The competency framework paediatric epilepsy nurse specialists (PENS)

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Contents

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This document describes a revised competency framework for paediatric epilepsy nurse specialists (PENS). Recognising the pioneering work of the first PENS roles in the early 1990s this revision strengthens a commitment to advancing the professional role of PENS so that health outcomes for children and young people with epilepsy may improve. Advances in understanding of the epilepsies clinically bring new approaches to assessment and management and reviews of research evidence (Campbell et al., 2019), and direct future research agendas regarding nursing interventions, support and models of care. Such progress within the specialist field is set against a backdrop of current evolving health policy across the four UK home nations, tackling child health inequality and increasing patient participation. It is therefore vital that the PENS role is fit for purpose and that there is a career pathway to produce a sustainable workforce. Individual PENS must demonstrate their competence and capability for meeting the health needs of children and young people with epilepsy in the current context, but also show leadership and innovation in shaping practice for the future.

This competency framework is a consensus view of best practice. It expresses the essential competencies of PENS practice at different levels, aiming to create a common language and understanding about the PENS role. The competency framework should become an essential tool for PENS at any stage of their career to prompt reflection and learning in practice and facilitate career progression. This should promote consistency and quality in PENS practice across organisations and clinical networks across the four nations and provide a resource for stakeholders who are developing epilepsy services for children and young people. Although developed in the UK, it is anticipated that this competency framework will have a global reach. Although country-specific professional standards, policy and service benchmarks would need to be considered, the PENS competency framework could find application to paediatric epilepsy nursing roles internationally.

2.1 Childhood epilepsies

Epilepsy is a neurological condition affecting approximately 112,000 children and young people (RCPCH, 2022). Epilepsy is not a single condition, and it is therefore more accurate to refer to these conditions as 'the epilepsies' (Scheffer et al., 2017). For over a decade, clinical guidelines have recognised the complexity inherent in assessing and managing the epilepsies. Wide-ranging recommendations for achieving accurate diagnosis, holistic management and psychosocial support now exist (e.g., NICE, 2022; SIGN, 2021). Optimal diagnosis and management are intended to reduce risk and minimise the impact of the epilepsies on emotional wellbeing, psychological and social functioning, and later employment. Given the diverse nature, outlook, and impact of the epilepsies, along with the need to consider developmentally appropriate healthcare, care pathways need to be flexible, and care should be individualised. PENS play a key role in achieving this through their clinical practice and educator roles, their understanding of research and capability for leadership at all stages of the care pathway.

2.2 Context of the paediatric epilepsy nurse specialist (PENS) role

Integrating epilepsy services across the entire care pathway for the epilepsies (NICE, 2022) remains key to form integrated teams supporting the child or young person and their family. There is considerable mandate and recognition of the PENS role being pivotal in this. Although currently under review, Quality Standards (NICE, 2013) have long recognized the essential benchmark that all children and young people with epilepsy should have access to an Epilepsy Specialist Nurse between scheduled reviews. Clinical guidelines continue to recommend that all children & young people have access to an epilepsy nurse specialist (NICE, 2022, SIGN, 2021). In England & Wales the number of PENS overall has increased and so has the percentage of NHS trusts and health boards with a PENS (RCPCH, 2022). However, there is still some way to go before all children and young people with epilepsy to have access to the expertise of a PENS. Efforts to develop the role are viewed as improvements to the infrastructure of care (Kirkpatrick et al., 2014). A sustainable, resilient PENS workforce is required which is expressed in a current vision for nursing (e.g., Scottish Government, 2017; CNO Wales, 2022; NIPEC, 2014; NHS England, 2019), able to work collaboratively across different settings (e.g., tertiary, secondary or community) and meet diverse epilepsy needs while remaining responsive to a rapidly changing wider health and social care context.

PENS may work in teams with other registered nurses in support, such as nurses with a special interest in epilepsy. Examples include a ward-based epilepsy link nurse, a community children's nurse with a special interest in epilepsy and associate nurse specialist roles. This skill mix within the nursing team opens up a different dynamic in service provision and can lead to career progression to become a PENS. A clear description of different levels of practice within this specialist field is therefore essential to maintain quality and effectiveness and set out a competency pathway towards the development of the PENS role. It is also critical to retain experienced, highly skilled PENS. The effectiveness of the PENS role and the impact on health outcomes are largely descriptive (Campbell et al., 2019). It is a matter of priority to attract highly skilled children's nurses to the PENS role to ensure the design of future research agendas and lead on the development of epilepsy services. Guidance on what the different levels of practice are within epilepsy nursing, including advanced practice, is therefore required.

2.3 Role of the PENS

The overall aim of the PENS role is to empower children, young people and their families to live well with their epilepsy and to enable children and young people to achieve their full potential. Therefore, PENS perform the following roles:

- Promote evidence-based practice in the assessment, diagnosis, treatment and care of children and young people with epilepsy.
- Support and advocate high-quality epilepsy services for the child/young person and family.
- Be the main point of contact for GPs and other professionals on epilepsy-related matters, liaising between agencies.

- Support the ongoing care of the child/young person and family, providing specialist information, emotional support and teaching, and referring them to other professionals when necessary, such as for counselling.
- Provide training, education, awareness raising and advice to other professionals, including in schools, primary and community care teams, social services and learning disability teams.
- Work as a key member of the multidisciplinary team (MDT), helping to develop responsive, evidence-based, accessible and appropriate services (including nurse-led clinics) and engaging children/young people and families in service reviews and developments.

A closer view of the PENS role is illustrated in the competency framework that is explained in **Section 3.3.1** of this document.

3.1 What is competence?

There is no consistent definition of competence, and the term is often used interchangeably with competency and competencies (Murrells, et al, 2009). Watson et al, (2002) distinguish between a behavioural approach to competence, in which there is a focus on skills and tasks (i.e., competencies or specific capabilities), and a more holistic view that regards competence in terms of attributes such as knowledge and critical thinking. Therefore, competence can be described as a generic quality referring to a person's overall capacity and Roach (1992) defines competence as "the state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's professional responsibilities". This framework outlines specific competencies that taken together represent the overall competence and capabilities expected of a PENS working at a novice, competent and expert level (see Section 3.3.3).

3.2 Purpose and uses of the competency framework

As Registered Nurses, PENS must uphold The Code (NMC, 2018a), demonstrate that they meet the Standards of Proficiency for Registered Nurses (NMC, 2018b) and the requirements for Revalidation (NMC, 2015). Alongside these regulatory standards, this competency framework is designed to be used by PENS to take a comprehensive approach to their learning and professional development.

It can prompt reflection on practice and be used to structure feedback from colleagues. Self and peer assessment can, along with appraisal, identify strengths and areas for development. Competencies can be used to formulate learning objectives and appropriate educational activities to ensure objectives are met. Evidence from applying the competency framework in practice could be used by registered nurses to support Revalidation (NMC, 2015), to evidence performance within their employer's annual appraisal system and to build a portfolio of evidence to support career progression.

The competency framework may also inform organisational systems and processes that are needed for safe and effective PENS practice, therefore contributing to clinical governance and appropriate supervision and support for PENS. It can also assist in the commissioning or design of accredited education programmes and non-accredited training or learning by professional organisations or education providers. It may stimulate the development of valid and reliable tools to assess achievement of competencies. Finally, the competency framework may also contribute to the research agenda evidencing the effectiveness of the PENS role.

3.3 Influences on the competency framework

There is much UK workforce strategy and policy that can inform the structure of a competency framework for PENS to evolve a career pathway approach. The Career Development Framework (Skills for Health, 2010) expresses nine levels of practice for all health careers and has been adopted into career frameworks across the four nations of the UK. Whilst acknowledging that some reviews of published frameworks are currently being commissioned (e.g., CNO Wales (2022)), these frameworks for specialist nursing and/ or advanced level practice (e.g., NLIAH, 2011; HEE, 2017; NIPEC, 2018; Scottish Government 2021) all share a consistent approach to defining levels of practice and emphasing four 'pillars' of practice. NHS Education for Scotland (NES) have recently updated their Nursing, midwifery and allied health professionals (NMAHP) development framework (NES, 2021a) and the benchmarks for Level 5 (Practitioner), Level 6 (Senior Practitioner) and Level 7 (Advanced Practitioner) from their Post-Registration Development Framework (NES, 2021b) significantly influence this PENS competency framework.

3.3.1 Four pillars of PENS practice

Throughout the contemporary post-registration career frameworks (e.g., NES, 2021b, NIPEC, 2018) and advanced level practice guidance (HEE, 2017) there is an emphasis on four 'pillars' of practice (See Table 1).

Table 1: Four pillars of practice (HEE, 2017; NES, 2021b)			
Clinical practice	**Facilitation of learning**	**Leadership and management**	**Evidence, research and development**
Safe, effective person-centred care using professional judgement and decision-making	Teaching, learning and assessment, and creation of the learning environment	Teamwork and development Professional and organisational leadership	Using or generating evidence for practice

The four pillars have therefore been used to structure four domains of this competency framework. The four pillars align well with the role of PENS, as is further illustrated below.

