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

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ABSTRACT

Objectives: Multiple studies have proposed adding a cognition dimension (bolt-on) to the EQ-5D. Our objective is 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 23 countries, with 64% of the studies originating from the Netherlands. 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: Cognition is the most widely used bolt-on for the EQ-5D, with a user demand across various medical specialties. The large number of different items and lack of robust development processes underscore the need for methodological rigor and harmonization in future bolt-on development.

INTRODUCTION

The EQ-5D is the most widely used generic preference-accompanied health-related quality of life (HRQoL) measure worldwide.[1,2] It covers five dimensions of HRQoL (mobility, self-care, usual activities, pain/discomfort and anxiety/depression).[3,4] The two adult versions, EQ-5D-3L and EQ-5D-5L, have demonstrated good validity, discriminatory power and responsiveness in a wide array of populations, health interventions and cultural contexts.[5-7] However, due to their brevity they may not capture all relevant areas of HRQoL in specific populations. In such areas, bolt-ons have been proposed to be added to the EQ-5D, aiming to improve its content validity and sensitivity.[8] By now, over 30 different bolt-ons exist for the adult EQ-5D versions, each comprising one or more items.[9] One of the earliest EQ-5D bolt-ons is cognition.[10]

Cognition, encompassing *'all forms of knowing and awareness, such as perceiving, conceiving, remembering, reasoning, judging, imagining and problem solving',*[11] 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) and occupational diseases (e.g. mercury exposure in miners).[12] Furthermore, given the current demographic trends and that some cognitive changes occur even with normal aging,[13] measuring cognitive functioning as part of generic HRQoL has become increasingly important. Some preference-accompanied measures, such as the Health Utilities Index (HUI), 15D and PROMIS preference-scoring system (PROPr), have separate items focusing on one or more aspects of cognition. 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.[14-18] Nevertheless, multiple studies, using different methods such as qualitative interviews, focus groups or surveys,[19-21] factor analysis and latent class analysis,[22,23] have identified cognition as an aspect of HRQoL missing from the EQ-5D.

In the last 25 years there has been an increase in the use of cognition bolt-ons for the EQ-5D-3L, and later, for the EQ-5D-5L, for various purposes including the measurement of HRQoL and disease burden or valuing health states.[10,14,24-30] 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.[9] Despite the growing interest in cognition bolt-ons, no systematic review has specifically focused on this particular bolt-on. Therefore, our objective is to conduct a systematic literature review to provide an overview of the studies that have 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 September 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.[9] 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 (Appendix 1). No restrictions for language were applied.

Study selection, inclusion and exclusion criteria

Study selection followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) 2020 guideline.[31] Selection (applying inclusion and exclusion criteria), data extraction and assessment of methodological quality were performed independently by two reviewers (F.R. and S.P.). First, records were screened based on title and abstract. Then, potentially eligible full texts were screened. If discrepancies occurred during either the selection or data extraction, a third researcher (M.F.J.) was consulted. 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). In cases of uncertainty, researchers within the EuroQol Group's network fluent in the respective language were consulted. The following data were extracted from eligible publications using a customized 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).[32]

Collecting missing information

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. We attempted to contact EQ member(s) among the authors, the first author, last author and corresponding author (when these differed), and in some cases co-authors that appeared on multiple included publications. In certain instances, EuroQol members or EuroQol Office scientists helped to contact authors they know or from their country, in their language. If there was no response from any of the authors, two reminders were sent over the following two months. A nonresponse was defined as failure to receive a response after three attempts to contact the abovementioned authors of a publication.

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.[8] 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.[8] These criteria focus on structure, dimension language and framing. A 12-point scorable checklist, presented in Appendix 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. 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 (Appendix 3). 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. The full list of included publications is available from the corresponding author.

Overall characteristics of included publications and studies

Most of the 181 included publications were in English (95%) and were journal articles or letters to the editor (91%) (Table 1). The publications showed a clear increasing trend in the use of cognition bolt-ons, with 39 publications released between 1997 and 2010 and 142 between 2011 and 2023 (Figure 1). The majority of the publications were funded by government (41%) or other foundation grants (17%), with only 5% funded by the EuroQol Research Foundation. Funding sources were not reported for almost a quarter of the publications.

The sample sizes of the included studies varied widely, ranging from 1 to 43,704 respondents. 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 10 studies (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. The identified studies originated from 23 countries, with the Netherlands (64%) leading, followed by China (6%), India (5%) and Belgium (4%) (Table 2). 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. Among these, 38 studies developed a new cognition bolt-on, resulting in a total of 52 different wordings: 23 for 3L and for 29 for 5L (Table 3). 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 developed in 38 studies was heterogeneous. On a 0-12-point scale, methodological quality was scored as follows: 5-6 in 4 cases (8%), 7-8 in 10 cases (19%), and 9-10 in 26 cases (50%). Only 11 bolt-on items (21%) scored 11 points, and one item scored 12 points. 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 2). 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 does not necessarily mean poor translatability. Wordings judged to be incomprehensible or ambiguous (3L: 39%, 5L: 14%) for example using terms like 'temporo-spatial orientation', were also common (Appendix 2). 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 4). The 96 studies conducted in patient populations included 71 different health conditions, covering most medical specialties in terms of ICD-11 groups (Table 5). The most common ICD-11 groups were 'injury, poisoning or certain other consequences of external causes' (n=25), 'mental, behavioural and neurodevelopmental disorders' (n=22) and 'certain infectious or parasitic diseases' (n=14). The most prevalent diagnoses were injury (other) (n=15), head or brain injury (n=13), dementia (n=12), depression (n=6), HIV, schistosomiasis, stroke, chronic kidney disease and burn (all n=4).

