

# ANNUAL REPORT 2017

**AUSCR**  
Australian Stroke Clinical Registry



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 @AustStrokeReg

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# EXECUTIVE SUMMARY

## The Australian Stroke Clinical Registry (AuSCR)

- 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 Clinical Guidelines for Stroke Management 2017 (<https://informme.org.au/Guidelines/Clinical-Guidelines-for-Stroke-Management-2017>).
- 2017 was the first full calendar year of data collection for several new processes of care including: discharge on antithrombotic and lipid-lowering medications, statistics on door-to-needle times for thrombolysis and door-to-puncture and recanalisation times for endovascular clot retrieval (ECR) procedures. This expansion in variable collection means that the AuSCR now collects data on all patient-related acute stroke clinical care standards.
- Efforts to support quality improvement within hospitals have included seven new on-demand, downloadable benchmarked reports. The AuSCR continued to be an active partner in two quality improvement projects in Queensland and Victoria. The aim of these programs is to embed the routine review of AuSCR data into everyday quality improvement activities using external facilitators.
- An online survey of hospitals participating in the AuSCR was used to identify the main uses of on-demand reports. The majority of hospital clinicians used these reports for team meetings (74%), informing quality improvement (68%) and reporting to hospital executives (58%).

## AuSCR participation in 2017

- In 2017, 59 hospitals contributed data to the AuSCR (44% from Victoria, 39% from Queensland, 7% from New South Wales and 5% each from Tasmania and South Australia).
- Information is presented on 13300 patients with 14184 admissions for acute stroke or transient ischaemic attack (TIA) to participating hospitals (a 25% increase in total episodes from 2016). Median case ascertainment increased to 81% from 77% in 2016 with 90% of hospitals participating (63% participated in 2016).

## Hospital performance against clinical care standards

- Provision of stroke unit care increased from 69% (2016) to 73% (2017), whilst thrombolysis rates were stable at 13%. The provision of aspirin within 48 hours, excluding cases of intracerebral haemorrhage, increased significantly from 41% in 2016 to 56% in 2017.
- The proportion of patients receiving thrombolysis in under 60 minutes for ischaemic stroke increased to 38% (2017) from 36% (2016). The overall median door-to-needle time was 73 minutes.

- There was a noticeable increase in the prescription of antihypertensive medication at discharge from 62% (2016) to 73% (2017). The provision of antithrombotic medication at discharge increased to 88% from 66% (2016) and lipid-lowering medication at discharge also increased to 77% from 47% (2016). Provision of a discharge care plan was stable at 59% in 2017.
- Performance benchmarks calculated for the AuSCR 2017 cohort show that the best performing hospitals could achieve: 98% for stroke unit care; 22% for thrombolysis; 68% for door-to-needle times less than 60 minutes; 95% for antihypertensives; 100% for antithrombotics, 98% for lipid-lowering medications and 100% for discharge care plans. These levels of care would ensure better outcomes for patients if all hospitals could achieve these standards.
- 1378 patients (11%) were discharged from hospital on a weekend. Patients discharged over the weekend were significantly less likely to have received:
  - stroke unit care
  - antihypertensive, antithrombotic and lipid-lowering medications on discharge
  - a discharge care plan.
- Several hospitals were found to be outside the limits set for normal variation in relation to key performance measures. Processes of care with the most variation were management in a stroke unit and provision of a discharge care plan following discharge to the community.
- Where telemedicine was in place, the use of thrombolysis increased marginally from 28% (2016) to 30% (2017). The median door-to-needle time also decreased from 91 minutes (2016) to 88 minutes (2017).
- A total of 597 patients at 13 hospitals received ECR. The median time from arrival to groin puncture decreased from 119 minutes (2016) to 54 minutes (2017). Median arrival to recanalisation times also decreased from 190 minutes (2016) to 112 minutes (2017).
- Overall, 1151 (8%) of the 2017 AuSCR registrants died in hospital.

## Discharge destination and post-discharge outcomes

- After discharge from acute care, 23% of patients went to rehabilitation (25% in 2016) and 50% returned to their usual residence, with or without some form of support (52% in 2016).
- At 90-180 days, collection of information from 65% of all eligible registrants was achieved (69% in 2016). With more hospitals contributing data in 2017, the total number of completed follow-ups increased by over 1400 from 2016.
- With respect to health-related quality of life (HRQoL), patients with intracerebral haemorrhage (ICH) reported the most problems across all five dimensions of the European Quality of Life measure of health status (EQ-5D-3L). Approximately two thirds of patients with ICH reported experiencing some level of disability on the modified Rankin Scale (mRS) at 90 to 180 days.
- In addition to those who died in hospital, a further 1138 (8%) of the 2017 AuSCR registrants died within 180 days of their stroke following discharge.

# 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).

Following the transition to the Australian Stroke Data Tool (AuSDaT) platform in 2016, the project team and members of the Governance Committees have continued to fine tune the data collection, data quality and reporting processes. In early 2017, all seven live data reports were finalised in the AuSDaT enabling hospitals to access summary on-demand nationally benchmarked data for local use. AuSCR State Coordinators and Data Managers also worked closely with sites in 2017 to assist with development of solutions for the electronic extraction of AuSCR variables from local Patient Administrative Systems to ease data entry burden. With a focus on data quality in 2017, new Case Ascertainment and Data Quality Reports were developed. These reports enabled hospitals to more efficiently identify eligible missing episodes and data variables in their local AuSCR dataset.

Eleven new sites across five states commenced data entry into the AuSCR in 2017 with data from South Australia included for the first time. A new contract for up to 19 acute thrombolytic centres to join the AuSCR in 2017 was signed with the New South Wales Agency for Clinical Innovation, and four of these hospitals commenced data entry in December 2017.

In late 2017, the project team also undertook an online survey of participating hospitals to obtain feedback on the AuSDaT and how AuSCR data were being used. Thirty-two surveys were completed from 27 hospitals with 68% of respondents indicating that care for patients with stroke at their hospitals had improved since participating in the AuSCR. The main uses for AuSCR live data reports were cited as team meetings (74%), informing quality improvement (68%) and reporting to hospital executives (58%). ***These data highlight the important role of the AuSCR, and related AuSDaT functionality, in closing the data quality loop for acute stroke care nationally.***



The AuSCR underwent an external review process in Victoria in 2017, funded by the Victorian Agency for Health Information. The results from this review of Clinical Quality Registries indicated that the AuSCR was one of the highest rated registries in the state, being considered as both high potential and high achieving. In Victoria, the AuSCR is now being used as an exemplar for other registries in relation to governance and data quality processes. As the AuSCR is a national registry, these Victorian findings also reflect on the registry at a national level. The operational success of the AuSCR 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.

Throughout the eight years of AuSCR data collection, 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 to inform policy and practice. Presentations and publications from 2017 are listed in Appendix E.

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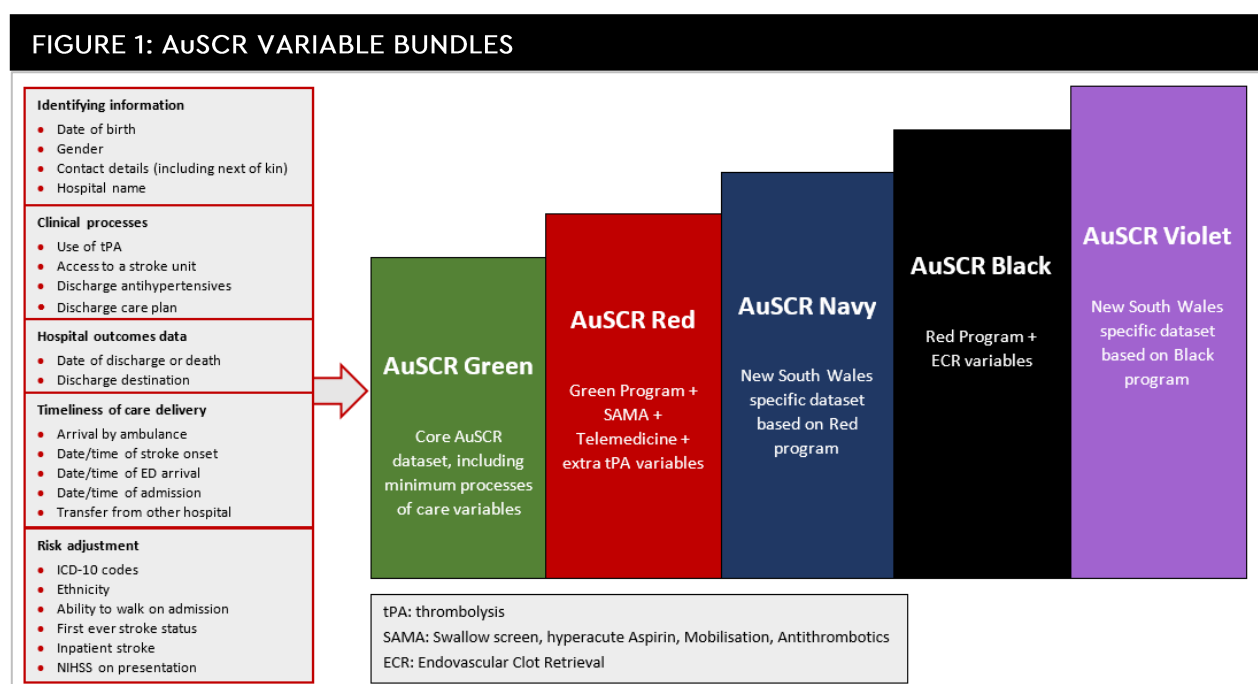
# INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) is a collaborative national effort to monitor and support improvements to the quality of acute care for patients with stroke and transient ischaemic attack (TIA). Since 2009, the AuSCR has provided reliable and representative national data on patients admitted to hospital with acute stroke or TIA, which has been used to inform improvements to the health system.<sup>1</sup>

The AuSCR adheres to the national guidelines for best-practice in clinical quality registries,<sup>2</sup> and operates in both public and private hospitals. Adult and paediatric cases are included. All participating hospitals are required to have ethics and site-specific governance approvals. As recommended for national registries,<sup>3</sup> 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. Data are collected in the Australian Stroke Data Tool (AuSDaT) which is a harmonised platform enabling standardised and systematic data entry for multiple stroke data collection programs (Box 1). The AuSDaT enables hospitals to select ‘bundles’ of variables for collection, to align with local care provision and quality monitoring priorities. All ‘bundles’ include the original national minimum processes of care for assessing quality of care.<sup>1</sup> These variable ‘bundles’ are grouped into five currently active AuSCR programs, as illustrated in Figure 1. Staff from participating hospitals can enter these data 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 reported outcomes are ascertained with a questionnaire (including age-appropriate paediatric questions) at follow-up, 90 to 180 days after admission. The AuSCR Office staff are responsible for following up registrants who have not:

- been reported as deceased;
- previously refused follow-up; or
- opted out of the registry.

For registrants unable to be contacted, survival status is determined via annual data linkage with the National Death Index (NDI) made available, through an ethically approved process, by the Australian Institute of Health and Welfare.

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 system issues, including examination of particular patient sub-groups. In addition, 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 2017 applications to the AuSCR Research Task Group).

In 2017, the *major* sources of funding for the registry were: the Victorian Government; Queensland Health; the Tasmanian Government; the Agency for Clinical Innovation (New South Wales), industry, Monash University and the Victorian Stroke Telemedicine (VST) program (see Appendix C). Where state government funding was unavailable, hospitals participated under a *user pays* system. Ongoing discussions continue in other 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 2017 report provide insights into the care received, and the health outcomes, for 13300 patients from 59 Australian hospitals. Additional 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.

## BOX 1: AuSCR VARIABLES COLLECTED IN THE AUSTRALIAN STROKE DATA TOOL

### Identifying information

- Name
- Date of birth
- Sex
- Address
- Telephone number/s
- Hospital name
- Medicare number
- Hospital UR number
- Contact details for next of kin and alternative contact

### Patient/episode characteristics

- Country of birth
- Language spoken
- Interpreter needed
- Aboriginal and Torres Strait Islander status
- Type and cause of stroke
- Date and time of stroke onset
- *Validated stroke screen and type*
- Date and time of arrival at ED
- Date and 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
- *Transfer to other wards*
- History of known risk factors
- *Dependency prior to admission*

### Indicators of evidence-based care

- Treatment in a stroke unit
- Date and time of first brain scan
- Use of tPA if an ischaemic stroke
- Discharged on an antihypertensive agent
- Care plan provided at discharge (any documentation in the medical record)
- Telemedicine consultation
- Date and time of thrombolysis
- Adverse event related to thrombolysis
- Swallow screen and formal speech pathologist assessment
- Aspirin administration, <48 hours
- Mobilisation during admission
- *Mood assessment*
- Discharged on antithrombotic medication
- Discharged on lipid-lowering drugs

### Allied health management

- *Patient seen by a physiotherapist, occupational therapist, speech pathologist, social work, dietitian*
- *Commencement of rehabilitation therapy*

### Communication and support for patient and family/carer

- *Carer receiving relevant training and support needs assessment*

### Complications during hospital admission

- *Aspiration pneumonia, deep vein thrombosis, falls, pulmonary embolism, symptomatic haemorrhagic transformation, new onset atrial fibrillation, stroke progression, urinary tract infection*

### Further rehabilitation

- *Rehabilitation plan documented*
- *Rehabilitation referral made*

### Endovascular clot retrieval (ECR) variables

- Date and time of subsequent brain scan
- Provision of ECR, including date and time
- NIHSS: before ECR and 24 hours after ECR
- Site of occlusion
- Final eTICI (expanded thrombolysis in central infarction) score
- Adverse event related to ECR

### Hospital outcomes/discharge data

- In-hospital death
- Date of discharge/death
- Discharge destination
- ICD-10 diagnosis codes and procedures
- *Functional status on discharge*

### 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

### Note:

Different programs within the AuSCR collect different bundles of variables, depending on hospital practices and priorities. Items in italics are variables which are collected only as part of the NSW Foundation Program.

# METHODS

## 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 a single episode), which may be merged if necessary.
- AuSCR training for staff at newly participating hospitals and new staff at existing hospitals, completed in person or via videoconference. Additional resources available on the AuSCR website containing training videos and written information.
- Assessment of data quality via missing and discrepant data reports, produced bi-annually.
- AuSCR Office audits of randomly selected medical records.
- Bi-annual case ascertainment assessments, completed by cross-checking hospital lists of all eligible admissions (based on the ICD-10 principal diagnosis codes related to stroke/TIA) with the episode data entered in the AuSCR.
- A detailed follow up manual, and training by AuSCR staff, to ensure standardised data collection and interpretation.
- Fact sheets, webinars, regular electronic newsletters for dissemination of new information, reminders and updates.

The *AuSCR Annual Data Quality Report* is a summary of all data quality processes and metrics undertaken with the 2017 dataset (e.g. time to record creation; data completeness; case ascertainment). A copy of this report can be obtained on the AuSCR website at <https://auscr.com.au/about/annual-reports/>

## OVERVIEW OF DATA ANALYSIS

The AuSDaT platform has enabled the AuSCR to implement multiple data collection programs (variable bundles) of which five are currently active (Figure 1). All programs contain core variables which allow individual hospitals to choose programs (guided to some extent by their state health departments) that are aligned to their operations e.g. use of telemedicine or endovascular clot retrieval (ECR). 2017 is the *first full calendar year* in which such a broad array of data were collected and is indicative of the rich information that will become available over time.

The data presented in this report include information on patients admitted to participating hospitals between 1 January and 31 December 2017. Data entry for these acute stroke/TIA episodes, and the associated follow-up assessments, was closed off, and data extracted, on 27 July 2018.

Duplicate data were checked by the AuSCR Data Manager using 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 de-identified for analysis. A second level of data checking was performed by Monash University statisticians.

For all process of care analyses presented in this report, *episodes with missing information are included in the denominator*, because, if the data were not provided, it was assumed that care related to that indicator was not offered. For the secondary prevention medications provided at discharge from hospital, patients who were indicated as being contraindicated were excluded from the denominator. Other performance measures based on published standards such as door-to-scan, door-to-needle, door-to-puncture and door-to-revascularisation times were also calculated. These were calculated using dates and times of arrival and treatment. When

dates and times were missing, these performance measures were not calculated. Negative times were excluded from analyses.

In the case where a specific process of care for any individual hospital contained greater than 30% missing data, these hospitals were excluded from any subsequent analyses of the specific process of care. Times to thrombolysis, times to brain scan, time to dysphagia screen/assessment, and days to mobilisation were also excluded when there was more than 30% missing data for thrombolysis, brain scan, dysphagia screening/assessment and mobilisation variables. Data related to ECR were not excluded due to missing data.

Hospital postcodes were mapped to the Accessibility/Remoteness Index for Australia 2011 (ARIA+) available from the Australian Bureau of Statistics (see [www.spatialonline.com.au/ARIA\\_2011](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 AuSCR national indicators were calculated based on a modified version of the Achievable Benchmark of Care (ABC™) methodology<sup>4</sup> which has been used and validated by Hall et al, 2013.<sup>5</sup> 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 then calculated for each hospital for each of the 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 (stroke severity), inpatient stroke, and patient transfer from another hospital, as appropriate. All episodes were eligible for follow up except:

- where acute data was not entered by the hospital within 180 days post-admission; or
- for those patients who were reported as deceased prior to the 90-180 day follow-up window.

In the case where there was a second admission within 180 days of the first admission, follow-up was only completed for the first admission.

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 2017. 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, transferred from another hospital and ability to walk on admission, was also performed.

*Health-related quality of life* (HRQoL) is measured in the AuSCR using the European Quality of Life measure of health status (EQ-5D™), specifically the three level version of the instrument EQ-5D-3L. The EQ-5D-3L 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-3L 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.

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 in 2016 and 2017 combined for cases of ischaemic stroke and greater than 50 episodes for ICH. 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. 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.

Variability between hospitals in the proportion of patients with VAS scores was compared using the same methodology as for the calculations of the RAMR.

