



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

5. ADULT INPATIENT CARE

Name of Trust/Board/Organisation: _____

CONFIDENTIAL

Who completed this questionnaire?

Name: _____

Position: _____

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 children and young people chronic disabling conditions, the cerebral palsies.

To examine the interface between different care settings

To examine the transition of care

Who should complete this form?

The clinician/s with the best overall knowledge of adult inpatient healthcare delivered by this organisation for young adults up to 25 years. If this is not an orthopaedic surgeon please discuss with relevant surgical colleagues in order to provide the most full and accurate picture of services.

To ensure confidentiality of the data, completed questionnaire must be returned directly to NCEPOD in the SAE provided.

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.

Following crisis or emergency referral, are there any standards set for assessment from time of referral?

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 pages 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.

ORGANISATIONAL ID

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DEFINITIONS

Reasonable adjustments	“Employers and organisations such as hospitals, care homes and GP surgeries must take steps to remove the barriers people face because of their disabilities” (CQC, 2015. http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#)
Interagency strategic partnership arrangements	A formal mechanism for considering the strategic needs of the local population of disabled children and young people
Out of hours	18:00 – 07:59 Monday to Friday and all day Saturday and Sunday
Accessibility of services	To be fully accessible, a service must have: <ul style="list-style-type: none"> o Accessible parking for the disabled o Ramped access o Doors wide enough for wheelchair access o Accessible toilets o Changing place for children and young people of all ages with cerebral palsies who are incontinent and need to be changed o Hoists o Accessible, height adjustable beds and examination couches o Appropriate scales e.g. wheelchair scales, hoist scales o Reasonable adjustments made to accommodate the specific needs of the disabled person
Individualised Emergency Health Care/Personal Resuscitation plan	Plan agreed with the lead clinician, that documents what has been discussed and agreed and with whom, about appropriate levels of intervention for the child/young person (e.g. any advance statements, advance decisions to refuse treatment, do not attempt cardiopulmonary resuscitation decisions, variations from advanced life support guidelines, treatment or intervention limitations.
Capacity	As defined in the Mental Capacity Act 2005 (applies in E&W) and equivalent legislation in Scotland and NI See https://www.disabilitymatters.org.uk/course/view.php?id=62
Best-interests decision-making	See https://www.disabilitymatters.org.uk/course/view.php?id=63
Gross Motor Function Classification System (GMFCS)	See: https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r



A. THE TRUST/ORGANISATION/PROVIDER/HEALTH BOARD

- 1a. From which age does this organisation provide acute adult care? (What does this organisation define as an adult?) Years
- 1b. From what age does this organisation provide acute adult care for disabled young adults? Years
- 1c. Is there a lead clinician or team for the care of disabled young adults whilst they are inpatients? Yes No

Please complete the remainder of this questionnaire in relation to the care provided to YOUNG ADULTS as defined by this organisation. For the remainder of this questionnaire patients will be referred to as young adults.

B. ACCESS TO SERVICES FOR YOUNG ADULTS WITH CEREBRAL PALSIAS

- 2a. Whilst an inpatient, is advice available out of hours from a clinician with expertise (def) in disability? Yes No
- 2b. If YES, is this
- Formally with an on call rota in place? Informal access to a disability expert clinician when available?
3. Is there a policy to accommodate reasonable adjustments (specific to the individual) for young adults who require acute care: Yes No

C. SERVICES AND PROCEDURES

4. Please indicate how the following services are accessed for inpatients? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Neuro-rehabilitation consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intensive care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopaedic surgeon (general)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spinal orthopaedic surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopaedic surgeon with expertise in disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastroenterologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



4. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
General surgeon with expertise in disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthotist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist nurse for disabled adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist dental services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT with disability expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatric assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning disability psychiatric assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5a. Do young adults within this organisation routinely have their (overall) care supervised by a lead clinician with expertise in neurodisability? Yes No

5b. If yes, where is this clinician typically located?
 Hospital Community Both

6a. Are young adults with cerebral palsies and associated significant co-morbidity that are admitted for planned surgery routinely cared for jointly by a physician with expertise in neurodisability as well as a surgeon? Yes No



6a. Are young adults with cerebral palsies and associated significant co-morbidity that are admitted for planned surgery routinely cared for jointly by a physician with expertise in neurodisability as well as a surgeon? Yes No

6b. If yes, where is this clinician typically located?
 Joint care at all levels Senior advice/input as required Trainee input as required

