

NINDS CDE Project Spinal Cord Injury Pediatric Recommendations Summary

Our approach to pediatric CDE development built upon the adult SCI CDE structure and other pediatric CDE structures. Specifically, the SCI Pediatric Working Group reviewed and evaluated every adult SCI CDE for relevance to pediatric SCI. We also reviewed the CDEs from the pediatric traumatic brain injury (TBI), Duchenne muscular dystrophy, congenital muscular dystrophy, spinal muscular dystrophy and myotonic dystrophy CDE structures and incorporated relevant ones into the pediatric SCI CDE structure. We intentionally included all relevant CDEs to support future comparative studies and pooling of data. We also created new pediatric SCI CDEs. Several guiding principles were used for selection and creation of the pediatric elements.

- **Growth, Development and Age:** Pediatric-onset SCI is a heterogeneous population because of growth and development. Thus, CDEs that may be relevant for one pediatric age group may not be relevant for another age group. For this reason, we reviewed, evaluated and created all of the elements for four age groups: 0-5 years, 6-12 years, 13-15 years and 16-18 years. These age groups were selected based on the recommendations set forth by DeVivo et al¹. There were three exceptions to the age group rule:
 - A) Due to substantial developmental differences in children under three years of age, age guidelines for several CDEs were given as “age in months” for children 3 years and younger.
 - B) For standard diagnostic methods (for example, electrodiagnostics and imaging), clinical guidelines and protocols used in practice were examined for age guidelines.
 - C) For standardized measures and outcomes instruments, research literature was examined for psychometric properties relevant to children and youth. Our recommendations for outcomes instruments are based on the findings of psychometric studies.
- **Research Support and Expert Consensus:** Whenever possible, we used results of published research studies to guide our recommendations. In the absence of empirical support, we reviewed clinical guidelines and protocols and garnered international content expert consensus, through an iterative process of review and revision.
- **Development of New CDEs, Relevant to Pediatric SCI:** For adult CDEs that were not appropriate for pediatrics, we attempted to identify pediatric CDEs that were equivalent; this was most frequently needed in “Functional Outcome Measures,” “Quality of Life and Participation,” “Alcohol and Tobacco” and “Sleep.” We also developed new CDEs that are highly relevant for pediatric SCI but not relevant for adult SCI (Caregiver, Birth injuries, Transport and Hospitalization).

The type of neurologic injury would not substantially differ between children and adults with SCI. However, typical cognitive development is a factor for several CDEs that require patient input and report. For example, neurologic classification utilizing the International Standards for Neurological Classification of SCI Worksheet (ISNCSCI) is unreliable in youth younger than 6 years of age as children under the age of 6-8 years may not be able to self-report. Likewise, use of some diagnostic studies for research endpoints may not be easily obtainable. As an example, MRI and DTI usually require sedation in children younger than 6-7 years of age; in this age group, the risks of sedation relative to the benefit of research participation are important to consider. Likewise, electrodiagnostics may be difficult to conduct in young children.

Summary Table:

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Participant Characteristics	
General Core	Instructions: note added: "For pediatric studies, the data elements on this CRF reflect child characteristics, not caregiver characteristics."
Demographics	<p>"Additional Pediatric-Specific Elements: These elements are recommended for pediatric studies" added to form after last question, followed by pediatric-specific questions (17-26)</p> <p>Define primary caregiver for question #25 in footnote: "A primary caregiver or carer is the main person who helps a young person with spinal cord injury with his or her physical and/or emotional needs. In many cases this may be a parent, but in others it may be an extended family member or close friend."</p> <p>Add note in General Instructions: "For pediatric studies, the data elements on this form reflect child, not caregiver, characteristics (unless otherwise specified)."</p> <p>"Birthplace – Record the state of birth. Include country if outside of the US. For country name, Choose one. It may be easier to record the full name of the country and code the data later using the ISO 3166-1 alpha-2 codes.</p> <p>Language spoken fluently text and corresponding ISO 639-2 code Language written fluently text and corresponding ISO 639-2 code"</p> <p>F1737 changes: Change C00004, C00205 to Exploratory; remove C04802, C19281, C19282; Add pediatric-specific CDEs: C17396, C18751, C18386, C00012, C00202, C21647 (new), C00023, C00004, C00005, C00024, C00025, C18732, C00013 and C21660 (new)</p>
Participant History and Family History	
<i>Epidemiology/ Environmental History</i>	
Alcohol and Tobacco Use	Add in instructions: "For pediatric studies, the data elements on this CRF are classified as Supplemental for ages 12 and older."

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Alcohol Use Disorders Identification Test (AUDIT)	Class: Supplemental: "SCI-Pediatric (for ages 14 and older)" References added: Allen, J. P., Litten, R. Z., Fertig, J. B., & Babor, T. (1997). A review of research on the Alcohol Use Disorders Identification Test (AUDIT). <i>Alcohol Clin Exp Res</i> , 21(4), 613–619. Knight, J. R., Sherritt, L., Harris, S. K., Gates, E. C., & Chang, G. (2003). Validity of brief alcohol screening tests among adolescents: a comparison of the AUDIT, POSIT, CAGE, and CRAFFT. <i>Alcohol Clin Exp Res</i> , 27(1), 67–73. Change F0371 to both Adult; Pediatric
Substance Use	Add note in instructions: "For pediatric studies, the data elements on this CRF are classified as Supplemental for ages 12 and older."
Food Frequency Questionnaire (FFQ)	New form F2075: Classification: after SCI, added: "(recommended for ages 18 years and older)"
Youth Adolescent Ques.	New instrument recommendation (F2077)
Child and Diet Evaluation Tool (CADET)	New instrument recommendation (F2073)
Calcium Counts! FFQ	New instrument recommendation (F2074)
<i>Disease/Injury Related Events</i>	
Birth Injury	New form F2068 added with the following CDEs: C15985, C21621, C11066 (PVs added: Intervention(s) for neonate breathing problems during labor or while giving birth; Hypotonia (floppiness); Brachial plexus birth palsy (BPBP)), C12625 (PVs added: Bag/mask ventilation), C12631, C21620, C11078, C11079, C17983, C11080, C11083, C12604, C00724, C00723, C12628 and C12629.
Pre-Hospital Assessment	F1791: "(18 years and older)" added after Glasgow Coma Scale; the word "Glasgow" inserted between "total" and "score" after the GCS (adult) Text added to end of CRF: " Additional Pediatric-Specific Specific Elements: These elements are recommended for pediatric studies. 1. Did the participant/subject experience hypotensive episode for longer than 5 minutes? (choose one): Hypotensive episode defined as: Systolic BP <60 mm Hg for term neonates (0-28 days old) Systolic BP <70 mm Hg for infants (1 month – 12 months old) Systolic BP <70 mm Hg + (2X age in years) in children 1 year to 10