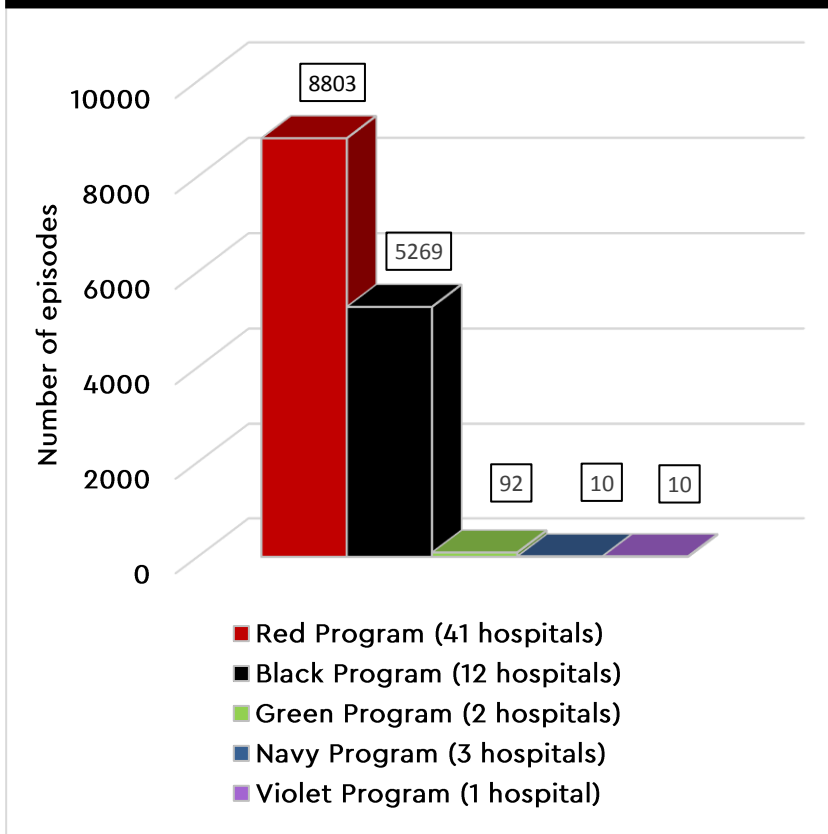
All analyses were performed using STATA/SE 14.0 (College Station, USA, 2015).

# CHARACTERISTICS OF HOSPITALS AND PATIENTS IN 2017

## HOSPITALS

In 2017, 59 hospitals provided data for 14184 episodes of admitted care. With the transition to the AuSDaT, five data collection programs were actively used (Figure 2), although two of these data collection programs (Violet and Navy) were only used by New South Wales (NSW) hospitals from December 2017 and 20 episodes of care were provided. The majority of hospitals (n=41) 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), while another 12 hospitals chose the black data collection program (the same as the red program plus ECR variables). Two hospitals (one paediatric and one regional) used the green program which is a minimum dataset of demographics and core processes of care.

FIGURE 2: NUMBER OF EPISODES ENTERED IN 2017, BY DATA COLLECTION PROGRAM





The characteristics of the 2017 participating hospitals are shown in Table 1. In 2017, there were four hospitals located in NSW, 23 in Queensland (QLD), 26 in Victoria (VIC), and three each in Tasmania (TAS) and South Australia (SA). Of the 59 hospitals, one was a private hospital located in QLD and one was a

children's hospital in VIC. There were 31 hospitals located in a major city. Overall, 53 participating hospitals had a stroke unit and 51 that provided thrombolytic therapy using intravenous tissue plasminogen activator (tPA). 42 hospitals registered 100 or more episodes of stroke/TIA during 2017.

**TABLE 1: CHARACTERISTICS OF PARTICIPATING HOSPITALS**

Year	2009	2010	2011	2012	2013	2014	2015	2016	2017					
	Total	Total	Total	Total	Total	Total	Total	Total	Total	QLD	VIC	TAS	SA	NSW
Number of hospitals	6	12	16	31	37	40	40	48	59	23	26	3	3	4
Annual number of episodes in the AuSCR*														
Low (<33 episodes)	0	1	4	11	2	2	2	2	7	0	3	0	0	4
Medium (33-99 episodes)	1	5	2	6	8	8	6	6	10	1	6	1	2	0
High (≥100 episodes)	5	6	10	14	27	27	32	40	42	22	17	2	1	0
Location#														
Major city	6	10	11	16	28	28	20	27	31	14	11	2	3	1
Regional/Rural	0	2	5	15	9	9	20	21	28	9	15	1	0	3
Stroke unit	6	10	14	28	35	35	38	43	53	23	23	2	3	2
Used telemedicine	0	0	0	0	0	0	27	29	40	18	18	1	2	1
Intravenous thrombolysis undertaken	6	9	10	22	31	31	38	46	51	22	23	2	3	1
Endovascular Clot Retrieval undertaken	0	0	0	0	0	0	9	9	13	3	5	1	3	1

\*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

## REGISTRANTS

In 2017, there were 13300 patients registered in the AuSCR (Table 2). Case-ascertainment in 2017 ranged from 28% to 100%, with a median of 81%. During a calendar year, patients may have multiple admissions for stroke or TIA that are eligible for inclusion in the AuSCR. In 2017, there were 14184 episodes of acute hospital care entered in the AuSCR for the 13300 individuals registered, with 717 (5%) being recurrent episodes. A total of 14155 adult

episodes of care were captured in the AuSCR in 2017.

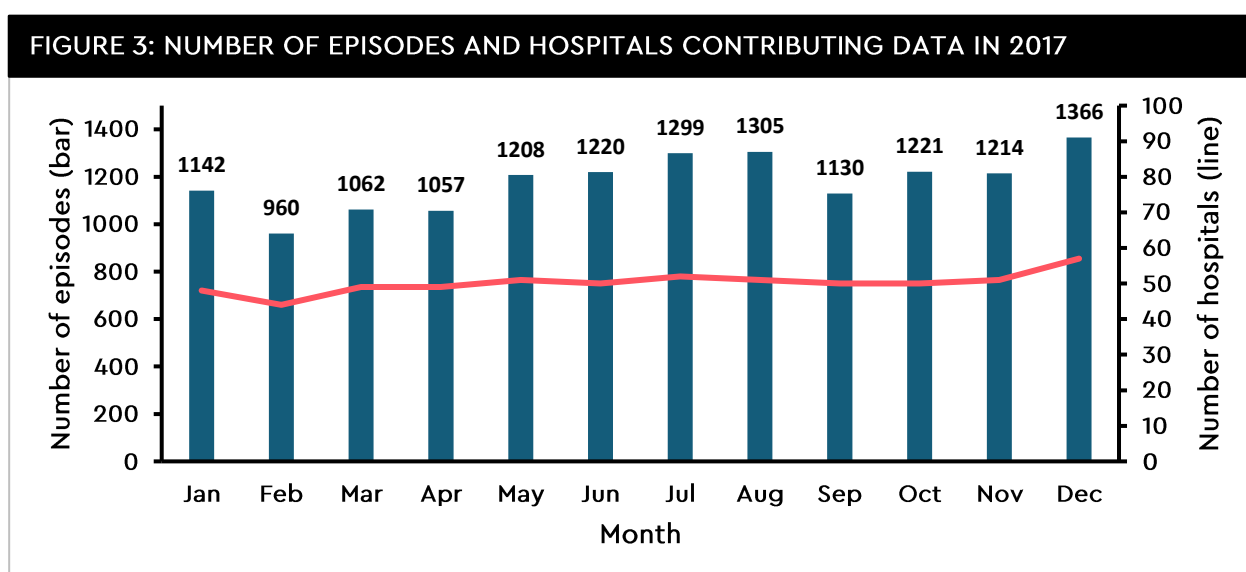
The median number of episodes per hospital was 202 (Q1 to Q3: 84 to 330). The minimum number of episodes registered for any particular site was one at a regional NSW hospital (due to being a new site approved to collect data in December) and the maximum number registered was at a metropolitan hospital in VIC (n=966).

**TABLE 2: NUMBER OF HOSPITALS, PATIENTS AND EPISODES IN 2017**

Number of hospitals contributing data	59
Number of episodes submitted	14184
Number of patients	13300
Number and percentage of multiple episodes	717, 5%

## EPISODES PER MONTH

Figure 3 shows the number of episodes (including multiple episodes) per month based on date of admission. The median number was 1211 per month. The minimum was 960 in February and the maximum was 1366 in December.



## REGISTRANT CHARACTERISTICS

Table 3 provides the baseline characteristics of patients and information related to their episodes of care. Adult and paediatric cases of stroke are presented separately. Eleven hospitals admitted paediatric cases (patients aged <18 years) in 2017.

Among the 13274 adult registrants, the most common country of birth was Australia (70%)

followed by the United Kingdom (7%). The remainder were from a range of mainly European or Asian nations. There were 255 adult patients (2%) who identified as having an Aboriginal or Torres Strait Islander background. The majority of the registered adult patients spoke English (93%). The adult registrants had a mean age of 73 years, with 5847 (45%) females.

**TABLE 3: BASELINE CHARACTERISTICS (ADULTS AND PAEDIATRICS)**

	Adults (n=13274)	Paediatrics (n=26)
<b>Episodes</b>	<b>14155</b>	<b>29</b>
Age in years, mean (SD)	73 (14)	8 (7)
Age in years, median (Q1 to Q3)	75 (65 to 84)	6 (0 to 15)
Female, n (%)	5847 (45)	11 (42)
Country of birth, n (%)		
Australia	8487 (70)	23 (88)
United Kingdom	891 (7)	1 (4)
Italy	341 (3)	0 (0)
Other European countries	1061 (9)	0 (0)
Asia	577 (5)	0 (0)
Others	702 (6)	2 (8)
Aboriginal and/or Torres Strait Islander, n (%)	255 (2)	2 (8)
English spoken, n (%)	11358 (93)	25 (96)

*SD: standard deviation*

*Q1: 25th percentile*

*Q3: 75th percentile*

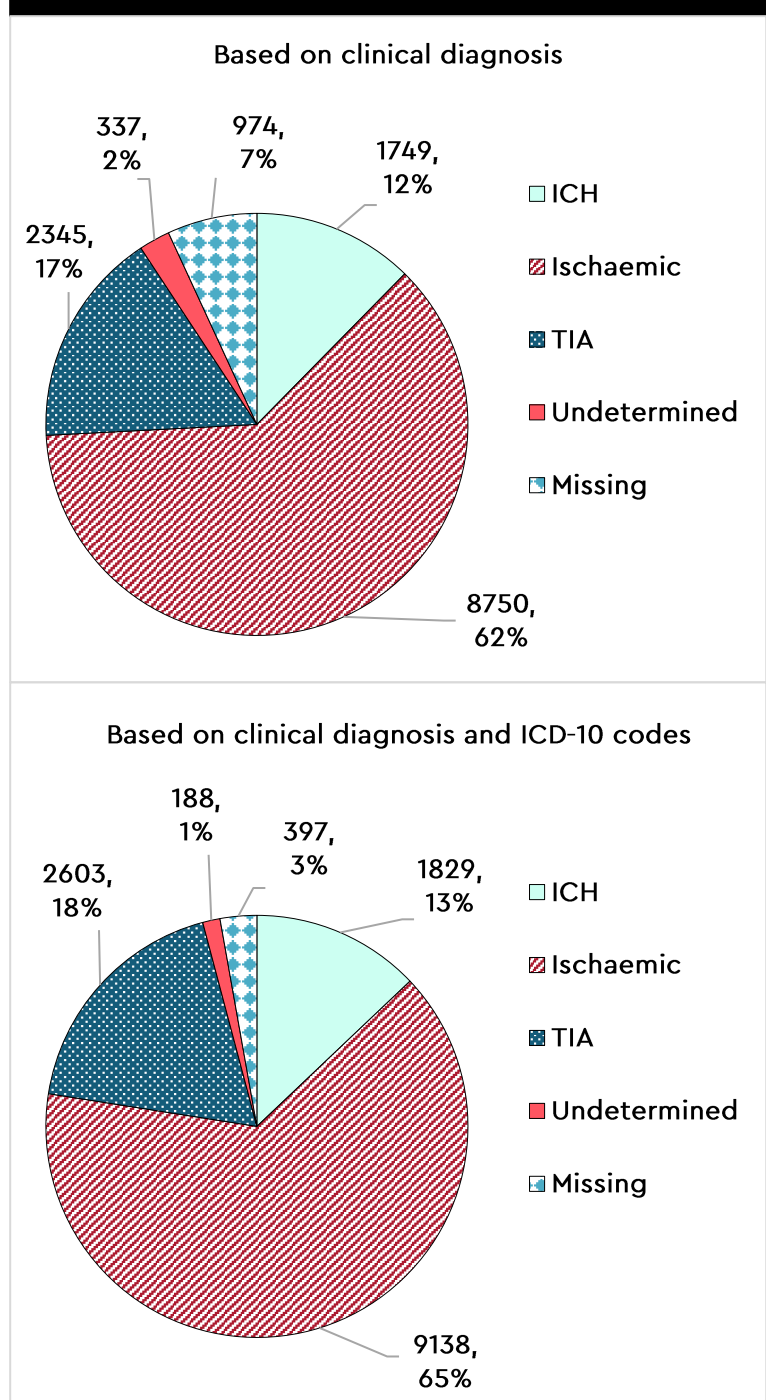
## CLINICAL CHARACTERISTICS

Of the 14155 adult episodes, clinicians indicated that there were 8,750 ischaemic strokes, 1749 intracerebral haemorrhages (ICH), 2345 TIAs and 337 episodes of undetermined stroke type. There were 974 episodes with the stroke type missing (Figure 4). Of the episodes with missing or undetermined stroke type for clinical diagnosis, ICD-10 codes were provided for 726 cases, which comprised ischaemic stroke (n=388), ICH (n=80), and TIA (n=258).

Among the adult episodes, 45% of patients were able to walk at the time of admission. There were 1,880 episodes (14%) transferred from another hospital and 584 episodes (4%) that occurred while patients were already in hospital for another condition. The majority of the inpatient episodes were ischaemic (n=449, 78%) and most of these (n=184, 32%) 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 11 days [Q1 to Q3: 5 to 19 days] vs. median 4 days [2 to 7 days] for those presenting 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 76%,  $p < 0.001$ ).

Among the 2345 episodes of TIA, the mean age was 72 years (SD 14 years), 48% were female and the median length of stay was one day (Q1 to Q3: 1 to 3 days).

FIGURE 4: DISTRIBUTION OF STROKE SUB-TYPES



## STROKE SEVERITY

There were 12520 episodes with ability to walk on admission recorded (88% of the 2017 cohort) and 4669 episodes with a National Institutes of Health Stroke Scale (NIHSS) score recorded at time of presentation to hospital (33% of the 2017 cohort).

Patients with a diagnosis of ischaemic stroke had the lowest proportion of missing NIHSS scores (60%). The NIHSS score was recorded for 617 episodes with a diagnosis of TIA (24%). There were ten episodes (3%) with a missing stroke type for which a NIHSS score was recorded. Of the episodes receiving thrombolysis, a NIHSS score was missing for 13%. Episodes treated in a stroke unit had a

greater proportion of NIHSS scores recorded than those treated in alternate ward settings (40% vs 16%,  $p < 0.001$ ).

Excluding those with TIA, there were 3893 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 indicating a moderate stroke (45%). Of those who were able to walk on admission, the majority (57%) had a NIHSS score indicating a minor stroke. These findings support the historical use of ability to walk on admission as a marker of stroke severity.

**TABLE 4: NIHSS AND ABILITY TO WALK ON ADMISSION**

National Institutes of Health Stroke Scale (NIHSS) categories	Ability to walk on admission	
	No n (%)	Yes n (%)
No stroke symptoms (0)	58 (2)	170 (12)
Minor stroke (1-4)	572 (23)	824 (57)
Moderate stroke (5-15)	1087 (45)	387 (27)
Moderate to severe stroke (16-20)	388 (16)	44 (3)
Severe stroke (21-42)	333 (14)	30 (2)
<b>Total N</b>	<b>2438</b>	<b>1455</b>

*Excludes episodes of TIA*

# ACUTE CARE DATA

## OVERALL ADHERENCE TO QUALITY INDICATORS

### Arrival within 4.5 hours of symptom onset

3202 patients with ischaemic stroke (37%) arrived within 4.5 hours of symptom onset (Figure 5).

### Arrival by ambulance

Method of arrival to the emergency department was collected for 12424 episodes. Of these, 9495 (76%) were transported by ambulance. The majority (85%) of the 1674 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 (48% vs 28%,  $p < 0.001$ ). The proportion of patients arriving by ambulance was smallest for TIAs (68%), and greatest for ICH (84%), as seen in Figure 6.

