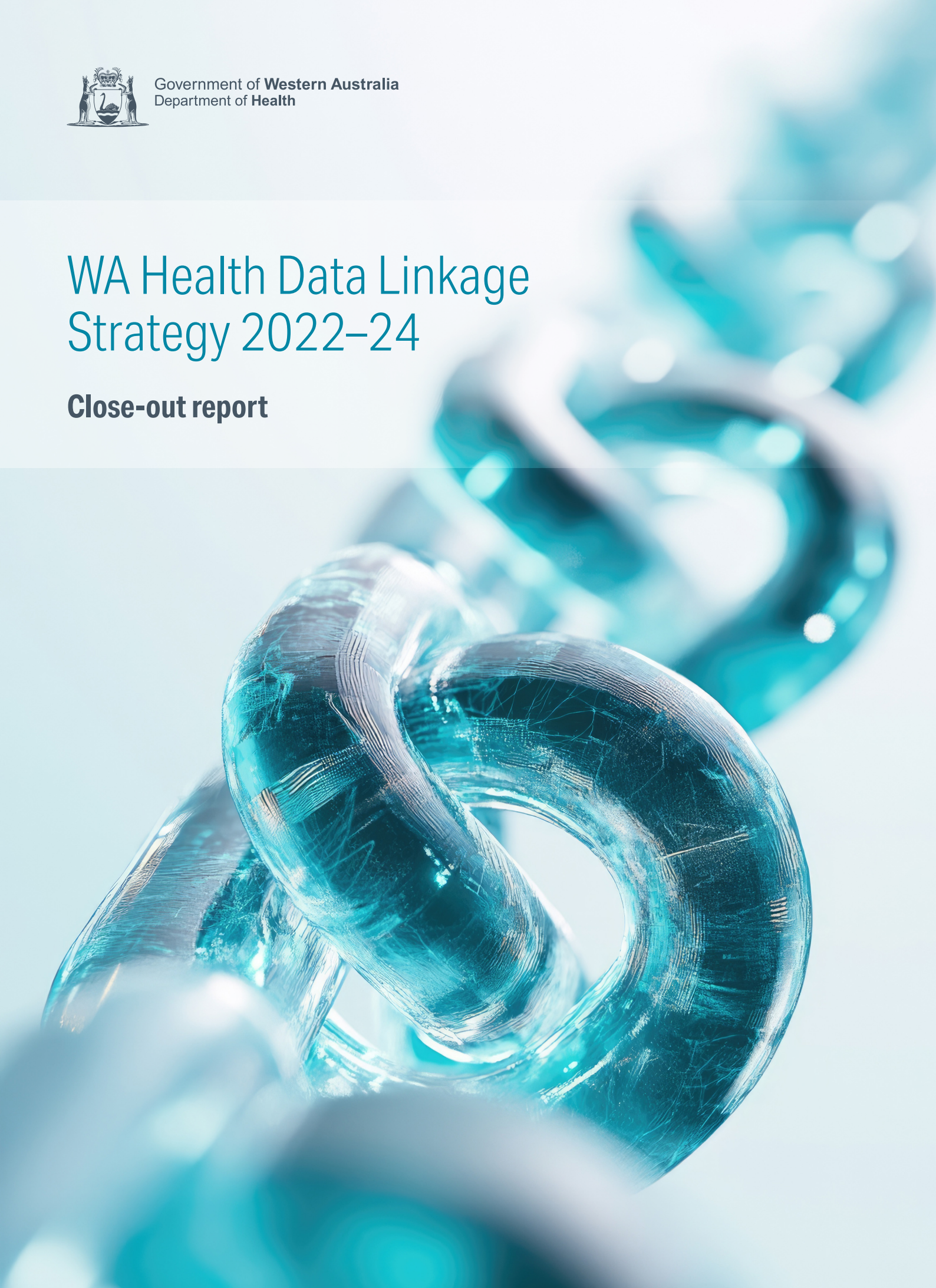
Government of **Western Australia**
Department of **Health**

WA Health Data Linkage Strategy 2022–24

Close-out report



Contents

Foreword

To our valued stakeholders,

On behalf of the Data Linkage Services (DLS) team, I am pleased to present the close-out report for the WA Health Data Linkage Strategy 2022–24 (the strategy).

Over the last 3 years, the WA Department of Health (the department) has delivered a broad program of reform projects to modernise, simplify and improve access to WA Health system data while maintaining privacy and security of our most valuable assets.

Grounded in the Data Linkage Expert Advisory Group's 'Review of Western Australia's Data Linkage Capabilities' (2016) and WA Health's 'Sustainable Health Review' (2019), this inaugural strategy formed the foundation of the Data Linkage Strategy and Reform Program (reform program). Its development was further shaped by the COVID-19 pandemic, which highlighted the urgent need for coordinated, timely access to linked data to understand the social, health and economic impacts of policy decisions.

During the public health emergency, WA was the only jurisdiction to rapidly link hospital, emergency department, pathology, immunisation and mortality datasets, delivering the COVID Vaccination Linked Data Repository. This resource was critical to informing state activities such as contact tracing, vaccine rollout and capacity and demand modelling.

Through the dedication and hard work of our exceptional team we radically accelerated our operational efficiency, enabling hourly and daily linkages. This marked the beginning of an ambitious transformation program aimed at re-establishing the department as the leading data linkage provider in Australia.

Significant investment in strategic and operational teams enabled a comprehensive set of reforms. These included the migration of our linkage infrastructure to a secure cloud environment, the establishment of an integrated data repository, the generation of synthetic health data and the introduction of a Project Application Tracker to improve timeliness and transparency.

We strengthened our governance through the publication of WA Health's first Data Linkage Policy and became the state's first accredited Data User and Data Service Provider under the national Data Availability and Transparency Scheme. We supported the development of the WA Health Aboriginal Data Governance Policy and the implementation of the Privacy and Responsible Information Sharing legislation.

Our collaborative efforts extend across sectors and jurisdictions. We co-developed the whole-of-government PeopleWA linked data repository with the Office of Digital Government and contributed to the design of integrated data systems at the national level.

One of the most critical outcomes of this reform has been expanding the use of linked data to support not only medical research, but also service planning, operational decision-making, and health policy development. Faster turnaround times, greater process transparency, and scalable infrastructure now enable WA Health teams, researchers and collaborators to use high-quality linked data more effectively. These enhancements also make WA a more attractive partner for national funding bodies such as the National Health and Medical Research Council (NHMRC), Australian Research Council (ARC) and Medical Research Future Fund (MRFF), unlocking new investment opportunities for research and innovation in the state.

As I look back, I am proud of the progress we have made. Our team has significantly improved the scope, efficiency, sustainability and value of the linked data infrastructure positioning it as a core enabler of a modern, responsive health system.

As we embark on the next phase of reform program, including development of the 2025–30 strategy, we remain committed to further improving how data is connected and used to benefit all Western Australians.

I extend my deepest gratitude and thanks to everyone who has contributed to this program, particularly our partners, collaborators, researchers, data scientists, subject matter experts, advisors and project teams. Thank you for helping us create a healthier and more connected community for all Australians.

Nasir David
Director, Data and Information Systems
Information and System Performance Directorate
Purchasing and Systems Performance Division
WA Department of Health

Executive summary

The WA Health Data Linkage Strategy 2022–24 (the strategy) was developed to transform how linked data is accessed, governed, and used across the WA Health system. Over the past 3 years, the department has delivered a suite of reforms to modernise data infrastructure, streamline service pathways, improve governance, and strengthen cross-sector engagement.

These reforms have established the foundations of a more responsive, scalable, and secure data environment, one that now supports a wide range of functions across the health system, including medical research, service planning, operational decision-making and policy development.

As a result of this work, the department has improved the timeliness and reliability of its DLS, offering users, from clinicians to researchers, greater certainty and transparency. These improvements are enabling faster access to high-quality linked data, which in turn enhances decision-making and resource allocation to support our patients across the system.

The reforms have also significantly improved WA's ability to support national and competitive research. Enhanced service efficiency now allows research teams to access data within project funding windows, making WA a more attractive destination for investment from the NHMRC, ARC, MRFF, and other funding bodies. This positions WA to contribute more actively to high-impact national collaborations and innovation-driven research.

Looking forward, the strategy has paved way for a new phase of reform. WA Health is currently developing a 2025–30 strategy that will build on these foundations, extending the reach and capability of the data linkage service. Priorities will include increased dataset availability, growing capability across the linked data landscape, and stronger alignment with both internal system needs and national data reform agendas.

With this work, the department is ensuring that high-quality, privacy-protected linked data remains a core enabler of a modern, efficient, and equitable health system, supporting improved outcomes for all Western Australians.

1. Introducing Data Linkage Services

1.1 Introduction

The successful delivery of the WA Health Data Linkage Strategy 2022–24 has been made possible through the collective expertise, collaboration and sustained effort of multiple teams across WA Health.

This section outlines the organisational structure and governance arrangements that supported the reform program, defines the core functions of the DLS team, and describes the key bodies responsible for strategic direction, advisory input and cross-sector engagement.

Together, these elements form the backbone of a modern and responsive data linkage system that serves the research community, policy-makers, operational leaders and service planners across the WA Health system.

1.2 Who we are

Data Linkage Services

DLS comprises the expertise and dedication of several teams at the department who each contribute to the provision of data services for research, to support policy development and implementation, and for service improvement.

DLS is located in the **Information and System Performance Directorate** (ISPD) which is responsible for the governance, transformation, maintenance, analysis and reporting of core health data. This work is fundamental to performance evaluation, resource allocation, policy development, and provision of evidence-based programs and services to improve the health of Western Australians.

The **Data Linkage** team manages the WA Data Linkage System (WADLS) to create, store, update and extract links between population-based administrative and research data collections in WA. Data engineers within the Data Linkage team routinely link both health and non-health datasets, create linkage keys and enhance data through geocoding, family connections and other value-adding services.

A dedicated **Systems** team ensures WADLS and other servers and systems are well maintained, secure and best equipped to manage the diverse and ever-increasing volume of data handled by the various teams. This includes writing software, maintaining server architecture, and assisting staff to keep technical operations running smoothly.

The **ISPD Client Services** team manage queries and requests for data on behalf of the entire directorate through the data request pipeline, liaising with clients and internal business units to facilitate and monitor requests for data provisioning. Our request coordinators work with research, governance and technical stakeholders to support consistent and reliable service delivery.

Established initially as a temporary function to develop a strategy, mobilise governance frameworks and deliver outcomes, the **Data Linkage Strategy** team operates across multiple workstreams, collaborating with cross-sectoral and cross-jurisdictional working groups on complex and ambitious projects within the reform program to progress significant reform in alignment with state and national priorities.

The **Data Innovation** team apply technology in innovative ways to help clients and end-users get more from data and data collections. This includes piloting new tools, embedding advanced analytics within applications and investigating automation, machine learning (ML) and artificial intelligence (AI) models to utilise data in innovative and progressive ways.

Responsible for the extraction and delivery of data sets to approved end-users, the **Data Engineering Outputs** team facilitate providing data to and from the Linked Data Warehouse, performing routine merging and quality assurance checks for linkage projects. The Data Engineering Outputs team also supports applicants through the preparation of metadata and documentation to assist with data analysis.

Research Data, Ethics and Governance, located in the Office of Medical Research and Innovation (OMRI), ensure compliance with established ethical principles, legislation, codes of practice and regulations. This includes processing ethics and research governance applications, conducting site reviews and providing comprehensive, confidential administrative support to the WA Health Central Human Research Ethics Committee (HREC).

1.3 The Data Linkage Strategy and Reform Program

The reform program is a comprehensive series of projects that were initiated to understand the themes and objectives of the strategy. Designed to modernise, simplify and improve access to WA Health system data, the projects were aligned with the recommendations of the Data Linkage Expert Advisory Group, chaired by the Chief Scientist of WA.

Agile by design, the reform program is based on an understanding of user requirements to develop a linkage service which is responsive and that can meet future demands.

'The new data linkage reforms allow for better interrogation of information across multiple datasets, while implementing industry-leading cyber security measures.'

