



Australian Government
**Australian Institute of
Health and Welfare**



PHRN Population
Health
Research
Network

NCRIS
National Research
Infrastructure for Australia

An Australian Government Initiative

Linkage of national health (and other) data in Australia

Dr Phil Anderson - Head, Health Linkage Unit
AIHW Data Integration Services Centre



AIHW

Stronger evidence,
better decisions,
improved health and welfare



- Role of AIHW
- Linkage of national data
- Current challenges and initiatives
- Linkage success stories

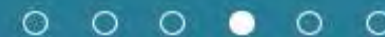




Stronger evidence, better decisions, improved health and welfare



In 2015, 10% of the burden due to vaccine preventable diseases was among Indigenous Australians



**Australia's welfare 2019:
data insights**

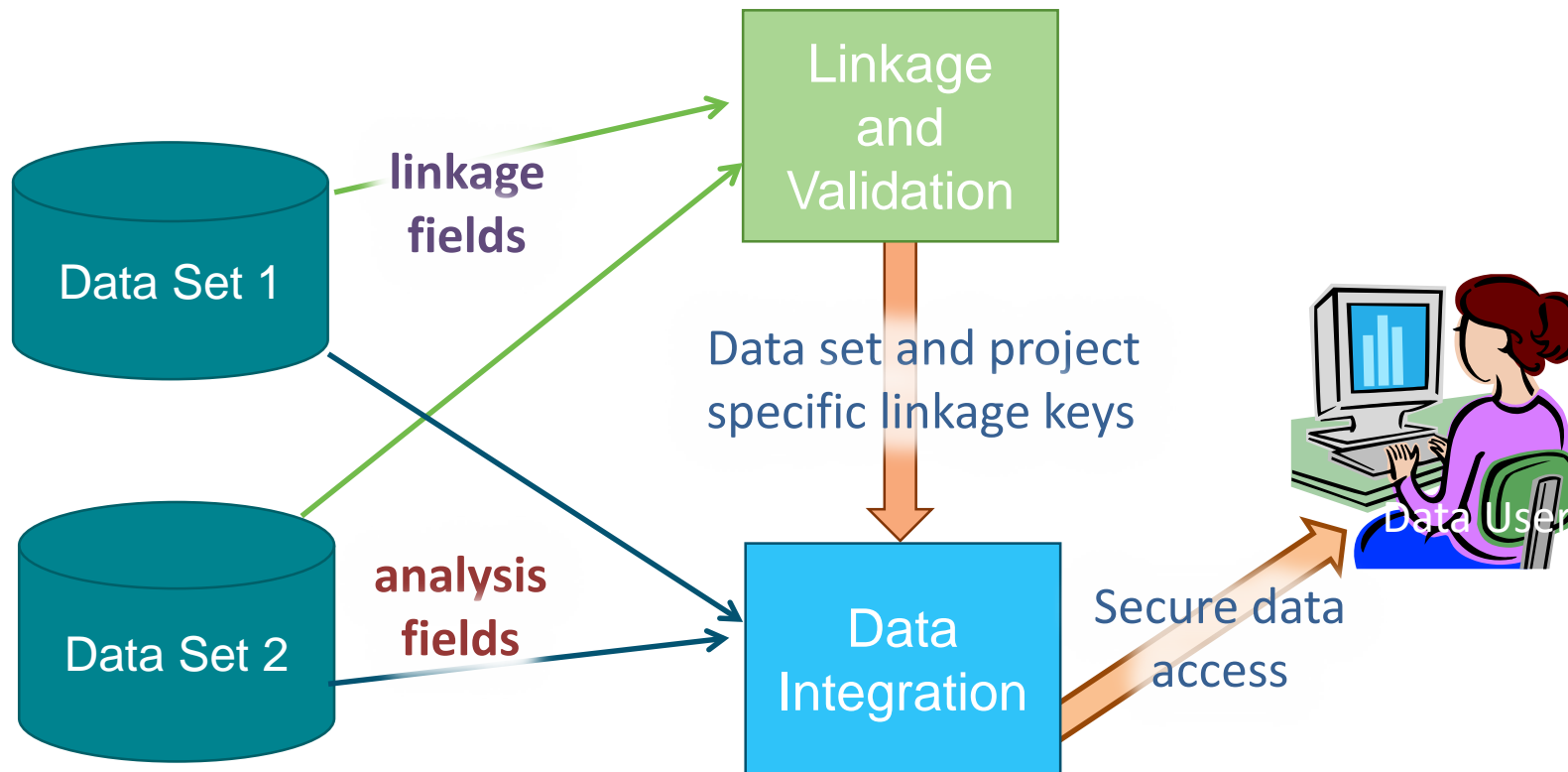
Australia's welfare 2019: data

Commonwealth Statistical Data Integration Framework

- High level principles
- Governance and institutional arrangements
- Integrating Authorities
 - Must be used for 'high risk' projects
 - End-to-end management of the linkage project
- National linkage unit in PHRN



