# **Original Paper**



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# Treatment and Outcomes of Working Aged Adults with Stroke: Results from a National Prospective Registry

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## **Keywords**

Stroke · Young adult · Registries · Stroke registries

## **Abstract**

**Background:** Given the potential differences in etiology and impact, the treatment and outcome of younger patients (aged 18–64 years) require examination separately to older adults (aged ≥65 years) who experience acute stroke. **Methods:** Data from the Australian Stroke Clinical Registry (2010–2015) including demographic and clinical characteristics, provision of evidence-based therapies and health-related quality of life (HRQoL) post-stroke was used. Descriptive statistics and multilevel regression models were used for group

comparisons. **Results:** Compared to older patients (age  $\geq$ 65 years) among 26,220 registrants, 6,526 (25%) younger patients (age 18–64 years) were more often male (63 vs. 51%; p < 0.001), born in Australia (70 vs. 63%; p < 0.001), more often discharged home from acute care (56 vs. 38%; p < 0.001), and less likely to receive antihypertensive medication (61 vs. 73%; p < 0.001). Younger patients had a 74% greater odds of having lower HRQoL compared to an equivalent agedmatched general population (adjusted OR 1.74, 95% CI 1.56–1.93, p < 0.001). **Conclusions:** Younger stroke patients exhibited distinct differences from their older counterparts with respect to demographic and clinical characteristics, prescription of antihypertensive medications and residual health status.

#### Introduction

There is some evidence that rates of stroke are increasing in younger people worldwide [1, 2]. Poor outcomes are common after stroke at all ages [3–6], but the impact of stroke in younger adults can be particularly devastating due to the loss or change in employment and family roles [7–9]. While rare causes of stroke are more common in younger patients than in older patients [10], there is increasing awareness that young adults with stroke exhibit conventional vascular risk factors [1, 11, 12] and benefit from receiving standard evidence-based therapies.

As separate guidelines for the treatment of young adults with stroke do not exist [2], clinical practice guideline recommendations for stroke apply uniformly across the age span. In Australia, key components of evidence-based acute stroke treatment include the use of intravenous thrombolysis for ischaemic stroke, treatment in a dedicated stroke unit, discharge prescription of an antihypertensive agent and provision of a care plan on discharge [13]. However, researchers in other developed countries have shown that there is differential provision of evidence-based care to younger patients with stroke compared to those who are older with, for example, discharge on antihypertensive medication significantly lower in younger cohorts [14–16].

The Australian Stroke Clinical Registry (AuSCR) is a collaborative national effort established in 2009 to routinely record processes of care and health outcomes of patients hospitalised with stroke or transient ischaemic attack (see protocol [13] and www.auscr.com.au) with the overall aim of improving real-time adherence to acute stroke evidence-based care indicators in Australia. To date, registry data from Australia have not been examined to compare the characteristics and outcomes of younger adult stroke survivors to older stroke survivors. Therefore, the aim of the current study was to compare the demographic and clinical characteristics, provision of evidence-based therapies, and the health-related quality of life (HRQoL) of younger working aged adults (aged 18-64 years) to older adults (aged ≥65 years) hospitalised with stroke using data retrieved from the AuSCR.

# **Materials and Methods**

Patient Population and Procedures

Data from the AuSCR from January 2010 to December 2015 were used for this study. During this period, there were 45 hospitals that contributed data to the AuSCR. The geographical distri-

bution of participating hospitals was as follows: Queensland = 23, Victoria = 11, New South Wales = 8, Tasmania = 1, Western Australia = 2. Only the first-ever cases of stroke registered in the AuSCR were included in these analyses.

Methodologically, the AuSCR adheres to the Australian guidelines for best-practice in clinical quality registries [17]. The AuSCR protocol incorporates an opt-out approach whereby all eligible cases are registered unless the patient or family nominates, via simple, cost-free options (i.e., free-call telephone call or postage-paid return envelope), to have their data excluded. This opt-out approach ensures that selection bias is minimised [18]. To date, <3% of registrants have opted out of the AuSCR.

