

Appendix-3.1

6D5L Health State Description System.

Dimensions and Severity Levels.

I. Mobility (Position = 1):

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC):

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

II. Self care (Position = 2):

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC):

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

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

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC):

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

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

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC)::

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

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

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC):

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

VI. Cognition (Position = 6):

A. What this dimension represents:

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

B. Severity Levels and Codes (SLC):

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

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

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

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

Appendix 3.3:

Long labels of health states, English and Telugu.

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

Appendix-3.4

6D5L Health state description system in Telugu.

కద-లిక (Mobility)

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

దిన-చ-ర్య (Self care)

- 1 నాకు దిన-చ-ర్యలో కష్టం లేదు
 - 2 నాకు దిన-చ-ర్యలో అప్పు-డ-ప్పుడు కష్టం
 - 3 నాకు దిన-చ-ర్యలో కొంచెం కష్టం
 - 4 నాకు దిన-చ-ర్యలో చాలా కష్టంగా ఉంది
 - 5 నేను స్వయంగా తిన-టం, స్నానం చేయడం మరియు తయార-వ-లే-క-పో-తు-న్నాను
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వృత్తి-ప-నులు (Work and leisure)

- 1 నాకు వృత్తి-ప-నులలో కష్టం లేదు
 - 2 నాకు వృత్తి-ప-నులలో ఎప్పు-డ-యిన ఇబ్బంది
 - 3 నాకు వృత్తి-ప-నులలో కొంచెం ఇబ్బంది
 - 4 నాకు వృత్తి-ప-నులలో చాలా ఇబ్బంది
 - 5 నను వృత్తి-ప-నులు చేసు-కో-లే-క-పో-తు-న్నాను
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6D5L Health state description system in Telugu Contd.

నాకు నొప్పిలేక బాధ (Pain- discomfort)

- 1 నాకు నొప్పిలేక బాధ లేదు
 - 2 కొంచెం నొప్పిలేక బాధ ఉంది
 - 3 నాకు షుమా-రుగా నొప్పిలేక బాధ ఉంది
 - 4 నాకు విప-రీ-తమైన నొప్పిలేక బాధ ఉంది
 - 5 నాకు భరిం-చ-లేనినొప్పిలేక బాధ ఉంది
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మనస్తాపము ఆందోళన (Anxiety - depression)

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

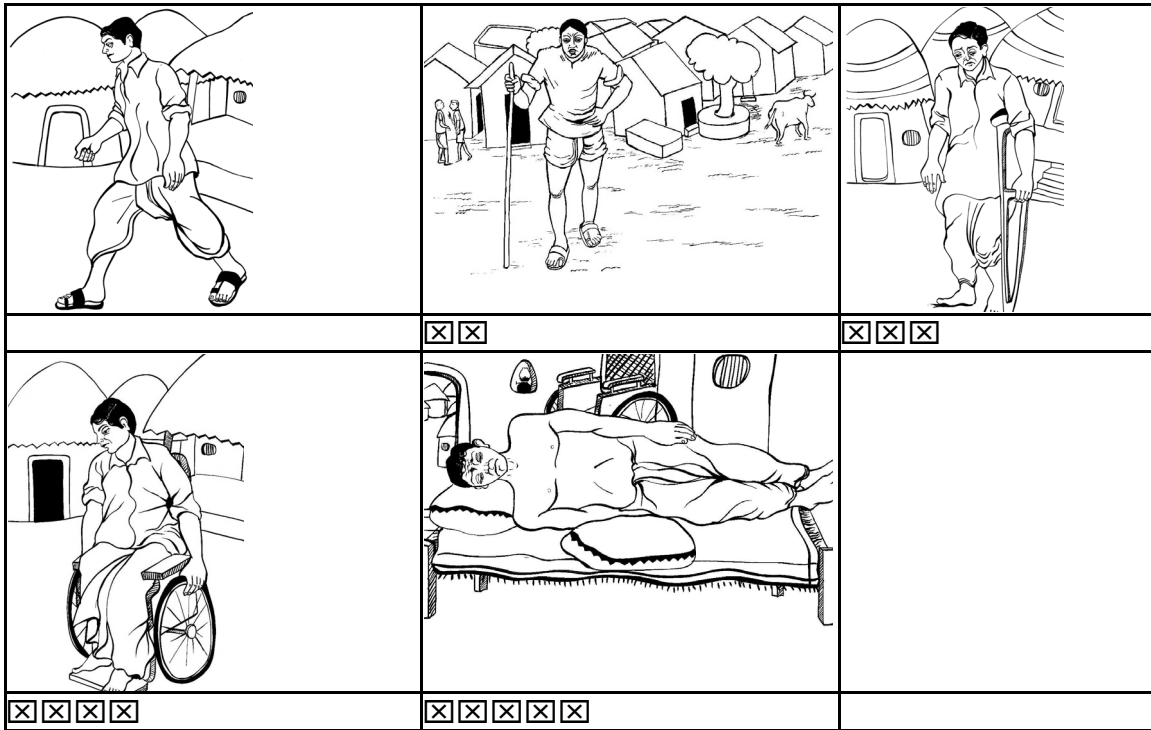
బుద్ధి/ మందత (Cognition)