FIGURE 5: ARRIVED WITHIN 4.5 HOURS OF SYMPTOM ONSET IF AN ISCHAEMIC STROKE ADMISSION

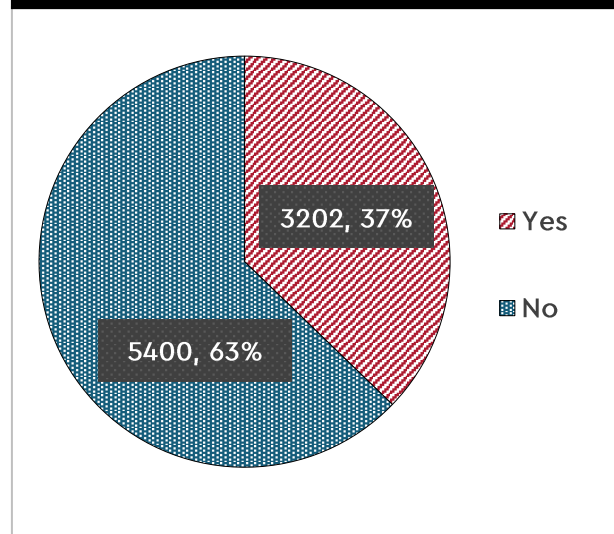
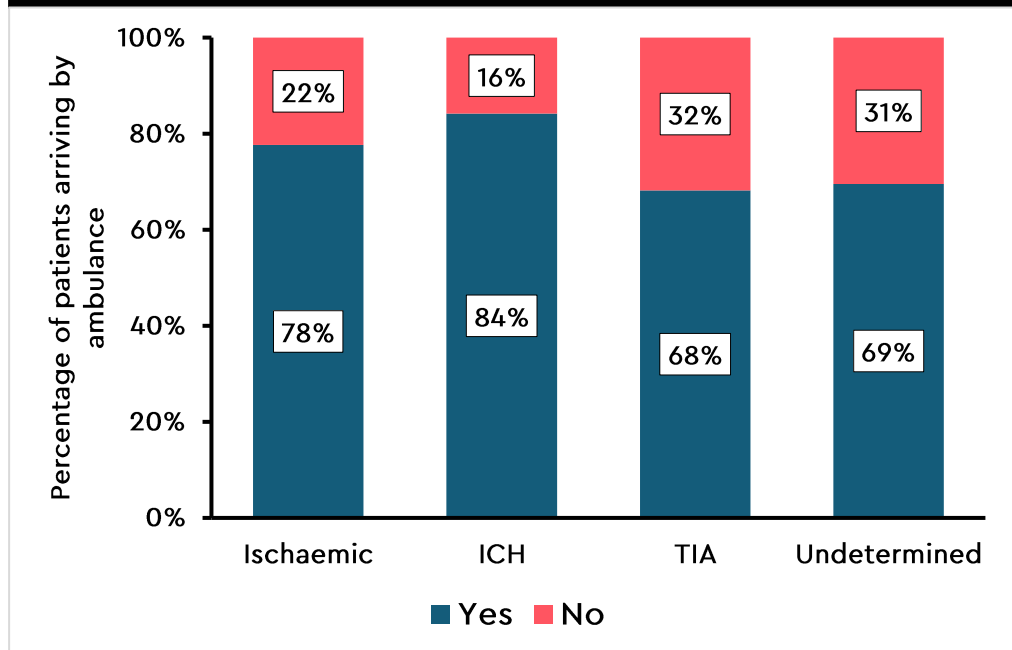


FIGURE 6: ARRIVAL BY AMBULANCE, STRATIFIED BY STROKE TYPE

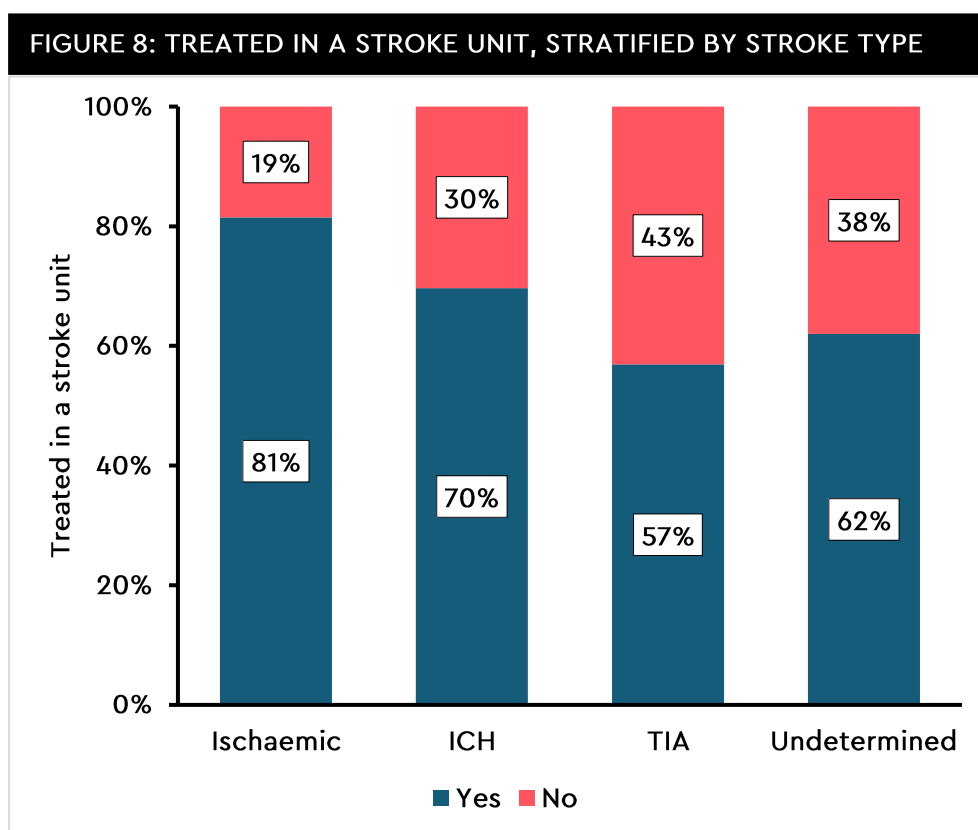
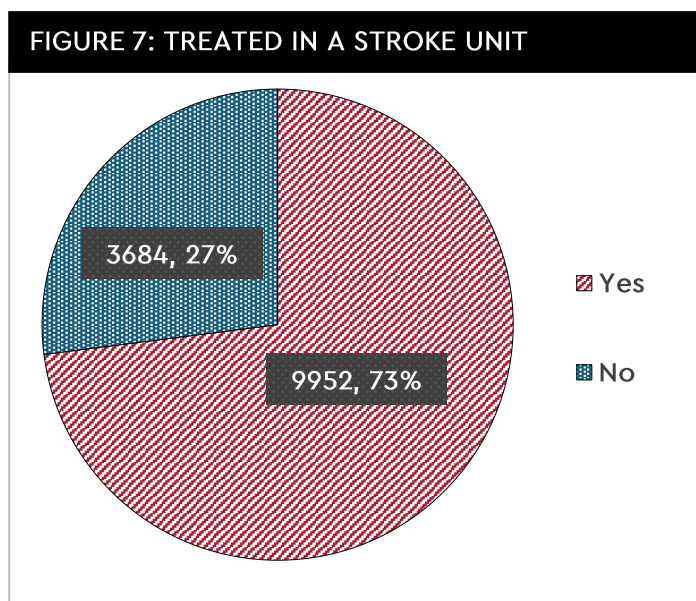


ICH: intracerebral haemorrhage

TIA: transient ischaemic attack

## Stroke unit care

Almost three quarters of episodes (73%) were treated in a stroke unit (Figure 7). Of the patients with ischaemic stroke, 81% were treated in a stroke unit, compared to 70% of those with ICH, 57% of those with TIA and 62% of those with undetermined stroke type (Figure 8).



ICH: intracerebral haemorrhage

TIA: transient ischaemic attack

## OTHER ACUTE ASSESSMENT AND MANAGEMENT PRACTICES

For the first time in 2017 we have a complete calendar year of data for a range of additional acute assessment and management practices including: brain scans, mobilisation, hyperacute aspirin, dysphagia screening and swallow assessment (Table 5).

### Hyperacute aspirin

Aspirin was provided within 48 hours of stroke onset time in 56% of episodes, based on the dates and times entered into the AuSCR (Table 5).

### Mobilisation

The majority of patients (83%) were mobilised on the same day, or the day after, admission.

### Dysphagia screening and swallow assessment

Dysphagia screening was undertaken in approximately half (52%) of all episodes, whereas a swallow assessment conducted by speech pathologists was completed in almost two thirds (73%) of episodes in 2017 (Table 5). A dysphagia screen or speech pathologist assessment that occurred *prior* to oral intake was documented in 51% of episodes.

**TABLE 5: STROKE EVALUATION AND THERAPY**

Hospital stroke care	All episodes	Ischaemic	ICH	TIA
Brain scan after stroke	90%	91%	89%	86%
Aspirin within 48 hours of stroke onset*	56%	54%	-	64%
Mobilisation during admission	86%	89%	66%	93%
<i>Same day or day after admission</i>	83%	82%	68%	96%
If unable to walk independently, patient mobilised	79%	83%	57%	92%
<i>Same day or day after admission</i>	76%	76%	59%	92%
Dysphagia screen conducted	52%	56%	39%	47%
<i>Screen within 24 hours</i>	80%	79%	76%	85%
Swallow assessment conducted	73%	80%	64%	55%
<i>Assessment within 24 hours</i>	59%	58%	54%	68%
Dysphagia screen and/or swallow assessment prior to oral intake	51%	55%	49%	38%

\* Excludes intracerebral haemorrhage, contraindicated and those provided with another antithrombotic medication

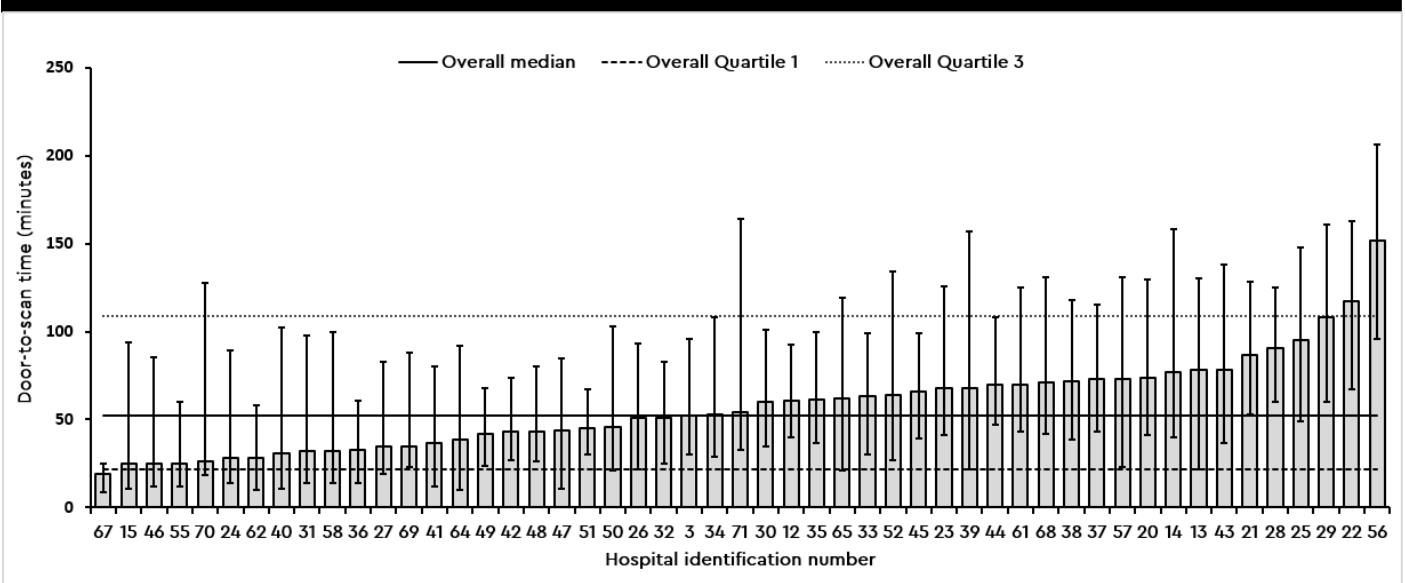


## Brain scans

In the hospitals collecting data on the provision of brain scans (n=57), there was evidence that 82% of patients were provided a brain scan. There were 318 patients who had a brain scan prior to transfer to the hospital at which they were admitted. Of those who had a brain scan after arrival to hospital, there were over 8000

cases where a time to brain scan was recorded. The median time to scan was 52 minutes, with four hospitals achieving a median time to scan of less than or equal to 25 minutes (Figure 9). The median time to brain scan from arrival was 27 minutes for patients with ischaemic stroke arriving within 4.5 hours of symptom onset.

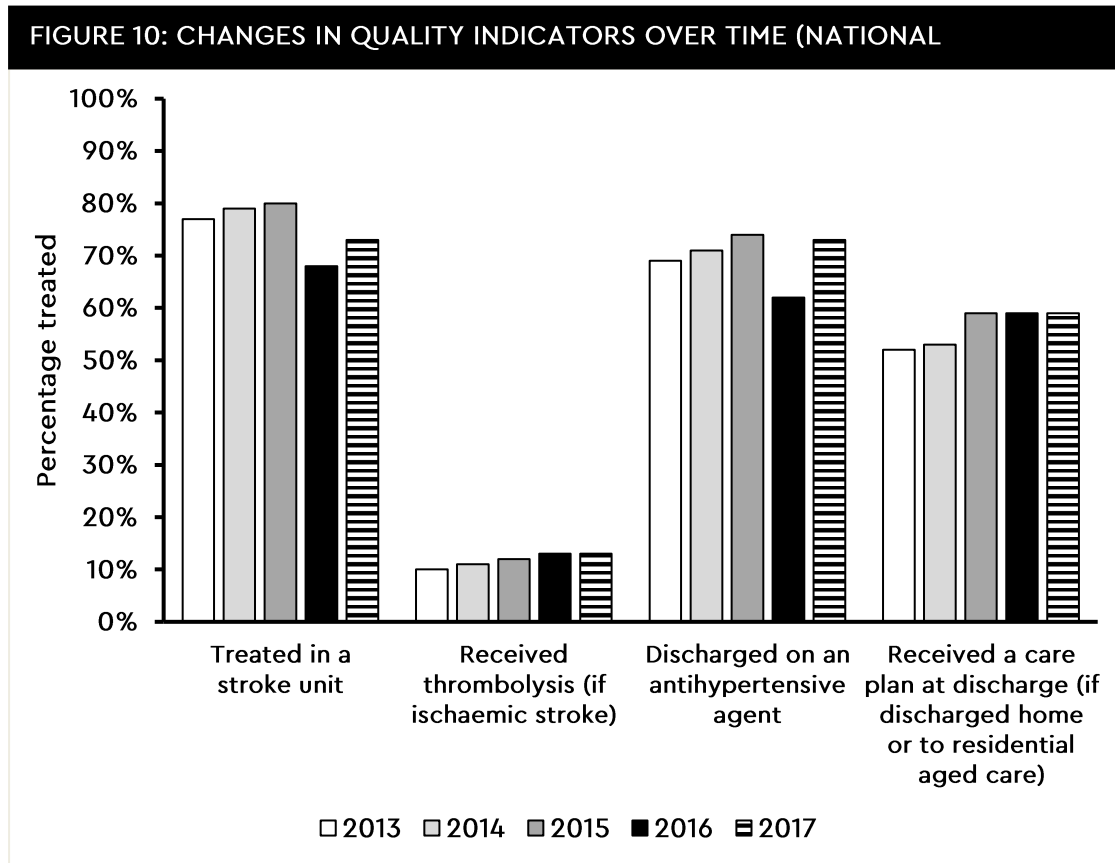
**FIGURE 9: MEDIAN DOOR-TO-SCAN TIME, BY HOSPITAL**



Data for cases where a scan was provided after 270 minutes of arrival are excluded  
Hospitals with fewer than 10 cases with door-to-scan times are excluded  
Number of cases with door-to-scan times by hospital range from 14 to 648

## CHANGES IN THE PROVISION OF QUALITY INDICATORS OVER TIME

Four quality indicators have been collected since the inception of the AuSCR. Compared with 2016, proportions of episodes receiving treatment in a stroke unit, provision of thrombolysis for ischaemic stroke and antihypertensive medication at discharge have increased (Figure 10). 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. All of these quality of care indicators align with the current national clinical care standards for acute stroke.<sup>6</sup> If the achievable benchmarks were reached by all AuSCR hospitals relative to the overall average adherence, then it is estimated that: a further 2979 patients would have benefited from care in a stroke unit; an extra 1140 from intravenous thrombolysis if an ischaemic stroke; an extra 342 provided intravenous thrombolysis within 60 minutes of arrival; an additional 1887 from antihypertensive medication; 1022 from antithrombotic medication; 1483 from lipid-lowering medication; and 2348 being provided with a care plan if discharged into the community.

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

Process of care	Benchmark* 2016	Benchmark* 2017	Top adherence# (%)	AuSCR adherence† (%)	Hospitals excluded n†	Participants excluded n/N (%)†
Received stroke unit care	94%	94%	98%	73%	3	520/14184 (4%)
Received intravenous thrombolysis if an ischaemic stroke‡	21%	22%	22%	13%	1	213/8767 (2%)
Door-to-needle time <60 minutes‡	68%	67%	71%	38%	1	213/8767 (2%)
Discharged on antihypertensive medication^	81%	88%	95%	73%	4	637/12577 (5%)
Discharged on antithrombotic medication^	90%	97%	100%	88%	5	1739/11351 (15%)
Discharged on lipid-lowering medication^	76%	90%	98%	77%	8	2255/11405 (20%)
Care plan provided if discharged to the community	89%	94%	100%	59%	2	209/6709 (3%)

\* Only sites with >50 cases were eligible for inclusion. Benchmarks were calculated based on a modified ABC™ method<sup>4,5</sup>

# The top performer adherence results are the unadjusted scores for a single hospital in this sample

† In 2017, data collected on a variable from a hospital were excluded if more than 30% of the data for that variable was missing

‡ Benchmarks related to thrombolysis exclude those who received thrombolysis prior to hospital arrival (e.g. prior to transfer)

^ Excludes patients with contraindications

# ADHERENCE TO QUALITY INDICATORS

Adherence to quality indicators by number of episodes registered in 2017 for each hospital is illustrated by the funnel plots in Figures 11 to 17. Funnel plots can be used to display deviations from the average achievement of quality of care.<sup>7</sup> Note that all of the funnel plots below exclude paediatric cases. Hospitals contributing fewer than 50 cases were excluded. Hospital data were also excluded from individual variable analyses if more than 30% of the data for that variable was missing.

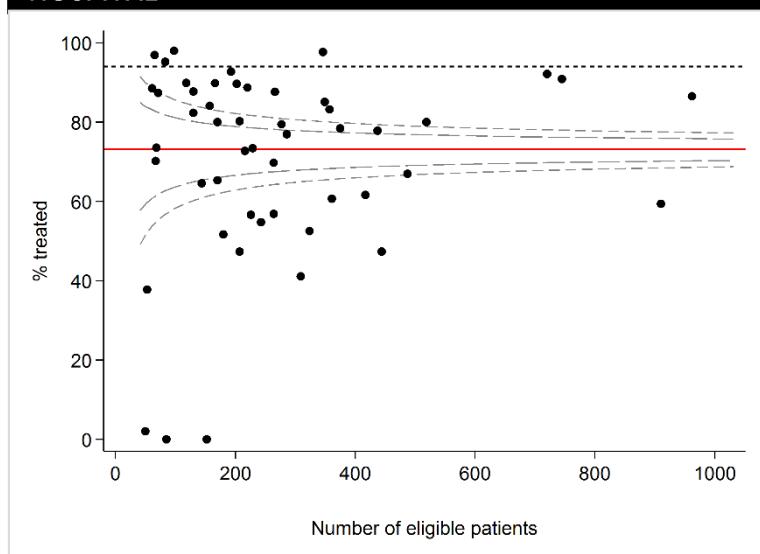
## How to read the funnel plots

The horizontal axis depicts the size of hospital in terms of number of episodes e.g. the greater 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 Figure 11, the overall proportion of patients admitted to a stroke unit was 73%. The dots show adherence for each individual hospital.

