AUSCR ANNUAL REPORT 2019

AUSCR
Australian Stroke Clinical Registry

DATA QUALITY

This report was produced on behalf of the Australian Stroke Clinical Registry (AuSCR) Consortium partners and was approved by the AuSCR Management Committee.

Suggested citation:

Morrison J, Breen S, Hancock S, Lester M, Kim J, Dalli L, Lam M, & Cadilhac CA on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Data Quality Report 2019. The Florey Institute of Neuroscience and Mental Health; December 2020, 21 pages.

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December 2020

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INTRODUCTION

The Australian Stroke Clinical Registry (AuSCR) was established in 2009 to provide national data on the processes of care and outcomes for patients admitted to hospital with acute stroke or transient ischaemic attack (TIA). The quality of the data in the Registry is critical to its purpose, which is to provide reliable and representative data to improve the quality of stroke care, nationally.

Accountability for the accuracy and completeness of hospital data is the responsibility of the participating hospitals. However, it is the role of the AuSCR office to support hospitals to collect high quality data via education, training and regular feedback. Therefore, the combined efforts of hospitals and the AuSCR office is to ensure the most complete and reliable data for each annual reporting period. Hospitals participating in the AuSCR are encouraged to use this report, in addition to site specific feedback provided throughout the calendar year, to improve data quality.

This annual Data Quality Report covers data collected for patients admitted to participating hospitals between 1 January 2019 and 31 December 2019. It is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2019 Annual Report Volume 1: Acute Care Provision (https://auscr.com.au/about/annual-reports/).

METHODS FOR ENSURING DATA QUALITY

Data quality is supported by ongoing training and education processes for all contributors of data to the AuSCR. In addition, the AuSCR office undertakes a range of regular data checking and quality assurance procedures to support improved data quality.

AUSDAT LOGIC

Since July 2016, the collection of AuSCR data by staff at participating hospitals has been facilitated by the Australian Stroke Data Tool (AuSDaT). The AuSDaT contains in-built functions to auto-check the logic of manually entered data to minimise the potential for inaccurate or discrepant data during data entry.

DATA CHECKS BEFORE IMPORT

For hospitals transferring their data to the AuSDaT via an import template, these data are reviewed by AuSCR Data Managers prior to upload. This centralised process is used to ensure the data are in the correct format and provide an opportunity for any inconsistent or erroneous data to be corrected prior to performing the import.

CASE ASCERTAINMENT

Case ascertainment is an essential process for ensuring that the data recorded in the AuSCR are representative of the patient population with stroke or TIA admitted to each participating hospital. It is a requirement for all clinical registries to collect and report this information. Case ascertainment results provide an indication of the representativeness of data and whether there are any potential selection biases in the patient sample.

For the AuSCR case ascertainment reports in 2019, non-Victorian hospitals were asked to provide a list of all admissions based on eligible ICD-10 stroke codes for comparison and matching with episodes recorded in the AuSCR. In Victoria, for the firs time, the AuSCR office staff with support from the Victorian Agency for Health Information, were able to facilitate data linkage with the government-held admitted episodes dataset to obtain case ascertainment results for all Victorian hospitals centrally.

DATA QUALITY REPORTS

Data quality reports are used to provide hospitals with a list of AuSCR episodes containing missing data and/or data discrepancies (e.g. a discharge date prior to an admission date). These reports are designed to assist hospitals to quickly identify and update, where appropriate, individual AuSCR episodes with. The dissemination of these reports is bi-annual and provides hospitals with the opportunity to action any updates to their data prior to closure of a calendar year. Data closure occurs annually in July prior to extraction for formal reporting or secondary research.

MEDICAL RECORD AUDITS

The AuSCR office conducts medical record audits at participating hospitals, to assess the accuracy of data in the registry compared to information documented in the local medical record. The auditor assesses a random selection of episodes for missing or discrepant data and looks for patterns in the variation of data collection. These audits assist in verifying that data collection for the AuSCR is standardised, and assists with the identification of the future training needs of staff at participating hospitals. Medical record audits are

scheduled to occur for a newly participating hospital following entry of the first 50 episodes of stroke/TIA and every two years thereafter. In 2019, 14 hospitals had medical record audits for 93 episodes of care.

DATA CLEANING

The cleaning of AuSCR data is completed following the closure of data entry for the year and prior to undertaking analysis for the AuSCR Annual Report. Duplicate data are identified and removed by the AuSCR Senior Data Manager using registrant identifiers (name, date of birth, Medicare number and/or hospital medical record number) in addition to date of stroke onset, date of hospital arrival and dates of admission and discharge. These data are subsequently de-identified and extracted for analysis. Additional data cleaning processes are then undertaken by Monash University epidemiologists prior to undertaking data analyses.

DATA COMPLETENESS

For 2019, 20,157 episodes of stroke and TIA care which were provided by 72 hospitals. Both the number of episodes and contributing hospitals were similar to 2018 which contained 20,051 episodes from 71 hospitals. The proportion of data completeness for individual variables is presented only for eligible episodes, since not all variables are relevant to every patient. Variables that are only captured in state-specific programs data collection programs are also not included in this report.