- 1 తెలివితేటలు మామూలుగా వున్నాయి
 - 2 నాకు కొంచెం మందత ఉన్నది
 - 3 నాకు షుమా-రైన మందత ఉన్నది
 - 4 నాకు తీవ్రమైన మందత ఉన్నది
 - 5 నాకు విప-రీ-త-మైన మందత ఉన్నది
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Appendix-3.5

6D5L Graphical Health State Description System


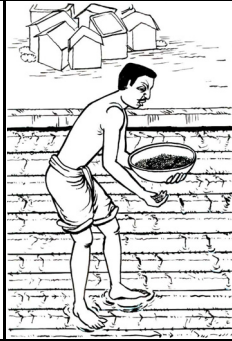
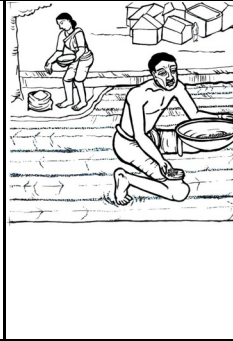
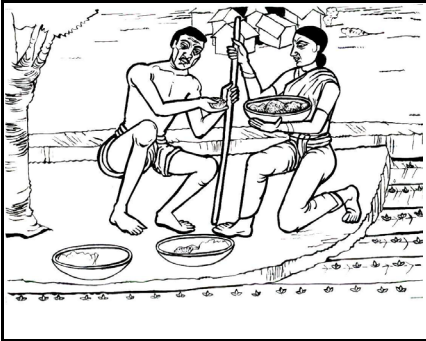
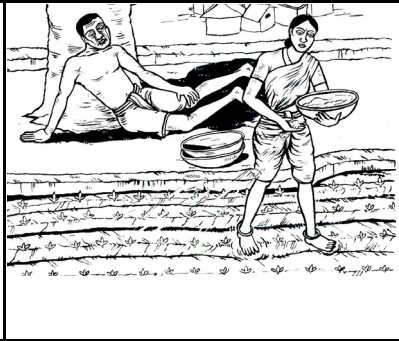
6D5L Graphics for Mobility



