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Development and use of cognition bolt-ons for the EQ-5D-3L and EQ-5D-5L: a systematic review

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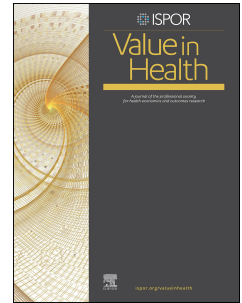
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Title: Development and use of cognition bolt-ons for the EQ-5D-3L and EQ-5D-5L: a systematic review

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Précis: This systematic review summarizes the existing literature on the development and use of cognition bolt-ons for the EQ-5D.

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ABSTRACT

Objectives: Multiple studies have proposed adding a cognition dimension (bolt-on) to the EQ-5D. Our objective was to systematically review the existing literature on the development and use of cognition bolt-ons for the EQ-5D.

Methods: A systematic literature review was conducted to identify studies that developed or used a cognition bolt-on for EQ-5D-3L or EQ-5D-5L (PROSPERO: CRD42023445567). We searched in three electronic databases, following PRISMA 2020 guidelines. The methodological quality of bolt-on items was assessed using criteria adapted from Mulhern et al. 2022.

Results: From 1997 to 2023, 181 publications (covering 137 studies) were included showing an increasing use of cognition bolt-ons over time. We identified 52 distinct wordings (three-level: 23, five-level: 29), with the most common dimension titles being cognition (29%) and thinking ability (19%), and examples such as concentration (60%), memory (39%) and remembering (31%). The methodological quality of bolt-on development was heterogeneous, often lacking qualitative input in item wording or clear phrasing. Bolt-ons were used in 28 languages across 24 countries, with 64% of the studies originating from the Netherlands. Overall, 16% of the studies used proxy-reporting. Most studies developed (n=38) and used or psychometrically tested EQ-5D+bolt-on(s) (n=120), with fewer valuation and disability weight studies (n=27). These studies covered 71 patient populations, most commonly injuries, dementia, depression, HIV, schistosomiasis and stroke.

Conclusion: There is a growing demand for cognition bolt-ons across various medical specialties. The variation in cognition bolt-on items poses challenges for comparability and consistent healthcare decision-making. Our findings will guide research toward selecting standardised cognition bolt-on item(s) for relevant contexts.

Keywords: EQ-5D-5L, EQ-5D-3L, bolt-on, cognition, systematic review, systematic literature review

HIGHLIGHTS

- Despite the widespread use of cognition bolt-ons for the EQ-5D, no systematic review has summarised their development and use, leading to uncertainty for health technology assessment bodies and researchers regarding their selection and application.
- Our systematic review identified 181 publications from 24 countries using 52 distinct cognition bolt-ons across 71 patient populations, primarily in the fields of neurology, psychiatry, traumatology and infectiology. The methodological quality of bolt-on development varied substantially, with only 23% meeting high quality standards. Two-thirds of studies originated from the Netherlands, potentially limiting generalisability.
- The proliferation of different cognition bolt-ons creates challenges for comparability across studies and decision-making. Our findings highlight the urgent need for standardisation in cognition bolt-on development and use. This systematic review provides a foundation for developing standardised guidance on cognition bolt-on selection and use in different contexts, supporting more consistent research practices and healthcare decision-making.

INTRODUCTION

Generic preference-accompanied measures are instruments that cover generic aspects of health-related quality of life (HRQoL) relevant across multiple populations and health interventions, and allow the estimation of quality-adjusted life years (QALYs) for cost-utility analyses of health interventions. The most common dimensions include physical functioning, mental health, pain and daily activities, which are found in almost all measures (e.g. EQ-5D, SF-6D, Health Utilities Index (HUI), 15D, and the PROMIS preference-scoring system (PROPr)).¹ However, some HRQoL dimensions, such as social relationships, energy and cognition, are not part of all these instruments.

Cognition, encompassing *'all forms of knowing and awareness, such as perceiving, conceiving, remembering, reasoning, judging, imagining and problem solving'*² is considered an important area of HRQoL. It is relevant across multiple patient populations, including dementia, attention deficit hyperactivity disorder (ADHD), epilepsy, stroke, traumatic brain injuries, cancer (brain cancer, brain metastases and chemotherapy-related cognitive impairment), neurocognitive deficits associated with infectious diseases (e.g. HIV, COVID, post-COVID) and occupational diseases (e.g. mercury exposure in miners).³ Furthermore, given the current demographic trends and that some cognitive changes occur even with normal aging,⁴ measuring cognitive functioning as part of generic HRQoL has become increasingly important. Some preference-accompanied measures, such as the HUI, 15D and PROPr, have separate items focusing on one or more aspects of cognition.⁵⁻⁷ Unlike these instruments, the EQ-5D has no cognition dimension; however, some argue that other dimensions may indirectly pick up consequences of impaired cognitive functioning.⁸⁻¹³

The EQ-5D is the most widely used generic preference-accompanied HRQoL measure worldwide.^{14,15} Being the shortest among all existing generic preference-accompanied measures

and showing a ceiling effect in some populations has led to a growing number of research efforts focused on appending additional dimensions (bolt-ons) to the EQ-5D to improve its content validity, discriminatory power and responsiveness to change.¹⁶ By now, over 30 different bolt-ons exist for the adult EQ-5D versions, each comprising one or more items.¹⁷ One of the earliest and so far, the most frequently used EQ-5D bolt-ons is cognition.¹⁸ A recent systematic review summarised all methodological studies that identified, developed, psychometrically tested or valued bolt-ons for the EQ-5D. The review included 28 articles covering 26 different bolt-ons, with cognition being the most frequently used.¹⁷ Despite the growing interest in cognition bolt-ons, no systematic review has specifically focused on this particular bolt-on. Therefore, our objective was to conduct a systematic literature review to provide an overview of the studies that had developed or used cognition bolt-ons for the two adult versions of the EQ-5D, and to identify all existing cognition bolt-on wordings.

METHODS

Study protocol, data sources and search strategy

The protocol for this systematic literature review was registered in PROSPERO (no. CRD42023445567). MEDLINE via PubMed and Web of Science were searched from their inception to February 15, 2023. EuroQol conference proceedings were searched on Sept 22, 2023. Google Scholar was used for hand-searching and citation tracking (last on March 10, 2023). Our search strategy was developed based on an approach used in an earlier review of bolt-on publications.¹⁷ It was based on keywords related to i) EQ-5D; ii) the names of existing cognition bolt-on items (e.g. EQ-6D, EQ-5D+C) and iii) cognitive functioning (Supplemental Table 1).

Study selection, inclusion and exclusion criteria

Study selection followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) 2020 guideline.¹⁹ Selection (applying inclusion and exclusion criteria), data extraction and assessment of methodological quality were performed by one researcher per article, but overall, two researchers were involved (F.R. and S.P.). These two researchers continuously consulted each other on any unclear data. Furthermore, in cases of disagreement, a third researcher (M.F.J.) was brought in for discussion. First, records were screened based on title and abstract. Then, potentially eligible full texts were screened. The following inclusion criteria were applied:

- 1) **Publication type:** original article (including published study protocols), short communication, research letter, conference paper (but not poster), master's or doctoral thesis or published working paper or research report.
- 2) **Publication language:** any language.
- 3) **Study type:** qualitative study, case study, cross-sectional study, cohort study, case-control study or clinical trial.
- 4) **Study population:** Studies involving any study population aged ≥ 16 years (the upper age limit of the EQ-5D-Y is 15 years), including any population, were eligible. Studies with mixed samples (both < 16 and ≥ 16 years) were also included.
- 5) **Intervention/exposure:** Any type of intervention or exposure was eligible.
- 6) **Instrument:** EQ-5D-3L or EQ-5D-5L
- 7) **Cognition bolt-on use:** studies that
 - Developed cognition bolt-on(s) for the EQ-5D;
 - Qualitatively or quantitatively investigated the psychometric properties of cognition bolt-on(s) for the EQ-5D;
 - Applied any existing cognition bolt-on for the EQ-5D to measure HRQoL;

- Investigated the impact of adding any cognition bolt-on to the EQ-5D on preferences for HRQoL;
- Obtained disability weights to measure disease burden associated with health conditions using the EQ-5D plus cognition bolt-on.

