
Article:
Rowen, D.L. orcid.org/0000-0003-3018-5109, Brazier, J., Ara, R. et al. (1 more author) (2017) The Role Of Condition-Specific Preference-Based Measures In Health Technology Assessment. PharmacoEconomics, 35 (Suppl 1). pp. 33-41. ISSN 1170-7690

https://doi.org/10.1007/s40273-017-0546-9

The Role Of Condition-Specific Preference-Based Measures In Health Technology Assessment

Running title: Condition-specific preference-based measures in HTA

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ABSTRACT

A condition-specific preference-based measure (CSPBM) is a measure of health related quality of life (HRQoL) that is specific to a certain condition or disease and that can be used to obtain the quality adjustment weight of the quality adjusted life year (QALY) for use in economic models. This article provides an overview of the role of CSPBMs, the development of CSPBMs, and presents a description of existing CSPBMs in the literature. The article also provides an overview of the psychometric properties of CSPBMs in comparison to generic preference-based measures (generic PBMs), and considers the advantages and disadvantages of CSPBMs in comparison to generic PBMs.

CSPBMs typically include dimensions that are important for that condition but may not be important across all patient groups. There are a large number of CSPBMs across a wide range of conditions, and these vary from covering a wide range of dimensions to more symptomatic or uni-dimensional measures. Psychometric evidence is limited but suggests that CSPBMs offer an advantage in more accurate measurement of milder health states. The mean change and standard deviation can differ for CSPBMs and generic PBMs, and this may impact on incremental cost-effectiveness ratios.

CSPBMs have a useful role in HTA where a generic PBM is not appropriate, sensitive or responsive. However due to issues of comparability across different patient groups and interventions, their usage in health technology assessment is often limited to conditions where it is inappropriate to use a generic PBM or sensitivity analyses.

KEY POINTS FOR DECISION MAKERS

- A condition-specific preference-based measure (CSPBM) is a measure of HRQoL that is specific to a condition or disease that also has a set of preference weights that enable a health state utility value to be generated each time the measure is completed.
- CSPBMs have a useful role in Health Technology Assessment (HTA) where a generic preference-based measure (generic PBM) is not appropriate, sensitive or responsive as they can provide appropriate health state utility values that capture change in that condition.
- Due to issues of comparability across different patient groups and interventions, the usage of CSPBMs in HTA is generally limited to interventions where it is inappropriate to use a generic PBM.

1 What is a condition-specific preference based measure of health?

This paper provides a definition of a condition-specific preference-based measure (CSPBM) of health or health-related quality of life and critically examines its role in HTA and beyond. The paper provides an overview and summary of all existing CSPBMs, thus providing a resource of references for all CSPBMs across all conditions that have been derived in the literature. The paper also summarises available psychometric evidence on the performance of CSPBMs, and provides guidance on the advantages and disadvantages of using CSPBMs for HTA in comparison to generic preference-based measures such as the EQ-5D.

A condition-specific preference-based measure (CSPBM) is a measure of health-related quality of life that is specific to a certain condition or disease and that also has a set of preference weights that enables a utility value to be generated from responses to the measure. Analogously to generic measures, a CSPBM consists of 1) items or questions that are typically completed by the patient to report their own health, 2) a classification system which is used to classify the self-reported health of the patient into a health state, and 3) a value set that enables a utility value to be produced for every health state described by the classification system. CSPBMs typically include dimensions that are important for that condition but generally not important across all patient groups. Each CSPBM is unique and their content varies substantially. Some CSPBMs include a range of dimensions covering both generic and condition-specific aspects (for example a cancer-specific measure with dimensions of physical functioning, role functioning, pain, emotional functioning, social functioning, fatigue and sleep disturbance, nausea, and constipation and diarrhoea [2]), whereas others are focussed upon symptoms (for example a measure for flushing (a side-effect of niacin medications) with dimensions of redness of skin, warmth of skin, tingling of skin, itching of skin, and difficulty sleeping [3]). Some CSPBMs are uni-dimensional and have several items relating to the same dimension (for example the measure for flushing [3]), whereas others are multi-dimensional (for example the measure for cancer [2]). CSPBMs can be developed from new, 'de novo', or can be derived from an existing condition-specific measure.

2 What is the role of condition-specific preference-based measures?

CSPBMs have a role in HTA where a generic PBM is not appropriate, or has poor psychometric performance in a condition or patient group, as they provide appropriate utility values under these

circumstances. Where a generic PBM has been shown to perform poorly in terms of sensitivity or responsiveness (for example, vision and hearing, severe and complex mental health problems, and dementia, as discussed in section 2) it is not expected that it will accurately capture the impact of an intervention on the HRQoL of the patient. For example, if a generic PBM has been shown to suffer from ceiling effects for a condition then an improvement in HRQoL following an intervention cannot be captured. In addition a generic PBM may fail to capture all aspects of HRQoL that are important for that patient group. In contrast, CSPBMs are designed to capture the aspects of HRQoL that are important for that condition, and unlike a generic PBM this is likely to include symptoms, sometimes alongside more generic dimensions of HRQoL ((for example a cancer-specific measure with dimensions of physical functioning, role functioning, pain, emotional functioning, social functioning, fatigue and sleep disturbance, nausea, and constipation and diarrhoea [2]).

