

**Application for Data**

**Personnel and Project Details**

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| **1. Project Title** |
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| **2. Applicants**  **Please include details for all project personnel, including their role in the project. Include additional researchers in an attachment if necessary.** | | | | |
| Chief Investigator | | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
| Role: |  | | | |
| Project Contact | | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
| Role: |  | | | |
| Phone: | Work: |  | Mobile: |  |
| Email: |  | | | |
| Co-Investigators | | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
| Role: |  | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
| Role: |  | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
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| Position: |  | | | |
| Role: |  | | | |
| Name & title: |  | | Organisation: |  |
| Position: |  | | | |
| Role: |  | | | |

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| **3. Project Details**  **Provide a concise and simple description of the project in not more than 400 words** | |
| Background |  |
| Aims |  |
| Research Design |  |
| Methods |  |

**Linkage and Extraction**

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| **4. Linkage Required (select one only)** | |
|  | Extraction of records from the Master Linkage Key (MLK) |
|  | Linkage of at least one external (ad hoc) dataset to the MLK *(you are providing your own external dataset(s) to be linked to data currently in the MLK)* |
|  | Linkage of two or more external (ad hoc) datasets *(you are providing the CHeReL with external datasets for linkage – no linkage to MLK data is required)* |
|  | Other – please provide details |

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| **5. Linkage of external dataset(s)**  Complete this section if you answered (Table 4) that you are providing an external dataset for linkage to the MLK.  Include details of each of the external datasets that are to be linked. Please also include in an attachment the variables you will be receiving from these external datasets. | | | |
| **Dataset 1** | | | |
| Name and/or brief description of dataset: |  | | |
| Number of records: |  | Year span of dataset: |  |
| Custodian Name: |  | Email/Phone No: |  |
| Personal identifiers available for linkage \* |  | | |
| **Dataset 2** | | | |
| Name and/or brief description of dataset: |  | | |
| Number of records: |  | Year span of dataset: |  |
| Custodian Name: |  | Email/Phone No: |  |
| Personal identifiers available for linkage \* |  | | |
| **Dataset 3** | | | |
| Name and/or brief description of dataset: |  | | |
| Number of records: |  | Year span of dataset: |  |
| Custodian Name: |  | Email/Phone No: |  |
| Personal identifiers available for linkage \* |  | | |
| **Expected linkage rates**  Please include any comments regarding the expected linkage rates of these data based on previous research | | | |
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\*The CHeReL recommends providing the following variables for linkage of external datasets where available:

* First name, middle name, surname
* Alternative names/aliases
* Address, and a date that is associated with the address (e.g. diagnosis date, admission date)
* Medical Record Number (MRN) if available
* Date of birth
* Gender
* Country of birth (if available as ABS 4 digit ASCCSS codes)

An encrypted record number for each record in the external dataset(s) must also be included.

Linkage to the MLK datasets will use personal identifiers held within the CHeReL MLK to maximise linkage rates

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| **6. Duration** | | | | |
| **Provide the start and finish dates for the study, including data analysis** | | | | |
| Anticipated start date: | |  | Anticipated finish date: |  |
| **Please indicate if updates to linkage/data extraction are required** | | | | |
|  | The study does not require future updates | | | |
|  | Ongoing updates are requested  *Please indicate when these are required (e.g. “annually until 2015”, “one further extract in 2012”)* | | | |

**NOTE: Project keys will be deleted by the CHeReL and custodians 12 months after final provision of data to the researchers.**

