

## Appendix: Core data sets

|                             |  |  | enrollment | Surveillance | botulinum toxin upper extremity | botulinum toxin lower extremity | botulinum toxin care | orthopedic surgery | intrathecal baclofen |
|-----------------------------|--|--|------------|--------------|---------------------------------|---------------------------------|----------------------|--------------------|----------------------|
| <b>patient demographics</b> | diagnosis                              | type & localisation motor disorder   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | imaging diagnosis (MRI)  | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | pregnancy duration   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             | additional disorders                   | intellectual disability (IQ <50, 50-69, >70)                                     | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | Presence of epilepsy, visual impairment, hearing impairment, behavioral problems | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             | functioning                            | GMFCS (mobility)   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | FMS (mobility)   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | MACS (arm hand dexterity)  | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | CFCS (communication)   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | EDACS (eating and drinking)  | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | VSS (speech)   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             | <b>treatment (current and history)</b> | current  | orthosis   | x            | o                               | o                               | o                    | o                  | o                    |
| tube feeding                |  |  | x          | o            | o                               | o                               | o                    | o                  | o                    |
| drain                       |  |  | x          | o            | o                               | o                               | o                    | o                  | o                    |
| medication                  |  |  | x          | o            | o                               | o                               | o                    | o                  | o                    |
| history                     |  | botulinum toxin A  | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | orthopedic surgery   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | selective dorsal rhizotomy   | x          | o            | o                               | o                               | o                    | o                  | o                    |
|                             |  | intrathecal baclofen   | x          | o            | o                               | o                               | o                    | o                  | o                    |
| <b>physical exam</b>        | anthropometrics                        | length   |            | x            | x                               | x                               | x                    | x                  | x                    |
|                             |  | weight   |            | x            | x                               | x                               | x                    | x                  | x                    |
|                             | characteristic s gait pattern          | type of gait pattern   |            | x            |                                 | x                               |                      | x                  | x                    |
|                             |  | presence adduction/endorotation  |            | x            |                                 | x                               |                      |                    |                      |
|                             |  | transfer   |            |              |                                 |                                 |                      | x                  | x                    |
|                             | motion lower extremity                 | range of motion: hip, knee, ankle  |            | x            |                                 | x                               | x                    |                    | x                    |
|                             |  | foot alignment   |            | x            |                                 | x                               | x                    |                    | x                    |
| foot deformity              |  |  |            |              |                                 |                                 | x                    | x                  |                      |

|                          |                             |  |  |                |                |                |                |                |   |
|--------------------------|-----------------------------|--|--|----------------|----------------|----------------|----------------|----------------|---|
|                          |                             | spasticity   |  | x              | x              | x              | x              | x              |   |
|                          | motion upper extremity      | range of motion: shoulder, elbow, wrist, thumb   |  | x              | x              |                | x              | x              |   |
|                          |                             | spasticity   |  | x              | x              |                | x              | x              |   |
|                          |                             | handfunctioning: Swanneck, Zancolli, House thumb classification  |  | x              | x              |                | x              | x              |   |
|                          | statics                     | leg length discrepancy   |  | x              |                | x              | x              | x              |   |
|                          |                             | scoliosis  |  | x              |                | x              | x              | x              |   |
|                          | selectivity lower extremity | selectivity lower extremity  |  | x <sup>1</sup> |                | x <sup>1</sup> | x              | x <sup>1</sup> |   |
|                          | functional strength         | functional strength  |  |                |                | x              | x              | x              |   |
|                          | dystonia                    | Barry-Albright Dystonia Scale  |  |                |                |                |                | x              |   |
| <b>imaging</b>           | back                        | Cobbs angle  |  | x              |                |                |                |                |   |
|                          | hip                         | X-ray  |  | x              |                |                |                | x              |   |
|                          |                             | migration percentage   |  | x              |                |                |                | x              |   |
|                          |                             | head-shaft angle   |  |                |                |                |                | x              |   |
|                          |                             | development acetabulum   |  |                |                |                |                | x              |   |
|                          | knee                        | X-ray  |  |                |                |                |                | x              |   |
|                          |                             | position patella   |  |                |                |                |                | x              |   |
| open growth plate        |                             |  |  |                |                |                | x              |                |   |
| <b>PROMs</b>             | daily life                  | screening questionnaire  |  | x              |                |                |                |                |   |
|                          | psychosocial screening      | SDQ  |  | x              |                |                |                |                |   |
|                          | daily functioning           | PEDI-NL  |  | x <sup>2</sup> | x <sup>2</sup> | x <sup>2</sup> | x <sup>2</sup> | x <sup>2</sup> |   |
|                          | daily functioning           | PEDI-CAT   |  | x <sup>3</sup> | x <sup>3</sup> | x <sup>3</sup> | x <sup>3</sup> | x <sup>3</sup> |   |
|                          | quality of life             | CP-CHILD   |  | x <sup>4</sup> | x <sup>4</sup> | x <sup>4</sup> | x <sup>4</sup> | x <sup>4</sup> |   |
|                          | patient evaluation          | satisfaction child/parents   |  |                |                |                | x              | x              | x |
|                          |                             | remarks  |  |                |                |                | x              | x              | x |
|                          |                             | negative treatment effects   |  |                |                |                | x              | x              | x |
|                          |                             | pain   |  |                |                |                | x              | x              | x |
|                          |                             | sleep  |  |                |                |                |                |                | x |
| hand use                 | ABILHAND                    |  |  |                |                | x              |                | x              |   |
|                          | (mini-)CHEQ                 |  |  |                |                | x              |                | x              |   |
| <b>treatment details</b> | treatment details           | details injection treatment (date, treated muscles, type of medication, dosage per muscle, injection method, general anesthesia) |  |                |                | x              | x              | x              |   |
|                          |                             | details surgery (tenotomy, muscle lengthening, muscle transfer, osteotomy)   |  |                |                |                |                | x              |   |
|                          |                             | details test treatment   |  |                |                |                |                | x <sup>5</sup> |   |

