Annual Report 2011

AuSCR

Australian Stroke Clinical Registry

29 August 2012

This publication has been produced on behalf of the Australian Stroke Clinical Registry Consortium partners and has been approved by the AuSCR Steering Committee.

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Report No: 3
August 2012

Consortium partners:

CONTENTS

SUMMARY

In 2011:

- Sixteen (16) hospitals contributed data to AuSCR.
- The final 2011 data reported in this document includes information on 2519 patients and 2593 acute stroke/TIA episodes.
- Following close off of the data for 2011 annual reporting (31 May 2011) there were 1215 of 1393 eligible registrants (87%) who provided follow-up data.
- AuSCR received a single, lead multicentre HREC approval for all hospitals in Queensland to contribute acute data to AuSCR.
- AuSCR participated in the Harmonisation of Multicentre Ethical Reviews (HoMER) pilot project for NHMRC, providing a first-opportunity to test expedited ethical review with lead ethical committees in non-randomised controlled trial projects. Within this HoMER project, three hospitals in Victoria accepted previously approved applications (lead committee approval) and required only local approval to participate in AuSCR, significantly reducing the time requirements for obtaining ethical approval for the AuSCR Office.
- The AuSCR Steering Committee approved a finalised Queensland sub-set of variables which is to be included as part of the AuSCR data-spine for Queensland hospitals to enable comparisons with previously collected performance data in that state. The Queensland sub-set will be released for use in 2012.
- AuSCR Research Task Group received their first requests for data linkage or access to the AuSCR database from external research groups, providing the first opportunity to test the Data Access Policy. In 2011, projects were approved using a template application form that was trialled. AuSCR was invited to participate in the Australian Commission of Quality and Safety in Health Care, Towards National Arrangements for Australian Clinical Quality Registries project for the Australian Health Ministers Advisory Council (AHMAC). Furthermore, representatives of the AuSCR Management Committee were invited to contribute to a committee to provide feedback on the Australian Safety and Quality Goals for Health Care.

ABOUT THE COLLABORATING ORGANISATIONS

The AuSCR initiative is undertaken by a consortium of two leading academic research institutes: the National Stroke Research Institute, a subsidiary organisation of The Florey Institute of Neuroscience and Mental Health, 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 stroke community.

PUBLICATIONS

Publications in peer-reviewed journals based substantially on data from AuSCR and released during the period of data covered by this report (2011) are listed below:

Lannin N, Cadilhac D, Anderson C, Lim J, Price C, Faux S, Levi C, Donnan G (2011). Community follow-up of stroke survivors in the Australian Stroke Clinical Registry (AuSCR). [ABSTRACT O53] *International Journal of Stroke* 6(Supplement 1): 17.

Cadilhac D, Lannin N, Anderson C, Kilkenny M, Lim J, Levi C, Price C, Faux S, Donnan G (2011). Australian Stroke Clinical Registry: management and outcome of patients with transient ischaemic attack (TIA) [ABSTRACT P10] *International Journal of Stroke* 6(Supplement 1): 37.

Cadilhac DA, Lannin NA, Anderson CS, Levi CR, Price C, Faux S, Donnan GA (2011). Management and outcome of patients admitted with transient ischaemic attack (TIA): the Australian Stroke Clinical Registry experience [ABSTRACT]. Cerebrovascular Diseases 31(Supplement 2): 266-267.

Annual Report Publication

Cadilhac D, Lannin N, Anderson C, Levi C, Faux S, Price C, Hata J, Lim J, Donnan G, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2010. The George Institute for Global Health and National Stroke Research Institute; September 2011 Report number 2; pages 38.

PUBLIC PRESENTATIONS (INVITED OR PEER REVIEWED)

In 2011, the following presentations about the Australian Stroke Clinical Registry were given:

Anderson C on behalf of the AuSCR Management Committee (2011). Acute care of stroke in indigenous populations in Australia. CSANZ Indigenous Cardiovascular Health Conference, Alice Springs, Australia, June 2011.

Anderson C on behalf of the AuSCR Management Committee (2011). Indigenous strokes. Statewide Stroke Clinical Network Forum, Townsville, Australia, November 2011.

Cadilhac D on behalf of the AuSCR Management Committee (2011). The Australian Stroke Clinical Registry: progress and future directions. Presentation to Southern Clinical School, Monash University, November 2011.

Cadilhac D on behalf of the AuSCR Management Committee. The Australian Stroke Clinical Registry: harmonisation potential and data linkage. National Stroke Data and Quality Improvement meeting, Adelaide, 13 September 2011.

Cadilhac DA behalf of the AuSCR Consortium Partners. Management and outcome of patients admitted with transient ischaemic attack - the Australian Stroke Clinical Registry experience. European Stroke Conference, Hamburg, Germany, May 2011. [POSTER]

Cadilhac D on behalf of the AuSCR Management Committee (2011). Life after stroke: community follow-up of Australian survivors of stroke. Smartstrokes 7th Australasian Nursing and Allied Health Stroke Conference, Surfers Paradise, August 2011.

Cadilhac D on behalf of the AuSCR Management Committee (2011). The Australian Stroke Clinical Registry: the first year of implementation. Heart Foundation National Conference, March 2011.

Cadilhac D on behalf of the AuSCR Management Committee (2011). The Australian Stroke Clinical Registry: progress and future directions. National Heart Foundation Melbourne Office staff, The University of Melbourne, September 2011.

Lannin N on behalf of the AuSCR Management Committee (2011). Life After Stroke: Community Follow-up of Australian survivors of Stroke. Stroke Society of Australasia Annual Scientific Meeting, Adelaide, September 2011.

Lim J on behalf of the AuSCR Management Committee (2011). Australian Stroke Clinical Registry in Queensland. Queensland Stroke Clinical Network Forum, November 2011.

Price C, Cadilhac D, Lannin N, Anderson C on behalf of the AuSCR Management Committee. Briefing paper. National Stroke Data and Quality Improvement meeting, Adelaide, 13th September 2011.

ACKNOWLEDGMENTS

We gratefully acknowledge contributions made by AuSCR staff - Joyce Lim, Jun Hata, Sabrina Small and Tiffany Schneider. We appreciate the contributions from The George Institute Information Technology and Data Management team in supporting the AuSCR maintenance and processes.

We thank the Stroke Society of Australasia who provided an unrestricted educational grant for this project during 2011.

We are grateful to the National Stroke Foundation for the compilation and mail out of AuSCR follow-up questionnaires.

During 2011, Dominique Cadilhac was supported by a National Health and Medical Research Council (NHMRC)/National Heart Foundation Australian-based Public Health Research Fellowship, and Natasha Lannin was supported by a Balnaves Fellowship from The Cerebral Palsy Institute.

This report would not have been possible without the efforts of doctors, nurses, ward clerks and data collectors who have contributed data to the AuSCR. Lead clinical staff for AuSCR at our participating hospitals are gratefully acknowledged:

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Susan Day
Elizabeth O’Brien
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Renee Hull
Genevieve Skinner
Meaghan Osborne
Carolyn De Wytt
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Noel Saines
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Diane Fichera

Victoria
Helen Dewey
Jamie Zanon
Kristen Rowe
Mark Mackay
Belinda Stojanovski
Chris Bladin
Jacqueline Venditti
Zofia Ross
Patrick Groot
Ernie Butler
Margaret Stevenson

Western Australia
David Blacker
Christine Gear
Jeannine Alford
Naanke Noordzy

CHAIRPERSON'S REPORT: STEERING COMMITTEE

In 2010, a new Steering Committee was convened for a 24 months term, until the end of 2011. The purpose of this Steering Committee is to oversee AuSCR governance, maintain the confidence of all parties involved, and to provide strategic direction. The committee consisted of several previous members from the initial Steering Committee, but we also welcomed several new members (Appendix A). The 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. In 2011 the Steering Committee met twice by teleconference, and an annual, final meeting face-to-face combined Management and Steering Committee meeting was held in September, conducted in conjunction with the Stroke Society of Australasia's Annual Scientific Meeting in Adelaide.

In review, the Steering Committee achieved the following in 2011:

- Provided support and oversight on the activities of the registry through the Management Committee;
- Reviewed and implemented the Data Custodianship policy for the data custodianship change, planned for 2012;
- Supported the development of the business case for future funding;
- Provided advice and sign off on the second AuSCR Annual Report (2010).

The Steering Committee acknowledges the excellent achievements of AuSCR in 2011, particularly in the 2010 Annual Report, with the first year of 12 months data and case ascertainment, acknowledgement as the top performer in the HoMER trust-building pilot, an initiative of the National Health and Medical Research Council (NHMRC) and the invitation to participate in the Commission of Quality and Safety in Health Care, Towards National Arrangements for Australian Clinical Quality Registries project for the Australian Health Ministers Advisory Council (AHMAC). Excitingly, we also have had interest from academics seeking to link our dataset with their research.

AuSCR continues to grow as a valuable asset to the stroke community. We thank all our partners and participating clinicians for their interest and generous support.

Professor Sandy Middleton

CHAIRPERSON'S REPORT: MANAGEMENT COMMITTEE

In 2011, AuSCR continued to maintain processes related to data collection and follow-up of patients associated with participating hospitals, whilst also expanding the network so that by the end of the year, 20 hospitals were participating in AuSCR across the nation.

Achievement highlights of 2011 include:

- Steady increase in the number of hospitals participating in AuSCR;
- Use of self-directed ethics committee application package to be used by sites in different states for site specific ethics applications;
- Approval from Queensland Health for development of additional variables specifically for that state to facilitate transfer from their current manual paper-based scanning data collection to the direct internet-based data collection system of AuSCR;
- Single multicentre ethics committee approvals obtained in Queensland, New South Wales, Victoria and Tasmania;
- Completion of an internal data quality audit for hospitals who participated during 2009 and 2010;
- Two requests for data access and linkage to AuSCR data, reviewed and approved by the independent Research Task Group.

The day-to-day operations continued with the routine data cleaning, regular desk audits and quality evaluation throughout the year, whilst coping with several staff changes at various sites, and financial constraints.

In addition, there was recognition of the good operating principles implemented into the running of AuSCR. This was seen in the various calls and invitations from external private and government bodies requesting information and learning from AuSCR. Boston Consulting, in particular, highlighted AuSCR as a high quality model disease register internationally.

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.

