



CHRONIC NEURODISABILITY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

PARENT CARER QUESTIONNAIRE

CONFIDENTIAL

What is this study about?

This is part of a big study that hopes to learn how health services work together to support children and young people with cerebral palsies, and their families.

Information is being collected across the UK.

We are very keen to hear what is working well for you and your child or young person. We also would like to know what is not working so well, so that we can highlight this and recommend how to improve services in the future.

Who should complete this form?

Please complete this form if you are a parent carer of a child or young person:

0 - 25 years old

Have a diagnosis of cerebral palsy (this may be called by a different name, for example: Hemiplegia, Diplegia, Quadriplegia, Tetraplegia etc.):

At the end of the questionnaire we ask some questions about your child/young person's condition and how it affects them. This is because we want to learn about the whole range of services for disabled children and young people, from those who can join in with the things they want to do, to those who depend on other people for all of their care and support.

As well as choosing the answers that fit best for your child/young person, you can choose to add your own comments if you can or would like to. All of your responses will be kept private.

Please share this questionnaire with other parent carers of children and young people with cerebral palsies too, so that they can have the chance to have their say.

How to complete the form

This form will be electronically scanned. Please use a black or blue pen to complete this questionnaire.

We would like to know if the health services your child/young person receives work for them and you, or not.

Please think from your point of view about health services that your child/young person receives now or has received in the past, and tell us:

- 1. Up to three things that are going well?**
 - a)
 - b)
 - c)

- 2. Up to three things that could be improved?**
 - a)
 - b)
 - c)

We know that your child/young person's health and wellbeing is affected by other services too, such as equipment, education, social care, voluntary organisations and independent services.

Please think about these other services that your child/young person receives or has received and tell us:

- 3. Up to three things that are going well?**
 - a)
 - b)
 - c)

- 4. Up to three things that could be improved?**
 - a)
 - b)
 - c)

5. We would like to know from which team your child/young person receives most of their healthcare. Please select one of the following options:
- ☐ Hospital - inpatient ☐ Hospital - outpatient ☐ Community
- ☐ GP ☐ Specialist disability
6. This question is about whether the professionals working with your child/young person listen to them and to you and take account of their views and your views in all decision-making about them and their health care.
- a) Please choose one of the following options:
- ☐ Most listen to my child/young person and take their views into account
- ☐ Most don't listen to my child/young person or take their views into account
- b) Please also choose one of the following options:
- ☐ Most listen to my child/young person and take their views into account
- ☐ Most don't listen to my child/young person or take their views into account
7. This question is about how your child/young person receives their healthcare. Choose one of the following options:
- ☐ She/he is seen by a team at the same appointment
- ☐ She/he is seen by separate professionals but they do seem to communicate with each other
- ☐ The health professionals don't seem to communicate with each other at all
- ☐ She/he only see the GP
- ☐ She/he doesn't see any health professionals
- 8a. When you have a health concern about your child/young person, which part of the health service is your first point of contact when the concern is:
- i) Urgent
-
- ii) Non urgent
-

- 8b. If you have used any of the following services, how confident are you that any URGENT health needs (e.g. long or difficult seizures, serious breathing problems, injuries) will be fully addressed by the:

	Not at all confident					Extremely confident		
	1	2	3	4	5	6		
i) GP team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
ii) Paramedic 999 ambulance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
iii) Emergency department (A&E)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
iv) Specialist nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
v) Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
vi) Other (Please specify) <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA

Comments:

- 8c. If you have used any of these services, how confident are you that your child/young person's usual health needs (e.g. pain, constipation etc.) will be fully addressed by the:

	Not at all confident					Extremely confident		
	1	2	3	4	5	6		
i) GP team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
iii) Emergency department (A&E)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
iv) Specialist nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
v) Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA
vi) Other (Please specify) <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA

Comments:

- 9a. Has your child/young person moved from children's to adult services? ☐ Yes ☐ No

	Not at all well					Extremely well		
	1	2	3	4	5	6		
9b. If YES, how well did this work for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA

9c. Is the care your child/young person receives in adult services:

- ☐ Better than in children's services
- ☐ The same/as good as in children's services
- ☐ Not as good as in children's services
- ☐ Non-existent

Comments:

To help us to make the best sense of your responses, we would like to know about the impact of your child/young person's cerebral palsy.

