Measuring Health State Values in Developing Countries: Report of a study in Andhra Pradesh, India.

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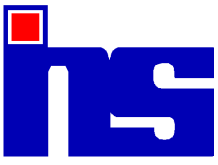

THE INSTITUTE OF HEALTH SYSTEMS

Measuring Health State Values in Developing Countries: Report of a study in Andhra Pradesh, India.

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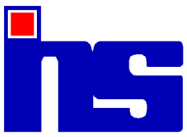

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Chapter 1:

Introduction

Valuation of health states by the general population is being attempted recently. Most of these studies have been in fully literate societies in the economically developed countries. For example, in Canada by Sacckett and Torrance (1978), UK (Gudex and others, 1996). Because population-based empirical assessments of health states are extremely limited, new surveys are needed. A study was conducted in Andhra Pradesh, by the Institute of Health Systems (IHS) to measure peoples preferences about various health states. To the best of our knowledge, this is the first community based health state valuation study in the developing world. Two distinct sources of assessment were made. First arm of the study consisted of a series of multi method health state valuation workshops for educated persons from different backgrounds. Participants of these workshops, valued health states using more than one procedure including, card sort, visual analogue scale, time trade-off, and person trade-off methods. Second arm of the study involved measurement of valuations given by general population drawn from a rural area. This was done by household surveys in a selected village in Ranga Reddy district. Respondents in the survey were requested to give their valuations using card sort followed by visual analogue scales. The study was conducted in the year 1999 and was funded by the WHO - Global Program on Evidence for Policy (GPE).

Broad goals of this study were;

1. To strengthen the methodological foundation for population based measurement of health state weights. In addition valuation protocols must be adapted for use in partly literate populations like that in India.
2. To measure local preferences for health states to be used for estimation of national and state burden of disease in India.
3. To understand the nature health state valuation function in people's mind and its implications for summary measures of population health status.

This report is organised into seven chapters including this introduction. This chapter introduces the subject of health state valuation, reviews current literature and outlines various methods of measurement. Chapters 2 - 5 describe methodology and organisational details of the study. Chapter 6 analyses data from the two arms of the study, to assess reliability and

validity of the health state valuation measurements. Analysis of test retest data also provides important insights into the nature of health state valuation function in people's mind. Results of these analyses are presented in chapter 6. Chapter - 7 presents results from the community survey of health state valuations and summarises findings of the study. The report includes a number of appendices containing various methodological and organisation details. We hope that these details will help researchers to easily implement health state valuation studies and contribute to reliability in study methodology.

Health State or Disability Weights for Computation of Disease Burden:

The key step in construction of synthetic measures of health status is assignment of weights to different health states. This methodological significance in construction of synthetic measures need to be distinguished from the quantitative impact, alternate sets of disability weights have on total disease burden estimate. Murray and Lopez (1996 p288) observed that rank order of diseases and injuries was insensitive to alternate set of disability weights. But relative size of disability to mortality components of disease burden changed. Using a set of disability weights sensitive to minor and trivial illnesses and small deviations from perfect health state decreased the disability adjusted life expectancy. Allen and others (1989) felt that ordinal ranking of cost per Quality Adjusted Life Years (QALY) for different interventions would not change with appreciable changes in corresponding index of health status. They observed that life saving procedures would always tend to score better than palliative or pain relieving measures which in turn would show lower cost to effectiveness ratio than expensive continuing therapy. However, there are other compelling reasons to attach importance to assignment of disability weights. Firstly, robustness of disease burden estimates or cost-effectiveness ratios to alternate set of disability weights is a feature of the current epidemiological state. As mortality continues to decline and prevalence of degenerative diseases rise further, the importance of disability weight for these results will increase. Secondly alternate sets of health state weights will certainly affect composition of the disability component of disease burden. This may, in certain circumstances, be an important input to policy analysis. For example, suppose mortality in a country has declined to a level close to our understanding of the biological potential of longevity. Then it would make sense to analyze the composition of disability as such to prioritize between

interventions seeking to improve health related quality of life. Last but not the least, the whole purpose of seeking out synthetic measures of health status would be defeated if adequate attention is not paid to component subjects of synthesis. More over, most health related quality of life measurements have taken place in the industrialised and economically developed countries. An important concern has been if the health state weights are robust across various cultural settings. Health related quality of life is now sought to be defined by restricting to domains of functioning that are universally, most essential to one's ability to pursue valued life goals (Shumaker and Naughton, 1995). Thus local measurement of disability weights is important from two perspectives, namely (a) sensitivity of national disease burden estimates to locally measured disability weights as opposed to use of global disability weights and (b) understanding health status weights across cultures.

Note that disability weights used in computation of Disability Adjusted Life Years (DALY) is the complement of health state weights or quality adjustment weights. Estimating one gives the other by simple arithmetic manipulation (disability weight = 1 - quality adjustment weight). These terms used here interchangeably.

Interpretations of Disability Weight:

Theoretical interpretations about the object of measurement has some bearing on the methodological path leading up to health status weights. Three different interpretations of it have been made in the literature, namely; (a) individual preference, (b) descriptive measure of health state and (c) social preference weight attached to the health state. Culyer (1989) distinguished between "welfarist[1]" and "extra-welfarist" approaches, among economists, and discussed its implication for the health sector. The "welfarist" approach is to view individual preferences (utility) as the source of all social welfare[2]. Health state or disability weight is viewed to represent individual preference for different health states. Since health outcomes at a personal level is characterised by uncertainty, Von Neuman and Morgenstern's (VNM) expected utility theory[3] is applied. Thus health state weights are viewed as VNM utility.

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[1] According to Culyer, the "welfarist" label was given by Amartya Sen (1977).

[2] There are important and unresolved issues regarding aggregation of individual preferences for quantification of social welfare. The impossibility of impossibility of aggregating cardinal measures of utility that would also satisfy certain reasonable assumptions. was shown by Arrow.

[3] von Neumann and Morgenstern (1944) proposed the expected utility theory. This is described in any text books on micro economic theory. One good exposition is in Mas-Collel, Whinstone and Green (1995).

Viewing health state weight as a measure of personal utility means that an equivalence with utility of other goods and services is straight forward. Advocates of personal utility interpretations may not make use of this equivalence in deference to strong emotional responses against valuation of human life in money terms. Nonetheless, the equivalence exists. From the Welfarist point of view, there is no theoretical basis for use rating scales for health state valuation, since these do not require the valuer to choose between two alternatives. The key theoretical underpinning of measurement of preference is ordering of alternatives by the individual. Since, rating scales simply ask the valuer to assign a weight in a scale without any reference to other health states, Welfarist's would argue, the resultant measurement can not be interpreted as a measure of utility. Welfarists may, however, tolerate visual analogue scaling as practical measurement device and seek to postulate empirically observed relationships between visual scaling and standard gamble or other trade-off methods.

The extra-welfarist approach of Amartya Sen (1979), Culyer argues, admits non-utility information about individuals into the process of comparing social states. An extra-welfarist approach allows for the concept of need as the basis of social welfare. The concept of need implies the existence of a goal which is considered reasonable. Extra-welfarists view health itself as a descriptive characteristic of people and as the principal maximand (out come to be maximised) of health services. The health state weight describes this output i.e. the health related quality of life (Bleichrodt, 1997). This later view allows for measurement by rating scales and magnitude estimation tools like the visual analogue scales, in addition to utility theory based measurement tools.

The third interpretation, that quality adjustment weights are values under a social welfare function is proposed by Nord (1994). Patrick et al (1973) also recognised that quality adjustment weight derived from the equivalence (person trade-off) method would represent valuation under some social welfare function.

Measurement Strategy:

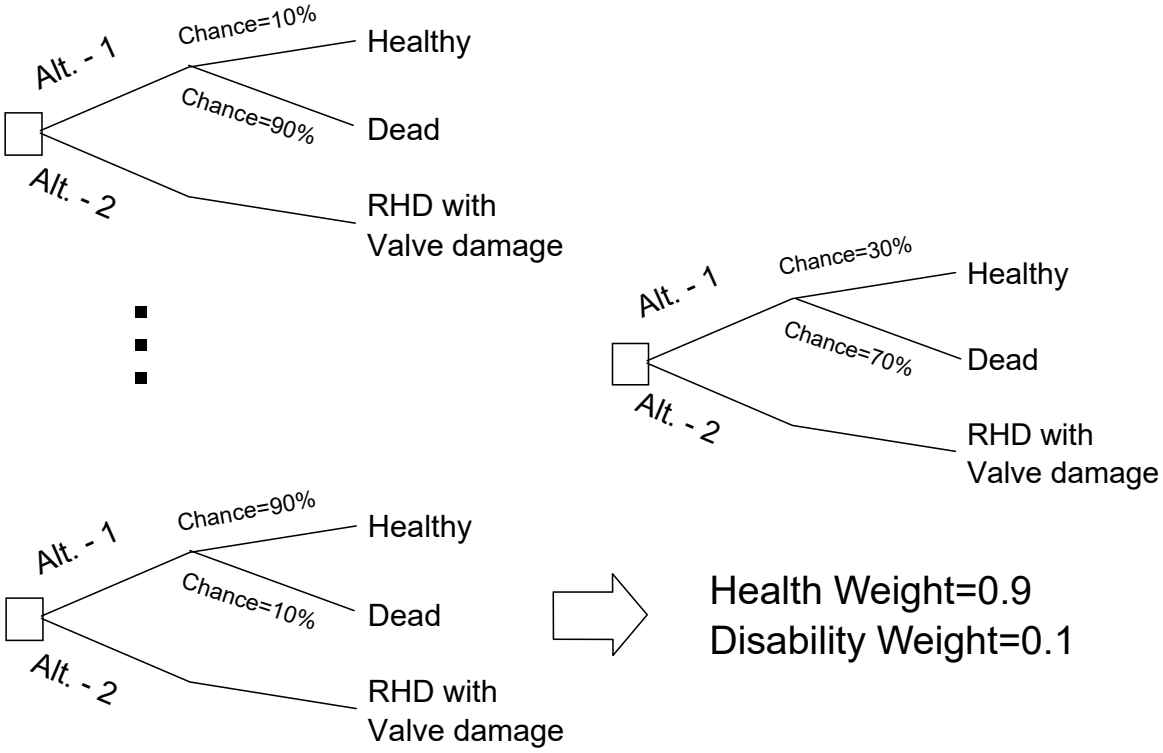
Torrance (1986) gives an overview of measurement of health state utilities for economic appraisal. In a four part series, Froberg and Kane (1989 I-IV) have summarised methodology for measurement of health state weights. The first article (Froberg and Kane, 1989-I) deals with measurement strategy, which refers to the overall structure for posing questions to respondents and corresponding method of data analysis. They divide extant measurement strategies into (a) holistic and (b) decomposed approaches. Torrance (1986) viewed these as alternative description of health states and used a similar classification, labeling the decomposed approach as health state classification system. In holistic approach each of the full range of health states is described as a whole including all its attributes. The respondent is presented with the description for all health states one after the other and asked to assign values. Thus the respondent has to judge each health state as a whole and all health states in the scale. As a result the procedure becomes cognitively demanding for the respondent. In decomposed designs the respondent does not have to value all health states in the profile. Decomposition may be explicit or achieved by statistical modeling. For statistically inferred decomposition the respondent is presented with the multiattribute description of a health state as in case of holistic approach. But only a few health states are presented to a single respondent, thus reducing cognitive overload. An algebraic model of multiattribute health states is constructed using statistical inferences from respondent evaluations. Explicit decomposition for health state measurement is rooted in multiattribute utility theory (Torrance 1982, 1986). Here the respondent is asked to evaluate each dimension of health separately, there by keeping it cognitively simple. Froberg and Kane (1989-I) recommend the statistically inferred strategy in view of its simplicity for respondents.

Scaling Methods

In the second article Froberg and Kane (1989-II) list six scaling methods. These are; (a) standard gamble, (b) time trade off, (c) rating scale, (d) magnitude estimation, (e) equivalence or person trade off, and (f) willingness to pay. Rating scales and magnitude estimation methods are psychometric in nature. Standard gamble, time trade off and willingness to pay are all preference based. Person trade off is preference based and has psychometric origins as well. A brief description of each of these methods is presented below.

Standard gamble:

Figure-1.1: An example of successive personal decision alternatives with uncertain outcomes (gambles) for valuation of the health state rheumatic heart disease (RHD) with valve disease.

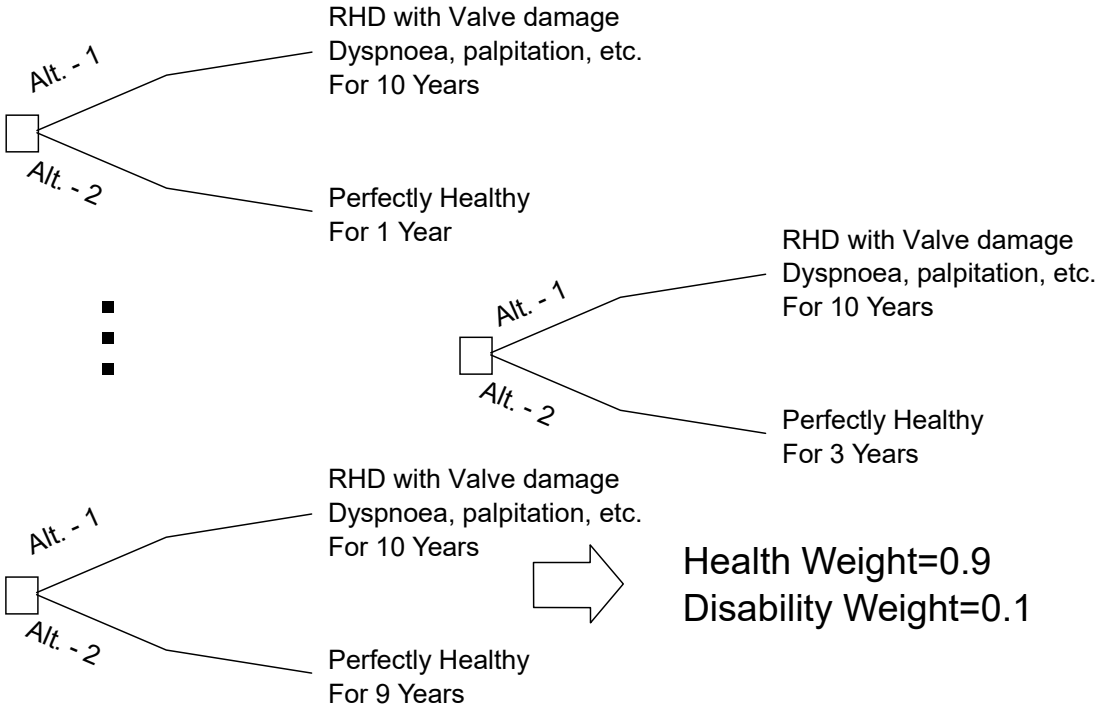


The standard gamble measures presents a random prospect (gamble), consisting of a best and a worst outcome, and the alternative of a certain prospect intermediate in desirability between the best and worst outcomes. The random prospect is completely defined by probability *p* of one of the two possible events. The other event will have a probability (*1-p*). For example the best outcome in the random prospect can be "perfectly healthy" and the worst outcome can be "dead". The certain prospect of intermediate desirability will then be a specific health state for example living with a particular disease state. To obtain quality adjusted weights the random prospect is defined by assigning probability *p* to the "perfectly healthy" outcome. The two alternative prospects defined by choice of disease state for the certain arm and *p* for the random arm are presented to a respondent with some initial value of *p*. The value of *p* is then varied till the respondent is indifferent between the certain prospect and the random prospect. The *p* that satisfies this condition is taken as the quality adjustment weight for the disease condition defined in the certain arm. Disability weight for this health

state is given by *(1-p)*. Instead we can define the random prospect by assigning probability *q* to the worst outcome (death in this set up). In that case the value of *q* satisfying the indifference condition is the disability weight. The standard gamble was proposed by von Neuman and Morgenstern (1944) as a tool to measure expected utility. The difficulty with this method is that it is not easily understood by many respondents.

Time Trade Off:

Figure-1.2: An example of successive personal time trade off alternatives for valuation of the health state rheumatic heart disease (RHD) with valve disease.



Time trade off was designed by Torrance et al (1973) for health status measurement, as a simpler and cognitively less demanding alternative to the standard gamble. Here the valuer's preferences for health states is assessed indirectly through the time (number of years, months, days, hours) (s)he wants to trade in to lead a completely healthy life, as against life with a particular less-than-perfect health state. The subject is offered two alternatives. Alternative 1: state *i* for time *t* (local life expectancy of an individual with the chronic condition) followed by death. Alternative 2 is a perfectly healthy state for time *x*, where *x* is

less than *t*. Time *x* is varied until the respondent is indifferent between the two alternatives, at which point the required preference value for state *i* is given by $h_i = \frac{x}{t}$.

Rating scales:

Rating scale consist of a range of values with clearly defined end points (anchors). For holistic health status measurement "perfect health" and "death" act as natural anchors. The range of values could be continuous or discrete. The visual analogue scale (VAS) consisting of a graduated line segment, one end labelled as death and the other labelled as perfect health is a continuous rating scale. Another form of continuous rating scale uses adjectival labels to describe intermediate points of a line anchored at both ends (for example see fig 4.4b at page 34 in Streiner and Norman, 1995). Except for the intermediate labels and smaller line length, they resemble the VAS. Rating scales using equally appearing intervals i.e. discrete points along the scale are called category rating scales (for example see fig 4.4a at page 34 in Streiner and Norman, 1995). Streiner and Norman (1995) describe rating scales as direct estimation methods (chapter 4 page 32-39) and category or continuous rating scales are described as adjectival scales. Rating scales are most frequently used to measure health state weights. Specter (1992) describes theoretical basis and practical steps in construction of rating scales for general psychometric use. Streiner and Norman (1995) provide similar description for construction of rating scales in the field of health status measurement.

The visual analogue scales are simple in construction. But respondents may not always agree. For example Streiner and Norman (1995) cite a study by Huskisson (1974) in which 7% of patients were unable to complete a VAS against 3% for category rating scale. Bosi Refaz et al (1990) found that illiterate respondents had more difficulty with VAS compared to category rating. In a comparative study of VAS and person trade off method, Nord (1991) asked his respondents to describe the meaning they attached to points in VAS chosen by them. Both ends of the VAS was anchored by worst and best imaginable health state, respectively. Sixty seven (out of a total of 105) respondents answered this question. Nineteen persons said that they viewed it as a percentage of best imaginable health state. Eleven did not mean anything and the remaining 37 did not answer the question directly but described specific dimensions of given condition taken into consideration by them. Nord

observed that subjects were expressing strength of preferences, through the VAS, in addition to ranking of health states. Person trade off implied by VAS were lower than ratios obtained from directly asked person trade off questions. With this finding coupled with the small size (19) of respondents reporting a conscious attempt to relate given state in percentage terms to one end of the scale, Nord concluded that one should not put too much emphasis on the numerical values obtained from VAS. But such an interpretation is flawed by many limitations of this study. Firstly, Nord appears to be denominating the 19 persons consciously trying to assign a ratio number with the 67 persons who gave some response to their question on meaning of valuations. More than half (37) of them did not give a direct answer to this question. So appropriate denominator to appreciate the relative size of the 19 consciously trying ratio raters would be the 30 persons who gave a direct answer to this question. Secondly Nord uses person trade off as a criterion, to compare results from VAS. The person trade off methodology is itself very sensitive to sample size, framing and start point bias found subsequently by Nord (1995).

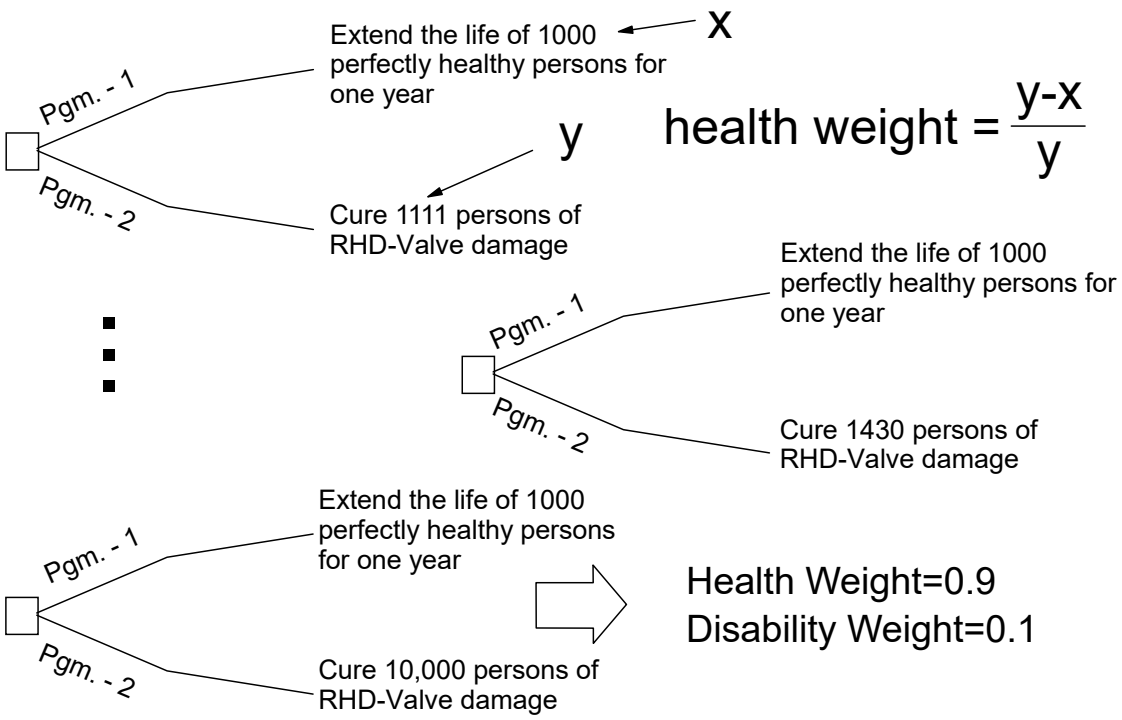
Magnitude estimation:

In magnitude estimation a reference state is identified and described. A numerical value (numerical estimation) or a line segment of certain length (line production) is assigned to the reference state. Respondents are presented with the health state of interest and asked to assess how it relates to the reference state. More specifically, how many times better or worse is the given health state in comparison to the reference state. They then assign a number proportional to the reference number (numerical estimation) or produce a line (line production) to show how it relates to the reference state. A higher number or larger length of line would mean better health state and a smaller number or line would mean worse health state. Calibration of respondents ability to reproduce magnitude estimates or at the least a practice session to orient them towards magnitude estimation is usually called for. Apart from the brief description in Froberg and Kane (1989b), McDowell and Newell (1987, 1996), magnitude scaling method is described by Lodge (1981).

Person Trade Off (PTO) or Equivalence:

Patrick et al (1973) adapted the method of adjustment or equivalent stimuli in psychometrics (Guilford, 1954; Torgerson, 1958) and devised the equivalence method for health status measurement. Froberg and Kane (1989b) opine that the person trade off (PTO) method is conceptually similar to magnitude scaling. In recent literature the same is referred to as person trade off method (Nord 1992, 1995). Here respondents are presented with two groups of persons distinguished by their health state and a constraint to the effect that only one of the two groups can be helped. One of the two groups is characterised by a reference health state (standard group) for example people with perfect health. The other group (evaluation group) is characterised by a specific health state of interest. The standard group with perfect health constitute the standard stimuli and number of persons in the evaluation group provides the variable comparison stimuli. Respondents are asked to choose between the two groups who should receive help. Number of persons in the evaluation group is varied till the respondent is indifferent between the two. Miles (1977) compared the person trade off method with category ratings. Difference in health states, between the two methods was not significant. Patrick and colleagues reported that this method was too complex. The unrealistic assumptions and the emotive nature of the task offended some judges. Similar observations were made by Nord (1995). In addition, Nord (1995) noted that the techniques need fairly large groups of respondents to keep measurement error within limits, is susceptible to start point bias, and is sensitive to question framing. To over come influence of question framing, respondents should be induced to arrive at an reflective equilibrium. To achieve this, Nord (1995) suggested a multistep procedure, through which respondents are presented all relevant arguments and to reconsider initial responses in the light of such arguments.

Figure-1.3: An example of successive PTO-2 social decision alternatives for valuation of the health state rheumatic heart disease (RHD) with valve disease.



A problem with this solution is; what arguments are considered relevant? For example Froberg and Kane (1989c) observed that "when an interviewer takes an active role the potential for influencing the rater is increased". For purposes of population health status measurement and resource allocation, this method is assumed to be valid by construction, since it asks respondents to weigh the claims of one group of persons with respect to another, distinguished only by their health states (Patrick et al, 1973; Nord 1991, 1995; Murray 1996). Knowledge of its reliability is limited since the method has not been used widely enough (Froberg and Kane, 1989d).

Murray (1996) used the PTO method to derive disability weights for the fifth revision of Global Burden of Disease (GBD) estimates. A good deal of effort was made to minimise usual problems associated with this method. To induce deliberation and reflection two PTOs were designed using different situational characteristics. In the first method (PTO1) respondents trade life extension for persons with the health state of interest with life extension for healthy persons. In the second method (PTO2) respondents trade improving health related quality of life to complete well being with life extension for perfectly healthy

persons. In general respondents assign a lower disability weight to the same health state in PTO1 compared to PTO2. Once the respondent completed the two PTOs for a given condition, the results are fed back to him while pointing out inconsistency if any between them. The respondent is then encouraged to revise the estimates to resolve the inconsistency. After evaluating all of the 22 indicator conditions, respondents are asked to give ordinal rank to these indicator conditions. This ordinal ranking is compared with the ranking implied by the reconciled PTO mentioned above. Any inconsistency is fed back to the respondent with instructions to reconcile them. Group discussions are encouraged at different stages to facilitate a consensus. Details of this protocol (GBD PTO protocol) are described in Murray (1996, pages 35-41 and appendix 1 at pages 90-98). A major deficiency that persisted is lack of standard description of health states. Since most participants were chosen from health professions, it was assumed that they would have a shared understanding of the health states in question. Interactions between interviewers and respondents as well as the group discussions were not fully structured.

Willingness to pay:

Willingness to pay is a straightforward application of welfarist notion of health status as a personal utility similar to other goods and services in the economy. A persons willingness to pay for curing or avoiding impairment, disability and handicaps associated with a health state is taken as a measure of quality adjustment weight for that health state. Willingness to pay to avoid the risk of death can be used as a denominator to derive quality adjustment weights in the range of [0,1]. Apart from ethical objections concerning welfarist approach to health and economic valuation of human life, measurement of willingness to pay is complicated by lack of a perfectly (or nearly perfect) competitive market in the health sector. Various alternatives like the contingent valuation method, cost of illness method are used to get around this problem. A comprehensive description of these methods can be found in Tolley, Kenkel and Fabian (1994).

Controlling Context Effects:

Froberg and Kane (1989-III) in their third article review observations about the effect of respondent characteristics and other contextual characteristics on health status measurement. They group these factors into three clusters, (a) differences among population (respondent characteristics); (b) inconsistencies due to the nature of human judgement process (framing); and (c) inconsistency due to situation specific variables (situational differences). They observe that respondent characteristics do not have any significant effect on valuation and hence can be ignored. Framing effects can be reduced by presenting the problem in more than one way and asking the rater to reconcile inconsistencies. This is same as the multistep approach (reflective equilibrium) suggested by Nord (1995). The solution to situational differences proposed by Froberg and Kane (1989-III) is to standardise them.

Psychometric Instruments for General Health Status Measurement:

A number of instruments are now available for health status measurement. McDowell and Newell (1987, 1996) provide an overview of these and distinguish two general classes, namely (a) instruments for measurement of general health status and (b) instruments designed for specific dimensions of health for example physical disability, psychological well being, pain etceteras. Our interest here is on the first category. McDowell and Newell (1996, chapter-9, pages 380-492) list 21 instruments for measurement of general health status. Eighteen of these instruments, called general health profiles, generate a profile of scores in different dimensions included in the instrument. Another three allow computation of a single index from out of the scores in component dimensions. These are called health indices. We will briefly describe four of these instrument, namely; (a) the sickness impact profile (SIP); (b) Short-form-36 (SF-36) health survey; (c) EuroQol, and (d) the quality of well being scale (QWB). The first two give a general health profile only. The last two produce general health indices in addition to profiles.

The sickness impact profile (SIP) seeks to measure changes in a person's behaviour on account of illness. Scoring is done along 12 categories or sub dimension. Respondent behaviour in each category is assessed by a set of questions graded according to severity or

intensity along the sub dimension. There are altogether 136 such graded questions. The 12 sub dimensions can be grouped into (a) physical health consisting of ambulation, mobility and body care; (b) psycho social health consisting of social interaction, alertness, emotional state and communication; and (c) five independent categories, namely (i) sleep and rest, (ii) eating, (iii) work, (iv) home management and (v) recreation. Item weights were arrived at from more than 100 judges with equal appearing interval scaling procedures. The profile can either be self administered or can be administered by an interviewer. It takes about 20 to 30 minutes to complete the questionnaire. The scale was developed by Bergner and others (1976a, 1976b, 1981).

The SF-36 instrument measures eight dimensions, namely (a) physical functioning, (b) role limitations due to physical problems, (c) pain, (d) social functioning, (e) general mental health, (f) role limitations due to emotional problems, (g) vitality, energy or fatigue and (h) general health perceptions. Physical functioning and role limitation due to physical problems can be viewed as one dimension. Similarly (d), (f) and (g) can be viewed as social functioning. Thus the dimensions covered in this instruments can be summarised as (a) physical function status, (b) social function, (c) psychological well being and (d) pain. Each dimension is assessed by category rating of multiple items which are themselves graded by severity or intensity. The form uses preceding one month as the time frame for all questions. Alternative forms using shorter time frames for acute conditions have also been used. Reliability and criterion validity (using common sense criteria like ability to work, symptoms, etc.) have been found to be fairly high (McDowell and Newell, 1996). It was developed out of the health insurance experiment (HIE) and medical outcomes study (MOS) conducted by the RAND corporation in USA. The SF-36 instrument has been described by Ware and Sherbourne (1992), Ware and others (1993), McHorney and others (1993, 1994), Aaronson and others (1992).

The EuroQol is a summated rating scale consisting of five dimensions. These are mobility, self care, usual activities, pain or discomfort and anxiety or depression. Each dimension is rated by a three point category rating scale. Weights for computation of composite index were developed by using valuation of 10 core health states on visual analogue scales. The instrument has four parts as follows: (a) description of patients own health (page 2) along five dimensions; (b) overall rating of own health using a visual

analogue scale (page 3); (c) valuation of a standard set of health states (pages 4-7); and (d) background information about the respondent (pages 8-9). Parts (a) and (b) are required to collect data on health related quality of life. A general health index can be computed using weights derived by the EuroQol team using responses from the valuation part (pages 4-7). For local weights these parts have to be implemented as well. The EuroQol instrument is described by the EuroQol group (1990), Brooks and the EuroQol group (1996), and McDowell and Newell (1987, 1996). The full instrument is reproduced in Shumaker and Berzon (1995 appendix -2).

The quality of well being (QWB) scale is a summated rating scale consisting of four dimensions, namely (a) mobility, (b) physical activity, (c) social activity, and (d) symptom problem complex. Estimation of QWB index proceeds in the following three steps: (a) assessment of functional status profile, (b) Scaling of responses to derive dimension specific weights for the composite index, and (c) estimation of transition probabilities to derive expected duration in each health state. Construction of synthetic measures like DALY or QALY, already takes into account expected duration in each health state. So measurement of disability weight or its complement quality adjustment weight requires only the first two steps i.e. assessment of functional status and dimension specific weights. Authors of the scale have derived a set of dimension specific weights from valuations by 867 raters and using an equal appearing interval rating procedure (Kaplan, Bush and Berry 1976; 1979; Patrick, Bush and Chen 1973a-b; Blischke, Bush and Kaplan 1975). This instrument has been described by Kaplan, Anderson and Ganiats (1992), and in McDowell and Newell (1987, 1996). QWB was used to gather community valuations for difference health states by the Oregon health services commission (OSHC). The scale was criticised when it was found that weights assigned by it to certain health states were clearly counter intuitive. However, it has been pointed out that the QWB scale was not properly applied by the OSHC and hence the counter intuitive results could not be attributed to the scale.

Local Issues in Choice of Instruments:

It would be useful to recognise certain issues, not covered in the methodological discussions above, and having a bearing on choice of these instruments. I discuss three important issues, namely; (a) need to account for minor and trivial illnesses and its implication for health status measurement, (b) cross cultural validity of health state valuation instruments, and (c) local feasibility and need for adaptation of health state valuation instruments.

Minor and Trivial Illness:

How to treat the large amount of illnesses that exists but for which people do not seek treatment? It has been observed that aggregate measures like sickness rate (number of persons becoming ill per time period) or illness episodes per time period based on simple count and the implied equal weightage to illnesses of all severity are too stable and non responsive to variations in incidence of more severe illnesses (Logan and Brooke 1957). This is in fact the primary motivation behind the search for a set of unequal health state weights. The relative weight to illness of different severity will depend on the current concept of health. At a time characterised by survival as the dominant concept of health, weights attached to all forms of morbidity are nearly zero. As the concept of health evolves to include absence of disease, more severe forms of disability start receiving higher weightage both in the minds of the patients and public. Further evolution of the concept of health to include quality of life would naturally enhance the weightage received by illnesses considered minor and trivial in an earlier era. Rosser (1983) notes that even though Logan and Brooke, in 1957, sought to increase the sensitivity of aggregate indicators of morbidity by splitting down some categories (there by assigning zero weightage to excluded conditions), such an approach would not relevant in view of increasing concerns about these so called minor and trivial illnesses.

Health status measures differ in sensitivity to minor and trivial illnesses. For example; the Quality of well being scale (QWB) is known to be more sensitive to small departures from perfect health (McDowell and Newell, 1996 p483-491). This is because the QWB construct includes a symptom complex dimension. For example; Erickson et al (1989) found that the QWB scale classified 95% of the 45-64 year old population in less than perfect health compared to 75% when activity limitation was used as the criterion. On the other hand

EuroQol is insensitive to small departures from perfect health (McDowell and Newell, 1996 p480-483). This instrument differentiates between more severe forms of morbidity but lumps all morbidities at the healthy end of the scale.

Thus choice of instrument to assign health state weight will have an impact on the kind of policy application to which the resultant aggregate measure of disease burden can be put. If the health state weighing instrument is not sensitive to minor and trivial illnesses, the resultant disease burden measure could not be used to assess need for ambulatory services.

Cross cultural validity:

Validity of an instrument across different cultural settings will depend on the conception of health from which it arises and the nature of dimensions included in it. If the judgement on some dimensions is influenced by specific cultural characteristics the instrument would not perform well in settings outside the place of its origin. Schumaker and Naughton (1995), recognising the need for portable health status measurement instruments for international use proposed that domains of health related quality of life be restricted to those "universally most essential to one's ability to pursue valued life goals". Most instruments purporting to measure health related quality of life do include such universally useful dimensions such as physical, social and psychological functioning; mobility and self care; and emotional well being. Although this principle is not in doubt, there is scope for wide ranging interpretations of the very generic characterisation of universally useful dimensions.

Another practical issue is ease and accuracy of translation. The translated instrument should retain its original validity and reliability characteristics. Leplege and Verdier (1995) have described methodological aspects of translation of health status measurement instruments. Generic instruments, which have been translated to different languages (Shumaker and Berzon 1995 appendix-1) include (a) the Short form health survey (SF-36); (b) Nottingham health profile (NHP); (c) sickness impact profile (SIP); (d) EuroQol and (e) Dartmouth COOP functional health assessment charts. Out of these five EuroQol is the only instrument to generate a composite index of health status. All other instruments produce general health profiles (McDowell and Newell, 1996).

Local feasibility:

A further issue is feasibility of administration in the local context. In Andhra Pradesh literacy is only about 45%. So the scope for self administration of questionnaires is limited. Local experience in measurement of health related quality of life is almost non existent. So even for interviewer administered questionnaire the items need to be simple and straight forward to ensure acceptable levels of compliance by interviewers and interviewee.

References:

Allen D., Lee R.H., and Lowson K. 1989. The use of QALYs in health service planning. International Journal of Health Planning and Management 4: 261-73.

Amartya Sen. Social Choice Theory: A Re-examination. Econometrica 1977; 45:53-90.

Amartya Sen. Personal utilities and public judgements: or Whats wrong with Welfare Economics. Economic Journal 1979; 89:537-58.

Anderson RT, Aaronson NK, Wilkin D. Critical review of the international assessments of health-related quality of life (review). Quality of Life Research 2(6), pp.3369-95. L993.

Bergner M., Bobbit R. A., Carter W. B., and others. 1981. The sickness impact profile: development and final revision of a health status measure. Medical Care 19: 787-805.

Bergner M., Bobbit R. A., Kressel S., and others. 1976. The sickness impact profile: conceptual formulation and methodology for the development of a health status measure. International Journal of Health Services 6: 393-415.

Bergner M., Bobbit R.A., Pollard W. E., and others. 1976a. The sickness impact profile: validation of a health status measure. Medical Care 14: 57-67.

Bleichrodt Han. 1997. Health utility indices and equity considerations. Journal of Health Economics 16: 65-91.

Brooks Richard and EuroQol group. EuroQol: the current state of play. Health Policy. 1996; 37:53-72.

Culyer Anthony J. 1989. The normative economics of health care finance and provision. Oxford Review of Economic Policy 5, no. 1: 34-58.

EuroQol Group. EuroQol. A new facility for measurement of health-related quality of life. Health Policy. 1990; 16:199-208.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-I: measurement strategies. Journal of Clinical Epidemiology, 1989; 42(4):345-354.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-II: scaling methods. Journal of Clinical Epidemiology. 1989; 42(5):459-471.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-III: population and context effects. Journal of Clinical Epidemiology. 1989; 42(6):585-592.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-IV: progress and a research agenda. Journal of Clinical Epidemiology. 1989; 42(7):675-685.

Gudex C.; Dolan P.; Kind P., and Williams A. Health state valuations from the general public, using the visual analog scale. Quality of Life Research. 1996; 5:521-531.

Huskisson, E.C. (1974). Measurement of pain. Lancet, ii, 1127-31.

Kaplan R.M.; Bush J.W., and Berry C.C. Health Status Index: category rating versus magnitude estimation for measuring level of well being. Medical Care. 1979; 17:501-523.

Kaplan R.M.; Bush J.W., and Berry C.C. Health Status: Types of calidity and the index of well being. Health Services Research. 1976; 11:478-507.

Kaplan Robert M., Anderson John P., Ganiats Theordore G. The quality of well being scale: rationale for a single quality of life index. In: Walker Stuart R., Rosser Rachel M., Editors. Quality of life assessment. Key issues in the 1990s. Boston//London//Dordrecht: Kluwer Academic Publisher, 1992: 62-94.

Leplege A., and Verdier A. 1995. The adaptation of health status measures: methodological aspects of the translation procedure. in The international assessment of health related quality of life. Theory, translation, measurement and analysis. Editors Shumaker Sally A., and Berzon Richard A.; Oxford, New York: Rapid Communications.

Lodge Milton. Magnitude scaling. Quantitative measurement of opinions. Newburry Park//London//New Delhi:Sage; 1981.

Mas-Collel Andreu, Whinstone Michael D., and Green Jerry. 1995. Micro economic theory. New York, Oxford: Oxford University Press.

McDowell Ian and Newell Claire. Measuring health: a guide to rating scales and questionnaires. New York / Oxford: Oxford University Press; 1987.

McDowell Ian and Newell Claire. Measuring health: a guide to rating scales and questionnaires. New York / Oxford: Oxford University Press; 1996.

McHorney C.A., Ware J. E. Jr., Lu J. F. R., and others. 1994. The MOS 36 item short-form health survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. Medical Care 32: 40-66.

Murray Christopher J.L., and Lopez Alan D. 1996. The global burden of disease in 1990: final results and their sensitivity to alternate epidemiological perspectives, discount rates, age weights and disability weights. in The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Editors Murray Christopher J. L., and Lopez Alan D. Boston: Harvard School of Public Health.

Nord Erik. The validity of a visual analogue scale in determining social utility weights for health states. International Journal of Health Planning and Management. 1991; 6:234-42.

Nord Erik. The Person-trade-off approach to valuing health care programs. Med Decis Making 1995;15:201-8.

Patrick D. L.; Bush J. W., and Chen M. M. Methods for measuring levels of well-being for health status index. Health Services Research. 1973; 8:228-245.

Pennifer Erickson, Kendall Allen, Andherson John P., and Kaplan Robert M. 1989. Using composite health status measures to assess the Nation's health. Medical care 27, no.3 Supplement:S66-S76.

Rosser Rachel. Issues of measrement in the design of health indicators: a review. In:Culyer A.J., Editor. Health indicators. An international study for the European Science Foundation. Oxford: Martin Robertson; 1983;pp.34-81.

Sackett D.L. and Torrance G.W. The utility of different health states as perceived by general public. Journal of Chronic Diseases. 1978; 7:347-358.

Shumaker Sally A., Naughton M.J. The international assessment of health related quality of life. in: Shumaker Sally A., Berzon Richard A., Editors. The international assessment of health related quality of life. Theory, translation, measurement and analysis. Oxford//New York: Rapid Communications, 1995.

Shumaker Sally A., and Berzon Richard A; Editors; The international assessment of health related quality of life. Theory, translation, measurement and analysis.; Oxford, New York: Rapid Communications, 1995.

Specter Paul E. 1992. Summated rating scale construction. An introduction. Newburry Park, London, New Delhi:Sage.

Streiner, D.L. & Norman G.R. 1995. Health Measurement Scales: A Practical Guide to their Development and use. New York: Oxford University Presss.

Tolley George, Kenkel Donald, and Fabian Robert; 1994; Valuing health for policy. An economic approach; Chicago and London: University of Chicago Press.

Torgerson W.S. 1958. Theory and methods of scaling. New York: John Wiley; page 141. Cited in Patrick et al 1973.

Torrance George W., Sackett David L., Thomas Warren H. Utility maximization model for program evaluation: a demonstration application. In: Berg Rober L., Chairman and Editor. Health status indexes. Proceedings of a conference conducted by Health Services Research, Tucson Arizona, October 1-4, 1972. Chicago: Hospital Research and Educatin Trust, 1973.

Torrance George W. Measurement of health state utilities for economic appraisal. A review. Journal of Health Economics. 1986; 5:1-30.

Torrance G.W., and Boyle M. H. 1982. Application of multiattribute utility theory to measure social preferences for health states. Operations Research 30: 1043-69. Cited in Froberg and Kane 1989-I.

Ware J. E., Snow K. K., Kosinski M., and others. 1993. SF-36 health survey: manual and interpretation guide. Boston, MA: The Health Institute, New England Medical Center.

Ware John E. Jr. and Sherbourne Cathy Donald. The MOS 36-item short form health survey (SF-36). Medical Care. 1992 Jun; 30(6).

Chapter 2

Materials and Methods of the AP Health State Valuation Study 1999

In this chapter, we present an overview of the study methodology. We first describe the study design followed by a description of our approach to select indicator conditions for the study. The methods and materials used to describe the health states for valuation are described in chapter three, titled "The 6D5L description system for health state valuation". Chapter four describes the multimethod deliberative health state valuation workshops. Chapter five describes methodological details about the community survey. Ideally chapters three to five should have been included here, since together they describe the study method. We decided to present them in separate chapters since some aspects of study method needed more detailed treatment. For example, development of the health state description system needed substantial efforts to facilitate its use in partially literate communities.

Study Design:

The study has two arms, namely; (a) the multimethod deliberative health state valuation (MDHSV) workshops, and (b) community survey. The MDHSV arm of the study is meant to test validity of community survey instrument. The MDHSV workshops allows for valuations using multiple instrument. Only educated persons are chosen as participants to facilitate communication of written guidelines about each of the valuation methods. We thought, this way, we can use the workshop format in the group with higher educational attainment to perform the more demanding cognitive tasks. This will allow us to check for convergent validity of the measurements in general population with results from the multimethod deliberative workshops. The community survey arm of the study was designed to obtain valuations for different health states from a community. These valuations would be the basis of disability weights to be used for computation of disease burden in the local area. In addition, we wanted to test feasibility of health state valuation studies in partially literate communities. It was planned to randomly select respondents from a village in a rural area. The village could be chosen according to convenience, but sampling within the village had to

random. A major challenge for health state valuation by illiterate and semi literate persons is how to communicate description of the health states, as well as guidelines for use of the measurement instrument. We needed to develop an instrument that can be used in a general population survey. This had to be simpler than time trade-off (TTO), person trade-off (PTO), or standard gamble (SG), which are known to require fairly good deal of cognitive effort. We thought of a card sorting exercise followed by valuation with a visual analogue scale. A structured interview format is preferred over a workshop format in view of the following:

1. Since, the survey instrument would consist of only card sort, and visual analogue scale, deliberation by the valuer can be promoted by asking the individuals to do the VAS with reference to the card sort ranks they would have just completed.
2. There is a risk of an uneducated group being influenced by dominant personalities, etc.
3. Interview format is a feasible option for large scale population based surveys.
4. Population surveys using card sort or some form of ranking and visual analogue scales are not new. The EuroQol group has been conducting similar studies in mostly OECD countries. This study was to distinguish itself by adaptation of these measurement techniques for use in a partially literate society.

A statistically inferred measurement strategy was planned. Valuers are presented holistic description of health states using functional levels along multiple dimensions. A statistical model of valuer's preference along different dimensions can be estimated from the directly measured health states. Valuations for other than directly measured health states can be predicted with help of the statistical model.

Selection of Index Health States (Conditions):

Although, synthetic health status measures would require, health state weights for a large number of conditions, a health state valuation study has its limitations to generate direct valuations for a large number of conditions. Health state valuation exercises are usually characterised by high cognitive load on the valuers. Hence a valuer is usually given a limited set of conditions. Increasing the number of conditions would lead to valuer fatigue resulting in poor validity and reliability of the measurements. A practical alternative is to use small set of conditions to measure peoples preference and then statistically infer the health state values for other states. The small set of conditions used to gather measurements on peoples

valuation of health states is referred to as index health states or synonymously indicator conditions.

Criteria for Selection of Indicator Conditions:

Following principles were considered by us for choice of index health states:

1. The number of health states presented to a single valuer, should be kept within manageable limits to minimise incidence of cognitive overload. This limit is a function of human attention span and cognitive behaviour, and is independent of sample size. Parts of the health state valuation exercise, require the valuer to deliberate about all health states at hand and assign values to each. This limit is all the more significant for population based surveys, where multiple sessions would not usually be feasible. Gudex and others (1996) limited the number of health states per valuer to 15, for a population based survey in UK. Sacket and Torrance included 10 health states for their population bases survey in Hamilton, Otario Canada (Sackett and Torrance, 1978). The EuroQol group (Brooks, 1996) found, it was feasible for a person to value about 12-16 health states using the EuroQol instrument. We fixed a limit of 11 health states including own health state, to be valued by a person in one session.
2. The set of index health states should represent widest range of health state profiles. This will allow statistical inference of health state weights for conditions for which no direct measurement is available. Hence it is important that set of indicator conditions maximise the independent variation in each dimension of health status. The need to maximise independent variation along each dimension and the constraint imposed by ability of valuers to deal with a number of conditions, are counter to each other. Since the limit on number of health states for valuation by an individual is fixed on psychometric grounds, the only scope to increase variation in dimensions of health status is to increase sample size and present different sets of conditions to different persons.
3. Comparability and linkage between different health states would require that some health states be common for all valuation sets. We call this core health states.
4. Inclusion of a few pairs of dominating and dominated health state will facilitate inference about validity of the measurement protocol. A state that is unequivocally worse than another state in at least one dimension and at most equivalent in all others is considered a dominated condition. One that is unequivocally better than another state in at least one dimension, and at the least, equivalent in all is considered a dominating condition. Examples of dominating and dominated pairs of health states are; below the knee amputation of one leg, and below the knee amputation of the both the legs, quadriplegia and paraplegia. Then the proportion of times that ranks for dominated states are inverted can be used as a measure of (or lack of) the health state comprehension.
5. Health states corresponding to diseases not found or very rare in the local population should be avoided. Since a descriptive label for each health state is retained to facilitate synthetic comprehension by the valuer, going for unheard of conditions

would not be helpful. Such conditions might de motivate valuers due to lack of apparent purpose of the exercise.

6. At least some health states corresponding to diseases highly prevalent and / or considered important public health problems in the local area should be included. This is required to increase valuer's motivation and allow for a sense of purpose in the valuation exercise.
7. Health states associated with disease labels known to be a taboo, to provoke a sense of outrage or subject to widely prevalent stereotypes should be avoided. The disease label is likely to dominate the valuers thought process to near total exclusion of the health state profile. There would appear to be some conflict between the need to avoid stereotypes and the goal of seeking locally prevalent health states, described earlier. Indeed, there would be some diseases which are highly prevalent and carry a strong stereotype. So, quite naturally,. the art of selecting indicator conditions requires careful weighing of potential confounding due to various factors, and the feasibility of getting valuers cooperation.

Health States Chosen for This Study:

The number of health state to be valued by a single valuer was limited to 11, to minimise incidence of cognitive overload, and valuer fatigue. The study, however, sought to directly measure disability weights for a larger set of conditions. According to original plan, 22 health states were chosen for the study, apart from the valuers own health state. Six of these health states were used as the core common to all valuers. The balance 16 health states were divided into four subsets. Each subset added to the core subset made a set of health states. Accordingly, the study designed for four sets of health states. The six core conditions were selected to represent a broad range of 6D5L profile and disability severity weights. While making up these lists, conditions known to be highly prevalent in Andhra Pradesh were included and conditions not found in AP were excluded, while trying to keep the list as comparable with the ones used at other study sites for international comparability. Thus selection of indicator conditions involved several rounds of discussion between local investigators at IHS and study coordinators at WHO-GPE. Sets were systematically assigned to balance assignment of valuers to different sets of health states.

