

**Seizures:
Stage A: SCOPING AND SET UP PROCESS**

Topic and/or Title of proposed guideline	Seizures in the palliative care setting, prioritising symptom experience over sustaining life at all cost with focus quality of life from the individual patient and families perspective.
Specialty area(s) to be addressed	<ol style="list-style-type: none"> 1. Seizures benefiting from palliative care intervention or support where they are or have received optimal management from neurology and other specialist services. 2. Multi-professional approach to seizure management 3. Management of seizures at end of life when they are expected to be the cause of death (terminal seizures) 4. Management of seizures as a symptom occurring during the deteriorating and/or end of life phase 5. Consideration of seizure management at different developmental stages eg neonates, child, adolescent
Background on the topic	<ul style="list-style-type: none"> • NICE guidance- limited evidence shown • Acknowledge patient populations that would benefit • Management of seizures- anxiety about this from professionals/families • Different patient experiencing different seizure phenotypes requiring different approaches -eg cluster, status, non-convulsive seizures • Seizures at different phases of palliative care requiring different approaches eg deteriorating phase vs end of life phase • Local guidance has been developed in some places • APLS/Neurology seizure guidance exists • Adult palliative care seizure guidance • Neonatal guidance (specific group)
Clinical need for guideline	<ul style="list-style-type: none"> • Gap in evidence • Non-pharmacological guidance needed eg triggers stimulation, light etc • Differentiating management from that of movement disorders- dystonia vs spasms vs seizure in palliative care setting • Management of escalating seizures (including status epilepticus) outside an intensive care setting • Balancing risk of seizure and management of seizures including interference with perceived quality of life and interference of activities of daily living
Describe the specific issues planning to address through key recommendations	<ul style="list-style-type: none"> • To generate definitions • To enable a consistent approach • To enable auditing practice (national) • Other areas identified by APPM members
Overall objective(s) of guidelines (scope)	<ol style="list-style-type: none"> 1. Quality of life for patient/carers 2. Seizure reduction and reduction in associated symptoms 3. Support desired place of care 4. Empowering professionals- minimising health care distress 5. Supporting a good death 6. Standardising paediatric palliative care across UK and across all health care settings 7. Satisfaction experience-families 8. To enable transferability of care between care settings and to optimise choice of care setting 9. Define where seizure management in collaboration with palliative care is recommended 10. To support risk/ benefit discussions with families, including young people when able. 11. To consider liaison with specialist palliative care for complex symptom management when not at end of life. 12. Consideration of transition to adult services

Specific Questions to be addressed	What pharmacological and non-pharmacological interventions are effective for the management of seizures in infants, children and young people with palliative care needs.
Current evidence existing guidelines? consensus expert opinion Include references	NICE guidance CHSW seizure management guidance Nicki Harris' paper APPM master formulary APLS guidance and National epilepsy guidance CCLG guidance Adult palliative care seizure guidance WHO neonatal seizure management
Target audience	Professionals caring for life-limited children from primary, secondary and tertiary services and third sector providers CYP should ideally be cared for by multidisciplinary paediatric palliative care team. Funding and commissioning bodies Infants, children and young people and those caring for them
Age range	1. Neonates 2. Children 3. Adolescents and young people (up to 19years)- over 16yrs may be managed by adult guidance
Population	CYP with life limiting conditions and complex seizures, benefiting from a palliative care approach. This might be defined by complexity, route of drug administration, place of care or phase of illness.
Excluded populations	1. CYP best managed by neurology / neurodisability/ general paediatric teams who do not require palliative care input 2. Children with complex seizures who are not life limited. 3. Age 19 years and over
Clinical condition(s)	<ul style="list-style-type: none"> • Terminal seizures. • Epileptic encephalopathy (e.g mitochondrial conditions) • Refractory epilepsy in the presence of space occupying lesions or meningeal disease. • Uncontrolled refractory seizures (Eg GMFCS level 5 CP) • Status (convulsive or non-convulsive) with secondary impact on respiratory reserve, where focus is symptom management experience.
Intervention(s)	<u>Pharmacological:</u> Midazolam, clobazam, clonazepam, levetiracetam, Phenobarbital, diazepam, lorazepam, paraldehyde, Steroids. <u>Non-pharmacological:</u> Trigger avoidance, music therapy Environmental triggers including sleep / pain/ agitation Information and support Surgery / radiotherapy Ketogenic diet
Comparison(s)	Placebo, No treatment / usual care Cross comparison between any of the above (within group and between group) Combinations of the above – reducing triggers and pharmacological management. Routes of administration (same drug or same drug class)
Health care setting or context	UK, Hospital, home, hospice and community settings where skills and resources allow. Managed clinical network support may enable this.
Outcome(s)	<ol style="list-style-type: none"> 1. Reduced frequency or intensity of seizures. 2. Reduced distress as experienced by child and family. 3. Care in place of choice. 4. Improved patient and family experience/ carer satisfaction. 5. Improved trust in healthcare support/ perceived quality of care / quality of experience. 6. Reduction in presentation to acute care. 7. Minimise harm / side effects - e.g unwanted levels of sedation. 8. Acceptability to patients / families and professionals. 9. Achieving a 'good' death as determined by patient and family. 10. Improving confidence and ability to participate in activities of daily living.
Stakeholders	APPM Clinical guidelines group and topic specific group Parents and users <u>Before literature review:</u> Neurologist (replied) BACCH and BACD (no reply)