10. Please choose only ONE option that best describes your child/young person's movement abilities:

- ☐ She/he can move around on her/his own without needing any equipment or wheelchair
- ☐ She/he can move around on her/his own but needs equipment to do so e.g. walking stick or frame
- ☐ She/he needs a wheelchair to move around, which she/he can work themselves
- ☐ She/he needs a wheelchair to move around, which always needs someone else to operate it

11. Please choose which of the following issues also affect your child/young person (choose all that apply):

- | | | | |
|--|---|--|---|
| <input type="checkbox"/> Pain | <input type="checkbox"/> Hand function | <input type="checkbox"/> Vision | <input type="checkbox"/> Hearing |
| <input type="checkbox"/> Communication | <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Eating & drinking | <input type="checkbox"/> Airway & breathing |
| <input type="checkbox"/> Continence (control of going to the toilet) | <input type="checkbox"/> Behaviour, mood or emotion | | |
| <input type="checkbox"/> Sleep | | | |

12. Please indicate where your child/young person receive most of their education?

- | | | |
|--|---|--|
| <input type="checkbox"/> Mainstream - unsupported | <input type="checkbox"/> Mainstream - supported | <input type="checkbox"/> Home educated |
| <input type="checkbox"/> Special educational provision | <input type="checkbox"/> No longer in education | <input type="checkbox"/> In employment |

13a. Which COUNTRY does your child/young person live in?

☐ England

☐ Wales

☐ Northern Ireland

☐ Scotland

☐ Offshore Islands

13b. Which COUNTY does your child/young person you live in?:

England

☐ Avon

☐ Berkshire

☐ Bristol

☐ Buckinghamshire

☐ Cambridgeshire

☐ Cheshire

☐ Cleveland

☐ Cornwall

☐ Cumbria

☐ Derbyshire

☐ Devon

☐ Devon

☐ Durham

☐ East Sussex

☐ East Yorkshire

☐ Essex

☐ Gloucestershire

☐ Greater Manchester

☐ Hampshire

☐ Herefordshire

☐ Hertfordshire

☐ Humberside

☐ Isle of Wight

☐ Kent

☐ Lancashire

☐ Leicestershire

☐ Lincolnshire

☐ London

☐ Merseyside

☐ Middlesex

☐ Norfolk

☐ North Yorkshire

☐ Northamptonshire

☐ Northumberland

☐ Nottinghamshire

☐ Oxfordshire

☐ Rutland

☐ Shropshire

☐ Somerset

☐ South Yorkshire

☐ Staffordshire

☐ Suffolk

☐ Surrey

☐ Tyne and Wear

☐ Warwickshire

☐ West Midlands

☐ West Sussex

☐ West Yorkshire

☐ Wiltshire

☐ Worcestershire

Scotland

☐ Aberdeen City

☐ Aberdeenshire

☐ Angus

☐ Argyll and Bute

☐ City of Edinburgh

☐ Clackmannanshire

☐ Dumfries and Galloway

☐ Dundee City

☐ East Ayrshire

☐ East Dumbartonshire

☐ East Lothian

☐ East Renfrewshire

☐ Falkirk

☐ Fife

☐ Glasgow City

☐ Highland

☐ Inverclyde

☐ Midlothian

☐ Moray

☐ North Ayrshire

☐ North Lanarkshire

☐ Orkney

☐ Perth and Kinross

☐ Renfrewshire

☐ Scottish Borders

☐ Shetland

☐ South Ayrshire

☐ South Lanarkshire

☐ Stirling

☐ West Dumbartonshire

☐ West Lothian

☐ Western Isles

Wales

- | | | | |
|--|--------------------------------|--|---|
| <input type="checkbox"/> Clwyd | <input type="checkbox"/> Dyfed | <input type="checkbox"/> Gwent | <input type="checkbox"/> Gwynedd |
| <input type="checkbox"/> Mid Glamorgan | <input type="checkbox"/> Powys | <input type="checkbox"/> South Glamorgan | <input type="checkbox"/> West Glamorgan |

Northern Ireland

- | | | | |
|------------------------------------|--------------------------------------|----------------------------------|---------------------------------|
| <input type="checkbox"/> Antrim | <input type="checkbox"/> Armagh | <input type="checkbox"/> Belfast | <input type="checkbox"/> Down |
| <input type="checkbox"/> Fermanagh | <input type="checkbox"/> Londonderry | <input type="checkbox"/> Derry | <input type="checkbox"/> Tyrone |

Offshore Islands

- | | | |
|--------------------------------------|---------------------------------|-----------------------------------|
| <input type="checkbox"/> Isle of Man | <input type="checkbox"/> Jersey | <input type="checkbox"/> Guernsey |
|--------------------------------------|---------------------------------|-----------------------------------|

14. How old is your child/young person?

15. Would you be willing to be contacted again about this work, to consider taking part in further surveys or focus groups?

☐ Yes ☐ No

If YES, please supply contact email address: _____

Or if you would rather send this in separately from your completed questionnaire, please email us at cp@ncepod.org.uk

Your answers are in the strictest confidence

Your answers will be confidential

Thank you for taking the time to answer these questions. We will make sure that all answers are taken into account as we continue the project. All answers will feed in to the final report.

If you would like more information on this work please go to: <http://www.ncepod.org.uk/cn.htm>

Please return all complete questionnaires to:

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