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TOOLS TO ASSESS THE MEASUREMENT PROPERTIES OF QUALITY OF LIFE INSTRUMENTS: A META-REVIEW

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-036038
Article Type:	Original research
Date Submitted by the Author:	27-Nov-2019
Complete List of Authors:	Lorente, Sonia; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology; Consorci Sanitari de Terrassa, Pediatric Area Viladrich, Carme; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology Vives, Jaume; Universitat Autònoma de Barcelona, Losilla, Josep-Maria; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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TOOLS TO ASSESS THE MEASUREMENT PROPERTIES OF QUALITY OF LIFE
INSTRUMENTS: A META-REVIEW

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The authors declare no conflict of interest. This work is supported by the Grant PGC2018-100675-B-I00, Spanish Ministry of Science, Innovation and Universities (Spain). Correspondence concerning this article should be addressed to Jaume Vives, Department of Psychobiology and Methodology of Health Science, Universitat Autònoma de Barcelona, UAB. E-mail: Jaume.Vives@uab.cat

ABSTRACT

Objective: Using tools to assess the measurement properties of health status instruments improves the methodological quality of systematic reviews of measurement properties. This meta-review aimed to discuss the methodological, research and practical applications of the reported tools in systematic reviews that assess the measurement properties of instruments evaluating Health-Related Quality of Life (HRQoL). **Design:** Meta-review. **Methods:** Electronic search was carried out on bibliographic databases, including PubMed, CINAHL, PsycINFO, SCOPUS, WOS, COSMIN database, and ProQuest Dissertations & Theses, being limited by time (2008-2019) and language (English). The meta-review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Guidelines (PRISMA). **Results:** A total of 226 systematic reviews were assessed. Concerning the quality of the review process, some methodological lacks were found, as the poor compliance with reporting or methodological guidelines. Regarding the procedures to assess the quality of measurement properties, 146 (64.6%) of reviewers applied one tool at least. Tool format and structure differed among standards or scientific traditions (i.e. psychology, medicine and economics), but most assess both measurement properties and the usability of instruments. As far as the results and conclusions of systematic reviews are concerned, only 60 (26.5%) linked the purpose of instrument to the evidence of measurement properties (e.g. evaluative to responsiveness). **Conclusions:** The quality of the review process increased over time, but reports should still improve with regard to adherence to guidelines. The COSMIN would be the most widespread and comprehensive tool both to assess the risk of bias of primary studies, and measurement properties of HRQoL instruments for evaluative purposes. Nonetheless, some improvements with respect to the length and structure, and the evaluation of the feasibility and burden may be advisable to increase its applicability and dissemination among researchers in order to conduct high quality systematic reviews. **PROSPERO**

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number: CRD42017065232. **Key words:** Meta-review, Quality of life, Health instruments, Measurement properties, Measurement standards, HRQoL.

For peer review only

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STRENGTHS AND LIMITATIONS

- The search strategy has been designed to be comprehensive, following the Peer Review of Electronic Search Strategies (PRESS) guidelines including specific filters for finding studies on psychometric properties of measurement instruments.
- A total of 226 systematic reviews were included and, to our knowledge, this meta-review provides the broadest overview of the most common tools used to assess measurement properties of HRQoL instruments and their relationship with measurement standards, scientific traditions and purposes of the measures.
- Some of the included systematic reviews poorly reported the review process, outcomes, and conclusions, and this fact may have led to miss some data.
- Inclusion of studies published in English only may have led to language bias.

INTRODUCTION

Systematic reviews of measurement properties critically appraise the content and measurement properties of all instruments measuring a certain construct of interest in a specific study population¹. Systematic reviews provide a comprehensive overview of the measurement properties of health instruments and support evidence in the selection of instruments for a given purpose (e.g. research, clinical practice, predictive)^{2,3}. Because of their relevance, in this type of systematic review, different authors have evaluated the methodological quality not only of their key phases, namely the search strategy, the bias risk assessment of the primary studies and the data synthesis, but also if the measurement properties of the health status instruments have been appraised with standardized procedures or tools during the data extraction phase^{1,2,4,5}. However, depending on the measurement standards upon these tools were developed, the approach to analyse the measurement properties of instruments may vary⁶, which could lead to different conclusions and recommendations in spite of the effort undertaken by the international Society for Quality of Life Research to set consensus based minimum standards⁷. Besides, according to Rosenkoetter and Tate⁶, the available assessment tools commonly used by clinicians and researchers to select the appropriate outcome measures for specific purposes show a variety of forms and cover a mix of standards related to reporting, methodological quality and statistical outcome quality.

The present meta-review aims to discuss the methodological, research and practical applications of the reported tools in systematic reviews that assess the measurement properties of instruments evaluating the quality of life within the context of health and disease, i.e., Health-Related Quality of Life (HRQoL)⁸. The specific objectives are to identify systematic reviews assessing the measurement properties of HRQoL instruments; identify the main tools applied to assess their measurement properties; describe the contents of the tools

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3 applied (validity, reliability, feasibility, etc.); identify the measurement standards upon which
4
5 these tools were developed or conform to, comparing their similarities and differences, and
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7 appraise how authors of these systematic reviews include the assessment of the measurement
8
9 quality in their results and conclusions, i.e. to what extent conclusions depend on the results
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11 of the evaluation of the measurement properties, as well as their relationship, if any, with the
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13 purpose of the HRQoL instrument (e.g. evaluative).
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METHODS

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19 The protocol of this review⁹ was prospectively registered. We conducted this meta-review
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21 following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis
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23 Guidelines (PRISMA)^{10,11}.
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Search strategy

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28 A systematic search was performed in PubMed, US National Library of Medicine, by
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30 National Center for Biotechnology Information (NCBI); CINAHL, Cumulative Index to
31
32 Nursing and Allied Health Literature, by EBSCOhost; PsycINFO, Psychological Information,
33
34 by APA PsycNET; SCOPUS by Elsevier; WoS ,Web of Science CORE, by Thomson
35
36 Reuters, and Consensus-based Standards for the selection of Health Measurement
37
38 Instruments database by COSMIN Initiative (<http://www.cosmin.nl/>). ProQuest Dissertations
39
40 & Theses Global was used for searching grey literature, and search alerts in all databases
41
42 were set. The search strategy followed the Peer Review of Electronic Search Strategies
43
44 (PRESS) guidelines recommendations^{12,13}, and consisted of 3 filters composed of search
45
46 terms for the following: (1) systematic review methodology; (2) HRQoL instruments; and (3)
47
48 measurement properties. The latter filter was developed by the Vrije University Medical
49
50 Center for finding studies on measurement properties of measurement instruments¹⁴. All
51
52 filters were adapted for all databases. Search was performed in July 2018, limited by time,
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54 and language (English) (See Supplementary File S1 for search strings for all databases).
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Inclusion criteria*Time frame*

We limited our search to studies published between 2008-2019, including search alerts.

Study design

Systematic reviews aiming to report or to assess the measurement properties of instruments evaluating the quality of life within the context of health and disease⁸. Systematic reviews were required to include the full results report and detailed information about the procedures used to assess the measurement properties. Systematic reviews exclusively focused on the evaluation of clinical interventions were excluded.

Setting and Participants

We included the whole range of ages (new-borns, toddlers, children, teenagers, young adults, middle-age adults and elderly people), in any healthcare setting.

Study screening

References identified by the search strategy were entered into Mendeley reference management software, and duplicates were removed. Titles and abstracts were screened independently by two reviewers. When decisions were unable to be made from title and abstract alone, the full paper was retrieved. Full-text inclusion criteria were checked independently by two reviewers. Discrepancies during the process were resolved through discussion (with a third reviewer when necessary).

Data extraction

Extracted information of each selected systematic review and meta-analysis included general information as author, year, and quality of review process of systematic reviews (e.g. protocol registration, reporting guidelines, use of flowchart). Information concerning the main identified tools applied to assess the measurement properties of HRQoL instruments included the title, purpose/use, number of items, response categories, instrument assessment

1
2
3 criteria, and measurement properties assessed. Information of how authors of these
4
5 systematic reviews include the assessment of the quality of HRQoL in their results and
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7 conclusions. Authors of eligible studies were contacted to provide missing or additional data
8
9 when necessary.
10

11 **RESULTS**

12 **Search results**

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17 Figure 1 shows the results of the search strategy, reported according to the PRISMA flow
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19 diagram. A total of 4280 references were identified through databases search. After removing
20
21 duplicates, 3015 titles and abstracts were screened. After the assessment of 485 full-text
22
23 documents for eligibility, plus 20 additional articles identified by citation alerts, a total of 226
24
25 systematic reviews were included in the qualitative analysis. These systematic reviews
26
27 covered a wide range of HRQoL instruments, both generic and disease-specific. A total of 23
28
29 (10.2%) of systematic reviews assessed the quality of one measurement property only, such
30
31 as the conceptual and measurement model or the content validity (See Supplementary File 2
32
33 for characteristics and references of studies).
34
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36

37 -----Insert Figure 1 here or near here-----
38

39 **Quality of review process of systematic reviews**

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41
42 Table 1 shows the quality of review process of systematic reviews. Findings showed that 18
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44 (8.0%) of reports registered the protocol prospectively, a figure that raised to 16% when
45
46 considering the reports from 2014 onwards; 64 (28.3%) followed reporting guidelines such as
47
48 PRISMA (45.3% the last six years), 33 (14.6%; 18.9% the last six years) assessed the
49
50 reporting and/or the methodological quality of primary studies using recommended guides,
51
52 such as Standards for the Reporting of Diagnostic Accuracy Studies (STARD) and Quality
53
54 Assessment of Diagnostic Accuracy Studies (QUADAS), respectively, 218 (96.5%) reported
55
56 the search strategy, 99 (43.8%) reported the detailed syntax for one database at least, 117
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(51.8%) made the article selection by two or more independent reviewers, 148 (65.5%) used a flowchart to report search outcomes, and 127 (56.2%) stated the funding. These last percentages slightly increased when reducing the time frame to the last six years.

-----Insert Table 1 here or near here-----

Assessment of measurement properties of HRQoL instruments

Assessment procedures of measurement properties varied considerably. A total of 146 (64.6%) out of 226 systematic reviews applied one tool at least, that is, a published and well accepted list of criteria, to rate the evidence on measurement properties of instruments; 38 (16.8%) applied their own author's criteria only; 30 (13.3%) followed literature recommendations included in very highly circulated books or papers only, and 12 (5.3%) used an *ad hoc* checklist of criteria only. A total of 80 (35.9%) systematic reviews did combine different procedures. Most usual combinations were the use of two tools or one tool and literature recommendations.

Tools to assess measurement properties of HRQoL instruments

The first twelve columns of Table 2 present the characteristics for the identified tools used to assess measurement properties using the last update we are aware of. Tools are reported in order of frequency of use, as pointed out in the last row of the table: 1) "Consensus-based Standards for the selection of Health Measurement INstruments (COSMIN)", COSMIN initiative^{15,16}; 2) "Quality Criteria for Measurement Properties", Terwee et al.¹⁷; 3) "Attributes and Criteria to assess Health Status and Quality of Life Instruments", Scientific Advisory Committee Medical Outcomes Trust (SACMOT)^{18,19}; 4) "Health Status Measures in Economic Evaluation", Brazier et al.^{20,21}; 5) "Guidance for Industry Patient-reported Outcomes Measures", Food and Drug Administration (FDA)^{22,23}; 6) "Evaluating Patient-based Outcomes Measures for use in clinical trials", Fitzpatrick et al.²⁴ (also known as Fitzpatrick's criteria); 7) "International Classification of Functioning" and "International

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3 Classification of Functioning for Children and Youth”, World Health Organization²⁵; 8)
4
5 “Evaluating Measures of Patient Reported Outcomes (EMPRO)”, Spanish Cooperative
6
7 Investigation Network for Health and Health Service Outcomes Research (IRYSS)²⁶; 9)
8
9 “Spinal Cord Injury Criteria”, Spinal Cord Injury Rehabilitation Evidence (SCIRE)^{27,28}; 10)
10
11 “Criteria for Assessing the Tools of Disability Outcomes Research”, Andresen²⁹ (also known
12
13 as Andresen’s tool); 11) “CanChild Outcomes Measures”, CanChild Center for Childhood
14
15 Disability Research³⁰, and 12) “Outcomes Measures in Rheumatology Clinical Trials
16
17 (OMERACT)”, OMERACT initiative³¹. Table 2 also includes a last column showing the
18
19 characteristics of Testing Standards by American Educational Research Association (AERA),
20
21 American Psychological Association (APA) and National Council on Measurement in
22
23 Education (NCME)^{32,33} initially published in 1954 and regularly updated every decade using
24
25 consensus based procedures. Because most of the technical vocabulary for measurement
26
27 properties in HRQoL instruments is inspired in the Testing Standards, they will be used as a
28
29 reference to compare the twelve identified tools. In fact, these standards have already been
30
31 recommended to establish a unified approach to validity and reliability of results derived from
32
33 psychometric instruments in clinical medicine, research and education³⁴.
34
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40 Different methodologies were used to develop the tools. The expert panel consensus and the
41
42 literature review were the most usual methods, led by Steering Committees or Staff/Working
43
44 Groups. The format and structure of these tools also vary. Whereas seven of them were
45
46 structured in items that allow obtaining quality scores, the other six took the form of
47
48 standards or guidelines. Tools with an item structure were the COSMIN, Quality Criteria for
49
50 Measurement Properties, EMPRO, SCI Criteria, Criteria for Assessing the Tools of Disability
51
52 Outcomes Research (Andresen’s tool), CanChild Outcomes Measures, and OMERACT.
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56 Among all measurement properties considered in Testing Standards, eleven out of the twelve
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58 tools recommended to assess the conceptual and measurement model; content, structural,
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3 convergent, discriminant, concurrent and predictive validity; responsiveness or sensitivity to
4
5 change; internal consistency, test retest and inter-rater reliability. However, the approach to
6
7 analyse these measurement properties vary, with examples found in construct validity,
8
9 criterion validity and reliability. Depending on the tool, construct validity can be evaluated
10
11 either by hypothesis confirmation in general (e.g. COSMIN or EMPRO), or by specific
12
13 hypothesis based on correlations with other measures, i.e. convergent and discriminant
14
15 validity (e.g. Andresen's tool). Criterion validity can be assessed either by the comparison
16
17 with a gold standard, specificity and sensitivity, or predictive values (e.g. FDA), or only by
18
19 the comparison with a gold standard (e.g. CanChild Outcomes Measures). Reliability can be
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21 analysed either by test retest reliability, inter-rater reliability and internal consistency (e.g.
22
23 FDA), or only by test retest and inter-rater agreement (e.g. Economic evaluation). Despite the
24
25 Testing Standards recommendations, just one tool include additional criteria to assess
26
27 consequential validity (SCI), and four assess the fairness (e.g. accessible forms for subjects
28
29 with vision impairment, or for specific populations) (SACMOT, FDA, SCI and Andresen's
30
31 tool). None of them include criteria to assess the validity of response processes. Other
32
33 HRQoL instrument characteristics, such as feasibility (e.g. cost of obtaining a sample),
34
35 acceptability (e.g. suitability from the patient perspective), or burden (e.g. the time or effort
36
37 placed on the administration of the instrument) are assessed instead. Finally, notice that some
38
39 concepts changed their place over time. The clearest case is evidence regarding cross-cultural
40
41 equivalence which was treated as an additional characteristic of the instruments in tools
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43 released before 2014 (e.g., EMPRO or SCI) but was considered a proper measurement
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45 property in the 2018's update of COSMIN. It is also considered a measurement property in
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47 Testing Standards where is included as a particular case of differential item functioning when
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49 assessing the internal structure of the instruments (See Supplementary File S3 for more
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51 details).
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-----Insert Table 2 here or near here-----

Purpose of instruments and their association to measurement properties

Some of the differences between tools can be attributed to the fact that they are devoted to the evaluation of instruments developed with different purposes. For instance, COSMIN aims at assessing the quality of instruments for an evaluative purpose whereas the Economic Evaluation tool aims at the assessment of instruments for analytical purposes. Nevertheless, the relation between the purpose of the instruments and the measurement properties assessed is not regularly included in the conclusions of the systematic reviews. Table 3 shows the purposes of instruments, based on the framework proposed by McDowell et al.³⁵, and the association to measurement properties that reviewers established in their conclusions. The purposes for which instruments had been more frequently used were Evaluative 168 (74.3%), and Impact of Disease on HRQoL assessment, 127 (56.2%), either alone or in conjunction. Other purposes were Analytic 33 (14.6%), Diagnostic 16 (7.1%), Descriptive 4 (1.8%), and Predictive 1 (0.4%). A total of 6 (2.7%) systematic reviews did not report or did not clearly state the purpose of the instruments. As far as the assessment and conclusions is concerned, only 60 (26.5%) systematic reviews linked the purpose of the instrument to measurement properties. The most usual purpose, Evaluative, was associated to responsiveness, content validity or reliability, to name a few. The assessment of the Impact of Disease on HRQoL was associated to conceptual and measurement model and content validity, the Analytic purpose to preference-based valuation (e.g. utility scores) and agreement, and the Diagnostic purpose to known groups validity and test retest reliability. To better understand these results, some examples are given. When evaluative purpose was associated to responsiveness, we found conclusions such as: “For use in longitudinal studies or clinical practice, where responsiveness is an issue, the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the Chronic Heart Failure Questionnaire (CFHQ) would be adequate”³⁶. When Impact of

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3 Disease on HRQoL purpose was associated to measurement model, conclusions resembled
4 this one, for instance: “None of the RLS specific QOL measures appears to have been
5 informed by a conceptual model or a conceptual framework. Consequently, none can be
6 considered comprehensive in terms of assessing the full impact of Rest Legs Syndrome on
7 QOL”³⁷. Third, an example illustrating general conclusions, i.e. conclusions that did not
8 associate the purpose of the instrument to any specific measurement properties, were as
9 follows: “None of the available instruments fulfils the psychometric demands of reliability,
10 validity and responsiveness to serve as a primary outcome measure in clinical trials”³⁸

Discussion

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23 The present meta-review identified 226 systematic reviews assessing measurement properties
24 of HRQoL instruments in order to analyse the quality of the review process, describe the
25 most used tools to assess measurement properties and examine how reviewers included the
26 assessment of the quality of HRQoL in their conclusions. It has been shown how the quality
27 of the review process has increased over time as well as how reviewers reported the search
28 strategy, stated inclusion and exclusion criteria taking the judgement of two or more
29 independent reviewers into account and used a flow chart to report search outcomes.
30 However, some crucial methodological lacks were also found. Practices such as the
31 registration of the protocol, reporting the detailed search syntax for one database at least,
32 adherence to reporting guidelines, and assessing the reporting and the methodological quality
33 of primary studies were quite sparse even in recent years. As Pussegoda et al.⁴ suggested, this
34 fact may be related to the perceived time-consuming task of using guidelines or to the lack of
35 information about the most appropriate tool. According to our data, there is still large room for
36 improvement in the assessment of the methodological quality of included studies in order to
37 attend to Terwee et al.’s warning² of avoiding the risk of presenting biased results, leading to
38 underestimate or overestimate the quality of an instrument.
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3 Assessment procedures of measurement properties of HRQoL instruments were diverse.

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5 Most of the reviewers used a tool or more than one. Nevertheless, there were reviewers that
6
7 applied their own criteria, followed literature recommendations or applied different *ad hoc*
8
9 devised checklists. It is noticeable the use of such diverse procedures, even in recent years,
10
11 when well accepted tools to assess measurement properties are available.
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15 Our meta-review identified up to twelve tools. Seven of them had an item structure, offering
16
17 a comparable approach to rate the evidence on measurement properties. Length and scoring
18
19 differed, but also the instrument assessment criteria. Actually, depending on the tool used, the
20
21 approach to assess properties varied greatly, with potentially serious consequences. The fact
22
23 that a single measurement property is or isn't required can change the status of quality of the
24
25 evidence supporting the same measurement instrument. The variety of forms found were in
26
27 concordance to results from related research, which also highlighted the complexity with
28
29 regard to definitions of measurement properties⁶. This complexity is also reflected in the
30
31 search filter developed by the COSMIN initiative¹⁴. They recommend using 3 filters that sum
32
33 up more than 100 search terms in order to get sensible and specific results. In addition, and
34
35 also depending on the tool used, other characteristics, such as feasibility, acceptability, and
36
37 burden were assessed. In spite of the dispersion, a shared conclusion can be stated as follows:
38
39 because these instruments are to be used in the daily practice, their usability should be always
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41 balanced with other characteristics considered as proper measurement properties^{39,40}. For
42
43 instance, an instrument needs to be long enough to ensure reliability and construct validity,
44
45 but short enough to ensure the adequate response rate and sample size. Otherwise the
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47 instrument purpose and sustainability will be on hazards³⁹.
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54 The differences between tools and their potentially serious consequences on the assessment
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56 of the quality of the primary studies may be better addressed in the light of three
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58 considerations: the date of publication, the main scientific tradition involved when
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 developing the tools, and the purpose of the instruments under assessment. Some differences
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5 can be simply explained by the date of publication of the tools. As an example, where more
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7 ancient tools require specific forms of validity evidence related to external variables such as
8
9 convergent and discriminant validity, recent tools incorporate the more general view of
10
11 hypothesis testing. That is, when developing a new use for an instrument, hypotheses should
12
13 be made regarding the expected relations with other relevant variables in their nomological
14
15 network and these hypotheses and no other should be tested³². Regarding the scientific
16
17 traditions, the assessment of outcomes is a constitutive part of the disciplines of Education
18
19 and Psychology where the Testing Standards come from. In these contexts, participation is
20
21 taken for granted as assessment practices result in high stakes decisions such as, for instance,
22
23 certification or personnel selection. The main concern regarding integrity of the instrument
24
25 purpose is its fakeability, which could distort the decision-making process, and this would
26
27 explain the interest in response processes in this field^{41,42}. By contrast, the main objective in
28
29 the discipline of Medicine is to provide health care services. Evaluation of subjective views
30
31 of patients was a late addition related to the inclusion of HRQoL in the accounting of health
32
33 care outcomes. As aforementioned, the integrity of the instrument purpose requires that it
34
35 does not interfere with the main objective of both patients and professionals³⁹. Specifically, in
36
37 the context of disability research, the administrative and respondent burden requires
38
39 additional consideration. The administrative burden may include the need for a Sign
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41 Language interpreter, and the respondent burden includes the length of the questionnaire,
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43 which is especially relevant when using HRQoL instruments with cognitively impaired
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45 subjects²⁹. Balancing the traditional psychometric criteria, the practicalities of the instruments
46
47 and patient preferences is a generic recommendation for health research, but becomes on
48
49 special obligation for research with people with specific needs²⁹. Moreover, devising test
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51 accommodations or accessible forms when needed is expected to become a required
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3 psychometric criterion in near future, provided that it has already been included under the
4 title “fairness in testing” as a new section next to validity and reliability in the chapter of
5 measurement foundations in the more recent update of Testing Standards³².
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9
10 The third in the party would be Economic evaluation, traditionally embedded in providing
11 quantitative judgments able to be integrated in mathematical models such as those used in
12 calculating quality-adjusted life years (QALYs) and using preference-based methods to
13 obtain their data. Due to that, some very popular measurement properties such as internal
14 structure based on factor analysis are not relevant and thus not considered in their tools. In
15 this tradition the main concerns regarding the integrity of the instrument purpose is whose
16 values should be considered when determining preferences and how well the preferences of
17 patients and decision makers are likely to conform to the main assumptions of the utility
18 models^{20,21}.
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30 In our view, considering in the first place the third consideration, the purpose of the
31 instrument, would help to reconcile the different requirements. Tools should be adapted or
32 extended in order to test the measurement quality of instruments intended to be used with
33 different purposes, such as evaluative, impact of disease on HRQoL assessment, analytic,
34 diagnostic, descriptive or predictive. Notice that depending on the purpose, some domains of
35 validity and reliability may be of greater or lesser relevance^{6,16}. For instance, an instrument
36 developed to assess longitudinal changes should demonstrate high responsiveness⁶, but when
37 the purpose is diagnostic, the instrument should be able to distinguish among individuals or
38 groups⁶, i.e. known groups validity, or the internal consistency reliability based on inter-item
39 relationships is not relevant for a preference-based instrument but is relevant for an
40 instrument based on a unidimensional measurement model. However, our data showed that
41 only few authors established a clear link in recommendations between the purpose of the
42 measure and the evidence of measurement properties reported. The vast field of HRQoL
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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2
3 offered a plethora of instruments but, as most reviewers did not take the purpose into account,
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5 the overall rating of measurement properties was not consistent and thus the instrument may
6
7 or may not be adequate. Because the evaluation and improvement of quality of life is
8
9 considered a public health priority⁸, we strongly encourage researchers to assess the quality
10
11 of measurement properties of HRQoL instruments according to the purpose of the measure.
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13 Otherwise there is a serious risk of biased results which could lead to underrate the quality
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15 and suitability of the instrument.
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Conclusions

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21 The quality of the systematic review process has been increasing over time, but it should still
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23 improve regarding to the prospective registration of protocol and with respect to the adoption
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25 of guidelines to increase its methodological quality and that of its report. In the specific
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27 context of systematic reviews of measurement instruments, enhancing the quality of the
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29 process also involves the assessment of measurement properties by using a standardized tool.
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31 Selection of the most suitable tool may be addressed according to the coverage of the
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33 appraised measurement properties, but also in the light of other important criteria, that are the
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35 purpose of the HRQoL instruments evaluated, the format of the tool, and if it assesses both
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37 usability (e.g. feasibility or burden) and accommodation (or accessible forms). First, the
38
39 assessment methodology should be adapted when necessary, establishing the relation
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41 between the purpose of the HRQoL instruments and the measurement properties assessed.
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43 Second, to standardize the review process, the tool's format should be item-structured,
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45 offering a comparable approach to rate the evidence on measurement properties. So, those
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47 tools that take the form of guidelines, as the SACMOT or the Economic Evaluation, would be
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49 considerably upgraded if the structure is reconverted, since the current format just allow to
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51 describe rather than to critically appraise the quality of an instrument, as well as difficult the
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53 comparability of results. Third, because systematic reviews on measurement properties aim to
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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2
3 help professionals to select the best instrument for a clinical scenario, the feasibility, patient's
4 preferences, administrator and respondent burden, and the accommodations (or accessible
5 forms) should be addressed and evaluated. Otherwise the suitability and purpose of
6 instruments might be compromised, especially in the context of disability research. Tools
7 identified in our meta-review that meet most of these criteria may be the COSMIN, EMPRO,
8 SCI criteria, Andresen's tool, Can Child Outcomes, and OMERACT, since all of them cover
9 a wide range of measurement properties, offer an item structure, and assess the usability of
10 instruments.

