Annual Report 2012

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Any enquires about, or comments on, this publication should be directed to:

Administration
Australian Stroke Clinical Registry Office
The Florey Institute of Neuroscience and Mental Health
245 Burgundy St
Heidelberg, Victoria 3084, Australia

Ph: +61 3 9035 7264
Fax: +61 3 9035 7304
Email: admin@auscr.com.au

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Consortium partners:

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SUMMARY

In 2012:

- Thirty-one (31) hospitals contributed data to the Australian Stroke Clinical Registry (AuSCR) indicating a 5-fold increase in site participation since the 2009 inception year.
- The final 2012 data reported in this document includes information on 4572 patients with 4734 acute stroke or transient ischaemic attack (TIA) episodes who were admitted to the participating hospitals in 2012.
    - Summary data on adherence to the quality indicators are shown for the first time according to the number of episodes at a hospital level and highlight the variability in care amongst hospitals managing patients with acute stroke or TIA, with the greatest variability being for the outcome 'discharge with a care plan'.
- Following the approval of the AuSCR Steering Committee in 2011 to add four additional quality four indicators for Queensland hospitals, this sub-set of variables went 'live' in August 2012. In this report, we highlight results for these additional quality indicator variables which provide consistency with historical Queensland performance monitoring of acute stroke care.
    - In 2012, data from 958 episodes of care from Queensland hospitals were entered into the AuSCR.
- Following close off of the data for 2012 annual reporting (30 June 2012), of 2835 eligible registrants, 2201 (78%) provided follow-up data 3-6 months following their stroke or TIA.

ABOUT THE COLLABORATING ORGANISATIONS

The AuSCR initiative is undertaken by a consortium of two leading academic research institutes: the National Stroke Research Institute, now a subsidiary organisation of The Florey Institute of Neuroscience and Mental Health (and now referred to as the 'Stroke Division' of The Florey), 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

Relevant publications in peer-reviewed journals highlighting the AuSCR program or data:

Cadilhac DA, Lannin N, Lim J, Price C, Faux S, Levi C, Donnan GA, Anderson C. Randomised comparative efficiency of telephone versus mail follow-up in the Australian Stroke Clinical Registry (AuSCR). *Cerebrovascular Diseases* 2012, 33(Supplement 2):21.

Cadilhac D, Amataya B, Lalor E, Rudd A, Lindsay P, Asplund K. Is there evidence that performance measurement in stroke has been used to influence health policy and positive changes to health systems? *Stroke* 2012;43:3413. [Invited Review]

Annual Report Publication

Lannin NA, Cadilhac D, Anderson C, Hata J, Lim J, Levi C, Faux S, Price C, Donnan G, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2011. The George Institute for Global Health and National Stroke Research Institute; August 2012, Report No 3, pages 44.

PUBLIC PRESENTATIONS (INVITED OR PEER REVIEWED)

In 2012, the following presentations about the Australian Stroke Clinical Registry were given:

Cadilhac DA, Lannin N, Lim J, Price C, Faux S, Levi C, Donnan G, Anderson C. Randomised comparative efficiency of telephone versus mail follow-up in the Australian Stroke Clinical Registry (AuSCR). European Stroke Conference, Lisbon, Portugal, May 2012.

Grabsch B on behalf of the AuSCR Management Committee. The Australian Stroke Clinical Registry - 2012 Update. Registry Special Interest Group, Melbourne, June 15th 2012.

Grabsch B on behalf of the AuSCR Management Committee. An introduction to the Australian Stroke Clinical Registry. Western Hospital, Melbourne, September 12th 2012.

Grabsch B on behalf of the AuSCR and Stroke123 teams. The Australian Stroke Clinical Registry - 2012 Update. The Florey Institute of Neuroscience and Mental Health, Stroke seminar, Melbourne, October 5th 2012.

Lannin N, Cadilhac D, Lim J, Hata J, Grabsch B, Donnan G, Dewey H, Anderson C on behalf of the AuSCR Management Committee. The Australian Stroke Clinical Registry: contributing to the quality of care and treatment outcomes in stroke. Austin Health Research Week, 15-19th October 2012. [POSTER]

Street S on behalf of the AuSCR Management Committee. Australian Stroke Clinical Registry in Queensland. Queensland Stroke Clinical Network Forum, May 2012.

Street S on behalf of the AuSCR Management Committee. Australian Stroke Clinical Registry in Queensland. Queensland Stroke Clinical Network Forum, November 2012.

ACKNOWLEDGMENTS

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

During 2012, members of the Management Committee (Dominique Cadilhac, Craig Anderson and Chris Levi) were supported by National Health and Medical Research Council (NHMRC) Fellowships that provide them with salary support to contribute to initiatives such as the AuSCR. Dominique Cadilhac's Fellowship was co-funded by the National Heart Foundation.

This report would not have been possible without the efforts of doctors, nurses, ward clerks and other relevant hospital staff who have contributed data to the AuSCR. Lead clinical staff for the AuSCR in 2012 at our participating hospitals are gratefully acknowledged:

New South Wales
Craig Anderson
Christie Britney
Susan Day
Melissa Gill
Geoffrey Herkes
James Hughes
Martin Jude
Erin Kerr
Chris Levi
Katherine Mohr
Elizabeth O'Brien
Rachel Peake
Elizabeth Ray
Fiona Ryan
Amanda Styles
Ian Wilson

Queensland
Pamela Atkinson
Pradeep Bambery
Haylee Berrill
Mary-Ellen Booker
Joanne Branch
Sean Butler
Carolyn De Wytt
Adel Ekaadious

Queensland (cont.)
Diane Fichera
Richard Geraghty
Rohan Grimley
Karen Hines
Francis Hishon
Renee Hull
Perry Judd
Sarah Kuhle
Paul Laird
Sue MacLean
Merv McAllister
Graham Mahaffey
Ian Mead
Meaghan Osborne
Donna Rowley
Arman Sabet
Noel Saines
Colleen Taylor
Eva Salud
Peter Simmons
Genevieve Skinner
Leah Thompson
Kim Walder
Richard White
Kaylene Williams
Ann Woolcock
Andrew Wong

Victoria
Chris Bladin
Ernie Butler
Chris Charnley
Douglas Crompton
Helen Dewey
Patrick Groot
Peter Long
Mark Mackay
Minh Phan
Anne Rodda
Zofia Ross
Kristen Rowe
Margaret Stevenson
Belinda Stojanovski
Jacqueline Venditti
Jamie Zanon

Western Australia
Tim Bates
Jennifer Blackburn
David Blacker
Naanke Noordzy

Tasmania
Helen Castley

CHAIRPERSON'S REPORT: STEERING COMMITTEE

The Steering Committee continues to oversee the governance and strategic direction of the Australian Stroke Clinical Registry (AuSCR) with two significant milestones in 2012. Firstly, the registry's data custodianship was transitioned from The George Institute for Global Health (Sydney) (TGI) to The Florey Institute of Neuroscience and Mental Health (Melbourne) (The Florey). Under the AuSCR Data Custodianship Policy, this process was approved by the Steering Committee on 20 February 2012. Secondly, the number of sites contributing data to the 2012 Annual Report grew to 31, almost double the number in 2011.

The data custodianship transition required exceptional planning and execution in the transfer of all processes and assets from one organisation to another. I would like to extend the Steering Committee's thanks to Craig Anderson, Joyce Lim and their staff at TGI who facilitated a smooth handover to Dominique Cadilhac and the newly appointed staff at The Florey. All processes were monitored and reviewed by the Steering Committee which was impressed with the professionalism and timeliness of the handover. As a consequence of the transition, the Steering Committee also reviewed and approved a number of the AuSCR updated policies.

2012 also saw the expansion of AuSCR sites with two noteworthy contributory factors. The awarding of an NHMRC Better Health Initiatives partnership grant (Stroke123 App No. 1034415; 2012-2015) to Dominique Cadilhac, and other investigators, provides funding for an initiative that will use AuSCR as a platform to monitor and improve hospital care and health outcomes associated with stroke. Significant additional financial contributions are to be provided by grant partners: Queensland Health, the National Stroke Foundation and Monash University. Dominique Cadilhac is to be congratulated for leading this successful application. Importantly, there is a Queensland based sub-study embedded within the Stroke123 protocol, which has facilitated significant expansion of the AuSCR in Queensland. Additionally, we value the support of the Victorian Stroke Clinical Network which provided funds to several Victorian hospitals to enable them to develop information technology solutions to support their AuSCR participation.

The funding received from state health departments, described above, raises the issue of ongoing support for registries, such as AuSCR, that do not have core funding and are reliant on research grants to maintain office support for participating hospitals. As stroke is the second leading cause of death in Australia, and the second leading cause of adult disability, federal and state governments need to recognise the valuable role that the AuSCR can play in providing unique and invaluable data on unwarranted clinical variations in care for people who have a stroke or transient ischaemic attack.

We are most appreciative that the members of the Steering Committee from 2011 have continued their commitment to being involved in AuSCR and I thank them for their dedication in 2012. On behalf of the Steering Committee, we look forward to AuSCR going from strength to strength in coming years.

Professor Sandy Middleton

CHAIRPERSON'S REPORT: MANAGEMENT COMMITTEE

The year 2012 saw increasing expansion in the number of hospitals participating in the AuSCR at the same time as the AuSCR data custodianship transitioned from The George Institute for Global Health (Sydney) to The Florey Institute of Neuroscience and Mental Health (Melbourne).

Within this context of change, the AuSCR Management Committee continued to meet monthly to oversee the day-to-day operations of the registry. New members to join the Management Committee included Helen Dewey, representing the Stroke Society of Australasia (SSA), and Kelvin Hill who has replaced Chris Price in representing the National Stroke Foundation (NSF).

Achievements in 2012 included:

- Thirty one sites contributing data to the 2012 Annual Report compared with 16 in 2011
- Submission, and approval, of ethics amendments for changes to data custodianship
- Enhancements to the AuSCR web-tool to improve the efficiency of the AuSCR Office processes
- As part of the Stroke123 project (referred to in the report from the Chair of the Steering Committee) a Queensland variables sub-set of the AuSCR data spine went 'live' in August to enable Queensland sites to collect information closely aligned to their previous quality assurance data collection process
- AuSCR Research Task Group review and approval of the 'Secondary Prevention in Stroke' project to utilise de-identified AuSCR data
- AuSCR presence at the NSF booth at the SSA/Smart Strokes conference in Sydney
- Presenting the AuSCR at the Registry Special Interest Group and Queensland Statewide Stroke Clinical Network meetings
- Negotiating donations from pharmaceutical companies to support some AuSCR operations

As the AuSCR grows, so does the volume of the routine day-to-day processes related to the participation of hospitals: ethics applications; training of hospital staff in data entry and access to live reports; data queries/entry/upload/cleaning; quality assurance (e.g. random patient files audits); and, follow-up of registrants 3-6 months post-stroke or TIA. The role of the Management Committee is to be constantly on the alert for appropriate funding sources to support the increasing volume of registry operations whilst trying to ensure minimum burden for staff at the participating hospitals.

All staff at The George and The Florey made significant contributions to the day-to-day operations of the AuSCR that ensured a seamless transition between the two institutions during the change of data custodianship. Staff at these institutions, along with the Management Committee members, worked diligently to ensure the AuSCR continues to build upon its firm foundation. As the volume of the registry data increases, so will the AuSCR's potential as a rich source of robust data for monitoring stroke treatment and outcomes, as well as providing information for future research.

Finally, I wish to thank Chris Price for his valuable contributions in setting up the AuSCR.

Professor Craig Anderson

FUNDING 2012

In 2012, the AuSCR office was supported by funds from The Florey, consumer donations, industry, and allocations from the NHMRC Stroke123 Partnership grant to support the AuSCR activities including expansion in Queensland. Support for senior researchers by the NHMRC, which provides salary via Fellowship awards, has assisted with containing staff costs. Further, substantial savings to the AuSCR Office in staff resources have been made possible because the National Stroke Foundation (NSF) provided significant in-kind support: providing shared booth resources at the 2012 SSA/Smart Strokes conference and, in particular, through the compilation and mailing of the AuSCR follow-up questionnaires which represents an in-kind contribution of approximately $10,000 to the project.

ORGANISATION	AMOUNT
The George Institute for Global Health (via NHMRC grant)	$22,620
Florey (via NHMRC grant)	$173,321
Florey (other)	$11,653
Queensland Health (Partnership grant)	$30,000
Monash University (Partnership grant)	$10,000
National Stroke Foundation (Partnership Grant)	$20,000
Industry (Ipsen)	$5,000
Consumer donations	$10,000
Other*	$1091
Total Funding received	**$283,685**

*Includes income from projects approved by the Research Task Group to access AuSCR data.

INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) Consortium and staff have great pleasure in presenting the 2012 Annual Report covering data collected from 1 January 2012 until 31 December 2012.

The 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 the various age groups. Further information about AuSCR and its development is available online at http://www.auscr.com.au or in our publication in the International Journal of Stroke (Cadilhac, Lannin et al, Int J Stroke 2010; 5(3):217-26).

The purpose of clinical quality registries is to measure quality of care.[2] The AuSCR adheres to the national guidelines for best-practice in clinical quality registries.[3] The overall goal of the AuSCR is to provide reliable and representative data that can be used to improve the quality of stroke care nationally. Presently, very few registries in Australia have national coverage.[4] The primary aim of AuSCR is to provide a mechanism to routinely and prospectively monitor the quality of acute stroke care in hospitals.[1] 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 uses an 'opt-out' consent protocol whereby all eligible cases are registered unless the patient or family nominates to have their data excluded via simple, cost-free avenues (free-call telephone number or postage-paid). Presently, each hospital has access to their own data and summary 'live' reports which the staff can download from the AuSCR to enable regular quality of care reviews.

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 2012, research to better understand the factors that impact on the quality of care and delivery of evidence-based stroke care was commenced through a four-year NHMRC Partnerships for Better Health grant. The awarding of this grant has permitted: greater expansion of the AuSCR in Queensland because it is the main source of data for the project; and closer collaboration with the National Stroke Foundation Audit program whereby the AuSCR variables form a sub-set of the National Stroke Foundation Acute Audit. In addition, a sub-study by post-doctoral neurologist Stacey Jankelowitz was approved by the Research Task Group, to permit a greater understanding of secondary prevention management: prescription rates for preventative medications at two intervention sites were to be compared with other hospitals contributing data to the AuSCR nationally. Another project approved in 2012 permitted the AuSCR registrants, who nominated to be contacted for further research, to participate in a large national survey of stroke survivors commissioned by the National Stroke Foundation. Following a mail-out to 602 eligible AuSCR registrants, coordinated by the AuSCR Office, the national Needs Survey was anonymously completed by 189 AuSCR registrants, which represented about 25% of the total survey population. Information on the findings of this important survey can be accessed at (http://strokefoundation.com.au/site/media/NSF700_SS_Needs_web2.pdf). In 2012, the *Fabry Disease in Stroke Screening Study,* led by Prof Craig Anderson, was finalising testing procedures before moving on to utilising the AuSCR as approved by the Research Task Group.

In this 2012 Annual Report, we provide information using data collected from contributing hospitals and the outcomes of registered patients who were able to be followed up 90 to 180 days after their first stroke registered in the AuSCR. We introduce more comprehensive graphs of performance by hospitals and health outcomes. We also provide case-mix adjusted comparisons of outcome for hospitals that have contributed at least 100 or more episodes of care into the registry in 2012.

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 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 highly valued support from the various state-wide Stroke Clinical Networks.

