

Review of Australia's health system performance information and reporting frameworks

Public consultation paper for the Australian Health Ministers' Advisory Council.

The proposed framework for whole of health system performance information and reporting

1. What are your views on the proposed framework for health system performance and reporting, including the recommendations on what should be included in the framework? Is there anything missing from the proposed framework?

We support the intention to create one overarching framework. Consolidation efforts should deliver greater efficiencies at a departmental level, and also among clinicians who input data. As a national charity working across the stroke journey, the Stroke Foundation works to reduce the impact of stroke. Despite being one of Australia's biggest killers and a leading cause of disability, there has been a lack of coordinated effort by successive Governments to collect high quality stroke data. In the face of this information vacuum, in 2007 the Stroke Foundation began the National Stroke Audit, collecting and evaluating data on the delivery of stroke care using standard indicators based on best-practice recommendations of the clinical guidelines. More recently we collaborated with the stroke community to develop the Australian Stroke Data Tool (AuSDaT), an integrated data platform collecting and housing information for the national stroke audit, the Australian stroke clinical registry (AuSCR) and other stroke programs. Whilst the proposed recommendation to align the framework with strategic priorities of the health system is welcomed, the current disconnect between the draft national Strategic Framework for Chronic conditions (listing cardiovascular disease as a key priority) and the NHPF (containing no stroke specific indicator set) is disappointing. National stroke audit results consistently show enormous variability in the quality of stroke care being delivered. Greater effort is needed federally to ensure the new framework collects the right data needed to address Australia's strategic health priorities. We agree the proposed framework should serve a number of purposes with clearly defined beneficiaries. Clinicians should be more clearly identified as both beneficiaries of the framework and active agents in driving improvements in health outcomes through QI at an operational level. Equity is a positive addition to the framework, and reflects our previous calls to narrow the gap between best and worst performing Australian hospitals.

Greater transparency of data will help achieve equity of care. As a consumer based organisation representing the voice of stroke in Australia, we welcome the proposed addition of consumer satisfaction measurements into the proposed new framework.

2. What are your views on the recommended principles for indicator selection?*

***Note: The review has recommended principles for the selection of indicators. A review of the indicators themselves was not in the scope of this review.**

We support the inclusion of outcome indicators in the new framework, and would like to see investigation into leveraging outcome data from existing disease specific registries such as AuSCR, a collaborative national effort involving Australia's stroke community to monitor, promote and improve the quality of acute stroke care. AuSCR collects and collates data from participating hospitals on type of care provided and care outcomes, via patient contact 3 to 6 months after stroke. We support placing greater focus on collection of indicators in primary and non-public health care settings and have long advocated for an indicator on Integrated Health Checks (IHCs). Conducted in primary care, IHCs use evidence based methods for the early detection and management of those at high risk of chronic disease, and have proven to be effective in chronic disease prevention. Better measurement of post stroke care at the primary health level is welcomed by the Stroke Foundation. Our consumer feedback suggests wide variability in people's recovery after stroke, with issues such as whether a discharge plan was provided, access to rehabilitation and provision of follow up from a health care professional after discharge playing a significant role in survivor experience. Limited data collection on stroke survivors in primary health settings hampers our ability to drive improvements for this vulnerable group. Among the Australian stroke community there is a clear and widely shared understanding of what quality stroke care looks like. It is embodied within the Commission for Safety and Quality in Health Care's Acute Stroke Clinical Standard and recent federal government funding to update stroke clinical guidelines will ensure that care recommendations rely on the most up-to-date clinical evidence. From the data available to us we know that current stroke clinical practice falls well short of our shared definition of high-quality care and alarmingly the standard has barely improved in the past two years. Given the significant burden of stroke in Australia – around 50,000 strokes a year, 440,000 survivors in the community and costing the economy \$5 billion - there is significant benefit to be realised from improving clinical practice. In order to drive improvement there must be a system in place to regularly monitor and report on stroke care standards.

The proposed model for the collection, supply and use of health data

3. What are your views on the proposed model for health data collection, supply and use, including the recommendations on what should be included in the model? Is there anything missing from the model?

The Stroke Foundation supports the proposed model for the collection, supply and use of health data. However we would like to see further exploration into the feasibility of leveraging existing data sets (such as AuSCR and the national stroke audit) in instances

where limited disease specific data is being collected (such as stroke). We would also like to see greater attention given to use of health data to assist clinicians in driving quality improvements at the operational level, including frameworks and tools to support clinicians on the ground. The Stroke Foundation has developed an online portal for health professionals (www.InformMe.org.au) which allows clinician access to relevant localised data collected through the previously mentioned AuSDaT tool. In addition, clinicians are also able to access the latest clinical guidelines and to develop and implement quality improvement plans to target care gaps identified through data collection. Empowering health professionals so that more patients receive evidence based care in acute and rehabilitation settings is central to the InformMe initiative, and we encourage the Australian Government to look at innovative strategies to utilise the data collected in the new framework in the most effective way possible.

4. What are your views on the proposed tiered reporting framework for health data?

Whilst the proposed tiered reporting framework is a sensible concept, the Stroke Foundation believes that effectively including researchers in the same category as the public is a missed opportunity. Providing researchers with a 'higher level of access' has the potential to deliver greater success in breakthrough health care treatment. Consideration of how the framework could also align with Australia's medical research and innovation priorities would be welcomed by the Stroke Foundation.

There is currently no reference in the report to NGO's/NFP's, professional associations, universities or research institutes – groups that participate heavily in the field of healthcare, data collection and research. Failing to acknowledge these various groups that are working hard for health system delivery, monitoring, evaluation, data collection, data reporting and data linkage is a disappointing oversight.

The proposed recommendations for implementation

5. What are your views on the recommendations for implementation? Is there anything else that should be considered?

The Stroke Foundation particularly supports the proposal to clarify the roles and responsibilities of the various organisations involved in Australia's health system performance information and reporting system. We hope that efforts are then made to communicate this information to the public. Understanding the function and capacity of these organisations has been at times challenging, particularly with the number of announcements in recent years regarding reform of Australia's health bureaucracy.

We support the suggested principles for the selection of indicators. In the establishment of new indicators, the Stroke Foundation would like to see relevant stakeholders consulted as part of any indicator development process. Over the past three years, the Stroke Foundation has worked collaboratively with the Australian Stroke Community to establish the national stroke data dictionary (NSDD), which sits within the AuSDaT and

is now consistently used in many stroke clinical settings for quality improvement data collection activities. Whilst some investigations have been made into getting the NSDD incorporated into the National Health Data Dictionary, the cost involved to do this has been a significant deterrent. Notwithstanding this, the stroke community's efforts to establish common stroke data definitions have been significant, and it would be disappointing if this body of work was overlooked in the future.