

Name

Address 1

Address 2 NSW XXXX

Survey. What do you think about the Stroke Research Register (Hunter)?

You can do the survey if:

1. You have had a stroke
2. You have had a TIA
3. You care for someone who has had a stroke or TIA



It will take about **ten (10) min**

There are **seventeen (17) questions**

We want to find out what you think about

- The Stroke Research Register, and
- How we as researchers can work better with you to improve the lives of people with stroke and TIA.

Thank you - prize draw:

Four (4) people who do the survey will **win a \$50 supermarket voucher.**



The Stroke Research Register connects people who have had a stroke or transient ischaemic attack (TIA) with researchers in the Hunter region. Register members get invitations to take part in research studies over time. This helps researchers from the University of Newcastle, Hunter Medical Research Institute (HMRI) and Hunter New England Local Health District (HNEHealth) test new treatments and rehabilitation approaches for stroke and TIA. There are now 500 people registered.



First - please read the info booklet

It says who we are and explains how we will use your answers.

Do the survey – use this form, or

Do the survey online  <http://bit.ly/10minstrokesurvey>

Thank you, from the research team for this survey (University of Newcastle).

Survey form.



Want help?

4042 0093 or

or strokeregister@hmri.org.au

- ☐ I have had a stroke or TIA, or care for someone who has
- ☐ I am 18 years or older
- ☐ I have read and understood the enclosed detailed information about how my answers will be used

1. Are you a member of the Stroke Research Register?

- ☐ Yes ✓
- ☐ No ✗ → go to Question 6
- ☐ Not sure ? → go to Question 6
- ☐ I care for someone who had a stroke or TIA → go to Question 6
- ☐ Other ✍ _____ → go to Question 13

If you **are** a member of the Stroke Research Register, answer Q 2-5.

2. Why did you join? Mark as many as apply to you

- ☐ I want to test new treatments that might help me
- ☐ I want to be informed about stroke research
- ☐ Family member recommended it
- ☐ Doctor / researcher / health professional recommended
- ☐ Not sure ?
- ☐ Other ✍ _____

3. What do you like about being a member of the Stroke Research Register?

- ☐ Being asked to take part in research
- ☐ Keeping up to date with research
- ☐ Feeling part of a community of people with stroke or TIA
- ☐ Hearing about community talks or events relevant to me
- ☐ Other ✍ _____
- _____
- _____

4. How would you rate your experience of being involved in the Stroke Research Register?

- ☐ Excellent 😊😊😊
- ☐ OK 😊
- ☐ Not sure ? 😐
- ☐ Bad 😞
- ☐ I'm not a member
- ☐ Why did you chose this rating?
- _____
- _____

5. Would you recommend other people with stroke or TIA join the Stroke Research Register?

- ☐ Yes ✓
- ☐ No ✗
- ☐ Not sure ?



Why?

6. Have you been invited to take part in any research studies about stroke?

- ☐ Yes ✓
- ☐ No ✗
- ☐ Not sure ?

How many have you been invited to?

Not sure

0

1 - 3

3 - 5

>5

How many have you been participated in?

0

1 - 3

3 - 5

>5

7. If you have **decided not to take part** in a study, **why not?**

Select all that apply to you

- ☐ I was too busy
- ☐ The study was asking too much of me
- ☐ The info was too complicated
- ☐ Transport was too difficult
- ☐ I wanted to, but a researcher told me I wasn't eligible
- ☐ The study wasn't relevant to me
- ☐ Other  _____
- _____
- _____

If you have participated in any research studies:

- ☐  I have never taken part in a study → go to Q12

8. Why did you take part?



9. What did you like about the study or studies? 😊



10. Was there anything you didn't like? 😞



11. How did you find out about the study / studies?

Mark all that apply to you

☐ Letter or email from Stroke Register team 

☐ Phone call from Stroke Register team 

☐ Doctor / health professional 

☐ Radio / newspaper 

☐ Family / friend told me 

☐ Social Media 

☐ Twitter

☐ Instagram

☐ Not sure 

☐ Other  _____

12. Which things would help when deciding to take part in a study?

Mark all that apply to you

- ☐ The study might help me
- ☐ The study might help others in the future
- ☐ A person with stroke or TIA tells me what it was like in the study
- ☐ Help with transport
- ☐ Simple info about the study (plain language summary)
- ☐ Detailed scientific info about the study

[illegible]

e: strokeregister@hmri.org.au



Health



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

