



**Australian Government**

**Australian Institute of  
Health and Welfare**

# **National Primary Health Care Data Asset**

## **Data Development Plan**

**Exposure draft for consultation v1**

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Australian Institute of Health and Welfare  
Canberra

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Draft

# Executive Summary

Primary health care is a vital component of Australia's health care system accounting for a large proportion of health care expenditure annually. It is often the first point of contact individuals have with the health system and encompasses a broad range of professions and services. Despite this, there is limited availability of primary health care system data making it difficult to assess the positive impact of this sector on the health of Australians and/or identify where improvements are needed.

It is envisaged that an enduring National Primary Health Care Data Asset will contain reliable, detailed, high-quality data about primary health care which will assist in the creation of a comprehensive understanding of the system and a patient's journey and experiences within it. It has the potential to create new avenues of analysis for providers, policymakers and healthcare researchers to enable better population health planning, help identify gaps in primary health care services and ultimately improve patient health outcomes.

Development of the Data Asset will be iterative and while initially focussed on general practice activity data in the short term, it will encompass other sources of primary health care data as they become available and practical mechanisms to access them are developed over time. The Data Asset does not seek to replace or duplicate existing sources of primary health care information but instead focus on accessing new and developing sources to add value to what is already known and provide data to bridge knowledge gaps.

The Data Asset will initially comprise aggregated general practice activity data however in the longer term it is envisaged that it will consist of unit record level data and represent a wider scope of primary health care activity.

Strong data governance is key in ensuring the trust of patient and providers regarding data management of the Data Asset. The AIHW's data governance framework, and the legal, regulatory and governance environment in which the AIHW operates, form the basis of the sound management of the Data Asset. Existing health information governance arrangements will be utilised in addition to the creation of an additional advisory group and a technical data working group, with functions that serve the Data Asset.

# 1 Introduction

Australia's primary health care system faces several ongoing challenges. These include inequalities in access relative to need for effective and coordinated care, as well as increasing demand (due to factors such as an ageing population and rising levels of chronic diseases and risk factors). Yet, despite its importance, the availability of reliable high-quality data on our primary health care system is limited. This makes it difficult to assess the system with the same rigour as applied to hospital care, and to further identify and monitor areas where improvements are needed. Limited data also restricts the ability to examine return on investment for Government. The Primary Health Care Advisory Group reported to the Australian Government in 2015 and outlined a strategic direction of 'nationally consistent aggregated data' that can be 'used at a national and regional level to target health resources and interventions, leading to improved population health and health system outcomes' (PHCAG 2015).

Following this was a Ministerial announcement in 2016 that a national primary health care data set would be established; to identify information to monitor performance, inform policy and identify priorities at a local, regional and national level.

Of high relevance from an information perspective are several factors:

- development of multiple data pools of general practice clinical activity data in various regions/catchments, with non-standard data elements, varied data extraction protocols/tools, data quality limitations and restricted access arrangements
- the potential for convergence of general practice data pools through adoption of standard terminologies by more players (e.g. SNOMED CT)
- cessation of the Bettering the Evaluation and Care of Health (BEACH) survey
- Commonwealth/state/territory efforts to improve linked data (e.g. The National Integrated Health Services Information (NIHSI) Analysis Asset)
- developmental work relating to the secondary use of My Health Record data
- the Productivity Commission's Report on Data Availability and Use and the Commonwealth Government response
- the National Health Information Strategy
- the Australian Health Performance Framework.
- the Aboriginal and Torres Strait Islander Health Performance Framework

Australians receive the majority of their primary health care through their general practitioners (GPs), although primary health care providers also include allied health professionals, community health workers, nurses, pharmacists, dentists, midwives and Aboriginal and Torres Strait Islander health workers and practitioners (Department of Health 2013). While acknowledging that primary health care encompasses a range of professions across a broad sector, the initial proposed scope of the Data Asset in the short to medium term will be the collection, analysis and reporting of general practice activity data.

General practice forms a substantial component of the primary health care system and has close to universal adoption of electronic health records and clinical information systems in which data can be made available for secondary use. This technology is not as widely established amongst other primary health care professions at this stage. The ensuing Data Development Plan (the Plan) reflects the Data Asset's early focus on general practice data.

## 1.1 The role of the AIHW and the vision of a National Primary Health Care Data Asset

In the May 2018 Federal Budget the AIHW received funding for primary health care data development and the Primary Health Care Data Unit was established to develop a National Primary Health Care Data Asset. This Data Asset will support a more comprehensive understanding of patient outcomes, diagnosis, treatment and experiences within the primary health care system.

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 dataset to inform the development of quality indicators)* as one of the goals of long-term system wide reform.

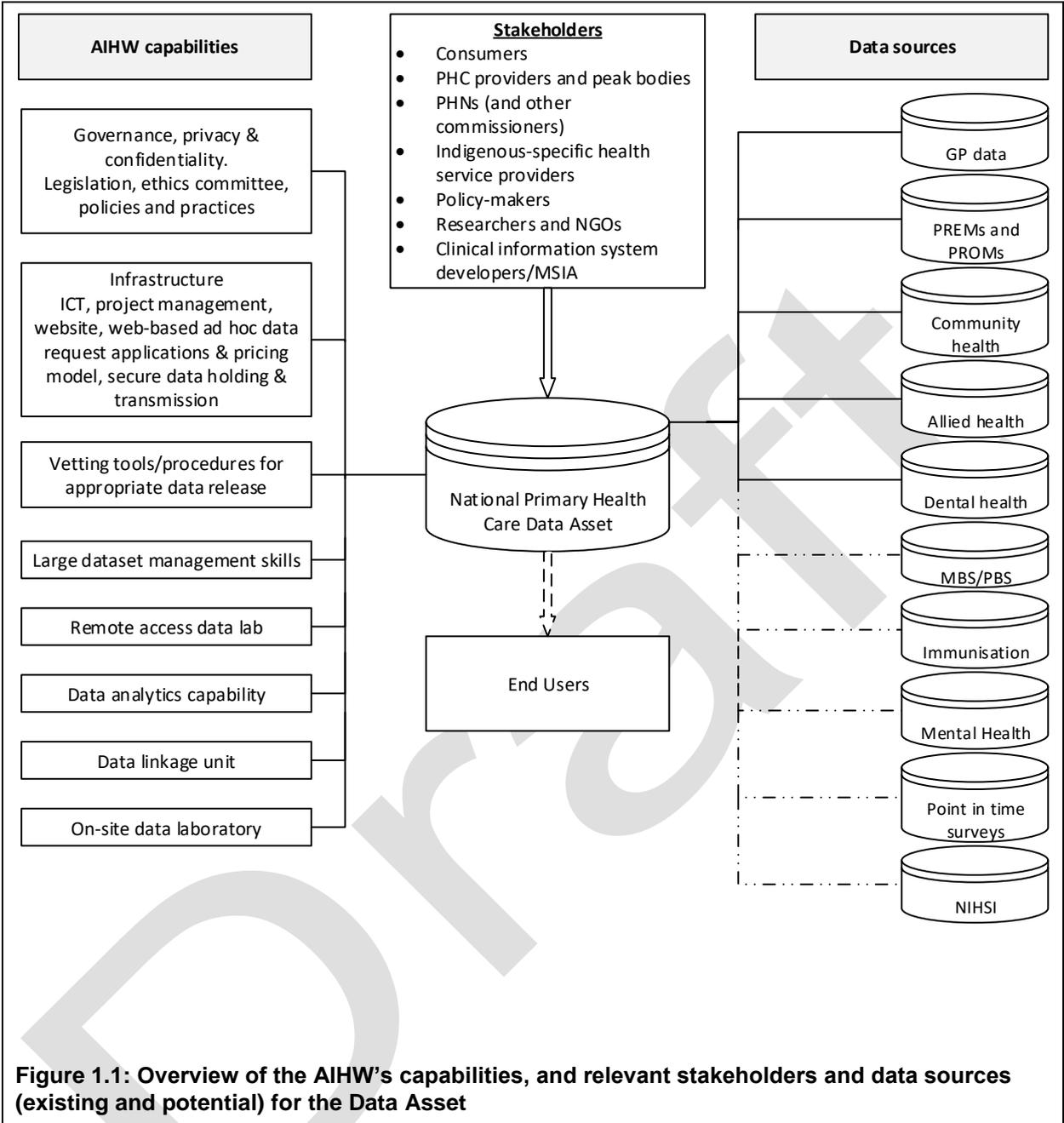
It is envisaged that the Data Asset will facilitate a better understanding of what happens to patients in the health system, including their diagnoses, treatments and outcomes by bringing together a range of collections of data over time. It will allow for the reporting of key primary health care indicators (to be agreed and developed) and support key priorities such as the reduction in potentially preventable hospitalisations and primary care type emergency department attendances.

The Data Asset will not duplicate current avenues for reporting of primary health care data through existing sources, and it will not impinge and compete with established governance arrangements. It will instead build on existing frameworks, data sources and governance processes and identify primary health care data gaps and new sources to fill them. Where possible, the Data Asset would seek to align any new data collected to enable comparisons to occur with existing collections, for example National Key Performance Indicators for Aboriginal and Torres Strait Islander primary health care (nKPIs).

The process of establishing the Data Asset will also be used to drive cyclical improvements in the quality and standardisation of its data.

For policy and service planners and commissioners, the envisaged Data Asset would:

- enable better population health planning
- support improved patient health outcomes, and enable comparison across geography, remoteness and socioeconomic gradients
- enable and inform integrated care
- help identify gaps in primary health care services and outcomes
- enable an assessment of the equitable distribution of care
- shape primary health care programs and policies
- allow for international comparisons.



## 1.2 Oversight of the Data Development Plan: decision-making and advisory arrangements

The AIHW has experience and expertise in end-to-end data services including data development and data governance that make the organisation well-placed to lead development of the Data Asset. In addition to this the AIHW has been utilising, and will continue to utilise, decision-making support and advisory arrangements, as appropriate, through the:

- AIHW-convened Primary Healthcare Advisory Committee (PHAC): this Committee includes a range of experts from the field and representatives of key stakeholder groups who provide subject matter advice.
- Strategic Committee for National Health Information (SCNHI): this Committee was established to provide strategic advice to the AIHW in relation to its national health information work, including overall priorities, and the Institute's health sector performance reporting work.
- The AIHW Board which serves as the AIHW's governing body.
- Other key committees such as the Health Services Principal Committee and those overseeing Indigenous primary health care data reporting, including AHMAC's National Aboriginal and Torres Strait Islander Health Standing Committee.

These groups will allow for valued input from the perspectives of clinicians, subject matter experts, policy makers and service delivery personnel.

Further, all data development and data governance will occur under the AIHW's robust data governance guidelines (see <<https://www.aihw.gov.au/about-our-data/data-governance>>).

## 1.3 Objectives of this Data Development Plan

This document outlines the AIHW's Plan for an enduring Data Asset. Data development begins with identifying what data are needed to support business requirements, and determining if the data already exist. Where gaps in the data exist, these are prioritised and consideration is given to how data can be collected in practical terms. Data development results in the building of a data set (data collection); principles of good data development include:

1. Creating data standards is part of data development
2. National and international standards should be used wherever available and applicable
3. Be clear about the purpose of the data collection
4. Data included must be required to meet the objectives of the data collection
5. Create once, use often
6. Acknowledge the limitations of data
7. Data development may be incremental
8. Data development is system independent
9. Data development should be mindful of privacy concerns
10. Data development should minimise collector/recording burden
11. Data development should reflect, not drive, practice (AIHW 2007).

These principles are taken into account in this Plan and will form the foundations of the Data Asset. Enduring data will also be central to the Data Asset so that the collection is able to remain pertinent in the context of changes over time in policy, funding arrangements, or government.

This Plan forms the basis for consultation with stakeholders at workshops relating to the Data Asset's development, to be held around Australian capital cities from February 2019.