Importantly, the enormous work effort and commitment of the AuSCR team and the consortium partners to support the Management Committee in the operational responsibility for the project, has allowed solid progress to be made in AuSCR. Subsequently, it is well positioned to provide a platform for monitoring stroke care and outcomes in clinical networks and health care sectors. AuSCR also provides an opportunity for future research and evaluation.

AuSCR continues to provide a tool for hospitals to collect and use their own data, as an important evidence base for quality improvement in acute stroke care.

Professor Craig Anderson

FUNDING 2011

In 2011, the AuSCR office was supported by surplus funds carried over from the previous year, in kind support from consortium partners including the National Stroke Foundation (NSF) and restricted research grants. Support for senior researchers by the NHMRC who provide salary via Fellowship awards has assisted with containing staff costs. Further, additional substantial savings to AuSCR Office in staff resources has been made possible because the NSF has taken on the responsibility of compiling and mailing the AuSCR follow-up questionnaires as a major contribution to the project.

ORGANISATION	AMOUNT
Stroke Society of Australasia	$20,000
The George Institute for Global Health	$40,000
Allergan Australia	$15,000
Ipsen	$5,000
Queensland Health	$35,000
Total Funding received	**$115,000**

INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) has great pleasure in presenting its 2011 Annual Report. This is the 3rd annual report from the registry and covers data collected from the 1st of January 2011 until the 31st of December 2011.

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 ischaemic 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 is minimised. To achieve this, AuSCR includes an ‘opt-out’ consent protocol whereby all eligible cases are registered 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). 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. Presently, each hospital has access to their own data and summary ‘live’ reports which the staff can download from AuSCR to enable regular quality of care reviews.

In this 2011 Annual Report, we provide information using data collected from contributing hospitals and the outcomes of registered patients 90+ days after stroke.

BACKGROUND

The purpose of clinical quality registries is 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 policies 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. AuSCR continues to strive towards collecting these data on all eligible cases from all eligible settings so that our annual reporting is able to include risk (case-mix) adjusted outcome analyses - these data will not, however, be available in the current (2011) report. Presently, very few registries in Australia have national coverage[4], however this remains our goal.

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], and it is on these technical standards that AuSCR was developed. 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. Further information about AuSCR and its development 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 George Institute for Global Health (TGI), affiliated with The University of Sydney, and the National Stroke Research Institute (NSRI), a subsidiary organisation of the Florey Institute for Neuroscience and Mental Health; 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 AuSCR Consortium partners and the Australian Stroke Coalition (ASC), a network of clinicians and professional associations (http://www.strokefoundation.com.au/asc), as well as the various state-wide Stroke Clinical Networks.

In 2011, we commenced discussions with Queensland Health to create new core variables within the AuSCR database for Queensland-based hospitals. This was because Queensland Health was interested in transitioning from their current manual collection methods to the AuSCR database and wanted to be able to make reliable historical comparisons with their current minimum dataset of quality performance measures. In addition, another advantage of using AuSCR across Queensland hospitals was the ability to provide hospitals with ready access to live summary data on-demand. Ethical clearance for the Queensland data sub-set was received in February 2011 and work has been ongoing with the Patient Safety and Quality Improvement Service – Statewide Stroke Clinical Network to develop and test the

Queensland sub-set for implementation. Only Queensland hospitals can access the additional data page in the database.

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. On completion of the pilot phase for AuSCR in 2009, the original Steering Committee was dissolved and a new Steering Committee convened in early 2010 for a period of 2 years. Therefore the committee remained the same in 2011. 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. The Steering Committee was chaired in 2011 by Professor Sandy Middleton (membership is listed in Appendix A).

The Management Committee includes representatives from the consortium partner organisations and remained the same in 2011 from 2010. 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, and working with AuSCR Office to manage day-to-day registry work. For 2011, the Management Committee membership was as follows:

Chair: Professor Craig Anderson	The George Institute for Global Health
Membership:	
A/Professor Dominique Cadilhac	National Stroke Research Institute, The Florey Institute of Neuroscience and Mental Health
Professor Geoffrey Donnan	National Stroke Research Institute, The Florey Institute of Neuroscience and Mental Health
A/Professor Steven Faux	St Vincent's Hospital, Sydney
A/Professor Natasha Lannin	La Trobe University and Alfred Health
Professor Chris Levi	Hunter Medical Research Institute
Mr Chris Price	National Stroke Foundation

Research Task Group

The Research Task Group is independent of the AuSCR Management Committee. The primary purpose of this Research Task Group is to ensure appropriate use of the Australian Stroke Clinical Registry data and ensure the protection of privileged personal data located on the registry. In 2011, the first applications to use AuSCR data were received. 2011 members of the Research Task Group were:

Chair:

Dr Sue Evans, Department of Epidemiology and Preventative Medicine, Monash University

Membership:

Professor Richard Lindley, The George Institute for Global Health
Professor Ian Cameron, Rehabilitation Studies Unit, The University of Sydney
Dr Coralie English, University of South Australia

Professor Leeanne Carey, National Stroke Research Institute, The Florey Institute of Neuroscience and Mental Health
Professor John McNeil, Department of Epidemiology and Preventive Medicine, Monash University
A/Professor Velandai Srikanth, Southern Clinical School, Monash Medical Centre, Monash University

METHODOLOGY

AuSCR has been designed to include an online database that enables the collection of a standardised dataset that can be used to describe and compare stroke care and outcomes within and between hospitals (Box 1). The AuSCR database 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 for any specified date range.

Hospital staff from participating hospitals enter data on all eligible patients either manually via the web-tool or using a data import process. AuSCR Office staff, with the assistance of the National Stroke Foundation, 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.

AuSCR is based on an “opt-out” consent model, whereby patients are distributed information outlining the nature and purpose of the information collected, offered an opportunity to view that data and ask questions, and given the various options available to request withdrawal of part or all of their data. This approach is explicitly suggested for registries by the Privacy Commissioner in his “Guidelines for the Health Sector” (www.privacy.gov.au/materials/types/guidelines/view/6517). To this end, AuSCR Office has provided to all participating hospitals a patient information sheet for each hospital to use (or a locally modified version to meet ethics committee requirements) to inform patients. At the time of data collection, each hospital is asked to comply with the conditions of the ethical approval and relevant privacy guidelines for the project.

Box 1. AuSCR minimum variable dataset

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 of arrival to emergency department
- date of admission and in-patient stroke status
- transferred from another hospital status
- ability to walk independently on admission
- first-ever (incident) episode status

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 episodes since discharge
- readmission to hospital
- quality of life (EuroQoL5D adults/ PedsQoL children up to 18 years old)

METHODS FOR ENSURING DATA QUALITY

In 2011, data quality in AuSCR was assessed monthly and missing data reports are sent to hospitals by AuSCR Office Staff bi-monthly. The online AuSCR database has built-in logic checks and variable limits to prevent inaccurate data being entered. Mandatory fields have also been created to reduce missing data. 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 episode).

Each new site is also subjected to a 10% random audit of medical records conducted by the AuSCR Office staff after about the first 50 patients are entered in the registry. Following the audit, the site is given a data quality report and ways of improving data quality are discussed 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 in AuSCR for ICD10 codes to be obtained.

IMPROVEMENTS TO THE REGISTRY IN 2011

Feedback on the perceived utility of AuSCR has been obtained on an ongoing basis 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 under the direction of the Project Coordinator (Ms Joyce Lim) to prioritise modifications to processes, documents, and the database given the available resources for the project. Date of database modification release during 2011 was 7th November 2011.

Improvements to the registry in 2011 included:

- Addition of Name, Medical Record Number and Date of Birth at the top of the episode screen, to assist when entering a new episode or editing the episode;
- Update of the ABS language and country codes;
- Hiding the “Individual Patient Identifier” to reduce confusion for the user;
- Change to the variable “GP mobile number” to “GP Fax number” which was more appropriate;
- Update of the latest acute data collection and follow-up forms into the database for easy download when hospitals require a blank copy of the form;
- Minor fixes of issues related to the different browsers and computer systems were also carried out throughout the year;
- Original options for follow-up were “in-progress” and “complete”. The addition of better definitions in the follow-up status include: “lost to follow-up”, “over 6 months”, “deceased” and “refuse follow-up”;
- Improved security of access to the database by inactivating users who are no longer employed by participating hospitals;
- The import function of hospital data to AuSCR also received an improvement to include country code in all address entries and acceptance of the relationship code of “unknown”;

In Queensland, negotiations commenced to develop a Queensland sub-set of variables which would be collected in addition to the main AuSCR variables. This included adding extra variables requested by the Queensland Stroke Network. Funding received from Queensland Health assisted in the appointment of ICM Pty Ltd to commence development of the Queensland sub-set for implementation in 2012.

2011 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 and 31 December, 2011***. Data entry for acute stroke/TIA episodes and follow-up assessments were closed on 31 May 2012. The dataset used for the analyses presented in the following sections was extracted from the AuSCR database on 1 June, 2012.

Statistical 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 Associate Professor Natasha Lannin and were principally based on the data format presented in the 2009 and 2010 Annual Reports as developed by Associate Professors Natasha Lannin and Dominique Cadilhac and the AuSCR Management Committee.

In the initial raw data extracted on 1 June, 2012, there were 2524 patient records and 2594 acute stroke/TIA 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. Five patient records appeared duplicated (admitted to two participating hospitals), among them, one patient was admitted to two hospitals for the same episode and the second admission was thus omitted from statistical analyses. Therefore, the final dataset reported in this document includes information on 2519 patients and 2593 acute stroke/TIA episodes.

FINDINGS FROM DATA COLLECTED IN 2011

HOSPITALS

In 2011, 16 hospitals provided data for AuSCR which is an increase from 2010. In 2010, 12 hospitals provided data. Collection from 1 hospital which participated in 2010 was on hold from January 2011, and a further 5 new hospitals joined AuSCR during 2011. Figure 1 shows the incremental shift in numbers of hospitals participating in AuSCR by month during 2011.