|                           |                  |  |  |  |  |  |  |   |   |   |   |   |   |
|---------------------------|------------------|--|--|--|--|--|--|---|---|---|---|---|---|
|                           |                  | details pump (date, type, size, location)        |  |  |  |  |  |   |   | x |   |   |   |
|                           |                  | details catheter (tip level, entry site, model)  |  |  |  |  |  |   |   | x |   |   |   |
|                           |                  | revision pump/catheter                           |  |  |  |  |  |   |   | x |   |   |   |
|                           |                  | details dosage (day dosage, modus, pump filling) |  |  |  |  |  |   |   | x |   |   |   |
|                           |                  | complications                                    |  |  |  |  |  | x | x | x | x | x |   |
|                           | after care       | casting  |  |  |  |  |  | x | x | x | x |   |   |
|                           |                  | orthosis   |  |  |  |  |  | x | x | x |   |   |   |
|                           |                  | paramedic care                                   |  |  |  |  |  | x | x | x |   |   |   |
| <b>goals and outcomes</b> | goals            | goal skills - GAS                                |  |  |  |  |  | x | x | x | x | x |   |
|                           |                  | goal disorder level                              |  |  |  |  |  | x | x | x | x | x |   |
|                           | goals (outcomes) | outcome skills - GAS                             |  |  |  |  |  | x | x | x | x | x |   |
|                           |                  | outcome disorder level                           |  |  |  |  |  | x | x | x | x | x |   |
|                           |                  | side effects                                     |  |  |  |  |  | x | x | x | x | x |   |
|                           | outcomes         | gait analysis - kinematics                       |  |  |  |  |  | x | x | x | x |   |   |
|                           |                  | gait analysis - foot contact                     |  |  |  |  |  | x | x | x | x |   |   |
|                           |                  | gait analysis - deformity                        |  |  |  |  |  | x | x | x | x |   |   |
|                           |                  | gait analysis - clearance                        |  |  |  |  |  | x | x | x | x |   |   |
|                           |                  | 6 minute walk test                               |  |  |  |  |  | x | x | x |   |   |   |
|                           |                  | grip strength                                    |  |  |  |  |  | x |   | x |   |   |   |
|                           |                  | pinch strength                                   |  |  |  |  |  | x |   | x |   |   |   |
|                           |                  | Assisting Hand Assessment                        |  |  |  |  |  | x |   | x |   |   |   |
|                           |                  | thumb opposition                                 |  |  |  |  |  | x |   | x |   |   |   |
|                           |                  | modified functional house (mini-)MACS            |  |  |  |  |  | x |   | x |   |   |   |
|                           |                  | FMS  |  |  |  |  |  |   |   |   |   |   | x |

x: required input

o: adjusted if needed

<sup>1</sup>: only at 6y

<sup>2</sup>: GMFCS I-III, <4y

<sup>3</sup>: GMFCS I-III, ≥4y

<sup>4</sup>: GMFCS IV-V

<sup>5</sup>: in case of test treatment

ICF level of function

ICF level of activity

ICF level of activity and participation

Consultation frequency:

- Surveillance: 0-6y: 2x/year; 7-18y: 1x/year
- Botulinum toxin A: pre; 3 months post
- Orthopedic surgery: pre; 1y post
- Intrathecal baclofen: pre; test treatment; 3 months post; 1x/year

Abbreviations:

- GMFCS: Gross Motor Function Classification System

- FMS: Functional Mobility Scale
- MACS: Manual Ability Classification System
- CFCS: Communication Function Classification System
- EDACS: Eating and Drinking Ability System
- VSS: Viking Speech Scale
- SDQ: Strengths and Difficulties Questionnaire
- PEDI-NL: Pediatric Evaluation of Disability Inventory - Dutch
- PEDI-CAT: Pediatric Evaluation of Disability Inventory - Computer Adaptive Test
- CP-CHILD: Caregivers Priorities and Child Health Index of Life with Disabilities
- CHEQ: Children's Hand-use Experience Questionnaire
- GAS: Goal Attainment Scaling
- MACS: Manual Ability Classification System
- FMS: Functional Mobility Scale