Consultation Report

Draft Stroke Clinical Care Standard

July 2014
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Introduction

The Australian Commission on Safety and Quality in Health Care (the Commission) was created by Health Ministers in 2006 to lead and coordinate health care safety and quality improvements in Australia. The National Health Reform Act 2011 established the Commission as an independent, statutory authority. It specifies that the Commission will formulate and monitor safety and quality standards and work with clinicians to identify best practice clinical care.

The National Health Reform Agreement 2011 identifies that the Commission will work with clinicians to develop clinical standards for ensuring the appropriateness of care for people with specific clinical conditions, and that the Commission will recommend to Health Ministers the clinical standards suitable for implementation as national clinical standards.

The Commission has been working with consumers, clinicians, health managers and researchers to develop the Stroke Clinical Care Standard.

It complements existing efforts by The National Stroke Foundation and The Australian Stroke Coalition to improve the care of people with stroke.

This report provides a summary of consultation findings regarding the draft Stroke Clinical Care Standard.
About the consultation

The public consultation period ran from 31 March 2014 to 23 May 2014. A total of 200 responses were received by the Commission as part of this consultation process.

Consultation documents for this Clinical Care Standard included:

- the draft Clinical Care Standard for Stroke. The document outlined key components of care that a person with stroke should receive from the onset of symptoms to the completion of their treatment in hospital. This included stroke assessment, thrombolysis if indicated, acute stroke care, initiation of rehabilitation, stroke prevention, carer training and support, and an individualised care plan.

- a summary of evidence sources used to support the development of the Clinical Care Standard.

- a draft indicator specification. This document outlined a set of suggested indicators developed to assist with local implementation of this Clinical Care Standard. These indicators intend to support health services in monitoring the implementation of the quality statements, and improvements as needed.

- draft consumer and clinician fact sheets.

The purposes of the consultation process were to determine if the draft Clinical Care Standard covered key components of care, the relevance of suggested indicators and fact sheets, and to identify potential enablers and barriers regarding the use of the Clinical Care Standard.

Stakeholders across Australia were contacted by post and requested to submit feedback on the draft Clinical Care Standard. The consultation was also promoted via the Commission’s website, Twitter account, On the Radar weekly publication and email bulletin. Members of the Stroke Topic Working Group also promoted this consultation.

Those contacted included medical colleges and societies, organisations, state health departments, Local Health Networks, Medicare Locals, consumer groups and private sector organisations. Feedback was received by either written response or online survey from a cross-section of these stakeholders. Additionally, key organisations met with the Commission to discuss the draft Clinical Care Standard in detail.

The following sections of the report provide a summary of the consultation process and responses.
Consultation process

Consultation questions

The Commission asked stakeholders to respond to the following consultation questions:

1. How well does each quality statement cover the key aspects of care that it describes? Please provide any comments you may have, and evidence to support any modification to a quality statement.

2. What factors currently prevent the care described in the Clinical Care Standard from being achieved?

3. What factors will support the practical application of this Clinical Care Standard?

4. How relevant are the suggested indicators in supporting the monitoring of the quality statements at the local health service level? Please provide any comments you may have, and evidence to support any modifications.

5. How should the Clinical Care Standards be disseminated?

6. Do you have any general comments in relation to each Clinical Care Standard?

Submissions received

A total of 200 submissions were received. A breakdown is provided below:

<table>
<thead>
<tr>
<th>Respondent type</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>124</td>
</tr>
<tr>
<td>College</td>
<td>6</td>
</tr>
<tr>
<td>Jurisdiction (state or territory response)</td>
<td>11^</td>
</tr>
<tr>
<td>Organisation:</td>
<td></td>
</tr>
<tr>
<td>- General</td>
<td>32</td>
</tr>
<tr>
<td>- Primary health care</td>
<td>2</td>
</tr>
<tr>
<td>- Private health care</td>
<td>0</td>
</tr>
<tr>
<td>Local Health Networks</td>
<td>24</td>
</tr>
<tr>
<td>Committee</td>
<td>1</td>
</tr>
<tr>
<td>Total responses</td>
<td>200</td>
</tr>
</tbody>
</table>

^ State and territory health departments and/or agencies.
Assessment of submissions

Submissions were allocated an identification number and classified according to scope of the Clinical Care Standard, quality statement, indicator, consumer fact sheets, language/structure of the document, enablers/barriers, dissemination, and general comments.

