

The Neurological Alliance: Neurosurgery service specification consultation response - September 2018

Does the impact assessment fairly reflect the likely activity, budget and service impact?

No

We've ticked no as we have a couple of concerns on this front:

- If disease epidemiology is growing at 2-5% as per A2.1, surely this should be reflected at A2.3 - we can expect greater numbers of people having these procedures?
- Moreover, A2.2 neglects the rising number of people living and dying with neurological conditions - given they are less likely to die from other diseases such as cancer. See Public Health England's 2018 Deaths Associations with Neurological Conditions reports.

Does the document describe the key standards of care and quality standards you would expect for this service?

Yes

Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that we have described?

[not got any]

Are there any changes or additions you think need to be made to this document, and why?

Section on elective care:

- Where appropriate a management plan is determined by the appropriate multidisciplinary team – add 'in partnership with the patient' (reason – needs to be made explicit that the patients get a say) and out-patient consultation and counselling is undertaken by the appropriate member/s of the multidisciplinary team (MDT).
- Subsequent out-patient care is determined by the patient's condition and progress add 'and preferences' (reason again, needs to be made explicit that the patient gets a say in their care)

National context

- The specialty developed initially through the treatment of add 'patient with' (reason one doesn't treat a condition as if it were separate from the person)-who has it) cranial trauma and intracranial mass lesions.
- Although paediatric neurosurgery is commissioned separately from adult neurosurgery, there exist important clinical, training and infrastructure links between the two neurosurgical services. – Add 'Moreover, strong links are necessary to smooth patient transition from paediatric to adult services.' (reason: seems an oversight to overlook patient needs in this paragraph, especially when I's well recognised that that many patients struggle when transferring from children's to adult's services)

Quality statement – aims of service

- The aims of neurosurgical services are to:
 - reduce the morbidity and mortality of add 'patients with' neurosurgical conditions;
 - o to minimise add "patients' " pain and disability;
 - o to optimise add "patients' " functional recovery and
 - improve the quality of life of neurosurgical patients (reason – again, you're treating patients, please put them front and centre by making explicit)

Elective care

- Under the section on 'resources' you spell out what SBNS stands for. But
 in the section on elective care, which comes further up the document, you
 don't. Normal practice is to spell out first time, so suggest you spell it out in
 the section on elective care.
- This also occurs with a few other acronyms later on (e.g. ICU). Suggest rectifying.

Service delivery

 Multi-professional teams will work together, across disciplines and locations, to achieve the optimal decision making, treatment and clinical outcomes – add 'for patients' (reason - as above)

Communication

 Patients will be provided with a full range of condition-specific information in appropriate formats suitable to the patient's communication needs. (reason – important to emphasise it must suit patient communication needs as per NHSE's accessible communications policy)

Continuing care and rehabilitation

 Please express in stronger terms the importance of clinicians engaging early on (if needed) with social care services, to ensure care packages are in place at the time of discharge. Suggested wording: Robust mechanisms for the repatriation of patients to their local secondary and primary care setting must be agreed as part of a regional framework to achieve the efficient and responsive working of the neurosurgical unit. - Add 'Early liaison with social care services should take place to ensure care packages, where needed, are in place at the time of discharge.' Ideally repatriation to referring hospitals should take place within 48 hours.

Indicators

- Half of the indicators table cannot be seen! Ought to have been corrected before going to open consultation.
- 102 Percentage of Aneurysmal SAH intervention within 48 hours of...
 - o add 'patient's' admission to the Neurosurgical Centre (reason again, you're treating patients, please put them front and centre by making explicit)
- 201 Patients are provided with Information
 - Currently too vague won't make the difference needed to ensure good provision of info to patients. Suggest changing to:
- 201 Patients are provided with information in a range of formats suitable to their communication needs. The information includes: - details relating to the procedure being undertaken; - patient pathway details; - national and local support groups; - emergency contact details.
- 202 The service is acting on Patient Feedback
 - o Again, currently too vague won't make the difference needed to ensure good provision of info to patients. Suggest changing to:
 - 'The service undertakes a patient and family/carer experience exercise at least annually, reviewing the feedback and implementing any actions as appropriate, and feeds back to patients/carers.'
 - o NB if it isn't felt appropriate to add this level of details in to the indicators in the main body of the document, how about having an appendix where more info is give, as in this example of a recently published service spec? https://www.england.nhs.uk/publication/environmental-control
 - equipment-for-patients-with-complex-disability-all-ages/
- Delayed transfers of care are a significant issue, as highlighted in the neurosurgery GIRFT report (key constraints on cranial neurosurgery throughput is a lack of available beds), perhaps this should be reflected in the indicators? E.g. Percentage of patients repatriated to referring hospitals within 48 hours
- Moreover/alternatively, given the huge impact on patients of delayed transfers of care, perhaps this could be added as an indicator under the section on patient experience? i.e. 204 - Percentage of patients who experience a delayed transfer of care.

Abbreviation and Acronyms Explained

Half of these are missing – needs rectifying.

Additional general comments

 Some people undergoing neurosurgery will need to access independent advocacy <u>under the Care Act</u> or the <u>Mental Capacity Act</u>, in order to be able to access their statutory rights. The need for referral to advocacy should be added, perhaps under the section on the care pathway, or the section on continuing care and rehabilitation.