

INTERNATIONAL SPINAL CORD INJURY DATA SET LOWER URINARY TRACT FUNCTION BASIC DATA SET

The Lower Urinary Tract Function Basic Spinal Cord Injury Basic Data Set was developed by Fin Biering-Sørensen, Michael Craggs, Michael Kennelly, Erik Schick, and Jean-Jacques Wyndaele (see Biering-Sørensen et al. The Lower Urinary Tract Function Basic Spinal Cord Injury Data Set. Spinal Cord 2008). For the terminology of the International Spinal Cord Injury Data Sets cf. Biering-Sørensen et al. The International Spinal Cord Injury Data Sets. Spinal Cord 2006;44(9):530-4.

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Organisations that have endorsed the International SCI Lower Urinary Tract Function Basic Data Set as of December 11, 2007

International Spinal Cord Society

American Spinal Injury Association

The Neurourology Committee of the International Continence Society

International Society for Physical and Rehabilitation Medicine

American Paraplegia Society

American Academy of Orthopaedic Surgeons

Using the Lower Urinary Tract Function Basic Spinal Cord Injury Data Set

It is advised to practice with the training cases before implementing the Lower Urinary Tract Function Basic Spinal Cord Injury Data Set.

Try first to fill in a blank scoring sheet (see The Lower Urinary Tract Function Basic Spinal Cord Injury Data Set Collection Form), and afterwards check with the filled in scoring-sheet to see if the scoring has been done correctly.

The documentation with explanations for the Lower Urinary Tract Function Basic Spinal Cord Injury Data Set is found in the Introduction to the Lower Urinary Tract Function Basic Spinal Cord Injury Data Set.

The training cases have been contributed by Fin Biering-Sørensen, Michael Craggs, Michael Kennelly and Jean-Jacques Wyndaele. The training cases were proof read by Susan Charlifue.

Questions and suggestions regarding the Lower Urinary Tract Function Basic Spinal Cord Injury Data Set should be directed to Vanessa Noonan Vanessa.Noonan@vch.ca or Fin Biering-Sørensen finbs@rh.dk.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

LOWER URINARY TRACT FUNCTION BASIC DATA SET - 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 | <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"/> |
| Sacral anterior root stimulation | <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 day during the last week ___

Any involuntary urine leakage (incontinence) within the last three months:

No Yes, average daily Yes, average weekly Yes, average monthly

Not applicable Unknown

Collecting appliances for urinary incontinence:

No Yes, condom catheter/sheath
 Yes, diaper/pad
 Yes, ostomy bag
 Yes, other, specify _____

Unknown

INTRODUCTION TO THE INTERNATIONAL SPINAL CORD INJURY LOWER URINARY TRACT FUNCTION BASIC DATA SET

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 minimal amount of information on the lower urinary tract in daily practice in accordance with the purpose and vision of the International Spinal Cord Injury 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 Lower Urinary Tract Function Basic SCI Data Set will generally will be used in connection with data in the International SCI Core Data Set (DeVivo et al. 2006), 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 whether a vertebral injury was present, whether spinal surgery was performed, whether associated injuries were present, whether 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.

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 specifically been defined in a way that is designed 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.

References:

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

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

Abrams P, Cardozo L, Fall M, Griffiths D, Rosier P, Ulmsten U, van Kerrebroeck P, Victor A, Wein A. The Standardisation of Terminology of Lower Urinary Tract Function: Report from the Standardisation Subcommittee of the International Continence Society. *Neurourology and Urodynamics* 2002;21:167-78.

Levi R, Ertzgaard P, The Swedish Spinal Cord Injury Council 1998. Quality indicators in spinal cord injury care: A Swedish collaboration project. *Scand J Rehabil Med* 1998;Suppl.38:1-80.

Stover SL, Lloyd K, Waites KB, et al. Review article. Urinary tract infection in spinal cord injury. *Arch Phys Med Rehabil* 1989;70:47-54.

