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AUSCR

Australian Stroke Clinical Registry

December 2017

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EXECUTIVE SUMMARY

- In 2016, 48 hospitals contributed data to the Australian Stroke Clinical Registry (46% of hospitals being from Queensland, 46% from Victoria and 4% from NSW and Tasmania respectively).
- Information is presented on 11204 patients with 11891 admissions for acute stroke or transient ischaemic attack (TIA) admitted to participating hospitals.
- Provision of stroke unit care dropped from 80% in 2015 to 68% in 2016, and thrombolysis increased slightly from 12% to 13%. There was a noticeable decline in the prescription of antihypertensive medication at discharge from 74% in 2015 to 62% in 2016. Provision of a discharge care plan was stable at 59%.
- Performance benchmarks calculated for the AuSCR 2016 cohort show that the best performing hospitals could achieve: 94% for stroke unit care; 21% for thrombolysis; 81% for antihypertensives; and 89% for discharge care plans. These levels of care would ensure better outcomes for patients if all hospitals could achieve these standards.
- Several hospitals were found to be outside the limits set for normal variation in relation to key performance outcome measures. Although the least variability was found for the provision of antihypertensive medication at discharge, six hospitals were still observed to perform poorly in comparison to their peers.
- After discharge from acute care, 25% of patients went to rehabilitation and 52% returned to their usual residence, with or without some form of support.
- Stroke is a serious condition: 1062 (9%) of the 2016 AuSCR registrants died in hospital and a further 993 (8%) died within 180 days of their stroke.
- Preliminary data for clinical variables have been collected for the first time and highlight the rich information that will be available in the future. For example (from small samples): the thrombolysis rate was 28% where telemedicine was in place, with a median door-to-needle time of 91 minutes; for endovascular clot retrieval the median time from arrival to groin puncture was 119 minutes and for recanalisation 190 minutes. The provision of aspirin within 48 hours, excluding cases of intracerebral haemorrhage, was 41%.
- At 90 -180 days, collection of information from 69% of all eligible registrants was achieved. Many survivors reported problems with health-related quality of life, ranging from 31% for self-care up to 56% for everyday activities.
- In addition to on-demand reports being available to participating hospitals, the AuSCR is an active partner in two projects (Queensland and Victoria) which aim to embed the routine review of data into everyday quality improvement activities in hospitals using external facilitation.
- The AuSCR is a mature Registry that provides a systematic, standardised mechanism to enable hospitals to monitor, review and improve stroke care in compliance with the recently released Clinical Guidelines for Stroke Management 2017 (https://informme.org.au/Guidelines/Clinical-Guidelines-for-Stroke-Management-2017).

GOVERNANCE REPORT




The AuSCR continues to operate under the data custodianship of the Florey Institute of Neuroscience and Mental Health (The Florey). Members of the Steering Committee, Management Committee, Research Task Group and Reperfusion and Telemedicine Subcommittee voluntarily contribute their time to ensure the rigorous operation and ongoing development of the Registry (see Appendices A, B and C for additional details on governance, membership lists and funding respectively).

Throughout 2016, the project team and members of the governance committees have continued to expedite the transition to the new integrated data management system - the Australian Stroke Data Tool (AuSDaT). Data entry into the original AuSCR webtool ceased on July 1st, 2016 when all new data were required to be entered into the AuSDaT. By August 13th, the AuSCR legacy data were migrated to the AuSDaT, thereby effecting a single portal for collecting standardised data for both the AuSCR and the Stroke Foundation audits. Other programs are expected to follow in the future. The build, implementation and harmonious operation of this new platform has been a major undertaking involving significant financial outlay but, importantly, has facilitated collaboration across

a number of stroke programs in an endeavour to create efficient and systematic data collection for improving the monitoring and enhancement of stroke care in Australia.

While the collection of data at the hospital level does provide resource challenges, we are hopeful that the availability of the AuSDaT and ongoing interest in quality assurance and quality improvement, at many levels, will fuel the support needed to enable sustainable data collection that can be used to inform meaningful clinical improvements.

Throughout the relatively short life of the Registry, the team has constantly endeavoured to share the findings and the learnings that have emerged. With the dataset having now reached a substantial size, considerable effort is being expended on preparing academic publications, particularly to highlight the gaps in clinical care that the AuSCR data are able to demonstrate empirically. Presentations and publications from 2016 are listed in Appendix E, and importantly these include studies that have used AuSCR data to drive clinical quality improvement.

The operational viability of the Registry is due to the efforts of many organisations and individuals (see Appendix D) but we must particularly acknowledge the hospital staff who contribute to the AuSCR, as well as the patients, and their carers, without whom the Registry could not exist.

Professor Sandy Middleton
(Chair, Steering Committee)

Professor Craig Anderson
(Chair, Management Committee)

Associate Professor Natasha Lannin
(Acting Chair, Management Committee)

Associate Professor Dominique Cadilhac
(Florey Data Custodian)

INTRODUCTION

The AuSCR has been operational since 2009. The goal is to provide reliable and representative national data, on patients admitted to hospital with acute stroke or transient ischaemic attack (TIA), to inform improvements to the health system.[1]

The AuSCR adheres to the national guidelines for best-practice in clinical quality registries,[2] and operates in both public and private hospitals. Adult and paediatric cases are included. All participating hospitals are required to have ethics approval. As recommended for national registries,[3] an 'opt-out' model for patient inclusion is used, in addition to a waiver of consent for people who die while in hospital.

In the AuSCR, data are collected on the provision of evidence-based therapies, supplemented with clinical and demographic patient information, to provide an indication of the quality of acute stroke care received. From July 1st, 2016, data were collected in the new Australian Stroke Data Tool (AuSDaT) which is a harmonised platform enabling standardised and systematic data entry for multiple stroke data collection programs. With the implementation of the AuSDaT, the number of variables collected was also expanded (Box 1). The AuSDaT also enabled hospitals to select 'bundles' of variables for collection, to align with local care provision. These variable 'bundles' were grouped into six AuSCR programs, as illustrated in Figure 1. Staff from participating hospitals can enter these data on all eligible patients either: manually via the web tool, by using a data import process, or a combination of both. Each hospital has access to their own data and summary 'live' reports that the staff can download to enable regular reviews of hospital performance.

Patient outcomes are ascertained with a questionnaire (including age-appropriate paediatric questions) at follow-up, 90 to 180 days after admission. The AuSCR Office staff, with the assistance of the Stroke Foundation, are responsible for following-up registrants who: are known to be alive; have not refused follow-up at the outset; or have 'opted-out' of the Registry. For registrants unable to be contacted, survival status is determined using annual data linkage with the National Death Index (NDI) made available, through an ethically approved process, by the Australian Institute of Health and Welfare (AIHW).

BOX 1: AuSCR NATIONAL VARIABLES COLLECTED IN THE AUSTRALIAN STROKE DATA TOOL (AuSDaT) *

IDENTIFYING INFORMATION

- name
- date of birth
- sex
- address
- telephone number/s
- hospital name
- Medicare number
- hospital medical record number
- contact details for next of kin and alternative contact

ENDOVASCULAR CLOT RETRIEVAL (ECR) VARIABLES

- date & time of subsequent brain scan
- endovascular therapy including date & time
- NIHSS: before endovascular clot retrieval/24 hour
- site of occlusion
- final TICI (thrombolysis in central infarction) score
- haemorrhage type if present, post-ECR

PATIENT/EPISODE CHARACTERISTICS

- country of birth
- language spoken
- interpreter needed
- Aboriginal and Torres Strait Islander status
- type and cause of stroke
- date & time of stroke onset
- date & time of arrival at emergency department
- date & time of admission
- in-patient stroke status
- transferred from another hospital status
- ability to walk independently on admission^
- first-ever (incident) stroke event status
- National Institutes of Health Stroke Scale (NIHSS) Score on presentation^
- arrived by ambulance

HOSPITAL OUTCOMES/DISCHARGE DATA

- in-hospital death
- date of discharge/death
- discharge destination
- ICD10 diagnosis codes and procedures

QUALITY INDICATORS OF EVIDENCE-BASED CARE

- treatment in a stroke unit+
- date & time of first brain scan
- use of intravenous thrombolysis (tPA) if an ischaemic stroke+
- discharged on an antihypertensive agent+
- care plan provided at discharge (any documentation in the medical record)+
- telemedicine consultation
- date & time of thrombolysis
- adverse event related to thrombolysis
- swallow assessment and formal speech pathologist reviews
- aspirin administration, <48 hours
- mobilisation during admission
- discharged on antithrombotic medication
- discharged on statins/lipid-lowering drugs

FOLLOW-UP VARIABLES 90 TO 180 DAYS AFTER ADMISSION

- survivor status
- place of residence
- living alone status
- subsequent stroke since discharge
- readmission to hospital
- quality of life
- modified Rankin Scale
- would like an information pack from the Stroke Foundation
- would be willing to participate in future research

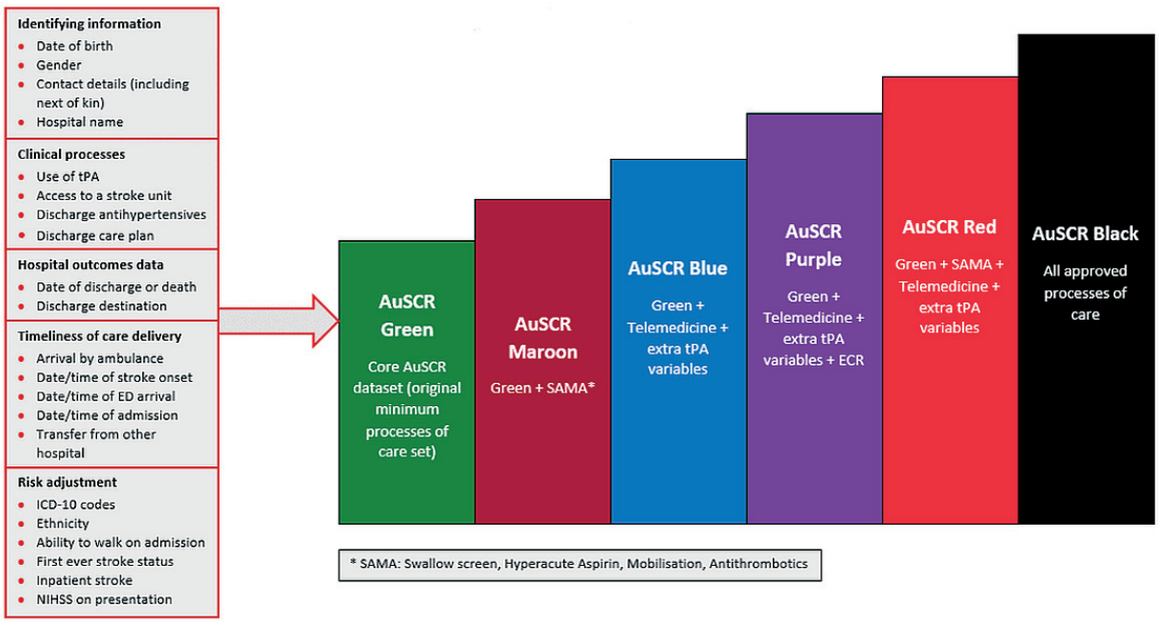
NOTES

^ Indicators of stroke severity.

+ Original core national process of care indicators.

* Different programs within the AuSCR collect different bundles of variables, depending on hospital practices and priorities.

FIGURE 1: AuSCR VARIABLE BUNDLES



As the Registry has matured, the large amount of cumulative data available permits analyses that can inform Australian policy and planning in relation to a range of epidemiological or health services issues, including for particular patient sub-groups. Additionally, approved third parties can access aggregated, anonymised data to address their own research questions, or to recruit registrants for studies. (See Appendix F for a list of the 2016 applications to the AuSCR Research Task Group).

In 2016, the major sources of funding for the Registry were: the Victorian government; the Stroke Foundation; and Queensland Health (see Appendix C). Where state government funding was unavailable, hospitals participated under a user pays system once the transition to the AuSDaT was implemented in mid-2016. Ongoing discussions continue in states and territories to procure funding support that will ensure representative data that can inform the provision of evidence-based stroke care nationally.

The data presented in this 2016 report provide insights into the care received, and the health outcomes, for 11204 patients from 48 Australian hospitals. Preliminary data on some relatively new variables, also now being collected internationally, have been presented for the first time, and provide a sense of the enriched AuSCR data that will emerge in the coming years to guide policy and practice.

METHODOLOGY

METHODS FOR ENSURING DATA QUALITY

From the outset, there have been consistent efforts to ensure complete and accurate data entry in the AuSCR. These quality control processes include:

- A comprehensive data dictionary (updated as required) with help notes to guide data entry (now incorporated as part of the National Stroke Data Dictionary developed in tandem with the AuSDaT).
- Database with built-in logic checks and variable limits to reduce the likelihood of data inaccuracies.
- Mandatory fields to reduce missing data.
- Inbuilt functions to identify duplicate entries and multiple patient records (for multiple episodes), which may be merged if necessary.
- AuSCR training for staff at newly participating hospitals and new staff at existing hospitals, completed in person or electronically. Additional resources available on the AuSCR website (ARM portal) containing training videos and written information.
- Assessment of data quality via missing and discrepant data reports.
- AuSCR Office audits of random medical records after approximately 50 patients are entered in the Registry and approximately every two years thereafter.
- Case ascertainment assessment by cross-checking a requested hospital list of all admissions (based on the ICD10 diagnosis codes related to stroke/TIA) with the episode data entered in the AuSCR.
- Frequently Asked Questions and regular electronic newsletters for dissemination of new information, reminders and updates.

For information on data quality reporting (e.g. time to record creation; data completeness reports; case ascertainment) a technical report has been developed separate to this annual report (in which the focus is on clinical data, quality of care and outcomes) and can be obtained upon request to admin@AuSCR.com.au.

OVERVIEW OF DATA ANALYSIS METHODS

When the AuSCR first commenced, all hospitals collected the same variables, but over time, small state-based variations were implemented. With the advent of the AuSDaT, the capacity of the tool enabled the development of six national data collection programs for the AuSCR (Figure 1). All contain core variables but allow individual hospitals to choose programs (guided to some extent by their state health departments) that are more aligned to their operations e.g. use of telemedicine or endovascular clot retrieval (ECR). 2016 represents the first year where such a broad array of data has been available. However, transition from the original AuSCR webtool to the AuSDaT was a challenging exercise, and there are some minor issues related to missing data as a result. Additionally, where variables have been collected for the first time in 2016, the data should be regarded as preliminary, but indicative of the rich information that will become available over time.

The data presented in this report include information on patients admitted to the participating hospitals between 1 January and 31 December, 2016. Data entry for these acute stroke/TIA episodes, and the associated follow-up assessments, was closed off and data extracted on 21 July 2017.

