

**Supplementary File 2**

Table S1. Description of Quality-of-Life Instrument used and Scoring Threshold (if appropriate) per Included Study

Author, year	Constipation	Small bowel obstruction	Fecal Incontinence	Difficulty defecating	Enterocolitis	Psychosocial problems
John, 2010			Quality of life (QOL) questionnaire The scale used ranged from 0-13 with a higher score meaning a better QOL			
Grano, 2010	Hirschsprung/Anorectal Malformation Quality of life Questionnaire (HAQL) Scores range from 0 to 100 with higher scores indicating higher levels of functioning		Hirschsprung/Anorectal Malformation Quality of life Questionnaire (HAQL) Scores range from 0 to 100 with higher scores indicating higher levels of functioning			Hirschsprung/Anorectal Malformation Quality of life Questionnaire (HAQL) Mean scores given.
Yang, 2016			Detailed questionnaire (unspecified)		Detailed questionnaire (unspecified)	

		Proportions given.	Proprtions given.
Yeh, 2014		Medical records and standardized telephone questionnaire (unspecified) Proportions given	Medical records and standardized telephone questionnaire (unspecified) Proportions given.
Yamataka, 2009	Continence evaluation questionnaire. Questionnaire used and values for score given is % of patients, higher % is more patients experienced symptom. Postoperative constipation did not occur in surgery groups.		
Wang, 2014			Questionnaire (undefined)

Granstrom, 2013	Patient records Proportions given, no scores	Patient records Proportions given		
Hukkinen, 2014		Bowel function score questionnaire. Proportions given. Bowel obstruction = acute intestinal obstruction.		Bowel function score questionnaire. Proportions given.
Roorda, 2018	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL disease specific QoL) Proportions given, no scores		Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL). Proportions given.	CHQ-PF50 and CHQ-CF87. Mean scores given. Scales range from 0-100 with higher scores indicating better perceived functioning. When parent and self- report yielded the same domain score, these were pooled and compared with normative data.

Levitt, 2013	Medical/patient records and telephone/email questionnaire. Proportions given.		Medical/Patient Records and telephone/email questionnaire. Proportions given.	
Sood, 2018	Cleveland Clinic Constipation Scoring System (CCCSS) Higher scores indicate severe constipation and a global score of 15+ means patient has constipation. 30 = severe constipation.	Baylor Continence Scale. (BCS). BCS scores range from 2 to 92, where better social continence is denoted by lower scores.	REDCap colorectal database. Proportions given.	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL). Mean scores given. No SD reported for control data.
Khalil, 2015	Peds QL 4.0-Core Measurement Scale. Proportions given	Peds QL 4.0-Generic Core Scales. Proportions given.		PedsQL 4.0 Core Measurement Model. Mean scores given. A 5-point Likert scale from 0 (never) to 4 (almost always) is used. Items are then reverse scored and linearly transformed to a 0 to 100 scale. Higher

				scores indicate better QoL.
Meinds, 2019	Rome IV. Proportions given, no scores. Constipation was defined by the Rome IV criteria for functional constipation. Patients need at least 2 of the following: straining, hard or lumpy stools, incomplete evacuation, anorectal obstruction, use of manual manoeuvres to defecate, or fewer than 3 bowel movements per week. Loose stools should rarely be present.	Rome IV. Proportions given	Rome IV. Proportions given	

Mathias, 2016	Quality of life related to fecal continence in children and adolescents (QQVCFCA). The final score is obtained by summing the mean score obtained in each domain, and ranges from 4 to 16. High scores indicate good standing.	
Lane, 2016	Baylor Continence Scale (BCS). Scores range from 2 to 92, with lower scores reflecting better fecal continence/control.	PedsQL Pediatric Quality of Life Inventory. Total parent reported HRQoL scores, and psychosocial scores were the sum of emotional, social and school functioning combined. Maximum score of 100, with higher

			score corresponding to better QoL
Collins, 2017	Cleveland Clinic Constipation Scoring System (CCCSS). A score of 0 indicates normal bowel function, 15 is defined as “constipation”, and 30 indicates “severe constipation”.	Baylor Continence Scale (BCS). Scores range from 2 to 92, with lower scores reflecting better fecal continence/control.	PedsQL 4.0 Generic Core Scale. Maximum score of 100, with higher score corresponding to better QoL
Aworanti, 2012	Pediatric Incontinence and Constipation Scoring System questionnaire (PICSS). Mean scores presented. The maximum score is 29 for constipation (higher score means no constipation).	Pediatric Incontinence and Constipation Scoring System (PICSS). Mean scores presented. Maximum score is 32 for incontinence scale, which implies continence (closer the score is to 32 = better continence)	