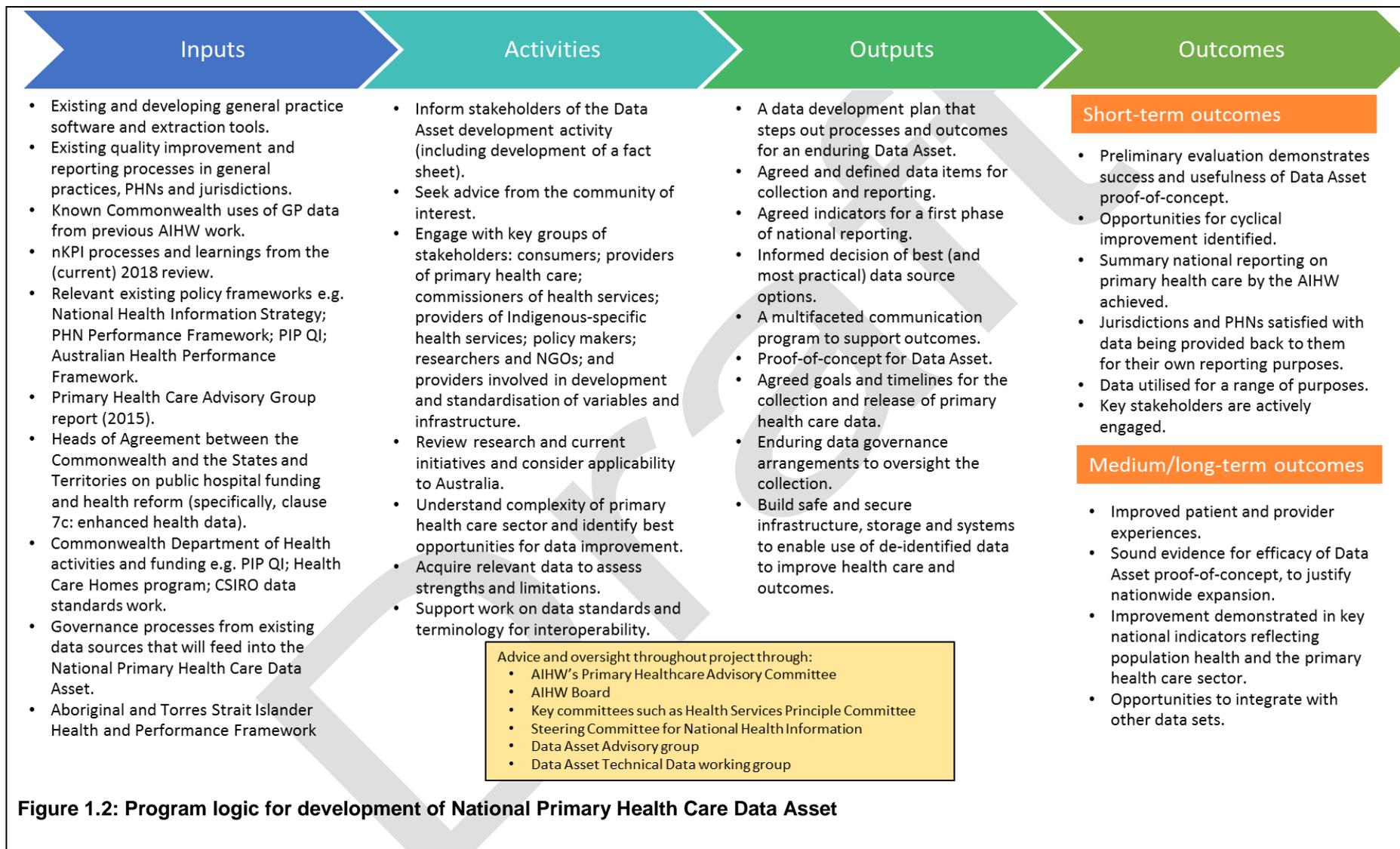
## 1.4 Program logic

A program logic was developed to identify the aims, objectives, activities and intended impacts and outcomes for the development of the Data Asset (Figure 1.1). It describes the activities being undertaken and planned for by the AIHW.

In terms of inputs, there are various Commonwealth Department of Health activities included here:

- various programs and policies require general practice activity data
- data are required for exploratory research to promote improved health outcomes
- improving data quality to enable the identification of populations with specified risk factors and health conditions should be a priority.

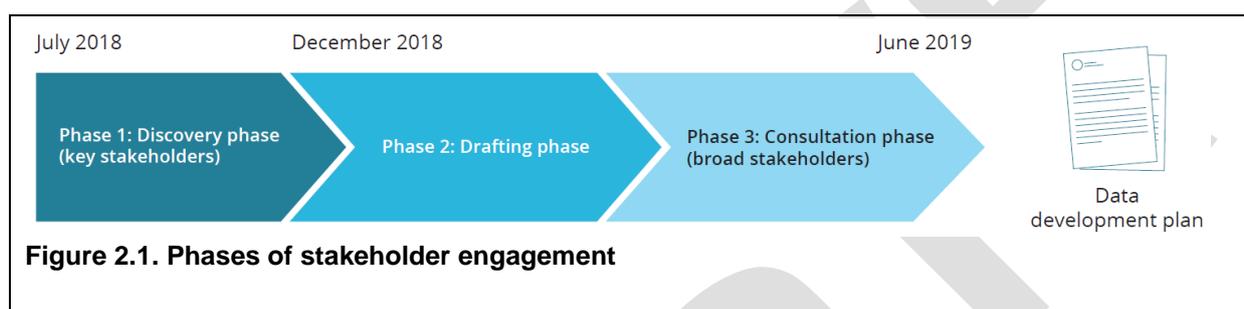
As the first 'output', this Plan will confirm and inform a number of other outputs.



**Figure 1.2: Program logic for development of National Primary Health Care Data Asset**

## 2 Stakeholder engagement

A systematic approach to stakeholder relations and communication is critical to ensuring the successful development of the Data Asset. As part of stakeholder engagement the AIHW is consulting a wide range of primary health care stakeholders, including organisations and individual experts across the primary care, research, consumer and government sectors. In addition, clinical software providers are key stakeholders for data sourcing and implementation. Ongoing stakeholder engagement is a central feature of the Data Asset's development, operation and continued refinement. There are three phases of engagement over the course of 2018–19, as Figure 2.1 below.



The overall purpose of AIHW's stakeholder engagement is to gain support for development of the Data Asset. Seven key groups of stakeholders with potential interest in the Data Asset have been identified:

- consumers (beneficiaries of the research and improvements resulting from the data)
- providers of primary health care at the practice and organisational level (for example, peak bodies)
- commissioners of health services (for example, primary health networks (PHNs))
- providers of Indigenous-specific health services, including Aboriginal Community Controlled Health Services
- policy makers (Commonwealth, State and Territory Health Departments, other government departments, international organisations)
- researchers and non-government organisations
- providers involved in the development and standardisation of selected primary health care data variables and infrastructure including clinical information systems (CIS).

The engagement aims to ensure effective communication with stakeholders in order to:

- build relationships and trust in the AIHW taking on this role
- gain insight into gaps where primary health care information needs are not met by current data sources
- inform and refine the Plan
- inform and refine the data elements and health system measures that the Data Asset needs to support
- understand preferred governance structures
- identify existing activity in the sector and insights from that activity
- expand the identification of possible uses of primary health care data

- gather intelligence on developments in the primary health care sector that may assist in building the Data Asset, for example the work of PHNs and others in extracting data from general practice software
- identify potential impacts and issues that will be covered in subsequent phases
- inform the scope and inclusions of the Data Asset.

The AIHW will consult with the range of stakeholders across all phases of engagement. The level and method of stakeholder engagement will vary dependant on the stakeholder group being targeted and the objective of the engagement as below.

<b>PHASE ONE – DISCOVERY: July – November 2018</b>		
<b>Objectives</b>	<b>Target Audience</b>	<b>Engagement methods</b>
<p>Inform stakeholders about this project and the process that will follow</p> <p>Identify priority uses of the Data Asset, data gaps and options for filling gaps</p> <p>Establish collaborations and knowledge sharing</p> <p>Strengthen relationships, cooperation and trust</p> <p>Identify stakeholder concerns and potential obstacles that may arise in the Data Asset's implementation and operation, so measures can be taken early to mitigate these risks</p> <p>Gather intelligence on current developments in the sector that may assist the development of the Data Asset.</p>	Selected Peak Bodies and Royal Colleges	<p>Letter of formal introduction from AIHW CEO</p> <p>One-on-one meeting with CEOs and AIHW CEO</p>
	Selected medical software providers of clinical information systems/Medical Software Industry Association	<p>Letter of formal introduction from AIHW CEO</p> <p>One-on-one meeting with CEOs and AIHW CEO</p>
	Primary Health Networks	<p>Email introduction to all 31 PHNs from AIHW CEO</p> <p>One-on-one meeting AIHW CEO and PHN CEOs at the Commonwealth Department of Health's 2018 National PHN Forum</p> <p>Oral presentation and stall at the Commonwealth Department of Health's 2018 National PHN Forum Expo</p>
	Commonwealth, State and Territory Health Departments	Targeted communication with health department representatives
	Selected Research Institutions	Research Institutes with a focus on primary health care will be targeted for F2F discussions
	All stakeholders	<p>Fact sheets with generic contact email for the Primary Health Care Data Unit provided at follow-up discussions or via mail-out</p> <p>Information on primary health care Data Asset development hosted on AIHW Primary Health Care web page</p>

		<p>AIHW Webpage includes a subscription link for updates and to register interest in attending consultation workshops</p> <p>Utilisation of the AIHWs twitter feed to promote and update on the AIHWs work in developing the primary health care Data Asset</p>
<b>PHASE TWO – DRAFTING: November 2018 to February 2019</b>		
<b>Objectives</b>	<b>Target Audience</b>	<b>Engagement activities/tactics</b>
Obtain advice and feedback on the draft Plan	<p>AIHW Advisory Committees:</p> <p>Primary Healthcare Advisory Committee</p> <p>Strategic Committee for National Health Information</p>	Draft Plan provided to committees for input and endorsement
<b>PHASE THREE – CONSULTATION: February – May 2019</b>		
<b>Objectives</b>	<b>Target Audience</b>	<b>Engagement activities/tactics</b>
<p>Refine the Plan</p> <p>Define the data elements and health system measures the Data Asset needs to support</p> <p>Prioritise measures and data elements</p> <p>Seek proposed data uses for policy and program planning</p> <p>Understand the potential data options whether existing or new developments</p> <p>Determine the need for and design of a pilot project intended to identify strengths and limitations of primary care data options</p> <p>Understand preferred governance structures</p>	<p>Representatives from all stakeholder groups in each state or territory</p>	<p>Facilitated structured workshops in each capital city with a mix of stakeholder groups</p> <p>Additional workshops to be held in associated rural areas as required</p>

# 3 Data sources

## 3.1 Existing data sources

Existing information on primary health care in Australia is limited but can be found in established collections such as MBS and PBS and national surveys (Figure 3.1). Also of potential relevance are the National Health Workforce Database, and data from the National Key Performance Indicators for Aboriginal and Torres Strait Islander primary health care (nKPIs), and other sources in the early stages of being established such as data from the Practice Incentive Program Quality Improvement (PIP QI) activities, and My Health Record.

These established and emerging sources will provide information external to the Data Asset to inform the context of primary health care in Australia and to provide indicator-based reporting. In contrast, the Data Asset will internalise new and developing sources of primary health care data to add value to what is already known. Existing governance arrangements would continue to apply for established data sourced externally to the Data Asset.

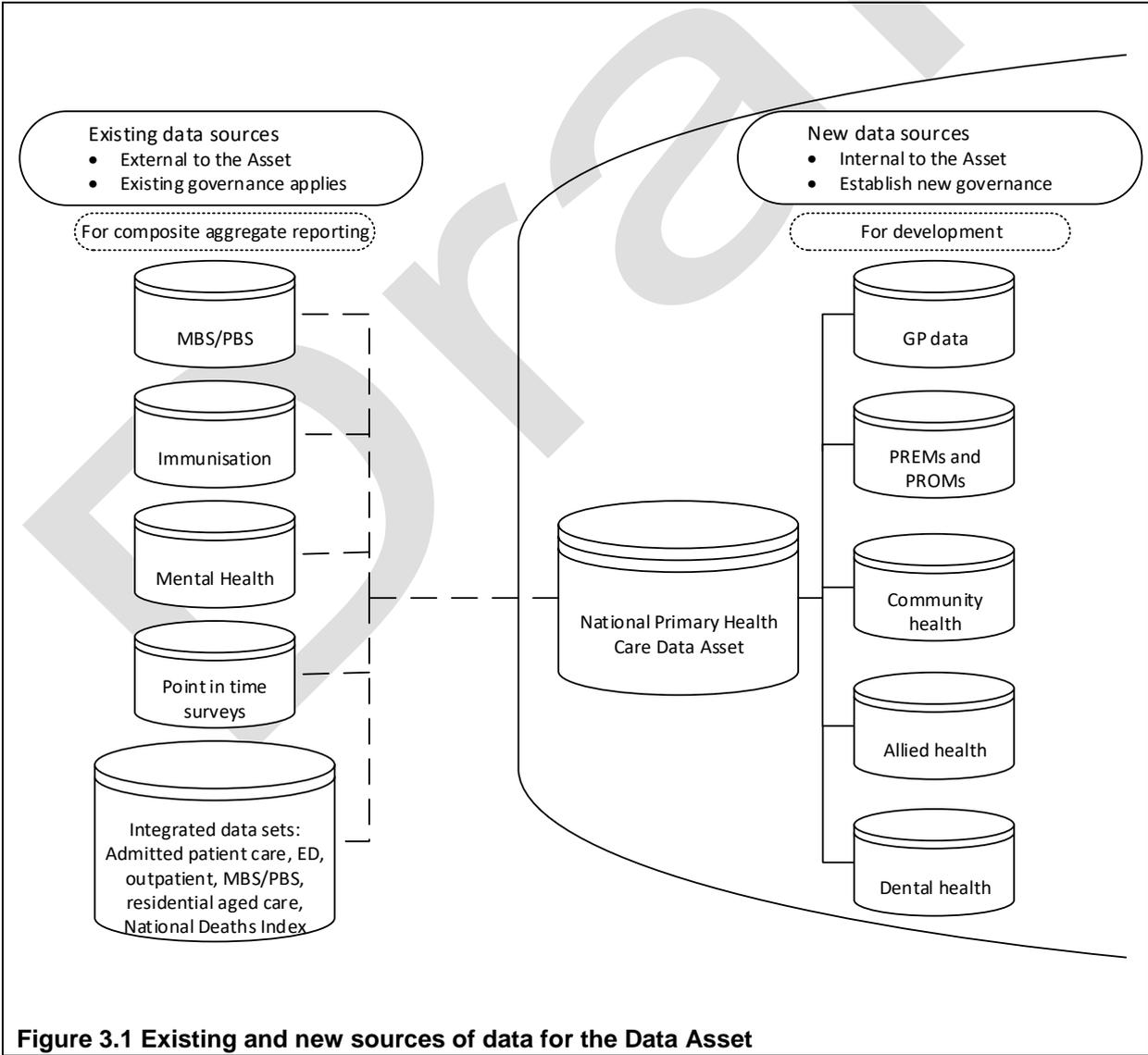


Figure 3.1 Existing and new sources of data for the Data Asset

## 3.2 New data sources

The development of the Data Asset and subsequent reporting of primary health care information will be iterative and include the establishment of agreements for sharing and secondary use. The Data Asset will encompass sources of primary health care data as they become available and practical mechanisms to access them will be developed.

