ANNUAL REPORT 2015

AuSCR

Australian Stroke Clinical Registry

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EXECUTIVE SUMMARY

On behalf of the AuSCR Consortium, we would like to draw your attention to some significant findings from the 2015 Annual Report of the Australian Stroke Clinical Registry (AuSCR).

- In 2015, 40 hospitals contributed data to the Australian Stroke Clinical Registry (AuSCR) (53% from Queensland and 40% from Victoria). In this report, information on 9053 patients with 9473 admissions for acute stroke or transient ischaemic attack (TIA) admitted to the participating hospitals is presented.
- Achievable benchmarks from the top performing hospitals in the AuSCR are provided as performance targets. **Important care gaps between the overall average performance and the benchmarks were noted and range from 7% (for the provision of thrombolysis) to 33% (for the provision of discharge care plans).** Hospital staff can use these data to review why underperformance may be an issue at their hospital and to determine whether changes can be implemented to the quality of care, where applicable.
- Several hospitals were outside the control limits for key performance outcome measures. The least variability was found for the provision of antihypertensive medication, where only two hospitals were observed to perform poorly in comparison to their peers in 2015.
- In 2015, 1455 (16%) of the registrants died within 90 days of their hospital admission.
- On average, 80% of the patients were managed in stroke units during 2015, but the **best performing hospitals were able to achieve 96% as the benchmark thereby ensuring better outcomes for their patients.** Using case-mix adjusted analyses, **we found that patients who were treated in a stroke unit had a 10 point greater self-rated health at 90 to 180 days after admission when compared to patients not treated in stroke units.**
- Patient reported outcome measures (also known as *PROMs)* provide important information about recovery after stroke from the perspective of patients or their primary caregivers. Among 5938 eligible registered episodes within 180 days of stroke, we were able to follow up 4342 using survey methods or from obtaining information about deaths (73%; the same as in 2014).
- In 2015, planning for the AuSCR to transition to a new integrated data management system was continued in collaboration with the Stroke Foundation and the Australian Stroke Coalition.
- Greater impetus to use the AuSCR has been supported by broader national policy initiatives including the publication of the *Australian Acute Stroke Clinical Care Standard* by the Australian Commission on Safety and Quality in Health Care in June 2015.
- In 2015 the NHMRC funded Stroke123 project concluded. The legacy of the Stroke123 Partnership project is significant for the AuSCR in that it provided the impetus for upscale and spread of the registry (from 16 hospitals to 58 with ethics approval), advancements in analytic methodology and data linkage, as well as more sustainable streams of future funding, albeit time-limited, from government.
- Overall, the AuSCR has grown in size but there are still challenges for hospitals in resourcing data collection alongside the provision of clinical care. With the advent of the new *Acute Stroke Clinical Care Standard* and the forthcoming new edition of the clinical guidelines (scheduled for release in 2017), we hope that quality assurance will be reinforced as a key process in ensuring unwarranted variations in clinical care between hospitals are eliminated.

GOVERNANCE REPORT

The Australian Stroke Clinical Registry (AuSCR) 2015 Annual Report represents the 7th annual report for this clinical quality registry. The AuSCR continues to operate under the data custodianship of the Florey Institute of Neuroscience and Mental Health (The Florey). We are grateful to The Florey, as well as all members of the Steering Committee, Management Committee and Research Task Group, for their voluntary contributions to the ongoing development and support of the Registry (see Appendices A, B and C for further details on governance, membership lists and funding respectively).

In 2015 the project team and members of the governance committees have been working on one of the most significant changes in the history of the AuSCR, the move to the new integrated data management system - the Australian Stroke Data Tool (AuSDaT). This integrated data management system, that is auspiced by the Australian Stroke Coalition (ASC), and funded by the Stroke Foundation and the Florey, will allow a single portal for collecting standardised data across multiple

stroke programs. The AuSDaT was used for the first time in 2015 to conduct the Stroke Foundation acute audit and the AuSCR data migration occurred in mid-2016. We look forward to presenting the outcomes of the evolution of the registry in the coming years.

To ensure that the AuSCR data continue to inform quality improvement we have provided updated achievable benchmarks derived from the top performing hospitals. This work supplements the standard reporting of national average performance, and highlights what is possible to achieve. The launch of the Acute Stroke Clinical Care Standard in June 2015 serves as a timely reminder of the importance of delivering evidence-based care in order to achieve optimal patient outcomes.

We do recognise that there can be hospital-level barriers to ongoing data collection, in particular related to hospital resources, and a number of hospitals have had to cease data collection from time to time. However we are hopeful that the importance of the systematic approach to quality assurance in the AuSCR, as exemplified by the data and analyses presented in this report, will continue to be recognised, appreciated and supported.

Once again we express our appreciation to the Stroke Foundation for its critical role in the follow-up mail out processes. We also acknowledge the sustained efforts of the AuSCR Office staff and the epidemiologists from the Stroke and Ageing Research Centre, School of Clinical Sciences, Monash University and, as required, Prof Leonid Churilov (Head of Statistics, The Florey). Last, but not least, we thank the hospital staff who contribute to the AuSCR, as well as the patients and their carers without whom the registry could not exist (see Appendix D for acknowledgements).

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(Chair, Steering Committee)
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INTRODUCTION

The AuSCR was established in 2009 to provide national data on patients admitted to hospital with acute stroke or transient ischaemic attack (TIA).[1] Further information about the AuSCR and its development is available on its public website at http://www.auscr.com.au, and in our publications (See Appendix E for a full list of publications and presentations for 2015).

The overall goal of the AuSCR is to provide reliable and representative national data on care in acute hospitals and patient outcome to inform improvements to the health system.[1] Fundamental to this aim is the registration of all patients with stroke or TIA admitted to the participating hospitals. The cumulative data available from the AuSCR also permit investigation, of relevance to Australian policy and planning, of a range of epidemiological or health services issues in large numbers of people, or in those with certain characteristics, which might otherwise have not been possible. (See Appendix F for a list of the 2015 applications to the AuSCR Research Task Group for 2015.)

The AuSCR adheres to the national guidelines for best-practice in clinical quality registries.[2] The registry is used in public and private hospitals and both adult and paediatric cases are included. All participating hospitals are required to have ethics approval. As recommended for national registries,[3] an 'opt-out' model is used or waiver for people who die while in hospital. This approach is also described in the 2015 updated version of the National Statement on Ethical Conduct in Human Research.[4]

In the AuSCR, data are collected on the provision of evidence-based therapies, supplemented with clinical and demographic information on patients, in order to provide an indication of the quality of acute stroke care received (see Box 1 for the AuSCR minimum data set). The indicators for the AuSCR were selected using a consultative process, which included consumers, medical doctors, administrators and researchers.[1] Collectively, the indicators form a minimum, nationally agreed 'care bundle' for patients with acute stroke in Australia and provide an overall measure of care quality. Additional quality indicators are collected in Queensland to permit historical comparisons, following Queensland's increased AuSCR uptake in 2012. Staff from participating hospitals enter these data on all eligible patients either manually via the web tool, or 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 their hospital performance. Patient outcomes are ascertained with a questionnaire at a follow-up 90 to 180 days after admission, which includes age-appropriate questionnaires for children.

The AuSCR Office staff, with the assistance of the Stroke Foundation, are responsible for contacting patients at 90 to 180 days after their stroke as long as they are known to be alive, have not refused follow-up at the outset or 'opted-out' of the registry. For registrants who are unable to be contacted, survival status is determined using annual data linkage with the National Death Index (NDI) data made available, through an ethically approved process, by the Australian Institute of Health and Welfare (AIHW).

The AuSCR Office staff also provide: five day helpdesk support for registrants; assistance to hospital staff with completing ethics applications; amendments and annual ethics progress reporting; training for new staff; quality control assessments to ensure hospital data are reliably obtained; and coordination of the committee meetings necessary for the governance of the AuSCR.

In 2015, the major sources of funding for the registry were: an NHMRC Partnership grant (Stroke123) that concluded this year after four years; the Victorian government; the Stroke Foundation; and Queensland Health (see Appendix C). The legacy of the Stroke123 Partnership project is significant in that it provided the impetus for upscale and spread of the registry, advancements in analytic methodology and data linkage, as well as more sustainable streams of future funding, albeit time-limited, from government.

BOX 1: THE AUSCR MINIMUM VARIABLE DATA SET USED IN 2015

IDENTIFYING INFORMATION

- date of birth
- sex
- address
- telephone number
- hospital name
- contact details for: next of kin (x 2); general practitioner

CLINICAL INFORMATION FOR RISK ADJUSTMENT AND MEASURING TIMELINESS OF CARE DELIVERY

- ICD10 codes (diagnosis, medical condition, complications and procedures)
- country of birth
- language spoken
- aboriginal and Torres Strait Islander status
- type of stroke
- date and time of stroke onset
- date and time of arrival to emergency department
- date and time of admission and inpatient stroke status
- transferred from another hospital status
- ability to walk independently on admission
- first-ever (incident) episode status

PROCESS INDICATORS OF EVIDENCE-BASED CARE

- use of intravenous thrombolysis (tPA) if an ischaemic stroke
- access to a stroke unit (geographically defined ward area)
- discharged on an antihypertensive agent
- care plan provided at discharge (any documentation in the medical record)

PROCESS INDICATORS OF EVIDENCE-BASED CARE (QLD ONLY)

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

HOSPITAL OUTCOMES DATA

- date of discharge, or
- date of death
- discharge destination

90 TO 180 DAY OUTCOME DATA

- survivor status
- place of residence
- living alone status
- recurrent stroke episodes since discharge
- readmission to hospital
- modified Rankin Scale
- quality of life (EuroQoL-5D™ adults/ PedsQoL children up to 18 years old)

INTRODUCTION CONT'D

METHODS FOR ENSURING DATA QUALITY

The online AuSCR database has built-in logic checks and variable limits to reduce the likelihood of inaccurate data being entered. Mandatory fields have also been created to reduce missing data. Inbuilt functions within the database are used to identify duplicate entries and multiple patient records, which may be merged if necessary (for example, if a patient had more than one admission in the same or different hospitals). Data quality in the AuSCR is assessed via missing and discrepant data reports which are sent to hospitals by the AuSCR Office staff.

Each new hospital is also subjected to a 10% random audit of medical records conducted by the AuSCR Office staff after approximately 50 patients are entered in the registry or approximately every two years thereafter. Following the audit, the hospital is given a data quality report and suggested ways of improving data quality are discussed. Additional training or amendments to data dictionary items to improve consistency in recording variables is also undertaken, as required.

At the end of the 2015 data collection period, hospitals were requested to provide a list of all admissions based on the selected ICD10 principal diagnosis codes related to stroke to enable a process of assessing case ascertainment by matching this list from each hospital to the episode data they submitted in the AuSCR. This process also permits missing data in the AuSCR for ICD10 codes to be obtained.

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

OVERVIEW OF DATA ANALYSIS METHODS

The data presented in this report include information on patients admitted to the participating hospitals between 1 January and 31 December, 2015. Data entry for these acute stroke/TIA episodes, as well as the associated follow-up assessment of registrants, was closed off on 1 August 2016 and the data were extracted on the same day.

For the purpose of data cleaning, duplicate data were checked by the AuSCR Data Manager using the registrants' 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 de-identified raw data were extracted. A second level of data checking was then performed by the Monash University analytic staff. Statistical analyses were performed using STATA software (Version 12.1 for Windows, Stata Corporation PL).

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

Hospital postcodes were mapped to the Accessibility/Remoteness Index for Australia 2011 (ARIA+) available from the Australian Bureau of Statistics (see http://www.spatialonline.com.au/ARIA_2011/). The ARIA+ is used to calculate remoteness and accessibility, based on road distance, to 'service centres' (defined as populated localities where the population is greater than 1,000 persons, of which there are 201). For this report ARIA+ Category 1 was defined as a major city and ARIA+ Categories 2 and 3 were combined to indicate a regional location. Paediatric cases were

not included in the overall patient characteristics, clinical and outcome data analyses and are presented separately.

Benchmarks for the four AuSCR national indicators were calculated based on a modified version of the Achievable Benchmark of Care (ABC™) methodology[5] which has been used and validated by Hall et al, 2013.[6] Only hospitals that had contributed data to the AuSCR for more than six months, and had submitted at least 50 cases, were eligible for inclusion. An Adjusted Performance Fraction (APF) score was calculated for each hospital for each of the four indicators. This approach allowed adjustment for under or over inflation due to small numbers present at some hospitals. The benchmarks were calculated as the mean APF scores of the top performing hospitals that represented at least 15% of the sample of eligible patients. We also report national averages and adherence achieved by the top ranked hospitals from the sample of hospitals that had registered at least 50 episodes of care.

Unless otherwise stipulated, the follow-up data were analysed using descriptive statistics and multi-variable logistic regression, with adjustment for patient casemix using age, sex, stroke type, ability to walk on admission, inpatient stroke or patient transferred from another hospital as appropriate. Except for Victoria, each individual patient is only followed up once, based on their first registered episode of care. In addition, the registrants were required to have their data entered in the AuSCR within 180 days of the index stroke onset in order to be eligible for follow-up.

Casemix adjusted survival analysis for deaths up to 180 days following admission was performed for those who had experienced an episode of care in 2015. It was possible to undertake these analyses for the whole registrant cohort since we had access to NDI data. Cox proportional-hazards regression comparing survival status for those who did and did not receive stroke unit care, adjusted for age, gender, 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 EuroQol-5D (EQ-5D™) instrument. The EQ-5D is a standardised instrument for use as a measure of health outcome (see http://www.euroqol.org/). It provides a simple descriptive profile across five dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Each of these profiles is divided into three levels: no problems (1), some or moderate problems (2) and extreme problems (3). In addition, the EQ-5D 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.

Index-based values ('utilities') for the EQ-5D can also be reported using health values derived using Discrete Choice Experiment (DCE) methods.[7] The advantage of reporting the utility scores is that it enables death data to be incorporated into the values and allows for scores less than zero to be counted, as these scores indicate a health state considered worse than death.