Clinical practice: PENS provide clinical expertise for the child or young person and their family throughout the course of their epilepsy. This may be during diagnosis, treatment or access to specialist pathways (e.g., epilepsy surgery). PENS use a holistic framework and adopt an individualised approach to optimise seizure control (through lifestyle advice and supporting or prescribing treatment) and the management of risk. Psychiatric comorbidities and neurodevelopmental disorders are common, but still underdiagnosed and treated (Mula et al, 2021). Therefore, identifying mental health needs, and supporting emotional wellbeing in children and young people with epilepsy is a priority for epilepsy services (RCPCH, 2022) and epilepsy nurse specialists can play a key role in improving satisfaction and emotional well-being (NICE (NGA), 2022a). Working to promote continuity between settings (e.g., home, school) and services (e.g., health and social care), and transition to adult services (NICE, 2016; NICE, 2022), PENS facilitate a coordinated approach, aiming to create a seamless service for children, young people and families. The clinical practice pillar of the PENS role therefore reflects the actual needs of children and young people with epilepsies and encompasses groups of competencies regarding:

- supporting diagnosis of childhood epilepsies
- assessing and managing continuing seizures
- assessing and managing risk
- assessing and managing the psychosocial impact of the epilepsies
- planning, implementing and evaluating nursing care
- managing treatment of the epilepsies
- managing emergency medication

Education: PENS integrate education, advice and support regarding the epilepsies into their clinical work. Education aims to empower children, young people, and their families to self-manage and achieve independence and adjust to living with epilepsy. This educational role also extends to the design and delivery of educational programmes for other health, education and social care professionals, and this enables a care plan for a particular child or young person to be implemented or enhances knowledge and understanding of the epilepsies more broadly among professionals and communities. The education pillar of the PENS role, although related to clinical practice, is a distinct aspect of practice and involves groups of competencies regarding:

- creating an effective learning environment
- educating children, young people and their families
- facilitating and evaluating professional learning.

Evidence, research and development: Contemporary nursing practice requires that clinical decisions be informed by the best available research evidence (NMC, 2018a). All PENS use research in practice and must therefore have comprehensive knowledge of contemporary clinical guidelines (e.g., NICE, 2022, SIGN, 2021). They also participate in and may lead research in practice, producing new understanding about what works in terms of models of nursing care and interventions. The research pillar of the framework specifies competencies related to:

- using research in practice
- doing audit, service evaluation and research.

Leadership and management: Being well placed to listen to and understand the needs and experiences of children and young people, PENS can work collaboratively to develop accessible, responsive, evidence-based services for children, young people and families living with a diverse range of epilepsies. Realising their clear leadership potential (Higgins et al., 2018), PENS can capitalise on initiatives designed to stimulate quality improvement in epilepsy services, such as the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) (RCPCH, undated). Ensuring tailored, quality services and practice that is safe and effective is also essential. Therefore, the leadership and management pillar include groups of competencies around:

- managing work
- professional responsibilities
- partnership working, negotiating and influencing
- leading innovation and service development.

Setting the PENS role in the language of a more generic framework such as the four pillars (HEE, 2017; NES, 2021b) will aid understanding of the PENS role within nursing and healthcare more generally. Having made the four pillars of the PENS role clear, along with a broad overview of the groups of competencies within each pillar, consideration can then be given to how specific knowledge, skills or values can be articulated at different levels of practice for each of the competencies.

3.3.2 Levels of practice

There has been ambiguity about what it means to be a specialist nurse and what qualifications and experience should be expected. This has led to posts that have not offered consistency across contexts and this lack of standardisation has not supported succession planning, transferability of skills or coherent planning for individual practitioners. Rather than considering roles or titles, it is essential to consider 'levels of practice' and to be able to state clearly what each level of practice involves. When examining PENS roles, it is important therefore to understand how 'advanced' practice relates to 'specialist' practice, both to reduce confusion for nurses and the public and to ensure effective governance of these roles.

Specialist practice is particular to a certain context or client group and should be viewed on a 'specialist–generalist' continuum (NES,2021b). PENS roles are therefore towards the specialist end of the continuum as PENS clearly work with a defined client group (i.e., children and young people with epilepsies and their families) and it is accepted that this is, in some way, specialist practice (See Figure 1). However, this may not necessarily mean that PENS are engaging in an advanced level of practice.

Advanced practice is a 'level' of practice not a role or title (RCN, 2018). An advanced level of practice is characterised by a high degree of autonomy and complex decision-making, and encompasses all four pillars of clinical practice, leadership and management, education and research. It represents an ability to manage clinical care in partnership, address complex problems in a range of settings and enable innovative solutions to enhance patient experience and outcomes. Advanced level practice is delivered by experienced, skilled and highly educated practitioners, who demonstrate core capabilities and area-specific clinical competence (HEE, 2017).

Advanced level practice can therefore be viewed as a particular step on an entirely different novice–expert continuum. As the novice–expert continuum intersects with the specialist–generalist continuum, it therefore becomes possible to be practicing as a 'novice' specialist or an 'advanced' or 'expert' specialist (NES, 2021b). This is illustrated in Figure 1. Indeed, clinical nurse specialists and nurse consultants leading specialist services are examples of the many nursing roles that are developing at an advanced level (RCN, 2018). This enables PENS to retain a description of 'specialist' but opens up opportunities to describe competencies that are typical of a specialist working at a novice level, such as practitioner (level 5) of the Post-Registration Development Framework (NES, 2021b), as well as competencies that are typical of a specialist working at an expert level, for example advanced practitioner (level 7) (NES, 2021b). It is therefore useful to think of the benchmarks from the Post-Registration Development Framework (NES, 2021b) as steps along a novice–expert continuum.

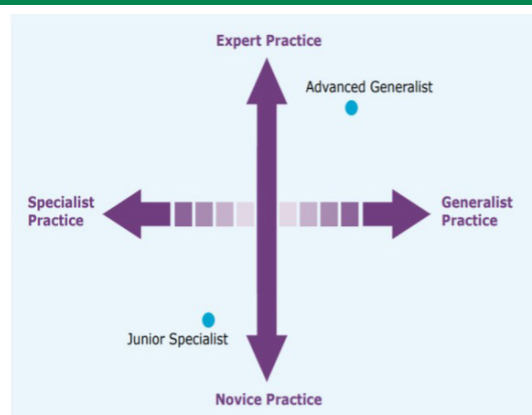**Figure 1: Relationship between specialist and advanced practice** (NES, 2021b)

Figure 1. Relationship between Specialist and Advanced Practice

Previous competency frameworks for adult epilepsy specialist nurses (ESNs) (ESNA, 2012) and ESNs working with people with a learning disability (ESNA, 2013) were influenced by Benner (1984), and both describe competencies at the level of a 'novice', 'competent' and 'expert' ESN. These frameworks are aligned with a level of practice approach and therefore, to promote shared understanding, collaboration around role preparation and/or evaluation, this competency framework for PENS also adopts such an approach and uses these labels (see Table 2). Benner's model of nursing competence is explained in more detail in **Appendix 3.**

Table 2: Levels of competency	
Novice nurse	Newly registered nurse, up to two years from taking post, or PENS nurses who wish to develop their epilepsy knowledge base, regardless of time post-registration
	Working at first-degree level
	Suggested Agenda for Change (AfC) level 6
Competent nurse	Qualified nurse who is developing expertise to use detailed theoretical and practical knowledge in the management of epilepsy for children and young people
	Working at first-degree level
	Suggested AfC level 6/7
Expert specialist nurse	Qualified nurse who has developed specialist psychosocial and clinical expertise to assess and manage epilepsy for children and young people
	Hold, or working towards, a master's degree
	Suggested AfC level 7 or above

3.3.3 Integrating levels and pillars of practice within the PENS competency framework

Combining a 'levels of practice' approach with the 'four pillars' of practice enables a career framework to emerge. PENS can readily see how and where the detail of their roles may cross-reference with current career frameworks and enable progression. Within each of the four pillars, it is possible then to describe the competencies that characterize the three levels of practice, ensuring that these reflect the benchmarks currently recommended (Skills for Health, 2010; NES, 2021b). Overviews of the three levels of practice are therefore described below and an overview provided in Table 3.

Table 3: Overview of levels of practice in PENS roles			
Level of PENS practice	**Novice**	**Competent**	**Expert**
Educational preparation and qualifications	Registered nurse Qualifications at diploma or degree level Working towards accredited qualifications and training related to childhood epilepsy	Registered nurse Qualifications at degree level Accredited qualifications and training related to childhood epilepsy Teaching and learning preparation (e.g., mentor preparation or equivalent) Non-medical prescribing qualification (dependent on role)	Registered nurse Qualifications at master's level Broad portfolio of accredited qualifications and training related to childhood epilepsy Teaching, learning and leadership preparation Non-medical prescribing qualification (dependent on role)
Suggested band **(Agenda for Change (NHS Employers, undated))**	6	6–7	7 and above
Post-Reg Development Framework **(NES, 2021b)**	Practitioner (level 5)	Senior practitioner (level 6)	Advanced practitioner* (level 7)
Possible job titles	• Associate nurse • Associate specialist nurse • Epilepsy link nurse • Staff nurse • Children's community nurse • School nurse • Learning disability nurse	• Clinical nurse specialist • Paediatric epilepsy nurse specialist	• Lead epilepsy nurse • Advanced nurse practitioner* • Nurse consultant *Meets advanced practice credentialing criteria (RCN, 2020) to use title

Novice' level of practice

In this competency framework for PENS, the 'novice' level of practice offers competencies that align with practitioner level (5) on the Post-Registration Development Framework (NES, 2021b). Practice at this level is typical of a registered nurse working in an epilepsy nursing service or in an associated service (e.g., community nursing team) who is keen to develop their practice in relation to epilepsy. This level of practice is dominated by competencies within the clinical pillar that enable the practitioner to meet a range of holistic needs in relation to epilepsy. However, it is unlikely that practice at this level would enable a role to function in the long term without the support of a 'competent' or senior practitioner, equivalent to level 6 in the Post-Registration Development Framework (NES, 2021b), in some way. Competencies within the education, research and leadership pillars at the 'novice' level are also framed in a way that indicates a role at this level would involve contributing to the outcomes of an epilepsy nursing service or clinical network rather than realising these as an individual practitioner. The competencies at this level serve as an entry point to a PENS role and could be useful to direct the initial orientation and development phase for a nurse newly appointed to a PENS role.

