



National Survey of people with long term neurological conditions (pilot stage)

Pxxxx: Team: xxx
COLOUROFSELFCOMP

Serial xxx-xxx
Card xxx
Batch xxx-xxx

Serial

PNo

What is the survey about?

This survey is about your experiences of living with a long-term neurological condition.

Your views are very important in helping us to find out how well the health and social care provided for your condition meets your needs and how they must be improved.

The information that you give will be added to information from a large group of people to get a general picture of how health and social care could be improved for people with long term neurological conditions. Your answers will be treated in confidence.

If you need help completing the questionnaire

If you have any difficulties completing this questionnaire on your own please ask a friend, family member or carer to help you.

If it is easier for you to complete the questionnaire electronically, then there is a web version at www.XXX.org.uk or you can request a Word version by e-mailing LTNC@natcen.ac.uk

Completing the questionnaire

For each question please tick clearly inside the box using a black or blue pen.

Sometimes you will find the box you ticked has an instruction to go to another question. By following these instructions carefully, you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. If you do not want to answer a question, please just leave it blank.

Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

Your participation in this survey is voluntary.

If you choose to take part, your answers will be treated in confidence.

A) Information about your condition

The following questions are about the information that you have been given about your neurological condition. If you have more than one neurological condition, please think about the first condition you were diagnosed with. *Please tick one answer for each question unless instructed to tick more than one.*

Q1 When did you first find out that you had a neurological condition?
(tick one)

- I have had a neurological condition since birth 1
- More than 10 years ago 2
- 5 to 10 years ago 3
- 3 to 4 years ago 4
- 1 to 2 years ago 5
- Less than one year ago 6
- I don't remember 7

xxxx

In the time since finding out that you had a neurological condition ...

Spare xxxx-xxxx

Q2 Have **health care professionals** provided you with **enough** information about your condition? (tick one)

- Yes, definitely 01
- Yes, to some extent 02
- No 03
- I did not need any information 04
- I am not sure 05

xxxx-
xxxx

Q3 Overall, has the information about your condition that you have been given by **health care professionals** been **helpful**?

- Yes, definitely 01 → Q4
- Yes, to some extent 02 → Q4
- No 03 → Q4
- I have not been given information by a healthcare professional / I did not need any information 04 → GO TO Q6
- I am not sure 05 → Q4

xxxx-
xxxx

Q4 Overall, have **health care professionals** given you information about your condition at the **right time** for you?

Yes, I was given it at the right time 01

No, I was given it later than I would have liked 02

No, I was given it earlier than I would have liked 03

I am not sure 04

xxxx-
xxxx

Q5 Did any **health care professional** tell you about specialist organisations (by this we mean organisations for people with your condition or your group of neurological conditions)? (*tick one*)

Yes 01

No 02

Not sure 03

xxxx-
xxxx

In the time since finding out you had a neurological condition ...

Q6 Have you received any information about your condition from a **specialist organisation** (by this we mean organisations for people with your condition or your group of neurological conditions)?

Yes 01 → **Q7**

No 02 → **Q9 on Page 4**

Not sure 03 → **Q9 on Page 4**

xxxx-
xxxx

Q7 Overall, has the information about your condition that you have been given by a **specialist organisation** been **helpful**?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

xxxx-
xxxx

Q8 Overall, did you get the information about your condition from a **specialist organisation** at the **right time** for you?

- Yes, I was given it at the right time 01
- No, I was given it later than I would have liked 02
- No, I was given it earlier than I would have liked 03
- I am not sure 04

xxxx-
xxxx

Q9 Since your diagnosis, have you received any advice on getting **welfare benefits** (such as Disability Living Allowance)?

- Yes 01 → Q10
- Some, but not enough 02 → Q10
- No, but I would have liked advice 03 → Q11
- I did not need advice 04 → Q11

xxxx-
xxxx

Q10 **Who or where** did you get advice from on getting welfare benefits? (*tick all that apply*)

- Health care professionals 01
- Social care professionals 02
- Specialist organisation for people with neurological conditions 03
- Organisation specialising in getting welfare benefits, such as Citizens' Advice Bureau 04
- Other 05
- I am not sure 06

xxxx-
xxxx

B) Planning your care

The following questions are about planning your care and support . *Please tick one answer for each question.*

Q11 Are you aware of a **care plan** for your neurological condition? (A care plan is a document that shows what health and/or social care services you need and who will provide them for you)

- Yes 01 → Q12
- No 02 → Q15 on Page 5

xxxx-
xxxx

Q12 Have you been given or offered a **written or printed copy** of your care plan?

Yes 01

No 02

I am not sure 03

xxxx-
xxxx

Q13 As far as you know, is your care plan **kept up to date**?

Yes 01

No 02

I am not sure 03

xxxx-
xxxx

Q14 Have you felt as **involved** as you would like to be in developing your care plan?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

xxxx-
xxxx

C) Health care professionals

The following questions are about some of the health care professionals who may be involved in providing your care in relation to your neurological condition. *Please tick one answer for each question.*

Q15 Do you have a **named** health care professional that you can contact for advice and information about your neurological condition?