The most common study designs were cross-sectional (38%), longitudinal cohort (38%) and randomised controlled trial (18%) (Table 4). 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 eqully used. Most studies (64%) positioned the bolt-ons after the five EQ-5D dimensions and before the EQ VAS. Only three 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 (multiple approches may be used within the same study) (Table 6). None of the studies developed a full value set for the EQ-5D+cognition bolt-on. 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.

Netherlands vs. other countries

The first cognition bolt-on was developed in the Netherlands, and since then, there has been increased adoption of this bolt-on compared to other countries (Figure 1). Out of the 52 different cognition bolt-ons identified, 21 were developed in Dutch (33% 5L) and 31 in other languages (71% 5L). In terms of wording, the Dutch versions were more similar to each other than those developed in other countries. The Dutch wordings included 13 different examples for the construct, while this was 23 for other languages. Almost half of the Dutch versions used 'thinking ability' (*denkvermogen*) as the dimension title, while none of the bolt-ons developed in other countries did. The most striking difference in the examples provided was the wide use of 'IQ (level)' as an example in the Netherlands (38% vs. 7%).

Studies with larger sample sizes (500+) were more prevalent in the Netherlands (31% vs. 19%). Dutch studies less frequently used 5L versions (23% vs. 37%), and the nomenclature EQ-6D or its variants was more common (46% vs. 20%). The use of other bolt-ons alongside cognition was rare in the Netherlands. Most longitudinal cohorts and randomised controlled trials incorporating this bolt-on originated from the Netherlands, whereas other countries predominantly used cross-sectional designs. While face-to-face administration was dominant in other countries (86%), the Netherlands typically used online and mail surveys (65%). Interviewer-administered mode of administration was less common compared to other countries (30% vs. 51%). Regarding study populations, the use of cognition bolt-ons in certain ICD-11 groups appeared less common in the Netherlands compared to other countries, such as 'certain infectious or parasitic diseases' (6% vs. 29%), while others were more prevalent, such as 'diseases of the nervous system' (11% vs. 3%), 'pregnancy, childbirth, or the puerperium' (8% vs. 0%) or 'injury, poisoning, or certain other consequences of external causes' (31% vs. 21%). In valuation and disability weight studies, the time trade-off method was more frequently used in the Netherlands (50% vs. 33%), and as opposed to other countries, studies often valued EQ-5D+cognition bolt-on health state descriptions without specifying a disease label (43% vs. 27%).

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. We extended the findings of a previous methodological review on bolt-ons, which identified substantially fewer studies.[9] Our findings suggest that cognition is the most widely used bolt-on for the EQ-5D, with a total of 181 publications. To our knowledge, this represents the largest amount of evidence available regarding any bolt-on. 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, leading them to create new 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. Furthermore, new wordings could have emerged from insufficient consideration of how wording impacts self-reported HRQoL. 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. This observation raises the question of whether a single global cognition item with a maximum of 3-4 examples can be suitable for use across all populations of interest, or if there is a need for multi-item bolt-ons with separate items for different areas of cognition that appear as examples in the global item. An ongoing project is currently exploring this by developing both a global item and multiple subitems in the UK and Australia.[33]

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.[10,24,25,34] Although in the early works, founding or long-standing members of the EuroQol Group were among the authors, it appears that the bolt-on was gradually embraced by the Dutch medical community. It subsequently diffused into several clinical trials and patient registries across multiple areas of medicine. The bolt-on item has even been incorporated into another instrument, The Older Persons and Informal Caregivers Survey-Composite Endpoint (TOPICS-CEP).[35]

Our systematic review primarily focused on adult populations using the adult EQ-5D; however, it also included studies with mixed populations, involving individuals both <16 and ≥16 years. It is noteworthy that 12% of the studies included populations below the age of 16, particularly in cases involving injuries or parasitic diseases. In addition, our search identified four studies exclusively involving paediatric samples, which were not included in this review. These findings suggest a potential need for such bolt-ons for younger populations as well. Recently, a set of cognition bolt-ons has been developed for the EQ-5D-Y-3L, incorporating items related to cognitive/mental abilities (thinking), concentration, memory (remembering) and school performance in Germany.[36] Currently, there is ongoing testing of these items in paediatric patients with ADHD in China.[37]

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 ('bolt-on' was used in only a very limited portion of publications). Moreover, often no reference appears 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,[8] 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.[38] 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. The checklist is also not straightforward regarding the item 'severity-type response levels', as it banned other forms of response levels, e.g. frequency or difficulty, which

might not align with the structure of the EQ-5D but can actually match the lived experience of patients with cognitive problems.[33] Despite these limitations, we consider the checklist as a useful tool for identifying suboptimal items. Nevertheless, we acknowledge that for items exhibiting superior performance, further assessment is required. This includes formal translatability assessments, qualitative and quantitative psychometric testing, and appraisal of their amenability to valuation. Such evidence would be necessary to recommend any of the identified 52 bolt-on items.

