

# PROCEDURE FOR OBTAINING LINKED DATA

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## 1. Obtain data linkage and dataset information

A comprehensive set of documentation and forms is available to researchers, including information on the datasets available for linkage, tips for their use and contact information for the data custodians. Please email the CHReL ([cherel@cancerinstitute.org.au](mailto:cherel@cancerinstitute.org.au)) or contact the Research Project Manager ([hilarie.tardif@cancerinstitute.org.au](mailto:hilarie.tardif@cancerinstitute.org.au)) to obtain this information. The CHReL website also contains additional information of interest to researchers: [www.cherel.org.au](http://www.cherel.org.au)

## 2. Complete the Data Linkage Project Plan

The Project Plan provides an outline of your project, the datasets and linkage required and enables us to provide you with a quote for our linkage services. Please email the completed form to the Research Project Manager: [hilarie.tardif@cancerinstitute.org.au](mailto:hilarie.tardif@cancerinstitute.org.au)

*Allow 2 weeks for us to review your project plan and provide a quote*

## 3. Prepare project documentation

### a. National Ethics Application Form (NEAF)

All studies using linked data must obtain ethics approval from the NSW Population and Health Service Research Ethics Committee. The NEAF is accessible at <https://ethicsform.org/au>.

The CHReL provides a Prototype NEAF form, in both .pdf and .xml format covering selected NEAF questions and appropriate answers for studies which involve data linkage by the CHReL. The .xml version can be uploaded to the NEAF website to facilitate preparation of the form.

For advice and guidance regarding the ethical issues of your application, please contact Sharon Falleiro on (02) 8374 5615, Marion Marson on (02) 8374 3562 or via email at: [ethics@cancerinstitute.org.au](mailto:ethics@cancerinstitute.org.au)

Note: the NEAF needs to specify and justify which datasets, years of data, and variables are required. Variables should be listed under two categories: personal identifiers for linkage, and research variables for analysis (as outlined in the Prototype NEAF).

## **b. NSW Privacy Form**

This form is required with each ethics application and to obtain approval for inclusion of Australian Bureau of Statistics (ABS) and Register of Births, Deaths and Marriages (RBDM) data. The form can be downloaded from:

[www.cancerinstitute.org.au/cancer\\_inst/research/ethicsformlinks.htm](http://www.cancerinstitute.org.au/cancer_inst/research/ethicsformlinks.htm)

## **c. Research Protocol**

A research protocol should accompany each ethics application - it provides evidence for the feasibility of a study, outlines the objectives, design, methodology, statistical considerations and how the study will be conducted and evaluated. The ethics committee has produced a template for the Research Protocol, available at:

[http://www.cancerinstitute.org.au/cancer\\_inst/research/ethicspopresearch.html](http://www.cancerinstitute.org.au/cancer_inst/research/ethicspopresearch.html)

When you have completed these three forms, please email them to the Research Project Manager for comment and advice on the data linkage component of the application. The CHeReL will then issue you with a Technical Feasibility letter which states that the linkage is feasible and will be conducted by the CHeReL.

*Please allow 4 weeks for this review and revision process.*

## **4. Obtain data custodian approval**

Data custodian approval is required for each dataset required in your study. The CHeReL arranges data custodian sign-off for the RBDM and ABS datasets. Approval from all other custodians is the researcher's responsibility.

The form for data custodian sign-off can be downloaded from:

[http://www.cancerinstitute.org.au/cancer\\_inst/research/pdf/e08-27783\\_ethics\\_ph\\_forms-data-custodian-sign-off-form.doc](http://www.cancerinstitute.org.au/cancer_inst/research/pdf/e08-27783_ethics_ph_forms-data-custodian-sign-off-form.doc)

Data custodian contact information is contained in the documents provided at Step 1.

*Please allow up to 4 weeks to obtain approvals from data custodians*

## **5. Submit your application to the NSW Population & Health Services Research Ethics Committee**

For full information on the required documentation for submission to the NSW Population & Health Services Research Ethics Committee, visit the website at:

[http://www.cancerinstitute.org.au/cancer\\_inst/research/ethicspopsubmit.html](http://www.cancerinstitute.org.au/cancer_inst/research/ethicspopsubmit.html)

For further information, contact Sharon Falleiro (02 8374 5615), Marion Marson (02 8374 3562) or email [ethics@cancerinstitute.org.au](mailto:ethics@cancerinstitute.org.au)

Please advise us when you have lodged your application with the ethics committee. You will be notified of the outcome following review by the committee. Please also inform the CHeReL of the outcome and any issues raised by the ethics committee. This allows us to schedule the project and provide further assistance if there are issues to address.

## **6. Data linkage and extraction**

Once approval has been granted by the ethics committee, please contact us to discuss the supply, linkage and extraction of data.

The CHeReL will advise you when the linkage is complete: a paper outlining the results of the linkage will be emailed to you, along with a brief summary of the aims of the project for publishing on our website and/or newsletter. Once you have reviewed and approved these documents the CHeReL sends the project keys (encrypted record numbers and Project Person Numbers) to the data custodians for data extraction.

*Allow 4 to 12 weeks after data for linkage has been received by the CHeReL*

## **7. Data supplied to the researcher by the data custodians**

The data custodians provide the approved data variables and Project Person Numbers to the researcher. The time frame for this process is variable but may take up to 12 weeks. Individual data custodians should be contacted for estimates of the likely time period.

## **8. Follow Up**

Please advise us once you have received the data and we will issue an invoice. We will also follow up on a yearly basis regarding research, publications and conference presentations arising from the data linkage study.