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**Australian Institute of
Health and Welfare**

Developing a National Primary Health Care Data Asset:

consultation report

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AIHW



Australian Government

**Australian Institute of
Health and Welfare**

Developing a National Primary Health Care Data Asset: consultation report

Australian Institute of Health and Welfare
Canberra

Cat. no. PHC 1

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Summary

This consultation report outlines feedback provided to the Australian Institute of Health and Welfare (AIHW) on the development of a National Primary Health Care Data Asset (Data Asset). Feedback was gathered through a series of facilitated consultation workshops, and an associated online public submission process, in the first half of 2019. While stakeholder engagement has occurred in various formats throughout all phases of the project to date, the scope of this report is confined to the feedback received through these forums during the consultation phase of the project.

The aim of the consultation was to gather comprehensive and considered input from a wide variety of stakeholders and the broader community on the development of the Data Asset, including to:

- identify issues and views
- build stakeholder confidence that de-identified patient and practice data will be curated for the Data Asset under robust data custodianship and governance by the AIHW
- communicate that the data will be used appropriately to drive clinical and population health improvements.

Feedback from the 8 capital city consultation workshops and the 40 submissions was consolidated and summarised. The main themes and sector-specific views are presented in Chapter 4 'Participants responses' as they relate to questions the AIHW posed on the exposure draft of the Data Development Plan and the Data Asset more broadly.

Key issues raised throughout the consultation—such as the need to build community acceptance—are summarised in Section 4.5 'What else should be considered?', while the next steps in progressing the development of the Data Asset are outlined in Chapter 5 'Next steps'.

The views expressed in this report reflect those of the individuals or organisations who provided them, and are not necessarily those of the AIHW. In this report, the AIHW does not commit to a particular course of action in response to the feedback received.

1 Introduction

The Australian Institute of Health and Welfare (AIHW) received funding in the May 2018 Federal Budget to develop an enduring National Primary Health Care Data Asset (Data Asset).

The Data Asset development aligns with priorities outlined in the 2018 Heads of Agreement on public hospital funding and health reform—specifically *Enhanced health data (including health system data and developing a Commonwealth–state primary and community care data set to inform the development of quality indicators)*—as 1 of the goals of long-term system-wide reform.

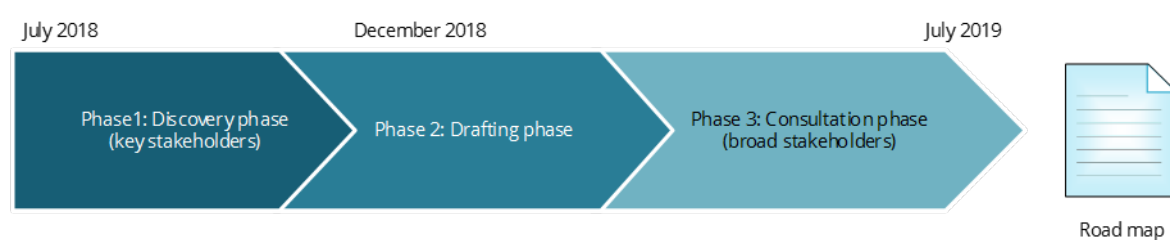
It is envisaged that the Data Asset will support a better understanding of what happens to patients in the health system—including their diagnoses, treatments, and outcomes—by bringing together various collections of data over time.

The Data Asset will not duplicate current avenues for reporting of primary health-care data through existing sources, and it will not impinge nor compete with established governance arrangements. Instead, it will build on existing frameworks, data sources, and governance processes, and identify primary health-care data gaps, and new sources to fill them.

The AIHW acknowledges the importance of engaging with stakeholders to ensure the successful development of the Data Asset. A Stakeholder Engagement Plan was developed, outlining a systematic approach to stakeholder relations and communication across 3 initial phases (Figure 1.1).

Throughout the engagement phases, the AIHW consulted with a wide variety of stakeholders in the mainstream primary health-care sector, including researchers, consumers, governments, health service providers, commissioners of health services, and medical software industry partners.

Figure 1.1: Phases of stakeholder engagement



The discovery phase involved direct bilateral and, where appropriate, multilateral engagements with stakeholders, to inform the development of a draft Data Development Plan for the Data Asset. The focus of this phase was on identifying and connecting with current users, producers, and providers of mainstream primary health-care data.

The drafting phase focused on the preparation of the draft plan, and included getting advice through key AIHW advisory processes, including the Primary Healthcare Advisory Committee and the Strategic Committee for National Health Information.

The draft Data Development Plan was presented to these key committees for their review and consideration between November 2018 and January 2019. Feedback was used to refine the plan before its release as an exposure draft, which was used for national consultation during the first half of 2019, during which the broader community were asked for input on developing the Data Asset.

Stakeholder engagement targeting specific groups, such as consumers, clinicians, and providers of Indigenous-specific primary health care is planned to start following this initial broad engagement. Ongoing consultation will be a key feature of the Data Asset.

2 The consultation

2.1 Facilitated consultation workshops

The AIHW formally invited key stakeholders to nominate a representative to attend 1 or all of the facilitated consultation workshops convened in each state and territory capital city. These included state and territory health departments, Primary Health Networks (PHNs), health service providers, their peak bodies and royal colleges, researchers, health consumers, and providers of clinical information systems (CIS) and data extraction tools.

The first consultation workshop was held in Melbourne on 22 February 2019, and the last in Darwin on 9 May 2019. A total of 163 participants attended the consultation workshops across 8 capital cities, with representation from 115 organisations (Appendix A). The objectives of the workshops were to:

- seek support for the development of a primary health-care Data Asset
- gather intelligence on existing initiatives that the Data Asset might leverage
- gain insights into the opportunities and challenges in developing the Data Asset.

2.2 AIHW Consultation Hub—online submissions

A publicly available online submission process seeking feedback on development of the Data Asset ran concurrently with the consultation workshops.

Access to the online survey through a link on the AIHW Consultation Hub was available from 13 March to 28 July 2019. Details of the public submission process were conveyed via:

- correspondence with the AIHW advisory committees
- communication with all consultation workshop participants
- announcements on the AIHW website
- communication with subscribers to the AIHW dedicated primary health-care data development mailing list—which, as at the end of July, comprised more than 700 subscribers
- AIHW social media activity to promote awareness of the consultation process.

Survey respondents were able to provide feedback through the structured survey, which asked questions about key aspects of the Data Development Plan, and through free-text fields for feedback on the Data Asset more generally.

The AIHW received 40 submissions on behalf of 33 organisations and 7 anonymised individuals. Consenting organisations are listed at Appendix A.

3 Questions asked

The AIHW sought views on various issues about the development of the Data Asset, through:

- structured qualitative and quantitative online survey questions
- plenary and group discussions during the consultation workshops, which also included capturing responses using an interactive survey tool (see Box 3.1 for questions asked).

In many instances, feedback provided in response to a particular question could also be attributed to other questions. To avoid repetition, responses to ‘How do you see the Data Asset leading to better health outcomes?’ have been consolidated under ‘key opportunities’, and responses to ‘What are the top three barriers and enablers in developing the Data Asset?’ have been combined with risks and advice.

Box 3.1: Survey and consultation workshop questions

Why do we need improved primary care data?

