National Institute for Health and Care Excellence

NICE Quality Standards Consultation – Head Injury

Closing date: 5pm – 12th June 2014

Organisation	**Headway – the brain injury association**
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Please note: comments submitted on the draft quality standard are published on the NICE website.	
Would your organisation like to express an interest in formally supporting this quality standard? ✓ Yes ☐ No For information about endorsing quality standards please visit http://www.nice.org.uk/guidance/qualitystandards/indevelopment	

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Please provide comments on the draft quality standard on the form below, putting each new comment in a new row. When feeding back, please note the section you are commenting on (for example, section 1 Introduction). If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor). If your comment relates to the standard as a whole then please put 'general'.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the quality standard.

Please add rows as necessary.

Section	Comments
List of quality standards	We are concerned about the lack of information for people who have sustained a minor brain injury and are experiencing post-concussion syndrome. Headway has long been campaigning for better awareness of this issue, with Headway's own research, in conjunction with Warwick Medical School and the University of Warwick, showing that 92% of hospitals were failing to provide the discharge advice recommended in the NICE Head Injury guidance. This can leave many people struggling with long-term effects that they do not understand and have no information to help them seek support for. Additionally, many GPs lack the information and training they need to spot the signs of mild/moderate brain injury and make appropriate treatment and referral decisions for their patients. For information see: https://www.headway.org.uk/news/headway-issues-statistics-on-head-injury-info.aspx https://www.headway.org.uk/minor-head-injury-awareness-campaign.aspx https://www.headway.org.uk/supporting-gps.aspx

Section	Comments
List of quality standards	Headway has, in numerous consultation responses, suggested that NICE includes the risk of hormonal imbalances after brain injury in its materials. While we appreciate that this would be outside the scope of this document, we would like to repeat our call for this important issue to be considered. For further information visit https://www.headway.org.uk/hormonal-imbalances.aspx
List of quality standards	While it is very positive that NICE is developing a QS to cover the rehabilitation stage after traumatic brain injury, this document should cover vocational rehabilitation either as part of quality standard 6 or as a new quality standard. This is carried out in some parts of the country by community neurorehabilitation teams and Headway groups; it is a distinct type of rehabilitation and would benefit from robust guidance regarding service provision. Numerous studies have concluded that vocational rehabilitation services are not sufficiently widespread or available, but have an extremely positive impact on the outcomes of people with brain injury. In terms of source guidance, see SIGN Guide 130 (section 8) or the BSRM/RCP/JobcentrePlus publication 'Vocational assessment and rehabilitation after acquired brain injury. Inter-agency guidelines' (2004) http://www.rcplondon.ac.uk/sites/default/files/documents/vocational-assessment-rehabilitation-abi.pdf
Outcome measures	The outcome measures currently included seem very vague and are not specific to traumatic brain injury. It is important to use tools that can measure improvement in cognitive, emotional and behavioural effects such as neuropsychological measures. This is particularly important for the rehabilitation quality statements.
Quality statement 4 (p16)	The use of GCS alone is not a reliable indicator of the need for neuroscience unit referral. We would suggest that a period of PTA should be included in this section as well as other diagnostic criteria. For instance, bedside assessments and imaging results should also be taken into account.