Data standards and terminology are being developed concurrently, and along with developing data requirements and developing data sources, will be incorporated into the Data Asset over time. While the ultimate aim of the Data Asset is for granular (unit record level) data to enable comprehensive and longitudinal reporting, it is likely that in its initial phases, data sources will only support aggregate reporting.

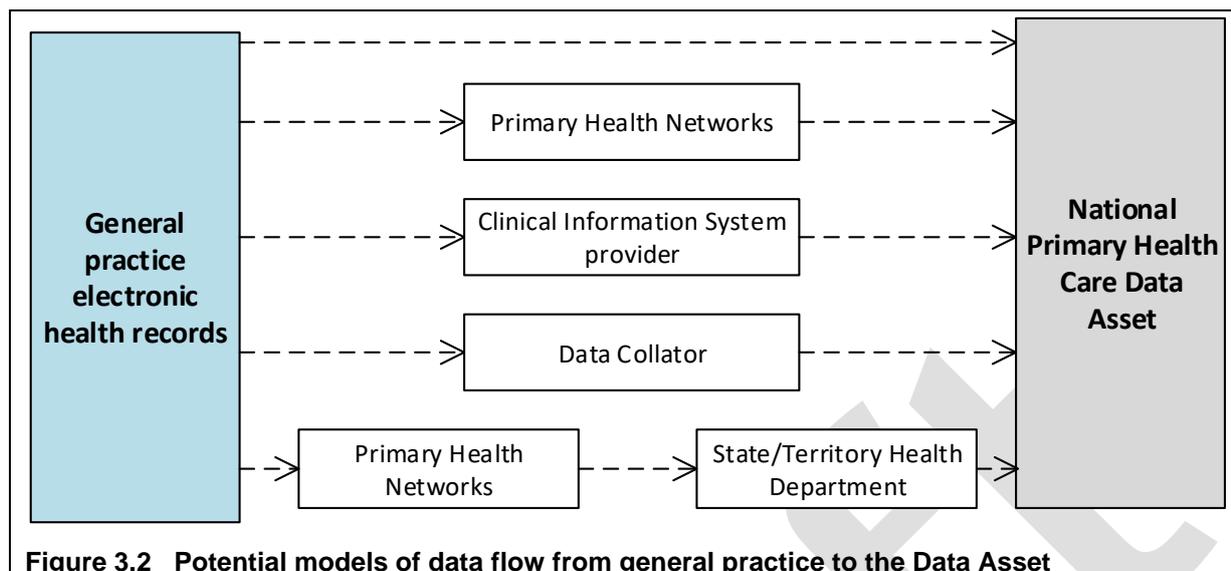
A decision making flow chart (Figure 3.3) outlines the considerations for the AIHW when assessing the feasibility and quality of data sources against relevant criteria. These relate to the major themes of governance, ethics, privacy/confidentiality/consent, representativeness, data documentation, data linkage potential, data transmission and storage, cost to access and benefit to stakeholder.

### **Short term (within first 2 years) – general practice activity data**

The Data Asset will focus on general practice activity data extracted from electronic health records (EHRs) in GP's clinical information software (see Box 3.2) with a phased approach to collection of data elements in the short term. Sources of general practice activity data need to be able to 'build a complete picture of why a typical patient went to a primary health care provider, what occurred during the consultation, what actions were recommended and taken, and with what outcome and cost' (PHCAG 2015).

There are a number of potential avenues for the flow of data from electronic health records (EHRs) in general practice clinical information systems to the Data Asset (Figure 3.2). For example, general practice data extracts from clinical software systems may first be provided to PHNs for consolidation before being provided to the Data Custodian of the Data Asset for compilation. Data access arrangements would be outlined in agreements with the contributing PHN and separate to the data governance framework established to govern the Data Asset. This would be a straightforward method for keeping track of coverage of practices by PHN in the initial stages. It is envisaged that this would be a two-way iterative process with information on data quality and other agreed measures being fed back to the PHN.

There are other options to consider, such as direct extraction or the use of an existing collection. AIHW will need to consider these various models in light of the information and views received through these consultations as well as in light of developments in potentially related Department of Health programs, for example, the Practice Incentive Program.



### Medium term (up to 5 years) – allied health data

Allied health professionals include a broad range of health practitioners who are not doctors, nurses or dentists. Allied health professionals include, but are not limited to, Indigenous health practitioners, optometrists, pharmacists, physiotherapists, psychologists and sonographers (Allied Health Professions Australia 2017).

There are limited comprehensive data on allied health services in Australia. Australians can access subsidised allied health services through their private health insurance if they have general treatment ('ancillary' or 'extras') cover, or through Medicare where eligible. At present, there are no national data on allied health services access outside of private health insurance or Medicare. Adoption of technical infrastructure such as clinical information system software in the allied health practice environment is unknown but considered to be low, however options for future data collection are being explored.

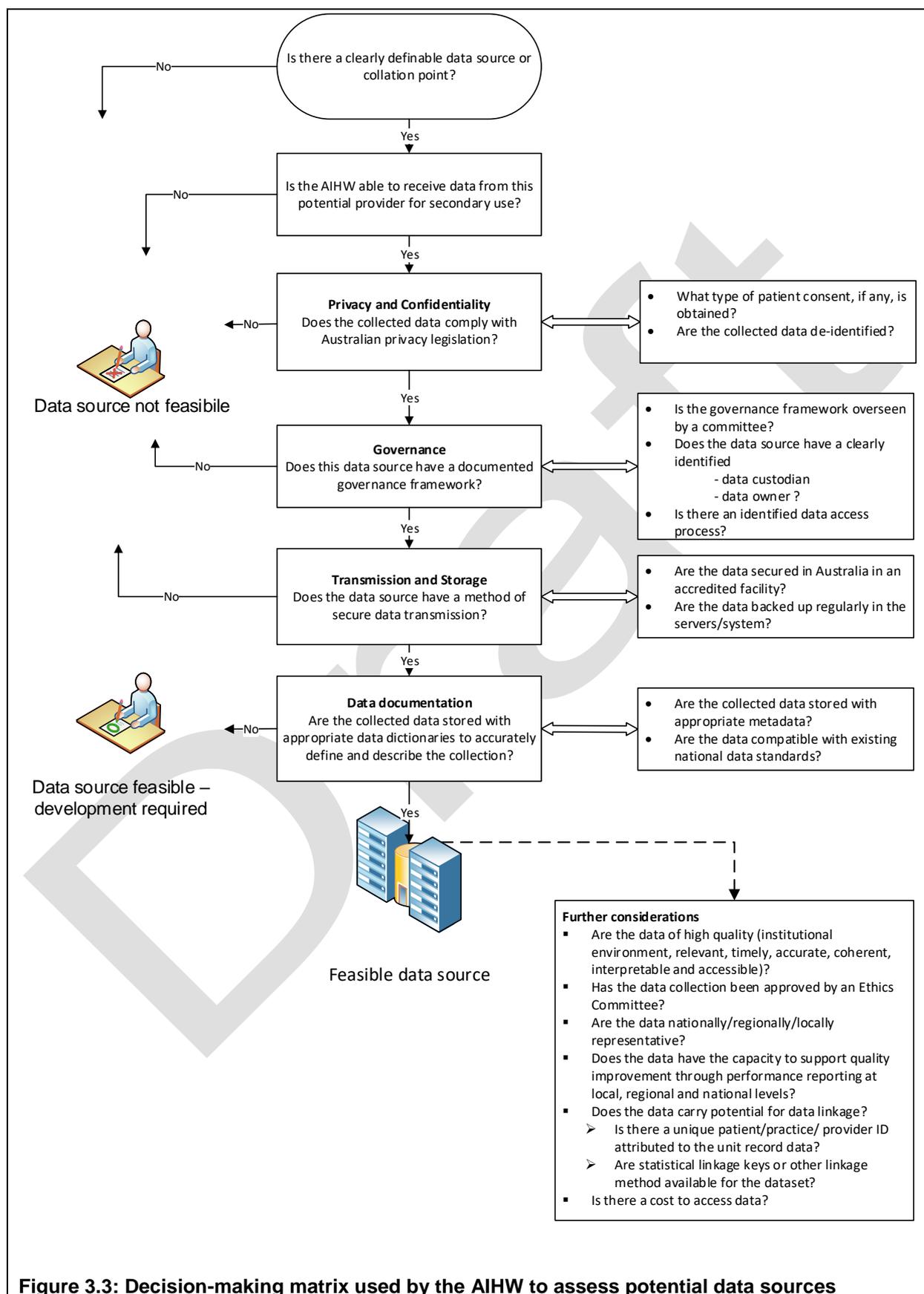
Sources such as pathology data, diagnostic imaging data and data that allow for reporting of patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) could also be considered during this time frame.

### Longer term (7-10 years) - community and dental health data

Community health services include non-residential health services offered to patients/clients in an integrated and coordinated manner in a community setting, or the coordination of health services elsewhere in the community. Such services are provided by, or on behalf of, state and territory governments.

Currently there is no comprehensive, national data source for community health services; options for future data collection are being explored.

Dental health care is a vital component of the primary health care system and accounted for 16.4 per cent of national expenditure on primary health care in 2016–17 (AIHW 2018). The AIHW currently collects, analyses and reports on a range of dental health data including from studies such as the National Child Oral Health Study and the Australian Burden of Disease Study, surveys including the National Dental Telephone Interview Survey, the National Survey of Adult Oral Health and the National Health Survey, and collections including the Public Dental Waiting Times National Minimum Data Set and the Australian Cancer Database.



**Figure 3.3: Decision-making matrix used by the AIHW to assess potential data sources**

### **Box 3.2: General practice activity data**

Raw data relating to patient encounters are collected by most GPs in practices as part of their EHRs. These data are the most comprehensive source of general practice activity data. Extracts of the EHR information, either as unit record de-identified information and/or as a selection of key indicators (e.g. practice population with diabetes care plan), are used within the practice and/or—for some GPs—submitted to data pooling arrangements for quality improvement purposes.

It is estimated that 96% of GPs in Australia use computers for clinical purposes. More than two-thirds (71%) reported being 'paperless' for their clinical work in 2014–15 (Britt et al. 2016), however software and systems and their use in practices are varied. The RACGP working with ADHA has released its minimum software requirements (RACGP 2019).

GPs may enter a range of information about a patient encounter into an EHR. This includes, for example:

- patient demographics, including Aboriginal and Torres Strait Islander identification
- medical history
- reason for encounter
- clinical notes
- medications
- allergies
- immunisations
- pathology and imaging reports.

#### **Benefits for GPs and patients**

The data entered into EHRs have many significant benefits for GPs and their clinical practice, that ultimately mean a better service for patients, including:

- improved safety, quality and efficiency of care (through, for example, the ability to identify at-risk patients)
- clinical decision support tools to improve quality of care and reduce errors (may include alerts for drug interactions and other patient issues that are flagged by the software, or suggestions to undertake immunisations or appropriate screening such as cardiovascular risk assessments for older patients)
- streamlined health information exchange between health professionals assisting with a patient's care
- promotion of adherence with evidence-based clinical guidelines and effective care
- knowledge of optimal treatments to improve the delivery of services
- avoidance of redundant diagnostic testing.

EHRs are also useful for practice administration and may be used for medico-legal purposes. The nature of EHRs means longitudinal analysis of patient data is an option (this kind of analysis is not possible on a national scale with existing data sources). The ability to follow a patient journey and measure/record outcomes adds significant value and is a critical aspect of any evaluation of patient outcomes at the population level or of the primary health care system.

# 4 Data governance

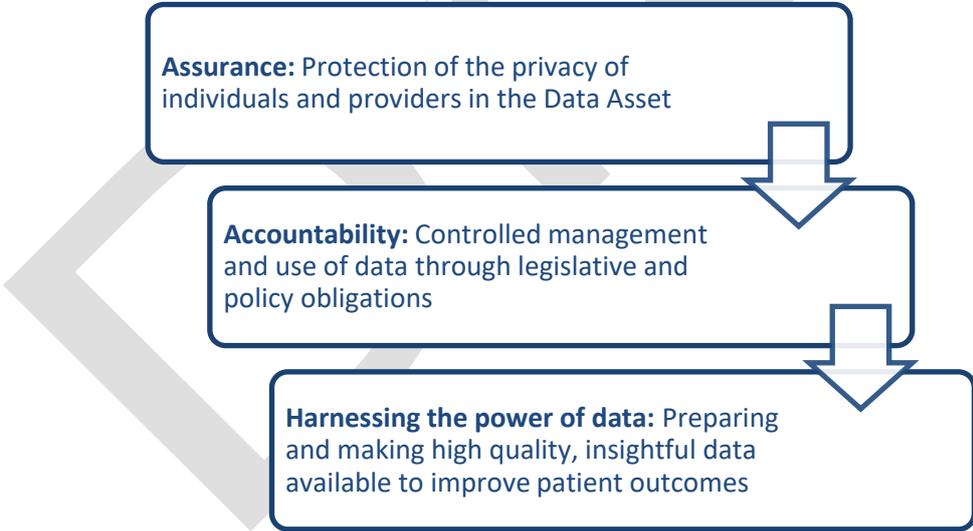
Data governance is ‘...a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions, with what information, and when, under what circumstances, using what methods’ (Data Governance Institute 2017). Data governance describes how data-related decisions are made within an organisation or group of organisations (AIHW 2014).

Strong data governance is key in ensuring the trust of patients and providers regarding management of the Data Asset. The AIHW’s data governance framework, and the legal, regulatory and governance environment in which the AIHW operates, form the basis of the sound management of the Data Asset (see <<https://www.aihw.gov.au/about-our-data/data-governance>> for more information).

Establishment of appropriate governance arrangements is an essential activity to precede data collection. The Data Asset will be drawn from a number of different data sources with differing data custodians—existing health information governance arrangements provide a solid foundation for the data sources that will likely feed into the Data Asset.

