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CARE EXCELLENCE

Quality standards

Consultation summary report: Epilepsies in children, young people and adults (update)

Quality Standards Advisory Committee post-consultation meeting: 12 September 2023

1. Introduction

The draft quality standard for epilepsies in children, young people and adults (update) was made available on the NICE website for a 4-week public consultation period between 15 June and 13 July 2023. 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 26 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. The appendix to this paper contains the full comments from registered stakeholders.

1. Questions for consultation

Stakeholders were invited to respond to 9 questions at consultation. These questions are listed in full in sections 3 and 4 of this report.

1. General comments

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

* Update of the quality standards is welcome and is enhanced by the addition of statement 5.
* Aims and the statements are supported, but there may be challenges due to limited resources.
* Equality and diversity considerations in the quality standard are positive.
* Wider healthcare needs of individuals need to be considered.
* Intellectual disability and neurodevelopmental disorder should be a specific group within the quality standard.
* Statements should make a distinction between people with controlled and uncontrolled epilepsy.
* Several stakeholders commented on aspects of NICE’s guideline rather than the draft quality standard.

### Consultation question 1: key areas for quality improvement

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

Stakeholders made the following comments in relation to consultation question 1:

* Quality standard identifies the key areas for quality improvement.
* Key areas are identified, but the following areas are not given sufficient focus:
  + Improved communication and information sharing with patients and families, especially in relation to SUDEP.
  + Identifying patients with drug resistant epilepsy.
  + Transition from paediatric to adult services.
  + Role of primary care, especially in transitioning stable patients back to primary care.
* Statement on epilepsy care plans is least valuable; would it improve outcomes?

### Consultation question 2: local data collection

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.

Stakeholders made the following comments in relation to consultation question 2:

* Data can be collected locally:
  + Potential data sources include: Epilepsy 12 audit (collects and reports data relevant for all statements for children and young people aged 0-24 years), HES data, outpatient data, patient records (electronic an paper), and patient surveys.
  + Responsibility for data collection should not fall on one group; primary care, secondary care, tertiary care and epilepsy specialist nurses (ESNs) all need to contribute.
* Data can possibly be collected locally:
  + Similar data to some measures is collected for cancer 2 week waits.
  + Templates (which are coded) could be developed within the GP / community IT systems.
* Data cannot be collected locally or would be difficult to collect:
  + Records would need to be reviewed locally to extract information.
  + New data collection using surveys and audits would be needed.
  + Staff will not have the time or ability to undertake these activities.
  + Data from different sources will overlap.
  + Different terminology/vocabulary is used across different organisations.
  + Clinicians with specialist epilepsy experience are embedded in a range of services that offer primary treatment (e.g., intensive care, HDU, high acuity wards).

### Consultation question 3: resource impact

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.

Stakeholders made the following comments in relation to consultation question 3:

* Statements are not achievable due to:
  + A lack of funding and resources in neurology, epilepsy services, neuropsychiatry and neuropsychology services. There are currently long waiting lists for many of these services.
  + Current climate of system pressure, high demand, backlogs and financial constraints.
  + More epilepsy specialists (neurologists) and ESNs are needed.
  + More training is needed for epilepsy specialists, and to deliver statement 5.
  + Confusion in the system over the terms tertiary epilepsy service and tertiary epilepsy centre.
  + Improved access to mental health professionals is needed to deliver and/or oversee mental health interventions.
  + Additional resources needed to collect and collate data.
* Statements are mostly achievable, but the specific timeframes for some statements may not be achievable within current resources.
* Potential cost savings, if the statements can be implemented, could result from:
  + Reduced emergency department attendances.
  + Preventing hospital admissions.
  + ESN posts being cost-effective.
  + Improved seizure control.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

People presenting with a first suspected seizure are seen by a clinician with expertise in epilepsy within 2 weeks of presentation. **[2013, updated 2023]**

### Consultation comments

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

Statement

* Agree with or support the statement.
  + Including the phrase ‘clinician with expertise’ is welcomed.
* The timeframe of within 2 weeks:
  + Is important and appropriate.
  + If not met can lead to problems with communication and increased likelihood of additional A&E visits and/or stays in hospital.
  + Should be a gold standard.
* Suggested amendments to the statement:
  + Include support and guidance for patients and families is needed following a first seizure, including signposting to epilepsy charities.
  + Is there is any imaging or investigation (CT / MRI / EEG) that could be ordered at the time of initial presentation to optimise the appointment with the expert in epilepsy? [Note NICE’s [transient loss of consciousness ('blackouts') in over 16s guideline](https://www.nice.org.uk/guidance/cg109) and [quality standard](https://www.nice.org.uk/guidance/qs71) recommend that EEGs are not routinely requested inappropriately in the generalist setting as a diagnostic test to investigate unexplained transient loss of consciousness.]
* Insufficient workforce to deliver the statement.

Measures

* The Epilepsy12 audit has updated metrics to align with the 2-week target.
* ‘Presentation’ may be difficult to define and measure. Epilepsy12 audit uses the first paediatric assessment as the trigger date, where input from a paediatrician with expertise is required two weeks from that point.

Audience descriptors

* Healthcare professionals audience descriptor should also include paediatricians who do not specialise in epilepsy or neurological conditions as they refer people presenting with a first seizure.

Definitions

* Clarification needed on a clinician with expertise in epilepsy:
  + What constitutes expertise is open to interpretation. There are agreed definitions of paediatrician with expertise and formal routes to achieve and maintain this competency.
  + Clarifying the location of the clinician with expertise in epilepsy would improve the statement, i.e., would this be this part of an admission, outpatient, specialist centre etc.?

### Consultation question 4

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?

Stakeholders made the following comments in relation to consultation question 4:

* The neurologist or paediatrician would be the clinician with the expertise of diagnosing epilepsy.
* ESNs cannot have this role for children and young people (NICE’s quality standard and guideline state it should be a paediatrician).
* ESNs are not trained to, and do not have the necessary expertise, to diagnose epilepsy.
* Identifying the cause of seizures and diagnosis are not part of the key competencies for ESNs.
* There is variation in skills and experience required for ESN posts; some are advertised with experience in management of epilepsy being desirable, but not essential.
* Diagnosing epilepsy can be complex, and ESNs may miss other important diagnoses they may be less familiar with such as atypical manifestations of migraine, cardiac syncope, carotid sinus hypersensitivity than epileptic seizures or dissociative attacks.
* Uncertainty in diagnosis is a reason for referral to tertiary services.
* It is feasible for ESNs to be the clinician with expertise but:
  + Specific training and governance arrangements would be needed for this to occur safely.
  + Appropriate supervision would be needed, e.g., from a consultant neurologist.
  + Additional qualifications would be needed (e.g., MSc in advanced clinical practice and independent nurse prescribing qualification).
  + Would upskilling of ESNs be the best use the additional resource needed?

### Issues for consideration

#### For discussion:

* Who should the clinician with expertise in epilepsy be for adults? The draft quality statement included ‘…a doctor, physician associate or epilepsy specialist nurse with training and expertise in assessing first seizures and diagnosing epilepsy’.
* Is ‘expertise’ defined correctly?

#### For decision:

* Who is the clinician with expertise in epilepsy for adults?
  1. Draft statement 2

Children referred urgently to a tertiary epilepsy service are seen within 2 weeks of referral and other people are seen within 4 weeks. **[2013, updated 2023]**

### Consultation comments

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

Statement

* Agree with and support the statement:
  + Statement will help address variation in access to tertiary epilepsy services.
  + Timely access to tertiary epilepsy services is especially important for people with Drug Resistant Epilepsy.
* Genomic testing should be integrated as a standard part of early diagnosis for epilepsy and not be part of the tertiary service.
* The wording ‘other people are seen within 4 weeks’ is confusing and does not make clear who it relates to.
* Alternative options for those who should be seen within 2 weeks were suggested (e.g., all people referred to tertiary services should be seen within 2 weeks, people with status epilepticus, people with worsening / changing symptoms).
* Could the pathway to tertiary services be streamlined? People see a clinician at first presentation, get referred to expert in epilepsy, then referred onto tertiary services.
* Ketogenic diet is described as part of tertiary specialist services, but it is not funded for adults by NHS England.
* Resources could be problematic for the specialist assessments, e.g., there is a lack of neuropsychiatrists nationally.

Measures

* Outcome measures should include waiting times for neurophysiology and radiology investigations (as the statement covers access to specialist investigations).

Equality and diversity considerations

* Should these also include / apply to people who are neurodiverse?

### Issues for consideration

#### For discussion:

* Is the statement wording clear about who is seen within 2 weeks and who is seen within 4 weeks?

#### For decision:

* Does the statement wording need to change?
  1. Draft statement 3

People with epilepsy have access to an epilepsy specialist nurse. **[2013, updated 2023]**

### Consultation comments

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

Statement

* Support or agree with the statement as ESNs have an important / essential role.
* Statement should include a timeframe for when and how often someone should have access to an ESN.
* Statement should clarify what is meant by access.
* Important phrase has been lost from the existing quality statements on ESNs: ‘…who they can contact between scheduled reviews’.
* Statement does not cover transition to adult services.
* There is a need to clarify the scope of work of ESNs.
* There is opportunity for ESNs to link up with work underway in Primary Care Networks.
* There are not enough ESNs and many people with epilepsy do not currently have access to one (fewer nurses per head of population than other conditions such as MS, MND and Parkinson's).
* The present service is mostly ‘reactive’ and reliant on patients contacting their ESN.

Measures

* Existing process measure b) (proportion of children and young people with epilepsy who have seen an epilepsy specialist nurse at their review) should be included for the updated statement.
* All people with epilepsy on the adult epilepsy nursing caseload of Kent Community Health NHS Foundation Trust have access to an ESN and this is measurable using the Rio electronic record system.

Equality and diversity considerations

* ‘Other complex needs’ should be defined, e.g. does it include those in transition from paediatric to adult service, between different health authorities who experience inconsistent joined up care and those with refractory epilepsy are in a ‘high risk group’ for SUDEP.

### Issues for consideration

#### For discussion:

* Does the statement capture the most important parts of the ESN role?
* Are the draft measures for the statement appropriate?
* Does ‘other complex needs’ need further explanation?

#### For decision:

* Does statement 3 need any changes?
  1. Draft statement 4

People with epilepsy have an up-to-date epilepsy care plan. **[2013, updated 2023]**

### Consultation comments

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

Statement

* Agree with and support the statement.
* Statement wording should include ‘agreed’ and ‘comprehensive’ like the existing quality statements do.
* Statement and care plan should also cover:
  + Non-epilepsy care, e.g., dental care.
  + Discussion of risks around epilepsy medications during pregnancy.
  + Discussion of risks around SUDEP and identification of patients who are at risk.
  + Identifying patients who are drug resistant so they can be offered alternative therapies.
  + How often the care plan will be reviewed.
  + Matters covered by statement 5.
* Care plans:
  + Are an essential part of epilepsy care.
  + Need to be electronically accessible across primary, secondary and tertiary care (and not rely on the patient to provide the information).
  + Are not always up to date; changes in medication may occur between reviews of a plan.
  + Statement could result in a care plan which is a checklist exercise or be interpreted as an emergency management plan for buccal midazolam that is not necessary for all patients.
  + Standard format is needed for an epilepsy care plan to prevent inconsistency.
  + Local template or checklist should be developed to ensure consistency in the content of each epilepsy care plan (as advocated by the statement).
  + Need for and nature of a care plan will vary according to individual circumstances.
* Is the statement and care plan needed? The actions are already covered in clinics and captured in clinic letters.

Measures

* Process measure c), Proportion of ‘women of childbearing potential’ who have an epilepsy care plan that covers preconception care and pregnancy, should include girls as it would encourage paediatric teams to start discussing contraception and pregnancy prevention from adolescence and align with MHRA valproate pregnancy prevention programme.
* Measurement would require using IT systems with an electronic template/checklist at clinic appointments. People on the adult epilepsy nursing caseload of Kent Community Health NHS Foundation Trust have a plan of care which is updated at each review, has quality outcomes and is measurable using the Rio electronic record system.

### Issues for consideration

#### For discussion:

* Is the statement wording correct?
* Are the most important aspects of a care plan covered?
* Is the detail in the definition of an epilepsy care plan helpful? Could it become a tick box exercise, or too onerous?

#### For decision:

* Does statement 4 need any changes?
  1. Draft statement 5

People with epilepsy are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. **[new 2023]**

### Consultation comments

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

Statement

* Support or agree with statement.
  + It is a valuable addition to the quality standard.
  + Discussing these matters in epilepsy appointments would be highly beneficial.
  + Important as depression and anxiety often seen as co-morbidities of epilepsy.
* Training to ensure relevant questioning and referral will also be important as well as the identification of which tools / questionnaires, etc. are best placed for use.
* May be opportunity to link up with the primary care network, particularly the ‘care coordinator’ and ‘social prescriber’.
* Aligns broadly with new measures in the Epilepsy12 audit which capture the presence of mental health conditions, including the screening and support received, and neurodevelopmental conditions including learning disabilities.
* Changes suggested to improve the statement include:
  + Moving neurodevelopment and learning disabilities to a separate statement.
  + Changing wording to say ‘People with epilepsy are assessed on an initial and ongoing basis around their…’.
  + Changing wording to add ‘… and provided with coordinated care’ to cover recommendations in section 9.1 of NICEs guideline [NG217 Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217).
  + Asking people about their speech, language and communication needs.
  + Including assessment.
  + Including onward referral.
  + Including a process for subthreshold symptoms (e.g., additional monitoring appointments).
  + Including proactive communication on information provided to patients regarding risks and mitigations they can put into place regarding living with epilepsy.
* Concerns raised about the statement include:
  + Asking questions alone is not enough.
  + Statement would increase time needed for each appointment and thereby decrease the capacity of appointments (see consultation question 6).
  + Are there enough clinicians and allocated time to deliver the statement.
  + Statement could exclude adults who have treatable symptoms and are stable.

Measures

* Structure measure is important to help facilitate the statement.

Audience descriptors

* People with epilepsy:
  + Epilepsy care team is not well defined, especially for those with those who have cognitive or learning disabilities associated with epilepsy.
  + Signposting to appropriate support groups would be a helpful addition.

### Consultation question 5

Statement 5 covers planned epilepsy appointments. Are there specific types of epilepsy appointments that should be included or excluded from this statement?

Stakeholders made the following comments in relation to consultation question 5:

* Statement should cover:
  + All appointments, including initial diagnosis / first appointments, with no exclusions.
  + Video and telephone appointments.
  + All planned appointments as per statement definition.
  + Inpatient admissions.
* All questions should not be asked at every appointment:
  + Mental health issues should be discussed at any type of appointment but not necessarily every time a patient is seen as some appointments may require the focus to be elsewhere.
  + Ask about difficulties, changes in cognition and wellbeing at all appointments as they are subject to change. For children, ask about development.
  + Neurodevelopmental condition or learning disability should not be asked about at every appointment for adults.
  + Neurodevelopmental issues or intellectual disability should not be discussed at every clinic appointment, but certainly at the first appointment with a specialist.
  + Some appointments require a focus, so it is not appropriate to ask all the questions.
  + Questions are more relevant when a life event occurs, e.g., new job, starting university, starting a new family.
  + Should be asked when unknown or unmanaged.
* Questions should be asked at specific intervals:
  + At least once every 12 months.
  + Statement should specify the intervals or frequency.
* Issues should be covered, and questions asked in a multidisciplinary team (MDT) clinic. People with cognitive function or learning disabilities may not be able to clarify whether they have psychological, cognitive and neurodevelopmental issues.

### Consultation question 6

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?

