

National Stroke Data and Quality Framework

Aim

This paper outlines a national framework for data and quality improvement in stroke. This framework has been developed through extensive consultation with Australian Stroke Coalition (ASC) members and other leaders within the stroke community to guide the development of systems aimed at improving the delivery of evidence-based care for people affected by stroke.

Background

Over the past five years there has been increased focus on quality improvement and data collection driven by members of the stroke community and by health reform. This work has included:

1. Establishment of the National Stroke Audit Program and development of a large set of indicators linked directly to processes of care outlined in the Clinical Guidelines for Stroke Management (2007)
2. Development of a set (14) of acute stroke indicators by an expert working group convened by the NSF (2008). This core set, representing good stroke care within the acute setting, was developed to enable comparison between audit cycles over time. In 2008/9 this set was further refined to eight indicators as part of the Australian Council on Healthcare Standards (ACHS) clinical indicator program (EQuIP).
3. In late 2008 a group of experts came together and helped develop the Australian Stroke Clinical Registry (AuSCR) minimum data set. In 2009, the AuSCR was piloted. The focus of AuSCR is to ensure a minimal dataset on all patients admitted to participating hospitals is obtained in a prospective manner and includes follow-up of survivors at 90+ days.
4. In 2010 a meeting was held as part of the review of the Acute Stroke Services Framework. There was general agreement that there should be nationally consistent data collection principles, that linkages between all data collection processes should be explored and that the National Audit data set should be the basis on which all others data sets are drawn. There was also general agreement of the importance of a common voice when discussing data collection. The data 'egg' was borne out of this meeting (fig. 1).
5. In April 2011, representatives from the National Stroke Research Institute (NSRI), The George Institute for Global Health (TGI), the National Stroke Foundation (NSF), and the Stroke Society of Australasia (SSA) met to consider how best to integrate the current national activities for data collection and quality improvement in stroke. This meeting resulted from feedback from clinicians that we needed to simplify the data collection processes and link where possible. The outcome of this meeting included agreement that:
 - a comprehensive, integrated system of data collection and quality improvement aimed at measuring adherence to evidence-based care and improving patient outcome should be strived for by government and non-government jurisdictions (fig. 2);
 - pilot programs to test the feasibility of integrating or linking data systems should be encouraged and commenced; and
 - a national workshop be held to discuss these concepts.
6. In September 2011, a national workshop was held in Adelaide to present a proposed national approach to data collection and quality improvement in stroke. Issues discussed included:
 - Current data collections in stroke and their merits, current government initiatives including the development of clinical standards;

- The issues and opportunities in harmonising and linking existing data collection systems (AuSCR, NSF Audit, AROC, etc). The importance of reducing data collection burden for clinicians and examples of current data linkage initiatives; and
- The importance of data collection linked to an evidence-based, quality improvement program to drive change in clinical practice (fig. 2)

The workshop finished with the need to develop a nationally agreed framework for data collection and quality improvement that can be used to advocate for government support. The ASC has recognised the need for consensus about the approach and the indicators to be collected.

7. In November 2011, a National Health and Medical Research Council Better Health Initiative Partnership grant was funded. The main aim of this 4-year project is to demonstrate that integrated and comprehensive data coupled with an active and evidenced-based clinical practice improvement program is more effective than when compared to the status quo. This will be facilitated by ensuring better use of existing stroke data in Australia to routinely monitor and improve the quality of care. The project is mainly focussed on demonstrating the benefits of these concepts in Queensland. However, it also includes data linkage pilot sub-studies between AuSCR and State health department data and a process to determine the best way to harmonise the AuSCR and NSF web-based data collection systems. The partner organisations involved are Florey Neuroscience Institutes (Stroke Division, previously the National Stroke Research Institute), National Stroke foundation (NSF); Queensland Health; Stroke Society of Australasia (SSA); The George Institute for Global Health; NSW Agency for Clinical Innovation; Monash University; Victorian Stroke Clinical Network (VSCN) Department of Health; Victorian Data Linkages, Department of Health; Statewide Stroke Clinical Network, South Australia Health; WA Stroke Clinical Leads, Department of Health.
8. **Australian Stroke Coalition discussion** - At the annual meeting of the Australian Stroke Coalition in April 2012, the member representatives discussed the proposed 'national stroke data and quality' framework with a view to endorsing its use in communications with government. The representatives agreed in principle with the framework. However, it was felt that an opportunity for wider input would be useful in confirming further consensus of the framework. It was agreed that this discussion paper would be further developed and sent through ASC representatives to the member organisations asking for information and comments and other key individuals or groups working in this area e.g. AUSCR Management and Steering Committees, particularly around how ASC member organisations and others may support its implementation. Further consultation occurred from April 2012 to August 2012 with overwhelming support given to the framework.
9. **Federal Government: The National Health Reform Agenda** - the National Health Reform Agenda places performance monitoring and clinical standards for improved quality and safety of care as a central tenant. The Health Reform process has established two new agencies to contribute to performance monitoring and establishment of clinical standards. This includes the National Health Performance Authority (NHPA) and the Australian Commission on Safety and Quality for Health Care (ACSQHC). The NHPA will determine and report on measures agreed to by the Council of Australia Governments (federal and state heads) whilst the ACSQHC will develop health care goals and standards for agreement by Australian Health Ministers.
10. In 2011/12 the ACSQHC developed the first set of safety and quality goals for health care. These goals focused on diabetes, acute coronary syndrome and stroke. In the stroke action guide under the title *Appropriateness of care* the paper states "In order to achieve appropriate care for transient ischemic attack and stroke, actions are required across the continuum of care that spans pre-hospital, hospital, and the community. This paper goes on to say that "success will be measured by having a national clinical standard for transient ischemic attack (TIA) and stroke in place, people receiving care in line with the standard, people with a TIA or stroke receive their care in a formally-integrated and coordinated system that involves ambulance services, the acute care system, the primary care system, and the community care system and there is a decrease in stroke mortality and the incidence of recurrent stroke."

