

**Epilepsies in children, young people and adults
Consultation on draft scope
Stakeholder comments table**

08/01/19 to 05/01/19

Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association of Paediatric Chartered Physiotherapists	9	23	The draft scope specifically includes surgery in adults for epilepsy such as lobotomy (p11, line 4) but does not mention surgery in children specifically. Procedures such as hemispherectomy and hemispherotomy are carried out in children – so will the efficacy of these be included in this guidance? Also both of which can have significant implications for children. They may have sequelae such as hemiplegia requiring ongoing rehabilitation. It would seem important to include the potential side effects, frequency and severity of such side effects and ongoing costs of the necessary rehabilitation, support at school etc. It may be that the advantages of reducing the epilepsy far outweigh the effects of the potential neurological sequelae of surgery but APCP consider it important for the guidance to present and evaluate the evidence.	Thank you for your comment. The effectiveness of surgical intervention in epilepsy covers both adults and children. This will be a committee discussion when setting the protocol as to whether this will look at all types of surgery together versus no surgery (drugs) to establish whether surgery in general is effective and cost effective, or also comparing different types of surgery to each other. The question on which type of surgery should be considered has now been removed, as this may fall under the wider effectiveness of surgery question.
Bial pharma UK Ltd	2	4	Would the guidelines consider SUDEP rates across UK as it is something which clinicians talk about but is never highlighted in the guidance documents. Clinicians link higher incidence of SUDEP with intolerance/non-adherence to medications.	Thank you for your comment. The guideline will address risk factors for epilepsy-related mortality including SUDEP, and what interventions are effective in reducing the risk of seizure-related mortality including SUDEP.
Bial pharma UK Ltd	6	22	Would there be more information regarding 'economic modelling' e.g what parameters will be considered? Loss of earnings, hospitalisation, injury, etc. Also, what criteria would indicate that a patient group or medication has 'economic considerations' that would make it relevant for modelling.	Thank you for your comment. The economic perspective taken is that of the NHS and personal social services. This includes costs that are borne by the NHS. Loss of earnings would not be captured in this as it would not fall on the NHS. Economic considerations are considered for all questions in a guideline, as this involves considering the cost of the intervention/tool/staff as well as any downstream resource use that could be affected such as hospitalisations avoided from an improvement in outcomes. Cost effectiveness is not only about cost but about the balance between costs and benefits so benefits or harms from an intervention in turn have resource consequences, and therefore health economics is an important consideration for all questions, and is also what sets NICE apart from international guidelines.
Bial pharma UK	8	10	Is this going to consider all medications equally based on	Thank you for your comments. The guideline will consider all

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Ltd			evidence on a level playing field? Will this take cost into account? Will the comparison be limited to only molecules with arguably different mechanisms of action? Will they compare the effectiveness of two sodium channel blockers if they are not contra-indicated but both bind either 'fast' or 'slow' voltage gated sodium channels e.g. Eslicarbazepine acetate & Lacosamide (if they do recognize these subtle differences in channels)? Will they compare the effectiveness of two sodium channel blockers if they are not contra-indicated but both bind different subpopulations of sodium channels? E.g Eslicarbazepine acetate & Lamotrigine	medications judged to be important for practice equally. Cost is also always taken into account.
Bial pharma UK Ltd	10	12	Will there be additional information on AEDs that have a paediatric licence, adult monotherapy licence, liquid form, range of tablet forms (including small increment dose) be given additional attention in the treatment of paediatric epilepsy?	Thank you for your comment. All relevant information on AEDs will be included if there is published evidence on benefit.
Bial pharma UK Ltd	12	Epilepsy overview	Will there be an algorithm detailing recommended 1st, 2nd, 3rd line medications depending on various types of epilepsy and severity of disease? Will this be presented as a flow chart?	Thank you for your comment. This depends both on the evidence and committee discussions in interpreting the evidence. Decisions for the sequencing of medication tend to be more individualistic in practice and therefore treatment algorithms may not be appropriate.
Bradford Community Epilepsy service	General	General	In keeping with the above comment, we believe that the guideline should include evidence on appropriate pharmacological management of depression in epileptic patients, because it has been nationally observed that this group are often under-treated and under-prescribed anti-depressants, mainly because of doctors' fears that anti-depressants will exacerbate their epilepsy. This leave many patients inequitably cared for with regards their psychiatric co-morbidities.	Thank you for your comment. We agree that depression in people with epilepsy is important, and we have revised the scope to include a review question to determine the prevalence of comorbidities including psychological disorders. However, it is outside of the scope of this guideline to provide recommendations on other conditions, and we would refer the stakeholder to the NICE guideline on depression.
Bradford Community Epilepsy service	General	General	On a similar theme above, the evidence on which anti-epileptic drugs are safest to use, in the context of psychiatric co-morbidities are important to include in the guidance. Tables of evidence on the risks of neuropsychiatric side effects will make choosing the best drugs for these patients and communication with patients	Thank you for your comment. The specific outcomes for each review question will be determined by the committee during the protocol development stage of the guideline. We anticipate that adverse events, such as psychiatric co-morbidities are likely to be included where relevant. We cannot comment at this stage how the evidence and risks will

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			on this issue easy to manage. It will help to reduce the risk of drug induced neuropsychiatric co-morbidities.	be presented in the guideline, but we acknowledge tables of evidence, and patient decision aids are useful to support shared decision making.
Bradford Community Epilepsy service	3	general	The draft scope does not include patients with mental health co-morbidities. This patient cohort have a poorer quality of life. Significant mental health co-morbidities are also a potential risk factor for SUDEP. Considering that up to 40% of patients seen in Tertiary epilepsy centres have depression, and that overall, up to 4-10% of patients with epilepsy might have psychosis, we feel this group should be included in the list of patients who have potential inequalities. We have observed that they are often patients who engage less well with services, they often do not attend appointments, and are more likely not to be managed adequately by both general practice and psychiatry teams, because of their co-morbid epilepsy diagnosis.	Thank you for your comment. Psychological disorders will now be addressed through an additional question on identifying their prevalence in people with epilepsy.
Bradford Community Epilepsy service	7	9	The draft scope does not include the clinical features that are likely to refute a diagnosis of epilepsy, or that suggest other non-seizure events. The draft scope only includes the features that indicate a likely diagnosis. The clinical analysis process needs to include both positive and negative features to help to define any medical diagnosis. The misdiagnosis of epilepsy is known to affect as many as 25% of patients, so clarity on diagnosis is the key to management.	Thank you for your comment. We agree with the stakeholder that clear diagnosis is important, and review questions 1.1-10 under section 3.5, cover a broad range of topics relating to accurate diagnosis. At this stage in the development of the guideline, we cannot state if the outcomes on diagnosis will be positive or negative; the committee will develop the protocols for each individual question, selecting what they consider to be the most relevant outcomes, for each question.
Bradford Community Epilepsy service	9	21	The draft scope does not include any evidence of the teratogenic risks of anti-epileptic drugs in female patients. We feel that the inclusion of risk tables that include collated data from pregnancy databases, will allow uniform country-wide counselling for all female patients of the pertinent conceptual issues, and allow patients to make better informed decisions. (The only clear data that is in national guidance currently is for valproate)	Thank you for your comment. The guideline will consider teratogenicity risks of all the anti-epileptic drugs under review.
Bradford Community Epilepsy service	9	30	The draft scope does not include the factors that predict the relapse of seizures after drug withdrawal, or the risks themselves. We feel that this evidence is equally important to include, alongside the criteria for drug withdrawal which	The risk of relapse after drug withdrawal will be considered under the question about AED withdrawal.