Stakeholders made the following comments in relation to consultation question 6:

* There is not enough time or capacity to ask these questions:
  + Longer appointments and changed clinic schedules would be needed.
  + The frequency of appointments needed may also change.
  + Clinic appointments at a Sheffield trust would need to change from 30 minutes to 40 minutes per new patient; and from 15 minutes to 20 minutes per follow-up patient.
  + More clinics and more staff would be needed.
  + People with learning and intellectual disability and those who are not English speaking should have longer appointment times.
  + Longer appointments would have adverse impacts on waiting lists and also affect other statements in the quality standard (e.g., ability to see people within 2 weeks of first seizure).
* There is not enough time and capacity for existing appointments:
  + Asking additional questions further increase pressures.
  + Appointments do not allow time to discuss the broader challenges of epilepsy and focus on getting the medication right. People attending appointments feel rushed and not listened to.
  + Example from one trust: people with epilepsy are asked how they are at each review, but there is not always time to carry out in depth questioning about mental health needs.
* There may be time to ask these questions if a focused approach is used, but it will vary depending on individual circumstances.
* Some information could be gathered between appointments via structured questionnaires and screening tools to reduce impact on appointment time.
* Actions may duplicate work that is happening in the community around LD reviews and other chronic disease management work,
* Use of the wider MDT rather than an epilepsy appointment with a clinician /nurse would enable a robust assessment and understanding of holistic needs.

### Consultation question 7

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?

Stakeholders made the following comments in relation to consultation question 7:

* No, it would not be helpful to focus the statement as:
  + Statement is relevant to all groups listed.
  + No patient groups should be excluded.
  + These issues are prevalent and often go undetected.
* Cognitive function / difficulties is relevant to all groups and should be asked about at all appointments.
* Cognitive function should be separate.
* Cognitive function should be more specific: assessment at diagnosis, before or after a new treatment is established, if a patient is reporting concerns and in the population over 65 years.
* Mental health and social and emotional wellbeing are relevant to all groups and should be a standard inquiry in all appointments.
* Neurodevelopment and learning disabilities should be separate entities of assessment depending on where that patient is in their life span.
* People with neurodevelopmental delays and/or learning disabilities can be assessed by other teams.
* For people with intellectual disability, gauging mental health problems can be more difficult and outside the skill set potentially of neurologists.
* Triaging after initial assessment and using an assessment tool would help ensure that those who are most in need of support with these issues get it.
* Focus should be on:
  + Those most risk of dying through a seizure, people losing their driving licence as they are having continued seizures, and those not able to work.
  + People who require the neuro-cognitive and neuro-psychiatric aspects to be assessed, in particular patients with medically refractory epilepsy, patients undergoing epilepsy surgery evaluation and patients with existing underlying learning disability / psychiatric history.
  + People for whom this information is unknown or unmanaged and where it is appropriate.

### Consultation question 8

What is an appropriate outcome measure for this statement? Please include any known data sources for suggestions.

Stakeholders made the following suggestions and comments in relation to consultation question 8:

* Outcome measure not needed. Process measures that show people are being asked about cognitive function, mental health, social and emotional wellbeing, neurodevelopment and learning disabilities are enough.
* Proportion of people referred to specialist mental health, neuropsychology, educational psychology and learning disability services from an epilepsy service.
* Developmental assessment, mental health assessment, self-reported wellbeing, reports on progress in education.
* Length of time without seizure / frequency of seizures.
* Patient reported outcome measure / patient satisfaction with holistic care, welfare, wellbeing.
* Use of mental health and neurodevelopmental screening tools in paediatric epilepsy care
* Epilepsy 12 performance indicators:
  + Percentage of children with epilepsy where there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire/measure.
  + Percentage of children with epilepsy and a mental health problem who have evidence of mental health support.
* Suggested data sources included small scale audits using clinic letters, referral systems, patient / service satisfaction surveys, Epilepsy 12 audit.

### Issues for consideration

#### For discussion:

* There is broad support for a statement, but little consensus on any detail.
* What should the focus of the statement be?
* Is asking questions the correct key action for the statement?
* When, where and how will the key action occur?
* Is there capacity for the action to be delivered?
* Can the action be measured?

#### For decision:

* Can statement 5 be amended or should it be removed from the quality standard?

1. Suggestions for additional statements

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

### Access to EEG and MRI in a timely manner

This was also suggested at topic engagement along with other specific investigations / assessments. It was not progressed as QSAC prioritised a statement on referral and assessment following a first seizure.

### Views of patients and the public on the quality of epilepsy services.

Patient and public views can be useful for measurement and can identify issues but are not an action for a quality statement. Quality statements should focus on actions that demonstrate high quality care or support.

### Structured judgement review of all patients with epilepsy who die.

A statement on this linked to appropriate escalation strategies including, the national Patient Safety Incident Response Framework, was suggested. There are no recommendations in the source guideline to support this.

### Prescribing of valproate and other antiseizure medications during pregnancy.

Antiseizure medications during pregnancy was discussed at the first QSAC but not prioritised for a statement. This area will be revisited after the Medicines and Healthcare products Regulatory Agency provide further information on [new safety measures for valproate-containing medicines](https://www.gov.uk/drug-safety-update/valproate-reminder-of-current-pregnancy-prevention-programme-requirements-information-on-new-safety-measures-to-be-introduced-in-the-coming-months) and [NICE’s guideline on epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) is updated accordingly.

### Joint care provided by maternity and neurology services during pregnancy.

Suggestions on management and service provision were considered at the first QSAC meeting and a care plan statement was prioritised. This includes pregnancy and preconception care, but it does not specifically cover the joint care suggested.

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# Appendix: Quality standard consultation comments table – registered stakeholders

