Frequently Asked Questions
Data Access, Participant Recruitment and Publications for external researchers

- The AuSCR is a national clinical quality registry designed to facilitate monitoring and improvement of hospital care of stroke and transient ischaemic attack. Acknowledged secondary purposes are to: provide reliable data for research; inform national and state-level policy and practice and; contribute to the international literature on stroke and quality registries.

- The AuSCR was established by a consortium of organisations including: the Florey Institute of Neuroscience and Mental Health (Data Custodian), The George Institute for Global Health, the Stroke Society of Australasia and the Stroke Foundation.

- Collection of data into the AuSCR occurs via a web-based tool. Since July 2016 this program has operated within the Australian Stroke Data Tool (AuSDaT). The AuSDaT is an integrated data management software system, which has a separate coordinating committee and is overseen by the Australian Stroke Coalition (http://australianstrokecoalition.com.au/ausdat/).

- Participating hospitals contribute acute care information, while the AuSCR Office obtains follow-up survey data (around 90-180 days post admission) from eligible patients discharged from acute hospitals. Updates of death records occur annually through linkage with national death registrations via the Australian Institute of Health and Welfare. The AuSCR Office supports hospitals to ensure the capture of high quality data.

What data can I access?

- Summary and de-identified data that have been archived for secondary use are available to researchers. Patient-level and hospital-specific data remain anonymised in publications and presentations. Reference to hospital-specific data may be in the form of an identification number where hospital comparisons are presented.

- Only archived clean, de-identified data will be made accessible to external researchers.

- You will only be provided access to variables that have been requested to answer the approved research questions as outlined in your written application.

How do I access AuSCR data?

- Access to archived data are subject to agreed policies and procedures endorsed by the AuSCR Steering Committee, and when used for research, are reviewed by an independent Research Task Group. Members of the Research Task Group are not members of the AuSCR Management Committee or have involvement in the proposed research activities. Following approval by the Research Task Group the project will also require approval from the AuSCR Management Committee and Chair of the Steering Committee.

- In addition, the proposal may need to be reviewed by the relevant topic-specific subcommittee e.g. Reperfusion and Telemedicine if there is a focus on that aspect of the data, to avoid duplication, and ensure relevant collaborators are involved in the research.

- A written application will need to be submitted to the AuSCR Research Task Group. Visit the AuSCR website www.auscr.com.au for more information. You will also need to discuss your application prior to submission with the AuSCR National Coordinator, who will provide a quote for the cost of data access, ensure that all required information is provided, and will then facilitate review by the relevant governance committees. You will also be required to complete an external investigator contract with the AuSCR.

- Approval from a Human Research Ethics Committee is required for projects involving AuSCR registrants. Projects must also meet appropriate standards of scientific merit and public health importance, and not have any major overlap with other proposed research that has already been approved.

- Proposed projects submitted to the AuSCR Office are cross-checked to ensure no duplication with other approved projects.

- You will be responsible for costs associated with the project, which will be determined prior to the project commencing.

- Data will be accessible via a secure and time-limited portal that restricts the ability to transfer data out, but includes a software toolkit for analysis of the data. Alternately you may provide AuSCR statisticians with your analysis code and we will run the relevant analyses on your behalf. The use of AuSCR statisticians would need to be costed as part of your data access application.

- Currently, AuSCR data are analysed using STATA software and the AuSCR statisticians based at Monash University may have programmed analysis coding that they are willing to share to ensure reliable and appropriate data analyses. We strongly encourage external researchers to contact one of our statisticians via the National Coordinator for further information, once their project is approved.

When can I access the aggregated archived data?

- When the AuSCR Office and the consortium investigators have finished using a data-set (e.g. each calendar year there is a new cleaned dataset used for the annual report) and pre-planned papers/reports based on grants or funding obligations then that data can become a resource for others to use for secondary analysis purposes (see Box 1).
- Researchers can submit an application to the AuSCR Research Task Group and, may or may not, choose to involve an AuSCR consortium investigator in the proposed research. However, in most instances to date these efforts have been collaborative to build capacity in the correct use and interpretation of the data, including data linkage projects. Researchers are strongly encouraged to consult with and/or collaborate with AuSCR analyst to ensure correct interpretation of AuSCR data.

How can I use AuSCR data?

- AuSCR data can only used for the purpose approved by the AuSCR Research Task Group in your written application.

Can I use the AuSCR to recruit participants for my Research Project?