## Outcomes

The variables compared between age groups included demographic and clinical characteristics. We also compared provision of evidence-based therapies through the collection of processes of care data in all participating hospitals including management on a dedicated stroke unit; treatment with intravenous thrombolysis (tissue plasminogen activator) of an ischaemic stroke; provision of an antihypertensive agent at discharge; and provision of a discharge care plan developed with the patient or family. For hospitals located in Queensland, an additional 4 processes of care have been collected since 2012 which further determine adherence to evidence-based care: whether the patient was mobilised during admission, received aspirin administration within 48 h, had a swallowing assessment and formal speech pathologist review, and were discharged on antithrombotic medications. When data was missing or unknown, it was assumed to be negative adherence to evidence-based therapies (range 0-8%).

Registrants discharged from participating hospitals and who had not opted-out from the AuSCR were followed-up by trained research staff at the AuSCR office (Florey Institute of Neuroscience and Mental Health) between 90 and 180 days after hospital admission [19]. A modified Dilman protocol was used, whereby 2 attempts at contacting the patient by post were made prior to an attempt made by contacting the patient on telephone. Although multiple episodes of care may have been registered in the AuSCR, registrants were only followed-up after their first episode. At follow-up, data on HROoL was collected using the EuroQoL-5 dimension-3 level (EQ-5D-3L) instrument [20]. The EQ-5D-3L instrument is a self-completed survey that measures health in 5 domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Each domain has 3 levels: no problems, some problems, extreme problems and the respondent is asked to rate his/her health status by marking the most appropriate statement in each of the 5 domains. Additionally, a vertical visual analogue scale (VAS) labelled 0-100 is used to record the respondent's selfrated health, with the endpoints labelled "best imaginable health state" and "worst imaginable health state." In the event that the follow-up is conducted over the telephone, the Eurogol EQ-5D-3L Telephone interview version is used. Other information collected at follow-up, but not used in these analyses, includes place of residence, self-reported readmissions and recurrent strokes and modified Rankin Scale.

Responses to the EQ-5D-3L were converted to index-based values ("utilities") using health values derived with Discrete Choice Experiment methods in Australia [21]. Utility scores range from –1 to 1 with negative utility scores indicating a state worse than death, a utility score of 0 corresponding to a state equivalent to

death, and a score of 1 representing perfect HRQoL. In the sensitivity analysis, those who had died at the time of follow-up were assigned a utility score of 0.

#### Data Linkage

Personal identifiers of all registrants in the AuSCR were linked to the National Death Index (NDI) using probabilistic matching [22] by the Australian Institute of Health and Welfare. For these analyses, mortality data in the NDI was used. Registrants' home address postcodes were used to match to an Index of Relative Socioeconomic Advantage/Disadvantage (IRSAD) score generated by the Australian Bureau of Statistics using the 2006 census data [23]. Calculation of the IRSAD score is based on economic and social conditions of households within areas including income, education, occupation and assets. The IRSAD score is standardised against a mean of 1,000 with a standard deviation of 100, with greater IRSAD scores indicating less relative disadvantage.

#### **Ethics**

Appropriate ethics and governance approvals were obtained for all hospitals participating in the AuSCR. Ethical approval was obtained from the Australian Institute of Health and Welfare to conduct data linkage to the NDI. Monash University Human Research Ethics approval was obtained for analysis of data.

## Statistical Analyses

Registrants were divided into 2 age-based groups: 18-64 years old (working-aged) and ≥65 years, with the cut-off age of 65 years for the older group based on eligibility for the aged pension in Australia. Kruskal-Wallis and chi-square tests were used to assess differences between age groups in registrant demographic and clinical characteristics and binary outcomes. Differences between age groups in the proportion of registrants provided with evidencebased therapies were compared using chi-square tests. Only those registrants eligible to receive the evidence-based therapy were included in the denominators when calculating these proportions. Outcome data was analysed by individual registrants and not by episodes. Logistic regression analysis was used to investigate differences in the provision of evidence-based therapies and outcomes after stroke between age groups. Quantile regression analysis was conducted to investigate differences in HRQoL utility scores between age groups. Regression models were adjusted for age, gender, type of stroke, in-hospital stroke, previous stroke, ability to walk on admission (as a validated measure of stroke severity [24]) and socioeconomic position. To account for potential correlations for patients who attend the same hospital, we adjusted for clustering directly. Due to the large sample size, we used a significance level of p < 0.01. Data were analysed using StataIC 12.1 (StataCorp 2013).

