The use of patient-reported outcome measures for pediatric surgical congenital anomalies

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TABLE OF CONTENTS

ABSTRACT **2**

RÉSUMÉ **4**

ACKNOWLEDGEMENTS **6**

DISCLOSURES **7**

CONTRIBUTION OF AUTHORS **8**

LIST OF ABBREVIATIONS **9**

CHAPTER 1: Introduction **10**
1.1 Rationale 10
1.2 Research Question 12
1.3 Hypothesis 12
1.4 Objectives 12

CHAPTER 2: Patient-Reported Outcome Measures in Pediatric Surgery - A Systematic Review **13**
HIGHLIGHTS 15
ABSTRACT 17
INTRODUCTION 19
METHODS 21
RESULTS 24
DISCUSSION 42
CONCLUSIONS 50
REFERENCES 52
SUPPLEMENTARY MATERIAL 65

CHAPTER 3: Discussion **107**
3.1 PROMs 107
3.2 Countries of Origin 109
3.3 Risk of Bias Analysis 111
3.4 Guiding PROMs Use 112
3.5 Future directions 114
3.6 Conclusion 116
3.7 References 118

ABSTRACT

Background

With the new shift towards patient-centered healthcare, pediatric surgical care has seen an increase in the use of patient-reported outcome measures (PROMs) in recent years. In fact, PROMs use in pediatric populations is of high importance, as children's concerns and perceptions regarding their illnesses must be heard and understood. Their use is even more important in patients suffering from congenital anomalies, as these children often suffer from multiple comorbidities, and therefore require long-term follow-up. Although PROMs have become more prevalent, their overall usage in the pediatric surgical specialty remains underdiscussed.

Objective

This work aimed to assess and characterize the PROMs currently in use in the pediatric surgical specialty, specifically for the treatment of some congenital anomalies.

Methods

A systematic review was conducted in order to scope the current literature.

Results

PROMs use in pediatric surgical care has considerably increased. However, their use remains heterogeneous as gold standards for congenital anomalies have yet to be established. Multiple tools currently in use are not validated in children, rendering them invalid for use in pediatric

populations. Moreover, none of the PROMs identified in this review were individualized PROMs (iPROMs), which denotes an area for improvement.

Conclusion

This is the first work to identify and appraise PROMs used in pediatric surgical care for congenital anomalies. The information provided by this research will help guide physicians in choosing and using the appropriate instruments for their practice.

RÉSUMÉ

Contexte

Avec la nouvelle évolution vers des soins de santé centrés sur le patient, les soins chirurgicaux pédiatriques ont connu une augmentation de l'utilisation des mesures des résultats rapportés par les patients (PROMs) ces dernières années. En fait, l'utilisation des PROMs dans les populations pédiatriques est d'une grande importance car les préoccupations et les perceptions des enfants concernant leurs maladies doivent être entendues et comprises. Leur utilisation est d'autant plus importante chez les patients souffrant d'anomalies congénitales, car ces enfants souffrent souvent de multiples comorbidités, et nécessitent donc un suivi à long-terme. Bien que les PROMs soient devenus plus répandus, leur utilisation globale dans la spécialité chirurgicale pédiatrique demeure peu discutée.

Objectifs

Cette recherche vise à évaluer et caractériser les PROMs actuellement utilisés dans la spécialité de chirurgie pédiatrique, plus spécifiquement pour le traitement de certaines anomalies congénitales.

Méthodes

Une revue systématique a été réalisée afin d’explorer la littérature actuelle.

Résultats

L'utilisation des PROMs dans les soins chirurgicaux pédiatriques a considérablement augmenté. Cependant, leur utilisation demeure inégale car des PROMs de référence pour les anomalies

congénitales n’ont pas été établis. Plusieurs questionnaires utilisés actuellement ne sont pas validés chez les enfants, ce qui les rend invalides pour une utilisation dans les populations pédiatriques. De plus, aucun PROM individualisé (iPROM) n'a été identifié dans la revue systématique de la littérature, ce qui dénote une opportunité d’amélioration.

Conclusion

Il s'agit du premier travail d'identification et d'évaluation des PROMs utilisés dans la prise en charge chirurgicale pédiatrique des anomalies congénitales. Les informations fournies par cette recherche aideront à guider les médecins dans le choix et l'utilisation des questionnaires appropriés pour leur pratique.

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DISCLOSURES

Anne-Sophie Besner has no conflicts of interest.

CONTRIBUTION OF AUTHORS

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SUPERVISION: Poenaru

LIST OF ABBREVIATIONS

ePROMs: Electronic Patient-Reported Outcome Measures

HIC: High-Income Country

HRQoL: Health-Related Quality of Life

iPROMs: Individualized Patient-Reported Outcome Measures

LMIC: Low Middle-Income Country

MMAT: Mixed-Methods Appraisal Tool

PROMs: Patient-Reported Outcome Measures

PROs: Patient-Reported Outcomes

RCT: Randomized Controlled Trial

ROB: Risk of Bias

CHAPTER 1: Introduction

1.1 Rationale

Current healthcare is moving in the direction of patient-centered care (1), where patients' needs and values are taken into consideration (2), allowing physicians to take into account what is important to the patients and to improve surgical care to reflect a better understanding of the patients' needs. The main goals of patient-centered care are for patients to be actively involved in decisions regarding their health, and for healthcare professionals to empower their patients by giving them the ability to be involved throughout the course of care (3,4). More importantly, this new shift towards patient involvement is associated with higher rates of patient satisfaction and better adherence to treatment (3). Patient-centered care encompasses health-related quality of life (HRQoL), a multidimensional concept where physical as well as mental well-being are associated with a patient's health status (5). HRQoL can be assessed through patient-reported outcomes (PROs), which are defined as measures "reported directly by the patient without interpretation of the patient's response by a clinician or anyone else" (6). PROs can not only measure HRQoL, but also functional status, symptoms and their burden, and the patient's experience with care, amongst others (6). These PROs can be measured with the use of questionnaires, called patient-reported outcome measures (PROMs). PROMs can be standardized or individualized. Standardized PROMs are composed of predetermined questions, whereas individualized PROMs (iPROMs) contain open-ended questions (7). PROMs can be used in all areas of healthcare, but this work is specifically focused on pediatric surgical care.

Pediatric surgery is significantly different from surgical disciplines where only adult patients are involved (8). One key difference is that not only the patient is involved in the surgical process, but the entire family unit. Thus, healthcare providers are expected to work as a team with both the child and the family. PROMs are therefore of utmost importance in pediatric surgical care, as not only the child, but the parent's concerns must be heard and discussed. It has in fact been shown that measuring PROs enhances patient engagement with care (9), highlighting their importance in modern healthcare settings.

Moreover, children suffering from chronic conditions can be impacted in multiple areas of their lives, namely concentration in school, academic performance, and overall quality of life (2). There has also been increasing recognition of the importance of parents' experience during their child's surgical process (10). It is thus of utmost importance that these outcomes be assessed, in order to address them with the family unit to evaluate the impact on their lives.

PROMs are of particular importance in the context of congenital anomalies. Since neonatal care has significantly improved in recent years, higher numbers of children suffering from congenital anomalies survive, and clinicians are thus faced with increasing numbers of patients with long-term morbidities (11). This can put a strain on various aspects of both children and their families' lives, which must be quantified using PROMs.

In recent years, various PROMs were developed for pediatric populations (12). However, despite the recent exponential increase in the number of instruments created, their use remains heterogenous (12), and few recommendations can be found regarding the best PROMs to use in

various clinical situations. Hence, based on the importance of PROMs and the increased recognition of their use in the field, a systematic review was conducted to assess the tools already in use and their characteristics.

1.2 Research Question

What is the current use of patient-reported outcome measures (PROMs) for pediatric surgical congenital anomalies?

1.3 Hypothesis

iPROMS are better suited for use in pediatric surgical care than standardized PROMs, as they better define patients' concerns regarding their illness.

1.4 Objectives

As mentioned above, PROMs use in pediatric surgery remains variable. The objectives of this work were two-fold. First, we aimed to map out the tools already in use in pediatric surgery, more specifically for congenital anomalies. Second, this work aims to guide future practices regarding which PROMs are best to use. In order to fulfill these objectives, a systematic review was conducted.

CHAPTER 2: Patient-Reported Outcome Measures in Pediatric Surgery - A Systematic Review

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HIGHLIGHTS

- PROMs are important for assessing outcomes of interventions, thus they are increasingly used in pediatric surgery.
- There is a lack of consensus in pediatric surgery on which PROM to adopt from the variety of available tools. Disease-specific PROMs predominate the field, yet validated and individualized PROMs are notably absent.

Keywords: child; quality of life; surgery; patient reported outcome

Type of Study: Systematic Review

Level of evidence: IIA

Abbreviations used:

HRQoL: Health-Related Quality of Life

QoL: Quality of Life

FDH: Functioning, Disability, and Health

PROM: Patient-Reported Outcome Measures

PRO: Patient-Reported Outcome

ABSTRACT

Purpose

With improved long-term survival rates, measuring the quality of surgical care has gradually shifted from clinical morbidity and mortality to patient-reported outcome measures (PROMs). Since the use of PROMs in pediatric surgery is still limited, we undertook a study to identify current PROMs, assess their characteristics, and identify gaps and areas for improvement.

Methods

A search was conducted in eight databases from their inception until May 2021 to identify PROMs that have been used in pediatric surgical patients. PRISMA standards were followed, and screening was completed by two independent reviewers. The quality of the included studies was appraised using the AXIS and the Mixed Methods Appraisal Tool.

Results

Of 8282 studies screened, 101 articles met the inclusion criteria. Most of the studies (99%) were cross-sectional. We identified 85 different PROMs among the studies, 53 being disease-specific and the rest generic. The PedsQL™ was the most frequently used tool (42 studies). Almost half of the instruments (41 studies) were not validated, and 28% were developed *ad hoc* for each specific study. Significantly, all PROMs encountered were standardized (consisting of pre-determined domains), with no individualized tools currently in use. The overall quality of the included studies was good.

Conclusions

PROMs are increasingly used in pediatric surgery. Disease-specific PROMs predominate the field, yet validated and especially individualized PROMs are notably absent. Future efforts are

needed to develop robust tools that reflect individual patient and family needs, preferences, and values, with the aim of furthering family-centered pediatric surgical care.

INTRODUCTION

Medical and surgical advances in the treatment of many congenital and chronic childhood conditions have increased the survival rates of pediatric patients undergoing surgery [1,2]. Consequently, as in other medical fields, the focus of outcome assessment in pediatric surgery has changed from mortality and morbidity towards health-related quality of life (HRQoL) [2]. HRQoL is a subjective multidimensional concept in which patient reporting is essential [1,3]. This patient report element is known as patient-reported outcomes (PROs), which are measured via patient-reported outcome measures (PROMs). A PROM assesses any aspect of a patient's health that stems directly from the patient, without interpretation by a physician or anyone else [4]. Standard features of PROs include patient symptoms, health status, functional status, quality of life, and health-related quality of life [3].

The advantages of assessing PROs are widely described in the literature. PROMs are relevant for promoting patient-centered care, assessing outcomes of healthcare interventions, resource allocation, and policymaking [5]. These instruments are also helpful in identifying and prioritizing health problems for individual patients, understanding burden of disease, facilitating communication between patients and healthcare providers, identifying unexpected health problems, aiding decision-making, and monitoring changes in a patient's health state [2,5]. Thus, PROMs have become critical in health system improvement through child and family-oriented care [6], and their inclusion in research and clinical consultations is encouraged by different health-governing authorities [3].

PROMs can be classified as generic and disease-specific. Generic measures evaluate individuals' overall quality of life and allow for a direct comparison between healthy and diseased

populations, while disease-specific measures focus on capturing specific and relevant issues for a target population [7]. These measures can also be classified into two other categories, standardized or individualized. The former have a predetermined set of questions and domains, whereas the latter do not. Individualized measures allow patients to provide their own definitions of HRQoL, hence challenging the prevailing approach of pre-defined PROMs [3].

Although there has been a growing interest in assessing components of HRQoL in children and adolescents, the current knowledge regarding their use is sparse [3,5]. The instruments currently available suffer from several limitations: poor agreement in their underlying conceptual framework, extensive variability of content and dimensions, lack of child-generated items, lack of disease-specificity and cultural appropriateness, inadequate validation, and discrepancies between child and parent ratings [1,3,5].

Likewise, the present literature on PROMs in pediatric surgery is heterogeneous, with little guidance regarding choice of appropriate measures to be used in each surgical context [1,2]. Furthermore, systematic reviews and meta-analyses summarizing current information about HRQoL in pediatric surgery are still rare [2].

Therefore, to the best of our knowledge, this is the first study to appraise the clinical use of PROMs in any pediatric surgical field. Our objectives are to identify the instruments most frequently used in the field and assess their characteristics. Our results are expected to enhance the future development and selection of patient-reported outcomes in pediatric surgery.

METHODS

The PRISMA guideline [8] and checklist for conducting systematic reviews was used (See Supplementary material) and the review was registered with the National Institute for Health Research's PROSPERO website (CRD42020181562) [9]. The search strategy was developed by a senior medical librarian (EG) and the following databases were searched from inception until May 28, 2021: Medline (Ovid), Embase (Ovid), Cochrane (Wiley), CINAHL (Ebsco), Global Health (Ovid), Global Index Medicus (WHO), Africa-Wide Information (Ebsco), and Web of Science (Clarivate Analytics). Variations in terms that relate to key concepts, found in the text words of the title, abstract or keyword fields, and relevant subject headings were adopted to retrieve articles looking at patient, family or caregiver reported outcome measures related to surgery in the pediatric population, with no language restrictions. See Supplementary material for the full search strategy. The PRISMA-S extension for searching was used for reporting and is included in the Supplementary material [10].

The online platform Rayyan [11] was used to perform the screening. The initial title and abstract screening as well as the full-text screening were all completed by two independent reviewers (ASB & JF), with a third reviewer (DP) resolving the discrepancies. The primary reason for exclusion was documented in an Excel document.

2.1 Inclusion and Exclusion Criteria

Studies were included if:

- PROMs (using both patient- and parental -reported (proxy) outcomes) were used to assess components of HRQoL in pediatric surgery related only to congenital anomalies;

- children's data were analyzed separately from that of the adult population when both samples were assessed;
- assessment of parental HRQoL following their child's surgical intervention was done.

Studies were excluded if:

- participant group was solely composed of adults (over 18 years of age);
- study was a validation, pilot, language translation, or development study or a review (including systematic or scoping reviews);
- outcomes were only assessed/reported by health care professionals rather than patients, or only assessed patient satisfaction with the surgical experience;
- condition studied was not surgical;
- surgical subspecialty was not pediatric surgery.

2.2 Data Extraction and Analysis

Data collected were compiled in an Excel spreadsheet. The following data were extracted from all studies: year of publication, country of origin, study design, condition studied, PROM type (generic, disease-specific or mixed generic and disease-specific) and instrument used. To analyze the content of each PROM, we collected information on instrument type (standardized/non-standardized), number and types of domains covered, and psychometric qualities. In determining the number of instruments, different versions of the same tool (e.g., versions for different age groups or proxies) counted as one. As defined in the literature, "standardized tools" were tools containing a predetermined set of questions and domains, while "individualized tools" were questionnaires which did not have predetermined domains.

We verified the instruments' validation status based on evidence found in the literature. PROMs were considered "validated" if the validation process was carried out in a pediatric population by evaluating associations between children's scores on the instrument and independent measures of similar constructs, or if it was done by comparison of scores among groups of children that were expected to differ on PROs (e.g. comparison of healthy children with those with chronic conditions). PROMs that were solely validated in adult populations were not considered validated in children. If validation studies using children as participants were not found for a particular tool used in a pediatric population, the tool was considered not validated. Modified validated questionnaires or those which were designed *ad hoc* for specific studies were classified as "in-house" PROMs.

The PROMs domains were identified using the Wilson and Cleary framework model [12]. The five domains used were: biological and physiological factors, symptom status, functioning, general health perceptions, and overall quality of life.

Questionnaires that assessed ability and intelligence were not considered PROMs.

2.3 Quality Assessment

Risk of bias assessment was done by two independent reviewers (ASB & JF). The cross-sectional studies were assessed using the AXIS tool [13], whereas the assessment of the randomized controlled trial was completed using the Mixed-Methods Appraisal Tool (MMAT) "Quantitative Randomized Controlled Trials" questionnaire [14].

RESULTS

The initial search yielded 9300 results. After duplicate removal, 8282 titles and abstracts were screened, of which 8137 were excluded. Out of the 122 studies included in the full-text review, 101 articles were included for final data extraction (see PRISMA flow diagram in Figure 1).

Fig. 1: PRISMA[8] flow diagram.