In circumstances where a generic PBM has been shown to be appropriate for a condition, CSPBMs can be used in sensitivity analyses of the economic model to indicate how the use of the generic PBM, which although appropriate may be less sensitive or responsive to changes in health, may have impacted on incremental cost-effectiveness ratios.

CSPBMs have a role in HTA external to the economic model to demonstrate additional benefits that may not be captured by the generic PBM and provide additional supporting evidence. CSPBMs also have a wide role outside of economic evaluation where they can be used to compare health and treatment effects across different studies within a patient group. The inclusion of CSPBMs in a wide range of studies provide utility values that are relevant for that condition as they take into consideration the specific aspects of health that are important for that condition. These utility values can be reported alongside the detailed HRQoL data provided from the condition-specific measure that the CSPBM is derived from (for example reporting condition-specific EORTC QLQ-C30 health-related quality of life data alongside CSPBM data from the EORTC-8D for patients with prostate cancer [4]).

3 Development issues

3.1 Development from an existing condition-specific measure

The advantage of deriving a preference-based measure from an existing condition-specific measure is that the existing measure has already been used in many studies, and therefore existing datasets

can be used to generate utility values. In addition, the existing measure is likely to have been validated and is likely to have evidence of good psychometric performance.

Figure 1 outlines the six-stage process developed by researchers at the University of Sheffield to derive a CSPBM from an existing condition-specific measure [1]. Stages I to IV derive the classification system and stages V to VI derive the value set for every health state described by the classification system. The classification system consists of multiple dimensions with typically one item to reflect that dimension, with several levels of severity.

Stages I to IV derive the classification system using a combination of factor analysis, Rasch analysis and classical psychometric analysis. Factor analysis can be used to either confirm the dimensional structure of the existing condition-specific measure, to propose a different dimensional structure indicating where dimensions are not independent or where items within the same dimension capture different concepts [1], or to propose a dimension structure for the existing condition-specific measure which does not have one proposed by the instrument developer [5, 6]. Rasch analysis is a mathematical technique that enables qualitative data to be converted onto a continous latent scale using a logit model [7, 8]. Classical psychometric analyses are used to indicate the performance of each item within each dimension and include floor and ceiling effects, correlation between items and dimensions, responsiveness over time and levels of missing data.

Stage I involves the derivation of the dimensions using a combination of factor analysis and the existing factor structure of the measure, and stage II uses Rasch analysis or item response theory and classical psychometric analysis to select the best item(s) to reflect each dimension in terms of coverage, ordering of levels, no differential item functioning across different groups, low floor and ceiling effects and good responsiveness. Stage III considers reducing the item levels to ensure that readers can accurately distinguish between each item level. Stage IV validates stages I-III, preferably on an independent dataset, to ensure the classification system has not been impacted on by the choice of dataset used to derive the classification system.

Stage V entails a valuation study typically with members of the general population to value a sample of health states as it is generally infeasible to value all health states within the full classification system as typically there are too many. Stage VI involves regression analysis of the valuation data to produce a decrement from the reference level for every level of every dimension. This enables a utility value to be generated for every health state described by the classification system. Stages V and VI typically involve the same procedure as valuation of a generic PBM, see section 2 for an overview. One additional challenge is that some CSPBMs may be uni-dimensional, or have a uni-

dimensional component, for example a CSPBM for flushing or common mental health problems. For uni-dimensional measures or components valuation can be adapted to take this uni-dimensionality into consideration through the selection of health states for valuation using Rasch analysis, which does not require independence of items [3, 9].

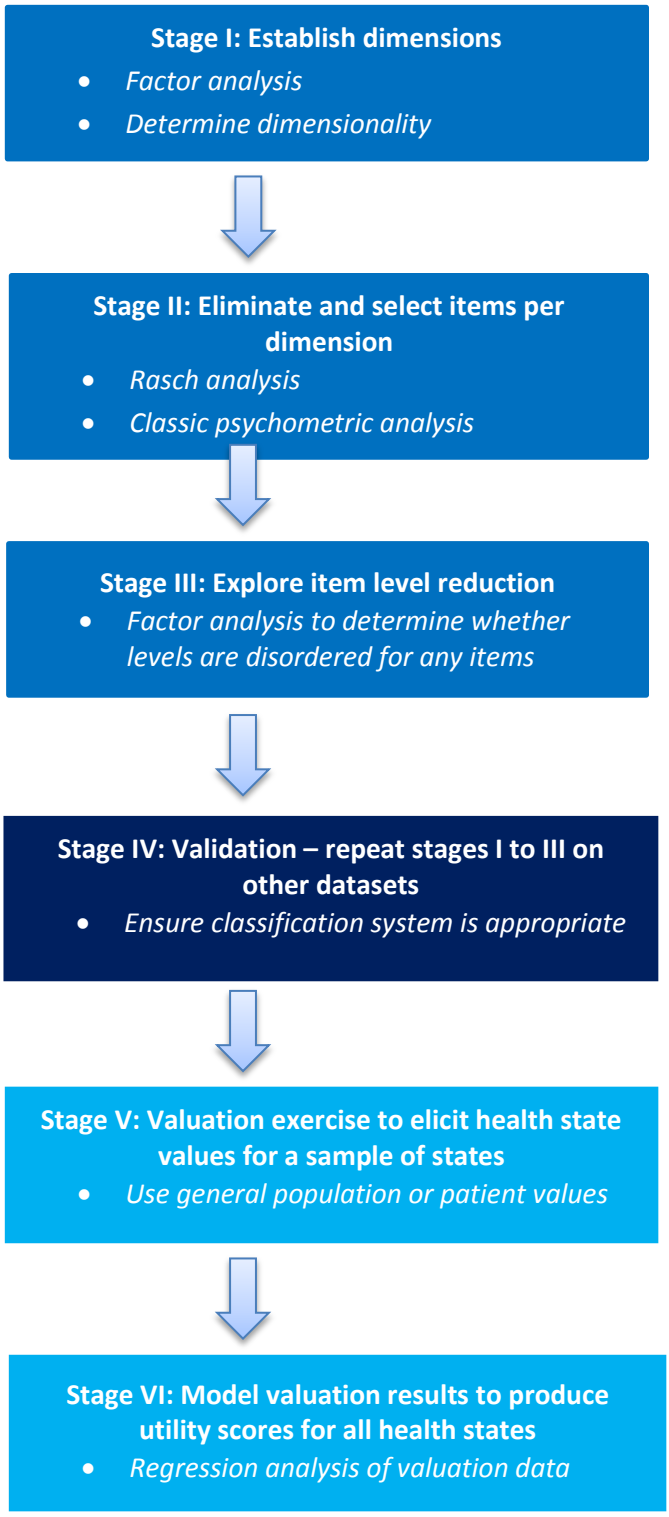
At every stage clinical input is used and often the instrument developer of the existing condition-specific measure is also involved. Some measures have also involved patients to ensure that the classification system includes all aspects that are important to patients (see for example [10]). Other measures have been developed using psychometric analyses on multiple existing condition-specific measures in order to select the best performing dimensions and items across these measures (for example [11]).

