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EXECUTIVE SUMMARY

The Australian Stroke Clinical Registry (AuSCR) provides a standardised approach for hospitals to monitor, review and improve stroke care in compliance with national acute stroke care standards. This report outlines the patient outcomes for 2019 stroke and transient ischaemic attack (TIA) admissions and is intended to be read in conjunction with the AuSCR 2019 Annual Report Volume 1: Acute Care Provision.

AuSCR participation in 2019 and the collection of patient-reported outcomes

- In 2019, 72 hospitals contributed data to the AuSCR (40% from Victoria, 29% from Queensland, 19% from New South Wales, 4% each from Tasmania and South Australia and 3% from the Australian Capital Territory).
- This report is intended to be read alongside the AuSCR 2019 Annual Report Volume 1: Acute Care Provision (<https://auscr.com.au/about/annual-reports/>).
- At 90-180 days after admission, collection of patient-reported outcomes was completed for 10,413 people who experienced a stroke or transient ischaemic attack (TIA) aged over 18 years. This represented 71% of all eligible episodes for 2019.
- Responders: were predominantly male (57%), had a median age of 72 years and had a median time to follow-up survey completion of 145 days following admission for stroke or TIA.

Patient-reported outcomes obtained 90-180 days following admission

- Most patients were living at home (85%). Compared to patients with ischaemic stroke, patients with intracerebral haemorrhage were less likely to report living at home (OR: 0.57; 95% CI: 0.48-0.69), while patients with TIA were more likely to report living at home (OR: 1.67; 95% CI: 1.37-2.04).
- Approximately 5% of patients had experienced a recurrent stroke, and 23% reported hospital readmissions.
- Almost half of respondents had a score of 0 (25%; representing no disability or symptoms) or 1 (22%; representing no significant disability despite symptoms) on the modified Rankin Scale. Fewer patients with intracerebral haemorrhage (ICH) reported no symptoms at follow up (13%) in contrast to ischaemic stroke (22%), undetermined stroke type (28%) or TIA (45%).
- Health-related quality of life as measured by the EuroQol Five Dimensions Three Levels (EQ-5D-3L) survey indicated that: 48% of patients reported problems with mobility; 31% with self-care; 57% with completion of usual activities; 47% had pain/discomfort; and 46% had anxiety or depression. Patients with ICH reported more problems on all of the five dimensions of quality of life than patients with other types of stroke or TIA.
- Self-reported overall health: The mean Visual Analogue Scale (VAS) score, which represents worst (0) and best (100) imaginable health, was 69 compared to the reported population norm of 83. Mean VAS scores were lowest for ICH (mean 63) and greatest in patients with undetermined stroke (mean 73).
- The overall minimum and maximum adjusted mean VAS scores differed between hospitals by almost 23 points highlighting variation in outcomes depending on which hospital a patient was treated in.

Survival outcomes

- Of the total acute stroke events recorded in 2019, 9% resulted in death prior to hospital discharge, 6% within 90 days of admission, and 2% between 90 and 180 days of admission.
- Treatment in a stroke unit was associated with a lower hazard of death at 180 days after admission than treatment in an alternate ward for patients with either ICH or ischaemic stroke.

Other

- Almost half (49%) of respondents requested more information about stroke at 90-180 days after admission.
- 62% of respondents agreed to be contacted for future research study opportunities.

INTRODUCTION

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

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

In the AuSCR, data are collected on the provision of evidence-based therapies, supplemented with clinical and demographic patient information, to provide an indication of the quality of acute stroke care received. Data are collected in the Australian Stroke Data Tool (AuSDaT) which is a harmonised online platform enabling standardised and systematic collection for multiple national stroke data collection programs.

AuSCR data collection programs facilitate the collection of data for patients with stroke/TIA who are admitted to participating hospitals, and also patients presenting to Emergency Departments (ED) prior to transfer for continued acute care at another hospital. The combination of programs enables the AuSCR to fully document the acute care treatment pathway for patients with stroke or TIA. These programs also enable the collection of the original national minimum processes of care dataset for assessing quality of care.²

For more information on acute data collection in the AuSCR, and acute care provision in 2019, please refer to the 2019 Annual Report Volume 1: Acute Care Provision (<https://auscr.com.au/about/annual-reports/>).

Patient-reported outcomes data are obtained via a standardised survey administered at 90-180 days after admission (also referred to as patient follow-up). In addition to objective outcomes, including subsequent stroke, hospital readmissions and current living arrangements, subjective outcomes including self-

reported functional disability and health-related quality of life are collected, namely the modified Rankin Scale (mRS)⁴ and the EuroQol Quality of Life measure (EQ-5D-3L).⁵ Function and health-related quality of life is also collected from paediatric patients. Paediatric patients use the Pediatric Quality of Life (PedsQL)⁶ Inventory Measurement Model which is a modular approach to measuring health-related quality of life in children and adolescents.

The AuSCR office staff are responsible for following up registrants who have not: been reported as deceased; previously refused follow-up; or opted out of the registry. Patient-reported outcomes data are collected via a paper survey or telephone. A postal survey with a reply paid envelope is mailed to each patient to collect post-discharge information. If the surveys are not returned within six weeks, another set of surveys are posted to the patient and/or next of kin. After another six-week period, a comprehensive telephone attempt to the patient (and next of kin) is conducted. Patient data collected via mail or telephone are entered into the AuSDaT.

If all forms of contact are unsuccessful, then the patient is deemed lost to follow-up, if survivor status is not verified. Survival status is determined via annual data linkage with the National Death Index (NDI) made available by the Australian Institute of Health and Welfare.

In 2019, we received follow-up data for 10,413 admitted episodes of patient care representing 18,733 individual patients from 72 Australian hospitals. The data presented in this report provide insights into the health outcomes of the 2019 registrants in AuSCR.

This report is intended to be read in conjunction with the AuSCR 2019 Annual Report Volume 1: Acute Care Provision (<https://auscr.com.au/about/annual-reports/>).

OVERVIEW OF POST-DISCHARGE OUTCOMES DATA ANALYSES

Unless otherwise stipulated, patient data collected at 90-180 days post admission (ie follow-up data), were analysed using descriptive statistics and multivariable logistic regression, with adjustment for patient case mix using age, sex, stroke type, ability to walk on admission (stroke severity), in-hospital stroke, and patient transfer from another hospital, as appropriate.

All episodes were eligible for follow-up except:

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

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

Where comparisons are presented with large sample sizes, the reader should consider that the clinical relevance related to proportional differences may be more important than the statistical significance.

Functional disability is measured using the modified Rankin Scale (mRS) which is a standardised instrument used to categorise deficits after stroke.⁴ It provides a simple descriptive profile across six levels including: 0 (no symptoms at all); 1 (no significant disability despite symptoms); 2 (slight disability); 3 (moderate disability); 4 (moderately severe disability) and 5 (severe disability). The mRS analyses in this report *do not* include values of 6 (to signify death) for patients who were deceased at the time of follow-up. Registrants were asked to rate their level of functional disability on the day of completion of the follow-up survey.

