

## **INTERNATIONAL SPINAL CORD INJURY LOWER URINARY TRACT FUNCTION BASIC DATA SET (version 2.0)**

**The first version of the International Spinal Cord Injury Lower Urinary Tract Function Basic Data Set** (Biering-Sørensen F et al. 2008) was developed by Fin Biering-Sørensen, Michael Craggs, Michael Kennelly, Erik Schick, and Jean-Jacques Wyndaele.

**The current revision of the International Spinal Cord Injury Lower Urinary Tract Function Basic Data Set** was performed by Fin Biering-Sørensen (chair), Michael Kennelly, Thomas M. Kessler, Todd Linsenmeyer, Jürgen Pannek, Lawrence Vogel, and Jean-Jacques Wyndaele.

**The International Spinal Cord Injury Lower Urinary Tract Function Basic Data Set (version 2.0) has been endorsed by the American Spinal Injury Association and the International Spinal Cord Society.**

**Questions and suggestions** regarding the International Spinal Cord Injury Lower Urinary Tract Function Basic Data Set should be directed to Fin Biering-Sørensen: [fin.biering-soerensen@regionh.dk](mailto:fin.biering-soerensen@regionh.dk) or Jürgen Pannek: [juergen.pannek@paranet.ch](mailto:juergen.pannek@paranet.ch).

Collection of data on lower urinary tract function is universal when individuals with spinal cord lesions consult doctors with knowledge regarding spinal cord lesions.

The purpose of the Lower Urinary Tract Function Basic Data Set for Spinal Cord Injury (SCI) individuals is to standardize the collection and reporting of a minimum amount of information on the lower urinary tract (LUT) in daily clinical practice in accordance with the purpose and vision of the International SCI Data Sets (Biering-Sørensen et al. 2006). This will also make it possible to evaluate and compare results from various published studies.

The data in this International SCI LUT Function Basic Data Set generally will be used with data in the International SCI Core Data Set (Version 2.0) (Biering-Sørensen et al. 2017), which includes information on date of birth and injury, gender, the cause of spinal cord lesion, and neurologic status. In addition, the Core Data Set contains information on: if a vertebral injury was present, spinal surgery was performed in relation to a traumatic injury, associated injuries were present, if the patient with spinal cord lesion was ventilator-dependent at the time of discharge from initial inpatient care, and the place of discharge from initial inpatient care. Other related International SCI Data Sets are the International SCI Urinary Tract Infection Basic Data Set (Goetz et al. 2013), the International SCI Urodynamic Basic Data Set (Biering-Sørensen et al. 2008 – being updated), and the International SCI Urinary Tract Imaging Basic Data Set (Biering-Sørensen et al. 2009).

A spinal cord lesion may be traumatic or non-traumatic in aetiology. All lesions to the spinal cord, conus medullaris, and cauda equina are included in the present context.

It is extremely important that data be collected in a uniform manner. For this reason, each variable and each response category within each variable has been defined to promote the collection and reporting of comparable minimal data.

Use of a standard format is essential for combining data from multiple investigators and locations. Various formats and coding schemes may be equally effective and could be used in individual studies or by agreement of the collaborating investigators.

## **Revisions to the International Spinal Cord Injury Lower Urinary Tract Basic Data Set – Version 2.0**

The International SCI LUT Basic Data Set Version 1.0 has been the accepted standard for collecting minimal clinical data relevant for bladder management for individuals with spinal cord lesions. All International SCI Data Sets undergo periodic review to ensure continued relevance, acceptance and usage by the SCI clinical/research community. In 2016, the International SCI Data Sets Committee proposed review of the International SCI LUT Basic Data Set. In 2016, the International SCI Data Sets were reviewed to ensure they are relevant for pediatric SCI and some revisions to the syllabus were recommended. When reviewing proposed revisions, the Working Group weighed the potential benefits of the proposal against the loss of continuity resulting from any revision. These changes, apart from minor corrections, are summarized in the ensuing narrative, followed by the revised syllabus and data collection form Version 2.0.

