AUSTRALIAN STROKE
CLINICAL REGISTRY

FACILITATING QUALITY

AuSCR DATA USE AND PUBLICATION POLICY

Version 5

Approved 11 March 2026

Approved by: AuSCR Advisory Board

1.0 Preamble

This document relates to the Australian Stroke Clinical Registry (AuSCR). This policy provides guidelines for the publication and broader use of AuSCR data beyond approved internal reporting by an organisation. This policy is necessary so that each contributing hospital has clarity about the use of data once submitted to the AuSCR via the data platform.

This policy covers AuSCR staff, members of the AuSCR Data Access Committee, members of the AuSCR hospital network, members of the AuSCR Clinical and Quality Improvement Committee and Advisory Board and any other individual with access to, or requesting access to, data from the AuSCR.

The publication policy does not apply to site-specific data, as hospitals are free to publish their own data at any time with acknowledgement of AuSCR as per section 1.7 of this policy. If hospitals wish to publish comparisons of their own hospital data with AuSCR published data (including data published in the AuSCR Annual Report) then the AuSCR sources of data must be cited in the references e.g. Annual Report, and be acknowledged as per section 1.7 of this policy. We strongly encourage those wishing to publish analyses of site-specific AuSCR data to consult with an AuSCR statistician to ensure reliable analyses and to facilitate accurate interpretation of results.

This policy does not include AuSCR activity reports such as the Annual Report or reports provided to participating hospitals or state/Commonwealth funders. The AuSCR staff will use the information held in the Registry to compile reports. All reports will contain de-identified patient-level aggregated data to ensure that confidentiality is maintained. Aspects of the Annual reports may be presented by representatives of AuSCR in media releases, webinars, conference presentations or in medical journals in consultation with the Advisory Board, Clinical and Quality Improvement Committee, Executive Director or Data Access Committee.

This policy should be read in conjunction with other relevant AuSCR polices, such as the *AuSCR Data Access Policy, Quality Assurance and Data Management Processes Policy,* and the *Data Security Policy*, which provide more information.

1.1 Overview of AuSCR

The AuSCR is a clinical quality registry that includes information about the acute treatment of people with stroke that has been collected and entered by participating hospitals across Australia. The AuSCR also contains patient health outcomes data collected three to six months after the time of hospital admission, via an approved survey (referred to as the Follow-up survey). Death data are also supplied by the Australian Institute of Health and Welfare. The AuSCR exists to monitor and improve the quality of acute stroke care in Australia, and to better understand the quality of stroke care provided in Australia, plan services and assist prevention efforts and treatment decisions. Summary data are made available in different formats for a range of purposes including internal and external reporting, and for research or health services evaluations.

The AuSCR Consortium partners include The Florey, Stroke Foundation, Australian & New Zealand Stroke Organisation and Monash University, and do not directly provide health care or medical advice.

1.2 Confidentiality of Information

Information held by the AuSCR is confidential. The procedures for making a request for access to data held in the AuSCR Database are outlined in the *AuSCR Data Access Policy.*

Sharing AuSCR data with healthcare agencies, clinical networks, the public and the general scientific community is an objective established from the outset of establishing the AuSCR and is supported by the Clinical and Quality Improvement Committee and the Australian Framework for National Clinical Quality Registries 2024.

In preparation for this level of data sharing, each of the AuSCR hospital sites include the following wording in their Patient Information sheets:

> ***How is your information kept private?***
>
> *Your information is kept* ***safe and secure*** *in the AuSCR.*
> - *Only approved staff can access it.*
> - *It's stored in a password-protected system.*
> - *Your name and personal details are not shown in any reports.*
> - *We will only share your information if you give permission or if the law requires it.*
>
> *Occasionally, AuSCR staff review your hospital medical record to check details.*
>
> *The registry is ongoing, which means we keep the data to track stroke care over time. If someone wants to use the data for research, they must first get approval from an Ethics Committee.*
>
> *Your Registry data may be securely linked with other health or government data (like hospital or death records) to help us better understand stroke care and long-term health outcomes. Once your data is linked it will be given a unique identification number for analysis.* ***This means that your name cannot be identified in any reports, and your privacy and confidentiality is maintained.***

1.3 Plans for Disseminating Registry Summary Data

Data held by the AuSCR will be used to provide summarised information on:

- hospitals providing stroke care, against the Stroke Clinical Care Standard,[1] national initiatives, e.g Stroke Unit certification, National Acute Stroke Targets, and other key performance metrics agreed upon by the AuSCR governance committees
- summarised statistics on the quality of stroke care in Australia;
- case-mix adjusted health outcome comparisons by subgroups or hospitals/geographical regions/jurisdictions.