Multivariable ordinal analysis of mRS data was performed using partial proportional odds models to assess changes across the scores between 0 to 5. As recommended by the European Stroke Organisation (<https://eso-stroke.org/outcome-measures-stroke-modified-rankin-scale-ordinal-logistic-regression/>), these analyses were adjusted for patient case mix differences, clustering by hospitals, and presented as common odds ratios. Common odds ratios can be interpreted as the odds of a patient shifting to a higher (or more severe) category of the mRS. For example, a common odds ratio of 0.80 for a treatment would mean that for a patient with an mRS of 4, the

treatment would increase a patients chance of reporting a mRS score of 0 to 3 by 20%.

Health-related quality of life (HRQoL) is measured in the AuSCR using the European Quality of Life measure of health status (EQ-5D™)⁵, specifically the three-level version of the instrument EQ-5D-3L. The EQ-5D-3L is a standardised survey instrument used as a generic 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 dimension is divided into three levels: no problems (1), some or moderate problems (2) and extreme problems (3). Responses to the EQ-5D-3L were dichotomised and reported based on whether registrants had 'any' (ie moderate or extreme) versus 'no' problems with each dimension.

Additionally, the EQ-5D-3L includes a self-rated summary score of overall health using a Visual Analogue Scale (VAS). The VAS responses range from zero (worst imaginable health state) to 100 (the best imaginable health state). Responses to the VAS were described using the mean (and standard deviation) to facilitate comparisons with published estimates for the normative population. For hospital comparisons, mean VAS scores were standardised to adjust for differences in case mix using methodology similar to that described below for mortality. Where possible, reference to the median (and interquartile range) was also made to assist in the interpretation of results.

Other patient-reported outcomes such as subsequent stroke(s), hospital readmissions, current living arrangements, need for stroke information and interest in future research participation are captured with single item standalone questions.

Case mix adjusted survival is measured using data obtained from linkage to the NDI. Analysis of deaths up to 180 days following admission was performed for those who had experienced an episode of care in 2019. Cox proportional hazards regression analysis was also performed on survival status for those who received stroke unit care, compared with those who did not. The survival analysis was adjusted for age, sex, stroke type, in-hospital stroke, transfer from another hospital and ability to walk on admission.

Risk-adjusted mortality rate (RAMR) was calculated for each hospital based on admitted patients who had died within 30 days of their admission. Separate RAMR were calculated for patients with ischaemic stroke and intracerebral haemorrhage (ICH). To ensure reliable estimates, analyses were conducted for individual hospitals that provided at least 200 episodes for cases of ischaemic stroke, and at least 50 episodes for ICH in 2019. For hospitals with fewer episodes, data from 2018 and 2019 were pooled and used to derive mortality estimates if the minimum number of episodes was achieved across both years (i.e. at least 200 episodes for cases of ischaemic stroke, and at least 50 episodes for ICH).

RAMR analyses were completed using two different methods. The first method *excluded* patients who were transferred from another hospital, in-hospital strokes and patients with TIA. This method is consistent with previous AuSCR Annual Reports whereby deaths are summarised for patients treated at only one hospital and are fully attributed to that hospital.

The second RAMR method *included* patients who were managed by more than one hospital for their episode of stroke care (ie included all patients treated at an individual hospital irrespective of whether they presented directly or were transferred). In this analysis, multiple episodes related to the same acute stroke event were included, and mortality was attributed equally to all hospitals involved in the provision of patient care for that stroke event. RAMR were calculated by dividing the risk-adjusted hospital specific mortality by the risk-adjusted average hospital mortality, and then multiplying by the unadjusted proportion of deaths in the whole sample. Hospitals with risk-adjusted mortality outside the three standard deviation threshold limits are considered to have 'special cause variation'. All analyses were performed using STATA/SE 16.0 (College Station, USA, 2019).

All RAMR models were adjusted for age, sex, country of birth, Indigenous status, socioeconomic position, stroke type, ability to walk on admission and previous history of stroke. Socioeconomic position was based on the Index of Relative Socioeconomic Advantage and Disadvantage, an area-based measure of social and economic circumstances published by the Australian Bureau of Statistics. This measure of socioeconomic

position was determined for each patient using the postcode of residence recorded in the AuSCR for the acute episode.

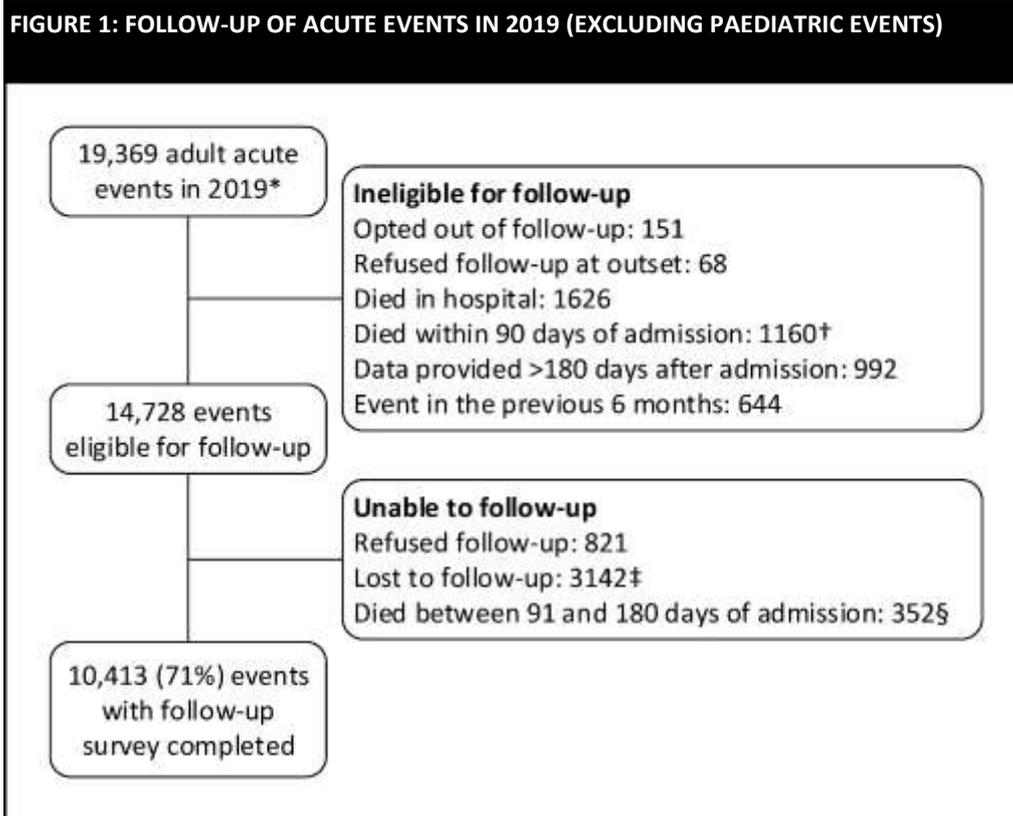
POST-DISCHARGE HEALTH OUTCOME INFORMATION

RESPONSE RATES

Of the 14,728 adult acute events eligible for follow-up by the AuSCR office, patients or their proxy provided follow-up data for 10,413 (71%) acute events (Figure 1). Median time to follow-up was 145 days from stroke admission (Q1 to Q3: 108 to 187 days).

There were 39 acute events occurring in patients under the age of 18. Of these, 27 were treated in a children's hospital and 12 were treated in adult

hospitals. Of the total paediatric stroke events, 14 were ineligible for follow-up as 3 events were fatal, 1 event was within 180 days of a previous event, and 10 were registered in the AuSCR after 180 days. Of the remaining 25 paediatric events eligible for follow-up, 21 follow-ups were completed by patients or their proxies. Three patients were aged less than 1 year, eight were aged between one and 11 years, and ten were aged between 12 and 18 years.



