

## WA Health Data Linkage Strategy 2022–2024

### Strategic # 🗸 theme

## **Engagement and transparency**

#### **Key objectives**

#### Improved community partnership and collaboration

 To actively engage, liaise and consult with key stakeholders to maintain positive working relationships, and ensure partnerships with the 'WA Data Linkage Community' (industry and/or end user groups) are open, informed, productive and effective.

#### **Robust governance**

 Provide a clear system of accountability and responsibility for the provision of data linkage services by WA Health, through development of robust governance, management and performance arrangements which are inclusive and reflective of stakeholder needs and are aligned to the relevant policies and legislation.

#### Building data linkage capability (staff and users)

 Invest in data linkage capabilities and associated training for WA public sector staff and linkage service users, to enable effective implementation of data linkage practices, and more timely access to high-quality linked data provided by WA Health for data-driven research and advanced analytics.

#### Activities

#### Improved community partnership and collaboration

#### **Presentations and forums**

- Develop and implement a 'WA Health Data Linkage Stakeholder Engagement Plan'.
- Promote presentations and forums to community and the sector to proactively inform of key developments to the WA Health Data Linkage Service.
- Include events managed by the Population Health Research Network (PHRN) and WA Health Translation Network (WAHTN).
- Creation of a forum to provide a platform for the data linkage community in WA to communicate, discuss and learn.

#### Communications

- Develop a communications strategy to keep stakeholders fully informed about reform, modernisation and priority setting plans and progress.
  - Communicate charging schedules and models and make them publicly available to improve charging transparency.
  - Creation and use of social media accounts to support timely dissemination of WA Health Data Linkage Service information and showcase the value of the service.
  - Review, re-design and improve the 'Data Linkage Western Australia' website to create an accessible medium for training, communications, information sharing and support.

#### **Partnerships**

- Seek and develop cross institutional partnerships and collaborations to build capability, support sustainable delivery of data linkage services, and increase transparency over activities, with e.g.:
  - research and academic sectors
  - not-for-profit/community sectors
  - cross-jurisdictional data linkage units established through the PHRN or any other legislative mechanism.

#### **Robust governance**

- Establish and maintain the 'WA Health Data Linkage Governance Committee Framework' to support development and implementation of the Strategy, in accordance with approved procedures:
  - WA Department of Health Data Linkage Executive Council
  - WA Department of Health Data Linkage Government Advisory Committee

### Strategic theme

## **Efficiency and effectiveness**

#### Key objectives

#### **Processes and procedures**

- Develop a systematic, streamlined, consistent and supported approach to accessing linked data.
- Promote and nurture a data linkage culture that seeks to continuously improve through innovation, forward thinking and the pursuit of excellence.
- Implement modern governance for timelier and more comprehensive access to data linkage services for more effective research, service planning and investment to meet community needs.

#### Technology / Infrastructure

Offer a dynamic and predictive data linkage capability that is flexible, scalable, and interoperable to accommodate existing and future requirements of the service, incorporating emerging technologies as appropriate.

#### Effective

Delivery of a data linkage service that meets reasonable expectations, is fit for purpose, and is rigorous in ensuring outcomes are valuable.

#### Activities

#### **Processes and procedures**

#### End to end use

- Review the end-to-end data linkage pipeline to identify opportunities for improvement and increased efficiency.
- Develop and implement mechanisms to accurately track and report on timeframes across the end-to-end data linkage service, increasing oversight of these individual functions.
- Develop and establish processes and data provision requirements that support clients to report the outcomes delivered through their Department of Health linked data use. This will enable better understanding of the crucial impacts of the linked data provided by WA Health.

#### Application

- Develop and implement a modern, simplified and integrated application process for access, governance and ethical approval of linked data provision by WA Health.
- Investigate the implementation of a 'standard data items' option for linked data requests, to streamline the application, extraction, review and data delivery process for several linked data requests of a similar nature.
- Develop effective client feedback mechanism to capture and proactively address common user issues.