Study protocols were included unless subsequent publications reported specific results from the same study. In such cases, only the publication detailing the results was included. However, multiple publications reporting results based on the same dataset were included. This approach was chosen due to the presence of large longitudinal studies with multiple data collection points reporting different results, which was considered an important indicator of interest in cognition as a bolt-on.

Studies were excluded if they met any of the following criteria: i) they were reviews, editorials, conference abstracts, posters or pre-prints; ii) they included solely populations <16 years; iii) they identified cognition as missing from the EQ-5D but did not develop or use a bolt-on; iv) they used other instruments' items as a cognition bolt-on without adapting them to the EQ-5D format; v) they were cost-utility analyses that used utilities based on the EQ-5D cognition bolt-on but referenced utilities from other publications; vi) the EQ-5D was not administered alongside the bolt-on or not all five core dimensions were used.

Data extraction and strategy for data synthesis

Publications written in a language not spoken by any members of the research team were translated into English using DeepL (DeepL SE, 2023, Cologne, Germany). The following data were extracted from eligible publications using a customised Microsoft Excel spreadsheet:

- Publication details: authors, year of publication, publication language, funding organisation

- Study characteristics: study design, sample size, country, language, setting (i.e. single vs. multi-centre)
- Characteristics of the study population: age, diagnosis
- EQ-5D + bolt-on(s) version: paper or electronic
- Mode of administration: onsite (face-to-face), online, email, mail (at home), telephone
- Completion: self-completed vs. interviewer-administered
- Reporting method: self-report vs. proxy (including perspective: proxy-proxy or proxy-patient)
- Characteristics of the cognition bolt-on: source and name of the bolt-on, version used [three-level (3L) or five-level (5L)], number of bolt-on items developed or used, precise wording of the bolt-on item(s), bolt-on position in relation to the EQ VAS, any modifications used (e.g. recall period or pictorial version) and other (non-cognition) bolt-on(s) used in the study
- Qualitative methods and population used for bolt-on development

Patient populations were categorised using the International Classification of Diseases 11th Revision (ICD-11).²⁰ Authors of cognition bolt-on publications were contacted via email or LinkedIn by F.R. or M.F.J. regarding missing information or when clarifications were needed, particularly regarding the precise wording of the bolt-on used or the ordering of the bolt-on in relation to the EQ VAS.

Assessment of methodological quality of bolt-on items

Many publications included in our systematic review developed a new cognition bolt-on without strictly following item or instrument development practices, such as those defined by Mulhern et

al. 2022.¹⁶ Therefore, for the purposes of this review, we defined ‘bolt-on development’ as the introduction of a new wording in a study, regardless of whether it underwent a formal development process such as using qualitative, quantitative or mixed methods research. The primary unit of assessment for ‘new wording’ was at the level of words. Therefore, the following did not count as new wordings but as variants of the same wording: i) very minor differences in wording, such as ‘problems in working things out’ vs. ‘problems working things out’; ii) using the same wording but providing examples after each response level instead of after the dimension title; iii) minor differences in conjunctions, such as using ‘for example’, ‘e.g.’ or ‘such as’; iv) differences in punctuation or parenthesis use, such as adding a semicolon at the end of the dimension title; and v) capitalisation or lack thereof in the dimension title descriptor.

The methodological quality of each individual bolt-on item identified was assessed using recently published criteria for bolt-on development proposed by Mulhern et al. 2022.¹⁶ These criteria focus on structure, dimension language and framing. A 12-point scorable checklist, presented in Supplemental Table 2, was devised by the research team in consultation with the membership of the Descriptive Systems Working Group of the EuroQol Group. The checklist underwent multiple iterations and was piloted with 10 different wordings before being finalised. We merged closely related items, excluded one related to psychometric characteristics, and added a missing criterion on first-person perspective compared to the Mulhern et al.¹⁶ criteria. Scores on the checklist range from 0 to 12, with higher scores indicating better methodological quality. For studies that developed multiple cognition items, each item was assessed separately for methodological quality, as these studies did not specify the simultaneous intended use of multiple items.

Reporting

The findings from the included studies were summarised using descriptive statistics (frequency and relative frequency) and narratively. In addition to the total sample, results were presented in three groupings where applicable. Firstly, results were reported separately under ‘studies’ and ‘publications’ to account for multiple publications arising from the same study, with the publication having the largest sample size considered the primary representation for the study. Secondly, due to a substantial proportion of included studies originating from the Netherlands, results were presented separately for this country versus all other countries. Lastly, certain results were categorised into ‘bolt-on development’, ‘use or psychometric testing’ and ‘bolt-on valuation or obtaining disability weights’ due to the clear distinction in methods between these categories.

RESULTS

Inclusion of relevant studies

The PubMed and Web of Science database search yielded 4,544 records, of which 82 met the inclusion criteria (Supplemental Figure 1). The majority of full texts were excluded because they did not use the EQ-5D or any cognition bolt-on. Altogether 117 records were identified through citation tracking and hand-searching in Google Scholar, as well as from EuroQol conference papers. Of these, 99 met the inclusion criteria, resulting in a total of 181 publications representing 137 individual studies (Supplemental Table 3).

Overall characteristics of included publications and studies

The publications showed a clear increasing trend in the use of cognition bolt-ons, with 22% released between 1997 and 2010 and 78% between 2011 and 2023 (Figure 1).

The sample sizes of the included studies varied widely, ranging from 1 to 43,704 respondents (median 239). Over a quarter of the 137 studies had a sample size of 500 respondents or above

(27%) (Table 1). Two-thirds of the studies (69%) developed or used the EQ-5D-3L with a 3L cognition bolt-on, using a variety of different nomenclatures, most frequently using the conjunction ‘plus’ or the ‘+’ sign to denote the bolt-on attached to the EQ-5D. All but two studies developed or used only one cognition bolt-on item, while 7% employed other non-cognition bolt-ons as well, with social relationships and sensory functioning (hearing and vision) being the most common. There were 38 studies that developed a new cognition bolt-on, 120 studies that used a cognition bolt-on to measure HRQoL and or assess at least one psychometric property of the bolt-on, and 27 studies that valued EQ-5D+cognition bolt-on health states or obtained disability weights for the EQ-5D+cognition bolt-on. Among the development studies, 53% gave no rationale for the development, while 18% mentioned relevance to a specific patient population. The remaining development studies aimed to improve comprehensiveness, capture preference impact or enhance psychometric performance. The identified studies originated from 24 countries, with the Netherlands (64%) leading, followed by China (6%), India (5%) and Belgium (4%) (Supplemental Table 4). Cognition bolt-ons were used in 28 different languages, with Dutch (66%) being the most common, followed by English (14%), Mandarin Chinese (6%) and French (4%).

Cognition bolt-on development: wording and methodological quality of items

We obtained the wording of the bolt-on item used for 127 (70%) publications (92 studies, 67%), either from the publication itself when it was clearly identifiable, or directly from the authors. For seven publications, the bolt-on wording was unavailable due to the loss of study materials. For five publications, the authors refused to share the information, and for 42 publications, we were unable to identify the wording. A total of 52 different wordings were identified: 23 for 3L and for 29 for 5L (Table 2). Overall, 17 different dimension titles were used in these items, with eight for the 3L and 15 for the 5L (overlaps possible). For the 3L bolt-ons, ‘thinking ability’ was the most common

(30%), while for the 5L, ‘cognition’ (35%) was predominant. We also identified three composite bolt-on items that combine concentration and memory in their dimension title. Twenty-five different examples were used to support understanding of the dimension title and construct, with 15 for 3L and 21 for 5L. The most commonly used examples were ‘concentrating’ (60%), ‘memory’ (39%), ‘remembering’ (31%), ‘IQ’ (19%) and ‘thinking (clearly)’ (15%).

