

Stroke Priority Setting Partnership

Are you:

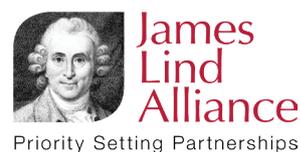
- over 16, living in the UK, and had a stroke?
- a relative or close friend (of any age*) caring for or supporting someone who has had a stroke?
- a health or social care professional working with people who have had a stroke?

Are there questions about stroke that you think are important for research to try to answer? **Your questions could help to improve treatment, rehabilitation and prevention in the future.**

See the separate Information Sheet and www.stroke.org.uk/jla for more details.

*If you are under 16 and supporting someone who's had a stroke, you can only take part if you have consent from a parent/guardian.

We're proud partners



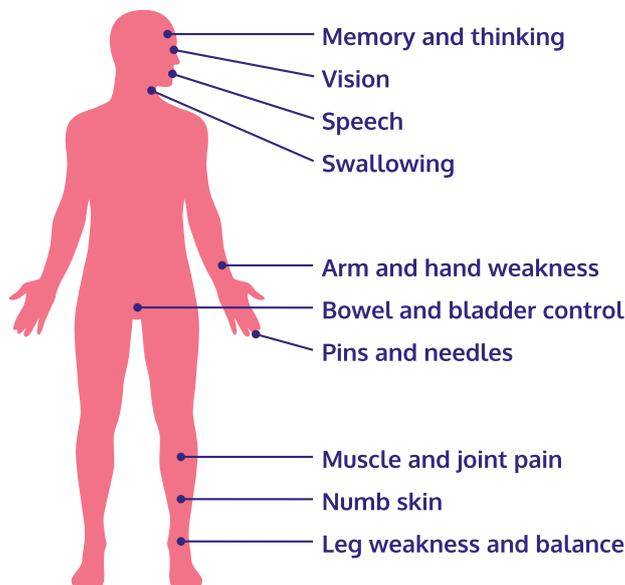
What questions do you have about stroke?

Stroke can affect life in all sorts of ways, such as returning to work, relationships with friends and family and the ability to do the things you want to do.

From your personal experience, what questions about stroke would you like to see answered by research? You can choose up to 3 things that are important to you, from any aspect of your experience.

You might have questions about:

- why strokes happen
- treatment or care
- stroke and other conditions
- what other people think about stroke
- effects of stroke such as emotional issues, sexual function or on other areas (such as those shown in the picture)



We're asking for up to 3 questions so that you start to think about what's most important.

It's OK to leave boxes 2 and/or 3 blank if you don't have that many questions.

You can continue on a blank sheet if you need more space.

It's also OK if you don't know how to write research questions. Just write in your own words. It's our job to turn what you tell us into questions that researchers can work with.

By taking part in this survey, you give us permission to publish your answers and use them in the next stages of the Partnership. Your name will not be included. It will not be possible to identify anyone or any organisation in later work or publications.

For everyone:

My first question

My second question

My third question

About you:

It is important that we know a little about you, so that we can:

- make sure different people from across the UK are giving us their views
- understand the questions being asked by different groups.

It would help us if you could answer these questions.

4. Which of these describe you? (Select the one that best describes you)

- I have had a stroke and am **over 16** [go to Q5]
- I am **under 16**, a relation or close friend of someone who has had a stroke, and am or have been, a **carer** for them – **I DO have consent** from my parent/guardian to take part in this survey [go to Q6]
- I am **under 16**, a relation or close friend of someone who has had a stroke, and am or have been, a **carer** for them – **I DO NOT have consent** from my parent/guardian to take part in this survey [You are not eligible to take part; please go to the end of survey]
- I am a relation or close friend of someone who has had a stroke, and am or have been, a **carer** for them [go to Q5]
- I am a **health or social care professional** working with people who have had a stroke [go to Q10]

For people affected by stroke:

5. How old are you?

- 16-24 25-44 45-59
- 60-69 70-79 80 and over
- I prefer not to say

[go to Q6]

6. If you can, please tell us which type of stroke you – or the person you care for – had (Select one):

- Don't know/unsure
- Transient Ischaemic Attack (mini-stroke)
- Ischaemic stroke (blockage)
- Haemorrhagic stroke (bleed): intracerebral
- Haemorrhagic stroke (bleed): subarachnoid

[go to Q7]

7. What **year** did you/the person you care for, have a stroke?

[go to Q8]

8. Which best describes your **gender**? (Select one)

- Female Male I prefer not to say

Other (please give your preferred term):

[go to Q9]

9. How do you describe your ethnic group?

- Asian/Asian British Black/African/Caribbean/Black British
- White Mixed multiple ethnic groups
- Any other ethnic group
- I prefer not to say

I prefer to describe myself as:

[go to Q12]

For health or social care professionals:

10. Where do you work? (Select one)

Hospital Community Hospital and community

Third sector and social work settings

Other (please specify):

[go to Q11]

11. Which of these best describe you? (Select one)

Care professional Dietitian

GP Neurologist

Neurosurgeon Occupational Therapist

Orthoptist Paramedic

Practice Nurse Physiotherapist

Psychologist Rehabilitation Support Staff

Social Worker Speech and Language Therapist

Stroke Nurse Stroke Physician

Stroke Support Co-ordinator

Other

[go to Q12]

For everybody:

12. Where do you **live**? (Select one)

- England Northern Ireland Scotland Wales
- I prefer not to say

What is the first part of your postcode (e.g. OX11):

[go to Q13]

13. Would you like to be kept informed about the Partnership?

This would mean receiving information about how you can get involved with deciding which questions are most important. You can then decide if you want to stay involved.

- Yes [Go to Q14] No [Go to what happens next]

If you choose to provide your contact details, we will keep them securely, separately from your answers, in accordance with the Stroke Association Privacy Policy. This can be seen on the internet here: www.stroke.org.uk/about-us/terms-and-conditions/privacy-policy. We will get in touch only to keep you updated about the Stroke Priority Setting Partnership.

14. If you would like to be kept informed, please give us your preferred contact details:

Name:

E-mail OR postal address:

We will get in touch only to keep you updated about the Stroke Priority Setting Partnership.

For more information: www.stroke.org.uk/about-us/terms-and-conditions/privacy-policy.

What happens next?

- We will look at all the questions and group them into themes.
- During the summer of 2020 we will turn them into research questions, where it is possible to do so. We will check existing research to see which questions have already been answered, as not everyone knows which have been. We will consider how best to share this information when we have it.
- If we receive questions that cannot be addressed by research, we will consider how best to respond to them.
- We will then have a long list of research questions. We will ask people affected by stroke, and health and social care professionals, to tell us which are the most important questions.
- In the autumn, we will hold workshops with some people affected by stroke, and health and social care professionals. They will work together to agree the Top 10 questions in one or more categories.
- Then we will publicise the results and work with research funders and researchers to address them.

How can you contact us?

If you have any questions, or would like to receive a paper copy of the survey, please contact

Sandra Regan

Email: sandra.regan@stroke.org.uk

Phone: **07703 319791**

For more information about the Stroke Priority Setting Partnership visit www.stroke.org.uk/jla

Follow us on Twitter

@PspStroke

#MySayforStroke

Email your completed form to sandra.regan@stroke.org.uk

If taking part in this survey has brought up any concerns, and you would like to talk to someone, you can call the Stroke Association Helpline on **0303 3033 100** or email helpline@stroke.org.uk.

If you live in Scotland, you can also contact the Chest, Heart and Stroke Scotland Adviceline:

Freephone: **0808 801 0899**. Email: adviceline@chss.org.uk

Text: NURSE to 66777

Thank you for taking part