Individual variables ranged in completeness from 56% for medical complication ICD-10 codes to 100% for a range of variables, with similar, overall results to the 2018 dataset (Table 1).

Three variables had ≥10% improvement in completeness when compared to 2018 data, including: acute occlusion site (increased from 83% to 100%); National Institute of Health Stroke Scale (NIHSS) before endovascular clot retrieval (ECR) (increased from 75% to 88%); medical complication International Classification of Diseases codes (ICD-10 codes) (increased from 43% to 56%). While the final Expanded Thrombolysis In Cerebral Infarction score (e-TICI) following ECR completion increased by 5% in 2019 compared to 2018, it remained the second most poorly completed variable overall.

Overall, 4 variables had reduced completion by more than 10% in 2019, including: time of stroke onset (decreased from 99% to 81%), emergency contact address (decreased from 87% to 73%); method of mobilisation (decreased from 99% to 86%) and details of haemorrhage within the infarct on follow-up imaging after ECR (decreased from 100% to 88%).

In addition to missing data, some variables such as the NIHSS have a large proportion of responses recorded as unknown (Table 2). In 2019, the combination of missing data plus the entry of unknown values meant that there were no valid data for: 44% of NIHSS at baseline; 34% of pre-ECR NIHSS; and 37% of post-ECR NIHSS. However, in contrast to 2018 data, the provision of valid responses for the baseline NIHSS improved by 6% in 2019, alongside an 8% improvement for post-ECR NIHSS.

Table 1: Completeness of variables in the Australian Stroke Clinical Registry by year

Variable N=20,157 episodes of care in 2019	2017 % complete N hospitals = 59**	2018 % complete N hospitals = 71**	2019 % complete N hospitals=72**
Patient details			
Title	95	100	95
First name	99	100	98
Surname	99	100	98
Date of birth	99	100	98
Medicare number (optional)#	93	97	**87**
Hospital Medical Record Number (MRN)	98	100	97
Gender	98	100	98
Country of birth	93	99	95
Language spoken	92	91	**85**
Interpreter needed	92	91	**85**
Aboriginal and Torres Strait Islander status	95	98	95
Patient phone number	92	98	93
Complete address (street address, suburb, state)	95	97	95
Emergency contact			
Emergency contact first name	93	95	**89**
Emergency contact last name	91	94	**87**
Address for emergency contact	**82**	**87**	**73**
Emergency contact phone number	**90**	92	**86**
Arrival and admission data			
Date of stroke onset	94	99	98
Time of stroke onset	**90**	99	**81**
Stroke occurred while in hospital	94	99	98
Date of arrival to ED	96	97	100
Time of arrival to ED	98	99	100
Arrival by ambulance	99	100	95
Transfer from another hospital	95	99	98
Date of admission	100	100	100
Time of admission	98	99	99
Treated in a stroke unit	95	99	99
History of known risk factors			
Documented evidence of a previous stroke	94	99	96
Acute clinical data			
NIHSS at baseline	91	97	98
Brain scan after this stroke	92	100	99
Date of first brain scan	**84**	96	99
Time of first brain scan	91	96	99
Date of subsequent brain scan	**49**	96	**89**
Time of subsequent brain scan	**80**	96	**89**
Type of stroke	93	99	99
Cause of stroke	92	98	**86**
Acute occlusion site	**90**	**83**	*100*

Table 1: Completeness of variables in the Australian Stroke Clinical Registry by year (continued)

Variable	2017 % complete N hospitals = 59	2018 % complete N hospitals = 71	2019 % complete N hospitals=72
Telemedicine and reperfusion			
Stroke telemedicine consultation conducted	**87**	93	*100*
Receipt of thrombolysis	98	100	97
Date of delivery	99	100	100
Time of delivery	93	100	99
Adverse event related to thrombolysis	94	98	98
Type of adverse event	95	99	100
Other reperfusion (ECR)	**55**	97	**87**
Treatment date for ECR	**59**	95	100
NIHSS before ECR	**90**	**75**	***88***
Time groin puncture	92	95	97
Time of completing	92	91	96
Final eTICI	**75**	**71**	**76**
24 hour data			
24 hour NIHSS	97	100	96
Haemorrhage within the infarct on follow up imaging	98	100	98
Details	91	100	**88**
Swallowing			
Swallowing screen	**86**	95	92
Date of swallowing screen	99	100	99
Time of swallow screen	99	100	95
Did the patient pass the screening	99	100	100
Swallowing assessment	**85**	94	**90**
Date of swallow assessment	99	100	100
Time of swallow assessment	99	100	99
Oral medications	**81**	**90**	91
Oral food or fluids	**81**	**90**	92
Mobilisation			
Ability to walk independently on admission	93	98	97
Mobilised during the admission	**84**	99	**89**
Date of mobilisation	99	100	98
Method of mobilisation	96	99	**86**
Antithrombotic therapy			
Aspirin given as hyperacute therapy	**84**	95	**90**
Date of administration	99	100	99
Time of administration	99	100	100
Secondary prevention			
Discharge antithrombotics	92	99	99
Discharge antihypertensives	94	99	99
Discharge lipid lowering	**90**	99	99