Duplicate data were checked by the AuSCR Data Manager using the registrant 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 by the AuSCR Office staff before the data were extracted and deidentified for analysis. A second level of data checking was performed by the Monash University analytic staff. Statistical analyses were performed using STATA/SE 14.0 (College Station, USA, 2015).

For all processes of care analyses presented in this report, ***episodes with missing information are included in the denominator***, because, if the data were not provided, we assumed that care related to that indicator was not offered in those circumstances.

Hospital postcodes were mapped to the Accessibility/Remoteness Index for Australia 2011 (ARIA+) available from the Australian Bureau of Statistics (see http://www.spatialonline.com.au/ARIA_2011/). The ARIA+ is used to calculate remoteness and accessibility, based on road distance, to 'service centres' (defined as populated localities where the population is greater than 1000 persons, of which there are 201). For this report ARIA+ Category 1 was defined as a major city and ARIA+ Categories 2 and 3 were combined to indicate a regional location. Paediatric cases were not included in the overall patient characteristics, clinical and outcome data analyses and are presented separately.

Benchmarks for the four AuSCR national indicators were calculated based on a modified version of the Achievable Benchmark of Care (ABC™) methodology[4] which has been used and validated by Hall et al, 2013.[5] Only hospitals that had contributed data to the AuSCR for more than six months, and had submitted at least 50 cases, were eligible for inclusion. An Adjusted Performance Fraction (APF) score was calculated for each hospital for each of the four indicators. This approach allowed adjustment for under or over inflation due to small numbers present at some hospitals. The benchmarks were calculated as the mean APF scores of the top performing hospitals that represented at least 15% of the sample of eligible patients. We also report national averages and adherence achieved by the top ranked hospitals from the sample of hospitals that had registered at least 50 episodes of care.

Unless otherwise stipulated, the follow-up data were analysed using descriptive statistics and multi-variable logistic regression, with adjustment for patient casemix using age, sex, stroke type, ability to walk on admission, inpatient stroke or patient

transfer from another hospital as appropriate. Hospital staff needed to ensure that acute data were entered within 180 days of the index stroke onset, in order for registrants to be eligible for follow-up. Until mid-2016, except for Victoria, each individual patient was only followed-up once, based on their first registered episode of care. Once data entry commenced in the AuSDaT, *all* episodes were followed-up unless they had occurred for the same patient less than 180 days apart.

Using data obtained from linkage to the NDI, ***casemix adjusted survival analysis*** for deaths up to 180 days following admission was performed for those who had experienced an episode of care in 2016. Cox proportional-hazards regression comparing survival status for those who did and did not receive stroke unit care, adjusted for age, sex, stroke type, inpatient stroke, transfer from another hospital and ability to walk on admission, was also performed.

Risk-adjusted mortality rate (RAMR) for each hospital at 30 days after admission was calculated. To ensure reliable estimates analyses were conducted for individual hospitals that provided at least 200 episodes between 2015 and 2016. Patients transferred from another hospital, in-hospital deaths and patients with TIA were excluded. The methods for calculating the RAMR for each hospital involved dividing the risk-adjusted hospital specific mortality by the risk-adjusted average hospital mortality, and then multiplying by the unadjusted proportion of deaths in the whole sample. All multi-level random effects models were adjusted for patient characteristics including age, sex, stroke type, indigenous status, country of birth, history of previous stroke and stroke severity, using the hospital as the level. Significant mortality variation was defined as *'normal variation'* (95% values) for hospitals within two standard deviation (SD) limits, and *'significant variation'* (99% of values) for hospitals above three SD limits.

Health-related quality of life (HRQoL) is measured in the AuSCR 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 profile is divided into three levels: no problems (1), some or moderate problems (2) and extreme problems (3). Additionally, the EQ-5D asks for a self-rated summary score of health using a Visual Analogue Scale (VAS) with a range of responses from zero to 100, with zero being the worst imaginable health state and 100 being the best imaginable health state.

All analyses were performed using STATA/SE 14.0 (College Station, USA, 2015).

CHARACTERISTICS OF HOSPITALS AND PATIENTS IN 2016

HOSPITALS

In 2016, 48 hospitals provided data for 11891 episodes. With the transition to the AuSDaT, six data collection programs were available (Figure 1), although only three of these data collection programs were used by hospitals from mid 2016. The majority of hospitals (n = 36) chose the red data collection program (demographics, indicators of evidence-based care, hospital outcomes and discharge data, additional variables related to provision of intravenous thrombolysis, and follow-up variables 90 to 180 days after admission) while another 11 hospitals chose the black data collection program (the same as red plus ECR variables). The green program contained demographics and core processes of care. See Figure 2.

The characteristics of the 2016 participating hospitals are shown in Table 1. In 2016, there were two hospitals located in New South Wales (NSW), 22 in Queensland (QLD), 22 in Victoria (VIC), and two in Tasmania (TAS). One of the 48 hospitals was a private hospital located in Queensland and one was a children's hospital in Victoria. There were 27 hospitals located in a major city, 43 that had stroke units and 44 that provided thrombolytic therapy using tPA. There were 40 hospitals that registered 100 or more episodes of stroke/TIA during 2016. For the first time, the use of telemedicine and the provision of ECR was captured in the AuSCR data.

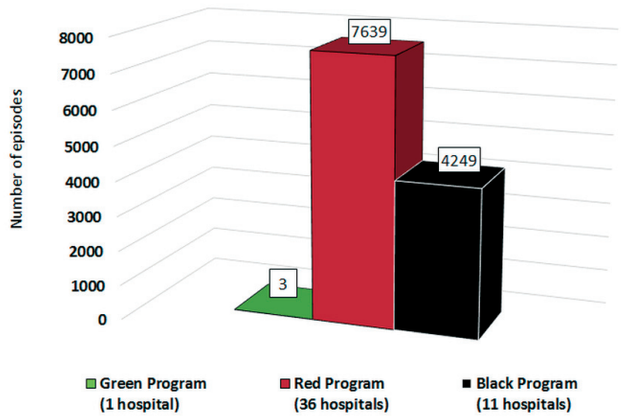
TABLE 1: CHARACTERISTICS OF PARTICIPATING HOSPITALS

YEAR	
NUMBER OF HOSPITALS	
ANNUAL NUMBER OF EPISODES IN THE AuSCR*	Low (<33 episodes)
	Medium (33-99 episodes)
	High (≥100 episodes)
LOCATION#	Major city (metropolitan)
	Regional (rural)
STROKE UNIT	
USED TELEMEDICINE	
INTRAVENOUS THROMBOLYSIS (TPA) UNDERTAKEN	
ENDOVASCULAR CLOT RETRIEVAL (ECR) UNDERTAKEN	

*Hospital categories as per the definitions used in Registry of the Canadian Stroke Network.
#Location categorised using Accessibility/Remoteness Index for Australia 2011 (ARIA+). Major city = category 1, Regional = categories 2 and 3.

2009	2010	2011	2012	2013	2014	2015	2016				
TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	NSW	QLD	VIC	TAS
6	12	16	31	37	40	40	48	2	22	22	2
-	1	4	11	2	2	2	2	-	-	1	1
1	5	2	6	8	8	6	6	-	1	5	-
5	6	10	14	27	27	32	40	2	21	15	1
6	10	11	16	28	28	20	27	2	13	11	1
-	2	5	15	9	9	20	21	0	9	11	1
6	10	14	28	35	35	38	43	2	19	20	2
-	-	-	-	-	-	27	29	0	15	14	0
6	9	10	22	31	31	38	46	2	21	21	2
-	-	-	-	-	-	9	9	0	3	5	1

FIGURE 2: NUMBER OF EPISODES ENTERED IN 2016 BY DATA COLLECTION PROGRAM TYPE



REGISTRANTS

In 2016, there were 11204 patients registered in the AuSCR (Table 2). Case ascertainment among the 48 hospitals ranged from 16% to 100%, median 77%. During a calendar year, patients may have multiple admissions for stroke or TIA that are also eligible to be included in the AuSCR. In 2016, there were 11891 episodes of acute hospital care entered in the AuSCR for the 11204 individuals registered. There were 620 patients who had 687 recurrent episodes registered in 2016. Among these, 60 registrants had three episodes each and six registrants had four episodes each. There were 11870 adult episodes.

The median number of episodes per hospital was 207 (Q1 to Q3: 137 to 299). The minimum number of episodes registered for any particular site was three at a metropolitan Victorian hospital and the maximum number registered was at a metropolitan hospital in Queensland (n = 804).

TABLE 2: NUMBER OF HOSPITALS, PATIENTS AND EPISODES IN 2016

Number of hospitals contributing data	**48**
Number of episodes submitted	**11891**
Number of patients	**11204**
Number and percentage of multiple episodes	**687 (6%)**

EPISODES PER MONTH

Figure 3 shows the number of episodes (including multiple episodes) per month based on date of admission. The median number was 976 per month. The minimum was 850 in January and the maximum was 1180 in July. Similar patterns were found in 2015.

REGISTRANT CHARACTERISTICS

Table 3 provides the baseline characteristics for patients and information related to their episodes of care. Adult and paediatric cases of stroke are presented separately. There were 13 hospitals that admitted paediatric cases (patients aged < 18 years).

Among the 11183 adult registrants, the most common country of birth was Australia (71%) followed by the United Kingdom (8%). The remainder were from a range of mainly European or Asian nations. There were 200 adult patients (2%) who identified as having an Aboriginal or Torres Strait Islander background. The majority of the registered adult patients spoke English (94%). The adult registrants had a mean age of 73 years, with 4862 (44%) females.

CLINICAL CHARACTERISTICS

Of the 11870 adult episodes, clinicians indicated that there were 6953 ischaemic strokes, 1359 intracerebral haemorrhages (ICH), 2088 TIAs and 497 episodes of undetermined stroke type. There were 973 episodes with the stroke type missing (Figure 4). Of the episodes with missing or undetermined stroke type for clinical diagnosis, ICD10 codes were provided for 755 cases, which comprised ICH (n = 51), ischaemic stroke (n = 288) and TIA (n = 416).

Among the adult episodes, the patient was noted as being able to walk at the time of admission in 42% of admissions. Among adults, there were 1596 episodes (14%) transferred from another hospital and 435 episodes (4%) that occurred while patients were already in hospital for another condition. The majority of the inpatient episodes were ischaemic (n = 318, 74%) and most of these (n = 139, 33%) occurred among patients aged between 75 and 84 years. The median length of stay was longer for patients who had an episode while already in hospital for another condition (inpatient median

FIGURE 3: NUMBER OF EPISODES PER MONTH IN 2016

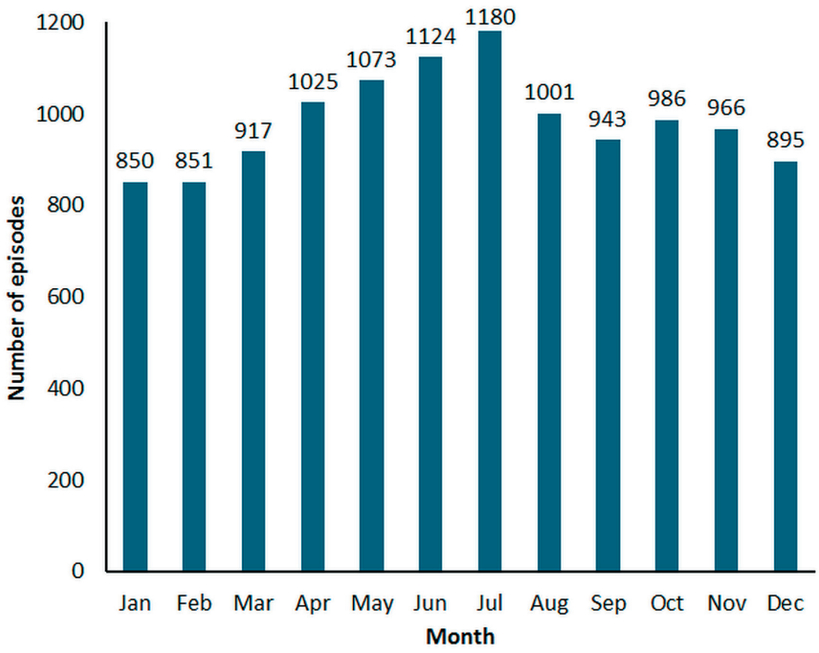
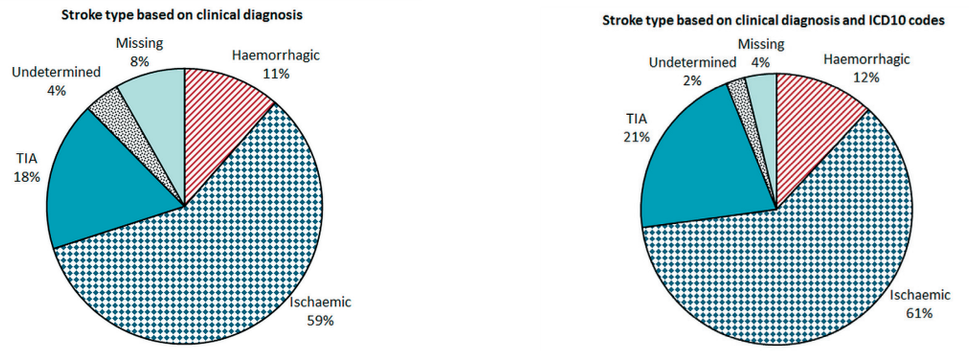


TABLE 3: BASELINE CHARACTERISTICS BY REGISTRANTS (ADULTS AND PAEDIATRICS)

REGISTRANTS		ADULTS (N=11183)	PAEDIATRICS (N=21)
Age, years, mean (SD)		73 (14)	6 (11)
Age, years, median (Q1 to Q3)		75 (64 to 83)	5 (1 to 16)
Female, n (%)		4862/10977 (44%)	6/21 (29%)
Country of birth, n (%)	Australia	7432/10433 (71%)	18/20 (90%)
	United Kingdom	801/10433 (8%)	1/20 (5%)
	Italy	325/10433 (3%)	0/20 (0%)
	Other European countries	886/10433 (8%)	0/20 (0%)
	Asia	366/10433 (4%)	0/20 (0%)
	Others	623/10433 (6%)	1/20 (5%)
Aboriginal and/or Torres Strait Islander, n (%)		200/10798 (2%)	2/21 (10%)
English spoken, n (%)		9689/10334 (94%)	20/21 (95%)

SD: standard deviation Q1: 25th percentile Q3: 75th percentile

FIGURE 4: DISTRIBUTION OF STROKE SUB-TYPES (INCLUDING MULTIPLE EPISODES)



11 days [Q1 to Q3: 6 to 20 days] vs. median 4 days [2 to 7 days] for non-inpatient events [presented from the community], $p < 0.001$). Patients who had an episode while already in hospital for another condition were treated in a stroke unit less often than those who presented from the community (60% vs 72%, $p < 0.001$).

