

REVIEW ARTICLE

# Quality of life instruments in acute and chronic pancreatitis: a consensus-based standards for the selection of health measurement instruments (COSMIN) approach

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## Abstract

**Background:** Pancreatitis is a common surgical emergency, associated with pain and poor quality of life for patients. However, assessment of patient-reported outcome measures in these patients is unclear. This study aimed to identify and evaluate the methodological quality of the health-related quality of life instruments used for patients with acute or chronic pancreatitis.

**Methods:** Prospective studies that evaluated health-related quality of life in acute or chronic pancreatitis were identified from systematic review of MEDLINE, EMBASE, and Web of Science until 28th June 2023 (PROSPERO: CRD42021274743). Instrument characteristics were extracted, and methodological quality assessed using COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) guidelines and GRADE approach. Narrative synthesis was conducted, with recommendations for use based on COSMIN criteria, evaluated according to World Health Organisation (WHO) quality of life domains.

**Results:** From 3850 records screened, 41 quality of life instruments were identified across 138 studies included. The majority (69.8%,  $n = 26$ ) were designed to assess general health-related quality of life, whereas the remainder were abdominal-specific ( $n = 5$ ) or pancreas-specific ( $n = 10$ ). Only ten instruments (24.3%) demonstrated sufficient content validity, incorporating items in  $\geq 5$  WHO quality of life domains. However, only nine instruments (21.9%) incorporated public and patient involvement. Only the Gastrointestinal Quality of Life Index and PAN-PROMISE met the criteria to be recommended for use based on COSMIN methodological assessment.

**Conclusion:** There is significant heterogeneity in instruments used to assess quality of life after pancreatitis, with almost all instruments considered insufficient. Robust, validated, and relevant instruments are needed to better understand and determine appropriate interventions to improve quality of life for these patients.

Received 22 November 2023; accepted 18 April 2024

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## Introduction

Acute pancreatitis is among the most frequent gastrointestinal causes of hospitalisation,<sup>1</sup> with the burden expected to continue to grow due to an increasing global prevalence of common aetiological factors (e.g. gallstone disease, alcohol use).<sup>2,3</sup> This has profound implications for both patients and health systems, given up to 20% of patients develop moderate or severe acute pancreatitis, involving local tissue necrosis and/or systemic inflammatory response.<sup>4</sup> These cases are associated with significant hospitalisation costs, and short-term morbidity and mortality.<sup>1,5</sup>

However, even after the acute episode has resolved, pancreatitis patients experience high rates of long-term sequelae, including high rates of recurrence (10–30%),<sup>6</sup> and progression to chronic pancreatitis (involving endocrine and exocrine insufficiency).<sup>7</sup> While it has been well established these complications can have a considerable impact on the health-related quality of life of these patients, this remains poorly characterised.<sup>8,9</sup> Without a clear understanding of life after pancreatitis, determining the success and cost-benefit of interventions, as well as identification of patient groups at risk of worse quality of life outcomes is challenging, for policymakers, clinicians and researchers.

While a variety of instruments have been previously used to assess quality of life in pancreatitis patients, there is no “gold standard” and there has been no formal assessment of the methodological rigour to determine the most appropriate for use.<sup>9</sup> Therefore, this review aimed to evaluate instruments previously used to evaluate quality of life of patients with acute and/or chronic pancreatitis, and determine their methodological quality using Consensus based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines.<sup>10</sup>

## Methods

### Search strategy

This systematic review was pre-registered on PROSPERO (CRD42021274743)<sup>9</sup> and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) and Consensus-based Standards for the selection of Health Measurement Instruments (COSMIN) guidelines.<sup>10</sup>

The search strategy was developed to identify all prospective studies assessing quality of life in patients with acute or chronic pancreatitis. This was conducted on three electronic databases: EMBASE (Ovid), MEDLINE (Ovid) & Web of Science Core Collection including studies published up to 28th June 2023. This search was supplemented through hand-searching citation and reference lists from relevant articles and was limited to publications in the English language due to practical restraints.

