Annual Report 2010

AuSCR

Australian Stroke Clinical Registry

29 September 2011

Contents

HIGHLIGHTS IN 2010

In 2010:

- Twelve (12) hospitals contributed data to AuSCR

- The final 2010 data reported in this document includes information on 1829 admissions from 1828 stroke episodes

- Several improvements to the registry were made including modifications to the web-tool, methods to avoid missing data, changes to the follow-up procedures of registrants and amendments to the data dictionary.

- Following close off of the data for 2010 annual reporting there were 973 eligible registrants (90%) who provided follow-up data.

- Future directions include on-going hospital recruitment; state-wide uptake support in Queensland; refining methods to ensure complete case-ascertainment; exploring the potential to harmonise AuSCR with the National Stroke Foundation (NSF) audit program; increase uptake of data importing solutions; and work to determine the feasibility and benefits of data linkage to other government and non-government datasets.

- Identifying an adequate and reliable funding base remains critical to the sustainability and effectiveness of AuSCR.

ABOUT THE COLLABORATING ORGANISATIONS

The AuSCR initiative was undertaken by a consortium of two leading academic research institutes: the National Stroke Research Institute, a subsidiary organisation of the Florey Neuroscience Institutes, and The George Institute for Global Health; and two leading non-government organisations: the National Stroke Foundation and the Stroke Society of Australasia. Collectively, these organisations represent a broad section of the Australian clinical and scientific community.

PUBLICATION INFORMATION

In 2010, the following publications about the Australian Stroke Clinical Registry were produced:

Cadilhac DA, Lannin NA, Anderson C, Levi C, Price C, Faux S, Middleton S, Lim J, Thrift AG, Donnan GA. Protocol and pilot data for establishing the Australian Stroke Clinical Registry. Int J Stroke 2010;5(3):217-26.

PUBLIC PRESENTATIONS (INVITED OR PEER REVIEWED)

In 2010, the following presentations about the Australian Stroke Clinical Registry were given:

Cadilhac, D. (2010). Overview and progress of the Australian Stroke Clinical registry. Registries Special Interest Group meeting, Monash CRE in Patient Safety, Alfred Hospital Prahran, February 2010

Cadilhac, D.A, Lannin NA, Anderson CS, Levi CR, Faux S, Price C, Paice K, Middleton S, Donnan GA on behalf of the AuSCR Consortium Partners. (2010). The Australian Stroke Clinical Registry: formative evaluation. Stroke Society of Australasia 2010 Annual Scientific Meeting, Melbourne. September

Cadilhac D, Paice K, Lannin N, Anderson C on behalf of the AuSCR Management Committee (2010). The Australian Stroke Clinical Registry (AuSCR): advancing information collection about hospital stroke care. Smart Strokes 6th Australasian Nursing and Allied Health Conference, Terrigal NSW. August

Cadilhac DA, Lannin NA, Anderson CS, Levi CR, Faux S, Price C, Middleton S, Donnan GA on behalf of the AuSCR Consortium Partners. The Australian Stroke Clinical Registry: achievements in the first year. European Stroke Conference Barcelona, Spain 2010.[POSTER]

Lannin NA, Cadilhac DA, Anderson CS, Price C, Lim J, Hung YT, Faux S, Levi CR, Donnan GA on behalf of the AuSCR Consortium Partners (2010). Comparison of response rates and completeness of postal versus telephone outcome assessment: a randomised evaluation of a Stroke Registry. Stroke Society of Australasia 2010 Annual Scientific Meeting, Melbourne. September 2010

Lim J (2010) on behalf of the AuSCR Management Committee. Updates and benefits of transferring to AuSCR for clinical data collection. Queensland Stroke Clinical Network Forum, November 2010.

Lim J (2010) on behalf of the AuSCR Management Committee. AuSCR updates and future plans. New South Wales, Agency for Clinical Innovation (ACI) Meeting, December 2010.

ACKNOWLEDGMENTS

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Christie Britney	Annette Will		
James Hughes	Diane Fichera		
Rachel Peake			
Susan Day			
Elizabeth O'Brien			
Geoffrey Herkes			

CHAIRPERSON'S REPORT: STEERING COMMITTEE

At completion of the pilot phase in 2009, the original Steering Committee was dissolved and a new Steering Committee convened in early 2010. The purpose of this Steering Committee is to oversee AuSCR governance, maintain the confidence of all parties involved, and to provide strategic direction.

Terms of reference were revised with membership lasting 24 months. The new committee consisted of several previous members from the pilot phase Steering Committee, but we also welcomed new members. The new Steering Committee consisted of individuals and organisations interested in the operations and success of AuSCR, comprising representatives from:

- Senior clinicians in a leadership role in the stroke specialty with representation from most Australian states
- Senior members of the Management Committee
- A consumer representative interested in stroke
- Representation from key national professional organizations interested in stroke
- Representation from State Stroke Clinical Networks (NSW, SA, QLD, VIC and TAS)

The Steering Committee members were committed in their involvement, and there were no meetings where a quorum (n=10, 63%) was not met. The Steering Committee met twice through the year by teleconference, and the annual final meeting was a face-to-face combined Management and Steering Committee meeting in September 2010, conducted in conjunction with the Stroke Society of Australasia's Annual Scientific Meeting in Melbourne.

In review, the Steering Committee achieved the following in 2010:

- Provided support and oversight on the activities of the Registry through the Management Committee, such as participation in the Harmonisation of Multi-Centre Ethical Review (HoMER) trust-building pilot and roll-out AuSCR;
- Approved nine (9) policies that are now all available on the AuSCR website;
- Provided advice on the strategies for the follow-up protocol following the pilot;
- Supported the development of the business case for future funding;
- Provided advice and sign off on the first AuSCR annual report (2009).

The Steering Committee also provided oversight of the Registry and Consortium partnership through close liaison with the Chair of the Steering Committee, who attended annual planning meetings and all special or extraordinary meeting held throughout the year. All issues identified at the Steering Committee meetings were forwarded to the Management Committee for action.

The Steering Committee acknowledges the excellent achievements of AuSCR in 2010, particularly in the completion of the first Annual Report and participation in the HoMER trust-building pilot, an initiative of the National Health and Medical Research Council (NHMRC). AuSCR is emerging as a valuable asset to the stroke care community and one that is only likely to strengthen with time.

Professor Sandy Middleton

CHAIRPERSON'S REPORT: MANAGEMENT COMMITTEE

In 2010, AuSCR achieved its first complete year of data collection and follow-up. It also continued the roll-out expansion of participating hospitals, closing the year with 12 active hospitals across the nation.

Highlight of achievements in 2010 include:

- the upgrading of the AuSCR database following wide ranging feedback received by users and consumers in the pilot evaluation;
- development and evaluation of a self-directed ethics package to be used by sites in different states for Site Specific Ethics Applications;
- successful participation in the NHMRC's HoMER trust-building pilot of centralised ethics application process. AuSCR was one of only two projects to complete the pilot. We were able to contribute valuable feedback on the necessary requirements for undertaking large-scale, national, multi-centre research projects through evaluations of three hospitals that used the one National Lead Committee in Victoria.

The day-to-day operations continued with the routine data cleaning, regular desk audits and quality evaluation throughout the year, whilst coping with several challenges associated with some staff changes, financial constraints, and expansion of the AuSCR network.

In addition, there was continued promotion of the purpose and benefits of participation in AuSCR as a quality tool, the ability to link routine data collection with daily clinical operations, and to monitor and benchmark such performance across other hospitals in Australia, and potentially, overseas.

The financial support received from Allergan and the Stroke Society of Australasia was pivotal to our maintenance of the infrastructure and continued work of AuSCR. However, most important, was the enormous work effort, commitment and support received from within and outside the Management Committee who had operational responsibility for the project. This has allowed us to further roll-out AuSCR through a waiting list of 40+ hospitals who have expressed an interest in participating.

With ongoing, often challenging, health care changes and focus, AuSCR is well positioned to provide a platform for monitoring stroke care and outcomes among clinical networks and different health care sectors, and provides an infrastructure for future research and evaluation. All this is because stroke continues to be one of the major causes of death, disability and cost in Australia and around the world.

Professor Craig Anderson

ACKNOWLEDGMENT OF FUNDERS IN 2010

In 2010, the AuSCR office was supported by surplus funds carried over from previous year, in kind supports from consortium partners and funding from:

ORGANISATION	AMOUNTS
Stroke Society of Australasia	$20,000
Allergan Australia	$45,000
The George Institute for Global Health	$40,000
Total Funding received	**$115,000**

We are also grateful to Allergan Australia who also funded the AuSCR exhibition booths at the SmartStrokes 2010 Conference in Terrigal, NSW and at the Stroke Society of Australasia, 2010 Annual Scientific Meeting in Melbourne.

We also thank the members of our Steering Committee, Management Committee, Research Task group and consortium partner organisations who provide in-kind resources to this initiative.

We thank the staff at the hospitals for participating in and supporting this initiative.

INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) was established in 2009 to provide national data on the process of care and outcomes for patients admitted to hospital with acute stroke or transient ischemic attack (TIA)[1]. Patients with TIA were included because, in Australia, there are limited data about the quality of care provided to patients with TIA who are admitted to hospital and care recommendations are similar to those for stroke (i.e. admission to a stroke unit, discharged on antihypertensive agents, etc). The registry was designed to be used in public and private hospitals, and is also applicable to adults and children, hence follow up data collection includes age-appropriate questionnaires for various age groups.