'Competent' level

The competencies at the 'competent' level are closely aligned with senior practitioner level (6) in the Post-Registration Development Framework (NES, 2021b) and reflect the expectations of a PENS role. This describes practice that is autonomous within the clinical pillar with a range of typical presentations, treatments, and psychosocial issues in the epilepsies, which enables a role at this level to stand alone within a clinical network (e.g., a PENS working with a paediatrician or in a tertiary specialist centre). However, the competency framework aims to permit fluidity and support professional learning and development. For example, a PENS may generally be working at 'competent' level but be new to a specific area of practice (e.g., providing an emergency telephone clinic) and therefore be working at the 'novice' level for that particular aspect of clinical practice while setting developmental objectives to become 'competent'. Although the clinical pillar is the mainstay of practice at the competent level, competencies within all four pillars are included to facilitate a future pathway to an advanced level of practice.

'Expert' level

It is recognised that advanced level practice requires capability across all four pillars of practice (RCN, 2018). The 'expert' PENS will therefore be educated to master's level and work autonomously to make sound clinical judgements where there is complex, competing, or ambiguous information and to manage varying levels of risk, holding accountability for decisions made (HEE, 2017; NES, 2021b). The clinical practice competencies expressed in this framework reflect this level of practice in the context of diagnosis, treatment, risk, and the psychosocial impact in childhood epilepsies as guided by contemporary clinical guidelines (NICE, 2022; SIGN, 2021). This framework also describes competencies for the 'expert' PENS to demonstrate leadership and innovation in service quality and development, research and education, and these mirror the expectations for this advanced level of practice expressed generically (e.g., HEE, 2017; NES, 2021b).

In summary, the competencies expressed in this document may benchmark what advanced practice looks like in epilepsy care. But this framework should not be used in isolation to develop PENS roles at this advanced level. In the UK, advanced level practice is not regulated by the Nursing and Midwifery Council (NMC), but its code of professional standards of practice and behaviour still applies to the scope of this practice (NMC, 2018a). The Royal College of Nursing (RCN) has a 'credentialing' system (RCN, 2020) for advanced practice nurses to log experience, competence and qualifications; however, responsibility for ensuring appropriate role development and regulation falls to employers and advanced practice level nurses themselves. PENS therefore need to work with their employer to develop effective systems of governance for this level of practice (RCN, 2018) and the clinical activities it includes (e.g., prescribing, (RPS, 2021)) along with appropriate education and development of the capabilities required regarding research, education and leadership. The Multi-Professional Framework for advanced clinical practice in England (HEE, 2017) sets out thorough guidance and resources in this regard.

3.4 The NHS Knowledge and Skills Framework (KSF)

The PENS competency framework is also designed to be used in conjunction with the NHS KSF dimensions, which provide a single, consistent, comprehensive and explicit framework on which to base review and development. This means every member of staff has the same opportunities for learning and development open to them while having the same structured approach to learning, development and review. The NHS KSF comprises six core dimensions and 24 specific dimensions that apply to some, but not all, roles within the NHS (Department of Health, 2004).

The following dimensions are relevant to the ESN role: health and wellbeing (HWB); information and knowledge (IK); and learning and development (G1) (see Table 4). The novice, competent and expert specialist nurse should be working towards, or already be working at, level 3/4 for all core and HWB dimensions, and level 2 for the IK and G1 dimensions.

Table 4: Core and specific dimensions of the KSF relating to the PENS competency framework	
Core dimensions	**Specific dimensions**
1. Communication 2. Personal and people development 3. Health, safety and security 4. Service improvement 5. Quality 6. Equality and diversity	1. HWB2 – assessment and care planning to meet health and wellbeing needs 2. HWB4 – enablement to address health and wellbeing needs 3. HWB6 – assessment and treatment planning 4. IK1 – information processing 5. G1 – learning and development

4.1 Using and reviewing the PENS competency framework

It is assumed that PENS working from novice nurse to expert specialist nurse should not only work on the competencies listed in their column but also fulfil the competencies in the level(s) below. Inevitably some competencies connect or overlap with others.

It is recommended that the PENS competency framework is reviewed between the individual PENS and their manager at least once annually to facilitate and ensure developmental planning and training. The authors suggest that the competency framework should be used more frequently for PENS new in post. Any variance in the role of the job as related to the competency set, for example significant strategic changes that may alter the services delivered, should flag the need for a review of the post.

4.2 The PENS competency framework

It is worth noting that the competencies outlined below continue to reflect the findings of both a 2011 Epilepsy Action survey and two more recent studies – SENsE (Higgins et al., 2018 and 2019) and ESPENTE (Campbell et al., 2019) – into what people with epilepsy and their families and carers value in an ESN, such as ongoing communication, support and information and a real understanding of epilepsy and its impacts.

Core KSF dimensions: 1, 2, 3, 4, 5

Specific KSF dimensions: HWB2; HWB4; HWB6

Pillars of practice: Clinical practice

Competency	Novice	Competent	Expert
A1 Understanding seizure types	Understand common seizure types (ILAE, 2022).	Understand seizure types in relation to developmental stage.	Understand seizure presentation in the context of etiology and comorbidities (e.g., movement disorders)
	Outline routine investigations and their role in diagnosing childhood epilepsies.	Discusses the role, benefits and risks of routine and some specialist investigations to support the child and family during diagnosis.	Considers appropriate routine and specialist investigations, interpreting findings, and identifying need for appropriate referral.
A2 Knowledge of epilepsy	Explain why diagnosis and assessment of childhood epilepsies can be complex and outline features of best practice in assessment.	Apply best practice in assessment and diagnosis of epilepsy (e.g., NG217 NICE 2022; SIGN 159, 2021) into own practice and support others to do the same using ILAE (2022) classification of seizures and epilepsies.	Active involvement in diagnostic decision-making with the child, young person, their family and the MDT and evaluate how nursing contribution to diagnosis influences outcomes.
	Understand how classification of epilepsies applies to a particular child or young person's diagnosis.	Use current classification schemes to accurately document epilepsies, and support others to understand the significance of this for the child/young person's outcome.	Apply classification in complex situations, recognise the limitations of the classification schemes and engage in constructive discussion with colleagues to enhance child and family experience of diagnostic process
	Outline the clinical presentation of common differential diagnoses at different stages of life (e.g., infancy, early childhood, adolescence).	Recognise the possibility of a differential diagnosis in a particular child or young person's history or presentation and communicate this appropriately to the MDT.	Interpret data from assessments and investigations to formulate an individualised strategy or onward referral for further assessment of a differential diagnosis.
	Demonstrate an understanding of epilepsy syndromes from birth to adolescence	Recognise the importance of making an accurate epilepsy syndrome diagnosis to inform prognosis and treatment choices.	Support and counsel CYP and their families in relation to the epilepsy syndrome diagnosis and actively instigate management/ treatment plans accordingly. Support families of CYP with life limiting epilepsies.
	Understand that epilepsy is not a single condition and has that it has various etiologies / comorbidities	Understand and recognise the key features and presentations of common epilepsies from birth through to adolescence	Integrate an in-depth understanding of the epilepsies, their etiology and prognosis into all aspects of clinical work.

Competency	Novice	Competent	Expert
A2 Knowledge of epilepsy (continued)	Understand the risk factors associated with epilepsy	Discuss the risk factors associated with epilepsy including SUDEP (Sudden unexplained death in epilepsy), prolonged seizures, heights and water safety etc. Support families to mitigate against the risks where possible.	Support and counsel the families of CYP with life limiting epilepsies and those at risk of sudden death due to etiology / epilepsy syndrome e.g., Dravet syndrome.
Evidence examples	• Can review patient record • Analyse seizure diary • Undertake some recognised training to support learning (i.e. PET1 and PET2) • Can produce patient-centred information • Understand and use ILAE classification for seizures	• Consult with other professionals and attend meetings • Can articulate clinical findings to children and families in a way they can understand • Produce accurate and up-to-date epilepsy management plans and ensure appropriate training needs are met • Can provide evidence of feedback from families and other professionals regarding professional competence • Able to present a case succinctly and factually, highlighting key areas for discussion by MDT	• Provide clinical supervision and support to team members • Undertake nurse triage clinic, request appropriate investigations and interpret findings • Recognise complicating factors in the assessment process and escalate appropriately
Further information	PET courses – https://courses.bpna.org.uk/index.php?page=paediatric-epilepsy-training		
A3 Assisting and supporting diagnosis	Explain and provide relevant literature and materials about the diagnostic process to children, young people and their families.	Sensitively manage child and family expectations and uncertainties during their diagnostic journey.	Use best practice guidelines to manage expectations and resolve uncertainties related to diagnosis among MDT.
	Use effective listening and communication to gather relevant clinical observations and complete relevant assessment tools.	Understand the elements of a holistic diagnostic history in childhood epilepsies and collate appropriate information.	Undertake more complex assessments when information is poorly differentiated.