### **List of specific revisions incorporated into the International SCI LUT Function Basic Data Set Version 2.0**

1. The International Continence Society has made an update on the terminology for adult neurogenic lower urinary tract dysfunction (Gajewski et al. 2018). As a consequence the wording of the comments are adjusted for the following variables: ‘Awareness of the need to empty the bladder’, ‘Bladder emptying’, ‘Any involuntary urine leakage (urinary incontinence) within the last four weeks’, and ‘Any change in lower urinary tract symptoms within the last year.’
2. For the pediatric age groups, for most variables it has been stated: “This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily by parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).”
3. For the variable “Awareness of the need to empty the bladder” to the item “Not applicable” comments have been added: “as well as for children younger than 3 years”. Further, the comments text for the pediatric population is slightly different. “This variable is appropriate for all pediatric age groups older than 3 years. If collecting information from pediatric patients, parents are the primary source of report for 3-5; and self-report primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).”
4. For the variable “Bladder emptying”, added in the data collection form to the response category ‘Normal voiding’ is: ‘Voluntary initiation of micturition without reflex stimulation or compression of the bladder. This does not presume entirely normal function’ to ensure that the data collector is aware of this fact. In addition, *Sacral Anterior Root Stimulator (SARS)* is now so rare there is no need for a separate response category, i.e. if used it should be mentioned under the response category “Other method, specify...”. Finally, for

*Non-continent urinary diversion/ostomy*, ileoureterostomy, ileal loop, and ileal conduit have been included to be consistent with wording used in the urological literature.

5. For the variable “Average number of voluntary bladder emptyings per 24 hours during the last week” ‘per day’ has been replaced by ‘per 24 hours’ to specify it to mean day and night, i.e. 24 hours. In addition, “Not applicable” was introduced for individuals using an indwelling catheter, and “Unknown” was introduced as someone like a child or an adult who wear diapers/nappies/incontinence briefs may not be aware of the number of bladder emptyings.
6. For the variable “Any involuntary urine leakage (urinary incontinence) within the last four weeks” ‘last four weeks’ has replaced ‘last three months’ to align this dataset with the time frame consistent across the various International SCI Data Sets. In addition, the response categories have been adjusted to: “Daily”, “Once or more per week (but not daily)”, “Less than once per week”, “Never”, “Not applicable” and “Unknown”.
7. For the variable “Any drugs for the urinary tract within the last four weeks” ‘last four weeks’ has replaced ‘last year’ since it is hard to reliably recall such a long time period and to align this dataset with the time frame consistent across the various International SCI Data Sets. In addition, antimuscarinics, have been added to the bladder relaxant drugs. Further it is specifically written into the data collection form that intradetrusor or intrasphincter injections are not included here.
8. For the variable “Surgical procedures on the urinary tract” ‘Sacral Anterior Root Stimulator (SARS)’ has been removed as it is so rarely implanted now that it was not found to be justified as a separate response category, i.e. if used should be mentioned under the response category “Other method, specify...”. In addition, to the response category ‘ileoureterostomy’ (ileal conduit) has been included to be consistent with the most common wording used in the urological literature.

#### Acknowledgements:

Comments and suggestions for version 2.0 of the International SCI LUT Function Data Set were received from Meier Sonja, Susan Charlifue, Eva Widerström-Noga, Lyn Jakeman, Marcel Post, Vanessa Noonan, and Thomas Bryce.

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD  
Unknown

COMMENTS: The collection of data on lower urinary tract function may be carried out at any time after the spinal cord lesion.  
Recording the date of data collection is imperative to associate the data collected to other data collected on the same individual at various time points. In addition, the date is important for calculating the time interval from date of birth (age), and time interval from date of lesion (time since lesion).

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VARIABLE NAME: Urinary tract impairment unrelated to spinal cord lesion

DESCRIPTION: This variable documents any type of urinary tract impairment unrelated to the spinal cord lesion on the date of data collection.

CODES: No  
Yes, specify \_\_\_\_\_  
Unknown

COMMENTS: To be able to evaluate the lower urinary tract function in an individual with spinal cord lesion it is necessary to know if there are any other urinary tract impairments unrelated to the spinal cord lesion.  
If there have been any urinary tract impairments unrelated to the spinal cord lesion this/these is/are recommended to be written in a text-field, from which it will be possible to retrieve more detailed data when necessary. Because many possible urinary tract impairments exist, it is not practical to give an exact list of impairments.  
If this information has been documented once and no additional urinary tract impairments unrelated to the spinal cord lesion have been identified it is only necessary fill in this item once, to avoid redundant data.  
This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional)

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VARIABLE NAME: Awareness of the need to empty the bladder

DESCRIPTION: This variable documents awareness of the need to empty the bladder on the date of data collection.

