



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

6. ADULT OUTPATIENT 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 outpatient/clinical-based healthcare that includes young adults with cerebral palsies delivered by your 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.

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 what age - in years - does this organisation provide adult outpatient care? (What does the organisation define as an adult?) Years
- 1b. From what age - in years - does this organisation provide adult outpatient care for disabled young adults? Years

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. POPULATION OVERVIEW DATA AND STRATEGIC ISSUES

2. Is there a lead clinician or team for the care of disabled young adults who receive outpatient care? Yes No

C. ACCESS TO SERVICES FOR YOUNG ADULTS WITH CEREBRAL PALSY

3. Is there an agreed, written care pathway for assessment, diagnosis and management of young adults with cerebral palsies who are seen in an outpatient clinic? Yes No NA

D. OPERATIONAL SERVICE DELIVERY MODEL FOR CLINICAL SERVICES

4. Are clinics for young adults for cerebral palsy: (Please tick all that apply)
- Non-specialist - seen as part of general clinical caseload
 - Specialist uni-disciplinary, i.e. each specialist sees the young adult separately
 - Multi-disciplinary for postural management (please specify below which professionals are involved in the MDT clinics)
 - Multi-disciplinary for feeding management (please specify below which professionals are involved in the MDT clinics)
 - Outreach clinics in special schools
 - Other (Please specify)
5. For young adults with cerebral palsy seen in the outpatient department, how do the various health professionals work together in delivering healthcare? (Please tick all that apply)
- Regular meetings
 - Ad hoc meetings focused on specific individuals
 - Multidisciplinary clinics
 - No meetings but communicate regularly by letter or email
 - Co-location of professionals
 - No regular arrangements for joint working
 - Other (Please specify)



E. SERVICES AND PROCEDURES

6. Please indicate how the following services are accessed for young adults who are seen as outpatients? (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"/>
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"/>
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 service	<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"/>



E. SERVICES AND PROCEDURES

7a. Which of the following procedures/interventions can be accessed for young adults with cerebral palsies seen in the outpatient department? (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"/>
Botulinum toxin injections under sedation	<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"/>

7b. If MRI is undertaken, is there specialist neuroradiological expertise available to interpret MRI findings? (not necessarily on-site) Yes No

7c. If yes, is this available: Routinely On an ad hoc basis

7d. What is the waiting list time for "routine" MRI from paediatric outpatient department for disabled children and young people?

No sedation Weeks Unknown

Under sedation Weeks Unknown

Under general anaesthetic Weeks Unknown

F. ACCESSIBILITY

ACCESSIBILITY OF OUTPATIENT SERVICES FOR YOUNG ADULTS WITH CEREBRAL PALSIES INCLUDING WHEELCHAIR USERS WHO ARE TOTALLY DEPENDENT ON OTHERS FOR ALL CARE

8a. In general, across this outpatient 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"/>



8a. Continued.

	Yes	No
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"/>

8b. If yes to any of the above, please give details:

G. SYMPTOM MANAGEMENT

9a. For young adults with cerebral palsies at GMFCS levels I and II (independently mobile without the need for devices) healthcare is most likely to be led by:

- GP
 General physician
 Neurologist
 Neurorehabilitation specialist
 Orthopaedic surgeon and physician (general or specialist)
 Orthopaedic surgeon only
 Other (Please specify)

9b. For young adults with cerebral palsies at GMFCS levels III and IV (dependent on devices or wheelchairs for mobility, but not completely dependent on other people, able to self-propel manually or in power chair) healthcare is most likely to be led by:

- GP
 General physician
 Neurologist
 Neurorehabilitation specialist
 Orthopaedic surgeon and physician (general or specialist)
 Orthopaedic surgeon only
 Other (Please specify)



