PHRN
Population
Health
Research
Network

Linking data today for a better tomorrow

Investment Plan 2023-2028

INTRODUCTION

> “Events of importance worth recording in the Book of Life are frequently put on record in different places since the person moves about the world throughout his lifetime. . . Yet, sometimes it is necessary to examine all of an individual’s important records simultaneously. It is necessary at times to link the various important records of a person’s life”. Dr Halbert Dunn, Head of the United States National Office of Vital Statistics, 1946

The PHRN’s coordinated, national data linkage infrastructure, built over the last 13 years, is a strong foundation on which to build the innovative linked data infrastructure of the future. We need linked data to tackle some of Australia’s greatest challenges and deliver economic benefits.

PHRN expertly links sensitive data and makes it available to researchers in ways that minimise privacy risks and meet legal and ethical requirements.

We operate on the principle that researchers need ***access to the right data, in the right format, at the right time*** to realise the benefits of linked data for the Australian community.

In this document we outline PHRN’s investment plan for and progress towards the further development and enhanced use of linked data to improve the health and wellbeing of all Australians.

This plan has been developed with reference to the recommendations in the 2021 National Research Infrastructure Roadmap and is designed to address a range of challenges outlined in the Roadmap with a particular focus on medical products, large-scale integrated data and environment and climate.

The investment plan supports the **PHRN Strategic Plan 2021-2030**. It has been developed with the support of the PHRN Board and after consultation with a wide range of stakeholders including government departments and agencies, researchers and industry.

THE IMPORTANCE OF DATA LINKAGE

From the moment each of us is born until the day we die, many organisations (including governments, private sector organisations and research institutions) collect information about us. This includes our birth, school enrolment, hospital admissions, pharmaceutical prescriptions and many more.

This information forms the jigsaw pieces that when connected show us the big picture of health and wellbeing in Australia. This picture explains why we are the way we are and helps us understand how to improve our lives.

Data linkage is the process of connecting the jigsaw pieces together. It is a method of bringing together information from different sources relating to the same person.

WHY LINK DATA?

Linked data is central to finding the answers to important questions that will improve the lives of Australians including:

- Is this drug, device, vaccine or therapy safe and effective?
- How do personal, lifestyle, social and economic factors affect our health and wellbeing?
- What are the risks and causes of diseases?
- How does the environment impact our health and wellbeing?

Linked data can also contribute to the development of new medical products including the enabling the long term follow-up of clinical trial participants.

However, linking data about individual people raises important questions about dignity, autonomy, privacy and sovereignty. We are acutely aware of these issues and address them with reference to specific political, legal, cultural and data environments.

We work with Australian consumers and the community more broadly to use linked data in ways that acknowledge the sensitivity of their data, minimise privacy risks and deliver the greatest impacts for Australia.

WHAT WE DO

From 2009, PHRN has operated Australia's only national network of specialist data linkage units, secure data laboratories and e-research services which support researchers' access to sensitive, linked population data. Our head office is in Perth, and we work nationally to address Australia's national science, research and health priorities to benefit not only Australia's economy, but also the health and wellbeing of all Australians.

We are experts in linking sensitive data and making it available to researchers in ways that minimise privacy risks and meet legal and ethical requirements. Maintaining community trust in our work is central to the way we operate. This is reflected in our core values of ethical conduct, community involvement and trustworthiness.

> "But what if this great data divide could be torn down and we could see the full picture? How many tens of thousands of lives would be saved and how many billions of dollars of waste would be averted?"
> Professor DA. Holman,
> Valedictory Address, 2014.

A COORDINATED AND EFFICIENT NATIONAL NETWORK

Strong national leadership, direction, coordination and collaboration are central to the PHRN approach. We partner with government, research and industry organisations both nationally and internationally across the health, human services and research sectors.

Our established network of Australia-wide specialist data linkage units routinely links and integrates large population datasets. These include:

- linking of Australian Government, state and territory data collections (single jurisdiction linkage)
- linking between Australian Government, state and territory data collections (cross-jurisdiction linkage).

We also conduct ad hoc linkages of research and clinical trial data to population level data on request.

We use an online application system to coordinate requests from researchers to use linked data from all Australian jurisdictions. This improves access and usability and our secure access environments enable researchers to analyse data with minimal risks to privacy.

PHRN is an internationally recognised national data linkage infrastructure. We are represented on international boards and committees and have related collaboration agreements.