#### Results

There were 26,220 first-ever strokes registered in the AuSCR between 2009 and 2015, with 6,526 (25%) aged 18-64 years at the time of admission (Table 1). The greatest proportion of patients were aged between 80 and 90 years of age (Fig. 1). Compared to those aged  $\geq 65$  years,

younger registrants were more often male, born in Australia, and of Aboriginal or Torres Strait Island origin than those aged  $\geq$ 65 years (p < 0.001). There were no differences between groups in terms of their socioeconomic position (according to IRSAD scores) and stroke type.

In terms of clinical characteristics, compared to those aged  $\geq 65$  years, the younger registrants were more often able to walk independently on admission and took longer to arrive at hospital after the onset of their symptoms (Table 1). Younger registrants were more often transferred from another hospital, more often had an unknown cause of stroke and less often had documented evidence of a previous stroke. Younger registrants were more often discharged home compared to older registrants, and among those discharged home, younger registrants were less often discharged home with support than older registrants. A greater proportion of older registrants were discharged to inpatient rehabilitation than younger registrants (37 vs. 27%, p < 0.001).

For the provision of evidence-based therapies, there were no significant differences between the 2 age groups with respect to the frequency of provision of care in a dedicated stroke unit, intravenous thrombolysis for ischaemic stroke and receipt of a discharge care plan if discharged to the community (Table 2). Younger registrants were less often discharged on an antihypertensive medication than those aged  $\geq$ 65 years. In the sub-group of episodes admitted to hospitals in Queensland (n=10,507), younger registrants were more often mobilised during their inpatient stay, more often received aspirin within 48 hours of admission and more often provided with anti-thrombotic medication at discharge from hospital.

After adjustment for registrant characteristics, younger registrants were more likely to be discharged home (excluding residential care; adjusted OR 1.89, 95% CI 1.76–2.02) and less often discharged to an inpatient rehabilitation facility (aOR 0.70, 95% CI 0.65–0.76).

According to the NDI, there were 4,859 registrants (19%) who died within 90 days of stroke. Of the remaining 21,361, 12,447 (58%) completed follow-up (Table 3). The younger group of registrants completed follow-up less often than registrants aged  $\geq$ 65 years (54 vs. 60%, p < 0.001). Median time to follow-up was 156 days after admission. For the entire group followed-up, registrants who completed follow-up were less often of Aboriginal or Torres Strait Island origin (1 vs. 2%, p < 0.001) and more often born in Australia (69 vs. 59%, p < 0.001).

Compared to registrants aged  $\geq$ 65 years, EQ-5D-3L, younger registrants only occasionally reported problems with self-care (21 vs. 39%, p < 0.001), undertaking usual

