

Riks-Stroke – 1-year follow-up



Every year around 30,000 people suffer a stroke in Sweden. It is very important that those people receive the best possible treatment and care.

The Riks-Stroke quality register maps out how post-stroke treatment works. We carried out a 3-month follow-up survey which you may have participated in previously.

We now plan to follow up everyone who has received stroke treatment at a hospital one year after the stroke as well as at three months. This will be done together with Swedish municipalities and county councils and the National Swedish Board of Health and Welfare.

The questionnaire covers health and support following your stay at the hospital as well as public efforts to provide treatment and care.

The objective of this questionnaire is to increase our knowledge about people who have suffered a stroke and their support and help requirements one year after the stroke. We will also compare the treatment and care provided by different county councils, hospitals and municipalities.

Your participation is therefore very important and will help us develop the aftercare for stroke patients. This also applies if you have fully recovered from your stroke. We would be grateful if you would take the time to answer the questions. It is important that the answers reflect your current situation as accurately as possible. The questionnaire will be carried out by ScandInfo on behalf of Riks-Stroke.

If anything relating to the questionnaire or specific questions is unclear, please contact ScandInfo. You will find the phone number on the next page. However, if you have any questions relating to your stroke, please contact your doctor directly.

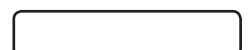
Please answer the questions and return the questionnaire in the stamped addressed envelope as soon as possible. You will find instructions on how to fill in the questionnaire on the next page.

Thank you in advance for your participation!

Yours sincerely,

Kjell Asplund
Professor, Head of Register
Norrlands universitetssjukhus

Josefine Björnsson
Questionnaire manager
ScandInfo



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Contact:

If you need to contact ScandInfo or have questions relating to the questionnaire, please contact ScandInfo's Riks-Stroke Support on:
telephone: 031-743 44 79, or
e-mail: riksstroke@scandinfo.se

Secrecy:

The information that you provide will be protected by the Swedish Secrecy Act as well as by the regulations in the Swedish Personal Data Act (PUL). Västerbottens läns landsting, Norrlands universitetssjukhus, 901 85 Umeå, Sweden is responsible for PUL.

Everyone that works with the questionnaire are covered by an obligation of secrecy according to chapter 9, 4§ of the Swedish Secrecy Act. In the results that will be reported, an individual's answers can never be identified. The number at the bottom of the questionnaire will help ScandInfo during the collection of data to see who has answered the questionnaire and who needs a reminder.

So that you will not have to answer questions relating to information that is available in the national register, the answers you give will be supplemented with information about your municipality and personal ID number at a later stage.

Riks-Stroke will also co-ordinate your answers with previous registration forms from the time of treatment and the 3-month follow-up.

Instructions:

- It is okay if you need help filling in the form. Please state who answered the form on your behalf in question 30.
- If you are filling in the form and do not know the answer to a question and there is no "Don't know" option, you should leave the question unanswered.

The questionnaire will be machine read.

We therefore ask that you think of the following when you answer the questions:

- Use a ballpoint pen with black or blue ink, not red. Do not use a pencil.
- Write numbers clearly.
- Mark like this: Not like this:
- If you happen to mark the wrong box, black out the whole box and mark the correct box:

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1. Where are you staying at present?

- In own accommodation without community home-help service +
- In own accommodation with community home-help service
- Arranged accommodation (e.g. nursing home, old people's home, service flat with full board, temporary accommodation, sheltered housing, alternate accommodation or equivalent)
- At acute-care ward (e.g. medical, neurological or surgical ward)
- At a geriatric or rehabilitation unit

2. Do you live on your own?

- Yes, I live entirely on my own
- No, I share the household with a spouse/partner or another person, e.g. sibling, child, parent

3. How mobile are you today?

- I move around without help both indoors and outdoors
- I move around without help indoors but not outdoors
- I need help to move around

4. Does someone help you with toilet visits?

- I manage toilet visits without any help
- I need help to go to the toilet

5. Does someone help you to dress/undress? +

- I manage to dress/undress without any help
- I need help to dress/undress

6. Does someone help you with your food shopping?

- I manage my food shopping without any help
- Someone helps me with my food shopping
- Not relevant, I live in arranged accommodation

7. Does someone help you with cleaning?

- I manage my cleaning without any help
- Someone helps me with cleaning
- Not relevant, I live in arranged accommodation

8. Does someone help you with your laundry?

- I manage my laundry without any help
- Someone helps me with my laundry +
- Not relevant, I live in arranged accommodation

9. Applied for aid or help from the Municipality

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Have you applied for an alarm system, transportation service, home-help etc.?

- Yes
- No
- Don't know

10. Home-help for personal care

Are your requirements fulfilled regarding getting dressed or undressed and/or toilet visits, for example?

- I don't need home-help for personal care
- Yes, completely fulfilled
- Yes, partly fulfilled
- No, not fulfilled at all
- Don't know

11. Home-help for domestic services

Are your requirements fulfilled regarding help with cleaning and/or food shopping, for example?