Feedback was themed for analysis and assigned into the following categories:

1. Consider now: Comments in this category were those relating to the scope of the Clinical Care Standard and the focus of each quality statement, terminology used, specificity, clarity of language particularly in the ‘what it means’ section, relevance of the proposed indicators, supporting evidence, and barriers and enablers relating to implementation.

2. Consider in the future: Comments in this category were those suggesting extending the current scope of the Clinical Care Standard (e.g. extending the Clinical Care Standard into the primary health care setting).

3. No action: Comments in this category expressed agreement and/or support for the Clinical Care Standard. Comments in this category also related to personal experience or suggestions to include background information that was out of scope of a Clinical Care Standard.

Following this assessment, this information was provided to the Stroke Topic Working Group for further refinement of the Clinical Care Standard.
Summary of consultation feedback

Overall, there was strong support for the development and draft content of the Clinical Care Standard for Stroke. Many saw the Clinical Care Standard as a positive step for improving stroke care and commended the Commission for undertaking this work. It was commented that the Clinical Care Standard will support the delivery of appropriate care, reduce unwarranted variation in care and aid decision-making between patients, carers, and clinicians.

There was strong support for the multidisciplinary composition of the Topic Working Group, particularly the involvement of consumers. Some respondents were, however, critical of the lack of rehabilitation physicians in the group.

Below is a summary, although not exhaustive, of the responses received.

Structure and language

In general, feedback was positive about the presentation of the information. The quality statements were seen as being easy-to-read, logical, succinct, well-structured, and having sufficient detail. The flow of the document was also seen as helpful.

The ‘What it means for you’ sections and the fact sheets were viewed as useful, particularly for consumers.

There was support for the patient-centred approach of the standard. The language was generally viewed as appropriate for consumers and providing a reasonable description of what consumers can expect. However, some respondents thought that the language may raise consumers’ expectations too high and that they may expect services not currently provided throughout Australia. Some were critical of the language in the section on the clot-busting medicine, which did not explain that the treatment was only suitable for some patients.

Suggested improvements included making the language more suitable for consumers and ensuring that patient-centred care is a focus throughout. Language suggestions included changing specific terms not commonly used by consumers (e.g. suffered a stroke), providing more information about some issues (e.g. education for secondary prevention), and ensuring that consumer involvement in decision-making and consumer preferences were included throughout the standard.

Scope and context

Generally, the standard was found to be comprehensive, covering the key aspects of care. The main concerns raised were the lack of coverage of ongoing community-based rehabilitation, the place and context of thrombolysis, and that children were not included.

Most of the feedback about scope related to the focus on acute stroke, with concern that ongoing rehabilitation in the community was not properly addressed. Some respondents were also concerned that the document did not include the management of transient ischaemic attack (TIA) and secondary prevention following TIA, other respondents commented on the lack of coverage of end-of-life care. Several respondents suggested that children should also be included in the standard.

There was substantial feedback about the place of thrombolysis within the Clinical Care Standard. The central issue being that thrombolysis could be perceived as a standard of care when it is only appropriate for some patients. There was also concern that its inclusion may give rise to expectations
that every health facility needs to offer it when there may not be the resources to do so. Some respondents felt that other treatment options should be mentioned.

**Quality statements**

*Draft quality statement: 1 Stroke assessment*

A stroke can be caused by bleeding (haemorrhagic stroke) or a blood clot (ischaemic stroke). A patient with suspected stroke is immediately assessed using a validated stroke screening tool at first clinical contact such as the Face, Arm, Speech and Time (F.A.S.T) tool.

