



INFORMATION FOR INDIVIDUALS OR ORGANISATIONS REQUESTING DATA FROM THE VCSR

This document is intended to provide information about the process of requesting data from the VCSR. It specifies the conditions for the release and use of VCSR data. Please read it when completing the Data Request Form.

What is the VCSR?

The Victorian Cervical Screening Registry (VCSR) was established in 1989 by an amendment to the Cancer (Central Registers) Act. The Registry provides a framework for a structured approach to cervical screening within Victoria and it assists with data collection for monitoring and evaluation of the Program.

The Registry is a confidential, opt-off computerised database of Victorian women's cervical screening results. The main functions of the Registry are to facilitate the regular participation of women in the National Cervical Screening Program by sending reminder letters when screening tests are overdue, and to provide a safety net for the follow-up of women with abnormal tests.

The Registry provides laboratories with quantitative data to assist with their quality assurance programs and screening histories to help with the accurate reporting of current tests.

VCSR functions

The Improving Cancer Outcomes Act (2014) came into effect from October 2015 and underpins the operations and reporting of cervical screening to the Registry.

The core functions of the VCSR are to:

- i. follow up positive results from cancer tests
- ii. send reminder notices to women who are due for cancer tests
- iii. subject to and in accordance with the regulations, provide access to the Register to persons studying cancer
- iv. compile and publish statistics
- v. provide data and screening histories to laboratories reporting cervical screening
- vi. provide aggregate data to the Australian Institute of Health and Welfare (AIHW) so that the National Cervical Screening Program can be judged against an agreed set of performance indicators.

Further information about the VCSR is available on the website: www.vcsr.org.au



Information stored by the VCSR

Information of all Victorian Cervical Screening Tests (excluding those women who chose to opt-off) is recorded by the VCSR. The data comes from laboratories reporting cervical screening in Victoria. The Victorian Cytology Service (VCS) reports approximately half of all Victorian Cervical Screening Tests.

Registry information is held in a database which dates back to 1989 and includes the following information:

- Name
- Date of birth
- Address
- Cervical Screening Test dates
- Results of Cervical Screening Tests (including HPV DNA tests and Cytology Result Codes according to the 2006 Cytology Coding Schedule)
- Practitioner and clinic details
- Details of reporting laboratory
- Relevant histology information

Information pertaining to a calendar year is usually not available before March of the next calendar year at the earliest. Some time is needed after the end of the year for entry of all results.

Information published by the VCSR

Annual data on Victorian cervical screening can be found in the annual *VCSR Statistical Report* (released usually in November of each year). The report provides a comprehensive summary of information recorded by the VCSR. Reports can be downloaded from the VCSR website (<http://www.vcsr.org.au/data-research/statistical-reports/annual-statistical-reports>) or posted out upon request.

A summary of quarterly statistics is also available on the VCSR website: <http://www.vcsr.org.au/data-research/statistical-reports/cervical-screening-in-victoria-statistics>.

Each year the *Evaluation of Cervical Screening Tests collected by Nurses* report is released. This report contains summary information on the number of tests collected by nurses for the previous year, remoteness of location of women screened, age distribution of women screened, endocervical status of tests collected by nurses, time since previous screening etc. This report is available from the VCSR website (<http://www.vcsr.org.au/data-research/statistical-reports/annual-nurse-reports>) or can be posted out upon request.

Who can access VCSR data?

Under the Improving Cancer Outcomes Act (2014) and Health Records Act (2001), the VCSR is able to provide data for the purpose of research or the compilation or analysis of statistics in the public interest. Practices, doctors, clinics and researchers are all examples of parties who might be interested in accessing data held by the VCSR.

Information that can be provided by the Registry on request

A request for data can be submitted to the VCSR after first discussing your requirements with the VCSR Data Team. Data provided by the VCSR can only be used for the explicit purpose for which it was requested and cannot be published in a format that could potentially identify a woman.

Data requests fall into two types:

- A. Summary or aggregate data
- B. Line/itemised data

A. Summary or aggregate data request

Upon request, aggregate or group summary data can be provided. No individual data are provided as the data are summarised. If the request for aggregate numbers is at a level small enough that an individual could possibly be identified (such as with age groups within a remote location) then a summary of the data may be provided, or censoring of some cells may occur.

Please discuss your request with the VCSR Data Team and then complete sections A and C of the Data Request Form.

In instances where ethical issues are a consideration the VCSR may require approval from a HREC (refer to next page).