* Number of acute events differ slightly from values reported in Volume 1 of the 2019 AuSCR Annual Report as a separate data extract was provided for this report in which additional data cleaning operations had been performed by the AuSCR office.

† Deaths after discharge and within 90 days of admission were determined using the NDI.

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

§ Deaths between 91 and 180 days of admission were determined using the NDI. Note that this figure does not represent total deaths between 91-180 days following admission as some deaths occurred after completion of the follow-up survey.

FOLLOW-UP DATA

Of the patients eligible for follow-up, differences were identified in both demographic and clinical characteristics, as well as in processes of care which are the basis of our quality indicators (Table 1).

At follow-up, approximately 5% of patients had experienced a recurrent stroke and almost one in four registrants (23%) reported hospital readmissions (Table 2). The most common reasons for readmissions were for recurrent stroke or TIA (18%) or for cardiovascular disease (16%; Table 2). There were no significant associations between stroke type and either recurrent stroke ($P=0.56$) or subsequent hospital readmission ($P=0.25$).

Most registrants were living at home (85%), while 24% of registrants were living alone. There were 1,124 registrants (11%) living in low- or high-level residential care for whom information at follow-up was obtained. Differences in living situation were observed based on stroke type after adjustment for age, sex, socioeconomic position, and ability to walk on admission. Compared to patients with ischaemic stroke, patients with intracerebral haemorrhage were less likely to report living at home (OR: 0.57; 95% CI: 0.48, 0.69) while patients with transient ischaemic attack were more likely to report living at home at the time of follow-up (OR: 1.67; 95% CI: 1.37, 2.04).

TABLE 1: CHARACTERISTICS OF PATIENTS WITH AND WITHOUT POST DISCHARGE INFORMATION

	Completed (N= 10,413)	Not completed (N= 4,315)	P Value
Age (years), mean (SD)	72 (13)	70 (15)	<0.001
Female, n (%)	4,389 (43)	1,887 (45)	0.003
Aboriginal and/or Torres Strait Islander, n (%)	164 (2)	136 (4)	<0.001
Type of stroke, n (%)			
<i>Ischaemic</i>	7,555 (73)	2,954 (70)	<0.001
<i>Intracerebral haemorrhage</i>	848 (8)	446 (11)	
<i>Transient ischaemic attack</i>	1,776 (17)	764 (18)	
<i>Undetermined</i>	163 (2)	68 (2)	
Able to walk on admission, n (%)	5,102 (52)	1,826 (46)	<0.001
Length of hospital admission (days), median (Q1 to Q3)	4 (2 to 7)	4 (2 to 8)	<0.001
Treated in a stroke unit, n (%)	8,534 (82)	3,351 (78)	<0.001

Excludes paediatric episodes

SD: standard deviation

Q1: 25th percentile

Q3: 75th percentile

TABLE 2: RECURRENT STROKES, READMISSIONS AND LIVING ARRANGEMENTS

	N= 10,413
	n (%)
Had a recurrent stroke	525 (5%)
Readmitted to hospital	2,331 (23%)
Time to readmission (days), median (Q1, Q3)	81 (42, 126)
Reason for readmission	N= 2,321
Stroke or transient ischaemic attack	428 (18%)
Cardiovascular disease	364 (16%)
Elective surgery	243 (10%)
Injury	228 (10%)
Other neurological condition	163 (7%)
Infection	151 (7%)
Respiratory disease	132 (6%)
Gastrointestinal disease	112 (5%)
Other	500 (22%)
Location at time of follow-up interview	N= 10,404
<i>Home</i>	8,840 (85%)
<i>Living alone</i>	2,150 (24%)
<i>Living with others</i>	6,636 (76%)
<i>With care support</i>	4,262 (48%)
<i>Without care support</i>	4,578 (52%)
<i>Institutional care or other setting</i>	1,497 (15%)
<i>In hospital</i>	108 (7%)
<i>Transitional care services</i>	97 (6%)
<i>Low level care (hostel care)</i>	97 (6%)
<i>High level care (nursing home)</i>	1,027 (69%)
<i>Inpatient rehabilitation</i>	103 (7%)
<i>Other</i>	65 (4%)

Missing data not included in denominators

Excludes paediatric episodes

DISABILITY – MODIFIED RANKIN SCALE

The mRS is widely used in stroke studies to describe person-centred global disability outcomes in terms of the degree of disability, or dependence, in daily activities with reference to pre-stroke activities. At follow-up, 25 percent of registrants reported they were free from disability (mRS score = 0) and 22 percent had no significant disability despite symptoms (mRS score = 1; Table 3).

The unadjusted median mRS score reported by patients with ICH was 3 (ie moderate disability), compared to a median mRS score of 2 (ie slight disability, but can manage own affairs without assistance) for patients with ischaemic stroke, and 1 (i.e. no significant disability despite symptoms) for patients with undetermined stroke or TIA (Figure 2).

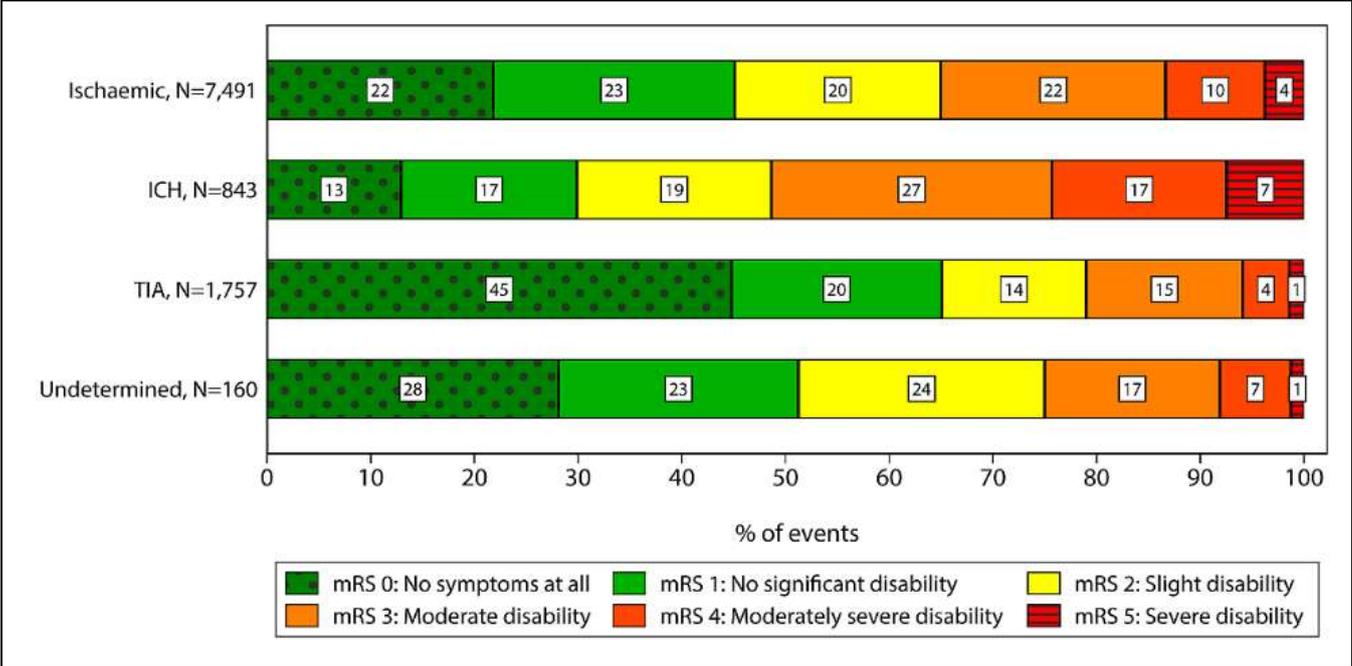
In the adjusted ordinal analysis of the mRS (<https://eso-stroke.org/outcome-measures-stroke-modified-rankin-scale-ordinal-logistic-regression/>), patients with ICH were 85% more likely to report disability across increasing categories of the mRS than patients with ischaemic stroke (common OR: 1.85; 95% CI: 1.62,2.12). In contrast, patients with undetermined stroke type were 27% less likely to report disability across increasing categories of the mRS compared to patients with ischaemic stroke (common OR: 0.73; 95% CI: 0.55,0.97). These estimates were adjusted for patient clustering by hospital as well as age, sex, socioeconomic position, Aboriginal or Torres Strait Islander background, ability to walk on admission, history of previous stroke, in-hospital stroke, hospital transfer status, management in a stroke unit, and country of birth.