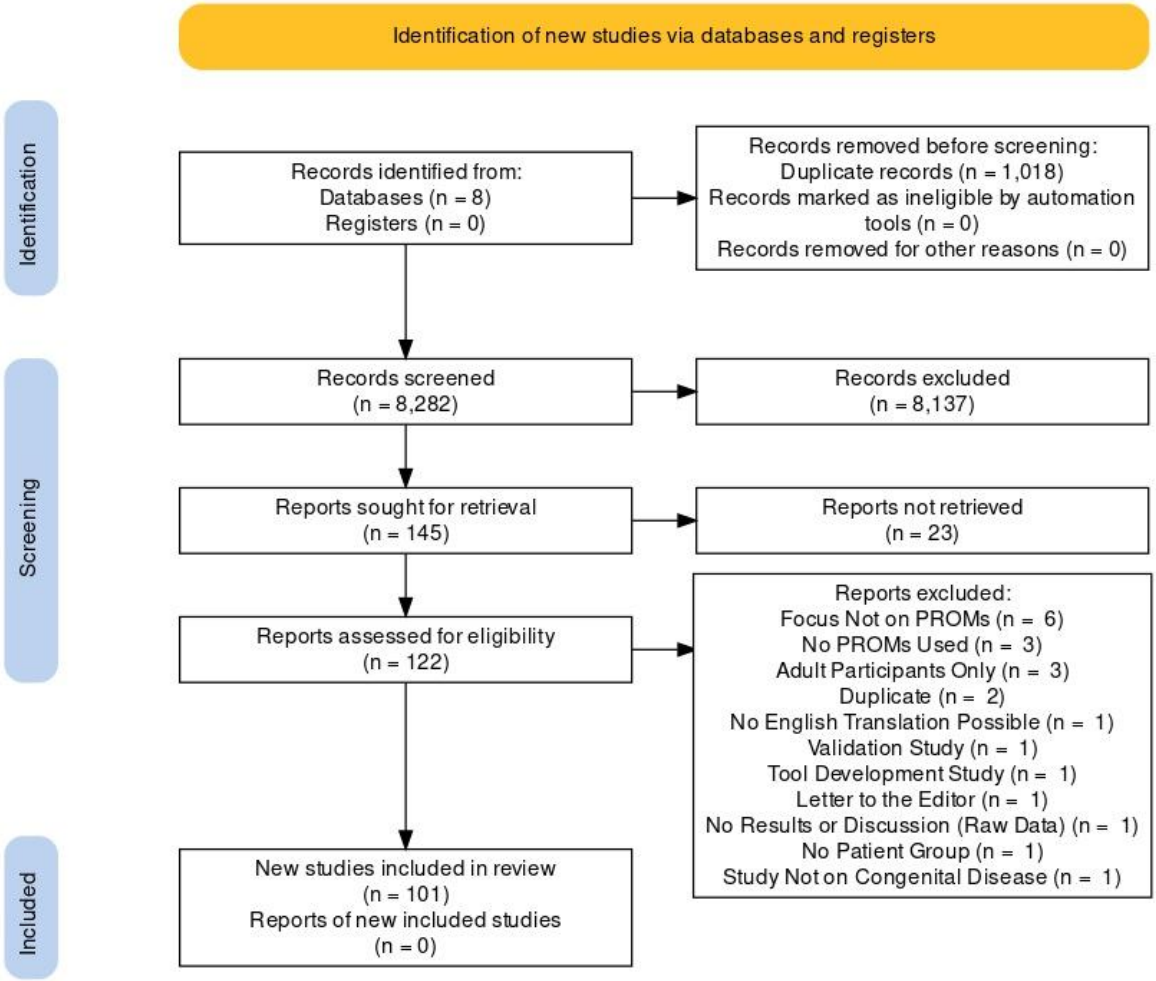


Table 1 displays all included articles and their characteristics based on author, year, country of origin, study design, condition studied, and type of instrument used.

Table 1: Included articles.

Author and Year	Country of Origin	Study Design	Condition Studied	PROM Type	Generic PROM Used	Disease-Specific PROM Used
Witt et al. 2021[32]	Germany and Sweden	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale, PedsQL™ Family Impact Module	EA-QOL
Loganathan et al. 2021[33]	India	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale, PedsQL™ Family Impact Module	BFS
Gallo et al. 2021[34]	The Netherlands	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	CHQ-CF87-BREF, TACQoL, TAAQoL (> 16 years old)	GIQLI
Darmaun et al. 2021[35]	France	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Bystrom et al. 2021[36]	Sweden	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	KIDSCREEN-52	BFS and an in- house questionnaire
Al Baroudi et al. 2021[37]	USA	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	PedsQL™ Family Impact Module	N/A
Davidson et al. 2021[38]	UK	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	BFS and a questionnaire adapted from the Danish Prostatic Score.
Wong et al. 2020[39]	China	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	Krickenbeck score, Kelly's score, HAQL
Townley et al. 2020[40]	UK	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PICS
Saysoo et al. 2020[41]	Indonesia	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	HAQL
Rozensztrauch et al. 2020[42]	Poland	Cross-Sectional	Esophageal Atresia	Generic	In-house questionnaire, PedsQL™ Family Impact Module	N/A
Power et al. 2020[43]	UK	Cross-Sectional	Congenital Diaphragmatic Hernia	Disease-Specific	N/A	In-house questionnaire
Peters et al. 2020[44]	India	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	Quality of life scores (Bai & Chen 2002) in-house questionnaire	Clinical bowel function score (Bai & Chen 2002) in-house questionnaire

Mille et al. 2020[45]	France	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	VSP-A; KIDSCREEN-10; Wechsler Children's Intelligence Scale; Rey Figure Test; NEuroPSYchological Assessment; SDQ; STAI and STAI-C	Krickenbeck score
Vinycomb et al. 2020[46]	Australia	Cross-Sectional	Duodenal Atresia	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PedsQL™ Gastrointestinal Module
Mikkelsen et al. 2020[47]	Norway	Cross-Sectional	Esophageal Atresia	Generic	IES-13, SDQ, PedsQL™ 4.0 Generic Core Scale	N/A
Li et al. 2020[48]	China	Cross-Sectional	Anorectal Malformations	Generic	WHOQOL-BREF	N/A
Stenstrom et al. 2020[49]	Denmark, Sweden, Norway and Finland	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	BFS
Kassa et al. 2020[50]	Sweden	Cross-Sectional	Esophageal Atresia	Generic	DISABKIDS, Beck Youth Inventories, Beck Anxiety Inventory and Beck Depression Inventory	N/A
Espeso et al. 2020[51]	France	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	HAQL, Krickenbeck score
Dellenmark-Blom et al. 2020[52]	Sweden and Germany	Cross-Sectional	Esophageal Atresia	DIsease-Specific	N/A	EA-QOL
Dai et al. 2020[53]	China	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PSE-HDAM scale, RHC
Moawd et al. 2020 [17]	Egypt	Randomized Controlled Trial	Congenital Diaphragmatic Hernia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Hambraeus et al. 2020 [54]	Sweden	Cross-Sectional	Sacrococcygeal Teratoma	Generic	PedsQL 4.0 Generic Core Scale, POSAS	N/A
De Bie et al. 2020 [55]	USA	Cross-Sectional	Gastroschisis	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PedsQL™ Cognitive Functioning Scale, GSS
Brooks et al. 2020 [56]	USA	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	BFS
Allin et al. 2020 [57]	UK and Ireland	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PICS

Zheng et al. 2019[58]	China	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	BCS
Witt et al. 2019 [59]	Germany	Cross-Sectional	Esophageal Atresia	Generic	Short-Form 8(SF-8), PedsQL™ 4.0 Generic Core Scale	N/A
Witt et al. 2019 [60]	Germany	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	EA-QOL
Wigander et al. 2019 [61]	Sweden	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	HAQL, BFS
Rozensztrauch et al. 2019 [62]	Poland	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Pederiva et al. 2019 [63]	UK	Cross-Sectional	Short-Bowel Syndrome	Generic	PedsQL Family Impact Module, PedsQL™ Healthcare Satisfaction Generic Module, PedsQL™ General Well-Being Scale, PedsQL™ 4.0 Generic Core Scales	N/A
Morsberger et al. 2019 [64]	USA	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PedsQL™ Gastrointestinal Symptoms Module
Meinds et al. 2019 [65]	The Netherlands	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	Child Health Questionnaire–CHQ-CF87	Pediatric Defecation and Faecal Continence (P-DeFeC) questionnaire, Defecation and Faecal Continence (DeFeC) questionnaire (for adults)
Kumari et al. 2019[22]	India	Cross-Sectional	Esophageal Atresia	Generic	Child Behavior Checklist, WHOQOL-BREF, Coping Strategies Checklist (CSCL)	Parental Stress Scale
Fritz et al. 2019[66]	USA	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	PedsQL™ 4.0 Generic Core Scale and a Family Impact survey	N/A
Flieder et al. 2019[20]	Germany and Sweden	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Youn et al. 2018[67]	South Korea	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	GIQLI
Svoboda et al. 2018[68]	UK	Cross-Sectional	Esophageal Atresia	Disease-Specific	N/A	In-house questionnaire

Sood et al. 2018[69]	Australia	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	N/A	Fecal Incontinence and Constipation Quality of Life, BCS, Cleveland Clinic Constipation Scoring System, VDESS
Roorda et al. 2018[70]	The Netherlands	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	CHQ-PF50	HAQL
Ost et al. 2018[71]	Sweden	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	KIDSCREEN-52	N/A
Nah et al. 2018[72]	Singapore	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scales, PedsQL™ General Well-Being Scale 3.0, PedsQL™ Family Impact Module 2.0	BFS
Kyrklund et al. 2018[73]	Finland	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Disease-Specific	N/A	BFS, GIQLI
Hong et al. 2018[74]	China	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	Kelly's score, Japanese Study Group of Anorectal Anomalies (JSGA) score
Dingemans et al. 2018[75]	Honduras and USA	Cross-Sectional	Anorectal Malformations	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Bojanic et al. 2018[76]	Croatia	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Ausili et al. 2018[77]	Germany	Cross-Sectional	Anorectal Malformations and spina bifida	Generic and Disease-Specific	Child Health Questionnaire–CHQ-PF50 for the parents of children from 6 to 11 years and the SF-36 for patients aged 12 to 17 years old	in-house questionnaire, Bristol scale
Arnold et al. 2018[78]	USA	Cross-Sectional	Gastroschisis	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	PedsQL™ Gastrointestinal Symptoms Module 3.0
Amin et al. 2018[79]	USA	Cross-Sectional	Congenital Diaphragmatic Hernia, Esophageal Atresia/Tracheoesophageal Fistula, Hirschsprung Disease, Gastroschisis,	Generic	PedsQL™ 4.0 Generic Core Scale	N/A

			Omphalocele & Necrotizing Enterocolitis			
Tannuri et al. 2017[80]	Brazil	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	Assessment of Quality of Life in Children and Adolescents with Fecal qIncontinence, Fecal Continence Index
Stenstrom et al. 2017[81]	Sweden	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	BFS
Raman et al. 2017[82]	India	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	Krickenbeck score, in-house questionnaire
Lampela et al. 2017[83]	Finland	Cross-Sectional	Biliary Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Holscher et al. 2017[84]	Germany	Cross-Sectional	Esophageal Atresia	Disease-Specific	N/A	In-house questionnaire
Hasserius et al. 2017[85]	Sweden	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	BFS
Collins et al. 2017[86]	Australia	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	Fecal Incontinence and Constipation Quality of Life; BCS, Cleveland Clinic Constipation Scoring System and VDESS
Zhong et al. 2016[87]	China	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	Kelly's score, QoL in-house questionnaire
Witvliet et al. 2016[88]	The Netherlands	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	WHOQOL-BREF	STAI-trait, STAI-state.
Versteegh et al. 2016[89]	The Netherlands	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	Krickenbeck score
Ost et al. 2016[90]	Sweden	Cross-Sectional	Congenital Diaphragmatic Hernia	Disease-Specific	N/A	In-house questionnaire
Lombardi et al. 2016[91]	Italy	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	AIMAR,GIQLI and modified Peña score system (in-house questionnaire)
Lane et al. 2016[92]	USA	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	VDESS, BCS

Kyrklund et al. 2016[93]	Finland	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	Erection Hardness Score, GIQLI
Dingemann et al. 2016 [94]	Germany	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	WHO-5; KIDSCREEN-27 for pediatric patients (self-report) and their parents (proxy-report)	N/A
Carpenter et al. 2016[95]	USA	Cross-Sectional	Gastroschisis	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Bal et al. 2016[96]	India	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Khalil, M. 2015[97]	United Arab Emirates	Cross-Sectional	Hirschsprung's Disease	Generic	PedsQL™ 4.0 Core Measurement Model, PedsQL™ 3.0 Healthcare Satisfaction Generic Module	N/A
Hartman et al. 2015[98]	The Netherlands	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic	TACQOL, containing a child self-report form and a parent proxy report form.	N/A
Grano et al. 2015[99]	Italy	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	HAQL
Witvliet et al. 2013[100]	The Netherlands	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	WHOQOL-BREF	STAI-trait, STAI-state)
Stenstrom et al. 2014[101]	Sweden	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	SF-36	GIQLI
Fernandez Ibieta et al. 2014[102]	Colombia	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	BFS, GIQLI modified (in-house questionnaire)
Michel et al. 2013[103]	France	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic and Disease-Specific	Strengths and Difficulties Questionnaire, KIDSCREEN-27, SF-36	13-symptom checklist (in-house questionnaire)
Lepeytre et al. 2013[104]	France	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Grano et al. 2013[105]	Italy	Cross-Sectional	Anorectal Malformations	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Bazo et al. 2013[106]	Argentina	Cross-Sectional	Hirschsprung's Disease	Generic	PedsQL™ 4.0 Generic Core Scale	N/A

Poley et al. 2012[107]	The Netherlands	Cross-Sectional	Anorectal Malformations & Congenital Diaphragmatic Hernia	Generic	EQ-VAS, a 20-cm visual analog scale and EuroQol EQ-5D	N/A
Mustafawi et al. 2012[108]	United Arab Emirates	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	2 in-house questionnaires, Wingspread scoring system
Legrand et al. 2012[109]	France	Cross-Sectional	Esophageal Atresia	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Cavusoglu et al. 2012[110]	Turkey	Cross-Sectional	Imperforate Anus, Hirschsprung's Disease, Esophageal Atresia, Intestinal Atresia, Congenital Diaphragmatic Hernia & Abdominal Wall Defects	Generic	PedsQL™ 4.0 Generic Core Scale	N/A
Pruthi et al. 2010[111]	India	Cross-Sectional	Anorectal Malformations	Generic	Zarit Burden Interview, WHOQOL-BREF	N/A
Hashish et al. 2010[112]	USA and Egypt	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	In-house questionnaire	In-house questionnaire
Grano et al. 2010[113]	Italy	Cross-Sectional	Anorectal Malformations	Disease-Specific	N/A	Krickenbeck score, HAQL
Peetsold et al. 2009[114]	The Netherlands	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	Wechsler Intelligence Scale for Children, Bourdon-Vos test, Beery Developmental Test of Visual Motor Integration, CBCL and Teacher Report Form, and health related quality of life assessed with the Child Child Health Questionnaire, and Health Utilities Index	N/A
Peetsold et al. 2009[115]	The Netherlands	Cross-Sectional	Esophageal Atresia	Generic	CHQ-PF50 CHQ-CF87	N/A
Faugli et al. 2009[116]	Norway	Cross-Sectional	Esophageal Atresia	Generic and Disease-Specific	General Health Questionnaire, 30-item version	State Trait Anxiety Inventory, Infant Behaviour Questionnaire

Niramis et al. 2008[117]	Thailand	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	Holschneider score
Mills et al. 2008[118]	Canada	Cross-Sectional	Hirschsprung's Disease	Generic and Disease-Specific	PedsQL 4.0 Generic Core Scale	Constipation scoring system by Agachan, fecal continence survey by Templeton and Ditesheim
Hartman et al. 2008[119]	The Netherlands	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	TACQOL, Self Perception Profile for Children and Adolescents	HAQL
Hartman et al. 2007[120]	The Netherlands	Cross-Sectional	Anorectal Malformations & Hirschsprung's Disease	Generic and Disease-Specific	TACQoL—TNO-AZL Child Quality of Life Questionnaire	HAQL
Chen et al. 2007[121]	USA	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	Functional Status IIR, Child Health Ratings Inventories General Health Module, National Survey on Children with Special Health Care Needs	N/A
Goyal et al. 2006[122]	UK	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	PedsQL™ 4.0 Generic Core Scale	BFS
Poley et al. 2004[123]	The Netherlands	Cross-Sectional	Anorectal Malformations & Congenital Diaphragmatic Hernia	Generic and Disease-Specific	TAIQOL, TACQOL, SF-36	In-house symptoms checklist
Poley et al. 2002[124]	The Netherlands	Cross-Sectional	Congenital Diaphragmatic Hernia	Generic	EuroQol EQ-5D questionnaire	N/A
Bai et al. 2002[125]	China	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	Clinical Bowel Function Scoring System (in-house questionnaire), Quality of life scoring criteria for children with fecal incontinence (in-house questionnaire)
Poley et al. 2001[126]	The Netherlands	Cross-Sectional	Anorectal Malformations	Generic	EuroQol EQ-5D questionnaire	N/A
Bai et al. 2000[127]	China	Cross-Sectional	Anorectal Malformations	Generic and Disease-Specific	CBCL	In-house questionnaire for disease impact and in-house questionnaire for quality of life scoring
Suita et al. 1998[128]	Japan	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	In-house questionnaire

Moore et al. 1996[129]	South Africa	Cross-Sectional	Hirschsprung's Disease	Disease-Specific	N/A	Kelly's score, modified Wingspread score (in-house questionnaire), Holschneider score

Legend: N/A - not applicable; EA-QOL - Esophageal Atresia Quality of Life Questionnaire; BFS - Rintala Bowel Function Score; CHQ-CF87-BREF - Child Health Questionnaire; TACQoL - TNO-AZL Children's Quality of Life; GIQLI - Gastrointestinal Quality of Life Index; HAQL - Hirschsprung's Disease/Anorectal Malformations Quality of Life Questionnaire; PICS - Paediatric Incontinence and Constipation Score; VSP-A Adolescents' Health and Perceived Health; SDQ - Strengths and Difficulties Questionnaire; STAI and STAI-C - Spielberger State, Trait Anxiety Inventory questionnaire; WHOQOL-BREF - Short version of theWorld Health Organization's Quality of Life Instrument; RHC - Revised Holschneider Criteria; POSAS - Patient Observer Scar Assessment Score; GSS - the PedsQL™ Gastrointestinal Symptoms Scale, BCS - Baylor Continence Scale; VDESS - Vancouver Dysfunctional Elimination Symptom Survey; SF-36 - Short-Form 36; CBCL - Child Behavior Checklist; CHQ - Child Health Questionnaire; USA- United Stats of America; UK- United Kingdom

The number of studies published each year progressively increased between 1996 (1) to 2021 (7). The highest number of studies in this review was published in 2020 (20, 19.6%), as the year 2021 only included studies until May.

