QUEEN'S UNIVERSITY BELFAST

Notification no.	Booklet no.

Northern Ireland Cerebral Palsy Register

A Register of children and young people with a motor deficit of central origin

Funded by the Public Health Agency, Northern Ireland *Revised January 2016*

Child's name:	Sex:
H&C number:	Date of birth:
Address:	
	Post code:
Date of 1st assessment for booklet completion:	
Date when child was first seen by clinician completing the booklet:	
Date of re-assessment for booklet completion:	
Date when child was first seen by clinician re-assessing the booklet:	

For office use only

First assessment	Date received:	Date entered:	Date validated:
Re-assessment	Date received:	Date entered:	Date validated:

GUIDELINES FOR COMPLETION AND RETURN

This form is intended as an epidemiological tool for collecting data on impairment and disability in children with a motor deficit of central origin (subsumed under the umbrella term 'cerebral palsy' or CP). It will provide the data necessary to identify groups of children with similar clinical profiles over a period of time as a basis for aetiological and health services research.

Please **return** the form to:

Northern Ireland Cerebral Palsy Register
Institute of Clinical Science
Mulhouse Building
Grosvenor Road
Belfast BT12 6DP

Tel: 028 9097 1616
Email:nicpr@qub.ac.uk

Visit our website for more information or more forms:
www.qub.ac.uk/research-centres/nicpr

Other useful websites:
http://www.scpenetwork.eu/

Have you given an information leaflet to parents/guardians?

This form is based on:

- Evans, P., Johnston, A., Mutch, L. and Alberman, E. (1989). *A standard form for recording clinical findings in children with a motor deficit of central origin*. Developmental and Child Neurology, 31; 119 – 127.
- *Surveillance of CP in Europe (SCPE)*: Authors (2000) Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. Developmental and Child Neurology, 42:816-824.
- *SCPE – charter on neuroimaging* available on http://www.scpenetwork.eu/en/about-scpe/scpe-net-project

DESCRIPTION OF IMPAIRMENT

1. **Abnormal unwanted movement** - observed. If present please tick appropriate **boxes**

	At rest	With excitement/ goal directed movement
None	☐	☐
Short and jerky	☐	☐
Slow and writhing	☐	☐
Tremor	☐	☐
Flexor/extensor spasms	☐	☐
Abnormal postures or grimacing resulting from voluntary movements elsewhere in the body	☐	
Inco-ordination (only if not secondary to increased tone or weakness)	☐	
Unknown	☐	

Other (please describe): _____

Comments:

2. **Felt tone**. Tick **one** box for **each** limb

	(R) Upper Limb	(L) Upper Limb	(R) Lower Limb	(L) Lower Limb
Within normal range	☐	☐	☐	☐
Increased	☐	☐	☐	☐
Decreased	☐	☐	☐	☐
Varying with time/position (e.g. sleep)	☐	☐	☐	☐

	Yes	No	Uncertain
Contractures	☐	☐	☐

If Yes, describe : _____

Comments (E.g. clonus, hyperreflexian operative procedure such as tendon release):

3. Distribution of involvement Tick one box for each question

	Yes	No	Uncertain
R/L asymmetry of tone or function	☐	☐	☐

	Right	Left
If yes, which side is worse	☐	☐

	Upper limbs	Lower limbs	Uncertain
Which limbs are more affected?	☐	☐	☐

FUNCTIONAL SEVERITY – DEVELOPMENTAL AGE APPROPRIATE

4. Head and neck (with shoulders held)

- Normal head control ☐
- Abnormal head control but can hold head up for extended periods of time ☐
- Poor head control; can only hold head for very short periods of time ☐
- No obvious head control ☐

5. Trunk

- Normal trunk control ☐
- Can sit unsupported but less secure and stable than normal child of same age ☐
- Cannot sit unsupported ☐
- Difficult to place or maintain in sitting – including inability to sit because of deformity ☐

Questions 6 and 8 ONLY to be completed if the child is 4 years or older

6. Upper limb function. Manual Ability Classification System (MACS). Tick **one** option.

Level I: Handles objects easily and successfully. At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities ☐

Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement. May avoid some tasks or use alternative ways of performance. However manual abilities do not usually restrict independence in daily activities. ☐

Level III: Handles objects with difficulty; needs help to prepare and/or modify activities. The performance is slow and achieved with limits success regarding quality and quantity. Activities are performed independently if they have been set up or adapted ☐

Level IV: Handles a limited selection of easily managed objects in adapted situations. Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment for even partial achievement of the activity ☐

Level V: Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance. ☐

7. Lower limb function – gait and walking aids. Tick **one** option.

	Yes	No	Uncertain
Aids regularly used to facilitate walking?	☐	☐	☐
(If yes, please indicate type): _____			
Gait fluent with no significant problems			☐
Gait functional but non-fluent			☐
Gait obviously abnormal reducing mobility and/or restricting lifestyle			☐
No independent walking			☐

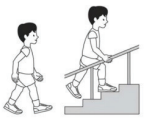
Comments:

8. Gross Motor Function Classification System (GMFCS) 4 to 6 year band[1]. Tick **one** option

Level I:
Gets in/out of chair and move from sit to stand without hand support. Walks indoors and outdoors and climb stairs. Emerging ability to run and jump.

☐

Level II:
Sits in a chair with both hands free to manipulate objects. Requires surface to push or pull on to move from sit to stand. Walks without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Uses stairs with railing. Unable to run or jump.



☐

Level III:
Sits on a regular chair but may require pelvic or trunk support to maximize hand function. Moves in and out of chair using a stable surface to push on or pull up on Uses hand-held mobility device on level surfaces and climb stairs with assistance from an adult. May propel manual wheelchair (may require assistance for long distance)

☐

Level IV:
Sits on a chair with adaptive seating for trunk control and to maximize hand function. Moves in and out of chair with assistance from an adult/stable surface to push or pull up on. Walking ability is severely limited even with assistance devices. Uses wheelchair most of the time; may propel their own powered wheelchair

☐

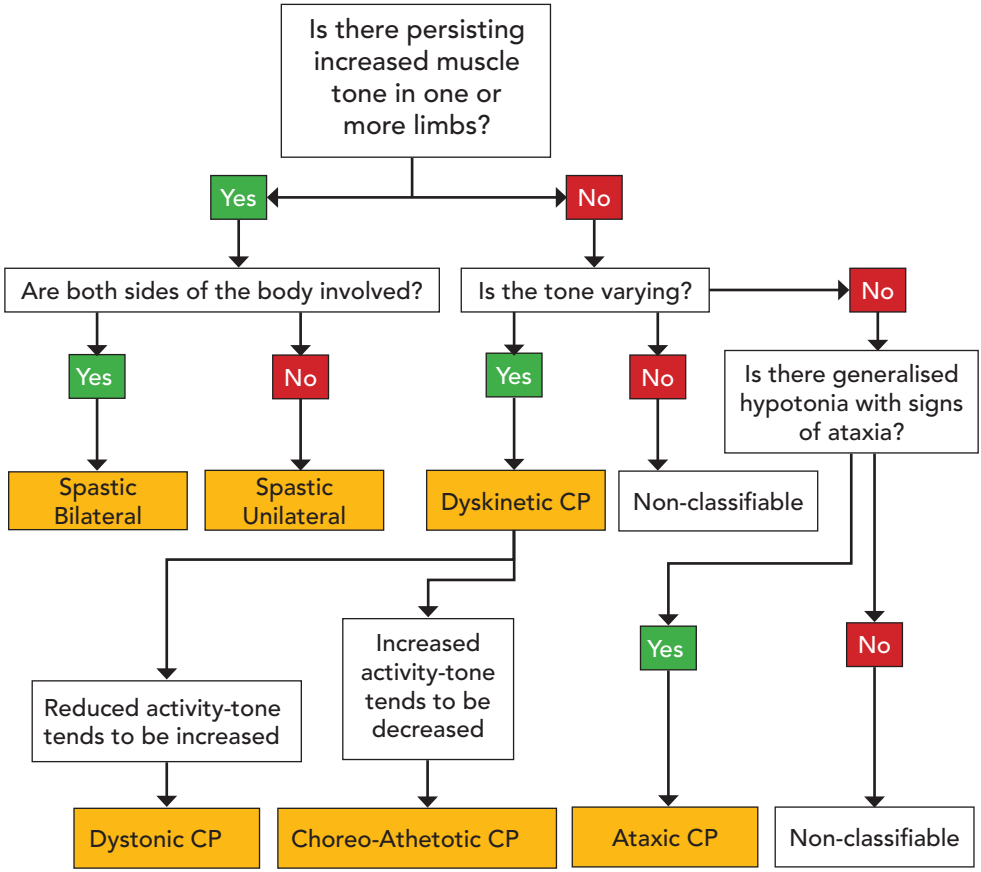
Level V:
Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. No means of independent movement. Some children may achieve self=mobility using powered wheelchair with extensive adaptations

