Australian Government

Australian Institute of Health and Welfare

Authoritative information and statistics to promote better health and wellbeing

Strategic Management of Cross-Jurisdictional Health Data

Australian Government Statistical Forum (AGSF)

30 May 2016

Health data infrastructure

- Health data held by both
  - Commonwealth (eg MBS/PBS) and
  - Jurisdictions (eg hospitals)
- AIHW collates, holds, manages and reports on health data
  - NMDSs particularly helpful in bringing together jurisdictional data

National Minimum DataSets (NMDS)

- NMDSs endorsed under national agreements
  - enables consistent collation of data
  - agreed standards and governance
- Brings together multi- jurisdictional data
  - does not usually identify cross-jurisdictional flows
  - does not identify individuals across service sectors

Bringing together health data

- Old model = project by project linkage
  - slow approvals and data destroyed afterwards
- PHRN linkage nodes hold Master Linkage Key (MLK) in each state
  - ongoing resource for 'linkage enabled' datasets
  - MLKs currently don't work across jurisdictions
- Jurisdictional infrastructure can extend to the national level as ongoing solution for health data

Cross-Jurisdictional Health Data Integration Model

Key Data Holdings

- Medical Benefits Schedule (MBS)
- Pharmaceuticals Benefits Scheme (PBS)
- Hospital NMDS
- National Death Index (NDI)
- National Mortality Database
- Australian Cancer Database
- Mental Health Services
- Drug and Alcohol Treatment Services
- National Aged Care Clearinghouse
- Indigenous health services
- Welfare datasets

Data Linkage Protocols

- Separation of personal/identifying data from analysis data
- Purpose-specific datasets created (not original complete datasets)
- Unique identifiers for each dataset
- No direct identifying data in linkage files
- Intermediate datasets & project specific identifiers deleted
- Physically & technically secure environment
- Separate secure network
- Risk based approaches to re-identification (trusted provider model)

Data Linkage Access and Approvals

- Flexible access options include
  - AIHW Data Lab
    - DISC secure area on-site at AIHW
  - SURE
    - Secure environment hosted by the Sax Institute
    - Part of existing PHRN infrastructure
- Data custodian and ethics committee approvals
  - Risk assessment, streamlining of ongoing arrangements

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Cross-Jurisdictional Data Linkage Example

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Better Cardiac Care Data Linkage (NSW)

MBS

NDI

AIHW

Linkage Domain
AIHW undertakes separate linkages to identifier data of each approved dataset, using the Cohort file.

Linkage keys

Merging Domain
AIHW obtains Content data separately from each approved data file and creates de-identified Content datasets with PPNs.

Hospital Cardiac Cohort data file
Contains identifier data and project-specific person number (PPN) of persons in scope of the project

CHeReL
(NSW Linkage Unit)

- Creates the 'Hospital Cardiac Cohort' file from the Master Linkage Key and assigns a PPN to each person on the Cohort file.
- Provides IDs and PPNs of Cohort records to state data custodians to extract Content data for Cohort records.

IDs of Cohort records are provided

IDs and PPNs are supplied to extract Content data for Cohort records

NSW APDC

NSW EDDC

ACT APC

ACT EDIS

Only Content data and PPNs are released to SURE

Secure Unified Research Environment

De-identified Content data and PPNs

Only Content data from MBS, NDI, NSW and ACT Hospital and Emergency datasets including PPNs are accessible

Only Content data and PPNs are released to SURE

Content data includes services, diagnostic, clinical and other data the researcher has approval to access.

Secure access

Cleared output

NSW
- **APDC: Admitted Patient Data Collection**
- **EDDC: Emergency Department Data Collection**

ACT
- **APC: Admitted Patient Collection**
- **EDIS: Emergency Department Information System**

Selected other projects

- Incidence and burden of childhood injuries (6 jurisdictions)
- Advanced Cancer Data System Study (SA)
- Better Cardiac Care (Qld – imminent)
- Human Papillomavirus (HPV) Vaccination (Vic)
- CT scan cancer risk (national)
- Youth justice, child protection and homelessness services (national)