The overall goal of AuSCR is to provide reliable and representative data that can be used to improve the quality of stroke care, nationally. The primary aim is to provide a mechanism to routinely and prospectively monitor acute stroke care in hospitals. Fundamental to this aim, is the registration of all eligible stroke cases admitted to the participating hospitals. In this way, selection bias can be kept to a minimum. Therefore, AuSCR use an 'opt-out' consent protocol whereby all eligible cases are included unless the patient or family nominates to have their data excluded. The opt-out consent protocol requires patients to be provided with information on the purpose of the registry, how the information is collected, and an explanation of the simple, cost-free avenues available to them should they wish to have their information excluded (free-call telephone number or postage-paid). This method is consistent with the ethics approach recommended by the Australian Commission on Safety and Quality in Health Care[2] and endorsed by the National Health and Medical Research Council (NHMRC) of Australia. A second aim of the AuSCR initiative is to provide a database that will enable future stroke research in large numbers of people, or in those with certain characteristics, which might otherwise have not been possible. In these early stages, use of data to implement large scale quality improvement strategies was not within scope, but is a future objective of the registry when data collection is fully established. Presently, each hospital has access to their own data and summary 'live' reports which the staff can download from AuSCR to enable quality reviews.

In this 2010 Annual Report, we provide information using data collected from contributing hospitals and the outcomes of registered patients 90+ days after stroke. In addition, the modifications made to improve the registry are outlined, as well as future plans for the registry.

BACKGROUND

The purpose of clinical quality registries are to measure quality of care[3]. AuSCR adheres to the national guidelines for best-practice in clinical quality registries. In brief, the recommended operating principles require a registry to have an appropriate governance structure and operations polices for data access and security, publications, and effective communication to allow results to be understood[2]. Moreover, registry data are required to be: kept minimal and not a burden to obtain; epidemiologically sound and reproducible; available on all eligible cases and collected from all eligible settings; and the results should be reported routinely and include risk (case-mix) adjusted outcome analyses. The recommended technical standards and architecture for registries depend on the various levels of data capture (e.g. paper-based and/or direct web entry) and on how a registry system operates and communicates with external data sources (e.g. single portal with one way transmission versus two way transmission, etc). These data-capture levels enable individuals and agencies responsible for clinical registries to easily navigate the Australian architecture and standards developed by the National e-Health Transition Authority (NeHTA)[2]. Furthermore, the recommended technical standards cover identity management, secure access controls, secure messaging, use of standard terminologies and data specifications (e.g. compliant with national and international electronic heath data dictionaries and standards), and the need for data storage and transmission features that comply with all relevant legislation and guidelines. Presently, very few registries in Australia have national coverage[4]. Further information about AuSCR is available online at http://www.auscr.com.au.

PARTNERSHIPS AND COLLABORATIONS

The AuSCR initiative is led by a consortium of two leading academic research institutes: the National Stroke Research Institute (NSRI), a subsidiary organisation of the Florey Neuroscience Institutes, and The George Institute for Global Health (TGI) of The University of Sydney and Royal Prince Alfred Hospital; and two leading non-government organisations: the National Stroke Foundation (NSF) and the Stroke Society of Australasia (SSA). These organisations provide a broad representation of the Australian clinical and scientific stroke community. Significant sanction from clinicians and professional associations for the AuSCR initiative has occurred through the Australian Stroke Coalition (ASC), a network of clinicians and professional associations (http://www.strokefoundation.com.au/asc) and various State-wide Stroke Clinical Networks.

In 2010, we collaborated with the NHMRC as part of their Harmonisation of Multi-Centre Ethical Review (HoMER) trust-building pilot (see http://www.nhmrc.gov.au/health-ethics/harmonisation-multi-centre-ethical-review-homer) as a method for testing the options for ethical clearance to roll-out AuSCR in more hospitals efficiently. AuSCR was one of only two projects to complete the pilot for NHMRC. We were able to contribute valuable feedback on the existing challenges and burdens when seeking ethical review nationally, when undertaking large-scale, multi-centre research projects. Specifically, the HoMER pilot was used to evaluate the acceptability of a single National Lead Committee's ethical approval of the AuSCR project at hospitals where it is usually required to have a separate full ethical review. AuSCR nominated nine new ethics committees to the NHMRC: two withdrew from the HoMER process and seven participated and provided important feedback to the NHMRC. Participation in the HoMER trust-building pilot had mutual benefits since it provided important information to the NHMRC; facilitated the roll-out of AuSCR to a larger network of hospitals than potentially would have been otherwise possible during 2010; and, importantly, placed the issues faced by all national registry projects on the ethical review agenda of the NHMRC.

GOVERNANCE STRUCTURE

Accountability and transparency are cornerstones for governance of a clinical registry program. This is particularly important when the dataset contains private and personal identifying information. At completion of the pilot phase for AuSCR in 2009, the original Steering Committee was dissolved and a new Steering Committee convened in early 2010. The purpose of this Steering Committee is outlined in agreed Terms of Reference and has a primary role in providing AuSCR governance, maintaining the confidence of all parties involved, and providing contributions to strategic direction. The committee has representatives from each state in Australia, as well as representation from clinicians, health informatics, epidemiology, consumers, the President of the SSA, and the Chair of the Management Committee. The Chair of the Steering Committee is a senior clinician-researcher in the area of stroke who is independent of the AuSCR consortium and operations. Steering Committee was chaired in 2010 by Professor Sandy Middleton. The Steering Committee membership is listed in Appendix A. Membership is currently for a 24 month period.

The Management Committee includes representatives from the consortium partner organisations and remained the same in 2010 as for the pilot phase. All members of the Management Committee have clinical backgrounds in medicine, nursing or allied health. The Management Committee is responsible for the day-to-day operation of AuSCR, with oversight from the Steering Committee.

For 2010, the Management Committee membership was as follows:

Professor Craig Anderson	Chair, The George Institute for Global Health
Professor Geoffrey Donnan	National Stroke Research Institute
A/Professor Dominique Cadilhac	National Stroke Research Institute
Dr Natasha Lannin	Rehabilitation Studies Unit
Professor Chris Levi	Hunter Medical Research Institute
A/Professor Steven Faux	St Vincent's Hospital, Sydney
Mr Chris Price	National Stroke Foundation

METHODOLOGY

AuSCR has been designed to include a database program that enables the collection of a standardised dataset that can be used to describe and compare stroke practices within and between hospitals (see box below). The AuSCR Web Portal is available to contributing hospitals (via www.auscr.com.au) and is where clinical staff, who have user access privileges, can view and download standard performance reports. The basic premise of data collection is that hospital staff enter data on all eligible patients either manually or using a data import process. AuSCR Office staff are responsible for contacting patients who are discharged from the participating hospitals 90+ days after stroke and who have not refused follow-up or 'opted-out' of the registry. AuSCR Office staff also provide a 5 day helpdesk, remote training for new hospital staff, and undertake quality control assessments to ensure hospital data are reliably obtained (see below).

Box 1. AuSCR minimum variable dataset

<table>
<tr><td>

Identifying information
- date of birth
- gender
- address
- telephone number
- hospital name
- contact details for next of kin (x 2) & general practitioner

Clinical information for risk adjustment and measuring timeliness of care delivery:
- ICD10 codes (diagnosis, medical condition, complications and procedures)
- country of birth
- language spoken
- aboriginal and Torres Strait Islander status
- type of stroke
- date & time of stroke onset
- date & time arrive emergency department
- date of admission and in-patient stroke status
- transferred from another hospital status
- ability to walk independently on admission
- first-ever (incident) event status

</td><td>

Process indicators of evidence based care
- 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 (any documentation in the medical record)

Hospital outcomes data
- date of discharge or
- date of death
- discharge destination

3-month Outcome data
- survivor status
- place of residence
- living alone status
- recurrent stroke event since discharge
- readmission to hospital
- quality of life (EuroQoL5D adults PedsQL children up to 18 years old)

</td></tr>
</table>

METHODS FOR ENSURING DATA QUALITY

Data quality in AuSCR is assessed weekly whereby data exports are conducted and missing data reports sent to hospitals by AuSCR Office Staff. The online web-tool has built-in logic checks and variable limits to prevent inaccurate data being entered. Mandatory fields have also been created to reduce missing data, since incomplete fields prevent progress to the next section of the web-tool. In-built functions within the database are also used to identify duplicate entries and multiple patient records, which may be merged if necessary (for example, if a patient has a recurrent stroke within the first three months of their primary registered event).

Each new site is also subjected to a 10% random audit of medical records conducted by the AuSCR Office staff after the first 50 patients are entered in the registry. Following the audit, the site is given a data quality report and discusses ways of improving data quality with AuSCR Office staff (this may also include additional training or AuSCR making amendments to data dictionary items which are ambiguous). At the end of each year, hospitals are requested to provide a list of all ICD10 stroke codes to enable a process of assessing case ascertainment by matching this list to the data in AuSCR. This process also permits missing data for ICD10 codes to be obtained.

OUTLIER HOSPITAL MANAGEMENT PLAN

A statistical methodology for detecting 'outliers' has been adopted for AuSCR to explore issues where a greater than expected mortality and morbidity is found at a participating hospital when adjustment for differences in patient case-mix has been made (see Quality Assurance Data Management Processes policy available at www.auscr.com.au). In brief, 'outliers' and 'exceptions' in the AuSCR occur when analysis of data highlights variability in care that falls outside two standard deviations of the average value for a quality of care indicator or health outcome measure. If non-parametric analyses are

warranted, then 'outliers' will comprise results that fall outside the interquartile range for median values when adjustment for case-mix has been made. In the event that an outlier is identified, the AuSCR Management Committee commences liaison with the hospital lead investigator to discuss reasons why these results may be occurring. This process is detailed in the AuSCR Outlier Communication Plan (www.auscr.com.au). Given the early stages of this registry, we have not undertaken individual hospital comparisons for this report, since we need to ensure that case ascertainment is at an adequate level in each site that has provided a full year of data.

