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Call for the establishment of a primary health care national minimum data set

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Key messages

- To date, no comprehensive, ongoing data set exists in relation to how and why people use and access primary health care services, what occurs in individual consultations and the health outcomes that occur as a result of these services. This is despite significant Commonwealth and individual investment in primary health care services.

- The Australian Government should support the National Primary Health Care Data Unit at the Australian Institute of Health and Welfare to lead the development of a Primary Health Care National Minimum Data Set that will allow Primary Health Networks to:
    - better support population health planning;
    - assist in identifying service gaps;
    - support policy development;
    - monitor system performance; and
    - provide insight into the patient journey across the health system.

- To be both effective and useful to Primary Health Networks, a primary health care national minimum data set needs to include standardised data on:
    - provider demographics to facilitate workforce planning;
    - patient demographics to support identification and monitoring of health issues of concern for specific groups and understand inflows and outflows of patients between Primary Health Network regions and local services;
    - patient health status and health-related behaviours to assist with local planning and targeting of health needs, monitor risk behaviours in local regions and identify areas for quality improvement based on agreed models of care for the management of specific health conditions;
    - patient encounters to understand why people are engaging with or using primary health care services and to monitor utilisation trends across healthcare services within a region; and
    - health outcomes to assist in evaluating the effectiveness and efficiency of primary health care service delivery.

Executive summary

There have been numerous calls to establish a national minimum data set for primary health care in Australia. Despite significant investment in the provision of primary health care services in Australia, little is known about what services are being delivered to whom, with what outcomes.

Australia has a robust arrangement for the development of national minimum data set in the health sector. Data collected through existing national minimum data sets are used variously for reporting, planning, policy development and program management.

Several existing sources of data relating to general practice and other primary health care services use and experience exist, however each collection has limitations. Without data on how and why people use and access primary health care services, and what occurs in individual consultations, it is difficult to detect variations and incentivise improvements in care provision.

Primary Health Networks were established to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and improve coordination of care to ensure patients receive the right care in the right place at the right time. Currently much of the data they rely on for planning and commissioning of services come from proxy measures and data sources outside of primary health care. Already, many general practices are providing de-identified data and working closely with Primary Health Networks to improve the quality of their data. Ongoing collection of data from general practice using standardised definitions and coding would potentially create enormous benefits for service planning and delivery, through greater accessibility and comparability of data relating to general practice management of health conditions and outcomes for patients.

Throughout the world, there are few examples where data is routinely and consistently collected about what happens in general practice consultations. Australia has recently established a Primary Health Care Data Unit at the Australian Institute of Health and Welfare to lead the development of a National Primary Health Care Data Asset.

This brief highlights the importance of capitalising on this initiative to develop a national minimum data set for primary health care. In so doing, it notes some key considerations such as the need for clarity about why the data are to be collected; practicalities associated with the collection of data; the need for workforce development, support, and/or training; the need to address consumer issues; assure privacy and security of data; and the need for alignment with other data sets through the application of the national framework for the governance of national data collections.

1 Background

This Issues Brief provides an argument in favour of the development of a Primary Health Care National Minimum Data Set. The paper has a focus on the potential benefits such a collection could offer for Primary Health Networks (PHNs) in fulfilling their roles of:

- contributing to reducing potentially preventable hospitalisations;
- attaining the highest standards in safety and quality;
- making meaningful use of eHealth systems; and
- analysing health needs in their regions.

1.1 Primary health care in Australia

Primary health care

In Australia, primary health care is the entry level to the health system and is typically the first point of contact people with a health concern have with the health system (Duckett and Swerissen, 2017, Biggs, 2013, Duckett et al., 2015, Orlando et al., 2011, Department of Health, 2013). Primary health care can contribute to a stronger health system by supporting the most cost-effective treatments, preventive strategies and interventions based on best practice (Productivity Commission, 2017).