As shown on the world map in the Supplementary material, the majority of the studies (15) originated in the Netherlands, followed by Sweden (13), and the United States (12). Seven studies included patients from more than one country, and were therefore represented more than once on the world map. According to the World Bank Classification [15] of countries based on income, 86 studies originated in high-income countries (HICs, 78.2%), 14 in upper middle-income countries (UMICs, 12.7%), and 10 in lower middle-income countries (LMICs, 9.1%). There were no studies originating in low-income countries.

A total of 85 PROMs were identified in the included studies, 73 (85.9%) of which were used in children. Out of all the PROMs, 32 (37.6%) were generic and 53 (62.4%) were disease-specific.

The majority of studies (39, 38.6%) used a combination of generic and disease-specific PROMs, closely followed by those that used only generic PROMs (35, 34.7%). Studies that only utilized disease-specific PROMs were the least prevalent (27, 26.7%).

Table 2 lists the characteristics of all PROMs used in at least two studies. By far the most frequently used tool was the PedsQL™ 4.0 generic core scale (PedsQL™ [16]), present in 42 studies (41.6%).

Table 2: Characteristics of children's PROMs (used in two or more studies).

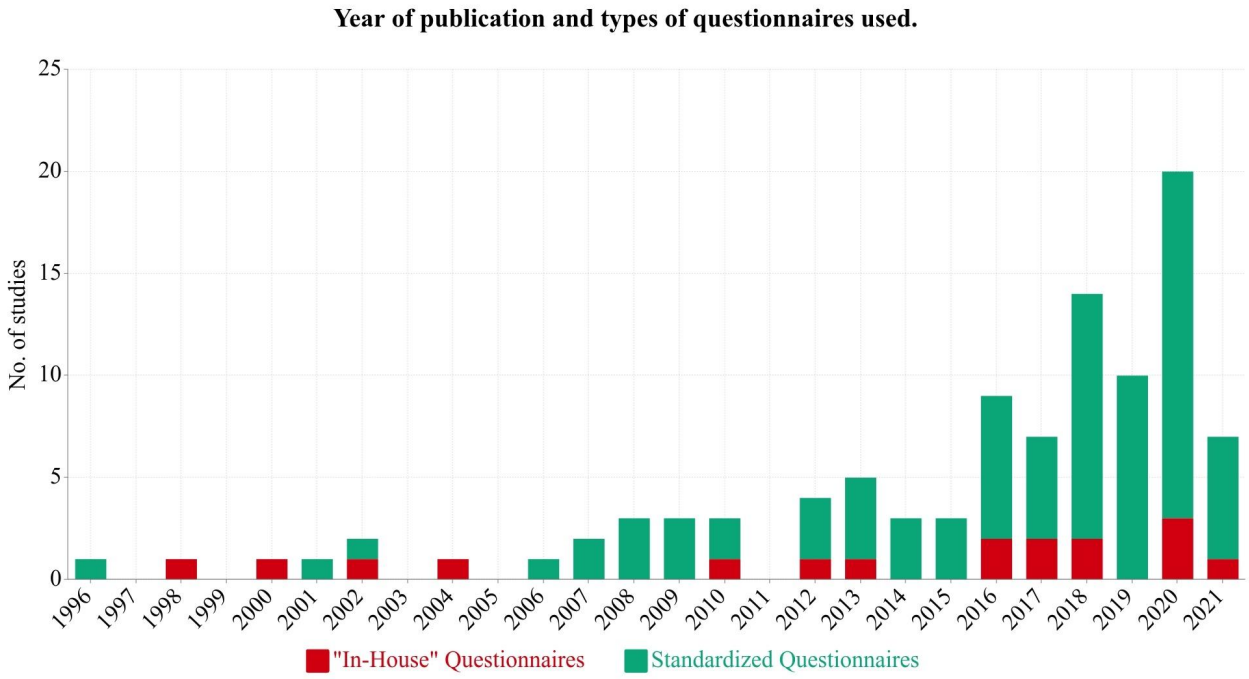
PROM NAME	ITEMS	DOMAINS COVERED					TYPE	VALIDITY	STUDIES
		Biological	*Symptoms*	*Function*	*Perception*	*Overall QOL*			
PedsQL™ 4.0 Generic Core Scale	23			X	X	X	Generic	Validated	42
Hirschsprung's Disease/ Anorectal Malformations Quality of Life Questionnaire (HAQL)	40	X	X	X	X	X	Disease-Specific	Validated	9
Gastrointestinal Quality of Life Index (GQLI)	36	X	X	X	X	X	Disease-Specific	Non-Validated	6
Rintala Bowel Function Score (BFS)	7	X	X	X		X	Disease-Specific	Non-Validated	8
Krickenbeck score	3	X	X	X		X	Disease-Specific	Validated	6
TNO-AZL Children's Quality of Life (TACQoL)	56	X	X	X	X	X	Generic	Validated	5
KIDSCREEN-52/27/10	52/27/10	X	X	X	X	X	Generic	Validated	5
Child Health Questionnaire– CHQ-CF87/ PF-50	87/50	X	X	X	X	X	Generic	Validated	5
Short-Form 36 (SF-36)	36		X	X	X	X	Generic	Non-Validated	3
Kelly's score	3	X	X	X			Disease-Specific	Non-Validated	4
PedsQL™ Gastrointestinal Symptoms Scale (GSS)/Module	58/74	X	X	X			Disease-Specific	Validated	4

Baylor Continence Scale (BCS)	23	X	X	X			Disease-Specific	Validated	3
Cleveland Clinic Constipation Scoring System (CCCS)	8	X	X	X			Disease-Specific	Non-Validated	3
Vancouver Dysfunctional Elimination Symptom Survey (VDESS)	14	X	X				Disease-Specific	Validated	3
Esophageal Atresia Quality of Life Questionnaire (EA-QOL)	18/ 27	X	X	X	X	X	Disease-Specific	Validated	3
EuroQol EQ-5D	5	X	X	X	X	X	Generic	Validated	3
Holschneider score	7	X	X	X		X	Disease-Specific	Validated	2
Paediatric Incontinence and Constipation Score (PICS)	13	X	X	X			Disease-Specific	Validated	2
Strengths and Difficulties Questionnaire (SDQ)	25		X	X			Generic	Validated	2
PedsQL General Well-Being Scale	7				X	X	Generic	Validated	2
Child Behavior Checklist (CBCL)	113			X			Generic	Validated	2
Fecal Incontinence and Constipation Quality of Life (FICQOL) Questionnaire	51		X			X	Disease-Specific	Validated	2
Modified Wingspread scoring system	1	X	X	X			Disease-Specific	Non-Validated	2

All PROMs encountered were standardized, and roughly equally split between validated (44, 51.8%) and non-validated (41, 48.2%) instruments. Twenty-four PROMs were classified as in-house questionnaires (28.2%).

Figure 2 shows the year of publication of the included studies and their use of in-house questionnaires. If one or more in-house questionnaires was used in a particular study, the study was classified as containing in-house questionnaires, regardless of the total number of tools used.

Fig. 2: Year of publication and types of questionnaires used. Legend: *The year 2021 only represents studies published until May.

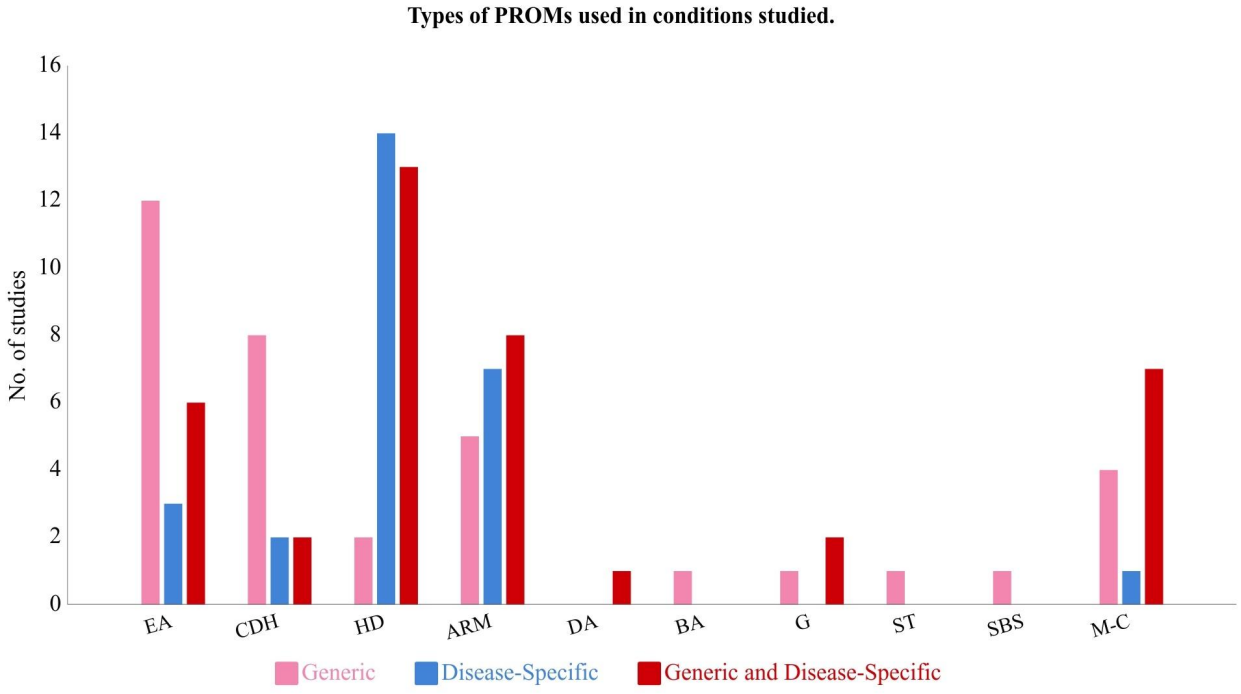


The most frequently studied condition in the included articles was Hirschsprung's disease, with 29 studies (28.7%). Other conditions studied included esophageal atresia (21, 20.8%), anorectal malformations (20, 19.8%), congenital diaphragmatic hernia (12, 11.9%), gastroschisis (3,

3.0%), duodenal atresia (1, 1.0%), biliary atresia (1, 1.0%), short-bowel syndrome (1, 1.0%), and sacrococcygeal teratoma (1, 1.0%). The “Multi-Conditions” category in Figure 3 refers to publications focusing on more than one condition - 12 such studies were identified (11.9%).

Figure 3 displays the types of PROMs used for each condition studied. Esophageal atresia and congenital diaphragmatic hernia studies predominantly used generic PROMs (12 and 8 studies, respectively). Studies focusing on Hirschsprung’s disease, on the other hand, mostly used disease-specific PROMs (14 studies), closely followed by those combining generic and disease-specific PROMs, with 13 studies. Studies on anorectal malformations utilized a balance of generic and disease-specific (8), disease-specific (7), and generic (5) PROMs.

Fig. 3: Types of PROM used in conditions studied. Legend: EA - Esophageal Atresia; CDH - Congenital Diaphragmatic Hernia; HD - Hirschsprung’s Disease; ARM - Anorectal Malformations; DA - Duodenal Atresia; BA - Biliary Atresia; G - Gastroschisis; ST - Sacrococcygeal Teratoma; SBS - Short-Bowel Syndrome; M-C - Multi-Conditions



Among the 101 studies included, 19 assessed components of the HRQoL of the parents of children who underwent surgery. Table 3 displays the 12 parental PROMs used with their characteristics.

Table 3: Characteristics of PROM used to interrogate parental HRQoL.

NAME	ITEMS	DOMAINS COVERED					TYPE	VALIDITY	STUDIES
		Biological	*Symptoms*	*Function*	*Perception*	*Overall QOL*			
PedsQL Family Impact Module	36			X	X	X	Generic	Validated	7
World Health Organization Quality of Life (WHOQOL)-BREF	26			X	X	X	Generic	Validated	5
Spielberg State–Trait Anxiety Inventory questionnaire (STAI)	20/10/6				X	X	Disease-Specific	Validated	3
WHO-5	5				X	X	Generic	Validated	2
Short- Form (SF-36/8)	36/8		X	X	X	X	Generic	Validated	2
Parental Stress Scale	18				X	X	Disease-Specific	Validated	1
Coping Strategies Checklist (CSCL)	36				X		Generic	Validated	1
Zarit Burden Interview	22					X	Generic	Non-Validated	1
CHQ-PF50: Parental Impact Emotional (PE) and Parental Impact Time (PT) scales and Physical and Psychosocial summary scales	25				X	X	Generic	Validated	1
AIMAR Questionnaire	15				X	X	Disease-Specific	Non-Validated	1

General Health Questionnaire	30				X	X	Generic	Validated	1
Parental self-efficacy in the management of home care of children with HD or ARM (PSE-HDAM) scale	19/17			X	X	X	Disease-Specific	Validated	1

3.1 Risk of bias

All studies used cross-sectional designs, with the exception of one randomized controlled trial (RCT) [17]. Risk of bias analysis showed that in all cross-sectional studies, the aim was clear, the study design was appropriate, the target population was clearly defined, the selection process was likely to identify subjects who would represent the target population, the risk factors and outcome variables measured were appropriate for the aims of the study, the basic data was appropriately described, the results were internally consistent, and the authors' discussions and conclusions were justified by the results. Only 13 cross-sectional studies (13%) had a response rate that would raise concerns regarding non-response bias. Over one fifth of the cross-sectional studies (21%) did not discuss the limitations of their research. Nine cross-sectional studies (9%) did not describe the methods sufficiently for replicability. Lastly, the single RCT had comparable groups at baseline, complete outcome data, outcome assessors blinded to the intervention provided and participants who adhered to the assigned intervention - yet the randomization was not correctly performed. The full risk of bias table is found in the Supplementary material.

DISCUSSION

This review examines the PROMs usage in pediatric surgery. Our key study findings were that PROMs are increasingly used in the field, disease-specific PROMs have gained space and now represent the majority of instruments used, but validation needs to be expanded and individualized PROMs are still notably missing.

Compared to adult literature, the measurement of HRQoL in children and adolescents is a relatively new development [2]. However, in recent years, the production of HRQoL instruments

for the pediatric population, particularly in the form of disease-specific questionnaires, has significantly increased [2,5]. Thus as expected, the number of studies using PROMs in pediatric surgery is increasing on an annual basis.

The most prolific countries for pediatric surgical PROMs publications were the Netherlands and the United States. A potential explanation for the high number of studies originating in HICs are divergent research priorities across the income divide. Indeed, HRQoL may not be a priority at a national level for some LMICs where resources need to be allocated to basic priorities like food, clean water, health services and education [18].

The current review found growing experience with the use of PROMs in the pediatric surgery subspecialty, despite substantial heterogeneity among the instruments used and a lack of consensus in the selection of appropriate PROMs for the demographic of interest. Eighty-five different PROMs were identified in the selected studies, with the majority (53) being disease-specific. This result confirms the trending interest in disease-specific measures, considered more specific and potentially more sensitive in identifying differences in the target population [3,5]. Both generic and disease-specific instruments were highly diverse in their conceptual framework, the number of items they used (3-87), and the domains covered (1-14). Because of this large number of domains encountered, and to adhere to a unifying conceptual framework, the most frequently used PROMs were reclassified based on the Wilson and Cleary model [12] (Tables 2 and 3). Twenty PROMs were used in more than one study in children, with only seven of them covering all model domains. The most represented domains were “symptoms and functioning”, suggesting that the pediatric PROMs probably focus more on Functioning, Disability, and Health (FDH), rather than quality of life (QoL) or health-related quality of life (HRQoL) [19].

Over 60% of the studies used only one PROM type, either generic or disease-specific. This is seen as a limitation, since a single instrument is unlikely to capture the multiple, rich, perspectives of children and adolescents facing an illness [1]. A more fitting approach may be to combine both generic and disease-specific PROMs, or use an instrument with both generic and disease-specific modules [3].

The most frequently used instrument was the PedsQL™ [16], present in almost 40% of the studies. This tool's popularity is likely due to its multidimensional child self-report (PROs) and proxy-report scales, the potential for use across a wide age range, and the opportunity of integration with the PedsQL™ disease-specific modules. In addition, the PedsQL™ has confirmed good reliability and validity for chronic diseases, making it attractive for clinical trials, research, and clinical practice [16]. The instrument has however not been developed for any surgical conditions, and therefore its modules do not cover the complexity of surgery [20]. Furthermore, Ow N. et al. showed that generic HRQoL measures are not sufficient to reflect the impact of rare diseases on children’s lives [21].

One possible explanation for pediatric surgeons' preference for popular generic PROMs is their comparability across studies [19]. This comparability is however limited by regional geographic and cultural differences, with some HRQoL dimensions acquiring greater or lesser importance for children in various parts of the world [18,20]. In addition, a PROM developed in high-income countries may use domains and item interpretations more relevant to the experiences of children and youth from those countries [18]. Furthermore, small sample size and single-centric cross-sectional methodology limit the generalizability of published results [22], a characteristic unfortunately applicable to almost all the studies included in this review.