FINDINGS FROM DATA COLLECTED IN 2015

HOSPITALS

In 2015, 40 hospitals provided data for the AuSCR, the same number as in 2014. During 2015, seven new hospitals received ethics approval and four of those started contributing data. Two hospitals stopped participating due to a lack of capacity. One Victorian hospital, approved in 2013, was also not yet collecting data. Figure 1 shows the incremental shift in numbers of hospitals participating in the AuSCR.

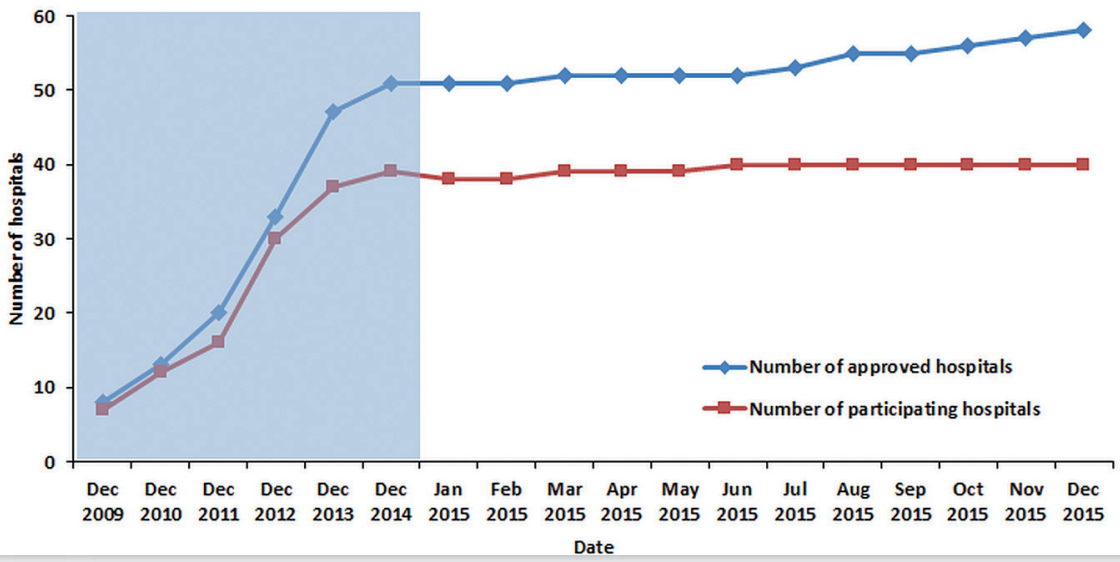
The characteristics of the 2015 participating hospitals are shown in Table 1. In 2015, there was one hospital located in New South Wales (NSW), 21 in Queensland (QLD), 16 in Victoria (VIC), one in Western Australia (WA), and one in Tasmania (TAS). There were 32 hospitals that had 100 or more episodes of stroke/TIA registered during 2015. There were 20 hospitals located in a major city, 38 that had provided stroke unit care and 37 that had provided thrombolytic therapy using tissue plasminogen activator (tPA). Two of the 40 hospitals were private hospitals, located in Queensland, and one was a children's hospital in Victoria.

TABLE 1: CHARACTERISTICS OF PARTICIPATING HOSPITALS

YEAR	
NUMBER OF HOSPITALS	
TOTAL NUMBER OF PATIENTS	
NUMBER OF EPISODES	
ANNUAL NUMBER OF EPISODES IN THE AuSCR*	Low (<33 episodes)
	Medium (33-99 episodes)
	High (≥100 episodes)
LOCATION#	Major city (Metro)
	Regional (Rural)
STROKE UNIT	
INTRAVENOUS THROMBOLYSIS (tPA) UNDERTAKEN	

*Hospital categories as per the definitions used in registry of the Canadian Stroke Network
#Location categorised using Accessibility/Remoteness Index for Australia 2011 (ARIA+): Major city = Category 1; Inner Regional = Category 2; Outer regional = Category 3.

FIGURE 1: NUMBER OF APPROVED AND PARTICIPATING HOSPITALS IN THE AUSCR OVER 2009-2015



2009	2010	2011	2012	2013	2014	2015					
TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	TOTAL	NSW	QLD	VIC	WA	TAS
6	12	16	31	37	40	40	1	21	16	1	1
457	1788	2519	4572	7325	8286	9053	288	4336	3909	158	362
469	1828	2593	4734	7614	8625	9473	290	4533	4118	162	370
-	1	4	11	2	2	2	0	1	1	0	0
1	5	2	6	8	8	6	0	2	4	0	0
5	6	10	14	27	27	32	1	18	11	1	1
6	10	11	16	28	28	20	1	12	6	1	0
-	2	5	15	9	9	20	0	9	10	0	1
6	10	14	28	35	35	38	1	21	14	1	1
6	9	10	22	31	31	37	1	19	15	1	1

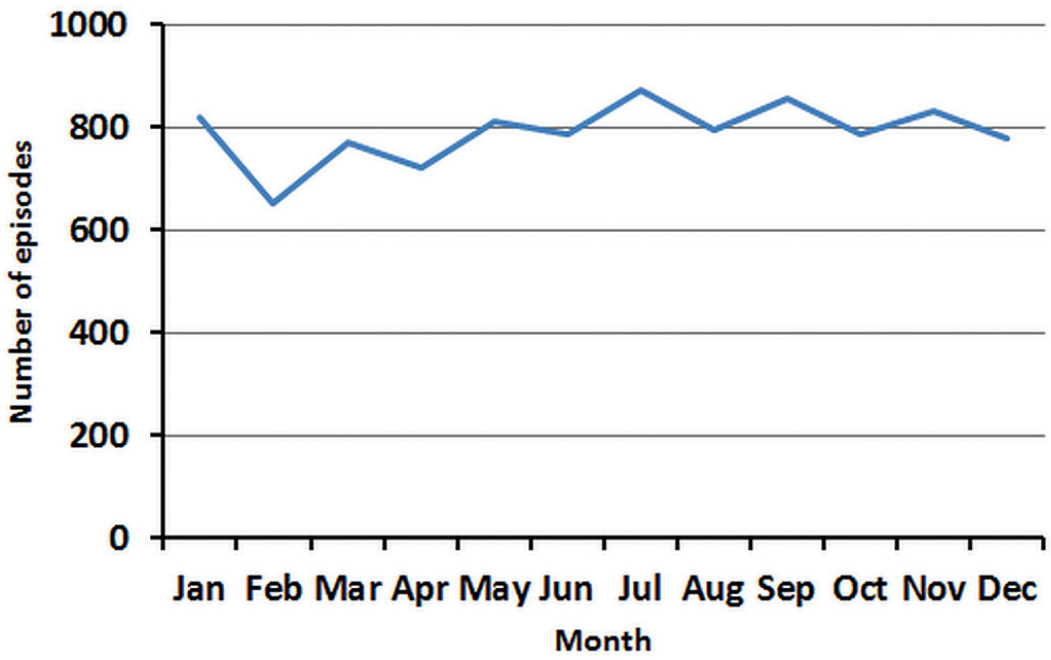
NUMBER OF REGISTRANTS

In 2015, there were 9053 patients registered in the AuSCR. During a calendar year, patients may have multiple admissions for stroke or TIA that are also eligible to be included in the AuSCR. In 2015, there were 9473 episodes of acute hospital care for the 9053 individuals registered. There were 388 patients (4%) who had multiple episodes registered in 2015. Among these, 36 had three episodes and 8 had four episodes. The minimum number of episodes registered for any particular hospital was 11 at a metropolitan Victorian hospital and the maximum number registered was at a metropolitan Victorian hospital (n = 659). The median number of episodes submitted per hospital was 178 (Q1, Q3: 116, 304).

CASES ADMITTED PER MONTH

Figure 2 shows the number of episodes (including multiple episodes) entered per month based on date of admission. The median number was 791 per month. The minimum was 651 in February and the maximum was 873 in July. These data provide evidence of increased activity for the AuSCR, whereby in 2014 the median number of episodes per month was 698, while in 2013 it was 645 per month.

FIGURE 2: NUMBER OF EPISODES ADMITTED PER MONTH IN 2015



REGISTRANT CHARACTERISTICS

Table 2 provides the baseline characteristics for patients and information related to their episodes of care. Adult and paediatric cases of stroke are presented separately. There were 10 hospitals that admitted paediatric (patients aged < 18 years) cases of stroke.

Among the 9033 adult patients, the most common country of birth was Australia (69%) followed by the United Kingdom (8%). There were 146 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 comprised 4135 (46%) females and the mean age was 73 years. There were 1190 adult registrants (12%) aged less than 55 years and 1261 patients (14%) were aged between 55 and 64 years.

From the total 9450 adult episodes, the clinicians specified 5998 ischaemic strokes, 1115 intracerebral haemorrhages (ICH), 1809 TIAs, 521 episodes of undetermined stroke type and seven episodes with missing stroke type data. Stroke type according to age group is presented in Figure 3.

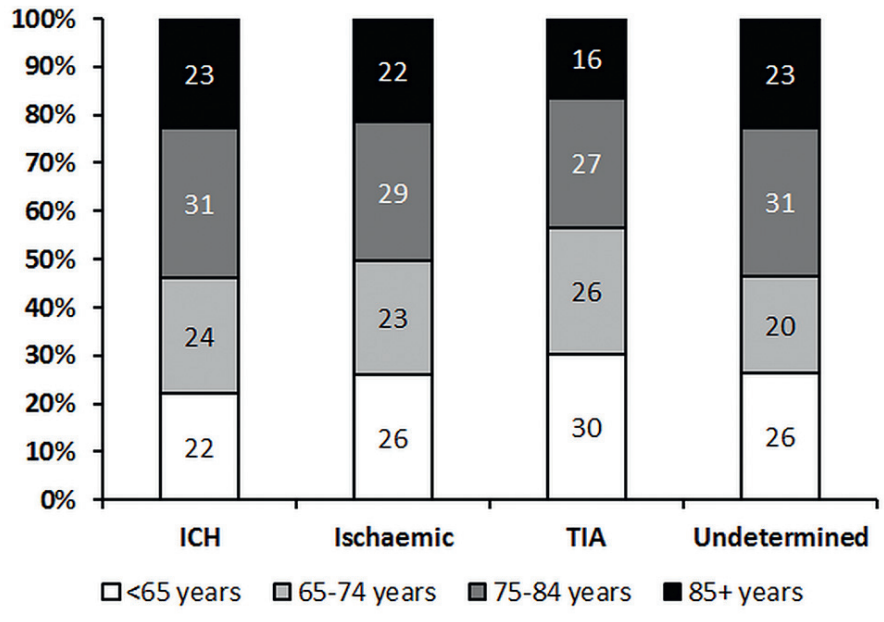
For the paediatric cases, the median age was 12 years with 53% being male. In 82% of the episodes, the stroke type was ischaemic.

TABLE 2: BASELINE CHARACTERISTICS BY REGISTRANTS AND EPISODES (ADULT AND PAEDIATRIC CASES)

REGISTRANTS		ADULTS (N=9033)	PAEDIATRICS (N=20)
Age, years, mean (SD)		73 (14)	10(7)
Age, years, median (Q1 to Q3)		75 (64 to 84)	12 (1 to 16)
Female, n (%)		4135/8970 (46%)	9/19 (47%)
Country of birth, n (%)	Australia	5650/8151 (69%)	14/17 (82%)
	United Kingdom	622/8151 (8%)	0/17 (0%)
	Italy	306/8151 (4%)	0/17 (0%)
	Other European countries	724/8151 (9%)	0/17 (0%)
	Asia	307/8151 (4%)	2/17 (12%)
	Others	542/8151 (7%)	1/17 (6%)
Aboriginal and/or Torres Strait Islander, n (%)		7309/7889 (93%)	1/20 (5%)
English spoken, n (%)		6887/7410 (93%)	17/18 (94%)
EPISODES (INCLUDING MULTIPLE EPISODES)		**ADULT EPISODES (INCLUDING MULTIPLE EPISODES) (n=9450)**	**PAEDIATRIC EPISODES (n=23)**
Able to walk on admission^, n (%) (Stroke severity indicator)		3484/8779 (40%)	9/20 (45%)
Cause of stroke known, n (%)		4879/9440 (52%)	7/22 (32%)

SD: standard deviation **Q1:** 25th percentile **Q3**: 75th percentile
^For cases of stroke occurring in hospital this is within the initial first 24 hours of symptom onset
Paediatric cases were those admitted to the participating paediatric hospital

FIGURE 3: DISTRIBUTION OF STROKE SUB-TYPES BY AGE GROUPS (INCLUDING MULTIPLE EPISODES)



Excludes paediatric cases and episodes with missing stroke type
ICH: intracerebral haemorrhage, TIA: transient ischaemic attack
Ischaemic n=5980, ICH n=1114, TIA n=1800, Undetermined n=522

STROKE SEVERITY

The National Institutes of Health Stroke Scale (NIHSS) score, which can be objectively used to quantify the impairment caused by a stroke and comprises 13 response items to obtain a score between 0 (no stroke symptoms) and 42 (severe stroke),[8] was introduced as an AuSCR variable in late 2014. In 2015, the NIHSS was collected for 1833 episodes (24% of the 2015 cohort). Nearly two thirds of these data (1109, 61%) were from Victoria, where the Victorian Stroke Clinical Network was strongly recommending the collection of this information. Among the patients with NIHSS scores, there were 1773 also with information on ability to walk on admission (a more simply collected measure of assessing stroke severity)[9] (Table 3). The greatest proportion of patients who were unable to walk on admission had an NIHSS score between 5 and 15, corresponding to a moderate stroke (43%). Of those who were able to walk on admission, the majority (58%) had an NIHSS between 1 and 4, corresponding to a minor stroke.

Ability to walk on admission was associated with stroke severity measured using the NIHSS. Compared to patients with no stroke symptoms, patients with minor stroke had a 55% decreased odds of being able to walk on admission (Odds ratio 0.45, 95% CI 0.32-0.64, $p < 0.001$). Patients with severe stroke had a 98% decreased odds of being able to walk on admission (Odds ratio 0.02, 95% CI: 0.01-0.05, $p < 0.001$). This finding provides further support for the use of ability to walk as a reliable broad indicator of stroke severity in the AuSCR, whilst experience in collecting the NIHSS is established.