Mid way through the study and before the household survey started, it was decided to replace two health states, namely common cold, and moderate anaemia with two relatively more severe conditions to improve the spread of health states under study. Common cold and moderate anaemia were replaced by hallucinatory fever and two broken arms in cast. As a

result, multiple valuation workshops ended up valuing altogether 24 health states, while the number of health states valued through the survey remained at 22. Set numbers 5 and 6 has been created to accommodate the mid course change. Thus set 5 shares some health states with set 2 and set 6 shares some health states with set 3. Set 5 has common cold, instead of severe hallucinatory fever and set 3 has moderate anaemia instead of broken arms with cast. We first planned do the survey with four sets (1-4). But during the course of implementation, some interviewers by mistake mixed up one or two conditions from other sets. In these cases the valuers worked on 11 health states including his / her own health state. But the conditions did not conform to the pre assigned sets. To distinguish these valuations from the rest, we assigned new set numbers to them. Thus set numbers 7 to 35 refer to these cases. Every other aspect of valuation method for these cases are same as other valuations. There are 29 such valuers in the data set with Set = [7 to 35].30

Table - 2.1: Assignment of sets of health states to valuers

Set	Survey	Workshop
1	269	45
2		
3	247	
4	218	45
5		14
6		15
7 to 34	29	0
All	1,010	150

In summary sets 1 to 4 are the primary sets of conditions used for the household survey and the workshops. Sets 5 and 6 were used for a few workshops in the beginning. Sets 7 to 35 correspond to some initial valuations in the household survey where the set of conditions did not exactly conform to the pre planned sets 1 to 4.

Table-2.2 shows the list of these health states and the number of valuations obtained for each from the survey and workshops respectively. Note that there are altogether 22 + 2 +1 = 25 conditions in this list. Twenty two conditions as originally planned, two mid course substitutes, and valuer's own health state. Actually we should say there are 24 plus conditions, since valuers own health state is not a single state as might appear from Table-2.2

Table - 2.2: Number of valuations obtained for each health state

Health State	GBD#	Sets	6D5L	Survey	Workshop	Both
Own Health Today		C		1010	180	1190
Watery Diarrhoea 5 times a day	Yes	C	111211	1006	180	1186
Mild diabetes, no symptoms		C	111121	1004	180	1184
Mild Tuberculosis with treatment		C	111221	1008	180	1188
Severe continuous migraine	Yes	C	113431	998	180	1178
Unipolar major depression	Yes	C	124142	1000	180	1180
Quadriplegia	Yes	C	554341	1008	180	1188
Bronchitis		1	112311	279	45	324
Pain and stiffness in joints		1	222311	278	45	323
Urinary incontinence		1	113331	279	45	324
Schizophrenia		1	234244	280	45	325
Infertility	Yes	2,5	111131	250	45	295
Angina	Yes	2,5	111321	253	45	298
Blindness	Yes	2,5	323122	247	45	292
Severe Hallucinatory Fever		2	444333	253	31	284
Peptic Ulcer		3,6	112321	258	45	303
Below the knee amputation (one leg)	Yes	3,6	322211	255	45	300
Below the knee amputation (two legs)		3,6	433221	258	45	303
Two broken arms in cast		3	154321	256	30	286
White marks on face	Yes	4	111131	235	45	280
Mild hearing disorder		4	112121	233	45	278
Continuous moderate back pain		4	212321	233	45	278
Severe heart failure (congestive)		4	434531	229	45	274
Common cold*		2,5	112211	0	14	14
Moderate Anaemia*	Yes	3,6	112211	0	15	15
All				11110	1980	13090

* These two health states were included in the respective sets in the beginning. Later, the sets were replaced by hallucinatory fever and two broken arms in cast, respectively. Hence number of valuations for these two are relatively small and confined to workshop only. Similarly the number of valuations through workshops is less for the replacement conditions.
# Yes if the condition was included among 22 indicator conditions in GBD study (Murray & Lopez, 1996)

Each valuer was presented with 10 health states plus his / her own health state for valuation. Potentially, there can be as many own health today profiles as there are valuers, limited by 15625[4] which is the maximum number of permutations of severity levels in the six dimensions. In practice, there would be a smaller number of unique own health today profiles, since many valuers would report the same own health state profiles. Examination of data from this study reveals that 292 unique own health state profiles were reported by valuers. Of these, 6D5L profiles chosen by 10 or more valuers are shown in the Table-2.3.

[4] Since there are 5 possible levels in each dimension and there are 6 dimensions altogether, the number of permutations works out to $5^6 = 15625$.

Table-2.3: Frequently reported own health today profiles

6D5L	Survey		Workshop		Both	
	#	Cum	#	Cum	#	Cum
111111	333	33%	93	52%	414	35%
111211	60	39%	13	59%	69	41%
111121	35	42%	18	69%	52	45%
111221	39	46%	9	74%	46	49%
111222	22	48%		74%	22	51%
111112	21	50%		74%	21	52%
112111	11	52%	9	79%	20	54%
112211	11	53%	3	81%	14	55%
112222	13	54%	1	81%	14	56%
222222	13	55%		81%	13	58%
112121	9	56%	5	84%	13	59%
111122	12	57%		84%	12	60%
112221	3	58%	8	88%	11	61%
111212	10	59%		88%	10	61%
All	1010	100%	180	100%	1190	100%

APHSV99 Data Set:

Data collected through this study is made available in electronic format in a separate publication (IHS, 2003) to facilitate further study and analysis by interested researchers.

References:

Brooks Richard and EuroQol group. EuroQol: the current state of play. Health Policy. 1996; 37:53-72.

Euroqol Group. EuroQol. A new facility for measurement of health-related quality of life. Health Policy. 1990; 16:199-208.

Gudex C.; Dolan P.; Kind P., and Williams A. Health state valuations from the general public, using the visual analog scale. Quality of Life Research. 1996; 5:521-531.

Institute of Health Systems (IHS) Andhra Pradesh Health State Valuation Dataset. Hyderabad: Institute of Health Systems (IHS), 2003.

Sackett D.L. and Torrance G.W. The utility of different health states as perceived by general public. Journal of Chronic Diseases. 1978; 7:347-358.

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Chapter 3:

The 6D5L Description System for Health State Valuation.

When we ask a person to value time spent in a health state without any information about the key domains of health, (s)he must guess a description of the health state. The description visualised by the valuer would usually by implicit in the valuation task. This will inevitably introduce measurement error and a potential for bias in the results. Another consideration is how to convey relevant information about a hypothetical health state to the individual undertaking the valuation, who might not have personally encountered the state. Disease labels are short and parsimonious, but do not convey adequate information about functional status. Moreover, disease labels are vulnerable to different interpretations based on cultural and personal settings. In this chapter we first review current literature on the theoretical question of how to describe health states for valuation. We then describe components of the 6D5L system developed to describe health states for valuation. In the third and final section of this chapter we present some results about the usage of the 6D5L system by valuers in this study.

How to Describe Health States for Valuation:

It is now widely recognised that health states should be described in terms of functional status. Functional status information can be presented either in a narrative or structured format. For example, Sacket and Torrance (1978) used brief scenarios written up with help of clinicians, to describe various health states. EuroQol uses a structured approach where each health state is described in terms of five dimensions and three severity levels within each dimension (Brooks, EuroQol Group, 1996). The Health Utilities Index uses a structured approach consisting of an eight dimensions and 5-6 severity levels within each dimension (Boyle et al. 1994). Torrance and others (1992) have also used structured formats consisting of seven dimensions and 4-5 severity levels within each. Issues relevant to development of a health state description systems have been described by Boyle and Torrance (1984), and Froberg and Kane I-IV (1989). Briefly, four important considerations

guide us in defining the description space (number of dimensions) and the inclusion of specific attributes[5] of human health.

1. Conceptual definitions of health and deduced description systems.
2. Empirically gathered health-related attributes, and description systems induced by them.
3. Attention span and cognitive capacity of the human mind to process multi-dimensional information.
4. Statistical analysis of multi-attribute measurements.

Conceptual Definitions of Health and Deduced Description Systems:

An ideal definition of health provides us the goal towards which a formal health state description system should work. Deductive lineage from an ideal definition, gives the description system its content validity. Hence a description system should incorporate as much of our ideal notion of health, as is practically feasible. Concepts of health as well as support to and criticism of various definitions of health has been reviewed by Fanshel (1972), Patrick et al (1973), Boyle and Torrance (1984), Noack (1987), Goldberg and Dab (1987), Stewart (1992) and Patrick and Ericson (1993). Based on an overview of concepts of health Noack (1987), highlighted two common elements in various definitions, namely (a) that health is a holistic concept, and (b) that health is a multidimensional concept. Intuitively appealing this view is invariably shared by researchers dealing with the subject of health and its measurement.

The holistic and multidimensional character of health is emphasised by the WHO definition of health. WHO's constitution defines health as a state of complete physical, mental and social well-being and not merely absence of disease or infirmity. This is a very inclusive definition. The definition certainly motivates health workers to integrate their role into a social well-being world-view. From the analytic perspective, there could be some doubt as to whether including social well-being within the health construct helps or hinders analysis. For example, restricting the concept of health status to physical and mental health would allow for testing of research questions as to how actions in the health care sector affect social well-being. On the other hand, an inclusive definition would make it difficult to identify the

[5] "Attributes" and "dimensions" are used in health status measurement literature, and here, interchangeably.

effect of actions in the health sector on an overall social well-being. Many generic health status measurement tools have drawn inspiration from the WHO's definition of health, using the physical, mental and social well- being triad as a starting point for the inclusion of dimensions and items within them. Some examples are: the EuroQol (Brooks, 1996), the health status index (Fanshel and Bush, 1970) which has since evolved into the more commonly known Quality of Well Being Scale (Kaplan and Bush, 1982) and the McMaster Health Index Questionnaire (Chambers, 1976). In the EuroQol instrument, for example, mobility and self-care would map to physical functioning; usual activities are linked to social functioning; and anxiety and depression would represent mental health.

Empirically gathered health-related attributes, and induced description systems:

Authors of the Quality of Well Being scale first abstracted "several hundred" case descriptions from medical texts. Then they consulted various survey instruments including the Health Interview Survey of the US National Center for Health Statistics, Alameda County Population Laboratory's community social surveys. Items from the survey instruments were selected to cover the range of disturbances in functional status (Patrick, Bush and Chen, 1973).

Development of the Sickness Impact Profile (SIP) began with accumulation of statements describing behavioural changes attributable to sickness. These statements were collected from a sample of enrollees in a prepaid group practice and persons attending a few other outpatient facilities. Sampling of enrollees in the group practice continued until the yield of new and usable statements diminished markedly (Bergner, 1976). A basic catalogue of 1100 statements was reduced to 312 unique items in 14 categories. The Nottingham Health Profile (NHP) generated its pool of items through a survey of 768 patients with acute and chronic ailments (Hunt et al, 1981). Items from the SIP were used in addition. The NHP contains 38 items grouped into six sections, namely physical abilities, pain, sleep, social isolation, emotional reactions and energy level.

Table-3.1: Mapping of selected health status description systems to EQ-5D.

SIP	QWB	NHP	EQ-5D*
Ambulation	Mobility	Physical abilities	Mobility
Mobility	Physical activity		
Body care and movements			Self care
Eating	Social activity - self care		
Work	Social activity - major		Usual activities +
Home management			
Recreation and pastimes	Social activity - other		
			Pain - discomfort
Emotional behaviour		Emotional reactions	Anxiety - Depression
Sleeping and rest		Sleep	
Social interaction		Social isolation	
Communication			
Alertness behaviour		Energy level	

+ Includes main activity and leisure which were separate in early versions of EuroQol.

The EuroQol group (1990) reviewed the health state description systems developed by the above studies to arrive at a parsimonious set of dimensions. The group sought to develop an instrument of generic health status measurement across multiple cultures. Table-3.1 shows the dimensions arrived at by studies leading to the three scales described above and the five dimensions adopted by EuroQol (EQ-5D). Except alertness and energy level, all other dimensions from SIP, QWB and NHP scales are represented in the EQ-5D system. Note that cognition did not appear as a distinct dimension in any of these scales.

The Rand Health Insurance Experiment, followed by the Medical Outcomes Study (MOS), systematically collected items to describe various aspects of health and studied their properties for construction of a generic health status measurement tool (Stewart, 1992, Brook et al 1979). The Short Form-36 (SF-36) instrument is an outcome of these extensive studies. SF-36 includes multiple items organised under eight dimensions[6] (Table-3.2). Cognition appeared in these studies as a distinct dimension. Most of these map to the EQ-5D system, except cognition, health perceptions, energy-fatigue, and physical-psychological symptoms.

[6] The number of dimensions in SF-36 can be viewed as four. Please see page 112-113 more discussion on SF-36.

Table-3.2: Mapping of MOS* Dimensions to EQ-5D.

Medical Outcomes Study (MOS)		EQ-5D
Mobility	Getting around in the community	Mobility
Physical functioning	Walking, climbing stairs	
	Self care	Self care
Role functioning	Performance of usual role activities such as working at a job, housework, child care, community activities and volunteer work	Usual activities
Pain	Subjective feeling of bodily distress of discomfort such as headaches, backaches.	Pain - Discomfort
Social functioning	Functioning in normal social activities with family, friends, neighbours, marital functioning, sexual problems.	
Psychological distress /wellbeing	Positive and negative psychological states including anxiety, depression, behavioural emotional control, loneliness, positive affect, feelings of belonging.	Anxiety - Depression
Sleep	Quantity, disturbance, adequacy of sleep	
Health distress	Psychological distress due to health	
Cognitive functioning	Cognitive problems, such as forgetfulness, difficulty in concentrating.	
Health perceptions	Personal evaluations of health in general, including current and prior health, health outlook, resistance to illness.	
Energy / fatigue	Feelings of energy, pep, fatigue, tiredness	
Physical / psychological. symptoms	Subjective perceptions about the internal state of the body, such as stiffness and coughing.	

* Source: Stewart Anita L.; The Medical Outcomes Study framework of health indicators, in Anita L Stewart and John E. Ware Jr. Eds, Measuring Functioning and Well being, Duke University Press, Durham, 1992, pp23-24.

The EQ-5D description system appears to be strongly rooted in its conceptual lineage to an ideal definition of health and its linkage to empirically rooted health status descriptions. Its emphasis on cross-cultural validity and feasibility of measurement are very attractive. However, the lack of cognitive dimension and the restriction of severity levels within each dimension to three, leaves us with some handicaps. Cognition, hitherto taken for granted, is clearly an important attribute of human health. Diseases affecting cognitive functioning are now being recognised. Recent research in a EuroQol member centre suggests that the addition of cognition as the sixth dimension, would make the EQ-5D system more comprehensive (Krabbe et al, 1998). These authors found that the inclusion of cognition

changed ratings for conditions with lower levels of disability in other dimensions. Valuations for conditions with severe levels of disability in other dimensions did not change much. Restriction of severity levels to three may be a reason for the insensitivity of EuroQol to minor and trivial illnesses.

Attention span and cognitive capacity of human mind to process multidimensional information:

Research in the field of psychology suggests that there is a limit to our capacity to process information (Saariluoma, 1998). Miller (1956) suggested that human beings process about 5 - 9 attributes (chunks of information) at a time. More recent evidence from research in working memory suggests that human capacity to simultaneously process multi-attribute information may range from 3 to 5 rather than 5 to 9 as was thought earlier (Halford, 1998). These findings imply that the number of dimensions used to describe the states should be kept as minimum as feasible, to allow adequate processing of health state descriptions by valuers. Recognising the need to keep the information load on valuers within manageable limits, researchers have tried to simplify health state description systems. For example, Brazier and others (1998) simplified the SF-36 profiles to a six-dimension (SF-6D) description system, which was used to obtain a holistic valuation of health states to be used for estimation of QALYs. Froberg and Kane (1989) propose that the number of dimensions in a description system should not exceed nine, and should preferably be less. Reviewing empirical evidences on the mode of presentation of health states, Froberg and Kane (1989) conjecture that "moderately detailed health state descriptions yield more accurate judgements of preference than either very scant descriptions or very lengthy descriptions that run the risk of overloading the rater's information processing capacity". We believe that the number of dimensions should not exceed six and should preferably be less. We have used six dimensions to describe health states in this study. We hope that future research will help identify more compact description systems with lesser number of dimensions without any loss of descriptive ability.

Statistical analysis of multi-attribute measurements:

The number of dimensions have implications about the type of statistical analyses that can be done on directly measured health state values. Froberg and Kane (1989) have referred

to Fischer's overview (1979) which found that with six or fewer dimensions, functional measurement and explicit decomposition procedures assigned similar values to a health state. The reliability of multi-attribute judgements deteriorate with larger number of dimensions. Froberg and Kane have referred to other investigators (Llewellyn-Thomas et al, 1984; Lyness and Cornelius, 1982) who found that when only a few dimensions are involved, multi-attribute judgements are more reliable than decomposed judgements. Thus, parsimony of dimensions is important to retain the holistic property of a description used for operational purposes.

How to convey health state descriptions effectively to an individual undertaking the valuations:

Effective communication of the description to individuals acting as valuers has many difficulties. The descriptive system must be comprehensible to the young, middle-aged and older adults with widely varying levels of educational attainment, socioeconomic and cultural backgrounds. For example, differences have been found between using paragraphs written in the first person in describing a health state, and using straight lists of levels in each domain of health (Llewellyn-Thomas et al. 1982). The descriptive system should be meaningful across cultures. Translation of instruments should produce equivalence in terms of word meanings and idioms i.e. semantic and idiomatic equivalence; equivalence in terms of situations and concepts evoked in the descriptions i.e. experiential and conceptual equivalence, respectively (Guillemin et al, 1993). The description system should enable communication with semiliterate as well as illiterate persons. The description systems used so far have been developed for literate societies like North America and Europe. Even here, studies have experienced communication difficulties due to language barriers. For example, in the Canadian study by Sackett and Torrance (1978), about 12% of the randomly selected sample had to be excluded, because the interviewees could not communicate in English. One way to deal with this problem is to supplement written descriptions with appropriate graphical representations. Some researchers have used multimedia methods for valuation exercises (Lennert and Hornberger 1996, Lennert and Soetikno 1997). One problem with multimedia solutions is that the computer may be a source of distraction, particularly where the general community has limited experience with multimedia. In any case, multimedia solutions need a graphical description system to start with. So description systems for partially literate and multi-lingual communities should ideally include a graphical description sub system.

The 6D5L Health State Description System:

The 6D5L description system is developed by expanding upon the EuroQol (EQ-5D) description system. Cognition has been added as the sixth dimension. Severity levels in each dimension are described using five levels instead of three. The EQ-5D system allowed for a maximum of 244 distinct health states[7]. This restricted the systems ability to discriminate moderate to small differences in functional status. The 6D5L system will give rise to $5^6 = 15625$ distinct health states. Some of these states may not exist in practice, for example 555555 (a person with total loss of cognitive function would not be anxious). Even then, the system provides for description of a fairly large number of distinct health states. We hope that this will improve 6D5L's sensitivity to minor illnesses.

The 6D5L health state description system, developed for the AP health state valuation study consists of the following distinct parts, each of which is described below.

1. A written description of dimensions and severity levels.
2. A Telugu language version of the dimensions and severity levels.
3. Locally valid graphical representation of dimensions and severity levels.
4. Identification protocols. Procedure to identify health state descriptions of diseases, clinical and epidemiologically encountered conditions.
5. Coding schema to represent different health states.

Written description of dimensions and severity levels:

Since most valuers would come in contact with the description system for the first time, we anticipated that they may have difficulty in interpreting the six dimensions and discriminating between them. Hence a set of explanatory notes on "What this dimension represents?" were developed to reliably communicate aspects of health represented by respective dimension. These notes first explain what are included in the dimension. Then an example of a condition, that does not affect the dimension at all, is given, followed by example of conditions that may affect the concerned dimension.

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[7] Five dimensions with three levels in each give rise to $3^5 = 243$ permutations. To this death is added .

Published literature on functional status measurement including Activities of daily living (ADL), Instrumental activities of daily living (IADL), Pain measurement questionnaires (McDowell and Newells 1987, 1996), health related quality of life measurement scales like the EuroQol (Brook, 1996), SF-36 (Ware and Sherbourne, 1992), etc. were reviewed to cull out expressions that may explain, elucidate, clarify, or discriminate the concerned dimension. Such expressions have been used in the "What this dimensions represents." part of the descriptive system. These expressions have been taken form many articles and functional status measurement scales. Often more than one article or scale, provided similar expressions. Hence it has not been feasible for us to acknowledge all sources of these expressions. During the study, we found that the expression "usual activities" is easily confused with self care in the Indian context. Hence the third dimension, namely usual activities, was assigned an alternative label of work and leisure[8].

Box 3.1 Written description of mobility dimension

Mobility (Position = 1):

A.What this dimension represents:

1. Transfers: Includes the management of all aspects of transfers to and from bed, mat, toilet, etc. More simply getting in and out of bed.
2. Ambulation: Includes coming to a standing position and walking about,
3. Stairs and environmental surfaces: Ability to handle environmental barriers, and includes climbing stairs, curbs, ramps or environmental terrain,
4. Community mobility: Ability to manage transportation.
5. Example of a condition that does not affect mobility: Vitiligo
6. Example of conditions that may affect mobility to various degrees: Back ache, paralysis of lower limbs.

B.Severity Levels and Codes (SLC):

1. Independent, i.e. no assistance required and no problem with mobility. Ability to run / flight in times of need. SLC =1
2. Occasional or very few problems in moving about. SLC =2
3. Some problems in moving about. SLC=3
4. Many problems in moving about. SLC=4
5. Unable i.e. totally dependent for mobility. SLC=5

Telugu version of the written description system:

A panel of doctors and nurses practicing in the area were invited for a health state description workshop. Tasks assigned to the workshop included (a) Telugu translation of the 6D5L description system, and (b) Telugu translation of disease labels. The Telugu translations obtained from the health state description panel was the starting document. The draft translated document was further worked upon by us with help of other faculty

[8] Since this fact was found mid way through the study, all instruments and printed material continued to have the label, usual activities, but interviewers and workshop coordinators were instructed to clarify to valuers about the correct meaning of this dimension.

knowledgeable in Telugu, to arrive at a provisional draft. The provisional draft was then discussed with experts in Telugu literature. They were requested to provide alternate translations. In the next step, persons who were not aware of our list of health states were given the provisional Telugu drafts and were asked to translate them back to English. The back translations that resulted in the original English version were chosen for the Telugu version. The resultant 6D5L written description system in Telugu is given at appendices 3.4 and 3.5.

Locally appropriate graphical representation of dimensions and severity levels:

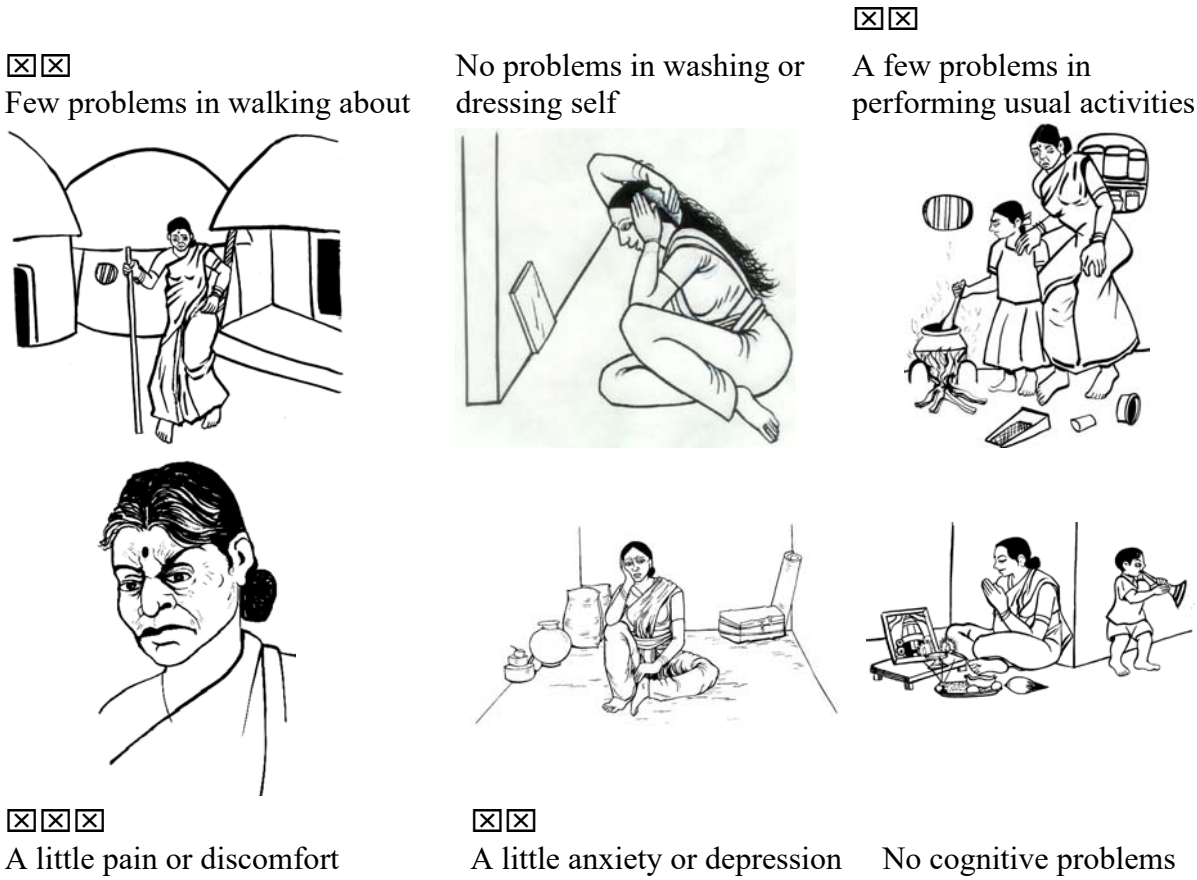
To facilitate communication of the 6D5L description system to semi-literate and illiterate valuers in the general population, we planned to develop a graphical description system for the 6D5L profiles. First an Artist brief (Appendix - 3.5) was prepared explaining the 6D5L description system, and describing the nature of task at hand. The brief gave examples of some what similar graphical representations, namely the Dartmouth Coop Function Charts (Nelson and others, 1987) and Faces scale (Andrew and Withey, 1976). The art teams task was to arrive at the most appropriate pictorial representation of the severity levels under each of the six health dimensions. A team of fine art students from the University of Hyderabad school of performing and fine arts were identified with the help of the school's faculty. This team of artists worked to draw pictures of the five severity levels in each of the six dimensions. Multiple sets of graphics were drawn by the artist team. We found the scaling and reproducibility of graphics using more of lines and less of shades was better. To facilitate preparation of health state description cards, etc. we preferred art works with more of line drawings and less of shading. Artists were asked to make sure that characters used in the pictures have;

1. To minimise gender bias separate sets of graphics are developed using female and male characters respectively.
2. Features similar to the local population,
3. Dress is consistent with dress pattern prevalent in rural areas of Andhra Pradesh for the respective gender,
4. Background, foreground, and other artifacts in the pictures are consistent with the rural scenario in Andhra Pradesh, and
5. Activities shown in the picture are consistent with usual roles for respective gender, currently prevalent in the state.

The pictures were reviewed many times. Persons not directly involved in the study were shown different sets of the pictures and asked to interpret them. The pictorial systems, that were perceived by these judges to represent the severity levels of the corresponding dimension were selected and used. The graphical description system consists of a collection of two sets of pictures, with six sub sets in each. Each sub set in turn represents one of the six health dimensions and consists of five pictures to represent the five severity levels. Thus basic element of the 6D5L graphical description system is a picture meant to convey a given level of severity in a particular health dimension. Altogether 30 such pictures consisting of five for each of the six health dimensions, and with a female person as the primary character constitutes the graphical description system for females. A similar set is prepared for the males. Figures-3.1 shows a set of five pictures for a single dimension (self care) using male characters. The complete set for all six dimensions, and both genders is provided in appendix-3.5.

Figure-3.1: 6D5L Graphics for Self Care

Figure - 3.2**: Continuous Moderate Back Pain**



A health state can be pictorially described by choosing the appropriate picture from each of the six sub sets. So a graphical 6D5L profile would consist of a set of six pictures. For example Figures-3.2 show the 6D5L graphical profiles for continuous moderate back pain in a female character. Figures with Telugu labels were used for the general population survey and those with English labels were used in MDHSV workshops.

Identification of 6D5L profiles:

Identification of 6D5L profiles may be required in the following two situations. Firstly, description of typical functional status of disease states. Here, we use the term disease state to include clinically and epidemiologically encountered conditions, which may not necessarily be considered disease states. Secondly, identification of labels for specific 6D5L profiles to facilitate holistic processing of 6D5L information by valuers. The need for association of labels to 6D5L profiles for purposes of valuation and how we arrived at the labels used in this study has already been described earlier. We will discuss here the need for

mapping of specific disease states to 6D5L profiles, and then proceed to describe our efforts to operationalise the same.

Health state valuations are usually obtained for incorporation into summary measures of population health status which may be computed to allow for disaggregated analysis. If disaggregated analysis is required then identification of 6D5L profiles for disease states becomes necessary. Summary measures of population health combine cause of death, descriptive epidemiological data on incidence, prevalence, duration, etc. and health state values. Cause of death data is invariably tabulated according to disease labels. Descriptive epidemiological information is largely available for health states identified by specific disease labels. The system of labeling causes of death is usually similar to the system of nomenclature of morbidities. Where there is some variations a mapping of disease state labels to cause of death label is usually feasible. Hence it becomes imperative for most researchers to use the disease categories as a convenient classification mechanism for disaggregated analysis of summary measures. Disaggregation by risk factor is usually achieved by tracing incidence of mortality and morbidity to the risk factor through different disease categories. Thus to incorporate health state values into a summary measure of population health status that allows disaggregated analysis, we need to arrive at health state or disability weights for disease categories included in the computation. If health states were valued separately for each of the disease categories, similar to incidence prevalence measurements, then the computations will be straight forward.

Although valuation of health status of persons suffering specific disease conditions is feasible, such measurements are not used for summary measures of population health status, for various reasons. Valuation of health states is known to be conditioned by the locus of the valuer. Valuation of the same health state by a person in that sate is usually different from the valuations given to that state by doctors and nurse. These two valuations differ from the ones given by the general population. Since summary measures are used for health policy analysis and allocation decisions, valuations by the general populations are preferred. To cope with various methodological difficulties, direct measurement of health state values is done for a limited set of indicator conditions followed by statistical modeling to infer health state values for other 6D5L profiles. We need to relate the health state values thus arrived at to disease states used for disaggregated analysis of summary measures. Hence the need for a protocol to

identify the 6D5L profile corresponding to disease states. We decided to use expert judgement arrived by a consensus development method for identification of 6D5L profiles for identified disease states. A workshops was organised to bring together a panel of physicians and nurses from various fields working in public and private hospitals. Altogether a group of 19 physicians and 4 clinical nurses participated. All panel members had clinical positions in local hospitals. See workshop proceedings in appendix - 3.7. The panel recommended a assigned 6D5L profiles to each of the 22 diseases.

While planning the study, we had provisionally selected a list of indicator conditions along with their 6D5L profiles. We set aside the 6D5L profile of indicator conditions, till recommendations of the description panel was available. We then compared the provisionally identified 6D5L profiles with the description panel recommendations. In four out of 22 cases the two matched. These were; Watery diarrhoea 111211, Infertility 111131, Mild hearing disorder 112121, Paraplegia 444431. There was discrepancy for other conditions. We discussed these discrepancies among ourselves and sought additional expert opinion where necessary. Finally, we accepted panel recommendations for 5 states, adopted a modified profile partially accepting panel recommendations for six cases and maintained our provisional profile for 7 conditions. Appendix - 3.8 shows provisional, panel recommendations and final identification of 6D5L profiles for chosen disease states. Where ever, there was a difference between the provisional, and panel recommendations, we have shown our rationale for choosing the final profile as it stands now.

Labels:

Table-3.3: Short and long disease labels used in health state valuation exercises.

Disease labels	Labels used in the MDHSV workshops	6D5L Profile	Long labels used in the household survey
Diabetes	Mild diabetes, no symptoms	111121	Mild diabetes with no symptoms, controlled with pills
Tuberculosis	Mild tuberculosis with treatment	111221	Tuberculosis under treatment with very mild symptoms limited to occasional cough
Unipolar major depression	Unipolar major depression	124142	Depression, with loss of pleasure from most activities, low energy, and slight difficulties in thinking and concentrating
Congestive heart failure	Severe heart failure (congestive)	434531	Extreme chest pains and breathlessness caused by severe heart failure

Ceteris paribus, disease labels have been found to affect the value attached to a health state, by the valuer. For example, Sacket and Torrance (1978) found that labels had statistically significant effects upon health state utilities in both the positive (tuberculosis preferred over an unnamed contagious disease) and strongly negative directions (mastectomy for injury preferred over mastectomy for breast cancer. Pilot testing of the valuation exercises using the descriptions arrived so far, showed that valuers were clearly responding from their stereotyped understanding of the disease labels, without paying much attention to the 6D5L description. For example, people appeared to value tuberculosis much worse that what its 6D5L profile would justify. We could not be sure that the worse valuation was real or an effect, purely, of the label. In any case to minimise effect of label to the extent feasible, we decided to have longer descriptive labels emphasising the 6D5L profile. Table-3.3 shows the evolution of labels for selected health states. The first column shows the disease labels, that we began with. The second columns shows the label used by us for the MDHSV workshops. The last (fourth) column shows the longer labels, used for the household survey. Details for all health states is given in appendix 3.3 and the Telugu version of the labels is given at appendix 3.4.

Coding schema

A health state is described by a string of six ordered digits, such that position of the digit represents a particular dimension and value of the digit ranging from 1 -5 represents the severity level. For example health sate 111111 would mean perfect health. Positions in the ordered sequence of six digits first to sixth are respectively, mobility, self care, usual activities (work and leisure), pain / discomfort, anxiety / depression, and cognition (Figure-3.3).

Results from health state description exercise:

Usage of severity levels by people to describe their own health state:

We used a five levels of functional status within each dimension to improve the description system's ability to discriminate between more number of health states. Table-3.4 shows usage of severity levels and cognitive functional status by valuers of the AP health state valuation study, to describe their "Own Health" state. Own health state descriptions by 1190 persons falls into 295 distinct entities, which is more than the 244 limit in the EQ-5D system. As would be expected lower level severity codes are used more frequently. Given this asymmetry in usage of severity levels only three levels of functional status would lump many milder disabilities with perfect health.

Table-3.4: Usage of severity levels and cognitive functional status by valuers to describe "Own Health" states.

SLC= Severity Level Code	Distinct Health States	Persons
"Own Health" states	295	1,190
"Own Health" states with SLC =2 in at least one dimension	246	678
"Own Health" states with SLC =3 in at least one dimension	202	282
"Own Health" states with SLC =4 in at least one dimension	103	116
"Own Health" states with SLC >=2 in D6 (Cognition)	170	325
"Own Health" states with SLC =2 in D6 (Cognition)	98	234
"Own Health" states with SLC =3 in D6 (Cognition)	49	67
"Own Health" states with SLC =4 in D6 (Cognition)	17	18
"Own Health" states with SLC =5 in D6 (Cognition)	6	6

Usage of cognitive functional status by people to describe their own health state:

The sixth dimension of cognitive function was also used by people to describe their own health. A few persons described their cognitive functioning at levels 4 and 5! (Table-3.4). This is surprising. One would expect persons with such severe levels of cognitive dysfunction unable to carry out the Own health description task. To understand what's going on here, we first checked if these valuations tasks were done with the help of an assistant. It turns out that only 2 out of the 24 persons who reported a perceived cognitive dysfunction at levels 4 or 5 were assisted (8.33%) compared to 104 out of 1010 total valuers who communicated through an assistant (10.3%). Each interviewers for the household survey had been instructed to record his / her observation on a few observable health state attributes like hearing impairment, vision defect, usage of walking aid, defective walking, etc. Table-3.5 shows prevalence of such observed disabilities among the total survey population and the sub population who described their own health state to have severe levels of cognitive dysfunction. The sub population is clearly worse of than the total survey population in all areas of observed functional status. The pro forma for description of Own health state included a question asking the valuer to describe his / her current health state in comparison to his health over the last one year. Answers were coded as 1 for extremely well to 5 for worse. Table-3.6 (right most four columns) shows that the sub population of valuer perceived there current health state to be worse compared to their experience over past 12 months. Thus this sub population does appear to be clearly having comparatively worse health state than the total survey population.

Figure-3.3: Dimensions and their position in the 6D5L code

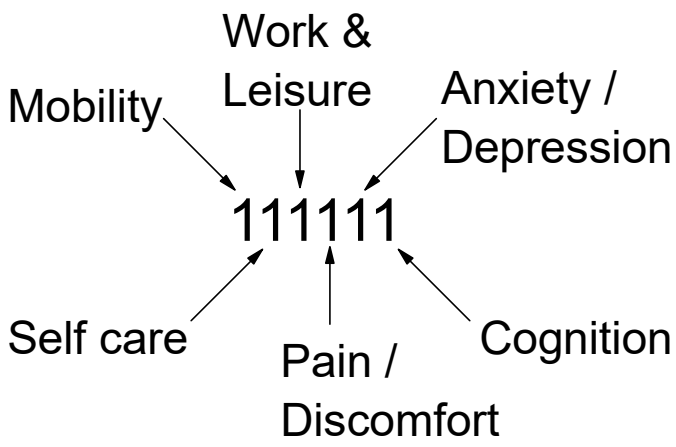


Table-3.5 Comparison of observed disabilities for all valuers and those describing their health state to have cognition at severity levels 4 or 5.

	Survey all		Own health has 4 or 5 in D6	
	#	%	#	%
Observed hearing impairment	38	3.76	10	41.67
Observed vision defect	68	6.73	10	41.67
Observed walking aid	27	2.67	4	16.67
Observed walking defect	34	3.37	7	29.17
Observed paralysis	6	0.59	1	4.17
Observed amputation	6	0.59	1	4.17
Observed cough	8	0.79	1	4.17
Observed shortness of breath	17	1.68	4	16.67
Total valuers	1010		24	

Table-3.6 also shows the accuracy of Own health state descriptions by total survey population and the sub population with D6 level 4 or 5 in their Own health state descriptions. This is based on the interviewers perception. The accuracy assessment has been coded as 1 for very accurate to 5 for least accurate. Valuations by the sub population was assessed as less accurate compared to the total survey population. Similarly the interviewers assessment of respondent cooperation is also slightly worse than that for the total survey population.

Table-3.6: Comparison of total survey population (all) and the sub population describing Own health state with levels 4 or 5 in the cognition dimension (D6 level 4,5).

	Perceived accuracy				Respondent Cooperation				Current Health State			
Code	All		D6 level 4,5		All		D6 level 4,5		All		D6 level 4,5	
	#	%	#	%	#	%	#	%	#	%	#	%
1	176	17.46	2	8.33	244	24.28	3	12.50	48	4.75	0	0.00
2	397	39.38	7	29.17	375	37.31	8	33.33	379	37.52	3	12.50
3	378	37.50	7	29.17	312	31.04	4	16.67	202	20.00	4	16.67
4	40	3.97	2	8.33	56	5.57	3	12.50	349	34.55	11	45.83
5	17	1.69	6	25.00	18	1.79	6	25.00	32	3.17	6	25.00
	1008		24		1005		24		1010		24	

These findings suggest that persons describing their own health state to have sever levels of cognitive dysfunction clearly have a poorer health state. The fact that they are able to describe their own health state accurately enough in other dimensions, would suggest that their actual levels of cognitive functioning would not be as severe as is perceived by them. It is possible that the depression associated with their poor health status is contributing to such assessments in the cognitive dimension. These issues need to be investigate further.

Final list of 6D5L profiles and labels recommended for the AP Health State Valuation Study, 1999:

6D5L	Labels used in the household survey
111121	Mild diabetes with no symptoms, controlled with pills
111221	Tuberculosis under treatment with very mild symptoms limited to occasional cough
124142	Depression, with loss of pleasure from most activities, low energy, and slight difficulties in thinking and concentrating
554341	Quadriplegia
111211	Watery diarrhoea 5 times per day, without major pain or cramps
113431	Severe migraine that does not go away
222311	Moderate pain and stiffness in the joints
113331	Loss of control over urination
112311	Frequent cough with expectoration and some difficulty breathing
234244	Schizophrenia, with confused speech and perception, severe difficulties in thinking or concentrate, mood swings and paranoia
444333	Severe fevered state with hallucinations, as in typhoid fever
111321	Moderate chest pain during slight exercise
111131	Wanting to have children but not being able to (infertility)
323122	Blindness
154321	Two broken arms set in stiff casts from above the elbow to the wrist
112321	Pain and burning sensation in stomach, as in peptic ulcer
322211	Below the knee amputation - one leg, with crutches available
433221	Below the knee amputation - two legs, with wheel chair available
111131	White marks on face
112121	Mild problems in hearing, but able to hear and understand loud speech and sounds
212321	Continuous moderate back pain
434531	Extreme chest pains and breathlessness caused by severe heart failure

Valuers feedback on difficulty in describing own health state:

One way to assess the usefulness of a description system is the ease with which information about health states was communicated to individual valuers. Valuer's feedback about the difficulty encountered to characterise his / her own health state using the given description system gives us some idea about communicability of a description system. A feedback questionnaire was introduced for the MDHSV workshops, midcourse. Only 34

persons returned responses to this questionnaire. One question was "Did you encounter any difficulty in description of your own health state?" 32 out of the 34 persons who gave feedback said, they had no difficulties. The other two had some difficulties and none experienced a lot of difficulty. In the household survey, interviewers were asked to record their observations, if the valuer experienced any difficulty in describing his / her own health state. 962 out of 965 returns said the valuers did not have any difficulty. The other three had some difficulty.

References:

Bergner M., Bobbit R. A., Kressel S., and others. 1976b. The sickness impact profile: conceptual formulation and methodology for the development of a health status measure. International Journal of Health Services 6: 393-415.

Boyle Michael; Furlong William; Torrance George, and Feeny David. Reliability of the Health Utilities Index - Mark III Used in the 1991 Cycle 6 General Social Survey Health Questionnaire. Ontario: Center for Health Economics and Policy Analysis; 1994.

Boyle MH and Torrance GW. Developing multiattribute health indexes. Medical Care. 1984; 22:1045-1057.

Brazier JE; Harper R.; Thomas K.; Jones N., and Underwood T. Deriving a preference based single index measure from the SF-36. Journal of Clinical Epidemiology. 1998; 51:1115-1129.

Brook RH; Ware JE; Davis-Avery A and others. Overview of adult health status measures fielded in Rand's health insurance study. Medical Care Supplement. 1979; 17(1).

Brooks Richard and EuroQol group. EuroQol: the current state of play. Health Policy. 1996; 37:53-72.

Chambers LW; Sacket DL, and Goldsmith CH. Development and application of an index of social function. Health Services Research. 1976; 11:430-441.

Euroqol Group. EuroQol. A new facility for measurement of health-related quality of life. Health Policy. 1990; 16:199-208.

Fanshel S. A meaningful measure of health for epidemiology. Int J Epidemiol 1972; 1(4):319-37.

Fanshel S., Bush J.W. A health status index and its application to health services outcomes. Operations Reseach 1970; 18:1021-65.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-I: measurement strategies. Journal of Clinical Epidemiology, 1989; 42(4):345-354.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-II: scaling methods. Journal of Clinical Epidemiology. 1989; 42(5):459-471.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-III: population and context effects. Journal of Clinical Epidemiology. 1989; 42(6):585-592.

Froberg D.G. and Kane R.L. Methodology for measuring health-state preferences, part-IV: progress and a research agenda. Journal of Clinical Epidemiology.1989; 42(7):675-685.

Goldberg M. and Dab W. Complex indexes for measuring a complex phenomenon. in: Abelin T.; Brzezinxki Z.J., and Carstairs Vera D.L., Eds. Measurement in health promotion and protection. Copenhagen: WHO Regional Office for Europe; 1987; pp. 174-194.

Halford Graeme S. Development of processing capacity entails representing more complex relations: implications for cognitive development. in: Logie Robert L. and Gilhooly Kenneth J., Editors. Working Memory and Thinking. Hove, East Sussex, UK: Psychology Press Ltd; 1998; pp. 139-157.

Hunt SM; McKenna SP; McEwen J. and others. The Nottingham Health Profile: subjective health status and medical consultations. Social Science and Medicine. 1981; 15:221-229. Cited in McDowell, ibid.

Krabbe Paul FM; Stouthard Marlies EA; Essink-Bot Marie Louise, and Bonsel Gouke. The effect of additing a cognitive dimension to the EuroQol multiattribute health-status classification system. Krabbe Paul M. The valuation of health outcomes. A contribution to the QALY approach. Rotterdam: Erasmus University Rotterdam, The Netherlands.; 1998 Jun; pp. 105-118.

Miller G.A. The magical number seven plus or minus two: some limits on our capacity to process information. Psychol Rev 1956; 63:81-97.

Noack H. Concepts of health and health promotion. in: Abelin T.; Brzezinxki Z.J., and Carstairs Vera D.L., Eds. Measurement in health promotion and protection. Copenhagen: WHO Regional Office for Europe; 1987; pp. 5-28.

Patrick D. L.; Bush J. W., and Chen M. M.; 1973; Towards an operational definition of health. Journal of Health and Social Behavior; 14:6-23.

Patrick and Erickson. Concepts of Health-Related Quality of Life. in: Patrick and Erickson. Health Status and Health Policy. 1993; pp. 76-112.

Saariluoma Pertti. Adversary problem-solving and working memory. in: Logie Robert L. and Gilhooly Kenneth J., Editors. Working Memory and Thinking. Hove, East Sussex, UK: Psychology Press Ltd; 1998; pp. 115-138.

Sackett D.L. and Torrance G.W. The utility of different health states as perceived by general public. Journal of Chronic Diseases. 1978; 7:347-358.

Stewart Anita L. The medical outcomes study for work of health indicators. in: Stewart Anita L. and Ware John E. Jr, Editors. Measuring functioning and well-being. Durham//London: Duke University Press; 1992.

Torrance George W., Zhang Yueming., Feeny David, Furlong William., Barr Ronald. Multi-Attribute Preference Functions for a comprehensive Health Status Classification System. Ontario: Centre for Health Economics and Policy Analysis, 1992.

Llewellyn-Thomas H.A., Sutherland H.J. and Tibshirani R. 1984a. Describing health states: methodological issues in obtaining values for health states. Medical Care, 22: 543-552.

Guillemin F., Bombardier C., Beaton D. 1993. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. Journal of Clinical Epidemiology 46(12): 1417-1432.

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Chapter 4:

Multi Method Deliberative Health State Valuation (MDHSV) Workshops:

In this chapter we describe methodological details of the MDHSV workshops. Many health state valuations have been done in workshop settings. For example; Murray and Lopez (1994, 1996) report health state valuation workshops of public health experts assembled at Geneva, during the Burden of Disease and Cost-effectiveness training programmes held every year at different places and at the Harvard Burden of Disease Unit. We first review the need for multiple methods of measuring health state values. The next section describes selection procedure other characteristics of the study population. This is followed by description of the workshop formats. Details of materials used for conduct of the valuation workshops, and typical workshop schedules are described. We conclude the chapter with description of participants' feedback about the valuation instruments, workshop materials and their overall experience in the valuation exercise.

The Need for Multiple Methods of Measuring Health State Values:

The concept of values given to different health states is essentially psychometric. We need to understand reliability and validity of measurement instruments before we can interpret the valuations obtained through them. Our aim is to measure health state valuations in the general population. Health state valuation instruments for wide spread use in the general population has to be simple and easily understood by most people. Experience has shown that any thing more complicated than rank ordering and the visual analogue scale is usually not feasible. Assessing validity of psychometric instruments, particularly for health state valuation, is a difficult task. Unfortunately we do not have a gold standard to test criterion based validity of health state valuation instrument, Instead, we have to rely on convergence of measurements from multiple instruments and logical consistency of the measurements to draw inferences about instrument validity.

Measuring valuation of different health states by individuals is a complex task. The measurement process require valuers to imagine the quality of life implied by the health state descriptions, deliberate on some thought experiments comparing the health states to anchor points like perfect health and death. The scaling method itself may require additional deliberations and thinking, so that the valuer is able to express his / her valuation reasonably well. These tasks require the valuer to understand the measurement set up and devote time to carry through the complex cognitive tasks of valuing each health state. Asking for valuations using more than one method will require yet more time.

Health state valuations in a workshop setting provides an opportunity to have full attention of participants on the valuation tasks. Workshops which collect a group of valuers at the same place and time, allows researchers to present and explain details of each valuation instrument. Some of the alternative health state valuation instruments like the time trade-off and person trade-off require the valuer to imagine decision situations that the valuer may not be facing regularly. The workshop setting provides a cost-effective format to clarify doubts of valuers.

The down side of the workshop format is that it is not easily amenable to population based studies. So we planned to study the properties and behaviour of measurement instruments including the one to be used for population based surveys, using the workshop format. We planned to test three health state valuation instruments, namely (a) ordinal rank consistent visual analogue scaling, (b) time trade off, and (c) person trade off. This chapter describes the detailed steps involved in recruitment of valuers, and conduct of the workshops.

The Study Population:

Valuers were chosen from different backgrounds. Convenience sampling was used. Recruitment of valuers for the workshop usually proceeded in the following steps. Either a primary mailing list was prepared and prospective respondents to the workshop were informed of the objectives of the study through mail, or identified institutional heads were addressed with a general invitation letter to be circulated in turn to the potential valuers. The letter provided investigators telephone, fax and e-mail addresses. Potential volunteers were encouraged to contact the investigators for any clarifications. Investigators promptly

responded to calls and messages seeking clarification. The letter to potential volunteers was followed up by a written and, where feasible, a telephonic reminder. The institutional heads were contacted over phone and by person to remind about the request and to ensure that the invitation was circulated to all concerned. A list of willing volunteers was prepared. These volunteers were informed about timing of the workshop through mail, followed by a telephonic reminder. A small number of workshops were organised taking advantage of the presence of potential valuers in the Institute of Health Systems, in connection with other programs. For example, participants of a training program for primary health centre medical officers, a health Intranet system administration course, and IHS own staff and faculty. Table - 4.1 shows dates and the primary group for whom the workshops were organised.

Table- 4.1 MDHSV workshops dates and the primarily targeted group of valuers

Date	Target group	Primary Mailing List	Number Accepted	Number Participated
24/Aug/99	Com. medicine teachers and students	59	-	16
02/Sep./99	Health Intranet system adm. students	IHS	15	15
17/Sep/99	IHS Staff and Faculty	IHS	9	9
20/Sep/99	Health and hospital administrators	31	22	15
01/Oct/99	Hospital administration interns	20	10	9
12/Oct/99	Psychology / Med. social work masters students, recruited for HSV study	16	16	16
29/Oct/99	Journalists	358	18	3
14/Nov.99	PHC Medical Officers	IHS	15	15
06/Dec/99	B.Sc. Nursing students	Instl. head	18	18
10/Dec/99	Nurses	Instl heads	26	15
19/Dec/99	College lecturers	25	18	17
24/Dec/99	Software professionals	35	28	17
26/Dec/99	High school teachers	45	25	15

Table - 4.2 shows actual distribution of workshop participants by their profession. Altogether 13 health state valuation workshops took place with a total of 180 participants consisting of 88 females and 92 males. On average each workshop had 15 to 17 participants, except on three occasions, when the attendance was poor. Attendance was relatively poor on three dates. For the workshop on 29/Oct/1999, we invited journalists. Out of 18 persons who had confirmed, 15 did not turn up. The workshop on 17/Sep/1999 was organised for the faculty and staff working in IHS itself. Some of them were traveling. Those present had to

split themselves into two groups, so that half of them could play host to those participating. We planned a workshop on 01/Oct./1999, for Hospital Administration Interns. Although we approached more than 30 potential valuers, only six agreed to participate. Another three valuers on this date were from within the IHS. We had planned to conduct a workshop for General Practitioners but dropped the idea, because we did not have adequate volunteers, and it was difficult to agree on a date convenient to all of them.