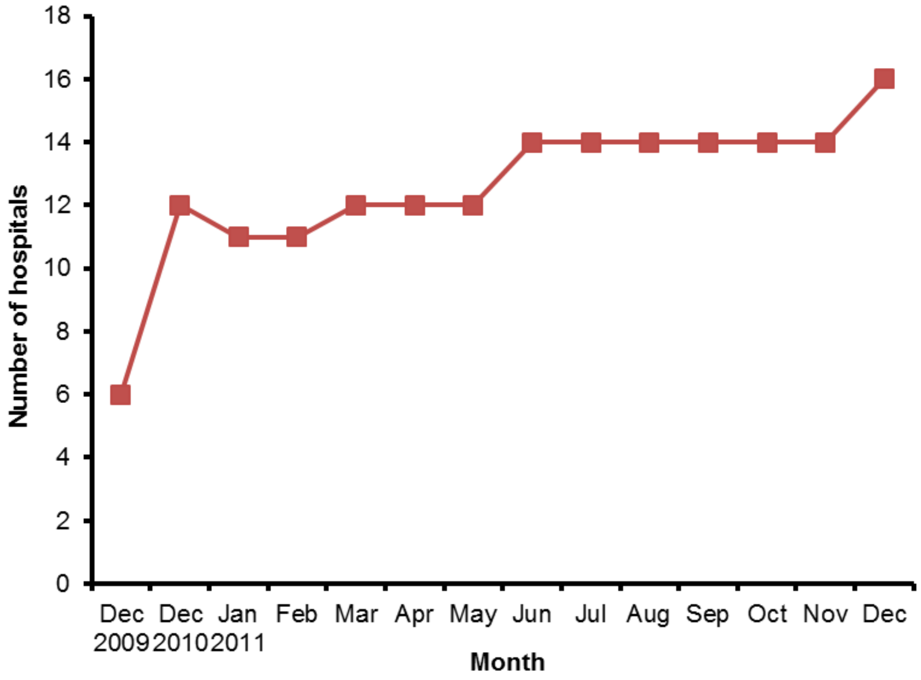

Figure 1: Number of participating hospitals in 2011

The characteristics of the 16 participating hospitals, according to state, are shown in Table 1. There were 7 hospitals located in New South Wales (NSW), 3 in Queensland (QLD), 5 in Victoria (VIC), and 1 in Western Australia (WA). There were 10 hospitals that had 100 or more registrations of stroke/TIA episodes during 2011. There were 11 hospitals located in metropolitan areas, 14 hospitals that had stroke units and 10 hospitals provided thrombolytic therapy using tissue plasminogen activator (tPA). Two of the 16 hospitals were private hospitals, and 1 hospital was a children's hospital.

Table 1: Characteristics of participating hospitals

States	2009 Total	2010 Total	2011 Total	NSW	QLD	VIC	WA
Number of hospitals	6	12	16	7	3	5	1
Annual number of episodes in AuSCR*							
Low (<33 episodes)	-	1	4	2	1	1	-
Medium (33-99 episodes)	1	5	2	1	-	1	-
High (≥100 episodes)	5	6	10	4	2	3	1
Location							
Metropolitan	6	10	11	3	3	4	1
Rural	-	2	5	4	-	1	-
Stroke unit	6	10	14	6	3	4	1
tPA undertaken	6	9	10	3	2	4	1

**Hospital categories as per the definitions used in registry of the Canadian Stroke Network*

NUMBER OF REGISTRANTS

In 2011, there were 2519 patients registered in AuSCR (Table 2). During a calendar year, patients may also have had multiple admissions for different stroke/TIA episodes which were then eligible to be recorded as different episodes. In 2011, there were 2593 episodes of acute hospital care entered in AuSCR for the 2519 individuals registered. Individual patients who had multiple episodes registered included 68 patients (3%) of which 63 had two episodes, 4 had three episodes, and 1 had four episodes. Multiple episodes were captured from 12 hospitals which had also provided the majority of data (n=2556 episodes combined). The minimum number of episodes registered was 1 at a rural NSW hospital and the maximum number was registered by a metropolitan Victorian hospital (n=383). The median number of episodes was 143 (interquartile range [IQR], 32 to 267).

Table 2: Number of hospitals, patients and episodes in 2011

Number of hospitals contributing data	16
Number of episodes submitted	2593
Number of patients	2519
Number and % of multiple episodes	68 (3%)

CASES REGISTERED PER MONTH

Figure 2 shows the number of episodes (including multiple episodes) per month. The median number was 210 per month. The minimum was 126 in April and the maximum was 292 in November.

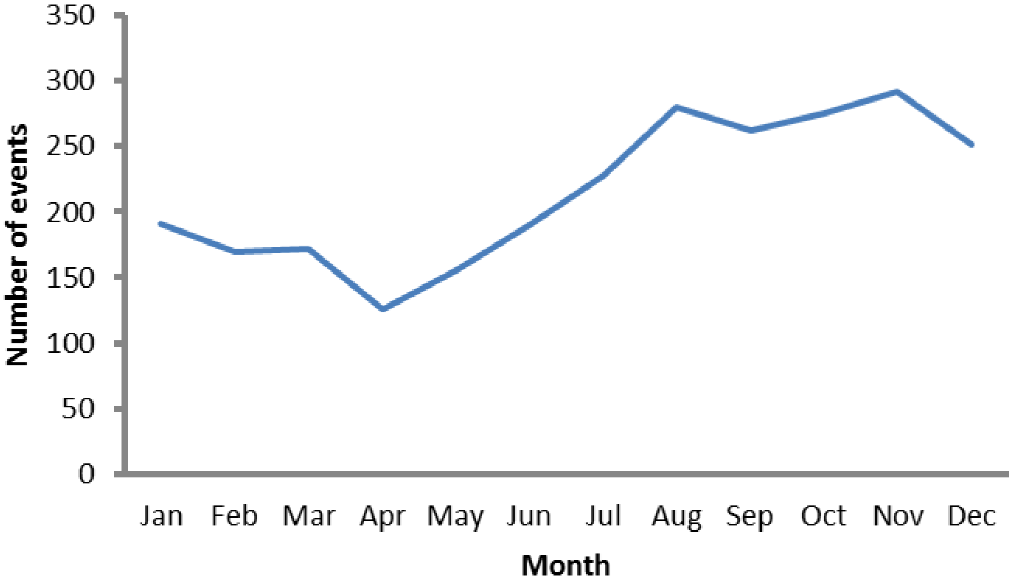

Figure 2: Number of episodes per month in 2011

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

Among the 2519 patients, the median number of days from the admission to the creation of the patient record in AuSCR was 43 days (IQR 12 to 84 days). The shortest median number of days according to hospital was 5 days, and the largest median number of days was 135 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 database (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. 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/).

During 2011, 128 'opt-out' requests were received from hospital staff or patients. The total number of 'opt-out' requests varied by hospital and ranged from 0 to 69. Clarification is still required at sites to differentiate between 'opt-out' versus refusal of follow-up as evidenced in Table 3.

Table 3: Opt out Requests and Fields

Total 'opt-out' cases	Complete episode and demographic data removed	Complete episode data removed (acute + follow-up)	Demographic data removed plus date of death	Refusal for follow-up)
n=128	n=1	n=2	n=1	n=125

DATA COMPLETENESS

A summary of the completeness of hospital collected data for the majority of fields within the registry for the 2593 episodes from 2519 patients in 2011 is presented below (Table 4). 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 tPA). Opted-out data were excluded from the denominators.

Table 4: Completeness of fields in the AuSCR database by year of registry being operational

Field	2009# % complete	2010 % complete	2011 n (% complete)
Person details (n=2519)			
First name	100%	100%	2499/2499 (100%)
Surname	100%	100%	2499/2499 (100%)
Date of birth	100%	100%	2502/2502 (100%)
Medicare number	67%	90%	2294/2501 (92%)
Patient contact (n=2519)			
Available (complete or partial for street address, suburb and state)	95%	99%	2465/2499 (99%)
Complete (street address, suburb and state)	97%	55%	2327/2499 (93%)
Telephone for patient (landline or mobile)	90%	96%	2360/2500 (94%)
Emergency and alternate contacts (n=2519)			
Address for one or both of emergency and alternate contacts	71%	47%	1945/2499 (78%)
Address for one contact	62%	40%	1726/2499 (69%)
Address for both contacts	10%	7%	219/2499 (9%)
Telephone for emergency and/or alternate contact (landline or mobile)	92%	94%	2253/2499 (90%)
General practitioner contacts (n=2519)			
Address	73%	46%	2096/2499 (84%)
Telephone for general practitioner (landline or mobile)	75%	71%	2042/2499 (82%)
Patient characteristics (n=2519)			
Title	99%	97%	2496/2502 (100%)
Hospital medical record number	100%	100%	2519/2519 (100%)
Gender	99%	98%	2492/2503 (100%)
Country of birth	92%	98%	2377/2503 (95%)
Language spoken	97%	84%	2407/2503 (96%)
Indigenous status	100%	100%	2493/2502 (100%)
Interpreter needed	100%	84%	2503/2503 (100%)

Table 4, continued

Field	2009# % complete	2010 % complete	2011 n (% complete)
Episode data (including multiple episodes) (n=2593)			
Date of arrival	100%	100%	2584/2592 (100%)
Time of arrival	100%	99%	2509/2592 (97%)
Date of stroke onset	100%	100%	2582/2592 (100%)
Date of admission	100%	100%	2592/2592 (100%)
Transfer from another hospital	100%	100%	2565/2592 (99%)
Stroke occurs while in hospital	100%	99%	2558/2592 (99%)
Able to walk independently on admission	100%	95%	2363/2592 (91%)
Documented evidence of a previous stroke	100%	98%	2375/2592 (92%)
Treated in a stroke unit	100%	99%	2582/2592 (100%)
Type of stroke	100%	100%	2592/2592 (100%)
Use of intravenous thrombolysis (if ischaemic stroke)	99.7%	98%	1672/1730 (97%)
Cause of stroke	100%	100%	2592/2592 (100%)
ICD10 coding (including multiple episodes) (n=2593)*			
Diagnosis code	63%	65%	2497/2592 (96%)
Medical conditions	-	220	913
Complications	1	65	170
Procedures	6	7	649
Discharge information (including multiple episodes) (n=2593)			
Deceased status	100%	100%	2592/2592 (100%)
Date of death (if deceased status is yes)	100%	100%	332/333 (100%)
Date of discharge (if not deceased while in hospital)	87%	97%	2326/2374 (98%)
Discharge destination (if not deceased while in hospital)	87%	97%	2309/2374 (97%)
Discharge on antihypertensive agent (if not deceased while in hospital)	87%	92%	2138/2374 (90%)
Evidence of care plan on discharge (if not deceased while in hospital)	87%	91%	2167/2374 (91%)

*Note that not every patient will have other medical conditions, complications and procedures coded therefore it is unclear what the denominator will be. # Only approximately 6 months of data were collected during the pilot year.