**Table 1.** Demographic and clinical characteristics of registrants

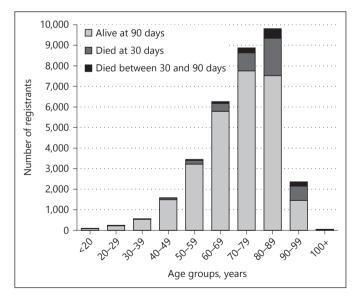
	Age, years				
	<65 ( <i>n</i> = 6,526)	≥65 ( <i>n</i> = 19,694)	p value		
Male, n (%)	4,081 (63)	10,049 (51)	< 0.001		
Stroke type			0.129		
Intracerebral haemorrhage	975 (15)	3,060 (16)			
Ischaemic	5,154 (79)	15,317 (78)			
Undetermined	391 (6)	1,282 (7)			
Born in Australia, $n$ (%)	4,539 (70)	12,345 (63)	< 0.001		
Aboriginal or Torres Strait Islander origin, <i>n</i> (%)	264 (4)	139 (1)	< 0.001		
IRSAD <sup>1</sup> , <i>n</i> (%)			0.016		
Quintile 1	1,164 (18)	3,451 (18)			
Quintile 2	1,480 (23)	4,481 (23)			
Quintile 3	700 (11)	1,835 (9)			
Quintile 4	1,335 (21)	4,139 (21)			
Quintile 5	1,760 (27)	5,473 (28)			
Transferred from another hospital, $n$ (%)	1,335 (21)	2,236 (12)	< 0.001		
Able to walk independently on admission, $n$ (%)	2,673 (45)	5,312 (30)	< 0.001		
Unknown cause of stroke, <i>n</i> (%)	3,330 (53)	9,217 (48)	< 0.001		
Documented evidence of a previous stroke, $n$ (%)	888 (14)	4,152 (23)	< 0.001		
Time from onset to arrival, min, median (IQR)	249 (85–915)	170 (76–585)	< 0.001		
Hospital length of stay, days, median (IQR)	5 (3–9)	5 (3–10)	< 0.001		
Died in hospital, <i>n</i> (%)	325 (5)	2,398 (13)	< 0.001		
Discharged home, <i>n</i> (%)	3,412 (56)	6,271 (38)	< 0.001		
With supports, <i>n</i> (%)	1,925 (56)	3,900 (62)	< 0.001		
Discharged to aged care facility, <i>n</i> (%)	31 (1)	1,230 (7)	< 0.001		
Discharged to inpatient rehabilitation facility, <i>n</i> (%)	1,632 (27)	6,156 (37)	< 0.001		

<sup>&</sup>lt;sup>1</sup> IRSAD, Index of Relative Socioeconomic Advantage and Disadvantage; Quintile 1 represents the highest relative socioeconomic disadvantage.

activities (53 vs. 64%, p < 0.001) and pain/discomfort (45 vs. 51%, p < 0.001; Table 4). Compared to those  $\geq$ 65 years old, EQ-5D-3L utility scores were greater in younger registrants (median scores 0.78 vs. 0.70, p < 0.001), as was the self-reported health measured using the VAS (median scores 75 vs. 70, p < 0.001).

When compared to normative population data from the United Kingdom [25], registrants more often had a lower VAS score than their age-matched population counterparts apart from those in the 55 to 64 year age group (Table 5). After adjustment, those aged 18–64 years had a 74% greater odds of having a VAS score lower than the median for their age-matched population counterparts than older registrants (aOR 1.74, 95% CI 1.56–1.93).

After adjustment, registrants who were aged 18–64 years had a 0.04 point greater median utility score (a 2.0% difference on a range of scores from –1 to 1) compared to those aged  $\geq$ 65 years (95% CI 0.03–0.05, p < 0.001). When registrants who had died during the follow-up period were



**Fig. 1.** Age distribution of registrants in the Australian Stroke Clinical Registry between 2009 and 2015.

**Table 2.** Provision of evidence-based therapies

	Age, years					
	$18-64 \ (n=6,526)$	≥65 ( <i>n</i> = 19,694)	chi-square, p value	aOR (95% CI)		
Care on a dedicated stroke unit	5,212 (80)	15,944 (81)	0.052	0.90 (0.83-0.99)		
Thrombolysis of an ischaemic stroke	581 (11)	1,749 (11)	0.775	1.11 (0.99-1.24)		
Discharged on an antihypertensive medication	3,681 (61)	12,232 (73)	< 0.001	0.53 (0.50-0.57)		
Discharge care plan <sup>1</sup>	1,909 (55)	4,013 (54)	0.058	1.06 (0.96–1.17)		
Queensland sub-group	n = 2,897	n = 7,610				
Mobilised during admission	2,306 (87)	5,681 (81)	0.006	1.44 (1.21-1.72)		
Swallowing assessment	1,182 (45)	1,377 (45)	0.536	0.76 (0.65-0.89)		
Aspirin within 48 h <sup>2</sup>	1,755 (76)	4,202 (70)	< 0.001	1.27 (1.10-1.45)		
Discharged on antithrombotic medication <sup>2</sup>	1,857 (88)	4,331 (85)	0.001	1.16 (0.96–1.41)		

aOR, adjusted OR; (reference category age 18–64 years compared to those aged ≥65 years).

