

# Annual Data Quality Report 2018



January 2020

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, Shehata S, Kim J, Tod E & Cadilhac CA on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Data Quality Report 2018. The Florey Institute of Neuroscience and Mental Health; January 2020, 18 pages.

Any enquires about, or comments on, this publication should be directed to:

Administration  
Australian Stroke Clinical Registry Office  
The Florey Institute of Neuroscience and Mental Health  
245 Burgundy Street  
Heidelberg, Victoria 3084, Australia

Ph: +61 3 9035 7264

Fax: +61 3 9035 7304

Email: [admin@auscr.com.au](mailto:admin@auscr.com.au)

Website: [www.auscr.com.au](http://www.auscr.com.au)

 @AustStrokeReg

January 2020

Consortium partners:



## **CONTENTS**

<b>Introduction.....</b>	<b>4</b>
<b>Methods for ensuring data quality .....</b>	<b>5</b>
<b>Data cleaning.....</b>	<b>6</b>
<b>Data completeness .....</b>	<b>6</b>
<b>Data discrepancies from medical record audits .....</b>	<b>10</b>
<b>Case ascertainment .....</b>	<b>13</b>
<b>Time to creation of registrant records by hospitals.....</b>	<b>15</b>
<b>Opt-out requests and refusal to complete follow-up survey.....</b>	<b>15</b>
<b>Discharge coding of stroke type compared with clinical diagnosis.....</b>	<b>16</b>
<b>Discussion.....</b>	<b>17</b>
<b>Acknowledgments .....</b>	<b>18</b>

## **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 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 guide improvements to their data quality processes.

This annual Data Quality Report covers data collected for patients admitted to participating hospitals between 1 January 2018 and 31 December 2018. It is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2018 Annual Report (<https://auscr.com.au/about/annual-reports/>).

## **METHODS FOR ENSURING DATA QUALITY**

Promotion of data quality is supported by various and ongoing training and education processes for all contributors of data to the AuSCR. The AuSCR Office undertakes a number of routine data checking procedures to ensure the quality for the AuSCR acute data supplied by hospitals, which include the following:

### **AUSDAT LOGIC**

Since July 2016, AuSCR data has been collected using the Australian Stroke Data Tool (AuSDaT). The AuSDaT contains in-built webtool functions which auto-check the logic of manually entered data thereby minimising inaccuracies and discrepancies in data entry.

### **DATA CHECKS BEFORE IMPORT**

For hospitals transferring their AuSCR data via an import template, data are reviewed by AuSCR Data Managers prior to upload to ensure the data are in the correct format and any inconsistencies or errors are corrected.

### **CASE ASCERTAINMENT**

Case ascertainment is an essential process for ensuring that data contained within 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 provides an indication of the representativeness of the data and whether there is any selection bias.

For the AuSCR case ascertainment reports in 2018, hospitals were asked to provide a list of all admissions based on eligible ICD-10 stroke codes for comparison and matching with episodes contained within the AuSCR.

### **DATA QUALITY REPORTS**

Data quality reports 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). They are designed to assist hospitals to quickly identify and update, where appropriate, individual AuSCR episodes with missing or discrepant/incorrect data. These reports are timed to provide sites with the opportunity to make these updates prior to closure of a calendar year before extraction for formal reporting or research.

### **MEDICAL RECORD AUDITS**

The AuSCR conducts medical record audits at participating hospitals to assess the accuracy of data in the registry compared to the local medical record. The auditor assesses a random selection of episodes for missing or discrepant data and also looks for patterns in the variation of data collection. These audits assist in verifying that AuSCR data collection is standardised, and helps to determine the future training needs of sites. Medical record audits are scheduled to occur for a new participant hospital following entry of the first 50 episodes and thereafter every two years.

## STROKE DENIAL REPORTS

From time to time the AuSCR office receives notifications from registrants stating that they have not had a stroke or TIA. The AuSCR office compiles a list of these cases and distributes this information to the relevant hospital in order to confirm eligibility. Patterns of stroke denial cases provide opportunities for review of registrant recruitment processes and patient education.

