Annual Data Quality Report 2017

Updated version with corrections, 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:

Breen S, Kim J, Kilkenny M, Shehata S, Morrison J, Tod E & Cadilhac DA on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Data Quality Report 2017. The Florey Institute of Neuroscience and Mental Health; March 2019, 18 pages.

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March 2019_V2

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CONTENTS

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 therefore encouraged to use this data quality 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 2017 and 31 December 2017. It is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2017 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 the AuSCR data has been collected with the Australian Stroke Data Tool (AuSDaT). The AuSDaT contains in-built webtool functions which auto-check the logic of entered data thereby minimising inaccuracies and discrepancies in data entry.

Data Checks Before Import

For hospitals transferring their AuSCR data via an export 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 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 2017, 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. The format of case ascertainment reports was also updated in 2017 to enable easier identification of missing episodes, as well as comparisons with national rates of case ascertainment.

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. In 2017 these reports were redesigned to make the identification of missing and discrepant variables easier, along with national comparisons of data completeness.

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 the AuSCR verify that data collection is standardized, and helps to determine the future training and educational 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 final 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

A summary of 2017 data completeness (i.e. where individual variables were not missing or coded as unknown) is presented in Table 1. The 2017 data provides the first full year of data since the transition to AuSDaT and the addition of new data variables. Information for data completeness following transition to the AuSDaT in 2016 is also presented as a reference. Completion rates in 2017 are generally similar or improved on 2016 rates with the exception of brain scan, hyperacute aspirin and endovascular clot retrieval (ECR) variables.

For 2017, unless otherwise stated in Table 1, the denominator was 14,184 episodes including 789 patients who had 1,673 recurrent episodes. 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.

In addition to missing data, some variables may also have a large proportion of responses listed as unknown which are not apparent in Table 1. This is particularly evident in the case of the National Institutes of Health Stroke Scale (NIHSS) variables where combined, missing and unknown values, mean that there are no data for: 66% episodes for the baseline NIHSS; 63% for pre-ECR NIHSS (although not always clinically required) and; 64% for post-ECR (24 hour) NIHSS (Table 2). This is also a consideration for process of care variables including discharge on lipid lowering medication (14%), discharge on antithrombotics (11%), and discharge on anti-hypertensive medication (10%).

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

Field	2016+ % complete N hospitals = 48	2017 % complete N hospitals = 59
Patient details		
Title	100	95
First name	99	99
Surname	99	99
Date of birth	99	99
Medicare number	**92**	**93**
Hospital Medical Record Number (MRN)	98	98
Gender	100	98
Country of birth	95	**93**
Language spoken	**94**	**92**
Interpreter needed	99	**92**
Aboriginal and Torres Strait Islander status	98	95
Patient phone number	**94**	**92**
Complete address (street address, suburb, state)	95	95
Emergency contact		
Emergency contact first name	96	**93**
Emergency contact last name	95	**91**
Address for emergency contact	**56**	**82**
Emergency contact phone number	90	**90**
Arrival and admission data		
Date of stroke onset	**91**	**94**
Time of stroke onset	**85**	**90**
Stroke occurred while in hospital	**92**	**94**
Date of arrival to ED	**88**	96
Time of arrival to ED	**89**	98
Arrival by ambulance	**89**	99
Transfer from another hospital	95	95
Date of admission	99	100
Time of admission	98	98
Able to walk independently on admission	**91**	**94**
Treated in a stroke unit	**93**	95
History of known risk factors		
Documented evidence of a previous stroke	**92**	**94**

Field		2016+ % complete N hospitals = 48	2017 % complete N hospitals = 59
Acute clinical data			
	NIHSS at baseline	**89**	**91**
	Brain scan after this stroke	**69**	**92**
	Date of first brain scan	99	**84**
	Time of first brain scan	99	**91**
	Date of subsequent brain scan	**97**	**49**
	Time of subsequent brain scan	100	**80**
	Type of stroke	**91**	**93**
	Cause of stroke	**87**	**92**
	Acute occlusion site	99	**90**
Telemedicine and reperfusion			
	Stroke telemedicine consultation conducted	**85**	**87**
	Receipt of thrombolysis	97%	98%
	Date of delivery	**90**	99
	Time of delivery	**90**	**93**
	Adverse event related to thrombolysis	**70**	**94**
	Type of adverse event	98	95
	Other reperfusion (ECR)	**64**	**55**
	Treatment date for ECR	**70**	**59**
	NIHSS before ECR	**69**	**90**
	Time groin puncture	**89**	**92**
	Time of completing	**89**	**92**
	Final eTICI	**78**	**75**
24 hour data			
	24 hour NIHSS	**92**	97
	Haemorrhage on follow up imaging	**93**	98
	Details	**79**	**91**
Swallowing			
	Swallowing screen	**72**	**86**
	Date of swallowing screen	99	99
	Time of swallow screen	99	99
	Did the patient pass the screening	99	99
	Swallowing assessment	**72**	**85**
	Date of swallow assessment	99	99
	Time of swallow assessment	99	99
	Oral medications	96	**81**