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	<p>years</p> <p>Systolic BP <90 mm Hg in children ≥ 10 years</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Suspected</p> <p><input type="checkbox"/> Unknown</p> <p>2. Did the participant/subject experience cardiac arrest? (choose one)</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Suspected</p> <p><input type="checkbox"/> Unknown</p> <p>Pediatric Glasgow Coma Scale (recommended for children < 18 years)</p> <p>1. Date and time of PGCS:</p> <p>2. Best eye response Score</p> <p>Best eye response (<i>choose one</i>):</p> <p><input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4</p> <p>1-No eye opening</p> <p>2-Eye opening to pain</p> <p>3-Eye opening to speech</p> <p>4-Eyes open spontaneously</p> <p>3. Best verbal response Score</p> <p><input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5</p> <p>1-No vocal response</p> <p>2-Inconsolable, agitated</p> <p>3-Inconsistently consolable, moaning</p> <p>4-Cries, but is consolable, inappropriate interactions</p> <p>5-Smiles, orients to sounds, follows objects, interacts</p> <p>4. Best motor response Score</p>

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	<p> <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 </p> <p>1-No motor response</p> <p>2-Extension to pain</p> <p>3-Flexion to pain</p> <p>4-Withdrawal from pain</p> <p>5-Localizing pain</p> <p>6-Obeys commands</p> <p>5.Total Glasgow Score (3-15; calculated field)</p> <p>3. Was a protective device used in the vehicle? (choose one)</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown </p> <p>4. What type of protective device was used? (choose one)</p> <p> <input type="checkbox"/> Helmet <input type="checkbox"/> Child safety restraint <input type="checkbox"/> Seat belt <input type="checkbox"/> Air bag <input type="checkbox"/> Other, specify: </p> <p>5. If child safety restraint used, indicate what type: (choose one)</p> <p> <input type="checkbox"/> Rear-facing seat <input type="checkbox"/> Forward-facing seat <input type="checkbox"/> Booster seat </p> <p>6. If seat belt used, indicate what type (choose one)</p> <p> <input type="checkbox"/> Lap belt <input type="checkbox"/> Three-point restraint <input type="checkbox"/> Five-point restraint <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown </p> <p>7. What was the position in the vehicle (choose one)</p> <p> <input type="checkbox"/> Front seat <input type="checkbox"/> Back seat <input type="checkbox"/> Other </p>

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	<p>8. Type of transport to the hospital:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ground ambulance with physician <input type="checkbox"/> Ground ambulance no physician <input type="checkbox"/> Private transportation/taxi/other from home/scene <input type="checkbox"/> By foot <input type="checkbox"/> Helicopter <input type="checkbox"/> Other, specify <p>9. For children 0-5 years, was backboard modified for transport?</p> <p>Cut-out to recess occiput:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <p>Double mattress pad to raise chest/trunk:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <p>Text added to Instructions: After GCS section: "The Pediatric Glasgow Coma Scale (PGCS) is a modified form of the GCS and is also comprised of three tests: eye, verbal and motor responses."</p> <p>Under AIS section: "Position in Vehicle: If "other" is chosen, please state where child was sitting (e.g., trunk of hatch backs; station wagons; back of pick-up trucks, etc.)."</p> <p>References added: "Pediatric-specific references: Haque IU, Zaritsky AL. Analysis of the evidence for the lower limit of systolic and mean arterial pressure in children. <i>Pediatr Crit Care Med</i>. 2007 Mar;8(2):138-44. PubMed PMID: 17273118. Herzenberg JE, Hensinger RN, Dedrick DK, Phillips WA. Emergency transport and positioning of young children who have an injury of the cervical spine. The standard backboard may be hazardous. <i>J Bone Joint Surg Am</i>. 1989 Jan;71(1):15-22. PubMed PMID: 2912996. Kirkham FJ, Newton CR, Whitehouse W. Paediatric coma scales. <i>Dev Med Child Neurol</i>. 2008 Apr;50(4):267-74. Zubrow AB, Hulman S, Kushner H, Falkner B. Determinants of blood pressure in infants admitted to neonatal intensive care units: a prospective multicenter study. Philadelphia Neonatal Blood Pressure Study Group. <i>J Perinatol</i>. 1995 Nov-Dec;15(6):470-9. PubMed PMID: 8648456."</p> <p>The following CDEs were added to F1791: C21622 (new), C05459, C21628</p>

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	<p>(new), C01020, C01022 (fixed typo in subset "cries but is consolable", C01021, C01017, C05433, C05434, C18772, C21623 (new), C21624 (new), C21625 (new), C05418, C18686, C21626 and C21627 (both new) The following CDEs were changed to Adult only: C05453, C05457, C19364, C01000, C01002, C01001, and C01016</p>
Assessments and Examinations	
<i>Hospital/Care Management</i>	
Acute Admission / Discharge	F1724: Add the following PVs for Type of ICU (2nd column): adult ICU; Pediatric ICU; ICU, unspecified: C21632
Rehabilitation Admission / Discharge	<p>F1722: Add question after #8 (new CDE C21657): "Rehabilitation facility type" with PVs: general adult rehabilitation; General pediatric rehabilitation; SCI adult rehabilitation; SCI pediatric rehabilitation; Other; Unknown Under specific instructions, add the note: "Rehabilitation facility type – "Other" includes community-based programs" Add question after #8 (new CDE C21657): "Rehabilitation facility type" with PVs: general adult rehabilitation; General pediatric rehabilitation; SCI adult rehabilitation; SCI pediatric rehabilitation; Other; Unknown</p>
<i>Physical Examinations</i>	

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Clinical Assessment	<p>Change all CDEs to "Adult, Pediatric" that were only "Adult"</p> <p>For "9. Awareness of the need to empty the bladder" add note "Note: Not Applicable includes too young to determine" on CRF and add in Disease Specific Instructions: "Note: Not applicable includes too young to determine" for C06014</p> <p>Add C19091, C19092, C21663 and C21664 (new): "14. Surgical procedures on the urinary tract:</p> <ul style="list-style-type: none"> -No -Yes -Unknown <p>If yes, indicate type of surgical procedure on the urinary tract:</p> <ul style="list-style-type: none"> -Supra-pubic catheter insertion Date last performed: Date -Bladder stone removal Date last performed: Date -Upper urinary tract stone removal Date last performed: Date -Bladder augmentation Date last performed: Date -Sphincterotomy/urethral stent Date last performed: Date -Botulinum toxin injection Date last performed: Date -Artificial sphincter Date last performed: Date -Ileovesicostomy Date last performed: Date -Ileoureterostomy Date last performed: Date -Continent catheterizable valves Date last performed: Date -Sacral anterior root stimulator Date last performed: Date -Other, specify: Date last performed: Date" <p>After " 13. Any change in urinary symptoms within the last year" (C06054) For C06186: "20. Awareness of the need to defecate (within the last four weeks)" add "Note: Not Applicable (too young to determine)"</p> <p>Page 14: add question after Scoliosis question: "56. Hip instability, subluxation and pelvic obliquity (C21629 Hip instability indicator)</p> <ul style="list-style-type: none"> - No - Yes <p>If yes, method of assessment (check all that apply) (C21630 Instability method of assessment)</p> <ul style="list-style-type: none"> - Observation - Palpation - Radiographs" <p>Add the word "Questions" after "Other Diagnoses" on page 15</p> <p>Page 15, add CDE: "74. Since your spinal cord injury, have you had any problems with your swallowing? PVs: Yes; No (C21631)</p> <p>Under General Instructions on last page of CRF: "Please note: Some questions on this form are not applicable to certain pediatric age groups and therefore do not need to be collected.</p> <p>Kids under 6 may have a difficult time reporting effects of bowel dysfunction on quality of life; choose "Unknown" in this case."</p>