## DATA CLEANING

The cleaning of AuSCR data is completed following the closure of data entry for the year and prior to analysis for the annual report. Duplicate data are identified and removed by the AuSCR National Data Manager using registrant identifiers (name, date of birth, Medicare number and/or hospital medical record number) in conjunction with dates of stroke onset, arrival, admission and discharge. Data are subsequently de-identified and extracted for analysis. Additional data cleaning is then undertaken by Monash University statisticians prior to analysis.

## DATA COMPLETENESS

For 2018, the denominator was 20,051 episodes, including 1,242 recurrent episodes where patients had multiple episodes in the year (between two and seven). All variables for opt-out episodes were classified as 'complete' regardless of whether they were collected prior to opt out. The proportion of data completeness is presented for applicable cases only, since not all variables are relevant to every patient, such as the use of intravenous thrombolysis.

Individual variable completion rates in 2018 were generally similar or higher than in 2017 with the completion rates for 22 individual variables improving by >5% (Table 1). Only three individual variables had lower completion rates than in 2017: acute occlusion site (7% decrease), National Institutes of Health Stroke Scale (NIHSS) before Endovascular Clot Retrieval (ECR; 15% decrease) and final eTICI following ECR (4% decrease). The lowest completion rate (43%) was for medical complication ICD10 codes; however, this is likely to be not required in some episodes where patients do not experience complications during their hospital visit.

In addition to missing data, some variables may also have a large proportion of responses listed as unknown (Table 2). This is particularly evident in the case of the National Institutes of Health Stroke Scale (NIHSS) variables where the combination of missing and unknown values means that there were no data for: 50% of episodes for the baseline NIHSS; 38% for pre-ECR NIHSS; and 45% for post-ECR (24 hour) NIHSS. In previous years the total unknown and missing values for discharge medications were also problematic. However, the documentation of discharge medication variables has improved in recent years by between 9-30% since 2016 (Table 2).

**Table 1: Completeness of fields in the AuSCR by year since transition to the AuSDaT**

Field	2016+ % complete N hospitals = <b>48</b>	2017 % complete N hospitals = <b>59</b>	2018 % complete N hospitals = <b>72</b>
<b>Patient details</b>			
Title	100	95	100
First name	99	99	100
Surname	99	99	100
Date of birth	99	99	100
Medicare number	<b>92</b>	<b>93</b>	97
Hospital Medical Record Number (MRN)	98	98	100
Gender	100	98	100
Country of birth	95	<b>93</b>	99
Language spoken	<b>94</b>	<b>92</b>	<b>91</b>
Interpreter needed	99	<b>92</b>	<b>91</b>
Aboriginal and Torres Strait Islander status	98	95	98
Patient phone number	<b>94</b>	<b>92</b>	98
Complete address (street address, suburb, state)	95	95	97
<b>Emergency contact</b>			
Emergency contact first name	96	<b>93</b>	95
Emergency contact last name	95	<b>91</b>	<b>94</b>
Address for emergency contact	<b>56</b>	<b>82</b>	<b>87</b>
Emergency contact phone number	90	<b>90</b>	<b>92</b>
<b>Arrival and admission data</b>			
Date of stroke onset	<b>91</b>	<b>94</b>	99
Time of stroke onset	<b>85</b>	<b>90</b>	99
Stroke occurred while in hospital	<b>92</b>	<b>94</b>	99
Date of arrival to ED	<b>88</b>	96	97
Time of arrival to ED	<b>89</b>	98	99
Arrival by ambulance	<b>89</b>	99	100
Transfer from another hospital	95	95	99
Date of admission	99	100	100
Time of admission	98	98	99
Treated in a stroke unit	<b>93</b>	95	99
<b>History of known risk factors</b>			
Documented evidence of a previous stroke	<b>92</b>	<b>94</b>	99
<b>Acute clinical data</b>			
NIHSS at baseline	<b>89</b>	<b>91</b>	97
Brain scan after this stroke	<b>69</b>	<b>92</b>	100
Date of first brain scan	99	<b>84</b>	96
Time of first brain scan	99	<b>91</b>	96
Date of subsequent brain scan	97	<b>49</b>	96
Time of subsequent brain scan	100	<b>80</b>	96
Type of stroke	<b>91</b>	<b>93</b>	99
Cause of stroke	<b>87</b>	<b>92</b>	98
Acute occlusion site	99	<b>90</b>	<b>83</b>

