The Australian Stroke Clinical Registry: achievements and aspirations

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on behalf of the AuSCR Management Committee

What is AuSCR?

A collaborative national effort to monitor, promote and improve the quality of acute stroke care

www.auscr.com.au

Developed using national operating principles & technical standards for clinical quality registries
**AuSCR purpose**

Overall goal is to provide prospective data on all stroke and TIA cases admitted to participating hospitals

- Monitor the quality of acute stroke care
- Monitor the impact of care on post discharge patient outcomes
- Develop a large comprehensive dataset for stroke research

**AuSCR in summary**

- Data collection since June 2009
- Appropriate governance and policies in place
- Online web-based data entry
- Opt-out consent or waiver for deaths in hospital
- Core information collected prospectively for all patients admitted with stroke and transient ischaemic attack (TIA)
- Locally accessible “live” reports for hospitals
- Centralised patient follow-up at 3-6 months by registry staff
Standardised data collection processes

- Collect patient data & upload/enter in AuSCR
- Ethics approval to participate
- Train hospital staff
- Sample data testing
- Established IT process for data extraction from hospital systems
- In-built logic processes
- Data quality audits of medical records
- Periodic data quality feedback
- Case ascertainment
- Follow-up coordinated by AuSCR Office

Ethics approved hospitals

- 63 hospitals
- 36,271 registrants
- 17,541 (73% of eligible) completed 3 month follow-up
- 2.6% opt-out rate
Acute Stroke Clinical Care Standards

A patient with ischaemic stroke for whom reperfusion treatment is clinically appropriate, and after brain imaging excludes haemorrhage, is offered a reperfusion treatment in accordance with the settings and time frames recommended in the Clinical guidelines for stroke management.

A patient with stroke is offered treatment in a stroke unit as defined in the Acute stroke services framework.

A patient with stroke, while in hospital, starts treatment and education to reduce their risk of another stroke.

Before a patient with stroke leaves the hospital, they are involved in the development of an individualised care plan that describes the ongoing care that the patient will require after they leave hospital. The plan includes rehabilitation goals, lifestyle modifications and medicines needed to manage risk factors, any equipment they need, follow-up appointments, and contact details for ongoing support services available in the community.
Clinical diagnosis versus ICD coding

<table>
<thead>
<tr>
<th>ICD coding - discharge diagnosis</th>
<th>Clinical diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>IS (N=5465) n (%)</td>
</tr>
<tr>
<td>I63: Cerebral infarction</td>
<td>4071 (74)*</td>
</tr>
<tr>
<td>G45: Transient cerebral ischemic attacks and related syndromes</td>
<td>68 (1)</td>
</tr>
<tr>
<td>I61 and I62: Nontraumatic ICH &amp; Other &amp; unspecified nontraumatic ICH</td>
<td>56 (1)</td>
</tr>
<tr>
<td>I64: Stroke, not specified ischaemic or haemorrhagic</td>
<td>519 (9)</td>
</tr>
</tbody>
</table>

- Orange shaded cells indicate a matching clinical and primary ICD10 diagnosis code
- IS: ischaemic stroke; TIA: transient ischaemic attack; ICH: intracerebral haemorrhage; SAH: subarachnoid haemorrhage

**Mortality**

- Annual linkages with the National Death Index
- 8,265 registrants in 2014
- 1,213 (15%) died within 90 days
- Stroke unit care associated with 59% reduced risk of death at 180 days*
- Adjusted mortality hazard ratio 0.41, 95% CI: 0.36-0.47, p<0.001

*Adjusted for age, gender, stroke sub-type, ability to walk on admission, inpatient stroke, transfer from another hospital
Benchmarking

- Benchmarking is used to compare performance metrics to industry best standards
- Establishing achievable benchmarks may promote realistic improvements in care quality

Common benchmarking methods

<table>
<thead>
<tr>
<th>METHOD</th>
<th>LIMITATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% adherence</td>
<td>May not always be realistic to achieve e.g. delivery of tPA</td>
</tr>
<tr>
<td>Published national averages</td>
<td>May underestimate targets</td>
</tr>
<tr>
<td>Based on top performing hospitals</td>
<td>May not always be reliable if based on small samples</td>
</tr>
</tbody>
</table>
Benchmarking method - AuSCR 2014

