

Note: It is recommended that this data set have two additional key variables:

- SITE (to distinguish the location where the data are recorded) and
- SUBJECT (to distinguish the patient/study participant)

INTERNATIONAL SPINAL CORD INJURY DATA SETS

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="text" value="EMBLADM"/>	<input type="checkbox"/> <input type="text" value="EMBLADS1"/>
Bladder reflex triggering		<input type="checkbox"/> <input type="text" value="EMBLADS2"/>
Voluntary (tapping, scratching, anal stretch, etc.)	<input type="checkbox"/>	<input type="checkbox"/> <input type="text" value="EMBLADS3"/>
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"/> <input type="text" value="OTHMTHS1"/>
Other method, specify _____	<input type="checkbox"/> <input type="text" value="OTHMTHM"/>	<input type="checkbox"/> <input type="text" value="OTHMTHS2"/>
<input type="checkbox"/> Unknown		<input type="checkbox"/> <input type="text" value="OTHMTHS3"/>

Average number of voluntary bladder emptying 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)) **BLADRELX**
- Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers, etc. (not intrasphincter injections)) **SPNCRELX**
- Yes, antibiotics/antiseptics: For treatment of urinary tract infection **ANTIUTI**
- For prophylactic reasons **ANTIPROP**
- Yes, other, specify **OTHDRG** — **OTHDRGSP**
- Unknown

Surgical procedures on the urinary tract:

- SPCATH** Yes, supra-pubic catheter insertion, date last performed YYYYMMDD **SPCATHDT**
- BSTNRM** Yes, bladder stone removal, date last performed YYYYMMDD **BSTNRMDT**
- USTNRM** Yes, upper urinary tract stone removal, date last performed YYYYMMDD **USTNRMDT**
- BLADAG** Yes, bladder augmentation, date last performed YYYYMMDD **BLADAGDT**
- USTENT** Yes, sphincterotomy/urethral stent, date last performed YYYYMMDD **USTENTDT**
- BOTOX** Yes, botulinum toxin injection into the detrusor, date last performed YYYYMMDD **BOTOXDT**
- ARTSPH** Yes, artificial sphincter, date last performed YYYYMMDD **ARTSPHDT**
- ILVSCS** Yes, ileovesicostomy, date last performed YYYYMMDD **ILVSCSDT**
- ILURTS** Yes, ileoureterostomy (ileal conduit), date last performed YYYYMMDD **ILURTSDT**
- CCATHV** Yes, continent catheterizable valves, date last performed YYYYMMDD **CCATHVDT**
- Yes, other, specify **OTHSRG** **OTHSRGSP** date performed YYYYMMDD **OTHSRGDT**
- Unknown

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

- No Yes Not applicable Unknown

Proposed 8 Character Variables:

								Bladder Emptying			
Data Element	Site	Subject	Time point	Date of data collection	Urinary tract impairment unrelated to spinal cord lesion	Specify urinary tract impairment unrelated to spinal cord lesion	Awareness of the need to empty the bladder	Main bladder emptying method	Specify other main method for bladder emptying	Supplementary bladder emptying method #1	Specify other supplementary method for bladder emptying #1
Format/ Codes				YYYYMMDD Unknown	No Yes Unknown	Free text	No Yes Not applicable Not known	Normal voiding Bladder reflex triggering, Voluntary Bladder reflex triggering, Involuntary Bladder expression, Straining Bladder expression, External compression Intermittent catheterisation, Self-catheterisation Intermittent catheterisation, Catheterisation by attendant Intermittent catheterisation, Catheterisation by attendant – Supplementary method Indwelling catheter, Transurethral Indwelling catheter, Suprapubic Non-continent urinary diversion/ostomy Other method Unknown	Free text	Normal voiding Bladder reflex triggering, Voluntary Bladder reflex triggering, Involuntary Bladder expression, Straining Bladder expression, External compression Intermittent catheterisation, Self-catheterisation Intermittent catheterisation, Catheterisation by attendant Intermittent catheterisation, Catheterisation by attendant – Supplementary method Indwelling catheter, Transurethral Indwelling catheter, Suprapubic Non-continent urinary diversion/ostomy Other method Unknown	Free text
8 Character Variable	SITE	SUBJECT	TIMEPT	LUTFXNDT	UTIMPRUN	UTIMPRSP	AWARBLAD	EMBLADM	OTHMTHM	EMBLADS1	OTHMTHS1

Proposed 8 Character Variables:

Data Element	Site	Subject	Time point					Voluntary bladder emptying			Collecting appliances for urinary incontinence			
				Supplementary bladder emptying method #2	Specify other supplementary method for bladder emptying #2	Supplementary bladder emptying method #3	Specify other supplementary method for bladder emptying #3	Average number of voluntary bladder emptying per 24 hours during the last week	Average number of voluntary bladder emptying per 24 hours during the last week unknown not applicable	Any involuntary urine leakage (urinary incontinence) within the last four weeks	Condom catheter/sheath used	Diaper/pad used	Ostomy bag used	Other collection appliance used
Format/Codes				Normal voiding Bladder reflex triggering, Voluntary Bladder reflex triggering, Involuntary Bladder expression, Straining Bladder expression, External compression Intermittent catheterisation, Self-catheterisation Intermittent catheterisation, Catheterisation by attendant Intermittent catheterisation, Catheterisation by attendant – Supplementary method Indwelling catheter, Transurethral Indwelling catheter, Suprapubic Non-continent urinary diversion/ostomy Other method Unknown	Free text	Normal voiding Bladder reflex triggering, Voluntary Bladder reflex triggering, Involuntary Bladder expression, Straining Bladder expression, External compression Intermittent catheterisation, Self-catheterisation Intermittent catheterisation, Catheterisation by attendant Intermittent catheterisation, Catheterisation by attendant – Supplementary method Indwelling catheter, Transurethral Indwelling catheter, Suprapubic Non-continent urinary diversion/ostomy Other method Unknown	Free text	Numeric	Not applicable Unknown	Daily Once or more per week Less than once per week Never Not applicable Unknown	No Yes Unknown	No Yes Unknown	No Yes Unknown	No Yes Unknown
8 Character Variable	SITE	SUBJECT	TIMEPT	EMBLADS2	OTHMTHS2	EMBLADS3	OTHMTHS3	AVBLADEM	AVBLADNA	INCONTNC	CONDCATH	DIAPERPD	OSTMYBAG	OTHCOLAP

Proposed 8 Character Variables:

				Any drugs with possible influence on the urinary tract within the last four weeks							Surgical procedures on the urinary tract			
Data Element	Site	Subject	Time point	Specify other collection appliance used	Bladder relaxant drugs used	Sphincter/bladder neck relaxant drugs used	Antibiotics/antiseptics used for treatment of urinary tract infection	Antibiotics/antiseptics used for prophylactic reasons	Other drugs used	Specify other drugs used	Supra-pubic catheter insertion	Date supra-pubic catheter insertion last performed	Bladder stone removal	Date bladder stone removal last performed
Format/Codes				No Yes Free text	No Yes Unknown	No Yes Unknown	No Yes Unknown	No Yes Unknown	No Yes Unknown	Free text	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown
8 Character Variable	SITE	SUBJECT	TIMEPT	COLAPSP	BLADRELX	SPNCRELX	ANTIUTI	ANTIPROP	OTHDRG	OTHDRGSP	SPCATH	SPCATHDT	BSTNRM	BSTNRMDT

Proposed 8 Character Variables:

Data Element	Site	Subject	Time point	Upper urinary tract stone removal	Date upper urinary tract stone removal last performed	Bladder augmentation	Date bladder augmentation last performed	Sphincterotomy/ urethral stent	Date sphincterotomy/ urethral stent last performed	Botulinum toxin injection into the detrusor	Date botulinum toxin injection into the detrusor last performed	Artificial sphincter	Date artificial sphincter last performed	Ileovesicostomy
Format/Codes				No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown
8 Character Variable	SITE	SUBJECT	TIMEPT	USTNRM	USTNRMDT	BLADAG	BLADAGDT	USTENT	USTENTDT	BOTOX	BOTOXDT	ARTSPH	ARTSPHDT	ILVSCS

Proposed 8 Character Variables:

Data Element	Site	Subject	Time point	Date ileovesicostomy last performed	Ileoureterostomy	Date ileoureterostomy last performed	Continent catheterizable valves	Date continent catheterizable valves last performed	Other type of surgery	Specify other type of surgery	Date other type of surgery last performed	Any change in lower urinary tract symptoms within the last year
Format/ Codes				YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	YYYYMMDD 99999999 = Unknown	No Yes Unknown	Free text	YYYYMMDD 99999999 = Unknown	No Yes Not applicable Unknown
8 Character Variable	SITE	SUBJECT	TIMEPT	ILVSCSDT	ILURTS	ILURTSDT	CCATHV	CCATHVDT	OTHSRG	OTHSRGSP	OTHSRGDT	URSXCHLY