



DATA TRANSFER AGREEMENT

BETWEEN

CURTIN UNIVERSITY OF TECHNOLOGY

And

INSERT DATA CUSTODIAN'S NAME

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1. PARTIES

CURTIN UNIVERSITY [CURTIN UNIVERSITY OF TECHNOLOGY ABN 99 143 842 569 a body corporate established pursuant to the provisions of the Curtin University of Technology Act 1966 (WA) and having its principal office at Kent Street, Bentley, Western Australia] acting through its Centre for Data Linkage (“CDL”);

And

[Data Custodian details] (“Data Custodian”)

2. BACKGROUND

- 2.1 The Australian Government Department of Innovation, Industry, Science and Research (DIISR) National Collaborative Research Infrastructure Strategy (NCRIS) supports and funds the development of research infrastructure to support research in Australia.
- 2.2 DIISR has entered into an agreement with the University of Western Australia to fund the Population Health Research Network (PHRN) to establish national infrastructure for the probabilistic linkage of datasets relevant to the health and wellbeing of the Australian population. The PHRN infrastructure will expand the capacity of existing data linkage units and will develop the capacity for the national linkage of datasets by establishing a secure data linkage facility for data linkage between jurisdictions.
- 2.3 The University of Western Australia has entered into an agreement with Curtin University of Technology to establish and provide a secure data linkage facility and related services that meet the objectives of the PHRN. Curtin University of Technology has established the Centre for Data Linkage (CDL) to establish a secure data linkage facility and related services. The CDL will hold Demographic Data and Data Linkage Keys as agent for and on behalf of all parties participating in the Population Health Research Network.
- 2.4 To play their role in the PHRN and in data linkage, the CDL and the Data Custodian have agreed to provide and accept data on the terms set out in this agreement and to regulate and manage the data provided, held, manipulated and disseminated by them.

3. PURPOSES OF THE AGREEMENT

- 3.1 The purposes of this agreement are to:
 - 3.1.1 Set out the responsibilities of the Parties to the agreement in establishing and supporting the creation of a research infrastructure for the linkage of datasets relevant to the health and wellbeing of the Australian population.
 - 3.1.2 Set out the responsibilities of the Data Custodian for the provision of data to the CDL.
 - 3.1.3 Set out how the CDL will hold, maintain and administer data provided by the Data Custodian, and set out the terms and conditions under which the CDL is licensed to hold, manipulate and disseminate the Supplied Data.
 - 3.1.4 Ensure the proper protection of the privacy and confidentiality of those individuals that the data relates to.

4. PROVISION OF INFORMATION BY THE DATA CUSTODIAN

- 4.1 The CDL requires demographic data and Jurisdictional Linkage Keys in order to provide the data linkage and related services under the auspices of the PHRN infrastructure.
- 4.2 In consideration for the CDL creating National Linkage Keys and the National Linkage Map and supplying Project Linkage Keys to the Data Custodian, the Data Custodian agrees to:
 - 4.2.1 transfer the Supplied Data identified in Schedule 1 to the CDL.
 - 4.2.2 transfer the Supplied Data on the date/s specified in Schedule 1
 - 4.2.3 transfer the Supplied Data in the manner specified in Schedule 1.
 - 4.2.4 establish procedures for the consideration of applications and the provision of data for approved research projects using the PHRN infrastructure.
- 4.3 The Data Custodian warrants that it has full legal rights to provide the information to the CDL for the purposes of establishing a secure data linkage facility and related services. Such legal rights include rights under [insert relevant legislation, regulations and guidelines if required/applicable]
- 4.4 The Data Custodian warrants that it has received research ethics approval from the relevant Human Research Ethics Committee to transfer the Supplied Data to the CDL
- 4.5 Risk in, and the obligation to protect the Supplied Data will pass to the CDL upon delivery. [The CDL only accepts responsibility for the Supplied Data when it is accepted by a CDL employee and acceptance is acknowledged in writing].