Competency	Novice	Competent	Expert
A3 Assisting and supporting diagnosis (continued)	Share information with the senior team in a timely and accurate manner.	Accurately communicate the outcomes or impression from diagnostic process to the child and family and/or MDT.	Facilitate ongoing constructive dialogue with child, young person, family and MDT when diagnosis is complex.
	Provide child and family-focused appropriate procedural support and explanation for routine investigations.	Formulate and arrange child and family-focused procedural support in more complex situations.	Problem-solve in situations where investigations or procedural support raise legal, consent and/or ethical issues.
A3 Care planning, implementation and evaluation	Outline how health policy and local or national guidelines influence the content of an epilepsy care plan.	Manage the balance between policy and local or national guidelines on content of an epilepsy care plan and the needs of the child or young person, or the care setting.	Influence the health policy and local or national guidelines that shape the content of an epilepsy care plan.
A3.1 Using personalised care plans	Develop an epilepsy care plan in collaboration with the child, young person and family that includes information about seizure description, safe seizure management (first aid), management of emergency and record of seizures.	Work collaboratively to formulate comprehensive individualised care plans that reflect current need and highlight relevant management information (e.g., possible triggers, patterns for seizures), lifestyle advice, risk management and emergency management.	Lead on comprehensive care planning in complex situations (e.g., safeguarding, ethical issues).
			Review the overall quality and effectiveness of care-planning processes.
	Explain how child development (e.g., physical growth, emotional, social and cognitive milestones) may influence an epilepsy care plan and refer arising issues appropriately.	Adjust care and management plans appropriately, considering changes in development (e.g., physical growth, emotional, social or cognitive) and evaluate outcomes.	Develop care-planning templates and pathways that incorporate developmental transitions.
	Contribute to the multidisciplinary care of children and young people with complex epilepsies (e.g., life-shortening syndromes).	Contribute to the multidisciplinary care of children and young people with complex epilepsies (e.g., life-shortening syndromes).	Evaluate the effectiveness of care plans for complex epilepsy, exploring innovative ways of meeting arising needs with other partners (e.g.e.g., children's hospice).

Competency	Novice	Competent	Expert
A3 Care planning, implementation and evaluation (continued) A3.1 Using personalised care plans (continued)	Ensure children, young people and families understand when and how to contact the specialist nursing service.	Facilitate access to specialist nursing in an equitable, needs-led way for children, young people and their families.	Evaluate referral and access pathways to ensure routine and emergency needs are being met.
Evidence examples	• Risk and safety information given to children and young people and their families • Management and care plans for all children • Supports families and children in decision-making (feedback from families)	• Use of RCPCH Epilepsy12 standards/ national quality standards to improve epilepsy care • Appropriate assessment tools are used • Patient information and comprehensive care plans • Accurate documentation in patient records • Feedback from families e.g., use of patient satisfaction surveys	• Notes of case conference and MDT meetings • Guidance and supervision provided to junior team members • Documentation of interventions and assessments • Local pathways to meet local needs and resources (e.g., transition)
Further information		Epilepsy12 – https://www.rcpch.ac.uk/ work-we-do/clinical-audits/ epilepsy12/about	
A4 Medicine and other treatment management	Explain how seizure type and syndrome influence treatment choice and expected outcomes.	Use knowledge of classification of the epilepsies, treatment choices and expected outcomes when discussing treatment.	Use knowledge of classification of epilepsies, treatment choice and outcomes when decisions are complex or routine treatments have failed.
	Support children, young people and families with an individualised plan for managing triggers and lifestyle factors that may influence seizure control.	Work in partnership to negotiate an evidence-based plan for managing identified triggers and lifestyle factors to optimise seizure control.	Resolve issues of complexity in relation to non-pharmacological dimension of management plans to optimise seizure control.
	Take opportunities to promote health and wellbeing (e.g., sleep, healthy eating, exercise) and liaise with the national Healthy Child Programme.	Adjust health promotion advice to take account of epilepsy-specific influences (e.g., antiseizure medication, lifestyle advice).	Manage potential long-term influence of epilepsy and/ or treatment on health and wellbeing

Competency	Novice	Competent	Expert
A4 Medicine and other treatment management (continued)	Explain the purpose, action and intended outcomes of treatment to children/young people and families.	Implement treatment plans to facilitate concordance and self-management.	Manage situations where enhanced support to understand the rationale for treatment and achieve concordance is required.
	Assess effectiveness of treatment on seizure frequency and explore common side effects, reporting concerns to prescribing specialist.	Assess effectiveness of antiseizure medication on seizures and QoL, exploring side effects and interactions, and either adjust treatment within scope of management plan or refer concerns appropriately.	Critically evaluate effectiveness of treatment on a range of outcomes, working to recognise effects of polypharmacy, interactions and short- and long-term side effects.
	Will not be expected to work with treatment histories alone but can support the information-gathering process.	Collate current and previous treatment histories and reasons for discontinuation of antiseizure medication to screen for viable treatment options and refer appropriately	Interpret treatment histories to identify feasibility of alternative treatment options when treatment appears to have failed
	Support children, young people and families to manage the practicalities of taking regular medication (e.g., storage, dosing, formulation, missed doses, holidays)	Work with a child, young person and family to resolve practical problems with the antiseizure medication regimen for a child, young person and family (e.g., advising on dosing, appropriate formulation, generic prescribing).	Educate the wider MDT regarding formulations, generic prescribing and when to consider drug monitoring, and work in partnership to develop appropriate protocols.
	Promote understanding of antiseizure medication and the importance of taking it as prescribed.	Offers opportunities for children, young people and families to identify potential concerns or changing needs and to find an evidence-based solution.	Provide expert advice on management (e.g., concordance) and the relationship between epilepsies and other health conditions (e.g., sleep disorder, dysphagia) that may influence management outcomes.
	Understand that certain groups (e.g., disabled children, young people) may encounter special considerations in relation to their treatment.	Adjust treatment advice and support appropriately in relation to special situations (e.g., disabled children, contraception and pregnancy in young women).	Apply expert knowledge of the range of considerations that may apply to routine and complex treatments for epilepsy.

Competency	Novice	Competent	Expert
Further information	Healthy Child Programme https://www.gov.uk/government/publications/commissioning-of-public-health-services-for-children/health-visiting-and-school-nursing-service-delivery-model		
A4.1 Emergency medication	Work within local policies relevant to emergency medication.	Contribute to the evaluation and development of local policies for emergency medication.	Provide expert advice on research and guidance to lead the review and evaluation of policies for emergency medications across organisational boundaries (e.g., health, social, third sector and education services).
	Explain the principles (e.g., rationale, timing, modes of action, side effects) of commonly used emergency medications.	Understand the commonly used evidence-based emergency medication regimens, applying knowledge of their rationale, indication, efficacy and tolerability to practice.	Facilitate others to understand the full range of evidence-based emergency medication regimens to improve care and education.
	Identify situations when emergency medication may be indicated for a prolonged and clusters of seizures and refer for specialist advice.	Identify the need for emergency medication appropriately for a range of seizure types and formulate a rationale for a management plan.	Identify the need for emergency medication in complex situations and formulate a rationale for a management plan.
	Monitor the effectiveness of emergency medication for a child/young person during routine reviews, referring for specialist advice if appropriate.	Assist the prescriber in selecting an appropriate medication, formulate an appropriate management plan for a child/young person and review effectiveness as part of routine reviews.	Initiate prescribing of an appropriate medication and facilitate the appropriate management plan, evaluating effectiveness.
	Support families and other carers to understand the emergency medication management plan and provide relevant education.	Work in partnership with families, carers and other professionals to implement an emergency medication management plan.	Advise appropriately to resolve complex issues in the implementation and evaluation of an emergency medication management plan.

Competency	Novice	Competent	Expert
Evidence examples	• Completed care plans • Use of clinical guidance from NICE/SIGN • Provide practical training • Seek advice through supervision	• Produce complex epilepsy management plans • Assess effectiveness of emergency medication • Develop, deliver and evaluate epilepsy training programmes in accordance with best practice guidelines (ESNA, 2019; ESNA, 2021)	• Prescribe appropriate rescue medication for prolonged or clusters of seizures • Oversee emergency plans and review in a timely manner • Audit to enable quality assurance of emergency management plans and training
A5 Epilepsy surgery and VNS	Understand the indications for epilepsy surgery and the process of surgical evaluation.	Use clinical guidelines to discuss the possibility of epilepsy surgery and liaise with MDT during the surgical evaluation process.	Identify potential surgical candidates and coordinate appropriate referrals for surgical evaluation within the network.
		Work in partnership with child, young person and family and MDT to explain the investigations, rationale and outcomes of the surgical evaluation process.	Respond with advanced support and interventions for more complex problems that arise in the surgical evaluation process.
		Ensure timely and appropriate reviews of holistic outcomes from epilepsy surgery, providing education and support with relevant devices.	Evaluate long-term outcome of epilepsy surgery in a range of physical and psychosocial domains, planning care and onward referral appropriately.
		Identify children and young people for consideration of antiseizure medication withdrawal and refer appropriately, supporting and monitoring the plan devised.	Initiate relevant investigations and discussion about appropriate antiseizure medication withdrawal and negotiate an appropriate plan.
	Understand the indications for other treatments should epilepsy surgery not be appropriate.	Use clinical guidelines to discuss the possibility of other epilepsy treatments such as the ketogenic diet (in liaison with specialist dieticians) and vagus nerve stimulation (VNS).	Identify appropriate children and young people to refer for treatments such as the ketogenic diet and VNS.
		Work in partnership with child, young person and family and MDT to explain the investigations, rationale and outcomes of the use of the ketogenic diet and VNS.	Respond with advanced support and interventions for more complex problems that arise in the use of the ketogenic diet and VNS.