**Table 3.** Demographic and clinical characteristics of registrants eligible for follow-up

	Follow-up completed			
	no $(n = 8,914)$	yes (n = 12,447)	p value	
Age, years, n (%)			< 0.001	
18-64	2,747 (31)	3,284 (26)		
≥65	6,167 (69)	9,163 (74)		
Male, n (%)	4,915 (55)	7,009 (56)	0.148	
Stroke type, <i>n</i> (%)			< 0.001	
Intracerebral haemorrhage	1,264 (14)	1,377 (11)		
Ischaemic	6,911 (78)	10,413 (84)		
Undetermined	714 (8)	646 (5)		
Born in Australia, n (%)	5,227 (59)	8,589 (69)	< 0.001	
Aboriginal or Torres Strait Islander origin, <i>n</i> (%)	216 (2)	143 (1)	< 0.001	
$(RSAD^1, n)$			< 0.001	
Quintile 1	1,875 (21)	1,851 (15)		
Quintile 2	1,985 (23)	2,915 (24)		
Quintile 3	799 (9)	1,318 (11)		
Quintile 4	1,653 (19)	2,770 (23)		
Quintile 5	2,463 (28)	3,419 (28)		
Fransferred from another hospital, $n$ (%)	1,296 (15)	1,696 (14)	0.034	
Able to walk independently on admission, $n$ (%)	2,996 (38)	4,655 (41)	< 0.001	
Unknown cause of stroke, <i>n</i> (%)	4,214 (50)	6,037 (49)	0.423	
Documented evidence of a previous stroke, n (%)	1,821 (22)	2,174 (18)	< 0.001	
Γime from onset to arrival, min, median (IQR)	218 (79–773)	199 (81–719)	0.062	
Hospital length of stay, days, median (IQR)	6 (3–10)	5 (3 –9)	< 0.001	
Discharged home, n (%)	3,690 (43)	5,779 (47)	< 0.001	
With supports, $n$ (%)	1,568 (42)	2,238 (39)	< 0.001	
Discharged to aged care facility, $n$ (%)	463 (5)	406 (3)	< 0.001	
Discharged to inpatient rehabilitation facility, $n$ (%)	2,909 (34)	4,478 (37)	< 0.001	

Patients who survived to 90 days according to the National Death Index are included.

<sup>&</sup>lt;sup>1</sup> If discharged to the community.

<sup>&</sup>lt;sup>2</sup> If not an intracerebral haemorrhage.

<sup>&</sup>lt;sup>1</sup> IRSAD, Index of Relative Socioeconomic Advantage and Disadvantage; Quintile 1 represents the highest relative socioeconomic disadvantage.

Table 4. Quality of life at follow-up

	Age, years	aOR (95% CI)		
		$\geq$ 65 ( $n = 9,163$ )	chi-square, p value	
Self-reported problems with, <i>n</i> (%)				
Mobility	1,682 (52)	4,798 (53)	0.219	0.97 (0.89-1.06)
Self-care	685 (21)	3,532 (39)	< 0.001	0.46 (0.41-0.51)
Usual activities	1,743 (53)	5,787 (64)	< 0.001	0.73 (0.67-0.80)
Pain and discomfort	1,467 (45)	4,653 (51)	< 0.001	0.83 (0.76-0.90)
Anxiety and depression	1,570 (48)	4,211 (47)	0.116	1.13 (1.04-1.24)
Any domain	2,765 (85)	8,060 (88)	< 0.001	0.85 (0.75-0.97)
				β (95% CI)
EQ-5D-3L-DCE utility score excluding deaths, median (IQR)	0.78 (0.58-0.89)	0.70 (0.48-0.89)	< 0.001	0.04 (0.03-0.05)
EQ-5D-3L-DCE utility score including deaths <sup>1</sup> , median (IQR)	0.69 (0.45-0.89)	0.47 (0.0-0.79)	< 0.001	0.17 (0.15-0.20)
Visual analogue scale score, median (IQR)	75 (58–88)	70 (50–80)	< 0.001	3.00 (1.93-4.07)

aOR, adjusted OR (reference category age 18–64 years compared to those aged ≥65 years).