TABLE 3: NATIONAL INSTITUTES OF HEALTH STROKE SCALE AND ABILITY TO WALK ON ADMISSION

	ABILITY TO WALK ON ADMISSION		
NIHSS	**No n (%)**	**Yes n (%)**	**Odds Ratio (95% CI)**
No stroke symptoms (0)	59 (5)	119 (21)	Reference
Minor stroke (1-4)	354 (29)	323 (58)	0.45 (0.32-0.64)
Moderate stroke (5-15)	520 (43)	102 (18)	0.10 (0.07-0.14)
Moderate to severe stroke (16-20)	146 (12)	5 (1)	0.02 (0.01-0.04)
Severe stroke (21-42)	140 (11)	5 (1)	0.02 (0.01-0.05)
Total	1219	554	

PROCESSES OF HOSPITAL CARE

Among adults, there were 1193 episodes (13%) transferred from another hospital and 422 episodes (5%) that occurred whilst patients were already in hospital for another condition. The majority of the inpatient episodes were ischaemic (n = 312, 74%) and most of these (n = 145, 35%) occurred among patients aged between 75 and 84 years.

A new Victorian variable, "Arrival at the emergency department by ambulance" was collected for 4103/4118 episodes, whereby 2540 (62%) were transported by ambulance.

OVERALL ADHERENCE TO QUALITY INDICATORS

Table 4 provides the results for the average adherence to the process of care indicators collected nationally in the AuSCR and the number of episodes discharged from hospital. Most episodes in the AuSCR were treated in a stroke unit and almost two thirds received a care plan at the time of discharge if they were discharged home or to an aged care facility.

TABLE 4: STROKE EVALUATION AND THERAPY (INCLUDING MULTIPLE EPISODES)

QUALITY INDICATORS OF HOSPITAL CARE	ALL EPISODES	ISCHAEMIC	ICH	TIA
Patients admitted to a stroke unit	7533/9443 (80%)	5220/5998 (87%)	842/1115 (76%)	1217/1809 (67%)
Patients who received intravenous thrombolysis (tPA) if an ischaemic stroke	n/a	703/5998 (12%)	n/a	n/a
Patients discharged (not deceased while in hospital)	8400/9124 (92%)	5462/5904 (93%)	809/1064 (76%)	1802/1803 (99.9%)
Patients discharged on an antihypertensive agent (if not deceased while in hospital)	6180/8400 (74%)	4059/5462 (74%)	608/809 (75%)	1293/1802 (72%)
Patients who received a care plan at discharge (if discharged home or to RACF)	2792/4721 (59%)	1692/2640 (64%)	130/240 (54%)	894/1653 (54%)

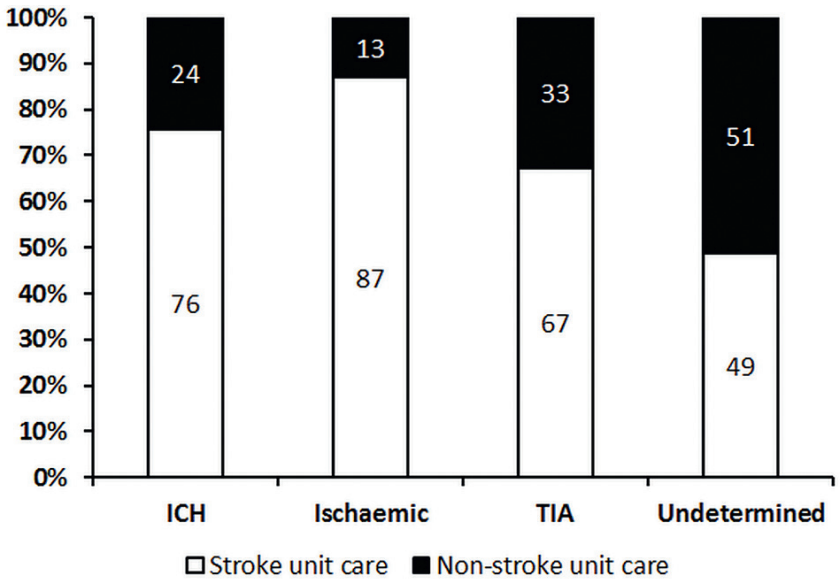
n/a: not applicable
Unknowns coded as no

RACF: Residential Aged Care Facility
Inpatient death determined using NDI data

Excludes those with missing stroke type
Excludes paediatric cases

There was a difference in the age of patients admitted to stroke units among the hospitals (mean age if managed in a stroke unit 73 years [SD 14] and non-stroke unit mean age 72 years [SD 15], $p = 0.013$). More patients with ischaemic stroke were treated in a stroke unit than the other types of stroke ($p < 0.001$) (Figure 4).

FIGURE 4: MANAGEMENT IN A STROKE UNIT ACCORDING TO STROKE SUB-TYPE (INCLUDING MULTIPLE EPISODES)



Excludes paediatric cases

ICH n=1117, Ischaemic n=6008, TIA n=1809, Undetermined n=521

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 5. If the achievable benchmarks were able to be achieved by all AuSCR hospitals, relative to the overall average adherence, then it is estimated that: a further 1511 patients would have benefited from care in a stroke unit; an extra 420 would have received intravenous thrombolysis if an ischaemic stroke; 1092 more prescribed secondary prevention with antihypertensive medication; and 1558 extra would have been provided with a care plan if discharged into the community.

TABLE 5: 2015 BENCHMARKING OF PERFORMANCE FOR NATIONAL CARE PROCESSES

PROCESS OF CARE	BENCHMARK* 2014 (%)	BENCHMARK* 2015 (%)	TOP ADHERENCE** (%)	AVERAGE ADHERENCE# (%)	OVERALL AVERAGE ADHERENCE^ (%)
Received stroke unit care	96	96	98	77	80
Received intravenous thrombolysis if an ischaemic stroke	20	19	20	10	12
Discharged on antihypertensive medication	88	87	91	75	74
Care plan provided if discharged to the community	86	92	96	52	59

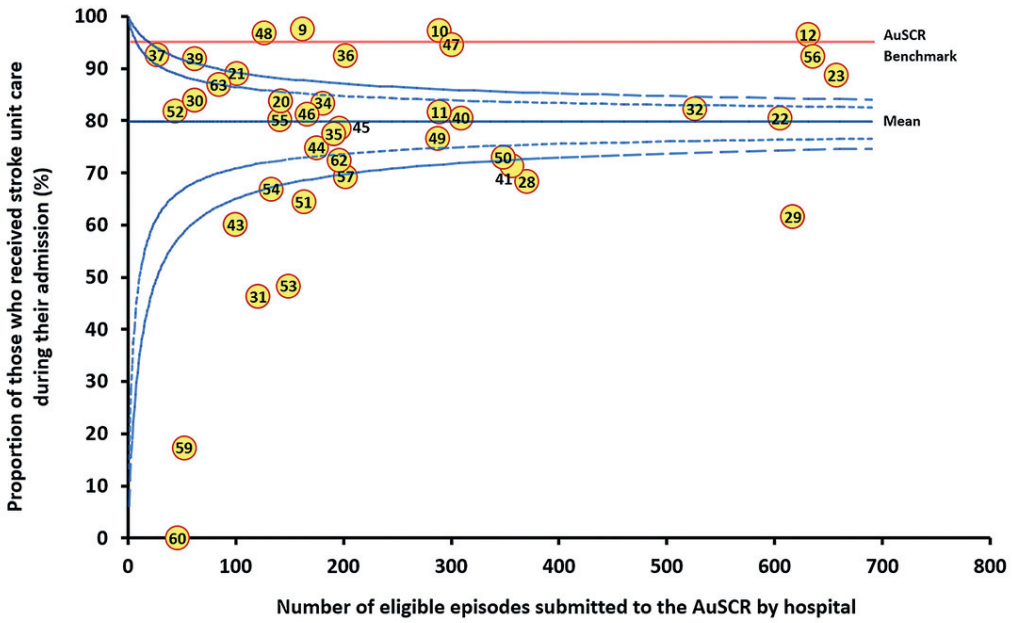
*Only hospitals that had contributed data for >6 months and had >50 cases were eligible for inclusion (n=36). Benchmarks were calculated based on a modified ABCTM method.[5,6] **The top performer adherence results are the unadjusted scores for a single hospital in this sample. #The average performance results were calculated as the sum of the unadjusted adherence score for each hospital in this sample divided by the total number of hospitals (n=36). ^Average adherence results from all hospitals (n=40) providing data in 2015.

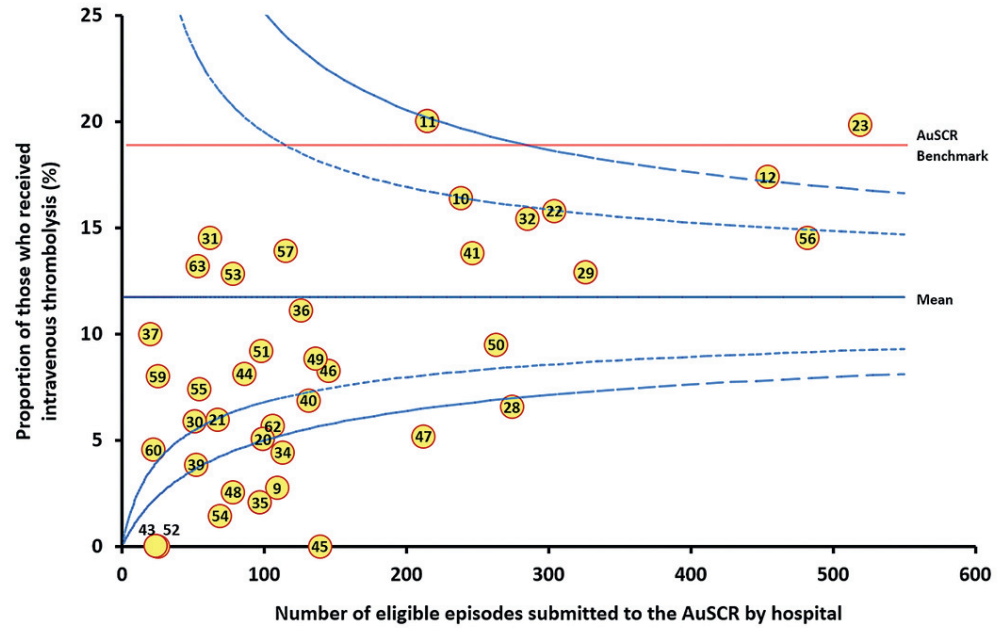
ADHERENCE TO QUALITY INDICATORS BY NUMBER OF ADMISSIONS PER HOSPITAL IN 2015

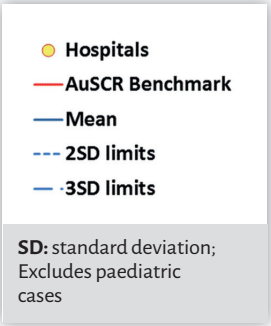
Adherence to the national quality indicators by number of episodes registered in 2015 for each hospital is shown in funnel charts see (Figure 5, Figure 6, Figure 7, and Figure 8). Funnel charts can be used to display deviations from the average achievement of quality of care.[10]

How to read the funnel charts: The horizontal axis depicts the size of the hospital in terms of the number of episodes they provided in 2015 i.e. the more episodes, the further to the right will be the representative circle. The vertical axis provides the level of adherence to the quality indicator, expressed as a proportion (%). The horizontal centre line is the overall average adherence for all included hospitals. The numbered circles represent the result for each individual hospital. The dashed lines constitute the funnel. They are the upper and lower control limits that represent the boundary between 'normal variation' and 'special cause variation'. The thicker red line, labelled as the 'AuSCR benchmark', indicates the achievable performance benchmark. Hospitals above or below the 3 SD limits line may be considered as having special cause variation (positive or negative), relative to the sample average performance, and explanations as to why they differ from other hospitals should be explored. 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 'normal distribution'.

Based on the 2015 data, variance existed in the proportion of patients who were managed in a stroke unit (Figure 5). The majority of hospitals, where the proportion of patients admitted to a stroke unit was below the 3 SD limit, were hospitals that submitted less than 300 episodes into the AuSCR in 2015.