In 2012, our collaborations have expanded through the awarding of an NHMRC Partnerships for Better Health grant with Monash University and Queensland Health contributing funding, along with our existing partner the National Stroke Foundation. Additionally, there is significant in-kind support from various State Stroke Clinical Networks to explore the potential to better understand the quality of care in hospitals using data linkage between AuSCR and government data. An important achievement in facilitating this work is that we implemented the Queensland sub-set variables. Only Queensland hospitals can access the additional data page in the database. We also are collaborating with the Australian Catholic University through Professor Sandy Middleton to ensure the AuSCR registrants are not followed up at 90 days twice because they are also part of a stroke clinical trial (the T^3 Trial) being conducted in several hospitals which also use the AuSCR. Other new collaborations in 2012 include working with staff from the Australian Institute of Health and Welfare, the Population Health Research Network and Data Linkage units based in State Health Departments to work through the processes to enable the linking of the AuSCR data with government data such as the National Death Index (see Future Directions for further information).

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. The AuSCR has a Steering Committee whereby members agree to participate for a two-year period. The Steering Committee was chaired in 2012 by Professor Sandy Middleton. Other members of the Steering Committee in 2012 are listed in Appendix A. The purpose of the Steering Committee is outlined in agreed Terms of Reference and its primary role is in providing AuSCR governance, maintaining the confidence of all parties involved, and providing contributions to strategic direction. The committee has representatives from most states in Australia, as well as representation from clinicians, health informatics, epidemiology, consumers, the President of the SSA, and the Chair of the Management Committee. In 2012, the Terms of Reference were amended to include the incumbent Data Custodian as a member of the Steering Committee for the duration of their custodianship.

The Management Committee includes representatives from the consortium partner organisations, all members having clinical backgrounds in medicine, nursing or allied health. The Management Committee is responsible for the day-to-day operation of the AuSCR, with oversight from the Steering Committee, and works with AuSCR Office to manage the ongoing operations of the registry. For 2012, the Management Committee membership was as follows:

Chair: Professor Craig Anderson	The George Institute for Global Health
Membership:	
A/Professor Dominique Cadilhac	The Florey Institute of Neuroscience and Mental Health, Monash University
Professor Geoffrey Donnan	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
A/Prof Helen Dewey	Stroke Society of Australasia
Mr Chris Price (until December 2012)	National Stroke Foundation
Mr Kelvin Hill (replacing Chris Price from November 2012)	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 whilst ensuring the protection of privileged personal data located on the registry when it is to be used for research purposes by third parties. In 2012, the members of the Research Task Group were:

Chair:

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

Membership:

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

The 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). In 2012, an additional four variables were added to the AuSCR database for use in Queensland hospitals (Box 2). The 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 ask questions; and are provided with the various options available to request withdrawal of part or all of their data. These options include: submission of an opt-out form to the AuSCR Office; calling the 1800 telephone number (free) ; emailing the AuSCR generic email; or hospital staff using the opt-out function in the AuSCR database (see Appendix B). This approach is explicitly suggested for registries by the Privacy Commissioner in the document 'Guidelines for the Health Sector' (www.privacy.gov.au/materials/types/guidelines/view/6517). To this end, the AuSCR Office has

provided a patient information sheet for each participating hospital to use (or a locally modified version to meet ethics committee requirements) to inform patients of their rights. Where patients may leave hospital before receiving the information sheet, the hospital has a specific letter that is posted with the information sheet. This information sheet is also provided in the follow-up questionnaire pack at three months. 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. As part of record management, the AuSCR Office staff also keep records of all 'opt-out' consents to supplement information in the AuSCR database (see Improvements to Registry in 2012 section). Further information about the opt-out process in the AuSCR is available in the Hospital User Manual: (http://www.auscr.com.au/health-professionals/forms-manuals/hospital-user-manual/).

Staff, from participating hospitals enter data on all eligible patients either manually via the web-tool, by using a data import process or a combination of both. The AuSCR Office staff, with the assistance of the National Stroke Foundation, are responsible for contacting patients who are discharged from the participating hospitals 90 to 180 days after stroke and who have not refused follow-up or 'opted-out' of the registry. The AuSCR Office staff also provide: a five day helpdesk; support for completing ethics applications and annual ethics reporting or amendments; training for new hospital staff; quality control assessments to ensure hospital data are reliably obtained; as well as coordination of committee meetings necessary for the governance of the AuSCR.

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.

Box 1. The 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 inpatient 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)

Box 2. Additional Quality Indicators collected in Queensland as part of the AuSCR minimum dataset

Process indicators of evidence based care (Queensland only)

- mobilisation during admission
- swallow assessment and formal speech pathologist review
- aspirin administration <48 hours
- discharged on anti-platelets or antithrombotics

METHODS FOR ENSURING DATA QUALITY

In 2012, data quality in the AuSCR was assessed monthly and missing data reports were sent to hospitals by the 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 approximately 50 patients are entered in the registry. Following the audit, the site is given a data quality report and suggested ways of improving data quality are discussed with the AuSCR Office staff (this may also include additional training or amendments being made to data dictionary items which are ambiguous). At the end of 2012, hospitals were 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 the AuSCR. Originally an annual process, the intent is to conduct this exercise every six months in order to facilitate less burdensome data cleaning. This process also permits missing data in the AuSCR for ICD10 codes to be obtained.

IMPROVEMENTS TO THE REGISTRY IN 2012

Feedback on the perceived utility of the AuSCR has been obtained on an ongoing basis since its inception. The Management Committee reviews all information and feedback from users, and has worked with the AuSCR Office staff to prioritise modifications to processes, documents and the database within the available resources for the project. Since changes to the AuSCR database are expensive, and funds are limited for these activities, all desired enhancements need to be carefully scrutinised on cost-benefit criteria. In addition, making administrative processes more efficient is a priority since the number of hospitals has doubled and follow-up processes and registrant support (e.g. opt-out consent activity) have increased in an environment where funding for the registry remains very constrained.

The major enhancement to the Registry was the implementation of the Queensland sub-set of variables on 1 August 2012 (see Box 2). This work was co-ordinated by Ms Joyce Lim (Project coordinator, The George Institute for Global Health).

Improvements to the registry in 2012 included:

- Added default value of '999' to the Follow-up Questionnaire that relates to the question – *What number between 0-100 best describes your health today?* Previously, '0' was being used as the missing value and also represents a valid value and was therefore ambiguous and required manual checking of all surveys with a '0' entry for previous annual reports.
- A change to the business rule for calculating 'length of stay' in the live report, in which arrival date was replaced by admission date. Admission date is a mandatory item and hence the calculation is no longer affected by missing or default values used for missing arrival dates (e.g.01/01/1900) which created inaccurate averages.
- As highlighted in Box 2, there were an additional four quality indicator measures for the Queensland variables sub-set. To support implementation of these variables, a separate Queensland Data Dictionary and Hospital User Manual were drafted and field tested in 2012.

- Establishment of a separate database to track the number of opt-out consents. This was agreed following a review of the current limitations of in-built administrative functions in the AuSCR web-tool and the process used in other registries to keep records of opt-out consent.

- Establishment of a separate database management system for follow-up procedures to track registrants who have been sent the mailed survey and ensure non-responders, after two mailed attempts, are contacted by telephone[5]. This was agreed following a review of the current limitations of the in-built administrative functions in the AuSCR web-tool to ensure time consuming manual tracking process could be avoided.

RESEARCHERS REQUESTING TO USE DATA FROM THE AUSCR

In 2012, there were no new applications submitted to the Research Task Group.

2012 DATA ANALYSIS METHODS

The data presented in this annual report includes all patients registered in the AuSCR database and admitted to the participating hospitals between ***1 January and 31 December, 2012***. Data entry for acute stroke/TIA episodes and follow-up assessments were closed off on 30 June 2013. Data for these analyses were extracted from the AuSCR database on 13 August 2013.

Statistical analyses were performed using STATA software (version 12.1 for windows, Stata Corporation PL) by Monique Kilkenny, Senior Research Officer at the Translational Public Health Division (Stroke & Ageing Research Centre) of Southern Clinical School at Monash University, under the supervision of Dominique Cadilhac using de-identified data supplied securely by the AuSCR Data Manager Francis Kung. The presentation of data was principally based on formats presented in the 2009-2011 Annual Reports as developed by Natasha Lannin and Dominique Cadilhac and the AuSCR Management Committee. The tables on completeness of case ascertainment and data (Tables 1 to 5) were analysed by Emily Warren (4th year Health Information Management student from Latrobe University) under the direction of Francis Kung (AuSCR Data Manager) who ensured that the follow-up data only included relevant 2012 cases e.g. only for those whose stroke onset date was in 2012.

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. Data cleaning was undertaken before the raw data were extracted.

In the final raw data extracted on 13 August, 2013, there were 4573 patient records and 4735 acute stroke/TIA episodes. One hospital (Hospital number 49, n=1 patient) had data recorded in the AuSCR in 2012, but was excluded from these analyses as ethics approval was granted in 2013. Therefore, the final dataset reported in this document includes information on 4572 patients with 4734 acute stroke/TIA episodes. A description of the methods for analysing adherence to the process of care (quality indicator) variables is provided in Appendix C.

To evaluate the ***completeness of case ascertainment***, each 2012 participating hospital was requested to send us the hospital record of patients who were admitted to the hospital during 2012 with ICD10 codes of stroke/TIA (i.e. G45.9, I61.0-I61.9, I62.9, I63.0-I63.9 and I64). Hospital records were then matched to the AuSCR database to detect *potentially missing* episodes of stroke or TIA. The lists of potentially missing episodes were sent to the hospitals and the AuSCR Office staff sought explanations for missing

episodes (for example, episode may have been misclassified as acute stroke or TIA). Once the data verification was finalised following these reviews, the proportion of completeness for case ascertainment was estimated using the following formula A/ (A+B) where 'A' was the number of episodes which were registered in the AuSCR and 'B' was the missed episodes in the AuSCR database.

Follow-up data were analysed using descriptive statistics and multi-variable logistic regression with adjustment for patient case-mix using age, gender, stroke type, inpatient stroke or transferred patient as appropriate. Since each individual patient is only able to be followed-up once, based on their first registered episode of care, these analyses only include registrants eligible for follow-up in 2012 and who had their data entered in the AuSCR within approximately 180 days of the index stroke onset. ***Case-mix adjusted outcome comparisons by hospital*** are also presented in a de-identified format. These analyses were only conducted on hospitals that had submitted 100 or more episodes in 2012 and excluded inpatient strokes and transfers from another hospital, since health outcomes may be impacted by these factors. Case-mix adjustment variables included: age, gender; stroke type; and ability to walk on admission. For these multivariable logistic regression analyses, we compared eligible hospitals to the reference hospital that was found to have the fewest deaths in 2012.

FINDINGS FROM DATA COLLECTED IN 2012

HOSPITALS

In 2012, 31 hospitals provided data for the AuSCR which is an almost two-fold increase from 2011 (16 hospitals). Collection from one hospital which participated in 2010 was on hold from January 2011, and a further 15 new hospitals joined the AuSCR during 2012. Figure 1 shows the incremental shift in numbers of hospitals participating in the AuSCR.

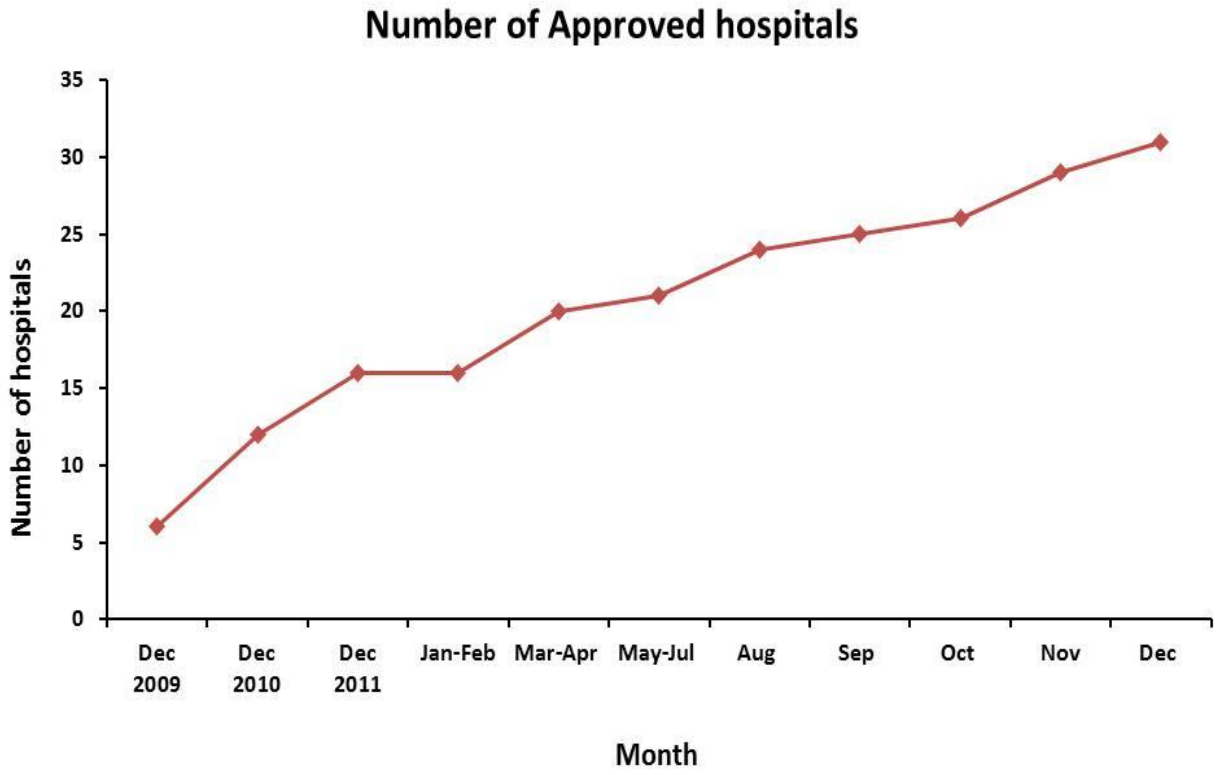

Figure 1: Number of participating hospitals in 2012

The characteristics of the 2012 participating hospitals are shown in Table 1. In 2012, there were eight hospitals located in New South Wales (NSW), 15 in Queensland (QLD), six in Victoria (VIC), one in Western Australia (WA), and one in Tasmania (TAS). There were 14 hospitals that had 100 or more registrations of stroke/TIA episodes during 2012. There were 16 hospitals located in metropolitan areas, 28 hospitals that had stroke units and 22 hospitals provided thrombolytic therapy using tissue plasminogen activator (tPA). Two of the 31 hospitals were private hospitals and one was a children's hospital.

Table 1: Characteristics of participating hospitals

Year	2009	2010	2011	2012				
	Total	Total	Total	Total	NSW	QLD	VIC	WA	TAS
Number of hospitals	6	12	16	31	8	15	6	1	1
Annual number of episodes in AuSCR*									
Low (<33 episodes)	-	1	4	11	3	6	2	-	-
Medium (33-99 episodes)	1	5	2	6	1	5	-	-	-
High (≥100 episodes)	5	6	10	14	4	4	4	1	1
Location									
Metropolitan	6	10	11	16	2	7	5	1	1
Rural	-	2	5	15	6	8	1	-	-
Stroke unit	6	10	14	28	7	14	5	1	1
tPA undertaken	6	9	10	22	5	10	5	1	1

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

NUMBER OF REGISTRANTS

In 2012, there were 4572 patients registered in AuSCR (Table 2). During a calendar year, patients may have multiple admissions for stroke or TIA that are also eligible to be included in AuSCR. In 2012, there were 4734 episodes of acute hospital care entered in AuSCR for the 4572 individuals registered. Individual patients who had multiple episodes registered included 162 patients (3%) of whom 153 had 2 episodes, nine had 3 episodes (eight were all stroke episodes and one all TIA episodes). Multiple episodes were captured from 18 hospitals that had also provided the majority of data (n=2940 episodes combined). The minimum number of episodes registered for any particular site was four at a rural NSW hospital and the maximum number registered was at a metropolitan Victorian hospital (n=630). The median number of episodes was 55 (Q1, Q3: 24, 174).