The conceptual framework underpinning PROMs requires particular mention. There is limited agreement in the literature on what generic instruments are intended to measure, and how to distinguish between FDH, QoL, and HRQoL domains [19]. The terms QoL and HRQoL are not interchangeable, although often used as such. QoL is a global construct embracing all aspects of a person's life, including material comfort and safety, relationships, learning and self-expression, work, leisure, and health [23]. In contrast, HRQoL is a narrower concept that can be defined as the impact of disease and treatment on disability and daily functioning, or the impact of perceived health on an individual's ability to live a fulfilling life [3,23]. Such conceptual knowledge of FDH and QoL/HRQoL is required before any PROM selection, regardless of the instrument's reported performance. Disregarding these concepts may result in studies with results which are either conflicting or challenging to interpret [19], as was occasionally encountered in the current review.

In clinical practice, surgeons need to consider multiple aspects when choosing a HRQoL instrument, including brevity, ease of administration and scoring, and interpretability [3]. In addition, it is essential to evaluate whether the questionnaire satisfies the scope of the investigation, if the relevant domains are covered, and if it is suited well to the target age group. Furthermore, uniquely when dealing with pediatric patients, the choice between self and parental (proxy) report must be carefully weighed - with preference to child self-report. Since discordance between parent-completed and child-completed questionnaires has been reported, and external parental perspectives do not necessarily reflect children's voices, whenever possible self-completed measures should be applied to children [3]. Healthcare providers should also choose instruments with confirmed responsiveness, validity, and reliability, especially if the study objective is to evaluate the effectiveness of an intervention or monitor the evolution of

health status over time [3,24]. In this context, responsiveness is the ability of a health-related PROM to detect change over time, validity is the extent to which an instrument measures what it intends to measure, and reliability is the degree to which the instrument is free from measurement error [3]. As different PROMs are often designed for and used in different populations, recommending a particular instrument over another is generally not feasible [3]. In order to assist however in instrument selection, Table 2 outlines the features of the PROMs encountered in our review.

All PROMs identified in this review were standardized rather than individualized. This finding reveals the shortage of patient-generated measures in the pediatric population. Individualized or patient-generated measures have been comparatively under-studied, despite some significant advantages over standardized measures when used in clinical practice [25]. Standardized measures are suitable for statistical comparisons between different populations for research purposes, but often lack true patient-centeredness [3]. By asking fixed questions to patients, the standardized tools limit the assessment of personal experiences to predetermined items. On the other hand, while individualized measures cannot be used for population comparisons, they can interrogate the amplitude of patients' individual needs using weighting systems, and can even identify health problems missed by standardized tools [3,25]. Individualised instruments are therefore patient rather than disease-specific [3] and their validation and usage in the pediatric population needs to be encouraged.

Regardless of the PROM type adopted for assessing pediatric HRQoL, precise and consistent measurements result from systematically developed and validated PROMs [3]. Although the instruments’ developmental characteristics were beyond the scope of this review, some questionnaires reviewed were created without any direct patient input, which is now recognized

as a major limitation [6]. Including patients in both the development of measurement tools and in the ensuing research process is considered a key step in patient participation and inclusion, and in the patient-centeredness and partnership of the health care system [2,6]. Children also need to be involved at crucial moments in the instrument development process through focus groups, interviews, and item reduction and validation processes [5]. In a study to assess child and family engagement in the selection and development of PROMs for clinical studies, McNeill et al. found that children and families were sparsely engaged as co-conductors or equal partners in these processes [6]. The engagement of patients and families as collaborators can however improve patient-centredness, rigour, and applicability of PROM [6]. In the current review, approximately half of the PROMs used were not validated in children. Moreover, over one fifth of the PROMs were in-house questionnaires developed *ad hoc* for specific studies, often not following the standard WHO guidelines for developing HRQoL instruments for children [26]. Such in-house instruments typically lack clearly-defined psychometric properties, and are therefore less credible than validated tools.

Our review identified some studies which used PROMs validated in adults but not in children. For instance, the Gastrointestinal Quality of Life Index (GIQLI) [27] and the 36-item Short-Form Survey (SF-36) [28] were used in several studies assessing children's HRQoL, despite neither being validated in pediatric populations [7]. The constraints of using outcome measures designed for adults in children have been well established, including age-related vocabulary restrictions and reduced understanding of health outcomes [24]. PRO measures designed for adults are also unlikely to address childhood realities or be sensitive to children's developmental changes over time. Thus, the use of adult-validated PROMs in the pediatric population is discouraged [24]. The nuances of children's HRQoL assessment [2] and the limited set of appropriate tools

available make instrument selection challenging [3] but does not justify the use of age-inappropriate PROMs in children [24].

The most frequently studied congenital diseases in this review were Hirschsprung's disease, esophageal atresia, anorectal malformations, and congenital diaphragmatic hernia, in this order. Studies focusing on Hirschsprung's disease and anorectal malformation used mainly disease-specific PROMs, and the Hirschsprung's Disease/Anorectal Malformations Quality of Life Questionnaire (HAQL) was used in a fifth of the studies covering the two conditions. On the other side, although there is a validated PROM explicitly developed for esophageal atresia, the Esophageal Atresia Quality of Life (EA-QOL) Questionnaire [29], most studies assessing this condition used predominantly generic PROMs, with the EA-QOL utilized in only 14.3% of the studies focusing on this disease. Similarly, studies on congenital diaphragmatic hernia primarily used generic tools, though that can be justified in part by the absence of a disease-specific questionnaire for this condition. Such findings highlight the lack of standards and consistency in pediatric surgical PROMs, and the gaps that need to be filled in future research. It is of the utmost importance for the pediatric surgical community to assume leadership and collaborate in the development, validation, and usage of high-quality, specialty-appropriate PROMs.

This review also included studies assessing the parental HRQoL of children who have undergone surgical interventions. From the 101 studies included, approximately 20% used PROMs to measure parental HRQoL, with 12 different tools. Despite only a fifth of the studies reviewed included parental HRQoL PROMs, this finding confirms the increasing recognition of the impact of children's health conditions on the quality of life of their caregivers and families [2]. Parents of chronically ill children face significant stress and experience a lower quality of life, which may negatively affect their children. Stable parental health is the basis for children's healthy

development and adjustment to their chronic condition [2]. Parental well-being is also a crucial factor affecting how parents perceive their children's HRQoL and how they therefore respond to proxy questionnaires [2,3]. Thus, assessing and improving the parents' psychosocial well-being is essential in providing family-centered care, and the routine inclusion of PROMs for parental HRQoL evaluation should be encouraged in pediatric surgical care and research [2].

Another finding of this review was that the majority of the studies used a cross-sectional design. Most studies were of good quality, having clear objectives, targeting the aimed population, analyzing the data appropriately and showing internal consistency in their results. In addition, only a small number of studies raised concerns of non-response bias. Unfortunately, a full one third of these cross-sectional studies used lower-quality, non-validated or in-house instruments, therefore limiting their validity.

This review has several strengths, using solid methodology and being the first to summarize the current use of PROMs in pediatric general surgery. Our study does, however, have several limitations. Due to the wide spectrum of instruments identified in the review, our analysis was overwhelmingly descriptive. Secondly, despite using the most widely cited conceptual framework of HRQoL [30] to reclassify the PROMs domains, the individual item inclusion in each Wilson and Cleary domain was based on the authors' interpretation, therefore introducing a selection bias. Several included studies reviewed lacked a clear classification of study design, requiring our team to use available descriptions to classify them following Grimes' algorithm of study designs [31] - again potentially adding bias. Regarding the risk of bias analysis, although the AXIS tool comprises 20 detailed criteria, it does not provide a final numerical scale, leaving the interpretation of the results to the user [13]. Additionally, it is possible that the notable absence of individualized PROMs might be due to the fact that our review was not explicitly

designed to identify this PROM type. Finally, due to the large number of studies found in our search, we limited our review to studies discussing congenital surgical diseases. This relatively narrow focus might have resulted in missing additional PROMs reported for other pediatric conditions.

CONCLUSIONS

Our review has confirmed the general recognition of PROMs as essential components of outcome measurement in pediatric surgery. There remain, however, several challenges to overcome, particularly in the quality and selection of the instruments.

We have identified the most frequently used PROMs in pediatric general surgery and their individual characteristics. This information should assist clinicians and researchers in the decision-making process of adopting the right PROM for their specific needs. It is vital that such PROMs be validated, reliable, responsive, and appropriate for the population under study. A conceptual understanding of FDH and QoL/HRQoL, prioritization of child self-reporting, and the inclusion of patients and family partners in PROMs development and selection are also strongly recommended. We discourage creating more in-house questionnaires for specific studies, and reinforce instead the further validation of quality existing PROMs, such as the EA-QOL and HAQL. We also advocate for specialty-wide collaboration and standardization of PROMs usage in pediatric general surgery, and the development and validation of individualized pediatric PROMs. Only a concerted, collaborative effort in this field will enable us to accurately measure children's and families' individual needs, preferences, and values, ultimately fostering true patient-centered pediatric surgical care.

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SUPPLEMENTARY MATERIAL

Supplementary Table 1: PRISMA checklist.

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pages 6, 7
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 6, 7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pages 7, 8
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pages 7, 8
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pages 7, 8
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Not applicable
Synthesis	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention	Page 7

methods		characteristics and comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 7
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Fig 1,2,3 Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Not applicable
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not applicable
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Page 8
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Not applicable
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Fig.1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Not applicable
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Supplementary
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 1, Fig. 1, 2, 3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Not applicable
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pages 8, 9, 10
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Not applicable
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not applicable
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 11-17

	23b	Discuss any limitations of the evidence included in the review.	Page 17
	23c	Discuss any limitations of the review processes used.	Page 17
	23d	Discuss implications of the results for practice, policy, and future research.	Page 11-17
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not applicable
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 18
Competing interests	26	Declare any competing interests of review authors.	Page 18
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Table 1, Supplementary

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Supplementary Table 2: PRISMA abstract checklist.

PRISMA 2020 for Abstracts Checklist

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	Yes
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Yes
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	No
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	No
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Yes
Synthesis of results	6	Specify the methods used to present and synthesise results.	No
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Yes
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Yes
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	No
Interpretation	10	Provide a general interpretation of the results and important implications.	Yes
OTHER			
Funding	11	Specify the primary source of funding for the review.	No

Section and Topic	Item #	Checklist item	Reported (Yes/No)
Registration	12	Provide the register name and registration number.	No

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Supplementary Table 3: PRISMA-S checklist.

PRISMA-S Checklist

Section/topic	#	Checklist item	Location(s) Reported
INFORMATION SOURCES AND METHODS			
Database name	1	Name each individual database searched, stating the platform for each.	p. 6 & Included in Supplementary Material
Multi-database searching	2	If databases were searched simultaneously on a single platform, state the name of the platform, listing all of the databases searched.	p. 6 & Included in Supplementary Material
Study registries	3	List any study registries searched.	N/A
Online resources and browsing	4	Describe any online or print source purposefully searched or browsed (e.g., tables of contents, print conference proceedings, web sites), and how this was done.	Conference proceedings included primarily within Embase (Ovid) as well as other databases.
Citation searching	5	Indicate whether cited references or citing references were examined, and describe any methods used for locating cited/citing references (e.g., browsing reference lists, using a citation index, setting up email alerts for references citing included studies).	References of included articles were verified.
Contacts	6	Indicate whether additional studies or data were sought by contacting authors, experts, manufacturers, or others.	N/A
Other methods	7	Describe any additional information sources or search methods used.	N/A
SEARCH STRATEGIES			
Full search strategies	8	Include the search strategies for each database and information source, copied and pasted exactly as run.	Included in Supplementary Material

Limits and restrictions	9	Specify that no limits were used, or describe any limits or restrictions applied to a search (e.g., date or time period, language, study design) and provide justification for their use.	p. 7
Search filters	10	Indicate whether published search filters were used (as originally designed or modified), and if so, cite the filter(s) used.	MUHC Pediatric filter used
Prior work	11	Indicate when search strategies from other literature reviews were adapted or reused for a substantive part or all of the search, citing the previous review(s).	Portions of the search were adapted from Niburski K, Guadagno E, Mohtashami S, Poenaru D. Shared decision making in surgery: A scoping review of the literature. Health Expect. 2020 Oct;23(5):1241-1249. doi: 10.1111/hex.13105. Epub 2020 Jul 22. PMID: 32700367; PMCID: PMC7696205.
Updates	12	Report the methods used to update the search(es) (e.g., rerunning searches, email alerts).	N/A
Dates of searches	13	For each search strategy, provide the date when the last search occurred.	p. 6
PEER REVIEW			
Peer review	14	Describe any search peer review process.	Used PRESS (McGowan J, Sampson M, Salzwedel DM, Cogo E, Foerster V, Lefebvre C. PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. J Clin Epidemiol. 2016 Jul;75:40-6. doi: 10.1016/j.jclinepi.2016.01.021) .

			Peer review provided with the assistance of Lindsay Hales of the MUHC McConnell Resource Centre.
MANAGING RECORDS			
Total Records	15	Document the total number of records identified from each database and other information sources.	p.9
Deduplication	16	Describe the processes and any software used to deduplicate records from multiple database searches and other information sources.	Initial deduplication done via Endnote X9.3.3 using modified version of Bramer WM, Giustini D, de Jonge GB, Holland L, Bekhuis T. De-duplication of database search results for systematic reviews in EndNote. Journal of the Medical Library Association : JMLA. 2016;104(3):240-243. doi:10.3163/1536-5050.104.3.014 (see McGill KS guide). Further deduplication manually performed in EndNote then in Rayyan online software.

PRISMA-S: An Extension to the PRISMA Statement for Reporting Literature Searches in Systematic Reviews
Rethlefsen ML, Kirtley S, Waffenschmidt S, Ayala AP, Moher D, Page MJ, Koffel JB, PRISMA-S Group. Last updated February 27,
2020.

Supplementary Table 4: Search strategy.

Pediatric Surgery PROMS SR - Databases Searched

Africa-Wide Information [EBSCO] (May 28, 2021)

#	Query	Results
S37	S33 OR S34 OR S35 OR S36	230
S36	TI (quality of life and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) N1 (funnel or sunken or excavatum or carinatum))))	3
S35	TI ((PedsQL or HRQoL) and (child* or paediatr* or pediatr* or adolescent*))	7
S34	TI ((PROM or PROMs or PROMIS or (patient* N1 report* N1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*))	15
S33	S12 AND S32	211
S32	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31	386,272
S31	TX ((pectus or chest) N1 (funnel or sunken or excavatum or carinatum))	53
S30	TX (congenital* and hernia* and diaphragm*)	166
S29	TX ((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) N2 diaphragm* N2 (hernia* or defect*))	157
S28	TX ((bochdalek* or morgagni*) N2 (hernia* or defect*))	41
S27	TX (agene* N2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) N1 diaphragm*)))	5
S26	TX ((anal or anus or anorect* or rectal) N3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*))	566
S25	TX ((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) N3 (atres* or atretic* or atroph*))	175
S24	TX ((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))	7,032
S23	TX (thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* N3 (endoscop* or incision*)))	1,481
S22	TX ((liver or hepatic or lung or lungs or pulmon* or kidney) N3 (transplant* or graft*))	4,808
S21	TX (fundoplicat* or ((nissen* or toupet or dor) N3 (operat* or procedur* or surger* or surgical*)))	129
S20	TX ((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))	5,586
S19	TX (escharotom* or ((skin or derm*) N2 (graft* or transplant*)))	871
S18	TX ((abdomen or abdominal or intestin* or bowel* or gastrointestin*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))	3,182
S17	TX ((tooth or teeth or dental or abcess) N2 (extract* or drain*))	832
S16	TX ((perforation* or incision* or laceration*) N3 (repair* or drain* or closure*))	473
S15	TX ((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) N5 (operat* or procedur* or surger* or surgical*))	1,776
S14	TX (adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or	16,168

	orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*)	
S13	TX (surger* or surgic* or surgeon* or operati* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or procedure* or debridement* or laparoscop* or laparotom* or postop*)	377,143
S12	S10 AND S11	1,187
S11	TX (newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)	438,627
S10	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9	4,355
S9	TX (PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS)	861
S8	TX ((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))	103
S7	TX ((((health or pediatric* or paediatric* or child*) N2 quality of life) or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) N report*)))	444
S6	TX (functional* N2 "health status")	36
S5	TX ((patient* or outcome*) N2 feedback)	125
S4	TX ((self or proxy*) N1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))	2,225
S3	TX ((patient* or child*) N1 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))	107
S2	TX ((patient* or child*) N1 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome*))	118
S1	TX ((patient* or child*) N1 (report* or centered or centred) N1 (outcome* or satisf* or "health status"))	531

CINAHL Plus [EBSCO] (May 28, 2021)