The methodological quality of the 52 bolt-ons was heterogeneous. On a 0-12-point scale (higher the better), methodological quality was scored as follows: 5-6 in 4 cases (8%),¹ 7-8 in 10 cases (19%),² and 9-10 in 26 cases (50%).³ Only 11 bolt-on items (21%) scored 11 points,⁴ and one item scored 12 points.⁵ For wordings scoring 10 or below, there was an almost equal proportion of 3L and 5L items (55% vs. 45%). In contrast, all high-scoring items (11 points or above) were 5L versions. The most common quality issue was the lack of qualitative research informing item wording (3L: 96%, 5L: 45%) (Figure 1). Only six studies used qualitative methods in bolt-on development, resulting in the creation of 18 different items (17 for 5L and one for 3L). These qualitative studies included expert panels (n=2), focus groups (n=3) and one-on-one interviews (n=2), with possible overlaps. Qualitative input was gathered from HRQoL experts (n=2), medical professionals (n=1), members of the general public (n=2), patients and caregivers of patients affected by relevant health conditions (e.g. dementia, stroke, brain injury) (n=1) and patients with any chronic diseases (n=2). The second most prevalent issue was the absence of translatability evidence (3L: 74%, 5L: 93%); however, this did not necessarily mean poor translatability.

Details of the references below can be found in Supplemental Table 3. Note that multiple bolt-ons may be published in a single paper.

¹ [52], [60], [80], [133]

² [86], [89], [105], [129], [135], [148], [159], [160], [180]

³ [9], [19], [29], [33], [55], [77], [85], [93], [99], [107], [123], [126], [128], [141], [147], [149], [151], [166], [169], [171], [177]

⁴ [8], [44], [72], [78], [141]

⁵ [152]

Wordings judged to be incomprehensible or ambiguous (3L: 39%, 5L: 14%) for example using terms like ‘temporo-spatial orientation’, were also common. Other items included vague wordings in response options, such as ‘normal’ or ‘well’, and examples like ‘not being confused’, which create a double-negative in the first response level. Furthermore, in certain bolt-ons ‘brain functions’ was used as a dimension title, which is primarily a physiological term. Inadequate examples or explanations were also common (3L: 35%, 5L: 14%), such as using ‘IQ (level)’ as an example for cognition. Note that IQ is a measure of intellectual capacity, and it does not capture an individual’s subjective experience of HRQoL.

Use of cognition bolt-ons to measure HRQoL

Overall, 80% of the 120 studies that administered EQ-5D and cognition bolt-ons used a patient population, 21% the adult general population, 8% older adults, and 8% caregivers (overlaps possible) (Table 3). The 96 studies conducted in patient populations included 71 different health conditions, covering most medical specialties in terms of ICD-11 groups (Table 4). The most common ICD-11 groups were ‘injury, poisoning or certain other consequences of external causes’ (26%), ‘mental, behavioural and neurodevelopmental disorders’ (23%) and ‘certain infectious or parasitic diseases’ (15%). The most prevalent diagnoses were injury (other) (16%), head or brain injury (14%), dementia (13%), depression (6%), HIV, schistosomiasis, stroke, chronic kidney disease and burn (all 4%).

The most common study designs were cross-sectional (38%), longitudinal cohort (38%) and randomised controlled trial (18%) (Table 3). The primary modes of administration were face-to-face (58%) and mail surveys (32%). Over 90% of the studies used self-reporting, while 16% used proxy reporting (overlaps possible), with the proxy-proxy and the proxy-patient perspectives being almost equally used. Most studies (64%) positioned the bolt-ons after the five EQ-5D dimensions

and before the EQ VAS. Only 2% of the studies positioned the bolt-ons after the EQ VAS, while 16% did not use the EQ VAS, and in 17% the use of the EQ VAS was unknown. Several studies introduced further modifications to the bolt-on compared to the standard EQ-5D format, such as changing the recall period (8%) or developing a pictorial version of the instrument along with the bolt-on (3%).

Inclusion of cognition bolt-ons in valuation of health states or in obtaining disability weights

In the 27 studies that valued health states including a cognition bolt-on, or obtained bolt-on disability weights, the visual analogue scale (67%) and time-trade-off (37%) were the most frequently used valuation methods, followed by ranking or card sorting and person trade-off (in some studies, multiple approaches were used within the same study) (Table 5). None of the studies developed a full value set for the EQ-5D+cognition bolt-on. However, the Australian disease burden study²¹ used a multiplicative regression model on previously elicited Dutch disability weights for specific disease states, enabling the estimation of disability weights for any EQ-5D-3L+cognition bolt-on health states. Nearly half of the studies included additional descriptions, such as disease labels, symptom descriptions or images in the health states. Two-thirds of the studies aimed to value health states for specific diseases, while approximately one-third valued EQ-5D health state descriptions without reference to any specific health condition.

DISCUSSION

This systematic review provides an overview of the literature on studies that developed, tested and used cognition bolt-ons for the adult EQ-5D versions. There seems to be a substantial interest in using the cognition bolt-on, as evidenced by the large number of studies, the 52 different items, and the over 70 different patient populations in which the bolt-ons were used. Cognition bolt-ons

appear to be pertinent across a broad spectrum of medical specialties, particularly neurology, psychiatry, traumatology and infectiology. The diverse range of patient populations in which the bolt-on was tested, often outside of economic evaluation contexts, underscores a significant demand from clinicians. This demand is further corroborated by the inclusion of the bolt-on in over 20 randomised controlled trials and more than 40 longitudinal cohorts, typically with large sample sizes (often exceeding 1,000 patients), rather than being driven by purely academic research projects. The cognition bolt-on also appears to be relevant for the general population, particularly in measuring HRQoL in older adults. Moreover, some studies have chosen to apply it in caregivers.

A large number of different cognition items have been identified. The motivation behind the constant changes in item wording remains unclear. Possible reasons for developing new wordings include instances where researchers could not find existing items that aligned with their objectives in terms of item content, leading them to create ones *de novo*. New wordings might have been developed to address new research questions, or researchers may have found the methods used for the development of existing items inadequate or sought greater detail in their measurements. It is also noteworthy that, particularly among the Dutch wordings, we identified numerous items with very similar phrasings, differing only in one or two examples provided alongside the dimension title. However, the publications did not provide any rationale for creating these alternatives. There was little evident connection between the chosen wordings and the study populations in which the items were used. For example, one might anticipate ‘remembering’, ‘memory’ and ‘thinking ability’, as useful items for dementia, while ‘concentration’ would be more appropriate for ADHD. Given the complexity of the concept of cognition and the various needs of different patient populations, both global (i.e. a single cognition item with a maximum of 3-4 examples) and subdimension items (e.g. memory, concentration), may have a role in the bolt-on palette. However,

clear guidance will be essential regarding when to recommend subdimension items and when to use a global item.²²

The fact that two-thirds of the identified studies originated from the Netherlands adds an interesting country-specific element to this systematic review. The cognition bolt-on clearly has its roots in the Netherlands, with several key studies related to this bolt-on being conducted there, including its initial development, first valuation, disability weight and population norm studies.^{18,23-25} It seems that the bolt-on was gradually embraced by the Dutch medical community and diffused into several clinical trials and patient registries across multiple areas of medicine.

Limitations of this systematic review include the following. It is very challenging to identify bolt-on publications due to the lack of standardised terminology for the additional dimensions. Moreover, often no reference appeared for the bolt-on use in the title and abstract of publications. Therefore, the research team decided to apply a less specific search strategy, and the role of complementary hand-searching and citation tracking was important, yet we cannot be sure that we identified all studies. Despite extensive efforts to reach out to authors, we could only confirm the wording for two-thirds of the studies, and some wordings may not have been included in this review. The scoring system used to assess the methodological quality of bolt-on items was based on criteria,¹⁶ which were not intended for post-development assessment but rather as development guidelines. Furthermore, we interpreted ‘translatability evidence’ in the sense that at least one translation was prepared for an item and successfully used for data collection in the same study or in any follow up study included in this systematic review. However, this cannot strictly be considered a proper translatability assessment, which has not been performed for any of the items.²⁶ Similarly, for the checklist item ‘bolt-on descriptors informed by language used in qualitative

work’, we did not evaluate the rigor of the qualitative studies in terms of sample size adequacy, or diversity and relevance of the populations included, given that vast majority of the studies introducing new items did not employ any qualitative methodologies, and the six studies that did had limited qualitative work included. Despite these limitations, we consider the checklist as a useful tool for identifying suboptimal items.

