# Victorian Cancer Screening Data Monitoring Framework

Data Request Guide

# Document Control

| Owner | Director Population Health, ACPCC |
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**Version History**

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|---|---|---|---|
| 1.0 | - | - | - |

# Data Request Guide

## 1.0 PURPOSE

This document is a guide to support individuals, researchers, and organisations to request Victorian Cancer Screening related data held in the Australian Centre for Prevention of Cervical Cancer's (ACPCC) Data and Reporting Solution (DRS).

## 2.0 OVERVIEW

The DRS is a key deliverable of Victorian Cancer Screening Framework (VCSF) Data, Research and Evaluation Strategy and can import, manage, and output data, and generate reports relating to cancer screening in Victoria. DRS data and reports aim to inform program planning, monitoring and evaluation of programs and activities, decision making, research, policy, and practice. The Victorian Department of Health (DH) has delegated ACPCC to administrate the Data and Reporting Solution.

The DRS holds three main data sources, including Bowel and Cervical Cancer Screening Raw Data extracts from the National Cancer Screening Register (NCSR) and Breast Screening data from BreastScreen Victoria (BSV). The data captures several parameters that help to understand screening in Victoria including invitations, follow up, and participation rates with key demographic variables.

## 3.0 SCOPE

This guide applies to all individuals, researchers and organisations who wish to submit a data request for Victorian Cancer Screening related data held in the ACPCC. Data requests covered in this process include research, policy, service planning, and various ad hoc requests other than regular VCSF monitoring reporting.

Any media related data requests should be directed to the Director, Government Relations, and Communications at ACPCC (contact details can be found at Contact Us - ACPCC).

If the data request is about you or of a personal nature, please request directly to the Department of Health, email: foi@health.vic.gov.au, under the Freedom of Information Act 1982.

## 4.0 PROCESS

**Step 1.** The requester will complete the Preliminary Data request form which is hosted online on the ACPCC website Population-health/data-requests

**Step 2**. Once the Preliminary Data request form is submitted, a member of the ACPCC Data and reporting team will contact the requester to arrange a preliminary discussion about the data request within 5 business days of the request being submitted. The discussion will obtain further information to initially assess the feasibility of the data request and availability of the data.

**Step 3**. Following the discussion, if the data request is deemed feasible (i.e., the data is available) and the requester wishes to continue with the data request, the requester will be asked to complete a more Detailed Data Request Form (DDRF). The completed Detailed Data Request Form should be emailed to dataandreporting@acpcc.org.au

PLEASE NOTE:

- All research requests, where relevant, will be required to provide a copy of the research proposal and ethics approval letters by a National Health and Medical Research Council registered Human Research Ethics Committee prior to data release.
- Definitions for identifiable data, non-identifiable data, and aggregated data are below:

| Data type | Definition |
|---|---|
| Identifiable data | Data from which the identity of a specific individual can reasonably be ascertained (NHMRC's National Statement on Ethical Conduct in Human Research (2007, updated May 2015).<br><br>Identifiable information is personal information. |
| Non-identifiable data | Data which have never been labelled with individual identifiers or from which identifiers have been permanently removed, and by means of which no specific individual can be identified |
| Aggregated data | Aggregate data are groupings of records, including counts, averages, percentiles, etc. |

**Step 4**. Once the Detailed Data Request Form is submitted the requester will receive an email of acknowledgement with associated timeframes and next steps.

**Step 5**. The ACPCC Data and Reporting Team will review the DDRF to ensure all relevant/ essential information is provided. A member of the ACPCC Data and Reporting Team may contact the requester to discuss any further clarification or obtain any additional information about the data request.

**Step 6**. Once the DDRF has been reviewed, the request may require assessment by the Data Review Group (DRG). The DRG consists of representatives from partner organisations of the VCSF and the Department of Health.

**Step 7.** Once a decision has been reached this will be communicated to the requester via email, with any additional approval requirements and an indicative timeline for the data release. Where a data request is declined, the ACPCC Data and Reporting Team will contact the requester to provide feedback and instructions for resubmission if applicable.

**Step 8**. The ACPCC Data and Reporting Team will then extract, prepare, and conduct quality reviews for the data request once the DRG has provided a decision to proceed.

**Step 9.** Final approval will be sought for the data to be released once the quality review is completed.

**Step 10**. Prior to receiving the data, all data requesters will need to comply with, and sign and return, the Conditions of Release Deed which aligns with the Department of Health Data Access and Release Policy and supporting procedure.

**Step 11**. The requester will be provided with the data via agreed secured data transfer methods.

**Step 12**. If the outputs of data request are planned to be made publicly available, such as in a conference presentation or publication purpose, the requester must provide ACPCC with a copy for technical review and approval.

# DATA REQUEST PROCESS FLOW CHART

Australian Centre
for the Prevention of
Cervical Cancer

Preliminary Data request form (PDRF) completed and submitted via online form hosted on the ACPCC website

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Preliminary discussion between ACPCC & the requester

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Requester submits DDRF and supportive documents if required.

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ACPCC to email to confirm the receipt of the DDRF and provide associated timeframes and next steps

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Data request to be assessed

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Submission of any additional supportive documents requested if required

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Communicate data request decision and any further steps with the requester

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Extraction, preparation, and quality review by ACPCC Data and Reporting Team

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Final approval for release by ACPCC Director Population Health

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Confirm Conditions of Release Deed signed and completed

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Release data securely

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The requester provides ACPCC and DH with a copy of research/ manuscript documents for technical review prior to the publication