**Table 1 (cont): Completeness of fields in the AuSCR by year since transition to the AuSDaT**

Field	2016+ % complete N hospitals = 48	2017 % complete N hospitals = 59	2018 % complete N hospitals = 72
<b>Telemedicine and reperfusion</b>			
Stroke telemedicine consultation conducted	85	87	93
Receipt of thrombolysis	97%	98%	100
Date of delivery	90	99	100
Time of delivery	90	93	100
Adverse event related to thrombolysis	70	94	98
Type of adverse event	98	95	99
Other reperfusion (ECR)	64	55	97
Treatment date for ECR	70	59	95
NIHSS before ECR	69	90	75
Time groin puncture	89	92	95
Time of completing	89	92	91
Final eTICI	78	75	71
<b>24 hour data</b>			
24 hour NIHSS	92	97	100
Haemorrhage on follow up imaging	93	98	100
Details	79	91	100
<b>Swallowing</b>			
Swallowing screen	72	86	95
Date of swallowing screen	99	99	100
Time of swallow screen	99	99	100
Did the patient pass the screening	99	99	100
Swallowing assessment	72	85	94
Date of swallow assessment	99	99	100
Time of swallow assessment	99	99	100
Oral medications	96	81	90
Oral food or fluids	96	81	90
<b>Mobilisation</b>			
Walk on admission	81	93	98
Mobilised this admission	71	84	99
Date of mobilisation	99	99	100
Method of mobilisation	97	96	99
<b>Antithrombotic therapy</b>			
Aspirin given as hyperacute therapy	98	84	95
Date	99	99	100
Time	99	99	100
<b>Secondary prevention</b>			
Discharge antithrombotics	85	92	99
Discharge antihypertensives	92	94	99
Discharge lipid lowering	82	90	99



**Table 1 (cont): Completeness of fields in the AuSCR by year since transition to the AuSDaT**

Field	2016 <sup>+</sup> % complete N hospitals = 48	2017 % complete N hospitals = 59	2018 % complete N hospitals = 72
<b>Discharge information</b>			
Patient deceased during hospital care	98	100	99
Date of death (if deceased status during hospital care is yes)	99	100	100
Date of discharge if not deceased while in hospital	98	97	100
Discharge diagnosis ICD10 code(s)	<b>88</b>	<b>93</b>	95
Medical condition ICD10 code(s)*	<b>25</b>	<b>72</b>	<b>72</b>
Medical complication ICD code(s)*	<b>12</b>	<b>38</b>	<b>43</b>
Medical procedure ICD10 code(s)*	<b>30</b>	<b>72</b>	<b>74</b>
Discharge destination if not deceased while in hospital	<b>93</b>	97	99
Evidence of care plan on discharge if discharged to the community	96	<b>94</b>	98

*Bold numbers indicate >5% missing or discrepant data.*

*Italicised numbers indicate >5% improvement in variables completion as compared to 2017 data.*

*\* First year of using the Australian Stroke Data Tool from July 2016 where new variables were added.*

*\* Denominator includes some patients with no other medical conditions, complications or procedures.*

*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 values to AuSCR variables by year since transition to the AuSDaT**

	2016 <sup>+</sup> % missing and unknown	2017 % missing and unknown	2018 <sup>+</sup> % missing and unknown
<b>National Institutes of Health Stroke Scale (NIHSS)</b>			
Baseline	73	66	50
Pre-ECR*	55	64	38
24 hour (post-ECR)	63	64	45
<b>Discharge medications</b>			
Antihypertensives	16	10	7
Antithrombotics	17	11	6
Lipid lowering	37	14	7

*\* First year of using the Australian Stroke Data Tool from July 2016 where new variables were added.*

*\* Note: a second NIHSS prior to ECR may not always be warranted depending on the time of the baseline NIHSS.*

*NIHSS: National Institutes of Health Stroke Scale.*

*ECR: Endovascular Clot Retrieval.*

## DATA DISCREPANCIES FROM MEDICAL RECORD AUDITS

Auditors from the AuSCR Office undertook site visits at 28 hospitals in 2018 and reviewed 187 medical records. Between five and ten randomly selected medical records were assessed at each audit. Table 3 lists the AuSCR variables common across all participating states, with discrepancies per variable, which may be incorrect or missing data. Note that state-specific variables (such as those collected in New South Wales) are not reported here. Discrepancies between medical records and AuSCR data are generally low, with the highest discrepancies (6-9%) occurring in variables such as stroke onset, mobilisation, hyperacute aspirin, discharge medications and discharge details.

