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| The Centre for Victorian Data Linkage |
| Data linkage assessment and approval process |
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Contents

[Data linkage requirements 1](#_Toc69807707)

[Applying for data linkage 2](#_Toc69807708)

[Assessing the data linkage’s technical feasibility 2](#_Toc69807709)

[Ethical Approval 3](#_Toc69807710)

[Data Custodian approval 3](#_Toc69807711)

[Privacy Impact Assessment 4](#_Toc69807712)

[Deed of Acknowledgment and Confidentiality 4](#_Toc69807713)

[Approval to collect non-DH data (if required) 4](#_Toc69807714)

[Data Linkage team 4](#_Toc69807715)

[Data Integration team 4](#_Toc69807716)

[Use of personal and health information 5](#_Toc69807717)

[Accessing linked data 5](#_Toc69807718)

[Timeframes 5](#_Toc69807719)

[Prior to any analysis publication 5](#_Toc69807720)

## Data linkage requirements

The Centre for Victorian Data Linkage (CVDL) provides data linkage facilities and services to researchers and policy-makers while adhering to the relevant legislative Acts, and information privacy principles related to the health of Victorians administered by the Department of Health (DH).

Requests for access to the linked data for research, and statistical purposes must be consistent with Information Privacy Principle 2.1(c) and Health Privacy Principle 2.2(g) and the statutory guidelines on research issued by the Victorian Health Complaints Commissioner. <https://hcc.vic.gov.au/about/legislation>

Links to the data linkage privacy Acts below, for more information:

* The Privacy and Data Protection Act 2014 (PDP Act) - outlined in Schedule 1 are the 10 Information Privacy Principles (IPPs)

<https://ovic.vic.gov.au/privacy/for-agencies/information-privacy-principles/>

* The Victorian Health Records Act 2001 (the Act) created a framework to protect the privacy of individuals’ health information by establishing the Health Privacy Principles (HPPs)

<https://www2.health.vic.gov.au/about/legislation/health-recordsact>

or <https://hcc.vic.gov.au/providers/health-records>

* The Health Services Act 1988 and Public Health and Wellbeing Act 2008 are designed to protect the health of Victoria’s population

<https://www2.health.vic.gov.au/about/legislation/public-health-and-wellbeing-act>

## Applying for data linkage

The Data Requestor completes and submits the CVDL’s data linkage application available at: <https://www2.health.vic.gov.au/cvdl/applicationform>

## Assessing the data linkage’s technical feasibility

Once the CVDL receives your data linkage application, it undergoes a technical feasibility assessment, which involves checking:

(i) the application against the Information Privacy and Health Privacy principles from respective Acts ensuring the individual’s privacy is maximise, and assessing the potential risk of re‑identification

(ii) the availability of requested data items, operational considerations, data access requirements, and alignment with the department’s objectives.

**Following this assessment:**

* a member of the Client services team will be in contact with the Data Requestor to arrange access to a secure folder within the CVDL’s SharePoint site.
* Once the Requestor’s credential has been authenticated, the Requestor is required to upload the research project’s supporting documents (a list of relevant documents is listed on the CVDL’s application form, as well as in your dedicated folder on SharePoint).
* Further discussion and details maybe requested. The data linkage application may need to be resubmitted to reflect relevant amendments.
* The costs of data access[[1]](#footnote-1) via the CVDL Microsoft Azure data analysis environment is scoped, and a quote is provided to the researcher.

**Note**: The timeframe to finalise a project is dependent on several factors such as linkage complexities, approvals and data sharing requirements. The CVDL’s Client services team will assist as much as possible to provide an indication on a completion timeframe for you to plan your project.

## Ethical Approval

* An ethical review and approval of all research projects is a statutory requirement under the Health and Information Privacy Principles. It is a key part of the consideration of the public interest in a research project and of the potential for harm to the participants who are the subject of the data.
* The Client services team can provide input/or feedback on the Human Research Ethics Committee (HREC) applications relating to accessing the linked data.
* **Requests from Data Requestors external to the Victorian Government:** Data Requestor must obtain HREC approval from an accredited Victorian HREC or, for cross-jurisdictional studies, from a HREC accredited under the National Mutual Acceptance scheme. Details on the requirements for HREC applications can be found here: (<https://www2.health.vic.gov.au/about/clinical-trials-and-research/health-and-medical-research>). Data Requestor must provide the CVDL with both the Ethics application submitted to the HREC, and approval letter.
* The Data Requestor’s ethics application needs to be clear that the data linkage process involves the use of personal information and that the unit-record level data the CVDL provides access to, although de-identified to varying degrees, should be considered as re-identifiable, and accordingly this needs to be considered as part of the HREC approval.
* **Requests from Data Requestors Internal to Victorian Government**: Data Requestors require Victorian HREC approval if the request is of a sensitive nature meets the criteria under Health Privacy Principle 2.2G or Information Privacy Principle 2.1C or is published externally.
* Projects where clear, **informed consent has not been given by the individuals** who are the subject of the data, are to be specifically considered by the HREC, and provide an endorsed ‘waiver of consent’ when applicable, as per the National Statement guidelines on Ethical conduct for Human Research projects. <https://www.nhmrc.gov.au/guidelines-publications/e72>
* Approval from a HREC is one step in the data linkage request assessment process, and does not constitute final approval for a data linkage project.