Primary health care services cover health promotion, prevention, early intervention and treatment of both acute and chronic conditions. Services are often delivered in general practices but also in other settings including community health centres, allied health and dental practices, pharmacies and Aboriginal Medical Services.

The primary health care workforce includes general practitioners, allied health professionals, community health workers, nurses (including nurse practitioners and midwives), pharmacists, dentists and Aboriginal health practitioners (Australian Institute of Health and Welfare, 2016, Australian Institute of Health and Welfare, 2018d).

1.2 Primary health care expenditure

In 2016-17, total health expenditure was $180.7 billion, of which $62.0 billion (approximately 34%) was spent on primary health care (Australian Institute of Health and Welfare, 2018e). The largest source of funds for primary health care come from the Australian Government and individuals, with unreferred medical services (largely general practitioners) and benefit-paid pharmaceuticals as the two largest areas of expenditure (Australian Institute of Health and Welfare, 2018e).

In 2017-18, almost 155 million general practice services were provided to consumers at a cost in Medicare benefits of $7.8 billion (Department of Health, 2018b). The volume and cost of these services increased by 4.9% and 5.5% respectively between 2016-17 and 2017-18 (Department of Health, 2018b).

In 2016-17, a total of 195.8 million PBS prescriptions were dispensed (a decrease of 4% from the previous financial year) amounting to expenditure of $12.0 billion (Department of Health, 2017b, Australian Institute of Health and Welfare, 2018e).

Given the large volume of primary health care service provision and expenditure in Australia, there is potentially much to gain from having better information about the primary health care sector, and general practice in particular.

1.3 National minimum data sets in Australia

National minimum data set (NMDS)

The Australian Institute of Health and Welfare (AIHW) defines a NMDS as a minimum set of data elements agreed for mandatory collection and reporting at a national level (Australian Institute of Health and Welfare, 2018g).

A NMDS is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection, but does not preclude agencies and service providers from collecting additional data to meet their own specific needs (Australian Institute of Health and Welfare, 2018g).

In the health sector at present, there are over ten NMDSs for admitted and non-admitted patient care in hospitals, elective surgery waiting times, as well as community and residential mental health care, public dental waiting times, perinatal data and others.

The data contained in these NMDSs are used variously for reporting, planning, policy development and program management (Australian Institute of Health and Welfare, 2018g, Australian Institute of Health and Welfare, 2014). As an example, data from the National Community Mental Health Care Database are used to describe the care provided by these services including the number of service contacts provided, the number of patients who received care, length of treatment period, principal diagnoses, type of services provided, characteristics of the patients who received services (e.g. age, gender, socioeconomic status, Indigenous status and mental health legal status).

This data collection enables comparisons of data over time, comparisons by state and territory, examination of the mix of services provided, and analysis of services provided to specific target populations such as child and adolescent, youth, older persons and forensic populations (Australian Institute of Health and Welfare, 2018f).

1.4 Primary Health Networks

Primary Health Networks (PHNS)

PHNs were established in July 2015, as an Australian Government initiative replacing Medicare Locals. The objectives of the PHNs are to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and to improve coordination of care to ensure patients receive the right care in the right place at the right time. It is intended that PHNs achieve these objectives through:

- understanding the health care needs of their local regions;
- providing support to general practices to enhance their ability to provide care in the community and help patients avoid having to go to emergency departments or be admitted to hospital;
- supporting general practices to attain high standards in safety and quality through support of continuous improvement;
- assisting practices make meaningful use of eHealth systems to streamline the flow of relevant patient information across local healthcare providers; and
- purchasing or commissioning services for local groups most in need e.g. patients with complex chronic conditions or mental illness (Department of Health, 2016b).

1.4.1 PHN Program Performance and Quality Framework

From 1 July 2018, the Department of Health implemented the PHN Program Performance and Quality Framework (The Framework). The Framework, released in September 2018, replaces the previous PHN Performance Framework (Department of Health, 2018e). The Framework was developed and implemented by the Department of Health to measure the overall performance of PHNs and how the activities and functions of PHNs contribute towards achieving the PHN Program's objectives (Department of Health, 2018e).

