



Submission to the

Australian Institute of Health and Welfare

**National Primary Health Care Data Asset
Data Development Plan**

28 June 2019

Introduction

The Australian Healthcare and Hospitals Association (AHHA) welcomes the opportunity to provide this submission to the Australian Institute of Health and Welfare (AIHW) on the *National Primary Health Care Data Asset Data Development Plan*.

AHHA is Australia's national peak body for public hospitals and healthcare providers. Our membership includes state health departments, Local Hospital Networks (LHNs) and public hospitals, community health services, Primary Health Networks (PHNs) and primary healthcare providers, aged care providers, universities, individual health professionals and academics. As such, we are uniquely placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

AHHA has developed a plan to transition the Australian healthcare system to a patient centred, outcomes focused and value-based healthcare system. *Health people, healthy systems*¹ identifies four domains of reform that are critical to achieving this goal. These include reforms to governance structures, the health workforce, funding arrangements, and performance information and reporting that is fit for purpose. This latter domain requires reform around data standards, information and communications technology infrastructure, and analytics and reporting capability.

Consolidated primary healthcare data in Australia is poor. However, individual providers of primary healthcare often hold significant information on the services provided to patients, the conditions for which they are being treated and the progression of patient's recovery or further deterioration of their condition. Consolidating this data could be facilitated ideally through the development of a primary healthcare national minimum dataset that provides common data standards and reporting frameworks.

Expenditure on primary healthcare is over a third of all health expenditure and there is wide acceptance of the importance of primary healthcare within the larger health, aged and disability care systems. This includes better earlier care in the community to avoid more costly hospital care and transport services, in addition to improving individuals' quality of life.

The development of a National Primary Health Care Data Asset (NPHCDA) provides the opportunity to move our health system in a direction that can better inform our understanding of population health, patient journeys through the healthcare system and to focus on the outcomes that patients value most. These outcomes should be viewed comprehensively to include clinical, service, and patient reported outcomes and experience measures.

AHHA supports the development of a comprehensive NPHCDA, and in the medium to longer term, a national minimum dataset for primary healthcare. However, we also recognise that the environment in which primary healthcare is delivered requires an initially pragmatic approach to the scope of primary healthcare services from which data can be collected.

On this basis, AHHA supports the initial collection of primary healthcare data only from general practices. However, AHHA also believes that the NPHCDA should have an explicit medium-term goal of expanded coverage of the primary healthcare sector to include specialists, pharmacy, allied

¹ Australian Healthcare and Hospitals Association. 2017. Healthy people, healthy systems. Available at https://ahha.asn.au/sites/default/files/docs/policy-issue/ahha_blueprint_2017_0.pdf.

health, dental, palliative care, community nursing, mental health, alcohol and other drugs, maternal and child health.

As the scope of primary healthcare services reported is broadened, the value of the NPHCDA as identified in the Exposure Draft for Consultation, will be enhanced. AIHW has the opportunity to articulate a plan to progressively move towards a more comprehensive dataset on primary healthcare through the collection of all data on care provided to patients outside of the hospital. Together with a more expansive understanding of individual's experience of healthcare through the collection of patient reported outcomes and experience measures, deeper insights will be available to inform how the healthcare system needs to be adapted to meet patient's needs and expectations.

National Minimum Dataset and Data Dictionary for Primary Healthcare

The NPHCDA should be developed with a data dictionary that has metadata aligned with acute care national minimum datasets to support data linkage and development of outcomes data reporting. As noted in METeOR, the repository for national metadata standards for health and maintained by AIHW, "It is well accepted in the world of statistics and large databases that metadata leads to better data. This is because they enable all people collecting, using and exchanging data to share the same understanding of its meaning and representation".²

While this may not be immediately achievable, it should be an explicit goal that is progressively worked towards. This could be facilitated by engaging with major industry suppliers of practice software and through mutually beneficial arrangements with general practice and other primary care providers. This could include, for example, providing appropriately anonymised benchmark information back to individual practices as an incentive to providing standardised data on a regular basis.