### Eligibility criteria

Studies were eligible for inclusion if they utilised a formal instrument to evaluate the quality of life in adults with acute or

chronic pancreatitis. Instruments did not have to be developed for pancreatitis-specific populations but had to be utilised for this population. However, the exclusion criteria were: (i) grey literature, reviews, conference abstracts, case reports, case-series or qualitative studies; (ii) studies in which an instrument did not assess at least one of the World Health Organisation (WHO) domains of quality of life<sup>11</sup>; (iii) studies which retrospectively evaluated patient quality of life; and (iv) studies that also included paediatric patients or both acute and chronic pancreatitis patients, but did not present results separately.

### Screening and data extraction

All records identified were uploaded onto the Covidence online systematic review tool,<sup>12</sup> with two-stage screening conducted to identify eligible studies. At each stage the records were reviewed by two independent reviewers (RG, WAC, MK, IJ, AR, & SB). In the event of disagreement, studies were evaluated by a third reviewer, and discussed to establish a consensus. Data was extracted using a standardised template by four reviewers (WAC, MK, SB & IK). These included data on each study across four areas: (i) metadata and context of the study (article title; authors; publication year; journal; country); (ii) characteristics of the quality of life instrument (number of items, item content, completion time, validation status, frequency of use); (iii) population characteristics (number of patients, years of data collection, proportion of acute and chronic pancreatitis). Items assessed within each quality of life instrument were classified according to WHO domains of quality of life (physical health, psychological health, level of independence, social relationships, environment, and personal values and beliefs).<sup>11</sup>

### Quality assessment and data synthesis

Narrative synthesis was conducted and quality of each quality of life instrument identified was assessed using the COSMIN guidelines according to its content validity, feasibility/interpretability, and psychometric properties (structural validity, internal consistency, cross-cultural validity, reliability, measurement error, hypothesis testing, criterion validity, responsiveness) (Supplementary Table 1; Supplementary Fig. 1).<sup>13</sup> All psychometric properties reported for an instrument in an individual study were evaluated according to:

- Methodology:** The methodological approach was graded as very good (++), adequate (+), doubtful (+/-), inadequate (-), or not assessed (?).
- Results:** The results reported were rated as sufficient (+), insufficient (-), inconsistent (+/-), or indeterminate (?).
- Level of evidence:** The quality of evidence provided as determined by the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach (high, moderate, low, or very low).

If more than one study described a single instrument, the assessment was repeated for each study, and the best grade resulting from individual assessments was ascribed to the instrument.

Overall recommendations for usage of instruments were classified according to COSMIN guidance ([Supplementary Fig. 1](#)): (A) Recommended for use: evidence of sufficient content validity (covering a minimum of 5 out of 6 of the WHO quality of life domains) and at least low-quality evidence for sufficient internal consistency; (B) Requires further research: Does not currently meet the criteria for A or C classification; (C) Not recommended for use: There is high-quality evidence for at least one insufficient psychometric property.

### Patient and public involvement

Patient and members of the public were involved at several stages of this systematic review, including the design, management, and conduct of the review. We received input from patients who had lived experience of acute pancreatitis to help with selection of search terms and providing advice on interpretation of data following assessment of quality. A user led organisation (GutsUK) supported regular patient and public involvement meetings. We intend to disseminate the main results to the

charity and will seek patient and public involvement in the development of an appropriate method of dissemination.