#	Query	Results
S41	S37 OR S38 OR S39	360
S40	S37 OR S38 OR S39	1,095
S39	TI (quality of life and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) N1 (funnel or sunken or excavatum or carinatum))))	56
S38	TI ((PROM or PROMs or PROMIS or (patient* N1 report* N1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*))	276
S37	S13 AND S36	805
S36	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35	706,876
S35	TI (((pectus or chest) N1 (funnel or sunken or excavatum or carinatum))) OR AB (((pectus or chest) N1 (funnel or sunken or excavatum or carinatum)))	441
S34	TI ((congenital* and hernia* and diaphragm*)) OR AB ((congenital* and hernia* and diaphragm*))	1,490
S33	TI (((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal*	1,456

	or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) N2 diaphragm* N2 (hernia* or defect*))) OR AB (((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) N2 diaphragm* N2 (hernia* or defect*)))	
S32	TI (((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) N5 (posterolateral* or substernal*) N2 hernia*)) OR AB (((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) N5 (posterolateral* or substernal*) N2 hernia*))	8
S31	TI (((bochdalek* or morgagni*) N2 (hernia* or defect*))) OR AB (((bochdalek* or morgagni*) N2 (hernia* or defect*)))	234
S30	TI ((agene* N2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) N1 diaphragm*)))) OR AB ((agene* N2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) N1 diaphragm*))))	13
S29	TI ((hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) N3 (congenital* or aganglion*)))) OR AB ((hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) N3 (congenital* or aganglion*))))	897
S28	TI (((anal or anus or anorect* or rectal) N3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*))) OR AB (((anal or anus or anorect* or rectal) N3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)))	1,379
S27	TI (((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) N3 (atres* or atretic* or atroph*))) OR AB (((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) N3 (atres* or atretic* or atroph*)))	773
S26	TI (((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))) OR AB (((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)))	27,111
S25	TI ((thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* N3 (endoscop* or incision*)))) OR AB ((thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* N3 (endoscop* or incision*))))	6,384
S24	TI (((liver or hepatic or lung or lungs or pulmon* or kidney) N3 (transplant* or graft*))) OR AB (((liver or hepatic or lung or lungs or pulmon* or kidney) N3 (transplant* or graft*)))	18,263
S23	TI (((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))) OR AB (((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)))	7,623

S22	TI ((fundoplicat* or ((nissen* or toupet or dor) N3 (operat* or procedur* or surger* or surgical*)))) OR AB ((fundoplicat* or ((nissen* or toupet or dor) N3 (operat* or procedur* or surger* or surgical*))))	1,227
S21	TI (((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))) OR AB (((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)))	41,483
S20	TI ((escharotom* or ((skin or derm*) N2 (graft* or transplant*)))) OR AB ((escharotom* or ((skin or derm*) N2 (graft* or transplant*))))	3,306
S19	TI (((abdomen or abdominal or intestin* or bowel* or gastrointestin*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))) OR AB (((abdomen or abdominal or intestin* or bowel* or gastrointestin*) N3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)))	14,830
S18	TI (((tooth or teeth or dental or abcess) N2 (extract* or drain*))) OR AB (((tooth or teeth or dental or abcess) N2 (extract* or drain*)))	3,337
S17	TI (((perforation* or incision* or laceration*) N3 (repair* or drain* or closure*))) OR AB (((perforation* or incision* or laceration*) N3 (repair* or drain* or closure*)))	2,645
S16	TI (((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) N5 (operat* or procedur* or surger* or surgical*))) OR AB (((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) N5 (operat* or procedur* or surger* or surgical*)))	5,105
S15	TI ((adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*)) OR ((adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*))	81,181
S14	TI (surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*) OR AB(surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*)	619,448
S13	S11 AND S12	8,079
S12	TI(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or	879,847

	juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*) OR AB(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)	
S11	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10	52,721
S10	TI (((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))) OR AB (((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)))	1,124
S9	TI (((((health or pediatric* or paediatric* or child*) N2 quality of life) or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) N report*)))) OR AB (((((health or pediatric* or paediatric* or child*) N2 quality of life) or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) N report*))))	6,509
S8	TI (functional* N2 "health status") OR AB (functional* N2 "health status")	617
S7	TI (((patient* or outcome*) N2 feedback)) OR AB (((patient* or outcome*) N2 feedback))	2,256
S6	TI (((self or proxy*) N1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))) OR AB (((self or proxy*) N1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)))	24,841
S5	TI (((patient* or child*) N1 (outcome* or report*) N1 measure*)) OR AB (((patient* or child*) N1 (outcome* or report*) N1 measure*))	8,210
S4	TI (((patient* or child*) N1 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))) OR AB (((patient* or child*) N1 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)))	1,725
S3	TI (((patient* or child*) N1 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome*))) OR AB (((patient* or child*) N1 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome*)))	1,480
S2	TI (((patient* or child*) N0 (report* or centered or centred) N0 (outcome* or satisf* or "health status"))) OR AB (((patient* or child*) N0 (report* or centered or centred) N0 (outcome* or satisf* or "health status")))	12,847
S1	(MM "Patient-Reported Outcomes")	1,661

Cochrane [Wiley] (May 28, 2021)

#1	((patient* or child*) NEAR/0 (report* or centered or centred) NEAR/1 (outcome* or satisf* or "health status")):ti,ab	6489
#2	((patient* or child*) NEAR/1 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome*)):ti,ab	291
#3	((patient* or child*) NEAR/1 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)):ti,ab	712
#4	((patient* or child*) NEAR/0 (outcome* or report*) NEAR/1 measure*):ti,ab	213
#5	((self or proxy*) NEAR/1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/0 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)):ti,ab	4218
#6	((patient* or outcome*) NEAR/1 feedback):ti,ab	466
#7	(functional* NEAR/1 "health status"):ti,ab	155
#8	((((health or pediatric* or paediatric* or child*) NEAR/0 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) NEAR/0 report*))):ti,ab	1004
#9	((health or pediatric* or paediatric* or child*) NEAR/1 ("quality of life")):ti,ab	1214

#10	((PRO or PROs) NEAR/1 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)):ti,ab	643
#11	(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS):ti,ab	2461
#12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #10 OR #11	15453
#13	(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*):ti,ab	206380
#14	#12 AND #13	1862
#15	(surger* or surgic* or surgeon* or operation? or laparoscop* or postop*):ti,ab	253409
#16	(adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or "herni*-plast*" or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or "roux-en-y" or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*):ti,ab	26021
#17	((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) NEAR/1 (operat* or procedur* or surger* or surgical*)):ti,ab	1277
#18	((perforation* or incision* or laceration*) NEAR/1 (repair* or drain* or closure*)):ti,ab	462
#19	((tooth or teeth or dental or abcess) NEAR/1 (extract* or drain*)):ti,ab	1700
#20	((abdomen or abdominal or intestin* or bowel* or gastrointestin*) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)):ti,ab	8321
#21	(escharotom* or ((skin or derm*) NEAR/1 (graft* or transplant*))):ti,ab	1162
#22	((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)):ti,ab	6979
#23	(fundoplicat* or ((nissen* or toupet or dor) NEAR/2 (operat* or procedur* or surger* or surgical*))):ti,ab	685
#24	((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)):ti,ab	3372
#25	((liver or hepatic or lung or lungs or pulmon* or kidney) NEAR/0 (transplant* or graft*)):ti,ab	3
#26	(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* NEAR/0 (endoscop* or incision*))):ti,ab	3283
#27	((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or	5184

	perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)):ti,ab	
#28	((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) NEAR/2 (atres* or atretic* or atroph*)):ti,ab	68
#29	((anal or anus or anorect* or rectal) NEAR/2 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)):ti,ab	579
#30	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) NEAR/2 (congenital* or aganglion*))):ti,ab	100
#31	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) NEAR/2 diaphragm* NEAR/2 (hernia* or defect*)):ti,ab	173
#32	(congenital* and hernia* and diaphragm*):ti,ab	182
#33	((pectus or chest) NEAR/1 (funnel or sunken or excavatum or carinatum)):ti,ab	78
#34	#15 OR #16 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33	267137
#35	#14 AND #34	218
#36	((PROM or PROMs or PROMIS or (patient* NEAR/1 report* NEAR/1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)):ti	25
#37	((PROM or PROMs or PROMIS or ("patient* report*" NEAR/1 (outcome* or experienc*))) NEAR/3 (child* or paediatr* or pediatr* or adolescent*)):ab	30
#38	((PedsQL or HRQoL) and (child* or paediatr* or pediatr* or adolescent*)):ti	7
#39	("quality of life" and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) NEAR/1 (funnel or sunken or excavatum or carinatum)))):ti	2
#40	#13 and ("quality of life" and ((self or patient* or prox*) NEAR/ report*)):ti	32
#41	#35 OR #36 OR #37 OR #38 OR #39 OR #40	301
#42	#35 OR #36 OR #37 OR #38 OR #39 OR #40 [no editorials]	299

Embase [Ovid] (May 28, 2021)

Embase Classic+Embase 1947 to 2021 May 27

1	patient satisfaction/	146584
2	satisfaction/	68102
3	1 or 2	210336
4	outcome assessment/	592623
5	treatment outcome/	881588
6	"quality of life"/	508702
7	daily life activity/	96816
8	convalescence/	56271
9	exp postoperative care/	101266

10	postoperative complication/	375368
11	postoperative pain/	73528
12	or/4-11	2371475
13	health care survey/	19285
14	self report/	129620
15	13 or 14	148256
16	3 and 12 and 15	2199
17	patient-reported outcome/	30688
18	((patient* or child*) adj1 (report* or centered or centred) adj1 (outcome* or satisf* or "health status")).tw,kw.	46695
19	((patient* or child*) adj1 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome*)).tw,kw.	1419
20	((patient* or child*) adj1 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).tw,kw.	4864
21	((patient* or child*) adj2 (outcome* or report*) adj1 measure*).tw,kw.	8891
22	((self or proxy*) adj1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).tw,kw.	41502
23	((patient* or outcome*) adj2 feedback).tw,kw.	5302
24	(functional* adj2 "health status").tw,kw.	1289
25	((((health or pediatric* or paediatric* or child*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) adj report*))).tw,kw.	12239
26	((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)).tw,kw.	5843
27	(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS).tw,kw.	17242
28	or/16-27	136355
29	exp pediatrics/ or exp child/ or exp *adolescent/	3226177
30	(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).tw,kw.	3500287
31	(pediatr* or paediatr*).jx.	781773
32	or/29-31	4535830
33	28 and 32	21083
34	exp surgery/	5557459
35	exp surgeon/	175034
36	(surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*).tw,kw.	4619240
37	or/34-36	7422978
38	33 and 37	4292
39	exp newborn disease/	1804343
40	exp digestive system disease/	3587427

41	exp urogenital tract disease/	2741978
42	exp hernia/	133444
43	exp musculoskeletal system malformation/ or exp musculoskeletal disease/	2616064
44	exp neoplasm/	5182673
45	exp respiratory tract malformation/	34931
46	exp torsion/ or torticollis/	23334
47	exp ear nose throat disease/	552721
48	exp eye disease/	1080063
49	exp osteomyelitis/	49562
50	brachial plexus neuropathy/	2295
51	exp brain disease/	2302683
52	exp infectious arthritis/	24212
53	(cochlear or adenoid* or otorhinol* or pharyngeal* or laryngeal* or laryngo* or ear or ear or nose or otitis or tonsil* or epistaxis or rhinorrhea* or rhinitis or otolog* or rhinootol* or head or neck or croup* or supraglott* or glottis or glottis or subglott* or trachea* or snoring or snore* or apnea or apnoea or sleep obstruct* or mastoiditis* or sinusitis or trichiasis or cataract* or hydrocephal* or cerebral palsy or muscular dystroph* or syndactyly* or radial club or amniotic band* or septic arthritis or osteomyelitis or flexor tenosynovitis or clubfoot or clubfeet or club-foot* or club-feet* or craniofacial* or cranio-facial* or frontoethmoidal meningoenceph* or hemorrhage* or hematoma* or spina bifida* or resuscitation* or schistosomias* or trachoma* or mediastinitis or buruli ulcer* or choledochal cyst* or cyst* echinococcosis or ilopsoas or epileps* or burr hole* or burn or burns or burned or scald* or burnt or thermal injur*).tw,kw.	2193255
54	(hypospadia* or epispadi* or cloaca* or cryptorchidism* or prolapse or phymosis or paraphymosis or hydrometrocolpos or (bladder adj2 exstroph*) or (undescen* adj2 test?s) or (buried adj1 penis) or (urinary adj2 (retention or lithiasis))).tw,kw.	96378
55	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) adj4 (congenital or aganglion*)) or ((anal or anus or anorect* or rectal) adj3 (artificial* or malformation or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret*))).tw,kw.	18401
56	((pierre-robin or apert*) adj2 (syndrome* or disease* or sequenc*)).tw,kw.	3143
57	(cleft adj2 (lip* or palate*)).tw,kw.	29414
58	(coarctation or (septal adj2 defect*) or (tetralogy adj2 fallot)).tw,kw.	61878
59	(brachial plexus adj2 (palsy or neuropath*)).tw,kw.	1883
60	((arthriti* or rheumat*) adj2 infect*).tw,kw.	4604
61	or/39-60	14639240
62	exp *surgery/	2675826
63	su.fs.	2251346
64	(surger* or surgical* or operati* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or procedure or procedures or debridement* or laparoscop* or laparotom*).tw,kw.	5624517
65	or/62-64	7143784
66	61 and 65	4259434

67	33 and 66	3020
68	(adenoidectom* or adenotonsil* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom* or ileostom* or colostom* or enterostom* or portoenterostom* or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom* or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*).tw,kw.	397542
69	((opthalmolog* or eye* or vision or ocular or retina* or retinopath* or cataract*) adj2 (operat* or procedur* or surger* or surgical*)).tw,kw.	46727
70	((perforation* or incision* or laceration*) adj2 (repair* or drain* or closure*)).tw,kw.	9855
71	((tooth or teeth or dental or abscess* or abcess*) adj2 (extract* or drain* or excision*)).tw,kw.	21900
72	((abdomen or abdominal or intestin* or bowel* or gastrointestin*) adj2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kw.	79538
73	(escharotom* or ((skin or derm*) adj2 (graft* or transplant*))).tw,kw.	33659
74	((cancer or neoplas* or tumor* or tumour* or carcinom*) adj2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kw.	194002
75	(fundoplicat* or ((nissen* or toupet or dor) adj3 (operat* or procedur* or surger* or surgical*))).tw,kw.	10253
76	((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) adj2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kw.	33060
77	((liver or hepatic or lung or lungs or pulmon* or kidney) adj2 (transplant* or graft*)).tw,kw.	230025
78	(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* adj3 (endoscop* or incision*))).tw,kw.	57108
79	((lung or lungs or pulmon* or wedge or trauma* or postrauma* or neurotrauma* or fracture*) adj2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kw.	106171
80	or/66-79	4649424
81	33 and 80	3258
82	esophagus atresia/	6697
83	((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) adj3 (atres* or atretic* or atroph*)).tw,kw.	6482
84	anus atresia/	4486

85	((anal or anus or anorect* or rectal) adj3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)).tw,kw.	15266
86	colorectal surgery/	15313
87	rectum disease/ or exp *rectum disease/	200140
88	Hirschsprung disease/	8291
89	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) adj3 (congenital* or aganglion*))).tw,kw.	8916
90	congenital diaphragm hernia/	6357
91	(agene* adj2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) adj1 diaphragm*))).tw,kw.	119
92	((bochdalek* or morgagni*) adj2 (hernia* or defect*)).tw,kw.	1648
93	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj5 (posterolateral* or substernal*) adj2 hernia*).tw,kw.	105
94	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj2 diaphragm* adj2 (hernia* or defect*)).tw,kw.	6906
95	(congenital* and hernia* and diaphragm*).tw,kw.	7926
96	musculoskeletal system malformation/	1014
97	funnel chest/	4503
98	pigeon thorax/	1337
99	((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)).tw,kw.	4140
100	or/82-99	255803
101	33 and 100	135
102	38 or 67 or 81 or 101	4619
103	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ti.	606
104	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ab. /freq=5	330
105	((PedsQL or HRQoL) and (child* or paediatr* or pediatr* or adolescent*)).ti.	232
106	(quality of life and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)))).ti,kw.	213
107	32 and (quality of life and ((self or patient* or prox*) adj report*)).ti.	320
108	(32 or 44) and (Patient* and outcome*).jw.	3
109	or/102-108	5802
110	remove duplicates from 109	5698
111	("23943728" or "28370564" or "30857849" or "33183312" or "25381182" or "28209722" or "30105620" or "29424008" or "31084256" or "30952740" or "27540697" or "33196410" or "12826956" or "25838334" or "23592314" or "32101476" or "20381868" or "33830343" or "24148211" or "19019720" or "26919411" or "25058258" or "32674943" or "27896941" or "32003447" or "31207183" or "28594696" or "8562630" or "18663886" or "15214283" or "33352321" or "25810358" or "32740582" or "14646706" or "33380962" or "26286444" or "24019130" or "32324662" or "27054453" or "26681655" or "29749912" or "20410376" or "30925497" or "21109039" or "25139009" or "33684009" or "32660954" or "24702614" or "33125739" or "25665957" or "22092665" or "23801295" or "16321326" or "25446659" or "31280258" or "24154841" or "26192881" or "21272317" or "21426526" or "25052528" or "17527105" or "25586983" or "28767629" or "28798984" or "22422539" or "24648129" or "32548146" or "24134432" or "12563069" or "28610795" or "28041938" or "10554936" or "33634600" or "24894777" or "26809202" or "19000349" or "28541759" or "30697099" or "31618249" or "24315010" or "33948419" or "29260883" or "29122268" or "32951699"	3595

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[Exclude Medline UI]	
112	110 not 111	3056

Global Health [Ovid] (May 28, 2021)

Global Health 1973 to 2021 Week 21, Database Field Guide Global Health Archive 1910 to 1972