The AuSCR Consortium does encourage the generation of scientific knowledge based on data held by the Data Custodian. The Clinical and Quality Improvement Committee is available to provide advice and feedback on draft manuscripts to ensure that the data and any limitations in scope or quality of the data provided has been properly described.

As outlined below, the AuSCR must be acknowledged in the appropriate way in all publications and presentations. AuSCR reserves the right to dissociate itself from conclusions drawn from the data if it deems necessary.

1.4 Applications for Data Use

The AuSCR Data Access Committee provides independent and unbiased review of external proposals seeking to use the AuSCR data. The *AuSCR Data Access Policy* provides full details of accessing the AuSCR data and information.

The *AuSCR Data Access Policy* and the *AuSCR Data Access Committee Terms of Reference* provide further information on the roles and responsibilities of the AuSCR Data Access Committee.

It is expected that most users of the AuSCR data will follow these guidelines in good faith and that most analyses will be of reasonable quality. The Data Access Committee does not intend to review manuscripts for scientific quality, preferring to let the peer-review process sort out quality.

1.5 Requests for Access to the AuSCR Data

Interested parties may present requests for access to datasets for the purposes of scientific investigation. Generally, only archived, clean, de-identified data will be made available to external researchers. These requests will be reviewed by the AuSCR and Data Access Committee on behalf of the Data Custodian. Where relevant, the proposal will be reviewed by a representative from a relevant topic-specific advisory group (e.g. Reperfusion and Telemedicine Advisory Group or Paediatric Advisory Group). All submitted requests require approval from a Human Research Ethics Committee, meet appropriate standards of scientific merit and public health importance and should not have any major overlap with other approved research. De-identified data access to external researchers will be time-limited and occur via a secure online platform which prevents the downloading of the AuSCR data onto external computers/servers.

The data available in the interactive data dashboards are pulled directly from the AuSCR and have not undergone any data quality checks or verification and should not be used for publication.

The *AuSCR Data Access Policy* provides full details of accessing the AuSCR data and information.

1.6 Authorship/Publication

The AuSCR Consortium expects that researchers who have been granted access to Registry information will, to the best of their ability, ensure that their research results are placed in the public domain. A project final report is required 12 months after the provision of access to data or invitation to participate in research, and failure to comply may impact future data requests.

The minimum requirement for authorship should accord with the principles outlined in the “Uniform requirements for manuscripts submitted to biomedical journals: writing and editing for biomedical publication”, established by the International Committee of Medical Journal Editors (ICMJE, www.icmje.org).

AuSCR Specific Principles

1. There are several options for authorship of publications using the AuSCR data. Where academic input has been provided in the study or manuscript by members of the AuSCR team or governance committee/s these should be included as authors. Other options include “on behalf of the AuSCR Collaboration”.
2. Depending on the type of data being reported, the AuSCR should be described in the following way in the methods section to describe and acknowledge the source data. See attachment A for an example.
3. Depending on the type of data being reported, authors are required to include an appendix to acknowledge individuals that have contributed to the AuSCR (including members of governance committees) or who have collected AuSCR data used in a manuscript, and should contact AuSCR Office staff or refer to relevant Annual Reports for these details. See attachment A for an example.
4. The corresponding author is responsible for following the publications rules, including that no eligible author is left out and that no inappropriate author is included (“honorary/courtesy authorships” are not accepted in the AuSCR).

The Data Access Committee will be guided in relation to any issues of authorship and intellectual property by the Australian Research Council “Australian Code for the Responsible Conduct of Research”, 2018 which is available at https://www.arc.gov.au/sites/default/files/2023-05/the-australian-code-for-the-responsible-conduct-of-research-2018.pdf

The AuSCR will maintain an up-to-date bibliography and repository of all publications pertaining to the AuSCR and these will be summarised in Annual Reports as part of ensuring ongoing transparency. Lead authors are required to provide the AuSCR with the most recent version of all publications and accepted abstracts.

