

# Data linkage concerning Aboriginal and Torres Strait Islander people: An overview

Ray Lovett

AIATSIS Health Research Fellow

Adjunct Post Doctoral Fellow NCEPH, ANU

Visiting Fellow Centre for Research and Action in Public Health,  
University of Canberra

*Worldwide  
knowledge and  
understanding  
of Australian  
Indigenous  
cultures, past  
and present*

# Outline

- Data linkage: what is it?
- Why we use it?
- Who does it in Australia?
- Data Linkage and Aboriginal and Torres Strait Islander people
- Ethical considerations
- Where to focus?

# What is linkage?

**Hx:** Computer assisted data linkage goes back as far as the 1950s, is essentially the process of linking and aggregating records from one or more data sources representing the same entity (patient, customer, business name, etc.)

## **Deterministic linkage**

Exact linkage, if a unique identifier of high quality is available (has to be precise, robust, stable over time)

- Examples: Medicare, ABN or Tax file number

## **Probabilistic linkage**

Apply linkage using available (personal) information

- like names, addresses, dates of birth, etc

# Why use linkage?

## Applications of data linkage

- Remove duplicates in a data set (internal linkage)
- Merge new records into a larger master data set
- Create patient or customer oriented statistics
- Compile data for longitudinal (over time) studies
- Geocode matching (with reference address data)

## Use of data linkage

- Immigration, taxation, social security, census
- Fraud, crime and terrorism intelligence
- Business mailing lists, exchange of customer data
- Social, health and biomedical research

Source: Christen, 2006

*Worldwide  
knowledge and  
understanding  
of Australian  
Indigenous  
cultures, past  
and present*

# Who performs linkage in Australia?

- Centre for Health Record Linkage (CheReL)
- Data Linkage Western Australia
- Centre for Data Linkage (Population Health Research Network)  
SA.NT DataLink
- Menzies Research Institute Tasmania Data Linkage Unit
- HealthlinQ
- Victorian Data Linkages (VDL)
- AIHW Data Linkage Unit
- Population Health Research Network Telethon Institute for Child Health

<https://www.sure.org.au/resources/australian-health-data-linkage-units>

Source: ABS, 2012

*Worldwide  
knowledge and  
understanding  
of Australian  
Indigenous  
cultures, past  
and present*

# Data Linkage and Aboriginal and Torres Strait Islander people

- Compare Indigenous status across data sets (under reporting in hospital data, registry data)
- Compare Indigenous and non-indigenous status on outcome variables of interest (Cancer, diabetes, smoking, alcohol use)
- Exclusively select Aboriginal and Torres Strait Islander people from data sets to study particular variables and link this with other datasets

<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129543445>

# Ethical considerations

- Gathering of information and its subsequent use are inherently political.
- Who makes decisions: what is collected, who collects it and who has access to it.
- Is it relevant to the questions, priorities and concerns of Aboriginal and Torres Strait Islander people.
- Collaborate from the start: from research design to community approval, don't leave it until the end.
- Involve Aboriginal and Torres Strait Islander expertise in (all stages) collection, analysis, interpretation and reporting

Schnarch, 2004

*Worldwide  
knowledge and  
understanding  
of Australian  
Indigenous  
cultures, past  
and present*

# Opportunities for data linkage in the Aboriginal and Torres Strait Islander Health space

- Current projects (with Aboriginal and Torres Strait Islander cohorts) provide opportunities (45 and Up) etc
- Australian Health Survey
- LSIC?
- ACCHSs ?
- New longitudinal studies (with strategic intent)?  
E.g. UAPS (Urban Aboriginal Peoples Study),  
Canada