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SCI Pressure Ulcer Scale (SCIPUS)	Classification added: "not recommended for youth younger than 18 years of age." Remove the pediatric age ranges under Short Description section. Change year of Mortenson, W. et al reference to 2008 (from 2007).
Braden Q Scale	New instrument recommendation (F2071)
Swallowing Disturbance Questionnaire	Add under Exploratory: "There are no references to support this measure in pediatrics; not recommended for youth < 18." New F# (separate from F0015 because of different classification from PD): F2118 (Adult only, Exploratory classification)
<i>Vital Signs and Laboratory Tests</i>	
Laboratory Tests	Move C19358 to #5 from 0; Add PV for 25-hydroxy Vitamin D, Table 11: add row for "25-Hydroxy Vitamin D"
<i>Spinal Imaging/Spinal Cord Imaging</i>	
Spinal Cord Imaging	Add note after Instrumentation paragraph: "• Pediatric: There are risks, benefits and needs for imaging studies in children under 7 who require sedation."
<i>Treatment/ Intervention Data</i>	
Rehabilitation Therapies	F1723: CDE changes: C06005 text "Date form completed" to "Date information collected" C19136 PVs changed to Yes; No; Unknown C19137 "Types of rehabilitation services" changed to "Rehabilitation services received" PVs changed to "During acute care; General in-patient rehabilitation; Specialized SCI in-patient rehabilitation; General out-patient rehabilitation; Specialized SCI out-patient rehabilitation; Other, specify" Remove C19139 C19140: Change question text to "Type of therapy" Add: PVs" Child life therapy; Exercise Physiology/Kinesiology" remove "physiatry" C19142 PVs added: Aquatic exercises/hydrotherapy; School/Education re-integration outing; Leisure/play education and counseling; Caregiver attendant education; Serial casting; Hippotherapy (therapeutic horseback riding) Remove C19144 C19145: Change PVs to "1x/wk;1-3x/mo;2-3x/wk;4-6x/wk;Daily;<1x/mo;Other, specify; Unknown;" and move their text to table on form (out of footer) C19150: Change question text to "Start Date" and C19151 to "End Date"

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	Remove C19152, C12683 Question #4 on form, add PV "Other follow-up (specify)"; C21661 (new) Additional question added to #4: "If yes," with pediatric;adult as PVs: C21662 (new)
SCI Falls Diary	New form F2069 revised ALS Clinical Milestones and Events CRF; CDEs added (all Supplemental): C10628; C21634 (new); C10629; C10630; C21635 (new); C21636 (new); C19144; C21637 (new); C21638 (new); C21639 (new); C21640 (new); C21641 (new); C21642; C21643 (both new)
Assistive/Mobility Devices and Orthoses	New form F2070: Revised from DMD External Devices and Other Treatments CRF CDEs added (all Supplemental): C12679, C12683 (Changed PVs to Manual wheelchair;Power wheelchair;Power assist wheelchair; Other, specify), C12684, C12685, C18183, C18188 (Add "Mobile Standers;Standing wheelchairs" to PVs), C19067, C12682 (Change text to "Does the participant/subject use lower extremity orthoses and assistive devices"), C12943 (add PVs Walker; Crutches; Cane), C18883, C12686, C18195, C18198, C12688 new CDEs: C21644, C21645, C21648, C21646, C21649, C21650, C21651, C21652, C21653, C21654, C21655, C21656
Outcomes and Endpoints	
<i>Neurological Outcomes</i>	
ISNCSCI	Add Pediatric recommendations to end of document; update CDE classifications for F0826 to Core for children age 6 and older (disease-specific instructions) and change classification to Adult/Pediatric
Modified Ashworth Scale	New form F2119; Pediatric only and Exploratory CDEs Add to form classification: "Exploratory: SCI – Pediatric " Rationale: "SCI-Pediatric: The Modified Ashworth Scale is relevant and appropriate, but has only adequate reliability and validity in pediatric SCI."
Tardieu Scale	F0950: Supplemental for Adult; Pediatric for FA and SCI Add "and SCI-Pediatric" on Exploratory; Rationale: "SCI-Pediatric: No current studies done with children; research is needed"
Spinal Cord Assessment Tool for Spastic Reflexes	Add: "and SCI-Pediatric" to classification on form Rationale: "SCI – Pediatric: Relevant and appropriate for children; pinprick may be problematic in young children as found by Mulcahey et al. 2011. Future research is needed."
NINDS Myotatic Reflex Scale	Add: Exploratory:"SCI-Pediatric" on form Rationale: "SCI-Pediatric-specific: Relevant and appropriate, but there are no studies done in youth."

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Penn Spasm Frequency Scale	<p>Classification: Exploratory for SCI-Peds (as patient/caregiver patient reported outcomes).</p> <p>Add note in Rationale section: "SCI-Pediatric-specific: No Studies with children, but relevant and appropriate with children. No age recommendation in literature. Future research is needed."</p>
Pendulum (Wartenberg) Test	<p>Add, "and SCI-Pediatric" to classification</p> <p>Rationale: "SCI-Pediatric-specific: No modifications needed for children age 30 months and older."</p>
<i>Electrodiagnostics</i>	
Peripheral Nerve Studies	<p>Add in instructions: SCI-Pediatric Specific Instructions:</p> <p>"Testing may be uncomfortable and not tolerated well by children if sensation is present. In general these tests should be performed only when there is clinical cause, not as part of studies. It may be beneficial to do a shortened exam (i.e. one UE and one LE only) as in reference below.: Kang, PB., MD. Pediatric Nerve Conduction Studies and EMG. The Clinical Neurophysiology Primer. 2007 pp 369-389."</p>
Quantitative Sensory Testing	<p>Instructions: "Although relevant for pediatrics, in its current form is likely to not be tolerated well by younger children. Subjects need to report intensity of stimulation and this may be difficult for younger children. The data elements on this form are recommend as Supplemental for SCI-Pediatric studies and should only be collected if the research team considers them appropriate for their study. In general these tests should only be performed when there is clinical cause, not as part of studies. QST is previously not tested in children younger than 6 years old and is recommended for children 8 years and older."</p> <p>Add: "Pediatric-Specific References Savic, G., Bergstrom, E. M., Davey, N. J., Ellaway, P. H., Frankel, H. L., Jamous, A., & Nicotra, A. (2007). Quantitative sensory tests (perceptual thresholds) in patients with spinal cord injury. J Rehabil Res Dev, 44(1), 77-82."</p> <p>Add note in Disease-specific instructions for all F1732 CDEs: "QST is previously not tested in children younger than 6 years old and is recommended for children 8 years and older."</p> <p>Change C18024 & C18027 to Adult; Pediatric</p>
Electrical Perceptual Threshold	<p>Add note in instructions, "SCI-Pediatric Specific Instructions: The data elements on this CRF module are recommended as Exploratory because they require verbal responses from the person being tested so not appropriate for all age groups. The elements have not been widely used clinically. In general these tests should only be performed when there is clinical cause, not as part of studies"</p> <p>F1739: Change to Adult (Supplemental) and make new form F2076 Electrical Perceptual Threshold - Pediatric (all CDEs are Pediatric, Exploratory)</p>

