

The Australian Stroke Clinical Registry Data Quality Report 2015



May 2017

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

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INTRODUCTION

This Data Quality Report is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2015 Annual Report. It covers data collected for patients admitted to participating hospitals between 1 January 2015 and 31 December 2015.

The AuSCR was established in 2009 to provide national data on the process of care and outcomes for patients admitted to hospital with acute stroke or transient ischaemic attack (TIA).¹ 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.

AuSCR staff employ a number of methods to measure data quality; as reported below: data cleaning, missing and discrepant data reports, random audits of hospital medical records, and case ascertainment.

This is the second year data quality measures have been described in annual reporting for the AuSCR. We anticipate this report will assist participating hospitals in assessing their performance and improve the quality of data they are contributing to the AuSCR.

METHODS FOR ENSURING DATA QUALITY

The AuSCR has a number of methods in place for ensuring data quality.

The online AuSCR database has built-in logic checks and variable limits to reduce data entry errors and mandatory fields to reduce missing data. In-built functions within the database are used to identify duplicate entries and multiple patient records, which may be merged if necessary (for example, if a patient had more than one admission in the same or different hospitals).

Data quality reports listing missing and discrepant data for each site are prepared by the AuSCR Office Staff and sent to hospitals to review, and amend where required.

Each new site undergoes a random audit of 10% of their medical records by AuSCR Office staff after approximately 50 patients have been entered in the registry. The site is given feedback via an audit report and ways of improving data quality are discussed, which may include additional training or amendments to the data dictionary for items which are found to be ambiguous. Audits are repeated approximately every two years thereafter.

At the end of 2015, we requested hospitals provide a list of all admissions based on the AuSCR's ICD10 stroke codes to enable a process of assessing case ascertainment by matching this list to the data in the AuSCR. This process also captures ICD10 codes that were missing from the AuSCR. Site are provided with feedback to review their processes to ensure all eligible patients are captured in the AuSCR.

DATA CLEANING

Before data analysis, duplicate data were checked by the AuSCR Data Manager using the registrants' identifiers (name, date of birth, Medicare number or hospital medical record number) and date of stroke onset, arrival, admission or discharge. Data cleaning was undertaken by the AuSCR Florey staff before the de-identified raw data were extracted for analysis. A second level of data checking was then performed by the Monash University analytic staff.

DATA COMPLETENESS

A summary of the completeness of hospital collected data for the majority of fields within the registry for the 9473 episodes, from 9049 patients, in 2015 is presented in Table 1. These estimates represent the proportion of data completeness for applicable cases only, since not all variables are relevant to every patient, such as use of intravenous thrombolysis.

Table 1: Completeness of fields in the AuSCR database by year of registry being operational

Field	2009# % complete	2010 % complete	2011 % complete	2012 % complete	2013 % complete	2014 n (% complete)	2015 n (% complete)
Person details (n=9049) excluding opt out cases							
First name	100	100	100	100	100	99	9001/9049 (99)
Surname	100	100	100	100	100	99	9001/9049 (99)
Date of birth	100	100	100	99	100	99	9003/9049 (99)
Medicare number	67	90	92	92	91	89	7937/9049 (88)
Patient contact (n=9049)							
Available (complete or partial for street address, suburb and state)	95	99	99	100	98	94	8272/9049 (92)
Complete (street address, suburb, state)	97	55	93	100	97	85	8146/9049 (91)
Telephone for patient (landline or mobile)	90	96	94	95	94	74	7959/9049 (88)
Emergency and alternate contacts (n=9049)							
Address for one or both of emergency and alternate contacts	71	47	78	75	75	77	7081/9049 (79)
Address for one contact	62	40	69	66	64	67	6592/9049 (73)
Address for both contacts	10	7	9	9	11	10	959/9049 (11)
Telephone for emergency and/or alternate contact (landline or mobile)	92	94	90	54	81	83	7277/9049 (81)
General practitioner contacts (n=9049)							
Address	73	46	84	65	74	76	5932/9049 (66)
Telephone for general practitioner (landline or mobile)	75	71	82	63	63	65	5391/9049 (60)
Patient characteristics (n=9049)							
Title	99	97	100	100	100	99	8990/9049 (99)
Hospital medical record number	100	100	100	100	100	100	9044/9049 (100)
Sex	99	98	100	100	100	99	8986/9049 (99)
Country of birth	92	98	95	97	94	95	8263/9049 (92)
Language spoken	97	84	96	86	84	90	7873/9049 (87)
Indigenous status	100	100	100	99	100	98	9003/9049 (99)
Interpreter needed	100	84	100	96	98	99	8984/9049 (99)

