W.DU(Model) \quad \text{Equation 11}$$

There is, however a complication in the mapping. This may be seen by setting all dimension utility scores equal to zero, except for dimension 1. This simplifies Equation 4 to:

$$DU_1(Model) = \frac{1}{k} \{1 + kw_1 DU_1(x_j) - 1\} \quad \text{Equation 12}$$

where 'DU(Model)' refers to the model score on the 00-1.00 scale.

Simplifying

$$DU(Model) = w_1 DU_1(x_j) \quad \text{Equation 13}$$

13

In this equation, the dimension worst disutility is obtained when

$$DU_1(x_1) = 1$$

$$DU(\text{worst, model space}) = W$$

From equation 11

$$DU(LD) = W.DU. \text{ Therefore:}$$

$$DU(\text{worst, LD space}) = W.W = W^2$$

This final expression gives an incorrect valuation of disutility on the life death scale, because, by construction, w_i is itself equal to the dimension worst disutility measured directly on the life death scale. Further transformation introduces error. For this reason it is necessary to replace the weights w_i with adjusted weights w_i/W . When these are substituted in equations 12, 13, and 14 for the model, the disutility value in LD space for the worst health state for dimension 1 becomes:

$$DU (LD) = W \cdot \frac{w_i}{W} = w_i$$

In summary, the reason for the adjustment arises from the use of dimension all worst weights measured on a wrong scale. Two scales exist. The first, described here as ‘model space’, has a maximum DU of 1.00 which corresponds with the AQoL all worst health state. The second, described here as ‘life-death space’ defines death as having a DU of 1.00 and the AQoL all worst, W , may be above or below this value. Dimension importance weights must be measured on the same scale as the other magnitudes in any computation. Without adjustment the formulae above constrain utilities within ‘model space’ but use weights calculated in life-death space. This introduces bias and, in the extreme could result in dimension disutilities greater than the AQoL all worst in model space. (This would occur if a dimension DU score measured on the life-death score exceeded 1.00.) To avoid this error, the unconverted model must use weights measured in ‘model space’ which is achieved by dividing the life-death values by the conversion factor $1/W$.

There is a second potential problem. This is cognitive overload arising from the complexity and unfamiliarity of the AQoL worst health state, W , for most and probably all respondents. This does not necessarily invalidate observed scores. It is possible that a cognitive overload will result in the same mean value and only a greater standard deviation in the data as compared with data from a simpler cognitive task. However it is likely that W may evoke a ‘shock-horror’ effect which could unduly increase the disutility score. In particular, human beings have enormous powers of adaptation which will not generally be understood before the need for adaptation.

In AQoL 1 this problem was mitigated by constructing ‘bridge’ health states at three additional points along the scale and the use of a mathematical solution to the resulting endogeneity of the bridge⁹. In AQoL 2, error in the evaluation of the AQoL all worst, W , was investigated and corrected by the second stage econometric correction of the AQoL formula outlined below.

The Rating Scale - TTO Transformation

TTO data were collected using a two part interview separated by at least two weeks and in a follow up postal questionnaire. The data obtained by this last method were the simplest and, quantitatively, the least important, viz, the dis-value of the different item responses (on a zero-item worst scale) and the dis-value of the item worst health states (on a zero-dimension worst scale). To increase the validity and reliability of results, the postal survey was restricted to individuals who had participated in the previous two stage interview.

This strategy resulted in the need for a transformation function between rating scale and time trade-off scores. The most common approach in the literature has been the use of a power function as this passes through two critical points; viz, (0,0) and (1.00, 1.00) which, in disutility space represent best health states and death respectively. Our approach to this task differed somewhat from the literature. Rating scales are known to ‘compress’ numerical scores into the

⁹ See Richardson et al 2001

middle of the range as compared with TTO or standard gamble procedures. The power function permits this compression at one end of the scale but has the opposite effect at the other end. That is, the function permits one of two options. First, relative to RS scores TTO scores may be compressed towards best health but the opposite in the vicinity of worst health. Alternatively, the scores may be compressed in the vicinity of worst health but the opposite in the vicinity of full health. Neither of these options is appropriate. Consequently, a 'cross over' point where RS = TTO was first estimated and two separate power functions fitted to the data above and below this point. The two part transformation function obtained was used to convert rating scale scores into an estimated TTO score.

Stage 2, Econometric Correction

As noted earlier there is no compelling reason for believing that the structure of the quality of life precisely fits the multiplicative model and, in particular, when the dimensions retain a degree of structural or preference interdependence. While modelling attempts to achieve these properties it may not be successful. In particular, the final utility scores are sensitive to the treatment of worse than death health states and to the transformation between the (0-1) scale produced by the multiplicative model and the (0-1) life-death scale used for true utility scores. Basing this transformation upon the single estimated value of the instrument all worst, W , creates the potential for bias as discussed above. The second stage econometric adjustment permits correction of bias introduced by this or any other distortion introduced by the procedures adopted.

In the second stage the utility scores of multi attribute health states were regressed on a number of independent variables. The modified experimental design methodology for selecting health states and the resulting health state scenarios are described in appendices.

In principle a large number of independent variables could be used to econometrically explain the utility of the MA health states. In the present study only a limited number were used. These were: dummy variables for the dimensions; dimension utility scores, respondent age and sex.

Implementation and Cognitive Difficulty

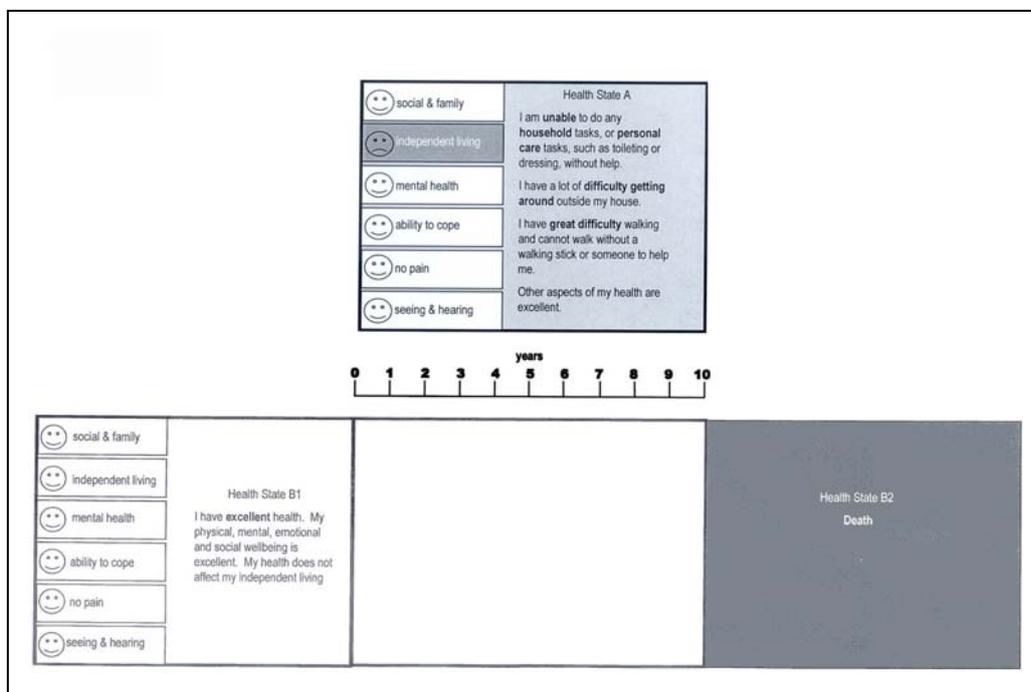
There were two innovations in the conduct of the TTO interviews which were included to increase the validity of responses. First, there was an attempt to encourage respondent deliberation. The almost universal practice in cost utility analysis has been to present respondents with a vignette or health state or, in the case of multi attribute models, the decomposed elements of the descriptive system. Responses are then elicited using the TTO, SG or PTO scaling instrument. While respondents are encouraged to think before responding, the time constraints upon the interview necessarily results in a 'spontaneous response'. People making real world decisions with respect to these health states would, in contrast, have the opportunity to contemplate the options at length and to discuss the issues involved with family and friends.

There has been almost no experimentation with the use of 'deliberative responses' (for exceptions see Murray and Lopez 1996; Shiell 2000). Consequently the AQoL 2 protocol employed two separate face-to-face interviews. Respondents were dichotomised. One half of respondents were provided with a deliberation kit designed to encourage thought and discussion of selected issues between the interviews. The remaining respondents were simply re-interviewed. Differences between the first and second interview responses in the second group may arise because of unreliability (a low test-retest correlation). However significant differences between the two groups in the second interview may be attributed to deliberation. If detected, the

scaling protocol allows for adjustment of spontaneous responses. The achievement of deliberative responses will be discussed more fully in elsewhere.

The second and potentially most important innovation during the scaling interviews was a change in the presentation of questions to minimise error arising from the ‘focusing effect’. For each of the multi attribute health states an overview of the full health states is included which indicates which of the dimensions are at the dimension all best, all worst, or at an intermediate health state. An example of the visual aid is shown in Box 3. The figure reproduces (on a smaller scale) the exact visual aid used in the interviews. The bottom half of the figure represents a slide with the black representing death. This was moved left and right in order to ‘flip-flop’ the number of years of full health until they were equivalent to 10 years in the health state depicted. While the respondent is asked to visualise the poor health state they are visually and forcefully reminded that other dimensions of their health are at their best health state.

Box 3 Visual aid for eliciting the TTO value when independent living is set at the dimension all worst



3 Surveys and Interviews

The scaling of AQL 2 required the following data:

- Type A TTO: item response (on AQL best full health-item worst scale)
 - Type B TTO: item worst (dimension best-dimension all worst)
 - Type C TTO: dimension worst (full health-death)
 - Type D TTO: AQL worst (full health-death)
 - Type E TTO: Multi Attribute health states (full health-death)
 - Type F TTO: 'Self TTO' (full health-death)
- PTO: Person trade-off for dimension worst and MA health states

Socio- and Demographic Status

As described earlier the data requirements were too large to obtain during interviews and consequently two interviews and a postal survey were conducted. Some data were collected at both interviews. These included dimension worst health states, the AQL worst health state and the person's 'self TTO'. The latter was obtained by asking each individual the number of years that they would sacrifice if, instead of remaining in their present health state for the remainder of their life, they had the option of improving their health status to the best health state described by the AQL.

Field Work

The project sought to obtain a representative group of respondents from within the Melbourne metropolitan area. To achieve this, the city was divided into 5 SES areas using SEIFA codes. Within these regions there was random selection of individuals using a computer readable telephone directory. After a preliminary letter explaining the study a telephone interview was used to collect personal information. After randomising by first name, one 'in-scope' individual was initially selected from each telephone service (usually a household). This procedure proved unwieldy and was replaced by selection based upon first initials. An adjustment was made to offset the increased chance of selection by individuals with multiple telephone listing. After these corrections for the number of subscribers per telephone number the sample represented a two stage unclustered sample design stratified by the following:

- postcode location and population size
- postcode areas: socio-economic status (use of SEIFA index in the selection of very small postcode areas).

The primary sampling unit was the telephone service, and the secondary sampling stage was the selection of one person from among those who regularly use the service. Up to four telephone calls were made to each number. In total, 10 waves of interviewing were carried out with adjustment in the number of approaches made in each SEIFA group in order to achieve the desired sample characteristics.

Those who agreed to be interviewed were offered the option of coming to a central location to be interviewed or to have the interview in their home. Those selecting the first option were given \$50 both as an encouragement to adopt the time minimising strategy for the research team but also as compensation for their travel costs. A large majority of respondents took up this offer. Interviews were carried out in a range of locations around the city of Melbourne in order to minimise travel time.

As discussed earlier, one of the reasons for undertaking the construction of AQoL 2 was a concern that the disutility scores obtained by AQoL 1 implied the excessive importance of quality relative to the quantity of life. One of the hypotheses considered was that a ‘focusing effect’ may have inflated disutility scores. Consistent with decision analytic methods, respondents were asked during the scaling survey to evaluate disutility on a particular dimension *assuming that on all other dimensions there was full health*. Thus, for example, a person might be told that they had a particular level of disability with respect to their ability to carry out household functions and their mobility while at the same time they had full health with respect to family and social relationships, psychological wellbeing, pain and the senses. Some combinations of health state are clearly inconsistent with full health elsewhere and this problem was taken into account by combining the health state with less than full health elsewhere.

In contrast, the hypothesised problem with the methodology of AQoL 1 (and, to our knowledge, other MAU instruments) is that despite the repeated statement that other aspects of life were very good, respondents might forget this information and interpret the poor health state on the dimension of interest as an indicator of the health state on all dimensions; that is, individuals focus excessively upon the dimension of interest and do not focus upon the off-setting effects of good health elsewhere. To overcome the focusing effect visual aids were constructed which represented all dimensions of the AQoL simultaneously and embedded the poor element of health in an overall health state description which ensured a recognition of good health elsewhere. An example of the TTO visual aid is given in Box 3. As shown, the upper quadrangle integrates all dimensions of the health state. The lower bar was presented to respondents as a TTO board in which the health state death could be increased or decreased according to the responses obtained.

In total, 10 interviewers were employed with an average of 7 in the field at any time. Each of these received intensive training. This included the use of a video outlining procedures, study material and simulated presentations of the interviews in their entirety. Subsequently audio tapes were collected to audit quality and weekly meetings were held to discuss problems as they arose. Only 1 interviewer proved to be unsatisfactory reflecting the care with which interviewers were initially selected, viz, by personal recommendation and not by open advertisement.

The field work coordinator was available at all times to answer questions. Respondents were provided with the option of contacting a senior member of the team concerning complaints or, in accordance with University requirements, an independent counsellor was nominated. No such complaints were received.

Details of the survey and interview methodologies are provided in the appendices. These explain or reproduce the following:

- The introductory letter and explanatory statement sent to potential interviewees (Appendix 2)
- The TTO questionnaire (Appendix 3)
- The Rating Scale introductory letter and questionnaire (Appendices 6, 7)
- The modified factorial design used for the selection of representative multi attribute health states (for use in the econometric Stage 2 scaling) (Appendix 7)
- The MAU health states selected (Appendix 7)
- Interviewer instructions (Appendix 10)

4 Results

Results from the 'fieldwork' are summarised in Table 1. As described, an initial letter was sent to selected households and were followed up by telephone. In total 2,244 letters were sent from which 1,319 successful telephone contacts were achieved. The principle reasons for non-contact were first, 261 cases where names on the letter did not correspond with the person contacted and 381 cases where no answer was received. Following successful contact 153 cases were dropped because of language difficulties and 136 because of age or ill health. Six hundred 'not interested' cases were recorded resulting in an overall response rate of 41.7 percent of possible respondents. Individuals were asked, in the first instance, to participate in two sets of interviews. As described these were conducted either at the individual's home or, for the vast majority, interviews were carried out at a common location close to their residence. Due to the volume of data collected the two interviews were followed up with a postal survey which was used to obtain rating scale data on item responses. In total 163 questionnaires were returned representing a response rate of 40 percent.

Table 1 Scaling Surveys: Respondents and Response Rates

| | PTO-TTO Interview | Mail Questionnaire |
|----------------------|-------------------|--------------------|
| Sample | 2244 | 411 |
| Successful contact | 1319 | |
| Possible respondents | 1030 | |
| Respondents | 430 | 180 |
| Response Rate | 41.7% | 43.8% |
| Respondents: | | |
| Sex % male | 35% | 31% |
| Age % age <25 | 3% | 3% |
| Age % age ≥60 | 22% | 33% |
| Education | | |
| A Primary % | 3% | 4% |
| B Secondary % | 47% | 50% |
| C Tertiary % | 50% | 46% |

As with previous AQoL surveys there was a disproportionate number of women and highly educated respondents. By design, there were no respondents under the age of 25 years. Interviewers did not find the difficulty with elderly respondents that has been reported by some research teams. This may reflect the care with which the interviews were constructed and the particular visual aids that were employed and, particularly, the use of a visual image to represent the mix of good health and poor health states.

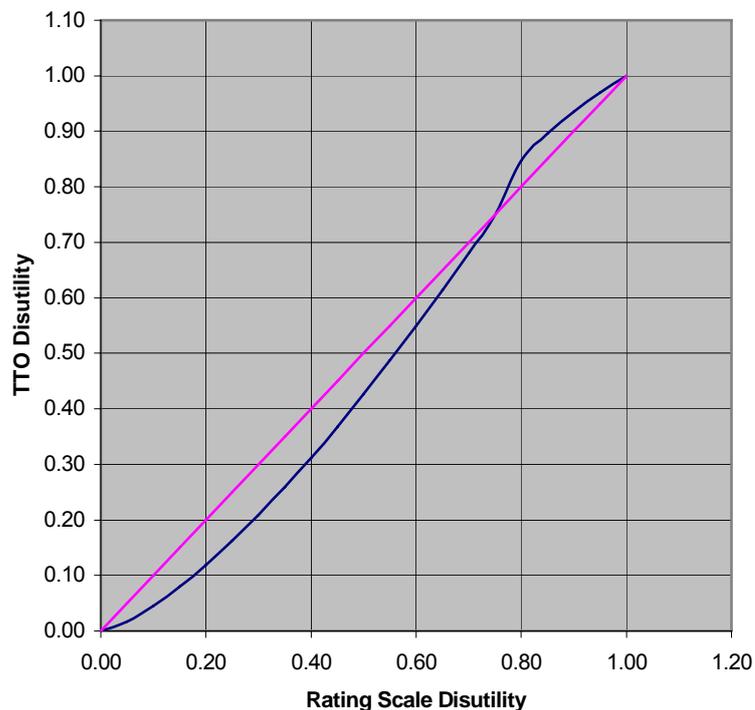
4.1 Rating Scale - TTO Transformation

Descriptive Statistics

Tables 2-6 report the mean values for the statistics required for the scaling of AQL 2.

TTO utility scores for item responses and for item worst responses were derived from rating scale survey data and from a transformation function between RS and TTO scores. As discussed earlier, this 'function' was in effect 2 power functions which applied above and below the point of inflexion where function convexity was replaced by concavity. The result is shown in Figure 3.

Figure 3 Two part power functions for transformation of rating scale into TTO disutilities



Power function point of inflexion at (0.75, 0.75) 45 degree line shows where TTO Disutility = RS Disutility

The transformation of negative utilities is described in Box 4. Table 2 presents the TTO values of the item responses estimated from the rating scale-TTO transformation. The corresponding results from the rating scale, presented in an appendix, include standard deviations which are very satisfactory for survey data.

Items were constructed to achieve two objectives. The first was that item responses should be approximately equi-distant between the best and the worst health state. Thus, for example, if the disutility scores for an item assumed values of 0.00; 0.02; 0.04; 0.06; 1.00, then the item would be unable to detect changes in the range 0.06-1.00. The second criterion was that there be greater sensitivity near full health than achieved in previous instruments. Data in Table 2 indicates that these dual criteria have been fulfilled. There are only four items which have a space between the TTO response values in excess of 0.5 (items 6, 15, 16 and 17). In contrast

the space between the first two response items is comparatively small. In ten cases it is less than 0.10 and the maximum gap is 0.20 (items 7 and 16).

Table 2 Item Disutilities (TTO Scores)

| | Dimension 1 | Dimension 2 | Dimension 3 | Dimension 4 | Dimension 5 | Dimension 6 |
|----------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|
| Response Level | Mean | Mean | Mean | Mean | Mean | Mean |
| | Item 1 | Item 5 | Item 8 | Item 12 | Item 15 | Item 18 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.07 | 0.07 | 0.13 | 0.06 | 0.13 | 0.03 |
| 3 | 0.44 | 0.46 | 0.39 | 0.34 | 0.64 | 0.22 |
| 4 | 0.82 | 0.84 | 0.84 | 0.72 | 1.00 | 0.62 |
| 5 | 1.00 | 1.00 | 1.00 | 1.00 | | 0.84 |
| 6 | | | | | | 1.00 |
| | Item 2 | Item 6 | Item 9 | Item 13 | Item 16 | Item 19 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.03 | 0.19 | 0.14 | 0.06 | 0.20 | 0.02 |
| 3 | 0.24 | 0.76 | 0.39 | 0.38 | 0.76 | 0.20 |
| 4 | 0.47 | 1.00 | 0.82 | 0.77 | 1.00 | 0.59 |
| 5 | 0.84 | | 1.00 | 1.00 | | 0.83 |
| 6 | 1.00 | | | | | 1.00 |
| | Item 3 | Item 7 | Item 10 | Item 14 | Item 17 | Item 20 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.04 | 0.20 | 0.10 | 0.06 | 0.07 | 0.19 |
| 3 | 0.25 | 0.65 | 0.33 | 0.42 | 0.33 | 0.70 |
| 4 | 0.57 | 1.00 | 0.78 | 0.83 | 0.75 | 1.00 |
| 5 | 0.83 | | 1.00 | 1.00 | 1.00 | |
| 6 | 1.00 | | | | | |
| | Item 4 | | Item 11 | | | |
| 1 | 0.00 | | 0.00 | | | |
| 2 | 0.04 | | 0.06 | | | |
| 3 | 0.30 | | 0.37 | | | |
| 4 | 0.80 | | 0.84 | | | |
| 5 | 1.00 | | 1.00 | | | |

Notes: Item best and worst disutilities are set equal to 0.00 and 1.00 respectively. Item best and worst responses are set as endpoints for rating scale evaluations.

Item worst scores were also estimated from rating scale values. Both these and the TTO results are shown in Table 3. In this case the appropriate evaluative criterion is that maximum values should not be too small—indicating an unimportant item—and, ideally, there should be no item in a dimension which dominates other results. From Table 3 these criteria have been achieved.

Only item 1 has an importance weight of less than 0.4 and 13 of the 20 values are 0.6 or above. No single item dominates the results.

Table 3 **Item Worst Scores**

| RS Values | | | | TTO Disutilities | | | | | | | | | |
|-----------|------|------|-------|------------------|------|------|-------|-----|------|------|-----|------|------|
| Dim | Item | Mean | (se) | Dim | Item | Mean | (se) | Dim | Item | Mean | Dim | Item | Mean |
| 1 | 1 | 0.44 | (.03) | 4 | 12 | 0.47 | (.03) | 1 | 1 | 0.39 | 4 | 12 | 0.42 |
| | 2 | 0.63 | (.03) | | 13 | 0.65 | (.03) | | 2 | 0.59 | | 13 | 0.64 |
| | 3 | 0.65 | (.03) | | 14 | 0.77 | (.02) | | 3 | 0.63 | | 14 | 0.77 |
| | 4 | 0.78 | (.03) | | 4 | 0.80 | | | | | | | |
| 2 | 5 | 0.65 | (.04) | 5 | 15 | 0.77 | (.03) | 2 | 5 | 0.64 | 5 | 15 | 0.63 |
| | 6 | 0.70 | (.03) | | 16 | 0.65 | (.03) | | 6 | 0.70 | | 16 | 0.77 |
| | 7 | 0.55 | (.03) | | 17 | 0.67 | (.03) | | 7 | 0.51 | | 17 | 0.65 |
| 3 | 8 | 0.66 | (.04) | 6 | 18 | 0.60 | (.03) | 3 | 8 | 0.64 | 6 | 18 | 0.58 |
| | 9 | 0.62 | (.03) | | 19 | 0.51 | (.03) | | 9 | 0.59 | | 19 | 0.46 |
| | 10 | 0.66 | (.03) | | 20 | 0.63 | (.03) | | 10 | 0.65 | | 20 | 0.61 |
| | 11 | 0.72 | (.03) | | 11 | 0.71 | | | | | | | |

Scale = Dimension Best (0.00) to Dimension Worst (1.00)

The quantitatively most important disutility results are those obtained for the dimension all worst health states and for the AQL all worst. In Tables 4 and 5 these are reported in more detail than previous results.

Dimension worst disutilities were collected in both of the face-to-face interviews which were conducted between 2 and 4 weeks apart. Mean values, reported in Table 4, reveal a high test-retest reliability with the second results generally lower than the first suggesting that after deliberation health states appear somewhat less serious than when they are first contemplated.

Table 4 Dimension Worst Disutility Scores

| Dimension | Interview 1 | | Interview 2 | | median | % negative | n |
|----------------------|-------------|-------|-------------|-------|--------|------------|-----|
| | mean | se | mean | se | | | |
| 1 Individual Living | 0.54 | (.02) | 0.47 | (.02) | 0.40 | 8.5 | 367 |
| 2 Social | 0.50 | (.02) | 0.45 | (.02) | 0.40 | 6.3 | 367 |
| 3 Mental Health | 0.51 | (.02) | 0.48 | (.02) | 0.45 | 7.4 | 367 |
| 4 Coping | 0.35 | (.02) | 0.35 | (.02) | 0.30 | 1.1 | 367 |
| 5 Pain | 0.54 | (.02) | 0.59 | (.02) | 0.50 | 16.1 | 367 |
| 6 Sensory perception | 0.68 | (.02) | 0.64 | (.02) | 0.60 | 19.1 | 367 |

The reported median scores are consistent with mean values and particularly those from the second interview. They indicate a skew in the distribution towards higher disutilities despite a compression of these to an upper limit of 1.25 on any disutility score.