3.2 Developing a new measure 'de novo'

The advantage of developing a new measure is that it does not have to be based on an existing condition-specific measure as for some patient groups existing measures may not cover all important aspects of HRQoL. However there will be no pre-existing evidence on the psychometric performance of the new measure, which can be important for some international agencies when they are examining the appropriateness of the usage of a CSPBM. It may therefore be necessary to establish the psychometric properties of the measure before it can be recommended for usage.

Developing a new measure involves a modification of the six-stage process. Guidelines for the development of dimensions and items for new measures are available from the US Food and Drug Administration (FDA) [12]. Patient involvement is emphasised at every stage of developing a classification system for a new measure including both the generation and the validation of the content. Approaches in the literature include qualitative research with patients to identify dimensions, items and item wording, (for example [13]). The valuation of the measure is as described above in stages V and VI used to value a CSPBM derived from an existing condition-specific measure.

Figure 1 Six stages for deriving a condition-specific preference-based measure from an existing condition-specific (non-preference-based) measure



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4 Description of condition-specific preference-based measures

Papers developing CSPBMs either from existing condition-specific measures or 'de novo' that were published in English were identified using 1) a literature search conducted in December 2010 [1] and updated in March 2016 for the purpose of this paper and 2) a recent review of the literature [14]. Measures have been excluded that: do not provide utility weights; that do not anchor utilities on the 1-0 full health-dead scale; that derive utilities by mapping from a condition-specific measure to own utility values (as this is mapping not a preference-based measure). In total 36 CSPBMs were identified across a range of 29 conditions. The CSPBMs are summarised in **Table 1** and further details are provided in appendix 3.

Table 1 Summary of existing condition-specific preference-based measures

Aspect	Extracted data	
Conditions	Amyotrophic lateral sclerosis [15]; arthritis [16]; asthma [17, 18]; cancer [2, 10, 19, 20]; COPD [21]; common mental health problems [9, 22]; dementia [23-25]; diabetes [26, 27]; epilepsy [28]; erectile (dys)functioning [29]; flushing [3]; fragile X syndrome [30]; lung cancer [31, 32]; menopause [33]; multiple sclerosis [16]; myelofibrosis [11]; overactive bladder [5, 34]; paediatric asthma [35]; paediatric atopic dermatitis [6]; Parkinson's disease [36]; prostate cancer [37, 38]; pulmonary hypertension [39]; schizophrenia or bipolar disorder [40]; sexual quality of life [56]; short bowel syndrome [57]; urinary incontinence [58,59]; lower urinary tract symptoms suggestive of benign prostatic obstruction [60]; venous ulceration [13]; vision/visual impairment [61,62,66,67]	
Classification system development	De novo	4 [13,35,36,61]
	Derived from an existing condition-specific measure	32[2,3,5,6,10,11, 15-17, 21, 22, 24-33, 38-40, 53-60, 62]
Classification system	Number of dimensions	2-10
	Number of severity levels	2-7
	Number of health states	9-6,000,000
Preference elicitation technique	DCE	1 [19]
	DCE, ranking and VAS	1 [53]
	LT-TTO	1 [57]
	Rating scale and SG	1 [37]
	SG	2 [6,58]
	TTO	22 [2,3,9,11,13,16,20,21,25, 28,29,30,33,34,39,55,56,60, 64,65,67]
	VAS	1 [31,32]

Aspect		Extracted data
	VAS and SG	4 [26,27]
	VAS and TTO	3 [40,59,66]
Country providing preference weights	Australia	2 [19,67]
	Canada	2 [37,67]
	Netherlands	7 [16,53,29,32,60]
	Spain	1 [40]
	Sri Lanka	1 [20]
	UK	22 [2,3,6,9,11,16,21,25,28,30,31,33,34,39,55,64,65]
	US	5 [15,26,27,35,36,67]
	Unclear	1 [66]
Population providing preference weights	General population	27 [2,3,6,9,11,13,15,16,19-21, 25,28,30-32, 34,35,39,55-57,59,60,64,65,67]
	Patients	6 [26,27,33,36,37,40,58]
	Professionals and general population	1 [53]
	Students and general population	1 [29]
	Unclear	1 [66]

Note: Numbers of extracted data refer to measures not papers, as the development of some measures is reported in multiple papers. Some measures provide preference weights for more than one country.

