



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)
CLINICAL QUESTIONNAIRE: ADMISSION 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 exemplar 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 clinician who was responsible for the patient (identified in the covering letter) at the time of admission to the acute hospital setting (paediatricians, acute physicians, and surgeons and/or senior nursing staff)

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 (the clinician completing the questionnaire) would like email confirmation of the completion of this questionnaire for your records, please clearly supply your email address to the right.

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 block capitals/clear writing that others can easily read 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:



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)	<p>Level 0/1: Normal ward care in an acute hospital</p> <p>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</p> <p>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</p>
Paediatric critical care unit	A discrete area within a ward or hospital where paediatric critical care is delivered.
Paediatric levels of critical care	<p>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.</p> <p>Level 2 PCCU: A discrete area or unit where Level 1 and Level 2 paediatric critical care are delivered.</p> <p>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.</p> <p>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).</p>



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	180 = Accident & Emergency
170 = Cardiothoracic Surgery	171 = Paediatric surgery	192 = Critical care medicine
190 = Anaesthetics	191 = Pain management	

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.)	



STRUCTURED COMMENTARY

Please use the box below to provide a brief summary of this case, adding 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.



USUAL LEAD CLINICIAN DETAILS

We are sending questionnaires to the lead clinician who is responsible for the overall care of the patient. In order to help us identify the relevant clinician we would be grateful if you could complete the following:

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

1b. If YES, please provide the details of this clinician:

Name: Specialty:

Address:

1c. If NO, is the patients overall neurodisability care delivered by the patients GP? Yes No Unknown

1d. If YES, please provide the details of this GP:

Name:

Address:

A. ARRIVAL DETAILS

2a. Date of arrival at hospital: Unknown
d d m m y y y y

2b. Time of arrival at hospital: (24 hour clock) Unknown
h h m m

3. Age of patient on date of arrival: Years Months

4. Gender: Male Female

5. What type of hospital was this patient admitted to?

- DGH <500 beds Specialist Tertiary Paediatric Centre Independent Hospital
 DGH >500 beds University Teaching Hospital Other Speciality Hospital

6a. Within this organisation, would this patient be defined as a child, adolescent/young person or adult (as defined by this Trust/Health Board)?

- Child Adolescent/Young person Adult

6b. What type of ward was the patient admitted to?

- Paediatric Adolescent Mixed paediatric & adolescent Adult

7. Admission category: Emergency (including urgent) Elective (including planned)



8a. Did the admitting team have ready access to the patient's community records/clinic letters for their cerebral palsy at the time of admission? Yes No Unknown

8b. If YES, did this include documentation of the GMFCs level? Yes No Unknown

9a. On arrival at hospital, was the patient accompanied? Yes No Unknown

9b. If YES, who accompanied the patient? (Answers may be multiple)

- Parent Friend Other family member Care worker
 Primary carer with parental responsibility but not parent
 Other (please specify)

10. What was the main reason(s) for admission? (Please specify)

11a. What was the DATE of the first recorded medical assessment on ARRIVAL? Unknown
d d m m y y y y

11b. What was the TIME of the first recorded medical assessment on ARRIVAL? (24 hour clock) Unknown
h h m m

11c. What was the GRADE and SPECIALTY of the clinician undertaking the first assessment on ARRIVAL? (Please use grade and specialty codes)
 Grade Unknown Specialty Unknown

12a. Were there any delays in the first assessment following ARRIVAL? Yes No Unknown

12b. If YES, what were the reasons for this delay? (answers may be multiple)

- Cot/Bed availability Delay in medical review/decision making
 Patient required prolonged initial resuscitation Other (please specify)

12c. In your opinion was this delay related to the patient's neurodisability? Yes No Unknown

12d. If YES, please give details

13a. Where appropriate, did the patient present with an Emergency Health Care Plan in place? Yes No NA Unknown

13b. Was the plan accessible and available to all at the time of admission? Yes No Unknown



14a. Where appropriate, was it clear at the point of admission what the resuscitation status of the patient was?

Yes No NA Unknown

14b. If YES was there documentation of a resuscitation decision/ DNACPR (or similar)?

Yes No Unknown
 NA - family declined limitation of intervention

B. ADMISSION PROCESS

Initial referral pathway to include admission process

15. How was the patient referred for hospital care?

- GP referral via the Emergency Department GP referral directly to the ward
 Self referral via the Emergency Department Self referral directly to the ward
 Planned via secondary or tertiary care physician or surgeon
 999 Ambulance Unknown
 Other (please specify)

16a. What was the DATE of ADMISSION?