Of the 1,220 episodes where endovascular clot retrieval (ECR) was provided in 2019, mRS data were available for 729 patients with completed follow-up surveys. The mRS scores of these patients who received ECR are shown in Figure 3. Of note is that people who are eligible for ECR have a more severe type of stroke associated with large vessel occlusion in an artery of the brain, and this is why the proportion of patients reporting independence after treatment will vary in contrast to all people who have experienced an ischaemic stroke.

TABLE 3: UNADJUSTED MODIFIED RANKIN SCALE SCORES AT FOLLOW-UP

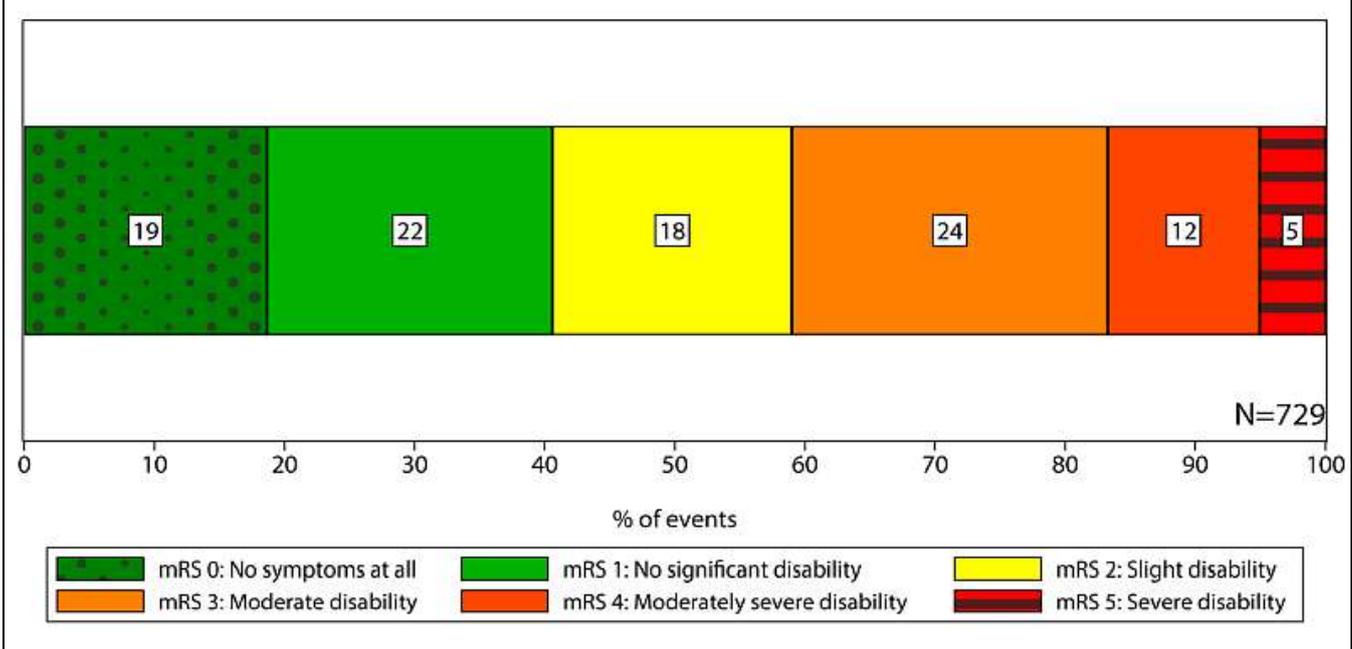
	N=10,413
	n (%)
Modified Rankin Scale	
<i>0 – No symptoms at all</i>	2,593 (25%)
<i>1 – No significant disability despite symptoms</i>	2,297 (22%)
<i>2 – Slight disability</i>	1,941 (19%)
<i>3 – Moderate disability</i>	2,155 (21%)
<i>4 – Moderately severe disability</i>	961 (9%)
<i>5 – Severe disability</i>	374 (4%)
<i>Missing</i>	92 (1%)

FIGURE 2: UNADJUSTED MODIFIED RANKIN SCALE SCORE BY STROKE TYPE AT FOLLOW-UP



mRS: modified Rankin Scale
ICH: intracerebral haemorrhage
TIA: transient ischaemic attack

FIGURE 3: UNADJUSTED MODIFIED RANKIN SCALE SCORE FOR PATIENTS RECEIVING ENDOVASCULAR CLOT RETRIEVAL AT FOLLOW-UP



mRS: modified Rankin Scale

HEALTH-RELATED QUALITY OF LIFE

With respect to health-related quality of life, problems were most frequently reported with completion of usual activities (Figure 4). This was consistent across all stroke types (Table 4). Patients with ICH reported problems in all dimensions of the EQ-5D-3L more commonly than the other diagnoses. Overall, 74% of respondents reported problems with at least one dimension of the EQ-5D-3L with this proportion being greatest for those diagnosed with ischaemic stroke (85%; Table 4).

The mean Visual Analogue Scale (VAS) score, which represents a registrants' self-reported overall health, was 69 (median: 73; min-max: 0-100). Differences in VAS scores were observed by stroke type, whereby registrants with ICH had the lowest aggregate VAS

scores (mean: 63; median 67; Table 4) and registrants with undetermined stroke had the greatest VAS scores (mean: 73; median 79).

The VAS scores reported by AuSCR registrants should be considered in relation to a mean of 83 reported for the normative population of adults in the United Kingdom.⁷ Compared to this reference population, the VAS scores of AuSCR registrants were >10 points worse after stratifying by age and sex (Table 4). As these differences exceed 8 points, they represent a clinically meaningful difference.⁸

The overall minimum and maximum adjusted mean VAS scores differed between participating hospitals by almost 23 points after adjustment for differences in patient and clinical characteristics (Figure 5).

