

# DATA QUALITY REPORT 2023

**AUSCR**  
Australian Stroke Clinical Registry

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**

The Australian Stroke Clinical Registry (AuSCR) provides national data on high priority, evidence-based clinical care and outcomes for patients admitted to hospital with acute stroke. The primary purpose is to provide reliable and representative data to improve the quality of stroke care in Australian hospitals. The quality of the data in the Registry is essential to its purpose.

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 feedback. Therefore, the combined efforts of hospitals and the AuSCR office ensures the most complete data for each annual reporting period. Hospitals participating in the AuSCR are encouraged to use this report alongside site-specific feedback provided throughout the calendar year to improve data quality. Information on data quality is also available in the various data dashboards that are updated every day within the data system.

This Data Quality Report covers data collected for patients admitted to participating hospitals between 1 January 2023 and 31 December 2023. It is supplementary to, and should be read in conjunction with, the Australian Stroke Clinical Registry 2023 Annual Report (<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.

Hospital users are encouraged to complete data within 90 days of admission, which is when the AuSCR office commences collection of patient-reported outcomes. Final 2023 data quality checks were completed in April and May 2024 and we requested all 2023 data be finalised by 31 May 2024. Data were extracted for linkage with the National Death Index on 7 June 2024. Information on deaths were included in the AuSCR and final data extracted for this report on 14 October 2024.

## **DATA PLATFORM DATA QUALITY FEATURES**

Since July 2016, the collection of AuSCR data by staff at participating hospitals has been facilitated in the Australian Stroke Data Tool (AuSDaT, <https://australianstrokecoalition.org.au/projects/ausdat/>).<sup>1</sup> 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. In AuSDaT there is also the function to search for incomplete records and records with data errors. New data dashboards released in 2023 also support routine checking for erroneous data.

## **DATA CHECKS BEFORE IMPORT**

Where data exports from hospital systems are supplied in separate files via secure cloud data sharing (SharePoint) for import into the AuSDaT, these 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. Hospital staff who import their own data into the AuSDaT can also request the AuSCR Data Managers check for errors prior to import into the live tool.

## **CASE ASCERTAINMENT**

Assessment for completeness of case ascertainment is an essential process for ensuring that the data recorded in the AuSCR are representative of the patient population with stroke admitted to each participating hospital. It is a requirement for all clinical registries to collect and report this information.<sup>2</sup> Case ascertainment results provide an indication of the representativeness of data and whether there are any potential selection biases in the patient sample.

To simplify this process, in 2023 only episodes where the stroke ICD-10 (International Statistical Classification of Diseases 10<sup>th</sup> revision) code was the principal diagnosis code were included. Patients diagnosed with TIA and those admitted and discharged on the same day were excluded from the case ascertainment calculation. Case ascertainment for Emergency Department (ED) presentations recorded prior to hospital transfer was not undertaken.

Information on hospital admissions for stroke based on ICD-10 codes was gathered either from state government agencies, or from hospitals directly. In Victoria and Queensland, state government agencies facilitated data linkage with the government-held admitted episodes data-sets. Hospitals in other states were asked to provide a list of all admissions with stroke principal diagnosis ICD-10 codes from their hospital systems.

Hospital-reported admissions were compared and matched with episodes recorded in the AuSCR. Following matching, the hospitals were provided with a list of episodes, per period, that are not in the AuSCR to assist with improving overall ascertainment of cases.

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

## **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. 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 QUALITY TABLES IN DASHBOARDS**

Five of the AuSCR QuickSight Dashboards, released between July 2023 and March 2024, include data quality tables listing records with missing or discrepant data (e.g. a negative door to brain scan time). The dashboards are updated at midnight each night so that any changes or additions made in AuSCR are reflected in the dashboards the following day. Hospital staff can login to the dashboards at any time to identify episodes that may require updating.

## **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 hospital medical record. These audits assist in verifying that data quality for the AuSCR and information on areas to improve standardised collection of variables. The process is useful to support specific areas

of data collection training that may be required for staff at participating hospitals. Therefore, the audit process helps support improved standardised data collection for the registry. Medical record audits are scheduled to occur for a new participating hospital following entry of the first 50 episodes of stroke, on request or every two years, where feasible.

