

Appendix F. Priorities identified in each phase of the study.

Delphi survey outcomes (items in bold met 70% threshold)	Patient Consultation Meeting	Consensus Meeting (threshold = 70%)	Outcome
1. Clustering/Fragmentation	—————→	Combine Clustering/Fragmentation and Incomplete Emptying (92% agreement)	Clustering/Fragmentation/Incomplete emptying/Difficulty emptying the bowel: sensation of incomplete evacuation / sense of residual stool after passing a bowel motion and / or the need to return to the toilet to pass multiple bowel motions"
2. Incomplete Emptying	—————→		
3. Difficulty emptying	—————→	Combine Clustering / Fragmentation / Incomplete Emptying and Difficulty Emptying (77% agreement)	
4. Stool frequency	—————→	Not discussed (already met criteria for consensus)	Increased stool frequency
5. Soiling	—————→	Need to be included separately as did not reach consensus (Poll to combine: 35% agreement)	Soiling: involuntary passage of a small amount of material onto clothing or sanitary items?
6. Faecal Incontinence	—————→		Faecal Incontinence: unintended passage of a large volume of faecal material?
7. Urgency	Could combine these items	Combine these items (96% agreement)	Urgency: need to rush to toilet to defaecate and / or the inability to defer defecation (passing a bowel motion)
8. Inability to defer defecation			
9. Variable/Unpredictable bowel function	—————→	Not discussed (already met criteria for consensus)	" Variable and/or unpredictable bowel function "
Tenesmus	Pain is an important concept but needs rephrasing	New wording: "pain on urge / pain on defecation / pain after defecation" (100% agreement)	Repeated painful stools: including pain on urge to pass a bowel motion and/or pain on passing a bowel motion and/or after passing a bowel motion
Gas incontinence	Danish group thought this should be included	Did not reach consensus (61% agreement)	
Inability to discriminate between gas and stool	Can be incorporated into other items above the line		
Time to evacuate	Considered to be important by some groups	Did not reach consensus (7% agreement)	
Diarrhoea	Considered important items but may have been misrepresented in the surveys as people have different ideas about "diarrhoea"	Discussion showed the concept was important, but 'diarrhea' was not the right description. Combine these items (77% agreement)	Altered stool consistency
Change in stool consistency			
Liquid stool incontinence	Can be incorporated into other items		
Concern that others will be able to smell the lack of bowel control	Can be incorporated into other items		
Need to wear a pad or diaper or sanitary item in case of stool leakage	Can be incorporated into other items		
10. Dissatisfaction with bowel function	This should be graded on a scale not yes/no question	Not discussed (already met criteria for consensus)	Dissatisfaction with bowel function.
11. Preoccupation with bowel function	—————→	Combine these items (71% agreement)	Preoccupation with bowel function
12. Fear / anxiety over bowel control	—————→		
13. Toilet dependence	—————→	<i>Include separately, cannot be combined with other coping strategies (82% agreement)</i>	Toilet dependence: Need to be near a toilet at all times
14. Need to use coping strategies	—————→	Needs to be included. General agreement so no poll taken.*	Need to use strategies or make compromises to manage bowel function.
15. Effect on quality of life	Danish group suggested incorporated these under a single item. Other groups suggested some amalgamation and/or rewording	Use a stem question with domains: <input type="checkbox"/> Relationships / intimacy <input type="checkbox"/> Mental / emotional wellbeing (can incorporate fear/anxiety/worry concept) <input type="checkbox"/> Roles / responsibilities (will incorporate impact on employment) <input type="checkbox"/> Social / daily activities (96% agreement)	Impact on the 4 'domains'. <input type="checkbox"/> Relationships / intimacy <input type="checkbox"/> Mental / emotional wellbeing including worrying about bowel function and/or bowel control <input type="checkbox"/> Roles / responsibilities / commitments <input type="checkbox"/> Social / daily activities May need to consider changing the wording of "impact".
16. Effect on overall wellbeing			
17. Effect on lifestyle/daily activities			
18. Effect on social activities			
Impact on sexuality and sexual life	Very important item but needs rewording "intimacy" is the important concept		
Effect on ability to perform work	Very important item but needs rewording/broader term - not just employment		

*Examples: medications including laxatives, enema, loperamide, probiotics, changes to diet, changes to daily activities, preparation including having an emergency bag or kit to deal with unexpected bowel function.