11
12 Special mention is due to the COSMIN, the most widespread and comprehensive tool to
13 assess measurement properties of health instruments designed for an evaluative purpose. As
14 mentioned above, the COSMIN should be adapted if it was generalized to the assessment of
15 health measurement instruments for purposes other than evaluative. In our opinion some
16 improvements concerning the length and structure of the COSMIN are also advisable, as the
17 current format is fairly complex and time-consuming, so requiring high expertise in the field
18 of psychometrics, and lots of resources. In this regard, the recent updated version of the
19 OMERACT, which provides a checklist with four steps to appraise the quality of the
20 measurement properties, might be an example of streamlining the review process and the
21 instrument selection³¹. Assessing the accommodation or accessible forms for specific
22 population as a psychometric criterion, as the Testing Standards recommend under the title
23 "fairness in testing", would be also recommendable. Finally, the feasibility, which the
24 COSMIN merely describes, should be rated, and the burden assessment should be included,
25 with examples found in EMPRO or Andresen's tool.

26
27 The process of systematic review of measurement instruments should also include the
28 appraisal of risk of bias (RoB) of the selected primary studies. It is noteworthy that the last
29 update of the COSMIN has incorporated a guideline to appraise the RoB of primary studies
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 according to the Cochrane methodology for systematic reviews of trial and diagnostic studies.
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5 It must be considered, however, that the RoB evaluation of studies is itself a productive field
6
7 of research with a long tradition, with specific tools that have been developed for different
8
9 research questions and study designs. Examples might be found in the Cochrane
10
11 Collaboration's Tool for Assessing the Risk of Bias of Clinical Trials⁴³, the Newcastle
12
13 Ottawa Scale (NOS)⁴⁴ for nonrandomised studies, or the Quality Assessment Tool for Cohort
14
15 Studies (Q-COH II)^{45,46}. From our point of view, the COSMIN proposal could also be
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17 simplified and improved by guiding the reviewers towards the identification of the most
18
19 appropriate RoB assessment tools instead of developing their own RoB appraisal guidelines,
20
21 taking advantage of knowledge and innovations in that field of research. And last, but not
22
23 least, improving the quality of systematic reviews encompasses researchers, sponsors and
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25 promoters, but also journals, that should require the full compliance with reporting and
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27 methodological guidelines, and the use of assessment tools.
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Patient and Public Involvement

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34 No patient or public involvement
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Ethics and dissemination

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39 Ethical approval is not necessary for meta-reviews
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Data availability statement

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44 Data are available upon reasonable request to the authors.
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46

Authors' contribution

47
48
49 All authors meet the criteria recommended by the International Committee of Medical
50
51 Journal Editors, ICMJE. All authors made substantial contributions to conception and design,
52
53 piloted the inclusion criteria and provided direction of the data extraction and analysis. SL
54
55 draft the article, and JV, CV and JML critically revised the draft for important intellectual
56
57 content. All authors agreed on the final version.
58
59
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Funding statement

This work was supported by the Grant PGC2018-100675-B-I00, Spanish Ministry of Science, Innovation and Universities (Spain).

Competing interests' statement.

The authors declare no conflict of interest. The authors have no financial relationships relevant to this article to disclose, and the funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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Table 1. Quality of review process of systematic reviews

	2008-2019		2014-2019	
	n	%	n	%
Protocol registered prospectively				
• Yes, PROSPERO	18	8.0	17	16.0
• No registered	208	92.0	89	84.0
Standards of systematic review reporting and/or quality assessment				
• Yes (AMSTAR, PRISMA, QUOROM...)	64	28.3	48	45.3
• No	162	71.7	58	54.7
Standards to assess reporting and/or quality assessment of primary				
• Yes (QUADAS, STARD...)	33	14.6	20	18.9
• No	193	85.4	86	81.1
Number of databases searched				
• 1-3	87	38.5	41	38.7
• 4-6	98	43.4	52	49.0
• 7-9	21	9.3	7	6.6
• >=10	17	7.5	5	4.7
• Not reported	3	1.3	1	0.9
Other sources				
• Official websites/Internet	25	11.1	7	3.8
• Virtual libraries	22	9.7	10	9.4
• Google/Google Scholar	20	8.9	9	8.5
• Scientific journals/Thesis	6	2.7	2	1.9
Search strategy				
Terms, databases, time period				
• Yes	218	96.5	103	97.1
• No	8	3.5	3	2.9
Search syntax				
• Detailed syntax reported (Truncations, Booleans...)	99	43.8	62	58.5
• Syntax not reported or not detailed enough to be replicable	122	54.0	43	40.6
• Supplementary file under request (not available)	5	2.2	1	0.9
Inclusion / Exclusion selection criteria				
• Reported and well-defined	209	92.5	102	96.2
• Not reported or not clearly stated	17	7.5	4	3.8
Article selection				
• By 2 or more independent reviewers	117	51.8	70	66.0
• Not reported or not clearly stated	109	48.2	36	34.0
Flow chart				
• Yes	148	65.5	90	84.9
• No	78	34.4	16	15.1
Funding				
• Reported	127	56.2	64	60.4
• Not reported or not clearly stated	99	43.8	42	39.6
TOTAL	226	100	106	100

PROSPERO= Prospective Register of Systematic Reviews; AMSTAR=Assessment of Multiple Systematic reviews; PRISMA= Preferred Reporting Items for Systematic Reviews and Meta-Analyses; QUOROM=Quality of Reporting of Meta-analysis; QUADAS= Quality Assessment of Diagnostic Accuracy Studies; STARD= Standards for the Reporting of Diagnostic Accuracy Studies; n= frequency; %= percentage

TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

Table 2. Tools to assess measurement properties. Characteristics and comparison to Testing Standards

Tools	1)COSMIN	2)TERWEE'S CRITERIA	3)ATTRIBUTES & CRITERIA	4)ECONOMIC EVALUATION	5)GUIDANCE FOR INDUSTRY	6)FITZPATRICK'S CRITERIA	7)ICF ICFCY	8)EMPRO	9)SCI CRITERIA	10)ANDRESEN'S TOOL	11)CANCHILD OUTCOMES	12)OMERACT	13)TESTING STANDARDS
Development	Delphi	Author criteria	Expert panel	Literature	Consensus	Literature		Expert panel	Expert panel Literature	Literature	Expert panel	Expert Panel Delphi	Consensus
Sponsor/s	COSMIN Initiative	Author	SACMOT Working group	Standing Group of Health Technology	FDA Staff	Standing Group of Health Technology	WHO Member States	IRYSS Committee	SCIRE Working group	Author	CanChild Center Staff	OMERACT Initiative	AERA, APA NCME
Approval Updates	2010 2018	2007	1996 2002, 2013	1999 2017	2006 2009	1998	2001 2019 ^a	2008	2008, 2016	2000	1987 ^b 2004	1992 1998,2007,2014, 2019	1954 1966, 1974, 1985, 1999, 2014
Items (scoring)	5-18 items/box (+/-/?)	8-9 items total (+/-/?)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	39 items(strongly agree, agree, disagree, strongly disagree)	3-5 items/box (++++/+++ / ++/+)	11 items total (A, B, C)	2-6 items/box (excellent, adequate, poor)	2-5 items/box (Green, amber, red, white)	Not item structured (no scoring)
Measurement properties	Content Construct (Int.Structure Cross-Cultural Hypotheses test) Criterion (Gold standard)	Content Construct (Hypotheses test) Criterion (Gold standard) Floor/Ceiling	Conceptual & measurement model Face Construct (Hypotheses test) Criterion (Gold standard)	Descriptive (Content Construct) Preference-based valuation Empirical (Criterion)	Conceptual model Content Construct (Hypothesis test, Discriminant, Convergent, Known groups) Criterion (Gold standard, sensitivity) Responsiveness	Purpose Content/Face Construct (Convergent, Discriminant, Int.Structure) Criterion (Predictive) Cut-score precision	Content	Conceptual & measurement model Construct (Hypotheses test) Criterion	Content Criterion (Concurrent Predictive "Discriminant") Clinical utility (Consequential validity) Floor/Ceiling	Conceptual & measurement model Instrument bias Int.Structure Convergent Discriminant	Purpose Scale construction Content Construct (Hypotheses test) Criterion (Gold standard) Responsiveness	Content, Face Construct (Convergent, Divergent) Criterion (Accuracy) Discrimination (Sensitivity over time & over treatment)	Content Response process Int. Structure (Dimensions, DIF) Relations to other variables (Hypotheses test, Convergent, Discriminant, Criterion, Responsiveness) Consequences
Validity													
Reliability	Int. Consistency Measurement error (Test retest, Agreement)	Int.Consistency Reproducibility (Agreement, Relative measurement error)	Int.Consistency Reproducibility (Test retest, inter-rater)	Test retest Inter-rater	Test retest Inter-rater Int.Consistency	Int.Consistency Reproducibility (Test retest)		Int.Consistency Reproducibility (Test retest, Inter-rater)	Int.Consistency Test retest	Int.Consistency Test retest	Int.Consistency Intra/Inter-rater Test retest	Reproducibility Test retest	Int.Consistency Test retest Alternate forms Scorers & Decision consistency/accuracy
Fairness													Equivalence of accommodations
Other characteristics									Norms	Norms, Standard values	Norms Standardization		Scales, norms, Score comparability
	Interpretability	Interpretability	Interpretability		Interpretability	Interpretability		Interpretability					Test development and revision
			Burden		Burden	Acceptability (Burden)		Burden	Burden	Burden			
			Administration Accessible forms		Administration Accessible forms			Administration	Administration Accessible forms	Administration Accessible forms			
			Cultural Adaptations	Practicality		Feasibility Cultural Adaptations		Cultural Adaptations	Applicability Cultural Adaptations	Cultural Adaptations	Clinical utility (Feasibility)	Feasibility	
Frequency of use (%)	49 (21.8)	42 (18.6)	33 (14.6)	17 (7.5)	14 (6.2)	14 (6.2)	7 (3.1)	4 (1.8)	2 (0.9)	2 (0.9)	1(0.4)	1 (0.4)	0

Note: DIF= Differential Item Functioning; %=Percentage; Invariance=Measurement invariance; Int.Structure= Internal Structure; Int. Consistency= Internal Consistency; AERA= American Educational Research Association; APA= American Psychological Association; NCME= National Council on Measurement in Education; SACMOT= Scientific Advisory Committee Medical Outcomes Trust; FDA= Food and Drug Administration; WHO= World Health Organization; IRYSS= Spanish Cooperative Investigation Network for Health and Health Service Outcomes Research; SCIRE= Spinal Cord Injury Rehabilitation Evidence; COSMIN=Consensus Standards for Selection of Health Measurement Instruments; TERWEE'S CRITERIA= Quality Criteria for Measurement Properties; ATTRIBUTES&CRITERIA= Attributes and Criteria to assess Health Status and Quality of Life Instruments; ECONOMIC EVALUATION= Health Status Measures in Economic Evaluation; GUIDANCE FOR INDUSTRY=Guidance for Industry patient-reported outcomes measures; FITZPATRICK'S CRITERIA=Evaluating patient-based outcomes measures for use in clinical trials.; ICF= International Classification of Functioning; ICFCY= International Classification of Functioning for Children and Youth; EMPRO= Evaluating Measures of Patient Reported Outcomes; SCI CRITERIA= Spinal Cord Injury guidelines; ANDRESEN'S TOOL=Criteria for Assessing the Tools of Disability Outcomes Research; CANCHILD OUTCOMES= CanChild Outcomes Measures; OMERACT= Outcomes Measures in Rheumatology Clinical Trials; TESTING STANDARDS= Standards for Educational and Psychological Testing. See text for references.

^aUpdated version at website, ^b Reference at 2004

TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

29

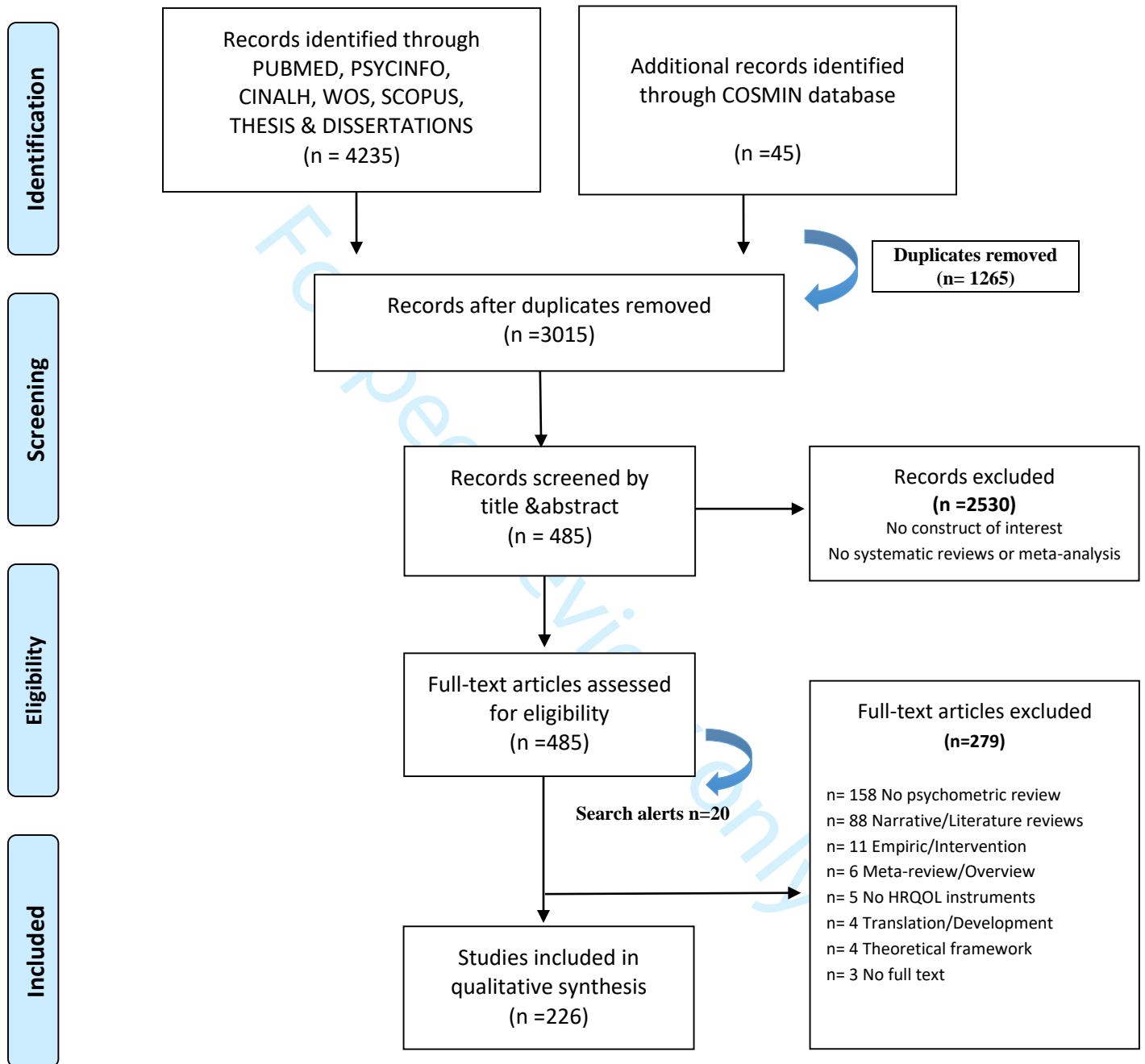
Table 3. Intended purpose of instruments and their association to measurement properties

Purposes of instruments identified across the systematic reviews		Frequency	% (Over 226)
Evaluative (Change scores pre-post studies. Effectiveness of an intervention)		168	74.3
Impact of disease on HROQL (disease symptoms, burden...)		127	56.2
Analytic (Health policies. Cost-effectiveness. Funding)		33	14.6
Diagnostic (Distinguish between groups, levels of severity...)		16	7.1
Descriptive (Health measures in surveys. Needs of groups of people)		4	1.8
Predictive (Anticipation of future health status. Risk factors. Risk profiles)		1	0.4
Purpose no reported or no clearly stated		6	2.7
Conclusions according to the purpose of instruments		n	% (Over 226)
Yes, reviewers made specific conclusions		60	26.5
No, reviewers made general conclusions		166	73.5
Measurement properties associated to the purpose of the instrument		n	% (Over 60)
Evaluative	Responsiveness / Conceptual and Measurement Model / Content validity / Reliability (internal consistency, test retest) / Respondent Burden / Convergent validity / Cross cultural validity	39	65.0
Impact	Conceptual and Measurement Model / Content validity	23	38.3
Analytic	Preference-based valuation / Agreement	10	4.4
Diagnostic	Known groups validity / Test retest	7	3.1

Note: (%) =Percentage



PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>

Supplementary File S1. Search strategy

Search strings for Pubmed

1	("Quality of Life"[Mesh] OR HRQL[tiab] OR HRQoL[tiab] OR QoL[tiab] OR "quality of life"[tiab])
2	(instrument[tiab] OR instruments[tiab] OR questionnaire[tiab] OR questionnaires[tiab] OR scale[tiab] OR scales[tiab] OR tool[tiab] OR tools[tiab])
3	(Validation Studies[pt] OR "reproducibility of results"[MeSH Terms] OR reproducib*[tiab] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tiab] OR clinometr*[tiab] OR "observer variation"[MeSH] OR observer variation[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR valid*[tiab] OR coefficient[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR "item correlation"[tiab] OR "item correlations"[tiab] OR "item selection"[tiab] OR "item selections"[tiab] OR "item reduction"[tiab] OR "item reductions"[tiab] OR agreement[tw] OR precision[tw] OR imprecision[tw] OR "precise values"[tw] OR test-retest [tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR "kappa's"[tiab] OR kappas[tiab] OR "coefficient of variation"[tiab] OR repeatab*[tw] OR ((replicab*[tw] OR repeated[tw]) AND (measure[tw] OR measures[tw] OR findings[tw] OR result[tw] OR results[tw] OR test[tw] OR tests[tw])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR "factor analysis"[tiab] OR "factor analyses"[tiab] OR "factor structure"[tiab] OR "factor structure"[tiab] OR dimensionality[tiab] OR subscale*[tiab] OR "multitrait scaling analysis"[tiab] OR "multitrait scaling analyses"[tiab] OR "item discriminant"[tiab] OR "interscale correlation"[tiab] OR "interscale correlations"[tiab] OR ((error[tiab] OR errors[tiab]) AND (measure*[tiab] OR correlat*[tiab] OR evaluat*[tiab] OR accuracy[tiab] OR accurate[tiab] OR precision[tiab] OR mean[tiab])) OR "individual variability"[tiab] OR "interval variability"[tiab] OR "rate variability"[tiab] OR "variability analysis"[tiab] OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR (limit[tiab] AND detection[tiab]) OR "minimal detectable concentration"[tiab] OR interpretab*[tiab] OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR "meaningful change"[tiab] OR "minimal important change"[tiab] OR "minimal important difference"[tiab] OR "minimally important change"[tiab] OR "minimally important difference"[tiab] OR "minimal detectable change"[tiab] OR "minimal detectable difference"[tiab] OR "minimally detectable change"[tiab] OR "minimally detectable difference"[tiab] OR "minimal real change"[tiab] OR "minimal real difference"[tiab] OR "minimally real change"[tiab] OR "minimally real difference"[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF [tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])
4	#1 AND #2 AND #3
5	("protocol"[ti] OR "addresses"[Publication Type] OR "biography"[Publication Type] OR "case reports"[Publication Type] OR "comment"[Publication Type] OR "directory"[Publication Type] OR "editorial"[Publication Type] OR "festschrift"[Publication Type] OR "interview"[Publication Type] OR "lectures"[Publication Type] OR "legal cases"[Publication Type] OR "legislation"[Publication Type] OR "letter"[Publication Type] OR "news"[Publication Type] OR "newspaper article"[Publication Type] OR "patient education handout"[Publication Type] OR "popular works"[Publication Type] OR "congresses"[Publication Type] OR "consensus development conference"[Publication Type] OR "consensus development conference"[Publication Type] OR "practice guideline"[Publication Type])
6	#4 NOT #5
7	FILTER: Article Type (Review or Systematic Review)
8	FILTER: Subject (Systematic Review)
9	FILTER: Language (English)
10	FILTER: Period (2008-2018)

Search strings for CINAHL

1	TI "quality of life" OR "HRQOL" OR AB "quality of life" OR "HRQOL"
2	TI (instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools) OR AB (instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools)
3	TI ("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence") OR AB ("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR 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4	TI review OR AB review
5	#1 AND #2 AND #3 AND #4
6	TI ("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
7	#5 NOT #6
7	FILTER: Language (English)
8	FILTER: Period (2008-2018)

Search strings for PsycInfo

1	it=Quality of life
2	it=Questionnaires OR it="Rating Scales" OR it=Screening OR it="Screening Tests" OR it="Psychological Assessment" OR it=Inventories OR it="Individual Testing" OR it="Human Factors Measures" OR it="Checklist Testing" OR it=Psychometrics
3	#1 AND #2
4	FILTER: Methodology (Literature Review)
5	FILTER: Language (English)
6	FILTER: Period (2008-2018)

Search strings for Scopus

1	TITLE-ABS-KEY("Quality of life" OR "HRQOL")
2	TITLE-ABS-KEY(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools)
3	TITLE-ABS-KEY("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence")
4	#1 AND #2 AND #3
5	TITLE("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
6	#4 NOT #5
7	FILTER: Document Type (Review)
8	FILTER: Language (English)
9	FILTER: Period (2008-2018)

Search strings for Web of Science (WoS)

1	TI=("Quality of Life" OR "HRQOL")
2	TS=(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools)
3	TS=("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence")
4	#1 AND #2 AND #3
5	TI=("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
6	#4 NOT #5
7	FILTER: Document Type (Literature Review)
8	FILTER: Language (English)
9	FILTER: Period (2008-2018)

Search strings for ProQuest Dissertations & Theses Global

1	ti("Quality of life" OR HRQOL) OR ab("Quality of life" OR HRQOL)
2	ti(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools) OR ab(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools)
3	ti("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR 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4	#1 AND #2 AND #3
5	ti(Systematic Review) OR ab(Systematic Review)
5	#4 AND #5
6	ti("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
7	#5 NOT #6
8	FILTER: Language (English)
9	FILTER: Period (2008-2018)

S2. Characteristics and references of studies.

