AUSTRALIAN STROKE CLINICAL REGISTRY
FACILITATING QUALITY

Information for patients and relatives

What is the Australian Stroke Clinical Registry (AuSCR)?

The Australian Stroke Clinical Registry (Registry) is a national program that collects information about people who have had a stroke and have been treated in hospital.

The Registry helps hospitals understand what's working well and where stroke care could be improved.

By sharing your information, you are helping improve stroke care in Australia.

How is information from the AuSCR used?

Information from the Registry helps improve stroke care in different ways:

- **Hospitals** get reports to show what they are doing well and where they can improve
- **Governments** can use the data to plan better stroke services
- **Annual Reports** show differences between individual hospitals and provides overall updates on stroke care across Australia (www.auscr.com.au/about/annual-reports)
- The information helps **people working in stroke care** make better decisions based on what's working

Your information will be added to the Registry unless you let hospital staff or the Registry know that you do not want it included.

Who runs the AuSCR?

The Registry is run by The Florey, located in Melbourne, Victoria.

Each participating hospital has a member of the stroke team who is responsible for managing the Registry. All participating hospitals have approved the AuSCR.

What information do we collect, and when?

We collect information at two times:

1. While you are in hospital
   Your hospital sends us:
   - **Basic details** like your name, date of birth, address, phone number and language spoken
   - **Information about your stroke** (e.g. type of stroke and treatments)
   - **Details about leaving hospital** (e.g. where you will live, medications provided)

2. After you leave hospital
   Around 3 to 6 months later, we'll contact you (or your next of kin) by mail, text message (SMS), phone or email to ask how you are doing.
   - If we send you an SMS, only your first name, hospital name, and admission date are shared with the SMS service.
   - If we contact your next of kin, we will let them know that you had a stroke and where you were treated.

   We'll ask questions like:
   - How is your health now?
   - Where are you living?
   - Have you needed hospital care since your stroke?
   - Would you like to hear about future research projects?
     - If so, we may contact you about studies you can choose to join.

For a full list of the information we collect, visit: https://auscr.com.au/health-professionals/variables-program-bundles/

If you are in other stroke programs, we may share your information securely, so you don't have to answer the same questions again.

How is your information kept private?

Your information is kept **safe and secure** in the AuSCR.

- Only approved staff can access it.
- It's stored in a password-protected system.
- Your name and personal details are not shown in any reports.
- We will only share your information if you give permission or if the law requires it.

Occasionally, AuSCR staff review your hospital medical record to check details.

The registry is ongoing, which means we keep the data to track stroke care over time.
If someone wants to use the data for research, they must first get approval from an Ethics Committee.

Your Registry data may be securely linked with other health or government data (like hospital or death records) to help us better understand stroke care and long-term health outcomes. Once your data is linked it will be given a unique identification number for analysis. **This means that your name cannot be identified in any reports, and your privacy and confidentiality is maintained.**

Are there risks or benefits?

- There are **no risks to your health** from being part of the registry.
- The benefit is that your information helps hospitals improve care for future stroke patients.

Participation is your choice - Your care won't change

Taking part in the Registry is **completely your choice**.
You will get the same care from your doctors and care team whether you take part or not.
If you don't want your personal information included, you can let us know. Hospitals will still provide general (non-identifiable) medical information about care you received to help improve stroke care.

- Email auscr@florey.edu.au
- Call us on **1800 673 053** (freecall)
- Fill in the opt-out form below and give to **hospital staff** or mail to:

Australian Stroke Clinical Registry
The Florey
245 Burgundy Street
Heidelberg VIC 3084

If you have a concern or complaint, you can contact the hospital research office or patient/consumer liaison department.

OPT-OUT FORM

*Please tick the boxes if you **do NOT** want to take part:*

☐ I **do not** want my personal information included in the Registry.

☐ I **do not** want the Registry to contact me after I have left hospital.

Patient Name (please print clearly): _____

Date of Birth: _____ **Phone/Mobile:** _____

Admission Date (if known): _____ **Patient ID/MRN (if known):** _____

Signature: _____ **Date:** _____