In conclusion, 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 identified wordings may contribute to ongoing cognition bolt-on development research. However, the abundance of bolt-on items and the lack of robust development processes highlight the necessity for methodological rigor and harmonization in future bolt-on development efforts. 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. However, we recommend waiting for the results of ongoing studies that are evaluating various cognition bolt-on item wordings using EQ-VT, Online elicitation of Personal Utility Functions (OPUF) and kaizen tasks.[39,40]

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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	5	5.7%	5	4.2%	7	13.0%	11	16%	5	13.2%	6	15.0%	11	9.2%	15	9.2%	0	0.0%	0	0.0%	11	8.0%	15	8.3%
400-499	6	6.9%	8	6.7%	0	0.0%	0	0%	2	5.3%	2	5.0%	6	5.0%	8	4.9%	1	3.7%	1	3.3%	6	4.4%	8	4.4%
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%

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	%
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%
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 Countries and languages where cognition bolt-ons are used

Characteristic	Bolt-on development				Bolt-on use or psychometric testing				Bolt-on valuation or obtaining disability weights				Total			
	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	%
Country, grouped by continent[*†]																
Europe (n=9 countries)	***24***	***63.2%***	***25***	***62.5%***	***89***	***74.2%***	***122***	***74.8%***	***18***	***66.7%***	***21***	***70.0%***	***100***	***73.0%***	***134***	***74.0%***
Belgium	2	5.3%	2	5.0%	5	4.2%	6	3.7%	0	0.0%	0	0.0%	5	3.6%	6	3.3%
France	1	2.6%	1	2.5%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
Germany	0	0.0%	0	0.0%	2	1.7%	4	2.5%	1	3.7%	1	3.3%	3	2.2%	5	2.8%
Hungary	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Netherlands	18	47.4%	19	47.5%	80	66.7%	111	68.1%	14	51.9%	17	56.7%	87	63.5%	119	65.7%
Spain	1	2.6%	1	2.5%	1	0.8%	1	0.6%	1	3.7%	1	3.3%	2	1.5%	2	1.1%
Sweden	2	5.3%	2	5.0%	0	0.0%	0	0.0%	3	11.1%	3	10.0%	3	2.2%	3	1.7%
Switzerland	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
United Kingdom	3	7.9%	3	7.5%	1	0.8%	1	0.6%	2	7.4%	2	6.7%	3	2.2%	3	1.7%
Asia (n=9 countries)	***10***	***26.3%***	***10***	***25.0%***	***21***	***17.5%***	***21***	***12.9%***	***5***	***18.5%***	***5***	***16.7%***	***24***	***17.5%***	***24***	***13.3%***
China	4	10.5%	4	10.0%	8	6.7%	8	4.9%	0	0.0%	0	0.0%	8	5.8%	8	4.4%
India	3	7.9%	3	7.5%	6	5.0%	6	3.7%	3	11.1%	3	10.0%	7	5.1%	7	3.9%
Indonesia	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Iran	0	0.0%	0	0.0%	0	0.0%	0	0.0%	2	7.4%	2	6.7%	2	1.5%	2	1.1%
Japan	0	0.0%	0	0.0%	2	1.7%	2	1.2%	0	0.0%	0	0.0%	2	1.5%	2	1.1%
Malaysia	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Thailand	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Türkiye	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Vietnam	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Oceania (n=2 countries)	***1***	***2.6%***	***2***	***5.0%***	***5***	***4.2%***	***15***	***9.2%***	***1***	***3.7%***	***1***	***3.3%***	***6***	***4.4%***	***16***	***8.8%***
Australia	0	0.0%	1	2.5%	2	1.7%	5	3.1%	1	3.7%	1	3.3%	3	2.2%	6	3.3%
New Zealand	1	2.6%	1	2.5%	3	2.5%	10	6.1%	0	0.0%	0	0.0%	3	2.2%	10	5.5%
Africa (n=2 countries)	***1***	***2.6%***	***1***	***2.5%***	***4***	***3.3%***	***4***	***2.5%***	***2***	***7.4%***	***2***	***6.7%***	***4***	***2.9%***	***4***	***2.2%***
South Africa	0	0.0%	0	0.0%	2	1.7%	2	1.2%	2	7.4%	2	6.7%	2	1.5%	2	1.1%
Zimbabwe	1	2.6%	1	2.5%	2	1.7%	2	1.2%	0	0.0%	0	0.0%	2	1.5%	2	1.1%
North America (n=1 country)	***1***	***2.6%***	***1***	***2.5%***	***1***	***0.8%***	***1***	***0.6%***	***0***	***0.0%***	***0***	***0.0%***	***1***	***0.7%***	***1***	***0.6%***
United States	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Country not specified	***0***	***0.0%***	***0***	***0.0%***	***0***	***0.0%***	***0***	***0.0%***	***2***	***7.4%***	***2***	***6.7%***	***2***	***1.5%***	***2***	***1.1%***
Language of bolt-on[*]																
Dutch	20	52.6%	21	52.5%	83	69.2%	114	69.9%	14	51.9%	17	56.7%	90	65.7%	122	67.4%
English	8	21.1%	9	22.5%	15	12.5%	26	16.0%	6	22.2%	6	20.0%	19	13.9%	30	16.6%
Farsi	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
French	4	10.5%	4	10.0%	4	3.3%	4	2.5%	1	3.7%	1	3.3%	5	3.6%	5	2.8%
German	0	0.0%	0	0.0%	2	1.7%	4	2.5%	1	3.7%	1	3.3%	3	2.2%	5	2.8%
Hungarian	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Indonesian	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Japanese	0	0.0%	0	0.0%	2	1.7%	2	1.2%	0	0.0%	0	0.0%	2	1.5%	2	1.1%
Korean	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Malay	1	2.6%	1	2.5%	3	2.5%	3	1.8%	1	3.7%	1	3.3%	3	2.2%	3	1.7%
Malayalam	1	2.6%	1	2.5%	3	2.5%	3	1.8%	1	3.7%	1	3.3%	3	2.2%	3	1.7%
Mandarin Chinese	4	10.5%	4	10.0%	8	6.7%	8	4.9%	0	0.0%	0	0.0%	8	5.8%	8	4.4%
Moroccan (not specified)	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	0	0.0%	2	1.1%
Moroccan-Arabic	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	1	0.7%	2	1.1%
Odia	1	2.6%	1	2.5%	1	0.8%	1	0.6%	1	3.7%	1	3.3%	2	1.5%	2	1.1%
Persian	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
Sarnámi-Hindustani	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	1	0.7%	2	1.1%
Shona	0	0.0%	0	0.0%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Spanish	1	2.6%	1	2.5%	1	0.8%	1	0.6%	1	3.7%	1	3.3%	2	1.5%	2	1.1%
Sranan Tongo	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	1	0.7%	2	1.1%
Surinamese	0	0.0%	0	0.0%	1	0.8%	2	1.2%	0	0.0%	0	0.0%	0	0.0%	2	1.1%
Swedish	1	2.6%	1	2.5%	0	0.0%	0	0.0%	1	3.7%	1	3.3%	1	0.7%	1	0.6%
Tarifit Berber	0	0.0%	0	0.0%	2	1.7%	3	1.8%	0	0.0%	0	0.0%	2	1.5%	3	1.7%
Telugu	2	5.3%	2	5.0%	2	1.7%	2	1.2%	2	7.4%	2	6.7%	3	2.2%	3	1.7%
Thai	1	2.6%	1	2.5%	1	0.8%	1	0.6%	0	0.0%	0	0.0%	1	0.7%	1	0.6%
Turkish	0	0.0%	0	0.0%	2	1.7%	4	2.5%	0	0.0%	0	0.0%	2	1.5%	4	2.2%
Vietnamese	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 reported	2	5.3%	2	5.0%	4	3.3%	4	2.5%	4	14.8%	4	13.3%	7	5.1%	7	3.9%