Table 2: Number of hospitals, patients and episodes in 2012

Number of hospitals contributing data	31
Number of episodes submitted	4734
Number of patients	4572
Number and % of multiple episodes	162 (3%)

CASES REGISTERED PER MONTH

Figure 2 shows the number of episodes (including multiple episodes) per month. The median number was 372 per month. The minimum was 306 in April and the maximum was 519 in October.

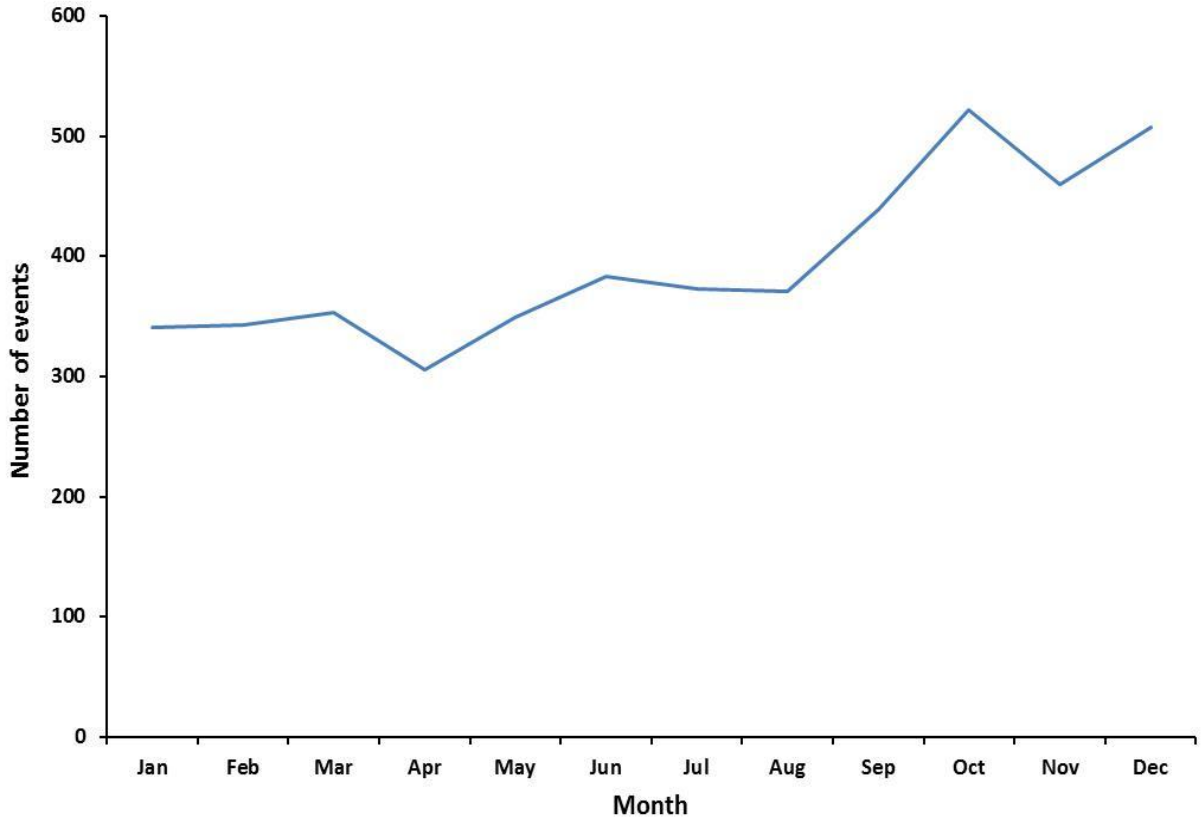

Figure 2: Number of episodes per month in 2012

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

Among the 4734 episodes of care, the median number of days from the admission to the creation of the patient record in AuSCR was 83 days (Q1 to Q3: 33 to 159 days). The shortest median number of days was one day, and the largest median number of days was 536 days. These data at a hospital level may be influenced by several factors such as numbers of eligible admissions, as well as the method of data capture and entry.

REGISTRANTS WHO NOMINATED TO OPT-OUT OF THE AUSCR

As highlighted, 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). During 2012, 215 (4.7%) opt-out requests were received from hospital staff or patients (Table 3). The total number of opt-out requests varied by hospital and ranged from 0 to 46. The breakdown of opt-outs for either personal or episode data or follow-up refusal is listed in Table 3. Overall, 86 (1.9%) of patients in 2012 wanted all of their personal and data removed from the registry.

Table 3: Opt out Requests and Fields

Total opt-out cases	Complete episode and demographic data removed	Complete episode data removed	Demographic data removed	Refusal for follow-up
215	86	91	134	172

DATA COMPLETENESS

A summary of the completeness of hospital collected data for the majority of fields within the registry for the 4734 episodes, from 4572 patients, in 2012 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 [tPA]).

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

Field	2009# % complete	2010 % complete	2011 % complete	2012 n (% complete)
Person details (n=4572)				
First name	100	100	100	4572/4572 (100%)
Surname	100	100	100	4572/4572 (100%)
Date of birth	100	100	100	4536/4572 (99%)
Medicare number	67	90	92	4190/4572 (92%)
Patient contact (n=4572)				
Available (complete or partial for street address, suburb and state)	95	99	99	4572/4572 (100%)
Complete (street address, suburb and state)	97	55	93	4572/4572 (100%)
Telephone for patient (landline or mobile)	90	96	94	4244/4572 (95%)
Emergency and alternate contacts (n=4572)				
Address for one or both of emergency and alternate contacts	71	47	78	3429/4572 (75%)
Address for one contact	62	40	69	3017/4572 (66%)
Address for both contacts	10	7	9	411/4572 (9%)
Telephone for emergency and/or alternate contact (landline or mobile)	92	94	90	2469/4572 (54%)
General practitioner contacts (n=4572)				
Address	73	46	84	2972/4572 (65%)
Telephone for general practitioner (landline or mobile)	75	71	82	2880/4572 (63%)
Patient characteristics (n=4572)				
Title	99	97	100	4572/4572 (100%)
Hospital medical record number	100	100	100	4564/4572 (100%)
Gender	99	98	100	4541/4572 (100%)
Country of birth	92	98	95	4423/4572 (97%)
Language spoken	97	84	96	3924/4572 (86%)
Indigenous status	100	100	100	4526/4572 (99%)
Interpreter needed	100	84	100	4388/4572 (96%)

Table 4, continued

Field	2009# % complete	2010 % complete	2011 % complete	2012 n (% complete)
Episode data (including multiple episodes) (n=4734)				
Date of arrival	100	100	100	4506/4734 (95%)
Time of arrival	100	99	97	4344/4734 (92%)
Date of stroke onset	100	100	100	4734/4734 (100%)
Date of admission	100	100	100	4734/4734 (100%)
Transfer from another hospital	100	100	99	4656/4734 (98%)
Stroke occurs while in hospital	100	99	99	4626/4734 (98%)
Able to walk independently on admission	100	95	91	4264/4734 (90%)
Documented evidence of a previous stroke	100	98	92	4357/4734 (92%)
Treated in a stroke unit	100	99	100	4678/4734 (99%)
Type of stroke	100	100	100	4722/4734 (100%)
Use of intravenous thrombolysis (if ischaemic stroke)	100	98	97	2937/3106 (95%)
Cause of stroke	100	100	100	3868/4734 (82%)**
ICD10 coding (including multiple episodes) (n=4734)*				
Diagnosis code	63	65	96	4491/4734 (95%)
Medical conditions	-	220	913	1904/4734 (40%)
Complications	1	65	170	1213/4734 (26%)
Procedures	6	7	649	1884/4734 (60%)
Discharge information (including multiple episodes) (n=4734)				
Deceased status	100	100	100	4734/4734 (100%)
Date of death (if deceased status is yes)	100	100	100	620/621 (100%)
Date of discharge (if not deceased while in hospital)	87	97	98	3939/4113 (96%)
Discharge destination (if not deceased while in hospital)	87	97	97	3993/4113 (97%)
Discharge on antihypertensive agent (if not deceased while in hospital)	87	92	90	3993/4113 (97%)
Evidence of care plan on discharge (if not deceased while in hospital)	87	91	91	3220/4113 (78%)**

*Note that not every patient will have other medical conditions, complications and procedures coded therefore the denominator is unknown. **The completeness of these variables is lower in 2012 compared with 2009-2011 due to technical issues with the AuSCR database; # Only approximately 6 months of data were collected during 2009, the pilot year.

Completeness of case ascertainment

Among 31 participating hospitals, 13 (42%) hospitals sent us their hospital records for all 2012 stroke and TIA admissions (see page 16), and of these 9 (29%) hospitals had participated in the AuSCR for a full year (Table 4). Table 5 shows the number of episodes that were registered (A) or missed (B) in the AuSCR database and the proportion of completeness for case ascertainment. From the hospitals that provided data for this review, case-ascertainment ranged from 51% to 100%. Processes to improve participating in this aspect of quality control for the registry are outlined in ***Future Directions*** on page 37.

Table 5: Summary of the case ascertainment

Hospital	Episodes in the database (n)	Episodes missed in the database (n)	Completeness
9†	146	18	76%
10	12	Not provided	
11†*	456	0	100%
12†*	609	408	60%
13†*	542	0	100%
15†	69	15	82%
16†	170	11	94%
17	237	Not provided	
18†	165	161	51%
19	20	0	100%
20†	174	20	81%
21†	137	16	82%
22†	458	Not provided	
23†*	584	Not provided	
25	13	Not provided	
26	9	Not provided	
27	22	Not provided	
28	190	Not provided	
29*	147	Not provided	
30	24	Not provided	
31	44	Not provided	
32	114	0	100%
34	27	6	82%
35	42	Not provided	
36	22	Not provided	
37	4	Not provided	
39*	39	Not provided	
40	25	Not provided	
41*	13	Not provided	
42	44	Not provided	
43	52	25	68%

Patients who opted out of participation in the AuSCR do not appear in the above table.
Not provided: data are not available as not provided by hospital
*These 7 hospitals use the data import function.
†These 11 hospitals participated in the AuSCR for the full 2012 year.

REGISTRANT CHARACTERISTICS

Table 6 shows the baseline characteristics for patients or episodes. Although paediatric characteristics are included in this table, these patients and episodes (n=20) were excluded from analyses.

Among the 4552 adult patients, the most common country of birth was Australia (71%) followed by the United Kingdom and Italy. The remainder were from a range of mainly European or Asian nations. There were 29 patients (1%) who identified as having an Aboriginal or Torres Strait Islander background. The majority of the registered patients spoke English (92%). The registrants comprised 2159 (48%) females and the mean age was 74 years. There were 487 patients (11%) aged less than 55 years and 579 patients (13%) were aged between 55 and 64 years.

From the total 4714 episodes, there were 3086 ischaemic strokes, 694 intracerebral haemorrhage (ICH), 717 TIAs, 205 episodes of undetermined type and 12 episodes with missing data. 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 4727 episodes, the patient was able to walk at the time of admission in about 43% of admissions.

Table 6: Baseline characteristics by patients (adults and paediatrics) and episodes

	Adults (n=4552)	**Paediatrics (n=20)**
Patients (n=4552)		
Age, mean (SD)	74 (14)	-
Age, median (Q1 to Q3)	76 (66 to 84)	5 (0.3 to 13)
Gender, female, n (%)	2159/4521 (48%)	7/20 (35%)
Country of birth, n (%)		
Australia	3005/4213(71%)	17/19 (89%)
United Kingdom	297/4213 (7%)	1/19 (5%)
Italy	151/4213 (4%)	
Other European countries	366/4213 (9%)	
Asia	197/4213 (5%)	1/19 (5%)
Others	197/4213 (5%)	
Aboriginal and/or Torres Strait Islander, n (%)	29/4552 (1%)	0
English spoken, n (%)	3582/3904 (92%)	18/20 (90%)
Episodes (including multiple episodes) (n=4714)	**Adult Episodes (including multiple episodes) (n=4714)**	**Paediatric Episodes (n=20)**
Type of stroke, n (%)		
Ischaemic	3086/4702 (66%)	20/20 (100%)
Haemorrhagic	694/4702 (15%)	
TIA	717/4702 (15%)	
Undetermined	205/4702 (4%)	
Able to walk on admission, n (%)	1805/4244(43%)	5/20 (25%)
Length of hospital admission (days), median (Q1 to Q3)	5 (2 to 9)	11 (5 to 33)
Cause of stroke known, n (%)	1764/3853 (46%)	3/15 (20%)

