

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
ACTIVITIES AND PARTICIPATION BASIC DATA SET DATA FORM (Version 1.0)**

Date of data collection ___ / ___ / ___ (YYYY/MM/DD)	DATACLDT	Satisfaction rating 0 Not satisfied 1 Somewhat satisfied 2 Very satisfied 8 Not applicable 99 Unknown
Performance rating	PERFRATE	
Mobility moderate distances (10-100 metres) 0 Requires total assistance 1 Needs electric wheelchair or partial assistance to operate manual wheelchair 2 Moves independently in manual wheelchair 3 Requires supervision while walking (with or without devices) 4 Walks with a walking frame or crutches (swing) 5 Walks with crutches or two canes (reciprocal walking) 6 Walks with one cane 7 Needs leg orthosis only 8 Walks without walking aids 99 Unknown	MOBILMOD	---
Dressing lower body 0 Requires total assistance 1 Requires partial assistance with clothes without buttons, zippers or laces (cwobzl) 2 Independent with cwobzl; requires adaptive devices and/or specific settings (adss) 3 Independent with cwobzl; does not require adss; needs assistance or adss only for bzl 4 Dresses (any clothes) independently; does not require adss. 99 Unknown	DRESLBDY	---
Feeding 0 Needs parenteral, gastrostomy or fully assisted oral feeding 1 Needs partial assistance with eating and/or drinking or for putting on/taking off adaptive device(s) needed for eating and/or drinking 2 Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers 3 Eats and drinks independently; does not require assistance or adaptive devices. 99 Unknown	FEEDING	---
Toileting 0 Requires total assistance 1 Requires partial assistance, does not clean self 2 Requires partial assistance, cleans self independently 3 Independent in all tasks, but needs adaptive equipment or special setting (eg bars) 4 Independent, does not need adaptive equipment or special setting 99 Unknown	TOILETIN	---
Paid work ___ hours a week	PWRKHRWK 99 unknown	---
Volunteer work ___ hours a week	VWRKHRWK 99 unknown	---
Education ___ hours a week	EDUCHRWK 99 unknown	---
Household ___ hours a week	HHOLHRWK 99 unknown	---
Spare time activities ___ hours a week	ACTIHRWK 99 unknown	---
Spousal relationship 0 No relationship 1 Married/living together 2 Romantic relationship, not living together 99 unknown	SPOUSREL	---
Family relationships (contacts) ___ different family members	99 unknown FAMRELCT	---
Friends relationships (contacts) ___ different friends	99 unknown FRIRELCT	---

INTERNATIONAL SPINAL CORD ACTIVITIES AND PARTICIPATION BASIC DATA SET

Proposed 8 Character Variables:			Activities and Participation Basic Data Set Table 1	
Data Element	Date of data collection	Performance rating	Mobility moderate distances	Dressing lower body
Format/ Codes	YYYY/MM/DD	0 Not satisfied 1 Somewhat satisfied 2 Very satisfied 8 Not applicable 99 Unknown	0 Requires total assistance 1 Needs electric wheelchair or partial assistance to operate manual wheelchair 2 Moves independently in manual wheelchair 3 Requires supervision while walking (with or without devices) 4 Walks with a walking frame or crutches (swing) 5 Walks with crutches or two canes (reciprocal walking) 6 Walks with one cane 7 Needs leg orthosis only 8 Walks without walking aids 99 Unknown	0 Requires total assistance 1 Requires partial assistance with clothes without buttons, zippers or laces (cwobzl) 2 Independent with cwobzl; requires adaptive devices and/or specific settings (adss) 3 Independent with cwobzl; does not require adss; needs assistance or adss only for bzl 4 Dresses (any clothes) independently; does not require adss. 99 Unknown
Table	1	1	1	1
8 Character Variable	DATACLDT	PERFRATE	MOBILMOD	DRESLBDY
Comments/Suggested Revisions				

INTERNATIONAL SPINAL CORD ACTIVITIES AND PARTICIPATION BASIC DATA SET

Proposed 8 Character Variables:			
Data Element	Feeding	Toileting	Paid work hours a week
Format/ Codes	<p>0 Needs parenteral, gastrostomy or fully assisted oral feeding</p> <p>1 Needs partial assistance with eating and/or drinking or for putting on/taking off adaptive device(s) needed for eating and/or drinking</p> <p>2 Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers</p> <p>3 Eats and drinks independently; does not require assistance or adaptive devices.</p> <p>99 Unknown</p>	<p>0 Requires total assistance</p> <p>1 Requires partial assistance, does not clean self</p> <p>2 Requires partial assistance, cleans self independently</p> <p>3 Independent in all tasks, but needs adaptive equipment or special setting (eg bars)</p> <p>4 Independent, does not need adaptive equipment or special setting</p> <p>99 Unknown</p>	<p>Numeric</p> <p>99 Unknown</p>
Table	1	1	1
8 Character Variable	FEEDING	TOILETIN	PWRKHRWK
Comments/Suggested Revisions			

INTERNATIONAL SPINAL CORD ACTIVITIES AND PARTICIPATION BASIC DATA SET

Proposed 8 Character Variables:							
Data Element	Volunteer work hours a week	Education hours a week	Household hours a week	Spare time activities hours a week	Spousal relationship	Family relationships (contacts)	Friend relationships (contacts)
Format/ Codes	Numeric 99 Unknown	Numeric 99 Unknown	Numeric 99 Unknown	Numeric 99 Unknown	Numeric 99 Unknown	Numeric 99 Unknown	Numeric 99 Unknown
Table	1	1	1	1	1	1	1
8 Character Variable	VWRKHRWK	EDUCHRWK	HHOLHRWK	ACTIHRWK	SPOUSREL	FAMRELCT	FRIRELCT
Comments/Suggested Revisions						Number of different family members	Number of different friends