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.

†The number of studies/publications by country may not add up at the continent category due to studies conducted in multicountry settings.

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

Table 3 Cognition bolt-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 4 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	5	6.3%	5	4.5%	7	16.3%	11	19.6%	11	9.2%	15	9.2%
400-499	6	7.5%	8	7.2%	0	0.0%	0	0.0%	6	5.0%	8	4.9%
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)	4	5.0%	9	8.1%	2	4.7%	3	5.4%	6	5.0%	11	6.7%
Proxy-patient perspective (proxy 2)	2	2.5%	2	1.8%	3	7.0%	4	7.1%	5	4.2%	6	3.7%
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%

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	%
After the EQ VAS	0	0.0%	0	0.0%	3	7.0%	3	5.4%	3	2.5%	3	1.8%
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 Ditshuizen 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 5 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%**
Abdomnial 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%

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	%
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%
Obstretic 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%
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%	15	17.2%	4	11.8%	7	14.9%	13	13.5%	21	16.0%
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 Ditshuizen 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 6 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 (but not value set development)	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.

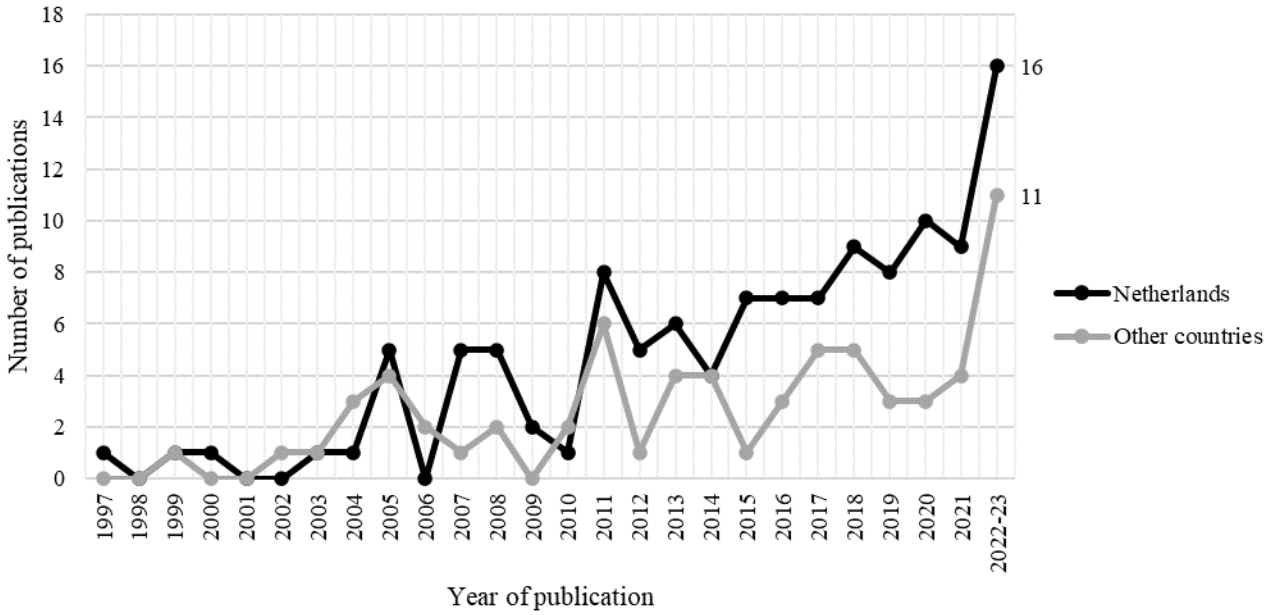
†There were 2 publications (2 studies) belonging to both Netherlands and other countries categories: Botes et al., 2021 and Schwarzinger et al., 2023.