The frequency distribution of the AQL all worst is summarised in Table 5. This indicates that, contrary to a common view, the entire population appears to be prepared to trade length for quality of life if the quality is sufficiently poor. The results indicate that none of our respondents refused to trade quality for quantity. Only 6 (1.6 percent) would give up less than half of the stated life expectancy while 75 percent indicated a preference for death rather than the AQL all worst. The median disutility of 1.24 indicates that the majority of respondents virtually refused to contemplate the worst health state irrespective of the subsequent positive prognosis. As this implies an untransformed utility approaching minus infinity the truncation process described earlier becomes of particular importance. For this reason in the analysis of AQL 1 significant attention was given to the alternative methods for estimating the mean score of the AQL all worst (Richardson and Hawthorne 2001). This task is circumvented in the present study because the econometric analysis described below was designed to adjust the profile of disutilities according to the multi attribute utility results elicited directly from patients. Additionally and for reasons discussed later the mean value of the AQL all worst is more plausible than the mean value implied by the responses obtained in the interviews for AQL 1.

Table 5 AQL All Worst, Survey 2

| Positive Utility | | | Negative Utility | | |
|------------------|----|-------|------------------|------|-------|
| DU (TTO) Range | n | Cum % | DU TTO Range | n | Cum % |
| 0.00 - 0.19 | 0 | 6 | 1.01 - 1.20 | 6 | 39.6 |
| 0.20 - 0.49 | 4 | 2.2 | 1.21 - 1.24 | 38 | 59.9 |
| 0.50 - 0.80 | 27 | 17.0 | 1.25 | 73 | 100 |
| 0.81 - 1.00 | 34 | 35.7 | Median | 1.24 | |
| | | | Mean | 1.08 | |

Table 6 Multi Attribute Health States

| Variable | Mean | Dimensions | n | Definition ¹ |
|----------|---------------|------------|-----|--|
| MA1 | 0.21 (.02) | (12) | 111 | MA1 = IL[1c 2e 3d 4d], SF [6b 6a 7a] |
| MA2 | 0.11 (.02) | (34) | 88 | MA2 = MH[8b 9c 10c 11b], CO [12c 18b 14b] |
| MA3 | 0.13 (.02) | (15) | 88 | MA3 = IL [1b 2d 3c 4b], PA [15b 16b 17c] |
| MA4 | 0.37 (.04) | (456) | 57 | MA4 = CO [13d 14c], PA [15b 16c 17c], SP [18c 19d] |
| MA5 | 0.27 (.03) | (235) | 57 | MA5 = SF [6b 7b], MH[10c 11c], SP [18b 20b] |
| MA6 | 0.50 (.05) | (2345) | 58 | MA6 = SF[5c 6c], MH [9d 10c], 12d 13d], PA[15c 16c 17d] |
| MA7 | 0.21 (.02) | (1356) | 54 | MA7 = IL[2c 3c], BH[10b 11b], PA[15b 16b 17b], SP[19d 20c] |
| MA8 | 0.24 (.03) | (134) | 54 | MA8 = IL[3e], MH[9c 10d], CO[12d 14c] |
| MA9 | 0.16 (.02) | (1251) | 54 | MA9 = IL[2c 3c], SF[5b 7b], PA[15b 16b 17b] |
| MA10 | 0.46 (.03) | (246) | 53 | MA10 = IL[3e], SF[6c 7c], CO[13d 14d], SP[18d 19e] |
| MA11 | 0.16 (.02) | (456) | 53 | MA11 = CO[12b 14b], PA[15b 16b], SP[19c 20a] |
| MA12 | 0.30 (.03) | (236) | 53 | MA12 = SF[5d 7c], MH[9d 11c], SP[18b 19b] |
| MA13 | 0.30 (.03) | (2345) | 45 | MA13 = SF[6b 7b], MH[8d 10d], CO[13c 14c], PA[15a 16b] |
| MA14 | 0.39 (.03) | (1345) | 45 | MA14 = IL[1d 2e 3e 4d], MH[9d 11c], PA[15b 16b], SP[18b 20a] |
| MA15 | 0.18 (.02) | (134) | 45 | MA15 = IL[1b 2c 3b], MH[8c 10d], CO[12d 13c] |
| MA16 | 0.53 (.04) | (125) | 44 | MA16 = IL[1d 2e 3e 4d], SF[5c 6b], PA[15c 16c] |
| MA17 | 0.42 (.04) | (1246) | 44 | MA17 = IL[1b 2c 3b], SP[5b 7d], CO[12c 14b], SP[19e 20c] |
| MA18 | 0.41 (.04) | (26) | 44 | MA18 = SP[5c 6c 7c], SP[18d 19e 20c] |

Key 1 numbers refer to item numbers; letters indicate the response category of the items; brackets delineate dimensions

The multi attribute health states to be used in the second stage econometric analysis of utilities are reported in Table 6 along with a summary statement of the dimensions employed and a full definition of the health state. The table reveals that disutilities of the health states were spread relatively evenly across the intervals 10-19; 20-29; 30-39 and 40-49. There are no health states with utilities less than 0.10 and only 2 with a disutility of 0.50 or above. Subsequent validation studies should concentrate upon these two important areas.

4.2 Item Response and Item Worst Scores

The 20 items of the AQoL 2 each had between 4 and 6 response categories. The TTO based utility score for each of these levels was estimated from the rating scale scores obtained in the postal survey. The two endpoints for each scale were the item best and item worst which assumed disvalue scores of 0 and 1.00 respectively. Item worst scores were likewise estimated from rating scale data where the endpoints for best and item worst were, respectively, the dimension best and the dimension worst health states.

To date transformations of rating scale into TTO utilities have generally used a power function as recommended by Torrance (1986). This has one of the necessary properties for a rating scale-TTO transformation, viz, a power function passes through the two endpoints of a scale, (1.00, 1.00) and (0.00, 0.00). As discussed above the function is not fully satisfactory. Relative to TTO scores the rating scale concentrates observations in the middle of a scale. This results in an 'S' shaped relationship around the 45° line when TTO is on the vertical and the rating scale on the horizontal axes. A single power function can either be convex or concave and thereby capture either the convexity at the bottom of the scale or the concavity at the top end of the scale. However it cannot capture both and the imposition of a simple power function will thereby introduce bias into the transformation.

To overcome this latter problem TTO scores were partitioned into intervals of 0.05 and average rating scale scores estimated for each interval. These were plotted and the point of intersection with the 45° (RS = TTO) line estimated. Data were partitioned into observations above and below this point of intersection. Power functions were then determined for the two sets of data. The results are shown in Equations 11 and 12.

$$TTO_1 = \left[\left(RS * \frac{4}{3} \right) \right]^{1.394} * 0.75, \quad RS < 0.75 \quad \text{Equation 11}$$

$$TTO_2 = \left\{ \left[(RS - 0.75) * 4.0 \right]^{0.588} \right\} \div 4 + 0.75 \quad RS > 0.75 \quad \text{Equation 12}$$

While unusual, these equations intersect at (0.75, 0.75). Equation 11 passes through (0, 0); equation 12 through (1.00, 1.00). Consequently the first equation was used to estimate TTO values from the rating scale results for rating scale scores less than 0.75. The second equation was used to obtain estimates for the TTO for the remaining observations.

The apparent complexity of these two equations occurs because the partitioned data must first be rescaled before fitting the power function and subsequently rescaled back to the original numerical interval, viz, 0-0.75 and 0.75-1.00 respectively. The result of these procedures was a correlation coefficient between the TTO and rating scale of 0.73 which, for individual level data, is a particularly good result.

4.3 Multiplicative Modelling

Multi attribute utility theory requires the initial decomposition of a multi attribute state into its constituent attributes, their evaluation and subsequent recombination of these values. AQoL 2 has two levels of disaggregation. First, aggregate health states are decomposed into dimensions. Secondly, these dimensions are disaggregated into items. The recombination at each level requires item and dimension importance weights. These are obtained by using, respectively, the item worst scores (measured on a dimension best to dimension worst scale) and the dimension worst scores (measured on the best health to death scale). These scores are given in Table 3 and Table 4.

The combination of attribute scores may employ an additive model in which the importance weights were rescaled so that they summed to unity. However multi attribute theory suggests that when the sum of importance weights exceeds unity a multiplicative model should be used. For independent reasons this model is also important in the context of health state utilities. The constraint upon the importance weights with this model is that in equation 8, the weights combine to produce a value of unity. This implies that the following condition is met:

$$k = \prod_{i=1}^n (1 + kw_i) - 1$$

The scaling constants, k, could be calculated one of two ways. First, the mean values of the item and dimension weights—the item and dimension worst scores—reported in Table 3 and 4 could be inserted into the equation and solved for k for each dimension and for the AQoL. Secondly, for each dimension and for the overarching AQoL model an individual scaling constant, k, could be obtained for every individual, and the mean value of k across individuals used in the multiplicative formula. This second approach is theoretically correct. The average value of k calculated separately for each individual is not the same as the value of k obtained from average disutility weights. The objective of the multiplicative formula for both dimensions and the AQoL is to provide the average of individual utilities not the utility of a constructed ‘average person’. The mean values of the scaling constant for each dimension and for the AQoL are given in Table 7. The standard error of the estimates are satisfactory.

Table 7 **Scaling Constants**

| Dimension, d | k_d | se (n) | |
|----------------------|-------------|--------|-------|
| 1 Ind. Living | -0.978 | .03 | (59) |
| 2 Social | -0.923 | .04 | (60) |
| 3 Mental Health | -0.983 | .04 | (60) |
| 4 Coping | -0.930 | .04 | (79) |
| 5 Pain | -0.962 | .04 | (79) |
| 6 Sensory perception | -0.851 | .04 | (78) |
| AQoL | $k = -.965$ | 0.02 | (373) |

Key: k_d = dimension scaling constants
 k = AQoL scaling constant

The overall multiplicative formula given in equation 4 employs a set of item or dimension weights equal to the scaling constant times the individual item or dimension weights. The calculation of these overall weights is shown in Tables 8 and 9.

Table 8 **Item Weights**

| Dimension Item | (-) $k_d w_i = wt_i$ | Dimension Item | (-) $k_i w_i = wt_i$ |
|-------------------|------------------------|-------------------|------------------------|
| Ind Living | | Coping | |
| 1 | (0.978) * (.39) = 0.38 | 1 | (0.930) * (.42) = 0.39 |
| 2 | (0.978) * (.59) = 0.58 | 2 | (0.930) * (.64) = 0.60 |
| 3 | (0.978) * (.63) = 0.62 | 3 | (0.930) * (.77) = 0.72 |
| 4 | (0.978) * (.80) = 0.78 | | |
| Social & Family | | Pain | |
| 1 | (0.923) * (.64) = 0.59 | 1 | (0.962) * (.63) = 0.61 |
| 2 | (0.923) * (.70) = 0.65 | 2 | (0.962) * (.77) = 0.74 |
| 3 | (0.923) * (.51) = 0.47 | 3 | (0.962) * (.65) = 0.57 |
| Mental Health | | Sensory | |
| 1 | (0.983) * (.64) = 0.63 | 1 | (0.851) * (.58) = 0.49 |
| 2 | (0.983) * (.59) = 0.58 | 2 | (0.851) * (.46) = 0.39 |
| 3 | (0.983) * (.65) = 0.64 | 3 | (0.851) * (.61) = 0.52 |
| 4 | (0.983) * (.71) = 0.70 | | |

Key k_d = Dimension Scaling constants (resp)
 w_i = Item weight = item worst DU
 wt_i = final weight

Disutility equations for each of the 6 dimensions and for the overarching AQL multiplicative model are obtained by entering these latter weights into equation 4. The resulting disutility equations are reproduced in Box 3. The utility form of the equations is obtained from equation 6. They are reproduced in Box 5.

Table 9 Dimension weights

| Dimension | | (-) k_d | x w_d | = | wt_d |
|-----------|-------------|---------------------|---------|---|--------|
| 1 | Ind. Living | 0.965 | x (.47) | = | 0.454 |
| 2 | Social | 0.965 | x (.45) | = | 0.434 |
| 3 | Mental | 0.965 | x (.48) | = | 0.463 |
| 4 | Coping | 0.965 | x (.35) | = | 0.338 |
| 5 | Pain | 0.965 | x (.59) | = | 0.570 |
| 6 | Senses | 0.965 | x (.64) | = | 0.618 |
| AQoL | | W/k 1.132/.965 | = | = | 1.17 |

Key k_d = Dimension scaling constant
 w_d = Dimension weight = dimension all worst
 wt_d = Final dimension weight

Box 4 Calculating negative utilities from TTO data

States worse than Death $V.T. + (10-T).1 = 0$

$$V = - (10-T)/T$$
 where T is the number of years in the (worse than death) health state
 V is the untransformed value of the health state.
 Note that as T approaches 10 years, V approaches infinity.

Transformation of V

An upper limit of 1.25 for disutility is obtained with any function of the form.

$$DU = 1.25 - 1/(nV-4)$$

The selected value of n determines the transformation path from DU = 1 to DU = 1.25 the selected value is n = 28.6. Reasons for this path and the upper limit of DU = 1.25 is given in Richardson et al 2001

Box 5 Multiplicative Disutility Equations

| Dimensions | |
|---|--|
| General Formula | $DU_d = \frac{1}{kd} \left[1 - \prod_{i=1}^n (1 - k_d w_i DU_i) \right]; k_d > 0$ |
| Independent Living | $DU_1 = 1.02 [1 - (1 - 0.38du_1)(1 - 0.58du_2)(1 - 0.62du_3)(1 - 0.78du_4)]$ |
| Social and Family | $DU_2 = 1.08 [1 - (1 - 0.59du_5)(1 - 0.64du_6)(1 - 0.47du_7)]$ |
| Mental Health | $DU_3 = 1.02 [1 - (1 - 0.63du_8)(1 - 0.58du_9)(1 - 0.64du_{10})(1 - 0.70du_{11})]$ |
| Coping | $DU_4 = 1.08 [1 - (1 - 0.39du_{12})(1 - 0.59du_{13})(1 - 0.72du_{14})]$ |
| Pain | $DU_5 = 1.04 [1 - (1 - 0.61du_{15})(1 - 0.74du_{16})(1 - 0.63du_{17})]$ |
| Senses | $DU_6 = 1.18 [1 - (1 - 0.49du_{18})(1 - 0.39du_{19})(1 - 0.51du_{20})]$ |
| AQoL General Formula | $DU_{AQoL} = \frac{W}{k} \left[1 - \prod_{d=1}^6 (1 - k w_d DU_{x_i}) \right]; k > 0$ |
| as | $\frac{W}{k} = (1.132/0.965) = 1.17$ |
| $DU_{AQoL} = 1.17 [1 - (1 - 0.454DU_1)(1 - 0.434DU_2)(1 - 0.463DU_3)(1 - 0.338DU_4)(1 - 0.570DU_5)(1 - 0.618DU_6)]$ | |

Key:

k_d = scaling constant, dimension d

k = scaling constant, AQoL

w_d = dimension weight, relevant dimension

DU_d = disutility, dimension d

w_i = item weights, relevant dimension

du_i = disutility, item i , relevant dimension

Box 6**Multiplicative Utility Formulae****General Formula for Utility Model***

$$U_d = \frac{1}{k_d} \cdot \prod_{i=1} [1 - k_d w_i (1 - u_i)] - \left(\frac{1}{k_d - 1} \right)$$

$$U_1 = 1.02_i [(0.62 + 0.38u_1)(0.42 + 0.58u_2)(0.38 + 0.62U_3)(0.22 + 0.78u_4)] - 0.02$$

$$U_2 = 1.08_i [(0.41 + 0.59u_5)(0.36 + 0.64u_6)(0.53 + 0.47u_7)] - 0.08$$

$$U_3 = 1.02_i [(0.37 + 0.63u_8)(0.42 + 0.58u_9)(0.36 + 0.64u_{10})(0.30 + 0.70u_{11})] - 0.02$$

$$U_4 = 1.08_i [(0.61 + 0.39u_{12})(0.41 + 0.59u_{13})(0.28 + 0.72u_{14})] - 0.08$$

$$U_5 = 1.04_i [(0.39 + 0.61u_{15})(0.26 + 0.74u_{16})(0.37 + 0.63u_{17})] - 0.08$$

$$U_6 = 1.18_i [(0.51 + 0.49u_{18})(0.61 + 0.39u_{19})(0.49 + 0.51u_{20})] - 0.18$$

AQoL General Formula

$$U_d = \frac{W}{k} \prod^{d=1} [1 - kw_d (1 - U_d)] - W \left(\frac{1}{k} - 1 \right)$$

$$U_{AQoL} = 1.17 [(0.546 + .454u_1)(0.566 + 0.434u_2)(0.537 + 0.463u_3) \\ (0.662 + 0.338u_4)(0.430 + 0.570u_5)(0.382 + 0.618u_6)] - 0.17$$

Key:

*The utility formula is derived from equations (4) and (6) earlier

 U_d = Utility score, dimension d u_i = utility score, item i k_d = scaling constant, dimension d k = scaling constant, AQoL w_i = item weight, item i w_d = dimension weight, dimension d

4.4 Econometric modelling

Rationale

The rationale for an econometric second stage adjustment to the scaling model was discussed earlier. While the multiplicative model represents a significant improvement upon the additive model it is still a relatively simple combination rule which imposes a questionable degree of uniformity in the relationships between items and dimensions: there is no difference in this relationship in the vicinity of full health and the vicinity of death. The same multiplicative relationship is assumed to exist between all items and dimensions. The purpose of the second stage adjustment was to introduce flexibility in both of these relationships.

Models:

The model derived from the multiplicative formula might be described as the 'base model' which hypothesises that the TTO score for multi attribute health states will be equal to the AQoL score derived from the multiplicative model. This hypothesis is tested by the percentage of the variance in TTO scores explained by predicted AQoL scores. This 'R²' coefficient (from a regression equation with the constant suppressed) is 0.65 and suggests a very high explanatory power for individual data.¹⁰

The first adjustment to the basic model is to impose a power function relationship of the following form:

$$TTO = AQoL^a$$

The functional form was dictated by the need for the function to pass through the two anchor points (0.00, 0.00) and (1.00, 1.00). The second adjustment is to introduce into the basic power function five additional variables, 'Slope_i'. This is defined by the following equation.

$$Slope_i = DUM_i * Ln(AQoL)$$

The full range of the AQoL score (0.00-1.25) is divided into five equal ranges and the five Slope variables are defined by the five dummy variables which take a value of 1 in the relevant range and 0 elsewhere. Slope 1 is excluded from regressions as a basis for comparison. Because the dummy is multiplied by Ln (AQoL) the model tested alters the value of the exponent as shown in the equation below.

$$TTO(1) = AQoL^x$$

$$\text{where } x \text{ equals } a + \sum b_i \text{ Slope}_i$$

A similar adjustment is made to allow for dimension effects. This results in TTO 3 as shown below.

$$TTO (3) = AQoL^x$$

$$\text{where } x = a + \sum_i d_i \text{ Dim}_i * Ln(AQoL)$$

¹⁰ The R² for an equation with the constant term suppressed is not directly comparable with the R² in unconstrained equations.

where Dim^i is a dimension dummy variable.

Slope and dimension shift variables are combined in TTO 4 as shown.

$$TTO (4) = AQL^x$$

$$\text{where } x = a + \sum_i b_i \text{ Dum}_i (\text{Ln AQL})$$

$$+ \sum_i d_i \text{ DIM}_i (\text{Ln AQL})$$

Finally Slope variables are created for each of the dimension variables; that is, the function allows for a change in the impact of the dimension variables at different levels of each of the dimensions. As with the AQL Slope variables five dummy variables are created for each of the six dimensions and the dummy for dimension is omitted.

4.5 Results

Results are reported in Table 10 (see Footnote 10). Equation 1 strongly supports the hypothesis that a power function and not a linear relationship exists between observations and AQL predicted scores. However the explanatory power (R^2) of the equation only marginally improves upon the R^2 of 0.65 for the basic model. Each of the equations 2, 3 and 4 improve the overall fit of the model. Equation 5 leaves the explanatory power unchanged. The best fit model (4 or 5) increases the explanatory power by 13.4 percent.

Table 10 Regressions for second stage correction

| Dependent Variable = Disutility E type MA health states | | | | | |
|---|-------------|--------------|---------------|---------------|-----------------------------|
| Dependent variables | Progression | | | | |
| | (1) | (2) | (3) | (4) | (5) |
| Ln AQL | 2.44 (50.0) | +1.63 (14.4) | (3.76 31.78) | 3.05 (20.31) | .34 (2.00) |
| Slope 2 | | 0.83 (6.47) | | 0.67 (5.66) | -0.62 (5.33) |
| Slope 3 | | +1.71 (9.55) | | 1.61 (9.88) | -1.63 (10.11) |
| Slope 4 | | +3.75 (1.08) | | 3.77 (7.00) | 3.72 (6.99) |
| | | | | | (3, -.43)(4, -.52) |
| | | | | | (2, -.76)(3, -.41)(2, -.57) |
| Dim 1 | | ns | | ns | (3, -.31) |
| Dim 2 | | -0.75 (-4.1) | | -0.77 (-4.22) | (3, -.45)(4, -.52) |
| Dim 3 | | | -0.79 (-4.1) | -0.81 (-4.41) | (2, -.76)(3, -.41) |
| | | | | | (5, -1.17) |
| Dim 4 | | | -1.50 (-5.98) | -1.39 (-5.88) | (2, -.58)(3, -.76)(4, -.61) |
| Dim 5 | | | -0.37 (-2.44) | -0.35 (-2.43) | (3, -.47)(4, -.39)(5, 4.1) |
| Dim 6 | | | ns | ns | (4, 31) |
| R^2 (Adj) | 0.67 | 0.70 | 0.73 | 0.76 | 0.76 |

Notes:

Entries are coefficients, t value .n = 1042

Slope = Dummy variables to alter the exponent in the range of AQL scores (0.25 > 0.5) (0.5, > 0.75), (0.75 < 1.0) (>1.0, < 1.25)

Dimi = Dimension i score * Ln AQL

** Column 3 entry (x, - .y) = dimension (level, coefficient)
where all entries are significant at 0.05 percent

The preliminary results reported here require additional testing before use in evaluation studies. This comment applies only to the current draft which, at the time of writing, has not been subject to thorough internal scrutiny. In particular there is a need to investigate the reason for the highly variable accuracy of prediction shown in Table 11 and to check the validity of the econometric results.

5 Discussion and Future Work

AQoL 1 introduced a number of desirable properties into the modelling of multi attribute utility instruments. These included a descriptive system incorporating a multi level model. The construct health was disaggregated into major dimensions and, at a lower level, these dimensions were each described by three items. Unlike alternative instruments the concept 'health' was modelled in terms of handicap. This implicitly incorporates the theory that utility—people's preferences—depend primarily upon the effect of their mental and physical state upon their ability to function in a social context. The multi level structure was also imposed in an attempt to partition the effects of redundancy—double counting—between the lower level items. This permitted a degree of redundancy within dimensions and this, in turn, permitted a more sensitive description of health states.

There was a two-fold motivation for the construction of AQoL 2. First, despite its relatively favourable performance against other MAU instruments the upper end of the descriptive system—health states close to full health—were insufficiently sensitive for the evaluation of health promotion interventions or other measures assisting people already in relatively good health. Secondly, despite the measures described above AQoL utilities were lower, not higher, than those in alternative instruments. (This is discussed in detail in Richardson, Hawthorne et al 2001). The authors hypothesised reasons for this and built in measures to off-set bias in the second instrument.

More generally the construction of AQoL 2 allowed a number of further initiatives with respect to both the descriptive system and the scoring algorithm. These were as follows:

1 Descriptive System

Increased sensitivity in the region of good health by the addition of additional items and item responses. In contrast with AQoL 1 which employed exploratory factor analysis AQoL 2 used the more recent techniques of multi level modelling to create a descriptive system. The resulting fit of the descriptive system to the pattern of responses in the construction survey was outstanding. The confirmatory factor index of 0.99 indicates that the structure of the model fully explains systematic variation between individual responses.

2 Scaling

The scaling of AQoL 2 was innovative in four respects. For the first time an attempt was made to elicit 'deliberative weights', ie a procedure was introduced to encourage contemplation between interviews. Second, and reflecting concern with the low disutility scores in AQoL 1, visual props were used specifically designed to off-set bias through 'focusing'. The tendency to judge all health by a possibly restricted number of negative elements was off-set by a visual representation of all dimension health states simultaneously. The third innovation was the use of a rating scale in combination with the time trade-off interviews. It will be possible to subdivide TTO based category responses by the results on the rating scale. This analysis has not been carried out to date. Finally, AQoL 2 employed a two part scaling procedure which involved, first, the standard multiplicative model described by decision theory (see Von Winterfeldt and Edwards 1986). This

was then used in a second stage econometric explanation of over 1,000 observations of multi attribute health states which had been collected for this second stage analysis.

Future Research

Instruments are never 'validated' in the sense that they are proven to be valid and reliable in all contexts. Instrument construction must be followed up with a *process of validation*. In each context the hypothesis is tested that the instrument performs in a particular way. The more tests the greater the confidence in the instrument's validity. As AQoL 2 was constructed to achieve upper end sensitivity for the purposes of evaluating health promotional activities validity testing in this context should be high on the research agenda.