Chief Scientist of WA,
Professor Peter Klinken (May 2022)

Through the reform program, we have:

- supported all relevant recommendations from the Review of Western Australia's Data Linkage Capabilities (2016), including whole-of-government recommendations collaboratively supported with other agencies
- aligned activities with recommendation 6 of the Service Priority Review (2017) to strengthen data sharing and improve Information and Communications Technology (ICT) performance and cyber security
- supported implementation of recommendation 21 of the WA Health's Sustainable Health Review (2019) to invest in analytical capability through establishing modern governance for timely and comprehensive access to DLS
- contributed to the delivery of substantial digital transformation projects in alignment with the WA Digital Strategy 2021–25.

'Improved linkage capabilities will enable decisions to be better informed by data and will aid researchers in their efforts to improve the health and wellbeing of all Western Australians.'

Minister for Medical Research,
Stephen Dawson (May 2022)

1.4 Structure and governance

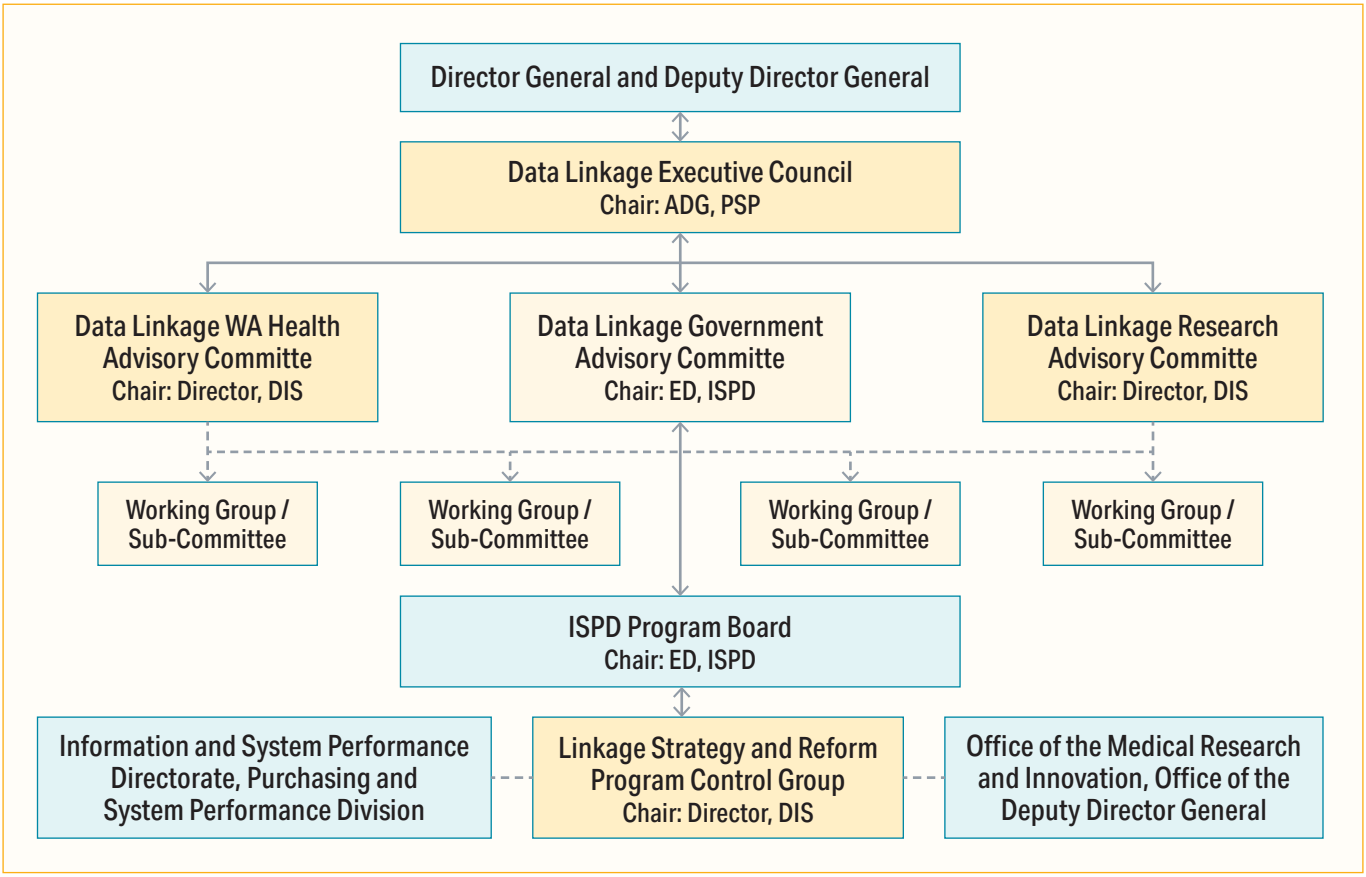


Chart 1. Data Linkage Governance Framework

The reform program established our current governance structure which consists of a decision-making body and 2 advisory committees established to reflect the subject matter expertise of a broad stakeholder group.

Reporting to the Director General and the Deputy Director General, the **Data Linkage Executive Council** (Executive Council) is the primary decision-making body for the reform program with membership from departmental executives and chaired by the Assistant Director General (ADG), Purchasing and System Performance (PSP).

The **Data Linkage WA Health Advisory Committee** (HAC) provides strategic advice to the Executive Council on contemporary data linkage with implications on the WA Health system. The establishment of HAC in August 2023 recognised the value provided by increased involvement from WA Health system entities to reduce duplication of functions, enhance information sharing and ensure effective use of outputs for improving WA Health system policies and programs.

Current membership of the HAC includes:

- Child and Adolescent Health Service
- Clinical Excellence Division
- East Metropolitan Health Service
- Health Support Services
- North Metropolitan Health Service
- Office of the Deputy Director General
- PathWest Laboratory Medicine (WA)
- Public and Aboriginal Health Division
- Purchasing and System Performance Division
- South Metropolitan Health Service
- Strategy and Governance Division
- WA Country Health Service.

The research community continues to be an important stakeholder in progressing strategic data linkage reform. Established in December 2022, the **Data Linkage Research Advisory Committee** (RAC) provides a forum for researchers to advocate their needs (at the organisation-level) and for us to share information on the work being undertaken as part of the reform program.

RAC provides strategic advice to the Executive Council on contemporary data linkage, research and governance matters including HREC functions and processes, applicable governance policies and procedures, approvals and application processes, user training and support materials and activities of WA universities and research institutions to support data linkage and accompanying analysis in WA.

Current membership of the RAC includes:

- Curtin University
- Department of Health (WA)
- Department of the Premier and Cabinet
- Edith Cowan University
- Fiona Wood Foundation
- Joondalup Health Campus
- LaTrobe University
- Murdoch University
- Population Health Research Network
- The Kids Research Institute Australia
- The University of Notre Dame
- The University of Western Australia
- The Western Australian Health Translation Network
- WA Data Science Innovation Hub
- WA Primary Health Alliance.

The **Data Linkage Government Advisory Committee** included representatives from several government departments, including the Departments of Justice, Education, Communities, as well as WA Police and Main Roads.

Following the successful implementation of PeopleWA, the Government Advisory Committee transitioned to newly established whole-of-government forums at the Department of the Premier and Cabinet (DPC), including the PeopleWA Governance Group, the Data and Linkage Advisory Committee, and the Business and Technology Advisory Committee. The final meeting of the Government Advisory Committee was held in November 2022.

> 'All work carried out in relation to the strategy has been incredibly crucial in building the platform to propel WA back to the forefront of data service delivery across the nation.'
>
> 'It has brought WA back to a leadership position across Australia and internationally.'
>
> Stakeholder feedback from the Data Linkage Strategy 2022–24 Stakeholder Feedback Survey

2. The strategy in review

Since the strategy was implemented, the reform program has delivered an ambitious suite of initiatives. The following quantifies some of the key achievements for this impressive program of work.

76
External engagements

204
Publications*

Number of Governance meetings by group

Forum	Number of meetings convened
Executive Council	4
Research Advisory Committee	8
Health Advisory Committee	3
Governance Advisory Committee	2
Program Control Group	28
Total	**44**

161
Projects delivered
(new projects where all data was provided)*

36m
Records – Largest infrastructure dataset in WADLS

555,000
Clerical reviews completed (2022–24)

376,000
Manual cleans completed (2022–24)

11
Daily linkages

187,822,894
Records linked

31
Cross-collaborations

1,652,072,516
Records released*

85
Infrastructure datasets in WADLS

24
Ad hoc linkages*

50%
Reduction in processing times

7x
Processing speeds

* as of 30 June 2024

3. The Data Linkage Strategy 2022–24

Following extensive consultation with research, not-for-profit and government sectors, the strategy was released by the Minister for Medical Research at Science on the Swan in May 2023. Aligned to recommendations from both the 2016 *Review of Western Australia's Data Linkage Capabilities* and the *Sustainable Health Review* 2019 (the reviews), the strategy provided an ambitious program of work to improve how data was delivered in WA, improving decision-making and the health and wellbeing of all Western Australians.

3.1 Vision

Our vision is to:

> Improve community outcomes by putting linked data at the core of decision-making and research through a collaborative, coordinated, consistent and safe approach.

3.2 Purpose

The strategy's purpose is 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.

As part of the strategy's implementation, we embarked on various activities to improve the scope, efficiency, affordability, sustainability and value of linked data through WA's established linked data infrastructure, to support government service delivery, policy, programs and health-related research.

> 'Improved linkage capabilities will enable decisions to be better informed by data and will aid researchers in their efforts to improve the health and wellbeing of all Western Australians.'
>
> Minister for Medical Research, Stephen Dawson (May 2022)

3.3 Strategic themes, objectives and activities

The following diagram introduces each strategic theme, its objectives and the initiatives or projects that have been delivered. Given the extent and depth of the projects, some activities fall under more than one theme. The initiatives are further explored in the following section.

Strategic theme and objective	Section	Initiatives delivered
Strategic theme 1: Engagement and transparency This captures the importance of engaging with consumers and key stakeholders to provide clear communications. By strengthening community partnerships, implementing clear governance and investing in WA public sector staff and data linkage users, the department fosters positive relationships and recognises the value these collaborations bring.	4.1	Recruitment and enhancement of data capabilities
	4.3	Implementing a whole-of-government data repository, PeopleWA
	4.4	Project Application Tracker and Key Performance Indicator Dashboard
	4.5	Reforming the funding and charging model – WA Data Services Prioritisation and Costing Framework
	4.7	Synthetic Data Generation Project
	4.8	Developing and promoting training materials and educational resources
	4.11	Improved communication through updating the DLS website
	4.12	Robust governance
	4.15	Streamlining the application for data process
Strategic theme 2: Efficiency and effectiveness This emphasises the need for an efficient, innovative service that promotes continuous development to pursue excellence as a world-renowned data linkage unit. By streamlining data access and modernising governance, the department ensures timely and comprehensive services to maintain its status as one of the world's leading data linkage units.	4.2	Migration of the WA Data Linkage System to the Cloud
	4.3	Implementing a whole-of-government data repository, PeopleWA
	4.4	Project Application Tracker and Key Performance Indicator Dashboard
	4.5	Reforming the funding and charging model – WA Data Services Prioritisation and Costing Framework
	4.6	Updating linked data infrastructure and attracting new datasets for linkage
	4.10	Implementing Privacy Preserving Record Linkage as a service
	4.12	Robust governance
	4.13	Research ethics and governance reform
	4.14	Client Services Feedback Survey
	4.15	Streamlining the application for data process
	4.16	Implementing an e-research platform for evaluation

Strategic theme and objective	Section	Initiatives delivered
Strategic theme 3: Data availability and integrity This highlights the importance of providing accessible, affordable, high-quality data to support research and population health initiatives in WA and Australia. The Data Linkage Service ensures high quality data by evaluating completeness, validity, consistency and timeliness to maintain the integrity of linked data throughout its lifecycle.	4.3	Implementing a whole-of-government data repository, PeopleWA
	4.5	Reforming the funding and charging model – WA Data Services Prioritisation and Costing Framework
	4.6	Updating linked data infrastructure and attracting new datasets for linkage
	4.8	Developing and promoting training materials and educational resources
	4.17	National data initiatives
Strategic theme 4: Compliance Linking sensitive health data requires strict security and privacy measures to ensure this valuable data is secure and protected. The compliance theme emphasises maintaining privacy and confidentiality in alignment with legislation and policy. By ensuring compliance throughout the data linkage process, including transmission, storage, use and destruction of linked data records, the department safeguards sensitive health information.	4.7	Synthetic Data Generation Project
	4.9	Accreditation as a Data Service Provider under the *Data Availability and Transparency Act Scheme 2022* including publishing the Department of Health Data Linkage Policy
	4.10	Implementing Privacy Preserving Record Linkage as a service
	4.16	Implementing an e-research platform for evaluation

4. WA Health Data Linkage Strategy and Reform Program 2022–24 achievements and impacts

The strategic themes and objectives outline the framework guiding our efforts to modernise, simplify and improve access to WA Health system data. This section highlights the achievements and impacts of these initiatives and their benefits.