- How do you see it leading to better health outcomes?
- What are the key opportunities in developing the Data Asset?

What are your top primary health-care data needs?

- What are the top three barriers and enablers?
- Rank uses of the Data Asset in priority order.

Your preferred model of data flow: general practice to Data Asset?

- Implications, challenges, and opportunities of general practice data flow model.
- Data flow models that could capture other sources of primary health-care data.
- Additional sources of primary health-care data you would like included.

What is the current policy context?

- what features of the current context present opportunities and risks?

Governance and data protections?

What hasn't been considered that can assist Data Asset development?

What do you see as the biggest risks to Data Asset development?

Do you have any final advice for the AIHW?

4 Participants responses

Overall feedback, both online and throughout the workshops, has been positive. Participants recognised the potential for the Data Asset to improve understanding of the nature, importance, and diversity of primary care in Australia. They strongly supported the need for primary health-care data that can inform quality improvement, planning, and population health.

In addition to the broad system planning benefit, specific benefits that were highlighted included:

- raising the profile and political leverage of primary health care, relative to acute services
- improving the visibility of primary health service needs in rural and remote communities
- providing greater visibility of the wide variety of professions that operate in the primary health-care sector—for example, nurse practitioners, allied health workers, and dental health workers.

The main recurring issues that were raised included the following:

- The purpose and scope of the Data Asset must be clearly defined and articulated.
- A communication strategy should be developed for the Data Asset, outlining the benefits, uses, and questions of privacy and consent, which could be categorised into the community, providers, and system.
- Trust and participation must be built through, highlighting the visibility of the benefits and usefulness of the Data Asset to all those who provide, use, or are affected by the data.
- Strong advocacy for the Data Asset to be used to improve consumer awareness of the health system, leading to better health choices and outcomes.
- The Data Asset should reflect the wide variety of primary health-care professions, and should not focus exclusively on general practice.
- There is strong support for the benefits of linked unit record data to enable understanding and investigation of the entire patient journey through the Australian health system.
- Government needs to set medical terminology (semantic) and system (technical) standards, to maximise the quality, consistency, and interoperability of all information collected in CISs.
- Poor data quality could affect any meaningful interpretation and the utility of the Data Asset.

4.1 Feedback themes from stakeholder groups

Consumers

- The development and operation of the asset should have open and transparent processes and governance.
- There must be active and ongoing engagement with consumers to build trust, and to convey the benefits.
- The Data Asset must balance protection of consumer privacy, while supporting consumer health-care choices.

Clinicians

- Any data being collected should not create additional burden to busy clinicians, and provision of data should be incentivised and resourced.
- There is a need to provide clinicians with business intelligence and benefits, such as the opportunity to view the transition between primary and acute care, as well as interactions with other health-care providers, including specialists.
- The Data Asset should reflect the wide variety of primary health-care practice, to accurately demonstrate what is happening in primary care. For example, nurses are a large provider of primary care, but are generally not identifiable in the data.
- The data collection process should be transparent, with specified criteria, be profession-led, and, in the example of general practice data, a general practice cultural lens should be applied, to ensure accurate interpretation of the data.
- There must be a high level of transparency in any release of data from consulting clinicians, to ensure trust is maintained between client and clinician.
- The Data Asset should enable data-driven quality improvement at the practice level, and any reported measures should not be punitive.

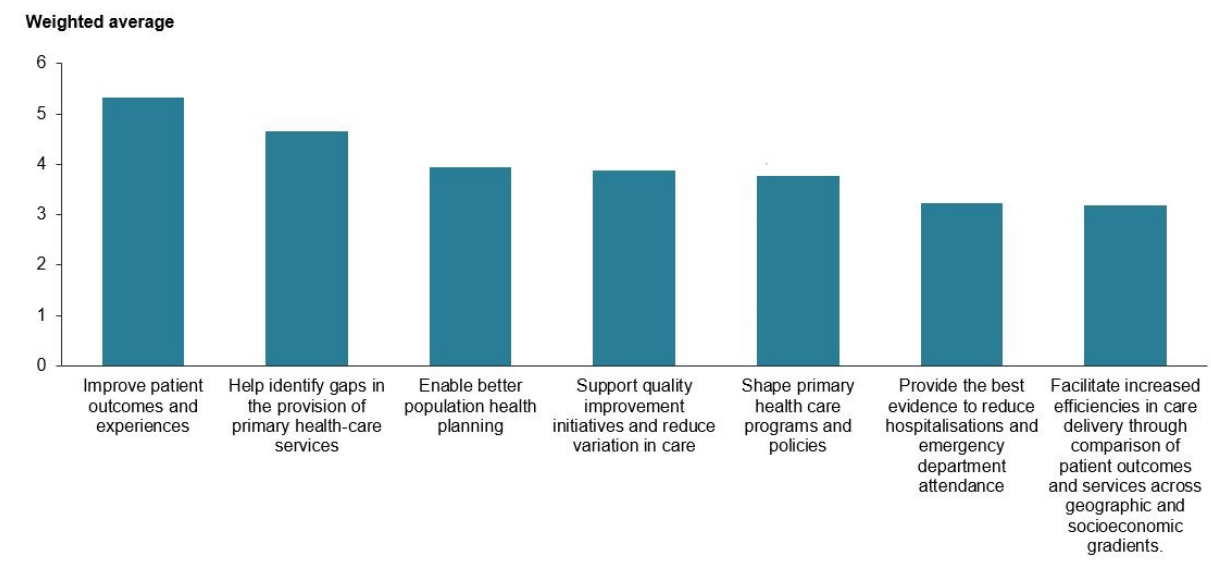
Researchers

- Transparent governance arrangements and processes that support equitable access and use of the Data Asset for research purposes are essential.
- Unit record-level data, which can be linked over time to enable exploration of patient journeys, demonstrate outcomes, and identify best practice, are key.
- Assessment of data quality is essential, as suboptimal data quality (conformance, completeness, and plausibility) affects interpretation.
- There is a need to strengthen and promote a culture of good digital documentation with a greater focus on high quality, reliable denominator data.
- Clearly defined data items, with a shared understanding on their measurability and quality, must be developed.

4.2 Why do we need better primary care data?

Improving patient outcomes and experiences was ranked the highest priority use of the Data Asset by the majority of workshop and submission participants who responded to this question (Figure 4.1).

Figure 4.1: Selected Data Asset uses, ranked from highest to lowest priority



Key opportunities

When asked what they saw as the key opportunities in developing the Data Asset, participants provided a wide variety of views, including the Data Asset could:

- enable a better understanding of the primary health-care landscape, by bringing together the multiple sources of primary health-care data—this covers the diversity of practice scope, both profession-specific and geographical, service delivery, service use, access, gaps, and workforce
- drive quality improvement, and enable key measures of comprehensive primary health-care delivery to be developed in a way that supports best practice and continuous quality improvement, and is not punitive
- enable a more comprehensive understanding of patient-reported experiences and outcomes, including measures of performance against outcomes considered important to the patient
- provide evidence for the efficacy of primary health care and, by extension, support evidence-based funding—this would include producing data that highlight the important role of primary care in the health system
- enable better population health planning and direction of resources, through understanding current and future population health needs and the interplay between effective services and workforce
- improve the visibility of rural and remote primary care needs, and the rural generalist model of care, which occurs to meet patient need in these settings

- better understand the patient journey using longitudinal data that map individual pathways, by linking primary with tertiary care and other data collections (emergency department presentations, ambulance, registry data, education)
- capture nationally consistent data that identify population health needs, priorities, and gaps—with a focus on equity in access to primary health care—and help to shape primary health-care programs and policies
- prevent or reduce the impact of conditions, by identifying those that benefit from early intervention and prevention
- help increase consumer health literacy, and enable more informed health choices that ultimately drive the national focus on primary health care.

