NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Head Injury

Date of Quality Standards Advisory Committee post-consultation meeting:
9th July 2014

2 Introduction

The draft quality standard for head injury was made available on the NICE website for a 4-week public consultation period between 15th May and 12th June 2014. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 31 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2. [Two separate appendices for internal and external comments. However, appendix 2 should be deleted before publication and this cross reference updated.]

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Stakeholders generally welcomed and supported the need for a quality standard document; however a number of stakeholders felt that there needed to be a clearly defined and inclusive set of statements.
- Stakeholders felt that the statements should include the role of families and carers, since they have a significant function in the care of the person with a head injury. This was extended to include the support of families and carers as stakeholders felt that staff members should provide them with information and

support. It was suggested that this could be reduced by receiving specialist rehabilitation and continued support.

- A number of stakeholders felt that the language used throughout the document and the quality standards themselves should be more focused; for example instead of noting “outcomes” as a general term, the document should state specific outcomes.
- Stakeholders commented that they would like a definition of head injury to be included.
- It was noted that there is no mention of Cognitive Communication Disorder (CCD), when this is one of the most common deficits after a traumatic brain injury.
- Concerns were raised that it is not clear if all of the quality standards cover all levels/stages of traumatic brain injury. This is particularly relevant when discussing people with less serious (mild) brain injuries that may require treatment, rehabilitation, and discharge advice which could result in negative long-term effects as it was felt that these were not addressed and should be the focus of a quality statement.
- It was felt that for people living with the consequences of a brain injury, transition from children to adult services are an important service, which are not mentioned in any of the statements or throughout the document.
- For a number of stakeholders it was felt that there needed to be information relating to training for GPs, clinicians and staff managing a brain injury. To ensure that people are receiving the appropriate care, and in order for the signs of brain injury to be recognised earlier. It was suggested in particular areas such as the detection of potentially disabling intracranial or cervical spine injury, management of Post traumatic confusion (PTC), the application of the Mental Capacity Act, management of post concussional symptoms and the identification of patients requiring referral to rehabilitation services.
- Stakeholders felt that the quality statements overall focused primarily on the management of acute head injury and that the rehabilitation of people with a head injury as an addition rather than a focus of the statements, furthermore they felt that rehabilitation should not be limited to in-patient or community settings and should look at a longer-time period.

- Stakeholders commented that the quality statements should include training and support of families and carers for people with head injuries.
- Stakeholders noted that there should be a consideration made for the potential effects of drugs and alcohol on people with head injuries. In addition to those people who have a head injury when in police custody who may be intoxicated.
- Concerns were raised over limiting falls to greater than 3 metres as this reduces the significance and severity of shorter falls, especially in children and older people.
- Consider including consideration adjustments for age and people with thyroid cancer as there are increased numbers of CT head and neck scans for this population.
- Concerns were raised in relation to the capacity of services being able to respond to 1 hour scan targets, especially since these are determined by referral indications for scanning/x-rays, which is particularly pertinent for children following a head injury. Stakeholder felt that this will place pressure on commissioners and providers to ensure rapid assessment and diagnostics.
- Stakeholders felt that the priorities of the statements should be re-evaluated as currently there are three separate statements dedicated to imaging, which does not appear to be effective.
- It was noted by stakeholders that it should be considered that any person suffering from a severe head injury must have their care delivered by a neurosurgical consultant led team.

Consultation comments on data collection

- Stakeholders would like the measures for time to scan (statements 1 and 2) to also include reporting time. It was noted that the time from accident to the scan is of both unknown and uncollected data.
- It was felt that for a number of stakeholders, data collection for statements 5 and 6 relating to rehabilitation is not routinely collected, that it would be difficult to collect and that there would not be consistency across commissioners.
- Stakeholders felt that the outcome measures currently included seem vague and are not specific to traumatic brain injury.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Children and adults with a head injury have a CT head scan within 1 hour of a risk factor for brain injury being identified that indicates it necessary.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- A number of stakeholders suggested that this particular standard should include time to report the CT scan as well as time for the results to be available, as a scan is worthless without the inclusion of a report on what the image indicates.
- Stakeholders noted that it was not made clear how measures of patient experiences will be addressed, for example a 1 hour scan may not alter patient experiences.
- The use of vomiting as an indicator was felt to be a concern as there were no timeframes attached as a measure.

5.2 Draft statement 2

Children and adults with a head injury and any specific risk factor for cervical spine injury have a CT cervical spine scan within 1 hour of the risk factor being identified.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- A number of stakeholders suggested that this particular standard should include time to report the CT scan as well as time for the results to be available, as a scan is worthless without the inclusion of a report on what the image indicates.
- Stakeholders felt that there was little need to have separate statements on cervical spine injury as all people with a requirement for a CT head scan will also require a scan of the spine, therefore the mechanism should not be used to dismiss the requirement for a spine scan.

- It was suggested by stakeholders that there is no longer a role for plain x-rays in this setting, therefore to remove the option of plain films and using CT Cervical scans in all appropriate cases.
- Stakeholders felt that the maintenance and removal of cervical spine protection in children with suspected or actual head injury should be included.
- There was concern that there are recommendations on CT scanning, but not the levels of expertise or training required to undertake these. For example an adult radiologist may not be experienced enough to know the acceptable limits of variability in a child's results.
- Stakeholders felt that this statement needs to be broadened to include computerised tomography (CT) or magnetic resonance imaging (MRI) for children especially one who has an MR for suspected spinal injury instead of a CT scan is not counted as a "fail".

5.3 Draft statement 3

Children and adults with a head injury who are taking warfarin have a CT head scan within 8 hours of the injury, even if no other risk factor for brain injury is identified.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Stakeholders noted that although the guideline notes specifically warfarin – the wording of the statement should be changed to include all anticoagulants
- Stakeholders note that there could be a potential breach of the 4 hour recommendation in emergency departments as an 8 hour quality standard in emergency departments may be misleading. Therefore, acute hospitals should have arrangements in place to locate people whilst awaiting a scan without compromising the 4 hour timeframe.
- Stakeholders were concerned with the broad definition of head injury and noted that this particularly related to those who are on warfarin and have a head injury as there is a risk of over-scanning people.

- Stakeholders were concerned that implementing this statement may cause unnecessary emergency 999 calls. When people with a head injury could potentially attend the emergency department themselves, this statement may prompt them to call an ambulance instead.

5.4 Draft statement 4

Children and adults with a head injury and a Glasgow coma scale score (GCS) of 8 or less at any time have access to specialist treatment through ongoing liaison with or transfer to a neuroscience unit.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- It is not easy to monitor people whose care is managed in conjunction with a neuroscience centre, or appropriate to transfer people from their local hospital to a neuroscience unit, therefore considerations should be made to assess whether it is feasible to measure compliance with this statement.
- Stakeholders noted that they would like the statement to include ‘have access to specialist treatment through ongoing liaison with, or transfer to their regional neuroscience unit’ because there are a number of cases where people have been transferred outside their regions which leads to delays in access of definitive treatment for patients, increased travel for families and also impacts on service delivery in the transferring hospital where staff are often required to seek beds at an alternative centre and facilitate the transfer.
- Stakeholders have noted concern that Glasgow Coma Scale (GCS) alone is being used as an indicator to instigate neuroscience liaison. Stakeholders do not feel that this is a reliable enough when alone as a measure and should also consider imaging and assessment results. Additionally, it was noted that there are diagnostic techniques that refer to GCS, and should also be changed.
- Stakeholders noted that the statement should be more specific to children in that when a child is transferred to a neuroscience unit, the department that they are sent to should have expertise in dealing with children.

- Stakeholders felt that although the standard covers rehabilitation for adults after traumatic brain injury (TBI), they are expected to contribute to improvements only in recovery after moderate or severe head injury. It was suggested that such patients are included in recommendations for recovery.
- Stakeholders commented that community rehabilitation services should have multi-agency co-ordination to social care, drug, alcohol, mental health and voluntary services.

5.5 Draft statement 5

Adults (aged 16 and 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Stakeholders felt that excluding children from the population in this statement was inappropriate and should be revised. In particular it was noted that children with head injuries have more scope to experience late and/or delayed negative effects.
- Stakeholders noted that commissioners may find it difficult to meet, need and quantify demand.
- Stakeholders noted that it should be stated whether the assessment in question will be the first assessment.
- Stakeholders noted that they would like to see this statement go beyond assessment and cover referral for people with head injuries, and additionally to note how the assessment will be undertaken i.e. what measures will be used such as cognitive impairment.
- It was felt that this statement does not note if there has been any previous rehabilitation and so should be included.

