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REVIEW

A critical COSMIN-informed scoping review of complex abdominal wall hernia quality of life tools: making a case for patient-driven tool development

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Abstract

Background Health-Related Quality of Life (HRQoL) is increasingly recognized as a key outcome measure in Complex Abdominal Wall Hernia (CAWH) surgery. However, selecting an appropriate HRQoL tool is challenging due to the variety of available instruments and their variable psychometric properties.

Aim This scoping review systematically reviews and evaluates the six CAWH-specific HRQoL tools using the Consensus-based Standards for the Selection of Measurement Instruments (COSMIN) framework. The aim of this scoping review was to assess the clinical suitability and developmental robustness of CAWH-specific HRQoL instruments. This review does not assess post-operative HRQoL outcomes, but rather evaluates the design, content, and methodological quality of CAWH-specific tools themselves using the COSMIN framework.

Methods A scoping review was conducted in accordance with PRISMA-ScR and informed by COSMIN and Joanna Briggs Institute (JBI) scoping methodology. Four databases (MEDLINE, EMBASE, Cochrane CENTRAL, ClinicalTrials.gov) were searched (March 2024) to identify studies that used or evaluated CAWH-specific HRQoL tools. Tools were assessed across key COSMIN domains: conceptual framework, psychometric properties, respondent burden, and patient involvement in development.

Results Six CAWH-specific HRQoL instruments were identified: CCS, HerQLes, EuraHS-QoL, AAS/mAAS, AHQ, and HERQL. While these tools demonstrated utility, none fully integrated patient perspectives from initial domain development, and all exhibited gaps in content and structural validity. Comparative psychometric data across tools were limited, further complicating selection.

Conclusion Despite growing interest in measuring HRQoL in CAWH surgery, existing tools show important developmental limitations. While these tools demonstrate utility, none fully integrate patient perspectives throughout their development, and all exhibit gaps in content and structural validity. Additionally, comparative psychometric data remain limited, further complicating tool selection. Given these limitations, there is a clear need for further development—either by refining existing tools or creating a new, patient-informed HRQoL instrument that adheres to robust psychometric standards.

Keywords Health-Related Quality of Life · Complex Abdominal Wall Hernia · Consensus-based Standards for selection of Measurement INstruments

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Introduction

Complex Abdominal Wall Hernia (CAWH) occurs after at least 20% of laparotomies [1]. In 2024, a Delphi consensus endorsed by the European Hernia Society (EHS) defined a complex abdominal wall hernia as one characterised by at least one of eighteen agreed variables. These include factors such as hernia width > 10 cm, loss of domain, multiple recurrences, prior component separation, presence of fistula

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or mesh infection, and a BMI ≥ 40 kg/m^2, among others [2]. Ramshorst et al. note how, *"the natural history of abdominal hernias has demonstrated that with time a patient's quality of life will worsen"* [3]. CAWH impact includes significant *"physical, social and emotional repercussions"* linking to issues concerning mental health and body image. CAWH reconstruction is a growing subspecialty whereby patients undergo complex surgery *"aimed at improving quality of life*" [4]. Health-Related Quality of Life (HRQoL) is increasingly used as a surgical outcome measure in CAWH repair [5–10]. Whilst some studies demonstrate that repairing a hernia improves HRQoL [1, 11, 12], HRQoL in CAWH is *"poorly understood"* [13] in terms of meaning and measurement [4, 14–16].

There has been discourse on instituting processes for measuring quality of life before and after surgery [17]. We believe this helps surgeons understand the patient's concerns and allows them to counsel patients on realistic outcomes and then tailor surgery accordingly, thus making for a better patient experience. However, choosing the best tool is difficult due to the variance in the items of the available tools [17]. Therefore, this paper reviews and evaluates currently available CAWH HRQoL tools and aims to identify the most appropriate HRQoL tool for CAWH patients and propose further developments if needed. Given the breadth and heterogeneity of existing HRQoL instruments, a scoping review methodology was chosen to enable systematic mapping of CAWH-specific tools without aiming to synthesise outcomes or test hypotheses. Although the primary framework utilised was COSMIN, the review design aligns with the Joanna Briggs Institute (JBI) scoping review methodology, focusing on comprehensive literature identification, systematic screening, and structured data extraction to provide a comprehensive overview of HRQoL tools and identify areas for future development. This review therefore aims to systematically map and critically appraise CAWH-specific HRQoL tools, identifying both their clinical utility and any shortcomings in their development or validation. It is important to clarify that this review does not analyse clinical outcome data or changes in HRQoL following hernia repair. Instead, it focuses on the tools themselves, evaluating their design, development process, and psychometric strength.

Methods

This study follows a structured approach to identify, review, and evaluate Health-Related Quality of Life (HRQoL) tools for Complex Abdominal Wall Hernia (CAWH) patients. An initial review was performed to systematically identify both generic and CAWH-specific HRQoL instruments. The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) framework was applied to assess their validity, reliability, and overall suitability [18]. The primary aim of this study is to critically appraise the methodological quality, content validity, and clinical applicability of existing CAWH-specific HRQoL tools. Additionally, this review seeks to identify key limitations, particularly regarding patient involvement in tool development and psychometric robustness, to determine whether current instruments effectively capture the full spectrum of quality-of-life concerns relevant to CAWH patients. The findings will help inform whether existing tools require modification or if a new, comprehensively validated HRQoL instrument should be developed.

While the review was not conducted strictly in accordance with the Joanna Briggs Institute (JBI) scoping review methodology, it adheres to the general principles of scoping review design as outlined by JBI, including systematic searching, screening, and data extraction to map the existing literature on HRQoL tools for CAWH.

Search strategy

A scoping review was performed to identify HRQoL tools. The search strategy was developed to systematically capture all relevant HRQoL tools, utilizing multiple databases, manual searches of key journals, and backward citation tracking, in line with JBI recommendations. On 22nd March 2024, Medline, EMBASE, the Cochrane Central Register of Controlled Trials and clinicaltrials.gov were accessed. The following words were entered into the free-text search string:

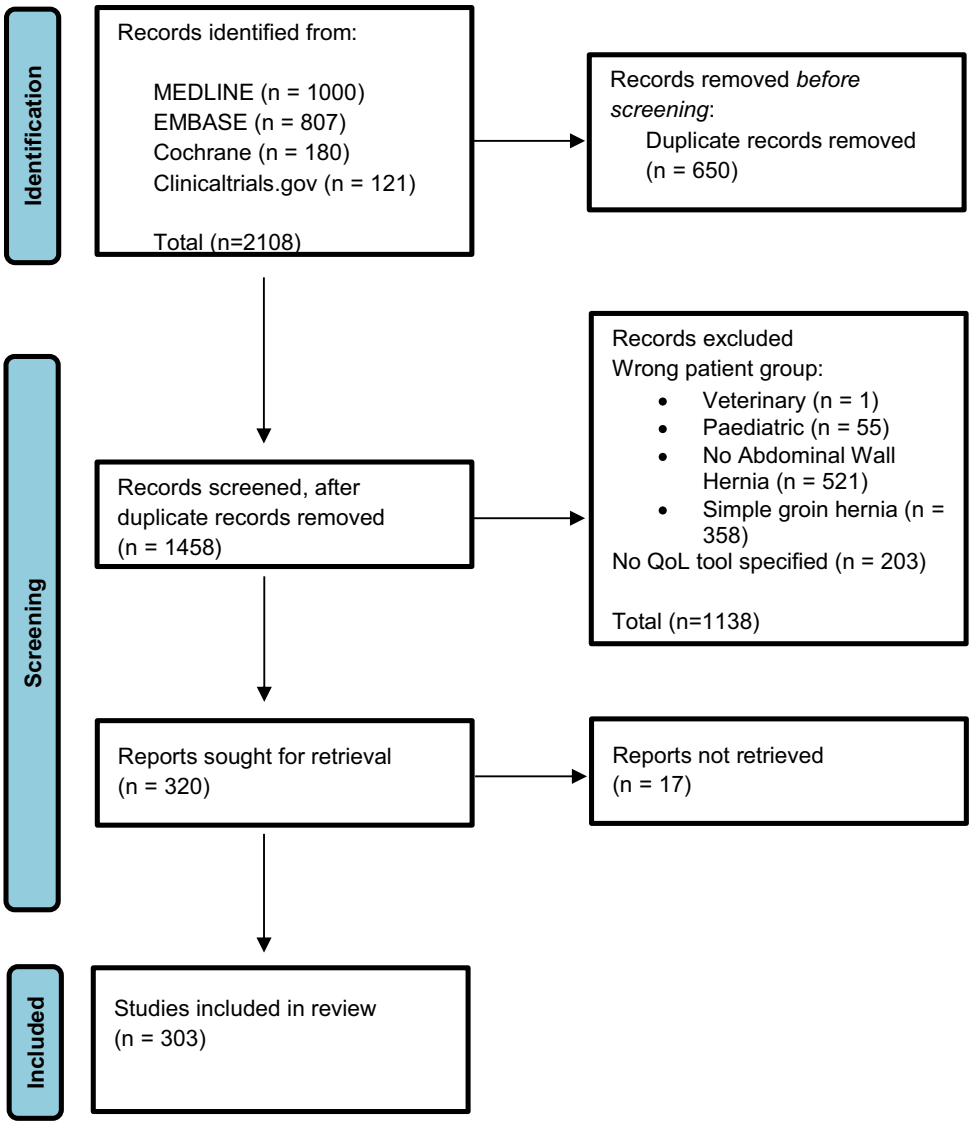
(abdominal OR ventral OR incisional OR "post operative" OR parastomal) adj2 hernia) AND ("quality of life" OR QOL OR HRQOL) adj3 (tool OR questionnaire* OR measure* OR instrument* OR survey* OR scale* OR score* OR method*).*

After removing duplicates this updated search initially yielded 1458 articles, which were then screened for eligibility based on their abstracts (Table 1).

Studies retrieved from these databases were imported into a reference management software. Data management, citation tracking, and reference formatting were conducted using Zotero (version 7.0.15).

This scoping review was not registered in a formal registry (e.g., OSF, PROSPERO) as the primary objective was to map existing HRQoL instruments and assess their developmental robustness using the COSMIN framework, rather than to synthesize quantitative outcomes or assess clinical efficacy. Future updates or systematic reviews based on the findings of this scoping review will be considered for registration to enhance transparency and reproducibility.

Table 1 Identification of studies via databases and registers



Screening process

Following the initial search, all identified studies were imported into a reference management system, where duplicate records were removed.

The included studies comprised both quantitative and qualitative research. The diverse study designs allowed for comprehensive evaluation of the identified HRQoL tools, aligning with the COSMIN framework to assess both psychometric properties and patient-reported outcomes. The manuscripts included in this scoping review comprised a range of study types, including randomized controlled trials, observational cohort studies, systematic reviews, narrative reviews, and qualitative research reports. Each study type was assessed for its contribution to the evaluation of HRQoL tools in CAWH, with a focus on identifying tool validation studies and qualitative assessments that specifically addressed tool development or patient perspectives. Quantitative studies provided data on psychometric properties, such as reliability and validity, while qualitative studies contributed insights into patient experiences, perceptions, and tool relevance. Both perspectives were considered essential to comprehensively assess the developmental robustness and applicability of the identified HRQoL instruments.

The first stage involved screening of titles and abstracts by author OS and CO independently, with any uncertainties or borderline cases reviewed collaboratively by all authors. Articles were considered relevant if they addressed Quality of Life measurement specifically in relation to complex abdominal wall hernias in adult populations. Studies clearly addressing only simple groin hernias, paediatric populations, animal (veterinary) subjects, or those failing to explicitly mention or

utilize an HRQoL measurement tool were excluded at this stage.

The second stage involved a detailed full-text review, independently conducted by authors OS and CO. Articles were included at this stage only if they clearly assessed HRQoL in adult patients diagnosed with CAWH and explicitly utilized an identifiable HRQoL instrument. Any discrepancies or disagreements between reviewers were resolved through discussion with the wider authorship team to ensure consistency and adherence to inclusion criteria.

After identifying studies that met the criteria for inclusion in the review, a retrieval attempt was made. Additional studies that could not be accessed due to institutional or database restrictions were excluded from analysis.

Data extraction and summary analysis

Descriptive data were extracted from each included study, including the name of the HRQoL tool used, its stated purpose (generic or CAWH-specific), and the number of times each tool appeared in the literature. A structured data extraction form was piloted and used by two reviewers (OS and CO) to ensure consistency. Frequencies of tool usage were calculated manually to inform Table 2. No inferential statistical analyses were performed, as the purpose of this scoping review was to map and evaluate tool characteristics rather than synthesize outcome data across studies.

Evaluation framework

To systematically assess the identified Health Related Quality of Life (HRQoL) tools, this study applied the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) framework for reviewing and evaluating which HRQoL CAWH tool captures the most meaningful information [18]. COSMIN provides a structured methodology for evaluating the validity, reliability, and applicability of measurement instruments, ensuring that the selected tools accurately reflect the patient experience and are suitable for clinical and research use.

The evaluation focused on four key domains outlined within the COSMIN framework:

1. **Conceptual and Measurement Model:** Each HRQoL tool was assessed for its underlying conceptual framework, examining whether it was designed to capture the multidimensional nature of Quality of Life (QoL) in CAWH patients. Particular attention was given to whether the tool incorporated shifting items, which indicate meaningful changes in HRQoL over time. Additionally, the relevance of the tool's structure—whether it was generic or disease-specific—was critically appraised.

