CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

CLINICAL QUESTIONNAIRE: LEAD CLINICIAN FOR THE PATIENT'S ONGOING NEURODISABILITY CARE QUESTIONNAIRE

CONFIDENTIAL

NCEPOD number: | | | | | | |

Who completed this questionnaire?

Name: _____ **Position:** _____ **Specialty** _____

What is this study about?

This study explores the quality of health care for children and young people aged 0-25 with chronic neurodisability across the UK.

Aims

- To identify remediable factors in the quality of care provided to children and young people with chronic disabling conditions, using the examplar conditions: the cerebral palsies.
- To examine the interface between different care settings
- To examine the transition of care to adult services

Who should complete this questionnaire?

For completion by the lead clinician who is responsible for the overall care of the patient (identified in the covering letter). We recognise that particularly in older patients and those that have moved location of care, information may be less accessible. Please base your answers on what is known from referral letters etc. Please complete this questionnaire in regards to (up to) the last three years of care provided to this patient.

CPD accreditation:

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

If you would like email confirmation of the completion of this questionnaire for your records, please clearly supply your email address.

How to complete the form:

Information will be collected using two methods; box cross and free text, where your opinion will be requested.

This form will be electronically scanned. Please use a black or blue pen. Please complete all questions with either block capitals or a bold cross inside the boxes provided e.g.

Were there any delays in the first assessment following arrival?

☒ Yes ☐ No

If you make a mistake, please "black-out" the incorrect box and re-enter the correct information, e.g.

■ Yes ☒ No

Unless indicated, please mark only one box per question.

Questions or help?

A list of definitions is provided on page 2 of the questionnaire.

If you have any queries about this study or this questionnaire, please contact

cp@ncepod.org.uk

Or telephone: 020 7251 9060

Thank you for taking the time to complete this questionnaire. The findings of the study will be published in late 2017.

Email address:

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DEFINITIONS	
GMFCS levels	https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r
Seriously ill patient	A seriously ill patient is defined as a patient who requires or potentially requires critical care (level 3 care) whether their condition is medical, surgical or trauma related.
Levels of care (adults)	Level 0/1: Normal ward care in an acute hospital Level 2: High Dependency Unit for patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care e.g. ICU Level 3: For patient requiring advanced respiratory support alone or monitoring and support for two or more organ systems. Includes all complex support for multi-organ failure e.g. Intensive Care Unit
Paediatric critical care unit	A discrete area within a ward or hospital where paediatric critical care is delivered.
Paediatric levels of critical care	Level 1 PCCU: A discrete area or unit where Level 1 paediatric critical care is delivered. With Paediatric Critical Care Network agreement, CPAP for bronchiolitis may be initiated or continued in a number of Level 1 Paediatric Critical Care Units. Level 2 PCCU: A discrete area or unit where Level 1 and Level 2 paediatric critical care are delivered. Other than in specialist children's hospitals, Level 2 units should be able to provide, as a minimum, acute (and chronic) non-invasive ventilation (both CPAP and BiPAP support) and care for children with tracheostomies and children on long-term ventilation, but should not be expected to deliver specialist Level 2 interventions such as ICP monitoring or acute renal replacement therapy. Within specialist children's hospitals, Level 2 units may provide some or all of these additional specialist interventions. Level 3 PCCU: A unit delivering Level 2 and Level 3 paediatric critical care (and Level 1 if required). This unit may also be called a Paediatric Intensive Care Unit (PICU).

CODES FOR SPECIALTY

SURGICAL SPECIALTIES

100 = General surgery	101 = Urology	110 = Trauma & orthopadics
130 = Ophthalmology	140 = Oral surgery	145 = Oral and maxillo facial surgery
150 = Neurosurgery	160 = Plastic surgery	
170 = Cardiothoracic Surgery	171 = Paediatric surgery	180 = Accident & Emergency
190 = Anaesthetics	191 = Pain management	192 = Critical care medicine