| ID | Stakeholder | Section (statement or question number) | Comments |
| --- | --- | --- | --- |
| SH | Angelini Pharma UK-I Limited | General | This QS (quality standard) overall covers the right areas. Key challenges we highlight are:  1.Resourcing to deliver on this QS. Please see details in following questions.  2. The language around tertiary epilepsy services causes confusion and limits access to the newer ASMs (Anti-seizure medicines), which can be initiated by someone with relevant experience (as stated in statement 1) and is not dependent on a being seen at a specific type of centre. Please see details below. This will impact all statements but particularly when measuring statement 2.  3. The role of primary care in ongoing management is not covered and transition of care of stable patients is a real challenge to supporting specialist services to achieve the other statements here, particularly 1,2,3 and 5. |
| SH | British Academy of Childhood Disability | General | This quality standard has been enhanced by the addition of Statement 5 which recognises the higher prevalence of learning and neurodevelopmental disabilities in individuals with epilepsy. BACD supports this addition which should help improve the quality of care for children and young people who are neurodevelopmentally diverse. The equality and diversity considerations are also positive and promote reasonable adjustments for disabled children and young people when accessing epilepsy care. |
| SH | Hampshire Hospitals Foundation Trust | General | Page 64 briefing paper: should not include: <https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf> *This is the stillbirth and neonatal death report* |
| SH | Jazz Pharmaceuticals | General | >600k people live with epilepsy in the UK. This means it is a condition often managed in primary or community settings. This quality standard draft focuses on secondary and tertiary care for the most part, and neglects the potential quality gains in primary care. The removal of domains of the epilepsy quality outcome framework (QOF) in primary care has been suggested as a reason for a decline in primary care review rates (Minshall, Epilepsy Behav. 2021 Nov;124:108354. doi: 10.1016/j.yebeh.2021.108354). Could the role of primary and social care be more explicit? |
| SH | Jon Shaw Foundation | General | I am pleased that the guidelines are being updated, having lost my son to SUDEP and supporting many families with monitoring equipment I formed felt that there were many gaps, and that epilepsy was not really taken seriously enough. Hopefully these updates will be followed by clinicians and nurses supporting people living with epilepsy. The transition between paediatric and adult services needs special care, particularly for those with additional needs. Dual appointments leading up to handover really need to happen. |
| SH | LivaNova | General | LivaNova agree with the quality standards listed. We also agree with NICE’s statement that “optimal management improves health and wellbeing, including reducing the impact of epilepsy on social activities, education and career choices, and reduces the risk of SUDEP” and support patients having access to the treatment modalities listed, including non-pharmacological therapies.  In addition, for patients to be offered relevant treatment modalities, they should be identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the Epilepsies in children, young people and adults (NG217): “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication (ASM). Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'.”  As the number of ASMs prescribed can be monitored via prescribing data, this could be monitored in practice as part of the Quality standards to ensure patients with Drug resistant epilepsy (DRE) are identified timeously. |
| SH | NHS England: Learning disability and autism programme | General | We think there needs to be greater clarity in regard to if training also includes educational professionals |
| SH | NHS England: Learning disability and autism programme | General | 1) We strongly think that Intellectual Disability and neurodevelopmental disorder should be a specific group rather than in conjunction with all listed groups. Rationale includes prevalence and prescribing rates:   1. Higher prevalence rates in learning disability – between one third and one fifth 2. Higher prescribing rates and increasing trends in prescribing – NHS Digital 3. Multiple anti-seizure medication prescribing rising with age and severity of intellectual disability 4. Risks of polypharmacy and hepatic based interaction potential 5. Complex presentations and specific seizure types linked to genetic syndromes e.g. Tuberous sclerosis, Fragile X, Rett syndrome 6. Dual diagnosis and use of medication for epilepsy as well as co-morbid mental health and behaviour thought to be challenging indications   2) Rationale based on need for reasonable adjustments and appropriate communication standards:   1. Specific communication needs and understanding by professionals with expertise in intellectual disability 2. Need for good recording, understanding, implementation and sharing of reasonable adjustments 3. Availability and use of specific educational material to inform joint decision making 4. Link to scaffolding by liaison learning disability nurses and or learning disability nurse epilepsy specialist – see statement 3)   3) Rationale based on specific, often unusual, pharmacokinetic and pharmacodynamic variations in learning disability and neurodevelopmental disorder   1. Susceptibility to the side effects of medication – seen especially in neurodevelopmental disorder 2. Unusual metabolic handling in learning disability and autism leading to understanding of appropriate dosing   4) Rationale based on workforce understanding and experience   1. Need for holistic, person-centred, structured medication review by a prescriber experience in learning disability and autism. 2. Understanding of medication use, review, monitoring and optimisation to appropriate regular intervals 3. An outcome measure, in line with STOMP, is the requirement for regular review and monitoring with formal evaluation of benefit and side effect profile |
| SH | NHS England: Paediatric critical care Clinical Reference Group | General | Good aims in general but may be challenging at the moment due to shortages of staff |
| SH | Royal College of Nursing | General | Thank you for the opportunity to take part in this consultation.  We have had no member comments this time. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | General | It was great to see that a range of stakeholders were involved in this process. Can we check that patients/parents/families were also consulted?  It was positive to see that the project team acknowledged the differing needs of different population groups, eg. Neurodiverse individuals, ethnic minorities, deprived groups etc. RCPCH agrees that the quality statements aim to improve access to care (professionals, services, treatment) for all groups and reduce inequalities in care and outcomes.  RCPCH were impressed with the quality standards and welcomes their focus on core components of epilepsy care including access to key health professionals and services, the importance of care planning and having discussions around mental health and neurodevelopmental conditions. |
| SH | Royal College of Physicians | General | The RCP is grateful for the opportunity to respond to the above consultation.  We would like to endorse the response submitted by The British Society for Clinical Neurophysiology (BSCN) |
| SH | Royal College of Speech and Language Therapists | General | RCSLT proposes that acknowledgement of the wider healthcare needs of individuals need to be taken into consideration within the standard – a first seizure may be part of a wider health presentation and so focus may not be the seizure, which may impact on referral / review by an appropriate HCP. |
| SH | Royal College of Speech and Language Therapists | General | RCSLT suggests that statements should include the importance of access and signposting to information / support groups and forums. Encourage use of accessible information already available. |
| SH | Royal College of Speech and Language Therapists | General | RCSLT recommends that more emphasis is needed on transition between paediatric and adult services, with reference to existing NHS guidance – discussion about this needs to be part of initial first seizure presentation in children from around 14 (NHS Long Term Plan, 2019). |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | General | The quality standards are aspirational. However, the majority of neurology tertiary units in the UK would struggle to achieve the proposed standards and will require substantial investment from the government. More details as elaborated below. |
| SH | The British Association of Prosthetists and Orthotists | General | This document focusses on the cause and medical management of epilepsy and seizures, however there is no reference made to orthotics and the need for referral for cranial protection e.g in the case of drop falls. At the bottom of page 80 of the guidance, there is a reference to cerebral contusions from previous head injury, however nothing for cranial protection.  There also isn't reference for physiotherapy in the non-pharmacological section. |
| SH | The British Society for Clinical Neurophysiology | General | We broadly support the standards as stated in the NICE Guidance. We have had feedback from some of our members that they would have liked some guidance for home video telemetry, which I do not believe was included. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | UCB Pharma Ltd | General | UCB welcomes the quality standard for epilepsy and thanks all those who have contributed to this work. Have the team considered potential regional differences in care, and whether this is something that could be explored as part of this standard? |
| SH | UK Rare Epilepsies Together (UKRET) | General | This ambitious draft quality standards clearly highlights the key areas for improvement, however, taking into account the current resources, we anticipate that significant investment will be required to work towards improved outcomes.  Regarding point: 1.4.2 ‘When making decisions about which tests to offer, refer to the NHS National Genomic Test Directory for rare and inherited disease for information on genetic tests commissioned by the NHS in England’, discussions with clinicians suggests that the NHS National Genomic Test Directory is insufficient as a resource. UKRET query this as a recommended course of action for medical professionals as it’s reportedly not delivering.  UKRET would support the introduction of a distinction in the draft quality standard statements between those with controlled and uncontrolled epilepsy. Those with uncontrolled seizures typically have more complex (medical and other) needs and it is necessary to ensure the quality standards are inclusive of this population to ensure service provision is targeted to those most in need.  Despite the excellent statements aimed at improving diagnosis and referrals, information about follow-up care is lacking from this draft. UKRET would welcome the inclusion of further details about how frequently people are seen in secondary or tertiary care, especially for those with uncontrolled seizures. The only current reference is included under ‘Other areas of management’ which states that ‘Children and young people with epilepsy should have a review with a specialist at a frequency which takes account of the nature of their epilepsy.’ This statement is vague and cannot be aligned with outcomes measures. Specific timeframes should be included.  Regarding point 7.3.4: ‘After a prolonged non-convulsive seizure (a non-convulsive seizure that continues for more than 2 minutes longer than a person’s usual seizure) agree an emergency management plan with the person if they do not already have one and there is concern that prolonged non-convulsive seizures may recur’, this statement is impractical as for a number of epilepsy syndromes, including those represented by UKRET, people may have a non-convulsive seizures that can last 20, 30, 40 mins to even hours or days. This statement appears naïve to these syndromes and is likely misleading in terms of action. |
| SH | Young Epilepsy | General | In the introductory information for the quality standard, the term “people” should be defined as “children, young people and adults” in order to clarify that this means people of all ages. |
| SH | Angelini Pharma UK-I Limited | Question 1 | Yes, it does. The one area missing is potentially capturing the role of primary care given the challenges of transitioning stable patients back to primary care that exist. Having a measure around this and an associated QOF (Quality Outcomes Framework) would support the services and reduce the burden on secondary and tertiary care. |
| SH | Association of British Neurologists | Question 1 | I think these are all key areas for either continuing as a standard or clearly requiring improvement.  Statements 1 and 2 have long been aspirational and, without serious investment, are likely to remain so.  Q5 will require investment in mental health services. |
| SH | British Academy of Childhood Disability | Question 1 | Yes, we agree this draft accurately reflects key areas for quality improvement. |
| SH | Epilepsy Action | Question 1 | We believe the draft quality standard accurately reflects the key areas, but we would also suggest including a statement covering the patient journey taking into consideration the prescribing of valproate and other Anti-Seizure Medications (ASMS) during pregnancy and ensuring that people with epilepsy have access to alternative treatments such as surgical options and Vagus nerve stimulation (VNS). |
| SH | Hampshire Hospitals Foundation Trust | Question 1 | It could be improved by adding the following statements and recommendation for audit of these standards:  **For policy makers, service planners/commissioners and service managers**   * Develop clear standards of care for joint maternity and neurology services, which allow for: early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens; rapid referral for neurology review if women have worsening epilepsy symptoms; pathways for immediate advice for junior staff out of hours; postnatal review to ensure anti-epileptic drug doses are appropriately adjusted [ACTION: NHSE/I and equivalents in the devolved nations and Ireland]. * Ensure each regional maternal medicine network has a pathway to enable women to access their designated epilepsy care team within a maximum of two weeks. [ACTION: Maternal Medicine Networks and equivalent structures in Ireland and the devolved nations]. * Ensure all maternity units have access to an epilepsy team [ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards].   Reference: Marian Knight, Adrian Wills, Sreeman Andole, Kathryn Bunch, Samantha Holden, Sebastian Lucas, Kim Morley, Catherine Nelson-Piercy, Judy Shakespeare, Esther Youd on behalf of the MBRRACE-UK neurology chapter-writing groupIn Knight M, Bunch K, Tuffnell D, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers’ Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016-18. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2020: pIV​ [MBRRACE UK Maternal Dec 2020 report](https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_Dec_2020_v10.pdf) |
| SH | Jon Shaw Foundation | Question 1 | I think the draft quality standard generally reflects the areas for improvement quite well, I think it has missed the opportunity to include improved communication and information sharing with patients and families. In my personal experience, we were never informed about SUDEP, we were never informed about the alternatives to medications and supplementary treatments. Long term or side effects of anti-seizure medication was never discussed only the changes to dosage. |
| SH | Kent Community Health NHS Foundation Trust | Question 1 | Yes, the draft quality standard accurately reflects the areas where improvement is required. However, our service is a community adult epilepsy nursing service therefore statements 1 and 2 are not applicable. |
| SH | LivaNova | Question 1 | LivaNova agree that the quality standards listed reflect key areas for quality improvement. We also agree with NICE’s statement that “optimal management improves health and wellbeing, including reducing the impact of epilepsy on social activities, education and career choices, and reduces the risk of SUDEP” and support patients having access to the treatment modalities listed, including non-pharmacological therapies.  In addition, for patients to be offered relevant treatment modalities, they should be identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the Epilepsies in children, young people and adults (NG217): “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication (ASM). Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'.”  As the number of ASMs prescribed can be monitored via prescribing data, this should be monitored in practice as part of the Quality standards to ensure patients with Drug resistant epilepsy (DRE) are identified timeously.  We therefore feel that this warrants inclusion in 1. The checklist proposed in statement 4 as part of routine follow up appointments and also 2. Monitoring the number of ASMs prescribed to ensure early identification of DRE and appropriate treatment initiation. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 1 | Yes |
| SH | NHS England: Primary care team | Question 1 | Yes, I think so although effective Qi starts with an accurate baseline so you can see where you are |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 1 | Yes, the 5 statements cover a broad range of epilepsy care including access to key health professionals and services, care planning and mental health/well-being and neurodevelopmental conditions.  However, it was disappointing that there was no focus on the transition from paediatric to adult services.   * RCPCH agree with the following standard from QS27 2013; “Quality Statement 9: Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.” |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 1 | Yes. |
| SH | The Association of Clinical Psychologists -UK | Question 1 | Yes the standard does highlight areas which are needed to include quality. |
| SH | The British Society for Clinical Neurophysiology | Question 1 | We are broadly supportive of this. We think it would be helpful for the diagnostic services if there was an explicit standard regarding the ability to have access to EEG and MRI in a timely manner. |
| SH | The Peter Doody Foundation | Question 1 | Yes although would recommend SUDEP conversation and patient understanding also a proposed key area. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 1 | Yes, we agree that this draft quality standard accurately reflects the key areas for quality improvement. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 1 | Yes, we believe that this quality standard accurately addresses the key areas for quality care improvements. |
| SH | Young Epilepsy | Question 1 | We agree that the draft quality standard reflects key areas for quality improvement. However, we note that transition from paediatric to adult epilepsy care is not mentioned in the standards themselves. A joint review of young people’s care - with both paediatric and adult services – should be an essential part of the transition process.  We note that data on the proportion of young people who have an epilepsy care plan that covers transition to adult services is given as an example of how quality statement 4 could be measured. Quality statement 4 could be strengthened with an explicit mention of the role of epilepsy care plans for young people transitioning from paediatric to adult services. These care plans should include input from both paediatric and adult services. |
| SH | Angelini Pharma UK-I Limited | Question 2 | Overall yes using HES data and electronic records albeit the ability to do this varies across localities |
| SH | Association of British Neurologists | Question 2 | 1)      Yes.  2)      Yes.  3)     No necessarily. Some epilepsy nurse specialists (ESNs) are employed in the community rather than hospitals so ascertaining this data is tricky in some areas. Also this needs further defining. What number of patients for each epilepsy nurse specialist is realistic for them to be able to safely manage? Who is still eligible to contact them: is it only if they are still having seizures?  4)      No. Care plans for people with epilepsy could take various forms and so being able to identify them and work out if they were current would be difficult.  In the detail of the quality standard they recommend a local template/checklist. On newer IT systems this could be doable with an electronic template/checklist that is used at clinic appointments but without IT systems that can supply this it would not be doable.  5)      No: review of clinic letters would be required. In the future with machine learning this may be possible for electronic records but not currently without considerable manpower. |
| SH | British Academy of Childhood Disability | Question 2 | Yes, as the draft suggests information can be collected locally from various sources e.g. Epilepsy 12 audit data, patient records (paper or electronic), patient surveys. |
| SH | Epilepsy Action | Question 2 | We do not believe that the necessary resources are in place for the data on the proposed quality measures to be collected locally. The data sources for measuring all of the quality statements rely in part or wholly on records being reviewed locally or new local data collection methods such as surveys, and we do not believe staff will have the time or ability to undertake these activities locally. While for some statements there are also external data sources/repositories that can be used, these would not be sufficient alone to measure the statement. For example, for statement 1, outpatient data and Epilepsy12 would go some way to provide the required data, however further audits would also be needed and in addition an audit plan and digital platform to support these. |
| SH | Hampshire Hospitals Foundation Trust | Question 2 | The data for the proposed quality measures can be collected locally.  The Data sources will be varied depending on standard recommendation. It is important the ownness of this is not on one persons shoulders, i.e the ESN and primary, secondary and tertiary care are included. |
| SH | HOPE for Paediatric Epilepsy: London | Question 2 | There will be difficulty collecting this data locally. This includes potential overlapping of data from different sources. Another potential source of difficulty would be the use of different terminology/vocabulary across different organisations.  In terms of General Practitioner practices, there is no national minimum standard as to what is coded outside of QOF (Quality and Outcomes Framework) data. The only epilepsy related QOF is maintaining a register of people who are over 18 years of age and taking epilepsy medication. It will be difficult to extract relevant data from General Practitioner patient records with any degree of consistency. An alternative might be for two or three medical students in medical schools to have a project of looking through hospital data, which will be coded and recorded with greater consistency, especially for the presentation of first seizure and whether they were then seen within 2 weeks by an epilepsy specialist. |