Table 2 QoL tools identified via literature review. An extended version of this table including references for all articles is included in Supplementary file 1

Tool	Total number of articles using the tool
CAWH—Specific QoL tools	
CCS	88
HerQLes	80
EuraHS QoL	37
AAS/mAAS	14
AHQ	12
HERQL	3
Generic QoL tools	
SF-36	64
SF-36v2	2
SF-12	11
Sf-12v2	2
EQ-5D	11
EQ-5D-3L	4
EQ-5D-5L	3
EQ-5D VAS	1
WHO-QOL BREF	1
SHS	1
Pain only tools	
VAS	44
Verbal rating scale	2
Quebec Back Pain Scale	3
SPS	2
PROMIS	18
Mcgill pain scale	2
BPI	1
VHPQ	3
PEG	3
NRS-11	2
Body image only tools	
BIQ	4
DAS24	2
Functional assessment only tools	
IPAQ	3
KPS	1
LASA	2
Tools for specific patient subgroups	
Comi-hernia	2
SOMS	3
FACT-G	2
EORTC C30	2
CR29	1
GIQLI	4
PAC QOL	1
Stoma-QoL	1
OAS	1

2. **Psychometric Properties:** The validity and reliability of each HRQoL tool were examined using available literature. Validity measures included content validity (whether the tool captures issues that are meaningful to CAWH patients), construct validity (whether the tool measures what it intends to measure), and criterion validity (how well the tool compares to established HRQoL measures) [19]. Reliability assessments focused on internal consistency and test–retest reliability, where data were available.
3. **Administration and Patient Burden:** The practicality of each HRQoL tool was considered in terms of ease of administration, response burden, and scoring format. Tools with shorter, well-structured item sets that minimized patient fatigue while maintaining sensitivity to changes in HRQoL were preferred. The use of Likert scales versus binary response options was also noted, given that Likert-based measures are generally more sensitive to incremental changes.
4. **Patient Involvement in Tool Development:** The involvement of patients in the tool development process was critically reviewed, as tools that were created primarily by expert panels without direct patient input may lack relevance to those experiencing CAWH. Patient involvement is essential in HRQoL tool development to ensure that the selected domains accurately reflect the lived experiences, priorities, and concerns of the target population, rather than being limited to the perspectives of clinicians or researchers [20, 21].

By systematically evaluating each HRQoL tool within this framework, this study aimed to determine whether the existing instruments were fit for purpose in CAWH research and clinical practice. The findings from this assessment informed the discussion on whether current tools should be refined or if a new, patient-driven instrument is required.

Results

Identification of HRQoL tools

The review identified 1,458 studies across four databases. After removal of 650 duplicates, 1,458 unique articles were screened for eligibility. Following title and abstract screening, 1,138 studies were excluded due to focusing on non-abdominal wall hernias, paediatric populations, or lacking HRQoL tools. Of the 320 studies sought for full-text retrieval, 17 could not be accessed despite multiple retrieval attempts, leaving 303 studies that met the inclusion criteria and were included in the final analysis.

Among the included 303 studies, HRQoL tools were identified through a structured data extraction process. Tools were categorized based on their stated purpose, with those explicitly developed for CAWH classified as CAWH-specific HRQoL tools, while those designed for broader health conditions or surgical populations were categorized as generic HRQoL tools. Through this approach, six CAWH-specific HRQoL tools and ten generic HRQoL tools were identified. These classifications were based on tool descriptions provided within the studies, their stated development goals, and prior usage in CAWH research.

Additionally, several tools designed for specific HRQoL domains were extracted, including pain-specific tools, body image measures, functional assessment scales, and instruments tailored for specific patient subgroups. For example, Stoma-QoL which would not be applicable to CAWH patients who do not have a stoma. These classifications were based on tool descriptions provided within the studies, their stated development goals, and prior usage in CAWH research.

A full breakdown of the identified tools and their frequency of use is provided in Table 2.

Characteristics of CAWH-Specific HRQoL tools

The six CAWH-specific HRQoL tools identified were: Carolinas Comfort Scale (CCS), Hernia-Related Quality of Life Scale (HerQLes), European Registry of Abdominal Wall Hernias QoL Scale (EuraHS-QoL), Activities Assessment Scale (AAS/mAAS), Abdominal Hernia-Q (AHQ), and HERQL. These have been listed in order of year of development (Table 3).

The tools varied in scope, content, and intended application. Some, such as the CCS and AAS, primarily assessed pain and functional impairment [9, 22]. Others, such as HerQLes and AHQ, incorporated broader domains, including mental health, body image, and social impact [23, 24]. The number of items in each instrument ranged from 4 to 24. Some tools, such as EuraHS-QoL and HerQLes, were originally validated for inguinal hernia patients before later being used in CAWH populations [25, 26]. Others, such as AHQ, were developed specifically for CAWH patients [23, 24].

Table 3 provides a summary of the CAWH specific tools identified, detailing key information concerning the instruments suggested by Burckhardt and Anderson [27] such as: “What does the tool measure?” and “How was the tool developed?”.

Psychometric properties of CAWH-specific tools

It is relevant for surgeons to understand the psychometric properties underpinning the different HRQoL tools so that

Table 3 QoL tools

CAWH HRQoL Tool						
Question	AAS	CCS	HerQLes	EuraHS-QoL	HERQL	AHQ
What does it measure?	A functional assessment scale; arguably hernia specific but not a CAWH specific QoL tool	Pain and comfort related to mesh repair	Pain, function, sexual intercourse, mental health	Pain at the site of the hernia or the hernia repair, restriction of activities and cosmetic discomfort	Symptom, function, operation-related, and patient satisfaction	Pain, function, body image, mental health
Year developed	1995 but published in 2005	2008	2012	2012	2017 (for inguinal hernia) 2020 (for use in AWH)	2020
How was it developed?	Focus group session seeking expert opinion of 6 general surgeons at a Chicago Surgical Society meeting in 1995. In-depth personal interviews were conducted with six hernia patients who had undergone either *open or laparoscopic inguinal hernia repair.* This focused on activities that were meaningful to patients, but no details are provided as to how these interviews were conducted, analysed or what the domains identified were.	Unclear. Components appear to be based on patient complaints from the author's clinical practice. The domains were correlated against those of the SF-36. Personal correspondence with Dr. Todd Heniford (creator of CCS) states that the tool was developed prior to patient delivery and that it was modelled on other QoL tools used in other surgical areas.	Expert opinion of 4 consultant general surgeons	Proposed by the EuraHS working group. The working group included a multinational European expert panel with specific interest in abdominal wall hernias. Created for use in mesh and non-mesh repairs and is based on a Numerical Rating Scale.	Originally designed for use in groin hernia and abdominal wall hernia patients. Tool design and its use in inguinal hernia were explored in the 2017 publication. Later, authors revisited the tool and validated it for use in abdominal wall hernia (2020) Content and dimensions of the HERQL were conceptualized from literature reviews and panel discussions of the Taiwan Hernia Society. Published hernia-specific instruments including the AAS, CCS and inguinal pain questionnaire were consulted.	University of Penn team used the Scientific Advisory Committee of the Medical Outcomes Trust and the National Quality Forum guidelines for PROM measure development as a framework to create the psychometric properties AHQ scores. A 45-item framework was generated. Purposively sampled hernia patients completed this, with patients then interviewed regarding the content of the questionnaire. Their responses were subject to content analysis.