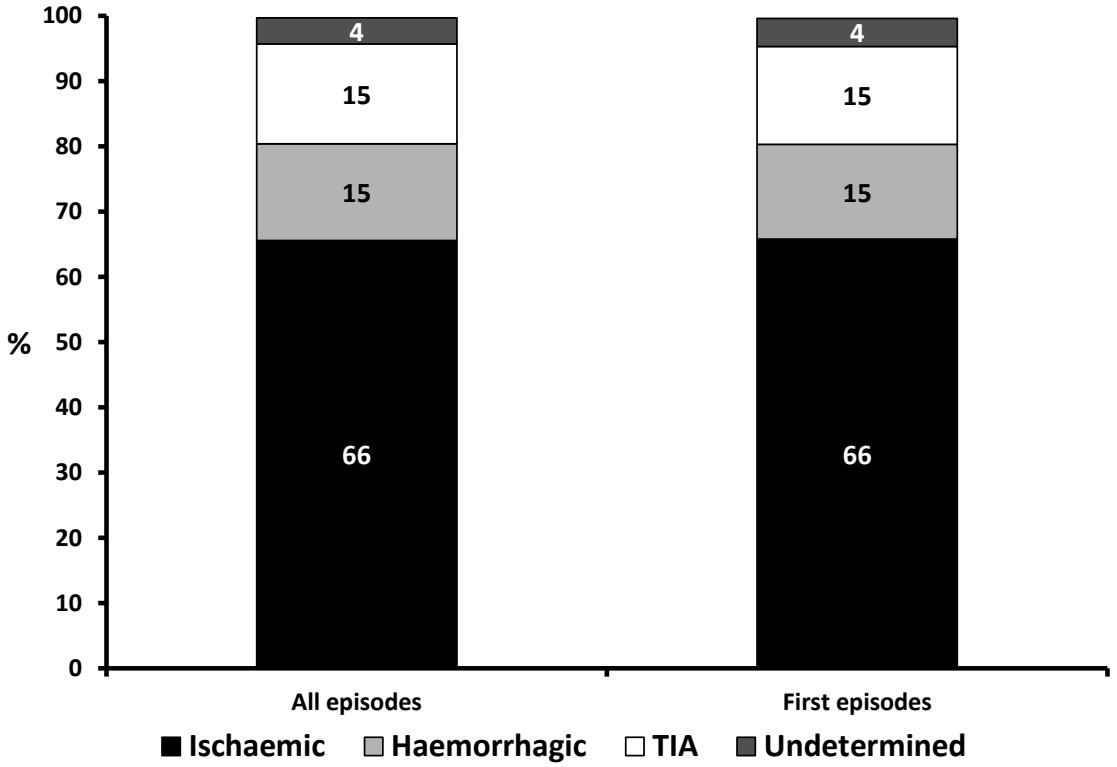

Figure 3: Distribution of stroke subtypes in all and the first episodes

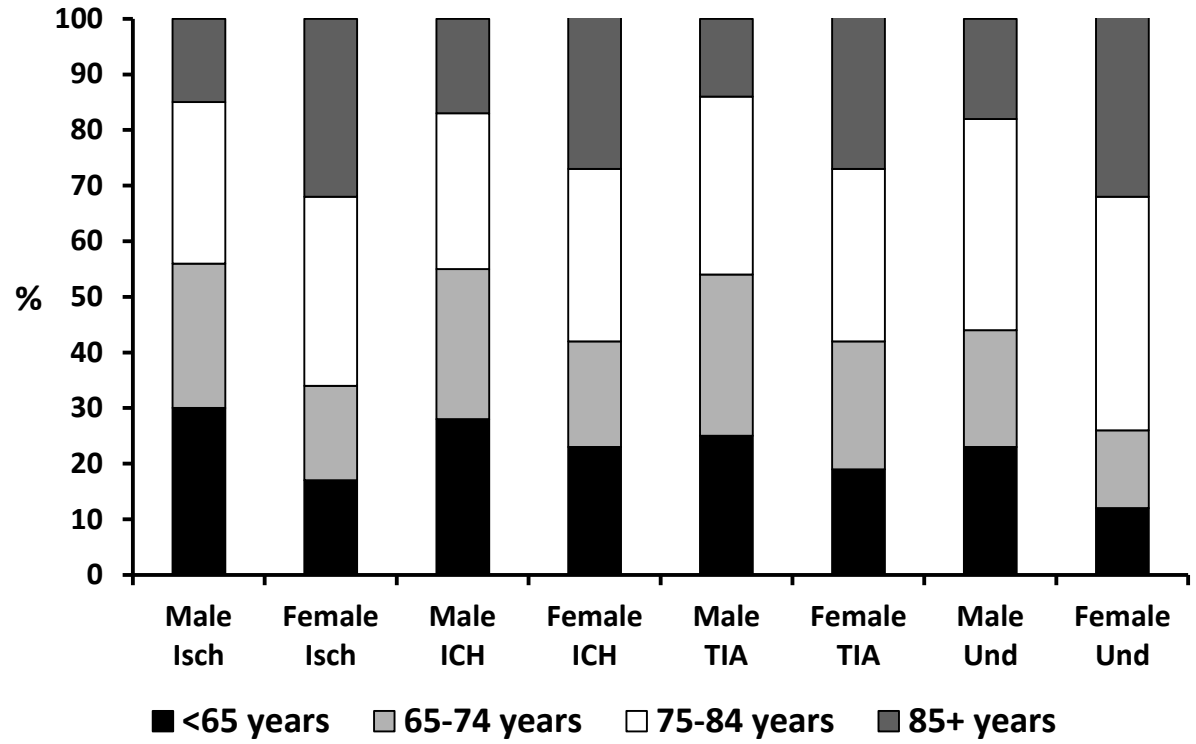

Figure 4: Distribution of stroke subtypes by sex and age groups (including multiple episodes)

PROCESSES OF HOSPITAL CARE

Of the 4714 episodes, there were 623 episodes (13%) transferred from another hospital and 298 episodes (7%) of inpatient stroke whilst patients were already in hospital for another condition. The majority of the inpatient strokes were ischaemic (n=208, 70%) and most of these (n=105, 35%) occurred among patients aged between 75 and 84 years. The median length of stay was longer for patients who had a stroke while already in hospital (inpatient median 14 days [Q1 to Q3: 6 to 24 days] vs. median 5 days [2 to 9 days] for non-inpatient stroke admissions, p<0.001).

OVERALL ADHERENCE TO QUALITY INDICATORS

Adherence to the process of care indicators collected in the AuSCR is outlined in Table 7. Most patients registered in the AuSCR were treated in a stroke unit and about two-thirds received a care plan at time of discharge. Adherence to each of these quality indicators by participating hospital, and by number of episodes registered in 2012, is presented in a de-identified format in Appendix D and Appendix E respectively.

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

Hospital Stroke Care	All episodes	Ischaemic	TIA
Patients admitted to a stroke unit	3506/4714 (74%)	2512/3086 (81%)	482/717 (67%)
Patients who received intravenous thrombolysis (tPA) if an ischaemic stroke	n/a	366/3086 (12%)	n/a
Patients discharged (not deceased while in hospital)	4060/4590 (89%)	2699/3014 (90%)	714/715 (100%)
Patients discharged on an antihypertensive agent (if not deceased while in hospital)	2348/3944 (60%)	1634/2645 (62%)	422/688 (61%)
Patients who received a care plan at discharge (if not deceased while in hospital)	1607/2384 (67%)	1122/1564 (72%)	296/521 (57%)

n/a: not applicable

There was no difference in the age of patients admitted to stroke units among the hospitals (mean age if managed on a stroke unit 74 years (SD 14) and non-stroke unit mean age 74 years (SD 14) (p=0.67) (Figure 5). In addition, there were more patients with ischaemic stroke treated in a stroke unit than the other types of stroke (p<0.001) (Figure 6).

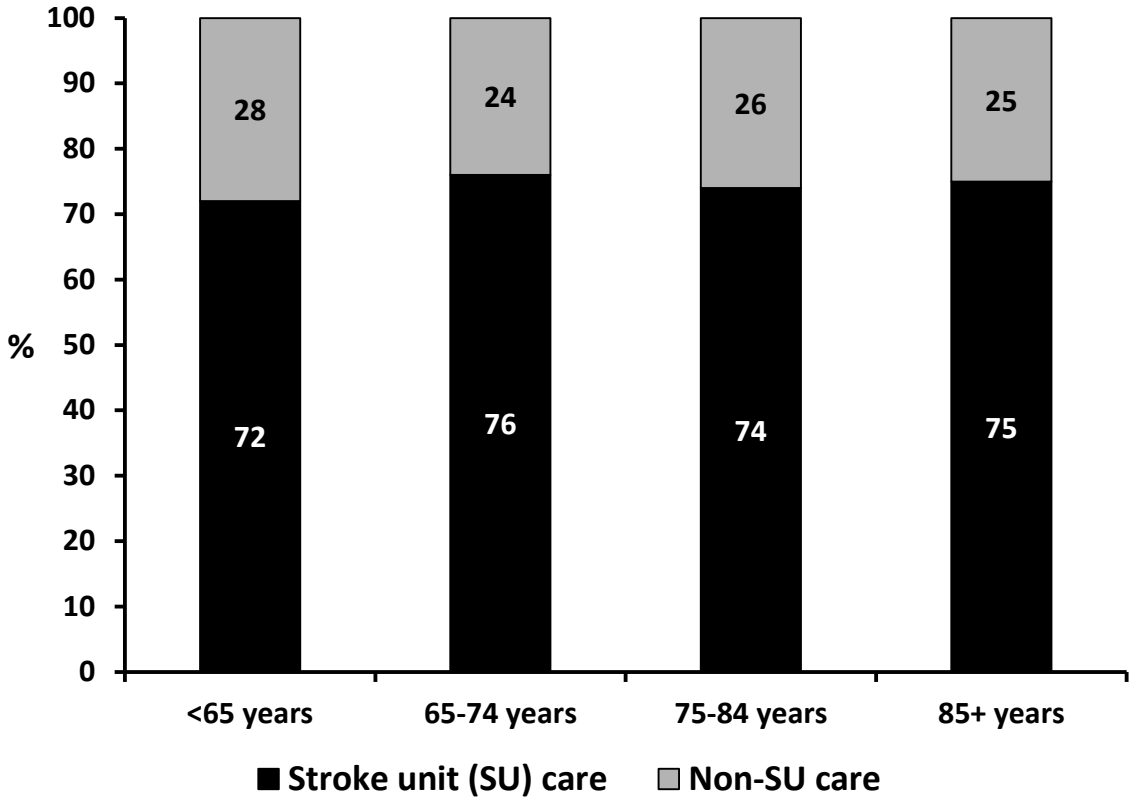

Figure 5: Management in a stroke unit according to age group (including multiple episodes)

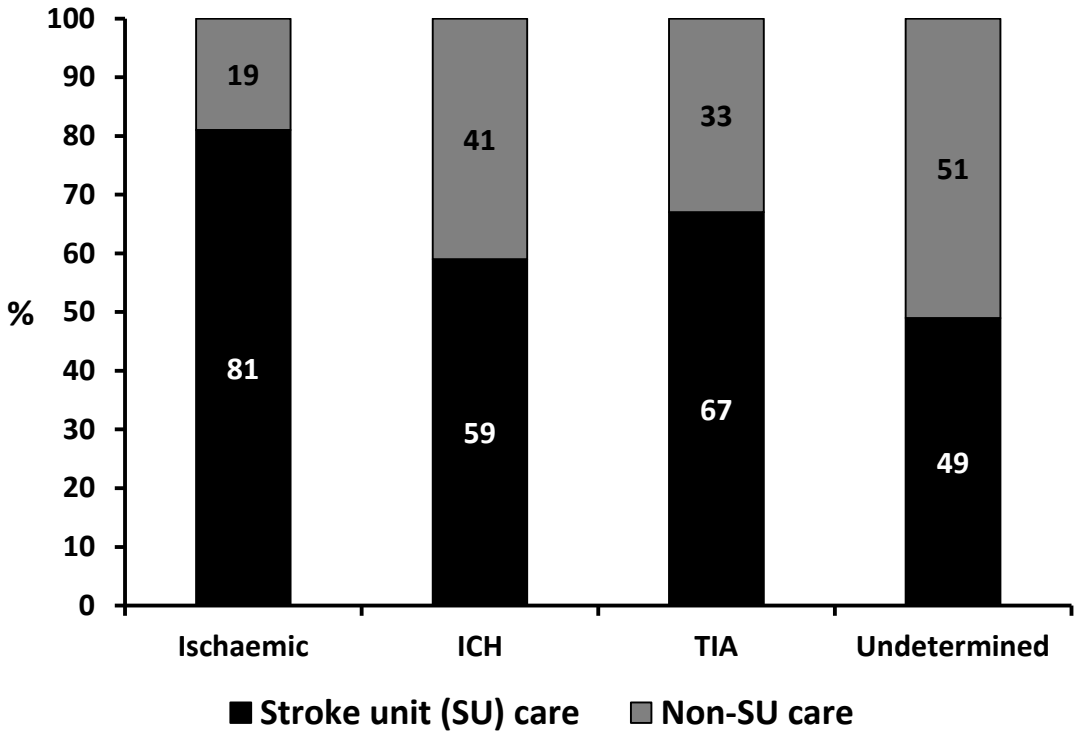

Figure 6: Management in a stroke unit according to stroke subtype (including multiple episodes)

PATIENTS ADMITTED WITH TRANSIENT ISCHAEMIC ATTACK

Among the 717 episodes of TIA, the mean age was 74 years (SD 13 years) and 49% were female. One patient with TIA was reported to have died while in hospital. The median length of stay was two days (Q1 to Q3: 1 to 4 days). Of those who were discharged, 57% received a care plan and 61% were discharged on an antihypertensive agent (Table 7). Most patients (85%, n=608) were discharged to a home setting and 4% (n=28) went to rehabilitation. Using the principal diagnoses discharge coding provided by hospitals: 92% of TIA episodes were coded as TIA, 5% of TIA episodes were coded with stroke codes, and 3% with other diagnostic codes.

Using the principal diagnoses discharge coding provided by hospitals, 82% of ischaemic stroke episodes were coded within the I63 range (I63.0-I63.9), 10% of ischaemic stroke episodes were coded as I64 codes, and 8% with other diagnostic codes.

OVERALL ADHERENCE TO QUALITY INDICATORS SPECIFIC TO QUEENSLAND HOSPITALS

Adherence to the additional quality indicators collected in the AuSCR for Queensland is outlined in Table 8. About two-thirds of Queensland patients registered in the AuSCR were mobilised during admission. Of the 245 patients who were unable to walk independently, the method of mobilisation was either walking (50%), standing (25%) or sitting (25%). Approximately one-third were assessed for dysphagia, about half received aspirin within 48 hours, and three in five patients with ischaemic stroke or TIA were discharged on anti-platelets or antithrombotics.

Table 8: Stroke evaluation and therapy (including multiple episodes): Queensland specific variables

Hospital Stroke Care	All episodes	Ischaemic	TIA
Mobilisation during admission	621/913 (68%)	373/542 (69%)	168/216 (78%)
Same day or day after admission	513/621 (83%)	298/373 (80%)	155/168 (92%)
If unable to walk independently , patient mobilised	245/422 (58%)	176/292 (60%)	31/47 (66%)
Same day or day after admission	179/245 (73%)	125/176 (71%)	30/31 (97%)
Dysphagia screen tool used within 24 hours	320/913 (35%)	219/542 (40%)	63/216 (29%)
Screen or swallow assessment undertaken	583/913 (64%)	386/542 (71%)	116/216 (54%)
Within 24 hours	413/913 (45%)	270/542 (50%)	91/216 (42%)
Aspirin administration within 48 hours	463/816 (57%)	305/542 (56%)	131/216 (61%)
Discharged on antiplatelets or antithrombotics	453/693 (65%)	299/464 (64%)	141/202 (70%)

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 five days (Q1 to Q3: 2 to 9 days). Among the 4060 episodes where the patient was discharged, 8% (n=303) of episodes had a length of stay of 21 days or more. Similar to our

findings in 2011, there was a statistically significant difference between the length of stay for episodes treated in stroke units (median 5 days, Q1 to Q3: 3 to 10 days) and those not managed in stroke units (median 4 days, Q1 to Q3: 1 to 9 days) (p<0.001). This may be due to more severe cases being treated in the stroke unit and requires further exploration. Regardless, these lengths of stays are very short (and 2 days shorter than the median for stroke unit in 2011 which was 7 days) and may indicate better transitions to the next phase of care at these hospitals. Patients with TIA were more likely to have a short length of stay (less than 4 days) compared to patients with stroke (75% TIA, Stroke 41%, p<0.001).

DISCHARGE STATUS

In 2012, the majority of registered patients were discharged directly to a home environment (n=2103; 52%), (Figure 7). Patients managed in a stroke unit had a 1.4 fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed on a stroke unit (95% confidence interval [CI] 1.2 to 1.8) 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.