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD
Unknown

COMMENTS: This collection of data on lower urinary tract function may be carried out at any time after the spinal cord lesion.
Therefore the date of data collection is imperative to be able to identify the data collected in relation to other data collected on the same individual at various time points. In addition, the date is likewise important to calculate the time interval from date of birth (age), and time interval from date of lesion (time since lesion).

VARIABLE NAME: Urinary tract impairment unrelated to spinal cord lesion

DESCRIPTION: This variable documents any type of urinary tract impairment unrelated to 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.

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), i.e. *normal* (the individual is aware of bladder filling and increasing sensation up to a strong desire to void), *increased* (the individual feels an early and persistent desire to void), *reduced* (the individual is aware of bladder filling but does not feel a definite desire to void) *or non-specific bladder sensation* (the individual reports no specific bladder sensation, but may perceive bladder filling as abdominal fullness, vegetative symptoms like sweating or spasticity). 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 (the individual reports no sensation of bladder filling or desire to void) (Abrams et al. 2002) is not exactly the same as filling sensation and desire to void can be absent while temperature sensation or electrosensation can be present.

“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.

VARIABLE NAME: Bladder emptying

DESCRIPTION: This variable documents the method(s) used by the spinal cord injured individual 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
 Sacral anterior root stimulation – Main method
 Sacral anterior root stimulation – 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 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 spinal cord lesioned individual him/herself or by the attendant.

Involuntary bladder reflex triggering imply that there is no voluntary triggering of the voiding, but the individual with spinal cord lesion just let the urine run by itself when the reflex detrusor contraction occur by itself.

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 Credé manoeuvre (Abrams et al. 2002).

Straining include 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 a urinary reservoir (Abrams et al. 2002).

Intermittent catheterisation is defined as drainage or aspiration of the bladder or urinary reservoir / continent urinary diversion with subsequent removal of the catheter.

The following types of intermittent catheterisation are defined by the International Continence Society (Abrams et al. 2002):

Intermittent self-catheterisation is performed by the individual with spinal cord lesion himself/herself

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

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

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.

Sacral Anterior Root Stimulator (SARS): Emptying the bladder by electrical stimulation of the anterior sacral nerve roots via implanted electrodes.

Non-continent urinary diversion/ostomy: This includes ureteroileocutaneostomy (Bricker 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 are generally rare, it is not practical to give an inclusive list of bladder emptying methods. Use of diapers etc. because of incontinence is not to be reported here, but under “Collecting appliances for urinary incontinence”.

VARIABLE NAME: Average number of voluntary bladder emptyings per day during the last week

DESCRIPTION: This variable documents the average number of voluntary bladder emptying per day during the last week

CODES: Number

COMMENTS: The average number of voluntary bladder emptying per day 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 separate or in combination: normal voiding, voluntary bladder reflex triggering, bladder expression, intermittent catheterization, or sacral anterior root stimulation. If a combination of methods is used during the same bladder emptying it should only be counted as one bladder emptying. The number is given as an average for the last week only, as the individual is not expected to remember this for a longer period of time. The number is given as the nearest integer number.

VARIABLE NAME: Any involuntary urine leakage (incontinence) within the last three months

DESCRIPTION: This variable documents the average involuntary urine leakage (incontinence) over the last three months prior to the date of data collection.

CODES: No
 Yes, average daily
 Yes, average weekly
 Yes, average monthly
 Not applicable
 Unknown

COMMENTS: Urinary incontinence is defined by International Continence Society (Abrams et al. 2002) as the **complaint** of any involuntary leakage of urine. In each specific circumstance the urinary incontinence should be further described by specifying relevant factors such as type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life, etc. (Abrams et al. 2002). In the Basic Data Set only a simple indication of severity and collection of urine is given. More detailed information is to be given in an Expanded Data Set (Biering-Sørensen et al. 2006).

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 fall off and the individual **complains** of incontinence then it should be recorded as “Yes”.