**Table 3: Discrepancies within AuSCR fields noted during 2018 data quality audits**

Fields	Discrepant number	%	No. of sites with discrepancy
<b>N=187 records audited from 28 hospitals</b>			
<b>Patient details</b>			
Title	4	2%	3
First name	1	1%	1
Last name	0	0%	0
Date of birth	0	0%	0
Medicare number	4	2%	3
Hospital Medical Record Number (MRN)	0	0%	0
Gender	0	0%	0
Country of birth	5	3%	5
Language spoken	2	1%	2
Interpreter needed	3	2%	3
Aboriginal and Torres Strait Islander status	3	2%	3
Patient phone number	5	3%	5
Patient mobile number	8*	4%	6
Address	5	3%	5
<b>Emergency contact</b>			
Emergency contact first name	5*	3%	4
Emergency contact last name	2	1%	2
Address for emergency contact	4	2%	4
Emergency contact phone number	5*	3%	4
Emergency contact mobile number	11*	6%	6
Emergency contact relationship to participant	1*	1%	1
<b>Arrival and admission details</b>			
Date of stroke onset	12	6%	9
Accuracy of stroke onset date	2	1%	2
Time of stroke onset	12	6%	9
Accuracy of stroke onset time	4	2%	3
Stroke occurred while in hospital	2	1%	2
Date of arrival to ED	8	4%	7
Accuracy of date of arrival to ED	4	2%	3
Time of arrival to ED	10	5%	5

**Table 3 (cont): Discrepancies within AuSCR fields noted during 2018 data quality audits**

<b>Fields</b>	<b>Discrepant number</b>	<b>%</b>	<b>No. of sites with discrepancy</b>
Accuracy time of arrival	5	3%	2
Direct admission to hospital (bypass ED)	1	1%	1
Arrival by ambulance	5	3%	4
Transfer from another hospital	3	2%	3
Date of admission	3	2%	3
Time of admission	6	3%	5
Treated in stroke unit	4	2%	3
Reason for transfer	1	1%	1
<b>History of known risk factors</b>			
Documented evidence of a previous stroke	5	3%	5
<b>Acute clinical data</b>			
NIHSS at baseline	12	<b>6%</b>	9
Brain scan after this stroke	0	0%	0
Date of first brain scan	6*	3%	5
Time of first brain scan	3	2%	3
Date of subsequent brain scan	0	0%	0
Time of subsequent brain scan	1	1%	1
Type of stroke	3	2%	2
Cause of stroke	1	1%	1
Acute occlusion site	0	0%	0
<b>Telemedicine and reperfusion</b>			
Stroke telemedicine consultation conducted	11	<b>6%</b>	7
Use of IV thrombolysis (if ischaemic)	8	4%	6
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	0	0%	0
Time groin puncture	0	0%	0
Time of completing	0	0%	0
Final eTICI	0	0%	0
<b>24 hour data</b>			
24 hour NIHSS	0	0%	0
Haemorrhage on follow up imaging	0	0%	0
Details	0	0%	0
<b>Swallowing</b>			
Swallowing screen	9*	5%	6
Date of swallowing screen	2	1%	2
Time of swallow screen	4	2%	4
Did the patient pass the screening	3	2%	2