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Sensory Evoked Potentials	<p>Instructions: "SCI-Pediatric Specific Instructions: The data elements on this CRF module are recommended as Supplemental as they are relevant and appropriate for pediatrics in current form. Somatosensory evoked potentials are predictive of ambulatory capacity and hand function."</p>
Motor Evoked Potentials	<p>Add note under general instructions: "SCI-Pediatric Specific Instructions: The data elements on this CRF module are recommended as Supplemental as they are relevant and appropriate for pediatrics in current form." Add C21659 to F1780</p>
Brain Motor Control Assessment	<p>Two forms posted on website: F1795 (only Adult CDEs) and F2082 (only Pediatric CDEs) Add pediatric-specific recommendations to end of pediatric form: "SCI-Pediatric Specific Recommendations The elements on this form are recommended as Exploratory for SCI-Pediatric studies. Duration of test is long and may be difficult for children to endure since subject needs to be lying supine and cooperative during testing. Additionally, subject needs to follow directions of test. Lower age limit could be around 8 years of age but would depend on subject and maturity. Reference: Zoghi M, Galea M, Morgan D. A Brain Motor Control Assessment (BMCA) protocol for upper limb function. PLoS One. 2013 Nov 4;8(11):e79483." Add "SCI Version 1.0" to footer in pediatric form Change F1795 to Adult only (Supplemental CDEs) and make new form F2082: Pediatric, all CDEs Exploratory</p>
Sympathetic Skin Responses	<p>Under General Instructions: "SCI-Pediatric Specific Instructions: The data elements on this CRF module are relevant and appropriate for pediatrics in their current form and are recommended as Supplemental. In general these tests should be performed only when there is clinical cause, not as part of studies" References: "Pediatric-Specific Reference Zheng, Z., Liu, G., Chen, Y. and Wei, S. Olfactory ensheathing cell transplantation improves sympathetic skin responses in chronic spinal cord injury. Neural Regen Res. 2013 Oct 25; 8(30): 2849–2855. "</p>
<i>Functional Outcomes</i>	

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Berg Balance Scale	<p>Classification: Add "Not recommended for youth < 18" after SCI</p> <p>Comments: "SCI-Pediatric: Pediatric Balance Scale, has been evaluated in children age 5-15 with known balance impairments. Shows good test-retest and inter-rater reliability. Child must be able to follow directions. It has not been evaluated specifically for children with SCI."</p> <p>Reference added for pediatric: "SCI-Pediatric Specific: Franjoine MR, Gunther JS, Taylor MJ. Pediatric balance scale: a modified version of the berg balance scale for the school age child with mild to moderate motor impairment."</p> <p>Add additional link for pediatric modification to Berg Balance Scale in Availability section</p> <p>Change classification for F2031 to Supplemental – Highly Recommended (Adult only)</p>
Quadriplegia Index of Function	<p>Classification section: "Spinal Cord Injury (SCI); not recommended for youth < 18 years"</p> <p>Comments: "SCI-Pediatric specific: There are no psychometric studies of the QIF in children. While some of the items are appropriate for younger child, in its entirety, it could be used in children aged 16 and older."</p>
SCI-Functional Ambulation Inventory (SCI-FAI)	<p>Classification add: "Spinal Cord Injury (SCI) and Pediatric SCI (ages 18 and over) Exploratory: Pediatric SCI (ages 2-18)"</p> <p>Comments: "Pediatric SCI: This has only been evaluated in adults at this point. It does show excellent reliability and validity in adults with SCI. Items seem appropriate for children."</p>
Sollerman Hand Function Test	<p>Classification add: "not recommended for youth < 20"</p> <p>Comments: "SCI-Pediatric specific: There are no psychometric studies of the Sollerman Test of Hand Function (Sollerman & Ejeskar, 1995) in children. The only pediatric related study was with young adults with pediatric onset of TBI (Ahlander, et al., 2013)."</p>
SCI-Functional Index (SCI-FI)	<p>Add to Classification: "not recommended for youth < 18"</p> <p>Comments: "SCI-Pediatric specific: To date the SCI-FI has only been evaluated in adults. A current ongoing study is evaluating the ability to link the Pediatric SCI CAT with the SCI-FI CAT for use in the pediatric population."</p> <p>References: "SCI-Pediatric specific: Jette AM, Tulskey DS, Ni P et al. Development and initial evaluation of the spinal cord injury-functional index. Arch Phys Med Rehabil. 93(10) 2012. Calhoun CL, Haley SM, Riley A, Vogel LC, McDonald CM, Mulcahey MJ. Development of items designed to evaluate activity performance and participation in children and adolescents with spinal cord injury. Int J Pediatr. 2009(854904): 2009 doi: 10.1155/2009/854904"</p>

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Activities Based Level Evaluation (ABLE) Scale	Add: "not recommended for youth < 18" Comments: "SCI-Pediatric specific: There are no studies with children. Performance items appear appropriate for kids of typically sitting, standing and walking age. Self-report items are too complex for child."
10 M Timed Walk	Classification: SCI-Pediatric-Supplemental (age 2 years and over); Comments/special instructions: "SCI-Pediatric: Assistive devices can be used but should be kept consistent and documented. Collect 3 trials and calculate the average of the 3 trial times."
2 Minute Walk	Add Exploratory: "and SCI-Pediatric (age 4-18): Comments: "SCI-Pediatric-specific: Assistive devices can be used but should be kept consistent and documented."
6 Minute Walk Test	For Supplemental, add: "SCI-Pediatric (age 4 and over)" In comments, add: "SCI-Pediatric-Specific: Assistive devices can be used but should be kept consistent and documented."
Bayley Scales of Infant Development	New for SCI (F1475); Exploratory: SCI-Pediatric (age 1 month-42 months) Under short description: "SCI-Pediatric comments: Designed to measure the developmental functioning of infants and toddlers. Motor- includes Fine and Gross Motor subtests. Fine motor (66 items) includes testing of eye movements, perceptual-motor integration, motor planning and motor speed. Gross motor (72 items) measures movement of the limbs and torso." Under Recommendations/comment: "SCI-Pediatric: Has many items on cognitive development" Reference added: SCI-Pediatric: Nellis L., Grdiley BE. (1994) Review of the Bayley Scales of Infant Development--Second Edition. Journal of School Psychology, 32, 201-209.
Borg Rating of Perceived Exertion Scale	Edit classification section: "Supplemental – Highly Recommended: Exercise Studies in Mitochondrial Disease Exploratory: Spinal Cord Injury (SCI) and SCI-Pediatric (age 10 and over)" References added: "SCI-Pediatric-specific: Hommerding PX1, Donadio MV, Paim TF, Marostica PJ. The Borg scale is accurate in children and adolescents older than 9 years with cystic fibrosis. Respir Care. 2010 Jun;55(6):729-33. ReYelling M, Lamb KL and Swaine IL. Validity of a pictorial perceived exertion scale for effort estimation and effort production during stepping exercise in adolescent children. 2002. European Physical Education Review [1356–336X(200206)8;2] Volume8(2):157–175:024780." Comments: "SCI-Pediatric-specific: Reliability of measures using pictures is better established in children. Cognitive testing for Borg is not available and should be limited to kids >10 with consideration for their understanding."