IMPROVEMENTS TO THE REGISTRY IN 2010

Feedback on the perceived utility of AuSCR has been obtained since its inception. Both quantitative and qualitative methods of evaluation were used and provided evidence of areas to improve the registry. The Management Committee reviewed all information and worked with AuSCR Office staff to prioritise modifications to processes, documents, and the web-tool given the available resources for the project. An updated version of the database was uploaded in October 2010 incorporating many of the suggested improvements.

Web-Tool improvements included:

- Modification of the database was undertaken to enable alpha numeric medical record numbers to be entered.

- Automation of saving the patient address was initiated from previously having to click the 'Add' button after entering address details. Previously, this step was often missed and addresses were not saved. Similar changes for the emergency and alternate contact addresses were also made.

- The 'Individual Healthcare Identifier' was masked out from the New Patient screen because this was not currently being used and was potentially confusing for site staff.

- Expansion of the Primary Diagnosis ICD 10 code variable to allow entry of other numbers since the original list was inadequate, especially in circumstances of in-patient stroke where the primary diagnosis may be a range of conditions.

- Addition of "Add" and "Delete" buttons to Medical Condition, Complications and Procedure variables with free text format to capture any conditions or predisposing factors.

Other changes to Registry processes and documents included:

- Minor modification of the paper based hospital data collection form, such as enlarging of the boxes for writing and removing the asterisk (*) in the "Telephone" field.

- The change of the follow-up method to *all postal follow up*. One comprehensive phone follow-up is undertaken only if no responses are received following three postal attempts (using each contact provided). This decision was based on a structured evaluation that was presented during a planning day held by the Management Committee with several members of the Steering Committee. Previously, eligible registrants were randomly allocated to receive either a telephone follow-up or a postal questionnaire at 90+ days after stroke. Following review of the follow-up methods using data from 559 registrants, it was determined that AuSCR follow up by

postal questionnaire resulted in an equivalent response rate to a telephone interview. However, postal questionnaires were significantly slower to achieve completion, but less expensive to provide per completed questionnaire. The data from this nested evaluation are being submitted for publication in the peer-reviewed literature.

- An updated Data Dictionary and communication to all users of the new version changes.

- Amendments to ethics to obtain a 'waiver of consent' for patients who are deceased while in hospital or who are deemed by hospital staff to be incapable of understanding written information and who do not have a next of kin or person responsible who is able to receive the information about the AuSCR registry. In 2010, this change to consent was approved by the lead HRECs in Victoria, Queensland and New South Wales.

2010 DATA ANALYSIS METHODS

The data presented in this annual report include all patients who were registered in the AuSCR database and admitted to the participating hospitals between *1 January 2010 and 31 December, 2010*. Data entry for 2010 acute stroke/TIA episodes and follow-up assessments were closed on 31 May 2011. The dataset used for the analyses presented in the following sections was extracted from the AuSCR database on 3 June, 2011.

Statistic analyses were performed using SAS 9.2 by Jun Hata, a Visiting Research Fellow at The George Institute for Global Health. These analyses were performed under the direction of Dominique Cadilhac and Natasha Lannin, the AuSCR Senior Research Fellows, and were principally based on the data format presented in the 2009 Annual Report.

In the initial raw data extracted on 3/6/2011, there were 1870 episodes. For the purpose of data cleaning, we checked duplicate data by the patients' identifiers (name, date of birth, Medicare number or hospital medical record number) and date of stroke onset, arrival, admission or discharge. Then, 6 episodes with duplicate data were deleted from the dataset. Thirty-five episodes which had been registered between 1/5/2011 and 3/6/2011 were deleted from the SAS dataset, because these episodes were created after we started the inquiries for missing data at these hospitals. One registrant was admitted to 2 participating hospitals for the same stroke episode. These data were kept in the SAS dataset, but the second episode was omitted from the statistical analyses. Therefore, the final 2010 dataset reported in this document includes information on 1829 admissions from 1828 stroke episodes.

Findings from data collected in 2010

Hospitals

In 2010, 12 hospitals provided data for AuSCR. This is a 100% increase when compared with the number who contributed data in 2009 (n=6). Figure 1 shows the incremental shift in numbers of hospitals participating in AuSCR by month in 2010.
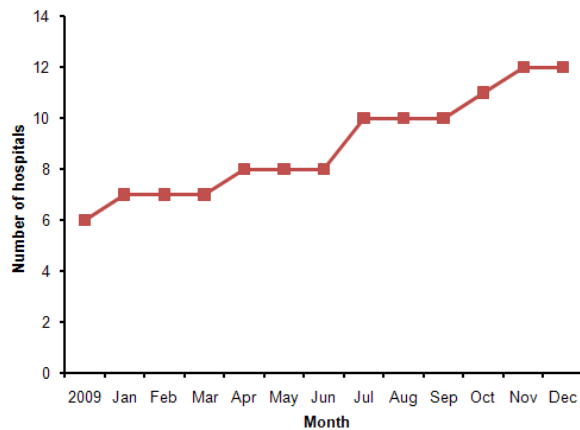
Figure 1: Number of participating hospitals in 2010

The characteristics of the twelve participating hospitals are shown in Table 1 according to state. There were five hospitals located in New South Wales (NSW), three in Queensland (QLD), two in Victoria (VIC), and two in Western Australia (WA). There were six hospitals that had 100 or more registrations of stroke/TIA patients during 2010. There were 10 hospitals located in metropolitan areas; 10 hospitals that had stroke units, and nine hospitals provided thrombolytic therapy using tissue plasminogen activator (tPA). Two of the 12 hospitals were private hospitals, and one hospital was a Children's Hospital.

Table 1: Characteristics of participating hospitals

States	2009 Total	2010 Total	VIC	QLD	WA	NSW
Number of hospitals	6	12	2	3	2	5
Annual number of patients in AuSCR*						
Low (<33 episodes)	-	1	1	-	-	-
Medium (33-99 episodes)	1	5	-	2	-	3
High (≥100 episodes)	5	6	1	1	2	2
Location						
Metropolitan	6	10	2	3	2	3
Rural	-	2	-	-	-	2
Stroke unit	6	10	1	3	2	4
tPA undertaken	6	9	1	2	2	4

Hospital categories as per the definitions used in Registry of the Canadian Stroke Network
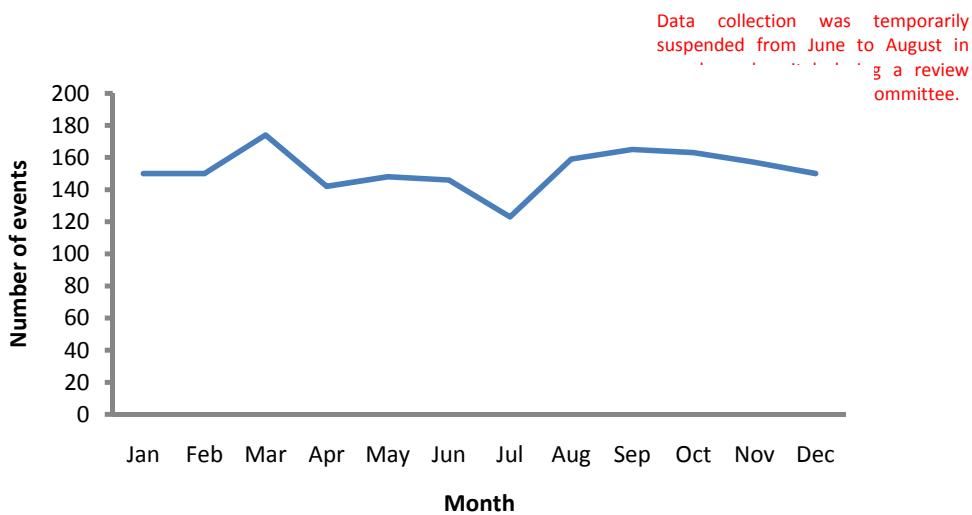
Number of registrants

In 2010, there were 1788 patients registered in AuSCR (Table 2). During a calendar year, patients may also have had multiple admissions to the same hospital for different stroke/TIA episodes which were then eligible to be recorded as different episodes. In 2010, there were 1828 episodes of acute hospital care entered in AuSCR for the 1788 individuals registered. Thirty seven patients (2%) had multiple episodes in 2010 (34 had two episodes and three had three episodes). Multiple episodes were captured from eight hospitals which had also provided the majority of data (n=1667 episodes combined). The minimum number of patients registered was 6 at The Royal Children's Hospital (Melbourne) and the maximum was 508 from Austin Health. The median number of registrants was 93 (interquartile range [IQR], 46 to 229).

Table 2: Number of hospitals, patients and episodes in 2010

Number of hospitals contributing data	12
Number of episodes submitted	1828
Number of patients	1788
Number and % of readmissions	37 (2%)

Cases registered per month

Figure 2 shows the number of episodes (including multiple episodes) per month. The median number was 150 per month. The minimum was 123 in July and the maximum was 174 in March. The low participation seen between June and August corresponds with a period of non-participation by a large hospital participating in the registry. Participation was temporarily suspended during a hospital/HREC review of the procedure for providing information about the AuSCR project to families of patients who die in hospital. Once a waiver of consent for including acute data only about this group of patients was obtained, participation recommenced (September 2010).

Data collection was temporarily suspended from June to August in a large hospital during a review committee.

Figure 2: Number of episodes per month in 2010

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

Among the 1788 patients, the median number of days from the admission to the creation of patient record in AuSCR was 64 days (IQR 15 to 128 days). The shortest median number of days according to hospital was four days, and the largest median number of days was 184 days. However, these data at a hospital level may be influenced by several factors such as numbers of cases registered, as well as the method of data capture and entry.

