

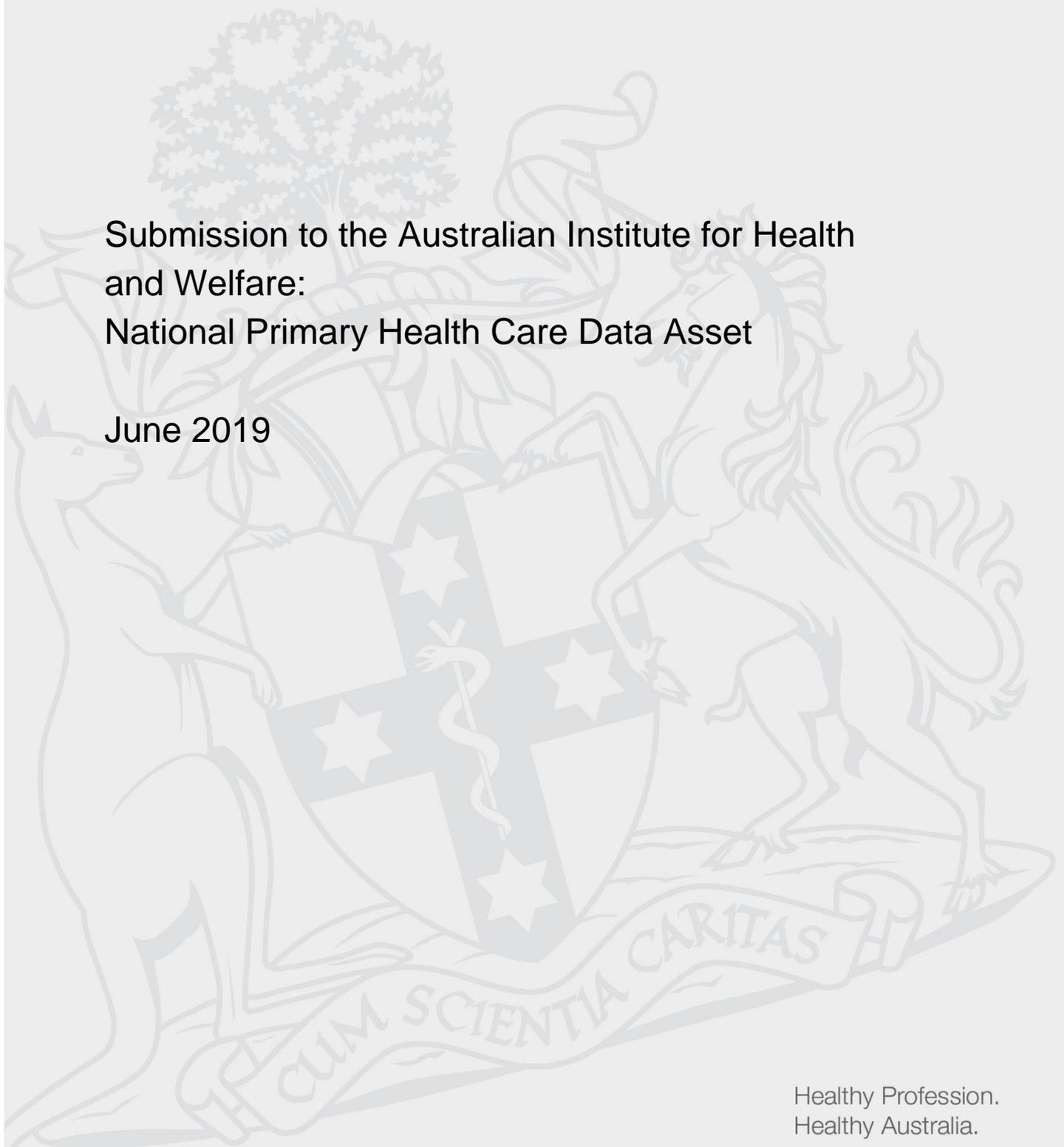


RACGP

Royal Australian College of General Practitioners

Submission to the Australian Institute for Health
and Welfare:
National Primary Health Care Data Asset

June 2019



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1. Key recommendations

The Data Asset must not be used to support pay-for-performance systems. The Royal Australian College of General Practitioners (RACGP) would also strongly oppose use of the Data Asset to publically measure and benchmark individual general practitioners and practices.