FIGURE 4: UNADJUSTED PROPORTION OF PATIENTS REPORTING PROBLEMS WITH THE EQ-5D-3L

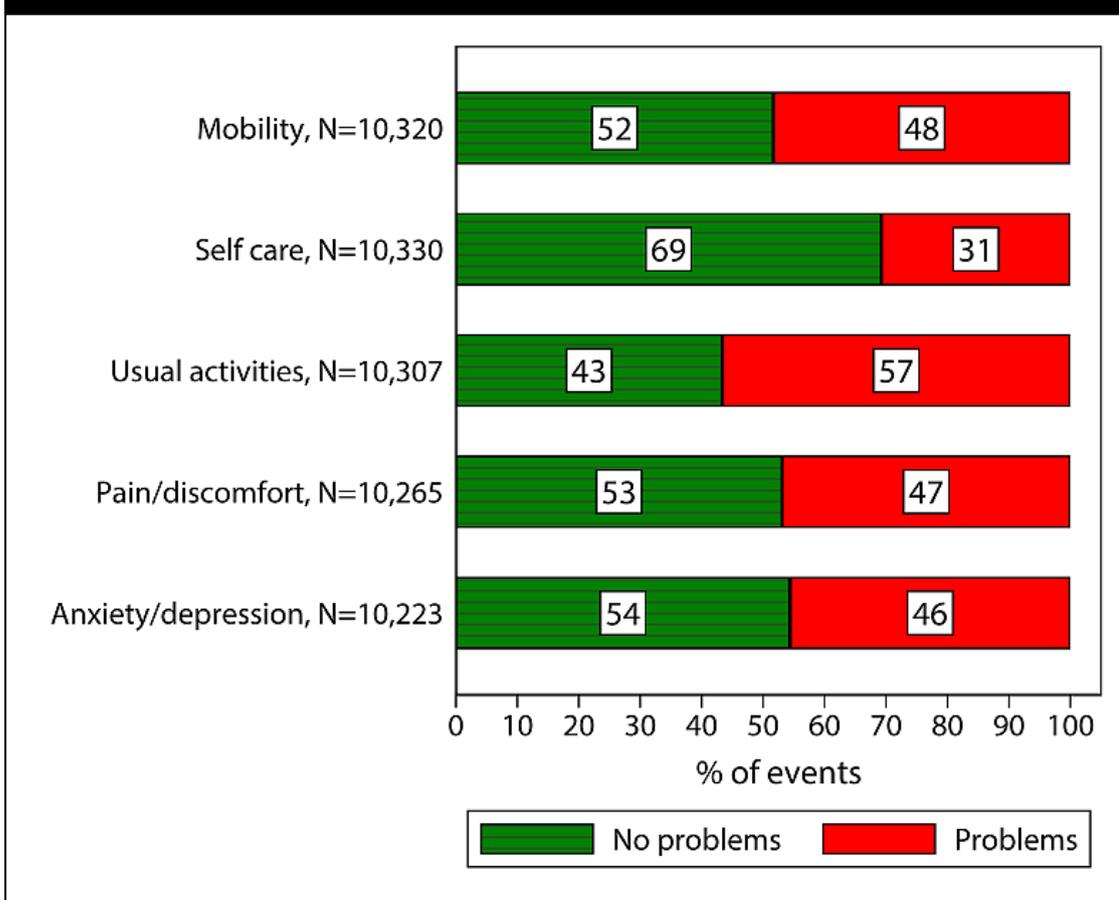


TABLE 4: UNADJUSTED QUALITY OF LIFE ASSESSMENT AMONG SURVEY RESPONDENTS, STRATIFIED BY STROKE TYPE

	Ischaemic N=7,555	ICH N=848	TIA N=1,776	Undetermined N=163
Proportion of patients reporting problems with each dimension of the EQ-5D-3L				
<i>Mobility</i>	49%	61%	40%	41%
<i>Self-care</i>	31%	46%	21%	26%
<i>Usual activities</i>	58%	74%	43%	51%
<i>Pain/Discomfort</i>	47%	56%	42%	48%
<i>Anxiety/Depression</i>	46%	55%	41%	46%
Proportion of patients reporting problems with ≥1 dimension of the EQ-5D-3L	85%	75%	65%	75%
VAS mean (SD)	68 (22)	63 (23)	72 (20)	73 (19)
VAS median (Q1-Q3)	73 (50-85)	67 (50-80)	75 (60-89)	79 (60-85)

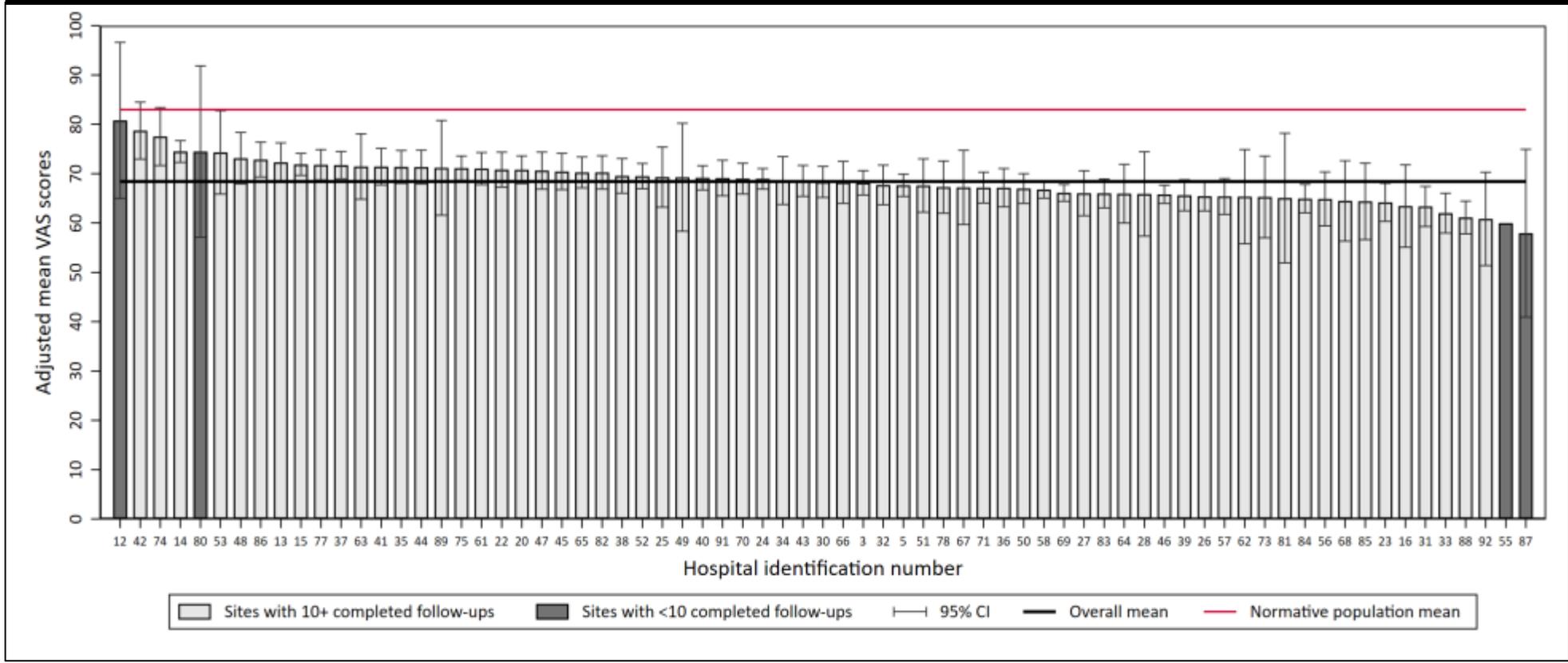
Missing responses (<2%) excluded from denominators

ICH: intracerebral haemorrhage

TIA: transient ischaemic attack

Excludes paediatric episodes

FIGURE 5: HEALTH-RELATED QUALITY OF LIFE SCORES ACCORDING TO THE ADJUSTED VAS AT FOLLOW-UP, BY HOSPITAL



Adjusted for differences in patient age, sex, socioeconomic position, country of birth, Indigenous status, type of stroke, in-hospital stroke, history of previous stroke, and ability to walk on admission.

