Appendix B The Decision Rules including application and deviation from these rules.

The results of Round 1 will be reviewed by the steering group with pre-determined levels of inclusion and exclusion of items for Rounds 2 and 3 based on the following principles:

1. All items meeting inclusion criteria from Round 1 and all newly suggested items will be re-presented for voting by expert panels in subsequent rounds.
2. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (likely in excess of 67% but final level to be determined by steering group) across all three expert panels will be eliminated from the voting process after any round.
3. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (>67%) in two out of three expert panels, AND where less than 15% of the total participants have ranked the item as high priority (Likert 7-9), will be eliminated from the voting process after any round.
4. Items that have achieved high levels of both accordance across panels and high priority (Likert 7-9) in Round 1 will be listed for purpose of information in Round 2 but will not need to be ranked again until Round 3.
5. Any items with significant differences in median rankings (median ranking differs by 3 or more points) between panels, or that demonstrate wide heterogeneity within a single panel, will be included in subsequent rounds, but may need critical assessment as per Principle 10.
6. The steering group will be responsible for wording of new items for inclusion in Round 2, based on suggestions from Round 1.
7. Round 2 results will be subjected to principles 2 and 3 to identify items for further exclusion.
8. Round 3 will include all remaining items from Round 2 and all included items meeting principle 4 from Round 1.
9. The steering group will give consideration to ensure that patient views are prioritised and not lessened by implementation of principle 3.
10. The steering group will monitor heterogeneity in the scoring within and between the expert panels, and suggest any necessary alterations in phraseology, language or explanation to address this issue.
11. The steering group will provide guidance on the number of items to be carried through to subsequent rounds.
12. Panellists will have sight of their own score from the previous round, the median score for their panel, and the median scores from the other panels.
13. All steering group decisions during the Delphi process will be recorded, together with reasoning for decision.
14. All items “voted in” or still under consideration at the end of voting in Round 3 will be discussed at the consensus meetings.

Decision Rule	Outcome	Deviation (with reasons)
Rules applied in Round 1		
2. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (likely in excess of 67% but final level to be determined by steering group) across all three expert panels will be eliminated from the voting process after any round.	No items met this criterion	No items met rule 2 or 3 so a lower limit was discussed for use in Round 2 as the panels were less discriminatory in their rankings than had been expected.
3. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (>67%) in two out of three expert panels, AND where less than 15% of the total participants have ranked the item as high priority (Likert 7-9), will be eliminated from the voting process after any round.	No items met this criterion	
4. Items that have achieved high levels of both accordance across panels and high priority (Likert 7-9) in Round 1 will be listed for purpose of information in Round 2 but will not need to be ranked again until Round 3.	These items were ranked as high priority by a majority of all 3 expert groups so progressed to Round 3: *Effects on lifestyle or daily activities* *Effect on overall wellbeing* *Effect on quality of life* *Toilet dependence* *Inability to defer defecation* *Clustering / Fragmentation* *Incontinence (of any kind) – note comment below* *Faecal urgency (of any kind)*	
5. Any items with significant differences in median rankings (median ranking differs by 3 or more points) between panels, or that demonstrate wide heterogeneity within a single panel, will be included in subsequent rounds, but may need critical assessment as per Principle 10.	No significant difference in median rankings (3 or more points) for any items.	
6. The steering group will be responsible for wording of new items for inclusion in Round 2, based on suggestions from Round 1.	New items added from thematic analysis of free text responses: *Tiredness or fatigue* *Concern about dehydration* *Social isolation* *Inability to cope with bowel function* *Bowel noises* *Rectal spasms or cramping* *Preoccupation with bowel function over all other activities* *Fear and/or anxiety over bowel control* *Variable or unpredictable bowel function* *Effect on urinary function*	