- You will need to prepare a written application to the AuSCR Research Task Group, who provide independent reviews of proposals seeking to use AuSCR data, and advise the AuSCR Management Committee on data requests.
- All access to registry data will require approval from relevant Human Research Ethics Committees.
- Projects must meet appropriate standards of scientific merit and public health importance, and not have a major overlap with an already approved project.
- Registrants are asked during follow-up data collection (at 90 to 180 days following admission) by the AuSCR office whether they would like to be contacted for future research. The survival status of AuSCR registrants is verified once a year using data linkage with the National Death Index. Only those registrants who are known to be alive and have agreed to be contacted and meet study inclusion criteria will be contacted.
- Once the Research Task Group, Management Committee and Chair of the Steering Committee have approved the project, the AuSCR Office will contact potential registrants on your behalf that meet the eligibility criteria. Registrant contact details will not be released to researchers. Registrants will be invited to complete and return relevant documents directly to the researchers as per the approved study protocol.
- Visit the AuSCR website www.auscr.com.au for more information. You will also need to discuss your application prior to submission with the AuSCR National Coordinator who will provide a quote for the cost of data provision, ensure that all required information is provided, and will then facilitate review by the relevant governance committees.
- You will be responsible for costs associated with the project, which will be determined prior to the project commencing.

What is the process for manuscript approval?

- The AuSCR Consortium expects that researchers who have been granted access to Registry data will, to the best of their ability, ensure that their research results are reported in the public domain.
- To ensure that the data, and any limitations in scope or quality of the data provided, has been properly understood by the user, pre-publication drafts of manuscripts must be submitted to the AuSCR Management Committee for review and potential advice on data interpretation. Where concerns about data analyses and interpretation are raised, you may be asked to consult and/or collaborate with an AuSCR statistician.
- Lead authors are required to provide AuSCR with the most recent version of all accepted publications and abstracts.
- The AuSCR should be acknowledged in any publication using data provided by the Registry in line with the AuSCR publication policy. Please provide the AuSCR office with relevant reports, presentations and publications that use AuSCR data on an annual basis.
- The AuSDaT should also be acknowledged in any publication using data from 2016 onwards as per the AuSDaT publication policy (http://australianstrokecoalition.com.au/ausdat/)

For more information on the AuSCR data access and publication policies please visit www.auscr.com.au

Box 1: Overview of the AuSCR national data acquisition and use process

Data collection and quality control at hospital level (annual cycle)

- Annual data collection for admissions occurring between January 1st to December 31st with data entry and quality control completed by the participating hospital no later than April of the subsequent year.

Follow-up data collection and death records updated from National Death Index (Australian Insitute of Health and Welfare)

- Collection and data entry of patient follow-up data is closed on June 30th of the subsequent year.
- Death data from the National Death Index is used to update AuSCR data.
- Data are extracted by Florey staff, de-identified, and securely transferred to Monash University for cleaning and analysis for AuSCR annual reporting.

Monash University approved staff only have access to de-identified data and manage the archived data on behalf of the AuSCR Consortium

- Data are merged with previous years data and managed in an archive by Monash University.
- Approved Monash Unviersity epidemiologists analyse the data on behalf of the AuSCR Office, and investigator,s for a range of agreed purposes including reports for government funders.

Data are usually 24 months old once ready for analysis for core activity approved projects

- Aggregated data are used for core, agreed reporting priorities by the Coordinating Principal Investigator (PI) and AuSCR Management Committee as approved by the Chairs of the Research Task Group and AuSCR Steering Committees.
- Clinical leads representing state clinical networks contributing data, or members of the AuSCR Steering Committee with relevant expertise, are invited to be on writing committees for specific papers.
- Hospital PIs, or nominees, are invited to be on a writing committee with selection based on active contribution of data to be included in that publication and not having had previous involvement on a writing committee.