In addition to adhering to the Services Agreement as outlined above, the following limitations regarding access to data must be adhered to:

- Identified patient-level data shall remain confidential under all circumstances.
- Site-specific data shall remain confidential and shall not be used in publications, presentations, or other public use (e.g. for outcome comparisons between hospitals)

without the written consent of the site AuSCR Principal Investigator who is the nominated representative responsible for the registry at a hospital.

- Following completion of a data access application data release may be granted, but only summary and de-identified data will be provided. Please refer to the *AuSCR Data Access Policy* for further information.
- Any use of the data must not compete with, or interfere with, the development, operation, or marketing of the AuSCR data, unless approved in writing by the Clinical and Quality Improvement Committee or Advisory Board.
- Industry sponsors will not have any editorial control over an approved project's methods, interpretation of results or final publications or presentations either using the AuSCR data or prepared by the AuSCR investigators.

Authorship Criteria

All publications of AuSCR data should meet the Australian Research Council's "Australian Code for the Responsible Conduct of Research", 2018 (Australian Code for the Responsible Conduct of Research 2018 | NHMRC) and the "Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals", established by the International Committee of Medical Journal Editors (ICMJE, www.icmje.org).

Authorship is substantive participation where all of the following conditions are met:

1. Substantial contributions to conception or design, or data acquisition, analysis or interpretation;
2. Drafting the article or revising it critically for important intellectual content;
3. Final approval of the version to be published;
4. Agreement to be accountable for the work.

All others who have contributed, but do not meet all of the criteria listed above, should be named in the acknowledgements with a description of their contribution.

- Where authorship is attributed to a group, such as the Clinical and Quality Improvement Committee, all members of the group who are named as authors should meet the criteria for authorship.
- Publications should include information on sources of financial support for research.

Acknowledgements

The AuSCR should be acknowledged in any publication using data provided by the Registry (see example attachment A). It is also a requirement to acknowledge use of the Australian Stroke Data Tool (AuSDaT) and/or Adaptive Health Data Platform (AHDaPt) (see AuSDaT policies https://australianstrokecoalition.org.au/portfolio/ausdat/)

Individuals coordinating data collection at local hospitals who do not meet the criteria for authorship may be named in the Acknowledgements section of the manuscript, including the site lead (as listed on the relevant HREC approval) and/or primary data collectors, as relevant.

Submission of Publications to the Data Access Committee

The purpose of the Data Access Committee is to provide independent review of applications seeking access to the AuSCR data. Please refer to the *Data Access Committee Terms of Reference* and the *AuSCR Data Access Policy* for further information.

The applicant will provide the AuSCR Data Access coordinator and Executive Director a copy of any manuscripts submitted to peer-reviewed journals, and the reference once published. Abstracts submitted to conferences should also be provided. The information will be used for reporting purposes including our Advisory Board and funders, as requested.

Tracking of Data Use and Publications

If the AuSCR data are used in publications, authors will be required to:

1. Include recommended language describing the AuSCR methods and data gathering;
2. Cite AuSCR using approved language as in the acknowledgements section, above
3. Consult and/or collaborate with an AuSCR statistician where concerns about data analysis and interpretation are raised
4. Inform the AuSCR of acceptance or rejection of the manuscript;
5. Provide manuscript or abstract citation to the AuSCR Office upon acceptance and
6. Provide URL to the published work, if possible.

Researchers are strongly encouraged to contact one of the AuSCR statisticians *prior* to manuscript preparation to ensure that robust analyses have been undertaken and to facilitate the accurate interpretation of results.

1.7 Unusual Situations

Failure to Follow Services Agreement. If users inadvertently violate the Services Agreement, it is likely that they will self-correct as infractions are discovered. If users deliberately violate the Services Agreement, the sole sanction available to the AuSCR will be to revoke access to the AuSCR data. This may include reporting the violation to the relevant Human Research Ethics Committee.

