



Victorian Lung Cancer Clinical Quality Registry

Data Access and Publication Policy

Access to information collected and collated by the Victorian Lung Cancer Clinical Quality Registry is guided by strict protocols and procedures to ensure that privacy and other ethical principles are maintained at all times. Provision of data to the Victorian Lung Cancer Clinical Quality Registry is subject to the study protocol which has been submitted to all hospitals, and Monash University Ethics Committee. In particular, specific measures have been put in place to maintain the confidentiality of personal identifying information.

This document outlines the Victorian Lung Cancer Clinical Quality Registry Data Access and Publication Policy, as agreed to by the Victorian Lung Cancer Clinical Quality Registry Steering Committee.

1. Access to the data is subject to the Specific Access Guidelines given on pages 3-5 of this document;
2. Only Victorian Lung Cancer Clinical Quality Registry staff who report directly to the Data Custodian of the Victorian Lung Cancer Clinical Quality Registry have direct access to the data base;
3. All use of the Victorian Lung Cancer Clinical Quality Registry data, in whatever context, must receive prior approval from the Victorian Lung Cancer Clinical Quality Registry Steering Committee. In some instances, specific hospital ethics committee approval is also required;
4. Any material to be published using the Victorian Lung Cancer Clinical Quality Registry data must be approved by the Victorian Lung Cancer Clinical Quality Registry Steering Committee before it is released for publication;
5. Under no circumstances will individually identifiable unit record data be made available to third parties;
6. In general, requests from contributing clinicians and academic organisations will be fulfilled without charge. Request from other bodies are considered on a case-by-case basis by the Victorian Lung Cancer Clinical Quality Registry Steering Committee, and may be subject to a processing fee;
7. All third party requests for access to Victorian Lung Cancer Clinical Quality Registry data must take appropriate timelines into account as these requests will need to be scheduled along with routine Victorian Lung Cancer Clinical Quality Registry tasks. As a general rule, requests for tabulated data will take 2-4 weeks to complete.

8. All other requests must be first made to the Database Custodian, who will then table the request at the next Steering Committee meeting. Steering Committee meetings are held bi-annually and data cannot be extracted until approval is given. Under exceptional circumstances, when data is required earlier, the Database Custodian may request out of session approval by the Steering Committee.

Lodging an application

All data requests must be formally lodged via email to: vlcr@med.monash.edu or mail to:

The Victorian Lung Cancer Registry Research Group
School of Public Health and Preventive Medicine / Monash University
Department of Epidemiology & Preventive Medicine
Level 6 The Alfred Centre
99 Commercial Road
Melbourne Vic 3004

For any queries relating to VLCR Research, please contact the VLCR Data custodian:

Dr Sue Evans

Database Custodian
The Victorian Lung Cancer Registry
Department of Epidemiology & Preventive Medicine
Monash University
Email: sue.evans@monash.edu
Ph: +61 3 9903 0017
Fax: +61 3 9903 0556
Website: <http://vlcr.registry.org.au/>

Victorian Lung Cancer Clinical Quality Registry SPECIFIC ACCESS GUIDELINES

Data access process

1. All requests for data must be in writing to the Victorian Lung Cancer Clinical Quality Registry Database Custodian using the Release of Data Application Form.
2. The Registry Database Custodian will take the data request to the next Steering Committee meeting. A decision on whether to grant access to the data will be considered following advice from the Steering Committee.
3. *Contributing hospitals* may have access to their own case-level data. The release of these data must be authorised by a nominated senior consultant within each hospital. This nominated person would normally be the Head of the department from which data is being requested.
4. If a *researcher* requires data from a particular hospital or hospitals, a specific ethics application approval from that hospital(s) will be required before data is able to be made available. This ethics approval should be made jointly with the Victorian Lung Cancer Clinical Quality Registry. A caveat and conditions of use statement will be provided with the data.
5. Where tabulated summary data is requested, this information can be provided by Victorian Lung Cancer Clinical Quality Registry staff. Such provision of data would not require Steering Committee advice but Registry staff will require a formal request in writing and will keep a record of such requests. The Steering Committee will be given a summary record of such requests on a biannual basis. A caveat and conditions of use statement will be provided with the data.

Privacy restrictions

6. The Commonwealth Privacy Act impacts on release of some forms of data. In particular, individually identifiable data will not be released.
7. If a third party research or student project requires individual data for linkage, this will not be provided directly. However, it may be possible for the third party to provide their data to the Victorian Lung Cancer Clinical Quality Registry for linkage purposes and for the Victorian Lung Cancer Clinical Quality Registry to provide aggregate data summaries based on the linked data. All such projects will require separate ethics committee approval from each hospital involved.
8. Data is released for the specific purpose set out in the Release of Data Application Form; use for any other purpose is not permitted without prior approval by the Victorian Lung Cancer Clinical Quality Registry Steering Committee.

Publication

9. If data from the Victorian Lung Cancer Clinical Quality Registry is the primary source for a report or publication, a copy of this must be submitted to the Victorian Lung Cancer Clinical Quality Registry prior to its publication. It is a condition of use of Victorian Lung Cancer Clinical Quality Registry data that the source of the data is acknowledged, along with a statement that the analysis and interpretation are those of the author, not the Victorian Lung Cancer Clinical Quality Registry (see Attribution of publications section below).

Attribution of publications

10. Where a member of a participating hospital has analysed data provided by the Victorian Lung Cancer Clinical Quality Registry and subsequently prepared a manuscript, then "Victorian Lung Cancer Clinical Quality Registry " should be acknowledged as a secondary institution in addition to the author's Hospital or University. This applies whether the primary data analysis is performed by the author or by Victorian Lung Cancer Clinical Quality Registry staff. Where the author is a Victorian Lung Cancer Clinical Quality Registry staff member then the primary attribution should be "Victorian Lung Cancer Clinical Quality Registry".
11. Where Victorian Lung Cancer Clinical Quality Registry data is only a minor portion of the work, then it may be more appropriate to acknowledge the source explicitly in the "Acknowledgements" section.

In both cases the disclaimer below should be included.

The data has been supplied by the Victorian Lung Cancer Clinical Quality Registry. The interpretation and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Victorian Lung Cancer Clinical Quality Registry.

12. In all cases the source and treatment of the data should be made clear in the "Methods" section. Preferably the abstract (and keywords if applicable) should also include "Victorian Lung Cancer Clinical Quality Registry" which would allow for searching Registry publications.

Fees for the provision of data

13. The VLCCR Research Team encourages Research collaboration with Investigators. All Research Collaboration will **not** incur a fee.

Non-collaborative Research will incur a fee for the provision of data as outlined below:

- Access to data and requests for data from the VLCCR are subject to strict access guidelines outlined above.

- All data summaries and analyses may incur a fee to cover the costs for staff to undertake this work.
- The charge per hour of work (or part thereof) is \$150 (ex GST). The minimum no. of hours charged is 2. Thus, a data analysis/report requiring 2.5 hours of staff time will be charged \$450 (ex GST).
- The fee of \$150 (ex GST) per hour (or part thereof) is for basic tabulations and data extractions only. When more detailed analysis of data is required (e.g. statistical comparisons, statistical modelling, etc.), this will be charged at a higher rate (available upon application).
- Upon receipt of a data analysis request, the VLCR Research team will provide a cost estimate for the work. This will normally be within 2 weeks of receipt of the request. Those requesting data must agree to these costs (in writing) before any data request will be met.

This Policy has been ratified by the Victorian Lung Cancer Clinical Quality Registry Steering Committee on __/__/____.



Signed

Rob Stirling

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