**Table 5.** Net difference in median overall health scores in the AuSCR compared with the normative population by age group, reported as median (IQR)

VAS <sup>1</sup> , median (IQR)	Age, years							
	18-24	25-34	35-44	45-54	55-64	65-74	75+	total
Normative population <sup>2</sup>	90 (80-95)	90 (80–97)	90 (80–95)	90 (75–95)	75 (70–95)	80 (70–90)	75 (60–90)	90 (75–95)
AuSCR <sup>3</sup>		<i>n</i> = 109 80 (65–90)			, , , , , , ,	<i>n</i> = 2,660 75 (60–88)		n = 8,624 70 (50–85)
Difference in VAS medians between the normative population and the AuSCR	5	10	10	15	0	5	6	20

<sup>&</sup>lt;sup>1</sup> VAS, Visual Analogue Scale or overall health on a scale 0–100 reported by patients followed up at 90–180 days. Excludes patients who died within 90 days of admission.

included in the utility score, those who were aged 18-64 years had a 0.17 point greater median utility score compared to those aged  $\geq 65$  years (95% CI 0.15-0.20, p < 0.001).

#### Discussion

There is limited research on the quality of care and outcomes of patients of working age who have had a stroke. A major finding was that older registrants were more often

prescribed secondary prevention medications at discharge from hospital than younger registrants. An interesting finding was that younger registrants reported mobility problems after stroke as often as their older counterparts, and while HRQoL scores were generally higher in the younger registrants than older registrants, our younger respondents did demonstrate a greater difference from their aged-matched general population counterparts. Some of the differences in HRQoL scores observed between the age groups were in the range of clinical significance [26].

<sup>&</sup>lt;sup>1</sup> Number of deaths at follow-up assigned a utility score of 0: n = 532 age group 18–64; n = 4,917 age group ≥65.

<sup>&</sup>lt;sup>2</sup> VAS normative population: data from the UK as reported in Jansen et al. [25].

<sup>&</sup>lt;sup>3</sup> AuSCR, Australian Stroke Clinical Registry; IQR, interquartile range.

We found evidence that the provision of antihypertensive medications was different between the age groups compared. This is consistent with previous research from the United Kingdom, the United States and Canada [14-16]. While antihypertensive medications are recommended after stroke or a transient ischaemic attack irrespective of age or blood pressure values [27], it is possible that the younger registrants with stroke in these international studies and our study had fewer comorbidities and less frequently had hypertension than their older counterparts [14-16]. As the AuSCR does not capture comorbidities, in particular the cause of stroke and pre-existing hypertension, we cannot completely determine if these registrants still received appropriate care. Perhaps of greater concern is that the proportion of patients who were discharged with antihypertensive medication in our older registrant group (72%) was well short of treatment achieved at benchmark hospitals, although according to population data these older registrants are more likely to have a history of hypertension and therefore a clearer rationale for being prescribed antihypertensive medication.

Our finding that younger registrants were more likely to be of Aboriginal and Torres Strait Island origin compared to older registrants (4 vs. 1%) may reflect the proportions seen across the general Australian population (according to the 2016 Australian census data), rather than a higher incidence of stroke in younger Aboriginal and Torres Strait Islanders. We acknowledge that Aboriginal and Torres Strait Islander people are, however, disproportionately affected by cardiovascular disease [28]. Epidemiological monitoring as the AuSCR registry continues to grow in both episodes and coverage will provide future opportunity to potentially target evidence-based therapies to reduce the burden of stroke in Aboriginal and Torres Strait Islander peoples.