7a. Are young adults with cerebral palsy and associated significant co-morbidity admitted for emergency surgery routinely cared for jointly by a physician as well as surgeon? Yes No

7b. How would you describe the level of this input?
 Joint care at all levels Senior advice/input as required Trainee input as required

8a. Is it routine practice for young adults with SEVERE neurodisability to be admitted for surgery/procedures through the day surgery unit in this organisation? Yes No

8b. If no to question 8a, why is this?
 Surgical/anaesthetic risk is felt to be too great
 Physical facilities are inappropriate in day procedure unit (e.g. lack of access, special beds etc.)
 Lack of nurse competencies to care for patient
 Other (please specify)

9. To what extent does a multidisciplinary team (MDT) work together to plan the routine peri-operative care of young adults with severe neurodisability (GMFC III-V) in this hospital? (Please tick all that apply)

- MDT discussion prior to all planned major surgery
- MDT discussion for high risk patients and/or major planned surgery
- MDT discussion for high risk patients and/or major urgent or emergency surgery
- Routine pre-assessment clinics with medical/anaesthetic input prior to planned surgery
- Existing guidelines and protocols for peri-operative care of young adults with severe neurodisability
- Specific care plans for particular surgical pathways e.g. scoliosis surgery which include management of common co-morbidities associated with cerebral palsies

10. Which of the following procedures/interventions can be carried out for children and young people with cerebral palsies whilst receiving inpatient care? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Magnetic resonance imaging without sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



14. Continued.

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Magnetic resonance imaging with sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Magnetic resonance imaging under general anaesthetic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Standardised pelvic xray for hip surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
pH studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fundoplication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ACE procedure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastrostomy tube placement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastrostomy tube emergency replacement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deep brain stimulation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Botulinum toxin injections under general anaesthetic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Botulinum toxin injections under sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Soft tissue orthopaedic surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bony orthopaedic surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scoliosis surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limb reconstruction/leg length equalisation procedures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intrathecal baclofen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Selective dorsal rhizotomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non invasive respiratory support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



D. ACCESSIBILITY

Accessibility of services for inpatient paediatric medical and surgical services for all children and young people with cerebral palsies, including wheelchair users who are totally dependent on others for all care

11a. In general, across the ADULT MEDICAL inpatient service are there any problems with access to:

	Yes	No
Accessible parking for the disabled	<input type="checkbox"/>	<input type="checkbox"/>
Ramped access	<input type="checkbox"/>	<input type="checkbox"/>
Doors wide enough for wheelchair access	<input type="checkbox"/>	<input type="checkbox"/>
Accessible toilets	<input type="checkbox"/>	<input type="checkbox"/>
A changing place providing privacy for essential personal care	<input type="checkbox"/>	<input type="checkbox"/>
Accessible height adjustable beds and examination couches	<input type="checkbox"/>	<input type="checkbox"/>
Hoists	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate scales (e.g. wheelchair scales, hoist scales)	<input type="checkbox"/>	<input type="checkbox"/>
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	<input type="checkbox"/>	<input type="checkbox"/>

11b. If yes to any of the above, please give details:

11c. In general, across the ADULT SURGICAL inpatient service are there any problems with access to:

	Yes	No
Accessible parking for the disabled	<input type="checkbox"/>	<input type="checkbox"/>
Ramped access	<input type="checkbox"/>	<input type="checkbox"/>
Doors wide enough for wheelchair access	<input type="checkbox"/>	<input type="checkbox"/>
Accessible toilets	<input type="checkbox"/>	<input type="checkbox"/>
A changing place providing privacy for essential personal care	<input type="checkbox"/>	<input type="checkbox"/>
Accessible height adjustable beds and examination couches	<input type="checkbox"/>	<input type="checkbox"/>
Hoists	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate scales (e.g. wheelchair scales, hoist scales)	<input type="checkbox"/>	<input type="checkbox"/>
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	<input type="checkbox"/>	<input type="checkbox"/>

11d. If yes to any of the above, please give details:

12. Is single room accommodation always available for planned admissions for young adults with cerebral palsy at this organisation?