Table-4.2 Professional background of workshop participants

Workshop date	CT	HAdm	HSR	Nurse	PHCMO	SW Prof.	Std	HT	Misc.	All
24/Aug/99			16							16
02/Sep/99							15			15
17/Sep/99		3	2				2		2	9
20/Sep/99		16								16
01/Oct/99		7	2							9
12/Oct/99							15			15
29/Oct/99									3	3
14/Nov/99					15					15
06/Dec/99							18			18
10/Dec/99				16						16
19/Dec/99	16									16
24/Dec/99		1	1			14			1	17
26/Dec/99			1					14		15
Total	16	27	22	16	15	14	50	14	6	180

HAdm = Health / Hospital Administration
HSR = Health Systems Research / Comm. Medicine
PHCMO = Primary Health Centre Medical Officer
Std = Students (B. Sc. Nursing, Health Intranet System Administration, and Masters in Psychology.
CT = College Teacher (Faculty)
SW Prof. = Software Professional
HT = (High School) Teacher
Misc. = Includes Journalists (3), Librarian (1), Accountant (1), and Secretarial Asst. (1).

Age, gender and literacy of participants:

Table-4.3 shows that both genders were evenly represented. Since participants were sought from work places, all of them belong to 20-59 years age. Relatively younger adults are slightly over represented. All participants had graduate or equivalent (15 years) of schooling. This is in accordance with the study design to recruit educated persons for these workshops.

Table-4.3: % Distribution of Health State Valuers by Age and Literacy

Age Group				**Years of Schooling (Literacy)**			
Years	Females	Males	All	Years	Females	Males	All
15-19	0	0	0	1-5	0	0	0
20-29	67.05	61.96	64.44	6-9	0	0	0
30-44	23.86	23.91	23.89	10-12	0	0	0
45-59	9.09	13.04	11.11	13-15	45.45	16.3	30.56
60-69	0	1.09	0.55	16-18	43.18	65.22	54.44
70+	0	0	0	19	11.36	18.48	15

Workshop Format:

MDHSV Workshop kit:

As a part of the registration procedure, participants received a pack of workshop materials consisting of the following:

1. A visual scale platform, consisting of a $2' \times 1'$ cork board with a visual analogue scale pinned up on it.

2. The visual scale (Figure-4.1) consisting of a straight line showing the two end points, namely (a) Best imaginable health state and (b) death. These two points are connected by a straight line. The line is divided into 100 equal parts with labelling for every even divider.

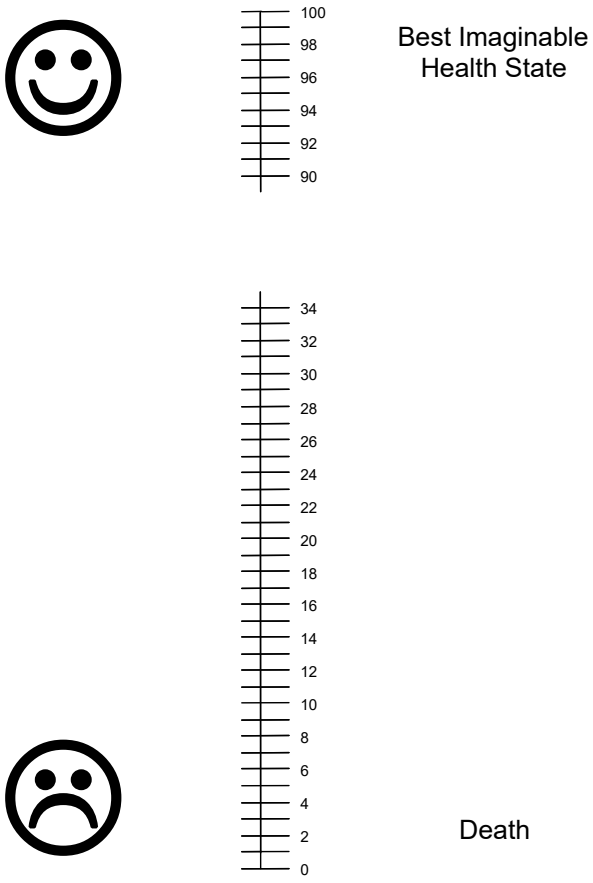
3. Two sets of 10 cards describing each of the 10 pre assigned health states to be valued by the person. These A5 sized cards, measuring $14.8cm \times 21cm$, show written and graphical descriptions of the health state. One set is free of any attachment, suitable for sorting by hand. The other set is pin mounted to facilitate easy planting of cards on the cork board platform for visual scale.

4. A "Your Own Health State Today" description form (Appendix-1). This form helps researchers to explain the 6D5L description system to the participants, who then use it to describe their own health state on the day of the workshop.

5. Two "Your Own Health State Today" Cards similar in size to the cards described earlier, one free and the other pin mounted. Participants choose the appropriate level for each dimension of their description of "Your Own Health State Today" and fix it on to these

cards. The filled in "Your own health today" cards go to the respective (free or pin mounted) sets of cards.

Figure-4.1 A scaled down picture of the visual analogue scale (Actual size = Legal)



6. A sheet containing Instructions for card sort and visual scaling exercises (Appendix-4.2).

7. A card sorting log, where the participant is expected to write down the list of health states in the order obtained by him / her from the card sort exercise (Appendix-4.3).

8. Time trade-off (TTO) exercise worksheets consisting of; one example sheet, ten sheets for each of the indicator condition (sample illustrated later in this chapter), and Your own health state worksheet, generated from out of the own health state description given by the participants.

9. Person trade-off (PTO) exercise worksheets consisting of; one example sheet, Ten "A" worksheets for each of the indicator condition, meant for PTO1 exercises, and Ten "B" worksheets for each of the indicator conditions meant for the PTO-2 exercises. Two "Your own health state worksheets", generated from the own health state description given by the participants. One each of these is put along with the A and B sheets, respectively.

10. A respondent's comments form to obtain participants feedback about the level of difficulty of each valuation exercise, and usefulness of various materials presented during the workshop (Appendix - 4.4).

Typical workshop schedule:

Incoming participants registered themselves at the reception. They were requested to fill in a registration form, through which we collected required personal data. At this stage, each participant was assigned an Id from a randomly ordered list of Ids. The Id consisted of a serial number followed by the assigned set id, and the direction of progression of the alternative choice in the trade-off valuation exercises (TTO and PTO). In the time trade-off and person trade-off worksheets, we provided about ten rows of suggested choices, to convey the idea of the time trade-off (in TTO) or equivalence (in PTO). For example if a person was faced with a less than perfect health state with a life expectancy of say 12 years, the time trade-off alternative can start from a period slightly less than 12 years and progress downwards (d) or can start from a very low value of say 0.6 years and progress upwards (u). Starting the alternatives from the upper end and progressing downwards or vice versa for all valuers might have biased the valuation. So we decided to prepare two sub sets of worksheets for each set of health states, one showing alternative-2 progressively decreasing and the other with the same alternative progressively increasing from the other end. These subsets were assigned to valuers alternatively. To simplify this process and facilitate handing over of the appropriate workshop package, we prepared in advance a list of participants Id, such that the health state sets (1 to 4) and the direction of progression of alternatives was systematically assigned according to the planned cycle. The cycle for set number was four and the cycle for direction of progression was two. Thus the first two cycles of Ids for workshop participants were; 1_1u, 2_2d, 3_3u, 4_4d, 5_1d, 6_2u, 7_3d, 8_4u. The prefix W was added to the workshop participants later, to distinguish these Ids from the household survey Ids. Thus the workshop valuers Ids looks like W1_1u, W6_2u, etc. in the data set.

The workshops usually started with an introduction about objectives of the study and role of the participants. A written guideline (Appendix - 4.5) was given. At the very beginning, objectives of the study were reviewed and role of the participants as valuers of health states from the societal perspective was explained. We emphasised that each participant has to perform a quasi judicial function in assigning weights to different health states. First each participant described his / her own health state using the 6D5L description system. Participants then moved on to rank ordering of the 11 health states by card sort, visual analogue scaling of each health state, Time Trade-off and if time permitted Person

Trade-off. Before beginning each type of scaling exercise, valuers were given detailed explanation on how to use the respective instruments. At the end of each session the participants were given an opportunity to check and compare their valuations with card-sort rankings and make necessary changes. Several iterations are carried on until the valuations match. Two tea breaks and a lunch break were provided to break the monotony and mental fatigue as these workshops are highly cognitively loading. Participants were allowed to stop and discontinue the valuation exercise, if they felt fatigued or showed signs of frustration. A vote of thanks as well as an honorarium was given to all the participants of the workshop.

HSV - Date Entry Deliberative Interactive Tool (DEDIT):

To facilitate deliberations by valuers a computer based interactive deliberative tool was developed using Lotus-123 workbook as a platform (IHS, 2003). This tool is called for use only after the valuer has completed one round of card sorting and visual analogue scaling. The rank ordering and scaling data generated by the valuer in first round, along with some personal information about the valuer is entered into this tool. Personal information includes the participants Id, which forms the basis on which the tool picks up health state for the set assigned to him / her. The tool then checks for logical consistency of card sort ranks with the VAS score and points out discrepancies if any. By pointing out logical discrepancies between card sort ranks and VAS scores, the tool assists the valuer in deliberating over the valuations given by him. After reconciling logical inconsistencies between card sort and VAS, the valuer would then move on to scaling by time trade-off (TTO) method. The tool allows for printing of a TTO worksheet for "Your own health state today" to be used at this stage. Once first round of TTO valuations are entered, the tool checks for logical consistency of card sort ranks with TTO valuations. Discrepancies, if any are pointed out in a report titled "Time trade-off - reflections: Review the magnitude of disability weights" (Figure-4.2). After TTO valuations are reconciled with card sort ranks or the valuer decides to give up and move on to valuation by PTO, the tool allows for printing of "Your own health state today" worksheets for PTO 1 & 2 and reports to facilitate reflections by the valuer. Data generated by the valuation process is captured by the tool, while it supports the deliberations by the valuer. Since use of the tool starts with entry of valuation data and the program was stored in a Lotus 123 template, the tool was alternatively referred to as the HSV Data Entry Template.

Figure - 4.2: A report generated by the HSV Workshop Data Entry Program

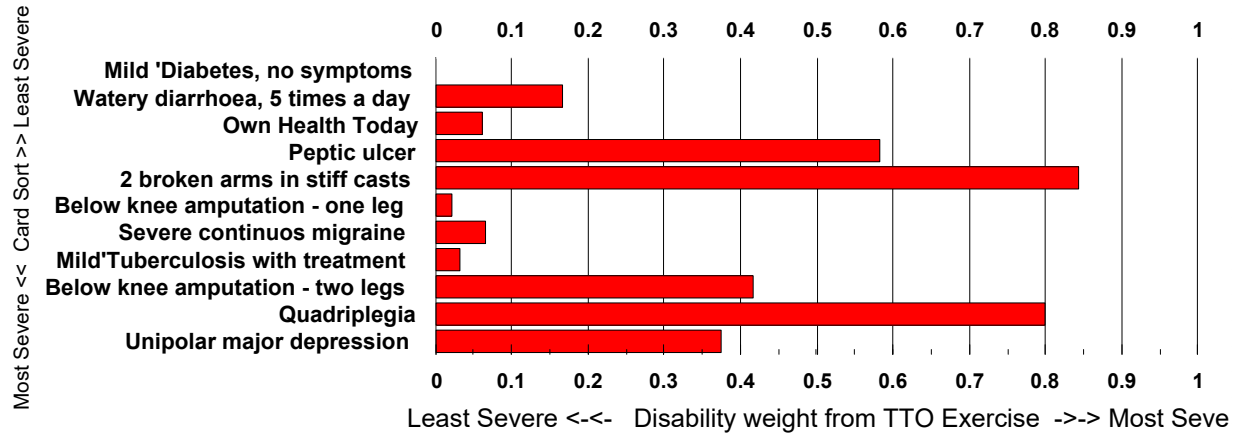
Time tradeoff - reflections: Review the magnitude of disability weights

Date: 13/10/99

Participant ID: 75_3 Name: Xxxxxxx Yyyyyyy **Attempt: 2**

Thank you for valuing the given health states using the Time Trade Off exercise. We have computed the disability weights implicitly assigned by you to each condition. These are shown on the right side of this note. The level of disability implied by your choice in the Time TradeOff exercise is also shown in the graph below. You may recall the rank ordering of conditions done by you in the card sort exercise earlier. We have arranged the conditions according to your card sort rank, so that you can reflect if your current valuations are consistent with the ordering of severity judged by you earlier.

Sl	Health State Condition	DWt
1	Mild 'Diabetes, no symptoms	0.00
2	Watery diarrhoea, 5 times a day	0.17
3	Own Health Today	0.06
4	Peptic ulcer	0.58
5	2 broken arms in stiff casts	0.84
6	Below knee amputation - one leg	0.02
7	Severe continuos migraine	0.07
8	Mild'Tuberculosis with treatment	0.03
9	Below knee amputation - two legs	0.42
10	Quadriplegia	0.80
11	Unipolar major depression	0.38



Please reflect upon the degree of severity you have determined for each condition above, as well as any discrempancies between the card sort and Time Tradeoff exercises. Based on this reflection you may wish to revise your Time Tradeoff evaluations. We would recommend that you do not revise the card sort at this stage, since you have already reflected on it adequately. Now please reflect and revise your valuations and let us have your revised estimations.

Participants came from varied background, with different levels of familiarity with computers. Asking them to work with the DEDIT directly might have lead to distractions. More over, the tool development was a gradual process. We designed a template to start with. As we learnt more about valuer needs, and encountered bugs, we revised it to add more features and remove bugs. Each valuer in the MDHSV workshop was assigned to a host. Each host served about two to three valuers. The host was responsible to create a file for each valuer from the HSV Data Entry Template, enter valuation data, print reports and hand it over to the valuer. The workshop coordinator, explained how to use the reports brought by the hosts. The reports themselves had written explanation of further task to be done by the valuer.

Description of "Own health today" by valuers:

The first task for each of the valuers was to describe his / her own health state using the 6D5L description system. Each participant was given a worksheet containing the written 6D5L description system, along with check boxes against the severity levels under each dimension. The valuers first checked appropriate severity level, applicable to him / her, under each of the six dimensions. Each valuer was supplied with two cards showing "Your own health today" title and the six dimension labels preceded by blanks to fill in the severity levels. One of the cards was mounted on a long pin to allow easy planting of the card on the cork board platform of the visual analogue scale. Valuers filled in the blanks based on the severity levels, they had already filled in the written 6D5L check list. The "Your own health today" cards are then added, respectively, to the free and pin mounted set of cards containing description of the health states assigned to the valuer.

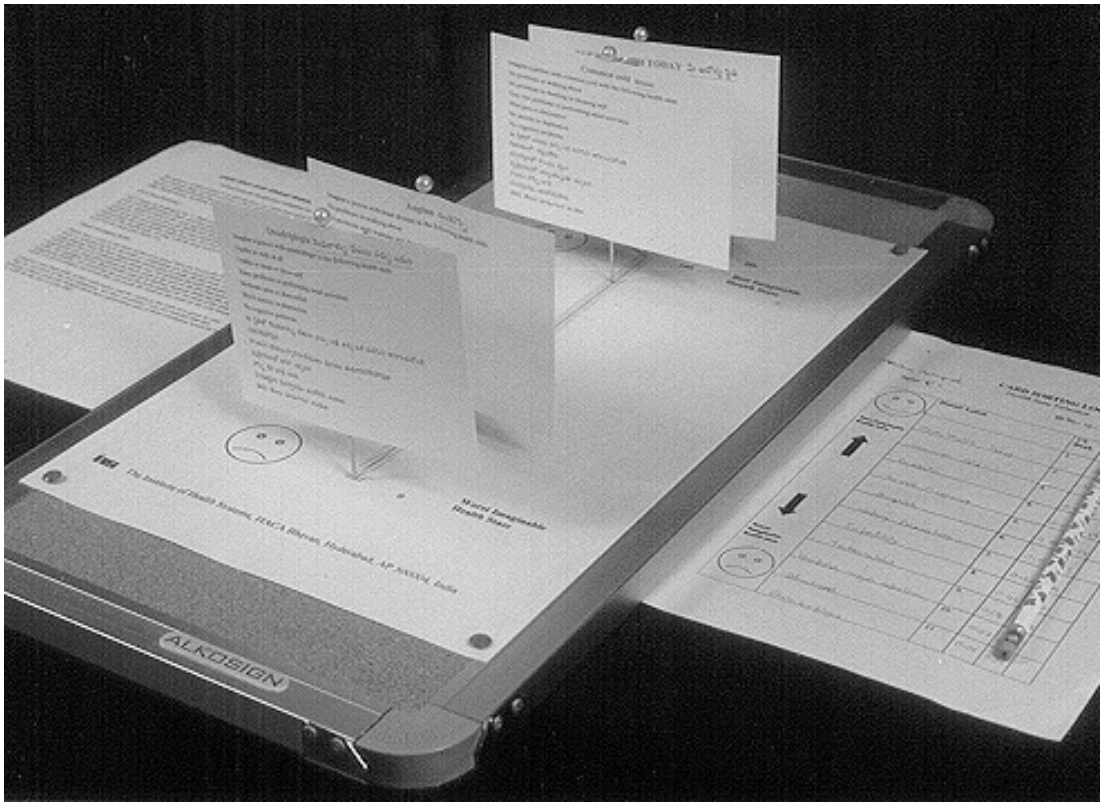
Card Sort and VAS:

The valuer works with the free pack of health state cards including the "Own health state" card just prepared. Valuer is asked to order the cards from best health state in the pack to worst health state in the pack. The valuer then records rank order of the card on the card sort log provided in the workshop packet. The data derived from this is a rank order within the respective set of health states. The participant then moves on to valuation by visual analogue scales. (S)he works with the pin mounted pack of health state cards and the VAS platform (Figure-4.3).

The VAS platform has the picture of a visual analogue scale (VAS) labelled at either ends to represent the two extremes of the health continuum, namely best imaginable health state and death (Figure-4.2). The VAS is a vertical straight line with divisions ranging from 0 to 100, with every even division labelled. Zero represents death and 100 represents perfect health. A picture of happy face near 100 on one side and a picture of a sad face near 0 further focuses a valuer to the directions. The valuers are instructed to plant the pin mounted health state cards along the scale according to the magnitude of their severity. The assigned host

collects the card sort log and the VAS platform. The host first transfers the scale values to a VAS measurement log. A workbook is created for the valuer using the IDT template. Data from the card sort log and VAS score log is then input to the spreadsheet. The Card sort - VAS report from the IDT tool titled "Reflections: Reconcile Card Sort and Scale Based Valuations" is then printed. The report shows if the card sort and VAS ranks matched, or, if they did not match, the nature of discrepancy. See following page for a sample report. The report is printed and furnished to the valuer. In case of persisting discrepancy, the valuer is requested to review his / her VAS locations of various health states. The revised valuations are then entered into the HSV-IDT data entry program and the process repeated. These iterations are continued till the two valuations match.

Figure-4.3: Visual scaling platform with pin mounted health state cards.



Time Trade-off (TTO):

Here valuer's preferences for health states is assessed indirectly through the time (number of years, months, days, hours) (s)he wants to trade in to lead a completely healthy life as against life with a particular less than perfect health state. The subject is offered two

alternatives- alternative 1; state *i* for time *t* (local life expectancy of an individual with the chronic condition) followed by death and alternative 2 which is a perfectly healthy state for time *x* where *x* is less than *t*. Time *x* is varied until the respondent is indifferent between the two alternatives, at which point the required preference value for state *i* is given by $h_i = \frac{x}{t}$.

To facilitate TTO valuations, we prepared TTO worksheets for each health state assigned to the valuer. The worksheets were generated using a Lotus-123 worksheet program using estimates of following parameters for the respective health states.

1. The health state / disease label.
2. The 6D5L profile corresponding to the health state. This is used to generate a structured description of the health state along the six dimensions.
3. Age at onset of the disease / health state concerned. This is used to remind the valuers about the age (s)he has to assume while judging time trade-offs for the concerned health state.
4. Local life expectancy of persons at the age of onset of the disease concerned. Local life expectancy at birth was assumed to be 62 years, for Andhra Pradesh.
5. A set of progressive adjustment factors. For the decreasing direction we chose a starting value of 0.95 decreasing by 0.05 in steps to reach 0.05 by the 10th row. For the increasing direction, we just reversed it by using (1-factor in decreasing direction). The worksheet uses these factors to determine the duration of perfectly healthy life shown under the alternative -2 column.

The TTO Worksheet program allows for printing of eight sets of worksheets for one cycle of valuers in the systematically randomized list of workshop participant Ids. Sample of a TTO worksheet for quadriplegia with progressively increasing alternative-2 is shown on the following page. This is followed by another worksheet for the same condition, but with progressively decreasing alternative-2. Before moving on to the TTO exercise, the workshop coordinator explains the method using a health state not included in the indicator conditions. We used paraplegia as an example in most cases. The valuers are walked through a sample worksheet with the example condition. This is done to familiarise participants with the TTO methodology. Most valuers, would usually have questions about the methodology. We found it helpful to explain the valuers that if a health state was considered very severe then a person would usually be willing to trade in that health state for a relative much shorted duration of life in perfect health. This helped valuers to grasp the nature of the TTO exercise.

Valuers were encouraged to reflect on their initial TTO valuations, if the rank ordering of conditions implied by it did not match with the card sort ranks. Initial valuation data was fed into the DEDIT spreadsheet and printed "Reflection reports" pointing out discrepancies along with a graphical comparison of the TTO valuations with card sort was printed and given back to the concerned valuer. (S)he was asked to revise the TTO valuations in the light of discrepancies pointed out in the Reflection report. Subsequent valuations were entered into the DEDIT spreadsheet and a fresh Reflection report generated.

Towards the beginning of the study, we continued this iterative process till the valuer reconciled the card sort ranks and TTO ranks completely. However, we did not succeed in our efforts completely. Despite our insistence, we found, some people were not able to reconcile the two valuations even after 13 additional iterations. We found that after the first few iterations, most participants stopped deliberating and thinking about the issue. Instead, they tried to figure out a way, by hit and trial, to some how match the TTO valuations with card sort rank. Thus participants appeared to reflect and deliberate for the first few iterations and then simply gave up. We then decided not to insist on complete matching of card sort ranks with TTO valuations. From the fourth workshop (20 September 1999) onwards, we asked participants to continue for as many iterations as they felt comfortable and then stop. By this time we had also improved the DEDIT Reflection reports to include a bar chart of TTO valuations arranged according to the card sort rank order. This visual tool appeared to help communicate the discrepancy more effectively.

Health state (Quadriplegia) valuation worksheet -1

We want to know your opinion about the burden that different diseases represent to individuals and families who are affected by them. By burden we mean loss of physical and social functioning (Mobility, self care and usual activities, physical and mental discomfort, anxiety or depression and loss of cognition. We do not have in mind the economic burden to society (for instance loss of production or incomes), and you should not take them into account when you respond to the question below.

Quadriplegia

Totally dependent for mobility.
Totally dependent for self care.
Many problems in performing usual activities like work, employment, household work , etc.
Moderate, discomforting pain.
Much anxiety or depression.
No impairment of cognitive function. No cognitive problems

Alt.-2: Progressively Increasing

Imagine your age as 50.

Imagine that you are living in the health state described above, and must choose between two alternatives:
Alternative 1: You may continue to live in this health state for the rest of your life, that is, 12 more years.
Alternative 2: You may accept a medical intervention that will improve your health state to perfect health, but will reduce your life expectancy. Alternative 2, in other words, allows you to live a shorter number of years, but in better health.
We would like to know the smallest number of years of perfectly healthy life you would accept in exchange for the 32 years in the reduced state of health described above. If you find the health state above to be extremely undesirable, you may be willing to trade it for a fairly short period of perfectly healthy life. On the other hand, if the health state above is rather mild in severity, then you may not want to give up much of your remaining life expectancy for an improvement to perfect health.
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer alternative 1 (mark the box on the left), would definitely prefer alternative 2 (mark the box on the right), or would find it difficult to choose between the two (mark the box

You should start with the first row and then continue to answer each question until you reach a situation for

Prefer Alt-1	Alternative-1	Doubt	Alternative-2	Prefer Alt-2
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 0.6 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 1.2 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 2.4 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 3.6 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 4.8 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 7.2 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 8.4 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 9.6 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 10.8 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 11.4 years.	☐

Your indifference point:

Live another 12 years with Quadriplegia

☐ Years of perfectly healthy life.

Health state (Quadriplegia) valuation worksheet -1

We want to know your opinion about the burden that different diseases represent to individuals and families who are affected by them. By burden we mean loss of physical and social functioning (Mobility, self care and usual activities, physical and mental discomfort, anxiety or depression and loss of cognition. We do not have in mind the economic burden to society (for instance loss of production or incomes), and you should not take them into account when you respond to the question below.

Quadriplegia

Totally dependent for mobility.
Totally dependent for self care.
Many problems in performing usual activities like work, employment, household work , etc.
Moderate, discomforting pain.
Much anxiety or depression.
No impairment of cognitive function. No cognitive problems

Alt.-2:Progressively Decreasing

Imagine your age as 50.

Imagine that you are living in the health state described above, and must choose between two alternatives:
Alternative 1: You may continue to live in this health state for the rest of your life, that is, 12 more years.
Alternative 2: You may accept a medical intervention that will improve your health state to perfect health, but will reduce your life expectancy. Alternative 2, in other words, allows you to live a shorter number of years, but in better health.
We would like to know the smallest number of years of perfectly healthy life you would accept in exchange for the 32 years in the reduced state of health described above. If you find the health state above to be extremely undesirable, you may be willing to trade it for a fairly short period of perfectly healthy life. On the other hand, if the health state above is rather mild in severity, then you may not want to give up much of your remaining life expectancy for an improvement to perfect health.
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer alternative 1 (mark the box on the left), would definitely prefer alternative 2 (mark the box on the right), or would find it difficult to choose between the two (mark the box

You should start with the first row and then continue to answer each question until you reach a situation for

Prefer Alt-1	Alternative-1	Doubt	Alternative-2	Prefer Alt-2
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 11.4 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 10.8 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 9.6 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 8.4 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 7.2 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 4.8 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 3.6 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 2.4 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 1.2 years.	☐
☐	Live another 12 years with Quadriplegia	☐	Live a perfectly healthy life for another 0.6 years.	☐

Your indifference point:

Live another 12 years with Quadriplegia

☐ Years of perfectly healthy life.

Table-4.3 shows the distribution MDHSV each workshop's valuers according to the number of TTO iterations in addition to the first TTO valuation. The last column shows the number of valuers on each date whose TTO values and card sort ranks finally matched. This table shows that, given freedom to stop at will, valuers did not purse the TTO exercise beyond about four iterations. The number of valuers with complete match of TTO valuation with card sort ranks reduced significantly, after participants were given the option to stop at will. For future studies, it would appear desirable to plan on a maximum of six iterations including the first round and improve rate of matched valuations by further improving the feedback communication strategy and workshop coordination skills.

Table - 4.3: Distribution of MDHSV valuers according to number of additional TTO iterations

Date of workshop	Number of additional TTO iterations														Matched
	NA	1	2	3	4	5	6	7	8	9	10	11	13	Total	
24-Aug-99[1]	16													16	11
02-Sep-99				1	1	1	3	4		1	2	1	1	15	12
17-Sep-99		2			2	3	1		1					9	7
20-Sep-99					3	4	3	3	2	1				16	8
01-Oct-99				1	3	1	2	1		1				9	7
12-Oct-99		4	8	2	1									15	2
29-Oct-99	1				1	1								2	
14-Nov-99		4	6	4			1							15	2
06-Dec-99			12	5	1									18	6
10-Dec-99		9	7											16	0
19-Dec-99		1	13	2										16	5
24-Dec-99			14	1	2									17	3
26-Dec-99	1	3	12											15	2
Total	19	22	72	16	13	7	11	8	4	4	1	2	1	179	65

[1] For the first workshop (24 Aug. 99) we did not record the number of iterations. NA=Not available.

PTO Exercises:

Here the valuer is asked to place himself / herself in the role of a decision maker, having resources, enough to provide for one of two mutually exclusive health interventions. Intervention-A can extend the life of a reference unit (say x) of healthy individuals for one

year. Intervention - B will help *y* people in the adverse health situation *i* that is the subject of valuation. The number *y* is then varied until the valuer finds the two groups equivalent in terms of needing help. The person trade-off method as described in Murray and Lopez (1996) was used in this study. This requires the valuer to look at the alternatives from two perspectives namely PTO1 and PTO2. Contents of intervention-A helping the reference unit of healthy persons remains the same for both perspectives. PTO1 and PTO2 differ only in the manner in which the intervention - B is framed.

In PTO1 Intervention - B will extend the life of a larger number of individuals but with a less than perfect health state for one year. In other words this intervention will not be able to cure the disability. But it will enable the persons living with the disease to live longer by one more year. Here the health state value for condition *i* is given by $h_i = \frac{x}{y}$. In PTO2 the Intervention - B will cure a larger number of individuals of the adverse health situation. In other words these persons will be able to enjoy perfect health for one year. Here the health state for condition *i* is given by $h_i = \frac{y-x}{y}$. As can be seen above, PTO1 presents the perspective of extending the life of a group of persons with some disability. Thus the valuer has to factor in his / her mind the net gain (h_i) in healthy years to the community and compare the same to intervention-A. In PTO2, the valuer is buying an intervention that cures the disability. So the valuer has to mentally factor in his / her estimate of disability with the number of persons being benefited (life year gained = (1-h_i) * No of persons benefited) to compare with the persons benefited by intervention-A. The two perspectives are presented to facilitate deliberation by the valuers.

We prepared PTO1 and PTO2 worksheets for each health state assigned to the valuer. The worksheets were generated using two Lotus-123 worksheet program for the corresponding health state label, the 6D5L profile, and a set of progressive adjustment factors as in case of TTO. For the decreasing direction we chose a starting value of 10 decreasing by 2 in steps till 4 and then 3, 2.5, 2, 1.75, 1.5, 1.25 and 1.1. For the increasing direction, we just reversed it by using (11.1 - factor in decreasing direction). The worksheet uses these factors to determine the number of persons under the alternative - B. The PTO Worksheet program allows for printing of eight sets of PTO1 and PTO2 worksheets. Sample of a PTO1 and PTO2 worksheets for quadriplegia with progressively increasing alternative - 2 is shown on the

following pages. An user manual for the PTO Worksheet programs is given in appendix 4.8. Before moving on to the PTO exercise, the workshop coordinator explains the method.

Most valuers did not get to the PTO exercise test. Only 28 valuers attempted PTO (Table-4.4). Of these 18 were females and 10 males, 22 were between 20 to 29 years age and the rest six were between 30 to 36 years age. Table-4.4 also shows the number of iterations of PTO valuation done by these valuers. Out of the 28 persons who attempted the PTO exercise, the PTO rank orders matched with card sort rank order only for 7 persons.

Table - 4.4: Distribution of the 28 valuers who attempted PTO exercise, by workshop date, and number of iterations done by them.

Date of workshop	Number Attempted	Number of additional PTO iterations					Matched
		0	1	2	3	4	
17-Sep-99	8		1	4	2	1	7
12-Oct-99	14	14	1				0
06-Dec-99	1	1					0
10-Dec-99	3	3					0
26-Dec-99	2	2					0
Total	28	20	2	4	2	1	7

[1] None of the valuers in the rest eight workshops attempted the PTO exercise.

Health state (2 broken arms in stiff casts) valuation worksheet -2A

We want to know your opinion about the burden that different diseases represent to individuals and families who are affected by them. By burden we mean loss of physical and social functioning (Mobility, self care and usual activities, physical and mental discomfort, anxiety or depression and loss of cognition. We do not have in mind the economic burden to society (for instance loss of production or incomes), and you should not take them into account when you respond to the question below.

2 broken arms in stiff casts

No assistance required and no problem with mobility. Ability to run / flight in times of need.

Totally dependent for self care.

Many problems in performing usual activities like work, employment, household work , etc.

Moderate, discomforting pain.

A little anxiety or depression.

No impairment of cognitive function. No cognitive problems

PTO1

Your are a decision maker that has only enough money to provide for one of following two mutually exclussive health interventions.

Intervention-A: Will extend the life of 1000 healthy individuals for one year

Intervention-B: Will extend the life of a larger number of individuals but with a less than perfect health state for one year. In other words this intervention will not be able to cure the disability. But it will enable the persons living with the disease to live longer by one more year.

We would like to know the largest number of people with above disability, that should be covered by intervention-B for you to accept it in exchange for the intervention-A. If you find the health state above to be extremely undesirable, you may be willing to trade the intervention extending 1000 perfectly healthy life years only if a very large number of people with the above health state are benefitted.

On the other hand, if the health state above is rather mild in severity, then you may be willing to give up the intervention - A in favour of intervention - B if it benefits a little more than 1000 persons.

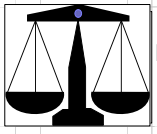
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer Intervention - A (mark the box on the left), would definitely prefer Intervention B (mark the box on the right), or would find it difficult to choose between the two (mark the box in the middle).

You should start with the first row and then continue to answer each question until you reach a situation for

Prefer Intvn-A	Intervention-A	Doubt	Intervention-B	Prefer Intvn-B
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 12200 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 9760 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 7320 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 4880 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 3660 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 3050 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 2440 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 2135 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 1830 individuals with 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will extend the life of 1525 individuals with 2 broken arms in stiff casts for one year.	

Your indifference point:

Will extend the life of 1000 healthy individuals for one year



Life years as shown on the right box, be it with 2 broken arms in stiff casts

Health state (2 broken arms in stiff casts) valuation worksheet -2B

We want to know your opinion about the burden that different diseases represent to individuals and families who are affected by them. By burden we mean loss of physical and social functioning (Mobility, self care and usual activities, physical and mental discomfort, anxiety or depression and loss of cognition. We do not have in mind the economic burden to society (for instance loss of production or incomes), and you should not take them into account when you respond to the question below.

2 broken arms in stiff casts

No assistance required and no problem with mobility. Ability to run / flight in times of need.

Totally dependent for self care.

Many problems in performing usual activities like work, employment, household work , etc.

Moderate, discomforting pain.

A little anxiety or depression.

No impairment of cognitive function. No cognitive problems

PTO2

Your are a decision maker that has only enough money to provide for one of following two mutually exclussive health interventions.

Intervention-A: Will extend the life of 1000 healthy individuals for one year

Intervention-B: Will cure a larger number of individuals of the above disability. In other words these persons will be able to enjoy perfect health for one year.

We would like to know the largest number of people with above disability, that should be covered by intervention-B for you to accept it in exchange for the intervention-A. If you find the health state above to be mild, you may be willing to trade the intervention extending 1000 perfectly healthy life years only if a very large number of people with the above health state are benefitted.

On the other hand, if the health state above is extremely undesirable, then you may be willing to give up the intervention - A in favour of intervention - B if it benefits a little more than 1000 persons.

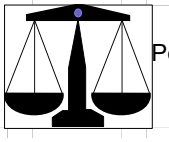
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer Intervention - A (mark the box on the left), would definitely prefer Intervention B (mark the box on the right), or would find it difficult to choose between the two (mark the box in the middle).

You should start with the first row and then continue to answer each question until you reach a situation for

Prefer Intvn-A	Intervention-A	Doubt	Intervention-B	Prefer Intvn-B
	Will extend the life of 1000 healthy individuals for one year		Will cure 1342 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 3782 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 6222 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 8662 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 9882 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 10492 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 11102 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 11407 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 11712 individuals of 2 broken arms in stiff casts for one year.	
	Will extend the life of 1000 healthy individuals for one year		Will cure 12017 individuals of 2 broken arms in stiff casts for one year.	

Your indifference point:

Will extend the life of 1000 healthy individuals for one year



Persons cured of 2 broken arms in stiff casts for one year.

Retest workshop:

A retest workshop was conducted on May 27, 2000 with 15 participants. The gap between the original workshop attended by them and the repeat workshop was about six months. Only VAS and TTO were repeated. PTO was dropped from the repeat tests, since the number of original PTO valuations satisfying ordinal rank consistency were small (seven) and finding valuers from this small group for the repeat test was difficult.

Participant's feedback about workshop:

Usefulness of written and spoken instructions:

Valuers in the workshops were asked to give their feedback (appendix 4.4) about usefulness of written instructions (WI) and spoken instructions (SI) on respective valuation exercises. We introduced these feedback questions starting with the workshop on 01 October, 1999. However, the data set does not have data for a large number of valuers who attended workshops after this date. These participants did not return the feedback questionnaires. Since these forms were introduced mid course, we could not integrate them into the workshop protocol well enough to achieve full compliance. Frequency distribution of feedback received from 34 participants is shown in Table-4.5. Most of the participants who turned in feedback, reported that the written and spoken instructions were very helpful for each component of the workshop.

Table - 4.5: Frequency of participants feedback about usefulness of written and spoken instructions on various valuation exercises (Total feed backs received = 34).

Workshop component ↓	Written Instructions ↓	Spoken Instructions: Not helpful	Some what helpful	Very helpful	Row total
Background material on workshop purpose	Not helpful				0
	Some what helpful		3	7	10
	Very helpful		3	21	24
	Column total	0	6	28	34
Card Sorting	Not helpful			1	1
	Some what helpful		3	5	8
	Very helpful		2	23	25
	Column total	0	5	29	34
Visual Analogue Scaling	Not helpful			1	1
	Some what helpful		4	5	9
	Very helpful		2	22	24
	Column total	0	6	28	34
Time Trade-off (TTO)	Not helpful				0
	Some what helpful		7	4	11
	Very helpful		4	19	23
	Column total	0	11	23	34
Person Trade-off (PTO)	Not helpful	1	2		3
	Some what helpful		7	2	9
	Very helpful		1	21	22
	Column total	1	10	23	34

Difficulty encountered in exercises:

Each participant was asked (Appendix 4.4) to make an assessment about the extent of difficulty encountered by him / her while dealing with different exercises in the workshop. Feedback is available from 34 valuers only. Table 4.6 shows the frequency distribution of these feedback. Evidently almost all of the participants, who gave feedback, did not have difficulty with description of health state, and card sort. Some had difficulty in understanding the visual analogue scaling. More people had difficulty in dealing with the TTO and PTO exercises. These feedback are on expected lines.

Table - 4.6: Frequency distribution of participants' feedback on difficulties encountered with different MDHSV workshop exercises.

Workshop component ↓	No difficulties	Some difficulties	A lot of difficulties	Can't Assess	Total
Description of own health	32	2	0	0	34
Card sorting	31	2	1	0	34
Visual analogue scaling	27	7	0	0	34
Time Trade-off (TTO)	13	11	10	0	34
Person Trade-off (PTO)	9	9	4	0	22

References:

IHS; Health State Valuation Software Tools (HSV Tools) Version 1.0. Hyderabad: Institute of Health Systems (IHS); 2003.

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Chapter 5:

Community Based Health State Valuations in Kondakkal Village of Andhra Pradesh, India.

Study Population:

To identify a village, we approached another civil society institution, namely MV Foundation, which is working to improve educational status of people. The MV Foundation is operating in many areas of the Ranga Reddy district. We requested them to help us identify a typical village, with more than 1000 households. Kondakkal was chosen on the basis of their suggestions and an exploratory visit by faculty from the Institute of Health Systems (IHS). Kondakkal has a population of 2342 adults and is typical of villages in Telengana area of Andhra Pradesh.

The electoral (voters) list for females and males containing 1127 and 1215 entries respectively was used as the sampling frame. A simple random sample of 550 persons from each of the two strata was drawn. Altogether, a list of 1100 potential valuers was prepared, consisting equal number of females and males. 1010 persons were actually interviewed (Non response proportion = 0.08). Table-5.1 shows age sex distribution and literacy of sampled population who did health state valuation using card sort and visual analogue scales. Similar data about the workshop participants, from Table-4.3, is reproduced for comparison. In addition, distribution of 15 years and older population in rural Andhra Pradesh according to the 1991 census is shown in the last three columns of Table-5.1. Age sex distribution is on expected lines and appears representative of the adult population of the village, except for the very young adults in the age group 18-19 years. Persons in this age group are slightly under represented.

Literacy and years of schooling by valuers is shown on the lower panel of Table-5.1. For comparison, NFHS-2 survey (IIPS and ORC Macro, 2000) data for rural females of the state of AP, for a similar period, i.e. 1998-99 is shown in the right columns. Years of schooling data for the MDHSV workshop participants is shown in the left columns. In

contrast to the workshop participants, about 70% of the valuers in the community survey were illiterate. The level of illiteracy in the sampled population is comparable with state-wide illiteracy recorded around the same time by the NFHS-2 survey.

Table-5.1: Age and Literacy of health state valuers.

Characteristic	Workshops			Survey			AP Rural		
	Females	Males	All	Females	Males	All	Females	Males	All
Number of valuers	88	92	180	491	519	1,010	1991 Census / NFHS-2		
Age Group									
18-19	0	0	0	2.51	2.98	2.75	6.88	6.63	7.08
20-29	67.05	61.96	64.44	31.11	41.67	36.52	29.68	27.54	30.13
30-44	23.86	23.91	23.89	35.70	33.13	34.38	31.38	32.99	32.47
45-59	9.09	13.04	11.11	19.83	15.28	17.50	19.59	20.18	18.98
60-69	0	1.09	0.55	9.19	5.56	7.32	8.11	8.32	7.42
70	0	0	0	4.18	4.37	4.27	4.37	4.33	3.92
Years of schooling									
0	0	0	0	84.93	56.07	70.1	71.6		
1-5	0	0	0	4.28	12.91	8.71	5.6		
6-9	0	0	0	5.7	11.18	8.51	13.3		
10-12	0	0	0	4.07	17.53	10.99	4.1		
13-15	45.45	16.3	30.56	1.02	1.73	1.39			
16-18	43.18	65.22	54.44	0	0.58	0.3			
19+	11.36	18.48	15	0	0	0	1.2		

[1] AP Rural population is from 1991 census for rural areas of Andhra Pradesh.
[2] Literacy figures for AP-Rural are taken from NFHS-2 which refers to 1998-99. NFHS literacy data is for women aged 15-49 years, and is available for females only since the survey covers only women.

The Constitution of India recognises certain castes as specially disadvantaged. These castes included in the appropriate schedule of the constitution are referred to as Scheduled castes. The Constitution provides another schedule of tribes and aboriginal people living mostly in remote areas. These groups are called scheduled tribes. Back ward classes are caste groups recognised by the state government as economically backward. All others not covered in any of the above three groups are classified under the residual category of "Other castes". Table-5.2 shows distribution of health state valuers by their caste. Caste composition of the valuers is broadly similar to the all state distribution of population by caste. Scheduled castes are slightly over represented in the sample.

Table-5.2: Caste composition of health state valuers in Kondakkal village, AP. Percentages

Caste group	Kondakkal			All AP
	Females	Males	Persons	Persons
Scheduled Castes	19.55	19.27	19.41	15.90
Scheduled Tribes	7.33	6.17	6.73	6.30
Back ward Classes	51.12	56.07	53.66	
Other castes	22.00	18.50	20.20	

Household durable and agricultural assets give indirect evidence of the economic status of households in rural areas. Table-5.3 shows the number of valuer households that own the listed household durable and agricultural assets. Similar figures from a state wide random sample of about 4000 households obtained by the NFHS-2 survey is shown in the last column. The households in Kondakkal village appear to be comparatively better off than the state average for rural areas. For example, 87% of sampled households in Kondakkal own some land compared to 55% in case of the sate-wide NFHS-2 random sample. Kondakkal households are better in terms of ownership of almost all household durable for which comparable data is available, except for radios. Access to various utilities like water supply, toilets, household fuel etc. give an idea about the economic status and immediate environment of people. Table-5.4 shows access to such services by valuer's households. Most people live in semi pucca houses, have protected water supply, use fire wood for cooking and do not have access to flush toilets. Here also the households in Kondakkal fair much better than the sate wide rural average from NFHS-2 sample. Comparatively more number of households in Kondakkal have access to protected water supply, flush toilets, cooking gas, and enjoy comparatively better housing.

Table-5.3: Ownership of household and agricultural assets by households of health state valuers in Kondakkal village.

Type of asset	Female	Male	Persons	%	AP Rural (NFHS-2)
Own house	473	510	982	100	
Radio	117	157	273	28	31.6
TV (B/W or Color)	263	308	571	58	22.1
Refrigerator	15	28	43	4	2

Bicycle	312	375	687	70	34.7
Two wheeler	117	95	273	28	4.3
Sewing machine	54	55	109	11	5.5
Sofa	30	44	74	8	
Owns Land	405	445	849	87	55.2
Live stock	192	240	432	44	
Bullock	183	211	394	40	
Bullock Cart	52	73	125	13	10.4
Water Pump	237	267	504	51	9.1
Electric Fan	333	367	699	71	43.8

Table-5.4: Access to health related utilities by valuer's households.

Utility / Living facility	Utility / Facility Type	Kondakkal	(NFHS-2) Rural AP
Water source	Private protected	22.67	
Protected: Piped / deep bore well	Public protected	72.08	40.00
	Private unprotected	0.89	
Unprotected: shallow bore well / open well	Public unprotected	4.06	59.40
	Natural unprotected	0.10	
	Other	0.20	0.60
Toilets	Private flush toilet	12.48	
	Shared flush toilet	0.10	6.50
	Public flush toilet	0.50	
	Pit latrine	5.64	6.00
	Other	0.50	
	No facility	80.79	87.50
Primary fuel used for cooking	Liquid petroleum gas (LPG)	10.00	6.70
	Biogas	2.18	0.70
	Kerosene	12.18	3.10
	Coal	0.30	0.10
	Fire wood / straw	75.15	86.50
	Dung	0.10	0.20
	Other	0.10	2.70
Type of house	Rented	0.99	
	Pucca	29.77	29.80
	Kachha	9.40	37.20
	Semi pucca	59.84	32.90

Standard of living index (SLI) was computed following the scoring system adopted by NFHS-2 (IIPS and ORC Macro, 2000 p27-29). Comparable data is available for most of

the household durable. However, the Kondakkal data does not have information about ownership of chairs. Instead it gives information about ownership of sofa sets, which have been scored by us as chairs. We did not collect information about ownership of mattress, pressure cooker, cot / bed, table and clock or watch. Each of these items get a score of 1 if present and 0 otherwise, according to the NFHS-2 SLI scoring plan. We did not collect information about the extent of land owned and irrigation status of land. Instead, we ascertained if the valuer's household did own any land or not. Thus all land owning households get a score of 2. If we had full details about extent of land owned, some would have received higher scores of 3 or 4, depending on the extent owned. In addition, some of the households would have got an additional score of 2 in case some of the land owned by them was irrigated. Thus the total SLI score of Kondakkal households would be slightly lower than the NFHS-2 SLI scores. Table-5.5 compares distribution of Kondakkal households and NFHS-2 AP rural sample households by the standard of living index (SLI). Clearly the households in Kondakkal enjoy a higher standard of living compared to the state average for rural areas. Only 27% of Kondakkal households fall in low SLI category compared to 48% for the state wide rural areas sample. Nearly 62% of Kondakkal households are in medium SLI category compared to only 43% for the state wide rural sample. Percentage of households in high SLI category is also higher for Kondakkal village.

Table-5.5: Standard of Living Index (SLI) of households of health state valuers in Kondakkal village, and NFHS-2 sample for rural AP.

SLI	Kondakkal	AP Rural
Low (less than 14)	27.03	47.8
Medium (15 to 24)	61.68	43.2
High (25 or more)	11.29	8.5

Valuation protocol:

Card sort and VAS:

Each valuer was required to assess 11 health states, including his / her own health state. The valuation exercises were limited to card sorting and visual analogue scaling (VAS). The card sorting and VAS exercises are similar to the ones done in the MDHSV workshops. The primary challenge here was to come up with a 6D5L description system for use by semi literate or illiterate persons. The graphical description system, developed for this purpose has already been described. We had to develop a Velcro mounted version of the graphical description system to facilitate preparation of the "Your own health state today" cards to be used in the card sorting and VAS exercises. Design of this is described below under "HSV kit for general population".

Pilot testing of valuation exercise protocol:

The Telugu version of health state cards and the pictorial format of the instrument was pilot tested in the Kondakkal village by IHS faculty. Study coordinator and faculty learnt and perfected their interviewing skills through this process. Some amendments were made to the valuation protocol. For example, the decision to substitute more descriptive labels for the short disease labels was taken to minimise effect of disease labels on the valuation.

The health state valuation (HSV) kit for general population:

The HSV kit for a general population had to be designed keeping in mind the lowest common literacy and educational status of the population. For most developing countries, including a state like Andhra Pradesh, this implies that the HSV kit design should enable illiterate valuers to express their judgement about the severity of different health states. The HSV kit for general population to be carried by surveyors included the following:

1. A visual scale platform consisting of a $2' \times 1'$ cork board with a visual scale pinned up on it.
2. The visual scale consisting of a straight line showing the two end points, namely (a) Best imaginable health state and (b) Death. These two points are connected by a straight line. The line is divided into 100 equal parts with labelling for every even divider.
3. One set of Velcro mounted 6D5L graphical description cards to enable the valuer pictorially describe his / her own health state. The set consists of six dimension holders, two sets of 30 severity level picture cards, and a "Your own health state" description holder. Each dimension holder is a card with five small pieces of Velcro fixed on it to hold the severity level picture cards. The severity level picture cards, with a small piece of Velcro fixed on the back of each. There are altogether 30 such severity level picture cards at the rate of five for each of the six dimensions. The severity level picture cards come in two versions: male and female. A "Your Own Health State" holder. This is a card with six small pieces of Velcro fixed on it.
4. Two sets of 10 printed cards each containing written and pictorial description of the 10 health states to be valued by the participant. These cards have the health state labels in Telugu. One is a free set of cards suitable for hand sorting. This is used for the card sort exercise. The other is pin mounted set, suitable for planting on the cork board VAS platform.
5. A survey schedule to be used by the interviewer to record biodata and other relevant valuer characteristics.
6. Interviewer's observation report (IOR) form to enable the interviewer to record his / her observations, after administering the exercises to each valuer.
7. A specially designed bag to hold all the pictures cards, forms and the cork board VAS platform, with designated pockets for each item.

Preparations for the survey:

Selection and training of surveyors:

The surveyors for the study were selected from among postgraduate students in Psychology, Social Work and Anthropology. A screening interview was conducted. Those found to be sensitive to rural culture were given preference. Selected surveyor's were trained for a week in the objectives and methods of the survey. Initially, they participated as valuers in a health state valuation workshop, so that each surveyor understood and experienced the nature of valuation process. The training included familiarisation visits to the village and trial administration of the valuation protocol under direct supervision of faculty who had learnt the protocol earlier. At the end of training period, the surveyor recruits were evaluated for their interviewing skills. Persons found to have some difficulty in communication with

interviewees were assigned other roles like camp management and accounts keeping.
A written manual was prepared and given to each surveyor. A copy of the manual is given as Appendix-5.1. An EPI-INFO data entry program was written and tested in advance. Surveyors were trained to use the data entry program. This training took place during the first two days of the survey camp.

Local coordination and logistics:

The village Sarpanch (elected head of Gram Panchayat), local school committee chairman, and other village elders were approached about the survey. We explained the objectives of our study and the survey plan. They approved of the survey and were very supportive of the work. Approval by formal and opinion leaders is important to secure cooperation by individual villagers for the survey. We did explain each interviewee and sought his / her consent for participation. We knew, however, that most villagers would look up to the opinion leaders and would want to know their opinion. Hence, we first approached the formal and informal leaders and explained to them about the study. Officials of the MV Foundation, played a helpful role in introducing the Institute of Health System, this study and its objectives to the village leaders. The village administrative functionaries of the state were also approached. They assisted in locating households. Additional personnel from the village were temporarily hired to escort the surveyors and introduce them to the interviewees in the sample. Camping arrangements for the study team was made. The health sub centre in the village was used as the camping site. The female health assistant posted at the health centre helped in introduction to villagers and in camping arrangements. A work group of personal computers was set up at the camp site to facilitate daily data entry and concurrent review of data entry errors if any. A standby power generator was installed. Arrangements for cooking of meals at the camp site, and such other ancillary arrangements to support the study team at the camp site for the two week study period was made. Our objective of describing these logistical aspects of the study is to emphasise the importance of conforming to the time constraints imposed by the work habits of sampled valuers, who could be contacted during early morning and late afternoon or evening hours. Thus on site camping, becomes important to get undivided attention of valuers on the health state valuation task.

The Survey:

The survey was conducted over a period of 12 days during October 15 - 26, 1999. As most of the valuers were engaged in agricultural labour, we were advised by the village opinion leaders to conduct the surveys early mornings as well as late evenings. The surveyors had to start as early as 6:00 am in the morning for the early morning sessions. Each surveyor took around 1 to 1 1/2 hours to complete one household survey. They were able to complete around 3 surveys in the morning and 3 in the afternoon. There were exceptional situations where the surveyor could not keep up to this schedule. Then they came back to the study camp, where they discussed their experiences. Every alternate day the project coordinator conducted review meetings with all the surveyors in order to keep the surveyors focused as well as deal with any emergent situation.

To estimate test retest reliability, a sub-sample of 110 valuers were selected by simple random sampling at the rate of 55 females and males from respective strata. A resurvey / retest was administered to 10% of the sample who participated in the original survey. After a one week gap, a retest valuation interview was done with these persons. The retest interviewees were administered the same set of indicator conditions originally assigned to them.

A typical valuation session with a villager:

Each surveyor was provided with a local escort recruited from the village. The local escort helped in locating households and introducing the surveyor to the interviewee. The surveyor usually spent some time to acquaint with the valuer and his / her household. Then s(he) would start filling out the personal information form (Appendix-5.3). English version of the personal information form is given in Appendix-5.2.

Surveyors used a set of Velcro mounted 6D5L graphical description cards appropriate for the interviewee's gender. Surveyor explains each of the six dimensions, one after the other, using the Velcro mounted cards. Within each dimension, the five levels of severity are explained. The valuer is then asked to pick up a picture from set of 5 pictures in the mobility

dimension, that describes his / her own mobility status. The valuer then stick this picture to a blank "Your own health today" card. The process is repeated for all six dimensions. Thus the valuer build a "Your own health today" card by picking up appropriate pictures to represent severity levels in each of the six dimensions. At the end of this exercise, the valuer is asked to take a fresh look at the "Your own health state today" card just built by him / her and review the same if necessary. The labels on each picture are read out to the valuer. Once the valuer makes up his / her mind and freezes the "Your own health today" card, a pin mounted version of the same card is made by the surveyor. These two cards are added to the free and pin mounted set of cards to make up the complete set of 11 cards.

The surveyor would present cards in the assigned set, one by one explaining the levels in each of the health states. The valuer is requested to select the health condition, including his / her own health state, that was worst of all the conditions. After selecting one s(he) was then asked to choose the next worst from the remaining 10. This process continued until there were no cards left. If the valuer had difficulty in identifying the next to most worse health state, then (s)he was asked to find the best health state from the remaining cards. Thus in some case the sorting proceeded step wise from worst to best, or in some other cases from best to worst, and in yet other cases in a cyclical fashion worst, best, worst. Yet another way of getting valuers to order the cards was by pair wise comparison. Surveyors, had to resort to one of these methods, depending on the valuer's comfort level. After completion of ordering of all 11 health state cards, the surveyor read out the health states one by one in a sequential order from worst to the best, and sought confirmation by the valuer. Although the sorting exercise proceeded in different manners according to the valuers liking, the rank orders assigned by the interviewee was recorded from best to worst. Thus the best health state received rank order 1 and the worst state got rank 11.

The pin mounted set of cards are sorted according to the card sort rank. The cork board visual scale is presented to the valuers. The valuer is then asked to, one by one, pin the cards showing his / her opinions for these health states as being near or far from “best imaginable health state” and “death” as well as from each other. Surveyors were instructed to look for any qualitative remark or information given by the valuer and record them in a form (Appendix-5.4) provided for the purpose.

After this the surveyor thanked the valuer and gave him / her the small gift as a token of gratitude. Then the surveyor sat for a few minutes to fill out the interviewer's observation report (IOR) form (Appendix-5.5). A valuation session is now considered to be complete.

Interviewer's feedback:

Table-5.6: Frequency distribution of interviewers' feedback on difficulties encountered by the valuer, cooperation and accuracy.

Difficulty encountered by the valuer:					
	None	Some	A lot	Can't say	Total
Description of own health	962	3	0	0	964
Card sorting	803	7	0	0	809
Visual analogue scaling	772	8	0	0	779
Personal information questionnaire	984	1	0	0	984
Respondent's cooperation and perceived accuracy:					
	V. High / Excellent	High / V. Good	Average / Good	Low / Fair	V. Low / Poor
Respondent cooperation	244	375	312	56	18
Accuracy	176	397	378	40	17

Comments by valuers on specific health states:

Brief summary of the comments by valuers for each health state is provided in Appendix-5.6. In Table-5.7 we compare the mean disability weight computed for valuers who made some comments, with the mean of all valuations. For most health states, there is a difference in the mean disability weights. Mean disability weights from people who made some comments, appear to be generally higher than the mean of all valuations. In a few cases the mean disability weight from those who made comments is lower than the grand mean. It would appear that the valuers who made some comments were aware that they were deviating from the communal norm and hence felt the need to explain the variation. Study of these comments, from multiple studies and over time may help us understand the nature of valuation process in people's mind.

Table 5.7: Comparison of mean disability weights (DWt) from valuers who made some comments and mean of all valuations.

Health State	No of Comments	DWt with comments		DWt from all	
		Mean	SD	Mean	SD
Quadriplegia	74	0.93	0.11	0.90	0.13
Severe heart failure (congestive)	4	0.88	0.14	0.69	0.21
Schizophrenia	4	0.80	0.09	0.61	0.25
Below the knee amputation (two legs)	11	0.79	0.15	0.78	0.15
Blindness	14	0.77	0.18	0.77	0.18
Two broken arms in cast	15	0.72	0.18	0.68	0.19
Urinary incontinence	4	0.71	0.24	0.59	0.22
Peptic Ulcer	6	0.66	0.24	0.55	0.21
Angina	6	0.64	0.24	0.48	0.25
Severe continuous migraine	24	0.64	0.28	0.60	0.22
Mild Tuberculosis with treatment	15	0.59	0.26	0.42	0.23
Unipolar major depression	22	0.59	0.20	0.49	0.24
Infertility	11	0.58	0.22	0.46	0.26
Bronchitis	5	0.57	0.07	0.47	0.23
Severe Hallucinatory Fever	8	0.52	0.26	0.53	0.23
Own Health Today	3	0.49	0.31	0.09	0.13
Mild diabetes, no symptoms	13	0.48	0.24	0.30	0.20
Mild hearing disorder	7	0.47	0.26	0.39	0.23
Continuous moderate back pain	4	0.46	0.12	0.56	0.22
Pain and stiffness in joints	7	0.46	0.13	0.51	0.23
White marks on face	13	0.44	0.27	0.29	0.22
Watery Diarrhoea 5 times a day	15	0.40	0.22	0.36	0.22
Below the knee amputation (one leg)	2	0.28	0.30	0.51	0.21

References:

International Institute for Population Sciences (IIPS), Kulkarni Sumati, Arnold Fred et al. National Family Health Survey 1998-99. Andhra Pradesh. Mumbai (Bombay): International Institute for Population Sciences (IIPS), 2000.

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Chapter-6:

Reliability and Validity of Health State Valuation Tools.

In the first section we describe our assessment of reliability of the health state valuations done in this study. An important consideration for estimation of reliability is measurement stability, which is linked to the theoretical conceptualisation of the health state valuation function. We explore the ordinal rank measurements obtained through this study and conjecture that the health state valuation function is a multi valued function. The second section discusses issues regarding validity of these measurements.

Reliability of Health State Valuation Tools:

Concept of reliability of a measurement tool and its measurement:

The reliability of an instrument refers to the reproducibility of its measurements when applied to the same object. Reliability is to be distinguished from the concept of validity. An instrument may measure reliably but may not be valid. Reliability is a necessary but not sufficient condition for validity. In the physical world let us take the case of a one litre liquid measure that has a dent in it, reducing its volume by, say, 10 ml. Such a measure when applied to say 10 litres of edible oil will reveal the result as 10.1 litre. If the same quantity of oil is measured by the same liquid measure repeatedly, the result will consistently be distributed around 10.1 litre, except for random errors, and assuming that we have a set up that allows no spillage. This is a reliable but not valid measure of volume. To illustrate the concept of validity using the same example, now suppose we have a reliable measure with its volume exactly equal to one litre. This is both a reliable and valid measure of volume. But this is not a valid measure of weight[9]. One implicit assumption in the example given above is that the object of measurement, namely, the quantity of oil being measured, remained the

[9] .The example of oil is chosen deliberately to illustrate the concept of validity. One litre of oil does not equal one kilogram of oil. Volume of a liquid is related to its weight as a function of the temperature at which the measurement is taken and the specific gravity of the liquid.

same (hence the assumption of no spillage). This is referred to as measurement stability. In the physical world, the measurement stability is not usually a problem, although even this can surface. When we apply the concept of reliability to psychometric measurements, the assumption of measurement stability may have to be tested.

In psychometrics, the concept of test (i.e. measurement instrument) reliability and its measurement is visualised using two theoretical models, namely: (a) the classical test theory, and (b) generalizability theory (G theory). More detailed introductions to the concept of reliability, validity, classical test theory and generalizability theory can be found in Carmines and Zeller (1979) and Shavelson and Webb (1991). Streiner and Norman (1995) describe these concepts in the context of health measurement scales[10]. Deyo et al (1991) describe the concept of reliability in the context of health status measurement and supplement it with some interesting computational formulae for computation of reliability coefficients.

Using classical test theory in the context of health state valuation, we would assume that the valuer (i.e. the respondent whose valuation we are measuring) has a true valuation for each of the health state being evaluated by him / her. We cannot observe this true valuation. The health state value assigned by a valuer (this is what we observe) contains within it both the true valuation and a random error. More formally; $h_i = H_i + e_i$ where h_i is the value assigned by valuer i to a health state. H_i is the true valuation in the mind of the valuer i for the health state, and e_i is the random error in measurement that is unrelated to the health state and the person. We further assume that the random error is distributed as normal with mean error of zero and an error variance $N(0, \sigma_e^2)$. These reasonable assumptions would imply that if a health state is valued by many individuals, the variance of the observed health state values will consist of the true variance of the valuations given to the health state by different individuals and the error variance. We can arrive at estimates that separate the error variance from the true variance if we have parallel measurements (for example test-retest). In psychometrics, reliability is assessed by various types of parallel measurements including (a) test-retest, (b) alternative forms of the same instrument, (c) split halves method and (d) internal consistency of test items. Except the test-retest method, all other methods are appropriate only to instruments consisting of multiple items. The health state valuation

[10] Note that the equation in page 110 illustrating computation of Sum of squares (error) is a printing error. The authors have confirmed this. However their result is correct. A correct version of this equation would be a follows:
Sum of squares (errors) = (6-7-5+6)^2 + (4-5-5+)^2 + ...+ (7-7-6+6)^2 + (5-5-6+6)^2 + ... + (8-7-8+6)^2 = 10

instruments like the VAS, TTO and PTO are single items scales. Hence the test-retest appears to be the only method appropriate for our purposes.

If we plot test and retest measurements from a perfectly reliably instrument, our theoretical conception of reliability implies that the result will be a straight line from origin with a 45^0 slope (concordance). This will also imply a perfect correlation between test and retest measurements. Hence traditionally, correlation coefficients (Pearson's and/or Spearman) between test and retest valuations have been used to describe the reliability of tests (Torrance, 1976, Bergner and others 1981, Bass and others 1993). The advantage of correlation coefficient is that it is quite well recognised as a measure of association. The problem in the context of reliability measurement is that the correlation coefficient would continue to be high even if the retest results are systematically different. If the retest valuations are systematically different then the difference in test-retest group means would be systematically different also. This can be tested by a *t* test for paired differences or difference in means. A statistically insignificant *t* statistic coupled with a high correlation coefficient would serve as evidence in support of test reliability. For example, see its usage by Torrance (1976), and Bass et al (1993) cited above. A near-perfect correlation coefficient coupled with statistically insignificant difference in test and retest mean does not, however, assure complete concordance of test and retest valuation. A linear combination retest valuations allowing for a non zero intercept can give rise to perfect correlation with not very dissimilar means. We could probably deal with this situation by testing statistical significance of the intercept from a theoretical value of zero. An intra-class correlation coefficient (ICC) is a single statistic that combines correlation between test retest and concordance of the two means. ICC measures not only the strength of correlation, but also the deviation of the slope and intercept from that expected for replicate measures (Deyo et al, 1991). An ICC under the classical test theory is defined as: $ICC = \frac{\sigma^2_{Persons}}{\sigma^2_{Persons}+\sigma^2_{Occasion}+\sigma^2_{error}}$ where σ^2 is the total variance and other variances correspond to their respective subscripts, the occasion meaning test or retest. An ICC can be computed for interval level measurements. Its counterpart for ordinal rank ordered measurements is the weighted kappa (Streiner and Norman, 1995; Kramer and Feinstein, 1998).

According to classical test theory, the variance of measurements by an instrument is visualised to consist of two parts, namely the systematic difference in valuations by the

persons using the instrument to indicate their valuations (this is the primary object of our measurement) and error. All other variance components except the one attributable to the object of measurement are wrapped into the error variance. Any source of systematic variation other than the variance within subject is considered to affect the validity of the measurements but not the reliability. The generalizability theory relaxes this restriction by allowing for teasing out of some more components from the error variance. These are variance components that can clearly be attributed to aspects of the measurement process. This implies that systematic effects on the valuations is further decomposed into aspects of measurement and residual systematic effects if any. The residual systematic effect, if any, affects validity of the measurements. For purposes of generalizability studies, residual effects, if any, are clubbed with the error term. Generalizability theory (Cronbach and others 1972) assumes that there are multiple sources of error in the measurement process. Each of the recognisable sources of error is considered a facet of measurement. These facets may be fixed (fixed facets) or we may want to generalise results to the universe of the concerned facet (facets of generalisation). The object of measurement is considered the facet of differentiation. Using analysis of variance computations, the variance components for each of the facets and their interactions are computed. The generalizability coefficient calculated from the variance components is a measure of reliability. The intra class correlation coefficient (ICC) described above happens to be a special case of the generalizability coefficient, in a one-facet model.

The feasibility of various test - retest reliability measures for health state valuation instruments can be summarised using a schema from Van Agt et al (1994) with some further modifications in the light of above discussions (Table-6.1). Although, we have retained Van Agt et al's columns for rank ordered data, test-retest reliability of rank orders assigned to the same set of health states by the same individual is not at issue. We treat the rank ordering of health states as the primitive expression of individual's true preference of ordering at the time of exercise. Hence we assume rank orders to be reliable and instead use the reliability measures to estimate concordance of rank ordering from test to retest. The test-retest concordance of rank orderings will help us assess the extent of measurement stability which is fundamental to interpretation of reliability measures.

Table-6.1: Feasibility of test - retest reliability measures for health state valuation

instruments

	Interval		Ranks	
	Per health state	All health states	Per health state	All health states
Individual	Irrelevant	Person's correlation	Irrelevant	Spearman's ρ Kendal's τ Weighted Kappa
Group	ANOVA: Classical test theory (ICC)	ANOVA: Generalizability Theory (Generalizability coefficient)	ANOVA: Friedman's by ranks	

[1] Source: Adapted from van Agt HM; Essink-Bot ML, and Krabbe PFM (1994)

Measurement stability in health state valuation:

The reliability of the health state valuation instrument is predicated on stability of expressed valuations. Consistency in expression of value for a health state is dependent on the nature of the true valuation of the health state in the valuer's mind. Let us take another look at the classical measurement model $h_i = H_i + e_i$ described earlier. It is conventionally assumed that H_i (the true quantity in the valuers mind) is a single value. Differences in the observed value h_i are wholly due to e_i , i.e. the error component. Such an interpretation assumes that every person has a well-formed and crystallised value attached to every health state, irrespective of the incidence of occasions and events encountered by him / her that would be cause for deliberation about this matter. Such an interpretation, however, does not appear to be the case in reality. People do not directly confront such questions in their daily life, although they do handle situations that implies choices between different health alternatives. It would appear more plausible that the true valuation in most person's mind is a fuzzy set consisting of a range of values for each health state. Thus we view H_i to be a multivalued set, and each attempt by the valuer i to express a value would actually be a sample endogenously drawn by the valuer from this set. For some health states, this range may be narrow, as is the case for extreme disabilities such as quadriplegia or unequivocally trivial illnesses such as common cold. For some other health states, the true valuation set may consist of a wider range. The set may narrow down as the individual deliberates on the characteristics of the health state, its relationship to other health states, and its implications for a person. If the true valuation in the minds of persons is a fuzzy set, and each valuation

attempt is a sampling from that state, then there would be scope for instability in expressed valuations.

For example, consider health states A, and B with overlapping true value sets as shown in Figure-6.1. Suppose a person with these true value sets is asked to express his / her valuation on an occasion (test). (S)he may report health as being state B as being better than health state A by tapping into his / her true value set in the manner shown in Figure-6.1. On another occasion, (s)he may sample his / her true value set in the manner shown for the retest, in Figure-6.1, in which case (s)he will report state A to be better than state B. Since the health state valuation instrument measures the expressed valuation the stability of the expressed valuation of health states is confounded with the reliability of the measurement instrument.

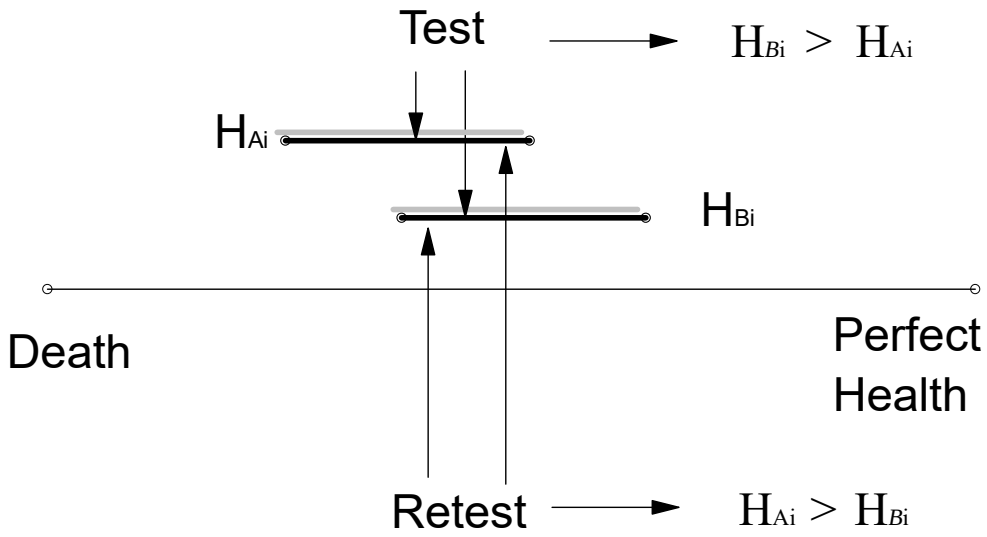
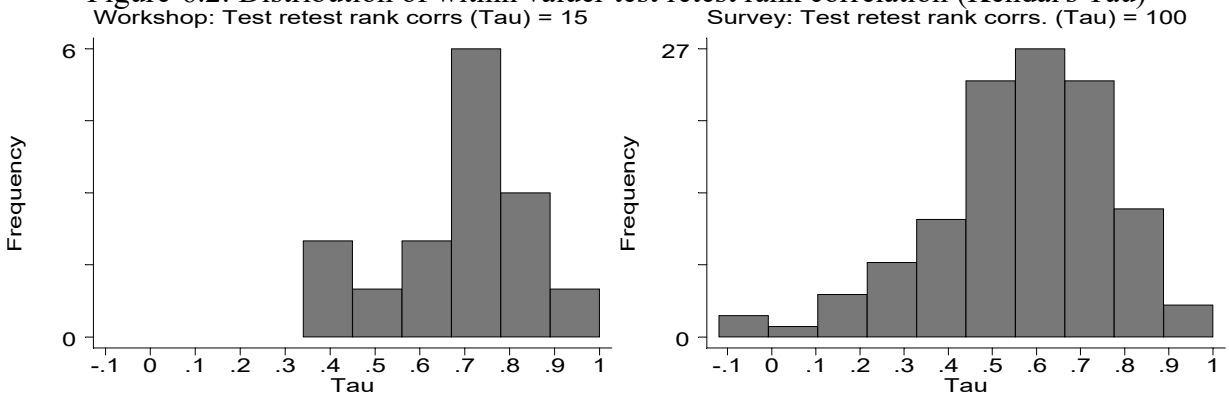


Figure-6.1 : Potential for rank reversal of health states in retesting.

The rank orderings provide us with a means of testing the above hypothesis as to whether people's valuation of health state is a single valued quantity or a multivalued set which a person maps each time (s)he intends to assign a numerical value to the health state. We assume that ordinal ranking suffers from minimal measurement error. Thus major changes in ordinal ranking from test to retest would support the above argument that the nature of true valuation in peoples mind is in the form of a fuzzy set of values with different degrees of clarification for different health states. We computed both Spearman's Rho and

Kendal's Tau and performed tests of statistical significance on both. Each of these correlation coefficients was computed from 11 pairs of valuation by an individual. Figure-6.2 shows distribution of individual level rank correlation of test retest ranks. We choose Kendal's Tau for the graphical presentation since the magnitude of the Tau statistic is less sensitive to extreme values giving rise to a more normal spread compared to distribution of the Rho. The left graph shows distribution of rank correlation coefficients estimated for the 15 test retest valuers from the workshop. The right graph shows the same for 100 test-retest valuers in Kondakkal village. Note that none of the valuers could exactly reproduce their original rank orderings. Rank correlations from the workshop valuers are more tightly distributed around 0.7. The rank correlations from the community survey is centred at 0.6 but are more dispersed. We tested the null hypothesis of no correlation between test and retest rank orders using the Spearman's Rho and Kendal's Tau. For the workshop participants, we were able to reject the null hypothesis at 95% level of confidence, in 13 (87%) out of 15 test-retest cases. For the community survey we were able to reject the null hypothesis at 95% level of confidence, in case of 69 (69%) correlations out of the total of 100. In the balance 31 cases we fail to reject the null hypothesis of no correlation.

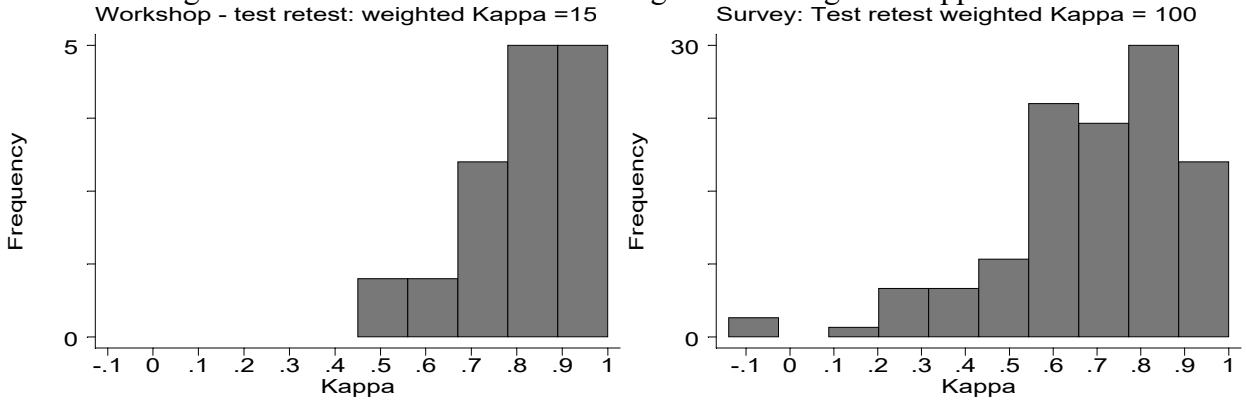
Figure-6.2: Distribution of within valuer test retest rank correlation (Kendal's Tau)



One possibility, if rank order of health states is not fully retained from test to retest, is that the valuers are randomly drawing from an undefined number space (0,1)? That would mean that persons do not have a value set and instead are simply giving a totally random response in the interval (0,1). To test this we turn to some measure of agreement, that allows us to test statistically whether the test-retest agreement is purely due to chance. Note that the reliability measures we discussed earlier are essentially measures of concordance. When we

can assume that measurement stability is satisfied, we use these statistics to measure reliability. Turning these measures around to a situation where we assume that the measurements (rank orderings here) are reliable, we can use them as measures of concordance. The rank correlation measures trend in each variable, whereas we are interested in concordance. This is the motivation for the intra-class correlation coefficient as a more appropriate measure of reliability in case of interval level data. Its equivalent for rank ordered data is the weighted kappa statistic. The weighted kappa (Cohen 1968) statistic computes the actual agreement between test-retest ranking and compares it with the agreement expected at random[11]. Figure-6.3 shows frequency distribution of quadratic weighted kappa by the value of the statistic for the test retest cases from the workshops (left graph) and the community survey (right graph). Kappa coefficients from the workshops are more tightly distributed around 0.9, where as these are more spread out in case of the community survey. We tested the null hypothesis that the agreement between test and retest rank orders is not any different from what would be expected at random, given the set of health states valued by respective valuers. We rejected this hypothesis for all 15 test retest valuers at 95% confidence. In case of the village population, we rejected the hypothesis for 82 valuers at 95% confidence and failed to reject hypothesis for the remaining 18 persons.

Figure-6.3: Distribution of test retest agreement weighted Kappa statistic



Finally we turn to the description and rank ordering of own health states by the valuers in test and retest. Out of fifteen test-retest valuers in the workshop, only one person changed the own health state rank. The remaining fourteen persons retained the ranking of their own health state. In case of the community survey 33 out of 100 test retest valuers changed the own health state rank and the remaining 77 retained the ranking from the first

[11] The Kappa statistic is described in Streiner and Norman (1995, pp116-118).

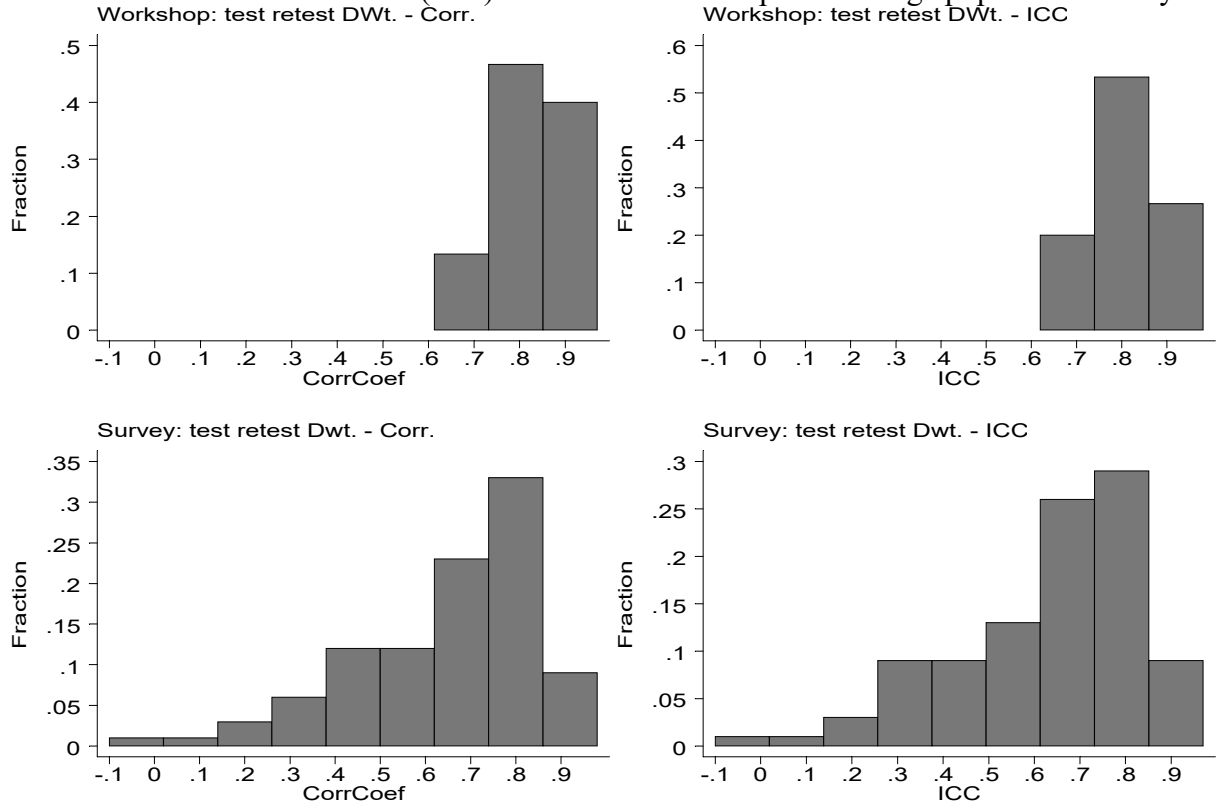
occasion. It may be of some interest to see the changes in 6D5L description of own health states. If all those who changed ranks also changed the 6D5L profile of their own health state, we cannot then rule out the possibility of real changes in valuer's own health, leading to a change in its ranking on the second occasion. In case of the workshop, 8 out of the 15 test retest valuers did not change the 6D5L profile of their own health state. The person who changed the own health state rank, however, did not change the 6D5L profile. In case of test-retest valuers from the village, 81 out of 100 persons ranked their own health state as one among the 11 health states ordered by them. 77 of these persons (85%) retained Rank 1 for their own health state, of whom 52 retained the 6D5L profile and the rest changed the profile to some extent. The four persons who changed the rank of their own health state from 1 to 2 also changed the 6D5L descriptions. The 19 persons who gave their own health state Rank 2 or higher (rank 1 = best and rank 11 = worst) in the test changed the ranks mostly to lower ranks and usually with some change in 6D5L descriptions. Most of the changes in ranking of own health status were associated with some change in 6D5L profile.

The above findings are consistent with our hypothesis. Certain additional conjectures appear. We find that stability of expressed valuations are somewhat better for the educated group and in case of "Own health" state for both groups. In case of the community survey 85% of persons who ranked their own health state as one, did not change the ranking in retest. In case of the workshop 93% did not change ranking of their own health state. It would then be reasonable to conjecture that the valuation set H_{Ai} is subject to continuous revision in the light of the persons experience and knowledge about the health state *A,* and about other health states. The valuation space, that starts as a fuzzy set, would get gradually clarified to various degrees, based on different factors, including experience and knowledge about the health state or related matters. We surmise that education is an indicator of a broader range of cumulative experience. Similarly everyone, irrespective of educational status, has more intimate knowledge of their own health state. Hence the stability of expressed valuations in the presence of these two factors appear to be better. These conjectures and hypotheses will need to be investigated further. For example, one implication of the above hypothesis is that the valuation set is likely to be clarified by repeated measurement, since these will provide repeated occasions for the valuer to deliberate on the concerned health status. Of course, the extent of clarification may not be the same for all health states. But some trend should be visible, if a large number of health states are measured.

Reliability of ordinal rank consistent visual analogue scales (VAS):

Conventional and Classical reliability measures:

Figure-6.4: Distribution of within valuer test-retest product moment correlation and intra class correlation coefficients (ICC). Data from workshops and village population survey.



The ordinal rank consistent visual analogue scale was used as one of the scaling methods in the multi method health state valuation workshops. This was the primary scaling method for the survey among Kondakkal village population. Retests were done with a sub sample of valuers to assess test-retest reliability in the Indian context. To assess reliability we first computed simple product moment correlation and intra class correlation coefficients separately for each individual. Figure-6.4 shows the frequency distribution of these coefficients. The top panel of two graphs show frequency distribution of correlation coefficient and ICC for the workshop participants (n=15). The bottom panel of two graphs show the same information for the 100 test retest valuers from the village population-based survey. Most of the correlation is reasonably high and distributed around 0.7 to 0.9. The ICCs

are also distributed similarly. The difference in distribution of correlation from the workshop and the village population are noteworthy. The coefficients from the workshop are more tightly distributed when compared to the village population. Test valuations from some persons do not correlate at all with the retest valuations.

Intra class correlation coefficients for all health states combined and by each health state ICCs were calculated (Table-6.2) using the computational formula described by Deyo (1991). Finally, for all health states, the ICC was 0.81 for workshop participants and 0.6 for the village population. But ICCs by health states look puzzling. We would expect the ICCs by health state to be positive and high in case of health states where valuation in the community is diffused and positive but not so high for health states where the valuation in the community is tightly distributed around a central value. Measurement error will also drive the ICC value towards zero. Hence, it is difficult to separate measurement error from crystallised valuations in the community. This is an important problem with usage of ICC to measure reliability of health state valuation instruments.

Table-6.2: Intra class correlation coefficients (ICC) by health state from workshops and community survey.

Health State	Workshop		All villagers		Literate villagers	
	n	ICC	n	ICC	n	ICC
All states	165	0.81	1100	0.61	297	0.677
Mild diabetes, no symptoms	15	0.48	100	-0.01	27	0.22
Mild tuberculosis with treatment	15	0.44	100	0.24	27	0.21
Own Health	15	0.62	100	0.06	27	0.33
Quadriplegia	15	0.56	100	0.05	27	0.12
Severe migraine	15	0.49	100	0.16	27	-0.01
Unipolar major depression	15	0.60	100	0.26	27	0.19
Watery diarrhoea	15	0.26	100	0.14	27	0.09
Continuous moderate back pain	5	-0.81	21	0.20	5	0.01
Mild hearing disorder	5	0.93	21	0.00	5	0.15
Severe heart failure	5	0.81	21	0.07	5	-0.14
White marks on face	5	-0.75	21	-0.12	5	-0.18
Bronchitis	4	0.36	23	-0.15	10	0.25
Pain and stiffness of joints	4	0.63	23	0.15	10	-0.14
Schizophrenia	4	-0.17	23	0.45	10	0.67
Urinary incontinence	4	0.28	23	-0.27	10	-0.30
Below knee amputation - one leg.	2	0.76	26	0.04	5	0.12
Below knee amputation - two legs.	2	0.30	26	-0.02	5	0.35
Peptic ulcer	2	0.05	26	-0.06	5	-0.24
Two broken arms in cast	2	0.18	26	0.31	5	0.60
Angina	4	0.22	30	-0.14	7	0.02

Blindness	4	0.69	30	0.16	7	0.94
Infertility	4	-0.89	30	-0.08	7	-0.27
Severe hallucinatory fever	4	0.40	30	0.19	7	0.36

[1] n = number of valuations for the concerned health state.

We do not, however, expect negative ICC values. But the ICC for some health states are negative. We cannot dismiss these values as statistically not different from zero. For example, consider the ICCs from workshop participants for white marks on face (-0.75), infertility (-0.89), and continuous moderate back pain (-0.81). Note that all these ICCs are based on too few observations. Table-6.2 has been ordered by the number of observations on which the ICCs for each health state was computed. The top part of the table with more observations, does not show any extreme negative value of ICC. Among the top eight rows, where the sample sizes are relatively higher, mild diabetes has an ICC = 0.01 from community survey and severe migraine has an ICC = 0.01 for the literate sub group in community survey. Probably the extreme negative ICC values are just a matter of chance. In the light of our conjecture about measurement stability, we suspected that educational status may improve the ICC. So the ICCs were recomputed for the literate subset of test-retest cases from the village population. Only persons who had some formal schooling only were included in this subset. The last two columns in Table-6.2 show ICCs for this subset. We focus on the top eight rows only. No definite inference can be drawn. The ICCs improve in some cases and reduce in some others.

Generalisability study:

The generalisability study allows us to model the measurement situation as a multifaceted process where each facet has an effect on the measurement. The effect of each facet is identified. The object of measurement facet (facet of differentiation) and facets of generalisations are identified. In our case, health state is the object of measurement. Appreciation of the extent to which the instrument helps differentiate the object of measurement and effect of facets of generalisation gives us an idea about generalisability and dependability of the measurements. In the present case, we have three facets namely, (a) the valuers (v), (b) the health states (h) and (c) two occasions (o) of measurement. The valuers are a random sample of the universe of valuers. Similarly the occasions of measurement are

random. We want to be able to generalise the measurements to any other occasion. The health states used for this study are a subset of a large number of health states for which the health state valuation instrument is to be applied. Since all three facets are random, we assume a fully crossed $v \times h \times o$ model of measurement. A fully crossed design requires that all test-retest valuers valued all health states which in our case did not happen. Each valuer worked on 11 health states including the own health state. The valuers were assigned health states from one of four sets. Thus those assigned to a set of health sets worked on the same health states on both occasions. In other words, if the generalisability study is restricted within each set, the fully crossed design of measurement can be analysed. Within a given set we have measurements by all valuers assigned to that set, on all health states in that set and on both the occasions (test and retest). We first describe the computational steps and then present results for each of the four sets of health states.

As discussed earlier, the analysis for the generalisability study starts with partitioning of the variance components. For this purpose let *a, b, c,* respectively be the number of valuers, health states and occasions. In this case, we have 11 health states and two occasions. The number of valuers vary depending on the set of health states. Further let MS = Mean Squares i.e. mean squared deviation terms, and TSS = Total sum of squares i.e. sum of the squared deviation of each observation from the grand mean. MS with the appropriate subscript v, h or o and their combinations represents the mean square for the concerned facet or their interaction terms. To partition the variance components, we first compute the following mean squares from the given data.

$$MS_v = \frac{abc \sum_{v=1}^{a} (\bar{x}_{v..} - \bar{x})^2}{a-1}$$

$$MS_h = \frac{abc \sum_{h=1}^{b} (\bar{x}_{.h.} - \bar{x})^2}{b-1}$$

$$MS_o = \frac{abc \sum_{o=1}^{c} (\bar{x}_{..o} - \bar{x})^2}{c-1}$$

$$MS_{vh} = \frac{abc \sum_{v=1}^{a} \sum_{h=1}^{b} (\bar{x}_{vh.} - \bar{x}_{v..} - \bar{x}_{.h.} + \bar{x})^2}{(a-1)(b-1)}$$

$$MS_{vo} = \frac{abc \sum_{v=1}^{a} \sum_{o=1}^{c} (\bar{x}_{v.o} - \bar{x}_{v..} - \bar{x}_{..o} + \bar{x})^2}{(a-1)(c-1)}$$

$$MS_{vo} = \frac{abc \sum_{h=1}^{b} \sum_{o=1}^{c} (\bar{x}_{v.o} - \bar{x}_{..o} - \bar{x}_{.h.} + \bar{x})^2}{(b-1)(c-1)}$$

$$TSS = \sum_{v=1}^{a} \sum_{h=1}^{b} \sum_{o=1}^{c} (x_{vho} - \bar{x})^2$$

$$MS_{vho,e} = \frac{TSS - SS_v - SS_h - SS_o - SS_{vh} - SS_{vo} - SS_{ho}}{(a-1)(b-1)(c-1)}$$

We then arrive at estimates of variance components using the mean squares based on expected mean square equations from Shavelson and Webb (1991, p33).

$\hat{\sigma}_v^2 = \frac{MS_v - MS_{vho,e} - bMS_{vo} - cMS_{vh}}{bc}$ i.e. variance component - valuers,

$\hat{\sigma}_h^2 = \frac{MS_h - MS_{vho,e} - bMS_{ho} - cMS_{vh}}{ac}$ i.e. variance component - health states,

$\hat{\sigma}_o^2 = \frac{MS_o - MS_{vho,e} - aMS_{ho} - bMS_{vo}}{ab}$ i.e. variance component - occasions of measurement,

$\hat{\sigma}_{vh}^2 = \frac{MS_{vh} - MS_{vho,e}}{c}$ i.e. variance component - valuer health state interaction,

$\hat{\sigma}_{vo}^2 = \frac{MS_{vo} - MS_{vho,e}}{b}$ i.e. variance component - valuer occasion interaction,

$\hat{\sigma}_{ho}^2 = \frac{MS_{ho} - MS_{vho,e}}{a}$ i.e. variance component - health state occasion interaction, and

$\hat{\sigma}_{vho,e}^2 = MS_{vho,e}$ i.e. variance component - random error.

Results of the variance component analysis separately done for the four sets of health states is shown in Table-6.3. About 56 to 67% of variance is attributed to health states, the primary object of our measurement. The generalisability coefficient ranges from 0.56 to 0.67. Peculiarly some variance components are negative. Negative variance components could be due to misspecification of the measurement model or due to of sampling error (Shavelson and Webb, 1991). Most of the negative variance components in this study reside either in the valuers or interaction terms of valuers and health states. These negative variance components are compensated by a larger and positive error variance. This could be due to unstable

valuations for certain health states, and differences in stability of valuations for different health states. The problem of unstable valuations and valuer health state interaction can not be dealt by changes in the measurement model. Instead, a larger sample size may help improve stability of measurements at the group level.

Table-6.3: Estimated variance components for VAS-based health state valuations from village population.

Source	df	MS	Variance Component	% Total Variance	% total variance from sets 2-4		
					Set-2	Set-3	Set-4
Valuers (v)	22	0.05	0	-2	3	3	2
Health states (h)	10	2.58	0.05	60	56	67	56
Occasions (o)	1	0.06	0	0	1	0	-1
v * h	220	0.03	0	6	-29	-25	-31
v*o	22	0.08	0	6	2	0	3
h*o	10	0.05	0	1	0	0	2
vho,e	220	0.02	0.02	29	67	54	69
TSS	253	0.17	0.09	100	100	100	100

[1] Columns 2 to 5 shows details of variance components analysis for set-1 health states.

Table-6.4: Generalizability of health state values by VAS. Variance components in percentages, reported by different studies.

Source	APHSV99	Van Agt et al (1994)[1]	Shibuya (1999)[2]
Valuers (v)	-2 to 3	2.87	3.8
Health states (h)	56 to 67	81.96	71.3
Occasions (o)	-1 to 1	0.05	0.3
v * h	-31 to 6	4.35	12.5
v*o	0 to 6	1.31	3.2
h*o	0 to 2	0.12	0.1
vho,e	29 to 69	9.33	8.8

[1] Standard EuroQol instrument. Postal survey in Rotterdam, Netherlands, Jan. 1991.
[2] Ordinal rank consistent VAS. Medical students in Japan, 1999.

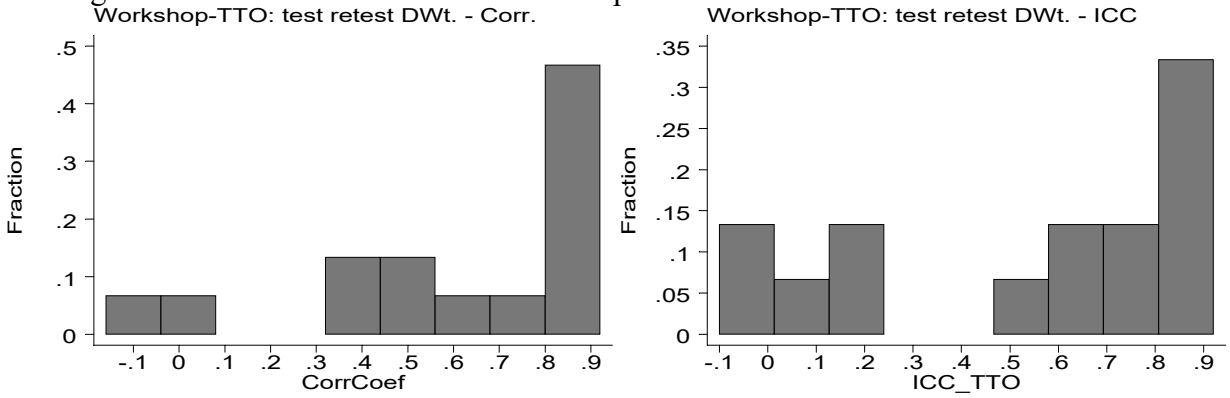
Generalisability study to assess reliability of health status measurements is being done recently. We are aware only of two studies in the area of health state valuation conducted hitherto. Helen van Agt and others (1994) did a generalisability study of health state valuation using different versions of the EuroQol instrument administered through a postal survey. Shibuya (1991) has compared different health state valuation methods used by medical students in Japan. A study by Krabee et al (1997) performed the generalisability

analysis, but in the context of comparing different methods of valuation, and is therefore excluded from the comparisons here. Table-6.4 compares results from three studies, including the present one. Generalisability coefficients (simply the % variance due to health states expressed as a proportion) obtained in this study are comparatively lower than the other two studies. This difference could be due to the educational status of the valuer population. The Netherlands study was on educated urban professional and the study in Japan involved medical students where as this study was done in an Indian village, with many of the valuers being illiterate. Hence we conjecture that the slightly lower generalisability coefficient could be due to the difference in educational status of the valuers.

Reliability of health state valuations by TTO:

Product moment and intra class correlation coefficients were computed for valuations by the TTO method. Correlation between test and retest were computed for each of the test retest valuer. The same 15 workshop participants attending the retest workshop repeated the TTO exercise. Figure-6.5 shows the frequency distribution correlation coefficients (left graph) and ICCs (right graph). The distribution is bimodal. A majority of participants had high correlation and concordance between their valuations on the two occasions. The poor correlation of test- retest valuations for some individuals could to some extent be attributed to their discomfort with the TTO valuation method and on account of unstable valuations for different health states.

Figure-6.5: Distribution of TTO test retest product moment and intra class correlation.



Intra class correlation coefficients were estimated by health state (Table-6.5). The overall ICC for all health states is about 0.44 which is lower than the level of overall

concordance achieved by the VAS (0.81) for the same number of valuers and health states. Some health states show negative ICCs, suggesting unstable valuations for these states in the minds of the valuers. Two of such states, namely, continuous moderate back pain and vitiligo had negative ICCs under the VAS. For some health states, the ICC under VAS and TTO differed in the direction of agreement: for example, infertility and angina. Since the sample size is quite small in many cases (2 to 5) we can not attach much significance to the health state ICC statistics.

Table-6.5: TTO test retest ICC by health states

Health States	n	ICC	Health States	n	ICC
All	165	0.438	Bronchitis	4	0.84
Mild diabetes, no symptoms	15	0.23	Infertility	4	0.36
Mild tuberculosis with treatment	15	0.25	Pain and stiffness of joints	4	0.23
Own health	15	-0.02	Schizophrenia	4	-0.52
Quadriplegia	15	0.01	Severe hallucinatory fever	4	-0.27
Severe migraine	15	-0.35	Urinary incontinence	4	-0.23
Unipolar major depression	15	0.20	Blindness	4	0.62
Watery diarrhoea	15	-0.10	Angina	4	-0.51
Continuous moderate back pain	5	-0.46	Below knee amputation-one leg.	2	0.91
Mild hearing disorder	5	0.25	Below knee amputation-two legs.	2	0.92
Severe heart failure	5	-0.15	Peptic ulcer	2	0.33
White marks on face	5	-0.94	Two broken arms in cast	2	0.98

Validity of the Health State Valuation Measurements:

An instrument is valid if it measures what it is intended to measure. Here we are trying to measure the value that people assign to life in different health states. We assess the validity by looking at the instrument's performance from different perspectives. The following three main perspectives are usually studied. Firstly, instrument's content, which would include administration protocol as well. Secondly, the comparative performance of the instrument in relation to a criterion: for example, performance in relation to a "gold standard" and finally, the consistency of measurements by the instrument with theoretical constructs around the subject of measurement. The above three perspectives are commonly referred to as content or face validity, criterion validity and construct validity respectively. Such descriptions have erroneously suggested the existence of a typology of validity. However, it is important to recognise that validity is a single concept. We are interested to know if an

instrument is valid. We try to infer this by looking at the instrument from different perspectives.

Details of the health state description system used to describe the health states subjected to valuation have been described earlier. Adequacy, accuracy and effective communication of health states contribute to the content of these instruments. The theoretical basis of the three scaling strategies, namely VAS, TTO and PTO have already been referred to earlier. Each of these three scaling strategies were aided by card sorting. Ordinal ranking of a set of conditions is considered to be a primordial expression of preference and valuation. Hence we believe that modification of the three scaling techniques by seeking consistency with card sort by the same valuer enhances the content of these instruments. The written and spoken instructions, examples and the health state valuation protocol, all contribute to the instrument's content.

Table-6.6: Correlation of health state values obtained from different methods and effect of deliberation.