SD: standard deviation; Excludes paediatric cases

FIGURE 5: MANAGEMENT IN A STROKE UNIT BY HOSPITAL

FIGURE 6: RECEIVED INTRAVENOUS THROMBOLYSIS BY HOSPITAL

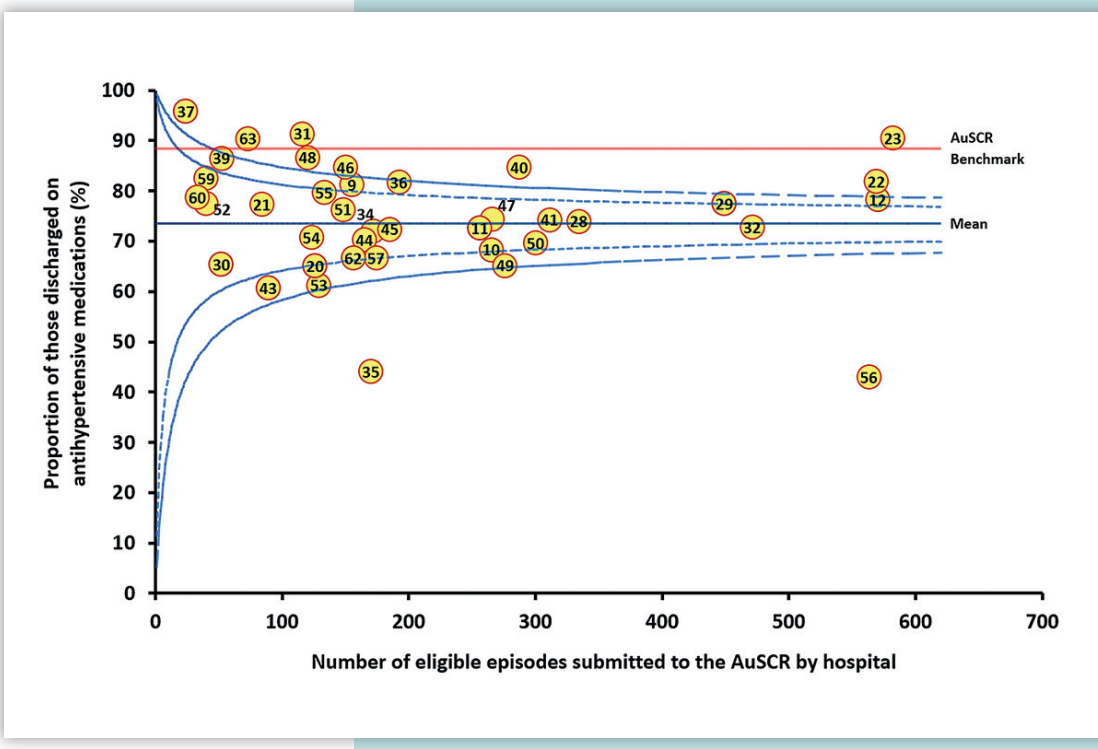
FIGURE 7: DISCHARGED ON ANTIHYPERTENSIVE MEDICATIONS BY HOSPITAL

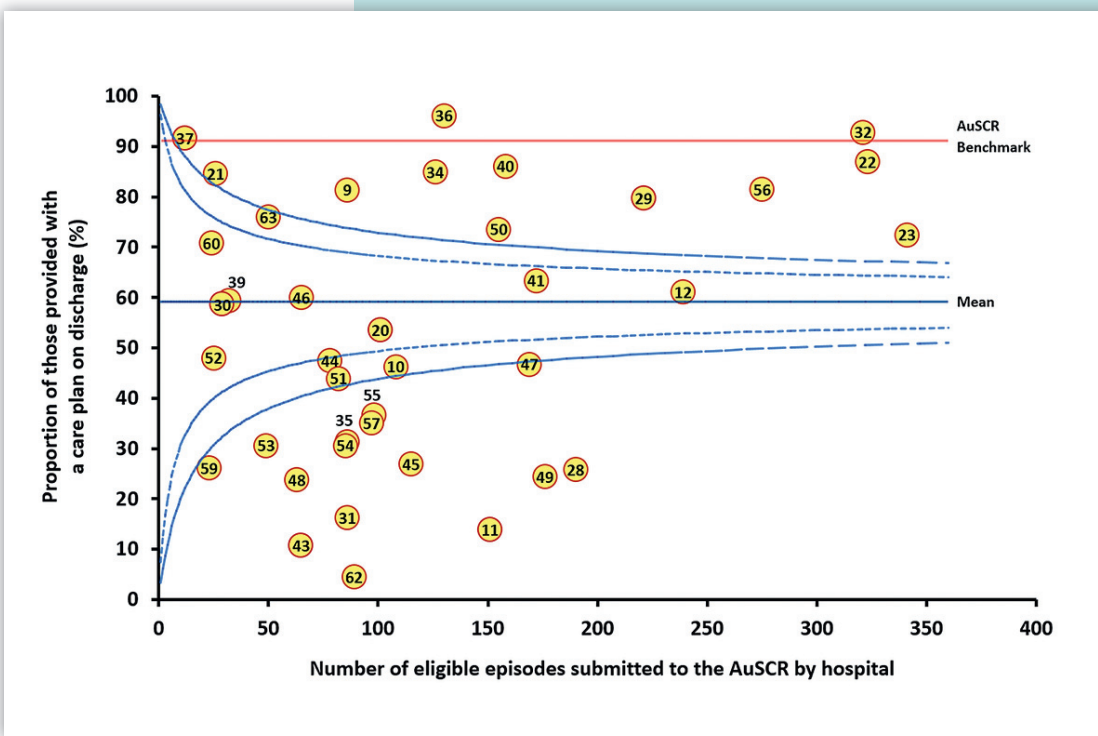
FIGURE 8: CARE PLAN PROVIDED BY HOSPITAL IF DISCHARGED HOME OR TO A RESIDENTIAL AGED CARE FACILITY BY HOSPITAL

Three of the participating adult hospitals did not provide thrombolysis in 2015. Two of these hospitals had less than 100 stroke episodes recorded in the AuSCR. There were two large hospitals (i.e. those with more than 200 patients recorded in the AuSCR) whereby performance regarding this indicator was above the benchmark (Figure 6).

Being discharged on antihypertensive medication was the most consistently adhered to quality indicator. Only two hospitals were below the 3 SD limit for this indicator (Figure 7).

Adherence to receiving a care plan on discharge, if discharged home or to residential care, showed the greatest variation between hospitals (Figure 8). Many hospitals were not within 'normal variation' indicating 'special cause variation' in comparison to the overall average. However, these data need to be interpreted with caution. It was noted that 471 episodes of care that resulted in a discharge to home or to a residential aged care facility were incorrectly classified by hospital staff as being ineligible. These episodes were re-categorised during analysis so that they were counted as eligible, but did not receive a care plan at discharge. There is continuing work to ensure appropriate and standardised collection of this variable.

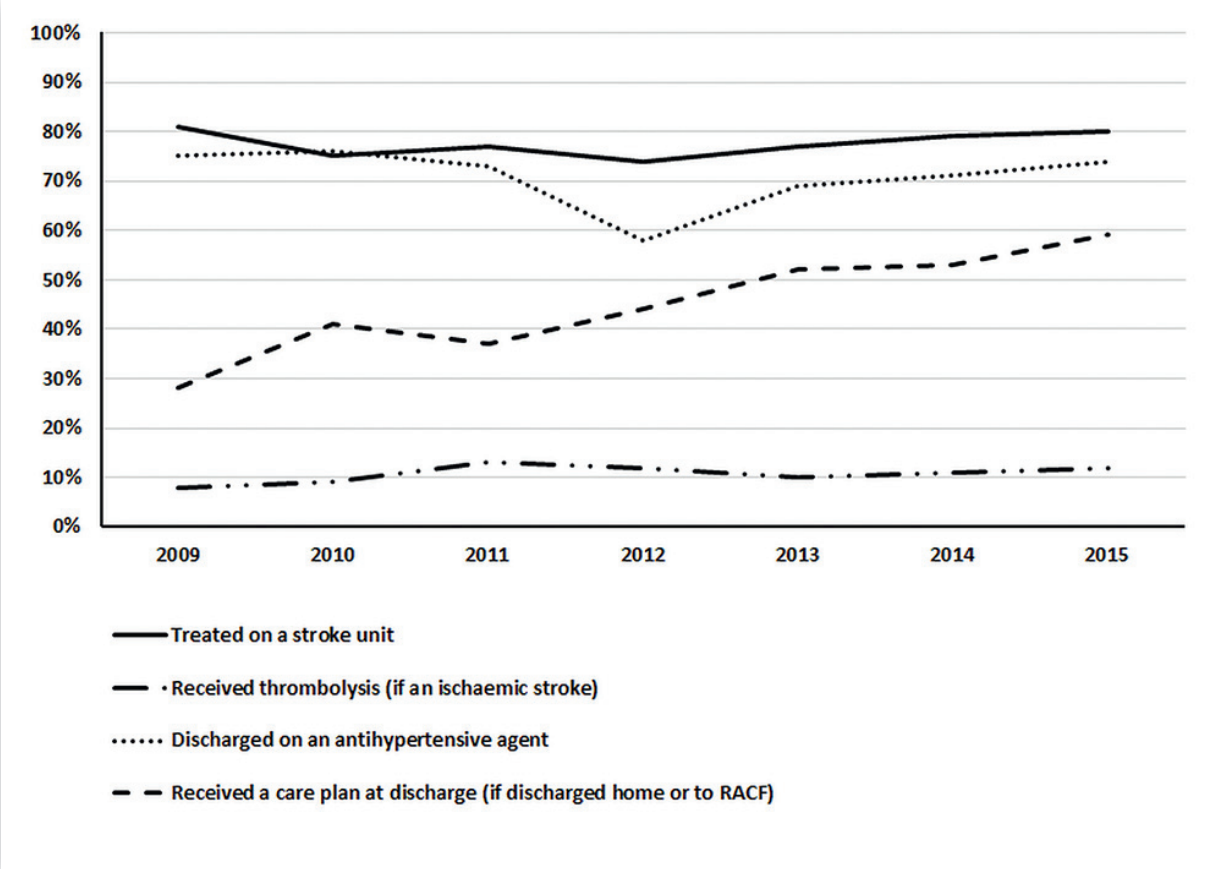




CHANGES IN QUALITY OF CARE OVER TIME

Analysis of the AuSCR process of care data over the seven year period from 2009-2015 showed some fluctuations in the provision of evidence-based therapies (Figure 9). The number of hospitals contributing data and the number of patients included in the AuSCR has increased considerably over time. Few hospitals have contributed data over all seven years. Therefore, these data may not truly represent improvements or declines in the quality of care.

FIGURE 9: CHANGES IN QUALITY OF CARE OVER TIME



OVERALL ADHERENCE TO QUALITY INDICATORS SPECIFIC TO QUEENSLAND HOSPITALS

Adherence to the additional quality indicators collected in the AuSCR for Queensland is outlined in Table 6. The majority (85%) of Queensland patients registered in the AuSCR were mobilised during their admission. Among the 1961 patients who were unable to walk independently on admission, the method of mobilisation was either walking (50%), standing (24%) or sitting (26%). More than one-third (46%) were assessed for dysphagia, 75% received aspirin within 48 hours, and approximately 96% with ischaemic stroke or TIA were discharged on antiplatelets or antithrombotic medication.

TABLE 6: QUEENSLAND SPECIFIC PROCESSES OF CARE (INCLUDING MULTIPLE EPISODES)

HOSPITAL STROKE CARE	ALL EPISODES	ISCHAEMIC	ICH	TIA
Mobilisation during admission	3845/4526 (85%)	2477/2720 (91%)	350/521 (67%)	898/996 (90%)
Same day or day after admission	3316/3837 (86%)	2082/2469 (84%)	254/351 (72%)	866/897 (97%)
If unable to walk independently, patient mobilised	1961/2367 (83%)	1470/1681 (87%)	240/392 (61%)	185/204 (91%)
Same day or day after admission	1578/1958 (81%)	1187/1466 (81%)	158/241 (66%)	173/185 (94%)
Dysphagia screen tool used within 24 hours	2065/4526 (46%)	1357/2720 (50%)	210/521 (40%)	410/996 (41%)
Screen or swallow assessment undertaken	3772/4526 (83%)	2505/2720 (92%)	395/521 (76%)	739/996 (74%)
Within 24 hours	2782/3772 (74%)	1815/2505 (72%)	282/395 (71%)	577/739 (78%)
Aspirin administration within 48 hours (if not intracerebral haemorrhage)	3003/4005 (75%)	2116/2720 (78%)	n/a	789/996 (79%)
Discharge on antiplatelet/antithrombotic agent(s) (if not intracerebral haemorrhage)	3251/3374 (96%)	2241/2312 (97%)	n/a	910/937 (97%)

Includes only patients admitted to hospitals in Queensland

PATIENTS ADMITTED WITH TRANSIENT ISCHAEMIC ATTACK

Among the 1809 episodes of TIA, the mean age was 71 years (SD 14 years) and 47% were female. One patient with TIA was reported to have died while in hospital. Among those alive at discharge, 72% were discharged on an antihypertensive agent. Among patients with TIA who were discharged home, or to a residential aged care facility, 54% received a care plan (see Table 4). Most patients with TIA (88%, n = 1592) were discharged to a home setting, 3% (n = 46) 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 61 registrants with TIA who were discharged to residential aged care, 39% had a documented history of a previous stroke.

PROCEDURE CODES ASSIGNED TO REGISTRANTS WHILE IN HOSPITAL

As part of the discharge coding process, multiple procedure codes can be assigned to patients while they are in hospital which may provide information on additional aspects of clinical care. At least 20% of the patients received allied health interventions including: physiotherapy; occupational therapy; speech pathology; social work; pharmacy; dietetics; diabetes education; and pastoral care.

DISCHARGE INFORMATION

Hospital outcome measures include length of stay, discharge destination and discharge status. These data are presented per episode.

LENGTH OF STAY

The median length of stay for adults was four days (Q1 to Q3: 2 to 7 days). Of the 8403 episodes discharged, 364 (4%) 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 managed in stroke units (median 2 days, Q1 to Q3: 1 to 6 days) ($p < 0.001$). This finding may be due to more severe cases being treated in the stroke unit and requires further exploration.

The median length of stay for patients with TIA was two days (Q1 to Q3: 1 to 3 days). Patients with TIA more often had a short length of stay (less than four days) compared to patients with stroke (87% TIA, 47% stroke, $p < 0.001$). For paediatric cases the median length of stay was four days (Q1 to Q3: 2 to 167 days). The median length of stay was longer for patients who had an episode while already in hospital for another condition: inpatient median 10 days (Q1 to Q3: 5 to 18 days) vs. median 4 days (2 to 7 days) for non-inpatient events (i.e. presented from the community), $p < 0.001$).

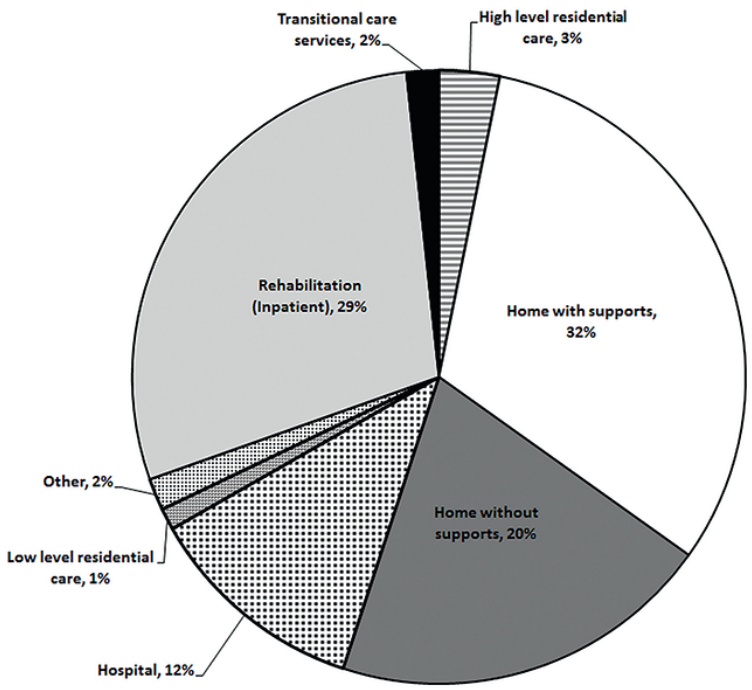
IN-HOSPITAL DEATHS

Among the 9462 adult episodes of care, 724 (8%) patients died whilst in hospital. Case fatality in hospital was 24% greater for women after adjustment for age ($p = 0.007$). There were no paediatric in-hospital deaths.

