

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 EXTENDED SCI DATA SET – DATA FORM

Date of data collection: YYYYMMDD **BFXNEXDT**

Duration of constipation: **CONSTDUR**

- Less than a year 1-5 years 6-10 years 11-20 years
- More than 20 years Not applicable Unknown

Unsuccessful attempts at defecation (within the last three months): **DEFUNSUC**

- Never Less than once per month Less than once per week but at least once per month Once or more per week but not every day
- 1-3 per day 4-6 per day 7-9 per day 10 times or more per day
- Not applicable Unknown

Incomplete rectal emptying after defecation (within the last three months): **RECEMPIC**

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

Abdominal bloating (within the last three months): **ABBLOATG**

- Daily 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

Abdominal pain/discomfort (within the last three months): **ABPNDCMF**

- Daily 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

Any respiratory discomfort (shortness of breath/difficulty in taking a deep breath) considered to be entirely or partly due to a distended abdomen (within the last three months):

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

Perianal pain during defecation (within the last three months): **PANLPN**

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

Frequency of flatus incontinence (within the last three months): FLINCFRQ

- Daily 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
 Not applicable Unknown

Frequency of incontinence to *liquid* stools (within the last three months): LSINCFRQ

- Two or more episodes per day Once daily
 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
 Not applicable Unknown

Frequency of incontinence to *solid* stools (within the last three months): SSINCFRQ

- Two or more episodes per day Once daily
 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
 Not applicable Unknown

Ability to defer defecation for 15 minutes or more (within the last three months): DEFERDEF

- Yes No Not applicable Unknown

Position for bowel care (within the last three months):

- Bed BCBED Toilet chair/Commode BCCOMMOD Raised toilet seat BCRAISED
 Conventional toilet BCTOILET Other, specify: BCPOTHSP _____ Unknown
 BCPOTHER

Degree of independency during bowel management (within the last three months):

- Requires total assistance Requires partial assistance; does not clean self BMNGINDP
 Requires partial assistance; cleans self independently
 Uses toilet independently in all tasks but needs adaptive devices or special setting (e.g. bars)
 Uses toilet independently; does not need adaptive devices or special setting
 Unknown

BCDIGIT

BCGASTRO

Bowel care facilitators (within the last three months):

- Digital stimulation or evacuation Abdominal massage BCMASSAG
 Gastrocolonic response Other, specify: BCFOTHSP _____
 None Unknown BCFOTHER

Events and intervals of defecation (1): Average time from initiation of bowel care to stool comes out (within the last three months): DEFINTR1

_____minute(s)

- Not applicable Unknown

Events and intervals of defecation (2): Average time during bowel movement that stool intermittently or continuously comes out with or without assistance (within the last three months): DEFINTR2

_____minute(s)

- Not applicable Unknown

Events and intervals of defecation (3): Average time spent waiting after last stool passes before ending bowel care (within the last three months): DEFINTR3

_____minute(s)

- Not applicable Unknown

Lifestyle alteration due to *anal incontinence* (within the last three months): LFANLINC

- Lifestyle altered each day Lifestyle altered at least once per week but not every day
 Lifestyle altered more than once per month but not every week
 Lifestyle altered once per month Lifestyle altered less than once per month
 Life style not altered Not applicable Unknown

Lifestyle alteration due to *constipation* (within the last three months): LFACONST

- Lifestyle altered each day Lifestyle altered at least once per week but not every day
 Lifestyle altered more than once per month but not every week
 Lifestyle altered once per month Lifestyle altered less than once per month
 Life style not altered Not applicable Unknown

Self reported impact on quality of life due to bowel dysfunction: BDFXNQOL

- Major impact Some impact Little impact No impact
 Unknown

To be collected after physical examination:**Anal tone:****ANALTONE**
 Normal Reduced Excessive Not tested Not applicable
Voluntary contraction of the anal canal:**ANALCNTR**
 Yes No Not tested Not applicable
To be collected after X-ray investigation:**Total Gastrointestinal or Colonic Transit Time:**

_____ days _____ hours

 Not tested**TCOTRNHR****Right Colonic Transit Time:**

_____ days _____ hours

 Not tested**RCOTRNHR****Left Colonic Transit Time:**

_____ days _____ hours

 Not tested**LCOTRNHR**

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Data Element	Site	Subject	Date of data collection	Duration of constipation	Unsuccessful attempts at defecation (within the last three months)	Incomplete rectal emptying after defecation (within the last three months)	Abdominal bloating (within the last three months)	Abdominal pain/discomfort (within the last three months)
Format/ Codes			99999999 = Unknown	Less than a year 1-5 years 6-10 years 11-20 years More than 20 years Not applicable Unknown	Never Less than once per month Less than once per week but at least once per month Once or more per week but not every day 1-3 times daily 4-6 times daily 7-9 times daily 10 times or more per day Not applicable Unknown	Daily Not every day but at least once per week Not every week but at least once per month Less than once per month Never Not applicable Unknown	Daily 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	Daily 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
8 Character Variable	SITE	SUBJECT	BFXNEXDT	CONSTDUR	DEFUNSUC	RECEMPIC	ABBLOATG	ABPNDCMF