Data governance should consider the point in the data flow cycle at which data must be de-identified and outputs made confidential, depending on the purpose for which the data are being used. In keeping with the ‘single provision, multiple use’ principle guiding Australian health information policy (for example, the National Health Information Agreement) data governance should build in the considerations of the full spectrum of data users.

The key principles to guide data governance of the Data Asset are outlined below.



# 4.1 Data governance principles: overview and description of proposed processes

<b>Assurance: protection of the privacy of individuals and providers</b>	
<b>Overarching legal and policy environment</b>	National and agency-specific legislation and policy inform the management of data. Data custodian-specific legislation and policies regarding the collection, use and disclosure of data from existing data sets may also apply. This includes enabling legislation for some agencies. The protection of patient privacy is central to all legislation and policy and would continue to be where the development of further data governance was required.
<b>Australian Privacy Principles</b>	Consumer and healthcare provider trust are at the forefront of the Data Asset: the protection of sensitive information is balanced with the safe and efficient sharing of information to ensure its full value is realised. The Australian Privacy Principles (APPs) in the <i>Privacy Act 1988 (Cwlth)</i> outline how government must handle, use and manage personal information.
<b>Identification of patients and providers; and de-identification</b>	<p>The de-identification approach is applied in the vast majority of existing health-related national minimum data sets and would likely be appropriate for routine summary-type reporting of data from the Data Asset. Additional governance and protections would be required by the AIHW because release of de-identified data to some parties may not be legally permissible.</p> <p>The terms of data access outline the user’s conditions and their responsibilities under legislation. Data in a de-identified data set may become identifiable if merged or compared with other data sets, ‘creating’ identifiable information; this important complexity is taken into consideration by the AIHW in the context of a Data Asset.</p> <p>The Five Safes model helps to establish safe and functional de-identification. Whether data comprise personal information for the purposes of the Privacy Act, and therefore whether patient consent is required, is usually dependent on whether data are identified or reasonably re-identifiable. In certain circumstances, pursuant to section 95 of the Privacy Act, consent can be waived by a Human Research Ethics Committee (HREC) where the public interest in the research outweighs the public interest in privacy and the impact on the privacy of individuals.</p>
<b>Ethics</b>	Data collection, linkage and release activities conducted by Commonwealth agencies are subject to oversight by a Human Research Ethics Committee (HREC), registered by the National Health and Medical Research Council (NHMRC). Ethics processes—coordinated by the Data Custodian—ensure the Data Asset complies with the appropriate guidelines.

<b>Accountability: controlled management and use of data</b>	
<b>Oversight</b>	<p>At the Australian Government level, activities conducted by the Commonwealth Health portfolio (including the AIHW) are oversighted by numerous bodies including, for example, the:</p> <ul style="list-style-type: none"> <li>• Australian Parliament and its various Committees</li> <li>• Health Minister</li> <li>• Australian Information Commissioner, Commonwealth Privacy Commissioner and Freedom of Information Commissioner</li> <li>• Commonwealth Ombudsman</li> <li>• Auditor-General</li> <li>• Australian National Audit Office</li> <li>• general public.</li> </ul>
<b>Data custodianship</b>	<p>The AIHW is responsible for managing the use, disclosure and protection of source data of the AIHW—taking on a Data Custodian role. This includes facilitating data sharing and release while maintaining public trust and actively managing risk. The Data Custodian determines appropriate access to the data for various purposes, and manages analysis of, and/or access to, unit record data for more specific, defined purposes. The Data Custodian is also responsible for managing data quality, including maximising the currency and quality of data and reporting on data quality.</p> <p>The role of the Data Custodian also encompasses the maintenance of infrastructure necessary for ensuring data security, including secure servers and remote access protocols.</p>
<b>Data access and release</b>	<p>Access to the Data Asset varies according to the user, and according to the intended purpose; that is, data access and output is fit-for-purpose.</p> <p>A ‘trusted user’ model will be implemented (4.3). This model ensures that only de-identified data and non- re-identifiable information about patients and providers is made available to data users.</p> <p>Data access would be based on the ‘Five Safes’ model: a model based on a set of 5 ‘risk (or access) dimensions’:</p> <ol style="list-style-type: none"> <li>1. Safe projects: is the use of the data appropriate?</li> <li>2. Safe people: can the researchers be trusted to use it in an appropriate manner?</li> <li>3. Safe data: is there a disclosure risk in the data itself?</li> <li>4. Safe settings: does the access facility limit authorised use?</li> <li>5. Safe outputs: are the statistical results non-disclosive?</li> </ol>
<b>Evaluation and review</b>	<p>Monitoring and evaluation mechanisms should periodically assess whether the uses of the data have met the intended health-related public interest purposes. These functions will be undertaken by the Data Custodian. Evaluation will review the end-to-end processes, outputs, outcomes and data quality. In the first instance, evaluation of the proof-of-concept for the Data Asset will consider this.</p>

## Harnessing the power of data: preparing and making high quality, insightful data available

<p><b>Data analysis and reporting</b></p>	<p>A summary of primary health care activity data from the Data Asset will be produced annually for the general public and reported by the AIHW. This reporting will aim to meet the needs of a wide range of stakeholders. The Data Custodian is responsible for ensuring high-quality data and reporting.</p> <p>This reporting will be high-level and iterative as data development evolves. As with all data uses beyond the practice level, individuals and practices will not be identifiable. This type of reporting will likely reflect nationally agreed measures where applicable.</p> <p>Additionally, the Data Custodian will make available richer data for more detailed analyses to PHNs, to support them in their role of informing and educating primary health care practitioners to ultimately achieve high-quality patient care. Third-party researchers will be able to apply for access to de-identified data for approved purposes through the trusted user model.</p>
<p><b>Interoperability</b></p>	<p>In order to collect reliable and nationally consistent primary health care activity data, agreed standards would need to be adopted in every clinical system. Additionally, consistent and standardised interface terminology is central to achieving interoperability so that computerised systems can exchange information and make use of (interpret) exchanged information—that is, achieve interoperability.</p> <p>Work is currently underway to achieve this in general practice through work facilitated by the CSIRO and partners to progress the adoption of SNOMED-CT, within general practice clinical information software.</p>
<p><b>Maximising use of the data</b></p>	<p>The inclusion of unit record level data (rather than solely aggregate data) would maximise the utility of the Data Asset. Strong data governance will be key in increasing the trust of providers regarding data management.</p> <p>Unique patient identifiers are crucial to enable longitudinal analysis of individual patients, or linkage with other datasets in future—including improved patient care through targeted follow-up and longitudinal analysis. However, linkage to other key data sets such as MBS and PBS, mortality and hospitals would require that a Data Custodian/s oversee re-identification of patients in the datasets in a safe manner, under appropriate ethics approvals.</p>

## 4.2 Management and storage of data

The AIHW has an exemplary record of protecting the data in its custody. Stakeholders can be confident that the AIHW uses its data to create authoritative reports that benefit the public, while protecting the confidentiality of the data and minimising any risk of inappropriate use and access. As part of its routine work the AIHW collates large volumes of data from numerous data providers, including data collected under nationally agreed specifications (for example, Admitted Patient Care NMDS; Community Mental Health Care NMDS). As a result, the AIHW has very advanced secure data portal and online validation capabilities.

Data held at the AIHW must be stored so as to meet:

- the storage and archival requirements of the National Archives of Australia (NAA)

- written directions from AIHW management for ongoing collections, including any applicable governance instruments, and
- requirements of data providers and/or the Ethics Committee.

## **AIHW Ethics Committee**

The AIHW Ethics Committee is established under section 16(1) of the *Australian Institute of Health and Welfare Act 1987*. The AIHW (Ethics Committee) Regulations 1987 set out the committee's functions and role. The regulations give the committee the power to make determinations on the ethical acceptability of Institute activities, and activities engaged in by external parties under arrangements with the AIHW. The committee reviews all projects, including internal project proposals that involve the use of identifiable information, the creation of new data sets or data linkage. In forming its opinion, it considers relevant guidelines, such as the National Health and Medical Research (NHMRC) National Statement on Ethical Conduct in Human Research.

## **4.3 The 'trusted user' model for data access and release**

Data access would be based on the 'Five Safes' model. The basic premise is a set of five 'risk (or access) dimensions':

1. Safe projects: is this use of the data appropriate?
  - i. Refers to the legal, moral and ethical considerations surrounding the use of the data.
2. Safe people: can the researchers be trusted to use it in an appropriate manner?
  - i. Refers to assessment of the knowledge, skills and incentives of the users to store and manage data to required standards.
3. Safe data: is there a disclosure risk in the data itself?
  - i. Primarily refers to the potential for identification of individuals in the data.
4. Safe settings: does the access facility limit authorised use?
  - i. Refers to the practical controls relating to data access (e.g. access from a supervised physical location versus no restrictions to publicly available data). Deliberate and accidental disclosure needs to be explicitly considered.
5. Safe outputs: are the statistical results non-disclosive?
  - i. Relates to the residual risk in publications based on sensitive data. Options for management include data managers checking access before release (Desai, Ritchie & Welpton 2016; p.5).

The provision of open data that is not already available for broad public use (published on data.gov.au) may be an option in future. In this form, data will be prepared for public release so that it is not possible to identify individuals.

Data Asset access and data release will make use of a 'trusted user' model to data which are stored securely and managed/curated by the AIHW.

## 4.4 Data Asset governance

### Patient consent

Any data set requires established, clear guidelines around the requirement for, and obtaining of, patient and practitioner consent. Whether data comprise personal information for the purposes of the Privacy Act, and therefore whether consent is required, is usually dependent on whether data are identified or reasonably re-identifiable. However, recent public concern about sharing of health information through the My Health Record emphasises the need to consider the social licence and level of community support for data sharing activities.

This evolving environment around consent for the secondary use of health data, even if de-identified, will need to be factored into the design and implementation of the Data Asset. In time, the feasibility of moving to a dynamic consent model may be explored so that consumers may decide to allow or not allow access for defined secondary uses on a case-by-case basis.

The recently released *Minimum requirements for general practice clinical information systems to improve usability* (RACGP 2019) states that general practices, as custodians of patient data, ‘...must protect patient rights and privacy when providing data for secondary use.’ The RACGP recommends that practices ‘...should make patients aware they are providing de-identified data for secondary purposes...’ and ‘...include functionality to ensure that patients who do not consent to secondary use of their data, or subsets of their data, are removed from any data extraction process.’ Importantly this consent applies to the secondary use of both identified and de-identified data.

Different levels of health literacy and health system usage among Australian consumers will also need to be considered when considering the use of different models of consent in any data source associated with the Data Asset.

### Data custodianship

The AIHW’s stringent data governance processes ensure that data collections are established and managed effectively, appropriately and consistently, with clear accountability requirements and governance arrangements. Data custodians at the AIHW are responsible for approving access to, and use of, data holdings for which they are responsible, in accordance with legislative, data provider and Ethics Committee requirements.

Where new data sources that flow into the Data Asset become the responsibility of the AIHW, the AIHW would take on the role of Data Custodian. For existing data sources, the AIHW will use the existing governance arrangements that oversight those collections.

### Committee oversight

While existing committees associated with the AIHW could oversee various aspects of the management of the Data Asset, an additional advisory group and a technical data working group, with functions that serve the Data Asset would be created (Figure 4.1).

The advisory group would comprise representatives from data source providers, consumers, GPs, primary health care data experts, Commonwealth and state and territory health department representatives, and PHN representative/s. The committee would be kept informed of all data reporting and collection activities and assist with decision-making for data requests and ethics committee referrals as appropriate.

The technical data working group would be established to assist with the functions of data management and provision, data specifications, standards and cyclical data improvements.