5 Psychometric properties of condition-specific preference-based measures

5.1 Psychometric performance of condition-specific preference-based measures in comparison to existing condition-specific measures

There is limited evidence comparing CSPBMs to the existing condition-specific measure they are derived from [1, 14]. However, evidence suggests largely comparable psychometric performance in terms of discrimination across severity groups and responsiveness to change over time between the existing condition-specific measure and CSPBM for asthma, cancer, common mental health problems and overactive bladder [1].

5.2 Psychometric performance of condition-specific preference-based measures in comparison to generic preference-based measures

There is limited evidence comparing CSPBMs and generic PBMs [1, 14]. However, evidence suggests that CSPBMs in asthma, cancer, common mental health problems and overactive bladder offer an

advantage for measuring milder health states, and are less prone to ceiling effects than the EQ-5D [1]. The ceiling effects of EQ-5D have been widely reported in the general literature examining the performance of EQ-5D (see for example [41]), and therefore for patients with mild health problems CSPBMs may be more likely to provide a more accurate measurement of HRQoL and capture change in HRQoL. The evidence also suggests that these CSPBMs and a measure in vision better discriminated across severity groups than the generic PBM they were compared to [1, 42-44]. It is recommended that the psychometric properties of any CSPBM are examined prior to their usage to inform HTA, and preferably compared to a generic PBM to confirm where they offer an advantage.

Mean change over time and differences in utility values between different severity groups have been found to be smaller for CSPBMs than generic PBMs, with smaller standard deviation, in particular in comparison to EQ-5D [1] (although this may not always be the case [43, 45]). Any differences may impact on incremental cost-effectiveness ratios, and may potentially impact upon whether interventions are considered cost-effective. However, research in this area has been limited to a small number of datasets on a small number of conditions, CSPBMs and generic PBMs and the existing published evidence is unlikely to be representative across all CSPBMs. Further research in this area is encouraged.

6 Selecting a measure for economic evaluation

Recent ISPOR task force guidance provides a framework for researchers considering the collection of utility data for HTA [46]. An important consideration is the appropriateness of the measure for the condition and population, and the choice will also depend on the requirements of the agency to which the economic evaluation will be submitted (see [47]). However an important consideration is whether to use a generic PBM or a CSPBM. **Table 2** outlines the advantages and disadvantages of generic PBMs and CSPBMs with reference to different criteria: completion of the measure by the patient; psychometric performance; HRQoL coverage; issues with the valuation process used to elicit the utility values; comparability of values for use in HTA.

Overall CSPBMs offer advantages of lower patient burden for completion, are more relevant to the patient, are less likely to suffer from ceiling effects, and the existing condition-specific measures they are derived from are typically sensitive and responsive. However they suffer from disadvantages that they may not be able to capture the impact of all side-effects and comorbidities, their elicited utility values may be prone to exaggeration from focussing effects, the values they generate are not

directly comparable across different conditions, and they are not accepted in the base-case cost-effectiveness analyses by many international agencies.

It is important to note that the advantages and disadvantages of CSPBMs vary both by the exact measure and the patient group it is administered to. The content of CSPBMs varies widely, where for example a CSPBM in cancer [2, 10] may be perceived as more generic in its dimensions, and could even have 'bolt-on' dimensions for certain cancers, whereas other CSPBMs such as for flushing are uni-dimensional [3]. It is also important to note that the psychometric performance of measures differs across patient groups, and hence a measure that is appropriate for use in some patient groups is not necessarily appropriate in all patient groups.

Generic PBMs offer the advantage that they offer comparability across patient groups and interventions, have no issues in their valuation and can arguably capture comorbidities where these occur in the generic dimensions of HRQoL. However they may not be responsive or sensitive and suffer from ceiling effects, and may not be relevant to the patient and potentially increase patient burden where they are included in addition to the condition-specific measures that are included for multiple reasons unrelated to populating the economic model.

It has been argued that CSPBMs can provide utility values that are comparable to generic PBMs as they can be derived using the same methodology as a generic PBM (for example a large number of CSPBMs have been derived using time trade-off interview with the UK general population as also used by the EQ-5D UK value set), and utility values are anchored on a comparable 1-0 full health-dead scale required to generate QALYs. However, there remains the issue of the differences in descriptive systems, and issues in the valuation of CSPBMs due to labelling the condition (disease labelling of health states can impact on elicited values [48]) and focussing effects (respondents focus only on the areas of HRQoL mentioned and exaggerate their importance) that may mean that there are important underlying issues of comparability. For this reason, to enable comparability in HTA conducted across interventions and patient groups a generic PBM is typically recommended for use in base case analyses, and a CSPBM is typically only recommended where evidence demonstrates a generic PBM is inappropriate (see for example prescriptive guidance by NICE[49]), or for use alongside a generic PBM in sensitivity analyses.

