

Stroke Rehabilitation Research Project

***EXTRAS***

24 Month  
Assessment

Patient Name:

Study Number:

Centre Number:

## HOW TO ANSWER THE QUESTIONS

Thank you for filling in this questionnaire. All of your answers will be treated as confidential and are for research purposes only. Please try to answer every question even if you do not think it applies to you, or it if seems repetitive.

There are several types of questions in this booklet. Most of them can be answered by ticking a box  for either NO or YES.

For example:

Do you live in North Tyneside?

NO

YES

Some of these questions have several boxes and you may be asked to tick one only, or tick as many boxes as apply to you.

For example:

Which vegetables do you like?

*(please tick all boxes that apply)*

Carrots

Spinach

Brussel sprouts

Cabbage

A small number of questions ask you to write in your answer on a line.

For example:

In what area of North Tyneside do you live?

I live in Whitley Bay

If you need help with the questions, please ask a friend or relative to assist you.

If you find a question too difficult to answer or if you do not wish to answer it, please move on to the next question.

If you have any queries or concerns about the EXTRAS trial, please contact:

Stroke Research Group  
Institute for Ageing & Health  
Newcastle University  
3-4 Claremont Terrace  
Newcastle upon Tyne  
NE2 4AE

Telephone: 0191 222 6779

## PART ONE – YOUR DETAILS

1. Please provide your contact details so we can ensure that our records are correct.

Address:

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Telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_

2. Date questionnaire completed:   /   /

3. Please tell us what type of residence you live in:

- Own house/flat
- Living with family/friends
- Sheltered housing
- Residential care/nursing home
- Other, please state  \_\_\_\_\_

4. Do you live alone?

No  Yes

5. Have you suffered any new medical illnesses in the last 12 months?

No  Yes

If yes, please provide details:

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5. Have you suffered any falls resulting in injury in the last 12 months?

No  Yes

If yes, please provide details:

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## PART TWO – YOUR GENERAL HEALTH

For each question below, please tick the box  which best describes you **currently**. Please record what you have **actually** done in the last week or so **NOT** what you think you could do, ought to do or would like to do.

	No	With help	On my own with difficulty	On my own
<b>Mobility</b>				
Do you walk around outside?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you climb stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you get in and out of the car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you walk over uneven ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you cross roads?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you travel on public transport?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	With help	On my own with difficulty	On my own
<b>In the kitchen</b>				
Do you manage to feed yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you manage to make yourself a hot drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you take hot drinks from one room to another?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you do the washing up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you make yourself a hot snack?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	With help	On my own with difficulty	On my own
<b>Domestic tasks</b>				
Do you manage your own money when you are out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you wash small items of clothing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you do your own shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you do your own housework?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you do a full clothes wash?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	With help	On my own with difficulty	On my own
<b>Leisure activities</b>				
Do you read newspapers or books?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you use the telephone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you write letters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you go out socially?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you manage your own garden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you drive a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**For this next question, please tick ONE box  next to the sentence which best describes your present health:**

*(Please tick ONE box only)*

0. I have no symptoms at all and cope well with life.
1. I have a few symptoms but these do not interfere with my everyday life.
2. I have symptoms which have caused some changes in my life but I am still able to look after myself.
3. I have symptoms which have significantly changed my life, prevent me coping fully on my own, and I need some help in looking after myself.
4. I have quite severe symptoms which mean I need to have help from other people but I am not so bad as to need attention day and night.
5. I have major symptoms which severely handicap me and I need constant attention day and night.



For each of the five sets of statements below please tick one box  that best describes your own health TODAY.\*

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**Mobility**

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- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

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**Self Care**

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- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

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**Usual activities (e.g. work, study, housework, family or leisure activities)**

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- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

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**Pain/Discomfort**

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I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

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**Anxiety/Depression**

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I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