MEDICAL SPECIALTIES

300 = General medicine	301 = Gastroenterology	302 = Endocrinology
303 = Clinical haematology	314 = Rehabilitation	315 = Palliative medicine
320 = Cardiology	321 = Paediatric cardiology	330 = Dermatology
340 = Respiratory medicine	350 = Infectious diseases	360 = Genito-urinary medicine
361 = Nephrology	370 = Medical oncology	400 = Neurology
420 = Paediatrics	421 = Paediatric neurology	501 = Obstetrics
502 = Gynaecology	600 = General medical practice	700 = Learning disability
710 = Adult mental illness	711 = Child & adolescent psychiatry	712 = Forensic psychiatry
713 = Psychotherapy	800 = Clinical oncology	823 = Haematology
900 = Community medicine		

CODES FOR GRADE

01 – Consultant	02 – Staff grade/Associate specialist
03 – Trainee with CCT	04 – Senior specialist trainee (ST3+ or equivalent)
05 – Junior specialist trainee (ST1 & ST2 or CT equivalent)	06 – Basic grade (HO/FY1 or SHO/FY2 or equivalent)
07 - Specialist Nurse (Nurse consultant, Nurse practitioner, clinical nurse specialist)	08 - Senior staff nurse, enrolled nurse (EN) etc)
09 - 1st Level nurse, staff nurse (RGN)	10 - Allied Health Professional (Physiotherapy/ Speech & language therapy/Occupational therapy
11 - Non-registered staff (HCA etc.)	

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USUAL LEAD CLINICIAN DETAILS

This questionnaire is to be completed by the usual lead clinician who is responsible for the overall care of the patient, (or someone nominated by them). You have been sent this questionnaire for completion as you have been identified as the lead clinician following the patients recent admission to hospital.

In order for us to confirm these details, please answer the following questions:

1a. Does this patient have a usual lead clinician for neurodisability care? ☐ Yes ☐ No ☐ Unknown

1b. If YES, are you the lead clinician responsible for this patients ongoing neurodisability care? ☐ Yes ☐ No ☐ Unknown

1c. If NO, (you are not the lead clinician responsible for this patients ongoing neurodisability care), please provide the correct contact details for the patients usual lead clinician and return this questionnaire to us in the envelope provided:

Name: Specialty:

Address:

☐ Lead clinician details unknown

1d. If NO to 1a (the patient does not have a usual lead clinician for neurodisability care), is the patients overall neurodisability care delivered by the patients GP? ☐ Yes ☐ No ☐ Unknown

1e. If YES to 1d, please provide the details of the GP and return it to us in the envelope provided:

Name:

Address:

1f. If YES to 1b (you are the lead clinician), what was the date of most recent assessment by you (lead clinician)/your team?: ☐☐ ☐☐ ☐☐☐☐ (d d m m y y y y) ☐ Unknown

1g. For how long have you (the lead clincian) been leading on neurodisability care for this patient? ☐☐ Years ☐ Unknown

1h. If less than 1 year, prior to this was care delivered within the same or a different centre?

☐ Same centre ☐ Different centre ☐ Unknown

1i. Do you have ready access to this patients previous records of neurodisability care, to inform ongoing care? ☐ Yes ☐ No ☐ Unknown

STRUCTURED COMMENTARY

Patients have been identified for inclusion in the study following an episode of inpatient care. The clinician who was responsible for the patient at the time of discharge has been sent a questionnaire to complete regarding their in hospital care.

Please use the box below to provide a brief summary of the ongoing health needs and healthcare for this patient, concentrating in particular on the last 3 years of care, including any challenges or barriers to meeting the patient's needs. Please add any additional comments or information you feel relevant. You should be assured that this information is confidential. Please write clearly for the benefit of case reviewers. You may also continue on the back of the form or on additional pages if need be.

NCEPOD attaches great importance to this summary. Please give as much information as possible about the care of this patient.