A second set of extensions may increase the construct validity of AQoL 2 by re-estimating the final utility weights in the second stage econometric scaling of AQoL 2. One such study with respect to the visually impaired is in process and by mid 2004 should result in a 'Vis-QoL' instrument. Specific plans have been drawn up for a Psy-QoL (psychiatric) quality of life instrument. While AQoL 1 has already performed well in this domain and AQoL 2 will be better the importance of mental health for the future burden of disease warrants an enhanced and validated multi attribute utility instrument.

Further data collection could and should be conducted to improve the population sample which is under-represented in the present AQoL. This includes a larger number of respondents with low educational attainment and NESP groups. Along a second dimension additional multi attribute states need to be measured which result in low disutility scores.

The final dimension of subsequent work includes further examination of alternative scaling systems. The AQoL 2 data collection obtained, for the first time, information obtained by time trade-off, person trade-off and self TTO, ie the willingness to trade life for an improvement in the respondent's current health state. Preliminary results indicate the need for significant research into this important but almost ignored perspective. Some of these issues are discussed further in Report 3.

Comparing AQoL 1 and AQoL 2 one difference stands out. This is that the disutility scores measured by AQoL 2 are significantly less than those elicited during the AQoL 1 interviews. In both projects interviewers were thoroughly trained and monitored. Editing of data was similar. The remaining explanation for the discrepancy is—as hypothesised at the beginning of the AQoL 2 study—that without visual aids AQoL 1 results were significantly influenced by the 'focusing effect'; that is, respondents did not take into account the fact that other elements of health not directly described in each health state scenario was at its best level. As described and illustrated earlier, AQoL 2 forced respondents to recognise the overall health state.

This result is important. The literature has paid very little attention to the importance of the 'fieldwork' methodology. The present results indicate that these may influence numerical values as much as or more than the choice of scaling instrument or model.

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Appendix 1 AQoL 2 Questionnaire

Assessment of Quality of Life (AQoL) Mark 2.

How to answer

Please read the Explanatory Statement and sign a consent form before you begin.

Each question has two parts. You answer the first part by ticking the box next to the response that best fits your situation. The second part of each question is a horizontal scale. You mark a cross somewhere along the scale to show how your quality of life is affected by the situation you describe in your answer to the first part of the question. Look at the example answer for more information.

Example answer

Mr Smith's relationships with his family make him generally happy, so he marks the second box from the top to show his answer :

i) My relationships with my **family** make me:

- very happy
- generally happy
- neither happy nor unhappy
- generally unhappy
- very unhappy
- this question is not relevant to me..

Mr Smith feels his quality-of-life is greatly improved by the fact that his relationships with his family make him "generally happy", so he marks a cross on the left hand end of the scale.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

When you finish answering all the questions, please hand the questionnaire back.

Many thanks!

Assessment of Quality of Life (AQoL) Mark 2.

Q1 How much help do I need with household tasks (eg preparing food, cleaning the house or gardening):

- I can do all these tasks very quickly and efficiently without any help
- I can do these tasks relatively easily without help
- I can do these tasks only very slowly without help
- I cannot do most of these tasks unless I have help
- I can do none of these tasks by myself.

| |
|--|
| <p>How does this affect my quality of life?</p> <p>greatly improved no effect either way totally ruined</p> |
|--|

Q2 Thinking about how easy or difficult it is for me to get around by myself outside my house (eg shopping, visiting):

- getting around is enjoyable and easy
- I have no difficulty getting around outside my house
- a little difficulty
- moderate difficulty
- a lot of difficulty
- I cannot get around unless somebody is there to help me.

| |
|--|
| <p>How does this affect my quality of life?</p> <p>greatly improved no effect either way totally ruined</p> |
|--|

Q3 Thinking about how well I can walk:

- I find walking or running very easy
- I have no real difficulty with walking or running
- I find walking or running slightly difficult. I cannot run to catch a tram or train, I find walking uphill difficult
- walking is difficult for me. I walk short distances only, I have difficulty walking up stairs
- I have great difficulty walking. I cannot walk without a walking stick or frame, or someone to help me
- I am bedridden.

| |
|--|
| <p>How does this affect my quality of life?</p> <p>greatly improved no effect either way totally ruined</p> |
|--|

Q4 Thinking about washing myself, toileting, dressing, eating or looking after my appearance:

- these tasks are very easy for me
- I have no real difficulty in carrying out these tasks
- I find some of these tasks difficult, but I manage to do them on my own
- many of these tasks are difficult, and I need help to do them
- I cannot do these tasks by myself at all.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q5 My close and intimate relationships (including any sexual relationships) make me:

- very happy
- generally happy
- neither happy nor unhappy
- generally unhappy
- very unhappy

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q6 Thinking about my health and my relationship with my family:

- my role in the family is unaffected by my health
- there are some parts of my family role I cannot carry out
- there are many parts of my family role I cannot carry out
- I cannot carry out any part of my family role.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q7 Thinking about my health and my role in my community (that is to say neighbourhood, sporting, work, church or cultural groups):

- my role in the community is unaffected by my health
- there are some parts of my community role I cannot carry out
- there are many parts of my community role I cannot carry out
- I cannot carry out any part of my community role.

| | | |
|--|----------------------|----------------|
| How does this affect my quality of life? | | |
|  | | |
| greatly improved | no effect either way | totally ruined |

Q8 How often did I feel in despair over the last seven days?

- never
- occasionally
- sometimes
- often
- all the time.

| | | |
|--|----------------------|----------------|
| How does this affect my quality of life? | | |
|  | | |
| greatly improved | no effect either way | totally ruined |

Q9 And still thinking about the last seven days: how often did I feel worried:

- never
- occasionally
- sometimes
- often
- all the time.

| | | |
|--|----------------------|----------------|
| How does this affect my quality of life? | | |
|  | | |
| greatly improved | no effect either way | totally ruined |

Q10 How often do I feel sad?

- never
- rarely
- some of the time
- usually
- nearly all the time.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q11 When I think about whether I am calm and tranquil or agitated:

- always calm and tranquil
- usually calm and tranquil
- sometimes calm and tranquil, sometimes agitated
- usually agitated
- always agitated.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q12 Thinking about how much energy I have to do the things I want to do, I am:

- always full of energy
- usually full of energy
- occasionally energetic
- usually tired and lacking energy
- always tired and lacking energy.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q13 How often do I feel in control of my life?

- always
- mostly
- sometimes
- only occasionally
- never.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q14 How much do I feel I can cope with life's problems?

- completely
- mostly
- partly
- very little
- not at all.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q15 Thinking about how often I experience **serious pain**. I experience it:

- very rarely
- less than once a week
- three to four times a week
- most of the time.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q16 How much pain or discomfort do I experience:

- none at all
- I have moderate pain
- I suffer from severe pain
- I suffer unbearable pain.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q17 How often does pain interfere with my usual activities?

- never
- rarely
- sometimes
- often
- always.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

Q18 Thinking about my vision (using my glasses or contact lenses if needed):

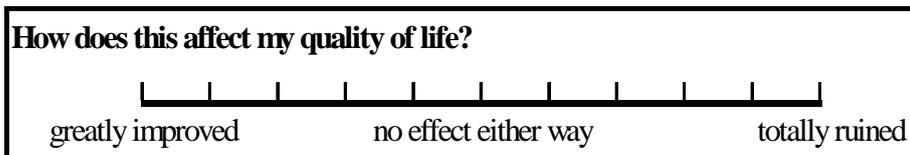
- I have excellent sight
- I see normally
- I have some difficulty focusing on things, or I do not see them sharply. E.g. small print, a newspaper or seeing objects in the distance.
- I have a lot of difficulty seeing things. My vision is blurred. I can see just enough to get by with.
- I only see general shapes. I need a guide to move around
- I am completely blind.

How does this affect my quality of life?

greatly improved no effect either way totally ruined

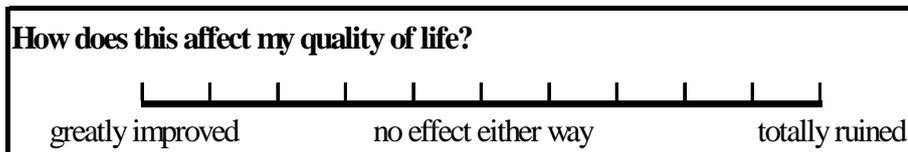
Q19 Thinking about my hearing (using my hearing aid if needed):

- I have excellent hearing
- I hear normally
- I have some difficulty hearing or I do not hear clearly. I have trouble hearing softly-spoken people or when there is background noise.
- I have difficulty hearing things clearly. Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
- I hear very little indeed. I cannot fully understand loud voices speaking directly to me.
- I am completely deaf.



Q20 When I communicate with others, e.g. by talking, listening, writing or signing:

- I have no trouble speaking to them or understanding what they are saying
- I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
- I am understood only by people who know me well. I have great trouble understanding what others are saying to me.
- I cannot adequately communicate with others.



AQoL Study Background Questions

Please tick one box per question.

21 Are you:

male female

22 In what year were you born? 19_____

23 Where were you born?

Australia Other country? ☞ Which one? _____

24 Is English your first language?

yes no ☞ Specify: _____

25 What is your highest level of education?

- primary schooling only
- secondary schooling completed
- secondary schooling not completed. ☞ How many years completed? ____
- trade qualification or TAFE: ☞ Specify course: _____
- University or other tertiary study
- Other or not applicable: please describe: _____

26 Which best describes your work situation: (Tick as many boxes as apply)

- full-time: self-employed or employee
- part-time: self-employed or employee
- unemployed, seeking work
- working in the home / home duties
- retired
- student
- other: please describe: _____

If You Are Employed Or Self-Employed Or Seeking Work:

27 What is your occupation? _____

28 What do you do in your job? _____

29 Do you receive any Government pension or benefit?

no

yes ➔ Which pension(s) or benefit(s): _____

30 Are you:

married or living with a partner

single: never married

single: widowed

single: divorced or separated

31 How would you rate your current level of health, for someone of your age?

excellent

very good

good

fair

poor

very poor

extremely poor

32 Mark one box on the scale to show how important or unimportant is religion or spirituality is in your life



very
important

important

unimportant

very
unimportant

33 Please mark one box to show your HOUSEHOLD income, either annually, monthly or weekly. Include income that comes to the household from all sources. You may estimate either before or after tax.

| yearly | monthly | fortnightly | weekly |
|---|------------------|--------------------|-------------------|
| <input type="checkbox"/> under \$20,000 | under \$1,665 | under \$800 | under \$385 |
| <input type="checkbox"/> \$20,001-\$30,000 | \$1,665-\$2,500 | \$800-\$1,155 | \$385-\$575 |
| <input type="checkbox"/> \$30,001-\$40,000 | \$2,501-\$3,330 | \$1,156-\$1,535 | \$576-\$770 |
| <input type="checkbox"/> \$40,001-\$50,000 | \$3,331-\$4,165 | \$1,536-\$1,925 | \$771-\$960 |
| <input type="checkbox"/> \$50,001-\$60,000 | \$4,166-\$5,000 | \$1,926-\$2,305 | \$961-\$1,155 |
| <input type="checkbox"/> \$60,001-\$80,000 | \$5,001-\$6665 | \$2,306-\$3,075 | \$1,156-\$1,540 |
| <input type="checkbox"/> more than \$80,000 | more than \$6665 | more than \$3,075 | more than \$1,540 |

34 Please mark a box to show whether your answer is before or after tax.

before tax

after tax

Thank you! Please bring this questionnaire with you when you attend the group session/interview.

Appendix 2 Introductory letter and explanatory statement

23 Aug 2002

Wave 9(ii)

Mr/Ms «Initials» «Surname» «ID»

«Street_Number__Address_line_1»,

«Suburb»

«St» «PC»

Re: **Assessment of Quality of Life (AQoL) Project**

Dear Mr or Ms «Surname»,

I am writing to ask if you, or a member of your household, will agree to participate in an important medical services research study that will have major benefits to the community. The aim of the study is to find out what Victorians value and what they mean by “good health” and “quality of life”. This information will help us identify which services should be added to Medicare. Your views on how you value different health states are very important.

I have described the study in more detail in the Explanatory Statement attached. In the next week, a member of my research team will telephone you at home. If a member of your household is agreeable, he or she will be sent a questionnaire and an interview time will be arranged.

Alternatively, I would greatly appreciate if you would ring the project manager, Angelo Iezzi, in the next few days on 9496 4412 during business hours (mobile 0419 338 241) to register your willingness or refusal to participate in the AQoL study.
One participant per household, 18 years of age or over.

Your participation in the study will involve attending two interviews involving the participant with an interviewer, during the day or evening, either at home or at one of our interview offices in your local area for approximately 1-2 hours. The interviews involve an interesting and challenging process of making judgements about a number of different health states.

For interviews conducted at an interview location, participants will receive a payment of \$50 after the second meeting, to cover travel costs. Home interviews will not attract any payment.

Various postcodes have been selected to represent a cross-section of the Australian population. Within your postcode, your name was chosen by random selection from the telephone directory. Your answers will represent the views of Victorians living in households like yours.

I do hope you can assist me with this important task.

Yours sincerely,

Jeff Richardson

Professor and Director

Health Economics Unit, Centre for Health Program Evaluation

Monash University

Assessment of Quality of Life (AQoL) Project

Explanatory Statement

The “Assessment of Quality of Life” (AQoL) research study has developed a set of questions that can measure quality of life before and after a patient receives medical care.

The present AQoL questionnaire is being used by more than 40 research teams (see accompanying list) to measure and compare the effects of different health programs. It is an important research instrument and was created to help these teams identify the medical services which best improve a person’s quality of life.

600 people selected at random from the telephone directory in Victoria are being asked to assist us in developing an improved version of the AQoL questionnaire. As one of the selected households, your personal involvement is of vital importance in ensuring that the research results give as accurate a picture as possible of the views of the Victorian population.

Your role in the research study

If you agree to participate, we will ask you a series of questions about different health states and how you would value these states. We would like to ask questions in two interviews and, if you agree, we will give you some of the questions to think about after the first interview.

These questions involve different choices about the quality and length of life that you would select if you had to make a choice in real life.

The questionnaire may be completed at the Centre for Health Program Evaluation in Heidelberg West or at one of our interview offices in your local area. We will grant you a \$50 payment after the second interview, to cover your travel costs and associated expenses.

Your participation is voluntary. You may refuse to answer any questions or withdraw from the project at any stage.

All your answers are confidential and your privacy will be protected, under strict university rules for the conduct of research. It will not be possible to identify individual people in the research reports. Your name and address will not be recorded with your answers, and will be erased when the study is completed.

Who is conducting the study

The research is being carried out by the Centre for Health Program Evaluation, a joint centre of Melbourne and Monash Universities, which has established an international reputation for its pioneering work on health related quality of life.

The Victorian Health Promotion Foundation, VicHealth, is funding the study.

The principal investigator is Professor Jeff Richardson, who may be contacted on (03) 9496 4433.

Should you have any concerns as a result of your involvement in this research, you may contact a professional adviser. The adviser is independent of the study and may be able to give you advice or refer you to a person or service to assist with any problem.

The adviser, Susan Day, may be contacted at the Centre for Health Program Evaluation on (03) 9496 4408.

Should you have any complaint concerning the manner in which this research (ref 98/140) is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary
The Standing Committee on Ethics in Research on Humans
Monash University
Wellington Road
Clayton, Victoria, 3168
Tel. (03) 9905 2052, Fax (03) 9905 1420

The University reference number of the project is 98/140

Appendix 3 TTO questionnaire

Examples of visual props used in the TTO interview, including:

Health State Summaries

C Type Questions 1 to 6

All Worst

Own Health

Multi Attribute Question

Scoring Sheet

Health State Summaries



social & family

My role in the family and community is unaffected by my health. My close and intimate relationships make me very happy.



independent living

I can live independently. I can do all household and personal care tasks (such as dressing myself) quickly and efficiently without any help. I find walking, running and getting around outside my house is enjoyable and easy.



mental health

I have good mental health. I am never worried or in despair, I never feel sad and I am always calm and tranquil.



ability to cope

I always feel in control of my life. I feel that I can completely cope with life's problems. I am always full of energy.



no pain

I have no pain. I very rarely experience serious pain or have other pain or discomfort. Pain never interferes with my activities.



seeing & hearing

I have excellent sight and hearing. I have no trouble speaking to others or understanding what they are saying.



social & family

My social and family relationships are badly affected by my health.

Because of my health, I cannot carry out any part of my family role or of my community role. My close and intimate relationships make me very unhappy.



independent living

I cannot live independently because of my health.

I can do no household tasks or personal care tasks by myself. I am bedridden and I cannot get around outside my house unless somebody is there to help me.



mental health

I have poor mental health.

I am worried and in despair all the time. I am always agitated and nearly always sad.



ability to cope

I cannot cope with life's problems at all.

I never feel I am in control of my life and I am always tired and lacking energy.



pain

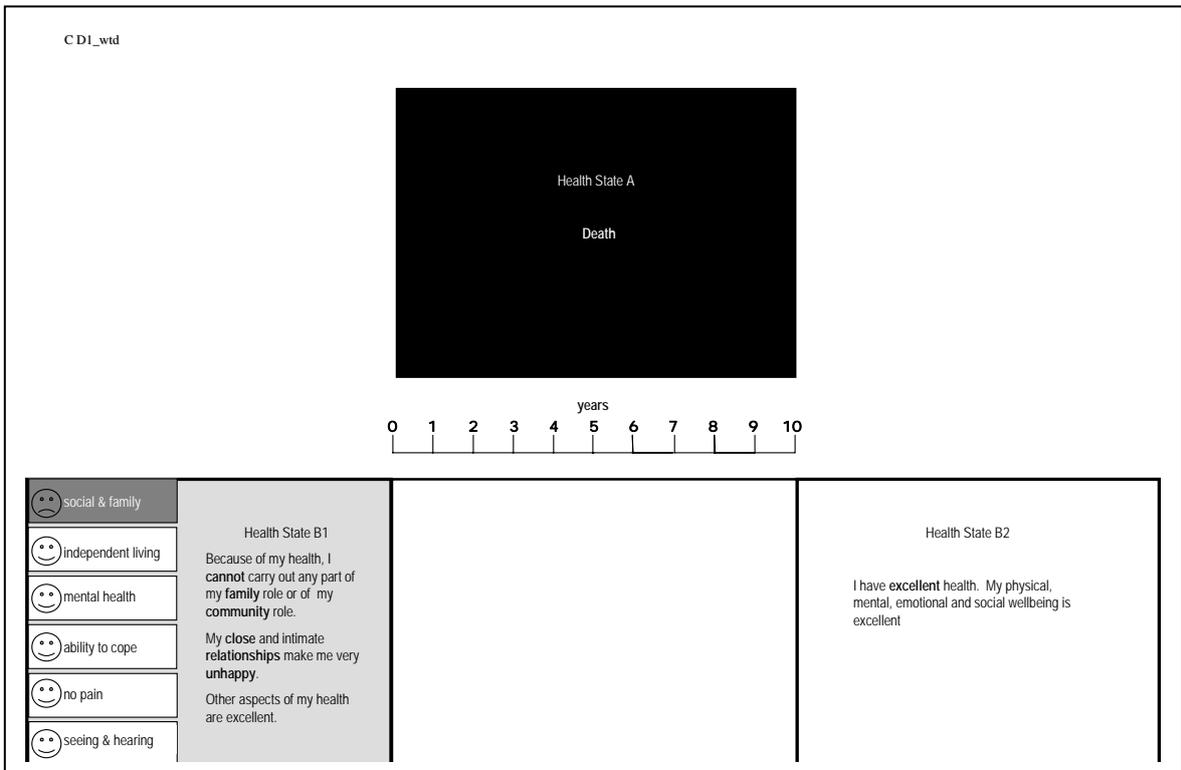
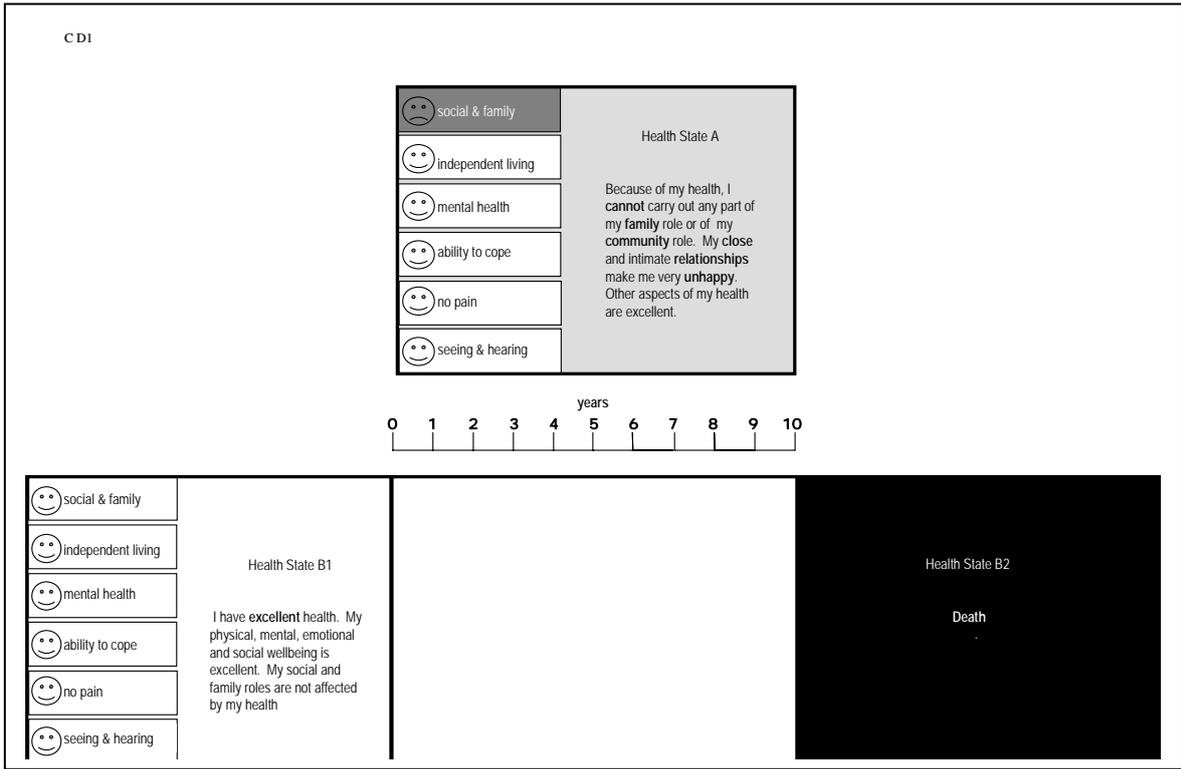
I suffer unbearable pain. Most of the time I have serious pain which always interferes with my activities.