Among the 2088 episodes of TIA, the mean age was 72 years (SD 13 years), 45% were female and the median length of stay was one day (Q1 to Q3: 1 to 3 days).

STROKE SEVERITY

There were 9839 episodes with ability to walk on admission recorded (83% of the 2016 cohort) and 3031 episodes with a National Institutes of Health Stroke Scale (NIHSS) score recorded (28% of the 2016 cohort), at time of presentation to hospital.

Patients with a diagnosis of ischaemic stroke had the lowest proportion of missing NIHSS scores (34%), followed by patients with an undetermined type of stroke (20%). The NIHSS score was recorded for 358 episodes with a diagnosis of TIA.

There were seven episodes (1%) with a missing clinical diagnosis of stroke type for which a NIHSS score was recorded. Of the episodes receiving thrombolysis, a NIHSS score was missing for 22%. Episodes treated in a stroke unit had a greater proportion of NIHSS scores recorded than those treated in alternate ward settings (33% vs 10%, $p < 0.001$).

Excluding those with TIA, patients who were able to walk on admission had lower NIHSS scores compared to those unable to walk (Figure 5).

Excluding those with TIA, there were 2468 episodes with both stroke severity variables recorded (Table 4). The greatest proportion of patients who were not able to walk on admission had a NIHSS score between five and fifteen, corresponding to a moderate stroke (42%). Of those who were able to walk on admission, the majority (63%) had a NIHSS score indicating a minor stroke. These findings support the historical use of ability to walk as a marker of stroke severity.

How to read the box plot: The boxes illustrate the range for the 25th to 75th percentiles, with the midline showing the median score and the vertical lines representing the entire range of scores.

FIGURE 5: DISTRIBUTION OF NIHSS SCORES ON ADMISSION STRATIFIED BY ABILITY TO WALK ON ADMISSION

TABLE 4: NATIONAL INSTITUTES OF HEALTH STROKE SCALE (NIHSS) AND ABILITY TO WALK ON ADMISSION

	ABILITY TO WALK ON ADMISSION	
NIHSS	**No n (%)**	**Yes n (%)**
No stroke symptoms (0)	46 (3)	94 (11)
Minor stroke (1-4)	385 (24)	520 (63)
Moderate stroke (5-15)	684 (42)	194 (23)
Moderate to severe stroke (16-20)	258 (16)	15 (1)
Severe stroke (21-42)	264 (16)	8 (1)
Total	1637	831

ACUTE CARE DATA

OVERALL ADHERENCE TO QUALITY INDICATORS

Arrival within 4.5 hours of symptom onset

2573 patients with ischaemic stroke (38%) arrived within 4.5 hours of symptom onset (Figure 6).

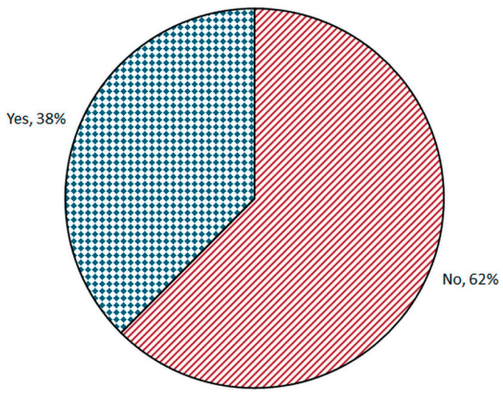


FIGURE 6: ARRIVED WITHIN 4.5 HOURS OF SYMPTOM ONSET IF AN ISCHAEMIC STROKE

Arrival by ambulance

Method of arrival to the emergency department was collected for 8796 episodes. Of these, 6543 (74%) were transported by ambulance. The majority (83%) of the 1180 patients who were transferred from another hospital arrived by ambulance. A greater proportion of patients arriving by ambulance arrived within 4.5 hours of symptom onset than those patients arriving by other modes of transport (47% vs 28%, $p < 0.001$). The proportion of patients arriving by ambulance was lowest for TIAs (64%, Figure 7), and highest for ICH (83%).

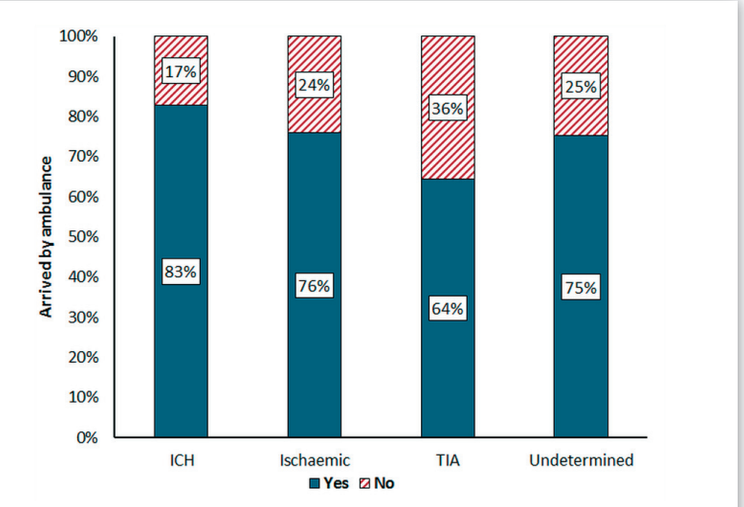


FIGURE 7: ARRIVAL BY AMBULANCE STRATIFIED BY STROKE TYPE

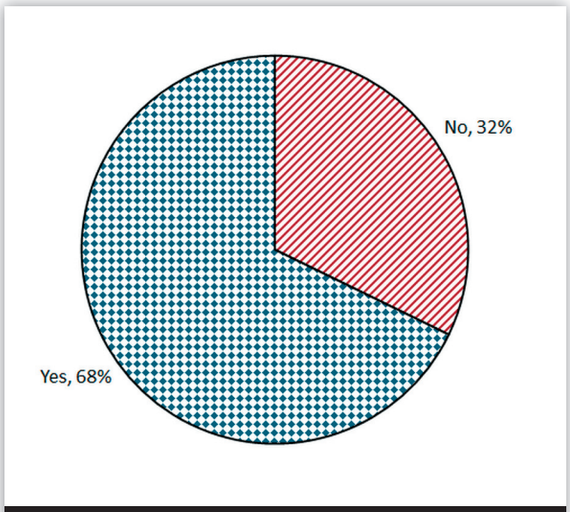


FIGURE 8: TREATED IN A STROKE UNIT

Stroke unit care

There were 8047 episodes of care where patients were treated in a stroke unit, making up 68% of the total episodes (Figure 8).

Of the patients with ischaemic stroke, 81% were treated in a stroke unit, compared to 65% of those with ICH, 54% of those with TIA and 52% of those with an undetermined type (Figure 9).

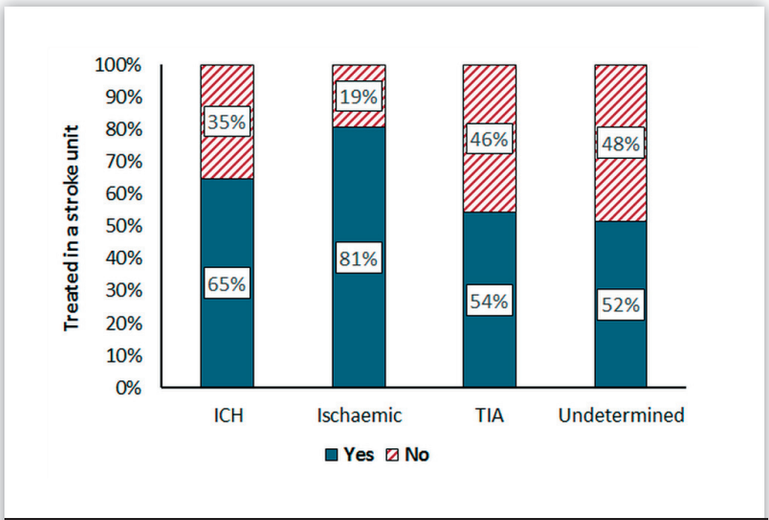


FIGURE 9: TREATED IN A STROKE UNIT STRATIFIED BY STROKE TYPE

OTHER ACUTE ASSESSMENT AND MANAGEMENT PRACTICES - QUEENSLAND

In Queensland, since 2012, additional variables had been collected which did not become available to the other states until after the migration to the AuSDaT in mid-2016. Only Queensland data are reported in this section, as the data collection for other states is incomplete for 2016. The majority of patients were mobilised on the same day, or the day after, admission (Table 5). Screening for dysphagia was conducted in 59% of episodes and swallow assessment was conducted for around three quarters of episodes. Of those receiving the screen or assessment, 62% were conducted within 24 hours.

MINIMISING RISK OF ANOTHER STROKE

Nationally, among those alive at discharge, 62% were discharged on an antihypertensive medication. In those with an ICH, 65% were discharged on an antihypertensive medication (Figure 10).

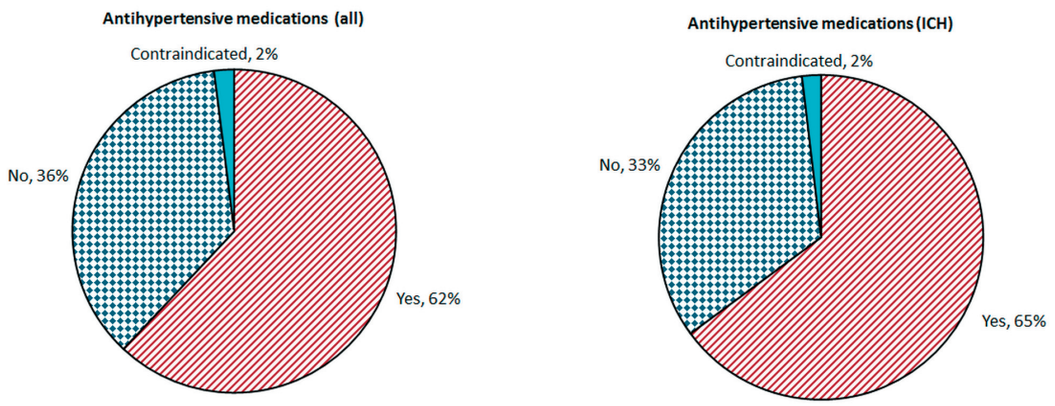
Contraindications were recorded as reasons for not prescribing secondary prevention medications at time of discharge from acute care for the first time from July 2016 (so is not captured in all of the episodes). Overall, contraindications for antihypertensive medications were reported for 173 (2%) of episodes.

TABLE 5: STROKE EVALUATION AND THERAPY

HOSPITAL STROKE CARE	ALL EPISODES	ISCHAEMIC	ICH	TIA
Mobilisation during admission	4711/5018 (94%)	3029/3111 (97%)	461/486 (95%)	1109/1203 (92%)
Same day or day after admission	3891/4589 (85%)	2437/2954 (83%)	329/453 (73%)	1033/1072 (96%)
If unable to walk independently, patient mobilised	2341/2375 (99%)	1698/1710 (99%)	298/305 (98%)	307/320 (96%)
Same day or day after admission	1781/2302 (77%)	1280/1669 (77%)	187/293 (64%)	287/303 (95%)
Dysphagia screen conducted	3282/5597 (59%)	2233/3431 (65%)	338/690 (49%)	634/1233 (51%)
Screen within 24 hours	2526/3261 (77%)	1684/2214 (76%)	230/334 (69%)	546/632 (86%)
Screen assessment conducted	4277/5597 (76%)	2965/3431 (86%)	457/690 (66%)	758/1233 (61%)
Assessment within 24 hours	2639/4276 (62%)	1782/2962 (60%)	257/456 (56%)	539/756 (71%)

Includes only patients admitted to hospitals in Queensland.

FIGURE 10: PRESCRIPTION OF ANTIHYPERTENSIVE MEDICATIONS AT DISCHARGE



TRANSITION FROM HOSPITAL CARE

Among the 5508 episodes resulting in discharge home or to a residential aged care facility, 59% received a care plan (Figure 11).

Of the patients with ischaemic stroke, 65% were provided a care plan at discharge, compared with 62% of those with ICH, 56% of those with TIA and 42% of those with an undetermined type (Figure 12).

FIGURE 11: PATIENTS DISCHARGED TO THE COMMUNITY WITH A CARE PLAN

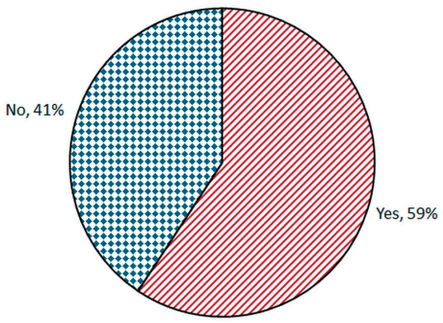


FIGURE 12: PATIENTS DISCHARGED TO THE COMMUNITY WITH A CARE PLAN STRATIFIED BY STROKE TYPE

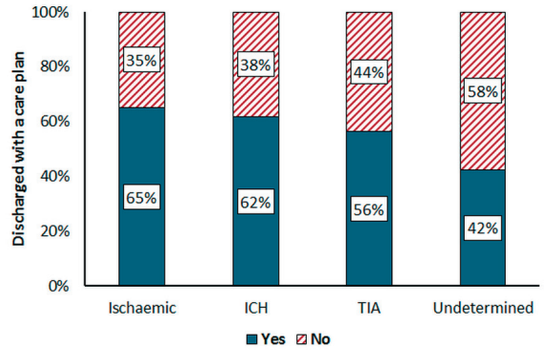
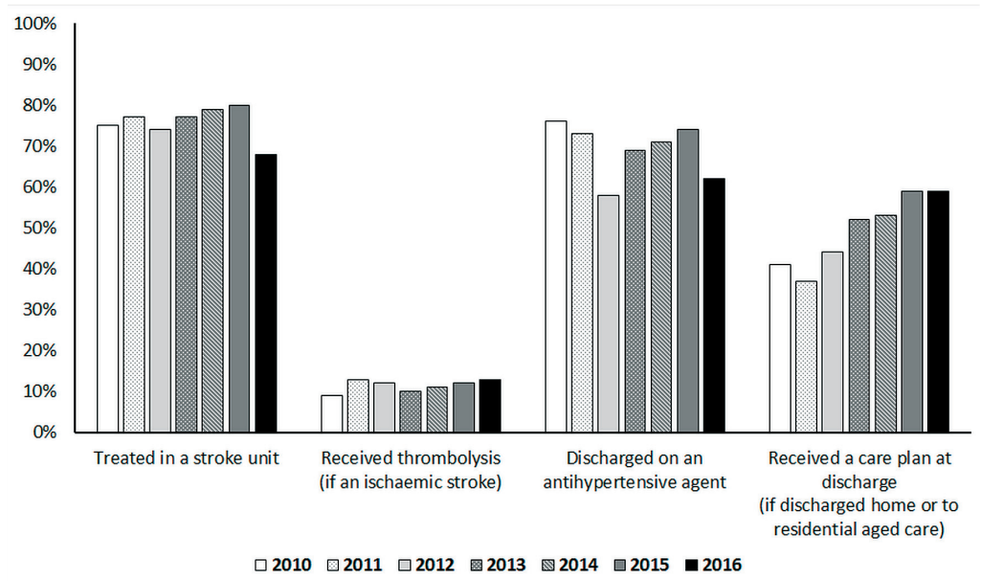


FIGURE 13: CHANGES IN QUALITY INDICATORS OVER TIME (NATIONAL AVERAGES)



CHANGES IN THE PROVISION OF QUALITY INDICATORS OVER TIME

Four quality indicators have been collected since the inception of the AuSCR (Figure 13). Compared with previous years, proportions receiving treatment in a stroke unit and antihypertensive medication at discharge appear to have decreased. These are, however, aggregate data and the analysis has not been limited to hospitals that have contributed data consistently since 2010.