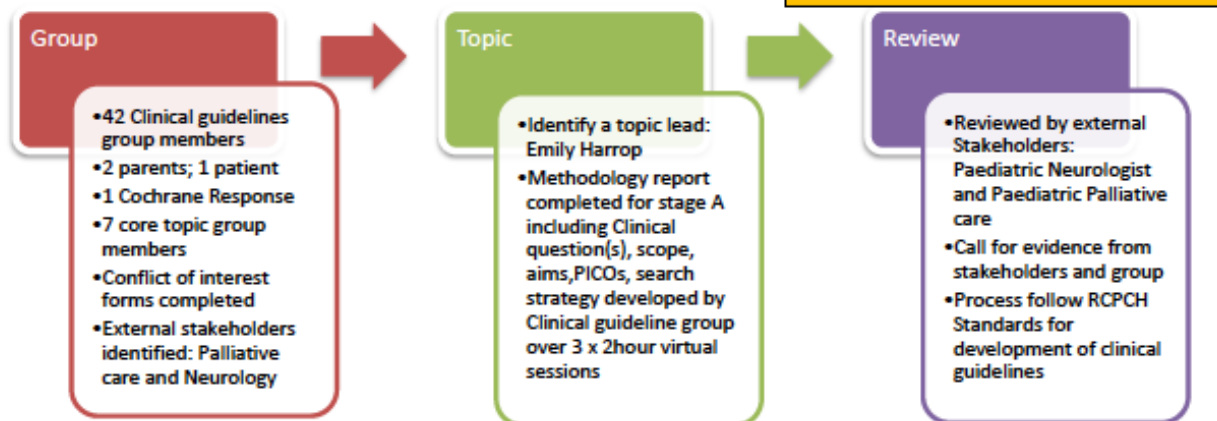
	<p><u>After literature review:</u> Wider APPM membership Neurologist (replied)</p>
Conflict of interest forms	<p>Completed No conflict of interest</p>
Questions formulated	<ol style="list-style-type: none"> 1. What pharmacological and non-pharmacological interventions in infants, children and young people with palliative care needs are effective for: <ol style="list-style-type: none"> A. the reduction in quantity and quality of seizures? B. the management of seizures at end of life? C. the reduction in symptoms associated with seizures? D supporting a good death? E. support desired place of care? 2. What interventions or measures may be helpful: <ol style="list-style-type: none"> A. in improving quality of life for patients who experience seizures and/or carers? B. in empowering professionals- minimising health carer distress C. in standardising paediatric palliative care across UK and across all health care settings D. in ensuring family/carer satisfaction (or minimising trauma) E. to enable transferability of care between care settings F. to optimise choice of care setting G. to support risk/ benefit discussions with families, including young people when able. 3. How do we define when seizure management in collaboration with palliative care is recommended? 4. How do we signpost liaison with specialist palliative care for complex symptom management when the patient is not at end of life.
Literature review	<p>20 years Child only to start, including adult, dependant on results. All study design – including single case reports, posters and abstracts from meetings.</p>
Search strategies	<p>Embase, MEDLINE, PsycINFO, CINAHL, Cochrane, CENTRAL, NICE, HDAS (Health education England), Grey literature (abstracts, unpublished papers, posters)</p>
Search words	<p>Epilepsy, seizures, end of life, terminal, infant, children, young people, paediatric, palliative, neonatal, adolescent, fits, quality of life, convulsions, trust, communication, confidence, reassurance, syringe driver, anti-epileptics, anti-convulsants, (all interventions), Adolescent, minors , terminally ill, dying, hospice care, letter, editorial, news, comment, case report, randomized controlled trial, midazolam, clobazam, clonazepam, levetiracetam, phenobarbital, diazepam, lorazepam, paraldehyde, trigger avoidance, music therapy, Ketamine, steroids, ketogenic diet, VNS (Vagal Nerve stimulation)</p>