Method ↓→		TTO	PTO
First TTO / PTO valuation			
VAS	All valuations (180 valuers)	0.51 (1969)	PTO1: 0.02 PTO2: 0.03 (319)
	Ordinal rank consistent (162 valuers)	0.52 (1782)	PTO1: 0.47 PTO2: 0.28 (275)
TTO	First iteration (179 valuers)		PTO1: -0.00 PTO2: 0.13 (319)
Last round of TTO / PTO valuation			
	All valuations (180 valuers)	0.62 (1969)	0.89 (82)
	Ordinal rank consistent (162 valuers)	0.64 (1782)	0.89 (82)
	All valuations (179 valuers)		0.84 (82)
	Ordinal rank consistent (70) valuers)		0.87 (71)
All valuations consistent with card sort			
	VAS	0.80 (770)	0.93 (77)
	Time trade-off (TTO)		0.89 (77)

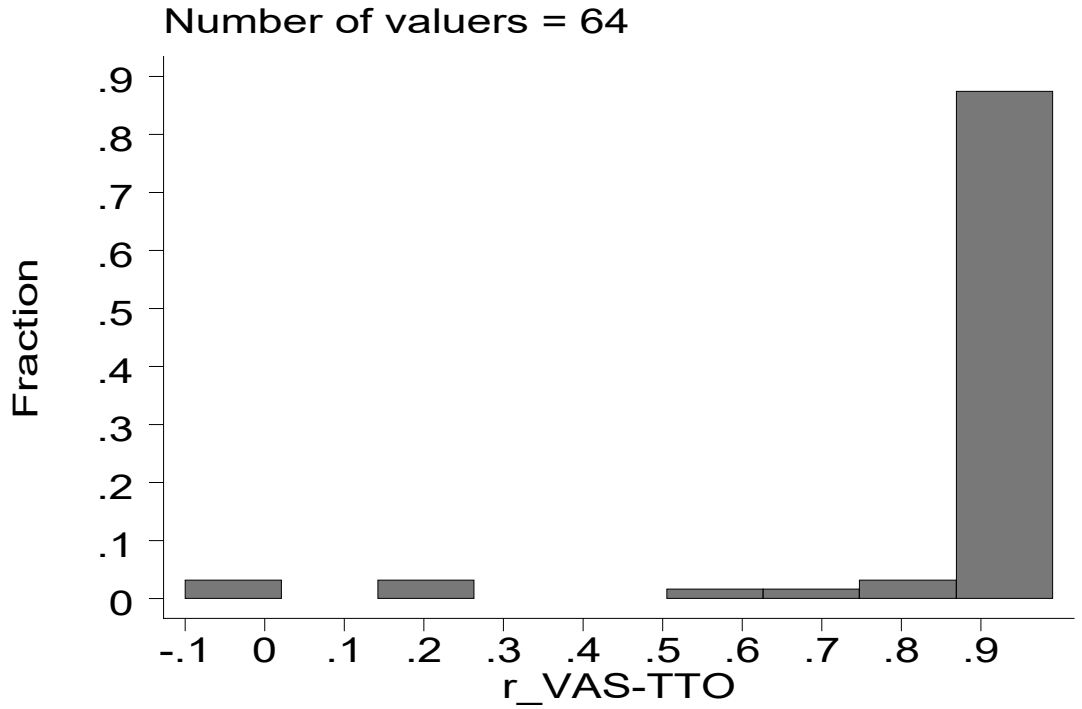
[1] Figures within parentheses show number of valuations based on which the correlation coefficient is estimated. This number divided by 11 rounded up gives the number of valuers which is equal to the min (row method valuers, column method valuers).

A "gold standard" measure of health state values does not exist. Hence a criterion-related validity assessment is not feasible. Instead, we turn to examine consistency of measurements with different constructs about psychometric measurements in general and health state valuation in particular. One construct frequently resorted to is convergence. If

measurements from an instrument converge with measurements from other instruments appropriately built to measure the same concept, we take the evidence as a support to validity of the instrument. Table-6.6 shows correlation of visual analogue scale valuations with results from two other scaling methods, namely TTO and PTO. Correlation coefficient for VAS and TTO scores is 0.8. The correlation between VAS and PTO scores is 0.93 and between TTO - PTO scores it is 0.89. The correlation with PTO valuations is based on a small number of valuations (seven valuers and 77 valuations). We consider the correlation coefficients of about 0.8 between different scaling strategies as suggestive of convergence.

The reader may recall that valuation protocol encouraged a deliberative iterative process. Key components of this process were multiple iteration of valuation - consistency with card sort feed back loop. The top panel of Table-6.6 "First TTO / PTO valuation" shows the correlation of VAS scores with the first round of TTO and PTO values. The correlation of VAS and first round TTO scores stood at 0.51. This improves marginally to 0.51 if we restrict to ordinal rank consistent VAS scores . The improvement in correlation between VAS and PTO is more marked (0.04 to 0.47 and 0.07 to 0.28 for PTO1 and 2 respectively). Some valuers did not pursue the TTO / PTO exercise till their ordinal rankings matched completely with the card sort ranks while some others pursued these exercises till the rankings matched with card sort. The middle panel, "Last round of TTO /PTO valuation" shows correlation between VAS with the last round of TTO and PTO scores. The last round of TTO / PTO scores includes scores from valuers whose card sort ranking did not match fully and those whose ranking matched completely. Correlation of VAS with TTO scores at this stage improved from 0.51 / 0.52 earlier to 0.62 / 0.64 for amalgamated and ordinal rank consistent VAS scores respectively. Stronger correlation (0.89) between the VAS to PTO valuations appeared. These correlation improved further if the TTO / PTO valuations were restricted to completely matched cases only (i.e. card sort ranking and TTO / PTO ranking for these valuers matched completely). Correlation of VAS - TTO scores improved from 0.6 to 0.8. These findings are consistent with our belief that the ordinal rank consistency criteria and use of the deliberative interactive tools help clarify the valuation process.

Figure-6.6: Frequency distribution of within valuer correlation between VAS and TTO valuations.



Now let us consider at convergence at disaggregated level. We can disaggregate the correlation between different scaling methods by valuer and by health states. First we look within valuer correlation between scaling methods. Correlation coefficients were estimated for each valuer, between their valuations using VAS and TTO methods. The set of health states assigned to the individual did not change between instruments. There are 64 valuers in the data set whose valuations are ordinal rank consistent for both VAS and TTO valuations. Figure-6.6 shows the frequency distribution of these correlation coefficients. Clearly, valuations from the two instruments correlated very strongly at the individual level. Most of the correlation coefficients were about 0.9. Similar correlation between VAS and PTO scores showed that all seven (i.e. the number of valuers who completed ordinal rank consistent PTO) were 0.9 and above.

Let us now consider to convergence at the health state level. Table-6.7 shows correlation of VAS scores with TTO and PTO scores for each health state. The health states are shown in descending order of estimated correlation coefficient of VAS and TTO. Valuations by different instruments positively correlated with each other for most health

states. However, VAS and TTO valuations for a few health states, like common cold, schizophrenia and below the knee amputation of two legs, did not correlate at all. It is difficult to say whether such lack of correlation would suggest systematic interaction between health state and scaling method, lack enough sample valuations or some unknown factor. This aspect needs to be investigated further.

Table-6.7: Within health state correlation of valuations by different instruments

Health state	VAS-TTO		VAS-PTO	
	n	*n*	*n*	*n*
Severe hallucinatory fever	5	0.99		
Bronchitis	14	0.86		
Infertility	15	0.82		
Urinary Incontinence	14	0.80		
White marks on face	14	0.79		
Watery diarrhoea 5 times a day	64	0.77	7	0.93
Blindness	15	0.71		
Mld diabetes, no symptoms	64	0.70	7	0.73
Mild tuberculosis with treatment	64	0.65	7	0.90
Severe congestive heart failure	14	0.62		
Unipolar major depression	64	0.62	7	0.67
Severe migraine	64	0.61	7	0.89
Continuous moderate back pain	14	0.60		
Mild hearing disorder	14	0.53		
Angina	15	0.44		
Pain and stiffness in joints	14	0.41		
Valuer's own health state	64	0.39	7	0.49
Two broken arms in cast	12	0.39		
Quadriplegia	64	0.29	7	0.83
Peptic ulcer	21	0.24		
Amputation of one leg below knee	21	0.21		
Moderate anaemia	9	0.11		
Common cold	10	0.01		
Schizophrenia	14	-0.01		
Amputation of both legs below knee	21	-0.10		

Logical consistency of valuations would throw some light on validity of the instruments. Our subject of valuations, namely the health states, differed in their 6D5L profiles. We identified pairs of health states such that one of the two 6D5L profile weakly dominates (i.e. is worse in at least one dimension and same in other dimensions). We have

nine such dominant - dominated (dd) health state pairs (Table-6.8). We looked for valuations under a scaling method where DWt (dominant state) ≤ DWt (dominated state). Lets call such a valuation as counterintuitive. We counted such counter intuitive valuations under each scaling method.

Table-6.8: Incidence of counter intuitive valuations for dominating and dominated pairs.

Pair #	Dominating (first line) and Dominated (second line) Health State	6D5L	NDD[1]	distance	All Valuations		Card sort matched	
					VAS	TTO	VAS	TTO
1	Quadriplegia	554341	5	7	11%	34%	10%	22%
	Amputation below the knee(both legs)	433221			45	44	41	23
2	Severe Hallucinatory Fever	444333	6	8	19%	35%	21%	6%
	Blindness	323122			31	31	28	16
3	Amputation below the knee(both legs)	433221	4	4	2%	14%	0%	0%
	Amputation below the knee (one leg)	322211			45	44	41	23
4	Mild Tuberculosis with treatment	111221	1	1	19%	25%	17%	19%
	Mild diabetes, no symptoms	111121			180	179	163	70
5	Mild Tuberculosis with treatment	111221	1	1	19%	39%	19%	26%
	Watery Diarrhoea 5 times a day	111211			180	179	163	70
6	White marks on face	111131	1	1	62%	64%	62%	67%
	Mild diabetes, no symptoms	111121			45	45	42	15
7	Angina	111321	1	1	40%	49%	38%	38%
	Mild Tuberculosis with treatment	111221			45	45	40	16
8	Mild hearing disorder	112121	1	1	62%	56%	62%	60%
	Mild diabetes, no symptoms	111121			45	45	42	15
9	Severe continuous migraine	113431	1	1	38%	53%	35%	56%
	Urinary incontinence	113331			45	45	40	16

[1] NDD = Number of dominating dimensions.

[2] For each pair the top row shows % of valuations where value assigned to dominating condition was less than equal to the value assigned to the dominated condition. The bottom row shows the number of valuations for this pair i.e. the denominator for the % shown in top row.

Table-6.8 shows occurrence of counter intuitive valuations for the nine dominating and dominated pairs under VAS and TTO methods. The two columns under "All valuations" show the occurrence of counter intuitive valuations for all valuers irrespective of whether their valuation was consistent with the ordinal ranks assigned by them to the same health states. The next two columns (right most) under "Card sort matched" restricts the

denominator set to ordinal rank consistent valuations only. The column titled NDD shows the number of dimensions in which the dominant condition's profile is strictly worse than that of the dominated state. The NDD value can be considered as a measure of the magnitude of dominance. The column titled "distance" shows difference in the equally weighted sum of the severity level codes contained in 6D5L profile of dominant and dominated condition. For example, the severity codes in the 6D5L profile for quadriplegia add up to 22 and the same for amputation of both legs below the knee add up to 15. So the distance between the two health state profiles is taken as 7. Note that this assumes an explicitly defined multifaceted health state value model consisting of six attributes and each attribute weighting equally. This need not be actually the case. The imperfect distance measure thus arrived, however, gives us some idea of the magnitude of difference in the two profiles.

The disability weight of the dominant state is expected to be greater than the value of the dominated state. If a dominant - dominated pair of health state is valued by many individuals using a perfectly valid instrument, the frequency of counterintuitive valuations will tend to zero as the number of valuers increase. In a less than perfect but real world, occurrence of counterintuitive valuations will be rarer as the validity of the instrument improves. One would also the expect that occurrence of counter intuitive valuations for a dd pair will be less as the NDD value and distance between the two increases. Earlier we have argued that requiring ordinal rank consistency improves instrument validity. That would imply that occurrence of counter intuitive valuations would be comparatively less for ordinal rank consistent valuations as opposed to amalgamated valuations containing both consistent and inconsistent measurements. Now let's examine the numbers in Table-6.8 in the light of the above theoretical expectations. Occurrence of counter intuitive valuations under card sort matched scaling was 0 to 21% for pairs with NDD values of 4 to 6 with distances from 4 to 8. Compare this with occurrences ranging from 17% to 62% for pairs with NDD value or distance of one. VAS appears to produce relatively less counterintuitive valuations in comparison to TTO. Ordinal rank consistency appears to slightly reduce the occurrence of counterintuitive valuations. But the magnitude of this effect is small for VAS measurements. Consistency of TTO measurements appear to improve much more when ordinal rank consistency is insisted. Further study is required to understand what aspect of these instruments, mode of administration, etc. need to be changed to reduce occurrence of counterintuitive valuations.

Relationship of VAS measurements to TTO valuations:

Mean disability weights, their standard errors (SE), and number of observations (n) obtained from different valuation methods in the workshops is shown in Table-6.9. Results from the PTO exercise are based on very few participants. Although we have shown the mean values here, we do not use them for comparative purposes in view of the small sample size.

Table-6.9: Mean disability weights from the workshops.

Health state	VAS			TTO			PTO		
	n	Mean	SE	n	Mean	SE	n	Mean	SE
Angina	45	0.46	0.03	45	0.47	0.03	1	0.70	
Below knee amputation one leg.	45	0.51	0.04	44	0.45	0.04	2	0.45	0.20
Below knee amputation two legs	45	0.69	0.03	44	0.64	0.04	2	0.85	0.05
Blindness	45	0.64	0.03	45	0.56	0.05	1	0.69	
Bronchitis	45	0.35	0.03	45	0.29	0.04	2	0.39	0.13
Common cold	14	0.12	0.03	14	0.09	0.02	1	0.09	
Continuous moderate back pain	45	0.36	0.03	45	0.36	0.03	3	0.47	0.12
Infertility	45	0.37	0.04	45	0.41	0.04	1	0.60	
Mild hearing disorder	45	0.21	0.03	45	0.28	0.04	2	0.19	0.01
Mild tuberculosis with treatment	180	0.42	0.02	179	0.42	0.02	8	0.68	0.06
Moderate anaemia	15	0.29	0.06	15	0.20	0.04	2	0.28	0.00
Mild diabetes	180	0.29	0.02	179	0.26	0.02	8	0.50	0.08
Own health	180	0.03	0.01	179	0.05	0.01	7	0.11	0.02
Peptic ulcer	45	0.36	0.03	44	0.35	0.03	2	0.60	0.00
Pain and stiffness in joints	45	0.49	0.03	45	0.42	0.04	2	0.79	0.03
Quadriplegia	180	0.86	0.01	179	0.75	0.02	7	0.86	0.04
Severe hallucinatory fever	31	0.77	0.04	31	0.67	0.06	0		
Severe heart failure	45	0.73	0.03	45	0.65	0.05	3	0.75	0.13
Severe migraine	180	0.50	0.02	179	0.46	0.02	7	0.51	0.06
Schizophrenia	45	0.79	0.03	45	0.71	0.04	2	0.91	0.02
Two broken arms in cast	30	0.59	0.04	29	0.66	0.04			
Unipolar major depression	180	0.60	0.02	179	0.51	0.02	7	0.71	0.04
Urinary incontinence	45	0.50	0.03	45	0.41	0.04	2	0.79	0.01
Watery diarrhoea	180	0.25	0.01	179	0.27	0.02	8	0.44	0.08
White marks on face	45	0.24	0.03	45	0.26	0.04	2	0.41	0.17

Some researchers (for example, Torrance, 1976) have argued that the valuations obtained through VAS and TTO are not comparable. One hypothesis implied by Torrance (1976) is that the valuations from trade-off techniques reflect the true stimulus in the mind of the valuer. What we measure is the response of the valuer to his / her endogenous stimulus. We would then model such a relationship with a power function from stimulus response

theory in psycho physics[12]. If we assume that the VAS valuation is the response and trade-off valuation like the TTO is a more direct reflection of the endogenous stimulus in valuer's mind then the power function relating the two measurement can be written as; $DW_{VAS} = k\, DW_{TTO}^{b}$.

To test if the VAS and TTO valuations were different, we did a pair-wise difference of means test. The null hypothesis of no difference in means from VAS and TTO was rejected at 95% level confidence (p value = 0.0108). This gives credence to the view that the valuations from two methods are different. Hence we estimated parameters of the power function relating the two valuations. For this purpose, the power function described above can be linearised as $\ln(DW_{VAS}) = \ln(k) + b\ln(DW_{TTO})$. Ordinary least squares (OLS) estimation of this linearised model using data from this study, gives the model.

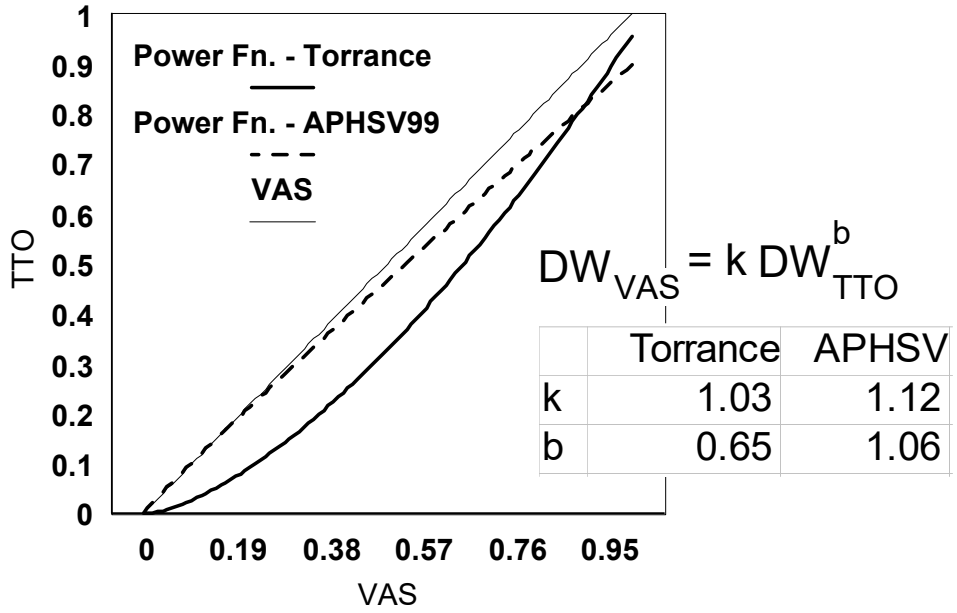
$$\ln(DW_{VAS}) = .1128692 + 1.063455\ln(DW_{TTO}).$$

Recovering k and b from the estimated model, we have the following equation to convert VAS valuations to a ratio scale; $DW_{TTO} = \left(\frac{DW_{VAS}}{k}\right)^{\frac{1}{b}} = \left(\frac{DW_{VAS}}{1.12}\right)^{\frac{1}{1.06}}$ where k = 1.12 and b = 1.06 (compare these with k=1.03 and b=0.65 obtained by Torrance, 1976). Although the model is statistically significant ($p<0.001$) and has a good fit (Adjusted R^2=0.95), the 95% confidence interval of the estimated parameter b is .9665101 to 1.160399 straddling one within it. Thus we can not reject the null hypothesis that the true value of b = 1.

Figure-6.7 shows the plots of TTO disability weights predicted from our VAS-based measurements using the model estimated by us from this study (made up of dashed line), and the model estimated by Torrance (thick continuous line). The thin straight line represents VAS measurements without any transformation. Clearly, we did not find differences between VAS and TTO measurements, to the extent observed by Torrance (19976) among the Canadian population.

[12] See McDowell and Newell, 1996 p15-18 for a brief summary of results from psycho physics about the power function in the context of health status measurement

Figure-6.7: Power function models of TTO from VAS: Torrance (1976) and APHSV99.



	Torrance	APHSV
k	1.03	1.12
b	0.65	1.06

Minimal differences between VAS and TTO based valuations found in this study could have more than one explanation. Firstly, it may be true that ordinal rank consistent VAS measurements of health state valuations are not very different from the TTO based valuations. Secondly, a design feature of this study might have blurred the differences between VAS and TTO based valuations. In the APHSV study, the TTO worksheets presented to each valuer had about 8 to 10 alternative durations of life in perfect health presented to the valuers. We did this to be more effective in communicating the time trade-off idea to the valuers. These alternatives had been calculated starting with say 95% of life expectancy at the age of onset and progressively decreasing to 5% of life expectancy at the age of onset of the concerned health state. One possibility might be that valuers did not consider a duration of healthy life beyond the lower and upper bounds contained in the worksheets. In such a case, relatively milder health states would be valued as worse, if the valuer did not consider to trade a duration of life less than 5% of the life expectancy at the age at onset. Severe conditions will be valued better, if the valuer did not consider trading a duration of life more than 95% of the life expectancy at age at onset. If this framing effect acted only predominantly for the milder conditions, then the TTO valuations have been

biased upwards. However, if such a framing effect did in fact operate, then we would not have any observations of disability weight less than 0.05 or more than 0.95. We filtered the MDHSV workshop data, by excluding the valuations for own health state, and all valuations where the disability weight from TTO valuations was in the range [0.05, 0.95]. After filtering these out, we get 8% valuations where the assigned disability weight was either less than 0.05 or more than 0.95 given by 40% of the total workshop valuers. Thus 40% of the valuers did in fact chose valuations outside the range suggested by the alternatives given in the worksheets. A little more than half of these (22%) valuers chose valuations giving disability weights as less than 0.05. Milder conditions like watery diarrhoea and mild diabetes received many such valuations. That would mean that the framing effect, if any, of the specific alternatives in the TTO worksheets was either non existent or minimal. Although the TTO valuations observed in this study are not very much lower than the disability weights given by VAS, the direction is similar to the model estimated by Torrance (1976).

Figure-6.8: Two way scatter plot of mean disability weights from TTO and VAS

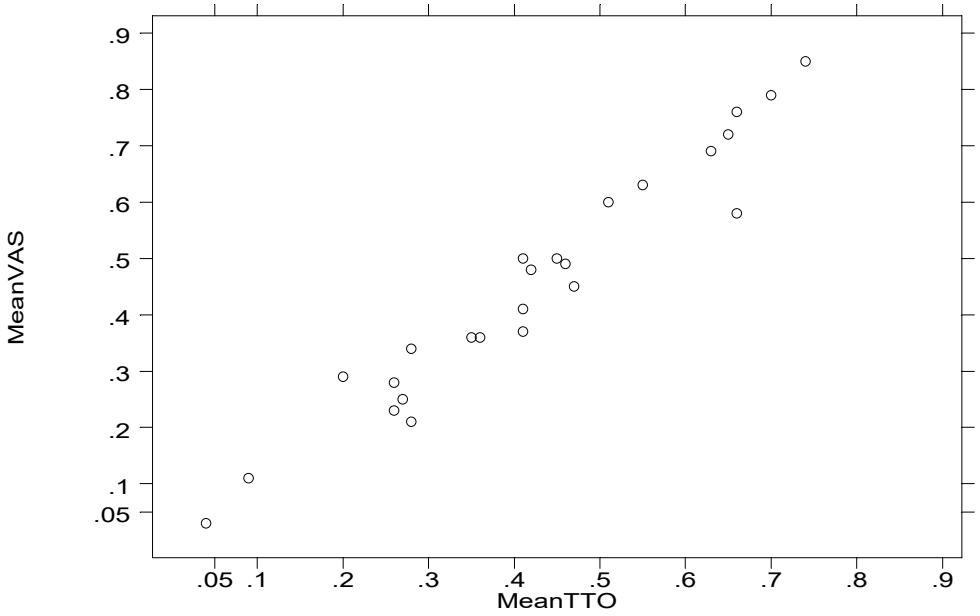


Figure-6.9: One-way scatter plot of mean disability weights for different health states obtained by visual scaling (VAS) and time trade-off (TTO).

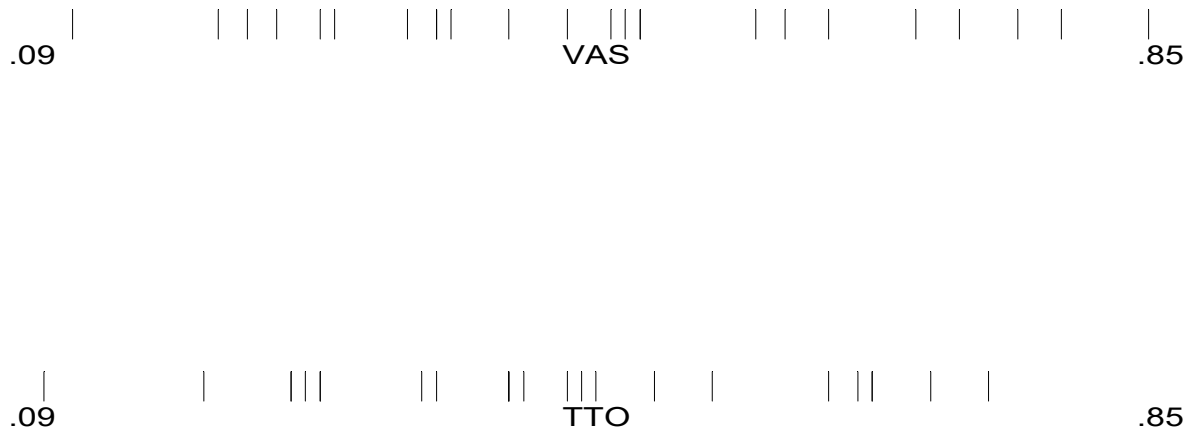
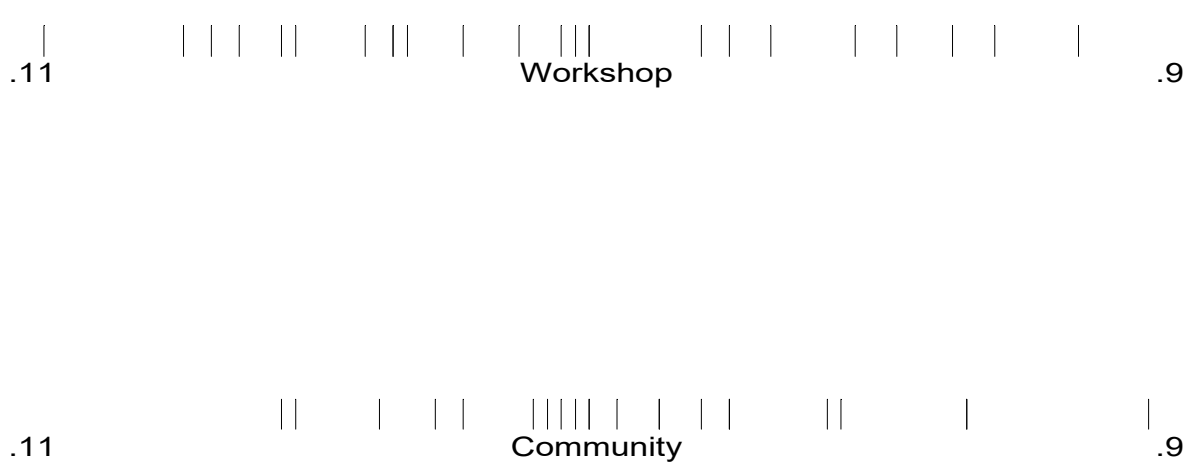


Figure-6.10: One-way scatter plot of mean disability weights for different health states obtained by visual scaling (VAS) from MDHSV Workshops and Community Survey



Another potential problem with rating scales is that the valuations may tend to cluster towards the midpoint of the scale or at both ends. Figure-6.8 shows a two-way plot of mean disability weights from TTO and VAS. Hardly any difference is visible in the spread of mean valuations across the full range of 0 to 1 scale. Differences in spread can be better appreciated with one-way plots shown in Figure-6.9. The upper plot shows spread of the VAS valuations and the lower one shows the same for TTO valuations. There is not much difference in the spread of valuations from two methods. If at all, the VAS valuations are slightly more spread out than the TTO valuations. So transforming the VAS valuations using the power function model described earlier would either leave the spread of VAS values as it were or marginally narrow it down. The spread of mean disability weights for different health states obtained from the community-based survey shrinks towards middle part of the scale (Figure-6.10). This could be due to real differences between valuations by the community and the participants in the workshops, and/or due to measurement error. This will have to be investigated further.

References:

Andrews F.M. and Withey S.B. Social indicators of well being: Americans' perceptions of life quality. New York: Plenum; 1976. Cited in McDowell and Newell, 1987, 1996 ibid.

Bass E.B.; Steinberg E.P.; Pitt H.A. and others. Comparison of the rating scale and the standard gamble in measuring patient preferences for outcomes of gallstone disease. Medical Decision Making. 1994; 14:307-314.

Berg Robert L. 1973. Establishing the value of various conditions of life for a health status index. in Health status indexes. Proceedings of a conference conducted by Health Services Research, Tucson Arizona, October 1-4, 1972. Chairman and Editor Berg Robert L. Chicago: Hospital Research and Educational Trust.

Bergner M., Bobbit R.A., Carter W.B., and others. 1981. The sickness impact profile: development and final revision of a health status measure. Medical Care 19:787-805.

Bergner M., Bobbit R.A., Kressel S., and others. 1976b. The sickness impact profile: conceptual formulation and methodology for the development of a health status measure. International Journal of Health Services 6:393-415.

Bergner M., Bobbit R.A., Pollard W.E., and others. 1976a. The sickness impact profile: validation of a health status measure. Medical Care 14:57-67.

Bleichrodt Han. 1997. Health utility indices and equity considerations. Journal of Health Economics 16:65-91.

Blischke W. R.; Bush J. W., and Kaplan R. M. Successive intervals analysis of preference measures in a health status index. Health Services Research. 1975; 10:181-198.

Carmines Edward G. and Zeller Richard A. Reliability and validity assessment. Beverly Hills, London, New Delhi: Sage publications; 1979; ISBN: 0-8039-1371-0.

Casella George & Berger Roger L. Statistical inference. Belmont, CA: Duxbury Press; 1990.

Chronbach L.J., Gleser G.C., Nanda H. and Rajaratnam N.; The dependability of behavioral measurements: Theory of generalizability for scores and profiles, Wiley New York, 1972, cited in Streiner and Norman (1995) and Shavelson and Webb (1991).

Cohen J. Weighted Kappa: Nominal scale agreement with provision for scaled disagreement or partial credit. Psychological Bulletin. 1968; 70:213-220.

Deyo RA; Diehr P, and patrick DL. Reproducibility and Responsiveness of Health Status Measures: Statistics and Strategies for Evaluation. Controlled Clinical Trials. 1991; 12:142S-158S.

Dolan Paul. Modeling valuations for EuroQol health states. Medical Care. 1997(11):1095-1108.

Dolan Paul; Gudex C.; Kind P., and Williams A. The time trade off method: results from a general population study. Health Economics(5):141-154.

Guilford J.P. 1954. Psychometric methods. New York: McGraw Hill; page 24. Cited in Patrick et al 1973.

Kaplan R. M. and Anderson J. P. A general health policy model: update and applications. Health Services Research. 1988; 23:203-235.

Kaplan R. M.; Bush J. W., and Berry C.C. Health Status Index: category rating versus magnitude estimation for measuring levels of well being. Medical Care. 1979; 17:501-523.

Kaplan R. M.; Bush J. W., and Berry C.C. Health status: types of validity and the index of well being. Health Services Research. 1976; 11:478-507.

Kaplan RM and Bush JW. Health-related quality of life measurement for evaluation of research and policy analysis. Health Psychology. 1982; 1:61-80.

Kaplan Robert M. Using quality of life information to set priorities in health policy. Social Indicators Research. 1994; 33:121-163.

Kleinman, A. 1987. Anthropology and Psychiatry: the role of culture in cross-cultural research on illness. British Journal of Psychiatry 151: 447-454.

Krabbe Paul M. The valuation of health outcomes. A contribution to the QALY approach. Rotterdam: Erasmus University Rotterdam, The Netherlands.; 1998 Jun.

Krabbe P. F. M., Essink-Bot M. L., Bonsel G. J. The comparability and reliability of five health state valuation methods. Social Science Medicine, Vol 45, No.11, pp.1641-1652. 1997.

Kramer M. S. and Feinstein A. R. Clinical biostatistics LIV. The biostatistics of concordance. Clinical Pharmacology and Therapeutics. 1981; 29:111-123.

Lenert L. A. and Hornberger J. C. 1996. Computer-assisted quality of life assessment for clinical trials. Proceedings of the AMIA Annual Fall Symposium, 922-996.

Lenert L.A. and Soetikno R.M. 1997. Automated Computer Interviews to Elicit Utilities: Potential Applications in the Treatment of Deep Venous Thrombosis. Journal of the American Medical Informatics Association, 4(1): 49-56.

Magdelaine M., Misrahi A., Rosch G.; Un Indicateur de la Morbidite Applique aux Donnees dune Enquete sur la Consommation Medicale; Consommation, Annales du CREDOC Centre de Recherches et de Documentation sur la Consommation, 2, 3-41; cited by Rosser (1983).

Mahapatra Prasanta, Salomon Josh, Nanda Lipika, and Rajashree, KT; Measuring Health State Values in Developing Countries: Report of a study in Andhra Pradesh, India; Institute of Health Systems, HACA Bhavan, Hyderabad, AP 500004, India, Report.

Murray Christopher J. L.; 1996. Rethinking DALYs. in The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Editors Murray Christopher J. L., and Lopez Alan D. Boston: Harvard School of Public Health.

Murray Christopher J.L. and Lopez Alan D; The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Boston: Harvard School of Public Health; 1996.

Nelson EC; Wasson J.; Kirk J and others. Assessment of function in routine clinical practice: description of the COOP chart method and preliminary findings. Journal of Chronic Diseases. 1987; 40 (Suppl 1):55S-63S, cited in McDowell and Newell, 1987, 1996 ibid.

Packer A.H. Applying cost-effectiveness concepts to the community health system. Operations Research. 1968; 16:227-253.

Pennifer Erickson, Kendall Allen, Anderson John P., and Kaplan Robert M. 1989. Using composite health status measures to assess the Nation's health. Medical Care 27, no. 3 Supplement: S66-S76.

Rosser Rachel. Issues of measurement in the design of health indicators: a review. in: Culyer A.J., Editor. Health indicators. An international study for the European Science Foundation. Oxford: Martin Robertson; 1983; pp. 34-81.

Shavelson Richard J. and Webb Noreen M. Generalizability theory: A primer. Newburry Park / London / New Delhi: Sage Publications; 1991.

Shibuya Kenji; Quantifying the economic impact and health consequences of disease: implications for studies on smoking, unpublished thesis Harvard University School of Public Health, Boston, MA USA, 1999.

Specter Paul E. 1992. Summated rating scale construction. An introduction. Newburry Park, London, New Delhi: Sage.

Streiner, D. L. & Norman G. R. 1995. Health Measurement Scales: A Practical Guide to their Development and use. New York: Oxford University Press.

Torgerson W.S. 1958. Theory and methods of scaling. New York: John Wiley; page 141. Cited in Patrick et al 1973.

Torrance George W. Social preference for health states: an empirical evaluation of three measurement techniques. Socio-Economic Planning Sciences. 1976; 10:129-136.

Torrance George W., Thomas Warren H., and Sackett David L. 1972. A utility maximization model for evaluation of health care programs. Health Services Research 7: 118-33.

Trotter, R.T., Ustun, B., Chatterji, S., Rehm, J., Room, R., Kennedy, C., Saxena, S., 1999. Cross-Cultural Applicability research on Disablement: Models, Methods and Contribution to Revision of the International Classification, Human Organization.

Van Agt H.M.; Essink-Bot M.L., and Krabbe P.F.M. Test-retest reliability of health state valuations collected with EuroQol questionnaire. Social Science and Medicine. 1994; 39(11): 1537-1544.

Von Neumann J. and O. Morgenstern; 1944; Theory of games and economic behavior.; Princeton, New Jersey: Princeton University Press.

Wagstaff A. 1991. QALYs and the equity-efficiency tradeoff. Journal of Health Economics 10: 21-41.

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Chapter-7:

Results from the Community Survey in Andhra Pradesh to Measure Health State Valuations.

The methodological aspects of the Andhra Pradesh Health State Valuation study 1999 (APHSV99), reliability, and validity of these measurements were described in chapters 2-6. To recapitulate, the study consisted of two arms, namely (a) multiple method deliberative health state valuation (MDHSV) workshops, and (b) community based measurement of health state valuations through household survey of Kondakkal village in Andhra Pradesh. A six-dimension five-level (6D5L) system was used to describe health states to valuers. The 6D5L description system was built by expanding upon the EuroQol five dimension three level system. Cognition was added as the sixth dimension. Severity levels were described in five categories. In addition, the 6D5L system includes a graphic description system to communicate with partially literate and illiterate valuers. The MDHSV workshops, and test or retest valuations by 100 respondents in the community survey provided data required to estimate reliability and validity of the measurements. The socio-demographic profile of the valuers in both arms of the study was also described earlier. Participants for the MDHSV workshops were urban professionals recruited by convenience, although efforts were made to broadbase their professional backgrounds. The sample for the community survey is randomly drawn from the voters list, with balanced representation of males and females and adults in all age groups. In this chapter, results from the community survey are presented and discussed. Findings of the APHSV99 study are summarised. We start with an examination of the distribution of valuations by the community for different health states. In the second section, disability weights obtained from this (APHSV99) study with results from other studies in the world are compared. The next section deals with operational issues of how to incorporate local health state valuation into National Burden of Disease (NBD) estimate. Then a few future research needs for health state valuation, based on our experience in this study and unresolved issues are discussed. The fifth and final section presents the summary and conclusions from the health state valuation study.

Distribution of valuations for different health states:

The distribution of disability weights, as measured through the community survey, was plotted for each health state. The following three pages, show these plots for 22 health states in Figures-7.1-3. The X - axis in all these plots is the disability weight obtained through VAS. The Y - axis is the fraction of total valuations for the respective health state. The total number of valuations range from 230 - 280 for most health states, except for the core conditions. The reader may recall that the core conditions, namely watery diarrhoea, mild diabetes, mild tuberculosis, severe continuous migraine, unipolar major depression and quadriplegia, were included in all sets of health states. So the total number of valuations for these six core health states is around 1010 each. One characteristic that stands out for most health states valued in this study is that the distributions are unimodal. A few health states, like continuous moderate back pain and severe heart failure show a bimodal distribution. The two modes in these cases are close to each other. Unimodal distributions for most health states would suggest that members of the community do share some commonality in the valuation of health states. This is important for measurement of population health status. Without any consensus on valuations to be assigned to different health states, it would be impossible to combine non-fatal health outcomes into a measure of population health status.

However, the crystallisation of the valuations for different health states clearly vary. The distribution plots in Figures-7.1-3 have been arranged on the basis of the extent of diffuseness and clarification of valuations for different health states, and labelled as Group A, B, C respectively for identification (Table-7.1). The classification is based on a visual examination of the frequency plots for each health state and hence is subjective. As we gather more experience from examination of health state valuation distributions, it will be useful to develop objective criteria for the classification. For example, we have used size of tallest frequency bin as a criteria to aid our judgement. The valuations for Group A health states in Figure-7.2 are all quite diffused. The tallest frequency bin is about 0.2 or less. Take, for example, the distribution of disability weights for infertility. The valuation for infertility appears to be distributed more or less uniformly between 0 to 0.7 and tapers off thereafter. This tells us that most people would not consider infertility to be worse than, say 0.7. But within the broad range of (0, 0.7), opinions vary a Lot.

Figure - 7.1 Distribution of disability weights. Group - A health states.

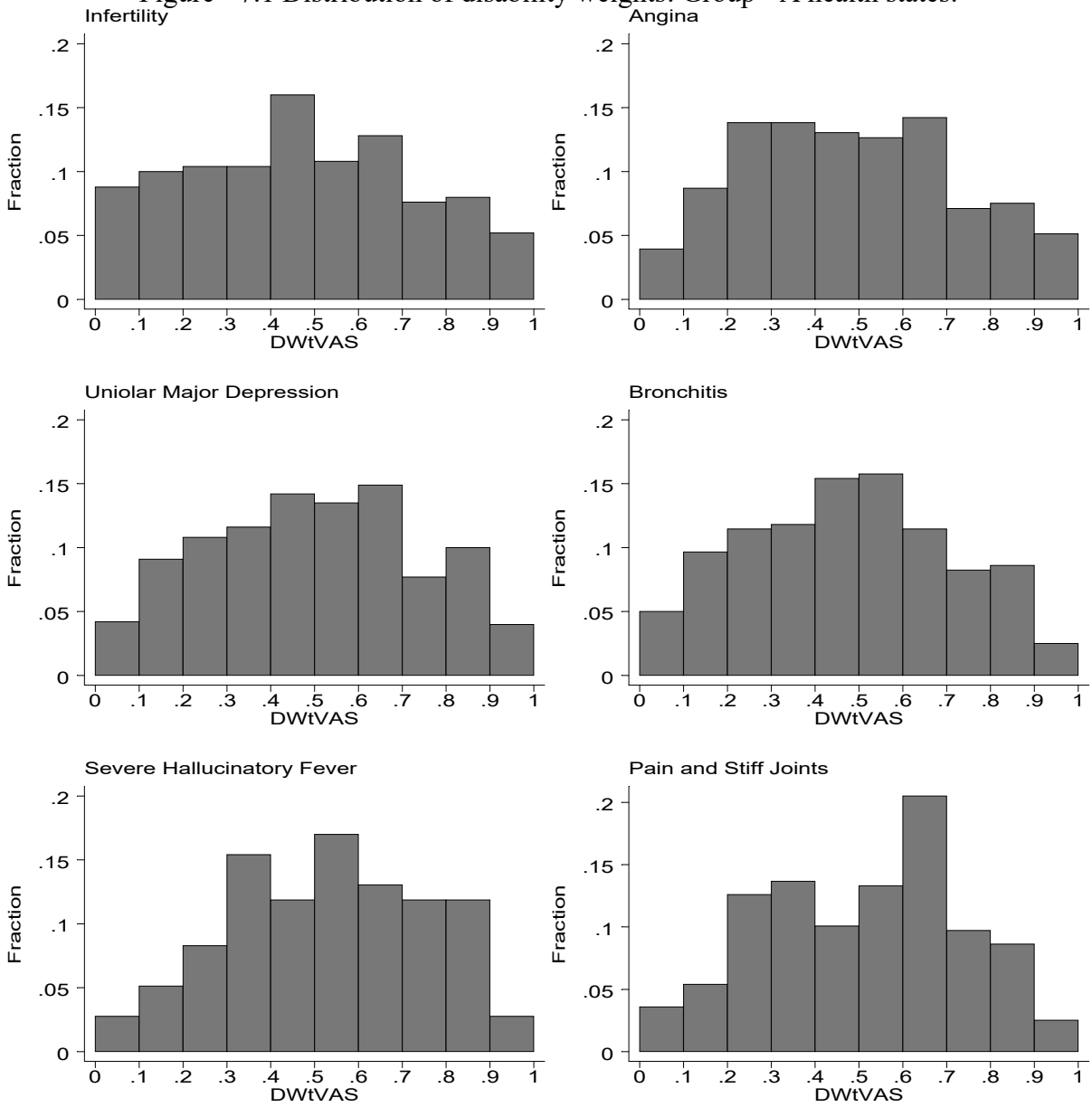
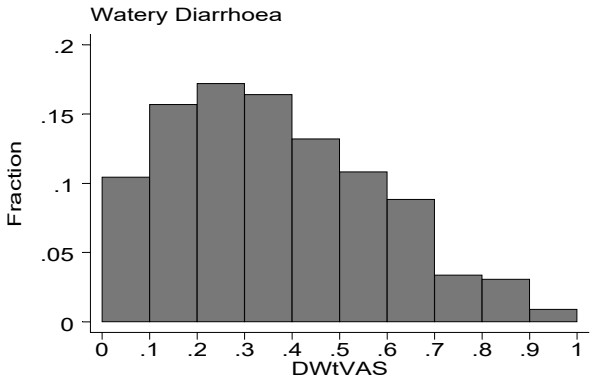


Figure - 7.2 Distribution of disability weights. Group - B health states.


Watery Diarrhoea
Fraction
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.05
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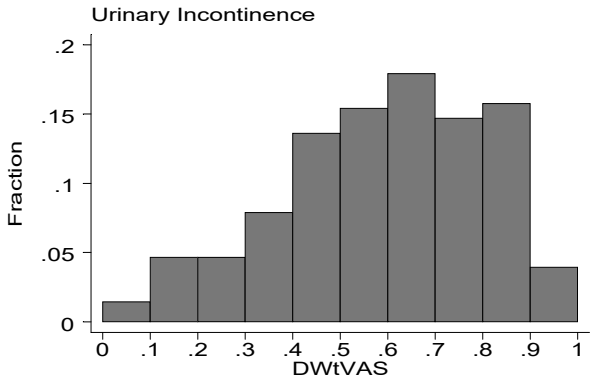
.15
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Urinary Incontinence
Fraction
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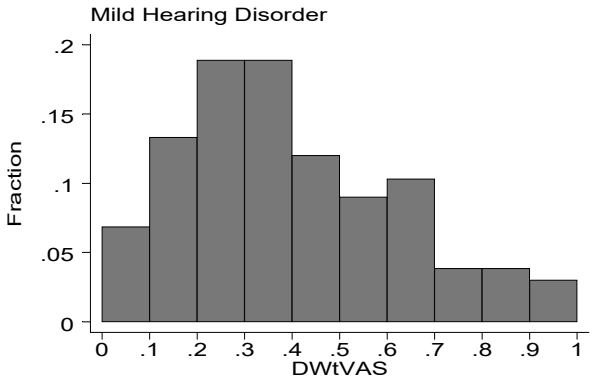
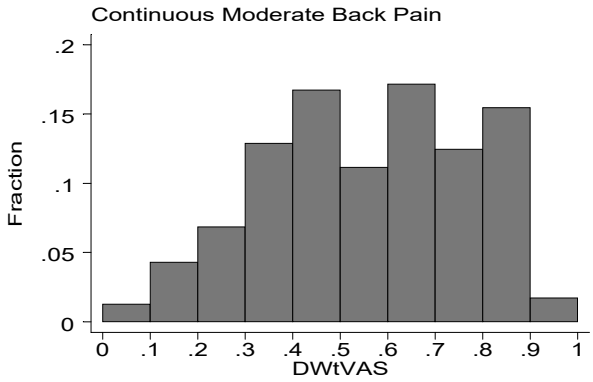
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Mild Hearing Disorder
Fraction
0
.05
.1
.15
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Continuous Moderate Back Pain
Fraction
0
.05
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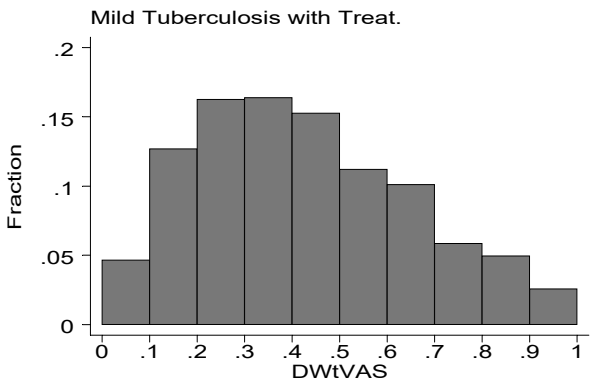
.15
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Mild Tuberculosis with Treat.
Fraction
0
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.1
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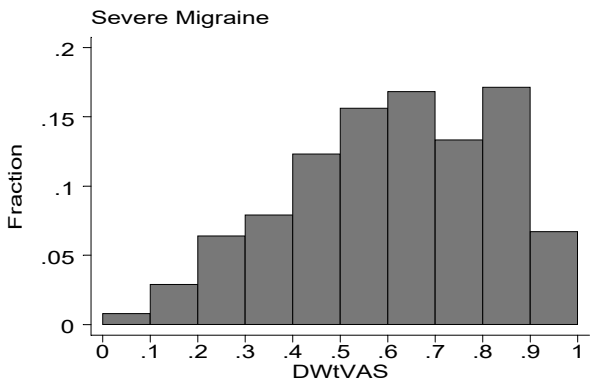
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Severe Migraine
Fraction
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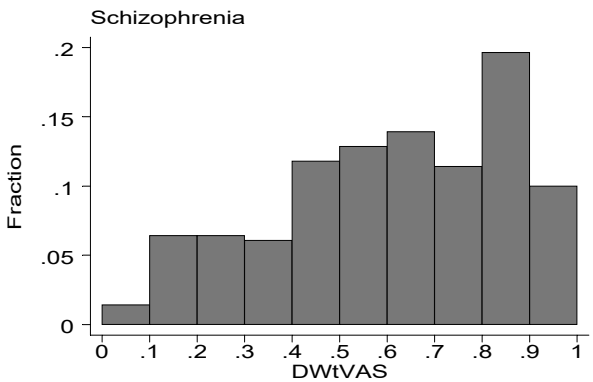
.05
.1
.15
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Schizophrenia
Fraction
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.05
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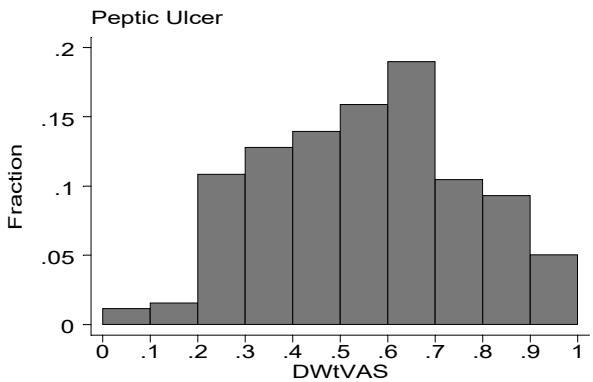
.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS


Peptic Ulcer
Fraction
0
.05
.1
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.2
0 .1 .2 .3 .4 .5 .6 .7 .8 .9 1
DWtVAS

Figure - 7.3 Distribution of disability weights. Group - C health states.

