

INTERNATIONAL SPINAL CORD INJURY UPPER EXTREMITY BASIC DATA SET FORM (Version 1.0)

Date performed: YYYY/MM/DD

UPEXTRDT

Evaluation of the RIGHT and LEFT upper extremity separately:

Ability to reach and grasp (part of the GRASSP test):	Shoulder function classification:
<p>1. No upper extremity function at or below the elbow No voluntary control of elbow, wrist, or hand muscles; no grasping function; severely limited active placing or reaching of the arm.</p> <p>2. Passive tenodesis hand Passive hand functions with neither voluntary control of extrinsic and intrinsic hand muscles nor ability to actively extend the wrist. Opening and closing of the hand is only possible by supination or pronation of the forearm (passive tenodesis effect) with no active grasping movements of hand. Bimanual grasping by stabilizing objects between two hands or passive tenodesis grasp is effective only in a limited workspace.</p> <p>3. Active tenodesis hand No voluntary control of extrinsic and intrinsic hand muscles but active wrist extension allowing for passive movements of fingers dependent on a tenodesis effect. Limited single-handed grasping function in a restricted workspace.</p> <p>4. Active extrinsic hand Voluntary control of wrist and some extrinsic hand muscles allowing for grasping with or without tenodesis enabling some active opening and closing of the hand but reduced dexterity and reduction of workspace.</p> <p>5. Active extrinsic-intrinsic hand Voluntary control of extrinsic and intrinsic hand muscles with full workspace and the ability to perform different grasp forms (e.g. power grip, precision grip, lateral power pinch, precision pinch) but potential limitations of muscle strength and dexterity.</p>	<p>A. No active placing or reaching of the arm.</p> <p>B. Severely limited but able to position hand on a desk, without assistance, but not able to reach to the mouth/head (gravity compromises the movements).</p> <p>C. Limited but able to reach mouth/head, with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension.</p> <p>D. Full range of movement (ROM) of shoulder and independent reaching forward and upward.</p>

Basic right hand - upper extremity function: __ __ (select one number (1-5) and one letter (A-D) from above corresponding to the best description of the hand and upper extremity function)

HANDBASR

UPEXFXNR

Basic left hand - upper extremity function: __ __ (select one number (1-5) and one letter (A-D) from above corresponding to the best description of the hand and upper extremity function)

HANDBASL

UPEXFXNL

Use of assistive devices (all equipment like splints, adaptive equipment, surface functional electrical stimulation (FES), etc.) used to enhance upper extremity function:

UEDEVICE

 Never or less than monthly

 Not weekly, but one or more times monthly

- Not daily, but one or more times weekly
 Used daily

Complications to upper extremity function like pain, spasms, contractures, oedema, etc.: **UECOMPLI**

- Minimal – no complications or complications have minimal impact on function
 Moderate – complications have moderate impact on function
 Extensive – complications have extensive impact on function

Upper Extremity/Hand Reconstructive Surgery **UERECSNG**

- Yes No Unknown

If Yes, fill in below

Performed Upper Extremity/Hand Reconstructive Surgery

Check all that apply

	Type of surgery	Yes / No / Unknown	Date of surgery (yyyy/mm/dd)
Soft Tissue Reconstruction	Tendon transfer for elbow extension (right) TTRELEXR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TTRELRDT
	Tendon transfer for elbow extension (left) TTRELEXL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TTRELLDT
	Tendon transfer for wrist extension (right) TTRWREXR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TTRWRRDT
	Tendon transfer for wrist extension (left) TTRWREXL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TTRWRLDT
	Restoration of pinch and/or grasp (right) RESPIGRR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	RESPGRDT
	Restoration of pinch and/or grasp (left) RESPIGRL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	RESPGLDT
	Tendon/muscle releases or lengthenings (right) TDRELENR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TDRELRDT
	Tendon/muscle releases or lengthenings (left) TDRELENL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	TDRELLDT
	Other, specify: STROTHER STROTHSP	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	STROTHDT
Osteotomy with or without rotation and/or Arthrodesis	Humerus (right) OSTHUMER	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTHURDT
	Humerus (left) OSTHUMEL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTHULDT
	Radius (right) OSTRADIR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTRARDT
	Radius (left) OSTRADIL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTRALDT
	Ulnar (right) OSTULNAR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTULRDT
	Ulnar (left) OSTULNAL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTULLDT
	Wrist (right) OSTWRISR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTWRRDT
	Wrist (left) OSTWRISL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTWRLDT
	Fingers/Thumb (right) OSTFINTR	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTFIRDT
	Fingers/Thumb (left) OSTFINTL	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OSTFILD
Implantable FES	specify: IMPLTFES IMPFESSP	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	IMPFESDT
Other	specify: OTHER OTHERSP	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	OTHERDT