Competency	Novice	Competent	Expert
A5 Epilepsy surgery and VNS (continued)		Ensure timely and appropriate reviews of holistic outcomes of the use of the ketogenic diet and VNS, providing education and support and adjustment of relevant devices.	Evaluate long-term outcome of the use of the ketogenic diet and VNS in a range of physical and psychosocial domains, planning care and onward referral appropriately.
Evidence examples	• Understand NICE and SIGN guidance regarding treatment choices • Recognise side effect profiles of drugs and other treatments • Collate seizure diary with drug or treatment changes • Aware of medication risks in certain groups of children	• Ensure medications/ treatments are evaluated effectively • Document and share information in a timely and accurate manner • Share information within clinical governance frameworks • Assess risks associated with medication withdrawal and discuss with families • Non-medical prescriber qualification	• Non-medical prescriber qualification • In-depth knowledge of drug metabolism and associated risks • Apply appropriate guidance when a CESS/ SPESS referral might be needed, and discuss with families • Provide regular nurse-led independent reviews of children and young people
Further information			CESS https://www.england.nhs.uk/publication/childrens-epilepsy-surgery-service-cess/ SPESS https://children.nhslothian.scot/departments-services/?_sft_category=epilepsy-surgery

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB2; HWB4; HWB6

Pillars of practice: Clinical practice

Competency	Novice	Competent	Expert
B1 Understanding patient needs	Outline common risks associated with the epilepsies and seizures and the potential impact on quality of life.	Conduct and document discussions about risks associated with epilepsies with children, young people, and families (e.g., SUDEP, water safety, heights and treatment risks as per NICE guidelines) while promoting the development of independence.	Use in-depth understanding of current research about risks (e.g., SUDEP) associated with epilepsies as a resource for the MDT.
	Understand that some groups of children and young people with epilepsies have elevated risks of SUDEP (NICE, 2022; SIGN, 2021) and be able to provide appropriate general information	Integrate consideration and discussion about SUDEP risk and interventions (NICE, 2022) into all aspects of clinical work on an ongoing basis.	Evaluate the effectiveness of nursing practice and service provision in responding to needs of children and young people at risk of SUDEP.
	Collate data to support a specific risk assessment and work collaboratively with families to implement agreed risk control measures.	Select appropriate risk assessments (identification methods and assessment strategies, including checklists and recording charts) and formulate risk-control measures).	Complete risk assessments and formulate effective response in complex situations, sharing outcomes of assessments with the MDT.
	Identify risks that may need further intervention, seeking timely support and supervision.	Advise on environmental risks and work with MDT regarding safety adjustments, equipment and seizure alert technology	Advise the MDT or specialist funding panels on relevant technology.
	Recognise vulnerable children and those at risk of harm, making a safeguarding referral when appropriate.	Make safeguarding referrals in line with statutory guidance and work with safeguarding team to ensure correct pathways followed.	Work with other agencies to offer expert knowledge regarding the epilepsies relevant to safeguarding referrals.

Competency	Novice	Competent	Expert
Evidence examples	• Produce or inform risk assessment and risk management documents • Confirmation regarding safeguarding training • QoL management plan • Completed referral forms	• Review of clinical papers • Evidence of complex risk assessment • Evidence of referrals/request for aids and equipment • Minutes of risk strategy meeting	• Evidence of policy development • Prescribing records • Clinical management notes • Evidence of clinics
B2 Using risk assessment tools	Use appropriate assessment tools (e.g., history taking, diaries, seizure description pro formas) to gather information about seizure description, type, classification, frequency, severity (duration, pre- and post-ictal) pattern, triggers and consequences (e.g., injuries), and collate this coherently.	Understand the range of assessment tools and history-taking techniques, select relevant tools for the type of information required and collate a holistic assessment of seizures.	Devise or request specific assessment tools or further investigations to obtain information to holistically assess a more complex clinical presentation of seizures.
Evidence examples	• Seizure diary with changing factors i.e., illness or medication changes		
B3 Controlling seizures	Understand current approaches to classifying seizures and how these apply to a particular child or young person's seizures.	Use current classification schemes to accurately document and classify common patterns of seizure semiology.	Use current classification schemes to accurately document and classify complex seizure semiology, recognizing limitations of classification schemes, and engage in constructive discussion with colleagues.
	Explain the functioning of the brain and central nervous system and how this relates to the presentation of focal and generalised seizure types.	Have a working knowledge of seizure types in ILAE classification and their presentation in different age groups and understand their relationship with epilepsy syndrome and prognosis.	Work expertly with seizure classification in relation to classification of syndrome and underlying aetiology and prognosis, and support others to understand these relationships.

Competency	Novice	Competent	Expert
B3 Controlling seizures (continued)	Apply communication skills safely to assess seizures and collate relevant information in a variety of planned situations (e.g., by telephone or in clinic).	Use a range of communication techniques to assess seizures in planned and unplanned situations, deciding when to use telephone or clinic consultation appropriately.	Confidently manage complex consultations that are unexpected and/or distraught to assess and plan care.
	Identify situations where assessment is challenging and seek support.	Work responsively in situations where information is being collected from a third party (or by proxy).	Manage assessment situations where information is incomplete or difficult to obtain.
	Monitor the management of seizures through planned reviews, documenting and communicating outcomes.	Promote continuity of care through regular reviews, selecting and carrying out appropriate mode (e.g., home visits, structured clinic) and interval, and then disseminating review outcomes appropriately.	Work autonomously in a variety of modes of ongoing review and/ or identify the most appropriate clinician for the child/young person's ongoing management.
	Understand the factors that exacerbate seizure frequency and recognise when a child or young person's seizure control may be deteriorating, making a timely referral to more specialist colleagues.	Accurately identify deterioration in seizure control, explore relevant causes and make appropriate adjustments to management plans and review intervals.	Formulate ongoing clinical questions about diagnosis, classification and treatment, and lead multidisciplinary review to ensure that seizure control is optimised.
Evidence examples	• Provide timely patient updates as requested by the team • Recognise the need to seek further advice if seizures worsen • Gather information from outside agencies with consent from parents/carers	• Structured approach to consultation • Regular clinical supervision and work with a team to provide optimum care and treatment choices • Recognise and act on worsening seizure control or adverse medication side effects	• Plan complex treatment regimens and evaluate their clinical effectiveness • Work independently in the clinical setting • Support families and CYP with complex decision-making • Able to analyse and audit databases for service development and quality improvement initiatives

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB2; HWB4; HWB6

Pillars of practice: Clinical practice; facilitation of learning

Competency	Novice	Competent	Expert
C1 Understanding the psychosocial impact of epilepsy on children and young people and their families	Understand that seizure freedom is not always achievable and describe the potential psychosocial impact of epilepsies on the child and family at different stages of development.	Understand and apply evidence-based tools and discussion to assess the impact of epilepsies (e.g., seizure frequency and severity and effects of treatment) on a child's psychosocial and emotional wellbeing at different stages of development.	Understand the specific psychosocial implications of a range of epilepsies and be responsive to changing psychosocial needs either through epilepsy or developmental trajectory.
	Recognise how equality, diversity and cultural issues may impact on child and family's experience of epilepsies.	Provide equitable, culturally competent nursing, seeking advice when necessary.	Evaluate and work to achieve a balance between equality, diversity and cultural beliefs and responses to diagnosis, treatment, early intervention and support.
	Empathise with the range of emotional responses the child, young person and family may have to a diagnosis of epilepsy.	Manage the range of emotional responses to a diagnosis of epilepsy with appropriate child and family interventions.	Provide advanced interventions with relevant therapeutic colleagues where child and family adjustment to diagnosis is complex.
	Work in partnership with children, young people and their families to implement interventions that promote QoL.	Implement a range of evidence-based interventions to promote QoL.	Facilitate programmes of psychosocial interventions within a service and critically evaluate their effectiveness.
	Using relevant guidelines ((NICE, 2022, SIGN, 2021) Identify signs that indicate children and families may require additional psychosocial or mental health support and seek advice appropriately.	Formulate appropriate referrals for increased support when more complex psychosocial needs or mental health needs are emerging.	Work collaboratively with social, psychology and mental health colleagues to share expert knowledge of the epilepsies to develop practice.

Competency	Novice	Competent	Expert
C2 Understanding the potential cognitive impact of epilepsy on children and young people	Recognise that the child and family may have differing aspirations and support them to make aspirations achievable.	Work with children and young people and their families to identify their aspirations and facilitate appropriate strategies to meet these.	Create frameworks/ policies to ensure that children and young people can meet their aspirations.
	Have a basic understanding of the differing cognitive impairments and support the child and family to get the most appropriate support.	Recognise common patterns of cognitive impairment and potential impact on learning and educational achievement and contribute to Educational Health Care Plans as required.	Work collaboratively with educational psychology/ neuropsychology colleagues to provide specialist knowledge of cognitive impairment and intervention strategies to ensure legal frameworks around education and support are implemented.
	Help gather supporting information from the child's wider network to aid a more formal assessment.	Identify the need for screening or formal cognitive assessment appropriately and liaise with the MDT to implement management plans.	Use expert knowledge on epilepsy, aetiology and treatment to contextualise significance of cognitive assessment recommendations and contribute to the planning of onward management.
C3 Understanding the psychiatric comorbidities in Children and Young People with epilepsy	Be aware of the increased rates of anxiety and depression in people with epilepsy (CYPWE) and routinely enquire about depression and anxiety symptoms	Use available validated screening tools to identify CYPWE at risk of psychiatric comorbidities.	Develop referral pathways for CYPWE and psychiatric comorbidities.
	Be aware that the symptoms of anxiety and depression can differ in CYPWE.	Develop collaborative working relationships with psychological and psychiatric services.	Audit services for CYPWE and psychiatric comorbidities.
	Acknowledge the need to refer patients onward for appropriate support.	Ensure strong advocacy for patients with epilepsy and psychiatric comorbidities.	Enhance and work collaboratively to develop services that are responsive to CYPWE with psychiatric comorbidities.