Table 1: Completeness of variables in the Australian Stroke Clinical Registry by year (continued)

Variable	2017 % complete N hospitals = 59	2018 % complete N hospitals = 71	2019 % complete N hospitals=72
Discharge information			
Patient deceased during hospital care	100	99	98
Date of death (if deceased status during hospital care is yes)	100	100	100
Date of discharge if not deceased while in hospital	97	100	99
Discharge diagnosis ICD-10 code(s)	93	95	94
Medical condition ICD-10 code(s)*	**72**	**72**	**79**
Medical complication ICD-10 code(s)*	**38**	**43**	***56***
Medical procedure ICD-10 code(s)*	**72**	**74**	**79**
Discharge destination if not deceased while in hospital	97	99	97
Evidence of care plan on discharge if discharged to the community	94	98	99

Bold numbers indicate ≥10% missing or discrepant data.
Italicised numbers indicate ≥10% improvement in variable completion compared to 2018 data.
** Denominator includes some patients with no other medical condition, complication or procedure codes.*
***Includes data from a paediatric hospital*
#Variable became optional in late 2018 potentially impacting the rate of completion in the 2019 dataset.
NIHSS: National Institutes of Health Stroke Scale.
ECR: Endovascular Clot Retrieval.
eTICI: Expanded Thrombolysis In Cerebral Infarction.
ICD: International Classification of Diseases.

Table 2: Missing and unknown data recorded for Australian Stroke Clinical Registry variables by year

Variable	2017 % missing and unknown	2018 % missing and unknown	2019 % missing and unknown
National Institutes of Health Stroke Scale (NIHSS)			
Baseline	66	50	44
Pre-ECR*	64	38	34
24 hours post-ECR	64	45	37

**Note: a second NIHSS score prior to ECR may not always be warranted depending on the time of collection of the baseline NIHSS.*
NIHSS: National Institutes of Health Stroke Scale.
ECR: Endovascular Clot Retrieval.

FEVER SUGAR SWALLOW DATASET

The optional Fever Sugar Swallow (FeSS) dataset went live on 1 July 2019. The FeSS dataset includes a total of six variables in addition to the swallow variables collected in the admitted datasets (Table 1). Hospitals chose to complete these variables for all admitted episodes entered in the AuSCR, or for only a subset of the admitted cohort of patients. Seventeen hospitals contributed 988 episodes during 2019. All six variables were 100% complete.

Queensland hospitals were unable to contribute to the FeSS dataset in 2019 until October 2020, due to the requirement of an amendment to the Deed of Disclosure with Queensland Health enabling the collection of the six addition variables. In 2019, the FeSS variables were also not included in the bi-annual feedback of data quality reports to participating hospitals, since this was an optional dataset.

Table 3: Completeness of Fever, Sugar, Swallow dataset variables in the Australian Stroke Clinical Registry

Variable N= 988 episodes of care	2019 % complete N hospitals=17
Temperature recorded at least four times on day one of admission	100
Fever development in the first 72 hours following admission	100
Paracetamol for the first elevated temperature administered within 1 hour	100
Finger-prick blood glucose level recorded at least four times on day one of admission	100
Elevated glucose in the first 48 hours following admission	100
Insulin administered within 1 hour if elevated glucose	100

EMERGENCY DEPARTMENT DATASET

The Emergency Department (ED) dataset is an optional program that went live on 1 July 2019. This dataset enables the collection of data for stroke/TIA patients who presented to an ED and prior to transfer to another hospital for ongoing acute stroke care. The ED dataset includes 85 variables. Twenty hospitals contributed 113 episodes during 2019. The completeness of ED variables ranged from 84% (for baseline NIHSS) to 100% for a range of variables.

Queensland hospitals were unable to participate in the ED dataset in 2019, due to the requirement of an amendment to the Deed of Disclosure with Queensland Health to approve the collection of the specific variables within this dataset. In 2019, the ED dataset variables were not included in the bi-annual feedback of data quality reports to participating hospitals, since this was an optional dataset.

Table 4: Completeness of Emergency Department dataset variables in the Australian Stroke Clinical Registry

Variable N=113 episodes of care	2019 % complete N hospitals=20
Stroke onset and arrival data	
Stroke onset date	100
Stroke onset time	92
Date of arrival to emergency department	100
Time of arrival to emergency department	95
Did the patient arrive by ambulance?	100
Pre-hospital notification by paramedics	97
Acute clinical data	
Functional status prior to stroke (mRS)	94
Triage category	95
NIHSS at baseline	**84**
Brain scan after this stroke	100
Date of first brain scan	99
Time of first brain scan	99
Advanced imaging	100
Type of stroke	100
Telemedicine consultation	100
Receipt of thrombolysis	100
Date of delivery	100
Time of delivery	100
Drug used	100
Type of adverse event	100
Swallow screen	100
Was the swallow screen or swallow assessment performed before the patient was given:	
Oral medications	100
Oral food or fluids	100
Walk on admission	100
Transfer	
Date of transfer	95
Time of transfer	93
Reason for transfer	95
Discharge Information	
What is the discharge destination	100

Bold numbers indicate ≥10% missing or discrepant data.
NIHSS: National Institutes of Health Stroke Scale.
mRS: Modified Rankin Scale.

