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 be 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[1] 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 effect of actions in the

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

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 description systems induced by them:

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	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.

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 enrolees in a prepaid group practice and persons attending a few other outpatient facilities. Sampling of enrolees 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.

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[2] (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.

[2] 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, socio-economic 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. 1984). 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 semi-literate 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[3]. 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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[3] Five dimensions with three levels in each give rise to $3^5 = 243$ permutations. To this death is added .

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

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[4].

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

[4] 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.

draft translated document was further worked upon by us with help of other faculty 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 artefacts 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. 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.

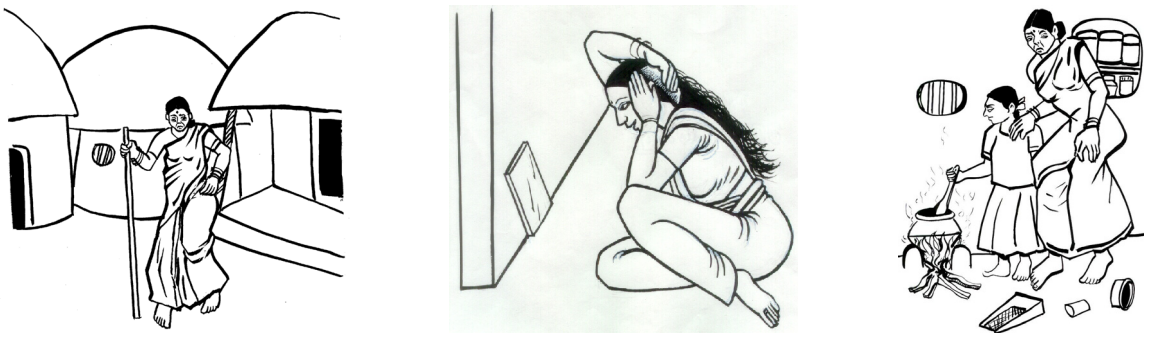
Figure-3.1: 6D5L Graphics for Self Care

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

☒☒
Few problems in walking about

No problems in washing or dressing self

☒☒
A few problems in performing usual activities



☒☒☒
A little pain or discomfort

☒☒
A little anxiety or depression

No cognitive problems

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 labelling 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 modelling 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

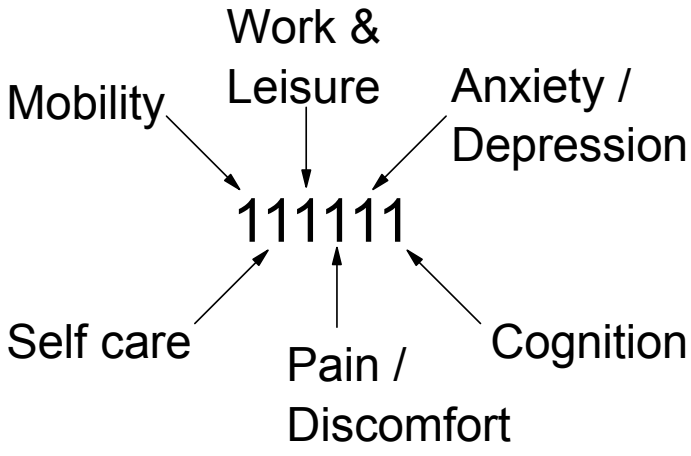
Ceteris paribus, disease labels have been found to affect the value attached to a health state, by the valuer. For example, Sacket and Torrance (1978) found that labels had statistically significant effects upon health state utilities in both the positive (tuberculosis preferred over an

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).

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



Results:

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.

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.

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.

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

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