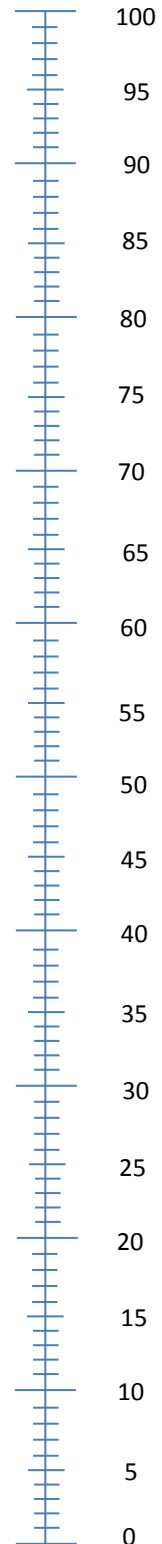
I am severely anxious or depressed

I am extremely anxious or depressed

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

**YOUR HEALTH TODAY =**

The best health  
you can imagine



The worst health  
you can imagine

*\*EQ-5D: UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group*

### Hospital Anxiety and Depression Scale (HADS)\*

Clinicians are aware that emotions play an important part in most illnesses. This section is designed to help the researchers to know how you feel. Read each item below and place a tick in the box  opposite the reply that comes closest to how you have been feeling *in the past week*. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought out response.

**1. I feel tense or 'wound up':**

Most of the time

A lot of the time

From time to time, occasionally

Not at all

**2. I still enjoy the things I used to enjoy:**

Definitely as much

Not quite so much

Only a little

Hardly at all

**3. I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me

Not at all

**4. I can laugh and see the funny side of things:**

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

**5. Worrying thoughts go through my mind:**

- A great deal of the time
- A lot of the time
- Not too often
- Very little

**6. I feel cheerful:**

- Never
- Not often
- Sometimes
- Most of the time

**7. I can sit at ease and feel relaxed:**

- Definitely
- Usually
- Not often
- Not at all

**8. I feel as if I am slowed down:**

Nearly all the time

Very often

Sometimes

Not at all

**9. I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all

Occasionally

Quite often

Very often

**10. I have lost interest in my appearance:**

Definitely

I don't take as much care as I should

I may not take quite as much care

I take just as much care as ever

**11. I feel restless as if I have to be on the move:**

Very much indeed

Quite a lot

Not very much

Not at all

**12. I look forward with enjoyment to things:**

As much as I ever did

Rather less than I used to

Definitely less than I used to

Hardly at all

**13. I get sudden feelings of panic:**

Very often indeed

Quite often

Not very often

Not at all

**14. I can enjoy a good book or radio or television programme:**

Often

Sometimes

Not often

Very seldom

*\* HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994.  
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## PART FOUR – EXPERIENCE OF SERVICES

Please could you tell us about your experience of the services you have received in the last 12 months as a result of your stroke. Please tell us to what extent you agree with the following statements by ticking the box which best reflects your views.

### A. About the services

To what extent do you agree that...		Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply
1.	Staff were welcoming and friendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Staff treated you with dignity and respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Staff assessed your needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Staff met your needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	You have been involved as much as you wanted to be in decisions about your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	You were able to discuss your preferences, beliefs, and concerns as part of your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	You were told who to contact if you had any worries or concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	You were confident that the staff you saw had the right skills and knowledge to help you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



<b>To what extent do you agree that...</b>		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Does Not Apply</b>
9.	You were treated fairly, regardless of your age, race, gender, belief, sexual orientation or disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	You were given the information you wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	You were able to see the same healthcare professional/team whenever possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	If you had important questions to ask, you got answers that you could understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	If you needed more than one service, staff made sure they were well coordinated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	If you needed more than one service, staff made sure that your care information was clearly and accurately shared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	You were told who to contact if you had any ongoing health care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. If you answered 'Strongly Disagree' or 'Disagree' to any of the questions above, please tell us more about this and how this could be improved:


**B. Overall**

1. Overall, how satisfied are you with the services you received?

Extremely Satisfied	Very Satisfied	Quite Satisfied	Not Very Satisfied	Extremely Unsatisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**C. Meeting your needs**

1. In the last 12 months, have you had enough help with **speaking difficulties** from the NHS?

Yes, definitely	Yes, to some extent	No I did not get enough help from the NHS	I did not have any speaking difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the last 12 months, have you had enough treatment to help **improve your mobility** (e.g. walking, moving your legs) from the NHS?