CASES WHO NOMINATED TO 'OPT-OUT' OF AuSCR

Registrants are informed by hospital staff that they are able to 'Opt-out' some or all of their data from the AuSCR web-tool (e.g. personal identifying information) (see Appendix B). Opt-out requests were received by the AuSCR Office staff from registered patients or relatives on receipt of an opt-out form; telephone call to the 1800 telephone number; email to the AuSCR generic email; or by hospital staff who used the opt-out function in the AuSCR database. As part of record management, AuSCR Office staff also keeps a record of each opt-out to supplement information in the AuSCR database.

During 2010, 115 opt-out requests were received from hospital staff or patients. The total number of opt-out requests varied by hospitals and ranged from 1 to 50. Hospitals with high opt-out rates (>n=10) were contacted to determine if the opt-out process was being used appropriately; whether greater staff training was required in the explanation of the registry; or if there were any project improvements necessary. The main information that was opted-out included removing personal identifying details, such as address.

The AuSCR Data Administrator monitors and provides the final approval of all opt-out requests. Within the AuSCR web-tool the ability to 'opt-out' data is ultimately determined by a Superuser (administrator) confirmation prior to final deletion of the requested data. This process is undertaken by AuSCR Office on a fortnightly basis. Further information about the 'Opt-out' process in AuSCR is available in the Hospital User Manual (http://www.auscr.com.au/health-professionals/forms-manuals/hospital-user-manual/).

Data Completeness

Table 3 provides a summary of the completeness of hospital collected data for the majority of fields within the registry for the 1828 episodes from 1788 patients in 2010. These figures represent the proportion of data completeness for applicable cases only, since not all variables are relevant to every patient (such as use of intravenous thrombolysis or t-PA). Opted-out data were excluded from the denominators.

Table 3: Completeness of fields in the AuSCR database

Field	2009 % complete	2010 n (% complete)
Person details (n=1788)		
First name	100%	1775/1775 (100%)
Surname	100%	1775/1775 (100%)
Date of birth	100%	1778/1778 (100%)
Medicare number	67%	1595/1776 (90%)
Patient contact (n=1788)		
Available (complete or partial for street address, suburb and state)	95%	1757/1778 (99%)
Complete (street address, suburb and state)	97%	967/1774 (55%)
Telephone for patient (landline or mobile)	90%	1708/1774 (96%)
Emergency and alternate contacts (n=1788)		
Address for one or both of emergency and alternate contacts	71%	831/1774 (47%)
Address for one contact	62%	709/1774 (40%)
Address for both contacts	10%	122/1774 (7%)
Telephone for emergency and/or alternate contact (landline or mobile)	92%	1664/1774 (94%)
General practitioner contacts (n=1788)		
Address	73%	808/1774 (46%)
Telephone for general practitioner (landline or mobile)	75%	1254/1774 (71%)
Patient characteristics (n=1788)		
Title	99%	1732/1780 (97%)
Hospital medical record number	100%	1787/1788 (100%)
Gender	99%	1744/1780 (98%)
Country of birth	92%	1749/1781 (98%)
Language spoken	97%	1501/1781 (84%)
Indigenous status	100%	1778/1782 (100%)
Interpreter needed	100%	1503/1781 (84%)
Episode data (including multiple episodes) (n=1828)		
Date of arrival	100%	1818/1827 (100%)
Time of arrival	100%	1814/1827 (99%)
Date of stroke onset	100%	1825/1827 (100%)
Date of admission	100%	1827/1827 (100%)
Transfer from another hospital	100%	1823/1827 (100%)
Stroke occurs while in hospital	100%	1812/1827 (99%)
Able to walk independently on admission	100%	1738/1827 (95%)
Documented evidence of a previous stroke	100%	1789/1827 (98%)
Treated in a stroke unit	100%	1803/1827 (99%)
Type of stroke	100%	1824/1827 (100%)
Use of intravenous thrombolysis (if ischaemic stroke)	99.7%	1155/1175 (98%)
Cause of stroke	100%	1820/1827 (100%)
ICD10 coding (including multiple episodes) (n=1828)*		
Diagnosis code	63%	1182/1827 (65%)
Medical conditions	-	220
Complications	1	65
Procedures	6	7

Discharge information (including multiple episodes) (n=1828)		
Deceased status	100%	1827/1827 (100%)
Date of death (if deceased status is yes)	100%	214/ 215 (100%)
Date of discharge (if not deceased while in hospital)	87%	1622/1674 (97%)
Discharge destination (if not deceased while in hospital)	87%	1627/1674 (97%)
Discharge on antihypertensive agent (if not deceased while in hospital)	87%	1538/1674 (92%)
Evidence of care plan on discharge (if not deceased while in hospital)	87%	1518/1674 (91%)

*Note that not every patient will have other medical conditions, complications and procedures coded therefore it is unclear what the denominator will be.

In 2010, the % of complete data varied when compared with 2009 pilot data. It was reassuring that the main quality indicators and discharge information were completed consistently above 95%, and there was an improvement in the proportion of ICD10 information obtained. Areas where there appeared to be a problem included less complete address details for emergency/alternate contacts. Feedback we obtained about these issues was mainly related to the time to enter demographic data and the fact that these are often not mandatory fields; and these data are not always available (e.g. information for alternate contacts). These results may also be partly explained by a number of technical issues e.g. clinical staff forgetting to click the 'add' button for patient address). Subsequently, we have made changes to the web-tool to ensure address details are automatically saved when entered manually.

These results highlight the need to put resources into getting a greater uptake of the import function for demographic variables which should improve data quality and compliance with these variables. However, resources both in AuSCR and the hospital will be needed for this to happen. This is because Patient Administration Systems, from which the data need to be extracted, vary across the country and a single solution is not possible. Although the hospital clinical staff are committed to AuSCR, establishment of data importing processes also requires resources from hospital information technology services.

Completeness of case ascertainment

To evaluate the completeness of case ascertainment, we asked each participating hospital to send us the hospital record of patients who were admitted to the hospital during 2010 with ICD10 codes of stroke/TIA (i.e. G45.9, I61.0-I61.9, I62.9, I63.0-I63.9 and I64). Among 12 participating hospitals, 6 hospitals sent us their hospital records and among these 6 hospitals, 2 hospitals had participated for a full year (Table 4). Hospital records were then matched to the AuSCR database to detect "potentially missing" episodes of stroke/TIA. The lists of potentially missing episodes were sent to the hospitals and we inquired whether these episodes had been actually missed in the database or there was another explanation (e.g. Patient who did not admit to the hospital; Episode which was not acute stroke/TIA in this admission).

Table 4 shows the number of episodes which were registered (A) or missed (B) in the AuSCR database. Completeness of case ascertainment was defined as A/(A+B)x100 (%).

Table 4: Summary of the case ascertainment

Hospital	Episodes in the database (n)	Episodes missed in the database (n)	Completeness
1*†	279	Not available	
2†	115	Not available	
3*†	321	204	61%
4†	185	Not available	
5*†	531	107	83%
6	71	41	63%
7	35	13	73%
8	123	36	77%
9†	49	Not available	
10	69	Not available	
11	6	Not available	
12	44	9	83%

Patients who opted out of participation in AuSCR do not appear in the above table.

*These 3 hospitals use the data import functions. Among 204 missing episodes in Hospital No.3, 56 were missed because the medical records were not available, 136 episodes were missed because data collection was on hold from June to August in this hospital. Among 107 missing episodes at Hospital No.5, 99 were missed because they were not referred to the stroke unit team or managed on the Stroke Unit ward.

†These 6 hospitals had participated in AuSCR for a full year.

Registrant characteristics

Table 5 shows the baseline characteristics in adult patients or episodes. Therefore, 6 patients from the children's hospital were excluded from the following analyses.

Among the 1782 patients, the most common country of birth was Australia (65%) followed by the United Kingdom and Italy. The remainder were from a range of mainly European or Asian nations. There were 30 patients (2%) identified as having an Aboriginal or Torres Strait islander background. The majority of the registered patients spoke English (89%). The registrants comprised 44% females and the mean age was 72 years. There were 201 patients (11%) aged less than 55 years and 270 patients (15%) aged between 55 and 64 years.

Among the 1822 episodes, there were 1169 ischaemic strokes, 248 intracerebral haemorrhage (ICH), 344 TIAs, and 57 episodes of undetermined type. The proportion of stroke events, according to the clinician-based classification of stroke subtype for all episodes and first registered episodes are provided in Figure 3. Stroke subtype according to gender and age is presented in Figure 4. Among the 1822 episodes, in 695 (40%) episodes the patient was able to walk at the time of admission.