Further analysis of the extracted data will focus on assessing the psychometric properties of the identified cognition bolt-ons. Reviewing the valuation evidence available about these bolt-ons is also an important future research direction. The addition of bolt-ons to the EQ-5D may impact cost-utility outcomes and financial decisions, especially in populations where bolt-on dimensions are more relevant than the core five dimensions (where the EQ-5D may lack content validity). In these cases, bolt-ons may enhance the EQ-5D-5L’s ability to capture HRQoL impairment due to a certain disease or condition and the QALY gains achievable with treatment. Developing a valuation protocol applicable to all bolt-ons and aligned with core EQ-5D value sets is crucial for their acceptance by HTA bodies and to ensure responsible healthcare decision-making.

CONCLUSIONS

This systematic review has provided a summary of studies that developed or used cognition bolt-ons for the two adult EQ-5D instruments, including a summary of item wordings and patient populations. The widespread and continuously increasing use of cognition bolt-ons indicates strong demand from users across various medical specialties. The abundance of bolt-on items and the lack of robust development processes highlight the necessity for methodological rigor and harmonisation, as the wide variety of items currently available hinders comparability across studies and undermines consistency in HTA submissions and subsequent healthcare decision-making. Our

findings will guide ongoing research on cognition bolt-on development and testing, ultimately leading to the selection of standardised cognition bolt-on item(s) for use in relevant contexts.

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Figure Legends:

Figure 1: Number of publications included in the systematic review by year and quality assessment of bolt-on items (proportion of the 52 bolt-ons that received positive assessment).

Table 1 Summary of the characteristics of the publications and studies

Characteristic	Netherlands				Other countries				Bolt-on development				Bolt-on use or psychometric testing				Bolt-on valuation or obtaining disability weights				Total†			
	Studies (n=87)		Publications (k=119)		Studies (n=54)		Publications (k=67)		Studies (n=38)		Publications (k=40)		Studies (n=120)		Publications (k=163)		Studies (n=27)		Publications (k=30)		Studies (n=137)		Publications (k=181)	
	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%
PUBLICATION DETAILS																								
Publication language																								
English	84	96.6%	115	96.6%	48	88.9%	61	91%	36	94.7%	38	95.0%	111	92.5%	153	93.9%	26	96.3%	29	96.7%	128	93.4%	171	94.5%
Dutch	3	3.4%	4	3.4%	0	0.0%	0	0%	0	0.0%	0	0.0%	3	2.5%	4	2.5%	1	3.7%	1	3.3%	3	2.2%	4	2.2%
Mandarin Chinese	0	0.0%	0	0.0%	5	9.3%	5	7%	2	5.3%	2	5.0%	5	4.2%	5	3.1%	0	0.0%	0	0.0%	5	3.6%	5	2.8%
Japanese	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Publication type																								
Journal article or letter to editor	81	93.1%	111	93.3%	46	85.2%	59	88%	32	84.2%	33	82.5%	111	92.5%	152	93.3%	20	74.1%	22	73.3%	123	89.8%	165	91.2%
EuroQol conference paper	2	2.3%	3	2.5%	2	3.7%	2	3%	2	5.3%	3	7.5%	3	2.5%	4	2.5%	1	3.7%	2	6.7%	4	2.9%	5	2.8%
Master's or doctoral thesis	1	1.1%	2	1.7%	2	3.7%	2	3%	1	2.6%	1	2.5%	3	2.5%	4	2.5%	0	0.0%	0	0.0%	3	2.2%	4	2.2%
Other research reports or published working paper	3	3.4%	3	2.5%	4	7.4%	4	6%	3	7.9%	3	7.5%	3	2.5%	3	1.8%	6	22.2%	6	20.0%	7	5.1%	7	3.9%
STUDY CHARACTERISTICS																								
Funding source*																								
EuroQol Research Foundation	3	3.4%	5	4.2%	4	7.4%	4	6%	4	10.5%	4	10.0%	6	5.0%	8	4.9%	2	7.4%	2	6.7%	7	5.1%	9	5.0%
Foundation	13	14.9%	19	16.0%	11	20.4%	15	22%	8	21.1%	9	22.5%	21	17.5%	30	18.4%	3	11.1%	3	10.0%	22	16.1%	31	17.1%
Government	33	37.9%	46	38.7%	22	40.7%	30	45%	14	36.8%	14	35.0%	44	36.7%	65	39.9%	12	44.4%	12	40.0%	54	39.4%	75	41.4%
Health insurer	3	3.4%	3	2.5%	0	0.0%	0	0%	1	2.6%	1	2.5%	3	2.5%	3	1.8%	1	3.7%	1	3.3%	3	2.2%	3	1.7%
Industry	10	11.5%	11	9.2%	1	1.9%	1	1%	3	7.9%	3	7.5%	11	9.2%	12	7.4%	0	0.0%	0	0.0%	11	8.0%	12	6.6%
University	7	8.0%	9	7.6%	9	16.7%	13	19%	4	10.5%	5	12.5%	14	11.7%	20	12.3%	2	7.4%	3	10.0%	15	10.9%	21	11.6%
Not funded	8	9.2%	11	9.2%	7	13.0%	7	10%	2	5.3%	2	5.0%	12	10.0%	15	9.2%	3	11.1%	3	10.0%	14	10.2%	17	9.4%
Not reported	23	26.4%	31	26.1%	12	22.2%	12	18%	8	21.1%	9	22.5%	32	26.7%	39	23.9%	6	22.2%	8	26.7%	35	25.5%	43	23.8%
Sample size**																								
Lower than 50	10	11.5%	12	10.1%	5	9.3%	5	7%	4	10.5%	4	10.0%	8	6.7%	10	6.1%	6	22.2%	6	20.0%	15	10.9%	17	9.4%
50-99	10	11.5%	15	12.6%	6	11.1%	6	9%	5	13.2%	5	12.5%	13	10.8%	18	11.0%	5	18.5%	6	20.0%	15	10.9%	20	11.0%
100-199	15	17.2%	22	18.5%	13	24.1%	16	24%	5	13.2%	6	15.0%	26	21.7%	35	21.5%	5	18.5%	7	23.3%	27	19.7%	37	20.4%
200-299	10	11.5%	12	10.1%	9	16.7%	11	16%	6	15.8%	6	15.0%	16	13.3%	19	11.7%	2	7.4%	2	6.7%	18	13.1%	21	11.6%
300-399	6	6.9%	6	5.0%	7	13.0%	11	16%	6	15.8%	7	17.5%	12	10.0%	16	9.8%	0	0.0%	0	0.0%	12	8.8%	16	8.8%
400-499	5	5.7%	7	5.9%	0	0.0%	0	0%	1	2.6%	1	2.5%	5	4.2%	7	4.3%	1	3.7%	1	3.3%	5	3.6%	7	3.9%
500-999	12	13.8%	18	15.1%	3	5.6%	3	4%	3	7.9%	3	7.5%	15	12.5%	21	12.9%	1	3.7%	1	3.3%	15	10.9%	21	11.6%
1000 and more	15	17.2%	23	19.3%	7	13.0%	11	16%	6	15.8%	6	15.0%	21	17.5%	33	20.2%	4	14.8%	4	13.3%	22	16.1%	34	18.8%
Not reported	4	4.6%	4	3.4%	4	7.4%	4	6%	2	5.3%	2	5.0%	4	3.3%	4	2.5%	3	11.1%	3	10.0%	8	5.8%	8	4.4%
EQ-5D+COGNITION BOLT-ON USE																								
EQ-5D+bolt-on level of responses																								
EQ-5D-3L and 3L bolt-on	65	74.7%	90	75.6%	33	61.1%	46	69%	21	55.3%	22	55.0%	87	72.5%	124	76.1%	13	48.1%	14	46.7%	95	69.3%	132	72.9%
EQ-5D-5L and 5L bolt-on	20	23.0%	26	21.8%	20	37.0%	20	30%	17	44.7%	18	45.0%	31	25.8%	36	22.1%	13	48.1%	15	50.0%	39	28.5%	45	24.9%
EQ-5D-5L and 3L bolt-on	1	1.1%	2	1.7%	0	0.0%	0	0%	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	1	0.7%	2	1.1%
EQ-5D-5L and unknown bolt-on	1	1.1%	1	0.8%	0	0.0%	0	0%	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Not applicable (used dimension titles but not the response levels)	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
Nomenclature of the EQ-5D+ cognition bolt-on*																								
EQ-6D/EuroQol-6D/EuroQol 6-Dimensions/EuroQol 6D3L/EuroQuol-6D/EQ6D/EQ-6D-3L/Six-Dimensional EuroQol/Six-Dimensional EuroQuol/6D5L/EQ-6D-5L	40	46.0%	51	42.9%	11	20.4%	11	16%	15	39.5%	15	37.5%	49	40.8%	60	36.8%	6	22.2%	6	20.0%	51	37.2%	62	34.3%
EQ-5D+C/EQ-5D+/EQ5D+/EQ-5D+cognition/ EuroQol-5D+C/EQ-5D plus/Extended version of the EuroQol 5D/EQ-5D-3L+cognition	40	46.0%	57	47.9%	28	51.9%	36	54%	15	39.5%	17	42.5%	52	43.3%	75	46.0%	18	66.7%	21	70.0%	65	47.4%	89	49.2%