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Data Element	Site	Subject	Any respiratory discomfort (shortness of breath/difficulty in taking a deep breath) considered to be entirely or partly due to a distended abdomen (within the last three months weeks)	Perianal pain during defecation (within the last three months)	Frequency of flatus incontinence (within the last three months)	Frequency of fecal incontinence to liquid stools (within the last three months)	Frequency of fecal incontinence to solid stools (within the last three months)
Format/ Codes			Daily Not every day but at least once per week Not every week but at least once per month Less than once per month Never Not applicable Unknown	Daily Not every day but at least once per week Not every week but at least once per month Less than once per month Never Not applicable Unknown	Daily 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 Not applicable Unknown	Two or more episodes per day Once daily 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 Not applicable Unknown	Two or more episodes per day Once daily 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 Not applicable Unknown
8 Character Variable	SITE	SUBJECT	RESPDCMF	PANLPN	FLINCFRQ	LSINCFRQ	SSINCFRQ

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Proposed 8 Character Variables:			Position for bowel care						
Data Element	Site	Subject	Ability to defer defecation for 15 minutes or more (within the last three months)	Position for bowel care - Bed	Position for bowel care - Toilet chair/ Commode	Position for bowel care - Raised toilet seat	Position for bowel care - Conventional toilet	Position for bowel care - Other	Position for bowel care - Other, specify
Format/ Codes			Yes No Not applicable Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes	
8 Character Variable	SITE	SUBJECT	DEFERDEF	BCBED	BCCOMMOD	BCRAISED	BCTOILET	BCPOTHER	BCPOTHSP

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Proposed 8 Character Variables:			Bowel care facilitators						
Data Element	Site	Subject	Degree of independence during bowel management (within the last three months)	Bowel care facilitators - Digital stimulation or evacuation	Bowel care facilitators - Abdominal massage	Bowel care facilitators - Gastrocolonic response	Bowel care facilitators - Other	Bowel care facilitators - Other, specify	Events and intervals of defecation (1): Average time from initiation of bowel care to first stool coming out (within the last three months)
Format/ Codes			Requires total assistance; Requires partial assistance, does not clean self; Requires partial assistance, cleans self independently; Uses toilet independently in all tasks but needs adaptive devices or special setting (e.g. bars); Uses toilet independently, does not need adaptive devices or special setting; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes; Unknown	No; Yes		9898 = Not applicable; 9999 = Unknown
8 Character Variable	SITE	SUBJECT	BMNGINDP	BCDIGIT	BCMSSAG	BCGASTRO	BCFOTHER	BCFOTHSP	DEFINTR1

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Data Element	Site	Subject	Events and intervals of defecation (2): Average time during bowel movement that stool intermittently or continuously (in the case of a single defecation) comes out with or without assistance (within the last three months)	Events and intervals of defecation (3): Average time spent waiting after last stool passes before ending bowel care (within the last three months)	Lifestyle alteration due to anal incontinence (within the last three months)	Lifestyle alteration due to constipation (within the last three months)	Self reported impact on quality of life caused by neurogenic bowel dysfunction
Format/ Codes			9898 = Not applicable; 9999 = Unknown	9898 = Not applicable; 9999 = Unknown	Lifestyle altered each day Lifestyle altered at least once per week but not every day Lifestyle altered more than once per month but not every week Lifestyle altered once per month Lifestyle altered less than once per month Life style not altered Not applicable Unknown	Lifestyle altered each day Lifestyle altered at least once per week but not every day Lifestyle altered more than once per month but not every week Lifestyle altered once per month Lifestyle altered less than once per month Life style not altered Not applicable Unknown	Major impact Some impact Little impact No impact Unknown
8 Character Variable	SITE	SUBJECT	DEFINTR2	DEFINTR3	LFANLINC	LFACONST	BDFXNQOL

Bowel Fxn Ext Revised 8char

Proposed 8 Character Variables:

Data Element	Site	Subject	Anal tone	Voluntary contraction of the anal canal	Total Gastrointestinal or Colonic Transit Time - in hours	Right Colonic Transit Time - in hours	Left Colonic Transit Time - in hours
Format/ Codes			Normal Reduced Excessive Not tested Not applicable	Yes No Not tested Not applicable	9999 = Not tested	9999 = Not tested	9999 = Not tested
8 Character Variable	SITE	SUBJECT	ANALTONE	ANALCNTR	TCOTRNHR	RCOTRNHR	LCOTRNHR