**Table 3 (cont): Discrepancies within AuSCR fields noted during 2018 data quality audits**

Fields	Discrepant number	%	No. of sites with discrepancy
Swallowing assessment	6*	3%	4
Date of swallow assessment	3	2%	2
Time of swallow assessment	5	3%	3
Oral medications	13	<b>7%</b>	9
Oral food or fluids	8	4%	5
<b>Mobilisation</b>			
Walk on admission	13	<b>7%</b>	8
Mobilised this admission	13	<b>7%</b>	7
Date of mobilisation	11	<b>6%</b>	7
Method of mobilisation	1	1%	1
<b>Antithrombotic therapy</b>			
Aspirin given as hyperacute therapy	16	<b>9%</b>	9
Date	2	1%	2
Time	5	3%	5
<b>Secondary prevention</b>			
Discharge antithrombotics	13	<b>7%</b>	11
Discharge hypertensives	12	<b>6%</b>	9
Discharge lipid lowering	13	<b>7%</b>	9
<b>Discharge information</b>			
Patient deceased during hospital care	4	2%	3
Date of death	0	0%	0
Date of discharge known	6	3%	4
Date of discharge	15	<b>8%</b>	9
Discharge diagnosis ICD 10	7	4%	4
Medical condition ICD 10 Code(s)	9	5%	6
Medical complication ICD 10 Code(s)	13	<b>7%</b>	4
Procedure ICD Code(s)	5	3%	4
Discharge destination	14	<b>7%</b>	11
Discharge care plan	15	<b>8%</b>	8

*Bold numbers indicate >5% missing or discrepant data.*

*\* Indicates >50% of data were missing*

*NIHSS: National Institutes of Health Stroke Scale*

*ECR: Endovascular Clot Retrieval*

*ICD: International Classification of Diseases*

## CASE ASCERTAINMENT

During 2018, the AuSCR office requested data on hospital admissions of eligible stroke or TIA admissions twice for the purpose of determining case ascertainment. The first was for the period 1 January to 30 June 2018, and the second was the full year, 1 January to 31 December 2018. Of the 71 hospitals contributing data in 2018, one hospital (paediatric) was excluded from this analysis, and 56 (79% of eligible hospitals) provided data for at least one case ascertainment round. More hospitals participated in case ascertainment in 2018 than 2017, however the proportion of participating hospitals was smaller compared to 2017 (90%). Forty-three hospitals (61%) provided an extract of eligible stroke episodes for the full year, and 13 provided an extract for the first half of the year only. Where hospitals provided extracts for both rounds of case ascertainment, the full year figure is presented here.

The proportion of completeness for case ascertainment was estimated using the formula  $A/(A+B)$ , where 'A' is the number of episodes that were registered in the AuSCR and 'B' is the number of episodes included in the hospital record that were missing from the AuSCR database.

Table 4 shows the 2018 case ascertainment outcomes for all hospitals, with 2017 comparisons. For the 56 hospitals that provided data, case ascertainment ranged from 42% to 100% with a median of 83%. This was slightly above the median of 81% obtained in 2017. Note that case matching for case ascertainment may be affected by data entry errors whereby variables used to match episodes between the datasets (e.g. names, medical record number) were incorrectly entered into the AuSCR and matches not made. However, we believe that these cases would make up a relatively small proportion of the overall total, as both automated and manual matching processes between the datasets are undertaken by the AuSCR office.

**Table 4: Case ascertainment results for 2018, with 2017 comparison**

Hospital ID	Episodes in the AuSCR (n)	Episodes in hospital records not in the AuSCR (n)	Case ascertainment 2018	Case ascertainment 2017
3	363	164	67%	67%
5	547	163	73%	32%
12	130	Not provided	Not provided	44%
13	133	6	95%	61%
14	622	Not provided	Not provided	59%
15	803	101	89%	89%
16	249	282	46%	Not applicable
20	410	36	83%*	91%
22	170	80	47%	41%
23	201	33	85%	80%
24	728	146	79%	87%
25	227	4	99%	99%
26	380	33	88%	83%
27	311	95	72%	75%
28	48	Not provided	Not provided	40%
29	120	2	100%*	83%
30	286	38	80%	89%
31	456	Not provided	Not provided	100%
32	183	48	78%	60%
33	144	12	89%	51%
34	223	40	82%	45%
35	269	9	98%	83%
36	182	112	59%	42%
37	476	44	91%	56%
38	168	35	78%	Not provided
39	347	6	98%	96%
40	558	133	79%	72%
41	242	8	90%*	92%
42	48	21	57%	42%
43	222	25	93%	94%
44	210	21	93%	80%
45	248	124	59%	81%
46	826	Not provided	Not provided	Not provided
47	239	31	87%	86%
48	59	Not provided	Not provided	Not provided
49	49	7	81%	81%
50	211	25	88%	96%
51	90	Not provided	Not provided	96%
52	431	10	98%	53%
53	643	93	82%	28%
55	150	16	88%	89%
56	18	116	87%	82%
57	340	2	100%*	93%
58	1117	170	86%	97%
61	161	Not provided	Not provided	Not provided
62	64	49	49%	76%
63	135	5	79%*	73%
64	92	Not provided	Not provided	84%
65	551	26	92%*	91%