Data Linkage under the IA Framework



Linkage at AIHW

➤ Commonwealth data

- Medical Benefits Schedule and Pharmaceutical Benefits Scheme
- Australian Immunisation Register
- DOMINO (Department of Social Services Data Over Multiple Individual Occurrences)
- National Aged Care Data Clearinghouse
- National Diabetes Services Scheme
- [National Cancer Screening Register](#)

The Medicare logo is displayed within a green rectangular box. The word "medicare" is written in a bold, lowercase, yellow sans-serif font, with a dark green shadow effect behind the letters.

Linkage at AIHW

➤ National Data

- National Death Index
- Australian Cancer Database
- ANZDATA
- Alcohol and Other Drugs Treatment Services NMDS
- Community Services data (eg homelessness, disability, youth justice, child protection)
- Australian Early Development Census

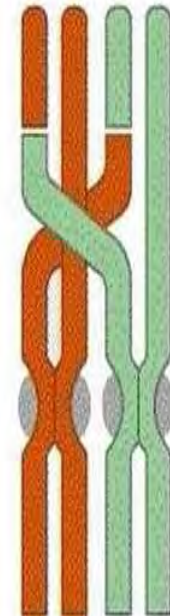
➤ Extensive collaboration with state data linkage units for linkage of state and national data

- Commonwealth to state linkage
- Multi-jurisdictional projects

AIHW Data Integration Services Centre (DISC)

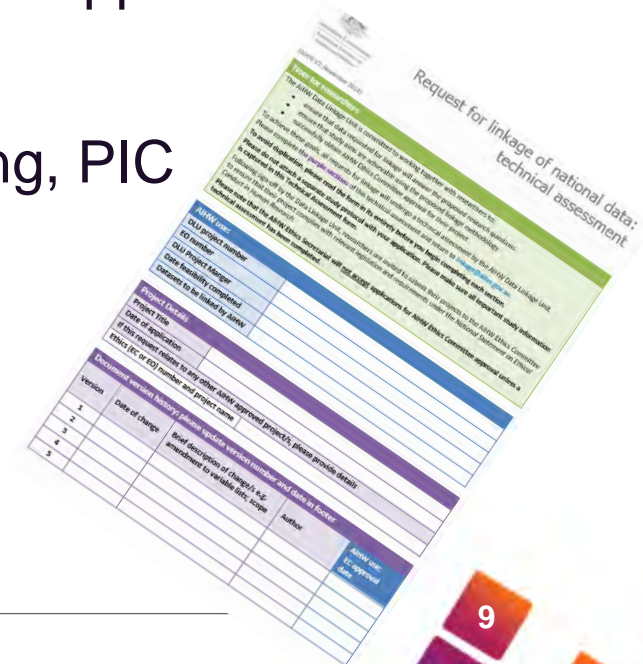
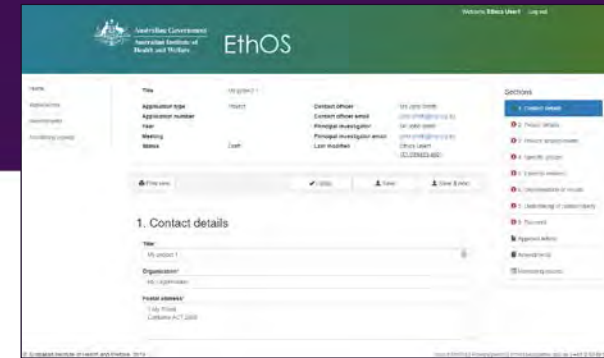


- Support research needs
 - Relies on subject matter/analysts expertise
- Adhere to separation and de-identification principles
- As approved by ethics
- In accordance with other confidentiality principles
- Outputs are safe, fit for purpose and validated
- Completed as rapidly as possible within constraints



Data linkage: approval processes

- New EthOS
- New technical assessment form
 - Clear two-stage process: technical feasibility before ethics approval
 - Involvement of data custodians
 - Better integration with other documentation (ethics briefing, PIC documentation, amendments, reporting, Five Safes)
 - One source of truth, particularly for variable lists
- Revised process for approval of releases
- Update to web pages





Data linkage

+ Committees >

+ Data on request >

Data linkage

> Researcher resources

> Data linkage services

> Data collections

> Our secure linkage environment

> Approved AIHW linkage projects

+ International collaboration >

+ Metadata support >

Validata >

Data linkage: accessing data

When you first contact the AIHW Data Integration Services Centre, you will be assigned a Project Manager who will guide you through the linkage journey.