Unknown
d d m m y y y y

16b. What was the TIME of ward ADMISSION?

(24 hour clock) Unknown
h h m m

17a. What was the DATE of the first recorded medical assessment on ADMISSION? (This may be the same as the date of arrival (Q11a))

Unknown
d d m m y y y y

17b. What was the TIME of the first recorded medical assessment on ADMISSION? (This may be the same as the time of arrival (Q11b))

(24 hour clock) Unknown
h h m m

17c. What was the GRADE and SPECIALTY of the clinician undertaking the first assessment on ADMISSION? (Please use grade and specialty codes)

Grade Unknown Specialty Unknown

18a. Were there any delays in the first assessment on admission?

Yes No Unknown

18b. In your opinion was this delay related to the patient's neurodisability?

Yes No Unknown

18c. If YES, please give details

19. What was the DATE and TIME this patient was first seen by a consultant following presentation to hospital? (Please use grade and specialty codes)

Unknown (24 hr clock) Unknown
d d m m y y y y h h m m



20a. Was GMFCS level clearly assessed and documented ON admission? (Please see definitions) Yes No Unknown

20b. If NO, (not documented on admission) was GMFCS documented anywhere during the admission? Yes No Unknown

20c. If YES to 20a or 20b, what was the patients documented GMFCS? (Please see definitions)

GMFCS I GMFCS II GMFCS III GMFCS IV GMFCS V

21. Was a level of learning ability clearly assessed and documented on admission? Yes No Unknown

22a. Did the patient have any co-morbidities? Yes No Unknown

22b. If YES please select all that apply:

Scoliosis Epilepsy Lung disease
 Congenital Heart Disease Endocrine disease Other (please specify)

23a. Did the patient have any associated conditions? Yes No Unknown

23b. If YES please select all that apply:

Constipation Drooling Gastro-oesophageal reflux
 Sleep issues Airway issues Respiratory issues
 Medication administration issues Behavioural/emotional issues
 Continence Disease Nutritional issues Postural/transfer issues
 Other (please specify)

24a. Did the patient have any additional impairments? Yes No Unknown

24b. If YES please select all that apply:

Visual impairment Hearing impairments Special communication needs
 Other (please specify)

25. Did this patient require any of the following technologies/equipment required to facilitate day to day care? (please tick all that apply)

Gastrostomy or other feeding tube Ventilation/CPAP Hearing aid(s)
 Hoist for transfer Other (please specify)

26a. What was the patient's weight on admission? kg Unknown

26b. Was this actual or estimated? Actual Estimated Unknown



26c. If the (actual) weight was not recorded what were the reason(s) for this? (Please tick all that apply)

- Lack of availability of suitable equipment Patient in pain and could not be moved
 Patient too sick to be moved No reason given

27a. What was the patient's height/length on admission? cm Unknown

27b. Was this actual or estimated? Actual Estimated

27c. If the (actual) height/length was not recorded what were the reason(s) for this? (Please tick all that apply)

- Lack of availability of suitable equipment Patient in pain and could not be moved
 Patient too sick to be moved Not routinely done
 No reason given

28. Did this patient have ALL basic physiological variables recorded on admission?

- Heart rate Yes No Unknown
Blood pressure Yes No Unknown
Oxygen saturation Yes No Unknown
Temperature Yes No Unknown
Respiratory rate Yes No Unknown
Glasgow Coma Score Yes No Unknown
Early Warning Score (paediatric or adult) Yes No Unknown

29a. Was a pain assessment made on admission? Yes No Unknown

29b. If YES, was a pain assessment tool used that was appropriate for the age, communication and cognitive ability of the patient? Yes No Unknown

29c. If YES to 29a, was the patient in significant pain on admission? Yes No Unknown

C. CARE OF EMERGENCY (INCLUDING EMERGENCY) ADMISSIONS

If the patient was admitted electively please go to question 36

If the patient was admitted as an emergency (including urgent admissions):

30. Was this patient seriously ill on admission? (Please see definitions) Yes No Unknown

31a. Where was the patient managed initially? (Please see definitions and tick all that apply)

- Emergency Department Children's Assessment Unit
 Assessment Unit (including Emergency Medical Unit)
 Surgical Assessment Unit Ward area (levels 0&1)
 Paediatric critical care (levels 1 – 3) Adult critical care (levels 2 & 3)
 Other (please specify)



31b. If the initial care was in an EMERGENCY OR ASSESSMENT UNIT, where was their care subsequently managed?