Table 5: Baseline characteristics

Patients (n=1782)	
Age, mean (SD)	72 (14)
Gender, female, n (%)	770/1738 (44%)
Country of birth, n (%)	
Australia	1141/1743 (65%)
United Kingdom	147/1743 (8%)
Italy	97/1743 (6%)
Other European countries	199/1743 (11%)
Asia	94/1743 (5%)
Others	65/1743 (4%)
Aboriginal and/or Torres Strait Islander, n (%)	30/1772 (2%)
English spoken, n (%)	1326/1495 (89%)
Episodes (including multiple episodes) (n=1822)	
Type of stroke, n (%)	
Ischaemic	1169/1818 (64%)
Haemorrhagic	248/1818 (14%)
TIA	344/1818 (19%)
Undetermined	57/1818 (3%)
Able to walk on admission, n (%)	695/1732 (40%)
Length of hospital admission (days), median (IQR)	7 (4 to 13)
Treated in a stroke unit, n (%)	1425/1797 (79%)
Cause of stroke known, n (%)	880/1814 (49%)
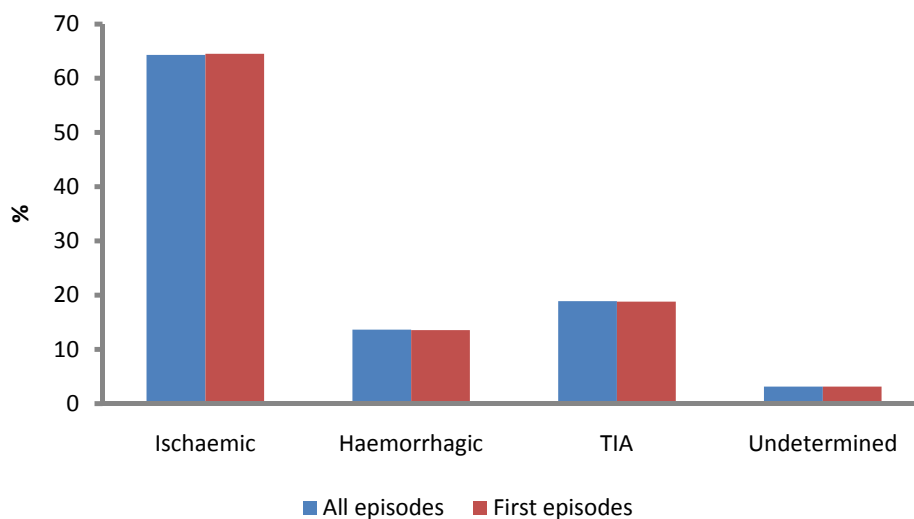
Figure 3: Distribution of stroke subtypes in all and the first episodes
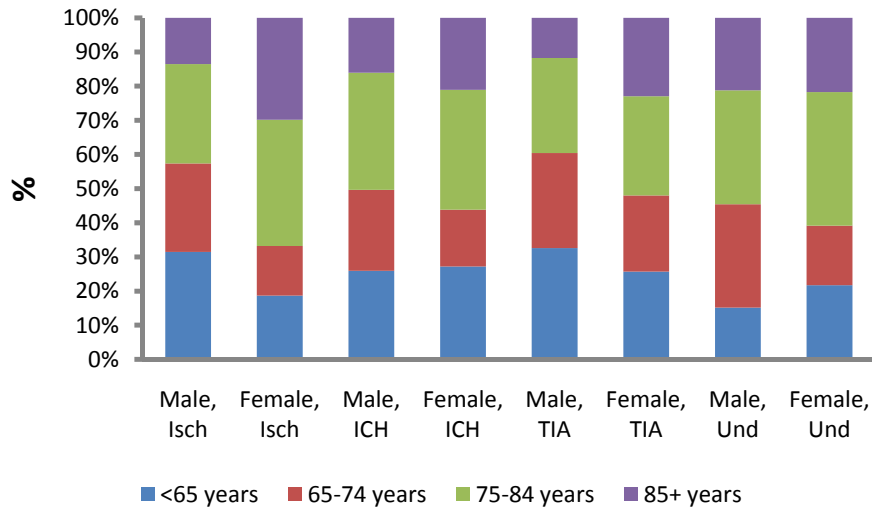
Figure 4: Distribution of stroke subtypes by sex and age groups (including multiple episodes)

Processes of hospital care

Among the 1822 episodes, there were 292 episodes (16%) transferred from another hospital. There were 80 episodes (4%) that experienced a stroke while already in hospital for another condition. The majority of the inpatient strokes were ischaemic (n=62) and most of these occurred among patients aged between 75 and 84 years. The median length of stay was longer for patients that had a stroke while already in hospital (inpatient median 14 days [IQR 7 to 26 days] vs. median 7 days [4 to 12 days] for non-inpatient stroke admissions, p<0.001).

## Overall adherence to quality indicators

Adherence to the process of care indicators collected in AuSCR is outlined in Table 6. Most patients registered in AuSCR were treated in a stroke unit and few received a care plan at time of discharge.

**Table 6: Stroke evaluation and therapy (including multiple episodes)**

Hospital Stroke Care	All episodes	Ischemic	TIA
Patients admitted to a stroke unit	1425/1797 (79%)	978/1148 (85%)	243/342 (71%)
Patients who received intravenous thrombolysis if an ischaemic stroke (tPA)		112/1149 (10%)	
Patients discharged (if not deceased while in hospital)	1668/1821 (92%)	1077/1169 (92%)	344/344 (100%)
Patients discharged on an antihypertensive agent (if not deceased while in hospital)	1225/1532 (80%)	787/978 (80%)	261/325 (80%)
Patients who received a care plan at discharge (if not deceased while in hospital)	460/1512 (30%)	303/977 (31%)	114/308 (37%)

There was a statistically significant difference for the age of patients admitted to stroke units among the hospitals (mean age if managed on a SU 72 years (SD 14) and non-SU mean age 74 years (SD 15)(p=0.003) (Figure 5). In addition, there were more ischaemic stroke patients treated in a stroke unit than the other types of stroke (p<0.001) (Figure 6).
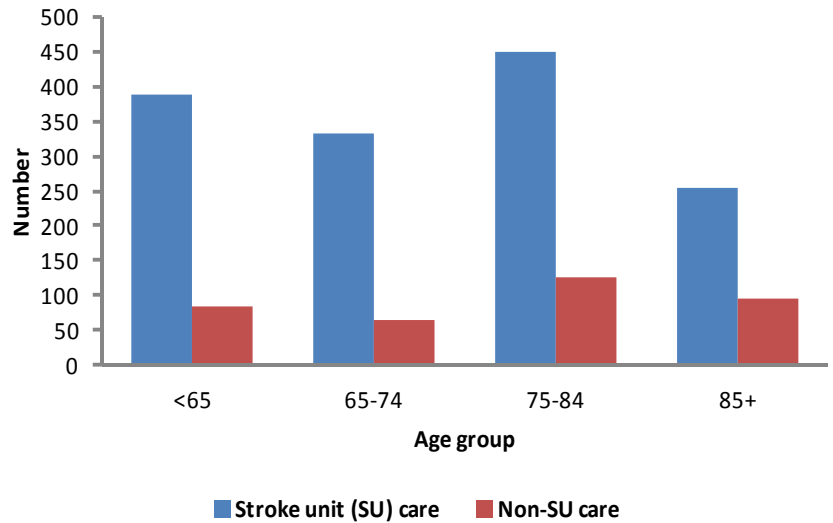
Figure 5: Management in a stroke unit according to age group (including multiple episodes)
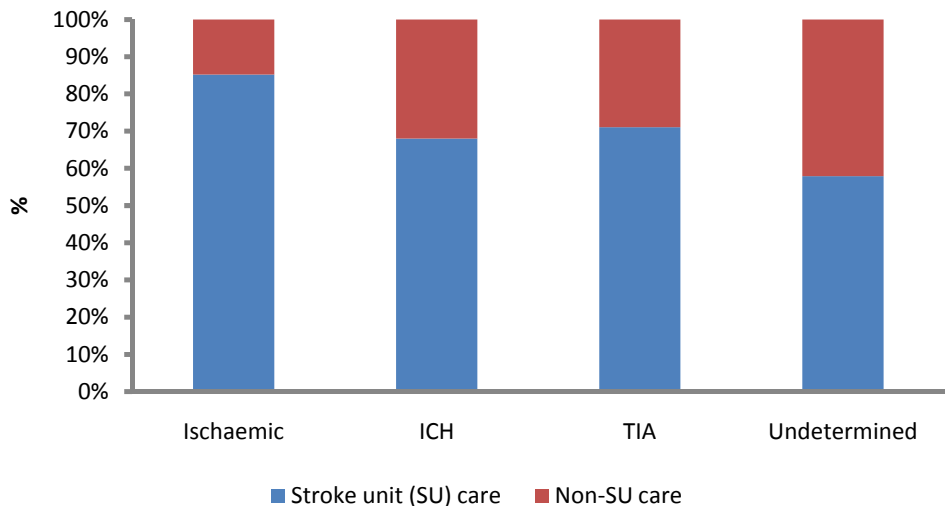
Figure 6: Management in a stroke unit according to stroke subtype (including multiple episodes)

Patients admitted with transient ischaemic attack

Among the 344 episodes of TIA, the mean age was 72 years (SD 13 years) and 44% were female. No patient with TIA was reported to have died while in hospital. The median length of stay was 4 days (IQR 2 to 6 days). Of those who were discharged, 37% received a care plan and 80% were discharge on an antihypertensive agent (Table 6). Most patients (89%, n=211) were discharged to a home setting and 3% (n=11) went to rehabilitation.

Discharge information

Hospital outcome measures include length of stay, discharge destination and discharge status. When the data for an individual person are segregated across two hospitals for the same stroke event, the discharge information is reported from the first hospital providing care. Unless otherwise stated, the data presented in this section relates to the hospital that provided the initial care.

Length of stay

The median length of stay was 7 days (IQR 4 to 13 days). In the 2010 sample, 13% (n=222) of episodes had a length of stay of 21 days or more. There was no statistically significant difference between the length of stay for episodes treated in stroke units (median 5 days, IQR 1 to 10 days) and those not treated in stroke units (median 5 days, IQR 1 to 10 days) (p=0.26).

Discharge status

In 2010, the majority of registered patients were discharged directly to a home environment (n=789; 48%) (Figure 7). Patients managed in a stroke unit had a 2.7 fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed on a stroke unit (95% confidence interval [CI] 1.9 to 3.8) when adjusted for age, gender, presence of ischaemic stroke, ability to walk on admission, whether an inpatient stroke or if transferred from another hospital.