*One study may belong to more than one category.

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

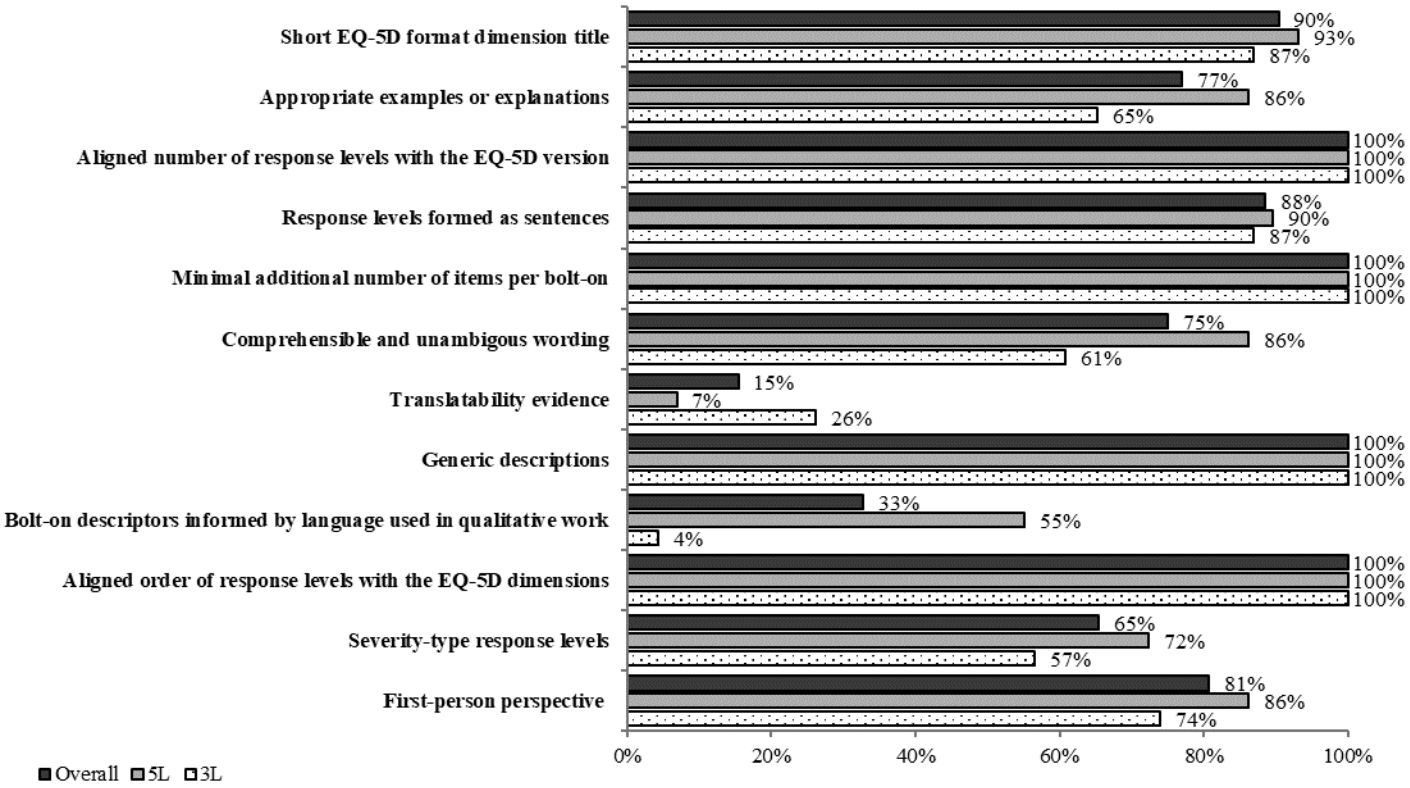
***For study protocols, the expected sample size was considered.