1	((patient* or child*) adj1 (report* or centered or centred) adj1 (outcome* or satisf* or "health status")).ti,ab,id.	782
2	((patient* or child*) adj1 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome*)).ti,ab,id.	92
3	((patient* or child*) adj1 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).ti,ab,id.	190
4	((patient* or child*) adj2 (outcome* or report*) adj1 measure*).ti,ab,id.	605
5	((self or proxy*) adj1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).ti,ab,id.	4797
6	((patient* or outcome*) adj2 feedback).ti,ab,id.	202
7	(functional* adj2 "health status").ti,ab,id.	110
8	((((health or pediatric* or paediatric* or child*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) adj report*))).ti,ab,id.	872
9	((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)).ti,ab,id.	234
10	(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS).ti,ab,id.	818
11	or/1-10	8415
12	pediatrics/ or exp children/ or exp infants/ or exp adolescents/	486389
13	(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).ti,ab,id.	614941
14	or/12-13	631718
15	11 and 14	2040
16	(surger* or surgic* or surgeon* or operati* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or procedure* or debridement* or laparoscop* or laparotom* or postop*).ti,ab,id.	327720
17	(adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*).ti,ab,id.	19512
18	((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) adj5 (operat* or procedur* or surger* or surgical*)).ti,ab,id.	1659
19	((perforation* or incision* or laceration*) adj3 (repair* or drain* or closure*)).ti,ab,id.	850
20	((tooth or teeth or dental or abcess) adj2 (extract* or drain*)).ti,ab,id.	1061
21	((abdomen or abdominal or intestin* or bowel* or gastrointestin*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).ti,ab,id.	5705

22	(escharotom* or ((skin or derm*) adj2 (graft* or transplant*))).ti,ab,id.	911
23	((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).ti,ab,id.	6174
24	(fundoplicat* or ((nissen* or toupet or dor) adj3 (operat* or procedur* or surger* or surgical*))).ti,ab,id.	129
25	((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).ti,ab,id.	945
26	((liver or hepatic or lung or lungs or pulmon* or kidney) adj3 (transplant* or graft*)).ti,ab,id.	12196
27	(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* adj3 (endoscop* or incision*))).ti,ab,id.	1295
28	((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).ti,ab,id.	4596
29	((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) adj3 (atres* or atretic* or atroph*)).ti,ab,id.	177
30	((anal or anus or anorect* or rectal) adj3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)).ti,ab,id.	674
31	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) adj3 (congenital* or aganglion*))).ti,ab,id.	358
32	(agene* adj2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) adj1 diaphragm*))).ti,ab,id.	0
33	((bochdalek* or morgagni*) adj2 (hernia* or defect*)).ti,ab,id.	17
34	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj5 (posterolateral* or substernal*) adj2 hernia*).ti,ab,id.	0
35	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj2 diaphragm* adj2 (hernia* or defect*)).ti,ab,id.	138
36	(congenital* and hernia* and diaphragm*).ti,ab,id.	187
37	((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)).ti,ab,id.	48
38	or/16-37	341728
39	15 and 38	134
40	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ti.	14
41	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ab. /freq=3	14

42	((PedsQL or HRQoL) and (child* or paediatr* or pediatr* or adolescent*)).ti.	12
43	(quality of life and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)))).ti,id.	1
44	14 and (quality of life and ((self or patient* or prox*) adj report*)).ti.	19
45	or/39-44	182
46	remove duplicates from 45	182

Global Index Medicus [WHO] (May 28, 2021)

1	(tw:(patient* or child* or parent* or mother* or father* or family* or families or caregiver* or care-giver*)) AND (tw:(reported*)) AND (tw:(outcome*)) AND (tw:(surger* or surgic* or operation? or postop*))	4.734
2	tw:((tw:(patient* OR child* OR parent* OR mother* OR father* OR family* OR families OR caregiver* OR care-giver*)) AND (tw:(reported*)) AND (tw:(outcome*)) AND (tw:(surger* OR surgic* OR operation? OR postop*))) AND (mj:("Child"))	215

Medline [Ovid] (May 28, 2021)

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1	Personal satisfaction/	20279
2	Patient Preference/	9413
3	or/1-2	29662
4	"outcome assessment (health care)"/	76138
5	treatment outcome/	1028475
6	"quality of life"/	211602
7	"Activities of Daily Living"/	66791
8	Recovery of Function/	55534
9	Postoperative Care/	60086
10	Postoperative Complications/	376986
11	Postoperative Pain/	41609
12	exp Postoperative Period/	58306
13	or/4-12	1740874
14	"Surveys and Questionnaires"/	494935
15	exp health status indicators/	320654
16	patient health questionnaire/	611
17	Self Report/	36360
18	or/14-17	805683
19	3 and 13 and 18	2990
20	patient reported outcome measures/	8350
21	patient outcome assessment/	5134
22	((patient* or child*) adj1 (report* or centered or centred) adj1 (outcome* or satisf* or "health status")).tw,kf.	28139
23	((patient* or child*) adj1 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome*)).tw,kf.	1007
24	((patient* or child*) adj1 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).tw,kf.	2901
25	((patient* or child*) adj2 (outcome* or report*) adj1 measure*).tw,kf.	5502
26	((self or proxy*) adj1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).tw,kf.	30178
27	((patient* or outcome*) adj2 feedback).tw,kf.	2794
28	(functional* adj2 "health status").tw,kf.	963
29	((((health or pediatric* or paediatric* or child*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) adj report*))).tw,kf.	8122
30	((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)).tw,kf.	2581
31	(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS).tw,kf.	9359

32	or/19-31 [PROMs]	90168
33	exp pediatrics/ or exp child/ or exp infant/ or *adolescent/	2574034
34	(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).tw,kf.	2601623
35	(pediatr* or paediatr*).jw.	591843
36	or/33-35	3635659
37	32 and 36 [PROMs Peds]	13883
38	exp Specialties, Surgical/	205003
39	exp Surgical Procedures, Operative/	3255490
40	exp Surgeons/	10768
41	su.fs.	2055087
42	(surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*).tw,kf.	3287809
43	or/38-42	5521380
44	37 and 43 [PROMs Peds Gen Surg]	2968
45	exp "Congenital, Hereditary, and Neonatal Diseases and Abnormalities"/	1265090
46	exp Digestive system diseases/	1787462
47	exp Urologic Diseases/ or exp Male urogenital diseases/ or exp Female urogenital diseases/ or exp Prolapse/	1516212
48	exp Hernia/	77988
49	exp Musculoskeletal Abnormalities/ or exp Musculoskeletal Diseases/	1116775
50	exp Neoplasms/	3471904
51	exp Respiratory System Abnormalities/	11498
52	exp Torsion Abnormality/ or Torticollis/	13132
53	exp Otorhinolaryngologic Diseases/	380890
54	exp Eye Diseases/	582763
55	exp Osteomyelitis/	23287
56	exp Brachial Plexus Neuropathies/	3864
57	exp Hemorrhage/	338206
58	exp Brain Diseases/	1262960
59	exp Arthritis, Infectious/	14877
60	(cochlear or adenoid* or otorhinol* or pharyngeal* or laryngeal* or laryngo* or ear or ear or nose or otitis or tonsil* or epistaxis or rhinorrhea* or rhinitis or otolog* or rhinootol* or head or neck or croup* or supraglott* or glottis or glottis or subglott* or trachea* or snoring or snore* or apnea or apnoea or sleep obstruct* or mastoiditis* or sinusitis or trichiasis or cataract* or hydrocephal* or cerebral palsy or muscular dystroph* or syndactyly* or radial club or amniotic band* or septic arthritis or osteomyelitis or flexor tenosynovitis or clubfoot or clubfeet or club-foot* or club-feet* or craniofacial* or cranio-facial* or frontoethmoidal meningoenceph* or hemorrhage* or hematoma* or spina bifida* or resuscitation* or schistosomias* or trachoma* or mediastinitis or buruli ulcer* or choledochal cyst* or cyst* echinococcosis or ilopsoas or epileps* or burr hole* or burn or burns or burned or scald* or burnt or thermal injur*).tw,kf.	1558192

61	(hypospadia* or epispadi* or cloaca* or cryptorchidism* or prolapse or phymosis or paraphymosis or hydrometrocolpos or (bladder adj2 exstroph*) or (undescen* adj2 test?s) or (buried adj1 penis) or (urinary adj2 (retention or lithiasis))).tw,kf.	62431
62	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) adj4 (congenital or aganglion*)) or ((anal or anus or anorect* or rectal) adj3 (artificial* or malformation or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret*))).tw,kf.	13617
63	((pierre-robin or apert*) adj2 (syndrome* or disease* or sequenc*)).tw,kf.	2315
64	(cleft adj2 (lip* or palate*)).tw,kf.	23395
65	(coarctation or (septal adj2 defect*) or (tetralogy adj2 fallot)).tw,kf.	42781
66	(brachial plexus adj2 (palsy or neuropath*)).tw,kf.	1501
67	((arthriti* or rheumat*) adj2 infect*).tw,kf.	2738
68	or/45-67	9414218
69	exp Specialties, Surgical/	205003
70	exp Surgical Procedures, Operative/	3255490
71	su.fs.	2055087
72	(surger* or surgical* or operati* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or procedure or procedures or debridement* or laparoscop* or laparotom*).tw,kf.	3976279
73	or/69-72	5904506
74	68 and 73	2916434
75	37 and 74 [PROMs Peds Surg condition]	1845
76	(adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*).tw,kf.	262941
77	((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) adj5 (operat* or procedur* or surger* or surgical*)).tw,kf.	36849
78	((perforation* or incision* or laceration*) adj3 (repair* or drain* or closure*)).tw,kf.	9402
79	((tooth or teeth or dental or abcess) adj2 (extract* or drain*)).tw,kf.	15392
80	((abdomen or abdominal or intestin* or bowel* or gastrointestin*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kf.	72902
81	(escharotom* or ((skin or derm*) adj2 (graft* or transplant*))).tw,kf.	26030
82	((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kf.	212890

83	(fundoplicat* or ((nissen* or toupet or dor) adj3 (operat* or procedur* or surger* or surgical*))).tw,kf.	6607
84	((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kf.	29753
85	((liver or hepatic or lung or lungs or pulmon* or kidney) adj3 (transplant* or graft*)).tw,kf.	139890
86	(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* adj3 (endoscop* or incision*))).tw,kf.	38166
87	((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) adj3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)).tw,kf.	105053
88	or/76-87	874532
89	37 and 88 [PROMs Peds Surg sp]	464
90	Esophageal Atresia/	3672
91	((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) adj3 (atres* or atretic* or atroph*)).tw,kf.	4695
92	anus, imperforate/	2540
93	((anal or anus or anorect* or rectal) adj3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)).tw,kf.	10379
94	Colorectal Surgery/	3678
95	Rectal Diseases/ or exp *Rectal Diseases/	154892
96	hirschsprung disease/	4591
97	(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) adj3 (congenital* or aganglion*))).tw,kf.	6840
98	Hernias, Diaphragmatic, Congenital/	4949
99	(agene* adj2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) adj1 diaphragm*))).tw,kf.	83
100	((bochdalek* or morgagni*) adj2 (hernia* or defect*)).tw,kf.	1257
101	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj5 (posterolateral* or substernal*) adj2 hernia*).tw,kf.	78
102	((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) adj2 diaphragm* adj2 (hernia* or defect*)).tw,kf.	5367
103	(congenital* and hernia* and diaphragm*).tw,kf.	5901
104	musculoskeletal abnormalities/	1511
105	funnel chest/	2478
106	pectus carinatum/	121

107	((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)).tw,kf.	3121
108	or/90-107 [Specific surg cond]	188377
109	37 and 108 [PROMS Peds Specific Surg]	103
110	44 or 75 or 89 or 109 [All PROMs Peds Surg]	3148
111	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ti.	366
112	((PROM or PROMs or PROMIS or (patient* adj1 report* adj1 (outcome* or experienc*))) and (child* or paediatr* or pediatr* or adolescent*)).ab. /freq=5	185
113	((PedsQL or HRQoL) and (child* or paediatr* or pediatr* or adolescent*)).ti.	202
114	(quality of life and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) adj1 (funnel or sunken or excavatum or carinatum)))).ti,kf.	168
115	36 and (quality of life and ((self or patient* or prox*) adj report*)).ti.	206
116	36 and 43 and (Patient* and outcome*).jw.	12
117	or/110-116	3936
118	remove duplicates from 117	3928

Web of Science [Clarivate Analytics] (May 28, 2021)

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# 44	1,030	#42 not #43

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# 42	2,813	#41 OR #40 OR #39 OR #38 OR #37
# 41	158	#12 and TI=("quality of life" NEAR/3 ((self or patient* or prox*) NEAR/0 report*))
# 40	144	TI=("quality of life" and (esophag* atres* or congenital* diaphragm* hernia* or hirschsprung* or anorect* malformat* or ((pectus or chest) NEAR/1 (funnel or sunken or excavatum or carinatum))))
# 39	215	TI=((PedsQL or HRQoL) NEAR/5 (child* or paediatr* or pediatr* or adolescent*))
# 38	213	TI=((PROM or PROMs or PROMIS or (patient* report* NEAR/0 (outcome* or experienc*))) NEAR/1 (child* or paediatr* or pediatr* or adolescent*))
# 37	2,161	#36 AND #13
# 36	4,081,157	#35 OR #34 OR #33 OR #32 OR #31 OR #30 OR #29 OR #28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14
# 35	2,441	TI=((pectus or chest) NEAR/1 (funnel or sunken or excavatum or carinatum)) OR AB=((pectus or chest) NEAR/1 (funnel or sunken or excavatum or carinatum))
# 34	5,470	TI=(congenital* and hernia* and diaphragm*) OR AB=(congenital* and hernia* and diaphragm*)

# 33	5,324	TI=((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) NEAR/2 diaphragm* NEAR/2 (hernia* or defect*)) OR AB=((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) NEAR/2 diaphragm* NEAR/2 (hernia* or defect*))
# 32	62	TI=((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) NEAR/5 (posterolateral* or substernal*) NEAR/2 hernia*) OR AB=((congenital* or neonat* or neo-nat* or newborn* or new-born* or birth* or maternal* or fetal or fetus* or fetu or feto or foet* or prenatal* or pre-natal* or antenatal* or ante-natal* or trimester* or pregnan* or uter* or preterm* or pre-term* or premature* or pre-mature* or preemie*) NEAR/5 (posterolateral* or substernal*) NEAR/2 hernia*)
# 31	989	TI=((bochdalek* or morgagni*) NEAR/2 (hernia* or defect*)) OR AB=((bochdalek* or morgagni*) NEAR/2 (hernia* or defect*))
# 30	116	TI=(agene* NEAR/2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) NEAR/1 diaphragm*))) OR AB=(agene* NEAR/2 (hemidiaphragm* or diaphragm* or ((unilat* or hern*) NEAR/1 diaphragm*)))
# 29	5,810	TI=(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) NEAR/1 (congenital* or aganglion*))) OR AB=(hirschsprung* or ((megacolon or colon* or rectosigmoid or intestin*) NEAR/1 (congenital* or aganglion*)))
# 28	8,853	TI=((anal or anus or anorect* or rectal) NEAR/3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*)) OR AB=((anal or anus or anorect* or rectal) NEAR/3 (artificial* or malformat* or mal-format* or anomal* or abnormal* or ectopic or stenosis or atres* or atroph* or imperforat* or inperforat* or praet* or pret* or fistula*))
# 27	3,811	TI=((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) NEAR/3 (atres* or atretic* or atroph*)) OR AB=((esophag* or oesophag* or endoesophag* or intraesophag* or tracheoesophag*) NEAR/3 (atres* or atretic* or atroph*))
# 26	102,098	TI=((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) NEAR/3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)) OR AB=((lung or lungs or pulmon* or wedge or trauma* or postrauma* or posttrauma* or neurotrauma* or fracture*) NEAR/3 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))
# 25	29,695	TI=(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* NEAR/2 (endoscop* or incision*))) OR AB=(thoracoscop* or thoracotom* or pleurectom* or pleuroscop* or pleuracotom* or pleurotom* or (pleura* NEAR/2 (endoscop* or incision*)))
# 24	184,058	TI=((liver or hepatic or lung or lungs or pulmon* or kidney) NEAR/2 (transplant* or graft*)) OR AB=((liver or hepatic or lung or lungs or pulmon* or kidney) NEAR/2 (transplant* or graft*))
# 23	20,615	TI=((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or