- | | |
|----------------------------------------------------------------|---------------------------------------------------------------|
| <input type="checkbox"/> Paediatric ward (medical or surgical) | <input type="checkbox"/> Adult Medical ward |
| <input type="checkbox"/> Adult surgical ward | <input type="checkbox"/> Paediatric Critical care (level 1-3) |
| <input type="checkbox"/> Adult critical care (levels 2 & 3) | <input type="checkbox"/> Transferred to another hospital |
| <input type="checkbox"/> Operating theatre | |
| <input type="checkbox"/> Other (please specify) | <input type="text"/> |

32. Was an emergency scoring system (eg the Paediatric Early Warning Score) used to identify severity of illness on admission? Yes No Unknown

33a. Were there delays in identifying severity of illness? Yes No Unknown

33b. If YES, in your opinion, why did this occur? (answers may be multiple)

- | | |
|--------------------------------------------------------------------------|--------------------------------------------------------|
| <input type="checkbox"/> Delay in hospital presentation | <input type="checkbox"/> Initial assessment incomplete |
| <input type="checkbox"/> Lack of knowledge/experience of attending staff | <input type="checkbox"/> Symptoms/signs unclear |
| <input type="checkbox"/> Delay in senior and/or consultant review | <input type="checkbox"/> Other (please specify) |

34a. Were there delays in providing resuscitation if required? Yes No Unknown

34b. If YES, in your opinion, why did this occur? (answers may be multiple)

- | | |
|------------------------------------------------------------------------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> Delay in hospital presentation | <input type="checkbox"/> Diagnostic uncertainty |
| <input type="checkbox"/> Technical difficulty (e.g. difficult venous access) | <input type="checkbox"/> Delay in senior and/or consultant review |
| <input type="checkbox"/> Uncertainty about how active/aggressive resuscitation should be | |
| <input type="checkbox"/> Other (please specify) | <input type="text"/> |

35a. Was there delay in commencing specific treatment (e.g. antibiotics)? Yes No Unknown

35b. If YES, why do you think this occurred? (Answers may be multiple)

- | | |
|--------------------------------------------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> Delay in hospital presentation | <input type="checkbox"/> Diagnostic uncertainty |
| <input type="checkbox"/> Technical difficulty (e.g. difficult venous access) | |
| <input type="checkbox"/> Uncertainty about how active/aggressive treatment should be | |
| <input type="checkbox"/> Other (please specify) | <input type="text"/> |

35c. If YES to 35a, (delays occurred) do you think this affected outcome? Yes No Unknown



D. INVOLVEMENT OF THE MULTIDISCIPLINARY TEAM

36a. Is there clear documentation as to who led on cerebral palsy care overall for this patient prior to admission? Yes No Unknown

36b. If YES, which individual led/co-ordinated overall patient care? (Answers may be multiple)

- | | | |
|--------------------------------------------------------------|--------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> GP | <input type="checkbox"/> Community paediatrician | <input type="checkbox"/> General paediatrician |
| <input type="checkbox"/> Disability specialist paediatrician | | <input type="checkbox"/> Paediatric neurologist |
| <input type="checkbox"/> Paediatric surgeon | <input type="checkbox"/> Physician | <input type="checkbox"/> Neurologist |
| <input type="checkbox"/> Neurorehabilitation specialist | <input type="checkbox"/> Orthopaedic surgeon | <input type="checkbox"/> Other surgeon |
| <input type="checkbox"/> Patient/parent carer | | |

37a. During this admission were other teams involved in the daily care and management of this patient? Yes No Unknown

37b. If YES please specify: (Answers may be multiple)

Allied health professionals

- | | | |
|------------------------------------------------------------------------------------------------------------------|-----------------------------------------|------------------------------------------------|
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Nutrition team | <input type="checkbox"/> General paediatrician |
| <input type="checkbox"/> Specialist nursing team (e.g. stoma nursing, epilepsy nurse, learning disability nurse) | | |
| <input type="checkbox"/> Speech and Language Therapy | | <input type="checkbox"/> Occupational Therapy |

Surgeons

- | | | |
|--------------------------------------|----------------------------------|--------------------------------|
| <input type="checkbox"/> Orthopaedic | <input type="checkbox"/> General | <input type="checkbox"/> Other |
|--------------------------------------|----------------------------------|--------------------------------|