Table 2 Advantages and disadvantages of generic and condition-specific preference-based measures

Aspect	Generic preference-based measure	Condition-specific preference-based measure
Completion: patient burden	May not be included in trial to reduce patient burden, though this may be more important for larger measures e.g. deriving SF-6D values from SF-36	Condition-specific (non-preference-based) measures are typically included in trials, these responses can then be directly converted into CSPBM
Completion: relevance to patient	Not always relevant to the patient	Relevant to the patient
Performance: ceiling effects	Evidence shows EQ-5D suffers from ceiling effects for some conditions [1]	Evidence demonstrates little ceiling effects [1]
Performance: sensitivity and responsiveness	Not sensitive and responsive for some conditions [50]	Sensitive and responsive [50]
Coverage: missing dimensions	Includes important generic dimensions but may not include all symptoms that are important to the patient (though the impact of these may be captured if they impact on the generic dimensions)	May not include all important generic dimensions but typically includes all important symptoms (though there may be exceptions e.g. a CSPBM in cancer may not include all symptoms relevant for all types of cancers)
Coverage: side-effects and comorbidities	Will capture more general side-effects and co-morbidities but may miss some symptomatic side-effects and co-morbidities (though again the impact of these may be captured if they impact on the generic dimensions)	May not capture comorbidities or all relevant side-effects
Valuation: condition labels	No problems with valuation	Use of condition labels in health state valuation exercises can impact on values e.g. inclusion of cancer label produces lower utility values than no condition label for the same health states [48]
Valuation: focussing effect	No problems with valuation	Focussing on problems with a condition rather than generic dimensions may produce artificially lower utility values [51] and may mean respondents make assumptions about the generic aspects of health that are not mentioned
Comparability across interventions and patient groups	Comparable	Limited comparability
Acceptability for use in	Accepted and typically recommended [52]	Often not mentioned, or accepted only when the generic is

Aspect	Generic preference-based measure	Condition-specific preference-based measure
HTA		inappropriate [52]

Notes: CSPBM – condition-specific preference based measure; HTA – health technology assessment.

7 Summary

The paper provides an overview and summary of all existing CSPBMs, providing a resource for researchers. There are a large number of CSPBMs across a wide range of conditions, and the coverage of these measures varies from covering a wide range of dimensions to more symptomatic or uni-dimensional measures. CSPBMs have a useful role in HTA where a generic PBM is not appropriate, sensitive or responsive. Due to issues of comparability across different patient groups and interventions, their usage in HTA is typically limited to conditions where it is inappropriate to use a generic PBM, or in sensitivity analyses. Widespread use of CSPBMs rather than generic PBMs in HTA would reduce comparability of evaluations of interventions across different patient groups. For this reason CSPBMs are not recommended as a common replacement for generic PBMs, rather they offer important evidence alongside generic PBMs or where generic PBMs are inappropriate. Evidence suggests that CSPBMs offer an advantage in more accurate measurement of milder health states. However CSPBMs can fail to capture comorbidities and all side-effects. Mean change and standard deviation can differ to generic PBMs, and this may impact on incremental cost-effectiveness ratios.

Disclosure statement

This article is published in a special edition journal supplement wholly funded by Takeda Pharmaceutical International AG, Zurich, Switzerland.

Acknowledgement

The authors would like to thank Prof Jon Karnon, PhD of The University of Adelaide and Dr Andrew Lloyd, Phd of Bladen Associates Ltd for their editorial review.

Author contributions

DR reviewed the literature and wrote the first draft of the manuscript and subsequent versions. JEB, RA and IA contributed to draft and final versions of the manuscript.

Compliance with Ethical Standards

Funding This study was funded by an unrestricted grant from Takeda Pharmaceuticals International AG.

Conflict of interest Ismail Azzabi Zouraq is employed by Takeda Pharmaceuticals International AG. Donna Rowen, John Brazier and Roberta Ara have no conflicts of interest.

Online Appendix

Table A1 Descriptive systems of condition-specific preference-based measures

Condition: name of CSPBM (where available)	First author	Non-preference-based measure	No. of dimensions	Severity levels	No. of states defined by system	Dimensions
Amyotrophic lateral sclerosis (ALS): ALS Utility Index	Beusterien [15]	Amyotrophic Lateral Sclerosis Functioning Rating Scale - Revised (ALSFRS-R)	4	5-6	750	Speech and swallowing; eating, dressing and bathing; leg function; respiratory function
Arthritis: HAQ-PBM	Versteegh [16]	Health Assessment Questionnaire (HAQ)	5	4	1,024	Stand up from a straight chair; walk outdoors on flat ground; get on/off toilet; reach and get down a 5-pound object (such as a bag of sugar) from just above your head; open car doors
Asthma: AQL-5D	Young [17]	Asthma Quality of Life Questionnaire (AQLQ)	5	5	3,125	Concern about asthma; shortness of breath; weather and pollution stimuli; sleep problems; activity limitation
Cancer: EORTC-8D	Rowen [2]	EORTC QLQ-C30	8	4-5	81,920	Physical functioning; role functioning; pain; emotional functioning; social functioning; fatigue and sleep disturbance; nausea; constipation and diarrhoea
Cancer: QLQ-PBM	Versteegh [16]	EORTC QLQ-C30	8	2-4	32,768	Trouble taking a long walk; limited in doing either your work or other daily activities; pain; nausea; tired; difficulty in concentrating; worry; social activities
Cancer: QLU-C10D	King [10]	EORTC QLQ-C30	10	4	1,048,576	Physical functioning; role functioning; social functioning; emotional functioning; pain; fatigue; sleep; appetite; nausea; bowel problems
Chronic obstructive pulmonary disease (COPD): EXACT-U	Petrillo [21]	Exacerbations of chronic obstructive pulmonary disease tool (EXACT)	5	3-5	960	Chest discomfort; cough; shortness of breath with activity; psychological state; weak/tired
Common mental health problems: CORE-6D	Mavranezouilli [22]	Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM)	6	3	729	Functioning – close relationships; functioning – social relationships; functioning – general; symptoms – anxiety; risk/harm to self; physical health
Dementia: DEMQOL-U	Mulhern [24, 25]	DEMQOL (self-report)	5	4	1,024	Positive emotion; memory; relationships; negative emotion; loneliness
Dementia: DEMQOL-Proxy-U	Mulhern [24, 25]	DEMQOL-Proxy (carer proxy-report)	4	4	256	Positive emotion; memory; appearance; negative emotion
Dementia: DQI	Scholzel-Dorenbos [53] Arons [54]	Dementia Quality of Life Instrument	6	3	729	Physical health; self-care; social functioning; mood; memory; orientation
Diabetes: Diabetes Utility	Sundaram [26,	Audit of Diabetes-	5	3-4	768	Physical ability and energy level; relationships; mood and