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			are being considered in 6.3. To include only the criteria, and not the evidence of risk of relapse and the factors that influence this, means that we will have the evidence on when to counsel patients about the withdrawal of drugs, but no evidence to counsel them on the risks of relapse – which is probably the most important thing the patient needs to know to make this choice.	
Bradford Community Epilepsy service	10	10	The only “service design and delivery” consideration to be considered is on epilepsy specialist nurses. There is a growing consensus that a good model for good community-based care, which would satisfy the needs of a large proportion of patients with epilepsy, is a multi-disciplinary community-based team – including GPs with a special interest in epilepsy working alongside epilepsy specialist nurses and psychologists with a special interest in epilepsy. Identifying the effectiveness of this model would help to complement the important contribution that epilepsy specialist nurses make around the country.	Thank you for your comment. The guideline will not include the model of care/management. From our experience we believe it is unlikely that there will be substantial work to include within an evidence review on the models of good community-based care; therefore, we decided to specifically look at specialist nurses, the exact definition of which be determined by the committee during the protocol development stage. We do not include a question on how a care plan should be provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
British Academy of Childhood Disability (BACD)	4	22	In addition to 'Non-pharmacological management of epileptic seizures' it is important to address pharmacological and non-pharmacological management of comorbidities.	It is recognised that comorbidities are important. A separate section on the prevalence of epilepsy co-morbidities is now included to highlight this important aspect Cross reference will be made to NICE guidance for other conditions where applicable.
British Academy of Childhood Disability (BACD)	5	4	In children and young people it is important to consider learning as well as behaviour and psychological interventions for epilepsy (similarly to adults) in addition to neurodevelopmental considerations. Consideration should be given to comorbidities in children. These are important questions for children and young people affected by epilepsy.	Thank you for your comment. We agree that learning and behavior are important considerations for children and young people with epilepsy, and it is our intention to cover these aspects within the guideline. In light of stakeholder comments we have redrafted our proposed questions, to explicitly state we will determine the prevalence of comorbidities such as impaired cognitive development.
British Academy of Childhood Disability (BACD)	7	9	I would also add something like: What clinical features (symptoms and signs) indicate a likely progression to severe paediatric epilepsy syndromes?	Thank you for your comment. We agree this is important and progression will be covered in the guideline by the section on monitoring and referral, specifically “ <i>what are the criteria for referral to specialist services?</i> ”
British Academy	8	23	I would add – What AEDs (individually or in combination)	Thank you for your comment. There are a large number of

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of Childhood Disability (BACD)			are effective in the treatment of status epilepticus and ESES ?	epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence and if there is clear evidence of benefit of specific therapies.
British Academy of Childhood Disability (BACD)	9	19	I would add – What AEDs (individually or in combination) are effective in the treatment of status epilepticus and ESES ?	There are a large number of epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence and if there is clear evidence of benefit of specific therapies.
British Academy of Childhood Disability (BACD)	10	28	I would consider adding Psychological intervention for children as well. Consider challenging behaviour.	Thank you for your comment. The wording has been revised to focus on the effectiveness of psychological interventions in the treatment of seizures in young people and adults with epilepsy. A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has also been added (see review questions 7.1 and 2 under section 3.5).
British Academy of Childhood Disability (BACD)	11	23	Change to: neurodevelopment (children) and learning outcome (young people). Add: neurodevelopmental and mental health comorbidities: Autism, ADHD, Challenging behaviour, Learning Disability etc.	Thank you for your comment. Section 3.6 gives an overview of the likely outcomes that could be chosen. Specific outcomes to be included in the guideline will be discussed during the committee meeting when signing off the review protocols.
British Nuclear Medicine Society (BNMS)	12	8	Epilepsy overview, Diagnosis and assessment: PET and SPECT (in adults only). We routinely use PET and SPECT successfully in children as well. Therefore, we feel that the comments “adults only” should be removed.	Thank you for your comment. The section on surgical questions for adults only has been removed because it was considered that these are highly specialised services within a surgical centre and could not be adequately covered within general guidance on the diagnosis and management of epilepsies. The focus on surgery for both populations will now be on criteria for referral into surgical services, and the effectiveness of surgery in general.
Coeliac UK	9	22	Under “Non-pharmacological management of epileptic seizures”, there is no reference to the role of the gluten free diet in epilepsy . Evidence of the associations with coeliac disease and epilepsy are emerging. A recent systematic review has demonstrated an increased prevalence of	Thank you for your comment. The cause of an epilepsy will be covered under diagnosis. The role of the gluten-free diet is outside the remit of the guideline, but you may wish to consider suggesting a new topic for a guideline to NICE via their website.

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			<p>coeliac disease and gluten sensitivity amongst people with epilepsy [1]. The review also highlights the potential role of the gluten free diet in improving management of epilepsy, with proposed mechanisms including the improved absorption of anti-epileptic drugs or a reduction in neurological insult caused by gluten ingestion.</p> <p>The NICE guideline for coeliac disease (NG20) has highlighted the importance of screening for coeliac disease in people with unexplained neurological symptoms. While the guideline development group recognised that the literature in this area is scarce, it was noted that a considerable number of people with coeliac disease are detected by neurologists on the basis of the recommendations by NICE.</p> <p>[1] Julian, T., Hadjivassiliou, M. & Zis, P. J Neurol (2018). https://doi.org/10.1007/s00415-018-9025-2</p>	
Department of Health and Social Care	General		I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation	Thank you for your comment.
Epilepsy Action			1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?	Note to NICE. We don't think this is a comment from the SH
Epilepsy Action			Cost saving interventions and examples of innovative approaches have been considered in relation to all comments in this submission. In addition, Epilepsy Action believe the following areas should be considered for inclusion in this guideline.	Thank you for your comment, please see individual responses to each comment.
Epilepsy Action			<ul style="list-style-type: none"> • <u>Online self-management programmes</u> <p>Epilepsy Action would encourage detailed and thorough engagement with self-management programmes as a potential cost-saving intervention with positive health outcomes.</p> <p>Self-management should play a key role in the management of a person's epilepsy. Self-management courses can increase patient activation, thereby improving</p>	Thank you for your comment. We will be considering self-management through the use of new technologies. The committee will consider the inclusion of other aspects of self-management when discussing the review question on information and support.

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			<p>the health outcomes and quality of life of engaged participants.</p> <p>In light of the above, Epilepsy Action designed the Epilepsy and You online self-management programme in collaboration with patients and professionals.</p> <p>An evaluation by Coventry University noted the economic and social impact of the programme with a Social Return on Investment ratio of £1: £18.15. Participants highlighted a range of specific social and economic outcomes including increased social interaction, reduced isolation and a reduction in seizure frequency.</p> <p>http://dev.selfcareforum.org/wp-content/uploads/2017/05/EPILEPSY-AND-YOU-POSTER-A3-version-20.9.17.pdf</p>	
Epilepsy Action			<ul style="list-style-type: none"> • <u>Telephone clinics</u> <p>Epilepsy Action would encourage engagement with alternative methods of service delivery as a potential innovative and cost saving approach. One such alternative method is the 'Open Access Model' that aims to provide patients and families with a point of contact via ESNs to discuss issues as they arise and effectively triage patients in a timely and appropriate manner.</p> <p>A recent evaluation of the utility and value of this 'Open Access Model' highlighted that timely ESN led telephone interventions significantly reduced the need for outpatient appointments in the study cohort. Of the 368 patient encounters involving an ESN led telephone call, 72% led to a prevention of a clinic appointment (268 appointments avoided). This reduced need for outpatient appointments has led to reductions in waiting times and significant improvements in the number of patients successfully managed in the community.</p> <p>https://www.sciencedirect.com/science/article/pii/S1059131118308136</p>	Thank you for your comment. Telephone interventions may be included as part of the review on the role of nurse specialist management, or could potentially be identified as helpful support under the 'information and support' section.

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Epilepsy Action			<ul style="list-style-type: none"> <u>Technologies</u> <p>Epilepsy Action would encourage detailed and thorough engagement with relevant technologies as part of the guideline process. Relevant technologies include but are not limited to wearable technologies and apps. Relevant technologies can improve the self-management of a person's epilepsy, allow patients to better manage risks and allow for more detailed and accurate information to be made available to clinicians during appointments.</p>	Thank you for your comment. We will be examining the effectiveness of new technologies in the guideline. Examples of these have been provided but the committee will prioritise the technologies to be included in the systematic review.
Epilepsy Action	2	15-18	<p>Epilepsy Action welcomes the reference to the updated International League Against Epilepsy (ILAE) operational classification of seizure types and classification of the epilepsies (2017).</p> <p>We note the increased focus on co-morbidities, amongst others, within the new ILAE definitions and classifications and would encourage the final scope to reflect this. We would also encourage relevant engagement with the recommendations of the ILAE Neuropsychology Task Force during the guideline process.</p> <p>https://onlinelibrary.wiley.com/doi/full/10.1111/epi.12962)</p>	Thank you for your comment. Depression will now be considered as a comorbidity in the guideline in a new question that has been added on prevalence of psychological disorders in epilepsy. Other comorbidities will be signposted to appropriate NICE guidance.
Epilepsy Action	3	15-16	<p>Epilepsy Action welcomes the reference to people living in more deprived areas as part of the equality considerations of the draft scope.</p> <p>Public Health England's report on 'Deaths Associated with Neurological Conditions; 2001 to 2014', published in January 2018, notes that – 'the rate of deaths associated with epilepsy in areas ranked as the most deprived in England is nearly three-times larger than the least deprived areas, 13 deaths per 100,000 population verses 4 deaths per 100,000 population.' (p.13, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683998/Deaths_associated_with_neurological_conditions_data_briefing.pdf).</p> <p>In light of this, specific consideration should be given to</p>	Thank you for your comment. Risk factors for epilepsy related mortality is included within the scope and where evidence is found for people in deprived areas the committee will consider this.