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 2011 with ICD10 codes of stroke/TIA (i.e. G45.9, I61.0-I61.9, I62.9, I63.0-I63.9 and I64). Among 16 participating hospitals, 9 hospitals sent us their hospital records and among these 9 hospitals, 8 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 AuSCR Office sought explanations for missing episodes (for example, episode may have been misclassified as acute stroke/TIA). Table 5 shows the number of episodes which were registered (A) or missed (B) in the AuSCR database. Proportion of completeness for case ascertainment was defined as A/(A+B) x 100.

Table 5: Summary of the case ascertainment

Hospital	Episodes in the database (n)	Episodes missed in the database (n)	Completeness
9†	118	Not available	
10†*	382	6	98%
11†	205	Not available	
12†*	383	209	65%
13†	305	162	65%
15†	41	30	58%
16†	122	21	85%
17†	295	207	59%
18	22	Not available	
19†	9	5	64%
20†	163	22	88%
21	77	7	92%
22	238	Not available	
23	227	Not available	
25	5	Not requested	
26	1	Not requested	

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

n/a: data is not available

*These 2 hospitals use the data import function.

†These 9 hospitals participated in AuSCR for the full 2011 year.

REGISTRANT CHARACTERISTICS

Table 6 shows the baseline characteristics in adult patients or episodes. All paediatric patients and episodes (n=9) were excluded from analyses.

Among the 2510 adult patients, the most common country of birth was Australia (72%) followed by the United Kingdom and Italy. The remainder were from a range of mainly European or Asian nations. There were 18 patients (1%) identified as having an Aboriginal or Torres Strait Islander background. The majority of the registered patients spoke English (91%). The registrants comprised 47% females and the mean age was 73 years. There were 259 patients (10%) aged less than 55 years and 345 patients (14%) were aged between 55 and 64 years.

From the total 2584 episodes, there were 1721 ischaemic strokes, 350 intracerebral haemorrhage (ICH), 427 TIAs, and 85 episodes of undetermined type. The proportion of stroke episodes, according to the clinician-based classification of stroke subtype for all episodes and first registered episodes, is provided in Figure 3. Stroke subtype according to gender and age is presented in Figure 4. Among the 2584 episodes, the patient was able to walk at the time of admission in about 39% of admissions.

Table 6: Baseline characteristics

Patients (n=2510)	
Age, mean (SD)	73 (14)
Gender, female, n (%)	1173/2483 (47%)
Country of birth, n (%)	
Australia	1706/2368 (72%)
United Kingdom	136/2368 (6%)
Italy	103/2368 (4%)
Other European countries	227/2368 (10%)
Asia	114/2368 (5%)
Others	82/2368 (3%)
Aboriginal and/or Torres Strait Islander, n (%)	18/2484 (1%)
English spoken, n (%)	2175/2398 (91%)
Episodes (including multiple episodes) (n=2584)	
Type of stroke, n (%)	
Ischaemic	1721/2583 (67%)
Haemorrhagic	350/2583 (14%)
TIA	427/2583 (17%)
Undetermined	85/2583 (3%)
Able to walk on admission, n (%)	920/2354 (39%)
Length of hospital admission (days), median (IQR)	7 (4 to 12)
Cause of stroke known, n (%)	1298/2583 (50%)

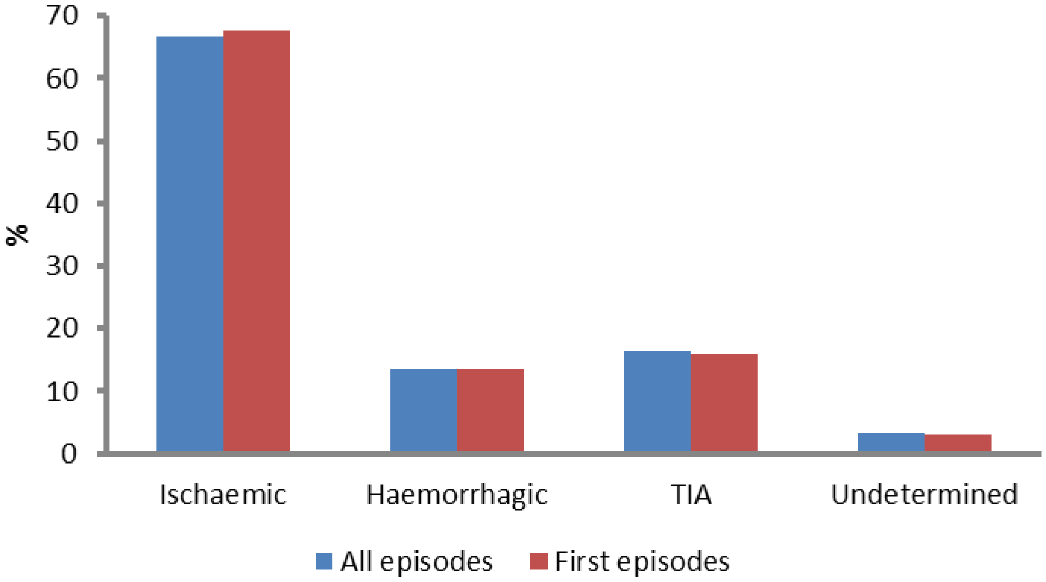

Figure 3: Distribution of stroke subtypes in all and the first episodes

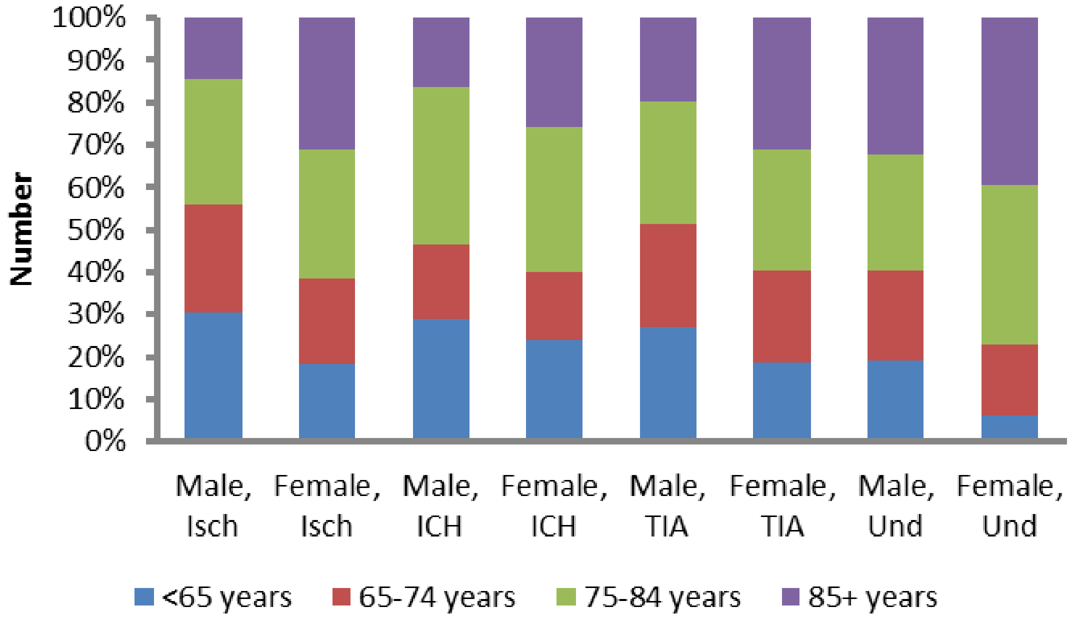

Figure 4: Distribution of stroke subtypes by sex and age groups (including multiple episodes)

PROCESSES OF HOSPITAL CARE

Of the 2584 episodes, there were 334 episodes (13%) transferred from another hospital and 128 episodes (5%) of in-patient stroke while already in hospital for another condition. The majority of the inpatient strokes were ischaemic (n=97, 76%) 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 (in-patient median 15 days [IQR 9 to 25 days] vs. median 6 days [4 to 11 days] for non-in-patient stroke admissions, p<0.001).

OVERALL ADHERENCE TO QUALITY INDICATORS

Adherence to the process of care indicators collected in AuSCR are outlined in Table 7. Most patients registered in AuSCR were treated in a stroke unit and about one-third received a care plan at time of discharge. Adherence by participating hospital is presented in Appendix C in a de-identified format.

Table 7: Stroke evaluation and therapy (including multiple episodes)

Hospital Stroke Care	All episodes	Ischaemic	TIA
Patients admitted to a stroke unit	1988/2573 (77%)	1449/1717 (84%)	271/425 (64%)
Patients who received intravenous thrombolysis if an ischaemic stroke (tPA)		225/1664 (14%)	
Patients discharged (not deceased while in hospital)	2317/2535 (91%)	1559/1684 (93%)	426/426 (100%)
Patients discharged on an antihypertensive agent (if not deceased while in hospital)	1672/2129 (79%)	1141/1446 (79%)	322/411 (78%)
Patients who received a care plan at discharge (if not deceased while in hospital)	707/2158 (33%)	486/1462 (33%)	131/409 (32%)

There was no difference in the age of patients admitted to stroke units among the hospitals (mean age if managed on a SU 73 years (SD 14) and non-SU mean age 73 years (SD 15)(p=0.60) (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).