We found that older registrants with stroke in Australia had greater in-hospital mortality and poorer survival. Similar findings were observed in the United States and Canada [14, 16]. We found that the younger registrants in our study appeared to have less severe strokes than the older registrants, based on the percentage of those able to walk independently on hospital admission. In contrast to the study conducted in Canada, we found that our younger registrants were less likely to be transferred to inpatient rehabilitation [14]. There may be several reasons for this difference in results, including that the AuSCR registry only captures data from inpatient (and not community-based) rehabilitation models. Additionally, it is possible that the milder stroke severity seen in our younger registrants and potentially fewer comorbidities (e.g., heart fail-

ure, respiratory disease, arthritis) compared to the older registrants may have decreased the need for ongoing rehabilitation.

In our subgroup of registrants followed up at 90–180 days post-admission, the proportion of younger registrants reported problems with mobility was similar to older registrants. While a greater proportion of older registrants were expected to report having problems with mobility, this may reflect greater expectations of young patients with respect to mobility. Research on expectations for recovery after stroke is lacking. It is also possible that the lower levels of access to rehabilitation in younger registrants may lead to greater mobility impairments at 3 months post-stroke.

A strength of the study is the large national dataset of consecutive registrants admitted to hospital for stroke. While this is a strength of the study, we acknowledge that some of the limitations of the study also arise through the use of the data registry, including that information relating to comorbidities and community-based rehabilitation is not collected and therefore could not be included in analyses. The state distribution of hospitals participating in the data registry was also skewed, with a high representation from Queensland and Victoria, and fewer registrants from the non-Eastern states of Australia.

A perceived limitation of the registry dataset is that ability to walk on admission is captured as a proxy for stroke severity. Stroke severity as measured by ability to walk has been validated by Counsell et al. [24], and within the AuSCR registry, there is "good" discrimination between ability to walk and case fatality at 30 days after admission according to the area under the ROC curve (unpublished). Further, in a sub-group of AuSCR registrants with recorded NIHSS scores, there was a decreasing odds of being able to walk on admission [29]. Another limitation was the non-response rate at follow-up at 90-180 days, which was high in both age groups, but highest in the younger group (46%). It is possible that those lost to follow-up may have been more mobile and higher HRQoL, characteristics more common in our younger registrants. Other registries have reported on higher nonresponse rates in younger versus older adults [30], and thus future investigation of non-responders in the stroke registry may be warranted.

Given the physical burden, increased levels of depression and changes to work status (and thus, financial status) that arise after a stroke at a younger age, more research in the area of stroke for younger, working age Australians is clearly needed. Further research to determine the influence of various demographic and clinical

characteristics on outcomes in younger registrants will be of interest. Understanding the need for and access to inpatient and community based on younger registrants with stroke would also be worthwhile. As registrant numbers grow, data collected in the AuSCR will continue to be of value by allowing disparities in care based on age (and other factors) in Australian hospitals to be investigated.

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#### References

- 1 Putaala J: Ischemic stroke in the young: current perspectives on incidence, risk factors, and cardiovascular prognosis. Eur Stroke J 2016;1:28–40.
- 2 Smajlović D: Strokes in young adults: epidemiology and prevention. Vasc Health Risk Manag 2015;11:157–164.
- 3 Cadilhac DA, et al: Multicenter comparison of processes of care between stroke units and conventional care wards in Australia. Stroke 2004;35:1035–1040.
- 4 Hoffmann TC, Lindley RI: Stroke care in Australia: why is it still the poor cousin of health care? Med J Aust 2013;198:246–247.
- 5 Cadilhac DA, et al: Estimating the long-term costs of ischemic and hemorrhagic stroke for Australia: new evidence derived from the North East Melbourne Stroke Incidence Study (NEMESIS). Stroke 2009;40:915–921.
- 6 Synhaeve NE et al: Poor long-term functional outcome after stroke among adults aged 18 to 50 years: follow-up of transient ischemic attack and stroke patients and unelucidated risk factor evaluation (FUTURE) study. Stroke 2014;45:1157–1160.
- 7 Daniel K, et al: What are the social consequences of stroke for working-aged adults? A systematic review. Stroke 2009;40:e431–e440.
- 8 Essue BM, et al: How are household economic circumstances affected after a stroke? The Psychosocial Outcomes In StrokE (POISE) Study. Stroke 2012;43:3110–3113.
- 9 Maaijwee NA, et al: Long-term increased risk of unemployment after young stroke: a longterm follow-up study. Neurology 2014;83: 1132–1138.
- 10 Rolfs A, et al: Prevalence of fabry disease in patients with cryptogenic stroke: a