- Stakeholders noted concern that for this statement to be effective a re-examination of the data collection may be required; quality is defined on a local level and so stakeholders would like to see a recommendation of expected levels of achievement. Local data collection could be difficult to implement without robust guidance, as data is not collected routinely on discharge.
- It was noted that stakeholders would like to see a timeframe added to rehabilitation assessment. Additionally, stakeholders noted that there is no mention of major trauma networks and rehabilitation prescriptions, which are an important part in the rehabilitation process.
- Stakeholders commented that they would like to see the statement (or another statement) cover remote assessment as well as vocational rehabilitation.
- Stakeholders expressed that they would like to see more emphasis placed upon clinicians and those with milder head and brain injury.
- It was commented that the Quality Standard does not currently define many aspects of how services should be provided, and 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.
- Stakeholders noted that stating a 72-hour time frame may not be useful, since many people only experience the effects of brain injury after this when they have returned home. Stakeholders also questioned the use of a 72-hour time frame.
- In the 'Healthcare professionals' section, stakeholders recommended a more defined definition of who is to perform the assessment. Specialists such as neuropsychologists, neuropsychiatrists, neurologists and rehabilitation consultants may be suitable, depending on need.
- Suggested change in 'what the QS means for patients and carers', from "specialised treatment to help them recover normal functions" to "specialised treatment to help them maximise their recovery". Full recovery is often unobtainable, so the QS must use realistic language.

5.6 Draft statement 6

Community rehabilitation services are available to provide a range of interventions to help support adults (aged 16 and over) with continuing cognitive deficits after a moderate or severe traumatic brain injury.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- Stakeholders felt that rehabilitation should be recommended for those with continuing physical, cognitive, emotional, behavioural and psychological problems, and not just cognitive deficits.
- Stakeholders felt that excluding children from the population in this statement was inappropriate and should be revised. In particular, it was noted that children with head injuries have more scope to experience late and delayed negative effects.
- Stakeholders noted that commissioners may find it difficult to meet need and quantify demand in relation to rehabilitation services.
- Stakeholders commented that families and carers could be added into this statement as they have a large role in the rehabilitation process.
- It was felt that ‘community rehabilitation’ may or may not mean inpatient services, outpatient services, or time limited community team input, all of which must have specialist skilled staff, and many Community teams do not.
- Stakeholders were concerned with the data collection for this statement as they felt that there are no agreed processes for data collection, and that there are and may be a number of concerns regarding commissioning.
- Stakeholders noted that this statement should consider re-wording of ‘community’, since people with a head injury move from specialist rehabilitation through to community rehabilitation, and those with more severe injury have prolonged admissions.

- Stakeholders commented that access and availability are not the same, and that therefore it is important to ensure that people can access rehabilitation in a sensible timeframe.
- Concerns were raised by stakeholders that the language used is not defined enough to have an impact, e.g. using language such as ‘ensure systems are in place’ and ‘consider the benefits of community rehabilitation’.
- Stakeholders felt that community rehabilitation should also be available for people with less severe brain injury and issues that are not directly related to the head or brain injury for all people, such as remaining in employment and coping with daily tasks.
- Concerns were raised that recommending community rehabilitation in this way does not capture the continuing rehabilitation that people with head injuries require; it was noted that rehabilitation should be available at different points over time.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Stakeholders noted that there are a number of people who survive a head injury, but live with severe disability, therefore considerations should be made for treatment of these people and at what point to limit or cease treatment.
- Stakeholders felt that the quality standards should include the issue of antibiotic prophylaxis for skull fractures.
- It was noted by stakeholders that there appears to be a need for an area concerning hormonal imbalances and pituitary dysfunction after brain injury, as these can be serious and poorly represented.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
001	British Paediatric Neurology Association	Quality statement 5 & 6		The extension of the quality standards to include post-acute rehabilitation issues (statements 5 & 6) is a welcome step in the right direction but the exclusion of children from these two is indefensible on equity grounds. Children (0-16) comprise a significant proportion of all TBI cases, and the right of children to receive high quality trauma care is explicitly acknowledged in Statements 1-4, making their exclusion from Statements 5 & 6 all the more striking. There is a large body of literature emphasising the potential for TBI in the immature brain to cause late cognitive, behavioural and forensic morbidity if appropriate cognitive and educational assessment, support and provision is not provided. Although the evidence base for the efficacy of paediatric neurorehabilitation is less developed than for adults it is *a priori* likely that children have as great a capacity to benefit from effective rehabilitation. The British Paediatric Neurology Association strongly objects to the exclusion of children from these statements.
002	British Infection Association		General	This QS does not deal with the issue of antibiotic prophylaxis for skull fractures and we have no further comments to offer to you. Many thanks.
003	South Wales Critical Care Network	Quality statement 4		While it is relatively easy to monitor the number of people who are transferred to a neuroscience centre with a traumatic brain injury, it is not as easy to monitor those patients whose care is managed in conjunction with a neuroscience centre. The Network agrees that it is not always appropriate or necessary to transfer patients from their local hospital to a neuroscience centre to manage their head injury. However, consideration should be given to whether or not it is practically feasible to measure and monitor the number of patients whose care is discussed with neurologists and neurosurgeons without transferring them from one hospital to another and, if so, how this could be done. The statement suggests that there should be a documented record of ongoing liaison. If the data collected to measure compliance with this statement is something that is done on an ongoing basis in each individual case, it can be very difficult to capture meaningful measurement and monitoring from a performance perspective.
003	South Wales Critical Care	Quality		The Network wholeheartedly supports the provision of services for patients with ongoing inpatient and

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
	Network	statement 5 & 6		community rehabilitation needs after their acute phase of care is complete. However, this is an area where there is considerable unmet and hidden need where commissioners may struggle to quantify the scale of existing demand, let alone that arising from this statement. It would be helpful for the commissioning guidance that accompanies the Quality Standards to focus on this area in particular. Input from Public Health, Critical Care, Neuroscience and Rehab Service to the quantification of demand for a commissioned inpatient and community services for brain injury rehab will be vital to ensuring that the services meet the needs of this patient group. If provided for appropriately, commissioners will not only see the benefit in quality and outcomes for patients who require ongoing rehabilitation; they also have the chance of making better use of inpatient and Critical Care beds. Critical care units in particular make for an inappropriate setting for many brain-injured people or those with high spinal injuries requiring ongoing ventilation, and not only release capacity in this expensive and scarce resource but also increase the chances of people receiving rehabilitation getting good outcomes from their programmes.
003	South Wales Critical Care Network	Quality statement 6		There may be an opportunity to capture and link to measures for carers in this statement. The ongoing cognitive deficits experienced by people with head injuries can cause enormous distress for carers and family members. Including them in the assessment could help to ensure that these people are properly supported and also improve the care for the individuals with head injury by providing a more holistic approach to supporting the individual in their home environment. The Network recognises that this may be outside the scope of the Standard. However, in the spirit of ensuring that patients and carers are at the centre of the statements, it may be worthwhile the committee considering this in the post-consultation meeting.
004	UK Acquired Brain Injury Forum	Quality Statement 5		It should be clear that this is not the first assessment if an assessment prior to 72 hours is possible. The reason for the assessment is stated as to decide on their need for inpatient rehabilitation. If at 72 hours the patient who suffered a severe – moderate brain injury (defined through GCS 8 or less on admission) still has cognitive issues, they should not just be assessed but should be referred to specialist inpatient rehabilitation services. Results of improved outcomes, and avoidance of sequelae in

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
				behaviour and physical challenges, are well documented where rehabilitation has commenced in a specialised service within 10 days of the head injury.
004	UK Acquired Brain Injury Forum	Quality Statement 5	Measures	There has not been an agreed process or method to collect this data or mapping information. We have many examples of where providers have well established and quality services (mainly independent_ who have not been included in scoping exercises. Presently, we are aware that again, the Strategic Clinical Networks in Neurology are not all acting to ensure they are fully aware of all providers and therefore cannot collect accurate figures of numbers of people undergoing rehabilitation. Although some independent providers secure man of their referrals directly through insurance company funded patients, these patients will at some point in their recovery, enter the NHS and Social care sector and therefore, it is not enough that the SCN's rely on NHS service to contribute to workshops and planning sessions. Therefore, there is no mechanism that is efficient that collects local data and it seems that whilst over 60% of inpatient rehabilitation is provided by the independent and third sector, they are not being included in some regions
004	UK Acquired Brain Injury Forum	Quality Statement 6		'Community rehabilitation' may or may not mean inpatient services, outpatient services, or time limited community team input, all of which must have specialist skilled staff, and many Community teams do not. Therefore the quality of rehabilitation is not going to be acceptable in some (the majority) of generic services
004	UK Acquired Brain Injury Forum	Quality Statement 6	Measures	There has not been an agreed process or method to collect this evidence. As reported we have many examples of where providers have well established and quality services (mainly independent_ who have not been included in scoping exercises) Presently, we are aware that CCG's who are responsible for commissioning local rehabilitation services are not informed either by the Level 1 services or eth LAT's specialist commissioning teams, of eth services available in their locality. Access to the CCG's by providers is limited only to NHS rehabilitation services that are usually generic rehabilitation services for elderly or orthopaedic patients. Therefore, if the local commissioners are unaware and not in communication with specialist Head Injury providers, the arrangements will not be appropriate or the best quality available for achieving the outcomes desired. Subsequently , there will be a paucity of evidence of local arrangements or the local arrangements may be inadequate.