Competency	Novice	Competent	Expert
C4 Understanding of the developmental disorders associated with epilepsy in children and Young People	Understand that the prevalence of neurodevelopment disorders are higher in children and adolescents with epilepsy.	Understand the mechanisms which explain the high rates of comorbidity between epilepsy and neurodevelopmental disorders (Autistic Spectrum disorder, Attention Deficit Hyperactivity disorder and intellectual disability.	Understand the differentiation of early onset epileptic seizures on brain development and underlying pathology or a genetic condition
	Be aware of the features of neurodevelopmental disorders	Inform assessments within the multidisciplinary team. Use knowledge to support families, schools and social care organisations supporting CYPWE and associated neurodevelopmental disorders.	Audit / evaluate care pathways for children and young people with neurodevelopmental disorders and epilepsy.
Evidence examples	• Completed appropriate screening tools • Patient-centred care planning/signposting/ self-help counselling	• Referrals to MDT meeting • Referral to CAMHS • Referrals to Educational Psychology • Evidence of regular review and evaluation	• Evidence of creating individualised care plans • Evidence of making reasonable adjustments • Referrals to Neuropsychology

Core KSF dimensions: 1, 2, 3, 4, 5

Specific KSF dimensions: G1

Pillars of practice: Facilitation of learning; leadership and management

Competency	Novice	Competent	Expert
D1 Time and workload management	Demonstrate a professional approach to practice through sound diary planning.	Understand and apply the dynamic process of goal setting to manage workload in practice.	Manage a team and/ or portfolio of complex responsibilities to ensure outcomes are effective.
	Accurately and promptly input workload/activity data into relevant systems.	Measure and adjust capacity for workload based on available activity data.	Interpret available activity data to ensure appropriate nurse– caseload ratio and develop service capacity.
	Understand and use databases to keep records of patient information and outcomes.	Initiate database development to enhance records of patient information and outcomes.	Evaluate the contribution of databases in providing data for service delivery or audit and research.
	Understand how a variety of nurse-led clinics operate and contribute to their delivery.	Operationally manage a variety of nurse-led clinics to ensure quality in delivery.	Lead and develop a variety of nurse-led clinics, reviewing quality and clinical and financial outcomes.
	Understand the role of telephone consultations in assessing, planning, implementing and evaluating care, and undertake planned telephone consultations.	Manage a range of planned, unplanned, and urgent telephone consultations to respond to changing patient needs.	Evaluate quality and effectiveness of telephone consultations and review models of delivery, provide supervision and support staff in complex situations.
	Prioritise work to make the most effective use of time and resources by considering priorities, clinical urgency and professional responsibilities.	Respond effectively to unplanned or clinically urgent workload and changing service needs within scope of practice, supporting others where applicable.	Pre-emptively manage resources and service capacity within constraints to meet changing service needs.
	Seek support and guidance appropriately when experiencing workload pressures.	Provide support to others to ensure patient safety when experiencing workload pressures, escalating concerns as appropriate.	Respond to workload pressures with innovation and change to ensure clinical governance.

Competency	Novice	Competent	Expert
Evidence examples	• Diary log • Work log/workload tool • Clinical supervision	• Review of database • Annual report outlining service demands • Critical incident reviews	• Business plans/cases • Evidence of team building • Clinical and peer supervision • Case study review
D2 Recognising professional and personal development needs	Identify learning goals through critical reflection on practice and formulate a personal development review (PDR) with manager, seeking appropriate learning opportunities.	Formulate learning goals through critical reflection on practice and evaluate the effectiveness of learning opportunities in meeting those learning goals, and support others with this process.	Formulate learning goals in a self-directed way to advance knowledge and practice, critically evaluating the impact of advanced learning on practice.
	Recognise the value of supervision and establish effective working relationships and engagement with an appropriate supervisor.	Seek own supervision, and provide this for a range of colleagues, identifying and resolving any conflicts of interest.	Evaluate outcomes from supervision systems and work collegially across teams and networks to provide mutual support and coaching among experienced colleagues.
Evidence examples	• PDR • Diary/contact sheets/PDP • Demonstrate evidence of working towards a qualification in epilepsy or the neurosciences at NVQ level 4 or above	• Evidence to support level of practice as 'competent' from professional coaching or supervision • Reflect on goals set and outcomes • Evidence of participation in relevant local and national networks describing benefits to care and service provision • Demonstrate evidence of academic progression working towards clinically appropriate qualification	• Evidence to support level of practice as 'expert', from professional supervision or coaching • Evidence of strategic leadership in the development of epilepsy nursing services • Evidence of leadership and participation at local and national level • Demonstrate evidence of academic progression, working towards MSc or PhD in a relevant subject area

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB2; HWB4; HWB6; IK1; G1

Pillars of practice: Leadership and management

Competency	Novice	Competent	Expert
E1 Being part of a multidisciplinary team	Understand how own role and roles within MDT impact on outcomes for children and young people with epilepsy and their families.	Promote and develop the role of the PENS as a key member of the MDT.	Advance the role of the PENS across a range of contexts through leadership and innovation.
E2 Professional networking	Establish relationships with other professionals that promote partnership working to enhance the management of epilepsy.	Develop interprofessional relationships that contribute to a seamless provision of care for a child/young person.	Facilitate collaborative ethical practice among the MDT to advance partnership working.
	Identify opportunities for effective networking and show understanding of how these may influence epilepsy care.	Maximise effective networking across health, social care, education and voluntary settings to influence outcomes for children and young people with epilepsy and their families.	Create sustainable professional networks in relation to policy, quality improvement, education and research at a national and/ or international level to influence epilepsy outcomes.
E3 Integration and development of services	Use established systems (e.g., patient satisfaction surveys, practice reflection, supervision) to explore patient experience of services and communicate this appropriately.	Work confidently with established systems to enable children and young people with epilepsy to evaluate their experience of services and interpret the outcomes.	Use evidence from patient experience of service to inform service strategy and evaluate the impact of recognising patient experience at a strategic level.
		Critically reflect on how service provision (e.g. health, social and voluntary sectors) and models of care benefit outcomes for children and young people with epilepsy and contribute ideas for improvement.	Critically evaluate policy, strategy and legislative changes in both wider health or social care context and specialist community to generate ideas for change and innovation.

Competency	Novice	Competent	Expert
E3 Integration and development of services (continued)		Understand how services are commissioned and shape local service priorities and the parameters for evaluation.	Influence commissioning of services (e.g., statutory and voluntary sector) and policy at local and national level and shape the parameters for evaluation.
	Work within existing partnerships between health, social, voluntary and independent sectors to foster a sense of mutual trust and respect.	Establish and further develop partnerships between health, social, voluntary and independent sectors that support review and evaluation of service quality.	Seek new and innovative partnerships to address limitations in service quality and enhance provision of care for children and young people with epilepsy and their families.
	Recognise the role children, young people and their families can play in the development of epilepsy services.	Encourage and signpost opportunities for children, young people and their families to participate in service development.	Facilitate an ethical framework for children, young people and their families to participate in service development.
	Work collaboratively with a service improvement plan, contributing to specific aims and objectives and evaluating progress.	Take responsibility for developing and implementing a service improvement plan within a team, evaluating outcomes and reporting challenges.	Lead innovation, policy and service development across MDTs and organisational boundaries.
Evidence examples	• Demonstrate links with other departments and providers of services • Appraisal with other team members and services	• Provide evidence of advocacy through meetings and referrals • Evidence of service development • Evidence of the delivery of different models of care	• Business plans • Minutes of meetings with action points • Policy and protocol development • Development of new care pathways or shared care guidelines

Competency	Novice	Competent	Expert
E4 Negotiation, influencing and leading innovation	Use a range of communication skills to foster a child-centred philosophy of care.	Use a wide range of therapeutic communication strategies to respond to challenges in child-centred philosophies of care.	Create and sustain a values-based approach to child-centred philosophies of care so that therapeutic relationships can thrive.
	Work in partnership with children and young people with epilepsy and their families and understand the nurse's role in advocacy.	Advocate for the needs of children and young people with epilepsy and their families at unit, team and local level.	Advocate for the needs of children and young people with epilepsy and their families at a strategic level (e.g., trust, clinical commissioning group, health board).
Evidence examples	• Feedback from patients • Evaluation of service • Development of a network contact list • Documentation of minutes from networking groups	• Minutes of meetings with action points • Patient forums • Patient satisfaction surveys from user groups • Development of service to meet ongoing needs • Expert patient reviews • Linking with local charities/support groups	• Minutes of meetings including evidence of patient/public involvement • Evidence of the development of epilepsy services • Research articles • Evidence of development of networks • Terms of reference and membership lists for new networking groups • Evidence that the views of patients have been listened to and acted on