DATA DISCREPANCIES IDENTIFIED USING HOSPITAL MEDICAL RECORD AUDIT DATA

Auditors from the AuSCR office undertook site visits at 14 hospitals in 2019 and reviewed a total of 93 medical records. Between five and eleven randomly selected medical records were assessed during each audit. Table 5 displays the AuSCR variables common across all participating states, with discrepancies shown for each variable, reflecting either incorrect data or missing data in the AuSCR, compared to local hospital medical record documentation.

The variables collected in the two AuSCR optional datasets (ED and FeSS) were also not subject to medical record audit in 2019, given the infancy of these two data collection programs.

Discrepancies between medical record audit data and AuSCR data were generally low, with the greatest discrepancies (9% to 13%) recorded for variables such as time of stroke onset, NIHSS at baseline, aspirin given as hyperacute therapy and discharge medications (Table 5).

Table 5: Discrepancies within AuSCR variables identified during 2019 medical record audits

Variables	Discrepant number	%	No. of sites with discrepancy
N=93 records audited from 14 hospitals			
Patient details			
Title	0	0%	0
First name	2	2%	2
Last name	0	0%	0
Date of birth	1	1%	1
Medicare number	4	4%	3
Hospital Medical Record Number (MRN)	0	0%	0
Gender	1	1%	1
Country of birth	1*	1%	1
Language spoken	0	0%	0
Interpreter needed	0	0%	0
Aboriginal and Torres Strait Islander status	2	2%	2
Patient phone number	2	2%	2
Patient mobile number	2	2%	2
Address	0	0%	0
Emergency contact			
Emergency contact first name	0	0%	0
Emergency contact last name	1	1%	1
Address for emergency contact	0	0%	0
Emergency contact phone number	2	2%	2
Emergency contact mobile number	1	1%	1
Emergency contact relationship to participant	1	1%	1
Arrival and admission details			
Date of stroke onset	1	1%	1
Accuracy of stroke onset date	2	2%	2
Time of stroke onset	9	9%	6
Accuracy of stroke onset time	1	1%	1

Table 5: Discrepancies within AuSCR variables identified during 2019 medical record audits (cont)

Variables		Discrepant number	%	No. of sites with discrepancy
N=93 records audited from 14 hospitals				
	Stroke occurred while in hospital	1	1%	1
	Date of arrival to ED	1	1%	1
	Accuracy of date of arrival to ED	0	0%	0
	Time of arrival to ED	5	5%	4
	Accuracy time of arrival	0	0%	0
	Direct admission to hospital (bypass ED)	0	0%	0
	Arrival by ambulance	2	2%	2
	Transfer from another hospital	1	1%	1
	Date of admission	1	1%	1
	Time of admission	3	3%	1
	Treated in stroke unit	0	0%	0
	Reason for transfer	0	0%	0
History of known risk factors				
	Documented evidence of a previous stroke	2	2%	2
Acute clinical data				
	NIHSS at baseline	10	**10%**	6
	Brain scan after this stroke	1	1%	1
	Date of first brain scan	0	0%	0
	Time of first brain scan	4	4%	3
	Date of subsequent brain scan	0	0%	0
	Time of subsequent brain scan	0	0%	0
	Type of stroke	2	2%	1
	Cause of stroke	2	2%	2
	Acute occlusion site	1	1%	1
Telemedicine and reperfusion				
	Stroke telemedicine consultation conducted	2	2%	2
	Use of IV thrombolysis (if ischaemic)	1	1%	1
	Date of delivery	0	0%	0
	Time of delivery	0	0%	0
	Adverse event related to thrombolysis	0	0%	0
	Type of adverse event	0	0%	0
	Other reperfusion (ECR)	0	0%	0
	Treatment date for ECR	0	0%	0
	NIHSS before ECR	1	1%	1
	Time groin puncture	0	0%	0
	Time of completing	0	0%	0
	Final eTICI	1	1%	1
24-hour data				
	24-hour NIHSS	0	0%	0
	Haemorrhage on follow up imaging	0	0%	0
	Details	0	0%	0

Table 5: Discrepancies within AuSCR fields noted during 2019 data quality audits (cont)