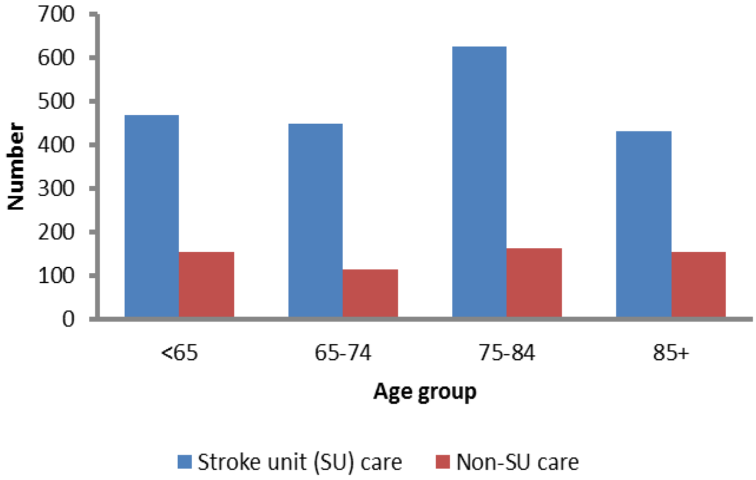

Figure 5: Management in a stroke unit according to age group (including multiple episodes)

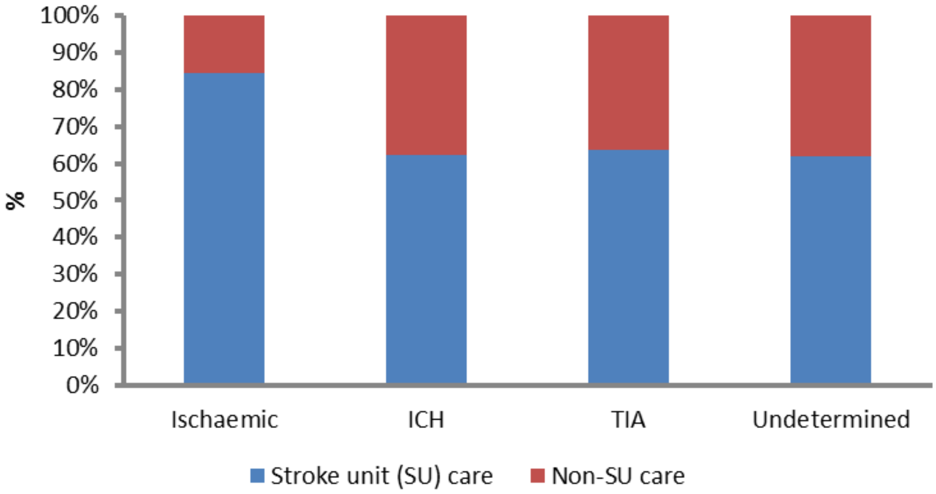

Figure 6: Management in a stroke unit according to stroke subtype (including multiple episodes)

PATIENTS ADMITTED WITH TRANSIENT ISCHAEMIC ATTACK

Among the 427 episodes of TIA, the mean age was 74 years (SD 13 years) and 43% 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, 32% received a care plan and 78% were discharged on an antihypertensive agent (Table 7). Most patients (86%, n=365) were discharged to a home setting and 5% (n=19) went to rehabilitation.

DISCHARGE INFORMATION

Hospital outcome measures include length of stay, discharge destination and discharge status. In the case where data for an individual person is segregated across two hospitals for the same stroke episode, 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 12 days). Of the 2584 episodes, 11% (n=283) of episodes had a length of stay of 21 days or more. There was a statistically significant difference between the length of stay for episodes treated in stroke units (median 7 days, IQR 4 to 12 days) and those not treated in stroke units (median 5 days, IQR 3 to 10 days) (p<0.001).

DISCHARGE STATUS

In 2011, the majority of registered patients were discharged directly to a home environment (n=1173; 51%) (Figure 7). Patients managed in a stroke unit had a 1.9 fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed on a stroke unit (95% confidence interval [CI] 1.4 to 2.5) when adjusted for age, gender, presence of ischaemic stroke, ability to walk on admission, whether an inpatient stroke and transferred from another hospital.

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

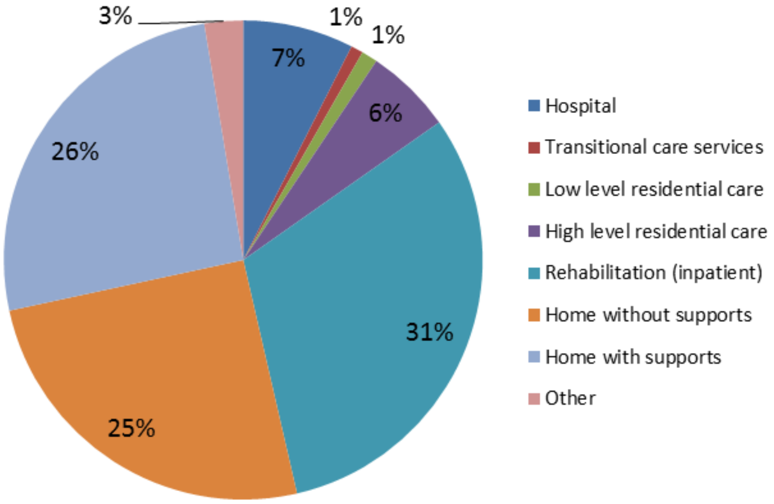

Figure 7: Discharge status including multiple episodes (excludes patients who died in hospital) n=2300

DEATHS IN HOSPITAL

Of the total number of 2510 registered adult patients (i.e. excludes <18 years paediatric cases), 210 (8%) patients had died in hospital. Although case fatality in hospital was greater for women (Figure 8), there were no gender differences in case fatality during hospitalisation after adjustment for age (p=0.23). There were no paediatric in-hospital deaths reported.

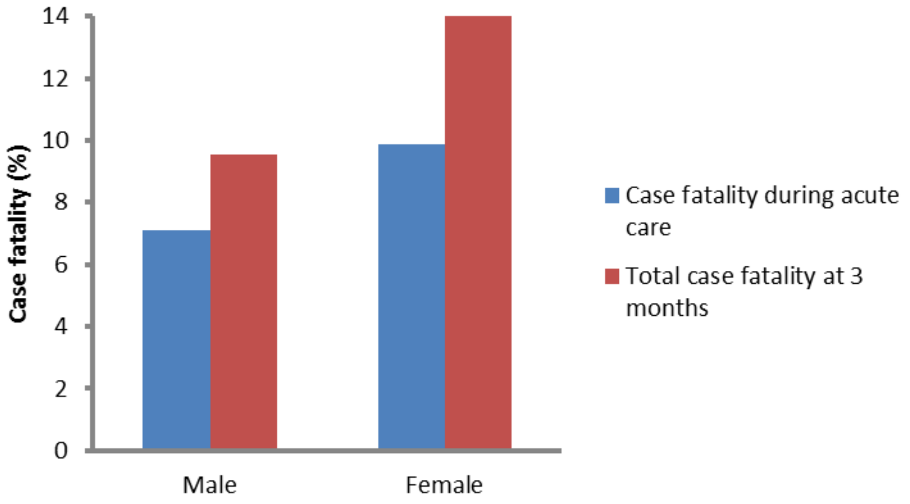

Figure 8: Case fatality (the 1st episode only) from admission date to 90 days n=2510

POST-DISCHARGE HEALTH OUTCOME INFORMATION

The aim of 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 patient 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 2519 patients registered in 2011. Since 26 patients had a previous registration in 2009 or 2010 (including 1 patient who died during hospitalisation in 2011), 2493 registrants were eligible for follow-up. Of these 2493 registrants, 66 registrants had indicated a refusal for follow-up and 281 registrants were known to have died; these registrants were therefore ineligible. Follow-up assessments were planned for the remaining 2146 registrants. Forty-three refused follow-up assessments, 710 were not followed-up because their primary data were entered into the AuSCR system after the 180 day limit; and a further 78 registrants were lost to follow-up.

As of 31 May 2012, follow-up was completed in 1215 registrants and was in progress in 100 registrants (Figure 9). In 2011, median time from the stroke onset to the completion of follow-up for the 1215 patients was 162 days (IQR 138 to 194 days). A total of 281 patients had already died prior to generating the follow-up survey, therefore a total of 1496 patients had follow-up data after discharge.

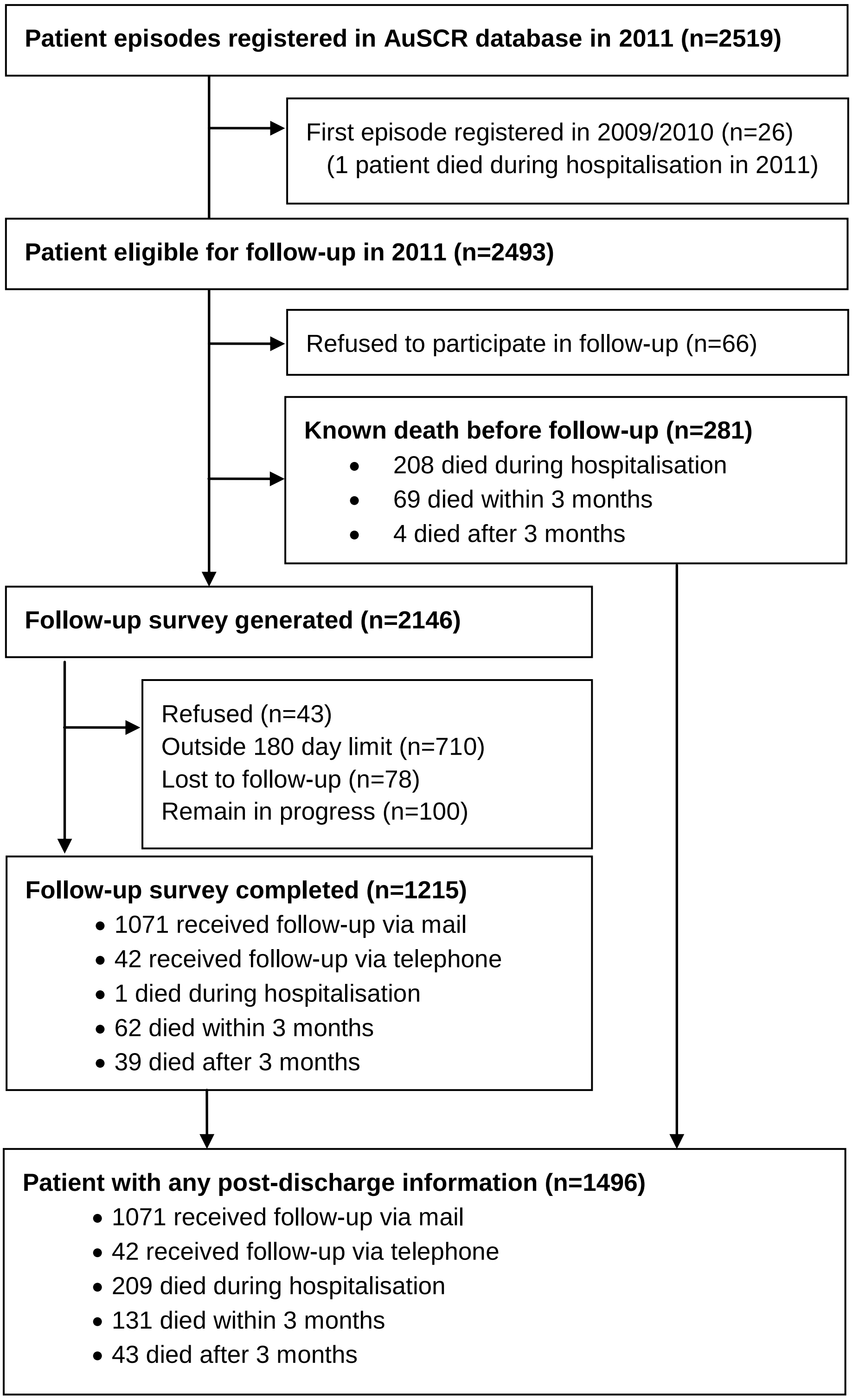

Figure 9: Flow diagram of the follow-up assessments for patients admitted in 2011

Characteristics of the 1496 registrants with any post-discharge information are summarised in Table 8. The mean age was 75 years and 47% were female; 69% of them had an ischaemic stroke.