ACHIEVABLE BENCHMARKS FOR QUALITY INDICATORS

The AuSCR benchmarks for the quality indicators compared to other commonly used performance metrics (i.e. adherence achieved by top performing hospitals or average adherence rates) are shown in Table 6.

If the achievable benchmarks were reached by all AuSCR hospitals relative to the overall average adherence, then it is estimated that: a further 3110 patients would have benefited from care in a stroke unit; an extra 543 from intravenous thrombolysis if an ischaemic stroke; 1897 from antihypertensive medication; 2502 from antithrombotic medication; 3196 from lipid lowering medication; and 1634 being provided with a care plan if discharged into the community.

TABLE 6: ACHIEVABLE PERFORMANCE BENCHMARKS FOR QUALITY INDICATORS AND CORRESPONDING AVERAGE PERFORMANCE

PROCESS OF CARE	BENCHMARK* 2014	BENCHMARK* 2015	BENCHMARK* 2016	TOP ADHERENCE** IN 2016 (%)	AuSCR ADHERENCE† (%)
Received stroke unit care	96	96	94	98	68
Received intravenous thrombolysis if an ischaemic stroke	20	19	21	25	12
Door-to-needle time <60 minutes	-	-	68	71	36
Discharged on antihypertensive medication^	88	87	81	88	64
Discharged on antithrombotic medication^	-	-	90	95	66
Discharged on lipid-lowering medication^	-	-	76	83	47
Care plan provided if discharged to the community	86	92	89	98	60

* Only sites with >50 cases were eligible for inclusion (n=43). Benchmarks were calculated based on a modified ABC™ method[4, 5]
** The top performer adherence results are the unadjusted scores for a single hospital in this sample.
† Overall % adherence from all AuSCR hospitals (n=48) providing data in 2016.
Benchmarks related to thrombolysis in 2016 exclude those who were indicated as receiving thrombolysis prior to hospital arrival.
^ Excludes patients with contraindications.

ADHERENCE TO QUALITY INDICATORS BY NUMBER OF ADMISSIONS PER HOSPITAL IN 2016

Adherence to quality indicators by number of episodes registered in 2016 for each hospital is illustrated by the funnel plots in Figure 14 to 18. Funnel plots can be used to display deviations from the average achievement of quality of care.[6] Note that all of the funnel plots below exclude paediatric cases.

How to read the funnel plots: The horizontal axis depicts the size of hospital in terms of number of episodes e.g. the larger the number of episodes, the further to the right will be the representative circle. The vertical axis measures the adherence to quality indicators, expressed as a proportion (%). The horizontal solid centre line shows the overall (all hospitals combined) adherence e.g. in the funnel plot in Figure 14, the overall proportion of patients admitted to a stroke unit was 68%. The dots show adherence for each individual hospital. The large dashed lines constitute the funnel based on standard deviation (SD). They are the upper and lower control limits that represent the boundary between 'normal variation' (2 SDs from the mean) and 'special cause variation' (3 SDs from the mean). The small dashed line indicates the achievable performance benchmark. Hospitals above the three SD limits line may be considered as having 'good performance', while those below the three SD limits line may be considered as having 'poor performance', relative to the sample average performance. Care must be taken in interpreting these data when they are skewed because the control limits rely on the assumption that the distribution of data follows a bell curve or 'normal distribution'.

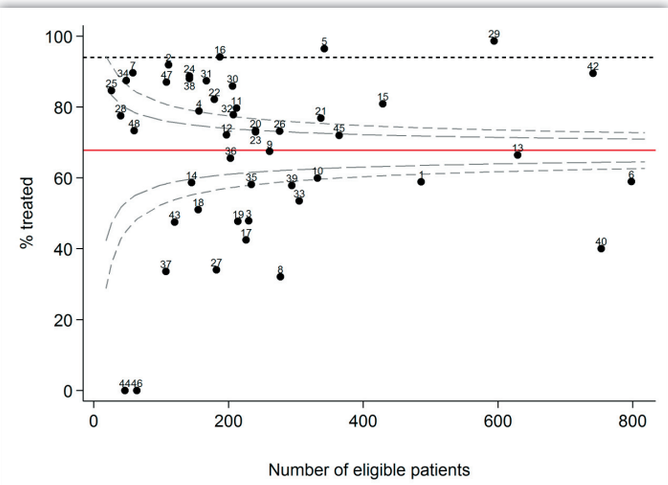


FIGURE 14: MANAGEMENT IN A STROKE UNIT BY HOSPITAL

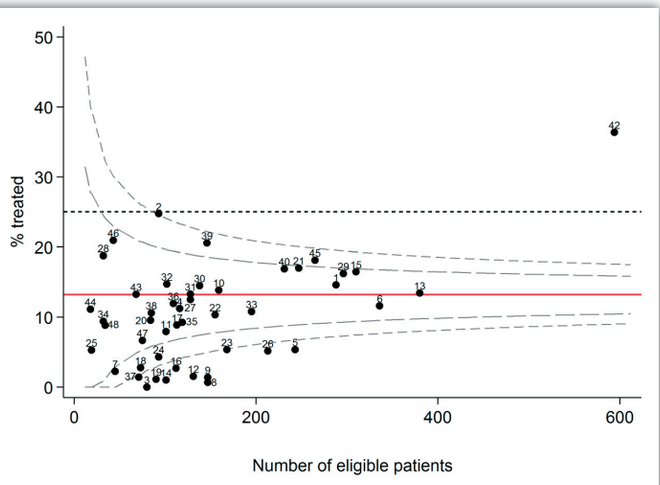


FIGURE 15: RECEIVED INTRAVENOUS THROMBOLYSIS BY HOSPITAL (INCLUDING TRANSFERS)

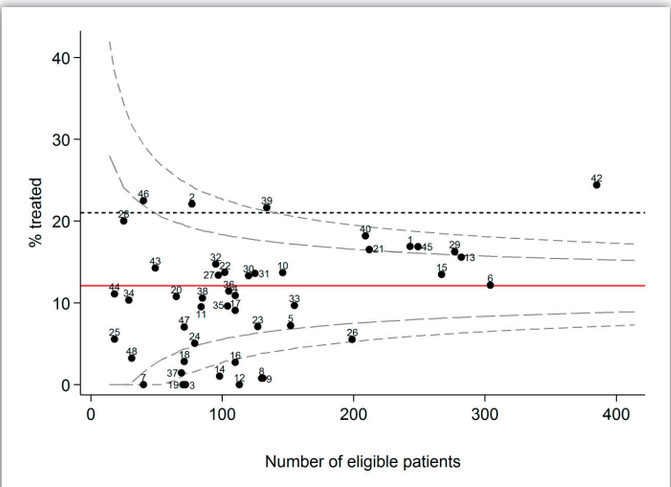


FIGURE 16: RECEIVED INTRAVENOUS THROMBOLYSIS BY HOSPITAL (EXCLUDING TRANSFERS)

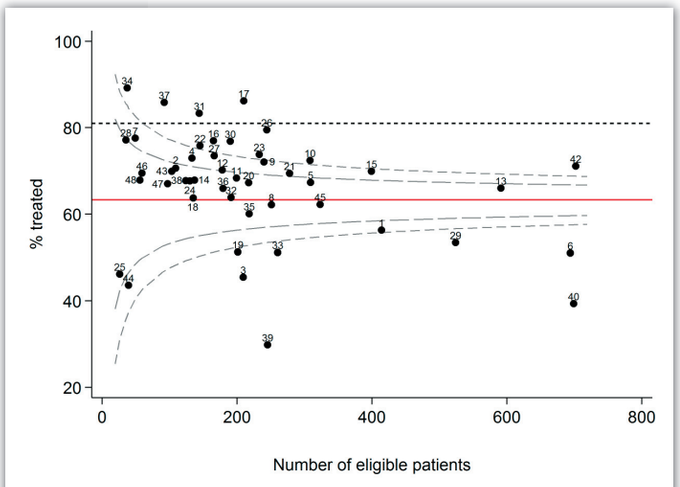


FIGURE 17: DISCHARGED ON ANTIHYPERTENSIVE MEDICATIONS BY HOSPITAL

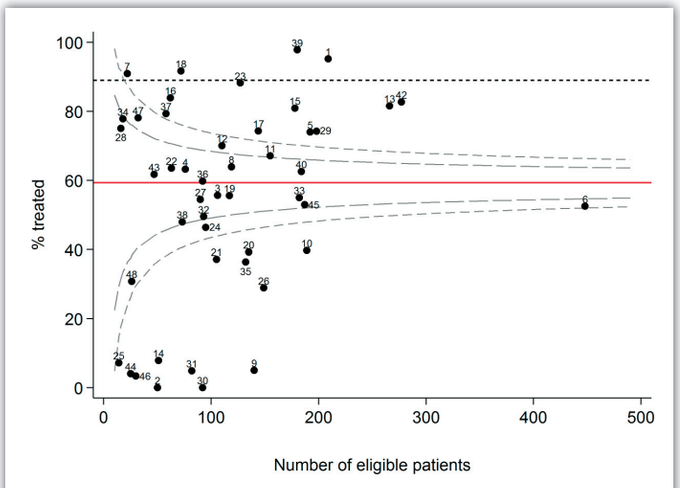


FIGURE 18: CARE PLAN PROVIDED BY HOSPITAL IF DISCHARGED HOME OR TO A RESIDENTIAL AGED CARE FACILITY BY HOSPITAL

EMERGING PROCESS OF CARE DATA SINCE TRANSITION TO THE AuSDaT

Some existing variables were modified and new variables were collected after the transition to the AuSDaT on 1 July 2016. Data in the old AuSCR system were migrated to the AuSDaT system in August 2016. Data entered from September onwards were uniformly collected in the AuSDaT.

In the following sections, data on new variables captured in the AuSCR since transition to the AuSDaT system are presented. These data are preliminary and are not intended to be representative of activity across Australia in these areas.

Time to brain scan

The median time to brain scan from arrival was 24 minutes for patients with ischaemic stroke arriving within 4.5 hours of symptom onset. There were 134 patients who had a brain scan prior to arrival at the hospital at which they were admitted.

Reason for transfers

The reason for transfer was collected for hospitals participating in the AuSCR Black program. Transfer for thrombolysis was indicated for six patients and transfer for endovascular therapy was indicated for 129 patients.

Thrombolysis timing

Of the 6953 episodes of ischaemic stroke, 917 (13%) were provided with thrombolysis treatment. There were 134 cases where thrombolysis was provided prior to hospital transfer.

Onset or arrival times were not documented for some patients who were provided with thrombolysis, and there may be some inaccuracies with the dates and times entered into the AuSCR. Of the 2573 patients with ischaemic stroke arriving within 4.5 hours of symptom onset, 719 (28%) were provided with thrombolysis. For the 486 patients who had times documented, 177 (36%) had a door-to-needle time under 60 minutes, median door-to-needle time was 72 minutes and median onset-to-needle time was 162 minutes. For those

provided thrombolysis, median door-to-scan time was 17 minutes.

Preliminary data on registrants for whom telemedicine was used as part of their acute stroke care

Use of telemedicine for acute stroke was recorded from 15 hospitals in Queensland (8 in regional areas) and 14 hospitals in Victoria (11 in regional areas) after July 2016. Among these 29 hospitals, there were 529 telemedicine consultations documented for adult patients, making up 11% of all admitted episodes at these hospitals. There were 371 patients who had an ischaemic stroke and received a telemedicine consultation (Figure 19). Of these, 105 patients (28%) were provided with thrombolysis. Median door-to-needle time for these cases was 91 minutes (Q1 to Q3: 66 to 116). This is 23 minutes longer on average than for non-telemedicine cases ($p < 0.001$).

Of those episodes involving telemedicine, there were 14 cases (13%) where an adverse event occurred after thrombolysis was provided, with eight of these adverse events being intracranial haemorrhage.

Preliminary data on endovascular clot retrieval (the AuSCR BLACK program)

From July 2016, we received data for 143 patients who received ECR from five hospitals in Victoria and three hospitals in Queensland. For cases for which times of arrival and treatment were collected, median time from arrival to groin puncture was 119 minutes and median arrival to recanalisation was 190 minutes (Figure 20).

For hospitals participating in the AuSCR Black Program, a NIHSS score was collected pre-ECR and 24 hours post-ECR, in addition to the NIHSS score obtained at hospital arrival. Data quality for this variable could be improved, as the majority were missing or unknown. Of the 143 cases provided with ECR, 68 had a NIHSS score pre-ECR recorded (48% complete) and 53 had a NIHSS score post-ECR recorded (37% complete), as illustrated in Figure 21.

Discharge medications

For the first time in 2016, the provision of lipid-lowering medications were collected, and the provision of antithrombotic medications was collected outside of Queensland. Excluding those with intracerebral haemorrhage, antithrombotic medications were prescribed for 78% of patients on discharge from hospital. Lipid-lowering medications were prescribed for 65% of all patients on discharge from hospital. Excluding those with contraindications, 52% of patients with ischaemic stroke were discharged on a combination of antihypertensive, antithrombotic and lipid-lowering medications.

Dysphagia screening

Dysphagia screening and swallow assessment have been collected previously (in Queensland), but whether these were conducted prior to oral intake was captured for the first time in 2016. The proportion of episodes where a swallow screen or speech pathologist assessment occurred prior to oral intake was 40% (Table 7).