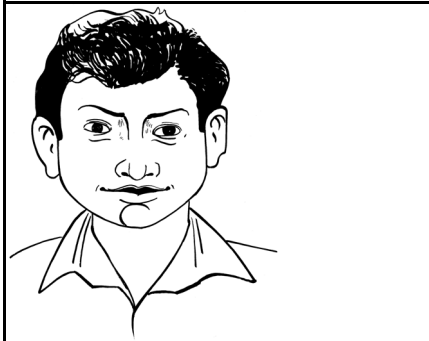




6D5L Graphics for Self Care



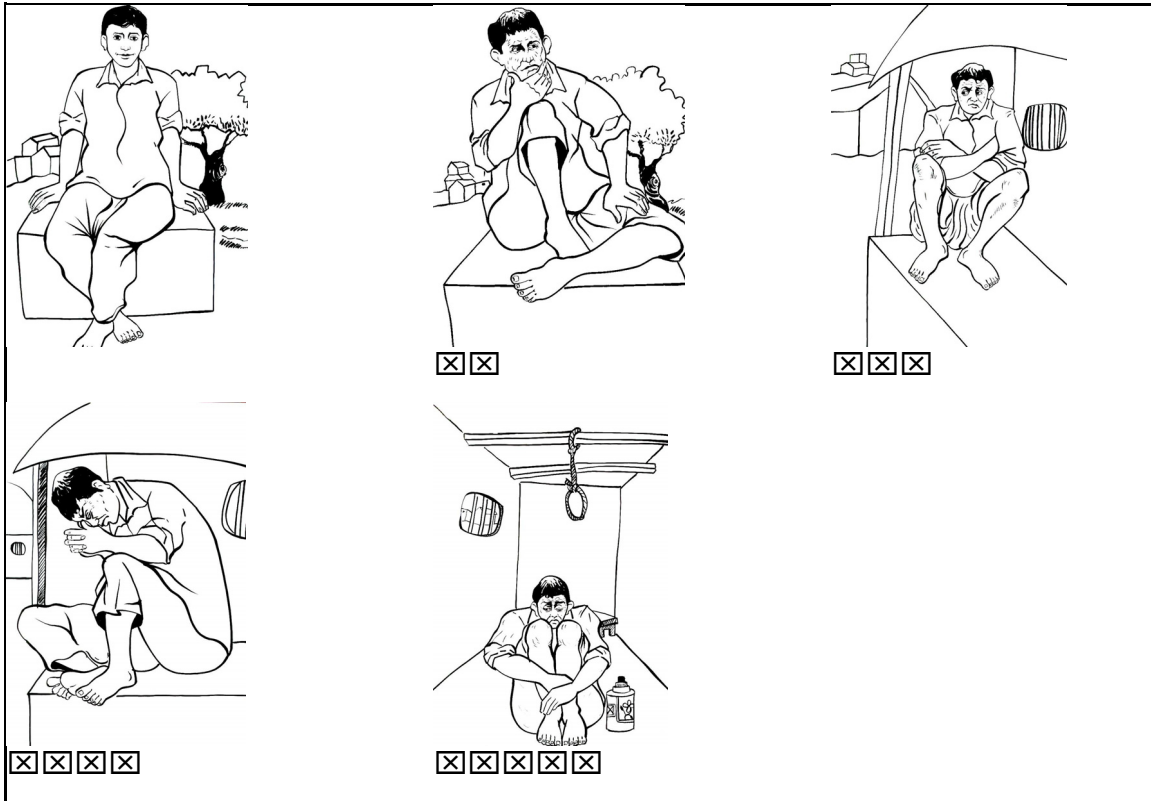
6D5L Graphics for Usual Activities

		
	<p>☒ ☒</p>	<p>☒ ☒ ☒</p>
		
<p>☒ ☒ ☒ ☒</p>	<p>☒ ☒ ☒ ☒ ☒</p>	

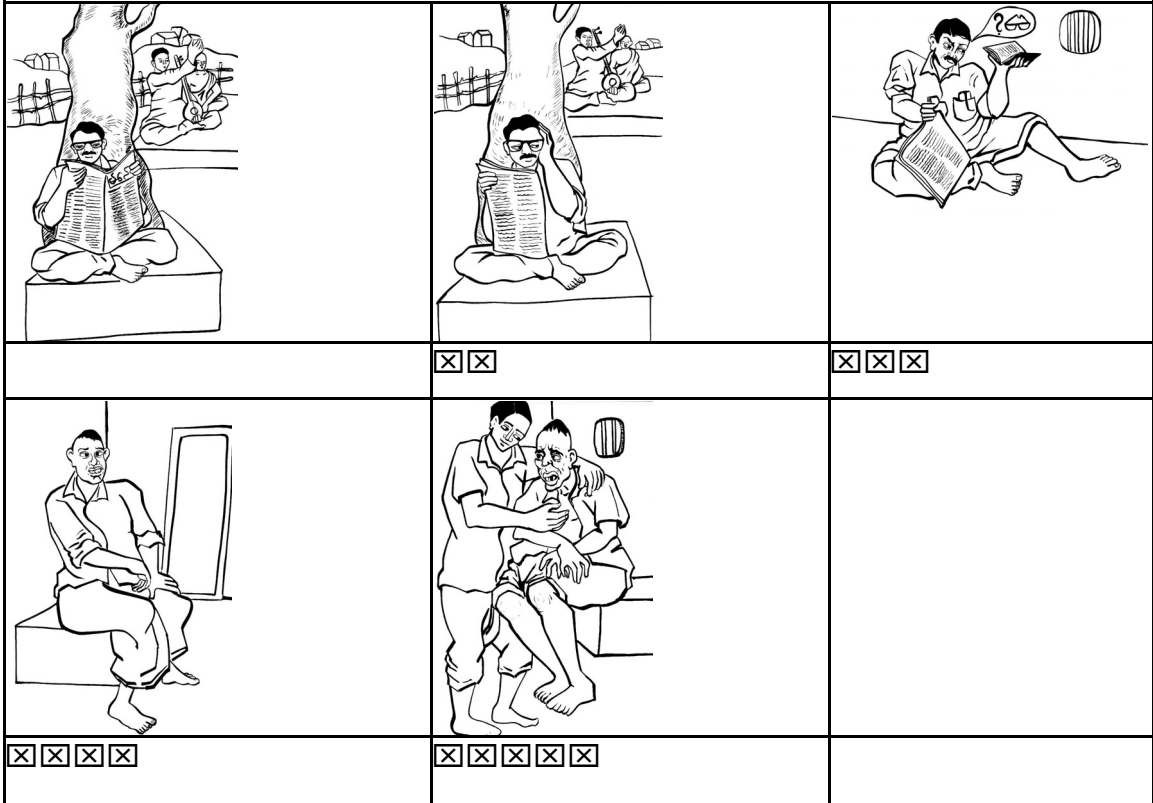
6D5L Graphics for Pain

		
	☒ ☒	☒ ☒ ☒
		
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6D5L Graphics for Anxiety - Depression



6D5L Graphics for Anxiety - Cognition



Appendix-3.6

Artists brief to design pictorial representations of health dimensions

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

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

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

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

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

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

Enclosures:

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

Appendix-3.7

Health state description workshop - proceedings.