A. PATIENT DETAILS

2. Age of the patient at the time of most recent assessment: ☐☐ Years ☐☐ Months ☐ Unknown

3. Gender: ☐ Male ☐ Female

4. What was the age of the patient when the cerebral palsy diagnosis was confirmed? ☐☐ Years ☐☐ Months ☐ Unknown

☐ Not available in the currently accessible notes

5a. What terminology does the local team currently use to describe this patients cerebral palsy? (Please specify)

5b. Using the Surveillance of Cerebral Palsy in Europe (SCPE) classification system, please indicate the specific cerebral palsy diagnosis:

☐ Worster Drought Syndrome

☐ Spastic Unilateral Left ☐ Spastic Unilateral Right ☐ Spastic Bilateral

☐ Dyskinetic ☐ Dystonic ☐ Choreoathetoid

☐ Ataxic ☐ Unable to classify ☐ Not recorded

6. When was the diagnosis of cerebral palsy made? ☐ ≤3 years ago ☐ >3 years ☐ Unknown

If cerebral palsy was diagnosed >3 YEARS AGO please go to question 10a

If diagnosed ≤3 years:

7a. In your opinion, was the diagnosis of cerebral palsy delayed? ☐ Yes ☐ No ☐ Unknown

7b. If YES, by how long was this diagnosis delayed? ☐☐ Months ☐ Unknown

8. Was the cause of the cerebral palsy related to a:

☐ Neonatal event (<28 days) ☐ Post-neonatal (>28 days) event (Please go to question 11a)

☐ Antenatal event (please go to question 11a) ☐ Unknown

If the cerebral palsy was related to A NEONATAL EVENT:

9a. How many foetuses were there? ☐ number ☐ Unknown

9b. What was the patients gestational age at birth? ☐☐ weeks ☐ Unknown

9c. What was the birth weight? ☐☐☐☐ g ☐ Unknown

9d. What was the place of delivery? ☐ Hospital ☐ Home ☐ Unknown

9e. Was the patient admitted to NICU? (Not including SCBU) ☐ Yes ☐ No ☐ Unknown

9f. Was there evidence of hypoxic ischaemic encephalopathy? ☐ Yes ☐ No ☐ Unknown

9g. Were any other syndrome/s or congenital malformation/s present? ☐ Yes ☐ No ☐ Unknown

9h. If YES, please specify:

10a. If the cerebral palsy was diagnosed >3 years ago, in your opinion were there any issues (i.e. delays in diagnosis, the quality of the diagnostic work up)? ☐ Yes ☐ No ☐ NA ☐ Unknown

10b. If YES, please specify:

11a. Did the patient undergo an MRI brain scan as part of their cerebral palsy diagnostic work up WITHIN THE LAST THREE YEARS? ☐ Yes ☐ No ☐ Unknown

11b. If YES, what was the age of the patient at the time of MRI? ☐☐ weeks ☐ Unknown

11c. If YES, what were the PREDOMINANT findings? (please select only one option)

- ☐ Normal
- ☐ Abnormal, not able to specify further
- ☐ Malformation
- ☐ Abnormal other than malformation, but not able to specify further
- ☐ Predominant white matter injury
- ☐ Predominant grey matter injury
- ☐ Miscellaneous findings, not specified above
- ☐ MRI findings not recorded

11d. If NO to 11a, (an MRI was not undertaken at the time of diagnosis), why was this? (Please tick all that apply)

- ☐ MRI not available
- ☐ MRI not considered
- ☐ MRI offered but declined
- ☐ Unknown

12a. What was the patient's level of gross motor function at the time of their MOST RECENT ASSESSMENT? (Please see definitions)

- ☐ I Walks indoors and outdoors + climbs stairs. Emerging ability to run & jump
- ☐ II Walks without need for assistive mobility device indoors and for short distances on level surfaces outdoors. Climbs stairs holding rail. Unable to run or jump.
- ☐ III Sits on regular chair but may require pelvic or trunk support to maximise hand function. Walks with assistive mobility device on level surfaces and may climb stairs with assistance from adult. Frequently transported when travelling for long distances or outdoors on uneven terrain.
- ☐ IV May at best walk short distances with a walker and adult supervision but has difficulty turning and maintaining balance on uneven surfaces. Transported in the community. May achieve self-mobility using a power wheelchair.
- ☐ 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.
- ☐ Not recorded

12b. In your opinion, had this patient's GMFCS level changed over the last 3 years? ☐ Yes ☐ No ☐ Unknown

12c. If there has been a reduction in GMFCS level, in your opinion, could this have been prevented? ☐ Yes ☐ No ☐ Unknown

☐ NA – no reduction in GMFCS

☐ NA – GMFCS level improved

At the time of the patients most recent assessment:

13. What was the patients level of hand function?

☐ No limitations

☐ Significant difficulties – requires support and/or equipment

☐ Not assessed

☐ Difficulties with using both hands together

☐ No useful hand function – totally dependent on others

☐ Unknown

14a. What was the patient's level of intellectual ability/disability?

