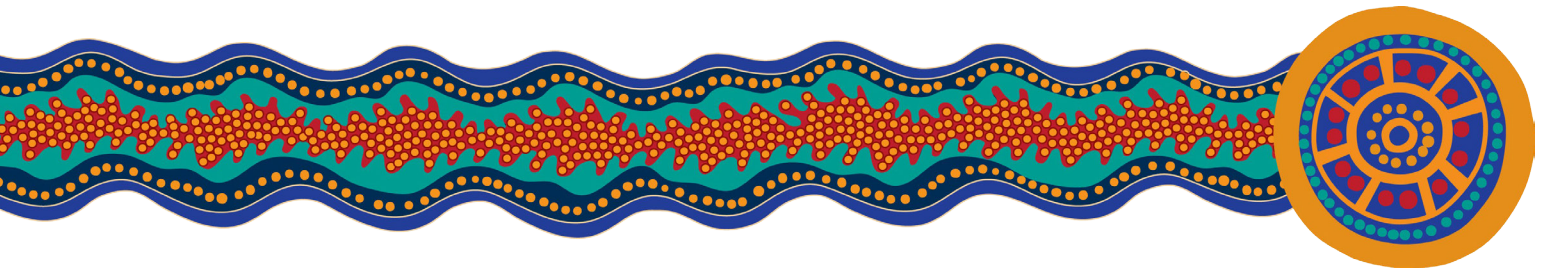




Queensland Data Linkage and Data Sharing Vision and Strategic Roadmap 2024-2027

July 2024



We respectfully acknowledge the Aboriginal and Torres Strait Islander peoples as the Traditional and Cultural Custodians of the lands on which we live and work to deliver healthcare to all Queenslanders and recognise the continuation of First Nations peoples' culture and connection to the lands, waters, and communities across Queensland.



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Introduction



This project was funded through a grant from the Commonwealth Department of Health and Aged Care (CDHAC) to enable the Queensland PHNs Collective's engagement in the Queensland - Commonwealth Partnership (QCP).

Context

National context

- The last four years has seen significant recognition about the importance of health data to better inform health system planning, decision making and population health management.
- The COVID-19 pandemic underscored the need for a comprehensive health data set spanning primary to secondary care to better inform population health management and decision-making. Queensland Health initiated the ATHENA COVID-19 data linkage study to address this gap, aiming for better health service data and population health insights.
- In late 2023, the National Health Ministers approved funding for a project led by NSW Health on behalf of all jurisdictions and the Commonwealth, aiming to co-design a national approach for sharing and linking primary and secondary care data.
- The National Primary and Acute Care Data Linkage Project entails establishing jurisdictional leads and consultative committees in each state and territory, to develop a co-designed blueprint for a national data sharing system, and creating a business case for securing funding.
- Commencing in 2024, the national project involves resourcing at both national and jurisdictional levels. In Queensland, the project is being led by Queensland Health and the national rollout is leverage existing expertise in data linkage managed by the Statistical Services Branch, and aligned to other work that has been progressed for data sharing and linkage between primary and secondary care data in the state.

Queensland context

- The QCP was established in 2022 from bilateral discussions between the CDHAC and Queensland Department of Health. The QCP's vision, guiding principles, priority areas and enablers are detailed on the following page in Figure 1. **Data and joint planning** have been identified as one of three critical priority areas for the QCP to achieve its common vision. **Shared Data** has also been identified as a key enabler for the vision.

Figure 1: Queensland health system vision, guiding principles, priority areas

Queensland Commonwealth Partnership - Joint Statement

Our shared commitment to Queensland's health system

Our common vision

Together we will:

- Lead a dynamic and responsive health system for all Queenslanders.
- Enable better integrated, patient-centred care aimed at improving people's experiences and health outcomes and supporting equitable access to care.*

To do this, we will focus on:

Community

Providing place-based solutions to keep people, and their healthcare in their local community where appropriate - with a focus on priority populations.

Outcomes

Striving for good health and wellbeing of all Queenslanders - with a focus on improving care integration and system navigation, health literacy, the social determinants of health, and information sharing.

Partnerships

Working together as equals as we plan and build the future of healthcare in Queensland.

Our value proposition

Connecting across the health continuum, driving health equity and person-centred care

Our guiding principles

Our actions will be guided by these fundamental principles



Our priority areas

We will focus on the following opportunities for action

Data and joint planning

Using and sharing data to drive innovation, better understand consumers' needs, and jointly plan healthcare services based on population health needs and shared outcome-based indicators.

Strengthening primary and community care

Keeping Queenslanders closer to home, focusing on prevention and wellbeing, reducing duplication and tailoring care to individual needs.

Building a governance framework

Creating the systems that will keep us accountable and effective sharing ideas and building trust.

Our enablers

Funding

Workforce

Governance

Collaborative
Commissioning

Shared Data

Objectives

The *Queensland Data Sharing and Linkage Strategic Vision and Implementation Roadmap's* overarching objective is to support and build an understanding of the WHY and the WHAT of data sharing and linkage in the Queensland health system, particularly for primary care data.

Objective 1 'the WHY'

To develop a 'Queensland Data Sharing and Linkage Strategic Vision' Statement that:

- drives more efficient and effective healthcare delivery, enhances population health needs assessment and planning, and ultimately, improves population health outcomes
- optimises healthcare safety, quality, and outcomes for the Queensland community.

Objective 2 'the WHAT'

To develop a strategic roadmap for data sharing and linkage initiatives aimed at modernising, simplifying, and enhancing access to health data within the Queensland health system, particularly primary care data.

This vision and roadmap articulate the 3-5 year aspiration for the future of data linkage and data sharing of primary and acute care data in Queensland. As the sponsors for the development of the Queensland Strategic Vision and Plan, on behalf of the QCP, the PHN Collective will continue to collaborate with Queensland Health to ensure alignment of the Queensland Strategic Vision and Plan with the national primary and secondary care linkage project. By closely aligning the two projects, Queensland's Strategic Vision and Plan (the WHY and the WHAT) will be used as a key input and enabler for the Queensland approach to co-designing the national blueprint for a national primary and secondary care data sharing system and a business case for securing funding will be developed, the HOW.

The objectives are to:

- ✓ modernise and simplify the Queensland Health System, enhancing access to quality health data for informed decision-making and strategic planning
- ✓ enable partners to use data for needs assessment, service planning and interventions, fostering continuous improvement in safety and quality of healthcare
- ✓ drive positive healthcare outcomes for the Queensland community by leveraging data to inform policies and interventions tailored to local needs.

Scope and approach

The development of this vision and roadmap was informed by an analysis of key literature, including national, jurisdictional and regional health strategies and work plans, as well as peer-reviewed publications. It also incorporates input received through extensive consultations with Queensland stakeholders including: the Institute for Urban Indigenous Health; Queensland Aboriginal and Islander Health Council; PHN Consumer Council representatives; Health Consumers Queensland; various Queensland Health divisions; general practitioners; academics; the Queensland GP Alliance; the Primary Care Queensland Forum; the Queensland PHNs Collective Chief Executive Group; the Joint Data and Analytics Working Group; and the QCP Steering Committee (PaSCo).

In the evolving healthcare landscape, achieving both **digital reform** through point-of-care information sharing and **data reform** via data linkage, are pivotal to enhancing patient outcomes, system efficiencies, and overall healthcare delivery as depicted in Figure 2: Digital and data reform descriptions, below.

Figure 2: Digital and data reform descriptions

Digital Reform

Deliver seamless, near real-time information exchange to improve patient-provider decisions at the point of care.



Data Reform

Deliver robust evidence bases and data-sharing pipelines to enable data-driven policy, service delivery and system navigation.



As digital solutions mature, they will enable more granular and detailed data analyses.

Vision



The vision provides the ‘WHY’: To develop a **Queensland Data Sharing and Linkage Strategic Vision Statement** that drives more efficient and effective healthcare delivery, enhances population health needs assessment and planning, and ultimately, improves population health outcomes; and optimises healthcare safety, quality, and outcomes for the Queensland community.

The graphic on the following page, illustrates the comprehensive framework for Queensland’s vision of data sharing and data linkage in transforming healthcare. It encompasses the vision, use cases, impacts and outcomes, and foundational principles, highlighting how these interconnected elements collectively guide stakeholders towards a more connected, efficient, and effective health system.

Vision: the Queensland vision of data sharing and data linkage for a transformative healthcare future.

Use cases: known exemplars and priority use cases that demonstrate practical application of data linkage and sharing that align to the vision.

Impacts and outcomes: these priority areas demonstrate the tangible outputs and outcomes of data sharing and data linkage in the health system, which will occur at various stages of implementation aligned to various use cases.

Foundational principles: the Queensland vision and roadmap are founded on seven key principles, designed to be the foundational elements underpinning and guiding stakeholders across all data sharing and linkage activities.



The vision provides the aspiration for the future of data linkage and data sharing of primary and acute care data in Queensland.

Queensland Vision for Data Sharing and Data Linkage

Queensland actively shares and links primary and acute care data to ensure optimal, equitable, and accessible patient care. This approach is central to improved population health outcomes, evidence-based decisions, shaping public health policies, effective resource allocation and optimum cost efficiency.

The strategic use cases demonstrate what this can look like:

PHASES: predicting and reducing risk of cardiovascular disease

First Nations perinatal/maternity outcomes monitoring

Clinical care and service coordination: Improved access and coordination of care between hospital and primary care

The vision will drive the following impacts and outcomes:



Equitable and accessible care. Every patient, regardless of background or location receives the same high-quality health care services.



Improved population health outcomes. Clinicians are empowered with comprehensive information to effectively identify and address health needs and outcomes, resulting in better value and overall health for the Queensland community.



Evidence-based decisions. Enable informed planning, prioritisation and implementation of health services at every level: regional, state, and national.



Shaped public health policies. Implementation of policies that effectively address the real health needs of the community, ensuring equitable access to tailored health care solutions.



Optimum resource allocation and cost efficiency. Optimise health care resource allocation, highlighting the benefits of providing care in one setting over another.

The foundational elements underpinning and guiding stakeholders across all activities:

- Empower First Nations
- Embed active and diverse consumer voices
- Meaningful engagement with general practice and providers across the continuum of care
- Robust governance and effective partnerships
- Safeguard privacy and confidentiality
- Support data management and technology
- Data literacy for all

Benefits and use cases



The overarching benefits of data linkage and data sharing to the healthcare system include:

- provides a complete picture of the patient journey throughout the healthcare system
- supports individual practice change insights
- informs decision-making
- supporting evidence-based policy
- highlights service utilisation and cost efficiency
- guides regional and state-wide planning, implementation and evaluation
- information exchange to inform clinical practice
- data sharing for disease surveillance and monitoring

Three current use cases are presented below to highlight the potential benefits that would accrue from strategic healthcare data linkage and data sharing endeavours in Queensland. They provide priority exemplars for initial focus as part of implementation of the approach to data linkage and sharing set out in the Queensland Vision and Roadmap.

The use cases based on current activities fall into three broad categories:

- Activities that propose data linkage and sharing that are well aligned to the population health and system enablement envisaged by the Queensland Data Linkage and Data Sharing Vision, that are already prioritised and funded, but are yet to commence.
- Activities/programs that are already in place that would benefit from having consideration given to inclusion of data linkage and sharing, aligned to the vision / roadmap implementation.
- Activities that are part of a First Nations use case at conceptual and planning stage.

Together these use cases signal opportunities for practical application of data linkage and sharing aligned with the Queensland Vision and Roadmap, and opportunities to demonstrate the potential value to be harnessed.

USE CASE 1 – an existing activity proposing data linkage and sharing, well aligned to the vision and the roadmap

Preventing Heart Attacks and Stroke Events through Surveillance (PHASES) with Primary Sense™

Background

In collaboration with the Queensland Primary Health Network Collective, Qld Health, and the Commonwealth, Country to Coast Qld (CCQ) has identified an opportunity to improve the management and treatment of cardiac risk factors across Queensland.

This project aims to use Primary Sense™¹ and its ability to deliver patient-specific clinical decision support to enable early intervention, improving the treatment of cardiovascular disease in primary care and to subsequently reduce the demand and cost to Queensland's hospital and health services.

Problem Statement

There is a lack of effective and efficient early intervention and management of cardiovascular disease which directly impacts the health and well-being of Queenslanders, as well as impacting sustainability of Queensland's hospital and health services. Queensland research has shown that a large proportion of patients presenting to hospital with acute coronary syndromes were at high CVD risk prior to their event, and the majority were not on guideline-recommended treatment. In addition, general practitioners have self-reported conducting CVD risk assessments in a low proportion of the eligible patient population.

PHASES with Primary Sense™ aims to increase early intervention of CVD in a primary care setting using contemporary digital health capabilities to reduce the burden of cardiovascular disease (CVD) for patients and their community, and subsequently reducing the demand and costs associated with addressing advanced stage CVD in the acute care sector.

The Opportunity

The project seeks to leverage the data sharing and data analytics capability of the Primary Sense™ tool, the Primary Health Insights™ platform, and the Johns Hopkins ACG® System to deliver patient-specific, clinical decision support enabled surveillance and intervention, improving the treatment of cardiovascular disease in primary care:

- **Primary and Acute Care Data Linkage** will enable widespread surveillance and detection of patients with CVD risk in a primary care setting.
- **Primary and Acute Care Data Linkage** of General Practice CVD risk data with hospitalisation and mortality data to understand how CVD risk impacts hospitalisation rates, and how well the new CVD risk prediction equation detects those at high risk in an Australian (Queensland) population.
- **Primary and Acute Care Data Linkage** to estimate the number of heart attacks and strokes potentially averted if high CVD risk treatment was improved, as well as identifying gaps in CVD prevention.
- **Primary and Acute Care Data Linkage** to provide the digital capabilities to support the intervention and ongoing management of CVD in primary care.
- The PHASES with Primary Sense provides an exemplar that already aligns well to the Queensland Vision and Roadmap. It has the potential to become an 'implementation demonstrator' of the Vision, its principles, its impacts, and its outcomes.

¹ Primary Sense™ is population health management and to provide general practice staff with real time medication alerts, reports and patient care prompts. See www.primarysense.org.au for further details.

USE CASE 2 - an existing activity that would benefit from data linkage and sharing aligned to the vision

Primary Care Pilot: Care Collective – South West

Background

The Commonwealth Department of Health and Aged Care (CDHAC) provided Primary Care Pilot funding to states and territories to test innovative models of care. The Reform Office received the CDHAC funding and subsequently funded the Brisbane North Health Alliance for the Care Collective – Caboolture program and expansion to Redcliffe, and the South West Primary Care Pilot.

The South West Primary Care Pilot has leveraged the established South West Queensland Primary Care Alliance for the consultation, codesign and implementation of the Primary Care Pilot in South West Queensland. This enabled the design and implementation of a pilot that will meet local needs.

Care Collective – South West aims to improve the health and wellbeing for those living with complex health condition/s.

Initially the Pilot will be delivered in the Far South West Queensland region, covering Charleville, Quilpie, Cunnamulla, Thargomindah and surrounding areas.

Service providers participating in the South West Pilot include South West Hospital and Health Service (GPs and acute), Charleville and Western Area Aboriginal and Torres Strait Islander Community Health (CWAATSICH), Cunnamulla Aboriginal Corporation for Health (CACH), the Royal Flying Doctor Service (RFDS), private GP practice. Western Queensland PHN (WQPHN) are also involved as a key partner.

The pilot has just commenced implementation with an interim insights report due Jan/Feb 2025 and final evaluation post-completion (approx. August 2025).

Problem Statement

There is a need for place-based models of primary care, including appropriate workforce models, for better pathways of care across settings for people living regionally and remotely with chronic and complex health conditions.

The pilot aims to improve access to coordinated and integrated care for people living with chronic conditions. The proposed model builds on existing hospital and primary care pathways with Community Services Coordinators (focused on service and provider coordination) and Clinical Care Coordinators (focused on complex chronic disease care coordination) based in primary care.

Through scoping and engagement with health providers, stakeholders and consumers in South West Queensland, it was identified that many residents in the western hub, particularly in the Far South West and Charleville, experience challenges in accessing primary health care services and the coordination and integration of care. Limited or inconsistent resourcing of workforce and services was also evident. Through the Primary Care Pilot, this presents an opportunity to collaborate with local services and health providers to build on existing strengths and address identified gaps.

As well as significant stakeholder engagement, we looked at the following quantitative data to determine where in South West to focus (i.e. why we picked far South West):

- Demographics
- Frequent presenters and cat 4 and 5 ED presentations
- Potentially preventable hospitalisations
- Chronic conditions of active patients (taken from HHS practice data reports for HHS)
- Patient travel subsidy and retrievals.

The Opportunity

This South West Primary Care Pilot provides an exemplar of a health system innovation at an early stage of implementation that would benefit from Primary and Acute Care Data Linkage. Data linkage would enable understanding of the impact of the pilot on the healthcare system and the client benefits, including tracking service use across settings and the relationship of care received to outcomes for people and the system.

The program has already engaged a diverse range of provider, community, and consumer participants in a priority endeavour to improve the health and wellbeing of Queenslanders. As a use case, the Pilot provides the opportunity to demonstrate mobilisation of data linkage aligned to the Queensland Vision and Roadmap, as part of the roll out of an existing prioritised and funded activity.



USE CASE 3 – an existing activity proposing data linkage and sharing, well aligned to the vision and the roadmap

Digital Infrastructure For improving First Nations matERNal and Child hEalth (DIFFERENCE)

Background

The Birthing in our Community (BiOC) program was designed, developed and implemented as an Indigenous led partnership between The Institute for Urban Indigenous Health (IUIH) Aboriginal Community Controlled Health Network, The Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) Brisbane and Mater Mothers Hospital, established in 2013. In its decade of operation, the BiOC model of birthing care has delivered exceptional outcomes for Aboriginal and Torres Strait Islander mothers, babies and their families, including:

- Closing the gap in perinatal outcomes including preterm birth
- Reducing the risk of child removal at birth three-fold
- Delivering these outcomes with significant savings to the healthcare system¹

Nevertheless, our current disconnected infrastructure operating across healthcare services does not support a whole-of-health system approach to improve health outcomes for First Nations families. We have two unmet clinical primary care data infrastructure needs:

- **Connectivity** - when pregnant mothers require both primary and hospital care, their data does not seamlessly follow their care. This results in a high risk of fragmentation of care. This problem is not unique to First Nations clients, families, and communities, nor to the BiOC service model, but the potential impact on our communities is disproportionate.
- **Integration** - because perinatal data for First Nations women and babies are disintegrated, collected, and stored in silos in either primary or hospital data systems, the full story for our women, babies, and families is not visible. The scope for identifying strengths and gaps is more limited, as are opportunities for implementation of continuous quality improvement activities and for robust, comprehensive ongoing evaluation and research aimed at answering key questions of importance for communities, policymakers, and system and service leaders, ultimately with the goal of sustaining and improving outcomes for First Nations women, their babies, and families.

Problem Statement

The DIFFERENCE project aims to address the lack of effective and efficient connectivity and integration in data infrastructure for First Nations maternal and child health care, which directly impacts the health and well-being of Aboriginal and Torres Strait Islander families and affects the sustainability of the healthcare system. The disconnected infrastructure results in fragmentation of care and limits the visibility of the full health story for First Nations women and babies. This problem affects the implementation of continuous quality improvement activities, ongoing evaluation, and research, which are crucial for sustaining and improving health outcomes.

¹ Birri O'Dea, Yvette Roe, Yu Gao, et al. (2024) Breaking the cycle: Effect of a multi-agency maternity service redesign on reducing the over-representation of Aboriginal and Torres Strait Islander newborns in out-of-home care: A prospective, non-randomised, intervention study in urban Australia, *Journal of Child Abuse & Neglect*, Volume 149, 2024. ISSN 0145-2134. <https://doi.org/10.1016/j.chiabu.2024.10666>

Gao, Y., Roe, Y., Hickey, S., Chadha, A., Kruske, S., Nelson, C., Carson, A., Watego, K., Reynolds, M., Costello, J., Tracy, S., Kildea, S. (2023). Birthing on Country service compared to Standard Care for First Nations Australians: a cost-effectiveness analysis from a health system perspective, *The Lancet Regional Health-Western Pacific*. March 2023. <https://doi.org/10.1016/j.lanwpc.2023.100722>

Sue Kildea, Yu Gao, Sophie Hickey, Carmel Nelson, Sue Kruske, Adrian Carson, Jody Currie, Maree Reynolds, Kay Wilson, Kristie Watego, Jo Costello, Yvette Roe. Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomised, interventional trial. *Lancet Glob Health* March 17, 2021 [https://doi.org/10.1016/S2214-109X\(21\)00061-9](https://doi.org/10.1016/S2214-109X(21)00061-9)

The Opportunity

The DIFFERENCE project leverages the “Three Horizons” framework for digital transformation to optimize identifiable and non-identifiable data streams, providing a unique opportunity to enhance healthcare outcomes for First Nations communities.

- **Aim 1: New Digital Infrastructure and Digital Workflows (Horizon 1)** - To examine, define, and map the data currently being routinely collected for First Nations pregnancies at our three healthcare settings. We will create the relevant interoperability standards using Fast Health Interoperability Resource (FHIR) and map the data set to a globally recognised common data model (CDM), the Observational Medical Outcomes Partnership (OMOP).
- **Aim 2: Data and Analytics (Horizon 2)** -
 - a) To create an identifiable data stream to connect care for mothers who access care across primary and tertiary care.
 - b) To develop deidentified descriptive, predictive, and prescriptive analytics from Aim 1 data in near real-time for connected clinical care across primary and tertiary care and for research purposes to allow iterative quality improvement and high-quality research outputs.
- **Aim 3: New Models of Care (Horizon 3)** - To redesign care based on data-driven analysis of outcomes (from Aim 2) to facilitate better maternal and perinatal health outcomes for this population. The digital workflows and analytics will be leveraged to create high-impact research outputs and to create continuous iterative improvement and a learning healthcare system where routinely used data is aggregated and used to continuously and iteratively enable data-driven decision-making to improve outcomes.

Currently within its second year (ending in 2026), the project has made significant progress in:

- Building the infrastructure that supports the data in a fit-for-purpose data ecosystem as above.
- Continuing to explore and apply First Nations Data Governance and Data Sovereignty principles into practice, taking steps to actualise an accountability framework to ensure urban Aboriginal and Torres Strait Islander people autonomously decide what, how, and why Indigenous information and/or knowledge are generated, collected, accessed, analysed, interpreted, managed, disseminated, and otherwise used.
- A sub-project has explored critical themes of consent, investigating the views of BiOC Aboriginal and Torres Strait Islander Family Support Practitioners and BiOC mothers and families to gauge what and how data should be shared between primary and secondary care providers to develop models of consent for identified and de-identified data streams and to stage our approach accordingly.

Strategic roadmap



The roadmap that complements the vision, outlines the key activities to drive the implementation of data sharing and data linkage in Queensland. This roadmap provides the WHAT: *To develop a strategic roadmap for data sharing and linkage initiatives aimed at modernising, simplifying, and enhancing access to health data within the Queensland Health System, particularly primary care data.*

The roadmap highlights:

Activities: The activities in the roadmap articulate WHAT needs to be done to achieve the intended vision, impacts and outcomes.

Dynamic evolution: The activities noted in this strategic roadmap are not static and will evolve dynamically over varying time horizons based on previous actions, external influences, and ongoing priorities and requirements, at national, state and regional levels.

Interdependency: Some activities within the roadmap will be interdependent.

Agile and flexible: An agile and flexible approach to implementation will be required to capitalise on initiatives being implemented at the national level, such as the national primary and secondary care data linkage project and adapt to shifting priorities.

Collaboration: A collaborative process inclusive of Queensland partners and interdependent with national activities, for example, ensuring governance is co-designed across partners sharing data. The Queensland arm of the national primary and acute care linkage project will support the progression of this collaboration.

- The roadmap timeline (page 20) identifies the implementation of activities across four-time horizons. It includes ongoing monitoring to ensure priorities and activities can be adjusted as the health landscape evolves.
- The roadmap also comprises six domains, each with specific objectives and activities. The six domains cover:
 1. collaboration and engagement
 2. scope of the data linkage and sharing
 3. governance
 4. privacy, consent and legal
 5. data management and technology
 6. funding and execution

Domain 1: Collaboration and engagement

Key Objectives

- Enhance collaboration across stakeholder groups to ensure effective data sharing and linkage.
- Build trust through transparent communication and inclusive stakeholder participation.

Activities

Stakeholder engagement and communication

- Identify all stakeholder groups, specific needs, concerns and expectations.
- Establish mechanisms for genuine stakeholder input.
- Establish clear and regular communication on progress.
- Empower patients by showcasing real-world examples of data linkage benefits.
- Leverage and communicate early to drive progress.

Data linkage literacy and capability

- Build data sharing and linkage literacy for consumers, system planners, clinicians, and researchers.
- Provide training and resources to enhance the capabilities of stakeholders in understanding, using, managing, and sharing linked data effectively.

Empower First Nations

- Build mechanisms to capture First Nations Peoples' perspectives and community needs meaningfully.
- Embed shared decision-making structures involving First Nations Peoples' representatives.

Embed active and diverse consumer voices

- Actively engage diverse groups of consumers through regular consultations, workshops, and feedback sessions to ensure their needs and concerns are addressed in data sharing and linkage initiatives.
- Utilise Consumer Advisory Committees from Health Consumers Queensland, PHNs, Hospital and Health Services and other healthcare providers, to capture diverse geographical representation.
- Include consumer representation on governance committees.

Meaningful general practice and provider engagement

- Establish partnerships with primary care and other providers.

Domain 2: Scope of the data linkage and sharing

Key Objectives

- To define the data sources and priorities to ensure comprehensive data sharing and linkage.

Activities

Current landscape, population, and system priorities

- Identify and agree priority data sets to be included over time, noting those already linked through the Queensland Health Master Linkage Key, including identifying who the data custodians are.
- Identify current and required standards to ensure data are comparable, complete, and reliable.
- Identify priority population groups to be selectable in the data, e.g. culturally and linguistically diverse, rural and remote communities, lower socio-economic, elderly, Aboriginal and Torres Strait Islander peoples, health conditions of interest etc.

Domain 3: Governance

Key Objectives

- Embed transparent governance structures and processes.
- Clarify responsibilities for data custodianship and accountability.

Activities

Robust governance structures

- Utilise Queensland's existing collaborative working groups (such as the QCP's Joint Data Analytics Working Group) to drive the development and implementation of data linkage and data sharing.

Policies and procedures

- Align policies and regulations with best practices for data sharing and linkage, ensuring legal and ethical compliance.
- Establish new policies and procedures, where required, for governing data sharing, access and usage, and share these with relevant stakeholders.
- Review, develop and update risk management plans and protocols.

Data custodianship

- Clearly define data custodianship.
- Specify who is entrusted to manage decisions about data privacy and access.
- Appoint data stewards responsible for data quality, accuracy, and integrity.
- Ensure data custodians collaborate with stewards for ongoing effective governance.
- Consult with other agencies to determine sub-populations included in data collections and repositories.

Indigenous Data Sovereignty

Support a community-led approach to:

- Collaboratively design data strategies with First Nations people.
- Establish ownership, control and decision making over Indigenous health data.
- Practising Indigenous Data Sovereignty through Indigenous data governance.
- Ensure data ownership and control remain within Indigenous communities.
- Educate policymakers, data custodians, and users about the importance of respecting Indigenous Data Sovereignty.
- Align Indigenous Data Sovereignty with contemporary practice².

Continuous improvement

- Establish processes and KPIs to monitor the implementation of the roadmap and make changes as required.
- Establish mechanisms to monitor and assess the effectiveness and impact of data linkage and sharing activities.

² <https://www.niaa.gov.au/sites/default/files/documents/2024-05/framework-governance-indigenous-data.pdf>

Domain 4: Privacy, legal, consent

Key Objectives

- Implement measures to ensure robust patient data privacy and security.
- Ensure adherence to all legal and regulatory requirements.
- Ensure all projects meet high ethical standards.

Activities

Policies and procedures

- Review and update privacy policies and protocols to safeguard sensitive information and prevent unauthorised access or data breaches.

Consent

- Explore the range of consent models, including individual consent, identified data sharing permissions, and waivers of consent for data sharing and data linkage scenarios.
- Explore consent options for deidentified linkage across primary care service providers for the same individual.
- Develop mechanisms for obtaining and managing consent for data sharing and or linkage.
- Provide options and mechanisms for withdrawal of consent.
- Improve understanding of where consent is required and the drivers for this requirement.
- Improve understanding of legislative provisions that relate to data sharing without explicit individual consent and the intent and scope of these provisions.

Legal compliance

- Identify relevant laws and regulations (e.g. Privacy Act 1988, Health Records and Information Privacy Act 2002, Queensland Hospital and Health Boards Act 2011).
- Document the purposes of data sharing and data linkage clearly.
- Establish clear governance structures, policies, and procedures to guide the ethical and legal aspects of data sharing and linkage, for example, data sharing agreements or memoranda of understanding.
- Develop and implement ethical guidelines for data use.

Privacy and security

- Implement secure access protocols for all users and external data sharing and linkage activities.
- Develop robust safeguards to protect patient privacy.
- Address cybersecurity risks.
- Implement mechanisms for monitoring data access, use, and sharing activities to identify unauthorised or inappropriate use.
- Conduct regular privacy impact assessments to ensure data privacy and security measures are robust and compliant with regulations.
- Develop plans for responding to data breaches.
- Ensure secure access environments by incorporating requirements aligned with the DAT Act and ONDC accreditation processes for data access environments, or by utilising ISRAP specifications.

Domain 5: Data management and technology

Key Objectives

- Establish data management policies and practices that prioritise the secure, ethical, and responsible handling of data across all sharing and linkage processes.
- Promote ways of working that enhance interoperability among systems and foster collaborative efforts to maximise the value and utility of shared and linked data.

Activities

Data extraction, transfer, and management

- Undertake a stocktake of existing and future data management systems and technologies.
- Establish standards and procedures to maintain the accuracy, consistency, and reliability of shared and linked data.
- Establish standardised data formats, protocols, and governance frameworks that ensure consistency and interoperability across different systems and organisations.
- Implement Fast Healthcare Interoperability Resources (FHIR) protocols for data exchange.
- Implement automated data extraction tools and use secure data transfer protocols.
- Develop data handling protocols.
- Implement processes for quality assurance and validation to maintain data accuracy, completeness, and reliability throughout the linkage process.

Data storage

- Identify where and how the data will be stored.
- Develop minimum data storage principles, for example collection and storage of only the essential health data required.
- Implement encrypted databases and secure storage solutions.
- Implement tiered storage based on data sensitivity and access frequency.
- Regularly review and update storage solutions to maintain security.

Data infrastructure

- Explore Application Programming Interface (API) integration to facilitate interoperability between systems.
- Implement or enhance technical infrastructure to facilitate efficient and secure data sharing, including infrastructure in rural and remote communities.
- Implement real-time data processing systems for data and information sharing at the point of care.

Domain 6: Funding and execution

Key Objectives

- To secure funding for the effective execution of data linkage and data sharing.

Activities

Funding

- Identify the key cost drivers and potential funding sources for establishing and maintaining a Queensland primary and secondary care linked data initiatives.
- Identify the key cost drivers and potential funding sources for establishing and maintaining real-time data sharing at the point of care.

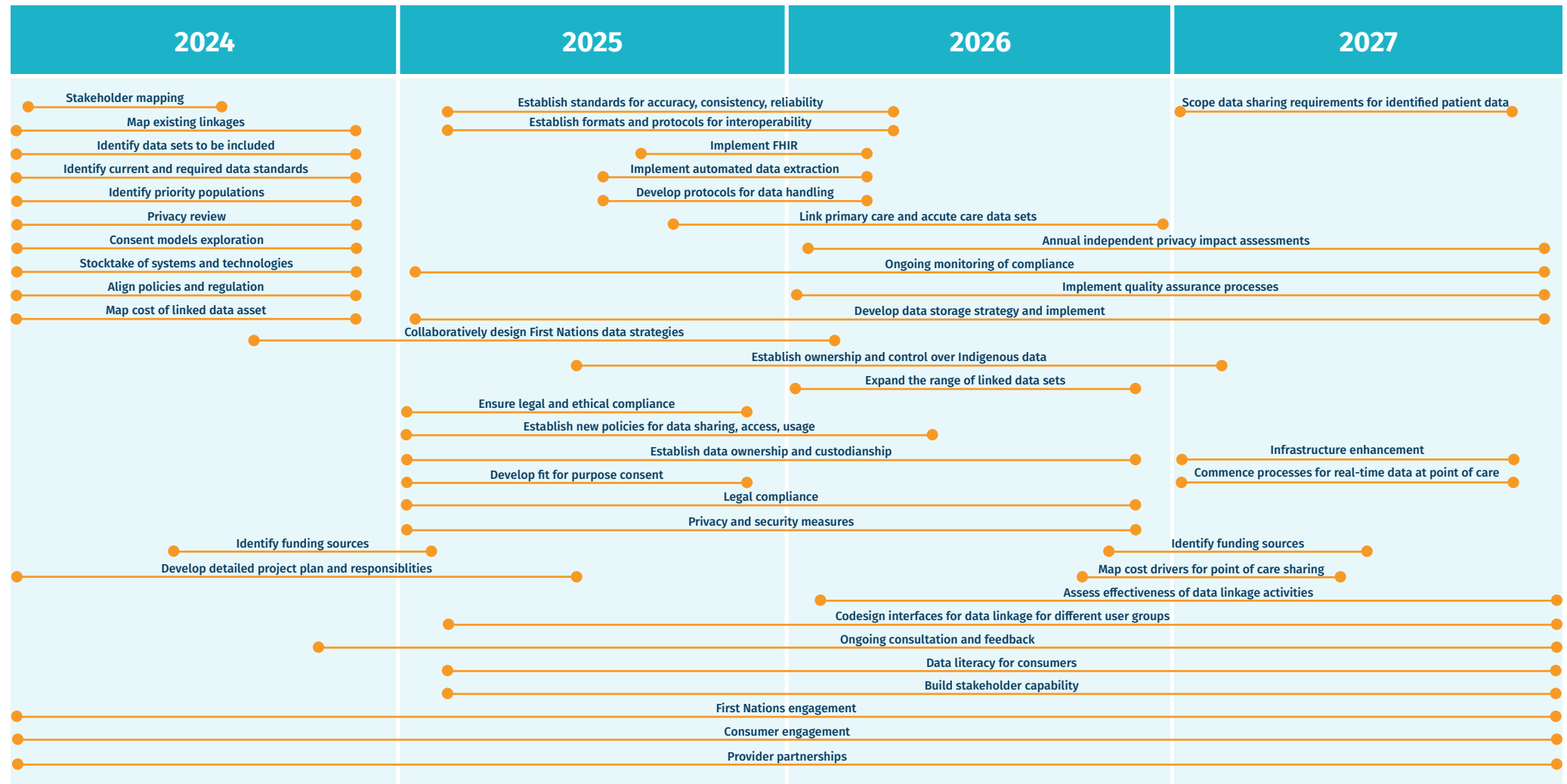
Execution

- Develop a detailed plan for executing data sharing and linkage activities in Queensland, including timelines and responsibilities.
- Codesign user friendly interfaces for different user groups to understand and optimise data sharing and linkage in Queensland.

Timeline

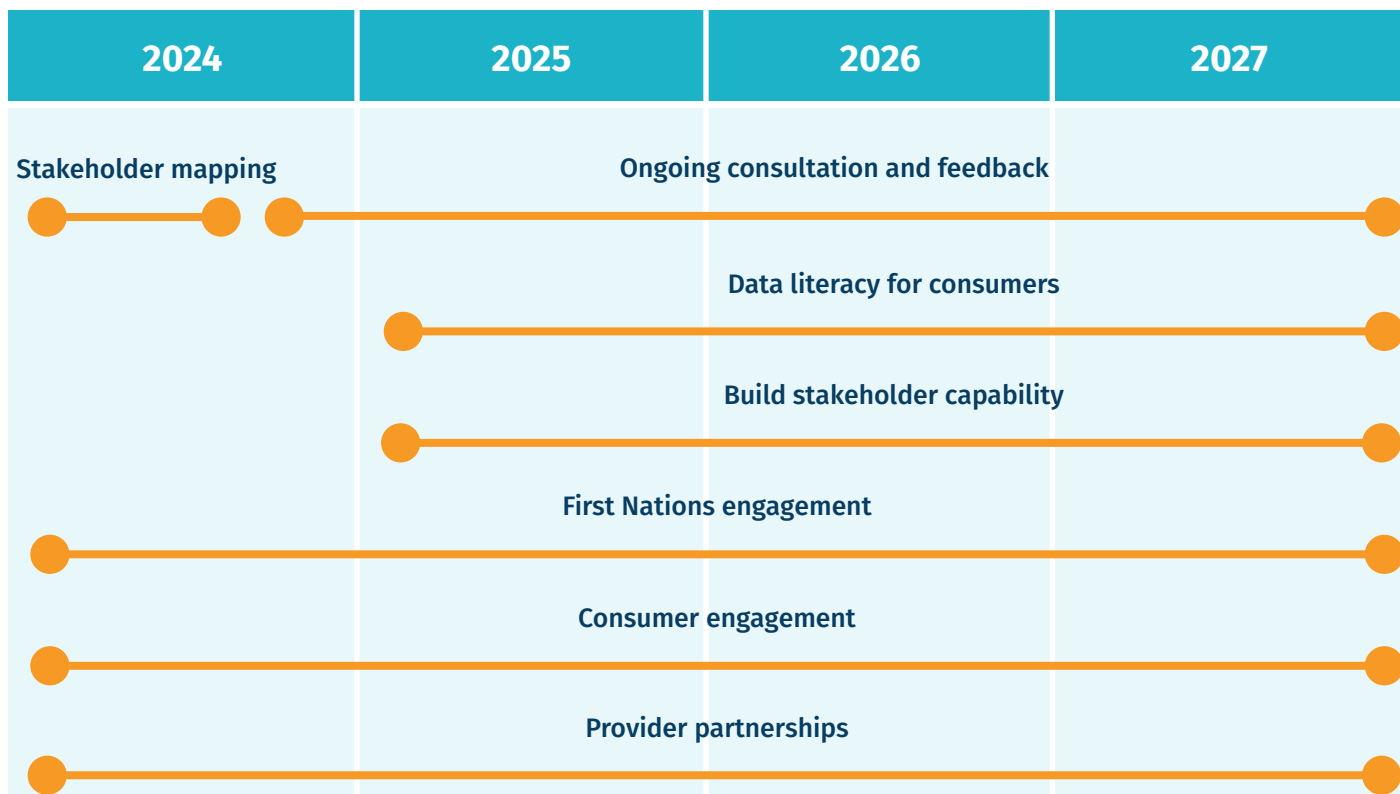


The roadmap timeline identifies the implementation of activities across four time horizons. It includes ongoing monitoring to ensure priorities and activities can be adjusted as the health landscape evolves.

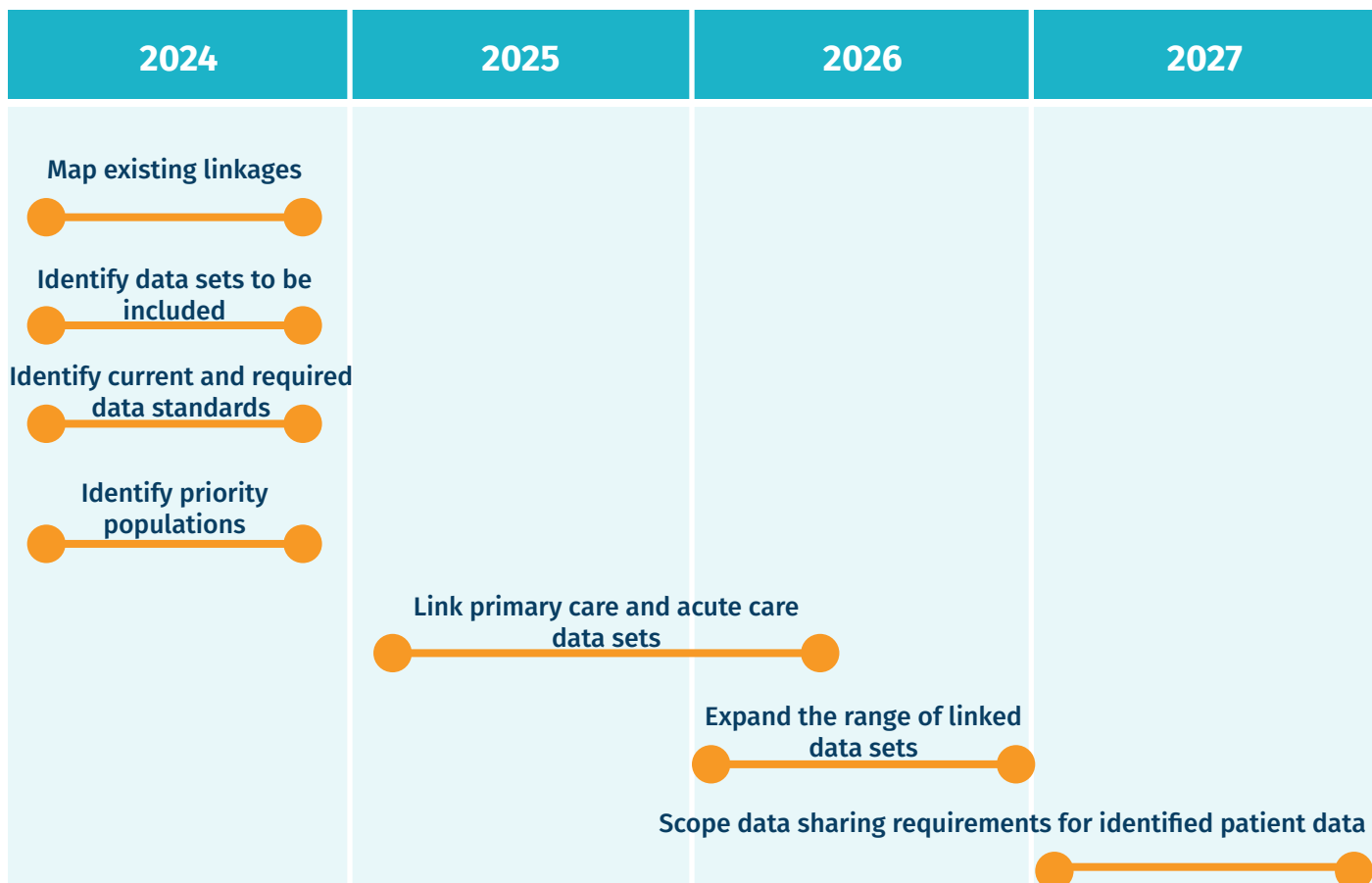


Some activities will need to run concurrently across the full roadmap timeframe, involving iterative improvements as other aspects mature; following the consolidated timeline, the individual timelines for each of the six domains are presented below, offering detailed insights and key milestones specific to each area.

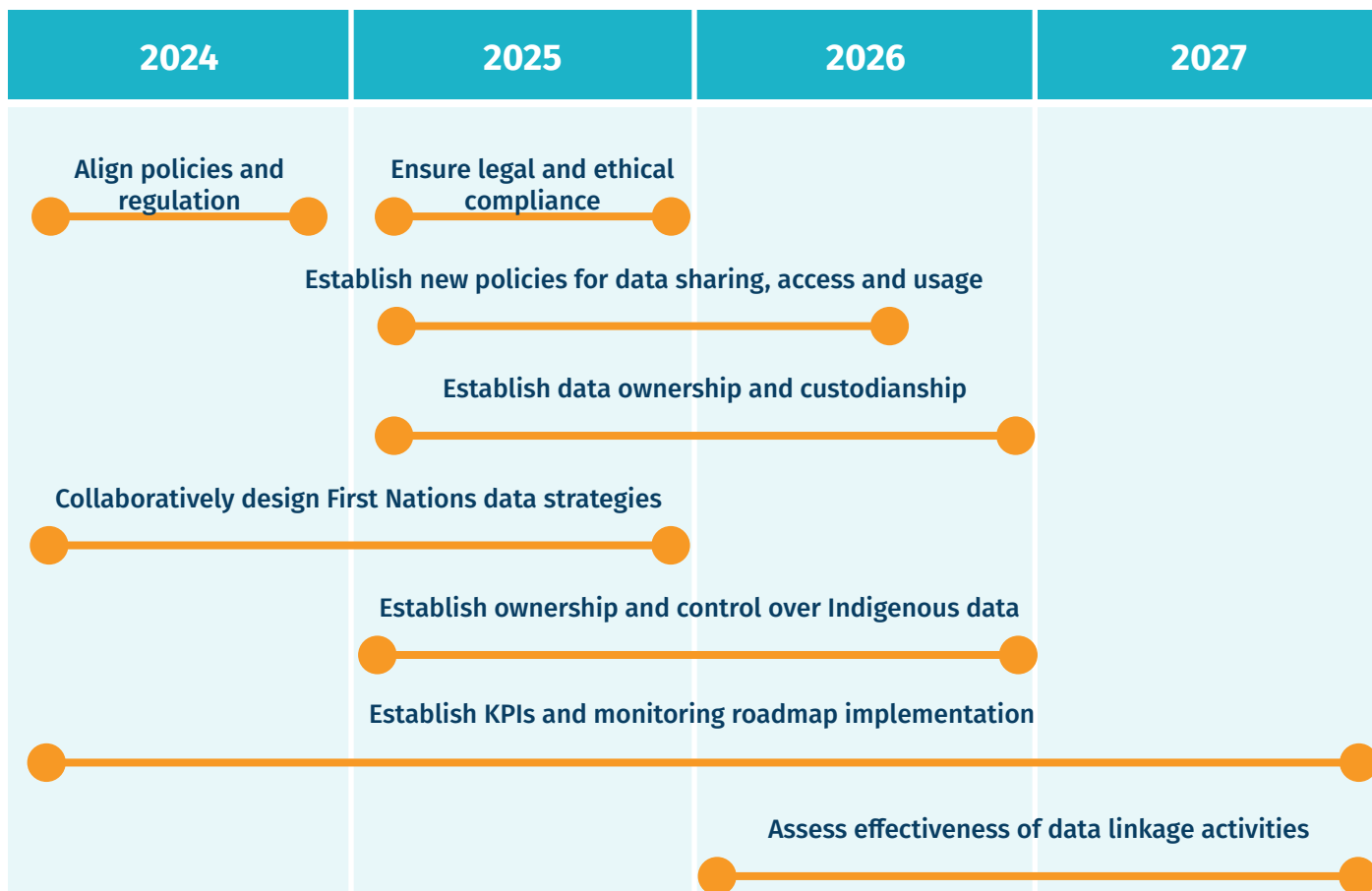
Domain 1: Collaboration and engagement



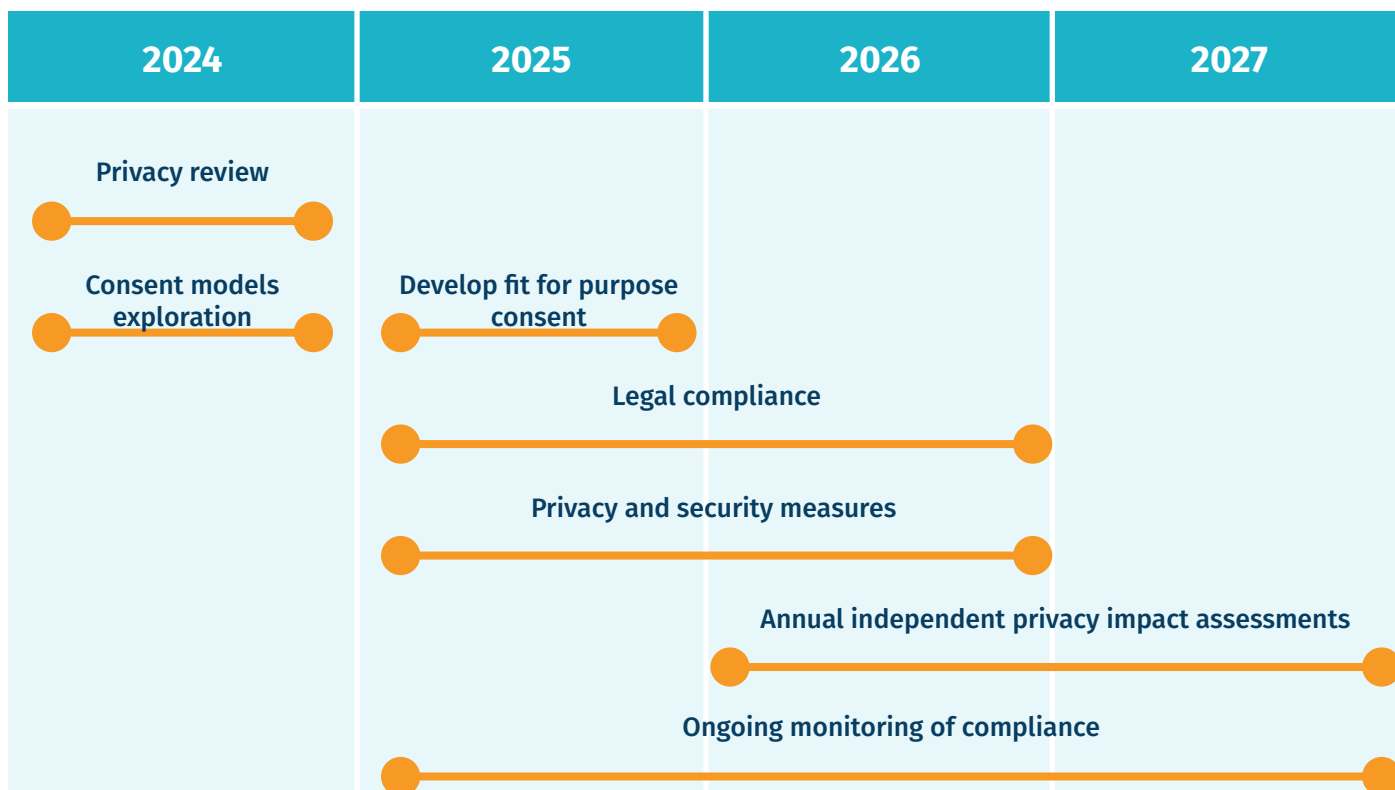
Domain 2: Scope of the data linkage and sharing



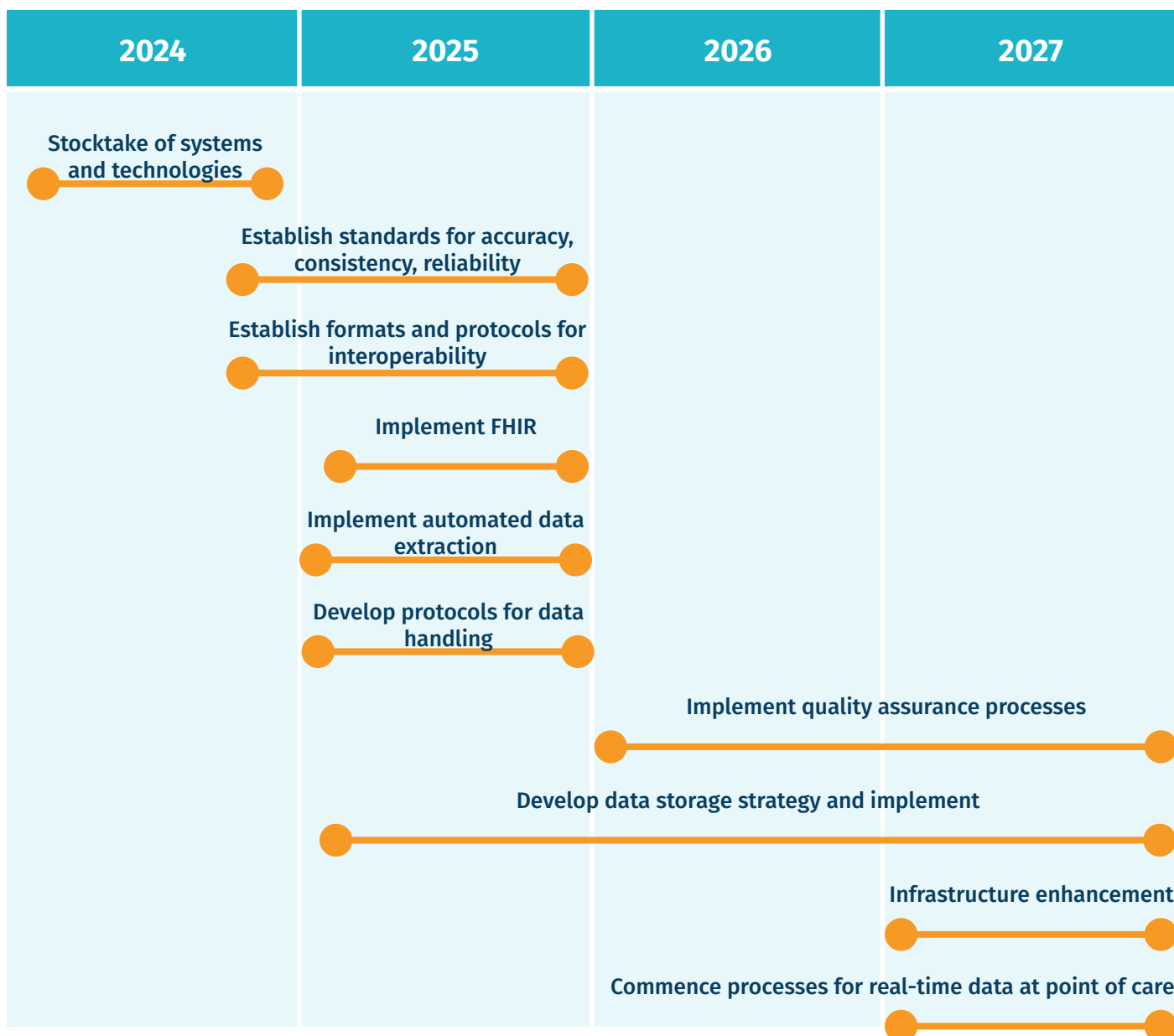
Domain 3: Governance



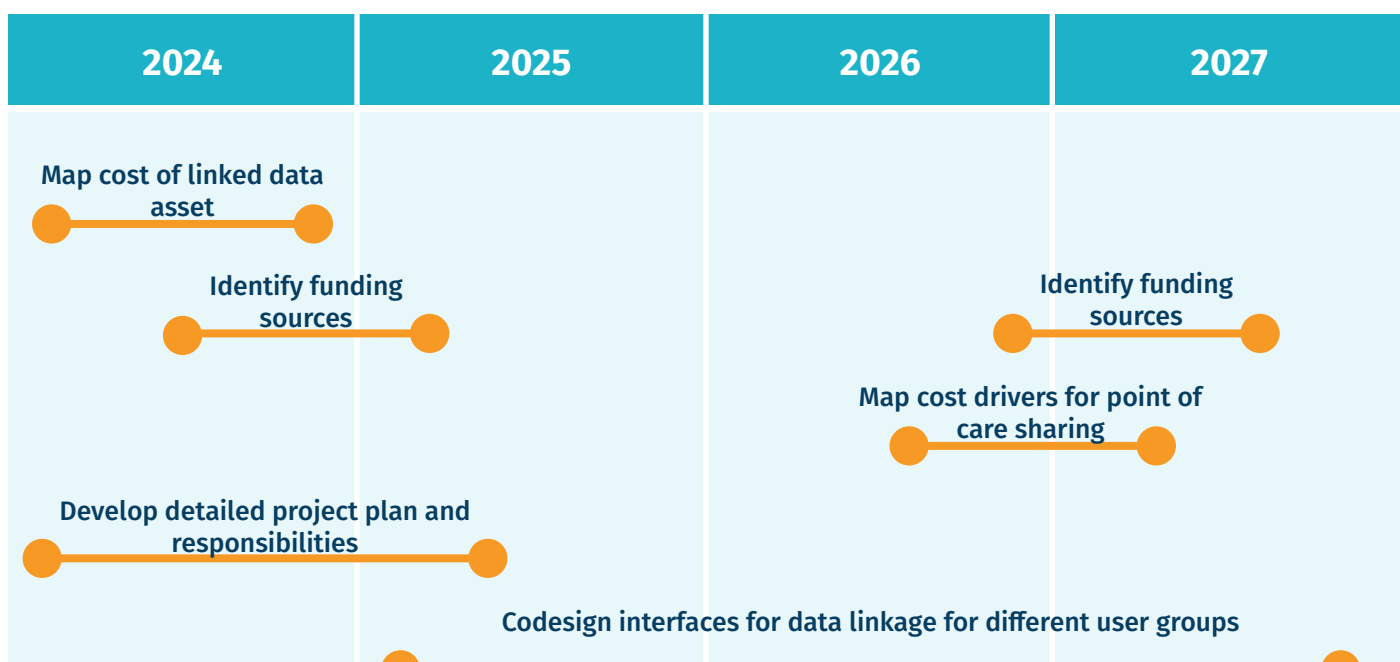
Domain 4: Privacy, legal and consent



Domain 5: Data management and technology



Domain 6: Funding and execution



Next steps



The Vision and Roadmap has been endorsed by the Queensland PHN CEOs' Collective and the Queensland - Commonwealth Partnership. The next step will be for the Queensland - Commonwealth Partnership to co-design an implementation plan for the Vision and Roadmap.



Appendix 1: Data linkage use cases



The table below provides a diverse array of projects that highlight the depth and breadth of data linkage opportunities. These projects range from conceptual phases to more advanced stages of implementation, and highlight multiple levels of readiness for data linkage across the healthcare sector. The information below has been provided by the key contacts as listed for each project.

Linkage topic	Description of project and data sharing and linkage opportunity	Lead Agency	Key Contact
<p>PHASES with Primary Sense project (CVD)*</p>	<p>Background In collaboration with the Queensland Primary Health Network Collective, QLD Health, and the Commonwealth, Country to Coast QLD (CCQ) has identified an opportunity to improve the management and treatment of cardiac risk factors across Queensland. This project aims to use Primary Sense™ and its ability to deliver patient-specific clinical decision support to enable early intervention, improving the treatment of cardiovascular disease in primary care and to subsequently reduce the demand and cost to Queensland’s hospital and health services. Primary Sense™ is a population health management tool and to provides general practice staff with real time medication alerts, reports and patient care prompts. See www.primarysense.org.au for further details.</p> <p>Data Linkage Opportunity</p> <ul style="list-style-type: none"> • The PHASES with Primary Sense project seeks to leverage the data sharing, and analytics capability of the Primary Sense™ tool, the Primary Health Insights™ platform, and the Johns Hopkins ACG® System to deliver patient-specific, clinical decision support enabled surveillance and intervention, improving the treatment of cardiovascular disease in primary care. • The PHASES with Primary Sense project is a statewide project that all QLD PHNs are collaborating on • The PHASES with Primary Sense project will generate the General Practice CVD risk data, such that it can be linked with hospitalisation and mortality data through the associated PHASES Linkage project. • Furthermore, it is expected that there will be a need for the PHASES with Primary Sense project to leverage and work with the PHASES Linkage project to undertake proper evaluation of the expected and actual outcomes. • While this project is not specifically undertaking data linkage, it is being run in association with the PHASES Linkage project below. <p>Professor Kim Greaves is the Clinical Lead for the PHASES Linkage and PHASES with Primary Sense projects.</p>	<p>CtCPHN</p>	<p>Tim Garden TGarden@c2coast.org.au</p>

<p>PHASES Linkage project (CVD)</p>	<p>Background The PHASES Linkage project aims to leverage and link General Practice CVD risk data with hospitalisation and mortality data to understand how CVD risk impacts hospitalisation rates, and how well the new CVD risk prediction equation detects those at high risk in an Australian (Queensland) population. The study will estimate the number of heart attacks and strokes potentially averted if high CVD risk treatment was improved, as well as identifying gaps in CVD prevention. The project will also establish the framework for a state-wide CVD risk and outcome surveillance system.</p> <p>Data linkage opportunities The PHASES Linkage project will:</p> <ul style="list-style-type: none"> • link GP CVD risk data with hospitalisation and mortality data to understand how CVD risk impacts hospitalisation rates, and how well the new CVD risk prediction equation detects those at high risk in an Australian (Queensland) population. • estimate the number of heart attacks and strokes potentially averted if high CVD risk treatment was improved, as well as identifying gaps in CVD prevention • provide the digital capabilities to support the intervention and ongoing management of CVD in primary care. • In addition, the PHASES Linkage project will be developing the digital capabilities to enable ongoing efficient linkage of acute and primary care data sets by leveraging the secure Primary Health Insights platform. <p>Professor Kim Greaves is the Clinical Lead for the PHASES Linkage and PHASES with Primary Sense projects.</p>	<p>QDH</p>	<p>Kim Greaves Kim.Greaves@health.qld.gov.au</p>
<p>Primary Care Pilot: Care Collective – South West*</p>	<p>Background</p> <ul style="list-style-type: none"> • The Commonwealth Department of Health and Aged Care (DoHAC) provided Primary Care Pilot funding to states and territories to test innovative models of care. The Reform Office received the DoHAC funding and subsequently funded the Brisbane North Health Alliance for the Care Collective – Caboolture program and expansion to Redcliffe, and the South West Primary Care Pilot (SWPCP). • The SWPCP has leveraged the established South West Queensland (SWQ) Primary Care Alliance for the consultation, codesign and implementation of the Primary Care Pilot in SWQ. This enabled the design and implementation of a pilot that will meet local needs. • Care Collective – South West aims to improve the health and wellbeing for those living with complex health condition/s. The model has been determined by a place-based approach and includes service and care coordination workforce. • Initially the Pilot will be delivered in the Far SWQ region, covering Charleville, Quilpie, Cunnamulla, Thargomindah and surrounding areas. • The pilot has just commenced implementation with an interim insights report due Jan/Feb 2025 and final evaluation post-completion (approx. August 2025). <p>Data linkage opportunities</p> <ul style="list-style-type: none"> • Data linkage would enable us to truly understand the impact of the pilot on the healthcare system and the client benefits across the different settings, e.g. tracking client movements and usage across different settings. • Providers for potential linkage in the South West pilot include South West Hospital and Health Service (GPs and acute), Charleville and Western Area Aboriginal and Torres Strait Islander Community Health (CWAATSICH), Cunnamulla Aboriginal Corporation for Health (CACH), the Royal Flying Doctor Service (RFDS), private GP practice. Western Queensland PHN (WQPHN) is also involved as a key partner. 	<p>QDH</p>	<p>Heidi Atkins heidi.atkins@health.qld.gov.au</p>

Urgent Care Clinics (UCCs)	<p>Background UCCs have been funded by the Commonwealth Department of Health and Aged Care to help reduce pressure on hospitals and emergency departments, allowing them to focus on higher urgency and life-threatening conditions. Medicare UCCs complement existing state run emergency diversion initiatives.</p> <p>Data linkage opportunity The de-identified UCC data is being collected and linked to other relevant health system datasets such as 13 Health referral data, Queensland Ambulance data, and hospital emergency department data to enable the health system to monitor the impact of the initiative and inform service planning and improve the service, as well as evaluate the relevant urgent care government policies and programs.</p>	DoHAC/ QDoH	Trisha Johnston trisha.johnston@health.qld.gov.au Damon Atzeni Damon.Atzeni@health.qld.gov.au
Care Collective Caboolture and Redcliffe	<p>Background The program was created to support people living with specific chronic and complex health conditions and aims to improve access to their existing General Practice, improve communication between health care providers involved in their health care and support them to live a healthier life in their home/community. The model has been determined by a place-based approach and includes service and care coordination workforce, including a Complex Care Coordinator (nurse).</p> <p>Data linkage opportunity The program requires patient information about health and treatment plan(s) to be shared securely with the services involved in the care delivery to better understand the consumer's health service usage and improve coordination of their care. The data sharing includes data from the regular General Practitioner, Queensland Health facilities including public hospital emergency departments and hospital clinics, Queensland Ambulance Service, the BNPHN, Team Care Coordination Service, other identified care providers, and Silverchain Complex Care Coordinators.</p>	BNPHN	Pete Boffey peter.boffey@brisbanenorthphn.org.au
Mental Health and Suicide Prevention	<p>Background There is growing concern about the number of young people who may have multiple touchpoints with health services across primary and secondary care who may then go on to die by suicide, where there may have been missed opportunities to intervene.</p> <p>Data linkage opportunity The ability to link data across Mental Health Care Plans, Qscripts, paediatrics, emergency department presentations, alongside Youth Justice and Child Safety and potentially pathology and other information from coroner's office would enable mental health teams to learn and identify opportunities where further intervention may have prevented death by suicide.</p>	GCH	Shilpa Aggarwal Shilpa.Aggarwal@health.qld.gov.au Justin Williams Justin.Williams@health.qld.gov.au
National Digital Pregnancy Health Record and Digital Child Health Record	<p>Background The Commonwealth's First 2000 Days Strategy, and the Enhanced Models of Care Program aspires to create a longitudinal digital health record for every child born in Australia, spanning birth to adulthood. One of the National Children's Digital Health Collaborative aims is to achieve 'One National Digital Child Health Record & Pregnancy Health Record'. A lack of a digital pregnancy health record (dPHR) poses significant risks to safe, effective and collaborative maternity care for women in our community. In 2020, a trial of a DPHR linking to the Child Data Hub between the DPHR Project team, Cairns & Hinterland Hospital and Health Service (CHHHS) and eHealth Queensland was defunded due to other priorities.</p>	RACGP/GCH	KK Cheung kakiucheung@hotmail.com (RACGP clinical lead rep/GP/GCHHS)

<p>National Digital Pregnancy Health Record and Digital Child Health Record</p>	<p>Data linkage opportunity The DPHR will be nationally consistent and integrated and will capture and share information currently held in isolated electronic systems in an easy-to-use digital format that removes risks of misplaced or double-entered data providing pregnant women and their treating clinical teams with all relevant information at the point of care. The aim of this project is to prioritise the dPHR and dCHR as test use cases with agreed core datasets and stakeholder agreements, that were ready to pilot in QLD (dPHR) and in NSW (dCHR) in 2020.</p>	<p>RACGP/GCH</p>	<p>KK Cheung kakiucheung@hotmail.com (RACGP clinical lead rep/GP/GCHHS)</p>
<p>Pregnancy loss after influenza and CV-19 vaccination project</p>	<p>Background Influenza and COVID-19 vaccines are recommended in pregnancy, but their uptake is decreasing. Concerns around the safety of early vaccination in pregnancy is understood to be contributing to this, and current data collection methods cannot provide this evidence.</p> <p>Data linkage opportunity Linking immunisation and pregnancy datasets within Primary Sense with vaccination data from the Australian Immunisation Register (AIR) data enables calculation of whether there is an increased risk in pregnancy loss <28 weeks gestation among women who have received influenza +/- COVID-19 vaccinations in early pregnancy, compared to the risk of pregnancy loss <28 weeks gestation in unvaccinated pregnancies, and will provide a more robust estimate of vaccine coverage in pregnancy.</p>	<p>UQ/GCPHN/QH/AIHW</p>	<p>Lisa McHugh l.mchugh@uq.edu.au</p>
<p>Patient Care Facilitator in General Practice</p>	<p>Background</p> <ul style="list-style-type: none"> • The Patient Care Facilitator in General Practice Pilot (the Pilot) was identified as a Ministerial priority under the Government’s five-point plan, with an aim to address patient flow and ambulance ramping, by working with General Practices to employ Patient Care Facilitators in Queensland. • By facilitating the transfer of care from unplanned hospital admissions to primary care, the Pilot seeks to reduce emergency department representations and admissions and strengthen access to quality care in community, closer to home. • The pilot targets two South East Queensland locations: Ipswich in the West Moreton Hospital and Health Service (HHS) and Logan in the Metro South HHS. • Queensland Health has consulted with peak professional bodies (including Australian Medical Association Queensland, Royal Australian College of General Practitioners, Australian Primary Health Care Nurses Association and Australian Association of Practice Management), Primary Health Networks and Hospital and Health Services to determine service model components, principles, funding models and general practice identification and staff recruitment. • Ipswich Hospital, West Moreton Hospital and Health Service (HHS) and Logan Hospital, Metro South HHS, in conjunction with the Darling Downs and West Moreton and Brisbane South Primary Health Networks (PHNs) respectively, have co-designed and developed localised service models to facilitate the transfer of care from an unplanned hospital admission to primary care, with an aim to reduce unnecessary emergency department representations and readmissions. • Recruitment of General Practices through targeted approaches and expressions of interest, with contracts with participating practices starting as early as April 2024. • Recruitment of Hospital-based Discharge Coordinators to support patient identification and facilitate the transfer and notification of patients from hospital to primary care. 	<p>DDWMPHN BSPHN Reform Office WMHHS MSHHS</p>	<p>Brian Kurth brian.kurth@ddwmpn.com.au</p> <p>Angela How ahow@bspn.org.au</p> <p>Katelin Haynes khaynes@bspn.org.au</p> <p>Heidi Atkins heidi.atkins@health.qld.gov.au</p>

<p>Patient Care Facilitator in General Practice</p>	<p>Background</p> <ul style="list-style-type: none"> • As at 15 June 2024: <ul style="list-style-type: none"> • 3 Logan GP Practices under contract and 7 more in progress. • Logan HHS Discharge Coordinator onboarding in progress. • 7 Ipswich GP Practices under contract – 5 to commence as of 17 June and 2 currently accepting patients under the program. • 1 Ipswich patient successfully referred into PCF service and 2 patients identified for referral once discharged from hospital. • Ipswich HHS Discharge Coordinator onboarded as of 10 June. • Ipswich exploring the expansion of patient criteria to include any condition on the General Medical Ward who is an active patient with any of the onboarded GP Practices. <p>Data linkage opportunities</p> <p>The opportunity is to join primary care and hospital care data, to better understand patient journeys, how people in the local area access care, with a particular focus on discharge planning and how people can better maintain access to healthcare within the community. This would be linking the general practice and hospital data directly.</p>	<p>DDWMPHN BSPHN Reform Office WMHHS MSHHS</p>	<p>Brian Kurth brian.kurth@ddwmpfn.com.au</p> <p>Angela How ahow@bsphn.org.au</p> <p>Katelin Haynes khaynes@bsphn.org.au</p> <p>Heidi Atkins heidi.atkins@health.qld.gov.au</p>
<p>Healthy Outback Communities (HOC)</p>	<p>Background</p> <p>The HOC initiative shifts from an illness-focused approach to a wellness-focused model, enhancing engagement, access, and navigation in underserved remote communities. It features a strategic leadership alliance, a dedicated wellbeing workforce (Wellbeing Connector, Practitioner, and Responder), and the RFDS Virtual Health and Wellbeing Hub (VHWH).</p> <p>Data linkage opportunities</p> <ul style="list-style-type: none"> • Principal Opportunity: Seamless data sharing between the RFDS, who provide fortnightly primary care clinics and the VHWH, with the CWHHS, who host visiting services and provide acute care via local Primary Health Clinics. Currently, there is no system integration or data sharing, requiring clinicians to manually print and scan patient records. • Supplementary Opportunities: Integration of various digital health components to support the HOC model: - Strategic collaboration to address interoperability issues (e.g., Data Collaboration Agreement). - Enhanced use of tools like Pen CS, My Health Record, and secure messaging platforms to support patient care and information exchange. - Adoption of ePrescribing and improved medicine reconciliation during care transitions. - Utilisation of digital communication tools (e.g., Health Engine, My Community Diary) for efficient patient engagement and service awareness. - Addressing digital literacy and connectivity challenges through initiatives like Digital Mentor Training. - Streamlined credentialing for visiting health professionals via Provider Connect Australia. - Aggregated data sharing for service evaluation, quality improvement, and reporting to the Commonwealth. These integrated efforts aim to identify community needs and implement sustainable solutions. 	<p>WQPHN</p>	<p>Aidan Hobbs Senior Manager and HOC Project Lead</p>

<p>First Nations' BiOC DIFFERENCE project* (existing consented group)</p>	<p>Background Currently the databases for both Birthing in Our Community (BiOC) program which uses MMEx software, and the Mater Mothers' Hospital services which use Matrix/Verdi software, don't communicate with each other. Sharing of this data and information would improve the way in which BiOC cares for mob. The aim of the Digital Infrastructure For improving First Nations matERNal and Child hEalth (DIFFERENCE) project is to create a digital system that connects primary and secondary healthcare information (information sharing between care providers).</p> <p>Data linkage opportunities This project will be achieved through:</p> <ul style="list-style-type: none"> • live sharing of data for clinical care • linking de-identified data to better understand and improve the service. 	<p>IHUI</p>	<p>Adrian Carson Adrian.Carson@iuih.org.au</p> <p>Dawn Schofield dawn.schofield@iuih.org.au</p> <p>Carmel Nelson Carmel.Nelson@iuih.org.au</p> <p>Kristel Modderman kristel.modderman@iuih.org.au</p>
<p>Aged Care / Care Finders' Program</p>	<p>Background Increasingly PHNs are working at the interface between the health and aged care service systems. The Care Finder Program funds PHNs to commission care finder networks to provide specialist help to older Australian who need extra support the access aged care and other community supports.</p> <p>Data linkage opportunities</p> <ul style="list-style-type: none"> • It would be beneficial to link datasets from the care finder program with records in the My Aged Care Portal relating to Regional Assessment Services (RAS) and Aged Care Assessment Team (ACAT) assessments and referrals, Commonwealth Home Support Program and Home Care Package eligibility and utilisation to provide greater understanding of people's journeys through, and utilisation of aged care services. • This would also assist in understanding the waiting times for different population cohorts in various parts of the system, and the impact of specific health conditions (e.g. mental health, drug and alcohol use) and socio-demographic characteristics on service accessibility. • Furthermore, linkage between these aged care datasets and healthcare datasets (primary care and acute care) would be of value in exploring the interaction between access to and use of aged care services and their impact on health service utilisation. 	<p>BNPHN</p>	<p>Sharon Sweeney sharon.sweeney@brisbanenorthphn.org.au</p>



Developed in collaboration with Queensland Health and our partners