DISCHARGE STATUS

In 2015, approximately half of the episodes of care resulted in discharge home ($n = 4357$; 52%), (Figure 10). 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 (95% confidence interval [CI] 1.7 to 2.4) when adjusted for age, gender, 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 rehabilitation regardless of whether or not they were able to walk on admission.

FIGURE 10: DISCHARGE STATUS INCLUDING MULTIPLE EPISODES, N=8415



Excludes paediatric cases and episodes of care resulting in death in hospital
Queensland registrants coded as sub- or non-acute patients (SNAP) were included in the hospital category
n=323 had missing discharge destination

POST-DISCHARGE HEALTH OUTCOME INFORMATION

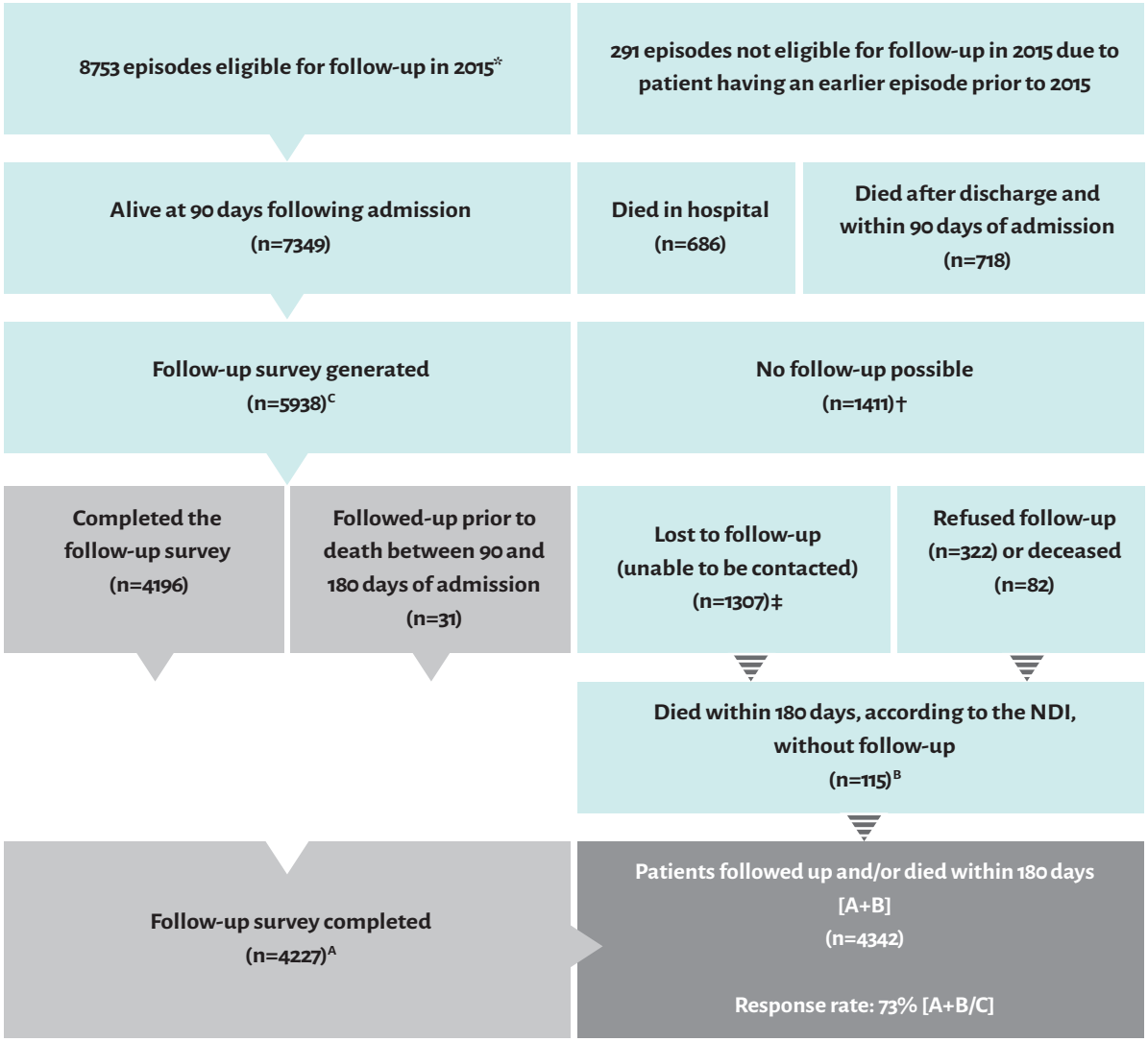
The following section provides the findings from the registrants who were eligible for follow-up in 2015.

There were 9033 adult patients registered in 2015. In Victoria recurrent episodes that were not within 180 days of a previous episode were eligible for follow-up; there were 11 of these events. Of these 9044 episodes, 686 (8%) resulted in a death in hospital and another 718 (8%) resulted in a death after discharge but within 90 days of admission. No attempt at follow-up was made for 1411 episodes (16%) with primary data entered into the AuSCR web tool after the 180 day follow-up limit, and 291 episodes (3%) related to non-Victoria registrants with a previous stroke/TIA in the AuSCR prior to 2015. (See flow diagram in Figure 11.)

Of the remaining 5938 episodes, 322 (5%) refused follow-up, 82 (1%) were reported as deceased, and 1307 (22%) registrants were unable to be followed up via survey methods because their details were not accurate or had changed, and they were considered 'lost to follow-up'. According to the NDI linkage, there were 33 episodes lost to follow-up as a result of death between 90 and 180 days.

A follow-up survey was completed, or death status determined, for 4377 episodes (66%) for which a follow-up survey was generated in 2015. Median time from the stroke onset to the completion of follow-up for these episodes was 101 days (IQR 94 to 112 days). As we are able to link the registrant data to the NDI, survival status in the community was known for each episode registered in 2015.

FIGURE 11: FLOW DIAGRAM OF THE FOLLOW-UP ASSESSMENTS FOR PATIENTS ADMITTED IN 2015



* Includes only adult episodes
† There were 1411 registrants who had their data entered into the AuSCR database after 180 days post their admission
‡ There were 33 patients lost to follow-up who died within 180 days of their admission

We obtained follow-up information after 4342 episodes of care (follow-up survey completed or known to have died between 90-180 days post-stroke). The mean age of these patients was 72 years and 44% were female; 67% of them were following an ischaemic stroke. These patients were older (72 years vs 69 years, $p < 0.001$) and less often of Aboriginal and/or Torres Strait Islander descent (1% vs 3%, $p < 0.001$) when compared to patients without follow-up information (refused or lost to follow-up at 180 days). Consistent with data in the 2014 Annual Report[11] a survival advantage of stroke unit care, representing a 51% reduced hazard of death at 180 days, compared to non-stroke unit care, was found after adjustment for age, gender, stroke sub-type, ability to walk on admission, in hospital stroke and transfer from another hospital (adjusted mortality hazard ratio 0.49, 95% CI: 0.43 – 0.55, $p < 0.001$).

FOLLOW-UP DEATH AND SURVEY DATA

There were 9044 episodes in the AuSCR considered for follow-up, comprising 9033 adult registrants plus 11 Victorian registrants with recurrent episodes. Of these 9044 episodes, 1654 resulted in a death within 180 days of admission, with 705 (43%) of these deaths occurring while in hospital and 750 (45%) after discharge and within 90 days of admission (Figure 12).

Of the 4227 episodes with completed follow-up surveys, there were 4013 (95%) where all questions were answered and 214 (5%) where some were answered. The majority of participants (86%) were living at home at the time of follow-up (Figure 13).

The Modified Rankin Scale (mRS) was collected at follow-up for the first time in 2015. Of those who completed follow-up surveys, 1124 (27%) said they were free of disability (Figure 14).

There were 212 episodes (5%) where there had been a recurrent stroke and 819 episodes (20%) with a readmission to hospital, of which 187/819 (23%) were reported to be for a readmission related to a stroke or cardiovascular cause.

FIGURE 12: TIMING OF DEATH AFTER STROKE OR TIA

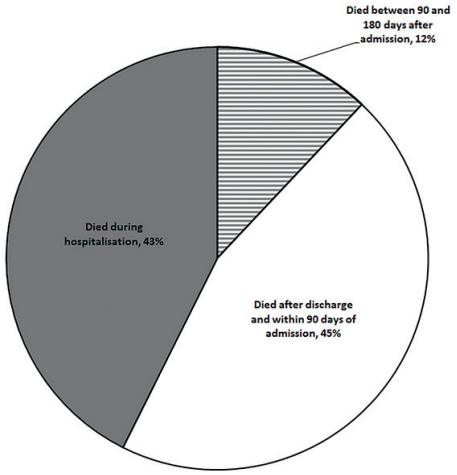


FIGURE 13: PLACE OF RESIDENCE AT THE TIME OF FOLLOW-UP

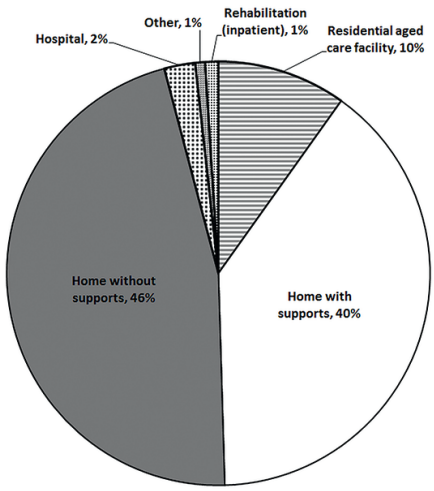


FIGURE 14: LEVEL OF DISABILITY AT THE TIME OF FOLLOW-UP AS MEASURED BY THE MODIFIED RANKIN SCALE

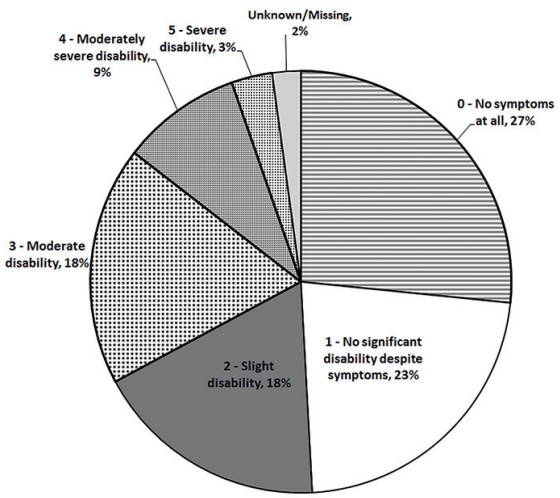


FIGURE 15: EQ-5D QUALITY OF LIFE DIMENSIONS

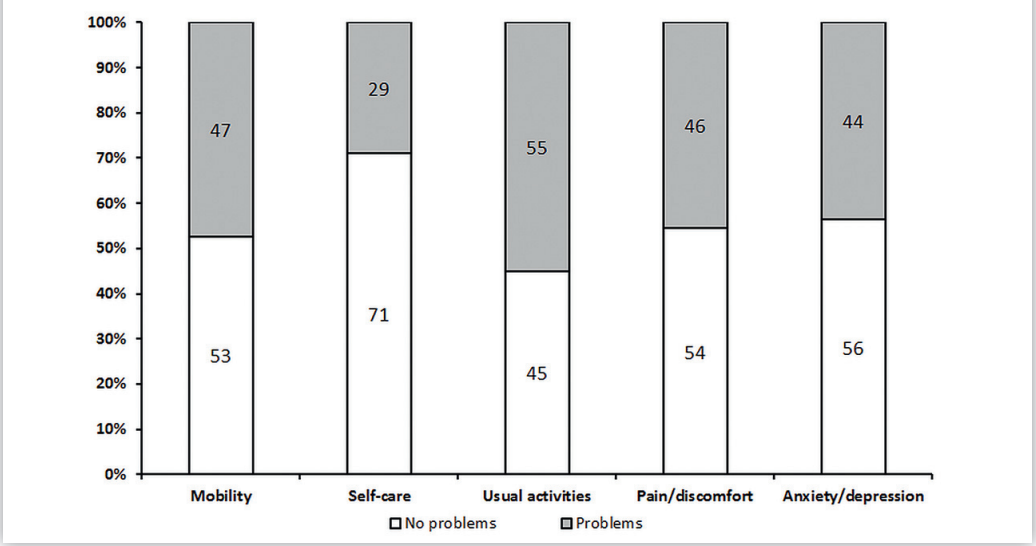
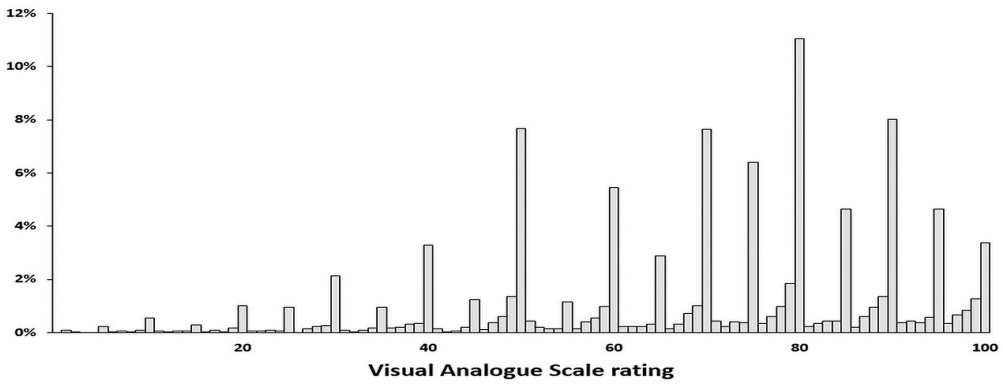