Field		2016[+] % complete N hospitals = 48	2017 % complete N hospitals = 59
	Oral food or fluids	96	**81**
Mobilisation			
	Walk on admission	**88**	**93**
	Mobilised this admission	**71**	**84**
	Date of mobilisation	99	99
	Method of mobilisation	97	96
Antithrombotic therapy			
	Aspirin given as hyperacute therapy	98	**84**
	Date	99	99
	Time	99	99
Secondary prevention			
	Discharge antithrombotics	**85**	**92**
	Discharge antihypertensives	**92**	**94**
	Discharge lipid lowering	**82**	**90**
Discharge information			
	Patient deceased during hospital care	98	100
	Date of death (if deceased status during hospital care is yes)	99	100
	Date of discharge if not deceased while in hospital	98	97
	Discharge diagnosis ICD10 code(s)	**88**	**93**
	Medical condition ICD10 code(s)*	**25**	**72**
	Medical complication ICD code(s)*	**12**	**38**
	Medical procedure ICD10 code(s)*	**30**	**72**
	Discharge destination if not deceased while in hospital	**93**	97
	Evidence of care plan on discharge if discharged to the community	96	**94**

[+] *First year of using the Australian Stroke Data Tool from July 2016 where new variables were added.*
Bold numbers indicate >5% missing or discrepant data.
* *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[+] % missing and unknown	2017 % missing and unknown
NIHSS		
Baseline	73	66
Pre-ECR*	55	63
24 hour (post-ECR)	63	64
Discharge medications		
Antihypertensives	16	10
Antithrombotics	17	11
Lipid lowering	37	14

[+] *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 15 hospitals in 2017 and reviewed 108 medical records. Between four and 12 randomly selected medical records were assessed at each audit. A summary of the discrepancies, which may be incorrect or missing data, for the AuSCR data fields are presented in Table 3.

Table 3: Discrepancies within AuSCR fields noted during 2017 AuSCR data quality audits

Fields	Discrepant number	%	No. of sites with discrepancy
N=108 records audited from 15 hospitals			
Patient details			
Title	1	1	1
First name	0	0	0
Last name	0	0	0
Date of birth	0	0	0
Medicare number	3*	3	3
Hospital Medical Record Number (MRN)	1	1	1
Gender	0	0	0
Country of birth	4	4	4
Language spoken	7*	**6**	4
Interpreter needed	4	4	4
Aboriginal and Torres Strait Islander status	3	3	3
Patient phone number	3	3	3
Patient mobile number	5	5	5
Address	4	4	4
Emergency contact			
Emergency contact first name	4	4	4
Emergency contact last name	1	1	1
Address for emergency contact	1	1	1
Emergency contact phone number	5	5	4
Emergency contact mobile number	4	4	3
Emergency contact relationship to participant	5*	5	2
Arrival and admission details			
Date of stroke onset	7	**6**	3
Time of stroke onset	14	**13**	9
Accuracy of stroke onset time	4	4	4
Stroke occurred while in hospital	0	0	0
Date of arrival to ED	7	**6**	6
Accuracy of date of arrival to ED	1	1	1
Time of arrival to ED	3	3	2
Direct admission to hospital (bypass ED)	1	1	1
Arrival by ambulance	5	5	5
Transfer from another hospital	3	3	3
Date of admission	1	1	1
Time of admission	5	5	4
Treated in stroke unit	1	1	1