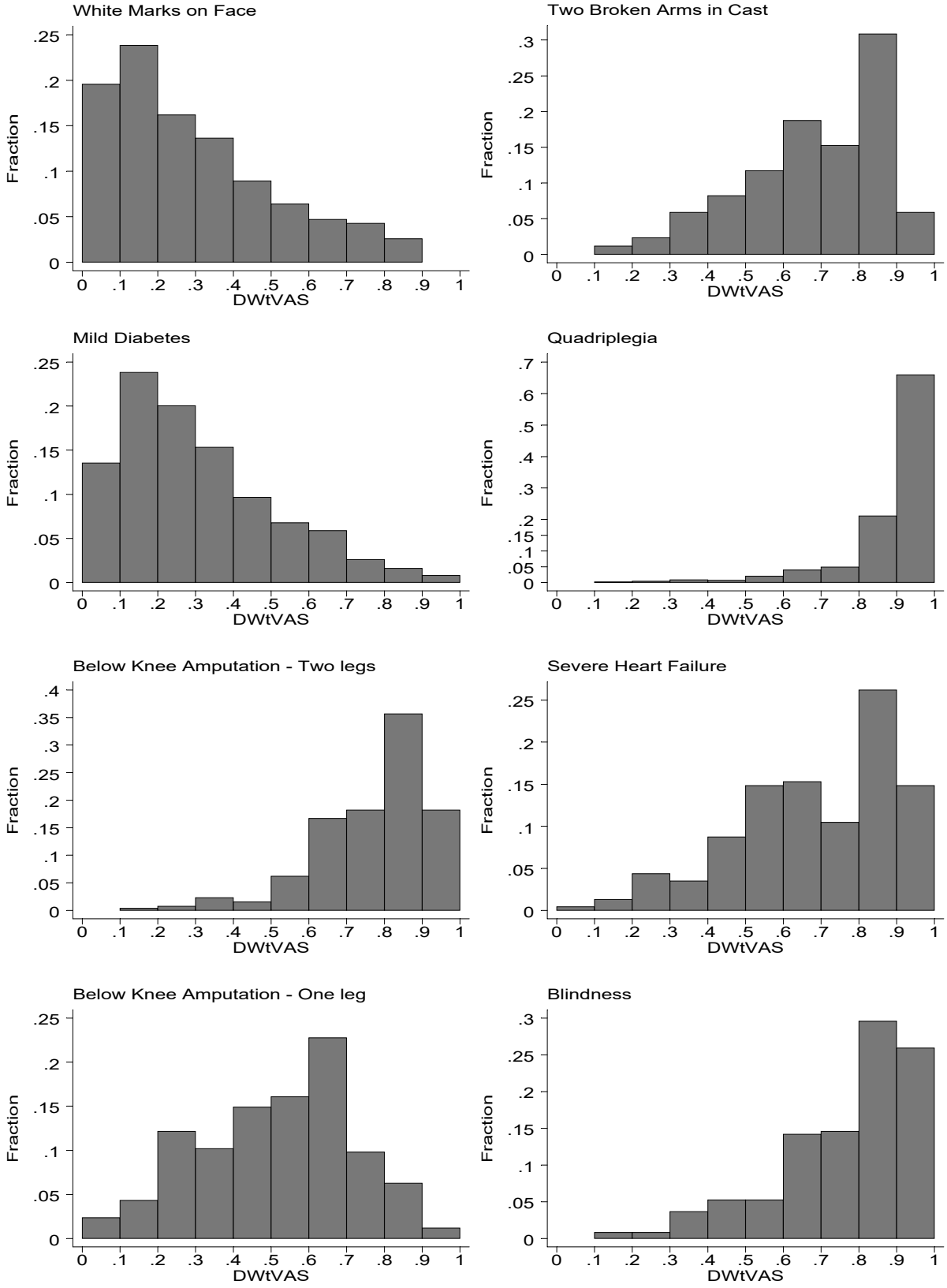


Table-7.1 Classification of health states by degree of crystallisation of community valuations

Group A: Diffused	Group B: Intermediate	Group C: More crystallised
Infertility	Watery diarrhoea	White marks on face
Angina	Urinary incontinence	Two broken arms in cast
Unipolar major depression	Mild hearing disorder	Mild diabetes
Bronchitis	Continuous moderate back pain	Quadriplegia
Severe hallucinatory fever	Mild TB with treatment	Below knee amputation- two legs
Pain and stiffness in joints	Sever continuous migraine	Severe heart failure
	Schizophrenia	Below knee amputation - one leg
	Peptic ulcer	Blindness

The eight health states organised into group B show less diffused and more crystallised valuations. The tallest frequency bin for all these plots is about 0.2 or less, i.e., same as in case of group A. However, the distributions are less diffuse and show increasing mass around the peaks. The Group C plots in Figure-7.3 show more peaked distributions, usually skewed to the right or left, depending on whether the health state concerned has low or high disability attached to it. For example, the distribution for quadriplegia has concentrated disability weights in the range (0.9, 1). The distribution for quadriplegia is unique in the sense that the fraction of valuations in the tallest bin is about 0.7, i.e. 70% valuers valued disability due to quadriplegia in the range (.9,1). The fraction of valuations in the tallest bin, for all other health states included in group C is in the range of (0.25, 0.4).

The differences in the degree of crystallisation of valuations in the community are consistent with our hypothesis about the nature of health state valuation process described earlier. Individual level valuations defined in fuzzy sets with different degrees of clarification would explain different degrees of crystallisation of the distributions at the community level. The degree of crystallisation of valuation in the community for different health states has important implications for NBD estimation. The range of disability weight inputs for each of the health states included in the sensitivity analysis should depend on distribution of the valuation in the community. Health states with diffused valuations would call for a wider range of disability weight inputs. For the health states with crystallised valuations in the community, a narrower range would suffice. Parametric[13] description of the distributions

[13] We conjecture is that the sub family of unimodal beta distributions $(\alpha > 1, \beta > 1)$ may serve well to describe distribution of health state valuations. Further work is needed to examine goodness of fit, estimate the distributions and study factors that may contribute to differences in the distribution of health state values. For a description of the family of beta distributions, see Cassela and Berger (1990, p107-110).

should facilitate uncertainty analysis of NBD estimates, and will enable further analysis to improve our understanding of what contributes to diffuseness and crystallisation of community valuation of health states.

Comparison with Disability Weights Reported by Other Studies:

The GBD96 study generated a set of disability weights for the global burden of disease estimates (Murray and Lopez, 1996), referred here as the GBD96 disability weights. More recently a group in Netherlands have elicited a set of disability weights (Stouthard and others, 1997). These are commonly referred to as the Dutch disability weights. The Dutch study used PTO and VAS valuation methods. All 38 valuers were urban professionals. Most of them were from medical and health background and some from other areas.

Table-7.2: Comparative statement of mean disability weights from different studies.

Health state	This study			GBD96	Dutch study	
	6D5L	Wkshp	Survey		6D5L	Mean
Angina	111321	0.460	0.480	0.227	111121	0.080
Below knee amputation one leg.	322211	0.510	0.510	0.300		
Below knee amputation two legs	433221	0.690	0.780			
Blindness	323122	0.640	0.770	0.600	123121	0.430
Bronchitis	112311	0.350	0.470	0.099	112211	0.170
Common cold	112211	0.120		0.000	111211	0.020
Continuous moderate back pain	212321	0.360	0.550		212211	0.060
Infertility	111131	0.370	0.460	0.180		0.110
Mild hearing disorder	112211	0.210	0.390		112111	0.110
Mild tuberculosis with treatment	111221	0.420	0.420	0.264	112211(40%) 222221(60%)	0.290
Moderate anaemia	112121	0.290		0.011		
Mild diabetes	111121	0.290	0.300	0.012	111111(90%) 112221(10%)	0.070
Peptic ulcer	112321	0.360	0.550	0.115	111111(20%) 111211(60%) 112211(10%) 112221(10%)	0.020
Pain and stiffness in joints	222331	0.490	0.510	0.233	122211	0.210
Quadriplegia	554341	0.860	0.900	0.895	332111(70%) 333221(30%)	0.840
Severe hallucinatory fever	444333	0.770	0.530			
Severe heart failure	434531	0.730	0.690	0.323	223321	0.650
Severe migraine	113431	0.500	0.600	0.738		
Schizophrenia	234244	0.790	0.610	0.627-0.667	222223	0.810
Two broken arms in cast	154321	0.590	0.680	0.137-0.180		
Unipolar major depression	124142	0.600	0.490	0.600	223232	0.760
Urinary incontinence	113331	0.500	0.590			
Watery diarrhoea	111211	0.250	0.360	0.086-0.119		
White marks on face	111131	0.240	0.290	0.020		

[1] Following mappings are used for comparisons with GBD96 disability weights: Bronchitis Ë Lower respiratory infection - chronic sequela, Common cold Ë Upper respiratory infections - episodes, Below knee amputation - one leg Ë Amputations leg, Mild tuberculosis Ë Tuberculosis HIV zero negative cases age 15-44, Mild diabetes Ë Diabetes cases, Severe heart failure Ë Congestive heart failure,

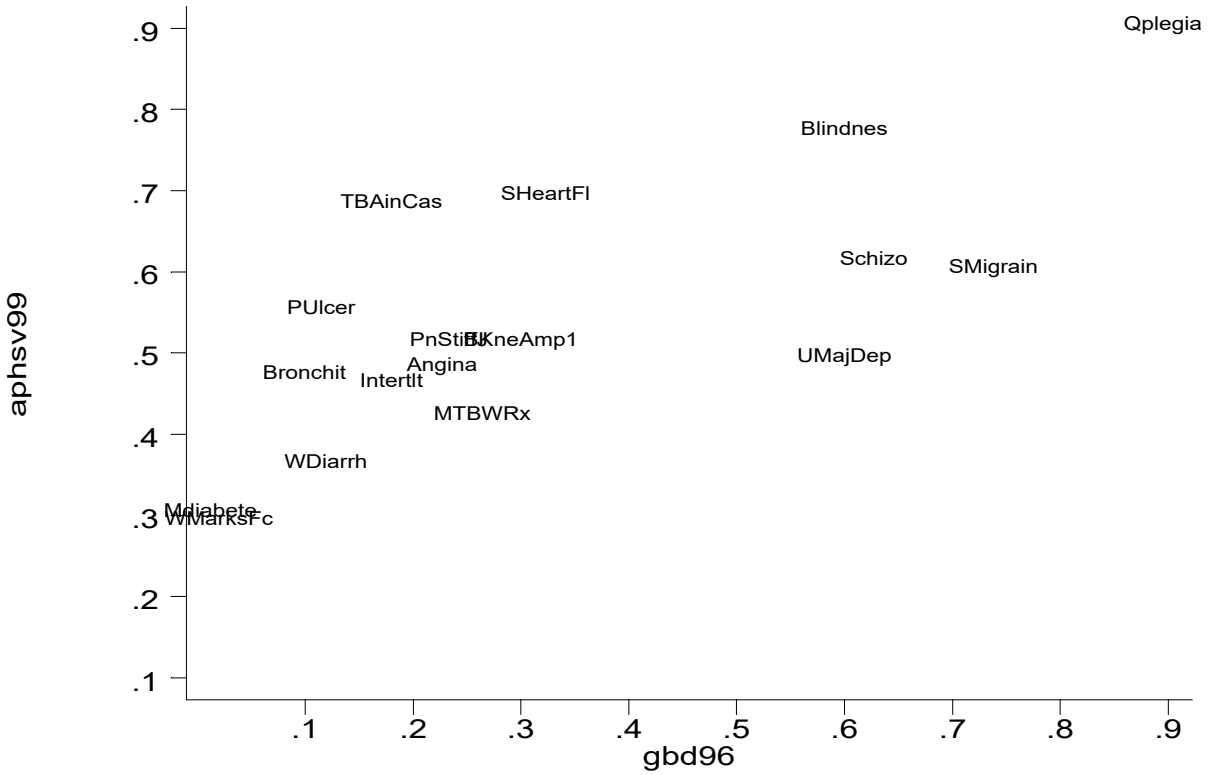
Table-7.2 shows the disability weights obtained by this study from the MDHSV workshops and community-based survey along with 6D5L profiles of the health states. In addition, the GBD96 weights and Dutch disability weights are indicated for the closest comparable conditions. For the Dutch disability weights, the 6D3L profiles are also shown. Actually the authors (Stouthard and others, 1997) named this as the EQ5D+ profile. The

profile consists of six dimensions as in this study but has three severity levels instead of the five levels in this study[14]. We have substituted EQ5D+ with 6D3L to reflect the similarity and differences between profiles from the two studies.

The GBD96 and Dutch disability weights are quite similar to each other. They differ from the weights obtained in this study (APHSV99) by a fairly wide margin in most cases. Figure-7.4 shows the scattered plot of GBD96 weights versus the weights obtained by this study. At first sight, the APHSV99 disability weights appear to be a linear function of the GBD96 weights, with the former giving higher disability weights to most health states. In other words, the community in Andhra Pradesh effectively adds a fixed disability weight of about 0.3 to the valuations obtained by the GBD96. But there are some exceptions. In lower end of the disability scale (0.1,0.4), a few health states are given much higher disability weight by the APHSV99 study than what a linear function would predict. Such as , bronchitis, two broken arms in cast, peptic ulcer, and severe heart failure for instance. In the upper end of the scale, the gap in the two valuations is relatively smaller. Unfortunately there are not many common estimates in the middle range disability weight around 0.5. If we assume that the valuations from two studies, in the mid- range would be more similar and closer to each other, then the relationship of the two estimations would be sigmoid. In lower range, APHSV99 weights would be much higher, followed by a flattening of the curve in middle ranges and higher weights by APHSV99 again in the upper ranges.

[14] Also note that the Dutch study has labelled their results as disability weights but has in fact provided health state weights. So their weights were transformed to disability scale (disability weight = 1- health state weight) for purposes of this comparison.

Figure-7.4 Scatter plot of GBD96 disability weights versus APHSV weights



One reason why the APHSV99 disability weights appear higher could be due to the fact that these are essentially VAS measurements. Although, we did not find much difference in magnitude of the VAS and TTO weights in this study, we cannot rule out the possibility that the VAS response is overestimating true disability weights for milder conditions. To see how APHSV99 weights compare with VAS measurements elsewhere, we obtained results from a health state valuation study among public health professionals using VAS. These valuations were done in the Burden of Disease and Cost-effectiveness workshop held at Lorne, Australia in November, 1999. Let's call this the BODWorkshop99-VAS weights. Figure-7.5 shows a scatter plot of APHSV99-VAS weights and BODWorkshop99-VAS weights. Data for nine health states, common to both studies, is used. Clearly, the APHSV99-VAS weights are higher by about 0.1 for all the nine health states.

Figure-7.5 Mean VAS disability weights from APHSV study and BoD workshop 1999

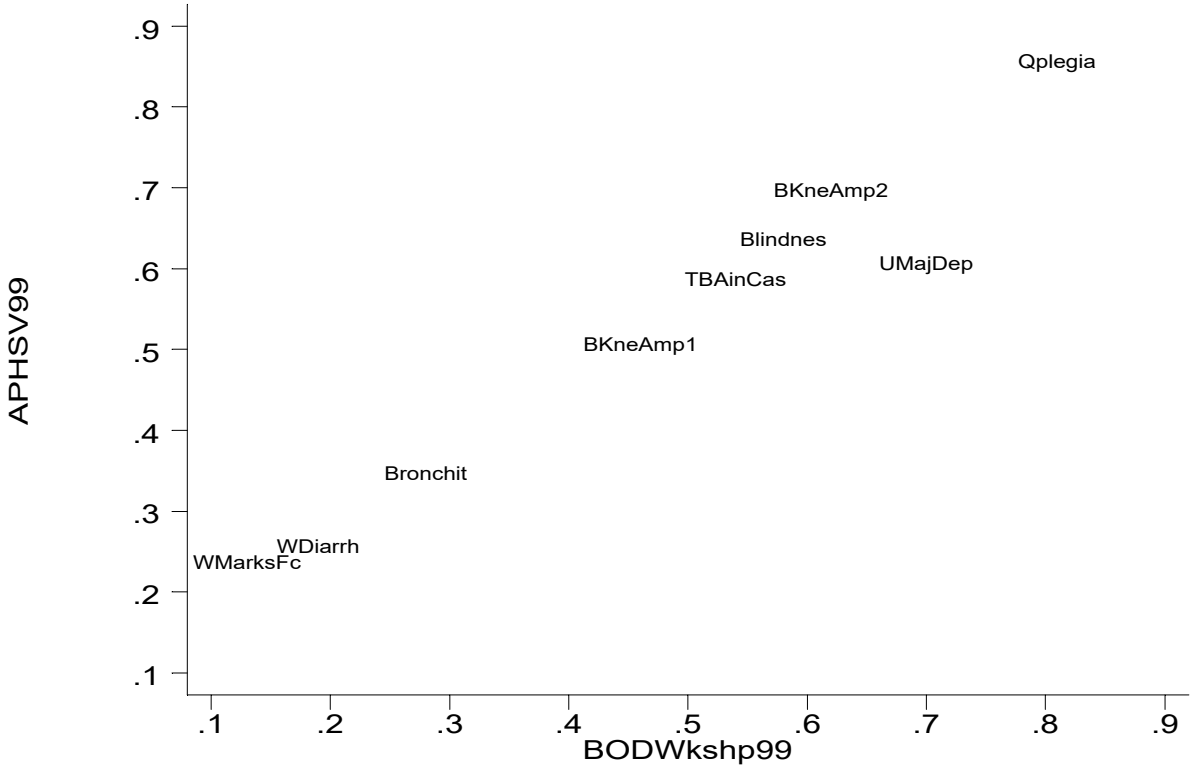


Table-7.3: Mean VAS disability weights from APHSV99 and Dutch health state valuation study 1997

Health State	Dutch Study 1997		APHSV99	
	6D3L	Disab. Wt	6D5L	Disab. Wt
Angina	111211	0.16	111321	0.46
Blindness	123121	0.38	323122	0.64
Back pain	212211	0.13	212321	0.36
Mild diabetes	112221	0.12	111121	0.29
Pain and Stiff Joints	222331	0.70	222331	0.49

In Table-7.3 we compare the APHSV99-VAS disability weights with the Dutch disability weights for five indicator conditions found to be common to both the studies. Table-7.3 shows the mean disability weights from these two studies, as well as the 6D3L (in case of the Dutch study) and 6D5L (for APHSV99) descriptions. For four out of five conditions APHSV99-VAS weights are higher than the corresponding Dutch study weights. The difference is 0.17 for mild diabetes and more than 0.2 for the remaining three conditions.

In case of pain and stiffness of joints (rheumatoid arthritis) the Dutch study weight is higher. This exception can be explained by the fact that the Dutch study valued severe rheumatoid arthritis and the APHSV study used a less severe description of pain and stiffness of joints. Overall, APHSV99-VAS disability weights appear to be higher than the Dutch disability weights by about 0.2.

It is worth while to ponder, what could be reason for higher disability weights assigned by the community in the APHSV99 study? Firstly, we can not rule out measurement error altogether. Further improvements in description of the health states may increase the spread of valuations toward endpoints of the scale, particularly in the low disability direction. Secondly, differences in method of valuation would explain a part of the difference between the APHSV99 weights and GBD96 weights. Thirdly, real differences in valuations by the community from the valuations given by the public health experts in the GBD96 group of valuers is also plausible. We have seen that the VAS valuations by the community in AP are higher than the VAS valuations by urban professionals in the Dutch study and public health experts in the Burden of Disease workshop 1999. One possible explanation is that the community in AP views any disruption in perfect health as substantial deterioration. If we suppose the community in Andhra Pradesh views any deviation from perfect health more seriously, such that a fixed disability weight is attached to the binary states of perfect health versus illness. In that case, the disability weight assigned by the community to a specific illness will be a combination of the fixed disability weight for the state of any illness plus the additional disability specific to the concerned health state. Based on the comparisons of APHSV99 data with results from other studies, we conjecture that the size of the fixed disability weight may be any where between 0.1 to 0.3. However, each of the above possibilities and other unknown factors need to be investigated further, for us to have a more define opinion about the determinants of differences in valuation of health states by different persons and at different sites.

Incorporating Local Health State Valuation into NBD Estimate:

How do we integrate the findings from the local health state valuation studies into the NBD estimation? We could use the local values directly as inputs for the computation of the YLD component, if we have valuations for all disabling sequela of the health states included in the NBD study. Two possibilities, in the absence of direct measurements for all disabling sequela, would be:

1. To identify 6D5L profile for all disabling sequela. Statistically predict the disability weights for all disabling sequela using the data from local community valuations.
2. To use the GBD96 system of disability weights with appropriate modifications to account for local differences in the valuation of health states.

A procedure for identification of 6D5L profile for health states has been described earlier. We used this process to identify 6D5L profile for the index health states. One option would have been to continue with that process and identify 6D5L profiles for all disabling sequela. Using health state valuations for the index states, we can thus statistically estimate a bridging model to predict the disability weight for every 6D5L profile. See for example Dolan (1997) where data for estimation of the bridge model has been collected. However, identification of 6D5L profiles for all disabling sequela could not be pursued, mainly due to lack of funding. However, further studies are planned for identification of 6D5L profiles and further analysis of data collected in this study.

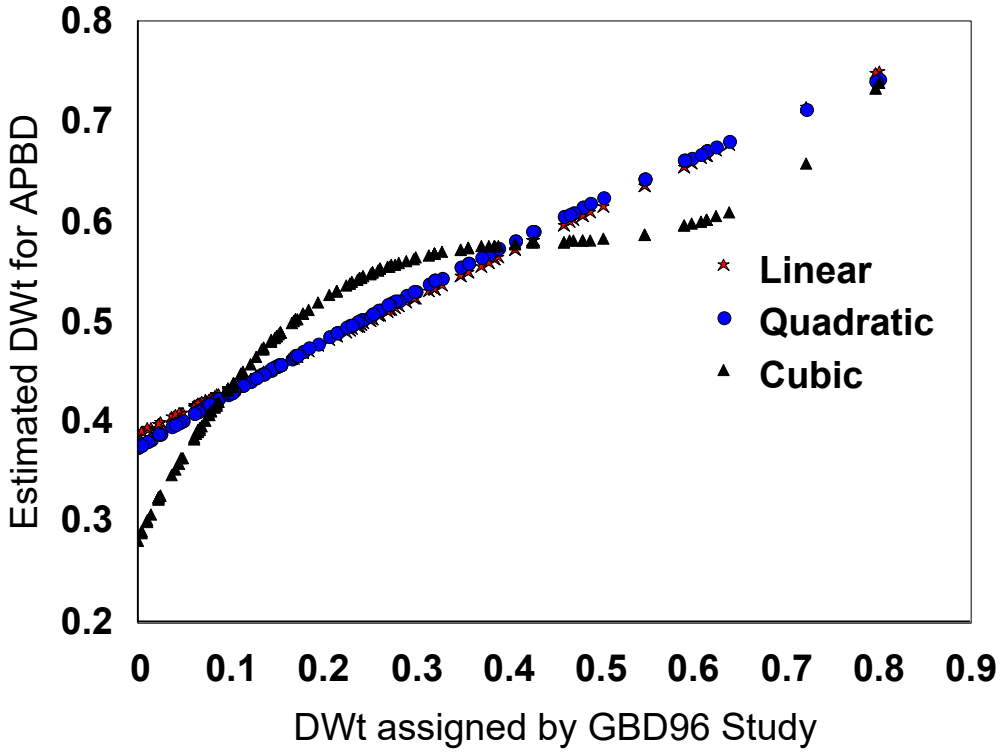
In the meanwhile, I follow the second option, to estimate disability weights for the AP Burden of Disease Estimate, using the GBD96 system of disability weights. Two sets of disability weights are estimated. These are: (a) APHSV99-VAS weights, and (b) APHSV99-Torrance-TTO weights. The APHSV99-VAS weights are based on the mean disability weights obtained from the community survey in Kondakkal village. The APHSV99-Torrance-TTO weights are a transformation of the APHSV99-VAS weights through the power function estimated by Torrance (1976) modeling the relationship of VAS and TTO valuations. For the APHSV99-VAS weights, the following three models were fitted to the 17 matching pairs of mean disability weights from the APHSV99 and GBD96 studies. The GBD96 system of disability weights describe weights by age and sex. For most sequela, the weights are similar across age sex groups. Hence, disability weights for the adult females

in age group 15-44 were taken from the GBD96 study to estimate the relationship with APHSV weights.

Model	Adjusted R2
$DWt^{AP} = 0.3878 + 0.4514G$	0.52
$DWt^{AP} = 0.375 + 0.5547G - .1214G^2$	0.49
$DWt^{AP} = 0.28 + 1.925G - 4.214G^2 + 3.144G^3$	0.59

Figure-7.6 compares plots of predicted values from the three models. The linear and quadratic functions are similar in terms of the projected estimates. The cubic model appears to fit the two data slightly better. This model has a comparatively higher adjusted R2. I have used this function to project disability weights of all sequela to estimate the burden of disease in Andhra Pradesh. The projected weights have not been provided, since they can be computed from the weights published by Murray and Lopez (1996, p412-416).

Figure-7.6 APHSV99-VAS weights for AP versus GBD96 weights



Future Research Needs for Health State Valuation:

More extensive research is required if community-based measurements of health state valuations are to be used in summary measures of population health status. Apropos, the nature of the valuation function and its characteristics for different health states, we have seen, from test and retest data, that ordinal rankings are not consistent with conventional notion that the individual has a single valued function. Conventional economic theory of well-ordered preferences assumes that an individual has a clear pair wise ordering of alternatives. Our observations in this study suggests that the valuation in a person's mind for a given health state may be a multivalued function. The range of values over which the valuation function is defined is a function of the health state and the extent of cumulative deliberations by the individual. This hypothesis needs to be tested through more studies. There are two research questions here: whether the health state valuation functions are multivalued or single valued and if the health state valuation function is indeed multivalued, which factors determine the range of values (i.e. the image space) it can assume. The incidence/prevalence of the health state, associated taboo, severity level, health state description system, and deliberations by the individual are some factors worth exploring . The extent to which a person has deliberated about a health state may affects the size of the health state valuation image space. Our conjecture is that, upto some point, increased opportunity for deliberations about the value of a health state would narrow down the health state valuation image space. This has important implications for the methodology to be adopted for community measurement of health state valuations. If increased opportunity for deliberations do indeed lead to narrowing of the health state valuation image space, then repeated measurements accompanied by an opportunity for deliberation and reflections on the concerned health state would improve the reliability of measurements. If there are no such relationships, then a larger sample size may be the only means to improve reliability of health state valuation measurements from a community.

So far health state valuation studies have used a set of indicator conditions to obtain valuations from a community and have used various interpolation strategies to assign disability weights to other health states. Such interpolated values are estimates of mean health state values that might have been measured from the community. This study has clearly brought out the reference that health states vary in the extent to which community has

crystallised valuations for it. The extent to which community valuations for a health state is diffused or crystallised has important implications for its use in summary measures of population health status. The mean disability weight may be adequate enough for health states with crystallised community valuations. In case community valuation for a health state is diffused, the mean does not have much significance as an input for summary measures of population health state. For such health states, either an uncertainty analysis by multiple simulations or a sensitivity analysis giving endpoint values from the range of valuations would be desirable. In other words, the distribution of valuations in the community is of as much importance as the estimated mean of health state valuations. It is difficult to predict the distribution of all health states from the distribution of indicator conditions. Hence, future research will have to directly measure valuation by communities for all health states. Operationalising such measurements in single studies may be difficult. But appropriate strategies can be found out once we are clear of the need for direct measurements from communities for as many health states as is possible.

Thirdly, more research is required to study the efficacy of health state description systems in reliably communicating the same state to all individuals. This line of research will be more culture-specific. Two areas need attention: the semantic content of statements used to describe the severity levels along each dimension and the validity and reliability of the graphical description system. In this study we have developed a graphical description system. The graphics were chosen from out of about five to six alternatives, by showing the pictures to a convenience sample of persons. It will be useful to study more formally the validity and reliability of the graphical description system in communicating a given health state. Such research projects should include plans for further refinement of the graphics. These studies are important for measurement of health state values in partially literate, as well as multicultural communities. Once we know enough about semantically equivalent statements of severity levels and have equivalent graphics, it should be possible to develop multimedia description systems.

Finally, more studies are required about the nature of relationship between different measurement methods. For example, the VAS and TTO valuations in the study was found to be similar. This is different from earlier findings that TTO generally gives lower disability weights for milder conditions, compared to VAS. Future studies should carefully document

details of measurement techniques, measurement context, interviewer and valuer characteristics, so that factors contributing to differences in valuations between the two methods and between sites can be identified.

Summary and Conclusions from the AP Health State Valuation study, 1999 (APHSV99):

An important contribution of this study is the advancement of methodological aspects of health state valuation in developing country communities. A health state description system incorporating a graphical description component was developed to facilitate communication in partially literate communities. Some deliberative tools for conduct of health state valuation workshops for educated persons were developed. The experience gained for valuation of health states in developing country settings, we hope, will help in future research.

Apropos the substantive aspect of the subject, this study has shed some light and raised many questions about the nature of the health state valuation process in our minds. Analysis of test and retest data on ordinal ranking of health states, valuation of own health state and differences in distribution of valuations at the community level, all lead us to hypothesise that the true health state valuation in our minds is a multivalued fuzzy set with different degrees of clarification. Conventional theory that the true valuation is a single valued function is not consistent with our observations, and appears intuitively less appealing.

Health state valuation studies will have to contend with the problem of measurement error, as is the case in most other areas of psychometric measurement. Unfortunately, we do not yet have a fully worked out measurement model for health state valuations. Most studies use reliability measures conceived under the classical test theory developed in the context of educational testing and measurement. In the field of educational measurement, it is generally assumed that the object of measurement is distributed normally with some variance. If the variance component attributable to subjects is high, then educational tests are considered reliable. We have seen that community valuation of health states follow different distributions. Health state valuations are not personal endowments that can be assumed to be

distributed normally in a fashion similar to, say, intelligence. If community valuation for a health state is well crystallised, then the true variance of subjective valuations will be less as compared to health states where the valuation is more diffused. The generalisability theory allows for a more realistic modeling of the measurement process. Reliability of the health state valuations in this study can be said to be moderate, on the basis of obtained generalisability coefficient (0.56 to 0.67) and conventional reliability measures like ICC (0.6), within valuer correlation (around 0.6 to 0.8) and within valuer ICC (0.6 to 0.8). However, a more appropriate measurement model of health state valuation will help in correct estimation of reliability.

The incidence of measurement error and our present understanding about the nature of valuation process would suggest that community level valuation of health states requires a large sample size as also repeated measurements. Large sample sizes would help minimise the measurement error for mean values estimated form community surveys. Repeated measures, it is anticipated, will occasion repeated deliberation by the valuers and thereby help clarification of their value sets. The tradeoffs between sample size and repeated measurements will have to be studied.

The health state valuation instruments used in this study have good content validity, considering that they have been derived by many people working from similar conceptual definitions of health and are based on empirical listing of health state attributes by some large studies. The criterion validity of health state valuation instruments cannot be tested, since we do not have a good standard for this purpose. The instruments have shown good convergent validity. Measurements from multiple methods like, the visual analogue scale, time trade off, and person trade off agreed quite well with each other. Incorporation of ordinal rank consistency requirement in valuation tasks appeared to facilitate deliberation.

Ordinal rank consistent visual analogue scaling (VAS) turned out to be a fairly valid tool for the measurement of health state values. The VAS valuations agreed quite well with valuations from other methods like time trade-off and person trade-off. In fact VAS did better in some cases. For example, the incidence of counterintuitive valuations was lower for VAS. Considering its simplicity, and the feasibility for community surveys, VAS appears to be the instrument of choice for measurement of health state valuations.

So far, researchers have focused on the mean valuations. This study has demonstrated that community valuation of all health states do not follow the same distribution. The degree of crystallisation of valuations appears to be health state dependent. Valuations for some states are quite diffused, for example, infertility. Valuations for some others are well crystallised, for example, quadriplegia. Differences in distribution of valuations by the community for different health states has policy implications, and hence, should be the subject of further research. This implies that health state valuation studies using a few indicator conditions will not provide required inputs for summary measures of population health. Data on indicator conditions, allow for statistical decomposition of multiattribute valuations and model based estimation of disability weights for other health states. These statistical models can estimation mean valuations only, but can not provide any information about distribution. The only way to understand distribution of valuations for all health states is to measure valuations for each of them in the concerned community.

References:

Dolan Paul. Modelling valuations for EuroQol health states. Medical Care. 1997(11):1095-1108.

Murray Christopher J.L., and Lopez Alan D. 1996. The global burden of disease in 1990: final results and their sensitivity to alternate epidemiological perspectives, discount rates, age weights and disability weights. in The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Editors Murray Christopher J. L., and Lopez Alan D. Boston: Harvard School of Public Health.

Stouthard Marlies EA; Essink-Bot Marie Louise; Bonsle Gouke J.; Barendregt Jan J.; Kramers Pieter GN; Harry PA van de Water; Gunning-Scheepers Louise J, and Paul J. van der Maas. Disability Weights for Diseases in Netherlands. Rotterdam, The Netherlands: Department of Public Health, Erasmus University, PO Box 1738, 3000 DR, Rotterdam, The Netherlands. Fax 31 10 436 6831, email: mgz@mgz.fgg.eur.nl; 1997.

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Appendix - 2

APHSV99 Data Set - Explanatory Notes

I. File format:

1. The data set is provided in a single floppy disk containing a file named APHSVDataSet99.TXT.
2. Data is provided in ASCII text file format, with comma as delimiters and "" as text qualifiers. The first row contains the field labels.

II. Overview of records and arrangement of data:

1. Data is provided in a panel format. since each valuer provided valuations for 11 health states, there are 11 records for each valuer. Thus the valuer's personal information is repeated for all the 11 corresponding rows.

Table-A2.1: Overview of records in the AP Health State Valuation-99 Data set

Data set parameter	Survey			Workshop	Total
	No retest	With retest	Sub total		
Number of valuers	910	100	1,010	180	1,190
Record / valuer	11	11	11	11	11
Total records in the data set	10,010	1,100	11,110	1,980	13,090

III. Fields common to both Workshop and Household survey:

A. VID:

1. Valuer's unique Id.
2. Users may notice that the first character of the Id is usually W for valuers in workshops and F (female) or M (male) for valuers in the household survey. However, we recommend that the specific fields namely Wkshop, Female, be used instead of the pattern in the Valuer's Id.

Table-A2.2: Assignment of sets of health states to valuers and corresponding Vnos

Set	Survey		Workshop	
	No of valuers	Vno block	No of valuers	Vno block
1	269	201- 469	45	1-45
2	247	470-715	31	46-76
3	247	716-962	30	77-106
4	218	962-1181	45	107-151
5			14	152-165
6			15	166-180
7 to 34	29		0	
All	1,010		180	

B. VNo:

1. An integer id for valuers (table-8.2). Some statistical packages require an integer unique id for certain manipulations. For example, executing reshape command in state becomes easier if we have a numeric id in serial. The blocks of numbers were assigned to each of the six sets of the health states. Numbers from the respective block is assigned in serial to valuers who worked on that set of health states. Correspondence of blocks of Vno to sets of health states is given below. For valuers

who worked with one of the non standard sets of health states (sets 7 and above) the Vno field may be empty.

C. Wkshp :

1. This is a numeric field containing Boolean values of 1 or 0.
2. Wkshp=1 if the data in the record was from the health state valuation workshop.
3. Wkshp=0 if the data in the record is from the valuation by household survey.

D. Set:

1. This is an integer field containing the set of health states assigned to the valuer.

E. HealthSt:

1. Health State Code limited to 10 characters corresponding to the name of the health state for which valuation data is contained in the record.

List of these health states and the number of valuations obtained for each from the survey and workshops respectively is shown below.

Table-A2.3: Number of valuations obtained for each health state

HealthSt		Sets+	Survey	Workshop	Both
Angina	Angina	2,5	253	45	298
BKneAmp1	Below the knee amputation (one leg)	3,6.	255	45	300
BKneAmp2	Below the knee amputation (two legs)	3,6	258	45	303
Blindness	Blindness	2,5	247	45	292
Bronchitis	Bronchitis	1	279	45	324
CCold	Common cold*	2,5	0	14	14
CMdBkPain	Continuous moderate back pain	4	233	45	278
Infertlty	Infertility	2,5	250	45	295
Mdiabetes	Mild diabetes, no symptoms	C	1004	180	1184
MHrgDis	Mild hearing disorder	4	233	45	278
MTBWRx	Mild Tuberculosis with treatment	C	1008	180	1188
MdAnemia	Moderate Anaemia*	3,6	0	15	15
OwnHlth	Own Health Today	C	1010	180	1190
PnStiffJts	Pain and stiffness in joints	1	278	45	323
PUlcer	Peptic Ulcer	3,6	258	45	303
Qplegia	Quadriplegia	C	1008	180	1188
Schizo	Schizophrenia	1	280	45	325
SMigraine	Severe continuous migraine	C	998	180	1178
SHallFevr	Severe Hallucinatory Fever	2	253	31	284
SHeartFlr	Severe heart failure (congestive)	4	229	45	274
TBAinCast	Two broken arms in cast	3	256	30	286
UMajDep	Unipolar major depression	C	1000	180	1180
UrIncont	Urinary incontinence	1	279	45	324
WDiarrh	Watery Diarrhea 5 times a day	C	1006	180	1186
WMarksFc	White marks on face	4	235	45	280
	All		11110	1980	13090

* These two health states were included in the respective sets in the beginning. Later, the sets were replaced by hallucinatory fever and two broken arms in cast, respectively. Hence number of valuations for these two are relatively small and confined to workshop only. Similarly the number of valuations through workshops is less for the replacement conditions.

+ Only major sets are shown in this column. A few come from 29 survey valuers for whom the assigned sets, got mixed.

F. 6D5L:

1. The 6D5L description of the health state mentioned in the HealthSt field. This is six character string consisting of six digits. Each digit ranges from 1 to 5 corresponding to five levels. The digit in the first position from left represents the functional level in the mobility dimension. The digit in the second position from left represents the functional level in the self care dimension. Similarly, the third to sixth digits represent usual activities, pain, anxiety / depression, and cognition respectively.

G. CurrHlSt:

1. Each valuer both in the workshop and in case of the household survey was administered a questionnaire asking for description of his / her own health state on the date of valuation. The questionnaire is titled "Your Health State Today" and presents the 6D5L descriptive system.
2. In addition to the 6D5L descriptive system, the "Your Health State Today" contained a general question comparing his / her health state on the day of valuation with his / her health state over the last one year. The field **CurrHlSt** contains code for valuers response to the statement "Compared with my general level of health over the past 12 months, my health state is:" 1 for extremely well to 5 for worse.
3. Response codes have the following meaning.

Codes used in the field "CurrHlSt"

Compared with my general level of health over the past 12 months, my health state is:

Code	Meaning
1	Extremely well
2	Better
3	Much the same
4	Bad
5	Worse

H. CSRnk:

1. Card sort rank. The ranking given by the valuer to this health state among the 11 health states, valued by him / her. This number ranges from 1-11.
2. Rank 1 means best and rank 11 means worst among the set of 11 health states for which the card sorting is done.
3. Note that ranks have meaning within respective sets. Although cross referencing through the ranks of the core health states should be feasible.

I. DWtVAS:

1. Disability weight from the visual analogue scale based valuations.
2. Actually the valuers were asked to value by assigning a health state weight in a scale from 0 = worst imaginable health state to 100 best imaginable health state. These valuations have been converted to weights in a 0-1 scale (by deflating all measurements with 100). This health state weight is then transformed to disability weights [Disability weight = (1 - Health state weight)]. The disability weights are given in the data set. Health state weights can be recovered by reverse transformation.
3. The DWtVAS value for quadriplegia in case of VID=W15_3d is zero, even though the card sort rank assigned, by this person, is 11 i.e. the worst of all. This person could not reconcile the CS & VAS ranks and hence the discrepancy.

J. VASMatchd:

1. 1 if rank order of VAS scale value matched with card sort rank order, 0 if did not match.

K. RTstDone:

1. For 100 randomly chosen valuers in household survey, the valuation exercise was repeated after a gap of about one week to 10 days, to estimate test retest reliability of the measurement tools and valuation methodology.
2. For 15 valuers in the workshop repeat VAS and TTO exercise was done after a gap of three months.
3. RTstDone=1 implies that the retest was done.
4. RTstDone=0 means that retest was not done.

L. CSRnk_R:

1. Rank assigned to the health state by the valuer, in the retest. As in case of card sort rank for the first time, rank 1 means best and rank 11 means worst among the set of 11 health states for which the card sorting is done.

M. DWtVAS_R:

1. Same as DWtVAS i.e. disability weight from the visual analogue scale based valuations, but this field contains the results from the retest valuation in household survey.

N. DTOFINT:

1. Date of the primary valuation exercise. In case of workshop this is the workshop date. In case of household survey, the date of the first interview. This field is about the date of primary interview and not the retest.

O. INTWCODE:

1. MDHSV Workshop co-ordinator, or, in case of HSV household survey, the interviewer code.

P. POINTINT:

1. Place of first survey interview or workshop as the case may be.
2. Note that the survey took place in Kondakal village (1007) and Seriguda (3 valuers) hamlet of the same village. So this field contains either of these two strings for records from the survey.
3. All workshop were conducted at IHS and hence all workshop records show IHS in this field.

Q. Age:

1. Age of the valuer in years. Range of values in the data set: 16-86 years.

R. Female:

1. This field is to denote sex. Thus if female = 0 it would mean that the valuer was a male.
2. Sex composition of valuers is given below:

Table-A2.4 Gender composition of valuers

Study arm	Female	Males	Total
Survey with retest	50	50	100
Survey, no retest	441	468	909
Workshop	88	92	180
All	579	610	1,189

S. Schoolyr:

1. Years of schooling including formal education beyond the high school, received by the valuer.

T. "Difficulty Encountered" fields:

1. In case of the survey, interviewer's were asked to make an assessment about the extent of difficulty encountered by the valuer while dealing with different aspects of the measurement tool.
2. In case of workshops, valuers were asked to give their own assessment.
3. For workshops data is available for 34 valuers only, since the response sheet in which these questions were included, was introduced mid course from the 10th workshop onwards.
4. For the survey, data is available for all valuers.
5. Since TTO (Time tradeoff) and PTO (Person Tradeoff) were specific to the workshop, the fields containing valuer's assessment of difficulty encountered with these two valuation exercises is described under the section "Fields specific to the valuation workshops".

Table-A2.5: Fields containing observations about the valuation instrument

Field name	Expansion of the field name	Codes			
		0	1	2	8
DECSort	Difficulty encountered while performing the card sort	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess
DEOwnHl	Difficulty encountered in assessing own health	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess
DEVAS	Difficulty encountered while performing the VAS	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess

IV. Fields specific to the valuation workshops:

A. Prof:

1. Profession of the valuer. Field type is string.

B. Qual:

1. Educational qualification of the valuer. Field type is string.

C. VASItn1:

1. First VAS response. Field type is numeric.
2. If a person did only one iteration, the same values are reflected in the DWtVAS field also.

D. VASItn:

1. Number of iterations by the valuer, to arrive at the final VAS valuation of the health states. Values range from 0-4. 0 means no additional iterations were necessary and the valuers completed the valuation in one attempt.

E. TTOAtmptd:

1. 1 if the valuer attempted the TTO exercise, 0 if did not attempt. Null if wkshp=0
2. All, except one (VID=W83_3u), attempted the TTO exercise.

F. TTOItn1:

1. First TTO response.
2. Values for the following 19 records in this field are zero for all health states. W1_*, W2_, W3_, W4_, W5_, W6_, W7_, W8_, W9_, W10_, W11_, W12_, W13_, W14_, W15_, W16_, W83_, W180_, W41_.
3. Out of these the VIDs W1 to W16 correspond to the first workshop. The data entry cum feedback spread sheet did not have the facility to record the number of iterations. The idea of recording the number of iterations occurred to us, mid course, since we realised that this may give some clue about the practicality of TTO exercise.
4. For VID W83_, the valuer left the workshop and hence was not available to complete the TTO exercise.
5. For VIDs W180_ & W41_ the valuers uniformly filled in a value outside of the plausible range. Hence the spread sheet program resulted in an error.
6. If a person did only one iteration, the same values are reflected in the DWtTTO field also.

G. TTOItn:

1. Number of iterations by the valuer, to arrive at the final TTO valuation of the health states. Values range from 0-13. 0 means no additional iterations were necessary and the valuers completed the valuation in one attempt.

H. DwtTTO:

1. Disability weight arrived through the TTO exercise.
2. Some valuers did not get to reconcile their TTO valuations with card sort ranks and gave up mid course. For them the latest round values are incorporated in this field.
3. The DWtTTO value for VID=W172_4d may appear implausible for conditions like Severe heart failure (0.05) and Severe continuous migraine (0.9). We have actually double checked with records and the values are correctly reflected in the data set.

I. DwtTTO_R:

1. Disability weight arrived through a repeat TTO exercise.
2. Only 15 valuers in the workshop were administered the retest.

J. TTOMatchd:

1. 1 if rank order of TTO valuation matched with card sort rank order, 0 if did not match. Null, if wkshp=0

K. PTOAtmptd:

1. 1 if the valuer attempted the PTO exercise, 0 if did not attempt. Null if wkshp=0

L. PTO1Itn1:

1. First PTO1 response. Field type is numeric.

M. PTO2Itn1:

1. First PTO2 response. Field type is numeric.

N. PTOItn:

1. Number of iterations by the valuer, to arrive at the final PTO valuation of the health states. Values range from 0-4. 0 means no additional iterations were necessary and the valuers completed the valuation in one attempt. Field type is numeric.

O. DWtPTO:

1. Disability weight arrived through the PTO exercise.

2. Although efforts were made to persuade valuers to reconcile their card sort rank with the rank implied by their TTO valuation, all valuers did not like to do this. For those who stopped because they felt uncomfortable with the reconciliation exercise, or were exhausted due to many iterations, the CSRnk and the ranking implied by DWtTTO values may not match.
3. Field type is numeric.

P. PTOMatchd:

1. 1 if rank order of PTO valuation matched with card sort rank order, 0 if did not match. Null, if Wkshp=0 Or (Wkshp=1 And PTOAtmptd=0)

Q. "Difficulty Encountered" fields:

1. Valuers in the workshops were asked to give their own assessment about the difficulty they encountered in working with the TTO and PTO instrument. Refer to the section describing variables common to the workshop and survey, where another three such variables have been described.
2. However, data for all valuers in the workshops is not available.

Table-A2.6: Fields containing observations about the valuation instrument

Field name	Expansion of the field name	Codes			
		0	1	2	8
DEPTO	Difficulty encountered while performing the PTO	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess
DETTO	Difficulty encountered while performing the TTO	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess

R. Workshop feedback fields:

1. Valuers in the workshops were asked to give their feedback about usefulness of written instructions (WI) and spoken instructions (SI) on respective valuation exercises.

Table-A2.7: Fields containing valuer's feedback about usefulness of written and spoken instructions

Field	Expansion of the field name	Codes for all fields
WBWP	Written background on the workshop purpose	0 = Not helpful 1 = Somewhat helpful 2 = Very helpful
SPDHS	Spoken Presentation on different domains of health status	
WICS	Written instructions on the Card sort	
SICS	Spoken instructions on the Card sort	
WIVAS	Written instructions on the VAS	
SIVAS	Spoken instructions on the VAS	
WITTO	Written instructions on the TTO	
SITTO	Spoken instructions on the PTO	
WIPTO	Written instructions on the PTO	
SIPTO	Spoken instructions on the PTO	

2. We introduced these feedback questions starting with the workshop on 01 October, 1999. However, the data set does not have data for a large number of valuers who attended workshops after this date. These are: W64_, W65_, W69_-W98_, W100_-W111_, W132_, W139_, W143_, W144_, W146_, W149_-W161_, W163_-W165_, and W167_.

3. These participants did not return the feedback questionnaires. Since these forms were introduced mid course, we could not integrate them into the workshop protocol well enough to achieve full compliance.

V. Fields specific to the household survey:

A. Assisted:

1. This is a numeric field with Boolean values of 1 and 0. Assisted = 1 if an assistant was used to communicate and Assisted = 0 if communication between interviewer / researcher and valuer was direct.

B. AsstRel:

1. For valuation through household survey, some times, it was difficult for the interviewer to directly communicate with the valuer in the study sample. In such situations assistance of a relative or friend was sought. This field record the relationship of such assistants, if any, to the valuer.
2. Following relationships have been recorded:

Relationship	Explanatory notes if any	Relationship	Explanatory notes if any
Brother		Mother	
Brother in law	Spouse's brother	Mother in law	
Co-Sister	Husband's brother's wife	Nephew	
Cousin		Paternal uncle	
Daughter		Sister	
Daughter in law		Sister in law	
Father		Son	Spouse's sister
Grand daughter		Son in law	
Grand mother		Wife	
Husband			

C. Caste:

1. Caste of the valuer:

Codes used in the field "Caste"

Code	Meaning
0	Not available
1	SC i.e. member of a caste listed in the schedule to the Indian constitution.
2	ST i.e. member of a tribe listed in the Indian constitution.
3	BC i.e. member of a caste identified as backward by the state.
4	OC, i.e. all other castes

D. OWNSHOUS:

1. This is a numeric field containing Boolean values to represent if the valuer owns a house. OWNSHOUS=1 implies that the valuers owns a house and OWNSHOUS=0 means that (s)he does not own a house.

E. Fields giving information about ownership of consumer durables or agricultural equipment that provide indirect evidence about economic status of the valuer's household:

1. The following fields are numeric containing a Boolean value of 1 or 0. 1 means that the valuer's household has the particular consumer durable with them. These data was collected to provide some idea about the economic status of the valuer's household.
   i. RADIO

ii. TV
iii. FRIDGE
iv. BICYCLE
v. TWOWHEEL
vi. SEWMCHNE
vii. SOFA
viii.LAND
ix. LIVESTOK
x. BULLOCK
xi. CART
xii. PUMP
xiii.FAN

F. WaterSc:

1. This is a numeric field containing coded information about the type of water source enjoyed by the valuer. Codes are as follows:

Codes used in the field "WaterSc"

Type	Meaning
1	Private protected (piped / deep bore well)
2	Private unprotected (shallow bore well, open well)
3	Public protected (piped, deep bore well)
4	Public Unprotected (open well)
5	Natural unprotected (spring, river, pond, lake)
6	Other

G. Toilets:

1. This is a numeric field containing coded information about the type of toilets available to the valuer. Codes are as follows:

Codes used in the field "Toilets"

Type	Meaning
1	Private flush toilet
2	Shared flush toilet
3	Public flush toilet
4	Traditional pit latrine
5	Ventilated improved pit latrine
6	Other
7	No facility/bush/field

2. None of the valuer's use pit latrine. Hence there are no records in the data set where Toilets = 4.

H. Fuel1, Feul2, and Fuel3:

1. The fuel fields present in the database are FUEL1, FUEL2, FUEL3. These fields describe the order of priority of the fuels used in the valuer's household. Thus Fuel1 is the fuel used having highest priority i.e. the primary fuel used by the household. Fuel2 and Fuel3 are used to capture data from households using more than one fuel. The first secondary fuel is recorded in Fuel2 and the next secondary fuel is recorded in the field Fuel3. Same codes are used for the three fuel fields. The fields are filled in the database depending on the fuel types used in a valuer's household. Thus, the field

FUEL1 is mandatory for any valuer's household; if the valuer's household uses more than one type of fuel, then the fields FUEL2 and FUEL3 are filled in.