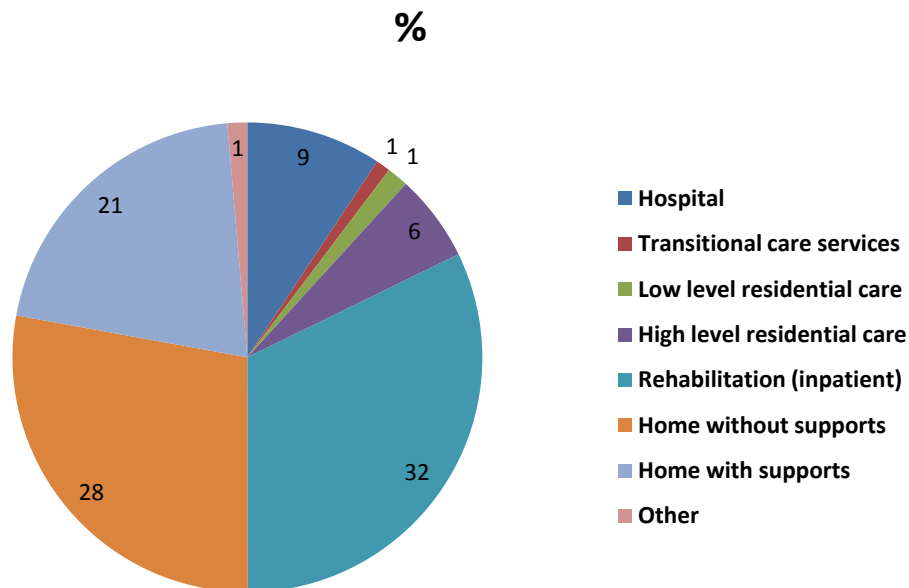Those who died while in hospital were excluded from this analysis.

%

Figure 7: Discharge status including multiple episodes (excludes patients who died in hospital) n=1621

Deaths

Among 1782 patients, 150 (8%) patients died during hospitalisation. Within 90 days of admission to hospital, a further 52 (3%) patients died, resulting in a total of 202 deaths within 90 days of admission (11%). There was no significant sex differences in case fatality during hospitalisation (p=0.82) and in total case fatality at 3 months (p=0.44) after adjustment for age.
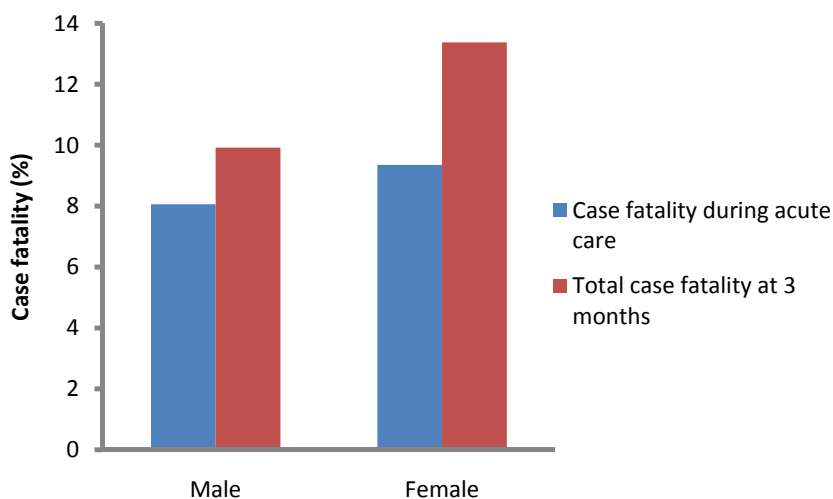

**Figure 8: Case fatality (the 1st episode only) n=1782**

Post-Discharge Health Outcome Information

The AuSCR protocol is to obtain follow up data for all registered cases discharged from hospital between 3 to 6 months after stroke onset. Each individual person is only followed-up once based on their first registered episode of care. No follow-up occurs after 180 days post stroke onset.

Median time to Follow-up

There were 1828 episodes registered in 2010. Since 40 cases were readmitted in this same year, 1788 registrants were eligible for follow-up. After excluding 61 registrants who refused follow-up assessments, 194 who died in hospital, and 2 registrants who had insufficient details in the database, we initiated the follow-up survey for 1531 registrants. Among these eligible registrants, 53 refused or opted-out from the follow-up assessments, 405 were not followed-up because they were uploaded into the system late[1] and were beyond the 180 day limit; and 60 registrants (including 3 children) were lost to follow-up. As of 31 May 2011, follow-up was completed in 973 registrants and, in 40 registrants, the follow-up was 'in-progress' and not complete at the time we closed the dataset for this annual report (Figure 9).

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[1] When data importing functions were initiated at one large hospital a backlog of data were imported several months after patients were discharged.
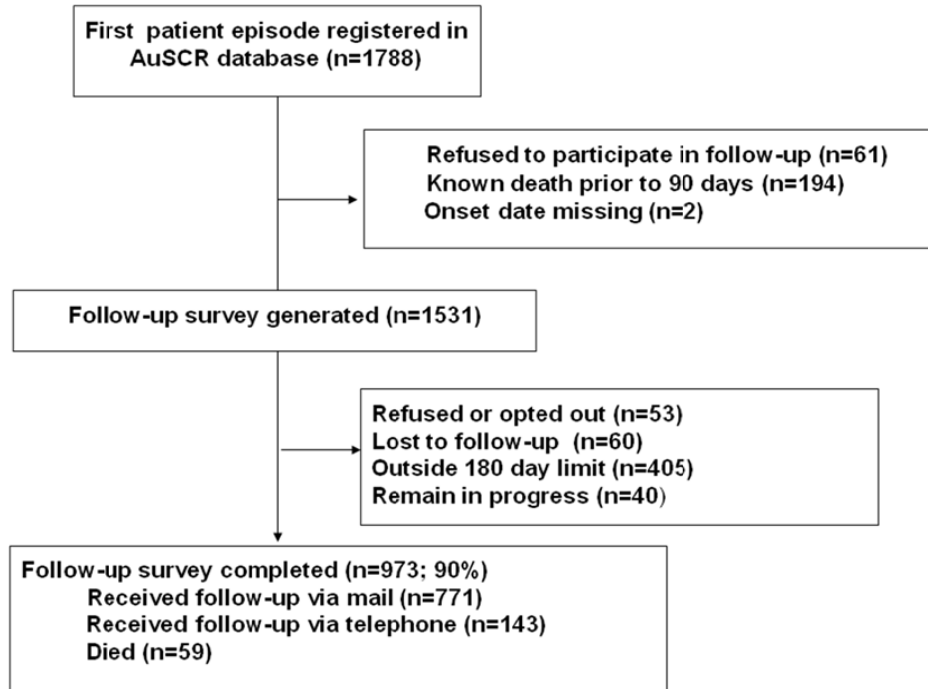
Figure 9: Flow diagram of the follow-up assessments for patients admitted in 2010

Characteristics of the 973 registrants who completed follow-up assessments are summarised in Table 7. The mean age was 72 years and 43% were female; 66% of them had ischemic stroke. This information is consistent with the entire registrant baseline sample characteristics presented in Table 7.

Table 7: Baseline characteristics for 973 registrants with complete follow-up and 809 registrants without follow-up data

	Patients with complete follow-up (n=973)	Patients without follow-up data (n=809)	p value
Age (years), mean (SD)	72 (14)	72 (15)	0.55
Gender, female, n (%)	408/951 (43%)	362/787 (46%)	0.20
Aboriginal and/or Torres Strait Islander, n (%)	11/972 (1%)	19/800 (2%)	0.04
Type of stroke, n (%)			0.003
Ischaemic	639/971 (66%)	508/807 (63%)	
Haemorrhagic	108/971 (11%)	133/807 (16%)	
TIA	198/971 (20%)	136/807 (17%)	
Undetermined	26/971 (3%)	30/807 (4%)	
Able to walk on admission, n (%)	429/918 (47%)	257/775 (33%)	<0.001
Length of hospital admission (days), median (IQR)	7 (4 to 12)	7 (4 to 14)	0.20
Treated in a stroke unit, n (%)	788/965 (82%)	599 (76%)	0.002

Survival

Among the 973 registrants who participated in the follow-up, 59 (6%) had died after discharge from hospital. There were 914 (94%) registrants who were able to answer all or some of the questions. The main follow-up results are summarised in Table 8.

Table 8: Follow-up survey results

Since discharge	n/N
Registrants who died	59/973 (6%)
Registrants who answered all questions	848/973 (87%)
Registrants who answered some questions	66/973 (7%)
Registrants who had another stroke	66/898 (7%)
Registrants who were readmitted to hospital	180/899 (20%)
Reasons for readmission was a stroke/cardiovascular cause	69/180 (38%)
Location of stroke survivor at time of follow-up interview	
In hospital	12/908 (1%)
Transitional care service	7/908 (0.8%)
Receiving hostel care	23/908 (3%)
High level care (nursing home)	74/908 (8%)
Inpatient rehabilitation	21/908 (2%)
Living at home without support	421/908 (46%)
Living at home with support	305/908 (34%)
Other place	45/908 (5%)
Living alone	188/893 (21%)

Readmissions

There were 180 registrants (20%) that reported that they were readmitted to hospital and 69 (38%) of these were reported to be readmission related to a stroke/cardiovascular cause (Table 8).

Quality of life

In AuSCR, we measure health-related quality of life using the EQ-5D instrument. The EQ-5D™ is a standardised instrument for use as a measure of health outcome (see http://www.euroqol.org/). It provides a simple descriptive profile across 5 dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Each of these profiles is divided into three levels: no problems (1), some or moderate problems (2), and extreme problems (3). In addition, the EQ-5D provides a single index value for health status using a visual analogue scale. Possible scores span a scale from 0%, to 100%. An EQ-5D index score of zero corresponds to a health-related quality of life state that is all but death, while a score of 100% would represent perfect quality of life.

Based on the various dimensions of the EQ-5D questionnaire, more than half of the respondents reported problems in self care and anxiety/depression (Table 9). The summary score for overall HR-QoL was well below the normal population measure for people aged 70 to 79 years (Figure 10).