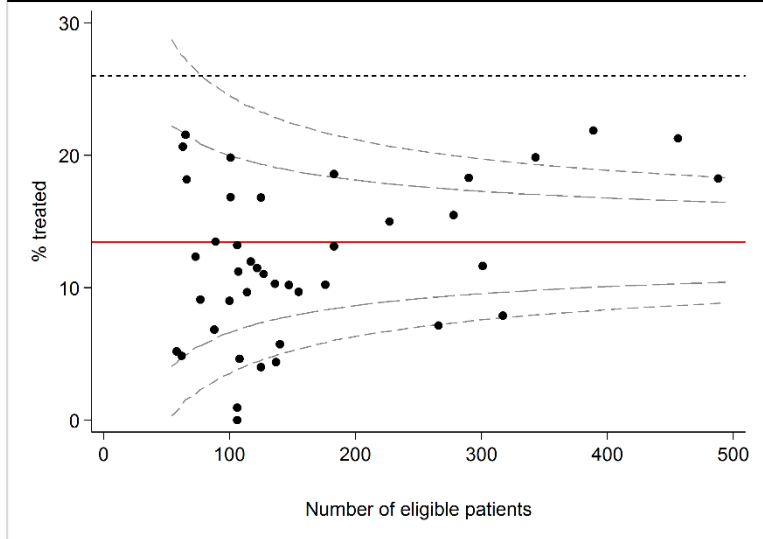
The large dashed lines constitute the funnel based on standard deviation (SD). They are the upper and lower control limits that represent the boundary between ‘normal variation’ (two SDs from the mean) and ‘special cause variation’ (three SDs from the mean). The small dashed line indicates the achievable 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*’.

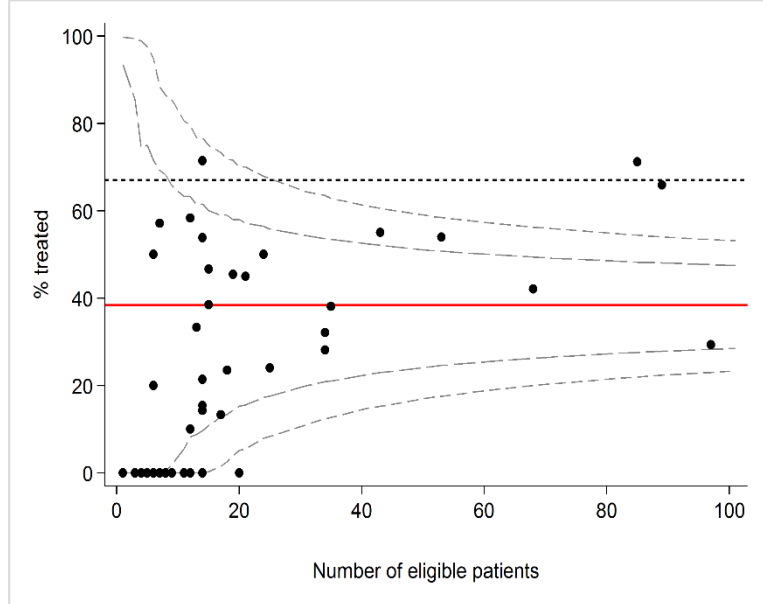
**FIGURE 11: MANAGEMENT IN A STROKE UNIT, BY HOSPITAL**



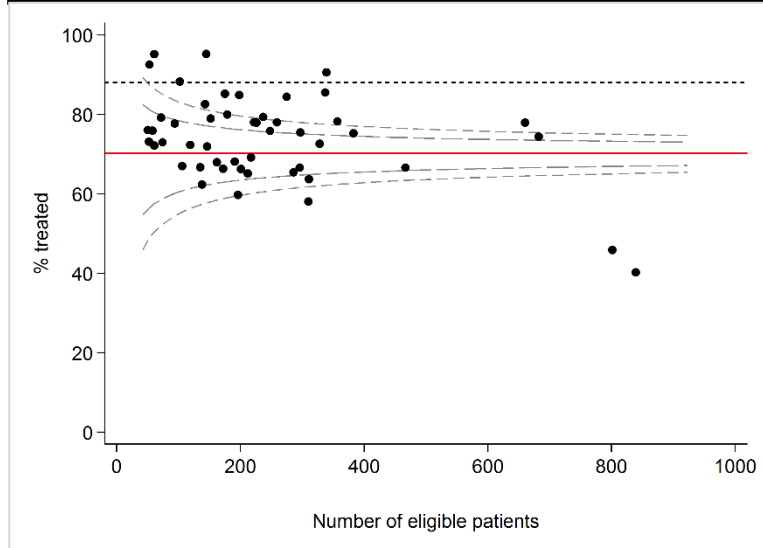
**FIGURE 12: RECEIVED INTRAVENOUS THROMBOLYSIS, BY HOSPITAL (EXCLUDING TRANSFERS)**



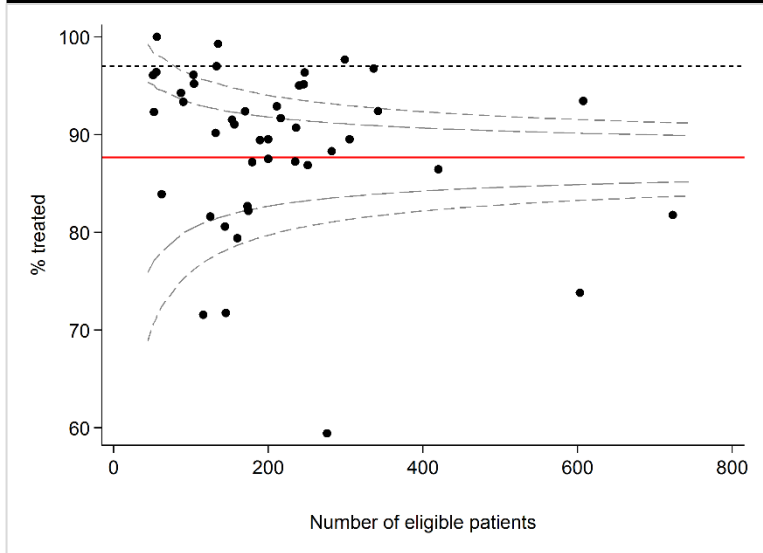
**FIGURE 13: DOOR-TO-NEEDLE TIME <60 MINUTES OF ARRIVAL, BY HOSPITAL (EXCLUDING TRANSFERS)**



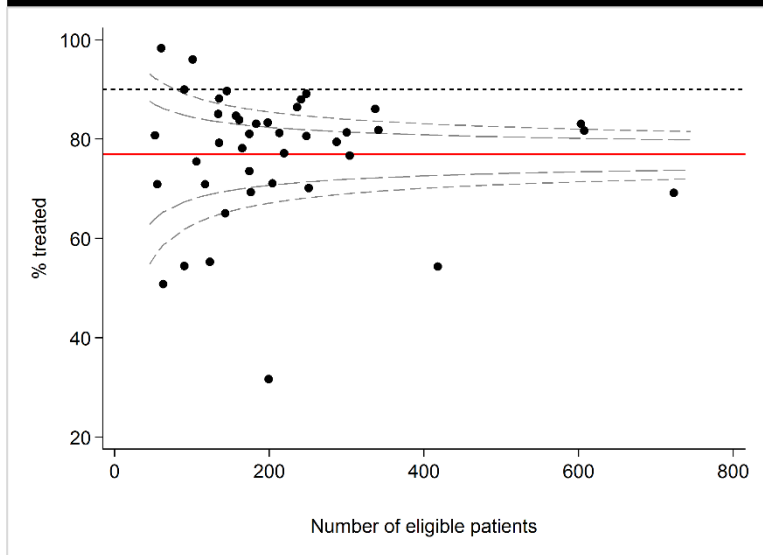
**FIGURE 14: DISCHARGED ON ANTIHYPERTENSIVE MEDICATIONS, BY HOSPITAL**



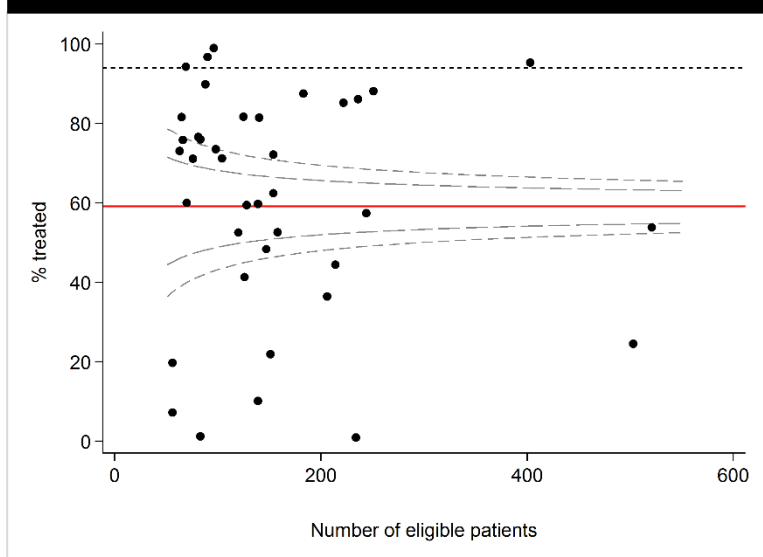
**FIGURE 15: DISCHARGED ON ANTITHROMBOTIC MEDICATIONS, BY HOSPITAL**



**FIGURE 16: DISCHARGED ON LIPID-LOWERING MEDICATIONS, BY HOSPITAL**



**FIGURE 17: CARE PLAN PROVIDED IF DISCHARGED HOME OR TO RESIDENTIAL AGED CARE, BY HOSPITAL**



## EMERGING PROCESS OF CARE DATA – TRANSFERS AND REPERFUSION THERAPIES

*In the following sections, data on new variables captured for the first time over a full calendar year are presented.*

### Reason for transfers

The reason for transfer was collected for hospitals participating in the AuSCR Black data collection program, as outlined in Figure 1. Transfer for thrombolysis was indicated for 21 patients and transfer for endovascular therapy was indicated for 308 patients.

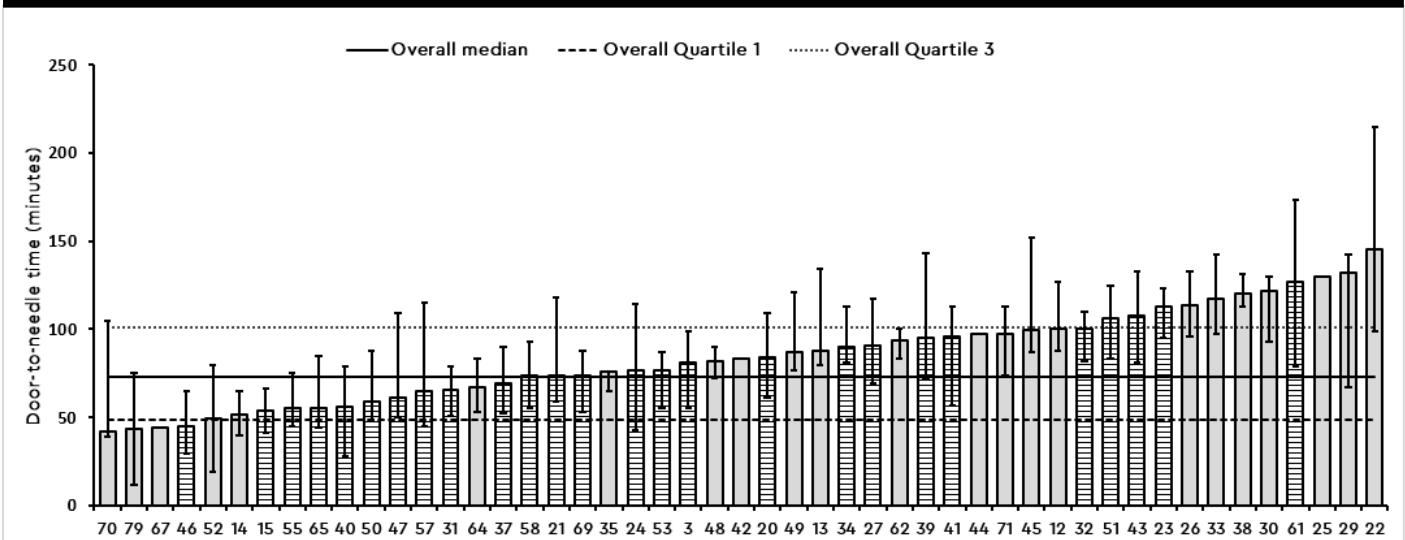
### Thrombolysis treatment delivery

Of the episodes of ischaemic stroke, 14% were provided with thrombolysis treatment. There were 165 cases where thrombolysis was provided prior to hospital transfer.

Of the 3124 patients with ischaemic stroke arriving within 4.5 hours of symptom onset, 31% were provided with thrombolysis. For those patients with times documented, 39% had a door-to-needle time under 60 minutes, median door-to-needle time was 73 minutes and median onset-to-needle time was 156 minutes. For those provided with thrombolysis, median door-to-scan time was 18 minutes.

At a hospital level, eleven hospitals had a median door-to-needle time under 60 minutes (Figure 18).

**FIGURE 18: DOOR-TO-NEEDLE TIMES, BY HOSPITAL**



Data for cases where thrombolysis was provided after 270 minutes of arrival are excluded.

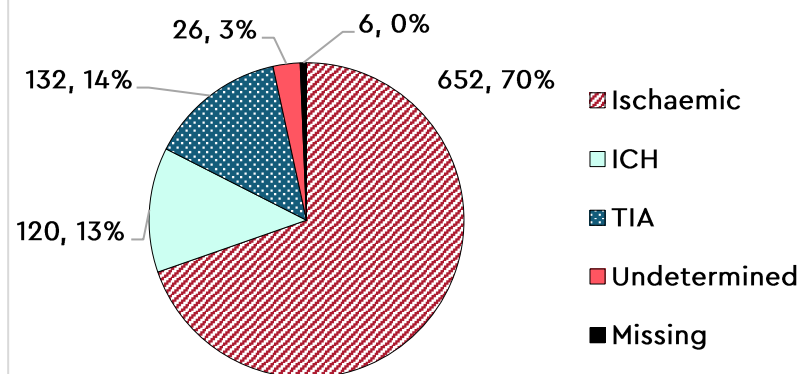
Bars with stripes indicate hospitals contributing more than 10 cases with door-to-needle times

Number of cases with door-to-needle times by hospital range from 1 to 100

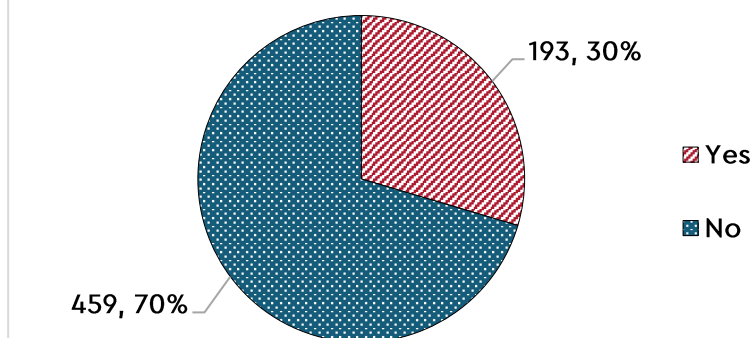
## Involvement of telemedicine in acute stroke care

Telemedicine consultations were provided at 40 hospitals (1 hospital in NSW, 18 hospitals in QLD, 2 hospitals in SA, 1 hospital in TAS and 18 hospitals in VIC). At these 40 hospitals, there were 936 telemedicine consultations documented for adult patients, making up 11% of all episodes at these hospitals. There were 652 patients who had an ischaemic stroke and received a telemedicine consultation (Figure 19). Of these, 193 patients (30%) were provided with thrombolysis (Figure 20). Median door-to-needle time for these cases was 88 minutes (Q1 to Q3: 64 to 120). This is 20 minutes longer on average than for non-telemedicine cases ( $p < 0.001$ ). Three hospitals had a median door-to-needle time under 60 minutes when telemedicine was used (Figure 21).

**FIGURE 19: DIAGNOSIS OF PATIENTS PROVIDED WITH A TELEMEDICINE CONSULTATION**



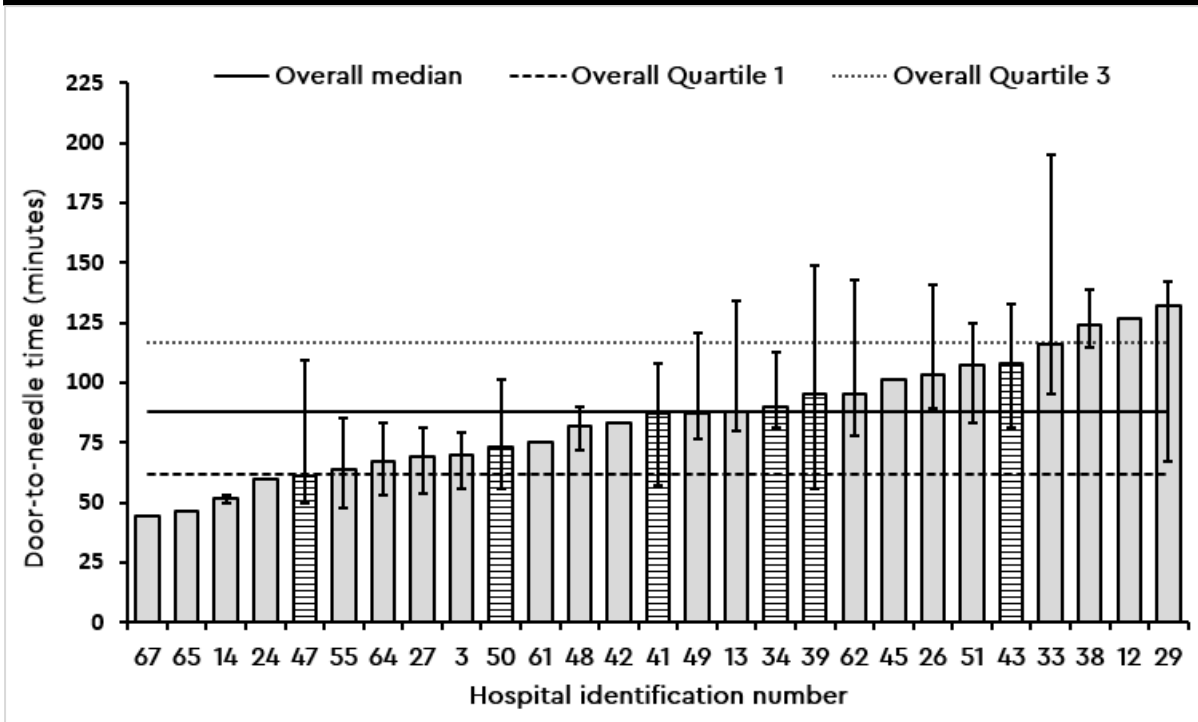
**FIGURE 20: PATIENTS WITH A TELEMEDICINE CONSULTATION WHO RECEIVED THROMBOLYSIS**



*Ischaemic stroke type only*



**FIGURE 21: DOOR-TO-NEEDLE TIMES FOR PATIENTS WHO WERE PROVIDED A  
TELEMEDICINE CONSULTATION, BY HOSPITAL**

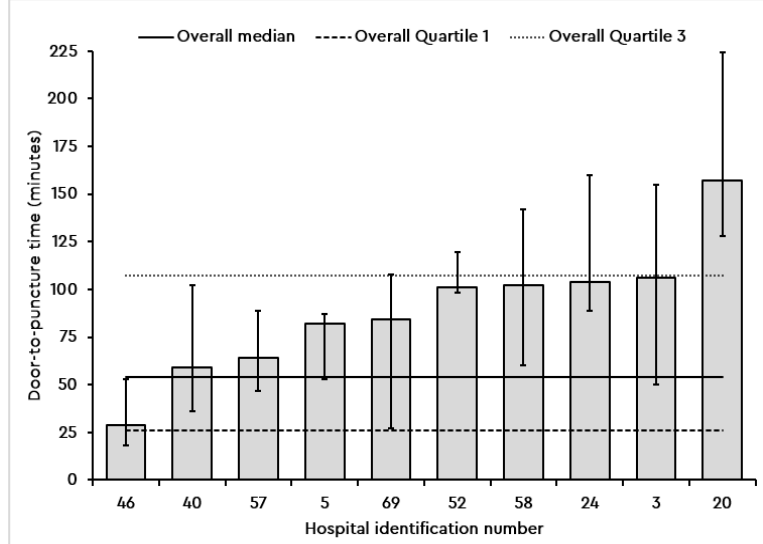


Data for cases where thrombolysis was provided after 270 minutes of arrival were excluded  
 Bars with stripes contributed more than 10 cases with door-to-needle times  
 Number of cases with door-to-needle times by hospital range from 1 to 15

## Endovascular clot retrieval (ECR)

There were 597 patients who received ECR at 13 hospitals (5 in VIC, 3 in QLD, 3 in SA, 1 in NSW and 1 in TAS). For cases where times of both arrival and treatment were collected, median time from arrival to groin puncture was 54 minutes (Figure 22) and median arrival to recanalisation was 112 minutes (Figure 23).