Table 3 (continued)

CAWH HRQoL Tool						
Question	AAS	CCS	HerQLes	EuraHS-QoL	HERQL	AHQ
How many items?	13	8	12	11	4	24
Psychometric analysis studies?	Lacks evidence on content and structural validity (18,27–29)	Extensive investigation looking at internal consistency but lacks evidence on content and structural validity (9,18,30–37)	Lacks evidence on content and structural validity (8,18,38–41)	Lacks evidence on content and structural validity Generated as part of the EuraHS online platform for registration and outcome assessment of abdominal wall hernia. However, validation of the EuraHS-QoL score was part of the research by the EuraHS working group following the launch of the platform (42,43)	Lacks evidence on content and structural validity but has criterion validity (8,18,38–41,44)	Recently developed tool. Test re-test score available. Has content validity. Internal validity. Convergent and discriminant validity correlated against HerQLes and SF-12 (19,45) [20, 45]
In which populations has it been used?	CAWH Women undergoing pelvic reconstruction Inguinal hernia in men Laparoscopic v open hernia repair	All types of hernia with mesh	CAWH Abdominal malignancy	CAWH	Inguinal and abdominal wall hernia patients in Taiwan	Pre and post-operative ventral hernia patients
Country in which tool was developed	USA	USA	USA	Belgium	Taiwan [19, 50]	USA
References	(26–28,46,47)	(6,48)	(40)	(42,43)	(44,49)	(19,45)

[1] *CCS* Carolinas Comfort Scale (CCS); *AAS* Activities Assessment Scale; *HerQLes* Hernia Related Quality of Life Scale; *AHQ* Abdominal Hernia Q; *AWH* Abdominal Wall Hernia

they and their research teams select the right instrument to answer their posed question. COSMIN provides a useful taxonomy concerning what constitutes psychometric properties, which are detailed in Supplementary file 2.

The psychometric properties of the six CAWH-specific HRQoL tools varied, with limited validation data available for several instruments. Content validity, which assesses whether a tool captures all relevant aspects of a patient's Quality of Life, had been formally evaluated for the AHQ [23, 24], while other tools lacked documented content validation studies.

Reliability and internal consistency had been investigated for the CCS, HerQLes, and AHQ, with studies reporting acceptable levels of internal consistency [6, 18, 22, 28–34]. However, formal structural validity testing, which examines the underlying factor structure of a tool, was only available for AHQ and had not been comprehensively assessed for other instruments [23, 24]. No studies directly compared the psychometric properties of these six CAWH-specific tools in a single cohort.

A summary of the available psychometric data for each tool is provided in Table 3.

Administration and burden of CAWH-Specific tools

The six CAWH-specific HRQoL tools varied in length, response format, and ease of administration. The AAS and CCS had fewer than 15 items, while the AHQ contained 24 items [23, 24].

Most tools utilized Likert-scale response formats, allowing for multiple response options to capture gradations in HRQoL changes. Tools, such as EuraHS-QoL, included binary response options [25, 26]. The extent to which these formats affected response burden and completion rates was not consistently reported across studies.

No studies explicitly evaluated the acceptability to patients though some instruments, such as AHQ and CCS, had been used in multiple studies across different settings [23, 24].

A detailed comparison of tool length, response format, and administration considerations is provided in Table 3.

Patient involvement in tool development

Among the six CAWH-specific HRQoL tools, the extent of patient involvement during development varied. The majority of tools were developed based on expert opinion without direct input from CAWH patients during the initial stages of item generation.

The CCS and HerQLes were derived from existing HRQoL tools [9, 22] in other surgical specialties, with no documented evidence of patient engagement in their initial development. The EuraHS-QoL was designed by a European expert panel [25, 26], while the AAS was created with input from six surgeons but lacked documentation of patient contributions [35–37].

The AHQ was the only tool that incorporated patient input, though this was limited to patients reviewing and commenting on pre-existing questionnaire items, rather than generating items from the outset [23, 24]. No identified tools followed qualitative methodologies, such as focus groups or patient interviews, to establish domains prior to questionnaire design.

A summary of the development methods for each tool is presented in Table 3.

Discussion

Summary of key findings

This review identified six CAWH-specific HRQoL tools and evaluated their conceptual framework, psychometric properties, administration burden, and patient involvement in development using the COSMIN framework. By employing a comprehensive search strategy, dual-stage screening, and structured data extraction, the review adheres to JBI guidelines aimed at ensuring methodological transparency, comprehensive data coverage, and robust reporting of findings. A key finding is that none of the tools comprehensively capture all aspects of Quality of Life relevant to CAWH patients, particularly variable was the lack of patient input during tool development. Additionally, psychometric validation remains incomplete for most instruments, with gaps in content and structural validity.

Although ten generic HRQoL tools were also identified, these were not evaluated in depth using the COSMIN framework as they were not designed specifically for CAWH patients and lacked the disease-specific relevance required for tailored outcome measurement in this population. Instead, these generic tools serve as broad assessments of general health status, often used in hernia research but without the specificity to fully capture the unique quality-of-life concerns associated with CAWH.

The tools vary in their measurement approach, with some focusing primarily on pain and function, with only a few including mental health and body image. Despite these differences, all tools face challenges in ensuring relevance, responsiveness, and usability. The absence of comparative psychometric data between instruments makes it difficult to determine which tool, if any, is most suitable for assessing HRQoL in CAWH patients. These limitations raise concerns about the appropriateness of current tools and highlight the need for a more patient-driven approach to HRQoL measurement in this population.

The conceptual and measurement model

A HRQoL tool is made up of a stem of items that measure different aspects of HRQoL. A shift in the rating of the items indicates either an improvement or deterioration in HRQoL. Shifting items are important when selecting a HRQoL measure and a 'good' questionnaire may benefit from many shifting items [38]. The shift of items depends mainly on what questions are included within the stem, for example: if a tool does not ask about a problem relevant to HRQoL in that patient population the items will not shift, meaning problems and improvements go unreported; and questions relating to a mild impairment in patients HRQoL are also less likely to demonstrate evidence of improvement.

QoL, by its very nature, is specific to an individual [27], meaning that item relevance is important when deciding whether to use a generic HRQoL measure or a specific tool [39]. An important question is 'are we capturing specific HRQoL data related to a patient living with a CAWH'? The generic scales such as SF-36 do not capture this in detail. Work by Heniford et al. showed that SF-36 has limited sensitivity and specificity in comparing hernia surgery outcomes between patients or changes in QOL during the postoperative period [9].

