### 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 palsy.
- 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)

### 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?

- [X] Yes
- [ ] No

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

- [ ] Yes
- [X] 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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**Who completed this questionnaire?**

Name: ____________________  Position: ____________________  Specialty: ____________________

**NCEPOD number:**

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**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.
### DEFINITIONS

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Seriously ill patient</strong></td>
<td>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.</td>
</tr>
</tbody>
</table>
| **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

<table>
<thead>
<tr>
<th>Surgical Specialties</th>
<th>Medical Specialties</th>
</tr>
</thead>
<tbody>
<tr>
<td>100 = General surgery</td>
<td>300 = General medicine</td>
</tr>
<tr>
<td>130 = Ophthalmology</td>
<td>301 = Gastroenterology</td>
</tr>
<tr>
<td>150 = Neurosurgery</td>
<td>303 = Clinical haematology</td>
</tr>
<tr>
<td>170 = Cardiothoracic Surgery</td>
<td>320 = Cardiology</td>
</tr>
<tr>
<td>190 = Anaesthetics</td>
<td>340 = Respiratory medicine</td>
</tr>
<tr>
<td></td>
<td>361 = Nephrology</td>
</tr>
<tr>
<td></td>
<td>420 = Paediatrics</td>
</tr>
<tr>
<td></td>
<td>502 = Gynaecology</td>
</tr>
<tr>
<td></td>
<td>710 = Adult mental illness</td>
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<tr>
<td></td>
<td>713 = Psychotherapy</td>
</tr>
<tr>
<td></td>
<td>900 = Community medicine</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>101 = Urology</td>
<td>314 = Rehabilitation</td>
</tr>
<tr>
<td>140 = Oral surgery</td>
<td>315 = Palliative medicine</td>
</tr>
<tr>
<td>160 = Plastic surgery</td>
<td>321 = Paediatric cardiology</td>
</tr>
<tr>
<td>171 = Paediatric surgery</td>
<td>350 = Infectious diseases</td>
</tr>
<tr>
<td>191 = Pain management</td>
<td>370 = Medical oncology</td>
</tr>
<tr>
<td></td>
<td>421 = Paediatric neurology</td>
</tr>
<tr>
<td></td>
<td>600 = General medical practice</td>
</tr>
<tr>
<td></td>
<td>711 = Child &amp; adolescent psychiatry</td>
</tr>
<tr>
<td></td>
<td>800 = Clinical oncology</td>
</tr>
<tr>
<td></td>
<td>712 = Forensic psychiatry</td>
</tr>
<tr>
<td></td>
<td>823 = Haematology</td>
</tr>
</tbody>
</table>

- 110 = Trauma & orthopaedics
- 145 = Oral and maxillo facial surgery
- 180 = Accident & Emergency
- 192 = Critical care medicine

### CODES FOR GRADE

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Consultant</td>
</tr>
<tr>
<td>03</td>
<td>Trainee with CCT</td>
</tr>
<tr>
<td>05</td>
<td>Junior specialist trainee (ST1 &amp; ST2 or CT equivalent)</td>
</tr>
<tr>
<td>07</td>
<td>Specialist nurse (nurse consultant, nurse practitioner, clinical nurse specialist)</td>
</tr>
<tr>
<td>09</td>
<td>1st Level nurse, staff nurse (RGN)</td>
</tr>
<tr>
<td>11</td>
<td>Non-registered staff (HCA etc.)</td>
</tr>
<tr>
<td>02</td>
<td>Staff grade/associate specialist</td>
</tr>
<tr>
<td>04</td>
<td>Senior specialist trainee (ST3+ or equivalent)</td>
</tr>
<tr>
<td>06</td>
<td>Basic grade (HO/FY1 or SHO/FY2 or equivalent)</td>
</tr>
<tr>
<td>08</td>
<td>Senior staff nurse, enrolled nurse (EN) etc</td>
</tr>
<tr>
<td>10</td>
<td>Allied Health Professional (Physiotherapy/ Speech &amp; language therapy/Occupational therapy)</td>
</tr>
</tbody>
</table>
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 patient's 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 Specialty 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  ☐ Unknown

☐ 999 Ambulance

☐ Other (please specify)

16a. What was the DATE of ADMISSION?

☐ d d m m y y y y

☐ Unknown

16b. What was the TIME of ward ADMISSION?

☐ h h m m (24 hour clock)

☐ Unknown

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

☐ d d m m y y y y

☐ Unknown

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

☐ h h m m (24 hour clock)

☐ Unknown

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)

☐ d d m m y y y y

☐ Unknown  ☐ (24 hr clock)  ☐ Unknown

(24)
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)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of availability of suitable equipment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient in pain and could not be moved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient too sick to be moved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No reason given</td>
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<td></td>
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</tbody>
</table>

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

27b. Was this actual or estimated?