| SH | Jon Shaw Foundation | Question 2 | I have no knowledge of how data can be collected locally or what data is collected by the Neurology department at the University Hospital in Stoke. |
| SH | Kent Community Health NHS Foundation Trust | Question 2 | Statement 3: All people with epilepsy on the KCHFT adult epilepsy nursing caseload have access to an epilepsy specialist nurse; this is measurable and can be collated via the Rio electronic record system. Statement 4: All people with epilepsy on the KCHFT caseload have a plan of care initiated on their first assessment, this is then updated at their subsequent epilepsy nursing reviews. Quality outcome assessments are completed at each review assessment and these are measurable using the Rio electronic record system. Statement 5: assessment is carried out if need is indicated, and recorded within the patient review and care plan, but are not collated as quality outcome measures within our service. |
| SH | LivaNova | Question 2 | For patients to be offered relevant treatment modalities, they should be identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the Epilepsies in children, young people and adults (NG217): “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication (ASM). Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'.”  As the number of ASMs prescribed can be monitored via prescribing data, this could be monitored in practice as part of the Quality standards to ensure patients with Drug resistant epilepsy (DRE) are identified timeously.  This should be monitored locally |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 2 | Hopefully but there may be regional variance |
| SH | NHS England: Primary care team | Question 2 | I think so as we do this already for the cancer 2 week waits and that is a very important pathway in the minds of patients and the wider health community. Templates (which are coded and thus easier to search) could be developed within the GP / community IT systems but I am less sure about how this is done in secondary care. Presume that have a way of collecting this as they do the 2ww. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 2 | The Epilepsy12 audit collects and reports on the following measures, which can be used to inform the quality statement for children and young people (CYP) (0-24 years) at local levels:   * Performance Indicator (PI) 1. **Paediatrician with expertise in epilepsy;** Percentage of children with epilepsy, with input by a ‘consultant paediatrician with expertise in epilepsies’ within two weeks from first paediatric assessment \*   + Informs quality statement 1. * PI 3a. **Tertiary input**; Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year\*   + Informs quality standard 2. * PI 2. **ESN**; Percentage of children with epilepsy input by an epilepsy specialist nurse by first year\*   + Informs quality statement 3. * PI.9 **Care planning agreement and content**; The percentage of children with epilepsy after 12 months where there is evidence that: care planning includes a patient held individualised epilepsy document or copy clinic letter that includes care planning information, there is patient/carer/parent agreement to the care planning and care planning has been updated where necessary \*   + Informs quality standard 4. * Data items for quality statement 5 are described in question 8 below.   Currently, services can review their data annually at Trust/Health Board level compared to regional and national averages. From July 2023, this data will be publicly available at quarterly intervals for the performance metrics (\*) at Trust/Health Boards, ICB, regional and national levels. From December 2023, this data will also be available to clinical teams in a real-time feedback table accessible only to audit users for their own Trust/Health Board data, compared to ICB, regional and national averages.  Note that the above are new performance indicators introduced in September 2022 and are only reported on cohort 5 patients from July 2023.   * Audit methodology: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission> * Methodology overview document: <https://www.rcpch.ac.uk/sites/default/files/2022-09/epilepsy12_round_4_methodology_overview.pdf> |
| SH | Royal College of Speech and Language Therapists | Question 2 | Data collection will be challenging where clinicians with specialist epilepsy experience are embedded in services that offer primary treatment and so have much earlier contact e.g., intensive care, HDU, high acuity wards. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 2 | No concerns about feasibility of data collection. |
| SH | The Association of Clinical Psychologists -UK | Question 2 | Data could be sourced locally in terms of how long a person is waiting from referral to be seen by a specialist service. A definition is needed in relation to whom is a clinician with expertise in epilepsy or what would constitute tertiary care to know if this standard is being met locally. It would be possible to see from the notes if a person was being seen for review by specialist nurse as there should be reference in the notes or letters. To establish whether a person has access if needed would be harder to assess as absence of notes or letters would not necessarily indicate the person does not have access rather that input is not needed at that time. It is assumed a care plan would be documented and in the notes so whether it was there or not should be possible to see. It should be possible to review the medical notes to see if reference is made to checking cognitive function, mental health, social and emotional wellbeing. |
| SH | The British Society for Clinical Neurophysiology | Question 2 | Many of the measures are already captured for the Epilepsy 12 programme and should be obtainable from NHS databases. |
| SH | The Peter Doody Foundation | Question 2 | Unable to comment |
| SH | UK Rare Epilepsies Together (UKRET) | Question 2 | Yes, it is feasible to collect the proposed data from local sources such as patient records and surveys. |
| SH | Angelini Pharma UK-I Limited | Question 3 | No. The 2019 ABN (Association British Neurologists) report and recent Northern Ireland report shows major issues in terms of core resources in neurology generally and in epilepsy also. The NHS digital data shows back logs in outpatient waiting times and issues with patient follow up.  Additionally in many areas primary care will not take epilepsy patients back from tertiary or specialist care (as per national guidance around transfer of care) meaning the Trust side is under resourced and the capacity to deliver the care identified in this QS is not achievable sadly. More specialists (Drs and nurses are needed)  The term tertiary epilepsy service is also causing confusion and variability operationally which will limit the ability to achieve these statements. Many commissioners are seeing it as the actual centre due to the language, as opposed to the expertise of the treating professional, which we believe it should focus on ,unless a certain intervention is needed e.g. Vagus Nerve Stimulation. Whilst sometimes referral to the centre is key for some services stated, other areas such as antiseizure medications (ASMs) being initiated, do not need referral to a centre but can be done at the spoke clinic (given the hub and spoke model) being run by the epilepsy specialist. This is causing issues in terms of variable access to the newer ASMs and we would urge NICE to differentiate this aspect to ensure patients can continually access NICE approved medicines and quality standard 2 can be met. The term ‘clinician with expertise in epilepsy, (as per statement 1) would be more appropriate for ASM initiation and should also be updated in TA 753 for consistency with the QS and to avoid variability in patient access. |
| SH | Association of British Neurologists | Question 3 | Broadly speaking these are not achievable within the current resource funding and structure.   1. Currently the workforce for delivering rapid appointments for first seizure clinics is insufficient. Savings could be gained by reduced ED (emergency department) attendance because of rapid diagnosis. 2. Providing tertiary clinic appointments is certainly not possible within the current resources. Savings for this could possibly come from reduced attendances at hospital but this is a smaller gain. If patients’ seizure control is improved there may be financial benefits holistically in terms of getting patients into the workforce or reducing care needs and costs. These would be difficult benefits to prove and the funding for these is not linked. 3. There are insufficient epilepsy nurse specialist resources in most areas. It is key to define a safe patient “load” which would be manageable or safe for an epilepsy nurse specialist to cover. Giving patients the contact number for someone who has too many patients under their care is potentially counter productive. Savings could come from preventing hospital admissions although the funding streams for acute and chronic care are separate. 4. Care plans are possible within the current structure, depending on the definition of these- they probably would not have a clear cost saving in most. 5. This is partially achievable - by remembering to discuss these factors in each clinic review - potentially signposting to online mental health support / local mental health services / discussion with GP. Asking this for everyone would require longer appointments and therefore more neurologists or epilepsy nurse specialists unless pre-clinic questionnaires were reliably completed- even then those would potentially need analysing/discussing. The next step is to have sufficient resource to then treat a patient’s mental health problems which have been uncovered. This would not have a cost saving that would be clearly derived or offset. |
| SH | British Academy of Childhood Disability | Question 3 | Increased resources may be necessary to deliver some of the statements e.g. Statement 2 regarding timely access to tertiary specialist services, which may be challenging in some locations if there is increased clinical demand. Also the addition of Statement 5 may require additional training of staff members / increased appointment times. However, this will be a driver to hopefully access additional funding. If epilepsy nurse specialists assume the role of ‘clinician with expertise in epilepsy’ where appropriate this may create additional capacity and offer potential cost savings in the longer term. |
| SH | Epilepsy Action | Question 3 | The statements in the draft quality statement are not achievable with the existing resources. Significant improvements need to be made in regard to funding, staffing and resourcing of current epilepsy services, in addition to neuropsychiatry and neuropsychology services.  As previously stated, further resource would also be needed to ensure a fully resourced audit plan to ensure that data for measuring the proposed quality standards can be put in place.  Some cost savings can be made by hiring more Epilepsy Specialist Nurses (ESNs) across the UK (studies have shown that [ESNs are cost-effective](https://www.epilepsy.org.uk/app/uploads/2022/08/The-ESPENTE-Study-8.7.19-Version-1.pdf)), in addition to adopting best practice models, such as the use of coordinators (to free up ESNs) and open access/patient initiated follow up services. This paper shows the effectiveness of an open access service (OAS) in reducing in reducing waiting times: <https://jnnp.bmj.com/content/85/10/e4.186> |
| SH | Epilepsy Society | Question 3 | We do not think there are sufficient resources to meet the quality standards. We are already hearing of long waits (months) for someone to see a specialist. Also, not everyone has access to an Epilepsy Specialist Nurse currently. This is an area where investment is needed. Also a need for more neurologists. |
| SH | Hampshire Hospitals Foundation Trust | Question 3 | With the workload as it stands and the lack of time to collate retrospective data, this may best sit as a prospective register with most of the quality standards included. NICE could provide this register in digital format assisted by NHS digital and it would be a matter of entering the data after each encounter. Regarding resources, more funding should be provided for recruitment of epilepsy specialist nurse in order these standards can be fulfilled as much of this work can be fulfilled by them. Each NHS Trust should have an equal team of ESNs with a carer progression requirement. |
| SH | Jon Shaw Foundation | Question 3 | I am aware that there is a shortage of Epilepsy specialist nurses and clinicians specialising in epilepsy at the Team serving our area, I would imagine that some investment would be needed to provide enough specialists to offer the appointments within the times stated in the guidance. So I think there may be a struggle |
| SH | Kent Community Health NHS Foundation Trust | Question 3 | Statement 1: local services exist for people to be seen, however KCHFT is a community service, I can not comment upon whether these services meet the 2 weeks expectation to be seen.  Statement 2: Is not applicable to our service. However, paediatric services are available locally and if aware to the guidelines should be able to refer to tertiary services within the 2 week time frame.  Statement 3: Within our service inscope people with epilepsy must have had a seizure within the last year and be under the care of a consultant neurologist or have been referred to a consultant neurologist at the time of referral to our service.  Statement 4: All people with epilepsy within our service have an up to date care plan. It is feasible for all people with epilepsy to have an up to date care plan prepared by their medical practice team but I am unable to comment upon whether this is being carried out for all people with epilepsy outside of our caseload.  Statement 5: whilst people with epilepsy may have their issues acknowledged by the epilepsy nursing team and may be referred onwards for support, mental health and specialist psychiatry and neuropsychiatry, and psychology services do have long waiting lists in this area may not be achievable unless they had additional resources to support them. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 3 | There would need to be investment of resources to collect, collate and send data – either manually or investment in developing systems to gather this data from electronic patient records. |
| SH | NHS England: Primary care team | Question 3 | It is hard to answer this question as I don’t think we have mapped this in terms of programme budgets. Saying that, a first seizure is already a reason to refer on the 2 week wait in Gloucestershire (presume that must be national) which is an important starting point. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 3 | The majority of the quality statements would be achievable by local teams. The July 2023 Epilepsy12 annual report (<https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2023>) finding showed that:   * 91% of CYP with epilepsy in England and Wales were seen by a paediatrician with expertise in their first year of care (PI 1).   + However, only 21% were seen between 0-2 weeks from first assessment. * Only 52% of CYP with epilepsy meeting the defined tertiary referral criteria had tertiary involvement within he first year of care (PI 3a). * 77% of CYP with epilepsy in England and Wales were seen by an ESN in their first year of care (PI 2). * 74% of CYP with epilepsy had individualised, agreed and up to date care plans (PI 10) and 79% had comprehensive care plans (PI 11). * There may be CYP with epilepsy missing out on or having delayed identification of mental health conditions and neurodevelopmental conditions, and treatment for these conditions. If these topics are not discussed at epilepsy appointments, this may lead to underdiagnosis and/or underreporting in the audit.   The timeliness aspects may be harder to achieve considering the extreme pressures faced by clinical teams since the COVID-19 pandemic, including long waiting lists for surgery services. This will depend on the services’ capacity or resource. |
| SH | Royal College of Speech and Language Therapists | Question 3 | RCSLT understands from members that there is not currently adequate capacity to meet needs of people presenting with a first seizure accessing an appropriate healthcare professional within two weeks.  RCSLT would encourage consideration of utilising the wider HCP workforce, for example AHPs, ACPs, PAs to enable timely investigations. It is also essential for NHS services to work closely with third sector organisations to maximise efficient support for patients. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 3 | As below. |
| SH | The Association of Clinical Psychologists -UK | Question 3 | In terms of local services we do not currently have sufficient staff for all people with epilepsy to be routinely reviewed by the epilepsy nurses. We also no not have sufficient resources for specialist assessment of cognitive function and mental health and wellbeing in the context of diagnosis and symptom management. Investment would be needed in the local neuropsychology services in order for more people to routinely access. It would be expected that routine question regarding cognition and mental health at review appointments would identify more people that would benefit from being seen by neuropsychology services and neuro rehabilitation services which are not sufficiently resourced. |
| SH | The British Society for Clinical Neurophysiology | Question 3 | These statements make good targets, but for many regions of England and Wales it will not be possible to deliver these due to shortages in staff. For example in a DGH with only one neurologist it will not be possible to offer a 2 week wait if the doctor is expected to take annual leave. |
| SH | The Peter Doody Foundation | Question 3 | Do not believe that presently this would be achievable by local services given the present lack of resources required to optimally deliver them i.e. ESN’s and epilepsy specialist neurologists.  An increased uptake on clinicians and other appropriate services is needed with an interest shown in epilepsies as a chosen vocation and/or area of interest.  Significant funding and investment into specialist epilepsy training, services and resources would be necessary for all of the five statements.  A potential saving in accident and emergency admissions with improvement in epilepsy care provision. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 3 | The provision of Epilepsy Specialist Nurses (ESNs) will be required to increase to achieve draft statements 3, 4 and 5. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 3 | Given the current provision of epilepsy specialist nurses (ESNs) and neurologists we do not believe draft quality standards 3, 4 or 5 are achievable. |
| SH | Young Epilepsy | Question 3 | Epilepsy specialist nurse provision needs to increase to enable implementation of the quality standard. Paediatric epilepsy clinics should also have access to mental health professionals to deliver and/or oversee mental health interventions.  The latest Epilepsy12 audit shows that 91% of children diagnosed with epilepsy received input from a paediatrician with expertise within the first year of care. However, only 77% of children received input from an epilepsy specialist nurse within their first year of care. Epilepsy nurses play a central role in coordinating care, providing holistic support, being a point of contact and developing care plans.  Currently only 20% of trusts facilitate mental health provision within epilepsy clinics (10% provide co-located mental health support). Although integrated mental health support is included in the best practice tariff for paediatric epilepsy care, no funding is provided to deliver this element of care. Funding for mental health provision should be integrated into resourcing for all paediatric epilepsy clinics. |
| SH | Angelini Pharma UK-I Limited | Question 4 | Yes. In our experience they have great expertise and can support patients from first diagnosis through to complex cases. Consultants place great trust and faith in their expertise. |
| SH | Association of British Neurologists | Question 4 | This is very dependent on the experience of the ESN and I think there would need to be specific training and governance arrangements for this to occur safely.  They may be less familiar with atypical manifestations of migraine, cardiac syncope, carotid sinus hypersensitivity than epileptic seizures or dissociative attacks which could risk missing important diagnoses.  The majority of our epilepsy advisory group would feel uncomfortable with specialist epilepsy nurses having a role in diagnosis.  We feel that this question would also be very important to ask of the various epilepsy nurse specialist organisations of which there are a few. |
| SH | British Academy of Childhood Disability | Question 4 | For children and young people as the draft specifies the ‘clinician with expertise in epilepsy’ should be a paediatrician. For young adults with learning disability, if an epilepsy specialist nurse is the ‘clinician with expertise in epilepsy’, they should also have clinical competencies in learning disability nursing. It would be dependent on the clinical experience of the individual epilepsy specialist nurse if they could potentially take on this role. |
| SH | Epilepsy Action | Question 4 | It would only be feasible to meet this aim by increasing the number of consultant nurses, providing more support and resources to existing consultant nurses and increasing access to radio neurology, neuropsychiatrists and neuropsychologists. Epilepsy specialist nurses who are not consultant nurses or classed as advanced nurse practitioners could not feasibly be expected to identify the cause of seizures or make a diagnosis. These skills aren’t part of the key competencies for ESNs, aren’t included in training and aren’t what ESNs signed up to do. Retraining enough ESNs to be able to perform this role would not be feasible. |
| SH | Epilepsy Society | Question 4 | NICE point out in the guideline rationale that it is important that people see a specialist early as epilepsy is complex and can be misdiagnosed. We do not think that an ESN will have the necessary expertise to diagnose. |
| SH | Hampshire Hospitals Foundation Trust | Question 4 | Yes, this is feasible but qualifications should include in addition to RN or Registered LD Nurse: MSc in Advanced Clinical Practice and independent nurse prescribing qualification. The nurse should have full range of requesting investigations including ECG and 24 hour ECG tape, all blood investigations including antibody testing, EEG, 24 hour EEG, MRI brain scan and when appropriate and available, video telemetry. They should also be able to refer to neuropsychology, neuropsychiatry, respiratory colleagues for sleep investigations and genomic testing where appropriate, and be treated as an equal in the MDT neurophysiology patient discussions. The ESN should be banded as 8A with carer progression as she becomes more autonomous and experienced within the role. Her supervision should come from the epileptologist of neurologist with specialist interest in epilepsy and the advanced clinical practitioner and independent nurse prescriber network. The nurse should also receive the equivalent secretarial support to the neurologists. |