Fields		Discrepant number	%	No. of sites with discrepancy
N=93 records audited from 14 hospitals				
Swallowing screen and assessment				
	Swallowing screen	3	3%	3
	Date of swallowing screen	2	2%	2
	Time of swallow screen	2	2%	2
	Did the patient pass the screening	0	0%	0
	Swallowing assessment	3	3%	3
	Date of swallow assessment	4	4%	3
	Time of swallow assessment	1	1%	1
	Oral medications	4	4%	4
	Oral food or fluids	4	4%	4
Mobilisation				
	Walk on admission	5	5%	3
	Mobilised this admission	2	2%	2
	Date of mobilisation	4	4%	3
	Method of mobilisation	3	3%	3
Antithrombotic therapy				
	Aspirin given as hyperacute therapy	13	**13%**	6
	Date	2	2%	2
	Time	2	2%	2
Secondary prevention				
	Discharge antithrombotics	9	9%	5
	Discharge antihypertensives	8	9%	5
	Discharge lipid lowering	10	**10%**	6
Discharge information				
	Patient deceased during hospital care	0	0%	0
	Date of death	3	3%	2
	Date of discharge known	0	0%	0
	Date of discharge	3	3%	3
	Discharge diagnosis ICD-10	3*	3%	1
	Medical condition ICD-10 Code(s)	4	4%	3
	Medical complication ICD-10 Code(s)	0	0%	0
	Procedure ICD-10 Code(s)	2	2%	1
	Discharge destination	1	1%	1
	Discharge care plan	5	5%	3

Bold numbers indicate ≥10% missing or discrepant data.
** Indicates >50% of data were missing*
NIHSS: National Institutes of Health Stroke Scale
ECR: Endovascular Clot Retrieval
ICD-10: International Classification of Diseases, 10th Revision

CASE ASCERTAINMENT

For 2019 admissions, the AuSCR office conducted two rounds of case ascertainment reviews with participating hospitals. The first was for the period 1 January to 30 June 2019, and the second included the full 2019 calendar year. In order to complete the case ascertainment calculations, the AuSCR office requires individual hospitals to provide a list of admissions for all eligible ICD-10 stroke and TIA codes. In 2019, a new process was piloted in Victoria, whereby admissions for all eligible ICD-10 codes were obtained centrally from the Victorian Government (via the Victorian Agency for Health Information) as a subset of the Victorian Admitted Episodes Database.

Patients admitted and discharged on the same day, and episodes where the eligible stroke and TIA ICD-10 codes were not recorded in the first three (for non-Victorian hospitals), or five (for Victorian hospitals) discharge diagnosis code positions were excluded from the case ascertainment calculation. One hospital (a paediatric hospital) was excluded from the case ascertainment analysis. Case ascertainment for ED presentations recorded prior to hospital transfer was also not undertaken.

The overall proportion of completeness for case ascertainment was estimated using the formula (A+B)/(A+C), where: 'A' was the number of episodes that were registered in the AuSCR, 'B' was the number of episodes that were opted out of the registry, and 'C' was the number of episodes included in the hospital's list of eligible episodes that were missing from the AuSCR database.

Episode matching for case ascertainment may be affected by data entry errors, in those variables used to match episodes between the datasets (e.g. patient names, hospital medical record number). However, following assessment of the resultant cases using automated and manual matching processes conducted by the AuSCR office, these matching errors made up a relatively small proportion of the overall total.

Of the 72 hospitals that contributed data in 2019, 60 (85% of eligible hospitals) provided data for at least one case ascertainment round, an increase of 6% compared to 2018 participation. Fifty-five hospitals (77%) participated in case ascertainment for the full year in 2019, an increase of 16% compared to 2018. *Where an individual hospital provided an extract for both rounds of case ascertainment, the figure for the full calendar year is presented in Table 6*.

For the 60 hospitals that provided data for at least one case ascertainment round, the overall case ascertainment estimates ranged from 16% to 100%. The median case ascertainment result was 77% in 2019 in contrast to the median of 83% recorded in 2018.

Table 6: Hospital case ascertainment results for 2019 data compared to the 2018 dataset

Hospital ID	Episodes in the AuSCR 2019 (n)	Episodes in hospital records not in the AuSCR 2019 (n)	Case ascertainment 2019 (%) N=60 hospitals	Case ascertainment 2018 (%) N= 56 hospitals
3	442	159	73%	67%
5	605	143	79%	73%
12	13^	Not provided	Not provided	Not provided
13	145	7	96%	95%
14	708	152	79%	Not provided
15	817	38	97%	89%
16	86^	Not provided	Not provided	46%
20	415	82	82%	83%*
22	178	85	66%	47%
23	223	12	94%	85%
24	738	298	70%	79%
25	146	24	83%	99%
26	372	15	97%	88%
27	272	106	79%	72%
28	29	25	29%†	Not provided
30	306	3	100%	80%
31	424	111	78%	Not provided
32	193	72	71%	78%
33	188	50	70%	89%
34	195	116	60%	82%
35	232	3	99%	98%
36	203	120	59%	59%
37	402	35	80%†	91%
38	213	127	61%	78%
39	329	11	98%	98%
40	613	185	77%	79%
41	226	27	89%	90%*
42	42	27	60%	57%
43	278	24	94%	93%
44	226	25	89%	93%
45	225	61	71%	59%
46	945	277	76%	Not provided
47	226	19	92%	87%
48	87	11	89%	Not provided
49	46	17	70%	81%
50	272	19	95%	88%
51	139	11	94%	Not provided
52	413	180	67%	98%
53	399	283	52%	82%
55	40^	131	23%	88%
56	140	8	94%	87%
57	308	112	70%	100%*
58	1104	274	78%	86%
61	205	Not provided	Not provided	Not provided
62	53	26	68%	49%
63	78^	22	70%	79%*
64	103	8	93%	Not provided
65	638	Not provided	Not provided	92%*