Top primary health-care data needs

Responses to this question reflected the diverse interests and broad scope of individual, organisational, and sector-based perspectives. Responses included outlining requirements for collecting specific data elements and the CIS requirements to enable their capture, capturing sector-based data—for example, on mental health, Indigenous health, and suicide prevention—capturing disease-specific and risk factor-specific data, and general needs for high-quality accurate data that enable all of the key opportunities to be realised.

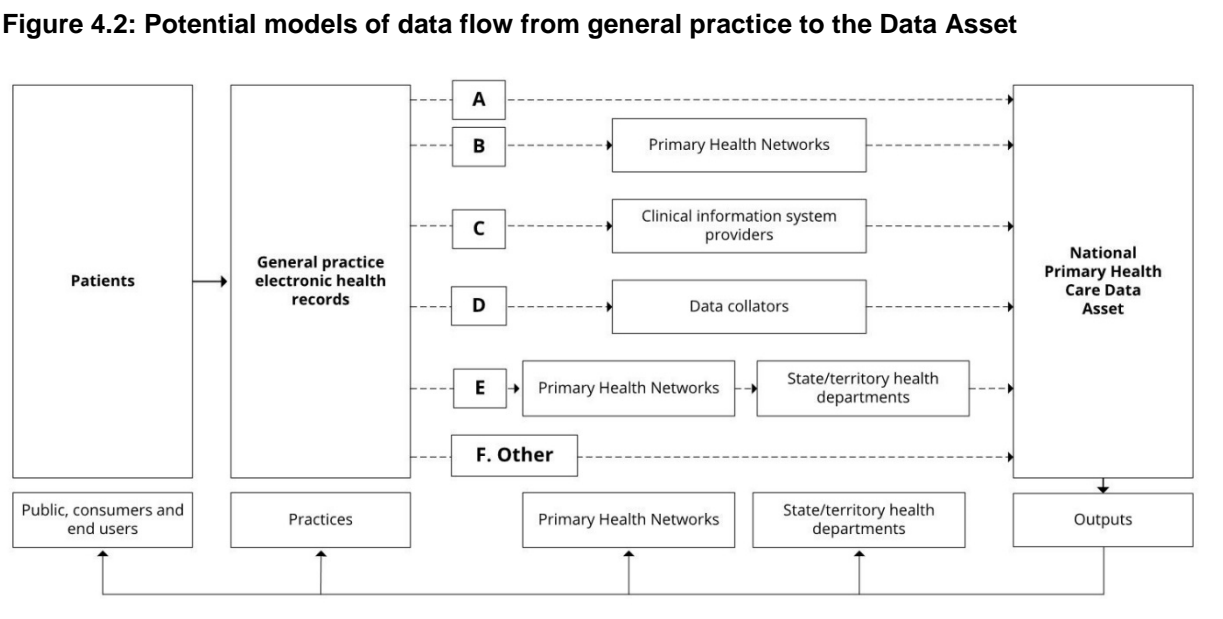
Recurring themes included the need for:

- data that build a complete picture of the patient’s primary health-care journey
- unit record-level data that can be linked to other data sets, to help build a complete picture
- combined data that can be used to inform all levels of system planning and quality improvement activities
- geographically granular data to enable local planning, particularly where statistical areas mask important variation and initiatives occurring at local levels
- data that demonstrate key factors, such as reason for encounter, diagnosis, treatment, outcomes, and types of referrals across the spectrum of primary health-care professions
- data that clearly identify the service provider in each patient encounter, to ensure the value and importance of all primary health-care professions is visible and recognised
- data that capture the wide variety of primary health-care providers, including nursing, allied health, and the various sectors in which they are engaged, such as community health, disability, and mental health
- patient and provider experience and patient outcomes data, to contribute to a people-centred view of the performance of the health system
- data that include social determinants of health, to inform issues of health equity, and contribute to understanding comprehensive models of primary care
- data that identify service gaps and opportunities for primary care, especially in non-metropolitan areas
- consistently reliable and valid high-quality data.

4.3 What model of data flow should be adopted?

Exploration of the various different ways general practice data might be sourced, captured, and flow to the Data Asset were discussed, in relation to the proposed data flow models shown in Figure 4.2.

Broadly, there was support for an intermediary body between general practices and the AIHW, for collation and cleansing of data, and potentially to feed it back to providers and others at a local and regional level.



A total of 143 respondents (32 from the online survey, and 111 from the workshops) expressed their preferred model of data flow from general practice to the Data Asset (Figure 4.3).

A majority (25%) supported the role of PHNs as the intermediary body in the data flow from general practices to the Data Asset. Participants emphasised that as PHNs already have established relationships with about 60% of general practices, it made sense to capitalise on existing mechanisms to collect and report the data and importantly include return-to-source feedback as part of a quality improvement cycle. It was noted that this pathway adheres to the principle of collect once, use multiple times.

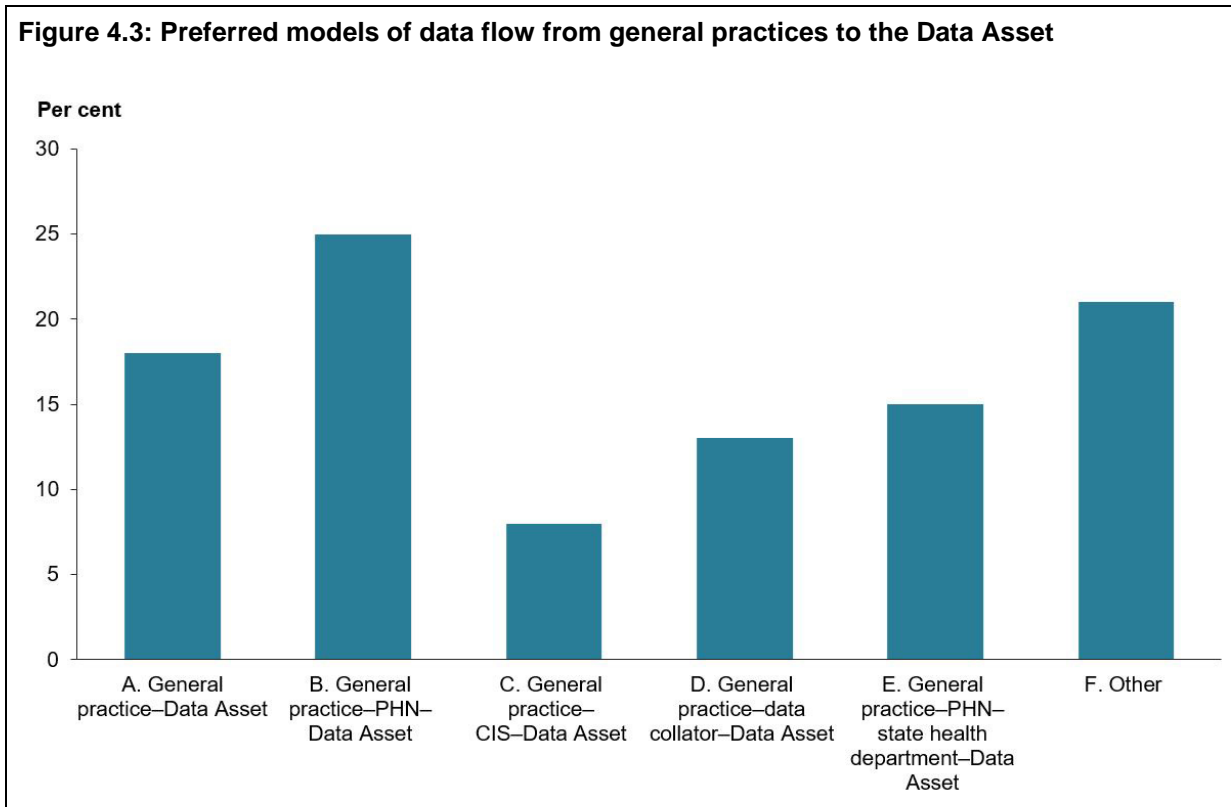
A contrasting view was proposed for data flow through a CIS to the Data Asset, as although all general practices with electronic records have a CIS, not all provide these data to PHNs or data collators.