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			mitigating additional risk factors that may unduly impact people with epilepsy living in more deprived areas.	
Epilepsy Action	6	2-7	<p>Epilepsy Action welcomes the reference to the NICE technology appraisal guidance, cannabidiol for adjuvant treatment of seizures associated with Dravet syndrome or Lennox-Gastaut syndrome.</p> <p>In light of recent changes to these technology appraisals, the two syndromes are now being appraised separately as ID1211 and ID1308 respectively. We would suggest clarifying this in the final scope and subsequent guidelines.</p>	Thank you for your comment. This has been amended in the scope.
Epilepsy Action	7	32	<p>2 Information and support needs – Epilepsy Action would recommend making explicit reference to care plans in this section. This could be as a standalone question or as an addition to draft question 2.2.</p> <p>Despite existing NICE guidance, a lack of professional agreement around what constitutes best practice in care planning and too little focus on shared decision making has contributed to a notable discrepancy between the number of service providers who state they routinely offer care plans (92%) and patients reporting being offered a care plan (17%) (Epilepsy Health Services in the UK in 2017, Epilepsy Action, 2018).</p> <p>Individualised care plans can help manage risks, reduce emergency hospital admissions and support relevant self-management approaches. Any specific references to care plans in the final scope should also make reference to shared decision making processes that are central to effective care plans.</p>	Thank you for your comment. We agree that care planning is important, the question the stakeholder refers to aims to determine what information and support people want, and this may include care plans, but until the review is conducted we cannot state this. We do not specifically include a question on how a care plan should be provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
Epilepsy Action	7	32	<p>2 Information and support needs – Epilepsy Action would recommend making explicit reference to conversations around risk in this section. As above, this could be as a standalone question or as an addition to draft question 2.2</p> <p>Discussions about risk between clinicians and people with epilepsy can help patients to make informed decisions to minimise risks, improve seizure control and reduce incidences of premature epilepsy-related mortality.</p>	Thank you for your comment. The question the stakeholder refers to aims to determine what information and support people want, and this may include some discussion regarding risks but until the review is conducted we cannot state this. We agree that risk factors, and discussion of these with the patient is important; within the section on epilepsy-related mortality we specifically aim to review these risk factors.

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			https://link.springer.com/article/10.1007/s00415-016-8203-3	
Epilepsy Action	10	23-27	<p>2 Neurodevelopmental assessment and interventions – Epilepsy Action would recommend expanding this key issue and subsequent draft questions to include other psychological interventions beyond neurodevelopmental.</p> <p>Given the high prevalence of mental health comorbidities amongst children with epilepsy, this is an area that merits further consideration within the draft scope and subsequent guidelines. The recent Epilepsy 12 Audit conducted by the Royal College of Paediatrics and Child Health (RCPCH) highlighted that only 12.8% of Health Boards/ Trusts facilitate mental health provision within epilepsy clinics (https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-report-2018).</p> <p>Mental health interventions for children with epilepsy are also the focus of a project at University College London (UCL) and Great Ormond Street Hospital (GOSH) (https://www.ucl.ac.uk/psychological-medicine/Projects/mice.html).</p>	<p>Thank you for your comment. The guideline will include a question on the effectiveness of psychological interventions in the treatment of seizures in young people and adults with epilepsy, see review question 7.2 under section 3.5. The guideline will also look at the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders (review question 7.1 under section 3.5).</p>
Epilepsy Action	10	1-2	<p>Epilepsy Action would recommend expanding this question to include reference to other causes of premature epilepsy-related mortality.</p> <p>Additional mortality risks for people with epilepsy include but are not limited to, unintentional injury and an increased risk of suicide as highlighted by Dr Hayley Gorton, amongst others.</p> <p>https://jamanetwork.com/journals/jamaneurology/article-abstract/2677847</p>	<p>Thank you for your comment. All causes of epilepsy-related mortality will be considered, see section review questions 8.1 and 2 in section 3.5.</p>
Epilepsy Action	11	4	<p>2.1 What are the indications for surgery in adults with epilepsy – Epilepsy Action would recommend that this draft question also be applied to young people and children. While we recognise that the effectiveness of surgical interventions in adults, children and young people is included in the draft scope there is a similar need for indications for surgical interventions to be applied to all age groups.</p>	<p>Thank you for your comment. The section on surgical questions for adults only has been removed because it was considered that these are highly specialised services within a surgical centre and could not be adequately covered within general guidance on the diagnosis and management of epilepsies. The focus on surgery for both populations will now be on criteria for referral into surgical services, and the effectiveness of surgery in general.</p>

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			<p>We are aware that referral criteria for surgery in epilepsy are better established in paediatrics when compared to adult services but there remains a need to increase the number of suitable children with epilepsy receiving surgical interventions. This position is also presented by the Children's Epilepsy Surgery Service (CESS).</p> <p>https://www.england.nhs.uk/wp-content/uploads/2013/05/cess-quick-ref-crds-210513.pdf</p>	
Epilepsy Advisory Group of the Association of British Neurologists	5	7	Surgical interventions should be reviewed for children as well as adults	Thank you for your comment. We have revised our review questions so that the effectiveness of surgical interventions also includes children and young people.
Epilepsy Advisory Group of the Association of British Neurologists	9	1-19	The effectiveness of the AEDs should be the same as for people who are not girls, women who are able to get pregnant etc and this section (4.1 – 4.8) should focus on safety and risks of these treatments in this particular group of people rather than effectiveness.	Thank you for your comment. Pharmacological management in girls and women who are able to get pregnant (including those who are pregnant or breastfeeding) is being treated differently because the most effective drug may not be appropriate if known to have an effect on the child. Safety and risks of AEDs will be considered.
Epilepsy Advisory Group of the Association of British Neurologists	9	26	The term 'monitoring' is vague. Does this mean follow up, review in clinic	Thank you for your comment. The question will encompass follow-up and review in clinic.
Epilepsy Advisory Group of the Association of British Neurologists	10	9	Not clear what is meant with 'effectiveness' of epilepsy nurse and how this is going to be measured	Thank you for your comment. This question aims to clarify the effect of a nurse specialist in the management of epilepsy. Possible measures of effectiveness will be considered by the guideline committee when discussing the review protocol for this question.
Epilepsy Advisory Group	10	24	Not clear what is meant with 'effectiveness' of neurodevelopmental psychological assessment	Thank you for your comment. The wording has been revised to focus on the effectiveness of psychological interventions in

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of the Association of British Neurologists				the treatment of seizures in young people and adults with epilepsy. A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has also been added (see review questions 7.1 and 2 under section 3.5).
Epilepsy Advisory Group of the Association of British Neurologists	11	5-8	Not clear why PET and SPECT have been singled out as presurgical investigations to be assessed specifically as it does not seem appropriate that individual presurgical investigations are part of the NICE review.	Thank you for your comment. The section on surgical questions for adults only has been removed because it was considered that these are highly specialised services within a surgical centre and could not be adequately covered within general guidance on the diagnosis and management of epilepsies. The focus on surgery for both populations will now be on criteria for referral into surgical services, and the effectiveness of surgery in general.
Epilepsy Advisory Group of the Association of British Neurologists	11	3	Video-telemetry and neuropsychological evaluations are more commonly performed pre-surgical investigations, and should be included in the review of surgical treatment	Thank you for your comment. This will be considered by the guideline committee when signing off the protocol for the review question on surgical interventions.
Epilepsy Advisory Group of the Association of British Neurologists	11	3	The role of intra-cranial EEG in complex epilepsy surgery needs to be included. Techniques (stereo EEG versus subdural grids), quality standards, composition of MDT, levels of training and expertise should be specified	Thank you for your comment. This will be considered by the guideline committee when signing off the protocol for the review question on surgical interventions.
Epilepsy Advisory Group of the Association of British Neurologists	11	10	This should include laser and possibly also thermocoagulation.	Thank you for your comment. The section on surgical questions for adults only has been removed because it was considered that these are highly specialised services within a surgical centre and could not be adequately covered within general guidance on the diagnosis and management of epilepsies. The focus on surgery for both populations will now be on criteria for referral into surgical services, and the effectiveness of surgery in general.
Epilepsy Advisory Group of the	12	9	PET and SPECT are included in the diagnosis, assessment box in the flowchart. These are usually only used in some presurgical cases and could be removed from the general	Thank you for your comment. You are correct that these re in the wrong part of the box. These areas have however now been removed from the scope and the diagram will be