Table 6: Hospital case ascertainment results for 2019 data compared to the 2018 dataset (continued)

Hospital ID	Episodes in the AuSCR 2019 (n)	Episodes in hospital records not in the AuSCR 2019 (n)	Case ascertainment 2019 (%)	Case ascertainment 2018 (%)
66	257^	135	65%	Not applicable
67	61	3	98%	84%
68	75	17	79%	91%*
69	1189	6	100%†	96%*
70	324	Not provided	Not provided	99%*
71	474	Not provided	Not provided	97%*
73	43	18	67%	52%
74	108	21	83%	52%
75	518	338	64%	71%
77	253	129	66%	75%*
78	168^	198	40%†	51%*
80	24^	82	16%	Not provided
81	23^	Not provided	Not provided	Not provided
82	236	Not provided	Not provided	92%
83	235	183	31%†	75%
84	376	36	91%	Not provided
85	148^	Not provided	Not provided	Not provided
86	214	177	49%	49%
87	7^	Not provided	Not provided	Not provided
88	332	Not provided	Not provided	82%
89	39^	65	27%	80%*
91	168^	16	61%	Not applicable
92	19^	81	45%	Not applicable

^Hospital did not contribute data to the AuSCR for the full 2019 calendar year.
**Hospital provided case ascertainment data for January to June 2018 only.*
†Hospital provided case ascertainment data for January to June 2019 only.
Excludes paediatric hospital.

TIME TO RECORD CREATION

The median time from admission to record creation in the AuSCR was 81 days (interquartile range: 42 to 112 days) which was 4 days sooner than in 2018 (median 85 days). Eight Victorian hospitals were impacted by a cyber-attack during 2019 which delayed their creation of AuSCR records. The shortest hospital-level median time to record creation was 2 days, and the longest was 372 days (from a hospital which experienced technical issues with local hospital data extract processes during 2019).

OPT-OUT REQUESTS AND REFUSAL TO COMPLETE FOLLOW-UP SURVEY

Since 2016, approval from National Human Research Ethics Committees (HREC) for the AuSCR to retain anonymous clinical data independently of personal data opt-outs has been in place. Though registrants are provided with the opportunity to opt-out *both* their personal and clinical data upon request.

A total of 459 opt-out requests (2.3% of all episodes) were received from patients or their nominated contact person for 2019 admissions (Table 7). These data are consistent with the opt-out rate recorded in 2018 of 2.2%. The rate of opt-out requests varied by hospital, ranging from zero to 18.1%. The request for removal of both clinical and personal data has remained very low each year, at less than 0.1%. The number of patients refusing follow-up participation prior to 90 days post-admission remained low at less than <1%.

Table 7: Opt-out requests and refusal to complete follow-up survey data

Year	Total episodes	Total opt-out episodes	Complete clinical and personal data to be removed	Personal data only to be removed	Refused to complete follow-up survey prior to 90 days
2018	20,051	443 (2.2 %)	18 (<0.1 %)	425 (2.1 %)	185 (0.9 %)
2019	20,157	459 (2.3 %)	16 (<0.1 %)	443 (2.2% %)	101 (0.5 %)

COMPARISON OF CLINICAL STROKE DIAGNOSIS AND CODED DISCHARGE DIAGNOSIS

The AuSCR office reviews the clinical designation of stroke type within the registry against the International Classification of Diseases 10th Revision (ICD-10) discharge coding undertaken by hospital administrative staff. The ICD-10 discharge diagnosis code was compared to the documented clinical stroke type. Stroke and TIA discharge diagnosis codes were either recorded as the principal diagnosis, or in the medical complication or medical condition fields available in the AuSCR dataset. Where more than one eligible stroke or TIA code was recorded for an individual episode, it was included in both clinical diagnosis categories.

For episodes recorded clinically as an ischaemic stroke, 83% of these episodes had a I63 discharge diagnosis code (ICD-10 codes for cerebral infarction: I63.0 to I63.9), and 5% were coded as I64 (stroke, not specified). Whilst the proportion of stroke coded as I64 was the same as 2018, this has significantly decreased over the past five years from 11% in 2015. For episodes recorded as a TIA by the clinician, 89% of episodes had a TIA ICD-10 code (ICD-10 code for TIA: G45.9) (Table 8). Eighty-six percent of episodes recorded as an intracerebral haemorrhage by the clinician were coded as an intracerebral haemorrhage code (ICD-10 code range: I61 and I62.9). These results are an improvement compared to the 2018 results. One explanation may be, that for the first time, both medical condition and medical complication ICD-10 codes were included for these calculations.