In the context of the above, the RACGP recommends:

- strong general practice representation on the development and implementation of the Data Asset and in particular the proposed data governance committee
- a strong governance framework and data policy underpin the Data Asset
- data analysis is carried out by persons that understand general practice including GP researchers and informaticians
- that the RACGP has access to the Data Asset so the profession can see and share in realising the Asset's value
- that the creation of the new Data Asset does not lead to duplication or additional reporting burdens for the GP community. Any data collection from GP clinical information systems should not be intrusive
- providing additional investment to support primary care staff and data analysts to carry out the work required to create a useful Data Asset. Current funding and time/focus should not be diverted to this initiative at the expense of existing programs and clinical care.

2. Executive summary

The RACGP welcomes the opportunity to provide written comment to the Australian Institute of Health and Welfare: National Primary Health Care Data Asset. We recognise the value of having national primary care data collection to better inform policy, population health, research and other needs.

The RACGP's mission is to improve the health and wellbeing of all people in Australia by supporting general practitioners (GPs), general practice registrars and medical students. The RACGP is Australia's largest medical organisation, representing more than 40,000 members who provide more than 154 million general practice services each year to more than 24 million Australians.

It is essential that the RACGP plays a key role in the development and implementation of a National Primary Health Care Data Asset.

For the Data Asset to be successful, it needs to address the challenges of data quality and collection. Those providing data need to see the benefits and AIHW must maintain its position as a trusted independent expert.

3. Consultation response

3.1 Key areas of opportunity, barriers and enablers in developing the National Primary Health Care Data Asset

The RACGP has identified the following as key areas of opportunity for the National Primary Health Care Data Asset:

- Bringing together multiple existing data sources.
- Informing general practice sector about areas for improvement in a timely manner.
- Informing the government about areas that are under-resourced.
- Improving patient outcomes through a more coordinated approach to patient primary health care.
- Enabling general practice research.

The RACGP has identified the following as key barriers in developing the National Primary Health Care Data Asset:

- The form and quality of existing data records that are kept for the purpose of longitudinal clinical care and not for research or population health analysis purposes.
- Concerns around the security of data, including potential to re-identify data.
- Lack of standardisation and interoperability between different medical software systems.
- The lack of incentives for GPs to collect and record data in their electronic records in ways that not only serve their needs but better support use of that data for future analysis.
- Reduced acceptability to data if governance of the Data Asset is overly restrictive in terms of allowing data-sharing for analysis by general practice.

The RACGP has identified the following as enablers in developing the National Primary Health Care Data Asset:

- The Australian Institute for Health and Welfare is a trusted authority (although could have a higher profile in General Practice), therefore well-placed to deliver the Data Asset.
- The AIHW's capacity for data linkage.
- General practice as holding the most extensive and potentially accessible Australian primary health care data because general practice is highly computerized, and prescribe and record clinical data electronically.

3.2 Top primary health care data needs

The following top primary health care data needs have been identified:

- Information that supports better coordination of patient care between GPs and other specialties.
- Making data available for primary care research purposes that aims to improve health outcomes
- Standardised data.
- Improved usability of GP computer information systems to facilitate data recording and collection.

3.3 Data sources

The RACGP supports the use of the National Primary Health Care Data Asset to enable better population health planning, support quality improvement, improve patient outcomes and experiences, help identify gaps in the provision of primary health care services, and to develop the evidence-base for optimal primary care.

The RACGP's preferred model of data flow is *General Practice to Clinical Information System to Data Asset*, as all general practices with electronic records use a clinical information system and not all general practices provide data to PHNs or data collators. Any model of data flow will be impacted by the following:

- Generation of incomplete data sets due to poor quality data entry.
- GP engagement in providing the data. Data is perceived as having intrinsic value, so GPs have the right to be compensated for providing it. GPs traditionally make notes and records for their own purposes, and will need clarity on the benefits of spending valuable clinical time on data entry. Education and incentives for data quality and collection must be provided to GPs for the Data Asset to be successful.
- Clear guidelines for the process of data collection, cleaning and storage.
- Clear articulation of secondary use of data needs and uses - data should only be used for the purposes intended.