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Bruininks-Oseretsky Test of Motor Proficiency	<p>New for SCI, add F1648; Classification: Exploratory: Spinal Cord Injury (SCI)-Pediatric (age 4-12 years)</p> <p>Add Comments/Special Instructions section: "SCI-Pediatric-specific: Fine motor can be done from wheelchair level. All gross motor items require ambulation."</p> <p>References: "SCI-pediatric specific reference: There have been no studies in children with SCI."</p> <p>Update general reference: Bruininks, R. H. and B. D. Bruininks. (2005). "Bruininks-Oseretsky Test of Motor Proficiency Second Edition (BOT™-2)" Retrieved 24 February, 2015, from http://www.pearsonclinical.com/therapy/products/100000648/bruininks-oseretsky-test-of-motor-proficiency-second-edition-bot2.html?Pid=PAa58000.</p>
Capabilities of Upper Extremity Questionnaire (CUE-Q)	<p>Classification: Supplemental: "and SCI-Pediatric (age 16 and over)" Exploratory: SCI-Pediatric (age 6-15)</p> <p>Rationale/justification: add: "SCI-Pediatric-specific: Psychometric properties were established on 16-70 yo. Reliability and validity are being investigated in children by Mulcahey et al."</p> <p>Reference: move Marino, Mulcahey, et al. reference to pediatric-specific section</p>
Canadian Occupational Performance Measure (COPM)	<p>Classification: SCI-Pediatric (age 2 and over for parent report; age 6 and over for child report)</p> <p>Change Construct Measured from "Activities of Daily living, mobility, participation" to "Performance and satisfaction in leisure productivity and self-care from client perspective."</p> <p>References: Add to SCI-Ped specific section: Cusick, A., Lannin, N. and Lowe, K. (2007). Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. <i>Disabil Rehabil.</i> 30;29(10):761-6.</p> <p>Moved from general SCI to pediatric-specific section (and revised): Cusick, A., McIntyre, S., Novak, I., Lannin, N., & Lowe, K. (2006). A comparison of goal attainment scaling and the Canadian Occupational Performance Measure for paediatric rehabilitation research. <i>Pediatr Rehabil</i>, 9(2), 149–157.</p> <p>Mulcahey, M. J., Smith, B. T., Betz, R. R., & Weiss, A. A. (1995). Outcomes of tendon transfer surgery and occupational therapy in a child with tetraplegia secondary to spinal cord injury. <i>Am J Occup Ther</i>, 49(7), 607–617.</p>

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Capabilities Upper Extremity Test (CUE-T)	<p>Classification add: "SCI-Pediatric (age 16 years and over; not recommended for children under 16)"</p> <p>Rationale/justification: "SCI-Pediatric-specific: Demonstrated to be reliable and valid in adult populations. Currently undergoing revision to improve sensitivity. Reliability and validity are being investigated in children by Marino et al. (2015)"</p> <p>References:"There are no published psychometric studies on the CUE-T in youth with SCI."</p> <p>Revised under general SCI references: Marino, R. J., Kern, S. B., Leiby, B., Schmidt-Read, M., & Mulcahey, M. J. (2015). Reliability and validity of the capabilities of upper extremity test (CUE-T) in subjects with chronic spinal cord injury. <i>J Spinal Cord Med</i>, 38(4), 498–504.</p>
Five Times Sit to Stand Test	<p>Add: "and SCI-Pediatric (age 4 and over)"</p> <p>Add reference: "SCI-Pediatric: Kumban, W., Amatachaya, S., Emasithi, A., Siritaratiwat, W. (2013). Five-times-sit-to stand test in children with cerebral palsy: Reliability and concurrent validity. <i>Neurorehabilitation</i>. 32(1):9-15."</p>
Grasp and Release Test	<p>Add: "and SCI-Pediatric (age 7 years and over)" to classification</p> <p>Added pediatric references: Velstra, I. M., Ballert, C. S., & Cieza, A. (2011). A systematic literature review of outcome measures for upper extremity function using the international classification of functioning, disability, and health as reference. <i>Physical Therapy</i>, 3(9), 846–860.</p> <p>Move the two Mulcahey references to pediatric-specific section.</p>
GRASSP	<p>Add: "and SCI-Pediatric (age 5 and over)" to classification</p> <p>Comments: "SCI-Pediatric-specific: Validation in children currently under way."</p>
Gross Motor Function Measure (GMFM)	<p>New for SCI; Add F1596</p> <p>Classification: Exploratory: "and Spinal Cord Injury (SCI)-Pediatric (5 months to 16 years)"</p> <p>Comments: "The GMFM 88 is a validated, age-appropriate tool for children with severe neurological and neuromuscular impairment. While currently validated for children with cerebral palsy (5 months to 16 years), the instrument considers quality of movement and is designed to track change over time. The GMFM does not provide age equivalency; all items are able to be performed by a typically developing 5 year old. Allows for testing of all motor skills, allowing children to demonstrate strength in any skill area, rather than cutting off due to inability to perform a particular skill.</p> <p>There are no studies of the GMFM for youth with SCI."</p> <p>Add general references: Russell, D., Rosenbaum, P., Cadman, D., Gowland, C., Hardy, S., and Jarvis, S. (1989). The Gross Motor Function Measure: a means to evaluate the effects of physical therapy. <i>Dev Med Child Neurol</i> 31, 341-352.</p>

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
	Alotaibi M, Long T, Kennedy E, Bavishi S. The efficacy of GMFM-88 and GMFM-66 to detect changes in gross motor function in children with cerebral palsy (CP): a literature review. Disabil Rehabil.
Intl SCI Upper Extremity Basic Data Set	Changes for F1748: change to Supplemental – Highly Recommended and Adult; Pediatric; under disease-specific references add: http://www.nature.com/sc/journal/v52/n9/full/sc201487a.html
Jebsen Taylor Hand Function Test	Add "and SCI-Pediatric (age 6 years and over)" to Supplemental classification section.
Neuromuscular Recovery Scale	<p>Add "and SCI-Pediatric (over 12 years old)" to classification</p> <p>Add to comments: "Psychometric studies in adults show: Strong test-retest ($r=+.92$); inter-rater reliability ($W=.82-.89$) and better responsiveness than comparative measures.</p> <p>SCI-Pediatric-specific:</p> <p>The NMR Scale is not indicated for youth 12 years old and younger. Work is under way to develop a pediatric version (see Pediatric Neuromuscular Recovery Scale)."</p> <p>References added: Basso, D. M., C. Velozo, D. Lorenz, S. Suter and A. L. Behrman (2015). Interrater reliability of the Neuromuscular Recovery Scale for spinal cord injury. Arch Phys Med Rehabil 96(8): 1397–1403.</p> <p>Tester, N. J., D. J. Lorenz, S. P. Suter, J. J. Buehner, D. Falanga, E. Watson, C. A. Velozo, A. L. Behrman and D. Michele Basso (2015). Responsiveness of the Neuromuscular Recovery Scale During Outpatient Activity-Dependent Rehabilitation for Spinal Cord Injury. Neurorehabil Neural Repair. In Press.</p>
Pediatric Neuromuscular Recovery Scale	New instrument recommendation (F2081)
NIH Neuro-QoL Pediatric Functional Health (Quality of life in Neurological Disorders Pediatric Functional Health)	New instrument recommendation (F2116)