4.1 Recruitment and enhancement of data capabilities

The key achievement of the reform program has been a significant increase in capability through the substantial investment in professional development and new staff. Since 2022, 18 new positions have been created to advance key reform initiatives and staff have had opportunities for industry-led development, to acquire new skills through modernising technology and processes, and grow into leaders. Across ISPD, the workforce has contributed valuable knowledge and expertise to strengthen the program and position us as a world-class data linkage unit.

Achievements and impacts

Commitment to data linkage at the department

ISPD and the former Research and Innovation Office (now OMRI) committed to modernising data linkage across the WA Health system through the creation of a dedicated strategy project team. Recognising the success of this model and reflecting the department's ongoing commitment to support data linkage, the project roles were made permanent within a year.

Transition of Research Data Services function

After assessing the research experience, staff changes and resourcing challenges, the 1. Deputy Director General and ADG PSP decided to transition the former Research Data Services to consolidate with data linkage teams within ISPD. This transition expanded ISPD's scope to 2. establish the ISPD Client Services team, which manages research and non-research data requests and serves as a consistent and supportive interface between internal and external stakeholders. As a result, ISPD also 3. took on responsibility for 187 research data requests across various stages. Following the 4. successful handover of key functions, 6. ISPD resumed operational research data service activities with 5. a structured communication and prioritisation plan to support timely processing of applications for WA Health system data.

Establishment of synthetic data subject matter expertise

As a result of the strategy the department has been recognised as a national leader in developing synthetic data, strengthened by ISPD resources, collaborators and the investment in subject matter expertise. The appointment of a skilled Lead Data Scientist and support team delivered 3 representative synthetic datasets for the 2023 WA Data Science and Innovation Hub (WADSIH) Health Hackathon. The team now leads the way in the generation of a linked representative synthetic dataset for safe and secure health system analytics.

Benefits

- Increased productivity – over 1 billion records were released over the course of the strategy due to increased staff numbers and capacity. This has profound benefits for research, service improvement and planning.
- Supported stakeholders – the investment in staff and building capability has ensured an informed, responsive and timely service that not only meets the needs of data users and collaborators, but also provides opportunities for knowledge translation and increased capability.
- Job creation and satisfaction – the creation of jobs benefits all Australians and helps retain subject matter knowledge and expertise in WA. Through skill building opportunities, staff are supported to develop their expertise and key transferrable skills, contributing to increased job satisfaction.
- Contributed to the department's reputation as a world class data linkage service – the department's reputation has been promoted through staff development and investment in new and innovative endeavours, such as generating representative synthetic data.

4.2 Migration of the WA Data Linkage System to a cloud server

A key reform project was the successful migration of legacy infrastructure from physical servers at Royal Street, East Perth, to cloud-based servers. This shift to a more powerful, scalable and flexible system was essential to align with best practice industry standards and to address the technical, maintenance, performance, cost and security risks of the previous on-premises environment.

Extensive review of relevant legislation, Department Cloud Policy and application data sharing agreements to identify data management risks were undertaken to ensure all datasets were transitioned in strict compliance with prescribed requirements.

Achievements and impacts

- Processing speed increased sevenfold allowing:
  - more routine linkage updates through reduced clerical review wait times
  - enhanced linkage strategies to identify additional links between datasets
  - an increase in Data Linkage team productivity providing opportunities to automate tasks.
- No disruption to critical data linkage operations, including routine COVID-19 linkages to support monitoring and surveillance activities and no adverse impacts to core systems or reports.

Benefits

- Increased capacity – the move to a more contemporary and scalable architecture provides opportunities to commit to more complex projects and meet future data linkage demands. This included supporting daily linkages of vaccination data from the Australian Immunisation Register for the state's COVID-19 response and increasing the frequency of routine linkages.
- Promoted innovation and development – the migration informed development of the linked data repository and enabled the whole-of-government linked data asset, PeopleWA.
- Improved security – superior security features offered by the Cloud significantly lowers the risk of data breaches and unauthorised access. Automated security tasks and encryption lowers the likelihood of errors.

4.3 Implementing a whole-of-government data repository, PeopleWA

The 2022 investment of more than $8 million from the Digital Capability Fund to provide a central, world-class data linkage system in WA recognises the capability of our staff.

The proposal for a whole-of-government linked data repository, PeopleWA, was co-developed by the department and DPC through the Office of Digital Government (DigiGov), with the Departments of Treasury, Justice, Communities, Education, the Mental Health Commission and WA Police.

As the state's lead linkage agency, we are commissioned by the State Government to provide our expertise to deliver technical cross-sectoral DLS to create and maintain links held within the whole-of-government data repository. We have enabled PeopleWA to successfully leverage vast administrative data routinely collected by government agencies to create a consolidated cross-sectoral integrated data and analytics system in WA, providing timely access to public sector data for vital medical research and government service planning.

PeopleWA now operationalises more than 75 million linked government records through a new research platform. Together with the department, PeopleWA has developed data sharing agreements via memoranda of understanding with current and new cross-sector partners to provide a valuable and expanding data asset for the benefit of the WA community.

PeopleWA currently includes linked data relating to:

- health
- child protection
- disability
- education
- public housing
- police
- justice
- life events (births and deaths)
- workforce training.

Achievements and impacts

- In the financial year 2023–24, we delivered more than 1 billion health service data records to PeopleWA. Through streamlined processes, infrastructure upgrades and increased resources, recent health service data is now more readily accessible to support contemporary research, service improvement and policy.
- We have worked closely with PeopleWA stakeholders to streamline data access processes via a consolidated online data application system that provides one clear pathway for access to linked government data.
- Expanding PeopleWA to include valuable non-health state government and research datasets is crucial for maintaining the repository's value, and we have committed to linking 4 additional non-health datasets annually.
- From October 2024, we successfully expanded our health data offering within PeopleWA to include data from:
  - Emergency Department Data Collection
  - Hospital Morbidity Data Collection
  - Midwives Notification System
  - Mental Health Information Data
  - WA Cancer Registry
  - WA Notifiable Infectious Disease Database
  - WA Registry of Developmental Anomalies.
- We provide quarterly updates of health linkage products and service level data, ensuring PeopleWA has access to the most recent data available.
- We have worked with DigiGov to form common standards for core data fields to build capability, support streamlined processes and facilitate a common language across government, research and external sectors.

> 'The sheer volume of data linked in PeopleWA is incredible. This data will allow the State Government, researchers and non-profit organisations to make better informed policy and strategy decisions.'
>
> Minister of Medical Research, Stephen Dawson

Benefits

Developing governance frameworks and technical capabilities to link and provide a comprehensive view of service provision and access across WA with PeopleWA has profound benefits for the WA community.

- Improved collaboration – breaking down the silos between government agencies has created a shared understanding of access to services across social and health domains which will ultimately improve service provision for Western Australians and beyond.
- Developed user competency – education, training and the development of supporting materials have promoted a consistent language across the WA data landscape, improving knowledge and promoting a data-driven culture.
- Improved access – the streamlining of application processes across jurisdictions and the provision of one point of entry to access whole-of-government data has reduced fragmentation and ensured timely access to data, free of unnecessary administrative burden.
- Developed partnerships – WA's expertise and progress has received national recognition, fostering opportunities for further collaborations and partnerships.

> 'WA has a long history of data linkage, and PeopleWA will help enhance community outcomes by placing data at the forefront of the decision-making and research.'
>
> Chief Scientist of WA, Professor Peter Klinken

4.4 Project Application Tracker and Key Performance Indicator Dashboard

The Project Application Tracker and Key Performance Indicator (KPI) Dashboard reporting tools are key infrastructure we developed to track and report timeframes across the end-to-end data linkage service, improving transparency and oversight. The Project Application Tracker allows data applicants to access the most up to date information on the status of their requests for WA Health data publicly via the WA DLS website. The KPI Dashboard provides high-level information to Data Linkage executives and includes key data for the department's bi-annual Commonwealth reporting to the Population Health Research Network (PHRN).

Benefits

Establishing transparent communication with data users and key stakeholders has ensured consistent reporting across the data linkage pipeline.

- Increased consumer engagement – a proactive communication line with applicants on the progress of their data requests and the provision of an appointed contact for further assistance has ensured access to the most up-to-date information and prompt support with queries.
- Increased capacity – by providing an avenue for applicants to view their application's progress, the Project Application Tracker has freed resources within our ISPD Client Services team.
- Improved user knowledge – the Project Application Tracker has helped with educating stakeholders and data applicants on the WA Health DLS request for data process, including the roles and responsibilities of the various stakeholders.

4.5 Reforming the funding and charging model – WA Data Services Prioritisation and Costing Framework

We offer a range of high-quality products and services based on specialised linkage knowledge and technologies, employing a highly skilled team of data engineers, system administrators, request coordinators and project officers to deliver these products and services.

Given finite resources and the need to ensure consistency and transparency in actioning data requests, we developed a prioritisation framework. The framework is used to ensure all applications are assessed consistently with clear criteria used to inform decision making and actively manage demand for data services.

Our WA Data Services Prioritisation and Costing Framework includes revisions to the charging model for WA data services to promote research using WA Health system data and ensures greater consistency in charges across application types. The updated model reflects significant improvements and investment made to the department's data infrastructure and processes to provide a clear costing model based on time and resources required to deliver a data request. To support this, we developed an online self-serve pricing calculator which is available through the Project Application Tracker. This has been widely praised

by stakeholders, including the PHRN, for providing clear and open communication and supporting the research community to provide cost estimates for grant applications.

Benefits

The WA Data Services Prioritisation and Costing Framework provides another method to increase transparency and communication with data users and stakeholders whilst providing staff guidance.

- System priorities – the production of a framework that prioritises system needs, legal requirements and funded research has ensured timely data access for critical issues, accelerating the implementation of findings.
- Increased transparency – through the provision of a clear and simple charging formula that links project resources to costs, we have improved transparency with all data users.
- Increased accountability – the Data Service Prioritisation and Costing Framework holds the department and stakeholders accountable to established service levels.
- Reduced administrative burden – through providing a self-serve price estimate calculator, the administrative burden on the ISPD Client Services team has reduced, freeing up time to work on other tasks.
- Improved user and staff capability – through the production of publicly available guidance resources a consistent approach to service delivery has been established, improving the capability of data users and staff.

4.6 Updating linked data infrastructure and attracting new datasets for linkage

The WA Health Linked Data Warehouse was launched in February 2023 and reflects the redevelopment and modernisation of linked data infrastructure into a linked data repository. This allows for linked WA Health system data to be extracted through a single platform, significantly reducing the time required to identify cohorts and extract data for approved projects.

Given the success of modernising the department's data storage and our linkage infrastructure, the strategic intent to attract, link and store new datasets became achievable. With formal approval from the ADG PSP, we began collaborating with PathWest to build a linked pathology dataset for system manager use and approved research by enabling the provision of information from PathWest Soft Laboratory Information Systems to ISPD for linkage and incorporation within the Data Warehouse.

Updating the linked data infrastructure has provided a comprehensive architectural design, documents to support operation and maintenance of the platform and created the ethical pathways to facilitate the transition of datasets to the data warehouse.

Benefits

- More informed research and policy – the upgrade has increased the breadth, relevance and currency of data, providing the community with more current linked datasets to drive insights and improve health and social outcomes.
- Reduced processing time – the time taken to extract and deliver data for research projects since the upgrade has reduced by 50 per cent (overall timeline for data delivery from finalisation of custodian approval).
- Increased projects delivered – the number of projects extracted after the upgrade has increased, reflecting improvements in timeliness and reduced queues compared to the legacy system.
- Reduced resource consumption – the upgrade has reduced the number of resources required to facilitate data extraction and quality assurance, creating a more sustainable and automated process for data engineers.
- Increased staff competency – data capability amongst staff has improved through the process of developing the warehouse and working with stakeholders such as PathWest to integrate their datasets.

