

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION EXTENDED DATA SET (Version 1.0) – COMMENTS

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The majority of individuals with spinal cord injury (SCI) suffer from neurogenic bowel dysfunction including constipation, fecal incontinence and abdominal pain or discomfort (Stone et al. 1990, Glickmann & Kamm 1996, Krogh et al. 1997, Finnerup NB et al. 2008). Constipation related symptoms become significantly more severe with time since injury (Stone JM et al. 1990, Faaborg PM et al. 2007).

In accordance with the aims of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al. 2006) the aim of the Bowel Function Extended Data Set for Spinal Cord Injury is to standardize the collection and reporting of an extended amount of information on bowel function in individuals with SCI. The Bowel Function Extended SCI Data Set makes it possible to evaluate and compare results from various published studies on bowel dysfunction after SCI.

The Bowel Function Extended SCI Data Set is applicable to adult individuals with traumatic or non-traumatic supraconal, conal or cauda equina lesions. To ensure that data are collected in a uniform manner each variable and each response category within variables have been specifically defined. As colorectal symptoms may vary within each individual, most symptoms within the present data set are given for a specifically defined period of time.

The Bowel Function Extended Data Set is to be used in connection with the background information within the International SCI Core Data Set (DeVivo et al. 2006) and the minimum amount of information given within the Bowel Function Basic SCI Data Set. Accordingly, information about gastrointestinal or anal sphincter dysfunction prior to SCI, abdominal and perianal surgery or trauma unrelated to neurogenic bowel dysfunction, surgical treatment of neurogenic bowel dysfunction, oral laxatives, use of constipating medicine, and concomitant medication affecting bowel function can be found within the Bowel Function Basic SCI Data Set. Concomitant disease affecting gastrointestinal function has not been included in the present dataset, but may, in some settings, be important.

Several scores for fecal incontinence and constipation exist but none have yet been generally accepted for use in individuals with SCI. All information necessary for computation of the Skt. Marks score (SMS) (Vaizey et al. 1999) and the Wexner score (WS) (Jorge et al. 1993) for fecal incontinence, the Cleveland Constipation Score (CCS) (Agachan et al. 1996), and the Neurogenic Bowel Dysfunction Score (NBD) (Krogh et al. 2006) can be obtained from data included in the Bowel Function Basic Data Set and the Bowel Function Extended Data Set.

The only objective parameters included within the Bowel Function Extended Data Set are digital ano-rectal examination, total gastrointestinal or colonic transit times, right colonic and left colonic transit times determined by radioopaque markers. Though widely used, the validity and reproducibility of these variables need further study in individuals with SCI. However, it is the opinion of the working-group that these objective measures provide important information in addition to the subjective information obtained from the other variables.

Anorectal manometry, barostat measurements, rectal impedance planimetry, and scintigraphic assessment of colorectal transport at defecation or during administration of enema may be recommended for use in specific studies of neurogenic bowel function. However, these investigational tools are considered too special to be included in this data set.

References:

Agachan F, Chen T, Pfeiffer J, Reisman P, Wexner SD. A constipation scoring system to simplify evaluation and management of constipated patients. *Dis Colon Rectum* 1996; 39: 681-685.

Biering-Sørensen F, Charlifue S, DeVivo M, Noonan V, Post M, Stripling T, Wing P. International spinal cord injury data sets. *Spinal Cord* 2006;44(9):530-4.

Catz A, Itzkovich M, Tesio L, Biering-Sørensen F, Weeks C, Laramée MT, Craven BC, Tonack M, Hitzing SL, Glaser E, Zeilig G, Aito S, Scivoletto G, Mecci M, Chadwick RJ, El Marsy WS, Osman A, Glass CA, Silva P, Soni BM, Gardner BP, Savic G, Bergstrom EM, Bluvshstein V, Ronen J. A multicenter international study on the spinal cord independence measure; version III: Rasch psychometric validation. *Spinal Cord* 2007;45(4):275-91.

DeVivo M, Biering-Sørensen F, Charlifue S, Noonan V, Post M, Stipling T, Wing P. International Spina Cord Injury Core Data Set. *Spinal Cord* 2006;44(9):535-40.

Drossman DA. The functional gastrointestinal disorders and the Rome III process. *Gastroenterology* 2006; 130:1377-1390.