- Method previously used by Hall et al\textsuperscript{1} and based on the Achievable Benchmark of Care (ABC\textsuperscript{™})\textsuperscript{2}
- Adjusted Performance Fraction (APF) is calculated using the formula:
  \[
  \text{APF} = \frac{(n+1)}{(N+2)}
  \]
  \(n\) = number of patients receiving the measure
  \(N\) = number of patients eligible for the measure
- The benchmark is the mean adherence score from the top performing hospitals that represent ~15\% of sample


Performance benchmarks for national care processes

<table>
<thead>
<tr>
<th>Process of care</th>
<th>Benchmark (%)</th>
<th>Top performer (%)</th>
<th>Average (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received stroke unit care</td>
<td>96</td>
<td>98</td>
<td>74</td>
</tr>
<tr>
<td>Received intravenous thrombolysis</td>
<td>20</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>Discharged on antihypertensive medication</td>
<td>88</td>
<td>93</td>
<td>72</td>
</tr>
<tr>
<td>Care plan provided if discharged to the community</td>
<td>86</td>
<td>90</td>
<td>48</td>
</tr>
</tbody>
</table>

Annual Report: 2014
Clinical indicators for stroke

Stroke unit care

Annual Report: 2014

AuSCR outputs

- Trialling the “Operating Principles and Technical Standards for Clinical Quality Registries” for ACSQHC
- Trial of efficiency of telephone versus mail follow-up
- Data linkage: NDI; Dept. of Health – Qld, NSW, WA, Vic
- Stroke123 Project: data linkage; data harmonisation with NSF Audit; quality improvement sub-study (Qld)
- Other sub-sets of the AuSCR data spine e.g. telemedicine
- National Stroke Workshops – research translation
Stroke123

In 2011, a 4-year NHMRC Partnerships for Better Health grant was awarded for Stroke123, a collaborative, national effort to monitor, promote and improve the quality of stroke care in Australia.

- Establishing high quality, integrated national stroke data
  - AuSCR + hospital data + death data
  - Harmonising AuSCR and NSF Audits

- Queensland sub-study using a historical control design, using integrated data and an externally facilitated quality improvement program to improve clinical practice
  - AuSCR + NSF Audit + linked hospital data

- Policy and practice translation
  - Annual national workshops, advocacy with Clinical Networks, publications and registry annual reports, QI feedback

Stroke123: data harmonisation

- AuSCR data pre-populated the 2013 NSF Acute audit within NSF web tool
- Learnings fed into development of the Australian Stroke Data Tool (AuSDaT) – more about this later
  - Mapping of NSF and AuSCR variables
  - Developing Master Data List for AuSDaT
  - Creation of National Stroke Data Dictionary
- AuSCR data pre-populated the 2015 NSF Acute audit within AuSDaT

AuSCR: Australian Stroke Clinical Registry; NSF: National Stroke Foundation
**Stroke123: data linkage**

- Test case for linking data from a non-government registry with hospital and death data across multiple jurisdictions
- Linkage with the National Death Index and Emergency Department & Hospital Admission Data from Queensland, NSW, Western Australia, Victoria
- Encountered numerous legislative barriers specific to linkages with a clinical registry and across states
- High quality linkages have improved data utility

**Stroke123: quality improvement sub-study**

- 20 hospitals in Queensland (Lead HREC + governance)
- Controlled before and after cohort design
- Plan-Do-Study-Act model of intervention
- NSF StrokeLink quality improvement workshops with external facilitation to improve adherence to clinical care processes
- Data from: NSF audit; AuSCR; and Queensland Health
- Pre-/post-intervention surveys of hospital staff
AuSDaT background

- Researchers and clinicians spend much time and effort collecting data:
  - Complicated by having to use multiple systems to collect the same variables on the same patients and creates duplication/inefficiencies

- In 2013, the Australian Stroke Coalition agreed to:
  - Focus efforts on improving the sustainability of data collection for quality monitoring
  - Endorsed development of an integrated technological solution to collect data through a single portal across multiple programs

*The AuSDaT is a comprehensive, secure data management system for collecting high quality, standardised data on stroke care quality and outcomes.*
Australian Stroke Data Tool

- AuSDaT: data collection TOOL not a program
- Efficient, innovative, secure data management system for collecting high quality, standardised data
- Vision realised through a collaborative process with partners
- Program partners: NSF audit, AuSCR, SITS & INSPIRE
- Harmonised data collection – piloted with NSF audits
- Capacity for time-limited research programs to use AuSDaT
- AUSCR and others to transition in 2016-2017
- Master Data List & National Stroke Data Dictionary