Examples of aggregate data requests may include:

- number of women screened and age breakdown for all of Victoria by calendar year and quarter.
- the number of women estimated to be eligible for cervical screening. These figures use population data from the Australian Bureau of Statistics. Population estimates are adjusted to exclude a proportion of women which have had a hysterectomy and therefore not eligible for the National Cervical Screening Program.
- the estimated participation rate of women by age group for specific areas.
- time since last Cervical Screening Test by age groups for all of Victoria by calendar year and quarter.



B. Line/itemised data request

Individual de-identified line data may be provided by the VCSR subject to the researchers providing documentation of ethical approval for release from a properly constituted Human Research Ethics Committee (HREC), and following review and approval by the VCSR. Under the Improving Cancer Outcomes Act (2014), the VCSR is prohibited from providing information identifying an individual woman without consent and thus cannot provide identifiable individual level line data.

In the instance that individual line data is being requested the VCSR will require a copy of the research proposal, any ethics submission/s and written approval from a HREC.

Where third parties hold individual consent from the consumer to release information held on the VCSR to them, individually identifiable data can be lawfully released from the VCSR.



Human Research Ethics Committee (HREC) approval

As stated above HREC approval is required for all line data requests. The VCSR reserves the right to request that HREC approval is obtained, including requests for aggregated data. Whilst a HREC will determine the ethical acceptability of such proposals, the authority to release data lies with the VCSR.

If HREC approval from the researcher's own institution is not possible then an approval can be sought through the Victorian Department of Health and Human Services (DHHS) HREC. Information regarding this process can be found on the DHHS website (<http://www.health.vic.gov.au/ethics/>).

The VCSR reserves the right to request ethical clearance through the DHHS HREC even if ethical approval has been granted from another institution.

Limitations to data that can be provided by the VCSR

Data on participation rates in the Cervical Screening Program can be provided but when interpreting such data it is important that researchers are aware that measurement error may affect both the denominator and the numerator. This may come from imperfect record-linkage between multiple tests from the same woman (resulting in an overestimate of the number of women screened) and from inaccuracies in the VCSR database in recording whether the test was taken from a woman with or without a cervix. Also, applying the estimated hysterectomy rates to the denominator (particularly for small area information) can result in measurement error.

Other additional (but probably lesser) sources of measurement error derive from:

- the proportion of Victorian Cervical Screening Tests reported by laboratories outside of Victoria who do not report to the VCSR (this will mainly affect areas located on the Victoria/New South Wales and Victoria/South Australia borders); and
- the differences between the postal areas assigned by the Australian Bureau of Statistics to the Estimated Resident Population data and the postcode nominated by the woman.

For these reasons data provided by the VCSR is intended to be used as a guide only and should be interpreted with caution.

Process to request data from the VCSR

The steps to request data are summarised below.

1. To determine the precise data needs, the request should first be discussed with the VCSR Data Team:

Ph: (03) 9250 0399

Email: data@vcs.org.au

Initial discussions with the Data Team will assist in clarifying what is required and the feasibility of the request.

2. It is helpful to be specific with your request by documenting which variables are required, the time frame, the location and the population. Providing a mock-up table of how you would like the data presented is very useful.
3. The researcher must then submit a Data Request Form. Ensure that any necessary attachments are also provided. Applications can be submitted by fax (03) 9349 1818 or by email to the Data Team: data@vcs.org.au
4. The application will be reviewed internally by the VCSR Data Committee and researchers may then be informed whether HREC approval or additional scientific peer review is required. If HREC approval is required and then provided, the VCSR will again review the request for release of data. Researchers will then be given a timeline for the release of the data.

Review of data requests by the VCSR

Data requests are reviewed by the VCSR Data Committee. The membership of this committee includes the Medical Director, the Director Registry Operations, the Data Team and the VCS Executive Director. All applications are reviewed for compliance with VCS and VCSR policies as well as determining if ethics approval or scientific peer-review is required. The committee will review applications in a timely manner.

Even with the approval from a HREC the VCSR can still decline to disclose information to other parties (as per Statutory Guidelines on Research issued by the Health Service Commissioner, Guideline 1.6).

Data format

Data files containing de-identified information will typically be in Microsoft Excel format and password protected as required, unless otherwise discussed.

Conditions for the release and use of data

All individuals who sign the Data Request Form must agree to and comply with the following requirements.