FIGURE 16: VISUAL ANALOGUE SCALE RATING DISTRIBUTION

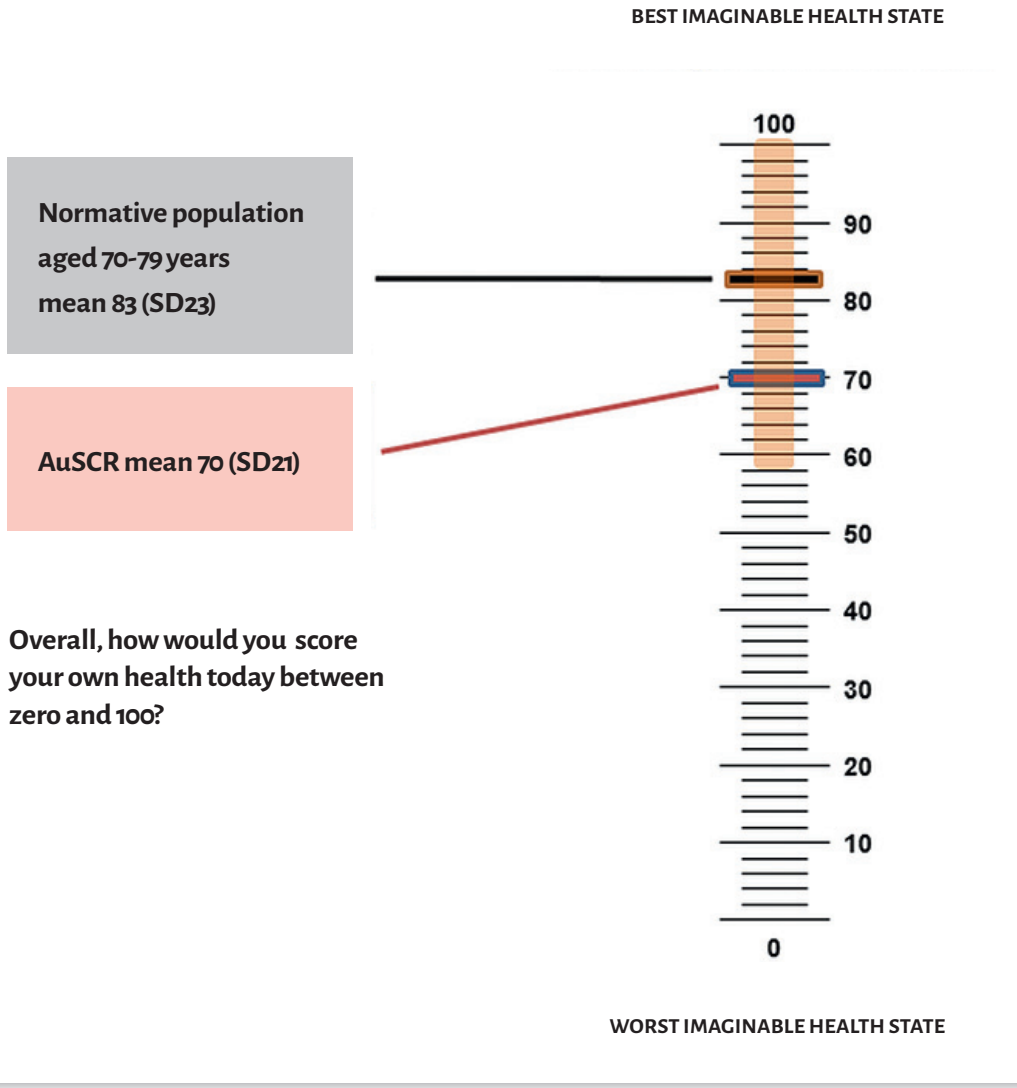


HEALTH-RELATED QUALITY OF LIFE

Almost half of the respondents reported problems with mobility (47%) and more than half reported problems with usual activities (55%) (Figure 15). When EQ-5D responses were converted to a utility score using the DCE method, 256 (6%) had a utility score of less than zero at the time of their follow-up – a health state rated to be worse than death. EQ-5D-DCE utility scores ranged from -0.516 to 1.0.

The Visual Analogue Scale (VAS) is a quantitative measure of overall perceived health, as judged by the individual respondents, that helps capture subjective characteristics or attitudes that cannot be directly measured.[12] The mean EQ-5D VAS rating for respondents in the AuSCR was 13 points below the normal population measure for people aged 70 to 79 years. Half of the respondents rated their health as 75 or better. The distribution of VAS ratings is shown in Figure 16 and a comparison to the normative population for a similar age group is shown in Figure 17.

FIGURE 17: VISUAL ANALOGUE SCALE RATING SUMMARY



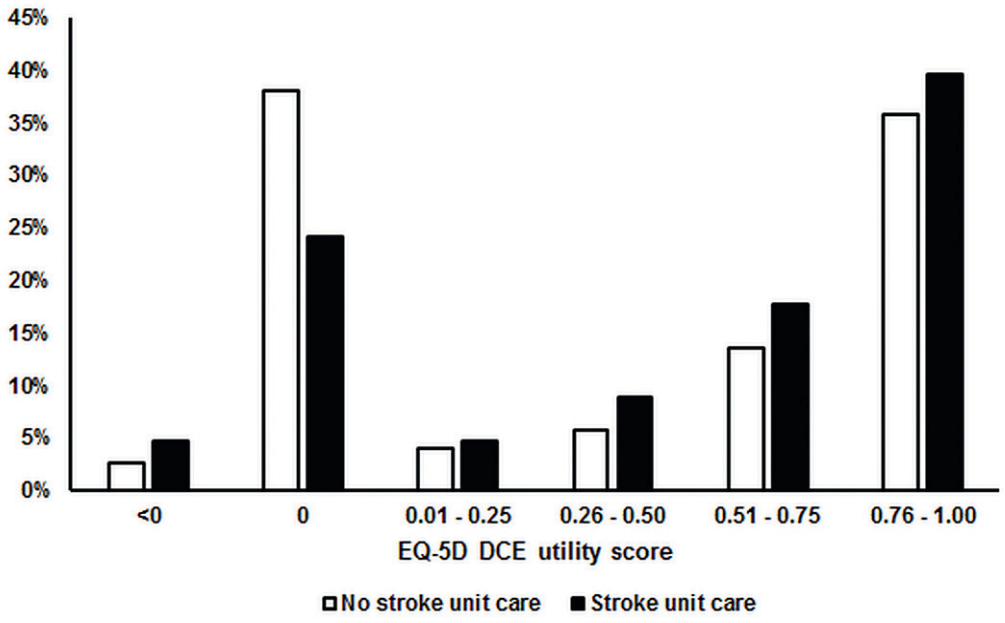
Normative population Visual Analogue Scale responses obtained from Kind et al[13]

HEALTH-RELATED QUALITY OF LIFE AND THE INFLUENCE OF STROKE UNIT CARE

A clinically meaningful difference in EQ-5D scores, for patients with stroke, has been determined to be 8 and 12 points.[14] There were no statistically significant differences in the VAS ratings between those receiving care in a stroke unit and those not receiving care in a stroke unit at a median of 101 days for survey respondents. When the entire cohort was taken into account, whereby those who had died at the time of follow-up were included in the analysis and assigned a VAS rating of zero, patients treated in a stroke unit had a 10 point greater VAS score than those not treated in a stroke unit at the time of follow-up (β 9.59, 95% CI: 5.01 – 14.17, $p < 0.001$). This result is considered clinically meaningful.

Similarly when we calculated results based on DCE methods, patients who were treated in a stroke unit had an 11 point greater EQ-5D DCE utility score compared to patients who were not treated in a stroke unit (β 0.11, 95% CI: 0.06 – 0.16, $p < 0.001$). This result was also considered clinically meaningful and provides impetus to ensure all patients with stroke get access to stroke units. EQ-5D DCE utility scores stratified by treatment in a stroke unit are shown in Figure 18.

FIGURE 18: EQ-5D DCE UTILITY SCORES STRATIFIED BY TREATMENT IN A STROKE UNIT



PAEDIATRIC OUTCOMES

There were 23 episodes occurring in patients under the age of 18. Of these, 11 were admitted to a children's hospital and 12 were admitted to adult hospitals. Six of these episodes were followed up at 90 to 180 days after admission. Three were aged between one and 12 years, and three were aged between 13 and 18 years. For two of the paediatric episodes there was complete data collected at follow-up.

PARTICIPATION IN FUTURE RESEARCH

Among the 3914 registrants who answered the question about whether they would be willing to be contacted to participate in future research, 2338 registrants (60%) replied affirmatively. Compared to those who did not reply in the affirmative, these patients were younger (70 vs 74 years, $p < 0.001$) and more often male (60% vs 50%, $p < 0.001$). Eligible registrants may have subsequently been offered the opportunity to participate in a range of approved research projects (see Appendix F).

UNMET INFORMATION NEEDS

Stroke can be a devastating and life changing event and there is a possibility that stroke survivors and their carers have unmet needs. The AuSCR follow-up survey, at 90 to 180 days post stroke or TIA provides an opportunity to ask registered patients whether they would like to receive further information from the Stroke Foundation. In 2015, 44% (n = 1875) of 4227 registrants requested this information which includes literature on understanding and preventing stroke plus details about the Stroke Foundation's online resource for stroke survivors and their families, enableme (www.enableme.org.au).

USE OF AUSCR DATA TO IMPROVE THE QUALITY OF CARE: SELECTED CASE STUDIES

The primary purpose of the AuSCR is to facilitate the monitoring, promotion and improvement of the quality of acute stroke care. The most significant program of work has been through the Stroke123 project, which concluded in 2015. The Stroke 123 Partnership project was funded by the NHMRC, Queensland Health, the Stroke Foundation and

Monash University with in-kind support from state government departments and other university partners. The legacy of the Stroke123 project is significant for the AuSCR in that it provided the impetus for upscale and spread of the registry, advancements in analytic methodology and data linkage, as well as more sustainable streams of future funding, albeit time-limited, from government. A summary of the achievements, from the commencement of the Stroke123 project in 2012 until 2015, is provided in Table 7.

There have been a number of smaller projects, or sub-studies, emanating from Stroke123 that have formally used the AuSCR data to guide quality improvement initiatives in hospitals, for example:

» The Queensland sub-study of the Stroke123 project whereby, for the first time, AuSCR data were included as part of the StrokeLink workshops conducted by the Stroke Foundation to facilitate review of performance gaps with clinicians

» "Improving discharge from hospital after stroke: a focus on prevention medication and discharge planning" (a Queensland-based pilot project funded by the Nancy and Vic Allen Fund) which led to the design of an externally facilitated, multifaceted, organisational intervention to support clinicians to improve care

» Queensland Stroke Quality Improvement Program (in collaboration with the Stroke Foundation and funded by Queensland Health) which has extended access to the StrokeLink program and the AuSCR until 2018

TABLE 7: SUMMARY OF ACHIEVEMENTS FROM THE STROKE123 PARTNERSHIP PROJECT

IN JANUARY, 2012	IN DECEMBER, 2015
16 hospitals : 2,530 care episodes in the AuSCR	58 hospitals: 35,295 episodes of care in the AuSCR
Working in silos	Work groups established and continuing beyond project, some with modified formats/membership
Use of national average for benchmarks	Application of achievable benchmarks to motivate greater quality improvement (QI) targets
Duplication of effort	Pre-population of Stroke Foundation Acute Audit data for hospitals in the AuSCR and establishment of the Australian Stroke Data Tool to ensure future seamless sharing of common data for individual patients within different QI programs
No data linkage	Data linkage with AIHW, QLD, NSW, VIC, WA and NSW
Limited evidence on externally facilitated QI programs	Pilot project on secondary prevention and discharge care planning funded and found to be effective Enhanced StrokeLink utilising the AuSCR and Stroke Foundation data
No direct government support	Funding in Victoria and Queensland
Limited information on the outcome of patients with stroke in Australia	New evidence on: TIAs admitted to hospital; mortality rates between hospitals; impact of stroke units.

Use of the data by hospitals

By collecting data in the registry and accessing their benchmarked live reports, hospitals have a readily available mechanism for reviewing their own clinical practice to facilitate quality improvement. Some examples of quality improvement activities, where AuSCR data were used, that have been self-reported to our AuSCR Site Coordinators from participating hospitals are listed below:

- Increased access to stroke units
- Highlighted need for improved access to stroke units and fostered engagement of bed managers and Emergency Department
- Stroke unit admissions - review of processes for 'rural feeder' hospitals
- Thrombolysis
- Sought more education, made care pathway amendments and increased clinical trial participation, where relevant
- Swallow assessment data
- Provided opportunity for communication and improved collaboration with Emergency Department staff and speech pathologists
- Improved documentation of swallowing assessments
- Discharge care planning
- At numerous hospitals the AuSCR data triggered discussion and assessment of whether care planning was conducted according to clinical guidelines
- Raised awareness of need for better communication with staff and patients
- > 15% improvement overall (pilot hospital 1: 18%; pilot hospital 2: 30%) (from pilot quality improvement project in Queensland)
- ICD10 discharge coding quality
- Discussion with coding staff to enhance coding accuracy for stroke
- Quality of life/mood assessments
- A number of hospitals were able to lobby administration and get increased involvement from social workers, often including seven day cover
- Supporting need for additional/existing resources
- Data used to justify stroke coordinator role, demonstrating improved quality of care since their commencement

DISCUSSION

In this 2015 report, we provide information contributed from 40 hospitals in Australia on 9473 episodes of stroke or TIA. As in our 2014 report, there continues to be wide variability in adherence to the nationally endorsed quality indicators among the participating hospitals, resulting in important care gaps. With the launch of the *Acute Stroke Clinical Care Standard* in June 2015 we intend to focus our analytic efforts on mapping processes of care, recorded in the AuSCR, to these nationally endorsed indicators.