Condition: name of CSPBM (where available)	First author	Non-preference-based measure	No. of dimensions	Severity levels	No. of states defined by system	Dimensions
Index	27]	Dependent Quality of Life (ADDQoL) plus additional items				feelings; enjoyment of diet; satisfaction with managing diabetes
Epilepsy: NEWQOL-6D	Mulhern [28]	Quality of Life in Newly Diagnosed Epilepsy measure (NEWQOL)	6	4	4,096	Worry about attacks; depression; memory; cognition; stigma; control
Erectile (dys)functioning	Stolk [29]	IIEF Index of Erectile Function	2	5	25	Ability to attain an erection sufficient for satisfactory sexual performance; ability to maintain an erection sufficient for satisfactory sexual performance
Flushing	Young [3]	Flushing Symptoms Questionnaire (FSQ)	5	4-5	2,500	Redness of skin; warmth of skin; tingling of skin; itching of skin; difficulty sleeping
Fragile X syndrome: ABC-UI	Kerr [30]	Aberrant Behavior Checklist-Community (ABC-C)	7	3	2,187	Mood changes quickly; easily distractible or restless, unable to sit still; aggressive towards others (verbally and physically); being impulsive (acting without thinking); repetitive speech; shows few social reactions to others and isolating yourself from others; repetitive hand, body or head movements
Lung cancer	Kind [31], Lamers [32]	FACT-L	6	2	64	Physical; social/family; emotional; functional; symptoms - general: symptoms – specific
Menopause	Brazier [33]	Menopause-specific quality of life questionnaire	7	3-5	6,075	Hot flushes; aching joints/muscles; anxious/frightened feelings; breast tenderness; bleeding; vaginal dryness; undesirable androgenic signs
Multiple sclerosis	Goodwin [55]	Multiple Sclerosis Impact Scale (MSIS-29)	8	4	65,536	Physical; social; mobility; daily activities; fatigue; emotion; cognition; depression
Multiple sclerosis: MSIS-PBM	Versteegh [16]	Multiple Sclerosis Impact Scale (MSIS-29)	8	4	65,536	Problems with your balance; being clumsy; limitations in your social and leisure activities at home; difficulties using your hands in everyday tasks; having to cut down the amount of time you spent on work or other daily activities; feeling mentally fatigued; feeling irritable, impatient or short tempered; problems concentrating
Myelofibrosis: MF-8D	Mukuria [11]	MF-SAF and EORTC QLQ-C30	8	2-5	2,560	Physical functioning; emotional functioning; fatigue; itchiness; pain under ribs on left side; abdominal discomfort; bone or muscle pain; night sweats
Overactive bladder: OAB-5D	Young [5]	OABq overactive bladder questionnaire	5	5	3,125	Urge to urinate; urine loss; sleep; coping; concern
Paediatric asthma:	Choiu [35]	N/A	3	2-3	12 – but only	Symptoms; emotion; activity

