The Australian Stroke Clinical Registry Data Quality Report 2016

May 2018

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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TABLE OF CONTENTS

INTRODUCTION

The Australian Stroke Clinical Registry (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). 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.

This annual Data Quality Report covers data collected for patients admitted to participating hospitals between 1 January 2016 and 31 December 2016. It is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2016 Annual Report.

The AuSCR Office uses a number of methods to assess data quality including: data cleaning, missing and discrepant data reports, audits of randomly selected hospital medical records, and case ascertainment. Each of these quality processes for the data are outlined in this report.

Participating hospitals are encouraged to use this report to guide improvements to the quality of the data that they are contributing to the AuSCR.

METHODS FOR ENSURING DATA QUALITY

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

Missing and discrepant AuSCR data

The logic checks built into the AuSCR to reduce data entry errors have been enhanced with the transition in July 2016 to the Australian Stroke Data Tool (AuSDaT) for AuSCR data collection. In-built functions within the AuSDaT 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). Logic checks to limit discrepancies in date fields are also used within the AuSDaT.

In 2016, AuSCR staff prepared data quality reports listing missing and discrepant data for each site on two occasions. These reports were sent to hospitals for review, and correction of the data was undertaken where required.

Accuracy of AuSCR data

Each new participating AuSCR hospital undergoes a random medical record audit of approximately 10% of their AuSCR episodes by AuSCR staff after approximately 50 patients have been entered into the registry. Hospital clinicians are then given feedback via an audit report. Mechanisms for improving data quality are also discussed following the audit and may include additional training to assist with interpretation of the AuSCR Data Dictionary or data entry processes. Audits are repeated approximately every two years thereafter or upon identification of recurrent data quality issues.

Case ascertainment

At the end of 2016, 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. Case ascertainment reports were generated by the AuSCR Office and provided back to participating hospitals. In 2016,with the focus on the transition to the AuSDaT, only one case ascertainment report was undertaken.

DATA CLEANING

Following closure of data entry for the 2016 dataset, any duplicate data were identified and removed by the AuSCR National Data Manager. Duplicate identification used both registrant identifiers (name, date of birth, Medicare number and/or hospital medical record number) and date of stroke onset, arrival, admission or discharge. Data were subsequently de-identified and extracted for analysis by Monash University statisticians. Additional data cleaning was then undertaken by Monash University staff prior to analysis for the AuSCR 2016 annual report.

DATA COMPLETENESS

A summary of 2016 data completeness (i.e. where individual variables were not missing or coded as Unknown) is presented in Table 1. Due to the transition to the AuSDaT in 2016, and the introduction of new variables, the completeness of some previously reported variables were unable to be calculated. Information for data completeness since 2013 is also presented as a reference.

For 2016, unless otherwise stated in Table 1, the denominator was 11891 episodes including 620 patients who had 687 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.

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

Field	2013 % complete	2014 % complete	2015 % complete	2016 % complete
Person details				
First name	100	99	99	99
Surname	100	99	99	99
Date of birth	100	99	99	99
Medicare number	91	89	88	92
Patient contact				
Available (complete or partial for street address, suburb and state)	98	94	92	96
Complete (street address, suburb, state)	97	85	91	95
Telephone for patient	94	74	88	94
Emergency and alternate contacts				
Address for one or both of emergency and alternate contacts	75	77	79	83
Address for one contact	64	67	73	58
Address for both contacts	11	10	11	26
Telephone for emergency and/or alternate contact	81	83	81	90
General practitioner contacts				
Address	74	76	66	NA
Telephone for GP	63	65	60	NA
Patient characteristics				
Title	100	99	99	100
Hospital medical record number	100	100	100	98
Sex	100	99	99	100
Country of birth	94	95	92	95
Language spoken	84	90	87	94
Indigenous status	100	98	99	98
Interpreter needed	98	99	99	98

Field	2013 % complete	2014 % complete	2015 % complete	2016 % complete
Episode data				
Date of arrival	95	95	100	88
Time of arrival	93	95	100	89
Date of stroke onset	100	99	100	91
Date of admission	100	100	100	99
Transfer from another hospital	98	99	100	95
Stroke occurs while in hospital	97	99	100	92
Able to walk independently on admission	88	90	100	91
Documented evidence of a previous stroke	92	94	100	92
Treated in a stroke unit	98	97	100	93
Type of stroke	100	100	100	91
Use of intravenous thrombolysis if ischaemic stroke (2016 n = 6958)	95	97	100	97
Cause of stroke	98	100	100	87
ICD-10 coding				
Principal diagnosis code	95	89	87	88
Medical conditions*	40	46	56	25
Complications*	13	11	13	12
Procedures*	35	43	53	30
Discharge information				
Deceased during hospital care status (2016 n = 1001)	100	100	100	98
Date of death (if deceased status during hospital care is yes)	100	100	100	99
Date of discharge if not deceased while in hospital (2016 n = 10662)	95	99	100	98
Discharge destination if not deceased while in hospital (2016 n = 10662)	98	99	100	93
Discharged on antihypertensive agent if not deceased while in hospital (2016 n = 10662)	86	93	100	92
Evidence of care plan on discharge if discharged to the community (2016 n = 5519)#	86	91	100	96