☐ Unlikely to need/is not receiving/has not received specialist educational provision for intellectual disability (IQ 70+)

☐ Likely to need/is receiving/has received specialist educational provision for intellectual disability (IQ 50-70)

☐ Severe intellectual disability (IQ<50)

☐ Not recorded

14b. Was the patients assessment of intellectual ability/disability:

☐ Derived from psychometric test result

☐ Derived from clinical assessment

15. What was the patient's level of vision?

☐ No vision impairment ☐ Visual impairment ☐ Blind or no useful vision

☐ Not accurately assessed - clinical suspicion of impairment

☐ Not accurately assessed - clinically no impairment

16a. What was the patient's level of hearing?

☐ No hearing impairment

☐ Hearing impaired, but not profound or severe

☐ Profound or severe >70dB

☐ Not accurately assessed - clinical suspicion of impairment

☐ Not accurately assessed - clinically no impairment

16b. Did the patient have:

Hearing aid/s ☐ Yes ☐ No ☐ Unknown

Cochlear implant/s ☐ Yes ☐ No ☐ Unknown

17. What was the patient's level of communication?

- ☐ No impairment
- ☐ Impairment but communicates using speech
- ☐ Needs alternative, formal method to communicate
- ☐ Young child - clinical suspicion of communication impairment
- ☐ Young child - clinical assessment suggests no emerging communication impairment

18. What was the patient's level of communication ability?

- ☐ Communicated clearly
- ☐ Communication difficulties but could get message across with speech
- ☐ Required alternative/augmentative communication method
- ☐ Dependent on others to interpret body language
- ☐ Not assessed
- ☐ Unknown

19. What was the patient's level of eating and drinking ability?

- ☐ No eating and drinking difficulties
- ☐ Some difficulties but could eat orally with some adjustments
- ☐ Required feeding tube to augment oral feeding
- ☐ Unable to eat or drink safely – required feeding tube for total nutrition
- ☐ Not assessed
- ☐ Unknown

20. Was the nutritional status of this patient considered and recorded in the last year? ☐ Yes ☐ No ☐ Unknown

21a. Has this patient ever had seizures, excluding neonatal seizures? ☐ Yes ☐ No ☐ Unknown

21b. If YES, what was the age at onset of seizures?

☐ <1 year ☐ 1-2 years ☐ 3-5 years ☐ 5+ years ☐ Unknown

21c. If YES, what was the seizure frequency?

- ☐ No seizures or medication in last year
- ☐ Seizures in last year and/or on medication

22a. Has this patient ever been diagnosed with epilepsy? ☐ Yes ☐ No ☐ Unknown

22b. If YES, who led/leads on epilepsy management?

- ☐ GP
- ☐ General paediatrician
- ☐ Community paediatrician
- ☐ Disability paediatrician
- ☐ Paediatrician with specific expertise in epilepsies
- ☐ Paediatric neurologist
- ☐ Children's epilepsy surgical service
- ☐ General physician
- ☐ Neurologist
- ☐ Epilepsy surgical service
- ☐ Other (please specify) _____

22c. If epilepsy was present, from evidence in the medical records, were guidelines followed appropriately? ☐ Yes ☐ No ☐ Unknown

22d. If the patient had active epilepsy and a risk of status epilepticus is there evidence that a written epilepsy care plan was in place? (This may be part of an emergency healthcare plan) ☐ Yes ☐ No ☐ Unknown

B. ACUTE INPATIENT CARE

Patients were included in the study following an admission to hospital between Monday 7th September – Sunday 18th October 2015. The date of admission is documented in the questionnaire covering letter.