Condition: name of CSPBM (where available)	First author	Non-preference-based measure	No. of dimensions	Severity levels	No. of states defined by system	Dimensions
Paediatric Asthma Health Outcome Measure (PAHOM)					10 are valid	
Paediatric atopic dermatitis	Stevens [6]	Un-named questionnaire on atopic dermatitis	4	2	16	Activities; mood; settled; sleep
Parkinson's disease	Palmer [36]	N/A	2	2-5	10	Disease severity; proportion of the day with 'off-time' (impact on QOL due to condition covering domains: social function, ability to carry out daily activities, psychological function)
Prostate cancer: PORPUS-U	Krahn [38]	Patient-Oriented Prostate Utility Scale	10	4-6	6,000,000	Pain and disturbing body sensations; energy; support from family and friends; communication with doctor; emotional well-being; urinary frequency; leaking urine; sexual function; sexual interest; bowel problems
Pulmonary hypertension	McKenna [39]	Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR)	4	2-3	36	Social activities; travelling; dependence; communication
Schizophrenia or bipolar disorder	Montejo [40]	Tolerability and Quality of Life questionnaire (TooL questionnaire) (Spanish version)	8	4	65,536	Anxiety and depression; function capabilities; fatigue or weakness; body weight; stiffness and tremor; bodily restlessness; sexual function; dizziness or nausea
Sexual quality of life: SQOL-3D	Ratcliffe [56]	Sexual quality of life questionnaire (SQOL)	3	4	64	Sexual performance, sexual relationship, sexual anxiety
Short bowel syndrome	Lloyd [57]	Short bowel syndrome health-related quality of life scale (SBS-QoL)	6	2	64	Diet, eating and drinking habits; diarrhoea; fatigue/weakness; mobility and self-care/everyday activities; leisure activities/social life; emotional life
Urinary incontinence	Brazier [58]	The King's Health Questionnaire (used for urinary incontinence and lower urinary tract symptoms)	5	4	1,024	Role limitations; physical limitations; social limitations/family life; emotions; sleep/energy
Urinary incontinence: Incontinence Utility Index (IUI)	Cuervo [59]	Incontinence Quality of Life Questionnaire (I-QOL) and Neurogenic Module	5	3	243	Depression; urine smell; sleep; bladder control; drinks
Lower urinary tract symptoms (LUTS) suggestive of benign	Kok [60]	International Prostate Symptom Score (IPSS)	2	3	9	Irritative (frequency, urgency, nocturia); obstructive (incomplete emptying, intermittency, weak stream, hesitancy)

Condition: name of CSPBM (where available)	First author	Non-preference-based measure	No. of dimensions	Severity levels	No. of states defined by system	Dimensions
prostatic obstruction						
Venous ulceration	Palfreyman [13]	N/A	5	3-5	720	Pain; mobility; mood; smell; social activities
Vision/visual impairment: VisQoL/AQoL-7D	Misajon [61]	N/A	6	5-7	45,360	Physical well-being; independence; social well-being; emotional well-being; self-actualization; planning and organization
Vision: VFQ-UI	Kowalski [62]	National Eye Institute Visual Function Questionnaire-25 (NEI VFQ-25)	6	5	15,625	Near vision; social vision; distance vision; role difficulty; vision dependency; vision-related mental health

Note: Table updated and modified from [63]. **Key**: ABC-C – Aberrant Behaviour Checklist-Community; ABC-UI – Aberrant Behaviour Checklist-Utility Index; ADDQoL – Audit of Diabetes-Dependent Quality of Life; ALS – amyotrophic lateral sclerosis; ALSFRS-R – Amyotrophic Lateral Sclerosis Functioning Rating Scale - Revised; AQLQ – Asthma Quality of Life Questionnaire; AQL-5D – Asthma Quality of Life 5 dimension; CAMPHOR – Cambridge Pulmonary Hypertension Outcome Review; CORE-OM – Clinical Outcomes in Routine Evaluation - Outcome Measure; CORE-6D – Clinical Outcomes in Routine Evaluation 6 dimension; COPD – Chronic obstructive pulmonary disease; DEMQOL – Dementia-specific Quality of Life; DEMQOL-Proxy – Dementia-specific Quality of Life, for carers; DEMQOL-Proxy-U – Dementia-specific Quality of Life-Utility, for carers; DEMQOL-U – Dementia-specific Quality of Life - Utility; DQI – Dementia Quality of Life Instrument EORTC-8D - European Organisation for Research and Treatment of Cancer 8 dimension; EORTC-C30 – European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire; EXACT – Exacerbations of chronic obstructive pulmonary disease tool; EXACT-U – Exacerbations of chronic obstructive pulmonary disease tool-Utility; FACT-L – Functional Assessment of Cancer Therapy-Lung; FSQ – Flushing Symptoms Questionnaire; HAQ – Health Assessment Questionnaire; HAQ-PBM – Health Assessment Questionnaire-Preference-Based Measure; IIEF – International Index of Erectile Function; IPSS – International Prostate Symptom Scale; I-QOL – Incontinence Quality of Life Questionnaire; IUI – Incontinence Utility Index; LUTS – Lower urinary tract symptoms; MF-8D – Myelofibrosis-specific Quality of Life 8 dimension; MF-SAF - Myelofibrosis Symptom Assessment Form; MSIS-PBM – Multiple Sclerosis Impact Scale-Preference-Based Measure; MSIS-29 – Multiple Sclerosis Impact Scale-29; N/A – Not available; NEI VFQ-25 – National Eye Institute Visual Function Questionnaire-25; NEWQOL-6D – Quality of Life in Newly Diagnosed Epilepsy Instrument; NEWQOL-6D – Quality of Life in Newly Diagnosed Epilepsy Instrument 6 dimension; OABq – Overactive Bladder Questionnaire; OAB-5D – Overactive Bladder Questionnaire 5 dimension; PAHOM – Paediatric Asthma Health Outcome Measure; PORPUS-U- Patient-Oriented Prostate Utility Scale; QLQ-PBM – Quality of Life Questionnaire-Preference-Based Measure; QLU-C10D – Core Quality of Life Utility 10 dimension; SBS-QoL – Short Bowel Syndrome health related quality of life scale; SQOL – Sexual Quality of Life; SQOL-3D – Sexual Quality of Life 3 dimension; VFQ-UI – Visual Function Questionnaire-Utility Index; VisQoL/AQoL-25 – Vision-related Assessment of Quality of Life 7 dimension.