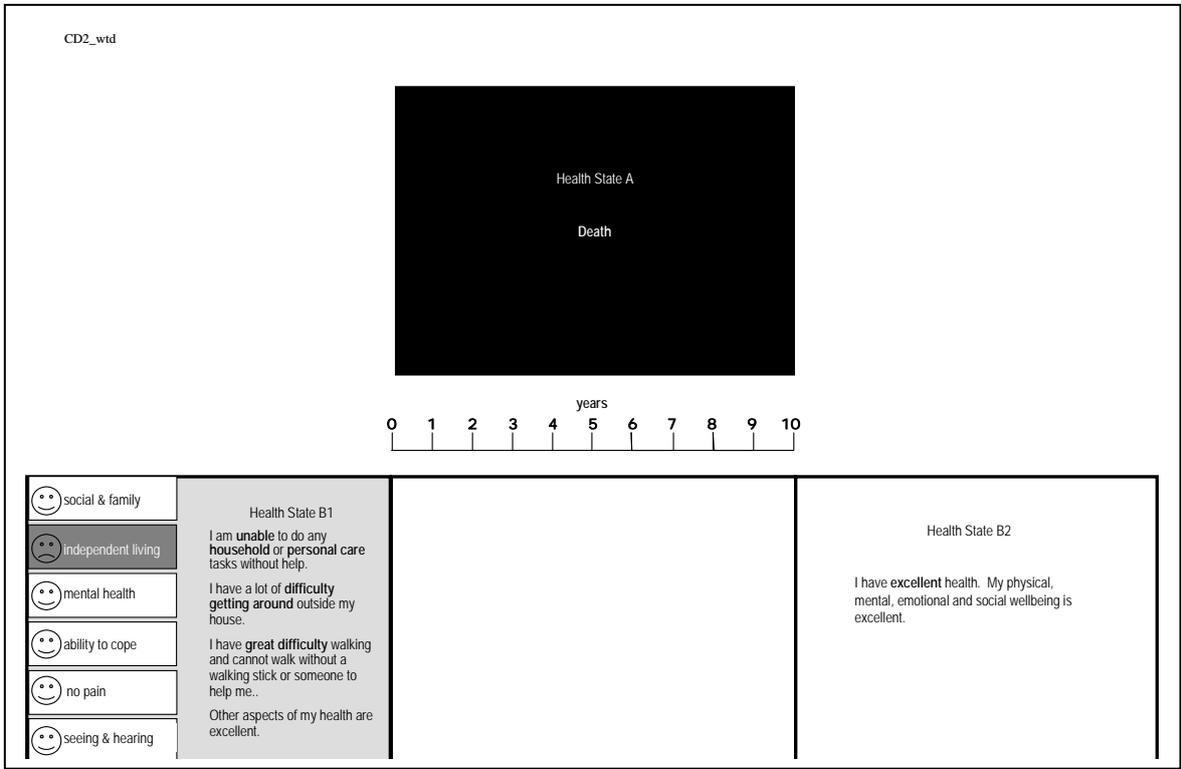
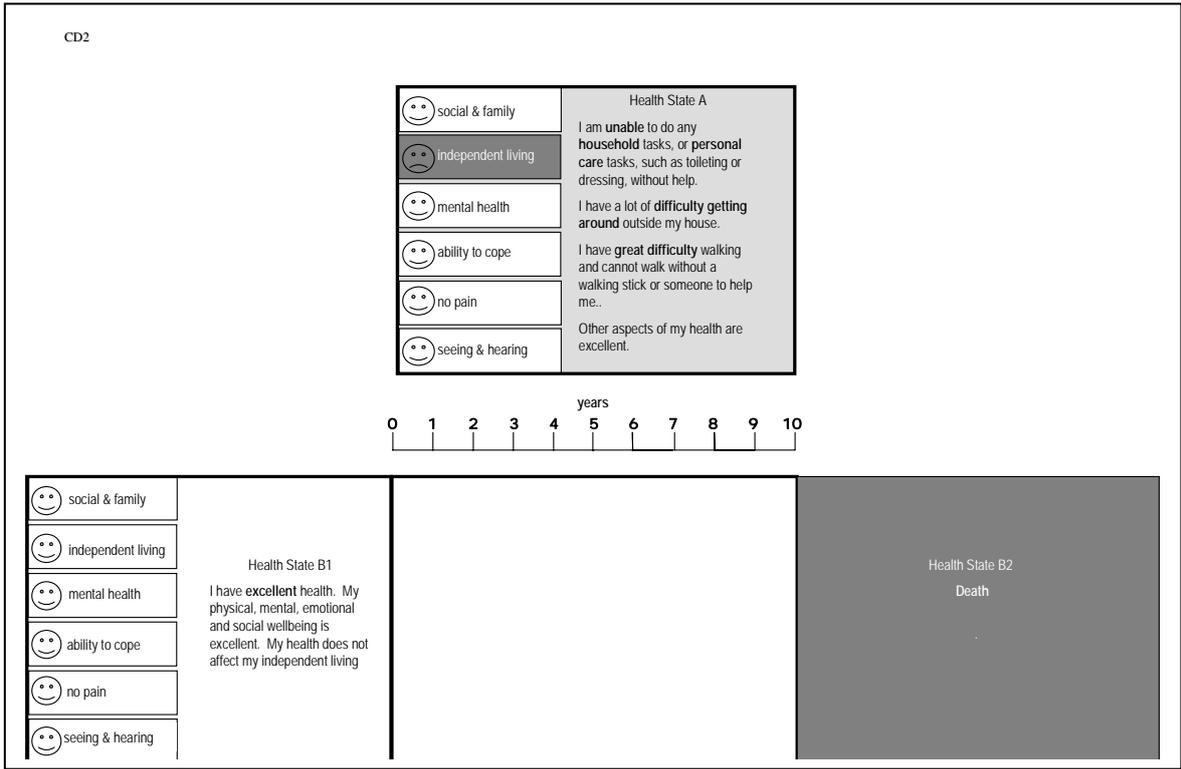


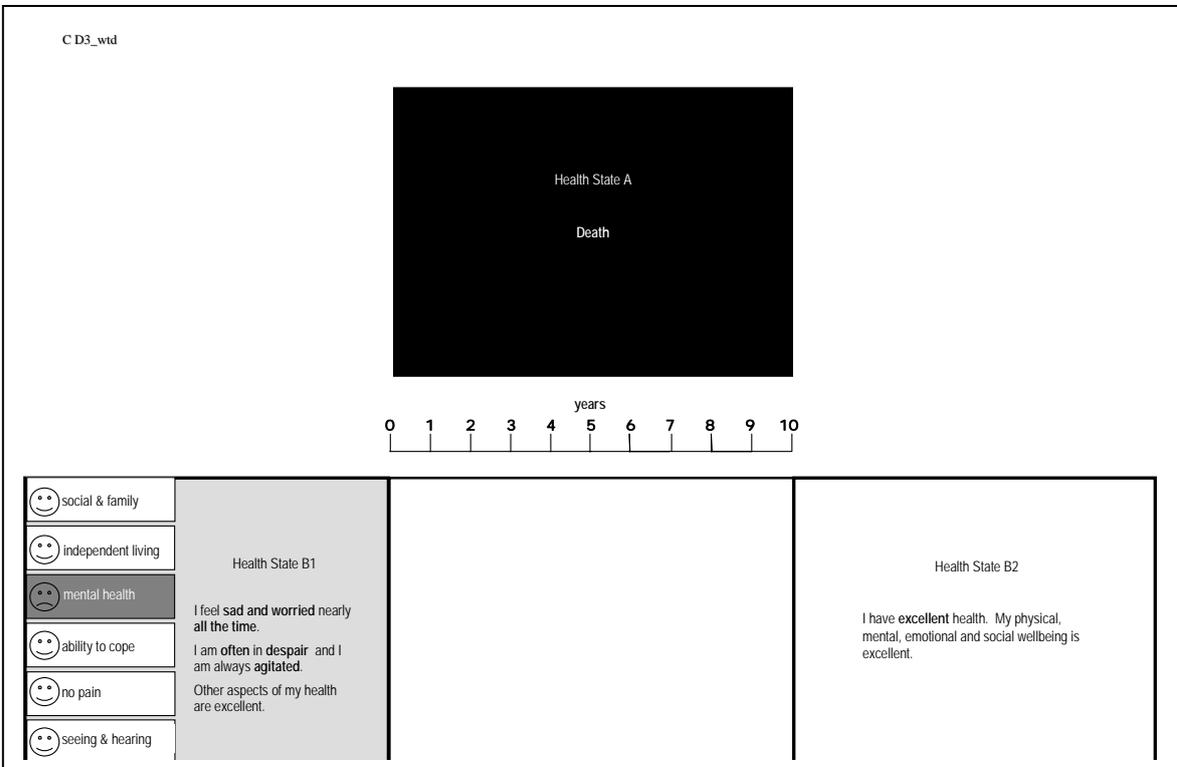
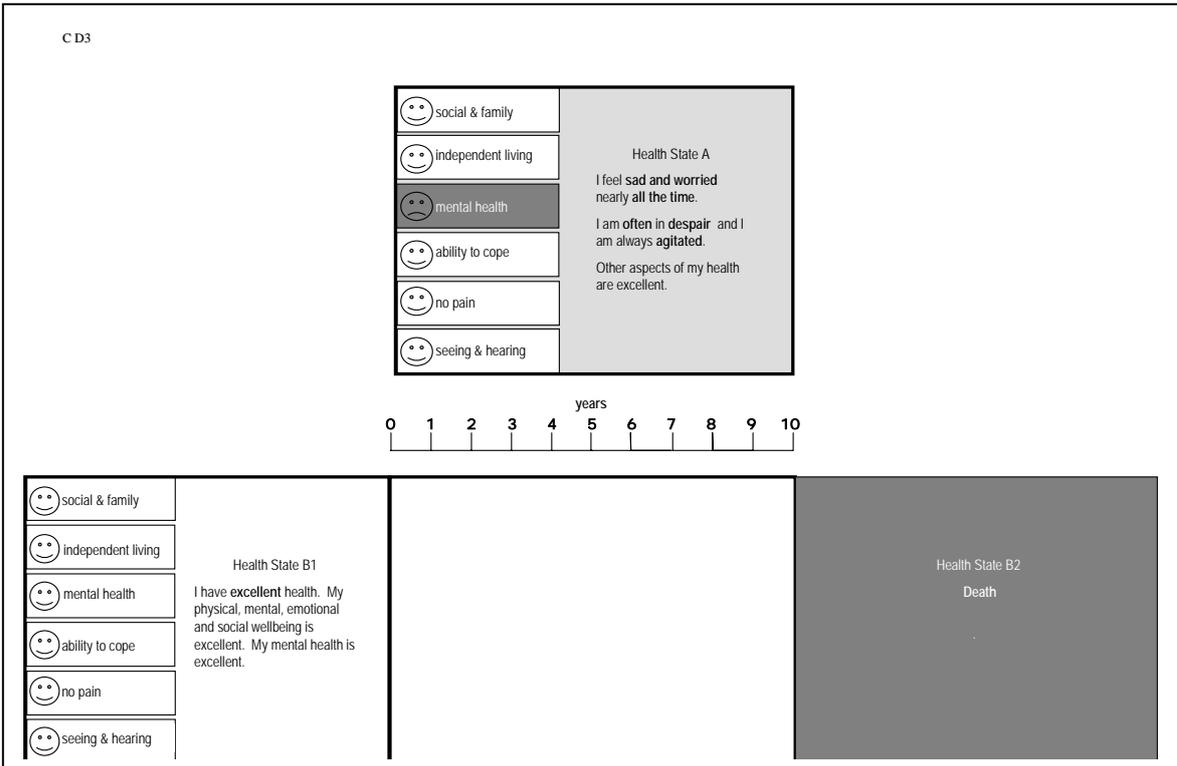
seeing & hearing

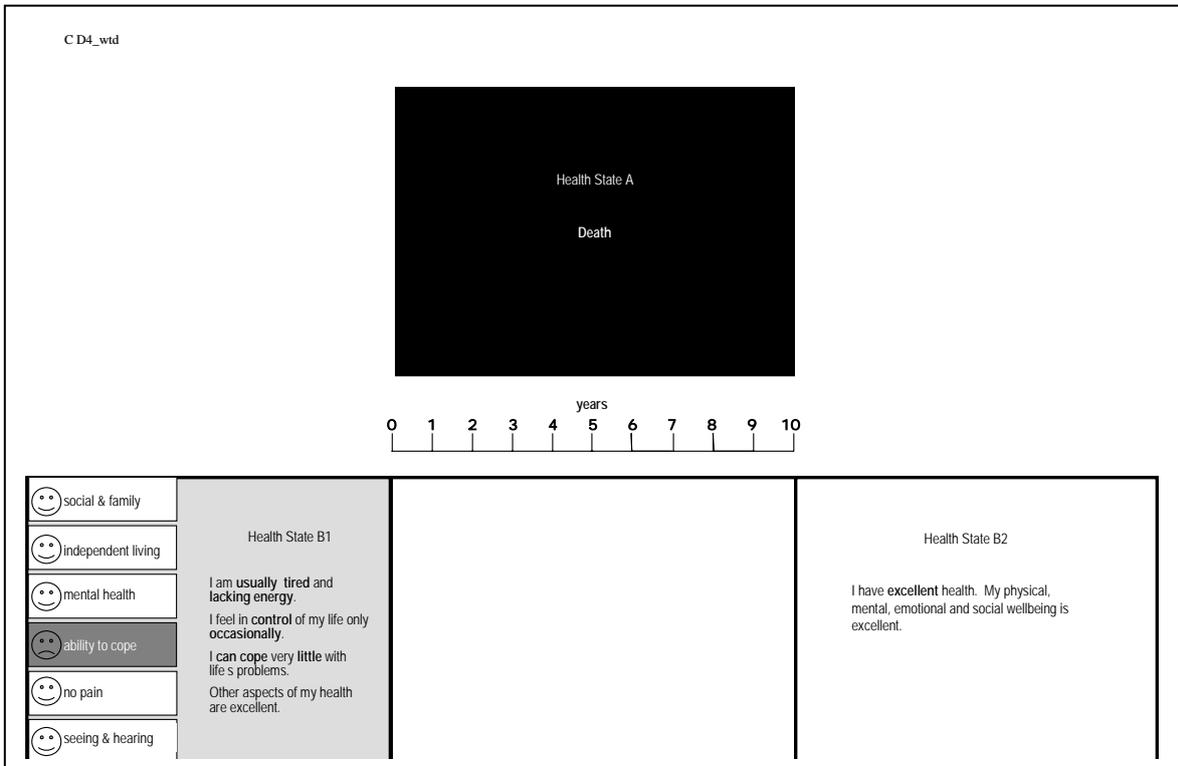
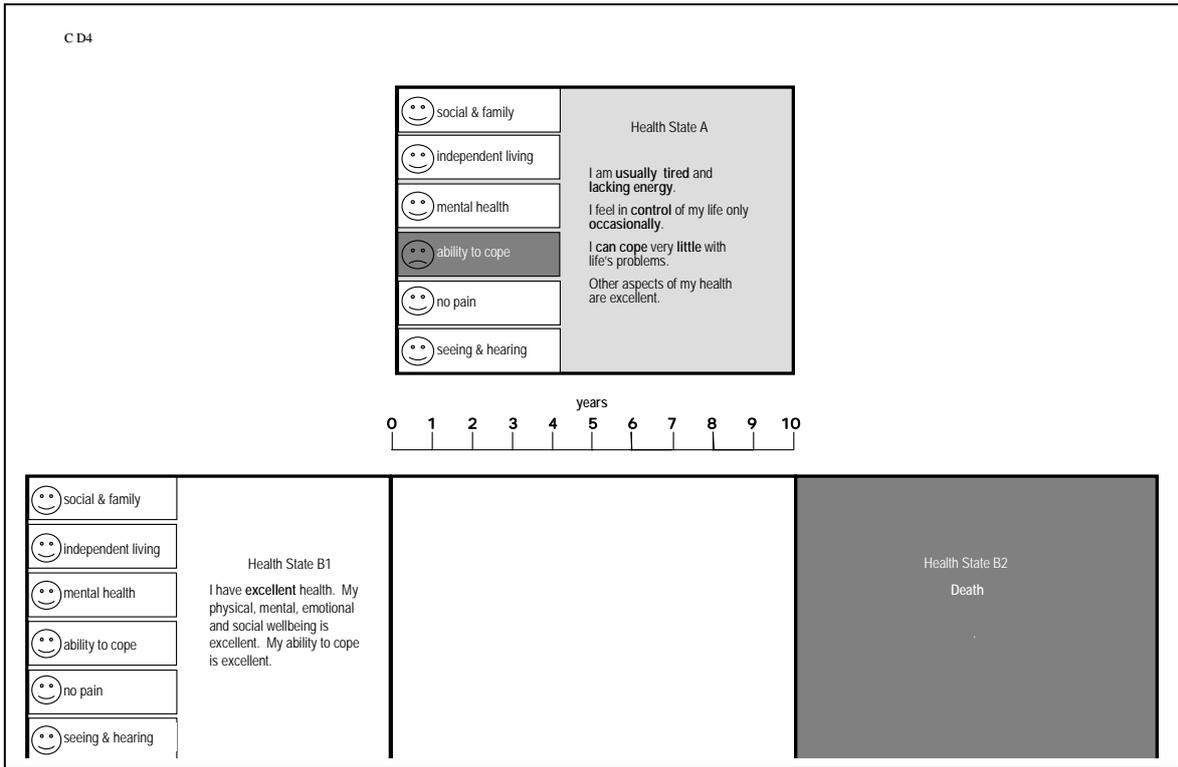
I am completely blind and deaf.

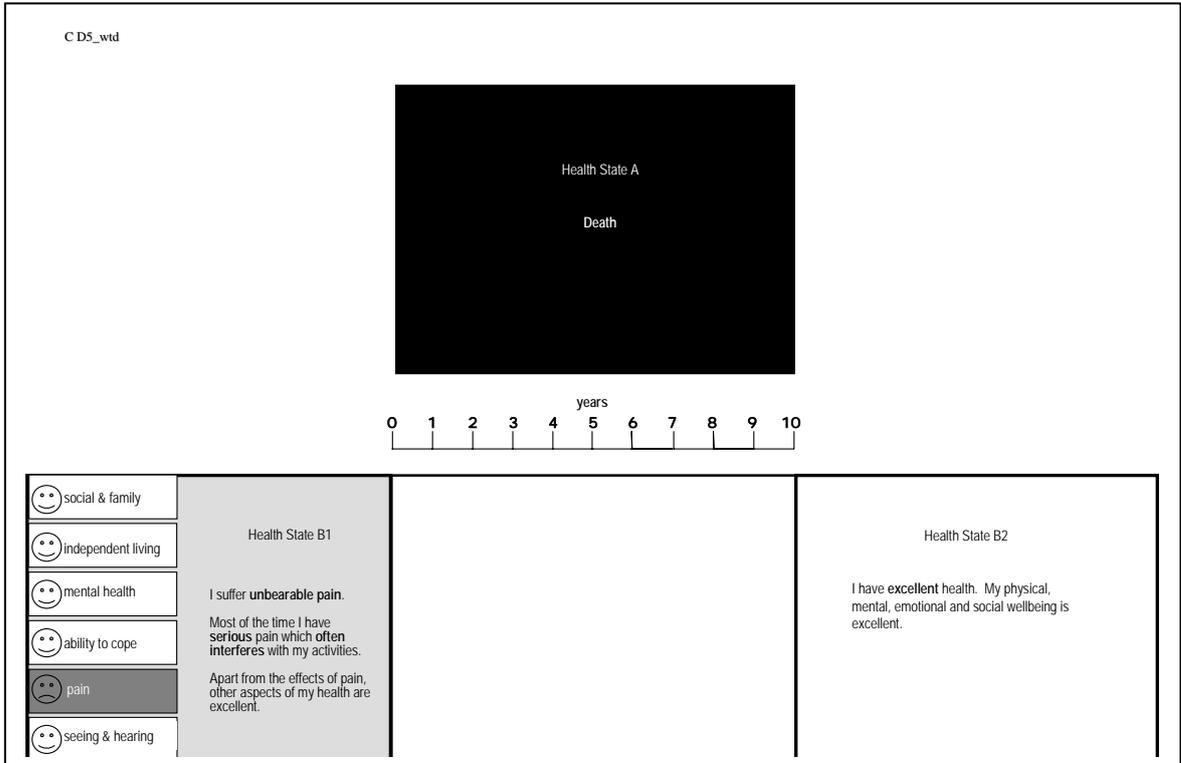
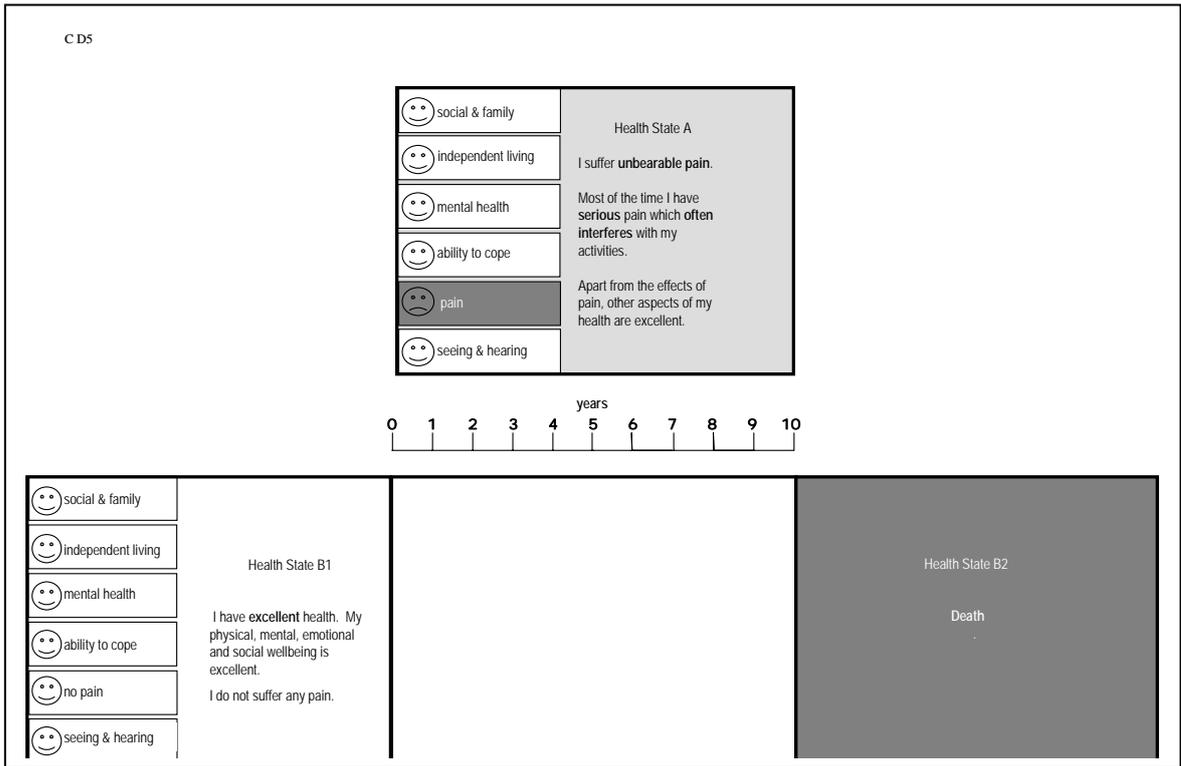
I cannot adequately communicate with others.

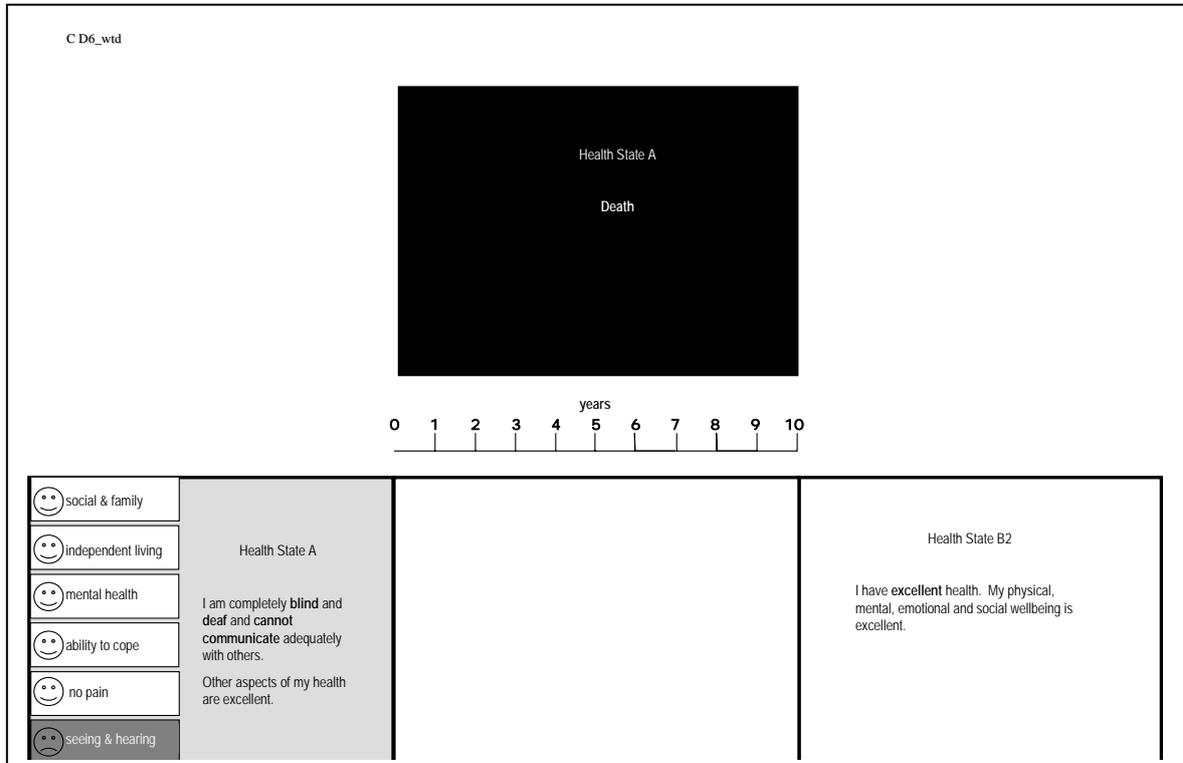
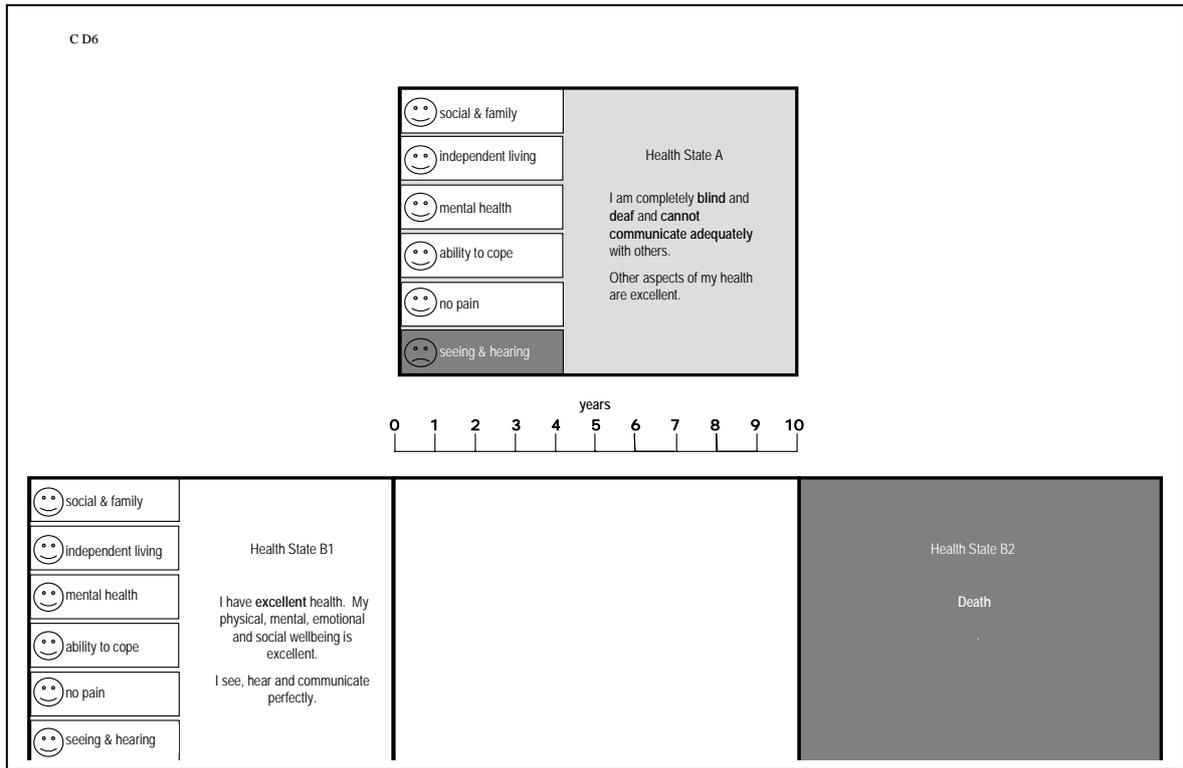