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Association of British Neurologists			pathway.	amended.
Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit	General	General	<p>There is no specific mention of contraception in the draft scope, although the intention may well be to include this in section 4. FSRH consider it essential that clear information is given regarding</p> <ol style="list-style-type: none"> 1. The fact that enzyme-inducing AEDs can reduce the effectiveness of oral contraception (both combined and progestogen-only) and the subdermal implant, but NOT of the progestogen-only injectable or of intrauterine contraception. These latter methods should be advised for women using enzyme-inducing drugs. 2. The use of very effective contraception (typical use failure rate <1%) during use of AEDs that are potentially teratogenic and the Pregnancy Prevention Programme. This includes the progestogen-only subdermal implant (unless a woman is also using an enzyme inducer) and intrauterine contraception (the copper IUD and levonorgestrel-releasing intrauterine system). Intrauterine contraception is NOT contraindicated by young age or nulliparity. If less effective contraceptive methods are used (oral contraception or the progestogen-only injectable), condoms should be used in addition. 3. If both a teratogen and an enzyme inducer are being used, intrauterine contraception or a progestogen-only injectable WITH condoms should be advised. 4. Contraceptive advice should be offered to all women aged 13 to 55 using teratogenic AEDs or enzyme inducing AEDs, including those aged 13-16 years and women in the perimenopause. <p>Please see the following FSRH guidance for further information CEU Clinical Guidance: Drug Interactions with Hormonal Contraception - November 2017</p>	<p>Thank you for your comment. The specific outcomes for each review question will be determined by the committee during the protocol development stage of the guideline and as such do not explicitly appear in the scope document. Review questions 4.1-9 under section 3.5 relate to women and girls who are able to get pregnant and drug interactions, such as AEDs and their influence on the contraceptive pill will be covered. We thank the stakeholder for their suggested topics for inclusion; however, until the reviews within the guideline have been conducted we cannot state exactly what information will be given.</p>

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			<p>FSRH CEU Statement: Contraception for women using known teratogenic drugs or drugs with potential teratogenic effects - (February 2018)</p> <p>CEU Guidance: Intrauterine Contraception - October 2015</p> <p>FSRH Guidance: Contraception for Women Aged over 40 Years (November 2017)</p> <p>In addition, we are aware that the RCGP is currently leading development of a guidance document on use of valproate in women of reproductive age.</p>	
Genetic Alliance UK	General	General	We are concerned that the guideline scope focuses on more straightforward epilepsies and does not adequately engage with more complex and syndromic forms. Patients with rare or genetic conditions involving epilepsy, or who experience seizures as part of an undiagnosed genetic condition tend to have complex, variable and frequently unmet support needs which differ significantly from those of a healthy adult with epilepsy. However, other than a couple of mentions of Dravet and Lennox-Gastaut syndromes these issues are completely missing from the scope document.	Thank you for your comment. Thank you for your comment. There are a large number of epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence and if there is clear evidence of benefit of specific therapies. We also have a section on monitoring and referral to specialist services, and we would expect complex cases to be referred for tertiary care.
Genetic Alliance UK	3	21-26	In addition to the reference to people with learning disabilities, this section should also list people with other disabilities or comorbid health conditions as well as with complex and syndromic epilepsies.	Thank you for your comment. Some complex and syndromic epilepsies will be considered. It would not be possible to look at all epilepsy syndromes due to their large number. The section on specific considerations lists populations in which interventions might have differing implications to others with epilepsy and the committee may consider if separate recommendations are required. Depression has been identified as an important comorbidity in people with epilepsy and the guidance will include a review on its prevalence.
Genetic Alliance UK	7	28-29	This item appears to largely be asking about pharmacogenetic testing, however genetic testing can also have other benefits, such as the identification of likely complications and determination of prognosis, as well as benefits to the broader family such as enabling reproductive decision making.	Thank you for your comment. We do include the role of genetic testing in the management of epilepsy and this would include securing an accurate diagnosis. Unfortunately we cannot cover every aspect of genomic testing within the guideline, such as the role of testing in reproductive decision making.

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Genetic Alliance UK	8	26-32	It is not clear which specialist services are being referred to here, as obviously these will differ for a healthy adult with epilepsy compared to a child with complex needs including epilepsy.	In the revised scope, for both children and adults, when to refer to specialist epilepsy services and, as a separate question, when to refer to epilepsy surgical services will be considered
Genetic Alliance UK	8	22-25	The scope does not address the topic of breathing and respiratory support during seizures, and the training and equipment required. This section would appear to be the most appropriate location for a question on this topic.	Thank you for your comment. The topic of breathing and respiratory support during seizures has not been prioritised for inclusion in the scope. For example, it is considered outside of scope whether home oxygen is indicated in people with epilepsy who require buccal midazolam in community settings
Genetic Alliance UK	8	27-30	These questions ignore the wide variety of other syndromic and complex epilepsies beside Dravet and Lennox-Gastaut syndromes, which should not be left out of this guideline.	Thank you for your comment. The guideline is unable to cover all syndromes and complex epilepsies and the most prevalent syndromes have been prioritised. Reference to more rare syndromes will be made in the referral question in the guideline. The appropriateness of when genetic testing should be performed will be considered in the diagnostic section
Genetic Alliance UK	8	4-5	This question should recognise that information and support needs will vary hugely depending on the form of epilepsy experienced.	Thank you for your comment. The guideline will consider subgroups in the question on information and support, and report any evidence found for these particular populations
Genetic Alliance UK	8	24	This item should also include a question about the support needed to enable the patient and their family to follow the ketogenic diet, which is currently not being provided.	Thank you for your comment. While there is not a question specifically on support needed for a ketogenic diet, this information will likely be considered by the committee.
Genetic Alliance UK	10	15-22	Once again this section only mentions a very small number of the wide variety of complex and syndromic epilepsies which this guideline should cover.	Thank you for your comment. , Thank you for your comment. There are a large number of epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence and if there is clear evidence of benefit of specific therapies. We also have a section on monitoring and referral to specialist services, and we would expect complex cases to be referred to tertiary care.

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Genetic Alliance UK	10	8-10	This section should also include questions on: <ul style="list-style-type: none"> - health and social care support - managing epilepsy in a school context - emergency medicines and care plans - training and equipment needs - barriers to access to appropriate support 	Thank you for your comment. As the stakeholder suggests we will be looking at the treatment of seizures within the guideline. In addition we have a question on information needs, and we will not exclude interventions which are conducted in a school context. However we will not be covering the school environment in general, nor training needs; these are broad subject areas and are beyond the scope of the guideline.
NHS RightCare, NHS England	3	20	The guidance states it will be for children, young people and adults – will there be specified age ranges for each category, as there are differences in service provision across the country on when children/young people become adults and move into adult services (e.g. some are at 16, others 18, others 19).	Thank you for your comment. This will be discussed as part of protocol setting for the questions as to what ages determine children and adults. The scope now includes a specific section on transition, and ages for transition will be considered.
NHS RightCare, NHS England	3	26	Will any consideration be given to those with mental health conditions as well?	Thank you for your comment. Psychological disorders will now be addressed through an additional question on identifying their prevalence in people with epilepsy.
NHS RightCare, NHS England	4	16	Information and support needs is very broad, will the guidance consider the use of personalised care planning and shared decision making?	Thank you for your comment. Thank you for your comment. We agree that care planning is important, the question the stakeholder refers to aims to determine what information and support people want, and this may include care plans, but until the review is conducted we cannot state this. We do not specifically include a question on how a care plan should be provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
NHS RightCare, NHS England	7	5	Who is making the diagnosis of epilepsy, will it solely be neurologists or is there potential for others to make the diagnosis for example in LD services epilepsy can be diagnosed by psychiatrists. There is a lack of neurologists around the country and if it is only neurologists that can make a diagnosis there will be variation in the timeframe of people to be able to get a diagnosis due to capacity issues. The current guideline talks about a medical practitioner with	Thank you for your comment. At this stage we cannot comment on who is the most appropriate person to diagnose epilepsy. In the scope we outline what the guideline is going to cover, and we refer the stakeholder to review questions 1.1-10 under section 3.5, where we have a set of questions referring to diagnosis.