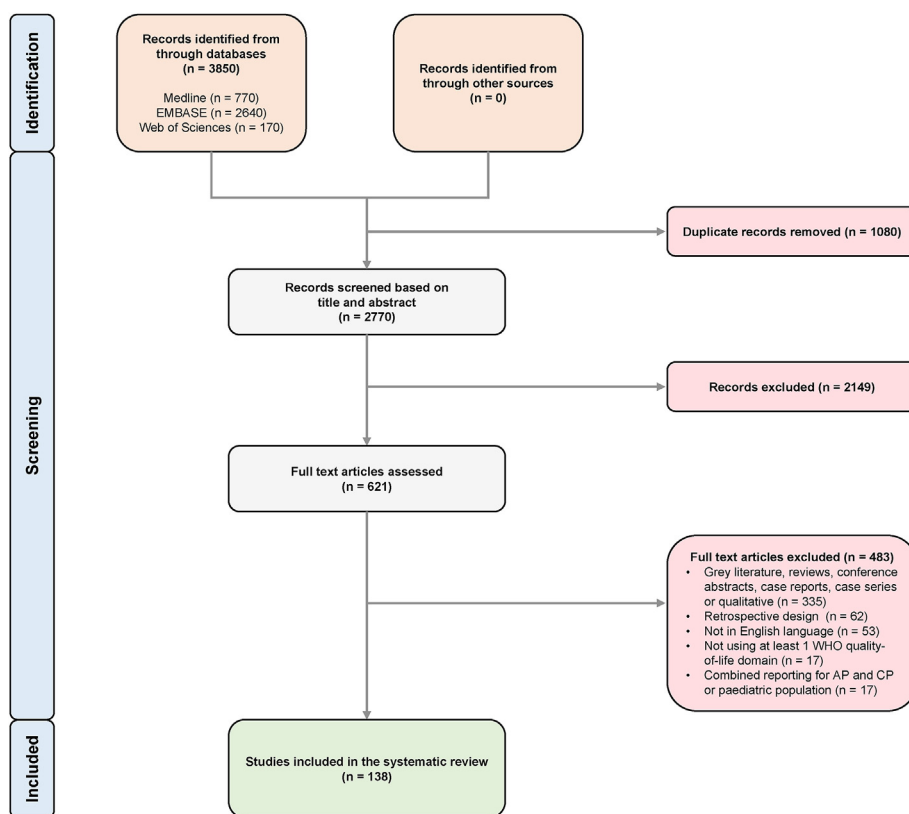
## Results

### Search results

Of the 3580 unique records identified in the literature search ([Fig. 1](#)), 621 full texts were assessed for eligibility. Following full-text review, 138 studies<sup>6,14–147</sup> were eligible for inclusion, encompassing 41 unique quality of life instruments used to assess the quality of life after acute or chronic pancreatitis ([Table 1](#)). The studies were published between 1993 and 2023 and majority of studies were single centre (80.4%, n = 111) ([Supplementary Table 2](#)). Overall, the studies included 21,523 patients, of which 5170 acute pancreatitis (n = 26 studies) and 16,353 were chronic pancreatitis (n = 112 studies).

### Instrument characteristics

Of the 41 instruments reported ([Fig. 2](#)), the majority (69.8%, n = 26) were designed to assess general health-related quality of life, whereas the remainder were abdominal-specific (n = 5) or pancreas-specific (n = 10). Ten (22.3%) instruments were previously validated (SF-36, GIQLI, ASIS, EORTC QLQ C30,