Visit our [Researcher resources](#) for information about national datasets and helpful tips to assist you along the linkage pathway.

There are two compulsory steps to the data linkage process:

+ **Technical assessment**

+ **Ethics approvals**

Please note that the AIHW Ethics Committee will only consider linkage projects that have undergone a technical assessment by the Data Integration Services Centre.

Please leave plenty of time for the technical assessment. Although the Data Integration Services Centre will make every effort to progress your project as quickly as possible, we cannot guarantee that all projects will be assessed in time for submission to an up-coming AIHW Ethics Committee meeting.

Please begin both the technical assessment and ethics approval process early on.

Please contact the AIHW Data Integration Services Centre at linkage@aihw.gov.au.

An estimate of the costs associated with linkage can be requested at any time. A final quotation will be issued once the technical assessment has been completed.

Data custodian approval for Commonwealth data

Public Interest Certificate (PIC)

- Project Manager will organise this in collaboration with researchers
- Application informed by '5 Safes' risk assessment
- PIC signed by Chief Data Steward at the Department of Health
- Authorises DISC to release data to researchers
- Release is "necessary in the public interest"

Suitable analysis environment

- Secure research access environment:
 - data custodian requirement for some Commonwealth data collections (MBS, PBS, AIR)
 - Secure Unified Research Environment (SURE)
 - AIHW, ABS, AIFS data labs
 - AIHW curates all inputs and outputs once Commonwealth data uploaded

The Five Safes (AIHW adoption)

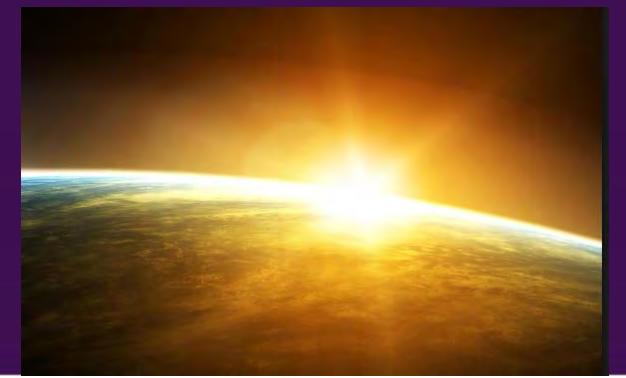
- Considers four environmental aspects, as well as the data itself, to ascertain risk of re-identification
- De-identification is not an exact science - does not avoid the need for complex judgement calls



Changing data environment

- Number and complexity of projects and collections: management
 - Data landscape more complex, changing and expanding
- Expectations around research programs and outputs
- Metadata management
- Changes in legislation and sharing arrangements
 - National Data Commissioner, proposed Data Sharing and Release Act
- Government priorities (Whole-Of-Govt initiatives, provide once use many times, need to understand impacts of govt programs)