## **ROUTINE DATA CLEANING PROCESSES BY AUSCR OFFICE**

The overall assessment and cleaning of AuSCR data is completed fortnightly. Duplicate data are identified and removed by an AuSCR 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. Episodes that appear ineligible or with incorrect dates of birth are flagged with hospitals for checking. Additional checks are undertaken following the closure of data entry for the year and prior to undertaking analysis for the AuSCR Annual Report. These data are subsequently de-identified and extracted for analysis. Additional data cleaning processes including logic checks for erroneous data are then undertaken by Monash University epidemiologists prior to undertaking data analyses, and additional feedback provided to hospitals, where required. The deidentified, final data for each year are then archived.

## **TIME TO RECORD CREATION**

The median time from admission to record creation in the AuSCR was 78 days (interquartile range: 47 to 110 days), 14 days faster than the median in 2022 of 92 days. More than half of AuSCR hospitals (n=37 hospitals; 62%) had a median time to record creation under 90 days, a slight improvement from 2022 (57% below 90 days). The shortest hospital-level median time to record creation was one day, and the longest was 300 days.

## **DATA COMPLETENESS**

For 2023, 65 hospitals provided data for 18,662 episodes care. After excluding data from two hospitals that commenced data collection mid-way through 2023 and did not complete clinical data, and 456 episodes of TIA (51% male; median age 74 years), the final analysis sample was 18,090 episodes of stroke care in 2023 (17,535 admitted episodes and 555 emergency department [ED] episodes) were provided by 63 hospitals. The proportion of data completeness for individual variables is presented only for eligible episodes, since not all variables are relevant to every patient. Episodes of transient ischaemic attack (TIA) are not included in this report, to align with the main Annual Report.

Individual variables ranged in completeness from 25% for medical complication ICD-10 codes, which do not occur in every episode, to 100% for a range of variables, with similar overall results to the 2022 dataset (n=17,184 episodes from 61 hospitals, Table 1).

Three variables had  $\geq 5\%$  improvement in completeness compared to 2022 data, including: date of first brain scan (increase from 93% to 99%), time of first brain scan (increase from 89% to 95%), and type of adverse event following thrombolysis (increase from 87% to 94%).

Three variables had reduced completion by more than 5% in 2023, including: details of haemorrhage within the infarct on follow up imaging post-ECR (decreased from 91% to 85%), medical condition ICD-10 code(s) (decreased from 78% to 70%), and medical procedure ICD-10 code(s) (decreased from 77% to 70%), noting that these may not be present for every episode.

Completion of the National Institutes of Health Stroke Scale (NIHSS) score also improved in 2023 to 74% at baseline compared to 69% in 2022 and 78% post-ECR compared to 70% in 2022 (Table 2).

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

<b>Variable</b> <b>N=17,535 episodes in 2023</b>	<b>2022</b> <b>% complete</b> <b>N hospitals=61</b>	<b>2023</b> <b>% complete</b> <b>N hospitals=63</b>
<b>†Patient details</b>		
Title	99	99
First name	99	100
Surname	99	100
Date of birth	98	100
Medicare number (optional)	99	<b>85</b>
Hospital Medical Record Number (MRN)	98	100
Gender	98	100
Country of birth	98	99
Language spoken	<b>89</b>	<b>88</b>
Interpreter needed	<b>89</b>	<b>89</b>
Aboriginal and Torres Strait Islander status	92	100
Patient phone number	99	95
Complete address (street address, suburb, state)	91	99
<b>†Emergency contacts</b>		
Emergency contact first name	<b>88</b>	<b>88</b>
Emergency contact last name	<b>88</b>	<b>87</b>
Address for emergency contact	<b>74</b>	<b>72</b>
Emergency contact phone number	<b>85</b>	<b>85</b>
<b>Arrival and admission data</b>		
Date of stroke onset	96	97
Time of stroke onset	<b>79</b>	<b>81</b>
Stroke occurred while in hospital	99	100
Date of arrival to ED	98	99
Time of arrival to ED	98	99
Arrival by ambulance	95	96
Transfer from another hospital	99	100
Date of admission	100	100
Time of admission	99	100
Treated in a stroke unit	100	100
<b>History of known risk factors</b>		
Documented evidence of a previous stroke	98	98
<b>Acute clinical data</b>		
Brain scan after this stroke	100	100
Date of first brain scan	93	99
Time of first brain scan	<b>89</b>	95
Date of subsequent brain scan	100	100
Time of subsequent brain scan	99	99
Type of stroke	99	100
Cause of stroke	99	100
Acute occlusion site	100	100
<b>Telemedicine and reperfusion</b>		
Stroke telemedicine consultation conducted	99	100
Receipt of thrombolysis	97	98
Date of delivery	100	100
Time of delivery	99	100
Adverse event related to thrombolysis	99	99
Type of adverse event	<b>87</b>	94
Other reperfusion (ECR)	100	100
Treatment date for ECR	100	100
Time groin puncture	99	100
Time of completing	98	100
Final eTICI	<b>79</b>	<b>81</b>