**Figure 1** PRISMA diagram of included studies in the systematic review

**Table 1** Summary of patient reported outcome measure tools used in included studies

Type of instruments	Instrument USAGE		Pancreatitis populations	Instrument characteristics			
	First published (year)	Studies, n		PPI	Validation	Items, n	Time to complete, mins
<b>Pancreas-specific instruments</b>							
EORTC – Chronic Pancreatitis (EORTC QLQ – PAN28)	2009	8 <sup>42,46,56,127,129–131,140</sup>	Acute & Chronic	No	Yes <sup>163</sup>	26	NR
EORTC – Pancreatic Cancer (EORTC QLQ – PAN26)	2010	4 <sup>38,97,101,137</sup>	Acute & Chronic	Yes	No	28	NR
FACT – Pancreatic (FACT – Pancreatic)	2003	1 <sup>94</sup>	Chronic	No	No	1	NR
Health-Related Quality of Life – Chronic Pancreatitis (HRQoL-CP)	2009	1 <sup>91</sup>	Chronic	No	No	24	NR
Izbicki Pain Score	2019	8 <sup>26,47,65,88,108,109,136,137</sup>	Acute & Chronic	No	No	4	<3
Pancreatitis Quality of Life Instrument (PANQOLI)	2017	3 <sup>16,43,117</sup>	Chronic	Yes	Yes <sup>151</sup>	18	NR
PAN-PROMISE	2021	2 <sup>21,40</sup>	Acute	Yes	Yes <sup>21,40</sup>	7	10 min
Self-designed	–	–	–	–	–	–	–
Self-designed EORTC QLQ 30 modification – Bloechle 1995	1995	1 <sup>55</sup>	Chronic	No	No	20	NR
Self-designed instrument – Milovic 2011	2011	1 <sup>98</sup>	Chronic	No	No	30	NR
Self-designed instrument – Mohan 1998	1998	1 <sup>100</sup>	Chronic	No	No	30	NR
<b>Abdominal-specific instruments</b>							
Abdominal Surgery Impact Scale (ASIS)	2015	2 <sup>32,33</sup>	Acute	No	Yes <sup>164</sup>	18	NR
FACT – Hepatobiliary (FACT – HPB)	2014	1 <sup>27</sup>	Acute	Yes	No	45	5–10 min
Gastrointestinal Quality of Life Index (GIQLI)	2006	4 <sup>36,63,86,147</sup>	Acute & Chronic	No	Yes <sup>149</sup>	36	NR
Gastroparesis Cardinal Symptom Index (GCSI)	2017	1 <sup>83</sup>	Chronic	No	Yes <sup>165</sup>	9	NR
Patient Assessment of Upper Gastrointestinal Disorders-Symptom Severity Index (PAGI-SYM)	2017	1 <sup>83</sup>	Chronic	Yes	Yes <sup>166</sup>	20	NR
<b>General quality of life instruments</b>							
Beck's Depression Index (BDI)	2012	2 <sup>42,134</sup>	Chronic	No	Yes <sup>167</sup>	21	NR
Brief Pain Inventory (BPI)	2012	10 <sup>49,72,74,90,93,110,117,123,133,168</sup>	Chronic	Yes	No	15	5 min
Cantril Ladder	2009	1 <sup>38</sup>	Acute	No	No	1	NR
Centre for Epidemiological Studies Depression Scale (CESD)	2014	2 <sup>49,104</sup>	Chronic	No	No	20	5 min
Current Opioid Misuse Measure (COMM)	2014	2 <sup>49,104</sup>	Chronic	No	No	17	NR
Depression Anxiety Stress Scale (DASS)	2012	2 <sup>87,142</sup>	Chronic	No	No	21	5–10 min
Epworth Sleepiness Scale (ESS)	1991	1 <sup>43</sup>	Chronic	No	No	8	5–10 min
EORTC QLQ C30	2009	64 <sup>15,22,31,34,38,42,44–47,50-53,55–57,60,62,64,70–72,74,76,78–82,84,85,87,90,93,95–97,99,101,108–110,113-116,129–131,133,135–137,139,140,143,146,147,168</sup>	Acute & Chronic	No	Yes <sup>163</sup>	30	12

Table 1 (continued)

Type of instruments	Instrument USAGE			Instrument characteristics			
	First published (year)	Studies, n	Pancreatitis populations	PPI	Validation	Items, n	Time to complete, mins
EQ-5D	2019	4 <sup>26,59,73,131</sup>	Acute & Chronic	No	No	6	NR
FACT – General (FACT – General)	2007	1 <sup>35</sup>	Acute	No	No	27	5–10 min
FACT – Treatment Satisfaction (FACT – TS)	2005	2 <sup>50,132</sup>	Chronic	Yes	Yes <sup>169</sup>	8	<5
Hospital Anxiety and Depression Score (HADS)	2009	2 <sup>38,168</sup>	Acute & Chronic	No	No	14	NR
Insomnia Severity Index (ISI)	2011	1 <sup>43</sup>	Chronic	No	No	7	5 min
McGill's Pain Questionnaire	2010	4 <sup>67,87,134,138</sup>	Chronic	Yes	No	28	10 min
Pain Disability Index (PDI)	2012	2 <sup>134,142</sup>	Chronic	No	No	7	5 min
Patient Reported Outcomes Medical Information System (PROMIS)	2019	2 <sup>43,58</sup>	Chronic	Yes	No	1–165	NR <sup>a</sup>
Patient's Global Impression of Change (PGIC)	2011	2 <sup>110,112</sup>	Chronic	No	No	1	1 min
Profile of Mood States	2007	1 <sup>128</sup>	Chronic	No	No	65	NR
Rosser disability and distress scale	1993	1 <sup>25</sup>	Acute	No	No	2	NR
Self-rating anxiety scale	1986	1 <sup>156</sup>	Chronic	No	No	20	15 min
Short Form-12 (SF-12)	2009	23 <sup>17,24,30,34,43,49,66,83,92,103–107,120–122,134</sup>	Acute & Chronic	No	No	12	NR
Short Form-36 (SF-36)	2006	41 <sup>6,14,16,18–20,22,23,26,28,29,37,39,41,48,54,58,59,61,65,67,68,75,77,88,89,102,111,119,124,125,128,138,140,141,144,145,156,170,171</sup>	Acute & Chronic	No	Yes <sup>172</sup>	36	NR
Spitzer's Quality of Life Index	1995	1 <sup>55</sup>	Chronic	No	No	5	NR
Symptoms of Stress Inventory	2007	1 <sup>128</sup>	Chronic	No	No	56	5–10 min
Visual Analogue Scale (VAS)	1921	24 <sup>14,27,31,47,57,60,73,75,76,81,82,84,91,94,116,124,126,129–132,134,137,142</sup>	Acute & Chronic	No	No	1	5–10 min
Zung Self-Rating Depression Scale	1995	2 <sup>118,156</sup>	Acute & Chronic	No	No	20	5–10 min