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			training and expertise in epilepsy – there could be a role for GPs with special interests to support diagnosis and management but is it difficult to access training to become a GPsWSI in epilepsy.	
NHS RightCare, NHS England	7	6	The draft question asks about what the risk factors for a further seizure are, but should this also consider what prevention measures should be addressed to limit further seizures i.e is there a link between lifestyle factors in future seizures (smoking, obesity, alcohol use?)	Thank you for your comment. We agree that prevention of seizures is important; however, this guideline is specifically for the diagnosis and management of epilepsy. We hope by including the diagnosis of risk factors, we can indirectly suggest what may help to prevent seizures occurring. We agree that specific risk factors that may be amenable to modification can predispose to seizures - for example, hypertension. While the guideline may highlight this risk, management of hypertension will not be addressed as this is covered in separate NICE guidance.
NHS RightCare, NHS England	8	1	The scope only considers assessing the risk of seizures through new technology but there is likely to be a wider role in the use of technology, i.e to monitor current seizure frequency, use of telemedicine/ virtual clinics for support outside of scheduled appointments or delivering routine appointments. I think in light of the long-term plan putting an emphasis on the digital tools the scope should be widened to incorporate these recommendations. Patients themselves would also welcome better use of data and technology in the use of appointments instead of having to travel long distances	Thank you for your comment. The wider role of the use of technology has not been prioritised for inclusion within this scope as there is unlikely to yet be sufficient evidence in this sphere. A question on nurse specialist management is included and this may result in evidence for alternative methods of delivering care.
NHS RightCare, NHS England	8	4	Part of the information and support needs to consider care plans (and how these are shared across settings) as these are variable around the country in terms of content and how they are used and guidance on what should be contained within a care plan would be welcomed to get some consistency across the country. Again, personalised care, patient activation and shared decision making are very important to enable patients to self-manage. Also having a named care coordinator would be encouraged to support people with epilepsy in managing their condition, helping to arrange appointments/ reminders of appointments etc. Signposting to local services including voluntary sector is important to support patients when they are waiting for specialist input as there can be delays in accessing	Thank you for your comment. We agree that care planning is important, the question the stakeholder refers to aims to determine what information and support people want, and this may include care plans, but until the review is conducted we cannot state this. We do not specifically include a question on how a care plan should be provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.

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			<p>specialist support due to capacity issues. Patients also need to be supported with information on how to access services or to be able to refer themselves back in if they require it for example sudden onset of seizures after a long period of being stable etc. Also, requirements for information and support to carers/ families on medications, what to do in an emergency, who to contact etc</p>	
NHS RightCare, NHS England	9	26	<p>This is important as again we understand from patients that ongoing monitoring is variable, depending on capacity on whether it is 6 monthly or annual. Also need to consider who can undertake monitoring, can this be done in primary care to reduce demand on specialist services. GPs are not confident in dealing with epilepsy queries (links back to the lack of specialised training) and therefore refer into specialised services. Also needs to address who is undertaking the monitoring – e. g epilepsy specialist? However, would require a definition of what an epilepsy specialist is.</p>	Thank you for your comment. The question on how should monitoring be undertaken has now been widened to include who should undertake the monitoring.
NHS RightCare, NHS England	9	32	<p>As per the point above, this needs to be defined clearly and support provided to community/ primary care on the criteria because at present patients are referred into specialist services due to lack of confidence of primary care in being able to manage issue with epilepsy.</p>	Thank you for your comment. The guideline will highlight much relating to management of epilepsy in the community and when it is appropriate to refer to specialist services. The aim is to promote better harmonisation of care between primary, secondary and tertiary care which, it is hoped, will provide support at all levels
NHS RightCare, NHS England	10	3	<p>Need to also consider the mortality risk when a person has multiple comorbidities (e.g. respiratory disease or CVD)</p>	Thank you for your comment. We include a review question on risk factors for epilepsy-related mortality see section 8.1.
NHS RightCare, NHS England	10	6	<p>Interventions to manage mortality risk include education of families/ carers of the risk of SUDEP. Implementation of the SUDEP and Seizure Safety Checklist or other tool to identify/ stratify those at higher risk of mortality/SUDEP</p>	Thank you for your comment. We include a review question to determine the effectiveness of interventions for reducing the risk of seizure related mortality see section 8.1.
NHS RightCare, NHS England	10	9	<p>Are there other professionals that need to be considered alongside nurse specialist, e.g. pharmacists to support self-management and meds reviews. What is the definition of a nurse specialist? What is the role of the MDT in the management of epilepsy inc wider staff groups?</p>	Thank you for your comment. From our experience we believe it is unlikely that there will be substantial work to include within an evidence review on the role of MDTs; therefore, we decided to specifically look at specialist nurses, the e exact definition of which be determined by the committee during the protocol development stage. We do not include a question on how a care plan should be

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				provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
NHS RightCare, NHS England	10	11	Need clarification on what the age of transition should be from CYP to adult services, this is widely variable across the country (from 14-19 years). Needs to have clear parameters on the minimum data/information exchange to support transition or have a clear transition plan in place that is agreed upon by sending and receiving services.	Thank you for your comment. We agree there is discrepancy across practice regarding the transition period; the exact definitions of what will be included within the review question will be determined during the protocol development stage. We will use the knowledge of the committee to develop an appropriate search strategy and inclusion/exclusion criteria to ensure all variants are included within the review.
NHS RightCare, NHS England	11	1	This needs to be widened so that the focus is not solely around psychological interventions around treatment of seizures, but it is about supporting mental health to self-manage and have a better quality of life when living with epilepsy. Support around anxiety and depression needs to be addressed as these are commonly associated with people who have epilepsy and consideration to be given around dual diagnosis with mental health and the associated increase risk of suicide in people with epilepsy.	A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has been added (see review questions 7.1 under section 3.5). Unfortunately it is impossible to cover all mental health strategies in people with epilepsy. Appropriate signposting to other NICE guidance in this area will be provided
Pennine Care NHS Foundation Trust	4-5		In 'activities, services or aspects of care 3.3'. You only include psychological interventions for epilepsy in adults we think this should also include children.	Thank you for your comment. This question now covers both adults and children.
Pennine Care NHS Foundation Trust	2-3	21-26	The guideline does not include schools, we believe if the guidance included educational settings there would be improved outcomes in relation to cognitive outcomes for these children.	Thank you for your comment. The guidance is being developed for health and social care practitioners, but may also be relevant to educational sectors
Pennine Care NHS Foundation Trust	10	14-27	There is no mention of psychological support for children, only effectiveness of neurodevelopmental psychological assessment. It is difficult for children to obtain psychological support around their diagnosis and new guidance around this would be beneficial in commissioning provision.	Thank you for your comment. We have amended the proposed review questions and aim to determine the effectiveness of psychological interventions in young people. We cannot during the scope stage determine what the recommendations around these will be; however, it is unlikely to include information on access to services as this is not a service delivery guideline.
Pennine Care NHS Foundation	10	23	Questions 5.1 "What is the effectiveness of surgical intervention in epilepsy?" is a useful question but there	Thank you for your comment. We have revised our review questions so that the effectiveness of surgical interventions

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Trust			should be discussion on indications for surgical intervention for children to mirror the adults section (on page 11 line 4)	also includes children and young people.
Royal College of General Practitioners	General	General	Overall a comprehensive scope	Thank you for your comment
Royal College of General Practitioners	General	General	RCGP Resources for Epilepsy https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/epilepsy.aspx	Thank you for your comment
Royal College of General Practitioners	8	26	People with learning disabilities have a designated GP learning disability lead. The committee should consider how GP learning disability leads can help manage epilepsy, and the possibility of integrating specialist annual epilepsy and annual learning disability health checks. The committee should also consider how atypical presentations could be managed	Thank you for your comment. People with epilepsy and learning disability are considered as a specific group. Appropriate monitoring of people with epilepsy is covered and, if evidence exists, for annual reviews in people with learning disability this will be highlighted. Similarly, there will be comment on patients with complex needs in the sections relating to when to refer on to specialist services
Royal College of General Practitioners	9	1	The 2019/20 GP contract puts forward a mandate for practices to undertake a programme of quality improvement for girls and women of childbearing potential currently being prescribed valproate (https://www.england.nhs.uk/wp-content/uploads/2019/01/gp-contract-2019.pdf). Key points are to ensure an annual specialist medication review and medication compliance with the pregnancy prevention programme as documented by a specialist in the annual risk acknowledgement form. GP practices are asked to ensure a robust system in place to identify and refer for annual specialist review any new at-risk patients being prescribed valproate and should ensure continuous measurement of this measure. MRHA alert April 2018, updated October 2018 https://www.gov.uk/guidance/valproate-use-by-women-and-girls	Thank you for your comment. The guideline will be covering the frequency of monitoring. Girls and women who are able to get pregnant (including those who are pregnant and breastfeeding) are a group that will be given special consideration. The guideline will refer to the MHRA guidance on valproate prescribing throughout.
Royal College of General Practitioners	11	12	The committee should consider listing quality of life and social functioning as critical outcomes. Quality of life is particularly important as this encompasses the whole	Thank you for your comment. Quality of life and social functioning are included in the list of outcomes in section 3.6. The guideline committee will assess which outcomes should

