AUSTRALIAN STROKE CLINICAL REGISTRY

FACILITATING QUALITY

AuSCR DATA ACCESS POLICY FOR RESEARCH PROJECTS

Version 3

Approved 20 November 2025

Approved by: AuSCR Advisory Board

1.0 Purpose and Scope

Access to data from the Australian Stroke Clinical Registry (AuSCR) is governed by policies and procedures to protect against potential breaches of privacy, or the inappropriate use of AuSCR data. These procedures also apply when requesting access to data or access to participants from the Volunteer Research Cohort[1]. In consideration of the approval for access to AuSCR data, the AuSCR Data Access Committee seeks to balance i) the protection and reuse of AuSCR data for research projects, and ii) the potential participation burden to registrants with that of the public benefit of the research. The Data Access Committee also seeks to avoid duplication of research efforts or topics to be reported in publications. The AuSCR Data Access Committee reserves the right to deny approval of projects based on our criteria and risk assessment. This policy does not cover individual hospital use of their own data, as hospitals may use their own data as they wish, including for publication. *This document should be read in conjunction with the AuSCR Data Security Policy, and AuSCR Data Use and Publication Policy.*

1.1 Background

The AuSCR is a national Clinical Quality Registry that contains information collected from participating hospitals in Australia, about the management of acute stroke and includes patient-reported outcome measures. The information collected in the AuSCR is used to inform efforts to: understand the quality of health care provided in Australia; plan services; and assist with improved treatment and prevention efforts as part of supporting quality improvement efforts. The aggregated data are also used as part of observational studies to describe stroke care and outcomes of patients in Australia. The details of the variables collected in AuSCR are outlined in Appendix 1 and on the AuSCR website http://www.auscr.com.au/.

The initial data collection occurs during hospital admission and eligible patients are requested to complete a single survey between 90-180 days post admission. Eligible registrants (i.e. those entered within the eligible timeframe, not known to be deceased, and not opted out) are contacted and asked to complete the patient-reported outcome questionnaire, generally via mail, SMS or email. The patient-level data are linked to national death registrations by the Australian Institute of Health and Welfare yearly so all registrant deaths can be determined and updated routinely.

The Volunteer Research Cohort includes people living with stroke who request to be invited to participate in future research studies. There are two ways people are included in the Volunteer Cohort. The primary way is via answering affirmatively to this question in the AuSCR[1], the secondary way is via self-referral. That is, when a person submits their personal information via an online form on the AuSCR website, they give consent to be included. The AuSCR Office staff will also confirm their stroke details via a telephone call in response to the form being supplied, if required. The investigators of research studies who seek to access the Volunteer Research Cohort will be required to obtain consent for their project via the method approved in their ethics application.

[1] People in AuSCR who completed the outcome survey 90-180 days after their admission for stroke, and who indicated their willingness to be contacted for new research opportunities.

1.2 Data Access process

1. Any research using the AuSCR data requires a Human Research Ethics Committee (HREC) approval.

2. Seeking early advice from AuSCR is recommended as to whether the data access application being proposed is feasible.

3. All requests for access to AuSCR data must be submitted electronically to the AuSCR Office via the online form along with a copy of the ethics approval and project protocol. Where relevant, a copy of documents that will be provided to potential participants from the Volunteer Research Cohort e.g. Patient Information Sheet, cover letter, surveys, etc. must also be submitted.

4. The Executive Director, through the AuSCR Office, will confirm the cost estimate of the data request, statistical, or other effort required for approved projects. An application submission fee will be required for each application submitted and will need to be paid when the application is approved. The Data Access Coordinator supports the preparation and processing of applications and quotes.

5. Applications will undergo review by the Data Access Committee for appropriate use of AuSCR data.

6. Feedback from the review will be sent to the Executive Director or Co-chair of the Data Access Committee and delegate of the Data Custodian (The Florey) as appropriate, for final approval or rejection.

7. Applicants will be notified of the application outcome and legal documentation to be signed by both parties (Services Agreement and Statement of Work).

8. Access to the pre-specified data will be overseen by the AuSCR Executive Director as detailed in the Statement of Work.

9. Prior to providing access to the prepared data, or the contacting of eligible people in the Volunteer Research Cohort on behalf of approved applicants, full payment of the project submission fee and any additional fee as agreed in the Statement of Work is required.

10. Access to data will be made available via the Secure Research Platform (SeRP) at Monash University, with the AuSCR Office facilitating this arrangement with the Senior Epidemiologist assigned to manage the AuSCR archived data on this platform. For access to linked AuSCR data via the National Health Data Hub, separate arrangements will also need to be made with the Australian Institute of Health and Welfare. Depending on the complexity of the data or planned analyses, applicants should consider seeking assistance from our pool of Monash University Stroke and Ageing Research epidemiologists who are experienced in the analysis of the AuSCR data. Any associated fees will be negotiated separately by Monash University staff.