No involuntary urine leakage (incontinence) within the last three months implies no leakage of urine outside the urinary tract or a closed urinary collection system. Instances of leakage less than monthly is considered as “no” unless the individual with spinal cord lesion does consider it a problem, and then it is to be coded as “monthly”.

Average daily involuntary urine leakage (incontinence) within the last three months implies leakage one or more times per day on average over the last three months.

Average weekly involuntary urine leakage (incontinence) within the last three months implies average leakage one or more times per week but not daily within the last three months.

Average monthly involuntary urine leakage (incontinence) within the last three months implies on average leakage one or more times per month but not weekly within the last three months.

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

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 with spinal cord lesions 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 excluded (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.

VARIABLE NAME: Any drugs for the urinary tract within the last year.

DESCRIPTION: This variable documents use of any drugs, systemic or intravesical, for the urinary tract within the last year on the date of data collection.

CODES: No
 Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressant, etc.)
 Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc.)
 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 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 respective 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.

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, date last performed YYYYMMDD

Yes, artificial sphincter, date last performed YYYYMMDD
 Yes, ileovesicostomy, date last performed YYYYMMDD
 Yes, ileoureterostomy, date last performed YYYYMMDD
 Yes, continent catheterizable valves, date last performed YYYYMMDD
 Yes, sacral anterior root stimulator, date 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 is corresponding to the formerly ileal loop or ureteroileocutaneostomy (Bricker conduit).

The continent catheterizable valves, include Monte and Mitrofanoff procedures.

For other possible surgical procedures 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.

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

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

CODES: No
 Yes
 Not applicable
 Unknown

COMMENTS: Lower urinary tract symptoms are according to the International Continence Society 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 (Abrams et al. 2002). Symptoms may either be volunteered or described during the data collection interview with the individual with spinal cord lesion. The information may be qualitative as well as quantitative, e.g. change in frequency, urgency, nocturia, incontinence, hesitancy, slow stream, etc. Many individuals with spinal cord lesion and bacteriuria have 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 reported in persons with spinal cord lesion and pyelonephritis, bacteremia, upper tract obstruction by calculi, renal abscesses, and periphrenic

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 intakes. 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.

CASES FOR TRAINING OF THE INTERNATIONAL LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD INJURY DATA SET

CASE 1 FOR LOWER URINARY TRACT FUNCTION BASIC DATA SET TRAINING

35 years old man, who previously has been completely healthy without any diseases or particular complaint, was shot twice in the neck nearly four months before. This resulted in cervical vertebral fractures 1, 2 and 7 with cervical spinal cord lesion and tetraplegia with respiratory insufficiency leading to tracheostomy and intermittent artificial ventilation.

He was seen in the clinic 20th of March 2003 and reports that initially he had an indwelling urethral catheter but has changed to intermittent sterile catheterisation by the personnel. He has some indirect feeling of voiding, as he feels warm in the neck region and uses this for timing of the catheterisations. The catheterisations are performed with hydrophilic catheters Ch 12. On average he has bladder emptying 6 times per day, and this has been the same for the last month. In particular when he is mobilised in his electrical wheelchair he is urinary incontinent daily, which has been the reality nearly from the beginning of his spinal cord injury, and for this reason he uses diapers. He has tried anticholinergic drugs, but he had adverse effects and they did not really help on the incontinence. He has had three urinary tract infections since injury, which had to be treated with antibiotics. Otherwise the only medication he has and is using is gabapentine and noritrene due to neuropathic pain. A recent urodynamic investigation showed detrusor sphincter dyssynergia with identical cystometric bladder capacity and post void residual volume of 260 mL, and a leak point pressure and maximum detrusor pressure of 20 cm H₂O. Due to the incontinence he is thinking about having a supra-pubic catheter inserted in the future.

LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD INJURY DATA SET – FORM

CASE 1

Date of data collection: 20030320

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 | <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 checked="" type="checkbox"/> | <input type="checkbox"/> |
| Indwelling catheter | | |
| Transurethral | <input type="checkbox"/> | <input type="checkbox"/> |
| Suprapubic | <input type="checkbox"/> | <input type="checkbox"/> |
| Sacral anterior root stimulation | <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 emptying per day during the last week 6

Any involuntary urine leakage (incontinence) within the last three months:

No Yes, average daily Yes, average weekly Yes, average monthly
 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 for the urinary tract within the last year:

- No Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressant, etc.)
 Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc.)
 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, date last performed YYYYMMDD
 Yes, artificial sphincter, date last performed YYYYMMDD
 Yes, ileovesicostomy, date last performed YYYYMMDD
 Yes, ileoureterostomy, date last performed YYYYMMDD
 Yes, continent catheterizable valves, date last performed YYYYMMDD
 Yes, sacral anterior root stimulator, date performed YYYYMMDD
 Yes, other, specify _____, date performed YYYYMMDD
 Unknown

Any change in urinary symptoms within the last year:

- No Yes Not applicable Unknown

CASE 2 FOR LOWER URINARY TRACT FUNCTION BASIC DATA SET TRAINING

39 year old man who was in good health up to the time of his injury. At the age of 14 he incurred a complete paraplegia at T5-6 after falling from a tree in parent's garden in Edinburgh, Scotland. He developed a scoliosis/kyphosis during late teenage years, which was corrected by extensive spinal fixation. There is little information on bladder management (except for a brief mention of tapping) up to the age of 24 when he moved to become a newspaper journalist in Sheffield, England in 1993. He was managed at the local spinal injuries unit for the next 5 years until moving to London to become a television news editor. He became a patient of the London Spinal Cord Injuries Centre. A review of the patient revealed a catalogue of attempts to manage a series of lower urinary problems including detrusor sphincter dyssynergia (DSD), renal stones and pyelonephritis. DSD was treated with sphincterotomy August 5th 1993 and stent August 15th 1996, the latter was removed May 20th 1998. Left renal stones were removed June 27th 1998. Video-urodynamics (with prophylactic antibiotics) showed a bladder capacity of about 500mL (with no sensation at capacity) and a serious DSD leading to a small leakage generated by a detrusor pressure just over 40 cm H₂O with a post-void (leak) residual of nearly 500mL. The patient experienced slight symptoms of autonomic dysreflexia during this procedure. Some ureteric reflux was corrected by the "Sting" procedure September 30th 1998. Mag3 renogram showed renal function of 20% left and 80% right kidney. In London he underwent further phases of management including botulinum toxin injection of the striated sphincter November 14th 1998, sheath with leg-bag drainage and May 15th 1999 insertion of a supra-pubic catheter, which was removed July 1st 1999. The patient did not want to use clean intermittent self-catheterisation because of the nature of his job in a busy TV newsroom. Finally in July 15th 1999, after much consultation and attention to his spinal fixation scaffolding (which extended from about T 5 to the sacrum), a Finetech-Brindley extra-dural sacral anterior root stimulator (SARS) was implanted, but without posterior root rhizotomy, as part of a research project to develop a new implant. At the time of his most recent examination July 25th 2004, and entry into the LUT Function Basic Data Set, his management is going very well with good bladder capacity, very efficient voiding with SARS five times a day, with incontinence less than weekly, low post-void residuals (<less than 5% of bladder capacity), no ureteric reflux and less than one urinary tract infection per year. He relies entirely on the SARS implant for his LUT management and use no incontinence aids. He declares a significantly improved quality of life.

LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD INJURY DATA SET – FORM

CASE 2

Date of data collection: 20040725

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 | <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"/> |
| Sacral anterior root stimulation | <input checked="" 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 day during the last week 5

Any involuntary urine leakage (incontinence) within the last three months:

No Yes, average daily Yes, average weekly Yes, average monthly
 Not applicable Unknown

Collecting appliances for urinary incontinence:

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

CASE 3 FOR LOWER URINARY TRACT FUNCTION BASIC DATA SET TRAINING

A 29 year old male who was otherwise healthy without any significant past medical issues, was involved in a car accident on 1/25/2006. The patient as a result suffered C3, C4, and C5 fractures and required intubation and tube feedings. He subsequently underwent open reduction and internal fixation of the C3, C4, and C5 fractures with fusion of C3-C5. The patient initially had an indwelling foley catheter, which was removed on 2/8/2006. The patient then began managing his bladder with reflex voiding and clean intermittent catheterization while in the hospital. However, he decided he would like to attempt to do reflex voiding only. The patient was initially started on Flomax 0.4 mg daily. The patient was then reflex voiding and required catheterization once daily for volumes ranging from 200-300cc. The patient was using a sterile straight Mentor catheter for catheterization and an all silicone condom catheter. He had no feeling of bladder filling, and was complaining of multiple urinary tract infections as well. He subsequently underwent urodynamic testing which showed him to have a baseline pressure of 20 cm/H₂O and void 250cc with a residual of 205cc. The patient voided with pressures ranging from 67cm/H₂O-76 cm/H₂O. Based on the results of his urodynamic studies, the patient is considering botulinum toxin chemodenervation to the internal and external sphincter to improve his voiding efficiency.

LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD IINJURY DATA SET – FORM

CASE 3

Date of data collection: 20061011

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 | <input type="checkbox"/> | <input type="checkbox"/> |
| Bladder reflex triggering | | |
| Voluntary (tapping, scratching, anal stretch, etc.) | <input type="checkbox"/> | <input type="checkbox"/> |
| Involuntary | <input checked="" 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 checked="" 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"/> |
| Sacral anterior root stimulation | <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 emptying per day during the last week 1

Any involuntary urine leakage (incontinence) within the last three months:

No Yes, average daily Yes, average weekly Yes, average monthly
 Not applicable Unknown

Collecting appliances for urinary incontinence:

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

CASE 4 FOR LOWER URINARY TRACT FUNCTION BASIC DATA SET TRAINING

A 29 year old female who was otherwise healthy without any significant past medical issues, was involved in a car accident on 01/25/2004. As a result she had a C6 pedicle fracture with C6-C7 bilateral facet dislocations. She underwent C5-C7 posterior segmental instrumentation, C5-C7 posterior arthrodesis with autograft, and left posterior iliac crest bone graft harvest. The patient initially had a foley catheter, which was removed on 2/12/04. Upon removal of the foley catheter the patient was placed on the oxytrol patch, two patches every three-four days, and began performing self-catheterization every six hours. She has no awareness of bladderfilling. Due to multiple urinary tract infections, leakage between catheterizations, as well as significant detrusor hyperreflexia with detrusor external sphincter dyssnergia on urodynamic studies, the patient underwent botulinum toxin chemodenervation to the bladder on June 6th 2006. The patient had no improvement of symptoms after her botulinum toxin chemodenervation and began Oxybutinin ER 10mg twice daily. Due to difficulty with self-catheterization and leakage between catheterizations, the patient had changed her form of bladder management to a 14 Fr silicone indwelling foley catheter in September 2006. She has not had any urologic issues with her catheter and gets is changed every 4 weeks. Her most recent urodynamic testing showed the patient to have a small bladder capacity of 114 ml. with a decrease in bladder compliance. She had an elevated detrusor leak point pressure of 85 cm/H2O. Ultimately the patient would like to resume self-catheterization via a continent catheterizable valve and discontinue the foley catheter. The patient is currently contemplating reconstructive surgery including a bladder augmentation with an Mitrofanoff appendicovesicostomy.

LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD INJURY DATA SET – FORM

CASE 4

Date of data collection: 20070511

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 | <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 checked="" type="checkbox"/> | <input type="checkbox"/> |
| Suprapubic | <input type="checkbox"/> | <input type="checkbox"/> |
| Sacral anterior root stimulation | <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 emptying per day during the last week 0

Any involuntary urine leakage (incontinence) within the last three months:

No Yes, average daily Yes, average weekly Yes, average monthly
 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 for the urinary tract within the last year:

No Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressant, etc.)

- Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc.)
- 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, date last performed **20060606**
 - Yes, artificial sphincter, date last performed YYYYMMDD
 - Yes, ileovesicostomy, date last performed YYYYMMDD
 - Yes, ileoureterostomy, date last performed YYYYMMDD
 - Yes, continent catheterizable valves, date last performed YYYYMMDD
 - Yes, sacral anterior root stimulator, date performed YYYYMMDD
 - Yes, other, specify _____, date performed YYYYMMDD
- Unknown

Any change in urinary symptoms within the last year:

- No Yes Not applicable Unknown

CASE 5 FOR LOWER URINARY TRACT FUNCTION BASIC DATA SET TRAINING

75 years old man with thoracic 7 paraplegia for 14 years as the result of a motor traffic accident, who came for follow-up August 12 2007. Urological history: transurethral resection of benign prostate hyperplasia at the age of 63.

He had developed a neurologic overactive bladder with detrusor sphincter dyssynergia. This was treated originally with bladder relaxant drugs and intermittent self catheterisation. The urological evolution was without problems till 5 years ago when bilateral hydronephrosis was diagnosed during a period of recurrent infections. Urodynamic testing showed a low compliant, high pressure bladder with bilateral vesicoureteral reflux. The creatinine was slightly increased.

A period of indwelling catheter had to be stopped because erosion of the urethral meatus and glans penis. Botulinum toxin could not be used because of too high expense (no reimbursement in patient's country). Enterocystoplasty was refused by the patient.

Sphincterotomy (November 22, 2001) and condom catheter were 4.5 years ago.

During follow up 2004 visit raise of PSA was found (31 ng/ml ; normal for his lab < 4.6 for his age).

Prostate biopsies showed adenocarcinoma of the prostate pT2 Gleason 3+3, n0, m0

Focused radiotherapy was given which made the PSA lower at 0.1.

During the next year severe problem of decubic ulcers at penile skin. Diabetes was found.

Iliac conduit was performed April 2, 2005.

With two years follow up no hydronephrosis. Creatinine at same level. PSA no rise. No problems at stoma site.

LOWER URINARY TRACT FUNCTION BASIC SPINAL CORD INJURY DATA SET – FORM

CASE 5

Date of data collection: 20070812

Urinary tract impairment unrelated to spinal cord lesion:

- No Yes, specify: Transurethral resection of benign prostate hyperplasia at the age of 63. 2004 raise of PSA (31 ng/ml; normal for his lab < 4.6 for his age). Biopsies showed adenocarcinoma of the prostate pT2 Gleason 3+3, n0, m0. Focused radiotherapy was given which made the PSA lower at 0.1.
- Unknown

Awareness of the need to empty the bladder:

- No Yes Not applicable Not known

Bladder emptying:

| | Main | Supplementary |
|---|-------------------------------------|--------------------------|
| Normal voiding | <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"/> |
| Sacral anterior root stimulation | <input type="checkbox"/> | <input type="checkbox"/> |
| Non-continent urinary diversion/ostomy | <input checked="" 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 day during the last week ___

Any involuntary urine leakage (incontinence) within the last three months:

- No Yes, average daily Yes, average weekly Yes, average monthly
- 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 for the urinary tract within the last year:

- No Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressants, etc.)
 Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc.)
 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 20011122
 Yes, botulinum toxin injection, date last performed YYYYMMDD
 Yes, artificial sphincter, date last performed YYYYMMDD
 Yes, ileovesicostomy, date last performed YYYYMMDD
 Yes, ileoureterostomy, date last performed 20050402
 Yes, continent catheterizable valves, date last performed YYYYMMDD
 Yes, sacral anterior root stimulator, date performed YYYYMMDD
 Yes, other, specify _____, date performed YYYYMMDD

Unknown

Any change in urinary symptoms within the last year:

- No Yes Not applicable Unknown