CODES: No  
Yes  
Not applicable  
Not known

COMMENTS: Awareness of the need to empty the bladder indicates **any** kind of bladder sensation as defined by International Continence Society (Abrams et al. 2002, Gajewski et al. 2018), i.e. *normal sensation* (awareness of bladder filling and increasing sensation up to a strong desire to void), *reduced sensation* (definite desire to void occurs later to that previously experienced despite an awareness that the bladder is filling), *increased bladder sensation* (the desire to void during bladder filling occurs earlier or is more persistent to that previous experienced. This differs from urgency by the fact that micturition can be postponed despite the desire to void), *abnormal sensation* (characterized by e.g. “tingling”, “burning”, or “electric shock”), or *non-specific bladder awareness* (perceive bladder filling as abdominal fullness, vegetative symptoms like sweating (as part of autonomic dysreflexia) urethral sensations or spasticity) (Abrams et al. 2002, Gajewski et al. 2018).  
No awareness of the need to empty the bladder should be noted as “no”. *Absent bladder sensation*, according to the definition of bladder sensation by the International Continence Society, i.e. the individual reports no sensation of bladder filling or desire to void (Abrams et al. 2002, Gajewski et al. 2018).  
“Not applicable” is to be used when the individual with spinal cord lesion has, for example, an unclamped indwelling catheter or non-continent urinary diversion.  
This variable is appropriate for all pediatric age groups older than 3 years. If collecting information from pediatric patients, parents are the primary source of report for 3-5; and self-report primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).” However, for very young children (birth- to 3 years) this variable is “Not applicable”.

VARIABLE NAME: Bladder emptying

DESCRIPTION: This variable documents the method(s) used to empty the bladder on the date of data collection.

CODES: Normal voiding – Main method  
Normal voiding – Supplementary method  
Bladder reflex triggering, Voluntary – Main method  
Bladder reflex triggering, Voluntary – Supplementary method

Bladder reflex triggering, Involuntary – Main method  
 Bladder reflex triggering, Involuntary – Supplementary method  
 Bladder expression, Straining – Main method  
 Bladder expression, Straining – Supplementary method  
 Bladder expression, External compression – Main method  
 Bladder expression, External compression – Supplementary method  
 Intermittent catheterisation, Self-catheterisation – Main method  
 Intermittent catheterisation, Self-catheterisation – Supplementary method  
 Intermittent catheterisation, Catheterisation by attendant – Main method  
 Intermittent catheterisation, Catheterisation by attendant – Supplementary method  
 Indwelling catheter, Transurethral – Main method  
 Indwelling catheter, Transurethral – Supplementary method  
 Indwelling catheter, Suprapubic – Main method  
 Indwelling catheter, Suprapubic – Supplementary method  
 Non-continent urinary diversion/ostomy – Main method  
 Non-continent urinary diversion/ostomy – Supplementary method  
 Other method, specify \_\_\_\_\_ – Main method  
 Other method, specify \_\_\_\_\_ – Supplementary method  
 Unknown

**COMMENTS:**

For each method of bladder emptying, indicate whether this is a main or a supplementary method. Two main and one or more supplementary methods may be indicated (adopted from Levi and Ertzgaard 1998).

*Normal voiding:* Voluntary initiation of micturition without reflex stimulation or compression of the bladder. This does not presume entirely normal function (Levi and Ertzgaard 1998).

*Bladder reflex triggering* comprises various manoeuvres performed by the individual with spinal cord lesion or an attendant in order to elicit reflex detrusor contraction by exteroceptive stimuli. The most commonly used manoeuvres are suprapubic tapping, thigh scratching and anal/rectal manipulation (Abrams et al. 2002).

*Voluntary* bladder reflex triggering indicates that the bladder reflex is triggered by the individual with spinal cord lesion him/herself or by the attendant.

*Involuntary* bladder reflex triggering implies that there is no voluntary triggering of the voiding, but the individual with spinal cord lesion allows the urine to pass by itself when the reflex detrusor contraction occurs.

*Bladder expression* comprises various manoeuvres aimed at increasing intravesical pressure in order to facilitate bladder emptying. The most commonly used manoeuvres are abdominal straining, Valsalva's manoeuvre and external manual suprapubic pressure (Credé manoeuvre) (Abrams et al. 2002, Gajewski et al. 2018). *Straining* includes abdominal straining, Valsalva's manoeuvre.

*External compression* includes Credé manoeuvre.

*Catheterisation* is a technique for bladder emptying employing a catheter to drain the bladder or urinary reservoir (Abrams et al. 2002).