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			patient experience of epilepsy beyond freedom from seizures. Epilepsy can have a profound impact on a person's life beyond the actual disease process, for example the uncertainty that a seizure might occur may lead a person to worry and to limit their daily activities and can have an impact on their personal relationships. This should be considered when deciding how to manage the condition, and therefore listed as a critical outcome to ensure this is integral to the guideline committee's decision making.	be considered as critical when signing off the review protocols.
Royal College of Nursing	General	General	<p>The Royal College of Nursing (RCN) welcomes proposals to develop NICE guidelines for Epilepsies in children, young people and adults.</p> <p>The RCN invited members who care for people with this condition to review the draft scope and comment on its behalf. The comments below reflect the views of our reviewers.</p>	Thank you for your comment.
Royal College of Nursing	4	10	It would be helpful to include some guidance about the use of cannabis oil in epilepsy management.	Thank you for your comment. A separate NICE guideline is being undertaken on the use of cannabis based products for medicinal use, and will include the severe treatment-resistant epilepsy population.
Royal College of Nursing	5	6	<p>The guidance talks about "Psychological interventions" but does not specify 'what' this could mean.</p> <p>It is also unclear why psychological interventions is not also available for children, particularly for older children/young people? The guidance need to make clear the rationale for this exclusion.</p>	Thank you for your comment. We have revised our review questions so that the effectiveness of psychological interventions also includes children and young people. We have not explicitly stated what these interventions are at this stage of the guideline, during protocol development the committee will prioritise relevant psychological interventions.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)			This is an important and timely review of the clinical guidelines for epilepsy, especially considering new and selective imaging and diagnostic criteria, and availability of new anticonvulsant medication which may have specific indications but may be costly.	Thank you for your comment.
Royal College of Paediatrics and Child Health (on behalf of the			The clinical guideline covers paediatric and adult practice but it is difficult to understand why some of the recommendations for assessment and management are considered appropriate only for children and young people	Thank you for your comment. The scope has been revised and all questions will address both child and adult populations other than childhood-onset epileptic seizures and epilepsy syndromes. Transition between child and adult

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British Academy of Childhood Disability)			and other recommendations for adults only. This will be confusing as there is often delay in transition between children's and adult services, or a young person with epilepsy and an autistic spectrum disorder may not have had a comprehensive neurodevelopmental assessment completed until under the care of adult services.	services is included in the guideline.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	Although it does mention 'community settings' and 'carers' the scope does not mention anything about 'schools' specifically. For children, school is a huge part of their life and school undertake huge amount of responsibility for children with epilepsy and possible learning issues the child may have affecting academic achievement.	Thank you for your comment. We agree that the school place is important for children and young people with epilepsy. We will include interventions which are conducted in the school environment within the reviews; however, we are not intending to specifically look at the school setting.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	Paediatric/child epilepsy nurses for every child or young person with epilepsy is needed but not every area has one in place and some guidance is needed for who oversees that child.	Thank you for your comment. We have a review question within the scope which aims to determine "the effectiveness of a nurse specialist in the management of epilepsy?" (see review question 9.1 under section 3.5).
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	The draft scope incorporates everything that a professional needs to know.	Thank you for your comment.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	Could the scope also look at the Centralised epilepsy surgery Pathway for children and young people? It is clear when this should be referred to, but the timeline for assessment and generating outcome is not clearly outlined and where individual/organisational responsibilities lie when multiple organisations are involved.	Thank you for your comment. We do not specifically include a question on how a care plan should be provided, as determining a model or framework of care is not the remit of this guideline (this is not a service delivery guideline). However, we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
Royal College of Paediatrics and	General	General	There needs to be some clarification on what qualifies a paediatrician to have special training and expertise in	Thank you for your comment. This is the scope document for the guideline on diagnosis and management of epilepsy;

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Child Health (on behalf of the British Academy of Childhood Disability)			epilepsy.	therefore, it is not appropriate to discuss qualifications and training of clinicians.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	The need for a child to be seen by a paediatrician with an interest within two weeks after a first suspected seizure in all cases needs to be refined.	Thank you for your comment. In this scope document we outline what areas of research we think are relevant to the diagnosis and management of epilepsies in children, young people and adults. We cannot refine recommendations until the reviews within the guideline have been conducted.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	It is suggested that there needs to be a caseload number per FTE ESN.	Thank you for your comment. In this scope document we outline what areas of research we think are relevant to the diagnosis and management of epilepsies in children, young people and adults. Caseload numbers are outside the remit of NICE guidelines.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	It is suggested that a caseload number needs to be set for new paediatricians and there needs to be a follow up for a paediatrician with an interest in epilepsy.	Thank you for your comment. In this scope document we outline what areas of research we think are relevant to the diagnosis and management of epilepsies in children, young people and adults. Caseload numbers are outside the remit of NICE guidelines.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	Could there be advice about comorbidity screening in epilepsy clinics.	Thank you for your comment. We agree co-morbidities are important and we have included a question to determine the prevalence of psychological disorders, neurodevelopmental, cognitive, and behavioral disorders (see review question 7.1 under section 3.5). Until the review has been conducted we cannot comment on what the recommendations may be.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	It is suggested that in each district the diagnosis of epilepsy should only be made by someone with an interest and expertise in epilepsy.	Thank you for your comment. We agree accurate diagnosis is important and we have a section on this (see review question 1.1-10 under section 3.5). Until the reviews have

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behalf of the British Academy of Childhood Disability)				been conducted we cannot comment on what the recommendations may be.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	Special school epilepsy clinics should be done by someone with an interest and expertise in epilepsy.	Thank you for your comment. Until the reviews have been conducted we cannot comment on what the recommendations may be, however we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	All children with epilepsy should be managed by someone with an interest and expertise in epilepsy and with continuity.	Thank you for your comment. Until the reviews have been conducted we cannot comment on what the recommendations may be, however we do include a section on monitoring and referral of people with epilepsy, and we anticipate this will include who should conduct the monitoring, as well as what monitoring is needed.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	There is a need for access to psychology and cognitive assessments collocated with paediatric epilepsy clinics.	Thank you for your comment. At this stage in the scope we cannot comment on service provision and access to these services. The guideline will cover referral to specialist services and will determine the effectiveness of psychological interventions in children and young people, which we hope will address the stakeholders concerns.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	General	General	There is a need for a better best practice tariff to drive improvements.	Thank you for your comment. It is not within the remit of this scope document to comment on funding.
Royal College of Paediatrics and Child Health (on behalf of the		Prolonged seizures 4.7 and 6.3 withdrawal of	It would be useful to have some guidance on withdrawing emergency medication for prolonged seizure and some information on when this could occur. The guidance only talks about the management for prolonged seizure and the	Thank you for your comment. We will be considering when to no longer suggest emergency medication for prolonged seizures in the review question on withdrawal of AEDs.

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British Academy of Childhood Disability)		AEDS	status and withdrawal of AEDS later on in the draft.	
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 10 -11	Lines 1-11	Why are neurodevelopmental assessment and psychological interventions for children only? Why is psychiatric evaluation and specific types of surgery considered only in the adult guideline?	Thank you for your comment. The wording has been revised to focus on the effectiveness of psychological interventions in the treatment of seizures in young people and adults with epilepsy. A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has also been added (see review questions 7.1 and 2 under section 3.5). The scope has been amended to address criteria for referral into surgical services, and the effectiveness of surgery in general for adults, children and young people (see review question 5.1 under section 3.5)..
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 4	Line 22	In addition to 'Non-pharmacological management of epileptic seizures' it is important to address pharmacological and non-pharmacological management of comorbidities.	Management of co-morbidities of epilepsy is beyond the remit of the guideline. A separate section on the prevalence of epilepsy co-morbidities is now included to highlight this important aspect. Cross reference will be made to NICE guidance for other conditions where applicable aspect
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 5	Lines 1-7	Why are psychological interventions or surgery not included in management options for children and young people?	Thank you for your comment. We have revised our proposed questions to include psychological interventions for children and young people. Review question 5.1 focuses on the effectiveness of surgical interventions in children and young people.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 5	Line 5	In children and young people, it is important to consider learning as well as behaviour and psychological interventions for epilepsy (similarly to adults) in addition to neurodevelopmental considerations. Consideration should be given to comorbidities in children. These are important questions for children and young people affected by epilepsy.	Thank you for your comment. We agree that learning and behavior are important considerations for children and young people with epilepsy, and it is our intention to cover these aspects within the guideline. In light of stakeholder comments we have redrafted our proposed questions, to explicitly state we will determine the prevalence of comorbidities such as impaired cognitive development.
Royal College of	Page 7	Line 9	It would be beneficial to include something like: What	Thank you for your comment. We agree this is important and