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

- a. The groups started out by identifying 6D5L profiles for the assigned diseases.
- b. The next task was to arrive at the Telugu labels for the given diseases. Panelists were reminded that the health states (with the standard descriptions) will be used in a household survey in order to elicit valuation as perceived by the general and sometimes illiterate population. They were requested to keep in mind that these labels will have to be understood by the lay persons in villages of Ranga Reddy District, where the household survey was to take place.
- c. Finally the groups translated a part of the 6D5L descriptive system, assigned to them, in to Telugu. Two of the six dimensions were assigned to each group. First they translated the dimension labels and then the levels within each dimension.
- v. Plenary: After group discussions, participants from all groups met in a plenary session. Each group presented their recommendations followed by discussions to arrive at a plenary level consensus.
- vi. Open session: There was a final open session to discuss and share individual or group experiences of the workshop. During the open session, it was observed that;
 - 1) Participants tended to confuse between the first three dimensions namely;
 - i) Mobility
 - ii) Self care
 - iii) Usual activities
 - 2) People assumed that pain / discomfort will tend to affect the first three dimensions always. Since there are five levels, people tended to use the milder disability levels. For example a reduced level of functionality in the mobility dimension was assigned to a health state like severe migraine on the premise that persons with such severe headache will not want to move about, even though the locomotion system was perfectly all right. We realised that participants had difficulty in discriminating between the first three dimensions i.e. mobility, self care and usual activities. They tended to assume that if some one had some degree of pain that will affect all these three dimensions as well. They ended up giving positive levels of disability along these three dimensions almost for every condition.
 - 3) It was felt that most participants had been introduced to the concept of summary measures, health status measurement and functional indexes for the first time. Most participants felt that they needed to know more of these concepts, in order to deliberate on the descriptive system.
 - 4) More over, they wanted to study the supplied literature and briefs in greater detail and ponder over them.
 - 5) So it was decided to reassemble in a second workshop after a gap of about two weeks.
3. Second workshop of the description cum translation panel: In order to clarify doubts and reduce biases a second workshop was organised with the same set of participants.
 - i. The following concepts of Impairment, Disability and Handicap (IDH) were presented to them.
 - a. **Impairment:** A reduction in physical or mental capacities. Impairments are generally disturbances at the organ level. They need not be visible and may not have adverse consequences for the individual. Where the effects of an impairment is not corrected a disability may result.
 - b. **Disability:** Restriction in a persons ability to perform a function in a manner considered normal for a human being. For example; to walk, to have full use of one's

- senses. Disability may or may not limit the individual's ability to fulfill a social role, depending on the severity of disability and what the person wishes to do.
- c. **Handicap:** Social disadvantage (e.g. loss of income) that may arise from disability. A minor injury can handicap an athlete but may not noticeably restrict some one else.
 - ii. There was some discussion regarding the EuroQol instrument dimensions and levels and modifications to the EuroQol by the 6D5L system. This was done in order to show the EuroQol lineage of the 6D5L instrument.
 - iii. In order to make things more clear, concepts of ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) were presented.
 - iv. Following scales used to measure functional status in different settings were briefly mentioned, based on descriptions largely obtained from McDowell and Newell (1987, 1996).
 - a. Activities of daily living (ADL) scales.
 - 1) PULSES profile
 - 2) Barthel Index
 - 3) Index of ADL: Index of independence in activities of daily living.
 - 4) Kenny Self care evaluation.
 - b. Instrumental activities of daily living scales (IADL):
 - 1) Functional Status Index.
 - v. A consensus developed that secondary effect of dysfunction in one dimension on another dimension, particularly when the secondary effect leads to a certain choice by the person but does not necessarily affect his / her ability in that dimension, should be ignored while assigning level of functionality in the other dimension.

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

Appendix-3.7a

General guidelines to participants for the health state description workshop

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

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

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

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

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

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

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

1. Mobility
2. Self care

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

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

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

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

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

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

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

D. Plenary:

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

Appendix-3.7b

The EuroQol Instrument - An overview

I. Health Related Quality of Life Measurements:

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

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

II. EUROQol:

EuroQol is a health related quality of life measure¹. It is a generic multidimensional health status measuring instrument. The EuroQol Group first met in 1987 to test the feasibility of jointly developing a standardised non-disease-specific instrument for describing and valuing health-related quality of life. The EuroQol instrument has been purposefully developed to generate a generic cardinal index of health. This ability of giving a cardinal measure makes it useful health care evaluation. It provides a simple descriptive profile and generates a single index value for health status on which full health is assigned a value of 1 and death a value of 0.

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

A. EuroQol Dimensions:

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

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

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

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

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

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

B. Components of the EuroQol instrument:

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

C. Uses of EuroQol instrument:

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

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

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

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

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

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

IV. References:

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

Appendix-3.8

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

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

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

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