23a. Were you aware/made aware of this patients acute admission during the study period? ☐ Yes ☐ No ☐ Unknown

23b. Were you made aware of /copied into discharge summaries and further planning? ☐ Yes ☐ No ☐ Unknown

24a. In your opinion, could this hospital admission have been avoided? ☐ Yes ☐ No ☐ Unknown

24b. If YES, what factors would have prevented the need for hospital admission? (Answers may be multiple)

- ☐ More proactive input/management from the primary healthcare team
- ☐ More proactive input/management from lead clinician
- ☐ More proactive input/management from specialist nurse
- ☐ Other (please specify) _____

25a. How many hospital admissions had this patient had in the last three years? ☐☐ Number ☐ Unknown

25b. In your opinion, could any of these admissions have been avoided? ☐ Yes ☐ No ☐ Unknown

25c. If YES, please give details:

C. SYMPTOM MANAGEMENT IN THE COMMUNITY

26. At the time of the most recent assessment, please indicate if any of the following were present for this patient, and where present if they were they symptomatic or quiet on treatment?

Symptom	Present	If YES, current status:
Constipation	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Feeding/ swallowing issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Gastro-oesophageal reflux	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Drooling	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment

26. Continued

Symptom	Present	If YES, current status:
Sleep issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Airway issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Respiratory issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Medication administration issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Nutritional issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Behavioural, emotional issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Continence issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment
Postural/ transfer issues	☐ Yes ☐ No ☐ Not documented	☐ Active/Symptomatic ☐ Quiet on treatment

Pain

27. In your opinion, at the time of the most recent assessment had adequate enquiries been made by clinicians about the presence of pain in this patient? ☐ Yes ☐ No ☐ Unknown

28. Does this patient have ongoing chronic pain? ☐ Yes ☐ No ☐ Unknown

29a. In your opinion, has this patient's pain been adequately managed? ☐ Yes ☐ No ☐ Unknown

29b. If NO, please specify:

Spasticity

30a. Is spasticity present in this patient? ☐ Yes ☐ No ☐ Unknown

If NO, please go to Q35

If YES

30b. Does this patient have routine access to a network of care that uses agreed care pathways supported by effective communication and integrated team working? ☐ Yes ☐ No ☐ Unknown

30c. Does this network include healthcare professionals experienced in the care of patients with spasticity? ☐ Yes ☐ No ☐ Unknown

30d. Following the initial diagnosis of spasticity in this patient, was there any delay in the patient being referred to a member of this (spasticity) expert network? ☐ Yes ☐ No ☐ Unknown

30e. If YES to 30d, what was the length of the delay?

☐ <3 months ☐ 3-6 months ☐ >6 months ☐ Unknown

30f. If YES to 30d, what was the reason for the delay?

☐ No clear pathway ☐ Lack of available clinical expertise ☐ Unknown

☐ Other (please specify) _____

31. Does this patient receive regular review from the team with spasticity expertise? ☐ Yes ☐ No ☐ Unknown

32. If this patient had treatments or interventions to target spasticity, were the effects of these evaluated and documented? ☐ Yes ☐ No ☐ Unknown

☐ NA – treatment/ intervention >3 years ago

33. Were this patient's views about the effectiveness of treatments and interventions recorded, as appropriate for age and cognitive ability? ☐ Yes ☐ No ☐ Unknown

☐ NA – treatment/ intervention >3 years ago

34. Does this patient have fixed contractures? ☐ Yes ☐ No ☐ Unknown

Hips

35a. Was the patients current hip status documented? ☐ Yes ☐ No ☐ Unknown

35b. If YES, what is the patient's current documented hip status?

☐ Both hips known to be completely in joint ☐ Unknown

☐ One or both hips MIGRATING (moving out of joint)

☐ One or both hips completely DISLOCATED

35c. What was the date of the last assessment of hip position? ☐☐ ☐☐ ☐☐☐☐ (d d m m y y y y) ☐ Unknown

☐ Not documented

35d. If ONE OR BOTH HIPS ARE MIGRATING OR DISLOCATED, is there input from an orthopaedic surgeon? ☐ Yes ☐ No ☐ Unknown

36. Where applicable, before skeletal maturity was reached, was there documentation of hip status AT LEAST ANNUALLY for those at GMFCS III-V (non-walkers)? ☐ Yes ☐ No ☐ NA ☐ Unknown

Spine

37a. What is the patient's current documented spine status?