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
1	2008	Barbosa & Gaviao	Oral health-related quality of life in children: Part III. Is there agreement between parents in rating their children's oral health-related quality of life? A systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
2	2008	Basra et al	The Dermatology Life Quality Index 1994–2007: a comprehensive review of validation data and clinical results	Studies on the quality of one instrument to measures HRQoL in general population	Disease-specific	One instrument	Multiple properties
3	2008	Carabin et al	Quality of life measurement tools for people living with HIV/AIDS.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
4	2008	Chassany et al	Systematic review: health-related quality of life (HRQOL) questionnaires in gastro-oesophageal reflux disease.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
5	2008	El Achhab et al	Disease-specific health-related quality of life instruments among adults diabetic: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
6	2008	Finger et al	Quality of life in age-related macular degeneration: a review of available vision-specific psychometric tools.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
7	2008	Franic & Bothe	Psychometric evaluation of condition-specific instruments used to assess health-related, quality of life, attitudes, and related constructs in stuttering	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
8	2008	Janssens et al	Health-related quality-of-life measures for long-term follow-up in children after major trauma.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
9	2008	Klassen et al	Clinical research in Pediatric plastic surgery and Systematic review of quality of life questionnaires	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
10	2008	Kluivers et al	Systematic review on recovery specific quality of life instruments	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
11	2008	Langham et al	Health-related quality of life instruments in studies of adult men with testosterone deficiency syndrome: a critical assessment.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
12	2008	Pearce et al	Measuring quality of life in cancer survivors: a methodological review of existing scales	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
13	2008	Price et al	Measures of functional status and quality-of-life in schizophrenia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
14	2008	Quittner et al	Systematic review of health-related quality of life measures for children with respiratory conditions.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
15	2008	Reaney et al	Understanding and assessing the impact of alcoholism on quality of life. A systematic review of the content validity of instruments used to assess health related quality of life in alcoholism	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
16	2008	Schalarman et al	The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
17	2008	Solans et al	Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
18	2008	Tschiesner et al	Content comparison of quality of life questionnaires used in head and neck cancer based on the international classification of functioning, disability and health: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
19	2008	Upton et al	Parent-child agreement across child health-related quality of life instruments: a review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
20	2009	Davies N.	Measuring health-related quality of life in cancer patients.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
21	2009	Derret et al	Outcome after injury-a systematic literature search of studies using the EQ-5D	Studies on the quality of one instrument to measures HRQoL in general population	Generic	One instrument	Multiple properties
22	2009	Epton et al	Quality of life in amyotrophic lateral sclerosis/motor neuron disease: a structured review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
23	2009	Fitzsimmons et al	A systematic review of the use and validation of health-related quality of life instruments in older cancer patients.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
24	2009	Garin et al	Disease-specific health-related quality of life questionnaires for heart failure: A systematic review with meta-analyses.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
25	2009	Garvie et al	Quality of life measurement in paediatric and adolescent populations with HIV: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
26	2009	Guo et al	Measuring health-related quality of life in tuberculosis: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
27	2009	Jay et al	A review of quality of life instruments used in liver transplantation.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
28	2009	Speight et al	Not all roads lead to Rome-a review of quality of life measurement in adults with diabetes.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
29	2009	Street et al	Health related quality of life assessment in metastatic disease of the spine: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
30	2009	Waters et al	Quality of life instruments for children and adolescents with neurodisabilities: How to choose the appropriate instrument.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
31	2009	Wettergren et al	The use, feasibility and psychometric properties of an individualised quality-of-life instrument: A systematic review of the SEIQoL-DW.	Studies on the quality of one instrument to measures HRQoL in general population	Generic	One instrument	Multiple properties
32	2010	Albers et al	Evaluation of quality-of-life measures for use in palliative care: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
33	2010	Branski et al	Measuring quality of life in dysphonic patients: a systematic review of content development in patient-reported outcomes measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
34	2010	Bronsard et al	What are the best outcome measures for assessing quality of life in plaque type psoriasis? A systematic review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
35	2010	Carlon et al	A systematic review of the psychometric properties of Quality of life measures for school children with cerebral palsy	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
36	2010	Chen et al	Measuring Quality of Life in Oncologic Breast Surgery: A Systematic Review of Patient-Reported Outcome Measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
37	2010	Forhan et al	A systematic review of the quality of psychometric evidence supporting the use of an obesity-specific quality of life measure for use with persons who have class III obesity: Diagnostic in Obesity and Complications	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
38	2010	Danquah et al	Quality of life measures for patients on hemodialysis: a review of psychometric properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
39	2010	Hill et al	Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
40	2010	Kamalski et al	Measuring disease-specific health-related quality of life to evaluate treatment outcomes in tinnitus patients: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
41	2010	Klassen et al	Quality of life questionnaires for children with cancer and childhood cancer survivors: a review of the development of available measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
42	2010	Kwon et al	Quality of life of women with urinary incontinence: a systematic literature review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
43	2010	Luckett et al	Assessing health-related quality of life in gynecologic oncology: a systematic review of questionnaires and their ability to detect clinically important differences and change.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
44	2010	Palfreyman et al	Assessing current health-related quality of life questionnaires administered to patients with venous ulcers: Can they be used in economic evaluations?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
45	2010	Palfreyman et al	A systematic review of health-related quality of life instruments used for people with venous ulcers: an assessment of their suitability and psychometric properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
46	2010	Passarelli et al	Validity Studies of Quality of Life Instruments for Eating Disorders	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
47	2010	Riordain & McCreary	The use of quality of life measures in oral medicine: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in general population	Both	More than two instruments	Multiple properties
48	2010	Speight & Howarth	Quality of life in restless legs syndrome: A systematic review of clinical trials and a critical review of instruments.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
49	2010	Street et al	Introducing a New Health Related Quality of Life Outcome tool for metastatic disease of the spine	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property

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50	2010	Zeng et al	Quality of life measurement in women with cervical cancer: implications for Chinese cervical cancer survivors	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
51	2011	Carlton & Kaltenthaler	Health-related quality of life measures (HRQoL) in patients with amblyopia and strabismus: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
52	2011	Carlton & Kaltenthaler	Amblyopia and quality of life: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
53	2011	da Silva et al	Quality of life assessment after Acute Coronary Syndrome: Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
54	2011	Eckstein et al	Measuring Quality of Life in Cleft Lip and Palate patients: currently available patient reported outcomes	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
55	2011	Fayed et al	Health status and QOL instruments used in childhood cancer research: deciphering conceptual content using World Health Organization definitions	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
56	2011	Glover et al	Understanding and assessing the impact of End-Stage renal disease on QOL. A systematic review of the content validity...	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
57	2011	Hounsoms et al	EQ-5D as a Quality of Life measure in people with dementia and their carers: evidence and key issues	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
58	2011	Janssen et al	The use of the EQ-5D preference based health status measure in adults with type 2 diabetes mellitus	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
59	2011	Kowal- Bielecka	Analysis of the validation status of WOL and Functional measures in Pulmonary Arterial Hypertension.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	Comparison of two instruments	Multiple properties
60	2011	Lien et al	Comparison of the EORTC QLQ-C15-PAL and the FACIT-Pal for assessment of quality of life in patients with advanced cancer	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	One specific property
61	2011	Luckett et al	Choosing between the EORTC QLQ-C30 and FACT for measuring health related quality of life in cancer clinical research: issues, evidence and recommendations	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
62	2011	Mordiffi et al	Quality of life tools for adult patients with cancer undergoing chemotherapy: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
63	2011	Noyes et al	EQ-5D for the Assessment of Health-Related Quality of Life and Resource Allocation in Children: A Systematic Methodological Review	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
64	2011	Papaioannou et al	How valid and responsive are generic health status measures, such as EQ-5D and SF-36, in schizophrenia? A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
65	2011	Reavey et al	Measuring quality of life and patient satisfaction after body contouring: a systematic review of patient-reported outcome measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
66	2011	Schiarti et al	Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning Quality of life in people with venous leg ulcers: an integrative review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
67	2011	Tayyem et al	Analysis of Health-Related quality of life instruments measuring the impact of bariatric surgery: systematic review of instruments and their content validity	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
68	2011	Virginia et al	Quality of life in people with venous leg ulcers: an integrative review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
69	2011	Whitehurst et al	Systematic review and empirical comparison of contemporaneous EQ-5D and SF-6D group mean scores	Studies on the quality of a selection of instruments to measure HRQoL in general population	Generic	Comparison of two instruments	One specific property
70	2011	Wilson et al	Spinal cord injury and quality of life: a systematic review of outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
71	2012	Bhatt et al	Health outcome measures for diabetes mellitus: a review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
72	2012	Chopra & Kamal	A systematic review of quality of life instruments in long-term breast cancer survivors.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
73	2012	Cormier et al	Health related quality of life in patients with melanoma. Overview of instruments and outcomes	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
74	2012	Correia & De Carlo	Evaluation of quality of life in a palliative care context: an integrative literature review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
75	2012	Gräske et al	Dementia-Specific Quality of Life Instruments and Their Appropriateness in Shared-Housing Arrangements--A Literature Study.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
76	2012	Ho et al	Measuring Quality of life and patient satisfaction in facial paralysis patients: a systematic review of patient reported outcome measures	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
77	2012	Hogg et al	Measures of health related quality of life in diabetes-related foot disease: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
78	2012	Luquiens et al	Quality of life among alcohol-dependent patients: how satisfactory are the available instruments? A systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
79	2012	Madureira et al	Quality of life measurements in patients with osteoporosis and fractures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
80	2012	Milne et al	Measuring Health-Related Quality of Life for Patients with Diabetic Retinopathy	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
81	2012	Ojo et al	A Systematic Review of Head and Neck Cancer Quality of Life Assessment Instruments	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
82	2012	Popovic et al	Comparison of the EORTC QLQ-BM22 and the FACT-BP for assessment of quality of life in cancer patients with bone metastases	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
83	2012	Quintanilla et al	Comparison of disease-specific quality of life instruments in the assessment of chronic rhinosinusitis	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
84	2012	Rajmil et al	Health-related quality of life measurement in children and adolescents in Ibero-American countries, 2000 to 2010.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
85	2012	Shin & Shin	Measurement of quality of life in menopausal women: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
86	2012	Smith et al	Measuring health-related quality of life in diabetic peripheral neuropathy: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
87	2012	Tosh et al	A review of generic preference-based measures of health-related quality of life in visual disorders.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
88	2012	Townsend-White et al	Review: a systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
89	2012	Walker et al	Are they worth it? A systematic review of QOL instruments for use with mentally disordered offenders	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
90	2012	Whitehurst et al	A review of preference-based health-related quality of life questionnaires in spinal cord injury research.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
91	2012	Yip et al	Reliability, validity and feasibility of quality of life instruments for adult patients with cancer undergoing chemotherapy: Result from a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
92	2013	Al Sayah et al	Health related quality of life measures in Arabic speaking populations: A systematic review on cross-cultural adaptation and measurement properties	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
93	2013	Basra et al	Infants' Dermatitis Quality of Life Index: a decade of experience of validation and clinical application.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
94	2013	Castelino et al	Comparison of the psychometric properties of health-related quality of life measures used in adults with systemic lupus erythematosus: a review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
95	2013	Chandratne et al	Health-related quality of life in gout: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
96	2013	Chow et al	Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
97	2013	Davis et al	A review of the psychometric performance of the EQ-5D in people with urinary incontinence.	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
98	2013	de Almeida et al	Quality of life instruments for skull base pathology: Systematic review and methodologic appraisal	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
99	2013	Djan et al	A systematic review of questionnaires to measure the impact of appearance on quality of life for head and neck cancer patients.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

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100	2013	Gakhar et al	Health-related quality of life assessment after antiretroviral therapy: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
101	2013	Hitzig et al	Identifying and classifying quality-of-life tools for assessing pressure ulcers after spinal cord injury.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
102	2013	Jabir et al	Assessing Improvement in Quality of Life and Patient Satisfaction following Body Contouring Surgery in Patients with Massive Weight Loss: A Critical Review of Outcome Measures Employed.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
103	2013	Lee et al	A systematic review of patient-reported outcome instruments of nonmelanoma skin cancer in the dermatologic population	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
104	2013	Levterova et al	Instruments for disease-specific quality-of-life measurement in patients with type 2 diabetes mellitus--a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
105	2013	Li et al	Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
106	2013	Lin et al	Evaluation of content on EQ-5D as compared to disease-specific utility measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
107	2013	Mitera et al	Quality of life measures used in radiation therapy trials for patients with metastatic spinal cord compression (MSCC)	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
108	2013	Mogos et al	A Systematic Review of Quality of Life Measures in Pregnant and Postpartum Mothers.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
109	2013	Mousavi et al	Assessment of Questionnaires Measuring Quality of Life in Infertile Couples: A Systematic Review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
110	2013	Moyle et al	Health-related quality of life in older people with severe dementia: challenges for measurement and management	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
111	2013	Muzzatti et al	Assessing quality of life in long-term cancer survivors: a review of available tools.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
112	2013	Paltzer et al	Measuring the health-related quality of life (HRQoL) of young children in resource-limited settings: a review of existing measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
113	2013	Perales et al	Health-related quality-of-life instruments for Alzheimer's disease and mixed dementia.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
114	2013	Pusic et al	Quality of life among breast cancer patients with lymphedema: A systematic review of patient-reported outcome instruments and outcomes.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
115	2013	Roncada et al	Specific instruments to assess quality of life in children and adolescents with asthma.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
116	2013	Salek et al	Clinical experience and psychometric properties of the Children's Dermatology Life Quality Index (CDLQI), 1995-2012	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
117	2013	Testart et al	Quality of life and other outcome measures in caregivers of patients with schizophrenia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
118	2013	Weldam et al	Evaluation of Quality of Life instruments for use in COPD care and research: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
119	2013	Wheelright et al	A systematic review of health-related quality of life instruments in patients with cancer cachexia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
120	2013	Yang et al	An assessment of validity and responsiveness of generic measures of health-related quality of life in hearing impairment.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
121	2014	Anthony et al	Considering quality of life for children with cancer: a systematic review of patient-reported outcome measures and the development of a conceptual model	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
122	2014	Aspden et al	Quality-of-life measures for use within care homes: a systematic review of their measurement properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
123	2014	Balioussis et al	Identifying and classifying quality of life tools for assessing spasticity after spinal cord injury.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
124	2014	Brazier et al	A systematic review, psychometric analysis and qualitative assessment of generic preference-based measures of health in mental health populations and the estimation of mapping functions from widely used specific measures	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
125	2014	Chiu et al	Comparison of three shortened questionnaires for assessment of quality of life in advanced cancer.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
126	2014	Chow et al	Comparison of the EORTC QLQ-BN20 and the FACT-Br quality of life questionnaires for patients with primary brain cancers: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
127	2014	Garin et al	Assessing health-related quality of life in patients with heart failure: a systematic, standardized comparison of available measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
128	2014	Gilchrist et al	Assessment of the quality of measures of child oral health-related quality of life.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
129	2014	Grubbs et al	A review of quality of life measures in dry eye questionnaires.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
130	2014	Gupta et al	The COPD assessment test: a systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
131	2014	Hawkins et al	A Systematic Review of Functional and Quality of Life Assessment after Major Lower Extremity Amputation	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
132	2014	Hewison et al	An evaluative review of questionnaires recommended for the assessment of quality of life and symptom severity in women with urinary incontinence.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
133	2014	Ikeda et al	Assessment of quality of life in children and youth with autism spectrum disorder: a critical review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
134	2014	Jardine et al	Self-reported quality of life of young children with conditions from early infancy: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
135	2014	Kuspinar et al	A review of the psychometric properties of generic utility measures in multiple sclerosis.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
136	2014	Lee et al	Measurement properties of rheumatoid arthritis-specific quality-of-life questionnaires: Systematic review of the literature.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
137	2014	Lieu et al	Pediatric quality of life in children with otolaryngologic disease: what inventories are available and what is still needed?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
138	2014	Longworth et al	Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
139	2014	Makai et al	Quality of life instruments for economic evaluations in health and social care for older people: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
140	2014	Niu et al	Health-related quality of life in women with breast cancer: a literature-based review of psychometric properties of breast cancer-specific measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
141	2014	Salvilla et al	Disease-specific health-related quality of life instruments for IgE-mediated food allergy	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
142	2014	Schmidt et al	Assessing quality of life in patients with prostate cancer: a systematic and standardized comparison of available instruments.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
143	2014	Smith et al	Most domains of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30 are reliable.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	One specific property
144	2014	Souza et al	Tools used for evaluation of Brazilian children's quality of life	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
145	2014	Swigris et al	The psychometric properties of the St George's Respiratory Questionnaire (SGRQ) in patients with idiopathic pulmonary fibrosis: a literature review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
146	2014	Timmerman et al	Psychometric characteristics of health-related quality-of-life questionnaires in oropharyngeal dysphagia.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
147	2014	Treanor & Donnelly	A methodological review of the Short Form Health Survey 36 (SF-36) and its derivatives among breast cancer survivors	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
148	2014	Watt et al	Assessing health-related quality of life in patients with benign non-toxic goitre	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
149	2014	Wolpe et al	Assessing the impact of urinary incontinence on quality of life: systematic review of instruments in Portuguese.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
150	2015	Alrubaiy et al	Systematic review of health-related quality of life measures for inflammatory bowel disease	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
151	2015	Aspesberro et al	Health-related quality of life following pediatric critical illness.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
152	2015	Bédard et al	Systematic review of vision-related quality of life questionnaires for older institutionalised seniors with dementia	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
153	2015	Bowling et al	Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
154	2015	Conijn et al	Assessing the quality of available patient reported outcome measures for intermittent claudication: a systematic review using the COSMIN checklist.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
155	2015	de Climens et al	Review of patient-reported outcome instruments measuring health-related quality of life and satisfaction in patients with type 2 diabetes treated with oral therapy.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
156	2015	Dronavalli & Thompson	A systematic review of measurement tools of health and well-being for evaluating community-based interventions.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
157	2015	Hamoen et al	Measuring health-related quality of life in men with prostate cancer: A systematic review of the most used questionnaires and their validity.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
158	2015	Hu et al	How Quality of Life as Patient-Reported Outcome Has Been Studied for Rheumatoid Arthritis in Chinese-Speaking Population	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
159	2015	Janssens et al	Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
160	2015	Launois et al	Health-related quality-of-life scales specific for chronic venous disorders of the lower limbs.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
161	2015	Monticone et al	Measurement properties of translated versions of the Scoliosis Research Society-22 Patient Questionnaire, SRS-22: A systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
162	2015	Nguyen et al	EORTC QLQ-BR23 and FACT-B for the assessment of quality of life in patients with breast cancer: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
163	2015	Oliveira et al	Evaluation of cross-cultural adaptation and measurement properties of breast cancer-specific quality-of-life questionnaires: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
164	2015	Polinder et al	Health-related quality of life after TBI: a systematic review of study design, instruments, measurement properties, and outcome.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
165	2015	Taghavi et al	Health-related quality of life in polycystic ovary syndrome patients: A systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
166	2015	Wong et al	Systematic review recommends the European Organization for Research and Treatment of Cancer colorectal cancer-specific module for measuring quality of life in colorectal cancer patients	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
167	2016	Algar et al	Measuring the quality of life and well-being of people with dementia: A review of observational measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
168	2016	Bryant et al	A Systematic Review of Psychometric Properties of Health-Related Quality-of-Life and Symptom Instruments in Adult Acute Leukemia Survivors.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
169	2016	Coombes et al	Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
170	2016	Dichter et al	Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements-a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
171	2016	Ganesh et al	Comparison of the FACT-C, EORTC QLQ-CR38, and QLQ-CR29 quality of life questionnaires for patients with colorectal cancer: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
172	2016	Gutiérrez-Vargas et al	Instruments to measure the quality of life in patients with oral mucositis undergoing oncological treatment: a systematic review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
173	2016	Hand et al	Measuring health-related quality of life in adults with chronic conditions in primary care settings: Critical review of concepts and 3 tools	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
174	2016	Heinl et al	Measurement properties of adult quality of life measurement instruments for eczema: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
175	2016	Kotecha et al	Patient-Reported Outcomes for Quality of Life Assessment in Atrial Fibrillation: A Systematic Review of Measurement Properties.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
176	2016	Lee et al	A systematic review of measurement properties of the instruments measuring health-related quality of life in patients with irritable bowel syndrome.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
177	2016	Maratia et al	Assessing health-related quality of life in patients with breast cancer: a systematic and standardized comparison of available instruments using the EMPRO tool.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
178	2016	Mestre et al	Rating scales for behavioral symptoms in Huntington's disease: Critique and recommendations.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
179	2016	Spinou et al	The validity of health-related quality of life questionnaires in bronchiectasis: a systematic review and meta-analysis	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
180	2016	Tapia et al	Health-Related Quality-of-Life Instruments for Pediatric Patients with Diverse Facial Deformities: A Systematic Literature Review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
181	2016	Wong et al	A systematic review of quality of thyroid-specific health related quality of life instruments recommends ThyPRO for patients with benign thyroid diseases	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
182	2016	Woo et al	Comparison of the EORTC STO-22 and the FACT-Ga quality of life questionnaires for patients with gastric cancer.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	Comparison of two instruments	Multiple properties
183	2017	Ahmadi et al	Acceptability, reliability, and validity of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) across languages: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
184	2017	Baghdadli et al	Measurement properties of screening and diagnostic tools for autism spectrum adults of mean normal intelligence: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
185	2017	Best et al	Identifying and classifying quality of life tools for neurogenic bladder function after spinal cord injury: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
186	2017	Chen et al	Inflammatory bowel disease-specific health-related quality of life instruments: a systematic review of measurement properties.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
187	2017	Frew et al	Disease-specific health related quality of life patient reported outcome measures in Genodermatoses: a systematic review and critical evaluation.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
188	2017	Heaney et al	A review of the psychometric properties and use of the Rheumatoid Arthritis Quality of Life Questionnaire (RaQoL) in clinical research	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
189	2017	Heinl et al	Measurement properties of quality-of-life measurement instruments for infants, children and adolescents with eczema: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
190	2017	Kandel et al	Patient-reported Outcomes for Assessment of Quality of Life in Refractive Error: A Systematic Review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
191	2017	Kao et al	Scoping Review of Pediatric Tonsillectomy Quality of Life Assessment Instruments	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
192	2017	Khan et al	Health Status and Quality of Life in Tuberculosis: Systematic Review of Study Design, Instruments, Measuring Properties and Outcomes.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
193	2017	Kwan et al	A systematic review of quality-of-life domains and items relevant to patients with spondyloarthritis	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
194	2017	Limpberg et al	Health-related quality of life questionnaires in individuals with haemophilia: a systematic review of their measurement properties	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
195	2017	Lucendo et al	Systematic review: health-related quality of life in children and adults with eosinophilic oesophagitis-instruments for measurement and determinant factors. Systematic review: health-related quality of life in children and adults with eosinophilic oesophagitis-instruments for measurement and determinant factors.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
196	2017	Page et al	Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
197	2017	Poku et al	Systematic review assessing the measurement properties of patient-reported outcomes for venous leg ulcers.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
198	2017	Roydhouse et al	Systematic review of caregiver responses for patient health-related quality of life in adult cancer care.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
199	2017	Strada et al	Measuring quality of life in opioid-dependent people: a systematic review of assessment instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
200	2017	Sullivan et al	Assessing quality of life of patients with hypospadias: A systematic review of validated patient-reported outcome instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
201	2017	Tang et al	Assessing quality of life in diabetes: II - Deconstructing measures into a simple framework.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
202	2017	Tax et al	Measuring health-related quality of life in cervical cancer patients: a systematic review of the most used questionnaires and their validity.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
203	2017	Xin & McIntosh	Assessment of the construct validity and responsiveness of preference-based quality of life measures in people with Parkinson's: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
204	2018	Aber et al	Themes that Determine Quality of Life in Patients with Peripheral Arterial Disease: A Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
205	2018	Chiarotto et al	Evidence on the measurement properties of health-related quality of life instruments is largely missing in patients with low back pain, a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
206	2018	Cornelissen et al	Quality of Life Questionnaires in Breast Cancer-Related Lymphedema Patients: Review of the Literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
207	2018	de Vries et al	Recommendations on the most suitable quality-of-life measurement instruments for bariatric and body contouring surgery: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
208	2018	Dow et al	How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
209	2018	Grobet et al	Application and measurement properties of EQ-5D to measure quality of life in patients with upper extremity orthopaedic disorders: a systematic literature review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
210	2018	Haywood et al	Assessing health-related quality of life (HRQoL) in survivors of out-of-hospital cardiac arrest: A systematic review of patient-reported outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
211	2018	Luan et al	A Review of Studies of Quality of Life for Chinese-Speaking Patients with Ischemic Heart Disease	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
212	2018	Mason et al	Evaluating patient-reported outcome measures (PROMs) for bladder cancer: a systematic review using the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN)	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
213	2018	Mohammed et al	Pharmaceutical care and health related quality of life outcomes over the past 25 years: Have we measured dimensions that really matter?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
214	2018	Mpundu-Kaambwa et al	A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
215	2018	Pollo et al	Evaluation Instruments for Quality of Life Related to Melasma: An Integrative Review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
216	2018	Tian & Cao	Systematic review of the psychometric properties of disease-specific, quality-of-life questionnaires for patients with hepatobiliary or pancreatic cancers	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
217	2018	van Ierssel et al	Identifying the concepts contained within health-related quality of life outcome measures in concussion research using the International Classification of Functioning, Disability, and Health as a reference: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
218	2018	van Roij et al	Measuring health-related quality of life in patients with advanced cancer: a systematic review of self-administered measurement instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
219	2018	Yarlas et al	Psychometric validation of the SF-36@Health Survey in ulcerative colitis: results from a systematic literature review	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
220	2018	Yazdani et al	Psychometric Properties of Quality of Life Assessment Tools in Morbid Obesity: A Review of Literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
221	2018	Zaror et al	Assessing oral health-related quality of life in children and adolescents : a systematic review and standardized comparison of available instruments	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
222	2018	Hettiarachchi et al	Pediatric Quality of Life Instruments in Oral Health Research: A Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
223	2019	Hughes et al	Psychometric properties and feasibility of use of dementia specific quality of life instruments for use in care settings: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
224	2019	Speyer et al	"Measurement properties of self-report questionnaires on health related quality of life and functional health status in dysphonia: a systematic review using the COSMIN taxonomy"	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
225	2019	van der Hout et al	Measuring health-related quality of life in colorectal cancer patients: systematic review of measurement properties of the EORTC QLQ-CR29	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
226	2019	Vasconcelos et al	Quality of Life in Women with Defecatory Dysfunctions: Systematic Review of Questionnaires Validated in the Portuguese Language	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

Note: The concept "Both" is referred to generic and disease-specific instruments.