Fraudulent Use of Data. Open access to hospital sites raises the possibility that individuals could obtain access to data under false pretenses. Should the AuSCR discover an attempt to publish data obtained fraudulently, the data user will be sanctioned through the Advisory Board communication with them or their academic supervisor(s). As soon as the AuSCR becomes aware of any breach of the Data Use Agreement, immediate steps will be taken to end the violation. In extreme and/or deliberate cases, this may include discontinuing the user's data access and/or reporting the violation to the relevant Human Research Ethics Committee.

Journal Objections: It is possible that journal editors may object to a group authorship format where authors credited have gathered data but *not* otherwise contributed to data analyses or writing of the manuscript. In these cases contributions to data collection will be acknowledged via another mechanism that is acceptable to the specific journal.

1.8 Use of Quick Suite Interactive Data Dashboards

The AuSCR provides access to Quick Suite interactive data dashboards to support participating hospitals, AuSCR staff, and authorised users in internal quality improvement and service monitoring activities.

Data displayed within the Quick Suite dashboards are extracted directly from the AuSCR database and have not undergone final data cleaning, validation, or verification processes. As such, these data may be incomplete, subject to change, or contain inaccuracies that would normally be resolved through standard AuSCR quality assurance procedures applied to datasets released for reporting or research purposes. These data are not the same data used in Annual Reports which is a curated dataset subject to additional cleaning and logical data checks. The annual report data are kept in a separate anonymised archive. Currently AuSCR does not provide dashboards using the finalised annual report data.

Accordingly:

- Hospitals contributing to the AuSCR may use dashboard outputs using only data from their own hospital for external reporting such as conference presentations, or journal publications, with clear acknowledgement of the above limitations.
- Multi-site data accessed via the Quick Suite dashboards must not be used for external reporting, public dissemination, academic publication, conference presentation, or media release.
- Dashboard outputs are not covered by Data Access Committee approval for research or publication.

The AuSCR Executive Director, Clinical and Quality Improvement Committee or Advisory Board may provide exceptions to the above where aggregated data from dashboards are publicly available, such as to support the 30/60/90 National Targets by featuring updates on their website or in newsletters.

Use of Quick Suite dashboard data is strictly limited to internal quality improvement, clinical audit, and service development purposes for individual participating organisations, and only utilising local hospital data. Any intention to use AuSCR data beyond these purposes requires a formal data request and approval in accordance with the AuSCR Data Access Policy and this Publication Policy, using cleaned and verified datasets supplied by AuSCR.

Where this policy is not followed, the AuSCR takes no responsibility for the accuracy of the data reported. The AuSCR reserves the right to review and restrict access to Quick Suite dashboards where data are used inconsistently with these conditions.

References

1. Australian Commission on Safety and Quality in Health Care. Acute Stroke Clinical Care Standard. Sydney; ACSQHC, 2019. (Available at: Acute Stroke Clinical Care Standard)

Attachment A

Examples of how to acknowledge the AuSCR:

1. Where AuSCR data have been used:
   The authors acknowledge the Australian Stroke Clinical Registry (AuSCR) for the collection and provision of data used in this research, as well as participating hospitals and patients whose data are included.

2. Where AuSCR was used for recruitment:
   The authors acknowledge the Australian Stroke Clinical Registry (AuSCR) for supporting participant identification and recruitment for this study, and the participating hospitals and patients.

3. Methods section of a publication for CONSORT-ROUTINE:
   The Australian Stroke Clinical Registry is a national opt-out registry that contains information collected from participating hospitals in Australia, about the management of acute stroke and includes patient -reported outcome measures (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 not known to be deceased, entered within the eligible timeframe and not opted out) are contacted and asked to complete the patient-reported outcome questionnaire, generally via mail, SMS or email.

   The AuSCR collects information for any stroke episodes that occurred at hospitals participating in the registry. Since inception to December 2025 the AuSCR has recorded over 215,000 episodes of stroke care, increasing by 20,000 per year, and collected approximately 95,000 patent reported outcome surveys.

4. Acknowledgement of individuals that have contributed to the AuSCR for publications:
   See AuSCR annual reports for the list of individuals involved for the date range of the data request (https://auscr.com.au/about/annual-reports/)