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
004	UK Acquired Brain Injury Forum		Overarching indicator 3.6ii	This is unclear whether the patient has received any rehabilitation at all at this stage and as this is an improvement target it should be qualified.
004	UK Acquired Brain Injury Forum		Levels of achievement	It is not appropriate that quality should be defined locally and that post codes be allowed to play a part in the quality and standard of rehabilitation patient receive, We support a) adherence to the BSRM standards for rehabilitation following brain injury b) adherence to the Neuroscience and neuropsychiatry (CRG) service specifications and outcome measure of the UKROC (UK Rehabilitation outcomes collaborative) c) the self-regulatory standard of INPA (Independent Neurorehabilitation Providers Alliance) The limits of some of these bodies collection of quality and outcomes is lack of audit that covers the ongoing rehabilitation, past the level 2a.; inpatient rehabilitation continuing in level 2a and 2b. These bodies already have information and evidence of measures of quality and expected achievements for the ongoing (post-acute) rehabilitation. We highly recommend this NICE guidance includes expected levels of achievement and grades the progress i.e. all quality minimum standard must be achieved but higher can be achieved.
005	Faculty of Intensive Care Medicine	Quality Statement 3		Although the published evidence is only available for warfarin we would prefer to see the text changed to 'Children and adults with a head injury who are receiving anticoagulants have a CT scan within 8 hours of the injury,'
005	Faculty of Intensive Care Medicine	Quality Statement 4		We would like to see the statement strengthened to read 'have access to specialist treatment through ongoing liaison with or transfer to their regional neuroscience unit.' There remain examples where critically ill patients are transferred outside their region due to lack of bed availability despite national recommendations (Society of British Neurosurgeons) that emergency treatment is carried out at the regional neuroscience centre and then transfer undertaken as necessary. This leads to delay in access of definitive treatment for patients, increased travel for families and also impacts on service delivery in the transferring hospital where staff are often required to seek beds at an alternative centre and facilitate the transfer.
005	Faculty of Intensive Care Medicine	Quality Statement		There is no indicator of the time-frame within which this assessment should be made. Many patients with moderate and severe head injury have prolonged admissions in intensive care and acute ward beds due

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
		5		to delays in timely access to assessment. As such we would also support measurement of time to assessment..
005	Faculty of Intensive Care Medicine	Quality Statement 6		We would recommend removal of the word 'community'. Although we strongly support the requirement for rehabilitation, this should be from specialist through to community based rehabilitation, dependent solely on patient need. Many patients with moderate and severe head injury have prolonged admissions in intensive care and acute ward beds due to delays in timely access to appropriate rehabilitation. As such we would also support measurement of time to access of appropriate rehabilitation.
005	Faculty of Intensive Care Medicine	Quality Statement 1		Quality measure should also include time to report for the CT scan. Delays in reporting contribute to delays in access to definitive care including appropriate discharge from hospital.
005	Faculty of Intensive Care Medicine	Quality Statement 2		Quality measure should also include time to report for the CT scan. Delays in reporting contribute to delays in access to definitive care including appropriate discharge from hospital.
006	The Society and College of Radiographers		General	The new guidelines seem very sensible, clear and workable in an acute clinical situation. Scanning the cervical spine whilst the patient is in the scanner is very sensible and to be recommended.
006	The Society and College of Radiographers	Quality Statements 1,2 & 3		These statements should include the results being available not just the scan time itself. Of importance to note is a CT of the head and/or CT spine to be completed within an hour is of no value unless there is a report on what the image indicates i.e. a report and the standards need to make this clear. Appropriately trained and competent reporting radiographers would have a role in reaching these standards
006	The Society and College of Radiographers	Quality Statement 6		Needs to ensure that adults can access the community rehab within a sensible timeframe. Availability and access is not the same thing.
006	The Society and College of Radiographers		General regarding data collection	From an Imaging perspective data can be measured from the point of referral for CT to the scan time but not necessarily from the point of a risk factor being identified. The time from the accident to the scan is often unknown/uncollected data. This may be something able to be developed for EPR but not yet currently available without a manual search through data. It is also be more complex to identify those patients on Warfarin and their timescales to tie of scan.
007	ICUsteps		Page 4	In second sentence beginning "if appropriate" we wold prefer a change of emphasis so that family and

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
			Role of families and carers paragraph	carers be involved **unless** there is good reason why not as they have a significant role to play when healthcare professionals are not present.
007	ICUsteps	Quality Statement 6	Page 5	The other statements are supported by time frames in which actions should be taken. The availability of community rehabilitation should also have a time frame to ensure continuity of care and emphasis that rehabilitation is a core part of the care pathway and not an optional extra or bonus.
007	ICUsteps			The recommendation that a patient with a moderate or severe head injury is assessed at 72 hours for the requirement for inpatient rehabilitation seems extremely early. At this stage, many such patients are fully sedated and ventilated, and it is difficult or impossible to know what the rehab potential might be.
007	ICUsteps		General	No mention is made re the support of patients and relatives. We would suggest designating a member of staff to provide information and support to families throughout the patient journey.
008	The College of Emergency Medicine	Quality Statement 1		TARN data doesn't collect data about most head injured patients, this is an insufficient data source to identify any problems here. This would need to be collected locally. I am not convinced it is clinically sensible or necessary to subject all children with suspected NAI and some of these lower risk factors to CT scanning within one hour. A more considered approach may be more appropriate. The criteria for CT scanning in children are too liberal and will have a large and unjustifiable number of normal scans.
009	Association of Chartered Physiotherapists In Neurology- Yorkshire branch	Quality Statement 6		Community Rehab: why is it only cognitive deficits that are highlighted in this guidance document? There are other significant factors that affect return to independence (work, education etc…) for example physical deficits including vestibular impairments and balance problems. There are serious psychological changes that can occur including behavioural issues, anxiety and depression. Whilst cognitive changes are obviously a fundamental factor following brain injury, they cannot be considered in isolation. It is felt that the guidance is not specific, using language such as 'ensure systems are in place' and 'consider the benefits of community rehab'.
009	Association of Chartered Physiotherapists In Neurology- Yorkshire branch			It seems unusual that a document that discusses cognitive rehab does not have an occupational therapist or neuropsychologist on the list of authors.

ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.
009	Association of Chartered Physiotherapists In Neurology- Yorkshire branch			This feedback is sent on behalf of Yorkshire ACPIN, and was disseminated to us last week by our national ACPIN committee so unfortunately we have not had much time to discuss this as a group, but we felt it was important to send some comments. We appreciate this document focuses mainly on early management and less severe HI but cognitive changes might not be the only residual problems.
010	The Intensive Care Society		General	I think the “Outcome” throughout the Standard should use mortality and “disability” and not just mortality
010	The Intensive Care Society		General	Should there be consideration for the proportion of patients who survive but with severe disability? Should the standard consider, at some stage treatment limitation or treatment withdrawal?
010	The Intensive Care Society		Introduction	I am unclear why rehabilitation applies to adults only
010	The Intensive Care Society	Quality Statement 1	Definitions; risk factors	I think there should a consideration for the potential effects of drugs/and or alcohol
010	The Intensive Care Society	Quality Statement 2	Risk factors	I would suggest that there is no longer any role for plain xrays in this setting. I would advocate removing the option for plain films and using CT C spine in all appropriate cases.
010	The Intensive Care Society	Quality Statement 2	Risk factors	I am unconvinced by the need for a separate standard for C Spine imaging. All patients with a requirement for CT Head will require CT Cspine. The mechanism should not be used to rule out the need for CT Cspine.
010	The Intensive Care Society	Quality Statement 3		I am unclear why the standard uses 8 hours and not less.
010	The Intensive Care Society	Quality Statement 4		I am not sure why GCS < 8 alone is being used to trigger neuroscience liaison. This excludes patients with other risk factors such as confounding drugs and alcohol, abnormal CT head, Skull fracture,
010	The Intensive Care Society	Quality Statement 5		Should there be a time window on rehabilitation assessment (ie within 2-3 days)?
011	Leeds Teaching Hospitals NHS Trust	Quality Statement 4		There is a defined section of the population who are not accessing the RNC (regional neurosurgical centre) after brain injury, namely the elderly patient with comorbidity and / or anticoagulant therapy. A recurring feature of my ancillary role as coroner is processing the investigation of deaths arising initially