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Supplementary File S3. Tools to assess measurement properties.

¹Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) (2010, 2018)

1. Reliability	The degree to which an instrument is free from random error.
1.1. Internal consistency	The degree of the interrelatedness among the items. <i>In COSMIN (2018) internal consistency is derived from internal structure evaluation.</i>
1.2. Reliability	Scores for patients who have not changed are the same for repeated measurement under several conditions
1.3. Measurement error	The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
2. Validity	The degree to which a Health Related-Patient Reported Outcome (HR-PRO) instrument measures the construct(s) it purports to measure. <i>Concept with major changes in COSMIN (2018) the definition and classification changed to content, structural, cross-cultural validity/measurement invariance, criterion, and hypothesis testing for construct validity (convergent, discriminative or known groups)</i>
2.1. Content (including Face validity)	The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured (or looks as though the items are an adequate reflection)
2.2. Construct (Structural, Hypothesis, Cross-cultural)	The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured. Scores of an HR-PRO instrument are consistent with hypotheses. Performance of the items on a translated or culturally adapted HR-PRO instrument is an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
2.3. Criterion	The degree to which the scores of an HR-PRO instrument are an adequate reflection of a "gold standard"
3. Responsiveness	The instrument's ability to detect change over time in the construct to be measured
4. Interpretability	The degree to which one can assign easily understood meaning to an instrument's quantitative scores. <i>A complementary attribute, not a measurement property in COSMIN (2018), plus feasibility</i>

²Quality Criteria for Measurement Properties (Terwee et al. 2007)

1. Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire
2. Internal consistency	The extent to which items in a (sub)scale are inter correlated, thus measuring the same construct
3. Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard
4. Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured
5. Reproducibility	
5.1. Agreement	The extent which the scores on repeated measures are close to each other (absolute measurement error)
5.2. Reliability	The extent to which patients can be distinguish from each other (relative measurement error)
6. Responsiveness	The ability of a questionnaire to detect clinically important changes over time
7. Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score
8. Interpretability	The degree to which one can assign qualitative meaning to quantitative scores

³Attributes and Criteria to assess Health Status and Quality of Life Instruments (1996, 2002)

1. Conceptual and measurement model	The rationale for a description of the concepts and the populations that a measure is intended to assess and the expected relationship between these concepts
2. Reliability	The degree to which an instrument is free from random error
2.1. Internal consistency	The precision of a scale, homogeneity (inter correlations) of items at one point in time
2.2. Reproducibility	Stability of an instrument over time (test-retest) and inter-rater agreement
3. Validity	The degree to which the instrument measures what it purports to measure.
3.1. Content validity	The domain of an instrument is appropriate relative to its intended use
3.2. Construct-related validity	Interpretation of scores based on theoretical implications associated with the construct to be measured
3.3. Criterion-related validity	The extent to which scores of the instrument are related to a criterion measure (gold standard).
4. Responsiveness	The instrument's ability to detect change overtime
5. Interpretability	The degree to which one can assign easily understood meaning to an instrument's quantitative scores
6. Respondent and administrative burden	The time, effort, and other demands placed on those to whom the instrument is administered (respondent burden) or on those who administer the instrument (administrative burden)
7. Administration/Accessible forms	Data collection method, including self-report, interviewer-administered, trained observer rating, computer-assisted interviewer-administered, performance-based measures. Accommodations (e.g. Braille)
8. Cultural and language adaptations	Assessment of conceptual and linguistic equivalence.

¹Prinsen C, Mokkink L, Bouter L, et al. COSMIN guideline for systematic reviews of Patient-Reported Outcome Measures. *Qual Life Res.* 2018;0(0):1-11. doi:10.1007/s11136-018-1798-3. Mokkink L, Terwee C, Patrick D, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol.* 2010;63(7):737-745. doi:10.1016/j.jclinepi.2010.02.006. ²Terwee C, Bot S, de Boer M, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol.* 2007;60(1):34-42. doi:10.1016/j.jclinepi.2006.03.012. ³Lohr KN, Aaronson NK, Alonso J, Burnam MA, Patrick DL, Perrin EB, et al. Evaluating quality-of-life and health status instruments: Development of scientific review criteria. *Clin Ther.* 1996;18(5):979-92. Aaronson N, Alonso J, Burnam A, et al. Assessing health status and quality-of-life instruments and review criteria. *Qual Life Res.* 2002;11(3):193-215.

Supplementary File S3. Continue

⁴Health Status Measures in Economic Evaluation (1999, 2017)

1.	Practicality	Time to complete the instrument. Response rate. Rate of completion
2.	Reliability	The degree to which an instrument is free from random error
2.1.	Test-retest	Ability to reproduce results over repeated measurements with the minimum amount of random error
2.2.	Inter-rater	Reliability between places of administration
3.	Validity	Dimensions covered. Items relevant for population. Ability of an instrument to reflect known or expected differences and changes in health to reflect preferences.
3.1.	Descriptive validity (Content, Face, Construct)	
3.2.	Valuation	Values used. Main assumptions of the model and how well the preferences of the patients and decision makers are likely to conform to these assumptions.
3.3.	Empirical	Evidence regarding whether or not a measure could generate values which reflect people's preferences using revealed preferences; stated preferences or hypothetical preferences as criteria

⁵Guidance for Industry patient-reported outcomes measures (2006, 2009)

1.	Conceptual model	Conceptual framework.
2.	Administration/Accessible forms	Data collection method, including self-report or interviewer, format and scoring. Adaptations for children and adolescents, patients cognitively impaired, or unable to communicate, culture and language subgroups
3.	Respondent/Administrator Burden	Length, formatting, font size, instructions for items, privacy, time, need for physical support in responding.
4.	Reliability	
4.1.	Test retest	Stability of scores over time when no change has occurred in the concept of interest
4.2.	Internal consistency	Whether the items in a domain are inter correlated, as evidenced by an internal consistency statistic
4.3.	Inter interviewer reproducibility	Agreement between responses when the PRO is administered by two or more different interviewers
5.	Validity	
5.1.	Content validity	Whether items and response options are relevant and are comprehensive measures of the domain or concept
5.2.	Construct validity (Hypotheses testing, including discriminant, convergent, known groups validity)	Ability to measure the concept. Whether relationships among items, domains, and concepts conform to what is predicted by the conceptual framework for the PRO instrument itself and its validation hypotheses
6.	Criterion	Scores of a PRO instrument are related to a known gold standard. When the gold standard is not possible to be evaluated, criterion measure assesses sensitivity specificity, and predictive values
7.	Responsiveness. Ability to detect change	Evidence that the instrument is equally sensitive to gains and losses in the measurement concept and to change at all points within the entire range expected for the clinical trial population

⁶Evaluating patient-based outcomes measures for use in clinical trials (1998) (Fitzpatrick's criteria)

1.	Reliability	The extent to which the instrument is free from random error and may be considered as the amount of a score that is a signal rather than noise
1.1.	Internal consistency	The extent to which individual items in a questionnaire scale measure the same construct (homogeneity of items in the scale)
1.2.	Reproducibility (test retest)	Whether and instrument yields the same results on repeated applications, when respondents have not changed on the domain being measured. Stability of the questionnaire over time
2.	Validity	The extent to which it measures what it purports to measure
2.1.	Criterion and Predictive validity	When a new measure correlates with other measures generally accepted as a more accurate variable. When the new measure correlates with future values of the criterion variable
2.2.	Face and content validity	Face validity refers to what an item appears to measure based on its manifest content. Content validity refers to how well a measurement battery covers important parts of the health components to be measured
2.3.	Construct validity	A health status measure is intended to assess a postulated underlying construct.
2.3.1.	Convergent validity	Correlations are expected to be strongest with the most related constructs
2.3.2.	Discriminant validity	Correlations are expected to be weakest with most distally related constructs
2.3.3.	Internal structure	A set of assumed relationships between underlying constructs
2.3.4.	Validity for specific purposes	Measures need to be assessed for health status, personal preferences and utilities, and social values.
3.	Responsiveness (sensitivity to change)	Ability to detect changes over time. Effect size, sensitivity and specificity of scores.
4.	Precision	How precise are the distinctions between levels of health and illness (sensitivity). Format categories.
5.	Interpretability	How meaningful are the scores from an instrument
6.	Acceptability	Evidence of acceptability is associated with high response rates. Respondent burden.
7.	Cultural applicability	Rigorous translation can by itself establish the appropriateness of an instrument
8.	Feasibility	Impact of different patient-based outcome measures upon staff and researchers. Administrator burden.

⁷International Classification of Functioning (ICF) & International Classification of Functioning for Children and Youth (ICFCY) (2019)

1.	Content validity	Health and Health-related domains.
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⁴ Brazier J, Deverill M, Green C, Harper R, Booth A. A review of the use of health status measures in economic evaluation. *Health Technol Assess (Rockv)*. 1999;3(9). Brazier J, Ara R, Rowen D, Chevrou-Severac H. A Review of Generic Preference-Based Measures for Use in Cost-Effectiveness Models. *Pharmacoeconomics*. 2017;35(s1):21-31. doi:10.1007/s40273-017-0545-x. ⁵Department of Health and Human Services. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims; draft guidance. *Health Qual Life Outcomes*. 2006;20:1-20. doi:10.1186/1477-7525-4-79. Department of Health and Human Services. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.; 2009. doi:10.1111/j.1524-4733.2009.00609.x. ⁶Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating Patient-Based Outcome Measures for Use in Clinical Trials. Vol 2.; 1998. doi:9812244. ⁷World Health Organization. International Classification of Functioning (ICF). www.who.int/classifications/icf/en/.

Supplementary File S3. Continue

⁸Evaluating Measures of Patient Reported Outcomes (EMPRO) (2008)

1	1.	Conceptual and Measurement model	The rationale for description of the concept and the populations that a measure is intended to assess and the relationship between these concepts
2	2.	Reliability	The degree to which an instrument is free from random error
3	2.1.	Internal consistency	The precision of a scale, based on the homogeneity of the scale's items at one point in time
4	2.2.	Reproducibility	The stability of an instrument over time (test retest) and inter-rater agreement at one point in time
5	3.	Validity (including content, criterion, hypotheses testing and construct)	The degree to which the instrument measures what it purports to measure
6	4.	Responsiveness	The ability to detect change over time
7	5.	Interpretability	The degree to which one can assign meaning to an instrument's quantitative scores
8	6.	Burden (Respondent/Administrator burden)	Time, effort and other demands placed on the administration of the instrument
9	7.	Administration mode	Data collection method. For each mode of administration, the information about validity, reliability, responsiveness, interpretability and burden should be assessed.
10	8.	Cultural and language adaptations	Methods to achieve linguistic equivalence are adequately described and appropriate. Differences from the original are adequately described and appropriate.

⁹Spinal Cord Injury Criteria (2008, 2016)

11	1.	Content	Description. Items. Scale development. Internal structure or subscales
12	2.	Administration/Accessible forms	Data collection method. Items, time, training, burden of administering. Disability adaptation (e.g. Braille)
13	3.	Reliability (test retest, internal consistency)	Degree to which an instrument is consistent or free from random error
14	4.	Criterion oriented validity (concurrent, predictive, discriminant, and clinical validity)	Scale predicts other measures of the same construct. Gold standard and/or sensitivity and specificity. Scale distinguish between scores and/ or groups. Clinical utility, also called prescriptive and consequential validity
15	5.	Responsiveness, sensitivity to change	Evidence of change in expected direction using methods such as standardized effect sizes
16	6.	Floor and ceiling effects	Floor and ceiling issues can determine whether change is detected or obscured by the measure
17	7.	Population application (Applicability in SCI groups, languages, norms)	Description of use in people with spinal cord injury (vs other people). Information of norms are available. Available in other languages

¹⁰Criteria for Assessing the Tools of Disability Outcomes Research (2000) (Andresen's Tool)

18	1.	Conceptual model	Relevant domains are completely covered
19	2.	Norms, standard values	Published data (or public-domain data) are available for both general population and with disabilities
20	3.	Measurement model	Tool captures the detail and breadth of real differences among persons, includes floor/ceiling effects
21	4.	Instrument bias	In practical or statistical terms, individual questions (or scores) are biased for the population
22	5.	Respondent burden	Length and content are acceptable to the intended subjects
23	6.	Administrative burden	Ease to administer, score and interpret
24	7.	Reliability (test retest and internal consistency)	Instrument gives a consistent answer
25	8.	Validity (discriminant, convergent, structure)	The tool measures what it purports to measure. It distinguish among different levels of mobility
26	9.	Responsiveness	Instrument is sensitive to changes in interventions
27	10.	Administration/Accessible forms	Data collection method, as interviews, self-administration, computer surveys. Adaptations (e.g. Braille)
28	11.	Culture/language adaptations	Tested versions of the tool for subgroups (including ethnicity, gender, disability)

¹¹CanChild Outcomes Measures (2004)

29	1.	Focus. Purpose	Focus of measurement (using the International Classification of Functioning Framework, ICF). Rating attributes measured. List the primary purpose for which the scales have been designed (discriminative, predictive, evaluative, etc.). Describe population. Evaluation of the context
30	2.	Clinical utility	Clarity of instructions, format, time to complete the assessment, administration, scoring and interpretation. Specify whether formal training is required. Cost of the manual and score sheets.
31	3.	Scale construction	Item selection, weighting, level of measurement
32	4.	Standardization	Manual (published, specific procedures for administration, scoring) Norms.
33	5.	Reliability	
34	5.1.	Internal consistency	The degree of homogeneity of test items to the attribute being measured. Measured at one point in time
35	5.2.	Intra/Inter observer	Measures variation within an observer; measures variation between two or more observers
36	5.3.	Test retest	Measures variation in the test over a period of time
37	6.	Validity	
38	6.1.	Content	The instrument is comprehensive and fully represents the domain of the characteristics it claims to measure
39	6.2.	Construct	Measurements of the attribute conform to prior theoretical relationships among characteristics or individuals
40	6.3.	Criterion	Measurements obtained by the instrument agree with another more accurate instrument (gold standard)
41	6.4.	Responsiveness	Ability to detect minimal clinically important change over the time

⁸Valderas JM, Ferrer M, Mendivil J, et al. Development of EMPRO: A tool for the standardized assessment of patient-reported outcome measures. *Value Heal*. 2008;11(4):700-708.

doi:10.1111/j.1524-4733.2007.00309.x. ⁹Johnston M V., Graves DE. Towards Guidelines for Evaluation of Measures: An Introduction With Application to Spinal Cord Injury. *J Spinal Cord Med*. 2016;31(1):13-26. doi:10.1080/10790268.2008.11753976. *Spinal Cord. Spinal Cord Injury Rehabilitation Evidence*. <https://scireproject.com>. ¹⁰Andresen EM. Criteria for assessing the tools of disability outcomes research. *Arch Phys Med Rehabil*. 2000;81(12 SUPPL. 2):15-20. doi:10.1053/apmr.2000.20619. ¹¹Law M. Outcome Measures Rating Form Guidelines.; 2004. Available from: <https://www.canchild.ca/system/tenon/assets/attachments/000/000/371/original/measguid.pdf>

Supplementary File S3. Continue

¹²Outcomes Measures in Rheumatology Clinical Trials (OMERACT) (2019)

1.	Truth	
1.1.	Face validity (credibility)	Overall appropriateness of the method to be used for evaluation of the outcome, as assessed by the investigators and clinicians
1.2.	Content validity (comprehensiveness)	Ability of the outcome measure to include or predict all those components of health status that are relevant to the intervention being assessed
1.3.	Criterion validity (accuracy)	Ability of the outcome measure to reflect the best available estimate of the true clinical status of the patient. Comparison with the "gold standard"
1.4.	Construct validity (convergent/divergent)	Ability of the outcome measure to match with the hypothesized expectations of the investigator when compared with other indirect assessments
2.	Discrimination	
2.1.	Sensitivity to change over time	Based on calculation of the standardized response mean (SRM) using repeated measures performed in a given population at 2 different time-points without therapeutic intervention
2.2.	Discrimination capacity over treatment	Based on calculation of effect size (ES) in randomized controlled trials or SRM in open-label trials
2.3.	Reliability (reproducibility)	Based on evaluation of intra- and interclass correlations
3.	Feasibility	The measure's ease of use, cost-effectiveness, availability in different centres, and overall usefulness. Practicalities of using the instrument, as cost, burden, length, translations, equipment needs.

¹³Testing Standards (1999, 2014)

1.	Evidences of Validity	
1.1.	Test Content	Themes, tasks, format of the items, wording, and processes of administration and scoring
1.2.	Response Processes	Cognitive processes engaged in by test takers with consequences in the scores.
1.3.	Internal Structure (Dimensionality, Differential item functioning)	The degree to which the relationships among test items and components conform to the construct on which the proposed test score interpretations are based including equivalence of scores among different populations.
1.4.	Relations to other variables (Convergent, Discriminant, Criterion, nomological network including responsiveness)	The degree to which relationships with other variables are consistent with expectations derived from theory underlying the construct
1.5.	Consequences of testing	Value judgement about unintended positive and negative consequences of test use
2.	Reliability	<i>Revised Standard (2014) also includes Decision consistency/accuracy</i>
2.1.	Internal consistency, Test- retest, Alternate forms, <i>Scorers Consistency, Decision consistency, Accuracy</i>	The degree to which an instrument is free from random error. The precision of a scale, homogeneity (inter correlations) of items. Replicability of the testing procedure.
3.	Fairness	Characteristics of all individuals must be considered throughout all stages of development, administration, scoring, interpretation and use of test. <i>Revised Standards (2014) emphasize the role of the Fairness as a measurement property</i>
4.	Scales, Norms and Score Comparability	Reference points should be documented based on population norms and/or expert criteria. Linking procedures devised to guarantee comparability of different measures of similar constructs should be described
5.	Test development and revision	Tests and their supporting documents should be periodically reviewed. New forms such as those derived from translation to other languages should be thoroughly tested for equivalence

¹² OMERACT. Instrument selection for Core Outcome Measurement Sets. In: OMERACT Handbook [Internet]. 2019. Available from: <https://omeracthandbook.org/handbook>. ¹³ American Educational Research Association, American Psychological Association, National Council on Measurement in Education. Standards for Educational and Psychological Testing. American Educational Research Association.; 1999. American Educational Research Association, American Psychological Association, National Council on Measurement in Education. Standards for Educational and Psychological Testing. American Educational Research Association; 2014.



PRISMA 2009 Checklist

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Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Pag 1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Pag 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Pag 5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Pages 5-6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Pag 6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Pag 6-7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Pag 7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary File1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Pag 6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Pag 7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Pag 7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	No applicable
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	No applicable
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	No applicable



PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	No applicable
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	No applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Pag 8 & Fig1(pag. 27)
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Supplementary File 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	No applicable
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	No applicable
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	No applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	No applicable
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	No applicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Pag 13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Pag 4 (Strengths&Limitations)
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Pag 17
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Pag 1, pag 20

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42 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097.
 43 doi:10.1371/journal.pmed1000097

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TOOLS TO ASSESS THE MEASUREMENT PROPERTIES OF QUALITY OF LIFE INSTRUMENTS: A META-REVIEW

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-036038.R1
Article Type:	Original research
Date Submitted by the Author:	15-Jun-2020
Complete List of Authors:	Lorente, Sonia; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology; Consorci Sanitari de Terrassa, Pediatric Area Viladrich, Carme; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology Vives, Jaume; Universitat Autònoma de Barcelona, Losilla, Josep-Maria; Universitat Autònoma de Barcelona, Department of Psychobiology and Methodology of Health Science Area of Behavioral Science Methodology
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Qualitative research
Keywords:	QUALITATIVE RESEARCH, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, STATISTICS & RESEARCH METHODS

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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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TOOLS TO ASSESS THE MEASUREMENT PROPERTIES OF QUALITY OF LIFE
INSTRUMENTS: A META-REVIEW

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The authors declare no conflict of interest. This work is supported by the Grant PGC2018-100675-B-I00, Spanish Ministry of Science, Innovation and Universities (Spain). Correspondence concerning this article should be addressed to Jaume Vives, Department of Psychobiology and Methodology of Health Science, Universitat Autònoma de Barcelona, UAB. E-mail: Jaume.Vives@uab.cat

ABSTRACT

Objective: This meta-review aims to discuss the methodological, research and practical applications of tools that assess the measurement properties of instruments evaluating Health-Related Quality of Life (HRQoL) that have been reported in systematic reviews. **Design:** Meta-review. **Methods:** Electronic search from January 2008 to May 2020 was carried out on PubMed, CINAHL, PsycINFO, SCOPUS, WoS, Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) database, Google Scholar, and ProQuest Dissertations & Theses. **Results:** A total of 246 systematic reviews were assessed. Concerning the quality of the review process, some methodological shortcomings were found, such as poor compliance with reporting or methodological guidelines. Regarding the procedures to assess the quality of measurement properties, 164 (66.6 %) of reviewers applied one tool at least. Tool format and structure differed across standards or scientific traditions (i.e. psychology, medicine and economics), but most assess both measurement properties and the usability of instruments. As far as the results and conclusions of systematic reviews are concerned, only 68 (27.5 %) linked the intended use of the instrument to specific measurement properties (e.g. evaluative use to responsiveness). **Conclusions:** The reporting and methodological quality of reviews have increased over time, but there is still room for improvement regarding adherence to guidelines. The COSMIN would be the most widespread and comprehensive tool to assess both the risk of bias of primary studies, and the measurement properties of HRQoL instruments for evaluative purposes. Our analysis of other assessment tools and measurement standards can serve as a starting point for future lines of work on the COSMIN tool, such as considering a more comprehensive evaluation of feasibility, including burden and fairness; expanding its scope for measurement instruments with a different use than evaluative; and improving its assessment of the risk of bias of primary studies. **PROSPERO number:** CRD42017065232. **Key words:** Meta-review,

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Quality of life, Health instruments, Measurement properties, Measurement standards,
HRQoL.