The overall performance of PHNs are measured across various indicators which align to the seven PHN priority areas: mental health, Aboriginal and Torres Strait Islander Health, population health, workforce, digital health, aged care, and alcohol and other drugs (Department of Health, 2018e).

For mental health, the Primary Mental Health Care Minimum Data Set is referenced as a data source used in The Framework to measure performance against mental health-related indicators. Indicators relating to general practice include the rate of accredited general practices in the PHN region, a measure of support PHNs provide to general practices, and the rate of accredited general practices sharing data with PHNs (Department of Health, 2018e).

It is understood that almost half (46%) of general practices provided de-identified general practice data to PHNs in 2017 (Whitlock, 2018, personal communication). These survey results suggest many general practices are willing to work closely with PHNs to improve data quality and better understand their data.

2 Current context of primary health care data in Australia

Despite the significant government and individual investment in primary health care in Australia, and general practice in particular, there is currently no consistent, nationally agreed, continuous collection of data items that can be used to describe and monitor the activities and services being provided.

Consequently, the reasons for patient use of and engagement with the primary health care system, patient characteristics, diagnoses, frequency of referrals, interventions and outcomes are currently not well understood (Productivity Commission, 2017, Duckett and Swerissen, 2017, Sussan Ley, 2016, Comino et al., 2006, Sturgiss, 2018).

Data itself will not solve the increasing pressures on the health system, but without it, being able to understand what is happening in primary health care, monitoring changes from a baseline understanding of the status quo, understanding the relationships between primary care and other elements of the health system, and making improvements are extremely difficult, if not impossible.

Some of the existing sources of data relating to general practice use in the Australian primary health care system include administrative data collected through the Medicare Benefits Scheme (MBS), electronic health records (EHRs) used by service providers, Patient Experience Surveys (PES) conducted by the Australian Bureau of Statistics (ABS) and the Coordination of Health Care Study (CHC) conducted by the ABS and the AIHW (Australian Bureau of Statistics, 2016, Australian Bureau of Statistics, 2018, Department of Health, 2018c).

The MBS, EHRs, PES and CHC provide valuable insights into health care service usage and patient experiences. However, unlike the acute sector, the primary health care sector currently has no information on diagnoses, procedures or treatments. Without data on how and why people use and access primary health care services, and the extent to which practitioners adhere to agreed models of care, it is difficult to detect variations and incentivise improvements in care provision (Duckett and Swerissen, 2017).

2.1 The Medicare Benefits Scheme

The MBS collects and reports information on individual items, the broad type of service based on groups and items in the MBS (e.g. non-referred GP service/vocationally registered GP attendances, enhanced primary care attendances, Practice Nurse items, Allied Health items), volume of services (e.g. quarterly comparisons, annual comparisons), locations of services by State and Remoteness Area Classification (based on the patient's Medicare enrolment postcode) and cost of primary health care services provided (bulk billing rates, schedule fee observance and average patient contribution per service) (Australian Government, 2018b).

Data from the MBS also provides information by State and Territory, Remoteness Classification, Statistical Area Level 3 and PHN about the number of general practitioners providing services, the GP head count per 100,000 population, the gender of GPs, place of basic qualifications (e.g.

Australia/New Zealand, overseas), GP type (e.g. vocationally registered, trainee) and GP age group (Department of Health, 2018c, Department of Health, 2018d)

Data from the MBS are an administrative by-product of administration of the Medicare fee-for-service payment system for which a claim has been processed and does not enable exploration of diagnoses, referrals, patient characteristics, details about patient encounters and experiences or patient outcomes.

2.2 Electronic Health Records

EHRs, used by many primary health care service providers, have primary health care data which has yet to be systematically collected, integrated or analysed (Duckett and Swerissen, 2017, Wallace et al., 2013). Incomplete data entry into EHRs by general practice has been identified as a key issue – consistent and comprehensive entry of data is required in key data fields of importance (Schattner et al., 2010, Gordon et al., 2016). Incomplete EHRs have also been identified as a problem in acute care (Connor et al., 2016).