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Nine Hole Peg Test	<p>Add: "SCI-Pediatric (age 4 years and over)" to Exploratory classification Rationale: "SCI-Pediatric-specific: Normative data and validation complete to 4 yo. Add to References: "Pediatrics: Poole, J. L., Burtner, P. A., Torres, T. A., McMullen, C. K., Markham, A., Marcum, M. L., . . . Qualls, C. (2005). Measuring dexterity in children using the Nine-hole Peg Test. <i>J Hand Ther</i>, 18(3), 348–351. Smith, Y. A., Hong, E., & Presson, C. (2000). Normative and validation studies of the Nine-hole Peg Test with children. <i>Percept Mot Skills</i>, 90(3 Pt 1), 823–843. "</p>
Pediatric SCI Activity Measure (PEDI-SCI AM)	<p>New instrument recommendation (F2083)</p>
Peabody Developmental Motor Scales	<p>New for SCI, add F1923; Add in Classification: "Exploratory: Spinal Cord Injury (SCI)-Pediatric (ages 0-5 years)" Pediatrics references added: "Pediatric: Connolly, B. H., N. O. McClune and R. Gatlin (2012). Concurrent validity of the Bayley-III and the Peabody Developmental Motor Scale-2. <i>Pediatr Phys Ther</i> 24(4): 345–352. Darrah, J., J. Magill-Evans, J. Volden, M. Hodge and G. Kembhavi (2007). Scores of typically developing children on the Peabody Developmental Motor Scales: infancy to preschool. <i>Phys Occup Ther Pediatr</i> 27(3): 5–19. Folio, M. R. and R. R. Fewell. (2000). Peabody Developmental Motor Scales, Second Edition (PDMS-2). Retrieved 11 January, 2016, from http://www.pearsonclinical.com/therapy/products/100000249/peabody-developmental-motor-scales-second-edition-pdms-2.html Gebhard, A. R., K. J. Ottenbacher and S. J. Lane (1994). Interrater reliability of the Peabody Developmental Motor Scales: fine motor scale. <i>Am J Occup Ther</i> 48(11): 976–981. Hinderer, K. A., P. K. Richardson and S. W. Atwater (1989). Clinical implication of the peabody developmental motor scales: a constructive review. <i>Phys Occup Ther Pediatr</i> 9(2): 81–106. van Hartingsveldt, M. J., E. H. Cup and R. A. Oostendorp (2005). Reliability and validity of the fine motor scale of the Peabody Developmental Motor Scales-2. <i>Occup Ther Int</i> 12(1): 1–13. Wang, H. H., H. F. Liao and C. L. Hsieh (2006). Reliability, sensitivity to change, and responsiveness of the peabody developmental motor scales-second edition for children with cerebral palsy. <i>Phys Ther</i> 86(10): 1351–1359."</p>

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Pediatric Evaluation of Disability Inventory (PEDI)	<p>New for SCI, add F1606; Classification: "Supplemental – Highly Recommended: Spinal Cord Injury (SCI)-Pediatric (ages 6 months to 7 years)"</p> <p>Description: "The Pediatric Evaluation of Disability Inventory (PEDI) is a descriptive measure of a child’s current functional capabilities performance and also tracks changes over time (Haley, Coster et al. 1992, Haley, Coster et al. 1992, Haley, Coster et al. 2010). The PEDI has been developed into a CAT and SF. The PEDI-CAT™ is a computerized adaptive test version (Haley, Coster et al. 2012). The PEDI measures both capability and performance of functional activities in three content areas: Self-care, Mobility and Social Function (Boston University 2016). The PEDI-CAT™ also measures abilities across three functional domains of Daily Activities, Mobility and Social/Cognitive and “can be used across all clinical diagnoses and community settings.”(Boston University 2016). It also includes a Responsibility domain that measures the extent that a caregiver or child takes “responsibility for managing complex, multi-step life tasks.” (Dumas and Fragala-Pinkham 2013, Boston University 2016)."</p> <p>SCI-peds references: “SCI-Pediatric: Choksi, A., E. L. Townsend, H. M. Dumas and S. M. Haley (2010). Functional recovery in children and adolescents with spinal cord injury. <i>Pediatr Phys Ther</i> 22(2): 214–221. Choong, K., S. Al-Harbi, K. Siu, K. Wong, J. Cheng, B. Baird, D. Pogorzelski, B. Timmons, J. W. Gorter, L. Thabane, M. Khetani and Canadian Clinical Care Trial Group (2015). Functional recovery following critical illness in children: the "wee-cover" pilot study. <i>Pediatr Crit Care Med</i> 16(4): 310–318. Coster, W. J., S. M. Haley, P. Ni, H. M. Dumas and M. A. Fragala-Pinkham (2008). Assessing self-care and social function using a computer adaptive testing version of the pediatric evaluation of disability inventory. <i>Arch Phys Med Rehabil</i> 89(4): 622–629. Dumas, H. (2001). "Clinical review of the pediatric evaluation of disability inventory. <i>Pediatr Phys Ther</i> 13(1): 47–48. Dumas, H. M. and M. A. Fragala-Pinkham (2012). Concurrent validity and reliability of the pediatric evaluation of disability inventory-computer adaptive test mobility domain. <i>Pediatr Phys Ther</i> 24(2): 171–176; discussion 176. Dumas, H. M., M. A. Fragala-Pinkham, S. M. Haley, P. Ni, W. Coster, J. M. Kramer, Y. C. Kao, R. Moed and L. H. Ludlow (2012). Computer adaptive test performance in children with and without disabilities: prospective field study of the PEDI-CAT. <i>Disabil Rehabil</i> 34(5): 393–401."</p>
Pediatric PROMIS Measures	New instrument recommendation (F2117)