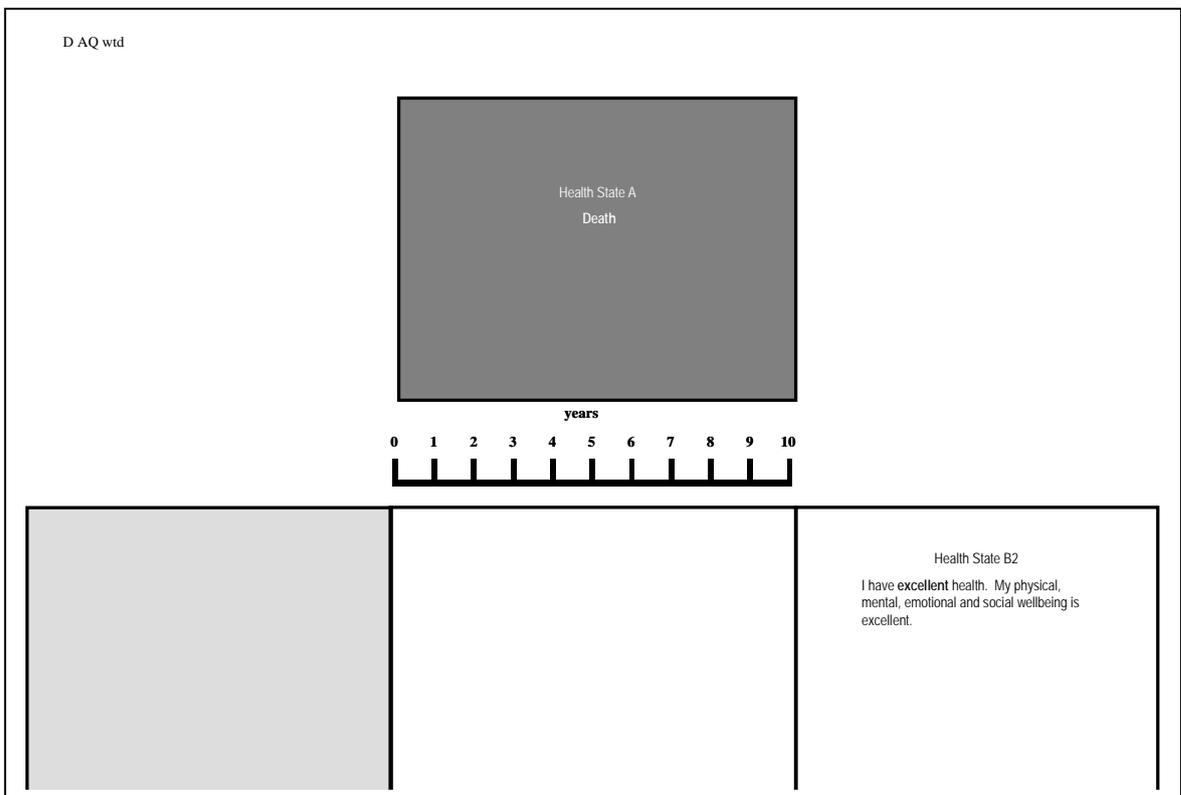
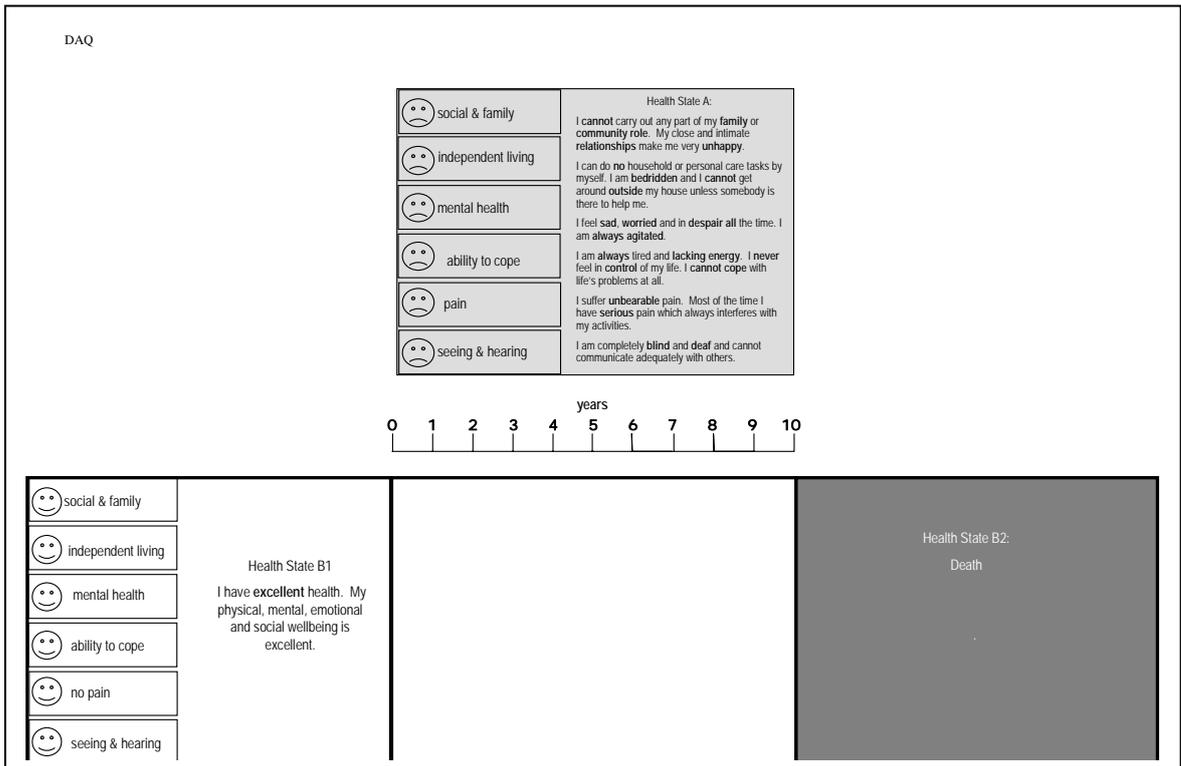


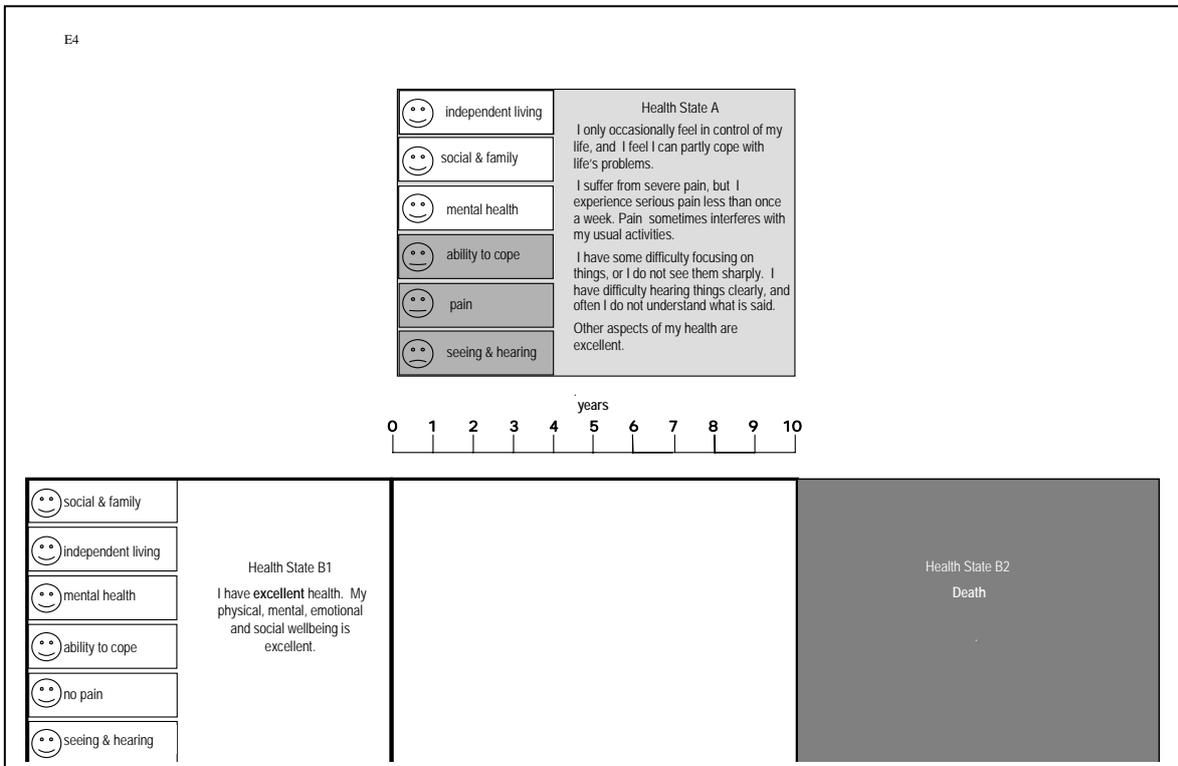
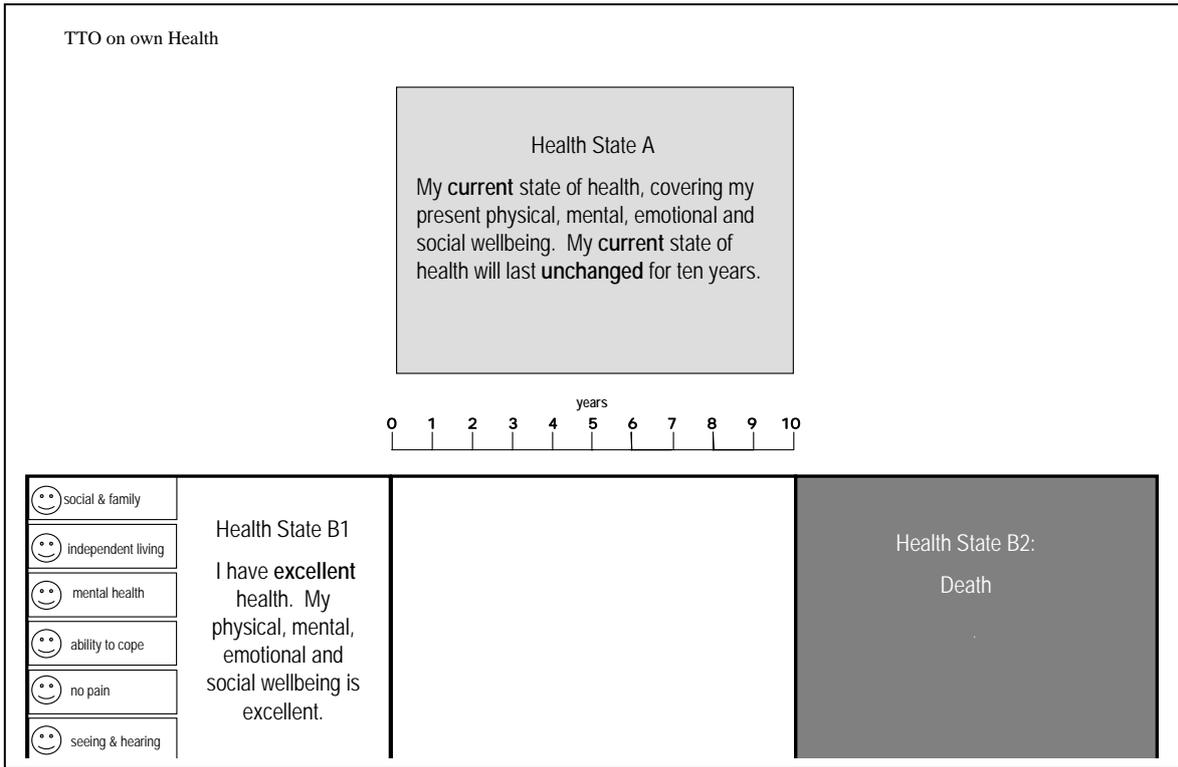


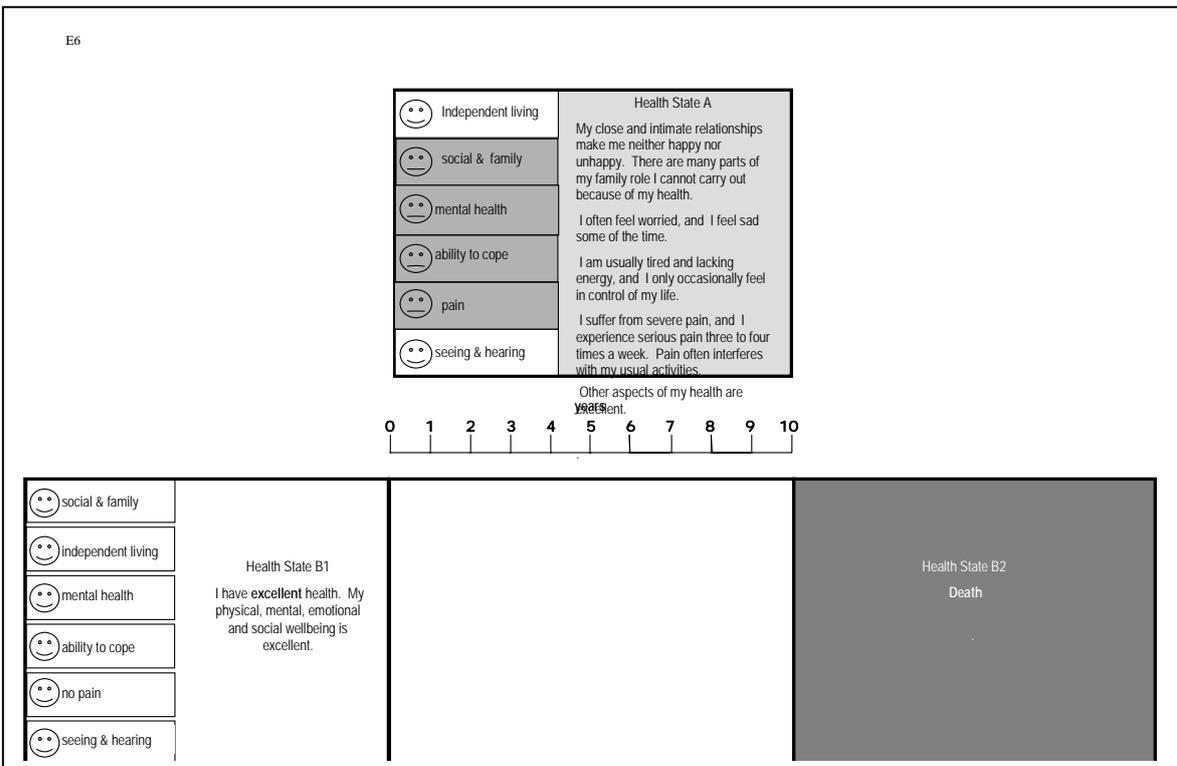
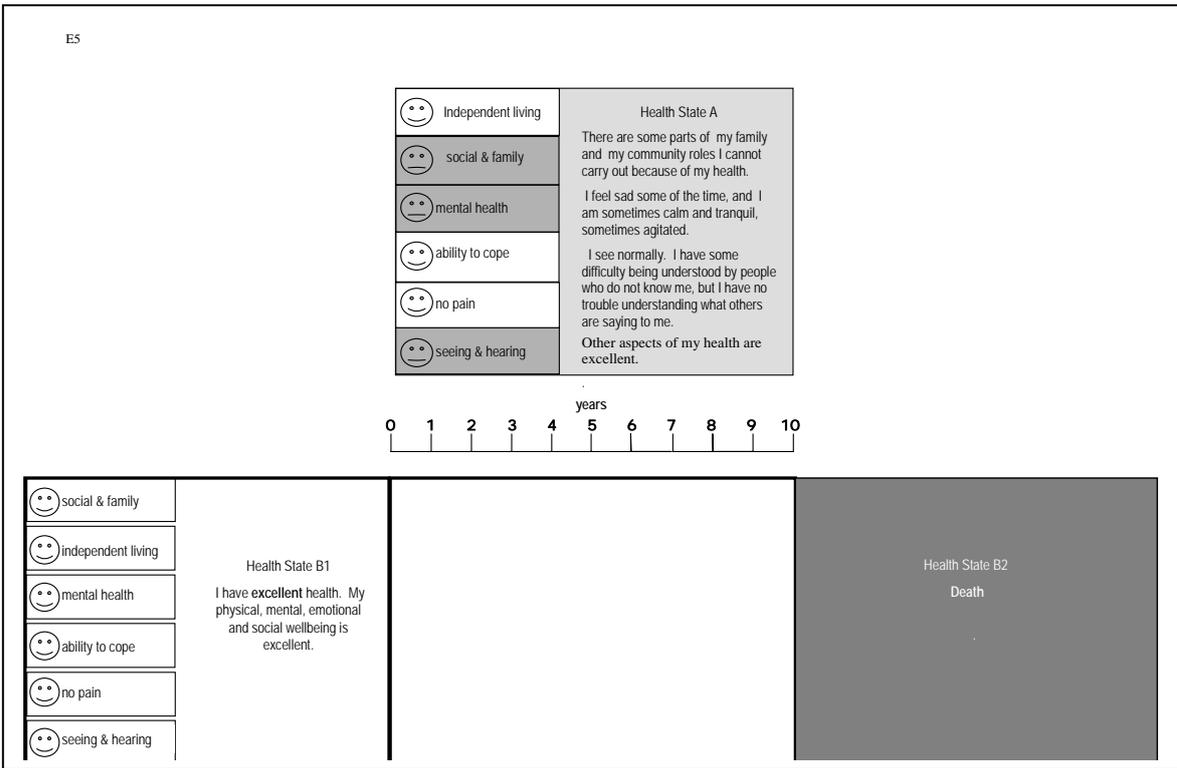












AQoL TTO Scoring Sheet - Sort 2
(Type C, D, E only)

ID Number.....
Interview Date.....

| Item | Score out of 10 | Notes |
|--------------------------------------|-----------------|--|
| Comparing | | |
| Sit in the cinema or walk and drink? | | |
| Simple example | | |
| Health State Summaries | | |
| TTO on your current health state | | |
| <u>C- TYPE</u> | | |
| Item C D6 | | If = 0 or less, go to CD6 wtd |
| Item C D6 Worse than Death | | |
| Item C D1 | | If = 0 or less, go to CD1wtd |
| Item C D1 Worse than Death | | |
| Item C D5 | | If = 0 or less, go toCD5 wtd |
| Item C D5 Worse than Death | | |
| Item C D2 | | If = 0 or less, go to CD2 wtd |
| Item C D2 Worse than Death | | |
| Item C D3 | | If = 0 or less, go to CD3 wtd |
| Item C D3 Worse than Death | | |
| Item C D4 | | If = 0 or less, go to CD4 wtd |
| Item C D4 Worse than Death | | |
| <u>D-TYPE</u> | | |
| Item DAQ | | If = 0 or less, go to S48, otherwise S49 |
| Item D AQ Worse Than Death | | |
| <u>E-TYPE</u> | | |
| Item E4 | | |
| Item E5 | | |
| Item E6 | | |

Appendix 4 TTO Schedule

TTO Instructions: D. Question Sorts

Different participants will be asked slightly different sets of TTO and PTO questions. You will be told which set of questions (a sort) to ask different participants in advance.

- (i) D type TTO and PTO questions – first question for all participants.
- (ii) C type TTO and PTO questions – to follow D type, all participants to complete CD1-CD6 questions, but the order of CD1-CD6 questions will vary (because the ordering of questions may affect responses).
- (iii) E type TTO and PTO questions – 3 E type questions for all participants, but which E type questions will vary between participants.

Participants will be divided into one of 6 groups with 6 corresponding question sorts. The table shows the order of C type questions and the 3 E type questions for each sort. This will apply for TTO questions in Interview I, and TTO and PTO questions in Interview II.

| | Sort1 | Sort2 | Sort3 | Sort4 | Sort5 | Sort6 |
|-----------------------------------|-------|-------|-------|-------|-------|-------|
| C type order | C1 | C6 | C5 | C3 | C5 | C6 |
| | C2 | C1 | C3 | C6 | C4 | C5 |
| | C3 | C5 | C4 | C5 | C1 | C1 |
| | C4 | C2 | C6 | C2 | C3 | C3 |
| | C5 | C3 | C1 | C1 | C2 | C4 |
| | C6 | C4 | C2 | C4 | C6 | C2 |
| E type questions and order | E1 | E4 | E7 | E10 | E13 | E16 |
| | E2 | E5 | E8 | E11 | E14 | E17 |
| | E3 | E6 | E9 | E12 | E15 | E18 |

Please:

- (a) organize C type and E type questions following the sort for each participant
- (b) double check the order of C type questions, and the E type questions asked against the TTO and PTO answers sheets, which should give you a cross reference (ie check question numbering on answer sheets matches questions being asked).

Appendix 5 Rating Scale Letter and Survey

28 February 2003

«ID»

«Title» «Initials» «Surname»

«Street_Number__Address»,

«Suburb»

«St» «PC»

Assessment of Quality of Life (AQoL) Study

Dear **(HAND WRITE)**

I would like to thank you for participating in this research study, and to ask for your help one last time in filling out the accompanying short questionnaires.

The answers you have already given have been extremely valuable, and have raised important issues that require some further questions.

It would significantly improve the study if this information could be obtained from people like yourself who have already completed the interviews. As you are already familiar with the Assessment of Quality of Life questions, the process should not be too difficult. We would like you to:

1. Complete the Assessment of Quality of Life (AQoL) Questionnaire
2. Complete AQoL Scales Questionnaire using the scales provided
3. Return **all your completed forms** in the self-addressed envelope

I have described who is conducting the study in more detail over the page. If you have any questions please contact the project manager, Angelo Iezzi, on 9496 4412 during business hours (mobile 0419 338 241).

I do hope you can help one last time, and apologise for not being able to remunerate you this time for your help.

Yours sincerely,

(HAND SIGN)

Professor Jeff Richardson
Health Economics Unit
Centre for Health Program Evaluation
Monash University

Appendix 6 Rating Scale Questionnaire

Instructions

Make sure you have completed the Assessment of Quality of Life Questionnaire.

On the following pages you will be asked to consider how **strongly you feel about** different health states – by indicating **how much you prefer** one health state compared to another. Questions use a **scale** which runs from **0 to 100**. You will be asked to use the scale to show **how much you prefer** different health states.

Questions have been split into Sections A, B and C.

Section A - 11 questions

Section B - 3 questions

Section C - 3 questions

Please **look at the scale used for each question carefully**, because different types of scales are used in Sections A, B and C.

There are no right or wrong answers, we would like to know **how much you prefer** different health states. **Note: Section A 20 questions, divided into Sort 1 and Sort 2**

Section B 6 questions, divided into Sort 1 and Sort 2

Section C 6 questions, divided into Sort 1 and Sort 2

Section A

Each page in Section A relates to a **single question** from the **Assessment of Quality of Life Questionnaire**. Please answer parts (a) and (b) on each page.

- (a) Questions use a **scale** which runs from **0 to 100**. You will be asked to use the scale to show **how much you prefer** different health states.

Read the descriptions of the health states in the boxes on the left of the scale.

The bottom box shows the **worst health state for each question** and is set at **0**.

The top box shows the **best health state for each question** and is set at **100**.

For each of the remaining boxes, imagine you are in that health state.