Aims of the AuSDaT

- Standardise the collection of stroke data using the same variable names and definitions
- Reduce the data entry burden and duplication of effort through centralised data entry for multiple programs
  ➢ Based on collect once use many times principle
- Provide a common process for importing data
- Enhance accuracy and reliability of data collected with consistent data logic checks and rules
- Provide a system for health services to collect data of local interest
- Provide a range of real-time web-based summary reports benchmarked against peer group, state and national performance
- Includes a formative evaluation phase during the AuSDaT implementation to inform potential enhancements in the early stages of use
AuSDaT timeline

- **2013**: ASC: sustainability of data collection for quality monitoring
- **2014**: Master Data List & National Stroke Data Dictionary
- **2014**: "Supertool" conceptualised
- **2014**: Tender process & build commences
- **2015**: NSF acute audit in AuSDaT
- **2015**: AuSDaT ethics approval
- **2016**: NSF rehabilitation audit in AuSDaT
- **2016**: AuSCR functionality & data migration
- **2017**: INSPIRE SITS
- **2017**: Research projects & local audits

Situation before AuSDaT...

[Diagram showing data collection and audit processes]
…After AuSDaT

AuSDaT data entry site
New program participation options

Identifying information
- Date of birth
- Gender
- Contact details (incl NOK)
- Hospital name

Clinical processes
- Use of tPA
- Access to a stroke unit
- Discharge antihypertensives
- Discharge care plan provided

Hospital outcomes data
- Date of discharge or death
- Discharge destination

Timeliness of care delivery
- Arrival by ambulance
- Date/time stroke onset
- Date/time ED arrival
- Date/time admission
- Transfer from other hospital

Risk adjustment
- ICD-10 code
- Ethnicity
- Ability to walk on admission
- First-ever stroke status
- In-patient stroke
- NIHSS on presentation

SAMA: Swallow screen, Hyperacute Aspirin, Mobilisation, Antithrombotics

AuSCR: core variables

Identifying information
- Date of birth
- Gender
- Contact details (incl NOK)
- Hospital name

Clinical processes
- Use of tPA
- Access to a stroke unit
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- ICD-10 code
- Ethnicity
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AuSCR: extra variables in AuSDaT

**EXTRA PROCESSES OF CARE**
(currently Queensland only)
- Dysphagia
- Hyperacute aspirin
- Mobilisation
- Antithrombotics at discharge

**TELEMEDICINE / THROMBOLYSIS**
(currently Victorian Telemedicine only)
- Telemedicine consultation - yes/no
- Brain scan – yes/no/date/time
- Date/time thrombolysis
- Serious adverse event – yes/no/type

**ENDOVASCULAR CLOT RETRIEVAL**
- Bypass ED
- Reason for transfer
- Subsequent brain scan - date/time
- ECR – yes/no/date/time
- NIHSS before/after ECR
- Final TICI score
- Haemorrhage – yes/no/details

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AuSDaT governance and communication
## AuSDaT policies

- **Communication**
- **Complaints**
- **Data security**
- **Data request**
- **Intellectual property**
- **Patient follow-up**
- **Consumer and community participation**
- **National Stroke Data Dictionary operational**
- **Quality assurance and data management**
- **Publications**
- **New program request**
- **Data custodian and inter-program data sharing**