Faaborg PM, Christensen P, Finnerup N, Laurberg S, Krogh K. The pattern of colorectal dysfunction changes with time since spinal cord injury. *Spinal Cord* 2008; 46: 234-238.

Finnerup NB, Faaborg P, Krogh K, Jensen TS. Abdominal pain in long-term spinal cord injury. *Spinal Cord* 2008; 46: 198-203.

Glickmann S, Kamm MA. Bowel dysfunction in spinal cord injury patients. *Lancet* 1996; 347:1651-1653.

House JG, Stiens SA. Pharmacologically initiated defecation for persons with spinal cord injury: effectiveness of three agents. *Arch Phys Med Rehabil* 1997; 78: 1062-1065.

Jorge JMN, Wexner SD. Etiology and management of faecal incontinence. *Dis Colon Rectum* 1993; 36: 77-97.

Krogh K, Nielsen J, Djurhuus JC, Mosdal C, Sabroe S, Laurberg S. Colorectal function in patients with spinal cord lesions. *Dis Colon Rectum* 1997; 40: 1233-1239.

Krogh K, Mosdal C, Laurberg S. Gastrointestinal and segmental colonic transit times in patients with acute and chronic spinal cord lesions. *Spinal Cord* 2000; 38: 615-621.

Krogh K, Christensen P, Sabroe S, Laurberg S. Neurogenic bowel dysfunction core. *Spinal Cord* 2006; 44: 625-631.

Leduc BE, Spacek S, Lepage Y. Colonic transit time after spinal cord injury: Any clinical significance. *J Spinal Cord Med* 2002; 25: 161-166.

Lestar B, Pennickx F, Kerremans R. The composition of the anal basal pressure. *Int J Colorectal Dis* 1989; 4: 118-122.

Pedersen IK, Christiansen J. A study of the physiological variation in anal manometry. *Br Surg* 1989; 76: 69-70.

Rogers J, Laurberg S, Misiewicz JJ, Henry MM, Swash M. Anorectal physiology validated: a repeatability study of the motor and sensory tests of anorectal function. *Br J Surg* 1989; 76: 607-609.

Stone JM, Nino-Murcia M, Wolfe VA, Perkas I. Chronic gastrointestinal problems in spinal cord injury patients: a prospective analysis. *Am J Gastroenterol* 1990; 84: 1114-1119.

Thompson WG, Longstreth GF, Drossman DA, Heaton KW, Irvine EJ, Muller-Lissner SA. Functional bowel disorders and functional abdominal pain. *Gut* 1999; 45 (Suppl II): II43-II47.

Vaizey CJ, Carapeti E, Cahill JA, Kamm MA. Prospective comparison of faecal incontinence grading systems. *Gut* 1999; 44: 77-80.

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VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD

COMMENTS: As the collection of data on Bowel Function may be carried out at any time since SCI, the date of data collection is imperative to compute time since injury and to identify the data collected in relation to other data collected on the same individual at various time points.

VARIABLE NAME: Duration of constipation

DESCRIPTION: This variable documents the duration of constipation

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

COMMENTS: Functional constipation is usually defined according to the Rome II (Thompson 1999) or Rome III (Drossman 2006) criteria. Accordingly, within a specified period of time individuals should report at least one of the following: straining > ¼ of defecations, lumpy or hard stools > ¼ of defecations, sensation of incomplete evacuation > ¼ of defecations, sensation of anorectal obstruction/blockade > ¼ of defecations, manual maneuvers to facilitate defecation > ¼ defecations, or < 3 defecations per week. The Rome criteria have not been specifically developed for individuals with SCI. However, in this data set they are used to define the term constipation.

In most individuals with SCI the duration of constipation is equal to the time since SCI. However, constipation related symptoms may become more severe with time after SCI and some individuals may develop constipation years later. The code “Not applicable” is mainly for individuals with stomas. This variable is necessary to compute the CCS.

VARIABLE NAME: Unsuccessful attempts at defecation (within the last three months)

DESCRIPTION: This variable documents the average number of daily unsuccessful attempts at defecation within the last three months

CODES: 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

COMMENTS: Unsuccessful attempt at defecation is a common sign of obstructed defecation. To be considered as one attempt the bowel emptying procedure should be separated from the previous bowel emptying procedure by some other activity. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the CCS.