Yes, one named contact 01

Yes, more than one named contact 02

No 03

I am not sure 04

xxxx-
xxxx

Q16 In the last 12 months, have you seen a neurologist at a hospital or clinic about your neurological condition?

Yes 01 → **Q17**

No 02 → **Q19**

I am not sure 03 → **Q19**

xxxx-
xxxx

Q17 Last time you saw a neurologist did he or she **listen carefully** to what you had to say?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

xxxx-
xxxx

Q18 Last time you saw a neurologist were you given **enough time to discuss** your condition or treatment with him or her?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

I did not need to discuss anything 05

xxxx-
xxxx

Q19 In the last 12 months, have you seen a **GP** about your neurological condition? {WORDING CHANGE: Have you seen a GP about your neurological condition in the last 12 months?}

Yes 01 → **Q20**

No 02 → **Q22 on Page 7**

xxxx-
xxxx

Q20 Last time you saw your GP about your neurological condition did he or she **listen carefully** to what you had to say?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

xxxx-
xxxx

Q21 Last time you saw your GP about your neurological condition were you given **enough time to discuss** your condition or treatment with him or her?

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure 04

I did not need to discuss anything 05

xxxx-
xxxx

D) Social care and other support

The following questions are about any social care or other support you may have received to help you cope with your condition and live more independently. *Please tick one answer for each question.*

Q22 In the last 12 months, have you had help from any social care staff with your **personal care** at home (such as dressing, washing or eating)?

Yes 01 → Q23

No, but I would have liked some 02 → Q24

No, I did not need it 03 → Q24

xxxx-
xxxx

Q23 How well did the help you received with personal care at home meet your needs?

Very well 01

Fairly well 02

Not very well 03

I don't remember 04

xxxx-
xxxx

Q24 In the last 12 months, have you received any **emotional and/or psychological support** (e.g. counselling) from health or social care professionals to help you cope with your neurological condition?

Yes 01 → Q25

No, but I would have liked some 02 → Q26

No, I did not need it 03 → Q26

xxxx-
xxxx

Q25

Did you find this emotional and/or psychological support helpful?

Yes, definitely 01Yes, to some extent 02No 03I am not sure 04xxxx-
xxxx**Q26**

Do you feel that the social care and health professionals who plan your care work well together?

Yes, definitely 01Yes, to some extent 02No 03I am not sure 04xxxx-
xxxx**E) Rehabilitation Support**

The following questions are about any rehabilitation support you may have received.

Q27

Have you received any rehabilitation support for your neurological condition?

*By rehabilitation support we mean you have taken part in any activity or therapy related to your neurological condition, designed to improve your ability to live independently. Examples include physiotherapy, basic life-skills training and speech therapy.*Yes 01 → **Q28**No, but I would have liked some 02 → **Q30 on Page 9**No, rehabilitation is not relevant for my condition 03 → **Q30 on Page 9**No, I personally don't need any 04 → **Q30 on Page 9**I am not sure 05 → **Q30 on Page 9**xxxx-
xxxx**Q28**Overall, has the rehabilitation support you have received so far **helped you to live more independently?**Yes, definitely 01Yes, to some extent 02No 03I am not sure or it is too early to say 04xxxx-
xxxx

Q29

Do you feel you have received enough rehabilitation support?

Yes 01xxxx-
xxxxNo, a little less than I would have liked 02No, a lot less than I would have liked 03Don't know 04OR I am still receiving rehabilitation support 05**F) Equipment and changes to your home**

The following questions are about any changes that have been made to your home (such as bathroom adaptations, stair lift, grab rails) and any equipment you have used (such as wheelchair, walking stick, special computer software) to help you live more independently.

Q30

Have you ever had **an assessment** for any changes to your home or equipment that you might need to help you with your neurological condition?Yes, I have had at least one assessment 01xxxx-
xxxxNo, but I would have liked an assessment 02No, I have not needed an assessment 03I am not sure 04

Q31

Since you were diagnosed with your neurological condition have you **moved home** in order to live in accommodation that is **more suitable** for your condition?Yes 01xxxx-
xxxxNo, but I would have liked to 02No, I have not needed to 03I have moved home, but not to live somewhere more suitable 04

Q32

Do you currently live in a residential care home?

Yes 01 → Q37 on Page 10xxxx-
xxxxNo 02 → Q33

Q33 Have any **changes, large or small, been made to your current home** (such as bathroom adaptations, stair lift, grab rails) to help you with your condition?