11. A project report is required 12 months after data access, and failure to comply may impact future data requests. If a project is not completed and published within this timeframe, an extension can be requested.

12. The AuSCR Data Access Committee expects that applicants who have been granted access to registry data will, to the best of their ability, ensure that their research results are placed in the public domain. All publications will acknowledge AuSCR as per the AuSCR Publication Policy.

13. The applicant will provide the AuSCR Data Access Committee coordinator and Executive Director with either the DOI (Digital Object Identifier) of a publication or an electronic copy of the manuscript once published. The information will be used for reporting purposes including to the AuSCR Advisory Board and funders.

1.3 Data Access Statements

The AuSCR Data Access Committee, Executive Director and Data Custodian:

- encourage the use of the AuSCR's accumulated data for research relevant to any aspects of stroke treatment, prevention, improvements in quality care and quality of life;
- will only facilitate access to AuSCR data for projects that meet appropriate standards of ethical approval and public health importance as determined by the AuSCR Data Access Committee, and/or AuSCR sub-committee or their nominee/s (e.g. Reperfusion and Telemedicine, Paediatrics);
- will not approve applications that are a reputational risk to the registry or do not have risk mitigation steps in place;
- will only provide access to data that have previously been reported on by AuSCR Office as part of the annual reporting process and form part of the AuSCR data archive;
- will recruit research subjects on behalf of applicants using contact information entrusted to AuSCR with all the appropriate approvals being in place as outlined above;
- will only provide access to identifiable data that can be linked with other data held by government data linkage units or official health data integrating authorities including the Australian Institute of Health and Welfare, for approved projects using a project-specific linkage ID variable. All data linkage processes are overseen by the Executive Director at the request of Data Access Committee and/or the Advisory Board;
- will not provide registrant contact details. All contact with registered patients will be conducted by the AuSCR office overseen by the Executive Director at the request of Data Access Committee and/or the Advisory Board;
- will provide access to the least sensitive level of data that is practicable in order to fulfil the uses identified in the research proposal submitted with the data request;
- in releasing aggregate data, will suppress all individual cells with counts less than 5, because of the potential risk of identifying an individual person;
- will generally provide access to data on a non-exclusive basis.

Note: exceptions will be considered for clinical networks and funding partners in use of dashboard for quality improvement projects and programs.