Fuel Fields

Code	Meaning	Code	Meaning	Code	Meaning
1	LPG / Natural gas	4	Coal	7	Other
2	Biogas	5	Fire wood / straw		
3	Kerosene	6	Dung		

2. For valuers whose household use only one type of fuel, the fields Fuel2, and Feul3 are blank.

I. HouseTp:

1. Type of house in which the valuer lives. Following codes are used.

Codes used in the field "HouseTp"

Code	Meaning
0	Rented accommodation
1	Pucca house
2	Kachha house
3	Semi pucca

J. Fields recording Interviewer's Observation about health status of valuer:

1. The interviewers for the survey were asked to observe the valuer and record their finding on a few verifiable aspects of the valuer's health status. This data was collected to facilitate correlation of valuer's response on 6D5L about his / her own health state with observable functional states.

Table-A2.8: Fields containing interviewers observations about the valuers

Field Name	Expansion of the field name	Codes		
		0	1	8
ObAmptn	Amputation	No	Yes	Can't Assess
ObCough	Cough	No	Yes	Can't Assess
ObHrgImp	Hearing impairment	No	Yes	Can't Assess
ObPlysis	Paralysis	No	Yes	Can't Assess
ObShbrth	Shortness of Breath	No	Yes	Can't Assess
ObVisnDf	Vision difficulty	No	Yes	Can't Assess
ObWlkAid	Use of walking aid	No	Yes	Can't Assess
ObWlkgDf	Walking difficulty	No	Yes	Can't Assess

K. Accuracy :

1. Overall accuracy of respondent's valuation as judged by the interviewer, using following codes.

1	Excellent
2	Very Good
3	Good
4	Fair
5	Poor

L. ResCoop:

1. Respondents cooperation level, using following codes.

1	Very High
2	High
3	Average
4	Low
5	Very Low

M. "Difficulty Encountered" fields:

1. Interviewer's were asked to make an assessment about the extent of difficulty encountered by the valuer while dealing with different aspects of the measurement tool.
2. Refer to the section describing variables common to the workshop and survey, where another three such variables have been described.

Fields containing interviewer's observations about the valuation instrument

Field name	Expansion of the field name	Codes 0	1	2	8
DEPInfo	Difficulty encountered while providing personal information	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't Assess

VI. Following information not included to protect respondent and interviewer's personal id:

A. Valuer's Name

B. Interviewer Name

Appendix-3.1

6D5L Health State Description System.

Dimensions and Severity Levels.

I. Mobility (Position = 1):

A. What this dimension represents:

1. Transfers: Includes the management of all aspects of transfers to and from bed, mat, toilet, etc. More simply getting in and out of bed.
2. Ambulation: Includes coming to a standing position and walking about,
3. Stairs and environmental surfaces: Ability to handle environmental barriers, and includes climbing stairs, curbs, ramps or environmental terrain,
4. Community mobility: Ability to manage transportation.
5. Example of a condition that does not affect mobility: Vitiligo
6. Example of conditions that may affect mobility to various degrees: Back ache, paralysis of lower limbs.

B. Severity Levels and Codes (SLC):

1) Independent, i.e. no assistance required and no problem with mobility. Ability to run / flight in times of need. SLC =1
2) Occasional or very few problems in moving about. SLC =2
3) Some problems in moving about. SLC=3
4) Many problems in moving about. SLC=4
5) Unable i.e. totally dependent for mobility. SLC=5

II. Self care (Position = 2):

A. What this dimension represents:

1) Eating / feeding.
2) Personal hygiene, washing, bathing, grooming, dressing up.
3) Toilet use, bladder, and bowel.
4) Example of a condition that does not affect self care: ring worm infection of skin.
5) Example of conditions that may affect self care to various degrees: fracture of limbs, cerebral paralysis.

B. Severity Levels and Codes (SLC):

1) Independent, i.e. no assistance required and no problem with self care. SLC=1
2) Occasional or very few problems with self care like eating, bathing, dressing etc. SLC=2
3) Some problems with self care like eating, bathing, dressing etc. SLC=3
4) Many problems with self care like eating, bathing, dressing etc. SLC=4
5) Unable i.e. totally dependent for self care. SLC=5

III.Usual activities (Work and leisure), (Position = 3):

A. What this dimension represents:

1. Work, occupation and employment.
2. House work: Includes shopping, cooking, cleaning, washing clothes.
3. Family or leisure activities.
4. Example of a condition that does not affect usual activities: ring worm infection of skin.
5. Example of conditions that may affect usual activities to various degrees: Severe schizophrenia.

B. Severity Levels and Codes (SLC):

1. No assistance required and no problem with usual activities like work, employment, household work, etc. SLC=1
2. Occasional or very few problems in performing usual activities like work, employment, household work, etc. SLC=2
3. Some problems in performing usual activities like work, employment, household work, etc. SLC=3
4. Many problems in performing usual activities like work, employment, household work, etc. SLC=4
5. Unable i.e. totally dependent for usual activities. SLC=5

IV.Pain / Discomfort, (Position = 4):

A. What this dimension represents:

1. Pain: Includes pain, aches, chills, etc.
2. Discomfort: Includes physical distress, stiffness, weakness, numbness, breathlessness, burning, itching, etc.
3. Example of a condition that is not characterised by pain or discomfort: Squint
4. Example of conditions that is characterised by pain or discomfort: Herpes Joster, Slipped inter vertebral disc, Congestive heart failure.

B. Severity Levels and Codes (SLC)::

1. No pain and no discomfort. SLC=1
2. Mild pain or discomfort. SLC=2
3. Moderate, discomforting pain. SLC=3
4. Distressing pain. SLC=4
5. Excruciating, unbearable pain. SLC=5

V. Anxiety / Depression, (Position = 5):

A. What this dimension represents:

1. Anxiety: Includes nervousness, strain, stress, or pressure, being tense, anxious, worried, upset, difficulty in relaxing, and difficulty while trying to calm down.
2. Depression: Includes sorrow, being discouraged, feeling hopeless, downhearted, and / or blue, low spirits, and brooding about things.
3. Emotional adjustment: Includes frequency and severity of depression, anxiety, frustration, lability, unresponsiveness, agitation, ability to cope with and take responsibility for emotional behaviour.
4. Social adjustments: Includes frequency and initiation of social contacts, responsiveness in one to one and group situations, appropriateness of behaviour in relationships, and spontaneity of interactions.
5. Example of a condition that is not characterised by anxiety or depression: Common cold.
6. Example of conditions that is characterised by various degree of anxiety or depression: Psoriasis, Stammering.

B. Severity Levels and Codes (SLC):

1. No anxiety and no depression. SLC=1
2. A little anxiety or depression. SLC=2
3. Moderate anxiety or depression. SLC=3
4. Much anxiety or depression. SLC=4
5. Severe anxiety or depression. Extremely anxious and depressed. SLC=5

VI.Cognition (Position = 6):

A. What this dimension represents:

1. Attention span and concentration: Including distractibility, level of alertness and responsiveness, ability to concentrate on a task, ability to follow directions, immediate recall as the structure, difficulty and length of the task varies,
2. Orientation: Includes visual spatial processing.
3. Judgement and reasoning.
4. Memory: Includes short and long term memory.
5. Verbal linguistic processing.
6. Problem-solving.
7. Example of a condition that does not affect cognition: Inguinal hernia, Transient amnesia.
8. Example of conditions that may affect cognition to various degrees: Hypothyroidism, Alzheimer's disease.

B. Severity Levels and Codes (SLC):

1. No impairment of cognitive function. No cognitive problems. SLC=1
2. A little / Very few cognitive problems. SLC=2
3. Moderate impairment of cognitive function. SLC=3
4. Considerable impairment of cognitive function. SLC=4
5. Severe impairment of cognitive function. SLC=5

Appendix-3.2: Labels Used in MDHSV Workshops and Household Survey

Disease labels	Labels used in the MDHSV workshops	6D5L Profile	Labels used in the household survey
Own health today	Own health today		Your own health state today
Diabetes	Mild diabetes, no symptoms	111121	Mild diabetes with no symptoms, controlled with pills
Tuberculosis	Mild tuberculosis with treatment	111221	Tuberculosis under treatment with very mild symptoms limited to occasional cough
Unipolar major depression	Unipolar major depression	124142	Depression, with loss of pleasure from most activities, low energy, and slight difficulties in thinking and concentrating
Quadriplegia	Quadriplegia	554341	Quadriplegia
Watery diarrhoea	Watery diarrhoea 5 times / day	111211	Watery diarrhoea 5 times per day, without major pain or cramps
Severe Migraine	Severe continuous migraine	113431	Severe migraine that does not go away
Arthritis	Pain and stiffness in joints	222311	Moderate pain and stiffness in the joints
Urinary incontinence	Urinary incontinence	113331	Loss of control over urination
Bronchitis	Bronchitis	112311	Frequent cough with expectoration and some difficulty breathing
Schizophrenia	Schizophrenia	234244	Schizophrenia, with confused speech and perception, severe difficulties in thinking or concentrate, mood swings and paranoia
Typhoid	Severe hallucinatory fever	444333	Severe fevered state with hallucinations, as in typhoid fever
Angina	Angina	111321	Moderate chest pain during slight exercise
Infertility	Infertility	111131	Wanting to have children but not being able to (infertility)
Blindness	Blindness	323122	Blindness
Two broken arms in cast	Two broken arms in cast	154321	Two broken arms set in stiff casts from above the elbow to the wrist
Peptic Ulcer	Peptic Ulcer	112321	Pain and burning sensation in stomach, as in peptic ulcer
Below knee amputation-one leg	Below the knee amputation (one leg)	322211	Below the knee amputation - one leg, with crutches available
Below knee amputation-two legs	Below the knee amputation (two legs)	433221	Below the knee amputation - two legs, with wheel chair available
Vitiligo on face	White marks on face	111131	White marks on face
Mild hearing disorder	Mild hearing disorder	112121	Mild problems in hearing, but able to hear and understand loud speech and sounds
Back pain	Continuous moderate	212321	Continuous moderate back pain

Disease labels	Labels used in the MDHSV workshops	6D5L Profile	Labels used in the household survey
	back pain		
Congestive heart failure	Severe heart failure (congestive)	434531	Extreme chest pains and breathlessness caused by severe heart failure
Common cold	Common cold	112211	
Moderate anaemia	Moderate anaemia	112211	

Appendix 3.3:

Long labels of health states, English and Telugu.

English	Telugu
Your own health state today	ఈరోజు మీ ఆరొగ్య స్థితి
Mild diabetes with no symptoms, controlled with pills	కొద్దిగా చెక్క-ర-వ్యాధి, ఎటు-వంటి రోగ-ల-క్షణాలు లేవు. మందు-లతో అదు-పులో పుంచ-వచ్చు
Tuberculosis under treatment with very mild symptoms limited to occasional cough	చికిత్స చేయించు-కుం-టున్న క్షయ-వ్యాధిగ్రస్తుడు, కొద్దిగా రోగ -ల-క్షణాలు,అప్పు-డ-ప్పుడు దగ్గు
Depression, with loss of pleasure from most activities, low energy, and slight difficulties in thinking and concentrating	మన-స్తా-పము, ఎ పని-చే-యా-డా-ని-కైన అయి-ష్ట-త, తక్కువ శక్తి, ఆలోచిం-చ-డంలో మరియు కేంద్రి-క-రిం-చ-డంలో కొద్దిగా కష్టం
Quadriplegia	రెండు కాళ్లు చేతులు చచ్చు-బ-డుట
Watery diarrhoea 5 times per day, without major pain or cramps	చాలా నొప్పి/ పోట్లు తో కూడ-న-టు-వంటి నీళ్ల-వి-రే-చ-న-ములు (రోజుకు **5** సార్లు)
Severe migraine that does not go away	ఎప్ప-టికి తగ్గన-టు-వంటి తీవ్ర-మైన తల-పోటు
Moderate pain and stiffness in the joints	కొద్దిగా నొప్పి, కీళ్లు పట్టే-సి-నట్లు ఉండుట
Loss of control over urination	మూత్ర-ములో స్వాధినం లేక-పో-వుట
Frequent cough with expectoration and some difficulty breathing	ఎప్పుడు ఉండే తెమడ/ కళ్లెతో కూడి-న-టు-వంటి దగ్గు మరియు శ్వాస- తీసు-కో-వ-డంలో కష్టం
Schizophrenia, with confused speech and perception, severe difficulties in thinking or concentrate, mood swings and paranoia	మతిస్థిమి-తం-లే-క-పో-వుట, మాట తడ-బాటు మరియు ఆలో-చ-నలో తిక-మక, ఆలో-చిం-చుట, కేంద్రి-క-రించుట-లో చాల కష్టం, మనసు స్థిమితం లేక-పో-వుట
Severe fevered state with hallucinations, as in typhoid fever	తీవ్ర-మైన జ్వరం పలన ఆలో-చనలు స్వాధి-నం-లే-క-పో-వుట -(టైఫా-యిడ్ జ్వరం పలె)
Moderate chest pain during slight exercise	కొద్ది-పాటి వ్యాయమము చేయు-న-పుడు ఛాతీ(చెస్ట్) లో కొద్ది గా నొప్పి
Wanting to have children but not being able to (infertility)	సంతా-నము కావాలనీ కోరిక వున్నా కన-లే-క-పో-వుట
Blindness	గుడ్డిత-నము
Two broken arms set in stiff casts from above the elbow to the wrist	విరి-గిన రెండు చేతు-లకు కట్లు
Pain and burning sensation in stomach, as in peptic ulcer	కడు-పులో బాధ మరియు మంట --- (కడు-పులో పుండు పలే ఉన్నది)
Below the knee amputation - one leg, with crutches available	ఒక-మో-కాలి క్రింది-భా-గ-ము- తీసి-వే-యుటనడ-వ-డా-నికి వీలైన సాధ-న-ములు కలవు (క్రచ్స్)
Below the knee amputation - two legs, with wheel chair available	రెండు మోకాలి క్రింది-భా-గములు తీసి-వేయుట ------చక్రాల కుర్చి కల-దు (వీల్‌చైర్)
White marks on face	ముఖ-ము-మీద తెల్లని మచ్చలు
Mild problems in hearing, but able to hear and understand loud speech and sounds	విన-డంలో కొద్దిగా కష్టం అయితే గట్టిగా మాట్లా-డినా, పెద్ద శబ్ద-మైనపుడు మాత్రమే విన-గ-లడు
Continuous moderate back pain	ఎప్పుడు ఉండే కొద్దిపాటి వెన్ను-నొప్పి
Extreme chest pains and breathlessness caused by severe heart failure	తీవ్ర-మైన గుండె-జబ్బు కార-ణంగా భరిం-చ-లేని ఛాతీలో నొప్పి మరియు (దమ్ము) శ్వా-స-తీ-సు-కో-లే-క-పో-వడం

Appendix-3.4

6D5L Health state description system in Telugu.

కద-లిక (Mobility)

1 నాకు కద-ల-టంలో కష్టం- లేదు
2 నాకు కద-ల-టంలో ఎప్ప-డ-యిన కష్టంగా ఉంటుంది
3 నాకు కద-ల-టంలో కొంచెం కష్టంగా ఉంటుంది
4 నాకు కద-ల-టంలో చాలా కష్టంగా ఉంటుంది
5 నేను అస్సలు కద-ల-లేక పోతున్నాను

దిన-చ-ర్య (Self care)

1 నాకు దిన-చ-ర్యలో కష్టం లేదు
2 నాకు దిన-చ-ర్యలో అప్పు-డ-ప్పుడు కష్టం
3 నాకు దిన-చ-ర్యలో కొంచెం కష్టం
4 నాకు దిన-చ-ర్యలో చాలా కష్టంగా ఉంది
5 నేను స్వయంగా తిన-టం, స్నానం చేయడం మరియు తయా-ర-ప-లే-క-పో-తు-న్నాను

వృత్తి-ప-నులు (Work and leisure)

1 నాకు వృత్తి-ప-నులలో కష్టం లేదు
2 నాకు వృత్తి-ప-నులలో ఎప్పు-డ-యిన ఇబ్బంది
3 నాకు వృత్తి-ప-నులలో కొంచెం ఇబ్బంది
4 నాకు వృత్తి-ప-నులలో చాలా ఇబ్బంది
5 నేను వృత్తి-ప-నులు చేసు-కో-లే-క-పో-తు-న్నాను

6D5L Health state description system in Telugu Contd.

నాకు నొప్పిలేక బాధ (Pain- discomfort)

1 నాకు నొప్పిలేక బాధ లేదు
2 కొంచెం నొప్పిలేక బాధ ఉంది
3 నాకు ఘమా-రుగా నొప్పిలేక బాధ ఉంది
4 నాకు విప-రీ-తమైన నొప్పిలేక బాధ ఉంది
5 నాకు భరిం-చ-లేనినొప్పిలేక బాధ ఉంది

మనస్తాపము ఆందోళన (Anxiety - depression)

1 నాకు మనస్తాపము ఆందోళన లేదు
2 నాకు కొంచెం మనస్తాపము ఆందోళన ఉంది
3 నాకు ఘమా-రుగా మనస్తాపము ఆందోళన ఉంది
4 నాకు ఘమా-రుగా మనస్తాపము ఆందోళన ఉంది
5 నాకు విప-రీ-త-మైన మనస్తాపము ఆందోళన ఉంది

బుద్ధి/ మందత (Cognition)

1 తెలివితేటలు మామూలుగా వున్నాయి
2 నాకు కొంచెం మందత ఉన్నది
3 నాకు ఘమాగైన మందత ఉన్నది
4 నాకు తీవ్రమైన మందత ఉన్నది
5 నాకు విప-రీ-త-మైన మందత ఉన్నది

Appendix-3.5

6D5L Graphical Health State Description System

6D5L Graphics for Mobility

		
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	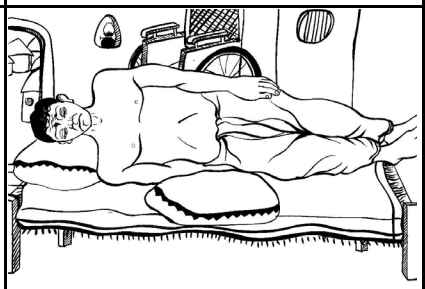	
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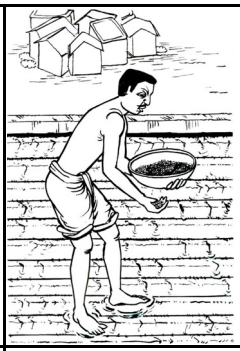
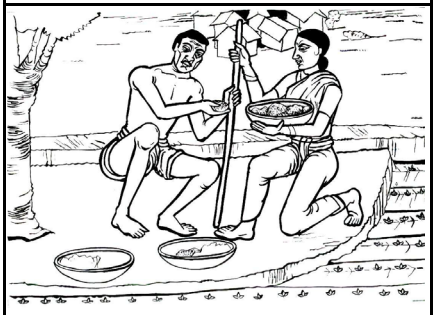
A22

6D5L Graphics for Self Care

6D5L Graphics for Usual Activities

		
	☒☒	☒☒☒
		
☒☒☒☒	☒☒☒☒☒	

6D5L Graphics for Pain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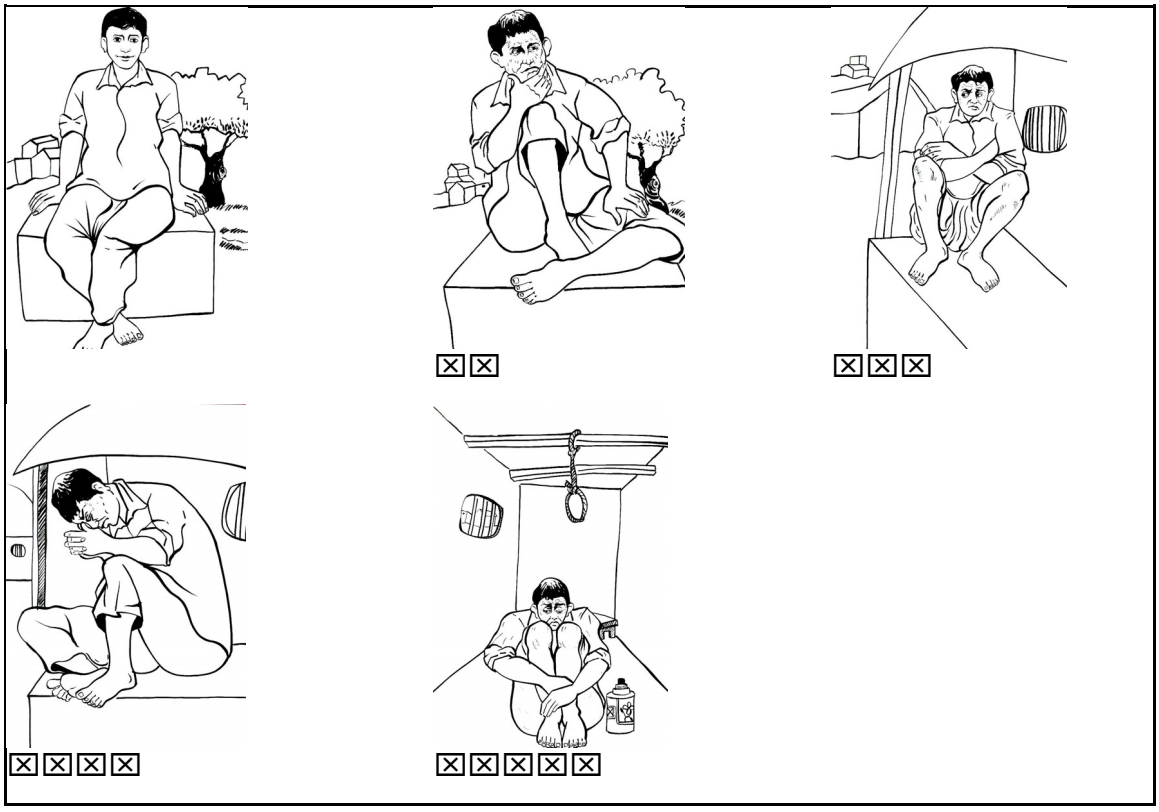
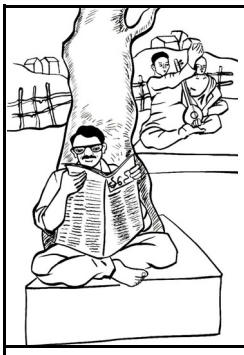
6D5L Graphics for Anxiety - Depression



6D5L Graphics for Anxiety - Cognition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Appendix-3.6

Artists brief to design pictorial representations of health dimensions

The Institute of Health System is carrying out a study to measure valuations given by people to different health states. The study will have two components: Part I - Health state valuation workshop in which educated participants will be requested to assign weights to different health states. Part II - Household survey in which a sample of adult population, irrespective of their educational status, will be interviewed to assess their valuation of different health states. One of the key inputs for the population survey instruments is to develop a description of each health state that can be well understood by the respondent population. Since the respondents are most likely to be uneducated, and considering the level of literacy in our population, it will be desirable for us to provide pictorial description of various dimensions (domains) of the different health states. To describe health states (Disease or Morbidity) we are going to use six dimensions as follows :

1. Mobility,
2. Self-care,
3. Usual activities,
4. Pain / discomfort,
5. Anxiety / Depression, and
6. Cognition.

Each dimensions / domains, will have five levels according to severity. A note titled "Health state dimensions for assessment of disability weights" and describing each of the dimensions and the levels under each is enclosed.

Following examples of pictorial representations used by for some what similar studies elsewhere is enclosed. Note that these pictures are given here to partially illustrate the kind of pictorial instrument to be developed. However, the artists should allow themselves the full freedom and brainstorm from ground up to arrive at the pictorial representations, for the present study.

i. Dartmouth Coop Function Charts (Nelson, E.C., Landgraf, J. M., and others), as reproduced in David Wilkin, Lesley Hallam, and Marie-Anne Doggett, a “Measures of Need and Outcome for Primary Health Care”, Oxford Medical Publications. 1991, Pg. 159-164.
ii. Faces Scale (Andrew and Withey SB), as reproduced in McDowell IAN and Claire Newell, “Measuring Health” - A Guide to Rating Scales and Questionnaires”, Oxford University Press, Pg. 215.

The art team task is to arrive at the most appropriate pictorial representation of each of the six Health state dimensions for assessment of disability weights.

Enclosures:

1. Health state dimensions for assessment of disability weights
2. Dartmouth Coop Function Charts
3. Faces Scale.

Appendix-3.7

Health state description workshop - proceedings.

1. We decided to use expert judgement arrived by a consensus development method for identification of 6D5L profiles for identified disease states. A workshops was organised to bring together a panel of physicians and nurses from various fields working in public and private hospitals. Altogether a group of 19 physicians and 4 clinical nurses participated. All panel members had clinical positions in local hospitals. Since the panel members were in their practice communicating with patients and attendants in the Telugu language (the primary language in the study area), we planned to obtain an initial draft of Telugu translations of the written description system as well as the disease state labels. The panel worked over two sittings. Thus the panel had two primary tasks, identification of 6D5L profiles for disease states and translation of the health state description system from English to Telugu.
2. First workshop of the description cum translation panel:
    i. The following written documents were provided to participant immediately after registration. Participants were then requested to go through them, allowing for required time in the workshop program.
        a. General guidelines to participants for the health state description workshop (appendix - 3.2a)
        b. The EuroQol Instrument - An overview (appendix - 3.2b).
        c. Health state description worksheet containing the list of disease states for which 6D5L profiles had to be arrived at.
    ii. Participants were given brief introduction about summary measures of population health, the concept of health state weights and disability weights, the EuroQol health valuation method, the 6D5L description system, and the tasks for the workshop.
    iii. Following task list was given to the participants for their reference:
        a. Arrive at a typical description of each given disease.
        b. Arrive at a description of each of the given disease along the six dimensions using the five levels of severity within each dimension.
        c. Arrive at Telugu labels for the given disease states, keeping in mind the local dialect of the Ranga Reddy district.
        d. Arrive at Telugu translation of the dimensions and the corresponding five levels under each dimension.
    iv. Participants were divided into three groups trying to keep each of them as multidisciplinary as possible. Each group was assigned a number of diseases / health states. The group members were advised to nominate a facilitator to record the group deliberations. They were requested to arrive at the description by consensus. If description for any health state could not be agreed upon, it was to be flagged for discussion in the plenary session. Participants were encouraged to discuss frankly and could ask investigators for clarification of doubts or questions at any time. If they thought that the draft matrix had anything missing they were also encouraged to make a note of it. They were informed that at the end of their deliberations there would be plenary session where the group has to present the descriptions arrived at by them followed by discussion on each of the health states to develop a broader consensus. Finally participants would also get a chance to reflect on their experiences about the description exercise.

a. The groups started out by identifying 6D5L profiles for the assigned diseases.
b. The next task was to arrive at the Telugu labels for the given diseases. Panelists were reminded that the health states (with the standard descriptions) will be used in a household survey in order to elicit valuation as perceived by the general and sometimes illiterate population. They were requested to keep in mind that these labels will have to be understood by the lay persons in villages of Ranga Reddy District, where the household survey was to take place.
c. Finally the groups translated a part of the 6D5L descriptive system, assigned to them, in to Telugu. Two of the six dimensions were assigned to each group. First they translated the dimension labels and then the levels within each dimension.

v. Plenary: After group discussions, participants from all groups met in a plenary session. Each group presented their recommendations followed by discussions to arrive at a plenary level consensus.
vi. Open session: There was a final open session to discuss and share individual or group experiences of the workshop. During the open session, it was observed that;
   1) Participants tended to confuse between the first three dimensions namely;
      i) Mobility
      ii) Self care
      iii) Usual activities
   2) People assumed that pain / discomfort will tend to affect the first three dimensions always. Since there are five levels, people tended to use the milder disability levels. For example a reduced level of functionality in the mobility dimension was assigned to a health state like severe migraine on the premise that persons with such severe headache will not want to move about, even though the locomotion system was perfectly all right. We realised that participants had difficulty in discriminating between the first three dimensions i.e. mobility, self care and usual activities. They tended to assume that if some one had some degree of pain that will affect all these three dimensions as well. They ended up giving positive levels of disability along these three dimensions almost for every condition.
   3) It was felt that most participants had been introduced to the concept of summary measures, health status measurement and functional indexes for the first time. Most participants felt that they needed to know more of these concepts, in order to deliberate on the descriptive system.
   4) More over, they wanted to study the supplied literature and briefs in greater detail and ponder over them.
   5) So it was decided to reassemble in a second workshop after a gap of about two weeks.

3. Second workshop of the description cum translation panel: In order to clarify doubts and reduce biases a second workshop was organised with the same set of participants.
   i. The following concepts of Impairment, Disability and Handicap (IDH) were presented to them.
      a. **Impairment**: A reduction in physical or mental capacities. Impairments are generally disturbances at the organ level. They need not be visible and may not have adverse consequences for the individual. Where the effects of an impairment is not corrected a disability may result.
      b. **Disability**: Restriction in a persons ability to perform a function in a manner considered normal for a human being. For example; to walk, to have full use of one's

senses. Disability may or may not limit the individual's ability to fulfill a social role, depending on the severity of disability and what the person wishes to do.

c. **Handicap**: Social disadvantage (e.g. loss of income) that may arise from disability. A minor injury can handicap an athlete but may not noticeably restrict some one else.

ii. There was some discussion regarding the EuroQol instrument dimensions and levels and modifications to the EuroQol by the 6D5L system. This was done in order to show the EuroQol lineage of the 6D5L instrument.

iii. In order to make things more clear, concepts of ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) were presented.

iv. Following scales used to measure functional status in different settings were briefly mentioned, based on descriptions largely obtained from McDowell and Newell (1987, 1996).

a. Activities of daily living (ADL) scales.
   1) PULSES profile
   2) Barthel Index
   3) Index of ADL: Index of independence in activities of daily living.
   4) Kenny Self care evaluation.

b. Instrumental activities of daily living scales (IADL):
   1) Functional Status Index.

v. A consensus developed that secondary effect of dysfunction in one dimension on another dimension, particularly when the secondary effect leads to a certain choice by the person but does not necessarily affect his / her ability in that dimension, should be ignored while assigning level of functionality in the other dimension.

After this presentation all the selected disease conditions were described one by one on the six dimensions and five levels, as was recommended by them in the earlier workshop. This time it was much easier for the participants to identify 6D5L profiles for the chosen disease conditions.

Appendix-3.7a

General guidelines to participants for the health state description workshop

The purpose of this workshop is multi-fold. Usefulness of summary measures of population health status and the need for health state weights shared by the general population has been explained in the earlier presentations. The following is a task list for your reference:

1. Arrive at description of each given disease state across the six dimensions using the given five level description of each dimension.
2. Arrive at a clinical description of each given disease corresponding to the six dimension rating given in the step described above.
3. Arrive at the Telugu labels for the given disease states, keeping in mind the local dialect of the Ranga Reddy district.
4. Arrive at the Telugu translation of the dimensions and the corresponding five levels under each dimension.

We will divide you into three groups before any deliberations regarding the description starts. Each group will be assigned a number of disease / health states as well as some levels pertaining to dimensions to work upon. The group members will nominate a facilitator to record the group deliberations. A consensus method may be adopted to arrive at agreed descriptions. If there are some descriptions that cannot be agreed upon then they can be flagged for later discussion in the whole group. Please feel free to make frank discussions. You are also free to ask any doubts and questions at any time. If you think the draft matrix has anything missing you may make a note of that too. At the end of your deliberations as a group we will provide a presentation of the consolidated description of the disease states across the six dimensions and five levels. There will be a presentation and discussion of the summary list of the translated terms. Finally you will be reflect on your experiences about the description exercise.

A. Arriving at description of each given disease state across the six dimensions using the given five level description of each dimension

Before we proceed further, I would like to revisit the dimension and the levels in each dimension so that it becomes easier to complete the tasks. (Insert here the section on the definitions and examples of dimensions and levels)

The first step in the exercise is to arrive at an agreed description of the disease / health states proposed to be studied. Please refer to the sheet with the heading “Selected health state conditions along the six dimension”. This sheet contains a matrix of some disease conditions selected by the IHS team in order to be used in a later population survey to elicit disability weights. Please go through all the conditions assigned to your group and prepare a description of the disease conditions as understood by you by its label. Please use a sheet of paper in order to write down the distinguishing features of the disease conditions. We have some medicine text books available for your reference if required.

There is a sheet with the heading “Severity codes along various dimensions”, containing the different dimensions with the names and description of each dimension and level with examples. To standardise the descriptions, we have chosen the six dimensions:

1. Mobility
2. Self care

3. Usual activities
4. Pain / Discomfort
5. Anxiety / Depression
6. Cognition

Please go through the meanings and the examples of the different dimensions and levels (See separate sheet on this). Examples of disease states showing deviations along each of the dimensions have been developed by us to help explain each dimension and distinguish between them. You will notice that each dimension has five levels. The first level characterises no difficulty in the functioning along the particular dimension and the fifth level characterises to most difficulty resulting in nonfunctioning along that particular dimension.

The objective of this workshop is to come up with reliable and valid description of the dimensions and levels. Once you have agreed upon that, you may then move to the sheet with the selected disease conditions and reach a consensus regarding the levels to be assigned to each of the dimensions for each of the conditions assigned to you. Please fill out the matrix of the disease conditions provided to you. If there are some disease conditions for which you could not reach a consensus, you may flag them and move on to the other sections. It will be useful if you do not stick on one condition for a very long time as a result of which there may not be sufficient time to discuss the rest.

B. Arriving at the Telugu labels for the given disease states, keeping in mind the local dialect of the Ranga Reddy district

The next task is to arrive at the Telugu labels for the given disease states. As mentioned before, you may be aware that these disease states with the standard descriptions will be used through a survey method in order to elicit disability weights as perceived by the general population. In order to carry out this exercise we need to translate the disease labels to Telugu. Keep in mind that those labels will have to be understood by the local people in villages of Ranga Reddy District. So we have to keep in mind the local dialect of Ranga Reddy district. You may use the consensus method to translate the disease labels for the disease conditions assigned to your group.

C. Arriving at the Telugu translation of the dimensions and the corresponding five levels under each dimension.

The last but not the least task that we have in our list is the Telugu translation of the dimensions and the levels. Two of the six dimensions have been assigned to your group. Let us take each dimension, one at a time, and then reach a consensus as to which Telugu translation can best be understood by the local lay as well as illiterate person. After completing the translation of the dimensions, we can discuss each level in two dimensions.

D. Plenary:

After group discussions, we will all break for lunch. The post lunch session will be devoted for the plenary session, where each group will present their recommendations followed by discussions, if any is needed. Finally we will have an open session to discuss and share our experiences in this workshop.

Appendix-3.7b

The EuroQol Instrument - An overview

I. Health Related Quality of Life Measurements:

The earliest population health indices used readily available numerical indicators such as mortality rates. But as societies evolve, health problems alter in salience and new health indicators must be chosen to reflect changing health issues.

Improvements in public health have led to a shift away from viewing health in terms of survival, through a phase of defining it in terms of freedom from disease, thence to an emphasis on the individual's ability to perform his daily activities, and now to the current emphasis on positive themes of happiness, social and emotional well-being, and quality of life. In recent years, health-related quality of life (HRQOL) has emerged as an important component of clinical research. Traditional indices of health are now routinely augmented with measures of HRQOL, both to characterise populations and to assess the efficacy of various interventions.

II. EUROQol:

EuroQol is a health related quality of life measure[1]. It is a generic multidimensional health status measuring instrument. The EuroQol Group first met in 1987 to test the feasibility of jointly developing a standardised non-disease-specific instrument for describing and valuing health-related quality of life. The EuroQol instrument has been purposefully developed to generate a generic cardinal index of health. This ability of giving a cardinal measure makes it useful health care evaluation. It provides a simple descriptive profile and generates a single index value for heath status on which full health is assigned a value of 1 and death a value of 0.

From the outset, the EuroQol Group has been multi-country, multi-centre and multidisciplinary. Main focus of the Group has been global and the capacity to generate cross-national comparisons has been viewed as main aim.

A. EuroQol Dimensions:

EuroQol classification comprises five dimensions covering physical, mental and social functions.

1. Mobility
2. Self care
3. Usual activities
4. Pain / discomfort, and
5. Anxiety / depression.

The first three dimensions represent the physical aspect of health. Usual activities represent social well being aspect of health, and the fifth dimension, namely anxiety / depression represents mental health.

One of three levels is chosen for each dimension and thus the health state can be defined by a five digit number. By combining different levels from each dimension, EQ-5D defines a

---

[1] Other major HRQOL instruments include SF-36, SF-26, Nottingham Health Profile, Sickness Impact Profile (SIP), etc.

total of 243 health states. These may be converted to a score using "sets of values" derived from general population samples.

B. Components of the EuroQol instrument:

1. The EuroQol Instrument (EQ-5D) has four components
   i. Description of the respondent's own health by means of the EuroQol classification.
   ii. Rating of own health by means of the EuroQol thermometer: This is a 'thermometer' is a vertical 20 cm visual analogue scale with endpoints of 100 (best imaginable health state) at the top and 0 (worst imaginable health state) at the bottom. The EQ-5D thermometer offers a simple method for obtaining a self-rating of current health-related quality of life by generating a score. This page should be used in conjunction with the five-digit classification on page 2 to build an accurate profile of the respondent's health status.
   iii. Valuation of a standard set of health states defined by the EuroQol classification (pages 5 and 6):A selected list of indicator conditions are given to the respondent and (s)he is asked to classify each condition as per the above format.
   iv. Background information about the respondent: These are a series of questions designed to elicit background information on the valuer.

C. Uses of EuroQol instrument:

The responses from EQ-5D can be used in the following ways:

1. The descriptive data from page 2 may be used as a profile indicating problems across the 5 dimensions, either through time for a particular respondent or cross-sectionally, comparing outcomes for different respondents.
2. The descriptive data from page 2 can generate a weighted health index, based on tables of values derived from general population samples.
3. The score on the self-rated "thermometer" indicating the patient's own assessment of their health state may be used to analyse changes in the health status of individuals or groups of individuals over time.
4. Age / sex norms have been established for the general population in national surveys. Comparative data are available from a range of international clinical studies.
5. EQ-5D has widespread potential use and can be used to fulfill several important functions including:
   i. Monitoring the health status of patient groups at different moments in time, e.g. referral, admission, discharge, follow-up of outpatients.
   ii. Evaluation and audit of health care, by measuring changes in health status in individual patients and in groups of patients.
   iii. Assessing the seriousness of conditions at different moments in time.
   iv. Providing relevant information for resource allocation at a variety of levels.
   v. Assisting in providing evidence about medical effectiveness in processes where drugs or procedures have to be approved.
   vi. Establishing levels of population health status both locally and nationally. Examples include health surveys carried out in Canada, Finland, Spain (1994 Catalan health survey interview) and the UK (UK Department of Health Omnibus Sample Survey 1996, Health Survey for England).

6. We are discussing EuroQol today because it provides the foundation for the dimensions we propose to use to assess health state weights for estimation of Global Burden of Disease (GBD).

III. Dimensions for assessment of disability weights used to measure global burden of disease:

Although the EuroQol covers most of the important aspects of our current concept of health, there has been some discussion and doubts about the need to include additional dimensions. There is a feeling among many researchers that cognitive aspect of a healthy life is not well covered in the present five dimensions. Research on this issue suggest that adding cognition as the sixth dimension will improve information content of the EuroQol measurements. The health state valuation for purposes of summary measures of health status and burden of disease estimation seeks to use six dimensions. The fist five are same as the recent EQ-5D instruments. The sixth dimension is cognition. Hence we will use the following six dimensions for purposes of the health state valuation study in Andhra Pradesh. Another modification is in the number of levels under each dimension. We propose to describe the variation and intensity of disability along each dimension using five levels, instead of three as in EQ-5D. The levels will range from no problem to complete dysfunction.

1. Mobility
2. Self care
3. Usual activities
4. Pain / Discomfort
5. Anxiety / Depression
6. Cognition.

IV. References:

1. Brooks Richard and EuroQol group. EuroQol: the current state of play. Health Policy. 1996; 37:53-72.
2. McDowell Ian and Newell Claire. Measuring health: a guide to rating scales and questionnaires. New York / Oxford: Oxford University Press; 1987.
3. McDowell Ian and Newell Claire. Measuring health: a guide to rating scales and questionnaires. New York / Oxford: Oxford University Press; 1996.

Appendix-3.8

Table-3.1: Identification of 6D5L profiles: Provisional, panel recommended and final.

Health States	Prov. Panel Final	Remarks
Tuberculosis	112221 111121 111221	Classical pulmonary tuberculosis can cause some discomfort due to cough, tiredness. Usual activities do not get affected untill very late stages, although physical productivity may slightly be lower.
Diabetes	112121 111121 111121	Panelists assumed non insulin dependent diabetes controlled by exercise or oral antidiabetic. At this stage most diabetics are able to do their usual activities.
Quadriplegia	554341 555441 554341	Provisional profile rated pain - discomfort lower than the panelists. Although, panelists probably kept in mind the discomfort aspect of this dimension, we thought it would not merit the worst dysfunction in pain / discomfort dimensions and felt level 4 in provisional profile was quite alright.
Angina	112321 111321 111321	Provisional profile assumed that usual activities will also be affected. Panelists felt, that people with angina are usually able to go about their work, except during the attacks which is a separate disease state (acute myocardial infarction).
Severe migraine	233524 113431 113431	Panelists felt, migraine does not affect cognition. People with migraine can certainly take care of their eating, bathing, etc. The provisional profile appeared to have exagerated dysfunction in some dimensions.
Unipolar major depression	113133 114152 124142	The provisional profile and the panel appeared to refer to two different patient categories. The question is which is more prevalent. We consulted experts at the National Institute of Mental Health and Neurosciences (NIMHANS) Bangalore about the profile that is more prevalent. Their recommendation was 224142. Our final profile adopted the same with mobility level revised to 1.
Arthritis	222211 312321 222311	The rating of mobility can be either way. Hence it is a question of prevalence. Probably most patients experience some difficulty rather than a lot. So we agreed with the provisional rating of 2 in this dimension. But kept the pain - discomfort at 3 as recommended by the panel.
Urinary incontinence	112221 113431 113331	The provisional profile probably took into account better support and aids available in the developed countries to handle incontinence. We agreed on an intermediate profile.
Moderate anaemia	112121 112211 112211	Both agree on rating of usual activity domain. The panelists felt there is some pain - discomfort due to moderate anaemia. This is usually due to easy fatiguability, breathlessness, etc. The provisional profile, on the other hand meant these people are anxious some what. Panelists experience was that many people with moderate anaemia come to terms with it and suffer the discomfort. Usually they do not complain. We agreed with the panel recommendation.

Health States	Prov. Panel Final	Remarks
Peptic ulcer	112321 111321 112321	Both are same on the last three dimensions. Provisional profile meant that usual activity is affected some what. We decided to continue with the provisional profile.
Common cold	112211 111211 112211	The two differ only in respect of usual activities. The provisional profile meant some restriction in usual activities due to common cold. We decided to stick with this view.
Bronchitis	112311 111211 112311	The provisional list and panelists appeared to refer to two different severity levels. We felt most persons with bronchitis have some restriction on usual activities and hence continued with the provisional profile.
Schizophrenia	234245 123134 234244	The pattern is similar in both cases. We consulted experts at the at the National Institute of Mental Health and Neurosciences (NIMHANS) Bangalore and accepted their recommendation.
Blindness	323121 123222 323122	Blindness certainly affects mobility, particularly community mobility. Blindness can affect cognition by limiting the sensory input. Panelists rated 2 in pain-discomfort dimension, probably thinking of discomfort. We felt most blind people usually adapt and do not experience much of pain - discomfort. Since we are rating 2 in anxiety - depression domain, we can rate the pain-discomfort domain as 1.
Below knee amputation – two legs	433221 433331 433221	The rating on first three domains are same. The rating on anxiety - depression will depend on our assessment about the extent of coping. We know that these people generally cope well and hence we agreed with a lower rating on anxiety - depression as in provisional profile. Pain-discomfort after the amputation is usually minimal. So we preferred the provisional profile.
Below knee amputation – one leg	322211 322231 322211	As above.
Severe sore throat	NA 112311 112311	We did not have this in the provisional profile. We added this disease label to be used as examples to explain the scaling methods.
Severe heart failure (Congestive)	444431 234532 434531	There is usually no cognitive loss in patients with CCF. The pain and discomfort can be really bad, particularly when we are talking of severe CCF. These patients do retain control of their bladder and bowel and can ease themselves with some assistance. So we revised self care as 3 and pain / discomfort as 5.
Vitiligo on face	111121 111131 111131	We differed on assessment of the amount of stigma attached with vitiligo. This can be culture specific and can be gender specific also. So used the local assessment.

Provisional profile and panel recommendations matched for the following four diseases; Watery diarrhoea 111211, Infertility 111131, Mild hearing disorder 112121, and Paraplegia 444431.

Appendix - 4.1

Your Health State Today

We would like you to describe your current health today using the health state dimensions introduced earlier. By placing a tick (thus þ in one box in each group below, please indicate which statements best describe your own health state today.

Mobility:

- o I have no problems in walking
- o I have occasional or very few problems in moving about
- o I have some problems in moving about
- o I have many problems in moving about
- o I am unable to move at all

Self Care:

- o I have no problems with self care.
- o I have very few problems with self care like eating, bathing, dressing etc.
- o I have some problems with self care like eating, bathing, dressing etc.
- o I have many problems with self care like eating, bathing, dressing etc.
- o I am unable to bathe, dress or eat myself

Usual Activities:

- o I have no problems with usual activities like work, employment, household work.
- o I have occasional or very few problems in performing usual activities.
- o I have some problems in performing usual activities.
- o I have many problems in performing usual activities.
- o I am unable to perform my usual activities.

Pain/Discomfort:

- o I have no pain and no discomfort.
- o I have mild pain or discomfort.
- o I have moderate pain or discomfort.
- o I have distressing pain or discomfort
- o I have excruciating, unbearable pain or discomfort

Anxiety/Depression:

- o I am not anxious or depressed.
- o I am a little anxious or depressed.
- o I am moderately anxious or depressed.
- o I am much anxious or depressed.
- o I am extremely anxious or depressed.

Cognition:

- o I have no impairment of cognitive function or no cognitive problems
- o I have a little/very few cognitive problems.
- o I have moderate impairment of cognitive function.
- o I have considerable impairment of cognitive function.
- o I have severe impairment of cognitive function.

Compared with my general level of health over the past 12 months, my health state is:

(Please tick one)

- o Extremely well
- o Better
- o Much the same
- o Bad
- o Worse

Appendix - 4.2

Card Sort and Visual Analogue Scale

Instructions for health state valuation exercises

The purpose of this section is to find out how you value time spent in different health states. Your answers help us build a picture of how individuals value their health. Please imagine a series of different health states. For each state, consider how this state would compare to other health states, including the best and worst imaginable health states.

Card Sort Exercise:

Let's begin by looking at the 11 flash cards (10 preprinted + one prepared by you describing your own health today). Each card describes a different health state. What we would like you to do is compare each of the cards and sort them according to how undesirable each card would be if you were to have the health state described on the card for the rest of your life.

Please keep the card representing the most undesirable health state away from you. The card representing the most healthy stage near you. Sort and arrange all cards in order of the severity of the health state, starting with the least severe near you and moving towards the most severe ones away from you.

Visual Analogue Scale:

Please take a look at the scale on the cork board. Now we would like to ask you to use this scale to indicate just how desirable or undesirable you find each of these health states on a scale ranging from the best imaginable health state to death. On this scale, 0 indicates a health state that is as undesirable as death, and 100 indicates the most desirable health state imaginable. For each state, please pin these cards to the spot on the line that indicates this value. For example, if you find a health state to be halfway between death and the best imaginable health, you would pin the card on the point labeled 50. For each of the index cards you have ranked, we would like you to pin the cards on this scale on the cork board.

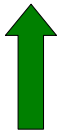
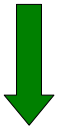
Compare your rank order of the cards earlier and the values in the scale now given by you. Take an overview of the two valuations. Are they consistent ? Are you satisfied that this ordering reflects your true beliefs about how undesirable each of these conditions would be to live with for the rest of your life?

Appendix - 4.3

CARD SORTING LOG

Health State Valuation

Name: **ID No.:**

	**Disease Labels**	**CS Rank**	**VAS Score**		
		1.			
Best imaginable health state		2.			
		3.			
		4.			
		5.			
		6.			
		7.			
		8.			
Worst Imaginable health state		9.			
		10.			
		11.			

Appendix - 4.4

Respondent Comments, Valuation workshops

Name:

Please indicate the level of difficulty you encountered in answering the questions or tasks on …

	No difficulties	Very few difficulties	Some difficulties	A lot of difficulties
Assessing your own health status	**0**	**1**	**2**	**3**
Card sort exercise	**0**	**1**	**2**	**3**
Visual analog exercise	**0**	**1**	**2**	**3**
Time trade-off exercise	**0**	**1**	**2**	**3**
Person trade-off exercise	**0**	**1**	**2**	**3**

How helpful did you find the following materials or presentations?

	Not helpful	Somewhat helpful	Very helpful
Written background on workshop purpose	**0**	**1**	**2**
Spoken presentation on different domains of health status	**0**	**1**	**2**
Written instructions on card sort exercise	**0**	**1**	**2**
Spoken instructions on card sort exercise	**0**	**1**	**2**
Written instructions on visual analog scale	**0**	**1**	**2**
Spoken instructions on visual analog scale	**0**	**1**	**2**
Written instructions on time trade-off	**0**	**1**	**2**
Spoken instructions on time trade-off	**0**	**1**	**2**
Written instructions on person trade-off	**0**	**1**	**2**
Spoken instructions on person trade-off	**0**	**1**	**2**

Any other comments?