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				from relatively minor head injury where there is primary discussion with the RNC and the patient is considered 'too good' to transfer for intervention and regular interventions and repeat CT scanning are recommended, but when the patient deteriorates neurologically, secondary discussion with the RNC invariably results in a declaration that the injury is untreatable and unsurvivable, and the patient is not therefore accepted for transfer. Clearly there will be cases in which operative intervention is inappropriate but it can be reasonably anticipated that there will be a subsection of patients who would benefit from early transfer, monitoring and intervention to minimise the chances of avoidable death or survival with a more profound neurological deficit. There are two identifiable elements driving this approach; bed availability and a desire to avoid a high mortality rate for the unit because of the negative implications of this latter finding. There is little audit of outcome of this decision-making despite my opinion that the numbers refused admission are at least as high as those accepted for admission, and despite the potential for excess mortality, excess neurological deficit in survivors, and predictable loss of potential organ donors. It is difficult to consider how this issue can be addressed within the current standards document, but I believe there should be wider consultation on an aspect of head injury management that is largely and inappropriately ignored.
012	NHS Choices		Briefing Paper Page 35 Appendix 2	The briefing paper still refers to NHS Direct which ceased to operate 1.4.14.
012	NHS Choices			Please could you consider guidance for the remote assessment of head injury in the development of the quality standard. In our service model users would access remote assessment via the web
013	Royal College of Paediatrics and Child Health	Quality Statement 6		Rehabilitation services are only mentioned for adults (>16). This seems markedly inequitable for Children who should surely also have rehabilitation services available to them following moderate to severe head injury. As a Group of General Paediatricians we often see children with complex post HI neurocognitive, neuroendocrine and behavioural problems who are not provided with any commissioned service to systematically address these issues. The guideline would benefit from a clear statement to the effect that children are also included in access to these rehabilitation and supportive services.
013	Royal College of Paediatrics and Child Health	Quality Statement 1 & 2		Should both standards include information on interpretation and reporting on CT scans, specifically related to who should report and within what time frame?

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-13	Royal College of Paediatrics and Child Health		1.4.10	Some concerns that limiting to fall >3 metres misses significance of shorter falls for younger children. Evidence from studies previously about significance of fall > twice height
013	Royal College of Paediatrics and Child Health		1.5.11	Is there any risk adjustment for age and thyroid cancer – seems like potential big increase in CT neck scans over current protocols
013	Royal College of Paediatrics and Child Health	Quality Statement 2		Would it not be appropriate to mention cervical spinal protection in children with suspected or actual head trauma? There is a recommendation regards scanning, but not of the level of expertise required to read the C-Spine CT. Given that an adult radiologist may lack experience of the acceptable limits of variability for children how should this be dealt with? Secondly, I could not find any recommendation for the maintenance of C-spine protection, or indications for its removal.
014	The Royal College of Radiologists and the British Society of Neuroradiologists		General	• The Royal College of Radiologists (RCR) and the British Society of Neuroradiologists (BSNR) feel that the draft Quality Standard adequately reflects the overall content of the NICE guidelines for the management of head injuries. However, they note that the current draft Quality Standard does not seem to reflect the recommendations of that guideline in a consistent way. The RCR and BSNR therefore advise that this be addressed in the drafting of the final version.
015	Department of Health			Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
016	Barking, Havering and Redbridge Hospitals NHS Trust			Please briefly define what does head mean
016	Barking, Havering and Redbridge Hospitals NHS Trust			It can be difficult as first priority is ABC/ intubation….2 hours limit needs further discussion and probably time window amendment.
017	Society of British Neurological Surgeons			I am writing on behalf of the Society of British Neurological Surgeons (SBNS) to confirm agreement with the standards indicated in the draft document
018	Royal College of Nursing		Introduction - table	*'Patient experience of A&E services'* and *'emergency re-admission within 30 days of discharge from hospital'*

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			2 and table 3, points 4.3 & 4.11	Members expressed that they would like to see more emphasis laid upon clinicians to highlight the fact that some patients may develop mild symptoms of nausea, poor concentration, altered sleep pattern and lethargy for a period of up to 3 weeks following (usually) minor head injury. Currently this is not apparent in much discharge head injury advice. These patients are likely to be discharged from ED with a diagnosis of minor head injury and may not re-attend on an unscheduled basis if they develop the symptoms outlined and have been warned of their nature and the fact that they should not in themselves prompt re-attendance.
018	Royal College of Nursing	Quality Statement 3		'*Children and adults with a head injury who are taking warfarin have a CT head scan within 8 hours of the injury, even if no other risk factor for brain injury is identified'* This amendment of the previous guidance is welcomed. However it would be useful to make it clear in the recommendations for pre-hospital/primary care and community staff about indications for transfer to hospital. Under the circumstances in QS3 the patient may be safely transported by their own transport, or non-urgent transport providing that anticoagulation is an isolated finding and that the transfer time will not exceed the recommended 8 hours. It is a fear expressed by members that if this is not made clear a lot of otherwise well patients may be travelling needlessly in a 999 ambulance. It should also be borne in mind that with an 8 hour recommendation for CT scan these patients represent potential breaches of the 4 hour quality standard in ED (whereas before the 2014 recommendations they either would have been admitted for observation or perhaps scanned and discharged). Acute hospitals should have arrangements in place to locate these patients in either a clinical decision unit within ED or in an ambulatory care area within an assessment unit in order that they can be safely monitored whilst awaiting scan without compromise of the 4 hour standard and without needless admission to a hospital bed.
018	Royal College of Nursing		General	For the sake of clarity and in line with inter-collegiate recommendations the RCN would advise that Accident and Emergency (A&E) is referred to as Emergency Department (ED).
019	Association of British Neurologists		General	• Not clear if standards cover all TBI with all GCS,; there are many less severely injured who need follow up and rehab;(80% of attendees at our emergency department have a mild TBI and are discharged, but 25% of our referrals to neurotrauma clinic are of people with problems that have not been admitted to hospital). Small amounts of assessment and advice can reduce morbidity

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				considerably. • It is welcomed that these standards are recommending rehab for those with psychological problems . I think it would better to recommend that Rehabilitation should be available to all those with physical, cognitive and emotional impairments after TBI; this should include review by rehabilitation medicine team, neuropsychiatry and clinical psychology when indicated. • Community neurorehabilitation teams need to be set up to work closely with all relevant agencies in particular social services and drug and alcohol teams as well as 3rd sector organisations such as Headway UK. The community teams need to be well linked in to acute services and have regular support from or include in their team, either rehabilitation medicine physicians or Neurologists with expertise in TBI rehabilitation. • Transition from children services to adult (very crucial time for people living with consequences of TBI) are not mentioned ie there needs to be good mechanism in pace to facilitate such transition to community TBI rehab services • Training is needed in assessment of Post traumatic amnesia and the use of the mental capacity act with TBI patients • This quality standards doc has not referred to any of the currently available BSRM / RCP standards such as The National Clinical Guidelines (BSRM/RCP 2003)which recommends rehabilitation referral of patients with continuing impairment of concentration or mobility at 48 hours to rehabilitation medicine. Rehab Medicine consultation at that time would offer support in the management of acute symptoms (pain, seizures, dizziness, confusion), advice on prognosis and access to alternative rehabilitation services as illustrated in Fig 3.1 of the report on Medical rehabilitation in 2011 and beyond

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				• To include in the coordination section…The Major trauma networks are not really mentioned or the use of rehabilitation prescriptions; (TBI accounts for at least 60% of the complex admissions to many Major trauma centres and involvement of TBI as part of complex major trauma increases rehab needs and complexity and increases length of stay).Both of these are now written in to most commissioning arrangements and do help with encouraging provision of early review of rehabilitation needs and advice and with coordination between those admitting people after TBI and rehabilitation services. Good coordination of rehab and other services after TBI can be delivered by appropriate use of rehabilitation prescriptions
020	Royal College of General Practitioners	Quality Statement 1		The presentation of patients and the capacity of services to respond is determined by clear referral indications for scaning/xrays and is particularly pertinent for children following head injury. This guidance is helpful but will place pressure on commissioners and providers to ensure rapid assessment and diagnostics Most/all of the referral indicators would and should be treated as medical emergencies
020	Royal College of General Practitioners	Quality Statement 6		The provision of community rehab is lacking following head injury and is likely to require resources and timely response.
021	Headway – the brain injury association		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:

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				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
021	Headway – the brain injury association		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
021	Headway – the brain injury association		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
021	Headway – the brain injury association		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.
021	Headway – the brain injury association	Quality Statement 4	Page 16	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.

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				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.
021	Headway – the brain injury association	Quality Statement 4	Page 16	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.)
021	Headway – the brain injury association	Quality Statement 5 & 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. 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.