VARIABLE NAME: Incomplete rectal emptying after defecation (within the last three months)

DESCRIPTION: This variable documents the presence of any sense of incomplete rectal emptying after defecation within the last three months

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

COMMENTS: A sense of incomplete rectal emptying after defecation is a common sign of obstructed defecation. Most individuals with complete SCI do not have any subjective sense of rectal filling. In such cases the code “Never” and not the code “Unknown” should be used. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the CCS.

VARIABLE NAME: Abdominal bloating (within the last three months)

DESCRIPTION: This variable documents the presence of abdominal bloating within the last three months

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
Unknown

COMMENTS: Abdominal bloating is a common symptom in chronic constipation and other motility disorders. In this data set bloating is either a subjective feeling of excessive intraabdominal gas or visible/palpable abdominal distension due to gas. In spite of severe constipation, some individuals with high complete lesions may not feel abdominal bloating. In such cases the code “Never” and not the code “Unknown” should be used. This variable is included in the CCS.

VARIABLE NAME: Abdominal pain/discomfort (within the last three months)

DESCRIPTION: This variable documents the presence of abdominal pain or discomfort within the last three months

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
Unknown

COMMENTS: Abdominal pain or discomfort is a common symptom in individuals with SCI but also in chronic constipation or irritable bowel syndrome. It should be documented separately from abdominal bloating and perianal symptoms covered by those specific variables. In some individuals abdominal pain is an indirect signal of the need to defecate. In such cases it is covered both by that specific variable in the Bowel Function Basic SCI Data Set and here. In subjects unable to feel abdominal pain the term “Never” should be used. The variable is included in the CCS.

VARIABLE NAME: 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)

DESCRIPTION: This variable documents any respiratory discomfort due to distended abdomen within the last three months

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

COMMENTS: Due to a distended abdomen constipation and bloating may cause or contribute to respiratory discomfort. This is defined as a feeling of shortness of breath or difficulty in taking a deep breath entirely or partly due to a distended abdomen. Accordingly, subjects do not have to be able to clearly differentiate between bowel versus other causes of respiratory discomfort. However, respiratory symptoms entirely due to higher level SCI are not included in this variable.

VARIABLE NAME: Perianal pain during defecation (within the last three months)

DESCRIPTION: This variable documents the presence of perianal pain during defecation within the last three months

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

COMMENTS: Perianal pain during defecation is a common sign of difficult bowel evacuation. Most individuals with complete SCI are unable to feel perianal pain during defecation. In such cases the code "Never" and not the code "Unknown" should be used. Indirect indicators of perianal pain during defecation such as perspiration, spasms or headache are not registered here. The code "Not applicable" is mainly for individuals with stomas. This variable is included in the CCS.

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

DESCRIPTION: This variable documents the frequency of flatus incontinence within the last three months

CODES: 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

COMMENTS: Flatus incontinence is defined as involuntary passage of flatus. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the SMS, WS and NBD.

VARIABLE NAME: Frequency of fecal incontinence to *liquid* stools (within the last three months)

DESCRIPTION: This variable documents frequency of fecal incontinence to *liquid* stools within the last three months

CODES: 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

COMMENTS: Fecal incontinence is defined as involuntary passage of stools. It has profound influence on quality of life and may cause severe restriction on social activities. If the individual has not had liquid stools within the last three months the code “Never” and not the code “Unknown” should be used. In individuals with episodes of fecal incontinence to liquid stools before the last three months without any episodes within in the last three months the code “Never” and not the code “Less than once per month” be should used. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the SMS and WS.

VARIABLE NAME: Frequency of fecal incontinence to *solid* stools (within the last three months)

DESCRIPTION: This variable documents frequency of fecal incontinence to *solid* stools within the last three months

CODES: 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

COMMENTS: Fecal incontinence is defined as involuntary passage of stools. It has profound influence on quality of life and may cause severe restriction on social activities. In individuals with episodes of fecal incontinence to solid stools before the last three months without any episodes within the last three months the code “Never” and not the code “Less than once per month” should be used. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the SMS and WS.

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

DESCRIPTION: This variable documents the ability to defer defecation for 15 minutes or more within the last three months

CODES: Yes
No
Not applicable
Unknown

COMMENTS: Inability to defer defecation may cause fecal incontinence and restrict social activities. The code “Not applicable” is mainly for individuals with stomas or individuals without sensation of need to defecate. This variable is included in the SMS.