3.4 Data governance

The RACGP supports the data governance arrangements described in the Data Development Plan. Strong general practice representation on any data governance committee or advisory group relating to the Data Asset is essential. A strong governance framework and data policy is required, especially in relation to data linkage. Providers of data and healthcare consumers need to understand where their data is held, how their

data may be used and how their data will be linked. A robust de-identification process must be put in place, there must be strict security and accessibility protocols in place. Ideally, those who supply the data should share in the value generated by the Asset and have access to data for research and quality improvement activities.

3.5 Data requirements

Basic practice demographic information should be included as part of the data requirements, including the size of practice, number of staff and the role of staff, number of hours worked by staff, and total patient population.

Universal coding (e.g. presentation, diagnoses) also needs to be sufficiently flexible.

The RACGP does not support pay-for-performance funding models and would not want to see data being used to publically measure/benchmark individual GPs/practices. Pay for performance can lead to a range of unintended and perverse incentives, including:

- financial gain rather than patient preferences
- reluctance to treat certain patient groups, and
- attention to arbitrary targets and measurable indicators, that do not account for the complexities of multimorbidity, as opposed to patient care.

Lastly, people analysing and interpreting the data must understand general practice, how the data is collected, and the limitations of the data.

4. RACGP Aboriginal and Torres Strait Islander Health Faculty and the national Key Performance Indicators experience

Improving the health of Aboriginal and Torres Strait Islander people is one of Australia's highest health priorities. General practice and Aboriginal health services are vital to improving the health and wellbeing of Aboriginal and Torres Strait Islander people and their communities throughout Australia. The College also strongly supports the vital role of Aboriginal and Torres Strait Islander health workers and people in partnership with general practice to deliver comprehensive health care.

As there is no mechanism or precedent for primary care reporting in the way outlined in the Data Asset, there are important lessons and guidance that can be taken from the Aboriginal and Torres Strait Islander primary healthcare sector, who report annually the national Key Performance Indicators (nKPIs).

4.1 Purpose for Data Asset

To facilitate implementation of a primary healthcare data set, one of the key issues that requires consideration relates to clarity of purpose, ie. why the data is needed.ⁱ Aboriginal and Torres Strait Islander primary healthcare organisations are already required to collect data as part of their funding agreements under the Indigenous Australians Health Programme, against the nKPIs.

The nKPIs were developed with a number of purposes in mind. At the service-level, the measures support continuous quality improvement, to drive health outcomes and enhance patient experience. However on their own, the nKPIs are not sufficient to achieve these changes. In fact, the nKPIs and other data sets are most valuable when they are incorporated into broader continuous quality improvement processes that identify opportunities for change and measure progress towards achieving that change.ⁱⁱ

At a broader state and national-level, the nKPIs are designed to support monitoring of progress against high-level policy initiatives (for example, the Closing the Gap targets) and policy development and planning.ⁱⁱⁱ However, it can be difficult to sell this concept as valuable for services, unless they too are benefitting from the information gathered, and the subsequent decisions being made. Although the data is collected at local levels, comparisons made at national and international levels can hide the diversity of local and regional challenges and successes. In addition, there is a risk that the data is not necessarily accurately reflecting prevalence or service provision, which could lead to a misinterpretation of the data. Quality improvement comes from practice level data and is most valuable and meaningful for application in health services.

It is important that there is a consistent understanding of the purpose for the data collection and who the data is to benefit. In the recent development of a needs-based funding model for Indigenous Primary Healthcare, the nKPIs were considered as a tool to support funding decisions.

Use of data for funding decisions risks undermining the quality improvement aims of an initiative. It can change the approach to data collection and reporting. It can encourage prioritising certain results, and could lead to funding being re-directed away from services in communities with complex patients. This has been evidenced in the United Kingdom, which has adopted a pay-for-performance model in primary healthcare, which found that the indicators used represent a limited, biomedical view of health; they divert practices from other aspects of providing high quality of primary care and from prioritising those patients with the greatest needs; have contributed to the poor morale in general practice and large migration of GPs to Australia and other countries; and there is no definitive evidence of important impacts on population health.^{iv}

Concerns have been raised in the past about the nKPIs driving clinical practice. Practices may be understandably wary of providing their practice data to the Department of Health or other government agency and would prefer to maintain a focus on using data to improve health outcomes.