2.3 The Patient Experience Survey

The Patient Experience Survey (PES)

The PES, conducted annually by the ABS through a survey people aged 15 years and over, explores consumer experience in relation to access and barriers to health care services across the primary health care and acute care sector, including:

- general practitioners (GPs);
- medical specialists;
- dental professionals;
- imaging and pathology tests;
- hospital admissions; and
- emergency department visits.

The PES is a topic within the Multipurpose Household Survey, a supplement to the monthly Labour Force Survey. The Multipurpose Household Survey is designed to collect statistics for a number of small, self-contained topics (Australian Bureau of Statistics, 2018).

The PES collects data on aspects of communication between patients and health professionals (Australian Bureau of Statistics, 2018). In primary health care, patient experience data provides insight into the perceived availability of general practitioners, cost barriers to health care and behavioural aspects of general practitioners.

While patient experience data is self-reported, these surveys provide useful information on the quality of service delivery and enable service gaps to be identified and addressed (The George Institute for Global Health et al., 2018). The data are used in national health performance assessment, however responses are not necessarily related to experiences with a single service provider or organisation and are not able to be used to support service improvement because they do not identify the specific service provider(s) used (Australian Institute of Health and Welfare, 2018d).

2.4 Coordination of Health Care Study

In 2016, the ABS and AIHW developed the CHC (Australian Bureau of Statistics, 2016), which explores patient experiences of coordination of care across Australia (Australian Bureau of Statistics, 2016).

The Survey of Health Care (SHC), the first component of the CHC, explores the experiences with coordination and continuity of care for consumers over 45 years of age to understand whether people have (Australian Institute of Health and Welfare, 2018d):

- a relationship with a usual GP or place of care;
- experiences with person-centred care;
- experiences with transfer of information between a GP or practice and hospitals' emergency departments and specialists; and
- respondents' access and barriers to care.

High users of general practice visits were oversampled, as these consumers were considered more likely to have complex health care needs and a broad range of experiences across various health disciplines (Australian Bureau of Statistics, 2016).

The second component of the CHC will conduct data linkage to enable insights into consumers' self-assessed health and experiences, in alignment with actual service usage via the MBS, PBS, Repatriation Pharmaceutical Benefits Scheme (RPBS) hospital and emergency department data (Australian Bureau of Statistics, 2016). Results will be made available at the local level to enable PHNs to compare to a national benchmark and measure performance of coordination of care in the primary health care sector. However, because the SHC captures data only on those aged 45 years and over who have seen a GP in the preceding 12 months, the data cannot be used to investigate unmet health needs for the whole population (Australian Institute of Health and Welfare, 2018d).

Ideally, PHNs would value access to information about patient journeys and experiences of health care across the whole population.

2.5 The Bettering the Evaluation and Care of Health survey

From 1998 to 2016, the Bettering the Evaluation and Care of Health (BEACH) program by the Family Medicine Research Centre at the University of Sydney collected survey data on general practitioner reports and patient encounters (Britt and Miller, 2016).

The BEACH program was designed to provide insights into primary health care, including general practitioner patient encounter data, patient risk factors and health status, prevalence of chronic conditions and multimorbidity, and the inflow and outflow of patients between PHN regions (Britt and Miller, 2016).

The BEACH survey produced primary health care data that was not available elsewhere. Over a 12-month data collection period, a random sample of 1,000 general practitioners was selected from Medicare records. Each participating GP recorded information from 100 consecutive consultations, resulting in the collection of de-identified details of approximately 100,000 patient encounters.

BEACH reports using general practice data enabled primary health care to be compared and benchmarked on a national scale. Various stakeholders including government bodies, general practice organisations, researchers and consumers remain interested in primary health care data captured through the BEACH survey.