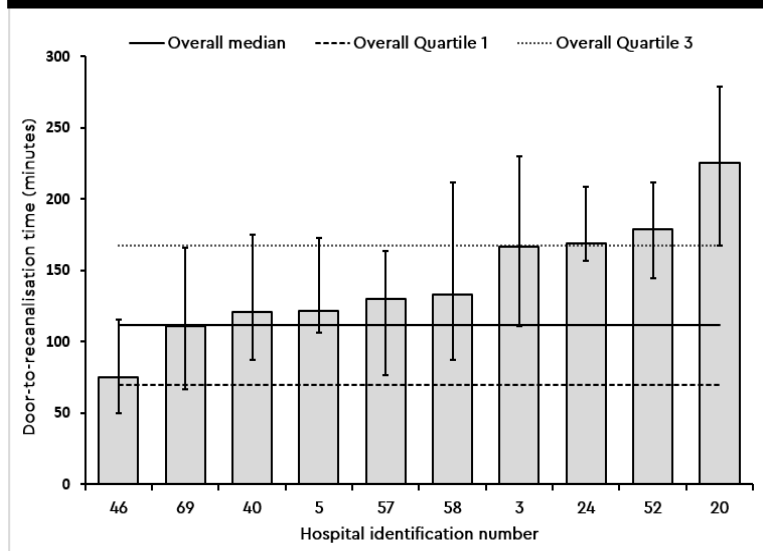
**FIGURE 22: DOOR-TO-PUNCTURE TIMES FOR PATIENTS WHO WERE PROVIDED ECR, BY HOSPITAL**



Data for cases where door-to-puncture time was greater than 720 minutes are excluded

Number of cases with door-to-puncture times by hospital range from 4 to 215

**FIGURE 23: DOOR-TO-RECANALISATION TIMES FOR PATIENTS WHO WERE PROVIDED ECR, BY HOSPITAL**



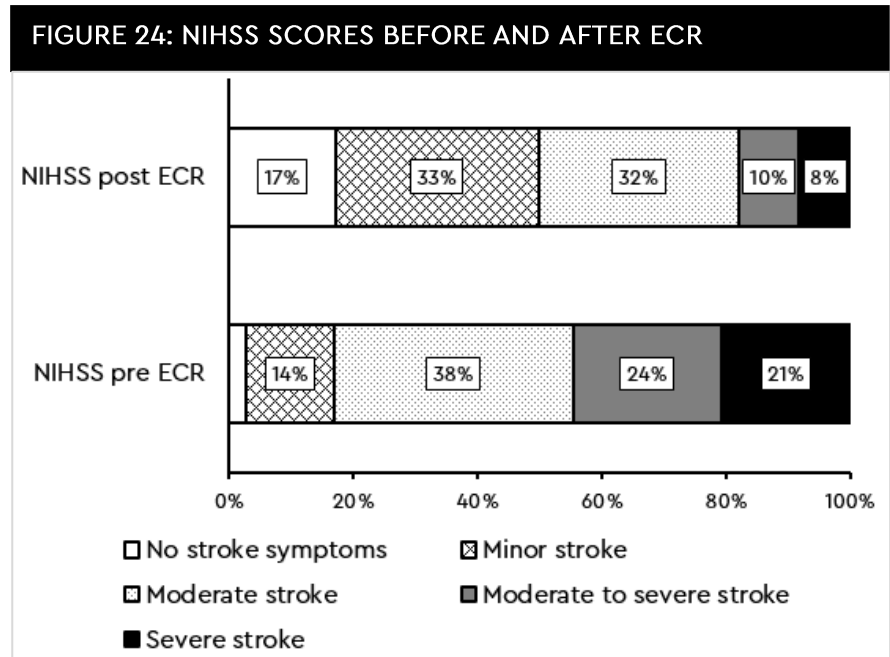
Data for cases where door-to-recanalisation time was greater than 720 minutes are excluded

Number of cases with door-to-recanalisation times by hospital range from 4 to 210

## National Institutes of Health Stroke Scores (NIHSS) before and after ECR

Stroke severity is able to be assessed with the NIHSS. The score is also used to assess eligibility for some treatments, as well as effects of treatments.

In addition to the NIHSS score obtained at hospital arrival, hospitals participating in the AuSCR Black Program also collect a NIHSS score before ECR and 24 hours after ECR. Data quality for the pre- and post-ECR NIHSS variable was generally poor, with the majority being either missing or reported as unknown. Of the 597 cases provided with ECR, 255 had a NIHSS score pre-ECR recorded (43% complete) and 217 had a NIHSS score post-ECR recorded (36% complete). A summary of NIHSS scores before and after ECR is given in Figure 24.



## Discharge medications

Nationally, among those alive at discharge, 70% were discharged on an antihypertensive medication. In those with an ICH, 69% were discharged on an antihypertensive medication. Excluding those with ICH, antithrombotic medications were prescribed for 88% of patients at discharge from hospital, and lipid-lowering medications were prescribed for 77% of patients at discharge from hospital (Table 7).

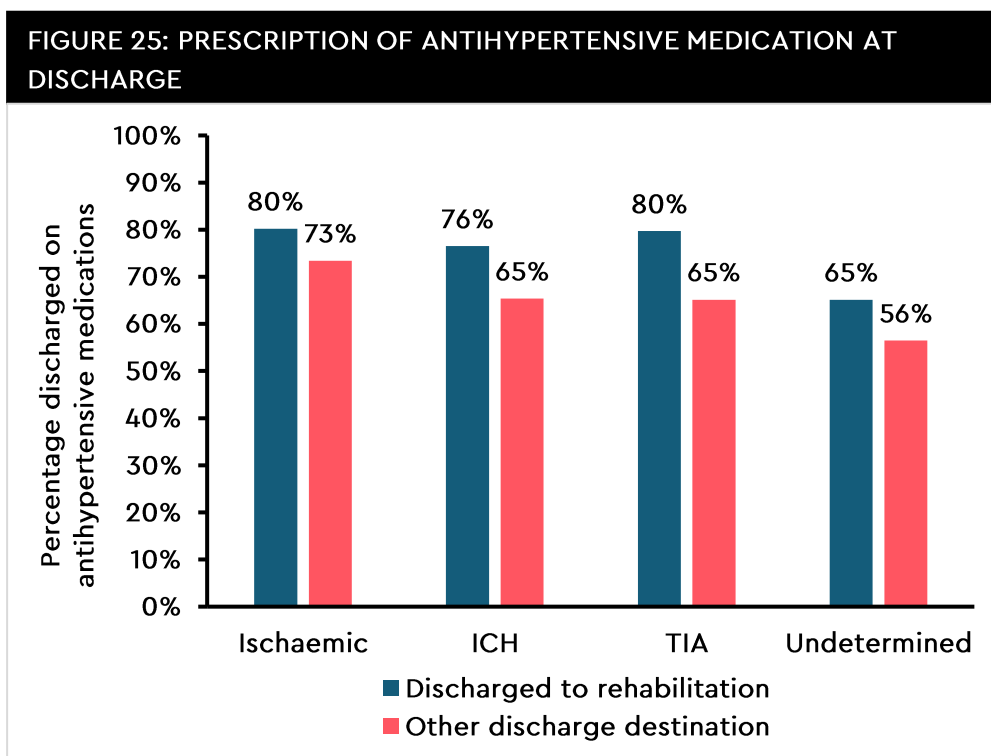
Of the patients with ischaemic stroke, 55% were discharged on antihypertensive, antithrombotic and lipid-lowering medications. Patients who were discharged to rehabilitation more often were prescribed antihypertensive medication at discharge than patients discharged to other settings in all sub-types of stroke (Figure 25).

**TABLE 7: DISCHARGE MEDICATIONS, BY STROKE TYPE**

Medication on discharge	All episodes	Ischaemic	ICH	TIA
Discharged on an antihypertensive medication*	70%	75%	69%	66%
Discharged on an antithrombotic medication*	88%	90%	-	88%
Discharged on a lipid-lowering medication*	77%	79%	-	74%
Discharged on a combination of secondary prevention medications*^	49%	55%	-	50%

\*Excludes patients with contraindications

^A combination of antihypertensive, antithrombotic and lipid-lowering medications



## WEEKEND DISCHARGE AND QUALITY INDICATORS

Of the 12278 patients registered in the AuSCR with a documented date of discharge, 1369 (11%) were discharged on the weekend. In a recent publication we identified that patients discharged on the weekend were less likely to receive evidence-based care when compared with those discharged during the week.<sup>8</sup> High quality of stroke care should be consistent irrespective of the timing of hospital discharge.

**TABLE 8: WEEKEND DISCHARGE AND QUALITY INDICATORS**

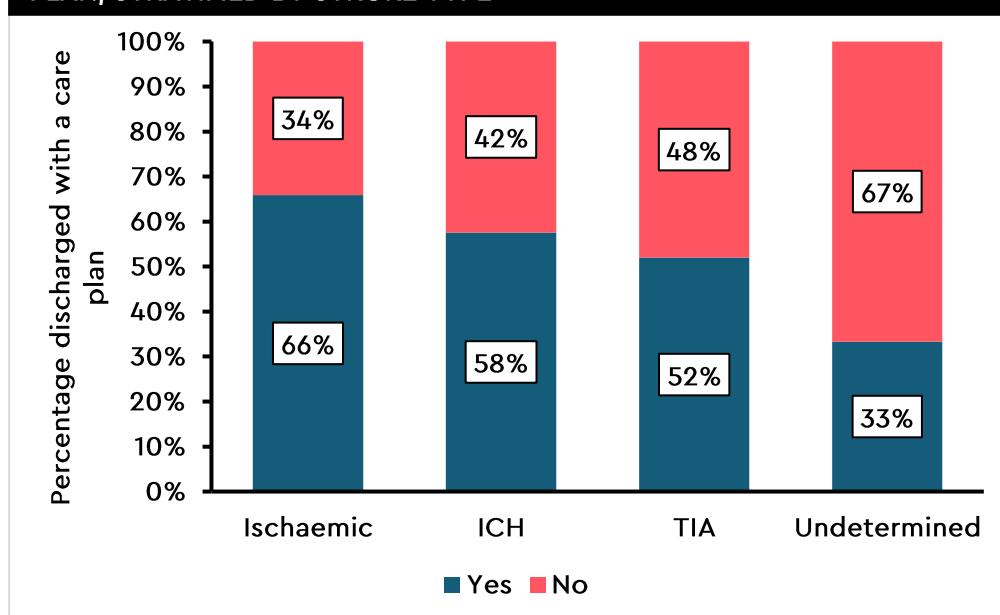
Process of care	Weekday discharge	Weekend Discharge	p-value
Received stroke unit care	76%	63%	<0.001
Discharged on antihypertensive medication <sup>^</sup>	74%	65%	<0.001
Discharged on antithrombotic medication <sup>^</sup>	90%	86%	<0.001
Discharged on lipid-lowering medication <sup>^</sup>	79%	71%	<0.001
Care plan provided if discharged to the community	62%	49%	<0.001

<sup>^</sup> Excludes patients with contraindications

## TRANSITION FROM HOSPITAL CARE

Among the 6486 episodes resulting in discharge home or to a residential aged care facility, 59% received a care plan. Of the patients with ischaemic stroke, 66% were provided a care plan at discharge, compared with 58% of those with ICH, 52% of those with TIA and 33% of those with an undetermined stroke type (Figure 26).

**FIGURE 26: PATIENTS DISCHARGED TO THE COMMUNITY WITH A CARE PLAN, STRATIFIED BY STROKE TYPE**



# 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 14155 adult episodes of care, 1164 (8%) patients died while in hospital. Case fatality in hospital was 11% greater for women after adjustment for age ( $p=0.089$ ). 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 six days (Q1 to Q3: 3 to 12 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 two days (Q1 to Q3: 1 to 5 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 five days) compared to patients with stroke (90% TIA, 49% stroke,  $p<0.001$ ).

Of the 12927 episodes that were discharged, 12219 had information provided on length of stay. Of these episodes, 571 (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,  $p<0.001$ ).

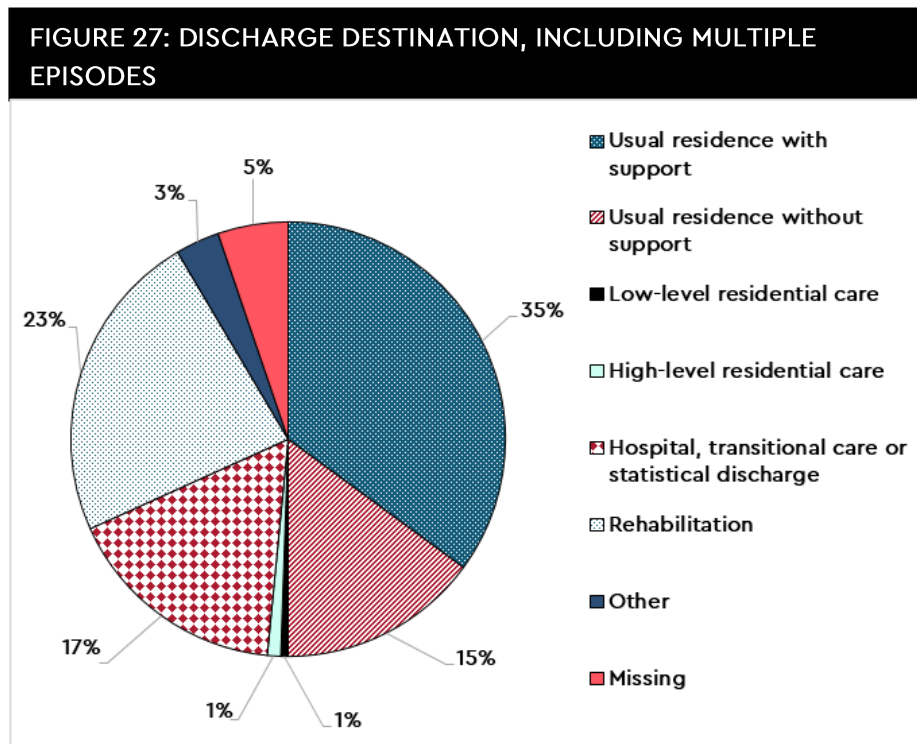
## DISCHARGE DESTINATION

In 2017, excluding in-hospital deaths, approximately half of the episodes of care resulted in patients being discharged to their usual residence (n=6498; 50%), with the majority of these patients requiring support (Figure 27). 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 a two-fold increased odds of being discharged to a rehabilitation facility compared to those patients not managed in a stroke unit (odds ratio 2.45, 95% confidence interval 2.14–2.80, 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 (35% vs 15% unable to walk on admission, p<0.001 ; 16% vs 7% able to walk on admission, p<0.001).

Most patients with TIA (87%, n=2046) were discharged to a home setting, 3% (n=71) 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 23 registrants with TIA who were discharged to residential aged care, 22% had a documented history of a previous stroke.



n=12991 episodes

Excludes paediatric cases and episodes of care resulting in death while in hospital

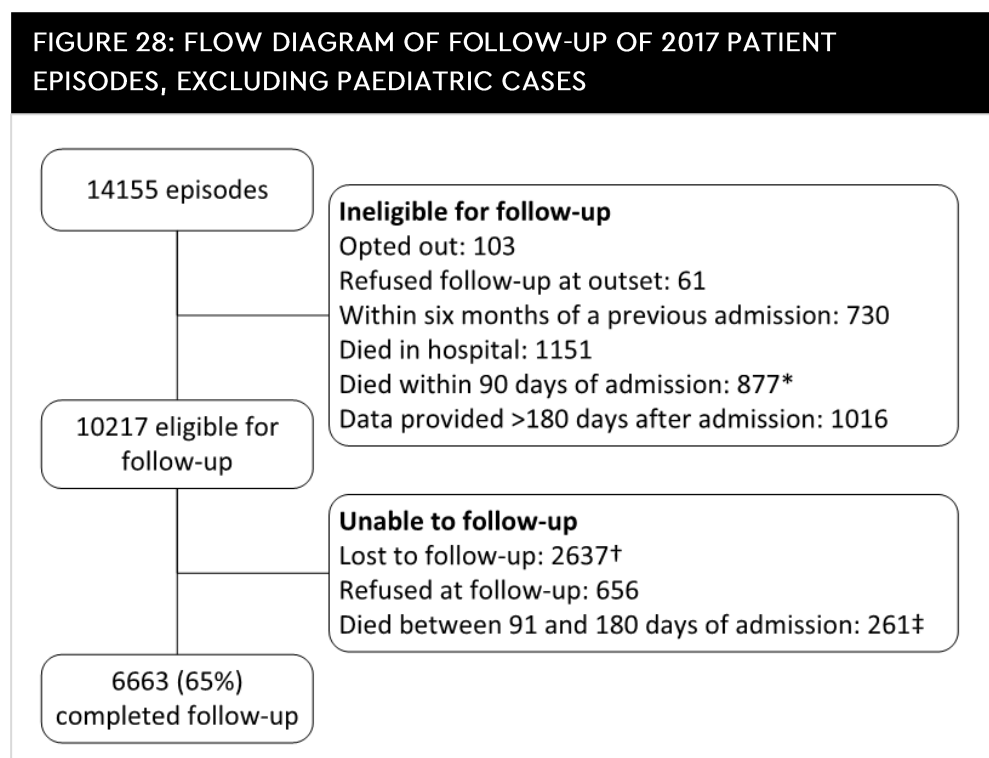
# POST-DISCHARGE HEALTH OUTCOME INFORMATION

## RESPONSE RATES

Of the 10217 adult episodes eligible for a follow-up survey, 6663 (65%) of patients or their proxy provided information about their health status (Figure 28). Median time to follow-up was 144 days from stroke admission date (Q1 to Q3: 108 to 183 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.