4.7 Synthetic Data Generation Project

Data access and sharing comes with privacy and security risks especially when it is associated with sensitive healthcare collections. To address barriers and ensure access to sensitive health data for planning purposes, there is a need to share data without unnecessary risk to the privacy of health consumers. The Synthetic Data Generation Project aims to support safe and secure analysis of systemic health issues, minimising the release of 'health information' defined under section 213 of the *Health Services Act 2016* (WA).

Representative synthetic data is artificially manufactured from real data and has the same population level statistical properties as the original data. Synthetic data is produced using statistical and ML techniques to mimic the original data. The creation of representative synthetic data is a risk mitigation strategy to provide users with data while preserving the privacy of individuals and the confidentiality of real data.

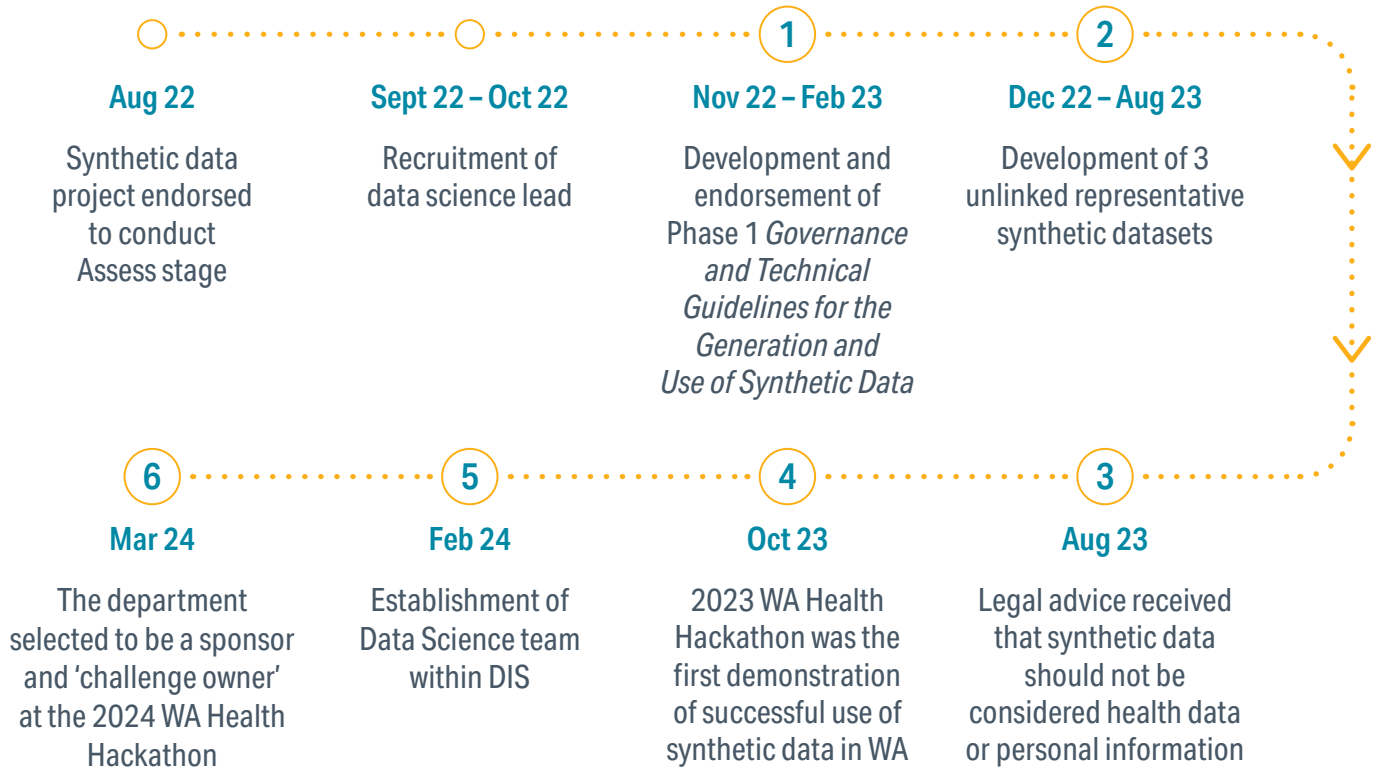
We commenced the Synthetic Data Generation Project in 2022 as a proof-of-concept (Phase 1) with the primary objective to generate non-linked representative synthetic data for use at the 2023 WA Health Hackathon, facilitated by the WADSIH. Historically the scope of the department's involvement in hackathons has been restricted due to privacy and confidentiality concerns regarding provision of patient sensitive data to users outside of WA Health.

The successful development and use of representative synthetic data at the 2023 WA Health Hackathon paved way for the project to be expanded. In May 2024, the department commenced Phase 2 of the project and began establishing the governance framework and technical capacity to generate linked representative synthetic data. Linked data is valuable for data analysis as it provides a more complete picture of the population or cohort. Phase 2 has 2 main objectives:

1. Develop and implement techniques and algorithms with the aim of creating linked representative synthetic datasets with specific properties preserved from pre-linked source datasets (i.e. Emergency Department Data Collection 2022 and Hospital Morbidity Data Collection 2022).
2. Develop a robust governance framework to enable the provision of linked representative synthetic data in WA to support research, system evaluation monitoring and innovative events.

Phase 2 is currently in progress and due for completion by October 2025.

Achievements and impacts



1. Development of the Phase 1 *Governance and Technical Guidelines for the Generation and Use of Synthetic Data* (the guidelines) to mitigate against the release of personal and health information. The guidelines were endorsed by the Director General in February 2023.
2. Development of 3 unlinked representative synthetic datasets using the Emergency Department Data Collection, Hospital Morbidity Data Collection and WA Cancer Registry data. In September 2023 the ADG approved the release of these datasets to authorised users participating in the 2023 WA Health Hackathon.
3. On receipt of advice from the department's Legal and Legislative Services, a decision was made that the synthetic data generated by the department should not be considered personal or health information, allowing this data to be utilised without compromising privacy.
4. The use of synthetic data for the 2023 WA Health Hackathon was the first demonstration of successful use of synthetic data in WA. The ability for participants to develop innovative solutions to real-world healthcare challenges using the synthetic datasets supplied by the department is a testimony to the usability of the data. Director, Data and Information Systems at the department was invited to be a member of the judging panel for the 2023 WA Health Hackathon finale.
5. Establishment of a Data Science team within Data and Information Systems at the department and successful recruitment to these positions to support existing staff and strengthen the skillset and expertise required to progress Phase 2 of the Synthetic Data Generation Project.
6. The department was selected to be a sponsor and 'challenge owner' at the 2024 WA Health Hackathon. A superior quality of unlinked representative data was generated using advanced synthesising techniques developed in Phase 2. This improved version was provided to support the challenge question devised by the Data Science team for the event.

Benefits

The generation of representative synthetic data enables the provision of data to assist projects that otherwise could not be supported due to privacy concerns and legislative restrictions.

- More timely access to data – synthetic data reduces the time required for governance processes associated with gaining access to sensitive health information, accelerating access to representative health care data.
- Maintained privacy and security – synthetic data can replicate important statistical properties of real health information without releasing real data, eliminating the risk of data breaches and reducing privacy concerns.
- Promotes innovation and excellence – the provision of quality representative synthetic data for public innovation supports the translation of data into actionable solutions that help reform the WA healthcare landscape.
- Assistance for the research community (Phase 2) – synthetic data contains the same field names, value domains and general trends of real data, which allows researchers to test their methodologies or commence the creation of analytical scripts in preparation for the receipt of real data.

4.8 Developing and promoting training materials and educational resources

We published training materials, educational resources, guidance documents and frameworks to support linkage service users, data providers and WA public sector staff. The development of these resources was a direct response to share the significant wealth of knowledge and expertise developed over the last 30 years to improve capability and increase knowledge across the data landscape.

We also saw the benefit of encouraging a common language across jurisdictions and the cost and time efficiencies this would provide through promoting partners' training materials and resources. The free to access PHRN Online Researcher Training was informed by the department and has been a valuable resource to build knowledge of the application process, improving access to data and increasing capability across the sector.

Achievements and impacts

Since 2022, we have worked closely with subject matter experts and stakeholders to create various guidance documents and frameworks, including:

- Limitations and Suitable Use of Linked Data (2024) – publicly available guide supporting service users' understanding of data quality and the appropriate uses for linked data in line with industry best practice.
- WA Data Services Prioritisation and Costing Framework (2023) – revised charging model with clear and transparent guidelines for data users to support access to data linkage products and services.

- Research Data Services Roles and Responsibilities (2023) – comprehensive guide to stakeholders involved in facilitating access to data for research purposes, and interdependent legislative and policy requirements for each stage of application.
- 'Minimum Data Requirements for Linkage' (2023) – data quality best practice guidelines to support data providers sharing high-quality data for linkage, improving data availability and integrity.
- 'Governance and Technical Guidelines for the Generation and Use of Synthetic Data' (2023) – comprehensive guide to techniques, methods and governance required to produce and use representative synthetic health data.
- 'Privacy Preserving Record Linkage Guide' (2023) – outlining department processes and procedures to securely link information that is subject to legislative, policy or security restrictions.
- The department informed the development of the PHRN Online Researcher Training to provide jurisdictional information on the research application for data process to improve understanding and ultimately, access to data.

Benefits

- More timely access to data – access to educational resources enables effective implementation of data linkage practices, contributing to more timely access to high-quality linked data.
- Improved capability – enhanced staff and user capability by openly communicating and sharing standardised processes and procedures across the data landscape.
- Reduced resource consumption – freeing up our resources by providing informed, standardised and current procedures as a first point of query resolution.
- A common language across the data landscape – through the promotion of jurisdictional resources, a common language and understanding is being built across the nation, supporting data service providers and users to work together.
- Less duplication of effort across the sector – time and cost efficiencies have been achieved through the promotion of jurisdictional resources, reducing the duplication of effort across the sector.

4.9 Accreditation as a Data Service Provider under the *Data Availability and Transparency Act Scheme 2022* including publishing the Department of Health Data Linkage Policy

In 2023, we performed procedural and policy reforms to enhance transparency for users relating to data linkage processes. These reforms also focused on establishing clear requirements to support the implementation of best-practice data linkage and integration standards across the WA Health system.

Following the introduction of the *Data Availability and Transparency Act 2022* (DAT Act), the Office of the National Data Commissioner (ONDC) established a new scheme for sharing Australian Government data, underpinned by consistent processes.

This scheme overcomes barriers to data sharing using appropriate safeguards. Australian state and territory government bodies and Australian universities can request Australian Government data once accredited.

The department was the first WA body to apply for accreditation under the DAT Act and worked closely with the ONDC to ensure compliance with complex application requirements. Key to this accreditation was the application of the Separation Principle, the gold standard for safe and secure linkage practices.

We developed the WA Health system's first Data Linkage Policy and compendium in collaboration with internal technical and governance stakeholders, the Policy and Governance team and the Policy Framework Support team.

In addition to capturing the Separation Principle, the policy supports a higher standard for linkage activities. This includes adopting the national best practice guidelines when dealing with data linkage activities relating to Aboriginal people when developing Aboriginal and Torres Strait Islander flags.

As part of the drafting process, the department consulted DPC representatives and the ONDC to ensure alignment in the description of data linkage and integration functions captured within the DAT Act and forthcoming Privacy and Responsible Information Sharing (PRIS) legislation.

This policy will undergo regular reviews to ensure alignment with whole-of-government strategic consolidation of data linkage service models through PeopleWA. It will also support the application of person-based linkage models applied for approved data sharing projects.

Achievements and impacts

- The National Data Commissioner virtually attended the RAC in December 2023 to present to research stakeholders on the operation of the Data Availability and Transparency Act Scheme (DATA Scheme) and the 'Dataplace' platform.
- The first Data Linkage Policy and supporting compendium were published in May 2024, formally capturing the requirement for the Separation Principle to ensure the highest standards are upheld when using personal information for data linkage.
- The department was the first WA body to be accredited as both a Data User and Data Service Provider under the new DATA Scheme.

Benefits

- Ensured adherence to best practice – the Data Linkage Policy helps the WA Health system uphold effective and responsible data linkage processes, as well as safeguard privacy and maintain ethical consideration and integrity.
- Defined roles and responsibilities – in addition to providing greater transparency on service operation, the policy documents assist in clearly defining roles and responsibilities in data linkage service delivery to identify and overcome gaps in data linkage governance and technical processes.
- Improved data access – through accreditation under the DATA Scheme, the department has increased the opportunity to offer highly valuable Australian Government data to support service delivery, inform government policy and programs, and support world-leading research and development.