While BEACH provided into insight on why people engaged with primary health care services, the Department of Health determined that a refreshed approach to research and data was necessary to progress future work in the primary health care sector (Skilton, 2016).

The BEACH survey ceased in June 2016 and consequently information about the reason why people visit general practices and what happens in those consultations at a national scale are not currently available to PHNs and other government, not for profit and research organisations.

3 Why PHNs need a primary health care NMDS

3.1 Increasing the efficiency and effectiveness of medical services for patients

Despite the PHNs' objective to increase the efficiency and effectiveness of medical services for patients, there are no systematic mechanisms for collecting, integrating or analysing primary care data that would illuminate variations in patient management and the extent to which treatments provided improve patients' health (Duckett and Swerissen, 2017). This is unlike the acute care sector where comparisons can be made between hospitals and states and territories against national benchmarks (Australian Institute of Health and Welfare, 2018b).

The acute care sector is aware of the most commonly treated conditions and where demands for services or treatments are not well met (Australian Institute of Health and Welfare, 2017d). Without this data in the primary health care setting, it is difficult for PHNs to identify where opportunities exist for health professionals to improve primary health care services for patients (Duckett and Swerissen, 2017).

A primary health care NMDS could rectify this by capturing uniform data to identify the reasons people present to general practice, patient characteristics, quality indicators such as adherence to agreed models of care, and information about conditions and complications that are preventable through better primary care (Duckett and Swerissen, 2017).

An ongoing collection of these items would enable monitoring of changes and improvements in primary care services over time, and enhanced understanding of the impact of different management approaches for those at risk of poor health outcomes.

3.2 Improving coordination of care

Effective commissioning and provision of support to general practices and other primary care providers is key to improving the management of chronic conditions and coordinating care across the primary health care sector (Department of Health, 2016a).

Consistent patient encounter data would enable PHNs to better understand why patients are engaging with primary health care services as well as enabling them to identify emerging health issues within communities and appropriately commission services to address local health needs. Commissioners need information about the quantity and quality of health services in their communities to identify areas requiring quality improvement and/or service gaps.

PHNs currently rely on a range of proxy measures and other data sources outside of primary health care whereas decisions relating to the primary health care sector should ideally be derived from primary health care data (Davis et al., 2016). A primary health care NMDS could strengthen the ability of PHNs to conduct effective planning through improved access to and better use of primary health care data (Productivity Commission, 2017).

Furthermore, such data could enable PHNs to provide more targeted education and training to assist the primary health care workforce in delivering quality and safe health care (Duckett and Swerissen, 2017, Department of Health, 2016b).

Table 1 outlines some of the data elements proposed for a primary health care NMDS required by PHNs and their expected outcomes.

Table 1. Proposed data elements to be included in a primary health care NMDS

Data element	Description of data element	Expected outcomes
Provider demographics	Organisational and individual level information on the primary health care service provider, including: sex, year of birth, Indigenous status, type of provider (Department of Health, 2018f, Australian Institute of Health and Welfare, 2018a, Department of Health, 2016c, Woo and Pennebaker, 2002, Britt and Miller, 2016, Beck et al., 2018).	Practitioner data is intended to provide workforce planning data for use regionally by PHNs and nationally by the Department of Health (Department of Health, 2018f). Collect information which informs workforce planning and enhance understanding about the extent to which local capacity can meet local needs (Scott et al., 2011, Beck et al., 2018).