Secondly, most tools we examined compared data sets across different patients and then factor analysed these to see how items/questions compare to each other – either for the purpose of reducing the number of questions to increase acceptability to patients or to compare them to other generic questionnaires as a way of establishing validity in the eyes of the researchers. This method is flawed when you are aiming to examine specific areas of QoL related to a specific 'disease' as it arguably means the nuances and the items not previously identified will be lost. At its worst, factor analysis could reduce all the items down to one 'How do you feel?'. Though extreme, it describes the aim of many researchers and often the aim of their factor analysis.

Hyland states that he has *"never come across a QoL scale that is incapable of demonstrating validating correlations with other QoL scales"* [38]. One of the reasons is that *"self-report measures are strongly correlated with the personality trait of negative affectivity (e.g., neuroticism, depression, anxiety)"* [38]. Thus, non-specific or generic QoL scales will inter-correlate amongst themselves as they are possibly measuring the patient's personality trait rather than comparing specific QoL issues such as "Can you bend down and touch your toes?".

Psychometric properties of CAWH tools

Psychometric properties are very important to consider when selecting any HRQoL tool, so it is worth bearing two things in mind. Firstly, where scales do not have psychometric properties, they should not be used. Secondly, when two similar scales are both adequate the one that is most reliable should be selected [38]. Whilst psychometric properties ensure 'reliability' they should also ensure they inform us if the *right* questions are being asked ('validity') and ensure these questions are 'responsive to changes'. At present, no study compares the psychometric properties between the outlined CAWH specific HRQoL tools. This may be because they are incomparable given that none appear to be based on any existing HRQoL model and consist of differing items. Furthermore, tools like the HerQL use mathematical modelling to justify the tool, but while it satisfies statistical parameters, it does not mean that it is asking relevant questions to begin with. For instance, the authors state that it was developed with AWH and groin hernia patients in mind [40, 41]. These tools are heterogenous and, therefore, do not account for if different things matter to groin hernia patients compared with CAWH patients in terms of HRQoL.

As with inguinal hernia measures [42] and most outcome measures used in general surgery [43], CAWH specific HRQoL tools are insufficiently validated. These tools still have a utility but lack insufficient evidence, particularly concerning *content and structural validity*.

Content validity (Suppl. file 2) has not been established for CCS, HerQLes and AAS nor for the EuraHS-Qol or the HerQL. Therefore, we do not know whether patients perceive the items within these tools as truly and/or wholly reflective of their CAWH experience. This is pertinent to the above issues highlighted in the previous section. Typically, content validity is attained via individual qualitative interviews or focus groups where patients are specifically asked about their opinions regarding the tools and their relevancy [38]. In this regard, the AHQ achieves content validity through using the Scientific Advisory Committee of the Medical Outcomes Trust and the National Quality Forum guidelines for PROM development as a framework to create the AHQ score. This process generated a framework containing 45 items, with purposively sampled hernia patients commenting on this preliminary instrument. These patients then underwent focus groups responding to the content of the questionnaire, which were content analysed. Whilst valid, patients were not involved in the development of the initial 45 items, meaning items may be missing that are important to CAWH patients, and a wholly patient-centred approach not attained.

Structural validity (Suppl. file 2) provides evidence for construct validity by measuring and assessing the number of dimensions that comprise an instrument. For instance, the AHQ consists of three factors in the post-operative element [24]. Therefore, a three-factor model should be substantiated by statistical methods such as factor analysis, which would provide useful information about the relationship between

items [44]. It is necessary to note that although HRQoL CAWH tools lack evidence for content and structural validity, it does not mean that these tools are completely insufficient or lack utility, it simply means that such evidence is inconclusive.

Some CAWH specific QoL tools are not truly HRQoL measures. Due to confusing lexicon within the literature, it is possible that some instruments are being promoted as HRQoL tools when they perhaps more accurately fall under the umbrella of functional assessment tools. For instance, the CCS is a tool used widely in CAWH and has been tested for reliability across varying cultures as well as other types of hernia [57]. It was *"specifically designed to evaluate patient abdominal function as it relates to the patient's hernia and hernia repair"* [45]. However, it was also proposed as a *"quality-of-life survey pertaining specifically to patients undergoing hernia repair with mesh"* [9]. Undoubtedly, it is a useful tool and represents an important step towards hernia specific HRQoL tools but its use is limited pre-operatively; limited to only patients who have had mesh repair; and because of the focus on mesh related symptoms and pain related to movement, and because of its assumption that the effect of a prosthetic on a patient encompasses CAWH related QoL [45], it is perhaps best served as a predominantly functional assessment tool.

Similarly AAS, despite non-CAWH origins, is classified as a CAWH HRQoL tool in systematic reviews [4, 14]. Whilst the AAS has been used to measure HRQoL in CAWH patients [46], it has otherwise been used as a reliable and valid instrument to evaluate patient function in two different patient populations – laparoscopic and open groin hernia [36], and in women post pelvic reconstruction surgery [37]. Again, this draws questions of validity and whether the AAS is better served as a "functional assessment tool". It is necessary to move away from automatically equating function with HRQoL without acknowledging the broader multidimensional QoL [47, 48].

The HerQLes tool consists of several logical items, but its sole base on expert opinion means it lacks content and structural validity. The creators of the HerQLes revised this instrument, now promoting its use in AWH [45]. Given the necessary COSMIN due diligence, such extensions may be less valid than designing instruments from scratch with key intentions and outcomes in mind.

At the time of writing, the AHQ is a relatively new tool, meaning that there is limited but developing information published pertaining to its use. The one existing study assesses user burden, test–retest reliability and longitudinal validation (against HerQLes and the generic Short Form-12) [23]. This tool is promising but, at present, there is insufficient data to draw any firm conclusions, especially given the criticism regarding the tools it has been validated against.

It is relevant for surgeons to understand the psychometric properties underpinning the different HRQoL tools so that they and their research teams select the right instrument to answer their posed question. COSMIN provides a useful taxonomy concerning what constitutes psychometric properties, which are detailed in Supplementary file 2.

Tool administration and respondent burden

If a HRQoL tool is disease specific and asks questions that are specific to a certain population of patients, then arguably the item set can be relatively short. Some studies have shown that "good scales" are around 30–40 items long [49]. Fewer items may be used: such as one item scales, which are very short and can be extremely sensitive, but the disadvantage is that they do not tell the researcher the nuanced ways in which HRQoL is improving or deteriorating [49]. The aim is to produce a scale that can be administered in an accessible (i.e. patient understands), effective (i.e. measures improvement or deterioration) and efficient (i.e. is not burdensome) manner. Responses may be binary or in a scale format (for example, the Likert scale). Scales are typically more sensitive to change than binary formats and allow slight improvements in HRQoL to be detected. Hyland states that a *"good longitudinal QoL scale is likely to be quite short, describing commonly experienced problems relevant to the population to be investigated and have a multi-response format"* [38].

