



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

2. PAEDIATRIC 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

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.

Who should complete this form?

The clinician/s with the best overall knowledge of paediatric inpatient healthcare delivered by this organisation. 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. Please link with colleagues (to include surgeons) as need be to inform the most accurate possible response.

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

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. Up to what age, in years, does this organisation provide acute paediatric care? (What does this organisation define as a child?) Years
- 1b. Up to what age, in years, does this organisation provide acute paediatric care for disabled children and young people? Years
- 1c. What does this organisation define as an adolescent? (age range in years)
-
2. Does the care of adolescents fall under the care of any of the following? (Please tick all that apply)
- Paediatric pathway Specific adolescent pathway Adult pathway
3. Does this organisation have a specific adolescent ward or area? Yes No
4. Is there a lead clinician or team for adolescent care? Yes No
5. Is there a lead clinician or team for the care of disabled children and young people? Yes No
6. Is there an agreed written transition pathway? Yes No

Please complete the remainder of this questionnaire in relation to the care provided to CHILDREN AND ADOLESCENTS as defined by this organisation. For the remainder of this questionnaire children and adolescents will be referred to as children and young people.

B. ACCESS TO SERVICES FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

- 7a. Whilst the child or young person is an inpatient, is advice available out of hours from a clinician with expertise in children and young people's disability? Yes No
- 7b. If YES, is this
- Formally with an on call rota in place? Informal access to a disability expert clinician when available?

C. OPERATIONAL SERVICE DELIVERY MODEL FOR CLINICAL SERVICES

8. Is there a policy to accommodate reasonable adjustments (specific to the individual) for disabled children and young people who require acute care? Yes No



C. SERVICES AND PROCEDURES

9. Please indicate how the following services are accessed for children and young people who are inpatients? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Paediatrician with specialist expertise in neurodisability/cerebral palsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric gastroenterologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric surgeon/general surgeon with an interest in childre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician with specific interest in epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric intensive care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric pain specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopaedic surgeon with expertise in children and young people's cerebral palsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spinal orthopaedic surgeon with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT surgeons with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiology with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmology with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric respiratory physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's specialist community nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



9. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Children and young people's learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child and adolescent mental health service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child and adolescent mental health service specifically for children and young people with learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist children and young people's dental services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support for parents/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D. SERVICES AND PROCEDURES

- 10a.** Are children and young people with cerebral palsies and associated significant co-morbidity that are admitted for planned surgery routinely cared for jointly by a paediatrician as well as a surgeon? Yes No
- 10b.** If yes, how would you describe the level of this input?
 Joint care at all levels Senior advice/input as required Trainee input as required
- 11a.** Are children and young people with cerebral palsy and associated significant co-morbidity admitted for EMERGENCY surgery routinely cared for jointly by a paediatrician as well as a surgeon? Yes No
- 11b.** If yes, how would you describe the level of this input?
 Joint care at all levels Senior advice/input as required Trainee input as required
- 12a.** Is it routine practice for children and young people with SEVERE neurodisability to be admitted for surgery/procedures through the day surgery unit in this organisation? Yes No
- 12b.** If NO to question 12, why is this? (Please tick all that apply)
- Surgical/anaesthetic risk is felt to be too great Lack of nurse competencies
- Physical facilities are inappropriate in day procedure unit (e.g. lack of access, special beds etc.)
- Other (please specify)



13. To what extent does a multidisciplinary team (MDT) work together to plan the routine peri-operative care of children and young people 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 children and young people 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

14. 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"/>
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"/>
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"/>



14. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
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"/>
Gait analysis	<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"/>

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

15a. In general, across the paediatric MEDICAL 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"/>



15a. Continued

	Yes	No
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	<input type="checkbox"/>	<input type="checkbox"/>

15b. If yes to any of the above, please give details:

16a. In general, across the SURGICAL 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"/>



16b. If yes to any of the above, please give details:

17a. Is single room accommodation always available for planned admissions for young people with cerebral palsy at this organisation?

Yes No NA

F. SUPPORT SERVICES

18. What family support systems are available for disabled children and young people whilst receiving inpatient care on PAEDIATRIC INPATIENT WARDS? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Children's social work team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents information officer	<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 children and young people	<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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (Please specify)



19. What family support systems are available for disabled children and young people whilst receiving paediatric medical inpatient care on SURGICAL INPATIENT WARDS? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Children's social work team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents information officer	<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 children and young people	<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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (Please specify)

20a. Are children and young people with cerebral palsies and associated significant co-morbidity that are admitted for planned surgery routinely cared for jointly by a paediatrician as well as a surgeon?

All families with disabled children and young people routinely?

Only involved if there are safeguarding issues?

NA

20b. What are the thresholds for the involvement of the team?

21a. Is education support available for disabled children and young people requiring paediatric inpatient care?

Yes No

G. COMMUNICATION ISSUES

22a. Whilst an inpatient, are children and young people given the opportunity to speak to health professionals without a parent present if they prefer to?

Yes No



22b. Are discharge planning meetings that include the child or young person's usual healthcare team held?:

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

22c. If discharge planning meetings are held for inpatient episodes lasting a specified number of weeks, what is the minimum time period (in weeks)?

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

	Paediatric inpatients	Children's 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"/>

Communication in an emergency

24a. 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

24b. How well is this system implemented in the regular care of severely disabled children and young people?
 Completely (all patients with complex needs have such a plan in place) Partially Not implemented

H. TRAINING

25. Is any training provided (either for specific procedures or broad areas of management) for children and young people who receive paediatric inpatient care in aspects of self management? Yes No

26. Is any training provided for parent carers of disabled children and young people who receive paediatric inpatient care in aspects of management, including technology dependencies (for example ventilator, gastrostomy tube, VP shunt)? Yes No



27a. How is disability awareness training delivered for staff who provide paediatric inpatient care (paediatric medicine and children's surgery)?

- Routinely integrated into induction Ad hoc (only some staff/ward areas)
- Included in mandatory education programme None
- Other (Please specify)

27b. Are disabled children, young people, and/or families involved in delivering any of the above training? Yes No NA

27c. If YES, please provide details:

I. TRANSITION TO ADULT SERVICES

28. 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
29. Are young people offered the opportunity to be seen separately from their parent/carer in the acute medicine service, e.g. on ward rounds? Yes No
30. Are young people offered the opportunity to be seen separately from their parent/carer in the surgical service, such as on ward rounds? Yes No
31. To what services do young people with cerebral palsies transfer when leaving children's medical/surgical services, when inpatient care is required? (Answers may be multiple)
- Specialist service for disabled young adults
- General medical/surgical/orthopaedic services with pathways/protocols in place for adjustments in view of disability
- General medical/surgical/orthopaedic services, no specific pathways/protocols for adjustments
- Other (Please specify)

J. DECISION MAKING WITH YOUNG ADULTS WITH CEREBRAL PALSIES

- 32a. Is capacity routinely assessed for young people aged 16 years or over who receive paediatric inpatient care where there are concerns that the young person may have an impairment of brain or mind? Yes No
- 32b. Does this always occur? Yes No



33. Is a best interests decision-making process embedded for young people over 16 years of age who receive paediatric inpatient care who have been assessed as not having capacity to make a specific decision at a specific time and in specific circumstances? Yes No
34. Are children and young people of all ages routinely included in the decision making and consent process and assisted to complete written consent where possible and as appropriate to level of understanding prior to surgery/invasive procedures? Yes No
35. Are there systems in place for the views of children and young people to inform service design and delivery on the PAEDIATRIC INPATIENT WARDS? Yes No
36. Are there systems in place for the views of children and young people to inform service design and delivery on the CHILDREN'S SURGICAL INPATIENT WARDS? Yes No
37. Are there systems in place for the views of parent carers to inform service design and delivery on the PAEDIATRIC INPATIENT WARDS? Yes No
38. Are there systems in place for the views of parent carers to inform service design and delivery on the CHILDREN'S SURGICAL INPATIENT WARDS? Yes No

K. PALLIATIVE AND END OF LIFE CARE

39. Who provides palliative care for inpatient children and young people with cerebral palsies? (Please select all that apply)
- General paediatrician Community paediatrician
- Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care
- Paediatric palliative care consultant Adult palliative care physician
- Community children's nurse Specialist palliative care nurse
- Other (Please specify)

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE



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