Characteristic	Netherlands				Other countries				Bolt-on development				Bolt-on use or psychometric testing				Bolt-on valuation or obtaining disability weights				Total†			
	Studies (n=87)		Publications (k=119)		Studies (n=54)		Publications (k=67)		Studies (n=38)		Publications (k=40)		Studies (n=120)		Publications (k=163)		Studies (n=27)		Publications (k=30)		Studies (n=137)		Publications (k=181)	
	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%	n	%	k	%
7D5L ***	0	0.0%	0	0.0%	3	5.6%	3	4%	1	2.6%	1	2.5%	3	2.5%	3	1.8%	0	0.0%	0	0.0%	3	2.2%	3	1.7%
EQ-10D ****	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Not reported	8	9.2%	12	10.1%	13	24.1%	18	27%	8	21.1%	8	20.0%	17	14.2%	26	16.0%	3	11.1%	3	10.0%	20	14.6%	29	16.0%
Number of cognition bolt-on items used																								
1	87	100.0%	119	100.0%	52	96.3%	65	97%	36	94.7%	38	95.0%	119	99.2%	162	99.4%	27	100.0%	30	100.0%	135	98.5%	179	98.9%
4	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
7	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
OTHER BOLT-ONS IN THE SAME STUDY																								
Number of other bolt-ons used in the study, if any																								
1	1	1.1%	2	1.7%	4	7.4%	4	6%	2	5.3%	2	5.0%	3	2.5%	5	3.1%	0	0.0%	0	0.0%	4	2.9%	6	3.3%
3	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
4	0	0.0%	0	0.0%	2	3.7%	2	3%	2	5.3%	2	5.0%	2	1.7%	2	1.2%	1	3.7%	1	3.3%	2	1.5%	2	1.1%
6	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
8	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
10	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Other bolt-ons used in the study																								
Breathing problems	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Close relationships/contacts with others/relationships/social participation/social relations/social relationships/social support	0	0.0%	0	0.0%	9	16.7%	9	13%	5	13.2%	5	12.5%	8	6.7%	8	4.9%	2	7.4%	2	6.7%	9	6.6%	9	5.0%
Communication/speaking	0	0.0%	0	0.0%	2	3.7%	2	3%	2	5.3%	2	5.0%	2	1.7%	2	1.2%	0	0.0%	0	0.0%	2	1.5%	2	1.1%
Energy/fatigue/tiredness/vitality	1	1.1%	1	0.8%	5	9.3%	5	7%	4	10.5%	4	10.0%	5	4.2%	6	3.7%	1	3.7%	1	3.3%	5	3.6%	6	3.3%
Finances	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
Happiness	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Hearing/vision/seeing and hearing	0	0.0%	0	0.0%	6	11.1%	6	9%	5	13.2%	5	12.5%	5	4.2%	5	3.1%	1	3.7%	1	3.3%	6	4.4%	6	3.3%
Itching/skin irritation	1	1.1%	1	0.8%	1	1.9%	1	1%	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	1	0.7%	2	1.1%
Religion/personal beliefs	0	0.0%	0	0.0%	2	3.7%	2	3%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	1	3.7%	1	3.3%	2	1.5%	2	1.1%
Self-confidence	0	0.0%	0	0.0%	1	1.9%	1	1%	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Sleep	0	0.0%	0	0.0%	5	9.3%	5	7%	4	10.5%	4	10.0%	5	4.2%	5	3.1%	1	3.7%	1	3.3%	5	3.6%	5	2.8%
Stress	0	0.0%	0	0.0%	1	1.9%	1	1%	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%

Notes.

1. Overlaps may occur among the "Bolt-on development," "Bolt-on use or psychometric testing," and "Bolt-on valuation or obtaining disability weights" categories/columns as studies may have had multiple aims.

2. *Multiple publications may have arisen from a single study. In instances where a study has yielded multiple publications, the one with the largest sample size was considered the primary representation of the study.*

[†]In case of multicountry studies, studies or publications conducted in the Netherlands may also belong in the other countries category.

* One study or publication may belong to more than one category.

** For study protocols, the expected sample size was considered.

***7D5L comprises the five core EQ-5D dimensions and 2 additional dimensions: cognition and social participation.

EQ-10D comprises the five core EQ-5D dimensions and 5 additional dimensions: sleep, memory/concentration, fatigue/energy, seeing and hearing, and contact with others.

Table 2 Cognition on-on wordings

	Dutch		Other languages		3L		5L		Total	
	n	%	n	%	n	%	n	%	n	%
Total number of different wordings	21	100.0%	31	100.0%	23	100.0%	29	100.0%	52	100.0%
Dimension title										
Brain function(s)	2	9.5%	0	0.0%	1	4.3%	1	3.4%	2	3.8%
Cognition	6	28.6%	9	29.0%	5	21.7%	10	34.5%	15	28.8%
Cognition-related activity(ies)	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Cognitive ability(ies)	0	0.0%	3	9.7%	3	13.0%	0	0.0%	3	5.8%
Cognitive function (or functioning)	1	4.8%	3	9.7%	3	13.0%	1	3.4%	4	7.7%
Cognitive problems	0	0.0%	1	3.2%	1	4.3%	0	0.0%	1	1.9%
Concentration	0	0.0%	2	6.5%	0	0.0%	2	6.9%	2	3.8%
Concentration/memory*	1	4.8%	2	6.5%	2	8.7%	1	3.4%	3	5.8%
Confusion	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Intellectual activities	0	0.0%	2	6.5%	1	4.3%	1	3.4%	2	3.8%
Language	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Learning	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Memory	1	4.8%	2	6.5%	0	0.0%	3	10.3%	3	5.8%
Mental ability	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Reasoning	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Thinking ability	10	47.6%	0	0.0%	7	30.4%	3	10.3%	10	19.2%
Understanding	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Dimension title examples or response levels**										
Adaptability	1	4.8%	0	0.0%	0	0.0%	1	3.4%	1	1.9%
Attention	2	9.5%	1	3.2%	2	8.7%	1	3.4%	3	5.8%
Being confused	2	9.5%	0	0.0%	2	8.7%	0	0.0%	2	3.8%
Coherence	3	14.3%	2	6.5%	3	13.0%	2	6.9%	5	9.6%
Communicating	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Comprehension	2	9.5%	3	9.7%	3	13.0%	2	6.9%	5	9.6%
Concentrating (or concentration)	16	76.2%	15	48.4%	19	82.6%	12	41.4%	31	59.6%
Distracted	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Endurance	0	0.0%	1	3.2%	1	4.3%	0	0.0%	1	1.9%
Fogginess	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Following directions	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Forget(fulness)	1	4.8%	2	6.5%	1	4.3%	2	6.9%	3	5.8%
IQ (level)	8	38.1%	2	6.5%	7	30.4%	3	10.3%	10	19.2%
Irritable	0	0.0%	1	3.2%	1	4.3%	0	0.0%	1	1.9%
Learn(ing ability or skills)	1	4.8%	4	12.9%	3	13.0%	2	6.9%	5	9.6%
Making decisions	0	0.0%	2	6.5%	0	0.0%	2	6.9%	2	3.8%
Making phone calls	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Memory	9	42.9%	11	35.5%	13	56.5%	7	24.1%	20	38.5%
Paying for things	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%
Problem-solving	0	0.0%	2	6.5%	1	4.3%	1	3.4%	2	3.8%
Remembering	9	42.9%	7	22.6%	7	30.4%	9	31.0%	16	30.8%
Temporo-spatial orientation	0	0.0%	1	3.2%	1	4.3%	0	0.0%	1	1.9%
Thinking (clearly)	3	14.3%	5	16.1%	3	13.0%	5	17.2%	8	15.4%
Understanding	2	9.5%	1	3.2%	0	0.0%	3	10.3%	3	5.8%
Working things out	0	0.0%	1	3.2%	0	0.0%	1	3.4%	1	1.9%

*Alternate order found: Memory/concentration.