11. Following on from the national health care goals for stroke, the ACSQHC proposes the development of national standards for stroke care. These standards will draw on existing clinical guidelines and be developed with extensive consultation across the Australian clinical community. The standards are due to be finalised by June 30 2013.

To support these national health care goals and developing standards, a number of performance indicators will be measured and systems will be needed to ensure the indicators are reliable, attributable, and comparable and have the ability to measure progress over time. The system to measure these indicators is required to be administratively simple and cost effective. Work done in recent years, by the stroke community, on the development of clinical indicators, systems for data collection, and health care priorities has contributed to the stroke being chosen as an area of focus. It is critical that stroke maintain a strong presence within the national health reform agenda and continues to capitalise on the progress made over the last 5 years. In light of all of this work the following National Framework for data and quality improvement is proposed.

National Stroke Data and Quality Framework

It is proposed that a national data and quality improvement framework for stroke be a comprehensive, integrated system of data collection and quality improvement aimed at measuring and reporting adherence to evidence-based care, national standards and improving patient outcome and that this framework should be adopted by government and non-government jurisdictions (fig. 2).

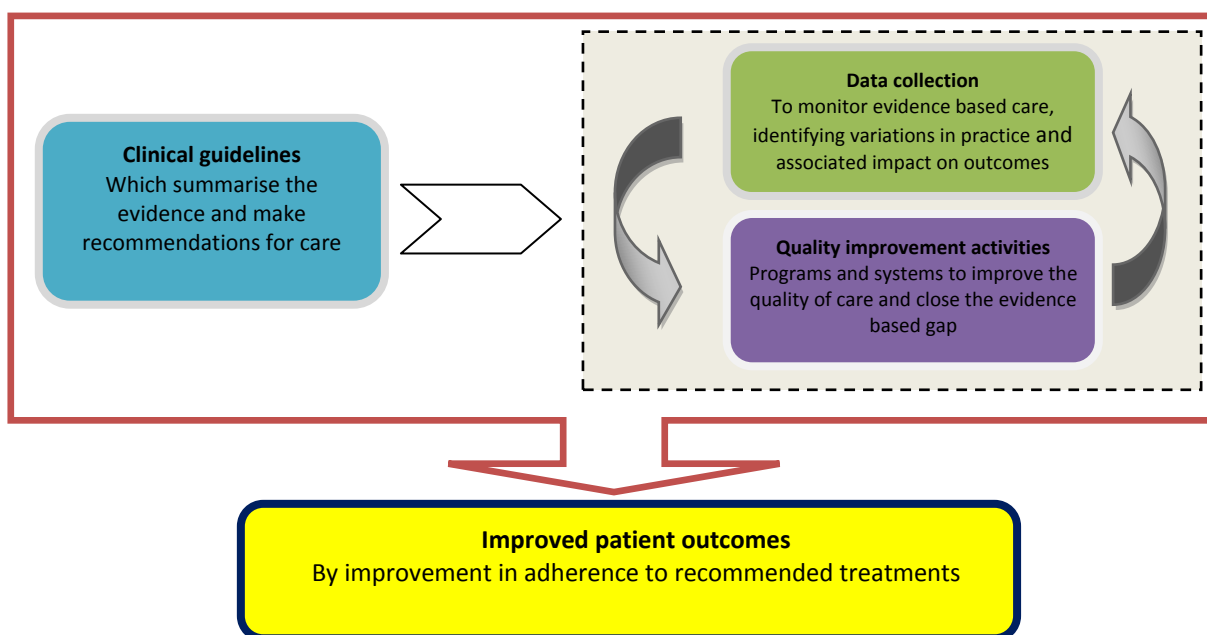


Figure 2. Processes required to ensure delivery of evidence based clinical care

Linked to national standards and performance measures the framework comprises two components:

1) **Integrated Stroke data collection:**

- A clinical registry – a continuously collected small set of variables collected in all acute hospitals, on all patients, through AuSCR.
- An audit collected every two years alternating between acute and rehabilitation in patient settings. This is a collection of larger sets of variables based on the stroke clinical guidelines, collected in all hospitals admitting strokes for acute and rehabilitation inpatient care (n=351).

- An ability to reliably link patient data from each of the above processes to avoid duplication of effort and maximize use of high quality data.
- Availability of other flexible data collection outside of registry and national audit and the capacity to link data across all systems to minimize data entry burden.
- Clear governance and reporting mechanisms in line with national operating principles and standards for data and quality
- Ensuring adequate resourcing and sustainability into the future

2) Quality Improvement Activities

- The provision of targeted quality improvement activities aimed at closing the gaps identified through data collection.
- Building on the foundation of quality data collection, a systematic process of feedback, education, local review and consensus, development of agreed action plans and targeted quality improvement activities should be promoted.

Summary

In summary, much work has already occurred within stroke agreeing on data sets, collecting data and testing quality improvement activities. Stroke is in a unique position to take advantage of current health reform initiatives including the development of clinical standards, supporting the collection of clinical information designed to measure performance and improve the delivery of evidence-based care. Strong consensus, coordinated advocacy and a common voice will facilitate this. The membership of the ASC is ideally placed to develop and coordinate an advocacy strategy to ensure the uptake and implementation of the framework.

The next step is for members of the ASC to formally endorse the framework and to develop an agreed advocacy plan.

References

1. National Institute of Clinical Studies. Evidence-Practice Gaps Report Volume 1: A review of developments: 2004-2007. Canberra: National Health and Medical Research Council, 2008:44.
2. Scobie S, Thomson R, McNeil JJ, Phillips PA. Measurement of the safety and quality of health care. *Med J Aust* 2006;184(10 Suppl):S51-5.
3. Dewey HM, Thrift AG, Mihalopoulos C, Carter R, Macdonell RA, McNeil JJ, et al. Cost of stroke in Australia from a societal perspective: results from the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke* 2001;32(10):2409-16.
4. National Health Reform Performance and Accountability Framework

Appendix 1

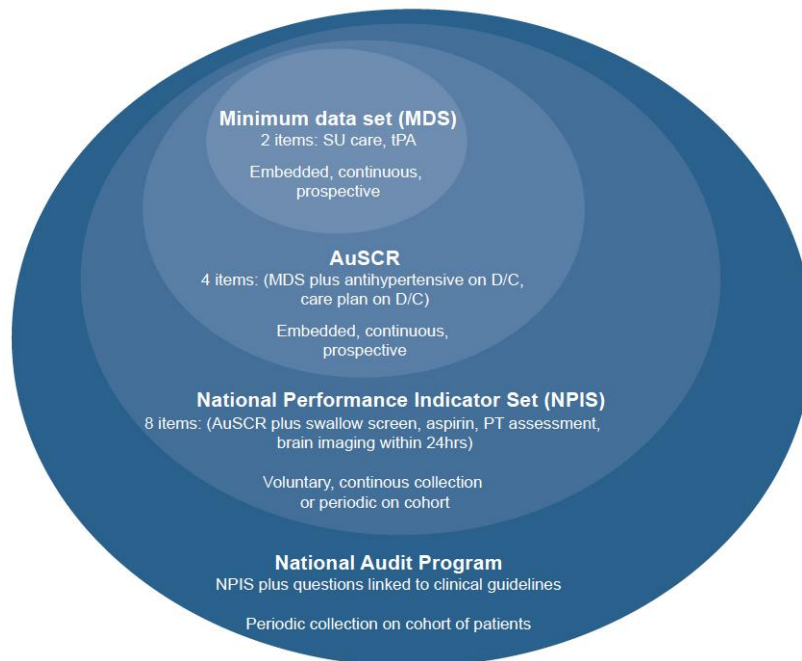


Figure 1: Recommended Integrated Quality Data Collection Model for Stroke in Australia