For peer review only

STRENGTHS AND LIMITATIONS

- The search strategy has been designed to be comprehensive, following the Peer Review of Electronic Search Strategies (PRESS) guidelines including specific filters for finding studies on psychometric properties of measurement instruments.
- A total of 246 systematic reviews were included and, to our knowledge, this meta-review provides the broadest overview of the most common tools used to assess measurement properties of HRQoL instruments and their relationship with measurement standards, scientific traditions and the intended use of the measures.
- Some of the included systematic reviews poorly reported the review process, outcomes, and conclusions, and this fact may have led to the loss of some data.
- Inclusion of studies published in English only may have led to language bias.

INTRODUCTION

The systematic reviews of measurement properties critically appraise the content and measurement properties of all instruments that assess a certain construct of interest in a specific study population¹. These systematic reviews provide both a comprehensive overview of the measurement properties of health instruments and supportive evidence for the selection of instruments for a specific purpose (e.g. research, clinical practice, predictive)^{2,3}. In this type of systematic review, different authors have evaluated not only the methodological quality of their key phases, -namely the search strategy, the bias risk assessment of the primary studies and the data synthesis- but also whether the measurement properties of the health status instruments have been appraised with standardized procedures or tools during the data extraction phase^{1,2,4,5}. However, depending on the measurement standards upon which these tools were developed, the approach to analyse the measurement properties of instruments may vary.⁶ This could lead to different conclusions and recommendations, in spite of the effort undertaken by the international Society for Quality of Life Research to set consensus-based minimum standards⁷. Besides, according to Rosenkoetter and Tate⁶, the assessment tools commonly used by clinicians and researchers to select the appropriate outcome measures for specific purposes show a variety of forms and cover a mix of standards related to reporting, methodological quality and statistical outcome quality.

The aims of this present meta-review are to: 1) identify systematic reviews assessing the measurement properties of HRQoL instruments; 2) identify the main tools applied to assess their measurement properties; 3) describe the contents of the applied tools (validity, reliability, feasibility, etc.); 4) identify the measurement standards upon which these tools were developed or conform to, comparing their similarities and differences, and 5) appraise how authors of these systematic reviews include the assessment of the measurement quality in their results and conclusions, i.e., to what extent conclusions depend on the results of the

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3 evaluation of the measurement properties, as well as their relationship, if any, with the
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5 intended use of the HRQoL instrument (e.g. evaluative).
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METHODS

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10 The protocol of this review⁸ was prospectively registered. We conducted this meta-review
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12 following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis
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14 Guidelines (PRISMA)^{9,10}.
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Search strategy

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19 A systematic search was performed in PubMed, US National Library of Medicine, by
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21 National Center for Biotechnology Information (NCBI); CINAHL, Cumulative Index to
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23 Nursing and Allied Health Literature, by EBSCOhost; PsycINFO, Psychological Information,
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25 by APA PsycNET; SCOPUS by Elsevier; WoS ,Web of Science CORE, by Thomson
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27 Reuters; Consensus-based Standards for the selection of Health Measurement Instruments
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29 database, by COSMIN Initiative (<http://www.cosmin.nl/>); and Google Scholar (up to 400
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31 links). ProQuest Dissertations & Theses Global was used for searching grey literature, and
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33 search alerts in all databases were set. The search strategy followed the Peer Review of
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35 Electronic Search Strategies (PRESS) guidelines recommendations^{11,12}, and consisted of 3
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37 filters composed of search terms for the following: (1) systematic review methodology; (2)
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39 HRQoL instruments; and (3) measurement properties. The latter filter was developed by the
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41 Vrije University Medical Center for finding studies on measurement properties of
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43 measurement instruments¹³. All filters were adapted for all databases. The searches were
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45 completed in May 2020. Restrictions by language (English) and publication date (from
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47 January 2008) were applied. (See Supplementary File S1 for search strings for all databases).
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Inclusion criteria

Systematic reviews specifically aiming to report or to assess the measurement properties of instruments evaluating the quality of life within the context of health and disease¹⁴ were included. Systematic reviews were required to include the full results report, and detailed information about the procedures used to assess the measurement properties.

Exclusion criteria

Systematic reviews exclusively focused on evaluating clinical interventions were excluded. Systematic reviews specifically focused on assessing Patient-reported outcomes measures (PROMs) other than HRQoL for specific diseases, clinical conditions or populations, were excluded. Systematic reviews that did not report full information about the procedures to assess the measurement properties were also excluded (e.g. conference abstracts).

Study screening

References identified by the search strategy were entered to Mendeley reference management software, and duplicates were removed. Titles and abstracts were screened independently by two reviewers (SL and JV). When decisions were unable to be made from title and abstract alone, the full paper was retrieved. Full-text inclusion criteria were checked independently by two reviewers (SL and JV). Discrepancies during the process were resolved through discussion (with independent reviews of JML and CV when necessary).

Data extraction

Extracted information of each selected systematic review and meta-analysis included general information such as author, year, and quality of review process of systematic reviews (e.g. protocol registration, reporting guidelines, and use of flowchart). Information concerning the main identified tools applied to assess the measurement properties of HRQoL instruments included the title, intended use, number of items, response categories, instrument assessment

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criteria, and measurement properties assessed. Information on how authors included the assessment of the quality of HRQoL in their results and conclusions was also extracted.

Authors of eligible studies were contacted to provide missing or additional data when necessary.

Study aim

To examine the methodological, research and practical applications of the reported tools in systematic reviews that assess the measurement properties of instruments evaluating quality of life within the context of health and disease, i.e. HRQoL.

RESULTS**Search results**

Figure 1 shows the results of the search strategy, reported according to the PRISMA flow diagram. A total of 4320 references were identified through database searches. After removing duplicates, 3055 titles and abstracts were screened. After the assessment of 525 full-text documents for eligibility, a total of 246 systematic reviews were included in the qualitative analysis. These systematic reviews covered a wide range of HRQoL instruments, both generic and disease-specific. A total of 24 (9.8 %) of the systematic reviews assessed the quality of one measurement property only, such as the conceptual and measurement model or the content validity (See Supplementary File 2 for characteristics and references of studies).

-----Insert Figure 1 here or near here-----

Reporting and methodological quality of the studies

Table 1 shows the reporting and methodological quality of systematic reviews. Findings showed that 27 (10.9 %) of the reports registered the protocol prospectively, a figure that raised to 20.8 % when considering the reports from 2014 onwards; 78 (31.7 %) followed reporting guidelines such as PRISMA (50.8 % the last six years); 42 (17.0 % since 2008; 23.8 % for the last six years) assessed the reporting and/or the methodological quality of primary

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3 studies using recommended guides, such as Standards for the Reporting of Diagnostic
4 Accuracy Studies (STARD) and Quality Assessment of Diagnostic Accuracy Studies
5 (QUADAS), respectively; 238 (96.7 %) reported the search strategy; 116 (47.41%) reported
6 the detailed syntax for one database at least; 134 (54.4 %) made the article selection by two
7 or more independent reviewers; 166 (67.5 %) used a flowchart to report search outcomes, and
8 132 (53.7 %) stated the funding. These last percentages slightly increased when reducing the
9 time frame to the last six years.

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Assessment of measurement properties of HRQoL instruments

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23 Assessment procedures of measurement properties varied considerably. A total of 164 (66.6
24 %) out of 246 systematic reviews applied one tool at least, that is, a published and well
25 accepted list of criteria, to rate the evidence on measurement properties of instruments; 41
26 (16.6 %) applied their own author's criteria only; 30 (12.2 %) followed literature
27 recommendations included in very highly circulated books or papers only, and 14 (5.7 %)
28 used an *ad hoc* checklist of criteria only. A total of 98 (39.8 %) systematic reviews did
29 combine different procedures. Most usual combinations were the use of two tools or one tool
30 and literature recommendations.

Tools to assess measurement properties of HRQoL instruments

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The first twelve columns of Table 2 present the characteristics for the identified tools used to
assess measurement properties using the last update we are aware of. Tools are reported in
order of frequency of use, as pointed out in the last row of the table: 1) "Consensus-based
Standards for the selection of Health Measurement INstruments (COSMIN)", COSMIN
initiative^{15,16}; 2) "Quality Criteria for Measurement Properties", Terwee et al.¹⁷; 3)
"Attributes and Criteria to assess Health Status and Quality of Life Instruments", Scientific
Advisory Committee Medical Outcomes Trust (SACMOT)^{18,19}; 4) "Health Status Measures

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3 in Economic Evaluation”, Brazier et al.^{20,21}; 5) “Guidance for Industry Patient-reported
4 Outcomes Measures”, Food and Drug Administration (FDA)^{22,23}; 6) “Evaluating Patient-
5 based Outcomes Measures for use in clinical trials”, Fitzpatrick et al.²⁴ (also known as
6 Fitzpatrick’s criteria); 7) “International Classification of Functioning” and “International
7 Classification of Functioning for Children and Youth”, World Health Organization²⁵; 8)
8 “Evaluating Measures of Patient Reported Outcomes (EMPRO)”, Spanish Cooperative
9 Investigation Network for Health and Health Service Outcomes Research (IRYSS)²⁶; 9)
10 “Spinal Cord Injury Criteria”, Spinal Cord Injury Rehabilitation Evidence (SCIRE)^{27,28}; 10)
11 “Criteria for Assessing the Tools of Disability Outcomes Research”, Andresen²⁹ (also known
12 as Andresen’s tool); 11) “CanChild Outcomes Measures”, CanChild Center for Childhood
13 Disability Research³⁰; and 12) “Outcomes Measures in Rheumatology Clinical Trials
14 (OMERACT)”, OMERACT initiative³¹. Table 2 also includes a final column showing the
15 characteristics of Testing Standards by American Educational Research Association (AERA),
16 American Psychological Association (APA) and National Council on Measurement in
17 Education (NCME)^{32,33} (hereinafter “Testing Standards”) initially published in 1954 and
18 regularly updated every decade using consensus based procedures. The Testing Standards are
19 the source of most of the technical vocabulary for measurement properties in HRQoL
20 instruments, therefore they will be used as a reference to compare the twelve identified tools.
21 In fact, these standards have already been recommended to establish a unified approach to
22 validity and reliability of results derived from psychometric instruments in clinical medicine,
23 research and education³⁴.

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51 Different methodologies were used to develop the tools. The expert panel consensus and the
52 literature review were the most usual methods, led by Steering Committees or Staff/Working
53 Groups. The format and structure of these tools also vary. Whereas seven of them were
54 itemized to allow the assignment of quality scores, the other six took the form of standards or
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 guidelines. Tools with an itemized structure were the COSMIN, Quality Criteria for
4 Measurement Properties, EMPRO, SCI Criteria, Criteria for Assessing the Tools of Disability
5 Outcomes Research (Andresen's tool), CanChild Outcomes Measures, and OMERACT.
6
7 Among all measurement properties considered in Testing Standards, eleven out of the twelve
8 tools recommended to assess the conceptual and measurement model; content, structural,
9
10 convergent, discriminant, concurrent and predictive validity; responsiveness or sensitivity to
11 change; and internal consistency, test-retest and inter-rater reliability. However, the approach
12 to analyse these measurement properties varied, with examples found in construct validity,
13 criterion validity and reliability. Depending on the tool, the validity of the construct can be
14 evaluated either by hypothesis confirmation in general (e.g. COSMIN or EMPRO), or by
15 specific hypothesis based on correlations with other measures, i.e. convergent and
16 discriminant validity (e.g. Andresen's tool). Criterion validity can be assessed either
17 exclusively by calculating the correlation coefficient with a gold standard (e.g. CanChild
18 Outcomes Measures) or by obtaining variously correlation, specificity and sensitivity, or
19 predictive values (e.g. FDA). Reliability can be analysed either by test retest reliability, inter-
20 rater reliability and internal consistency (e.g. FDA), or only by test retest and inter-rater
21 agreement (e.g. Economic evaluation). Despite the Testing Standards recommendations, just
22 one tool includes additional criteria to assess consequential validity (SCI), and four assess
23 fairness (e.g. accessible forms for subjects with vision impairment, or for specific
24 populations) (SACMOT, FDA, SCI and Andresen's tool). None of them includes criteria to
25 assess the validity of response processes. Other HRQoL instrument characteristics, such as
26 feasibility (e.g. cost of obtaining a sample), acceptability (e.g. suitability from the patient
27 perspective), or burden (e.g. the time or effort placed on the administration of the instrument)
28 are assessed instead. Finally, notice that some concepts have changed their place over time.
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30 The clearest case is evidence regarding cross-cultural equivalence, which was treated as an
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3 additional characteristic of the instruments in most tools released before 2014 (e.g., EMPRO
4 or SCI), but was considered a proper measurement property in the COSMIN's 2018 update. It
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6 is also considered a measurement property in Testing Standards where it is included as a
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8 particular case of differential item functioning when assessing the internal structure of the
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10 instruments (See Supplementary File S3 for more details).
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15 -----Insert Table 2 here or near here-----
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17 **Intended uses of instruments and their association to measurement properties**

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19 Some of the differences between tools can be attributed to the fact that they are devoted to the
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21 evaluation of instruments developed with different intended uses. For instance, COSMIN
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23 aims at assessing the quality of instruments for an evaluative purpose whereas the Economic
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25 Evaluation tool aims at the assessment of instruments for analytical purposes. Nevertheless,
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27 the relation between the intended use of the instruments and the measurement properties
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29 assessed is not usually included in the conclusions of the systematic reviews. Table 3 shows
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31 the intended use of instruments, based on the framework proposed by McDowell et al.³⁵, and
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33 the association to measurement properties that reviewers established in their conclusions. The
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35 instruments were most frequently used for evaluation (178, 72.3 %) and for assessment of
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37 impact of disease on HRQoL (138, 55.1 %), either alone or in conjunction. Other purposes
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39 were analytic (35, 14.2 %), diagnostic (16, 6.5 %), descriptive (4, 1.6 %), and predictive (2,
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41 0.8 %). A total of 6 (2.4 %) systematic reviews did not report or did not clearly state the
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43 intended use of the instruments. As far as the assessment and conclusions is concerned, only
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45 68 (27.6 %) systematic reviews linked the intended use of the instrument to measurement
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47 properties. The most common use was evaluative, generally associated to responsiveness,
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49 content validity or reliability, for example. When the purpose was the assessment of the
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51 impact of disease on HRQoL, the conceptual and measurement model and content validity
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53 were usually reported. The analytic purpose involved reporting preference-based valuation
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(e.g. utility scores) and evidence of agreement, and the diagnostic use was linked to known groups validity and test-retest reliability. To better understand these results, some examples are given. First, the evaluative purpose was associated to responsiveness, we found conclusions such as: “For use in longitudinal studies or clinical practice, where responsiveness is an issue, the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the Chronic Heart Failure Questionnaire (CFHQ) would be adequate”³⁶. Second, the intended use was the assessment of the impact of disease on HRQoL, the usual association was to the measurement model and conclusions resembled this one: “None of the RLS specific QOL measures appears to have been informed by a conceptual model or a conceptual framework. Consequently, none can be considered comprehensive in terms of assessing the full impact of Rest Legs Syndrome on QOL”³⁷. Third, an example illustrating general conclusions, i.e. conclusions that did not associate the intended use of the instrument to any specific measurement properties, was as follows: “None of the available instruments fulfils the psychometric demands of reliability, validity and responsiveness to serve as a primary outcome measure in clinical trials”³⁸

Discussion

The present meta-review identified 246 systematic reviews assessing measurement properties of HRQoL instruments in order to analyse the quality of the review process, describe the most used tools to assess measurement properties and examine how reviewers included the assessment of the quality of HRQoL in their conclusions.

Reporting and methodological quality of the studies

Findings showed how the reporting and methodological quality of systematic reviews has increased over time. Most reviewers reported the search strategy, stated the inclusion and exclusion criteria taking the judgement of two or more independent reviewers into account and used a flow chart to report search outcomes. However, some crucial methodological

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3 shortcomings were found. Practices such as registration of the protocol, reporting the detailed
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5 search syntax for one database at least, adherence to reporting guidelines, and assessing the
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7 reporting and the methodological quality of primary studies were quite sparse even in recent
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9 years. As Pussegoda et al.⁴ suggested, this fact may be related to the perceived time-
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11 consuming task of using guidelines or to the lack of information about the most appropriate
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13 tool. According to our data, there is still large room for improvement in the assessment of the
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15 methodological quality of included studies in order to attend to Terwee et al.'s warning² of
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17 avoiding the risk of presenting biased results, leading to underestimation or overestimation of
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19 the quality of an instrument.
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23 **Assessment of measurement properties of HRQoL instruments**

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25 Assessment procedures of measurement properties of HRQoL instruments were diverse.
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27 Most of the reviewers used at least one tool. Nevertheless, there were reviewers that applied
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29 their own criteria, followed literature recommendations or applied different *ad hoc* devised
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31 checklists. The use of such diverse procedures is noticeable, even in recent years, when well-
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33 accepted tools to assess measurement properties are available.
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38 Our meta-review identified up to twelve tools. Seven of them had an itemized structure,
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40 offering a comparable approach to rate the evidence on measurement properties. Length and
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42 scoring differed, but also the instrument assessment criteria. Actually, depending on the tool
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44 used, the approach to assess properties varied greatly, with potentially serious consequences.
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46 The fact that a single measurement property is or isn't required can change the status of
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48 quality of the evidence supporting the same measurement instrument. The variety of forms
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50 found were in concordance to results from related research, which also highlighted the
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52 complexity with regard to definitions of measurement properties⁶. This complexity is also
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54 reflected in the search filter developed by the COSMIN initiative¹³. They recommend using 3
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56 filters that sum up more than 100 search terms in order to get sensible and specific results. In
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 addition, and also depending on the tool used, other characteristics, such as feasibility,
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5 acceptability, and burden were assessed. In spite of the diversity, a shared conclusion can be
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7 stated as follows: because these instruments are to be used in the daily practice, their usability
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9 should be always balanced with other characteristics considered as proper measurement
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11 properties^{39,40}. For instance, an instrument needs to be long enough to ensure reliability and
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13 construct validity, but short enough to ensure the adequate response rate and sample size.
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17 Otherwise the instrument intended use and sustainability will be at hazard³⁹.

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19 The differences between tools and their potentially serious consequences on the assessment
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21 of the quality of the primary studies may be better addressed in the light of three
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23 considerations: the date of publication, the main scientific tradition involved when
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25 developing the tools, and the intended uses of the instruments under assessment. Some
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27 differences can be simply explained by the date of publication of the tools. As an example,
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29 where older tools require specific forms of validity evidence related to external variables such
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31 as convergent and discriminant validity, recent tools incorporate the more general view of
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33 hypothesis testing. That is, when developing a new use for an instrument, hypotheses should
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35 be made regarding the expected relations with other relevant variables in their nomological
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37 network and these hypotheses and no other should be tested³². Regarding the scientific
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39 traditions, the assessment of outcomes is a constitutive part of the disciplines of Education
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41 and Psychology where the Testing Standards come from. In these contexts, participation is
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43 taken for granted as assessment practices result in high stakes decisions such as, for instance,
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45 certification or personnel selection. The main concern regarding integrity of the instrument
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47 purpose is its fakeability, which could distort the decision-making process, and this would
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49 explain the interest in response processes in this field^{41,42}. By contrast, the main objective in
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51 the discipline of Medicine is to provide health care services. Evaluation of subjective views
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53 of patients was a late addition related to the inclusion of HRQoL in the accounting of health
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3 care outcomes, despite the instruments assessing the patient experience should be acceptable
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5 to both patients and clinicians, as Beattie et al. (2014) highlighted³⁹. Specifically, in the
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7 context of disability research, the administrative and respondent burden requires additional
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9 consideration. The administrative burden may include the need for a Sign Language
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11 interpreter, and the respondent burden includes the length of the questionnaire, which is
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13 especially relevant when using HRQoL instruments with cognitively impaired subjects²⁹.
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15 Balancing the traditional psychometric criteria, the practicalities of the instruments and
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17 patient preferences is a generic recommendation for health research, but becomes a special
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19 obligation for research with people with specific needs²⁹. Moreover, devising test
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21 accommodations or accessible forms when needed is expected to become a required
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23 psychometric criterion in the near future, given that it has already been included under the
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25 title “fairness in testing” as a new section next to validity and reliability in the chapter of
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27 measurement foundations in the most recent update of Testing Standards³².
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29 Another criterion is that of Economic evaluation, traditionally embedded in providing
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31 quantitative judgments able to be integrated into mathematical models such as those used in
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33 calculating quality-adjusted life years (QALYs) and using preference-based methods to
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35 obtain their data. Due to that, some very popular measurement properties such as internal
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37 structure based on factor analysis are not relevant and thus not considered in their tools. In
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39 this tradition the main concerns regarding the integrity of the instrument purpose is whose
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41 values should be considered when determining preferences and how well the preferences of
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43 patients and decision makers are likely to conform to the main assumptions of the utility
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45 models^{20,21}.
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Intended uses of instruments and their association to measurement properties

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55 In our view, considering in the first place the intended use of the HRQoL instrument would
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57 help to reconcile the different requirements included in each tool. Tools for evaluating the
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 measurement quality of instruments should be adapted or extended according to the different
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5 intended uses of these instruments, such as evaluative, impact of disease, analytic, diagnostic,
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7 descriptive or predictive. Notice that depending on the intended use of the measure, some
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9 domains of validity and reliability may be of greater or lesser relevance^{6,16}. For instance, an
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11 instrument developed to assess longitudinal changes should demonstrate high
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13 responsiveness⁶, but if used for diagnostic purposes, it should be able to distinguish among
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15 individuals or groups⁶, i.e. known groups validity. Another example is the internal
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17 consistency reliability based on inter-item relationships, that may be not relevant for a
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19 preference-based instrument but is relevant for an instrument based on a unidimensional
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21 measurement model. However, our data showed that only a few authors established a clear
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23 link in their recommendations between the intended use of the measure and the reported
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25 evidence of measurement properties. The vast field of HRQoL offered a plethora of
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27 instruments but, as most reviewers did not take the intended use of the instrument into
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29 account, the overall rating of measurement properties was not consistent and thus the
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31 instrument may or may not have been adequate for its intended use. Because the evaluation
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33 and improvement of quality of life is considered a public health priority¹⁴, we strongly
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35 encourage researchers to assess the quality of measurement properties of HRQoL instruments
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37 according to the intended use of the measure. Otherwise, there is a serious risk of biased
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39 results, which could lead to underrating the quality and suitability of the instrument.
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Conclusions

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48 The quality of the systematic review process has been increasing over time, but it should still
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50 improve with regard to the prospective registration of protocol, and with respect to the
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52 adoption of guidelines to improve both the methodological and reporting quality of the
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54 reviews. In the specific context of systematic reviews of measurement instruments, enhancing
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56 the quality of the process also involves the assessment of measurement properties by using a
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 standardized tool. The selection of the most suitable tool may be addressed according to the
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5 coverage of the appraised measurement properties, but also according to other important
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7 criteria, such as the intended use of the HRQoL instruments, the format of the tool, and
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9 whether it assesses both usability (e.g. feasibility or burden) and accommodation (or
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11 accessible forms). First, the assessment methodology should be adapted when necessary,
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13 establishing the relation between the intended use of the HRQoL instruments and the
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15 measurement properties assessed. Second, to standardize the review process, the tool's format
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17 should be itemized offering a comparable approach to rate the evidence on measurement
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19 properties. Those tools that take the form of guidelines, such as the SACMOT or the
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21 Economic Evaluation would be considerably upgraded if the structure is reconverted, since
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23 the current format only allows description rather than critical appraisal of the quality of an
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25 instrument, and furthermore it complicates comparison of results. Lastly, because systematic
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27 reviews on measurement properties aim to help professionals to select the best instrument for
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29 a clinical scenario, the feasibility, patient's preferences, administrator and respondent burden,
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31 and the accommodations (or accessible forms) should be addressed and evaluated. Otherwise
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33 the suitability and the intended use of instruments might be compromised, especially in the
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35 context of disability research. Tools identified in our meta-review that meet most of these
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37 criteria are the COSMIN, EMPRO, SCI criteria, Andresen's tool, CanChild Outcomes, and
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39 OMERACT, since all of them cover a wide range of measurement properties, offer an item
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41 structure, and assess the usability of instruments.