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Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)			clinical features (symptoms and signs) indicate a likely progression to severe paediatric epilepsy syndromes?	progression will be covered in the guideline by the section on monitoring and referral, specifically "what are the criteria for referral to specialist services?"
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 8	Line 23	It would be beneficial to add – What AEDs (individually or in combination) are effective in the treatment of status epilepticus and ESES?	Thank you for your comment. There are a large number of epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence and if there is clear evidence of benefit of specific therapies. -
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 9	Line 19	It would be beneficial to add – What AEDs (individually or in combination) are effective in the treatment of status epilepticus and ESES?	Thank you for your comment. There are a large number of epilepsy syndromes and to make a guideline manageable it would not be possible to include them all. Syndromes were prioritised based on the basis of prevalence.
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 10	Line 28	Psychological intervention for children should also be included. Challenging behaviour should also be considered.	Thank you for your comment. The wording has been revised to focus on the effectiveness of psychological interventions in the treatment of seizures in young people and adults with epilepsy. A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has also been added (see review questions 7.1 and 2 under section 3.5).
Royal College of Paediatrics and Child Health (on behalf of the British Academy of Childhood Disability)	Page 11	Line 23	Change to: neurodevelopment (children) and learning outcome (young people). Add: neurodevelopmental and mental health comorbidities: Autism, ADHD, Challenging behaviour, Learning Disability etc.	Thank you for your comment. Section 3.6 gives an overview of the likely outcomes that could be chosen. Specific outcomes to be included in the guideline will be discussed during the committee meeting when signing off the review protocols.
Royal College of Psychiatrists	3	13-16	Another potential inequality is 'children and young people with who are looked after or in care'	Thank you for your comment. Where evidence is found for this population the committee will consider whether specific

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				guidance is required.
Royal College of Psychiatrists	5	4	It is unclear what 'neurodevelopmental assessment' covers – does this include assessment for neurodevelopmental conditions like Autism and ADHD, or even more extensive mental health assessment since conditions like Psychotic Disorders are also considered neurodevelopmental conditions?	Thank you for your comment. In line with stakeholder comments, we have revised the scope to look at the prevalence of psychological, neurodevelopmental and cognitive disorders as comorbidities in epilepsy. We will therefore not focus on the assessment of these disorders as the assessment of the condition would be no different in children with epilepsy as to those children without, and therefore it is not specific to this guideline.
Royal College of Psychiatrists	7	5-31	Another key issue and review question related to diagnosis and assessment is 'What are the mental disorders associated with paediatric epilepsy?'	Thank you for your comment. We agree with the stakeholder and have revised the scope to include a question to determine the prevalence of psychological disorders, neurodevelopmental, cognitive, and behavioral disorders
Royal College of Psychiatrists	8	6-30	Should adverse or side effects of AEDs be included within this scoping section?	Thank you for your comment. Adverse events will be included in the guideline reviews on AEDs and the guideline committee will determine which adverse events should be reported.
Royal College of Psychiatrists	10	23-27	It is unclear what the term "neurodevelopmental psychological" refers to as it does not align with typical nomenclature. We would also advise against the potential for confusion between 'psychological' and 'psychiatric' – we would therefore recommend the term 'mental health assessment/intervention'.	Thank you for your comment. The wording has been revised to focus on the effectiveness of psychological interventions in the treatment of seizures in young people and adults with epilepsy. A question examining the prevalence of psychological, neurodevelopmental and cognitive, and behavioural disorders has also been added (see review questions 7.1 and 2 under section 3.5).
Royal College of Psychiatrists	11	23	We would suggest including 'mental health outcomes'	Thank you for your comment. Section 3.6 gives an overview of the likely outcomes that could be chosen. Specific outcomes to be included in the guideline will be discussed during the committee meeting when signing off the review protocols.
SUDEP Action	1	23-24	Statistics are used earlier in this paragraph to illustrate the importance of this guideline. If statistics are to be used in any context sections to the new guidelines, could a figure relating to epilepsy mortality (not just SUDEP) also be included here to add weight to this argument?	Thank you for your comment. Mortality will be included as an outcome in the reviews which the committee will consider throughout the guideline.
SUDEP Action	2	27-28	Voluntary organisations can find guidelines incredibly important for example in working with policy makers, local clinical services, clinicians and people living with epilepsy & their families. They can provide an evidence base for	Thank you for your comment. The guideline development will follow NICE methodology. Further information is provided in the Developing NICE guidelines manual https://www.nice.org.uk/process/pmg20/chapter/introduction-

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			<p>pushing for change and supporting those living with the condition.</p> <p>However, this can only be the case if the evidence considered via the guideline process considers a wide scope of evidence. We would encourage this to be the case with these epilepsy guidelines. There have been examples of late among both NICE and SIGN guidelines of which we have both been active stakeholders and had bereaved supporters as lay members, where process has led to significant aspects and research being excluded due to unyielding criteria. Yet in other aspects of the same guideline more 'opinion-based' evidence has been included; leading to poor content coverage, missing many key aspects. If such a methodology was to be adopted in this guideline, we would have to question this and the validity of such a document/process and would be unable to support these guidelines once published.</p>	<p>and-overview</p>
SUDEP Action	2	4	<p>SUDEP is singled as a key motivation for reducing epilepsy risks, and while it is a significant cause of epilepsy deaths, the other 50% of epilepsy-related deaths are due to other causes (eg: accidents, suicide, status epilepticus, drownings). Will the other causes also gain recognition in the guideline as there is evidence that much can be done to reduce risks across all causes of epilepsy deaths?</p>	<p>Thank you for your comment. SUDEP is being used as an exemplar and guidance may be appropriate for reducing other causes of epilepsy-related mortality.</p>
SUDEP Action	4	5-8	<p>There are numerous initiatives currently underway within NHS England looking at epilepsy service provision, from multiple angles eg: specialised commissioning, primary care/RightCare, maternity.... Will the guideline reflect these, helping to draw together and highlight existing pathways, & will they be recognised by this guideline process?</p>	<p>Thank you for your comment. The principal aim of the guideline is to optimise diagnosis and management for people with epilepsy. As such the guideline may suggest optimal pathways although specific commenting on how epilepsy services/ sub-services should be commissioned will not be included.</p>
SUDEP Action	4	6	<p>Will 'ongoing monitoring' include the discussion, review and management of epilepsy risks associated with epilepsy mortality? Since the removal of QoF for an annual epilepsy review in primary care, this practice is varied and can occur for as few as 4% of patients (Waddell et al, 2013), yet research has demonstrated that repeated, standardised risk communication and review can lead to reduce epilepsy risks (Shankar et al, 2017).</p>	<p>Thank you for your comment. We anticipate that the review questions on monitoring and referral of people with epilepsy (see review questions 6.1-5 under section 3.5 will include who should conduct the monitoring, as well as what monitoring is needed.</p> <p>There is also a question on information and support, which is also likely to cover risks associated with epilepsy mortality. Additionally there are questions specifically related to risk</p>

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				factors for epilepsy related mortality and interventions effective in reducing the risk of seizure related mortality, which will also inform the discussion with patients about risk. The details of the review questions will be finalised by the guideline committee.
SUDEP Action	4	9	Will content relating to transition be replicated in both the adult and child guidelines? How will the information reflect the current NHS Long Term Plan of a '0-25 years' service (pg 55, section 3.47)	Transition between child and adult services will be considered throughout the guideline and a specific section dedicated to this has now been designated. The guidelines will signpost existing NICE guidance on the general principles of transition from paediatric to adult services (NG43) and if relevant aspects specific to those with epilepsy will be considered with respect to both paediatric and adult guidance.
SUDEP Action	4	27	Should read 'Sudden Unexpected Death in Epilepsy (SUDEP)' rather than sudden unexpected death in epilepsy-related mortality. However, the other 50% of epilepsy-related deaths are also absent from this point, and there is evidence that there are additional risks linked to epilepsy which can be mitigated, outside of those which are SUDEP related. Perhaps an alternative wording/focus should be 'Reducing the risk of epilepsy mortality including risk of Sudden Unexpected Death in Epilepsy (SUDEP)'.	Thank you for your comment. The heading has been amended.
SUDEP Action	5	14	Where will information on managing NEAD be held? Will it be added to another guideline or will the existing information in the current epilepsy guidelines be lost? While this condition is not strictly categorised as epilepsy, there is a link, and in some instances will be part of existing epilepsy pathways. As an organisation we are aware of deaths in those with NEAD; so, would urge there to be consideration that this information features somewhere.	Thank you for your comment. Managing NEAD was not included in the previous guideline; this is addressed by NICE guideline CG109 Transient loss of consciousness
SUDEP Action	6	10-11	Are these guidelines updates of the existing 2012 guideline or will they be superseding the current guideline with two distinct guidelines? This is unclear given the information in this scope and in previous communications regarding the guideline. If the latter, will these new guidelines be utilising on the existing guideline information and building on it, ensuring important information is not lost between	The guideline is a full update and will replace the existing 2012 guidance. All key areas previously covered within the guideline are included in the current scope. New guidance will be developed in light of current evidence, with the aim of optimising care for people with epilepsy