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

<b>Variable</b> <b>N=17,535 episodes in 2023</b>	<b>2022</b> <b>% complete</b> <b>N hospitals=61</b>	<b>2023</b> <b>% complete</b> <b>N hospitals=63</b>
<b>24 hour data</b>		
Haemorrhage within the infarct on follow up imaging	100	100
Details	91	<b>85</b>
<b>Swallowing</b>		
Swallowing screen	91	<b>90</b>
Date of swallowing screen	100	99
Time of swallow screen	94	96
Did the patient pass the screening	100	100
Swallowing assessment	91	<b>90</b>
Date of swallow assessment	100	100
Time of swallow assessment	98	98
Oral medications	91	<b>90</b>
Oral food or fluids	91	<b>90</b>
<b>Mobilisation</b>		
Ability to walk independently on admission	95	95
Mobilised during the admission	94	94
Date of mobilisation	100	100
Method of mobilisation	<b>90</b>	<b>90</b>
<b>Antithrombotic therapy</b>		
Antithrombotic given as hyperacute therapy	92	90
Date of administration	100	98
Time of administration	96	96
<b>Secondary prevention</b>		
Discharge antithrombotics	100	100
Discharge antihypertensives	99	99
Discharge lipid lowering	100	100
<b>Discharge information</b>		
Patient died during hospital stay	99	100
Date of death (for episodes deceased during hospital stay)	100	100
Date of discharge if not deceased while in hospital	99	99
Principal diagnosis ICD-10 code(s)	<b>83</b>	<b>79</b>
Medical condition ICD-10 code(s)*	<b>78</b>	<b>70</b>
Medical complication ICD-10 code(s)*	<b>29</b>	<b>25</b>
Medical procedure ICD-10 code(s)*	<b>77</b>	<b>70</b>
Discharge destination if not deceased while in hospital	99	100
Evidence of care plan on discharge if discharged to the community	97	97

Bold numbers indicate  $\geq 10\%$  missing or discrepant data.

Includes data from paediatric hospitals.

† Excludes patients that have opted out their personal information

\* Denominator includes some patients with no other medical condition, complication or procedure codes.

ECR: Endovascular Clot Retrieval.

eTICI: Expanded Thrombolysis In Cerebral Infarction.

ICD: International Classification of Diseases.



**Table 2: Completeness of National Institutes of Health Stroke Scale Scores in the Australian Stroke Clinical Registry**

<b>Variable</b> <b>N=17,535 episodes in 2023</b>	<b>2022</b> <b>% complete</b>	<b>2023</b> <b>% complete</b>
National Institutes of Health Stroke Scale (NIHSS)		
Baseline	<b>69</b>	<b>74</b>
Pre-ECR*	97	98
24 hours post-ECR	<b>70</b>	<b>78</b>

\*Note: where Pre-ECR NIHSS was not captured, baseline NIHSS is used in this calculation.

NIHSS: National Institutes of Health Stroke Scale.

ECR: Endovascular Clot Retrieval.

## **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 who presented to an ED and prior to transfer to another hospital for ongoing acute stroke care. The ED dataset includes 85 variables. There were 30 hospitals that contributed 555 episodes of stroke during 2023 (20 in Victoria, 7 in QLD, 2 in SA, and 1 in TAS), four more than in 2022. The completeness of ED variables ranged from 84% (for NIHSS baseline) to 100% for a range of variables and was overall similar to 2022.

Emergency Department dataset variables were included in the data quality report provided to participating hospitals for the full 2023 year in May 2024.