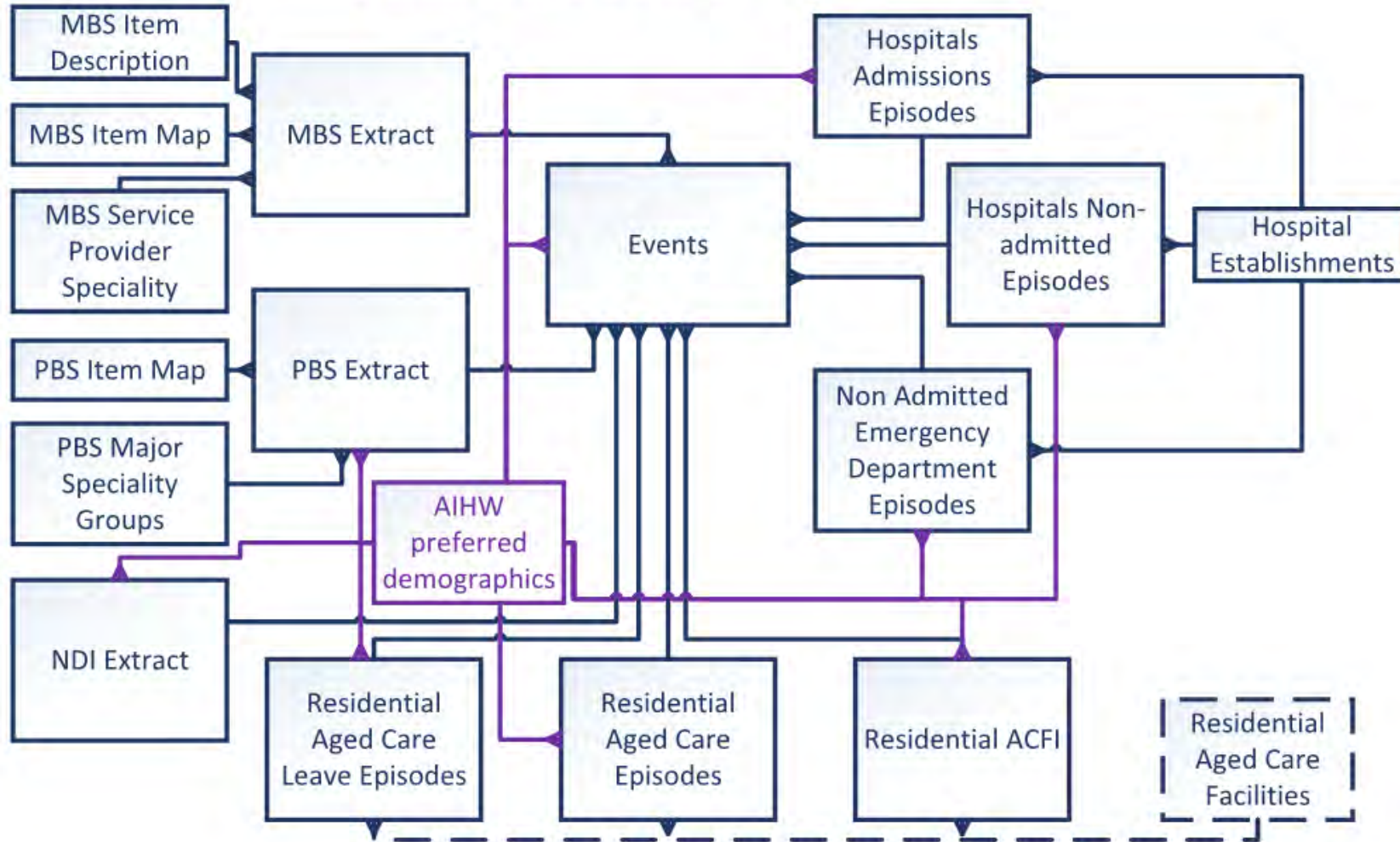
Project-based to systemic linkage



- Ongoing Medicare to National Death Index linkage
- Use of MEF as an intermediate linkage file
- Aged care linkage spine
- NIHSI AA (National Integrated Health Services Information Analysis Asset)
- National Disability Data Asset (NDDA), other linkages to DOMINO
- CAT-Link: linked cancer MBS/PBS project, plans for others
- Veterans linkage program

NIHSI Data Structure

Data Structure



v0.5
MBS, PBS,
NDI, RAC,
hospital and
ED data from
4 states

v1.0
Planned two
year update
with 7
jurisdictions

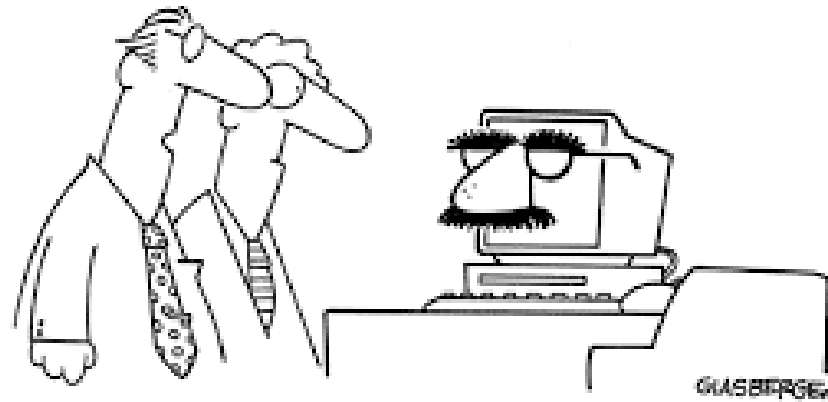
Other Initiatives

- Secure Remote Access Environment (SRAE)
- Machine Learning
- Data Integration Partnerships for Australia
 - Interoperability with ABS
- Collaborating on possible models for building a National Linkage system
 - More systematic arrangements with state linkage units



Questions?

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"I'm sure there are better ways to disguise sensitive information, but we don't have a big budget."



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