#### **Policies**

- Review and amend linked data access policies and procedures to:
  - simplify the WA Health linked data application process and ensure metadata is available to users in a timely and effective manner
  - clearly define roles and responsibilities in data linkage service delivery and identify any gaps in the data linkage technical or governance processes.

#### **Culture of continuous improvement**

- Establish a multi-sectoral knowledge exchange (e.g. among policymakers, researchers, service providers, health consumers and other key stakeholders) to encourage a community of best practice.
- Incorporate innovation forums in operational environment such as an ideas box or a biannual innovation challenge.

#### Technology / Infrastructure

Create a WA Health Enterprise Linked Data Warehouse, in conjunction with WA public sector agencies, (i.e. Consolidated Linked Data Repository) to enable more timely access to key datasets (health and non-health).

Note: through additional investment to increase the number of datasets routinely linked and updated as part of the existing WADLS and CARES infrastructure.

- WA Department of Health Data Linkage Research Advisory Committee
- Information and System Performance Directorate Program Board
- Data Linkage Strategy and Reform Program Control Group.
- Develop key performance metrics to ensure transparency over service provision and provide clarity on reasonable expectations for service delivery.
- Providing regular advice on reform progress, including activities related to the engagement of the data linkage community (e.g. Government, research, not-for-profit sectors).

#### Building data linkage capability (staff and users)

- Produce training materials and educational resources that can be widely accessed by WADLS staff, the HREC, other Data Linkage units and service users.
- Regular training inductions and workshops facilitated by WA Health.
- Promote journal publications outlining key developments and learnings with respect to the WA Health Data Linkage Service, including successful reform activities.
- Implement the PHRN's National Training Framework as a locally-specific resource.
- Develop and make publicly available guidance resources (i.e. policy and procedure manuals) for public sector staff that clearly describe processes, ensuring a consistent approach to service delivery.

- Migrate the WADLS to a cloud-based platform to provide a rapidly scalable, flexible data linkage and secure access environment.
- Deploy test instance of the E-Research Institutional Cloud Architecture (ERICA) platform, co-designed with service users.
- Automate data linkage processes to enable near-real time linkage of commonly linked datasets within the WADLS and faster linkage of ad hoc datasets to routinely linked administrative data.
- Investigate and pilot the use of future technologies to support optimisation of linkage processes.

#### Effective

- Establish mechanisms that support future evaluation of the effectiveness of the linked data service provided by assessing the project outcomes against the project objectives.
- Implement a regular review of declined applications or those that required significantly amended applications as a mechanism for planning and service improvements (PPRL is already an example of this).
- Develop, implement and analyse an annual survey which directly seeks feedback from service users and review findings to evaluate services.
- Develop appropriate feedback mechanisms to provide routine project status updates to applicants.



# Strategic #3 Data availability and integrity

#### **Key objectives**

#### **Availability**

• Improve scope, affordability and value of data available through the WA Health data linkage service for all users

#### Integrity

- Attain a high level of data quality (completeness, validity, consistency, and timeliness) with balance across these dimensions.
- Ensure the level of data integrity (changes over time, differences between data sets) within and across linked data collections and linkage processes is consistently described.

#### Activities

#### **Data availability**

- Develop data sharing agreements with current and new data providers to facilitate timely, comprehensive 'whole-of government' and 'research' access to WA Health linked data sets for improved data linkage outcomes.
- Identify and attract new and valuable datasets for routine linkage, including non-Health administrative WA Government cross-sectoral datasets (e.g. Education, Communities, Justice and WA Police), key clinical datasets (e.g. imaging and pathology) and other key cross-jurisdictional and Commonwealth datasets (MBS, PBS and Primary Care). This is to increase the number of datasets available to users through the WADLS infrastructure.

**Note:** Priority and timing for inclusion of additional datasets will be determined in accordance with stakeholder feedback and service priorities determined through the 'Data Linkage Governance Framework'.