Appendix - 4.5

Health state valuation workshop: General guidelines to participants

1. "The purpose of this workshop is to find out your opinion about the burden that different diseases represent to individuals who are affected by them. By burden we mean loss of physical and social functioning, discomfort, anxiety or depression and loss of cognition. Loss of physical and social functioning would include loss of mobility, ability to take care of oneself and to do usual activities. We do not have in mind the economic burden to the individual or society for example, loss of income or production. Hence you should not take the economic consequences into account when you do the valuations give your judgement throughout this workshop.
2. We are going to ask you to imagine a series of different health states. For each state, we will ask you to consider how this state would compare to other health states, including the best and worst imaginable states.
3. The workshop will start with a self assessment exercise to describe your own health state today. This exercise will allow you to assess your own health state today and in the process give you an idea of the six dimensions and levels of functionality under each dimension, being used by us to describe a persons health state.
4. The self assessment exercise will be followed by exercises to attach a preference value to a set of health states with reference to the best and worst imaginable health states. Your own health state will be included in this set. The other conditions included in the set have been chosen by us. We will use more than one exercise of to facilitate your valuation from different perspectives. These exercises in order are:
   i. Card sort: Each card represents a health state. You will be required to sort them in order of the severity of each health state.
   ii. Visual analogue scale: You will be required to fix the degree of severity of a health state on a scale extending from the best imaginable health to worst imaginable health state.
   iii. Time Trade off (Health State Valuation Worksheet -1) : You will consider hypothetical health conditions faced by yourself. In this thought experiment, you will be required to choose between a certain time lived in perfect health against a longer duration spent in a given health state (i.e. disease condition).
   iv. Person Trade off (Health State Valuation Worksheet -2A ,2B): You will play the role a decision maker. In this thought experiment, you will be presented with alternative interventions and health care programmes seeking to either extend the life of a group of perfectly health people or benefit a group of people suffering from a given health state (disease state). You will have to make choices, in view of constraint in resources.
5. At intermediate stages, you will be called upon to reflect upon your valuations through different exercises and methods. Inconsistencies between valuation of the same health state by different methods will be pointed out. You will be required to revise you valuation(s) to make them consistent across different methods and instruments.
6. The final session of the workshop will provide the ultimate opportunity to reflect on your valuations and revise them to achieve consistency across various methods."

Appendix - 4.6

HSV-DEDIT Data Entry Template - User manual.

A. Installation:

1. The template file named HSVWkshpDataEntry.12M. Copy this file to the same directory where Lotus 123 smart masters are stored (Usually C:\lotus\smasters\123).

B. Opening a new instance of the IDT (HSV Data Entry) Spreadsheet:

1. You will need to open a separate spreadsheet file for each valuer.
2. Start Lotus 123 and click the File-New icon. When the new workbook dialog box appears, select the smart master named "HSV-IDT: Date Entry and Report" and click OK to open the template.
3. The untitled work book contains altogether 11 sheets, namely PrsnlData, CardSort_VAS, TTO_OwnHlth, TTO_Data, TTORflctn1, TTORflctn2, PTO1_OwnHlth, PTO2_OwnHlth, PTO1_2, Post_PTO, and Definitions.

C. Personal data:

1. The first sheet of the workbook is to collect personal data. The work book usually opens with the cursor positioned on "Valuer Name".

Name:	Valuer Name		
Sex:	Female	**Date:**	13-Oct-99
Age	21		
Participant ID:	75_3u		
Own Health Description			
	Dimension		Level
	Mobility		1
	Self Care		1
	Usual Activities		1
	Pain - Discomfort		1
	Anxiety - Depression		2
	Cognition		1
Assigned health states for valuation:			Set3

2. Fill in the personal data. In a color screen, Lotus-123 shows the data entry areas in blue. The workbook uses information form this data entry area to make choices about contents of subsequent reports. So all required personal data must be filled in here.
   i. The participant Id should be of the format Serialnumber_Setnumber+u or d. The right most character of the participant Id must be u (for upwards) and d (down wards). The second character from the right (set number) must be a number ranging from 1-4, since this workbook allows only four sets of indicator conditions.

D. Card sort and VAS:

1. After filling in the personal data click the next tab "CardSort_VAS". This sheet has two panels. The upper data entry panel and the lower report panel. The list of health states is automatically taken from a dictionary based on the set number extracted from the participant id entered in the personal data sheet.
2. Following is a screen capture of the upper panel after entering data from the first iteration:

Card Sort and Visual Analogue Scale Data Entry

Iteration Order (1 for first attempt, 2 for the second attempt, 3 for third attempt, so on ...): 1

Iteration order of the final results, i.e. 'Ranks match' for all the 11 health states:

		First attempt		Subsequent Attempts		Final Results	
SI	Health State Conditions	CS_Ogl	VAS_Ogl	CS_SA	VAS_SA	CS_Final	VAS_Final
1	Own Health Today	3	1				
2	Mild 'Diabetes, no symptoms	1	20				
3	Watery diarrhoea, 5 times a day	2	30				
4	Peptic ulcer	4	44				
5	2 broken arms in stiff casts	5	32				
6	Mild'Tuberculosis with treatment	8	60				
7	Below knee amputation - two legs	9	40				
8	Below knee amputation - one leg	6	50				
9	Severe continuos migraine	7	76				
10	Unipolar major depression	11	81				
11	Quadriplegia	10	90				

Card sort ranking is from best to worst, i.e. best is rank 1 and worst is rank 11.

3. Note the cell in the upper right corner. Fill in the iteration order for which you are entering data. If the data relate to the first iteration, enter 1 here. If its the second iteration, enter 2 here. Also note that you need to enter the card sort rank and VAS data in different columns depending on the iteration order which generated the data. If the data is from the first iteration then enter them in the area under "First attempt". The two columns are CS_Ogl for the card sort ranks from the first attempt, and VAS_Ogl for the VAS values from the first attempt. Data from subsequent iterations is to be entered in the area under "Subsequent Attempts". The card sort ranks from subsequent iterations are entered under CS_SA and VAS values from subsequent iterations are entered under VAS_SA. Thus when you enter the data from second iteration, you will find the columns empty. When you enter data from the third iteration, you will have to over write the data from second round. The final results area in the upper panel shows the card sort ranks and
4. Now move down to the lower panel and print the "Reflections" report (see next page for a sample corresponding to the data entered in the upper panel shown above) at the lower panel to be given to the valuer for reflection. Note that none of the VAS values is consistent with the card sort rank. So the number for which ranks match (between card sort and VAS) is shown as zero at top left corner of the report. The report then explains to the valuer about itself, and gives a comparative statement of card sort and VAS ranks, along with remarks about the nature of discrepancy, if any.
5. Note that the valuer gives his / her valuation in terms of the health state weight. The "Reflections" report converts that into a disability weight while presenting a comparison of the card sort. This was done deliberately, to remind the valuers the relationship between health state weights and disability weights. This reminder helps valuers to keep in mind that the two are complements of each other and valuing one implicitly values the other.

Reflections: Reconcile Card Sort and Scale Based Valuations

Participant ID: 75_3u **Name: Valuers' Name** **Date: 13/10/99** **Attempt: 1**

Thank you for valuing the given health states using the scale board and the set of cards with pins. We have measured the scale values of health assigned by you to each condition. These are given below. Based on these scale values of disability, we have arrived at the rank ordering of the conditions. You may recall that rank ordering of conditions assigned by you in the card sort exercise earlier. We have shown below all these assignements given by you earlier, namely;

(a) Rank from Card Sort exercise.
(b) Disability weight assigned by you to the condition using the Scale board.
(c) Rank order of conditions based on the disability weight from the Scale board exercise.

Sl	Health State Condition	CS_Rank	DWt	DWt_Rank	Remarks
1	Mild 'Diabetes, no symptom	1	0.8	10	Scale based value ranks more sever than Card
2	Watery diarrhoea, 5 times a	2	0.7	9	Scale based value ranks more sever than Card
3	Own Health Today	3	0.99	11	Scale based value ranks more sever than Card
4	Peptic ulcer	4	0.56	6	Scale based value ranks more sever than Card
5	2 broken arms in stiff casts	5	0.68	8	Scale based value ranks more sever than Card
6	Below knee amputation - or	6	0.5	5	Card sort ranks more severe than scale based
7	Severe continuos migraine	7	0.24	3	Card sort ranks more severe than scale based
8	Mild'Tuberculosis with treatr	8	0.4	4	Card sort ranks more severe than scale based
9	Below knee amputation - tw	9	0.6	7	Card sort ranks more severe than scale based
10	Quadriplegia	10	0.1	1	Card sort ranks more severe than scale based
11	Unipolar major depression	11	0.19	2	Card sort ranks more severe than scale based

Please reflect upon the above discrepancy. To reconcile your valuations in the two exercises, you can do all or any of the following:

(a) Redo the Card Sort **Note: Dwt = 1-(Scale Value / 100)**
(b) Redo the Scale based valuation
(b) Both

Now please reflect and revise your valuations and let us have your revised estimations.

6. Now suppose the valuer has given his second iteration results as follows:

Card sort rank	3	1	2	4	5	8	9	6	7	11	10
VAS Value	80	90	85	75	60	40	30	55	45	5	20

7. When you enter this data in the subsequent attempts area, you will see the following upper panel.

Card Sort and Visual Analogue Scale Data Entry

Iteration Order (1 for first attempt, 2 for the second attempt, 3 for third attempt, so on ...): 2

Iteration order of the final results, i.e. 'Ranks match' for all the 11 health states:

		First attempt		Subsequent Attempts		Final Results	
SI	Health State Conditions	CS_Ogl	VAS_Ogl	CS_SA	VAS_SA	CS_Final	VAS_Final
1	Own Health Today	3	1	3	80		
2	Mild 'Diabetes, no symptoms	1	20	1	90		
3	Watery diarrhoea, 5 times a day	2	30	2	85		
4	Peptic ulcer	4	44	4	75		
5	2 broken arms in stiff casts	5	32	5	60		
6	Mild'Tuberculosis with treatment	8	60	8	40		
7	Below knee amputation - two legs	9	40	9	30		
8	Below knee amputation - one leg	6	50	6	55		
9	Severe continuos migraine	7	76	7	45		
10	Unipolar major depression	11	81	11	5		
11	Quadriplegia	10	90	10	20		

Card sort ranking is from best to worst, i.e. best is rank 1 and worst is rank 11.

No for which Ranks Match = 11

8. Note the bottom right message, that shows that ranks have matched for all the 11 conditions. Once you get all the 11 ranks to match, type in the iteration number in the cell B:I13 which is immediately below the iteration number on the top right corner. That means you have the same iteration number repeated twice and appearing one below the other. Once you hit the Enter key after typing in the iteration number in cell B:I13, you see the final results from Card sort - VAS exercise appearing in the "Final Results" area and the upper panel looks as follows. If the ranks form the two estimates match in the first iteration itself, then simply type in 1 in cell B:I13 and proceed.

Card Sort and Visual Analogue Scale Data Entry

Iteration Order (1 for first attempt, 2 for the second attempt, 3 for third attempt, so on ...): 2

Iteration order of the final results, i.e. 'Ranks match' for all the 11 health states: 2

		First attempt		Subsequent Attempts		Final Results	
SI	Health State Conditions	CS_Ogl	VAS_Ogl	CS_SA	VAS_SA	CS_Final	VAS_Final
1	Own Health Today	3	1	3	80	3	0.8
2	Mild 'Diabetes, no symptoms	1	20	1	90	1	0.9
3	Watery diarrhoea, 5 times a day	2	30	2	85	2	0.85
4	Peptic ulcer	4	44	4	75	4	0.75
5	2 broken arms in stiff casts	5	32	5	60	5	0.6
6	Mild'Tuberculosis with treatment	8	60	8	40	8	0.4
7	Below knee amputation - two legs	9	40	9	30	9	0.3
8	Below knee amputation - one leg	6	50	6	55	6	0.55
9	Severe continuos migraine	7	76	7	45	7	0.45
10	Unipolar major depression	11	81	11	5	11	0.05
11	Quadriplegia	10	90	10	20	10	0.2

Card sort ranking is from best to worst, i.e. best is rank 1 and worst is rank 11.

No for which Ranks Match = 11

9. Note that the VAS_Final column shows the health state weights.
10. The "Reflections" report in the lower panel will look like the one shown on next page. It reiterates the message that ranks for each of the 11 health states match and shows the

disability weights for the latest iteration that matched the two estimates.

Reflections: Reconcile Card Sort and Scale Based Valuations

Participant ID: 75_3u **Name: Valuers' Name** **Date: 13/10/99** **Attempt: 2**

Thank you for valuing the given health states using the scale board and the set of cards with pins. We have measured the scale values of health assigned by you to each condition. These are given below. Based on these scale values of disability, we have arrived at the rank ordering of the conditions. You may recall that rank ordering of conditions assigned by you in the card sort exercise earlier. We have shown below all these assignements given by you earlier, namely;

(a) Rank from Card Sort exercise.
(b) Disability weight assigned by you to the condition using the Scale board.
(c) Rank order of conditions based on the disability weight from the Scale board exercise.

Sl	Health State Condition	CS_Rank	DWt	DWt_Rank	Remarks
1	Mild 'Diabetes, no symptom	1	0.1	1	Ranks match
2	Watery diarrhoea, 5 times a	2	0.15	2	Ranks match
3	Own Health Today	3	0.2	3	Ranks match
4	Peptic ulcer	4	0.25	4	Ranks match
5	2 broken arms in stiff casts	5	0.4	5	Ranks match
6	Below knee amputation - on	6	0.45	6	Ranks match
7	Severe continuos migraine	7	0.55	7	Ranks match
8	Mild'Tuberculosis with treatr	8	0.6	8	Ranks match
9	Below knee amputation - tw	9	0.7	9	Ranks match
10	Quadriplegia	10	0.8	10	Ranks match
11	Unipolar major depression	11	0.95	11	Ranks match

Please proceed to the next exercise

Note: Dwt = 1-(Scale Value / 100)

11. The "Reflection" report, at the bottom, instructs the valuer to proceed to the next exercise[1].

E. Time Tradeoff:

1. To move the valuer to the next exercise, click on the "TTO_OwnHlth" tab and print the "Your Own Health Today": Valuation worksheet -1, a sample of which is shown on the next page.

[1] The "Reflection" according to the original design of this program, continued to show the same instructions as for the care of less than complete match. The spread sheet was like this for most of the workshops in the study. We orally instructed the participants to proceed to the next exercise. Changes in the program to reflect his were done after all the workshops in this study were completed. We have done the changes, for future use of the spreadsheet.

"Your Own Health Today": Valuation worksheet -1

Participant ID: 75_3u Name: Valuers' Name Date: 13/10/99

We want to know your opinion about the burden that different diseases represent to individuals and families who are affected by them. By burden we mean loss of physical and social functioning (Mobility, self care and usual activities, physical and mental discomfort, anxiety or depression and loss of cognition. We do not have in mind the economic burden to society (for instance loss of production or incomes), and you should not take them into account when you respond to the question below.

Your Own Health Today

No assistance required and no problem with mobility. Ability to run / flight in times of need.

No assistance required and no problem with self care.

No assistance required and no problem with usual activities like work, employment, household work , etc. .

No pain and no discomfort.

A little anxiety or depression.

No impairment of cognitive function. No cognitive problems

Your age is 21.

Imagine that you are living in the health state described above, and must choose between two alternatives:
Alternative 1: You may continue to live in this health state for the rest of your life, that is, 42 more years.
Alternative 2: You may accept a medical intervention that will improve your health state to perfect health, but will reduce your life expectancy. Alternative 2, in other words, allows you to live a shorter number of years, but in better health.
We would like to know the smallest number of years of perfectly healthy life you would accept in exchange for the period in the reduced state of health described above. If you find the health state above to be extremely undesirable, you may be willing to trade it for a fairly short period of perfectly healthy life. On the other hand, if the health state above is rather mild in severity, then you may not want to give up much of your remaining life expectancy for an improvement to perfect health.
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer alternative 1 (mark the box on the left), would definitely prefer alternative 2 (mark the box on the right), or would find it difficult to choose between the two (mark the box in the middle). You should start with the first row and then continue to answer each question until you reach a situation for

Prefer Alt-1	Alternative-1	Doubt	Alternative-2	Prefer Alt-2
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 39.4 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 37.4 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 33.2 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 29.1 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 24.9 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 16.6 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 12.5 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 8.3 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 4.2 years.	☐
☐	Live with Your Own Health Today fo 42 years.	☐	Live a perfectly healthy life for 2.1 years.	☐

Your indifference point:
Live with Your Own Health Today fo 42 years. ☐ ☐ Years of perfectly healthy life.

2. To enter data from the first round of TTO valuations click on the TTO tab and enter the data into columns labeled Alt-1Yrs (Years of life available in Alternative-1), and InfifYrsFA (Number of years in Alternative-2 at which the valuer is indifferent between alternative - 1 and 2). Enter the iteration number at top right in cell number D:I2.

Post TTO Data Entry

Iteration Order (1 for first attempt, 2 for the first revision, 3 for second revision, so on ...): 1

Iteration order of the final results, i.e. 'Ranks match' for all the 11 health states:

			First attempt			Subsequent Attempts			Final Results	
SI	Health State Conditions	Alt-1Yrs	IndifYrsFA	FADWt	FARank	IndifYrsSA	DWtSA	SARank	IndifYrs	DWt
1	Own Health Today	32	28	0.13	6					
2	Mild 'Diabetes, no symptoms	32	30	0.06	3					
3	Watery diarrhoea, 5 times a da	30	28	0.07	4					
4	Peptic ulcer	24	10	0.58	9					
5	2 broken arms in stiff casts	32	5	0.84	11					
6	Mild'Tuberculosis with treatmer	30	29	0.03	2					
7	Below knee amputation - two l	24	14	0.42	8					
8	Below knee amputation - one l	47	46	0.02	1					
9	Severe continuos migraine	30	28	0.07	4					
10	Unipolar major depression	24	15	0.38	7					
11	Quadriplegia	30	6	0.80	10					

Card sort ranking is from best to worst, i.e. best = rank 1 and worst health state = rank 11.

No for which Ranks Match = 1

3. After entering the data here, click the next tab, namely TTORflctn1, select the "Reflection" report and print it out for the valuer. A sample of the report is given below.

Time tradeoff - reflections: Review the magnitude of disability weights

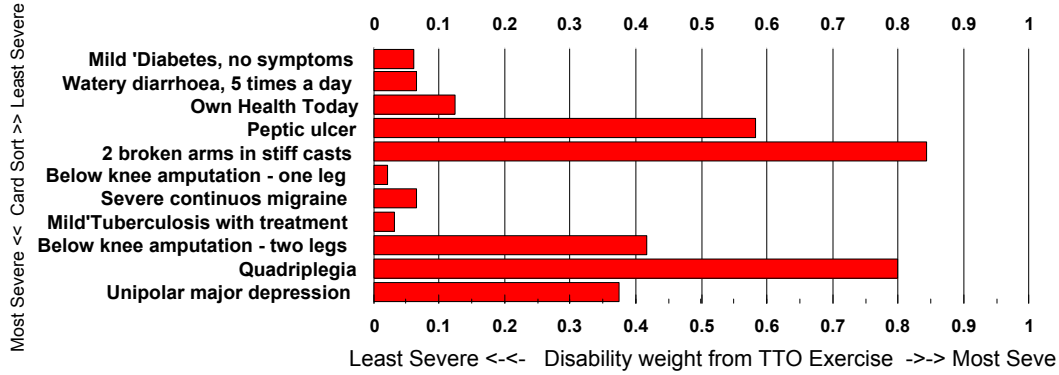
Date: 13/10/99

Participant ID: 75_3Name: Valuers' Name

Attempt: 1

Thank you for valuing the given health states using the Time Trade Off exercise. We have computed the disability weights implicitly assigned by you to each condition. These are shown on the right side of this note. The level of disability implied by your choice in the Time TradeOff exercise is also shown in the graph below. You may recall the rank ordering of conditions done by you in the card sort exercise earlier. We have arranged the conditions according to your card sort rank, so that you can reflect if your current valuations are consistent with the ordering of severity judged by you earlier.

SI	Health State Condition	DWt
1	Mild 'Diabetes, no symptoms	0.06
2	Watery diarrhoea, 5 times a day	0.07
3	Own Health Today	0.13
4	Peptic ulcer	0.58
5	2 broken arms in stiff casts	0.84
6	Below knee amputation - one leg	0.02
7	Severe continuos migraine	0.07
8	Mild'Tuberculosis with treatment	0.03
9	Below knee amputation - two legs	0.42
10	Quadriplegia	0.80
11	Unipolar major depression	0.38



Please reflect upon the degree of severity you have determined for each condition above, as well as any discrempancies between the card sort and Time Tradeoff exercises. Based on this reflection you may wish to revise your Time Tradeoff evaluations. We would recommend that you do not revise the card sort at this stage, since you have already reflected on it adequately. Now please reflect and revise your valuations and let us have your revised estimations.

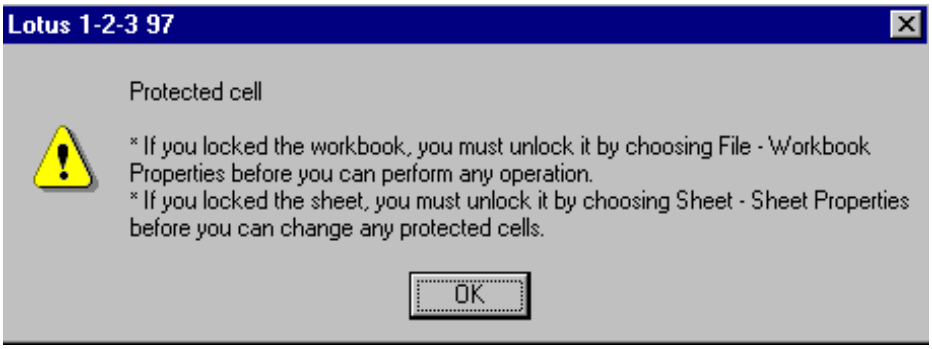
4. To enter data for the second and subsequent iterations click the TTO_Data tab and enter the revised number of years in Alternative-2 at which the valuer is indifferent between alternative - 1 and 2 under the column labeled IndifYrsSA (D:G6 .. D:G16). Note that this is the only additional information generated by subsequent rounds of TTO, since, other information remain fixed across iterations.
5. Fill in the iteration number to which the data relates in D:I2. Then watch the No for which the ranks match information given at the bottom of the data entry panel in cell D:I18. When you see 11 here, you know that all ranks matched and you can proceed to the next exercise, namely PTO. Till then keep repeating the process for every subsequent round.
6. The "Reflection" report in TTORflctn2 tab is an alternative to the report in the TTORflctn1 tab. You can chose either of these.

F. Person Tradeoff (PTO):

1. To enable the valuer move to the next exercise, i.e. PTO, click on the PTO1_OwnHlth tab and print the "Your Own Health Today: Valuation worksheet - 2A".
2. Then move to the next tab called PTO2_OwnHlth and print the "Your Own Health Today: Valuation worksheet - 2B".
3. The PTO1_2 tab is where you enter the PTO1 and PTO2 results.
4. The Post_PTO tab contains the "Reflections" report which is similar to the "Reflections" report for the TTO exercise, with an additional upper panel summarising the PTO 1 & 2 results. A sample is shown on the next page.

G. Definitions tab & protection:

1. The last tab named "Definitions" contains definition of the sets of health states, etc. used by the spreadsheet program. Users should not modify any thing in this area.
2. The spreadsheet is supplied under a protected mode. Users can enter data only in designated areas. If you try to edit the protected cells, you will get the following protected cell message.



3. All computed cells have been protected to prevent inadvertent changes to the formulae. Users do not need to do any thing with the protected cells. The areas where data entry is required are all unprotected. If, however, you need to debug a spreadsheet giving problems, contact IHS for technical support through e-mail: ihsnet@hd2.dot.net.in, by telephone 91-40- 3210136, 3210139 or by fax 91-40-3241567 or send a surface mail to "The Institute of Health Systems , HACA Bhavan, Hyderabad, AP 500004, INDIA.

PTO1-2 Data brought forward and Final PTO Results

		PTO-1: Extend life of disabled - buy (1-YLDs			PTO-2: Cure disability i.e. buy YLDs			Final Results
Sl	Health State Conditions	Healthy	Disabled	DWtPTO1	Healthy	Disabled	DWtPTO2	DWt
1	Own Health Today	1000	1067	0.06	1000	16000	0.06	0.06
2	Mild 'Diabetes, no symptoms	1000	1071	0.07	1000	14000	0.07	0.07
3	Watery diarrhoea, 5 times a day	1000	1143	0.13	1000	8000	0.13	0.13
4	Peptic ulcer	1000	2400	0.58	1000	1725	0.58	0.58
5	2 broken arms in stiff casts	1000	6400	0.84	1000	1190	0.84	0.84
6	Mild'Tuberculosis with treatment	1000	1022	0.02	1000	50000	0.02	0.02
7	Below knee amputation - two le	1000	1071	0.07	1000	14000	0.07	0.07
8	Below knee amputation - one le	1000	1034	0.03	1000	40000	0.03	0.03
9	Severe continuos migraine	1000	1714	0.42	1000	2400	0.42	0.42
10	Unipolar major depression	1000	5000	0.80	1000	1250	0.80	0.80
11	Quadriplegia	1000	1600	0.38	1000	2600	0.38	0.38

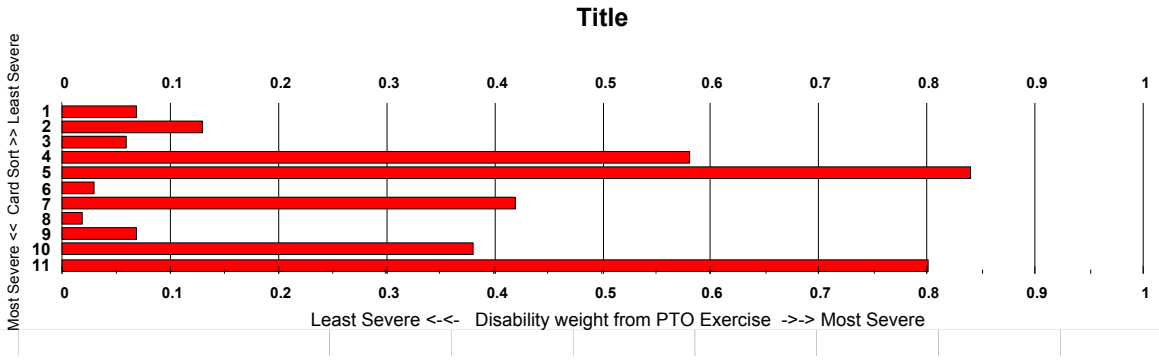
Person tradeoff - reflections: Review the magnitude of disability weights

Date: 13/10/99

Participant ID: 75_3u **Name: Valuers' Name** **Attempt: 1**

Thank you for valuing the given health states using the Time Trade Off exercise. We have computed the disability weights implicitly assigned by you to each condition. These are shown on the right side of this note. The level of disability implied by your choice in the Person TradeOff exercise is also shown in the graph below. You may recall the rank ordering of conditior done by you in the card sort exercise earlier. We have arranged the conditions according to your card sort rank, so that you can reflect if your current valuations are consistent with the ordering of severity judged by you earlier.

Sl	Health State Condition	DWt
1	Mild 'Diabetes, no sympt	0.07
2	Watery diarrhoea, 5 times a day	0.13
3	Own Health Today	0.06
4	Peptic ulcer	0.58
5	2 broken arms in stiff cas	0.84
6	Below knee amputation -	0.03
7	Severe continuos migrain	0.42
8	Mild'Tuberculosis with tre	0.02
9	Below knee amputation -	0.07
10	Quadriplegia	0.38
11	ar major depression	0.8



Please reflect upon the degree of severity you have determined for each condition above, as well as any discrempancies between the card sort and Time Tradeoff exercises. Based on this reflection you may wish to revise your Time Tradeoff evaluations. We would recommend that you do not revise the card sort at this stage, since you have already reflected on it adequately. Now please reflect and revise your valuations and let us have your revised estimations.

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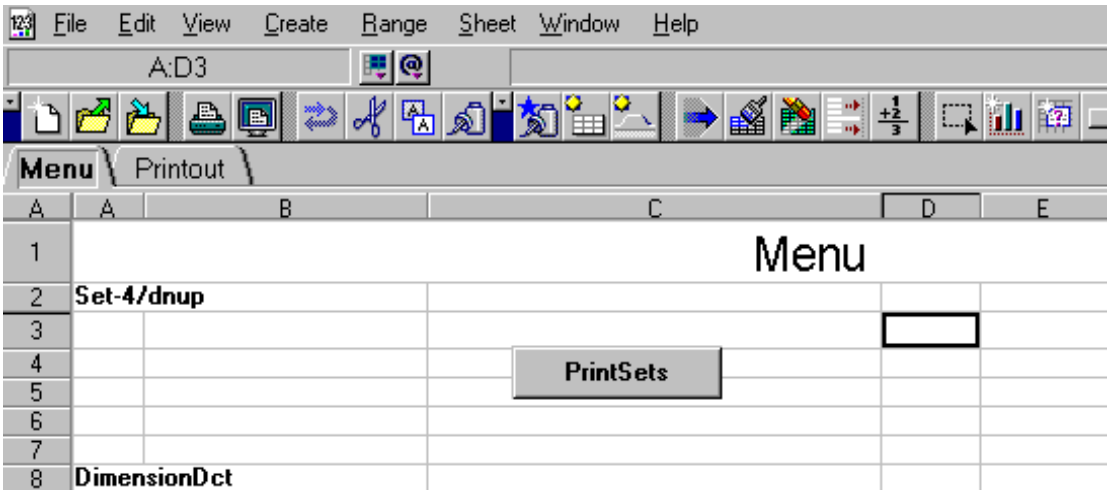
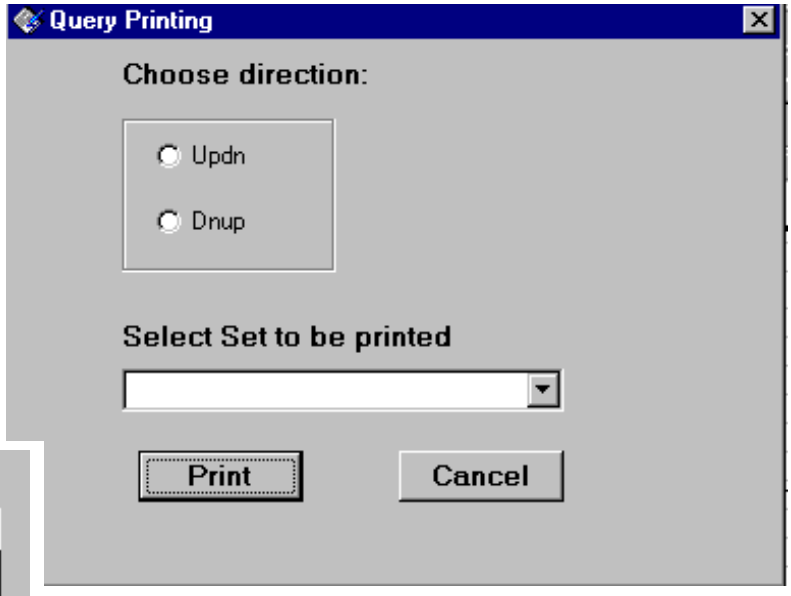
Appendix - 4.7

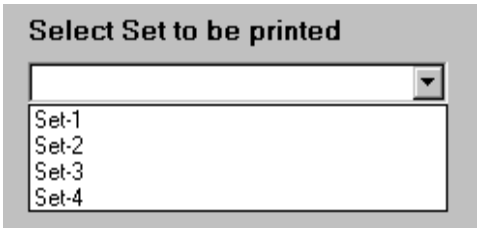
TTO Worksheet User manual.

1. To print TTO Worksheets: Make sure the default printer setting in Windows 95 matches with the printer you want to use. Open the file TTOWksheets.123 using Lotus-123 97 edition. Click the Menu tab, if you are not already there. You will see a PrintSets button in the first sheet named "Menu". This area looks as follows.



2. Click the PrintSets button. You will a dialog box as shown here. Choose one of the options "Updn" for progressively decreasing adjustment factors, and "Dnup" for progressively increasing adjustment factors.
3. Then select the set to be printed from the drop down box, which list the four sets. Then click the Print button to print.





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Appendix - 4.8

PTO Worksheet User Manual.

1. There are two files, namely PTO1wksheets.123, and PTO2Wksheets.123.
2. You use these two workbooks exactly in the same way as you do the TTOWksheets.123, which has been described in appendix 4.7. The only difference here is that there are two workbook files respectively for the PTO1 and PTO2 exercises
3. To print the worksheets for PTO1, open the PTO1wksheets.123 and click "PrintSets" button. Choose required options and the set to be printed and then click the Print button.
4. For PTO2, follow the same process using PTO2Wksheets.123.

Appendix - 5.1

AP Health State Valuation Study 1999 - Manual for Surveyors

A. General

1. "Please take a look at the checklist that has been prepared before you start for a survey. This will help you be organised so that you do not fumble for things during the course of your survey. Make sure you have all the things with you before you start for the survey. Please have the escort accompany you so that you do not knock at someone's door as a stranger. First find out from the escort the location of the valuer. The valuer's list has all the person's name by house number. Wait for the escort to introduce you to the prospective valuer. First confirm the name and husband or father's name to make sure the person you want to interview is in your master list.

B. Interview and the valuation exercise:

1. Please take some time to get acquainted with the valuers. You may ask questions like how many people are there in the family and what are the children doing and so on. Ask regarding how the crop has been this year, and also take some time to wish other persons in the family.
2. Start with the "Valuer's personal information" form. Fill out all the details. If you see a T.V, radio or other household item in the room do not ask them if they own one. At the same time do not guess their age, caste and other details. You will have to be careful while asking questions regarding land and cattle ownership. Please specify that you are not from the government and this is just a standard pattern to know their standard of living.
3. After this form you will have to ask regarding their own health states. To assess this, you need to show them the cards with pictures of all the levels in each dimension one by one. You can explain to them the meaning of the dimensions along with examples. You will also have to explain the meaning of each level. Go step by step in order to explain the degree of severity of the levels in the dimensions. Once you have covered all the levels of all the dimensions, pick up the card that has all the levels of mobility and ask the valuer which level describes her own level of mobility. Allow him/her to pick the picture of the level and once s(he) picks up the picture of her choice, stick it on to the first box (left upper corner, meant for the mobility dimension) of the "own health today" card. Continue this process until s(he) has chosen levels for all the dimensions. Keep sticking them in their assigned places in the "own health today" condition card. Then show this card to the valuer. Show them the levels of the dimensions that describes his/her health state on that day. Ask them to review the card and agree on their own health as on that day.
4. Then move on to describing each of the health states. Make sure to read out the detailed labels of the health states. For each of the health states start explaining the condition as having the assigned dimension levels. You can use the number of x signs as a cue for assessing the levels of the dimensions quickly. If there are no signs under a particular dimension it means that this dimension has a level of 1. If two signs then level 2 and so on. Place all the 11 cards in front of you so that the valuer can see all the pictures of all the health states. Then ask the valuer which condition she considers the worst of all the health states, i.e., including his/her own health state. You will have to read the detailed

labels of the health states along with the levels of the dimension in each card again. Assume that the valuer is having difficulty remembering all the levels of the dimensions in all the cards. At the same time do not feel impatient of the time they take to choose a health state. If they take more time, it means they are having difficulty in remembering all the health states. Now you may read out the detailed labels of all the 11 health states. You will then find them choosing one health state. Pick up this card from the 11 and then ask them which card is the next worst health state of the remaining 10. It may be a good idea now to point out the levels of the dimensions that are more than 1 in individual health states. Continue this process until the valuer has chosen all the cards. Keep mentioning all the levels of the dimensions in the health states. Once s(he) has selected all the 11 health states in order of preference, read out the order that she has actually given to these health states. If she wants to make any changes, make the necessary changes to the order. Now, you can write down the order of the health states in the card sorting log form. Please note down all the comments that she makes regarding the health states in this process. This information is very valuable for our study. The backside of the card sorting log form has all the health states of the four sets. We have provided this space for the qualitative information. Write down the comments beside the names of the health states.

5. Once the card sorting is done, arrange the set of pin mounted health state cards in the order from best to worst, based on the valuer's rank order given earlier. Again stick the pictures of the levels of the dimensions that the valuer has chosen for him / her. Now keep the cork board with the VAS form pinned to it in front of the valuer. Explain to him / her the following:
   i. "This straight line has 100 small divisions. The sad face is near the lower end of the line and the happy face is at the upper end. I would like you to pin these cards along this straight line. Any health state that you consider being worse should be pinned towards the lower end of this line and any health state that you consider to be not that worse should be pinned towards the upper end. Please look at the expressions of these faces. The sad face represents suffering and the happy face represents no suffering. If you think that any of these 11 health states is the best imaginable health state then you should probably pin it on the upper most end of the line. But you have to understand that this is the best health state that anyone can have. If you think that you know of health states that are better than all in this list then you should not pin the best in your list on the highest point. Think how far the best health state that we have here is from the best health state that you know. Now look at this card that you have sorted as the worst. Do you think there isn't any health state worse than this. Any health state that is equal to death should be pinned to the lowest point in this line. So, if the health state that you have rated as the worst is equal to death then you can pin to the lowest end. But if you think that there is any other health state that is worse than this then you may leave some space and pin this."
   ii. Then give the card that has a ranking of 2 from best to worst and give it to the valuer to pin it to the line. Give a lot of emphasis to the distance of this card from the best card. Ask the valuer as how far it is from the best imaginable health state and also from death. The valuer has to be kept focused to the two ends of the line and also to the distance of each disease from each other. Look for any other qualitative information (like the comments that the valuer makes through the course) and record

them in the form. Once s(he) has pinned all the cards, measure the points by the paper scale and note down the scores under the "VAS Scores" column in the card sorting log form. Then wish the valuer in the traditional manner and take leave after offering a small token of appreciation that have been determined by your project coordinator.

6. After completing each household survey, sit down in one place and fill out the IOR (Interviewer Observations and Report, HSV Household) form. This form is pretty simple to understand. Make sure to write down the ID and name of the valuer as well as all your observations for this particular valuer."

C. Other things that surveyors are cautioned to keep in mind:

1. Please keep in mind the dress code and wear a dress that is acceptable to the rural persons.
2. Do not laugh or make fun of them or at any response they make. You have to keep in mind that there is no right answer regarding health state preference. So we should give equal importance to the responses that people have.
3. Be careful not to suggest your own preferences to the valuers. You can do this by non-verbal cues and the length of time you take to stress the different dimensions in the health states.
4. Stress on the healthy states rather than the disease states in each of the conditions.
5. Please do not be impatient with the valuers. You have to understand that this task carries cognitive load that may be difficult for the rural and illiterate persons to deal with.
6. Follow the instructions carefully and do not deviate from the format. If you find that there is a better way to carry out this survey, first consult the coordinator and then use them. Otherwise stick to the format given to you. We want all the surveyors to use a standard format.
7. You will be expected to complete in between 6 to 8 interviews every day. In between the surveys you have to come back to your base and start entering the data of the survey. Each person will be responsible for the entry of his / her data. Please do not keep a backlog of too much data as it will be difficult to enter too much at one go.
8. Each of you will have an escort in the village. Be friendly with them. Your success as a surveyor will depend on how you maintain your interpersonal relationship with your escorts. Do not give them an impression that there is a big difference level between them and you.
9. There will be a review meeting with the study coordinator every alternate day. Note down all the issues to be discussed during this time.
10. Please be prepared to forgo some luxuries of the urban life and be prepared to tolerate some inconveniences in toilet and bath facilities available in the village.
11. Remember always that we are a team and we will work together and make the whole project a grand success.

Apendix 5.2

Valuer's Personal Information

I. Valuation Information:

Valuer ID

Interviewer Code

Date of Interview

Place of Interview

II. Respondent:

Name

Same as valuer Attendant Relationship with Valuer

III. Valuer Information:

Name

Age Sex: Male ☐ Female ☐ Caste: SC ☐ ST ☐ BC ☐ OC ☐

If age >= 15 years; How many years you have attended school?

If age <15 years; How many years has the mother attended school?

Can you write a letter to your relatives / friends? Yes ☐ No ☐

IV. Valuer's Household Information:

A. Does your house have -

	Yes	No
a radio		
a television?		
a refrigerator?		
a bicycle?		
a moped, motor cycle or scooter?		
a sewing machine?		
a sofa set?		

B. Does your household own -

	Yes	No
Agricultural land?		
Any live stock?		
A bullock?		
A bullock cart?		
A water pump?		
A fan?		

C. What is the main source of drinking water for members of your household?

Private protected (piped / deep bore well)	
Private unprotected (shallow bore well, open well)	
Public protected (piped, deep bore well)	
Public unprotected (open well)	
Natural unprotected (spring, river, pond, lake)	
Other	

D. What kind of toilet facility do most members of your household use?

Private flush toilet	
Shared flush toilet	
Public flush toilet	
Traditional pit latrine	
Ventilated improved pit latrine	
Other	
No facility / bush / field	

E. What type of fuel does your household mainly use for cooking?

LPG / Natural gas	
Bio-gas	
Kerosene	
Coal	
Fire wood / straw	
Dung	
Other	

F. Do you own a house? Yes ☐ No ☐

1. If yes, type of house owned:

Pucca house	
Kachha house	
Semi pucca	

Appendix - 5.3

వాల్వువర్ యొక్క స్వ సమాచారము

I. వాల్వుపషన్ సమాచారము

వాల్వ-పర్ ఐ.డి.

ఇంటర్వు చేసిన వారి కోడ్

ఇంటర్వు చేసిన తేది

ఇంటర్వు చేసిన స్థలము

II. సమాధానము ఇచ్చువారు

పేరు

సంబం-దిత వ్యక్తి బంధుత్వం

III.వాల్వపర్ సమాచారము

పేరు

వయస్సు స్త్రీ☐ పురు-షుడు☐ కులము: ఎస్సి ☐ యస్.టి☐ బి.సి ☐ ఒసి☐

వయస్సు

మీ వయస్సు **15**సంవ-త్స-రాలు మించి-న-ట్ల-యితే: మీరు ఎన్ని సంవ-త్స-రాలు స్కూలుకి వెళ్లి-నారు
మీ వయస్సు **15**సంవ-త్స-రాలు కన్నా తక్కు-వైతే: మీ తల్లి-గారు ఎన్ని సంవ-త్స-రాలు స్కూలు కి వెళ్లి-నారు

IV.వాల్వపర్ కుటుంబ సమాచారము

A. మీరు స్వంతంగా కలిగి ఉన్నవి

	అవును	కాదు
రేడియో		
టెలి-వి-జన్ (దూర-ద-ర్శన్)		
రె ఫ్రి-జ-రే-టర్ (ఫ్రిజ్)		
సైకిలు		
మోటారు వావా-న-ము ఎ్కాటరు)		
కుట్టు యంత్రము		
సో ఫా		
గోడ గడి-యా-రము		
ఫ్రజర్ కుక్కర్		

B. మీ కుటుంబం స్వంతంగా కలిగి ఉన్నవి

	అవును	కాదు
వ్వప-సాయ భూమి		
చరాస్థి		
ఎద్దులు		
ఎద్దుల బండి		
మోటారు పంపు		
ఫంకా (ఫ్యాను)		

A. మీ యొక్క కుటుంబము కలిగియున్న తాగునీటి సౌకర్యము ఎటువంటిది?

స్వంతంగా నిర్మిం-చు-కొ-న్నవి(పైపు/ గొట్ట-పు-బావి)	
ప్రభుత్వం నిర్మిం-చి-నవి (పైపు/ గొట్టపు బావి)	
సహ-జ-ముగా ఎర్ప-డి-నవి(నది/ కొలను / గుంట/ సరస్సు	
ఇత-ర-ములు	

B. మీ కుటుంబసభ్యులు ఉప-యో-గిం-చు-చున్న మరు-గు-దొడ్ల సౌక-ర్యము ఎటు-వం-టిది

స్వంతంగా నిర్మిం-చు-కొ-న్నవి	
కొంత-మంది కలసి నిర్మిం-చు-కొ-న్నవి	
ప్రభుత్వ మరు-గు-దొడ్లు	
పురా-తన మరు-గు-దొడ్లు	
ఇత-ర-ములు	
ఎ సౌక-ర్య-ము-లేదు/ పొదలు / ఆరు-బ-యట ప్రదే-శము	

C. మీ కుటుంబము వంట కొరకు ఉపయోగించుచున్న పద్ధతి ఎమిటి?

ఇంధనము (గ్యాస్)	
బయో-గ్యాస్	
కిరో-సిన్	
బొగ్గు	
వంట చెరకు	
పేడ	
ఇత-ర-ములు	

D. మీరు ఇల్లు స్వంతంగా కలి-గి-ఉ-న్నారా? అవును/కాదు

పక్కా యిల్లు			
కచ్చా-యిల్లు(మట్టి యిల్లు			

Appendix-5.4

Comments by the valuer for health states to be captured in this sheet

Core Set	Space for comments
ఈరోజు మీ ఆరొగ్య స్థితి	
కొద్దిగా చెక్క-ర-వ్యాధి, ఎటు-వంటి రోగ-ల-క్షణాలు లేవు. మందు-లతో అదు-పులో వుంచ-వచ్చు	
చికిత్స చేయించు-కుం-టున్న క్షయ-వ్యాధిగ్రస్తుడు, కొద్దిగా రోగ -ల-క్షణాలు,అప్పు-డ-ప్పుడు దగ్గు	
మన-స్తా-పము, ఎ పని-చే-యా-డా-ని-కైన అయి-ష్ట-త, తక్కువ శక్తి, ఆలోచిం-చ-డంలో మరియు కేంద్రి-క-రిం-చ-డంలో కొద్దిగా కష్టం	
రెండు కాళ్లు చేతులు చచ్చు-బ-డుట	
చాలా నొప్పి/ పోట్లు తో కూడ-న-టు-వంటి నీళ్ల-వి-రే-చ-న-ములు (రోజుకు 5 సార్లు)	
ఎప్ప-టికి తగ్గన-టు-వంటి తీవ్ర-మైన తల-పోటు	
Set -1	
కొద్దిగా నొప్పి, కీళ్లు పట్టే-సి-నట్లు ఉండుట	
మూత్ర-ములో స్వాధినం లేక-పో-వుట	
ఎప్పుడు ఉండే తెమడ/ కళ్లెతో కూడి-న-టు-వంటి దగ్గు మరియు శ్వాస- తీసు-కో-వ-డంలో కష్టం	
మతిస్థిమి-తం-లే-క-పో-వుట, మాట తడ-బాటు మరియు ఆలో-చ-నలో తిక-మక, ఆలో-చిం-చుట, కేంద్రి-క-రించుట-లో చాల కష్టం, మనసు స్థిమితం లేక-పో-వుట	
Set - 2	
తీవ్ర-మైన జ్వరం వలన ఆలో-చనలు స్వాధి-నం-లే-క-పో-వుట -(ఫ్లైఫో-యిడ్ జ్వరం వలె)	
కొద్ది-పాటి వ్యాయమము చేయు-న-పుడు ఛాతీ(చెస్ట్) లో కొద్ది గా నొప్పి	
సంతా-నము కావాలనీ కోరిక వున్నా కన-లే-క-పో-వుట	

గుడ్డిత-నము

Set - 3 Space for comments

విరి-గిన రెండు చేతు-లకు కట్లు

కడు-పులో బాధ మరియు మంట --- (కడు-పులో పుండు పలే ఉన్నది)

ఒక-మో-కాలి క్రింది-భా-గ-ము-
తీసి-వే-యుటనడ-ప-డా-నికి వీలైన సాధ-న-ములు కలపు
(క్రచ్స్)

రెండు మోకాలి క్రింది-భా-గములు తీసి-వేయుట
------చక్రాల కుర్చి కల-దు (వీల్చైర్)

Set - 4

ముఖ-ము-మీద తెల్లని మచ్చలు

విన-డంలో కొద్దిగా కష్టం అయితే గట్టిగా మాట్లా-డినా, పెద్ద శబ్ద-మైనపుడు మాత్రమే విన-గ-లడు

ఎప్పుడు ఉండే కొద్దిపాటి వెన్ను-నొప్పి

తీవ్ర-మైన గుండె-జబ్బు కార-ణంగా భరిం-చ-లేని ఛాతీలో నొప్పి మరియు (దమ్ము) శ్వా-స-తీ-సు-కో-లే-క-పో-వడం

Apendix 5.5

Interviewer Observations and Report, HSV Household Survey (IOR)

Valuer Name:

ID	M F				

Did the respondent…

	No	Yes	Can't assess
…have a hearing impairment?	0	1	8
…have any vision problems?	0	1	8
…use crutches, cane, other walking aid or support?	0	1	8
…have any difficulties walking?	0	1	8
…have paralysis in the arms, hands or legs?	0	1	8
…have any amputations of arms, hands or legs?	0	1	8
…cough continually?	0	1	8
…have shortness of breath?	0	1	8

Did the respondent have difficulties understanding the questions or tasks on…?

	No difficulties	Yes, some difficulties	Yes, a lot of difficulties	Can't assess
Personal information	0	1	2	8
Own health status assessment	0	1	2	8
Card sort exercise	0	1	2	8
Visual analog exercise	0	1	2	8

Respondent's cooperation was:

Excellent	Very good	Good	Fair	Poor
1	2	3	4	5

Overall, how would you rate the accuracy and completeness of the respondent's answers?

Very high	High	Average	Low	Very low
1	2	3	4	5

Any unusual circumstances or happenings during the interview:

Any other comments:

Appendix - 5.6

Summary of comments about specific health states from valuers in the household survey.

HealthSt	No of Comments	6D5L	Comments
Quadriplegia	74	554341	Useless life. Equal to death. Totally dependent on others. Burdened life.
Severe continuous migraine	24	113431	Cannot concentrate. Difficult to work.
Unipolar major depression	22	124142	Cannot work. Makes life miserable. Cannot concentrate.
Mild Tuberculosis with treatment	15	111221	Stigma. Anxiety. Isolation.
Two broken arms in cast	15	154321	Cannot work.
Watery Diahorrea 5 times a day	15	111211	Cannot work. Weakness.
Blindness	14	323122	Dependent on others. Difficult to work.
Mild diabetes, no symptoms	13	111121	Has to take medicine daily. Food restrictions. Risk of complications.
White marks on face	13	111131	Problems in social life. Depression. But not a big problem.
Below the knee amputation (two legs)	11	433221	No use living. Difficult to work. Dependent on others.
Infertility	11	111131	Life long depression. Anxiety of loosing spouse. No problem.
Severe Hallucinatory Fever	8	444333	No problem. Can be cured. Risk of death.
Mild hearing disorder	7	112121	Prone to traffic accidents. Difficult to work.
Pain and stiffness in joints	7	222331	Difficult to walk. Difficult to work.
Angina	6	111321	May cause death. Difficult to work. No concentration.
Peptic Ulcer	6	322211	No concentration. Difficult to work.
Bronchitis	5	112311	Inconvenience
Continuous moderate back pain	4	212321	Pain. Problem in work.
Schizophrenia	4	234244	Useless life.
Severe heart failure (congestive)	4	434531	Unexpected death.
Urinary incontinence	4	113331	Problem in social life. Difficult to work.
Own Health Today	3		
Below the knee amputation (one leg)	2	322211	Little problems. Difficult to work.

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