CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

3. PAEDIATRIC 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

Who should complete this form?

The clinician/s with the best overall knowledge of outpatient 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

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 | | | | | | |

1 957446 309978

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: 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 paediatric outpatient care? (What does this organisation define as a child?) ☐☐ Years

1b. Up to what age, in years, does this organisation provide paediatric outpatient care for disabled children and young people? ☐☐ Years

1c. What does this organisation define as an adolescent? (age range in years)

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. POPULATION OVERVIEW, DATA AND STRATEGIC ISSUES

2a. Is there a lead clinician or team for the general paediatric outpatient care of disabled children and young people? ☐ Yes ☐ No

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

3a. Is there an agreed, written care pathway for assessment, diagnosis and management of children and young people with cerebral palsies who are seen in the general paediatric outpatient department? ☐ Yes ☐ No

3b. Does this include:

	Yes	No
Hip surveillance	☐	☐
Magnetic Resonance Imaging of head and/or spine	☐	☐
Pain identification and management	☐	☐
Anthropometric measurement and monitoring of growth and nutrition	☐	☐
Spine monitoring and when to refer to spinal orthopaedic surgeon	☐	☐

3c. If yes to 3a, where is this pathway published so that referrers and parents know how to access the service? (Answers may be multiple)

☐ Local Offer (England) ☐ Organisation website ☐ Not published

☐ Written referral guidance for GPs, health visitors etc.

☐ Other (Please specify)

D. OPERATIONAL SERVICE DELIVERY MODEL FOR CLINICAL SERVICES

4. Are clinics for children and young people with 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 child or young people separately
- ☐ Multi-disciplinary for postural management (please specify which professionals are involved in the MDT clinics in the space below)
- ☐ Multi-disciplinary for feeding management (please specify which professionals are involved in the MDT clinics in the space below)
- ☐ Outreach clinics in special schools
- ☐ Other (Please specify)

5. For children and young people seen in general paediatric outpatient clinics, how do the various health professionals work together in delivering healthcare for children and young people with cerebral palsy? (Please tick all that apply)

- ☐ Regular meetings
- ☐ Multidisciplinary clinics
- ☐ Co-location of professionals
- ☐ Ad hoc meetings focused on specific individuals
- ☐ No meetings but communicate regularly by letter or email
- ☐ No regular arrangements for joint working
- ☐ Other (Please specify)

E. SERVICES AND PROCEDURES

6. 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	☐	☐	☐	☐
Paediatric neurologist	☐	☐	☐	☐
Paediatric gastroenterologist	☐	☐	☐	☐
Paediatric surgeon/general surgeon with an interest in children	☐	☐	☐	☐
Paediatrician with specific interest in epilepsy	☐	☐	☐	☐

6. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Orthopaedic surgeon with expertise in children and young people's cerebral palsies	☐	☐	☐	☐
Paediatric pain specialist	☐	☐	☐	☐
Orthopaedic surgeon with expertise in children and young people's cerebral palsies	☐	☐	☐	☐
Spinal orthopaedic surgeon with paediatric expertise	☐	☐	☐	☐
ENT surgeons with paediatric expertise	☐	☐	☐	☐
Audiology with paediatric expertise	☐	☐	☐	☐
Ophthalmology with paediatric expertise	☐	☐	☐	☐
Paediatric respiratory physician	☐	☐	☐	☐
Paediatric physiotherapist	☐	☐	☐	☐
Paediatric dietician	☐	☐	☐	☐
Paediatric occupational therapist	☐	☐	☐	☐
Paediatric clinical psychology	☐	☐	☐	☐
Paediatric speech and language therapist - communication	☐	☐	☐	☐
Paediatric speech and language therapist - dysphagia, feeding and swallowing	☐	☐	☐	☐
Children's specialist community nurse	☐	☐	☐	☐
Children and young people's learning disability nurse specialist	☐	☐	☐	☐
Children's epilepsy nurse specialist	☐	☐	☐	☐
Paediatric continence specialist practitioner	☐	☐	☐	☐
Child and adolescent mental health service	☐	☐	☐	☐
Child and adolescent mental health service specifically for children and young people with learning disability	☐	☐	☐	☐

6. Continued.

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Specialist children and young people's dental services	☐	☐	☐	☐
Psychological support for parents/family members	☐	☐	☐	☐