- **FACE:** Check their face. Has their mouth drooped?
- **ARMS:** Can they lift both arms?
- **SPEECH:** Is their speech slurred? Do they understand you?
- **TIME:** Time is critical. If you see any of these signs call 000 now.

The majority of comments were about the FAST tool and its limitations. A common concern was that while the FAST tool is suitable for the general public, other screening tools are more suitable for clinicians. Several respondents suggested including the ROSIER tool in the statement as it is the preferred screening tool in the Emergency Department and has been validated.

Other issues raised were that the quality statement implies that the FAST tool determines stroke, whereas it only identifies potential stroke. Some respondents suggested mentioning other tests and assessment tools which are used to diagnose stroke. Additional information for consumers to explain the benefit of rapid assessment of stroke was also suggested.

*Draft quality statement 2: Thrombolysis*

A patient with stroke who is potentially eligible for thrombolysis (administration of a clot-busting medicine) is rapidly transported to a hospital able to provide thrombolysis. If eligible, the patient has treatment offered and administered within 60 minutes of arrival to hospital.

The chief feedback was that thrombolysis may be perceived to be the standard of care or the main treatment for stroke when it is only suitable for a small proportion of people. Several respondents thought that thrombolysis should be mentioned alongside other treatments (e.g. supportive physical and psychological care), while other respondents expressed support for raising the profile of thrombolysis for people who may benefit.

The fact that not everyone may benefit from thrombolysis should be highlighted and that the treatment can only be offered if clinically appropriate. ‘Eligibility’ was not considered an appropriate term to describe patients who meet the clinical criteria for thrombolysis, as it can imply non-clinical factors, such as scope of service or availability of funding. Some respondents identified that the statement does not mention the steps required to identify people who can be offered this treatment; such as the need for CT scanning and clinical assessment.

Another theme was that patients may be led to believe that thrombolysis is offered at all hospitals. Some respondents suggested being more explicit that there are services that can and cannot provide thrombolysis. Others suggested adding more information about the systems that need to be put in place to support rapid transfer to places where thrombolysis is given.
Patient consent for thrombolysis should be mentioned and that treatment depends on the patient’s preferences.

Some respondents questioned the evidence-base to support thrombolysis and considered that this treatment may do more harm than good. Because some considered the treatment controversial, they also questioned the ‘time imperative’ and the resources and effort needed to facilitate timely treatment.

The 60 minutes timeframe was flagged as confusing, as it does not take into account pre-hospital assessment and transfer, which also needs to be timely. The recommended window of treatment (4.5 hours from onset of symptoms, as per national guidelines) was suggested as being universally understood and a better timeframe to promote. However, there were also questions about the evidence base for receiving thrombolysis between 3 and 4.5 hours, with the suggestion that patients should not receive therapy 3 hours or more after symptom onset.

**Draft quality statement 3: Acute stroke care**

A patient with stroke receives treatment in a stroke unit through an organised formal stroke network.

There was broad agreement of the benefit of stroke unit care, but terms ‘organised formal stroke network of care’ and ‘designated stroke unit’ were seen as unclear and ambiguous. One respondent suggested that the need for stroke unit care was being confused with implementation models and that this information should be stated separately. There was also uncertainty about whether consumers would understand the meaning of ‘network of people, services and hospitals’.

A common view was that the multidisciplinary nature of stroke unit care should be highlighted, but the standard also needs to mention the variation of stroke unit care in low volume regional centres, in which patients may receive care by the same multidisciplinary team and according to local protocols but in a ward shared with patients with other conditions.

Several respondents thought that the safety and risk to the patient and ambulance services of transferring a patient rapidly should be weighed up against the benefit to the patient.

Some respondents suggested citing the stroke national guidelines in the quality statement so people can refer to the different types of stroke care.

**Draft quality statement 4: Initiation of rehabilitation**

A patient’s rehabilitation needs and goals are assessed within 24 hours of admission to hospital and this directs rehabilitation therapy that starts during the acute hospital admission.