Draw a line from each box to the scale to indicate **how strongly you feel** about that health state. Where you draw your line to the scale shows **both**:

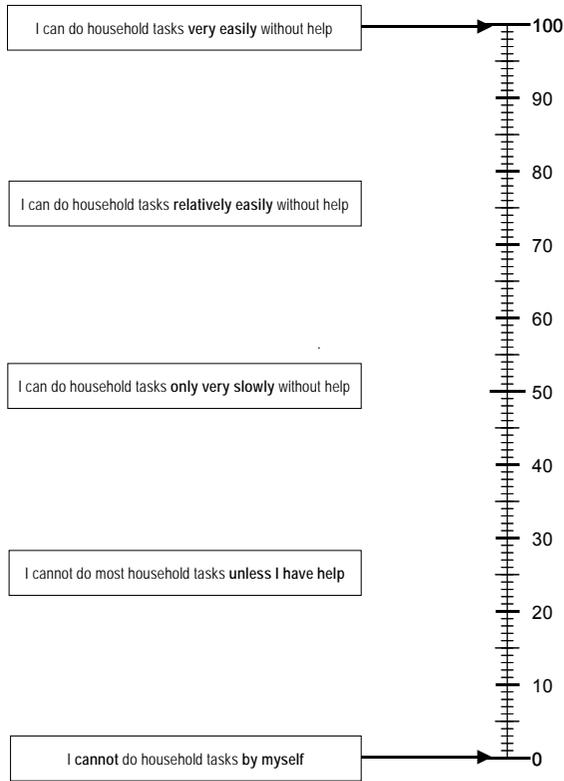
how much more you prefer that health state to 0 (the worst health state); **and**
how much less you prefer that health state to 100 (the best health state).

- (b) Questions use a **different** scale. Imagine you are in the health state described in the box (all other aspects of your physical, mental, emotional and social wellbeing are excellent). **Mark a cross** on the scale to indicate how being in this health state would affect your quality of life.

There is an example on the next page

A1. How much help do I need with household tasks? (e.g. preparing food, cleaning the house or gardening):

(a) Draw a line from each box to the scale to show where it fits. Be sure your lines touch the scale!



(b) Imagine you **cannot** do household tasks **by yourself** (the worst health state for this question). All other aspects of your health are excellent.

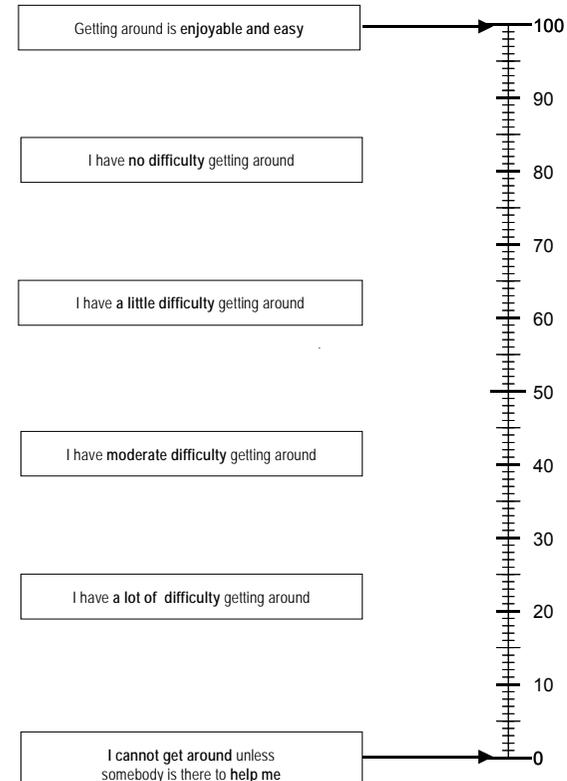
How would this affect your quality of life?



S1 AQ1

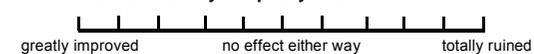
A2. Thinking about getting around by myself outside my house (e.g. shopping, visiting):

(a) Draw a line from each box to the scale to show where it fits. Be sure your lines touch the scale!



(b) Imagine you **cannot get around** unless somebody is there to **help you** (the worst health state for this question). All other aspects of your health are excellent.

How would this affect your quality of life?



S1 AQ2

A3. Thinking about how well I can walk:

(a) Draw a line from each box to the scale to show where it fits. Be sure your lines touch the scale!

I find walking or running very easy

I have no real difficulty with walking or running

I find walking or running slightly difficult

Walking is difficult for me, I walk short distances only

I have great difficulty walking. I cannot walk without a walking stick or frame, or someone to help me

I am bedridden

(b) Imagine you are **bedridden (the worst health state for this question). All other aspects of your health are excellent.**

How would this affect your quality of life?

greatly improved no effect either way totally ruined

S1 AQ3

A4. Thinking about personal care tasks (e.g. washing, toileting, dressing, eating or looking after my appearance):

(a) Draw a line from each box to the scale to show where it fits. Be sure your lines touch the scale!

Personal care tasks are very easy for me

I have no real difficulty in carrying out personal care tasks

I find some personal care tasks difficult, but I manage to do them on my own

I find personal care tasks difficult, and I need help to do them

I cannot perform personal care tasks by myself at all

(b) Imagine you **cannot perform personal care tasks by yourself (the worst health state for this question). All other aspects of your health are excellent.**

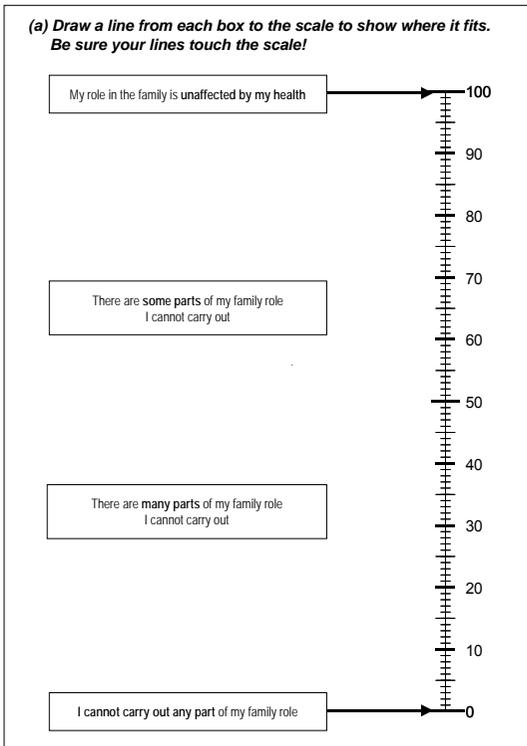
How would this affect your quality of life?

greatly improved no effect either way totally ruined

S1 AQ4

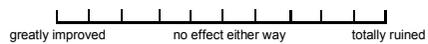
A5. Thinking about my health and my relationship with my family:

(a) Draw a line from each box to the scale to show where it fits.
Be sure your lines touch the scale!



(b) Imagine you **cannot carry out any part** of your family role because of your health (the worst health state for this question). All other aspects of your health are excellent.

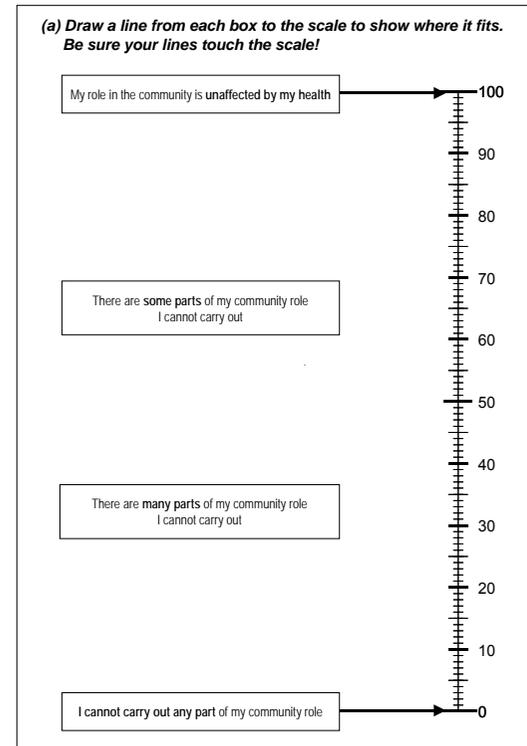
How would this affect your quality of life?



S1 AQ6

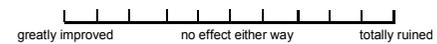
A6. Thinking about my health and my role in the community (e.g. sporting, work, church or cultural groups):

(a) Draw a line from each box to the scale to show where it fits.
Be sure your lines touch the scale!



(b) Imagine you **cannot carry out any part** of your community role because of your health (the worst health state for this question). All other aspects of your health are excellent.

How would this affect your quality of life?



S1 AQ7

Section B

Each page in Section B relates to a **dimension** (a group of questions) from the **Assessment of Quality of Life Questionnaire**. Each page will ask you to think about different health states **from one of the following dimensions**:

INDEPENDENT LIVING

- how well you can perform **household tasks**
- how well you can **get around** by yourself outside your house
- how well you can **walk** or run
- how well you can perform **personal care tasks**

SOCIAL AND FAMILY

- your health and the ability to carry out your role in your **family**
- your health and the ability to carry out your role in your **community**
- how you feel about your **close and intimate relationships**

MENTAL HEALTH

- how often you feel in **despair**
- how often you feel **worried**
- how often you feel **sad**
- how often you are **calm** and **tranquil** or **agitated**

Section B

Questions use a **scale** which runs from **0 to 100**. You will be asked to use the scale to show **how much you prefer** different health states.

On this scale:

- The bottom box is the **worst health state for each dimension** which is set at **0**.
- The top box is the **best health state for each dimension** which is set at **100**.

Read the descriptions of the health states in the boxes on the left of the scale.

Each box shows the **worst health state for one question from the dimension** with **other aspects of health in the dimension being excellent**. Other aspects of general health (physical, mental, emotional and social wellbeing) are also excellent. For each box, imagine you are in that health state.

Draw a line from each box on the left to the scale to indicate **how strongly you feel** about that health state. Where you draw your line to the scale shows **both**:

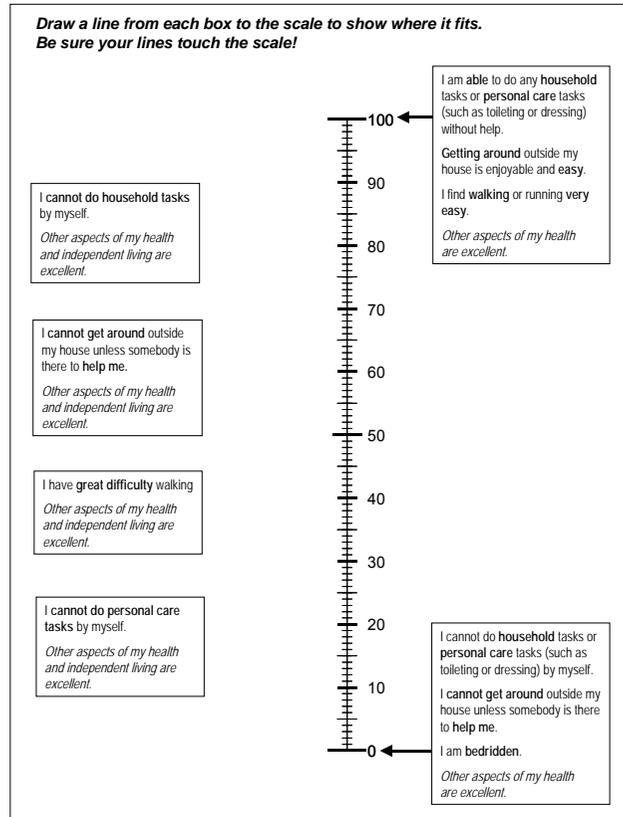
how much more you prefer that health state to 0 (the worst health state); **and**
how much less you prefer that health state to 100 (the best health state).

There is an example on the next page.

B1. Independent Living

Independent Living relates to:

- how well you can perform **household tasks**
- how well you can **get around** by yourself outside your house
- how well you can **walk** or run
- how well you can perform **personal care tasks**

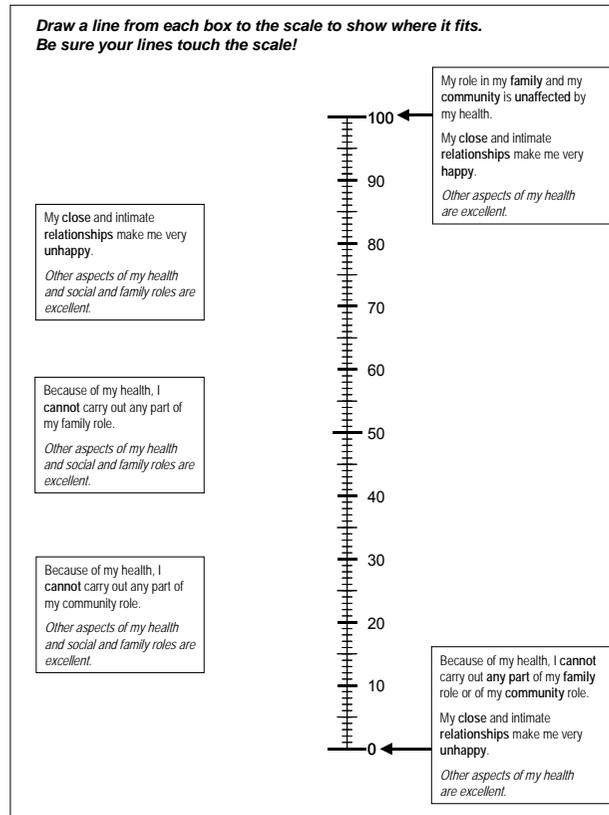


S1 BD1

B2. Social and Family

Social and Family relates to:

- your health and the ability to carry out your role in your **family**
- your health and the ability to carry out your role in your **community**
- how you feel about your **close and intimate relationships**



S1 BD2

Section C

Each page in Section C relates to a **dimension** (a group of questions) from the **Assessment of Quality of Life Questionnaire**. Each page will ask you to think about the worst health state **from one of the following dimensions**:

INDEPENDENT LIVING

- how well you can perform **household tasks**
- how well you can **get around** by yourself outside your house
- how well you can **walk** or run
- how well you can perform **personal care tasks**

SOCIAL AND FAMILY

- your health and the ability to carry out your role in your **family**
- your health and the ability to carry out your role in your **community**
- how you feel about your **close and intimate relationships**

MENTAL HEALTH

- how often you feel in **despair**
- how often you feel **worried**
- how often you feel **sad**
- how often you are **calm** and **tranquil** or **agitated**

Section C

Questions use a **different scale**. You will be asked to use the scale to show **how much you prefer** different health states.

On this scale:

- The top box is **Excellent Health** which is set at **100**.
- The middle box is **Death** which is set at **0**.
- **Worse Than Death** health states are given scores **below 0**.

Read the description of Health State A in the box on the left of the scale. The box shows the **worst health state for the dimension**. Other aspects of general health (physical, mental, emotional and social wellbeing) are excellent. Imagine you are in Health State A. **Do you feel that Health State A is worse than death?** (if there was no way to improve your health, would you rather be dead than be in Health State A?)

If you feel Health State A is worse than death:

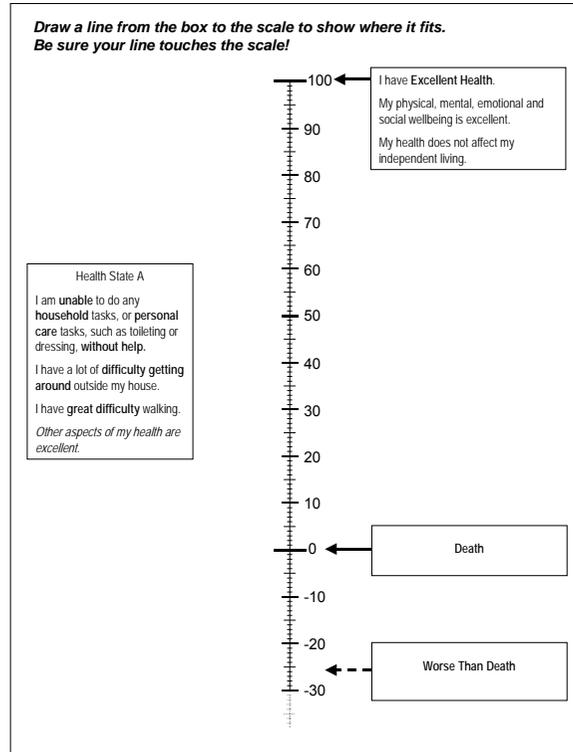
Draw a line from the box to a point on the scale that is **below 0** to indicate **how strongly you feel**. Where you draw your line to the scale shows: **how much less you prefer** Health State A to 0 (Death).

If you feel Health State A is not worse than death:

Draw a line from the box to a point the scale that is **between 0 and 100** to indicate **how strongly you feel**. Where you draw your line to the scale shows **both**: **how much more you prefer** Health State A to 0 (Death); **and** **how much less you prefer** Health State A to 100 (Excellent Health).

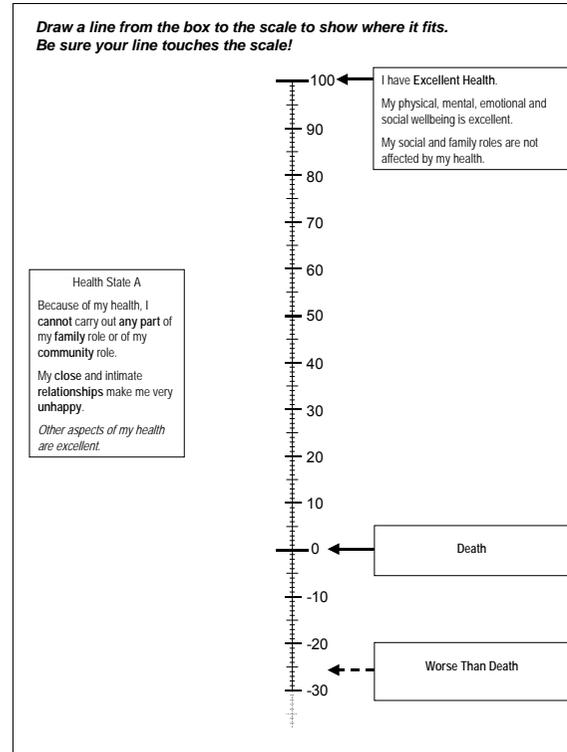
There is an example on the next page.

C1. Independent Living



S1 CD1

C2. Social and Family



S1 CD2

Please turn over, there is one final question on the next page.

Appendix 7 Selection of the (e-type) MAU health states; MAU health states

Generation of E type MAU Health States

The discrete choice modelling literature selects subsets of possible combinations of attributes and their corresponding levels in estimating multi-attribute random utility functions. Attributes represent the characteristics which utility/preferences can be decomposed into for a given choice (e.g. top speed, safety, and fuel economy in choosing a car) which are typically measured in terms of discrete levels (e.g. 150km/h, good safety, poor fuel economy). Subsets of combinations of attributes and their levels are picked from matrices based on fractional factorial experimental design. This experimental design allows efficient estimation of the random utility function.

The AQOL II consists of 20 questions. Fractional factorial designs are not readily available for use with 20 attribute models. Further, the AQOL is based on a nested hierarchy which is not strictly comparable with a simple 20 attribute model (i.e. the 20 questions are nested within 6 dimensions).

Summary of AQOL II Structure

Dimension 1 Independent Living (4 Items)

Q1 5 levels
Q2 6 levels
Q3 6 levels
Q4 5 levels

Dimension 4 Coping (3 Items)

Q12 5 levels
Q13 5 levels
Q14 5 levels

Dimension 2 Social (3 Items)

Q5 5 levels
Q6 4 levels
Q7 4 levels

Dimension 5 Pain (3 Items)

Q15 4 levels
Q16 4 levels
Q17 5 levels

Dimension 3 Mental Health (4 Items)

Q8 5 levels
Q9 5 levels
Q10 5 levels
Q11 5 levels

Dimension 6 Sensory Perception (3 Items)

Q18 6 levels
Q19 6 levels
Q20 4 levels

The nearest approximation of a fractional factorial design is to:

- (i) determine the efficient subset of combinations of AQOL dimensions to be used in E type MAU states, and then
- (ii) determine the efficient subset of combinations of AQOL items to be used for each subset of dimensions used in the E type MAU states

(i) AQOL Dimension Sets

Attributes: 6 AQOL dimensions

2 Levels: 0 = do not include dimension in E type MAU health state

1 = include dimension in E type MAU health state

(Experimental Design - 8 tests, Master Plan 2, Cols 3,4,5,6,7,9)

Fractional Factorial Design Matrix

| Dimension | 1 | 2 | 3 | 4 | 5 | 6 |
|------------------|----------|----------|----------|----------|----------|----------|
| DimSet0 | 0 | 0 | 0 | 0 | 0 | 0 |
| DimSet1 | 0 | 0 | 0 | 1 | 1 | 1 |
| DimSet2 | 0 | 1 | 1 | 0 | 0 | 1 |
| DimSet3 | 0 | 1 | 1 | 1 | 1 | 0 |
| DimSet4 | 1 | 0 | 1 | 0 | 1 | 1 |
| DimSet5 | 1 | 0 | 1 | 1 | 0 | 0 |
| DimSet6 | 1 | 1 | 0 | 0 | 1 | 0 |
| DimSet7 | 1 | 1 | 0 | 1 | 0 | 1 |

DimSet0 is the “null set” and is spurious (no dimensions selected). This leaves 7 sets of combinations of dimensions for generating E type MAU health states.

(ii) Item Sets within Dimensions

Attributes: AQOL Items within dimensions

4 dimensions have 3 items

2 dimensions have 4 items

(a) Dimensions with 3 items

Attributes: 3 AQOL Items within respective dimensions

2 Levels: 0 = do not include item in E type MAU health state

1 = include item from the dimension in E type MAU health state

(Experimental Design - 4 tests, Master Plan 1, Cols 1,2,3)

Fractional Factorial Design Matrix

| Item | 1 | 2 | 3 |
|-------------|----------|----------|----------|
| ItemSet0a | 0 | 0 | 0 |
| ItemSet1a | 0 | 1 | 1 |
| ItemSet2a | 1 | 0 | 1 |
| ItemSet3a | 1 | 1 | 0 |

ItemSet0a is the “null set” and is spurious (no items selected). This leaves 3 sets of combinations of items for dimensions with 3 items.

(b) Dimensions with 4 items

Attributes: 4 AQOL Items within respective dimensions

2 Levels: 0 = do not include item in E type MAU health state

1 = include item from the dimension in E type MAU health state

(Experimental Design - 8 tests, Master Plan 2, Cols 3,4,6,9)

Fractional Factorial Design Matrix

| Item | 1 | 2 | 3 | 4 |
|-----------|---|---|---|---|
| ItemSet0b | 0 | 0 | 0 | 0 |
| ItemSet1b | 0 | 0 | 1 | 1 |
| ItemSet2b | 0 | 1 | 0 | 1 |
| ItemSet3b | 0 | 1 | 1 | 0 |
| ItemSet4b | 1 | 0 | 0 | 1 |
| ItemSet5b | 1 | 0 | 1 | 0 |
| ItemSet6b | 1 | 1 | 0 | 0 |
| ItemSet7b | 1 | 1 | 1 | 1 |

ItemSet0b is the “null set” and is spurious (no items selected). This leaves 7 sets of combinations of items for dimensions with 4 items.

(iii) Combining Dimension and Items within Dimension Sets

Even this truncated fractional factorial design yields an impossibly large number of combinations of items within dimension sets (see table, total number of combinations = 1119).

| Dimension | 1 Ind Liv | 2 Social | 3 MH | 4 Coping | 5 Pain | 6 SensPer | |
|---|-----------|----------|----------|----------|----------|-----------|----------------------------------|
| No. Items within dimension | 4 | 3 | 4 | 3 | 3 | 3 | |
| No. of combinations of items within dimension sets | | | | | | | Total No. of combinations |
| DimSet1 | - | - | - | 3 | 3 | 3 | 3x3x3 = 27 |
| DimSet2 | - | 3 | 7 | - | - | 3 | 3x7x3 = 63 |
| DimSet3 | - | 3 | 7 | 3 | 3 | - | 3x7x3x3 = 189 |
| DimSet4 | 7 | - | 7 | - | 3 | 3 | 7x7x3x3 = 441 |
| DimSet5 | 7 | - | 7 | 3 | - | - | 7x7x3 = 147 |
| DimSet6 | 7 | 3 | - | - | 3 | - | 7x3x3 = 63 |
| DimSet7 | 7 | 3 | - | 3 | - | 3 | 7x3x3x3 = 189 |
| Total | | | | | | | 1119 |

However, we can hand pick item sets to be used in each of the 7 dimension sets based on the design matrices shown under (ii) (see tables below for Item Sets).

| Dimension | 1 Ind Liv | 2 Social | 3 MH | 4 Coping | 5 Pain | 6 SensPer |
|-----------------------------------|------------------|-----------------|-------------------|-----------------|---------------|------------------|
| No. Items within dimension | 4 | 3 | 4 | 3 | 3 | 3 |
| ItemSet1 | Q3,Q4 | Q6,Q7 | Q10,Q11 | Q13,Q14 | Q16,Q17 | Q19,Q20 |
| ItemSet2 | Q2,Q4 | Q5,Q7 | Q9,Q11 | Q12,Q14 | Q15,Q17 | Q18,Q20 |
| ItemSet3 | Q2,Q3 | Q5,Q6 | Q9,Q10 | Q12,Q13 | Q15,Q16 | Q18,Q19 |
| ItemSet4 | Q1,Q4 | | Q8,Q11 | | | |
| ItemSet5 | Q1,Q3 | | Q8,Q10 | | | |
| ItemSet6 | Q1,Q2 | | Q8,Q9 | | | |
| ItemSet7 | Q1,Q2, Q3,Q4 | | Q8,Q9, Q10,Q11 | | | |

Some of the item sets indicated by the experimental design produce counterintuitive poor health states. Items sets excluded are:

Ind Liv - ItemSets1,2,4,5,6 – all provide pairs of poor health on independent living items for which it is implausible to suggest that health would be good on other items within the dimension. E.g. it is difficult to imagine a person having difficulty in walking and toileting/washing, but no difficulty in household tasks. These sets are replaced with two “arbitrary” items sets (Q1,Q2,Q3) and (Q3).

