

STROKE QUESTIONNAIRE

What is the survey about?

This survey is about your treatment for a stroke at the National Health Service hospital named in the letter enclosed with this questionnaire.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, from a friend or carer, the answers should be given from his/her point of view – not the point of view of the person who is helping. It can also be completed over the phone with a researcher at Picker Institute Europe, via the FREEPHONE number: **0800 197 5273**.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. There is a space at the end of the questionnaire for any other comments.

Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire; or would like someone to complete it over the phone with you, please call the Picker Institute Europe helpline number:

FREEPHONE 0800 197 5273

Calls are free and the lines are open Monday-Friday 9am to 5pm, and we will do our best to help.

Your participation in this survey is voluntary. **Your answers will be treated in confidence.**

Please return to: Picker Institute Europe
FREEPOST (SCE10829)
Oxford
OX1 1YE

NNNN

DIAGNOSIS

1. When were you **first** told that you had had a stroke?

- Before I went into hospital
- In the hospital
- After I left hospital
- Don't know/ Can't remember

2. Do you think your stroke was diagnosed quickly enough?

- Yes
- No it should have been quicker
- Don't know/ Can't remember

3. If your stroke was not diagnosed quickly enough, what was the **main** reason?

- My stroke **was** diagnosed quickly enough
- My GP did not recognise that I had had a stroke
- Doctor/s at the hospital did not recognise that I had had a stroke
- Equipment at the hospitals to carry out tests was not available
- Another reason
- Don't know/ Can't say

ADMISSION TO HOSPITAL

4. In your opinion, were you admitted to hospital quickly enough?

- Yes, I was admitted as soon as I thought was necessary
- I should have been admitted **a bit** sooner
- I should have been admitted **a lot** sooner
- I was already in hospital when I had a stroke
- Don't know/ Can't say

5. When you were first admitted to a bed on a ward, what type of ward was it?

- 1 Stroke unit
- 2 Acute assessment ward
- 3 An intensive care unit
- 4 Other type of ward/unit
- 5 Don't know/ Can't remember

6. What type of ward were you on for most of your hospital stay?

- 1 Stroke unit
- 2 Acute assessment ward
- 3 An intensive care unit
- 4 Other type of ward/unit
- 5 Don't know/ Can't remember

HOSPITAL DOCTORS

NOTE: Please answer all the following questions about the hospital or unit where you spent most of your time

7. When you had important questions to ask a doctor, did you get answers that you could understand?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get answers I could understand
- 4 I had no need to ask
- 5 I was not able to ask

8. Did you have confidence and trust in the doctors treating you?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

9. Did doctors talk in front of you as if you weren't there?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

10. In your opinion, did the doctors who treated you know enough about the treatment of stroke?

- 1 All the doctors knew enough
- 2 Most of the doctors knew enough
- 3 Only some of the doctors knew enough
- 4 None of the doctors knew enough
- 5 Can't say

NURSING STAFF

11. When you had important questions to ask nursing staff, did you get answers that you could understand?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get answers I could understand
- 4 I had no need to ask
- 5 I was not able to ask

12. Did you have confidence and trust in the nursing staff treating you?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

13. Did nursing staff talk in front of you as if you weren't there?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

14. In your opinion, were there enough nursing staff on duty to care for you in hospital?

- 1 There were always or nearly always enough nursing staff
- 2 There were sometimes enough nursing staff
- 3 There were rarely or never enough nursing staff
- 4 Don't know / Can't remember

15. In your opinion, did the nursing staff who treated you know enough about the treatment of stroke?

- 1 All of the nursing staff knew enough
- 2 Most of the nursing staff knew enough
- 3 Only some of the nursing staff knew enough
- 4 None of the nursing staff knew enough
- 5 Can't say

YOUR CARE AND TREATMENT IN HOSPITAL

Please remember to answer the questions about the hospital or unit where you spent most of your time.

16. Were **you** involved as much as you wanted to be in decisions about your care and treatment in hospital?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I was not involved in decisions about my care and treatment

17. Were you able to understand the information you were given in hospital about your stroke?

- 1 Yes, I understood most or all of it
- 2 Yes, I understood some of it
- 3 No, I understood little or none of it
- 4 I was not given any information

18. Was your stroke diagnosis discussed with you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, it was not discussed
- 4 It was not necessary to discuss it
- 5 Don't know/ Can't remember

19. If a member of your family or someone else close to you wanted to talk to the staff, did they have enough opportunity to do so?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but they wanted to talk to the staff
- 4 No, but they did not want or need to talk to the staff
- 5 I did not want family or friends to talk to the staff
- 6 Can't say

20. When you needed help from staff **getting to the toilet/using a bed pan** did you get it in time?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff
- 5 I had a catheter

21. When you needed help from staff in **eating your meals**, did you get it when you needed it?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff
- 5 I had a nasogastric (NG) or PEG tube

22. Were you able to get **healthy meals** from the hospital menu?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I could not get healthy meals
- 4 I did not eat hospital food
- 5 I had a nasogastric (NG) or PEG tube
- 6 Don't know/ Can't remember

23. When you needed help from staff with **washing**, did you get it when you needed it?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff

24. While you were in hospital, did you get enough help for difficulties with **swallowing**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any difficulties with swallowing

25. While you were in hospital, did you get enough help with **speech and communication** problems?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any speech or communication problems

26. While you were in hospital, did you get enough treatment to help **improve your mobility**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any mobility difficulties

27. While you were in hospital, did you get enough help and support with any **emotional issues** that might be affecting you (such as confusion, depression or crying)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any emotional issues

28. Sometimes in hospital, a member of staff will say one thing, and another will say something quite different. Did this happen to you?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

29. Did you feel you were treated with **respect and dignity** while you were in the hospital?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, little or none of the time

LEAVING HOSPITAL

30. Before you left hospital, did staff give you information about **changes in your diet** that might help prevent another stroke?