**Abbreviations:** EORTC QLQ = European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire, FACT = Functional Assessment of Cancer or Chronic Illness Therapy, NR = Not reported, PPI = Patient and Public Involvement.

<sup>a</sup> Since this combines multiple different instruments, no 'time to completion' can be given due to varying number of questions.

EORTC QLQ PAN 26, PANQOLI, BDI, PAGI-SYM, GCSI, and FACIT-TS). More than half of the studies (50.7%, n = 70) used a single instrument, 48 studies (34.7%) used two instruments and 20 studies used 3 or more instruments (14.4%). EORTC QLQ-C30 was the most used instrument (26.9%, n = 64), followed by SF-36 (17.2%, n = 41), and visual analogue scale (10.1%, n = 24) (Fig. 2). Only nine (21.9%) of the tools reported public and patient involvement in their design.

### Feasibility of quality of life instruments

Across the 41 quality of life instruments, there was substantial heterogeneity in the number of items with a median of 20 per instrument (IQR: 9 to 65, range: 1 to 165) (Table 1). However, only 18 (43.9%) instruments reported estimated time needed for completion (range: 1 min to 10–15 min). These questionnaires were most administered by healthcare staff (40.5%, n = 56/138

studies), during in person follow-up visits (31.1%, n = 43/138) (Supplementary Table 2).

### Content validity

Using instrument content analysis, all items were categorised into 24 variables nested across overall quality of life. Six domains were identified in 41 quality of life instruments (Fig. 3). All components of the WHO domains were assessed by at least one instrument, except four from the environmental domain (i.e., (i) physical safety and security; (ii) opportunities for acquiring new information and skills; (iii) physical environment (pollution/noise/traffic/climate); and (iv) transport). Physical health was the most featured domain (87.8%, n = 36), followed by psychological health (73.2%, n = 30). Only two instruments (4.9%) considered the impact of health on personal beliefs and values.