7. Which of the following procedures/interventions can be accessed for children and young people with cerebral palsies seen in the general paediatric outpatient clinic? (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	☐	☐	☐	☐
Magnetic resonance imaging with sedation	☐	☐	☐	☐
Magnetic resonance imaging under general anaesthetic	☐	☐	☐	☐
Standardised pelvic xray for hip surveillance	☐	☐	☐	☐
pH studies	☐	☐	☐	☐
Botulinum toxin injections under sedation	☐	☐	☐	☐
Gait analysis	☐	☐	☐	☐

7b. If MRI is undertaken, is this arranged for children and young people with suspected cerebral palsies:

☐ Routinely ☐ Selectively depending on clinical assessment

(If MRI is selectively undertaken, please specify criteria)

7c. Is there specialist paediatric neuroradiological expertise available to interpret MRI findings (not necessarily onsite)? ☐ Yes ☐ No

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

7e. What is the waiting list time for "routine" MRI from the paediatric outpatient department for disabled children and young people? (in weeks)

No sedation	☐☐	Weeks	☐	Unknown
Under sedation	☐☐	Weeks	☐	Unknown
Under general anaesthetic	☐☐	Weeks	☐	Unknown

F. ACCESSIBILITY

ACCESSIBILITY OF OUTPATIENT SERVICES FOR ALL CHILDREN AND YOUNG PEOPLE 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	☐	☐
Ramped access	☐	☐
Doors wide enough for wheelchair access	☐	☐
Accessible toilets	☐	☐
A changing place providing privacy for essential personal care	☐	☐
Accessible height adjustable beds and examination couches	☐	☐
Hoists	☐	☐
Appropriate scales (e.g. wheelchair scales, hoist scales)	☐	☐
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	☐	☐

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

G. SYMPTOM MANAGEMENT

9a. For children and young people 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
- ☐ Community paediatrician
- ☐ General paediatrician
- ☐ Disability paediatrician
- ☐ Orthopaedic surgeon only
- ☐ Orthopaedic surgeon and paediatrician
- ☐ Other (Please specify) _____

9b. For children and young people 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
- ☐ Community paediatrician
- ☐ General paediatrician
- ☐ Disability paediatrician
- ☐ Orthopaedic surgeon only
- ☐ Orthopaedic surgeon and paediatrician
- ☐ Other (Please specify) _____

9c. For children and young people 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
- ☐ Community paediatrician
- ☐ General paediatrician
- ☐ Disability paediatrician
- ☐ Orthopaedic surgeon and paediatrician
- ☐ Other (Please specify) _____

10. Is there a policy of ALWAYS enquiring about the presence (or not) of pain at each consultation? ☐ Yes ☐ No

11a. In general, who is responsible for hip surveillance? (Tick all that apply)

- ☐ Physiotherapist
- ☐ GP
- ☐ Community paediatrician
- ☐ General paediatrician
- ☐ Disability paediatrician
- ☐ Orthopaedic surgeon
- ☐ Ad hoc hip surveillance
- ☐ No standardised hip surveillance in place

11b. In general, who is responsible for spine surveillance for those at GMFCS III-V? (Tick all that apply)

- ☐ Physiotherapist
- ☐ GP
- ☐ Community paediatrician
- ☐ General paediatrician
- ☐ Disability paediatrician
- ☐ Orthopaedic surgeon
- ☐ Ad hoc hip surveillance
- ☐ No standardised hip surveillance in place

12a. If a scoliosis or other spinal curvature is identified, is a referral made to the spinal orthopaedic surgeon? ☐ Yes ☐ No

12b. 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

13. 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

14a. 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
Children's social work team	☐	☐	☐	☐
Parents information officer	☐	☐	☐	☐
Carer support groups	☐	☐	☐	☐
Clinical psychology	☐	☐	☐	☐
Parent carer forum/council	☐	☐	☐	☐
Young people's forum	☐	☐	☐	☐
Young carer support	☐	☐	☐	☐
Short breaks	☐	☐	☐	☐
Advice on benefits and financial support	☐	☐	☐	☐
Sibling support including psychology	☐	☐	☐	☐

Other (Please specify)