BUILDING ON OUR STRENGTHS, INVESTING FOR THE FUTURE

PHRN is addressing Australia's grand challenges in health services, new therapeutics, healthy ageing, social and environmental impacts on health, and prevention of emerging diseases.

PHRN has already shown both economic and health and wellbeing impacts, and the return on investment in the PHRN is estimated to be $16 for every $1 invested.[1]

We understand that to realise the benefits of linked data for the Australian community, researchers need ***access to the right data, in the right format, at the right time.*** We need to build on the existing PHRN national data linkage infrastructure to provide new and improved services, facilities and data products as described below. This will deliver sensitive integrated data to Australian researchers, from epidemiologists to clinical trialists and environmental scientists, whilst meeting all legal and ethical requirements.

Continuing PHRN investment priorities

Investment priority	Facility/service/infrastructure
DATA	**Routine linkage of new sensitive data collections** Linkage and integration of additional large-scale, sensitive data collections including population level administrative, clinical, registry, biobank, research, longitudinal cohort and clinical trials data
LINKAGE	**National network of data linkage units** Maintain the coordinated delivery of linked, sensitive data to researchers through continued investment in existing data linkage units. Support and enhance high quality linkage methods and technology.
	Ad hoc data linkage service Expand ad hoc linkages of sensitive research collected data such as longitudinal cohorts and clinical trials to population level administrative data.
	Cross-jurisdictional linkage Progress routine and enduring linkage between state/territory linkage maps and Commonwealth linkage map to delivery cross-jurisdictional linked data to researchers more efficiently.
SECURE RESEARCH ENVIRONMENTS	**Secure research environments** Enable researchers to meet sensitive data governance requirements through support for and enhancement of the most suitable secure research environments. This includes support for analytic tools.
GOVERNANCE	**Single Online Data Application** Coordinate transparent and streamlined data application and approval processes that meet legal, ethical and community expectations through a national application portal.
TRAINING	**Training and Education** Develop and provide training and education for researchers, data linkage unit staff and ethics committees on: • Good governance principles and practice • Application and approval processes • Research design using linked data

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[1] Lateral Economics. Population Health Research Network (PHRN) Impact and Return on Investment Report. October 2017.

FUTURE INVESTMENT AND LONG-TERM VALUE

The PHRN's vision is for linked data to improve the wellbeing of all Australians. To achieve this vision we need a step-change. We want linked data to be an integral part of Australia's research translation infrastructure particularly medical product development infrastructure, through greater use in clinical trials, clinical quality registers and biobanks. We want more researchers to have access to linked data to answer a broader range of important research questions. We also want linked data to support the investigation of environmental impacts on health and wellbeing.

We will continue to improve and scale the existing PHRN data linkage infrastructure including our network of Australia-wide specialist data linkage units, national online application system and secure remote access environments. We will also expand the number and type of routinely linked data collections with a focus on clinically relevant data such as pathology, imaging, general practice, and clinical quality registries.

To achieve a step-change and assist researchers to access the right data, in the right format at the right time we will:

- make routinely linked data collections more discoverable by building a metadata toolbox.
- develop a range of linked data products including, open, synthetic and aggregate data that does not require the lengthy approval processes of sensitive, person-level linked data.
- work towards the harmonisation or standardisation of commonly linked, large-scale data collections to make data analysis easier.
- develop approaches to avoid secure research environments becoming data silos including enabling federated analytics and interoperability.
- develop an ethics, legal and social implications service to investigate ethics, legal and social issues related to the use of linked data, provide advice to data linkage infrastructure providers, researchers, industry and policy makers and promote community and consumer participation in linked data decision making and research.
- develop and deliver training and education on data linkage, ethics and governance of linked data, and data management and use of linked data.

> We will continue to improve and scale the existing PHRN data linkage infrastructure including our network of Australia-wide specialist data linkage units, national online application system and secure remote access environments.

New PHRN investment priorities 2023-2028

Investment priority	Facility/service/infrastructure
DATA	**New linked data products** Develop new large-scale, linked data products including open, synthetic and aggregate data products that are more easily accessible for researchers, particularly the therapeutic development sector, than sensitive, person-level linked data.
	Metadata toolbox Build tools to enable all the large-scale, sensitive data linked through the PHRN to be more discoverable and enhance the ability of researchers to evaluate the utility of data collections for their specific research purposes.
	Harmonised or standardised data Provide linked, sensitive data to researchers in standardised forms to reduce the burden on individual researchers to clean and standardise data and support federated analytics.
SECURE RESEARCH ENVIRONMENTS	**Coordination of secure research environments** Interoperability and federated analytics for secure research environments
GOVERNANCE	**Consumer and Community Involvement** A comprehensive program to support community knowledge of and involvement in data linkage infrastructure and research using linked data
	Ethics, legal and social implications service An expert service to investigate emerging ethical and legal issues, provide advice on ethics, law and governance, and advocate for improved legislation, regulation, and policy to support sharing of sensitive data for research.
TRAINING	**Training and Education** Develop and implement training and education materials and activities on data management and use of sensitive data.