	Loss of sensation around the anus *Perianal soreness* *Bloating and/or abdominal discomfort* *Excessive wind (flatus)* *Concern that others will be able to smell the lack of bowel control* Items not added as considered to be covered by pre-existing items: Difficulty evacuating soft stool; Influence of diet on bowel function Small bowel obstruction was suggested but not added - but abdominal pain/bloating was added.	
9. The steering group will give consideration to ensure that patient views are prioritised and not lessened by implementation of principle 3.	Items also progressed to Round 3: *Dissatisfaction with bowel function* *Stool frequency: number of bowel motions per 24 hours* *Stool frequency >4 per 24 hours* *Soiling: involuntary passage of faecal material onto clothing or sanitary items* *Incomplete emptying / Incomplete evacuation*	Items ranked as high priority by the majority (>67%) of the patient panel progressed to Round 3 to ensure there is adequate recognition of the patient voice and to allow participants to discriminate between the remaining items in Round 2 more effectively
10. The steering group will monitor heterogeneity in the scoring within and between the expert panels, and suggest any necessary alterations in phraseology, language or explanation to address this issue.	No changes made.	
11. The steering group will provide guidance on the number of items to be carried through to subsequent rounds.	*Incontinence (of any kind)* and *faecal incontinence* were considered to be redundant, so *Incontinence (of any kind)* was removed. Stool frequency >4 per 24 hours and stool frequency: number of bowel motions per 24hours/per day were considered to be redundant so an amalgamated term Stool Frequency was presented for round 3.	
Rules applied in Round 2		
1. All items meeting inclusion criteria from Round 1 and all newly suggested items will be re-presented for voting by expert panels in subsequent rounds.	Round 2 included the 24 items that progressed from round 1 (below) and the 15 new items generated in round 1 (see above): *Effects on or restriction in diet.* *Effects on social activities.* *Effects ability to perform usual work.* *Effect on sexual function.* *Preference for a stoma "bag".* *Nocturnal bowel motions: Awoken from sleep to pass a bowel motion.* *Change in stool consistency following surgery.* *Diarrhoea: loose (mushy) or watery stool.* *Constipation: lumpy or hard stools.* *Tenesmus: repeated painful urge to defecate.* *Difficulty emptying the bowel.* *Time to evacuate: unable to empty bowel within 15 minutes.*	

	Straining to pass a bowel motion. *Pain on passing a bowel motion.* *Loss of the desire/urge to pass a bowel motion.* *Use of anti-diarrhoeal medications.* *Use of evacuatory aids (laxatives, enemas, suppositories, irrigation, digitation) to empty the bowel.* *Inability to discriminate between gas and stool.* *Faecal incontinence: unintended passage of solid or liquid faecal material.* *Solid stool incontinence: unintended passage of solid faecal material.* *Liquid stool incontinence: unintended passage of liquid faecal material.* *Flatus (gas) incontinence: unintended passage of gas.* *Need to wear a pad/diaper/sanitary item in case of stool leakage.* *Nocturnal incontinence: unintended passage of solid, liquid or gaseous faecal material while asleep.*	
5. Any items with significant differences in median rankings (median ranking differs by 3 or more points) between panels, or that demonstrate wide heterogeneity within a single panel, will be included in subsequent rounds, but may need critical assessment as per Principle 10.	Responses to *loss of sensation around anus* varied between the expert panels (median scores: patients 2; healthcare professionals 25; surgeons 4) but because this was ranked as low priority by a majority of patients this item did not progress to the subsequent round.	
7. Round 2 results will be subjected to principles 2 and 3 to identify items for further exclusion.	Items that progressed from Round 2 to 3 using new criteria: *Concern others will be able to smell lack of bowel control* *Difficulty emptying* *Diarrhoea* *Effect on ability to perform work* *Effect on sexual function* *Effects on social activities* *Faecal incontinence* *Fear and / or anxiety over bowel control* *Flatus incontinence* *Inability to cope with bowel function* *Inability to discriminate between gas and stool* *Liquid incontinence* *Need to wear a pad/diaper/sanitary item in case of stool leakage.* *Preoccupation with bowel function over all other activities* *Stool consistency* *Tenesmus* *Time to evacuate* *Variable or unpredictable bowel function*	The patient expert panel was more discriminatory than the other expert panels, so the Scientific Committee agreed to focus on patient high priority rankings. There was a "drop off" in high priority rankings at 55% so a new criterion was used: **Items ranked as high priority by a majority (55% or more) of patients AND ranked as low priority by less than 33% of patients progressed to Round 3.** These criteria overrode decision rules 2 and 3.