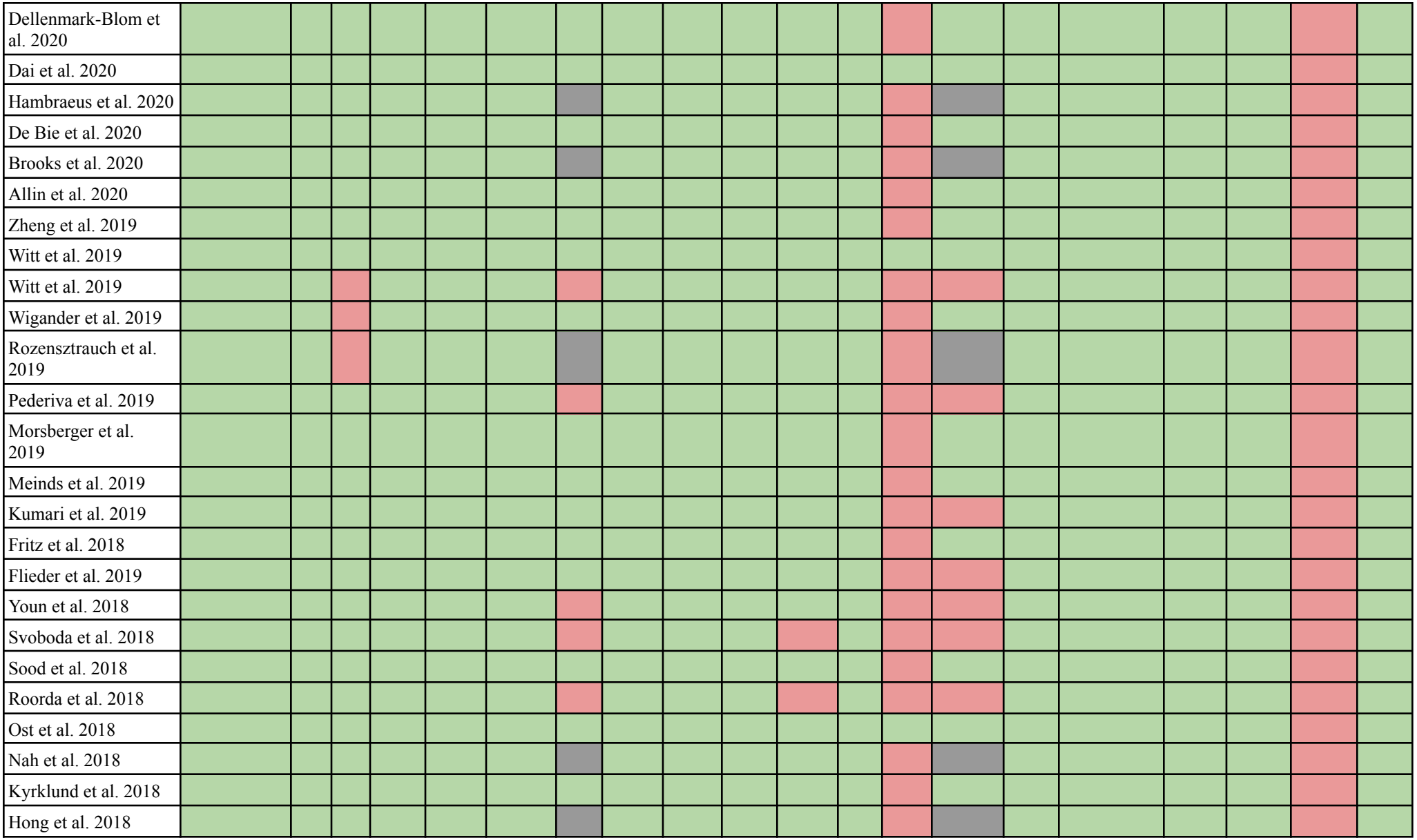
		intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)) OR AB=((hernia* or extraperitoneal or preperitoneal or peritoneal or TEP or TAPP or umbilic* or inguinal or omphalocele* or exomphalos) NEAR/1 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))
# 22	6,458	TI=(fundoplicat* or ((nissen* or toupet or dor) NEAR/2 (operat* or procedur* or surger* or surgical*))) OR AB=(fundoplicat* or ((nissen* or toupet or dor) NEAR/2 (operat* or procedur* or surger* or surgical*)))
# 21	190,472	TI=((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) NEAR/2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)) OR AB=((cancer or neoplas* or tumor* or tumour* or carcinom* or sarcoma*) NEAR/2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or biopsy or biopsie* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))
# 20	18,692	TI=(escharotom* or ((skin or derm*) NEAR/2 (graft* or transplant*))) OR AB=(escharotom* or ((skin or derm*) NEAR/2 (graft* or transplant*)))
# 19	60,723	TI=((abdomen or abdominal or intestin* or bowel* or gastrointestin*) NEAR/2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*)) OR AB=((abdomen or abdominal or intestin* or bowel* or gastrointestin*) NEAR/2 (ablat* or excis* or laparoscop* or laparotom* or operativ* or surger* or surgical* or reconstruct* or repair* or resect* or intraoperative* or perioperative* or perisurg* or postoperative* or postsurg* or preoperative* or presurg*))
# 18	13,223	TI=((tooth or teeth or dental or abcess) NEAR/2 (extract* or drain*)) OR AB=((tooth or teeth or dental or abcess) NEAR/2 (extract* or drain*))
# 17	7,980	TI=((perforation* or incision* or laceration*) NEAR/2 (repair* or drain* or closure*)) OR AB=((perforation* or incision* or laceration*) NEAR/2 (repair* or drain* or closure*))
# 16	20,176	TI=((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) NEAR/2 (operat* or procedur* or surger* or surgical*)) OR AB=((opthalmolog* or eye* or vision or ocular or retina* or retinopath*) NEAR/2 (operat* or procedur* or surger* or surgical*))

# 15	212,257	TI=(adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*) OR AB=(adenoidectom* or laryngectom* or laryngoplast* or laryngoscop* or pharygectom* or tonsillectom* or tympanoplast* or tracheostom* or tracheotom* or orchidopex* or orchiopex* or orchiectom* or orchidectom* or herniorrhaph* or hernioplast* or herniaplast* or herni*-plast* or herniotom* or circumcis* or gastrostom or ileostom* or colostom* or enterostom* or portoenterostom or roux-en-y or kasai or pyloromyotom* or piloromyotom* or pyloromiotom* or piloromiotom* or diverticulectom* or diverticulotom* or cholecystectom* or cholangiopancreatograph* or cholangio-pancreatograph* or choledoduodenostom* or choledo-duodenostom or appendicectom* or appendectom* or splenectom* or pneumonectom* or amputation* or amputate* or craniotom* or craniostom* or hydrocelectom* or thoracostom* or fasciotom*)
# 14	3,695,168	TI=(surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*) OR AB=(surger* or surgic* or surgeon* or procedure* or operation? or laparoscop* or postop*)
# 13	19,375	#12 AND #11
# 12	3,150,880	TI=(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*) OR AB=(newborn* or new-born* or neonat* or neo-nat* or infan* or child* or paediatr* or pediatr* or baby* or babies* or toddler* or kid or kids or boy* or girl* or adolesc* or juvenile* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)
# 11	130,763	#10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1
# 10	11,201	TI=(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) OR AB=(PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS)
# 9	4,077	TI=((PRO or PROs) NEAR/2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)) OR AB=((PRO or PROs) NEAR/2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))
# 8	16,322	TI=((((health or pediatric* or paediatric* or child*) NEAR/2 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) NEAR/0 report*))) OR AB=((((health or pediatric* or paediatric* or child*) NEAR/2 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview* or ((self or proxy*) NEAR/0 report*)))
# 7	1,070	TI=(functional* NEAR/2 "health status") OR AB=(functional* NEAR/2 "health status")
# 6	4,547	TI=((patient* or outcome*) NEAR/2 feedback) OR AB=((patient* or outcome*) NEAR/2 feedback)
# 5	59,480	TI=((self or proxy*) NEAR/1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)) OR AB=((self or proxy*) NEAR/1 (report* or rated or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/1 (outcome* or experience* or assess* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))
# 4	14,787	TI=((patient* or child*) NEAR/1 (outcome* or report*) NEAR/1 measure*) OR AB=((patient* or child*) NEAR/1 (outcome* or report*) NEAR/1 measure*)

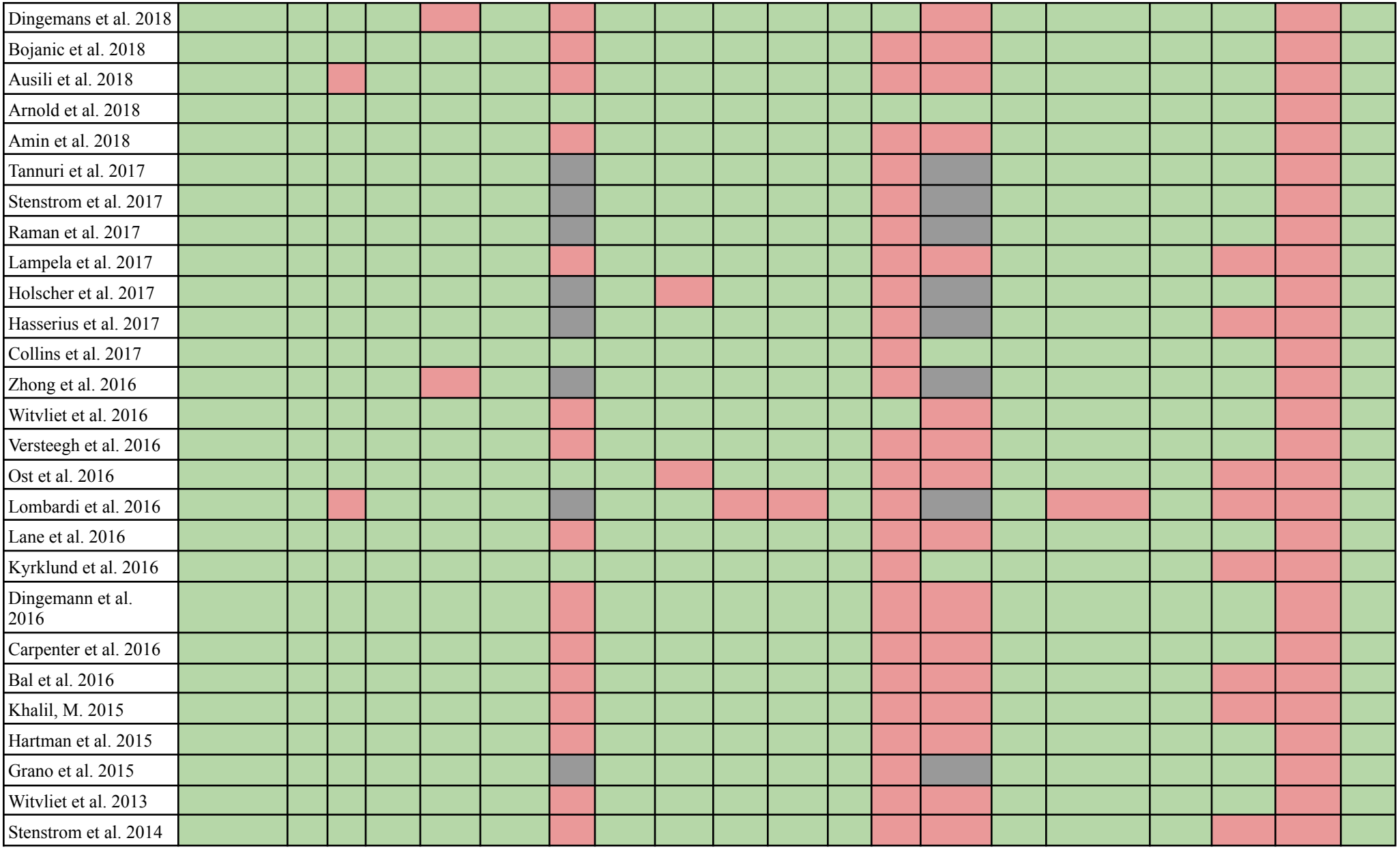
# 3	5,495	TI=((patient* or child*) NEAR/1 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) OR AB=((patient* or child*) NEAR/1 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))
# 2	2,859	TI=((patient* or child*) NEAR/1 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome*)) OR AB=((patient* or child*) NEAR/1 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome*))
# 1	30,824	TI=((patient* or child*) NEAR/1 (report* or centered or centred) NEAR/1 (outcome* or satisf* or "health status")) OR AB=((patient* or child*) NEAR/1 (report* or centered or centred) NEAR/1 (outcome* or satisf* or "health status"))

Supplementary Table 5: Risk of Bias assessment.

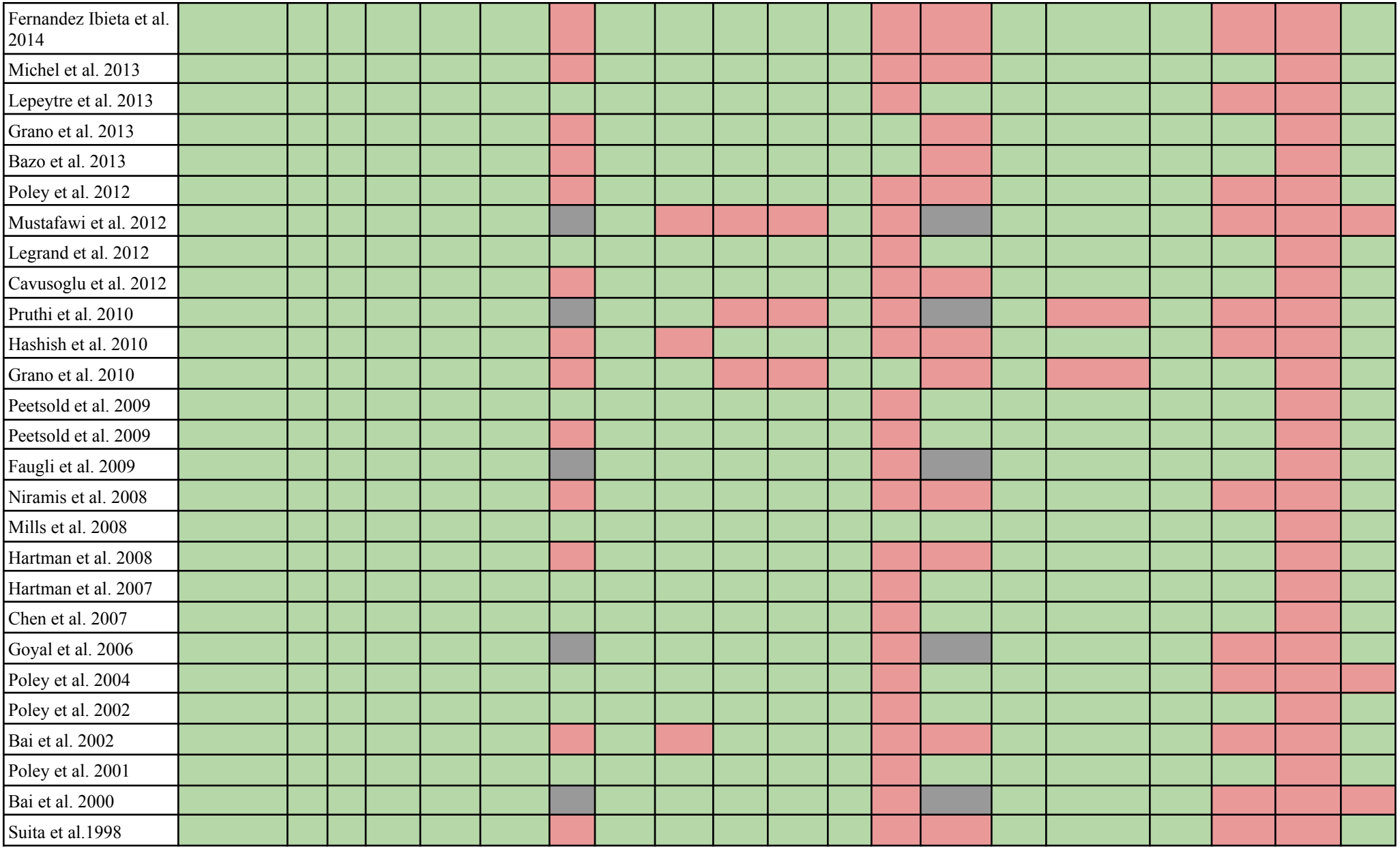
Cross-Sectional Studies (100) - AXIS Tool [13]																				
	Introduction	Methods										Results					Discussion		Other	
Author	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Witt et al. 2021																				
Loganathan et al. 2021																				
Gallo et al. 2021																				
Darmaun et al. 2021																				
Bystrom et al. 2021																				
Al Baroudi et al. 2021																				
Davidson et al. 2021																				
Wong et al. 2020																				
Townley et al. 2020																				
Saysoo et al. 2020																				
Rozensztrauch et al. 2020																				
Power et al. 2020																				
Peters et al. 2020																				
Mille et al. 2020																				
Vinycomb et al. 2020																				
Mikkelsen et al. 2020																				
Li et al. 2020																				
Stenstrom et al. 2020																				
Kassa et al. 2020																				
Espeso et al. 2020																				

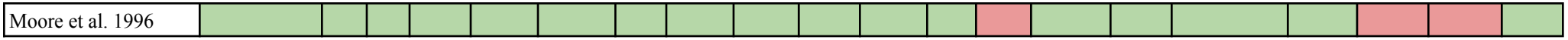

Dellenmark-Blom et al. 2020
Dai et al. 2020
Hambraeus et al. 2020
De Bie et al. 2020
Brooks et al. 2020
Allin et al. 2020
Zheng et al. 2019
Witt et al. 2019
Witt et al. 2019
Wigander et al. 2019
Rozensztrauch et al. 2019
Pederiva et al. 2019
Morsberger et al. 2019
Meinds et al. 2019
Kumari et al. 2019
Fritz et al. 2018
Flieder et al. 2019
Youn et al. 2018
Svoboda et al. 2018
Sood et al. 2018
Roorda et al. 2018
Ost et al. 2018
Nah et al. 2018
Kyrklund et al. 2018
Hong et al. 2018