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

DESCRIPTION: This variable documents the position for bowel care used within the last three months

CODES: Bed
Toilet chair/Commode
Raised toilet seat
Conventional toilet
Other, specify _____
Unknown

COMMENTS: The position for bowel care is important for bowel management. Whenever appropriate more than one code could be used for the same individual. If the individual uses a stoma, then it is to be specified under "Other".

VARIABLE NAME: Degree of independence during bowel management (within the last three months)

DESCRIPTION: This variable documents the degree of independence during bowel management within the last three months

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

COMMENTS: The degree of independence during bowel management is important to most individuals with SCI. The codes used are identical to those used in the Spinal Cord Independence Measure III (SCIM III) (Catz 2007).

VARIABLE NAME: Bowel care facilitators (within the last three months)

DESCRIPTION: This variable documents the use of bowel care facilitators practiced regularly within the last three months

CODES: Digital stimulation or evacuation
Abdominal massage
Gastrocolonic response
Other, specify: _____
None
Unknown

COMMENTS: Individuals with SCI may use a number of maneuvers to facilitate bowel care. Digital ano-rectal stimulation is digital triggering of rectal contractions and anal relaxation and thus rectal emptying. Digital evacuation is the need to dig out stools with a finger. Though the effect is not validated, abdominal massage is recommended by some to improve colorectal transit. The gastrocolonic response stimulates colorectal motility after the intake of a meal. It remains after SCI and many individuals with SCI use it by performing bowel care shortly after breakfast.

VARIABLE NAME: Events and intervals of defecation (1): Average time from initiation of bowel care to first stool coming out (within the last three months)

DESCRIPTION: This variable documents the time from initiation of bowel care to first stool coming out within the last three months

CODES: _____minute(s)
Not applicable
Unknown

COMMENTS: This variable is an attempt to describe the time spent at bowel care in more detail than just total time spent at defecation (House 1997). The code given in minutes is based on each individual's own assessment of average time consumption. The code "Not applicable" can be used by some individuals with stomas.

VARIABLE NAME:	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)
DESCRIPTION:	This variable documents 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
CODES:	_____minute(s) Not applicable Unknown
COMMENTS:	This variable is an attempt to describe the time spent at bowel care in more detail than just total time spent at defecation (House 1997). It begins at the end of the previous variable. The code given in minutes is based on each individuals own assessment of time consumption.
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VARIABLE NAME:	Events and intervals of defecation (3): Time spent waiting after last stool passes before ending bowel care (within the last three months)
DESCRIPTION:	This variable documents time spent waiting after last stool passes before ending bowel care within the last three months
CODES:	_____minute(s) Not applicable Unknown
COMMENTS:	This variable is an attempt to describe the time spent at bowel care in more detail than just total time spent at defecation (House 1997). It begins at the end of the previous variable. The code given in minutes is based on each individuals own assessment of time consumption. End of bowel care is defined as end of dressing. If this is not applicable end of bowel care is end of clean-up.
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VARIABLE NAME: Lifestyle alteration due to anal incontinence (within the last three months)

DESCRIPTION: This variable documents lifestyle alterations due to *anal incontinence* within the last three months

CODES: 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

COMMENTS: Anal incontinence covers fecal incontinence and flatus incontinence. This variable only covers altered lifestyle due to anal incontinence or the risk of anal incontinence. Examples may be by avoidance of social activities, traveling, sexual activities etc. The code “Not applicable” is mainly for individuals with stomas. This variable is included in the SMS and WS.

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

DESCRIPTION: This variable documents lifestyle alterations due to *constipation* within the last four weeks

CODES: 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
Lifestyle not altered
Not applicable
Unknown

COMMENTS: This variable only covers altered lifestyle due constipation related symptoms including difficult bowel evacuation. Examples may be by avoidance of social activities, traveling etc.

VARIABLE NAME: Self reported impact on quality of life caused by neurogenic bowel dysfunction

DESCRIPTION: This variable documents self reported impact on quality of life caused by neurogenic bowel dysfunction

CODES: Major impact
Some impact
Little impact
No impact
Unknown

COMMENTS: Self reported impact on quality of life caused by neurogenic bowel dysfunction covers the subjects own assessment of the impact of all aspects of neurogenic bowel dysfunction. This parameter is important for any choice of treatment modality.