*Intermittent catheterisation* is by the International Continence Society defined as drainage of the bladder or a urinary reservoir with subsequent removal of the catheter mostly at regular intervals (Gajewski et al. 2018).

In the International SCI LUT Function Basic Data Set the following types of intermittent catheterisation can be reported:

*Intermittent self-catheterisation* is performed by the individual himself/herself.

*Intermittent catheterisation* can also be performed by an *attendant* (e.g. family member or personal aid).

This means there will not be distinguished between the techniques used and defined by the International Continence Society, i.e. Clean, Aseptic, Sterile or No-touch technique intermittent catheterization (Gajewski et al. 2018).

*Indwelling catheterisation*: an indwelling catheter remains in the bladder, urinary reservoir or urinary conduit for a period longer than one emptying (Abrams et al. 2002, Gajewski et al. 2018).

In the International SCI LUT Function Basic Data Set the following types of indwelling catheterisation can be reported:

*Transurethral indwelling catheterisation* indicates that the urine is drained through a catheter placed in the urethra.

*Suprapubic indwelling catheterisation* indicates that the urine is drained through a catheter via the abdominal wall.

*Non-continent urinary diversion/ostomy*: This includes ureteroileocutaneostomy (ileoureterostomy, ileal loop, Bricker conduit, ileal conduit), ileovesicostomy, vesicostomy.

*Other method*, specify \_\_\_\_\_

If any other method is used for bladder emptying it is recommended to be written in a text-field, from which it will be possible to retrieve more detailed data when necessary. Because other methods of bladder emptying, including sacral anterior root stimulators, are generally rare, it is not practical to give an inclusive list of bladder emptying methods.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

**VARIABLE NAME:** Average number of voluntary bladder emptyings per 24 hours during the last week

**DESCRIPTION:** This variable documents the average number of voluntary bladder emptyings per 24 hours during the last week

**CODES:** Number

Not applicable

Unknown

**COMMENTS:** The average number of voluntary bladder emptying per 24 hours during the last week is given separately. This number refers to the number of voluntary bladder emptyings irrespective of the method. Any of the following methods may be used separately or in combination: normal voiding, voluntary bladder reflex triggering, bladder expression, intermittent catheterization, or others. If a combination of methods is used during the same bladder emptying it should be counted as only one bladder emptying. The number is given as an average for the last week, as the individual is not expected to remember this for a longer period of time. The number is given as the nearest integer number.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

“Not applicable” is to be used for individuals using an indwelling catheter.

“Unknown” may be used if someone such as a child or an adult who wears diapers/nappies/incontinence briefs is not aware of the number of bladder emptyings.

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**VARIABLE NAME:** Any involuntary urine leakage (urinary incontinence) within the last four weeks

**DESCRIPTION:** This variable documents the average involuntary urine leakage (urinary incontinence) within the last four weeks prior to the date of data collection.

**CODES:**

- Daily
- Once or more per week (but not daily)
- Less than once per week
- Never
- Not applicable
- Unknown

**COMMENTS:** Urinary incontinence is defined by the International Continence Society (Abrams et al. 2002, Gajewski et al. 2018) as the **complaint** of involuntary loss of urine. In each specific circumstance the urinary incontinence should be further described by specifying relevant factors such as type (Stress, Urgency, Mixed incontinence or Enuresis), frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life, etc. (Abrams et al. 2002, Gajewski et al. 2018). In the International SCI LUT Function Basic Data Set only a simple indication of severity and collection of urine is given.

Bladder reflex triggering including into a collection system, e.g. condom catheter may be voluntary and thus not considered as incontinence. However, if the condom

or ostomy bag falls off and the individual **complains** of incontinence then it should be recorded as “Yes”.

Involuntary urine leakage (urinary incontinence) within the last four weeks implies leakage of urine outside the urinary tract or a closed urinary collection system.

“Not applicable” may be used when the individual has, for example, a non-continent urinary diversion.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

**VARIABLE NAME:** Collecting appliances for urinary incontinence.

**DESCRIPTION:** This variable documents use of any collecting appliances for urinary incontinence on the date of data collection.