PROMs for pediatric surgical congenital anomalies



PROMs for pediatric surgical congenital anomalies



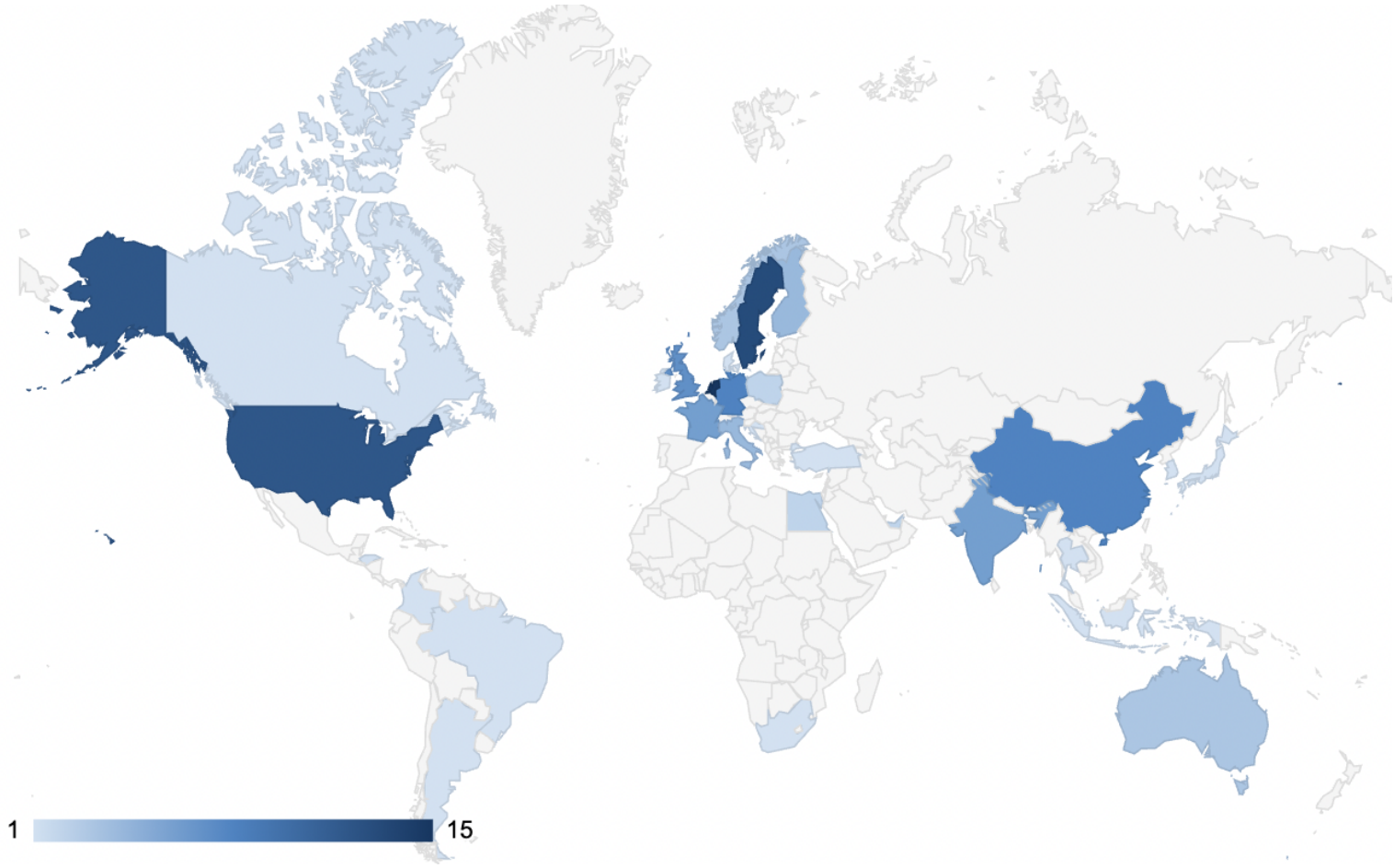


Legend: the red colour means "no", the green "yes", the grey “not applicable”. 1 - Were the aims/objectives of the study clear?; 2 - Was the study design appropriate for the stated aim(s)?; 3 - Was the sample size justified?; 4 - Was the target/reference population clearly defined? (Is it clear who the research was about?); 5 - Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?; 6 - Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?; 7 - Were measures undertaken to address and categorise non-responders?; 8 - Were the risk factor and outcome variables measured appropriate to the aims of the study?; 9 - Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?; 10 - Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals); 11 - Were the methods (including statistical methods) sufficiently described to enable them to be repeated?; 12 - Were the basic data adequately described?; 13 - Does the response rate raise concerns about non-response bias?; 14 - If appropriate, was information about non-responders described?; 15 - Were the results internally consistent?; 16 - Were the results presented for all the analyses described in the methods?; 17 - Were the authors' discussions and conclusions justified by the results?; 18 - Were the limitations of the study discussed?; 19 - Were there any funding sources or conflicts of interest that may affect the authors’ interpretation of the results?; 20 - Was ethical approval or consent of participants attained?

Randomized Controlled Trial (1) - Mixed Methods Appraisal Tool (MMAT) [14]					
Author	**Is randomization appropriately performed?**	**Are the groups comparable at baseline?**	**Are there complete outcome data?**	**Are outcome assessors blinded to the intervention provided?**	**Did the participants adhere to the assigned intervention?**
Moawd et al. 2020					

Legend: the red colour means "no", the green "yes".

Supplementary Fig. 1: World map of included studies.



Legend: the countries are coloured according to the number of studies published. Gray: no studies identified. Lightest blue: one study, darkest blue: 15 studies.

CHAPTER 3: Discussion

3.1 PROMs

This review identified a high number of PROMs currently used in the pediatric surgery specialty, more specifically for certain congenital anomalies. Although this number is encouraging, as it displays an interest in PROs in pediatric surgery, it also exhibits shortcomings as a gold standard does not appear to have been established for these conditions. In fact, there were almost as many different PROMs identified as the number of articles included in this review, which shows the heterogeneity of the instruments currently in use. Multiple tools were only used once in all of the included articles, highlighting the lack of consensus regarding which questionnaires are best suited for various congenital anomalies. In addition, the most frequently used tool, the PedsQL 4.0 questionnaire, is not tailored to the pediatric surgery specialty. There is therefore a need to develop generic quality instruments to measure HRQoL in children who underwent surgery.

Multiple factors must be taken into consideration when implementing a PROM in healthcare practice. These include patient involvement in the PROM development process and validity of the questionnaire in the population of interest, amongst others (13). The strength of a PROM relies on its psychometric properties, which include reliability and validity (14). PROMs should ideally be psychometrically validated to ensure that they are measuring what they were designed to measure and accurately assess changes in PROs over time (15). PROM validity encompasses three domains: content, criterion and construct validity (14).

Content validity is defined as "the extent to which the PRO instrument measures the appropriate content and represents the variety of attributes that make up the measured construct" (14). This validity subtype is usually important in the PROMs development process, where focus groups and cognitive interviews can, and should, be used to extract appropriate information in order to create a questionnaire (14). In order to develop an adequate questionnaire, both the target population and instrument development experts should be involved during the item selection process (16). Content validity thus verifies if all pertinent aspects of a particular disease are covered by the measurement tool (17).

Criterion validity relates to the degree of agreement with an external gold standard measure (14,16,17). When assessing criterion validity, the standard used to make the comparison must be deemed as a true gold standard measure (16). A gold standard is a questionnaire that has been extensively tested and holds a reputation as a reliable tool for use in a particular population (18).

Construct validity refers to the degree to which the measure relates to other measures that are consistent with theoretical hypotheses regarding the concepts that are assessed (14,16). This validity subtype is generally used when no gold standard can be found as a comparison to the measure (17). Construct validity is typically quantified using statistical analyses (14), such as the calculation of a correlation coefficient (17). For the purpose of this research, the systematic review solely assessed construct validity as a measure of PROM validation.

Lastly, another important concept when evaluating a PROM is responsiveness. This measures a tool's ability to capture clinically relevant changes in a patient's condition over time (14,17), and thus is particularly useful in longitudinal studies (16).

In this review, multiple “in-house” questionnaires were developed for the sole purpose of use in a single study. This could be explained by the aforementioned lack of gold standard in the current PROMs literature. Researchers are forced to create new questionnaires to cater to their needs, which contributes to the heterogeneity of PROMs in current literature. More importantly, these “in-house” questionnaires are not validated, rendering them less reliable to use. Validation of a tool requires evidence supporting the use and interpretation of a PROM in a particular context (19). In the case of this project, validation thus requires tools to be validated in pediatric populations. In this review, aside from the “in-house” tools, multiple PROMs identified were non-validated in children populations. Using PROMs in unvalidated populations complicates the interpretation of the outcomes by the investigator (20), as the information gathered may not be accurate. In this review, multiple PROMs had been previously validated in adult populations, but not in children. This could bias the outcomes, as the questions might not have been tailored to children, and therefore might not represent the realities they face. For instance, there must be guidelines regarding the vocabulary used in children’s questionnaires (21). The comprehension level of children answering and the minimum age at which children can provide reliable answers must also be considered (21). There is therefore a need for validation studies in pediatric populations, in order for the PROMs used to be appropriate and representative of the children’s PROs.

3.2 Countries of Origin

This study has shown the low number of studies originating from low-income countries. The majority of studies originated from high-income countries (HICs), with very few from upper middle- and low middle-income countries (LMICs). This could be explained by a publication bias in HICs. It has in fact been shown that manuscript acceptance rates are higher when the first

author resides in an English-speaking high income country (22). This phenomenon is supported by the data in the present systematic review, as the second most prolific country in regards with publication was the United States. In fact, a randomized crossover experiment conducted recently showed that changing the country of origin of an abstract from a low-income country to a HIC significantly increased the perceived relevance of the abstract, and the probability of a reviewer to refer this abstract to others (23). This displays a bias favouring research from HICs, which can be transposed to our results, as 78% of the countries represented in the included articles are HICs. Lastly, another study conducted in 2017 showed moderately strong implicit associations between "rich countries" and "good research" (24). This could explain the high number of HICs in our systematic review, as articles perceived as "good research" are more likely to be published than those labeled as "bad research". Although ten research articles originating from LMICs were included, there is a notable scarcity of publications from these countries. The numbers and disparities observed in this review denote a clear area for change, as research from LMICs could be highly beneficial to the field of PROMs in pediatric surgery.

Aside from the above-mentioned publication bias, the low number of studies originating in LMICs could be explained by multiple factors. First, our inclusion criteria required the articles to be written in English. This alone could have prematurely discounted multiple PROMs publications originating in LMICs, if the publications were in any language other than English. Second, the current focus of care in LMICs might not be the same as that of HICs. It is known that low-income countries are burdened by high rates of illness, more particularly infectious diseases, and malnutrition (25). This could be due to numerous factors, namely low food supplies, no drinking water and poor sanitation amongst others (25). As described by Maslow's

hierarchy of needs, if basic physiological needs, such as nutrition and shelter, are not met, higher order needs, namely safety, social interaction, esteem, and self-actualization, cannot be attained (26). Thus, LMICs might not prioritize research, as their focus must be placed on their basic needs, including water, sanitation and hygiene (27), hence potentially explaining the lack of research originating from these countries in this review.

3.3 Risk of Bias Analysis

The risk of bias (ROB) analysis was initially conducted using the "Mixed-Methods Appraisal Tool" (MMAT) (28), for both cross-sectional studies and the single randomized controlled trial. We used the "Quantitative non-randomized studies" questionnaire for the 100 cross-sectional studies, as well as the "Quantitative randomized controlled trials studies" questionnaire for the sole randomized controlled trial (RCT) included in this review. The MMAT questionnaire for the RCT was used in the review, as we deemed it appropriate for the article. However, the MMAT questionnaire for cross-sectional studies was replaced by the AXIS Risk of Bias Assessment Tool (29). We considered the MMAT questionnaire too broad for the cross-sectional studies, as the questions left a lot to the interpretation of the person analyzing the articles. The AXIS tool was then chosen, as it comprises twenty questions regarding each section of manuscripts, with its categories labelled as "Introduction", "Methods", "Results", "Discussion" and "Other". We deemed this tool to be more specific and standardized than the MMAT questionnaire previously used. ROB results showed an overall good quality of the included studies, both cross-sectional and the RCT, which strengthens the quality of this work.

3.4 Guiding PROMs Use

Patients have identified various roles of PROMs in healthcare, namely including the patient's overall well-being into the treatment process and improving communication and patient involvement in their own course of care (30). PROMs have also been reported to increase the feeling of validation felt by patients when their concerns are heard by physicians (30). However, despite their importance in current healthcare, PROMs are in need of improvement, particularly in pediatric care (31). This includes, amongst others, taking into consideration the response shift expected as children age and therefore have different priorities (31).

In the present systematic review, none of the PROMs identified were individualized for the patient, hence all the questionnaires were standardized. Individualized PROMs (iPROMs) focus on domains deemed important *by the patients*, and thus capture the individualistic nature of HRQoL (32,33). More importantly, iPROMs have been shown to be useful in prioritizing and tracking the health of patients with multiple comorbidities (32). Standardized PROMs are typically restricted to specific domains, namely physical, emotional and social functioning, as well as somatic sensation (33). These tools, however, fail to capture the individuality of the patient's experience with illness as the questions restrict and orient patient input to predetermined questions (34), and therefore tend to limit dialogue and communication (33,35). When comparing patients and clinicians' areas of concerns by using the Short-Form 36 questionnaire (SF-36) (36), a traditional PROM, discordances were found between the two groups (37). Physicians were more concerned with physical symptoms of the disease, whereas patients were mostly burdened by more abstract domains, such as mental health (37). In contrast, iPROMs allow patients to individually quantify their HRQoL, since the scores are derived from

the weights attributed to various domains determined by the patients themselves (33). iPROMs have numerous advantages, one of which being the increased attention given to patients' preferences regarding the course of care (38). iPROMs would be particularly useful in pediatric surgical care, as the realities of children living with medical conditions might not be fully grasped by traditional PROMs. Restraining questionnaires to a few domains does not allow investigators to fully capture the entirety of children's experience with disease. Given their clear advantage over traditional PROMs due to their ability to better acknowledge patients' priorities (39), a reasonable next step in pediatric PROMs research would therefore be to create and implement iPROMs for clinical care.

An example of an iPROM that has been widely used in the literature is the Patient-Generated Index (PGI) (40). This tool is divided in three steps where patients are asked to 1) identify the areas of their lives most affected by their conditions, 2) allot a score to each area based on how affected they are, and 3) distribute a set number of points to the areas they would like to improve most (41). The PGI has been shown to shed light on patients' perspectives regarding their disease and treatment (42). The open-ended nature of the tool allows patients to disclose any information they consider pertinent, and lets them attribute weight to areas that they deem more important or problematic (43). Although the PGI was developed for adults, some of our colleagues are working on developing a pediatric version (44). This new pediatric iPROM would be highly useful in the field of pediatric surgery, since children would be able to voice their views freely without any constraints from restrictive instruments. Once published, this work could lead to implementing such iPROMs into pediatric care.

Recent evidence has also further proven the usefulness of iPROMs. In fact, research has shown that when comparing iPROMs' and standardized PROMs' content, a large portion of the concerns mentioned when collecting iPROMs data were not covered by the standardized PROMs (38). Participants tended to report more diverse problems than those covered by traditional PROMs, iPROMs appearing to cover patients' stories more holistically than standardized tools (38). These findings further demonstrate the importance of iPROMs, as they allow patients to openly disclose any information they deem pertinent to their HRQoL - which is not always possible when using traditional tools. In fact, patients who are presented with both open and closed-ended questions tend to report more diverse categories of signs and symptoms when answering open-ended questions, compared to predetermined questions answerable by "yes" or "no" (45). Open-ended questions, as found in iPROMs, tend to provide more in-depth data of the patients' experience with illness (45), again suggesting that PROMs should move in the direction of individualized questionnaires. Perhaps the most efficient way to utilize PROMs would be to include both standardized and individualized questionnaires, which would allow a clear depiction of the patients' realities (46). By using both standardized and individualized measurement tools, one can ensure that the patient's entire profile and perceptions are accounted for.

3.5 Future directions

Although PROMs use has increased in recent years, they are not yet common in clinical and surgical practice, particularly in pediatric surgical care. PROMs must be increasingly used in pediatrics, and more specifically for children suffering from chronic conditions and congenital anomalies. These children often suffer from various morbidities, which emphasizes the importance of hearing their concerns. Previous research has shown that future PROMs studies should focus on integrating PROs in the decision-making process, adding PROs to patient's

electronic health records, and ensuring quality of PROs measurement (47). Hence, future work should focus on validating PROMs in children populations, so that the outcomes measured can be reliable and trusted. The current lack of validation in this population prevents the accurate measurement of outcomes in children suffering from various medical and surgical conditions. Future studies could focus on determining if differences in PROM data (or lack thereof) arise from instrument development not meeting validation criteria. This could help pinpoint areas of improvement in the PROMs validation process.

Furthermore, both generic and disease-specific quality instruments must be generated for pediatric congenital anomalies, which would allow for a more homogeneous use of questionnaires. Investigators would also benefit from gold-standard instruments, as the burden of choosing a PROM or having to create a new one would become obsolete.

In addition, future studies could include an assessment of clinical practice before and after using PROMs, to determine the impact of taking PROs into consideration. In fact, it has been shown that using PROMs in routine pediatric clinical care improved communication regarding HRQoL, increased HRQoL scores, and ameliorated satisfaction with care (2). Since the benefits of using PROMs in routine clinical practice have been previously quantified, future steps could include conducting similar studies to evaluate the importance of PROMs use in pediatric surgical care. The results could then guide physicians into adapting their practices to include PROMs in their daily assessments.

Our future work will first involve identifying domains important to children regarding their course of care in pediatric surgery. To do so, questionnaires have been drafted and will be administered in pediatric surgical patients, at multiple time points throughout their lifespan. The information collected will provide insight in the domains that matter most to children suffering from pediatric surgical congenital anomalies. The data gathered is expected to be different depending on the child's age and their developmental stage (48). It is therefore important to gather information for a large and varied group of children to obtain an accurate depiction of what matters most based on age. Secondly, from the previously acquired data, we will aim to choose PROMs that cover the areas mentioned by the children. In order to choose the most appropriate instruments for a given population, notions such as the target population, the content of the PROM, the validity and the reliability of the tool must all be considered (49). This will ensure that the realities of children are heard and understood during the PROMs data collection process.

3.6 Conclusion

We scoped the literature on PROMs in pediatric surgery, more specifically for children suffering from congenital anomalies. We assessed and characterized these questionnaires, and established areas where some elements were lacking, such as validation and iPROMs. We verified and confirmed our hypothesis, and we identified avenues of future research. This work is the first step into using PROMs more ubiquitously in pediatric surgical care. Future work should focus on validating instruments in pediatric populations, establishing gold standards and implementing iPROMs for use in everyday practices.

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