Data element	Description of data element	Expected outcomes
Patient demographics	Information on the patient, including: sex, date of birth, country of birth, postcode of residence, Indigenous status, and preferred language (Department of Health, 2018f, Australian Institute of Health and Welfare, 2018a, Department of Health, 2016c, Woo and Pennebaker, 2002, Davey et al., 2017, Britt and Miller, 2016, Orlando et al., 2011, Blignault and Haghshenas, 2005, Ghosh et al., 2014).	Ensure safe and quality health care is provided to patients through keeping current and accurate records (Nadathur, 2010, Productivity Commission, 2017). Ensure culturally appropriate services are delivered to patients (Blignault and Haghshenas, 2005). Measure the inflow and outflow of patients between PHN regions to more easily identify service gaps and inform service planning (Britt and Miller, 2016). Support identification and monitoring of health issues of concern for specific groups, and assist in future service planning (Blignault and Haghshenas, 2005).
Patient health status and health-related behaviours	Details on the current health status (e.g. chronic conditions) and lifestyle choices of the patient (e.g. risk factors such smoking, alcohol use, diet, and physical activity) (Davey et al., 2017, Orlando et al., 2011).	Identify potential areas for improvement and deliver quality care to patients (Ghosh et al., 2016). Conduct planning of primary health care services specifically targeting health needs, demands and requirements of the local community (Ghosh et al., 2014). Estimate and monitor prevalence of chronic conditions in local regions to inform health service planning (Ghosh et al., 2014). Measure risk behaviours in local regions (Department of Health, 2013, Ghosh et al., 2016) and identify those at-risk of developing chronic conditions (Ghosh et al., 2014).
Patient encounters	Patient reason for engaging in primary health care services (Miller et al., 2005, Department of Health, 2016c, Britt and Miller, 2016, Productivity Commission, 2017), patient characteristics, diagnoses, frequency of referrals, and interventions (Productivity Commission, 2017, Duckett and Swerissen, 2017, Sussan Ley, 2016, Comino et al., 2006, Sturgiss, 2018).	Identify public health trends (Independent Hospital Pricing Authority, 2018) and proactively respond by providing/commissioning more targeted programs/services (Ghosh et al., 2016, Britt and Miller, 2016, Ghosh et al., 2014, Australian Institute of Health and Welfare, 2007, Davis et al., 2016, Woo and Pennebaker, 2002). Avoid duplication of services provided to a patient (Australian Institute of Health and Welfare, 2007, Davis et al., 2016, Woo and Pennebaker, 2002). Improve collaboration between general practice and other primary health care services (Britt and Miller, 2016), and across the entire health system (Connor et al., 2016).
Health outcomes	Information relating to the outcome of the consultation (Davey et al., 2017, Department of Health, 2016c, Productivity Commission, 2017), including patient referral pathways (Davey et al., 2017).	Evaluate the effectiveness and efficiency of health outcomes achieved in the primary health care setting (Productivity Commission, 2017).

Consultation with key stakeholders about these proposed data elements will inform the content of further data elements.

4 Primary health care NMDS development

4.1 National Primary Health Care Data Asset

In the 2018-19 Federal Budget, additional funding for the AIHW was announced under the National Health and Medical Industry Growth Plan (Australian Government, 2018a). This additional funding has enabled further data development and analysis in the primary health care sector (Australian Institute of Health and Welfare, 2018c, Australian Institute of Health and Welfare, 2018h).

A Primary Health Care Data Unit has been established to lead the development of a National Primary Health Care Data Asset (Australian Institute of Health and Welfare, 2018h). The Data Asset will support the collection and reporting of primary health care data to better understand patient outcomes and experiences.

The repository of information collected from the primary health care sector will enable better population health planning, assist in identifying service gaps, support policy development, and provide insight into the patient journey across the health system (Australian Institute of Health and Welfare, 2018h). The approaches used in collecting and reporting data will also enable the Primary Health Care Data Unit to drive improvements in data quality and standardisation (Australian Institute of Health and Welfare, 2018h).

Data standardisation in primary health care is needed in order to accurately assess system performance, identify and monitor areas for improvement and explore return on investment for government (Australian Institute of Health and Welfare, 2018h).

The establishment of this Primary Health Care Data Unit at the AIHW is an important step forward on the journey towards establishment of a primary health care NMDS.

5 Key recommendations for establishing a primary health care NMDS

To facilitate the implementation of a primary health care NMDS the following issues will require consideration:

- clarity about why the data are needed;
- practicalities associated with the collection of data;
- need for workforce development, support, and/or training;
- addressing consumer and service provider issues;
- privacy and security; and
- need for alignment with other data sets.