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43 Special mention is due to the COSMIN, the most widespread and comprehensive tool to
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45 assess measurement properties of health instruments designed for an evaluative purpose. The
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47 COSMIN standards were developed in a Delphi study⁴³ aiming to improve the selection of
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49 the most appropriate health instrument for a clinical scenario. The most recent version of the
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51 COSMIN consists of a manual for conducting systematic reviews of health instruments,
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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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3 providing different steps with respect to the literature search process, the assessment of
4 measurement properties and feasibility of instruments, and the evaluation of the risk of bias
5 (RoB) of studies according to the Cochrane methodology¹⁶. Additionally, the COSMIN
6 initiative recently developed a guideline exclusively focused on assessing the content validity
7 of health instruments, considered the most important property to ensure the adequate
8 reflection of the construct measured^{44,45}. In the light of these considerations, we strongly
9 recommend the application of the latest version of the COSMIN to conduct high quality
10 systematic reviews on measurement properties of health instruments for an evaluative
11 purpose, or for other purposes with appropriate adaptation.
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23 Despite COSMIN's many strengths, our analysis of the other assessment tools and
24 measurement standards allow us to suggest future lines of work on this tool. First, the current
25 format of COSMIN is fairly complex, requiring high expertise in the field of psychometrics
26 and specific training for its proper application. The reporting of the inter-rater agreement
27 coefficients when reviewers use the last version of COSMIN may provide useful data about
28 its reliability. Second, consideration should be given to the Testing Standards
29 recommendation on the inclusion of the assessment of fairness (i.e., evaluation of accessible
30 forms for specific populations). Third, the feasibility of the measurement instruments, merely
31 described in COSMIN, and their burden, should be properly rated, with examples found in
32 EMPRO or Andresen's tool. Fourth, it must be considered that the RoB evaluation of studies
33 is itself a productive field of research with a long tradition, with specific tools that have been
34 developed for different research questions and study designs. Examples might be found in the
35 Cochrane Collaboration's Tool for Assessing the Risk of Bias of Clinical Trials⁴⁶, the
36 Newcastle Ottawa Scale (NOS)⁴⁷ for nonrandomised studies, or the Quality Assessment Tool
37 for Cohort Studies (Q-COH II)^{48,49}. From our point of view, the COSMIN proposal could also
38 be simplified and improved by guiding the reviewers towards the identification of the most
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appropriate RoB assessment tools instead of developing their own RoB appraisal guidelines, taking advantage of knowledge and innovations in that field of research.

And last, but not least, improving the quality of systematic reviews encompasses researchers, sponsors and promoters, but also journals, which should require full compliance with reporting and methodological guidelines, and the use of assessment tools.

Patient and Public Involvement

No patient or public involvement.

Ethics and dissemination

Ethical approval is not necessary for meta-reviews.

Data availability statement

Data are available upon reasonable request to the authors.

Authors' contribution

All authors meet the criteria recommended by the International Committee of Medical Journal Editors, ICMJE. All authors made substantial contributions to conception and design, piloted the inclusion criteria and provided direction of the data extraction and analysis. SL drafted the article, and JV, CV and JML critically revised the draft for important intellectual content. All authors agreed on the final version.

Funding statement

This work was supported by the Grant PGC2018-100675-B-I00, Spanish Ministry of Science, Innovation and Universities (Spain).

Competing interests' statement.

The authors declare no conflict of interest. The authors have no financial relationships relevant to this article to disclose, and the funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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Figure legend: PRISMA flowchart. Flow diagram for search results.

For peer review only

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TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

28

Table 1. Reporting and methodological quality of studies

	2008-2020		2014-2020	
	n	%	n	%
Protocol registered prospectively				
• Yes, PROSPERO	27	10.9	26	20.5
• No registered	219	89.1	100	79.3
Standards of systematic review reporting and/or quality assessment				
• Yes (AMSTAR, PRISMA, QUOROM...)	78	31.7	64	50.8
• No	168	68.3	62	49.2
Standards to assess reporting and/or quality assessment of primary				
• Yes (QUADAS, STARD...)	42	17.0	30	23.8
• No	204	83.0	96	76.2
Number of databases searched				
• 1-3	96	39.1	50	39.6
• 4-6	107	43.4	61	48.4
• 7-9	22	8.9	8	6.3
• >=10	18	7.3	6	4.7
• Not reported	3	1.2	1	0.8
Other sources				
• Official websites/Internet	25	10.1	7	5.5
• Virtual libraries	24	9.7	12	9.4
• Google/Google Scholar	25	10.1	14	11.0
• Scientific journals/Thesis	6	2.4	2	1.6
Search strategy				
Terms, databases, time period				
• Yes	238	96.7	123	97.6
• No	8	3.3	3	2.4
Search syntax				
• Detailed syntax reported (Truncations, Booleans...)	115	46.7	79	62.7
• Syntax not reported or not detailed enough to be replicable	125	50.8	46	36.5
• Supplementary file under request (not available)	5	2.1	1	0.8
Inclusion / Exclusion selection criteria				
• Reported and well-defined	229	93.1	122	96.8
• Not reported or not clearly stated	17	6.9	4	3.2
Article selection				
• By 2 or more independent reviewers	134	54.4	87	69.0
• Not reported or not clearly stated	112	45.6	39	31.0
Flow chart				
• Yes	166	67.5	108	85.7
• No	80	32.5	18	14.1
Funding				
• Reported	132	53.7	69	54.8
• Not reported or not clearly stated	114	46.3	57	45.2
TOTAL	246	100	126	100

PROSPERO= Prospective Register of Systematic Reviews; AMSTAR=Assessment of Multiple Systematic reviews; PRISMA= Preferred Reporting Items for Systematic Reviews and Meta-Analyses; QUOROM=Quality of Reporting of Meta-analysis; QUADAS= Quality Assessment of Diagnostic Accuracy Studies; STARD= Standards for the Reporting of Diagnostic Accuracy Studies; n= frequency; %= percentage

TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

Table 2. Tools to assess measurement properties. Characteristics and comparison to Testing Standards

Tools	1)COSMIN	2)TERWEE'S CRITERIA	3)ATTRIBUTES & CRITERIA	4)ECONOMIC EVALUATION	5)GUIDANCE FOR INDUSTRY	6)FITZPATRICK'S CRITERIA	7)ICF ICFCY	8)EMPRO	9)SCI CRITERIA	10)ANDRESEN'S TOOL	11)CANCHILD OUTCOMES	12)OMERACT	13)TESTING STANDARDS
Development	Delphi	Author criteria	Expert panel	Literature	Consensus	Literature		Expert panel	Expert panel Literature	Literature	Expert panel	Expert Panel Delphi	Consensus
Sponsor/s	COSMIN Initiative	Author	SACMOT Working group	Standing Group of Health Technology	FDA Staff	Standing Group of Health Technology	WHO Member States	IRYSS Committee	SCIRE Working group	Author	CanChild Center Staff	OMERACT Initiative	AERA, APA NCME
Approval Updates	2010 2018	2007	1996 2002, 2013	1999 2017	2006 2009	1998	2001 2019 ^a	2008	2008, 2016	2000	1987 ^b 2004	1992 1998,2007,2014, 2019	1954 1966, 1974, 1985, 1999, 2014
Items (scoring)	5-18 items/box (+ / - / ?)	8-9 items total (+ / - / ?)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	Not item structured (no scoring)	39 items(strongly agree, agree, disagree, strongly disagree)	3-5 items/box (++++ / +++ / ++ / +)	11 items total (A, B, C)	2-6 items/box (excellent, adequate, poor)	2-5 items/box (Green, amber, red, white)	Not item structured (no scoring)
Measurement properties	Content Construct (Int.Structure Cross-Cultural Hypotheses test) Criterion (Gold standard)	Content Construct (Hypotheses test) Criterion (Gold standard) Floor/Ceiling	Conceptual & measurement model Face Construct (Hypotheses test) Criterion (Gold standard)	Descriptive (Content Construct) Preference-based valuation Empirical (Criterion) (Gold standard)	Conceptual model Content Construct (Hypothesis test, Discriminant, Convergent, Known groups) Criterion (Gold standard, sensitivity) Responsiveness	Use Content/Face Construct (Convergent, Discriminant, Int.Structure) Criterion (Predictive) Cut-score precision	Content	Conceptual & measurement model Construct (Hypotheses test) Criterion	Content Criterion (Concurrent Predictive "Discriminant") Clinical utility (Consequential validity) Floor/Ceiling	Conceptual & measurement model Instrument bias Int.Structure Convergent Discriminant	Use Scale construction Content Construct (Hypotheses test) Criterion (Gold standard) Responsiveness	Content, Face Construct (Convergent, Divergent) Criterion (Accuracy) Discrimination (Sensitivity over time & over treatment)	Content Response process Int. Structure (Dimensions, DIF) Relations to other variables (Hypotheses test,Convergent, Discriminant, Criterion, Responsiveness) Consequences
Validity													
Reliability	Int. Consistency Measurement error (Test retest, Agreement)	Int.Consistency Reproducibility (Agreement, Relative measurement error)	Int.Consistency Reproducibility (Test retest, inter-rater)	Test retest Inter-rater	Test retest Inter-rater Int.Consistency	Int.Consistency Reproducibility (Test retest)		Int.Consistency Reproducibility (Test retest, Inter-rater)	Int.Consistency Test retest	Int.Consistency Test retest	Int.Consistency Intra/Inter-rater Test retest	Reproducibility Test retest	Int.Consistency Test retest Alternate forms Scorers & Decision consistency/accuracy
Fairness													Equivalence of accommodations
Other characteristics									Norms	Norms, Standard values	Norms Standardization		Scales, norms, Score comparability Test development and revision
	Interpretability	Interpretability	Interpretability		Interpretability	Interpretability		Interpretability					
			Burden		Burden	Acceptability (Burden)		Burden	Burden	Burden			
			Administration Accessible forms		Administration Accessible forms			Administration	Administration Accessible forms	Administration Accessible forms			
			Cultural Adaptations	Practicality		Feasibility Cultural Adaptations		Cultural Adaptations	Applicability Cultural Adaptations	Cultural Adaptations	Clinical utility (Feasibility)	Feasibility	
Frequency of use (%)	61 (30.4)	45 (22.4)	33 (16.4)	17 (8.4)	14 (6.9)	14 (6.9)	7 (3.4)	4 (2.0)	2 (1.0)	2 (1.0)	1(0.5)	1 (0.5)	0

Note: DIF= Differential Item Functioning; %=Percentage; Invariance=Measurement invariance; Int.Structure= Internal Structure; Int. Consistency= Internal Consistency; AERA= American Educational Research Association; APA= American Psychological Association; NCME= National Council on Measurement in Education; SACMOT= Scientific Advisory Committee Medical Outcomes Trust; FDA= Food and Drug Administration; WHO= World Health Organization; IRYSS= Spanish Cooperative Investigation Network for Health and Health Service Outcomes Research; SCIRE= Spinal Cord Injury Rehabilitation Evidence; COSMIN=Consensus Standards for Selection of Health Measurement Instruments; TERWEE'S CRITERIA= Quality Criteria for Measurement Properties; ATTRIBUTES&CRITERIA= Attributes and Criteria to assess Health Status and Quality of Life Instruments; ECONOMIC EVALUATION= Health Status Measures in Economic Evaluation; GUIDANCE FOR INDUSTRY=Guidance for Industry patient-reported outcomes measures; FITZPATRICK'S CRITERIA=Evaluating patient-based outcomes measures for use in clinical trials.; ICF= International Classification of Functioning; ICFCY= International Classification of Functioning for Children and Youth; EMPRO= Evaluating Measures of Patient Reported Outcomes; SCI CRITERIA= Spinal Cord Injury guidelines; ANDRESEN'S TOOL=Criteria for Assessing the Tools of Disability Outcomes Research; CANCHILD OUTCOMES= CanChild Outcomes Measures; OMERACT= Outcomes Measures in Rheumatology Clinical Trials; TESTING STANDARDS= Standards for Educational and Psychological Testing. See text for references.

^aUpdated version at website, ^b Reference at 2004

TOOLS TO ASSESS HRQOL MEASUREMENT PROPERTIES

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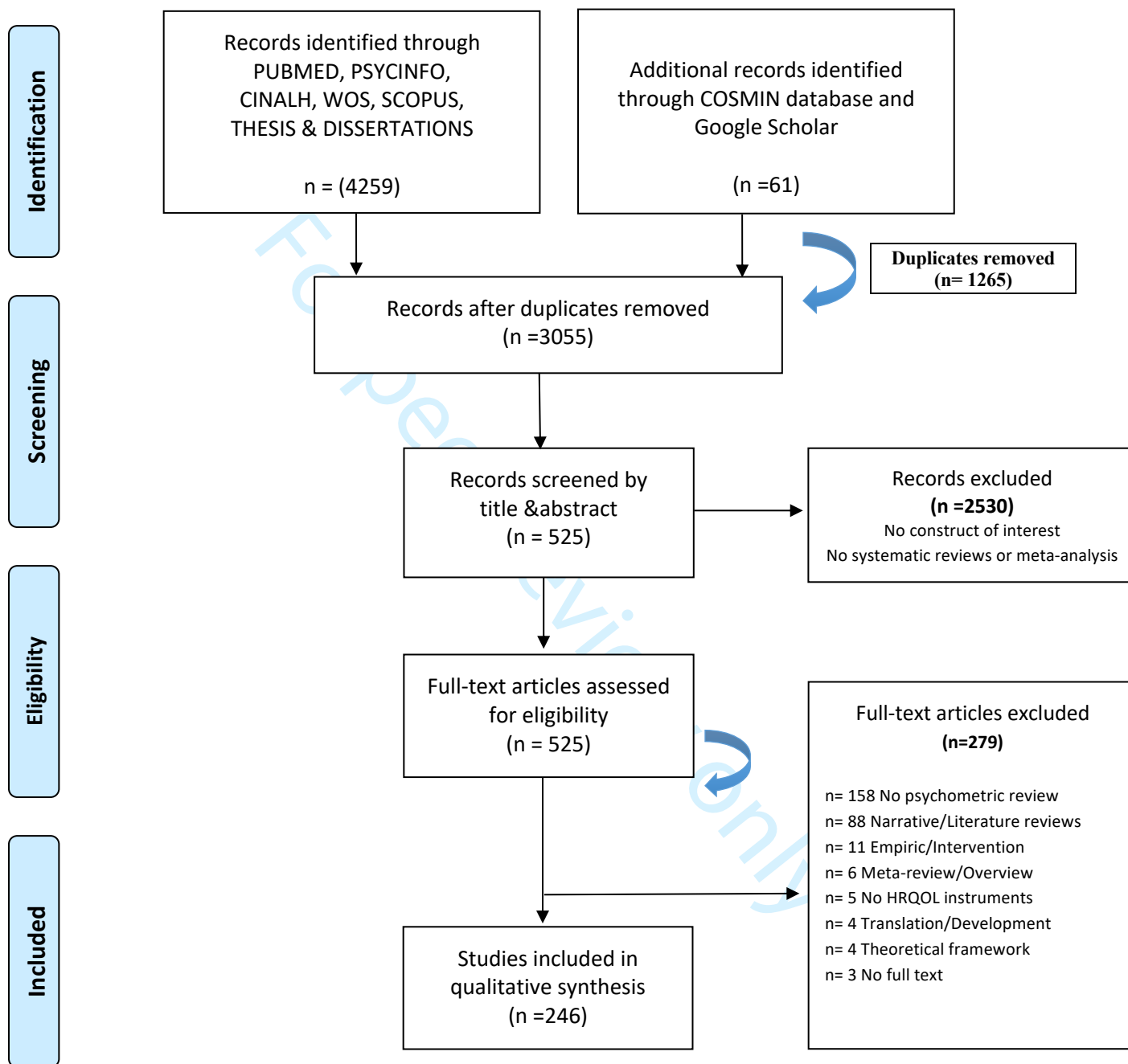
Table 3. Intended use of instruments and their association to measurement properties

Intended use of instruments identified across the systematic reviews		Frequency	% (Over 246)
Evaluative (Change scores pre-post studies. Effectiveness of an intervention)		178	72.3
Impact of disease on HRQoL (disease symptoms, burden...)		138	55.1
Analytic (Health policies. Cost-effectiveness. Funding)		35	14.2
Diagnostic (Distinguish between groups, levels of severity...)		16	6.5
Descriptive (Health measures in surveys. Needs of groups of people)		4	1.6
Predictive (Anticipation of future health status. Risk factors. Risk profiles)		2	0.8
Intended use is no reported or no clearly stated		6	2.4
Conclusions according to the intended use of instruments		n	% (Over 246)
Yes, reviewers made specific conclusions		68	27.6
No, reviewers made general conclusions		178	72.4
Measurement properties associated to the intended use of the instrument		n	% (Over 68)
Evaluative	Responsiveness / Conceptual and Measurement Model / Content validity / Reliability (internal consistency, test retest) / Respondent Burden / Convergent validity / Cross cultural validity	41	60.3
Impact	Conceptual and Measurement Model / Content validity	29	42.6
Analytic	Preference-based valuation / Agreement	11	16.2
Diagnostic	Known groups validity / Test retest	7	10.3
Predictive	Sensitivity and specificity	1	1.5

Note: (%) =Percentage



PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>

Supplementary File S1. Search strategy

Search strings for Pubmed

1	("Quality of Life"[Mesh] OR HRQL[tiab] OR HRQoL[tiab] OR QoL[tiab] OR "quality of life"[tiab])
2	(instrument[tiab] OR instruments[tiab] OR questionnaire[tiab] OR questionnaires[tiab] OR scale[tiab] OR scales[tiab] OR tool[tiab] OR tools[tiab])
3	(Validation Studies[pt] OR "reproducibility of results"[MeSH Terms] OR reproducib*[tiab] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tiab] OR clinometr*[tiab] OR "observer variation"[MeSH] OR observer variation[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR valid*[tiab] OR coefficient[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR "item correlation"[tiab] OR "item correlations"[tiab] OR "item selection"[tiab] OR "item selections"[tiab] OR "item reduction"[tiab] OR "item reductions"[tiab] OR agreement[tw] OR precision[tw] OR imprecision[tw] OR "precise values"[tw] OR test-retest [tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR "kappa's"[tiab] OR kappas[tiab] OR "coefficient of variation"[tiab] OR repeatab*[tw] OR ((replicab*[tw] OR repeated[tw]) AND (measure[tw] OR measures[tw] OR findings[tw] OR result[tw] OR results[tw] OR test[tw] OR tests[tw])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR "factor analysis"[tiab] OR "factor analyses"[tiab] OR "factor structure"[tiab] OR "factor structure"[tiab] OR dimensionality[tiab] OR subscale*[tiab] OR "multitrait scaling analysis"[tiab] OR "multitrait scaling analyses"[tiab] OR "item discriminant"[tiab] OR "interscale correlation"[tiab] OR "interscale correlations"[tiab] OR ((error[tiab] OR errors[tiab]) AND (measure*[tiab] OR correlat*[tiab] OR evaluat*[tiab] OR accuracy[tiab] OR accurate[tiab] OR precision[tiab] OR mean[tiab])) OR "individual variability"[tiab] OR "interval variability"[tiab] OR "rate variability"[tiab] OR "variability analysis"[tiab] OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR (limit[tiab] AND detection[tiab]) OR "minimal detectable concentration"[tiab] OR interpretab*[tiab] OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR "meaningful change"[tiab] OR "minimal important change"[tiab] OR "minimal important difference"[tiab] OR "minimally important change"[tiab] OR "minimally important difference"[tiab] OR "minimal detectable change"[tiab] OR "minimal detectable difference"[tiab] OR "minimally detectable change"[tiab] OR "minimally detectable difference"[tiab] OR "minimal real change"[tiab] OR "minimal real difference"[tiab] OR "minimally real change"[tiab] OR "minimally real difference"[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF [tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])
4	#1 AND #2 AND #3
5	("protocol"[ti] OR "addresses"[Publication Type] OR "biography"[Publication Type] OR "case reports"[Publication Type] OR "comment"[Publication Type] OR "directory"[Publication Type] OR "editorial"[Publication Type] OR "festschrift"[Publication Type] OR "interview"[Publication Type] OR "lectures"[Publication Type] OR "legal cases"[Publication Type] OR "legislation"[Publication Type] OR "letter"[Publication Type] OR "news"[Publication Type] OR "newspaper article"[Publication Type] OR "patient education handout"[Publication Type] OR "popular works"[Publication Type] OR "congresses"[Publication Type] OR "consensus development conference"[Publication Type] OR "consensus development conference"[Publication Type] OR "practice guideline"[Publication Type])
6	#4 NOT #5
7	FILTER: Article Type (Review or Systematic Review)
8	FILTER: Subject (Systematic Review)
9	FILTER: Language (English)
10	FILTER: Period (2008-2018)

Search strings for CINAHL

1	TI "quality of life" OR "HRQOL" OR AB "quality of life" OR "HRQOL"
2	TI (instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools) OR AB (instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools)
3	TI ("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence") OR AB ("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal 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4	TI review OR AB review
5	#1 AND #2 AND #3 AND #4
6	TI ("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
7	#5 NOT #6
7	FILTER: Language (English)
8	FILTER: Period (2008-2018)

 Search strings for PsycInfo

- | | |
|---|--|
| 1 | it=Quality of life |
| 2 | it=Questionnaires OR it="Rating Scales" OR it=Screening OR it="Screening Tests" OR it="Psychological Assessment" OR it=Inventories OR it="Individual Testing" OR it="Human Factors Measures" OR it="Checklist Testing" OR it=Psychometrics |
| 3 | #1 AND #2 |
| 4 | FILTER: Methodology (Literature Review) |
| 5 | FILTER: Language (English) |
| 6 | FILTER: Period (2008-2018) |

 Search strings for Scopus

- | | |
|---|---|
| 1 | TITLE-ABS-KEY("Quality of life" OR "HRQOL") |
| 2 | TITLE-ABS-KEY(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scale OR tool OR tools) |
| 3 | TITLE-ABS-KEY("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence") |
| 4 | #1 AND #2 AND #3 |
| 5 | TITLE("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline") |
| 6 | #4 NOT #5 |
| 7 | FILTER: Document Type (Review) |
| 8 | FILTER: Language (English) |
| 9 | FILTER: Period (2008-2018) |

Search strings for Web of Science (WoS)

1	TI=("Quality of Life" OR "HRQOL")
2	TS=(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools)
3	TS=("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR (error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence")
4	#1 AND #2 AND #3
5	TI=("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
6	#4 NOT #5
7	FILTER: Document Type (Literature Review)
8	FILTER: Language (English)
9	FILTER: Period (2008-2018)

Search strings for ProQuest Dissertations & Theses Global

1	ti("Quality of life" OR HRQOL) OR ab("Quality of life" OR HRQOL)
2	ti(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools) OR ab(instrument OR instruments OR questionnaire OR questionnaires OR scale OR scales OR tool OR tools)
3	ti("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR 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OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real change" OR "minimal real difference" OR "minimally real change" OR "minimally real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence") OR ab("Validation Studies" OR "reproducibility of results" OR reproducib* OR "psychometrics" OR psychometr* OR clinimetr* OR clinometr* OR "observer variation" OR observer variation OR "discriminant analysis" OR reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation" OR "item correlations" OR "item selection" OR "item selections" OR "item reduction" OR "item reductions" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR "kappa's" OR kappas OR "coefficient of variation" OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure" OR "factor structure" OR dimensionality OR subscale* OR "multitrait scaling analysis" OR "multitrait scaling analyses" OR "item discriminant" OR "interscale correlation" OR "interscale correlations" OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv* OR responsive* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal 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4	#1 AND #2 AND #3
5	ti(Systematic Review) OR ab(Systematic Review)
5	#4 AND #5
6	ti("protocol" OR "addresses" OR "biography" OR "case reports" OR "comment" OR "directory" OR "editorial" OR "festschrift" OR "interview" OR "lectures" OR "legal cases" OR "legislation" OR "letter" OR "news" OR "newspaper article" OR "patient education handout" OR "popular works" OR "congresses" OR "consensus development conference" OR "consensus development conference" OR "practice guideline")
7	#5 NOT #6
8	FILTER: Language (English)
9	FILTER: Period (2008-2018)

S2. Characteristics and references of studies.

