

# National Institute for Health and Care Excellence

## Epilepsies in children, young people and adults (update)

**Consultation on draft quality standard – deadline for comments 5pm on 13/07/23**

**Please email your completed form to: [QualityStandards@nice.org.uk](mailto:QualityStandards@nice.org.uk)**

Note: During development of the draft quality standard, the Medicines and Healthcare products Regulatory Agency announced that new safety measures for valproate-containing medicines are to be put in place. NICE's guideline on epilepsies in children, young people and adults will be updated when more information on these safety measures is published. The draft quality standard does not cover the new safety measures.

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

Use the form to comment on the content of the quality standard (i.e. the statements and other sections e.g. rationale, measures etc.), as well as answer the following questions:

- Question 1. Does this draft quality standard accurately reflect the key areas for quality improvement?
- Question 2. Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected.
- Question 3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.
- Question 4. For draft quality statement 1: Is it feasible for epilepsy specialist nurses to be the 'clinician with expertise in epilepsy' who identifies the cause of a seizure and ensures a correct diagnosis is made?
- Question 5. For draft quality statement 5: Statement 5 covers planned epilepsy appointments. Are there specific types of epilepsy appointments that should be included or excluded from this statement?
- Question 6. For draft quality statement 5: Is there enough time and capacity at epilepsy appointments to ask about cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities?
- Question 7. For draft quality statement 5: Statement 5 covers cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. It also covers all people with epilepsy. Would it be helpful to focus the statement on a smaller number of areas or a particular population group? If so, what should it focus on?
- Question 8. For draft quality statement 5: What is an appropriate outcome measure for this statement? Please include any known data sources for suggestions.

Question 9. What are the challenges to implementing the NICE guidance underpinning this quality standard? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives).

## Organisation details

<b>Organisation name</b> (if you are responding as an individual rather than a registered stakeholder please leave blank)	<b>The Royal College of Physicians of Edinburgh (the RCPE).</b>
<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	<b>The RCPE does not have direct or indirect links to, or receive funding from, the tobacco industry.</b>
<b>Name of person completing form</b>	<b>Douglas Pattullo, Policy Officer.</b>
<b>Supporting the quality standard</b> Would your organisation like to express an interest in formally supporting this quality standard? <a href="#">More information.</a>	
<b>Type</b>	<b>[Office use only]</b>

## Comments on the draft quality standard

<b>Comment number</b>	<b>Statement or question number</b> Or 'general' for comments on the whole document	<b>Comments</b> Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.
<i>Example 1</i>	<i>Statement 1</i>	<i>This statement could be improved by...</i>
1	General	The RCPE welcomes the opportunity to comment on this draft quality standard and the comments here are based on the views of Fellows working within neurology who have significant experience in this field.

2	Question 1	The RCPE considers that the standard is a generally highly positive one that effectively reflects a number of important areas that continue to require attention despite many years of prominence. Some Fellows saw less value in annual epilepsy care plans and asked for evidence that these improved care and outcomes. In addition, some Fellows indicated that they felt mortality should be included and a suitable quality standard might mandate a structured judgement review of all patients with epilepsy who die, linked to appropriate escalation strategies including the national Patient Safety Incident Response Framework. Similarly, some Fellows felt the views of patients and the public on the quality of epilepsy services they receive could prove beneficial if used properly – a suitable quality standard might mandate commissioners or providers to regularly review feedback from the public with respect to the quality of services provided.
3	Question 2	
4	Question 3	We consider that while this will vary, these should be often achievable within current budgets for care, provided they are constructed to include suitable quality assurance activities. Fellows consider that part of the agreed contract should include provision for this type of activity to support service delivery, and clinicians should be supported by their trusts to deliver quality activity with realistic budgets and job plans.
5	Question 4	We consider that it is generally feasible for an epilepsy nurse specialist to identify the cause of a seizure and ensure that the correct diagnosis is made. However, to achieve this, reform of the relevant training may be required to allow them to develop these skills in an objective and measurable way, and to provide assurance that they are suitably qualified. The same would apply to Physician Associates.
6	Question 5	Fellows consider this information should be sought if it is unknown and/or unmanaged, so that patients can be suitably directed to appropriate care but this does not need to be blanket applied to every appointment.
7	Question 6	Fellows consider this will vary and depend on individual circumstances but that there may be time provided this information is looked for in a focussed way.
8	Question 7	Again, we consider that these questions should be focussed on those for whom this information is unknown or unmanaged and where it is appropriate; there would be little to be gained in, for example, asking a patient with severe brain injury with 24 hour care if they have cognitive problems.
9	Question 8	Fellows consider Patient reported outcome measures (PROMs) on how holistic the care they received was may be appropriate here and understand that this would have to be collected locally.
10	Question 9	Fellows highlighted a lack of available trained resource combined with a lack of available training capacity. Some suggested that a clearly defined skills framework might allow some of the less specialised activity to

		be picked up by other staff e.g. in GP surgeries/community paediatrics/learning disability services, but understand that this would have to be carefully managed; they described the balance that needs to be achieved between diluting specialist skills and preventing any change or improvements being made at all.
11	Statement 1	The RCPE supports this statement. Some Fellows raised their desire to see guidance being provided for a suggested syncope pathway to support first seizure clinics given that some clinicians see first seizures as collapse, something which may increase waiting times.
12	Statement 2	The RCPE supports this statement.
13	Statement 3	The RCPE supports this statement. Some Fellows noted with concern that while epilepsy is the most common chronic neurological disorder, excluding stroke, as a specialty, it has fewer nurses per head of population than other conditions such as MS, MND and Parkinson's.
14	Statement 4	Some Fellows expressed the view that they already effectively did this through clinics and questioned whether there was genuine patient demand for a further written document with all this information when it should already be covered in clinic letters. They noted the potentially significant extra workload from creating these plans.
15	Statement 5	While supportive of the aims here, some Fellows suggested that this would require 30 minute return appointments for Consultants and 45 minutes for nurses and that this could lead to a significant decrease in capacity if adopted for all appointments.

Insert more rows as needed

## Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use

Please return to [QualityStandards@nice.org.uk](mailto:QualityStandards@nice.org.uk)

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

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.