As part of addressing the challenges of quality assurance and quality improvement, hospital staff need endorsement and support for submitting their AuSCR data. The AuSCR has always provided a systematic approach to stroke data collection, but the process will be enhanced from mid-2016 when all AuSCR data will be collected in the AuSDaT. This online, integrated data management tool allows comprehensive data entry across a number of stroke programs and will avoid duplication for data collection at the hospital level. As with the original AuSCR web tool, there is also capacity in the AuSDaT to import data that have been extracted from hospital administrative systems. Funding opportunities identified by the Victorian Stroke Clinical Network through an Operational Infrastructure Support Grant have enabled many Victorian hospitals to streamline their data entry processes for the AuSCR through local exports of administrative or clinical data that can be directly imported into the AuSCR. Some hospitals in Queensland and New South Wales are also actively developing similar automated processes.

Once again, we have utilised our linking of the AuSCR data to the NDI, to conduct analyses of the casemix adjusted data, and consistent with 2014 findings, demonstrated the survival advantage of stroke unit care (i.e. 51% reduced risk of death at 180 days) compared to non-stroke unit care. The follow-up of patients at 90-180 days, for those who are discharged from hospital, is a unique attribute of the AuSCR in providing longer term outcome data on stroke or TIA. Patient reported outcome measures (PROMs) have become an increasing focus of state government endeavours to assess the impact of health care and the AuSCR already has this capacity. In this annual report, we have showcased clinically important differences in HRQoL for registrants who did, or did not, receive care in a stroke unit. These findings provide impetus to ensure all patients with stroke have access to stroke unit care. In the 2015 Stroke Foundation Acute Care Audit, which includes a broader range of hospitals than those that participate in the AuSCR, only 67% of patients included had access to a stroke unit.[15] The AuSCR case-mix adjusted HRQoL outcome data provide strong evidence for why care in stroke units is so important, over and above any survival benefit.

Lastly, the NHMRC Stroke123 partnership grant allowed us to advance over the last four years. From a finite (12 month) grant from the Australian Commission on Safety and Quality in Health Care in 2008, the AuSCR has managed to grow successfully and support a number of important initiatives including the greater embedding of performance monitoring for stroke and availability of PROMs. We have established the feasibility of cross-jurisdictional data linkage between the AuSCR, the National Death Index and hospital data from four states to maximise the use of existing data. Our ongoing work in linking AuSCR data with state health department data sets will continue to provide a rich source of information about the patient journey (e.g. readmissions, comorbidities) which we hope to provide in future annual reports. Various activities in quality improvement support for hospitals have occurred or been enhanced, including the StrokeLink program in Queensland. These successes have helped garner further funding for the AuSCR from Queensland Health and the Victorian government. We are also very grateful to the Australian Stroke Coalition in recognising the need to reduce duplication of effort related to national performance monitoring which led to the Stroke Foundation supporting the initial build of the AuSDaT. We will transition our data in 2016 to the AuSDaT, and look forward to continuing to consolidate and adapt the registry to meet the needs of clinicians and consumers, while also supporting research that can be used to improve the health care system for stroke in Australia.

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APPENDIX A

AUSCR GOVERNANCE AND COLLABORATIONS

The AuSCR initiative is undertaken by a consortium of two leading academic research institutes, The Florey Institute of Neuroscience and Mental Health (Stroke Division; AuSCR Data Custodian) and The George Institute for Global Health, and two leading non-government organisations, the Stroke Foundation and the Stroke Society of Australasia (SSA). Collectively, these organisations represent a broad section of the Australian clinical and scientific stroke community. Significant sanction from clinicians and professional associations for the AuSCR initiative has occurred through the AuSCR Consortium partners and the Australian Stroke Coalition (ASC), a network of clinicians and professional associations (www.australianstrokecoalition.com.au).

The AuSCR Steering Committee provides: governance; maintains the confidence of all parties involved; and contributes to strategic direction. Professor Sandy Middleton continued to be the Chairperson in 2015. 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. Professor Craig Anderson retained the position of Chairperson in 2015. (See Appendix B for committee membership lists.)

In 2015, our NHMRC Partnerships for Better Health grant collaborations through the Stroke123 project have continued with Monash University and Queensland Health contributing funding, along with our existing partner the Stroke Foundation. (See Appendix C for further details on funding.)

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

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 (Victoria, Western Australia, Queensland and New South Wales) 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 data sets and emergency department admissions.

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

Once again in April 2015, we were supported by Boehringer Ingelheim in conducting a national workshop on stroke data and quality that was co-convened with the Stroke Foundation and the Victorian Stroke Clinical Network. Such events provide additional opportunities for clinicians and academics to be involved in translational activities to further enhance stroke care and outcomes.

A significant collaboration has been that of working closely with the Stroke Foundation and the ASC to develop and commence the build of the Australian Stroke Data Tool (AuSDaT). The AuSDaT, when fully implemented, will provide an integrated data management system for several national stroke programs (AuSCR, Stroke Foundation audits, SITS [Safe Implementation of Treatments in Stroke] and INSPIRE [International Stroke Perfusion Imaging Registry]). A significant investment of time, good will and effort will result in a more efficient, standardised approach to stroke data collection in Australia.

APPENDIX B

COMMITTEE MEMBERSHIP

AuSCR STEERING COMMITTEE MEMBERSHIP 2015 (with organisational and state affiliation)

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

Prof Craig Anderson
Senior Director, Neurological & Mental Health Div, The George Institute for Global Health & Head, Neurology Department, Royal Prince Alfred Hospital [NSW]

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

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

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

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

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

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

Dr Erin Lalor
Chief Executive Officer, Stroke Foundation [VIC]

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

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

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

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

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

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

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

Dr Peter Hand
Neurologist, Royal Melbourne Hospital [VIC]

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

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

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

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

AuSCR MANAGEMENT COMMITTEE MEMBERSHIP 2015 (with organisational and state affiliation)

Prof Craig Anderson (Chair)
Senior Director, Neurological & Mental Health Div, The George Institute for Global Health & Head, Neurology Department, Royal Prince Alfred Hospital [NSW]

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

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

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

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

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

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

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

Dr Peter Hand
Neurologist, Royal Melbourne Hospital [VIC]

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

AuSCR RESEARCH TASK GROUP MEMBERSHIP 2015 (with organisational and state affiliation)

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

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

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

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

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

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

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

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

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

APPENDIX C

FUNDING 2015

In 2015, the AuSCR Office was supported by funding and in-kind support from:

- The Florey
- Industry partners
- The NHMRC Stroke123 Partnership grant to support the AuSCR activities in Queensland, which then transitioned to support via a joint initiative with the Stroke Foundation funded by Queensland Health
- The Victorian Stroke Clinical Network
- NHMRC Fellowships that provided salary support to members of the Management Committee (Dominique Cadilhac, Craig Anderson and Chris Levi) to enable them to contribute to initiatives such as the AuSCR. Dominique Cadilhac's Fellowship was co-funded by the Heart Foundation
- The NHMRC: which provides salary via fellowship awards for senior researchers which has assisted in containing staff costs
- Stroke Foundation: provision of significant in-kind support (representing approximately $13,300) in collating and mailing the AuSCR follow-up questionnaires
- Stroke Society of Australasia/Smart Strokes 2015 Conference organising committee: generous provision of exhibition display resources at their conference facilitating an important opportunity to promote the AuSCR and to interact with participating hospital staff at the conference
- Members of the Management Committee and Steering Committee and Research Task Group provide their time 'in-kind'
- We also received *pro bono* legal advice from Roberta Bozzoli (Thomson Geer [Brisbane]) for progressing the Queensland Health Deed of Disclosure

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

ORGANISATION	AMOUNT
2015 Income	
Florey (via NHMRC grant)	$167,307
Florey (other)	$38,978
Queensland Health	$50,000
Monash University*	$125,263
National Stroke Foundation (Partnership Grant)	$90,000
Industry	$8,000
Consumer donations	$0
Victorian government	$210,455
Other**	$4,236
Total	**$694,239**

*NHMRC Partnership grant contribution; staff costs to cover analytic work data reports and 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.
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APPENDIX D

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We gratefully acknowledge contributions made by the AuSCR staff at the Florey Institute of Neuroscience and Mental Health (The Florey): Karen Moss, Adele Gibbs, Alison Dias, Gary Eaton, Grant Stephens, Enna Salama, Kasey Wallis and Kate Paice. We also appreciate the expert statistical advice from Professor Leonid Churilov (The Florey) and contributions from the Information Technology team at The Florey in supporting the AuSCR server hosting and other technical processes.

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

We acknowledge the generous financial support of the AuSCR operations in Victoria by the Victorian Stroke Clinical Network, through State Government Victoria. The National Health and Medical Research Council (NHMRC), Monash University, Queensland Health and the Stroke Foundation have also provided financial support through the Stroke123 Better Health Partnerships grant (2012-2015).

The Florey Institute of Neuroscience and Mental Health also acknowledges the strong support of participating hospitals from the Victorian Government through its Operational Infrastructure Support Grant.

We also acknowledge the staff at 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

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

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

Monash University

Joosup Kim, Nadine Andrew, and Monique Kilkenny (Stroke and Ageing Research Centre, Monash University) conducted the AuSCR data analyses for this report and as required throughout 2015. We are most appreciative of their contributions. The majority of analyses presented in this report were undertaken by Dr Joosup Kim, Research Fellow, under the supervision of Associate Professor Dominique Cadilhac using de-identified data supplied securely by Mr Sam Shehata (AuSCR Data Manager [2015]). Dr Monique Kilkenny (Senior Research Officer) was responsible for the analysis of the risk adjusted mortality data (in consultation with Associate Prof Leonid Churilov from the Florey). Dr Nadine Andrew was responsible for establishing the AuSCR clinical performance benchmarks.

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 2015 and participating hospitals are gratefully acknowledged below.

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Simon Chou
Damiane Clifford
Deirdre Cook
Zoe Cotton
Dijana Cukanovic-Krebs
Jason Denman
Debbie Duncan
Martin Dunlop
Amanda Dyson-Windle
Paula Easton
Diane Fichera
Susan Freiberg
Nisal Gange
Richard Geraghty
Rohan Grimley
Graham Hall
Nicola Hall
Dawn Harwood
Joel Iedema
Peter Jones
Sarah Kuhle
Kylie Lodge
Graham Mahaffey
Jennifer Mann
Merv McAllister
Marie McCaig
Josie McDuff
Gai Meade
Ian Meade
Mandy Parrish
Michaela Plante
Timothy Richardson
Linda Roche
Juan Rois-Gnecco
Linda Roper
Donna Rowley
Arman Sabet
Noel Saines
Lyndell Scott
Robert Scott
Amanda Siller
Rebecca Sjodin
Christopher Staples
Leah Thompson
Lisa Warburton
Richard White
Marie Williams
Raylene Williams
Andrew Wong
Jerry Wong
Lillian Wong
Ann Woolcock

Victoria
Lauren Arthurson
Michaela Bauwens
Carolyn Beltrame
Chris Bladin
Ernie Butler
Chris Charnley
Skye Coote
Joanne Cottrell
Douglas Crompton
Vanessa Crosby
Helen Dewey
Sharan Ermel
Maria Fox
Tanya Frost
Patrick Groot
Casey Hair
Rose Hahn
Peter Hand
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Alison Lowe
Mark Mackay
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Trisha Oxley
Penny Pendrey
Lauren Pesavento
Anne Rodda
Zofia Ross
Kristen Rowe
Jaya Rupesinghe
Margaret Stevenson
Belinda Stojanovski
Vincent Thijs
Vicki Thomas
Lyndsay Trewhella
Mel Ulgade
Louise Weir
Judith Walloscheck

Western Australia
Timothy Bates
Cathy Forrester
Susanne Nielson

Tasmania
Helen Castley
Deirdre Broadby

Participating hospitals

New South Wales
Royal Prince Alfred

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

Victoria
Albury Wodonga Health (Albury)
Austin Health
Ballarat Health Services
Bendigo Health
Eastern Health (Box Hill)
Echuca Regional Health
Goulburn Valley Health
Latrobe Regional
Mildura Base
Northern
Peninsula Health (Frankston)
Royal Children's
Royal Melbourne
South West Healthcare (Warrnambool)
Swan Hill District Health

Western Australia
Swan District

Tasmania
Royal Hobart

APPENDIX E

PUBLICATIONS AND PRESENTATIONS

Journal Publications

Andrew NE, Kilkenny MF, Naylor R, Purvis T, Cadilhac DA. The relationship between caregiver impacts and the unmet needs of survivors of stroke. Patient Preference and Adherence; 9:1065-1073, 2015. *(AuSCR registrants used as a source of respondents [comprised 24% of sample] for the survey that was undertaken on behalf of the Stroke Foundation.)*

Kilkenny MF, Dewey HM, Sundararajan V, Andrew, NA, Lannin, NA, Anderson CA, Donnan GA, Cadilhac DA. Readmissions after stroke: linked data from the Australian Clinical Stroke Registry and hospital databases. MJA, 203(2):102-106, 2015. *(Pilot work undertaken in collaboration with one hospital using data from 2009 and 2010.)*

Annual Report Publication

Cadilhac DA, Lannin NA, Anderson CS, Andrew N, Kilkenny M, Kung F, Grabsch B, Levi C, Faux S, Dewey H, Hill K, Donnan G, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2014. The Florey Institute of Neuroscience and Mental Health; December 2015, Report No 6, pages 65.

Presentations and posters

Multi-Disciplinary Memphis Stroke Conference, The University of Tennessee, Memphis, TN, USA, February, 2015.

Cadilhac, D. Quality metrics and nursing care (invited presentation).

European Stroke Organisation Annual Conference, Glasgow, Scotland, April 2015.

Andrew NE, Kilkenny MF, Lannin NA, Anderson CS, Donnan GA, Hill K, Middleton S, Levi C, Faux S, Grimley R, Thrift AG, Kim J, Grabsch B, Cadilhac DA. Does the association between prescription of antihypertensive medication at discharge from acute care hospitals and post-discharge outcomes vary by stroke subtype? ***Abstract*** published in International Journal of Stroke, 10(S2):16, 2015.