The main comment was that the coverage of rehabilitation is limited to the acute phase of stroke. Many respondents criticised the lack of emphasis on ongoing rehabilitation to the recovery of people with stroke and that this requires specialised rehabilitation teams and programs. The quality statement may imply that this early assessment determines rehabilitation in the community, whereas patients should be reassessed as their condition changes.

Although there was general support for early rehabilitation assessment, several respondents were concerned that there is no evidence to support very early rehabilitation, that is, within 24 hours of hospital admission. There was also concern that achieving this is unrealistic in terms of resources and staffing, particularly for admissions on the weekend, and because some patients may not be able to participate in decision-making or rehabilitation until they are clinically stable.
One respondent suggested taking into account ‘cultural appropriateness’ when assessing the needs and goals of indigenous Australians and people from culturally and linguistically diverse backgrounds.

Other suggestions included: rephrasing the statement to indicate that the patient should be assessed and reassessed in community as their condition changes; stating that the assessment needs to be done by a rehabilitation physician or delegate from the multidisciplinary team; qualifying that rehabilitation may not be appropriate or desired by some patients so as not to falsely raise expectations of patients and their families; providing more information in the consumer section about what services are provided; citing a rehabilitation assessment tool developed by the Australian Stroke Coalition; specifying that rehabilitation should start as soon as possible not just rehabilitation assessment; and emphasising that consumers are included in the goal setting process of assessment.

**Draft quality statement 5: Stroke prevention**

**A patient with stroke receives assessment, treatment and education to reduce their risk of a future stroke before they leave the hospital.**

There was general agreement of the need to initiate treatment and education about stroke risk before patients leave hospital. The main comments were about the lack of clarity of the education component. Several respondents suggested that education should cover not only the risk of future stroke but also other aspects of managing life after stroke, such as rehabilitation, secondary complications of stroke and long term management options.

Several suggested providing examples of lifestyle changes for the consumers section, and emphasising that lifestyle changes are in addition to medicines not an alternative.

Some were concerned that the statement did not reflect consumer involvement in decision-making and that clinicians work in partnership with them. The carer should also be involved.

Feedback was also received about the difficulty of measuring the impact of education provided to patients in hospital.

**Draft quality statement 6: Carer training and support**

**A carer of a patient with stroke is given practical training to enable them to provide care, support and assistance to a patient with stroke with everyday activities of living.**

There was overall agreement with this quality statement and many respondents commended that there was a section specifically for carers. The main suggestion was that the quality statement should also include the provision of emotional support not just training.

Some suggested that the training is dependent on the patient’s outcome post stroke and it may be too early to commence carer training until this is known.

Some comments highlighted the challenges with implementation such as limited resources to provide carer training and uncertainty about who will provide it.
Draft quality statement 7: Individualised care plan

Before a patient with stroke leaves the hospital, they are involved in developing an individualised care plan that identifies and addresses their recovery and rehabilitation goals, their risk factors, any equipment they need, and the contact details for ongoing support services available in their community. This plan is also provided to the patient’s general practitioner.

The main suggestions were to add that the carer is involved in development of the plan, add that the plan should include referral to a rehabilitation service, specify that the individualised care plan is provided to the patient before they leave hospital, and to add that the plan should be given to other clinical providers (e.g. ongoing support services, pharmacists) as well as GPs.

Other suggestions were to include more information about what the plan provides in the consumer section and to explain that the plan is in addition to a standard discharge summary. Several respondents suggested emphasising the importance of education about medicines before patients leave hospital to promote long-term medication adherence.

There was also feedback about the lack of evidence to support provision of an individualised care plan, which may impact on the implementation of this quality statement.

Several highlighted the need to develop community-based services to train staff and meet patient needs, while one suggestion of having a ‘system navigator’, a go-to person in the community, to assist the patient with implementing their plan.

Consideration should be given to mentioning that the plan will need to be reassessed depending on the patient’s progress and condition post discharge.
Feedback on indicators

In general, feedback on the Stroke Clinical Care Standard indicator set was supportive, with some suggestions for refinements.