Table 8: Comparison of clinical stroke diagnosis and ICD-10 diagnosis codes

Principal, medical or complication code	Clinical diagnosis			
	ICH N=2410 (%)	Ischaemic N=14104 (%)	TIA N=3049 (%)	Undetermined N=266 (%)
ICH ICD-10 codes (I61 range and I62.9)	**86%**	4%	<1%	4%
Ischaemic ICD-10 codes (I63 range)	5%	**83%**	4%	26%
TIA ICD-10 code (G45.9)	1%	2%	**89%**	14%
Unspecified stroke ICD-10 code (I64)	1%	5%	1%	**44%**
Missing or non-stroke/TIA ICD-10 codes	10%	9%	6%	14%

Bold numbers indicate a match between clinical diagnosis recorded by the clinician and ICD-10 codes.
Excludes 228 patients with missing data for clinical diagnosis recorded by the clinician.
ICH: intracerebral haemorrhage

SUMMARY

In 2019, three new public hospitals contributed data to the AuSCR, with two other hospitals ceasing their contribution. The AuSCR office continue to actively monitor and provide feedback on various aspects of data quality to all participating hospitals, and work actively with hospital staff to facilitate improvements to the quality and representativeness of their data within the registry.

The overall data quality of the 2019 AuSCR dataset remained consistently high and was comparable to data quality previously reported in 2018. Nonetheless, several individual variables recorded in 2019 are of concern as they have been either completed poorly over several years, or have decreased by ≥10% in 2019 such as stroke severity, clinical outcomes or demographic details.

Although completion of the NIHSS variables at baseline and pre/post ECR have improved over time, there still remains a large proportion of cases with NIHSS scores documented as unknown (44% baseline; 34% pre-ECR and 37% post ECR). Baseline NIHSS is an important prognostic indicator of stroke severity, alongside the ability to walk independently on admission. These variables are important for conducting fair comparisons of patient outcomes between hospitals as they are used in case-mix adjusted analyses. Post-ECR NIHSS is also an important measure used to in the determination of the success of ECR treatments. In 2019, proportion of missing ECR outcome variables data increased: final e-TICI score (24% missing) and details of haemorrhage within the infarct following ECR treatment (12% missing). Although, ECR cases accounted for only 6% of all AuSCR episodes in 2019, the missing patient outcomes data following ECR remain a concern. The AuSCR office will continue to work with staff from participating hospitals to improve the documentation of baseline NIHSS scores, as well as hospitals providing ECR services, to ensure future completion rates for these variables improve.

The collection of patient-reported outcomes from AuSCR registrants (follow-up), at 90-180 days following admission is an important aspect of the AuSCR. Follow-up is completed centrally by the AuSCR office and therefore the provision of addresses and phone numbers for both patients and their emergency contacts is a prerequisite to facilitate the completion of follow-up process. In 2019, an overall increase in missing data for patient demographic variables was observed, especially for the details for the emergency contacts of registrants (e.g. 27% missing emergency contact address). Improvements to the collection of contact details will be a priority area for the AuSCR office in 2020 using tailored education and training for staff from participating hospitals, as well as the development of fact sheets, to ensure the importance of these data are understood.

Compared to 2018 data, missing data for the provision of hyperacute aspirin increased by 5% in 2019, and was accompanied by the greatest error rate (13%) identified using medical record audit data. Some of these errors may have related to changes in the Clinical Guidelines for Stroke Management and uncertainty about how this information should be documented in the AuSCR. In response, the AuSCR office updated the variable to capture all antiplatelets, and accompanied this with changes to the data dictionary, fact sheets and a webinar held in July 2020. We are confident these strategies will improve the understanding among staff from participating hospitals and that improvements related to the completion of this variable will be present in the 2020 dataset.