A cautionary note was sounded that all 31 PHNs are in the process of drafting their own individual governance structures and that without national coordination to lead this process it might result in various inconsistent processes across PHNs complicating the data access arrangements required for data to flow to the Data Asset.

Another 21% voted for option F, highlighting that there is unlikely to be a ‘one size fits all’ model, due to the wide variety of professions and resulting data streams involved in primary care.

It was suggested that multiple pathways might be required, either concurrently or consecutively, as the Data Asset matures over time or alternate sources of primary care data become available. Some participants chose Option F as they felt none of the other options were suitable.

Figure 4.3: Preferred models of data flow from general practices to the Data Asset



An argument for option A, in which the data flow directly to the Data Asset, was that a more direct approach would enable better control over data quality and security, be more timely, potentially cost less, and remove the complexity of multiple levels of involvement. There was some support for a standardised national tool to be developed to help this extraction.

There was also support for option E in which the PHN sends the data to state and territory health departments. Participants suggested that this would help service planning at the state level, where much of the decision making about health services occurs, and encourage a more integrated system. This system would potentially strengthen the involvement of states and territories in primary care planning, and help build momentum across Australia, by involving a broader responsible group. A proposed benefit of this approach would be that it enabled primary care data to be linked with other state/territory data collections, such as hospital, emergency, cancer, perinatal, births, and deaths. Participants suggested that the state and territory departments could then send a primary care data set to the AIHW each year as they do for other national data sets.

There was definite agreement among all participants that other sources of primary health-care data, such as nursing, allied health, dental, pharmacy, complementary medicine, aged care, disability, mental health, and telehealth are all essential in building a comprehensive picture of primary health care in Australia.

In addition, sourcing data from non-government organisations such as the Heart Foundation, Arthritis Australia, and Diabetes Australia should all be considered. Participants acknowledged the complexity of capturing data that reflect the important contribution of these

other primary care professions, and encouraged the AIHW to investigate potential opportunities, through ongoing consultation, engagement, and concept testing with the relevant stakeholder professions.

A commonly expressed limitation to capturing data from sources outside of general practice was the absence of government incentives for adopting digital infrastructure, such as CIS, in other professions offering primary care services, such as allied health. Participants stressed that whatever data flow model is adopted, it must include a feedback loop that returns data to source, and a mechanism by which the provider has input into any arising use or interpretation of that data.

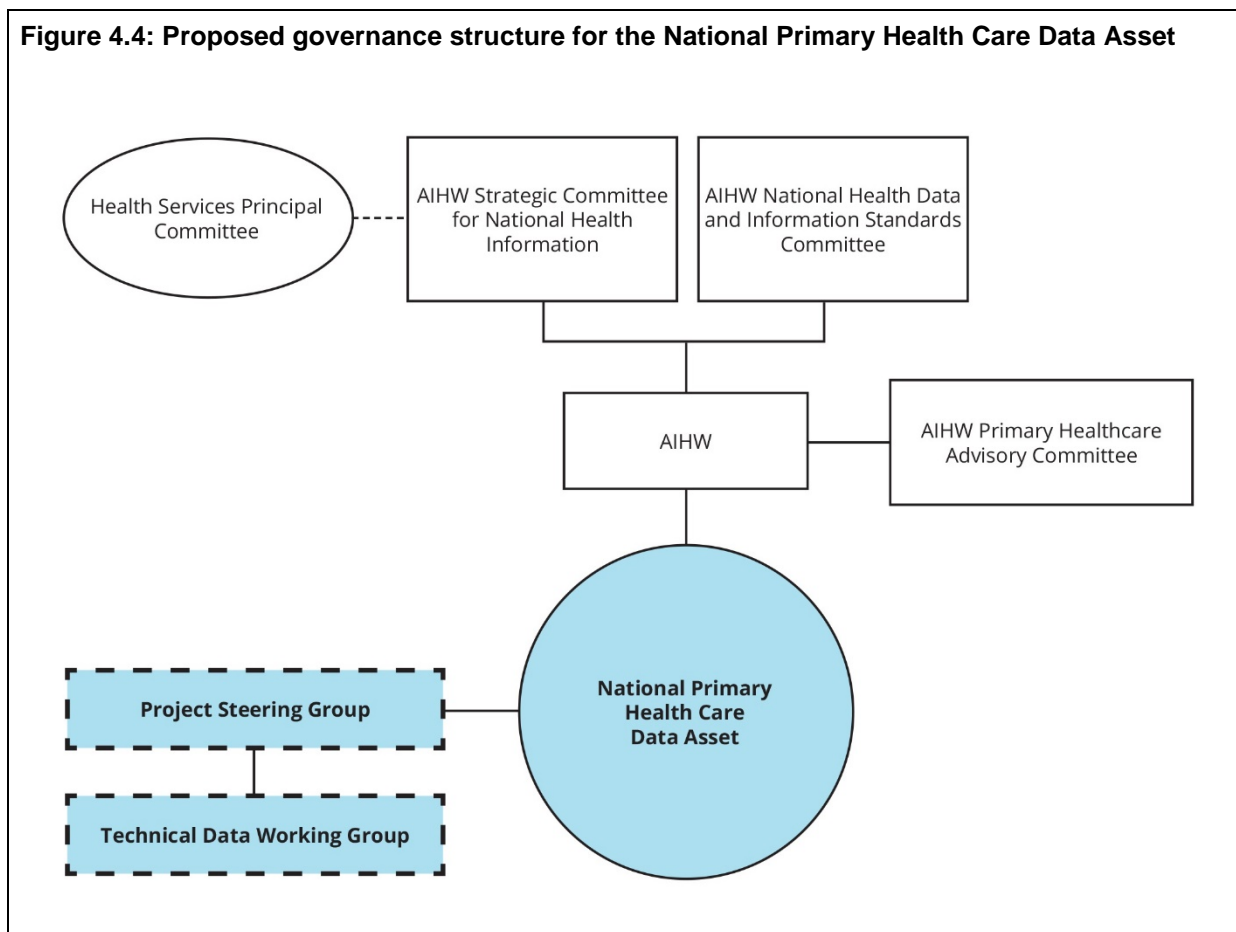
4.4 What about governance and data protection?