- prospective study. Lancet 2005;366:1794–1796.
- 11 Bevan H, Sharma K, Bradley W: Stroke in young adults. Stroke 1990;21:382–386.
- 12 Bergman EM, et al: National registry-based case-control study: comorbidity and stroke in young adults. Acta Neurol Scand 2015;131: 394–399.
- 13 Cadilhac DA, et al: Protocol and pilot data for establishing the Australian Stroke Clinical Registry. Int J Stroke 2010;5:217–226.
- 14 Saposnik G, et al: Age disparities in stroke quality of care and delivery of health services. Stroke 2009;40:3328–3335.
- 15 Simpson CR, et al: Evidence for age and sex differences in the secondary prevention of stroke in scottish primary care. Stroke 2005; 36:1771–1775.
- 16 Fonarow GC, et al: Age-related differences in characteristics, performance measures, treatmenttrends, and outcomes in patients with ischemic stroke. Circulation 2010;121:879–891.
- 17 Evans SM, et al: Development of clinicalquality registries in Australia: the way forward. Med J Aust 2011;194:360–363.
- 18 Tu JV, et al: Impracticability of informed consent in the registry of the canadian stroke network. N Eng J Med 2004;350:1414–1421.
- 19 Lannin NA, et al: Telephone follow-up was more expensive but more efficient than postal in a national stroke registry. J Clin Epidemiol 2013;66:896–902.
- 20 Dorman PJ, et al: Is the EuroQol a valid measure of health-related quality of life after stroke? Stroke 1997;28:1876–1882.
- 21 Viney R, et al: An Australian discrete choice experiment to value EQ-5D health states. Health Econ 2014;23:729–742.

- 22 Jaro MA: Probabilistic linkage of large public health data files. Stat Med 1995;14:491–498.
- 23 Australian Bureau of Statistics, Socio-Economic Indexes for Areas (SEIFA). Canberra,
- 24 Counsell C, et al: Predicting outcome after acute and subacute stroke: development and validation of new prognostic models. Stroke 2002;33:1041–1047.
- 25 Janssen B, Szende A: Population norms for the EQ-5D; in Szende A, Janssen B, Cabases J (eds): Self-Reported Population Health: An International Perspective Based on EQ-5D. Dordrecht, Springer Netherlands, 2014, pp 19-30
- 26 Kim SK, et al: Estimation of minimally important differences in the EQ-5D and SF-6D indices and their utility in stroke. Health Qual Life Outcomes 2015;13:32.
- 27 National Stroke Foundation, Clinical Guidelines for Stroke Management. Melbourne,
- 28 Vos T, et al: Burden of disease and injury in Aboriginal and Torres Strait Islander peoples: the indigenous health gap. Int J Epidemiol 2009;38:470–477.
- 29 Cadilhac DA, Lannin NA, Anderson CS, Kim J, Andrew N, Kilkenny M, Shehata S, Grabsch B, Levi C, Faux S, Dewey H, Hill K, Donnan G, Hand P, Grimley R, Middleton S; AuSCR Consortium: The Australian Stroke Clinical Registry Annual Report 2015. The Florey Institute of Neuroscience and Mental Health, December 2016, Report No. 7, pages 42.
- 30 Imam MA, et al: Loss to follow-up after total hip replacement: a source of bias in patient reported outcome measures and registry datasets? Hip Int 2014;24:465–472.

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