4.10 Implementing Privacy Preserving Record Linkage as a service

We implemented the 'privacy by design' model for data linkage, which utilises the Separation Principle and clear text identifiers to ensure the highest quality matches whilst protecting personal privacy. In instances where clear text identifiers cannot be provided, Privacy Preserving Record Linkage (PPRL) may be a viable option.

PPRL is a linkage methodology that preserves the privacy of individuals through specialised software to irreversibly 'hash' demographic variables and derive a new string. This new string enables record linkage but does not identify an individual, which significantly reduces the risk of sharing record-level data.

PPRL can be used to support data sharing and integration for government services, research, and other initiatives to improve health outcomes at state and national levels, while adhering to the Australian Privacy Principles.

We collaborated with Curtin University's Centre for Data Linkage, as a third-party PPRL provider, to advance proof-of-concept projects focused on evaluating PPRL implementation feasibility. The following 2 projects were successfully delivered using the PPRL model:

1. Understanding the incidence, prevalence, and rates of progression of chronic kidney disease in WA.
2. Privacy Preserving Record Linkage for Western Australian birth defects and Australian Pharmaceutical Benefits Scheme claims data.

While clear text identifiers are ideal for high linkage quality, PPRL can bridge gaps where sharing of identifying data is restricted. At a state level, the PPRL method was used to support the integration of Department of Justice data for the PeopleWA platform, due to current limitations of the *Children's Court of Western Australia Act 1988* (WA) restricting the release of personal information for data linkage purposes.

Achievements and impacts

- We created the following third-party provider agnostic resources to support the implementation of PPRL and ensure the PPRL service can be undertaken by any third-party provider. These resources have been published on the WA Data Linkage Services website:
  - PPRL Guide
  - PPRL application form
  - External providers data checklist
  - PPRL process flowchart.
- The Executive Council formally endorsed the transition of PPRL from a concept to an operational service within the department, which has been subsequently implemented.

Benefits

PPRL engages and supports state and multi-jurisdictional projects that require data that otherwise cannot be provided due to legislative and safety barriers.

- Wider scope – provides access to data collections commonly restricted by legislative and policy barriers, allowing us to make a broader scope of data available.
- Improved capability – enhancement of data linkage and extraction capabilities have improved the skill set of departmental staff.
- Improved transparency of roles and responsibilities – establishing roles and responsibilities between the department and third-party PPRL providers has improved the capacity to support sustainable DLS, providing transparency on the delineation of roles and facilitation of future projects.

> 'We will be able to study a person's interactions with the health system and overlay big data analytics with the ultimate aim of new research discoveries.'
>
> Professor Gavin Pereira, Curtin Health Research and Data Analytics Hub.

4.11 Improved communication through updating the DLS website

Supported by the reviews, the strategy was developed to reform and innovate the linked data provision process. A key enabler was the review and re-design of the WA DLS website, improving the medium for training, communication, information sharing and support for key stakeholders including data users, data providers and data linkage staff.

Driven by user-feedback, the WA DLS website update modified the layout for improved access and readability to ensure the content was clear, relevant, informative and current for the needs of the community.

Achievements and impacts

- Provided an avenue for feedback through the Client Services Feedback Survey, allowing data applicants to share their experiences accessing health data. The survey data assesses system performance and informs strategic reforms to improve service effectiveness.
- The Project Application Tracker enables data applicants to track their applications, increasing transparency on projects. It provides us with important information about the number of projects received, delivered or currently active within a given year, offering a measurable value reflecting the efficiency of DLS.
- We published a Minimum Data Requirements for Linkage guideline to communicate best-practice guidance for data providers to maintain high-quality data and efficient data linkage practices. By remaining transparent and actively sharing these guidelines with data providers and stakeholders, we ensure data is high quality and in a consistent format to maintain the integrity of the state's data linkage infrastructure.
- The WA DLS website update involved publishing the WA Data Services Prioritisation and Costing Framework, which provides all stakeholders with key information regarding the department's prioritisation and costing approach. The publication of this framework ensures that all applications are assessed consistently with clear criteria used to inform decision making and manage the demand for data services.

Benefits

The update of the WA Data Linkage Services website provides us with a platform to share and disseminate crucial information in the scope of data linkage, which improves engagement and transparency with data linkage users. This website update has contributed to several key benefits.

- Improved user communication – provides accurate, current and relevant information for the website's primary users, including researchers and data providers.
- Encouraged feedback and growth – provides data applicants with a direct line of feedback to the ISPD Client Services team, which allows user-centric recommendations to be implemented for continuous growth and innovation.
- Improved reputation – restored the department's credibility with data users who were previously dissatisfied with the previous WA Data Linkage Services website, whilst increasing traffic to the updated website through improved search engine ranking, improving user experience and increasing engagement with stakeholders and data applicants.
- Increased user and provider capabilities – enhanced data quality from data providers and the quality of applications from researchers through publishing guidelines, minimum requirements and a link to PHRN's Online Researcher Training, improving the capability of users and providers for more efficient DLS.

4.12 Robust governance

The development and implementation of the WA Health Data Linkage Governance Framework (defined and illustrated in **1.4 Structure and Governance**) laid the foundation for an ambitious reform program consisting of effective decision-making, expertise and partnerships. It has fostered open communication to all key stakeholders across the WA data landscape, including the research and not-for-profit sectors, health services and jurisdictional partners, promoting collaboration, capability uplift and knowledge translation. Through these fora, priorities can be identified, outcomes shared and knowledge disseminated.

We have created information governance documentation to support data access, disclosure and use, information currency and protection for the E-Research Infrastructure Cloud Architecture (ERICA) platform and Wrike project management tool, with the WA Data Linkage System and Data Warehouse information governance documents currently in development.

As a key stakeholder within the PRIS Implementation Steering Committee, we have contributed knowledge and expertise to develop the WA Health Aboriginal Data Governance Policy, in line with mechanisms to support Aboriginal Data Sovereignty and Governance in WA as part of the PRIS Bill.

Benefits

- System priorities – key stakeholder groups are consulted with and represented to support informed decision-making, ensuring system priorities are identified and projects are well-advised.
- Maximise data access and use – information governance documentation ensures necessary information is accessible to achieve department functions in accordance with the *Health Services Act 2016* (WA) and other written laws.
- Build capability – provides employees with the knowledge and ability to safely access information.
- Transparency – provides open communication with stakeholders on program developments across the WA data landscape.

4.13 Research ethics and governance reform

As part of its efforts to simplify processes and promote research activity across the WA Health system, the department established the WA Health Central Human Research Ethics Committee (Central HREC) in May 2024. The Central HREC streamlines the ethical approval process and provides greater consistency in ethical review practices across the WA Health system.

The Central HREC, which is based at the department's Royal Street office with support from the Central Office for Research Ethics (CORE), comprises a pool of 120 to 140 members and expert reviewers and meets 6 times in every 4-week period. To manage the administrative functions of the Central HREC, 8 new positions have been created within the OMRI to form the foundation of the CORE.

Through a process of stepped integration, the Central HREC has taken over some, if not all, the functions of the 8 WA Health HRECs based at WA Health Service Providers (HSPs). By late-2025 the Central HREC will be responsible for the review and oversight of all human research projects conducted at WA Health sites.

In parallel to the ethics reform, OMRI has been working closely with the Commonwealth and other Australian jurisdictions to develop the National One Stop Shop; a national initiative to create an ICT platform that will provide coordinated approval and reporting processes for human research, including clinical trials in Australia.

The National One Stop Shop will transform the ability of patients to access clinical trials and therapeutic interventions. It will also make it easier for industry, sponsors and researchers, to find, invest and conduct research in Australia.

Benefits

- Streamlined processes – the introduction of one central HREC has provided opportunities for efficiency through a centralised service.
- Consistency in ethical review – the centralised services ensures that a common suite of resources is available to members to assist with their ethical review providing consistency of decisions to HREC applicants.

4.14 Client Services Feedback Survey

In the pursuit to improve and support the evolving needs of users and the WA community, we developed an online survey to capture user comments and experiences. The Client Services Feedback Survey was published and released via the WA DLS website in June 2023, with surveys being retrospectively sent out to all data recipients to assess qualitative measures pertaining to service performance. The overall survey findings are also reported as part of annual key performance measures submitted to the PHRN, which is used to compare and benchmark the quality of WA data services with other jurisdictions. The findings from the feedback are captured within the Internal KPI Dashboard and are utilised to support future evaluation of the effectiveness of the linked data service and inform strategic reform activities.

Benefits

- Increased communication – the reform program has ensured that feedback received is acknowledged and actioned, providing a direct channel of communication with data recipients. This has promoted trust and ensures customers feel valued and heard.
- Improved service quality – the Client Services Feedback Survey enables the department to meet its reporting obligations to stakeholders, such as the PHRN, offering the opportunity to benchmark service quality with other jurisdictions and identify areas for improvement.

4.15 Streamlining the application for data process

Stakeholder feedback leading up to the implementation of the strategy expressed concerns with the application for data process, that it was overly burdensome, lengthy and required duplicating resources when processing requests. We reviewed the end-to-end data linkage pipeline to identify opportunities for improvement and increased efficiency in processing and tracking project applications within the ISPD Client Services team.

Several projects were undertaken to streamline the application process during the reform journey.

Achievements and impacts

- The Research Data Services Roles and Responsibilities document was pivotal in mapping the intricacies of the data application process, identifying the respective teams, roles and processes at each stage. This document identified inefficiencies, highlighting where reform was needed.
- With a detailed view of the research application process now available, the ISPD Client Services team began the process of formally documenting every procedure undertaken by the team to progress data requests across all application types (research linked and unlinked, non-research record level, non-research aggregate level, Masterfile access). The documentation of every process into Standard Operating Procedures (SOPs) not only standardised ways of working, but it contributed to a large-scale reform project to provide a detailed electronic view of every project as it moved through the stages to receive data.

- The migration of every project into an online project management system, Wrike, was a significant effort aimed at coordinating data requests and capturing KPIs for internal and external reporting. This valuable data formed the foundation for the Project Application Tracker and KPI Dashboard, facilitating open communication with data requestors who could track the progress of their requests and understand competing demands across the request for data pipeline.
- The project explored the use of emerging technologies such as REDCap, which are either free to use or covered under existing department software licences, to automate parts of the application process, enhancing the digital capabilities of the ISPD Client Services team and stakeholders. The project resulted in the creation of an online application form for non-research aggregate data requests, however, could not be implemented due to software limitations and the technical expertise required to maintain the solution.

Benefits

The significant reform to streamline the application process has contributed to several benefits, including:

- Improved service quality – enhanced the timeliness of receiving data and provided opportunities for open and transparent communication with applicants, improving the department's reputation and increasing customer satisfaction as identified in the Client Services Feedback Survey.
- Documented application processes – ensured business continuity, devolved process knowledge and built subject matter expertise.
- Increased staff capability – boosted the technical capability and expertise of the ISPD Client Services team who have improved their skills in project management and process flow software.
- Improved partnerships – strengthened relationships through extensive consultation across health, including different departments, resulting in more productive relationships, greater understanding of stakeholder needs and increased stakeholder engagement for future technical projects.
- Improved reputation among stakeholders – enhanced trust from stakeholders through genuine attempts to improve processes.

In conjunction with the broader achievements of the strategy, this has seen a significant improvement in the research sector's capacity to access linked data within realistic project timelines. Recent system redesigns and governance improvements have made it easier for WA researchers to meet the requirements of nationally competitive funding schemes. This operational reliability has strengthened the reputation of WA's research community with grant-making bodies such as the NHMRC, ARC and MRFF, helping to unlock greater levels of investment into health and medical research across the state. As a result, WA's research environment is becoming more attractive to partners and funders seeking to deliver timely, data-informed impact.

4.16 Implementing an e-research platform for evaluation

Our current procedure to provide linked data to approved users requires manual linked data extracts and relies on agreements for secure use, storage and destruction of data. Aside from significant security risks, this approach is not scalable to support future demands for data or complex requests. In response, we trialled an e-research platform which would enable us to offer secure access data services as an accredited Data Service Provider under the DATA Scheme.

