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 - 4.2 shows actual distribution of workshop participants by their profession

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

Date	Target group	Primary mailing list	No accepted	No participated
24/Aug/99	Com. medicine teachers and students	59	-	16
02/Sep./99	Health Intranet system admn. 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

Altogether 13 health state valuation workshops were took place with a total of 180 participants. 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 travelling. 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 / Community 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: Age and Literacy of health state valuers.

Characteristic	Females	Males	All
Number of valuers	88	92	180
Age Group			
15-19	0	0	0
20-29	67.05	61.96	64.44
30-44	23.86	23.91	23.89
45-59	9.09	13.04	11.11
60-69	0	1.09	0.55
70	0	0	0
Years of schooling			
0	0	0	0
1-5	0	0	0
6-9	0	0	0
10-12	0	0	0
13-15	45.45	16.3	30.56
16-18	43.18	65.22	54.44
19+	11.36	18.48	15

Workshop format:

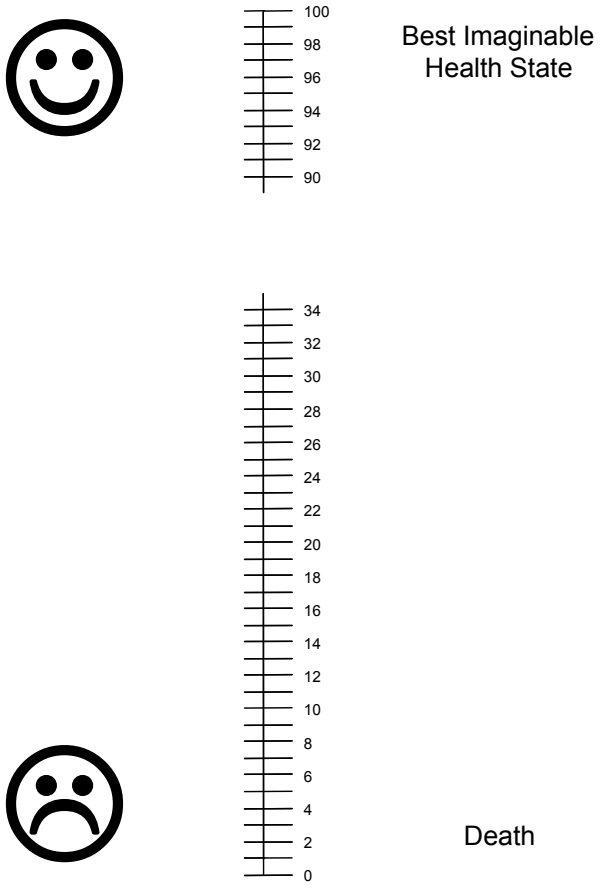
MDHSV Workshop kit:

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.

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



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.
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 were1_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. 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

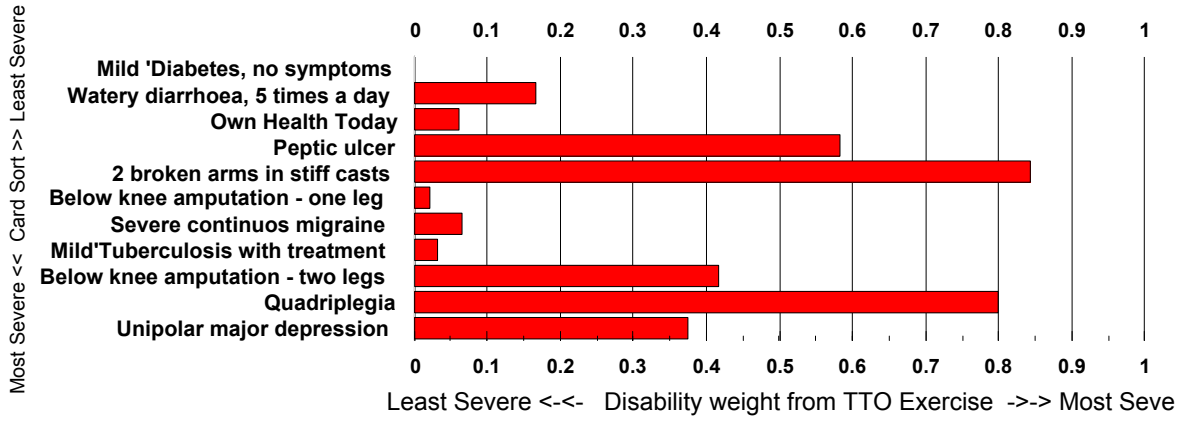
Time tradeoff - reflections: Review the magnitude of disability weights

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. A more detailed user manual of the DEDIT is given in Appendix-4.6.