Specialist paediatricians/physicians

- | | | |
|--------------------------------------|------------------------------------------|-------------------------------------------|
| <input type="checkbox"/> Paediatrics | <input type="checkbox"/> Neurodisability | <input type="checkbox"/> Gastroenterology |
| <input type="checkbox"/> Respiratory | <input type="checkbox"/> Neurology | <input type="checkbox"/> Pain team |
| <input type="checkbox"/> Other | | |

38a. Did multidisciplinary team meetings occur to discuss care for this patient during this admission? Yes No Unknown

38b. If YES, were the results of discussions clearly documented in shared notes during the admission? Yes No Unknown

38c. Was the patient and /or their carers made aware of the outcomes of these discussions? Yes No Unknown



E. CRITICAL CARE REFERRAL

Including High Dependency Care

39a. On admission, was the patient admitted directly to critical care?
(Please see definitions) Yes No Unknown

39b. If NO, was the patient subsequently referred to critical care during their admission? (On site or off site) Yes No Unknown

If NO (no critical care stay) go to Q49

If the patient was referred for critical care

40a. What was the date of this referral? Unknown
d d m m y y y y

40b. What was the time of this referral? (24 hour clock) Unknown
h h m m

40c. To which group of critical care clinicians was the referral made?

- Paediatric critical care team ON SITE Adult critical care team ON SITE
 Paediatric critical care or transfer team OFF SITE Adult critical care team OFF SITE

40d. What was the GRADE and SPECIALTY of the clinician who made this referral? (Please use grade and specialty codes)

Grade Unknown Specialty Unknown

40e. Did this referral trigger on site patient review by a member of the critical care team Yes No Unknown
 NA - critical care not on site

40f. Was the referral to critical care accepted? (On or off site) Yes No Unknown

If NO, (referral not accepted)

41. If NO to 40f, (NOT accepted for critical care) what was the stated documented reason(s) for this?

- Patient acuity/severity of illness did not meet need for Critical Care management
 Lack of clinical consensus about appropriateness of referral/intervention
 Lack of clarity about the appropriate levels of intervention Lack of beds
 Lack of appropriate bed (e.g. PICU, Neuro ICU)
 Discussions and agreement with the family
 Other (Please specify)

If YES (referral was accepted)

42a. If YES to 40f, (accepted for critical care), were there any problems encountered during the referral process? Yes No Unknown



42b. If YES, please what were the reasons for these problems? (Answers may be multiple)

- Lack of clinical consensus about appropriateness of referral
- Lack of clarity about the appropriate levels of intervention
- Lack of beds Delays in retrieval/transfer
- Discussions and agreement with the family
- Other (Please specify)

42c. If there was LACK OF CLINICAL CONSENSUS ABOUT APPROPRIATENESS OF REFERRAL, for which group(s) of clinicians were these concerns documented? (Answers may be multiple):

- Member (s) of the referring acute team (paediatrician, physician, surgeon, intensive care)
- Member(s) of team responsible for long term care (neurodisability)
- Team accepting referral (paediatric critical care, adult critical care)
- Family

43a. Following referral, was the patient subsequently admitted to Critical Care? (On or off site)

- Yes - on site
- Yes - off site
- No (go to Q49)
- Unknown

43b. If YES (on or offsite) how many hours/days after the first referral? Hours Days Unknown

For ALL patients admitted to critical care (on or off site)

44. Was this a planned or unplanned admission? Planned Unplanned Unknown

45. What was the duration of the critical care admission? Days Weeks Unknown

If the patient was transferred offsite for critical care:

46a. Was there a delay in retrieval or transfer? Yes No Unknown

46b. If YES, how long was this delay? Hours Unknown

46c. If there was a DELAY IN RETRIEVAL OR TRANSFER to critical care did this result from lack of consensus about the benefits of critical care management for this patient? Yes No Unknown

46d. If there were DELAYS IN RETRIEVAL OR TRANSFER PROCESS do you believe that this resulted in preventable morbidity or mortality? Yes No Unknown

For ALL patients admitted to critical care (either on or off site)

47. What was the outcome of the critical care admission? Patient survived to critical care discharge Patient died on critical care Unknown



48a. If the patient DIED IN THE CRITICAL CARE UNIT was this following a decision to limit interventions? Yes No Unknown

48b. If YES who participated in the decision making process to withdraw or limit interventions?