Mean of 83 for the normative adult population was obtained from the United Kingdom.⁷

The median number of responders to the VAS survey per hospital was 119 (min-max: 1-666).

SURVIVAL

Survival status was ascertained for the entire AuSCR cohort using data linkage with the National Death Index. Of the total acute stroke events recorded in 2019, 9% of events resulted in death prior to hospital discharge, 6% between discharge and 90 days of admission, and 2% between 91 and 180 days of admission. For patients with ischaemic stroke, treatment in a stroke unit was associated with a 50% lower hazard of death at 180 days after admission than treatment on an alternate ward (hazard ratio 0.50, 95% confidence interval 0.45,0.55, $p < 0.001$, Figure 6). A larger effect of a 64% lower hazard of death, was found for patients with ICH (hazard ratio 0.36, 95% confidence interval 0.31,0.41, $p < 0.001$, Figure 7). These analyses were adjusted for age, sex, ability to walk on admission, in-hospital stroke and transfer from another hospital.

FIGURE 6: CUMULATIVE HAZARD OF DEATH, BY TREATMENT IN A STROKE UNIT (ISCHAEMIC STROKE)

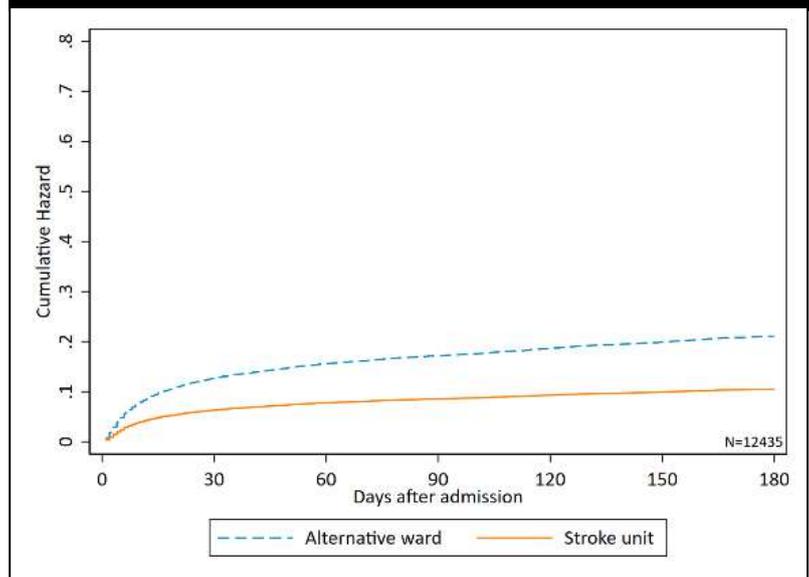
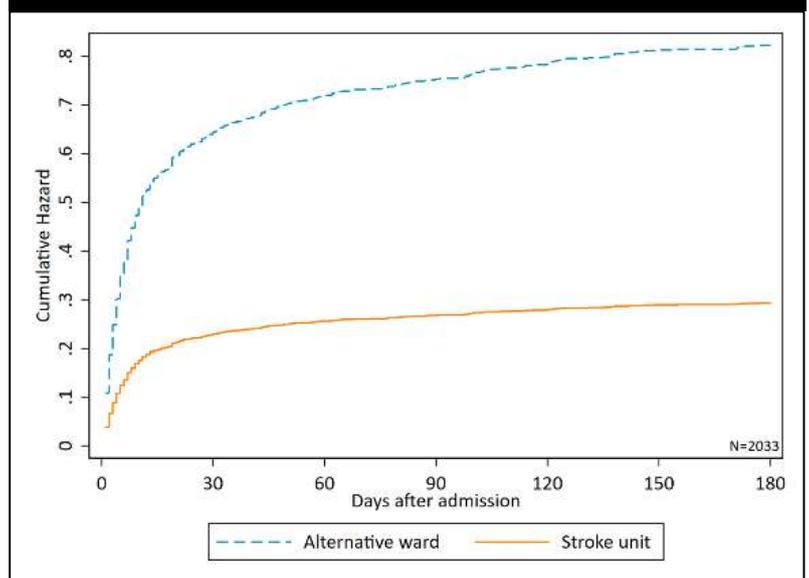


FIGURE 7: CUMULATIVE HAZARD OF DEATH, BY TREATMENT IN A STROKE UNIT (INTRACEREBRAL HAEMORRHAGE)



RISK-ADJUSTED MORTALITY

Risk-adjusted mortality rate comparisons at 30 days following admission for ischaemic stroke and ICH have been plotted for tertiary referral hospitals that offer ECR services (yellow dots) and for other hospitals that do not offer ECR services (black dots; Figures 8 to 11).

To ensure reliable estimates, analyses were conducted for individual hospitals that provided at least 200 episodes of ischaemic stroke and at least 50 episodes of ICH in 2019. For hospitals with fewer episodes, data from 2018 and 2019 were pooled and used to derive mortality estimates if the minimum number of episodes was achieved across both years (ie at least 200 episodes of ischaemic stroke and at least 50 episodes of ICH).

The risk-adjusted mortality rate for tertiary referral hospitals have been colour-coded separately as these hospitals are more likely to treat a different cohort of patients with stroke, including more complex and severe cases, than other hospitals participating in the AuSCR.

For the first time in the evaluation of overall risk-adjusted mortality, we have also analysed and reported data for patients managed by more than one hospital for their stroke event. In this analysis, mortality was attributed equally to all hospitals involved in the treatment of the acute stroke event (Figures 10 and 11). The inclusion of hospital transfers in RAMR calculations resulted in an additional 3,182 episodes being included for ischaemic stroke and 561 for ICH.

All RAMR models were adjusted for age, sex, country of birth, Indigenous status, socioeconomic position, stroke type, ability to walk on admission and previous history of stroke. Combined 2018 and 2019 data were used to maximise the sample size available for analysis, where required, at smaller hospitals.

While there was some evidence of variation in RAMR between hospitals, no hospitals exhibited special cause variation (ie mortality more than three standard deviations above the mean).

