



# CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

## ORGANISATIONAL QUESTIONNAIRE

### 1. EMERGENCY 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 to adult services

#### Who should complete this form?

The clinician/s with the best overall knowledge of emergency healthcare that includes children and young people with cerebral palsies delivered by this organisation. 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.

#### 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](mailto: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. <a href="http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#">http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#</a> )
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"> <li>o Accessible parking for the disabled</li> <li>o Ramped access</li> <li>o Doors wide enough for wheelchair access</li> <li>o Accessible toilets</li> <li>o Changing place for children and young people of all ages with cerebral palsies who are incontinent and need to be changed</li> <li>o Hoists</li> <li>o Accessible, height adjustable beds and examination couches</li> <li>o Appropriate scales e.g. wheelchair scales, hoist scales</li> <li>o Reasonable adjustments made to accommodate the specific needs of the disabled person</li> </ul>
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 <a href="https://www.disabilitymatters.org.uk/course/view.php?id=62">https://www.disabilitymatters.org.uk/course/view.php?id=62</a>
Best-interests decision-making	See <a href="https://www.disabilitymatters.org.uk/course/view.php?id=63">https://www.disabilitymatters.org.uk/course/view.php?id=63</a>
Gross Motor Function Classification System (GMFCS)	See: <a href="https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r">https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r</a>



## A. THE TRUST/ORGANISATION/PROVIDER/HEALTH BOARD

Please complete this questionnaire in relation to the care provided to CHILDREN AND YOUNG PEOPLE BETWEEN THE AGES OF 0 - 25

- 1a. Does this organisation provide emergency care for:
- Children and young people only       Adults only       All ages
- 1b. If emergency care is only provided for CHILDREN AND YOUNG PEOPLE, up to what age is this provided for:
- 
2. Is there a lead clinician or team for the care of CHILDREN AND YOUNG PEOPLE in the emergency department?       Yes       No
3. Is there a lead clinician or team for the care of disabled ADULTS in the emergency department?       Yes       No

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

4. Do children and young people have access to accommodation within the emergency department which provides treatment areas that are audio-visually separate from adults?       Yes       No
5. Do CHILDREN AND YOUNG PEOPLE have access to cubicle accommodation which allows space for family members and equipment?       Yes       No
6. Does this organisation provide cubicles with doors to allow for privacy and confidentiality when young people are being seen/interviewed?       Yes       No
- 7a. When a CHILDREN AND YOUNG PEOPLE presents to the emergency department is advice available out of hours and at weekends from a clinician with expertise in children and young people's disability?       Yes       No
- 7b. Is this clinician with expertise in children and young people's disability a:
- Children and young people only       Adults only
- 7c. Is this:
- Formal support with an on call rota in place?       Informal access to disability expert clinician when available?
- 8a. When a YOUNG ADULT presents to the emergency department is advice available out of hours and at weekends from a clinician with expertise in young adult's disability (up to 25 years)?       Yes       No
- 8b. Is this:
- Formal support with an on call rota in place?       Informal access to disability expert clinician when available?
9. Within the emergency department is there a policy to accommodate reasonable adjustments (specific to the individual) for disabled patients who require emergency care?       Yes       No



## C. SERVICES AND PROCEDURES

10. Please indicate how the following services are accessed whilst in the emergency department?  
(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	<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"/>
Paediatric respiratory physician	<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 disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>



10. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Spinal orthopaedic surgeon	<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"/>
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"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<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"/>
ENT with disability expertise	<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"/>
Acute psychiatric assessment including for patients with learning disabilities	<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"/>
Acute learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## D. ACCESSIBILITY

11a. In general, across the emergency department 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:



## E. COMMUNICATION

12. Is the emergency department summary routinely copied to the following? (please tick all that apply)
- GP  Usual lead clinician  
 Usual therapists  Parent carers/child/young person
13. Within the emergency department, are CHILDREN AND YOUNG PEOPLE given the opportunity to speak to health professionals without a parent present if they prefer to?  Yes  No
- 14a. 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 needs?  Yes  No
- 14b. 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
- 14c. Does this system involve care at presentation with the Emergency Department?  Yes  No
- 14d. Were senior emergency department clinicians involved in preparation/planning of this system?  Yes  No
15. Are emergency plans fully accessible for disabled CHILDREN AND YOUNG PEOPLE that attend the emergency department, e.g. emergency passport/card holder?  Yes  No

## F. TRAINING

16. Do all clinical staff working in the emergency department have a minimum level of skill and knowledge to care for children and young people?  Yes  No
17. Does this emergency department have a lead nurse for safeguarding/child protection in children and young people?  Yes  No
- 18a. How is disability awareness training delivered for staff within the emergency department? (Please tick all that apply)
- Routinely integrated into induction  Ad hoc  
 Routinely available into a mandatory education programme  None  
 Other (please specify)
- 18b. Are disabled children, young people and families involved in delivering any of the above training?  Yes  No  NA



18c. If disabled children, young people and/or families are involved in delivering training, please provide details:

## G. DECISION-MAKING WITH CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

- 20a. Is capacity routinely assessed in the emergency department for patients aged 16 years or over where there are concerns that the young person may have an impairment of brain or mind?  Yes  No
- 20b. If YES, does this always occur?  Yes  No
21. Is a best interests decision-making process embedded in the emergency department for young people 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
22. Are there systems in place for the views of CHILDREN AND YOUNG PEOPLE to inform service design and delivery within the emergency department?  Yes  No
23. Are there systems in place for the views of disabled CHILDREN AND YOUNG PEOPLE to inform service design and delivery within the emergency department?  Yes  No
24. Are there systems in place for the views of parent carers to inform service design and delivery within the emergency department?  Yes  No

**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

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