



Australian Stroke Clinical Registry

Statement on Consumer and Community Participation

Version 2.1

Approved 29 August 2012

1.1 What is a Clinical *Quality* Registry?

Clinical registries, such as the Australian Stroke Clinical Registry (AuSCR), are established and operated with the aim of improving patient care and outcomes through greater understanding of events, treatments and outcomes. The data collected by a registry over time are analysed and used to identify positive and negative trends. These analyses can be used, generally by clinicians, to lead to improvements in practice and in medication usage. Registries build on data collected during hospital admissions and use this information to assess care provision and provide feedback to drive quality improvement where required.

1.2 The Australian Stroke Clinical Registry

The Australian Stroke Clinical Registry (AuSCR) is a database that will be used to significantly improve the quality of hospital care in Australia for all patients admitted with stroke or transient ischaemic attacks (TIAs).

The AuSCR database includes information about patients with stroke to determine the patterns of treatment, rehabilitation and recovery of patients. The data collected provides information about the severity of stroke at three months after stroke, as well as the quality of stroke treatment in hospitals, and includes questions such as:

- Whether the patient was treated in a Stroke Care Unit?
- Whether the patient and family received a care plan on discharge?
- Whether the patient received blood pressure medication on discharge?
- Whether the patient has had another stroke since discharge from hospital?
- How the patient rates their quality of life three months after stroke?

The information recorded in the AuSCR database will allow individual hospitals to monitor the care they provide to patients. National and state-based comparisons of the quality and outcomes of care are also possible. The goal of the AuSCR database is to obtain the most accurate picture about stroke, the care received everyday by patients who have had a stroke, and whether or not the best-quality interventions are being provided to all stroke patients. Collecting the data is not, in itself, sufficient to improve quality of care. Systems are in place within AuSCR to ensure that data are analysed in a timely manner, with clinical interpretation on findings. The findings are then fed back to appropriate personnel/bodies to ensure that appropriate action occurs. In this way, patients are the ultimate beneficiaries of AuSCR, by receiving safer care.

AuSCR has a well-documented governance structure which incorporates representation from stakeholders, including consumers, clinicians, jurisdictions, funders, researchers, and policy developers. The AuSCR governance structure (Figure 1) ensures that the AuSCR database runs efficiently; operates at all times within legal constraints, particularly with regard to data security and confidentiality; is able to monitor outcomes and deal appropriately with clinical issues arising from the data analysis; is appropriately managed by people who have clearly identified roles and responsibilities; and has processes for engagement and commitment of all relevant stakeholders.

The AuSCR governance structure comprises a Steering Committee, responsible for the clinical register, and a Management Committee who take responsibility for managing the day-to-day operations of the clinical register. In addition to these structures, AuSCR has an independent human research ethics committee approval in operation at each participating hospital to provide

confidence that perceived misuse or inappropriate use of data can be investigated. The following definitions have been used for the purposes of this Statement on Participation:

The Steering Committee is a committee who oversee the governance of the AuSCR register and maintain the confidence of all parties. It provides strategic direction and ensures that deliverables are met.

The Management Committee is a committee that is responsible for managing day-to-day aspects of the AuSCR register. Data quality measures should be reported regularly to the management committee.