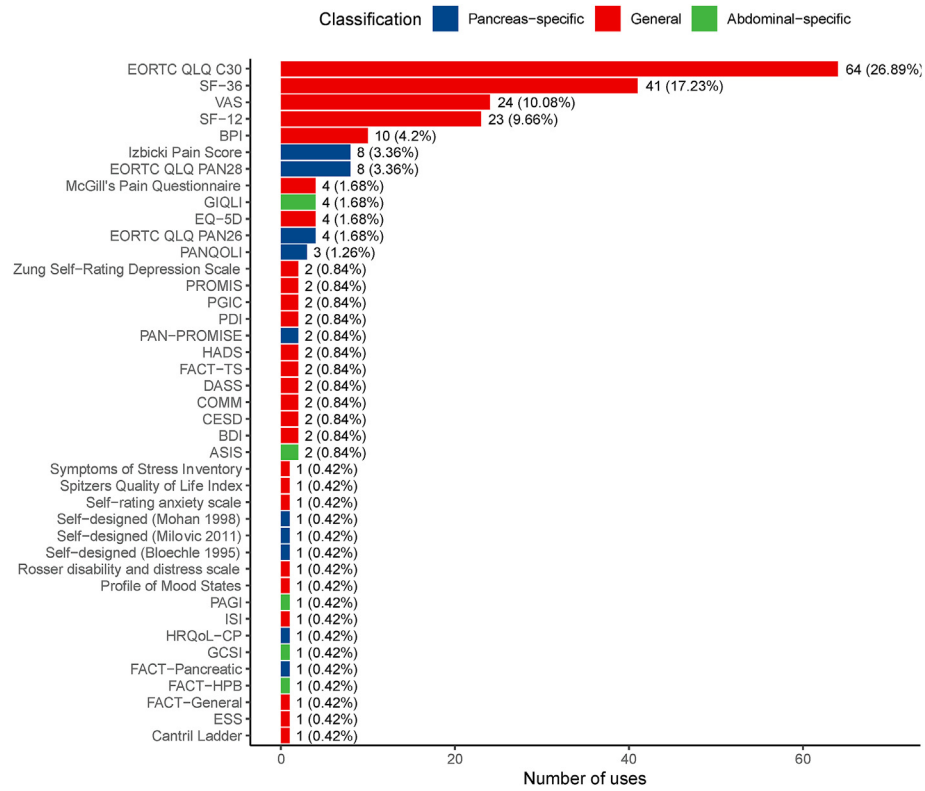


Figure 2 Patient reported outcome measure tools used across included studies

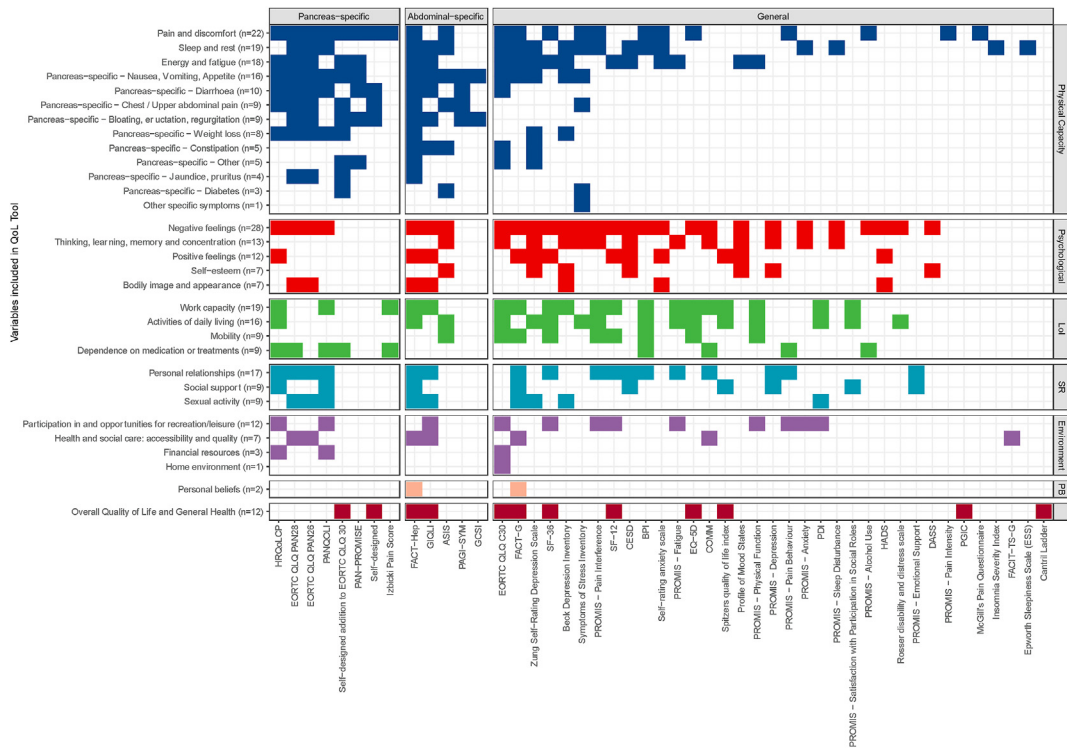


Figure 3 Content validity heatmap of domains and variables included in quality-of-life tools



physical domain of quality of life and developed for an acute pancreatitis population. Overall, only the PAN-PROMISE and PANQOLI instruments have been validated in acute and chronic pancreatitis populations, respectively, with the remaining validation being performed in other disease groups.<sup>150,151</sup> Since both these patient populations are different, use of well validated instruments are needed for both clinical practice and research, with focus on long-term follow-up.