Some respondents expressed concern about the burden of data collection. There was a suggestion by some for standardised mandatory data collection into a central registry.

Some recommended additional indicators, a number of which had previously been considered and put aside by the Stroke indicator sub-group.

The main themes emerging from the consultation feedback were:

- **The evidence for thrombolysis and time of administration.** One respondent challenged this assumption by stating that the evidence for thrombolysis therapy for ischaemic patients is weak. Other respondents suggested using the 0-3 hour window rather than the 0-4.5 hour window as an indicator for thrombolysis, because of the weaker evidence for thrombolysis 3-4.5 hours after symptom onset. A number of additional indicators were also suggested for this quality statement, focusing on assessment by a neurologist and transfer from the Emergency Department to a stroke unit.

- **Specifying whether rehabilitation assessment is conducted by a physiotherapist, multidisciplinary team or other allied health professionals.** A number of respondents queried the restriction of assessment to that by physiotherapists. Other health professionals suggested for inclusion were speech pathologists, rehabilitation physicians, dietitians and/or social workers, while some suggested multidisciplinary team case conferencing.

- **Whether to measure and report at the hospital or local network level.** Some respondents identified that the indicators supporting stroke unit care were dependent on the functioning of hospital networks rather than a hospital and therefore data should be collected and reported at the local network level.

- **Expansion or refinement of the discharge medication indicators.** One respondent advised that patients with ischaemic stroke should receive a combination of an antithrombotic, antihypertensive and a statin when they are discharged from hospital and that the ‘or’ should be removed from between antihypertensives and antithrombotics as they are not alternatives to one another. The same respondent suggested adding in the novel anticoagulant agents, which like warfarin are also used for atrial fibrillation. There was also a suggestion for an indicator focusing on provision of written information to patients when prescribed warfarin.

There were a number of specific suggestions about the wording of some indicators, information that should be included in the comments sections (e.g. adding that patients who are telethrombolysed are included; further contraindications to thrombolysis), and changes to the order of some indicators.
Barriers and enablers to care identified in the Clinical Care Standard

Barriers affecting the implementation of the Clinical Care Standard were classified as follows:

- **Poor consumer awareness and lack of involvement in decisions.** A lack of consumer awareness of the need for urgent attention for stroke symptoms was the main concern identified. Related to this, patient preferences on how and where they would like to be treated may be a barrier to rapid assessment, and language and cultural issues may affect stroke recognition in some remote Aboriginal communities. A lack of patient involvement in decision-making, particularly among older patients and patients living in rural areas was also highlighted.

- **Poor clinician awareness, knowledge and leadership.** There is a lack of awareness and knowledge among clinicians (doctor, nurse, paramedic) of the need for rapid assessment, assessment tools and thrombolysis protocols. Lack of medical leadership was also raised as a barrier. Resistance among some doctors to the use of thrombolysis as a standard of care for ischaemic stroke was also highlighted.

- **Insufficient resources and staffing.** Limited resources and services in regional and remote areas was a common theme. Specific issues highlighted were: a lack of a regional stroke code or policy, limited access to rapid transport to stroke units (inadequate ambulance service or limited availability of Royal Flying Doctor Service), lack of 24/7 access to CT imaging services, lack of adequately trained radiographers, lack of neurologists, lack of 24/7 acute thrombolysis centres, lack of stroke rehabilitation services. Another common concern was levels of hospital staffing generally, in particular, that hospitals are inadequately staffed to provide a rapid response on a 24/7 basis. Other staffing gaps identified in both urban and rural settings: access to neurologists, access to CT radiographers, lack of allied health and lack of access to them on weekends and after hours, lack of specialist stroke nurses. Inadequate number of acute stroke units and stroke unit beds were also identified as barriers.

- **Poor communication and coordination.** Poor communication and coordination between facilities during patient transfers can cause delays in treatment. Poor communication between acute and rehabilitation services was also highlighted.