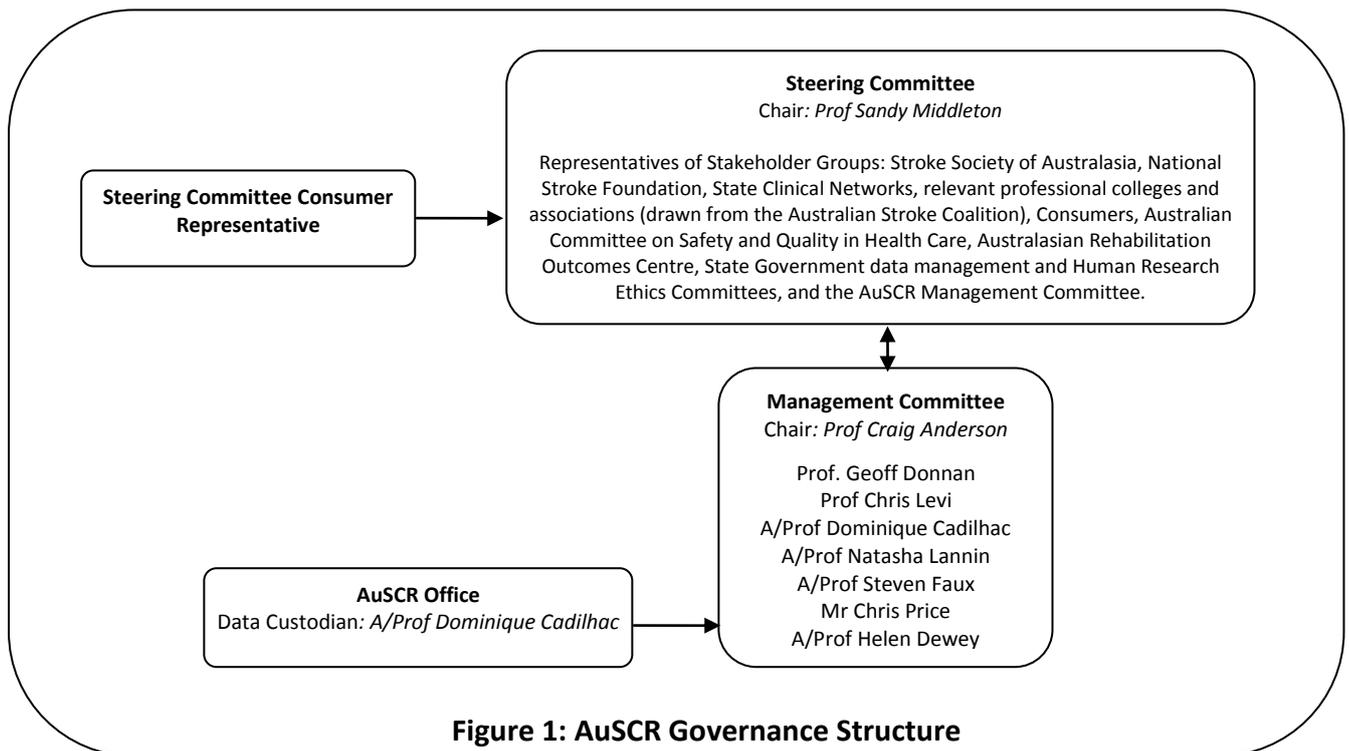


Figure 1: AuSCR Governance Structure

AuSCR is a collaborative initiative between The George Institute for Global Health, the National Stroke Research Institute being a division of the Florey Institute of Neuroscience and Mental Health, the National Stroke Foundation, and the Stroke Society of Australasia. These four organisations represent the breadth of clinical, research and consumer and community interest in stroke in Australia, and together they form the AuSCR Consortium. There is representation from the AuSCR Consortium on the Management and Steering Committees.

The AuSCR Management Committee will use the information from all hospitals to describe the quality and outcomes of care of national, state-based or particular patient subgroups. All reports will be presented as *aggregated* data, and not as individual patient, physician, or hospital data. No individual patient will be identified.

2.0 A note about the term 'consumer'

We adopt the term consumer as this term is already widely in use within the National Stroke Foundation and Stroke Society of Australasia, and because it is difficult to identify any other term that is universally acceptable.

The term 'consumer' can mean different things to different people. The following definition was used for the purposes of this Statement on Participation:

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 consumer perspective, from the position of a patient who has experienced a stroke or TIA.

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

2.1 What is meant by Participation?

Consumer and community participation includes consumer and community involvement in policy formation and the role of consumers and community members as advocates on certain issues. AuSCR uses both *participation* and *consultation* as methods of including consumer and community involvement.

Participation is about being part of the process. It is about more than observing and commenting on processes but comprises actual involvement in committees or forums, the authoring of documents or the development of policies.

Consultation is when consumers are asked for their view. Consultation is a level of participation at which people are offered some choices on what is to happen, but are not involved in developing additional options or actions.

2.2 Consumer and Community Participation in AuSCR

The AuSCR Management and Steering Committees believe that direct consumer participation aids the development and maintenance of a high-quality and relevant Registry. AuSCR Management and Steering Committees use both *participation* and *consultation* to engage with consumers in the following potential ways:

- Consumer representative membership of Steering Committee: The AuSCR Steering Committee includes at least one consumer representative member who voices the consumer perspective and participates in the decision making process on behalf of consumers.
- Consumer consultation on the review of training materials, marketing documents and ethics documents, including consent materials such as patient information sheets on an ad-hoc basis. Such consultation may be engaged using one-on-one, small group or forum methodologies. The Management Committee maintains the right to decide when and which consumers are required for such purposes, and this should not affect the day to day operations of the Registry.

3.0 Consumer Membership

People who are interested in being involved in consumer participation and/or consultation for the AuSCR can join the AuSCR Consumer Interest Group by completing the Consumer Membership Form. Being a member of the Consumer Interest Group may not automatically mean participation in the AuSCR Steering Committee or activities. However all Consumer Members will receive a copy of the AuSCR Newsletter and be invited to attend future AuSCR Consumer Forums when convened.

The Consumer Membership Form should also be completed if you would like to receive the AuSCR Newsletter or if you would like to receive a copy of the AuSCR Annual Report via email. The annual reports will also be available to download via the AuSCR website.

3.1 Consumer Membership Form

To join the Consumer Interest Group it is a requirement that a Consumer Membership form be completed. This will also help us inform you of important events and to give you the opportunity to nominate for future participation in AuSCR activities.

Completed forms can be returned via email: admin@auscr.com.au or Fax: (03) 8888 4990. For further information, contact the AuSCR office on 1800 673 053, email admin@auscr.com.au, or write to the AuSCR Project Coordinator at the Florey Institute of Neuroscience and Mental Health, 245 Burgundy Street, Heidelberg, Victoria, 3084.

Consumer Membership Form

We would appreciate you completing the following form to be part of the Australian Stroke Clinical Registry (AuSCR) Consumer Interest Group. Any personal information collected is kept strictly in accordance with the Privacy Regulations and is used solely for consumer participation and consultation activities of the AuSCR registry. By completing this form you agree to be contacted by AuSCR staff to regularly receive information and updates about AuSCR and/or contribute a consumer perspective as requested for AuSCR activities or initiatives.

Please return completed form to: admin@auscr.com.au or Fax: (03) 8888 4990

Name:

Contact Address:

Postcode:

Phone Number:

E-mail Address:

1. I have had a stroke or TIA
2. I am a parent/carer/partner/friend/advocate for someone who has had a stroke
3. General community (neither 1 or 2 above apply)

My past experiences that will help in my role as an AuSCR Consumer Member (e.g. parent, carer, nurse, teacher, advocate, etc):

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I am most interested in: Steering Committee membership Working Groups/Forums
 Review policies/Annual reports Helping with the newsletter Volunteer in the AuSCR Office

Any consumer or patient TIA support groups that you are associated with:

I wish to receive the Australian Stroke Clinical Registry Newsletter: Yes No

I wish to receive the Australian Stroke Clinical Registry Annual Report via email: Yes No

I would like to be contacted to hear about Consumer participation and consultation opportunities within the Australian Stroke Clinical Registry: Yes No