

Release of data on notifiable conditions in Victoria

Release policy

Guidelines for applicants

1. Introduction

The Health Protection Branch (HPB) of the Department of Health is responsible for the monitoring, prevention and control of prescribed conditions affecting the Victorian community. HPB manages incidents of notifiable conditions received by the department as prescribed under Public Health and Wellbeing legislation. The 65 conditions that are notifiable in Victoria are listed on our website at: ideas.health.vic.gov.au/notifying/what-to-notify.asp

A range of surveillance data relating to these notifiable conditions is freely available to the general public from the Infectious Disease Epidemiology and Surveillance (IDEAS) website: ideas.health.vic.gov.au/surveillance.asp

This website contains data that are updated daily and aggregated by condition for the following areas: State; Victorian Government Regions; Local Government Areas; Division of General Practice. State-wide data are also available for each notifiable condition by Indigenous status, notified cases of salmonellosis, by serovar and phage type, notified cases of pertussis, and notified cases of influenza. Various other descriptive reports are available on the IDEAS website, including: Monthly HIV/AIDS Summary Reports; half-yearly Sentinel Surveillance Reports on selected blood borne viruses and sexually transmissible infections; the Victorian Infectious Diseases Bulletin (VIDB) containing quarterly surveillance data, and Annual Reports.

Not all needs for data are met by these routinely published data. External enquiries for additional data are regularly made by the general public, academia, business, hospitals, other government departments and the media.

2. Purpose and scope

This policy sets out the framework by which the department must comply regarding the release and disclosure (either internally or externally) of all notifiable condition data collected. It identifies circumstances under which data held by the department can be released to third parties.

3. Legislation and other guidelines

This policy is intended to be used in accordance with the:

- *Health Records Act 2001* (which articulates the Health Privacy Principles)
- *Information Privacy Act 2000*
- *Public Health and Wellbeing Act 2008*
- Public Health and Wellbeing Regulations 2009
- Office of the Health Services Commissioner Statutory Guidelines on Research 2002 (the Guidelines)
- National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research 2007 (the National Statement) (particularly Chapter 3.2: Databanks)

4. Responsibilities of applicants

- 4.1. Requests for data should be submitted to the Manager, Communicable Disease Epidemiology and Surveillance using the 'Data Request Form'. The Data Request Form can be accessed from the department's website at ideas.health.vic.gov.au/publications.asp or by calling 1300 651 160.
- 4.2. The data that are provided to the applicant must be used for the intended purpose as stated in the completed 'Data Request Form'. If the applicant wishes to use the data for other purposes, the applicant must apply for this by completing another 'Data Request Form' as this will be treated as a new request.
- 4.3. If at any point the applicant intends to publish the data, and the review or approval of the department has been a condition of the data release, it is the responsibility of the applicant to provide a copy of the publication materials to the department for review/approval prior to publication.
- 4.4. It is the responsibility of the applicant to ensure that they protect the security and integrity of data released into their care. Data supplied to the applicant:
 - 4.4.1. Must be stored securely
 - 4.4.2. Must be destroyed when no longer required by the applicant
 - 4.4.3. Must not be accessed or used by a third party
 - 4.4.4. Data supplied to the applicant must meet the requirements for data storage as set out in the National Statement (see 5.2 below).

5. General principles governing data release

- 5.1. Data release will be in accordance with legal requirements, including:
 - 5.1.1. The Health Privacy Principles, particularly Health Privacy Principle 2, which governs the disclosure of health information; and
 - 5.1.2. The Office of the Health Services Commissioner Guidelines, which govern the disclosure of health information for the purposes of research under Health Privacy Principle 2.2(g), which prescribes that:

"An organisation must not use or disclose health information about an individual for a purpose (the "secondary purpose") other than the primary purpose for which the information was collected unless...the use or disclosure is necessary for research, or the compilation or analysis of statistics [is] in the public interest."
- 5.2. Data release will be in accordance with the National Statement, particularly sections 3.2.5 and 5.1.2, which prescribe that:

"It is the duty of the custodian to ensure that the data are used responsibly and respectfully, and that the privacy of participants is safeguarded; and

"Each institution needs to be satisfied that: (a) its human research meets relevant scholarly or scientific standards; (b) those conducting its human research: (i) are either adequately experienced and qualified, or supervised; (ii) understand the need to assess risks to their own safety and that of participants; and (iii) are free to withdraw from research on conscientious grounds."
- 5.3. Only those data items essential to the applicant's stated purpose will be released.
- 5.4. The purpose for requesting the data must be stated by the applicant and will be considered in determining whether the data may be released. Suitable purposes for obtaining data may include for use in public presentations, intended publications, research, media articles, policy development and other general public enquiries related to public health care planning, program evaluation, health surveillance and/or quality assurance analysis.¹

¹ From Manitoba Health Information Data Request Form

- 5.5. The risk of identification of individuals will be minimised by ensuring that data are not released with a combination of demographic data items that distinguishes groups with an estimated resident population of less than 1,000.² Further, the risk of disclosing information which could be re-identified or linked through 'data mining' and other techniques will be minimised by not releasing unique identification numbers and limiting the disclosure of dates.
- 5.6. Combinations of data that may enable the potential identification of individuals will not be released unless the release is properly authorised through a Human Research Ethics Committee (HREC), if necessary.
- 5.7. The department may reject a request for data if it considers that the requirements in the Guidelines or the National Statement are not met.