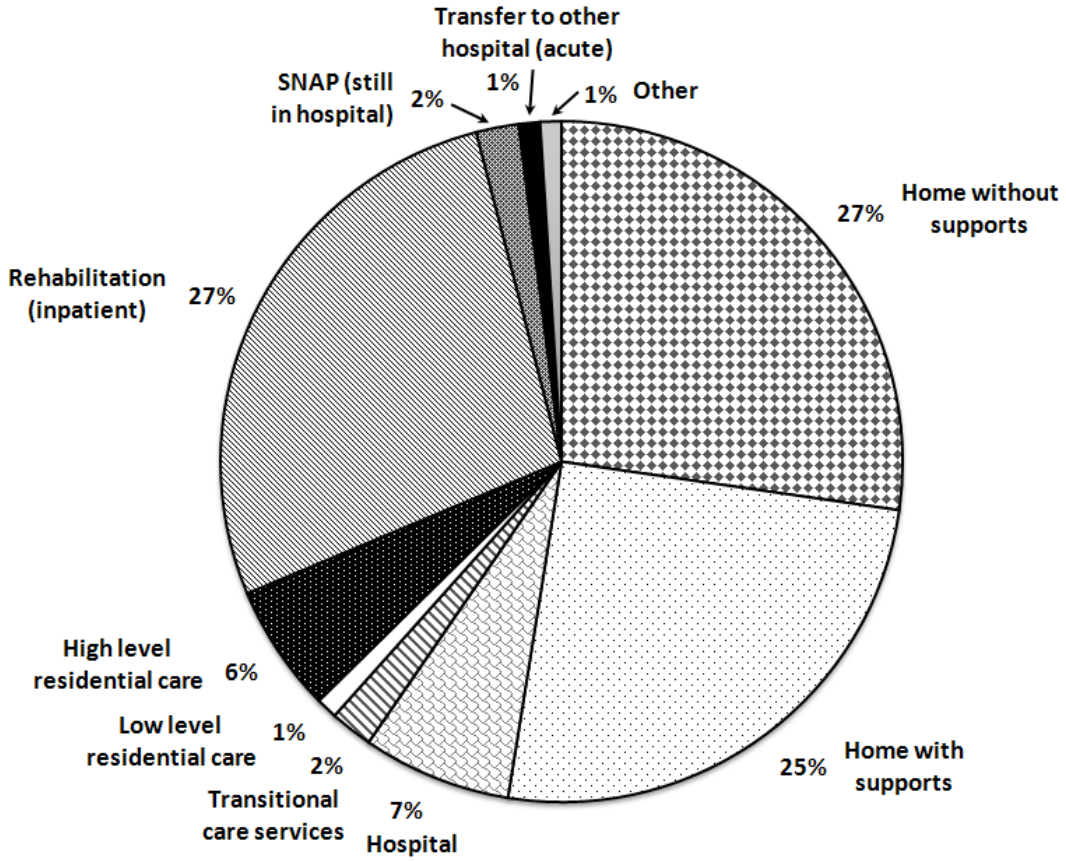

Figure 7: Discharge status including multiple episodes (excludes patients who died in hospital), n=4060

DEATHS IN HOSPITAL

Of the total number of 4435 registered adult patients with discharge destination recorded (i.e. excludes <18 years paediatric cases), 517 (12%) patients died whilst 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*=0.14). There were no paediatric in-hospital deaths reported. We found that there were differences among the hospitals in the odds of dying in-hospital for first-episode stroke admission in 2012 and this requires further investigation (Appendix F).

Figure 8: Case fatality (the 1st episode only) from admission date to 90 days (n=4552)

POST-DISCHARGE HEALTH OUTCOME INFORMATION

The following section provides findings from the patients who were eligible for follow-up in 2012.

MEDIAN TIME TO FOLLOW-UP

There were 4552 patients registered in 2012. Since 79 patients had a previous registration in 2009, 2010 or 2011 (including 9 patients who died during hospitalisation in 2012), 4473 (98%) registrants were eligible for follow-up three to six months following their stroke or TIA. Of these 4473 registrants, 180 (3%) registrants had indicated a refusal for follow-up and 602 (14%) registrants were known to have died leaving 3691 (83%) registrants for follow-up. Seventy-seven (2%) refused follow-up assessments, 856 (23%) were not followed-up because their primary data were entered into the AuSCR system after the 180 day limit; and a further 557 (15%) registrants were lost to follow-up. There were no follow-ups that remained in progress.

As of 21 June 2013, follow-up was completed for 2201 (60%) registrants (Figure 9). In 2012, median time from the stroke onset to the completion of follow-up for the 2201 patients was 148 days (IQR 126 to 173 days). A total of 602 (13%) patients had already died prior to generating the follow-up survey, therefore a total of 3691 (83%) patients had follow-up data after discharge.

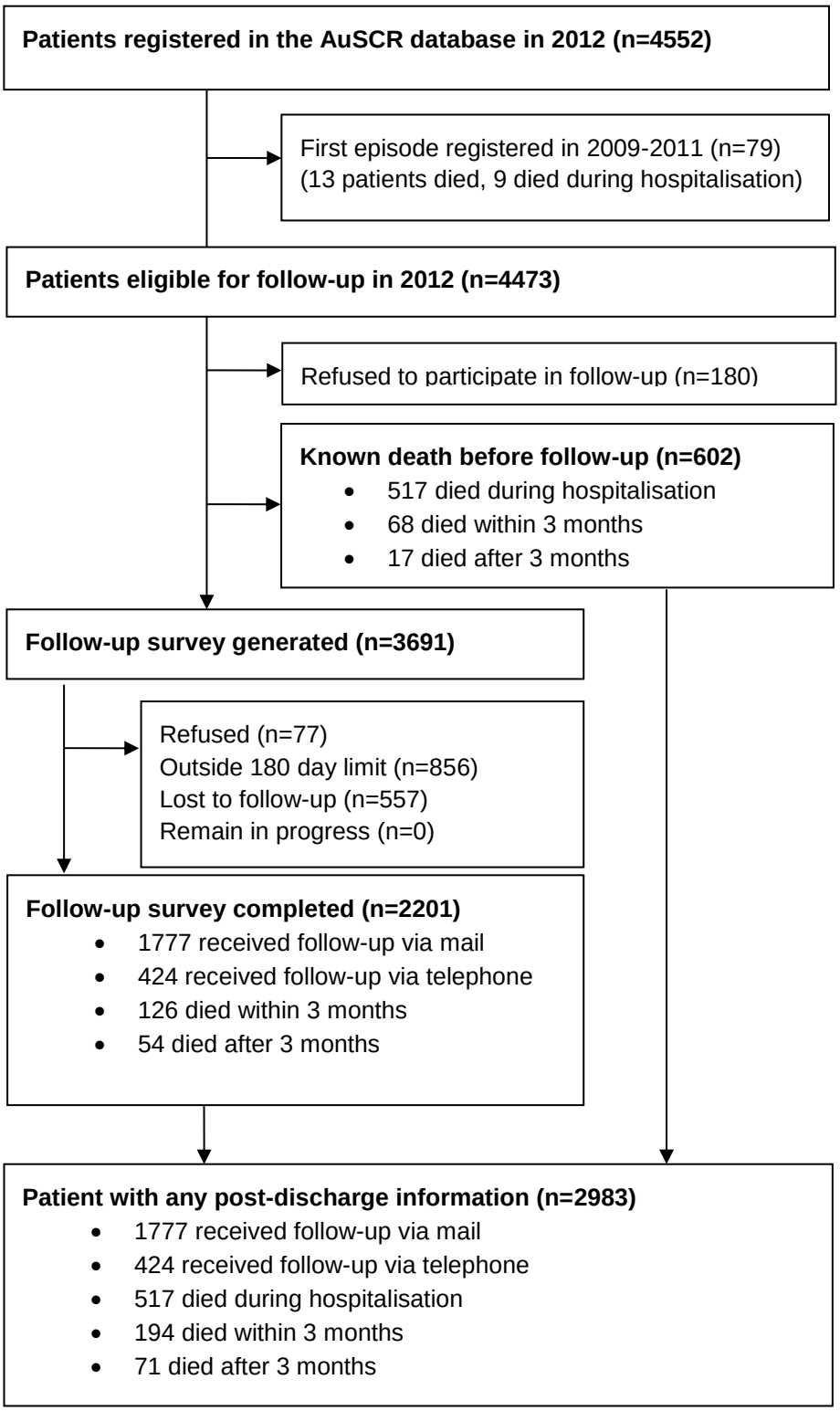

Figure 9: Flow diagram of the follow-up assessments for patients admitted in 2012

Characteristics of the 2983 registrants with any post-discharge information are summarised in Table 9. The mean age was 75 years and 48% were female; 67% of them had an ischaemic stroke.

Table 9: Baseline characteristics for 2983 registrants with (and 1490 registrants without) any post-discharge information

	Patients with any post-discharge information (complete follow-up or death) (n=2983)	Patients without post-discharge information (refused, lost, after 6 month, or in progress) (n=1490)	*p* value
Age (years), mean (SD)	75 (13)	72 (15)	<0.001
Gender, female, n (%)	1430/2963 (48%)	689/1479 (46%)	0.29
Aboriginal and/or Torres Strait Islander, n (%)	16/2983 (1%)	13/1490 (1%)	0.19
Type of stroke, n (%)			0.001
Ischaemic	2006/2981 (67%)	937/1482 (63%)	
Haemorrhagic	432/2981 (15%)	216/1482 (15%)	
TIA	441/2981 (15%)	246/1482 (17%)	
Undetermined	102/2981 (3%)	83/1482 (6%)	
Able to walk on admission, n (%)	1072/2743 (39%)	648/1283 (51%)	<0.001
Length of hospital admission (days), median (IQR)	5 (2 to 9)	5 (3 to 11)	<0.001
Treated in a stroke unit, n (%)	2293/2983 (77%)	1040/1490 (70%)	<0.001

SURVIVAL

Of 2983 registrants with post-discharge information available, 711 registrants (24%) had died within 3-months of admission (inclusive of the 517 registered in-hospital deaths) (Figure 10 and Table 10). Case fatality for women was significantly greater than for men (p=0.05) after adjustment for age within three months following stroke. At the time of the follow-up assessment (>3 months after stroke), a further 71 registrants were reported to have died. We found that there were differences among the hospitals in the odds of dying for first stroke episode in three to six months post stroke or TIA and this requires further investigation (Appendix F).

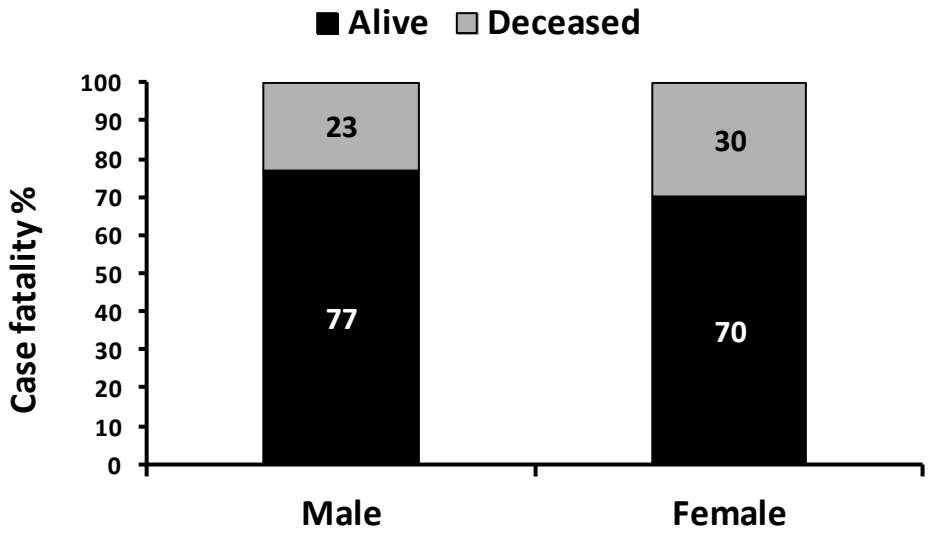

Figure 10: Three to six month case fatality (n=2983, n=782 deaths)

There were 2201 registrants who were able to answer all or some of the questions at follow-up. The main follow-up results are summarised in Table 10.

Table 10: Post-discharge information

Follow-up status	**n/N (%)**
Registrants who died	782/2983 (26%)
Died during hospitalisation	517/2983 (17%)
Died after discharge and within 3 month of admission	194/2983 (7%)
Deaths registered after 3 months	71/2983 (2%)
Registrants who answered all questions	2025/2201 (92%)
Registrants who answered some questions	176/2201 (8%)
Registrants who had another stroke	119/2201 (5%)
Registrants who were readmitted to hospital	439/2201 (20%)
Reasons for readmission was a stroke/cardiovascular cause	130/439 (30%)
Location of stroke survivor at time of follow-up interview	
Home	1835/2201 (83%)
Living alone	464/2201 (21%)
Living at home without support	1086/2201 (49%)
Living at home with support	749/2201 (34%)
Institutional care or other setting	
In hospital	18/2201 (1%)
Transitional care service	22/2201 (1%)
Low level care (hostel care)	39/2201 (2%)
High level care (nursing home)	227/2201 (10%)
Inpatient rehabilitation	21/2201 (1%)
Other place	26/2201 (1%)

READMISSIONS

There were 439 registrants (20%) who reported that they were readmitted to hospital and 130/439 (30%) of these were reported to be for a readmission related to a stroke/cardiovascular cause (Table 10).

HEALTH-RELATED QUALITY OF LIFE

In the AuSCR, we measure health-related quality of life (HRQoL) 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 five 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 (VAS). Possible scores span a scale from 0% to 100%. An EQ-5D index score of zero corresponds to a HRQoL state that is all but death, while a score of 100% would represent perfect quality of life.

In 2012 our sample providing EQ-5D data was twice that presented in 2011 (n=1100). Based on the various dimensions of the EQ-5D questionnaire, more than half of the respondents reported problems in mobility and usual activities (Table 11). The summary score for overall HRQoL was well below the normal population measure for people aged 70 to 79 years (Figure 11: normative mean 83, 2012 mean 68, p<0.001), but better than the mean visual analogue scale obtained in 2011 (2012 mean 68; 2011 mean 63, p<0.001).

Table 11: Quality of life assessment

EQ-5D dimensions		**n/N (%)**
Mobility	No problems (Level 1)	1096/2190 (50%)
	Problems (Levels 2 & 3)	1094/2190 (50%)
Self-care	No problems (Level 1)	1506/1737 (87%)
	Problems (Levels 2 & 3)	231/1737 (13%)
Usual Activities	No problems (Level 1)	929/2181 (43%)
	Problems (Levels 2 & 3)	1252/2181 (57%)
Pain/Discomfort	No problems (Level 1)	1120/2053 (55%)
	Problems (Levels 2 & 3)	933/2053 (46%)
Anxiety/Depression	No problems (Level 1)	1175/2168 (54%)
	Problems (Levels 2 & 3)	993/2168 (46%)
Visual Analogue Scale (0 – 100) reported by survivors*		
Mean (SD)		68.0 (21.5)
Median (IQR)		71 (50 to 85)

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

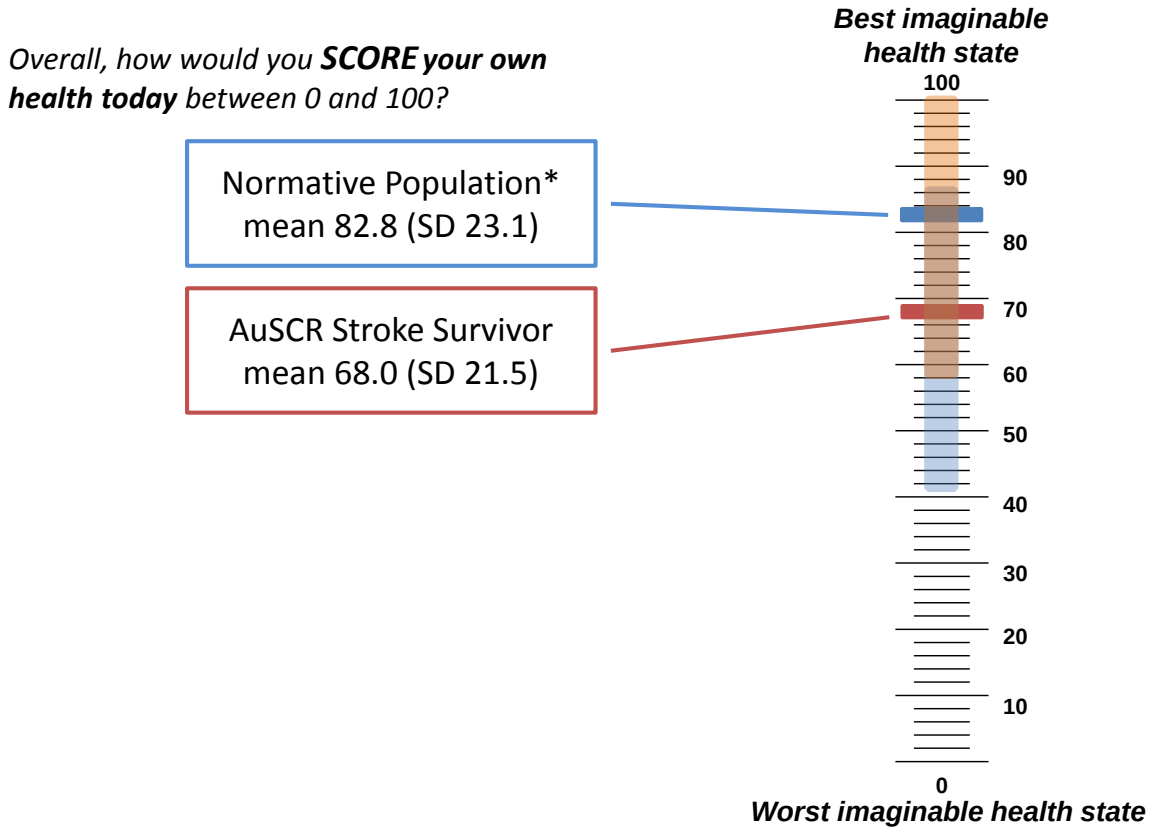

Figure 11: Summary of Visual Analogue Scale responses for 2012 AuSCR registrants

*Kind P, Dolan P, Gudex C, Williams A. Variations in population health status: results from a United Kingdom national questionnaire survey BMJ 1998;316 (7133): 736-41

PARTICIPATION IN FUTURE RESEARCH

Of the 2028 respondents who answered the question about whether they would be willing to be contacted to participate in future research, 1286 registrants (63%) replied affirmatively.