| SH | HOPE for Paediatric Epilepsy: London | Question 4 | To include in the wording ‘Parents may prefer to see an epilepsy nurse over a GP **or paediatrician** as specialism is important’ Could the wording include ‘or paediatrician’ as the same applies for a paediatrician who does not specialise in epilepsy or neurological conditions as for a General Practitioner, albeit to a lesser extent.  In theory it may be feasible for epilepsy specialist nurses to diagnose, but there is variation in how long nurses have been in post for, the level of expertise and training that individual nurses have. Some posts are being advertised as ‘having experience in management of epilepsy desirable, but not essential’ so not all nurses come into the role with the same level of knowledge/experience.  There will also be a need to evaluate realistic workload management due to high percentage of burnout in specialist nurses. |
| SH | Jon Shaw Foundation | Question 4  Statement 1 | I’m not sure it would be feasible for the specialist nurse to be the “clinician” who identifies the cause of the seizure and ensures a correct diagnosis is made. The guidance has identified the investigations needed to correctly diagnose and identify the cause of epilepsy and should be managed by specialist clinicians preferably an epileptologist. In my experience access to appointments with the nurse in a supporting and monitoring role are difficult already. The specialist nurse should continue in a supporting role to work with both the clinician and family. |
| SH | Kent Community Health NHS Foundation Trust | Question 4 | Our service is a community nurse led adult epilepsy nursing team, we are not trained to diagnose, nor does our service carry a budget for specialist training. At present our service is run with the minimum amount of staff to fulfil the requirement of existing demands, neither does the team have access to diagnostic facilities. Therefore, it is not feasible for any of the epilepsy specialist nurses within the team to be the ‘clinician with expertise in epilepsy’ who is able to accurately identify the cause of a seizure and ensures a correct diagnosis is made. |
| SH | NHS England: Learning disability and autism programme | Question 4 | Regarding the opposite question, we suggest that If this is within the Nurses' Specialist Scope of Professional Practice and there is appropriate training and oversight from the Employing Organisation we think this is feasible. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 4 | Unsure about this: There are strict criteria for referral on to tertiary neurology which could be followed by any specialist clinician, but one of the criteria is “uncertainty in the diagnosis” – do nurse specialists have the expertise to be able to confidently perform diagnostics in this field and do we have any evidence that the outcomes are comparable to doctors?  This should be a medical person with training in epilepsy and the ability to distinguish between epileptic seizures, movement disorders, tics etc. |
| SH | NHS England: Primary care team | Question 4 | I don’t have enough knowledge, but we could develop a hybrid approach based on risk stratified patient cohorts with investigations to support clinical decision-making meaning that the more ‘barn door’ diagnoses or secondary causes (brain tumour) follow a different pathway leaving the specialists to see the more complex cases. I am sure (although don’t know) a model like this would exist already in the country. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 4 | Within paediatrics the diagnostic role and competency is usually held by the paediatrician with expertise in epilepsies. The diagnosis of epilepsy involves whether it is epilepsy or something else, seizure type, syndrome, cause, co-morbidities. A specialist nurse often plays a key role in supporting the family and the diagnostic process but most pathways rely on the responsibility for diagnosis to rest with the paediatrician. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 4 | In principle, epilepsy specialist nurses could be trained to see first fit patients. However, there needs to be significant amount of investment into establishing this pathway because ESNs are not trained to be diagnosticians and will require supervision from a consultant neurologist. As it stands, there are long waiting lists for patients waiting to be seen by the ESNs for the first time and there is also significant back-logs of patients awaiting review by the ESNs. The ESN service is probably best bolstered by increase in ESN numbers to support the consultant-led epilepsy service, and consultants will be able to discharge and create capacity in clinics if we are certain that the ESN service is able to cope with number of patients that require follow-up and oversight of their treatment plans. |
| SH | The Association of Clinical Psychologists -UK | Question 4 | It would seem most appropriate that neurologist would be considered the clinicians with the expertise of diagnosing epilepsy. It is important that the correct diagnosis is made in order to identify the most appropriate treatment. It is possible that the epilepsy forms part of a number of neurological symptoms and the appropriate treatment pathway is needed for example tumour or infection or non-epileptic attack disorder. |
| SH | The Peter Doody Foundation | Question 4 | No. The concern being of the diluted outcomes on not only standard levels of epilepsy care but what should be the optimal levels of care. There is a severe lack of epilepsy specialist nurses with already impossibly high caseloads. A significant concern will be that extra responsibilities would contribute to patient disengagement due to clinician overwhelm with catastrophic consequences. In taking into consideration also that present NICE guidelines are not being met, increased responsibility would be concerning. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 4 | Yes, we believe it is feasible.  Epilepsy can be a primary manifestation in many rare genetic diseases, such as Tuberous Sclerosis Complex (TSC). A recent report by the Specialised Healthcare Alliance (SHCA) highlighted that diagnosis of a rare diseases takes on average over four years, includes 3 misdiagnoses and speaking to five doctors before receiving the correct diagnosis. It is well documented that delays in diagnosis can result in potentially preventable morbidity and mortality and that reducing the diagnostic delay is paramount. ESNs are highly trained and experienced healthcare professionals, if designating them the clinician with expertise increases access and reduces the time to diagnosis. If the ESN is identified as the appropriate clinician with expertise in epilepsy, it will be necessary to ensure education and training in rare and genetic diseases to continue progress towards reducing the diagnostic delay in these communities. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 4 | Rare (refractory) epilepsies are very complex and the diagnostic delays that patients can experience due to misdiagnoses can result in worsening of symptoms and overall prognosis. Given this is currently the case, if ESNs do become the ‘clinician with expertise in epilepsy’ who will identify the causes of seizures and correct diagnosis it will be paramount that they are continually supported through professional development to investigate and recognise these rare conditions.  UKRET queries whether, at present, ESNs have sufficient training in the relevant neurophysiology, imaging techniques and genetic testing (alongside other tests) to make an accurate diagnosis and whether upskilling this population of clinicians will be the best use of resource investment.  However, if the designation of ‘clinician with expertise in epilepsy’ to ESNs improves access and reduces diagnostic delays and access to appropriate treatments, this is an extremely welcome step to reduce morbidity and mortality. |
| SH | Angelini Pharma UK-I Limited | Question 5 | One comment here is how often are these follow up appointments? Data suggests waiting times for appointments in long and follow up is even more challenging. No comment on types of appointments to exclude. |
| SH | Association of British Neurologists | Question 5 | Mental health issues should be discussed at any type of appointment but not necessarily every time a patient is seen as some appointments may require the focus to be elsewhere.  We did not feel it was appropriate to ask about neurodevelopmental issues or intellectual disability at every clinic appointment but certainly at the first appointment with a specialist. |
| SH | British Academy of Childhood Disability | Question 5 | These issues are extremely important to cover in every epilepsy appointment and should become part of routine practice due to their significant impact on quality of life. |
| SH | Epilepsy Action | Question 5 | This measure should apply to every appointment (including video and telephone appointments) and is especially important at initial assessment/diagnosis and at least one every 12 months. |
| SH | Epilepsy Society | Question 5 | This is particularly important as young people transition from paediatric to adult services and begin to live more independently. This is a key area for assessing mental well being alongside a young person’s epilepsy. Previous guidelines stated that pwe should have an annual review. Making this by request only, may mean that people do not seek out a review because they do not know they can or do not want to ‘trouble’ their clinician and this may lead to issues such as side effects or mental health not being discussed. |
| SH | Hampshire Hospitals Foundation Trust | Question 5 | ‘People with epilepsy are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, (**neurodevelopment and learning disabilities-**this would be more with paediatric colleagues, transition and new appt in adults assessment. It doesn’t necessarily sit well on the same quality statement-may be better to focus on this separately and include education, schools and specialist learning disabilities services.’ |
| SH | Jon Shaw Foundation | Question 5  Statement 5 | I think it is vital that the mental health, changes in mood, anxieties, behaviour, engagement is assessed and monitored closely, and longer or specific appointments may be needed to accommodate this. Living with epilepsy can be difficult to adjust to and side effects of the medication can affect changes to the well-being of people with epilepsy. There should be some kind of structured assessment, like the questionnaire used for new mums and it should be repeated so that changes can be spotted. I think it is important that the care team should ensure that the patient and family are not just given information but understand it. A written care plan should be formulated between the clinician, nurse and patient/family including contact numbers, routine and emergency so that the family has a reference when unsure of what they need to do. Would a diagnosis or notes of pathway of additional needs written in the notes of people attending epilepsy appointments? How these will affect the care plan should be discussed and accounted for. |
| SH | Kent Community Health NHS Foundation Trust | Question 5 | Assessment of cognitive function, mental health, social and emotional wellbeing, neurodevelopment and learning disabilities is taken into account upon each contact with the person with epilepsy or their nominated spokesperson when assessing mental capacity and recording consent. In addition to initial assessment, needs are reassessed at each follow up appointment and ad-hoc advisory call requests. The latter frequently involves speaking to people with epilepsy in a state of distress who may require additional support as needed. When required we liaise mental health and learning disability services to ensure access to more specific assessments and treatment. |
| SH | LivaNova | Question 5 | LivaNova agree that the aspects in statement 5 should be assessed, e.g. symptoms of anxiety & depression and daily functioning, wellbeing & quality of life, which should be checked at all epilepsy appointments – which should ideally entail those stated in the draft consultation documents; “This includes all planned appointments with an epilepsy professional such as regular monitoring reviews, patient-initiated monitoring reviews and specialist nurse appointments”.  This is to ensure consistency in assessment and monitoring of changes over time. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 5 | Appointments where this has been reviewed recently it is not necessary to review all the points listed, a more focused approach may be more useful as time can be spent on areas where the child/young person needs support. |
| SH | NHS England: Primary care team | Question 5 | Not sure, but perhaps some of this work up could take place in the community with the PCN team (social prescriber) or via video consultation to save the patient a face-to-face appointment. Perhaps this could be linked to health inequalities (BAME and deprivation) work in the PCN to risk stratify higher risk patient cohorts who need more ‘active management’ as they are prone to worse outcomes and even dying. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 5 | These could be discussed at first appointment and then ongoing appointments thereafter. There would be particular points where it might be even more important.   * A new life event occurs, eg. Joint school, university or new job, if the person is trying to start a family etc * A young person is transitioning to adult services   Epilepsy12 has recommended more structured approaches to assessing these factors rather than ‘asking’. Screening and structured assessment is increasingly recognised as important. There should also be opportunities for the person with epilepsy to seek support from the clinical team for these issues between appointments. |
| SH | Royal College of Speech and Language Therapists | Question 5 | Someone with impaired cognitive function or learning disabilities may not be able to clarify whether they have psychological, cognitive and neurodevelopmental issues, especially as these difficulties are likely to affect communication. RCSLT recommends optimising and utilising the skills of the wider MDT (psychologists, speech and language therapists, occupational therapists etc.), potentially via an MDT clinic. This input needs to happen early on, in order to ensure needs/abilities are not presumed and to support long-term outcomes. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 5 | None. |
| SH | The Association of Clinical Psychologists -UK | Question 5 | It is appropriate that questions relating to difficulties or changes in cognition and wellbeing are asked at all appointments as they are subject to change. If a neurodevelopmental condition or learning disability is not part of the presentation it does not seem appropriate to ask at every appointment if an adult. If a child it is important that questions about development are routinely asked. |
| SH | The Peter Doody Foundation | Question 5 | No epilepsy appointment types should be excluded in this statement. This should apply to **all** appointments particularly in relation to time afforded to allow more time for discussion. Also in the provision of adequate and person centred information/literature andinvolving family members, carers, or an advocate and sharing information with those involved in their care. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 5 | It will be particularly important to monitor a patient’s mental wellbeing (and other listed parameters) at regular intervals. Appointments requested by/on behalf of the patients likely arise due to concerns and/or queries, therefore it will be particularly important to review wellbeing here, and this should be included in the quality standard (patient initiated appointments). Alongside this, rather than at specific appointment types, it might be useful to add a timeframe to this quality standard, e.g., at least once a year. |
| SH | UCB Pharma Ltd | Question 5 | UCB agrees that it would be beneficial to think about the specific nature of the type of epilepsy, it being a very individualised disease. For example, there may be very specific needs for some groups of patients with syndromic diagnosis, refractory epilepsies, and of those with intellectual disabilities as a comorbidity. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 5 | Mental health, and emotional and social wellbeing should be covered at every appointment. In particular, the quality standard should emphasise the importance of monitoring these parameters at self-requested appointments given that these likely arise due to a concern/query from/on behalf of the person with epilepsy. These parameters should also specifically be assessed if a person with epilepsy is seen as an in-patient. The requirement for in-patient care may be the indirect result of poor mental/emotional/social wellbeing (for example, poor mental wellbeing may influence medication adherence). |
| SH | Young Epilepsy | Question 5 | Statement 5 should apply to all planned epilepsy appointments. Many people struggle to access regular contact with their epilepsy professional. Planned appointments are an opportunity to review people’s holistic wellbeing. Trusts should ensure that sufficient time is allocated for healthcare professionals to review people’s needs. |
| SH | Angelini Pharma UK-I Limited | Question 6 | Please see above. Appointment lengths may be a challenge, but the data would suggest that frequency may be the biggest challenge for a meaningful and consistent focus on these elements which are clearly important. |
| SH | Association of British Neurologists | Question 6 | No - there is insufficient time in most clinics for all these questions to be covered in a meaningful rather than “tick-box” way.  There should be an expectation that patients with learning and intellectual disability and those who are not English speaking have longer appointment times.  Longer appointment times require more workforce- neurologists and ESN |
| SH | British Academy of Childhood Disability | Question 6 | At present this may be challenging in some clinical settings and changes to clinic schedules may be required to allow adequate time to incorporate these additional questions. |
| SH | Epilepsy Action | Question 6 | Currently there is not enough time or capacity to achieve this measure. We know that neurologists and epilepsy specialist nurses are already struggling to mention everything that is currently required in appointments, and adding additional items will only make that pressure worse. A survey carried out by the Association for British Neurologists (ABN) between November 2018 and March 2019 identified that the UK had fewer Neurologists per population than France and Germany. The ABN said this impact the quality of care this provided to patients with neurological conditions in the UK - <https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf>  This could be counteracted by scheduling longer appointments or using other ways to collect this information from patients. Additionally, close attention should be paid to the progress of the Scottish pilot of the mental health assessment tool for children which, if successful, could be replicated and could make these conversations shorter. |
| SH | Epilepsy Society | Question 6 | Doctor appointments do not allow time to discuss the broader challenges of epilepsy and tend to focus on getting the medication right rather than allowing time for lifestyle challenges. It is unlikely that there is currently enough time at appointments to discuss all these matters. We hear often that people feel rushed and not listened to. They are told to ‘take the tablets and get on with it. There seems to be little follow up to see how the person with epilepsy is getting on with their medication and little information about what to expect and what to do if they are having trouble with side effects. |
| SH | Hampshire Hospitals Foundation Trust | Question 6 | Having holistic care and empowering patient’s is ensuring you discuss their agenda and concerns as the priority in order every patient contact counts. With an experienced practitioner all the elements of the statement comes up but it maybe it is not the patient’s concern for that day. Are you therefore suggesting a checklist before, during or after every epilepsy contact appointment in order to audit this or does someone have to go through all the patient correspondence to check it has been covered? Time re appt should not be an issue providing the encounter is individually patient focused. |
| SH | Jon Shaw Foundation | Question 6  Statement 5 | There is not enough time during review appointments to discuss mental health etc effectively. We always had a friendly check in, “How are you? What are you doing? Etc but never a real discussion about how things have changed. This is a time for the assessment which should be evaluated there and then for changes. |
| SH | Kent Community Health NHS Foundation Trust | Question 6 | All people with epilepsy are asked how they are at each review, this will often lead to a discussion about their physical and mental wellbeing. There is not always time to carry out in depth questioning about mental health needs, unless indicated by review of the person with epilepsy’s care plan where a need has been highlighted or if the pre-assessment questionnaire that the person with epilepsy, or their caregiver, is invited to complete has indicated that support is needed. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 6 | Probably not in all follow up clinics where CYP have complex health needs. |
| SH | NHS England: Primary care team | Question 6 | This might be quite time consuming and also it may duplicate work that is happening in the community around LD reviews and other chronic disease management work – important to link it up to save effort and maximise impact of clinical contact. Might be that this could benefit from MDT working. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 6 | This should probably be evaluated further. The time for appointments varies considerably between services and more frequent appointments allows issues to be gathered over successive reviews.  Increasingly, there are opportunities for some information to be gathered in between appointments via structured questionnaires and screening tools. For example, MICE (Mental Health Intervention for Children with Epilepsy) and PAVES (Psychology Adding Value – Epilepsy Screening) have evidence of Strengths and Difficulties Questionnaires (SDQs) being used to support diagnosis and assessment of mental health. Information from education can support information around cognitive function and other well-being components. |
| SH | Royal College of Speech and Language Therapists | Question 6 | The focus of the clinician is likely to be medical, but an understanding of these wider needs is essential to truly address short and long term need. Utilising infographics and accessible information can signpost red flags / things to watch for to ensure support for these areas is optimised / care pathways identified. RCSLT suggests that use of the wider MDT would enable a robust assessment and understanding of holistic needs, while also enabling baselining, benchmarking, and research opportunities to address the lack of evidence around outcomes in epilepsy. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 6 | No. The consultant-led epilepsy clinics operate on a 30 minutes per new patient and 15 minutes per follow-up patient template in Sheffield. To include specific questions on cognition and mental health on every patient would require the clinics to operate on a 40/20 template rather than a 30/15. To achieve this, there will need to be significant investment into the STH epilepsy service because we will need more clinics and more staff to keep on top of the waiting list, especially if we were to fulfil the 2-week wait for first fits and 4-week wait for urgent epilepsy cases. |