VARIABLE NAME: Anal tone

DESCRIPTION: This variable documents anal tone

CODES: Normal
Reduced
Excessive
Not tested
Not applicable

COMMENTS: Digital examination of anal tone mainly provides information about the anal resting pressure. Under normal circumstances it is estimated that the internal anal sphincter muscle, consisting of smooth muscle cells, contributes with 55-85% of the anal resting pressure. The rest is from the striated external anal sphincter muscle and the pressure within the hemorrhoidal plexus (Lestar 1989). Sympathetic innervation is believed to increase the tone of the external anal sphincter. Accordingly, anal resting pressure is generally lower in individuals with spinal cord lesions at or above L2 than in those with lower lesions. However, spasms of the striated external anal sphincter muscle may cause an excessively high pressure. The resting anal pressure is very variable between individuals (Pedersen 1989 & Rogers 1989) and the reproducibility and validity of digital anal examination of individuals with SCI remains to be tested. Accordingly, this variable depends on the subjective assessment of the examiner and only three options are given for this. Evidence suggests that the amplitude of rectoanal inhibitory reflex mediating relaxation of the internal anal sphincter muscle during stretch of the rectal wall is affected by the level of SCI. Therefore, it is

recommended that the tone of the anal canal is evaluated before and not after digital examination of the rectum is performed.

The code “Not applicable” is used if e.g. anus is surgically closed.

VARIABLE NAME:	Voluntary contraction of the anal canal
DESCRIPTION:	This variable documents voluntary contraction of the external anal sphincter
CODES:	Yes No Not tested Not applicable
COMMENTS:	Digital evaluation of voluntary contraction of the anal canal is an assessment of the voluntary function of the external anal sphincter muscle. The comments about intersubjective variation and validity of the examination given above are also true for this variable. Accordingly, it is only assessed whether there is voluntary contraction of the anal canal or not. Voluntary anal contraction may be confused with spasms or reflex activity of the external anal sphincter muscle. Accordingly, it is recommended to ask the subject to contract the anal canal two times or more during the examination. The code “Not applicable” is used if e.g. anus is surgically closed.

VARIABLE NAME:	Total Gastrointestinal or Colonic Transit Time
DESCRIPTION:	This variable documents Total Gastrointestinal or Colonic Transit Time assessed by means of radioopaque markers
CODES:	_____ (days - hours) Not tested
COMMENTS:	Total gastrointestinal and colonic transit times are prolonged in many individuals with SCI. Transit time through the stomach and small intestine is usually just a few hours. Colonic transit time is, however, much longer. Some authors present transit times as total gastrointestinal transit time and others prefer colonic transit time. Unless multiple x-rays are taken the most correct term is total gastrointestinal transit time. Generally, transit time is prolonged throughout the colon in individuals with supraconal SCI. In contrast individuals with conal or cauda equina lesions often have severely prolonged rectosigmoid or left colonic transit

times. The intrasubjective variation remains to be studied and due to poor correlations between total gastrointestinal /colonic transit time and colorectal symptoms after SCI the clinical relevance of transit time measurement has been questioned (Leduc 2002). Future studies are needed to clarify this.

Several types of radiopaque markers and protocols for determining total gastrointestinal and colonic transit times exist. However, no evidence exists to recommend one from the others.

The code Unknown is used if the transit time is not determined.

VARIABLE NAME: Right Colonic Transit Time

DESCRIPTION: This variable documents transit time of the caecum, ascending- and transverse colon assessed by means of radioopaque markers

CODES: _____ (days - hours)

Not tested

COMMENTS: The physiology and innervation of the right colon (caecum, ascending colon and oral 2/3 of the transverse colon) is different from that of the left colon (splenic flexure, descending colon, and rectosigmoid). The right colon is mainly for storage and absorption and receives its parasympathetic innervation from the vagal nerve. The left colon is mainly a transit organ for defecation at receives its parasympathetic innervation from the sacral segments (S2-S4) of the spinal cord. Accordingly, colonic transit time is usually divided into right and left. Whether this is of clinical significance in SCI remains to be determined.

The code Not tested is used if the transit time is not determined.