Coping – ItemSets4,6,7 – purely to reduce numbers of potential item sets

Pain – ItemSet1 and 2 merged to make new ItemSet (Q15,Q16,Q17) to avoid problems about not asking both frequency and level of pain at the same time.

This gives a revised and simplified ItemSet list:

| Dimension | 1 Ind Liv | 2 Social | 3 MH | 4 Coping | 5 Pain | 6 SensPer |
|-----------------------------------|------------------|-----------------|-------------|-----------------|---------------|------------------|
| No. Items within dimension | 4 | 3 | 4 | 3 | 3 | 3 |
| ItemSet1 | Q2,Q3 | Q6,Q7 | Q10,Q11 | Q13,Q14 | Q15,Q16,Q17 | Q19,Q20 |
| ItemSet2 | Q3 | Q5,Q7 | Q9,Q11 | Q12,Q14 | Q15,Q16 | Q18,Q20 |
| ItemSet3 | Q1,Q2,Q3 | Q5,Q6 | Q9,Q10 | Q12,Q13 | | Q18,Q19 |
| ItemSet4 | Q1,Q2, Q3,Q4 | | Q8,Q10 | | | |

14 E type MAU Health States can then be generated by repeating the 7 DimSets twice and repeating the ordering of the ItemSets as shown below:

| | Code | 1 Ind Liv | 2 Social | 3 MH | 4 Coping | 5 Pain | 6 SensPer |
|---------|-------------|------------------|-----------------|-------------|-----------------|---------------|------------------|
| DimSet1 | E4 | - | - | - | Q13,Q14 | Q15,Q16,Q17 | Q18,Q19 |
| | E11 | - | - | - | Q12,Q14 | Q15,Q16 | Q19,Q20 |
| DimSet2 | E5 | - | Q6,Q7 | Q10,Q11 | - | - | Q18,Q20 |
| | E12 | - | Q5,Q7 | Q9,Q11 | - | - | Q18,Q19 |
| DimSet3 | E6 | - | Q5,Q6 | Q9,Q10 | Q12,Q13 | Q15,Q16,Q17 | - |
| | E13 | - | Q6,Q7 | Q8,Q10 | Q13,Q14 | Q15,Q16 | - |
| DimSet4 | E7 | Q2,Q3 | - | Q10,Q11 | - | Q15,Q16,Q17 | Q19,Q20 |
| | E14 | Q1,Q2,Q3,Q4 | - | Q9,Q11 | - | Q15,Q16 | Q18,Q20 |
| DimSet5 | E8 | Q3 | - | Q9,Q10 | Q12,Q14 | - | - |
| | E15 | Q1,Q2,Q3 | - | Q8,Q10 | Q12,Q13 | - | - |
| DimSet6 | E9 | Q2,Q3 | Q5,Q7 | - | - | Q15,Q16,Q17 | - |
| | E16 | Q1,Q2,Q3,Q4 | Q5,Q6 | - | - | Q15,Q16 | - |
| DimSet7 | E10 | Q3 | Q6,Q7 | - | Q13,Q14 | - | Q18,Q19 |
| | E17 | Q1,Q2,Q3 | Q5,Q7 | - | Q12,Q14 | - | Q19,Q20 |

The E type MAU health states to be used are shown below, with varying levels on different items. MAU E1-E3 were previously picked by hand, MAU E4-E17 selected following experimental design procedures. E18 was also picked by hand. The 18 E type questions will be divided into 6 sorts.

E Type MAU Health States

| MAU E1 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 3/5 | Q1 I can do household tasks only very slowly unless I have help. Q2 I have a lot of difficulty getting around outside, and Q3 walking is difficult for me. Q4 Many tasks like toileting and dressing are difficult and I need help to do them. |
| | 2 | 5/6 | |
| | 3 | 4/6 | |
| | 4 | 4/5 | |
| 2 Social | 5 | 2/5 | Q5 My close and intimate relationships make me generally happy. Q6 My role in my family and in Q7 my community is unaffected by my health. |
| | 6 | 1/4 | |
| | 7 | 1/4 | |
| 3 MH | | | Other aspects of my health are excellent. |
| 4 Coping | | | |
| 5 Pain | | | |
| 6 Sens Per | | | |

| MAU E2 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | Q9 I sometimes feel worried and Q10 sad. Q11 I am usually calm and tranquil, but Q8 I occasionally feel despair. |
| 2 Social | | | |
| 3 MH | 8 | 2/5 | Q12 I am occasionally energetic. Q13 I mostly feel in control of my life, and Q14 I can mostly cope with life's problems. |
| | 9 | 3/5 | |
| | 10 | 3/5 | |
| | 11 | 2/5 | |
| 4 Coping | 12 | 3/5 | Other aspects of my health are excellent. |
| | 13 | 2/5 | |
| | 14 | 2/5 | |
| 5 Pain | | | |
| 6 Sens Per | | | |

| MAU E3 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 2/5 | Q1 I can do household tasks relatively easily without help. Q2 I have moderate difficulty getting around outside, and Q3 walking is slightly difficult for me. Q4 I have no real difficulty with many tasks like toileting and dressing. |
| | 2 | 4/6 | |
| | 3 | 3/6 | |
| | 4 | 2/5 | |
| 2 Social | | | Q16 I have moderate pain, and Q15 I experience serious pain less than once a week. Q17 Pain sometimes interferes with my usual activities. |
| 3 MH | | | |
| 4 Coping | | | |
| 5 Pain | 15 | 2/4 | |
| | 16 | 2/4 | |
| | 17 | 3/5 | |
| 6 Sens Per | | | Other aspects of my health are excellent. |

| MAU E4 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | Q13 I only occasionally feel in control of my life, and Q14 I feel I can partly cope with life's problems. |
| 2 Social | | | |
| 3 MH | | | Q16 I suffer from severe pain, but Q15 I experience serious pain less than once a week. Pain Q17 sometimes interferes with my usual activities. |
| 4 Coping | 13 | 4/5 | |
| | 14 | 3/5 | |
| 5 Pain | 15 | 2/4 | Q18 I have some difficulty focusing on things, or I do not see them sharply. Q19 I have difficulty hearing things clearly, and often I do not understand what is said. |
| | 16 | 3/4 | |
| | 17 | 3/5 | |
| 6 Sens Per | 18 | 3/6 | Other aspects of my health are excellent. |
| | 19 | 4/6 | |

| MAU E5 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | <p>There are some parts of Q6 my family and Q7 my community roles I cannot carry out because of my health.</p> <p>Q10 I feel sad some of the time, and Q11 I am sometimes calm and tranquil, sometimes agitated.</p> <p>Q18 I see normally. Q20 I have some difficulty being understood by people who do not know me, but I have no trouble understanding what others are saying to me.</p> <p>Other aspects of my health are excellent.</p> |
| 2 Social | 6 | 2/4 | |
| | 7 | 2/4 | |
| 3 MH | 10 | 3/5 | |
| | 11 | 3/5 | |
| 4 Coping | | | |
| 5 Pain | | | |
| 6 Sens Per | 18 | 2/6 | |
| | 20 | 2/4 | |

| MAU E6 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | <p>Q5 My close and intimate relationships make me neither happy nor unhappy. Q6 There are many parts of my family role I cannot carry out because of my health.</p> <p>Q9 I often feel worried, and Q10 I feel sad some of the time.</p> <p>Q12 I am usually tired and lacking energy, and Q13 I only occasionally feel in control of my life.</p> <p>Q16 I suffer from severe pain, and Q15 I experience serious pain three to four times a week. Q17 Pain often interferes with my usual activities.</p> <p>Other aspects of my health are excellent.</p> |
| 2 Social | 5 | 3/5 | |
| | 6 | 3/4 | |
| 3 MH | 9 | 4/5 | |
| | 10 | 3/5 | |
| 4 Coping | 12 | 4/5 | |
| | 13 | 4/5 | |
| 5 Pain | 15 | 3/4 | |
| | 16 | 3/4 | |
| | 17 | 4/5 | |
| 6 Sens Per | | | |

| MAU E7 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 2 | 3/6 | <p>Q2 I have a little difficulty in getting around by myself outside my house, and Q3 I find walking or running slightly difficult.</p> <p>Q10 I rarely feel sad, and Q11 I am usually calm and tranquil.</p> <p>Q16 I have moderate pain, and Q15 I experience serious pain less than once a week. Q17 Pain rarely interferes with my usual activities.</p> <p>Q19 I have difficulty hearing things clearly, and often I do not understand what is said. Q20 I am understood only by people who know me well, and I have great trouble understanding what others are saying to me.</p> <p>Other aspects of my health are excellent.</p> |
| | 3 | 3/6 | |
| 2 Social | | | |
| 3 MH | 10 | 2/5 | |
| | 11 | 2/5 | |
| 4 Coping | | | |
| 5 Pain | 15 | 2/4 | |
| | 16 | 2/4 | |
| | 17 | 2/5 | |
| 6 Sens Per | 19 | 4/6 | |
| | 20 | 3/4 | |

| MAU E8 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 3 | 5/6 | <p>Q3 I have great difficulty walking, and I cannot walk without a walking stick or frame or someone to help me</p> <p>Q9 I sometimes feel worried, and Q10 I usually feel sad.</p> <p>Q12 I am usually tired and lacking energy, and Q14 I feel I can partly cope with life's problems.</p> <p>Other aspects of my health are excellent.</p> |
| 2 Social | | | |
| 3 MH | 9 | 3/5 | |
| | 10 | 4/5 | |
| 4 Coping | 12 | 4/5 | |
| | 14 | 3/5 | |
| 5 Pain | | | |
| 6 Sens Per | | | |

| MAU E9 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 2 | 3/6 | Q2 I have a little difficulty getting around outside my house, and Q3 I find walking or running slightly difficult. |
| | 3 | 3/6 | |
| 2 Social | 5 | 2/5 | Q5 My close and intimate relationships make me generally happy, and Q7 there are some parts of my role in the community I cannot carry out because of my health. |
| | 7 | 2/4 | |
| 3 MH | | | Q16 I have moderate pain, and Q15 I experience serious pain less than once a week. Q17 Pain sometimes interferes with my usual activities. |
| 4 Coping | | | |
| 5 Pain | 15 | 2/4 | Other aspects of my health are excellent. |
| | 16 | 2/4 | |
| | 17 | 2/5 | |
| 6 Sens Per | | | |

| MAU E10 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 3 | 5/6 | Q3 I have great difficulty walking, and I cannot walk without a walking stick or frame, or someone to help me. |
| 2 Social | 6 | 3/4 | |
| | 7 | 3/4 | Q6 There are many parts of my family, and Q7 community roles I cannot carry out because of my health. |
| 3 MH | | | Q13 I only occasionally feel in control of my life, and Q14 I feel I can cope with life's problems very little. |
| 4 Coping | 13 | 4/5 | |
| 5 Pain | 14 | 4/5 | Q18 I have a lot of difficulty seeing things, and Q19 I hear very little indeed. |
| | | | |
| 6 Sens Per | 18 | 4/6 | Other aspects of my health are excellent. |
| | 19 | 5/6 | |

| MAU E11 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | Q12 I am usually full of energy, and Q14 I feel I can mostly cope with life's problems. |
| 2 Social | | | |
| 3 MH | | | Q16 I have moderate pain, but Q15 I experience serious pain very rarely. |
| 4 Coping | 12 | 2/5 | |
| | 14 | 2/5 | Q19 I have some difficulty hearing, and I have trouble hearing softly-spoken people or when there is background noise. Q20 I have no trouble speaking to others or understanding what they are saying. |
| 5 Pain | 15 | 2/4 | |
| | 16 | 2/4 | Other aspects of my health are excellent. |
| 6 Sens Per | 19 | 3/6 | |
| | 20 | 1/4 | |

| MAU E12 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | Q5 My close and intimate relationships make me generally unhappy. There are many parts of Q7 my community role I cannot carry out because of my health. |
| 2 Social | 5 | 4/5 | |
| | 7 | 3/4 | Q9 I often feel worried, and Q11 I am sometimes calm and tranquil, sometimes agitated. |
| 3 MH | 9 | 4/5 | |
| | 11 | 3/5 | Q18 I see and hear normally. |
| 4 Coping | | | |
| 5 Pain | | | Other aspects of my health are excellent. |
| 6 Sens Per | 18 | 2/6 | |
| | 19 | 2/6 | |

| MAU E13 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | <p>There are some parts of Q6 my family and Q7 community roles I cannot carry out because of my health.</p> <p>Q8 I often feel despair, and Q10 I usually feel sad.</p> <p>Q13 I sometimes feel in control of my life, and Q14 I can partly cope with life's problems.</p> <p>Q16 I have moderate pain, and Q15 I experience serious pain very rarely.</p> <p>Other aspects of my health are excellent.</p> |
| 2 Social | 6 | 2/4 | |
| | 7 | 2/4 | |
| 3 MH | 8 | 4/5 | |
| | 10 | 4/5 | |
| 4 Coping | 13 | 3/5 | |
| | 14 | 3/5 | |
| 5 Pain | 15 | 1/4 | |
| | 16 | 2/4 | |
| 6 Sens Per | | | |

| MAU E14 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 4/5 | <p>Q1 I cannot do most household tasks unless I have help, and Q2 I have a lot of difficulty in getting around by myself outside my house. Q3 I have great difficulty walking, and I cannot walk without a walking stick or frame, or someone to help me. Q4 Many tasks like toileting and dressing are difficult and I need help to do them.</p> <p>Q9 I often feel sad, and Q11 I am sometimes calm and tranquil, sometimes agitated.</p> <p>Q16 I have moderate pain, and Q15 I experience serious pain less than once a week.</p> <p>Q18 I see normally, and Q20 I have no trouble speaking to others or understanding what they are saying.</p> <p>Other aspects of my health are excellent.</p> |
| | 2 | 5/6 | |
| | 3 | 5/6 | |
| | 4 | 4/5 | |
| 2 Social | | | |
| 3 MH | 9 | 4/5 | |
| | 11 | 3/5 | |
| 4 Coping | | | |
| 5 Pain | 15 | 2/4 | |
| | 16 | 2/4 | |
| 6 Sens Per | 18 | 2/6 | |
| | 20 | 1/4 | |

| MAU E15 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 2/5 | Q1 I can do household tasks relatively easily without help, and Q2 I have a little difficulty in getting around by myself outside my house. Q3 I have no real difficulty with walking or running. Q8 I sometimes feel despair, and Q10 I usually feel sad. Q12 I am usually tired and lacking energy, and Q14 I sometimes feel in control of my life. Other aspects of my health are excellent. |
| | 2 | 3/6 | |
| | 3 | 2/6 | |
| 2 Social | | | |
| 3 MH | 8 | 3/5 | |
| | 10 | 4/5 | |
| 4 Coping | 12 | 4/5 | |
| | 13 | 3/5 | |
| 5 Pain | | | |
| 6 Sens Per | | | |

| MAU E16 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 4/5 | Q1 I cannot do most household tasks unless I have help, and Q2 I have a lot of difficulty in getting around by myself outside my house. Q3 I have great difficulty walking, and I cannot walk without a walking stick or frame, or someone to help me. Q4 Many tasks like toileting and dressing are difficult and I need help to do them. Q5 My close and intimate relationships make me neither happy nor unhappy, and Q6 there are some parts of my family role I cannot carry out. Q16 I suffer from severe pain, and Q15 I experience serious pain three to four times a week. Other aspects of my health are excellent. |
| | 2 | 5/6 | |
| | 3 | 5/6 | |
| | 4 | 4/5 | |
| 2 Social | 5 | 3/5 | |
| | 6 | 2/4 | |
| 3 MH | | | |
| 4 Coping | | | |
| 5 Pain | 15 | 3/4 | |
| | 16 | 3/4 | |
| 6 Sens Per | | | |

| MAU E17 | | | |
|------------|-------|-------|--|
| Dimension | Items | Level | Description |
| 1 Ind Liv | 1 | 2/5 | Q1 I can do household tasks relatively easily without help, and Q2 I have a little difficulty in getting around by myself outside my house. Q3 I have no real difficulty with walking or running. |
| | 2 | 3/6 | |
| | 3 | 2/6 | |
| 2 Social | 5 | 4/5 | Q5 My close and intimate relationships make me generally unhappy. Q7 There are some parts of my community role I cannot carry out |
| | 7 | 2/4 | |
| 3 MH | | | Q12 I am occasionally energetic only occasionally feel in control of my life, and Q14 I feel I can mostly cope with life's problems. |
| 4 Coping | 12 | 3/5 | |
| | 14 | 2/5 | |
| 5 Pain | | | Q19 I hear very little indeed. Q20 I am understood only by people who know me well, and I have great trouble understanding what others are saying to me. |
| 6 Sens Per | 19 | 5/6 | |
| | 20 | 3/4 | Other aspects of my health are excellent. |

| MAU E18 | | | |
|------------|-------|-------|---|
| Dimension | Items | Level | Description |
| 1 Ind Liv | | | Q5 My close and intimate relationships make me neither happy nor unhappy. Q6 There are many parts of my family, and Q7 community roles I cannot carry out because of my health. |
| 2 Social | 5 | 3/5 | |
| | 6 | 3/4 | |
| | 7 | 3/4 | |
| 3 MH | | | Q18 I have a lot of difficulty seeing things, and Q19 I hear very little indeed. Q20 I am understood only by people who know me well, and I have great trouble understanding what others are saying to me. |
| 4 Coping | | | |
| 5 Pain | | | Other aspects of my health are excellent. |
| 6 Sens Per | 18 | 4/6 | |
| | 19 | 5/6 | |
| | 20 | 3/4 | |

Appendix 8 Rating scale item; item worst scores

Item Disutilities (Rating Scale Scores)

| | Dimension 1 | Dimension 2 | Dimension 3 | Dimension 4 | Dimension 5 | Dimension 6 |
|----------------|---------------|---------------|----------------|----------------|----------------|----------------|
| Response Level | Mean (sd) | Mean (sd) | Mean (sd) | Mean (sd) | Mean (sd) | Mean (sd) |
| | Item 1 | Item 5 | Item 8 | Item 12 | Item 15 | Item 18 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.13 (0.08) | 0.13 (0.08) | 0.19 (0.19) | 0.11 (0.07) | 0.19 (0.16) | 0.07 (0.05) |
| 3 | 0.50 (0.17) | 0.52 (0.17) | 0.45 (0.19) | 0.41 (0.16) | 0.66 (0.24) | 0.30 (0.17) |
| 4 | 0.81 (0.14) | 0.82 (0.13) | 0.82 (0.17) | 0.72 (0.16) | 1.00 | 0.64 (0.19) |
| 5 | 1.00 | 1.00 | 1.00 | 1.00 | | 0.82 (0.20) |
| 6 | | | | | | 1.00 |
| | Item 2 | Item 6 | Item 9 | Item 13 | Item 16 | Item 19 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.07 (0.05) | 0.26 (0.16) | 0.20 (0.17) | 0.11 (0.06) | 0.27 (0.17) | 0.06 (0.05) |
| 3 | 0.31 (0.18) | 0.75 (0.14) | 0.46 (0.18) | 0.45 (0.15) | 0.75 (0.22) | 0.28 (0.13) |
| 4 | 0.53 (0.18) | 1.00 | 0.81 (0.13) | 0.76 (0.17) | 1.00 | 0.61 (0.18) |
| 5 | 0.82 (0.14) | | 1.00 | 1.00 | | 0.81 (0.19) |
| 6 | 1.00 | | | | | 1.00 |
| | Item 3 | Item 7 | Item 10 | Item 14 | Item 17 | Item 20 |
| 1 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| 2 | 0.09 (0.05) | 0.26 (0.19) | 0.15 (0.16) | 0.11 (0.06) | 0.12 (0.12) | 0.26 (0.15) |
| 3 | 0.33 (0.15) | 0.67 (0.18) | 0.40 (0.20) | 0.49 (0.14) | 0.41 (0.18) | 0.70 (0.19) |
| 4 | 0.61 (0.18) | 1.00 | 0.77 (0.17) | 0.81 (0.15) | 0.75 (0.21) | 1.00 |
| 5 | 0.82 (0.16) | | | 1.00 | 1.00 | |
| 6 | 1.00 | | | | | |
| | Item 4 | | Item 11 | | | |
| 1 | 0.00 | | 0.00 | | | |
| 2 | 0.08 (0.07) | | 0.12 (0.08) | | | |
| 3 | 0.37 (0.19) | | 0.44 (0.15) | | | |
| 4 | 0.78 (0.17) | | 0.81 (0.13) | | | |
| 5 | 1.00 | | 1.00 | | | |

Notes: Item best and worst disutilities are set equal to 0.00 and 1.00 respectively. Item best and worst responses are set as endpoints for rating scale evaluations.

Appendix 9 AQoL interviewer instructions

TTO: INTERVIEW 1

PTO: INTERVIEW 2

FOR

CONTROL & DELIBERATION ARMS

AQoL Study

Interviewer Instructions: Interview 1 (Control and Deliberation Arms)

Materials required

1. TTO board with Sheets in place
2. TTO Scoring Sheet (Sort No....)
3. Attendance form
4. AQoL One Questionnaire
5. Deliberation Package:
 - A4 Envelope
 - AQOL II Questionnaire
 - 3 A4 TTO sheets
 - Worst Health State Experienced
 - AQOL D type (AQOL all worst)
 - 1 AQOL C type (dimension worst)
 - Death Card
 - Instructions for participant

Collect from the subject:

6. Subject Consent Form
7. AQoL Mark 2 Questionnaire

Instructions

Preliminary

Assuming participant has been recruited and agreed to be interviewed:

Thank them for being willing to participate in the study.

Explain that the first interview involves a range of different activities and will last approximately one hour.

The second interview will also last approximately one and a half hours.

We will also give them something to do at home (for 15 minutes) in between interviews. This is called Deliberation.

(Note: Notice that this part is introduced as a normal part of the informants contribution. The interviewer can always back away from this approach if too difficult or too emotive for informant and assign them to the control arm. At this stage of the sampling, as the interviewers know, we need to concentrate on Deliberations.)

Give a brief overview of the purpose of the study and how it will be used (use the explanatory statement and list of current users of the AQoL as a guide). Let them know that we will not be asking them any personal details about their health. However, if they feel uncomfortable at any time we can stop the interview.

- Ensure Consent Form is signed before proceeding.
- Check that each item of the AQoL 2 has been completed and that they had no problems with marking the scale.
- Have them complete the attendance form.
- Let them know that they will be sent a cheque for \$50 approximately 4 weeks after the second session.

AQoL One Questionnaire

Give the subject the AQL One questionnaire for self-completion. Explain that this is a preliminary step and try to avoid extensive discussion. This activity should take about 5 minutes.

Time Trade Offs (TTO):

Explain that this is part two of the study. In part one we interviewed people in hospital about how they measured quality of life, and from their answers we came up with six key aspects to quality of life. (Introduce the 6 health dimensions, asking them to imagine various medical conditions that might affect the 6 areas). Explain that the purpose of this part of the research is to find out if any of the aspects of quality of life are more important than any others.

(Bring out the TTO board)

“I am about to ask you to put yourself into various hypothetical situations. There are no right or wrong answers to the questions, rather we are interested in having people from the general public answer the questions based on their own values, and what is important to them. Obviously past experiences of health issues for you and your family and friends will affect your answers. This life experience provides us with valuable information about how people make decisions regarding their health in real life situations.”

Carefully explain the principle of the board using the examples. You can do this by using the cinema example or the simple example. You can “flip-flop” between high and low values using the slider to help subjects arrive at a value.

“For the purposes of this study we are asking everyone in the study to imagine that they have 10 years of their life left. Obviously asking an 18 year old what it would be like to be in a wheelchair for the rest of their life is different from asking an 80 year old the same question. Asking everyone to imagine they have 10 years left overcomes this problem.

You can chose to live out your 10 years in Condition A (point to the top box on the sheet) – or have a shorter life lived in excellent health (point to the lower section). Depending on how serious you consider the condition will determine how many years you are willing to trade off for excellent health. If you feel that Condition A is worse than death for you, or you don't feel that you could put up with it for 10 years, then say so, and I will then ask you a different question.”

Often the informant persists in believing that they would resolve the condition somehow, do something about it, learn Braille, etc.

Ask them to imagine that there is nothing that they can do to improve the condition – no medications that will work, and that the condition will not improve over time. They are being asked to consider themselves in Health State A. If they improved their condition then they would no longer be in Health State A and they would not be addressing the question validly.

Ask them to imagine that there is nothing that they can do to improve the condition – no medications that will work, and that the condition will not improve over time.

Work through the Own health state, the six C type questions, the D question, and finally the three E type questions. (Follow the order on the TTO score sheet, according to the appropriate Sort

number.) With each C type question make sure they are aware that only one of the areas is affected, that the others are all unaffected. (Assure them that we do realise that this is a totally hypothetical situation, and that in real life usually several areas are affected at once.)

If the values are greater than 0, skip the following “worse than death sheet”. Probe answers to check for “worse than death” values, e.g. “I would rather be dead than in Health State A for 10 years”.