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021	Headway – the brain injury association	Quality Statement 5 & 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 • 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.

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021	Headway – the brain injury association	Quality Statement 5 & 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.
021	Headway – the brain injury association	Quality Statement 5 & 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.
021	Headway – the brain injury association	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.
021	Headway – the brain injury association	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.
021	Headway – the brain injury association	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.
021	Headway – the brain	Quality		We would suggest the following change to the end of statement 5: "Adults (aged 16 or over) in hospital

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	injury association	Statement 5		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.
021	Headway – the brain injury association	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.
021	Headway – the brain injury association	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. 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.
021	Headway – the brain injury association	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.
021	Headway – the brain injury association	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.

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021	Headway – the brain injury association	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.
021	Headway – the brain injury association	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.
021	Headway – the brain injury association	Quality Statement 6		We suggest changing the wording of this statement to '...with continuing physical, cognitive, emotional and 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.
021	Headway – the brain injury association	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.
022	Royal College of Physicians		General	The RCP is grateful for the opportunity to comment on the draft quality standard. Our experts believe that the outlined quality standard for head injury is good and that the data sources are reasonable and realistic. Although, this standard is directed at moderate and severe head injury there are also major concerns surrounding the diagnosis, management and prognosis for mild traumatic brain injury ('concussion'), which are not addressed in the consultation. We believe that this area also needs to be the subject of a NICE Quality Standard.

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022	Royal College of Physicians	Quality Statement 3		There needs to be a tighter definition of head injury (in the notes it says any trauma to the head other than superficial injuries to the face). If the guideline indicates that all individuals who have a 'head injury' on warfarin need a scan, then there is the potential of over-scanning. Clinical judgement will clearly need to be exercised.
023	The Brain Injury Rehabilitation Trust		BIRT Introduction	• The Brain Injury Rehabilitation Trust (BIRT) welcomes the opportunity to respond to NICE's consultation on the draft quality standards of head injury. • BIRT provides a continuum of specialist neurobehavioral services to adults who present with severe and complex brain injuries. Our service users can be referred from acute care, other rehabilitation units or from the home where behavioural challenges have sometimes been overwhelming or this is simply the next step in the rehabilitation process for the individual. • Our overall focus remains on providing high quality and expert multi-disciplinary services. The end result is service users experiencing effective rehabilitation and returning to semi or full independent living after brain injury either in a residential, community or own home setting. • BIRT focus much of their campaigning efforts on driving forward the need for quality improvements in brain injury rehabilitation and are therefore pleased that NICE is addressing this area of quality standards for head injury. The need for good practice guidelines seems most relevant now with such occasional reports of patchy access to and accounts of poor quality services across the UK for individuals who require brain injury rehabilitation. • Through our own experience, we know that timely access to high quality brain injury rehabilitation services can result in improved long-term outcomes to the individual. Moreover as the debate around funding the integration of health and social care continues, it is important to note that whilst a secondary outcome to an improved quality of life for the individual, our own peer-reviewed research showed that the funder can expect lifetime care cost saving of up to £1 million per person if the individual enters effective rehabilitation within twelve months of their initial injury. • BIRT's response to this consultation was undertaken by Dr. Sue Copstick, Director of Clinical Services for BIRT and BIRT's Clinical Executive. We also surveyed our own multi-disciplinary teams to ensure all views were noted within our response.
023	The Brain Injury Rehabilitation Trust	Quality Statements 1-6	General	• We observed that the aim of the quality standards is to provide guidance on the management of triage, assessment, investigation and early management of head injury in infants, children and adults. The quality standard will serve to cover rehabilitation in adults (aged 16 years and older) with traumatic

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				brain injury. • However, our initial view is that the standards seem to be primarily directed at the management of acute head injury only. Whilst the latter part states it 'will also cover rehabilitation in adults' this doesn't seem to materialise strongly enough throughout the document and almost seems an 'add-on' or 'afterthought' to the main priority on the management of head injury. For example, the standards emphasise the first 72 hours following a head injury, and indicate that health professionals should assess the need for in-patient rehabilitation, and only offer individuals access to rehabilitation services on discharge. In essence the NICE draft quality standard only covers a small part of the type of rehabilitation that should and can be offered at time of discharge and does not go far enough to highlight the need for communication between health and social care professionals to ensure appropriate rehabilitation. In order to improve the outcomes we feel that next steps should not be limited to rehabilitation in an in-patient or community setting when in our experience it is likely a number of patients will require intensive, adult residential rehabilitation for a short or long period of time following acute care. This view would be consistent with the SIGN 130 document that references a wider range of rehabilitative services. • We question whether the quality standards do not go further in terms of discussing further long-term rehabilitation because this would be better placed in a social-care focussed set of draft quality standards for early head injury rehabilitation? Nevertheless we would ask NICE to consider producing a further quality standard that says "discharges from hospital to continue rehabilitation as an in-patient or in a community or residential-based setting should be facilitated in a manner that allows for an on-going continuum of care and initial rehabilitative goals as agreed by the individual, relevant family or friends and the treating clinician."
023	The Brain Injury Rehabilitation Trust	Quality Statement 5		• We are pleased to note that draft quality statement 5 directs the healthcare service to assess the need for inpatient-rehabilitation. However, we would recommend changing the wording from "cognitive deficits that continue 72 hours after a moderate or severe traumatic brain injury," to "cognitive deficits that continue at least 72 hours after a moderate or severe traumatic brain injury." In our experience acute management of the head injury is still the main priority up to and after the first 72 hours in hospital and we would be concerned that the focus would remain too much on the 72nd hour rather than eventually and in a timely manner seeking the correct rehabilitation for the individual, once acute needs have been met.

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023	The Brain Injury Rehabilitation Trust	Quality Statement 6		• Draft Quality Statement 6 – Whilst the first five quality standards are strongly worded on actions that must be taken, the last statement seems weak when it states only what community rehabilitation services are 'available.' Could the statement go further by saying, "appropriate community or residential rehabilitation services should be made available to all adults who suffer continuing cognitive deficits after a moderate or severe traumatic brain injury and following a cognitive impairment assessment."
023	The Brain Injury Rehabilitation Trust		Family and Friends Involvement - general	• BIRT welcomes the 'role of families and carers' wording in the document and agree that they play an important role in supporting people with a head injury and should be involved in the decision-making process if appropriate. However we feel that it might be helpful for an added draft quality standard that focusses solely on family systems, especially to provide assistance in terms of advice and support and/or therapy to family members most affected by the individual's brain injury (for example those who may have to become the main carer for the individual or young families who do not understand the full impact of the brain injury on the individual). However, it may be that this again steps into the realms of social care support that should be provided by the local authority and is therefore not a relevant quality standard for this document.
023	The Brain Injury Rehabilitation Trust		Question 2	• Draft Quality Standard 5 • It is important to note that assessments of need for individuals with a brain injury within a hospital setting may not highlight their true future care and support needs. Clinical research and experience suggests that if an individual with brain injury is in a structured setting (for example with fixed meal times and wash schedules for example) their behavioural disturbances (including sleep disorder) and lack of insight (when an individual has zero or little concept of their abilities post-brain injury) will only become obvious once they are discharged and return back to normal family and community life and routine. • To combat this, BIRT would suggest using a 'multi-disciplinary assessment' with a trail of home visits as part of routine discharge planning for those with cognitive deficits that persist after 72 hours (as per SIGN 130) to ensure an accurate picture of future care and support needs, including rehabilitation is arrived at following assessment. • Using the multi-disciplinary assessment would also mean that the non-specific term of 'assessment of need' eliminates different interpretations of carrying out assessment of needs on individuals with head injury. Further, most hospitals have access to multidisciplinary assessment of

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				needs that include cognition, functional daily living skills, physiotherapy and speech and language therapy. Embracing multi- disciplinary care which is person-centred and community/discharge orientated, is surely nothing but helpful in maximising use of existing clinical resources.
023	The Brain Injury Rehabilitation Trust		Question 2	• Draft Quality Standard 6 - • Currently we do not agree that it would be possible to collect proposed data for this draft quality standard as rehabilitation is not properly defined and is in fact limited to community and in-patient rehabilitation in the two final draft quality standards. We would suggest that SIGN 130's definition of rehabilitation, that is; 'goal-based, multi-disciplinary, specialist brain injury services' would allow for data capture of this draft quality standard. • Quality parameters may involve referrals being timely, and there is no time limit specified so people might be referred to rehabilitation services a day, a week, a month or a year after their brain injury and/or discharge from hospital. A time limit might be useful in encouraging use of multi-disciplinary needs assessments to access appropriate rehabilitation services.
023	The Brain Injury Rehabilitation Trust		General observation	• The document states that it consulted with SIGN 130, however the Trust struggles to identify what aspects of the SIGN guideline were used to define types of rehabilitation for brain injuries across the broad spectrum of the disability and the pathway of care from acute to long-term. The Trust has listed below particular quotes from the SIGN document that we feel could help positively further develop the draft quality standards: **'2.1 Assessment and treatment of mild brain injury:** '*Recommendation that people with mild traumatic brain injury are reassured by a suitably qualified clinician (defined by SIGN)'* 'Patients presenting with non-specific symptoms following mild traumatic brain injury should be reassured that the symptoms are benign and likely to settle within three months.(Evidence to support this was rated B)'. Measurement of this might be numbers of Mild TBI given reassurance vs. total number of mild TBI's seen at hospital (taken this will not be all mild TBI in that area as many do not go to hospital).