| SH | The Association of Clinical Psychologists -UK | Question 6 | It should be asked and then the referrals made to the appropriate clinician for further assessment e.g. if reporting cognitive difficulties then a referral to neuropsychology should be made for a cognitive assessment. If it relates to mental health and wellbeing, further questions may be needed to ask to establish which service is best place to provide further support e.g. specialist nurse, clinical psychologist, IAPT, mental health services, neuropsychiatry. |
| SH | The Peter Doody Foundation | Question 6 | No particularly considering the current limited appointment times. Patient to clinician ratio is also a significant factor in time aforded so without increased clinician epilepsy specialist availability, this would remain unlikely. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 6 | It is highly unlikely, there is sufficient time or capacity to review these parameters at current epilepsy appointments, to do so adequately would require increasing the length of the appointments which may in turn increase waiting lists for appointments, representing an access barrier. Alternatively, could patients/advocates be provided with pre-appointment questionnaire (link from NHS no reply service?) evaluating these parameters that can be used alongside the in-person assessment to guide further care? For the purpose of data collection and processing, asking at every appointment will be the most effective. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 6 | Many patients and families comment on the brevity of their appointments and based on this we do not believe that there is sufficient time to ask about the parameters outlined in draft statement 5. Further, clinicians must be prepared to offer immediate emotional support/comfort if necessary, which may be out-with the allocated appointment duration resulting in increased waiting times, placing additional responsibility on clinicians to work overtime. If appointment lengths are increased, it will be important to increase the staffing levels to ensure waiting lists do not become longer.   Regarding the capacity to ask about these parameters, it will be necessary to carefully consider the intellectual ability of the person with epilepsy: do they have the required cognitive function/physical ability to typically describe their wellbeing/mental health status (e.g. verbally)? What alternatives/accommodations will be implemented to ensure these people are able to effectively communicate? |
| SH | Young Epilepsy | Question 6 | Trusts should ensure that sufficient time is allocated for healthcare professionals to review people’s needs. This should reflect the broad impact that epilepsy can have and the high prevalence of co-occurring conditions. Trusts should also ensure that mental health support is funded as part of the provision within paediatric epilepsy care. |
| SH | Angelini Pharma UK-I Limited | Question 7 | No, for example questions around cognitive functions is relevant for most medications/combinations and mental health is such a prevalent comorbidity that you can’t remove patient groups. |
| SH | Association of British Neurologists | Question 7 | Cognitive function, mental health, social and emotional wellbeing are relevant to all groups.  In those with intellectual disability, gauging mental health problems can be more difficult and outside the skill set potentially of neurologists. Clear links with, or routine involvement of the Learning disability psychiatry teams would be essential in this group. |
| SH | British Academy of Childhood Disability | Question 7 | This statement should cover all of the areas listed and it should also apply to all individuals with epilepsy, as it focuses on holistic care. These areas should always be asked about, but may be less pertinent to some patient groups. The concern is that if not routinely asked about this will overlook important unmet needs of individuals with epilepsy. |
| SH | Epilepsy Action | Question 7 | We believe that statement 5 should apply to all people with epilepsy, but triaging after initial assessment, and using an assessment tool as previously mentioned, would help to ensure that those who are most in need of support with these issues get it. |
| SH | Epilepsy Society | Question 7 | It is important to incorporate the wider epilepsy group in this statement as mental health issues affect people across the full spectrum of epilepsy. Mental health issues may present following the accumulative challenges of living with epilepsy. |
| SH | Hampshire Hospitals Foundation Trust | Question 7 | As with question 5, neurodevelopment and learning disabilities should be separate entities of assessment depending on where that patient is in their life span. Cognitive function-you may want to be more specific with assessment at diagnosis then before or after a new treatment is established or if a patient is reporting concerns and in the population over 65 years; mental health should be a standard inquiry in all appts; social and emotional wellbeing-this should be an individual assessment for discussion and is part of good history taking. |
| SH | Jon Shaw Foundation | Question 7  Statement 5 | I think it would improve the statement if it focussed on the impact of epilepsy on mental health and Social and Emotional wellbeing. Cognitive and learning disabilities with epilepsy is also an important subject and should have a separate statement. |
| SH | Kent Community Health NHS Foundation Trust | Question 7 | The scope for statement 5 covers a broad population group. Cognitive function should be separate, as should neurodevelopment and learning disability as these relate to physical or developmental cause . Mental health, social and emotional wellbeing could be addressed together as these issues can each have an impact upon one another. |
| SH | LivaNova | Question 7 | LivaNova agree that is important to assess aspects like depressive symptoms, cognition and learning disabilities to ensure patients (and carers) have relevant treatment and support |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 7 | All the areas mentioned are important and could be impacted by epilepsy, it would be good practice to include all of them. |
| SH | NHS England: Primary care team | Question 7 | The short answer is yes, but need specialist input to better understand the potential groups, might need business intelligence input to identify the cohorts for PCNs to work on (with secondary care). I would have thought the most important group to focus on is that at most risk of dying through a seizure (perhaps linked to medication compliance), also people losing their driving licence as they are having continued seizures, also those not able to work thus risking poverty |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 7 | These issues are so prevalent in the whole epilepsy population and often go undetected or under prioritised. It would be important to support their assessment and management for all people with epilepsy. |
| SH | Royal College of Speech and Language Therapists | Question 7 | Excluding particular groups risks missing the social, cognitive, neurodevelopmental needs of patients, thus affecting their outcomes. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 7 | There are certain patient groups which would require the neuro-cognitive and neuro-psychiatric aspects to be assessed, in particular patients with medically refractory epilepsy, patients undergoing epilepsy surgery evaluation and patients with existing underlying learning disability / psychiatric history. Perhaps, focusing on those patient groups initially would be more achievable. |
| SH | The Association of Clinical Psychologists -UK | Question 7 | Cognitive difficulties and changes in mental health in relation to managing epilepsy should be routinely asked to all people with epilepsy. All people with epilepsy are susceptible to experiencing cognitive changes or changes in well-being. Early identification, appropriate assessment and support can improve outcomes for patients and therefore should be offered to all. Appropriate assessment and treatment of cognitive difficulties and clinical mood disorders can lead to improved compliance in epilepsy management which will have improved physical and psychological outcomes. |
| SH | The Peter Doody Foundation | Question 7 | Please refer to answer 5. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 7 | Reviewing each of these parameters at epilepsy appointments is important to reduce the likelihood of diagnostic overshadowing. They are all important to obtain a comprehensive understanding of the patient’s current health status and quality of life. Although not all of these parameters will result in referral to other services, they will highlight subthreshold symptoms that require monitoring. |
| SH | UCB Pharma Ltd | Question 7 | Yes we believe it would be helpful. With epilepsy being a group of diseases, we believe there is a need to consider sub-populations for example those with refractory epilepsies, or with specific syndromes (DEEs) for example. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 7 | Provided those with neurodevelopmental delays and/or learning disabilities are under/referred to the appropriate multidisciplinary teams these are parameters that can be assessed by other teams. |
| SH | Young Epilepsy | Question 7 | We welcome the fact that statement 5 is wide-ranging and applies to all people with epilepsy. It is of utmost importance that children and young people with epilepsy have access to this type of review. Early identification and support can prevent long-term detrimental impact on young people’s development. |
| SH | Angelini Pharma UK-I Limited | Question 8 | Not on a position to offer an additional view. Perhaps utilising QoF would be useful and support greater collaboration from primary care around epilepsy management. |
| SH | Association of British Neurologists | Question 8 | Small-scale audits reviewing clinic letters. This will be labour intensive until machine learning/AI can help. |
| SH | British Academy of Childhood Disability | Question 8 | Outcome measures for this statement should assess what proportion of individuals have been asked about their cognitive function, mental health, social and emotional wellbeing, neurodevelopment and learning disabilities in recent epilepsy appointments. This could be assessed from patient records or via patient questionnaire. Another outcome measure would be what proportion of individuals have been referred onto specialist mental health, neuropsychology, educational psychology and learning disability services from an epilepsy service. This could be assessed from referral data. Clinicians could be surveyed to ask if they routinely ask about these issues in epilepsy appointments – to capture if this brings about a change in practice. |
| SH | Epilepsy Action | Question 8 | As previously mentioned, as the statement is currently worded in would be difficult to measure, but if amended as suggested the rates of reassessment and referral times would be appropriate outcome measures. |
| SH | Hampshire Hospitals Foundation Trust | Question 8 | Consumer satisfaction surveys. i.e. friends and family test or a specific epilepsy questionnaire feedback form about the service. |
| SH | Jon Shaw Foundation | Question 8 | A measureable outcome for this statement would be a reduction in suicides, and a reduction in referral for specialist care for mental health issues. Patients would have a greater understanding of the effects of epilepsy on their mental and general wellbeing. |
| SH | Kent Community Health NHS Foundation Trust | Question 8 | At present we have standard quality of life questions in assessment measurable outcomes asking how they feel about their seizure control; how epilepsy affects their daily life; how involved they are in their epilepsy management; how well they feel on their epilepsy medication and if they are experiencing side effects, how informed do they feel they are about their epilepsy diagnosis and how many visits they have had to A&E in the past year as a result of their seizures. A high score can indicate a low quality of life and this would indicate that further action is required to support the person with epilepsy. However, this does not cover cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities in great detail or as specific assessments. |
| SH | LivaNova | Question 8 | Training to ensure relevant questioning and referral will also be important as well as the identification of which tools/ questionnaires, etc. are best-placed for use (e.g. Montgomery and Asberg Depression Rating Scale (MADRS) for depression, the Neurological Disorders Depression Inventory (NDDI) (which was developed to screen adults for depressive symptoms, excluding symptoms that may overlap with epilepsy and AED side effects) for depressive symptoms) so relevant people with epilepsy can be identified early for appropriate care plans to be put in place, including referrals for further assessment, to ensure consistency and also monitor changes over time.  These tools can monitored over time to assess the impact on people with epilepsy’s’ outcomes. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Question 8 | Outcome measures: developmental assessment, mental health assessment, self-reported wellbeing, reports on progress in education. |
| SH | NHS England: Primary care team | Question 8 | There are probably some ‘what’s the matter’ outcomes related to medical interventions like seizure free time / seizure frequency, but the ‘what’s the matter’ outcomes are more related to the patient eg. MY CAW is a validated tool which measures qualitative patient outcomes. This would be in the way of a patient questionnaire. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 8 | The following information could be used from the Epilepsy12 audit to help inform quality statement 5 for CYP (0-24 years):   * PI 6. **Assessment of mental health issues**; Percentage of children with epilepsy where there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire/measure \*   + Social and mental wellbeing could be captured here. * PI 7. **Mental health support**; Percentage of children with epilepsy and a mental health problem who have evidence of mental health support \* * We will also collect if a child of young person has a neurodevelopmental condition/learning disability diagnosis in the audit, however this won’t be regularly reported as it is not a performance indicator. |
| SH | Royal College of Speech and Language Therapists | Question 8 | Utilising the breadth of the MDT / HCP workforce may inform choice of specific outcome measures.  A patient reported outcome measure about experience in the service could capture aspects of this statement. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 8 | Not sure. |
| SH | The Association of Clinical Psychologists -UK | Question 8 | You could see if the medical notes make reference to the person being asked if they have difficulties or not in the areas. There are screening measures for both cognition and mood difficulties which could be used to assist identification. It is important for screening clinicians to be aware that some people will pass screens relating to cognition but still be experiencing changes in cognition. Possible screens for mood would include the Yale question, GAD-7 (anxiety) PHQ-9 (depression) in the general population. It would be appropriate to see what screens have been developed for use in epilepsy population and for those identified as have a neuro developmental condition or learning disability that an appropriate measure is used. Possible screens for cognition might include the MOCA or ACE-III, this would need to be completed by someone with training, able to interpret who can refer on for specialist neuropsychological assessment if needed. If the person is identified as having a learning disability or neurodevelopmental condition or is a child the appropriate cognitive screen would need to be used which has been validated for the patient population. |
| SH | The Peter Doody Foundation | Question 8 | An appropriate, easily facilitated and inexpensive outcome measure for draft quality statement 5 would be possible by the patient’s appointment attendance and information shared being recorded in the patients care plan and importantly signed by the patient/carer of its understanding and hard copy provided to the patient. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 8 | Outcome: patient satisfaction with their overall wellbeing.  A) the portion of people with epilepsy who have been asked about their overall wellbeing at appointments  Numerator: number of patients reporting being asked, denominator: total number of epilepsy appointments. Data sources: patient records.  B) The portion of people with epilepsy who feel they have been listened to regarding their overall welfare  Numerator: patient satisfaction, denominator: total number of epilepsy appointments. Data sources: numerator can be assessed via an adapted Friends and Family Test, denominator can be assessed via patient records. |
| SH | UK Rare Epilepsies Together (UKRET) | Question 8 | Outcome: patient satisfaction with their overall wellbeing  This could be assessed using an adapted Family and Friends Test from NHS No Reply. |
| SH | Young Epilepsy | Question 8 | Data on the use of mental health and neurodevelopmental screening tools in paediatric epilepsy care could be used as an outcome measure for statement 5. This data is already collected as part of the Epilepsy12 organisational audit. |
| SH | Angelini Pharma UK-I Limited | Question 9 | Clear lack of resource (as shown by reports mentioned in question 1); lack of any epilepsy and neurological focus in the national and therefore local plans. It is a challenge for secondary care and tertiary care to implement these standards given the resource and the challenges of engaging primary care in ongoing epilepsy management in stable patients, which further intensifies the resource challenges.  The tertiary epilepsy service language is causing unintentional variability and access in who can initiate the newer ASMs, even to the point where the same specialist cannot initiate the same medication if they are in a spoke clinic as opposed to their tertiary centre. We urge NICE to address this definition to remove confusion for ASMs and to also replace this language in TA 753 (such language is not present in Scotland or Ireland) and is creating variability in patient access across England given the difference is service design across regions. The term in statement 1 would be more appropriate: **Should be initiated by a clinician with expertise in epilepsy** as opposed to a tertiary epilepsy service. Using this and updating in TA 753 for consistency would support achievement of the overall QS but in particular, statement 2. |
| SH | Association of British Neurologists | Question 9 | Workforce – insufficient numbers of both neurologists and epilepsy nurse specialists is primarily behind the fundamental block to complying with these standards. This is both in terms of number of appointments and duration of appointments.  The IT systems are not standardised and are not always sufficiently good to extract the data. IT systems to collect this data put additional time burden on already overloaded clinicians.  The amount of administrative support for outpatient activity is also insufficient in many places. This has generally been cut with the introduction of IT systems and EPRs (electronic patient record) but that has come with additional disadvantages for managing clinics efficiently, reducing DNA (did not attend) rates and assistance with data collection.  There are also issues over the physical space to do consultations in many places. Virtual appointments have helped to some extent with this but discussing mental health problems virtually is more challenging and virtual appointments also disadvantage the economically challenged and those with intellectual disability, non-English speakers and those with communication problems for neurodevelopmental reasons. |
| SH | British Academy of Childhood Disability | Question 9 | Some challenges may exist in the additional training required for professionals in order to implement Statement 5. Disability Matters e-learning tools already freely available online could support training for professionals. [Disability Matters Hub](https://www.disabilitymatters.org.uk/) Additional time for appointments may be required in order to address the additional questions in Statement 5 and this may affect clinic capacity. Accessing tertiary services in a timely way may require additional resources if demand outweighs current capacity in some areas. |
| SH | Epilepsy Action | Question 9 | We believe there are many challenges to implementing the NICE guidance underpinning this quality standard, in addition to the concerns around resourcing, funding and staffing previously highlighted.  Quality improvement monitoring needs to be improved in order to properly measure performance.  Better service user engagement and coproduction is needed to ensure services are effective and appropriate for patients.  More needs to be done to address health inequalities and deprivation (including homelessness) which have been shown to have a detrimental impact on outcomes and access to services for people with epilepsy.  In addition, given the increasing use of phone and video appointments, consideration needs to be given to digital inequalities and other barriers these can create. The first paper form the Innovations project has just been published, talking about how telephone appointments make it difficult for companions to assist people with epilepsy <https://www.tandfonline.com/doi/pdf/10.1080/10410236.2023.2218143>  ESN case loads need to be addressed, as there are too few currently to provide equitable care ([The ESPETE report](https://www.epilepsy.org.uk/app/uploads/2022/08/The-ESPENTE-Study-8.7.19-Version-1.pdf) highlights the low patient to nurse ration for epilepsy compared to other conditions such as MS). Again this can be supported through the use of open access/patient initiated follow up systems |
| SH | Epilepsy Society | Question 9 | Challenges to implementing the standard are likely to be resource. It seems that there are too few neurologists and even fewer with expertise in epilepsy. Also, few ESN. |
| SH | Hampshire Hospitals Foundation Trust | Question 9 | Please wait until after 12th October when the next MBRRACE report is being presented and published. This includes up to date stats on maternal deaths epilepsy in pregnancy and the postnatal year. There are recommendations in the report which can be included in the quality standards.  Also wait for the next announcement from the MHRA re valproate update. |
| SH | Jon Shaw Foundation | Question 9 | Lack of resources nationally and locally will have an impact on applying the new guidance. Epilepsy should be given the consideration it needs and maybe the APPG for epilepsy could begin to address increased funding for this condition during its meetings. |
| SH | Kent Community Health NHS Foundation Trust | Question 9 | Please see responses in questions 3 and 4 |
| SH | NHS England: Primary care team | Question 9 | For me this involves setting up a pathway, which already exists in our area in terms of the 2 week wait. In terms of work force, particularly having epilepsy nurses, I am not sure if these people exist or need to be trained up. Makes sense to link to community work so we don’t duplicate especially if it relates to health inequalities. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Question 9 | The timeliness aspects may be hard to implement if the service does not have sufficient capacity or resource.  Quality statement 5 – clinicians can use published resources to discuss mental wellbeing with patients, for example, the Epilepsy12 Youth Advocates Clinic Chat Checklist: <https://www.rcpch.ac.uk/resources/epilepsy12-youth-advocates#support-with-worries-and-anxieties-linked-to-epilepsy> |