Yes, definitely	Yes, to some extent	No I did not get enough treatment from the NHS	I did not have any mobility difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. In the last 12 months, have you had enough help with **emotional problems** (such as confusion, depression or crying) from the NHS?

Yes, definitely	Yes, to some extent	No I did not get enough help from the NHS	I did not have any emotional problems
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## PART FIVE – YOUR CARE WITHIN THE LAST 12 MONTHS

**This final section is about the care you may have received in the last 12 months.**

*Please answer every question and take care not to tell us about the same thing twice across different areas. If you feel that an answer to any of the following questions fits into two or more places, just report it once.*

**1. In the last 12 months, have you spent any time living in a residential care home?**

*If your stay was in a nursing home, rather than a residential home, then please tell us about this in question 2 instead of here.*

**No**  **If no,** please go to question 2

**Yes**  **If yes,** how many nights did you stay there altogether? .....

**2. In the last 12 months, have you spent any time living in a nursing home?**

**No**  **If no,** please go to question 3

**Yes**  **If yes,** how many nights did you stay there altogether? .....

**3. In the last 12 months, have you visited an Accident & Emergency department (sometimes called A&E or casualty) because of any illness/injury?**

*Please include visits which took place immediately before any admissions to hospital.*

**No**  **If no,** please go to question 4

**Yes**  **If yes,** how many times? .....

**4. In the last 12 months, have you visited hospital for outpatient appointments (to see a doctor or for a test) because of any illness/injury?**

*An outpatient appointment is when you are referred for a test or to see a hospital consultant for a specialist opinion (which could be part of follow-up care after you've had a hospital admission) and you do not need to stay in hospital. Please exclude any hospital appointments for physiotherapy, occupational therapy or speech and language therapy – you can tell us about these later in question 7.*

No  **If no,** please go to question 5

Yes  **If yes,** please tell us more about this below

*For each episode (that is, a group of visits related to a particular problem), please write in brief the main medical reason for it (for example, the illness/injury you had) and how many appointments you have had. If you had just one visit related to a particular problem, treat that visit as one episode.*

Stay	Main reason for the appointment(s)	Number of appointments
1 <sup>st</sup> episode		
2 <sup>nd</sup> episode		
3 <sup>rd</sup> episode		
4 <sup>th</sup> episode		

**5. In the last 12 months, have you stayed in hospital overnight because of any illness/injury?**

**No**  **If no,** please go to question 6

**Yes**  **If yes,** please tell us more about this below

*Please tell us about your hospital stays below. For each stay, please write in brief the main medical reason for it (for example, the illness/injury you had) and how many nights you stayed.*

*If you were treated as a day patient (in other words, you did not have to stay in hospital overnight), then please tell us about this in question 6 rather than here.*

Stay	Reason for going into hospital	Number of nights
1 <sup>st</sup> stay		
2 <sup>nd</sup> stay		
3 <sup>rd</sup> stay		
4 <sup>th</sup> stay		

**6. In the last 12 months, have you had any hospital treatment as a day patient because of any illness/injury?**

*Being a day patient means needing a hospital bed for tests or surgery for a half day or full day, but not needing to stay overnight (also known as a day case). This is different to an outpatient appointment, which is usually a shorter visit. If you have had to stay overnight, please tell us about this in question 5 instead of here. If you think you have had an outpatient appointment, or a short visit as part of a series of outpatient appointments, then please tell us about this in question 4 instead of here.*

No  **If no,** please go to question 7

Yes  **If yes,** please tell us more about this below

*Please tell us about your day patient visits below. For each visit, please write in brief the main medical reason for it (for example, the illness/injury you had) and tick whether it was for a half or full day.*

Visit	Reason for going into hospital	Half day	Full day
1 <sup>st</sup> visit		<input type="checkbox"/>	<input type="checkbox"/>
2 <sup>nd</sup> visit		<input type="checkbox"/>	<input type="checkbox"/>
3 <sup>rd</sup> visit		<input type="checkbox"/>	<input type="checkbox"/>
4 <sup>th</sup> visit		<input type="checkbox"/>	<input type="checkbox"/>