**CODES:**

- No
- Yes, condom catheter/sheath
- Yes, diaper/pad
- Yes, ostomy bag
- Yes, other, specify \_\_\_\_\_
- Unknown

**COMMENTS:** Collecting appliances are any externally applied aids to avoid urinary leakage, or devices for collection of urine. Regular use of one or more collecting appliances is to be recorded. Individuals that use such appliances less than once a month, “for the sake of safety”, and who have no more than exceptional episodes of leakage during a year should be coded as “No” (adapted from Levi and Ertzgaard 1998). For other possible collecting appliances it is recommended to write them in a text-field, from which it will be possible to retrieve more detailed data when necessary. This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

**VARIABLE NAME:** Any drugs with possible influence on the urinary tract within the last four weeks.

**DESCRIPTION:** This variable documents use of any drugs, systemic or intravesical, with possible influence on the urinary tract within the last four weeks on the date of data collection.

- CODES:**
- No
  - Yes, bladder relaxant drugs (antimuscarinics, anticholinergics, tricyclic antidepressant, etc. (not intradetrusor injections))
  - Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc. (not intrasphincter injections))
  - Yes, antibiotics/antiseptics
    - For treatment of urinary tract infection
    - For prophylactic reasons
  - Yes, other, specify \_\_\_\_\_
  - Unknown
- COMMENTS:**
- Bladder relaxant drugs, i.e. drugs causing relaxation of the detrusor, include antimuscarinics, anticholinergics, tricyclic antidepressant, etc. These drugs may also be delivered intravesically. This does not include treatment with injections into the detrusor.
- Sphincter and bladder neck relaxant drugs include alpha adrenergic blockers, etc. This does not include treatment with injections into the sphincter.
- Antibiotics and antiseptics used for treatment or prophylaxis of urinary tract infections are coded separately. For prevention of urinary tract infections, drugs such as methenamine are included. For other possible drugs, it is recommended to write them in a text-field, from which it will be possible to retrieve more detailed data when necessary.
- This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

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**VARIABLE NAME:** Surgical procedures on the urinary tract.

**DESCRIPTION:** This variable documents any surgical procedures on the urinary tract up to the date of data collection. If more than one procedure of the same kind has been performed only the last one is documented with date of performance.

- CODES:**
- No
  - Yes, supra-pubic catheter insertion, date last performed YYYYMMDD
  - Yes, bladder stone removal, date last performed YYYYMMDD
  - Yes, upper urinary tract stone removal, date last performed YYYYMMDD
  - Yes, bladder augmentation, date last performed YYYYMMDD
  - Yes, sphincterotomy/urethral stent, date last performed YYYYMMDD
  - Yes, botulinum toxin injection into the detrusor, date last performed YYYYMMDD
  - Yes, artificial sphincter, date last performed YYYYMMDD
  - Yes, ileovesicostomy, date last performed YYYYMMDD
  - Yes, ileoureterostomy (ileal conduit), date last performed YYYYMMDD

Yes, continent catheterizable valves, date last performed YYYYMMDD  
 Yes, other, specify \_\_\_\_\_, date performed YYYYMMDD  
 Unknown

**COMMENTS:** Bladder stone or upper urinary tract stone removal includes any type of removal, including via endoscopy, extracorporeal shock wave lithotripsy (ESWL), or open lithotomy.  
 The ileoureterostomy (ileal conduit) is the same as ileal loop or ureteroileocutaneostomy (Bricker conduit).  
 The continent catheterizable valves, include the Monti and the Mitrofanoff procedures.  
 For other possible surgical procedures, including sacral anterior stimulator, it is recommended to write them in a text-field, from which it will be possible to retrieve more detailed data when necessary. If there is more than one “other” surgical procedure, this field may be duplicated or triplicated, with the latest date given when the particular procedure has been performed.  
 If the information has been documented once and no additional surgical procedures on the urinary tract have been performed, it is not necessary fill in this item again to avoid redundant data.  
 This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

**VARIABLE NAME:** Any change in lower urinary tract symptoms within the last year.

**DESCRIPTION:** This variable documents any change in lower urinary tract symptoms within the last year from the date of data collection.

