The Australian Stroke Clinical Registry (AuSCR) is a prospective method for collection of important stroke patient data that is nationally representative. The primary purpose of the AuSCR is to collect information that will lead to a) a better understanding of clinical care and health outcomes; b) the development of interventions and policies to improve the quality and safety of stroke care delivery in Australia; and 3) the assessment of changes in clinical practice and health outcomes over time. In the future, AuSCR may also provide a framework for other research.

BACKGROUND

In Australia, about 50,000 people suffer a stroke annually. Given the high cost and serious consequences of stroke, and the importance of well organised health care to improve outcomes, a national stroke registry is warranted. Such an approach is also endorsed in clinical guidelines by the National Stroke Foundation (NSF) and the World Health Organization who recommend monitoring of the quality of stroke care by use of national registries or regular audits.

In early August 2008, a consortium was formed between the National Stroke Research Institute (NSRI), The George Institute for International Health (TGI), the National Stroke Foundation (NSF) and the Stroke Society of Australasia (SSA) to submit a proposal for an Australian Stroke Clinical Registry (AuSCR) in response to a Request for Tender from the Australian Commission on Safety and Quality in Health Care. The consortium was successful and a one year pilot stroke project to develop and implement AuSCR commenced in November 2008. Allergan Australia has also provided an unrestricted educational grant for establishment of the Registry.

OVERVIEW OF THE PROJECT

AuSCR will be piloted at select sites as part of a development project to ensure national scalability. Pilot sites were nominated through state-based clinical networks. Pilot testing is essential for AuSCR to assess and overcome logistical issues and barriers to ensure ready participation of multiple sites beyond the pilot period. Pilot sites include both public and private hospitals, as well as those located in regional as well as metropolitan areas.

An online (web-based) Level 2 system is planned. A ‘Level 2’ registry is defined as a system that will allow web-based submission of data into the registry and may be combined with paper based reporting. However, wherever possible, technology will be developed with the long-term plan of meeting National e-Health Transition Authority standards for a Level 3 Registry (ability to link or cross-check data with external systems). We aim to ensure that AuSCR is compatible with the NSF Audit Program to avoid duplication of data entry.

INFORMATION COLLECTED IN AuSCR

Patients diagnosed with the various pathological forms of stroke will be included in the AuSCR i.e. ischaemic stroke, intracerebral haemorrhage, and transient ischaemic attack (TIA). These will be classified using international disease classification codes (ICD10).

The minimum dataset variables for AuSCR were agreed at a national workshop held in October 2008. To ensure comparative analyses of clinical care and patient outcomes are appropriately
adjusted for variations in patient case-mix, a number of background variables are recorded
(such as age, gender and ability to walk on admission).

The main clinical indicators in the minimum dataset are:
- Use of intravenous thrombolysis (tPA) if an ischaemic stroke
- Access to a stroke unit (geographically defined ward area)
- Discharged on an antihypertensive agent
- Care plan provided at discharge (defined as any documentation in the medical record)
- Hospital outcomes data including date of discharge or date of death, and discharge
destination

Data will be obtained from individual patient medical records during their hospital stay and at
discharge, and a separate questionnaire is used for a 3-month follow-up by telephone or mail.
Follow-up information includes survival, living situation and activities of daily living dependency,
and perceived general health and quality of life at 3 months.

Clinical staff at the participating institutions will be trained and supported by project staff. The Registry will also use standard data definitions for consistency with the NSF Audit Program.

ANALYSIS AND FEEDBACK

Analytical reports on process and outcome quality indicators will be created. The variables will
be analysed at the national and hospital levels. To facilitate data interpretation, background
information, including patient characteristics and coverage, is presented at the hospital level. All
patient data are presented in aggregated form and will be de-identified in site specific reports.
Participating hospitals will have access to a statistical and presentation package to analyse and
present their own data compared with national data. All data used in annual reports will be
aggregated and de-identified, that is no health care providers or individuals will be identifiable.

AuSCR Project Management and Governance

A governance structure has been developed according to national registry guidelines with
representation of all major stakeholders. A Steering Committee and Management Committee
have been formed. The governance structure ensures that the strategic aspects of AuSCR and
its day-to-day management and operation remain aligned to the objectives of the pilot project.

GOVERNANCE

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