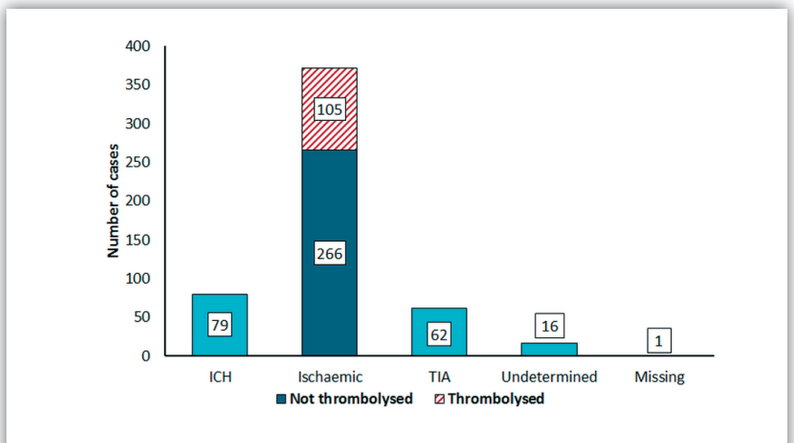


FIGURE 19: TELEMEDICINE ACTIVITY IN 2016

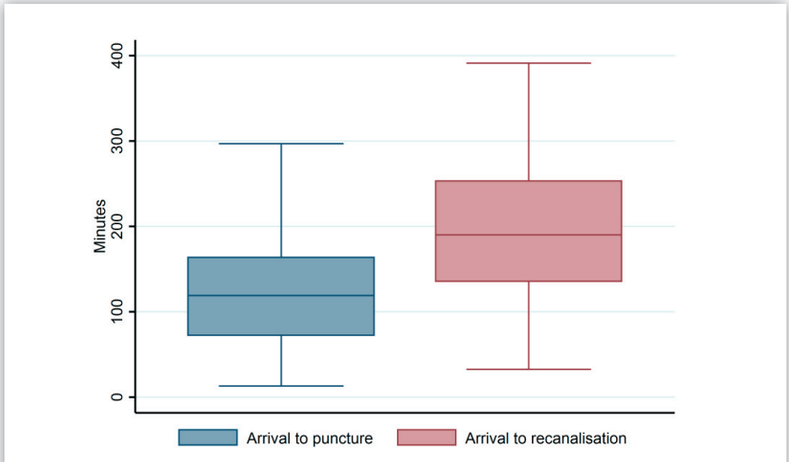


FIGURE 20: TIMES RELATED TO ENDOVASCULAR CLOT RETRIEVAL

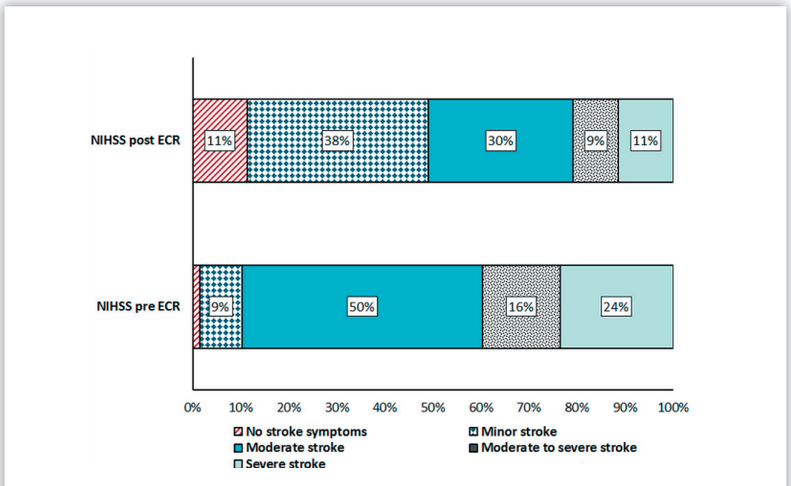


FIGURE 21: NIHSS SCORES BEFORE AND AFTER ECR

TABLE 7: DATA COLLECTED SINCE TRANSITION TO THE AuSDaT (SEPTEMBER TO DECEMBER 2017)

HOSPITAL STROKE CARE	ALL EPISODES	ISCHAEMIC	ICH	TIA
Brain scan after stroke	1037/1192 (87%)	749/843 (89%)	168/191 (88%)	107/141 (76%)
Discharged on an antithrombotic medication*	2931/3744 (78%)	2112/2504 (84%)	n/a	661/847 (78%)
Discharged on a lipid-lowering medication*	2505/3872 (65%)	1784/2510 (71%)	95/377 (25%)	546/848 (64%)
Discharged on a combination of secondary prevention medications*^	1892/3670 (52%)	1448/2678 (54%)	n/a	394/841 (47%)
Swallow screen or speech pathologist assessment prior to oral intake	1734/4293 (40%)	1208/2759 (44%)	222/529 (42%)	256/853 (30%)
Aspirin administration within 48 hours (if not intracerebral haemorrhage and not provided other antithrombotic medication)	1702/3231 (53%)	1186/2352 (50%)	n/a	455/749 (61%)

*Excludes patients with contraindications.
^A combination of antihypertensive, antithrombotic and lipid-lowering medications.

DISCHARGE INFORMATION

Hospital outcome measures include length of stay, discharge destination and discharge status. In the case where data for an individual person are 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 relate to the hospital that provided the initial care.

IN-HOSPITAL DEATHS

Among the 11870 adult episodes of care, 1062 (9%) patients died while in hospital. Case fatality in hospital was 17% lower for women after adjustment for age ($p = 0.005$). There were no paediatric in-hospital deaths reported.

LENGTH OF STAY

The median length of stay was four days (Q1 to Q3: 2 to 7 days). Patients with an ICH had a median length of stay of five days (Q1 to Q3: 2 to 10 days), patients with ischaemic stroke had a median length of stay of five days (Q1 to Q3: 2 to 8 days), patients with undetermined stroke had a median length of stay of three days (Q1 to Q3: 1 to 7 days) and patients with TIA had a median length of stay of one day (Q1 to Q3: 1 to 3 days). Patients with TIA more often had a short length of stay (less than four days) compared to patients with stroke (87% TIA, 50% stroke, $p < 0.001$).

Of the 10820 episodes discharged from hospital, 10318 had information provided on length of stay. Of these episodes, 518 (5%) stayed 21 days or more. There was a statistically significant difference between the length of stay for episodes treated in stroke units (median 4 days, Q1 to Q3: 2 to 8 days) and those not treated in stroke units (median 2 days, Q1 to Q3: 1 to 6 days, $p < 0.001$).

DISCHARGE DESTINATION

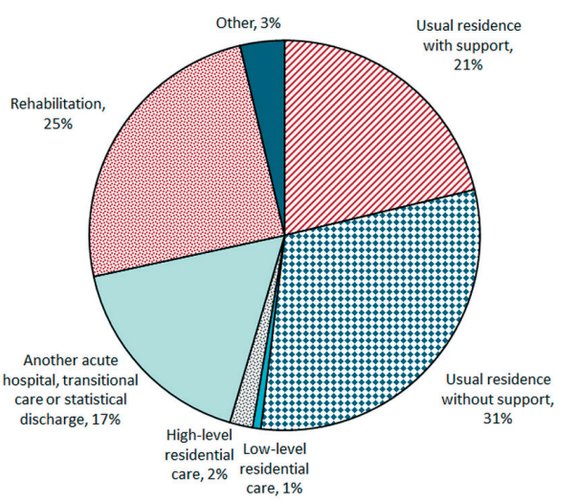
In 2016, excluding in-hospital deaths, approximately half of the episodes of care resulted in patients being discharged to their usual residence ($n = 5226$; 52%), in which many required support (Figure 22). The definition of support provided within a usual residence may include regular care and assistance by health professionals or volunteers including spouse or family members who may, or may not, be living in the same residence.

Patients managed in a stroke unit had two-fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed in a stroke unit (OR 2.17, 95% CI 1.9 – 2.5, $p < 0.001$) when adjusted for age, sex, type of stroke, ability to walk on admission, inpatient or community-onset stroke, and whether or not the patient was transferred from another hospital. Patients treated in a stroke unit were more often discharged to inpatient rehabilitation regardless of whether or not they were able to walk on admission (40% vs 18% unable to walk on admission, $p < 0.001$; 16% vs 9% able to walk on admission, $p < 0.001$).

Most patients with TIA (85%, $n = 1777$) were discharged to a home setting, 3% ($n = 56$) went to rehabilitation and the remainder went to aged care, transitional care services or other hospitals.

It is unclear whether these patients had already been in aged care prior to this event or had other co-morbidities, or complications while in hospital, which may have influenced their discharge destination. Of the 37 registrants with TIA who were discharged to residential aged care, 29% had a documented history of a previous stroke.

FIGURE 22: DISCHARGE STATUS INCLUDING MULTIPLE EPISODES



N=10066
Excludes paediatric cases and episodes of care resulting in death in hospital.
Queensland registrants coded as sub or non-acute patients (SNAP) were included in the hospital category.
n=754 had missing discharge destination.

POST-DISCHARGE HEALTH OUTCOME INFORMATION

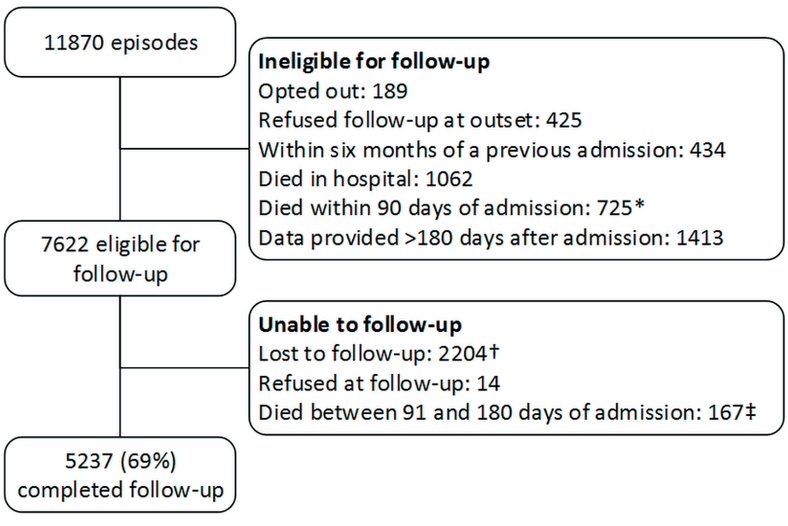
RESPONSE RATES

Of the 7622 adult episodes eligible for a follow-up survey, 5237 (69%) of patients provided information about their health status (Figure 23). Median time to follow-up was 143 days (Q1 to Q3: 107 to 169 days).

There were 21 episodes occurring in patients under the age of 18. Of these, three were admitted to a children's hospital and 18 were admitted to adult hospitals. Four of these episodes were followed up at 90 to 180 days after admission. Twelve were aged between one and 12 years, and nine were aged between 13 and 18 years.

Of the patients eligible for follow-up, differences were identified in both demographic and clinical characteristics, as well as in processes of care received (Table 8).

FIGURE 23: FLOW DIAGRAM OF THE FOLLOW-UP SURVEYS FOR PATIENTS REGISTERED IN 2016 EXCLUDING PAEDIATRIC CASES



* Deaths after discharge and within 90 days of admission were determined using the NDI.
† Contact unable to be made using our protocol (two postal attempts and one phone attempt).
‡ Deaths between 91-180 days of admission were determined using the NDI. Note that this figure does not represent total deaths between 91-180 days following admission for a variety of reasons including: patient completed follow-up, lost to follow-up, data provided >180 days after admission, refused follow-up, and opted out.

TABLE 8: BASELINE CHARACTERISTICS FOR PATIENT EPISODES WITH AND WITHOUT ANY POST-DISCHARGE INFORMATION

		COMPLETED (N=5237)	NOT COMPLETED (N=2385)	P VALUE
Age (years), mean (SD)		72 (13)	69 (15)	<0.001
Female, n (%)		2226/5234 (43%)	987/2380 (41%)	0.386
Aboriginal and/or Torres Strait Islander, n (%)		70/5215 (1%)	72/2272 (3%)	<0.001
Type of stroke, n (%)	**Ischaemic**	3125/4846 (64%)	1456/2154 (65%)	0.004
	Haemorrhagic	436/4846 (9%)	196/2154 (9%)	
	Transient ischaemic attack	1091/4846 (22%)	404/2154 (21%)	
	Undetermined	194/4846 (4%)	98/2154 (5%)	
Able to walk on admission, n (%)		2103/4412 (48%)	855/1907 (45%)	0.038
Length of hospital admission (days), median (Q1 to Q3)		3 (2 to 7)	4 (2 to 7)	0.167
Treated in a stroke unit, n (%)		3837/5237 (73%)	1644/2385 (69%)	<0.001

Excludes paediatric cases.
SD: standard deviation.
Q1: 25th percentile Q3: 75th percentile

FOLLOW-UP DATA

At follow-up, approximately one in four registrants reported that they had been readmitted to hospital (Table 9). Most registrants who were followed up were living at home (85%), while 20% of registrants were living alone. There were 590 registrants living in low level care or high level care for whom information at follow-up was obtained. According to the responses to the modified Rankin Scale (mRS), 25% were free from disability, reporting no symptoms at all.

Patients who had better functional status at follow-up, as measured by the mRS, appeared to have a shorter length of stay while in hospital (Table 10). There were 62 patients who were provided ECR and 386 patients provided thrombolysis who were followed up at 90-180 days after admission. Of these patients, more than half reported having no, or slight, disability according to the mRS.

HEALTH-RELATED QUALITY OF LIFE

With respect to health-related quality of life, almost half of the respondents reported problems with mobility (48%) but less than a third (31%) reported problems with self-care. Just under half (45%) of the respondents indicated problems in relation to anxiety and depression (Table 11). The Visual Analogue Scale (VAS) mean was 68.6 (compared with 70 in 2015), in comparison to the mean of 83 for the normative population of similar age.[7] Figure 24 shows the VAS scores stratified by mRS at follow-up.

TABLE 9: INFORMATION OBTAINED AT FOLLOW-UP

Had a recurrent stroke			307/5173 (6%)
Readmitted to hospital			1172/5166 (23%)
Location of stroke survivor at time of follow-up interview			
Home	Living alone		1029/5188 (20%)
	Living at home		4409/5199 (85%)
		Home with support	2045/4409 (46%)
		Home without support	2364/4409 (54%)
Institutional care or other setting	In hospital		48/5199 (1%)
	Transitional care services		62/5199 (1%)
	Low level care (hostel care)		79/5199 (2%)
	High level care (nursing home)		511/5199 (10%)
	Inpatient rehabilitation		45/5199 (1%)
	Other		45/5199 (1%)
Modified Rankin Scale (mRS)			
0 – No symptoms at all			1312/5221 (25%)
1 – No significant disability despite symptoms			1217/5221 (23%)
2 – Slight disability			883/5221 (17%)
3 – Moderate disability			1047/5221 (20%)
4 – Moderately severe disability			561/5221 (11%)
5 – Severe disability			174/5221 (3%)
Missing			27/5221 (1%)

Missing data not included in denominators
Excludes paediatric cases

TABLE 10: MODIFIED RANKIN SCALE AT FOLLOW-UP AND LENGTH OF STAY

			Length of stay (days)				
MODIFIED RANKIN SCALE AT FOLLOW-UP	**NUMBER OF PATIENTS**	**% OF TOTAL**	**MEDIAN**	**Q1**	**Q2**	**MEAN**	**SD**
0 – No symptoms at all	1,338	19%	2	1	4	3.19	4.17
1 – No significant disability despite symptoms	1,233	17%	3	2	5	4.09	4.43
2 – Slight disability	892	12%	4	2	7	5.11	4.93
3 – Moderate disability	1,063	15%	5	2	9	7.38	8.40
4 – Moderately severe disability	573	8%	6	3	10	8.79	9.90
5 – Severe disability	177	3%	9	5	16	12.80	12.82
6 – Died	1,803	25%	4	2	9	7.01	8.83
Unknown	130	2%	4	2	7	5.72	7.71
Total	7,209	100	4	2	7	5.87	7.53

Q1: 25th percentile Q3: 75th percentile

PARTICIPATION IN FUTURE RESEARCH

Among the 5216 registrants, who answered the question about whether they would be willing to be contacted to participate in future research, 3180 (61%) replied affirmatively. Compared to those who did not reply in the affirmative, these registrants were younger (71 vs 78 years, $p < 0.001$) and more often male (60% vs 53%, $p < 0.001$).