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Spinal Cord Independence Measure(SCIM)	Classification section; "Exploratory: SCI-Pediatric (up to 18 years)" Comments: "SCI-Pediatric-specific: There are no reported psychometric studies of the SCIM-III with youth with SCI. A current multi-center study is under way." Intended responded changed from "Participant" to "The measure was developed as a performance measure but has also been used in an interview (with participant) and self-report format."
SCIMeasure-Self Report for youth	New instrument recommendation (F2115)
Segmental Assessment of Trunk Control	New instrument recommendation (F2086)
Stair Climb Guidelines	Add to Classification: "and SCI-Pediatric (age 4 and over)" Add to comments: "SCI-Pediatric-specific: Assistive devices can be used but should be kept consistent and documented." Add to References: Finch, E., Walsh, M., Thomas, S. G., & Woodhouse, L. J. (1998). Functional ability perceived by individuals following total knee arthroplasty compared to age-matched individuals without knee disability. <i>J Orthop Sports Phys Ther</i> , 27(4), 255–263. Kennedy, D., Stratford, P. W., Pagura, S. M., Walsh, M., & Woodhouse, L. J. (2002). Comparison of gender and group differences in self-report and physical performance measures in total hip and knee arthroplasty candidates. <i>J Arthroplasty</i> , 17(1), 70–77. Lin, Y. C., Davey, R. C., & Cochrane, T. (2001). Tests for physical function of the elderly with knee and hip osteoarthritis. <i>Scand J Med Sci Sports</i> , 11(5), 280–286. Rejeski, W. J., Ettinger, W. H., Jr., Schumaker, S., James, P., Burns, R., & Elam, J. T. (1995). Assessing performance-related disability in patients with knee osteoarthritis. <i>Osteoarthritis Cartilage</i> , 3(3), 157–167. Under Other information about this instrument, add: "Bennell, K., Dobson, F., & Hinman, R. (2011). Measures of physical performance assessments: Self-Paced Walk Test (SPWT), Stair Climb Test (SCT), Six-Minute Walk Test (6MWT), Chair Stand Test (CST), Timed Up & Go (TUG), Sock Test, Lift and Carry Test (LCT), and Car Task. <i>Arthritis Care Res (Hoboken)</i> , 63 Suppl 11, S350–S370."
Stride Analysis and Gait Variability	Add: " and SCI-Pediatric (age 3 and over)" to supplemental classification; Comments: SCI-Pediatric specific: "Best used for intra-subject analysis, as normative data for pediatrics is unavailable."
Tetraplegia Hand Activity Questionnaire	Add: "and SCI-Pediatric (age 12 and over)" to Exploratory classification Comments: "Face validity established through Delphi Methods. No other psychometric properties have been assessed."

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Timed Up and Go	<p>F1349; Add in Classification: "and Spinal Cord Injury (SCI)-Pediatric (age 3 and over)"</p> <p>Rationale: "SCI-Pediatric specific: Studies investigating typically developing children as well as children with cerebral palsy and traumatic brain injury found it is a good tool to assess mobility in the pediatric population, as young as 3 years of age. The child must be able to follow directions. It has not been evaluated specifically with children with SCI."</p> <p>References: SCI-Pediatric: Nicolini-Panisson, R. D., & Donadio, M. V. (2013). Timed "Up & Go" test in children and adolescents. <i>Rev Paul Pediatr</i>, 31(3), 377–383.</p> <p>Williams, E. N., Carroll, S. G., Reddihough, D. S., Phillips, B. A., & Galea, M. P. (2005). Investigation of the timed 'up & go' test in children. <i>Dev Med Child Neurol</i>, 47(8), 518–524."</p>
Walking Index in SCI	<p>Add: "and SCI-Pediatric (age 3 and over)"</p> <p>Rationale: "SCI-Pediatric-specific: One pilot study (Calhoun, et al., 2012) to date examines the use of the WISCI in children. This pilot study recruited children as young as 5 but younger children may be able to participate if they are able to walk and understand directions. Based on discussion with clinicians, it is possible to use the measure with children as young as 3 years of age."</p> <p>Reference: "SCI-Pediatric: Calhoun CL, Mulcahey MJ. Pilot study of reliability and validity of the Walking Index for Spinal Cord Injury II (WISCI-II) in children and adolescents with spinal cord injury. <i>Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach</i>. 5(4): 2012."</p>
Functional Independence Measure for Children (WeeFIM)	<p>New for SCI; Add F1941; In Classification, add: "Spinal Cord Injury (SCI)-Pediatric (age 0 to 7 years)"</p> <p>Under Short Description: "SCI-Pediatric-specific: The WeeFIM® instrument may be used with children above the age of 7 years as long as their functional abilities, as measured by the WeeFIM® instrument, are below those expected of children aged 7 who do not have disabilities.</p> <p>To use the FIM and WeeFIM assessors, need to attend training and pass an online exam to become credentialed. Once an assessor has passed the exam, credentialing remains valid for two years, after which time the exam must be sat again. Also there is a cost to use for research."</p> <p>Add in References: "SCI-Pediatric: Garcia, R. A., Gaebler-Spira, D., Sisung, C., & Heinemann, A. W. (2002). Functional improvement after pediatric spinal cord injury. <i>Am J Phys Med Rehabil</i>, 81(6), 458–463.</p> <p>Prosser, L. A. (2007). Locomotor training within an inpatient rehabilitation program after pediatric incomplete spinal cord injury. <i>Phys Ther</i>, 87(9),</p>

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
	1224–1232."
Wheelchair Skills Test	<p>Add in Classification: "Spinal Cord Injury (SCI) and SCI-Pediatric (age 6 and over)" to Supplemental and "Exploratory: SCI-Pediatric (under 6 years)"</p> <p>Rationale: "SCI-Pediatric specific: Some items (reaching over head and reaching to the floor) may be difficult for smaller children or those in a higher wheelchair."</p> <p>References added: "SCI-Pediatric: Sawatzky B, Hers N and MacGillivray MK. Relationships between wheeling parameters and wheelchair skills in adults and children with SCI. Spinal Cord advance online publication, 17 February 2015; doi:10.1038/sc.2015.29 Sawatzky B, Rushton PW, Denison I, McDonald R. Wheelchair skills training programme for children: a pilot study. Aust Occup Ther J. 2012 Feb;59(1):2-9. doi: 10.1111/j.1440-1630.2011.00964.x. Epub 2011 Dec 5."</p>
Wheelchair Circuit	In Classification, add: "and SCI-Pediatric (age 5 and over)"
<i>Pain</i>	
Children's Activity Limitations Interview (CALI)	New instrument recommendation (F2088)
Functional Disability Inventory (FDI)	<p>Add in Classification: "Supplemental: Spinal Cord Injury (SCI)-Pediatric"</p> <p>Reference added: Kashikar-Zuck, S., Flowers, S. R., Claar, R. L., Guite, J. W., Logan, D. E., Lynch-Jordan, A. M., . . . Wilson, A. C. (2011). Clinical utility and validity of the Functional Disability Inventory among a multicenter sample of youth with chronic pain. <i>Pain</i>, 152(7), 1600–1607.</p>
Adolescent and Pediatric Pain Tool	New instrument recommendation (F2090)
Multidimensional Pain Inventory - Pain Severity Subscale	<p>Add: "Exploratory: Sci-Pediatric (age 12 and over) to Classification</p> <p>Comments: "SCI-Pediatric-specific: Given that pain severity is really intended to refer to a broader concept (e.g. suffering) the MPI Pain Severity Subscale is likely only really appropriate for older children."</p>
Faces Pain Scale - Revised	New instrument recommendation (F2114)
<i>Participation and Quality of Life</i>	
Child Health Questionnaire Youth Version	New for SCI F1484; Add: "and Spinal Cord Injury (SCI)-Pediatric" to Classification