☐ Documented as STRAIGHT ☐ Unknown

☐ Documented CURVATURE (e.g. scoliosis, kyphosis)

37b. If there is SPINAL CURVATURE, how severe is it? ☐☐ Degrees ☐ Unknown

37c. If SPINAL CURVATURE is present, is there evidence of regular input from a spinal orthopaedic surgeon? ☐ Yes ☐ No ☐ Unknown

37d. If SPINAL CURVATURE is present, what was the date of the last assessment by a spinal orthopeadic surgeon? ☐☐ ☐☐ ☐☐☐☐ ☐ Unknown
d d m m y y y y

38. Where applicable, before skeletal maturity was reached, was there documentation of spine status AT LEAST ANNUALLY for those at GMFCS III-V (non-walkers)? ☐ Yes ☐ No ☐ NA ☐ Unknown

Growth and nutrition

Taking into account your own knowledge of this patient and the information in the available case notes, at the patients last assessment:

39a. What was the most recent weight of the patient? ☐☐☐ kg ☐ Unknown

39b. What was the date of measurement? ☐☐ ☐☐ ☐☐☐☐ ☐ Unknown
d d m m y y y y

39c. If the weight was NOT RECORDED, why was this? (Please tick all that apply)

☐ Lack of availability of suitable equipment to assess weight

☐ Lack of available hoist ☐ Patient in pain and could not be moved

☐ No reason given ☐ Other (please specify)

39d. Where there any clinical concerns about the weight, growth or nutritional status of the patient? ☐ Yes ☐ No ☐ Unknown

40a. What was height/length of the patient? ☐☐☐ cm ☐ Not documented

40b. What was the date of measurement? ☐☐ ☐☐ ☐☐☐☐ ☐ Unknown
d d m m y y y y

40c. What was the age of the patient at the time of measurement? ☐☐ cm ☐ Unknown

40d. If the height/length was NOT RECORDED, why was this? (Please tick all that apply)

- ☐ Lack of availability of suitable equipment to assess height
- ☐ Lack of available hoist
- ☐ Patient in pain and could not be moved
- ☐ Postural deformities prevented accurate assessment
- ☐ No reason given
- ☐ Other (please specify)

41. What other anthopometric measurements were taken to monitor the nutritional status of the patient? (Please tick all that apply)

- ☐ Triceps skinfold thickness
- ☐ Mid arm circumference
- ☐ BMI
- ☐ Other (please specify)

42. If there was evidence of suboptimal nutritional status was input sought from:

Dietician	☐ Yes	☐ No	☐ Unknown
Gastroenterologist	☐ Yes	☐ No	☐ Unknown

Documentation and communication about levels of functioning and comorbidities

43. Please specify the level of documentation of each of the following within the last three years, and the date of the most recent documentation (dd/mm/yyyy)

Level of functioning	**Documentation**			**Date of most recent documentation**
	Clearly documented in each clinic letter	Documented in the case notes at least once	Not documented	
Walking/GMFCs	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Hand function	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Intellectual ability/ disability	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Visual ability/disability	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Hearing ability/disability	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Communication ability/ disability	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Communication method	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐
Eating/drinking ability	☐	☐	☐	☐☐ ☐☐ ☐☐☐☐

D. ACCESS TO A MULTIDISCIPLINARY TEAM

44a. In general, was the care of this patient delivered by an appropriate multidisciplinary team? ☐ Yes ☐ No ☐ Unknown

44b. If NO, what specialty input was not included that in your opinion should have been? (Please use specialty codes)

☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐

45. Is there evidence of input from:

	Yes in line with a planned program	On an ad hoc basis based on need	No documented evidence of physiotherapy input	Not required/ applicable
Physiotherapy	☐	☐	☐	☐
Occupational therapy	☐	☐	☐	☐
Specialist speech & language therapy (for communication impairment)	☐	☐	☐	☐

46. Is there evidence of any input from:

	Yes	No	Unknown	Not required/ applicable
Dysphagia competent speech and language therapist	☐	☐	☐	☐
Specialist services relating to a vision impairment	☐	☐	☐	☐
Specialist services relating to a hearing impairment	☐	☐	☐	☐