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
1	2008	Barbosa & Gaviao	Oral health-related quality of life in children: Part III. Is there agreement between parents in rating their children's oral health-related quality of life? A systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
2	2008	Basra et al	The Dermatology Life Quality Index 1994–2007: a comprehensive review of validation data and clinical results	Studies on the quality of one instrument to measures HRQoL in general population	Disease-specific	One instrument	Multiple properties
3	2008	Carabin et al	Quality of life measurement tools for people living with HIV/AIDS.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
4	2008	Chassany et al	Systematic review: health-related quality of life (HRQOL) questionnaires in gastro-oesophageal reflux disease.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
5	2008	El Achhab et al	Disease-specific health-related quality of life instruments among adults diabetic: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
6	2008	Finger et al	Quality of life in age-related macular degeneration: a review of available vision-specific psychometric tools.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
7	2008	Franic & Bothe	Psychometric evaluation of condition-specific instruments used to assess health-related, quality of life, attitudes, and related constructs in stuttering	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
8	2008	Janssens et al	Health-related quality-of-life measures for long-term follow-up in children after major trauma.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
9	2008	Klassen et al	Clinical research in Pediatric plastic surgery and Systematic review of quality of life questionnaires	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
10	2008	Kluivers et al	Systematic review on recovery specific quality of life instruments	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
11	2008	Langham et al	Health-related quality of life instruments in studies of adult men with testosterone deficiency syndrome: a critical assessment.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
12	2008	Pearce et al	Measuring quality of life in cancer survivors: a methodological review of existing scales	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
13	2008	Price et al	Measures of functional status and quality-of-life in schizophrenia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
14	2008	Quittner et al	Systematic review of health-related quality of life measures for children with respiratory conditions.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
15	2008	Reaney et al	Understanding and assessing the impact of alcoholism on quality of life. A systematic review of the content validity of instruments used to assess health related quality of life in alcoholism	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
16	2008	Schalarman et al	The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
17	2008	Solans et al	Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
18	2008	Tschiesner et al	Content comparison of quality of life questionnaires used in head and neck cancer based on the international classification of functioning, disability and health: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
19	2008	Upton et al	Parent-child agreement across child health-related quality of life instruments: a review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
20	2009	Davies N.	Measuring health-related quality of life in cancer patients.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
21	2009	Derret et al	Outcome after injury-a systematic literature search of studies using the EQ-5D	Studies on the quality of one instrument to measures HRQoL in general population	Generic	One instrument	Multiple properties
22	2009	Epton et al	Quality of life in amyotrophic lateral sclerosis/motor neuron disease: a structured review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
23	2009	Fitzsimmons et al	A systematic review of the use and validation of health-related quality of life instruments in older cancer patients.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
24	2009	Garin et al	Disease-specific health-related quality of life questionnaires for heart failure: A systematic review with meta-analyses.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
25	2009	Garvie et al	Quality of life measurement in paediatric and adolescent populations with HIV: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
26	2009	Guo et al	Measuring health-related quality of life in tuberculosis: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
27	2009	Jay et al	A review of quality of life instruments used in liver transplantation.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
28	2009	Speight et al	Not all roads lead to Rome-a review of quality of life measurement in adults with diabetes.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
29	2009	Street et al	Health related quality of life assessment in metastatic disease of the spine: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
30	2009	Waters et al	Quality of life instruments for children and adolescents with neurodisabilities: How to choose the appropriate instrument.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
31	2009	Wettergren et al	The use, feasibility and psychometric properties of an individualised quality-of-life instrument: A systematic review of the SEIQoL-DW.	Studies on the quality of one instrument to measures HRQoL in general population	Generic	One instrument	Multiple properties
32	2010	Albers et al	Evaluation of quality-of-life measures for use in palliative care: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
33	2010	Branski et al	Measuring quality of life in dysphonic patients: a systematic review of content development in patient-reported outcomes measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
34	2010	Bronsard et al	What are the best outcome measures for assessing quality of life in plaque type psoriasis? A systematic review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
35	2010	Carlon et al	A systematic review of the psychometric properties of Quality of life measures for school children with cerebral palsy	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
36	2010	Chen et al	Measuring Quality of Life in Oncologic Breast Surgery: A Systematic Review of Patient-Reported Outcome Measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
37	2010	Forhan et al	A systematic review of the quality of psychometric evidence supporting the use of an obesity-specific quality of life measure for use with persons who have class III obesity: Diagnostic in Obesity and Complications	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
38	2010	Danquah et al	Quality of life measures for patients on hemodialysis: a review of psychometric properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
39	2010	Hill et al	Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
40	2010	Kamalski et al	Measuring disease-specific health-related quality of life to evaluate treatment outcomes in tinnitus patients: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
41	2010	Klassen et al	Quality of life questionnaires for children with cancer and childhood cancer survivors: a review of the development of available measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
42	2010	Kwon et al	Quality of life of women with urinary incontinence: a systematic literature review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
43	2010	Luckett et al	Assessing health-related quality of life in gynecologic oncology: a systematic review of questionnaires and their ability to detect clinically important differences and change.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
44	2010	Palfreyman et al	Assessing current health-related quality of life questionnaires administered to patients with venous ulcers: Can they be used in economic evaluations?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
45	2010	Palfreyman et al	A systematic review of health-related quality of life instruments used for people with venous ulcers: an assessment of their suitability and psychometric properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
46	2010	Passarelli et al	Validity Studies of Quality of Life Instruments for Eating Disorders	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
47	2010	Riordain & McCreary	The use of quality of life measures in oral medicine: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in general population	Both	More than two instruments	Multiple properties
48	2010	Speight & Howarth	Quality of life in restless legs syndrome: A systematic review of clinical trials and a critical review of instruments.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
49	2010	Street et al	Introducing a New Health Related Quality of Life Outcome tool for metastatic disease of the spine	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
50	2010	Zeng et al	Quality of life measurement in women with cervical cancer: implications for Chinese cervical cancer survivors	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
51	2011	Carlton & Kaltenthaler	Health-related quality of life measures (HRQoL) in patients with amblyopia and strabismus: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
52	2011	Carlton & Kaltenthaler	Amblyopia and quality of life: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
53	2011	da Silva et al	Quality of life assessment after Acute Coronary Syndrome: Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
54	2011	Eckstein et al	Measuring Quality of Life in Cleft Lip and Palate patients: currently available patient reported outcomes	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
55	2011	Fayed et al	Health status and QOL instruments used in childhood cancer research: deciphering conceptual content using World Health Organization definitions	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
56	2011	Glover et al	Understanding and assessing the impact of End-Stage renal disease on QOL. A systematic review of the content validity...	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
57	2011	Hounsoms et al	EQ-5D as a Quality of Life measure in people with dementia and their carers: evidence and key issues	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
58	2011	Janssen et al	The use of the EQ-5D preference based health status measure in adults with type 2 diabetes mellitus	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
59	2011	Kowal- Bielecka	Analysis of the validation status of WOL and Functional measures in Pulmonary Arterial Hypertension.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	Comparison of two instruments	Multiple properties
60	2011	Lien et al	Comparison of the EORTC QLQ-C15-PAL and the FACIT-Pal for assessment of quality of life in patients with advanced cancer	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	One specific property
61	2011	Luckett et al	Choosing between the EORTC QLQ-C30 and FACT for measuring health related quality of life in cancer clinical research: issues, evidence and recommendations	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
62	2011	Mordiffi et al	Quality of life tools for adult patients with cancer undergoing chemotherapy: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
63	2011	Noyes et al	EQ-5D for the Assessment of Health-Related Quality of Life and Resource Allocation in Children: A Systematic Methodological Review	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
64	2011	Papaioannou et al	How valid and responsive are generic health status measures, such as EQ-5D and SF-36, in schizophrenia? A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
65	2011	Reavey et al	Measuring quality of life and patient satisfaction after body contouring: a systematic review of patient-reported outcome measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
66	2011	Schiarti et al	Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning Quality of life in people with venous leg ulcers: an integrative review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
67	2011	Tayyem et al	Analysis of Health-Related quality of life instruments measuring the impact of bariatric surgery: systematic review of instruments and their content validity	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
68	2011	Virginia et al	Quality of life in people with venous leg ulcers: an integrative review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
69	2011	Whitehurst et al	Systematic review and empirical comparison of contemporaneous EQ-5D and SF-6D group mean scores	Studies on the quality of a selection of instruments to measure HRQoL in general population	Generic	Comparison of two instruments	One specific property
70	2011	Wilson et al	Spinal cord injury and quality of life: a systematic review of outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
71	2012	Bhatt et al	Health outcome measures for diabetes mellitus: a review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
72	2012	Chopra & Kamal	A systematic review of quality of life instruments in long-term breast cancer survivors.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
73	2012	Cormier et al	Health related quality of life in patients with melanoma. Overview of instruments and outcomes	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
74	2012	Correia & De Carlo	Evaluation of quality of life in a palliative care context: an integrative literature review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
75	2012	Gräske et al	Dementia-Specific Quality of Life Instruments and Their Appropriateness in Shared-Housing Arrangements--A Literature Study.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
76	2012	Ho et al	Measuring Quality of life and patient satisfaction in facial paralysis patients: a systematic review of patient reported outcome measures	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
77	2012	Hogg et al	Measures of health related quality of life in diabetes-related foot disease: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
78	2012	Luquiens et al	Quality of life among alcohol-dependent patients: how satisfactory are the available instruments? A systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
79	2012	Madureira et al	Quality of life measurements in patients with osteoporosis and fractures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
80	2012	Milne et al	Measuring Health-Related Quality of Life for Patients with Diabetic Retinopathy	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
81	2012	Ojo et al	A Systematic Review of Head and Neck Cancer Quality of Life Assessment Instruments	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
82	2012	Popovic et al	Comparison of the EORTC QLQ-BM22 and the FACT-BP for assessment of quality of life in cancer patients with bone metastases	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
83	2012	Quintanilla et al	Comparison of disease-specific quality of life instruments in the assessment of chronic rhinosinusitis	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
84	2012	Rajmil et al	Health-related quality of life measurement in children and adolescents in Ibero-American countries, 2000 to 2010.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
85	2012	Shin & Shin	Measurement of quality of life in menopausal women: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
86	2012	Smith et al	Measuring health-related quality of life in diabetic peripheral neuropathy: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
87	2012	Tosh et al	A review of generic preference-based measures of health-related quality of life in visual disorders.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
88	2012	Townsend-White et al	Review: a systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
89	2012	Walker et al	Are they worth it? A systematic review of QOL instruments for use with mentally disordered offenders	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
90	2012	Whitehurst et al	A review of preference-based health-related quality of life questionnaires in spinal cord injury research.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
91	2012	Yip et al	Reliability, validity and feasibility of quality of life instruments for adult patients with cancer undergoing chemotherapy: Result from a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
92	2013	Al Sayah et al	Health related quality of life measures in Arabic speaking populations: A systematic review on cross-cultural adaptation and measurement properties	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
93	2013	Basra et al	Infants' Dermatitis Quality of Life Index: a decade of experience of validation and clinical application.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
94	2013	Castelino et al	Comparison of the psychometric properties of health-related quality of life measures used in adults with systemic lupus erythematosus: a review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
95	2013	Chandratne et al	Health-related quality of life in gout: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
96	2013	Chow et al	Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
97	2013	Davis et al	A review of the psychometric performance of the EQ-5D in people with urinary incontinence.	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
98	2013	de Almeida et al	Quality of life instruments for skull base pathology: Systematic review and methodologic appraisal	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
99	2013	Djan et al	A systematic review of questionnaires to measure the impact of appearance on quality of life for head and neck cancer patients.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
100	2013	Gakhar et al	Health-related quality of life assessment after antiretroviral therapy: A review of the literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
101	2013	Hitzig et al	Identifying and classifying quality-of-life tools for assessing pressure ulcers after spinal cord injury.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
102	2013	Jabir et al	Assessing Improvement in Quality of Life and Patient Satisfaction following Body Contouring Surgery in Patients with Massive Weight Loss: A Critical Review of Outcome Measures Employed.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
103	2013	Lee et al	A systematic review of patient-reported outcome instruments of nonmelanoma skin cancer in the dermatologic population	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
104	2013	Levterova et al	Instruments for disease-specific quality-of-life measurement in patients with type 2 diabetes mellitus--a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
105	2013	Li et al	Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
106	2013	Lin et al	Evaluation of content on EQ-5D as compared to disease-specific utility measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
107	2013	Mitera et al	Quality of life measures used in radiation therapy trials for patients with metastatic spinal cord compression (MSCC)	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
108	2013	Mogos et al	A Systematic Review of Quality of Life Measures in Pregnant and Postpartum Mothers.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
109	2013	Mousavi et al	Assessment of Questionnaires Measuring Quality of Life in Infertile Couples: A Systematic Review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
110	2013	Moyle et al	Health-related quality of life in older people with severe dementia: challenges for measurement and management	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
111	2013	Muzzatti et al	Assessing quality of life in long-term cancer survivors: a review of available tools.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
112	2013	Paltzer et al	Measuring the health-related quality of life (HRQoL) of young children in resource-limited settings: a review of existing measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
113	2013	Perales et al	Health-related quality-of-life instruments for Alzheimer's disease and mixed dementia.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
114	2013	Pusic et al	Quality of life among breast cancer patients with lymphedema: A systematic review of patient-reported outcome instruments and outcomes.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
115	2013	Roncada et al	Specific instruments to assess quality of life in children and adolescents with asthma.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
116	2013	Salek et al	Clinical experience and psychometric properties of the Children's Dermatology Life Quality Index (CDLQI), 1995-2012	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
117	2013	Testart et al	Quality of life and other outcome measures in caregivers of patients with schizophrenia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
118	2013	Weldam et al	Evaluation of Quality of Life instruments for use in COPD care and research: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
119	2013	Wheelright et al	A systematic review of health-related quality of life instruments in patients with cancer cachexia	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
120	2013	Yang et al	An assessment of validity and responsiveness of generic measures of health-related quality of life in hearing impairment.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
121	2014	Anthony et al	Considering quality of life for children with cancer: a systematic review of patient-reported outcome measures and the development of a conceptual model	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
122	2014	Aspden et al	Quality-of-life measures for use within care homes: a systematic review of their measurement properties.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
123	2014	Balioussis et al	Identifying and classifying quality of life tools for assessing spasticity after spinal cord injury.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
124	2014	Brazier et al	A systematic review, psychometric analysis and qualitative assessment of generic preference-based measures of health in mental health populations and the estimation of mapping functions from widely used specific measures	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties

	ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
1								
2	125	2014	Chiu et al	Comparison of three shortened questionnaires for assessment of quality of life in advanced cancer.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
3								
4	126	2014	Chow et al	Comparison of the EORTC QLQ-BN20 and the FACT-Br quality of life questionnaires for patients with primary brain cancers: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
5	127	2014	Garin et al	Assessing health-related quality of life in patients with heart failure: a systematic, standardized comparison of available measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
6								
7	128	2014	Gilchrist et al	Assessment of the quality of measures of child oral health-related quality of life.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
8								
9	129	2014	Grubbs et al	A review of quality of life measures in dry eye questionnaires.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
10	130	2014	Gupta et al	The COPD assessment test: a systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
11								
12	131	2014	Hawkins et al	A Systematic Review of Functional and Quality of Life Assessment after Major Lower Extremity Amputation	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
13	132	2014	Hewison et al	An evaluative review of questionnaires recommended for the assessment of quality of life and symptom severity in women with urinary incontinence.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
14								
15	133	2014	Ikeda et al	Assessment of quality of life in children and youth with autism spectrum disorder: a critical review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
16								
17	134	2014	Jardine et al	Self-reported quality of life of young children with conditions from early infancy: a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
18								
19	135	2014	Kuspinar et al	A review of the psychometric properties of generic utility measures in multiple sclerosis.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
20	136	2014	Lee et al	Measurement properties of rheumatoid arthritis-specific quality-of-life questionnaires: Systematic review of the literature.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
21								
22	137	2014	Lieu et al	Pediatric quality of life in children with otolaryngologic disease: what inventories are available and what is still needed?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
23								
24	138	2014	Longworth et al	Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
25	139	2014	Makai et al	Quality of life instruments for economic evaluations in health and social care for older people: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
26								
27	140	2014	Niu et al	Health-related quality of life in women with breast cancer: a literature-based review of psychometric properties of breast cancer-specific measures.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
28								
29	141	2014	Salvilla et al	Disease-specific health-related quality of life instruments for IgE-mediated food allergy	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
30	142	2014	Schmidt et al	Assessing quality of life in patients with prostate cancer: a systematic and standardized comparison of available instruments.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
31								
32	143	2014	Smith et al	Most domains of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30 are reliable.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	One specific property
33								
34	144	2014	Souza et al	Tools used for evaluation of Brazilian children's quality of life	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
35	145	2014	Swigris et al	The psychometric properties of the St George's Respiratory Questionnaire (SGRQ) in patients with idiopathic pulmonary fibrosis: a literature review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
36								
37	146	2014	Timmerman et al	Psychometric characteristics of health-related quality-of-life questionnaires in oropharyngeal dysphagia.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
38	147	2014	Treanor & Donnelly	A methodological review of the Short Form Health Survey 36 (SF-36) and its derivatives among breast cancer survivors	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
39								
40	148	2014	Watt et al	Assessing health-related quality of life in patients with benign non-toxic goitre	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
41								
42	149	2014	Wolpe et al	Assessing the impact of urinary incontinence on quality of life: systematic review of instruments in Portuguese.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
150	2015	Alrubaiy et al	Systematic review of health-related quality of life measures for inflammatory bowel disease	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
151	2015	Aspesberro et al	Health-related quality of life following pediatric critical illness.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
152	2015	Bédard et al	Systematic review of vision-related quality of life questionnaires for older institutionalised seniors with dementia	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
153	2015	Bowling et al	Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
154	2015	Conijn et al	Assessing the quality of available patient reported outcome measures for intermittent claudication: a systematic review using the COSMIN checklist.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
155	2015	de Climens et al	Review of patient-reported outcome instruments measuring health-related quality of life and satisfaction in patients with type 2 diabetes treated with oral therapy.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
156	2015	Dronavalli & Thompson	A systematic review of measurement tools of health and well-being for evaluating community-based interventions.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
157	2015	Hamoen et al	Measuring health-related quality of life in men with prostate cancer: A systematic review of the most used questionnaires and their validity.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
158	2015	Hu et al	How Quality of Life as Patient-Reported Outcome Has Been Studied for Rheumatoid Arthritis in Chinese-Speaking Population	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
159	2015	Janssens et al	Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
160	2015	Launois et al	Health-related quality-of-life scales specific for chronic venous disorders of the lower limbs.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
161	2015	Monticone et al	Measurement properties of translated versions of the Scoliosis Research Society-22 Patient Questionnaire, SRS-22: A systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
162	2015	Nguyen et al	EORTC QLQ-BR23 and FACT-B for the assessment of quality of life in patients with breast cancer: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
163	2015	Oliveira et al	Evaluation of cross-cultural adaptation and measurement properties of breast cancer-specific quality-of-life questionnaires: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
164	2015	Polinder et al	Health-related quality of life after TBI: a systematic review of study design, instruments, measurement properties, and outcome.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
165	2015	Taghavi et al	Health-related quality of life in polycystic ovary syndrome patients: A systematic review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
166	2015	Wong et al	Systematic review recommends the European Organization for Research and Treatment of Cancer colorectal cancer-specific module for measuring quality of life in colorectal cancer patients	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
167	2016	Algar et al	Measuring the quality of life and well-being of people with dementia: A review of observational measures.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
168	2016	Bryant et al	A Systematic Review of Psychometric Properties of Health-Related Quality-of-Life and Symptom Instruments in Adult Acute Leukemia Survivors.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
169	2016	Coombes et al	Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
170	2016	Dichter et al	Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements-a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
171	2016	Ganesh et al	Comparison of the FACT-C, EORTC QLQ-CR38, and QLQ-CR29 quality of life questionnaires for patients with colorectal cancer: a literature review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
172	2016	Gutiérrez-Vargas et al	Instruments to measure the quality of life in patients with oral mucositis undergoing oncological treatment: a systematic review of the literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
173	2016	Hand et al	Measuring health-related quality of life in adults with chronic conditions in primary care settings: Critical review of concepts and 3 tools	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
174	2016	Heinl et al	Measurement properties of adult quality of life measurement instruments for eczema: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
175	2016	Kotecha et al	Patient-Reported Outcomes for Quality of Life Assessment in Atrial Fibrillation: A Systematic Review of Measurement Properties.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
176	2016	Lee et al	A systematic review of measurement properties of the instruments measuring health-related quality of life in patients with irritable bowel syndrome.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
177	2016	Maratia et al	Assessing health-related quality of life in patients with breast cancer: a systematic and standardized comparison of available instruments using the EMPRO tool.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
178	2016	Mestre et al	Rating scales for behavioral symptoms in Huntington's disease: Critique and recommendations.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
179	2016	Spinou et al	The validity of health-related quality of life questionnaires in bronchiectasis: a systematic review and meta-analysis	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
180	2016	Tapia et al	Health-Related Quality-of-Life Instruments for Pediatric Patients with Diverse Facial Deformities: A Systematic Literature Review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
181	2016	Wong et al	A systematic review of quality of thyroid-specific health related quality of life instruments recommends ThyPRO for patients with benign thyroid diseases	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
182	2016	Woo et al	Comparison of the EORTC STO-22 and the FACT-Ga quality of life questionnaires for patients with gastric cancer.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	Comparison of two instruments	Multiple properties
183	2017	Ahmadi et al	Acceptability, reliability, and validity of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) across languages: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
184	2017	Baghdadli et al	Measurement properties of screening and diagnostic tools for autism spectrum adults of mean normal intelligence: A systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
185	2017	Best et al	Identifying and classifying quality of life tools for neurogenic bladder function after spinal cord injury: A systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
186	2017	Chen et al	Inflammatory bowel disease-specific health-related quality of life instruments: a systematic review of measurement properties.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
187	2017	Frew et al	Disease-specific health related quality of life patient reported outcome measures in Genodermatoses: a systematic review and critical evaluation.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
188	2017	Heaney et al	A review of the psychometric properties and use of the Rheumatoid Arthritis Quality of Life Questionnaire (RaQoL) in clinical research	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
189	2017	Heinl et al	Measurement properties of quality-of-life measurement instruments for infants, children and adolescents with eczema: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
190	2017	Kandel et al	Patient-reported Outcomes for Assessment of Quality of Life in Refractive Error: A Systematic Review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
191	2017	Kao et al	Scoping Review of Pediatric Tonsillectomy Quality of Life Assessment Instruments	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
192	2017	Khan et al	Health Status and Quality of Life in Tuberculosis: Systematic Review of Study Design, Instruments, Measuring Properties and Outcomes.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
193	2017	Kwan et al	A systematic review of quality-of-life domains and items relevant to patients with spondyloarthritis	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
194	2017	Limpberg et al	Health-related quality of life questionnaires in individuals with haemophilia: a systematic review of their measurement properties	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
195	2017	Lucendo et al	Systematic review: health-related quality of life in children and adults with eosinophilic oesophagitis-instruments for measurement and determinant factors. Systematic review: health-related quality of life in children and adults with eosinophilic oesophagitis-instruments for measurement and determinant factors.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
196	2017	Page et al	Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
197	2017	Poku et al	Systematic review assessing the measurement properties of patient-reported outcomes for venous leg ulcers.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
198	2017	Roydhouse et al	Systematic review of caregiver responses for patient health-related quality of life in adult cancer care.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
199	2017	Strada et al	Measuring quality of life in opioid-dependent people: a systematic review of assessment instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
200	2017	Sullivan et al	Assessing quality of life of patients with hypospadias: A systematic review of validated patient-reported outcome instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
201	2017	Tang et al	Assessing quality of life in diabetes: II - Deconstructing measures into a simple framework.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
202	2017	Tax et al	Measuring health-related quality of life in cervical cancer patients: a systematic review of the most used questionnaires and their validity.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	Comparison of two instruments	Multiple properties
203	2017	Xin & McIntosh	Assessment of the construct validity and responsiveness of preference-based quality of life measures in people with Parkinson's: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
204	2018	Aber et al	Themes that Determine Quality of Life in Patients with Peripheral Arterial Disease: A Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
205	2018	Chiarotto et al	Evidence on the measurement properties of health-related quality of life instruments is largely missing in patients with low back pain, a systematic review.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiple properties
206	2018	Cornelissen et al	Quality of Life Questionnaires in Breast Cancer-Related Lymphedema Patients: Review of the Literature	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
207	2018	de Vries et al	Recommendations on the most suitable quality-of-life measurement instruments for bariatric and body contouring surgery: a systematic review.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
208	2018	Dow et al	How best to assess quality of life in informal carers of people with dementia: A systematic review of existing outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
209	2018	Grobet et al	Application and measurement properties of EQ-5D to measure quality of life in patients with upper extremity orthopaedic disorders: a systematic literature review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
210	2018	Haywood et al	Assessing health-related quality of life (HRQoL) in survivors of out-of-hospital cardiac arrest: A systematic review of patient-reported outcome measures	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
211	2018	Luan et al	A Review of Studies of Quality of Life for Chinese-Speaking Patients with Ischemic Heart Disease	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
212	2018	Mason et al	Evaluating patient-reported outcome measures (PROMs) for bladder cancer: a systematic review using the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN)	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
213	2018	Mohammed et al	Pharmaceutical care and health related quality of life outcomes over the past 25 years: Have we measured dimensions that really matter?	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	One specific property
214	2018	Mpundu-Kaambwa et al	A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy.	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
215	2018	Pollo et al	Evaluation Instruments for Quality of Life Related to Melasma: An Integrative Review.	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	One instrument	Multiple properties
216	2018	Tian & Cao	Systematic review of the psychometric properties of disease-specific, quality-of-life questionnaires for patients with hepatobiliary or pancreatic cancers	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
217	2018	van Ierssel et al	Identifying the concepts contained within health-related quality of life outcome measures in concussion research using the International Classification of Functioning, Disability, and Health as a reference: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
218	2018	van Roij et al	Measuring health-related quality of life in patients with advanced cancer: a systematic review of self-administered measurement instruments.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
219	2018	Yarlas et al	Psychometric validation of the SF-36® Health Survey in ulcerative colitis: results from a systematic literature review	Studies on the quality of one instrument to measure HRQoL in a particular population	Generic	One instrument	Multiple properties
220	2018	Yazdani et al	Psychometric Properties of Quality of Life Assessment Tools in Morbid Obesity: A Review of Literature.	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
221	2018	Zaror et al	Assessing oral health-related quality of life in children and adolescents : a systematic review and standardized comparison of available instruments	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
222	2018	Hettiarachchi et al	Pediatric Quality of Life Instruments in Oral Health Research: A Systematic Review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
223	2019	Balk et al.	Psychometric properties of functional, ambulatory, and quality of life instruments in lower limb amputees: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
224	2019	Belayneh et al.	A systematic review of the psychometric properties of the cross-cultural adaptations and translations of the prolapse quality of life questionnaire	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiples properties
225	2019	Bull et al.	Systematic review: measurement properties of patient-reported outcome measures evaluated with childhood brain tumor survivors or other acquired brain injury	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
226	2019	Choukou et al.	Identifying and classifying quality of life tools for assessing neurogenic bowel dysfunction after spinal cord injury	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
227	2019	Daliya et al.	A systematic review of patient reported outcome measures (PROMs) and quality of life reporting in patients undergoing laparoscopic cholecystectomy	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
228	2019	Gabes et al.	Measurement properties of quality-of-life outcome measures for children and adults with eczema: An updated systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
229	2019	Gondivkar et al.	Assessment of oral health-related quality of life instruments for oral submucous fibrosis: A systematic review using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
230	2019	Hasanvand et al.	A Critical Review of Instruments Measuring the Quality of Life of Cancer Patients in Iranian Studies and Their Psychometrics Properties	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
231	2019	Hughes et al.	Psychometric properties and feasibility of use of dementia specific quality of life instruments for use in care settings: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
232	2019	Hunt et al.	Quality of life in older adults after traumatic brain injury: a systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
233	2019	Kamilu et al.	Quality of life assessment scales in polio survivors: a scoping review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
234	2019	Lamsal et al.	Generic preference-based health-related quality of life in children with neurodevelopmental disorders: a scoping review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Generic	More than two instruments	Multiples properties
235	2019	Moshki et al.	The content comparison of health-related quality of life measures in heart failure based on the international classification of functioning, disability, and health: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	One specific property
236	2019	Speyer et al.	"Measurement properties of self-report questionnaires on health related quality of life and functional health status in dysphonia: a systematic review using the COSMIN taxonomy"	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties
237	2019	van der Hout et al.	Measuring health-related quality of life in colorectal cancer patients: systematic review of measurement properties of the EORTC QLQ-CR29	Studies on the quality of one instrument to measures HRQoL in a particular population	Generic	One instrument	Multiple properties
238	2019	Vasconcelos et al.	Quality of Life in Women with Defecatory Dysfunctions: Systematic Review of Questionnaires Validated in the Portuguese Language	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
239	2020	Crudgington et al.	Epilepsy-specific patient-reported outcome measures of children's health related quality of life: a systematic review of measurement properties	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiples properties
240	2020	Furtado et al.	Cross-cultural adaptations and measurement properties of the WORC(Western Ontario rotator cuff index): a systematic review	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiples properties
241	2020	Jones et al.	A feasibility assessment of functioning and quality of life patient reported outcome measures in adult epilepsy clinics. A systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiples properties
242	2020	Killian et al.	Measurement of health-related quality of life in pediatric organ transplantation recipients: a systematic review of the PedsQL transplant module	Studies on the quality of one instrument to measures HRQoL in a particular population	Disease-specific	One instrument	Multiples properties