Pancreatitis and the associated sequelae can affect every facet of a patient's life, and so assessment of the impact on health-related quality of life requires a multidimensional approach.<sup>102</sup> The majority of studies included in this review use generic instruments or those not pancreas specific (76.3%, n = 106/139). While this facilitates comparison to the general population, these are less sensitive to change in individual patients,<sup>152–154</sup> and do not encompass specific issues facing pancreatitis patients such as social stigma or potentially debilitating symptoms.<sup>150</sup> Even among the pancreas-specific instruments there remained substantial heterogeneity in aspects of pancreatitis considered (Fig. 3), with particularly poor consideration of the environmental and personal belief quality of life domains. Overall, only a quarter (n = 10/41) of the instruments were considered to have at least adequate content validity. This may reflect the common absence of patient and public involvement in design,<sup>155</sup> and it remains unclear whether these disease-specific instruments fully encompass the impact of pancreatitis on quality of life. This is of even greater concern given few instruments have been validated in a pancreatitis population,<sup>150,151</sup> with the remaining validations being performed in other disease populations. As such, the broader relevance of the other, unvalidated instruments is unclear, with the risk the true impact of the disease may have been misinterpreted.

Without confidence in the methodological quality of instruments used to assess quality of life in pancreatitis patients, we cannot have trust in the findings or their relevance to clinical care. The majority of instruments (90.2%, n = 37/41) had at least some methodological assessment performed. However, this was heterogeneous with significant omissions in the reporting of important measurement properties. These omissions are particularly important regarding internal consistency, given it is considered a key criterion needed for usage to be recommended (Supplementary Fig. 1). However, even for those studies which do examine methodological quality, to date the level of evidence to support the measurement properties is often very low quality. Just two instruments (GIQLI and PAN-PROMISE) were considered to have sufficient evidence of the methodological quality for usage, and only one was considered inadvisable for use (self-rating anxiety scale<sup>156</sup>) (Fig. 4). Most instruments lacked sufficient methodological assessment for a conclusion to be made. These issues regarding methodological assessment are common across instruments developed to assess PROMs in other contexts,<sup>157–159</sup> and why COSMIN guidelines were established.<sup>159</sup> Evaluating combined use of instruments are beyond the scope of this systematic review and will require appropriate

methodological evaluation to understand internal and external validity of new constructs. Therefore, they will require further research before incorporation into research studies or clinical practice can be recommended.

This systematic review is the first to comprehensively identify and evaluate instruments used to assess quality of life in pancreatitis patients. The use of the internationally recognised COSMIN methodology<sup>13</sup> allowed comparison according to current best practice regarding the reporting quality and evidence to support the validity of these instruments to assess quality of life in pancreatitis patients. COSMIN guidelines have already been applied to other diseases and areas of research to inform choices of most appropriate instruments.<sup>159–161</sup> This allows clear recommendations regarding the suitability for the intended population, and minimises the likelihood of using low-quality, unvalidated PROMs as part of clinical studies going forward. Furthermore, the WHO quality of life domains was utilised to categorise all items, providing a framework to understand how holistically each instrument assessed quality of life and identify variation between instruments. However, this review also has several limitations. Firstly, the search was limited to English language papers and databases, and so the review may not encompass every possible instrument developed or evaluated globally. Secondly, the recommendations for instruments are based on their methodological rigour according to COSMIN. This does not incorporate patient or clinician input regarding the content validity and feasibility, nor other psychometric properties beyond internal consistency. Furthermore, this does not consider availability of translations or licensing fees, nor the specific context or purpose the quality of life of these patients is being assessed for which may further influence instrument selection. Finally, we excluded grey literatures to ensure standardise reporting of the results during data extraction.

This systematic review demonstrated there remains large gaps in our knowledge of quality of life after pancreatitis, limiting our understanding of the efficacy of interventions to improve this. While GIQLI was the only PROM that received the Grade A Recommendation, its previous validation was not performed in either acute or chronic pancreatitis population. Therefore, the clinical relevance beyond the original population remains uncertain. This review provides a clear framework of standards for future scores developed to adhere to and demonstrates the need for greater methodological rigour and co-development with patient and public involvement in the design of new instruments, and further validation of current instruments to establish relevance to pancreatitis populations in large scale, prospective, international data. A Delphi consensus processes with clinician and patient input may be warranted to prioritise instruments for further investigation and establish a gold standard instrument for use.<sup>162</sup>

#### Funding sources

All authors declare no funding sources for this study and was supported by the GutsUK Charity for patients involved in the study.

### Conflicts of interest

All authors declare no competing interests.

### Appendix.

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#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.hpb.2024.04.004>.