Table 8: Baseline characteristics for 1496 registrants with (and 997 registrants without) any post-discharge information

	Patients with any post-discharge information (complete follow-up or death) (n=1496)	Patients without post-discharge information (refused, lost, after 6 month, or in progress) (n=997)	*p*-value
Age (years), mean (SD)	75 (13)	70 (16)	<0.001
Gender, female, n (%)	698/1479 (47%)	470/987 (48%)	0.84
Aboriginal and/or Torres Strait Islander, n (%)	5/1479 (0.3%)	13/988 (1%)	0.005
Type of stroke, n (%)			0.006
Ischaemic	1027/1496 (69%)	658/996 (66%)	
Haemorrhagic	216/1496 (14%)	117/996 (12%)	
TIA	211/1496 (14%)	185/996 (19%)	
Undetermined	42/1496 (3%)	36/996 (4%)	
Able to walk on admission, n (%)	497/1364 (36%)	384/908 (42%)	0.005
Length of hospital admission (days), median (IQR)	7 (4 to 12)	7 (4 to 13)	0.47
Treated in a stroke unit, n (%)	1132/1490 (76%)	779/993 (78%)	0.15

SURVIVAL

Of 1496 registrants with post-discharge information available, 340 registrants (23%) had died within 3-months of admission (inclusive of the 209 registered in-hospital deaths) (Figure 9, Figure 10). Case fatality for women was significantly higher than for men (*p*=0.03) after adjustment for age within 3 months following stroke. A further 43 registrants were reported to have died at the follow-up assessment (>3 months after stroke).

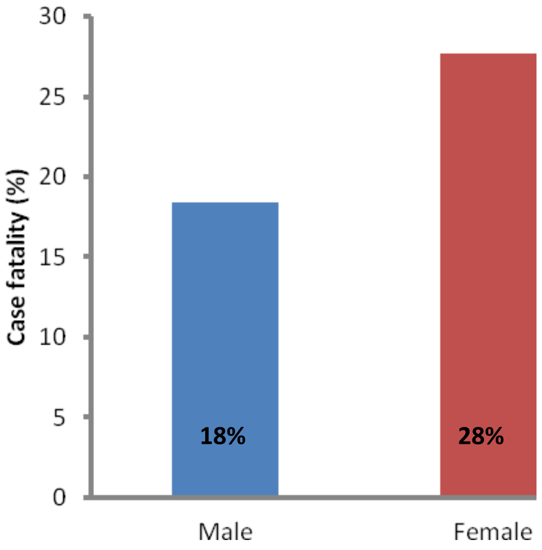

Figure 10: Three-month case fatality (n=1496)

There were 1113 (92%) registrants who were able to answer all or some of the questions at follow-up. The main follow-up results are summarised in Table 9.

Table 9: Post-discharge information

Follow-up status	
Registrants who died	383/1496 (26%)
Died during hospitalisation	209/1496 (14%)
Died after discharge and within 3 month of admission	131/1496 (9%)
Deaths registered after 3 months	43/1496 (3%)
Registrants who answered all questions	1005/1113 (90%)
Registrants who answered some questions	108/1113 (10%)
Registrants who had another stroke	56/1081 (5%)
Registrants who were readmitted to hospital	228/1097 (21%)
Reasons for readmission was a stroke/cardiovascular cause	81/228 (36%)
Location of stroke survivor at time of follow-up interview	
In hospital	10/1093 (1%)
Transitional care service	16/1093 (1%)
Receiving hostel care	31/1093 (3%)
High level care (nursing home)	112/1093 (10%)
Inpatient rehabilitation	16/1093 (1%)
Living at home without support	488/1093 (45%)
Living at home with support	363/1093 (33%)
Other place	57/1093 (5%)
Living alone	220/1093 (20%)

READMISSIONS

There were 228 registrants (21%) who reported that they were readmitted to hospital and 81 (36%) of these were reported to be for a readmission related to a stroke/cardiovascular cause (Table 9).

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 mobility and usual activities (Table 10). The summary score for overall HR-QoL was well below the normal population measure for people aged 70 to 79 years (Figure 11).

Table 10: Quality of life assessment

EQ-5D dimensions		
Mobility	No problems (Level 1)	547/1100 (50%)
	Problems (Levels 2 & 3)	553/1100 (50%)
Self-care	No problems (Level 1)	725/1103 (66%)
	Problems (Levels 2 & 3)	378/1103 (34%)
Usual Activities	No problems (Level 1)	445/1099 (40%)
	Problems (Levels 2 & 3)	654/1099 (60%)
Pain/Discomfort	No problems (Level 1)	567/1090 (52%)
	Problems (Levels 2 & 3)	523/1090 (48%)
Anxiety/Depression	No problems (Level 1)	570/1090 (52%)
	Problems (Levels 2 & 3)	520/1090 (48%)
Visual Analogue Scale (0 – 100) reported by survivors*		
Mean (SD)		63 (27)
Median (IQR)		70 (50 to 80)

*Deaths on the VAS are recorded as zero so these data have not been included in these estimates.

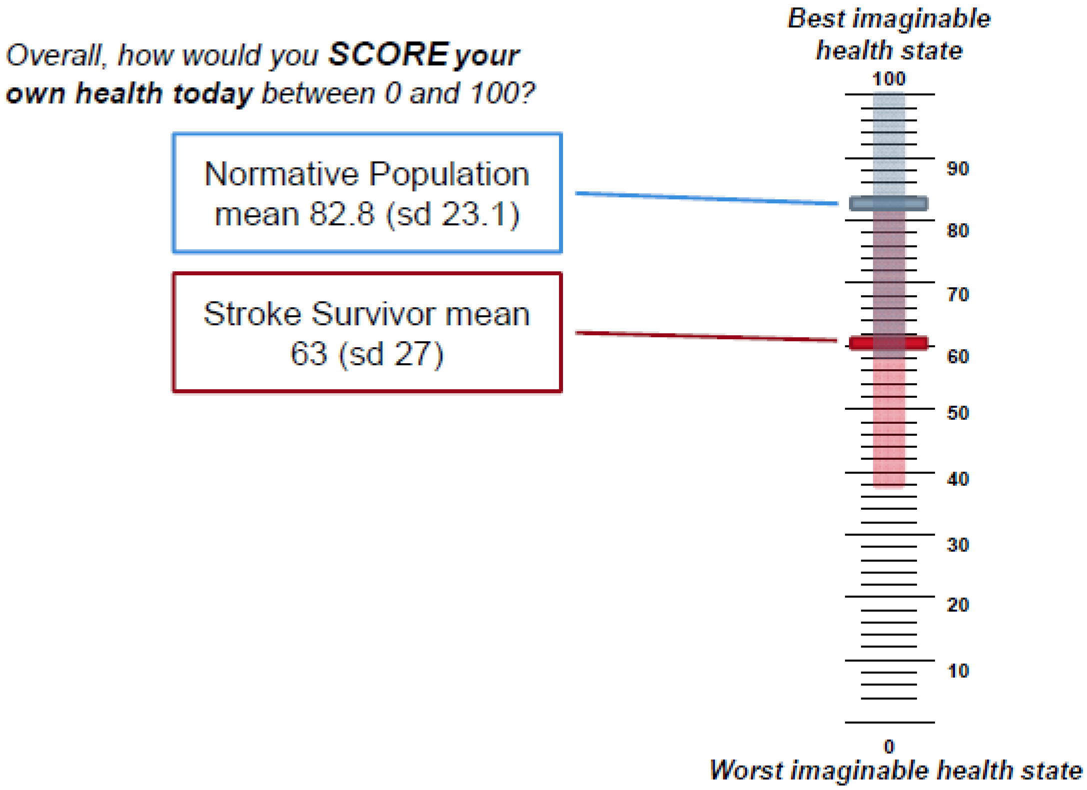

Figure 11: Summary of Visual Analogue Scale responses for 2011 AuSCR registrants

PARTICIPATION IN FUTURE RESEARCH

Of the 1003 respondents who answered the questions about whether they would be willing to be contacted to participate in future research, 656 registrants (65%) replied affirmatively that they would be willing to be contacted.

UNMET INFORMATION NEEDS

Stroke can be a devastating and life changing event for people and there is a possibility that stroke survivors and their care providers have unmet care and information needs. Given that the AuSCR protocol includes a follow-up survey with stroke survivors at 90+ days post-stroke, it presents an opportunity to ask registered patients whether they would like to receive further information about stroke from the National Stroke Foundation. In 2011, 10% (n=229) of AuSCR registrants or their caregivers indicated that they would like to receive information about stroke. We also found that more than 53% (n=1165) of the sample (n=2202) left this question blank on their follow-up survey and presumed that non-responses to this question meant that no further information was desired.

RESEARCH PROJECTS REQUESTING INFORMATION FROM AUSCR REGISTRANTS

In 2011, there were two requests submitted to the Research Task Group to conduct complementary studies using AuSCR registry data.

1. The **Fabry Disease in Stroke Screening Study** is being conducted by Professor Craig Anderson and Dr Mark Parsons. This is a prospective, hospital-based, cohort study of patients with unknown cause of stroke aged 18 to 55 years. Eligible patients who provide written informed consent will have their blood collected and tested for Fabry disease and will be followed-up by the treating physician on receipt of results. Potentially eligible cases can be identified using the AuSCR database, where participating hospitals are using this prospective registry, using the variables of age and cause of stroke (listed as ‘unknown’). Currently, this project is underway at the Royal Prince Alfred Hospital (Sydney).
2. **Australian Stroke Survivor and Carer Needs Assessment Project** is being conducted by the National Stroke Foundation with support from researchers at Monash University and A/Prof Dominique Cadilhac. The overall objective of this project is to undertake a needs assessment of stroke survivors who are living in the Australian community and who had their stroke more than one year ago. The findings from this survey will be used to identify priority areas in relation to the identified unmet needs so that evidence based policy, programs, and strategies may be developed to optimally support stroke survivors and their carers. A request to AuSCR was made by the researchers because it was possible to identify a broad sample of stroke survivors living in the community for more than one year from time of stroke. Registrants in AuSCR who had self-nominated to be contacted to be involved in research projects and met the other eligibility criteria were mailed the survey by AuSCR Office. No identifying information was passed on to the researchers. AuSCR is only one of several participant recruitment strategies being used to obtain over 1000 surveys of stroke survivors across Australia for this project. Results from this project are to be realised in 2012.