☐

[1]Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingstone, 2007. CanChild Centre for Childhood Disability Research, McMaster University

CP SUBTYPE, DIAGNOSIS, CONGENITAL ABNORMALITIES AND OTHER MEDICAL PROBLEMS

9. **CP subtype. Please select PREDOMINANT type of CP.** Please refer to the Classification Tree below[2]. **If mixed** tick all boxes that apply **and circle the PREDOMINANT subtype**.



Spastic bilateral
- 2 limb ☐
- 3 limb ☐
- 4 limb ☐

Spastic unilateral
- Right side ☐
- Left side ☐

Dyskinetic
- Dystonic ☐
- Choreo-athetotic ☐

Ataxic ☐

Unclassifiable ☐

[2]SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. Dev Med Child Neuro. 2000; 42:816-824

10. When do you think the child's motor impairment occurred?

Congenital CP: before/during the perinatal period ≤28 days of life ☐

Acquired CP: after the perinatal period > 28 days of life ☐

11. Acquired CP

Age of child (years and months) or **date** impairment occurred: _____

Possible causes for acquired CP: _____

_____

_____

_____

12. Congenital CP; likely cause of child's motor impairment. E.g. underlying disease, significant perinatal event

_____

_____

_____

13. Syndromes and congenital abnormalities

	Yes	No	Uncertain
Syndromes present	☐	☐	☐

If **yes**, please indicate: _____

_____

	Yes	No	Uncertain
Congenital abnormality	☐	☐	☐

If **yes**, please indicate: _____

_____

14. Other major medical problems:

_____

_____

_____

15. Brain-Head MRI

Yes	No	Uncertain
☐	☐	☐

If yes, please describe results and approximate age of child at time of MRI.

_____

_____

_____

MRI result classification. Please select the PREDOMINANT MRI finding.
1 Tick main category A, B, C, D, E or Unknown
2 If ticked A, B or C, please also tick subcategory if known, A1, A2, A3, A4, B1, B2, B3, C1, C2 or C3[3]

	Unilateral	Bilateral
A) Maldevelopments 1st & 2nd trimester patterns		
A.1 disorders of proliferation	☐	☐
A.2 disorders of migration	☐	☐
A.3 disorders of organisation	☐	☐
A.4 maldevelopments - other	☐	☐
Category A but uncertain whether is A1, A2, A3 or A4	☐	☐
B) Periventricular white matter lesions early 3rd trimester patterns		
B.1. PVL (mild/severe)	☐	☐
B.2. Sequelae of intraventricular haemorrhage (IVH) or periventricular haemorrhagic infarction (PHI)	☐	☐
B.3. combination of PVL and IVH sequelae	☐	☐
Category B but uncertain whether B1, B2 or B3	☐	☐
C) Cortical and deep grey matter lesions 'late 3rd trimester patterns'		
C.1. basal ganglia/thalamus	☐	☐
C.2. parasagittal watershed lesions	☐	☐
C.3. MCA infarctions	☐	☐
Category C but uncertain whether C1, C2 or C3	☐	☐
D) Other changes – not classified	☐	
E) Normal	☐	
Unknown	☐	