EQ-5D dimensions		
Mobility	No problems (Level 1)	439/907 (48%)
	Problems (Levels 2 & 3)	469/907 (52%)
Self care	No problems (Level 1)	587/909 (65%)
	Problems (Levels 2 & 3)	322/909 (35%)
Usual Activities	No problems (Level 1)	360/906 (40%)
	Problems (Levels 2 & 3)	546/906 (60%)
Pain/Discomfort	No problems (Level 1)	440/903 (49%)
	Problems (Levels 2 & 3)	463/903 (51%)
Anxiety/Depression	No problems (Level 1)	467/901(52%)
	Problems (Levels 2 & 3)	434/901 (48%)
Visual Analogue Scale (0 – 100)		
Mean (SD)		59 (30)
Median (IQR)		70 (40 to 80)

Table 9: Quality of life assessment
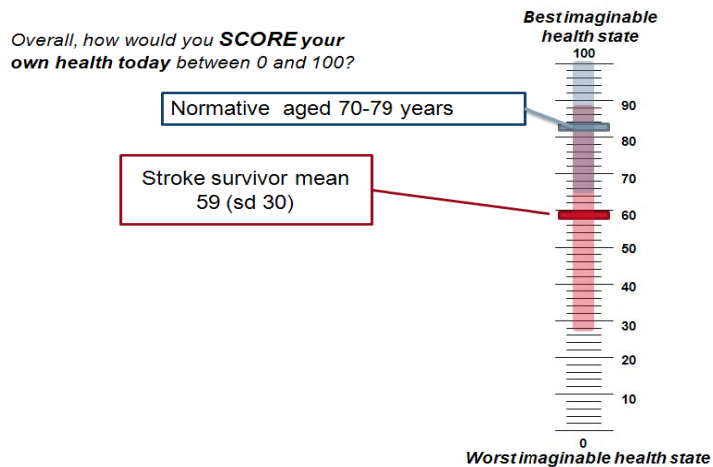
Figure 10: Summary of visual analogue scale responses for 2010 AuSCR registrants

Willingness to participate in future research

Of the 844 respondents who answered whether they would be willing to participate in future research, 511 registrants (65%) would be willing to participate in future research.

DISCUSSION

In 2010, AuSCR has continued to be used, evaluated and improved as an important national tool for measuring the quality of hospital care in stroke. The availability of reliable data on processes of care and outcomes is essential for improving clinical practice and providing feedback on temporal trends in patterns of care. The American Heart Association (AHA) has emphasised the importance of well-designed clinical registry programs in providing an important mechanism to monitor patterns of care, evaluate healthcare effectiveness and safety, and improve clinical outcomes[5]. For the first time in Australia, AuSCR provides a national system for collecting prospective quality of care data with community outcome information for stroke and TIA. In the second year of operation, the number of hospitals doubled and, for the first time, data importing was established in three hospitals. In addition, the improvements to the web-tool, policies and procedures including the data dictionary were made and follow-up of registrants was streamlined.

REPRESENTATIVENESS OF DATA

Data from individual hospitals was not meaningful to present in this second annual report. The benefits of the aggregated data provide evidence of the scope of information that can be reported from the AuSCR minimum dataset. The findings reported also allow us to gauge whether data collected in 2010 is representative of other stroke cohorts. This is important since case ascertainment at the hospitals varied and most hospitals that participate have a stroke unit. Therefore, the AuSCR hospitals may not be representative of all hospitals providing stroke care.

Since our registry has aligned our variables with the NSF audit, it is appropriate to compare our data with the results from this audit. The last published collection of information from the NSF acute services audit was reported for 2009[6]. Among 3,307 cases that were audited from 96 hospitals the median age was 77 (IQR 66 to 84), 53% were male, and 76% had an ischaemic stroke. In addition, 31% were able to walk independently on admission[6]. Our 2010 cohort appears to be younger with slightly more males and less severe stroke at time of admission (median age was 75 years[2] [IQR 64 to 83 years]; 56% male and 79% ischaemic stroke if TIA excluded from the denominator; 40% able to walk on admission). The proportion of patients managed on a stroke unit was 74% in the NSF audit compared with 79% in AuSCR. One explanation is that the NSF does not include patients with TIA who will have less severe stroke and may be younger, and children are also not included in the audit. Another explanation is that the AuSCR hospitals have a different proportional representation of SU hospitals compared to the 96 hospitals that participated in the 2009 NSF audit (AuSCR 83% compared with 63% NSF audit). Exploration of the AuSCR data in relation to TIA patients reveals that in the 2009-2010 sample, fewer TIA patients were likely to be admitted to a stroke unit than the patients with ischaemic stroke (TIA care on an stroke unit 72% compared with ischaemic stroke 85%)[7]. Our results may also possibly reflect that fact that improvements to case-ascertainment in the hospitals needs to continue as the registry matures. There were 80 episodes (4%) that experienced a stroke while already in hospital for another condition. It is likely that the proportion of in-patient strokes is underestimated. This is because we have determined from the case-ascertainment review that the clinical staff have not always realised that they needed to obtain these data from patients who may not be managed on their wards or referred to their

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[2] Data on age from children is excluded and 1 case where age information was not provided.

stroke service team. Establishing processes to captures these patients at a local hospital level will be a challenge going forward.

FUTURE DIRECTIONS

At a national level, clinical registry development should be prioritised to target conditions or procedures that are suspected of being associated with large variations in processes or outcomes of care and that impact significantly on health care costs and patient morbidity[4]. Given constrained resources for AuSCR with no on-going recurrent funding, future roll-out and modifications are based on pragmatic decisions and opportunities. These are outlined below.

ON-GOING HOSPITAL RECRUITMENT IN 2011

The majority of hospitals who nominate to participate in AuSCR have done so on an individual basis. The roll-out of AuSCR continued during 2010 and 2011, and was dependent on the resources within the interested hospitals and the approval of the local site Research Governance Office. The AuSCR Office has steadily been able to increase participation in AuSCR to 16 hospitals as of September 2011, and there are a further 7 hospitals and 1 lead ethics committee approvals pending. In most cases, these processes have been facilitated by provision of a self-directed site specific ethics application kit and the availability of remote hospital staff training by AuSCR Office.

Following presentation of AuSCR initiative to the Queensland Stroke Clinical Network in November 2009, much interest in using this registry was shown by this clinical network. Queensland hospitals currently collect stroke data using Teleforms, which only permit quality of care reporting on a quarterly basis. The ability to have 'live' reporting and a follow-up component, as provided with AuSCR, was considered very attractive. However, several key performance measures would need to be added as a separate Queensland specific data-spine. Subsequently, this clinical network obtained consensus from their members to fully participate in AuSCR from November 2010. A submission to Queensland Health to fund the development of the Queensland sub-set of variables was approved in February 2011. The Queensland Single Multicentre HREC was submitted and approved in February 2011. The variables to be included were agreed in April 2011 and signed off in July 2011. This clinical network is currently working with the AuSCR Project coordinator to facilitate the implementation of AuSCR as a State-wide initiative. A Tasmanian lead ethics application has been submitted and following approval, roll out to interested hospitals in Tasmania will be commenced.

ENSURING COMPLETE CASE ASCERTAINMENT FROM PARTICIPATING HOSPITALS

Case ascertainment was analysed for the first time at the close of the 2010 data collection period. These results have provided AuSCR with both important data and challenges. The newly established processes will be improved further for the 2011 reporting year, with consideration being currently given to having a quarterly case ascertainment review period, which would reduce the workload for larger hospitals and reduce the number of missed cases. The need for AuSCR Office to develop a companion document to assist hospitals to complete case ascertainment data collection was also identified, and the suggestion was posed that we include case ascertainment procedures in mandatory training for all new hospitals on commencement.

The most significant issue highlighted during the case ascertainment analysis process was that date of admission is currently used by AuSCR Office to identify missing cases; however hospital medical records

produce all reports based on date of discharge. Therefore, cases admitted at the end of 2010 but discharged in 2011 would not appear in a hospital report. Hospitals also reported difficulty in obtaining the report in the format requested by AuSCR because of a lack of resources in their hospital medical records department. This issue highlights the importance of sufficient AuSCR Office resourcing (time and availability) to reformat case ascertainment data contained in hospital reports to permit data extraction.

TECHNOLOGY SOLUTIONS FOR SIMPLIFYING DATA COLLECTION FOR CLINICIANS

During 2010, further enhancements were made to the database following user feedback. Responsiveness to user-requests and minimal downtime of the AuSCR online web-tool has been the main factors in supporting users. Current improvement plans underway include the need to provide faster search speed; a view of patient name and MRN in the episode screen; and an ability to view the total number of patients for the participating hospital in the search screen.

Potentially the most significant technology solution for simplifying data collection for clinicians was the availability of an import function within the web-tool. The import function is a solution to reduce manual entry of demographic information already held in the hospital's Patient Administration System. This function needs to be more widely used by participating hospitals. Currently, three hospitals have been able to establish monthly importing processes for AuSCR; and the feedback on the benefits in reducing data-entry time and greater case-ascertainment have been significant. The challenges faced in implementing the import function are primarily because of the need for hospital-based resourcing to a) program a report filter for appropriate patients; and b) transform the extracted data from the local Patient Administrative System into the AuSCR Excel template at the respective hospital.

Another potential future development is data linkage to hospital data held by Health Departments. A pilot study was commenced in 2011 to explore the feasibility and benefits of linking AuSCR and Health Department data. Pilot linked data from Victoria has shown >90% linkage success at the patient-level and ability to verify AuSCR cases. In the Victorian pilot, linkage to health department data with 789 patients registered in 2010 from 1 AuSCR site gave data on 4,819 occasions of service.