Allin, 2020	Pediatric Incontinence and Constipation Scoring System (PICSS) questionnaire. Mean scores presented. The maximum score is 29 for constipation (higher score means no constipation).	Pediatric Incontinence and Constipation Scoring System (PICSS). Mean scores presented. Maximum score is 32 for incontinence scale, which implies continence (closer the score is to 32 = better continence)	Pediatric Incontinence and Constipation Scoring System (PICSS). Proportions given.	PedsQL. Items are reverse scored and linearly transformed from 0 to 100. Higher scores indicate better quality of life.
Espeso, 2020		Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL). Mean scores given. Each dimension is scored over 100; the higher the score, the better quality of life. From 0-8 years, parents completed the HAQL.	Medical records. Proportions given. Two children aged 6-11 years experienced enterocolitis versus 0 aged 12-18.	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL). Mean scores given. Each dimension is scored over 100. The higher the overall score, the better the quality of life.



Saysoo, 2020	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL- different). A score from 0 to 3 was given in response for each item and a better QoL was indicated by a higher score	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL). A score from 0 to 3 was given in response to each item and a better QoL was indicated by a higher score.	Hirschsprung/ Anorectal Malformation Quality of life Questionnaire (HAQL/modified). Mean scores are not differentiated by parent vs adolescent report. A score from 0 to 3 was given in response for each item and a better QoL was indicated by a higher score.
Townley, 2020	The Paediatric Incontinence and Constipation Score (PICS). Data are given as mean (range). Scores range from 0-29 with higher scores indicating no constipation.	Pediatric Incontinence and Constipation Scoring System (PICSS). Mean scores (with SD or range) given. Maximum score is 32 for incontinence scale, scores closer to 32 = better continence.	
Wong, 2020	Wong, 2020-A: Hirschsprung/ Anorectal	Wong, 2020-A: Hirschsprung/ Anorectal	Mean scores given. For each item, the patient was asked to

<p>Malformation Quality of life Questionnaire HAQL: Mean scores given. For each item, patient asked to indicate the frequency of occurrence using a 5-point scale from 1 (never) to 5 (always). Responses recoded into a linear scale of 0- 100. Higher scores indicate higher functioning. Wong, 2020-B: Krickenbeck classification (grade 2): Proportions given. The Krickenbeck classification (2005) categorizes constipation into 3 types: grade 1 (manageable by</p>		<p>Malformation Quality of life Questionnaire (HAQL).  Mean scores given. For each item, patient asked to indicate the frequency of occurrence using a 5-point scale from 1 (never) to 5 (always). Responses were then recoded into a linear scale of 0- 100. Higher scores indicate higher levels of functioning. Wong, 2020-B: Kelly's score of continence: Mean scores given. An overall score of 5-6 is good, 3-4 fair, and 0-2 poor.</p>	<p>indicate the frequency of occurrence using a 5-point scale ranging from 1 (never) to 5 (always). The responses were recoded into a linear scale of 0- 100. Higher scores indicated higher levels of functioning.</p>
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	changes in diet); 2 (requires laxatives); and 3) resistant to diet and laxatives . Grade 2 is reported. No case or control had grade 3.	Zhuansun, 2020- A: (Quality of Life) QOL scoring criteria for children with fecal incontinence: Mean scores given. Frequent is assigned a 0. Normal is assigned a 2. Good = 9 to 12 points; fair = 5 to 8; poor = 0 to 4. Zhuansun, 2020-B: Mail communications and telephone interviews: Proportions given.	Mail communications and telephone interviews. Proportions given.
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