**FIGURE 28: FLOW DIAGRAM OF FOLLOW-UP OF 2017 PATIENT EPISODES, EXCLUDING PAEDIATRIC CASES**



\* Deaths after discharge and within 90 days of admission were determined using the NDI

† Contact unable to be made using our follow-up protocol (two postal attempts and one telephone attempt)

‡ Deaths between 91 and 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



## FOLLOW-UP DATA

Of the patients eligible for follow-up, differences were identified in both demographic and clinical characteristics, as well as in processes of care (Table 9).

At follow-up, approximately one in five registrants reported hospital readmissions (Table 10). Most registrants who were followed

up were living at home (85%), while 21% of registrants were living alone. There were 756 registrants living in low level care or high level care for whom information at follow-up was obtained. Twenty five percent of registrants completing follow-up were free from disability, reporting no symptoms at all on the modified Rankin Scale (mRS).

**TABLE 9: CHARACTERISTICS FOR PATIENTS WITH AND WITHOUT POST-DISCHARGE INFORMATION**

	Completed (n=6663)	Not completed (n=3554)	p value
Age (years), mean (SD)	72 (13)	70 (15)	<0.001
Female, n (%)	2805 (43)	1565 (46)	0.004
Aboriginal and/or Torres Strait Islander, n (%)	113 (2)	97 (3)	<0.001
Type of stroke, n (%)			
Ischaemic	4255 (67)	2184 (66)	0.038
Intracerebral haemorrhage	609 (10)	361 (11)	
Transient ischaemic attack	1357 (21)	644 (20)	
Undetermined	164 (3)	96 (3)	
Able to walk on admission, n (%)	3112 (52)	1491 (48)	0.001
Length of hospital admission (days), median (Q1 to Q3)	4 (2 to 7)	4 (2 to 8)	0.077
Treated in a stroke unit, n (%)	5085 (78)	2530 (74)	<0.001

*Excludes paediatric cases*

*SD: standard deviation*

*Q1: 25th percentile*

*Q3: 75th percentile*

**TABLE 10: INFORMATION OBTAINED AT FOLLOW-UP**

Had a recurrent stroke	298/6579 (5%)
Readmitted to hospital	1400/6524 (21%)
Location at time of follow-up interview	
<i>Home</i>	
<i>Living alone</i>	1360/6569 (21%)
<i>Living at home</i>	5604/6590 (85%)
Home with support	2631/5604 (47%)
Home without support	2973/5604 (53%)
<i>Institutional care or other setting</i>	
In hospital	71/6590 (1%)
Transitional care services	64/6590 (1%)
Low level care (hostel care)	78/6590 (1%)
High level care (nursing home)	678/6590 (10%)
Inpatient rehabilitation	38/6590 (1%)
Other	57/6590 (1%)
Modified Rankin Scale	
0 – No symptoms at all	1673/6663 (25%)
1 – No significant disability despite symptoms	1431/6663 (21%)
2 – Slight disability	1298/6663 (19%)
3 – Moderate disability	1330/6663 (20%)
4 – Moderately severe disability	642/6663 (10%)
5 – Severe disability	236/6663 (4%)
Missing	53/6663 (1%)

Missing data not included in denominators

Excludes paediatric cases

## HEALTH-RELATED QUALITY OF LIFE

With respect to health-related quality of life, patients with ICH reported problems in all dimensions of the EQ-5D-3L more commonly (Table 11). Problems in relation to usual activities were most common in all subtypes apart from TIA, in which problems were most commonly reported in relation to the pain/discomfort dimension (45% of respondents). Problems in relation to anxiety

and depression were reported most commonly in patients with ICH (54% of respondents). The Visual Analogue Scale (VAS) mean was greatest in patients with TIA (72) and least in patients with ICH (65). In both patients with ischaemic stroke and undetermined stroke, the VAS mean was 68. These VAS mean scores compare to the mean of 83 for the normative population of adults in the United Kingdom.<sup>9</sup>

**TABLE 11: QUALITY OF LIFE ASSESSMENT AMONG SURVEY RESPONDENTS, STRATIFIED BY STROKE TYPE**

	Ischaemic	ICH	TIA	Undetermined	All
<b>Proportion of patients reporting problems with EQ-5D-3L dimensions</b>					
<i>Mobility</i>	50%	58%	38%	49%	48%
<i>Self-care</i>	32%	39%	19%	32%	30%
<i>Usual activities</i>	60%	68%	41%	59%	57%
<i>Pain/Discomfort</i>	48%	56%	45%	55%	48%
<i>Anxiety/Depression</i>	46%	54%	40%	50%	46%
VAS mean (SD)	68 (22)	65 (23)	72 (20)	68 (22)	68 (22)
VAS median (Q1-Q3)	70 (50-85)	70 (50-80)	77 (60-89)	70 (50-89)	71 (50-85)
<b>Modified Rankin Scale</b>					
<i>0 – No symptoms at all</i>	20%	14%	45%	23%	25%
<i>1 – No significant disability despite symptoms</i>	22%	20%	21%	21%	21%
<i>2 – Slight disability</i>	21%	19%	15%	18%	20%
<i>3 – Moderate disability</i>	21%	23%	14%	23%	20%
<i>4 – Moderately severe disability</i>	10%	17%	5%	12%	10%
<i>5 – Severe disability</i>	4%	6%	1%	2%	4%
<i>Missing</i>	1%	1%	1%	2%	1%

ICH: intracerebral haemorrhage

TIA: transient ischaemic attack

Excludes paediatric cases

SD: standard deviation

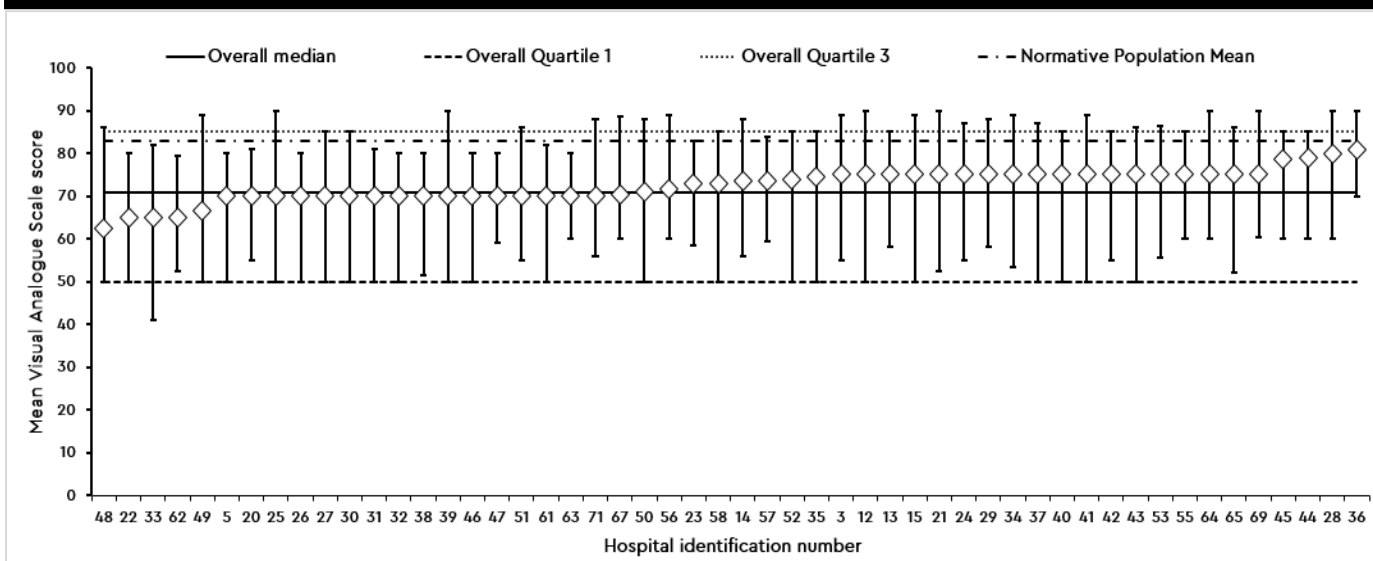
Q1: 25th percentile; Q3: 75th percentile

Figure 29 shows the unadjusted VAS scores of patients at follow-up by individual hospital. There was no evidence that VAS scores were different between hospitals after adjusting for patient characteristics.

Proportions of patients with VAS scores above the national median (68 points) were no

different between hospitals after adjustment for patient and clinical characteristics (Figure 30). The proportion of patients with VAS scores above the national median differed between the best and worst hospitals by less than 1.5%.

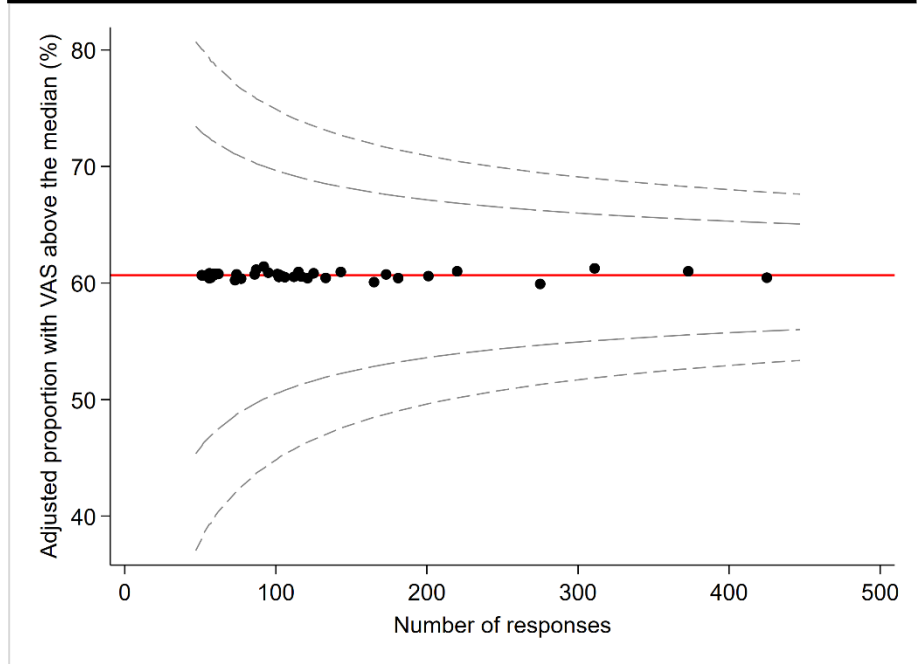
**FIGURE 29: HEALTH-RELATED QUALITY OF LIFE SCORE ACCORDING TO THE VISUAL ANALOGUE SCALE AT FOLLOW-UP, BY HOSPITAL**



Hospitals with fewer than 10 cases who completed follow-up were excluded

Mean of 83 for the normative population of adult were obtained from the United Kingdom<sup>9</sup>

**FIGURE 30: VARIABILITY IN VAS SCORES BETWEEN HOSPITALS**



*Hospitals with fewer than 50 cases providing a VAS score at follow-up were excluded*

*Model was adjusted for age, sex, stroke type, ability to walk on admission and previous history of stroke*

## **PARTICIPATION IN RESEARCH**

Among the 6531 registrants who answered the question about whether they would be willing to be contacted to participate in future research, 4191 (64%) replied affirmatively. Compared to those who did not reply in the affirmative, these patients were younger (median age 72 vs 77 years,  $p < 0.001$ ) and more often male (60% vs 53%,  $p < 0.001$ ).

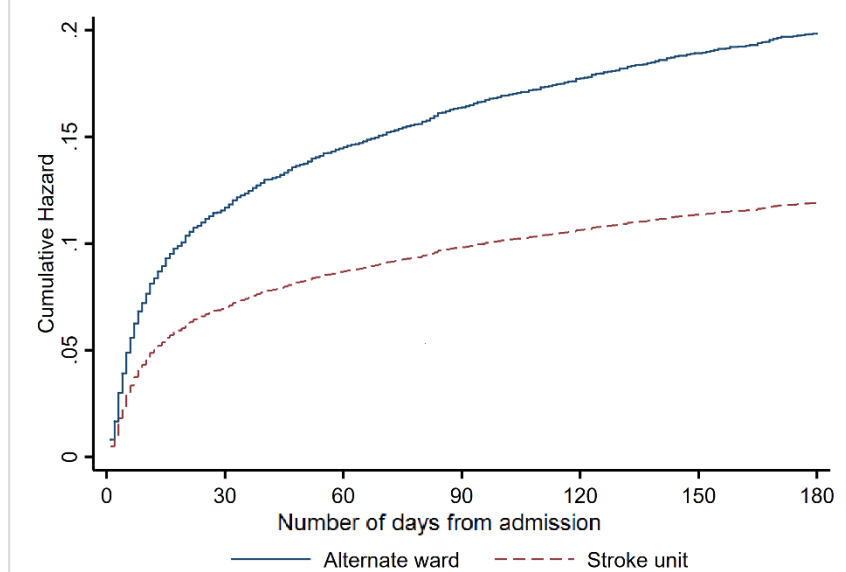
## **UNMET INFORMATION NEEDS**

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 2017, 50% ( $n = 3268$ ) of the 6545 registrants who answered this question, indicated that they would like to receive such information.

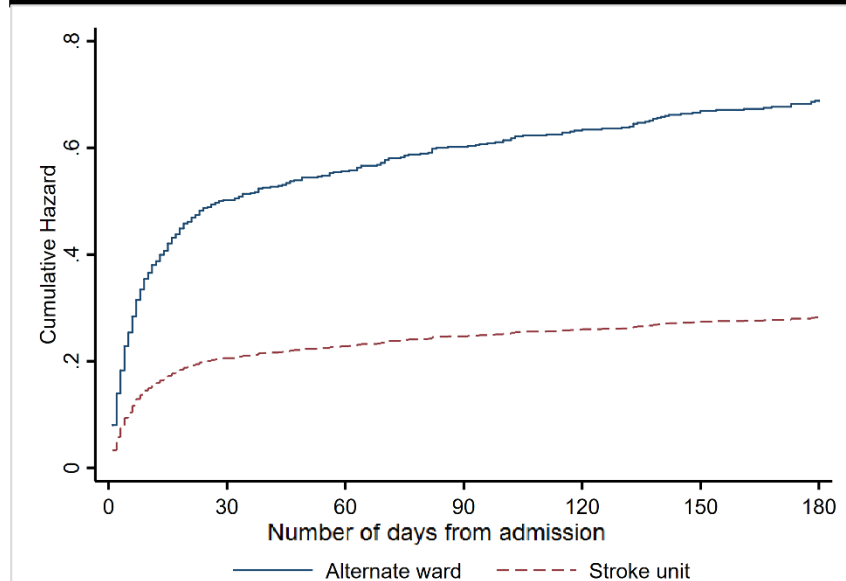
## SURVIVAL

According to the data in the National Death Index, there were 952 patients (7%) who died after discharge from hospital, but within 90 days of their admission, and 363 patients (3%) who died between 91 and 180 days of their admission. In patients with ischaemic stroke, treatment in a stroke unit was associated with a 40% lower hazard of death at 180 days after admission than treatment on an alternate ward (hazard ratio 0.60, 95% confidence interval 0.53-0.68,  $p < 0.001$ , Figure 31). A similar result was found for patients with ICH (hazard ratio 0.41, 95% confidence interval 0.34-0.49,  $p < 0.001$ , Figure 32). These analyses were adjusted for age, sex, ability to walk on admission, in-hospital stroke and transfer from another hospital.

**FIGURE 31: CUMULATIVE HAZARD OF DEATH, BY TREATMENT IN A STROKE UNIT (ISCHAEMIC STROKE)**



**FIGURE 32: CUMULATIVE HAZARD OF DEATH, BY TREATMENT IN A STROKE UNIT (INTRACEREBRAL HAEMORRHAGE)**

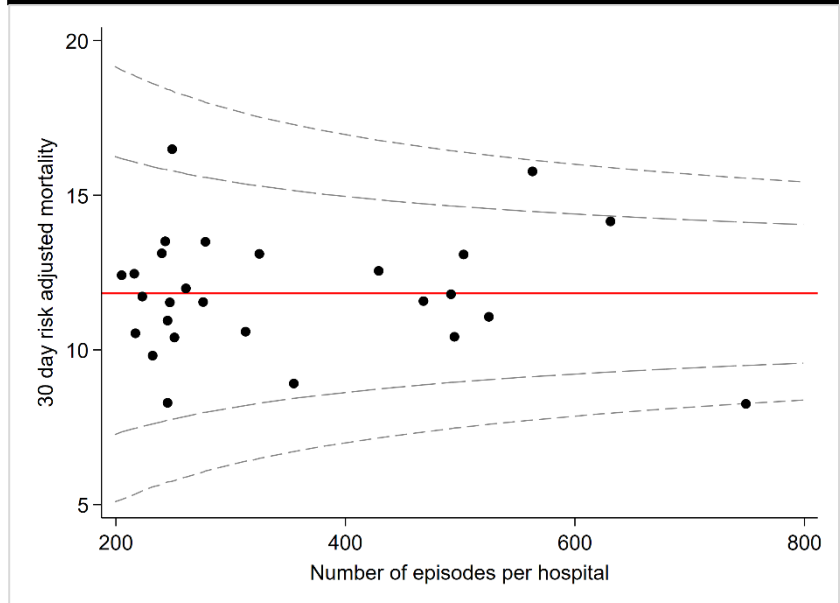


## RISK ADJUSTED MORTALITY

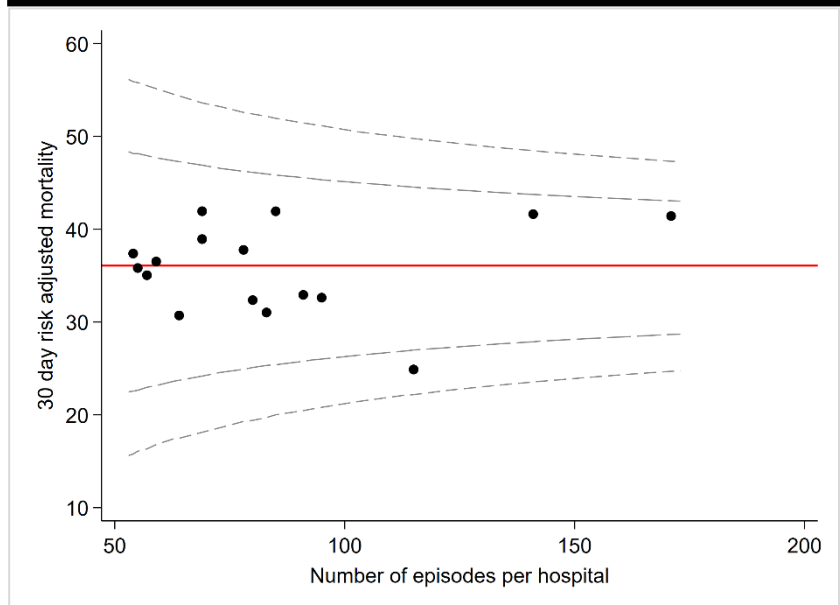
The combined 2016 and 2017 data provided evidence of some variation in mortality after stroke between hospitals (Figures 33 and 34). These estimates may be affected by data quality and confounding factors (provision of evidence-based therapies and unmeasured variables).