UNMET INFORMATION NEEDS

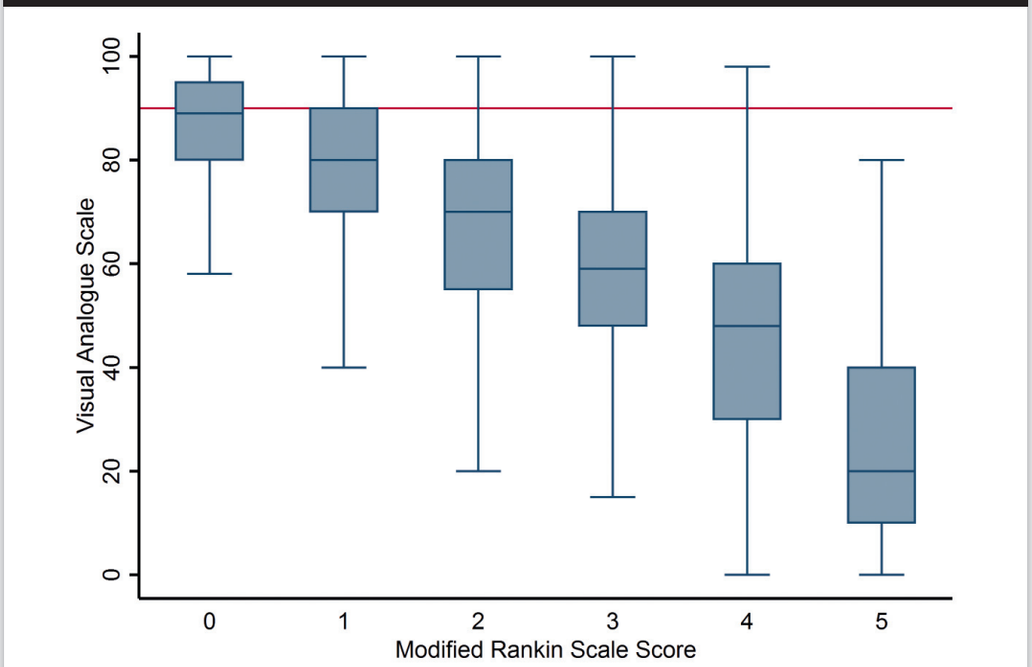
Stroke can be a devastating and life changing event for people and there is a possibility that stroke survivors and their care providers have unmet care and information needs. Given that the AuSCR protocol includes a follow-up survey with survivors at 90 to 180 days post stroke or TIA, it presents an opportunity to ask registrants whether they would like to receive further information about stroke from the Stroke Foundation. In 2016, 47% (n = 2441) of the 5226 registrants who answered this question, indicated that they would like to receive such information.

TABLE 11: QUALITY OF LIFE ASSESSMENT AMONG SURVEY RESPONDENTS

EQ-5D DIMENSIONS		n/N (%)
Mobility	No problems (Level 1)	2684/5212 (52%)
	Problems (Levels 2 & 3)	2528/5212 (48%)
Self-care	No problems (Level 1)	3608/5217 (69%)
	Problems (Levels 2 & 3)	1609/5217 (31%)
Usual Activities	No problems (Level 1)	2316/5218 (44%)
	Problems (Levels 2 & 3)	2902/5218 (56%)
Pain/Discomfort	No problems (Level 1)	2695/5187 (52%)
	Problems (Levels 2 & 3)	2492/5187 (48%)
Anxiety/ Depression	No problems (Level 1)	2846/5191 (55%)
	Problems (Levels 2 & 3)	2345/5191 (45%)
VISUAL ANALOGUE SCALE (0–100)		
Mean (SD)		68.6 (22.3)
Median (Q1 to Q3)		75 (50 to 85)

Excludes paediatric cases
SD: standard deviation
Q1: 25th percentile; Q3: 75th percentile

FIGURE 24: VAS SCORES AT FOLLOW-UP, STRATIFIED BY MODIFIED RANKIN SCALE SCORES



Modified Rankin Scale scores:
0 - No symptoms;
1 - No significant disability. Able to carry out all usual activities, despite some symptoms;
2 - Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities;
3 - Moderate disability. Requires some help, but able to walk unassisted;
4 - Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted;
5 - Severe disability. Requires constant nursing care and attention, bedridden, incontinent.
Solid horizontal line indicates population norm from the United Kingdom.

SURVIVAL

According to the data in the NDI, there were 725 patients (6%) who died after discharge from hospital, but within 90 days of their admission, and 268 patients (2%) who died between 91 and 180 days of their admission.

In patients with ischaemic stroke, treatment in a stroke unit was associated with a 33% lower hazard of death at 180 days after admission than treatment on an alternate ward (Hazard ratio: 0.67, 95% CI: 0.56 – 0.80, $p < 0.001$,Figure 25). A similar result was found for patients with ICH (Hazard ratio: 0.66, 95% CI: 0.50 – 0.87, $p = 0.003$, Figure 26).

RISK ADJUSTED MORTALITY RATE

The spread of risk adjusted mortality rate (RAMR) for all hospitals based on funnel plots of combined 2015 and 2016 data showed no evidence of 'significant variation' (Figure 27).

FIGURE 25: CUMULATIVE HAZARD OF DEATH BY TREATMENT IN A STROKE UNIT FOR EPISODES WITH ISCHAEMIC STROKE

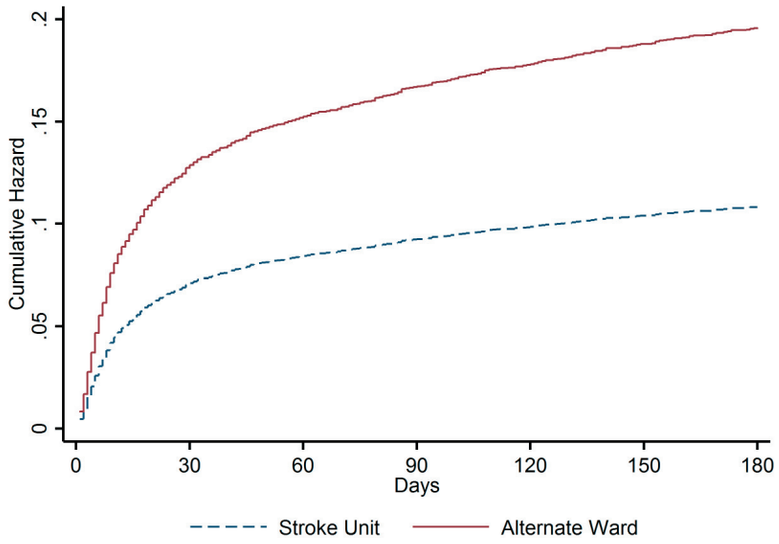


FIGURE 26: CUMULATIVE HAZARD OF DEATH BY TREATMENT IN A STROKE UNIT FOR EPISODES WITH INTRACEREBRAL HAEMORRHAGE

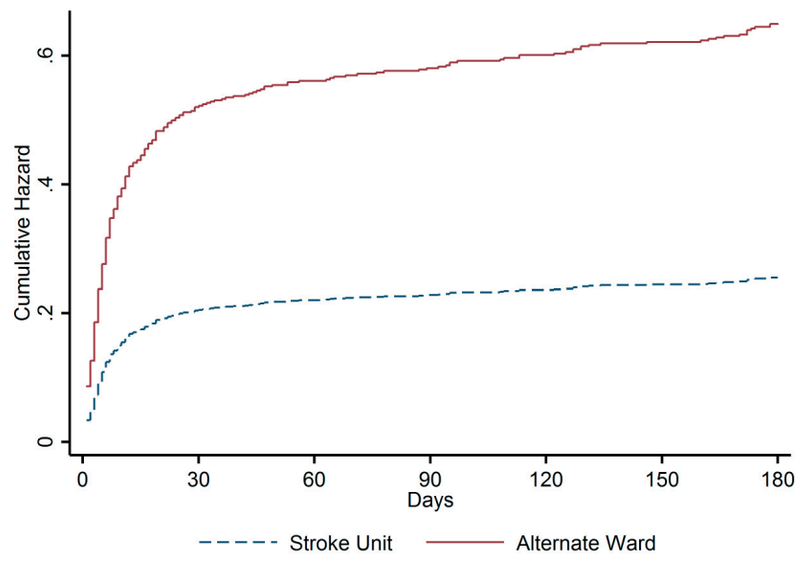
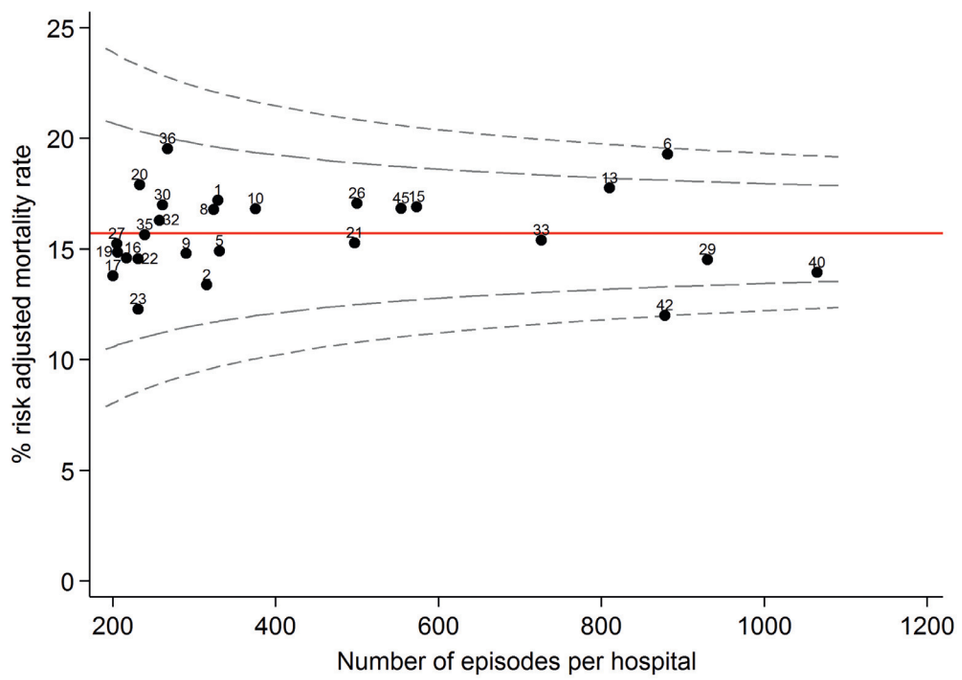


FIGURE 27: RISK ADJUSTED MORTALITY RATE BY HOSPITAL FOR COMBINED 2015 AND 2016 DATASETS



MEAN RATE

2 STANDARD DEVIATION LIMITS

3 STANDARD DEVIATION LIMITS

Model was adjusted for age, sex, stroke type, indigenous status, country of birth, history of previous stroke and stroke severity.
Excludes paediatric hospitals, in-hospital strokes and transfers from another hospital.

DISCUSSION

For this 2016 AuSCR Annual Report, we have presented information contributed by 48 Australian hospitals on 11891 episodes of stroke or TIA. The transition to the AuSDaT in 2016 was an exciting, albeit challenging, time for the AuSCR team. The AuSDaT has provided an intelligent user interface and an expansion of available variables, allowing the tool to be used collaboratively across various stroke data collection programs around Australia.

Data quality and completeness have always been important aspects of the AuSCR, and we expect that after the transition and bedding down of the new data entry portal (the AuSDaT) the process will be enhanced. Hospital staff, who have now used the AuSDaT for Stroke Foundation audits and their AuSCR data entry, should be benefiting from the reduced data entry burden resulting from a single data portal being used across multiple programs.

For the third consecutive year our casemix adjusted analyses of AuSCR data, linked with the NDI, have demonstrated a survival advantage of stroke unit care compared to non-stroke unit care. However, it is of concern that only 68% of the 2016 registrants were treated in a stroke unit (compared to 80% in 2015), even though 43/48 of the participating hospitals have a stroke unit. Discharge on antihypertensive medication was also less than 2015 (62% compared to 74%). The finding that fewer patients were treated in a stroke unit may be one reason for a reduction in prescription of antihypertensives, as research has shown that patients treated in stroke units are more likely to receive evidence-based care.[8,9] From a statistical perspective, absolute percentages do not tell the whole story when comparing outcomes over time. Complex casemix adjustment is required and will be investigated separately from this report. Nevertheless, it is critical that health services ensure that their patients have access to health care that facilitates optimal health outcomes.

The Stroke Foundation Acute Audit 2017[10] provides data from a larger number of hospitals but for just 40 consecutive stroke admissions from 1 July 2016 and discharged by 31 December 2016. In comparison to the AuSCR 2016 data, the Stroke Foundation audit rates of stroke unit care and thrombolysis delivery were equivocal. However, rates of discharge care plan provision (60% AuSCR; 65% Stroke Foundation Audit), receipt of thrombolysis within 60 minutes of hospital arrival (36% AuSCR; 46% Stroke Foundation Audit) and discharge on antihypertensive medications for patients with ICH (64% AuSCR; 80% Stroke Foundation Audit) were all lower in the AuSCR 2016 dataset.

Missing data still remain a significant issue for some AuSCR variables. For example, 72% of the cohort had a NIHSS score which was listed as unknown or missing, which was a slight improvement on the 76% reported in the 2015 dataset. Additionally, more than half of patients receiving ECR had a pre- and post-ECR score missing from the dataset. Although our data showed a good correlation between the NIHSS score and 'ability to walk on admission', capture of the NIHSS score as an indicator of stroke severity would be the preferred option. The availability of accurate stroke severity data variables can affect the accuracy of mortality analyses and impact apparent hospital performance rankings.[11] If we are to use the NIHSS score in analyses utilising casemix adjustment there needs to be a major improvement in data completeness.