4.2 Usefulness of the Data Asset

There is clear value in the collection of the nKPIs, which have been to support monitoring and improvements to performance, and for input for broader service development, such as input for board reports and funding proposals.^v However, according to the National Aboriginal Community Controlled Health Organisation (NACCHO), limited access to the data, and therefore its value, is a significant problem. The role of the Australian Institute for Health and Welfare is determined by its regulations, which are restrictive in terms of allowing data-sharing for analysis.^{vi} Investment in a national dataset must guarantee access to accurate and comparable data that is meaningful for services and practices.

4.3 Consideration for the broad set of enablers to ensure the Data Asset has value is required.

Some of these pre-conditions have already been identified. For example, a recent study of 53 Aboriginal Community Controlled Health Organisations,^{vii} found that elements such as: commitment to data quality from leadership, allowing a strong continuous quality improvement culture amongst all staff; clearly established workflows which align with the service's model of care, all contribute to a strong data management culture.

Workforce skills are critical to the effective development and use of a dataset in primary healthcare.ⁱⁱⁱ For some organisations, getting the most value out of the nKPIs has required substantial change to internal management and clinical systems, and putting processes in place to collect high-quality data. Analysing the data and adopting continuous quality improvement practices requires organisational resources, time and capability.^{vii} Ensuring there are effective programs of induction, training and ongoing monitoring; and resources and staff dedicated to reporting activities requires significant and ongoing investment and support.

4.4 Content

The quality, completeness, and timeliness of data are important to inform effective service delivery, better policies, and programs.

Aboriginal Community Controlled Health Organisations collect an extensive range of data, including primary, maternal and child healthcare, social and emotional wellbeing and substance-misuse services, personal client details (eg age, gender, occupation), details about medical conditions, and the lodging of MBS numbers. The data collected also includes information about the Aboriginal Community Controlled Health Organisations, such as: numbers of client contacts, services used, staffing numbers and employment roles.

The nKPIs have been the subject of ongoing discussions to ensure they continue to align with and support high quality clinical practice, are underpinned by current evidence and remain meaningful to Aboriginal and Torres Strait Islander community members.

It remains important that the indicators are easily documented as part of service provision (health care) and therefore easily extracted from the clinical software as service level data, and represent the best care possible for patients. The development of a Social and Emotional Wellbeing nKPI was discontinued owing to the inability to identify a measure that was both useful and reliable statistically, as well as reflective of good clinical practice. Current considerations of an nKPI for primary healthcare in hearing health faces similar barriers, relating to resources and availability of and access to key services including primary care, ear nose and throat, audiology. These challenges must be kept front of mind as the Data Asset is developed.

4.5 Reporting burden

The risk of creating reporting burdens for services and practices, without adding significant value is a potential issue. In the case of the Aboriginal Community Controlled Health Organisation sector, reporting is required through funding agreements with the Department of Health, which require services to collect extensive activity and performance information, representing a significant reporting burden.

A study conducted through the Cooperative Research Centre for Aboriginal Health^{viii} confirmed the "...complexity and fragmentation of funding, and the heavy burden of acquiring, managing, reporting and acquitting funding contracts for both providers and funders" as well as suggesting there to be evidence that, "...the contractual arrangements for Aboriginal and Torres Strait Islander organisations are more complex than for mainstream organisations." Though a level of transparency and accountability is welcome, it is disproportionate.

It is noted that the Exposure Draft suggests existing indicators, such as the nKPIs, will be incorporated into the primary healthcare Data Asset. It will be important to ensure that the creation of the new Data Asset does not lead to duplication or additional reporting burdens for the Aboriginal Community Controlled Health Organisations sector, which already reports at a greater rate than mainstream services.

Fundamentally, the role of service providers is to deliver high quality primary healthcare, not to collect data on behalf of governments. Without appropriate support to undertake these processes, data collection can become the goal, particularly if the purpose is linked to factors outside of quality improvement.