Figure 1 Number of publications included in the systematic review by year



There were 4 publications whose studies were conducted in both the Netherlands and other countries

Figure 2 Quality assessment of bolt-on items (proportion of the 52 bolt-ons that received positive assessment)



Note: All wording unfavorably scored in the 'Translatable bolt-on items' criterion was solely due to inapplicability, i.e. the absence of translatability evidence.

Appendix 1 Search strategy

PubMed: (#1 AND #2) OR #3	
#1	("EQ 5D"[tw] OR "EQ5D"[tw] OR "EQ5D5L"[tw] OR "EQ 5D 5L"[tw] OR "EQ5D3L"[tw] OR "EQ 5D 3L"[tw] OR "EuroQol"[tw] OR "Euro Qol"[tw] OR "Euro Quol"[tw] OR "EuroQuol" OR "European Quality of Life" [tw])
#2	("bolt on*"[tw] OR "bolton*"[tw] OR "six dimension*"[tw] OR "six domain*"[tw] OR "six item*" [tw] OR "six question*"[tw] OR "sixth dimension"[tw] OR "sixth domain"[tw] OR "sixth item"[tw] OR "sixth question"[tw] OR "6 dimension*"[tw] OR "6 domain*"[tw] OR "6 item*" [tw] OR "6 question*"[tw] OR "6th dimension"[tw] OR "6th domain"[tw] OR "6th item"[tw] OR "6th question"[tw] OR "6D"[tw] OR "6 D"[tw] OR "plus C"[tw] OR "plusC"[tw] OR "+C"[tw] OR "C"[tw] OR "cogniti*"[tw])
#3	("Euroqol 6D"[tw] OR "Euroqol6D"[tw] OR "Euroquol 6D"[tw] OR "Euroquol6D"[tw] OR "EQ 6D"[tw] OR "EQ6D"[tw] OR "EQ 5D C"[tw] OR "EQ5DC"[tw] OR "EQ6D3L"[tw] OR "EQ 6D 3L"[tw] OR "EQ6D5L"[tw] OR "EQ 6D 5L"[tw] OR "EQ5D3LC"[tw] OR "EQ 5D 3L C"[tw] OR "EQ5D5LC"[tw] OR "EQ 5D 5L C"[tw] OR "6D3L"[tw] OR "6D 3L"[tw] OR "6D5L"[tw] OR "6D 5L"[tw])
Web of Science: (#1 AND #2) OR #3	
#1	TS=("EQ 5D" OR "EQ5D" OR "EQ5D5L" OR "EQ 5D 5L" OR "EQ5D3L" OR "EQ 5D 3L" OR "EuroQol" OR "Euro Qol" OR "Euro Quol" OR "EuroQuol" OR "European Quality of Life")
#2	TS=("bolt on*" OR "bolton*" OR "six dimension*" OR "six domain*" OR "six item*" OR "six question*" OR "sixth dimension" OR "sixth domain" OR "sixth item" OR "sixth question" OR "6 dimension*" OR "6 domain*" OR "6 item*" OR "6 question*" OR "6th dimension" OR "6th domain" OR "6th item" OR "6th question" OR "6D" OR "6 D" OR "plus C" OR "plusC" OR "+C" OR "C" OR "cogniti*")
#3	TS=(("Euroqol 6D" OR "Euroqol6D" OR "Euroquol 6D" OR "Euroquol6D" OR "EQ 6D" OR "EQ6D" OR "EQ 5D C" OR "EQ5DC" OR "EQ6D3L" OR "EQ 6D 3L" OR "EQ6D5L" OR "EQ 6D 5L" OR "EQ5D3LC" OR "EQ 5D 3L C" OR "EQ5D5LC" OR "EQ 5D 5L C" OR "6D3L" OR "6D 3L" OR "6D5L" OR "6D 5L"))

