



CHRONIC NEURODISABILITY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

PATIENT 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 from across the UK.

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

Who should complete this form?

Please answer this form if you are:

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 own condition and how it affects you. 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 you, you can choose to add your own comments if you can or would like to. All of your responses will be kept private.

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 you receive work for you, or not.

Please think from your point of view about the health services you receive now, or have 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 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 you receive 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)

5. This question is about whether the health professionals working with you listen to you and take account of your views in all decision-making about you and your health care.
Choose one of the following options:

- ☐ Most listen to me and take account of my views
- ☐ Most don't listen to me or take my views into account

Comments:

6. This question is about how you receive your healthcare.
Choose one of the following options:

- ☐ I am seen by a team at the same appointment
- ☐ I am 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
- ☐ I only see my GP
- ☐ I don't see any health professionals

Comments:

- 7a. When you have a health concern, which part of the health service is your first point of contact when the concern is:

i) Urgent

ii) Non urgent

- 7b. 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:

- 7c. If you have used any of these services, how confident are you that your usual (non urgent) 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:

- 8a. Have you moved from children's to adults services? ☐ Yes ☐ No

	Not at all well					Extremely well		
	1	2	3	4	5	6		
8b. 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

8c. Is the care you receive 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 make best sense of your responses, we would like to know about the impact of your cerebral palsy.

9. Please choose only ONE OPTION that best describes your movement abilities

- ☐ I can move around on my own without needing any equipment or wheelchair
- ☐ I can move around on my own but need equipment to do so e.g. walking stick or frame
- ☐ I need a wheelchair to move around, which I can work myself
- ☐ I need a wheelchair to move around, which always needs someone else to operate it

10. Please choose which (if any) of the following issues also affect you? (please tick all that apply)

I have difficulties with:

- | | | | |
|----------------------------------------------------------------------|-----------------------------------------------------|--------------------------------------------|---------------------------------------------|
| <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 | | | |

11a. Which COUNTRY do you live in?: ☐ England ☐ Wales ☐ Scotland
☐ Northern Ireland ☐ Offshore Islands

11b. Which COUNTY do you live in?:

England

- | | | | |
|-------------------------------------------|---------------------------------------------|------------------------------------------|------------------------------------------|
| <input type="checkbox"/> Avon | <input type="checkbox"/> Berkshire | <input type="checkbox"/> Bristol | <input type="checkbox"/> Buckinghamshire |
| <input type="checkbox"/> Cambridgeshire | <input type="checkbox"/> Cheshire | <input type="checkbox"/> Cleveland | <input type="checkbox"/> Cornwall |
| <input type="checkbox"/> Cumbria | <input type="checkbox"/> Derbyshire | <input type="checkbox"/> Devon | <input type="checkbox"/> Devon |
| <input type="checkbox"/> Durham | <input type="checkbox"/> East Sussex | <input type="checkbox"/> East Yorkshire | <input type="checkbox"/> Essex |
| <input type="checkbox"/> Gloucestershire | <input type="checkbox"/> Greater Manchester | <input type="checkbox"/> Hampshire | <input type="checkbox"/> Herefordshire |
| <input type="checkbox"/> Hertfordshire | <input type="checkbox"/> Humberside | <input type="checkbox"/> Isle of Wight | <input type="checkbox"/> Kent |
| <input type="checkbox"/> Lancashire | <input type="checkbox"/> Leicestershire | <input type="checkbox"/> Lincolnshire | <input type="checkbox"/> London |
| <input type="checkbox"/> Merseyside | <input type="checkbox"/> Middlesex | <input type="checkbox"/> Norfolk | <input type="checkbox"/> North Yorkshire |
| <input type="checkbox"/> Northamptonshire | <input type="checkbox"/> Northumberland | <input type="checkbox"/> Nottinghamshire | <input type="checkbox"/> Oxfordshire |
| <input type="checkbox"/> Rutland | <input type="checkbox"/> Shropshire | <input type="checkbox"/> Somerset | <input type="checkbox"/> South Yorkshire |
| <input type="checkbox"/> Staffordshire | <input type="checkbox"/> Suffolk | <input type="checkbox"/> Surrey | <input type="checkbox"/> Tyne and Wear |
| <input type="checkbox"/> Warwickshire | <input type="checkbox"/> West Midlands | <input type="checkbox"/> West Sussex | <input type="checkbox"/> West Yorkshire |
| <input type="checkbox"/> Wiltshire | <input type="checkbox"/> Worcestershire | | |

Scotland

- | | | | |
|----------------------------------------------|--------------------------------------------|------------------------------------------------|------------------------------------------|
| <input type="checkbox"/> Aberdeen City | <input type="checkbox"/> Aberdeenshire | <input type="checkbox"/> Angus | <input type="checkbox"/> Argyll and Bute |
| <input type="checkbox"/> City of Edinburgh | <input type="checkbox"/> Clackmannanshire | <input type="checkbox"/> Dumfries and Galloway | |
| <input type="checkbox"/> Dundee City | <input type="checkbox"/> East Ayrshire | <input type="checkbox"/> East Dumbartonshire | |
| <input type="checkbox"/> East Lothian | <input type="checkbox"/> East Renfrewshire | <input type="checkbox"/> Falkirk | <input type="checkbox"/> Fife |
| <input type="checkbox"/> Glasgow City | <input type="checkbox"/> Highland | <input type="checkbox"/> Inverclyde | <input type="checkbox"/> Midlothian |
| <input type="checkbox"/> Moray | <input type="checkbox"/> North Ayrshire | <input type="checkbox"/> North Lanarkshire | <input type="checkbox"/> Orkney |
| <input type="checkbox"/> Perth and Kinross | <input type="checkbox"/> Renfrewshire | <input type="checkbox"/> Scottish Borders | <input type="checkbox"/> Shetland |
| <input type="checkbox"/> South Ayrshire | <input type="checkbox"/> South Lanarkshire | <input type="checkbox"/> Stirling | |
| <input type="checkbox"/> West Dumbartonshire | | <input type="checkbox"/> West Lothian | <input type="checkbox"/> 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 |
|--------------------------------------|---------------------------------|-----------------------------------|

12. How old are you?

13. 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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