| SH | Royal College of Speech and Language Therapists | Question 9 | Implementation will be challenging without consideration for the wider MDT / HCP workforce and their contribution to the services required for people presenting with a first seizure and across the healthcare journey.  It is critical that the NHS works closely with third sector organisations, including patient forums, to inform experiences and pathways. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Question 9 | Lack of resources and staff. |
| SH | The Association of Clinical Psychologists -UK | Question 9 | The challenges are having appropriate staff for diagnosis. There would also need to be increased resources for specialist assessment for cognition, neuro developmental and learning disability and mental health and wellbeing, whether this provided as part of the epilepsy multi-disciplinary team or by increasing staff in the services who exist but are likely to then receive more referrals. |
| SH | The British Society for Clinical Neurophysiology | Question 9 | For Neurophysiology services supporting early epilepsy diagnosis there are two major hindrances to delivery of timely diagnosis:   1. A shortage of clinical physiologists to record the EEGs across the whole UK. There is a need for increased training posts to overcome the deficit. 2. A shortage of Clinical Neurophysiology Consultants to be able to interpret the EEG. There is a need for increased training posts in all parts of the UK.   There is little value in a Neurologist seeing the patient in 2 weeks, if requested investigations take 6 months to be done. |
| SH | The Peter Doody Foundation | Question 9 | The challenges are in the national shortage of specialist clinicians to provide optimal care, a lack of awareness of the NICE guidance in primary and secondary care and a lack of clinician accountability and recorded decision making in why guidelines are not followed.  Regrettably until the guidelines become a directive there will be continual repetition of these challenges.  A great resource is in the increased inclusivity and encouragement of parents/carers and advocates in the provision of joined up cohesive care and in forming sustaining capable communities.  Another considered resource would be our Stop Sudep Silence campaign (<http://peterdoodyfoundation.org/stop-suped-silence>) and a forthcoming comprehensive training film package of interviews with clinicians (including the co-author of the Sudep and Seizure Safety Checklist), patient and parents, available later this year from the Peter Doody foundation. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Question 9 | The RightCare Epilepsy Toolkit includes several steps that can be taken to optimise the local health systems to support people living with epilepsy (<https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf> ). |
| SH | UCB Pharma Ltd | Question 9 | UCB agrees that nurses are a vital part of the care pathway.  However, the resource levels for neurologists and nurse-led/nurse-prescriber care can be very limited. Given this, how can prioritisation of resources be raised to enable increased epilepsy nurse support through service development and business cases? |
| SH | Young Epilepsy | Question 9 | In order to implement the NICE guidance that underpins this quality standard, epilepsy teams need to be sufficiently funded, staffed and co-ordinated with other relevant teams. There also needs to be improved communication and collaboration between paediatric and adult epilepsy care to ensure that the needs of young people are met as they transition from one service to the other. |
| SH | Angelini Pharma UK-I Limited | Statement 1 | This statement can be improved by including nurses as a clinician with expertise. |
| SH | British Academy of Childhood Disability | Statement 1 | We agree with this statement. |
| SH | Epilepsy Society | Statement 1 | There needs to be better support and guidance following a first seizure, even if epilepsy has not yet been diagnosed and ASMs have yet to be prescribed. The person presenting with a first seizure is particularly vulnerable before diagnosis and treatment begins. Lifestyle advice, risks and mitigation, including seizure first aid, should be fully explained and access to an epilepsy specialist nurse should be provided. People and their families should be signposted to the epilepsy charities (Epilepsy Society, Epilepsy Action, Young Epilepsy) for ongoing support. |
| SH | Hampshire Hospitals Foundation Trust | Statement 1 | That’s fine |
| SH | HOPE for Paediatric Epilepsy: London | Statement 1 | From a patient point of view, being seen within 2 weeks should be a gold standard.  Currently if not seen within 2 weeks, problems with communication (and with patients/families not knowing who to contact within the NHS – National Health Service) and increased likelihood of additional Accident and Emergency visits and/or stays in hospital.  Some patients are waiting for a long time to be seen after a suspected seizure before they receive a diagnosis of epilepsy or another condition.  There is also no nationally standardised information given to patients/families in relation to information on first responders, when to present at Accident and Emergency departments, when to ring 999, and safety information. |
| SH | Jon Shaw Foundation | Statement 1 | The statement covers early referral leading to diagnosis well |
| SH | LivaNova | Statement 1 | LivaNova agree with this statement to ensure people with epilepsy receive a timely diagnosis and relevant treatment plan |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Statement 1 | Time |
| SH | NHS England: Primary care team | Statement 1 | Agree, but I wonder if there is any imaging or investigation that could be ordered at the time of initial presentation to optimise that crucial appointment (making it a diagnosis appointment) with the expert in epilepsy? That might be a CT / MRI / EEG? |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Statement 1 | The added detail/including the phrase ‘clinician with expertise’ is welcomed and aligns with Epilepsy12’ s PI 1 paediatrician with expertise. This will help ensure specialised input into epilepsy care. It would be useful to clarify the definition of ‘clinician with expertise’ as it is open to interpretation. There are agreed definitions of paediatrician with expertise and formal routes to achieve and maintain this competency.  It is good to see a timeliness element incorporated into the standard and agree 2 weeks from presentation should remain as the target. Epilepsy12 has updated their metrics to align with NICE guidelines.   * ‘Presentation’ may be difficult to define, for example, date of first seizure, date of ED attendance, GP attendance, date of epilepsy diagnosis, date when episode determined to be epileptic seizure etc. Epilepsy12 use the first paediatric assessment as the trigger date, where input from a paediatrician with expertise is required two weeks from that point. These standardised definitions allow timeliness variations to be analysed more robustly. |
| SH | Royal College of Speech and Language Therapists | Statement 1 | This statement could be improved by clarifying the location of where the clinician with expertise in epilepsy may be, i.e., is this part of an admission, outpatient, specialist centre? |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Statement 1 | As per my comments on Question 4. |
| SH | The Association of Clinical Psychologists -UK | Statement 1 | Clarification about what is meant by a clinician with expertise in epilepsy. What constitutes expertise? |
| SH | The Peter Doody Foundation | Statement 1 | Agreed |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Angelini Pharma UK-I Limited | Statement 2 | This statement can be improved by incorporating the terminology ‘clinician with expertise in epilepsy’ as it doesn’t always need the patient to be referred to the service/centre itself given the hub and spoke model and variability of service design across the country. This should be updated in TA 753 to support consistency and achievement of statement 2.  This statement should seek to assess the quality of the referral and not just the number i.e. are the patients meeting the criteria which is defined as X (e.g. drug resistant) being referred in the target time. |
| SH | British Academy of Childhood Disability | Statement 2 | Agree, this is an appropriate quality statement. |
| SH | Epilepsy Society | Statement 2 | Genomic testing should be integrated as a standard part of early diagnosis for epilepsy and should not be seen as a last resort. Identification of a recognised syndrome could direct treatment and avoid prescription of potentially harmful ASMs for a particular syndrome. |
| SH | Hampshire Hospitals Foundation Trust | Statement 2 | That’s fine |
| SH | HOPE for Paediatric Epilepsy: London | Statement 2 | The term ‘other people’ is a blunt turn of phrase and indicates loose terminology.  Is there research that backs up the age of child compared to older children/adolescents mentioned in the proposal. Should other aspects be included in the 2 week wait as opposed to 4 week wait such as status epilepticus, worsening/changing symptoms or trialling of at least 2 different types of anti-seizure medication?  In the quality and diversity statements, as well as the other considerations as to who needs longer in appointments – should this also include people who are neurodiverse? |
| SH | Jazz Pharmaceuticals | Statement 2 | The rapid evolution (and to an extent democratisation) of access to genetic/genomic testing may quickly make this a less “tertiary” service. A rate limiting step in genetic testing is in gaining informed consent, particularly from probands. It would be worth considering commissioning/delivering testing in a non-tertiary setting to make this a better use of resource. If the tests are in progress, or available at the time of specialist consultation, it could exclude/direct a more specific diagnosis and treatment plan. |
| SH | Jon Shaw Foundation | Statement 2 | I feel that the time frame should be the same for all people and not differentiate between children and others. It would be better to say that people with an urgent referral to tertiary services should be seen within 2-4 weeks |
| SH | LivaNova | Statement 2 | [LivaNova supports the statement that “Children referred urgently to a tertiary epilepsy service are seen within 2 weeks of referral and other people are seen within 4 weeks”, especially as a recently published study (1)](https://www.seizure-journal.com/article/S1059-1311(22)00282-5/fulltext) showed that TEC consultations varied by National Health Service regions and Clinical Commissioning Groups. 37.5% of people (11.2%-75.0% across regions) had their index visit at a TEC; and, of those not initially seen at a tertiary epilepsy centre (TEC), 10.6% (6.5%-17.7%) subsequently attended a tertiary centre.  Specialist tertiary centres are best-placed to assess patients and determine the most appropriate treatment modality, including non-pharmacological therapies, where relevant.   1. Murphy et al, Variation in access to specialist services for neurosurgical procedures in adults with epilepsy in England, a cohort study Seizure: European Journal of Epilepsy, <https://doi.org/10.1016/j.seizure.2022.12.006> |
| SH | LivaNova | Statement 2 | LivaNova supports the statement that “Children referred urgently to a tertiary epilepsy service are seen within 2 weeks of referral and other people are seen within 4 weeks” as the Epilepsies in children, young people and adults (NG217) states to “ensure that all children, young people and adults with suspected or confirmed epilepsy have access to a [tertiary epilepsy service](https://www.nice.org.uk/guidance/ng217/chapter/terms-used-in-this-guideline#tertiary-epilepsy-service), if needed, via their specialist” at specified time points; including referring people with epilepsy to a tertiary epilepsy service, to be seen within 4 weeks, if any of the following apply:   * uncertainty about the diagnosis or cause of epilepsy, the seizure type or epilepsy syndrome * **the person has an epilepsy syndrome likely to be drug resistant, their seizures are drug resistant or their treatment is associated with intolerable side effects** * **further assessment and treatment approaches are indicated, such as: video electroencephalogram (EEG) telemetry, neuropsychology or neuropsychiatry, specialised neuroimaging, specialised treatments (for example, medication that can only be prescribed by a tertiary epilepsy service or a ketogenic diet), epilepsy surgery or vagus nerve stimulation** * the person is eligible for and wishes to participate in a clinical trial or research study.   Refer children with suspected or confirmed epilepsy to a tertiary paediatric epilepsy service to be seen within 2 weeks, if they:   * are aged under 3 years * are aged under 4 years and have myoclonic seizures (see recommendation 5.4.1 in the section on myoclonic seizures) * have a unilateral structural lesion * are showing deterioration in their behaviour, speech or learning.   LivaNova agree that the Quality Standard should reflect this updated guidance and include both adults and children.  This is especially important for people with Drug Resistant Epilepsy (DRE) as, compared with people in the general population and people with epilepsy that responds to treatment, people with DRE experience significantly more comorbidities, including depression, vascular disorders, seizure-related injuries, and neurological deficits (1,2). People with DRE also have a significantly higher mortality risk than those whose epilepsy responds to treatment (3,4). SUDEP, where a person with epilepsy suddenly dies during or following a seizure for no obvious reason, is a major cause of death in people with DRE (5). SUDEP is 40 times more likely to occur in people with epilepsy who continue to experience seizures versus those who are seizure-free (6).  People with DRE report significant reductions in health-related quality of life compared with those whose epilepsy responds to treatment, including in measures of physical and social functioning (7-9).  Referral to a tertiary epilepsy service within the specified timeframes for paediatric, adult and young people will help facilitate timely DRE assessment, and access to appropriate treatment options.  As such, patients should be screened and identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the Epilepsies in children, young people and adults (NG217): “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication. Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'.” As the number of Anti-seizure medications (ASMs) can be monitored via prescribing data, this could also be monitored in clinical practice and reported as part of the Epilepsy quality standards.  1 Strzelczyk A, Griebel C, Lux W, Rosenow F, Reese J-P. The Burden of Severely Drug-Refractory Epilepsy: A Comparative Longitudinal Evaluation of Mortality, Morbidity, Resource Use, and Cost Using German Health Insurance Data. Front Neurol. 2017;8:712-.  2 Kantanen AM, Reinikainen M, Parviainen I, Kälviäinen R. Long-term outcome of refractory status epilepticus in adults: A retrospective population-based study. Epilepsy research. 2017;133:13-21.  3. Wang T, Wang J, Dou Y, Yan W, Ding D, Lu G, et al. Clinical characteristics and prognosis in a large paediatric cohort with status epilepticus. Seizure. 2020;80:5-11.  4. Tian L, Li Y, Xue X, Wu M, Liu F, Hao X, et al. Super-refractory status epilepticus in West China. Acta Neurol Scand. 2015;132(1):1-6.  5. Novak JL, Miller PR, Markovic D, Meymandi SK, DeGiorgio CM. Risk Assessment for Sudden Death in Epilepsy: The SUDEP-7 Inventory. Front Neurol. 2015;6(252).  6. Tomson T. Mortality in epilepsy. J Neurol. 2000;247(1):15-21.  7. Sinoo C, de Lange IM, Westers P, Gunning WB, Jongmans MJ, Brilstra EH. Behavior problems and health-related quality of life in Dravet syndrome. Epilepsy & behavior : E&B. 2019;90:217-27.  8. Rassart J, Luyckx K, Verdyck L, Mijnster T, Mark RE. Personality functioning in adults with refractory epilepsy and community adults: Implications for health-related quality of life. Epilepsy research. 2020;159:106251.  9. Tritton T, Bennett B, Brohan E, Grant L, Cooper A, Fladrowski C, et al. Health utilities and quality of life in individuals with tuberous sclerosis complex (TSC) who experience epileptic seizures: A web-based survey. Epilepsy & behavior : E&B. 2019;92:213-20 |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Statement 2 | Resources – some of the assessments – e.g., cognitive, neurodevelopment to name a couple, are best completed by educational psychologists, neuro physiotherapists/ occupational therapists or paediatricians with specialist knowledge and skills to assess neurodevelopment. |
| SH | NHS England: Primary care team | Statement 2 | Agree, but could the pathway be streamlined? Risk is they see clinician at first presentation, then get referred to expert in epilepsy, only then are they referred onto tertiary services. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Statement 2 | Adding in a timeframe around urgent referrals is a welcomed addition and will help streamline tertiary referrals and access. They are challenging but welcomed statements. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Statement 2 | Ketogenic service is mentioned as part of tertiary specialist services. As it stands, ketogenic diet for adults is not funded by NHS England, and therefore there is no fixed funding stream for adult patients (or even patients transitioning from paediatrics to adult neurology) to start or stay on the ketogenic diet. A **national** funding pathway will need to be developed if ketogenic diet is to be considered as part of tertiary specialist services for epilepsy. In Sheffield, we have a ketogenic diet service for adults. Due to the lack of clear funding structures from NHS England, we are unable to open our service to out-of-area patients who may benefit from the ketogenic diet.  Furthermore, there is a lack of neuropsychiatrists nationally. Recruitment for a neuropsychiatrist would be exceptionally difficult and there is also lack of clear national directive with regards to which department (neurology or psychiatry) funds the post/service. |
| SH | The Association of Clinical Psychologists -UK | Statement 2 | The statement refers to children being referred to a tertiary epilepsy service. Is it also the recommendation that adults are seen by a specialist epilepsy service? The current line relating to others being seen in four weeks is not clear if this is general neurology or specialist epilepsy service. |
| SH | The British Society for Clinical Neurophysiology | Statement 2 | As the rationale for this statement includes specialist investigations, please would you consider adding waiting times for Neurophysiology and Radiology Investigations as part of your outcome measures. |
| SH | The Peter Doody Foundation | Statement 2 | This statement could be improved by **all** patients urgently referred to tertiary services should be seen within 2 weeks of referal as those referred to tertiary care are already considered high risk.  If looked at on a case by case basis then there is also the potential for urgently required treatment being missed and those adults who are in the increased risk category for SUDEP not being given optimal care. |
| SH | The Royal College of Physicians of Edinburgh | Statement 2 | The RCPE supports this statement. |
| SH | Angelini Pharma UK-I Limited | Statement 3 | This statement can be improved by stating how often they should be able to be seen by their nurse (minimum time). This will then focus on effective follow up |
| SH | British Academy of Childhood Disability | Statement 3 | Yes, very much agree, this is essential. |
| SH | Epilepsy Society | Statement 3 | This is inspirational but our survey of 2021, showed that only 54% of 1,051 respondees had access to an ESN. |
| SH | Hampshire Hospitals Foundation Trust | Statement 3 | That’s fine |
| SH | HOPE for Paediatric Epilepsy: London | Statement 3 | Epilepsy nurses are hugely important, they can often signpost to other sources of information, help with care plans, provide safety information and also have knowledge of pathways of care.  Lists of epilepsy nurses and where they are in post are often collected by voluntary organisations and are not always kept up-to-date.  Just because a person has a named epilepsy nurse, this may not indicate if they are seen regularly or that the named nurse is in a similar location to the patients/families.  No points around transition services and possible loss of knowledge of knowledge between child/adolescent services to adult services. There is a need for patients/families to be properly informed around transition to help both navigate often complex health system and multiple appointments with sometimes different specialities. There is no national standards around transition with some services providing this from the ages 14-16 years old, but not all. Important to provide examples of best practice.  We would like to take this opportunity to acknowledge that epilepsy specialist nurses often go above and beyond their job description in providing what they do for patients/families and that there is a need to clarify scope of work and provide additional training where necessary in order to prevent burnout.  Is there a possibility to expand epilepsy counselling services, which is not widely available, in order to further empower patients/families as well as help compliment the work of the epilepsy specialist nurses and to support them further. |
| SH | Jon Shaw Foundation | Statement 3 | I agree with the statement |
| SH | LivaNova | Statement 3 | As the National Audit of Seizure management in Hospitals third report identified that only 15% of adults with an existing epilepsy diagnosis who presented with a seizure to emergency departments between June 2018 and 30 June 2019 had seen an epilepsy specialist nurse in the previous year, LivaNova agrees with including this Quality Standard with the aim to increase consistency in all people with epilepsy (adults and paediatrics) having access to Epilepsy specialist nurses (ESNs), who provide training, support and follow up care to people with epilepsy.  LivaNova also support accommodating people with a learning disability or a mental health problem who may find it difficult to access tertiary services if their comorbidities overshadow their epilepsy needs - as their information and support needs should be considered and they may need longer appointments, for example.  ESNs can also aid in the identification of Drug resistant epilepsy (DRE) patients. Specialist epilepsy nurses can locally manage patients holistically along their patient pathway, including post-intervention for non-pharmacological treatments |