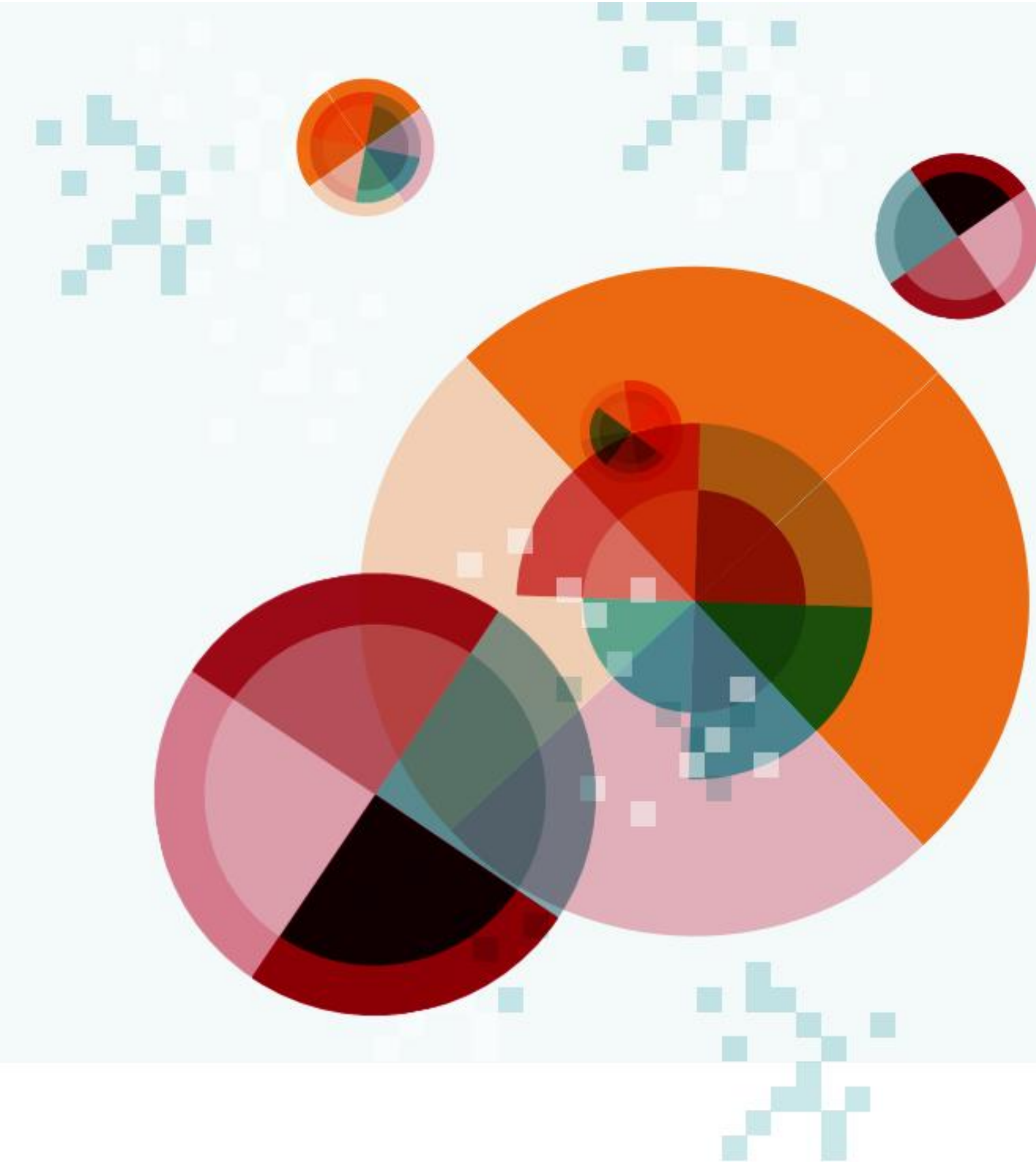
The capture of all eligible stroke and TIA episodes at participating hospitals is important to ensure that AuSCR data is unbiased and is a nationally representative sample. In support of this, the opt-out rate for the AuSCR remains very low at 2% with a median case ascertainment of 77%. Although the median case ascertainment was slightly lower compared to 2018 (83%), the case ascertainment details of a larger proportion of hospitals (85%) were able to be calculated, partly due to data linkage with the admitted episodes dataset in Victoria. The centralised case ascertainment in Victoria was used to reduce the burden on hospital staff to provide this information and enabled comparable case ascertainment results for a greater number of hospitals. The AuSCR office is currently investigating the feasibility of using a similar process in the Australian Capital Territory, Queensland and South Australia for 2020 admissions. However, it should be noted that case ascertainment is only an estimate of the representativeness of AuSCR data for each hospital, since clinical coding processes differs between states and the experience of administrative staff responsible for abstracting codes from the medical record information may vary between hospitals. In addition, the diagnosis of stroke or TIA may be subject to change following discharge from hospital, with post-discharge changes to diagnosis unable to be reflected within the admitted episodes data received by the AuSCR office for case ascertainment.

The AuSCR office values input from, and collaboration with, clinicians and in response in 2018, two new optional datasets were launched as part of the AuSCR on 1 July 2019. Seventeen hospitals participated in the FeSS dataset and recorded data for almost 1000 episodes, with a 100% completion rate for the six variables. A total of twenty hospitals participated in the ED dataset, and these data also had a high completion rate overall. Even though in 2019some hospitals were limited in their ability to contribute data to the new datasets due to regulatory and ethics requirements, we were pleased with the level of uptake and completeness of the data for these two programs. The delivery of educational webinars and fact sheets developed by the AuSCR office were important strategies used to facilitate the successful uptake of the new datasets and we look forward to more hospitals collecting data using these optional programs in 2020.

The quality of the data recorded in the registry is a result of the ongoing support to hospitals offered by the AuSCR office including: updates to the AuSCR Data Dictionary; hosting regular webinars; disseminating monthly newsletters; developing and disseminating fact sheets, improved training processes; and presentations related to data quality at external conferences and workshops. In 2020, the AuSCR office will continue to support staff from participating hospitals in using various mechanisms to ensure the optimal accuracy and representativeness of the data recorded within the registry.

ACKNOWLEDGMENTS

We gratefully acknowledge contributions made by the AuSCR staff based at the Florey Institute of Neuroscience and Mental Health (The Florey): Emma Tod, Natalie Wilson, Violet Marion, Kate Paice, Jot Ghuliani, Helen Carter, Adele Gibbs, Nancy Pompeani, Karen Moss, Olivia Ryan, Claire Weickhardt, Lilian Braighi, Marcus Lester and Sam Shehata. We also appreciate the support from the Information Technology team based at The Florey in relation to maintaining the AuSCR server host environment and other technical processes.



AuSCR

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