VARIABLE NAME: Left Colonic Transit Time

DESCRIPTION: This variable documents transit time of the descending colon (including the splenic flexure) and the rectosigmoid assessed by means of radioopaque markers

CODES: _____ (days - hours)

Not tested

COMMENTS: Same comments as for right colonic transit time.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION EXTENDED SCI DATA SET (Version 1.0) – DATA FORM

Date of data collection: YYYYMMDD Unknown

Duration of constipation:

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):

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):

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):

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):

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			
	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):

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):

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):

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):

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):

Yes No Not applicable Unknown

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

Bed Toilet chair/Commode Raised toilet seat
 Conventional toilet Other, specify _____ Unknown

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

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

Bowel care facilitators (within the last three months):

Digital stimulation or evacuation Abdominal massage
 Gastrocolonic response Other, specify: _____
 None Unknown

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

_____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):

_____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):

_____minute(s)
 Not applicable Unknown

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

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):

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:

Major impact	Some impact	Little impact	No impact
Unknown			

To be collected after physical examination:**Anal tone:**

Normal	Reduced	Excessive	Not tested	Not applicable
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Voluntary contraction of the anal canal:

Yes	No	Not tested	Not applicable
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To be collected after X-ray investigation:**Total Gastrointestinal or Colonic Transit Time:**

_____ days _____ hours	Not tested
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Right Colonic Transit Time:

_____ days _____ hours	Not tested
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Left Colonic Transit Time:

_____ days _____ hours	Not tested
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APPENDIX

A. The “Skt. Mark’s” score for fecal incontinence (SMS)

	Never	Rarely	Sometimes	Weekly	Daily
Incontinence for solid stool	0	1	2	3	4
Incontinence for liquid stool	0	1	2	3	4
Incontinence for gas	0	1	2	3	4
Alteration in lifestyle	0	1	2	3	4
				No	Yes
Need to wear a pad or plug				0	2
Taking constipating medicine				0	2
Lack of ability to defer defecation for 15 minutes				0	4

Never: No episodes in the past four weeks.

Rarely: One episode in the past four weeks.

Sometimes: >1 episode in the past four weeks but < 1 a day.

Weekly: 1 or more episode a week but < 1 a day.

Daily 1 or more episodes a day.

The Wexner score (Jorge et al. 1993) is not shown but is very similar to the Skt. Mark’s score.

B. The “Cleveland Constipation Score” (CCS)

The number of points for each possible answer is given in parenthesis.

Points are added to compute total score

1). Frequency of defecation

More than twice a week (0) Twice a week (1) Once a week (2) Less than once a week (3)
 Less than once a month (4)

2). Perianal pain during defecation

Never (0) Less than once per month (1) 1-4 times per month (2)
 More than once per week but not daily (3) Daily (4)

3). Incomplete rectal emptying at defecation

Never (0) Less than once per month (1) 1-4 times per month (2)
More than once per week but not daily (3) Daily (4)

4). Abdominal pain

Never (0) Less than once per month (1) 1-4 times per month (2)
More than once per week but not daily (3) Daily (4)

5). Average time spent at each defecation

5 minutes or less (0) 6-10 minutes (1) 11-20 minutes (2) 21-30 minutes (3)
More than 30 minutes (4)

6). Number of daily unsuccessful attempts at defecation

None (0) 1-3 (1) 4-6 (2) 7-9 (3) 10 or more (4)

7). Abdominal bloating

Never (0) Less than once per month (1) 1-4 times per month (2)
More than once per week but not daily (3) Daily (4)

8). Assisted defecation

Without assistance (0) Stimulative laxatives (1) Digital assistance or enema (2)

9). Duration of constipation

Less than a year (or no constipation) (0) 1-5 years (1) 6-10 years (2) 11-20 years (3)
More than 20 years (4)

C. The Neurogenic Bowel Dysfunction Score (NBD)

The number of points for each possible answer is given in parenthesis.

Points are added to compute total score

1). Frequency of defecation

Daily (0) 2-6 times every week (1) Less than once a week (6)

2). Time used for each defecation

0-30 minutes (0) 31-60 minutes (3) More than one hour (7)

3). Uneasiness, headache or perspiration during defecation

No (0) Yes (2)

4). Regular use of tablets against constipation

No (0) Yes (2)

5). Regular use of drops against constipation

No (0) Yes (2)

6). Digital stimulation or evacuation of the anorectum

Less than every week (0) Once or more every week (6)

7). Frequency of fecal incontinence

< Once every month (0) 1-4 times every month (6) 1-6 times every week (7) Daily (13)

8). Medication against fecal incontinence

No (0) Yes (4)

9). Flatus incontinence

No (0) Yes (2)

Perianal skin problems

No (0) Yes (3)

NBD score:

0-6: Very minor bowel dysfunction
7-9: Minor bowel dysfunction
10-13: Moderate bowel dysfunction
14 or more: Severe bowel dysfunction