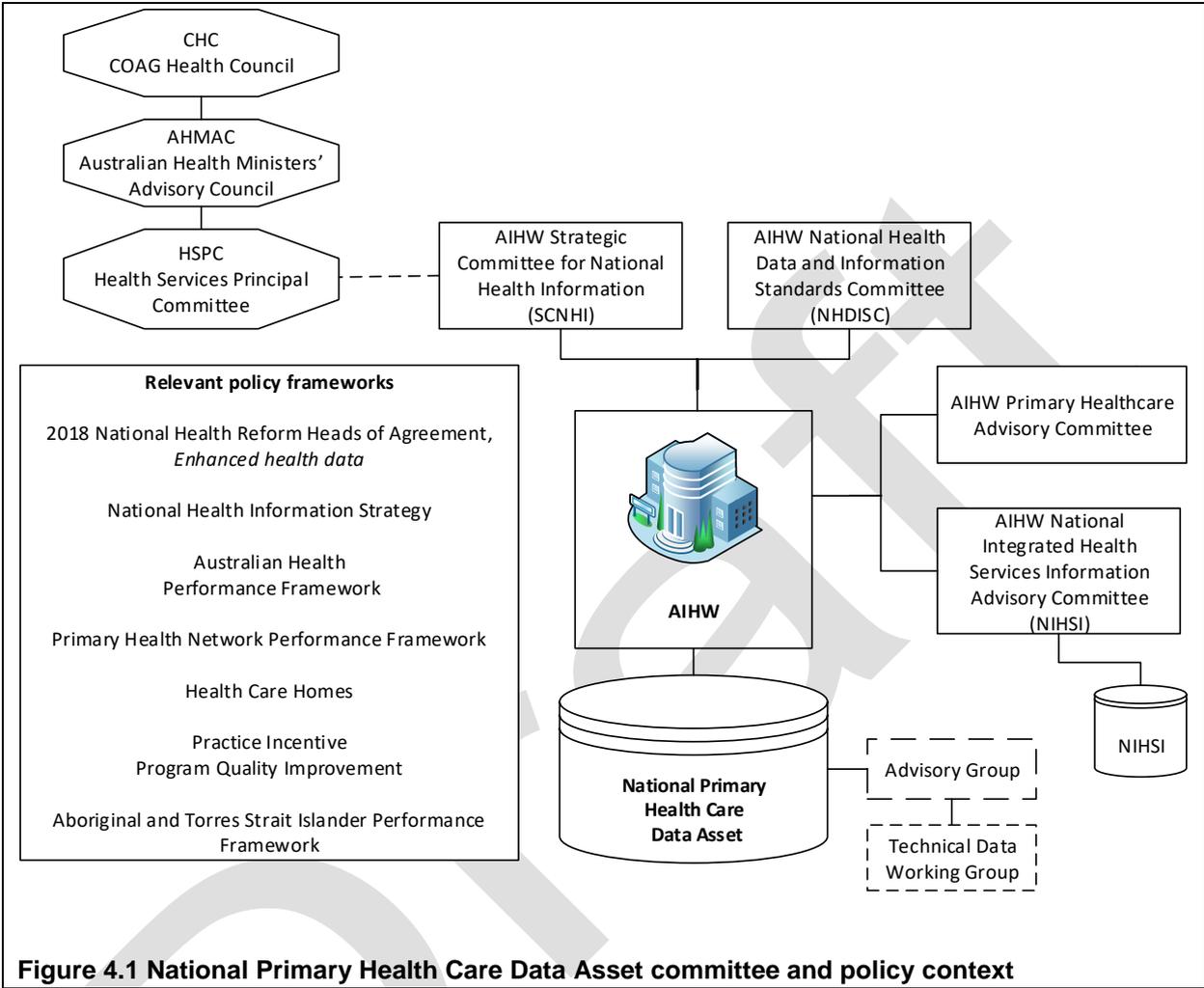
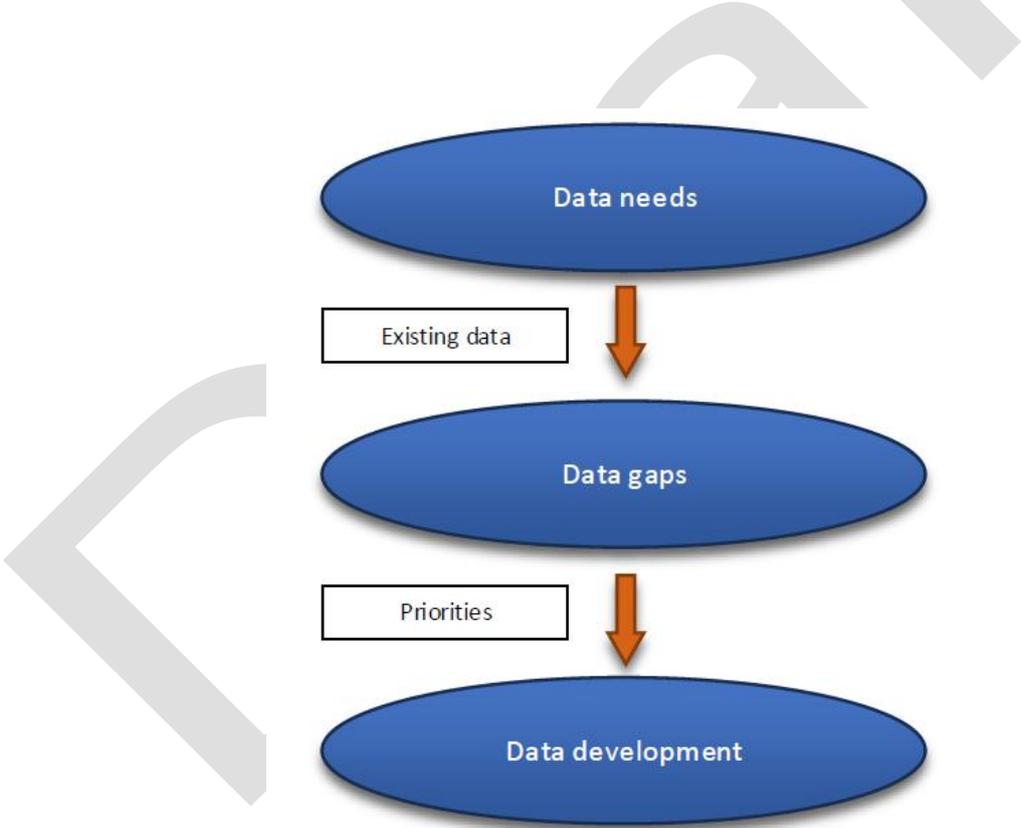


Figure 4.1 National Primary Health Care Data Asset committee and policy context

# 5 Data requirements

The Data Asset will house a wide range of data for varying purposes; a set of data elements will form its foundation and meet defined national data standards, with associated metadata and change management processes similar to a National Minimum Data Set (NMDS). In the short to medium term these data will mostly comprise aggregated general practice activity data however in the longer term it is envisaged that the Data Asset will consist of unit record level data and represent a wider scope of primary health care activity. All data elements will reflect agreed reporting priorities and be drawn from the Data Asset—prioritisation of data elements based on stakeholder engagement will be key.

Consultation from February 2019 and the AIHW’s work to date will inform selection of data elements; a focus will be on utilising existing specified data elements rather than the creation of new content. As an essential preliminary task for data development, identifying data needs and data gaps will be a focus in the lead up to, and during, consultation. Because of the anticipated high need for primary health care data, and data sources and data elements being at various stages of development, prioritisation of collection and reporting from the Data Asset will be essential.



## 5.1 Data element selection

While there is a range of potential data elements to capture general practice activity, 'core' data elements are proposed for possible inclusion in the Data Asset because they are considered necessary for many current and foreseeable reporting needs. The PHCAG recommended that data elements for primary health care reporting reflect indicators for population, care process, health outcomes and patient experiences and outcomes (PHCAG 2015).

Tables 5.1 and 5.2 outline these core data elements and whether each element is collected as raw data (i.e. entered directly into a field in an EHR by a GP or administrative staff) or derived. Potential uses for the data elements in primary health care reporting and whether nationally agreed data standards already exist in AIHW's Metadata Online Registry (METeOR) are also highlighted.

### Methodology for selecting core data elements

Proposed core data elements are based on 2 main criteria:

1. Core data elements must be useful and meaningful for reporting purposes: that is, they must be worthwhile for GPs to capture as a by-product of clinical/administrative practice; and
2. Core data elements must be useful for planning, system performance reporting and primary health care system monitoring.

Consideration was also given to data elements that have the potential to improve patient and provider experiences.

The proposed data elements and their use would need to be further tested and refined in consultation with a broader range of stakeholders (for example, as per the process of developing the Indigenous national key performance indicators (nKPIs)).

The core data elements have also been informed by international precedents, for example, the Pan-Canadian Primary Health Care Electronic Medical Record Content Standard, version 3.0. This Canadian work identifies a list of 'priority subset' data elements and associated 'clinician-friendly pick-lists' (CIHI 2014a; CIHI 2014b).

### Using core data elements for multiple purposes

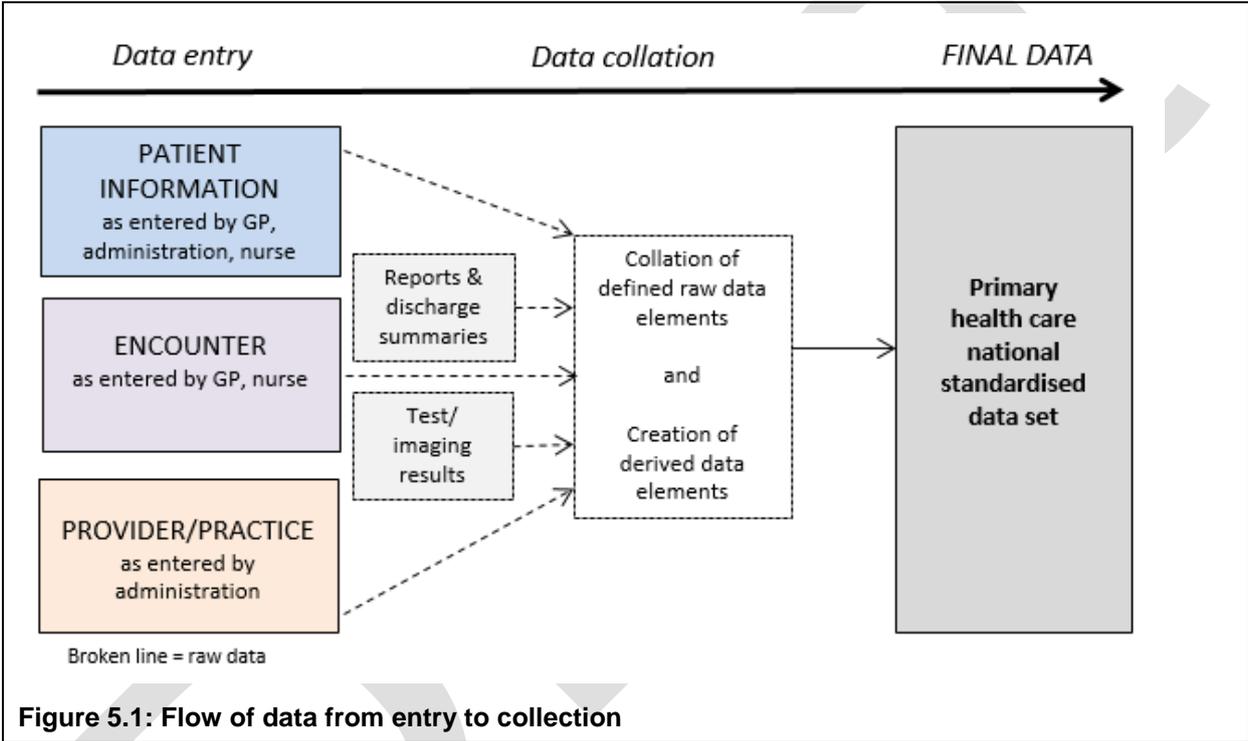
The core data that form the Data Asset's foundations can be used to derive further information by creating *derived data elements* through the use of formulas, compositions or aggregations. This may be a simple process, for example, a patient's weight and height being extracted to produce a body mass index (BMI)—or more complex, for example, specific algorithms using information from multiple fields in an EHR to flag a patient's chronic condition. The latter is a technique commonly used by parties currently collating and reporting on general practice data.

The list of data elements proposed for phases one and two are a combination of raw data entered directly into fields in an EHR (for example, sex) and derived data. Figure 5.1 helps to explain this process.

The usefulness of the Data Asset for exploring the appropriateness of preventing and managing chronic disease is highly contingent on capturing information about the population who have chronic conditions. This requires being able to use data to identify these populations. Many data elements essential to policy that require identification of specific

chronic conditions are derived and will need to be an area of particular focus during data development and implementation. The list of data elements proposed in this paper may seem relatively limited when considered alongside the multitude of proposed uses; however the collection of the proposed set allows for a much wider range of data elements to be derived and appear in the final set of collated data.

Some examples of important derived variables include flags for patients with chronic conditions, multi-morbidity, high blood pressure, high cholesterol, absolute CVD risk, diabetes mellitus, asthma, heart disease, end stage kidney disease, mental health conditions, cancer, COPD and liver disease. Other derived elements may be realised during consultation.



## 5.2 Data entry, extraction and development

The proposed data elements are a combination of information that would be directly entered into fields in an EHR by GPs or practice managers on specific occasions such as a first visit and information entered in an EHR at each encounter. Figure 5.1 explains this flow of data.

Further work is needed to refine data standards and data extraction processes for various core and derived variables. Missingness of fields (determined by data entry by GPs in the case of general practice activity data) would also need to be assessed. Comprehensive review of definitions, standards and the coding of free text fields forms a crucial component of the stakeholder consultation on the Plan.

An initial proof-of-concept will allow for feedback on data elements and processes to be incorporated.

### 5.3 A phased approach to implementation

Because data development and improvement is required, a phased approach to identifying and collected data elements is suggested, where additional important data elements can be added when the collection and collation of the core data items becomes fluent, and once indicators are confirmed. This staged approach to a standardised data collection was noted by the PHCAG is being 'key to its success' and reflects the recommendation of the Group that the set of data elements start small and be expanded over time with improvements in primary health care data (PHCAG 2015). The consultation process undertaken by the AIHW in 2019 will inform the selection and prioritisation of data elements.

Following the core data elements listed in Table 5.1, core data elements to be collected in a second phase (once collection of core data phase one has been established) are outlined in Table 5.2. Data elements will likely require substantial and concentrated efforts to develop and/or refine. Some may be tested in a proof-of-concept for the Data Asset. For some elements listed for phase two development, the data may exist in a source that may be used in the interim (for example, data collected by PHNs, NPS Medicine Insight data; Australian Immunisation Register data) but there may also be known data quality or interpretation issues.

Ongoing work will assist in determining the best methodology to extract and collate data that are already collected as part of EHRs.

