

Note: It is recommended that this Data Set have two additional key variables:  
- SITE (to distinguish the location where the data are recorded) and  
- SUBJECT (to distinguish the patient/study participant)

## INTERNATIONAL SPINAL CORD INJURY DATA SETS

### BOWEL FUNCTION BASIC DATA SET – DATA FORM

Date performed: YYYYMMDD

**BFXNDT**

**Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:**

No       Yes, specify **GIFXNSP**       Unknown **GIFXNUN**

**Surgical procedures on the gastrointestinal tract:**

No       Appendectomy, date performed YYYYMMDD **APNDEC**      **APNDEC DT**

Cholecystectomy, date performed YYYYMMDD **CHCYEC**      **CHCYEC DT**

Colostomy, date last performed YYYYMMDD **COLOST**      **COLOST DT**

Ileostomy, date last performed YYYYMMDD **ILEOST**      **ILEOST DT**

**OTGISURG**  Other, specify: **GISURGSP**, date last performed YYYYMMDD **GISURGDT**

Unknown

**Awareness of the need to defecate (within the last four weeks):** **DEFAWRNS**

Normal (direct)

Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)

None

Unknown

**Defecation method and bowel care procedures (within the last four weeks):**

**DEFMTHM** Main      Supplementary **DEFMTHS1**

Normal defecation   **DEFMTHS2**

Straining / bearing down to empty   **DEFMTHS3**

Digital ano-rectal stimulation

Suppositories

Digital evacuation

Mini enema (Clyisma  $\leq$  150 mL)

Enema ( $\geq$  150 mL)

Colostomy

Sacral anterior root stimulation

Other method, specify **OTHDEFM**   **OTHDEFS1**

Unknown **OTHDEFS2**

**OTHDEFS3**

**Average time required for defecation (within the last four weeks):**

0-5 minutes       6-10 minutes       11-20 minutes       21-30 minutes **AVDEFTM**

31-60 minutes       More than 60 minutes       Unknown

**Frequency of defecation (within the last four weeks):** **DEFFRQ**

- Three times or more per day     Twice daily     Once daily
- Not daily but more than twice every week
- Twice every week     Once every week
- Less than once every week, but at least once within the last four weeks
- No defecation within the last four weeks
- Not applicable     Unknown

**Frequency of fecal incontinence (within the last three months):**

- Two or more episodes per day     One episode per day
- Not every day but at least once per week
- Not every week but at least once per month
- Once every month     Less than once per month     Never
- Unknown

FCINCFRQ

**Need to wear pad or plug (within the last three months):**

- Daily use     Not every day but at least once per week
- Not every week but at least once per month
- Less than once per month     Never
- Unknown

WRPADPLG

**Medication affecting bowel function / constipating agents (within the last four weeks):**

- No     Yes, anticholinergics **ANTICHOL**
- Yes, narcotics **NARCOTIC**
- Yes, other, specify: \_\_\_\_\_ **OTHBFMED, BFMEDSP**
- Unknown

**Oral laxatives (within the last four weeks):**

- No     Yes, osmotic laxatives (drops) **OSMODRP**
- Yes, osmotic or bulking laxatives (tablets or granulates) **OSMOTAB**
- Yes, irritant laxatives (drops) **IRRTRDP**
- Yes, irritant laxatives (tablets) **IRRRTAB**
- Yes, prokinetics **PROKINET**
- Yes, other, specify: \_\_\_\_\_ **OTHORLAX, ORLAXSP**
- Unknown

HEMRHOID

**Perianal problems (within the last year):**

- None     Haemorrhoids     Perianal sores     Fissures     Rectal prolapse
- Other, specify \_\_\_\_\_     Unknown    **FISSURES**

PANLSORE

RECPRLPS

PANLOTH

PANLPRSP

Proposed 8 Character Variables:

Proposed 8 Character Variables:						Surgical procedures on the gastrointestinal tract										
Data Element	Site	Subject	Date of data collection	Gastrointestinal or anal sphincter dysfunction unrelated to SCI	Specify gastrointestinal or anal sphincter dysfunction unrelated to SCI	Appendectomy performed?	Date appendectomy performed	Cholecystectomy performed?	Date cholecystectomy performed	Colostomy performed?	Date colostomy performed	Ileostomy performed?	Date ileostomy performed	Other GI tract surgical procedure performed?	Specify other GI tract surgical procedure performed	Date other GI tract surgical procedure performed
Format/Codes			99999999 = Unknown	No; Yes; Unknown	Free text	No; Yes; Unknown	99999999 = Unknown	No; Yes; Unknown	99999999 = Unknown	No; Yes; Unknown	99999999 = Unknown	No; Yes; Unknown	99999999 = Unknown	No; Yes	Free text	99999999 = Unknown
8 Character Variable	SITE	SUBJECT	BFXNDT	GIFXNUN	GIFXNSP	APNDEC	APNDECDT	CHCYEC	CHCYECDT	COLOST	COLOSTDT	ILEOST	ILEOSTDT	OTGISURG	GISURGSP	GISURGDT