INTERNATIONAL SPINAL CORD INJURY UPPER EXTREMITY BASIC DATA SET

Proposed 8 Character Variables:				Table 1. Hand and Upper Extremity Function
Data Element	Site	Subject	Date performed	Basic hand-upper limb function Right
Format/ Codes			YYYY/MM/DD	1 No upper limb function at or below the elbow; 2 Passive tenodesis hand; 3 Active tenodesis hand; 4 Active extrinsic hand; 5 Active extrinsic-intrinsic hand
8 Character Variable	SITE	SUBJECT	UPEXTRDT	HANDBASR
Comments/Suggested Revisions	Key	Key		

INTERNATIONAL SPINAL CORD INJURY UPPER EXTREMITY BASIC DATA SET

Proposed 8 Character Variables:	Table 1. Hand and Upper Extremity Function (cont.)			
Data Element	Upper extremity function Right	Basic hand-upper limb function Left	Upper extremity function Left	Use of assistive devices
Format/ Codes	A No active placing or reaching of the arm.; B Severely limited but able to position hand on a desk, without assistance, but not able to reach to the mouth/head (gravity compromises the movements).; C Limited but able to reach mouth/head with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension.; D Full range of movement (ROM) of shoulder and independent reaching forward and upward.	1 No upper limb function at or below the elbow; 2 Passive tenodesis hand; 3 Active tenodesis hand; 4 Active extrinsic hand; 5 Active extrinsic-intrinsic hand	A No active placing or reaching of the arm.; B Severely limited but able to position hand on a desk, without assistance, but not able to reach to the mouth/head (gravity compromises the movements).; C Limited but able to reach mouth/head with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension.; D Full range of movement (ROM) of shoulder and independent reaching forward and upward.	Never or less than monthly; Not weekly, but one or more times monthly; Not daily, but one or more times weekly; Used daily
8 Character Variable	UPEXFXNR	HANDBASL	UPEXFXNL	UEDEVICE
Comments/Suggested Revisions				