** One study or publication may belong to more than one category.

Table 3 Characteristics of studies that administered cognition bolt-ons

Characteristic	Netherlands				Other countries				Total†			
	Studies (n=80)		Publications (k=111)		Studies (n=43)		Publications (k=56)		Studies (n=120)		Publications (k=163)	
	n	%	k	%	n	%	k	%	n	%	k	%
STUDY CHARACTERISTICS												
Study population*												
General population: Any, including older adults 55+	16	20.0%	25	22.5%	10	23.3%	10	17.9%	25	20.8%	34	20.9%
General population: Older adults 55+	8	10.0%	13	11.7%	2	4.7%	2	3.6%	9	7.5%	14	8.6%
Caregivers**	7	8.8%	9	8.1%	3	7.0%	3	5.4%	10	8.3%	12	7.4%
Patient population	64	80.0%	87	78.4%	34	79.1%	47	83.9%	96	80.0%	131	80.4%
Experts in valuation/disability weight study	1	1.3%	1	0.9%	1	2.3%	1	1.8%	2	1.7%	2	1.2%
Study population age												
≥16 years	72	90.0%	101	91.0%	36	83.7%	49	87.5%	106	88.3%	147	90.2%
Both <16 years and ≥16 years	8	10.0%	10	9.0%	7	16.3%	7	12.5%	14	11.7%	16	9.8%
Setting												
Single centre	20	25.0%	26	23.4%	10	23.3%	12	21.4%	30	25.0%	38	23.3%
Multicentre	40	50.0%	58	52.3%	15	34.9%	25	44.6%	53	44.2%	80	49.1%
Not reported	1	1.3%	2	1.8%	1	2.3%	1	1.8%	2	1.7%	3	1.8%
Not applicable***	19	23.8%	25	22.5%	17	39.5%	18	32.1%	35	29.2%	42	25.8%
Study design*												
Cross-sectional	19	23.8%	31	27.9%	27	62.8%	33	58.9%	45	37.5%	62	38.0%
Longitudinal cohort	35	43.8%	54	48.6%	12	27.9%	19	33.9%	45	37.5%	71	43.6%
Randomized controlled trial	22	27.5%	24	21.6%	0	0.0%	0	0.0%	22	18.3%	24	14.7%
Case control	1	1.3%	1	0.9%	3	7.0%	3	5.4%	4	3.3%	4	2.5%
Non-randomized clinical trial	2	2.5%	2	1.8%	0	0.0%	0	0.0%	2	1.7%	2	1.2%
Others	4	5.0%	4	3.6%	1	2.3%	1	1.8%	5	4.2%	5	3.1%
Sample size****												
Lower than 50	5	6.3%	7	6.3%	3	7.0%	3	5.4%	8	6.7%	10	6.1%
50-99	9	11.3%	14	12.6%	5	11.6%	5	8.9%	13	10.8%	18	11.0%
100-199	15	18.8%	21	18.9%	12	27.9%	15	26.8%	26	21.7%	35	21.5%
200-299	9	11.3%	11	9.9%	7	16.3%	9	16.1%	16	13.3%	19	11.7%
300-399	6	7.5%	6	5.4%	7	16.3%	11	19.6%	12	10.0%	16	9.8%
400-499	5	6.3%	7	6.3%	0	0.0%	0	0.0%	5	4.2%	7	4.3%
500-999	12	15.0%	18	16.2%	3	7.0%	3	5.4%	15	12.5%	21	12.9%
≥1000	15	18.8%	23	20.7%	6	14.0%	10	17.9%	21	17.5%	33	20.2%
Not reported	4	5.0%	4	3.6%	0	0.0%	0	0.0%	4	3.3%	4	2.5%
EQ-5D+BOLT-ON USE												
Version												
Paper	44	55.0%	57	51.4%	27	62.8%	38	67.9%	68	56.7%	91	55.8%
Electronic	12	15.0%	16	14.4%	2	4.7%	2	3.6%	14	11.7%	18	11.0%
Both paper and electronic	11	13.8%	17	15.3%	0	0.0%	0	0.0%	11	9.2%	17	10.4%
Unknown	13	16.3%	21	18.9%	14	32.6%	16	28.6%	27	22.5%	37	22.7%
Mode of administration*												
On-site (Face-to-face)	34	42.5%	42	37.8%	37	86.0%	50	89.3%	69	57.5%	89	54.6%
Online	19	23.8%	29	26.1%	2	4.7%	2	3.6%	21	17.5%	31	19.0%
Email	1	1.3%	1	0.9%	0	0.0%	0	0.0%	1	0.8%	1	0.6%
Mail (at home)	33	41.3%	50	45.0%	7	16.3%	15	26.8%	38	31.7%	62	38.0%
Telephone	12	15.0%	15	13.5%	6	14.0%	13	23.2%	18	15.0%	28	17.2%
Unknown	5	6.3%	12	10.8%	0	0.0%	0	0.0%	5	4.2%	12	7.4%
Completion*												
Self-completed	59	73.8%	80	72.1%	22	51.2%	33	58.9%	79	65.8%	110	67.5%
Interviewer-administered	24	30.0%	28	25.2%	22	51.2%	31	55.4%	45	37.5%	58	35.6%
Unknown	3	3.8%	10	9.0%	1	2.3%	1	1.8%	4	3.3%	11	6.7%
Reporting*												
Self-report	72	90.0%	97	87.4%	39	90.7%	52	92.9%	108	90.0%	145	89.0%
Proxy report	11	13.8%	16	14.4%	8	18.6%	11	19.6%	19	15.8%	26	16.0%
Proxy-proxy perspective (proxy 1)	3	3.8%	8	7.2%	2	4.7%	3	5.4%	5	4.2%	10	6.1%
Proxy-patient perspective (proxy 2)	3	3.8%	3	2.7%	3	7.0%	4	7.1%	6	5.0%	7	4.3%
Perspective not reported	5	6.3%	5	4.5%	3	7.0%	4	7.1%	8	6.7%	9	5.5%
Unknown	1	1.3%	7	6.3%	0	0.0%	0	0.0%	1	0.8%	7	4.3%
EQ-5D+bolt-on level of responses												
EQ-5D-3L and 3L bolt-on	60	75.0%	85	76.6%	29	67.4%	42	75.0%	87	72.5%	124	76.1%
EQ-5D-5L and 5L bolt-on	18	22.5%	23	20.7%	14	32.6%	14	25.0%	31	25.8%	36	22.1%
EQ-5D-5L and 3L bolt-on	1	1.3%	2	1.8%	0	0.0%	0	0.0%	1	0.8%	2	1.2%
EQ-5D-5L and unknown bolt-on	1	1.3%	1	0.9%	0	0.0%	0	0.0%	1	0.8%	1	0.6%
Bolt-on position in relation to the EQ VAS												
Before the EQ VAS	52	65.0%	74	66.7%	27	62.8%	36	64.3%	77	64.2%	107	65.6%
After the EQ VAS	0	0.0%	0	0.0%	3	7.0%	3	5.4%	3	2.5%	3	1.8%

Characteristic	Netherlands				Other countries				Total			
	Studies (n=80)		Publications (k=111)		Studies (n=43)		Publications (k=56)		Studies (n=120)		Publications (k=163)	
	n	%	k	%	n	%	k	%	n	%	k	%
Twice (both before and after the EQ VAS)	1	1.3%	1	0.9%	0	0.0%	0	0.0%	1	0.8%	1	0.6%
EQ VAS was not used	13	16.3%	19	17.1%	7	16.3%	10	17.9%	19	15.8%	28	17.2%
Unknown use of the EQ VAS	14	17.5%	17	15.3%	6	14.0%	7	12.5%	20	16.7%	24	14.7%
BOLT-ON MODIFICATIONS												
Modified recall period of the cognition bolt-on												
Retrospective assessment: Pre-accident, pre-burn, pre-hospitalization, or pre-injury	3	3.8%	7	6.3%	6	14.0%	13	23.2%	8	6.7%	18	11.0%
'Last week'	1	1.3%	1	0.9%	1	2.3%	1	1.8%	1	0.8%	1	0.6%
Pictorial version												
Pictorial EQ-5D-3L + pictorial 3L bolt-on	0	0.0%	0	0.0%	2	4.7%	2	3.6%	2	1.7%	2	1.2%
Pictorial EQ-5D-5L + pictorial 5L bolt-on	0	0.0%	0	0.0%	1	2.3%	1	1.8%	1	0.8%	1	0.6%

Notes.