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB4; G1

Pillars of practice: Facilitation of learning

Competency	Novice	Competent	Expert
F1 Teaching patients and their families/carers about epilepsy	Use opportunities for educating children and young people about routine aspects of epilepsy.	Use a range of opportunities (e.g., clinic, home visits, school meetings) to educate children, young people and their families about the epilepsies.	Create opportunities at different stages of the epilepsy pathway to educate children, young people and their families, and evaluate outcomes.
	Understand the concepts of empowerment and self-management and work to encourage responsibility for health and wellbeing.	Apply the concepts of empowerment and provide evidence-based self-management support to children, young people and their families.	Lead the MDT to create a culture of empowerment and realise opportunities for children, young people and families to self-manage.
	Support children, young people and their families with information, education or strategies to achieve a self-management goal (e.g. taking medication, sleep, first aid).	Work with children, young people and their families to formulate self-management goals and evidence-based plans of information, education and support to achieve these.	Challenge practices within the MDT that create dependency and renegotiate plans of care appropriately to support self-management.
	Explain how child development influences learning and identify potential barriers to learning (e.g., disability, language, culture) for children, young people and families.	Create an ongoing learning relationship with children, young people and families, working in a developmentally appropriate way to minimise barriers to learning.	Develop and evaluate partnerships and/or innovative resources that minimise potential barriers to learning and promote developmentally appropriate patient education.
	Outline the rationale and underpinning evidence base for routine education about epilepsies (e.g., NICE epilepsy checklists).	Apply knowledge of syndrome, aetiology, prognosis and risks of epilepsies to support children, young people and their families to understand their epilepsy.	Manage child and family understanding of the epilepsies where there is limited classification information and the clinical picture is complex.

Competency	Novice	Competent	Expert
F1 Teaching patients and their families/carers about epilepsy (continued)	Work with an agreed strategy to meet the routine psycho-educational needs of children, young people and their families at new diagnosis or during ongoing review.	Apply and evaluate a wide range of age-appropriate methods and resources to meet the psycho-educational needs of children, young people and families at all stages of the epilepsy care pathway.	Formulate evidence-based and innovative methods/resources to enhance psycho-education for children and families at all stages of the care pathway.
	Recognise the role of the family network in supporting the child/young person's understanding of their epilepsy and be alert to challenges (e.g., stigma coaching) and children's needs.	Work with the family network to strengthen their role in supporting an understanding of the child's epilepsy, exploring and seeking to resolve challenges and achieve a child-centred approach.	Work with more complex family dynamics around understanding of epilepsy, engaging with specialist colleagues to facilitate a child-centred approach.
Evidence examples	- Observed clinical reviews and teaching - Diary of teaching opportunities - Case studies - Patient/supervisor feedback	- Evidence of evaluation of teaching - Documentation of information giving - Patient/supervisor feedback	- Evidence that a high quality of training is delivered by all members of the epilepsy nursing team - Discussion of the use and limitations of different teaching tools - Evidence of the use of up-to-date educational materials and a wide variety of information materials
F2 Sharing knowledge and skills with MDT members and other colleagues	Contribute to the team learning culture by demonstrating positive learning behaviours and values.	Understand the relationship between a learning culture and effective specialist nursing for children and young people with epilepsy, and role model appropriate behaviours and values.	Create and sustain an effective learning culture within teams and wider professional networks.
	Share knowledge with nursing colleagues and provide mutual peer support.	Share knowledge, clinical expertise and best practice with other professionals in the MDT or professional network.	Develop knowledge, clinical expertise and best practice with professionals at regional, national and international levels.

Competency	Novice	Competent	Expert
F3 Developing, facilitating and evaluating educational programmes	Use relevant communication approaches to create learning experiences in daily practice.	Apply educational theory to facilitate learning through structured educational activities (e.g., education sessions, training programmes).	Evaluate the application of educational theory across the service or clinical network as a whole.
	Recognise the value of networking for sharing knowledge and best practice and seek networking opportunities relevant to own role.	Actively participate in local, regional and national specialist networks to share knowledge and best practice.	Advance knowledge and best practice in specialist networks nationally and internationally (e.g., speaking at conferences, writing for publication).
	Understand the relevant evidence that underpins content of epilepsy education sessions or training programmes.	Use research findings and literature to revise and develop evidence-based content for epilepsy education sessions or training programmes.	Identify the learning needs of the wider MDT and designs appropriate educational activities.
			Contribute curriculum content and/or exemplars for a range of accredited programmes of study.
	Participate in delivering epilepsy education sessions or training programmes for professional and non-professional groups.	Independently deliver epilepsy education sessions or training programmes in a variety of settings (e.g., health professionals, schools, social care, voluntary sector).	Use regional and national forums to deliver epilepsy education to a wider group of professionals.
	Support the provision of emergency medication training programmes to parents, carers and other professionals within best practice guidelines (ESNA, 2019; ESNA, 2021).	Independently deliver emergency medication training programmes to parents, carers and other professionals within best practice guidelines (ESNA, 2019; ESNA, 2021).	Ensure emergency medication training programmes are benchmarked and provide quality outcomes.
		Use a range of evaluation tools and analyses effectiveness of structured educational activities in promoting learning.	Interpret evaluation data over time to predict learning needs, redesign programmes and monitor overall quality of educational activities.

Competency	Novice	Competent	Expert
F3 Developing, facilitating and evaluating educational programmes (continued)	Supervise pre-registration learners in practice in accordance with NMC Standards for education (NMC, 2018c; NMC, 2018d).	Contribute to the assessment of pre-registration learners in practice (NMC, 2018c; NMC 2018d), acting as link for quality assurance of the practice learning environment.	Deliver theoretical teaching sessions in pre- and post-registration programmes.
Evidence examples	• Participate in teaching sessions • Participation feedback • Reflective diary of teaching opportunities • Review of evaluation sheets • Student evaluation • Read articles from relevant journals for CPD	• Assessment of learning outcomes for trainer and trainee • Feedback from MDT • Evidence of aims and objectives of training sessions • Review of training evaluation forms • Evidence and review training, and produce new material as required	• Demonstrate links to higher education institutions • Submit and review articles for publication • Appraisal • Feedback from the MDT • Evidence of development and assessment of educational programmes delivered at local and national level

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB2; HWB6; IK1; G1

Pillars of practice: Evidence, research and development

Competency	Novice	Competent	Expert
G1 Using research/ evidence in practice	Describe the process of evidence-based practice and seek to identify how current clinical practice is underpinned by research evidence and clinical guidelines.	Identify how current clinical practice is underpinned by research evidence and clinical guidelines and discuss this with colleagues and children, young people and their families.	Create structures and practice within teams (e.g., case supervision, networks, projects) that enable research evidence and clinical guidelines to be used in clinical practice.
	Conduct searches in relevant information databases and identify the types of information sources retrieved and their relevance for clinical practice.	Critically appraise sources of information and use research findings to support clinical decision-making in practice, identifying areas of tension between research evidence, patient preference, resources or ethical issues.	Facilitate supervision and support for others when the use of research findings for clinical decision making is more complex.
		Critically appraise research findings that have relevance for service provision and ways of working and generate evidence-based ideas for role and service development locally.	Evaluate the contribution of research findings for guidelines, policy and/or role and service developments, and contribute this at a regional and national level.
		Disseminate own understanding of research findings (from searching literature, reading, attending conferences, epilepsy network meetings) to colleagues.	Use a range of platforms (e.g., network meetings, conferences, publications) to disseminate own understanding of research findings on a range of issues relevant to epilepsy care.

Competency	Novice	Competent	Expert
Evidence examples	• Demonstrate search skills by completing a literature search and through discussion/ list of resources used • Provide explanations of what is meant by evidence-based practice	• Critical appraisal of publications e.g., read an epilepsy journal monthly or participate in journal clubs • Evidence that research is used to improve patient care	• Abstract/poster and platform presentations • Evidence of service development • Publications • Critically evaluate research papers • Evidence of research use in service delivery and development • Contribution to guidelines surrounding epilepsy care
G2 Critical appraisal of practice	Reflect on own clinical practice and seek support to identify areas of uncertainty and ask critical questions.	Critically reflect on own clinical practice and formulate an answerable question aimed at resolving an area of uncertainty.	Facilitate critical reflection for others and apply expert knowledge to refine answerable questions.
G3 Clinical trials	Explain the methodology and potential impact of a clinical trial on outcomes for childhood epilepsies and collect relevant data accurately.	Discuss with children, young people and families the purpose of a clinical trial, the recruitment criteria and study protocol, and collect data accurately, highlighting adverse events.	Coordinate a clinical trial ensuring best practice guidelines are upheld, acting as study site coordinator.
Evidence examples		• Actively recruit patients for clinical trial	• Evidence of working within clinical trial protocol
G4 Carrying out research	Explain the aim and purpose of epilepsy research being carried out in the local area.	Contribute to the design and practical implementation of local/ regional MDT epilepsy research projects.	Formulate research questions and lead research design, data collection, evaluation and dissemination of findings.
	Understand the requirements of consent and fundamental ethical considerations for research with children and young people.	Understand the ethical implications in relation to research with children and young people.	Demonstrate an in-depth knowledge of the ethical implications of research and apply the ethical approval pathway.