- I don't need home-help for cleaning or food shopping etc.
- Yes, completely fulfilled
- Yes, partly fulfilled
- No, not fulfilled at all
- Don't know

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12. Aids

Are your requirements fulfilled regarding walking frame, crutches, wheelchair, raised toilet seat, shower stool, housing adaptation or speech aids such as picture boards, communicator etc.?

- I don't need any such aids
- Yes, completely fulfilled
- Yes, partly fulfilled
- No, not fulfilled at all
- Don't know

13. Transportation service

Are your requirements fulfilled regarding transportation service?

- I don't need transportation service
- Yes, completely fulfilled
- Yes, partly fulfilled
- No, not fulfilled at all
- Don't know

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14. Home nursing

Are your requirements fulfilled regarding help with taking your medications, loading your pill dispenser, redressing wounds, managing your catheter, putting on support socks etc.?

- I don't need home nursing
- Yes, completely fulfilled
- Yes, partly fulfilled
- No, not fulfilled at all
- Don't know

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15. Rehabilitation after being discharged from hospital.

Rehabilitation includes training and exercises that help you improve or maintain your mobility and ability to manage everyday tasks.

Have your requirements for rehabilitation after your stroke been fulfilled?

- I didn't require any rehabilitation
- Yes, my rehabilitation requirements were fulfilled
- No, my rehabilitation requirements were only fulfilled in part
- No, my rehabilitation requirements were not fulfilled at all
- Don't know

16. Are you dependent upon family or friends for help or support today?

- No, not at all
- Yes, partly dependent
- Yes, completely dependent
- Don't know

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17. Have you returned to gainful employment?

- No, I was **not** gainfully employed before the stroke
- Yes, to the same extent as before the stroke
- Yes, but to a lesser extent than before the stroke
- No, but I plan to go back to gainful employment
- No
- Don't know

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18. Work-related rehabilitation

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Work-related rehabilitation refers to the setting up of a rehabilitation plan, adaptation of your work, provision of working aids, changing work tasks or working hours, work training, transfer or training courses, for example.

Have you received any work-related rehabilitation after the stroke?

- No, I was **not** gainfully employed before the stroke
- I didn't require any work-related rehabilitation
- Yes, very much so
- Yes, but not enough
- No, not at all

19. Have you received help from any of the following in order to go back to gainful employment? (more than one option may be applicable)

- Not relevant, I was **not** gainfully employed before the stroke
- Employer
- Social insurance office (Försäkringskassan)
- Employment office
- I am self-employed
- Don't know

20. During the last six months, have you visited a doctor, or do you have an appointment scheduled?

- Yes
- No
- Don't know

21. Have you checked your blood pressure since you were discharged from the hospital after your stroke?

- Yes
- No
- Don't know

22. Have you been to the dentist or dental hygienist in the last six months?

- Yes
- No
- Don't know

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23. How would you rate your general health?

- Very good
- Fairly good
- Pretty bad
- Very bad
- Don't know

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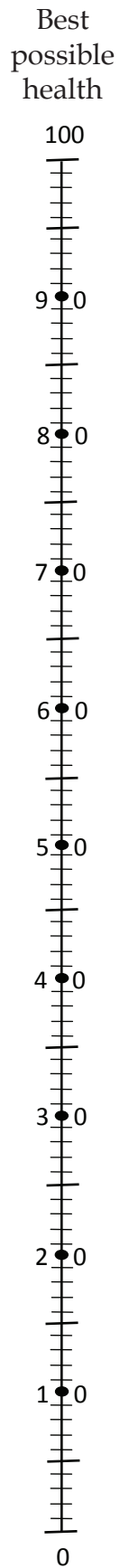
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24. To help determine how good or bad a person's health is, we use the 'thermometer' scale on the right. On this scale, your best possible health has been marked with 100, and your worst possible health has been marked with 0.

We would like you to indicate on the scale how good or bad you consider your own health to be. Please do this by drawing a line from the box below to the point on the scale that indicates how good or bad your current health is.

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Your current health



Please also estimate your current health using the numbers between 0 and 100, based on the scale to the right.

Your current health is:

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25. a) Do you smoke?

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- Yes
- No
- Don't know

b) Have you been offered an anti-smoke cure after your stroke?

- Not relevant, I didn't smoke before the stroke
- Yes
- No
- Don't know

26. Are you in pain?

- Never or almost never
- Sometimes
- Often
- Always
- Don't know

27. Have your pain relief requirements been fulfilled?

- I don't need any pain relief
- Yes, completely
- Yes, partly
- No, not at all
- Don't know

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28. Do you feel depressed?

- Never or almost never
- Sometimes
- Often
- Always
- Don't know

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29. Are you taking anti-depressants?

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- Yes
- No
- Don't know

30. Who completed this questionnaire?

- The patient alone in writing
- The patient with the help of a relative/friend or a member of medical staff
- Other person (e.g. trustee)
- Medical staff alone
- Relative or friend alone

Please check that you have answered all the questions 1–30!

Thank you very much for your participation!

Please return this questionnaire using the attached addressed envelope.

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