The AIHW has a well-established and publicly available Data Governance Framework, which, along with the legal, regulatory, and governance environment in which the AIHW operates, would form the basis for management of the Data Asset.

The AIHW proposed additional advisory mechanisms, in the form of:

- a Project Steering Group, to provide high-level strategic guidance and advice
- a Technical Data Working Group, to provide expert technical advice specific to the nature of the data being collected (Figure 4.4).

Figure 4.4: Proposed governance structure for the National Primary Health Care Data Asset



Overall feedback was positive and acknowledged the AIHW as having a trusted governance structure in place for existing data collections, with capacity to build new mechanisms to capture appropriate governance of the Data Asset.

Specific feedback included that there should be an independent governing body that is responsible for the transparent management of the data, and is capable of making decisions about how the data can be used to improve patient outcomes.

Participants suggested that the governance arrangements must be equitable, representative, robust, justifiable, cost-effective, timely, publicly transparent, and that they should be enabled by the Five Safes Framework.

There was strong advocacy for ensuring all primary health-care professions and other relevant stakeholders are represented, to ensure the data are accurately reflected and interpreted.

Others cautioned that it will be difficult to put in place a single group, due to the mix of individuals, professions, organisations, and regions/government departments. Participants emphasised that there will likely be alternative views about various issues (such as issues of data ownership and access, any necessary commercial arrangements with providers, involvement of PHNs or states/territories, data items to be collected and their definition, and approaches to consent). This will make it challenging to get a consistent view across all stakeholders.

Suggested structures included having state and territory-based jurisdictional working groups, or sector-based working groups that report through a representative to the main project steering group. A useful way forward suggested by some participants was to set up an advisory structure to guide the initial developmental work, which might change over time as the Data Asset becomes established.

Governance mechanisms will need to be future-proofed, to deal with evolving issues, such as what is meant by de-identified in the context of increasing volumes of data available on individuals, which could result in the potential for re-identification. To build and maintain trust, the goals of research, policy and quality improvement will need to be balanced with those of privacy for the patient, provider, and practice.

It was generally agreed that the more open, transparent, and inclusive the approach to development, the more likely the process will build trust, and avoid backlash from those not included or consulted.

Participants said that the structure of the developmental advisory process must be carefully thought through because, to be successful, it needs to build broad and diverse ownership, foster community acceptance and trust, and allow room for divergent views to be captured and debated at the national level.

4.5 What is the policy context?

This question of policy context was not asked in the online survey, but was discussed in each of the workshops. It was recognised that multiple initiatives at the state or territory and national level might have an impact on, or could be taken advantage of, in developing the Data Asset.

It was widely agreed that two major Australian Government initiatives—the Practice Incentives Program Quality Improvement (PIP QI) and My Health Record—will have important implications and, along with rural health and data sharing reforms, might provide opportunities in developing the Data Asset. The extension of the Health Care Homes program until 30 June 2021 was also raised as an opportunity to capture a more comprehensive picture of primary health-care interventions, as all Health Care Homes patients must have a shared care plan that can be shared electronically between health-care providers.

Practice Incentive Program Quality Improvement

The finalisation of the PIP QI was in progress during the workshop timeframes, so there was no definitive information about what its impact might be on the development of the Data Asset. But it was acknowledged that it could be of considerable significance by normalising the provision of data from mainstream general practice via PHNs to the government.

Since the end of the consultation period significant progress has been made in the development of the PIP QI. This section discusses key points to avoid confusion between the development of the Data Asset and what will be the existing arrangements for PIP QI.

The PIP QI began on 1 August 2019, and is a payment to general practices that participate in quality improvement activities to improve patient outcomes, and deliver best-practice care. The PIP Eligible Data Set is collected against 10 specified improvement measures from the CIS of participating practices and is submitted to the local PHN quarterly.

The Department of Health named the AIHW on 1 August 2019 as the National Data Custodian for the PIP Eligible Data Set. The AIHW's role will be to support the PIP QI program, and inform the development of the enduring arrangements for the National Data Custodian.

The AIHW will receive aggregate de-identified data collected against the 10 improvement measures and managed by the AIHW in accordance with the PIP Eligible Data Set Governance Framework. This work sits outside of, and separate to, the governance and scope of the AIHW's internally funded work on developing the Data Asset.

My Health Record

Each of the workshops reflected on the role of the My Health Record—both as a potential source of data and an example of a design and implementation process.

Several participants raised that the usefulness of My Health Record as a source of data is as yet unknown. This is because the data might not be complete or representative at a population level, due to the ability to opt-out, and at the individual level, where only part of a patient's medical record might have been uploaded. The overall view was that it presents an opportunity that can be built on as the system matures and further exploration can be made as to the type and quality of data being captured.

Participants also drew lessons from the recent public discussion of My Health Record during the 'opt-out' process. In particular, participants stated that more effort is needed to develop community acceptance and trust, and to articulate a case for both clinicians and patients to participate in My Health Record, with this needing to be done for a primary health-care data asset.

Participants also suggested that the heightened public awareness of issues about consent, data privacy, and security raised by My Health Record could be an opportunity, with many expressing the view that consumer expectation is that data sharing is already occurring.

The AIHW is the Data Custodian for My Health Record system data, for research and public health purposes, and is currently working with the Department of Health and the Australian Digital Health Agency to implement the *Framework for secondary use of My Health Record system data* released in May 2018.

As with PIP QI, this role is distinct from the role of the AIHW in developing the Data Asset. Any use of My Health Record data by the AIHW for the purposes of the Data Asset will not be possible until the revised legislation and the Framework are implemented, and requests for use are approved by the yet-to-be established Data Governance Board.

Data Sharing and Release Framework

Implementation of a new national Data Sharing and Release Framework by the Office of the National Data Commissioner, and the proposed new Australian Government Data Sharing and Release legislation have the potential to significantly change the way the Australian Government manages the data it holds on behalf of the Australian community.

The proposed legislation applies only to data held by the Commonwealth Government. But participants acknowledged that the concept of more open data sharing to enable the efficient use and re-use of public data, while maintaining the strong security and privacy protections expected by the public, were important considerations for the Data Asset. As such developments in this area will need to be monitored carefully.

Rural health

The establishment of the Office of the National Rural Health Commissioner and the subsequent appointment of a Commissioner in November 2017 highlights the important focus on rural health.

Development of the National Rural Generalist Pathway for medicine is under way, and the Commissioner supports this being broadened over time, to enable similar pathways for other specialties, including nursing and midwifery, allied health, and Aboriginal and Torres Strait Islander Health Practitioners.

The Commissioner has also been asked to develop advice on priorities to improve the access, distribution, and quality of rural and remote allied health services across Australia, and has recently run a consultation process on this work. It was suggested that these key pieces of work might present opportunities for accessing and collecting primary care data that reflect rural practice, which are currently not available.

