



Australian Stroke Clinical Registry

Patient and Public Involvement Statement: how we engage with consumer advocates

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AuSCR OFFICE

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Project Consortium:

The Florey Institute of Neuroscience and Mental Health, Stroke Foundation,
The George Institute for Global Health and Stroke Society of Australasia



1.1 What is the purpose of the Australian Stroke Clinical Registry (AuSCR)?

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

Clinical registries, such as the 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.

The Registry produces reports that monitor stroke treatment and care in Australia that are used by stroke clinicians to continuously improve patient treatment and care. Reports on the factors that influence stroke care, rehabilitation and the impact of a stroke for patients may be presented at conferences or submitted for publication in medical journals.

1.2 What is meant by the term 'consumer'?

The term 'consumer' can mean different things to different people. A consumer is different to other stakeholders, which include end-users of the data such as clinicians, hospital executives, funders and researchers. The following definition of a consumer is used in the context of the AuSCR:

A consumer is a person who has experienced a stroke (or TIA), or is a caregiver, family member or friend of a person with stroke, or is a member of a community organisation representing stroke consumers' interests (e.g. local stroke support groups). A consumer is able to voice the perspective of a patient who has experienced a stroke or TIA.

The main attribute that these people share is that they are not primarily researchers or health professionals. Their experience of stroke is as a health consumer or community member.

1.3 The Australian Stroke Clinical Registry Governance Structure

The AuSCR has a governance structure which incorporates representation from stakeholders, including clinicians, consumers, funders, researchers, and policy developers. The AuSCR governance structure ensures that the AuSCR runs efficiently and is appropriately managed by people who have clearly identified roles and responsibilities. All AuSCR data is held within the Australian Stroke Data Tool (AuSDaT). Input from the AuSDaT Committee, as well as other partners

such as the Stroke Foundation, the Australian Stroke Coalition and funders of the registry also play an important role within the Governance Structure (Figure 1).

The AuSCR Steering Committee oversees the governance of the AuSCR and maintains the confidence of all parties. It provides strategic direction and ensures that agreed policies and procedures are followed.

The AuSCR Management Committee is a committee that is responsible for oversight and direction for the day-to-day aspects of the AuSCR.

The AuSCR Data Custodian has day to day responsibility for the Registry and has relationships with funders, the Australian Stroke Coalition and the Stroke Foundation.

The AuSDaT Coordinating Committee provides advice relating to decisions regarding database infrastructure which holds the AuSCR.

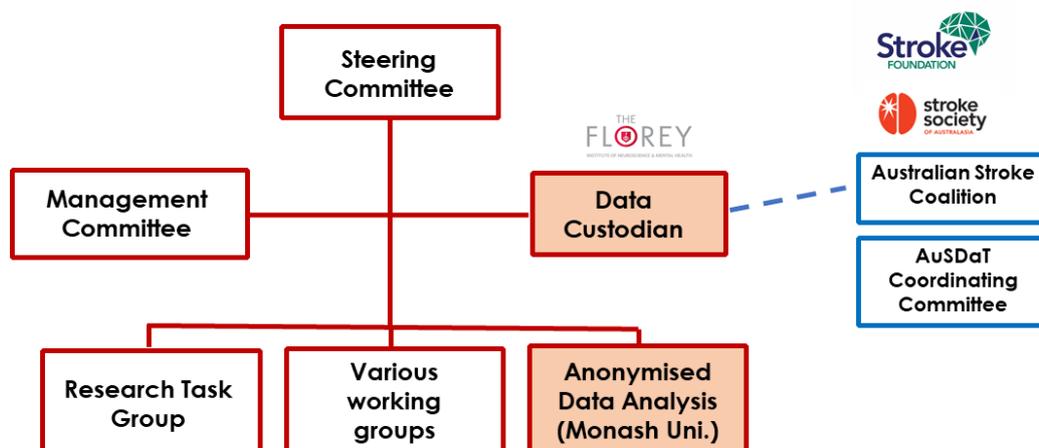


Figure 1: AuSCR Governance Structure

2.0 Consumer participation in the Australian Stroke Clinical Registry

Direct consumer participation in a Registry ensures it remains relevant to the people for which the data are being captured and enhances the program as it evolves. Participation by consumers in the AuSCR may include:

- Joining the AuSCR Steering Committee or the AuSCR Management Committee. These committees each include at least one consumer representative who is a survivor of stroke, or the caregiver of a stroke survivor. This consumer member provides a consumer perspective to the Committees and participates in the decision-making processes for the registry on behalf of consumers.
- Assisting the AuSCR Office who may need a consumer perspective on the day-to-day AuSCR operations, proposed innovations, or literature/documents such as patient information sheets intended for consumers. Such consultation may occur on a one-on-one or small group basis as needed.

2.1 What is meant by participation?

Participation refers to involvement by consumers in the work of the AuSCR. We use both *participation* and *consultation* as methods to describe consumer and community involvement.

Participation is about being an active part of the process. It includes involvement in committees or forums, providing input to documents or the development of policies, and contributing time and effort to the ongoing work of the Registry.

Consultation is when consumers are asked for their point of view. Consultation is a level of participation in which people share their insights, but are not involved in Registry processes.

3.0 How to register for participation in the AuSCR?

People who are interested in providing consumer support for the AuSCR can register with the AuSCR Office by completing the Patient and Public Involvement Form. Being registered may not automatically mean participation in the AuSCR Committees or activities, but it does allow for contact when opportunities for participation arise. Those who register may also choose to receive a copy of the monthly AuSCR Newsletter.

Note that you may withdraw from participating in the AuSCR at any time by notifying Registry staff using the contact details below.

Completed forms may be returned by mail to:

Australian Stroke Clinical Registry (AuSCR)
The Florey Institute of Neuroscience and Mental Health
245 Burgundy Street
Heidelberg, Victoria 3084

Or by email to:

admin@auscr.com.au

To learn more about the AuSCR see our website:

www.auscr.com.au

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