FIGURE 8: 30 DAY RISK-ADJUSTED MORTALITY FOR ISCHAEMIC STROKE, (EXCLUDING TRANSFERS)

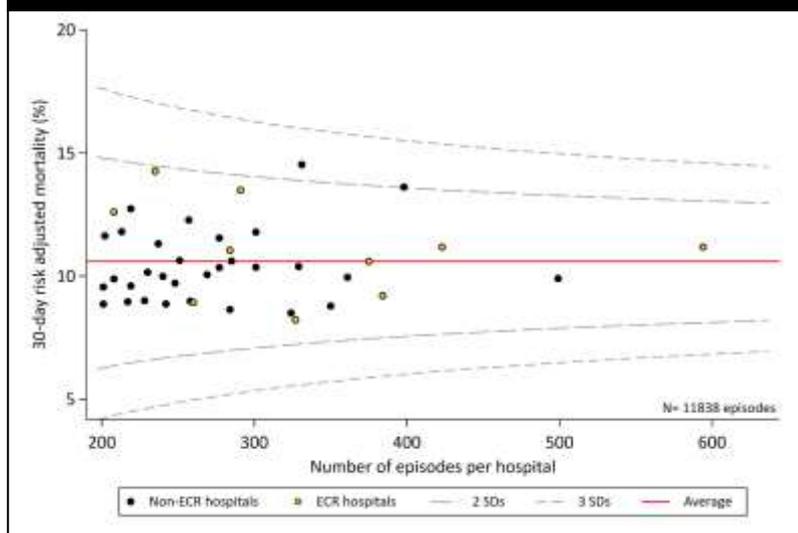
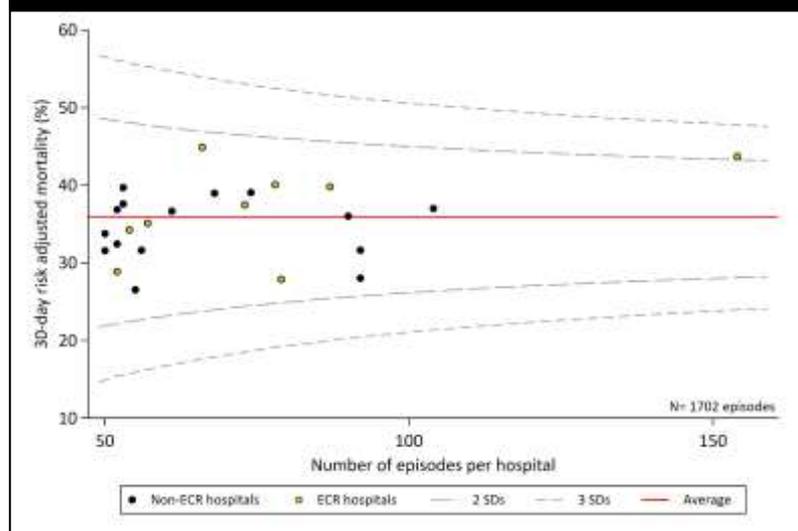


FIGURE 9: 30 DAY RISK-ADJUSTED MORTALITY FOR INTRACEREBRAL HAEMORRHAGE (EXCLUDING TRANSFERS)



Each dot represents the risk-adjusted percentage of patients who were deceased within 30 days of admission at each hospital.

Yellow dots represent large tertiary referral hospitals which provided ECR services (ie hospitals participating in the AuSCR Black or Violet programs). Black dots represent other hospitals which did not offer ECR services (ie hospitals participating in the AuSCR Red, Navy or Green programs).

Excludes transfers, in-hospital strokes and hospitals with less than 200 episodes for ischaemic stroke or less than 50 episodes for intracerebral haemorrhage.

Each dot represents the risk-adjusted percentage of patients who were deceased within 30 days of admission at each hospital.

Yellow dots represent large tertiary referral hospitals which provided ECR services (ie hospitals participating in the AuSCR Black or Violet programs). Black dots represent other hospitals which did not offer ECR services (ie hospitals participating in the AuSCR Red, Navy or Green programs).

Excludes in-hospital strokes and hospitals with less than 200 episodes for ischaemic stroke or less than 50 episodes for intracerebral haemorrhage.

FIGURE 10: 30 DAY RISK-ADJUSTED MORTALITY FOR ISCHAEMIC STROKE (INCLUDING TRANSFERS)

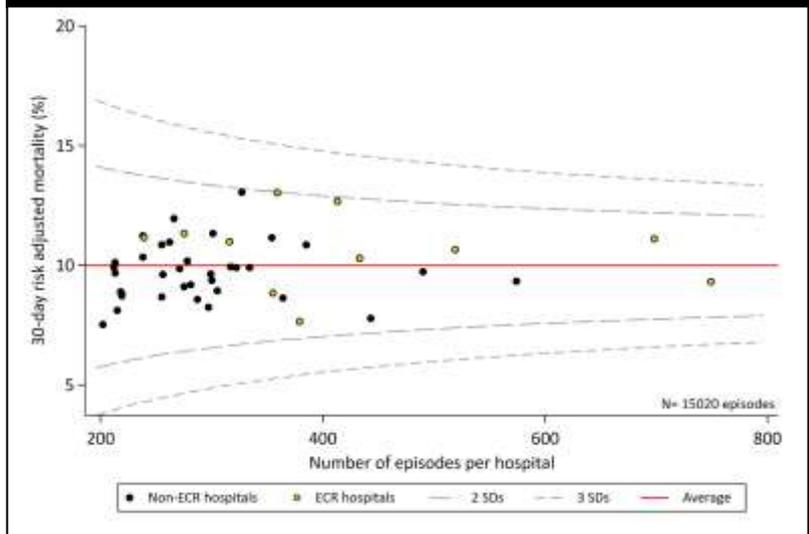
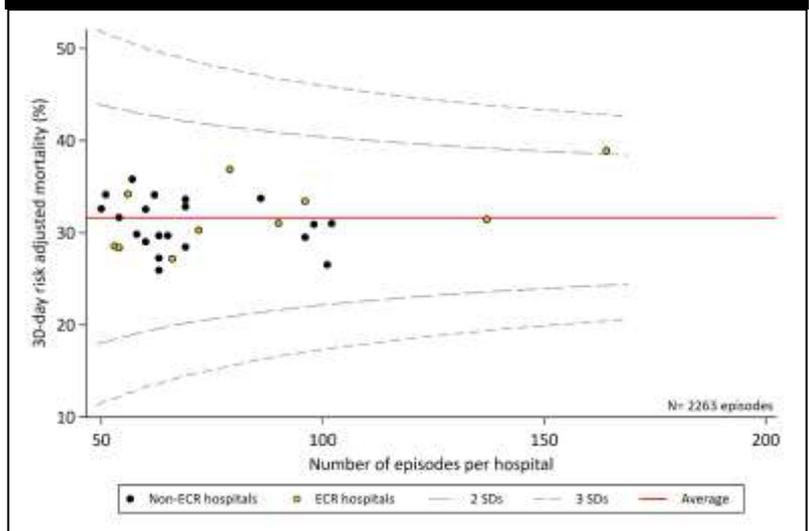


FIGURE 11: 30 DAY RISK-ADJUSTED MORTALITY FOR INTRACEREBRAL HAEMORRHAGE (INCLUDING TRANSFERS)



For information on how to interpret funnel plots please refer to page 7 of the AuSCR 2019 Annual Report Volume 1: Acute Care Provision.

PARTICIPATION IN RESEARCH

Among the 10,117 registrants who answered the question about whether they would be willing to be contacted to participate in future research, 6,254 (62%) replied affirmatively. Compared to those who did not reply in the affirmative, these patients were younger (median age 73 vs 77 years, $p < 0.001$) and more often male (60% vs 54%, $p < 0.001$).