NPS MedicineWise Medicine Insight program

The importance of not duplicating existing programs was emphasised throughout the consultation. Several participants cited the NPS MedicineWise Medicine Insight program as being highly valued by users. The program is a large primary health-care database, which produces information and insight into general practice activity, based on data collected from approximately 6% of participating general practices across Australia.

Bettering the Evaluation and Care of Health

Many participants noted the loss of the Bettering the Evaluation and Care of Health (BEACH) data collection as having created a large gap in primary care knowledge. The program ceased data collection in April 2016. While BEACH data are no longer being collected, it was noted that the BEACH resource comprising 18 years of data collection in primary care and general practice remain available through the University of Sydney.

4.6 What else should be considered?

Building trust

Confidence and trust in the integrity of the way patient data are collected, held, and reported is essential to developing trust and community support for the Data Asset. Building consumer (and provider) acceptance of the secondary use of primary health-care data for public benefit will be essential to the success of any data-sharing activities.

It will be critical to ensure that open and transparent processes and governance are in place, and outline the individual's privacy and confidentiality safeguards, while communicating the potential benefits of data driven improvements in health outcomes. Ongoing, active engagement with consumers, including having consumer representation in any Data Asset advisory structures, will be required to achieve and maintain community trust.

Generating consumer interest in the benefits, while providing reassurance that privacy will be maintained came through consistently as the biggest challenge to overcome.

Suggestions for strategies that could be adopted included:

- build from the normalisation of hospital data collection to help embed trust—hospitalisation data rarely raises privacy concerns and data collection is generally accepted by the population
- use champions to help build trust—for example, nurses are among the most trusted professions in Australia and could become professional champions
- design a carefully articulated message and communication approach—highlighting specific use cases that resonate with the public.

Aggregate or unit record-level data

The topic of whether the AIHW should start with aggregate or unit record-level data came up repeatedly throughout the consultation workshops and online submissions.

There was some support for the proposition put by the AIHW that the Data Asset might need to start with collecting aggregate data and later progress to collecting unit record data as trust is developed and the system matures.

But there was a strong argument, particularly from researchers, that the usefulness of the Data Asset will be compromised without unit record data that can be linked across the health system.

While participants generally agreed there was some benefit to planning and reporting back to communities from aggregated data at a district and regional level, there was a strong view that the real value is in unit record-level data. Participants suggested that linked data would best demonstrate the value of the Data Asset ensuring the public benefits are realised.

Further to this was the view that starting with aggregate data, and later changing the scope to unit record-level data is a potential risk, both in terms of public trust and acceptance of the Data Asset more broadly. It was suggested that this risk could be managed through continued consultation and engagement on the development of the Data Asset over time.

Standardisation of data and accreditation of systems

Another strong theme was the need for a much greater degree of standardisation across the various CISs that collect electronic health records at the practice level as well as in the quality of data being recorded within those systems.

To collect reliable and nationally consistent primary health-care data, participants thought it essential to use a consistent standardised clinical terminology, such as SNOMED CT AU, and to improve software programs so that practices could share information, minimising the risk of translation errors.

This should include the use of algorithms in clinical software and machine learning to enable analysis of free text fields. It was noted that work funded by the Department of Health, and facilitated by the Commonwealth Scientific and Industrial Research Organisation (CSIRO) and partners, is currently under way to achieve this goal of semantic and technical interoperability in general practice.

Some participants raised the possibility of national accreditation of CIS software as a way to pursue greater standardisation. Participants thought this could be included in practice accreditation requirements.

Aboriginal and Torres Strait Islander people's data

The focus of the Data Asset is on the collection of data from mainstream primary health-care services, which will potentially include data captured from about 50% of Aboriginal and Torres Strait Islander people who attend these mainstream services.

The opportunity to compare these mainstream data with those already reported by Indigenous-specific primary health-care services—through the national Key Performance Indicators and the Online Services Report—has been suggested as one of the opportunities of the Data Asset.

Participants emphasised the importance of ensuring data quality, including higher levels of Indigenous identification, before any interpretation or comparisons could be made. They noted that consultation and negotiation with Indigenous Australians and Aboriginal Community Controlled Health Organisations is required in all steps of collecting, analysing, and reporting these Indigenous data.

There was strong feedback that Australian Aboriginal and Torres Strait Islander data sovereignty and Indigenous data governance mechanisms should be recognised and considered in developing the Data Asset. This will ensure that the data rights of Aboriginal and Torres Strait Islander people are maintained, protected, and further safeguarded against the risk of inappropriate use. It would involve recognising the issues around Indigenous data ownership, and ensuring collection and reporting of data is culturally appropriate, safe, competent, and meaningful for Indigenous Australians.

Participants suggested that the AIHW could consider a permanent Indigenous data governance committee, with decision-making authority, for all its collections, as Indigenous data would always be included in wider population data.

Consultation with providers of Indigenous-specific primary health care was ongoing at the time of writing this report, so feedback summarised in this report might not fully reflect the broad spectrum of Indigenous views.

Voluntary or mandatory data provision

At least 1 of the workshops raised the possibility that the provision of data to the Data Asset might be mandated in some way; for example, the National Hospital Morbidity Database contains data provided by all states and territories under the National Health Information Agreement. This collection includes various databases comprising mandated national minimum data sets, and non-mandatory national best-endeavours data sets for which there is a national commitment to provide data.

The Australian Cancer Database is another example. Its relevant legislation requires that all new cases of cancer diagnosed in Australia since 1 January 1982, except basal and squamous cell carcinomas of the skin, are notified to the jurisdiction's central cancer registry. This is then supplied annually to the AIHW for the Australian Cancer Database.

Participants acknowledged that these examples involve the transfer of public health data between national and state or territory governments, and do not necessarily apply to the wide variety of practice in the primary health-care sector, a large proportion of which are private businesses.

A proposed approach that would more likely be successful was for the AIHW to highlight to providers the public health benefits and quality improvement gains in voluntarily contributing data to the Data Asset.

Phasing of new data sources

The Data Development Plan outlined a phased approach to source and collect primary health-care data in the short, medium and long term. It proposed a focus on general practice activity data in the short term, on allied health in the medium term, and on community health in the long term. Participants broadly felt that general practice is the right place to start collecting data, but acknowledged the many complex issues that might create barriers in collecting these data in the short term.

There was strong advocacy from the nursing sector for data to be captured that recognises the sector's important and large contribution to primary health care. Participants suggested that the AIHW should focus its attention on the data gaps, and investigate ways of collecting data from all areas of primary health care as a priority, while recognising this might require additional research time.

While participants favoured a slow and steady approach overall, there were also calls to explore some quick wins to show the benefits of the Data Asset through smaller proof-of-concept exercises, using data from nursing, allied health, and other providers of primary health care, where possible.

For example, submissions from the eye and vision health sector proposed including optometry and other relevant eye health and vision data in the shorter term, as a test case to explore how best to design and develop data collections that encompass various occupational groups across multiple settings.

4.7 What are the barriers/risks?

Online respondents and workshop participants were asked to identify the biggest risks and key barriers in developing a Data Asset. This section summarises this feedback.