Proposed 8 Character Variables:

Defecation method and bowel care procedures											
Data Element	Site	Subject	Awareness of the need to defecate	Main defecation method and bowel care procedures	Supplementary defecation method and bowel care procedures #1	Supplementary defecation method and bowel care procedures #2	Supplementary defecation method and bowel care procedures #3	Specify other main defecation method and bowel care procedures	Specify other supplementary defecation method and bowel care procedures #1	Specify other supplementary defecation method and bowel care procedures #2	Specify other supplementary defecation method and bowel care procedures #3
Format/ Codes			Normal; Indirect; None; Unknown	Normal defecation; Straining / bearing down to empty; Digital ano-rectal stimulation; Suppositories; Digital evacuation; Mini enema (Clyisma, <= 150 mL); Enema (>150 mL); Colostomy; Sacral anterior root stimulation; Other method; Unknown	Normal defecation; Straining / bearing down to empty; Digital ano-rectal stimulation; Suppositories; Digital evacuation; Mini enema (Clyisma, <= 150 mL); Enema (>150 mL); Colostomy; Sacral anterior root stimulation; Other method; Unknown	Normal defecation; Straining / bearing down to empty; Digital ano-rectal stimulation; Suppositories; Digital evacuation; Mini enema (Clyisma, <= 150 mL); Enema (>150 mL); Colostomy; Sacral anterior root stimulation; Other method; Unknown	Normal defecation; Straining / bearing down to empty; Digital ano-rectal stimulation; Suppositories; Digital evacuation; Mini enema (Clyisma, <= 150 mL); Enema (>150 mL); Colostomy; Sacral anterior root stimulation; Other method; Unknown	Free text	Free text	Free text	Free text
8 Character Variable	SITE	SUBJECT	DEFAWRNS	DEFCMTHM	DEFMTHS1	DEFMTHS2	DEFMTHS3	OTHDEFM	OTHDEFS1	OTHDEFS2	OTHDEFS3

Proposed 8 Character Variables:

Proposed 8 Character Variables:			Medication affecting bowel function / constipating agents							
Data Element	Site	Subject	Average time required for defecation	Frequency of defecation	Frequency of fecal incontinence	Need to wear pad or plug	Anticholinergics taken?	Narcotics taken?	Other medication affecting bowel function / constipating agents taken?	Specify other medication affecting bowel function / constipating agents taken
Format/ Codes			0-5 minutes; 6-10 minutes; 11-20 minutes; 21-30 minutes; 31-60 minutes; More than 60 minutes; Not applicable; Unknown	Three times or more per day; Twice daily; Once daily; Not daily but more than twice every week; Twice every week; Once every week; Less than once every week but at least once within the last four weeks; No defecation within the last four weeks; Not applicable; Unknown	Two or more episodes per day; One episode per day; Not every day but at least once per week; Not every week but more than once per month; Once per month; Less than once per month; Never; Unknown	Daily use; Not every day but at least once per week; Not every week but at least once per month; Less than once per month;	No; Yes; Unknown	No; Yes; Unknown	No; Yes	Free text
8 Character Variable	SITE	SUBJECT	AVDEFTM	DEFFRQ	FCINCFRQ	WRPADPLG	ANTICHOL	NARCOTIC	OTHBFMED	BFMEDSP

Proposed 8 Character Variables:			Oral laxatives							Perianal problems					
Data Element	Site	Subject	Osmotic laxatives (drops)	Osmotic or bulking laxatives (tablets or granulates)	Irritant laxatives (drops)	Irritant laxatives (tablets)	Prokinetics	Other oral laxative	Specify other oral laxative	Perianal problems - Haemorrhoids	Perianal problems - Perianal sores	Perianal problems - Fissures	Perianal problems - Rectal prolapse	Perianal problems - Other	Specify other perianal problems
Format/ Codes			No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes	Free text	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes	Free text
8 Character Variable	SITE	SUBJECT	OSMODRP	OSMOTAB	IRRDRP	IRRTAB	PROKINET	OTHLAX	ORLAXSP	HEMRHOID	PANLSORE	FISSURES	RECPRLPS	PANLOTH	PANLPRSP