**CODES:** No  
 Yes  
 Not applicable  
 Unknown

**COMMENTS:** According to the International Continence Society, lower urinary tract symptoms (LUTS) are the subjective indicator of a disease or change in conditions as perceived by the individual with spinal cord lesion, attendant or partner, and may lead him/her to seek help from health care professionals (Gajewski et al. 2018). Symptoms may be described during the data collection interview with the individual with spinal cord lesion. The information is usually qualitative, and may include change in frequency, urgency, nocturia, incontinence, hesitancy, slow stream, etc. LUTS can in individuals with spinal cord lesion indicate urinary tract infection even when bacteriuria has no associated signs or symptoms. Chills and

fever are often considered to be signs of acute pyelonephritis; however, these signs do not confirm an infection in the upper urinary tract (Stover et al. 1989). Nonetheless, chills and fever may be the only symptoms and signs experienced by people with a spinal cord lesion and pyelonephritis, bacteremia, upper tract obstruction by calculi, renal abscess, and perinephric abscess. Other suspicious signs and symptoms may include increased sweating, abdominal discomfort, costovertebral angle pain or tenderness, and increased muscle spasticity (Stover et al. 1989). Cloudy and malodorous urine and changes in urine pH may be signs of urinary tract infection, but can also occur with colonization, changes of bacterial organisms, and various food intake. Increased spontaneous voiding or larger residual urines including acute urinary retention may be seen with acute infection (Stover et al. 1989).

"Not applicable" is to be used when data reporting is performed within the first year after the spinal cord lesion.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

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## INTERNATIONAL SPINAL CORD INJURY LOWER URINARY TRACT FUNCTION BASIC DATA SET DATA COLLECTION FORM

**Date of data collection:** YYYYMMDD

**Urinary tract impairment unrelated to spinal cord lesion:**

No       Yes, specify \_\_\_\_\_       Unknown

**Awareness of the need to empty the bladder:**

No                       Yes                       Not applicable                       Not known

**Bladder emptying:**

	Main	Supplementary
Normal voiding (Voluntary initiation of micturition without reflex stimulation or compression of the bladder. This does not presume entirely normal function)	<input type="checkbox"/>	<input type="checkbox"/>
Bladder reflex triggering		
Voluntary (tapping, scratching, anal stretch, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Involuntary	<input type="checkbox"/>	<input type="checkbox"/>
Bladder expression		
Straining (abdominal straining, Valsalva's manoeuvre)	<input type="checkbox"/>	<input type="checkbox"/>
External compression (Credé manoeuvre)	<input type="checkbox"/>	<input type="checkbox"/>
Intermittent catheterisation		
Self-catheterisation	<input type="checkbox"/>	<input type="checkbox"/>
Catheterisation by attendant	<input type="checkbox"/>	<input type="checkbox"/>
Indwelling catheter		
Transurethral	<input type="checkbox"/>	<input type="checkbox"/>
Suprapubic	<input type="checkbox"/>	<input type="checkbox"/>
Non-continent urinary diversion/ostomy	<input type="checkbox"/>	<input type="checkbox"/>
Other method, specify _____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Unknown		

**Average number of voluntary bladder emptyings per 24 hours during the last week** \_\_\_\_\_

Not applicable       Unknown

**Any involuntary urine leakage (urinary incontinence) within the last four weeks:**

Daily       Once or more per week (but not daily)       Less than once per week  
 Never       Not applicable       Unknown

**Collecting appliances for urinary incontinence:**

No       Yes, condom catheter/sheath  
 Yes, diaper/pad  
 Yes, ostomy bag  
 Yes, other, specify \_\_\_\_\_  
 Unknown

**Any drugs with possible influence on the urinary tract within the last four weeks:**

- No       Yes, bladder relaxant drugs (antimuscarinics, anticholinergics, tricyclic antidepressants, etc. (not intradetrusor injections))
- Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc. (not intrasphincter injections))
- Yes, antibiotics/antiseptics:  For treatment of urinary tract infection  
 For prophylactic reasons
- Yes, other, specify \_\_\_\_\_
- Unknown

**Surgical procedures on the urinary tract:**

- No       Yes, supra-pubic catheter insertion, date last performed YYYYMMDD
- Yes, bladder stone removal, date last performed YYYYMMDD
- Yes, upper urinary tract stone removal, date last performed YYYYMMDD
- Yes, bladder augmentation, date last performed YYYYMMDD
- Yes, sphincterotomy/urethral stent, date last performed YYYYMMDD
- Yes, botulinum toxin injection into the detrusor, date last performed YYYYMMDD
- Yes, artificial sphincter, date last performed YYYYMMDD
- Yes, ileovesicostomy, date last performed YYYYMMDD
- Yes, ileoureterostomy (ileal conduit), date last performed YYYYMMDD
- Yes, continent catheterizable valves, date last performed YYYYMMDD
- Yes, other, specify \_\_\_\_\_ , date performed YYYYMMDD
- Unknown

**Any change in lower urinary tract symptoms within the last year:**

- No       Yes       Not applicable       Unknown