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 survivors at three to six months post stroke or TIA, it presents an opportunity to ask registered patients whether they would like to receive further information about stroke from the NSF. In 2012, 16% (n=602) of the AuSCR registrants, or their caregivers, indicated that they would like to receive information about stroke. We also found that more than 43% (n=1547) of the sample (n=3651) left this question blank on their follow-up survey and presumed that non-responses to this question meant that no further information was desired.

DISCUSSION

This is the fourth annual report of the AuSCR. Since the release of the first annual report in 2009, use of the AuSCR registry has continued to grow with a two-fold increase in participating hospitals since 2011; and a five-fold increase since 2009. In this 2012 report, we provide information contributed from 31 hospitals in Australia on 4572 episodes of stroke or TIA. The registry has not yet obtained complete coverage in any state or region and so the data have limited representativeness for providing: reliable death rates; stroke prevalence estimates; or information on the patterns of transfer across the system such as access to inpatient rehabilitation. In addition, case ascertainment remains variable across the participating hospitals and ongoing efforts to improve this through facilitating data uploads is an imperative. Hospitals that have been able to successfully and routinely create patient files for importing data into the AuSCR have excellent case-ascertainment, and ensure their data can be considered representative of the patients admitted to these hospitals. Currently, the AuSCR registry provides the only infrastructure to enable the routine monitoring of the quality of care in patients admitted to hospitals with new episodes of stroke or TIA and the data have great utility for clinicians. The expansion of the AuSCR to all Queensland hospitals in 2012/2013 is expected to enable, for the first time, comparisons of hospital data across one state. This will also provide an opportunity to understand case ascertainment issues better in 2013.

Analyses of 2012 AuSCR data show the continued benefits of a system-based approach to assessing stroke care and the wide variability that exists in adherence to nationally endorsed quality indicators among different hospitals. Data from individual hospitals is presented for the second time in this 2012 Annual Report (de-identified in Appendix D). We acknowledge that in our sample of participating hospitals there is a bias towards hospitals with stroke units and therefore the overall adherence to these quality indicators is anticipated to be greater than data reported in cross-sectional audits among hospitals with and without stroke units e.g. 76% of 2012 non-TIA AuSCR patients received their care within a specialised stroke unit while in the National Stroke Audit of Clinical Services (2011) only 60% of patients received care in a specialised stroke unit (note the National Stroke Foundation audit does not sample TIA patients and this means it is not always possible to make direct comparisons between these data). The value of these AuSCR data are that they highlight areas, in a large sample of patients presenting to each of these hospitals for these selected quality indicators, where improvements could be made. It is therefore important that hospitals use the AuSCR to its full potential and regularly review their summary data that are available in 'on-demand' reports to assist with directing areas to improve the quality of care at their hospital. To support hospitals in these efforts, the AuSCR Office provides a regular newsletter to: highlight ways in which the quality of the data could be improved; communicate progress being made; as well as shared successes and learnings. It was reassuring to see that in this fourth year of the AuSCR, and with a large increase in the number of participating hospitals, that the proportions of missing data were minimal for the majority of non-mandatory variables.

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, 15% of patients were living in institutionalised care and more than 83% were living at home. The three to six months outcomes data provide critical information about the overall quality of acute care received by people who have experienced stroke or TIA in Australia, and the capacity to monitor the burden of stroke post-discharge. This large sample provides the opportunity to assess health system and patient factors that may contribute to better or worse health outcomes after stroke or TIA. For example, these data show that one in five registrants were readmitted to hospital and in 30% of these cases this was due to a stroke or

cardiovascular cause. Understanding the factors that influence readmissions to hospital is important.[6] The AuSCR data provides information not available in current government data on hospital readmissions and can be explored to better understand factors that contribute to readmissions within 180 days of stroke.

The differences noted among hospitals with 100 or more episodes registered in the AuSCR for case-mix adjusted mortality following stroke illustrate the potential opportunity to review clinical practice and understand the factors that may be contributing to this variation. Further analytic work in this area needs to be done, including consideration of socioeconomic status or other non-clinical factors that may contribute to some of this variation. These data are presented for the first time in this Annual Report to illustrate the potential use of registry data that includes 90-day patient outcome assessment.

The AuSCR provides an important infrastructure for future research since about two-thirds of registrants indicate at the time of follow-up that they are willing to be contacted for future research projects if they are eligible. In 2012, we were able to demonstrate the successful use of the AuSCR cohort for contributing to a national survey to describe the needs of people living with stroke in Australia.

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 the 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 should be assessed yearly in a registry. Feedback received in 2013 on the process has indicated that this is quite an onerous task for hospitals to verify potentially missed cases. The Management Committee has agreed that from 2014 a request for ICD10 discharge data will occur at six monthly intervals to spread this work load and flag potential issues early, with final reporting yearly in the Annual Report. This may also help to encourage more hospitals to provide these data. Further we plan to establish use of routine data linkage with hospital data at a state level to ensure this task can sit outside the role of individual hospitals to reduce the workload in sourcing these data.

TECHNOLOGY SOLUTIONS FOR SIMPLIFYING DATA COLLECTION FOR CLINICIANS

Data importing is the key to reducing the manual data collection required for the AuSCR. Without adequate resourcing of the AuSCR, use of the import function remains difficult to apply unless hospitals or state-based clinical networks support hospitals in establishing processes for data importing. 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 hospitals. Investment in both Queensland and Victoria towards increasing the ability to import data into the AuSCR, has demonstrably advanced efforts to reduce the workload created by the AuSCR and also improved case ascertainment in 2012. As processes to improve data entry evolve this should also reduce delays in data entry.

HARMONISATION OF THE NATIONAL STROKE FOUNDATION AUDIT PROCESS WITH THE AUSCR

The successful awarding of a NHMRC Partnerships for Better Health grant (*Stroke123*) to Dominique Cadilhac, and other investigators, has meant that the work to progress the harmonisation of the NSF

Audit program and AuSCR commenced in 2012. This work was initially flagged at workshops held in 2011 to achieve consensus on recommendations and to outline the next steps for implementing a national approach to data collection and quality improvement for stroke care in Australia.[7] A separate working group, chaired by Natasha Lannin, was established as part of Stroke123 in 2012 with relevant staff who are involved in either program from the National Stroke Foundation, The Florey and Monash University. The goal of this working group is to ensure, for the 2013 National Stroke Foundation Acute Services Audit, that relevant data already collected in the AuSCR at hospitals that participate in both programs could be exported and submitted into the National Stroke Foundation audit tool, using a secure and de-identified format for the data. Subsequently, hospital staff are only required to enter additional information for the audit.

CLOSING THE QUALITY FEEDBACK LOOP

Efforts to ensure hospitals are using the AuSCR data are to be explored and promoted in 2013. Data from this report highlight that there are differences among hospitals for survival, both in-hospital and within 90 days of stroke onset. We will use the data to investigate whether there are factors related to care quality that may explain these findings and feed this information back to the relevant hospitals.

As part of the Stroke123 project, hospitals in Queensland will have additional support in reviewing and acting on their data. This work is being conducted in collaboration with the Queensland State-wide Stroke Clinical Network and the National Stroke Foundation who conducted the StrokeLink program in Queensland.

REDUCING THE DATA COLLECTION BURDEN ASSOCIATED WITH HEALTH SERVICES RESEARCH

In 2012, a clinical trial (T^3 Trial) led by Sandy Middleton, and designed to improve care for patients with stroke in the Emergency Department, was funded by the NHMRC. This trial is being conducted in potentially up to 15 sites that are also, or will be, participating in the AuSCR (Qld: 5; NSW: 4; Vic: 6) and includes collection of health outcome information at 90 days. To ensure responder burden is minimised and to avoid duplication of effort whilst maximising the available funds for both programs of work, it was agreed to: a) share funding for a Queensland-based project officer who would support Queensland hospital staff in contributing to AuSCR and the T^3 Trial; and b) include the AuSCR follow-up variables in the T^3 Trial 90 day questionnaire and establish a process for the applicable data to be securely submitted to the AuSCR at regular intervals so that patients will not be contacted twice for similar information. Ethical approval has been obtained for this process. Achieving these solutions shows the importance of how collaboration can be achieved to ensure maximal use of limited resources whilst placing the patient at the centre of our efforts to better understand and improve stroke care.

MAXIMISING THE USE OF DATA THROUGH DATA LINKAGE

Data on patients in Australia are collected in various forms, but are limited in their use because there is no relationship between the different pieces of information held in different databases. In order to ensure that the AuSCR data are maximised to their full potential, and can be used to provide a greater understanding of the factors that influence patient outcome, a data linkage substudy has been facilitated by the awarding of the Stroke123 grant.[8] As part of the opt-out consent, patients who have their data registered in the AuSCR are made aware that their data may be linked to other sources of data to enable the collection of further information regarding their health care needs and how they have recovered. In Stroke123, a number of validation studies will be performed to assess the feasibility and utility of linking the AuSCR data to various government datasets. These data may be used to evaluate the case ascertainment of the AuSCR against hospital data (at a state-level and so avoid individual hospitals needing to spend time on this task), as well as exploring the quality of routinely

collected stroke data. For example, ICD10 coding for stroke appears to misclassify many patients with a code of 'undetermined' when the majority have brain imaging and are known to have had an ischaemic event. A series of cohort studies may then be used to examine associations between both pre- and post-stroke hospital contacts (up to five years pre-stroke and four years post-stroke) using the first index stroke event recorded in the AuSCR. For example, these linked data may be used to explore: missed prevention opportunities preceding a stroke event; quality of acute stroke care; greater detail on why there may be hospital readmissions and frequency of recurrent events; and use of health care services e.g. number of ED presentations.

CONCLUDING COMMENTS

The purpose of the AuSCR is to provide high quality independent data on the quality of care and its relationship to health outcomes of acute stroke in Australia. The information provided by the AuSCR will continue to become increasingly valuable as time progresses and we continue to enhance the registry. It is hoped that the information presented in this 2012 report is useful to clinicians, patients and policy makers. The dataset is now of a significant size to enable useful analyses that can inform health care practice and policy in stroke, albeit with some limitations in terms of generalisability. The value of the AuSCR is also exemplified in the requests to use the AuSCR data for important research projects that may not have been feasible previously or to 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. 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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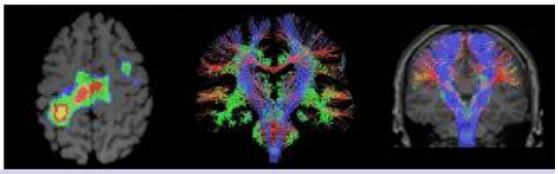
APPENDIX A: STEERING COMMITTEE MEMBERSHIP

Steering Committee Membership 2012			
Name	**Position**	**Organisation**	**State**
Prof Sandy Middleton	AuSCR Steering Committee, Chair Director, Nursing Research Institute Director, National Centre for Clinical Outcomes Research (NaCCOR)	St Vincent's and Mater Health Sydney Australian Catholic University	NSW
Prof Craig Anderson	Senior Director, Neurological & Mental Health Division Professor of Stroke Medicine and Clinical Neuroscience Head, Neurology Department, Royal Prince Alfred Hospital NMHRC Senior Principal Research Fellow	The George Institute for Global Health, affiliated with the Royal Prince Alfred Hospital and University of Sydney	NSW
Dr Michael Pollack	Director, Rehabilitation Medicine Chairman, Hunter Stroke Service Chairman, GMCT NSW	John Hunter Hospital	NSW
Ms Frances Simmonds	Director, Australasian Rehabilitation Outcomes Centre (AROC)	Australian Health Services Research Institute (AHSRI), University of Wollongong	NSW
A/Prof Julie Bernhardt	Head, Stroke Division Director AVERT, Very Early Rehabilitation Research Trail	The Florey Institute of Neuroscience and Mental Health	VIC
Prof Christopher Bladin	Director, Victorian Stroke Telemedicine Program Neurologist, Eastern Health	The Florey Institute of Neuroscience and Mental Health Eastern Health (Monash University)	VIC
Prof Geoffrey Donnan	Director Professor of Neurology,	The Florey Institute of Neuroscience and Mental Health University of Melbourne	VIC
Dr Mark Mackay	Paediatric Neurologist	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	Head, Epidemiology and Prevention Unit NHMRC Senior Research Fellow	Monash University	VIC
Dr Andrew Lee	Neurologist & Stroke Physician NHMRC - NICS Fellow	Flinders Comprehensive Stroke Centre, Flinders Medical Centre	SA
Dr Helen Castley	Neurologist & Head of Stroke Unit Chair, Tasmania Stroke Unit Network	Royal Hobart Hospital	TAS
Mr Greg Cadigan	Principal Project Officer	Queensland Statewide Stroke Clinical Network	QLD
Dr Rohan Grimley	Director Geriatrics and Rehabilitation SCWBDHS Southern Cluster Clinical Chair	Nambour Hospital Queensland Statewide Stroke Clinical Network	QLD
Prof Richard Lindley	Professorial Fellow	The George Institute for Global Health	
A/Prof Dominique Cadilhac	Head, Public Health, Stroke Division NHMRC/NSF Fellow	The Florey Institute of Neuroscience and Mental Health	VIC

APPENDIX B: EXAMPLE OF 'OPT-OUT' HOSPITAL SCREEN IN AUSCR

AuSCR
Australian Stroke Clinical Registry



Home

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			
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☐ 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