With respect to discharge medication data, missing or unknown values occurred in 16% of cases for antihypertensives, 17% for antithrombotics and 37% for lipid-lowering medication. For process of care analyses, ‘missing’ or ‘unknown’ is assumed to indicate that a specific process did not occur. However, the missing/unknown data may, to some degree, explain low rates found for secondary prevention in the AuSCR to AuSDaT transition year where collection was only commenced in August 2016. There still appears to be room for improvement as discharge on antihypertensive medications has been collected from the outset, yet data are still missing in 16% of episodes.

Analysis of missing data will be reported more fully in the AuSCR 2016 data quality report, but rates of missing data for selected variables are presented in Table 12.

TABLE 12: MISSING DATA FOR SELECTED AuSCR VARIABLES

VARIABLE	% MISSING (OVERALL)	MIN-MAX % MISSING PER SITE
Date of birth	2%	0%-15%
Gender	2%	0%-15%
Type of stroke	8%	0%-48%
Able to walk on admission	9%	0%-43%
NIHSS score on admission	10%	0%-63%
Treated in a stroke unit	6%	0%-42%
Discharged on antihypertensive medication	10%	0%-44%
Principal diagnosis ICD10 code	11%	0%-100%

Excludes registrants who opted out of the AuSCR

In order to harmonise stroke data collection across a number of stroke programs in the AuSDaT, it was necessary to change the way some variables were previously collected in the AuSCR e.g. hyperacute aspirin is now based on timing rather than provision alone. Furthermore, there is now enhanced capacity to capture contraindications for medications. Potentially, for this report, there may be some circumstances where it is not possible to differentiate between whether data for such variables have not been recorded or are legitimately missing. This circumstance should not arise for the 2017 report.

As a result of transitioning to the AuSDaT, we have had the opportunity to start collecting some new variables. Being the first year the sample sizes were small, but we look forward to being able to provide more in-depth analysis as the data accumulate. For example, there were data for 143 patients who underwent ECR and we determined that, in hospitals where telemedicine was operational, it was used in 11% of all admitted episodes to support differential diagnosis and subsequent appropriate management. The rate of thrombolysis was 28% at hospitals using a telemedicine service, compared with 13% in the whole 2016 sample. This is a testament to the benefits of a telemedicine consultation for determining acute care treatment decisions.[12,13] In 2016, more universal collection of contraindications for discharge medication commenced. The percentage responses were low and, at this stage, it is unclear whether that is a result of poor data collection with these new variables. Still, only 41% of patients with ischaemic stroke were provided all three types of secondary prevention medications. Of note is that this is substantially less than the 69% reported in the Stroke Foundation 2017 acute care audit.[10]

The follow-up of discharged patients at 90-180 days provides a unique, but resource-intensive, opportunity to determine longer-term outcome data on stroke or TIA. The 2016 response rate of 69% is slightly less than the 73% from 2015, although in absolute numbers 1000 more follow-ups were completed. We are exploring whether later data entry, perhaps as a result of the AuSCR to AuSDaT transition, has contributed to more registrants being lost to follow-up.

Our patient reported outcome measures continue to be a valuable source of information related

to health outcomes post-stoke. Six percent of registrants reported a recurrent stoke in the 90-180 days after the index episode. There is potential to explore this data in more depth, particularly in relation to the care they had received initially. Six percent had had a recurrent episode, and one quarter (25%) of the respondents at follow-up had been readmitted to hospital so this cohort is clearly dealing with a range of co-morbidities. In other analyses of the AuSCR data linked with state health department administrative datasets,[14] we found that readmission within *one year* of the index event was 42% with 12% of those due to stroke/TIA, so these are health issues (in association with co-morbidities) that constitute a significant impact on health services.

During the course of 2016, ethics approvals to enable full follow-up of paediatric patients at all participating hospitals was progressed. The five age appropriate versions of the paediatric follow-up form were added to the AuSDaT some time after transition, so it is still early days in the collection of these data. Additionally, our original children's hospital provided a small volume of data for the year while ethics issues were resolved. In the future, we hope to have more substantial numbers to enable a robust exploration of this under-researched sub-group of patients with stroke.

There have been ongoing efforts to facilitate bulk data imports from hospital administrative databases to reduce manual data entry. In Victoria, this process was championed by the Victorian Stroke Clinical Network through an Operational Infrastructure Support Grant and enabled many Victorian hospitals to streamline their data entry processes. In Queensland and New South Wales, similar processes, which are quite complex, are still under development.

Historically, patients were only eligible for the AuSCR if they were admitted to hospital, which imposed some limitations on the data. Going forward, there are plans, and the capacity exists, to include patients who are treated in the Emergency Department of one hospital but are transferred and subsequently admitted to another hospital. This approach will more comprehensively and accurately cover the patient care pathway where different treatments may have occurred at different hospitals. Currently, under-reporting may occur where data are captured only at the admitting hospital.

Various activities in quality improvement support for hospitals have occurred, including the StrokeLink program in Queensland (supported by Queensland Health) and STELAR (Shared Team Efforts Leading to Adherence Results; supported by the Ian Potter Foundation) in Victoria.[15] Such programs actively support hospitals in critically reviewing their data to inform clinical care improvements.

Each year, as we report our findings, there continues to be wide variability in adherence to the nationally endorsed quality indicators among the participating hospitals. Despite longstanding awareness of best practice in Australia, it would appear that optimal care is not always provided. We anticipate being able to shed some light on the reasons for such variations when the results for our Stroke123 study are published.

In 2016, the AuSCR has continued to grow nationally with plans to increase participating hospitals in the Australian Capital Territory, New South Wales and South Australia in 2017 and 2018. The AuSCR continues to be at the forefront of clinical quality registries with the collection of patient reported outcome measures 90 days post-discharge. While the transition to the new data collection tool (AuSDaT) has potentially impacted some elements of data collection in the 2016 dataset, it has also enabled the AuSCR to increase the range of acute stroke data collected. More importantly, it allows participating hospitals to generate on-demand, benchmarked reports to peer, state and national hospitals (or export datasets) to support quality improvement activities. It is these quality improvement activities, underpinned by programs such as STELAR, which will close the data quality loop and enable equitable stroke care provision and better outcomes for all patients with stroke.

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APPENDIX A

AuSCR GOVERNANCE AND COLLABORATIONS

The AuSCR initiative is undertaken by a consortium of two leading academic research institutes, The Florey Institute of Neuroscience and Mental Health (Stroke Division; AuSCR Data Custodian) and The George Institute for Global Health, and two leading non-government organisations, the Stroke Foundation and the Stroke Society of Australasia (SSA). Collectively, these organisations represent a broad section 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:

(www.australianstrokecoalition.com.au).

The AuSCR Steering Committee provides: governance; maintains the confidence of all parties involved; and contributes to strategic direction. Professor Sandy Middleton continued to be the Chairperson in 2016. 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 the AuSCR Office to manage the ongoing operations of the Registry. Associate Professor Natasha Lannin was Acting Chair for most meetings subsequent to Professor Craig Anderson's relocation to China. (See Appendix B for committee membership lists.)

There has been highly valued support from the Victorian Stroke Clinical Network (VSCN) and, since mid-2015, Queensland Health through a joint project (QSQIP) with the Stroke Foundation.

Collaborations are continuing with staff from the AIHW, the Population Health Research Network and data linkage units based in health departments within various states (Victoria, Western Australia, Queensland and New South Wales) to work through the processes to enable the linking of AuSCR data with government data such as the NDI and state level admitted episode datasets and emergency department admissions.

We have continued to work with the Australian Catholic University, through Professor Sandy Middleton, to ensure that the AuSCR registrants are not followed up twice at 90 days when they are also part of a stroke clinical trial (the T3 Trial) being conducted in several hospitals that also use the AuSCR. In Victoria, we have continued our collaboration with the Victorian Stroke Telemedicine (VST) program. This approach is mutually beneficial since the VST is required to report to government funders on the rates of intravenous thrombolysis use, and the AuSCR provides a system that can be embedded as part of routine health care monitoring to reliably obtain these data.

Once again in April 2016, we were supported by Boehringer-Ingelheim in conducting a national workshop on stroke data and quality that was co-convened with the Stroke Foundation and the VSCN. Such events provide additional opportunities for clinicians and academics to be involved in translational activities to further enhance stroke care and outcomes.

A continuing significant collaboration has been that of working closely with the Stroke Foundation and the ASC to progress the build and implementation of the AuSDaT to achieve our common goal of a more efficient, standardised approach to stroke data collection in Australia.

APPENDIX B

COMMITTEE MEMBERSHIP

AuSCR STEERING COMMITTEE MEMBERSHIP 2016
(with organisational and state affiliation)

Prof Sandy Middleton (Chair)
Director, Nursing Research Institute, St Vincent's Health Australia (Sydney) and Australian Catholic University [NSW]

Prof Craig Anderson
Executive Director, The George Institute, China & Professor of Neurology and Epidemiology, Faculty of Medicine, UNSW Sydney [NSW]

Dr Michael Pollack
Director, Rehabilitation Medicine & Hunter Stroke Service, John Hunter Hospital [NSW]

Ms Frances Simmonds
Director, Australasian Rehabilitation Outcomes Centre, Australian Health Services Research Institute, University of Wollongong [NSW]

Prof Julie Bernhardt
Head, Stroke Division, Florey Institute of Neuroscience and Mental Health [VIC]

Prof Christopher Bladin
Director, Victorian Stroke Telemedicine Program, The Florey Institute of Neuroscience and Mental Health & Neurologist Eastern Health [VIC]

Prof Geoffrey Donnan
Director, Florey Institute of Neuroscience and Mental Health & Professor of Neurology, University of Melbourne [VIC]

Dr Mark Mackay
Paediatric Neurologist, Royal Children's Hospital, Melbourne [VIC]

Ms Toni Aslett
Executive Director, Stroke Services, Stroke Foundation [VIC]

Prof John McNeil
Head, Department of Epidemiology and Preventive Medicine, Monash University [VIC]

Mr Mark Simcocks
Consumer Representative, Self-employed [VIC]

Prof Amanda Thrift
Head, Epidemiology and Prevention Unit & NHMRC Senior Research Fellow, Monash University [VIC]

Dr Andrew Evans
Geriatrician & Stroke Physician, Westmead Hospital [NSW]

Dr Helen Castley
Neurologist, Royal Hobart Hospital & Co-chair Clinical Advisory Group (Neurology & Stroke) [TAS]

Mr Greg Cadigan
Principal Project Officer, Queensland Statewide Stroke Clinical Network [QLD]

A/Prof Susan Hillier
Physiotherapist & Academic Researcher, University of South Australia [SA]

A/Prof Peter Hand
Neurologist, Royal Melbourne Hospital [VIC]

Dr Andrew Wesseldine
Geriatrician & Stroke Physician, St John of God Midland Hospital & State Stroke Director [WA]

Dr Rohan Grimley
Conjoint Senior Lecturer Sunshine Coast Clinical School & Clinical Chair Queensland Statewide Stroke Clinical Network [QLD]

Prof Richard Lindley
Professorial Fellow, The George Institute for Global Health & Professor of Geriatric Medicine, Sydney Medical School, Uni. of Sydney. [NSW]

A/Prof Dominique Cadilhac
Head, Public Health, Stroke Division, Florey Institute of Neuroscience and Mental Health & Head, Translational Public Health Division, Stroke and Ageing Research, Monash University [VIC]

AuSCR MANAGEMENT COMMITTEE MEMBERSHIP 2016
(with organisational and state affiliation)

Prof Craig Anderson (Chair)
Executive Director, The George Institute, China & Professor of Neurology and Epidemiology, Faculty of Medicine, UNSW Sydney [NSW]

A/Prof Natasha Lannin (Acting Chair)
Associate Professor, School of Allied Health, College of Science, Health and Engineering, La Trobe University, & Associate Professor in Occupational Therapy, Alfred Health [VIC]

Prof Geoffrey Donnan
Director, Florey Institute of Neuroscience and Mental Health & Professor of Neurology, University of Melbourne [VIC]

A/Prof Dominique Cadilhac
Head, Public Health, Stroke Division, Florey Institute of Neuroscience and Mental Health & Head, Translational Public Health Division, Stroke and Ageing Research, Monash University [VIC]

A/Prof Steven Faux
Director, Rehabilitation and Pain Medicine, St Vincent's Hospital, Sydney [NSW]

Prof Chris Levi
Director of Clinical Research and Translation - Research Innovation and Partnerships & Co-Director of Acute Stroke Services, John Hunter Hospital [NSW]

Prof Helen Dewey
Director of Neurosciences, Eastern Health and Monash University [VIC]

Mr Kelvin Hill
National Manger, Clinical Services, Stroke Foundation [VIC]

A/Prof Peter Hand
Neurologist, Royal Melbourne Hospital [VIC]

Dr Rohan Grimley
Conjoint Senior Lecturer, Sunshine Coast Clinical School & Clinical Chair, Queensland Statewide Stroke Clinical Network [QLD]

COMMITTEE MEMBERSHIP

AuSCR RESEARCH TASK GROUP MEMBERSHIP 2016 (with organisational and state affiliation)

The primary purpose of the Research Task Group is to ensure appropriate use and protection of the Australian Stroke Clinical Registry data when it is to be used for research purposes by third parties.