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				'Mental state should be routinely examined with an emphasis on symptoms of phobic avoidance, traumatic re-experiencing phenomena (e.g. flashbacks and nightmares) and low mood. (Evidence for this rated as C). Assessment and consideration of pre-existing health variables such as previous neurological disorders and substance misuse should be carried out for all patients with MTBI.'(evidence rated D) 'Referral for cognitive behavioural therapy following MTBI may be considered in patients with persistent symptoms who fail to respond to reassurance and encouragement from a general practitioner after three months'.(Evidence rated C) Again, this aspect of SIGN is measurable. **2.2 cognitive rehabilitation for more severe injuries:** *'Recommendation that people with a brain injury should have access to rehabilitation treatment for their memory problems'.* 'Patients with memory impairment after TBI should be trained in the use of compensatory memory strategies with a clear focus on improving everyday functioning rather than underlying memory impairment. Patients with mild-moderate memory impairment should have access to learning to use both external aids and internal strategies(e.g. use of visual imagery). For those with severe memory impairment external compensations with a clear focus on functional activities are recommended'. (Evidence to support this was D rated) 'Patients with attention impairment in the post-acute phase after TBI should be given strategy training relating to the management of attention problems in personally relevant functional situations'. (Evidence for this rated C) **Physiotherapy and occupational therapy.** 'Repetitive task-oriented activities are recommended for improving functional ability, such as sitting to-stand or fine motor control. **Speech and language therapy** 'Patients with communication deficits post TBI should be referred to speech and language therapy for

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				assessment and management of their communication impairments'. 'Instrumental assessment of dysphagia in patients post TBI should be considered where: - bedside assessment indicates possible pharyngeal stage problems (which would potentially include the aspiration of food and fluid into the lungs) - the risks of proceeding on the basis of the bedside assessment outweigh the possible benefits (the patient at very high risk of choking or aspiration if fed orally), and - the bedside assessment alone does not enable a sufficiently robust clinical evaluation to permit the drawing up of an adequate plan for swallowing therapy'. **2.3 service delivery – '***recommendation that people with a brain injury should have high intensity MDT rehabilitation and discharge plans to continue the treatments'.* 'For optimal outcomes, higher intensity rehabilitation featuring early intervention should be delivered by specialist multidisciplinary teams'.(evidence for this rated B)
024	Faculty of Forensic and Legal Medicine		Question 1	The FFLM is supportive of the statement but wishes to stress the importance of careful assessment of the intoxicated detainee who has a head injury in police custody. This association should be regarded as a risk factor.
024	Faculty of Forensic and Legal Medicine		General	The FFLM is supportive of the remaining quality statements.
025	Alder Hey Children's NHS Foundation Trust		Introduction	It is extremely disappointing that the under-16 age group has specifically been excluded from any consideration of rehabilitation and re-enablement needs following head injury, particularly as the introduction states that up to half of those injured annually are under 15. The comment in the Equality Assessment that SIGN 130 considered adults only and therefore there is no evidence to define any quality standards is not justification. Evidence exists as to the long-term neurocognitive impact of mild as well as moderate-severe head injury in children and the need for effective rehabilitation is just as great.
025	Alder Hey Children's NHS Foundation Trust		Questions for consultation	Draft quality indicators DO NOT reflect key areas for improvement as rehabilitation provision for under-16, and for the 16-18 transitional group, nationally is very underdeveloped and poor compared with adults, and must be improved. A quality statement that excludes this important group will only serve to direct the focus of CCGs and secondary care providers further away from under 16s. Collection of data can be facilitated through TARN, and the implementation of these quality standards

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				may help to improve submission to TARN from Trauma Units and Local Emergency Hospitals. However, the definition of timing from when "risk factor is identified" will make data collection open to interpretation and therefore difficult to accurately and reliably collect across organisations. It will also enable poor triage processes to continue, as a patient with a clear risk factor may wait several hours to be seen by a clinician who then "identifies" the risk factor and a CT may then occur within 1 hour, but this would not reflect a quality service. Time should begin at time of attendance to ED. This will then be in line with TARN and time to CT for GCS less than 13. This exception to this would be children who present in the "observe" group with more than 1 risk factor needed – these, for example persistent vomiting or abnormal drowsiness, may only be evident sometime after attendance at ED. A potential way of dealing with these is to exclude then from the denominator, concentrating on those children with clear risk factors. Good performance in these should still demonstrate a service that is able to assess need for and obtain timely CT in head injured children. Consideration also needs to be given to how to record those adults and children who might initially present to a Trauma Unit or Local Emergency Hospital for stabilisation prior to transfer to Major Trauma Centre. Many of these patients will have risk factors for head injury, but may never undergo CT at the local centre, having been appropriately transferred rapidly to the Major Trauma Centre.
025	Alder Hey Children's NHS Foundation Trust	Quality Statement 2		For children, we may on occasion perform MR scan as the first cross-sectional imaging so as to reduce radiation exposure. The measure needs to take this into account and broaden the measure to include CT or MR imaging as an option (so that a child who has MR for suspected spinal injury instead or CT is not counted as a "fail").
025	Alder Hey Children's NHS Foundation Trust	Quality Statement 4		The measure should be more specific in that for children, it should be a neuroscience centre that has expertise in children (i.e. one that regularly manages children and had paediatric neurosurgeons).
026	British Society of Rehabilitation Medicine		Introduction	Although the standards cover *rehabilitation for adults after traumatic brain injury (TBI)* they are expected to contribute to improvements only in *recovery after moderate or severe head injury.* Head injury and TBI are not synonymous and there are various classifications of severity. We presume that this refers to patients with a post resuscitation GCS of 12 or less. If so this will exclude more than 95% of patients with TBI, including many with a prolonged period of post traumatic amnesia (PTA) or with disabling post concussional symptoms after more minor TBI. We recommend that such patients are included in recommendations for recovery.
026	British Society of Rehabilitation Medicine		Coordinated	There needs to be good coordination between acute and rehabilitation services. This is addressed within the English Major Trauma Networks through the use of the Rehabilitation Prescription. This aims to

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			services	prevent patients getting lost on return to district hospitals and not receiving required rehabilitation. It explicitly requires consideration of psychological and social problems and, in an expanded form, serves as a referral instrument to Specialist Rehabilitation. Major Trauma Centres should have access to Consultants in Rehabilitation Medicine (RM) who are best placed to bridge the gap between acute and rehabilitation services and identify patients who require specialist services. There also needs to be effective multiagency coordination in the management of survivors of TBI. The majority of such patients come from deprived backgrounds and there is increasing evidence of a link between TBI (of any severity) with homelessness and criminality. Community TBI rehabilitation services should be designed such that there is an organic link with social care, drug, alcohol and mental health services as well as voluntary (3rd sector) organisations. Recommendations from NICE on this could be particularly valuable.
026	British Society of Rehabilitation Medicine		Training and Competencies	There should be training not only in the detection of potentially disabling intracranial or cervical spine injury but also in : The assessment of PTA, the management of Post traumatic confusion (PTC) and the application of the Mental Capacity Act : Identification of patients at risk of poor recovery after minor TBI because of poor prior mental health or the presence of an acute stress reaction/PTSD : Management of post concussional symptoms : Identification of patients requiring referral to rehabilitation services.
026	British Society of Rehabilitation Medicine		Role of Families and Carers	It should be recognised that as well as being given the opportunity to participate in decision making severe TBI presents a major risk to the health of family members and to family integrity. This is reduced if the patient has access to specialist rehabilitation and continued support.
026	British Society of Rehabilitation Medicine	Quality Statements 1-4		It is not clear that these statements address key priorities. Should three of the six statements refer to imaging? Statement 4 correctly identifies the need for the Neuroscience centre to be involved in the care of patients in coma but protocols in the English Major Trauma Networks should ensure that such patients would be admitted directly to Major Trauma Centres anyway. We would welcome statements that covered the aforementioned issues regarding training, the management of minor TBI and the care of long term survivors.
026	British Society of	Quality		*Cognitive deficits at 72 hours* could refer either to residual cognitive impairments (how assessed?) or