Operated at the University of New South Wales, ERICA is an e-research platform that provides a secure, customisable, cloud (AWS) computing environment for research using sensitive microdata. In June 2022, we commenced a comprehensive evaluation through deploying a test instance of ERICA to trial the platform under a free licence that would extend over 2 years. Across this period, the evaluation of ERICA provided many opportunities for cross-collaboration and partnership, including working with DPC who tested the platform for their own operational requirements as part of the evaluation. Following our trial, ERICA was later established by DPC for the whole-of-government initiative, PeopleWA. Through the DPC and Health partnership, researchers will be able to access key datasets for analysis using DPC's ERICA instance.

Achievements and impacts

- The evaluation of ERICA encouraged a culture of collaboration between teams across the department to achieve shared goals and assisted with the implementation of subsequent strategy projects.
- The department held a hackathon to mimic ERICA's implementation as an operational service, with multiple projects, users and workspaces accessing the environment at the same time.
- The ERICA Health Hackathon brought together more than 20 people across ISPD to address a health system issue using linked health data. The event was acknowledged by the department's Human Resources team as a fantastic way to break-down silos, engage staff and build capability while testing the platform's onboarding, storage and capacity to perform complex analytics, import and export functions, specific roles (i.e. project controller and data user) and SOP documentation.
- Thorough testing of ERICA was necessary to understand the requirements of all potential platform users across various technical aspects including the impact of organisation specific firewalls, interpretation of SOPs and platform capacity issues. The department thoroughly tested the platform with:
  - Curtin University
  - Department of the Premier and Cabinet
  - The East Metropolitan Health Service
  - The Kids Research Institute
  - University of Notre Dame.

> 'The opportunity to share knowledge and learn from other people was invaluable. Working with content data and properly analysing outcomes for the question has been fantastic.'
>
> ERICA Hackathon participant

Benefits

Comprehensive evaluation of ERICA resulted in the following benefits:

- Improved collaboration – broad and detailed consultation findings supported us in our assessment of e-research platforms.
- Improved stakeholder capability – stakeholders experienced a capability uplift as they were trained to use a new platform.
- Improved partnerships – the project broke down silos and fostered relationships across the e-research platform landscape.

4.17 National data initiatives

Towards the latter end of the strategy's implementation, we engaged in ongoing discussions regarding several national data sharing and linkage initiatives, demonstrating our maturity and technical capability as WA's leading linkage unit.

The National Health Data System

- Australian National Data Integration Infrastructure (ANDII)
- National Disability Data Asset (NDDA)
- National Health Data Hub (NHDH)
- Person-Level Integrated Data Asset (PLIDA).

WA will participate in the ANDII, NDDA, and NHDH through an endorsed 'federated data linkage model', which enables access to a comprehensive National Linkage Spine dataset to link and integrate WA Health and jurisdictional datasets. We play a critical role in supporting bilateral schedules, data sharing agreements, data linkage and data submission models with key stakeholders, including DPC, Department of Communities and Commonwealth agencies (e.g. Department of Social Services, Health and Aged Care, Services Australia, Australian Bureau of Statistics, Australian Institute of Health and Welfare). These initiatives are essential for facilitating the effective delivery of cross-jurisdictional linked data to support national and jurisdictional quality improvement initiatives, population research projects, and service delivery and planning, across the health and social service sectors. We are also exploring the integration of WA Health system data into the PLIDA, hosted by the ABS.

Australian Centre for Disease Control

The Australian Institute of Health and Welfare (AIHW) requested our expertise as part of consultations to define requirements for 'rapid data linkage' (<48 hours) of communicable diseases data with other hospital datasets for the Australian Centre for Disease Control (ACDC). We recommended the creation of a new 'segregated environment' within the linkage system to perform rapid data linkage, based on learnings from the rapid linkage of COVID-19 data, where raw data ingested from live admission and discharge sources compromised the integrity and quality of data linkage outputs, requiring significant manual review and intervention.

National Health Reform Agreement – Schedule G

We provided lead support in development of a jurisdictional version of the National Health Reform Agreement 2025–30 Schedule G ('Stronger System Stewardship and Governance'), to ensure appropriate alignment with key requirements of the National Health Data System within the Schedule.

National Primary and Acute Care Data Linkage Project

The National Primary and Acute Care Data Linkage Project (NPACDLP) aims to design a health data linkage system in Australia that supports insights across the continuum of care.

The department provides WA's jurisdictional representative to coordinate consultation and feedback from stakeholders across Primary Health Networks, health service providers, Aboriginal Community Controlled Organisations, consumers, GP representatives and the department to inform the development of a detailed roadmap and fully costed business case to securely connect primary care (e.g. GP clinics, Aboriginal health services and other primary health providers) and acute care (e.g. hospitals and emergency services) data to better understand patient journeys across care settings in Australia. This ambitious and essential piece of work will inform improvements in population health planning, service delivery and patient outcomes.

5. Stakeholder feedback

We undertook extensive consultation to understand the reach, impact and effectiveness of the strategy. This included an online Stakeholder Feedback Survey (the survey) which was promoted widely, including in the WA Health Happenings newsletter, on the WA DLS website, at an ISPD Information Showcase and through targeted emails. The survey findings were used as a launchpad for eliciting opinions and reflections from key stakeholder groups including the:

- RAC
- HAC
- Data Linkage Strategy and Reform Program Control Group (PCG).

A total of 73 people from across government, health service, research and not-for-profit sectors responded to the survey (see Figure 1). The majority indicated they engaged with us as data users (41. 56 per cent) or data providers (18. 25 per cent; see Figure 2).

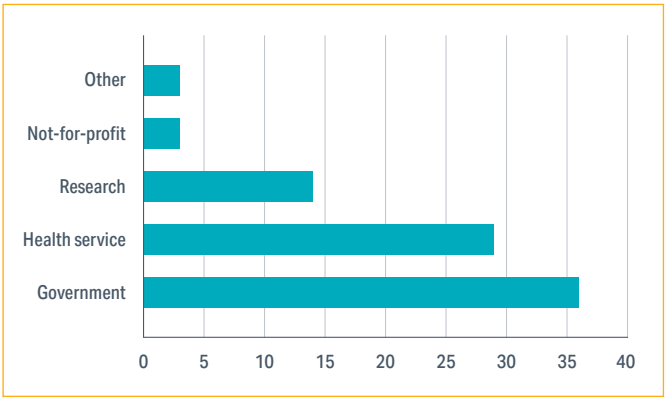


Figure 1: Sectors (respondents could select more than 1 response)

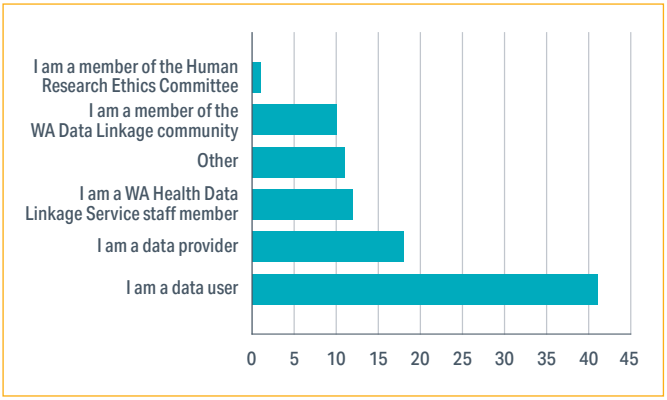


Figure 2: How do you currently engage with the Data Linkage Service

Government and research sectors had the strongest awareness of the strategy

Just over half of the respondents (39; 53 per cent) were aware of the strategy and more than three-quarters (59; 81 per cent) were either aware of the strategy or one or more of the activities it delivered. Awareness was highest amongst those from the government (33 of 36; 92 per cent) and research sectors (12 of 14; 86 per cent), while the lowest awareness was from those in the health service sector (17 of 29; 59 per cent).[1]

The majority (20 of 34; 59 per cent) of those not aware of the strategy were familiar with at least one activity it delivered. Whole-of-government initiatives such as PeopleWA (35; 48 per cent), the WA Health Linked Data Warehouse (34; 47 per cent) and the publication of the Minimum Data Requirements for Linkage: Best practice guidelines (29; 40 per cent) had the highest awareness across all respondents.

For those who were aware of the strategy, awareness of published tools and resources was high, including the Research Data Services Roles and Responsibilities Guideline (21 of 39; 54 per cent), Project Application Tracker (18 of 29; 46 per cent) and the Data Linkage and Integration Policy (17 of 39; 44 per cent).

The strategy was clear and relevant, but should seek a broader scope

Almost all (95 per cent) who were aware of the strategy considered the objectives clear and believed the strategy was relevant to their role or sector. The majority also agreed that the strategy was important (90 per cent), effective (74 per cent) and that the strategy activities were relevant to them (73 per cent).

The strategy's effectiveness in generating buy-in from strategic partners was praised by the department's internal stakeholders. HAC members felt the strategy clarified the local and national linkage context.

1. Respondents could select more than 1 sector.

Stakeholders noted the strategy's research focus and how the specific activities limited implementation agility. Stakeholders expressed a strong desire for greater treatment to the needs and priorities of health services and broader government sectors. They also preferred to focus on driving strategic principles that guide iterative development of a roadmap to achievement.

Communication presents opportunities for improvement

More than half (51 per cent) of respondents did not think that the activities of the strategy were well communicated and understood, or that the strategy's activities were well managed (53 per cent). This is understandable given that only a small majority (59 per cent) were aware of the strategy itself.

Throughout the strategy, it became clear that established avenues for disseminating information, such as advisory groups, were ineffective, leaving key stakeholders unaware of initiatives. This was echoed in the feedback received through the survey and retrospectives, which showed confusion or a lack of awareness of the strategy, including its scope, relevance and initiatives.

Stakeholders appreciated the breadth of information provided in implementation but acknowledged difficulty digesting and disseminating this to their networks in the current formats. Prioritising concise and targeted communication was valued and advisory committee stakeholders suggested leveraging the existing WA DLS website as a repository for detailed news and updates to allow direct communication to focus on key points and takeaways.

Promoting the tangible impact of the strategy should be prioritised

While most respondents believed that the activities of the strategy provided benefits to the WA community (59 per cent) and improved data capability in the public service (55 per cent), these results were not as strong as expected. Key stakeholders suggested that a spotlight on the translation of the strategy into tangible outcomes, such as published research, policy reform or operational benefits for HSPs, would help foster understanding and appreciation of the value and impact of the work being completed.

Program management within the department was effective, but can be strengthened

External stakeholders acknowledged the effective management of the strategy to deliver within promised timeframes and the open opportunities to engage and contribute to the strategy's implementation. Internal stakeholders highlighted that having a dedicated Data Linkage Strategy team to shepherd projects was very effective and allowed technical teams to work more efficiently by concentrating on work within their core skill sets.

Internal stakeholders noted significant pressure on delivering strategic projects without additional resources while maintaining business-as-usual services. They considered the established PCG effective in overseeing projects at a Data and Information Systems level, however noted that the cross-team membership could be better leveraged as a forum for collaboration and working through emerging risks and issues from projects.

6. Looking ahead: WA's data-driven health system strengthening the medical research ecosystem

The achievements of the strategy have established a strong foundation for WA's data linkage capabilities. As we continue to build on these successes, we are already developing the next phase of reform, a new 2025–30 strategy. This forthcoming strategy will expand on our progress by further modernising infrastructure, deepening cross-sector partnerships, and supporting a broader range of data users across medical research and innovation, policy, service planning and operations.

Whilst ongoing reform projects will transition to the new strategy, our immediate priorities include:

- improving the accessibility and scalability of linked data
- enhancing data quality and timeliness
- implementing digital reforms and improving infrastructure and processes
- aligning our governance and approvals processes with national best practice
- sharing information through collaboration and partnerships
- supporting national collaborations and whole-of-government initiatives
- education, advocacy and capacity building
- maintaining security and privacy
- implementing systemwide Aboriginal Data Sovereignty Governance policy.

These enhancements will ensure that data linkage continues to meet the needs of WA Health's internal users, including health planners, program designers, and operational teams and support excellence with our external medical researchers and collaborators.

The 2025–30 strategy will provide a coordinated platform for ongoing reform, helping WA Health remain at the forefront of data innovation. This work will enable faster access to actionable insights, support evidence-informed decision-making, and reinforce WA's national leadership in health data linkage and integration.