PLAN TO HARMONISE THE NSF AUDIT PROCESS WITH AuSCR

Considerable progress has been made in the development of datasets and validation of clinical performance indicators over the last decade. The Australian stroke community has recognised the importance of data collection in improving quality of care, and monitoring variations in care. Multiple, unlinked data collection processes leads to duplication of effort, inability to benchmark, poor use of resources, and indicators that may be poorly developed and not linked to evidence-based care (Figure 11). Since the AuSCR and NSF audit have overlapping variables, but use different systems of data collection there has been ongoing discussion in 2010 and 2011 with a view to bringing these two important national quality initiatives for stroke together, via a process of harmonisation.

The NSF stroke audit, undertaken every 2 years, uses retrospective patient case note audit to measure adherence to the NHMRC endorsed Clinical Guidelines for Stroke Care. Participating hospitals audit 40 consecutive patient case notes, as well as completing an organisational survey about available resources that support the provision of evidence-based stroke care. Since its inception in 2007, more than 6,000 cases of acute care have been audited and the audit will be repeated in 2011 in 113 hospitals, with an additional 29 hospitals completing the organisational survey only. Supplementary data collected through a registry, which acts as a data spine, can answer questions around more complex care longitudinally[2][4]. Harmonising such complementary data collection systems and processes, and

establishing reliable linkage of data, can ensure the greatest return for the effort expended in obtaining those data. A planning workshop to explore the progression of these activities with the main objective to develop agreement on how to implement a national approach to data collection and quality improvement in stroke will be held, in conjunction with the Stroke Society of Australasia 2011 Annual Scientific Meeting in Adelaide.
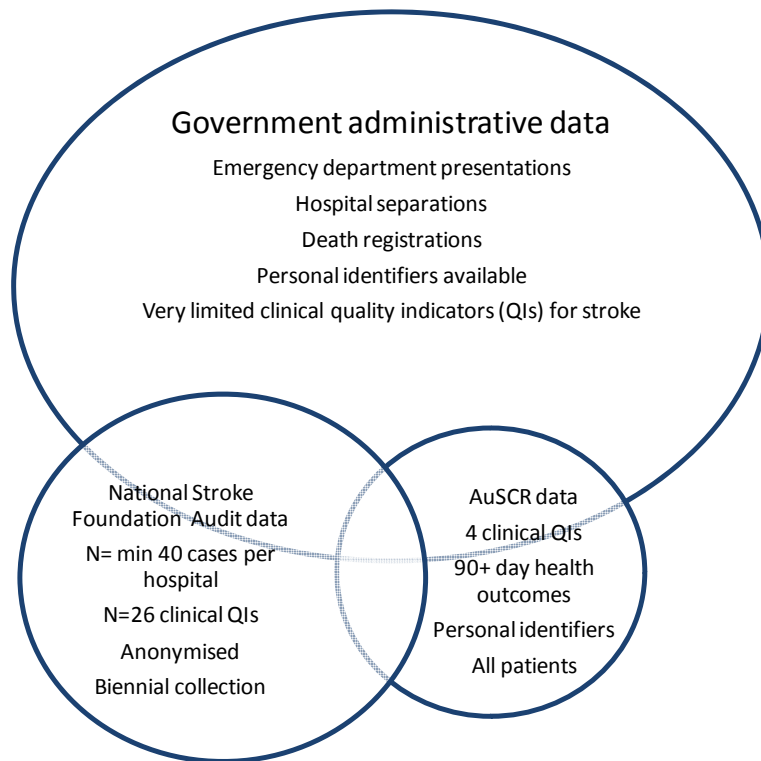
Figure 11. Summary of available national data for stroke

CONCLUDING COMMENTS

Australia is developing a national performance framework aimed at measuring health outcomes across the health system[4]. AuSCR is one of the few registries that can conform to this national framework agenda. This is because AuSCR has been designed to national standards and there is the future potential for establishing data linkage with other clinical registries or datasets, for example Cardiac, Rehabilitation and Ambulance registries. Such future capacity for data linkage will allow even more comprehensive assessments of the health service system for stroke. The added value will be that more sources of data will be available without increasing the burden of data collection at the clinical interface. Although the technology and logistical implications remain unclear, the recognised benefits of being able to have agreed, nationally comparable patient-level data linked and harmonised will provide greater capacity to answer a range of research, policy and clinical practice problems efficiently for Australia and within each of the jurisdictions. The current acceptable infrastructure and willingness to have better data in the field of stroke supports our on-going efforts to continue to refine and establish AuSCR. Identifying an adequate and reliable funding base remains critical to the sustainability and effectiveness of the AuSCR.

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APPENDIX A

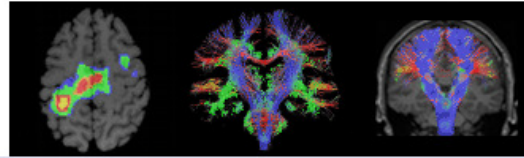| Name	Position	Organisation	State
Steering Committee Membership 2010			
Prof Sandy Middleton	AuSCR Steering Committee, Chair Director, Nursing Research Institute Director, National Centre for Clinical Outcomes Research (NaCCOR), Nursing and Midwifery, Australia Australian Catholic University.	St Vincent and Mater Health Sydney Australian Catholic University	NSW
Prof Craig Anderson	Director, Neurological & Mental Health Division Professor of Stroke Medicine and Clinical Neuroscience NMHRC Senior Principal Research Fellow	The George Institute for Global Health Affiliated with Royal Prince Alfred Hospital and The University of Sydney	NSW
A/Prof Julie Bernhardt	Director AVERT, Very Early Rehabilitation Research Program	National Stroke Research Institute	VIC
Mr Paul Bew	Allied Health Clinical Leader Member of QLD Statewide Stroke Clinical Network	Brighton Sub Acute Services Eventide Facility, Brighton	QLD
Mr Greg Cadigan	Principal Project Officer Statewide Stroke Clinical Network	Patient Safety and Quality Improvement Service Centre for Healthcare Improvement Queensland Health	QLD
Prof Chris Bladin	Director, Eastern Melbourne Neurosciences Chairman, Division of Medicine Chair, DHS, Victorian Stroke Clinical Network Committee	Box Hill Hospital, (Monash University),	VIC
Prof Geoff Donnan	Director, Florey Neuroscience Institutes Director, National Stroke Research Institute Professor of Neurology, University of Melbourne	Florey Neuroscience Institutes	VIC
Dr Helen Castley	Neurologist Chairman, Tasmania Stroke Unit Network	Head of Stroke Unit Royal Hobart Hospital	TAS
Dr Mark Mackay	Paediatric Neurologist	Melbourne Children's Clinic The Royal Children's Hospital Melbourne	VIC
Dr Erin Lalor	Chief Executive Officer	National Stroke Foundation	VIC
Dr Andrew Lee	Neurologist NHMRC - NICS Fellow Neurologist Stroke Physician	Flinders Comprehensive Stroke Centre Flinders Medical Centre	SA
Ms Sandra Martyn	Director Statistical Standards	Health Statistics Centre Queensland Health	QLD

Steering Committee Membership 2010 (continued)			
Name	Position	Organisation	State
Prof John McNeil	Head, Department of Epidemiology and Preventive Medicine	Monash University	VIC
Dr Michael Pollack	Director, Rehabilitation Medicine Chairman, Hunter Stroke Service Chairman, GMCT NSW	John Hunter Hospital	NSW
Mr Mark Simcocks	Consumer Representative	Self employed	VIC
Ms Frances Simmonds	Manager, Australasian Rehabilitation Outcomes Centre (AROC)	Centre for Health Service Development University of Wollongong	NSW
A/Prof Amanda Thrift	President, Stroke Society of Australia NHMRC Senior Research Fellow Head, Stroke Epidemiology Adjunct Associate Professor, Monash University	Stroke Society of Australia Baker IDI Heart and Diabetes Institute	VIC

APPENDIX B EXAMPLE OF OPT-OUT HOSPITAL SCREEN IN AuSCR

Comments:

Select All ☐   Do not contact for follow-up ☐

☐ First Name	☐ Last Name	☐ Date of Birth	☐ Medicare No	☐ Title
☐ Gender	☐ Phone Number	☐ Mobile Number	☐ Aboriginal/Torres St. Islander	☐ Country of Birth
☐ Language Spoken	☐ Interpreter Needed			
☐ Address/Mailing Address	☐ Address/Address Type	☐ Address/Street Address	☐ Address/Suburb	☐ Address/State
☐ Address/Postcode	☐ Address/Country			
☐ Contacts/First Name	☐ Contacts/Last Name	☐ Contacts/Phone Number	☐ Contacts/Mobile Number	☐ Contacts/Relationship
☐ Contacts/Address Type	☐ Contacts/Address	☐ Contacts/Suburb	☐ Contacts/State	☐ Contacts/Postcode
☐ Contacts/Country				
☐ Date of arrival to emergency department	☐ Time of arrival to emergency department	☐ Onset of stroke date	☐ Onset of stroke time	☐ Date of admission to hospital
☐ Was the patient transferred from another hospital?	☐ Did this stroke occur while the patient was in hospital?	☐ Was the patient able to walk independently on admission?	☐ Is there documented evidence of a previous stroke?	☐ Was the patient treated in a Stroke Unit at any time during their stay?
☐ Type of stroke	☐ Did the patient receive Intravenous Thrombolysis?	☐ Cause of stroke		
☐ ICD10 code - Diagnosis	☐ ICD10 code - Medical Condition	☐ ICD10 code - Complications	☐ ICD10 code - Procedures	
☐ Date of discharge known	☐ Date of discharge	☐ Discharge destination/mode	☐ Discharge on Antihypertensive agent	☐ Is there evidence that a care plan outlining post discharge care
☐ Deceased	☐ Date of death			

Save   Cancel