Patient involvement in tool development

Expert opinion has featured prominently in the development of CAWH QoL tools such as the EuraHS-QoL [25], while the HerQLes tool was based on a literature review by an expert panel of only four general surgeons [45]. The CCS was "*initially modelled on other questionnaires measuring quality of life in other areas of surgery because there was no QOL scoring system then for hernia repair or* AWR *but we moved through that phase quickly. We performed the questionnaire and discussed it with patients and moved to its current form"* (personal email correspondence from Dr. Todd Heniford). The AHQ tool was generated with some patient involvement via focus groups, where patients commented on an already pre-designed and itemised tool that had been based on expert opinion [50]. Finally, whilst the AAS tool interviewed patients regarding 'function', as well as conducting an expert panel of six surgeons [36], it did not explore the wider aspect of patient quality of life and was not based on any existing evidence based HRQoL model [47, 48].

The lack of patient input *at the time of genesis of a disease specific HRQoL tool* means that we cannot be sure

if the items comprising the tool are *appropriate* to assess change in QoL in CAWH patients. Also, when patients are asked to comment on a tool designed by experts, they may not feel they are able to due to power differentials and a 'surgeons know best' attitude. As such, the existing HRQoL CAWH tools may contain items important to operating surgeons, but may not include items that really matter to CAWH patients. This neglects the fact that no one knows more about how a pathology affects their own QoL than the person suffering with it—a sentiment noted in 2012 by Jon Stamford, a Parkinson's patient and patient advocate who stated that, "*it seems to be that Quality of Life is when you tell me what's missing in my life. That seems to me to be rather odd*" [51]. It is clear that current tools have not been developed from the ground up by asking CAWH patients what matters to them, and then developing on this fundamental knowledge base.

Whilst no doubt multi-casual, we note Wicks's (2014) point that, *"the primary concern of instrument developers was whether their scale would get published in a top journal or used in a clinical trial"* [51]. Whilst the development of the AHQ represents a shift away from this mindset, more work needs to be done to generate tools that measure what matters most to patients suffering with CAWH. The Abdominal Hernia-Q (AHQ) is the only tool among those reviewed to include some degree of patient involvement however, this participation was not present at the earliest stages of tool development. Patients contributed to reviewing a 45-item draft instrument and participated in focus groups and concept elicitation interviews; however, these occurred after a preliminary conceptual framework and item set had already been developed by the study team. As stated by Carney et al. in their initial paper on its development,"Semi-structured questions were developed by the research team and were based on a preliminary conceptual hernia framework developed by a team member (AB)", and the framework itself was informed"via a clinically derived set of domains… [including] plastic surgery principles relating to appearance and function as well as the senior authors' experiences treating hernia patients."[50]

Thus the foundational structure and content of the tool were clinician-generated prior to patient input. While patients did later complete the instrument and provide feedback ("patients independently completed the preliminary 45-item instrument") and contributed to qualitative refinement, the initial domains and items had already been defined. This is an important distinction. True patient-driven tool development begins with patients' lived experiences shaping the core domains, typically through qualitative interviews or focus groups before any items are generated [52]. Without this foundational step, tools may reflect the clinicians' understanding of what matters, rather than the authentic and nuanced experiences of those living with the condition. As such, while the AHQ represents progress toward patient-centred design, it does not meet the criteria for a wholly patient-derived instrument. We feel that this work should start with Gram-Hanssen et al.'s (2020) premise that, *"We do not know what is important to the individual patient if we do not ask them"* [42]. Such a move may enable a much more relevant, honest, and useful HRQoL to be developed.

The case for a patient-driven HRQoL tool

We have identified a factor which could contribute to all four highlighted COSMIN considerations: whether patients were involved in the genesis of the tool. Whilst expert opinion is important, qualitative researchers argue that the first step to produce a patient specific questionnaire is to establish "domains" by first interviewing the relevant group, being mindful to capture the responses and develop themes from them [53]. This argument seemingly speaks to Ann Bowling's quote [49]: *"What matters is how the patient feels, rather than how others think they feel"*. Therefore, there is an emerging thought that patients should be more involved in the generation of a HRQoL instrument [49, 53–55], making this topic an essential part of the review process. Cultural relativity, specificity, and homogeneity are discussed in relation to the six CAWH specific tools later.

Study limitations

While this review provides a comprehensive evaluation of CAWH-specific HRQoL tools, several limitations should be acknowledged.

Firstly, the study relied on published literature, meaning that unpublished tools or ongoing validation studies may not have been captured. Some relevant data on psychometric properties, content validity, or tool administration may exist in grey literature, clinical trials, or industry reports that were not accessible. Additionally, despite attempts to retrieve all eligible studies, 17 full-text articles could not be accessed, which may have contained relevant findings.

Secondly, the lack of direct comparative psychometric studies between CAWH-specific HRQoL tools makes it difficult to determine which tool, if any, performs best in assessing Quality of Life. Although COSMIN provides a structured framework for evaluating HRQoL instruments, the current review was limited by heterogeneous reporting of psychometric data, making direct comparisons between tools challenging. Future research should conduct head-to-head psychometric testing in CAWH populations to address this gap.

Finally, while this study highlights the lack of patient involvement in tool development, it does not include direct

patient perspectives on existing tools. Future research could engage CAWH patients in qualitative studies to validate and refine HRQoL domains based on lived experiences.

Despite these limitations, this review provides a critical assessment of existing tools, highlighting gaps in content validity, psychometric robustness, and patient-centred development. These findings reinforce the need for a more comprehensive, patient-informed HRQoL instrument for CAWH.

Conclusion

This article evaluates existing CAWH specific HRQoL instruments in order to inform evidence-based tool selection. Drawing initially upon COSMIN considerations [18] and then from the work of Burckhardt and Anderson [27] our review leads us to postulate that none of the six HRQoL CAWH tools are quite fit for purpose.

None of the tools have established that they have been built on what really matters to CAWH hernia patients in terms of their quality of life, contributing to a lack of robust content and structural validity. We advocate a holistic approach taking into account all aspects of Quality of Life important to the CAWH patients themselves rather than just one symptom or a stem, such as 'functional issues'. This is the missing piece from other QoL tools.

Since there is no "gold standard" HRQoL tool, it is clear more development work is needed in this area. Such work should start by adding to the only existing study, to our knowledge, that details what aspects of Quality of Life matter to patients affected by their CAWH [56]. This knowledge can then be used to inform a new, or amended, CAWH-specific instrument that involves patients' perspectives from design to implementation. This approach should part-inform what needs to be measured and how this can be done, without calumny of existing tools, by adhering to COSMIN guidelines to attain robust validity and reliability. The latter part of this development should ensure that any tool is cross-culturally resilient through an iterative process of recognizing interpretive nuances and ensuring readability.