Section	Comments
	Throughout the document there are references to diagnostic techniques for moderate/severe brain injury that focus only on GCS and these should also be changed.
Quality statement 4 (p16)	There is considerable anecdotal evidence that people with brain injury are treated in general units, mental health or geriatric care wards that are completely inadequate for their treatment and management. The Quality Standard should take into account studies such as 'Trend in head injury outcome from 1989 to 2003 and the effect of neurosurgical care: an observational study: Lancet 2005'. It has been shown that outcomes for patients with severe head injury are significantly improved with treatment in a specialist neurosurgical centre. If all current specialist neurosciences units were equipped to deal with their local population, then a recommendation of transfer to the patient's local specialist centre could remove the problem of lack of resources. Andy Eynon, Director of Neurosciences Intensive Care at Wessex Neurological Centre, has stated: "Once a patient has been recognised as having a severe head injury, even before the CT scan, the emergency transfer ambulance should be booked. The local neurosciences unit should be contacted and the neurointensivists should make arrangements to ensure that a bed is available. Only when the CT is available is the neurosurgeon required; to determine whether immediate surgery is necessary." (Eynon, C.A. What is the best outcome from severe head injury, JICS; 9 (3), p. 215.)
Quality statements 5 and 6	Headway's Approved Provider scheme offers accreditation for NHS and independent care providers that specialise in acquired brain injury, including hospitals and neuro-rehabilitation units, residential and nursing homes, and respite facilities. Through a robust assessment process and a series of independent inspections, the aim is to enable commissioners and families to identify high-quality services that will achieve the best possible outcome for patients. You can find out more about this at: https://www.headway.org.uk/approved-provider-scheme.

Section	Comments
	Given that the outcome measures in quality statements 5 and 6 rely heavily on local data collection that could be difficult to implement without robust guidance, we suggest that the QS should include information to help commissioners find high-quality services, such as a recommendation to utilise our Approved Provider scheme. We would like to offer our support to the QS development group if any further information is required.
Quality statements 5 and 6	The source guidance being relied on for these complex statements, which cover all stages of rehabilitation after head injury, is limited to the SIGN guide 130. While this is good guidance, there are other documents that more thoroughly define an ideal rehabilitation pathway and the services it should contain. In order for this QS to make a positive difference, it is essential that it draws on evidence from these. The documents we suggest should be included in the source guidance are: • QRs 4, 5 and 6 of The National Service Framework for Long Term (Neurological) Conditions (2005) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf • BSRM Standards for Rehabilitation Services Mapped on to the National Service Framework for Long-Term Conditions http://www.bsrm.co.uk/Publications/StandardsMapping-Final.pdf • Standards for specialist in-patient and community rehabilitation services – British Society of Rehabilitation Medicine BSRM 2002 http://www.bsrm.co.uk/ClinicalGuidance/standards.PDF • Rehabilitation following acquired brain Injury: national clinical guidelines. (Turner-Stokes Ed.) BSRM / RCP London 2003 http://www.rcplondon.ac.uk/sites/default/files/documents/rehabilitation-followingacquired-brain-injury.pdf

Section	Comments
	• NHS England Service Specification for Specialised Rehabilitation For Patients With Highly Complex Needs [D02/S/a] http://www.england.nhs.uk/wp-content/uploads/2014/04/d02-rehab-pat-high-needs-0414.
Quality statements 5 and 6	There is a strong reliance on local data collection in order to demonstrate the prevalence of long term disability after TBI. However, data is not routinely collected on discharge and the overall prevalence in the community is not known. We suggest that the Quality Standard strongly recommends improved data collection systems.
Quality statements 5 and 6	The Quality Standard does not currently define many aspects of how services should be provided. It should include information on the types of services required, how they should be co-ordinated, what therapies and disciplines should be involved and what capacity is needed for the local population. It should prioritise local services where possible, but make provision for out-of-area referral if necessary. It should also make clear that where possible services are made available for as long as a patient needs them. Priority needs to be placed on equality of access to, and timeliness of, appropriate services regardless of where a person lives. Such guidance needs to be available to commissioners and healthcare professionals if the Quality Standard is to have the desired effect.
Quality statement 5	The 72-hour threshold is arbitrary and may not be a helpful benchmark for all patients. We regularly speak to patients who appear to be 'fine' shortly after seemingly severe injuries and are discharged home, only to present with the effects of brain injury as they try to return to normal life. As such we would suggest that every patient who has sustained any moderate/severe brain injury should receive a specialist assessment, even if they do not appear to be showing any major effects.
Quality statement 5	Categorising by severity in this statement may be unhelpful as any patient who is displaying continuing cognitive deficits after a traumatic brain injury will require specialist support.