Standards for General Practice Electronic Health Records

As a medium-term objective, standards for general practices electronic health records should be developed and implemented. Elements to be addressed include:

- A defined electronic health record data model that links related data elements;
- Consistent data element labels and definitions;
- Use of standardised clinical terminologies and classifications; and
- Accreditation of general practices in terms of electronic health record capability and processes.

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A National Approach to Patient Centered Outcomes and Value-Based Health Care

A strategy should be developed for a standardised national approach to measuring value-based patient-centred outcomes, with this to be reported at different levels of the healthcare sector and

² AIHW. METeOR - About metadata. Available <https://meteor.aihw.gov.au/content/index.phtml/itemId/268284>. Accessed 24 May 2019.

to different audiences. This includes setting clear objectives, defining target audiences, developing transparent principles and methodology through broad consultation, and timely monitoring and reporting, and evaluation of unintended consequences.

While value-based healthcare can be operationalised in different ways, AHHA suggests a useful way to consider this concept is that it is the health outcomes that matter to patients relative to the resources or costs required. This conceptualisation was first proposed by Porter and Teisberg (2006) and has since been adopted by other organisations including the World Economic Forum (2017).^{3,4} Characteristics of value-based health care and the preparedness of Australia for its introduction was recently explored by Woolcock (2019).⁵

Nationally Consistent Collection of PROMs and PREMs

A whole-of-system framework should be developed for a nationally-consistent and coordinated approach to the collection and use of patient reported outcomes measures (PROMs) and patient reported experience measures (PREMs) across the health system, with standardised national definitions and descriptors. The collection of these details would broaden the assessment of patient care and facilitate a move towards value-based health care. Australia's Health (AIHW 2018) discuss the benefits and applications of PROMs and PREMs in Australia.⁶

The Delivery of Care in Primary Health

In addition to the collection of patient demographics, service related data, clinically related data, PROMs and PREMs, the NPHCDA should also investigate the collection of data on how primary healthcare is delivered by general practices. This could include such areas as how the general practice workforce is used in the delivery of care for particular services and the associated patient outcomes. Such information could inform workforce planning at the regional level and help identify innovative models of care.

Longitudinal Data

The collection of longitudinal data on patient healthcare would facilitate a deeper understanding of the progress or deterioration of an individual's healthcare and their pathways of care. This could usefully inform our understanding of public health issues, how service delivery could be alternatively provided to maximise patient outcomes and minimise system costs, and to facilitate a move towards value-based health care.

As discussed in the consultation paper, a patient identifier and unit record reporting of instances of primary healthcare would be required. The unique identification of patients should be achieved by AIHW requiring Individual Healthcare Identifiers to be reported along with data on each

³ Porter, M and Teisberg, E. 2006, Redefining health care: Creating value-based competition on results. Boston, Mass: Harvard Business School Press.

⁴ World Economic Forum. 2017, Value in healthcare: Laying the foundation for health system transformation. Available at http://www3.weforum.org/docs/WEF_Insight_Report_Value_Healthcare_Laying_Foundation.pdf.

⁵ Woolcock, K. 2019. Value Based Health Care: Setting the scene for Australia. Deeble Institute for Health Policy Research Issues Brief No 13. Available at <https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-31-value-based-health-care-setting>.

⁶ Australian Institute of Health and Welfare (AIHW). 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.

instance of primary healthcare.⁷ This has the advantage of being an existing identifier embedded in the record of all healthcare services and the established legislative controls over the use and disclosure of Individual Healthcare Identifiers. Such an approach should be progressed in a manner that is sensitive to any concerns held by the public or healthcare providers. The Independent Hospital Pricing Authority (IHPA) has recently identified the importance of developing a unique patient identifier and the growing interest and activity around value-based health care in their proposed 2020–21 framework for the pricing of public hospital services.⁸

AHHA believes that AIHW should make the reporting of Individual Healthcare Identifiers and unit record data of individual instances of primary healthcare an explicit medium-term objective of both the NPHCDA and a national minimum dataset in primary healthcare. Because of the sensitivities involved, this should proceed in an open and consultative manner that clearly articulates the benefits of using Individual Healthcare Identifiers and assembling longitudinal data, and the safeguards that will be in place to ensure patient privacy and confidentiality. In this latter respect, AIHW should consult with key stakeholders and the Australian Digital Health Agency on the recent experience with the My Health Record opt-out process to maximise public and primary healthcare providers' support for collecting this data.