Note that not every patient will have other medical conditions, complications and procedures coded, therefore the denominator is unknown ^Data completeness was lower for these variables in 2012 compared to other years due to technical issues with the AuSCR database. #Prior to AuSDaT implementation, the denominator was those not deceased while in hospital

DATA DISCREPANCIES FROM MEDICAL RECORD AUDITS

Auditors from the AuSCR Office undertook site visits at four hospitals in 2016 and reviewed 24 medical records. Between three and ten records were assessed at each audit. This number is lower than the previous year (83 records from 8 hospitals in 2015), due to the focus in 2016 being on the transition to the AuSDaT and providing hospital user training in the new data collection tool. A summary of the discrepancies for the AuSCR data fields when compared with site medical records for 2016 audits are presented in Table 2. Variables with >5% disagreements are bolded within the table. These disagreements represent either incorrect or missing data.

Table 2: Discrepancies within AuSCR fields noted during 2016 AuSCR data quality audits

Fields	2016	
N=24 audits from 4 hospitals undertaken in 2016	**Discrepant number**	**%**
Patient Details		
First name	0	0.0
Surname	0	0.0
Date of birth	0	0.0
Medicare number	0	0.0
Patient contact details available	0	0.0
Patient contact details complete	0	0.0
Patient phone number	0	0.0
Emergency and Alternate Contacts	0	0.0
Address for one, or both, emergency and alternate contacts	1	4.2
Alternate contact phone number	1	4.2
General Practitioner Contacts	0	0.0
GP address	0	0.0
GP phone number	1	4.2
Patient Characteristics	0	0.0
Patient title	0	0.0
Patient MR number	0	0.0
Sex	0	0.0
Country of birth	0	0.0
Language spoken	0	0.0
Aboriginal and Torres Strait Islander status	1	4.2
Interpreter needed	0	0.0
Episode Data	0	0.0
Date of arrival	0	0.0
Time of arrival	0	0.0
Accuracy of time of arrival	0	0.0
Date of stroke onset	2	**8.3**
Date of admission	0	0.0
Time of admission	2	8.3
Transfer from another hospital	1	4.2
Arrival by ambulance	0	0.0
Stroke occurred while in hospital	0	0.0
Able to walk independently on admission	1	4.2

Fields	2016	
Documented evidence of a previous stroke	2	**8.3**
Treated in stroke unit	0	0.0
Time of stroke	4	**16.7**
Type of stroke	1	4.2
Use of IV thrombolysis (if ischaemic)	1	4.2
Cause of stroke	1	4.2
In hospital stroke	1	4.2
First CT scan	1	4.2
NIHSS	0	0.0
ICD-10 coding	0	0.0
Diagnosis code	1	4.2
Medical conditions	0	0.0
Complications	0	0.0
Procedures	0	0.0
Discharge Information		0.0
Deceased status	0	0.0
Date of death	0	0.0
Date of discharge	0	0.0
Discharge destination	2	**8.3**
Discharge on antihypertensive agent	2	**8.3**
Evidence of care plan on discharge	2	**8.3**

CASE ASCERTAINMENT

Of the 48 hospitals contributing data in 2016, 30 (63%) sent case ascertainment information by the due date for 2016 stroke and TIA admissions (January to September only) which was a significant increase from the 38% participation rate in 2015. 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 ascertainment information that were missing from the AuSCR database.

Thirty-eight hospitals (80%) had participated in the AuSCR for a full year in 2016. Table 3 shows the number of episodes provided by hospitals for case ascertainment that were either entered into or missing from the AuSCR, as well as the calculated case ascertainment rate for each hospital.

From the 30 hospitals that provided data, case ascertainment ranged from 16% to 100%. Comparative percentages for 2015 are provided. In 2016 case ascertainment rates were influenced by the transition to the AuSDaT. Results were also affected by manual data entry errors whereby variables used to match episodes between the datasets, such as names or medical record number were incorrectly entered into the AuSCR.

Eighteen hospitals who did not provide case ascertainment data in 2015 did so in 2016, and of the 10 hospitals who participated in both years, eight had improved their case ascertainment.

Table 3: Summary of the case ascertainment in 2016 (in comparison with 2015)

AuSDaT Hospital ID	Episodes in the AuSCR (n)	Episodes in hospital records not in the AuSCR (n)	Case ascertainment 2016	Case ascertainment 2015
70	70	Not provided	Not provided	Not provided
104	218	59	78%	Not provided
105	75	Not provided	Not provided	Not provided
106	207	Not provided	Not provided	Not provided
112	584	103	85%	Not provided
114	40	32	56%	Not provided
115	195	2	99%	Not provided
118	177	Not provided	Not provided	Not provided
121	218	21	91%	83%
122	117	Not provided	Not provided	Not provided
124	119	39	75%	51%
127	503	34	94%	Not provided
130	120	130	48%	Not provided
131	259	5	98%	Not provided
132	161	Not provided	Not provided	Not provided
133	202	38	84%	50%
134	55	114	43%	Not provided
135	180	27	87%	Not provided
136	117	176	40%	94%
137	237	72	77%	56%
140	159	55	74%	66%
141	131	0	100%	Not provided
144	121	39	76%	Not provided
176	7	Not provided	Not provided	Not active
178	194	Not provided	Not provided	Not provided
179	123	Not provided	Not provided	82%
182	440	89	83%	80%
184	111	46	71%	87%
185	124	372	25%	Not active
187	177	44	80%	Not provided
188	276	0	100%	Not provided
198	35	27	56%	Not provided
201	28	145	16%	Not provided
205	180	18	91%	87%
207	65	0	100%	New
209	58	65	47%	Not provided
213	540	201	73%	Not provided
218	3	Not provided	Not provided	15%
219	499	Not provided	Not provided	Not provided
223	50	Not provided	Not provided	Not active
226	29	Not provided	Not provided	77%
227	203	Not provided	Not provided	Not provided
229	36	105	25%	Not active
230	79	209	28%	98%
235	37	Not provided	Not provided	47%

TIME TO CREATION OF REGISTRANT RECORDS BY HOSPITALS

The median time from patient admission to the creation of a patient episode in the AuSCR was 128 days. The shortest median time to creation was 21 days, and the longest was 360 days. The time to record creation was longer than in 2015 (76 days) and was likely caused by the migration to the AuSDaT and the requirement for re-training all hospital data collectors. In addition, several new AuSCR hospitals performed bulk uploads of eligible historic data, resulting in a greater than usual length of time to record creation.

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

In accordance with the AuSCR Protocol, registrants are informed by hospital staff that they are able to opt-out their personal data from the AuSCR database. During 2016, 224 opt-out requests (1.9% of all episodes) were received from patients or next of kin (Table 4) which was slightly lower than the 2.3% documented in 2015. The total number of opt-out requests varied by hospital, ranging from 0 to 35.

With the shift to the AuSDaT, the AuSCR received Human Research Ethics Committee approvals to retain anonymous clinical data independently of personal data opt-outs. This meant that while the rate of opt-outs was similar to previous years, the AuSCR clinical dataset was more complete in 2016. The breakdown of opt-outs for either personal, or personal and clinical data, are shown in Table 4, along with patients who refused follow-up at 90 days.

Table 4: Opt out Requests and Fields

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
11891	224	41	183	119

DISCHARGE CODING OF STROKE TYPE

The AuSCR provides an important opportunity to review the clinical designation of stroke type within the AuSCR against the International Classification of Diseases (ICD) discharge coding undertaken by hospital clinical coders. This was completed by comparing the principal diagnosis code (version ICD-10) with the stroke type provided by hospital clinicians.

For TIAs: 85% of TIA episodes were coded as TIA; 2% were coded with non-stroke diagnostic codes and the remainder had either other stroke codes or had no codes documented. For ischaemic strokes, 76% of episodes were coded within the I63 range (cerebral infarction: I63.0-I63.9), 8% were coded as I64 (stroke, not specified), and 16% were coded with other diagnostic codes or had no codes documented.

In-hospital stroke events did not account for the number of episodes assigned non-stroke principal diagnosis codes and may indicate a proportion of patients with significant comorbidities.

SUMMARY

Data completeness in the AuSCR differs by variable. Demographic data were near complete in 2016, with patient telephone number most likely to be missing (6%). ICD-10 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. While registry participation is voluntary, it is important that the data are not biased by missed cases, and that the processes of care reporting is reliable. Case ascertainment data were provided by 63% of participating hospitals. The improvement from 38% in 2015 is an indication that efforts to improve this process have had an impact.

Information from the on-site data quality audits highlighted the variables that were either not collected consistently or incorrectly recorded, although the results cannot be considered representative of AuSCR data in general, as there were few audits conducted during 2016. Time of stroke was most frequently in error (17% of cases), which may reflect poor recording in medical records or misinterpretation of the data dictionary. These audits give AuSCR staff the chance to clarify variable definitions with site staff and highlight areas requiring further training for all sites to improve reliability.

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