4.6 Investment in data collection

There are significant cost implications related to national data collection systems. The nKPI data collection process was outsourced to a private provider, and has been subject to major issues, exacerbated by poor technical capabilities, in terms of system functionality and compliance with data standards. The resultant costs have been significant. The work required to create a useful primary care data set is important and requires dedicated funding for primary care staff to conduct this work for the Australian Institute for Health and Welfare. This role in supporting population health should be supported with additional investment, and not divert current funding used in the provision of individual clinical care.

Data collection and sharing must also be respectful of the principles of Aboriginal and Torres Strait Islander data sovereignty, and seek to empower community involvement in all processes of data analysis and collection. There are ongoing concerns related to data collection amongst Aboriginal Community Controlled Health Organisations, for example the use of data without the establishment of data protocols based on appropriate practices, use of aggregated data to inform needs analysis that may not reflect health needs

accurately and the loss of control around how Aboriginal Community Controlled Health Organisation owned data is used.^{ix} Some of these data ownership concerns are relevant at a broader level, and have emerged as a result of the roll out of My Health Record. Trust and transparency must be at the heart of the development of this new Data Asset.

5. Final comments

The RACGP is a key stakeholder with the necessary expertise and knowledge to support the development of an Asset and to ensure the outputs of the Data Asset are valuable and meaningful.

An important initiative related to the Data Asset is the work the AIHW and the RACGP have been doing to reform the present preventable hospitalisations indicator. This work has demonstrated how the two organisations can work together, benefit from each other's expertise and contribute to enhancing our understanding of primary care. It has helped build trust and confidence in the AIHW and it's important that this valuable work continues and is not lost.

ⁱ Thorpe, M and Sweeney, S. 2019. Call for the establishment of a primary health care national minimum data set. Deeble Institute issues brief 29. Canberra: Australian Healthcare and Hospital Association.

ⁱⁱ Bailie RS, Si D, O'Donoghue L & Dowden M. 2007. Indigenous health: effective and sustainable health services through continuous quality improvement. *Medical Journal of Australia* 186(10): 525–7.

ⁱⁱⁱ SMS Management and Technology. 2015. Final Report: National Key Performance Indicators Data Quality Review. Viewed 12 April 2019 from: [http://www.health.gov.au/internet/main/publishing.nsf/Content/9A3654F963F938B0CA257DDA00771054/\\$File/nkpquality.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/9A3654F963F938B0CA257DDA00771054/$File/nkpquality.pdf)

^{iv} Forbes et al. Review of the Quality and Outcomes Framework in England. Dec 2016. Accessible at: <http://blogs.lshrm.ac.uk/prucomm/files/2017/02/Review-of-QOF-21st-December-2016.pdf>

^v KPMG. 2019. Data Quality Assessment and Support, Report to the Department of Health. Viewed 12 April 2019 from: [http://www.health.gov.au/internet/main/publishing.nsf/Content/7A55DA92332964B9CA25835C0002C7B5/\\$File/IAHP-Final-Report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/7A55DA92332964B9CA25835C0002C7B5/$File/IAHP-Final-Report.pdf)

^{vi} NACCHO. 2016. Inquiry into Data Availability and Use – Submission to Productivity Commission. Viewed 12 April 2019 from: https://www.pc.gov.au/data/assets/pdf_file/0006/205908/sub192-data-access.pdf

^{vii} Australian Institute of Health and Welfare 2018. National Key Performance Indicators for Aboriginal and Torres Strait Islander primary health care: results for 2017. Series no. 5;cat. no. IHW 200. Canberra: AIHW.

^{viii} Dwyer, J., O'Donnell, K., Lavoie, J., Marlina, U. & Sullivan, P. 2009, The Overburden Report: Contracting for Indigenous Health Services, Cooperative Research Centre for Aboriginal Health, Darwin.

^{ix} AHCWA. 2016. Inquiry into data availability and use – Submission to Productivity Commission. Viewed 12 April 2019 from: https://www.pc.gov.au/data/assets/pdf_file/0018/205452/sub181-data-access.pdf