**Table 5.1 Core data elements for consideration in a National Primary Health Care Data Asset (Phase 1)**

Potential core data element		Examples for use in primary health care-related reporting	Is there a current suitable data standard/specification?
<b>Data elements collected as raw data</b>			
<b>Patient information</b>	<b>Patient identifier</b>	Support analysis involving patient pathways or repeat activities	Yes, but each practice likely has their own patient identifiers (e.g. alphanumeric/numeric)
	<b>Date of birth</b>	Support analysis by age	Yes
	<b>Sex</b>	Support analysis by sex	Yes
	<b>Aboriginal and/or Torres Strait Islander status</b>	Support analysis by Aboriginal and/or Torres Strait Islander status	Yes
	<b>Concession/pension status</b>	Can be used to determine best options for services that may have special arrangements based on concession/pensioner status	Yes
	<b>Country of birth</b>	Supports analysis by culturally and linguistically diverse status	Yes
	<b>Language spoken at home</b>	Supports analysis by culturally and linguistically diverse status	Yes
	<b>Geographical identifier</b>	Support reporting by geography. Combination of postcode and state will likely be sufficient to derive PHN, SA3, locality and rurality.	Yes
	<b>Adverse reactions</b> (e.g. drug reactions, allergies)	Supports reporting on safety and quality indicators related to adverse reactions	No
	<b>Height</b>	Supports calculation of key performance and population health indicators	Yes
	<b>Weight</b>	Supports calculation of key performance and population health indicators	Yes
	<b>Tobacco smoking status</b>	Supports calculation of key performance and population health indicators	Yes
<b>Encounter</b>	<b>Date of encounter</b>	Assists tracking history of care provided to patient	Yes
	<b>MBS item/s claimed</b>	Supports calculation of several performance indicators (e.g. for specific care plans, fourth year developmental health check)	Yes
	<b>Reason/s for encounter</b>	Supports calculation of key performance indicators	No
	<b>Problem/s managed</b> (problem according to provider)	Supports calculation of key performance and population health indicators	No

Potential core data element		Examples for use in primary health care-related reporting	Is there a current suitable data standard/specification?
	<b>Diagnosis/diagnoses</b>	Supports calculation of key performance and population health indicators	Partial
	<b>Blood pressure (systolic and diastolic)</b>	Supports calculation of key performance and population health indicators	Yes
	<b>Type of referral</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>Referral requested date</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>PBS item number for prescriptions</b>	Supports calculation of key performance indicators	Yes
	<b>Reason for prescription</b>	Supports calculation of key performance indicators	No
	<b>Procedure/s performed</b>	Supports calculation of population health indicators	No
	<b>Diagnostic imaging test requested</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>Diagnostic imaging test requested date</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
<b>Practice/provider</b>	<b>Provider identifier</b>	Supports quality improvement and performance reporting	Yes
	<b>Practice geographical identifier</b>	Supports reporting of primary health care indicators by geography. Combination of state & postcode could be sufficient to map to SA3, PHN, locality & rurality (suppression may be necessary to protect identification in some instances).	Yes
	<b>Provider type/role</b>	Relevant for multidisciplinary care, could support Health Care Homes evaluation.	No
<b>Data elements derived from raw data (post-data entry)</b>			
<b>Patient information</b>	<b>Height and weight (BMI)</b>	Supports analysis by health risk factors	Yes
	<b>Alcohol consumption status</b>	Supports calculation of key performance and population health indicators	Yes
	<b>HbA1c recorded</b>	People with diabetes should have their HbA1c levels measured at least every 6 months. Capturing this information is an indicator of quality of care. Supports analysis by health risk factors and quality of care.	Yes
<b>Encounter</b>	<b>Diagnostic imaging results</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>Diagnostic imaging test performed date</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No

**Table 5.2 Core data elements for consideration in a National Primary Health Care Data Asset (Phase 2)**

Potential core data element		Examples for use in primary health care-related reporting	Is there a current suitable data standard/specification?
<b>Data elements collected as raw data</b>			
<b>Patient information</b>	<b>Birth weight for under 5 year olds</b>	Supports analysis by health risk factors	Yes
<b>Encounter</b>	<b>Encounter type</b> (e.g. face to face visit, phone call, video conference)	Supports calculation of key performance and population health indicators	No
	<b>Lab test requested</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>Drug strength</b>	Supports quality use of medicines and performance reporting	In BEACH/Medical Director fields
	<b>Drug dose</b>	Supports quality use of medicines and performance reporting	In BEACH form/Medical Director fields
	<b>Drug frequency</b>	Supports quality use of medicines and performance reporting	In BEACH form/Medical Director fields
	<b>Drug quantity</b>	Supports quality use of medicines and performance reporting	In BEACH form/Medical Director fields
	<b>Drug repeats</b>	Supports quality use of medicines and performance reporting	Yes
	<b>Drug – first date prescribed</b>	Supports quality use of medicines and performance reporting	In Medical Director fields – BEACH has boxes for 'new' or 'continuing'
	<b>Drug – last date prescribed</b>	Supports quality use of medicines and performance reporting	In Medical Director fields – BEACH has boxes for 'new' or 'continuing'
	<b>Drug over the counter?</b>	Supports quality use of medicines and performance reporting	In BEACH form/Medical Director fields
	<b>Drug - GP supplied</b>	Supports quality use of medicines and performance reporting	In BEACH form/Medical Director fields

Potential core data element		Examples for use in primary health care-related reporting	Is there a current suitable data standard/specification?
	<b>Date of vaccination</b>	Supports calculation of performance indicators and population health reporting on immunisation status and rates in the practice population. More complete information on childhood vaccinations may be contained in Australian Childhood Immunisation Register (ACIR).	Yes
	<b>Type of vaccination</b>	Supports calculation of performance indicators and population health reporting on immunisation status and rates in the practice population.	No - specifications exist for individual vaccinations
	<b>Vaccine sequence number</b>	Supports calculation of performance indicators and population health reporting on immunisation status and rates in the practice population.	No
<b>Practice/provider</b>	<b>Number of GPs</b>	Supports quality improvement and performance reporting	No
<b>Data elements derived from raw data (post-data entry)</b>			
<b>Encounter</b>	<b>Polypharmacy flag</b>	Supports reporting of patients who have been administered multiple prescriptions that may have complex and chronic conditions.	No
<b>Post-encounter</b>	<b>Lab test performed date</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
	<b>Lab test result value</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	Available for some specific tests e.g. FOBT
	<b>Lab test results unit</b>	Relevant for potential analysis of a patient's treatment journey and continuity of care	No
<b>Practice/provider</b>	<b>Practice identifier</b>	Supports feeding data back to providers for quality improvement and performance reporting	Yes
	<b>FTE staff and role</b>	Supports quality improvement and performance reporting	Yes

## 5.4 Reporting

There are a number of nationally reported indicators that may draw on data from the primary health care sector. Examples of these include the Australian Health Performance Framework; Aboriginal and Torres Strait Islander Health Performance Framework, Health Care Homes. In 2012, the Australian Commission on Safety and Quality in Health Care published a set of 35 practice-level indicators of safety and quality for primary health care (ACSQHC 2012).

### Potential indicators

Indicators can assist with simplifying complex information into a synthesised view of existing conditions and trends that can be used in decision-making (von Schirnding 2002). Indicators should be meaningful, simple and able to be understood by the general public. High quality performance indicators are those that are clearly linked to, and provide a signal of, progress towards desired objectives.

The Data Asset will be useful in providing contextual higher-level information to allow reporting on primary health care, whereas data elements that form a standardised national data collection will enable reporting of indicators. The data elements proposed in Table 5.1 of the Plan would allow for reporting of the indicators proposed in Table 5.3. Where possible, the proposed set of indicators would mirror existing national indicators that are already being reported. This will allow comparison of outcomes of services provided, for example, to the Aboriginal and Torres Strait Islander peoples in mainstream general practice to those who received their services through Indigenous specific health services.

This section suggests potential indicators for future development and implementation. An assessment of data requirement and their sources, and potentially data improvement activities would be required to enable accurate reporting for some indicators. For national reporting purposes, some of the principles to enable thorough investigation of the primary health care system include that data should be timely and actionable. In addition, the data should also be able to be:

- analysed at the individual patient level
- linked to each management action (such as a prescription, clinical procedure, pathology or imaging request) to a diagnosis or symptom pattern
- linked to allow tracking of presenting problems and management actions over time and to examine patient outcomes.

The type of indicators to reflect the activity of GPs can focus on ongoing monitoring, assessment of outcomes, and assessment against clinical guidelines, benchmarks and targets. A set of potential indicators for primary health care is proposed in Table 5.3. Two phases for reporting of the indicators are being recommended due to difficulty in data extraction from some GP systems.

Phase 1 indicators include many process type indicators. These indicators aim to measure the extent of the application of 'good' health care. They are usually defined by reference to best practice guidelines or standards for specific health interventions. Once good quality data has been received, this will allow for reporting of Phase 2 indicators. These indicators will focus on information routinely collected about the characteristics of the general practice population (e.g. their chronic disease and risk factor profile) and the extent to which GP treatment aligns with clinical or other best practice guidelines (e.g. RACGP) and priorities for

quality primary health care (e.g. ACSQHC). The rationale for, and feasibility of, these indicators is provided at Appendix A.

Interpretation of the indicators should be considered in the context of the characteristics of the population e.g. health status and sociodemographic factors.

For some indicators, GPs may be unable to have a direct influence in the near term (e.g. cancer screening participation), however these are still considered relevant because there can be actionable change in conjunction with PHNs and government. Data from these indicators could assist with understanding key challenges in their region and fulfil contractual requirements of PHNs to undertake a comprehensive population health needs assessment. It is also critical for governments and other stakeholders in understanding the context in which GPs operate and attempt to influence population health improvements.

Where indicators in Table 5.3 are noted to have data being reported back to practices by PHNs only, a mechanism for PHNs to report aggregate data to the Data Custodian (rather than the Data Custodian receiving lower level data) for performance reporting could be considered. This would enable high-level, national reporting. The opportunity for GPs to demonstrate improvements in specified indicators could assist with the provision of evidence of primary health care system improvements.

Four broad categories for 'reporting purpose' are included in Table 5.3 for each suggested indicator: context, benchmark, target and/or continuous quality improvement (CQI).

**Table 5.3: Potential indicators for general practice: suggested reporting level and purpose**

No.	Indicator	Reporting level	Reporting purpose
<b>Phase one indicators</b>			
1	Proportion of regular clients whose smoking status has been recorded	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> <li>CQI</li> </ul>
2	Proportion of regular clients whose weight and height have been recorded	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> <li>CQI</li> </ul>
3	Proportion of practices able to identify patients with chronic conditions	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>CQI</li> </ul>
4	Potentially preventable hospitalisations	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>Explore disaggregation at finer geographies</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>Target</li> <li>CQI</li> </ul>
5	Childhood immunisation coverage	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Benchmark</li> <li>Target</li> </ul>
6	Selected potentially avoidable GP-type presentations to EDs	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>Explore disaggregation at finer geographies</li> </ul>	<ul style="list-style-type: none"> <li>CQI</li> </ul>
7	Bowel cancer screening participation for target population	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>Explore disaggregation at finer geographies</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> </ul>
8	Breast cancer screening participation for target population	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>Explore disaggregation at finer geographies</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> </ul>
9	Cervical cancer screening participation for target population	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>Explore disaggregation at finer geographies</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> </ul>

10	Proportion of general practices whose GPs visit residential aged care facilities	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>CQI</li> </ul>
11	Proportion of regular clients with a mental health diagnosis who have had <ul style="list-style-type: none"> <li>a blood pressure check in the previous 12 months</li> <li>height and weight measured in the previous 12 months</li> </ul>	<ul style="list-style-type: none"> <li>National; disaggregated by state</li> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>CQI</li> </ul>
12	Proportion of practices that contribute shared health summaries to the My Health Record system for their patients	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Benchmark</li> <li>CQI</li> </ul>
13	Premature mortality	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> </ul>
14	Patient experience of GP care	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Benchmark</li> </ul>
15	Per person expenditure on MBS	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> </ul>
16	Per person expenditure on PBS	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> </ul>
17	Proportion of regular clients who had their first antenatal care visit within specified periods	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>Target</li> <li>CQI</li> </ul>
18	Proportion of regular clients with a chronic disease for whom a Team Care Arrangement (MBS item 723) was claimed	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> </ul>
19	Proportion of regular clients with a nationally notifiable communicable disease for whom a notification was made to the appropriate register	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>Target</li> <li>CQI</li> </ul>
<b>Phase two indicators</b>			
20	Proportion of regular clients with type 2 diabetes whose HbA1c measurement result was within a specified level	<ul style="list-style-type: none"> <li>National; disaggregated by state, PHN, SA3</li> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> </ul>
21	Proportion of regular adult clients whose alcohol consumption status has been recorded	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> <li>CQI</li> </ul>
22	Proportion of regular clients with a selected chronic disease who have had a kidney function test	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>CQI</li> </ul>
23	Proportion of regular clients with type 2 diabetes who have had a blood pressure measurement result recorded	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Target</li> <li>CQI</li> </ul>
24	Proportion of regular clients with coronary heart disease who received the following tests: <ul style="list-style-type: none"> <li>full fasting lipid profile</li> <li>blood pressure recording</li> <li>BMI assessment</li> </ul>	<ul style="list-style-type: none"> <li>PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>Context</li> <li>Benchmark</li> <li>CQI</li> </ul>

25	Proportion of regular clients who are taking mental health-related medication and have a recorded diagnosis for a mental health condition	<ul style="list-style-type: none"> <li>• National; disaggregated by state, PHN, SA3</li> <li>• PHNs report back to practices at practice level (where practices are able to identify their own practice only)</li> </ul>	<ul style="list-style-type: none"> <li>• Target</li> <li>• CQI</li> </ul>
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Note: CQI = continuous quality improvement

Further, the RACGP Standards for general practices (5th edition) specify indicators for patient health records (Standard C7.1—Content of patient health records).

## 5.5 De-identified versus identifiable data

Information collected in general practice and subsequently entered into an EHR contains information about patients that is identifying; that is it can be used alone or in combination with other information to identify a patient. Examples are data elements such as name and address. Information collected in general practice also contains information that can be used to identify a provider (for example, a provider ID or name), and the practice itself.

Information contained in the proposed Data Asset does not need to contain identifying information about patients and providers. Actions can be taken so that the identification of patients and providers does not leave the practice, and that only de-identified (*non-identifiable*) information about patients and providers is included in a national primary health care data set. This approach is applied in the vast majority of health-related NMDs that already exist and would likely be appropriate for routine use of this Data Asset. While ‘patient identifier’ and ‘date of birth’ are listed as core data elements they may be modified/restricted to de-identify patients.

