Why Data Linkage?

- To provide information and evidence to decision makers upon which informed choices can be based in order to continue to improve the health and wellbeing of the community.

- De-identified, linked data will enable researchers, analysts, evaluators and policy makers to better understand the impact of decision making and the complex interrelations between social, environmental, economic and health factors that impact on individual and community wellbeing.
There are 3 distinct stages in data linkage that are subject to ethical review. These include:

- the establishment of a Data Linkage Unit;
- the linking of new data collections; and
- individual researcher level - researchers require approval to gain access to linked data for their research project to certify that the study is valid and in the public interest.
The objectives of this workshop are to:

- describe the process of data linkage;
- identify the ethical issues specific to research using linked data;
- identify the “best practice protocol” related to the use of linkable data and its governance; and
- improve decision making in reviewing research applications proposing the use of linked data.
What is data linkage?
Module 1 - Objectives

By the end of this module, you will be able to:

- identify the three distinct groups involved in data linkage;
- name two example data collections;
- explain the three key steps in the data linkage process; and
- provide an example of how data linkage can be used to benefit the community.
Types of information

The main **health** linked data collections are:
- Perinatal/births
- Hospital morbidity/discharge
- Cancer registry
- Mental health

The main **human services** linked data collections are:
- births, deaths and marriages
- education
- community services
- disability and justice

Data collections generally hold decades of data for the whole state/territory population
Data linkage, in simple terms, is a way to bring together or link records of an individual, places and events from different datasets.

Records are compared and if a number of variables from each record are deemed to be the same then those records are considered to belong to the same person or entity.
Who is involved?

- Data custodians – the people who look after the data.
- Data linkers – the people who create and maintain linkage IDs.
- Data users/researchers – the people who use the data for analysis and research.
How does data linkage work?

- **Separation** – Data custodians separate content information from personal information and routinely send to DLU
- **Creation of Linkage IDs** – LDU attach master linkage key to all new records
- ** Provision of linkage data to researchers** – Researchers apply for data and seek approval from Data custodians, DLU and HREC
Figure 1. Proportions of name-identified and linked data extracts for research in WA
Case example
Ennie Citizen
The data collections

- Each hospital sends a summary or coded record to the Health Department of each hospital stay. This is a legislative requirement for the Health Department.
- The Registrar of Births, Deaths and Marriages collects a record of every birth, death and marriage.
Data Custodians

Health Department

Ennie Citizen

Name Ennie Citizen
Address 20 Wave Road
        Beach Town 6489
Sex 1
DOB 12.04.1972
Record ID XYZ345

ATSI 4
Marital 3
Diagnosis F30.2
Ad Date 09.05.2008
Sep Date 15.05.2008

Registry of Births
Deaths & Marriages

Ennie Citizen

Name Ennie Old Citizen
Address 20 Wave Street
        Beach Town 6489
Sex M
DOB 12.04.1972
Record ID HIJ123

Aborig N
DOD 26.05.2008
COD Y350

Ennie Citizen

Name Ennie Old Citizen
Address 20 Wave Street
        Beach Town 6489
Sex M
DOB 12.04.1972
Record ID HIJ123

Aborig N
DOD 26.05.2008
COD Y350
Data Linkage Unit

hospital record

Ennie Citizen

Name: Ennie Citizen
Address: 20 Wave Road
         Beach Town 6489
Sex: 1
DOB: 12.04.1972
Record ID: XYZ345

death record

Ennie Citizen

Name: Ennie Old Citizen
Address: 20 Wave Street
         Beach Town 6489
Sex: M
DOB: 12.04.1972
Record ID: HIJ123

Linkage ID - ABC3456NMKL67890DEFG
Data Linkage Unit

**hospital record**

Name: Ennie Citizen  
Address: 20 Wave Road, Beach Town 6489  
Sex: 1  
DOB: 12.04.1972  
Record ID: XYZ345

**death record**

Name: Ennie Old Citizen  
Address: 20 Wave Street, Beach Town 6489  
Sex: M  
DOB: 12.04.1972  
Record ID: HIJ123

Linkage ID: ABC3456NMKL67890DEFG  
Project Linkage ID: PQR234  
Record ID: XYZ345; HIJ123
### Health Department

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### Registry of Births, Deaths & Marriages

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### Hospital Record
- **Project ID**: PQR234
- **Sex**: M
- **Aborig**: N
- **Age**: 36
- **DOD**: 26.05.2008
- **COD Code**: Y350

### Study Data
- **Project ID**: PQR234
- **Sex**: M
- **ATSI**: 4
- **Age**: 36
- **Marital**: 3
- **Diagnosis**: F30.2
- **Sep Date**: 15.05.2008

### Death Record
- **Project ID**: PQR234
- **Sex**: M
- **ATSI**: N
- **Age**: 36
- **Marital**: 3
- **Diagnosis**: F30.2
- **DOD**: 26.05.2008
- **COD Code**: Y350
Uses of linked data

- Assess the safety, quality and costs of health care
- Explore relationships
- Investigate social and community influence on health
- Assess the effectiveness of preventative programs
- Obtain valuable follow-up information
Objectives

- Identify the three distinct groups involved in data linkage
- Name two types of data collections
- Explain the three key steps in the data linkage process
- Provide an example of how data linkage can be used for public good
MODULE 3

Consent
Objectives

By the end of this module participants should be able to:

- Describe the legal framework applicable to data linkage
- Describe the role of the HREC under privacy legislation in considering data linkage projects
- Apply the criteria for deciding on waiver of consent for data linkage projects
- Apply the public interest criterion to data linkage projects.
Waiver of consent

Data linkage projects seeking a waiver of consent must be approved by an HREC for two reasons:

- The National Statement on Ethical Conduct in Human Research says that only an HREC may grant a waiver of consent for research using personal information in medical research or personal health information (see NS 2.3.5); and

- Privacy legislation says that personal information cannot be used for research without the person’s consent unless it is approved by an HREC in accordance with the relevant guidelines.
Module 3 - Activity
Thank you

For more information about Ethics and Data Linkage Training, please contact our Training Coordinator, Kate Tan at ktan@ichr.uwa.edu.au or on 08 6389 7306.