Patient and Public Involvement Information

Stroke is a highly prevalent condition that is a leading cause of death and disability. The Australian Stroke Clinical Registry (AuSCR) stores the clinical details provided by participating hospitals for patients who have received treatment for either stroke or transient ischemic attack (TIA). AuSCR also stores follow-up information on patients' health status and recovery after stroke or TIA, which is collected three to six months after their hospital stay.

Clinical registries, such as the Australian Stroke Clinical Registry (AuSCR), aim to improve patient care and outcomes through greater understanding of events, treatments and outcomes. Analysis of data collected within the Registry enables clinicians, health services and researchers to monitor and improve the quality of stroke care for all Australians including:

- ensuring that patients affected by stroke receive the best possible treatment and care;
- preventing stroke from occurring or recurring; and
- enhancing the chance of recovery after stroke.

Data collected in the Registry, and through linkage with other health information systems, allows individual hospitals to monitor the care they have provided to their patients. National and state-based comparisons of the quality and outcomes of stroke care are monitored against National Health and Medical Research Council (NHMRC) endorsed Clinical Guidelines for Stroke Management.

How can I help?

Stroke survivors or their carers or family members can help the Registry achieve the aim of improving the treatment and outcomes for patients with stroke by volunteering as a 'consumer'. A consumer is a person who has experienced a stroke or TIA, or they could be a caregiver or family member, or a member of a community support group for stroke

Consumers can help the Registry in various ways, for example by telling their stories and sharing their experiences of stroke, or by reviewing and providing feedback on documents or the development of new registry processes.

Consumer representatives can also join: the AuSCR Management Committee, which is responsible for oversight and direction for the day-to-day aspects of the AuSCR; or the AuSCR Steering Committee, which oversees the governance and strategic direction of the AuSCR.

If you would like more information about how to participate in the AuSCR you can contact us by phone: **1800 673 053**, or email: admin@auscr.com.au. Alternatively, you could complete the details on the attached form and return it to us by mail/email and we will be in touch with you to discuss how you would like to contribute to the AuSCR as a consumer.

To learn more about the AuSCR see our website: www.auscr.com.au

Version 1, March 2021

AuSCR
Australian Stroke Clinical Registry

Patient and Public Involvement Form

Complete this form to register as a volunteer to support the Australian Stroke Clinical Registry (AuSCR). Any personal information provided is kept strictly in accordance with Privacy Regulations and is used solely for consumer participation and consultation activities for the AuSCR. By completing this form you agree to be contacted by AuSCR staff to coordinate your involvement in AuSCR activities or initiatives. Note that you may withdraw from participating in the AuSCR at any time by notifying Registry staff using the contact details below.

Please return the completed form to: admin@auscr.com.au or by post to: The AuSCR National Coordinator, Florey Institute of Neuroscience and Mental Health, 245 Burgundy Street, Heidelberg Victoria 3084.

Title: __________ **Name:** ____

Address: ____

_________________________________ **State:** ________ **Postcode:** __________

Phone: ( )_______________________________ **Mobile:** __________________________________

E-mail: ____

Reason for seeking participation in the AuSCR:

1. I have had a stroke or transient ischaemic attack (TIA) ☐

2. I am a family member/carer/friend/advocate for someone who has had a stroke/TIA ☐

3. Other/general community ☐

I am able to contribute as a volunteer consumer by:

☐ reviewing and providing feedback on documents or new registry processes (may be conducted by phone or email)

☐ sharing my story as a stroke survivor or carer/family member or community advocate

☐ joining the Management Committee

☐ joining the Steering Committee

Please list any other consumer or patient support groups that you are currently associated with:

Signed: **Date:**