1) Multiple publications may have arisen from a single study. In instances where a study has yielded multiple publications, the one with the largest sample size was considered the primary representation of the study.

2) The total number of studies and publications in this table is smaller than that in Tables 1 and 2, because it exclusively reports studies in which the bolt-ons were completed by respondents to self-report their own HRQoL.

†There were 4 publications (3 studies) belonging to both the Netherlands and Other countries categories: Boersma-van Dam et al., 2021, Boersma-van Dam et al., 2022, Botes et al., 2021, and Van Ditschneider et al., 2022

* One study or publication may belong to more than one category.

** Where caregivers' HRQoL was assessed.

***Studies whose data collection used population-level samples or others which did not fit into single or multicentre categories.

****For study protocols, the expected sample size was considered.

Table 4 ICD-11 groups and diagnoses in which cognition bolt-ons were administered

Patient population based on ICD-11*	Netherlands				Other countries				Total†			
	Studies (n=64)		Publications (k=87)		Studies (n=34)		Publications (k=47)		Studies (n=96)		Publications (k=131)	
	n	%	k	%	n	%	k	%	n	%	k	%
01 Certain infectious or parasitic diseases	4	6.3%	6	6.9%	10	29.4%	10	21.3%	14	14.6%	16	12.2%
Filariasis	0	3.1%	0	0.0%	2	5.9%	2	4.3%	2	2.1%	2	1.5%
HIV	2	0.0%	3	3.4%	2	5.9%	2	4.3%	4	4.2%	5	3.8%
Neurocysticercosis	0	3.1%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Q-fever	2	0.0%	3	3.4%	0	0.0%	0	0.0%	2	2.1%	3	2.3%
Schistosomiasis	0	0.0%	0	0.0%	4	11.8%	4	8.5%	4	4.2%	4	3.1%
Trichinosis	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
02 Neoplasms	4	6.3%	5	5.7%	1	2.9%	1	2.1%	5	5.2%	6	4.6%
Brain metastases	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Breast cancer	2	3.1%	2	2.3%	0	0.0%	0	0.0%	2	2.1%	2	1.5%
Neurological tumor	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Oncological surgery (type of cancer unknown)	1	1.6%	2	2.3%	0	0.0%	0	0.0%	1	1.0%	2	1.5%
04 Diseases of the immune system	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Allergy	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
05 Endocrine, nutritional or metabolic diseases	2	3.1%	2	2.3%	2	5.9%	2	4.3%	4	4.2%	4	3.1%
Diabetes	1	1.6%	1	1.1%	2	5.9%	2	4.3%	3	3.1%	3	2.3%
Levothyroxine monotherapy	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
06 Mental, behavioural or neurodevelopmental disorders	14	21.9%	16	18.4%	8	23.5%	10	21.3%	22	22.9%	26	19.8%
Anxiety	2	3.1%	2	2.3%	1	2.9%	1	2.1%	3	3.1%	3	2.3%
Cognitive impairment	1	1.6%	1	1.1%	1	2.9%	1	2.1%	2	2.1%	2	1.5%
Dementia	7	10.9%	9	10.3%	5	14.7%	7	14.9%	12	12.5%	16	12.2%
Depression	5	7.8%	6	6.9%	1	2.9%	1	2.1%	6	6.3%	7	5.3%
Dyslexia	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Personality disorder	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Pervasive developmental disorder	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Post-traumatic stress disorder	1	1.6%	1	1.1%	1	2.9%	1	2.1%	2	2.1%	2	1.5%
Schizophrenia	1	1.6%	1	1.1%	1	2.9%	1	2.1%	2	2.1%	2	1.5%
Self-harm	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Substance use	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Suicide attempt	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
08 Diseases of the nervous system	7	10.9%	8	9.2%	1	2.9%	2	4.3%	8	8.3%	10	7.6%
Chronic fatigue syndrome	3	4.7%	4	4.6%	0	0.0%	0	0.0%	3	3.1%	4	3.1%
Headache	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Migraine	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Stroke	4	6.3%	4	4.6%	1	2.9%	1	2.1%	4	4.2%	5	3.8%
09 Diseases of the visual system	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Chronic eye/visual disorder (e.g., low vision, glaucoma)	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
10 Diseases of the ear or mastoid process	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Hearing problems	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
11 Diseases of the circulatory system	5	7.8%	7	8.0%	1	2.9%	1	2.1%	6	6.3%	8	6.1%
Abdominal aorta aneurysm	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Cardiac arrest	2	3.1%	3	3.4%	0	0.0%	0	0.0%	2	2.1%	3	2.3%
Cardiovascular disease (not specified)	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Coronary heart disease	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Hypertension	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Vascular surgery	1	1.6%	2	2.3%	0	0.0%	0	0.0%	1	1.0%	2	1.5%
12 Diseases of the respiratory system	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Chronic respiratory disease (e.g., asthma, COPD)	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
13 Diseases of the digestive system	1	1.6%	2	2.3%	2	5.9%	5	10.6%	3	3.1%	7	5.3%
Dental problems (e.g. caries, fracture, periodontitis)	0	0.0%	0	0.0%	1	2.9%	4	8.5%	1	1.0%	4	3.1%
Gastroenterological surgery	1	1.6%	2	2.3%	0	0.0%	0	0.0%	1	1.0%	2	1.5%
Gastroesophageal reflux or gastric/peptic ulcer	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
14 Diseases of the skin	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Chronic skin disease	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
15 Diseases of the musculoskeletal system or connective tissue	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Chronic musculoskeletal disease (e.g., arthritis, arthrosis)	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
16 Diseases of the genitourinary system	2	3.1%	2	2.3%	2	5.9%	2	4.3%	4	4.2%	4	3.1%
Chronic kidney disease	2	3.1%	2	2.3%	2	5.9%	2	4.3%	4	4.2%	4	3.1%
18 Pregnancy, childbirth or the puerperium	5	7.8%	6	6.9%	0	0.0%	0	0.0%	5	5.2%	6	4.6%
Gestational diabetes mellitus	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Gestational hypertension	2	3.1%	2	2.3%	0	0.0%	0	0.0%	2	2.1%	2	1.5%
Intrauterine growth retardation	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Large-for-gestational-age infants	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Obstetric history (e.g. complications during pregnancy or labour)	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%