Note: The concept "Both" is referred to generic and disease-specific instruments.

ID	Year	Author	Title	Type of review	Instruments assessed	Number Instruments	Measurement Properties
243	2020	Losada-Puente	A systematic review of the assessment of quality of life in adolescents	Studies on the quality of a selection of instruments to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
244	2020	Moller et al.	Specific measures of quality of life in patients with multimorbidity in primary healthcare: a systematic review on patient-reported outcomes measures' adequacy of measurement	Studies on the quality of one instrument to measure HRQoL in a particular population	Disease-specific	More than two instruments	Multiple properties
245	2020	Qian et al.	Measurement properties of commonly used generic preference-based measures in East and South-East Asia: a systematic review	Studies on the quality of a selection of instruments to measure HRQoL in general population	Generic	More than two instruments	Multiple properties
246	2020	Santana-Berlanga et al	Instruments to measure quality of life in institutionalised older adults: systematic review	Studies on the quality of all available validated instruments to measure HRQoL in a particular population	Both	More than two instruments	Multiple properties

Note: The concept "Both" is referred to generic and disease-specific instruments.

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Supplementary File S3. Tools to assess measurement properties.

¹Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) (2010, 2018)

1. Reliability	The degree to which an instrument is free from random error.
1.1. Internal consistency	The degree of the interrelatedness among the items. <i>In COSMIN (2018) internal consistency is derived from internal structure evaluation.</i>
1.2. Reliability	Scores for patients who have not changed are the same for repeated measurement under several conditions
1.3. Measurement error	The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
2. Validity	The degree to which a Health Related-Patient Reported Outcome (HR-PRO) instrument measures the construct(s) it purports to measure. <i>Concept with major changes in COSMIN (2018) the definition and classification changed to content, structural, cross-cultural validity/measurement invariance, criterion, and hypothesis testing for construct validity (convergent, discriminative or known groups)</i>
2.1. Content (including Face validity)	The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured (or looks as though the items are an adequate reflection)
2.2. Construct (Structural, Hypothesis, Cross-cultural)	The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured. Scores of an HR-PRO instrument are consistent with hypotheses. Performance of the items on a translated or culturally adapted HR-PRO instrument is an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
2.3. Criterion	The degree to which the scores of an HR-PRO instrument are an adequate reflection of a "gold standard"
3. Responsiveness	The instrument's ability to detect change over time in the construct to be measured
4. Interpretability	The degree to which one can assign easily understood meaning to an instrument's quantitative scores. <i>A complementary attribute, not a measurement property in COSMIN (2018), plus feasibility</i>

²Quality Criteria for Measurement Properties (Terwee et al. 2007)

1. Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire
2. Internal consistency	The extent to which items in a (sub)scale are inter correlated, thus measuring the same construct
3. Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard
4. Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured
5. Reproducibility	
5.1. Agreement	The extent which the scores on repeated measures are close to each other (absolute measurement error)
5.2. Reliability	The extent to which patients can be distinguish from each other (relative measurement error)
6. Responsiveness	The ability of a questionnaire to detect clinically important changes over time
7. Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score
8. Interpretability	The degree to which one can assign qualitative meaning to quantitative scores

³Attributes and Criteria to assess Health Status and Quality of Life Instruments (1996, 2002)

1. Conceptual and measurement model	The rationale for a description of the concepts and the populations that a measure is intended to assess and the expected relationship between these concepts
2. Reliability	The degree to which an instrument is free from random error
2.1. Internal consistency	The precision of a scale, homogeneity (inter correlations) of items at one point in time
2.2. Reproducibility	Stability of an instrument over time (test-retest) and inter-rater agreement
3. Validity	The degree to which the instrument measures what it purports to measure.
3.1. Content validity	The domain of an instrument is appropriate relative to its intended use
3.2. Construct-related validity	Interpretation of scores based on theoretical implications associated with the construct to be measured
3.3. Criterion-related validity	The extent to which scores of the instrument are related to a criterion measure (gold standard).
4. Responsiveness	The instrument's ability to detect change overtime
5. Interpretability	The degree to which one can assign easily understood meaning to an instrument's quantitative scores
6. Respondent and administrative burden	The time, effort, and other demands placed on those to whom the instrument is administered (respondent burden) or on those who administer the instrument (administrative burden)
7. Administration/Accessible forms	Data collection method, including self-report, interviewer-administered, trained observer rating, computer-assisted interviewer-administered, performance-based measures. Accommodations (e.g. Braille)
8. Cultural and language adaptations	Assessment of conceptual and linguistic equivalence.

¹Prinsen C, Mokkink L, Bouter L, et al. COSMIN guideline for systematic reviews of Patient-Reported Outcome Measures. *Qual Life Res.* 2018;0(0):1-11. doi:10.1007/s11136-018-1798-3. Mokkink L, Terwee C, Patrick D, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol.* 2010;63(7):737-745. doi:10.1016/j.jclinepi.2010.02.006. ²Terwee C, Bot S, de Boer M, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol.* 2007;60(1):34-42. doi:10.1016/j.jclinepi.2006.03.012. ³Lohr KN, Aaronson NK, Alonso J, Burnam MA, Patrick DL, Perrin EB, et al. Evaluating quality-of-life and health status instruments: Development of scientific review criteria. *Clin Ther.* 1996;18(5):979-92. Aaronson N, Alonso J, Burnam A, et al. Assessing health status and quality-of-life instruments and review criteria. *Qual Life Res.* 2002;11(3):193-215.

Supplementary File S3. Continue

⁴Health Status Measures in Economic Evaluation (1999, 2017)

1.	Practicality	Time to complete the instrument. Response rate. Rate of completion
2.	Reliability	The degree to which an instrument is free from random error
2.1.	Test-retest	Ability to reproduce results over repeated measurements with the minimum amount of random error
2.2.	Inter-rater	Reliability between places of administration
3.	Validity	Dimensions covered. Items relevant for population. Ability of an instrument to reflect known or expected differences and changes in health to reflect preferences.
3.1.	Descriptive validity (Content, Face, Construct)	
3.2.	Valuation	Values used. Main assumptions of the model and how well the preferences of the patients and decision makers are likely to conform to these assumptions.
3.3.	Empirical	Evidence regarding whether or not a measure could generate values which reflect people's preferences using revealed preferences; stated preferences or hypothetical preferences as criteria

⁵Guidance for Industry patient-reported outcomes measures (2006, 2009)

1.	Conceptual model	Conceptual framework.
2.	Administration/Accessible forms	Data collection method, including self-report or interviewer, format and scoring. Adaptations for children and adolescents, patients cognitively impaired, or unable to communicate, culture and language subgroups
3.	Respondent/Administrator Burden	Length, formatting, font size, instructions for items, privacy, time, need for physical support in responding.
4.	Reliability	
4.1.	Test retest	Stability of scores over time when no change has occurred in the concept of interest
4.2.	Internal consistency	Whether the items in a domain are inter correlated, as evidenced by an internal consistency statistic
4.3.	Inter interviewer reproducibility	Agreement between responses when the PRO is administered by two or more different interviewers
5.	Validity	
5.1.	Content validity	Whether items and response options are relevant and are comprehensive measures of the domain or concept
5.2.	Construct validity (Hypotheses testing, including discriminant, convergent, known groups validity)	Ability to measure the concept. Whether relationships among items, domains, and concepts conform to what is predicted by the conceptual framework for the PRO instrument itself and its validation hypotheses
6.	Criterion	Scores of a PRO instrument are related to a known gold standard. When the gold standard is not possible to be evaluated, criterion measure assesses sensitivity specificity, and predictive values
7.	Responsiveness. Ability to detect change	Evidence that the instrument is equally sensitive to gains and losses in the measurement concept and to change at all points within the entire range expected for the clinical trial population

⁶Evaluating patient-based outcomes measures for use in clinical trials (1998) (Fitzpatrick's criteria)

1.	Reliability	The extent to which the instrument is free from random error and may be considered as the amount of a score that is a signal rather than noise
1.1.	Internal consistency	The extent to which individual items in a questionnaire scale measure the same construct (homogeneity of items in the scale)
1.2.	Reproducibility (test retest)	Whether and instrument yields the same results on repeated applications, when respondents have not changed on the domain being measured. Stability of the questionnaire over time
2.	Validity	The extent to which it measures what it purports to measure
2.1.	Criterion and Predictive validity	When a new measure correlates with other measures generally accepted as a more accurate variable. When the new measure correlates with future values of the criterion variable
2.2.	Face and content validity	Face validity refers to what an item appears to measure based on its manifest content. Content validity refers to how well a measurement battery covers important parts of the health components to be measured
2.3.	Construct validity	A health status measure is intended to assess a postulated underlying construct.
2.3.1.	Convergent validity	Correlations are expected to be strongest with the most related constructs
2.3.2.	Discriminant validity	Correlations are expected to be weakest with most distally related constructs
2.3.3.	Internal structure	A set of assumed relationships between underlying constructs
2.3.4.	Validity for specific purposes	Measures need to be assessed for health status, personal preferences and utilities, and social values.
3.	Responsiveness (sensitivity to change)	Ability to detect changes over time. Effect size, sensitivity and specificity of scores.
4.	Precision	How precise are the distinctions between levels of health and illness (sensitivity). Format categories.
5.	Interpretability	How meaningful are the scores from an instrument
6.	Acceptability	Evidence of acceptability is associated with high response rates. Respondent burden.
7.	Cultural applicability	Rigorous translation can by itself establish the appropriateness of an instrument
8.	Feasibility	Impact of different patient-based outcome measures upon staff and researchers. Administrator burden.

⁷International Classification of Functioning (ICF) & International Classification of Functioning for Children and Youth (ICFCY) (2019)

1.	Content validity	Health and Health-related domains.
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⁴ Brazier J, Deverill M, Green C, Harper R, Booth A. A review of the use of health status measures in economic evaluation. *Health Technol Assess (Rockv)*. 1999;3(9). Brazier J, Ara R, Rowen D, Chevrou-Severac H. A Review of Generic Preference-Based Measures for Use in Cost-Effectiveness Models. *Pharmacoeconomics*. 2017;35(s1):21-31. doi:10.1007/s40273-017-0545-x. ⁵Department of Health and Human Services. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims; draft guidance. *Health Qual Life Outcomes*. 2006;20:1-20. doi:10.1186/1477-7525-4-79. Department of Health and Human Services. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.; 2009. doi:10.1111/j.1524-4733.2009.00609.x. ⁶Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating Patient-Based Outcome Measures for Use in Clinical Trials. Vol 2.; 1998. doi:9812244. ⁷World Health Organization. International Classification of Functioning (ICF). www.who.int/classifications/icf/en/.

Supplementary File S3. Continue

⁸Evaluating Measures of Patient Reported Outcomes (EMPRO) (2008)

1.	Conceptual and Measurement model	The rationale for description of the concept and the populations that a measure is intended to assess and the relationship between these concepts
2.	Reliability	The degree to which an instrument is free from random error
2.1.	Internal consistency	The precision of a scale, based on the homogeneity of the scale's items at one point in time
2.2.	Reproducibility	The stability of an instrument over time (test retest) and inter-rater agreement at one point in time
3.	Validity (including content, criterion, hypotheses testing and construct)	The degree to which the instrument measures what it purports to measure
4.	Responsiveness	The ability to detect change over time
5.	Interpretability	The degree to which one can assign meaning to an instrument's quantitative scores
6.	Burden (Respondent/Administrator burden)	Time, effort and other demands placed on the administration of the instrument
7.	Administration mode	Data collection method. For each mode of administration, the information about validity, reliability, responsiveness, interpretability and burden should be assessed.
8.	Cultural and language adaptations	Methods to achieve linguistic equivalence are adequately described and appropriate. Differences from the original are adequately described and appropriate.

⁹Spinal Cord Injury Criteria (2008, 2016)

1.	Content	Description. Items. Scale development. Internal structure or subscales
2.	Administration/Accessible forms	Data collection method. Items, time, training, burden of administering. Disability adaptation (e.g. Braille)
3.	Reliability (test retest, internal consistency)	Degree to which an instrument is consistent or free from random error
4.	Criterion oriented validity (concurrent, predictive, discriminant, and clinical validity)	Scale predicts other measures of the same construct. Gold standard and/or sensitivity and specificity. Scale distinguish between scores and/ or groups. Clinical utility, also called prescriptive and consequential validity
5.	Responsiveness, sensitivity to change	Evidence of change in expected direction using methods such as standardized effect sizes
6.	Floor and ceiling effects	Floor and ceiling issues can determine whether change is detected or obscured by the measure
7.	Population application (Applicability in SCI groups, languages, norms)	Description of use in people with spinal cord injury (vs other people). Information of norms are available. Available in other languages

¹⁰Criteria for Assessing the Tools of Disability Outcomes Research (2000) (Andresen's Tool)

1.	Conceptual model	Relevant domains are completely covered
2.	Norms, standard values	Published data (or public-domain data) are available for both general population and with disabilities
3.	Measurement model	Tool captures the detail and breadth of real differences among persons, includes floor/ceiling effects
4.	Instrument bias	In practical or statistical terms, individual questions (or scores) are biased for the population
5.	Respondent burden	Length and content are acceptable to the intended subjects
6.	Administrative burden	Ease to administer, score and interpret
7.	Reliability (test retest and internal consistency)	Instrument gives a consistent answer
8.	Validity (discriminant, convergent, structure)	The tool measures what it purports to measure. It distinguish among different levels of mobility
9.	Responsiveness	Instrument is sensitive to changes in interventions
10.	Administration/Accessible forms	Data collection method, as interviews, self-administration, computer surveys. Adaptations (e.g. Braille)
11.	Culture/language adaptations	Tested versions of the tool for subgroups (including ethnicity, gender, disability)

¹¹CanChild Outcomes Measures (2004)

1.	Focus. Purpose	Focus of measurement (using the International Classification of Functioning Framework, ICF). Rating attributes measured. List the primary purpose for which the scales have been designed (discriminative, predictive, evaluative, etc.). Describe population. Evaluation of the context
2.	Clinical utility	Clarity of instructions, format, time to complete the assessment, administration, scoring and interpretation. Specify whether formal training is required. Cost of the manual and score sheets.
3.	Scale construction	Item selection, weighting, level of measurement
4.	Standardization	Manual (published, specific procedures for administration, scoring) Norms.
5.	Reliability	
5.1.	Internal consistency	The degree of homogeneity of test items to the attribute being measured. Measured at one point in time
5.2.	Intra/Inter observer	Measures variation within an observer; measures variation between two or more observers
5.3.	Test retest	Measures variation in the test over a period of time
6.	Validity	
6.1.	Content	The instrument is comprehensive and fully represents the domain of the characteristics it claims to measure
6.2.	Construct	Measurements of the attribute conform to prior theoretical relationships among characteristics or individuals
6.3.	Criterion	Measurements obtained by the instrument agree with another more accurate instrument (gold standard)
6.4.	Responsiveness	Ability to detect minimal clinically important change over the time

⁸Valderas JM, Ferrer M, Mendivil J, et al. Development of EMPRO: A tool for the standardized assessment of patient-reported outcome measures. *Value Heal*. 2008;11(4):700-708.

doi:10.1111/j.1524-4733.2007.00309.x. ⁹Johnston M V., Graves DE. Towards Guidelines for Evaluation of Measures: An Introduction With Application to Spinal Cord Injury. *J Spinal Cord Med*. 2016;31(1):13-26. doi:10.1080/10790268.2008.11753976. *Spinal Cord. Spinal Cord Injury Rehabilitation Evidence*. <https://scireproject.com>. ¹⁰Andresen EM. Criteria for assessing the tools of disability outcomes research. *Arch Phys Med Rehabil*. 2000;81(12 SUPPL. 2):15-20. doi:10.1053/apmr.2000.20619. ¹¹Law M. Outcome Measures Rating Form Guidelines.; 2004. Available from: <https://www.canchild.ca/system/tenon/assets/attachments/000/000/371/original/measguid.pdf>

Supplementary File S3. Continue

¹²Outcomes Measures in Rheumatology Clinical Trials (OMERACT) (2019)

1.	Truth	
1.1.	Face validity (credibility)	Overall appropriateness of the method to be used for evaluation of the outcome, as assessed by the investigators and clinicians
1.2.	Content validity (comprehensiveness)	Ability of the outcome measure to include or predict all those components of health status that are relevant to the intervention being assessed
1.3.	Criterion validity (accuracy)	Ability of the outcome measure to reflect the best available estimate of the true clinical status of the patient. Comparison with the "gold standard"
1.4.	Construct validity (convergent/divergent)	Ability of the outcome measure to match with the hypothesized expectations of the investigator when compared with other indirect assessments
2.	Discrimination	
2.1.	Sensitivity to change over time	Based on calculation of the standardized response mean (SRM) using repeated measures performed in a given population at 2 different time-points without therapeutic intervention
2.2.	Discrimination capacity over treatment	Based on calculation of effect size (ES) in randomized controlled trials or SRM in open-label trials
2.3.	Reliability (reproducibility)	Based on evaluation of intra- and interclass correlations
3.	Feasibility	The measure's ease of use, cost-effectiveness, availability in different centres, and overall usefulness. Practicalities of using the instrument, as cost, burden, length, translations, equipment needs.

¹³Testing Standards (1999, 2014)

1.	Evidences of Validity	
1.1.	Test Content	Themes, tasks, format of the items, wording, and processes of administration and scoring
1.2.	Response Processes	Cognitive processes engaged in by test takers with consequences in the scores.
1.3.	Internal Structure (Dimensionality, Differential item functioning)	The degree to which the relationships among test items and components conform to the construct on which the proposed test score interpretations are based including equivalence of scores among different populations.
1.4.	Relations to other variables (Convergent, Discriminant, Criterion, nomological network including responsiveness)	The degree to which relationships with other variables are consistent with expectations derived from theory underlying the construct
1.5.	Consequences of testing	Value judgement about unintended positive and negative consequences of test use
2.	Reliability	<i>Revised Standard (2014) also includes Decision consistency/accuracy</i>
2.1.	Internal consistency, Test- retest, Alternate forms, <i>Scorers Consistency, Decision consistency, Accuracy</i>	The degree to which an instrument is free from random error. The precision of a scale, homogeneity (inter correlations) of items. Replicability of the testing procedure.
3.	Fairness	Characteristics of all individuals must be considered throughout all stages of development, administration, scoring, interpretation and use of test. <i>Revised Standards (2014) emphasize the role of the Fairness as a measurement property</i>
4.	Scales, Norms and Score Comparability	Reference points should be documented based on population norms and/or expert criteria. Linking procedures devised to guarantee comparability of different measures of similar constructs should be described
5.	Test development and revision	Tests and their supporting documents should be periodically reviewed. New forms such as those derived from translation to other languages should be thoroughly tested for equivalence

¹² OMERACT. Instrument selection for Core Outcome Measurement Sets. In: OMERACT Handbook [Internet]. 2019. Available from: <https://omeracthandbook.org/handbook>. ¹³ American Educational Research Association, American Psychological Association, National Council on Measurement in Education. Standards for Educational and Psychological Testing. American Educational Research Association.; 1999. American Educational Research Association, American Psychological Association, National Council on Measurement in Education. Standards for Educational and Psychological Testing. American Educational Research Association; 2014.



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Pag 1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Pag 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Pag 5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Pages 5-6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Pag 6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Pag 6-7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Pag 7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary File1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Pag 6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Pag 7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Pag 7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	No applicable
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	No applicable
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	No applicable



PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	No applicable
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	No applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Pag 8 & Fig1(pag. 27)
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Supplementary File 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	No applicable
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	No applicable
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	No applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	No applicable
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	No applicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Pag 13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Pag 4 (Strengths&Limitations)
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Pag 17
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Pag 1, pag 20

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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