Seizures: Stage B: Development

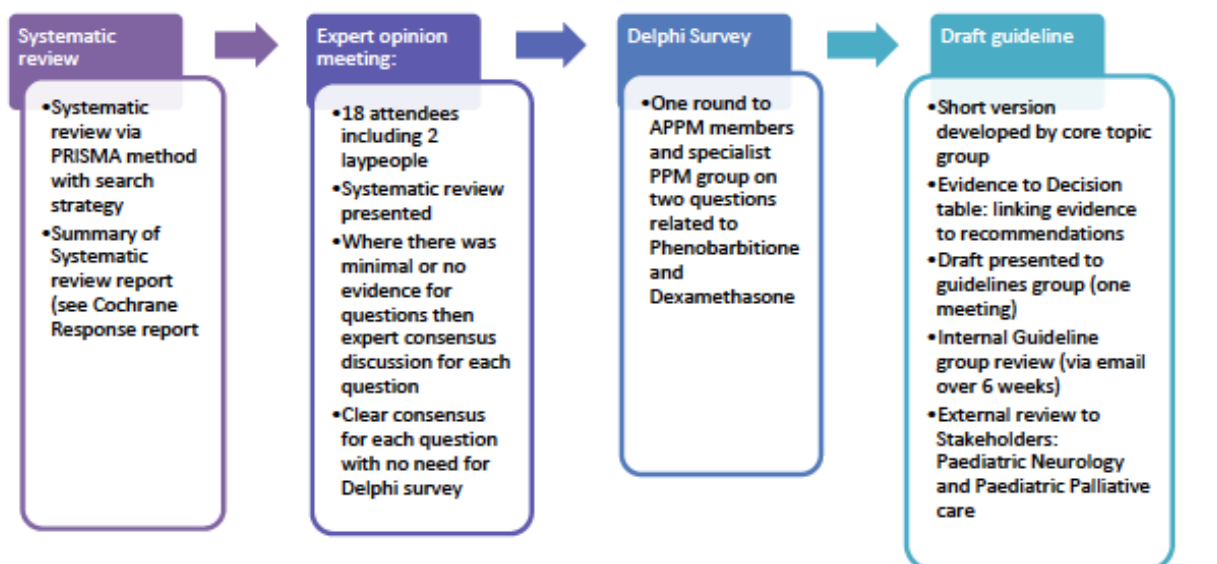
Guideline development process outline	<p>Scope identified and PICO created (stage A)</p> <ol style="list-style-type: none"> 1. Systematic review (stage B) 2. Expert opinion: draft developed against each scope identified using systematic review, where no evidence expert opinion used (Stage B) 3. Delphi survey- where no consensus was met with expert opinion 4. Evidence linked to each statement
1. Systematic review	<p>Completed by topic specific group and Cochrane Response</p> <p>Reports generated:</p> <ol style="list-style-type: none"> 1. Systematic review Protocol (Cochrane Response) 2. Systematic review results
2. Expert opinion	<p>Draft guidance created against each clinical statement</p> <p>Using systematic review but where no evidence expert opinion used</p> <p>Expert opinion process:</p> <ul style="list-style-type: none"> -topic specific group created draft -wider clinical guidelines review (meeting and post-meeting written draft shared)
3. Delphi method	<p>Delphi survey needed- for Phenobarbitone and Steroids. One round only required. Results reviewed by topic specific group and incorporated into guidelines.</p>
4. Evidence	<p>Each stated guidance has evidence link and grade/rating of quality of evidence.</p> <p>Reports generated:</p> <p>Evidence to Decision table</p> <p>Cochrane Protocol and report</p>
Guideline	<p>Completed January 2023</p>
Additional Information	<ol style="list-style-type: none"> 1. Methodology report 2. Guidelines process summary 3. Cochrane Response protocol for systematic review 4. Cochrane Response systematic review results 5. Evidence to Decision table 6. Delphi Survey results 7. Clinical guidelines participants list 8. Conflict of interest forms (on request)
Funding	<p>NHSE funding for completion of 3 topics and commencement of next 2 topics</p>

Guideline process for Seizures

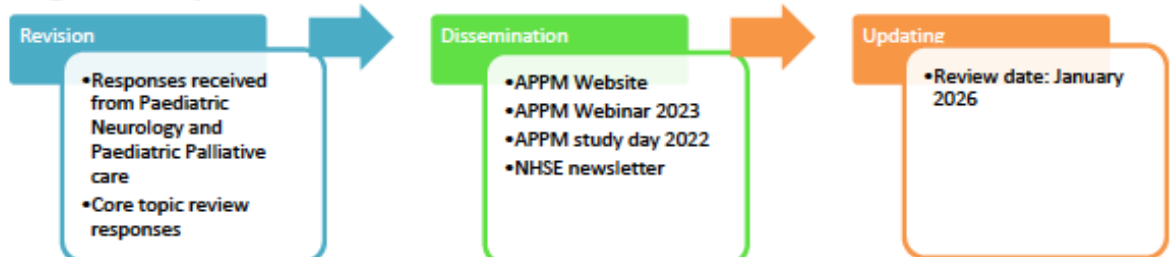
Stage A: Set up



Stage B: Production



Stage C: Completion



Seizures: Stage C: REVIEW AND PUBLICAION

Guidance final	Final draft sent out to stakeholders including APPM membership, specialist paediatric palliative care group and those involved in the scoping.
Economic impact of guidance	As discussed in evidence to decision table, availability and range of non-pharmacological interventions may be a significant issue in many clinical settings. Specialist palliative care expertise workforce across the systems remain very low.
Barriers to guidance stated	Concern that providing guidance could lead to individual clinician's working beyond their scope of practice. It is a clinician's responsibility to consider and understand their level of experience when using the guidelines.
Audit recommendations	To be developed
Dissemination and publication plan	APPM website and webinar series NHSE newsletter
Review date agreed	January 2026