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| **7. Cohort Description** |
| Please describe your cohort, specifying any exclusion/inclusion criteria  (e.g. “cohort is the external dataset described in Table 5” or “all women diagnosed with breast cancer 2002-2005”) |
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| Approximately how many records/individuals are in the cohort? |
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| How is your cohort to be defined?  (e.g. from the APDC - all separations during 2002 with the following ICD diagnoses).  If there are numerous ICD codes please attach these in a spreadsheet |
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| If your cohort is defined by ICD codes please indicate whether they should be applied to the principal diagnosis/procedure code only, or to any of the multiple diagnosis/procedure codes within a record |
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| If your cohort is defined by ICD codes please indicate if all linked records are required for these individuals or only those records relating to the specified condition  (e.g. for a cohort of patients with kidney disease: APDC records relating to kidney disease only vs. all linked APDC records for these patients whether or not they are related to the condition) |
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| **8. MLK Data Collections** | | | |
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| Please indicate the data required for your cohort | | Years | |
| From (e.g. Jul 2000) | To (e.g. Dec 2006) |
| NSW Admitted Patient Data Collection (from Jul 2001)  Based on:  Admission date **OR**  Separation date  ( † see note below for further information) |  |  |  |
| NSW RBDM Death Registrations (from 1985) |  |  |  |
| NSW RBDM Birth Registrations (from 1994) |  |  |  |
| Cause of Death Unit Record File (from 1985) |  |  |  |
| NSW Perinatal Data Collection (formally Midwives Data Collection) (from 1994) |  |  |  |
| The 45 and Up Study |  |  |  |
| NSW Emergency Department Data Collection (from 2005) |  |  |  |
| NSW Central Cancer Registry (from 1972) |  |  |  |
| NSW Perinatal Death Review Database (from 2000) |  |  |  |
| NSW Notifiable Conditions Information Management System (from 1993) |  |  |  |
| NSW Mental Health Ambulatory Data Collection (from 2001) |  |  |  |
| NSW Pap Test Register (from Jul 1996) |  |  |  |
| NSW Ambulance (from 2005) |  |  |  |
| NSW Breastscreen (from 1988) |  |  |  |
| ACT Admitted Patient Collection (from Jul 2004)  Based on:  Admission date **OR**  Separation date  ( † see note below for further information) |  |  |  |
| ACT Cancer Registry (from 1994) |  |  |  |
| ACT Emergency Department Data Collection (from Jul 2004) |  |  |  |
| ACT Notifiable Disease Management System (from 2000) |  |  |  |
| ACT Perinatal Data Collection (from 1997) |  |  |  |
| ACT BDM Birth Registrations (from 1997) |  |  |  |
| ACT BDM Death Registrations (from 1997) |  |  |  |
| Comments | | | |
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† Records in the NSW APDC and ACT APC are based on separations and do not include data for patients who have been admitted but not discharged from hospital.

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| **9. Please complete if a mother-baby linkage is required**  The CHeReL is able to identify mother-child relationships through information recorded in the birth registration. If your study requires a linkage to the mothers/children of your cohort please complete the following table, indicating the datasets required for this additional linkage and extraction | | | |
| Records for the mothers of the cohort are required  Records for the babies of the women in the cohort are required | | | |
| Please indicate the data required for your cohort | | Years | |
| From (e.g. Jul 2000) | To (e.g. Dec 2006) |
| NSW Admitted Patient Data Collection (from Jul 2001)  Based on:  Admission date **OR**  Separation date  ( † see note above for further information) |  |  |  |
| NSW RBDM Death Registrations (from 1985) |  |  |  |
| NSW RBDM Birth Registrations (from 1994) |  |  |  |
| Cause of Death Unit Record File (from 1985) |  |  |  |
| NSW Perinatal Data Collection (formally Midwives Data Collection) (from 1994) |  |  |  |
| The 45 and Up Study |  |  |  |
| NSW Emergency Department Data Collection (from 2005) |  |  |  |
| NSW Central Cancer Registry (from 1972) |  |  |  |
| NSW Perinatal Death Review Database (from 2000) |  |  |  |
| Notifiable Conditions Information Management System (from 1993) |  |  |  |
| NSW Mental Health Ambulatory Data Collection (from 2001) |  |  |  |
| NSW Pap Test Register (from Jul 1996) |  |  |  |
| NSW Ambulance (from 2009) |  |  |  |
| ACT Admitted Patient Collection (from Jul 2004)  Based on:  Admission date **OR**  Separation date  ( † see note above for further information) |  |  |  |
| ACT Cancer Registry (from 1994) |  |  |  |
| ACT Emergency Department Data Collection (from Jul 2004) |  |  |  |
| ACT Notifiable Disease Management System (from 2000) |  |  |  |
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| ACT BDM Birth Registrations (from 1997) |  |  |  |
| ACT BDM Death Registrations (from 1997) |  |  |  |
| Comments | | | |
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† Records in the NSW APDC and ACT APC are based on separations and do not include data for patients who have been admitted but not discharged from hospital.

**Consent, Storage and Retention**

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| **10. Consent** | | |
| Will consent be sought from study participants to use information collected about them? | Yes | No |
| If “Yes”, please attach the consent forms and information sheets that will be used | | |

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| **11. Location** |
| **List all locations where the data will be stored and analysed** |
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| **12. Storage of data** |
| **Please describe how the data will be stored during and after the research project** |
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| **13. Security Plan** |
| **Specify the measures taken to ensure the security of information from misuse, loss or unauthorised access during and after the research project** |
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| **14. Retention and disposal plan** |
| **Specify the period of retention of the data following completion of the project and how the information will be destroyed** |
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