**Table 3: Completeness of Emergency Department dataset variables**

<b>Variable N=555 episodes in 2023</b>	<b>2022 % complete N hospitals=26</b>	<b>2023 % complete N hospitals=30</b>
<b>Stroke onset and arrival data</b>		
Stroke onset date	99	99
Stroke onset time	93	92
Date of arrival to emergency department	99	100
Time of arrival to emergency department	99	100
Arrival by ambulance	99	100
Pre-hospital notification by paramedics	100	99
<b>Acute clinical data</b>		
Functional status prior to stroke (mRS)	98	98
Triage category	<b>80</b>	<b>85</b>
NIHSS at baseline	97	<b>84</b>
Brain scan after this stroke	100	100
Date of first brain scan	99	99
Time of first brain scan	98	97
Advanced imaging	100	100
Type of stroke	100	100
Telemedicine consultation	99	100
Receipt of thrombolysis	98	99
Date of delivery	100	100
Time of delivery	99	100
Drug used	100	100
Type of adverse event	98	100
Swallow screen	96	96
Was the swallow screen or swallow assessment performed before the patient was given:		
Oral medications	96	96
Oral food or fluids	96	96
Walk on admission	<b>86</b>	<b>85</b>
<b>Transfer</b>		
Date of transfer	99	99
Time of transfer	96	97
Reason for transfer	99	98
<b>Discharge Information</b>		
What is the discharge destination	99	98

NIHSS: National Institutes of Health Stroke Scale.

mRS: Modified Rankin Scale.

## 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. 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. There were 24 hospitals that contributed to the FeSS dataset in 2023, 4 more than in 2022. A total of 4,737 FeSS episodes were recorded (Table 4) over 1,000 more than in 2022 and were generally well completed.

**Table 4: Completeness of Fever, Sugar, Swallow dataset variables**

<b>Variable N= 4,737 episodes in 2023</b>	<b>2022 % complete N hospitals=20</b>	<b>2023 % complete N hospitals=24</b>
Temperature recorded at least four times on day one of admission	100	94
Fever development in the first 72 hours following admission	100	100
Paracetamol for the first elevated temperature administered within 1 hour	93	100
Finger-prick blood glucose level recorded at least four times on day one of admission	100	94
Elevated glucose in the first 48 hours following admission	100	98
Insulin administered within 1 hour if elevated glucose	96	100

## DATA DISCREPANCIES IDENTIFIED USING HOSPITAL MEDICAL RECORD AUDIT DATA

In 2023 the AuSCR conducted Medical Record Audits at nine hospitals, five in Victoria, three in Tasmania, and one in South Australia. Five to ten records were reviewed per site with a total of 59 records reviewed. There were several variables where >10% discrepancy between the auditor and hospital medical records was found, these listed in Table 5. In some cases, this was due to a known mapping issue between the hospital system and AuSCR. Other variables are noted to be challenging to capture, such as stroke onset time, which can be unclear from patient or family reporting, or documented at different times in different places in the medical record. Brain scan times are also often recorded within different patient management systems or different times within the medical record.

**Table 5: Variables with >10% discrepancy on medical record audit**

<b>Variable</b> <b>N=59 episodes reviewed in 2023</b>	<b>2023</b> <b>% with</b> <b>discrepancy</b> <b>N hospitals=9</b>
<b>Patient details</b>	
Medicare number (optional)	14
Language spoken <sup>#</sup>	12
Interpreter needed <sup>#</sup>	12
Emergency contact first name <sup>#</sup>	15
Emergency contact last name <sup>#</sup>	19
Address for emergency contact <sup>#</sup>	14
<b>Arrival and admission data</b>	
Time of stroke onset	24
Accuracy of stroke onset time	14
Time of arrival to ED	15
Time of admission	22
<b>Acute clinical data</b>	
NIHSS at baseline	17
Time of first brain scan	17
<b>Swallowing</b>	
Time of swallow screen	17
Time of swallow assessment	12
<b>Mobilisation</b>	
Date of mobilisation	24
Method of mobilisation	17
<b>Antithrombotic therapy</b>	
Antithrombotic given as hyperacute therapy	15
<b>Discharge information</b>	
Medical condition ICD-10 code(s)*	15

<sup>#</sup> Known mapping issue with state database for one hospital at time of audit

\* ICD-10 codes were unavailable for auditor to review at four hospitals.

## CASE ASCERTAINMENT

For 2023 admissions, the AuSCR office conducted three rounds of case ascertainment reviews. The first two rounds provide feedback to hospitals on episodes potentially missing in the AuSCR, the third round is completed once the dataset is closed and hospitals have had the opportunity to enter any additional episodes and feedback on ineligible episodes to the AuSCR office. The first was for the period 1 January to 30 June 2023, the second and third included the full 2023 calendar year.