Developed based on Geraerds et al. 2021

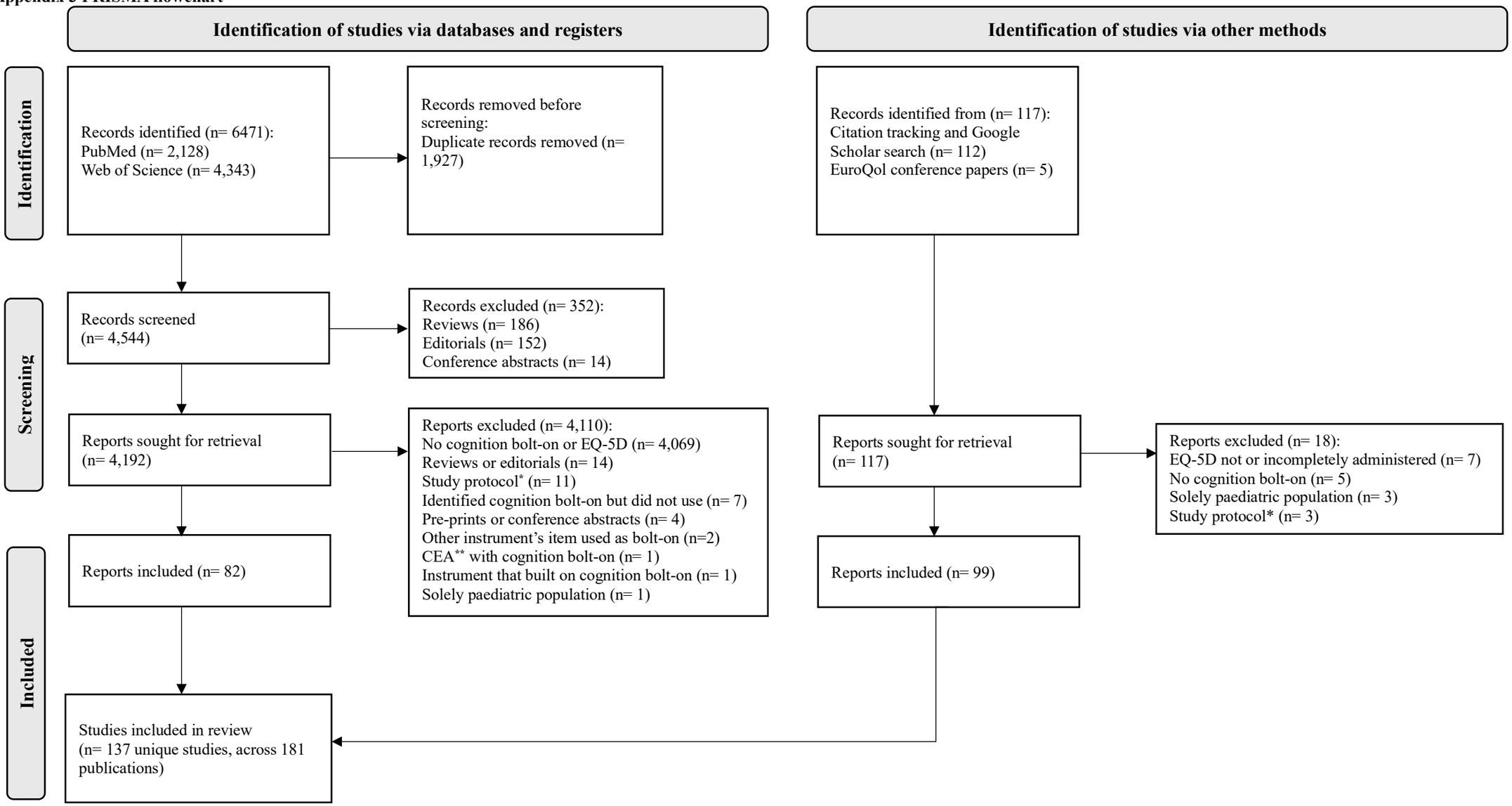
Appendix 2 Checklist to assess quality of bolt-on items in terms of structure, language and framing

	STRUCTURE, LANGUAGE AND FRAMING (0-12 POINTS)	POINTS GIVEN AND CRITERIA	EXAMPLE WORDING (translated to English, where applicable)	REFERENCE
1	Short EQ-5D format dimension title	0: no dimension title OR too long OR not consistent with the EQ-5D-format	The next statements relate to intellectual activities such as remembering, concentrating, thinking and solving day to day problems. 1 - No problems with intellectual activities 2 - Some problems with intellectual activities 3 - Were unable to perform intellectual activities	Derrett, S. et al. (2012). Inj Prev, 18(5), 343-346.
		1: short dimension title that is consistent with the EQ-5D format	COGNITIVE FUNCTIONING (e.g. memory, learning ability, concentration, comprehension) 1 - I have no problems in cognitive functioning 2 - I have some problems in cognitive functioning 3 - I have severe problems in cognitive functioning	Schaaf, R. E. et al. (2022). J Acquir Immune Defic Syndr, 91(3), 261-268.
2	Appropriate examples or explanations provided (where the concept would require one)	0: no examples are provided (where the concept would require one) OR one or more examples are inappropriate	***No examples:*** Cognition 1 - I have no impairment of cognitive function or no cognitive problems 2 - I have a little/very few cognitive problems 3 - I have moderate impairment of cognitive function 4 - I have considerable impairment of cognitive function 5 - I have severe impairment of cognitive function ***Inappropriate example:*** ('IQ') Thinking ability (e.g. remembering, concentrating, coherence, IQ level) 1 - I have no limitations in thinking abilities 2 - I have some limitations in thinking abilities 3 - I have severe limitations in thinking abilities	Mahapatra, P. et al. (2002). The 6D5L description system for health state valuation. In Summary Measures of Population Health (pp. 349-368). Krabbe, P. F. et al. (1999). J Clin Epidemiol, 52(4), 293-301.
		1: no examples are required for the concept OR appropriate examples are provided in parenthesis (where the concept would require one)	COGNITION 1 - I have no problems with my cognitive functioning (e.g. memory, concentration) 2 - I have some problems with my cognitive functioning (e.g. memory, concentration) 3 - I have severe problems with my cognitive functioning (e.g. memory, concentration)"	Meertens, L. J. E. et al. (2017). JMIR Res Protoc, 6(10), e203.
3	Aligning number of response levels to the EQ-5D version used	0: not aligning (e.g. EQ-5D-3L with 5L bolt-on or EQ-5D-5L with 3L bolt-on)	-	-
		1: aligning (i.e. EQ-5D-3L with 3L bolt-on or EQ-5D-5L with 5L bolt-on)	-	-
4	Response levels formed as sentences	0: not sentences	Cognitive functioning (e.g. memory, concentration) 1 - No problems 2 - Some problems 3 - Severe	De Brauwer, I. et al. (2023). Acta Clin Belg, 78(1), 16-24.
		1: sentences	Memory 1 - I am not forgetful 2 - I am slightly forgetful 3 - I am moderately forgetful 4 - I am severely forgetful 5 - I am very forgetful	Verdoorn, S. et al. (2018). BMC Geriatr, 18(1), 190.
5	Minimal additional number of items per bolt-on	0: not parsimonious according to the review team's judgement	-	-
		1: parsimonious according to the review team's judgement	-	-
6	Comprehensible and unambigous wording	0: wording is incomprehensible OR ambigous according to the review team's judgement	***Incomprehensible wording:*** ('temporo-spatial orientation') Cognitive problems, such as forgetfulness, difficulty in concentrating, loss of temporo-spatial orientation, etc. 1 - No problems in cognition 2 - Some problems with memory and concentration 3 - Severe problems in cognition (loss of temporo-spatial orientation) ***Ambigous wording:*** ('normal') Cognitive ability (difficulty concentrating, poor memory, etc.)	Lobo, E. et al. (2019). Front Public Health, 7, 276. Zhang, X. (2011). 云南省晚期血吸虫病经济负担及其影响因素研究 [Economic