**Table 4 (Cont): Case ascertainment results for 2018, with 2017 comparison**

Hospital ID	Episodes in the AuSCR (n)	Episodes in hospital records not in the AuSCR (n)	Case ascertainment 2018	Case ascertainment 2017
67	53	8	84%	81%
68	99	4	91%*	90%
69	1101	26	96%*	Not applicable
70	385	9	99%*	Not applicable
71	509	9	97%*	Not applicable
73	58	56	52%	Not applicable
74	101	69	52%	Not applicable
75	276	116	71%	Not applicable
77	245	33	75%*	Not applicable
78	135	63	51%*	Not applicable
79	288	373	42%	Not applicable
80	49	Not provided	Not provided	Not applicable
81	44	Not provided	Not provided	Not applicable
82	245	26	92%	Not applicable
83	313	101	75%	Not applicable
84	367	Not provided	Not provided	Not applicable
85	204	Not provided	Not provided	Not applicable
86	153	110	49%	Not applicable
87	178	Not provided	Not provided	Not applicable
88	201	35	82%	Not applicable
89	45	5	80%*	Not applicable

\*Hospital provided data for January to June 2018 only.  
Excluding paediatric hospital.

## TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

The overall median time from patient admission to the creation of a patient episode in the AuSCR for 2018 admissions was 85 days, a decrease of 12 days from 2017 (97 days). The shortest hospital-level median time to creation was 5 days, and the longest was 297 days. This includes several AuSCR hospitals that performed bulk uploads of eligible historic data resulting in a greater than usual length of time to record creation.

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

Since transitioning to the AuSDaT in late 2016, the AuSCR has Human Research Ethics Committee (HREC) approval to retain anonymous clinical data independently of personal data opt-outs, although registrants are still able to opt-out *both* personal and clinical data upon request.

A total of 443 opt-out requests (2.2% of all episodes) were received from patients or their next of kin for 2018 admissions (Table 5). This is identical to the 2017 opt-out rate. The rate of opt-out requests varied by hospital, ranging from zero to 8.6%. The requests for removal of *both* clinical and personal data remains very low 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 5: Opt out Requests and refusal to complete follow-up**

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
2017	14184	319	24	295	78
2018	20051	443	18	425	185

## DISCHARGE CODING OF STROKE TYPE COMPARED WITH CLINICAL DIAGNOSIS

The AuSCR reviews the clinical designation of stroke type within the registry against the International Classification of Diseases (ICD) discharge coding undertaken by hospital clinical coders. This was completed by comparing the discharge diagnosis code (version ICD-10) with the stroke type provided by hospital clinicians.

For clinically diagnosed TIAs, 86% of TIA episodes had a primary ICD10 code of TIA (G45.9). For episodes designated as ischaemic strokes, 80% of episodes had a primary diagnosis code within the I63 range (cerebral infarction: I63.0 to I63.9), and 5% were coded as I64 (stroke, not specified). These results are comparable to 2017 data. Eighty-two percent of clinically diagnosed haemorrhagic strokes were coded as haemorrhagic stroke (I61 range and I62.9) and 11% had a non-stroke primary diagnosis. See table 6 for comparison of all clinical diagnosis and associated ICD10 primary diagnosis codes. The AuSCR episodes with an ICD10 primary discharge diagnosis code other than the eligible stroke/TIA ICD10 codes may have presented with significant comorbidities or had a stroke while in hospital for another condition. In these episodes, the stroke code often appears as a secondary ICD10 code (medical condition or complication).

**Table 6: Comparison of clinical diagnosis and ICD10 primary diagnosis codes**

	Clinical diagnosis			
	ICH n=2517	Ischaemic n =14010	TIA n=2806	Undetermined n=494
ICH ICD10 codes (I61 range and I62.9)	<b>82%</b>	1%	0%	2%
Ischaemic ICD10 codes (I63 range)	3%	<b>80%</b>	3%	27%
TIA ICD10 code (G45.9)	1%	1%	<b>86%</b>	13%
Unspecified stroke ICD10 code (I64)	0%	5%	1%	<b>45%</b>
Missing ICD10 code	3%	5%	4%	4%
Other principal ICD10 code	11%	8%	5%	8%

*Bold numbers indicate matching between clinical diagnoses and coding.*

*Excludes 224 patients with a missing clinical diagnosis.*



## DISCUSSION

In 2018, 18 new public hospitals contributed data to the AuSCR. The AuSCR team continue to actively monitor and provide feedback on data quality to all participating hospitals, and work actively with hospital staff to improve the quality and representativeness of the data within the registry. The success of AuSCR site training and ongoing support is evidenced in this report by improvements in rates of variable completion and overall case ascertainment. Increased numbers of medical record audits completed in 2018 also provided State Coordinators with additional opportunities for face-to-face support and education to address site challenges and missing or misinterpreted variables.

The median time for hospitals to record creation for an admitted episode admission decreased in 2018 to 85 days. With the median now below 90 days, the majority of episodes in the 2018 dataset were entered in time to receive three complete follow-up attempts (i.e. two mail attempts and a comprehensive phone attempt). In 2019 the AuSCR office will continue to work with hospitals to highlight the importance of timely data entry for follow-up completion.

The capture of all eligible episodes at participating hospitals is important to ensure that the AuSCR contains an unbiased and nationally representative sample of stroke and TIA. In support of this, the opt out rate for the AuSCR remains very low at 2% and median case ascertainment was a respectable 83%. The AuSCR office are currently exploring centralised mechanisms for obtaining hospital admissions data for case ascertainment from all participating hospitals directly from state governments. This would reduce the burden on hospital staff to provide administrative data and provide comparable case ascertainment results for a greater number of hospitals.

In 2018, the completion of NIHSS at different time-points was variable. Completion for baseline and post-ECR NIHSS were very good at 100% and 97%, respectively. However, pre-ECR NIHSS completion was much lower at 75%. Feedback from hospitals has indicated that in many cases a pre-ECR NIHSS is not completed where a baseline NIHSS was previously completed. The large amount of missing data for this variable therefore reflects hospital practice rather than poor data entry. The main concern with baseline and post-ECR NIHSS scores is the large amount of episodes where the score was entered as 'unknown' (in 42% and 39% of episodes respectively). Audits of AuSCR records show that these unknown NIHSS scores are a true reflection of the medical record, and therefore represents a gap in current clinical practice, rather than entry into the AuSCR. Therefore, improvements in performing NIHSS for all patients is an issue for stroke clinical practice, nationally.

Overall, the 2018 completion of variables was greater than in preceding years. The improved completion was likely a result of ongoing support to hospitals by the AuSCR office including: updates to the AuSCR Data Dictionary; regular webinars; newsletters; improved training; and data quality presentations at external conferences and workshops. In addition, hospitals are becoming more familiar with the newer variables which were introduced in 2016. In 2019, the AuSCR office will continue to support hospitals in numerous ways to ensure the accuracy and representativeness of data contained within the registry.

## **ACKNOWLEDGMENTS**

We gratefully acknowledge contributions made by the AuSCR staff at the Florey Institute of Neuroscience and Mental Health (The Florey): Sibilah Breen, Sam Shehata, Julie Morrison, Emma Tod, Natalie Wilson, Violet Marion, Kate Paice, Jot Ghuliani, Helen Carter, Perrin Date, Adele Gibbs, Karen Moss and Olivia Ryan. We also appreciate the support from the Information Technology team at The Florey in supporting the AuSCR server hosting and other technical processes.