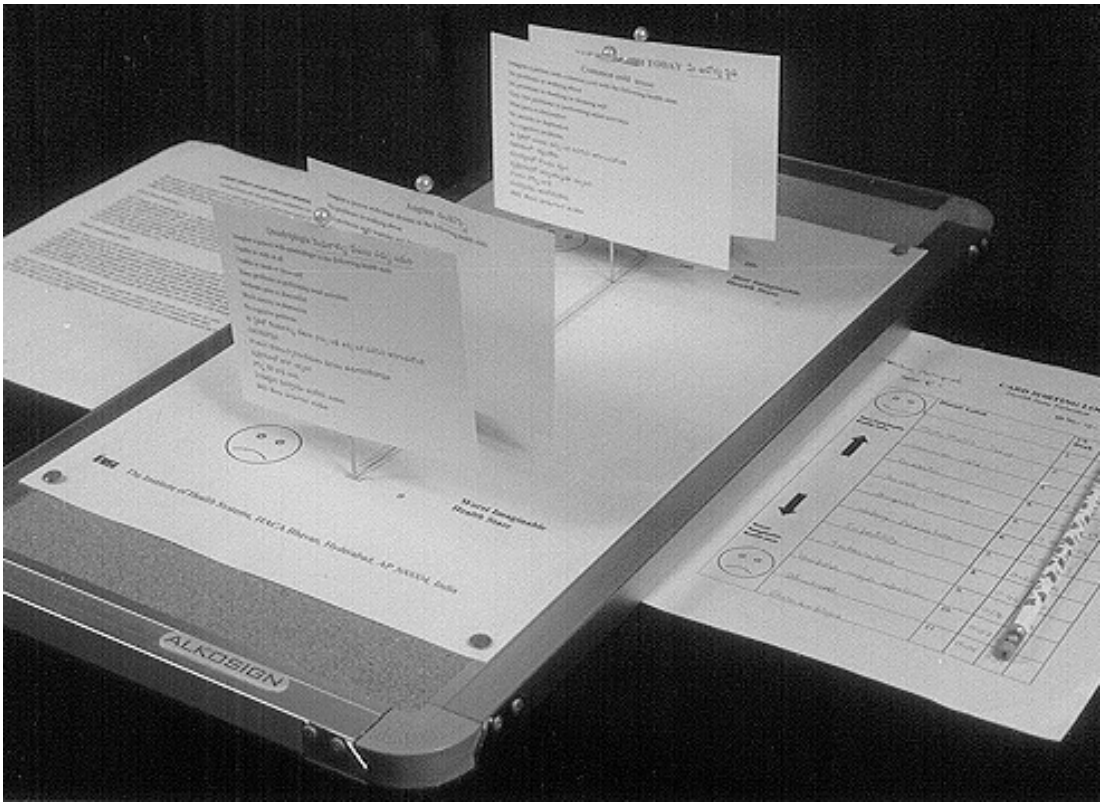
Description of "Own health today" by valuers:

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).

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



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.

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.

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.

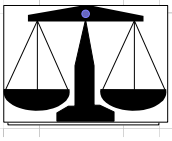
Imagine that you are living in the health state described above, and must choose between two alternatives:
Alternative 1: You may continue to live in this health state for the rest of your life, that is, 12 more years.
Alternative 2: You may accept a medical intervention that will improve your health 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.

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. 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	Number of additional TTO iterations														Match
workshop	NA	1	2	3	4	5	6	7	8	9	10	11	13	Total	ed
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	2
14-Nov-99		4	6	4			1							15	5
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	70

[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.

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.

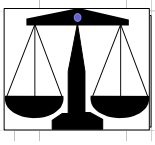
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer Intervention - A (mark the box on the left), would definitely prefer Intervention B (mark the box 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.

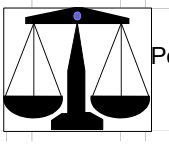
Below we present a series of choices representing this tradeoff. Each row should be considered as a separate decision question. For each situation (row), please indicate whether you would definitely prefer Intervention - A (mark the box on the left), would definitely prefer Intervention B (mark the box 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. ☐

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.

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 feedbacks 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:

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.

Murray C.J.L. and Lopez A. 1996. *The Global Burden of Disease*. Cambridge, Harvard University Press.

---------- O ----------