Through this continued investment in capability and collaboration, WA will be well positioned to deliver better services, attract more research funding, and ultimately improve outcomes for the community.

Case studies

PeopleWA

Linked data is extremely valuable to researchers and policy makers to study emerging health trends and address issues in a cohesive and comprehensive way. Information integrated through linkage provides a more complete picture of how certain factors interconnect and impact a variety of domains to improve planning and service delivery.

The state government collects a huge amount of information about complex social and economic problems, however a historically fragmented approach to data sharing, linkage and analytics across the public sector has made it difficult for researchers and analysts to access and use administrative data.

PeopleWA represents the state government's commitment to data-driven decision making and research, assisting agencies to accelerate data sharing and develop analytics capabilities across the State Government, in alignment with the strategy and the Digital Strategy for the WA Government 2021–25.

In 2021, the department in partnership with DPC, developed a coordinated approach and targeted investment strategy for improving data sharing and availability.

In 2023, the State Government successfully launched PeopleWA, a whole-of-government linked data asset, offering a powerful tool for research, government policy and service improvement.

This enduring cross-sectoral data infrastructure is supported by our linkage services to link data between the department, Department of Communities, Department of Education, Department of Justice, Registry of Births, Deaths and Marriages, WA Police Force, and Curtin University's Centre for Data Linkage.

By connecting multiple sources of information through our DLS, PeopleWA creates richer, more comprehensive datasets. The insights generated from these linked data collections helps to address the most complex social, health, environmental and economic issues facing the state.

> 'The WA community will benefit from PeopleWA's capability to enable evidence-based government decision-making and improve service delivery.'
>
> WA Chief Information Officer, Greg Italiano

In line with global standards, PeopleWA adheres to the Separation Principle to protect the privacy of individuals. Participating agencies contribute their demographic data to our team, who perform linkage and generate linkage keys, which are then used by DigiGov to integrate the separated content data provided by the agencies.

We provide complex data services for the PeopleWA initiative, facilitating linkages between 45 data collections to supply linkage keys to DigiGov. We have delivered more than 1 billion records to the PeopleWA repository in 2023–24, with regular data updates and new data collections being added every year.

Development of our state linkage spine in WA has achieved significant benefits, including:

- a consolidated whole-of-government linked data repository in WA
- one clear pathway for accessing all linked government data
- expansion of existing data linkage for all age groups
- more accurate and current linked data, updated more frequently
- continued expansion of non-health linkages
- reduced duplication of linkage activities
- consistency with other linkage models across Australia.

PeopleWA is now available to support crucial service analysis and research initiatives in our community, including the Australian Child and Youth Wellbeing Atlas. This freely available resource maps information on children and young people in communities across Australia, and can be used to identify gaps, priorities and research opportunities, aiding policy and investment decisions for tangible health improvements.

'The state government is leading Australia's transformation in data linkage, a cornerstone of the Digital Strategy for the Western Australian Government 2021–25. Since PeopleWA's inception, we have provided both researchers and government entities with access to high-quality linked data and encouraged the development of evidence-based findings to inform service delivery across various sectors including child and adolescent health, mental health, education and criminal justice. Harnessing the power of linked data not only advances research but also addresses complex policy and socio-economic issues for the benefit of the WA community.'

Natalie Kacperek, Chief Data Officer, Office of Digital Government

PeopleWA represents the WA Government's commitment to data-driven decision making and research, assisting agencies to accelerate data sharing and develop analytics capabilities across the State Government, in alignment with both the strategy and the Digital Strategy for the Western Australian Government 2021–25. We are proud to be a partner in this significant achievement which has greatly improved access to high-quality linked data and is sure to deliver tangible benefits to the WA community.

PeopleWA in 2024:

7
State Government agencies

2
linkage units

45
datasets linked via the WADLS

1,015,207,969
records delivered to PeopleWA by the department

Synthetic data

The department collects, stores and delivers extensive volumes of health data which can be used at all levels of the WA Health system to improve access and quality of care. Accessing real data comes with privacy concerns, limitations and regulations, particularly in the health sector. Representative synthetic data offers a solution by enabling the creation of high-quality, privacy-compliant data without the risks of providing real data.

Representative synthetic data is artificial data generated to mimic real datasets in structure, pattern and statistical properties, however it contains no identifiable information making it ideal for protecting privacy. It is produced using statistical and ML techniques. As it is a representation of the real data, it is not an exact match. The quality is dependent on the original dataset, the field elements used, as well as the methodology utilised to generate the synthetic data.

In alignment with Recommendation 21 of the Sustainable Health Review (2019) and strategy Themes 3 Availability and 4 Privacy and Security, we commenced a proof-of-concept project for the generation of representative synthetic data. The aim was to provide synthetic data for use at the 2023 WA Health Hackathon, a state Government initiative facilitated by the WADSIH.

Historically the department's involvement in WA Health Hackathons had been restricted due to privacy and confidentiality concerns surrounding the provision of patient sensitive data to users outside of the health system. The generation of representative synthetic data from real health datasets addressed this issue and ensured timely access to a useful representation of real data for the event without the need to release the real data. By providing representative synthetic data, we aimed to enable precise and relevant questions to be posed with actionable outcomes to foster health data science innovation in WA.

The project was progressed in 2 main stages by the Data Science team within ISPD. The first stage, 'Safe and Secure', had the primary objective to build the capability to produce safe synthetic datasets that protected the privacy concerns of the source datasets. The second stage, 'Useful', involved rounds of iterative evaluation and improvement of the synthetic data generated to assess usefulness in terms of similarity to the source and at a suitable level of data structure sophistication.

After obtaining the necessary approvals, 3 state health collection datasets were selected to be the source data for the generation of representative synthetic datasets:

1. WA Cancer Registry (WACR) 2010–22
2. Emergency Department Data Collection (EDDC) 2022
3. Hospital Morbidity Data Collection (HMDC) 2022

The guidelines were developed to support the generation of representative synthetic datasets and mitigate against the release of personal and health information. Generative Adversarial Networks based synthetic generation engines were assessed and determined to be suitable to generate synthetic data for the Hackathon event. For completeness, the project team explored and evaluated several different synthetic data generation methodologies. The guidelines directed 'Compliance Reports' were to document the outcomes of the synthesising process and demonstrate the technical measures taken to ensure compliance. These could be reviewed by relevant stakeholders with the intention to assist in the release process.

> 'The use of synthetic data for this Hackathon marked a significant milestone for Australia. It not only reflects our progressive approach towards innovation but also shows the limitless possibilities that synthetic data offers in reshaping and informing healthcare decisions.'
>
> WADSIH

Whilst generation of the representative synthetic datasets was progressing, we also collaborated with WADSIH to support the 2023 WA Health Hackathon. This was a first for the department and involved setting challenge questions, formulating workshops and garnering mentorship support for the participants.

By September 2023 we had successfully generated 3 representative synthetic datasets based on real EDDC, HMDC and WACR datasets. The synthetic datasets were assessed by a collaborative working group as resembling the desired qualities and trends of the source datasets, without releasing personal health information in the source data collections. The ADG approved the release of the datasets to authorised users participating in the 2023 WA Health Hackathon.

The provision of representative synthetic datasets for use at the 2023 WA Health Hackathon was a momentous achievement and described by WADSIH as 'a groundbreaking process for a Hackathon'. Participants developed innovative solutions to real-world healthcare challenges using the supplied synthetic datasets. It was the first demonstration of successful use of representative synthetic data in WA. The winning team, 'AI Advancements', developed a real-time AI application aimed to assist healthcare professionals and patients in understanding and navigating vast amounts of unstructured health reports and data related to a patient.

In addition to contributing towards the Hackathon's success, we raised the profile of synthetic data as a powerful tool for overcoming common data challenges. Following the event, the North Metropolitan Health Service (NMHS), a partner and sponsor of the 2023 WADSIH Health Hackathon, requested access to our EDDC 2022 synthetic dataset for their own proof-of-concept project. Access was approved and NMHS is currently utilising synthetic data to train and develop a localised Large Language Model with the aim of functioning as a virtual data analyst, capable of providing insights and statistics on hospital activities such as emergency department operations. This opportunity would not have been possible without synthetic data, as the risks and privacy concerns would have been too high. If the project is successful, healthcare professionals will have the ability to efficiently access and analyse key hospital metrics through intuitive, language-based queries.

We are currently progressing Phase 2 of the project and working towards the generation of linked representative synthetic data.

> 'The sheer commitment and effort from all parties involved ensured that the Hackathon had the best resources at its disposal and the use of this data was pioneering.'
>
> WADSIH

Accreditation as a Data Service Provider

We are committed to improving the scope of data and services available, ensuring access and disclosure of information complies with legislation and policy requirements.

The recently introduced DAT Act 2022 helps overcome barriers to data sharing through an authorisation to override Commonwealth, state or territory laws, that would otherwise prohibit the sharing, collection and use of certain data when appropriate safeguards are in place, without overriding the *Privacy Act 1988*.

This has established a new, best practice scheme for sharing Australian Government data, underpinned by strong safeguards and consistent, efficient processes, known as the DATA Scheme.

The DATA Scheme, administered by the ONDC, focuses on increasing the availability and use of Australian Government data to deliver government services that are simple, effective and respectful, inform better government policies and programs, and support world-leading research and development.

Under this new scheme, an accredited 'user' can request Australian Government data from a data custodian and an accredited 'Data Service Provider' can provide data services to support the data sharing project.

As the state's lead linkage agency, accreditation under the DATA Scheme is crucial to ensure WA participation in cross-jurisdictional projects, including the ANDII and NDDA initiatives.

Since 2022, the Information Performance and Governance (IPG) unit within the Information and ISPD have supported DLS by working closely with the ONDC and the National Data Commissioner to progress applications for accreditation under the DATA Scheme.

As part of the accreditation process, the Data Linkage Strategy team and IPG's Policy and Governance team collaborated with data linkage and engineering experts to create and implement the first mandatory systemwide Data Linkage Policy, to ensure that the department met the necessary criteria for accreditation as a Data Service Provider.

The department was the first WA organisation to successfully attain accreditation as a user in June 2023. As of December 2023, the department is recognised as an accredited Data Service Provider for Complex Data Integration and De-identification services under the DATA Scheme.

As a result, we can provide linkage, complex integration or de-identification services for accredited users such as government bodies or universities. This ensures that we can access and link highly valuable data collections, improving the availability of data available to our service users.

Linked Data Warehouse infrastructure upgrade

An enduring strategy for the WA Health system in the *Sustainable Health Review* (2019) is to increase investment in digital healthcare and improve the use of data. Improved data capabilities and enhanced data sharing mechanisms can better support access to valuable data for research, whole-of-government planning and social investments.

Since its modest beginnings in 1995, the WADLS data linkage infrastructure has grown to become one of the most comprehensive, high quality and enduring linkage systems worldwide. Today, it contains more than 200 million demographic records from 70 data collections.

Complementing the data linkage infrastructure, a new streamlined integration method for data extracts went live in 2013 and became the standard method for preparing linked data extracts for the next 10 years. This innovative custodian-controlled integration model has since been adopted by other linkage units in Australia.

The department has continued to innovate, optimise and streamline data integration processes. The advent of a global pandemic highlighted the technological limitations and opportunities for further process improvements. As the demand for linked data services increased, the bespoke nature of integration processes could not be sustained.

In 2020, the department designed, built and launched a consolidated WA Health Linked Data Warehouse.

The transition to the Linked Data Warehouse has delivered immediate benefits for staff, researchers and analysts increasing the accessibility of large volumes of data across a broader range of datasets.

The new Linked Data Warehouse is now a fully linked repository that streamlines data integration by allowing source data to be directly accessed from local databases. Advantages of the new infrastructure include:

- improved timeliness of data extraction, with fewer queues to process tasks
- improved efficiency of staff and resources, with the repository returning faster responses to queries
- greater capacity for operations with more projects being facilitated through the Linked Data Warehouse more often
- more current, reliable linked data extractions with daily updates of linkage keys, reflecting the most recent changes to the WADLS in near real-time
- advanced scalability within the repository to handle increasing amounts of data and traffic
- streamlined functionality for rapid development of new datasets and extraction pipelines
- automated and sustainable data engineering with less manual intervention, less dependencies and fewer handovers between teams
- improved data capability and skill level of staff in developing pipelines and extracting project data
- increased collaboration, greater insight and better working knowledge between teams across the department, providing a supportive environment for proactive and creative problem solving
- lower costs for low complexity data requests, reducing the financial burden on research applicants where linked data extractions can be fast-tracked through the Linked Data Warehouse.