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 63 hospitals that contributed data in 2023, 58 (92%) provided data for case ascertainment, similar to participation in 2022 (89%). Of the 58 hospitals that provided data, the overall case ascertainment estimates ranged from 43% to 100% (excluding sites on data pause for 2023). The median case ascertainment result was 87% in 2023, compared to 92% recorded in 2022. Two hospitals who began in late 2023, and did not participate in 2023 case ascertainment, were excluded from Table 5 as they provided predominantly demographic data.

**Table 5: Hospital case ascertainment results for 2023 data and the 2022 dataset**

Hospital ID	Episodes in the AuSCR 2023	Episodes in hospital records not in the AuSCR 2023	Case ascertainment 2023 N=63 hospitals	Case ascertainment 2022 N=61 hospitals
	n	n	%	%
1	174	-	Not provided	Commenced 2023
3	639	145	78%	79%
5	486	0	100%	97%
11	15	8	47%	65%
13	93	0	100%	100%
14	419	45	90%	76%
15	638	91	86%	66%
20	406	30	93%	94%
22	275	232	16%*	Not provided
23	148	2	99%	95%
24	705	131	82%	90%
26	237	107	55%	80%
27	233	21	93%	82%
29	145	0	100%	98%
30	206	119	43%	86%
31	361	57	84%	71%
32	234	134	43%	73%
33	186	59	68%	98%
34	190	28	86%	96%
35	238	0	100%	95%
36	242	44	82%	Not Provided
37	334	4	99%	98%
38	225	68	70%	96%
39	225	1	100%	Not provided
40	597	86	86%	99%
41	188	11	94%	95%
42	28	8	71%	54%
43	147	1	100%	99%
44	280	133	53%	55%
45	150	31	79%	82%
46	987	171	83%	85%
47	167	10	95%	87%
48	77	11	86%	93%
49	20	5	80%	58%
50	189	24	88%	95%
51	108	77	29%*	80%
52	500	134	80%	92%
53	511	69	86%	100%
57	246	61	76%	78%
58	988	0	100%	100%
61	96	-	Not provided	Not provided
62	35	0	100%	100%
63	92	0	100%	100%
64	68	0	100%	100%
65	598	146	76%	79%
66	456	60	87%	74%

**Table 5: Hospital case ascertainment results for 2023 data compared to the 2022 dataset (continued)**

Hospital ID	Episodes in the AuSCR 2023	Episodes in hospital records not in the AuSCR 2023	Case ascertainment 2023 N=63 hospitals	Case ascertainment 2022 N=61 hospitals
	n	n	%	%
67	33	0	100%	92%
68	50	3	98%	98%
69	1075	15	99%	100%
70	327	3	99%	100%
71	444	1	100%	61%
80	76	7	91%	90%
89	42	0	100%	70%
90	13	5	62%	Not provided
91	420	-	Not provided	93%
92	163	-	Not provided	65%
93	111	0	100%	99%
94	615	175	72%	73%
95	117	58	53%	Not provided
96	214	10	96%	Commenced 2023
97	292	1	100%	100%
108	1	-	Not provided	Commenced 2023
117	8	4	63%	Commenced 2023

\*Hospital had data pause and did not collect data for the full 2023 year

## 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 338 opt-out requests (1.8% of all episodes) were received from patients or their nominated contact person for 2023 admissions (Table 6). These data are consistent with the opt-out rate recorded in 2022 of 2%. 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 6: 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
2022	19,694	389 (2.0%)	5 (<0.05%)	384 (2.0%)	73 (0.4%)
2023	18,662	339 (1.8%)	4 (<0.05%)	335 (1.8%)	176 (0.9%)

## COMPARISON OF CLINICAL STROKE DIAGNOSIS AND CODED PRINCIPAL DIAGNOSIS

The AuSCR office reviews the clinician designated type of stroke within the registry against the ICD-10 discharge coding undertaken by hospital administrative staff. The ICD-10 discharge diagnosis code was compared to the documented clinical stroke type. Stroke 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 code was recorded for an individual episode, it was included in both clinical diagnosis categories.

For episodes recorded clinically as an ischaemic stroke, 74% of these episodes had an I63 discharge diagnosis code (ICD-10 codes for cerebral infarction: I63.0 to I63.9), and 4% were coded as I64 (stroke, not specified; Table 7). Seventy-six percent of episodes recorded as an intracerebral haemorrhage by the clinician were coded as an intracerebral haemorrhage (ICH) code (ICD-10 code range: I61.0 to I61.9 and I62.9). Undetermined stroke type was recorded clinically in 1.4% of episodes, fewer than in 2022 (2.7%). A larger proportion of missing or non-stroke ICD-10 codes were recorded in 2023 (17-18%) compared to 2022 (13-14%).