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Pediatric Measure of Participation (PMoP) CAT of SF	New instrument recommendation (F2092)
Child and Adolescent Scale of Participation (CASP)	New for SCI F1848; Add: "Exploratory: Spinal Cord Injury (SCI)-Pediatric" to Classification
Short Form 36-Item Health Survey (SF-36)	New for SCI F2122; Add to classification: "Exploratory: Spinal Cord Injury (SCI)-Pediatric"
Satisfaction With Life Scale-Child (SWLS-C)	New instrument recommendation (F2095)
Euro-QoL 5 Dimension Questionnaire	New instrument recommendation (F2096)
Psychological Status	
Generalized Anxiety Disorder (GAD-7)	Add to Classification: "Exploratory: SCI-Pediatric (ages 12 and older, but there is currently no pediatric data)" Comments: "SCI-Pediatric specific: Normative data is with the adult population." New F2120: Pediatric, Exploratory; add "(Pediatric CDEs)" to name field
Hospital Anxiety and Depression Scale (HADS)	Change classification to "Supplemental – Highly Recommended: Spinal Cord Injury (SCI) Supplemental: Amyotrophic Lateral Sclerosis (ALS), Headache, Huntington’s Disease (HD), Parkinson’s Disease (PD) and SCI-Pediatric (ages 12 and older)" Psychometric properties: "SCI-Pediatric specific notes: The scale is validated in individuals over 17 years; there is some data for children ages 12-17."
Impact Event Scale (IES)	Add under classifications: "*Note: not recommended for Pediatric SCI" Comments: "SCI-Pediatric specific: This scale is normed for adults; study found a number of items misinterpreted by children."
Children Impact of Traumatic Event Scale (CITES-13)	New instrument recommendation (F2097)
Children PTSD Symptom Scale (CPSS)	New instrument recommendation (F2098)

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Moorong Self-Efficacy Scale (MSEST)	Add: "*Note: Not recommended for SCI-Pediatric (no child data; normed with adults only)"
Multidimensional Scale of Perceived Social Support	Add in Classification: "and SCI-Pediatric (ages 12 and over)"
Patient Health Questionnaire-9 (PHQ-9)	Change classification section to "Supplemental –Highly Recommended: Spinal Cord Injury (SCI) and SCI-Pediatric (ages 12 and older) Supplemental: Epilepsy, Headache and Traumatic Brain Injury (TBI)" Change F2032 to Supplemental - Highly Recommended classification and add note in Disease-Specific Instructions: "Ages 12 and older."
Perceived Manageability Scale (PMnac)	Add in Classification: "Supplemental: Spinal Cord Injury (SCI) *Note: Not recommended for SCI-Pediatric (normed for adults only)"
Positive Affect and Well-Being Scale of the Neurology Quality of Life (Neuro-QOL) Measure	Add in Classification: "*Note: Not recommended for SCI-Pediatric (normed for adults only)"
Children’s Depression Inventory (CDI-2)	New for SCI F1398; Add in Classification: " and Spinal Cord Injury (SCI)-Pediatric" Add references: Anderson, C. J., Kelly, E. H., Klaas, S. J., Russell, H., Daharsh, E., & Vogel, L. C. (2009). Anxiety and depression in children and adolescents with spinal cord injuries. <i>Dev Med Child Neurol</i> , 51(10), 826–832. Flanagan, A., Kelly, E. H., & Vogel, L. C. (2013). Psychosocial outcomes of children and adolescents with early-onset spinal cord injury and those with spina bifida. <i>Pediatr Phys Ther</i> , 25(4), 452–459. Garma, S. I., Kelly, E. H., Daharsh, E. Z., & Vogel, L. C. (2011). Health-related quality of life after pediatric spinal cord injury. <i>J Pediatr Psychol</i> , 36(2), 226–236.
Beck Youth Inventories- 2 nd Edition (Depression, Anxiety, Anger, Self-Construct, Disruptive Behavior)	New instrument recommendation (F2100)
Revised Children's Manifest Anxiety Scale (RCMAS) 2nd Edition	New instrument recommendation (F2101)

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
<i>Sleep</i>	
AASM: International Classification of Sleep Disorders Criteria	In Classification add: "Supplemental: Parkinson's Disease (PD), Spinal Cord Injury (SCI) and SCI-Pediatric"
Adolescent Sleep Wake Scale (ASWS)	New instrument recommendation (F2102)
Infant Sleep Questionnaire	New instrument recommendation (F2103)
Tayside Children's Sleep Questionnaire	New instrument recommendation (F2104)
Epworth Sleepiness Scale (ESS) - Children's Version	New instrument recommendation (F2105)
Functional Outcomes of Sleep Questionnaire (FOSQ)	Under Classification add: "**Not recommended for SCI-Pediatric" Short description: "SCI-Pediatric specific: Not appropriate in current form for child report."
Adolescent Sleep Hygiene Scale (ASHS)	New instrument recommendation (F2107)
Berlin Questionnaire	F0781; Add note to classification: "**Note: not recommended for SCI-Pediatric"
Obstructed Sleep Apnea- 18 (OSA-18)	New instrument recommendation (F2109)
Brief Infant Sleep Questionnaire (BISQ)	New instrument recommendation (F2110)
Children's Sleep Habits Questionnaire (CSHQ)- Preschool and school-age	New instrument recommendation (F2111)
Children's Sleep Habits Questionnaire (CSHQ)- Older child/ Adolescent	New instrument recommendation (F2112)
Pediatric Sleep Questionnaire (PSQ)	New instrument recommendation (F2113)

Domain/ Subdomain / Case Report Form or Instrument	Pediatric Revisions
Pittsburgh Sleep Quality Index (PSQI)	Add F2123 for Adult; Pediatric SCI (both Exploratory); Add "and SCI-Pediatric" to Exploratory Classification Short description (under weaknesses) add:"SCI-Pediatric-specific: Frequently used in adults, but no data in children. Most questions will be applicable to children, but more appropriate for parent report or adolescents to complete."

There are several unique features of pediatric-onset SCI that warranted the development of additional CDEs, such as:

1. Pediatric-specific etiologies (birth-related SCIs and lap-belt injuries)
2. Sociodemographic features (such as educational and employment) variables distinguishing the child with SCI versus their caregivers (parents)
3. Cognitive development affecting use of adult measures such as the ISNCSCI
4. Musculoskeletal complications (scoliosis and hip dislocation) unique to pediatric-onset SCI
5. Physiological changes with aging such as blood pressure – for example, the need to use age - appropriate norms for hypotension.

A major challenge to developing the pediatric SCI CDE structure is the limited empirical data for many of the elements. A major advantage to the pediatric SCI CDE structure is the potential to use it across pediatric facilities so data can be pooled to build understanding of pediatric SCI and gain evidence in support of treatment.

There are several priorities for research:

- Validation of adult SCI outcome measures (such as upper extremity measures) for use in children with SCI. It is important to establish the psychometric support and the lower age limit of measures that will be used in SCI clinical trials. This will address one of the major barriers for including children with SCI in trials that may improve outcomes of pediatric SCI.
- Development and validation of pediatric versions of International SCI Datasets and utilization of these datasets by international pediatric providers
- Development of relevant and responsive outcome measures in pediatric SCI. Specifically in the areas of functional outcomes, pain and quality of life, measures must represent performance-based outcomes, child-reported outcomes and parent-reported outcomes.
- Funding to support multi-center training and utilization of the CDE and international data sets. Given the small pediatric SCI population, multi-center studies using common data elements is one avenue to achieve a large enough sample to answer the important research questions.

ⁱ [Spinal Cord](#). 2011; 49(5):596–599. doi: 10.1038/sc.2010.172.

Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. DeVivo MJ¹, Biering-Sørensen F, New P, Chen Y; [International Spinal Cord Injury Data Set](#).