

Frequently Asked Questions

Data Access and Publication Policies for AuSCR Hospital Contributors

- 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.

Do individual hospitals own their own data?

- Hospitals that contribute to the AuSCR retain ownership of their own data and can access and download their data for internal purposes as required. It should be noted that the data entered into the tool are ‘raw data’ and are therefore subject to change and are not case-mix adjusted.
- The aggregated data are managed and used to inform policy and practice by the Coordinating Principal Investigator (Prof. Cadilhac –Data Custodian) on behalf of the: consortium partners; co-investigators who established AuSCR; hospital collaborators and; in accordance with various funding agreements.

How can I access my Hospital’s data in the Registry?

- Hospital staff with an AuSDaT login at the level of “Hospital Coordinator” can export all of their data at any time into MS Excel. *Please note that the AuSCR Office does not take any responsibility for the quality of data extracted by hospitals since this is an iterative ‘raw’ dataset and therefore may differ to data which is extracted at subsequent time points.*
- Live reports summarising data from your hospital that include benchmarked comparisons against aggregate data (peer, state and national AuSCR hospitals) can also be downloaded or printed at any time. *Please note these data are subject to change based on iterative data collection and processes to improve data quality. Therefore, the same report downloaded at different times may vary.*

Can I publish data from my own hospital that is held in the Registry?

- You may analyse and publish data from your hospital at any time, with acknowledgement of the AuSCR as per the AuSCR publication policy (www.auscr.com.au). It is also a requirement to acknowledge use of the AuSDaT if data from July 2016 onwards are used (see AuSDaT policies <http://australianstrokecoalition.com.au/ausdat/>).
- If hospitals wish to publish comparisons of local hospital data with published AuSCR data (including data published in the Annual Report) AuSCR data must be referenced and acknowledged as per the AuSCR publication policy.
- We strongly encourage local site investigators to contact one of our statisticians via the AuSCR National Coordinator to ensure robust analyses have been undertaken based on existing methods e.g. calculation of performance benchmarks to facilitate the accurate interpretation of results.

How are the aggregated data in the Registry used by the AuSCR Data Custodian and investigators?

- The Coordinating Principal Investigator (Prof. Cadilhac), on behalf of the consortium partners and co-investigators who established AuSCR, is responsible for reporting of the aggregated data to provide evidence for practice and policy improvement. This includes generation of peer reviewed publications and reports required to meet funding obligations.
- Specifically, an AuSCR annual report is produced for each calendar year. The production of the annual report occurs after all 90-180 day outcome data from the previous year have been closed off (normally July of the current year). The report is usually distributed in December of the following year. For example, the 2016 report will be disseminated in December 2017.
- State governments that fund the AuSCR program also have requirements for additional state-level reports or extracts of data to be used to inform quality improvement planning.
- Dissemination priorities (including journal articles) using the aggregated data to improve the registry operations or inform policy and practice (as acknowledged core activities) are agreed and approved by the Chairs of the Management and Steering Committees, and the Chair of the Research Task Group or specific working group, following a submission by the relevant AuSCR investigators or research fellows. Projects led by AuSCR investigators not considered ‘core activity’ must go through the same process as for external researchers.

How will Hospital Contributors be acknowledged?

- In publications where hospital data have been used, the local site Principal Investigator (PI) will be acknowledged, or may be invited to contribute to co-authorship. It is the responsibility of local hospital PIs to inform the AuSCR Office of other local personnel who should be acknowledged based on a substantive role in data collection. This can be done at any time.

How is authorship on AuSCR Investigator/Consortium publications determined? How do I become involved as a hospital investigator?

- The AuSCR investigators only work on journal publications where there is capacity or funding to cover this activity.
- The AuSCR follows the Australian Code for the Responsible Conduct of Research and the International Committee of Medical Journal Editors requirements for authorship.
- In all cases where journal policies permit, all founding members of the Management Committee will be offered authorship as they have contributed to the design, data acquisition, and analysis of AuSCR data since 2009. Founding members of the Management Committee who are unable to meet the obligations of authorship will be named in the Acknowledgement section of the manuscript as appropriate.
- AuSCR aims to be inclusive for authorship and distribute authorship equitably between site investigators from participating hospitals and other collaborators involved with the leadership and design of the registry. Due to the large number of hospitals participating nationally, it is impractical to include all hospital Principal Investigators on all publications and meet authorship requirements. Where possible, publications will include a list of investigators from hospitals participating in the Registry, as part of a study collaborators list if they have not been involved as a co-author (see Figure 1).
- To be involved in an AuSCR publication, the following criteria will be considered:
 - Your hospital must have contributed data within the time frame covered in the proposed data analysis plan;
 - You have a known interest in a topic area (e.g. have previously published in the area) or have expressed an interest in working on a particular topic.
- You may then be invited to participate in a writing committee for that paper and therefore qualify for authorship. To ensure active author contributions and to meet international authorship guidelines, hospital Principal Investigators are allocated to different papers as part of separate writing committees based on their area of expertise related to the topic and to ensure the sharing of author contributions across all hospital Principal Investigators.
- From time to time, AuSCR staff may solicit interest from site PIs to lead the authorship of a publication with support from our analytical team. In addition, we encourage contacting the AuSCR Office if you have a **topic of interest** or research question you would like to investigate, and we can offer you support in analysis and manuscript preparation (see Box 1).

The screenshot shows a PubMed search results page. At the top, the URL is NCBI Resources > How To > PubMed. The search term 'PubMed' is entered in the search bar, and 'Advanced' search options are available. The results are formatted as Abstract. A link to 'Send to' is present. The first result is a study titled 'Better outcomes for hospitalized patients with TIA when in stroke units: An observational study.' by Cadilhac DA¹, Kim J², Lannin NA², Levi CR², Dewey HM², Hill K², Faux S², Andrew NE², Kilkenny MF², Grimaly R², Thrift AG², Grabsch B², Middleton S², Anderson CS², Donnan GA²; Australian Stroke Clinical Registry Consortium. Below the title, a 'Collaborators (51)' section lists numerous authors, including Hughes J, Jude M, Ryan F, Gill M, Herkes G, Wong A, Saines N, Geraghty R, Bambery P, Staples C, Siller A, White R, Sabet A, Salud E, Dunlop M, Gange N, Easton P, Mahaffey G, Hall G, De Wytt C, Butler S, Laird P, Hines K, Douglas D, Admin M, Milosevic S, Iedema J, Read S, Hishon F, Blacker D, Bates T, Castley H, Mackay M, Bladin C, Butler E, O'Brien P, Crompton D, Ermel S, Pollack M, Simmonds F, Bernhardt J, Lalor E, McNeil J, Simcocks M, Lee A, Lindley R, Cadigan G, Hand P, Evans A, Wesseldine A, Hillier S. A 'Author information' section is also visible.

Figure 1: Illustration of shared authorship on AuSCR publications and acknowledgment of all collaborators/data contributors.

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 1 January and 31 December, 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 Institute of Health and Welfare)

- Collection and data entry of patient follow-up data is closed on 30 June 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 University epidemiologists analyse the data on behalf of the AuSCR Office and investigators, for a range of agreed purposes including reports for government funders.

Data are usually up to 24 months old once ready for analysis for 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 to archived data by other researchers

- External researchers can only apply for access to data after 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 it has been confirmed that there is no duplication of topics and research questions.
- AuSCR Office staff maintain a record of use of the data, and follow up 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.