[3]SCPE – charter on neuroimaging available on http://www.scpenetwork.eu/en/about-scpe/scpe-net-project/

BIRTH HISTORY

16. Address (residence) at time of birth: _____

_____ **Postcode** _____

17. Hospital at birth _____

18. Birth weight: _____ **Gestation (complete weeks)** _____

19. Delivery

Normal vaginal delivery ☐

Instrumental vaginal delivery ☐

Caesarean section Elective/before labour ☐

Emergency/during labour ☐

Unknown ☐

Unknown ☐

20. Birth number

Singleton ☐

Twin ☐

Triplet ☐

Other ☐

21. If multiple birth, please indicate birth order

First ☐

Second ☐

Third ☐

Other ☐

22. Admission to NICU (not SCBU)

Yes ☐

No ☐

Unknown ☐

23. Ventilation, respiratory support (no resuscitation)

Yes – intubation ☐

Yes - CPAP ☐

No ☐

Unknown ☐

24. Apgar Scores

1 min _____ 5 min _____ 10 min _____ Unknown ☐

25. Umbilical cord pH at birth

Arterial _____ Venous _____ Unknown ☐

ASSOCIATED IMPAIRMENTS

**Ostomy: gastrostomy, jejunosotmy and gastrojejunostomy*

26. Swallowing and feeding, please tick **one** as appropriate

- No feeding problems ☐
- Fed orally but with difficulties (e.g. thickened diet) ☐
- Not fed orally ☐
- Unknown ☐

27. If not fed orally

	Yes	No	Uncertain
NG tube	☐	☐	☐
Ostomy* present	☐	☐	☐
If yes, please indicate date of insertion	/ /		
Ostomy* removed	☐	☐	☐
If yes, please indicate date when removed	/ /		

28. Excessive drooling Yes ☐ No ☐ Uncertain ☐

30. Articulation of speech – usual speech. Only to be completed if the child is **4 or older**

- Speech is not affected by motor disorder ☐
- Speech is imprecise but usually understandable to unfamiliar listeners ☐
- Speech is unclear and not usually understandable to unfamiliar listeners out of context ☐
- No understandable speech ☐

31. Method of communication Only to be completed if the child is **4 or older**

- Speech ☐
- Alternative formal methods (e.g. Makaton) ☐
- Not communicating by speech or formal methods (e.g. child may use grimacing, face expressions etc) ☐
- Unknown ☐

31. Intellectual impairment, please tick one as appropriate

- Unlikely to be intellectually impaired ☐
- Moderate delay ☐
- Severe delay ☐
- Delayed but unknown extent ☐

	Yes	No	Uncertain
Standardised assessment used?	☐	☐	☐

If yes, please name test used, overall score & age of child when performed:

_____

_____

32. Has ever had epileptic seizures (excluding febrile or neonatal seizures)

- Never ☐
- Yes, has had seizures but no longer active or needing medication ☐
- Yes, seizures still active needing medication ☐
- Unknown ☐

33. Hearing impairment

No	☐
Yes, not profound or severe	☐
Yes, profound or severe >70dB	☐
Unknown	☐

34. Vision impairment

No	☐
Yes, not blind or without useful vision	☐
Yes, blind or no useful vision	☐
Unknown	☐

Is there a visual field defect present? Yes ☐ No ☐ Uncertain ☐

Comments for associated impairments (feeding/speech/intellectual/communication/hearing/vision)

_____

_____

ADDITIONAL INFORMATION

35. Sibling with CP? Yes ☐ No ☐ Unknown ☐

If YES, give name: _____ **Sex:** ____ **Date of birth:** _____

36. Current school _____

37. Name of child's General Practitioner: _____

Address: _____

_____

38. Please list clinicians who may have additional information on this child

_____

_____

_____

39. Name of clinician completing form: _____

Position: _____

Address: _____

_____ Telephone: _____

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