Timeliness of Reporting

For the NPHCDA to have the greatest utility, it is important for data to be reported frequently and in a timely manner. In the Exposure Draft for Consultation, a number of uses and objectives for the NPHCDA are outlined, some of which would only be practically informed by data that is not out of date.

In developing the NPHCDA and establishing data sharing protocols with primary healthcare providers, this objective of regular and timely reporting of data should guide the processes that are put in place. It may also be useful to have varying timeframes around the frequency and timeliness of different classes of data. For example, data captured directly as part of a patient consultation is able to be collected and reported more frequently, whereas data collected after the consultation such as post-treatment PROMs, may occur at less frequent intervals.

Collation of General Practice Activity Data

AHHA believes that it is appropriate that the collection of general practice activity data, and primary healthcare data more generally, be facilitated through Primary Health Networks (PHNs).

PHNs have existing relationships with most general practices within their area and in many instances have existing data sharing arrangements in place. By leveraging off these current relationships, this would minimise the disruption and cost to general practice and deepen the mutually beneficial relationship the already exists between PHNs and general practices. This would also enable PHNs to be better informed about the local population health and healthcare service

⁷ The use of Individual Healthcare Identifiers may fall within the bounds of *Healthcare Identifiers Act 2010* s14(1) Item 5(b). If this is not the case, then AIHW should pursue appropriate legislative amendments.

⁸ Independent Hospital Pricing Authority (IHPA). 2019. Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2020–21 — June 2019. Available at <https://www.ihoa.gov.au/publications/consultation-paper-pricing-framework-australian-public-hospital-services-2020-21>.

delivery issues in pursuit of their Australian Government mandated responsibilities for increasing the efficiency and effectiveness of medical services for patients.

Collecting primary healthcare data via PHNs would also make the collation of the national data asset more tractable for AIHW as there would only be 31 PHN points of contact rather than having to work with thousands of general practices. As the NPHCDA is expanded beyond general practice, PHNs would be similarly ideally placed to facilitate the collection of primary healthcare data from other providers in their area for collation in the NPHCDA.

AHHA believes that collecting or filtering primary healthcare data at the jurisdictional level would be an unacceptable impediment to the collation of the NPHCDA. Data sharing arrangements do not exist between state and territory governments and general practices or other primary healthcare providers. It is also expected that if state and territory governments were responsible for coordinating a primary healthcare data collection they would be significantly less nimble and proactive in responding to issues at the local provider level.

Primary Healthcare Data and the National Key Performance Indicators Data Collection

In collating the NPHCDA, AIHW should include data separately reported to the Indigenous primary healthcare national Key Performance Indicators (nKPIs) data collection. The primary healthcare organisations reporting to this data collection include Aboriginal Community Controlled Health Services, state and territory-managed organisations, Primary Health Networks and other non-government organisations.⁹

Patient Privacy

While AHHA supports the development of the NPHCDA, and a national minimum dataset for primary healthcare in the medium to long term, it is also vital that patient privacy and confidentiality be retained. General practices and other primary healthcare providers must also have confidence in the integrity of the NPHCDA to which they will be contributing. As noted in the Exposure Draft for Consultation, trust in the integrity of the way patient data is collected and reported is vital for the social licence and community support for data sharing activities. AIHW should judiciously engage with consumers on the benefits of the NPHCDA and the safeguards that will be in place to ensure their privacy.

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⁹ Australian Institute of Health and Welfare 2018. National Key Performance Indicators for Aboriginal and Torres Strait Islander primary health care: results for 2017. National key performance indicators for Aboriginal and Torres Strait Islander primary health care series no. 5. Cat. no. IHW 200. Canberra: AIHW.