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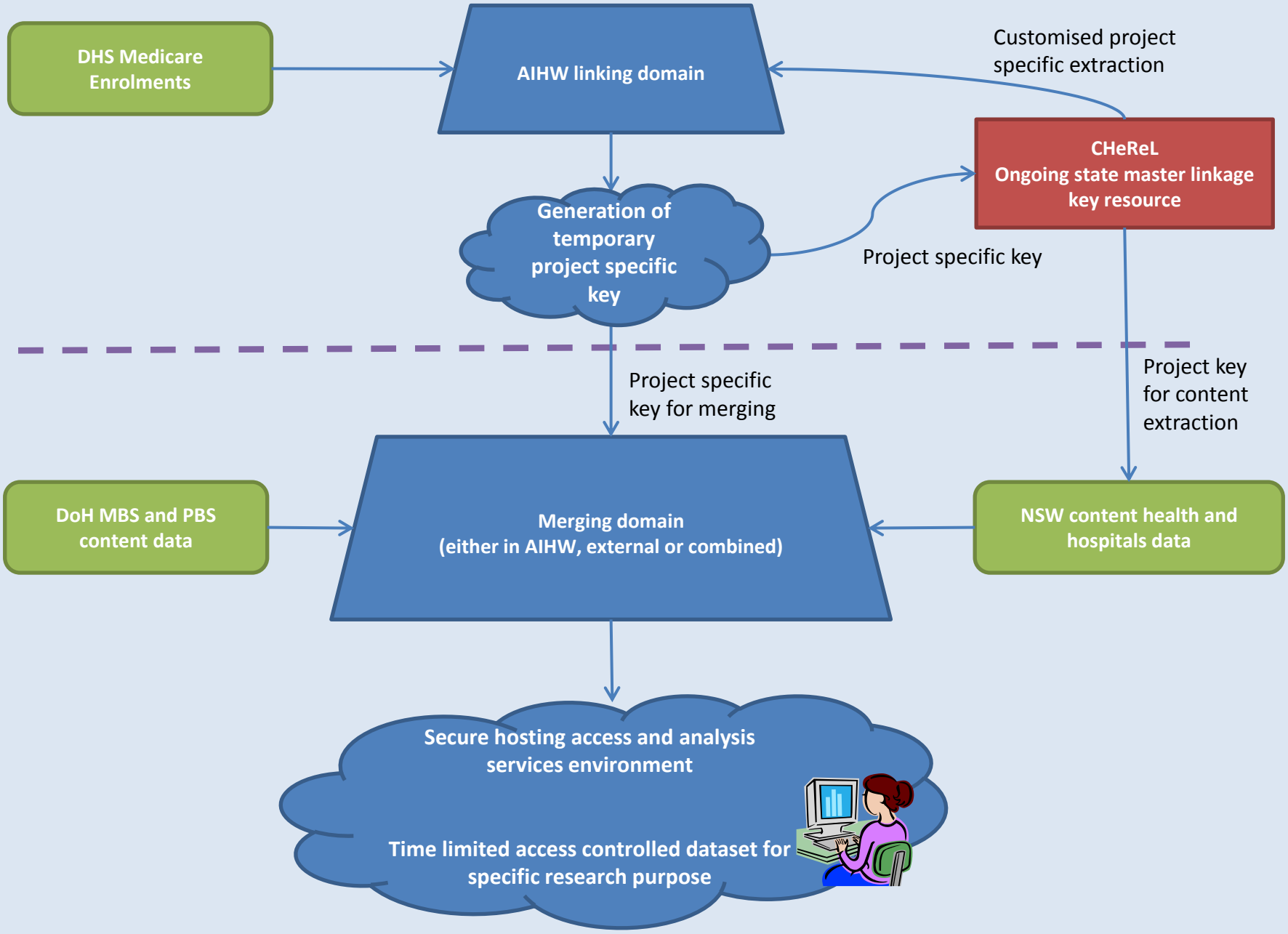
Enduring National Linkage Keys

