PhenX Toolkit

Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid investigators to integrate the collection of PhenX measures in your study. The PhenX measures that you selected and added to your Cart are presented in the DCW in alphabetical order. The DCW includes worksheets for data collection. Variables derived from the collected data are shown in the Data Dictionary (DD) with variable names and unique PhenX variable identifiers. The collection of DCWs produced by the Toolkit is not designed as a data collection instrument. Each investigator will decide how to integrate PhenX measures into data collection for their study.

International Pediatric Stroke Study (IPSS) Recovery and Recurrence Questionnaire

Note: If child has died since discharge from hospital, please go directly to item 8 (skip items 1-7)

Q1. Has your child recovered completely from the stroke?

[ ] Yes

[ ] No - If no, please answer the following questions:

1A. **Does your child have any problems with strength, coordination, or sensation including vision or hearing, as a result of the stroke?** If yes, please choose which of the following are present in your child:

[ ] Developmental delay

[ ] Difficulty with speaking clearly (problem with pronouncing words)

[ ] Abnormal tone

[ ] Difficulty with drinking, chewing, or swallowing

[ ] Weakness on one side of the body

[ ] Loss of sensation on one side of the body

[ ] Weakness on one side of the face

[ ] Other sensory problems

[ ] Unsteadiness on one side of the body

[ ] Difficulty with vision

[ ] Difficulty with hearing

[ ] Other problems with strength or coordination; Describe:_____

Does the problem affect your child's day-to-day activities?

[ ] Yes

[ ] No

	Right side face or body	Left side face or body
Not Done	n/t	n/t
None	0	0
Mild but no impact on function	0.5	0.5
Moderate with some limitations with daily functions	1	1
Severe or Profound with missing function	2	2

1B. Does your child have difficulty <u>expressing him/herself verbally</u>? (Exclude dysarthrias or pronunciation problems)

Not Done	n/t
None	0
Mild but no impact on function	0.5
Moderate with some limitations with daily functions	1
Severe or Profound with missing function	2

Please describe: _____

1C. Does your child have <u>difficulty understanding what is said</u> to her/him?

Not Done	n/t
None	0
Mild but no impact on function	0.5
Moderate with some limitations with daily functions	1
Severe or Profound with missing function	2

Please describe: _____

1D. Does your child have difficulty with his/her <u>thinking or behavior?</u>

Not Done	n/t
None	0
Mild but no impact on function	0.5
Moderate with some limitations with daily functions	1
Severe or Profound with missing function	2

Please describe: _____

TOTAL PARENTAL PSOM SCORE: _____/10

Q2. Does your child need extra help with day-to-day activities compared with other children of the same age?

[ ] Yes

[ ] No

Q3. Since the first stroke, has your child had another Stroke or Transient Ischemic Attack (TIA) or blood clot in any other blood vessel (e.g. in the leg, lung, heart, other location) ?

[ ] Yes

[ ] No

[ ] Unknown

If yes, which *type*?

[ ] Unknown

[ ] Stroke in a brain artery (usual form of 'stroke')

[ ] Stroke in a brain vein ('sinus thrombosis')

[ ] TIA

[ ] Other blood clot: (State location of blood clot :_____)

If yes, *when* was the recurrence (if unknown, please estimate)? Year_____ Month_____ Day____

Did your child have a *CT / MRI* at the time of the recurrence?

[ ] Yes

[ ] No

[ ] Unknown

If yes,

a) which test was done?

[ ] CT

[ ] MRI

[ ] Unknown

b) did the CT /MRI show a new stroke?

[ ] Yes

[ ] No

[ ] Unknown

Describe the new clinical symptoms at the time of the recurrence:

[ ] Difficulty walking

[ ] Difficulty using hands

[ ] Difficulty speaking

[ ] Difficulty with vision

[ ] Difficulty with drinking, chewing or swallowing

[ ] Other, describe: _____

Describe how long the symptoms lasted with the most recent attack:

[ ] Less than 6hrs

[ ] 6-24 hours

[ ] More than 24 hours

If there was more than one episode, how many episodes occurred?_____

What stroke treatment was he/she on at the beginning of the episode?

[ ] None

[ ] Aspirin

[ ] Low molecular weight Heparin (Enoxaparin, Loxaprin, injections under the skin)

[ ] Coumadin (blood thinning pill) Other (describe): _____

Q4. Does your child suffer from headaches or seizures since being discharged after the stroke(s)?

Headache:

[ ] Yes

[ ] No

Seizures:

[ ] Yes

[ ] No

If yes, is he/she on a seizure medicine now?

[ ] Yes

[ ] No

Q5. Have there been any other major health problems or procedures resulting from the stroke(s) or the stroke(s) treatment?

[ ] Yes

[ ] No

If yes, describe: _____

Q6. What medications are being used right now for stroke treatment?

[ ] None

[ ] Aspirin

[ ] LMWH (blood thinner injected under the skin)

[ ] Coumadin (blood thinner pill)

[ ] Other (describe): _____

Q7. What rehabilitation treatments is your child receiving now?

[ ] None

[ ] Occupational Therapy

[ ] Physical Therapy

[ ] Speech therapy

[ ] Special education services

[ ] Other (describe): _____

Q8. If your child is deceased, please specify:

Date of death: Year_____ Month_____ Day____

Cause of death: _____

Scoring:

The scores from questions 1A-1D are summed to give a total score, with higher scores indicating greater disability.

Protocol source: https://www.phenxtoolkit.org/protocols/view/820702#Source