Table A2 Valuation of condition-specific preference-based measures

Condition: name of CSPBM (where available)	First author	Theory and model type	Preference elicitation technique	Population	Country
Amyotrophic lateral sclerosis (ALS): ALS Utility Index	Beusterien [15]	Decomposed – multiplicative	VAS for states and for the levels per dimension and SG	Gen. population	US
Arthritis: HAQ-PBM	Versteegh [16]	Statistical – additive	TTO	Gen. population	Netherlands
Asthma: AQL-5D	Yang [64]	Statistical – additive	TTO	Gen. population	UK
Cancer: EORTC-8D	Rowen [2] Kularatna [20]	Statistical – additive	TTO TTO	Gen. population Gen. population	UK Sri Lanka
Cancer: QLQ-PBM	Versteegh [16]	Statistical – additive	TTO	Gen. population	Netherlands
Cancer: QLU-C10D	Norman [19]	Statistical – additive	DCE with duration	Gen. Population	Australia
Chronic obstructive pulmonary disease (COPD): EXACT-U	Petrillo [21]	Statistical - additive	TTO	Gen. population	UK
Common mental health problems: CORE-6D	Mavranezouilli [9]	Statistical – additive	TTO	Gen. population	UK
Dementia: DEMQOL-U	Rowen [65] Mulhern [25]	Statistical – additive	TTO	Gen. population	UK
Dementia: DEMQOL-Proxy-U	Rowen [65] Mulhern [25]	Statistical – additive	TTO	Gen. population	UK
Dementia: DQI	Scholzel-Dorenbos [53]	Maps DCE latent utilities onto EQ-5D utilities using rank/VAS data of DQI and EQ-5D	DCE, ranking and VAS	Professionals working with patients with dementia, Gen. population	Netherlands
Diabetes: Diabetes Utility Index	Sundaram [26, 27]	Decomposed – multiplicative	VAS and SG	Patients	US
Epilepsy: NEWQOL-6D	Mulhern [28]	Statistical – additive	TTO	Gen. population	UK
Erectile (dys)functioning	Stolk [29]	All states valued	TTO	Gen. population and students	Netherlands
Flushing	Young [3]	Maps Rasch logit scores onto mean utilities – additive	TTO	Gen. population	UK
Fragile X syndrome: ABC-UI	Kerr [30]	Statistical - additive	TTO	Gen. population	UK
Lung cancer	Kind [31] Lamers [32]	Statistical – additive Statistical - additive	VAS VAS	Gen. population Gen. population	UK Netherlands
Menopause	Brazier [33]	Statistical - additive	TTO	Patients	UK
Multiple sclerosis	Goodwin [55]	Statistical - additive	TTO	Gen. population	UK
Multiple sclerosis: MSIS-PBM	Versteegh [16]	Statistical - additive	TTO	Gen. population	Netherlands
Myelofibrosis	Mukuria [11]	Statistical - additive	TTO	Gen. population	UK
Overactive bladder: OAB-5D	Yang [34]	Statistical – additive	TTO	Gen. population	UK
Paediatric asthma: Paediatric Asthma Health Outcome Measure (PAHOM)	Choiu [35]	Power function used to convert VAS to SG, all states valued using VAS	VAS and SG	Gen. population	US

Condition: name of CSPBM (where available)	First author	Theory and model type	Preference elicitation technique	Population	Country
Paediatric atopic dermatitis	Stevens [6]	All states valued	SG	Gen. population	UK
Parkinson's disease	Palmer [36]	All states valued	VAS and SG	Patients	US
Prostate cancer: PORPUS-U	Tomlinson [37]	Decomposed – multiplicative	Rating scale for states and for the levels per dimension and SG	Patients	Canada
Pulmonary hypertension	McKenna [39]	Statistical – additive	TTO	Gen. population	UK
Schizophrenia or bipolar disorder	Montejo [40]	Decomposed – multiplicative	VAS for states and for the levels per dimension and TTO	Patients	Spain
Sexual quality of life: SQOL-3D	Ratcliffe [56]	Statistical – additive	TTO	Gen. population	UK
Short bowel syndrome	Lloyd [57]	Statistical – additive	LT-TTO	Gen. population	UK
Urinary incontinence	Brazier [58]	Statistical - additive	SG	Patients	UK
Urinary incontinence: Incontinence Utility Index (IUI)	Cuervo [59]	Decomposed – multiplicative	VAS for states and for the levels per dimension and TTO	Gen. population	UK
Lower urinary tract symptoms (LUTS) suggestive of benign prostatic obstruction	Kok [60]	All states valued	TTO	Gen. population	Netherlands
Venous ulceration	Palfreyman [13]	Statistical – additive	TTO	Gen. population	UK
Vision/visual impairment: VisQoL/AQoL-7D	Peacock [66]	Decomposed – multiplicative	VAS for the levels per dimension and TTO	Unclear	Unclear
Vision: VFQ-UI	Rentz [67]	Maps item response theory scores onto mean utilities – additive	TTO	Gen. population	Australia, Canada, UK, US

Note: Table updated and modified from [63].). [#] Preference elicitation technique is reported only if it was used to produce the recommended utility scores for all health states. **Statistical** = statistical inference (regression analysis); **decomposed** = multi-attribute utility theory (MAUT) or combination of MAUT and statistical inference. **DCE**: discrete choice experiment; **Gen. population**: general population; **LT-TTO**: lead-time trade-off; **TTO**: time trade-off; **SG**: standard gamble; **VAS**: visual analogue scale

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