A benefit of this arrangement is that identifying information can be collected and used within a practice for clinical decision making and to support provision of quality care, yet patient and provider confidentiality can be maintained (through de-identified data) when the data are used outside the practice to assist with activities such as system performance reporting, and health system policy, planning and population health monitoring.

However, there are significant benefits in establishing a system that would enable longitudinal analysis in relation to individual patients, or linkage with other datasets, to maximise the future uses of the proposed primary health care data set. Further work would be needed to progress the use of patient identifiers, or other options such as statistical linkage keys, to determine the acceptable approach in this case.

### Unique patient identifiers

Without a patient identifier to enable patients to be uniquely identified in a secure manner, we will not be able to realise the benefits of a complete longitudinal picture of a patient’s journey. The ability to see a comprehensive picture of patient care requires the establishment of unique patient identifiers; this should be considered once initial data collection and reporting has been established.

Some practices are able to re-identify data that have been analysed offsite. This can allow for improved patient care through targeted follow-up and also enables longitudinal analysis; however linkage to other key data sets such as MBS and PBS, mortality and hospitals would require that a Data Custodian/s oversee re-identification of patients in the data sets in a safe manner, under appropriate ethics approvals.

This could be facilitated by individual health care identifiers—a ‘unique number that has been assigned to individuals, and to health care providers and organisations that provide health services’ (Department of Health 2015). These identifiers have been developed for individuals

receiving health care services in Australia to ensure that the correct information is associated with the correct patient at the point of care, and to ensure that accurate patient information is conveyed in communication between health care providers (Department of Health 2015). The use of these identifiers may require further consideration (including of legislation) in the context of unit record primary health care data.

In the absence of approval for the extraction and provision of identifiable data, re-identification should occur at the originating practice to allow longitudinal records to be updated and again de-identified before being transferred for analysis and reporting.

## 5.6 Data gaps

Listed below are specific examples of gaps in primary health care data that, if filled, could provide crucial information for effective policy and planning. It is anticipated that the co-design consultation workshops being conducted by the AIHW in 2019 will identify further data gaps.

- palliative care services
- dental services
- allied health services
- ambulance activity
- state/territory community health activity
- Indigenous-specific health services.

### Patient-reported measures

Patient reported experience measures (PREMs) and patient reported outcome measures (PROMs) can identify what is important for the patient about their experiences and outcomes in the health system. It can also enable data that are more readily attributable to interventions. A recent literature review by the Australian Commission on Safety and Quality in Health Care reported growing international evidence that such measures:

- contribute to a more people-centred view of health system performance
- can lead to an improvement in the quality and safety of the services provided
- can help understand the relative effectiveness of different treatments and interventions
- enhance processes in the patient-clinician interaction.

These data are not widely available at the local level which limits comparability, although population surveys of patient experience have come a long way in recent years.

### Activities delivered in multiple settings

There are various examples of activities considered to be primary health care that may be delivered in settings that are not captured in any collated data source. Childhood immunisation can be delivered in multiple primary health care settings and a full picture of activity is available through capture of this information in the Australian Immunisation Register. However, this does not apply to other activities delivered in multiple settings, such as early childhood development checks, and influenza vaccinations which can be delivered outside primary health care (for example, in schools and workplaces). There is no complete data source for such activities.

## 6 Implementation

Early in the first year of implementation (2019–20), an Advisory Group will be formed to oversee the implementation of the Data Asset, to provide direction and to develop the long-term work plan noting that it will be phased; complex, and require knowledge of current and emerging developments in primary health care frameworks and policy. Figure 4.1 describes the Data Asset in relation to the AIHW, and its related committees, and more broadly the intergovernmental committees and the primary health care policy landscape.

In addition to an Advisory Group, a technical data working group will be required to assist with specialist technical knowledge of health information systems including software and data development, data governance, data collection management, provision and processing and stakeholder engagement. It is for this reason that a proof-of-concept, or pilot, is proposed in the Plan.

In the interim, it is appropriate to determine a methodology for the best use of general practice activity data that is already being collected as part of EHRs. Stakeholder consultation will inform which data will be included in the proof-of-concept of the Data Asset. Information about general practice activity that is currently being collected is subject to known data quality issues such as incomplete coverage and the use of differing clinical software packages for EHRs (meaning inconsistent metadata and standards).

### 6.1 Proof of concept

Initially, a proof-of-concept (or pilot) that reflects the goals and processes of the Data Asset will be established. Preliminary evaluation of the proof-of-concept will ensure that the usefulness and success of the Data Asset can be demonstrated, confirm data governance processes, confirm secure data infrastructure development and allow for cyclical improvement.

The proof-of-concept will be used for a first wave of summary reporting on primary health care by the AIHW. Data sources for inclusion in the proof-of-concept are being considered by the AIHW and may include data from PHNs and collectives of PHNs; jurisdictions; organisations that extract and collate data from GPs; and surveys of general practice.

Proof-of-concept or pilot testing allows for assessment of:

- the practicality and consistency of the interpretation of data elements and the comprehensiveness of the codes (range of possible answers);
- the quality of reported data;
- how easy or difficult it is to collect data;
- the transmission of data and data analysis;
- guidelines that will need to be implemented to ensure consistent interpretation and reporting; and
- anticipated costs of implementation.

Other aspects for consideration following implementation and review of the proof-of-concept include:

- providers, PHNs and jurisdictions satisfaction with the data being provided back to them;
- effectiveness of secure infrastructure for data access;

- data being utilised for a range of purposes including research;
- opportunities for enhancement are identified; and
- key stakeholders are actively engaged.

Medium and long-term outcomes can then be assessed, including:

- improved patient and provider experiences;
- sound evidence for the efficacy of the Data Asset, to justify expansion;
- improvement in national indicators reflecting population health and the primary health; care sector; and
- opportunities to integrate with other data sets.

The proof-of-concept will explore avenues for data flows between data sources and the AIHW where the AIHW is not a nominated Data Custodian. The focus here will be on the sources of general practice activity data. An important consideration will be processes for making data available to data providers for use beyond national reporting.

## 7 Summary

Having reliable, accurate and comprehensive data about health care services can improve the quality of care and lead to better health outcomes. Information on health needs, number of services delivered and costs assist with basic service delivery planning for primary health care. More detailed and high quality information can indicate whether primary health care services being delivered are equitable, of good quality, safe, appropriate, effective, evidence-based and whether they result in good outcomes for patients.

A strongly collaborative approach will be required in relation to moving forward with more comprehensive and representative general practice data. It will also be necessary for appropriate governance arrangements to be developed which should incorporate a coordinated approach for developing and managing data standards and associated data sets, and minimise data redundancy and unnecessary costs associated with developing data that already exists.

In working towards a proof-of-concept for the Data Asset, important issues to consider that, first and foremost, data collection should not interfere with the practitioner's clinical workflow and the collection burden should be minimised: testing phases to refine the process of data extraction and collation before implementing on a large scale will be key. Processes to feed data back to GPs should also be facilitated. The process should be efficient—collect once, use often.

More broadly, improving the standardisation with which data are captured and compiled would also support national and international developments about maximising the benefits to society of data collected as a by-product of public funding or subsidy, as outlined in the Productivity Commission's report on Data Availability and Use (Productivity Commission 2017). In that report, the health sector was singled out as being particularly poor at effectively sharing information for system improvement.

Indigenous-specific primary health care organisations have already made considerable progress in the standardised extraction of data about their activity. While this information is extracted in the form of aggregate information (for nKPI reporting) rather than de-identified unit record data the information in both settings would strongly align. More importantly, the rollout of the proposed Data Asset will seek to apply the experience from the Indigenous primary health care sector.

### 7.1 Building on existing work in primary health care

There is a level of existing investment in digital health (for example, promotion of improved data infrastructure), in some selected information areas (for example, investment in GP extraction tools and collation activities such as those by PHNs and by NPS MedicineWise) and for some population groups or service areas (e.g. Indigenous health, immunisation). Outcomes from these activities that could optimise the selection of data elements or indicators for general practice will be considered.

Structure and codification of data form the foundations of interoperability. Governance of interoperability, for example, mandating requirements for interface terminology across and within the clinical software offered to general practices by software vendors, will be informed by ongoing work.

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# Appendix A: Rationale and feasibility for proposed indicators

Detailed information about the current data source, frequency and timing of the release of data from these sources, and rationale and major limitations of potential candidate indicators is presented in Table A1.

**Table A1: Candidate indicators to be reported under national standardised reporting arrangements, and indicator attributes**

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
<b>Phase 1 indicators</b>					
1	Proportion of regular clients whose smoking status has been recorded <sup>(a)</sup>	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support.</i></p> <p>Smoking is among the top risk factors for chronic disease and a leading contributor to burden of disease and death in Australia.</p> <p>Reflects RACGP clinical indicator.</p>	<p><u>Limitations:</u> Requires ability to extract this information from clinical software data.</p> <p><u>Possible next steps:</u> Further exploration is needed regarding the capacity to detect differences over time with sufficient accuracy.</p>
2	Proportion of regular clients whose weight and height have been recorded	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support.</i></p> <p>While survey data report on the prevalence on overweight and obesity, there is no information on whether this important risk factor is being recorded in primary care. Overweight and obesity are amongst the top risk factors for chronic disease and a leading contributor to burden of disease and death in Australia.</p> <p>Prevention and management of overweight and obesity are recognised in clinical guidelines and general practice is identified as a first line of intervention.</p>	<p><u>Limitations:</u> Requires ability to extract this information from clinical software data.</p> <p><u>Possible next steps:</u> Further exploration is needed regarding the capacity to detect differences over time with sufficient accuracy. Consultation about suitable regularity for recording height and weight could further refine this indicator.</p>

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
3	Proportion of practices able to identify patients with selected chronic conditions	Survey/ GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support, policy support and exploratory research.</i></p> <p>This indicator would be the first step (of several) towards improved identification of the target group for intervention or coordinated and regularly reviewed management. For example, once a patient is identified as having COPD their record can be reviewed to establish whether recommended influenza vaccination and annual spirometry testing was provided. Once a patient is identified as having diabetes, their record can be reviewed to establish whether recommended HbA1c tests are performed.</p>	<p><u>Limitation:</u> No national reported data source—would require information to be collected from general practices.</p> <p><u>Possible next steps:</u> A first step could simply be gathering evidence that general practices have identified patients with chronic disease (and possibly comorbidity) in EHRs.</p> <p>While this would be an early step in obtaining more accurate information about patients with chronic complex health conditions and the appropriateness of their care, it would not produce an accurate prevalence estimate of the target population to use as a denominator in the near term.</p>
4	Potentially preventable hospitalisations <sup>(a)</sup>	AIHW National Hospital Morbidity Database (NHMD)/estimated resident population	Data reported annually, based on financial year. Data from the NHMD are released around 10 months after the end of the reference period.	<p><i>Maps to Commonwealth program support, policy support and exploratory research.</i></p> <p>Reported internationally and nationally, including at PHN level.</p> <p>Hospitalisations that are unnecessary may impose significant and otherwise avoidable costs on the health system and expose patients to unnecessary risks and a high rate may indicate poorer functioning of the non-hospital system (National Health Performance Authority 2013).</p> <p>This indicator can be presented as a total or separately by:</p> <ul style="list-style-type: none"> <li>• vaccine-preventable conditions (e.g. tetanus, measles, mumps, rubella);</li> <li>• acute conditions (e.g. ear, nose and throat infections)</li> <li>• chronic conditions (e.g. diabetes (principle diagnoses only), asthma, angina, hypertension, COPD)</li> </ul>	<p><u>Limitations:</u> The AIHW is currently working with the RACGP and others to refine this indicator to make it specific for general practice. There will likely be a need to report the indicator in its original form, as well as the modified indicator that is general practice specific.</p> <p><u>Possible next steps:</u> A possible solution is to further target the indicator to focus on major categories (vaccine-preventable/acute/chronic), specific age groups (e.g. children, 65+ or 70+), more specific disease groups (e.g. diabetes complications) or population groups (e.g. Indigenous). Therefore this objective could be multiple indicators, some under the heading of reduced potentially preventable hospitalisations and some under improved patient outcomes for chronic disease.</p>

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
5	Childhood immunisation coverage <sup>(a)</sup>	Australian Immunisation Register/ estimated resident population in age group	Data are collected continuously, and reportable quarterly with minimal lag between data collection and reporting. Data available as requested.	<p><i>Maps to Commonwealth program support and policy support.</i></p> <p>Reported internationally and nationally, including at PHN level. Reflects RACGP clinical indicator.</p> <p>Evidence of link between immunisation and improved health outcomes.</p> <p>Evidence of variation across regions.</p> <p>This indicator appears sensitive to change over time.</p>	<p><u>Limitations:</u> There are minor limitations in the coverage of the dataset, but has been estimated at above 90% (Hull et al. 2007). A standing agreement to supply data would likely need to be negotiated with the Australian Immunisation Register.</p> <p>This indicator does not include the adult population.</p> <p><u>Possible next steps:</u> Other considerations include a local indicator related to uptake/coverage of the human papillomavirus (HPV) vaccination and/or adult vaccination (recently added to the scope of the Australian Immunisation Register).</p>
6	Selected potentially avoidable GP-type presentations to EDs	National Non-Admitted Patient Emergency Department Care Database	Data collected annually, based on a financial year.	<p><i>Maps to Commonwealth program support and policy support.</i></p> <p>Previously reported internationally and nationally at the state/territory level.</p>	<p><u>Limitations:</u> The definition of what constitutes an 'appropriate' ED attendance varies across individuals, hospitals and local settings.</p> <p>The indicator has been widely criticised (including by the Australian College of Emergency Medicine in the MJA) as currently it is specified based on triage categories in the national ED dataset on several grounds including: triage category is not designed to reflect complexity of care (only urgency) and therefore appropriateness of management in primary care vs ED setting, some triage category 4-5 patients are known to be referred by GPs (suggests problem not appropriate for treatment in primary care), there is incomplete coverage of the dataset in remote areas and there is variation in service delivery models for primary care/emergency services/emergency department care that affect comparability across regions.</p> <p><u>Possible next steps:</u> Further data development to enhance the existing specification (e.g. to encompass new national data on problem managed in the ED and/or diagnosis at end of ED visit visits and/or by time of day/day of week of ED visit) with strong consultation with primary care clinicians/stakeholders is required for this indicator to be acceptable to the sector.</p> <p>A possible alternative could be ED visits for asthma which is currently a Canadian performance indicator; or ED visits by older people.</p>
7	Bowel cancer screening participation	National Bowel Cancer Screening Program Register	Data provided to AIHW for monitoring and reporting on a yearly basis.	<i>Maps to Commonwealth program support.</i>	<p><u>Limitations:</u> Data on people screened outside the program are not routinely collected; therefore, the level of underestimation of overall bowel cancer screening in Australia is unknown.</p> <p><u>Possible next steps:</u> The next step would be to confirm access to data for this purpose.</p>