DISCUSSION

This is the third annual report of the Australian Stroke Clinical Registry (AuSCR). Since the release of the first annual report in 2009, use of the AuSCR registry has continued to grow at a steady rate. Building from our 2009 report which included 6 hospitals contributing 470 episodes, our 2011 report includes data contributed from 16 hospitals in Australia on 2593 episodes of stroke or TIA.

Stroke is a leading cause of cause of global disease burden. In Australia, stroke is the second leading cause of death and largest cause of adult disability. Recent advances in treatments for acute stroke provide the opportunity for improved survival and reduced disability, while well coordinated multidisciplinary stroke care (i.e. in the form of a Stroke Care Unit [SCU]) that ideally includes early rehabilitation has been shown to improve recovery. Thus, a significant reduction in the burden from stroke could be achieved if such interventions were used consistently across Australia. As such it is essential to ensure that everything possible is done to monitor the use of quality, evidence-based interventions[5]. Inadequate outcome data, as well as variability related to different hospitals/stroke types/state funding arrangements, have made it difficult to identify the relative effectiveness and uptake of different interventions.

The AuSCR registry is used to monitor all types of stroke/TIA and specific interventions provided in real time. A registry is an effective method of monitoring safety and quality of health care because the data can be used to identify factors important in achieving successful outcomes after stroke. From these data, standards for long-term improvements in stroke care can be established and routinely monitored. The AuSCR registry has enabled monitoring of acute stroke care and analysis of these data show the continued benefits of a system-based approach to stroke care. The data in this report confirm that on average, the National Stroke Foundation guidelines are being followed, with 77% of patients receiving their care at a specialised stroke unit. It should be noted that these figures are greater than those reported in the National Stroke Audit of Clinical Services (2011) which found that 60% of patients received care in a specialised stroke unit. The difference may be due to the bias towards hospitals with stroke units included in the registry and difficulty in case ascertainment of patients who are not managed on a stroke unit. Our data also show that discharge on antihypertensive agents occurred in 77% of episodes.

Since the registry has not yet obtained complete coverage in any state or region, it is not yet possible to use AuSCR data to reliably provide information on death rates or stroke prevalence. Our discharge destination and in-hospital death rates may provide some indication of hospital outcome for hospitals that have stroke units. The patterns of transfer across the system indicate that 31% of acute patients registered in AuSCR were transferred to rehabilitation. The NSF guidelines recommend that all patients with confirmed stroke receive early, active rehabilitation, and that all patients, including those with severe stroke, should be assessed by a specialist rehabilitation team regarding their suitability for rehabilitation. While we are unable to determine who received assessments for rehabilitation, use of inpatient rehabilitation can be monitored over time. In addition, of the AuSCR registrants admitted with TIA, 5% went on to receive rehabilitation. This finding may reflect inaccurate diagnosis of TIA (since by definition symptoms resolve within a day) or the need for rehabilitation due to other comorbidities or functional decline experienced within the community.

The follow-up of patients who are discharged from hospital is a unique attribute of the AuSCR registry in providing national data on stroke. At the time of follow up, 13% of patients were living in institutionalised care and more than 75% were living at home. The 90+ day outcomes information provides critical information about the quality of acute care of stroke patients in Australia, and the capacity to monitor the burden of stroke post-discharge.

This is the first year in which AuSCR received requests for data linkage or access to the database from external research groups and provided the opportunity to test the Data Access Policy. These requests demonstrate the usefulness of the registry, not only to provide local hospitals with real-time feedback on their adherence to quality of care indicators, but also the ability to provide researchers with a substantive database on which to undertake meaningful research projects within stroke. Following implementation of the Data Access Policy, a significant finding from 2011 has been that this policy was found to provide adequate and appropriate guidance for managing these requests.

AuSCR continues to be a valuable monitoring tool of stroke care and outcome. On-going support and development of the registry, including the continued expansion of the number of participating sites and the further development of the database/upload data entry processes, will ensure the informed improvements to stroke care in Australia.

REPRESENTATIVENESS OF DATA

Data from individual hospitals is presented for the first time in the 2011 Annual Report (de-identified in Appendix C). Results demonstrate that ascertainment at the hospitals varied during 2011, and most hospitals that participate in AuSCR have a stroke unit. Therefore, the AuSCR hospitals may not be considered representative of all hospitals in Australia providing stroke care.

Ascertainment directly affects the representativeness of our results. One of the main challenges facing the registry is ensuring the completeness of case ascertainment. 2011 records show that completeness ranged from 64% to 98% (see Table 5) thus there is scope for improvement. It is acknowledged that increasing the completeness of case ascertainment requires ongoing attention and additional strategies to maximise case ascertainment are required. The expansion of AuSCR to all Queensland hospitals in 2012/2013 is expected to provide, for the first time, an opportunity to compare hospital data across one state. This will also provide an opportunity to understand case ascertainment issues better in 2012 and the inclusion of risk (case-mix) adjusted outcome analyses as part of the next annual report.

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 the constrained resources for AuSCR with a continued need for ongoing, recurrent funding, future goals and directions are outlined below.

ENSURING COMPLETE CASE ASCERTAINMENT FROM PARTICIPATING HOSPITALS

Case ascertainment was analysed for the second time at the close of the 2011 data collection period. Building on lessons from the 2010 reporting year, case ascertainment and determination of missing cases was based on a specific ICD10 codes (G45.9, I61,I62,I63 and I64) for hospital verification. Despite this, difficulties with case ascertainment remained, suggesting that ongoing work with sites is required to ensure the accuracy of case ascertainment, and the interpretation of these data by the AuSCR registry. Possible strategies that may be used include the introduction of a prospective system where "mandatory" manual cross-checking of discharge coding of stroke/TIA against the entered hospital AuSCR dataset occurs on a more regular basis; and, continuing efforts to link an automatic upload of hospital ICD10 stroke/TIA code patients into the local hospital AuSCR dataset for manual review and either inclusion or exclusion. The need for the AuSCR Office to develop a companion document to assist hospitals to complete case ascertainment data collection was identified in 2010, and this recommendation remains for 2011. Currently, once a year the hospitals receive support from AuSCR Office to complete a review of case ascertainment at their site. In 2011, this was further streamlined to limit the request for primary ICD10 codes for stroke to the first three primary discharge codes, since this provides better sensitivity and specificity in identifying true cases of stroke relevant for inclusion in AuSCR. In 2012, the methods will be further refined to improve the process of verifying case ascertainment and reducing the workload of sites in providing this information.

TECHNOLOGY SOLUTIONS FOR SIMPLIFYING DATA COLLECTION FOR CLINICIANS

The implementation of the data import function during 2010 simplified data collection for clinicians in those sites. Testing of this import function demonstrated that it reduces manual entry of demographic information already held in the hospital's Patient Administration System. However, despite its release in 2010, this function needs to be more widely used by participating hospitals. Currently, three hospitals continue to use monthly importing processes for AuSCR; and the feedback on the benefits in reducing data-entry time and greater case-ascertainment remain positive. There remains a need for local support for resourcing to a) program a report filter for appropriate patients; and b) transform the extracted data from the local Patient Administrative System to match the variable formats required for using the AuSCR Excel-based data import template at the respective hospital. Without adequate resourcing, use of the import function remains difficult and the AuSCR Management Committee is anticipating that the Clinical Network investments in both Queensland and Victoria towards increasing importing into AuSCR will advance uptake and case ascertainment in these states in 2012.

HARMONISATION OF THE NSF AUDIT PROCESS WITH AUSCR

The NSF stroke audit, undertaken every 2 years for acute hospital services, uses retrospective patient case note audit in a cross-section of patients (~40) to measure adherence to the NHMRC endorsed Clinical Guidelines for Stroke Care, while supplementary data collected through the AuSCR registry, which acts as a data spine, can answer questions around more complex care longitudinally[2 4].

Harmonising these complementary data collection systems and processes, and establishing reliable linkage of data, will ensure the greatest return for the effort expended at local hospitals in obtaining those data.

Since the AuSCR and NSF audit have overlapping variables, but use different systems of data collection there has been ongoing discussion since AuSCR began in 2009 to bringing these two important national quality initiatives for stroke together, via a process of harmonisation. With the successful awarding of NHMRC partnership project funding to Associate Professor Dominique Cadilhac and members of the Stroke123 Steering Committee in late 2011, support to progress the harmonisation of these data collection programs has occurred.

CONCLUDING COMMENTS

The purpose of the AuSCR is to provide high quality independent data on the outcome of acute stroke in Australia. It is now providing increasingly relevant information to health professionals working in stroke to assist them to make informed judgments on the best approach to use for individual patients. The information provided by the AuSCR registry will continue to become increasingly valuable as time progresses. This is because AuSCR provides longer term outcomes through the 90+ day follow-up than currently available to acute hospital services.

It is hoped that the information presented in this 2011 report is not only useful to clinicians, but also patients. Interpretation of information from the report can be very complex as many factors interact to influence the outcome of stroke or TIA. The intention of making this information available to everybody is to assist in promoting informed discussion about the outcome of stroke, the performance of hospitals with respect to evidence-based care, and quality of care, particularly between patients and their treating medical staff.

AuSCR continues to be a valuable tool for monitoring stroke care and outcome. The ongoing support and development of the registry, including the continued expansion of the number of participating sites and the further development of the database/upload data entry processes, will ensure continued, evidence-based improvements to stroke care in Australia. Identifying an adequate and reliable funding base remains critical to the sustainability and effectiveness of the AuSCR.