- **Conflicting policies.** These included: ambulance polices that may result in hospitals being bypassed, with a subsequent increase in patient travel time, and hospital policies that may delay the time to thrombolysis, such as doing a CT scan prior to transferring a patient.

- **Lack of incentives**, such as increased funding, for implementation of the standards.

- **Other barriers** included: concern about the resource-benefit in providing thrombolysis to patients 3-4.5 hours post stroke onset, where evidence of benefit is smaller; lack of ambulance insurance cover, meaning that some people may not call for an ambulance; concern that the standards may not be updated in line with new clinical guidelines on stroke.

Enablers that can support the implementation of the Clinical Care Standard were identified as follows:

- **Consumer and carer education and information.** Consumer education about the FAST tool, stroke symptoms and the need to call an ambulance. Pictorial presentations of FAST tool may be particularly useful for some Aboriginal and CALD communities. Regular educational campaigns seen as key. Consumer information about treatment choices for stroke, such as benefits and risks of thrombolysis. Information for carers about how they can support patients.
- **Education and training of doctors and nurses**, particularly in the use of assessment tools and thrombolysis protocols.

- **Stroke units and stroke networks**. Development of stroke unit networks within each state, so that patients in regional areas can be offered appropriate transfer to an acute stroke unit. Greater recognition of stroke units as significant specialist units, like coronary care units.

- **Resources and staffing**. Adequate resources, systems and services to support the implementation of the standards, such as full time neurology services, 24/7 access to CT scan, regional stroke centres/units. Adequate staffing of allied health and specialist stroke nurses in stroke units. Further development and expansion of Telemedicine services.

- **Policies, protocols and tools**. Development of a standardised patient transfer tool to improve relay of relevant patient information and speed of transfers between facilities. Implementation of tools for assessing patient rehabilitation needs, such as the Assessment for Rehabilitation Tool. Improvements for formulating care plans: improved access to resources for formulating care plans, such as My Stroke Plan; involvement of GP and local services so the plan is implementable; dissemination of the plan to all those involved in ongoing care, including pharmacists. Communication and dissemination of local hospital protocols and polices to drive the standards. A national data collection tool to facilitate and promote reporting, similar to the Australian Stroke Data Tool, currently being developed by the Australian Stroke Coalition. Standardised local reporting of the quality measures, such as within a hospital or hospital network.

- **Linkage to funding incentives**. Linking of Activity Based Funding to the implementation of the Clinical Care Standards to create a financial incentive, such as linking funding to reporting or to patient outcomes.
Dissemination strategies

A summary of the suggested mediums for dissemination of this Clinical Care Standard and associated documents is provided below:

- **Consumers**: web resources, public health campaign to raise awareness of stroke, links from websites, such as the National Stroke Foundation, patient education materials, media outlets, pamphlets and posters in medical units, foyers, rehabilitation units and stroke units
- **Clinicians**: the Commission’s website and newsletter, links from websites and existing resources (e.g. the National Stroke Foundation), printed resources (bulletins, newsletters), web resources, education and training resources, including undergraduate and continuing education. Communications and exposure at professional meetings and conferences and through the Colleges and other professional organisations (e.g. Stroke Societies of Australasia, Associations of Speech Pathologists, Association of Neurologists etc.), local health networks, stroke clinical networks.
- **Health services**: distribution of printed resources, particularly to acute stroke and rehabilitation services, email, intranet, incorporation in health service contracts.
Next steps

Feedback from the consultation process was collated and analysed, and a summary of key findings was presented to the Stroke Topic Working Group. Following this, the Clinical Care Standard was revised and finalised for submission to the Commission’s various committees.

The Clinical Care Standards will undergo a process of endorsement through the relevant channels.

It is envisaged that the Commission will provide high-level implementation support for this Clinical Care Standard, with activities and resources to be identified in the coming months.

Further information about this Clinical Care Standard can be found at www.safetyandquality.gov.au/ccs.

If you would like to be kept informed about the work of the Commission, sign up to the Commission’s newsletter online, or follow the Commission on Twitter @ACSQHC.