The models were adjusted for age, sex, stroke type, ability to walk on admission and previous history of stroke.

**FIGURE 33: RISK ADJUSTED MORTALITY AT 30 DAYS AFTER ADMISSION FOR ISCHAEMIC STROKE, BY HOSPITAL USING COMBINED 2016 AND 2017 DATA**



**FIGURE 34: RISK ADJUSTED MORTALITY AT 30 DAYS AFTER ADMISSION FOR INTRACEREBRAL HAEMORRHAGE, BY HOSPITAL USING COMBINED 2016 AND 2017 DATA**



# DATA QUALITY

A full report on the quality of the AuSCR data is available in the AuSCR 2017 Data Quality Report, which is available at <https://auscr.com.au/about/annual-reports>. The rate of hospital participation in case ascertainment was 90% with an overall ascertainment rate of 81% in 2017. A summary of missing data for variables relating to quality indicators and casemix adjustment is presented in Table 12. Overall, the majority of variables had an improved completion rate in 2017 when compared with 2016. These improvements were most evident in relation to discharge on lipid-lowering medication (8% improvement) and discharge on antithrombotic medication (7% improvement).

**TABLE 12: MISSING DATA FOR SELECTED AuSCR VARIABLES**

Variable	% missing 2017	% missing 2016
Date of birth	1%	1%
Gender	2%	0%
Type of stroke	7%	9%
Able to walk on admission	6%	9%
NIHSS score on admission	9%	11%
Treated in a stroke unit	5%	7%
Provision of thrombolysis	2%	3%
Discharged on antihypertensive medication+	6%	8%
Discharged on antithrombotic medication+	8%	15%
Discharged on lipid-lowering medication	10%	18%
Evidence of care plan on discharge if discharged to community	6%	4%
Principal diagnosis ICD-10 code	6%	4%

*Excludes registrants who opted out of the AuSCR*



# DISCUSSION

In the 2017 AuSCR Annual Report, we present information on 14184 episodes of stroke and TIA collected at 59 hospitals across five states. This is the largest annual number of episodes to be added to the AuSCR and represents an increase of 25% when compared to 2016.

Following the transition to the AuSDaT in mid-2016, the AuSCR was used to collect a wider range of quality indicators for acute stroke care in line with the clinical care standards.<sup>6</sup> The 2017 annual report represents the first full calendar year where many of these variables were collected. As outlined in the Methods section, for the 2017 dataset we have excluded a hospital's data from the analysis of process of care indicators where there was >30% missing data for the relevant variable. This approach was undertaken following the observation that a small number of hospitals were skewing the results or because some hospitals opted to not collect specific process of care variables. While the number of hospitals and episodes excluded were generally small (Table 6), readers should be aware that these exclusions may have had some impact on comparisons between the 2016 and 2017 datasets.

After the completion and implementation of all live data reports in 2017, the focus of the AuSCR office was on improving overall data quality. A range of strategies were implemented including revised data quality and case ascertainment reporting to hospitals, increased medical record audits and a series of information and training webinars. Subsequently, we saw an increase in hospital participation in case ascertainment to 90% (from 63% in 2016), accompanied by an improvement in the rate of case ascertainment to 81% (from 77% in 2016). The overall rates of missing data for individual variables also improved. The full review of data quality for the AuSCR in 2017 is available online in the 2017 AuSCR Data Quality Report at [www.auscr.com.au/about/annual-reports/](http://www.auscr.com.au/about/annual-reports/).

Despite overall reductions in the amount of missing data, some variables continue to be problematic when the proportion of 'unknown' responses are included with the missing data. For example, 66% of the cohort had a baseline NIHSS score which was listed as unknown or missing, which was still an improvement on the 73% reported in 2016. Additionally, 63% of patients receiving ECR had a pre-ECR NIHSS score missing from the dataset, although completion of post-ECR NIHSS improved with only 18% being unknown or missing. The availability of accurate stroke severity data variables can affect the accuracy of mortality analyses.<sup>10</sup> If we are to use the NIHSS score in analyses utilising casemix adjustment there needs to be a major improvement in data completeness. Completion of baseline NIHSS and pre-ECR NIHSS is also essential for assessing clinical improvements following ECR. The AuSCR office continues to work with participating hospitals to improve collection of the NIHSS.

Overall, the adherence to most quality care processes increased in 2017 when compared with 2016. The provision of hyperacute aspirin occurred in 56% of episodes (a 15% increase from 2016); provision of antithrombotics on discharge was 88% (a 22% increase from 2016); provision of lipid-lowering medication on discharge was 77% (a 30% increase from 2016); provision of antihypertensives was 73% (an 11% increase from 2016) and stroke unit care was 73% (a 4% increase from 2016). However, not all quality indicators improved in 2017, with provision of a discharge care plan remaining stable at 59% and thrombolysis provision for ischaemic stroke stable at 13%.

Although adherence to the nationally endorsed quality indicators improved overall, there continues to be wide variability amongst participating hospitals, especially in relation to stroke unit care and provision of a discharge care plan. Despite longstanding awareness of best practice in Australia, it would appear that optimal care is not always provided. In this report, and in a recent publication,<sup>8</sup> we have also shown that patients who were discharged on a weekend were significantly less likely to receive evidence-based care when compared with those discharged during the week. However, differences between hospitals in the provision of evidence-based therapies may be affected by the casemix of patients. Where unadjusted results are presented, these should be interpreted with caution despite the fact that exclusions based on the eligibility for a therapy have been applied.

The proportion for ischemic strokes receiving all three types of secondary medications increased to 55% in 2017 from 41% in 2016. However, this figure is still significantly smaller than the 69% reported in the 2017 Stroke Foundation acute care audit.<sup>13</sup>

It is essential that hospitals ensure that their patients have access to health care that facilitates optimal health outcomes. The importance of adherence to quality of care indicators is once again highlighted in 2017, where for the fourth consecutive year our casemix adjusted survival analyses illustrate the survival advantage of stroke unit care compared to non-stroke unit care.

In this report we provide a comparison of time metrics between all hospitals in Australia. We noted that door-to-brain scan times differed between some hospitals by more than two hours, which suggests that this may be an area for improvement. Delays with scans to diagnose patients may affect a patient's eligibility for time-critical therapies such as thrombolysis and ECR. Overall, the median door-to-needle time was stable at 72 minutes in 2017, and the proportion of hospitals with a median time of less than 60 minutes (gold standard objective for thrombolysis treatment) increased to 39% (a 2% increase from 2016). Door-to-needle times also varied between some hospitals by more than two hours. Time

to thrombolysis appeared to be longer when telemedicine was used than in cases where thrombolysis was provided without telemedicine. These times, however were not adjusted for patient characteristics or for the differences in the resources available within the hospitals. Therefore, this finding may reflect the difference between metropolitan hospitals and the regional hospitals where telemedicine is used. There is evidence from other studies that the availability of telemedicine improves the delivery of reperfusion therapies, including shorter times to treatment, at the hospitals where it is provided.<sup>11,12</sup>

The overall number of episodes receiving ECR also increased to a total of 597 episodes from 13 hospitals in 2017. However, two of these hospitals had greater than 30% missing data for the provision of this treatment. The AuSCR team will continue to work with these hospitals to improve data quality in 2018. Overall, the median door-to-puncture time was 54 minutes (a decrease from 119 minutes in 2016) and median door-to-recanalisation time was 112 minutes (a decrease from 190 minutes in 2016). However, these differences should be interpreted with caution given the small number of ECR cases submitted in 2016 (n=143). We look forward to the collection of a larger sample in 2018 to strengthen this information for Australia.

Historically, patients are only eligible for the AuSCR if they are admitted to hospital, which imposes some limitations on the data reported. With the advent of ECR, more patients are undergoing thrombolysis in the Emergency Department (ED), prior to transfer for other reperfusion treatment. This results in an under-reporting of thrombolysis at the transferring site, and an overestimation at the receiving site, where the compromise is to document that tPA has been provided prior to admission. This also effects calculations of door-to-needle times. For this reason, we have provided thrombolysis rates excluding transfers and have removed door-to-needle times from episodes where the patient had been transferred. In late 2017 we received funding from Boehringer Ingelheim and Ambulance Victoria to develop an ED dataset to document the care provided (including

thrombolysis) in the EDs that transfer patients to other hospitals. This approach will more comprehensively and accurately cover the patient care pathway where different treatments may have occurred at different hospitals. We look forward to working with clinicians nationally to develop this important new AuSCR dataset.

The follow-up of discharged patients at 90–180 days after admission provides a unique, but resource intensive, opportunity to determine longer-term outcome data on stroke or TIA. The 2017 response rate of 65% is slightly less than the 69% achieved in 2016, although in absolute numbers over 1400 more follow-ups were completed. Our patient reported outcome measures (PROMs) continue to be a valuable source of information related to health outcomes post-stroke. Five percent of registrants had a recurrent stroke in the 90–180 days after the index episode, and 21% were readmitted to hospital, indicating that this cohort is dealing with a range of co-morbidities, and some patients may require closer follow-up.

In other analyses of the AuSCR data linked with state health department administrative datasets, we found that readmission within one year of the index event was 42%, with only 12% of these due to stroke/TIA.<sup>14</sup> Co-morbidities and health issues other than stroke therefore constitute a significant impact on health services.

For the first time, we have presented inter-hospital comparisons of HRQoL at 90–180 days post admission. Overall variation between most hospitals was small. The identified health gap of approximately 10 points compared with normative data is

illustrative of the impact of stroke on people's lives. These health rating scores have not been adjusted for casemix differences among hospitals and are representative of survivors of stroke who completed the follow-up survey. We have also compared HRQoL between stroke types for the first time and have illustrated that patients diagnosed with ICH have the greatest impact on their HRQoL.

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.<sup>15</sup> Such programs are designed to actively support hospitals to review their data to inform clinical care improvements. The results of the 2017 AuSCR User Survey were also encouraging, with the main uses of on-demand AuSDaT data reports cited as being used in: team meetings (74%); informing quality improvement (68%) and reporting to hospital executives (58%). We look forward to the results of the STELAR project being finalised in 2019, and supporting further evidence for the role of stroke data (such as in AuSCR live reports) in improving the quality of clinical care for patients with stroke at a national level.

Overall, the AuSCR has provided compelling evidence of a continuing evidence-practice gap illustrating the potential gains that are yet to be realised in public health. These data should be used to enhance hospital services and process improvements in stroke care, in order to ensure all Australians have access to high quality care.

# REFERENCES

1. Cadilhac DA, Lannin NA, Anderson CS, et al. Protocol and pilot data for establishing the Australian Stroke Clinical Registry. *International Journal of Stroke* 2010;5:217–226.
2. Australian Commission on Safety and Quality in Health Care. *Operating Principles and Technical Standards for Australian Clinical Quality Registries*. Sydney: ACSQHC, 2008 November.
3. Evans SM, Loff B, Cameron PA. Clinical registries: the urgent need to address ethical hurdles. *Med J Aust* 2013;198:134–135.
4. Kiefe CI, Weissman NW, Allison JJ, Farmer R, Weaver M, Williams OD. Identifying achievable benchmarks of care: concepts and methodology. *International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua* 1998;10:443–447.
5. Hall RE, Khan F, Bayley MT, et al. Benchmarks for acute stroke care delivery. *International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua* 2013;25:710–718.
6. Australian Commission on Safety and Quality in Health Care. *Acute Stroke Clinical Care Standard*. Sydney: ACSQHC, 2015.
7. Spiegelhalter DJ. Funnel plots for comparing institutional performance. *Statistics in Medicine* 2005;24:1185–1202.
8. Kilkenny MF, Lannin NA, Levi C, Faux SG, Dewey HM, Grimley R, Hill K, Grabsch B, Kim J, Hand P, Crosby V, Gardner M, Rois-Gnecco J, Thijs V, Anderson CS, Donnan G, Middleton S, Cadilhac DA. Weekend hospital discharge is associated with sub-optimal care and outcomes: an observational Australian Stroke Clinical Registry study. *International Journal of Stroke* 2018 published online October 22.
9. Kind P, Dolan P, Gudex C, Williams A. Variations in population health status: results from a United Kingdom national questionnaire survey. *BMJ* 1998;316:736–741.
10. Cadilhac DA, Kilkenny MF, Levi CR, et al. Risk-adjusted hospital mortality rates for stroke: evidence from the Australian Stroke Clinical Registry (AuSCR). *The Medical Journal of Australia* 2017;206:345–350.
11. Bladin CF, Cadilhac DA. Effect of telestroke on emergent stroke care and stroke outcomes. *Stroke* 2014;45:1876–1880.
12. Bagot KL, Cadilhac DA, Kim J, et al. Transitioning from a single-site pilot project to a state-wide regional telehealth service: The experience from the Victorian Stroke Telemedicine programme. *Journal of telemedicine and telecare* 2017;23:850–855.
13. Stroke Foundation. *National Stroke Audit Acute Services Report*. Melbourne, Australia 2017.
14. Kilkenny MF, Dewey HM, Sundararajan V, et al. Readmissions after stroke: linked data from the Australian Stroke Clinical Registry and hospital databases. *The Medical Journal of Australia* 2015;203:102–106.
15. Cadilhac DA, Andrew NE, Salama ES, et al. Improving discharge care: the potential of a new organisational intervention to improve discharge after hospitalisation for acute stroke, a controlled before–after pilot study. *BMJ open* 2017;7:e016010.

# 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](http://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 2017. 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. In addition, a new partnership with the Agency for Clinical Innovation in New South Wales is highly valued.

Collaborations are continuing with staff from the Australian Institute of Health and Welfare, the Population Health Research Network and data linkage units based in health departments within various states (VIC, WA, QLD and NSW) to work through the processes to enable the linking of the AuSCR data with government data such as the NDI and state level admitted episode datasets and emergency department admissions.

In VIC, 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.

In May 2017, we were supported by Amgen and Shire 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 2017

Prof Sandy Middleton (Chair)	Director, Nursing Research Institute, St Vincent's Health Australia (Sydney) & Australian Catholic University [NSW]
Prof Craig Anderson	Executive Director, The George Institute, China & Professor of Neurology and Epidemiology, Faculty of Medicine, UNSW Sydney [NSW]
Ms Toni Aslett	Executive Director, Stroke Services, Stroke Foundation [VIC]
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]
Mr Greg Cadigan	Project Manager, Queensland Statewide Stroke Clinical Network [QLD]
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 Helen Castley	Neurologist, Royal Hobart Hospital & Co-chair, Clinical Advisory Group (Neurology & Stroke) [TAS]
Prof Geoffrey Donnan	Director, Florey Institute of Neuroscience and Mental Health [VIC]
Dr Andrew Evans	Geriatrician & Stroke Physician, Westmead Hospital [NSW]
Dr Rohan Grimley	Conjoint Senior Lecturer Sunshine Coast Clinical School & Chair, Queensland State-wide Stroke Clinical Network [QLD]
A/Prof Peter Hand	Neurologist, Royal Melbourne Hospital & Clinical Lead, Victorian Stroke Clinical Network [VIC]
A/Prof Susan Hillier	Dean, Research (and Research Education), Division of Health Sciences, University of South Australia [SA]
Prof Richard Lindley	Professorial Fellow, The George Institute for Global Health & Professor of Geriatric Medicine, Sydney Medical School, University of Sydney [NSW]
A/Prof Mark Mackay	Paediatric Neurologist, Royal Children's Hospital, Melbourne [VIC]
Prof John McNeil	Head, Department of Epidemiology and Preventive Medicine, Monash University [VIC]
A/Prof Michael Pollack	Chair, Hunter Stroke Service [NSW]
Mr Mark Simcocks	Consumer Representative, Self-employed [VIC]
Ms Frances Simmonds	Director, Australasian Rehabilitation Outcomes Centre, University of Wollongong [NSW]
Prof Amanda Thrift	Head, Epidemiology and Prevention Division, Stroke and Ageing Research, Monash University [VIC]
Dr Andrew Wesseldine	Geriatrician and Stroke Physician, St John of God Subiaco & State Stroke Director [WA]

## APPENDIX B (CONTINUED): COMMITTEE MEMBERSHIP

### AuSCR Management Committee membership 2017

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, La Trobe University, & Head of Occupational Therapy Research, Alfred Health [VIC]
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]
Prof Helen Dewey	Director of Neurosciences, Eastern Health & Professor, Eastern Health Clinical School, Monash University [VIC]
Prof Geoffrey Donnan	Director, Florey Institute of Neuroscience and Mental Health [VIC]
A/Prof Steven Faux	Director, Rehabilitation Unit, St Vincent's Hospital, Sydney [NSW]
Dr Rohan Grimley	Conjoint Senior Lecturer, Sunshine Coast Clinical School & Clinical Chair, Queensland Statewide Stroke Clinical Network [QLD]
A/Prof Peter Hand	Neurologist, Royal Melbourne Hospital & Clinical Lead, Victorian Stroke Clinical Network [VIC]
Mr Kelvin Hill	National Manager, Clinical Services, Stroke Foundation [VIC] (On leave in 2017; proxy Justine Watkins)
Prof Chris Levi	Director of Clinical Research and Translation - Research Innovation and Partnerships & Co-Director of Acute Stroke Services, John Hunter Hospital [NSW]