			1 - Memory is basically normal 2 - Memory is affected to some extent 3 - Above abilities are significantly reduced	burden of advanced schistosomiasis and its influencing factors in Yunnan] [(Master's thesis), Dali University].
		1: wording is comprehensible and unambigous according to the review team's judgement	Thinking ability such as remembering, concentrating 1 - I have no limitations in thinking ability 2 - I have some limitations in thinking ability 3 - I have severe limitations in thinking ability	Haagsma, J. A. et al. (2005). Comparing generic and disease specific health state valuations by a laymen panel. The 22nd Plenary Meeting of the EuroQol Group, Oslo, Norway.
7	Translatable bolt-on items (in terms of language, and cross culturally in countries where the bolt-on is applicable)	0: translatability tested as poor	-	-
		1: bolt-on item was successfully translated to at least one language	-	-
		n/a: no translatability assessment was performed	-	-
8	Generic descriptions	0: title or examples are condition-specific	n/a	n/a
		1: title and examples are generic	COGNITION (remembering, understanding, concentrating, thinking) 1 - I have no problems with cognition 2 - I have slight problems with cognition 3 - I have moderate problems with cognition 4 - I have severe problems with cognition 5 - I have extreme problems with cognition	Janssen, M. F. et al. (2013). The Cognition dimension revisited: a detailed study on its added value and interactions with EQ-5D core dimensions. The 30th Plenary Meeting of the EuroQol Group, Montreal, Canada.
9	Bolt-on descriptors informed by language used in qualitative work	0: language not informed by qualitative work	-	-
		1: language informed by qualitative work	-	-
10	Aligning order of response levels to the EQ-5D dimensions (best to worst)	0: worst-to-best direction	n/a	n/a
		1: best-to-worst direction	COGNITION 1 - I have no problems with remembering things 2 - I have slight problems with remembering things 3 - I have moderate problems with remembering things 4 - I have severe problems with remembering things 5 - I am unable to remember things	Finch, A. P. et al. (2021). Med Decis Making, 41(1), 89-99.
11	Severity-type response levels	0: not severity-type response levels (e.g. difficulty, frequency)	Memory / concentration 1 - I have no memory or concentration problems 2 - I have moderate difficulties with memory or concentration 3 - I have huge difficulties with memory or concentration	Perneger, T. V., & Courvoisier, D. S. (2011). Int J Qual Health Care, 23(1), 52-59.
		1: severity-type response levels	Learning 1 - I have no problems learning new knowledge or skills 2 - I have slight problems learning new knowledge or skills 3 - I have moderate problems learning new knowledge or skills 4 - I have severe problems learning new knowledge or skills 5 - I have extreme problems learning new knowledge or skill	Huang, Y. et al. (2021). Chin Pharm J(12), 203-208.
12	First-person perspective (using 'I' pronoun)	0: not first-person perspective	Lastly, a question about intellectual activities such as thinking, remembering, concentrating, and daily problem solving. Do you think that you: 1 - have no difficulties in intellectual activities? 2 - have slight difficulties in intellectual activities? 3 - have moderate difficulties in intellectual activities? 4 - have serious difficulties in intellectual activities? 5 - are unable in difficulties with intellectual activity?*	McAllister, S. et al. (2018). Int J Health Plann Manage, 33(1), e57-e66.
		1: first-person perspective	COGNITION (e.g. remembering things, thinking clearly, and making decisions) 1 - I have no problems with cognition 2 - I have slight problems with cognition 3 - I have moderate problems with cognition 4 - I have severe problems with cognition 5 - I have extreme problems with cognition	Sampson, C. et al. (2020) Candidate bolt-ons for cognition and vision: qualitative findings from a development programme. EuroQol Topical DSWG meeting, Virtual.

*Developed based on Mulhern et al. 2022. *Literal English translation of the wording; grammatically incorrect.*

Appendix 3 PRISMA flowchart



*Study protocols were included except in instances where subsequent publications reported the results of a specific study protocol. In such cases, only the publication detailing the results was included to avoid any overlaps; **CEA= Cost effectiveness analysis