- **Scope**—The Data Asset's objectives and priorities will not be achieved, because the scope has not been clearly defined and communicated. The broad diversity of primary care must be reflected or risk being misrepresented by the Data Asset.
- **Communication and engagement**—Insufficient engagement and consultation might result in a lack of support by essential stakeholders, such as consumers and clinicians, and in the public not accepting the use of primary health-care data for the public good.
- **Trust and expectation**—Issues of data collection, ownership, consent, and privacy must be addressed in an open and transparent way or risk losing public, consumer, and provider trust and support for the Data Asset.
- **Technical**—A lack of agreed standardised clinical terminology and technical enhancements within software programs to allow information sharing between practices could result in fragmented, inconsistent data that cannot be interpreted or compared.
- **Data quality**—A lack of agreed data standards could result in inconsistent and incompletely captured and recorded data that cannot be interpreted in a meaningful way. Reporting poor quality data could result in primary health care being misrepresented, which could lead to adverse policy decisions and outcomes.
- **Governance**—A lack of robust and transparent governance arrangements, and a lack of involvement by those who provide the data could lead to limited confidence and support for the Data Asset. Poor data security or handling could lead to data breach and loss of confidence, and could damage the reputation of the AIHW and the Australian Government.
- **Financial sustainability and incentives**—Availability of funding to build the Data Asset is not guaranteed, and subject to political expediency. Data will not be contributed to the Data Asset if incentives to do so are not made available.

4.8 Final advice from participants

Online respondents and workshop participants were asked to provide advice, including on ways to minimise identified risks, in developing the Data Asset. This section summarises this feedback.

- **Data Asset development**—While some advocated a quick-win approach, to secure early support for the benefits of the Data Asset, many advised that a slow-and-steady approach would be better in the long term. Participants felt that the Data Asset should be formed on the basis of an inclusive co-design method that maximises the use of existing structures, bodies, and processes. Participants thought the AIHW should build on previous work in this area, to avoid duplication and repeating errors from the past. The AIHW should consider mandating standards and data submission requirements through legislation.
- **Data governance**—Participants suggested that the Data Asset’s implementation should outline a transparent governance model, with an emphasis on how it will be accessed and used, while also upholding data security and privacy principles. The AIHW should consider establishing a broad representative steering group from the outset.
- **Data linkage**—Participants suggested that the AIHW should consider collecting data that are agile enough to enable linkages. Consideration should be given to exploring opportunities through proof-of-concept exercises to show how linked data will maximise the Data Asset’s public benefits.
- **Data gaps**—Participants suggested that the AIHW should concentrate initial efforts on collecting general practice activity data, given this sector is already highly digitised with existing mechanisms in place to access data. But others suggested that, due to the current complexity of issues surrounding the general practice environment, the AIHW might be more successful using its resources to explore the potential for other primary health-care sources to contribute data, such as nursing and allied health. Additionally, the Data Asset should enable better understanding of the needs of people in rural and remote areas as a matter of priority.
- **Stakeholder engagement and communication**—Participants suggested that the AIHW should continue to consult early and often across a broad spectrum of stakeholders and should engage powerful leaders who can champion the benefits of the Data Asset. The AIHW should build trust through open and transparent consultation and communication about the purpose and benefits of the Data Asset to consumers and providers. These benefits could be demonstrated by promoting the results and public health benefits of any pilot projects that arise.

5 Next steps

5.1 Proof of concept

The AIHW is in active discussion with various clinical researchers, professions and peak bodies in locations around Australia to identify and conduct proof of concept exercises that will demonstrate the value of the Data Asset in the short term.

These smaller projects will aim to test how best to design and develop data collections that will ultimately encompass various health service providers across multiple settings and be incorporated as part of an enduring Data Asset in the longer term.

Opportunities to use linked data within this testing phase will help to build consumer confidence in the AIHW's ability to manage this process securely under appropriate governance and privacy arrangements while demonstrating better health outcomes. The AIHW will seek to formalise arrangements for these projects and progress their implementation.

5.2 Ongoing stakeholder consultation

Consumers

Raising community and consumer awareness and acceptance of the Data Asset will be a specific focus in the second half of 2019.

The AIHW is negotiating options to engage with consumers, to ensure that ongoing communication and a high degree of transparency builds the trust required for the community to accept the Data Asset.

Reassuring the public that appropriate governance and security arrangements will be set up to protect any data collected will be integral to this process.

Clinicians

Engagement with clinicians will occur on specific proof-of-concept projects, to ensure they capture information of clinical relevance, and in a way that engenders their acceptance and support.

Communication with organisations representing those clinicians will be a priority in the second half of 2019 to raise their awareness of the work as it progresses and ensure a broad base of support for the Data Asset development activities.

Providers of Indigenous-specific primary health-care services

Ongoing engagement with Indigenous-specific primary health-care services will occur through various avenues to reinforce the message that there will be no impact on the current national Key Performance Indicators and Online Services Report data collection process.

The focus of the Data Asset is on collecting data from mainstream primary health-care services. This will theoretically enable capture of data from the Indigenous Australians who attend these mainstream services, and might enable several potential points of comparison to data captured from providers of Indigenous-specific primary health-care services. There will need to be considerable and sustained effort to drive improvements in Indigenous

identification and data quality in mainstream primary health-care services before any such comparisons could be considered. Indigenous data governance mechanisms will need to be recognised and considered during development of the Data Asset.

The AIHW is considering how it can best use and potentially expand membership of its Indigenous Statistical and Information Advisory Group, whose role includes providing expert advice and guidance on national information and statistics about Indigenous Australians.

5.3 Steering group

A project steering group will be established to guide the initial development and priorities of the Data Asset. The AIHW is currently considering the terms of reference and structure of this group. Once finalised, expressions of interest will be sought, so that the first meeting can be convened in early 2020.

The steering group will be made up of organisational representatives from peak bodies and professional associations engaged in delivering services and collecting data in the primary health sector, as well as individual members with experience and expertise in general practice, nursing, allied health, community health, rural and/or remote health.

The AIHW will determine the membership and its Chair, and will provide the secretariat and project officers.

5.4 Develop a road map

A road map will be developed by the end of 2019, based on the AIHW's consideration of feedback received during the consultation process. It will then be presented to the project steering group.

This road map will form the basis of the Data Asset's implementation, and will be informed and refined by the project steering group under its terms of reference, to ensure it meets the priority needs of stakeholders. It will also include a timeline for the proof-of-concept work, as well as a risk management plan addressing the risks identified through the consultation process.

Appendix A: Participating organisations

This list includes the names of all the organisations that consented to the publication of their organisational name.