Section	Comments
Quality statement 5	We suggest a stronger wording of the guidance to commissioners to require that acute in-patient rehabilitation is made available to those who are assessed as needing it. Unlike statement 6, this statement appears only to require an assessment, rather than to make services available or allow out of area referrals if local rehabilitation units are unavailable for a particular individual. The SIGN guide 130 supports the benefit of early, high-intensity multidisciplinary rehabilitation and associated improvement in outcomes.
Quality statement 5	We would suggest the following change to the end of statement 5: "Adults (aged 16 or over) in hospital with cognitive deficits that continue ~~72 hours~~ after a ~~moderate or severe~~ traumatic brain injury have an assessment of their need for inpatient rehabilitation, and an appropriate and timely referral for rehabilitation is made where appropriate". Importantly, this section needs to specify that commissioners must ensure sufficient in-patient rehabilitation capacity is available, as for community rehabilitation in statement 6.
Quality statement 5	The NHS England Service Specification (http://www.england.nhs.uk/wp-content/uploads/2014/04/d02-rehab-pat-high-needs-0414) specifies timescales and procedures for referral and assessment, determining what level and intensity of rehabilitation (Level 1/2a or 2b) is needed, and timescales for admission. We recommend that this document is included in the source guidance, and as an outcome measure at the beginning of this document.
Quality statement 5	In the 'Healthcare professionals' section, we recommend defines tighter definition of *who* is to perform this very specialist assessment. Healthcare professionals need to be fully trained in the sequelae of acquired/traumatic brain injury and experts in the national, regional and local services that are available. Specialists such as neuropsychologists, neuropsychiatrists, neurologists and rehabilitation consultants may be suitable here, depending on need. It would be helpful to define this in the guidance to commissioners so they can ensure sufficient resources are available.

Section	Comments
	The development group could consider availability of specialist assessors and a certain level of training or experience as an outcome measure for healthcare professionals involved in this process.
Quality statement 5	In 'What the QS means for patients and carers', we suggest you change the phrase "specialised treatment to help them recover normal functions" to "specialised treatment to help them maximise their recovery". Full recovery is unfortunately very often unobtainable, so the QS must use realistic language.
Quality statement 5	Quality requirement 4 ('Early and specialist rehabilitation') of the NSF for Long-term Conditions should be considered here as it highlights the rationale, benefits and structure of high-quality in-patient rehabilitation.
Quality statement 5	The quality measures focus solely on the assessment process, without any examination of the availability of rehabilitation and the outcomes of the patient. We appreciate this may be difficult, but auditing local services and measuring the outcomes of rehabilitation is essential to adequately measure its quality.
Quality statement 6	This statement is welcome as it defines a requirement to consider community rehabilitation services, which are currently very fragmented in different areas of the country. However, it is important that healthcare professionals and commissioners have clear guidance on what ideal community rehabilitation services should look like, and the additional source materials included above should be considered here. Community rehabilitation should take a multi-disciplinary approach and include a variety of services, from those provided by the NHS and local authorities to the essential support provided by voluntary sector organisations such as Headway. While a detailed specification may be outside the scope of this QS, it would be helpful if there was some mention of this to aid commissioners in forming their local service provision.
Quality statement	We suggest changing the wording of this statement to '...with continuing physical, cognitive, emotional and

Section	Comments
6	behavioural deficits...'. Rehabilitation is more effective if it takes on a multi-disciplinary approach to supporting the patient with all of their impairments and it is important that the QS reflects this.
Quality statement 6	Quality requirement 5 ('Community rehabilitation and support') of the NSF for Long-term Conditions should be considered here, as it provides a detailed overview of the benefits and structure of community rehabilitation services. In addition, quality requirement 6 ('Vocational rehabilitation') includes details information about vocational rehabilitation and helps highlight the importance of these services.

Closing date: Please forward this electronically by 5pm on **12th June 2014** at the very latest to QSconsultations@nice.org.uk

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.