Yes No NA



E. SUPPORT SERVICES

13. What family support systems are available for disabled young adults whilst receiving inpatient care on MEDICAL INPATIENT wards? (These may not necessarily be based on site.) (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Social work team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent carer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group for young disabled adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other

14. What family support systems are available for disabled young adults whilst receiving inpatient care on SURGICAL INPATIENT wards? (These may not necessarily be based on site.) (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Social work team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent carer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group for young disabled adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other

F. COMMUNICATION ISSUES

15. Whilst an inpatient, are young adults given the opportunity to speak to health professionals without a parent present if they prefer to? Yes No



16a. Are discharge planning meetings that include the young adult's usual healthcare team held?:

- For all inpatient episodes lasting a specified number of weeks
 For all inpatient episodes where the young adult's needs have changed significantly since admission
 On an ad hoc basis Rarely Never

16b. If discharge planning meetings are held for inpatient episodes lasting a specified number of weeks, what is the minimum time period (in weeks)?

17. Following medical or surgical inpatient care, is the discharge summary routinely copied to the following? (please tick all that apply)

	Medical inpatients	Surgical inpatients
GP	<input type="checkbox"/>	<input type="checkbox"/>
Usual lead clinician	<input type="checkbox"/>	<input type="checkbox"/>
Usual therapists (inpatient/outpatient/community team)	<input type="checkbox"/>	<input type="checkbox"/>
Parent carers/child/young person	<input type="checkbox"/>	<input type="checkbox"/>

G. COMMUNICATION IN AN EMERGENCY

18a. Is there an agreed system in place for preparing written emergency health care plans (which may include personal resuscitation plans) for those with the most complex medical/surgical needs? Yes No

18b. How well is this system implemented in the regular care of severely disabled young adults?
 Completely (all patients with complex needs have such a plan in place) Partially Not implemented

19. Are written communications, including Emergency Health Care Plans, available in other languages or formats if required? Yes No

H. TRAINING

20. Is any training provided (either for specific procedures or broad areas of management) for young adults with cerebral palsies who receive inpatient care in aspects of self management? Yes No

21. Is any training provided for PARENT CARERS of young adults with cerebral palsies who receive inpatient care in aspects of management, including technology dependencies (for example ventilator, gastrostomy tube, VP shunt)? Yes No



22a. How is disability awareness training delivered for staff who provide inpatient care?

- Routinely integrated into induction Ad hoc None
 Routinely available into a mandatory education programme

22b. Are disabled people involved in delivering any of the above training? Yes No

22c. If yes, please provide details.

I. TRANSITION TO ADULT SERVICES

23. Does this organisation have clear policies in place to ensure continuity of patient care, including close handover between professionals, and familiarisation with case histories, at all interfaces and points of transitions of care? Yes No
24. Are young adults offered the opportunity to be seen separately from their parent/carer in the acute medicine service, e.g. on ward rounds? Yes No
25. Are young adults offered the opportunity to be seen separately from their parent/carer on surgical ward rounds? Yes No
26. Are young adults with neurodisability offered the opportunity for a parent carer to be present for extended/flexible hours whilst an inpatient? Yes No
27. Is there a facility for a parent carer to stay on site/on the ward overnight if required? Yes No
28. Are young people with neurodisability admitted for planned procedures/surgery routinely given the following ward facilities to provide for their privacy and dignity?

	Yes	No
Single room accommodation	<input type="checkbox"/>	<input type="checkbox"/>
En suite toilet facilities	<input type="checkbox"/>	<input type="checkbox"/>
Space for special equipment (wheelchairs/hoist etc)	<input type="checkbox"/>	<input type="checkbox"/>

J. DECISION MAKING WITH YOUNG ADULTS WITH CEREBRAL PALSIES

29a. Is capacity routinely assessed for inpatient young adults aged 16 years or over where there are concerns that the young person may have an impairment of brain or mind? Yes No



- 29b. Does this always occur? Yes No
30. Is a best interests decision-making process embedded for young adults over 16 years of age who have been assessed as not having capacity to make a specific decision at a specific time and in specific circumstances? Yes No
31. Are competent young adults routinely included in the decision making and consent process and assisted in documentation of consent where possible prior to surgery and invasive procedures? Yes No
32. Are there systems in place for the views of inpatient disabled young adults to inform service design and delivery? Yes No
33. Are there systems in place for the views of parent carers of inpatient disabled young adults to inform service design and delivery? Yes No

K. PALLIATIVE AND END OF LIFE CARE

34. Who provides palliative and end of life care for inpatient young adults with cerebral palsies where this is required? (Please select all that apply)
- General paediatrician GP Palliative care physician Specialist nurse
- Other (Please specify)

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

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NCEPOD
Ground Floor, Abbey House
74-76 St John Street
London
EC1M 4DZ