Anderson CS, Cadilhac DA, Lannin NA, Kilkenny MF, Dewey HM, Grimley R, Faux S, Castley H, Bladin C, Middleton SM. Outcomes for younger adults with stroke in the Australian Stroke Clinical Registry (AUSCR). ***Abstract*** published in International Journal of Stroke, 10(S2):74, 2015.

Cadilhac DA, MF Kilkenny, Dewey HM, Lannin NA, Levi C, Hill K, Grabsch B, Grimley R, Anderson CS, Donnan G. Understanding in-hospital stroke management and outcomes in the Australian Stroke Clinical Registry (AUSCR). ***Abstract*** published in International Journal of Stroke, 10(S2):207, 2015.

Andrew NE, Kilkenny MF, Lannin NA, Cadilhac DA. Does the quality of discharge planning following acute stroke influence long-term quality of life and unmet needs? ***Abstract*** published in International Journal of Stroke, 10(S2): 352, 2015.

Australian Clinical Trials Alliance (ACTA) International Clinical Trials Symposium, Sydney, October 2015.

Cadilhac, D. Working smarter not harder: experience of cooperation in acute stroke with a national registry, health services research program and a clinical trial.

Stroke2015 Conference, Melbourne, September 2015.

Cadilhac DA, Andrew N, Salama E, Meade I, Kuhle S, Dunstan L, Horton E, Middleton S, Grimley R. Improving discharge from hospital after stroke: A focus on prevention medication and discharge planning (Workshop).

Thayabaranathan T, Andrew N, Branagan H, Salama E, Grabsch B, Hill K, Cadigan G, Grimley R, Middleton S, Cadilhac D. Understanding the benefits of external support for quality improvement activities in public hospitals for acute stroke: A sub study of Stroke123. Abstract published in International Journal of Stroke, 10 (S3):10-11, 2015.

Grimley RS, Andrew NE, Grabsch B, Coccetti A, Cornwell P, O'Connell C, Cadigan G, Lannin N, Anderson C, Middleton S, Cadilhac D. Dysphagia screening/assessment is associated with reduced 30 day mortality after acute stroke. ***Abstract*** published in International Journal of Stroke, 10 (S3):15, 2015.

Cadilhac DA, Kim J, Lannin N, Levi C, Andrew NE, Kilkenny MF, Grabsch B, Dewey HM, Hill K, Faux S, Grimley R, Middleton S, Anderson C, Donnan GA. The quality of care provided to patients hospitalised with a transient ischaemic attack. ***Abstract*** published in International Journal of Stroke, 10 (S3):27, 2015.

Andrew NE, Kilkenny MF, Lannin NA, Cadilhac D. Patient and system factors associated with the quality of discharge planning from the acute care setting. ***Abstract*** published in International Journal of Stroke, 10 (S3):29, 2015.

Kilkenny MF, Dewey HM, Andrew NE, Lannin NA, Anderson C, Grabsch B, Moss K, Grimley R, Donnan GA, Cadilhac D. Factors associated with readmission after stroke: new evidence from the Australian Stroke Clinical Registry experience. ***Abstract*** published in International Journal of Stroke, 10 (S3):30, 2015.

Cadilhac DA, Hill K, Grimley R, Leonard K, Markus R, Dewey H, Hand P, Branagan H, Mackay M on behalf of the Australian Stroke Coalition Data and Quality Working Group. Improving the quality of stroke care through the harmonization of national stroke data. ***Abstract*** published in International Journal of Stroke, 10 (S3):39, 2015.

Andrew NE, Sundararajan V, Kim J, Kilkenny MF, Katzenellenbogen J, Gattellari M, Thrift AG, Boyd JH, Flack F, Anderson P, Grabsch B, Cadilhac DA. Achieving national cross-jurisdictional data linkage for stroke: A substudy of Stroke 123. ***Abstract*** published in International Journal of Stroke, 10 (S3):45, 2015.

Cadilhac DA, Lannin N, Kilkenny MF, Grabsch B, Andrew NE, Kim J, Donnan GA, Levi C, Dewey HM, Hill K, Faux S, Middleton S, Anderson C. Survival advantage from stroke unit care: Evidence from the Australian Stroke Clinical Registry. ***Abstract*** published in International Journal of Stroke, 10 (S3):46, 2015.

Lannin NA, Cadilhac D, Anderson C, Kilkenny MF, Dewey H, Grimley R, Faux S, Castley H, Middleton S, Bladin C. Clinical outcomes among younger adults with stroke registered in the Australian Stroke Clinical Registry (AuSCR). ***Abstract*** published in International Journal of Stroke, 10 (S3):47, 2015.

Salama E, Andrew N, Meade I, Kuhle S, Grimley R, Cadilhac D. The use of gap analyses to support clinical practice improvement in acute stroke care. ***Abstract*** published in International Journal of Stroke, 10 (S3):53, 2015.

Cadilhac D, Kim J, Thrift A, Andrew N, Kilkenny M, Sundararajan V, Grabsch B, Anderson P, Gattellari M. Linkage of the Australian Stroke Clinical Registry to the National Death Index. ***Abstract*** published in International Journal of Stroke, 10 (S3):67, 2015.

Moss K, Lannin N, Grabsch B, Cadilhac D. Follow-up in a national stroke registry: Lessons learnt from respondents who complete telephone interviews. ***Abstract*** published in International Journal of Stroke, 10 (S3):73, 2015.

5th International Conference on Neurology & Epidemiology, Gold Coast, November 2015.

Andrew N, Lannin N, Anderson CA, Donnan GA, Kilkenny MF, Levi C, Dewey HM, Middleton S, Thrift AG, Faux S, Hill K, Grimley R, Cadilhac DA. Does patient age influence the quality of care received by patients with acute stroke? ***Abstract*** published in Neuroepidemiology, 45(4):321, 2015.

Kilkenny MF, Lannin N, Anderson CA, Dewey HM, Levi C, Faux S, Hill K, Grabsch B, Middleton S, Donnan GA, Grimley R, Thrift AG, Cadilhac DA. Impact of language barriers on stroke care and outcomes: evidence from the Australian Stroke Clinical Registry. ***Abstract*** published in Neuroepidemiology 45(4):324, 2015.

Cadilhac DA, Hill K, Hawker A, Leonard K, Grabsch B, Bladin C, Grimley R, Levi C, Markus R, Middleton S, Lannin N, Dewey HM, Lalor E. Evolution of a stroke data monitoring system to improve stroke care quality in Australia: the new frontier. ***Abstract*** published in Neuroepidemiology 45(4):325, 2015.

9th Health Services and Policy Research Conference, Melbourne, December, 2015.

Cadilhac D, Dewey H, Grimley R, Hill K, Middleton S, Lannin NA, Andrew N, Kilkenny M, Grabsch B, Thayabaranathan T, Salama E, Branagan H, Thrift A, Sundararajan V, Anderson C, Donnan G, Lalor E, Stroke 123 Investigators, ASC Data & Quality Working Group. Overview of stroke initiatives for improving the quality of hospital care.

Hill K, Cadilhac D, Hawker A, Leonard K, Grabsch B, Bladin C, Grimley R, Levi C, Markus R, Middleton S, Lannin NA, Dewey H, Lalor E, ASC Data & Quality Working Group. Efforts to improve national data collection for stroke in Australia.

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APPENDIX F

RESEARCHERS REQUESTING TO USE DATA FROM THE AUSCR IN 2015

In 2015, there were two external applications reviewed by the Research Task Group:

Prospective Memory Function in Stroke Survivors (PIs: Dr Nathan Rose, Prof Peter Rendell, Ms Renee Vella; Cognition and Emotion Research Centre, Australian Catholic University, Sydney). This project was to investigate prospective memory (PM) – the ability to remember to perform intended actions at the appropriate moment in the future - and related functions in community-dwelling stroke survivors.

A Comparison of Compensatory and Restorative Approaches to Memory Rehabilitation Post-Stroke (PIs: Dr Renee Stolwyk, Ms. Toni Withiel, Dr Dana Wong, Prof Jennie Ponsford & Assoc. Prof Dominique Cadilhac; School of Psychological Sciences, Monash University). The aim of the study was to investigate restorative and compensatory approaches to memory rehabilitation post stroke.

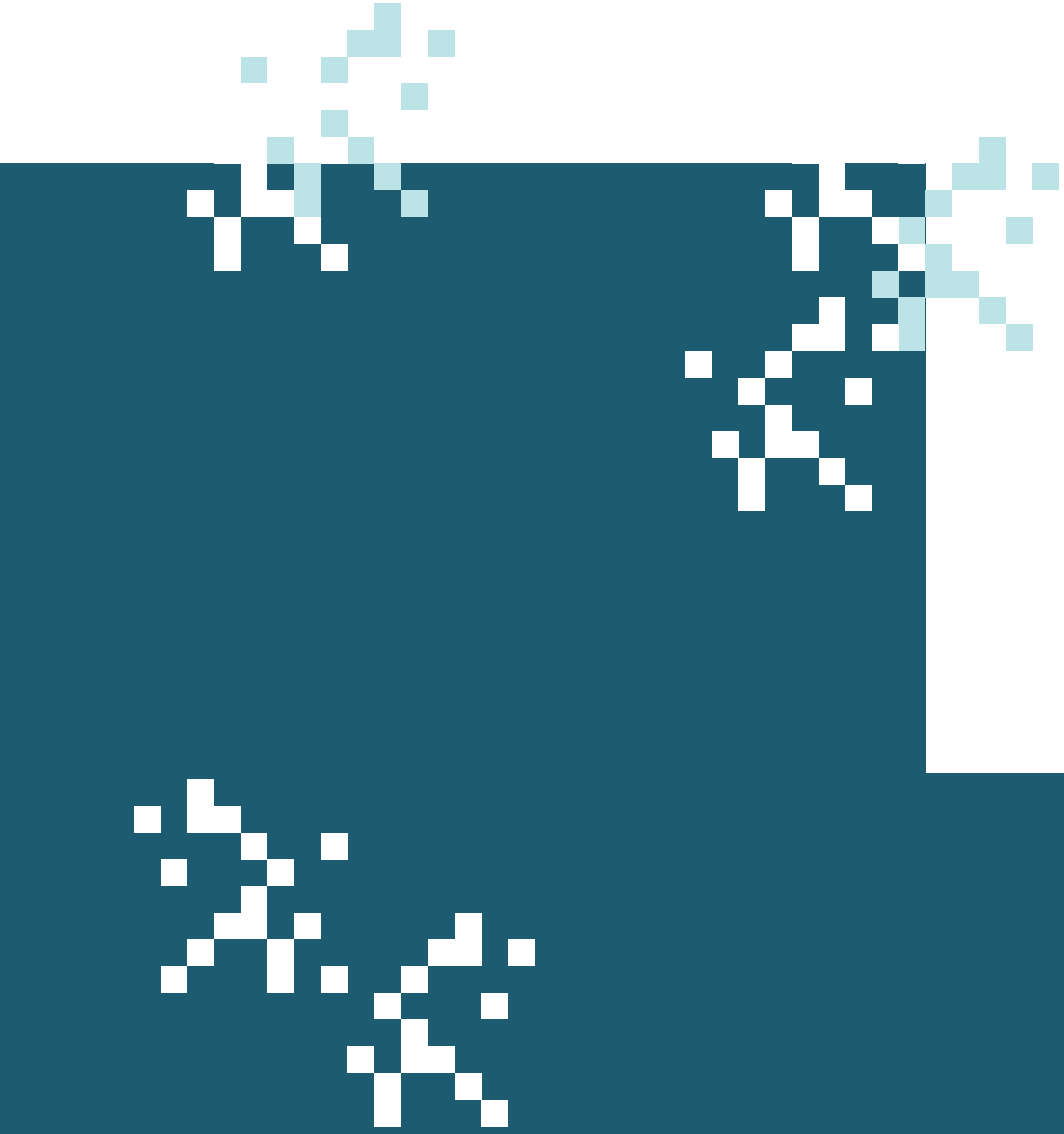
One *internal* project, submitted by AuSCR team members, was reviewed/approved by the Chairs of the Management Committee, Steering Committee and Research Task Group.

National Stroke Foundation (NSF) FAST Campaign Follow-up Evaluation (Investigators: Assoc Prof Dominique Cadilhac, Dr Monique Kilkenny, Ms Alison Wallace and Ms Kym Trobbiani; Monash University, The Florey and the Stroke Foundation). The objective for this project was to contribute to the FAST Campaign Follow-up Evaluation through analysing data from the AuSCR to determine whether the number of strokes and those who received thrombolysis varied over the Stroke Foundation FAST campaign period.

APPENDIX G

ACRONYMS

ABC™	Achievable benchmarks of care
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
APF	Adjusted performance fraction
ARIA	Accessibility/Remoteness Index of Australia
ASC	Australian Stroke Coalition
AuSCR	Australian Stroke Clinical Registry
AuSDaT	Australian Stroke Data Tool
DCE	Discrete Choice Experiment
EQ-5DTM	European Quality of Life - 5 dimension instrument
HRQoL	Health-related quality of life
ICD10	International Classification of Diseases (Version 10)
ICH	Intracerebral haemorrhage
INSPIRE	International Stroke Perfusion Imaging Registry
IQR	Interquartile range
mRS	Modified Rankin Scale
NDI	National Death Index
NHMRC	National Medical Research Council
NIHSS	National Institutes of Health Stroke Scale
NSDD	National Stroke Data Dictionary
QI	Quality improvement
QSSCN	Queensland Statewide Stroke Clinical Network
QSQIP	Queensland Stroke Quality Improvement Program
PROMs	Patient reported outcome measures
RACF	Residential Aged Care Facility
SD	Standard deviation
SITS	Safe Implementation of Treatments in Stroke
SLK	Statistical linkage key
SSA	Stroke Society of Australasia
TIA	Transient ischaemic attack
tPA	Tissue plasminogen activator
VAS	Visual Analogue Scale
VSCN	Victorian Stroke Clinical Network
VST	Victorian Stroke Telemedicine



AuSCR

Australian Stroke Clinical Registry