- Patient's long term lead Acute team lead(s) Critical care lead(s)
 Parents/family Patient Other (please specify)

F. SURGICAL/PROCEDURAL CARE

(Including endoscopy, radiological and other procedures (such as botulinum toxin injections) carried out under general anaesthetic or sedation)

49. Did the patient undergo surgery or a procedure during this admission? Yes No Unknown

If NO, please go to section G

If YES:

50. Was this planned or unplanned? Planned Unplanned Unknown

51. Please indicate the urgency of the surgery/procedure:

- Immediate** Immediate life or limb saving surgery. Resuscitation simultaneous with surgical treatment.
- Urgent** Acute onset or deterioration of conditions that threaten life, limb or organ survival; fixation of fractures; relief of distressing symptoms including acute surgical admissions not requiring an operation.
- Expedited** Stable patient requiring early intervention for a condition that is not an immediate threat to life, limb or organ survival.
- Elective** Surgical procedure planned or booked in advance of routine admission to hospital.

52a. Did a surgeon or person carrying out the procedure see and discuss the procedure (including possible risks and complications) with the patient and/or family prior to surgery/the procedure? Yes No Unknown

52b. If YES, what was the grade and specialty of this surgeon/operator? (Please use grade and specialty codes)

Grade Unknown Specialty Unknown

53. What was the grade and speciality of the most senior surgeon/operator performing or directly supervising at the operation/procedure?

Grade Unknown Specialty Unknown

54a. Was the procedure carried out under general anaesthetic or sedation? Yes No Unknown

54b. If YES, please specify: General Anaesthetic Sedation



54c. If YES to 54a, did an anaesthetist see and discuss the procedure (including possible risks and complications) with the patient and/or family prior to surgery? Yes No Unknown

54d. If YES to 54a, what was the grade of the anaesthetist? (Please use grade codes) Unknown

55. What was the grade of the most senior anaesthetist at the operation? (Please use grade codes) Unknown

56a. Were there any delays in the patient undergoing surgery/the procedure? Yes No Unknown

56b. If YES, in your opinion, what were the reasons for this? (Answers may be multiple)

- Delay in recognition of the need for surgery/intervention
- Delay in referral within hospital Need for pre-operative investigations
- Uncertainty about fitness for surgery Delay in diagnosis
- Need for pre-operative resuscitation/stabilisation
- Identification of post operative critical care bed locally
- Need for transfer to another centre e.g. for post op critical care
- Other (please specify)

56c. In your opinion, were these delays detrimental to outcome? Yes No Unknown

57. Were there any problems peri-operatively with any of the following? (Please tick all that apply)

- Administration of important long term medication (e.g. anticonvulsants)
- Fluid administration/fluid balance Re-introduction of enteral nutrition
- Skin or tissue damage Hypothermia
- Other (please specify)

Consent

If the operation/procedure WAS NOT carried out under general anaesthetic, please go to question 61a (peri-operative analgaesia)

If the operation/procedure was carried out under general anaesthetic:

58a. Who consented for the surgery/procedure? (Answers may be multiple)

- Patient Parent/Carer Clinician
- Patient advocate/Proxy Social Services Unknown

58b. If the PATIENT consented, how was this documented? (Please select all that apply)

- Standard NHS consent form completed
- Documentation of discussion, risks and complications and use of communication aids (as required) and standard consent form completed by operator
- Other (please specify)



59a. If NO WRITTEN CONSENT WAS TAKEN from the patient was this because: (Please tick all that apply)

Patient was physically unable to sign consent

Assessed by the team not to have capacity to consent (lack of capacity)

Emergency procedure

Other (please specify)

59b. If the patient was ASSESSED BY THE TEAM NOT TO HAVE THE CAPACITY TO CONSENT, was their level of competence/capacity formally assessed and clearly documented in the medical record during this admission?

Yes No NA Unknown

59c. If the patient was ASSESSED BY THE TEAM NOT TO HAVE CAPACITY TO CONSENT (FORMALLY OR INFORMALLY) was alternative or additional written consent obtained?

Yes No NA Unknown

59d. If YES, was this taken from?

Adult with parental responsibility

Social care

Legally appointed proxy

Part 4 of consent was completed by medical professional(s)

60. What was the grade and specialty of the person obtaining consent? (Please use grade and specialty codes)

Grade

Unknown

Specialty

Unknown

Peri-operative analgesia

61a. Did the patient have regular pain scoring peri-operatively?

Yes No Unknown

61b. If YES, was a pain assessment tool used that was appropriate for the age, communication and cognitive ability of the patient?