## Data Custodian approval

* The use of each dataset involved in a data linkage project must be approved by the relevant Data Custodian.
* **For datasets held by the Victorian Government**: the CVDL Client services team will liaise, and seek Data Custodians’ approval for the use of specific dataset in the research project, on behalf of the Data Requestor. The Data Custodians are provided with the Data linkage application, research protocol, ethics approval, the specific data variables requested, and any other supporting information including data flows. In considering the project, a Data Custodian will consider operational, policy and/or specific legislative requirements.
* **For datasets external to the Victorian Government***:* the Data Requestor must provide evidence of the relevant Data Custodians’ approval for the use of the dataset in the research project. The CVDL can assist in this process if required. More information on the Data Custodian’s role can be found at: <https://www2.health.vic.gov.au/about/reporting-planning-data/the-centre-for-victorian-data-linkage/data-custodians>

## Privacy Impact Assessment

* **Victorian Government Internal projects***:* Data Requestors from DH or other government departments are required to complete a privacy threshold assessment and if required a full Privacy Impact Assessment on their project.
* **External projects***:* The CVDL will undertake a privacy impact threshold assessment and if required a full Privacy Impact Assessment (PIA) for external research projects. These assessments are completed in conjunction with the Data Requestor, and the Information Sharing and Privacy Unit in the department and may incur a cost.

## Deed of Acknowledgment and Confidentiality

All external Data Requestors must complete the Department of Health (DH) Deed of Acknowledgment and Confidentiality which outlines the terms and conditions of access to the data (with signatures from all recipients of the data and from the organisation legally responsible for the project) and return to cvdl@health.vic.gov.au

## Approval to collect non-DH data (if required)

* It is a requirement of Victorian privacy legislation that the department may only collect health or personal information if it is necessary for one or more of the functions for activities of the department.
* The Chief Executive Officer, Victorian Agency for Health Information, must approve all collections of external data sources.
* If the collection of external datasets(s) into the department is approved, a Memorandum of Understanding may need to be negotiated between DH and the external Data Custodians to outline obligations and conditions for the collection and use of the data.

## Data Linkage team

The CVDL Linkage team uses the Victorian Linkage Map (VLM) to find records that belong to the individuals that are the subject of the project in the approved datasets, and assign an anonymous Linkage ID that represents an individual.

## Data Integration team

* The CVDL Integration/Content team uses the Linkage ID to extract the approved content data items from the relevant datasets and creates new project specific person IDs.
* Data de-identification processes are undertaken (i.e. aggregation and removal of personal identifiable data) to minimise the risk of re-identification of the data.
* Quality assurance is undertaken ensuring technical and administrative processes are aligned with the research request.
* A technical specification is produced and provided to the Data Requestor to finalise, and formalised what the disclosed linked output will entail (this is the final step before the Content team undertakes the content extraction, it is imperative that you ensure your requirement have been met.

Note any additional request once the linked data has been completed and released, will be considered as a brand-new request and subject to an updated Ethics approval.

## Use of personal and health information

Data linkage involves using personal information to locate records that belong to specific individuals across different datasets.  The use of personal and health information in Victoria is governed by the Privacy and Data Protection Act 2014 and the Health Records Act 2001.

The use of personal and health information in data linkage must accord with the Information Privacy Principles and Health Privacy Principles described in these Acts.

**Personal information** is information or an opinion (including information or an opinion forming part of a database), that is recorded in any form and whether true or not, about an individual whose identity is apparent, or can reasonably be ascertained.

**Health information** is information or an opinion that is Personal Information is also about:

* the physical, mental or psychological health (at any time) of an individual
* a disability (at any time) of an individual
* an individual's expressed wishes about the future provision of health services to him or her
* a health service provided, or to be provided, to an individual.

Further information on Victorian privacy legislation can be found here: <https://ovic.vic.gov.au/>

## Accessing linked data

* A project-specific virtual machine is created in the DH Microsoft Azure data analysis environment which contains the approved linked, unit-record level, de-identified data for the project.
* Creation and maintenance of the project-specific virtual machine will incur a cost which will be charged to the Data Requestor on a cost recovery basis.
* Approved Data Requestors’ login to the project-specific virtual machine and analyse the data using a range of data analysis tools. Using the project Linkage ID, the researcher can determine which records from different datasets belong to the same individual, without having access to personal identifiable information.
* Unit-record level data cannot be downloaded or copied from the virtual machine. Aggregated outputs are vetted by the CVDL before they can be removed from the environment.
* On completion of the project and/or after a timeframe approved by the CVDL, access to the virtual machine is removed.

## Timeframes

Finally, the timeframe to finalise a project is dependent on a number of factors including linkage complexities and approval requirements. The CVDL Client services will assist as much as possible to provide an indication on a project timeframe for you to plan your project.

## Prior to any analysis publication

As part of the department’s terms and conditions to access linked data, all analysis reports and/or presentation of linked data provided by DH must be provided to DH (via the CVDL Client services team at: cvdl@health.vic.gov.au) for review before submission for publication.

To receive this document in another format, email cvdl@health.vic.gov.au

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In this document, ‘Aboriginal’ refers to both Aboriginal and Torres Strait Islander people. ‘Indigenous’ or ‘Koori/Koorie’ is retained when part of the title of a report, program or quotation.

Available at <https://www2.health.vic.gov.au/cvdl>

1. The CVDL is moving towards a cost recovery model, there will be a cost to access the linked data via a Virtual Machine incurred by the Data Requestor, more information will be provided to the Data Requestor in due course. [↑](#footnote-ref-1)