Fields	Discrepant number	%	No. of sites with discrepancy
N=108 records audited from 15 hospitals			
History of known risk factors			
Documented evidence of a previous stroke	6	**6**	4
Acute clinical data			
NIHSS at baseline	7	**6**	4
Brain scan after this stroke	5*	5	1
Date of first brain scan	7*	**6**	1
Time of first brain scan	7*	**6**	3
Date of subsequent brain scan	6*	**6**	1
Time of subsequent brain scan	2	2	1
Type of stroke	1	1	1
Cause of stroke	4	4	4
Acute occlusion site	1	1	1
Telemedicine and reperfusion			
Stroke telemedicine consultation conducted	3	3	3
Use of IV thrombolysis (if ischaemic)	5*	5	3
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)	3*	3	1
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
24 hour data			
24 hour NIHSS	0	0	0
Haemorrhage on follow up imaging	0	0	0
Details	0	0	0
Swallowing			
Swallowing screen	9*	**8**	4
Date of swallowing screen	5	5	4
Time of swallow screen	6	**6**	6
Accuracy of time of swallow screen	1	1	1
Did the patient pass the screening	1*	1	1
Swallowing assessment	10*	**9**	5
Date of swallow assessment	1	1	1
Time of swallow assessment	1	1	1
Oral medications	10	**9**	7
Oral food or fluids	10	**9**	7
Mobilisation			
Walk on admission	8	**7**	5
Mobilised this admission	13*	**12**	6

Fields	Discrepant number	%	No. of sites with discrepancy
N=108 records audited from 15 hospitals			
Date of mobilisation	5	5	3
Method of mobilisation	8	**7**	5
Antithrombotic therapy			
Aspirin given as hyperacute therapy	13	**12**	7
Date	5	5	4
Time	3	3	3
Secondary prevention			
Discharge antithrombotics	6	**6**	5
Discharge hypertensives	3	3	2
Discharge lipid lowering	10	**9**	7
Discharge information			
Patient deceased during hospital care	2	2	2
Date of death	0	0	0
Date of discharge known	3	3	3
Date of discharge	5	5	4
Discharge diagnosis ICD 10	5	5	4
Medical condition ICD 10 Code(s)	5	5	1
Medical Complication ICD 10 Code(s)	3	3	1
Procedure ICD Code(s)	2	2	2
Discharge destination	10	**9**	7
Discharge care plan	7	**6**	6

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

Twice during 2017, the AuSCR office requested data on hospital admissions of eligible stroke episodes for the purpose of determining case ascertainment. Of the 59 hospitals contributing data in 2017, 7 (12%) were new and ineligible to participate, one hospital (paediatric) was excluded from this analysis, and 46 (90% of eligible hospitals) provided data for at least one case ascertainment round. Twenty-one hospitals provided an extrace of eligible stroke episodes for one period, and 25 hospitals provided an extract for both periods. This was a significant increase from the 63% participation rate in 2016. Values presented in Table 4 are the average of data provided to the AuSCR in the 2017 requests.

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 that were missing from the AuSCR database.

Table 4 shows the 2017 case ascertainment outcomes for all hospitals, with 2016 comparisons. For the 46 hospitals that provided data, case ascertainment ranged from 28% to 100% with a median of 81%. This was greater than the median of 77% obtained in 2016. Note that case matching for case ascertainment may be affected by manual 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 by year since transition to the AuSDaT

Hospital ID	Episodes in the AuSCR (n)	Episodes in hospital records not in the AuSCR (n)	Case ascertainment 2017	Case ascertainment 2016
3	357	240	67%	77%
5	346	110	32%	83%
12	118	52	44%	76%
13	130	80	61%	28%
14	487	287	59%	73%
15	745	663	89%	100%
20	444	404	91%	Not provided
21	144	0	Closed hospital	94%
22	130	54	41%	48%
23	207	166	80%	84%
24	917	798	87%	85%
25	183	181	99%	87%
26	309	256	83%	99%
27	278	209	75%	100%
28	67	27	40%	56%
29	180	149	83%	43%
30	286	255	89%	40%
31	417	417	100%	Not provided
32	194	116	60%	Not provided
33	171	86	51%	78%
34	207	93	45%	80%
35	264	219	83%	Not provided
36	166	70	42%	74%
37	349	195	56%	Not provided
38	220	Not provided	Not provided	Not provided
39	361	347	96%	91%
40	437	315	72%	98%
41	244	225	92%	Not provided
42	53	22	42%	Not provided
43	231	217	94%	16%
44	226	181	80%	75%
45	218	177	81%	Not provided
46	722	Not provided	Not provided	Not provided
47	264	227	86%	91%
48	61	0	Not provided	56%
49	50	40	81%	Not provided
50	170	163	96%	71%
51	98	94	96%	47%
52	336	178	53%	Not active
53	375	105	28%	25%
55	152	135	89%	25%
56	157	129	82%	100%
57	324	22	93%	Not provided
58	966	928	97%	Not active
61	202	0	Not provided	Not provided
62	68	52	76%	Not active
63	85	62	73%	Not active
64	65	55	84%	Not active
65	519	464	91%	Not active
67	20	16	81%	Not active
68	17	15	90%	Not active
69	266	0	Not applicable	Not active
70	83	0	Not applicable	Not active
71	71	0	Not applicable	Not active
77	6	0	Not applicable	Not active
79	10	0	Not applicable	Not active
81	1	0	Not applicable	Not active
82	3	0	Not applicable	Not active

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 was 97 days. The shortest hospital-level median time to creation was 2 days, and the longest was 316 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. In spite of this historical data upload by some sites, the median time to record creation was shorter than in 2016 (128 days).

OPT-OUT REQUESTS AND IN-HOSPITAL REFUSAL TO 90 DAY FOLLOW-UP

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. The 2017 data set represents the first full year of data collection since this amendment.

A total of 319 opt-out requests (2.2% of all episodes) were received from patients or their next of kin in 2017 (Table 5). The rate of opt-out requests varied by hospital, ranging from zero to 18%. The overall rate is slightly higher in total than 2016 (1.9%), however there has been a reduction in requests for removal of *both* clinical and personal data in line with the post-AuSDaT transition HREC approval. The number of patients refusing follow up participation at the time of hospitalisation has also declined to 0.55% in 2017 from 1% in 2016.

Table 5: Opt out Requests

Total episodes	Total opt-out cases	Complete clinical and personal data to be removed	Personal data only to be removed	Refused 90 day follow-up participation at time of hospitalisation
14184	319	24	295	78

DISCHARGE CODING OF STROKE TYPE

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: 88% of TIA episodes were coded as TIA; 4% were coded with non-stroke diagnostic codes and the remainder had either other stroke codes or had no codes documented. For episodes designated as ischaemic strokes, 79% of episodes were coded within the I63 range (cerebral infarction: I63.0 to I63.9), 7% were coded as I64 (stroke, not specified), and 14% were coded with other diagnostic codes or had no codes documented. This represents greater matching between clinical diagnosis and coding for all variables when compared to 2016 data. The AuSCR episodes with a non-stroke discharge diagnostic code are expected to describe those patients with significant other comorbidities or those who have had a stroke while in hospital for another condition.

DISCUSSION

The AuSCR continues to actively monitor and provide feedback on data quality to all participating hospitals, and works actively with hospital staff to improve the quality and representativeness of the data within the registry. In 2017, the first full year since the transition to the AuSDaT, we continued to work with hospitals on understanding new variables and data capture solutions to reduce data entry burden. Newly formatted data quality and case ascertainment reports were also introduced to make identification of missing episodes or data easier for hospitals. Eleven new hospitals commenced participation in the AuSCR 2017.

While registry participation is voluntary, it is important that the data are not biased by missed cases. Case ascertainment data were provided by 90% of participating hospitals. This is a significant improvement from the 63% participation in 2016, and is an indication that efforts to improve this process have had an impact. In addition the median rate of case ascertainment increased from 77% to 81% in 2017. Despite these improvements, case ascertainment rates between sites continue to vary significantly. In 2018 the AuSCR will continue to work closely with, and support, hospitals to improve data capture for all eligible patients.

It is also important that the reporting of acute stroke care quality indicators are reliable in the AuSCR dataset. Results from medical record audits, and calculations of data completeness on all 2017 episodes, indicate that overall the 2017 dataset is more complete than in 2016. This increase in data quality is likely a result of sites becoming more familiar with the AuSDaT and the new variables that were introduced in 2016. Despite this, some variables continue to be problematic, in particular the NIHSS at baseline and pre and post-ECR. Provision and treatment dates for ECR, dates and times for brain scans, swallow screening/assessment prior to oral intake, mobilisation and hyperacute aspirin also continue to be problematic, and will be areas of focus for the AuSCR in future.

Many more medical records were audited in 2017 than in previous years, giving the AuSCR state coordinators a valuable opportunity to identify problematic variables, discuss site challenges and address missing or misinterpretations of variables. These opportunities, along with other activities such as workshops, webinars and newsletters focusing on data quality and variable interpretation, will hopefully translate to further improvements in data quality.

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, Kate Paice Jot Ghuliani, Helen Carter, Perrin Date, Adele Gibbs and Karen Moss. We also appreciate the expert statistical advice from Professor Leonid Churilov (The Florey) and contributions from the Information Technology team at The Florey in supporting the AuSCR server hosting and other technical processes.