Table 1, continued

Field	2009# % complete	2010 % complete	2011 % complete	2012 % complete	2013 % complete	2014 n (% complete)	2015 n (% complete)
Episode data (including multiple episodes) (n=9473) excluding opt out cases							
Date of arrival	100	100	100	95	95	95	9473/9473 (100)
Time of arrival	100	99	97	92	93	95	9473/9473 (100)
Date of stroke onset	100	100	100	100	100	99	9452/9473 (99)
Date of admission	100	100	100	100	100	100	9473/9473 (100)
Transfer from another hospital	100	100	99	98	98	99	9473/9473 (100)
Stroke occurs while in hospital	100	99	99	98	97	99	9473/9473 (100)
Able to walk independently on admission	100	95	91	90	88	90	9473/9473 (100)
Documented evidence of a previous stroke	100	98	92	92	92	94	9473/9473 (100)
Treated in a stroke unit	100	99	100	99	98	97	9473/9473 (100)
Type of stroke	100	100	100	100	100	100	9464/9473 (100)
Use of intravenous thrombolysis (if ischaemic stroke)	100	98	97	95	95	97	6010/6010 (100)
Cause of stroke	100	100	100	82**	98	100	9443/9473 (100)
ICD10 coding (including multiple episodes) (n=9473)* excluding opt out cases							
Diagnosis code	63	66	96	95	95	89	8211/9473 (87)
Medical conditions	1	14	36	40	40	46	5285/9473 (56)
Complications	0	4	7	26	13	11	1275/9473 (13)
Procedures	9	23	25	60	35	43	5051/9473 (53)
Discharge information (including multiple episodes) (n=9473) excluding opt out cases							
Deceased status†	100	100	100	100	100	100	9473/9473 (100)
Date of death (if deceased status is yes) †	100	100	100	100	100	100	1475/1479 (100)
Date of discharge (if not deceased while in hospital)†	87	97	98	96	95	99	8468/8468 (100)
Discharge destination (if not deceased while in hospital)†	87	97	97	97	98	99	8468/8468 (100)
Discharge on antihypertensive agent (if not deceased while in hospital)†	87	92	90	97	86	93	8466/8468 (100)
Evidence of care plan on discharge (if discharged to the community)##	87	91	91	78**	86	91	4732/4741 (100)

*Incomplete: coded as unknown or missing *Note that not every patient will have other medical conditions, complications and procedures coded, therefore the denominator is unknown #Only approximately six months of data were collected during 2009, the pilot year. †Deceased status and date of death determined using the AuSCR data. **Data completeness was lower for these variables in 2012 compared to other years due to technical issues with the AuSCR database. ##Previously the denominator was those not deceased while in hospital*

DATA DISCREPANCIES FROM DATA QUALITY AUDITING

Auditors from the AuSCR Office undertook site visits at eight hospitals in 2015 and reviewed 83 medical records. Between nine and 13 records were assessed at each audit. Data recorded in the AuSCR data collection tool were compared with information recorded in the medical record. A summary of the discrepancies for the AuSCR data fields for audits completed in 2015 are presented below (Table 2). Variables with >5% disagreements are bolded within the table. These disagreements represented either incorrect or missing data.

Table 2: Discrepancies of fields in the AuSCR database noted during the AuSCR Office data quality audits

Fields	2015		
	N=83 audits from 8 hospitals undertaken in 2015 [#]	Discrepant number	%*
Patient Details			
First name	0	0	0
Surname	0	0	0
Date of birth	0	0	0
Medicare number	1	1.2	1.2
Patient contact details available	0	0	0
Patient contact details complete	3	3.6	3.6
Patient phone number	6	7.2	7.2
Emergency and Alternate Contacts			
Address for one, or both, emergency and alternate contacts	21	25	25
Alternate contact phone number	13	15.7	15.7
General Practitioner Contacts			
GP address	9	10.8	10.8
GP phone number	7	8.4	8.4
Patient Characteristics			
Patient title	1	1.2	1.2
Patient MR number	0	0	0
Sex	1	1.2	1.2
Country of birth	2	2.4	2.4
Language spoken	2	2.4	2.4
Aboriginal and Torres Strait Islander status	0	0	0
Interpreter needed	0	0	0
Episode Data			
Date of arrival	5	6	6
Time of arrival	6	7.2	7.2
Accuracy of time of arrival	1	1.2	1.2
Date of stroke onset	15	18.1	18.1
Accuracy of data of stroke onset	1	1.2	1.2
Date of admission	3	3.6	3.6
Transfer from another hospital	1	1.2	1.2
Arrival by ambulance	3	3.6	3.6
Stroke occurred while in hospital	1	1.2	1.2
Able to walk independently on admission	13	15.7	15.7
Documented evidence of a previous stroke	8	9.6	9.6
Treated in stroke unit	5	6.0	6.0
Time of stroke	15	18.1	18.1
Type of stroke	4	4.8	4.8
Use of IV thrombolysis (if ischaemic)	0	0	0
Cause of stroke	3	3.6	3.6
In hospital stroke	2	2.4	2.4
First CT scan	2	2.4	2.4