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Declarations

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References

1. Uranues S, Salehi B, Bergamaschi R (2008) Adverse events, quality of life, and recurrence rates after laparoscopic adhesiolysis and recurrent incisional hernia mesh repair in patients with previous failed repairs. J Am Coll Surg 207:663–669. https://doi.org/10.1016/j.jamcollsurg.2008.06.330
2. CapocciaGiovannini S, Podda M, Ribas S et al (2024) What defines an incisional hernia as "complex": results from a Delphi consensus endorsed by the European Hernia Society (EHS). Br J Surg 111:zna346. https://doi.org/10.1093/bjs/znad346
3. van Ramshorst GH, Eker HH, Hop WCJ et al (2012) Impact of incisional hernia on health-related quality of life and body image: a prospective cohort study. Am J Surg 204:144–150. https://doi.org/10.1016/j.amjsurg.2012.01.012
4. Grove TN, Muirhead LJ, Parker SG et al (2021) Measuring quality of life in patients with abdominal wall hernias: a systematic review of available tools. Hernia 25:491–500. https://doi.org/10.1007/s10029-020-02210-w
5. Rosen MJ, Bauer JJ, Harmaty M et al (2017) Multicenter, prospective, longitudinal study of the recurrence, surgical site infection, and quality of life after contaminated ventral hernia repair using biosynthetic absorbable mesh: The COBRA Study. Ann Surg 265:205–211. https://doi.org/10.1097/SLA.0000000000001601
6. Blair LJ, Cox TC, Huntington CR et al (2017) The effect of component separation technique on quality of life (QOL) and surgical outcomes in complex open ventral hernia repair (OVHR). Surg Endosc 31:3539–3546. https://doi.org/10.1007/s00464-016-5382-z
7. Criss CN, Petro CC, Krpata DM et al (2014) Functional abdominal wall reconstruction improves core physiology and quality-of-life. Surgery 156:176–182. https://doi.org/10.1016/j.surg.2014.04.010
8. Helgstrand F, Rosenberg J, Kehlet H, Bisgaard T (2013) Outcomes after emergency versus elective ventral hernia repair: a prospective nationwide study. World J Surg 37:2273–2279. https://doi.org/10.1007/s00268-013-2123-5
9. Heniford BT, Walters AL, Lincourt AE et al (2008) Comparison of generic versus specific quality-of-life scales for mesh hernia

repairs. J Am Coll Surg 206:638–644. https://doi.org/10.1016/j.jamcollsurg.2007.11.025
10. Urbach DR (2005) Measuring quality of life after surgery. Surg Innov 12:161–165. https://doi.org/10.1177/155335060501200216
11. Mussack T, Ladurner R, Vogel T et al (2006) Health-related quality-of-life changes after laparoscopic and open incisional hernia repair: a matched pair analysis. Surg Endosc 20:410–413. https://doi.org/10.1007/s00464-005-0440-y
12. Snyder CW, Graham LA, Vick CC et al (2011) Patient satisfaction, chronic pain, and quality of life after elective incisional hernia repair: effects of recurrence and repair technique. Hernia 15:123–129. https://doi.org/10.1007/s10029-010-0750-4
13. Ciomperlik H, Dhanani NH, Cassata N et al (2021) Patient quality of life before and after ventral hernia repair. Surgery 169:1158–1163. https://doi.org/10.1016/j.surg.2020.11.003
14. Majeed T, Chauhan MN (2019) Review of currently used standardized measures of quality of life after ventral incisional hernia repair: systematic review. Int Surg J 6:1827–34. https://doi.org/10.18203/2349-2902.isj20191921
15. Smith O, Chitsabesan P, Chintapatla S (2021) Some thoughts pertaining to quality of life. Hernia 25:231–232. https://doi.org/10.1007/s10029-020-02265-9
16. Smith O, Isaac M, Elanjithara T et al (2020) What can complex abdominal wall hernia surgeons learn about quality of life from ancient Greek philosophers? J Surg Res 03:309–316. https://doi.org/10.26502/jsr.10020086
17. Ubel PA, Loewenstein G, Jepson C (2003) Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. Qual Life Res 12:599–607. https://doi.org/10.1023/a:1025119931010
18. Mokkink LB, Prinsen CAC, Bouter LM et al (2016) The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) and how to select an outcome measurement instrument. Braz J Phys Ther 20:105–113. https://doi.org/10.1590/bjpt-rbf.2014.0143
19. Cook DA, Beckman TJ (2006) Current concepts in validity and reliability for psychometric instruments: theory and application. Am J Med 119:166.e7–16. https://doi.org/10.1016/j.amjmed.2005.10.036
20. Matheson D, Abdel-Aty H, O'Shea L (2023) Quality of life measurements from the patient perspective: capturing the heterogeneity of the patient experience in a standardised way. Eur Urol Focus 9:425–426. https://doi.org/10.1016/j.euf.2023.03.013
21. Ties D, Singh TK, Zhang X et al (2022) What really matters: a patient-centered instrument to evaluate health-related quality of life in cardiovascular disease. Eur Heart J - Qual Care Clin Outcomes 8:722–729. https://doi.org/10.1093/ehjqcco/qcab079
22. Heniford BT, Lincourt AE, Walters AL et al (2018) carolinas comfort scale as a measure of hernia repair quality of life: A reappraisal utilizing 3788 international patients. Ann Surg 267:171–176. https://doi.org/10.1097/SLA.0000000000002027
23. Patel V, Cunning JR, Rios-Diaz AJ et al (2022) Prospective assessment of the abdominal hernia-Q (AHQ)-patient burden, reliability, and longitudinal assessment of quality of life in hernia repair. Ann Surg 276:1039–1046. https://doi.org/10.1097/SLA.0000000000004713
24. Mauch JT, Enriquez FA, Shea JA et al (2020) The abdominal hernia-q: development, psychometric evaluation, and prospective testing. Ann Surg 271:949–957. https://doi.org/10.1097/SLA.0000000000003144
25. Muysoms F, Campanelli G, Champault GG et al (2012) EuraHS: the development of an international online platform for registration and outcome measurement of ventral abdominal wall hernia repair. Hernia 16:239–250. https://doi.org/10.1007/s10029-012-0912-7
26. Muysoms FE, Vanlander A, Ceulemans R et al (2016) A prospective, multicenter, observational study on quality of life after laparoscopic inguinal hernia repair with ProGrip laparoscopic, self-fixating mesh according to the European Registry for Abdominal Wall Hernias Quality of Life Instrument. Surgery 160:1344–1357. https://doi.org/10.1016/j.surg.2016.04.026
27. Burckhardt CS, Anderson KL (2003) The quality of life scale (QOLS): reliability, validity, and utilization. Health Qual Life Outcomes 1:60. https://doi.org/10.1186/1477-7525-1-60
28. Hope WW, Lincourt AE, Newcomb WL et al (2008) Comparing quality-of-life outcomes in symptomatic patients undergoing laparoscopic or open ventral hernia repair. J Laparoendosc Adv Surg Tech A 18:567–571. https://doi.org/10.1089/lap.2007.0192
29. Nielsen K, Poelman MM, den Bakker FM et al (2014) Comparison of the Dutch and English versions of the Carolinas comfort scale: a specific quality-of-life questionnaire for abdominal hernia repairs with mesh. Hernia 18:459–464. https://doi.org/10.1007/s10029-013-1173-9
30. Jensen KK, Munim K, Kjaer M, Jorgensen LN (2017) Abdominal wall reconstruction for incisional hernia optimizes truncal function and quality of life: A prospective controlled study. Ann Surg 265:1235–1240. https://doi.org/10.1097/SLA.0000000000001827
31. Groene SA, Prasad T, Lincourt AE et al (2016) Prospective, multi-institutional surgical and quality-of-life outcomes comparison of heavyweight, midweight, and lightweight mesh in open ventral hernia repair. Am J Surg 212:1054–1062. https://doi.org/10.1016/j.amjsurg.2016.09.003
32. Klima DA, Tsirline VB, Belyansky I et al (2014) Quality of life following component separation versus standard open ventral hernia repair for large hernias. Surg Innov 21:147–154. https://doi.org/10.1177/1553350613495113
33. Ross SW, Wormer BA, Kim M et al (2015) Defining surgical outcomes and quality of life in massive ventral hernia repair: an international multicenter prospective study. Am J Surg 210:801–813. https://doi.org/10.1016/j.amjsurg.2015.06.020
34. Colavita PD, Tsirline VB, Belyansky I et al (2012) Prospective, long-term comparison of quality of life in laparoscopic versus open ventral hernia repair. Ann Surg 256:714–722. https://doi.org/10.1097/SLA.0b013e3182734130
35. Neumayer L, Jonasson O, Fitzgibbons R et al (2003) Tension-free inguinal hernia repair: the design of a trial to compare open and laparoscopic surgical techniques. J Am Coll Surg 196:743–752. https://doi.org/10.1016/S1072-7515(03)00004-8
36. McCarthy M, Jonasson O, Chang C-H et al (2005) Assessment of patient functional status after surgery. J Am Coll Surg 201:171–178. https://doi.org/10.1016/j.jamcollsurg.2005.03.035
37. Barber MD, Kenton K, Janz NK et al (2012) Validation of the activities assessment scale in women undergoing pelvic reconstructive surgery. Female Pelvic Med Reconstr Surg 18:205–210. https://doi.org/10.1097/SPV.0b013e31825e6422
38. Hyland ME (2003) A brief guide to the selection of quality of life instrument. Health Qual Life Outcomes 1:24. https://doi.org/10.1186/1477-7525-1-24
39. Hyland ME (2002) Recommendations from quality of life scales are not simple. BMJ 325:599. https://doi.org/10.1136/bmj.325.7364.599/b
40. Huang C-C, Lien H-H, Wong J-U et al (2020) Revisiting HERQL, the hernia-specific quality-of-life assessment instrument, to extend the clinical applicability for abdominal wall hernias. Hernia 24:771–780. https://doi.org/10.1007/s10029-019-02066-9
41. Huang C-C, Tai F-C, Chou T-H et al (2017) Quality of life of inguinal hernia patients in Taiwan: The application of the hernia-specific quality of life assessment instrument. PLoS One 12:e0183138. https://doi.org/10.1371/journal.pone.0183138