5. LINKAGE PROCESS

- 5.1 The data linkage process will operate in two stages as more fully described in Schedule 2.
- 5.2 The two stage process is designed to:
 - 5.2.1 Maximise the conservation of individual privacy and confidentiality;
 - 5.2.2 Minimise access to personal information.

6. GENERAL REPRESENTATIONS AND UNDERTAKINGS

- 6.1 CDL represents and warrants that:
 - 6.1.1 The CDL will be a secure repository for the Supplied Data.
 - 6.1.2 The CDL will deal with and protect the Supplied Data subject to law and in accordance with the requirements of all applicable legislation and regulations.

[including - insert relevant legislation, regulations and guidelines if required/applicable]
 - 6.1.3 The CDL will carry out its role subject to the approval of [a properly constituted Human Research Ethics Committee.] or

[insert relevant HRECs if required/applicable]

7. AUTHORISED USE ACCESS AND DISCLOSURE

- 7.1 The CDL will use the Supplied Data to:
- 7.1.1 create National Linkage Keys and the National Linkage Map;
 - 7.1.2 conduct linkage with other data collections that are not included in the National Linkage Map for approved research projects;
 - 7.1.3 supply Project Linkage Keys to Data Custodians, as per the processes described in Schedule 2;
 - 7.1.4 supply feedback to the Data Custodian as part of quality assurance processes;
 - 7.1.5 carry out research in data linkage methodology to enhance its ability to carry out its functions;
 - 7.1.6 geo-code address information provided to it.

8. RESTRICTIONS ON USE, ACCESS AND DISCLOSURE

- 8.1 The CDL represents and warrants that:
- 8.1.1 The CDL will not use the Supplied Data other than for the purposes outlined in this agreement unless required or authorised by law, or the Data Custodian consents in writing to that use;
 - 8.1.2 The CDL will not disclose the Supplied Data to any other person unless required or authorised by law, or the Data Custodian consents in writing to that disclosure;
 - 8.1.3 The CDL will not carry out analyses of linked health records for the purposes of health research, compilation of health-related statistics, or planning and evaluation of health services.
 - 8.1.4 The CDL will not disclose the Supplied Data in any reports or publications.

9. DISCLOSURE AS REQUIRED BY LAW

- 9.1 The CDL may disclose any Supplied Data which the CDL is required by law to disclose, but only if the extent and the manner of the disclosure is strictly limited to what is required by law;
- 9.2 The CDL will immediately notify the Data Custodian if it becomes aware that disclosure of any Supplied Data is, or may be required by law, and will provide all assistance and co-operation which the Data Custodian reasonably considers necessary for the purpose of enabling the Data Custodian to seek a protective order or other relief from disclosure.

10. PROTECTION OF INFORMATION

- 10.1 The CDL will ensure that all reasonable administrative, technical and physical safeguards are taken to protect the Supplied Data from misuse, loss or any unauthorised access, use, modification or disclosure;

- 10.2 The CDL will implement and comply with the CDL Security Framework as set out in Schedule 3 and all applicable PHRN and Curtin University of Technology policies and procedures;
- 10.3 The CDL will ensure that only those personnel who are involved in the performance of this agreement have access to the Supplied Data on a strictly need to know basis;
- 10.4 The CDL will ensure that only authorised staff have access to the minimum amount of information necessary to carry out their function on a strictly need to know basis;
- 10.5 The CDL will ensure that its employees, agents and sub-contractors involved in the performance of this agreement are aware of and comply with their obligations to protect the Supplied Data from misuse, loss or any unauthorised access, use, modification or disclosure and that these obligations will continue after their employment ceases;
- 10.6 The CDL will ensure that its employees, agents and sub-contractors involved in the performance of this agreement sign confidentiality deeds with Curtin University; of Technology.
- 10.7 The CDL will immediately notify the Data Custodian if the CDL becomes aware of any unauthorised access to, or use or disclosure of the Supplied Data;
- 10.8 The CDL will comply with the *Privacy Act 1988* (Cth) and the Information Privacy Principles in the use, collection, storage or disclosure of any personal and/or health information.