APPENDIX C: EXPLANATION OF CALCULATION OF INDICATORS

Indicator	Numerator	Denominator	Comments
Gender - Male	Yes	Yes + No + Intersex/indeterminate	Excludes **Not stated / Inadequately described**
In-hospital stroke	Yes	Yes + No	Excludes **Unknown**
Transferred from another hospital	Yes	Yes + No	Excludes **Unknown**
Died	Yes	Yes + No	Different discharge options Excludes **missing**
Discharged home	Yes	Yes + No	Excludes **deaths** Excludes **missing**
Received care in SU	Yes	Yes + No + unknown	Include **missing**
Type of stroke	Yes	Yes + No	Excludes missing
Received intravenous thrombolysis if ischaemic stroke	Yes	Yes + No + Unknown	Includes ischaemic strokes only
Unable to walk on admission	Yes	Yes + No	Excludes **Not documented**
Care plan	Yes	Yes +No + unknown	Includes patients discharged only
Discharged on antihypertensive	Yes	Yes +No + unknown	Includes patients discharged only
Mobilisation during admission	Yes	Yes +No + unknown	Includes **Queensland** patients only
If patient unable to walk, patient mobilised	Yes	Yes +No + unknown	Includes **Queensland** patients only Includes only patient who are unable to walk independently
Dysphagia screen tool used	Yes	Yes +No + unknown	Includes **Queensland** patients only
Screen or swallow assessment undertaken	Yes	Yes +No + unknown	Includes **Queensland** patients only
Aspirin administration within 48 hours	Yes	Yes +No + unknown	Includes **Queensland** patients only
Discharged on antiplatelets or antithrombotics	Yes	Yes +No + unknown	Includes **Queensland** patients only Excludes patients with haemorrhagic stroke

APPENDIX D: ADHERENCE DATA BY PARTICIPATING HOSPITAL

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
Stroke unit			
9	146/146 (100)	106/106 (100)	28/28 (100)
10	11/12 (92)	10/11 (91)	--
11	329/461 (71)	259/353(74)	4/5 (80)
12	589/630 (93)	414/429 (97)	89/96 (93)
13	343/544 (63)	254/311 (82)	78/103 (76)
15	--	--	--
16	130/170 (77)	69/80 (86)	26/37 (70)
17	128/241 (53)	107/184 (58)	7/39 (18)
18	151/171 (88)	110/128 (86)	22/23 (96)
19	--	--	--
20	142/176 (81)	69/86 (80)	43/49 (88)
21	104/137 (76)	79/102 (78)	13/19 (68)
22	326/469 (70)	240/313 (77)	4/6 (67)
23	497/596 (83)	355/398(89)	56/79 (71)
25	12/13 (92)	9/10 (90)	3/3 (100)
26	8/10 (80)	5/7 (71)	3/3 (100)
27	22/23 (96)	17/18 (94)	2/2 (100)
28	172/226 (76)	132/156 (85)	28/47 (60)
29	129/142 (91)	100/104 (96)	15/21 (71)
30	25/25 (100)	17/17 (100)	1/1 (100)
31	30/45 (67)	17/20 (85)	11/22 (50)
32	115/118 (98)	80/81 (99)	27/29 (93)
34	1/27 (4)	0/21 (0)	0/5 (100)
35	--	--	--
36	16/22 (73)	13/18 (72)	2/3 (67)
37	4/4 (100)	2/2 (100)	1/1 (100)
39	20/39 (51)	16/27 (59)	2/10 (20)
40	18/25 (72)	9/11 (82)	6/10 (60)
41	11/14 (79)	9/11 (82)	1/2 (50)
42	24/45 (53)	13/21 (62)	9/14 (64)
43	3/55 (6)	1/12 (8)	1/23 (4)

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
tPA			
9		5/106 (5)	
10		4/36 (11)	
11		27/353 (8)	
12		71/429 (17)	
13		39/311 (13)	
15		--	
16		8/80 (10)	
17		25/184 (14)	
18		4/128 (3)	
19		--	
20		3/86 (4)	
21		8/102 (8)	
22		53/313 (17)	
23		70/398(18)	
25		--	
26		--	
27		1/18 (6)	
28		15/156 (10)	
29		9/104 (9)	
30		1/17 (6)	
31		4/20 (20)	
32		11/81 (14)	
34		--	
35		--	
36		1/18 (6)	
37		--	
39		2/27 (7)	
40		1/11 (9)	
41		4/11 (36)	
42		--	
43		--	

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
Discharged (not died in hospital)			
9	135/146 (93)	97/106 (92)	28/28 (100)
10	--	8/9 (89)	--
11	413/460 (90)	327/352 (93)	5/5 (100)
12	544/630 (86)	376/429 (88)	96/96 (100)
13	449/520 (86)	268/301 (89)	100/101 (99)
15	68/72 (94)	38/40 (95)	22/22 (100)
16	143/160 (89)	61/72 (85)	37/37 (100)
17	232/239 (97)	176/182 (97)	39/39 (100)
18	138/161 (86)	101/119 (85)	23/23 (100)
19	--	17/17 (100)	--
20	162/175 (93)	77/85 (91)	49/49 (100)
21	125/137 (91)	95/102 (93)	19/19 (100)
22	364/431 (85)	257/297 (87)	6/6 (100)
23	510/594 (86)	351/396 (89)	79/79 (100)
25	11/13 (85)	8/10 (80)	3/3 (100)
26	10/10 (100)	7/7 (100)	3/3 (100)
27	8/9 (89)	4/5 (80)	2/2 (100)
28	195/224 (87)	133/155 (86)	47/47 (100)
29	129/142 (91)	97/104 (93)	21/21 (100)
30	17/21 (81)	14/14 (100)	1/1 (100)
31	40/45 (89)	16/20 (80)	22/22 (100)
32	111/118 (94)	74/81 (91)	29/29 (100)
34	24/27 (89)	18/21 (86)	5/5 (100)
35	40/40 (100)	6/6 (100)	15/15 (100)
36	21/22 (96)	17/18 (94)	3/3 (100)
37	4/4 (100)	2/2 (100)	1/1 (100)
39	33/38 (87)	22/26 (85)	10/10 (100)
40	23/25 (92)	9/11 (82)	10/10 (100)
41	13/14 (93)	11/11 (100)	2/2 (100)
42	38/45 (84)	18/21 (86)	14/14 (100)
43	51/55 (93)	11/12 (92)	23/23 (100)

Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
Antihypertensive agent			
9	97/135 (72)	72/97 (74)	17/28 (61)
10	--	6/7 (86)	--
11	34/408(8)	29/322 (9)	2/5 (40)
12	445/542 (82)	312/376 (83)	79/96 (82)
13	131/440 (30)	102/261 (39)	25/98 (26)
15	47/68 (69)	26/38 (68)	16/22 (73)
16	83/127 (65)	41/57 (72)	19/32 (59)
17	132/228 (58)	97/172 (56)	23/39 (59)
18	114/136 (84)	83/83 (100)	19/23 (83)
19	--	1/17 (6)	--
20	101/162 (62)	49/77 (64)	28/49 (57)
21	109/122 (89)	84/94 (89)	15/17 (88)
22	280/348 (81)	208/245 (85)	5/6 (83)
23	344/506(68)	251/348 (72)	58/79 (73)
25	10/11 (91)	7/8 (88)	3/3 (100)
26	6/9 (67)	5/6 (83)	1/3 (33)
27	6/7 (86)	2/3 (67)	2/2 (100)
28	135/186 (73)	92/127 (72)	34/45 (76)
29	37/123 (30)	29/93 (31)	5/20 (25)
30	3/17 (18)	3/14 (21)	0/1 (0)
31	29/40 (73)	15/16 (94)	13/22 (59)
32	88/111 (79)	61/74 (82)	21/29 (72)
34	21/24 (88)	17/18 (94)	3/5 (60)
35	1/4 (25)	0/2 (0)	1/2 (50)
36	13/21 (62)	9/17 (53)	3/3 (100)
37	4/4 (100)	2/2 (100)	1/1 (100)
39	14/33 (42)	9/22 (41)	4/10 (44)
40	13/22 (59)	4/9 (44)	6/9 (67)
41	--	--	--
42	21/38 (55)	14/18 (78)	7/14 (50)
43	24/51 (47)	5/11 (46)	12/23 (52)

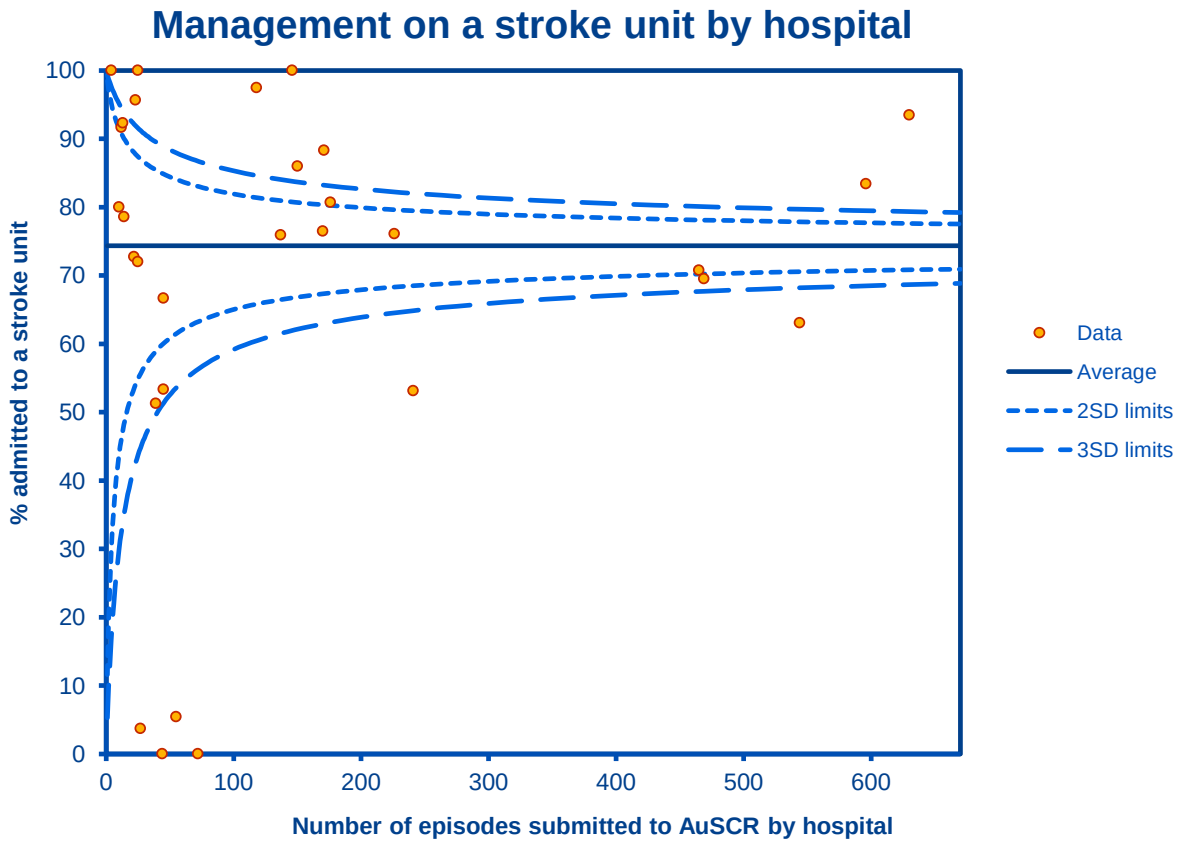
Hospital (coded)	All episodes, n/N (%)	Ischaemic, n/N (%)	TIA, n/N (%)
Care plan			
9	47/86 (55)	34/57 (60)	12/24 (50)
10	--	1/1 (100)	--
11	37/51(73)	32/42 (76)	2/2 (100)
12	155/215 (72)	91/125 (73)	49/72 (68)
13	158/175 (90)	120/135 (89)	33/33 (100)
15	56/60 (93)	32/33 (97)	19/21 (91)
16	10/87 (12)	6/39 (15)	1/25 (4)
17	16/67 (24)	14/47 (30)	2/17 (12)
18	111/130 (85)	84/96 (88)	19/22 (86)
19	--	--	--
20	6/101 (6)	3/37 (8)	1/40 (3)
21	112/122 (92)	88/94 (94)	14/17 (82)
22	302/329 (92)	224/235 (95)	5/6 (83)
23	380/424 (90)	272/304 (90)	64/70 (91)
25	6/7 (86)	3/4 (75)	3/3 (100)
26	7/8 (88)	6/6 (100)	1/2 (50)
27	6/6 (100)	3/3 (100)	2/2 (100)
28	18/105 (17)	13/62 (21)	4/39 (10)
29	13/91 (14)	10/67 (15)	2/17 (12)
30	14/15 (93)	12/12 (100)	1/1 (100)
31	30/32 (94)	12/12 (100)	18/19 (95)
32	24/108 (22)	18/72 (25)	6/29 (21)
34	2/23 (9)	1/17 (6)	0/5 (0)
35	1/3 (33)	1/2 (50)	0/1 (0)
36	6/15 (40)	5/11 (46)	1/3 (33)
37	1/4 (25)	1/2 (50)	0/1 (0)
39	18/28 (64)	10/18 (56)	7/9 (78)
40	13/21 (62)	7/9 (78)	4/9 (44)
41	--	--	--
42	26/30 (87)	12/14 (86)	12/13 (92)
43	31/40 (78)	7/8 (88)	14/19 (74)

APPENDIX E: ADHERENCE TO QUALITY INDICATORS BY SIZE OF HOSPITAL (IN TERMS OF NUMBER OF EPISODES SUBMITTED TO THE AUSCR)

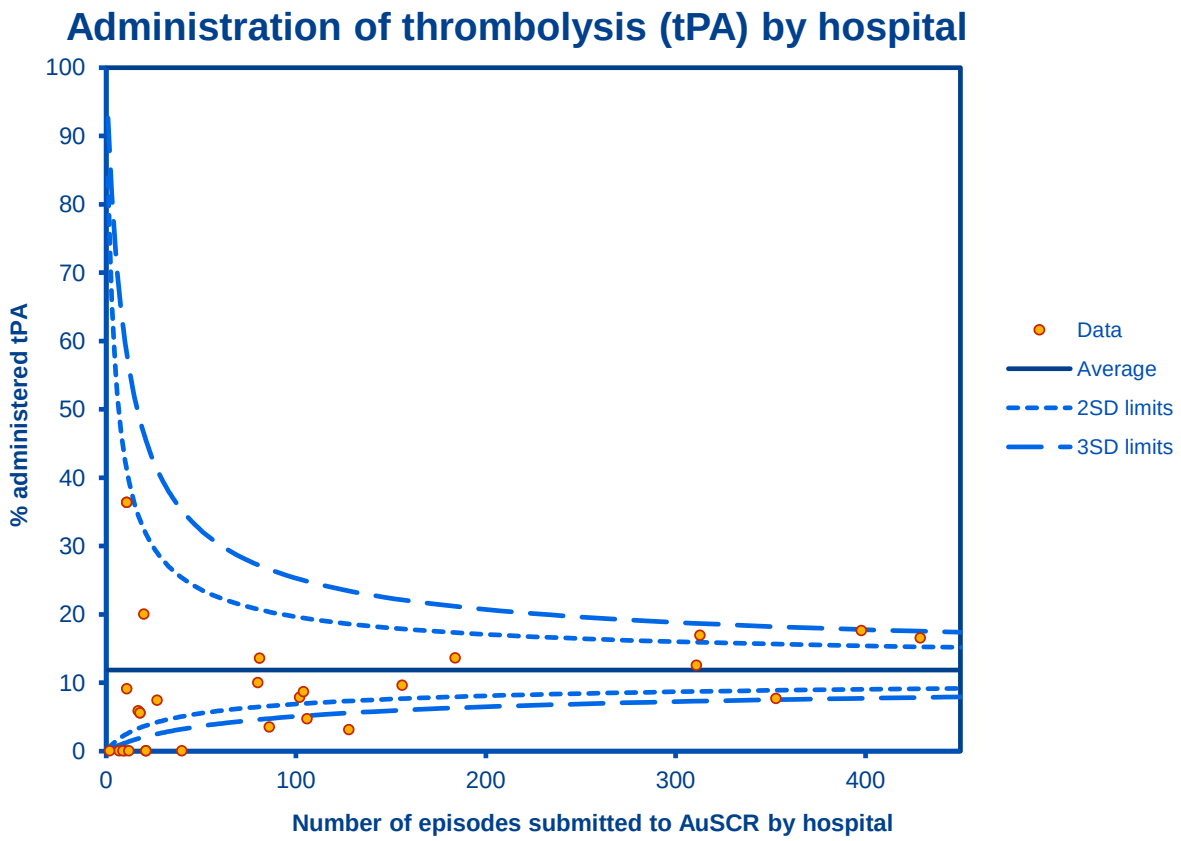
How to read the funnel chart figures?