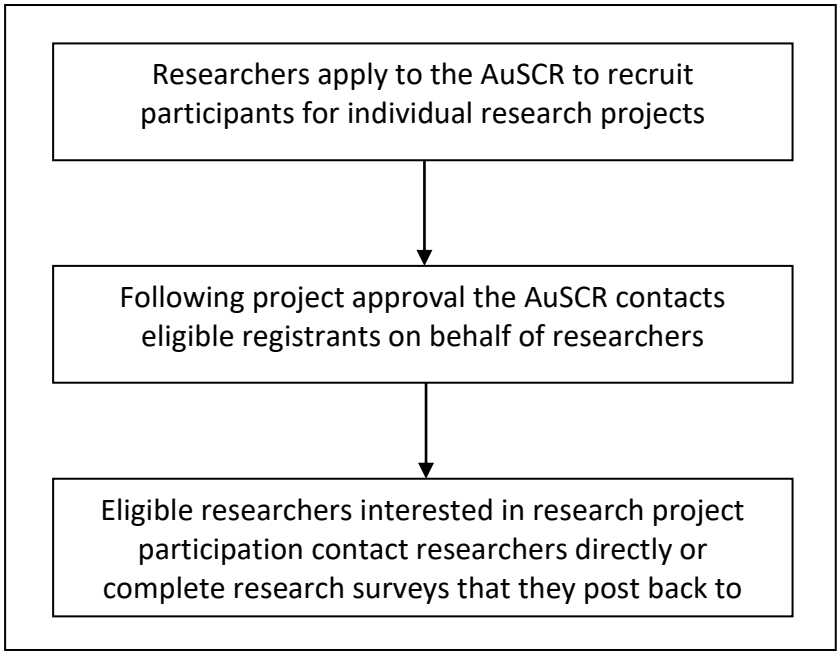

Figure 1: Process for participant recruitment to research projects via the AuSCR

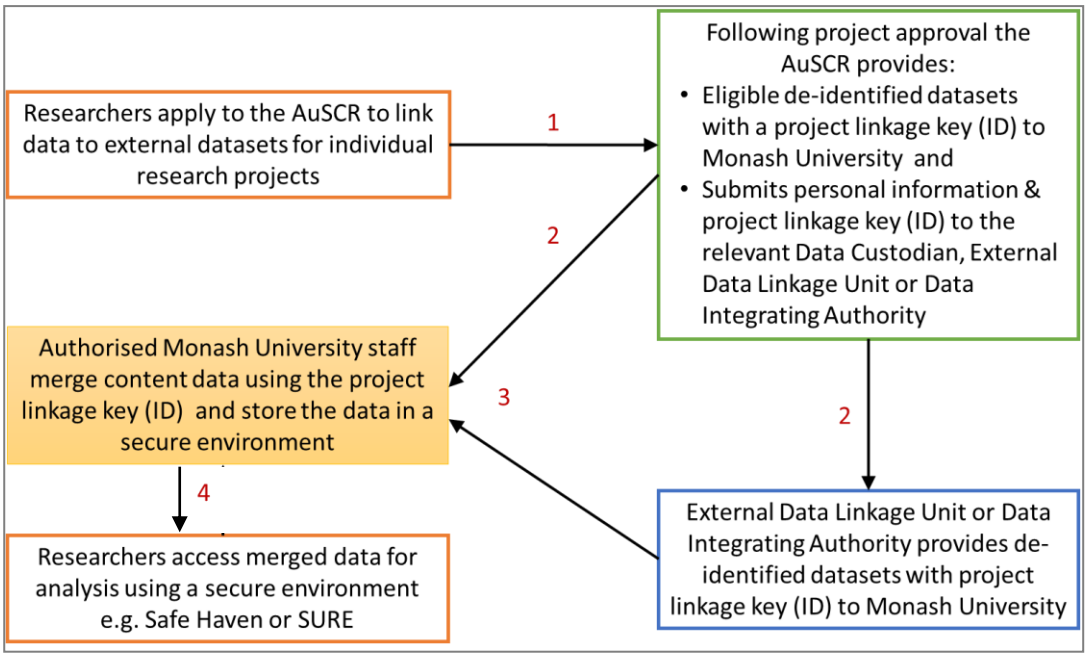

Figure 2: Process for using the AuSCR for data linkage projects

Appendix 1: AuSCR data variables

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Identifying information
- name
- date of birth
- sex
- address
- telephone number/s and e-mail
- hospital name and type of stroke service
- hospital Medical Record Number (MRN)
- contact details for next of kin
- Individual Healthcare Identifier (IHI)

Patient/episode characteristics
- country of birth
- language spoken/interpreter needed
- Aboriginal and Torres Strait Islander status
- type of stroke
- mechanism of stroke and known risk factors (P)
- date/time of stroke onset (including date/time of symptom discovery)
- date/time of notification to hospital
- date/time of arrival at emergency department
- date/time of admission
- direct admission (ED/P)
- in-patient stroke status
- transferred from another hospital status
- date/time of transfer, reason for transfer, mode of transfer transport (ED/P)
- pre stroke history including functional status prior to stroke; dependency prior to admission; triage category (ED)
- ability to walk independently on admission
- previous stroke and known risk factors prior to admission
- National Institutes of Health Stroke Scale (NIHSS) Score on presentation
- arrived by emergency services transport

Endovascular therapy (EVT)
- endovascular therapy including date/time of arterial access
- date/time of final reperfusion
- NIHSS: before EVT
- final eTICI (thrombolysis in central infarction) score
- site of occlusion
- adverse event related to EVT

Hospital outcomes/discharge data
- date of discharge (from acute care) or date of death
- discharge destination
- were rehabilitation services planned on discharge
- were palliative care services arranged at discharge
- ICD10 codes (discharge diagnosis, medical condition, complications and procedures)

Indicators of evidence based care	90 to 180 days after stroke outcome data
• treatment in a stroke unit (if yes, date/time; if no, reason) • was palliative treatment provided • date & time of first brain scan • type of stroke • advanced imaging types (ED/P) • date/time of telemedicine consultation • date & time of thrombolysis (tPA) for ischaemic stroke • date/time formal swallow screen performed including pass/fail • date/time swallowing assessment by a speech pathologist • swallow screen/swallow assessment before oral medications, or food or fluids? • assessment and management of fever (temperature recording, fever ≥37.5, paracetamol administered) • assessment and management of hyperglycaemia (recording blood glucose levels, glucose level ≥10mmol/L, administration of insulin) • date of rehabilitation assessment • discharged on an antihypertensive agent • discharged on antithrombotic medication • discharged on anticoagulation therapy (for patients with Atrial Fibrillation) • discharged on lipid-lowering medication • care plan provided at discharge (any documentation in the medical record)	• survivor status (or obtained from national death registry) • place of residence • living alone status • subsequent stroke since discharge • readmission to hospital • quality of life (EuroQoL5D24, 26 adults; PedsQL25, 26 children up to 18 years old) • modified Rankin Scale23, 24 • difficulties with communication/understanding • difficulties with mental health/ability to think • ability to carry out usual social activities/roles • fatigue • requiring a tube for feeding • Paediatric Stroke Outcome Measure Score (P) • would like an information pack from the National Stroke Foundation? • would be willing to participate in future research?

Note:

- Different programs within the AuSCR collect different bundles of variables, depending on hospital resources and priorities.
- Items with a (P) are collected only as part of the Paediatric dataset and items marked (ED) are collected only in the ED dataset.

Appendix 2: Associated documents

1. Data Access Request Form
2. Master Services Agreement and Statement of Work
3. AuSCR Data Use and Publication Policy