**7. In the last 12 months, have you used any of these other NHS or social services because of any illness/injury?**

*Many of these services are based in the community. If your contact was in a hospital, please check whether your answer fits into any of the questions above before writing it here. Please tick 'yes' or 'no' for each line. If you answer 'yes' to any of them, please tell us how many times you used that service altogether in the last 12 months. If you feel that an answer fits in two or more places on this form, just report it in one place.*

<b>Services at your local GP surgery/health centre</b>	<b>No</b>	<b>Yes</b>	<b>Total number of visits/calls in the last 12 months</b>
Saw GP at the surgery/health centre			
Saw GP at home			
Phoned GP, practice nurse or NHS Direct for advice			
Saw practice nurse at the surgery/health centre			

<b>Physiotherapist (do not include private visits)</b>	<b>No</b>	<b>Yes</b>	<b>Total number of visits in last 12 months</b>
Saw at a hospital			
Saw at home (do not include private visits)			
Saw at the GP surgery/health centre			
Saw elsewhere (do not include private visits)			



<b>Occupational therapist (do not include private visits)</b>	<b>No</b>	<b>Yes</b>	<b>Total number of visits in last 12 months</b>
Saw at a hospital			
Saw at home (do not include private visits)			
Saw at the GP surgery/health centre			
Saw elsewhere (do not include private visits)			

<b>Speech and language therapist (do not include private visits)</b>	<b>No</b>	<b>Yes</b>	<b>Total number of visits in last 12 months</b>
Saw at a hospital			
Saw at home (do not include private visits)			
Saw at the GP surgery/health centre			
Saw elsewhere (do not include private visits)			

<b>Community based health care professionals</b>	<b>No</b>	<b>Yes</b>	<b>Total number of contacts in last 12 months</b>
Community or district nurse			
Health visitor			
Geriatrician			
Psychiatrist			
Psychologist			
Chiropodist			
Optician			

<b>Social services</b>	<b>No</b>	<b>Yes</b>		<b>Total in last 12 months</b>
Got meals on wheels			Number of meals	
Home help visited to help me with personal care			Number of home visits	
Home help visited to help me with household tasks			Number of home visits	
Home help did shopping for me			Number of times	

**8. In the last 12 months, have you used any other NHS or social services because of any illness/injury that have not been covered above?**

No  **If no,** please go to question 9

Yes  **If yes,** please tell us more about this below

*Please tell us about any other services you used below. For each one, please describe in brief what it was and how many times you used it altogether in the last 12 months.*

	Brief description of service	Total contacts in the last 12 months
1 <sup>st</sup> other service		
2 <sup>nd</sup> other service		
3 <sup>rd</sup> other service		
4 <sup>th</sup> other service		

**9. In the last 12 months, have you had to modify or adapt your home because of your stroke (e.g. install bath or shower handles)?**

No  **If no,** please go to question 10

Yes  **If yes,** please tell us more about this below

*Please list the adaptations below.*

	<b>Brief description of adaptation or modification</b>
1 <sup>st</sup> adaptation or modification	
2 <sup>nd</sup> adaptation or modification	
3 <sup>rd</sup> adaptation or modification	

**10. In the last 12 months, have you received any health related benefits?**

*Please note that any information that you provide in this question will be treated in confidence and will only be used within this study to help us measure the effect of a stroke on a person's finances.*

No  **If no,** you have completed this set of questions

Yes  **If yes,** please tell us more about this below

*Please tick the boxes that apply to you:*

**Attendance Allowance**

Higher rate

Lower rate

**Disability Living Allowance**

Care component

Mobility component

**Other Allowance**

No

Yes

If yes, please state

**Were the questions in this questionnaire answered by:**

Person who has had a stroke

Person who has had a stroke  
with help from a relative or friend

Relative or friend on behalf of person  
who has had a stroke

Other – please state

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**Contact for further information:**

If you have any queries or require further information about the EXTRAS trial please contact:

Stroke Research Group  
Institute for Ageing & Health  
Newcastle University  
3-4 Claremont Terrace  
Newcastle upon Tyne  
NE2 4AE  
Tel: 0191 222 6779

**This is the end of the questionnaire.**

**Thank you for the time you have taken to complete it.**

**A researcher from Newcastle University will be contacting you shortly.**