The Linked Data Warehouse represents an enormous success and this amazing feat of interdisciplinary collaboration demonstrates the importance of a long-term strategy to ensure continuous improvement and growth.

By creating a unified linked data asset for commonly requested state government data, we can now offer a whole-of-government data linkage capability to enable cross-sectoral and cross-jurisdictional linkage initiatives, ensuring that we can rise to meet the challenges of the future.

The strategy supporting the future: The Western Australian Cohorts Network

Longitudinal cohort studies provide a richness, quality, depth and breadth of biopsychosocial data that is systematically collected, curated and stored for future research. Finding opportunities to link such quality data with existing datasets could open the door to more rapid translation of research to community benefits.

WA is home to 3 of the longest running longitudinal population health cohort studies globally, the Raine Study, the ORIGINS Project and the Busselton Health Study. These studies have united to form the Western Australian Cohorts Network which collectively has more than 35,000 participants, 50 million data points and 1,420,000 biological samples from pre-birth through to older adulthood and enables researchers to access retained health data without recruiting their own participants or processing samples, significantly reducing the time to conduct research. These cohort studies have assisted in more than 267 hypothesis-driven studies and produced 379 peer reviewed publications in the last 6 years.

> 'The Raine Study is one of the most successful and extensive studies of pregnancy, childhood and adulthood ever undertaken and has made many important discoveries over the past 30 years.'
>
> Minister for Medical Research, Stephen Dawson

The existence of these rich datasets presents an opportunity for data linkage to increase their already unquantifiable value. Linking longitudinal cohort studies with government agency data sets through the PeopleWA mechanism has the potential to improve clinical practice, policies and programs by providing insights into the health and social determinants of health across the population's life course. This would:

- improve the quality of research data
- link participants with family members to improve genetic and hereditary research
- find further longitudinal data for people lost to follow-up
- provide an opportunity to cross-check information provided in surveys across different health providers to improve the quality of data obtained.

The creation of the Western Australian Cohorts Network highlights the move away from data silos to an evolving data landscape that leverages collaboration and partnerships to realise the data's full potential. Through this combined data asset, we can move further toward a data-driven future to inform novel research and improve health policy and practices.

> 'We are punching well above our weight with this sort of research work being undertaken here in WA. The Cook Government is committed to continue our support of cohort studies which will deliver benefits for Western Australians.'
>
> Minister for Medical Research, Stephen Dawson

Appendix A: Community partnerships and collaborations

Fundamental to the success of the reform program has been collaboration and improved community partnerships. Through active participation and promotion of key developments within the strategy at stakeholder forums and through collaboration with partners, a joint vision of data linkage at state and national level was possible. The department undertook many engagements to share the data linkage vision, contribute subject matter expertise and develop a common understanding across the data landscape, through existing governance frameworks, internal workshops or opportunities to engage with external partners. The following table provides the key stakeholder engagements over the life of the strategy.

Table 1: Strategy engagements

Routine engagement
• Data Linkage Executive Council meetings
• Data Linkage Government Advisory Committee meetings
• Data Linkage Research Advisory Committee meetings
• Whole of Government Linkage Interagency Working Group meetings
• Linkage Strategy Subcommittee meetings (monthly)
• Linkage Transition and Implementation Group meetings
• Data linkage Program Control Group meetings (monthly)
• WA Health Translation Network Data Linkage meetings (monthly)
• PHRN Client Services Forum meetings (as required)
• PHRN Participant Council meetings (as required)
• Curtin Data Linkage Analytics Partnership meetings (monthly)
• PeopleWA Technical meetings (fortnightly)
• PeopleWA Governance Group meetings (quarterly)
• E-Research Institutional Cloud Architecture (ERICA) knowledge transfer meetings (fortnightly)
• Custodian Administered Research Extract Server (CARES) knowledge transfer workshops (as required)
• Synthetic Data Working Group meetings (as required)
2022 Q1
• The strategy was in the finalisation stages with routine engagements, such as monthly Linkage Strategy Subcommittee meetings forming part of this phase.
2022 Q2
• WA Health Data Linkage Strategy and Reform Program introductory presentation to the Epidemiology Directorate (April 2022)
• 'Innovations in the Health System: Whole-of-government Data Linkage and Analytics' presentation at the Western Australian Health Translation Network's 'Science on the Swan' conference (May 2022)
• Health Data Linkage Strategy and Reform Program introductory presentation to the Data Linkage Executive Council (June 2022)
• 'Privacy Preserving Record Linkage' internal presentation (June 2022)
2022 Q3
• The Reform Program continued to meet as part of monthly Data Linkage Program Control Group.
2022 Q4
• Data and Information Liaison Network meeting (October 2022)
• Australian Information Industry Association presentation (October 2022)

- Data and Linkage Advisory Committee meeting (November 2022)
- Briefing with the Minister for Medical Research for the Department of the Premier and Cabinet (November 2022)
- 'Planning for Partnership' workshop by the Western Australian Council of Social Service and the Health Consumers' Council of Western Australia (November 2022)
- 'Streamlining Back-End Processes to Support Citizens' Life Journeys' presentation to the Public Sector Network (November 2022)
- Synthetic Data Generation Project presentation to the Digital Health Cooperative Research Centre (December 2022)

2023 Q1

- Synthetic Data Generation Project – Purchasing and System Performance extended Senior Executive Team meeting (January 2023)
- The Kids Research Institute Linked Data Committee meeting (March 2023)
- Digital Health Cooperative Research Centre: Synthetic Data Roundtable meeting (March 2023)

2023 Q2

- Data Linkage Client Services workshop (May 2023)
- Launch of the Data Linkage Strategy at Western Australian Health Translation Network's 'Science on the Swan' conference (May 2023)
- WA Primary Health Alliance workshop (June 2023)

2023 Q3

- Data Linkage Information Session with the Association of Australian Medical Research Institutes (September 2023)

2023 Q4

- WA Health System: Data Custodian Information Sharing forum (October 2023)
- Person-Level Integrated Data Asset (PLIDA) consultation session with the Australian Bureau of Statistics (November 2023)
- Australian Centre for Disease Control requirements workshop with the Department of Health and Aged Care (November 2023)
- The Australian Institute of Health and Welfare Ethics Committee approved the establishment of the National Health Data Hub (December 2023)

2024 Q1

- Co-chair for the Synthetic Data Community of Practice meeting (January 2024)
- Primary Health Research Network Managers Forum (February 2024)
- Establishment of the Data Linkage Executive Health Council (March 2024)
- WA Primary Health Alliance data linkage consultation (March to May 2024)

2024 Q2

- PathWest Consultations (April 2024)
- WA Health Hackathon Coordination Group (April 2024)
- Primary Health Research Network: National Collaborative Research Infrastructure Strategy KPI Working Group (April 2024)
- Queensland Department of Health consultation about Data Linkage Services (April 2024)
- Primary Health Research Network Trial Link workshop (April 2024)
- Discussions with The Kids Research Institute to discuss options for data linkage and integration of longitudinal birth cohort study projects (April 2024)
- Digital Health Collaborative Research Centre and Synthetic Data Community of Practice Synthetic Data Guidelines workshop (April 2024)
- NHRA Performance and Data Working Group meetings (April to May 2024)
- Australian Research Data Commons Platforms E-Research Institutional Cloud Architecture (ERICA) Steering Committee (May 2024)
- Medicare Consumer Directory and National Master Linkage Key meetings with the Australian Institute for Health and Welfare (AIHW) (May 2024)

- WA Primary Health Alliance (WAPHA) collaboration to discuss requirements to establish WAPHA's planned data linkage capability (May 2024)
- WA Trauma Directors Committee meeting by East Metropolitan Health Service Trauma Services (May 2024)
- National Health Data Hub official launch (May 2024)
- Primary Health Research Network Participant Council Meeting (May 2024)
- 'Tackling Poverty and Disadvantage Through Data-Informed Decision Making' by the Life Course Centre and Melbourne Institute (May 2024)
- PHRN Australia and Health Data Research Network Canada Joint Workshop (May 2024)
- WA National Disability Data Asset Governance Group operational sub-group meeting (June 2024)
- WA Medical Research Strategy Government Reference Group to discuss programs pursuant to the WA Medical Research Strategy 2023–33 (June 2024)

2024 Q3

- 'Linking for Life' Research Management Group Meeting to discuss transition of the Social Investment Data Resource to the PeopleWA Repository (July 2024)
- 'Advancing Chronic Kidney Disease Care: Leveraging Data to Improve Patient Outcomes' workshop coordinated by Deakin University Health Economics (July 2024)
- 'Linkage Learning Webinar' hosted by Primary Health Research Network (July 2024)
- Regular meetings and ad hoc workshops with PathWest to progress development of a project plan for the routine provision of Laboratory Information System data (July to October 2024)
- WA National Disability Data Asset Governance Group Board Meetings (August 2024)
- ISPD and WA Chief Data Officer, Department of Premier and Cabinet presentation to the WA Health System 'Data Club' (August 2024)
- Synthetic Data Community of Practice Symposium by University of Queensland (August 2024)
- The department's lead data scientist, attended the Digital Health Cooperative Research Centre's Synthetic Data Symposium and Workshop event (August 2024)
- Communications with the Communicable Disease Control directorate to establish 'rapid data linkage' for the Australian Communicable Disease Centre Establishment Force (July 2024). A further WA-specific consultation was held with the Australian Institute of Health and Welfare to further review requirements of 'rapid data linkage' (September 2024)
- Discussion of linkage requirements and integration of the Intellectual Disability Exploring Answers (IDEA) database within PeopleWA with The Kids Research Institute and the Office of Digital Government (August 2024)
- WA Reference group meeting for the National Primary and Acute Care Data Linkage Project (August 2024)
- ISPD meeting with the Australian Institute of Health and Welfare to discuss WA joining the National Health Data Hub (September 2024)

2024 Q4

- Synthetic Data Hackathon 2024 (October 2024)
- Australian Institute of Health and Welfare presentation to Jurisdictional Implementation Leads regarding the National Disability Data Asset (October 2024)
- PathWest dataset development consultations (October to December 2024)
- ERICA panel evaluation (October 2024)
- Australian Centre for Qualitative Imaging Symposium presentation on PeopleWA and Synthetic Data (November 2024)
- Institute of Public Administration Awards 2024 – PeopleWA as a 2024 Nominee (December 2024)

Appendix B:
Our partners and collaborators

The department sincerely thanks its partners and collaborators for their valuable contributions and support of the strategy.

- Amazon Web Services Anonymiser Team
- Australian Bureau of Statistics
- Australian Coordinating Registry
- Australian Institute of Health and Welfare
- Centre for Data Linkage
- Child and Adolescent Health Service WA
- Clinical Labs WA
- Clinical Pathology
- Department of Education and Training
- Department of Health and Aged Care
- Department of Social Services
- Curtin University
- Developmental Pathways Project
- Digital Health Cooperative Research Centre
- DownUnder GeoSolutions
- East Metropolitan Health Service WA
- Edith Cowan University
- Fiona Wood Foundation
- Insurance Commission of WA
- Health Support Services WA
- Latrobe University
- Main Roads WA
- Mental Health Commission WA
- Murdoch University
- National Coronial Information System
- National Disability Insurance Agency
- NSW Ministry of Health
- North Metropolitan Health Service WA
- Notre Dame University
- The ORIGINS Project
- PathWest Laboratory Medicine WA
- Population Health Research Network
- The Raine Study
- Registry of Births, Deaths and Marriages WA
- Royal Flying Doctor Service
- Silver Chain Group
- South Metropolitan Health Service WA
- State and Territory Health Departments
- St John Ambulance
- The Kids Research Institute
- University of New South Wales
- University of Western Australia
- WA Country Health Service
- WA Data Science Innovation Hub
- WA Department of Communities
- WA Department of Education
- WA Department of Justice
- WA Department of Premier and Cabinet
- WA Department of Training and Workforce Development
- WA Department of Transport
- WA Department of Treasury
- WA Electoral Commission
- WA Health Translation Network
- WA Interagency Graduate Program 2024
- WA Police
- WA Primary Health Alliance

This document can be made available in alternative formats.

DOH-014844 JUN'25