The PHRN is a founding member of the NCRIS Health Group comprising of Australia's five health-related national research infrastructures. The investment set out in this plan will significantly enhance PHRN's contribution to a more seamless offering for Australian researchers in universities, research institutes and industry, and support delivery of an integrated therapeutic/medical products development pathway for Australia.

**"Data is the fabric of the modern world; just like we walk down pavements, so we trace routes through data, and build knowledge and products out of it."
Dr Ben Goldacre MBE, Bennett Professor of Evidence-Based Medicine University of Oxford, 2011**

THIRD BORN: HOW LINKED DATA REVEALED WHO TO TARGET IN VACCINATION CAMPAIGNS

Linked data allowed Australian researchers to identify the key groups where only 50 to 60 per cent of babies received their two, four and six-month immunisations on time. Importantly, it also suggested who would benefit from targeted interventions to improve vaccination rates, which can help keep babies out of hospital.

Australian childhood immunisation coverage rates are close to the target of 95 per cent for children at five years of age. However, there are still areas with lower coverage and some children are receiving their vaccinations later than recommended, but it was not clear why.

Given that skipping or delaying vaccinations puts children and those around them at risk of catching serious diseases, it's important that children receive vaccines on time, every time.

While Australia has a very good national immunisation register, it only contains limited information, such as a person's date of birth, postcode and the date a vaccine was given. This means we don't understand very much about the people who are being vaccinated. For example, it isn't possible to know if the vaccine is reaching high-risk groups or whether the vaccine works equally well in all population groups.

The only way to understand this is to link other data sets.

So epidemiologists Dr Hannah Moore (Telethon Kids Institute) and Associate Professor Heather Gidding (University of Sydney) worked with PHRN to link immunisation records, hospital data, birth records, laboratory data and infectious disease notifications for almost two million Australian children.

This work showed that third and fourth-born children are far less likely to be vaccinated on time than their older siblings.

Others at risk include children of Aboriginal and Torres Strait Islander descent, premature babies, and those born to younger mothers and mothers who smoked.

Dr Moore says it helped identify families who would benefit from targeted intervention, including SMS reminders or a recall notification.

"You want to target families with their third or fourth child," Dr Moore says. "They've got so much else going on that a reminder to vaccinate their third child on time is probably more important than for a first-time parent."

Shortly after the research was published, the Australian Government launched the Get the Facts campaign, encouraging Australian parents to get their kids vaccinated on time. This campaign was shown to have seen improvements in parents checking if any child(ren)'s vaccinations were up to date and booking an appointment to get their child(ren) vaccinated (among other factors).

The research would not have been possible without PHRN. "There's so much advantage and strength in pooling all of these data together," Prof Gidding says. "You couldn't do our research any other way."

**"If you really want to make a difference, you've got to look at the big picture"
Professor Fiona Stanley AC, 2003 National Press Club speech**

Governance

PHRN BOARD

The PHRN Board is an independent body consisting of five members plus a Chair. The PHRN Board reports through the University of Western Australia who is the PHRN Lead Agent. Its primary role is to provide oversight and strategic direction for the PHRN. Other responsibilities include monitoring contractual compliance and performance against key performance indicators, oversight of financial risk management, and facilitation of relationships with PHRN Stakeholders.

PHRN PARTICIPANT COUNCIL

The PHRN Board is supported by the Participant Council which provides advice on strategy, policy, funding priorities, stakeholder engagement, performance and accountability. All PHRN Participant organisations are represented on the Participant Council.

CHIEF EXECUTIVE

Dr Merran Smith

Our Funders and Partners

NCRIS
National Research Infrastructure for Australia
An Australian Government Initiative

Government of Western Australia
Department of Health

Australian Government
Australian Institute of Health and Welfare

VICTORIA
State Government

TDLU
Tasmanian Data Linkage Unit

Queensland Government

NSW GOVERNMENT

SA-NT DataLink

saxinstitute
SURE: Secure Unified Research Environment

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