Yes No Unknown

62. Was the overall level of pain relief felt to be adequate peri-operatively (as assessed by pain scoring and daily specific enquiry)?

Yes No Unknown

G. COMMUNICATION WITH THE PATIENT AND FAMILY

All admissions

63. Was the patient included throughout in the decision making process, and as appropriate to their level of understanding?

Yes No Unknown

64. Where appropriate, were sensitive discussions conducted with the patient in private when there was a need for confidentiality?

Yes No NA Unknown



65. Where appropriate, was the patient given the choice of whether to have parent(s)/carer(s) present for all discussions? Yes No NA Unknown
66. Were augmentative or alternative communication aids available and used to improve the quality of communication and as required, (e.g. symbol books, voice-output devices, sign support)? Yes No NA Unknown
67. Were discussions about important care decisions documented? Yes No Unknown
68. Were parent/carers encouraged to be part of the care process and as requested by patient? Yes No Unknown
69. Was it possible for a parent/carers to be resident and as required/ requested by the patient? Yes No Unknown

H. SAFEGUARDING

- 70a. Were there any identified safeguarding issues for this patient? Yes No Unknown
- 70b. If YES, in your opinion, were there any delays in the identification of safeguarding issues? Yes No Unknown
- 70c. If YES to 70b, was this because of lack of available specialist clinical expertise? Yes No Unknown

I. PATIENT OUTCOME AND DISCHARGE

- 71a. In your opinion, were there preventable/remediable factors in the process of care which might have led to a different outcome? Yes No Unknown

- 71b. If YES, what were these factors? (Please tick all that apply)

- Delayed recognition/diagnosis Delayed resuscitation Delayed treatment
- Lack of access to critical care Other (please specify)

72. What was the outcome of this admission?
- Discharged with an IMPROVED level of function/mobility compared with pre-admission
- Discharged with the SAME level of function/mobility compared with pre-admission
- Discharged with a WORSE level of function/mobility compared with pre-admission
- Discharged for higher level of support including critical care
- Death (Please go to question 79)



73. What was the discharge location?

- | | |
|--------------------------------------------------------------|---------------------------------------------------------------------|
| <input type="checkbox"/> Patient's home | <input type="checkbox"/> Neurorehabilitation in a community setting |
| <input type="checkbox"/> Respite care in a community setting | <input type="checkbox"/> Hospice/palliative care |
| <input type="checkbox"/> Another hospital | <input type="checkbox"/> Other (please specify) |

74. Did this patient have a named GP? Yes No Unknown

75. Where discharge was to a community setting, was there written communication with the following groups at discharge? (Please tick all that apply)

- | | |
|-----------------------------------------------------------------|-------------------------------------------------------------------|
| <input type="checkbox"/> GP | <input type="checkbox"/> Lead clinician for cerebral palsy care |
| <input type="checkbox"/> Social care | <input type="checkbox"/> Community care medical and nursing staff |
| <input type="checkbox"/> Community Allied Health Professionals | <input type="checkbox"/> Palliative care team |
| <input type="checkbox"/> No discharge summary in the case notes | |

76a. Did written communication contain a clear discharge plan? Yes No Unknown

76b. Were the patient and their families/carers copied into this discharge plan? Yes No Unknown

77. Did written communication include input from all relevant members of the multidisciplinary team providing care during admission? Yes No Unknown

78. Did written communication include information to all relevant members of the multidisciplinary team providing care to follow admission? Yes No Unknown

If the patient died during this admission

79. What was the stated cause of death? (as stated on the death certificate)

1a

1b

1c

2

Unknown

80. In your opinion were pain and symptom control adequately addressed prior to death? Yes No Unknown

81a. Was a palliative/end of life care plan, including documented resuscitation decision/DNACPR decision, in place for the patient when death occurred? Yes No Unknown

81b. If YES, was this plan put in place in a timely fashion? (i.e. to provide carers clear instructions for delivery of appropriate pain and symptom control, who to contact to avoid delays and to avoid unnecessary suffering) Yes No Unknown



- 81c. Was the care plan reviewed at any stage during this final admission to take account of any changes? Yes No Unknown
- 81d. As part of this plan do you believe that pain and/or symptom control was adequately addressed? Yes No Unknown
82. Was this death discussed at a multidisciplinary Morbidity/Mortality meeting? Yes No Unknown
- 83a. Did the family receive bereavement support? Yes No Unknown
- 83b. If YES, what was the waiting time for this appointment?
 <3 months 3-6 months >6 months Unknown

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE



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