5.1 Clarity about why the data are needed

The process of building a data set for a specific purpose requires a clear understanding of why the data are needed, for example a need for more complete information about clients and/or services,

to compare similar information collected in different places, to inform service planning, or to assess the quality of services being provided (Australian Institute of Health and Welfare, 2014, Australian Institute of Health and Welfare, 2007).

Given the range of potential reasons for data development in relation to primary care services, it will be important to begin with gaining consensus on the highest priority drivers or reasons for data development.

5.2 Practicalities associated with the collection of data

Where gaps in the desired data exist, consideration needs to be given to how the data can be collected in practical terms. Data development – or the process of building a data set for a specific purpose – is not tied to specific software or systems. Rather, data to be collected are well defined and standardised to enable consistent collection, and comparison and aggregation, regardless of the system or application that captures them. A primary health care NMDS should conform with the metadata standards established for Australia's national health data collections (Australian Institute of Health and Welfare 2018i). These promote comparability and consistency, facilitate sharing of data and synergy amongst multiple data sources, and support efficient national data development through reduced costs and efforts.

For valid national data to be compiled, it will be important to understand the diverse information systems from which the data may be drawn (Australian Institute of Health and Welfare, 2014, Australian Institute of Health and Welfare, 2007).

5.3 Need for workforce development, support, and/or training

Many primary health care providers operate as private businesses (Australian Institute of Health and Welfare, 2013, Biggs, 2013) and are responsible for the collection, management and use of their own practice data. It is well understood that primary health care professionals are constrained by time during patient consultations (Schattner et al., 2010, Ghosh et al., 2014). If some data for a primary health care NMDS are to be sourced from electronic health records within general practice, it will be important to strive for alignment of data elements with standard practice data collection procedures; ensuring that items are clinically relevant and do not require additional data entry from the primary health care workforce (Duckett and Swerissen, 2017, Davey et al., 2017, Department of Health, 2016c). Workforce skills are critical to the successful development and use of a NMDS in primary health care. Quality general practice data collection requires investment in training and time for data entry, data cleansing and analysis (Sturgiss, 2018).

The PHNs, which already provide support to general practice, could play an important role in equipping primary care staff to collect, maintain and report data through a NMDS.

5.4 Addressing consumer and service provider issues

Consumer engagement is necessary to ensure the process remains transparent as their data and information will be collected (The George Institute for Global Health et al., 2018). While many

people are surprised data sharing is not occurring more frequently (Olver, 2014), it is important that consumers understand how their privacy is protected and how their health data is being used (Liaw et al., 2016, The George Institute for Global Health et al., 2018).

Some people have concerns about sharing their data due to potential misuse or identifiability (Kaplan, 2014). These concerns can create reluctance in sharing data, particularly if the way data are used is unclear to health consumers (Kaplan, 2014). Therefore, open communication and transparency is required with health consumers in relation to establishing a NMDS in primary health care. Similarly, service providers need to be assured that data governance processes and privacy and security concerns are addressed in order to feel confident in providing data.

5.5 Privacy and security

Privacy and security concerns exist in relation to all types of data, particularly health-related data (Productivity Commission, 2017). Health-related data can contain intimate information about an individual, which patients only share to receive quality health care (Kaplan, 2014). For this reason, specific provisions are made in the *Privacy Act 1988* and in some state privacy legislation in relation to health data and information (Office of the Australian Information Commissioner, 2018). While privacy and security concerns must be acknowledged, increased access to and use of data does not necessarily increase privacy and security risks (Productivity Commission, 2017). Data misuse may occur more frequently through illegal activities, such as hacking data, than sharing or publicly releasing de-identifiable data (Productivity Commission, 2017).