1. Third parties who are provided with any data from the VCSR are required to comply with all relevant legislation and guidelines including but not limited to:
 - ◆ The Australian Privacy Principles (APP) (Privacy Act 1988 Cth) and Health Privacy Principles (HPP) (Health Records Act 2001 Vic). In particular:
 - ⇒ the collection and use of information is only for research or the compilation or analysis of statistics in the public interest or relevant to public health (HPP1.1e, HPP2g)
 - ⇒ information does not identify any individual or allow for any individual's identity to be reasonably ascertained (HPP2.2g)
 - ⇒ health information is not to be disclosed to another party or published in a form where an individual can be identified (HPP 2.2g)
 - ⇒ reasonable steps must be taken to protect the health information from misuse and loss, and to protect information from unauthorised access, modification or disclosure (HPP4.1 and APP 11.1)
 - ⇒ reasonable steps must be taken to destroy or permanently de-identify health information if it is no longer needed (HPP4.5 and APP 11.2)
 - ⇒ information can be transferred outside of Victoria if the recipient is subject to law similar to the HPPs (HPP 9.1). Information transferred out of Australia must abide by APP 8.
 - ◆ Statutory Guidelines on Research (Victorian Health Service Commissioner) and NHMRC Guidelines Under Section 95/95A of Privacy Act 1988 (Cth) including written proposals to a HREC to use health information.
 - ◆ A list of useful references related to legislation and guidelines is located at the end of this brochure.

2. Third parties are only to use data from the VCSR for the purpose specified on the Data Request Form. Any additional analyses or change to the research study will require approval by the VCSR and may require new Ethics approval.
3. Third parties must not recalculate or publish VCSR data without first informing the VCSR.
4. Third parties must provide a copy of all reports, manuscripts, abstracts and presentations to the VCSR.
5. The VCSR must be acknowledged in all publications and reports where VCSR data has been used.
6. Third parties must comply with any additional requirements specified by the VCSR as a condition of approving data release.
7. Third parties must ensure that any data, whether identifiable or de-identifiable, are stored securely and only those named on the application have access to it. Researchers must follow strict confidentiality provisions as specified in the Ethics approval.
8. Data from the VCSR is not to be published in a format that could potentially identify an individual (for example cells with fewer than five women).
9. Data released by the VCSR must not be linked to another data set without appropriate approval.
10. In the event that the personnel who hold the data changes then VCSR requires notification of this change in writing along with the contact details of the new person who will be in possession of the data. The original requirements relating to the use of the data still remain with any change in staff. In the event there is no-one to assume responsibility for holding the data, the VCSR is to be notified in writing and the data is to be returned.
11. Data provided by VCSR must be destroyed within five years of the date of receipt as specified unless an extension is negotiated by agreement. The VCSR must be informed when the data has been destroyed.
12. Third parties must agree to provide an annual update, or more frequently if requested, to the VCSR regarding the status of the research and use of the data, and to certify ongoing safe storage of the data. The purpose of this contact will be to:
 - ◆ assess that there have been no deviation from the study protocol and approved use of the VCSR data
 - ◆ confirm the ongoing secure storage of the data set
 - ◆ clarify the status of the research or any other specified use of the data (ongoing, completed, abandoned)
 - ◆ remind researchers of the conditions of use
 - ◆ confirm the details of the person who is primarily responsible for the data
 - ◆ confirm receipt by the VCSR of any publications, reports and presentations arising from the data.
13. Where applicable, third parties must agree to pay an administrative fee based on resources and time required to complete the request.

Useful References

The Health Records Act 2001 (Victoria)

<http://www.legislation.vic.gov.au/>

Improving Cancer Outcomes Act 2014 (Victoria)

<http://www.legislation.vic.gov.au/>

The Cancer (Central Registers) Act 1989 (Commonwealth)

The Health Service Commissioner, Statutory Guidelines On Research, 2002

https://hcc.vic.gov.au/sites/default/files/guidelines_research.pdf

NHMRC Guidelines Approved Under Section 95A of the Privacy Act 1988

<https://www.nhmrc.gov.au/guidelines-publications/pr2>

NHMRC Guidelines Approved Under Section 95 of the Privacy Act 1988

<https://www.nhmrc.gov.au/guidelines-publications/pr1>

National Statement On Ethical Conduct In Human Research (NHMRC, 2007)

<https://www.nhmrc.gov.au/guidelines-publications/e72>



Victorian Cervical
Screening Registry