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	Rehabilitation Medicine	Statement 5		continuing post traumatic amnesia/confusion. Length of PTA is the key prognostic criterion and we recommend that it is this that is assessed using a standard instrument. This can be difficult in patients with language impairments or if their first language is not English when assessment of PTC (essentially a state of delirium) is an alternative. We are uncertain why 72 hours was picked. The National Clinical Guidelines (BSRM/RCP 2003) recommends rehabilitation referral of patients with continuing impairment of concentration or mobility at 48 hours (4.2). RM consultation at that time would offer support in the management of acute symptoms (pain, seizures, dizziness, confusion), advice on prognosis and access to alternative rehabilitation services as illustrated in Fig 3.1 of the report on Medical rehabilitation in 2011 and beyond (RCP/BSRM 2010). Such a plan would be formalised in England around a Rehabilitation Prescription and the use of this to access Specialist Rehabilitation is described in the BSRM publication 'Specialist Rehabilitation in the Trauma Pathway: BSRM core standards' (2013). Less severely injured patients who are discharged early should have telephone contact at 1 week (BSRM/RCP 2003).
026	British Society of Rehabilitation Medicine	Quality Statement 6		This statement is supported but community rehabilitation should be available following less severe TBI and for patients with physical, emotional, behavioural as well as cognitive problems. The Consultant in RM has a key role in formulating the problems faced by such patients, many of which may not be due directly to the brain injury. Comprehensive community rehabilitation, incorporating Rehabilitation Medicine, neuropsychiatry and clinical neuropsychology as well as therapy disciplines, can prevent disability, maintain family relationships and is demonstrated to be effective at retaining employment after less severe injuries (RCP/BSRM 2010).
026	British Society of Rehabilitation Medicine		Question 2	Statement 5. In England it should be possible to measure the completeness and outcome of Rehabilitation Prescriptions in both Major Trauma Centres and Trauma Units complemented by a review after discharge covering return to work etc. An audit system is being developed which will link trauma admission data (TARN) with rehabilitation admission data from Specialist Rehabilitation Units in England (UK-ROC). Statement 6. Consider surveying hospitals managing TBI with reference to referral pathways and provision of rehabilitation services using the evidence based markers of good practice detailed for Quality Requirements 1, 4, 5, 6 and 10 of The National Service Framework for Long-term Conditions (DoH 2005).
027	College of Occupational Therapists	Quality Statement 5		Should say be assessed for need for rehabilitation as there are limited in-patient rehab facilities (perhaps this is why they have made this statement?) and in patient rehab may not be the most appropriate if good services in community. We also need to agree what indicator will be used to identify the presence

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				of 'cognitive deficits' and who will be assessing the patient if this data is being routinely collected (Drs, Psychology, OT?).
027	College of Occupational Therapists	Quality Statement 5	Page 5	Would it be worth stating who/which professionals would complete this assessment of need?
027	College of Occupational Therapists	Quality Statement 5		Guidelines state people in hospital for over 72 hours with cognitive deficits after a moderate or severe TBI need an assessment for inpatient rehab. points are:- - Why 72 hours? Although this figure is given in the SIGN guidelines, it differs from the figure of 48 hours given in the BRSM guidelines. - How are the cognitive deficits going to be assessed, by whom and is there a cut off level saying this person must/must not go to an inpatient unit? - There is no mention of behavioural problems or the emotional impact of the injury on both the person with the injury and their families. - Even though the effects of moderate and severe TBI are listed in the document, surely the fact the person is having problems enough to warrant access to rehab without using the terms moderate or severe TBI? Concern is the GCS scores will be applied to a person with a minor GSC score and commissioners can exclude that person from access to rehab on the basis they are 'minor' even though they are having problems. This happens in some services now. - Are these guidelines aimed solely at traumatic brain injury? If so, are similar guidelines going to be produced for people with acquired brain injury? There is a need for a specialist TBI case manager to assist with discharge and follow up in the community as this is well documented as a difficult time for both patients and families.
027	College of Occupational Therapists	Quality Statement 5		Many people with moderate brain injury who have rehab needs and who would benefit from inpatient rehab are discharged before 72 hours, particularly if they have no residual physical difficulties. These people get lost in the system and often do not get referred on for further rehab.
027	College of Occupational Therapists	Quality Statement 5 & 6		Not just cognitive difficulties, usually people have a combination of physical, emotional and behavioural difficulties as well as cognitive restrictions. Cognitive difficulties will be exacerbated by presence of these other factors.
027	College of Occupational	Quality		As above. In addition services need to be available at different points in a persons recovery often over a

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	Therapists	Statement 6		number of years. This needs to be made clear as often. Access to community rehab is time limited in terms of length of intervention e.g. 12 sessions only and also time post injury e.g. Intervention only offered up to 18 moths post injury. Glasgow Coma Scale given as a measure of severity. In terms of ongoing rehab needs severity of BI better measured by estimation of PTA.
027	College of Occupational Therapists	Quality Statement 6	Page 5	Could this be more detailed in relation to what community rehabilitation services and interventions will be available?
027	College of Occupational Therapists	Quality Statement 6	Page 22	Excellent to see returning to work included. Is it possible to be more specific about what the community rehabilitation would look like/be?
027	College of Occupational Therapists	Quality Statement 6		As cognitive rehabilitation is a specialist skill, access to specialist rehabilitation is required, not just general rehabilitation. The word 'specialist' is used in p23 but not in the overview statements on p5. Do they plan to define specialist? There is no mention of behavioural problems or the emotional impact of the injury on both the person with the injury and their families and how these are equally important factors after TBI. There is no mention of the fact specialist TBI rehabilitation is required long term as TBI is a long term condition. To help someone with a TBI return to work specialist TBI and vocational rehabilitation knowledge is required. Even though the effects of moderate and severe TBI are listed in the document, surely the fact the person is having problems enough to warrant access to rehab without using the terms moderate or severe TBI? Concern is the GCS scores will be applied to a person with a minor GSC score and commissioners can exclude that person from access to rehab on the basis they are 'minor' even though they are having problems. This happens in some services now. There is a need for a specialist TBI case manager to assist with discharge and follow up in the

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				community as this is well documented as a difficult time for both patients and families. Are these guidelines aimed solely at traumatic brain injury? If so, what happens for people with acquired brain injury?
027	College of Occupational Therapists	Quality Statement 5		Disappointed this is limited to presence of cognitive deficits – fails to acknowledge need for psychological difficulties and interaction with cognition, function and social participation. Also family members who require support.
027	College of Occupational Therapists		Overall comment	No (obvious) AHP TBI rehabilitation professionals or TBI experts on committee or project team. Guidelines only reference early management of Head injury documentation i.e. SIGN. Even though the SIGN guidelines refers to the fact that there are high levels of persisting disability at one and 5-7 year follow up even in patients admitted briefly with mild head injury (GCS 13-15), (SIGN Section 9 Follow-up). No reference is made to any rehabilitation guidelines e.g. (British Society of Rehabilitation Medicine et al. 2003; Turner-Stokes et al. 2005) guidelines.
027	College of Occupational Therapists			The quality standard will be very useful – we are pleased it is being published.
028	NHS England		Question 1	It is clear how the quality standard will address measures of clinical outcome such as social care OF domain 2 and NHSOF domain 3 and public health OF domain 4. It is not clear how measures of experience will be addressed ie NHSOF domain 4. For example, access to diagnostic testing within a 1 hour time frame may not alter the experience of care received in A&E. The time spent in A&E may not be reduced as it is dependent on a range of factors; relational aspects of care will not be affected / improved by reducing the wait in one step of the patient pathway.
028	NHS England		General	I would like to make an overall statement regarding the document Any person suffering a severe head injury must have their care DELIVERED by a neurosurgical consultant led team One can spend hours debating and defining what a severe head injury is but to me (as a surgeon and a parent –with some personal experience unfortunately)-but any head injury that ends up with hospital

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				admission must be considered as serious. There is a reluctance from neurosurgeons to become directly involved from the start –they are happy to comment on scans etc. but I feel in what we believe is a modern system of trauma the patient needs to be seen by a consultant led neurosurgery team with hours of admission and any surgery required must be done by a consultant or under his or her direct supervision (that is to say the neurosurgeon in the theatre complex)
029	Healthcare Quality Improvement Partnership			I know that there is concern about the use of vomiting as a discriminator and would suggest that a time frame in relation to the injury is needed (and in the absence of viral gastroenteritis) Other comments I have had: 'The draft document has six statements, the first four of which relate to “sharp end” care - Children and adults with a head injury have a CT head scan within 1 hour of a risk factor for brain injury being identified that indicates it necessary. - Children and adults with a head injury and any specific risk factor for cervical spine injury have a CT cervical spine scan within 1 hour of the risk factor being identified. - Children and adults with a head injury who are taking warfarin have a CT head scan within 8 hours of the injury, even if no other risk factor for brain injury is identified. - Children and adults with a head injury and a Glasgow coma scale score of 8 or less at any time have access to specialist treatment through ongoing liaison with or transfer to a neuroscience unit. which is all well and good. The last two for the first time acknowledge issues of post-acute rehab **BUT EXPLICITLY EXCLUDE CHILDREN** *- Adults (aged 16 and 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.* *- Community rehabilitation services are available to provide a range of interventions to help support adults (aged 16 and over) with continuing cognitive deficits after a moderate or severe traumatic brain injury'*