**Table 7: Comparison of clinician assigned stroke diagnosis and the ICD-10 principal diagnosis codes**

Principal, medical or complication code	Clinical diagnosis (N=17,489)		
	ICH N=2,592 (%)	Ischaemic N=14,649 (%)	Undetermined N=248 (%)
ICH ICD-10 codes (I61.x and I62.9)	<b>76%</b>	1%	1%
Ischaemic ICD-10 codes (I63.x)	3%	<b>74%</b>	41%
TIA ICD-10 code (G45.9)	<1%	<1%	3%
Unspecified stroke ICD-10 code (I64)	1%	4%	<b>36%</b>
Multiple stroke/TIA ICD-10 codes	3%	4%	2%
Missing or non-stroke/TIA ICD-10 codes	18%	18%	17%

Bold numbers indicate a match between clinical diagnosis recorded by the clinician and ICD-10 codes.

Excludes ED episodes and 269 episodes with missing data for clinical diagnosis recorded by the clinician.

ICH: intracerebral haemorrhage; TIA: transient ischaemic attack.

Clinical diagnosis of TIA excluded from table.

## SUMMARY

The overall quality of the data in the AuSCR in 2023 remained excellent for the majority of variables, and was comparable to that reported in 2022. The time for a hospital to create a record in the registry from admission reduced in 2023 to 78 days, 14 days sooner than in 2022. Having data entered prior to 90 days post-admission ensures patients can receive the patient reported outcome survey, and episodes will be included in AuSCR data quality checks providing sites with a greater opportunity to correct erroneous data. This improved timeliness may be partly attributable to the availability of near real-time dashboards being released in mid-2023 and eligibility for World Stroke Organisation Awards quarterly, with data reviewed just 17 days after the close of a quarter (e.g. January to March data reviewed on 17<sup>th</sup> April).

The representativeness of the data in the AuSCR remained high with a median case ascertainment result of 87% from 92% of participating hospitals. Centralised hospital administrative data on stroke admissions from Victorian and Queensland government agencies enabled case ascertainment to be conducted on most hospitals. The rate of patients wishing to opt-out of having their personal details stored in the registry remained low at 1.8%.

Overall completeness of variables was high and similar to 2022. The variable with the lowest completion, ICD-10 complication codes, is not relevant for all episodes. Baseline NIHSS is an important prognostic indicator of stroke severity and the capture of valid data for NIHSS scores has continued to improve this year to 74%. Brain scan times also improved from 89% complete in 2022 to 95% in 2023. Completion of variables in the optional FeSS and ED datasets was generally high, and comparable to 2022.

Fewer episodes were considered clinically 'undetermined' in 2023 (n=248, 1.4% of episodes) compared to 2022 (n=443, 3% of episodes). Most undetermined strokes were coded as ischaemic strokes (41%). There was good agreement between clinical diagnosis and intracerebral haemorrhage and ischaemic stroke coding, although there were more missing codes this year, which the AuSCR team will work with sites to correct.

Nine medical record audits were conducted in 2023, with many sites 'overdue' for a biannual audit due to the COVID-19 pandemic and resource limitations within the AuSCR office. A range of discrepancies were found, however these were generally explainable, and assisted AuSCR coordinators to discuss variable definitions and improve hospital staff understanding.

The AuSCR office continues to provide support to staff at participating hospitals to ensure the quality of data recorded in the registry. In mid-2023, the first two interactive data dashboards were released, giving hospital users the ability to view their data in near real-time (data updated at midnight daily) with various filters and data display options. Each dashboard also includes a data quality tab for users to monitor the quality of their data in real-time. We hope this assists with ensuring the quality of the data in the AuSCR.

## REFERENCES

1. Ryan O, Ghuliani J, Grabsch B, et al. Development, implementation, and evaluation of the Australian Stroke Data Tool (AuSDaT): Comprehensive data capturing for multiple uses. *Health Information Management Journal*. 2022;0(0). doi:[10.1177/18333583221117184](https://doi.org/10.1177/18333583221117184)
2. Australian Commission on Safety and Quality in Health Care. Australian Framework for National Clinical Quality Registries 2024. Sydney; ACSQHC, 2024.



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