There may be privacy concerns around the misuse of a primary health care NMDS, particularly if data were linked with other databases. Because of the sensitive nature of health data, only three bodies in Australia have permission to link Commonwealth government health data: which are the AIHW, ABS and Australian Institute of Family Studies (Productivity Commission, 2017, Department of Health, 2017a). The Population Health Research Network, established by the Commonwealth Government with the support of state and territory governments, provides national infrastructure for health data linkage for health-related research purposes (Population Health Research Network, 2018).

5.6 Need for alignment with other data sets

In the Australian health sector, minimum data sets and NMDSs have been established to measure and evaluate health care services in primary mental health care services, alcohol and other drug treatment services, and the acute care sector (Department of Health, 2018a, Department of Health, 2016c, Australian Institute of Health and Welfare, 2017b, Australian Institute of Health and Welfare, 2017c, Australian Institute of Health and Welfare, 2017a, Australian Institute of Health and Welfare, 2017e).

The minimum data set for primary mental health care services (PMHC-MDS) was established to monitor and evaluate primary mental health care services commissioned by PHNs (Department of Health, 2018a, Department of Health, 2016c).

The NMDS established in 2000 for alcohol and other drug treatment services (AODTS-NMDS) collects data on alcohol and other drug treatment services, client access to services, principal drug of concern and types of treatment services provided (Australian Institute of Health and Welfare, 2017b).

Two NMDSs in the acute care sector collect data on patients who present (non-admitted patient emergency department care NMDS) and/or are admitted to hospital (admitted patient care NMDS) (Australian Institute of Health and Welfare, 2017a, Australian Institute of Health and Welfare, 2017e).

Data standards implemented in a primary health care NMDS should be developed using standard definitions (such as those in METeOR – the national metadata registry system) and codes (e.g. SNOMED CT) to facilitate linkage to data sets used for hospitals and other primary health minimum data sets (Department of Health, 2013, Duckett and Swerissen, 2017). The National Health Information Agreement provides the overarching framework for the governance of national data collections (Australian Institute of Health and Welfare, 2014).

6 Conclusion

There have been numerous calls to establish a NMDS for primary health care in Australia (Australian Healthcare and Hospitals Association, 2017, The George Institute for Global Health et al., 2018). Despite significant investment in the provision of primary health care services in Australia, little is known about what services are being delivered to whom, with what outcomes.

Australia has a robust system for the development and maintenance of NMDSs in the health sector. Data collected through existing NMDSs are used variously for reporting, planning, policy development and program management (Australian Institute of Health and Welfare, 2018g, Australian Institute of Health and Welfare, 2014). They enable comparisons of data over time, by different geographic regions, examination of the mix of services provided, and analysis of the effectiveness of services provided to specific population groups (Australian Institute of Health and Welfare, 2018f).

Despite having a number of existing sources of data relating to general practice and other primary health care services use and experience, each collection has limitations. Without data on how and why people use and access primary health care services, and what occurs in individual consultations, it is difficult to detect variations and incentivise improvements in care provision (Duckett and Swerissen, 2017).

PHNs are intended to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and to improve coordination of care to ensure patients receive the right care in the right place at the right time. Currently much of the data PHNs rely on for planning and commissioning of services come from proxy measures and data sources outside of primary health care (Davis et al., 2016). Already, many general practices are providing de-identified data and working closely with PHNs to improve the quality of their data. Ongoing collection of data from general practice using standardised definitions and coding would potentially

create significant benefits for service planning and delivery, through greater accessibility and comparability of data relating to general practice management of health conditions and outcomes for patients (Sturgiss, 2018).

Throughout the world, there are few examples where data is routinely and consistently collected about what happens in general practice consultations (Sturgiss, 2018). Australia has recently established a Primary Health Care Data Unit at the AIHW to lead the development of a National Primary Health Care Data Asset (Australian Institute of Health and Welfare, 2018h). It is hoped that this is an important step forward on the journey towards implementing a primary health care NMDS to better support population health planning, assist in identifying service gaps, support policy development, monitor system performance, and provide insight into the patient journey across the health system (Australian Institute of Health and Welfare, 2018h).

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