Access of archived data by other researchers

- Data made available to external researchers only occurs once core research is completed and the data are contributed to the archive .
- Data are only made accessible in a de-identified format after approval processes have been met and confirmation that there is no duplication of topics and research questions.
- AuSCR Office maintains a record of use of the data and followup with researchers to ensure appropriate use and reporting in a timely manner.
- *Refer to the AuSCR Access and Publication for External Researchers FAQ and to the AuSCR data access policy at www.auscr.com.au*
- Researchers are strongly encouraged to consult, or collaborate, with an AuSCR statistician in relation to analysis of AuSCR data to ensure robust analyses and interpretation.
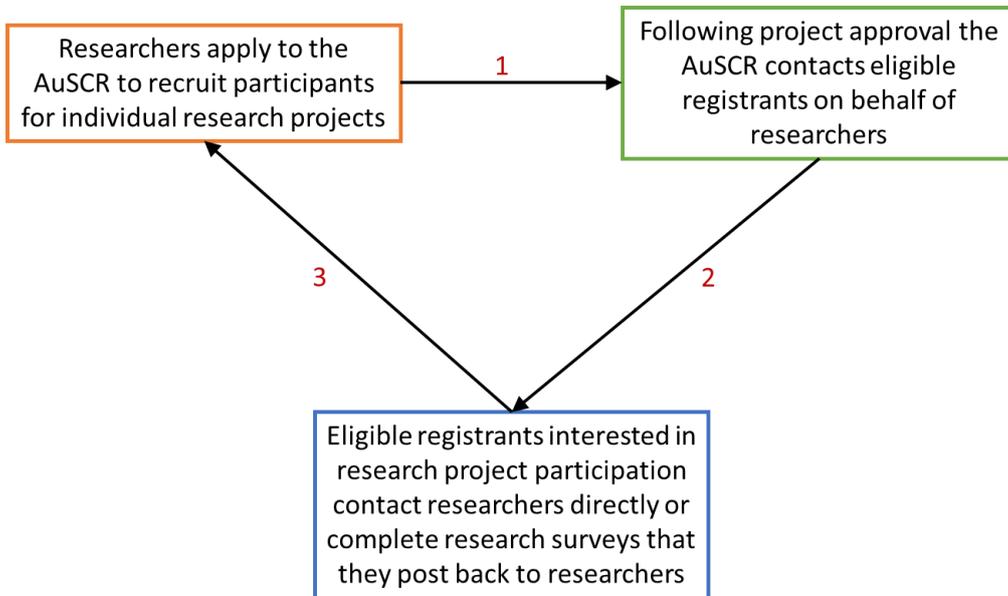
Figure 1: Process for participant recruitment to research projects via the AuSCR
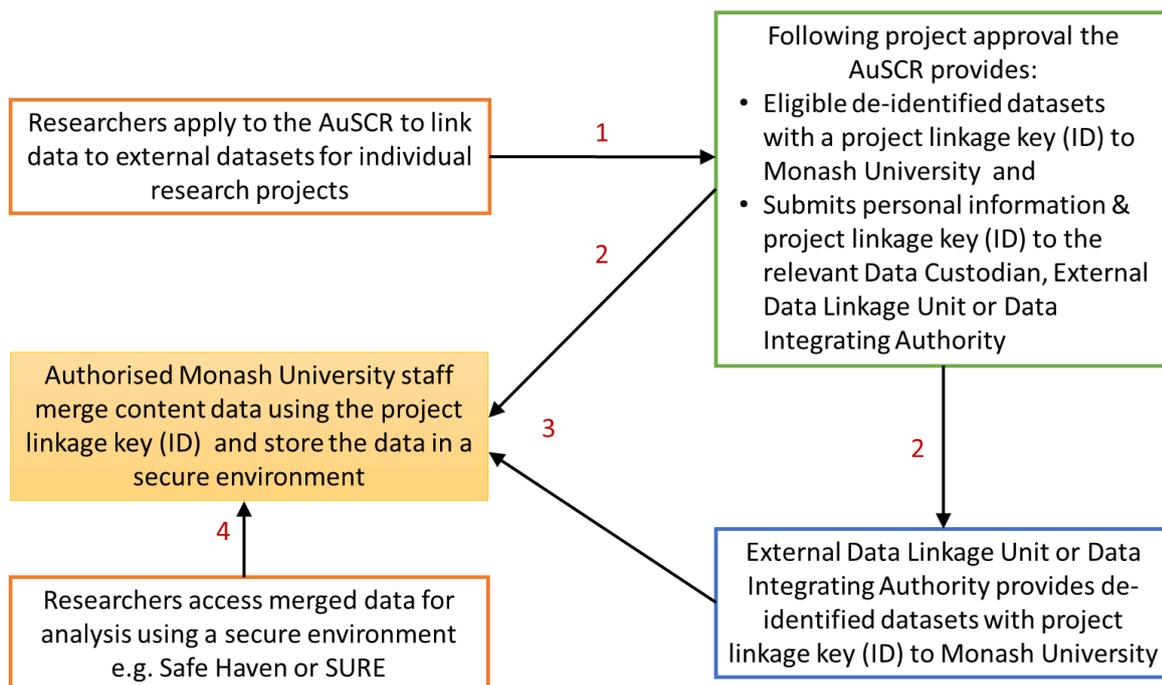

Figure 2: Process for using the AuSCR for data linkage projects

- Note: Project specific identification numbers are allocated to registrants for all data requests (i.e. AuSCR original identification numbers are not provided)