Proposed 8 Character Variables:			Table 2. Performed Upper Extremity/Hand Reconstructive Surgery	
Data Element	SCI-related complications to upper extremity function like pain, spasms, contractures, oedema, etc.	Upper extremity/hand reconstructive surgery	Soft tissue reconstruction: tendon transfer for elbow extension Right	Soft tissue reconstruction: tendon transfer for elbow extension Right - Date
Format/ Codes	Minimal – no complications or complications have minimal impact on function; Moderate – complications have moderate impact on function; Extensive – complications have extensive impact on function	Yes; No; Unknown	Yes; No; Unknown	YYYY/MM/DD
8 Character Variable	UECOMPLI	UERECSG	TTRELEXR	TTRELRTD
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Soft tissue reconstruction: tendon transfer for elbow extension Left	Soft tissue reconstruction: tendon transfer for elbow extension Left - Date	Soft tissue reconstruction: tendon transfer for wrist extension Right	Soft tissue reconstruction: tendon transfer for wrist extension Right -Date
Format/ Codes	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD
8 Character Variable	TTRELEXL	TTRELLDT	TTRWREXR	TTRWRRDT
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Soft tissue reconstruction: tendon transfer for wrist extension Left	Soft tissue reconstruction: tendon transfer for wrist extension Left - Date	Soft tissue reconstruction: restoration of pinch and or grasp Right	Soft tissue reconstruction: restoration of pinch and or grasp Right - Date
Format/ Codes	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD
8 Character Variable	TTRWREXL	TTRWRLDT	RESPIGRR	RESPGRDT
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Soft tissue reconstruction: restoration of pinch and or grasp Left	Soft tissue reconstruction: restoration of pinch and or grasp Left - Date	Soft tissue reconstruction: tendon/muscle releases or lengthenings Right	Soft tissue reconstruction: tendon/muscle releases or lengthenings Right - Date
Format/ Codes	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD
8 Character Variable	RESPIGRL	RESPGLDT	TDRELENR	TDRELRTD
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Soft tissue reconstruction: tendon/muscle releases or lengthenings Left	Soft tissue reconstruction: tendon/muscle releases or lengthenings Left - Date	Soft tissue reconstruction: Other	Soft tissue reconstruction: Other - Specify
Format/ Codes	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown	
8 Character Variable	TDRELENL	TDRELLDT	STROTHER	STROTHSP
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Soft tissue reconstruction: Other - Date	Osteotomy with or without rotation and or arthrodesis: humerus Right	Osteotomy with or without rotation and or arthrodesis: humerus Right - Date	Osteotomy with or without rotation and or arthrodesis: humerus Left
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown
8 Character Variable	STROTHDT	OSTHUMER	OSTHURDT	OSTHUMEL
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Osteotomy with or without rotation and or arthrodesis: humerus Left - Date	Osteotomy with or without rotation and or arthrodesis: radius Right	Osteotomy with or without rotation and or arthrodesis: radius Right - Date	Osteotomy with or without rotation and or arthrodesis: radius Left
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown
8 Character Variable	OSTHULDT	OSTRADIR	OSTRARDT	OSTRADIL
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Osteotomy with or without rotation and or arthrodesis: radius Left - Date	Osteotomy with or without rotation and or arthrodesis: ulnar Right	Osteotomy with or without rotation and or arthrodesis: ulnar Right - Date	Osteotomy with or without rotation and or arthrodesis: ulnar Left
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown
8 Character Variable	OSTRALDT	OSTULNAR	OSTULRDT	OSTULNAL
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Osteotomy with or without rotation and or arthrodesis: ulnar Left - Date	Osteotomy with or without rotation and or arthrodesis: wrist Right	Osteotomy with or without rotation and or arthrodesis: wrist Right - Date	Osteotomy with or without rotation and or arthrodesis: wrist Left
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown
8 Character Variable	OSTULLDT	OSTWRISR	OSTWRRDT	OSTWRISL
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Osteotomy with or without rotation and or arthrodesis: wrist Left - Date	Osteotomy with or without rotation and or arthrodesis: fingers/thumb Right	Osteotomy with or without rotation and or arthrodesis: fingers/thumb Right - Date	Osteotomy with or without rotation and or arthrodesis: fingers/thumb Left
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown	YYYY/MM/DD	Yes; No; Unknown
8 Character Variable	OSTWRLDT	OSTFINTR	OSTFIRDT	OSTFINTL
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)			
Data Element	Osteotomy with or without rotation and or arthrodesis: fingers/thumb Left - Date	Implantable FES	Implantable FES Specify	Implantable FES Date
Format/ Codes	YYYY/MM/DD	Yes; No; Unknown		YYYY/MM/DD
8 Character Variable	OSTFILD	IMPLTFES	IMPFESSP	IMPFESDT
Comments/Suggested Revisions				

Proposed 8 Character Variables:	Table 2. Performed Upper Extremity/Hand Reconstructive Surgery (cont.)		
Data Element	Other upper extremity/hand reconstructive surgery	Other upper extremity/hand reconstructive surgery Specify	Other upper extremity/hand reconstructive surgery Date
Format/ Codes	Yes; No; Unknown		YYYY/MM/DD
8 Character Variable	OTHER	OTHERSP	OTHERDT
Comments/Suggested Revisions			