Children's social work team

14b. If a CHILDREN'S SOCIAL WORK TEAM is available, does this team support:

☐ All families with disabled children and young people routinely

☐ Only involved if there are safeguardinig issues

14c. What are the thresholds for the involvement of the team? (Please specify)

I. COMMUNICATION ISSUES

15. Whilst an outpatient, are children and young people given the opportunity to speak to health professionals without a parent present if they prefer to? ☐ Yes ☐ No

16. Are "Right from the Start" (or equivalent) guidelines embedded in general paediatric outpatient practice to inform communication about diagnosis? ☐ Yes ☐ No

17. Has there been specific training in 'Right from the Start' (or equivalent) for those delivering general paediatric outpatient care? ☐ Yes ☐ No

18. Are parents given written information at the time of diagnosis? ☐ Yes ☐ No

J. COMMUNICATION IN AN EMERGENCY

19a. 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

19b. 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

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

21. For children and young people seen in general paediatric outpatient clinics is access to a key worker/lead professional for families?

☐ Routinely available for disabled children/young people and families

☐ Only available for those with the most complex disabilities

☐ Only available for pre-school children

K. TRAINING

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

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

L. TRANSITION TO ADULT SERVICES

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

25. Does the recognised transition framework or policy specify the following elements? (Please tick all that apply)

- ☐ A designated a specific care coordinator at transition?
- ☐ Clear written information including that of a key/lead contact within a particular agency?
- ☐ Clear information about emergency and out of hours access to advice if needed after transition?
- ☐ Regular and consistent age appropriate support at transition?

26. What arrangements are in place for young people who receive general paediatric outpatient care to support person-centred transition to adult services? (Please tick all that apply)

- ☐ Specialist transition team/Person-centred planners
- ☐ Specialist learning disability transition nurse/s
- ☐ Specialist disabled children's social work team to support transition
- ☐ No specific transition arrangements
- ☐ Other (Please specify) _____

27a. Within this organisation is transition to adult neurodisability services for young people based primarily on age? ☐ Yes ☐ No

27b. Is yes, at what age does transition generally occur between paediatric neurodisability services and services for adults? (Please specify)

_____

28. Is there a designated professional that leads on the planning of transition care between neurodisability services for young people and adults? ☐ Yes ☐ No

29. Does this organisation monitor how well the transition policy works? ☐ Yes ☐ No

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. To what services do young people with cerebral palsies transfer when leaving children's outpatient services, when outpatient care is required? (Answers may be multiple)

- ☐ No services to transfer to
- ☐ Specific transfer arrangements with GP
- ☐ Neuro-rehabilitation specialist
- ☐ Other specialist physician/surgeon (please specify)

_____

32. Are there MENTAL HEALTH 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

33. 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

34. Are there services available to support young people with cerebral palsies who receive general paediatric outpatient care with access to appropriate:

Work experience	☐ Yes	☐ No
Employment	☐ Yes	☐ No
Training	☐ Yes	☐ No

M. DECISION MAKING WITH CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

35. Is capacity routinely assessed for young people aged 16 years or over who receive general paediatric outpatient care where there are concerns that the young person may have an impairment of brain or mind? ☐ Yes ☐ No

36. Does this always occur? ☐ Yes ☐ No

37. Is a best interests decision-making process embedded for young people over 16 years of age who receive general paediatric 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

38. Are there systems in place for the views of children and young people to inform service design and delivery who receive general paediatric outpatient care? ☐ Yes ☐ No

39. Are there systems in place for the views of parent carers to inform service design and delivery who receive general paediatric outpatient care? ☐ Yes ☐ No

N. PALLIATIVE AND END OF LIFE CARE

40. For children and young people who receive general paediatric outpatient care, who provides palliative care? (Please select all that apply)

☐ GP ☐ General paediatrician ☐ Community paediatrician

☐ Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care

☐ Paediatric palliative care consultant locally ☐ Paediatric palliative care consultant regionally ☐ Adult palliative care consultant

☐ Adult physician ☐ Community children's nurse ☐ Specialist palliative care nurse

☐ Other (Please specify) _____

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

Funding for this study was provided by The Healthcare Quality Improvement Partnership (HQIP) as part of The Clinical Outcome Review Programme into Child Health.

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

NCEPOD

8 957440 780165