47. Is there evidence of person-centred, age and developmentally appropriate goal setting, which considered body structure and function as well as activity and participation? ☐ Yes ☐ No ☐ Unknown

48. Was there timely and adequate adjunctive physical therapy after treatments involving botulinum toxin type A, continuous pump-administered intrathecal baclofen, orthopaedic surgery or selective dorsal rhizotomy? ☐ Yes ☐ No ☐ NA ☐ Unknown

49a. In your opinion, does this patient have a clear overall multidisciplinary clinical management strategy in place ☐ Yes ☐ No ☐ Unknown

49b. If YES, how often has this been reviewed? (Please specify)

49c. If YES, has the clinical management strategy involved discussion with the patient and their family? ☐ Yes ☐ No ☐ Unknown

E. EARLY PROACTIVE MANAGEMENT APPROACHES

50a. Overall, (in the last three years) do you consider that a proactive approach has been taken to symptom and postural management, to troubleshoot for any issues so that they could be identified early and managed in a timely way? ☐ Yes ☐ No ☐ Unknown

50b. If NO, what were the reasons for this: (please tick all that apply)

☐ Lack of available specialist clinical expertise ☐ Lack of engagement with family

☐ Lack of engagement with patient ☐ Other (please specify)

F. SAFEGUARDING

51a. In the last three years, were there any identified safeguarding issues for this patient? ☐ Yes ☐ No ☐ Unknown

51b. If YES, in your opinion, were there any delays in the identification of safeguarding issues? ☐ Yes ☐ No ☐ Unknown

51c. If YES to 51b, was this because of lack of available specialist clinical expertise? ☐ Yes ☐ No ☐ Unknown

G. TRANSITION

52a. At the last neurodisability assessment, was the patient aged 14 years or older? ☐ Yes ☐ No ☐ Unknown

If NO please go to section H

If YES:

52b. What stage of transition from paediatric to adult services is this patient currently in?

☐ Patient has not yet transitioned from paediatric to adult services (go to Q53)

☐ Patient is currently transitioning from paediatric to adult services or transitioned less than three years ago prior to the stated admission (go to Q53)

☐ Patient transitioned more than three years ago prior to the stated admission (go to Q59)

For patients who have not yet transitioned, or who have transitioned within the last three years prior to the stated admission:

53. Was/is there evidence of planning for transition to adulthood and to adult services? ☐ Yes ☐ No ☐ Unknown

54. Is there a designated professional/named worker that lead on the planning of transition of care for this patient? ☐ Yes ☐ No ☐ Unknown

55a. Following discharge from paediatric services, is it clear who was/will be leading clinical care? ☐ Yes ☐ No ☐ Unknown

☐ NA – not yet transitioned

55b. IF YES, was/is the lead:

☐ The patient's GP ☐ A secondary care clinician

☐ Other (please specify) _____

55c. If the lead was/is the GP, was this because:

☐ This was/is appropriate to the patient's needs

☐ There was/is no specialist disability service available to take on the clinical lead role from the paediatrician

☐ Other (please specify) _____

56a. Was/is this patient involved in the planning of transition? ☐ Yes ☐ No ☐ NA ☐ Unknown

56b. If NO, why was/is this? (Please tick all that apply)

☐ Lack of engagement from the patient ☐ Lack of engagement from the family

☐ Patients level of function prohibitive ☐ No system in place (not routinely available)

☐ Other (please specify) _____

57a. Were/are parent carers involved in transition planning? ☐ Yes ☐ No ☐ Unknown

57b. If NO, why was/is this? (Please tick all that apply)

☐ Lack of engagement from the family ☐ No system in place (not routinely available)

☐ Other (please specify) _____

58. For this patient, was/is health transition planning integrated with education and care transition planning? ☐ Yes ☐ No ☐ Unknown

For patients who transitioned more than three years prior to the stated admission;

59a. In your opinion, did the transition of care from paediatric to adult services work well for this patient? ☐ Yes ☐ No ☐ Unknown

59b. Please give further details

For all patients aged 14 years or older:

60. Does this patient have a named GP? ☐ Yes ☐ No ☐ Unknown

H. SUPPORT SERVICES

From your knowledge as lead clinician for this patient and taking account of the information in the case notes from up to the last three years:

61. Has the patient and their family provided with written information about their cerebral palsy and any associated health conditions? ☐ Yes ☐ No ☐ Unknown

62a. Were the patient's psychological and emotional needs fully addressed? ☐ Yes ☐ No ☐ Unknown

62b. If NO, was this because of lack of available specialist clinical expertise? ☐ Yes ☐ No ☐ Unknown

I. COMMUNICATION AND DECISION MAKING

From your knowledge as lead clinician for this patient and taking account of the information in the case notes from up to the last three years:

63. In your opinion, is the patient and their family as involved as possible, in all decision-making about any interventions and all aspects of their healthcare? ☐ Yes ☐ No ☐ Unknown

64. If the patient was aged 16 or over and there were concerns that they may have an impairment of brain or mind, was capacity assessed? (Please see definitions) ☐ Yes ☐ No ☐ NA ☐ Unknown

65. Was there ongoing communication between different healthcare providers for this patient? e.g. acute, community, specialist (including in regional or national centres), therapies etc ☐ Yes ☐ No ☐ Unknown

66a. Was there clear written communication for the patient and family/carers about all aspects of management, including the goals and outcomes of any interventions? ☐ Yes ☐ No ☐ Unknown

66b. If YES, how often was this reviewed? (Please specify)

67a. Is it routine practice for the patients' clinic letters/community care notes to be accessible for to the teams in the usual admitting hospitals in your area? ☐ Yes ☐ No ☐ Unknown

67b. Do your patients receive copies of all clinic letters and do you encourage them to make these available in the event of needing hospital care? ☐ Yes ☐ No ☐ Unknown

68a. Has there been a documented discussion with the patient and their family or other primary carers about appropriate levels of intervention for the patient? ☐ Yes ☐ No ☐ Unknown

68b. What was the outcome of this discussion?

☐ No limitation to interventions – full resuscitation and intensive care as required

☐ Limitation to treatment – no intubation/intensive care

☐ Other (please specify)

68c. How often is the decision about appropriate levels of intervention reviewed? ☐ Yes ☐ No ☐ Unknown

☐ As dictated by clinical need but at least once a year

☐ Once recorded not reviewed further

☐ Other (please specify)

J. TRAINING

From your knowledge as lead clinician for this patient and taking account of the information in the case notes from up to the last three years:

69a. Was training provided (either for specific procedures or broad areas of management) for this patient in aspects of self management? ☐ Yes ☐ No ☐ NA ☐ Unknown

69b. If YES, in your opinion was this training adequate? ☐ Yes ☐ No ☐ Unknown

69c. If YES to 69a, was this regularly reviewed? ☐ Yes ☐ No ☐ Unknown

70a. Is there a clear pathway in place for parent carers to be provided with training in any specific competences they require in order to deliver care for their child in the following areas:

Moving, handling and postural management ☐ Yes ☐ No ☐ Unknown

Technology support e.g. gastrostomy, ventilator ☐ Yes ☐ No ☐ Unknown

Support for safe eating and drinking ☐ Yes ☐ No ☐ Unknown

Other (please specify) ☐

70b. If YES, in your opinion was this training adequate? ☐ Yes ☐ No ☐ Unknown

70c. If YES to 70a, was this regularly reviewed? ☐ Yes ☐ No ☐ Unknown

70d. If YES to 70a, did this include safe moving and handling training for the care of the non ambulant patient? ☐ Yes ☐ No ☐ NA ☐ Unknown

K. END OF LIFE CARE

71. Did the patient die during their acute admission? ☐ Yes ☐ No ☐ Unknown

If NO, please go to the end of the questionnaire

If YES:

72a. Was this sudden and unexpected? ☐ Yes ☐ No ☐ Unknown

72b. If NO, were you as the lead clinician made aware that the patient was dying? ☐ Yes ☐ No ☐ Unknown

72c. If YES to 72a, were you actively involved in the patients end of life care? ☐ Yes ☐ No ☐ Unknown

73a. Has this case been the subject of multidisciplinary review? ☐ Yes ☐ No ☐ Unknown

73b. If YES, have remedial factors of care been identified? ☐ Yes ☐ No ☐ Unknown

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

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