

29 July 2016

Data Availability and Use
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Via: <http://www.pc.gov.au/inquiries/current/data-access/make-submission#lodge>

Re: Public inquiry into data availability and use

Thank you for the opportunity to contribute to the Productivity Commission's public inquiry into Data Availability and Use. NPS MedicineWise considers the inquiry to be an important piece of work which will undoubtedly improve the availability and use of public and private sector data in Australia.

NPS MedicineWise is an independent and evidence based not-for-profit organisation primarily funded by the Australian Government Department of Health to improve the way medicines, tests and other medical technologies are prescribed and used in practice. We create better health outcomes through behaviour change interventions, evidence based information to support decision making and targeted health communication campaigns for health professionals and consumers in Australia.

Given our work in this area, we are particularly interested in the value, collection and availability of health related data and consumer expectations about data usage. Our programs have demonstrated that by using health data effectively we can improve health outcomes and reduce unnecessary health expenditure. We have outlined below some suggestions relating to data availability and use that may help to inform the inquiry.

1. High value public and private sector data

We commend the Productivity Commission's decision to further investigate the critical area of high value public and private data sets. Access to health data is an enabler for improving health outcomes at all levels of care from community, primary to acute. Comprehensive and accurate data underpins evidence based care, improves safety and quality, and improves patient outcomes, thereby adding significant value to consumers and health professionals in Australia. Furthermore, health data has the ability to:

- ▷ inform gaps in recording of information
- ▷ identify patients who might be slipping through the cracks
- ▷ identify opportunities to improve systematic care, such as chronic disease management
- ▷ enable safe clinical decision making
- ▷ identify opportunities for improved patient safety, such as minimising risk of medication error.

Additionally, data linkage offers insights into the patient's journey. High quality data is essential to optimise these insights. Linkage of comprehensive and high quality data will better enable comprehensive clinical handover and continuity of care, for example through improving the sharing of health information between providers.

To optimise the use of high quality data there are some fundamental areas that need to be considered and addressed, including:

- ▷ consistent terminology and classification systems
- ▷ minimum standards for clinical information systems
- ▷ an easier way for clinicians to record health information in a consistent way
- ▷ mandated use of electronic systems across different care settings.

The guiding principle of data use should be that it is for the public good. Therefore, ensuring appropriate and effective models for data custodianship is a very important consideration. Consumers should be front and centre, their data used with both consent and discretion, and their rights taken into consideration.

One example of good data governance you may be interested in learning more about is NPS MedicineWise's MedicineInsight program. This program is the first Australian large scale representative clinical data platform for policy and practice improvement. It seamlessly collects de-identified, encrypted, longitudinal primary patient data on a weekly basis from participating general practices. The data is used to build a comprehensive clinical dataset of prescribing practice and patient management linked to key demographics and clinical conditions that can be interrogated to inform and assist health professionals, policy makers and consumers to improve health and economic outcomes.

NPS MedicineWise's MedicineInsight program collects data from over 3.5 million patients in general practice. We currently have over 550 general practices involved in the program. More than 3,500 general practitioners and other primary health staff working in these practices receive valuable data on a range of clinical indicators and are able to re-identify patient details in-practice to follow up with patients as required.

NPS MedicineWise has developed a governance framework for MedicineInsight to ensure the data is properly managed throughout the organisation. Our governance framework complies with legal and ethical frameworks, including the NHMRC National Statement, RACGP ethics approval, Privacy Act, and Australian privacy principles. Opportunities to improve data quality is a key focus for all of our MedicineInsight interventions with general practices, from practice reports to our new visualisation portal.

In order to ensure robust data governance and appropriate data access, we have established an independent external data governance committee and an internal data governance group. The external committee guides data access principles and use, is responsible for the data quality, risk and compliance and establishes mechanisms that ensure proper and correct access to data. The internal group reviews low risk projects and has operational oversight.

As the data custodian, we ensure data security and privacy is safeguarded and clearly define the data lifecycle through access controls and disposal techniques. We also conduct regular risk assessments and audit and review of processes. We provide the facility for patients to opt out of the program in which case we will not share their data outside of the practice.

2. Systematic collection of public and private sector data

NPS MedicineWise is of the view that central data collection systems are generally preferable over individual systems. This helps avoid duplication and the need for multiple extractions. Governance structures, data security and safeguards are critical to ensuring public support and comfort. It is important that we establish standards around data collection.