| SH | NHS England: Primary care team | Statement 3 | Agree, but please link the nurse up to all the great work happening in the PCN – lots of opportunities to collaborate on improvement otherwise we risk more silos. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Statement 3 | The statement could be improved by incorporating a timeliness element. For example, access should include immediate access to an ESN from the point of diagnosis and ongoing access within the first year of care (as measured by Epilepsy12) and continuing access throughout their life with epilepsy.  This could be further improved by adding a description of what ‘access’ means, such as a contact-ability, eg. ESN access out of hours (24/7, 365 days). There is published data showing high levels of correlation between degree of access and satisfaction with epilepsy care. This statement could include the highlighted phrase from QS27 2013; “Quality statement 5: Children and young people with epilepsy are seen by an epilepsy specialist nurse/nursing team **who they can contact directly between scheduled reviews.”** |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Statement 3 | Achievable, as long as the ESN workforce is properly funded, planned and keeps up with the increasing population and demand year on year. |
| SH | The Association of Clinical Psychologists -UK | Statement 3 | Is the expectation that people with epilepsy remain under the care of their specialist nurse? If they are discharged can they self -refer back rather than being referred via neurology or GP. |
| SH | The Peter Doody Foundation | Statement 3 | Agreed however in relation to the rationale there are not enough ESNs to make this fit for purpose. The present service in reality is mostly ‘reactive’ due to ratio of patients to nurses.  There is a reliance on patients contacting their ESN and there are those who don’t make contact or find initiating that contact challenging.  In relation to equality and diversity what constitutes complex needs? This needs defining so clinicians are aware of its meaning. For example those in transition from paediatric to adult service, in between different health authorities who experience inconsistent joined up care and those with refractory epilepsy are in a ‘high risk group’ for SUDEP.  The considered present draft bullet points should apply to all PWE as placing patients in ‘boxes’ creates inconsistencies in care and of patients ‘slipping through the net’ and dying. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Statement 3 | This statement could be improved by carrying over outcome ‘b’ of current quality statement 5: ‘Proportion of adults with epilepsy who have seen an ESN at their review.’ To ensure equitable access, all patients should be scheduled to see their ESN at defined timeframes, they shouldn’t simply have their contact details. |
| SH | Angelini Pharma UK-I Limited | Statement 4 | No comment |
| SH | British Academy of Childhood Disability | Statement 4 | Also agree this is an essential part of epilepsy care. |
| SH | Epilepsy Society | Statement 4 | Epilepsy care plans should, where appropriate, be multi-disciplinary. For example, where seizures and treatment are likely to cause dental problems, a care plan should be devised to support effective dental care. Mental heath issues are also very common in epilepsy and care plans should reflect this with integrated care across epilepsy and psychology services.  Risks around epilepsy medications during pregnancy should be fully discussed in line with current guidelines. Risks around SUDEP should also be discussed, contextualised and personalised. |
| SH | Hampshire Hospitals Foundation Trust | Statement 4 | Page 20, draft quality standard,  Denominator – the number of women of childbearing potential with epilepsy. *This should include girls, as should all statements re women of childbearing potential.* This may then encourage paediatric teams to start discussing contraception and pregnancy prevention from adolescence and reduce the number of teenage pregnancies in under 18’s with epilepsy. This would also fit with the MHRA valproate PPP.  Page 64 briefing paper: should not include: <https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf> *This is the stillbirth and neonatal death report* |
| SH | Hampshire Hospitals Foundation Trust | Statement 4 | People with epilepsy have an up-to-date epilepsy care plan. *My problems* *with care plan is it can result in a checklist exercise with little room for narrative or interpreted as an emergency management plan for buccal midazolam that is not necessary for all patients.* This statement could be improved by putting: At each clinical epilepsy encounter, effective communication between the healthcare professional(s) and patients and families should be clearly evidenced. This documentation should include an individualised up to date agreed epilepsy and treatment management plan. This encounter documentation should evidence the patient/family have been included in the assessment conversation, asked open questions about themselves and been central to choice and shared decision making. |
| SH | HOPE for Paediatric Epilepsy: London | Statement 4 | Not all epilepsy care plans are up-to-date.  In between reviews of the plan, there may be changes in medication. Therefore there is an importance in keeping this part of the plan as a ‘working document’ including the possibility of not specifying doses, just names of medications.  As there is no one standard format for an epilepsy care plan, there is no easy way of evaluating plans and ensuring consistency. Some epilepsy charities signpost to good plan outlines. However, this creates a fractured knowledge base as not all patients/families will be aware of this, further highlighting the need of creating a national standard in formatting. |
| SH | Jazz Pharmaceuticals | Statement 4 | There will be many adults who cannot advocate for themselves where there may be a greater need for a healthcare led care plan, conversely, there are many people with epilepsy who have well-controlled symptoms, function and social function. Could the denominator be more nuanced, to account for those with the greatest need for a care plan, for example, those with multi-agency involvement, those that lack capacity. If not, could the precision of this be more evolved, for instance life event specific planning (e.g. going to university, older adults needing attention to bone health). The term “individualised” may not cover this. |
| SH | Jon Shaw Foundation | Statement 4 | I think that people with epilepsy should expect a written copy of the care plan to be referred to by the family and other services as necessary, e.g. Education provision or EHCP |
| SH | LivaNova | Statement 4 | LivaNova agrees with NICE’s rationale that “an individualised care plan provides details of diagnosis, treatment, care and support. It is discussed and agreed with the person and, if appropriate, their family or carers. The plan allows people to make informed choices about their epilepsy and helps to coordinate care between healthcare and other professionals in different settings.”  To ensure people with epilepsy’s care plan considers the relevant treatment modalities, it will be important to identify patients who are drug resistant timeously so they can be offered alternative therapies more appropriate to them.  As such, patients should be screened and identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the Epilepsies in children, young people and adults (NG217): “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication. Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'.”  As the number of ASMs can be monitored via prescribing data, this could be achieved in practice, and is an important consideration.  LivaNova agree that having a holistic care plan for all patients could also help in reducing epilepsy-related risks, including sudden unexpected death in epilepsy (SUDEP) and request that the quality standard also ensures identification of 1. Patients at risk of SUDEP and 2. Patients who are drug resistant so they can make informed decisions about their individualised epilepsy care plan that includes details about their care, treatment and preferences, which they develop and agree with their healthcare team, as described in the draft Quality Standard. |
| SH | LivaNova | Statement 4 | LivaNova endorses the use of “a local template or checklist that should be developed to ensure consistency in the content of each epilepsy care plan” and recommends that “assessment of Drug resistant epilepsy (DRE), and discussion about associated treatment options” is included to ensure that the relevant care plans can be put in place as soon as DRE is identified.  Patients should be screened and identified as “Drug resistant” when meeting the criteria, as defined on page 91 of the NG: “Epilepsy in which seizures persist and seizure freedom is very unlikely to be attained with further manipulation of antiseizure medication. Defined by the International League Against Epilepsy as 'failure of adequate trials of 2 tolerated and appropriately chosen and used antiseizure medication schedules (whether as monotherapy or in combination) to achieve sustained seizure freedom'” to ensure appropriate treatment modalities are discussed and incorporated into the person with epilepsy’s holistic care plan  People with Epilepsy’s risk of SUDEP should also be monitored at each visit via the checklist for consistency and to inform their up-to-date treatment plan |
| SH | LivaNova | Statement 4 | With regards to “statement 5”, the checklist proposed should also include assessments to ensure that people with epilepsy are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities.  Training to ensure relevant questioning and referral will also be important as well as the identification of which tools/ questionnaires, etc. are best-placed for use (e.g. Montgomery and Asberg Depression Rating Scale (MADRS) for depression, the Neurological Disorders Depression Inventory (NDDI) (which was developed to screen adults for depressive symptoms, excluding symptoms that may overlap with epilepsy and AED side effects) for depressive symptoms) so relevant people with epilepsy can be identified early for appropriate care plans to be put in place, including referrals for further assessment, to ensure consistency and also monitor changes over time.  Where appropriate, carers may also need to be consulted to obtain this information, which may also need to be added to the checklist for consistency. |
| SH | NHS England: Primary care team | Statement 4 | Agree, but what is the purpose? Opportunity to use population health management approach linking to community efforts, also looking at this through a health inequalities lens to optimise health outcomes (early deaths, also driving suspensions and ability to work etc). |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Statement 4 | We agree that it is important that care planning is kept up to date, however this statement could be improved by also including the following aspects:   * ‘People with epilepsy should have **agreed, comprehensive** and up-to-date epilepsy care planning’ * The above includes the elements from QS27 2013; “Quality statement 4: Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan”.   Comprehensive care planning is much more than a single proforma and has multiple elements and facets for different people, with different types of epilepsy in different settings. Epilepsy12 has defined both the core components of care planning and also the key features of a care planning framework. These are important when measuring this type of care component as there are many interpretations across the health and social landscapes around what a care plan constitutes. |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Statement 4 | Already part and parcel of each epilepsy consultation with either the consultant or the epilepsy specialist nurse. |
| SH | The Association of Clinical Psychologists -UK | Statement 4 | The statement should make reference to how often the care plan is reviewed. |
| SH | The Peter Doody Foundation | Statement 4 | This statement could be improved by ensuring the ECP is accessible across the board, i.e. primary, secondary and tertiary services to facilitate consistent joined up care. Electronically accessible throughout all individual health authority systems and to avoid reliance on the patient to provide this information solely at appointments if they are not in possession of their care plan at these times.  **Specific** information of SUDEP to be given and not just ‘risk’ information. It is dangerous to assume that general information giving around SUDEP risk is the same as a SUDEP conversation. The wording terminology is still, even now, ambiguous and cause for concern in relation to clinicians ‘ticking a box’ for SUDEP discussed when in reality it wasn’t but just a risk conversation. These are not the same and does not serve in safeguarding patients. To include also the understanding of SUDEP at regular intervals.  Again what defines complex needs? (see statement 3 above). |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Angelini Pharma UK-I Limited | Statement 5 | See answer to question 6 |
| SH | British Academy of Childhood Disability | Statement 5 | As above, this is a very valuable addition to the draft quality standard which we fully support. |
| SH | Epilepsy Action | Statement 5 | [Submitted against question 1]  We would also suggest amending statement 5 as it currently only suggests that people with epilepsy are asked about their cognitive function, mental health, social and emotional wellbeing, and neurodevelopment and learning disabilities, without any indication that these will be followed up. The statement should be amended to ensure that people with epilepsy are assessed for these issues, and then a referral made as appropriate. |
| SH | Epilepsy Society | Statement 5 | This is of paramount importance, as above, with depression and anxiety often seen as co-morbidities of epilepsy, and the suicide rate being higher in this cohort. There should be a permeable membrane between epilepsy and psychology services.  Anecdotally we know that people with epilepsy are not asked about their emotional wellbeing due to time constraints. It would be helpful if NICE would recognise this and ensure clinicians signpost to relevant sources of information and support from epilepsy charities. |
| SH | Hampshire Hospitals Foundation Trust | Statement 5 | This statement could be improved by making this: ‘and, where relevant, neurodevelopment and learning disabilities’ a separate quality statement. See suggestion above. |
| SH | HOPE for Paediatric Epilepsy: London | Statement 5 | To provide time in appointments to discuss issues around their cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities will be highly beneficial.  To talk about these issues in the appointments mentioned will help by the patients/families already being familiar with those present. Creating a tacit understanding that epilepsy will impact on these aspects of health and wellbeing will also reduce any stigma associated with them. Additionally, it will help in the sense that there may be perceived barriers going to new appointments, with new professionals (and often with waiting lists) to discuss these issues separately. |
| SH | Jazz Pharmaceuticals | Statement 5 | The general focus of the QS has many access points for those diagnosed as current paediatric patients (ie the children of today, referred and managed in tertiary care with traditional/parent carers). Narrowing the population being assessed for or asked about these domains (e.g. cognitive, learning disabilities) could neglect those that are now adults, that may have been diagnosed in childhood, and have treatable symptoms (seizures and beyond) that are not recognised because of there being a perception of “stability”. It would be worth considering how these assessments would extend to residential or social care settings for adults that may not routinely access secondary/tertiary care.  “The epilepsy care team” in this QS is not well defined. This is of particular importance for those that have cognitive or learning disabilities associated with epilepsy, who may have a more diverse team (e.g. social carers in the community) and less specialist input. |
| SH | LivaNova | Statement 5 | LivaNova agree that it is important that people with epilepsy (and their carers, where appropriate) are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities.  Training to ensure relevant questioning and referral will also be important as well as the identification of which tools/ questionnaires, etc. are best-placed for use (e.g. Montgomery and Asberg Depression Rating Scale (MADRS) for depression, the Neurological Disorders Depression Inventory (NDDI) (which was developed to screen adults for depressive symptoms, excluding symptoms that may overlap with epilepsy and AED side effects) for depressive symptoms) so relevant people with epilepsy can be identified early for appropriate care plans to be put in place, including referrals for further assessment, to ensure consistency and also monitor changes over time.  LivaNova agree that these aspects, e.g. symptoms of anxiety & depression and daily functioning, wellbeing & quality of life, should be checked at all epilepsy appointments - this includes all planned appointments with an epilepsy professional such as regular monitoring reviews, patient-initiated monitoring reviews and specialist nurse appointments.  LivaNova agrees that asking relevant questions as part of epilepsy care can help identify comorbidities and adverse effects of antiseizure medications to enable appropriate interventions and treatment adjustments.  LivaNova agrees that it will be important for there to be evidence of local referral pathways between epilepsy services and mental health, neuropsychology, educational psychology and learning disability services to help facilitate this. |
| SH | NHS England: Paediatric critical care Clinical Reference Group | Statement 5 | Unsure if there is enough clinical time allocated - i.e enough clinicians – to deliver this service so comprehensively |
| SH | NHS England: Primary care team | Statement 5 | Agree, but what are you going to do with this information? It might be that there is an opportunity to link up with the primary care network, particularly the ‘care coordinator’ and ‘social prescriber’ otherwise we risk accentuating the primary / community – secondary care divide. |
| SH | Royal College of Paediatrics and Child Health (RCPCH) | Statement 5 | Statements 5’s focus around mental health and neurodevelopment is a welcomed addition, and aligns broadly with new measures introduced into the Epilepsy12 audit. Although the audit does not capture all of the elements described here today, the new performance metrics capture the presence of mental health conditions, including the screening and support received for these, and neurodevelopmental conditions including learning disabilities.  This statement could be improved to state:   * ‘People with epilepsy are **assessed on an initial and ongoing basis**, around their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities’, |
| SH | Royal College of Speech and Language Therapists | Statement 5 | Asking questions about cognition, mental health and wellbeing is not enough in itself, patients will require the provision of appropriate support and onward referral/signposting where necessary. |
| SH | Royal College of Speech and Language Therapists | Statement 5 | Speech, language and communication difficulties are prevalent in all the comorbidities identified in Quality Statement 5.  People with learning disabilities in particular are highly likely to experience communication difficulties, in comparison with the general population. <https://pubmed.ncbi.nlm.nih.gov/31874425/>  Communication needs have also been specifically linked with epilepsy. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5826845/>  <https://onlinelibrary.wiley.com/doi/abs/10.1002/ana.410380412>  Considering this prevalence and the impact of communication needs on care and management e.g. understanding medication requirements, RCSLT would propose that asking specifically about “speech, language and communication needs” should be added to this statement |
| SH | Sheffield Teaching Hospitals NHS Foundation Trust | Statement 5 | As per my comments on Question 7 (Item 8) |
| SH | The Association of Clinical Psychologists -UK | Statement 5 | This statement should also reflect that the appropriate onward referrals are made when asking about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. |
| SH | The Peter Doody Foundation | Statement 5 | Agreed. |
| SH | The Royal College of Physicians of Edinburgh | 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. |
| SH | Tuberous Sclerosis Association | Statement 5 | This statement should include information on the process to be followed for subthreshold symptoms. In cases where patients do not meet the requirements for referral yet are documented to be experiencing a worsening of their symptoms, they should receive additional monitoring appointments to ensure timely referral for specialist assessments if required.  As part of ‘What the quality statement means for different audiences’ 🡪 ‘People with epilepsy’, signposting to appropriate support groups would be a helpful addition. These professional organisations, largely in the third sector, can provide support and guidance in the interim between referral and appointment access. |
| SH | UCB Pharma Ltd | Statement 5 | UCB welcomes the focus engaging with patients and their family’s mental health and emotional wellbeing. Should this statement also include the proactive communication on information provided to patients regarding how the risks and mitigations they can put into place on living with epilepsy, including lifestyle and seizure management and also risks around SUDEP, as appropriate |
| SH | Young Epilepsy | Statement 5 | Young Epilepsy welcomes the introduction of quality statement 5. This statement says that people with epilepsy should be asked about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities.  We recommend that quality statement 5 is strengthened to ensure that people with epilepsy receive coordinated care related to these areas of need. This could be achieved by adding “, and provided with coordinated care” at the end of the quality statement. The recommendations to provide coordinated care in these areas are included in [section 9.1 of the NICE guidelines](https://www.nice.org.uk/guidance/ng217/chapter/9-Psychological-neurobehavioural-cognitive-and-developmental-comorbidities-in-epilepsy).  It is important that epilepsy professionals are able to connect people with epilepsy with support for an identified need. Healthcare professionals may be reluctant to ask people about issues for which they are not able to provide relevant support. |

Note: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

## Registered stakeholders who submitted comments at consultation

* Angelini Pharma UK-I Limited
* Association of British Neurologists
* British Academy of Childhood Disability
* Epilepsy Action
* Epilepsy Society
* Hampshire Hospitals Foundation Trust
* HOPE for Paediatric Epilepsy: London
* Jazz Pharmaceuticals
* Jon Shaw Foundation
* Kent Community Health NHS Foundation Trust
* LivaNova
* NHS England (Paediatric critical care Clinical Reference Group, Primary care team, Learning disability and autism programme)
* Royal College of Nursing
* Royal College of Paediatrics and Child Health
* Royal College of Physicians
* Royal College of Speech and Language Therapists
* Sheffield Teaching Hospitals NHS Foundation Trust
* The Association of Clinical Psychologists -UK
* The British Association of Prosthetists and Orthotists
* The British Society for Clinical Neurophysiology
* The Peter Doody Foundation
* The Royal College of Physicians of Edinburgh
* Tuberous Sclerosis Association
* UCB Pharma Ltd
* UK Rare Epilepsies Together
* Young Epilepsy

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