- 1 Yes
- 2 No, I did not get any information
- 3 I did not need any information
- 4 Don't know/ Can't remember

31. Before you left hospital, did hospital staff give you information about **physical exercise** (e.g. walking) that might help prevent another stroke?

- 1 Yes
- 2 No, I did not get any information
- 3 I did not need any information
- 4 Don't know/ Can't remember

32. Before you left hospital, did a member of staff give you information about **stopping smoking**?

- 1 I did not smoke
- 2 Yes
- 3 No, I did not get any information
- 4 Don't know/ Can't remember

33. Did a member of staff explain the **purpose of the medicines** you were to take at home in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, it was not explained
- 4 I did not need an explanation
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember

34. Before you left hospital were you given enough **information about how to use the medicine(s)** (e.g. when to take it, how long to take it for, whether to take it with food)?

- 1 Yes, enough information
- 2 Some, but not enough
- 3 No information at all, and I wanted some
- 4 I did not want any information
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember

35. Did a member of staff tell you about **medication side effects** to watch for when you went home?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, I was not told about side effects
- 4 I did not need an explanation
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember

36. Did hospital staff tell you **who to contact** if you were worried about your condition or treatment after you left hospital?

- 1 Yes
- 2 No, I was not told who to contact
- 3 Don't know/ Can't remember
- 4 It was not necessary

37. Did hospital staff give you information about **voluntary and support groups** for people who have had a stroke in your local area?

- 1 Yes
- 2 No, but I would have liked some
- 3 No, but I got information from somewhere else
- 4 Not sure/ Can't remember

38. Did hospital staff give you information about **national stroke organisations** or useful websites?

- 1 Yes
- 2 No, but I would have liked some
- 3 No, but I got information from somewhere else
- 4 Not sure/ Can't remember

39. Overall, how would you rate the care you received during your hospital stay?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

AFTER YOUR STAY IN HOSPITAL

40. Were your own needs and wishes taken into account when planning your rehabilitation?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, my wishes were not taken into account
- 4 I have not had any rehabilitation

41. Were the services you needed after you left hospital arranged for you? (e.g. occupational therapist, physiotherapist)

- 1 Yes, **all** the services I needed
- 2 Yes, **some** of the services needed
- 3 No, but these services were needed
- 4 It was not necessary
- 5 The services were already in place before my stroke

42. As far as you know, was your GP given all necessary information about the treatment or advice that you received in hospital?

- 1 Yes
- 2 No, my GP was not given all the necessary information
- 3 Don't know
- 4 I am not registered with a GP

43. After you left hospital, did you get enough help with speaking difficulties?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough help
- 4 I did not have any speaking difficulties

44. After you left hospital, did you get enough treatment to **help improve your mobility**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough treatment
- 4 I did not have any mobility difficulties

45. After you left hospital, did you get enough help and support with any **emotional issues** that might be affecting you (such as confusion, depression or crying)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough help and support
- 4 I did not have any emotional issues

46. After you left hospital, did you get the **equipment and/or aids** (e.g. a wheelchair, commode or kitchen aids) you needed quickly enough?

- 1 Yes, I got it as soon as I thought was necessary
- 2 No, I would have liked it a **bit** sooner
- 3 No, I would have liked it a **lot** sooner
- 4 I did not need any equipment or aids
- 5 The equipment/aids were already in place before I had my stroke

47. Since your stroke have you received help from health and social services with getting benefits? (e.g. disability living allowance, attendance allowance, carer allowance)

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help
- 4 I was already receiving benefits

48. Who was the main person or people that filled in this questionnaire?

- 1 The person who was a **patient** in the hospital
- 2 A **friend or relative** of the patient
- 3 **Both** patient and friend/relative together
- 4 The patient with the help of a health professional

ABOUT YOU

49. Are you male or female?

- 1 Male
- 2 Female

50. What was your year of birth?

(Please write in) e.g.

1	9	3	4
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1	9		
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51. In the last 2 weeks did you require help from another person for everyday activities?

- 1 Yes
- 2 No

52. Do you feel that you have made a complete recovery from your stroke?

- 1 Yes
- 2 No

53. To which of these ethnic groups would you say you belong? (Tick **ONE** only)

a. WHITE

- 1 British
- 2 Irish
- 3 Any other White background (**Please write in box**)

b. MIXED

- 4 White and Black Caribbean
- 5 White and Black African
- 6 White and Asian
- 7 Any other Mixed background (**Please write in box**)

c. ASIAN OR ASIAN BRITISH

- 8 Indian
- 9 Pakistani
- 10 Bangladeshi
- 11 Any other Asian background (**Please write in box**)

d. BLACK OR BLACK BRITISH

- 12 Caribbean
- 13 African
- 14 Any other Black background (**Please write in box**)

e. CHINESE OR OTHER ETHNIC GROUP

- 15 Chinese
- 16 Any other ethnic group
(**Please write in box**)

54. Could we send you a survey again in a few months time to ask you about your follow-up care?

- 1 Yes, and I understand that this does not mean that I would have to take part in the future survey
- 2 No, I would prefer you not to contact me again

OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of stroke care, please write it here.

Was there anything particularly good about your stroke care?

Was there anything that could be improved?

Any other comments?

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

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