A/Prof Sue Evans (Co-Chair)
Head of the Clinical Registry Unit & Associate Director of the Centre of Research Excellence in Patient Safety Medicine, Nursing & Health Services, Monash University [VIC]

Prof Leeanne Carey (Co-Chair)
Head, Neuro-rehabilitation and Recovery, Florey Institute of Neuroscience and Mental Health & Adjunct Professor School of Allied Health, La Trobe University [VIC]

Prof Richard Lindley
Professorial Fellow, The George Institute for Global Health & Professor of Geriatric Medicine, Sydney Medical School, University of Sydney [NSW]

Prof Ian Cameron
Consultant Physician in Rehabilitation Medicine, Rehabilitation Studies Unit, University of Sydney [NSW]

Dr Coralie English
Senior Research Affiliate, NHMRC Centre for Research Excellence in Stroke Rehabilitation and Recovery, Priority Research Centre for Neuroscience and Mental Health, Hunter Medical Research Institute [NSW]

Prof John McNeil
Head, Department of Epidemiology and Preventive Medicine, Monash University [VIC]

Prof Velandai Srikanth
Geriatrician & Head, Stroke and Ageing Research, School of Clinical Sciences at Monash Health [VIC]

A/Prof Erin Godecke
Senior Research Fellow (Speech Pathology), School of Medical & Health Sciences, Edith Cowan University [WA]

Dr Benjamin Clissold
Head, Inpatient Services (Neurosciences), Barwon Health & Stroke Neurologist, University Hospital Geelong and Monash Medical Centre [VIC]

Dr Philip Choi
Consultant Neurologist, Department of Neurosciences, Eastern Health [VIC]

Dr Darshan Ghia
Consultant Neurologist and Head of Stroke Unit, Fiona Stanley Hospital [WA]

Prof Suzanne Kuys
National Head, School of Physiotherapy, Australian Catholic University & Principal Research Fellow, Queensland Health [QLD]

COMMITTEE MEMBERSHIP

AuSCR REPERFUSION AND TELEMEDICINE SUBCOMMITTEE MEMBERSHIP 2016 (with organisational and state affiliation)

A/Prof Bruce Campbell (Chair) Head, Hyperacute Stroke, Royal Melbourne Hospital [VIC]
A/Prof Dominique Cadilhac Head, Public Health, Stroke Division, Florey Institute of Neuroscience and Mental Health & Head, Translational Public Health Division, Stroke and Ageing Research, Monash University [VIC]
Dr Peter Hand Neurologist, Royal Melbourne Hospital [VIC]
Prof Peter Mitchell Head, Statewide Endovascular Clot Retrieval Service [VIC]
A/Prof Bernard Yan Neurointerventionist and Neurologist, Royal Melbourne Hospital [VIC]
Dr Henry Ma Neurologist, Monash Medical Centre & Adjunct Senior Lecturer, Stroke and Ageing Research Group, Southern Clinical School, Monash University [VIC]
Dr Andrew Wong Neurologist, Royal Brisbane and Women's Hospital [QLD]
Dr Ferdi Miteff Neurologist, Royal North Shore Hospital [NSW]
Prof Alan Coulthard Head, Discipline of Medical Imaging, University of Queensland [QLD]
Prof Christopher Bladin Director, Victorian Stroke Telemedicine Program, The Florey Institute of Neuroscience and Mental Health & Neurologist Eastern Health [VIC]

APPENDIX C

FUNDING 2016

In 2016, the AuSCR Office was supported by funding and in-kind support from:

- The Florey;
- Industry partners;
- A joint initiative with the Stroke Foundation funded by Queensland Health;
- The Victorian Stroke Clinical Network;
- NHMRC fellowships that provided salary support to members of the Management Committee (Dominique Cadilhac, Craig Anderson and Chris Levi) to enable them to contribute to initiatives such as the AuSCR. Dominique Cadilhac's Fellowship was co-funded by the Heart Foundation;
- The NHMRC: which provides salary via fellowship awards for senior researchers which has assisted in containing staff costs;
- Stroke Foundation: support in collating and mailing the AuSCR follow-up questionnaires;
- Smart Strokes 2016 Conference organising committee: generous subsidy of exhibition display resources at their conference, facilitating an important opportunity to promote the AuSCR and to interact with participating hospital staff at the conference;
- Members of the Management Committee and Steering Committee and Research Task Group provide their time 'in-kind';
- We also received pro bono legal advice from Roberta Bozzoli (Thomson Geer, Brisbane) for progressing the Queensland Health Deed of Disclosure.

In non-funded states, lack of funding options has necessitated the development of a 'user pays' system for individual hospitals which was implemented once the AuSCR went live in the AuSDaT in mid-2016.

ORGANISATION	AMOUNT
State Government	$601,300
Florey	$48,060
Monash University*	$64,545
Non-government organisations	$67,000
Industry	$20,000
Consumer donations	$0
Other**	$10,066
Total	$810,971

*Cost recovery through collaboration to cover follow-up data collection from Heart Foundation/Stroke Foundation Future Leader grant awarded to D Cadilhac.
**Includes income from projects approved by the Research Task Group to access the AuSCR data/registrants.

APPENDIX D

ACKNOWLEDGEMENTS

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Contribution to annual report

The Florey AuSCR Office

Brenda Grabsch was responsible for overall coordination of the AuSCR program and support to participating hospitals and other AuSCR program staff and collaborators.

Sam Shehata, the National Data Manager, has been essential in maintaining the integrity of the database, facilitating data quality checks and providing information for the completeness of data, opt-out and case ascertainment tables.

Monash University

Joosup Kim, Nadine Andrew, and Monique Kilkenny (Stroke and Ageing Research Centre, Monash University) developed and conducted the AuSCR data analyses for this report and as required throughout 2016. We are most appreciative of their contributions. The majority of analyses presented in this report were undertaken by Dr Joosup Kim, Research Fellow, under the supervision of Associate Professor Dominique Cadilhac using de-identified data supplied securely by Mr Sam Shehata (AuSCR Data Manager [2016]). Dr Monique Kilkenny was responsible for establishing the methodology for the analysis of the risk adjusted mortality rate data (in consultation with Associate Prof Leonid Churilov from The Florey). Dr Nadine Andrew was responsible for establishing the AuSCR clinical performance benchmarks.

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Participating hospitals

New South Wales

John Hunter
Royal Prince Alfred

Queensland

Bundaberg
Caboolture
Cairns
Gold Coast
Gympie
Hervey Bay
Ipswich
Logan
Mackay Base
Mater Adult
Nambour
Prince Charles
Princess Alexandra
Queen Elizabeth II Jubilee
Redcliffe
Redland
Robina
Rockhampton
Royal Brisbane and Women's
Toowoomba
Townsville
Wesley

Victoria

Albury Wodonga Health (Albury)
Albury Wodonga Health (Wodonga)
Alfred
Austin
Ballarat Health Services
Bendigo Health
Eastern Health (Box Hill)
Eastern Health (Maroondah)
Echuca Regional Health
Goulburn Valley Health
Latrobe Regional
Mildura Base
Monash Medical Centre (Clayton)
Northeast Health Wangaratta
Northern
Peninsula Health (Frankston)
Royal Children's
Royal Melbourne
South West Healthcare (Warrnambool)
St Vincent's (Melbourne)
Swan Hill District Health
University Hospital Geelong

Tasmania

Royal Hobart
Launceston General

APPENDIX E

PUBLICATIONS AND PRESENTATIONS

Journal Publications

Tse T, Carey L, Cadilhac D, Choon-Huat Koh G, Baum C. Application of the world stroke organization health system indicators and performance in Australia, Singapore, and the USA. International Journal of Stroke. 2016: 11(8), 852-859.

Andrew N, Kilkenny M, Lannin N, Cadilhac D. Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? Quality Of Life Research 2016: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation. 2016, 25(8), 2053-2062

Cadilhac D, Kim J, Lannin N, Levi C, Dewey H, Hill K, Faux S, Andrew N, Kilkenny M, Grimley R, Thrift A, Grabsch B, Middleton S, Anderson C and Donnan G. Better outcomes for hospitalized patients with TIA when in stroke units: an observational study. Neurology 2016: 86(22), 2042-2048.

Andrew N, Sundararajan V, Thrift A, Kilkenny M, Katzenellenbogen J, Flack F, Gattellari M, Boyd J, Anderson P, Grabsch B, Lannin N, Johnston T, Chen Y, Cadilhac D. Addressing the challenges of cross-jurisdictional data linkage between a national clinical quality Registry and government-held health data. Australian & New Zealand Journal Of Public Health [serial online]. October 2016; 40(5):436-44

Cadilhac D, Kim J, Lannin N, Kapral M, Schwamm L, Dennis M, Norrving B, Meretoja A. National stroke registries for monitoring and improving the quality of hospital care: a systematic review. International Journal of Stroke. 2016, 11(1):28-40.

Annual Report Publication

Cadilhac DA, Lannin NA, Anderson CS, Kim J, Andrew N, Kilkenny M, Shehata S, Grabsch B, Levi C, Faux S, Dewey H, Hill K, Donnan G, Hand P, Grimley R, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2015. The Florey Institute of Neuroscience and Mental Health; December 2016, Report No 7, pages 42.

Presentations and posters

Cadilhac D. How evidence based stroke care can improve patient outcomes, Hunter Stroke Service & Hunter New England Health Stroke Stream. Presented at Education and Professional Development Forum, Newcastle June 6th.

Cadilhac D. Update on the Australian Stroke Clinical Registry and health services research - a focus on improving the quality of care. Presented at University of Central Lancashire (3 May), and Nottingham University (4 May), England.

Cadilhac D. Update on the Australian Stroke Clinical Registry and health services research - a focus on improving the quality of care. Presented at Caledonian University (25/4) and University of Glasgow (28/4) (Scotland).

Cadilhac D. Australian Stroke Data Tool (AuSDaT) overview. Registry Programs, the Australian Stroke Data Tool and State Based Initiatives Session. Presented at National Stroke Data and Quality Improvement Workshop, Florey, Melbourne.

Cadilhac D. Improving hospital care: benefits of the Australian Stroke Clinical Registry. Presented at 5th Annual HMRC Symposium on Research Translation, Melbourne.

Cadilhac D, Kilkenny M, Lannin N, Levi C, Faux S, Dewey H, Grimley R, Hill K, Grabsch B, Andrew N, Anderson C, Donnan G, Middleton S. Weekend versus weekday hospital discharge: experience from the Australian Stroke Clinical Registry. The 2nd European Stroke Organisation Conference 2016 Barcelona, Spain. European Stroke Journal 2016,1(S1):214 [Abstract]

Cadilhac D, Andrew N, Kim J, Kilkenny M, Hill K, Grabsch B, Grimley R, Dewey H, Lannin N, Levi C,Faux S, Anderson C, Donnan G, Middleton S. Establishment of National Performance Benchmarks for Acute Stroke Care: New Evidence from the Australian Stroke Clinical Registry. Cerebrovascular Diseases 2016,42(S1):37 [Poster]

Denisenko S, Kelly P, Cadilhac D, Grabsch B, Clissold B, Burgess A, Hand P. Technology Solutions to Encourage Participation in the Australian Stroke Clinical Registry. Cerebrovascular Diseases 2016,42(S1):42 [Poster]

Denisenko S, Kelly P, Cadilhac D, Smith H, Hair C, Paice K, Wallis K, Grabsch B, Shehata S, Hand P. Innovation in data collection for the AuSCR – The Victorian experience. International Journal of Stroke 2016,11(S1):8 [Abstract]

Dewey H, Cadilhac D, Kilkenny M, Kim J, Andrew N, Hill K, Grabsch B, Grimley R, Lannin N, Levi C, Faux S, Middleton S, Anderson C, Donnan G. Quality of Care Over-Time: New Evidence from the Australian Stroke Clinical Registry. Cerebrovascular Diseases 2016,42(S1):45 [Poster]

Kilkenny M, Lannin N, Anderson C, Dewey H, Levi C, Faux S, Hill K, Grabsch B, Middleton S, Thrift A, Grimley R, Donnan G, Cadilhac D. Stroke Care and Outcomes for Patients Who Require an Interpreter: Evidence from the Australian Stroke Clinical Registry (AuSCR). Cerebrovascular Diseases 2016,51(S1):51 [Poster]

Kilkenny MF, Lannin NA, Anderson C, Dewey HM, Grabsch B, Middleton S, Thrift A, Grimley R, Donnan GA, Cadilhac DA. Quality of life is poor for patients who require an interpreter: Observations from the Australian Stroke Clinical Registry (AuSCR). 10th World Stroke Congress in Hyderabad, India. International Journal of Stroke October 2016,11 (S3):161[Poster]

Kim J, Andrew N, Kilkenny M, Lannin N, Hill K,Grabsch B, Grimley R, Dewey H, Thrift A, Levi C,Faux S, Middleton S, Donnan G, Anderson C, Cadilhac D. Changes in Post-Stroke Survival Over Time: New Evidence form the Australian Stroke Clinical Registry. Cerebrovascular Diseases 2016,42(S1):20 [Abstract]

Wallis K, Grabsch B, Drennan K, Paice K, Shehata S, Salama E, Hill K, Middleton S, Cadilhac D. Update on the transition of the Australian stroke clinical Registry to the new integrated data management system – The Australian stroke data tool. International Journal of Stroke 2016,11(S1):30 [Poster]

APPENDIX F

APPLICATIONS TO THE AuSCR RESEARCH TASK GROUP IN 2016

In 2016, there were six external applications reviewed by the Research Task Group:

- Sex differences in the management and acute outcomes after stroke (PI: Dr Seana Gall, The University of Tasmania).
- Building efficient and equitable pathways to and through rehabilitation in stroke: BEEPRS (PI: Dr Rohan Grimley, Queensland Health).
- Healthy Living After Stroke: Pilot study of an online secondary prevention program for stroke survivors (PIs: Alexandra Denham and Prof Billie Bonevski, University of Newcastle).
- Inspiring Virtual Enabled Resources following Vascular Events (iVERVE) pilot project (PIs: Assoc Prof Dominique Cadilhac and Dr Doreen Busingye, Monash University).
- John Hunter Hospital (JHH) and Tamworth Rural Referral Hospital (TRRH) Stroke Mortality Independent Report (PI: Prof Chris Levi, John Hunter).
- Emerging Treatments for Stroke Survey (PI: Prof Jane Mathias, AIs: Mr David Unsworth, Dr Diana Dorstyn and Prof Simon Koblar, University of Adelaide).

Two internal projects, submitted by AuSCR team members, were reviewed/approved by the Chairs of the Management Committee, Steering Committee and Research Task Group.

- Communicating disparities in patient outcomes in cardiovascular disease (Investigators: Assoc Prof Dominique Cadilhac, Dr Monique Kilkenny, Ms Brenda Grabsch; Monash University and The Florey).
- Stroke123 part 1: Establishing high quality, integrated national data for stroke: a substudy of Stroke123 (Investigators: Dr Nadine Andrew, Assoc Prof Dominique Cadilhac; Monash University and The Florey).

APPENDIX G

ACRONYMS

ABC™	Achievable benchmarks of care
AIHW	Australian Institute of Health and Welfare
APF	Adjusted performance fraction
ARIA	Accessibility/Remoteness Index of Australia
ASC	Australian Stroke Coalition
AuSCR	Australian Stroke Clinical Registry
AuSDaT	Australian Stroke Data Tool
ECR	Endovascular clot retrieval
ED	Emergency Department
EQ-5D™	European Quality of Life - 5 dimension instrument
HRQoL	Health-related quality of life
ICD10	International Classification of Diseases (Version 10)
ICH	Intracerebral haemorrhage
mRS	Modified Rankin Scale
NDI	National Death Index
NHMRC	National Health and Medical Research Council
NIHSS	National Institutes of Health Stroke Scale
Q1/Q3	25th percentile/75th percentile
QSQIP	Queensland Stroke Quality Improvement Program
PROMs	Patient reported outcome measures
RAMR	Risk-adjusted mortality rate
SD	Standard deviation
SNAP	Sub or non-acute patients
SSA	Stroke Society of Australasia
STELAR	Shared Team Efforts Leading to Adherence Results
TIA	Transient ischaemic attack
TICI	Thrombolysis in cerebal infarction
tPA	Tissue plasminogen activator
VAS	Visual Analogue Scale
VSCN	Victorian Stroke Clinical Network
VST	Victorian Stroke Telemedicine

AUSCR

Australian Stroke Clinical Registry