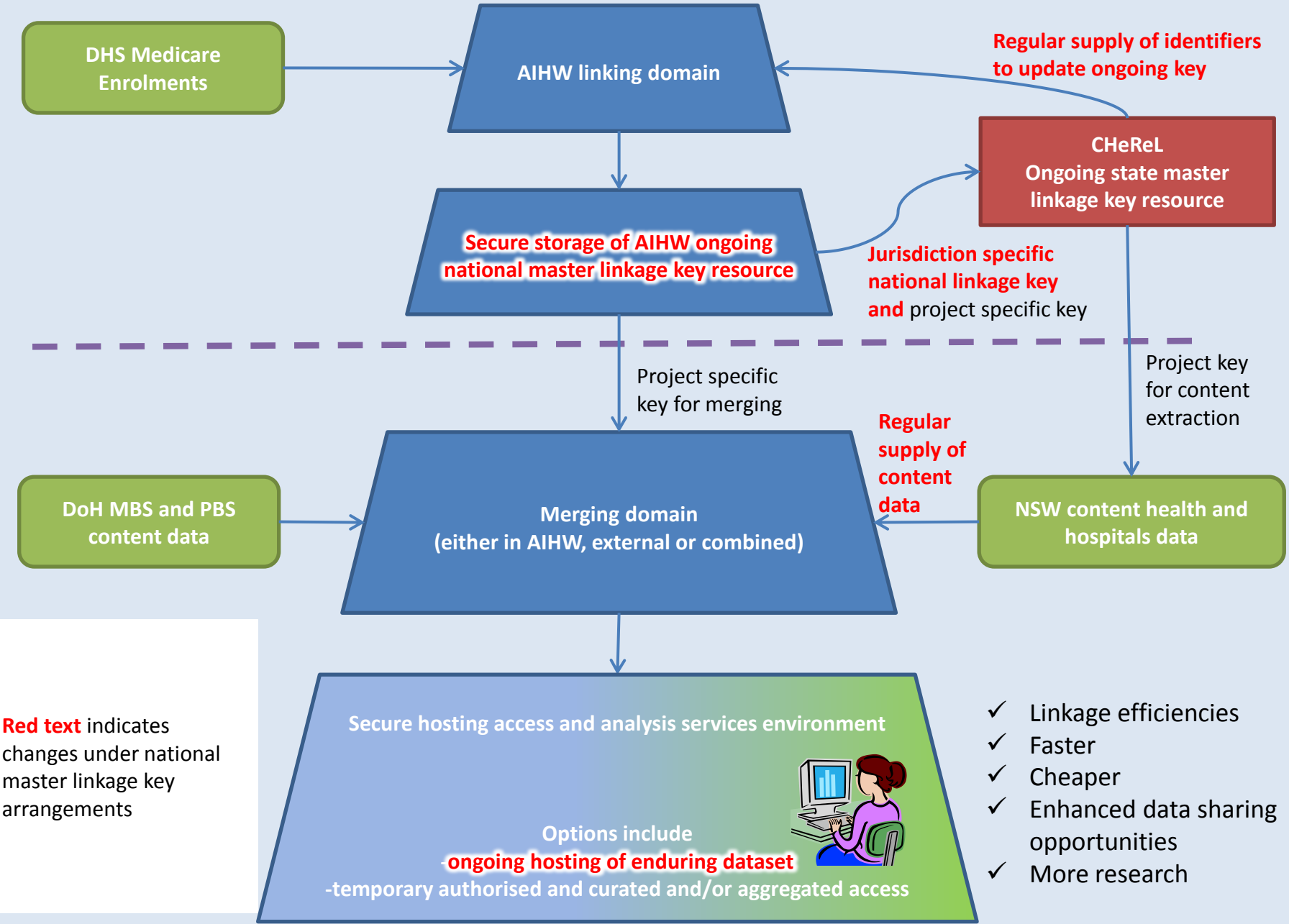
Extending existing infrastructure

- All jurisdictions built master linkage keys (MLKs)
  - Data pre- 'linkage enabled' with pointers to records relating to the same person in multiple datasets
  - Data can be brought together quickly and securely
- Can point national dataset to this infrastructure
  - ie build an enduring national linkage key
- Consistent national infrastructure for health data
  - Can evolve current system with ongoing extension

Data Flows Under a Project by Project Basis



Data Flows Using a National Master Linkage Key



Red text indicates changes under national master linkage key arrangements

- ✓ Linkage efficiencies
- ✓ Faster
- ✓ Cheaper
- ✓ Enhanced data sharing opportunities
- ✓ More research

Summary

- Increasing expectations from data
- Project by project flows of health data demonstrate possibilities for extension
- Ongoing jurisdictional infrastructure can be mirrored by a national node
  - Already doing this in part and piloting arrangements
  - Infrastructure broadly in place