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				The point is that children are not included in this aspect of care post head injury.
030	Child Brain Injury Trust		Section 1 Introduction and Quality Standard 6	Page 4: Role of families and carers. Although the introduction states “Quality standards recognise the important role families and carers..” the involvement of families and carers in the Quality Rehabilitation Standards is not mentioned, although this involvement is vital in maximizing recovery. Family functioning is a moderator of outcome and research indicates that children do not recover as well if their families are unsupported and unhelped to cope with the changes within their child. Working at the family level achieves the best rehabilitation outcomes Yeates, Taylor et al, 2010; Micklewright, King et al (2012); Antonini, Raj et al (2012); Brown, Whittingham et al (2012); Taylor, Yeates et al (2001). ! References: Antonini, T. N., Raj, S. P., Oberjohn, K. S., & Wade, S. L. (2012). An online positive parenting skills programme for paediatric traumatic brain injury: Feasibility and parental satisfaction. Journal of Telemedicine and Telecare, 18(6), 333-338. doi: 10.1258/jtt.2012.120404 Brown, F. L., Whittingham, K., Boyd, R., & Sofronoff, K. (2012). A systematic review of parenting interventions for traumatic brain injury: Child and parent outcomes. The Journal of Head Trauma Rehabilitation, Published online ahead of print May 28, 2012. doi: 10.1097/HTR.0b013e318245fed5 Micklewright, J. L., King, T. Z., O'Toole, K., Henrich, C., & Floyd, F. J. (2012). Parental distress, parenting practices, and child adaptive outcomes following traumatic brain injury. Journal of the International Neuropsychological Society, 18(2), 343-350. doi: 10.1017/S1355617711001792. Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Burant, C. (2001). Bidirectional child-family influences on outcomes of traumatic brain injury in children. Journal of the International

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				Neuropsychological Society, 7(6), 755-67. Yeates, K. O., Taylor, H. G., Walz, N. C., Stancin, T., & Wade, S. L. (2010). The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. Neuropsychology, 24(3), 345-356. doi: 10.1037/A0018387.
030	Child Brain Injury Trust		Section 1 Introduction and Quality Standards 5 & 6	Page 4: Role of voluntary organisations There is no mention of liaison with the voluntary sector in the Introduction and Quality Standards 5 and 6, although voluntary agencies play an important role in the rehabilitation of both adults and children, for instance Child Brain Injury Trust, Headway.
030	Child Brain Injury Trust	Quality Statements 5 & 6		Omission of children under the age of 16 in the Quality Standards on Rehabilitation: Despite the opening comment on page 1 of the Introduction:! “Each year, 1.4 million people attend accident and emergency departments in England and Wales with a recent head injury. Between 33% and 50% of these are children younger than ! 15 years” (Page 1)! Children then appear to be excluded from rehabilitation standards completely in this document - i.e. Quality Standards 5 and 6 specifically refer only to adults (over 16 years) although all the Quality Standards relating to acute care (1-4) refer to adults !and children. This omission is illogical, indefensible and unexplained.! ! International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation places emphasis on the functional change in the quality of life.The long-term effects on of TBI in children’s functioning has been documented for many years (Anderson et al, 2006, and 2011) and the lack of adequate comprehensive assessment and rehabilitation of all their physical, cognitive and psychological needs is well known. Why then do NICE exclude children’s rehabilitation from their quality standards, when they make

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				up 33-50% of those attending A&E departments with a recent head injury ?! ! The outcome of head injury in childhood is worse than in adults as children's brains are still developing and! many cognitive and psychological difficulties emerge slowly over time (Schwarz et al, 2003: Max et al, 2012), and need long term rehabilitation, which education cannot and does not give and is more appropriately delivered by NHS services, i.e. emotional support and therapy for psychological problems both within the child and their family. There is a growing body of research to support the efficacy of childhood rehabilitation (Wade, Carey and Wolfe, 2006: Woods, Catroppa et al, 2012).! ! IT IS THE OMISSION OF CHILDREN FROM THE QUALITY STANDARDS ON REHABILITATION THAT IS MOST STRIKING IN THIS DOCUMENT, which is done with no explanation at all. Anderson, V. A., Catroppa, C., Dudgeon, P., Morse, S. A., Haritou, F., & Rosenfeld, J. V. (2006). Understanding predictors of functional recovery and outcomes 30 months following early childhood head injury. Neuropsychology, 20, 42-57. Anderson, V. A., Brown, S., Newitt, H. & Hoile, H. (2011). Long-term outcome from childhood traumatic brain injury: intellectual ability, personality and quality of life. Neuropsychology, 25(2), 176-184. Max, J. E., Levin, H. S., Wilde, E. A., Bigler, E. D., MacLeod, M., Vasquez, A. C., . . . Yang, T. T. (2012). Psychiatric disorders after pediatric traumatic brain injury: a prospective, longitudinal, controlled study. The Journal of Neuropsychiatry and Clinical Neurosciences, 24(4), 427-436. Schwartz, L., Taylor, G. H., Drotar, D., Yeates, K. O., Wade, S. L., & Stancin, T. (2003). Long-term behavior problems following pediatric traumatic brain injury: Prevalence, predictors, and correlates. Journal of Pediatric Psychology, 28(4), 251-263.

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				Wade, S. L., Carey, J., & Wolfe, C. R. (2006a). The efficacy of an online cognitive-behavioural family intervention in improving child behaviour and social competence following paediatric brain injury. Rehabilitation Psychology, 51, 179-189. Woods, D., Catroppa, C., Giallo, R., Matthews, J., & Anderson, V. (2012). Feasibility and consumer satisfaction ratings following an intervention for families who have a child with acquired brain injury. NeuroRehabilitation, 30(3), 189-198. doi: 10.3233/nre-2012-0744
030	Child Brain Injury Trust		General	We are concerned that there appear to be no specialists in working with children or in working with the social psychological issues for families and children on the specialist committee in preparing this report.!
030	Child Brain Injury Trust		General	This document focused on Traumatic Brain Injury but we question why the term Acquired Brain Injury is not used, as many adults and children suffered brain injury from other causes than trauma, i.e. stroke, meningitis etc.
031	Royal College of Speech & Language Therapists	Quality Statement 5	Page 19	• Rationale - refers to intellect, sensory, physical and social behaviour and it would be better to refer to cognition rather than intellect and it is believed to be beneficial to mention communication as an additional area. Unclear with this standard whether it is referring to inpatient rehabilitation to be provided in the current environment, (i.e. acute neurosciences) or assessment for admission to a post-acute neurorehabilitation unit. Given the early assessment discussed it would be assumed that this would be for rehab to be provided in the acute setting. This quality standard does not then measure whether this rehab can be provided by services - will that be a future target?
031	Royal College of Speech & Language Therapists	Quality Statement 5	Page 23	• In combination with Quality Standards 5, this omits the role of specialist inpatient neurorehabilitation who also provide services to adults with continuing cognitive deficits.
031	Royal College of Speech & Language Therapists		Page 23	• Definitions - neurological deficits - aphasia is mentioned but the most common communication deficit after traumatic brain injury is Cognitive Communication Disorder.

Stakeholders who submitted comments at consultation

- Alder Hey Children's NHS Foundation Trust
- Association of British Neurologists
- Association of Chartered Physiotherapists in Neurology- Yorkshire branch
- Barking, Havering and Redbridge Hospitals NHS Trust
- British Infection Association
- British Paediatric Neurology Association
- British Society of Rehabilitation Medicine
- Child Brain Injury Trust
- College of Occupational Therapists
- Department of Health
- Faculty of Forensic and Legal Medicine
- Faculty of Intensive Care Medicine
- Headway – the brain injury association
- Healthcare Quality Improvement Partnership
- ICU steps
- Leeds Teaching Hospitals NHS Trust
- NHS Choices
- NHS England

- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians
- Royal College of Speech & Language Therapists
- Society of British Neurological Surgeons
- South Wales Critical Care Network
- The Brain Injury Rehabilitation Trust
- The College of Emergency Medicine
- The Intensive Care Society
- The Royal College of Radiologists and the British Society of Neuroradiologists
- The Society and College of Radiographers
- UK Acquired Brain Injury Forum