At the moment, too many individual organisations are trying to collect and warehouse data without robust secure systems, business continuity plans and policies for management of data. In the primary care sector, for example, there is no consistent minimal data set and many Primary Health Networks individually collect data for their regions in the absence of a national system. We believe it would be more efficient if there is

one data platform, such as MedicineInsight, responsible for consistently and reliably capturing national data that can be compared and benchmarked.

Although there are significant datasets available around prescribing practice, there is limited ability to understand patient behaviour directly. In 2014, we released MedicineList+, a free medication and health management smartphone application. The application allows consumers to create their own medicines list on their smartphone using barcoding or pick-list technology, with dose scheduling and reminder functions. Other notable features include ability to create multiple profiles, store information such as health conditions and allergies, track test results, and provide medicines information such as Consumer Medicines Information.

MedicineList+ has been designed to collect atomised data which results in a rich dataset. It is a useful tool for consumers and promotes adherence and self-management of medication (i.e. for chronic conditions). We believe that having access to consumers' experience and patient reported data can provide valuable insights for the design and evaluation of adherence programs and can be used to inform future policy. This kind of data is currently not captured systematically.

3. Gaps in availability of data

Not all sectors are currently represented in the availability, but also collection of healthcare data. There are significant gaps in the aged care and mental health sector, which means that there is limited ability to understand complex health issues in these areas. Many specialists and allied health in particular still use paper records and do not have the ability to share electronic information between providers.

In addition, accessibility of health data is critical to facilitating effective health policy and evidence based decision making. There are significant datasets in Australia, such as PBS and MBS data, and improved access to these will better inform decision making, remove duplication, improve efficiencies, and contribute towards national population health level data. NPS MedicineWise supports recent initiatives of the Australian Government to move these datasets to an open source system.

4. Consumer expectations about the availability and use of data

As mentioned earlier, we believe it is important to be up front and transparent about the use of consumer data and interfaces that allow them to use health system data for decision making.

It is equally important to engage consumers at all stages of data sharing. Many consumers expect their data to be shared between providers for continuity of care and are surprised how disjointed the system currently is. Where data is shared there should be a timely handover, such as sharing of discharge summaries from hospital to back to treating general practitioners, and secure transmission of data. Consumers should be informed about who their data will be shared with and for how long prior to their data being used. There should be ethical use considerations and consumers should also have the ability to opt out.

5. The importance of strategies to improve the quality of data

In general practice, there is significant variability between clinical information systems (CIS). This includes variability in data structures and elements, use of different clinical terminologies and classification systems. Work on national standards such as SNOMED-CT and the Australian Medicines Terminology has progressed slowly. This lack of standardisation makes it difficult to extract and analyse data from different CIS in general practice. It is also difficult to link general practice data with other data sets.

Moreover, it is difficult to maintain momentum when there are staff changes in general practice. It is thus important to have a whole of practice approach to improve the quality of care on a national level. Incentives

have already been shown to improve recording. It is also critical to educate new and future health professionals across all sectors of their training to increase uptake and support.

We believe there is a need to:

- ▷ encourage uptake and use of national terminologies and standards across the health sector
- ▷ develop a national framework that will encourage vendors to standardise some aspects of CIS that will provide the most benefit
- ▷ include more mandatory fields in clinical information systems, which will enforce coding and improve the systems
- ▷ develop strategies to encourage general practitioners to improve the quality of data recording.

6. The National Healthcare Identifiers Service

The Healthcare Identifiers Service is a national system for uniquely identifying healthcare providers and individuals. Healthcare identifiers help ensure individuals and providers have confidence the right information is associated with the right individual at the point of care. Current legislation is unclear regarding how national healthcare identifiers can be used for the purpose of data analysis, data linkage, quality improvement programs and research.

Current practice is that each organisation seeks their own legal advice on how or if this service can be used for their individual use cases. We believe this is confusing and it would be better if there were national guidance clarifying how national healthcare identifiers could be used to support data analysis.

Thank you again for the opportunity to contribute to the Productivity Commission's inquiry. Should the Productivity Commission be interested, we would be happy to provide further information on our unique take on the availability and use of prescribing data. Please do not hesitate to contact Kerren Hosking, Executive Manager Corporate Affairs and Governance, should you wish to discuss this further.

We look forward to seeing the draft report in due course.

Yours sincerely

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Chief Executive Officer