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
				<p>In Australia, the incidence of bowel cancer has been increasing slightly each year since 1982. A bowel cancer screening program can highlight individuals with signs of a potential bowel abnormality and reduce bowel cancer morbidity and mortality.</p> <p>Participation in bowel cancer screening is recognised in clinical guidelines and an indicator in a range of agreements/frameworks.</p> <p>The indicator is amenable to GP influence.</p> <p>Already reported by various regions.</p>	
8	Breast cancer screening participation	BreastScreen Australia Data are collected at the jurisdictional level, with de-identified aggregate and unit record level data provided to AIHW for reporting.	Data provided to AIHW for monitoring and reporting on a yearly basis. The program is for screening every two years therefore the monitoring covers a two year period.	<p><i>Maps to Commonwealth program support.</i></p> <p>Breast cancer is the most common cancer affecting Australian women (excluding basal and squamous cell carcinoma of the skin).</p> <p>Organised breast cancer screening aims to detect cases of unsuspected breast cancer in women, thus enabling intervention when the cancer is at an early stage. Finding breast cancer early often means that the cancer is small, which is associated with increased treatment options and improved survival.</p> <p>Participation in the BreastScreen program is recognised in clinical guidelines and is currently an indicator in a range of agreements/frameworks.</p>	<p><u>Possible next steps:</u> The next step would be to refine the existing specification for PHN purposes and confirm access to data for this purpose.</p>

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
9	Cervical cancer screening participation <sup>(a)</sup>	National Cervical Screening Program (data collected at jurisdiction level and provided to AIHW).	Data provided to AIHW for monitoring and reporting on a yearly basis.  The program is for screening every two years therefore the monitoring covers a two year period.	<i>Maps to Commonwealth program support.</i>  Cervical cancer is the 12th most common cancer affecting Australian women (excluding basal and squamous cell carcinoma of the skin).  The relatively low incidence and mortality of cervical cancer in Australia compared with other countries has been largely attributed to Australia's cervical screening program.  Participation in pap test screening is recognised in clinical guidelines.	
10	GP service utilisation by residents of Residential Aged Care Facilities	MBS data	Financial year data available on request to relevant agency.	<i>Maps to Commonwealth program support and policy support.</i>  Reported under the PAF by the NHPA for 2011–12.  Relates to the PIP GP Aged Care Access Incentive (ACAI), which aims to encourage GPs to provide increased and continuing services in RACFs. PIP incentives are claimable once the GP reaches 60 or 140 consultations (this PIP incentive ends in its current form on 30 April 2018).	<u>Limitations:</u> The originally proposed PAF indicator, based on MBS item numbers, suffers from many of the issues relating to MBS item numbers generally (i.e. incomplete capture of desired activity as same service may be delivered but not charged using this item number, not necessarily an indicator of quality care, may drive increase in uptake of a specific MBS item without evidence of improved quality of care).  <u>Potential alternative indicator:</u>  Other considerations could be an indicator on number of MBS items per RAC resident (using data linkage) or previously identified indicators under Divisions of General Practice reporting relating to the number and proportion of general practices whose GPs visit residential aged care facilities using reminder systems to facilitate review and appropriate action, or the proportion of practices involved in at least one program or activity to improve GP care of the aged.  <u>Possible next steps:</u> Any indicator not based on MBS data would need to be derived from a survey of GPs (potentially based on the PHCRIS Annual Survey of General Practice Divisions approach).
11	Proportion of regular clients with a mental health diagnosis who have had  i. a blood pressure check in the previous 12 months	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<i>Maps to Commonwealth policy support.</i>  The physical health of people suffering from mental health disorders is a priority area of the Fifth National Mental Health and Suicide Prevention Plan.	<u>Limitations:</u> Requires ability to extract this information from clinical software data.  <u>Possible next steps:</u> Developmental work to establish how to identify the cohort of regular clients with a mental health diagnosis would be the logical first step. These kinds of activities are being undertaken both domestically and internationally (notably, in Canada).

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
	ii. height and weight measured in the previous 12 months			People living with poorer mental health have poorer physical health than other Australians because their physical health needs are often overshadowed by their mental health needs. Screening and early detection is noted as a means of system improvement (Department of Health 2017).	A second phase could be assessing the physical health of those with severe mental health disorders. Those taking medication may be more prone to issues such as weight gain and metabolic syndrome.
12	Proportion of practices that contribute shared health summaries to the My Health Record system for their patients	GP clinical software data		<p><i>Maps to Commonwealth program support and policy support.</i></p> <p>Information sharing about a patient's care has the potential to enhance the efficiency, effectiveness and quality of care. There is also the possibility for secondary analysis using digital health data: outcome measurement, quality improvement, public health surveillance, research.</p> <p>There is evidence that electronic referrals and discharge summaries improve the quality and timeliness of clinical communication.</p> <p>The current PIP eHealth Incentive aims to encourage general practices to keep up to date with the latest developments in digital health and adopt new digital health technology as it becomes available.</p>	<p><u>Limitation:</u> Data source not clear i.e. Would this be obtained from a routine extract or as a separate count of practices.</p> <p><u>Possible next steps:</u> Investigate further with Australian Digital Health Agency.</p>
13	Premature mortality	Australian Bureau of Statistics deaths data or AIHW National Mortality Database	Annual data collection	<p><i>Maps to Commonwealth program support and exploratory research.</i></p> <p>Summary mortality statistics are usually influenced by diseases among the elderly and are less reflective of the patterns of deaths in younger age groups. Premature mortality describes deaths in people aged under 75.</p> <p>Examining the causes of premature death assists in explaining differences and changes in health status and guide health system planning.</p>	<u>Limitations:</u> Reporting at small geographies may have limitations due to population counts and/or number of death.

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
14	<p>Patient experience of GP care e.g. number of persons who saw a GP (for their own health) in the last 12 months who waited longer than they felt acceptable to get an appointment.</p> <p>Number of persons who needed to see a GP but delayed or did not go because of the cost.</p>	ABS Patient Experience Survey	<p>Data are reported annually, based on financial year. Indigenous data, however, are available every 6 years.</p> <p>Data turned around relatively quickly (November release for the previous financial year's data).</p>	<p><i>Maps to Commonwealth program support and exploratory research.</i></p> <p>Patient experience indicators are reported internationally and nationally, including at PHN level (using the ABS Patient Experience Survey).</p> <p>Relevant due to policy focus on patient-centred care.</p> <p>Responsiveness is a core dimension of relevance to patient experience or perceptions of care and therefore patient-centred care.</p>	<p>There are a large number of possible patient experience components that could be the focus of reporting using the ABS Patient Experience Survey.</p> <p><u>Limitations:</u> This type of information already available and presented may not support detection of change over time with sufficient accuracy without further investment (for example, increasing sample size); further investigation is warranted.</p> <p><u>Possible next steps:</u> Consideration of the use of technology to follow-up patient experiences of care (e.g. through automated short surveys through mobile phones).</p>
15	Per person expenditure on MBS	MBS data	Financial year data available on request.	<p><i>Maps to Commonwealth program support.</i></p> <p>To assist with monitoring health system efficiency.</p>	<u>Limitations:</u> This indicator would be most insightful as a local level indicator that allowed for comparisons.
16	Per person expenditure on PBS	PBS data	Financial year data available on request.	<p><i>Maps to Commonwealth program support.</i></p> <p>To assist with monitoring health system efficiency.</p>	<u>Limitations:</u> This indicator would be most insightful as a local level indicator that allowed for comparisons.
17	First antenatal care visit within specified periods (for pregnant women) <sup>(a)</sup>	National Perinatal Data Collection	Annual data with a two year lag between collection and reporting.	<p><i>Maps to Commonwealth program support.</i></p> <p>A newborn baby's health can be a key determinant of their health and wellbeing throughout life. Factors such as a baby's gestational age and birthweight can influence their chance of survival and health outcomes. A mother's attributes, such as her age, whether she smokes or drinks during pregnancy, and where she lives, can also affect obstetric and perinatal outcomes.</p>	<p><u>Limitations:</u> There are possible issues with interpretation as 95% of women had 5 visits or more; 0.1% had no visits in 2012.</p> <p>Data set overall is subject to lags that could potentially be improved through investment in state/territory collection.</p>

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
18	Proportion of regular clients with a chronic disease for whom a Team Care Arrangement (MBS item 723) was claimed <sup>(a)</sup>	MBS and GP clinical software data	MBS data: financial year data available on request.	<i>Maps to Commonwealth program support and policy support.</i> Patients with complex and chronic conditions can benefit from structured care from a multidisciplinary team.	<u>Limitations:</u> calculation of the denominator for this indicator relies on an accurate measure of the number of regular patients with a specified chronic condition/s.
19	Proportion of regular clients with a nationally notifiable communicable disease for whom a notification was made to the appropriate register	GP clinical software data, or state and territory, or NNDSS National Notifiable List of Diseases	Following necessary data development, available through data extraction as required (suggest annually).	<i>Maps to Commonwealth program support, policy support and exploratory research.</i> See National Framework for Communicable Disease Control, <a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-nat-frame-communicable-disease-control.htm">http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-nat-frame-communicable-disease-control.htm</a>  Also Discussion Paper: Towards a Communicable Disease Control Framework <a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/E5134F29919E9D74CA257CFB0082C7C5/\$File/w-Discussion-paper.docx">http://www.health.gov.au/internet/main/publishing.nsf/Content/E5134F29919E9D74CA257CFB0082C7C5/\$File/w-Discussion-paper.docx</a>	<u>Possible next steps:</u> consulting with the relevant federal and state and territory government areas.
<b>Phase two indicators</b>					
20	Proportion of regular clients with type 2 diabetes whose HbA1c measurement result was within a specified level <sup>(a)</sup>	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<i>Maps to Commonwealth program support, policy support and exploratory research.</i> The HbA1c test shows an average of blood glucose levels over the past 6–8 weeks and should be arranged by a GP every 3–6 months. Microvascular complications (e.g. retinopathy, nephropathy and neuropathy) increase with HbA1c level (Phillips 2012).	<u>Limitations:</u> calculation of the denominator for this indicator relies on an accurate measure of the number of regular patients with type 2 diabetes.
21	Proportion of regular adult clients whose alcohol consumption status has been recorded <sup>(a)</sup>	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<i>Maps to Commonwealth program support and exploratory research.</i> Risky levels of alcohol consumption are a risk factor for a number of chronic conditions including various cancers, and liver disease. Reflects RACGP clinical indicator.	<u>Next steps:</u> explore current ways of recording alcohol consumption across different clinical software systems.

No.	Candidate indicator	Data source(s)	Data frequency and timing	Rationale	Main limitations and possible next steps
22	Proportion of regular clients with a selected chronic disease who have had a kidney function test <sup>(a)</sup>	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support and exploratory research.</i></p> <p>Kidney disease is often referred to as a 'silent disease' as 90% of kidney function may be lost before symptoms appear. Chronic kidney disease and its risk factors (including smoking, high blood pressure, overweight and obesity and impaired glucose regulation) are largely preventable.</p> <p>Reflects RACGP clinical indicator.</p>	<u>Limitations:</u> calculation of the denominator for this indicator relies on an accurate measure of the number of regular patients with selected chronic diseases.
23	Proportion of regular clients with type 2 diabetes who have had a blood pressure measurement result recorded <sup>(a)</sup>	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support and exploratory research.</i></p> <p>High blood pressure is an important and treatable cause of disease and death. It is more common among people with diabetes. High blood pressure is a major risk factor for chronic conditions such as stroke, coronary heart disease and chronic kidney disease.</p>	<u>Limitations:</u> calculation of the denominator for this indicator relies on an accurate measure of the number of regular patients with type 2 diabetes.
24	Proportion of regular clients with coronary heart disease who received the following tests: - full fasting lipid profile - blood pressure measurement - BMI assessment	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to Commonwealth program support and exploratory research.</i></p> <p>Reflects RACGP clinical indicator.</p>	<u>Limitations:</u> calculation of the denominator for this indicator relies on an accurate measure of the number of regular patients with coronary heart disease.
25	Proportion of regular clients who are taking mental health-related medication and have a recorded diagnosis for a mental health condition	GP clinical software data	Following necessary data development, available through data extraction as required (suggest annually).	<p><i>Maps to program support and policy support.</i></p> <p>Allows for the assessment of best practice.</p>	<u>Potential alternative indicator:</u> Once clinical software data have been developed and have proven quality, other indicators such as 'proportion of regular clients who are taking a defined list of medications related to severe mental health disorders who have a diagnosed severe mental health disorder'. Polypharmacy and off-label use of medications could also be explored. It is acknowledged that in some cases, off-label use of medications may be appropriate.

(a) Indicator aligns with an Indigenous national key performance indicator