- Aboriginal Medical Services Alliance Northern Territory
- Abt Associates
- Allied Health Professions Australia
- Arche Health
- Australasian Association for Academic Primary care
- Australasian College of Health Informatics
- Australasian Sleep Association
- Australian Bureau of Statistics
- Australian College of Nurse Practitioners (New South Wales, Northern Territory, South Australia, Tasmania)
- Australian College of Nursing
- Australian College of Rural and Remote Medicine
- Australian College of Rural and Remote Medicine—eHealth
- Australian Commission on Safety and Quality in Health Care
- Australian Dental Association (national, Northern Territory, South Australia, Western Australia)
- Australian Digital Health Agency
- Australian e-Health Research Centre, CSIRO
- Australian Health Research Alliance
- Australian Healthcare and Hospital Association
- Australian Medical Association (national, South Australia)
- Australian Primary Health Care Nurses Association
- Australian Primary Health Care Research Institute, Australian National University
- Australian Research Data Commons
- Best Practice Software
- Bond University General Practice Discipline
- Brisbane Diamantina Health Partners
- Bureau of Health Information
- Carbal Medical Services
- Centre for Health Economics Research and Evaluation, University of Technology Sydney
- CFEP Surveys
- Consumers Health Forum of Australia
- Continence Foundation of Australia
- CRANApplus
- Curtin University—Health Research and Data Analytics Hub

- Danila Dilba Health Service
- Department of Health, Australian Capital Territory Government
- Department of Health, Australian Government
- Department of Health, Northern Territory Government
- Department of Health, Queensland Government
- Department of Health, South Australian Government
- Department of Health, Tasmanian Government
- Department of Health, Western Australian Government
- Department of Health and Human Services, Victorian Government
- Department of Prime Minister and Cabinet, Australian Government
- Flinders University
- Flourish
- Genie Solutions
- Grattan Institute
- Health Care Consumers Association of the Australian Capital Territory
- Health Consumers Alliance of South Australia Inc.
- Health Consumers Council Western Australia Inc.
- Health Consumers New South Wales
- Health Consumers of Rural and Remote Australia Inc.
- Health Issues Centre
- Health Services Research Association of Australia and New Zealand
- HealthShare Pty Ltd
- Healthy Happy Staff
- Inala Primary Care
- Independent Hospital Pricing Authority
- Indigenous Allied Health Australia
- Information and Privacy Commission NSW
- ISA Healthcare Solutions—MMEx
- Maridulu Budyari Gumal, Sydney Partnership for Health, Education, Research and Enterprise
- Medical Software Industry Association
- Melbourne Academic Centre for Health, University of Melbourne
- Menzies Centre for Health Policy, University of Sydney
- Menzies Institute for Medical Research, University of Tasmania
- Menzies School of Health Research
- Monash Partners Academic Health Science Centre
- Monash University School of Primary and Allied Health Care
- Murrumbidgee Primary Health Network
- National Aboriginal Community Controlled Health Organisation

- National Mental Health Commission
- NPS MedicineWise
- NSW Health
- NSW Poisons Information Centre
- Occupational Therapy Australia
- Ochre Health Tasmania
- Optometry Australia
- Oral Health Services Tasmania
- Outcome Health
- Pen CS
- Pharmacy Guild of Australia
- PHN, Adelaide
- PHN, Brisbane North
- PHN, Brisbane South
- PHN, Capital Health Network Ltd
- PHN, Central Queensland, Wide Bay, Sunshine Coast
- PHN, Darling Downs, and West Moreton
- PHN, Eastern Melbourne
- PHN, Gippsland
- PHN, Gold Coast
- PHN, Murray
- PHN, Murrumbidgee
- PHN, Nepean Blue Mountains (Wentworth Healthcare Ltd)
- PHN, Northern Queensland
- PHN, Northern Territory
- PHN, Primary Health Tasmania
- PHN, South Western Sydney
- PHN, Victorian and Tasmanian Alliance
- PHN, Western Australia Primary Health Alliance
- PHN, Western New South Wales
- PHN, Western Queensland
- PHN, Western Sydney (Wentwest Ltd)
- PHN, Western Victoria
- Population Health Research Network
- Productivity Commission
- Public Health Association of Australia
- Research Australia
- Royal Australasian College of Medical Administrators
- Royal Australasian College of Physicians

- Royal Australian College of General Practitioners (various)
- Royal Flying Doctor Service of Australia
- Rural Doctors Association, New South Wales, Tasmania
- Service for Australian Rural and Remote Allied Health
- Southgate Institute for Health, Society and Equity, Flinders University
- Tasmanian Health Service
- Telethon Kids Institute, University of Western Australia
- The Australasian College of Dermatologists
- The Australian and New Zealand Real-World Data Network (RADiANT)
- The Murdoch Children's Research Institute
- The Royal Australian and New Zealand College of Ophthalmologists
- The University of Melbourne
- The University of Melbourne, Australian Health Economics Society
- The University of Melbourne, Centre for Health Policy, Health Economics Unit
- The University of New South Wales, Centre for Big Data Research in Health
- The University of Notre Dame Australia
- The University of South Australia, Department of Rural Health
- The University of Tasmania, Division of Pharmacy, School of Medicine
- The University of Western Australia, The Rural Clinical School
- Therapeutic Goods Administration
- Top End Health Service Primary Health Care, Northern Territory Government
- University Centre for Rural Health, University of Sydney
- Victoria University
- Victorian Agency for Health Information
- Vision 2020 Australia
- World Health Organization, Collaborating Centre on Family Medicine and Primary Care

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Abbreviations

AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
CIS	clinical information systems
CSIRO	Commonwealth Scientific and Industrial Research Organisation
Data Asset	National Primary Health Care Data Asset
PHN	Primary Health Network
PIP QI	Practice Incentive Program Quality Improvement

Glossary

Aboriginal or Torres Strait Islander: A person of Aboriginal and/or Torres Strait Islander descent, who identifies as an Aboriginal and/or Torres Strait Islander. See also **Indigenous Australian**.

allied health: A health professional who is not a doctor, nurse, or dentist. Allied health professionals include (but are not limited to) Aboriginal and Torres Strait Islander health practitioners, chiropractors, occupational therapists, optometrists, osteopaths, pharmacists, physiotherapists, podiatrists, psychologists, sonographers, and speech pathologists.

clinical information system: A computer system used to manage client records

continuous quality improvement: A tool for improving the quality of services provided by organisations involving a systematic approach to collecting and reviewing data or information to identify areas for improvement.

data linkage: The linking of information from 2 or more different data sources that are believed to relate to the same entity (for example, the same individual or the same institution). This linkage can yield more information about the entity and, in certain cases, provide a time sequence. This helps to tell a story, show pathways, and perhaps unravel cause and effect. The term is used synonymously with 'record linkage' and 'data integration'.

general practitioner: A medical practitioner who provides primary comprehensive and continuing care to patients and their families in the community.

Indigenous Australian: A person of Aboriginal and/or Torres Strait Islander descent, who identifies as an Aboriginal and/or Torres Strait Islander. See also **Aboriginal or Torres Strait Islander**.

My Health Record: An online platform for storing a person's health information, including their Medicare claims history, hospital discharge information, diagnostic imaging reports, and details of allergies and medications.


national Key Performance Indicators: A set of indicators that monitor the major health issues of the regular client population of Indigenous-specific primary health-care services.

Primary Health Network (PHN): Primary Health Networks were established on 1 July 2015. These networks are intended to play a critical role in connecting health services across local communities, so that patients, particularly those needing coordinated care, have the best access to various health-care providers, including practitioners, community health services, and hospitals. Primary Health Networks work directly with general practitioners, other primary care providers, secondary care providers, and hospitals.

Five Safes framework: A risk assessment framework for data access that ensures safe people, safe projects, safe settings, safe data, and safe outputs.

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This Consultation Report outlines feedback provided to the Australian Institute of Health and Welfare on the development of a National Primary Health Care Data Asset. The report summarises feedback gathered through the AIHW consultation workshop series and the associated online public submission process in the first half of 2019 and includes:

- key issues raised throughout the consultation period and
- a brief outline of the next steps in progressing the development of the Data Asset.

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