The horizontal axis (line across) in these funnel charts measures the size of hospital in terms of number of episodes (volume) submitted to the AuSCR. The larger number of episodes (volume) submitted to the AuSCR, the further to the right will be its figure (represented by an orange dot); the smaller the volume, the further to the left its orange dot will be. The vertical axis measures the adherence to quality indicators, expressed as a proportion (%). The orange dots show each individual hospital adherence; and the horizontal centre line shows the *overall* (all hospitals combined) adherence. In this example the *overall* proportion of patients admitted to a stroke unit was 74%. The dashed lines constitute the funnel. They are the upper and lower control limits that represent the boundary between 'normal variation' and 'special cause variation'.

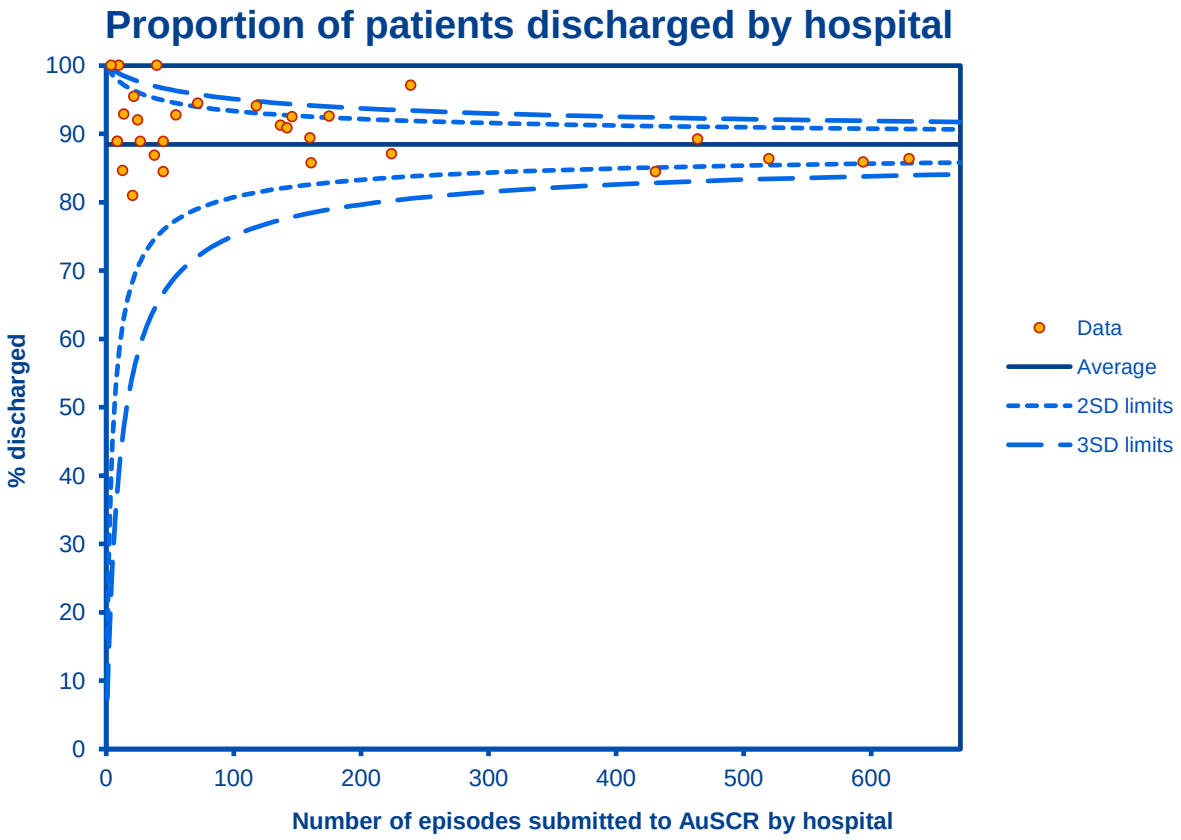
Looking at the hospital with the smallest volume, it had 10 episodes submitted to the AuSCR and 80% of patients were admitted to a stroke unit. The hospital with the largest volume had 600 episodes submitted to the AuSCR and 93% of patients were admitted to a stroke unit.



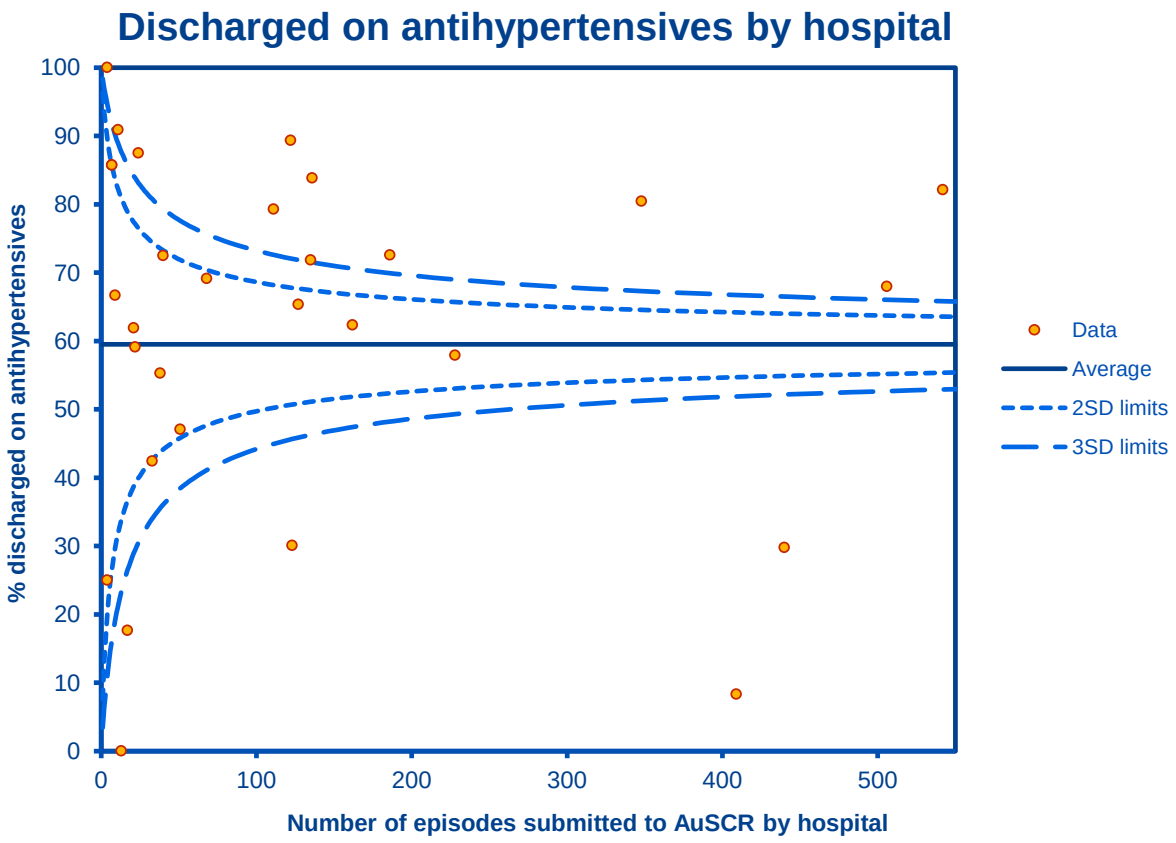
Source: AuSCR 2012



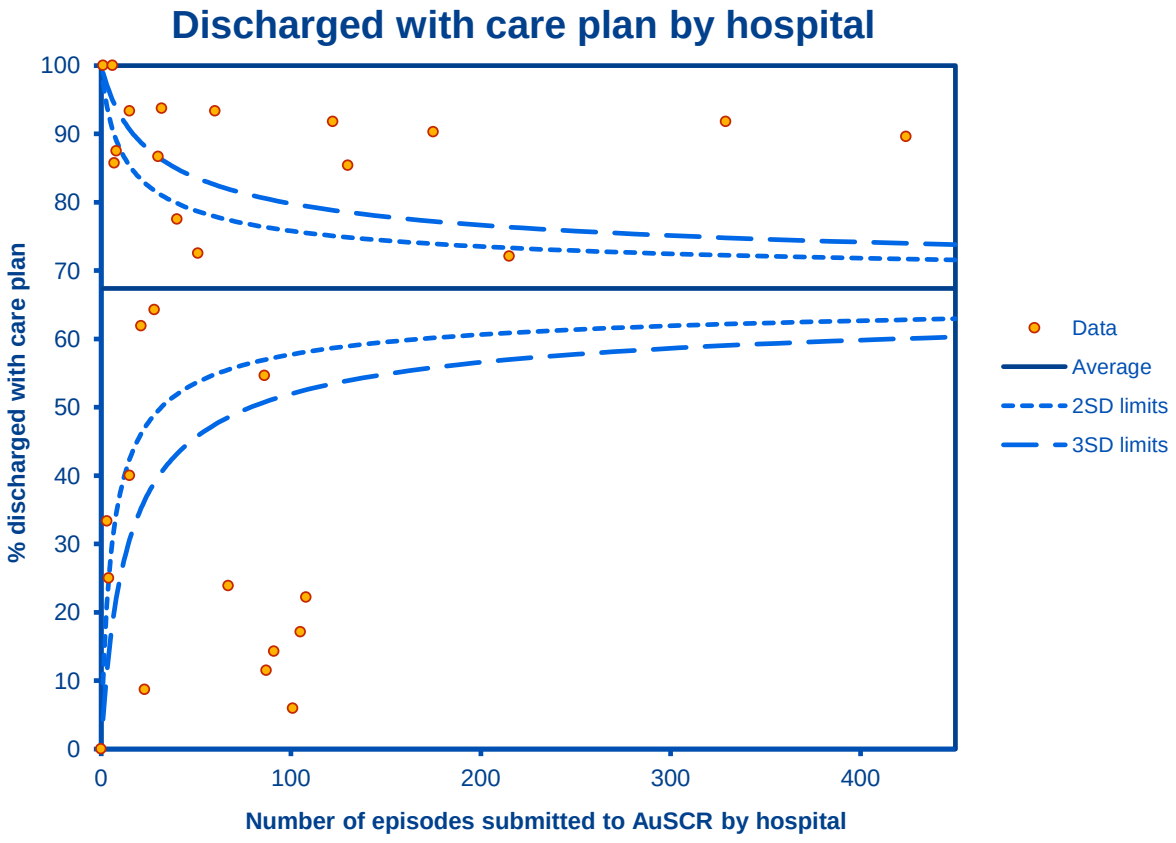
Source: AuSCR 2012



Source: AuSCR 2012



Source: AuSCR 2012



Source: AuSCR 2012

APPENDIX F: CASE-MIX ADJUSTED MORTALITY BY HOSPITALS WITH 100 OR MORE EPISODES OF CARE SUBMITTED IN 2012

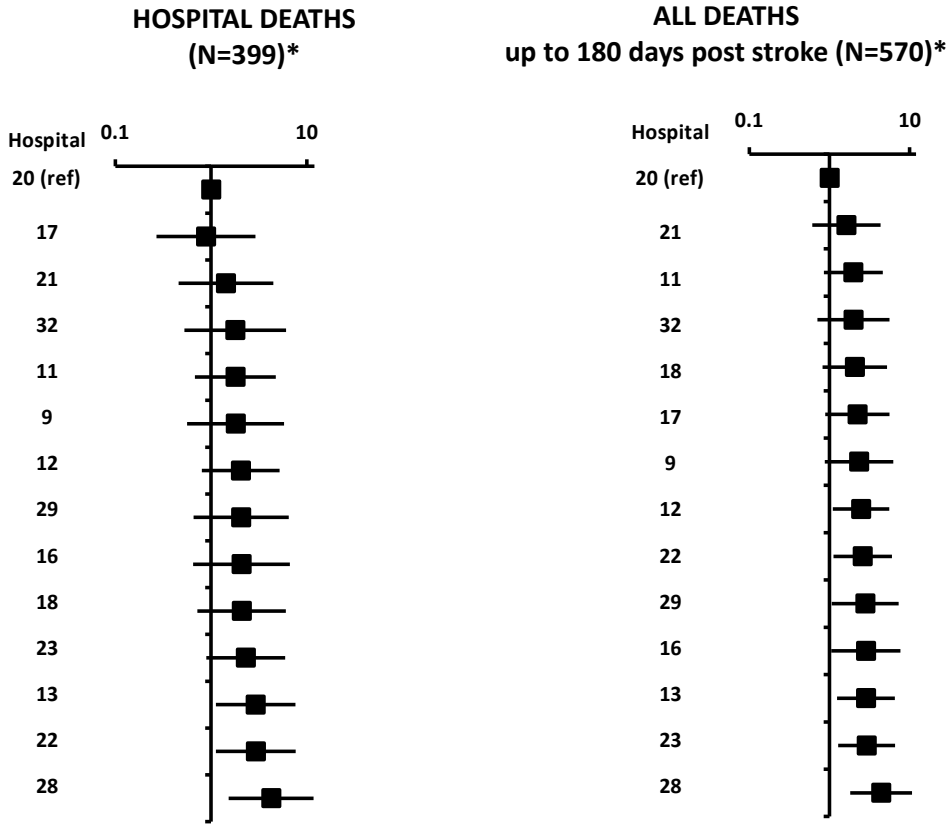
How to read the forest plot chart figure?

Hospital 20 is the reference group for these analyses.

Each hospital is represented by a line. The box in the line for each hospital is the point estimate, that is, the odds ratio for each hospital. The width of the line shows the confidence intervals of the effect estimate for each hospital.

There is a vertical line which corresponds to the value 1 in the plot shown. This is the line of no effect. If 1 is included in the 95% confidence intervals, it indicates that there is no statistical significance at 5% significance levels. If 1 is not included in the 95% confidence intervals, the results are statistically significant at 5% significance levels.

Hospitals to the left of the vertical line have 'lower mortality or number of deaths' and 'higher mortality or number of deaths' to the right of the vertical line.



Adjusted for age, gender, ability to walk and type of stroke.
Excludes in-hospital strokes, transfers and subsequent admissions for stroke in 2012
Includes only hospitals with 100 or more episodes entered in the AuSCR