6. Conditions of data provision

- 6.1. All data released requires the approval of the Manager, Communicable Disease Epidemiology and Surveillance Section and the Chief Health Officer.
- 6.2. Non-identifiable data — examples of non-identifiable data that can be released include:
 - 6.2.1. Total number of cases
 - 6.2.2. Age (which may be in five-year age groups)
 - 6.2.3. Sex
 - 6.2.4. Region or Local Government Area of residence
 - 6.2.5. Date of notification.
- 6.3. Potentially identifiable data—The following variables (either alone or used in conjunction with other variables) may pose a risk of identifying an individual:
 - 6.3.1. Place of residence and/or postcode
 - 6.3.2. Country of birth
 - 6.3.3. Age (in years)
 - 6.3.4. Date of birth
 - 6.3.5. Indigenous status.
- 6.4. The department reserves the right to decline the release of data where a risk of identification of individuals may occur, and the purpose for the data request has not been approved by a National Health and Medical Research Council (NHMRC) accredited HREC.

7. Provision of data relating to public health investigations

- 7.1. Datasets relating to a public health investigation may be released to the Local Governments provided that the disclosure of the data would assist to perform their duties or functions or exercise their powers under the *Public Health and Wellbeing Act 2008* and its associated regulations.
- 7.2. Datasets relating to a public health investigation may be disclosed to the department's surveillance partners: Victorian Infectious Disease Reference Laboratory, Microbiological Diagnostic Unit and Burnet Institute provided that the disclosure of the data would assist to perform their duties or functions.

8. Regular provision of data

- 8.1. Subject to all other conditions and after seeking the necessary approvals, some datasets for agreed specified purposes can be periodically provided to regular data requestors and stakeholders. These data requests will be approved for a specified period of time (e.g. 2 years, 5 years). A new data request should be submitted once the approved period elapsed.

² Known as the '1,000 denominator population rule' it is an example of the 'data reduction' principle described in Appendix 4 of the National Statistical Service Handbook. The population group are defined using any demographic information that is relevant (in the sense that the combinations of the demographic data items may enable individuals in the community to be identified) and for which resident population estimates are available from the Australian Bureau of Statistics (ABS). Hence the populations may be defined on the basis of geography (e.g. postcode or region of residence), age, sex, country of birth, Indigenous status or marital status.

9. Ethics clearance

- 9.1. For a request that seeks potentially identifiable data of a sensitive nature for research purposes, the applicant may be required to have had their research proposals cleared by an approved HREC that reports annually to the NHMRC. A copy of HREC approval must be provided to the department unless an exception is stated by the department.
- 9.2. Approval of an application by HREC does not constitute authority to the release of data; it is a prerequisite for an authorisation to occur. The release of any potentially identifiable data for research purposes requires a HREC approval in conjunction with approval from the department.

10. Accuracy and limitations of data

- 10.1. The data completeness for specific diseases may be variable and should be interpreted with caution. Data requestors are encouraged to discuss their data request, and the limitations in interpretation of the data with a suitably qualified person within the department.
- 10.2. The data reported are only of conditions that have been notified to the department and therefore do not represent a true incidence of the condition.
- 10.3. Changes in surveillance scope and practice, diagnostic techniques and reporting may contribute to different case ascertainment over time.

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health

Data request form

Date of request

Name of requesting person*

*I have read and understood the preceding 'Guidelines for applicants'

- No
 Yes

Agency/institution name

Address

Telephone

Email

DH/DHS employee?

- No
 Yes

Data are released for the purposes stated in this application only

Reason for request

Data requested

Format in which data is required

Is identifying information required?

- No
 - Yes—if Yes, specify why, whether consent has been obtained and whether the relevant privacy guidelines have been consulted:
-

If for research purposes, has this been approved by the DH Ethics Committee?

- Not applicable
 - No
 - Yes—If Yes, attach a copy of the letter and state approval date: ___/___/___
-

If no to above, will the project be submitted to the DH ethics committee?

- Not applicable
 - No
 - Yes
-

To whom and how will this information be disclosed/disseminated?

Date data required

___/___/___

DH Office Use Only

- Ad hoc
 - Ongoing—maximum of five years—expires on: ___/___/___
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- Not approved
 - Approved without conditions
 - Approved subject to right of comment on use of data and interpretation prior to publication
 - Approved subject to right of approval or veto of data and interpretation prior to publication
 - Approved subject to:
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Actioning officer

Release approved by

Manager, Communicable Disease Epidemiology and Surveillance:

Chief Health Officer:
