Australian Government
Australian Institute of Health and Welfare

AIHW

Data Governance Framework Roadmap for the

National Primary Health Care Data Collection

Contents

1 Introduction

Primary care is one of the first points of contact for many people seeking health care. In Australia, there were 194 million primary care attendances (General Practices (GPs), allied health, nurses and Aboriginal and Torres Strait Islander health workers) recorded in 2023–24 (AIHW, 2025a), compared with 12.6 million hospitalisations during the same year (AIHW, 2025b).

The information collected by primary care practitioners, such as the health conditions of patients, and the subsequent health treatments patients receive, can provide crucial insights into the health of Australians and their access to essential services. Although general practice information has increasingly been used by Primary Health Networks (PHNs) and by the GP professional community to improve health outcomes at the point of care, there is currently no comprehensive, national primary health care data collection for other uses, such as for population health planning.

Nationally consistent primary health care data are, therefore, a known information gap for effective population health research, policy, and planning.

The Australian Institute of Health and Welfare (AIHW) is committed to a work program that aims to fill this gap by leveraging existing data collected through one or more of primary health care initiatives underway, such as data collected by Primary Health Networks (PHNs) for local service delivery and planning (see Appendix A). AIHW will work with partners and stakeholders to develop processes for the governance, standardisation, collection, analysis and reporting of nationally consistent primary health care data within Australia. This work will ultimately form a National Primary Health Care Data Collection (NPHCDC), with development commenced on general practice and Aboriginal Community Controlled Health Organisations (ACCHOs). It will also consider other primary care data including nursing and allied health. The development of the collection is subject to both funding and the timelines of primary care initiatives underway.

Primary healthcare includes (DHDA, 2023):

- general practice
- Aboriginal Community Controlled Health Services
- community health centres and walk-in clinics
- community pharmacies
- community nursing services
- oral health and dental services
- mental health services
- drug and alcohol treatment services
- sexual and reproductive health services
- maternal and child health services
- allied health services, such as psychologists, physiotherapists, occupational therapists, chiropractors.

Primary use refers to the use of patient data for clinical care, but also for "administration or business support, medico-legal purposes, quality improvement, clinical audits of the practice population, and internal benchmarking" (RACGP, 2025).

Any other uses of data are secondary uses.

The development of an NPHCDC is essential for a coordinated, evidence-based health system that is responsive to community needs, and to develop health policies, programs and interventions to meet these needs. As outlined in the Department of Health and Aged Care's *Australia's Primary Health Care 10 Year Plan 2022–2032*, primary care data will facilitate improved measurement of services, support quality improvement initiatives, and enable targeted interventions across diverse populations.

The national collection will not provide real-time data for local service delivery or clinical support. The data will not be available for benchmarking, auditing or investigation of practices, staff or patients. The acceptable and unacceptable uses of an NPHCDC will be developed in consultation with collection partners and included in the NPHCDC Data Governance Framework.

A national primary health care data collection can provide significant insights into health care in Australia. These include:

- Population health planning and research
- Service provision planning at local, regional and national levels
- Understanding patient safety and quality
- Developing, monitoring and evaluating primary health care policy
- Mapping patient journeys through the health system, including across primary and acute care
- Health program design, monitoring and evaluation

While the potential utility of primary health care data is generally agreed, there are unique challenges in the collection and use of these data for non-clinical purposes. Primary health care providers (clinical care and service infrastructure) operate independently within an environment that is influenced by complex and interacting interests and priorities. While they collect and use the data, these data are about the patient, and health care providers have a responsibility to the patient. The sharing of primary health care data for purposes such as population health planning is complicated by federated data custodianship, multiple clinical information systems and data extractors, and requirements of state, territory and Commonwealth privacy legislation. More detail about the unique challenges of primary health care data is outlined in Appendix B.

The first steps in the development of the NPHCDC are to:

- understand the uses and requirements for the data
- develop the structures necessary to support a data collection
- identify the pathways to develop a national collection using existing data arrangements
- understand the quality of available data
- showcase the value of existing data
- engage and partner with key stakeholders and data providers on the development of an NPHCDC.

The AIHW has a range of activities underway to achieve these first steps. These include developing a data model, a data dictionary and undertaking small scale demonstration projects in partnership with Primary Health Networks and data extractors.

Concurrently with the development of a Data Governance Framework, AIHW is undertaking work on a data model and dictionary to apply to primary care data.

The NPHCDC Data Governance Framework will cover collection, oversight, decision making processes, collection arrangements, data access, dissemination and output arrangements.

Data governance is "... a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions, with what information, and when, under what circumstances, using what methods."

Data Governance Institute (2025)

To accommodate the multiple potential pathways towards an NPHCDC, the Framework will be principles-based and will manage risk, security and privacy in line with community expectations to meet stakeholder-driven uses. At the same time, the Roadmap and Framework recognise the key role of partners such as PHNs, ACCHOs, and extractors as an interface between primary and secondary uses of primary health care data.

This approach is crucial for progressing the development of an NPHCDC that is enduring, robust and secure. A coordinated national approach to a data collection, accounting for variations within the primary health care sector and across regions, is important for primary health care data to inform policy, and program management consistently across Australia.

2 Guiding principles and existing frameworks

The Framework will build on existing primary care and data governance frameworks including the AIHW Data Governance Framework (2022) and the Primary Health Network National Data Governance Policy (2021) as well as governance lessons from major data projects such as the AIHW's National Health Data Hub and governance of the Practice Incentives Program Quality Improvement Measures. The AIHW will develop the NPHCDC Data Governance Framework in line with the Australian Government's Framework for the Governance of Indigenous Data and the National Aboriginal and Torres Strait Islander Health Data Principles. The aim of the NPHCDC Data Governance Framework is to bring together existing arrangements (governance frameworks, data sharing agreements) with those specific for primary health care data.

The Framework will incorporate the Five Safes framework (outlined in Appendix C), an established mechanism for data security and a core feature of the AIHW Data Governance Framework that assesses and manages potential risks of data sharing and release. The Framework will also meet the Royal Australian College of General Practitioners (RACGP) requirements for secondary use of general practice data. Appendix D outlines how the existing AIHW data governance mechanisms address the RACGP requirements.

Activities to develop the NPHCDC Data Governance Framework are listed under the section NPHCDC Data Governance Framework Activities.

The NPHCDC design will also consider how it will support and align with national health and digital initiatives including, but not limited to, *Australia's Primary Health Care 10 Year Plan 2022–2032*, *Strengthening Medicare*, *Digital Health Blueprint and Action Plan 2023–2033*, the issues outlined in the *General practice data and electronic clinical decision support – Issues Paper (2022)*, and the *National Digital Health Strategy 2023–2028*.

The development of the Framework will recognise that the NPHCDC and its governance framework will be influenced by the direction of other public health initiatives and data schemes.

The Framework will be based on the following principles of the NPHCDC:

- consist of de-identified unit record patient data where privacy is preserved
- use existing processes and infrastructure wherever possible
- no additional burden on health practitioners or consumers
- data will be used for population health research, policy, and planning
- suppression and confidentialisation will be applied to small cells in published data
- clinicians and community representatives will be consulted in the development of the collection and data analysis and interpretation

Activities such as real-time monitoring or enhancing individual patient care are beyond the scope of the NPHCDC.

3 Partner and stakeholder consultation

To develop and manage an NPHCDC, ongoing close engagement and partnerships with stakeholders from Primary Health Networks (PHNs), health practices, peak bodies, research organisations, software vendors, federal and state/territory governments, First Nations people and health representatives, and health consumers are required to understand what value they want from a collection, how a collection can be constructed, how the data can be sourced, and what governance mechanisms should be put in place to provide sufficient oversight of an NPHCDC. This recognises the RACGP guidelines for secondary use of general practice data by third parties that "there must be a value proposition for general practice", "GP advisors must be involved in data analysis and interpretation" and "General practices must retain access and control over what can be extracted".

Partnering with stakeholders is also essential to understand what data and infrastructure are already in existence and how data could be brought together into a nationally consistent collection.

The AIHW is undertaking consultation throughout the data governance activities listed under the section NPHCDC Data Governance Framework Activities. These consultation activities have been developed in a partner and stakeholder engagement strategy in Stage 1 of the Roadmap (see Table 1). The consultation is being undertaken both through the existing governance arrangements and targeted consultation to understand partner and stakeholders' concerns and how they can be addressed through the Data Governance Framework and the collection.

Principles for partner and stakeholder engagement

When engaging on the NPHCDC Data Governance Framework, the AIHW will adopt the Australian Department of Health and Aged Care's Stakeholder Engagement Principles. These principles set standards for building open, respectful, and consistent relationships:

1. **Purposeful engagement:** We begin with a clear understanding of what we aim to achieve, focusing on strategic priorities and stakeholder objectives to ensure meaningful and effective engagement.
2. **Inclusive engagement:** We identify and enable participation from relevant stakeholders, ensuring accessibility for all, including those who may be harder to reach due to language, culture, or mobility.
3. **Timely engagement:** We involve stakeholders from the start, establishing clear timelines and expectations for involvement and feedback.
4. **Transparent engagement:** We maintain openness and honesty, providing stakeholders with the information they need to participate and ensuring they understand how their input will influence outcomes.
5. **Respectful engagement:** We recognise and value stakeholders' expertise, listening to diverse perspectives and adapting our communication to meet different needs.

The AIHW is initially engaging on this Roadmap through existing forums such as the PHN National Data Governance Committee and direct consultation across the primary care sector. This process will also be progressively undertaken on the deliverables outlined in Table 1.

The AIHW is also utilising two advisory groups that provide input from a range of partners and stakeholders to guide and support the development of the NPHCDC: Primary Healthcare Advisory Committee (the Committee) and the National Primary Health Care Data Collection Expert Advisory Group.

The Committee meets quarterly and provides high-level strategic advice covering contemporary issues in primary healthcare in Australia as they relate to the AIHW's functions.

The Expert Advisory Group provides expert technical advice on the direction of data development for the NPHCDC data collection. It also advises on priorities for the data collection including identifying new sources of primary health care data and opportunities for reporting and development activities. The group meets as required with the composition regularly reviewed to match member expertise with the development activities.

Additionally, the NPHCDC will draw on AIHW expertise in developing data collections and systems for the secure ingress, validation, storage, analysis and reporting of data.

To inform the development of the NPHCDC, the AIHW will also collaborate and align with other health and digital health data governance and consultations, such as those under the PHN National Data Governance Committee, with a view to removing duplication, leveraging existing capabilities and expertise, and achieving consistent expert governance.

3a NPHCDC data governance arrangements

Governance of the collection will require a dedicated oversight body. Feedback from the stakeholder consultation (AIHW, 2019) for the development of the NPHCDC highlighted the need for an independent governing body with representatives from all relevant stakeholders including professionals (practice manager, health practitioners, data users), consumers, and organisations. The consultation emphasised the importance of Indigenous Data Sovereignty and the principles of Governance of Indigenous Data as well as engagement with First Nations communities.

The NPHCDC oversight body will operate alongside other national data governance bodies such as the My Health Record Data Governance Board and the PHN National Data Governance Committee.

Governance of Indigenous Data

The AIHW will develop the NPHCDC Data Governance Framework in line with the Australian Government's Framework for the Governance of Indigenous Data (GID) and the National Aboriginal and Torres Strait Islander Health Data Principles.

The development of the NPHCDC is guided by the AIHW Primary Healthcare Advisory Committee and Expert Advisory Group which include representation from Australian Indigenous Doctors' Association, the National Aboriginal Community Controlled Health Organisation, and Aboriginal and Torres Strait Islander primary health care services.

Development of the NPHCDC Data Governance Framework will also be guided by the AIHW's Indigenous Statistical and Information Advisory Group (ISIAG). Established in 2016, it provides expert advice and guidance on national information and statistics about Aboriginal and Torres Strait Islander (First Nations) people to steer the production of high quality, relevant and accessible information. Specifically, the ISIAG provides expert advice on:

- AIHW projects including the content and methods of such projects, and the subsequent presentation and communication of the findings.
- current and emerging information needs and priorities about the health and wellbeing of Aboriginal and Torres Strait Islander people.

Furthermore, the AIHW Ethics Committee assesses proposals for health research with data on or about Aboriginal and Torres Strait Islander people using the Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders. These guidelines are based on six core values: spirit and integrity; cultural continuity; equity; reciprocity; respect; and responsibility.

The NPHCDC governance body will also include representation from First Nations people and organisations to oversee all aspects of an NPHCDC.

4 NPHCDC Data Governance Framework activities

The AIHW's short-term workplan for developing a Data Governance Framework for an NPHCDC is outlined in Table 1. Activities under the framework are well progressed.

Development of a data dictionary and small-scale demonstration projects will be occurring in parallel with the development of the Data Governance Framework. These activities will inform the next steps in the development of a national collection.

Future developments will aim to increase the scope of the collection (to include, for example, data on allied health and/or urgent care clinics), the quality of the collection (with the eventual implementation of digital standards through SPARKED/Fast Healthcare Interoperable Resources (FHIR)), the uses for the collection (including data linkage), and the depth of the collection (by increasing the quality and quantity of variables in the collection).

Additionally, the NPHCDC will leverage and align with ongoing and emerging developments in primary health care data and digital health reforms such as activities by PHNs using their Primary Health Insights platform to leverage primary health care data for secondary use.

Governing data quality

The purpose of primary care data is to support primary care practitioners to provide services at the point of care. Unlike data that are collected in hospitals, there are no arrangements in primary care to classify and code the information collected about patient care for other purposes such as for population health planning. Furthermore, there are multiple clinical information systems that capture and classify data in different ways. As a result, a national collection of primary care data is not possible without work to harmonise data across the different collection platforms, data sources and regions.

Part of the work in developing an NPHCDC is to understand the quality of the data collected and what can be brought together to provide meaningful insights about health in Australia. Work is underway to understand the quality of the data, including data demonstration project partnerships between PHNs and AIHW. For example, a project between 17 PHNs and AIHW to explore diagnosis of dementia in general practice (AIHW, 2025c) found general practice data has the potential to provide insights into the health conditions that impact the Australian population but also identified the need to improve the consistency, quality and accessibility of the data.

AIHW has also developed a draft data model for an NPHCDC and is working on a data dictionary of standard data elements which could be drawn from primary health care data.

An important part of governing the NPHCDC will be governing the completeness and quality of the data. This will include outlining how data will be assessed for the suitability for inclusion in a national collection, establishing metadata, providing data quality assessments for users to understand the limitations of the data and what the data can be used for, and identifying opportunities for improvements in the quality of data both for primary, clinical and other uses.

In the long term, the NPHCDC could benefit from the exchange of standardised health care information in Australia, currently under development in CSIRO's Sparked program.

This Roadmap and the resulting Data Governance Framework are designed to apply, with adaptation as required, to any data sources identified for the NPHCDC. These governance processes will guide the data development and identify the collection requirements including consent, approvals, and governing bodies.

	TASK	DELIVERABLE
STAGE 1 STAKEHOLDERS Dec '24 – Oct '25	Identify key stakeholders and relationships Identify purpose for engagement Develop mechanisms for engagement specific to each stakeholder Identification of collection use cases through stakeholder discussions Develop principles-based acceptable and unacceptable NPHCDC uses Mechanisms for dissemination of, and access, to data and reports for key stakeholders Develop Stakeholder Engagement Strategy	Preliminary definition of the purpose and scope of the collection NPHCDC output framework
STAGE 2 CONSENT Mar '25 – Oct '25	Review consent models of current general practice data collections to uncover potential gaps and inform the NPHCDC data sharing agreements Review of legislative environment	Consent models and communication material of privacy arrangements of NPHCDC NPHCDC approval principles and arrangements Mechanisms for social licence, legal obligations, governance of Indigenous data
STAGE 3 GOVERNANCE Jan '25 – Nov '25	Map the NPHCDC governing and advisory bodies relationships to other relevant data governance bodies including decision-making responsibilities covering the entire flow of data Assess existing terms of reference for governing bodies in primary health care data and identify options on how governance of the NPHCDC will fit within the broader system	Governance Framework Final definition of the purpose and scope of the collection
STAGE 4 GOVERNING BODIES Jul '25 – Nov '25	Develop terms of reference for governing bodies	Establish governing bodies and roles Governing bodies terms of reference
STAGE 5 POLICIES Sep '25 – Dec '25	Develop reporting rules (confidentialisation, suppression, approvals) Develop agreed rules and practices for adding, removing, maintaining and updating data items in NPHCDC, including for the supply and validation of data	NPHCDC workplan NPHCDC business rules
STAGE 6 PROCEDURES From Jan '26 (TBA)	Pursue AIHW Ethics approval (which meets the requirements of a Privacy Impact Assessment) Finalise data structure	Data Sharing Agreements aligned with Ethics Data quality assessment plan

5 Appendices

5a Appendix A. National primary healthcare data initiatives underway

National Initiative	Focus	Leads	Timelines	Possible contribution to a national primary care data collection
Sparked including Australian Clinical Data for Interoperability (AUCDI) and Australian eRequesting Data for Interoperability (AUeReqDI)	Clinical Creation and use of national Fast Healthcare Interoperability Resources (FHIR) standards for health care information exchange.	CSIRO Department of Health, Disability and Ageing (DHDA)	July 2023 to June 2026 for creation of standards	Creation of standardised primary care information on individuals that is portable between systems, including as statistical information. In the 2023–24 Federal Budget, the department established a program to achieve standardised health data exchange to support interoperability. Funding was provided to the CSIRO to work with all Australian Governments, the Australian Digital Health Agency (the Agency) and the health technology industry to develop and adopt Fast Health Interoperability Resources (FHIR) core standards. Sparked, Australia's national FHIR Accelerator Program, was launched in August 2023. The role of Sparked serves as a critical enabler of digital standards. By fostering collaboration across jurisdictions, industry and healthcare providers, Sparked will ensure that FHIR standards are implemented consistently and efficiently, better aligning data with Australian governments healthcare interoperability goals.

National Initiative	Focus	Leads	Timelines	Possible contribution to a national primary care data collection
My Health Record	*Clinical* Facilitates patient-controlled sharing of clinical information across health providers.	DHDA Australian Digital Health Agency AIHW	Commenced 2012 as the Personally Controlled Electronic Health Record. Commencing 2023–24, work is underway to modernise My Health Record to provide consumers better and faster access to their health information. This includes changes to sharing key health information by default, commencing with pathology and diagnostic imaging reports, and is anticipated to be implemented in 2025–26.	My Health Record is not yet available for research and public health purposes and will only be available once My Health Record research and public health governance arrangements are established. AIHW is the legislated data custodian who will be responsible for managing secondary use of data from My Health Record.
Practice Incentives Program Quality Improvement Incentive (PIPQI)	*Incentive payment* Nationally consistent, de-identified aggregate general practice data. Measures are collected as part of the PIPQI Incentive paid to general practices.	DHDA AIHW	Incentive commenced on 1 August 2019	Collects aggregate data on 10 improvement measures from most general practices (5,695 practices in 2024–25). AIHW is the national data custodian for PIPQI. The Expert Advisory Panel Review of General Practice Incentives recommends a new opt-in, simplified general practice payment architecture which should also require general practices to provide comprehensive service delivery information and data, to support quality improvement, monitor health outcomes, calculate reimbursements, and inform planning and evaluation.

National Initiative	Focus	Leads	Timelines	Possible contribution to a national primary care data collection
MedicineInsight	*Quality improvement* Primary care quality improvement program using data obtained directly from general practices to support best practice and identify key areas of improvement.	Australian Commission on Safety and Quality in Health Care (ACSQHC) Previously NPS Medicine Wise	First ACSQHC collection enumeration due in 2024 Last NPS Medicine Wise collection was 2020–21	A snapshot of primary care data. 471 individual general practices in 2020–21.
National Primary and Acute Care Data Linkage Project (NPACDLP) (Design Phase)	*Linkage* Develop a blueprint for a hub-and-spoke primary and acute care data linkage system. The design focusses on the potential to link de-identified data from general practices with other health data by leveraging existing infrastructure and successes across jurisdictions, such as the Lumos project in NSW, to provide better insights into patient journeys across the health system.	NSW Health, DHDA, and AIHW Funded representatives from DHDA, AIHW, state and territory health departments, Primary Health Network, National Aboriginal Controlled Community Health Organisations (NACCHO)	March 2023 to August 2025 (design phase)	Design of a hub-and-spoke primary and acute care data linkage system, which could be leveraged to support a general practice national minimum dataset (pending funding for implementation).

National Initiative	Focus	Leads	Timelines	Possible contribution to a national primary care data collection
Primary Health Networks (PHNs) data collection	*Service planning* PHNs collect data from many general practices through data sharing agreements for service planning, quality improvement, and program reporting (including PIPQI, mental health, through extractors and stored in Primary Health Insights). The PHN collaborative also developing a range of data collections including the GP Operational Data Store and linking GP data with other data to inform on health priorities such as cardiovascular disease.	PHNs Funded by DHDA	Ongoing	Potential to bring PHN data together as a partial national collection.
National Primary Health Care Data Collection	*Secondary data use*	AIHW	Not yet started	Bring together data from other data initiatives outlined in this table for secondary purposes, provide dashboards to key stakeholders and for public reporting.

National Initiative	Focus	Leads	Timelines	Possible contribution to a national primary care data collection
National Key Performance Indicators (nKPI) collection	*Secondary data use*	AIHW, DHDA	Ongoing	The national Key Performance Indicators (nKPI) collection is a set of primary health care indicators for Aboriginal and Torres Strait Islander people (Indigenous Australians) focusing on maternal and child health, preventative health, and chronic disease management. Data are supplied on the Indigenous regular clients of organisations receiving funding under the Indigenous Australians' Health Programme (IAHP) twice a year, with census dates in June and December. The period of data covered varies by indicator. Data are submitted by organisations via the Department of Health, Disability and Ageing's Health Data Portal (HDP). Data sent to the HDP then flow into a data storage facility, the Department of Health, Disability and Ageing's Enterprise Data Warehouse (EDW). The AIHW assist the 200 plus organisations providing data to the collection to resolve data quality issues (via a helpdesk) and manages data reporting from the collections (including requests for data).

5b Appendix B. The primary health care data environment

Primary care is health care people seek first in their community, such as GPs, pharmacists, allied health professionals, midwives, dentists, and Aboriginal and Torres Strait Islander (First Nations) health workers. Services can be provided in the home or in community-based settings such as in general practices, ACCHOs, other private practices, community health, local government and non-government service settings. Services can also be provided by telehealth and video consultations.

Figure A1 outlines the primary health care data environment and associated data use cases. It shows the interrelationships and dependencies between different use cases as it relates to data governance. The importance of data collection is evident, as the clinical and administrative data can be used for multiple purposes (collect once, use often) if managed with appropriate data governance. Each use case plays a specific role in supporting, informing and ultimately improving the broader primary health care system, and sound and efficient processes and procedures will allow the maximum benefit of the data be realised. The aims of the AIHW with a national primary healthcare data set include building from, aligning with and supporting the current data available while providing a national collection for population health research and reporting.

Data governance remains a challenge for primary health care data, including general practice data. Issues such as consent for the collection of primary health care data require more attention, as do clarity of data ownership, custodianship and stewardship. There is a need to better understand these aspects of data management to ensure community expectations are being met with regards to data use.

An additional challenge of primary care data is the inconsistent capture of non-standardised clinical data that are not interoperable. This could be addressed through the development of a core set of Fast Healthcare Interoperability Resources (FHIR) standards for health care information exchange in Australia through the Sparked program.

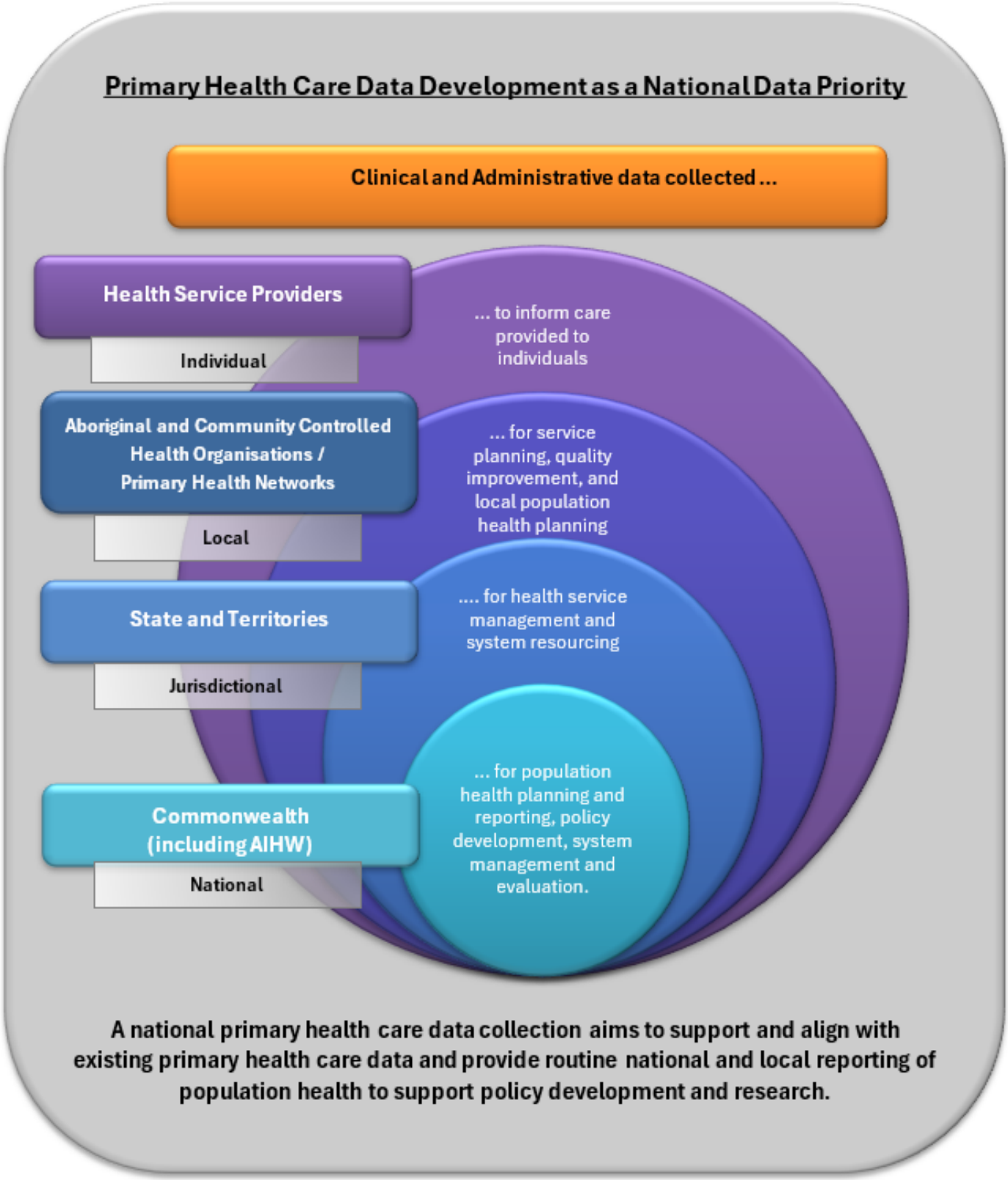
Sound data governance processes of primary care data are crucial to health consumers, practitioners and the broader primary health care system to establish accountability that data will be stored and used safely, and the privacy and security of the data is assured.

Data governance also sets frameworks around the accuracy and quality and efficient data sharing. Strong governance develops an environment for high quality data which allows for improved patient care. Accurate and more reliable data allows health practitioners to make more informed decisions, and provide more coordinated care across the health system, contributing to better effectiveness of healthcare delivery. Without overcoming data governance barriers, the primary health care sector will not be able to maximise the tangible benefits that a comprehensive national data set will bring.

Additional benefits of establishing transparent governance arrangements for primary health care data include:

- improved consumer and provider privacy and trust
- more efficient workflows (reducing administrative burden and providing more time for patient care)
- stronger data security and protection; and
- support for population health research, policy, and planning.

Figure A1: Primary health care data development as a national priority



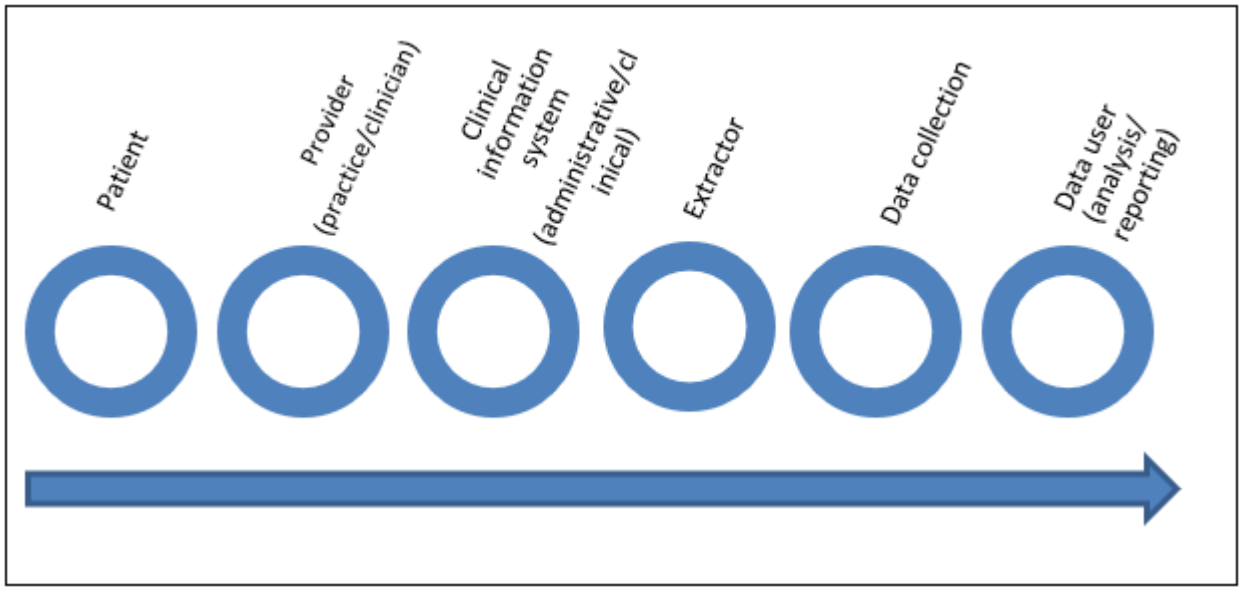
The RACGP provides guidance on legal and ethical use of general practice data for secondary purposes, through the *Three key principles for the secondary use of general practice data by third parties*; this aims to help GPs and general practice staff to understand when, how, and to whom general practice data should be provided. The principles include demonstrating best practice data management, transparency in data use and recognising the contribution of general practice. Appendix D outlines how the existing AIHW data governance mechanisms address the RACGP requirements. The principles can act as a point of reference in the establishment of formal data sharing agreements.

While the potential utility of primary care data is generally acknowledged (Braunack-Mayer *et al.*, 2024; Busingye, 2019; Varhol *et al.* 2022; Youens *et al.* 2020), challenges in the collection and use of this data remain. Primary health care providers (clinical care and service infrastructure) operate independently within an environment that is influenced by complex and interacting interests and priorities.

Primary care data lifecycle

The journey of patient information (clinical and administrative) from patient to national collection involves several points of interpretation and transformation as data are transferred from one system to another (**Figure A2**).

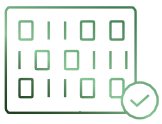
Figure A2: The primary health care data journey



Each entity (excluding the patient) has responsibility for undertaking its own data governance processes with respect to data collection, access, usage, storage, transfer and destruction. It is critical to know where data comes from and how the data changes as it moves between systems to have confidence that any secondary use of that data is occurring in an environment that respects privacy and confidentiality of both patients and providers.

5c Appendix C. Five Safes framework dimensions

The AIHW uses the Five Safes framework to access risk across 5 dimensions associated with a specific data situation. The dimensions are assessed separately, then considered jointly to evaluate whether the overall arrangements are such that the risk have been appropriately managed.

	Meaning	Potential risks to be mitigated
Safe projects 	*Is the use of the data appropriate?* AIHW Interpretation: Use of the data is legal, ethical and the project is expected to deliver public benefit.	• Breach of data supplier requirements. • Breach of AIHW Ethics Committee collection/ project approval conditions. • Project is not expected to deliver public benefits commensurate with risk. • Project design unlikely to meet stated objectives. • Consent arrangements are unlawful. • Using AIHW data for this project is outside community expectations.
Safe people 	*Can the users be trusted to use it in an appropriate manner?* AIHW Interpretation: Researchers have the knowledge, skills and incentives to act in accordance with required standards of behaviour.	Users of the data: • are subject to a conflict of interest • are subject to incentives to breach terms and conditions • are inexpert in the subject matter • have insufficient statistical skills to analyse the data effectively • and/or their organisation are unlikely to be able to manage data breach risks effectively • and/or their organisation have a history of breaching terms and conditions.
Safe data 	*Is there a disclosure risk in the data itself?* AIHW Interpretation: Data has been treated appropriately to minimise the potential for identification of individuals or organisations.	• Identifiers are not removed. • Data include variables not required for the project. • Data include records not required for the project. • Data treatments are insufficient to prevent disclosure of personal information (Privacy Act). • Data treatments are insufficient to prevent attribute disclosure. • Data treatments are insufficient to prevent identification of an information subject (AIHW Act s.29).
Safe settings 	*Does the access facility prevent unauthorised use?* AIHW Interpretation: There are practical controls on the way the data is accessed – both from a technology perspective and considering the physical environment.	Data are: • lost, intercepted or disclosed during transmission to the setting (data/ privacy breach) • subject to unauthorised access at the setting (data/ privacy breach) • used for purposes beyond those approved (including linking to other data) • removed from the approved setting • not destroyed on completion of the project.
Safe output 	*Are the statistical results non-disclosive?* AIHW Interpretation: A final check can be required to minimise risk when releasing the findings of the project.	• Outputs do not meet confidentiality requirements. • Outputs are released without required data supplier approval. • Output treatments are inconsistent with those of data already released.

5d Appendix D. Mechanisms addressing RACGP principles for secondary data use

The RACGP's Three key principles for the secondary use of general practice data by third parties document the College's support for the secondary use of primary health care data to support public health initiatives, research and service delivery. It establishes principles to support the legal and ethical responsibilities of practices. This appendix demonstrates how the AIHW's existing mechanisms address the RACGP's principles.

RACGP Principle[i]	AIHW Mechanism
1. All parties must demonstrate compliance with data management best practice	The AIHW has a strong reputation over 30 years collecting health and welfare data – including hospital data and data from health registers – and turning it into authoritative evidence to support better policy and service delivery decisions by ministers, government agencies and researchers. During this period, the AIHW has earned the respect and trust of our stakeholders as an independent and reliable information management agency that has well established and robust data governance arrangements, a rigorous privacy regime and strict confidentiality protocols. **Objective 1.3 of the AIHW's Strategic Directions 2022–2026 prioritises data management best practice: The AIHW will "lead the adoption of best practice in data collection, presentation, and analysis" including the use of the Five Safes, a comprehensive Data Governance Framework, and its status as a nationally accredited linking authority.**
1a. All parties must act in compliance with the Privacy Act and Privacy Principles	The AIHW's internal data governance ensures compliance with the external legal, regulatory and governance environment while achieving its purpose to create authoritative and accessible health statistics (AIHW Data Governance Framework, 2022). **AIHW complies with the *Privacy Act 1988* and the Australian Privacy Principles as well as the *Australian Institute of Health and Welfare Act 1987***. Where AIHW uses state and territory data, it complies with the relevant privacy, public health and other Acts.
1b. All parties must act ethically with regard to general practice data	**The AIHW Ethics Committee plays an integral role in ensuring that the work of the AIHW is ethically acceptable**. The Ethics Committee is part of AIHW's robust data governance arrangements that ensure privacy and confidentiality in the management and release of data. The Committee operates in line with best practice for Human Research Ethics Committees, as outlined in the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research, and **the Australian Government's Framework for the Governance of Indigenous Data**.

RACGP Principle[i]	AIHW Mechanism
1c. Data must only be used for agreed purposes	Section 6(a) of the *AIHW Act* gives the AIHW the power to enter into contracts or arrangements in connection with performance of its functions, and Section 29 places controls on the use and sharing of health- and welfare-related information. The AIHW can enter into legally binding contracts for data and information sharing with other government agencies and external entities. Subject to the needs of the parties, the AIHW also has the option of entering into non-legally binding arrangements, such as Memoranda of Understanding, Data and Information Sharing Agreements and other intergovernmental agreements. **These agreements make clear the expectations, obligations and considerations that have been agreed by the parties, including any data licensing arrangements which can impact on current and future use of the data (AIHW Data Governance Framework, 2022).**
1d. Data security is everyone's responsibility.	**The AIHW Security Plan prescribes the following security roles**, in accordance with the Australian Government Protective Security Policy Framework and the Australian Government Information Security Manual, to ensure the security of data: Chief Security Officer, Chief Information Security Officer, Information Technology Security Advisor, Agency Security Advisor. The AIHW has a long history of compliance with its privacy and confidentiality obligations and is well experienced in managing the risks associated with the use and release of data, using the Five Safes framework to reinforce management of the privacy and confidentiality of data.
1e. Special considerations apply for data linkage	**The RACGP (2025) specifically recognises the AIHW as a reputable body for data linkage processes.** The AIHW is an accredited Data Service Provider and follows data linkage best practice, including the separation principle for preserving privacy. The AIHW maintains the following national linked data collections: • National Health Data Hub • National Disability Data Asset • National Aged Care Data Asset • Child and Wellbeing Data Asset • COVID–19 Register and Linked Data Set
2. Healthcare consumers deserve transparency in the use of their health data 2a. General practices must provide information on secondary use to patients 2b. General practices must provide patients an opportunity to opt out of providing data for secondary uses 2c. Consent must be obtained from patients for particular secondary uses	In alignment with the RACGP Standards for general practices (5th edition), A**IHW's data sharing agreements and consent models** will support "general practices [to] advise patients about whether they provide de-identified data to third parties, and by whom and for what purpose the data is used". The AIHW Ethics Committee ensures alignment with the principles and standards established by the National Health and Medical Research Council such as the Australian Code for the Responsible Conduct of Research.

RACGP Principle[i]	AIHW Mechanism
2d. Special considerations apply for data on or about Aboriginal and Torres Strait Islander peoples 2e. Special considerations may apply for data collected specifically related to other patient groups	The AIHW Ethics Committee is required to apply the Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders as the basis for assessing proposals for health research with Aboriginal and Torres Strait Islander participation. These guidelines are based on six core values: spirit and integrity; cultural continuity; equity; reciprocity; respect; and responsibility. The AIHW and Australian Bureau of Statistics have produced a set of National Best Practice Guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people (AIHW, 2012). **The AIHW will implement the principles in the Australian Government's Framework for the Governance of Indigenous Data.** Additionally, the AIHW has extensive experience working with and reporting on data from special populations (for example, Reporting on the health of culturally and linguistically diverse populations in Australia: An exploratory paper) and the AIHW's work with Closing the Gap.
3. The contribution of general practice must be valued and recognised 3a. General practices must retain access and control over what can be extracted 3b. There must be a value proposition for general practice 3c. GP advisors must be involved in data analysis and interpretation	The AIHW's Developing a National Primary Health Care Data Asset: Consultation Report, published in 2019, summarised the feedback (including feedback from representatives in primary health care) identifying the key issues raised in developing the NPHCDC. The AIHW has continued to engage in active discussion with a broad range of stakeholders; including general practitioners, Primary Health Networks (PHNs), vendors and extractors of practice management systems, peak bodies, and allied health researchers. The development of the data collection is guided by the AIHW's **Primary Healthcare Advisory Committee** and the AIHW's **National Primary Health Care Data Collection Expert Advisory Group,** both of which features involvement from representatives in primary health care. Any primary health care data that the AIHW holds will have oversight by a governance committee in addition to expert advisory groups that will features representatives from primary health care.

5e Appendix E. Glossary

Term	Definition
Aboriginal and Torres Strait Islander health worker	An Aboriginal and/or Torres Strait Islander with a minimum qualification in the field of primary health care work or clinical practice. This includes Aboriginal and Torres Strait Islander health practitioners who are one speciality stream of health worker. Health workers liaise with patients, clients and visitors to hospitals and health clinics, and work as a team member to arrange, coordinate and deliver health care in community health clinics.
Aboriginal Community Controlled Health Organisation (ACCHO)	An Aboriginal Community Controlled Health Organisation is a community-run primary healthcare service that provides comprehensive, culturally informed care for Aboriginal and Torres Strait Islander people. These services address not only physical health but also the social, emotional, and cultural wellbeing of individuals, families, and communities, aiming to support healthier, happier lives.
aggregated data	Data that have been collected and combined from multiple individuals/units. This data can then be used to report on a population or group level. For example, to report on Medicare rebates by state/territory, the data on rebates claimed by individuals is combined. The individual data are not presented, just the rebate totals.
allied health professional	A health professional who is not a doctor, nurse or dentist. Allied health professionals include (but are not limited to) chiropractors, occupational therapists, optometrists, osteopaths, pharmacists, physiotherapists, podiatrists, psychologists and speech pathologists.
Australian Clinical Data for Interoperability (AUCDI)	The Australian Clinical Data for Interoperability (AUCDI) is a collection of data groups and data models representing the clinical (patient care) requirements for data entry, data use and sharing of health information supporting patient care. AUCDI has been developed and will continue to evolve to include health data to support care: • Across a person's life course • Across the health continuum (preventative, acute and chronic care), and • Across the health ecosystem (all domains, private and public, from primary to population health). The AUCDI is designed to support a comprehensive range of clinical use cases by enabling the collection and use of information beyond traditional medical data. This includes social, emotional, economic, and other contextual factors that influence a person's health across the life course. AUCDI aims to enhance continuity of care, inform policy, and support more holistic, person-centred healthcare delivery.
Australian eRequesting Data for Interoperability (AUeReqDI)	The AUeReqDI builds upon the work and community of Australian Clinical Data for Interoperability (AUCDI) and focuses on the use case of electronic requesting and ordering.

Term	Definition
Clinical Information Systems (CISs)	A Clinical Information System (CIS) is a computer-based system that gathers, stores, and alters clinical data on patients. These systems may be used at single locations or across entire healthcare systems. The purpose of CIS is to integrate, collect, store and manage data from a number of sources to support healthcare operational management, support policy decisions and manage patient data. Best Practice and MedicalDirector are examples of CISs.
confidentialisation	Confidentialisation involves both the removal of direct identifiers and then assessing and managing the risk of indirect identification occurring in the data.
data breach	A data breach happens when personal information is accessed, disclosed without authorisation, or is lost.
data custodian	The agency that collects or generates data for any purpose and is accountable and responsible for the governance of that data.
data lifecycle	Data exists within a lifecycle which includes processes that create or obtain data, those that move, transform, and store it and enable it to be maintained and shared, and those that use or apply it, as well as those that dispose of it. Throughout its lifecycle, data can be cleansed, transformed, merged, enhanced, or aggregated. As these processes occur often new data is created which form interconnecting processes.
data linkage/ linked data	Bringing together (linking) information from two or more data sources believed to relate to the same entity, such as the same individual or the same institution. The resulting data set is called linked data.
de-identification	De-identification involves removing or altering information that identifies an individual or is reasonably likely to enable their identification
diagnostic imaging	The production of diagnostic images; for example, computed tomography, magnetic resonance imaging, X-rays, ultrasound and nuclear medicine scans.
disclosure	An entity discloses personal information when it makes it accessible or visible to others outside the entity and releases the subsequent handling of the personal information from its effective control. This focuses on the act done by the disclosing party, and not on the actions or knowledge of the recipient. Disclosure, in the context of the Privacy Act, can occur even where the personal information is already known to the recipient.
extraction tools	Extraction tools are used to collect general practice data from practice management software to support data sharing, such as the sharing of PIP QI indicators and full datasets with PHNs. There are a number of extraction tools in the market and each extracts and processes information in different ways. Data extraction software companies also offer tools that provide feedback to general practices at the practitioner, practice and individual patient levels to support comparison and patient management. Examples include Primary Sense, POLAR and PenCS.

Term	Definition
Fast Healthcare Interoperability Resources (FHIR)	An open-source healthcare data standard that enables continuous real-time data exchanges between healthcare applications.
general practitioner (GP)	A medical practitioner who provides primary comprehensive and continuing care to patients and their families in the community.
identifier	An identifier is a number, letter or symbol, or a combination of any or all of those things, that is used to identify the individual or to verify the identity of the individual.
MedicineInsight	MedicineInsight is a primary care quality improvement program using data from Australian general practices to support best practice and the post-market surveillance of medicines. It allows general practitioners to reflect on their prescribing patterns and patient care and review their practice results as well as the aggregate of all participating MedicineInsight practices.
Medicare	A national, government-funded scheme that subsidises the cost of personal medical services for all Australians and aims to help them afford medical care. The Medicare Benefits Schedule (MBS) is the listing of the Medicare services subsidised by the Australian Government. The schedule is part of the wider Medicare Benefits Scheme (Medicare).
midwifery	Antenatal, intrapartum and postnatal care provided by a person who is trained to help women in childbirth.
MyHealth Record	The My Health Record system is the Australian Government's digital health record system that holds My Health Records. It was previously known as a Personally Controlled Electronic Health Record (PCEHR) or eHealth record. A My Health Record is an online summary of an individual's health information. It allows doctors, hospitals and certain other healthcare providers (such as a physiotherapist) involved in the individual's care to view their health information. An individual can also access their My Health Record online.
National Primary and Acute Care Data Linkage Project (NPACDLP)	The National Primary and Acute Care Data Linkage Project (Design Phase) is co-led by NSW Health, Commonwealth Department of Health and Aged Care and AIHW, in partnership with all state and territory health departments. The project is engaging key stakeholders, such as those from the Primary Health Network, general practice and Aboriginal community-controlled health sectors, during the consultation process to inform a blueprint for a hub-and-spoke data linkage system. It is envisaged that de-identified data from general practices would be linked with other health data by leveraging existing infrastructure and successes across jurisdictions, such as the Lumos project in NSW, to provide better insights into patient journeys across the health system.
nurse practitioner	A Registered Nurse with experience, expertise and authority to diagnose and treat people with a variety of acute or chronic health conditions.

Term	Definition
personal information	Personal information includes a broad range of information, or an opinion, that could identify an individual. What is personal information will vary, depending on whether a person can be identified or is reasonably identifiable in the circumstances. For example, personal information may include: an individual's name, signature, address, phone number, date of birth or sensitive information about an individual.
primary care	Primary care refers to those services in the community that people go to first for health care: general practices, ACCHS, community pharmacies, many allied health services, mental health services, drug and alcohol services, community health and community nursing services, maternal and child health services, sexual health services and oral health and dental services. It is differentiated from secondary health care delivered by specialists where a referral is usually required, and tertiary care delivered in hospitals.
primary health care	A whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs and as early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation and palliative care, and as close as feasible to people's everyday environment.
SPARKED	Delivering a core set of Fast Healthcare Inoperable Resources (FHIR) standards, developed by and for the community, for use in Australian settings.
specialist attendance	A specialist attendance usually requires a referral from a general practitioner. A specialist attendance is a referred patient-doctor encounter (with Medicare funding benefits), such as a visit, consultation and attendance (including a video conference) with a medical practitioner who has been recognised as a specialist or consultant physician for the purposes of Medicare benefits.
suppression	Data (cells) in tables may be suppressed in order to maintain the privacy or confidentiality of a person or organisation, or because a proportion or other measure related to a small number of events and may therefore not be reliable.
telehealth	Health services delivered using information and communication technologies, such as videoconferencing. Also called virtual care.
unit record data	Information relating to an individual person, household, business, organisation or event
Urgent Care Clinics	Medicare Urgent Care Clinics provide urgent care services for conditions and illnesses that are episodic and not immediately life-threatening, such as closed fractures, wounds, and minor burns. These services are bulk billed, resulting in no out-of-pocket costs to patients.

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