42. Gram-Hanssen A, Tolstrup A, Zetner D, Rosenberg J (2020) Patient-reported outcome measures for inguinal hernia repair are insufficiently validated: a systematic review. Int J Qual Health Care 32:223–230. https://doi.org/10.1093/intqhc/mzaa019
43. Fiore JF, Figueiredo S, Balvardi S et al (2018) How do we value postoperative recovery?: A systematic review of the measurement properties of patient-reported outcomes after abdominal surgery. Ann Surg 267:656–669. https://doi.org/10.1097/SLA.0000000000002415
44. Rust J, Kosinski M, Stillwell DJ (2021) Modern psychometrics: the science of psychological assessment, 4th edn. Routledge, Milton Park, Abingdon, Oxon New York, NY
45. Krpata DM, Schmotzer BJ, Flocke S et al (2012) Design and initial implementation of HerQLes: a hernia-related quality-of-life survey to assess abdominal wall function. J Am Coll Surg 215:635–642. https://doi.org/10.1016/j.jamcollsurg.2012.06.412
46. Cherla DV, Moses ML, Viso CP et al (2018) Impact of abdominal wall hernias and repair on patient quality of life. World J Surg 42:19–25. https://doi.org/10.1007/s00268-017-4173-6
47. Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL (2005) Conceptual model of health-related quality of life. J Nurs Scholarsh 37:336–342. https://doi.org/10.1111/j.1547-5069.2005.00058.x
48. Wilson IB, Cleary PD (1995) Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 273:59–65
49. Bowling A (2009) Handbook of health research methods: investigation, measurement and analysis. Reprinted. Open Univ. Press, Maidenhead
50. Carney MJ, Golden KE, Weissler JM et al (2018) Patient-reported outcomes following ventral hernia repair: designing a qualitative assessment tool. Patient - Patient-Centered Outcomes Res 11:225–234. https://doi.org/10.1007/s40271-017-0275-3
51. Wicks P (2014) Paul Wicks: Patients at the heart of quality of life research. In: thebmjopinion. https://blogs.bmj.com/bmj/2014/11/07/paul-wicks-patients-at-the-heart-of-quality-of-life-research/. Accessed 4 May 2025
52. De Vet HCW, Terwee CB, Mokkink LB, Knol DL (2011) Measurement in Medicine: A Practical Guide, 1st edn. Cambridge University Press
53. Fox-Rushby J, Parker M (1995) Culture and the measurement of health-related quality of life. Eur Rev Appl Psychol 45:257–264
54. McRackan TR, Velozo CA, Holcomb MA et al (2017) Use of adult patient focus groups to develop the initial item bank for a cochlear implant quality-of-life instrument. JAMA Otolaryngol Head Neck Surg 143:975–982. https://doi.org/10.1001/jamaoto.2017.1182
55. Mes MA, Chan AHY, Wileman V et al (2019) Patient involvement in questionnaire design: tackling response error and burden. J Pharm Policy Pract 12:17. https://doi.org/10.1186/s40545-019-0175-0
56. Smith OA, Mierzwinski MF, Chitsabesan P, Chintapatla S (2022) Health-related quality of life in abdominal wall hernia: let's ask patients what matters to them? Hernia 26:795–808. https://doi.org/10.1007/s10029-022-02599-6