11. TERM AND TERMINATION

- 11.1 This agreement commences from the Commencement Date and will continue in force for so long as the CDL continues to hold the Supplied Data.
- 11.2 The Data Custodian may direct the CDL at any time in writing, to:
 - 11.2.1 return or destroy (at the discretion of the Data Custodian) a specified portion of the Supplied Data (e.g. data from one specific collection);
 - 11.2.2 return or destroy (at the discretion of the Data Custodian) all of the Supplied Data;and the CDL must, within 30 days of receipt of the written notification, comply with such direction. The return or destruction of any data will not diminish or otherwise affect any other obligations under this agreement.
- 11.3 The Data Custodian may notify the CDL at any time in writing that it will supply no new data to the CDL, but that the CDL may retain and use all of the Data Custodian's data currently held by the CDL until further notice.
- 11.4 The CDL will notify the Data Custodian in writing within x days of no longer being able to provide data repository services to the Data Custodian.
- 11.5 In the event that the CDL no longer holds any of the Data Custodian's data, this agreement will automatically terminate.
- 11.6 Either Party may immediately terminate this agreement on written notice to the other Party (defaulting Party), if the defaulting Party breaches this agreement or goes insolvent.
- 11.7 The Parties will attempt in good faith to resolve through negotiation any disputes, claim or controversy arising out of or relating to this agreement.

12. GENERAL

- 12.1 This agreement constitutes the entire agreement between the Parties in relation to the subject matter of this agreement.
- 12.2 The rights and obligations of the Parties under this agreement will not be assignable without the prior written permission of the other Parties.
- 12.3 If any provision of this agreement is held unenforceable or void, the remaining provisions will be enforced in accordance with their terms.
- 12.4 Nothing in this agreement will be construed so as to make any Party an employee, agent or partner of another, or create any relationship of partnership, agency, or trust whatsoever.
- 12.5 This agreement may be signed in any number of counterparts.
- 12.6 This agreement shall be construed and governed in accordance with the laws of Western Australia.

13. INTERPRETATION

- 13.1 In this agreement unless the contrary intention appears:
- (a) Approved Project means a project that has received approval from the relevant Human Research Ethics Committees and Data Custodians.
 - (b) **Commencement Date** means the date of execution of this agreement by both Parties.
 - (c) **Content Data** means data in a record that contains service or clinical information and is used for research purposes. Content data does not include demographic information. It can also be referred to as 'clinical' or 'service' data.
 - (d) **Data Custodian** means the organisation or agency which is responsible for the collection, use and disclosure of information in that dataset. The Data Custodian is responsible for contributing to the guidelines and approval processes on the use of the data, including involvement with ethics committees and input to the protocols surrounding data use
 - (e) **Data Linkage** means the process of creating links between data thought to be from the same individual within or between administrative data sources generally based on demographic data.
 - (f) **Data Linkage Keys** means sets of data indexes which are used to group records that refer to the same person or entity. Data linkage keys are created and stored for use in encrypted form;
 - (g) **Demographic Data** means personal information derived from the Data Custodian and of the type identified in Schedule 1 and such other data which may, at the discretion of the Data Custodian, be provided to the CDL;
 - (h) **DIISR** means the Australian Government Department of Innovation, Industry, Science and Research;

