
Australian Stroke Clinical Registry (AuSCR)

Research Task Group

Terms of Reference

Background

A consortium consisting of representatives of the National Stroke Research Institute (NSRI), The George Institute for Global Health (TGI), the National Stroke Foundation (NSF) and the Stroke Society of Australasia (SSA) was established to bid for a tender announced by the Australian Commission on Safety and Quality in Health Care (ACSQHC) in August 2008. The consortium was successful in being awarded the tender to test and validate the draft 'Operating Principles and Technical Standards for Australian Clinical Quality Registries in a new Australian national stroke registry. The registry, called Australian Stroke Clinical Registry (AuSCR), will commence in a pilot phase across 6-20 sites in Australia during 2009.

By January 2009, the governance and management structures for AuSCR were in place, and development of the data collection process and evaluation methods were in an advanced stage. In compliance with the requirements *draft 'Operating Principles and Technical Standards for Australian Clinical Quality Registries*, the project needed to establish specific task groups in targeted areas of work related to the project.

1. Aim

- The primary purpose of this Research Task Group is to ensure appropriate use of the AuSCR data for high quality research projects and ensuring the protection of privileged personal data located on the registry.

2. Membership

- Members of the task group will consist of individuals with specific interest and expertise in epidemiology and clinical datasets in stroke and who are not members of the AuSCR management committee.
- Term of membership will be for 3 years.

3. Role of the Task Group

- The group will be charged with reviewing and providing recommendations on all applications for use of the AuSCR dataset. The criteria for judging of applications is to ensure that all of the following 11 items are fulfilled via a proforma checklist:

Criteria for approval of release of AuSCR data

1. Appropriate background and rationale for project
2. Appropriate study design
3. Feasible timelines
4. Appropriate level of statistical support
5. Appropriate funding including provision for the cost of obtaining data from AuSCR data set
6. Study conforms to the original consent statement
7. Clear level of protection of personal information
8. Ethics approval granted
9. Clear reporting process of results with appropriate acknowledgement of source of data
10. Overall recommendation for data release, including any recommendations to the applicants
11. Appropriate acknowledgement of AuSCR in any publication or presentation of the research project.

- In addition, the Task Group will provide written feedback recommendations to applicants, either for those approved or rejected, in order to potentially enhance the application or quality of the project.

4. Communication

- A leader/Chair will be appointed by the group.
- The AuSCR project coordinator will send research project applications to each member of the group, and organize meetings as required. The Chair is asked to keep minutes of meetings which will be undertaken independent of the Management Committee.
- Regular reports will be presented to the Steering committee via the chair of the Management committee.

5. Meetings

- To be held at least twice (2) per year and can be by teleconference or face to face as determined by the group.
- Support for the meetings will be provided by the AuSCR project coordinator which includes, taking of minutes, coordinating dates and location of meeting.

6. Declaration of conflict of interest

All members of the task group are required to declare any conflict of interest, at the establishment of the group and during the course of operation as necessary.

7. Confidentiality

During membership on the task group, the member will not reveal any confidential or proprietary information entrusted in the course of their duties. Upon cessation of membership, and thereafter, the member shall not reveal any confidential or proprietary information, which they obtained while a member of the group, and may not use or retain, or attempt to use or retain, any such information, documents or data.

8. Copyright

During membership, and thereafter, the member will respect the copyright of any information and resources developed under the auspices of the group as agreed by the full membership.