If the respondent is appearing to be heading towards 12 months OR LESS of excellent health in any of the CD1 – 6 questions, suggest an alternative:

Do you think that death would be a release from this health state?

If the respondent says **yes**, then

Do you think that this health state is actually worse than death?

If the subject says its worse than death:

When this happens, score 0 for the question, flip board over and direct the subject to the WTD version of the question. These questions can be difficult for some people. One simple way to explain the WTD question is as follows:

“What if you found yourself in this condition, that you have said is worse than death (or that you could not put up with for 10 years)? How long do you think that you could put up with it, if you knew at the end of that time, you could have a treatment that would return you to excellent health for the remainder of the ten years? Could you put up with it for one year? Etc.”

Flip flop back and forth until you arrive at the maximum length of time that they could put up with the condition. If they say they could not stand it at all, score 0 and move on to the next question.

If the subject is suitable for the deliberation condition, proceed to the next section.

Thank the person for their input and cooperation, arrange a time for Session 2 explaining that the second interview lasts 1.5 to 2 hours.

1. Assignment to Deliberative Arm

Assess whether the participant should be asked to complete the deliberation questions.

If the participant has found the TTO questions in Interview I either **very difficult or very emotive**, do not ask them to complete the deliberation tasks, assign them to the control arm, and finish Interview I.

Otherwise say:

“We have a take home pack so that you can think about the questions before the next interview.”

Ask the participant if they have a family member or friend that they think they will have an opportunity to talk to before the second interview.

If the answer is no, ask them whether they wish to do the deliberation task on their own (see below).

If the answer is yes, proceed with explaining the deliberation tasks.

Explain that we would like the participant to talk to a family member or friend about 3 questions before the second interview. We would like them to have the chance to discuss, and reflect on some of the issues we are researching. Ideally, the person they should talk to is the type of person they might discuss difficult issues with in their real life (e.g. a spouse, close relative, close friend etc.).

Important

Mark clearly on the top of the telephone selection and attendance sheets whether the participant has been assigned to the control or deliberative arm (i.e. write **control** or **deliberative**).

If the participant was assigned to the control arm indicate why they were not asked to complete the deliberative tasks.

Keep your own records and inform Angelo of how participants were assigned, because there will be a follow up phone call to them between Interview I and II.

Take 10-15 minutes at the end of Interview I to introduce the participant to the deliberation materials and explain what we would like them to do.

Write the participants name and ID no. on the envelope with the deliberation materials. Show the participant the materials we would like them to look at (instructions, reminder how to use the Time Trade-Off sheets, and the Time Trade-Off sheets). Make sure the ID no. is written on the TTO sheets and the AQoL questionnaire for the worst health state they have been in.

Note, they are to complete 3 TTOs:

Worst health state they have been in that they can remember

AQoL all worst

Pain **or** Sensory Perception Dimension worst (alternate which one is given to different participants)

Read through the instructions for participants **with them**

STEP ONE: COMPLETE AQOL 2 FOR WORST HEALTH STATE EVER

Discuss what a “worst health state” that they have been in is – that it may relate to physical or mental parts of health, or both.

- a. Start the participant thinking about the worst health state they can remember – get them to discuss what they think it might have been. We are interested in how they felt, not the doctors diagnosis (can have diagnosis but feel no symptoms). This will allow the mental and social aspects of this instrument to emerge.
- b. Explain that they are to use the AQoL questionnaire we have given them to describe the worst health state they have been in, and it should be completed as if they were in that health state now
- c. Note, if they find it too difficult to talk about the worst health state they have been in, or don't want to discuss it with others, they can choose a different poor health state they have experienced that they are comfortable thinking or talking about
- d. Emphasize that this is not a test of their memory – e.g. if they had a severe childhood illness, but cannot remember how they felt, choose a different “worst health state”
- e. We are interested in knowing more about poor health states participants have **personally experienced** and would like them to answer a TTO question on the worst health state they have experienced that they can remember
- f. Note, if the participant has cared for a relative/friend who was seriously ill we do not want them to use that person's health state – we want them to use a health state they have **personally experienced**. However, if they suffered poor health because of being a carer they may use their experiences if they choose to.

STEP TWO: COMPLETE THE 3 TTOs

Run through the 3 TTO sheets they are to use **with them**:

- a. read through the Reminder on how to use the Time Trade-Off sheets **with them**
- b. explain how to use the Health State B2 Death card as the slider
- c. explain that the first TTO is on the worst health state they have been in that they can remember
- d. explain that the second question is the AQoL all worst TTO, and the third question is a dimension worst TTO (CD5 or CD6) – and that they have already done these TTOs in Interview I
- e. explain that we are not giving them worse than death TTOs to complete, if they consider a health state to be worse than death they should record their answer as 0 years

STEP THREE: DISCUSS IT WITH A FRIEND

Alternative: If the participant is doing the deliberation on their own, ask them to spend time thinking about what factors influenced their decision. For example, the effect that being sick would have on their lifestyle or family; the pressures it might put on their relationships, past history of pain, etc.

Explain what they might discuss with a family member or friend

- a. We would like them to talk to someone they might talk to about their health if they were actually sick (e.g. a spouse, close relative or close friend)
- b. For example, someone they might talk to if they were deciding whether to have an operation or not
- c. Get them to identify one or two people they think they might be able to talk to before the second interview

We would like them to talk to this person about the three questions we have given them. They should discuss their answers and why they gave those answers (e.g. what part of a particular health state made it so bad etc.)

We would like to find out if talking to another person

- a. raised other important issues they had not thought of before
- b. what type of issues it raised
- c. whether it made them think more about their responses
- d. whether it made them change their mind about their responses
- e. why it may have changed their responses

Emphasize that it is the process of having the discussion that is important, so that the participant has an opportunity to think more about the questions and reflect on their responses.

STEP FOUR: REPEAT THE 3 TTOs ON YOUR OWN

Redo the 3 TTOs recording the answers on the sheets, and noting any reasons for any changes.

There are no right or wrong answers, we are just interested in their personal opinions.

Ask them if they would like a call between sessions to support them in doing the deliberation, and if so set up a time to do this. (See next page for details).

Reminder for Interview II

Remind them to bring all materials back to the second interview.

Make sure they know to write down their answers to the 3 TTO questions on the back of the TTO sheets, including any notes that help them remember any discussion/thoughts they had.

Deliberative Arm Follow Up Between Interview I & II

Phone the participant between Interview I & II.

Tell them you are ringing to remind them of the time, date & location of the second interview and to confirm the details, and to see if they have any questions about the "Take Home Pack".

Ask them:

- (a) Have you had an **opportunity** to discuss the questions we gave you with a family member or friend?
- (b) If they haven't, ask them if they think discussing the questions will change their mind about some of the questions?
- (c) Emphasize that changing their mind about responses is fine if they want to
- (d) Reassure them that whilst we would like them to discuss the questions, that if for some reason they don't have an opportunity, we would still like them to come back for the second interview

Discuss any problems they might have had, and go through how to answer the TTOs etc. if necessary.

Remind them to bring all the deliberation materials, their TTO answers, any notes that might help them remember their discussion/thoughts, and the AQOL questionnaire completed for the worst health state experienced, to the second interview with them.

Interviewer Instructions: Interview 2 (Control and Deliberation Arms)

Materials Required

Attendance Form – to be completed (same form as interview 1).
Deliberation materials (if in deliberative arm)

PTO Sheets & people cards
PTO Scoring Sheets

TTO board with Sheets in place
TTO Scoring Sheets

Running Order

| CONTROL | DELIBERATION |
|---|--|
| <p><u>1. Attendance form</u></p> <p><u>2. PTO questions</u> (a) SIX C Type (C D1 - C D6) (b) ONE D Type (D1) (c) THREE E Type (3 E Types)</p> <p><u>3. TTO questions</u> (a) SIX C Type (C D1 - C D6) (b) ONE D Type (D1) (c) Own Health State (d) THREE E Type (3 E Types)</p> | <p><u>1. Attendance form</u></p> <p><u>2. Debrief of deliberation</u></p> <p><u>3. TTO questions</u> (a) SIX C Type (C D1 - C D6) (b) ONE D Type (D1) (c) Own Health State (b) THREE E Type (3 E Types)</p> <p><u>4. PTO questions</u> (a) SIX C Type (C D1 - C D6) (b) ONE D Type (D1) (c) THREE E Type (3 E Types)</p> |
| <p><i>For the order of PTO/TTO C Type (C D1 – C D6) and 3 PTO/TTO E Type (from E1 – E18) see Sort Sheets.</i></p> | |

Instructions

Complete and collect Attendance Form. Tell the participant that you will lodge their attendance form with the pay office, and a cheque will be posted to them in approximately four weeks.

Consent Form should have been signed and collected at Interview I.

Explain that the participant will be asked to complete 2 sets of questions in Session II (PTO & TTO). Those in the deliberative arm will debrief on the deliberation, and then flow straight into the TTO. Those in the control arm will do the PTO first, and then the TTO.

Deliberative Arm Only - Debrief

Collect deliberation materials (3 TTO answers, AQOL questionnaire completed for worst health state experienced, & any notes made)

Take 10-15 minutes to go through the deliberation tasks the participant completed before the interview.

Check notes re: Factors influencing decision, Reasons for changes and Comments on the 3 TTO sheets. Interviewer can add comments that come up in going through together, especially noting who the participant discussed the questions with (family friend, friend, etc) and how long it took.

We would like to find out if talking to another person

- a. raised other important issues they had not thought of before
- b. what type of issues it raised
- c. whether it made them think more about their responses
- d. whether it made them change their mind about their responses
- e. why it may have changed their responses

PTO Instructions

INTRODUCTION

Explain the purpose of the PTO exercise in Session II:

In the first session the participant was asked to answer questions based on **his/her own imagined health** states with himself/herself as **RECEIVER of health services (PTO questions)**. He/she was asked to make a choice between a shorter, healthier life versus a longer but less healthy life.

We are now going to ask the participant to answer questions based on imagined **health states for other people** with himself/herself as **PROVIDER of money for health services (PTO questions)**. We would like them to choose between a number of people getting a treatment for a given illness/condition versus a number of people getting a different treatment for a different illness/condition.

A SIMPLE EXAMPLE

This is OPTIONAL. It can consume a lot of time, raise many questions than can interrupt the flow of the interview and lead to a confusing start, for both informant and interviewer. After the first interview, interviewers should be in a position to assess who would benefit from it, who doesn't need it and who would be confused further by it.

Present the PTO board to the participant using the **Simple Example PTO** sheet.

First, ask them to recall the example from the first interview (walking to a bar vs. staying in seat during intermission).

We are now going to ask them to imagine that they are the manager of the cinema deciding what type of bar or café to provide for customers. As manager, they have noticed that **customers ALREADY ARE both hungry and thirsty** by the intermission, and this spoils their enjoyment of the evening.

- (a) **Option A** uses the money to build a café to provide seating for 50 people to enjoy a snack and a drink during the intermission while seated, ie **provides both food and drink**. These 50 people return to their seats satisfied (content) for the rest of the evening.
- (b) **Option B** uses the money to build a bar which **provides a drink while standing**. People return to their seats for the rest of evening, but are not fully satisfied – they are no longer thirsty, but are still hungry.

That is:

- (a) **Option A “treats” hunger and thirst for 50 people which makes them content, by providing food and drinks**
- (b) **Option B “treats” thirst but not hunger for a number of people which makes them partly content, by providing drinks only and leaving them hungry.**

Only one of Option A or Option B can be provided – money is not an issue. The cinema holds 700 people.

Explain to the participant that we are going to ask them how many people in Option B would be needed to ensure that options A & B **give equivalent benefits to the patrons**. There are no right or wrong answers, we are interested in their views and opinions.

Explain the principle of the PTO board and the People Cards:

- (a) Spread the People Cards on the table beside the PTO board. Keep them in groups according to the number of people of each card, but don't arrange the groups of cards in any particular order.
- (b) Place a 50 People Card under Option A and a 50 People Card under Option B.
- (c) If you could provide Option A which "treats" hunger and thirst for 50 people or Option B which "treats" thirst for 50 people, which would you choose?
- (d) The participant should say Option A. Add Cards under Option B so that the total becomes 250 people, and ask them to choose again
- (e) Follow the principles of flip-flopping by adding and taking away People Cards under Option B until they say Option A and Option B are equivalent. Always leave the 50 People Card under Option A.

PTO QUESTIONS

Go to the PTO sheets

Briefly recap for the participant that:

- (a) they are to imagine they are a decision-maker in the Australian Health Department
- (b) they have to decide which treatments that improve health are provided
- (c) different treatments will improve health in different ways and can benefit different numbers of people
- (d) they have to choose between treatments because the country cannot afford to provide all treatments for all conditions

Emphasize

--no right or wrong answers.

--their own personal values and the importance they would put on different poor health states.

--we are not trying to change their minds or educate them; the usefulness and validity of the study depends on how well their answers reflect their own personal values – do this as BEST AS THEY ARE ABLE.

(If you find that you are working too hard to get an answer, back off and keep reminding the informant that the researchers are really interested in how they think and what values they hold about health.)

Explain that we are now going to ask them to **choose between two treatments which improve health for people with two different conditions.**

Ideally participants should complete all type C, D and E questions, as per their PTO Score sheet.

Notes:

- (a) **If Health State B is worse than death, participants should choose A as their response.** That is, if Health State B is worse than death they would not treat any people with Treatment B, they would rather let them die. The informant believes that condition B is so bad that death would be preferable.

Where participants indicate Health State B is worse than death, go to the Worse Than Death PTO question.

- (b) **If Health State B is not worse than death, participants should choose any number from 100 upwards.** They do not have to stick to choosing numbers shown on the People Cards – they are just a guide. Use the Cards to get participants to “add up” numbers for Treatment B.

If they choose 100, this implies Health State B is equally as good as Excellent Health. If they choose a number greater than 100, this implies Health State B is poorer than Excellent Health. The higher the number, the worse the informant believes the condition is. The money spent on treatment B would have to save many (more than 100) people, even if they end up in a “condition”, to justify not spending it to restore 100 people to excellent health, ie “condition-free”.

Of course, as we have found out, this can raise many issues, such as “I think it would be cruel to save more people only to have them live in such a dreadful state.” “I can’t bear to think of being responsible for more people like that living in the world.” etc.

Remember it’s their value we are interested in, whatever they think.

If the participant wants to go back and change answers later, allow them to. If they are repeatedly revising answers to earlier questions suggest they complete all questions and then go back.

C, D AND E TYPE PTO SCRIPT

We want you to think about different treatments that can improve health for people with two different conditions. Without treatment, people suffering from **either condition** will die within 3 months. We want you to think about two treatments:

- A.** 100 people in your country have a rapidly fatal condition which can be treated with **Treatment A**. The identity of these 100 people is unknown. **Without Treatment A** these 100 people will die suddenly in the next 3 months (Point to the top box – Immediate Death). **With Treatment A** these 100 people will live in excellent health (Point to Health State A – Excellent Health) for a normal life time.
- B.** A number of different people in your country have a different rapidly fatal condition which can be treated with **Treatment B**. The identity of these people is unknown. **Without Treatment B** these people will die in the next 3 months (Point to the top box – Immediate Death). **With Treatment B** these people will live in poor health (Point to Health State B) for a normal life time.

The people who would benefit from Treatment A or Treatment B represent a broad cross-section of the whole population, and there are no differences in terms of age, sex, race, socio-economic status etc. (*may not need to repeat this section after first couple of questions*).

From a quality of life point of view, how many people getting Treatment B would **they consider equivalent** to 100 people getting Treatment A? Flip-flop starting at 100 with the People Cards:

- (a) Spread the People Cards on the table beside the PTO board. Keep them in groups according to the number of people of each card, but don’t arrange the groups of cards in any particular order.
- (b) Place a 100 People Card under Treatment A and a 100 People Card under Treatment B. If you could provide Treatment B for 100 people, which would Treatment would you choose?
- (c) Follow the principles of flip-flopping by adding and taking away People Cards under Treatment B until they say Treatment A and Treatment B are equivalent. Always leave the 100 People Card under Treatment A.

| |
|---|
| <p>The higher the number the worse they consider the health state to be.</p> |
|---|

If Health State B is worse than death, participants should choose A as their response, and then go to the Worse Than Death PTO question (C, D type only).

If Health State B is not worse than death, participants should choose any number from 100 upwards, and then skip the Worse Than Death PTO question.

Record their answer.

Go through the remainder of the questions till all are answered.

TAKE A SHORT BREAK

INTERVIEWER PROMPTS FOR PTO INTERVIEWS.

Today we are going to be talking about Quality of Life for others instead of ourselves. Here we have *(point to black square Without Treatment)* a number of people who are suffering a disease that will see them die within the next three months.

Point to Treatment A

We have 100 of these people who will receive Treatment A and they will be returned to Excellent Health and live in that condition for the remainder of their life.

Point to Treatment B

We have another 100 of these people who will receive Treatment B and they will be returned from Immediate death but will live in Poor health (point to health state) for the rest of their lives.

From a Quality of Life point of view do you think the 100 people receiving Treatment B and living in this state for the rest of their lives, is equal to the people receiving Treatment A who are returning to excellent health for the rest of their lives. Does the scale (point to scale) sit balanced for you?

If the respondent says no, offer them the people cards and ask them to add to the 100 people in Treatment B until they think the scales are even.

If the number keeps increasing (say to 2000 and more), ask them if death would be a release. If yes, then inform them that that is worse than death.

Worse than Death question following PTOT C1-6 questions

If the respondent chooses the Worse than death answer –

Place 100 people above Treatment A and explain that *these people were living in this chronic condition (that they indicated was worse than death) for the rest of their lives but will receive Treatment A which will return them to excellent health.*

Place 100 people above Treatment B and explain that *these people were in suffering a terminal illness that would see them die within the next three months, but will receive Treatment B which will return them to excellent health.*

From a Quality of Life point of view do you think the 100 people living in this chronic condition (point to Health State A) who will receive Treatment A and go on to live in excellent health for the rest of their lives, is equal to these 100 people facing immediate death (point to Health State B) who will receive Treatment B and go on to live in excellent health for the rest of their lives.

Does the scale (point to scale) sit balanced for you?

If the respondent says no, offer them the people cards and ask them to add onto the 100 people in Treatment B until they think the scales are even.

C & D TYPE WORSE THAN DEATH PTO SCRIPT

We now want you to think some more about this Health State. This time, we want you to think about two different treatments which prevent poor health for people with two different conditions:

- A. 100 people in your country will get a chronic condition which can be prevented with **Treatment A**. The identity of these people is unknown. **Without Treatment A** these 100 people will live in very poor health (Point to Health State A) for a normal life time. Health State A is the Health State you told me you consider to be worse than death. **With Treatment A** these people will live in excellent health (Point to the top box) for a normal life time.
- B. A number of people in your country will get a rapidly fatal condition which can be prevented with **Treatment B**. The identity of these people is unknown. **Without Treatment B** these people will die in the next 3 months (Point Health State B – Immediate Death). **With Treatment B** these people will live in excellent health (Point to the top box) for a normal life time.

The people who would benefit from Treatment A or Treatment B represent a broad cross-section of the whole population, and there are no differences in terms of age, sex, race, socio-economic status etc. *(may not need to repeat this section after first couple of questions).*

From a quality of life perspective, how many people getting Treatment B would **they consider equivalent** to 100 people getting Treatment A? (flip-flop starting at 100 using the People Cards).

- (a) **If Health State A is worse than death, participants should choose any number from 100 upwards.**
- (b) **If Health State A is equally as bad as death, they should choose 100.**

Record their answer.

Go on to the next question.

TTO Instructions

Explain the purpose of the TTO exercise in Session II:

Participants will be asked to repeat the TTO questions they did in Session I. (This should take less than 30 min.)

All participants in the study are doing this. We are not testing participants memory, we would like to see if people give different answers to TTO questions after a gap of a few weeks, for whatever reason. There are no right or wrong answers.

Explain to the participant that they **should not try to remember** their answers from Interview I. We would like to know what their answers are today.

Recap principles of the TTO board. Repeat TTOs for C, D and E type questions following protocol from Interview I (6 C type TTOs, 1 D type TTO, Own Health State, & 3 E type TTOs).

After completing the TTOs ask the participant whether, between their first and second interviews, they:

- a. had **thought about any issues related to the questions** they have just completed (e.g. did they reflect on any of their responses from the first interview.
- b. **discussed any related issues**, or any of the questions and their responses **with other people** (e.g. friends, family, workmates etc.)
- c. had **experienced an event** or events which **made them reflect** on their responses (e.g. they, or a relative or friend, had an illness, went to hospital etc.)

Emphasize there are no right or wrong answers to the above, they were not expected to think about/discuss issues, but we are interested to know if they have.

Record any comments/make notes on the back of the TTO scoring sheet for Session II.

4. Finish

Ask the participant whether they found the questions from both sessions easy or hard? Did they find the TTO or PTO questions easier? Ask them to briefly explain why.

Ask the participant if there has been any change in their health between last session and now, and record this if they answer affirmatively. Clearly a change in their health could alter the way in which they answer questions.

Ask the participant if they had any comments/feedback on the process.

Record any comments/make notes on the back of the PTO scoring sheet for Session II.

Thank them for their time and assistance with our research.

C. Tape Recording Sessions

Explain to the participant:

For a number of interviews we ask the participant whether we can tape record the session. We tape record these sessions only to check that **interviewers** are asking questions in the same way for all participants. This is vital for our research to be valid. We are not checking up on anything you might say during the session.

All taping of sessions is anonymous and all tapes are erased after they have been checked.

All taping of sessions is only for **quality assurance in our research**.

Would you be willing to have the session tape recorded?

If the participant says yes: proceed with recording the session.

If the participant says no: ***take the tape out of the tape recorder in front of the participant and make sure it is turned off.***

D. Question Sorts

Different participants will be asked slightly different sets of TTO and PTO questions. You will be told which set of questions (a sort) to ask different participants in advance.

- (i) D type TTO and PTO questions – first question for all participants.
- (ii) C type TTO and PTO questions – to follow D type, all participants to complete CD1-CD6 questions, but the order of CD1-CD6 questions will vary (because the ordering of questions may affect responses).
- (iii) E type TTO and PTO questions – 3 E type questions for all participants, but which E type questions will vary between participants.

Participants will be divided into one of 6 groups with 6 corresponding question sorts. The table shows the order of C type questions and the 3 E type questions for each sort. This will apply for TTO questions in Interview I, and TTO and PTO questions in Interview II.

| | Sort1 | Sort2 | Sort3 | Sort4 | Sort5 | Sort6 |
|-----------------------------------|-------|-------|-------|-------|-------|-------|
| C type order | C1 | C6 | C5 | C3 | C5 | C6 |
| | C2 | C1 | C3 | C6 | C4 | C5 |
| | C3 | C5 | C4 | C5 | C1 | C1 |
| | C4 | C2 | C6 | C2 | C3 | C3 |
| | C5 | C3 | C1 | C1 | C2 | C4 |
| | C6 | C4 | C2 | C4 | C6 | C2 |
| E type questions and order | E1 | E4 | E7 | E10 | E13 | E16 |
| | E2 | E5 | E8 | E11 | E14 | E17 |
| | E3 | E6 | E9 | E12 | E15 | E18 |

Please:

- a. organize C type and E type questions following the sort for each participant
- b. double check the order of C type questions, and the E type questions asked against the TTO and PTO answers sheets, which should give you a cross reference (ie check question numbering on answer sheets matches questions being asked).

Appendix 10 Computation of Utilities: Technical Specifications

This appendix reports the algebraic calculations used to convert survey results into (dis)utility scores.

1. Basis of TTO Disutilities from TTO Interview Data

DISUTILITY RANGE (0.00 – 1.25)

0.00 = Excellent Health

1.00 = Death

1.25 = Worse Possible Health State

e.g. for dimension worst C1 from interview I

c1t1 = dimension C1 TTO response from interview I

c1wtdt1 = dimension C1 worse than death (wtd) TTO response from interview I

TTO response = no. years spent in excellent health

wtd TTO response = no. years tolerated in worse than death health state

duc1t1 = disutility for dimension 1 from TTO responses given at interview I

(i) Non worse than death responses

Utility (U) for C1 from interview I is found by dividing the number of years spent in excellent health by 10:

$$U_{c1t1} = c1t1/10$$

Disutility (DU) is found by taking the utility score away from 1:

$$duc1t1 = 1 - (c1t1/10) \quad (1)$$

(ii) Worse than death responses

If the participant indicates they consider C1 to be worse than death, they complete the C1 worse than death TTO question.

The “Apparent” Utility (UA) for C1 from the worse than death TTO from interview I is found from the following equation:

$$UAc1wtdt1 = - (10-c1wtdt1)/c1wtdt1$$

Simple conversion into a disutility for worse than death health states places death at 1.00 on the disutility scale and the worst possible health state at +infinity. The unbounded nature of the scale presents problems for analysis, and is not especially intuitive. Disutilities are therefore rescaled from the worse than death question, such that death remains at 1.00, but the upper bound of the scale (worst possible health state) is now 1.25. This is calculated using the formula:

$$DU_{c1t1} = 1.25 + (1/(28.57*(UAc1wtdt1)-4))$$

Which expands to:

$$duc1t1 = [1.25 + (1/((28.57*((10-c1wtdt1)/c1wtdt1))-4))] \quad (2)$$