#### **Funding and charging**

- Develop a capacity and demand model to outline the true cost and resourcing implications for maintaining current data linkage service scope and onboarding additional linkage infrastructure and services, in accordance with strategic outcomes.
- Review, develop and advise on options available for amending the current 'funding' and 'charging' model for delivery of data linkage services by WA Health.
- Implement, once endorsed, the preferred funding and charging framework through:
- preparation of relevant funding request/s to support improved data linkage service provision and centralisation of the linkage capability.
- establishment of cross-institutional and cross-jurisdictional partnerships, as required, to augment funding and support financially sustainable delivery of data linkage services delivered by WA Health (e.g. through development of external grant-funding arrangements).
- preparation of relevant charging schedules and procedures.

#### Integrity

- Develop data quality 'best practice' guidelines to support data providers in the provision of high-quality data for linkage (i.e. Advocacy and Education).
- Support and form whole-of-government common standards for core data fields, led by the WA Department of the Premier and Cabinet (Office of Digital Government).
- Explore the viability of implementing a mechanism that ensures draft manuscripts are reviewed prior to publication for quality assurance purposes including appropriateness, data security and appropriate reference to source data (i.e. WA Health datasets).
- Develop processes for review of the output of linked data provided to end-users to ensure the quality / integrity of data is accurately reported.
- Investigate the implementation of a data and linkage quality feedback process to identify

# Strategic #

### Compliance

#### Key objectives

#### **Access and disclosure**

• To ensure the access and disclosure of information complies with applicable legislation and policy requirements.

#### **Privacy and security**

• Enable access to and disclosure of information while protecting privacy and maintaining security. To ensure processes for access and disclosure (including transmission, transfer, storage, use and destruction of linked data) comply with security requirements of applicable legislation, policies and guidelines.

#### Activities

#### Access, disclosure and use

- Review current procedures for ensuring data security and privacy against requirements of applicable legislation, policy and best practice data linkage industry standards. This includes for example, review of key policy frameworks in WA Health for informed consent for use, sharing and release of data.
- Implement mechanisms that support WA Health conditions for use, storage and destruction of data.
- Develop and implement coordinated eResearch platform that supports timely and secure provisioning of data from the WA Health Enterprise Linked Data Warehouse for all users.

#### Privacy

- Support the implementation of 'privacy and responsible information sharing legislation' (PRIS Bill) in WA, led by the WA Department of the Premier and Cabinet (Office of Digital Government).
- Review and re-assess 'sensitive data items'.
- Conduct a proof-of-concept process to assess feasibility of implementing privacy preserving linkage mechanisms to provide a safe and effective approach to combine data from different sources.
- Investigate the application of synthetic data to support safe and secure analytics, minimising the release of personal information.

#### **Security**

- Automate security testing through penetration testing of applications exposed to the internet.
- Automate Quality Assurance over outgoing data collections and data items so that they are restricted to only those approved in the Application for Data.
- Maximise existing security functionality to ensure access and data availability is restricted only to 'approved users'

and support potential areas for improvement with data providers.

() WA Health Vision	A WA health system that delivers safe, high quality and sustainable services that support and improve the health of all Western Australians.
WA Health Data Linkage Strategy Vision	Using and sharing linked data to improve outcomes for the community by putting linked data at the core of decision-making and research, through a collaborative, coordinated, consistent and safe approach.
📿 Purpose	To reform and innovate the process for provision of linked data in a transparent way that is timely, affordable and of appropriate scope for the evolving needs of users and the community.
Target audience	WA Data Linkage Community, including WA Health Data Linkage Service Staff, Data Providers, the Human Research Ethics Committee and Users (e.g. Government, research, not-for-profit sectors).
Principles	④ Sharing culture 品 Collaborative 🎝 Adaptable 🖯 Safe 오 Sustainable 회 Feasible