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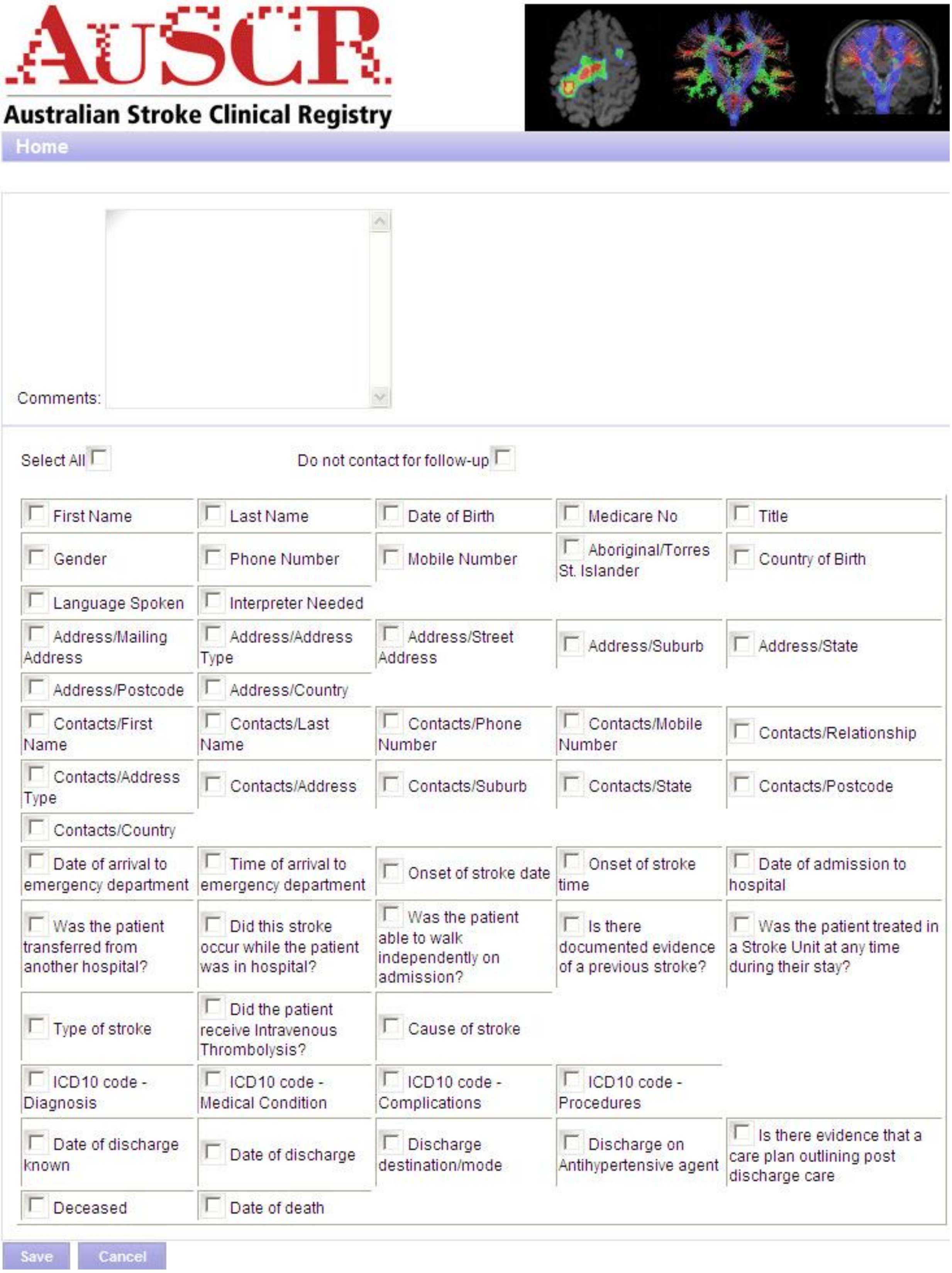
APPENDIX A: STEERING COMMITTEE MEMBERSHIP

Steering Committee Membership 2011			
Name	**Position**	**Organisation**	**State**
Prof Sandy Middleton	AuSCR Steering Committee, Chair Director, Nursing Research Institute Director, National Centre for Clinical Outcomes Research (NaCCOR), 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
Dr Michael Pollack	Director, Rehabilitation Medicine Chairman, Hunter Stroke Service Chairman, GMCT NSW	John Hunter Hospital	NSW
Ms Frances Simmonds	Manager, Australasian Rehabilitation Outcomes Centre (AROC)	Centre for Health Service Development University of Wollongong	NSW
A/Prof Julie Bernhardt	Director AVERT, Very Early Rehabilitation Research Program	Florey Institute of Neuroscience and Mental Health	VIC
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, The Florey Institute of Neuroscience and Mental Health Professor of Neurology, University of Melbourne	The Florey Institute of Neuroscience and Mental Health	VIC
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
Prof John McNeil	Head, Department of Epidemiology and Preventive Medicine	Monash University	VIC
Mr Mark Simcocks	Consumer Representative	Self employed	VIC
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

Steering Committee Membership 2011			
Name	**Position**	**Organisation**	**State**
Dr Andrew Lee	Neurologist NHMRC - NICS Fellow Neurologist Stroke Physician	Flinders Comprehensive Stroke Centre Flinders Medical Centre	SA
Dr Helen Castley	Neurologist Chair, Tasmania Stroke Unit Network	Head of Stroke Unit Royal Hobart Hospital	TAS
Mr Greg Cadigan	Principal Project Officer Statewide Stroke Clinical Network	Patient Safety and Quality Improvement Service Centre for Healthcare Improvement Queensland Health	QLD
Dr Rohan Grimley	Director Geriatrics and Rehabilitation SCWBDHS Southern Cluster	Nambour Hospital	QLD
Ms Sandra Martyn	Director Statistical Standards	Health Statistics Centre Queensland Health	QLD

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			

APPENDIX C: ADHERENCE DATA BY PARTICIPATING HOSPITAL

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
Stroke unit			
9	115/118 (97%)	81/82 (99%)	26/28 (93%)
10	171/381 (45%)	136/217 (63%)	6/83 (7%)
11	199/204 (98%)	163/167 (98%)	21/21 (100%)
12	368/383 (96%)	267/273 (98%)	48/54 (89%)
13	245/304 (81%)	191/205 (93%)	47/55 (85%)
15	0/41 (0%)	0/26 (0%)	0/8 (0%)
16	108/122 (89%)	39/47 (83%)	33/36 (92%)
17	213/293 (73%)	173/215 (80%)	28/61 (46%)
18	21/22 (95%)	12/13 (92%)	4/4 (100%)
20	142/162 (88%)	86/95 (91%)	34/38 (89%)
21	45/76 (59%)	29/49 (59%)	11/20 (55%)
22	165/237 (70%)	123/155 (79%)	1/1 (100%)
23	190/224 (85%)	145/169 (86%)	11/15 (73%)
25	5/5 (100%)	3/3 (100%)	1/1 (100%)
26	1/1 (100%)	1/1 (100%)	0/0 (0%)
tPA			
9		3/80 (4%)	
10		33/214 (15%)	
11		29/161 (18%)	
12		39/267 (15%)	
13		19/202 (9%)	
15		0/25 (0%)	
16		0/47 (0%)	
17		46/209 (22%)	
18		0/12 (0%)	
20		2/92 (2%)	
21		6/49 (12%)	

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
22		16/148 (11%)	
23		32/154 (21%)	
25		0/3 (0%)	
26		0/1 (0%)	
Discharged (not died in hospital)			
9	117/118 (99%)	82/82 (100%)	28/28 (100%)
10	326/382 (85%)	193/218 (89%)	83/83 (100%)
11	186/204 (91%)	151/167 (90%)	21/21 (100%)
12	333/381 (87%)	241/27 1 (89%)	54/54 (100%)
13	277/303 (91%)	190/205 (93%)	54/54 (100%)
15	37/37 (100%)	22/22 (100%)	8/8 (100%)
16	115/122 (94%)	41/47 (87%)	36/36 (100%)
17	278/280 (99%)	202/204 (99%)	62/62 (100%)
18	17/19 (89%)	10/11 (91%)	4/4 (100%)
20	152/161 (94%)	89/93 (96%)	38/38 (100%)
21	66/68 (97%)	40/41 (98%)	20/20 (100%)
22	209/233 (90%)	138/151 (91%)	1/1 (100%)
23	200/223 (90%)	157/169 (93%)	16/16 (100%)
25	3/3 (100%)	2/2 (100%)	1/1 (100%)
26	1/1 (100%)	1/1 (100%)	0/0 (100%)
Antihypertensive agent			
9	101/115 (88%)	71/81 (88%)	23/27 (85%)
10	242/313 (77%)	146/184 (79%)	65/81 (80%)
11	134/179 (75%)	110/147 (75%)	13/19 (68%)
12	282/334 (84%)	206/242 (85%)	46/54 (85%)
13	185/275 (67%)	125/188 (66%)	34/54 (63%)
15	28/34 (82%)	17/19 (89%)	7/8 (88%)
16	76/112 (68%)	27/41 (66%)	26/36 (72%)
17	199/272 (73%)	138/198 (70%)	48/60 (80%)

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
18	13/15 (87%)	9/10 (90%)	3/3 (100%)
20	111/144 (77%)	69/87 (79%)	25/34 (74%)
21	52/60 (87%)	29/37 (78%)	19/19 (100%)
22	128/135 (95%)	101/105 (96%)	1/1 (100%)
23	118/138 (86%)	91/105 (87%)	11/14 (79%)
25	2/2 (100%)	1/1 (100%)	1/1 (100%)
26	1/1 (100%)	1/1 (100%)	0/0 (0%)
Care plan			
9	39/117 (33%)	26/82 (32%)	13/28 (46%)
10	88/324 (27%)	48/193 (25%)	31/82 (38%)
11	93/181 (51%)	75/148 (51%)	8/19 (42%)
12	36/332 (11%)	26/241 (11%)	6/54 (11%)
13	183/267 (69%)	121/184 (66%)	43/53 (81%)
15	11/36 (31%)	6/21 (29%)	3/8 (38%)
16	3/115 (3%)	1/41 (2%)	1/36 (3%)
17	15/273 (5%)	14/200 (7%)	1/59 (2%)
18	15/15 (100%)	10/10 (100%)	3/3 (100%)
20	14/139 (10%)	10/80 (13%)	2/36 (6%)
21	57/65 (88%)	33/40 (83%)	19/20 (95%)
22	146/157 (93%)	111/115 (97%)	1/1 (100%)
23	5/134 (4%)	3/105 (3%)	0/9 (0%)
25	1/2 (50%)	1/1 (100%)	0/1 (0%)
26	1/1 (100%)	1/1 (100%)	0/0 (0%)