Patient population based on ICD-11*	Studies (n=64)		Publications (k=87)		Studies (n=34)		Publications (k=47)		Studies (n=96)		Publications (k=131)	
	n	%	k	%	n	%	k	%	n	%	k	%
Preeclampsia	2	3.1%	2	2.3%	0	0.0%	0	0.0%	2	2.1%	2	1.5%
Pregnancy with low-risk complication	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Small-for-gestational-age infants	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Spontaneous preterm birth	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
21 Symptoms, signs or clinical findings, not elsewhere classified	2	3.1%	3	3.4%	1	2.9%	1	2.1%	3	3.1%	4	3.1%
Ageing associated decline in intrinsic capacity	2	3.1%	2	2.3%	1	2.9%	1	2.1%	3	3.1%	3	2.3%
Tendency to fall	1	1.6%	1	1.1%	0	0.0%	0	0.0%	0	0.0%	1	0.8%
22 Injury, poisoning or certain other consequences of external causes	20	31.3%	35	40.2%	7	20.6%	14	29.8%	25	26.0%	46	35.1%
Burn	4	6.3%	7	8.0%	1	2.9%	2	4.3%	4	4.2%	7	5.3%
General surgery	1	1.6%	2	2.3%	0	0.0%	0	0.0%	1	1.0%	2	1.5%
Injury-head or brain	10	15.6%	16	18.4%	4	11.8%	7	14.9%	13	13.5%	22	16.8%
Injury-in armed conflict	1	1.6%	5	5.7%	0	0.0%	0	0.0%	1	1.0%	5	3.8%
Injury-other	12	18.8%	19	21.8%	4	11.8%	9	19.1%	15	15.6%	27	20.6%
Injury-spine	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Injury (not specified)	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Poisoning	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Trauma surgery	1	1.6%	2	2.3%	0	0.0%	0	0.0%	1	1.0%	2	1.5%
23 External causes of morbidity or mortality	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
Snakebite	0	0.0%	0	0.0%	1	2.9%	1	2.1%	1	1.0%	1	0.8%
24 Factors influencing health status or contact with health services	2	3.1%	2	2.3%	2	5.9%	2	4.3%	4	4.2%	4	3.1%
Mercury intoxication	0	0.0%	0	0.0%	2	5.9%	2	4.3%	2	2.1%	2	1.5%
Liver transplantation	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Solid organ transplantation (heart, lung, kidney, liver, and small bowel)	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%
Other diagnoses	4	6.3%	5	5.7%	1	2.9%	1	2.1%	5	5.2%	6	4.6%
Acute illness (not specified)	1	1.6%	1	1.1%	1	2.9%	1	2.1%	2	2.1%	2	1.5%
Chronic disease (not specified)	2	3.1%	3	3.4%	0	0.0%	0	0.0%	2	2.1%	3	2.3%
ICU admission survivors	1	1.6%	1	1.1%	0	0.0%	0	0.0%	1	1.0%	1	0.8%

Notes.

1) Multiple publications may have arisen from a single study. In instances where a study has yielded multiple publications, the one with the largest sample size was considered the primary representation of the study.

2) The total number of studies and publications in this table is smaller than that in Tables 1 and 2 because it exclusively reports studies in which respondents with a known diagnosis of conditions completed bolt-ons to self-report their own HRQoL.

*There were 3 publications (2 studies) belonging to both Netherlands and other countries categories: Boersma-van Dam et al., 2021, Boersma-van Dam et al., 2022, Van Ditschuijzen et al., 2022.

*One study may belong to more than one ICD category, and may be included in more than one diagnosis within the same ICD category.

Table 5 Valuation and disability weight studies assessing hypothetical health states using with cognition bolt-ons

Characteristic	Netherlands				Other countries				Total [†]			
	Studies (n=14)		Publications (k=17)		Studies (n=15)		Publications (k=15)		Studies (n=27)		Publications (k=30)	
	n	%	k	%	n	%	k	%	n	%	k	%
STUDY METHODS												
Study aims												
Valuation of a set of health states	8	57.1%	9	52.9%	5	33.3%	5	33.3%	12	44.4%	13	43.3%
Obtaining disability weights	6	42.9%	8	47.1%	10	66.7%	10	66.7%	15	55.6%	17	56.7%
Valuation method*												
Analytical hierarchy process	0	0.0%	0	0.0%	1	6.7%	1	6.7%	1	3.7%	1	3.3%
Pairwise choices/discrete choice experiment	1	7.1%	1	5.9%	2	13.3%	2	13.3%	3	11.1%	3	10.0%
Person trade-off	3	21.4%	3	17.6%	3	20.0%	3	20.0%	5	18.5%	5	16.7%
Ranking/card sorting	3	21.4%	3	17.6%	4	26.7%	4	26.7%	7	25.9%	7	23.3%
Time trade-off	7	50.0%	8	47.1%	5	33.3%	5	33.3%	10	37.0%	11	36.7%
Visual analogue scale	10	71.4%	13	76.5%	10	66.7%	10	66.7%	18	66.7%	21	70.0%
Other methods to obtain disability weights	0	0.0%	0	0.0%	3	20.0%	3	20.0%	3	11.1%	3	10.0%
Number of health states valued												
1-10	4	28.6%	5	29.4%	4	26.7%	4	26.7%	7	25.9%	8	26.7%
11-20	6	42.9%	6	35.3%	7	46.7%	7	46.7%	12	44.4%	12	40.0%
21-30	0	0.0%	0	0.0%	1	6.7%	1	6.7%	1	3.7%	1	3.3%
30+	4	28.6%	6	35.3%	3	20.0%	3	20.0%	7	25.9%	9	30.0%
Health state descriptions												
EQ-5D + bolt-on	5	35.7%	6	35.3%	6	40.0%	6	40.0%	10	37.0%	11	36.7%
EQ-5D + bolt-on + additional description of symptoms	6	42.9%	6	35.3%	5	33.3%	5	33.3%	10	37.0%	10	33.3%
EQ-5D + bolt-on + additional description of symptoms with images**	3	21.4%	5	29.4%	0	0.0%	0	0.0%	3	11.1%	5	16.7%
Individual EQ-5D dimension against bolt-on dimension choice pairs	0	0.0%	0	0.0%	1	6.7%	1	6.7%	1	3.7%	1	3.3%
Pictorial EQ-5D + pictorial bolt-on	0	0.0%	0	0.0%	3	20.0%	3	20.0%	3	11.1%	3	10.0%
Health condition in the focus of the study												
Building-related health problems	0	0.0%	0	0.0%	2	13.3%	2	13.3%	2	7.4%	2	6.7%
Dyslexia	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Gastroenteritis (incl. severe gastroenteritis and Campylobacter infection)	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Guillain-Barré syndrome	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Injury	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Major depression	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Multiple chronic diseases	3	21.4%	5	29.4%	7	46.7%	7	46.7%	9	33.3%	11	36.7%
Poisoning	0	0.0%	0	0.0%	1	6.7%	1	6.7%	1	3.7%	1	3.3%
Snakebite	0	0.0%	0	0.0%	1	6.7%	1	6.7%	1	3.7%	1	3.3%
Not applicable (EQ-5D health state descriptions were used without any reference to any specific health condition)	6	42.9%	7	41.2%	4	26.7%	4	26.7%	9	33.3%	10	33.3%
Sample*												
General population: Any, including older adults	10	71.4%	13	76.5%	9	60.0%	9	60.0%	17	63.0%	20	66.7%
General population: Older adults	1	7.1%	2	11.8%	2	13.3%	2	13.3%	2	7.4%	3	10.0%
Caregivers	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
Patient population	1	7.1%	1	5.9%	1	6.7%	1	6.7%	2	7.4%	2	6.7%
Experts	5	35.7%	5	29.4%	6	40.0%	6	40.0%	11	40.7%	11	36.7%
Sample size***												
Lower than 50	5	35.7%	5	29.4%	1	6.7%	1	6.7%	6	22.2%	6	20.0%
50-99	3	21.4%	4	23.5%	3	20.0%	3	20.0%	5	18.5%	6	20.0%
100-199	3	21.4%	5	29.4%	2	13.3%	2	13.3%	5	18.5%	7	23.3%
200-299	1	7.1%	1	5.9%	2	13.3%	2	13.3%	2	7.4%	2	6.7%
300-399	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
400-499	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
500-999	1	7.1%	1	5.9%	0	0.0%	0	0.0%	1	3.7%	1	3.3%
≥1000	0	0.0%	0	0.0%	4	26.7%	4	26.7%	4	14.8%	4	13.3%
Not reported	0	0.0%	0	0.0%	3	20.0%	3	20.0%	3	11.1%	3	10.0%

Note. Multiple publications may have arisen from a single study. In instances where a study has yielded multiple publications, the one with the largest sample size was considered the primary representation of the study.

[†]There were 2 publications (2 studies) belonging to both Netherlands and other countries categories: Botes et al., 2021 and Schwarzingner et al., 2023.

*One study may belong to more than one category.

**Images refer to representations of symptoms or diseases, but not pictorial EQ-5D.

***For study protocols, the expected sample size was considered.