## Programs, processes and data

<table>
<thead>
<tr>
<th>Program</th>
<th>Covers</th>
<th>Uptake</th>
<th>Data variables</th>
<th>Eligibility</th>
<th>Type of data</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSF Organisational Survey</td>
<td>Hospital resources &amp; infrastructure</td>
<td>~300 hospital services (Australian)</td>
<td>~60 organisational data variables</td>
<td>Pre-requisite prior to any patient level data entry in AuSDaT. Updated annually.</td>
<td>Unit level data outlining available infrastructure and resources</td>
</tr>
<tr>
<td>NSF Clinical Audit - acute</td>
<td>Acute clinical services</td>
<td>~110 hospitals (Australian)</td>
<td>~70 clinical data variables</td>
<td>~40 patients (stroke) admitted in preceding 6 months</td>
<td>Consecutive admissions until sample size obtained. Retrospective. De-identified.</td>
</tr>
<tr>
<td>NSF Clinical Audit - rehabilitation</td>
<td>Rehabilitation clinical services</td>
<td>~120 hospitals (Australian)</td>
<td>~70 clinical data variables</td>
<td>~40 patients (stroke) admitted in preceding 6 months</td>
<td>Consecutive admissions until sample size obtained. Retrospective. De-identified.</td>
</tr>
<tr>
<td>AuSCR</td>
<td>Acute clinical services and 3 month follow-up</td>
<td>~55 hospitals (Australian)</td>
<td>4-8 process indicators, and demographic information Patient follow up @ 90-180 days post-stroke. Reperfusion therapies.</td>
<td>All admitted patients (stroke, TIA)</td>
<td>Prospective. Identifiable.</td>
</tr>
<tr>
<td>SITS (export out only)</td>
<td>Acute stroke treatment</td>
<td>~20 hospitals (Australian)</td>
<td>10-20 reperfusion treatment variables</td>
<td>All admitted patients (stroke) receiving reperfusion and/or acute stroke care</td>
<td>De-identified.</td>
</tr>
<tr>
<td>INSPIRE (partial and export out only)</td>
<td>Acute clinical services</td>
<td>~12 hospitals (Australian)</td>
<td>Advanced stroke imaging</td>
<td>All patients admitted who undergo perfusion CT acutely</td>
<td>De-identified clinical and imaging data (imaging file/s stored in INSPIRE database).</td>
</tr>
</tbody>
</table>
Formative evaluation

• Feedback to be sought from health service and program users to inform potential future functionality enhancements
  - Online or paper-based survey *(voluntary and de-identified for analysis)*
  - Open discussions at forums or workshops
• Evaluation to be conducted by independent, external researcher at Monash University

AuSCR Office processes to transition data collection to AuSDaT

• Reviewed
  - AuSCR protocol
  - Policies & standard operating procedures
  - User manuals & data dictionary
• Ethics and governance amendments
• Information Technology
  • User acceptance testing of the tool functionality
  • Setting up new users
  • Establishing new programs – acute and follow up
  • Preparation of historical data for migration to the AuSDaT
• Training of AuSCR office staff and hospital users
AuSCR publications

- Presentations at national and international conferences

AuSCR facilitators

- Queensland Health
  - 2012-2015: Support for expansion in Queensland (through NHMRC partnership grant – Stroke123)

- Victorian Department of Health
  - AuSCR office support - consolidation in Victoria and future expansion to 24 sites (Victorian Stroke Clinical Network)
  - Hospital support for IT infrastructure to export data to AuSCR

- Victorian Stroke Telemedicine Project
  - Support for use of AuSCR in regional Victoria
### Achievements 2012 - 2016

<table>
<thead>
<tr>
<th>Then</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 hospitals: 2,530 care episodes in AuSCR</td>
<td>63 hospitals: 36,271 episodes of care in AuSCR</td>
</tr>
</tbody>
</table>
| Working in silos | 3 work groups established and continuing beyond project some with modified formats/membership:  
  - National Data Harmonisation: AuSDaT Data Content committee (now Coordinating group)  
  - National Data Linkage: AIHW, PHRN, academics, clinicians & state government data linkage unit experts  
  - Queensland Quality Improvement: QSQIP |
| Use of national average for benchmarks | Application of achievable benchmarks to motivate great QI targets |
| Duplication of effort | Pre-population of NSF Acute Audit data for hospitals in AuSCR – now seamless with AuSDaT (from 2016) |
| No data linkage | Data linkage with AIHW, QLD, NSW, VIC and NSW |
| Limited evidence on externally facilitated QI programs | Pilot project on secondary prevention and discharge care planning funded and found to be effective  
  - Enhanced StrokeLink with AuSCR and NSF data (analysis imminent) |
| No direct government support | Funding in Victoria and Queensland |
| Limited information on the outcome of patients with stroke in Australia | New evidence: on TIA’s admitted to hospital, mortality rates between hospitals, impact of Stroke Units...to be continued |

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**The AuSCR Team**

![Image of the team meeting]

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**The Florey**
Conclusion

- From finite (12 month) grant from ACSQHC in 2008 the AuSCR has grown & supported a number important initiatives to ensure quality of care is reliably monitored
- As the AuSCR dataset grows we are enabled to address many research questions related to the quality of care in stroke
- Strategic support from the Australian Stroke Coalition and inter-program collaboration has resulted in a harmonised, standardised stroke data collection platform (AuSDaT)

Acknowledgements