UNMET INFORMATION NEEDS

Stroke can be a devastating and life changing event for people and there is a possibility that stroke survivors and their care providers have unmet care and information needs. Given that the AuSCR protocol includes a follow-up survey with survivors at 90-180 days post stroke or TIA, it presents an opportunity to ask registrants whether they would like to receive further information about stroke from the Stroke Foundation. In 2019, 49% ($n=4,990$) of the 10,115 registrants who answered this question indicated that they would like to receive an information package.

DISCUSSION

This report outlines the patient outcomes for 2019 stroke and TIA admissions and is intended to be read in conjunction with the AuSCR 2019 Annual Report Volume 1: Acute Care Provision.

Follow-up data collection

The overall rate of follow-up completion for eligible registrants increased to 71% in 2019, from 69% in 2018 and 65% in 2017. This represents a very high rate of completion when compared to other international stroke registries such as SSNAP, which complete patient follow-up on 30% of eligible patients.⁹ The trend of increased rates of follow-up completion is a testament to the hard work and refined protocols of the AuSCR office. Ongoing training and support for hospital staff are provided by the AuSCR office, with an increased emphasis on timely data entry to enable follow-up completion at 90-180 days post admission since 2017.

Patient outcomes

This findings in this report illustrate high levels of patients reporting difficulty across all five dimensions of the EQ-5D-3L ranging from 31% for self-care to 57% for difficulties in completing the usual activities of daily living. The overall mean VAS score of 69 as a measure of overall health (when compared to the normative population mean value of 83) is also indicative of ongoing health problems. Twenty-three percent of patients documented readmissions at 90-180 days after admission (with 18% of these for recurrent stroke or TIA), and almost half (49%) of patients requested more information about stroke. To address these findings, there is a pressing need to consider improved models of care and support for patients with stroke following hospital discharge. National Registries, such as the AuSCR, are ideally placed to play an important role in the development and monitoring of such models of care, where routinely collected follow-up data could be used to identify patients with high levels of health needs, or those at risk of poor outcomes (eg readmissions). Summaries of individual patient data could then be fed back to participating hospitals and this information could prompt an outpatient review of those most in need and or at risk of poor outcomes. In the year ahead, the AuSCR will aim to build upon previous experience with summarising patient-reported

outcome data⁷ to develop and test the effectiveness of new models of care to improve patient outcomes after stroke.

Significant variation in case mix adjusted analyses of the EQ-5D-3L VAS was identified between hospitals in the 2019 dataset. The difference in mean VAS scores between the best and worst performing hospital was 23 points. The clinically meaningful difference in VAS scores for patients with stroke has been reported by previous authors as eight points⁷ and further analysis to explore the factors contributing to these variations is required. The results reported using the AuSCR 2019 dataset also suggest that the VAS data may play an important role in ongoing hospital quality improvement initiatives such as the, StrokeLink and Tasmanian Community of Practice programs.

The proportion of registrants who received endovascular clot retrieval and reported an unadjusted mRS scores of 0 to 2 was 59%. This is an encouraging finding when compared to the Highly Effective Reperfusion Using Multiple Endovascular Devices (HERMES) collaboration finding 46% (291/633) of patients with a mRS score between 0 to 2 using pooled data reported from multiple ECR interventional studies.¹² In the adjusted ordinal analysis of mRS data, patients with ICH were more likely to report disability across increasing categories of the mRS than the other stroke types or TIA. These observations align with the unadjusted mRS scores by stroke type reported using AuSCR data previously (<https://auscr.com.au/about/annual-reports/>).

For the first time in the AuSCR Annual Report series, the risk-adjusted mortality analyses were presented using different methods to analyse the 2019 data. This included delineation of tertiary referral hospitals and non-tertiary referral hospitals; and by reporting statistical models that both excluded and included patients who had been treated for their acute event by more than one hospital. Our analytical team and supporting Management and Steering Committee

representatives believe the delineation of tertiary referral hospitals in this report enabled clearer comparisons of mortality rates for hospitals that are likely to have a greater number of complex and severe patients. If we did not enhance the reporting of RAMR calculations, we may not have been able to account for all differences in our statistical models of case mix adjustment.

The inclusion of patients who were managed in more than one hospital (ie irrespective of whether they presented directly to a hospital or were transferred for care) for the RAMR analyses enabled a more realistic assessment of RAMR for hospitals with high rates of patient transfers. Large tertiary hospitals therefore have a complete overview of mortality for their patient cohort when compared with models that exclude patient transfers. In general, the exclusion or inclusion of transferred patients receiving care at more than one hospital made very little difference to RAMR.

While it is reassuring to report that no hospitals exhibited special cause variation in RAMR, it must be acknowledged that there may be other confounding factors which contribute to mortality rates (eg patient co-morbidities, size of the infarct or occlusion) and that the RAMR completed by the AuSCR can only adjust for routinely collected variables. The NIHSS is commonly used for case mix adjustment in the field of stroke.¹⁰ However, while the completion rate of the NIHSS variable has improved significantly since 2016 (with only 2% missing data in 2019), 42% of baseline NIHSS scores are still documented as 'unknown' ([see AuSCR 2019 Data Quality Report](#)). We are therefore unable to adjust RAMR reliably using the NIHSS, and continue to use the ability to walk on admission as a proxy for stroke severity.¹¹ The AuSCR will continue to work with hospitals to improve the rate of NIHSS documentation, and to identify barriers to completion of this measurement in clinical practice. Improvements in the methods for case mix adjustment for RAMR are also being explored, so that fairer comparisons between hospitals with similar patient cohorts can be included in future reports.

Patient outcomes presented in this report may also have been influenced by patient discharge destination, with the authors of previous studies reporting differences in patient outcomes for those discharged to inpatient rehabilitation, versus those who were discharge home or to a residential aged care facility.¹³ Associations between discharge destination and patient

outcomes such as mortality, subsequent readmissions, and Health-related Quality of Life (HRQoL) will be further explored in future AuSCR Annual Reports.

Conclusion

Patient outcomes for AuSCR registrations in 2019 were similar to those observed using 2018 data. The continued levels of unmet health needs reported by patients with stroke, and the demand for more information about stroke following hospital admission, support the development and testing of new post-discharge models of patient care. The collection of standardised patient-reported outcomes data at 90-180 days in the AuSCR, means this leading national registry is in an ideal position to facilitate the identification of patients with high levels of health needs, or those at risk of poor outcomes, for further support by treating hospitals. Future work will be undertaken to develop and test novel models of post-discharge support for patients with stroke.

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APPENDIX A: ABBREVIATIONS

AuSCR	Australian Stroke Clinical Registry	NIHSS	National Institutes of Health Stroke Scale
AuSDaT	Australian Stroke Data Tool		
ECR	Endovascular clot retrieval	Q1/Q3	25th percentile/75th percentile
ED	Emergency Department	PROMs	Patient-reported outcome measures
EQ-5D-3L™	European Quality of Life - five dimension three level instrument	RAMR	Risk-adjusted mortality rate
ECR	Endovascular clot retrieval	SD	Standard deviation
		SSNAP	Sentinel Stroke National Audit Program
HRQoL	Health-related quality of life	STELAR	Shared Team Efforts Leading to Adherence Results
ICH	Intracerebral haemorrhage		
mRS	Modified Rankin Scale	TIA	Transient ischaemic attack
NDI	National Death Index	VAS	Visual Analogue Scale