## APPENDIX B (CONTINUED): COMMITTEE MEMBERSHIP

### AuSCR Research Task Group membership 2017

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 Richard Lindley (Co-Chair)	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]
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]

### AuSCR Reperfusion and Telemedicine Subcommittee membership 2017

A/Prof Bruce Campbell (Co-Chair)	Head, Hyperacute Stroke, Royal Melbourne Hospital [VIC]
Prof Peter Mitchell (Co-Chair)	Head, Statewide Endovascular Clot Retrieval Service [VIC]
A/Prof Peter Hand	Neurologist, Royal Melbourne Hospital [VIC]
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]
Prof Bernard Yan	Neurointerventionist and Neurologist, Royal Melbourne Hospital [VIC]
A/Prof 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 2017

In 2017, the AuSCR Office was supported by funding and in-kind support from the following sources:

- The Florey
- Industry partners
- A joint initiative with the Stroke Foundation funded by Queensland Health
- The VSCN
- The Agency for Clinical Innovation in New South Wales
- 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
- The Stroke Foundation provided in-kind support in collating and mailing out follow-up surveys in the first quarter of 2017
- Smart Strokes 2017 Conference organising committee generously subsidised 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’

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 Governments	\$889,741
The Florey	\$45,008
Monash University*	\$55,570
Non-government organisations	\$67,750
Industry	\$55,000
Hospital opt-in payment	\$17,000
Consumer donations	\$0
Other**	\$53,415
<b>TOTAL</b>	<b>\$1,183,485</b>

\* 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

## Ongoing contribution to the AuSCR

We gratefully acknowledge contributions made by:

- The AuSCR staff at the Florey Institute of Neuroscience and Mental Health (The Florey): Julie Morrison, Emma Tod, Natalie Wilson, Jo Maxwell, Kate Paice, Karen Barclay-Moss, Jot Ghuliani, Helen Carter, Adele Gibbs, Perrin Date, Violet Marion and Brenda Grabsch;
- The epidemiologists from the Stroke and Ageing Research Centre, School of Clinical Sciences, Monash University: Drs Joosup Kim, Monique Kilkenny and Nadine Andrew;
- Professor Leonid Churilov (The Florey) for expert statistical advice;
- The Florey Information Technology team in supporting the AuSCR server hosting and other technical processes;
- The VSCN, through State Government VIC, for generous financial support of the AuSCR operations in VIC;
- QLD Health for support of the AuSCR in QLD via a joint project (QLD Stroke Quality Improvement Program [QSQIP]) with the Stroke Foundation;
- The Agency for Clinical Innovation through State Government of NSW for the generous support of AuSCR operations in NSW;
- The Stroke Foundation for providing AuSCR registrants with stroke information packages to registrants requesting additional information at the 90–180 day follow-up;
- The Australian Institute of Health and Welfare for their role in linking the AuSCR data to the National Death Index.

## Contribution to annual report

### *The Florey AuSCR Office*

Dr Sibilah Breen, the AuSCR National Coordinator, 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*

Drs 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 2017. 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 Professor Dominique Cadilhac using de-identified data supplied securely by Sam Shehata. Dr Monique Kilkenny was responsible for establishing the methodology for the analysis of the risk adjusted mortality rate data (in consultation with Professor Leonid Churilov from The Florey). Dr Nadine Andrew was responsible for establishing the AuSCR clinical performance benchmarks.

## APPENDIX D (CONTINUED): ACKNOWLEDGEMENTS

This report would not have been possible without the efforts of doctors, nurses, ward clerks and other staff from participating hospitals who have contributed data to the AuSCR. Lead clinical staff for the AuSCR in 2017 and participating hospitals are gratefully acknowledged below.

### **New South Wales**

Kate Crossley  
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Christopher Levi  
Katherine Mohr  
Stephen Moore  
Debra Sloane  
Jody Vaipulu  
Rhonda Walker

### **South Australia**

Michelle Bronca  
Lizzie Dodd  
Timothy Kleinig  
Matthew Willcourt  
Anthea Worley

### **Tasmania**

Brad Birleson  
Deirdre Broadby  
Helen Castley  
Carolyn Harrison  
Maxine Munting  
Dinesh Tryambake  
Annette Viney

### **Queensland**

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Haylee Berrill  
Elise Bertram  
Raewyn Beu  
Pauline Blaney  
Jonnel Boco  
Dijana Cukanovic-Krebs  
Paula Easton  
Linda Edwards  
Nisal Gange  
Michele Gardner  
Richard Geraghty  
Rohan Grimley  
Nicola Hall  
Anne Hooper  
Tara Hormann  
Joel Iedema  
Katherine Jaques  
Casey Jenkins  
Caitlin Kearney  
Alex Lau  
Donna Leary  
Nick Lown  
Marie McCaig  
Mark Parry  
Troy Reidy  
Timothy Richardson  
Juan Rois Gnecco  
Linda Roper  
Donna Rowley  
Noel Saines  
Amanda Siller  
Darshan Shah  
Betzy Shaju  
Rebecca Sjodin  
Melinda Spring  
Christopher Staples  
Jien-Mae Tan  
Leanne Whiley  
Richard White  
Rayelene Williams  
Andrew Wong  
Jerry Wong

### **Victoria**

Lauren Arthurson  
Stine Barnett  
Donna Brown  
Melanie Brown  
Ernie Butler  
Carla Borg Caruana  
Anna Clissold  
Ben Clissold  
Jo Cotterell  
Bronwyn Coulton  
Tessa Coupland  
Douglas Crompton  
Vanessa Crosby  
Bronwyn Daymond  
Helen Dewey  
Libby Fifis  
Brett Forge  
Tanya Frost  
Patrick Groot  
Kushantha Gunarathne  
Casey Hair  
Peter Hand  
Jason Hay  
Jonelle Hill-Uebergang  
Jarrod Hunter  
Thomas Kraemer  
Kanaga Lagma  
Jodi Lynch  
Henry Ma  
Mark Mackay  
Lyn Malone  
Krishna Mandaleson  
Janet May  
Emma Mollo  
Nerylee Morris  
Ashley Murray  
Maree O'Connor  
Lauren Pesavento  
Justin Rabl  
Anne Rodda  
David Rosaia  
Kristen Rowe  
Eloise Ryan

Lauren Sanders  
Patrick Scarff  
Heather Smith  
Louise Starkie  
Julie Stevens  
Margaret Stevenson  
Belinda Stojanovski  
Denbi-lee Thomson  
Vincent Thijs  
Lyndsay Trehwella  
Jessica Tsoleridis  
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Alexandra Warwick  
Sanath Weerakkody  
Tissa Wijeratne  
Jamie Zanon  
Jorge Zavala

## APPENDIX D (CONTINUED): ACKNOWLEDGEMENTS

### Participating hospitals

#### *New South Wales*

Dubbo Base  
John Hunter  
Lismore Base  
Wagga Wagga Rural Referral

#### *South Australia*

Flinders Medical Centre  
Lyell McEwin  
Royal Adelaide

#### *Tasmania*

Launceston General  
North West Health  
Royal Hobart

#### *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  
Sunshine Coast University  
Toowoomba  
Townsville  
Wesley

#### *Victoria*

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

# APPENDIX E: PUBLICATIONS AND PRESENTATIONS

## Journal Publications

Cadilhac, D. A., Andrew, N. E., Lannin, N. A., Middleton, S., Levi, C. R., Dewey, H. M., ... Anderson, C. S. (2017). Quality of Acute Care and Long-Term Quality of Life and Survival: The Australian Stroke Clinical Registry. *Stroke*. <https://doi.org/10.1161/STROKEAHA.116.015714>

Cadilhac, D. A., Andrew, N. E., Stroil Salama, E., Hill, K., Middleton, S., Horton, E., ... Grimley, R. (2017). Improving discharge care: The potential of a new organisational intervention to improve discharge after hospitalisation for acute stroke, a controlled before-after pilot study. *BMJ Open*. <https://doi.org/10.1136/bmjopen-2017-016010>

Cadilhac, D. A., Kilkenny, M. F., Andrew, N. E., Ritchie, E., Hill, K., & Lalor, E. (2017). Hospitals admitting at least 100 patients with stroke a year should have a stroke unit: a case study from Australia. *BMC Health Services Research*. <https://doi.org/10.1186/s12913-017-2150-2>

Cadilhac, D. A., Kilkenny, M. F., Levi, C. R., Lannin, N. A., Thrift, A. G., Kim, J., ... Anderson, C. S. (2017). Risk-Adjusted hospital mortality rates for stroke: Evidence from the Australian Stroke Clinical Registry (AuSCR). *Medical Journal of Australia*. [https://www.mja.com.au/system/files/2017-08/10.5694mja16.00525\\_0.pdf](https://www.mja.com.au/system/files/2017-08/10.5694mja16.00525_0.pdf)

Chapman, C., Morgan, P., Purvis, T., Cadilhac, D., & Andrew, N. (2017). Risk factors for the development of chest infections in acute stroke: A systematic review. *International Journal of Stroke*. <https://doi.org/10.1177/1747493017720548>

Craig, L. E., Taylor, N., Grimley, R., Cadilhac, D. A., McInnes, E., Phillips, R., ... Middleton, S. (2017). Development of a theory-informed implementation intervention to improve the triage, treatment and transfer of stroke patients in emergency departments using the Theoretical Domains Framework (TDF): The T3Trial. *Implementation Science*. <https://doi.org/10.1186/s13012-017-0616-6>

Kim, J., Andrew, N. E., Thrift, A. G., Bernhardt, J., Lindley, R. I., & Cadilhac, D. A. (2017). The potential health and economic impact of improving stroke care standards for Australia. *International Journal of Stroke*. <https://doi.org/10.1177/1747493017700662>

Kim, J., Lannin, N., Kilkenny, M., Anderson, C., Thrift, A., Moss, K., ... Cadilhac, D. (2017). Health-related quality of life of working-age adults in the Australian Stroke Clinical Registry. *International Journal of Stroke*. <https://doi.org/10.1177/1747493017720548>

Lynch, E. A., Cadilhac, D. A., Luker, J. A., & Hillier, S. L. (2017). Inequities in access to inpatient rehabilitation after stroke: An international scoping review. *Topics in Stroke Rehabilitation*. <https://doi.org/10.1080/10749357.2017.1366010>

Olaiya, M. T., Cadilhac, D. A., Kim, J., Nelson, M. R., Srikanth, V. K., Andrew, N. E., ... Thrift, A. G. (2017). Long-term unmet needs and associated factors in stroke or TIA survivors. *Neurology*. <https://doi.org/10.1212/WNL.0000000000004063>

Olaiya, M. T., Cadilhac, D. A., Kim, J., Ung, D., Nelson, M. R., Srikanth, V. K., ... Thrift, A. G. (2017). Effectiveness of an Intervention to Improve Risk Factor Knowledge in Patients with Stroke. *Stroke*. <https://doi.org/10.1161/STROKEAHA.116.016229>

Purvis, T., Moss, K., Francis, L., Borschmann, K., Kilkenny, M. F., Denisenko, S., ... Cadilhac, D. A. (2017). Benefits of clinical facilitators on improving stroke care in acute hospitals: a new programme for Australia. *Internal Medicine Journal*. <https://doi.org/10.1111/imj.13458>

Gall, S., Phan, H., Blizzard, L., Thrift, A., Anderson, C., Kim, J., Lannin, N., Cadilhac, D. Women and stroke poorer quality of life at 3–6 months after stroke in women compared to men is due to age and severity but not clinical care. *European Stroke Journal* 2017; 2(1S):66

## Annual Report Publication

Cadilhac DA, Lannin NA, Kim J, Anderson CS, Andrew N, Kilkenny M, Shehata S, Breen 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 2016. The Florey Institute of Neuroscience and Mental Health; December 2017, Report No 8, 53 pages.

## Presentations and posters

Kim, J., Lannin, N., Kilkenny, M., Anderson, C., Thrift, A., Moss, K., ... Cadilhac, D. (2017). Health-related quality of life of working-age adults in the Australian Stroke Clinical Registry. *International Journal of Stroke*, Vol. 12(3S):p10

Godecke, E., Armstrong, E., Middleton, S., Ciccone, N., Rai, T., Holland, A., ... Bernhardt, J. (2017). Therapy fidelity and trial progress in the Very Early Rehabilitation in SpEEch (VERSE) trial. *International Journal of Stroke*, Vol. 12(3S):p14

Cadilhac, D., Kilkenny, M., Andrew, N., Dewey, H., Flack, F., Boyd, J., ... S., Sundararajan, V. (2017). Pre-stroke hospital admissions for intracerebral haemorrhage: linked AuSCR registry and national hospital data. *International Journal of Stroke*, Vol. 12(3S):p16

Kilkenny, M., Sundararajan, V., Levi, C., Thrift, A., Churilov, L., Andrew, N., ... Cadilhac, D. (2017). Stroke severity is an important covariate to explain variability in stroke risk-adjusted mortality rates: linked AuSCR registry and national hospital data. *International Journal of Stroke*, Vol. 12(3S):p16

Thayabaranathan, T., Andrew, N., Kilkenny, M., Stolwyk, R., Thrift, A., Grimley, R., ... Cadilhac, D. (2017). Is self-reported anxiety or depression between 90–180 days post-stroke associated with patient factors or quality of acute care received? *International Journal of Stroke*, Vol. 12(3S):p23

Kilkenny, M., Sundararajan, V., Kim, J., Andrew, N., Dewey, H., Chen, Y., Johnston, T., Katzenellenbogen, J., Flack, F., Boyd, J., Grabsch, B., Gattellari, M., Thrift, A., Lannin, N., Middleton, S., Cadilhac, D. (2017). Larger comorbidity and risk factor burden before stroke is associated with readmissions: linked AuSCR registry and national hospital data. *International Journal of Stroke*, Vol. 12(3S):p29

Phan, H., Cadilhac, D., Blizzard, L., Lannin, N., Thrift, A., Anderson, C., ... Gall, S. Differences in stroke care and outcomes after stroke for women compared to men: Australian Stroke Clinical Registry (AuSCR). (2017). *International Journal of Stroke*, Vol. 12(3S):p30

Chapman, C., Andrew, N., Morgan, P., Kilkenny, M., Grimley, R., Sundararajan, V., ... Cadilhac, D. (2017). Factors associated with development of a chest infection within 30 Days of acute stroke. (2017). *International Journal of Stroke*, Vol. 12(3S):p39

Cadilhac, D., Andrew, N., Joosup, K., Grabsch, B., Kilkenny, M., Shehata, ... Lannin, N. (2017). Are we providing patients with the best achievable care? Update from the Australian Stroke Clinical Registry. *International Journal of Stroke*, Vol. 12(2S):p4.

Purvis, T., Kilkenny, M., Middleton, S., Cadilhac, D. (2017). Do stroke coordinators influence the delivery of acute care and hospital based patient outcomes? *International Journal of Stroke*, Vol. 12(2S):p10.

Middleton, S., Levi, C., Dale, S., Cheung, N., McInnes, E., Considine, ... M., Ward, J. (2017). The T3 Trial: triage, treatment and transfer of patients with stroke in emergency departments. *European Stroke Journal*, 2(1S):490 [Poster]

Cadilhac, D., Kilkenny, M., Grimley, R., Sundararajan, V., Johnston, T., Grabsch, B., ... Andrew, N. (2017). Pre-stroke hospital contacts for patients with intracerebral haemorrhage: an observational study using linked Australian Stroke Clinical Registry and hospital data from Queensland. *European Stroke Journal*, 2(1S):282 [Poster]

Andrew, N., Kilkenny, M., Sundararajan, V., Kim, J., Thrift, A., Johnston, T., Grimley, R., Cadilhac, D. (2017). Changes in hospital usage in the first year following acute stroke. *European Stroke Journal*, 2(1S):406 [Poster]

Kilkenny, M., Andrew, N., Grimley, R., Sundararajan, V., Johnston, T., Lannin, N., ... Cadilhac, D. (2017). Does linking the Australian Stroke Clinical Registry with admissions data provide a better explanation of variability in stroke risk-adjusted mortality rates? *European Stroke Journal*, 2:442

# APPENDIX F: APPLICATIONS TO THE AUSCR RESEARCH TASK GROUP

In 2017, there were three external applications reviewed by the Research Task Group:

- An investigator-initiated, prospective, feasibility study to describe the occurrence of Fabry disease in people, aged 18 to 55 years, living with stroke in the community in Australia (PI: Prof Craig Anderson; AIs: Assoc. Prof Dominique Cadilhac, Prof. Vincent Thijs, Ms Brenda Grabsch, Ms Joyce Lim, and Dr Alejandra Malavera; The George Institute).
- Identifying gaps and inequalities in access to General Practitioner coordinated care for survivors of stroke (PI: Nadine Andrew; AIs: Assoc. Prof Dominique Cadilhac, Prof Amanda Thrift, Assoc. Prof Vijaya Sundararajan; Monash University).
- Healthy living after stroke: An online intervention for improving stroke survivor health behaviours and quality of life (PI: Professor Billie Bonevski; AIs: Assoc Prof Andrew Searles, Prof Chris Levi, Prof Neil Spratt, Prof Amanda Baker, Prof Parker Magin, Dr Alyna Turner, Assoc Prof Michael Pollack, Prof Clare Collins, Prof Robin Callister, Dr Ashleigh Guillaumier, Dr Christopher Oldmeadow, Miss Alexandra Denham; University of Newcastle).



# APPENDIX G: ABBREVIATIONS

ABC™	Achievable benchmarks of care
AF	Atrial fibrillation
APF	Adjusted performance fraction
ARIA	Accessibility/Remoteness Index of Australia
ASC	Australian Stroke Coalition
AuSCR	Australian Stroke Clinical Registry
AuSDaT	Australian Stroke Data Tool
DVT	Deep vein thrombosis
ECR	Endovascular clot retrieval
ED	Emergency Department
EQ-5D-3L™	European Quality of Life - five dimension three level instrument
eTICI	expanded Thrombolysis In Central Infarction
HRQoL	Health-related quality of life
ICD-10	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
PE	Pulmonary embolism
PROMs	Patient reported outcome measures
RAMR	Risk-adjusted mortality rate
SD	Standard deviation
SSA	Stroke Society of Australasia
STELAR	Shared Team Efforts Leading to Adherence Results
TIA	Transient ischaemic attack
tPA	Tissue plasminogen activator
UTI	Urinary tract infection
VAS	Visual Analogue Scale
VSCN	Victorian Stroke Clinical Network
VST	Victorian Stroke Telemedicine

