

AANZGOSA Audit Data Request Policy

1. PURPOSE AND SCOPE

The Australia & New Zealand Gastric & Oesophageal Surgery Association (AANZGOSA) recognises the value of research and personalised assessment based on AANZGOSA Audit data and will consider requests for information and special reports.

This policy outlines the constraints involved in requesting and releasing information from the AANZGOSA Audit.

2. KEYWORDS

AANZGOSA Audit, Data Access, Authorship

3. BODY OF POLICY

3.1. Overview of AANZGOSA Audit

The AANZGOSA Audit was managed by the Morbidity Audits Department of the Royal Australasian College of Surgeons (RACS) under the direction of AANZGOSA, a specialty society for surgeons treating diseases of the stomach, oesophagus and upper gastrointestinal tract.

The AANZGOSA Audit aim was to improve the surgical care and management for all patients with oesophageal and gastric cancer, as well as patients with a gastrointestinal stromal tumour (GIST) in Australia and New Zealand through the careful collection and analysis of audit data. It also aimed to keep up to date with changes in treatment based on available evidence and ensure wide dissemination of this information to practitioners.

Data was collected from surgeons regarding the treatment of patients with oesophageal and gastric cancer and GIST in Australia and New Zealand. The database comprises a single surgeon or institution reporting treatment of these patients.

3.2. Privacy and Qualified Privilege

Information entered into the audit by surgeons/institutions may enable patient identification; however, no information will be released for research purposes that may be used to identify patients.

The audit's status as a Quality Assurance activity, protected by national legislation in both Australia and New Zealand, prohibits the disclosure of any information that could identify an individual participant beyond the agreed parameters of the activity. Data that might identify a particular surgeon or surgeons, therefore, will not be released unless written consent for the disclosure is received from each surgeon involved.

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3.3. Informal and formal requests for data

Participants have free access to their own data. Audit staff will provide assistance to surgeons seeking to extract and analyse their own data. A formal data request is not necessary if only simple analysis is required.

If a surgeon requires complex analysis of their data, however, or the data belongs to other surgeons, then a formal request should be made using the procedure outlined below.

Any external researcher who needs access to the AANZGOSA Audit data should also make a formal request.

3.4. Process for requesting data

Formal requests for access to AANZGOSA Audit data, or analysis of data by audit staff, must be made through the AANZGOSA Audit Data Request form, which is available to download from the AANZGOSA webpage (<https://aanzgosa.org/audit/>).

The form requires contact information of requester, details of specific information required, timeframe when data needed and details of how the data will subsequently be used. If identification of surgeons is required (or if the subset of data requested is small enough that a risk of identification is possible), signatures are required for each surgeon involved.

The request will be submitted to the AANZGOSA Scientific, Research and Audit Committee for consideration.

3.5. Role of AANZGOSA Scientific, Research and Audit Committee in data requests

The AANZGOSA Scientific, Research and Audit Committee will review each request for audit data provided to them by the audit staff. The request should be processed by the committee in a timely fashion (within two weeks of the request being submitted). Where additional information is required, the committee can request that this be provided.

The committee should review the request and consider any possible negative political, financial, workforce or other impact and to ensure that there are no breaches in the Qualified Privilege status in divulging the data. If concerns are raised, the request may be referred to the AANZGOSA Executive for further consideration.

Once a final decision has been made, audit staff will inform the requestor directly. The response should be in written form to facilitate the keeping of records.

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3.6. Ethics approval

The AANZGOSA Scientific, Research and Audit Committee may request evidence of ethics approval for any research activity sought to be undertaken by an external party prior to any release of data or aggregated results.

3.7. Charging for data requests

The AANZGOSA Scientific, Research and Audit Committee may decide that a request for data can be approved, but that some financial contribution must be made.

Data release fees are calculated based on the following factors and applied or not applied at the sole discretion of the Committee:

- the number of hours of work required
- complexity of analyses
- level of staff expertise required
- any external consultation required

An estimate will be provided to the requester prior to any work commencing on the request.

3.8. Use of AANZGOSA Audit data

Released data is confidential.

The data may only be used for the purpose approved by the AANZGOSA Scientific, Research and Audit Committee. That is, the purpose stated on the official Data Request Form, or a negotiated purpose approved by the committee.

Released data must not be disclosed to third parties without specific prior approval by the AANZGOSA Scientific, Research and Audit Committee.

3.9. AANZGOSA involvement in reporting of results

The AANZGOSA Scientific, Research and Audit Committee may decide that the release of data can only be approved on the condition of suitable participation of audit staff in the process of data analysis and report preparation. In this case, the staff member involved in the data analysis would be a co-author in the report/publication. This will be made clear to the requester prior to any release of data.

AANZGOSA should be provided with a copy of the resulting report/manuscript and, where the document is accepted for publication, notified of this.

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3.10. Acknowledgement

The AANZGOSA Audit must be acknowledged as the source of data in any report/publication.

Where an external researcher prepares a manuscript primarily based on AANZGOSA Audit data, the “AANZGOSA Audit” should be acknowledged as a secondary institution, regardless of whether an audit staff member was involved in specific preparation of the manuscript.

Where AANZGOSA Audit data forms part but is not a focus of the research, it should still be explicitly acknowledged as a source in the “Acknowledgements” section.

The following acknowledgement is required in either situation:

“The Authors acknowledge the data reported here has been supplied by the Royal Australasian College of Surgeons from the AANZGOSA Audit. The interpretation and reporting of these data are the responsibility of the authors and should not be seen as an official interpretation by the AANZGOSA Audit, the Australia & Aotearoa New Zealand Gastric & Oesophageal Surgery Association or the College.”

The source and treatment of the data should also be made clear in the “Methods” section of the manuscript. Preferably the abstract should include the phrase AANZGOSA Audit to allow for searching on Audit publications.

4. ASSOCIATED DOCUMENTS

AANZGOSA Data Request Form
<https://aanzgosa.org/audit/>

Approver AANZGOSA Scientific, Research and Audit Committee Chair
Authoriser AANZGOSA Scientific, Research and Audit Committee