

APPENDIX 2: Data Linkage EOI

Please submit to the CHeReL by 24 July 2020 at MOH-Biolink-CHeReL@health.nsw.gov.au.

Principal Investigator, Primary Contact	Name, Title, Institution and Email Address for the PI and the Contact
Description of Biospecimen Collection	1. Name of Biospecimen Collection or Grant <input type="text"/>
	2. How many people do you anticipate will be included in the biospecimen collection? <input type="text"/>
	3. How many people do you intend to recruit over the 3 years of the grant? <input type="text"/>
	4. Is the biospecimen collection existing or prospective or both? <input type="text"/>
	5. If an existing collection, how many people does the collection currently include? <input type="text"/>
Data Linkage	1. When do you anticipate the first linkage to occur? <input type="text"/>
	2. Are you requesting updates of the linkage? For example, annual until 2024 or one update in 2022 <input type="text"/>
NSW Health Datasets	<p>Please indicate which of the following NSW Health state-wide collections you intend to request for research purposes</p> <ul style="list-style-type: none"><input type="checkbox"/> Admitted Patient Data Collection (from 2001)<input type="checkbox"/> Death Registrations (from 1985)<input type="checkbox"/> Cause of Death Unit Record File (from 1985)<input type="checkbox"/> Birth Registrations (from 1994)<input type="checkbox"/> Perinatal Data Collection (from 1994)<input type="checkbox"/> Emergency Department Data Collection (from 2005 onwards)<input type="checkbox"/> Cancer Registry (registrations from 1972 and clinical data items from 2013)

	<ul style="list-style-type: none"> ❑ Notifiable Conditions Information Management System (from 1993) ❑ Mental Health Ambulatory Data Collection (from 2001) ❑ NSW Ambulance Electronic Medical Record and Patient Health Care Record (from 2009) ❑ NSW Ambulance Computer Aided Dispatch (from 2009) ❑ Controlled Drugs Data Collection (from 1985) ❑ Non-Admitted Patient Data Collection (from 2015) ❑ BreastScreen NSW (from 1988) ❑ Other NSW Health data collections (please specify, for example, NSW Pathology, Neonatal Intensive Care Unit data collection) <p>Detailed descriptions of these datasets are available at https://www.cherel.org.au/data-dictionaries or on request from the CHeReL at MOH-Biolink-CHeReL@health.nsw.gov.au</p>
<p>Briefly outline the purpose of requesting the datasets above? How will the datasets you have requested be leveraged for the flagship research described in your grant application?</p>	<p>The Grant Application (Question 10) requires that you address in 200 words or less the question of how the linked administrative datasets will be leveraged for your flagship research</p>

Information on Data Linkage

The CHeReL will review the EOI and provide comment and/or a letter of support for your grant application. Please be aware that the CHeReL review is limited in scope and future data access will require approval from data custodians and a relevant ethics committee in accordance with NSW Health policy.

The NSW Health Toolkit is recommended as a resource to assist in appropriately consenting participants to data linkage of NSW Health data collections.

As a condition of the grant you will be asked to provide sufficient personal information for consenting participants to the CHeReL to enable data linkage that can support future research. Typically, the information used for data linkage will include the full name, date of birth and address of the participant. The intent of providing this information is to enable specific NSW Health data for consenting participants to be included in a **Biospecimen Linked Standard Data Asset (BLSDA)**. The BLSDA will be maintained by the CHeReL and be limited in scope to appropriately consented participants from collections funded by OHMR through the Strategic Collection Grants. For these participants the BLSDA will contain a small number of different NSW Health datasets at the time of first linkage. New participants in collections will be added over time and the NSW Health datasets in the scope of the asset expanded.

The BLSDA is being created to simplify access to longitudinal data for future research. Access will require appropriate approvals for the project and be managed in accordance with the *NSW Health Statewide Biobank Access Policy*.

Further information is available from the CHeReL at MOH-Biolink-CHeReL@health.nsw.gov.au