- 9c. For young adults with cerebral palsies at GMFCS level V (completely dependent on other people to propel wheelchairs for mobility) healthcare is most likely to be led by:
- GP General physician Neurologist Neurorehabilitation specialist
 Orthopaedic surgeon and physician (general or specialist) Orthopaedic surgeon only
 Other (Please specify)
10. Is there a policy of ALWAYS enquiring about the presence (or not) of pain at each consultation? Yes No
- 11a. If a scoliosis or other spinal curvature is identified, is a referral made to the spinal orthopaedic surgeon? Yes No
- 11b. If yes, is this:
- Immediately on identification of the curvature
 When the clinician thinks the curvature may need surgical intervention
 Not referred to spinal orthopaedic surgeon, managed conservatively
12. Are evidence-based guidelines (e.g. NICE CG137/SIGN 143) followed for the assessment and management of patients with epilepsy? Yes No

H. SUPPORT SERVICES

13. What FAMILY SUPPORT systems are available for children and young people with cerebral palsies who attend paediatric clinics? (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"/>
Carers' support groups	<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"/>
Disabled people's support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carers' centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advice on benefits and financial support	<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. Are short breaks available for all disabled young adults and their families who need them? Yes No
15. Are you able to recommend accessible leisure opportunities that are available locally? Yes No
16. Is support available for young adults with cerebral palsies seen in the outpatient department to access the following? (Please tick all that apply)
- Work experience Employment Volunteering

I. COMMUNICATION ISSUES

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

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. If yes, 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 and 24 hour postural management plans, available in other languages or formats if required? Yes No
20. For young adults seen in the outpatient clinic is access to a key worker/lead professional for families?
- Routinely available for disabled young adults and families
- Only available for those with the most complex disabilities
- Not available for disabled adults

J. TRAINING

21. Is any training provided (either for specific procedures or broad areas of management) for young adults with cerebral palsies seen in the outpatient department in aspects of self management? Yes No
22. Is any training provided for parent carers of young adults seen in the outpatient department in aspects of management of cerebral palsies, including technology dependencies (either for specific procedures or broad areas of management)? Yes No
- 23a. Does the outpatient department team provide training for other professionals providing services for disabled young adults and their families (e.g. doctors, nurses, allied health professionals, social workers, education staff, leisure providers, support workers etc.)? Yes No



23b. If yes, does this training include the following? (Please tick all that apply)

Disability training at induction No disability-specific training

Disability training embedded in regular training

Other (Please specify)

23c. Are disabled young adults and/or their parent carers involved in delivering any of the above training?

Yes No

23d. If yes, please provide details:

K. TRANSITION

24. 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

25a. Within this organisation is transition to adult neurodisability services for young people based primarily on age?

Yes No

25b. If yes, at what age does transition generally occur between paediatric neurodisability services and services for adults? (in years)

Years

26. Is there a designated professional that leads on the planning of transition care between neurodisability services for young people and adults?

Yes No

27. Does this organisation monitor how well the transition policy works?

Yes No

28. What arrangements are in place for young adults seen in the outpatient department to support transition from paediatric to adult services? (Please tick all that apply)

Specialist transition team/person-centred planners Specialist learning disability transition nurse/s

Specialist disabled person's social work team to support transition No specific transition arrangements

Other (Please specify)

30. Is there a policy for young people to be offered the opportunity to be seen separately from their parent/carer in this service?

Yes No

31. Are there MENTAL HEALTH services for young adults with cerebral palsies: (Please tick all that apply)

For those with a learning disability For those without a learning disability Unknown

32. Are there SOCIAL CARE services for young people with cerebral palsies in adult services: (Please tick all that apply)

For those with a learning disability For those without a learning disability Unknown

For those who are completely dependent on others for all of their care



5 9 5 7 4 4 0 7 8 1 6 7 7

L. DECISION MAKING

- 33a. Is capacity routinely assessed for young adults who receive outpatient care where there are concerns that the young adult may have an impairment of brain or mind? Yes No
- 33b. Does this always occur? Yes No
34. Is a best interests decision-making process embedded for young adults who receive outpatient care who have been assessed as not having capacity to make a specific decision at a specific time and in specific circumstances? Yes No
35. Are there systems in place for the views of disabled young adults to inform service design and delivery who receive outpatient department care? Yes No

M. PALLIATIVE AND END OF LIFE CARE

36. For young adults with cerebral palsy who receive outpatient department care, who provides palliative care? (Please select all that apply)
- GP General physician Palliative care consultant Specialist palliative care nurse
- Other (Please specify)

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

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