Fields	2015	
N=83 audits from 8 hospitals undertaken in 2015 [#]	Discrepant number	%*
National Institute of Health Stroke Scale (NIHSS)	3	3.6
ICD-10 coding		
Diagnosis code	6	7.2
Medical conditions	1	1.2
Complications	0	0
Procedures	1	1.2
Discharge Information		
Deceased status	0	0
Date of death	0	0
Date of discharge	3	3.6
Discharge destination	12	14.5
Discharge on antihypertensive agent	4	4.8
Evidence of care plan on discharge	37	44.6
Average		

[#]Although audited in 2015, the case may have been submitted prior to 2015

*Variables with >5% disagreements are bolded within the table

COMPLETENESS OF CASE ASCERTAINMENT

Of the 40 hospitals contributing data, 15 (38%) sent case ascertainment information (by the due date) for 2015 stroke and TIA admissions. The proportion of completeness for case ascertainment was estimated using the formula $A/(A+B)$ where 'A' was the number of episodes which were registered in the AuSCR and 'B' was the missed episodes in the AuSCR database. Thirty-seven (93%) hospitals had participated in the AuSCR for a full year. Table 3 shows the number of episodes that were registered (A) or missed (B) in the AuSCR database, and the proportion of completeness for case ascertainment. From the hospitals that provided data for this review, case ascertainment ranged from 15% to 98%. Comparative percentages for 2013 and 2014 are provided in the last columns. The case ascertainment results were partly influenced by data quality issues where manual data entry of names or unit record numbers by hospital staff are recorded incorrectly and then do not match the data provided by hospitals for case ascertainment checking. Processes to improve these aspects of quality control for the registry continue to be a focus of the AuSCR Office. The other main reason for the low level of data completeness for some sites was that, due to resource limitations, only part of the data were entered into the AuSCR for the reporting period.

Table 3: Summary of the case ascertainment in 2015 (in comparison with 2013 and 2014)

Legacy Hospital ID	AuSDAT Hospital ID	Episodes in the database (n)	Episodes missed in the database (n)	Completeness	Completeness	Completeness
				2015	2014	2013
9	259	162	Not provided	Not provided	Not provided	82%
10†	137	287	243	56%	47%	Not provided
11†	70	291	Not provided	Not provided	57%	66%
12*†	182	631	222	80%	52%	79%
15~	2	0	90	0%	Not provided	43%
16~	80	0	Not provided	Not active	Not provided	Not provided
19†	218	11	17	15%	42%	42%
20†	144	143	Not provided	Not provided	82%	55%
21†	230	100	1	98%	Not provided	82%
22†	213	603	Not provided	Not provided	Not provided	Not provided
23*†	188	656	Not provided	Not provided	99%	100%
25~	64	0	Not provided	Not active	Not provided	26%
26~	7	0	Not provided	Not active	Not provided	Not active
28†	178	370	Not provided	Not provided	Not provided	100%
29*†	127	619	Not provided	Not provided	Not provided	79%
30†	130	63	Not provided	Not provided	29%	13%
31*†	133	119	151	50%	82%	Not provided
32*†	112	527	Not provided	Not provided	50%	75%
34*†	135	180	Not provided	Not provided	40%	Not provided
35†	115	191	Not provided	Not provided	Not provided	34%
36†	141	202	Not provided	Not provided	45%	Not provided
37†	114	28	Not provided	Not provided	Not provided	Not provided
39†	134	62	Not provided	Not provided	38%	Not provided
40†	136	311	20	94%	Not provided	66%
41*†	227	354	Not provided	Not provided	74%	100%
43†	104	100	Not provided	Not provided	64%	Not provided
44*†	187	176	Not provided	Not provided	94%	100%
45†	118	196	Not provided	Not provided	100%	81%
46†	140	167	144	66%	40%	38%
47†	106	301	Not provided	Not provided	Not provided	Not provided
48†	132	126	Not provided	Not provided	Not provided	36%
49†	121	287	60	83%	99%	Not provided
50*†	131	351	Not provided	Not provided	41%	18%
51†	179	162	41	82%	44%	New
52	235	44	45	47%	New	
53†	201	149	Not provided	Not provided	Not provided	New
54†	124	133	118	51%	73%	38%
55†	122	142	Not provided	Not provided	Not provided	Not provided
56†	219	629	Not provided	Not provided	Not provided	New
57†	205	205	42	87%	38%	New
59*†	198	52	Not provided	Not provided	New	
60*†	226	46	21	77%	New	
62*†	184	194	28	87%	Not provided	New
63*	209	84	Not provided	Not provided	New	
68~	207	0	Not provided	New	New	New
		9473	-	-	-	-

Patients who opted out of participation in the AuSCR do not appear in the above table
Not provided: Case ascertainment data not provided by the hospital for review
**These 13 hospitals used the data import function*
†These 37 hospitals participated in the AuSCR for the full 2015 year
~These 5 hospitals were inactive in the AuSCR for the full 2015 year

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

Among the 9473 episodes of care, the median number of days from the admission to the creation of the patient record in the AuSCR was 76 days (Q1 to Q3: 43 to 118 days) consistent with previous years (in 2014 the median was 77 days to patient record creation). By hospital, the shortest median number of days was 3 days, and the longest median number of days was 144 days. These data at a hospital level may be influenced by several factors such as numbers of eligible admissions, as well as the method of data collection.

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

As previously highlighted, registrants are informed by hospital staff that they are able to opt-out their personal data from the AuSCR database. During 2015, 211 (2.3%) opt-out requests were received from patients or next of kin (Table 4). Overall, 149 (1.6%) of registrants requested all of their personal and episode information removed from the registry. The total number of opt-out requests varied by hospital, ranging from 0 to 17. The breakdown of opt-outs for either personal or episode data or follow-up refusal (at the time of hospitalisation) is shown in Table 4.

Table 4: Opt out Requests and Fields

Total opt-out cases	Complete episode and personal data to be removed	Complete episode data only to be removed	Personal data only to be removed	Refused 90 day follow-up participation at time of hospitalisation
211	149	13	45	116

DISCHARGE CODING OF STROKE TYPE

The AuSCR provides an important opportunity to review the clinical classification of stroke or TIA against the international classification of diseases (ICD) discharge coding which is usually undertaken by health information managers in hospitals. Using the primary diagnosis discharge code (version ICD10) compared with the stroke sub-type provided by hospital clinicians, 83% of TIA episodes were coded as TIA and 17% of TIA episodes were coded with other or blank stroke codes. Three percent of TIA were coded with non-stroke diagnostic codes. For ischaemic strokes 69% of ischaemic stroke episodes were coded within the I63 range (cerebral infarction: I63.0-I63.9), 11% of ischaemic stroke episodes were coded as I64 codes (stroke, not specified), and 17% were coded with blank or non-stroke diagnostic codes. In-hospital stroke events did not account for the assignment of non-stroke discharge codes or 'undetermined' diagnoses by the clinicians for stroke sub-type. These data may provide evidence of where improvements to administrative discharge coding is needed to ensure more reliable data.

DISCUSSION

Data completeness in the AuSCR differs by variable. Demographic data were near complete, with patient telephone number most likely to be missing (12%). ICD10 codes for medical conditions, complications and procedures were most frequently missing, perhaps reflecting the difficulty or delay in obtaining these from Health Information Services within hospitals. Whilst registry participation is voluntary, it is important that the data are not biased by missed cases and that process of care reporting is reflective of the patient base. Case ascertainment data was only provided by 38% of participating hospitals and there was poor access to ICD10 codes being provided for medical conditions, complications and procedures. Stroke service staff are reliant on other departments to provide this information and it is usually not available until well after the patient has been discharged.

Information from the on-site data quality audits highlighted the variables that were either not collected consistently or incorrectly recorded. Evidence of a discharge care plan was most frequently in error (45% of cases), which may reflect poor recording in medical records or misinterpretation of the data dictionary. These audits give AuSCR Office staff the chance to clarify variable definitions with site staff and highlight areas requiring further training for all sites to improve reliability.

ENSURING COMPLETE CASE ASCERTAINMENT FROM PARTICIPATING HOSPITALS

Clinical quality registries should assess case ascertainment yearly. The modest response rate described in this report suggests that it is quite an onerous task for hospitals to verify potentially missed cases. Efforts to improve case-ascertainment review processes are ongoing.

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