9. The steering group will give consideration to ensure that patient views are prioritised and not lessened by implementation of principle 3.		See above
10. The steering group will monitor heterogeneity in the scoring within and between the expert panels, and suggest any necessary alterations in phraseology, language or explanation to address this issue.	Two items were reworded to accurately reflect the underlying concept based on advice from the patient representatives. *Inability to cope with bowel function* was reworded to *need to use coping strategies to manage bowel function*. *Effect on sexual function* was reworded to *impact on sexuality and sexual life*.	
Rules applied in Round 3		
2. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (likely in excess of 67% but final level to be determined by steering group) across all three expert panels will be eliminated from the voting process after any round.	No items met this criterion	Participants were as discriminatory so these rules were superseded by the criterion for progression presented below (majority of 70% ranking the item as high priority).
3. Items that have been voted as of low priority (Likert 1-3) by a majority of panellists (>67%) in two out of three expert panels, AND where less than 15% of the total participants have ranked the item as high priority (Likert 7-9), will be eliminated from the voting process after any round.	No items met this criterion	
5. Any items with significant differences in median rankings (median ranking differs by 3 or more points) between panels, or that demonstrate wide heterogeneity within a single panel, will be included in subsequent rounds, but may need critical assessment as per Principle 10.		
8. Round 3 will include all remaining items from Round 2 and all included items meeting principle 4 from Round 1.	Round 3 included the 29 items; 11 that progressed from round 1 (below) *Effects on lifestyle or daily activities* *Effect on overall wellbeing* *Effect on quality of life* *Toilet dependence* *Inability to defer defecation* *Clustering / Fragmentation* *Faecal urgency (of any kind)* *Dissatisfaction with bowel function* *Stool frequency* *Soiling* *Incomplete emptying / Incomplete evacuation* and the 18 from round 2: *Concern others will be able to smell lack of bowel control* *Difficulty emptying* *Diarrhoea*	

	Effect on ability to perform work *Effect on sexual function* *Effects on social activities* *Faecal incontinence* *Fear and / or anxiety over bowel control* *Flatus incontinence* *Inability to cope with bowel function* *Inability to discriminate between gas and stool* *Liquid incontinence* *Need to wear a pad/diaper/sanitary item in case of stool leakage.* *Preoccupation with bowel function over all other activities* *Stool consistency* *Tenesmus* *Time to evacuate* *Variable or unpredictable bowel function*	
9. The steering group will give consideration to ensure that patient views are prioritised and not lessened by implementation of principle 3.	When there was disagreement between the three expert groups the majority criterion (70%) was based upon patient panel rankings.	
10. The steering group will monitor heterogeneity in the scoring within and between the expert panels, and suggest any necessary alterations in phraseology, language or explanation to address this issue.	No changes made.	
11. The steering group will provide guidance on the number of items to be carried through to subsequent rounds.	The following items were retained at completion of the Delphi survey: *Clustering / Fragmentation* *Incomplete emptying / Incomplete evacuation* *Difficulty emptying* *Stool frequency* *Soiling* *Faecal incontinence* *Faecal urgency* *Inability to defer defecation* *Variable or unpredictable bowel function* *Dissatisfaction with bowel function* *Preoccupation with bowel function over all other activities* *Toilet dependence* *Need to use coping strategies to manage bowel function* *Fear and / or anxiety over bowel control* *Effect on quality of life* *Effect on overall wellbeing*	A discernible cut-off point was evident for each of the three expert panels above which the proportion of participants giving a high priority ranking sharply increased and the proportion of participants giving a low or moderate priority ranking sharply decreased. Therefore this cut-off point (majority of 70%) was used as the criterion items to be retained after Round 3.

	Effects on lifestyle or daily activities *Effects on social activities*	
Note: decision rules 7, 8, 12 – 14 were followed		