- (i) **Geo-coding** means the process of finding associated geographic coordinates (often expressed as latitude and longitude) from other geographic data, such as street addresses or postal codes.
- (j) **Human Research Ethics Committee** means a Human Research Ethics Committee registered with the National Health and Medical Research Council;
- (k) **Jurisdictional Linkage Keys** means the Data Linkage Keys created by the State and Territory Linkage Units (NSW/ACT, QLD, SA-NT, TAS, VIC, WA);
- (l) **National Linkage Keys** are Data Linkage Keys created by the CDL;
- (m) **National Linkage Map** means the information by which each Jurisdictional Linkage Key is associated with a National Linkage Key;
- (n) **Non-identifiable information** means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is not apparent, or cannot reasonably be ascertained, from the information or opinion
- (o) **Parties** means the CDL and the Data Custodian and Party means one of them;
- (p) **Personal information** means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion (Privacy Act 1988)
- (q) **PHRN** means the Population Health Research Network;
- (r) **Project Linkage Key** means an encrypted version of the National Linkage Key. The Project Linkage Key is created by the CDL and provided to the Data Custodian for use in supplying non-identifiable content data to researchers. Project Linkage Keys are never used in their original format - they are always encrypted and never shared between projects;
- (s) **Supplied Data** means Demographic Data, the Jurisdictional Linkage Keys, and such other data, as derived from the Data Custodian and of the type identified in Schedule 1, which may at the discretion of the Data Custodian be provided to the CDL;

EXECUTED AS AN AGREEMENT BY THE PARTIES:

CURTIN UNIVERSITY OF TECHNOLOGY

BY ITS DULY AUTHORISED SIGNATORY:

Name and Title of signatory:

Date:

[DATA CUSTODIAN]

BY ITS DULY AUTHORISED SIGNATORY:

Name and Title of signatory:

Date:

SCHEDULE 1

The Supplied Data

Title/s of the resources and/or general description of the Supplied Data, together with details of **when** it is to be supplied to the Centre for Data Linkage, Curtin University of Technology.

demographic data and jurisdictional linkage keys

[EXAMPLE Demographic Data to be provided will include names and addresses or part thereof, date of birth, sex and at the discretion of the Data Custodian, record descriptor variables such as record identity, record type, date of event, data collection identifier and person identifier specific to the data collection]

Data Type	Field Name
Record_type	e.g. "WA-HMD"
Encrypted unique record ID	E_REC_ID
Encrypted Jurisdictional Linkage Key	E_JLK
Family name	SURNAME
First Given Name	GIVEN1
Second Given Name	GIVEN2
Date of Birth	DOB (YYYYMMDD)
Gender	SEX
Street Number	ST_NO
Street Unit Number	ST_UNIT
Street Name	ST_NAME
Street_Type	ST_TYPE
Suburb/Locality	LOCALITY
Postcode	PCODE
Date of event	HOSP_ADMISSION_DATE

Transfer of Supplied Data

[Insert description of how data will be transferred from the Data Custodian to the CDL]

Example:

The Data Custodian will transfer the data to the [insert name of jurisdictional linkage unit] who will be responsible for transferring the Supplied Data to the CDL.

Frequency of transfer [insert frequency]

Mode of transfer [insert mode] e.g. via PHRN Data Delivery System or via encrypted disk.

SCHEDULE 2

Data Linkage Process

Stage 1

The Data Custodian will provide the CDL with the Supplied Data.

Through a process of Data Linkage, the CDL will examine the Supplied Data provided by all of the Data Custodians and determine matches between the data sets.

Each group of records that refer to the same person or entity will be allocated a National Linkage Key. The CDL will create and store these National Linkage Keys in a database in encrypted form. The National Linkage Keys will be dynamic, meaning that entries in the system will be added to and/or updated and/or deleted over time.

The CDL will use the National Linkage Keys to create a National Linkage Map. The purpose of the Map is to show the association between National Linkage Keys and encrypted Jurisdictional Linkage Keys. It will not contain any personal information.

Stage 2

Using the National Linkage Map, the CDL will create a set of Project Specific Linkage Keys for each project approved by the relevant Human Research Ethics Committee(s) and authorised by the relevant Data Custodians.

The Project Specific Linkage Keys will be provided by the CDL to the relevant Data Custodians. The Data Custodians will use the Keys to supply non-identifiable Content Data to researchers.

SCHEDULE 3

Data Security Policy and Procedures

To be supplied by CDL