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			versions? There is concern that vital information which was previously hard fought to be included, could become lost, or diluted; leading to backwards steps rather than positive developments. Should this occur to existing guidance on epilepsy risks, risk communication, epilepsy-related deaths including SUDEP or bereavement support, we would have little choice but to not support or endorse such guidelines.	
SUDEP Action	6	13	Where will the guideline committee stand on innovations, tools and resources which are available via a not-for profit model so therefore may not fit into economic models/analysis?	Thank you for your comment. The guideline will consider any interventions which are potentially relevant to the included questions and the NHS, regardless of the providers/manufacturers.
SUDEP Action	8	1-3	Technologies assessing risk of seizures will be considered, but will existing technologies monitoring/managing epilepsy risks also be included in this scope?	Thank you for your comment. At the protocol setting stage of the guideline process the guideline committee will determine which particular technologies to assess, and existing technologies will be considered.
SUDEP Action	8	4-5	Families bereaved by epilepsy should also be included in this question on information provision.	Thank you for your comment. The final question will be determined by the guideline committee but the information and support question includes the needs of both parents and carers.
SUDEP Action	9	28-29	There is a wealth of research published on the topic of when and how to monitor people with epilepsy (particularly in regard to epilepsy risks), though not as case-controlled trials. Will the guideline methodology take an open approach to considering such evidence as part of this process?	Thank you for your comment. We agree with the stakeholder that case-control studies are not the only relevant form of evidence in relation to mortality. We will conduct all our reviews in line with the NICE guideline manual (2018), for each individual review a protocol will be developed by the technical team, in consultation with the guideline committee. Each protocol is developed to be appropriate for each specific question to ensure the best, most relevant published evidence is captured. In addition, we have included a specific question on "information and support for people, parents or carers"; however, before the review is conducted we cannot explicitly state what this will cover in relation to mortality support.
SUDEP Action	10	1-7	While sections specifically covering SUDEP are vital, a wider stance to consider all epilepsy-related deaths is also important. The 2002 National Sentinel Audit highlighted that Epilepsy-related deaths could potentially be avoided in	Thank you for your comment. All causes of epilepsy-related mortality will be considered see review questions 8.1 and 2 in section 3.5. We agree with the stakeholder that case-control studies are

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			42% of cases. To reiterate previous comments consideration of existing evidence/research on this topic outside of case-control studies and NIHR reviews is important to reflect the significant developments and research in recent years on this topic. The inclusion of information in current guidelines on signposting bereaved families is also vital to ensure they get the specialised support they need immediately after the death of their loved one.	not the only relevant form of evidence in relation to mortality. We will conduct all our reviews inline with the NICE guideline manual (2018), for each individual review a protocol will be developed by the technical team, in consultation with the guideline committee. Each protocol is developed to be appropriate for each specific question to ensure the best, most relevant published evidence is captured. In addition, we have an included a specific question on "information and support for people, parents or carers"; however, before the review is conducted we cannot explicitly state what this will cover in relation to mortality support.
UCB Pharma	General		How will the guideline support the introduction of innovations (eg new drugs/classes) during its lifetime?	Thank you for your comment. We will include data from published peer review articles, which will include new drugs and drug classes if available. In addition, the guideline includes a review question on "new technologies" (see review question 2.1 under section 3.5) and again published evidence on these will be sought, following the methods set out in the NICE guideline manual.
UCB Pharma	7	5	Could the guideline provide a clear definition of what constitutes Drug Resistant Epilepsy/refractory epilepsy	Thank you for your comment. When the guideline itself is published there will be a glossary of all included terminology. It is not within the remit of this scope document to provide a glossary of terms.
UCB Pharma	7	26	Evidence suggests that some AEDs are a risk factor for cognitive impairment(?) Will the side effects of AEDS be assessed as a risk factor?	Thank you for your comment. We agree that cognitive impairment is important. Specific outcomes for AEDs will be determined during the protocol development stage for each review question, and adverse events, such as risk of cognitive impairment will be considered.
UCB Pharma	8	4	Could the guideline also consider who should provide the information?	Thank you for your comment. Information and support questions are often approached qualitatively and involve reporting information that is important to patients, from sources such as patient surveys. Who should provide the information could be a theme that comes out of such an analysis.
UCB Pharma	8	8	Could the guideline consider differentiating between primary and secondary generalised seizures?	Thank you for your comment. Yes we will be including data on epilepsy of generalised onset and focal to bilateral tonic-clonic seizures

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UCB Pharma	11	13	Could retention time on treatment be considered within the search criteria?	The search will be based on the inclusion and exclusion criteria defined in the review protocol which will be discussed and prioritised during the guideline committee meeting when agreeing the review protocol.
UK Drugs in Lactation Advisory Service (UKDILAS)	8	4, 5	Consider that specific sub-groups – e.g. women who are breastfeeding may need access to specialist information and advice. Make reference to the availability of specialist information services, preferably available from the NHS, such as UKDILAS (UK Drugs in Lactation Advisory Service).	Thank you for your comment. The guideline will consider subgroups in the question on information and support and report any evidence found for these particular populations
UK Drugs in Lactation Advisory Service (UKDILAS)	9	32	Consider that girls and women who are pregnant or breast feeding should be referred to a specialist service, such as a specialist NHS antenatal service, UKTIS (UK Teratology Information Service) and/or UKDILAS, as appropriate, at the earliest opportunity to ensure appropriate management.	Thank you for your comment. The guideline committee at the protocol setting stage will decide which are the specialist services
UK Drugs in Lactation Advisory Service (UKDILAS)	9	20, 21	Also include girls, or women, who are breastfeeding.	Thank you for your comment. This omission was an error. The population is in the stem of the section (which includes women or girls who are breastfeeding) and so the population in the question has been deleted.
UK Drugs in Lactation Advisory Service (UKDILAS)	12	9	Include breastfeeding women in the pharmacological management box.	Thank you for your comment. This has been amended.
Young Epilepsy	2	28	<p>The guidelines may also be relevant for “Professionals supporting children and young people with epilepsy in education settings”.</p> <p>As well as responding to seizures, educational professionals will need to be aware of the significant impact of epilepsy on children’s cognition and behaviour. State schools in England have a legal duty to support pupils with medical conditions (Children and Families Act 2014, s. 100).</p>	Thank you for your comment. The guidance is being developed for health and social care practitioners, but may also be relevant to educational sectors.

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Young Epilepsy	5	4	<p>Evidence should be sought on the prevalence of learning and behavioural difficulties in children with epilepsy. For example, Young Epilepsy (2014) found that:</p> <p>*95% of children with epilepsy had a significant difficulty in at least one area of cognition or behaviour. *58% of children with epilepsy were underachieving in memory tasks. *60% of children with epilepsy met diagnostic criteria or at least one behavioural or motor disorder.</p> <p>[Young Epilepsy (2014) The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study https://www.youngpilepsy.org.uk/professionals/research/research-projects-current/research-projects-archive/children-with-epilepsy-in-sussex-schools-research.html]</p>	<p>Thank you for your comment. We have now included a question to determine the prevalence of psychological disorders, neurodevelopmental, cognitive, and behavioral disorders.</p>
Young Epilepsy	11	22	<p>Will the terms “cognitive outcomes” and “neurodevelopment” include educational outcomes? For example, Young Epilepsy (2014) found that 42% of children with epilepsy were underachieving in at least one area of academic achievement, with greatest difficulty in mathematics and sentence comprehension.</p> <p>[Young Epilepsy (2014) The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study https://www.youngpilepsy.org.uk/professionals/research/research-projects-current/research-projects-archive/children-with-epilepsy-in-sussex-schools-research.html]</p>	<p>Thank you for your comment. Specific outcomes to be included in the guideline will be discussed during the committee meeting when signing off the review protocols.</p>

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