

## Cerebral Palsy CDE Revision History

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# Cerebral Palsy CDE Revision History

## February 2020

- The Participant Condition Characteristics case report form was posted on the Cerebral Palsy data standards page.
- New CDEs added to the case report form include: C58653, C58654, C58655, C58656, C58657, C58658, C58659, C58660, C58661, C58662, C58663, C58664, C58665, C58666, C58667, C05460, C58668, C58669, C58670, C58671, C58672, C58673, C58674, and C58675.

## January 2020

- General Core CRF updated to replace 'Gender' question with 'Sex assigned at birth' and 'Gender identity'.
- Two new CDEs added to CRF: C58676 (Sex assigned at birth) and C58677 (Gender identity). C00035 has been removed
- Start-Up document updated to reflect these changes.

## August 2019

- The Modified Ashworth Scale – Limb Tone Testing was moved from the Domain; Subdomain Assessments and Examinations; Physical and Neurological Examination to the Domain; Subdomain Outcomes and End Points; Spasticity / Movement.

## December 2018

- The External Device – CP case report form was posted on the Cerebral Palsy data standards page.
- New CDEs added to the case report form include: C56951, C56952, C56953, C56954, C58470, C58471, C58472, C58473, C58474, C58475, C58476, C58477, C58478, C58479, C58480, C58481, C58482, C58483, C58484, C58485, C58486, C58487, C58488, C58489, C58490, C58491, C58492, C58493, C58494, C58495, C58496, C58497, C58498, C58499, C58500, C58501, C58502, C58503, C58504, C58505, C58506, C58507, C58508, C58509, C58510, C58511, C58512, C58513, C58563, C58564, C58565, C58566, C58567, C58568, C58569, C58570, C58571, C58572, C58573, C58574, C58575, C58576, C58577, C58578, C58617, C58618, C58619, C58620, C58621, C58622, C58623, C58624, C58625, and C58626.
- The term 'subject' was removed from the question text for CDEs C12679, C12682, C12673, C58471, C58470, and C58472.
- The permissible value term 'Stroller' was revised to 'Medical/Adaptive Stroller' for CDE C12683.
- The permissible value term 'Inserts of any type' was revised to 'Shoe Inserts of any type' for CDE 58478.
- 'Thumb' was added as a permissible value for CDEs C58481 and C58483.

## Cerebral Palsy CDE Revision History

- Disease specific instructions were added to CDEs C18870, C58566, C58489, C58621, C58622, C58623, C58619, C58493, C58624, C58625, C58626, C58503, C58508, C58509, and C58617.
- Permissible values were revised for CDE C58488 from Position Device;Stander;Body jacket/Thoracic-lumbar-sacral orthoses (TLSO);Other, specify to 'Seated or Lying Position Device;Stander;Truncal Support Devices;Other, specify'
- The permissible value term 'Lift System' was revised to 'Lift system (e.g., Hoyer, ceiling track system)' for CDE C58499.

### July 2017

- The Participant Characteristics and Disease Injury Related Events Working Group Summary was updated.

### March 2017

- The Surgical and Hospitalization History CRF was updated to include:  
'type of Neurological surgery:  
 Selective dorsal rhizotomy (SDR)  Baclofen pump placement;' and  
'type of Bone orthopedic surgery?  
 Ankle/foot surgery  Elbow surgery  Hip surgery  Knee surgery  Shoulder surgery  
 Wrist surgery'
- The Behavioral History CRF was reformatted to be 508 compliant.
- The Medical History form was updated to include Optic atrophy and Visual field deficits under Eyes section and Epilepsy type to include the PVs 'Medically intractable' and 'Well controlled' under the Neurological History section.
- The Neuromotor Skill Functional Assessments Working Group Summary was updated.

### January 2017

- The email address to obtain permission to use the Segmental Assessment of Trunk Control (SATCo) was revised.
- Errors in the Neuroimaging Cerebral Palsy Magnetic Resonance Imaging CRF were corrected.
- The Neuroimaging Diagnostics Working Group Summary was posted to the NINDS CDE website.

### December 2016

- Cerebral Palsy CDEs were posted to the NINDS CDE Website.