<table>
<thead>
<tr>
<th>Status</th>
<th>Actual</th>
<th>Estimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ticked status</td>
<td></td>
<td></td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of availability of suitable equipment</td>
<td></td>
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</tr>
<tr>
<td>Patient in pain and could not be moved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient too sick to be moved</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Not routinely done</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No reason given</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Variable</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart rate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure</td>
<td></td>
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<td></td>
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<td>Oxygen saturation</td>
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<tr>
<td>Temperature</td>
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<td></td>
</tr>
<tr>
<td>Respiratory rate</td>
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<td></td>
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<tr>
<td>Glasgow Coma Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Warning Score (paediatric or adult)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29a. Was a pain assessment made on admission?

<table>
<thead>
<tr>
<th>Ticked status</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

29b. If YES, was a pain assessment tool used that was appropriate for the age, communication and cognitive ability of the patient?

<table>
<thead>
<tr>
<th>Ticked status</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

29c. If YES to 29a, was the patient in significant pain on admission?

<table>
<thead>
<tr>
<th>Ticked status</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

**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)

<table>
<thead>
<tr>
<th>Ticked status</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>Location</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Department</td>
<td></td>
</tr>
<tr>
<td>Assessment Unit (including Emergency Medical Unit)</td>
<td></td>
</tr>
<tr>
<td>Surgical Assessment Unit</td>
<td></td>
</tr>
<tr>
<td>Paediatric critical care (levels 1 – 3)</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>
31b. If the initial care was in an EMERGENCY OR ASSESSMENT UNIT, where was their care subsequently managed?

☐ Paediatric ward (medical or surgical)  ☐ Adult Medical ward
☐ Adult surgical ward  ☐ Paediatric Critical care (level 1-3)
☐ Adult critical care (levels 2 & 3)  ☐ Transferred to another hospital
☐ Operating theatre
☐ Other (please specify) ____________________________

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)

☐ Delay in hospital presentation  ☐ Initial assessment incomplete
☐ Lack of knowledge/experience of attending staff  ☐ Symptoms/signs unclear
☐ Delay in senior and/or consultant review  ☐ 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)

☐ Delay in hospital presentation  ☐ Diagnostic uncertainty
☐ Technical difficulty (e.g. difficult venous access)  ☐ Delay in senior and/or consultant review
☐ Uncertainty about how active/aggressive resuscitation should be
☐ Other (please specify) ____________________________

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)

☐ Delay in hospital presentation  ☐ Diagnostic uncertainty
☐ Technical difficulty (e.g. difficult venous access)
☐ Uncertainty about how active/aggressive treatment should be
☐ Other (please specify) ____________________________

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)
☐ GP  ☐ Community paediatrician  ☐ General paediatrician
☐ Disability specialist paediatrician  ☐ Paediatric neurologist
☐ Paediatric surgeon  ☐ Physician  ☐ Neurologist
☐ Neurorehabilitation specialist  ☐ Orthopaedic surgeon  ☐ Other surgeon
☐ 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
☐ Physiotherapy  ☐ Nutrition team  ☐ General paediatrician
☐ Specialist nursing team (e.g. stoma nursing, epilepsy nurse, learning disability nurse)
☐ Speech and Language Therapy  ☐ Occupational Therapy

Surgeons
☐ Orthopaedic  ☐ General  ☐ Other

Specialist paediatricians/physicians
☐ Paediatrics  ☐ Neurodisability  ☐ Gastroenterology
☐ Respiratory  ☐ Neurology  ☐ Pain team
☐ 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 Dependancy 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

40a. What was the date of this referral?
- □ dd mm yy

40b. What was the time of this referral?
- □ hh mm (24 hour clock)

40c. To which group of critical care clinicians was the referral made?
- □ Paediatric critical care team ON SITE
- □ Paediatric critical care or transfer team OFF SITE
- □ Adult critical care team ON SITE
- □ Adult critical care team OFF SITE

40d. What was the GRADE and SPECIALITY 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 □

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
   - 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/day after the first referral?
   - ___ Hours
   - ___ Days
   - Unknown

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:
☐ 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 specialty 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 analgesia)

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 □ NA □ Unknown

68. Were parent/carers encouraged to be part of the care process and as requested by patient? □ Yes □ No □ NA □ Unknown

69. Was it possible for a parent/carer to be resident and as required/requested by the patient? □ Yes □ No □ NA □ 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?
   □ Patient’s home  □ Neurorehabilitation in a community setting
   □ Respite care in a community setting  □ Hospice/palliative care
   □ Another hospital  □ 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)
   □ GP  □ Lead clinician for cerebral palsy care
   □ Social care  □ Community care medical and nursing staff
   □ Community Allied Health Professionals  □ Palliative care team
   □ 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

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