Yes, all I need 01 → Q34

Yes, some of what I need 02 → Q34

No, but I have needed some 03 → Q35

No, I have not needed any 04 → Q36

xxxx-
xxxx

Q34 Have these changes to your home **made it easier for you to live more independently?**

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure or it is too early to say 04

xxxx-
xxxx

Q35 Have you tried to arrange these, or any other, changes to your home **through health or social services?**

Yes 01 → Q36

No 02 → Q37

xxxx-
xxxx

Q36 If so, has either of the following been a problem for you? (*tick one box on each row*)

	Yes 1	No 2
Finding out how to arrange changes to your home	<input type="checkbox"/>	<input type="checkbox"/>
The length of time it takes to arrange changes to your home	<input type="checkbox"/>	<input type="checkbox"/>

xxxx

xxxx

Q37 Do you use, or have you used, any **equipment** (such as wheelchair, walking sticks, or computer software) to help with your condition?

Yes, all I need 01 → Q38

Yes, some of what I need 02 → Q38

No, but I need some 03 → Q39 on Page 11

No, I do not need any 04 → Q43 on Page 12

xxxx-
xxxx

Q38 Have these aids or equipment **made it easier for you to live more independently?**

Yes, definitely 01

Yes, to some extent 02

No 03

I am not sure or it is too early to say 04

xxxx-
xxxx

Q39 Have you tried to get this, or any other, equipment **through health or social services?**

Yes 01 → **Q40**

No 02 → **Q41**

xxxx-
xxxx

Q40 If so, have any of the following been a problem for you? (*tick one box on each row*)

	Yes 1	No 2	
Finding out how to get hold of suitable equipment	<input type="checkbox"/>	<input type="checkbox"/>	xxxx
The length of time it takes to get equipment	<input type="checkbox"/>	<input type="checkbox"/>	xxxx
The standard of equipment available	<input type="checkbox"/>	<input type="checkbox"/>	xxxx

Q41 Have you **bought** (or tried to buy) any equipment independently?

Yes 01 → **Q42**

No 02 → **Q43 on Page 12**

xxxx-
xxxx

Q42 If so, have any of the following been a problem for you? (*tick one box on each row*)

	Yes 1	No 2	
Finding out how to get hold of suitable equipment	<input type="checkbox"/>	<input type="checkbox"/>	xxxx
Knowing what equipment I need	<input type="checkbox"/>	<input type="checkbox"/>	xxxx
The price of equipment	<input type="checkbox"/>	<input type="checkbox"/>	xxxx

H) About you

These questions ask for some information about you. This will be used to look at patterns in experiences for different groups of people.

If you are helping to fill in this questionnaire for someone else, please fill in this section with reference to **the person this survey was sent to** rather than yourself.

Q43 What is the common named of the neurological condition(s) that you have? *Please write in*

xxxx-
xxxx

Q44 Are you male or female?

Male 01

Female 02

xxxx-
xxxx

Q45 What was your year of birth? *Please write in*

Write in

xxxx-
xxxx

Q46 What is your employment status? *Please tick all that apply*

In paid employment (full-time or part-time) 01

In full-time education 02

Working on a casual or voluntary basis 03

Not working, but looking for work 04

Permanently unable to work because of long-term sickness or disability 05

Retired from paid work 06

Looking after the home or family 07

Doing something else 08

xxxx-
xxxx

Q47

Do you live with any of the following people? *Please tick all that apply*

xxxx-
xxxx

- With spouse or partner 01
- With parent(s) 02
- With son(s) or daughter(s) 03
- With other relative(s) or friend(s) 04
- I live in a group setting or assisted living 05
- I live in a residential care home 06
- None of the above, I live alone 07
- Other (Please write in) _____ 08

Q48

Do you receive any care or support for your neurological condition from any of the following people?

xxxx-
xxxx

- Spouse or partner 01
- Parent(s) 02
- Son(s) or daughter(s) 03
- Other relative(s) 04
- Friends or neighbours 05
- Paid care workers 06
- None of the above 07
- OR I don't need any care or support for my neurological condition 08

Q49 To which of the following ethnic groups would you say you belong? *(Please tick one only)*

White:

British 01

Irish 02

Any other white background *(please write in)* _____ 03

Mixed:

White and black Caribbean 01

White and black African 02

White and Asian 03

Any other mixed background *(please write in)* _____ 04

Asian or Asian British:

Indian 01

Pakistani 02

Bangladeshi 03

Any other Asian background *(please write in)* _____ 04

Black or Black British:

Caribbean 01

African 02

Any other black background *(please write in)* _____ 04

Chinese or other ethnic group:

Chinese 01

Any other ethnic group *(please write in)* _____ 04

xxxx-xxxx

xxxx-xxxx

xxxx-xxxx

xxxx-xxxx

xxxx-xxxx

Q50 Who was the main person or people who filled in this form? *Please tick all that apply*

The person named on the envelope 01

A friend or relative of the person named on the envelope 02

A paid carer 03

Someone else 04

xxxx-
xxxx

If there is anything else you would like to tell us about your experiences of health and social care relating to your neurological condition, please do so here.

Is there anything particularly good about your care?

Is there anything that could be improved?

Anything else you would like to tell us?

Thank you for completing the questionnaire.

Please post this questionnaire back to us in the FREEPOST envelope provided:

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