Competency	Novice	Competent	Expert
Evidence examples	• Knowledge of protocols and contacts for local/ regional MDT epilepsy research groups • Knowledge of patients recruited to projects	• Participate in MDT epilepsy research projects • Attendance at research planning meetings	• Abstract/poster and platform presentations • Research proposals and grant applications • Publication and presentation of research projects • Participation in multi-centre research • Evidence of presenting at local or national conference or workshop
G5 Carrying out audit and service evaluation	Explain how audit, service evaluation and research contribute to clinical governance.	Apply knowledge of the difference between audit, service evaluation and research when working within a clinical governance framework.	Evaluate how audit, service evaluation and research projects contribute to realising the clinical governance agenda.
	Explain how the audit cycle contributes to ensuring and monitoring the quality of care.	Identify and coordinate appropriate audits that can monitor the quality of care and key outcomes in childhood epilepsies.	Devise and coordinate a programme of audit for a defined service and/ or contribute to multi-centre audit studies that monitor quality of care and key outcomes in childhood epilepsies across regional or national networks.
	Collect relevant data accurately for an agreed audit.	Develop and/or use a wide range of audit tools to collate data, benchmark findings and then present these in an appropriate format to make recommendations for practice.	Interpret and evaluate audit findings in the context of organisational, epilepsy network and patient experience agendas to prioritise recommendations for practice.
	Understand the implications of audit recommendations for own practice.	Facilitate a team approach to understanding and acting on audit recommendations.	Use audit recommendations at directorate or organisational level to negotiate improvements and/or promote service quality.

Competency	Novice	Competent	Expert
Evidence examples	• Discussion with mentor • Identify appropriate areas for audit • Evidence of agreed audit plan	• Audit of data for own service • Annual report and review of service • Evidence of patient satisfaction audit • Production of application forms for local/regional audit committee • Review of audit findings and evidence of implementation of recommendations	• Evidence of service development

Core KSF dimensions: 1, 2, 3, 4, 5, 6

Specific KSF dimensions: HWB2; HWB4; HWB6

Pillars of practice: Clinical practice

Competency	Novice	Competent	Expert
H1 Girls and Young women with epilepsy	Understands the importance of correct ASM choice in the context of age and epilepsy type	Works collaboratively with girls, young women and their families to make appropriate ASMs choices (NICE, 2022; Shakespeare & Sisodiya, 2020)	Sensitively discuss available data surrounding risks of epilepsy treatment on the developing foetus and women's health. Be aware of the limitations in teratogenic data for all ASMs and be able to discuss confidently
	Be familiar with restrictions in use of sodium valproate in WWE of childbearing age.	Discuss specific teratogenic of Sodium Valproate and options for alternative treatment. Discuss valproate pregnancy prevention programme and completion of ARAF and databases (MHRA, 2019).	Develop shared care agreement/database and standard operating procedure (SOP) for prescription of valproate.
	Be aware of the issues of hormones, menstrual health and contraception for young women with epilepsy and signpost to local sexual health services.	Be able to discuss available contraceptive options for young women taking ASMs taking account need for privacy and developing independence	Be able to advise young women and the MDT on hormones, menstrual health and appropriate and effective contraception for young women taking different ASMs.
	Understand the importance of planning pregnancy	Discuss the risks of unplanned pregnancy in the context of epilepsy and its treatment.	Sensitively support a young women with an un-planned pregnancy and liaise effectively with specialist services to formulate and implement a comprehensive care plan

Competency	Novice	Competent	Expert
Evidence examples	• Telephone log • Patient satisfaction surveys • Discussion with mentor • Documentation	• Testimony from Young woman • Case study review • Evidence of reflective practice • Discussion with mentor • Annual risk acknowledgment forms (ARAFs) • Case record review	• Discussion with mentor regarding critical incident review • Existence of joint epilepsy and obstetric clinics • Evidence of input/ development to local/national guidance and protocols
Further information		ARAF template https://assets.publishing. service.gov.uk/ media/5cac898eed915d 5d7318b646/Risk- acknowledgment.pdf	
H2 Boys & young men with epilepsy	Be aware of the impact of epilepsy and ASM's on boys & young men across the lifespan. Be aware of the specific risks associated with sodium valproate for men Be familiar with the current MHRA recommendations for the prescribing of sodium valproate in men aged under the age of 55 years MHRA (2023).	Be able to discuss the issues faced by young men across the lifespan of their epilepsy including parenting, libido, sexuality, contraception, fertility and bone health. Be able to discuss the current issues relating to men across the lifespan of their epilepsy and discuss ASM options for boys & young men in line with recent guidance MHRA (2023). Be able to discuss ASM options for boys & young men and be aware of the requirements for prescribing sodium valproate in men under 55.	Be able to discuss with boys & young men the current data on sodium valproate use in men and the potential impact on fertility in line with current MHRA (2023) advice. Lead on a robust and responsive pathway for decision-making for boys & young men with epilepsy considering the current MHRA (2023) guidance about ASMs in men under the age of 55 Ensure that boys & young men are monitored carefully to ensure optimal management of their seizures and have procedures in place to review if seizures are not controlled on their current ASM.

Competency	Novice	Competent	Expert
Evidence examples	• Telephone log • Patient satisfaction surveys • Discussion with mentor • Documentation	• Testimony from Young man with epilepsy • Case study review • Evidence of reflective practice • Discussion with mentor	• Discussion with mentor regarding critical incident review • Evidence of input/ development to local/national guidance and protocols
H3 Transition between child and adult services	Understand the overarching principles of transition (NICE, 2016). Be able to describe the differences between child-centred and adult-oriented healthcare systems.	Achieve cooperative working with adult services to provide transition services in a flexible manner to meet the needs of children, young people and their parents/carers during the transition period (NICE, 2016; NICE, 2022: NICE (NGA), 2022b).	Recognize gaps in transition services and influence local provision through supporting the infrastructure for transition and developing services (NICE, 2016).
	Support a young person and their family with an agreed plan for transition to adult epilepsy services.	Plan and implement an evidence-based transition to adult services with young people, their families and relevant services.	Lead transition to adult services in complex situations with significant risk.
	Be alert to the risk of stigma and social exclusion for young people with epilepsy	Support the young person with transition using recognized tools (e.g., Ready Steady Go, TIER, 2022)) to promote engagement with services	Ensure young people are embedded into adult care before discharging from children's epilepsy services
Evidence examples	• Observed clinics • Evidence of ability to build positive patient/ nurse relationship • Evidence of reflective practice	• Case study review • Evidence of reflective practice • Evidence of advocacy • Benchmark against other services (Epilepsy12) • Named Nurse throughout transition to ensure continuity (NICE, 2016)	• Evaluation of patient and carer satisfaction surveys • Business plans • Policy and protocol development • Analysis of engagement with services during transition

Competency	Novice	Competent	Expert
H4 Neuro-oncology – children and young people with brain tumours	Understand that children and young people with brain tumours are at increased risk of developing seizures.	Ensure collaborative working relationships with oncology services to meet the needs of children and young people with brain tumours and epilepsy.	Recognise the need for a joined-up service between epilepsy and neuro-oncology.
	Be aware of the brain tumours most commonly associated with epilepsy and the potential treatment options.	Provide a responsive service to children and young people who have brain tumours and their parents/carers.	Develop a responsive service for children and young people and brain tumours in close collaboration with oncology services and parents/carers.
	Recognise the clinical features of seizures associated with brain tumours.		Complete audit/patient satisfaction surveys and use to improve services provided for children and young people with brain tumours and their parents/carers.
Evidence examples	• Observed clinics • Evidence of understanding of the WHO classification of tumours of the central nervous system • Evidence of reflective practice	• Case study review • Evidence of reflective practice • Evidence of links between epilepsy and neuro-oncology services e.g., referral pathways/joint clinics	• Evaluation of patient and parent/carer satisfaction surveys • Business plans to enhance service provision • Policy and protocol development • Presentation at neuro-oncology meetings/ conferences

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The ESNA paediatric steering group would welcome feedback from nurses at all levels who use the framework; this will enable it to be updated and amended in future. If you have any feedback on the framework, please contact the chair of ESNA, who will lead this work, by emailing ESNAepilepsynursesassociation@outlook.com.

Evaluation of this version of the PENS competency framework will begin two to three years after its launch.

What will be evaluated and reviewed?

Evaluation will address different aspects of the framework based on responses to the following questions.

Use of the competency framework:

- How did you use the PENS competency framework?
- Did using the PENS competency framework support your professional development?
- Did the process of using the PENS competency framework fit with supervision or mentoring processes in place in your organisation? If not, could anything be done to better support the use of the PENS competency framework?

Possible improvements:

- Were any of the dimensions included in the PENS competency framework difficult to understand?
- Were any of the dimensions easy/difficult to provide evidence for in your PDP, and why?
- Could you suggest any improved explanations or sources of evidence we can include in the PENS competency framework?

The impact on ESN practice:

- What do you think you are doing differently since using the PENS competency framework?
- How do you plan to use the PENS competency framework in future?
- What would you say is useful about the PENS competency framework to a new specialist nurse?
- What impact do you think the PENS competency framework has on individual patients and their families / carers?

Evaluation and review methods

This framework will be evaluated using the following methods.

Feedback requests

Following the launch of this new competency framework, we will ask PENS for feedback on their initial interpretation of it. There will also be sessions to gather the views of all ESNs using the framework at events such as ESNA and Epilepsy Action conferences.

Portfolio evidence

Evidence used in portfolios (and feedback on this) will be assessed against the PENS competency framework.

Evaluation form

The PENS competency framework will be further assessed on an ongoing basis via the feedback from evaluation forms received within the framework itself.

Appraisals

The competency framework will be used by a variety of managers and mentors who are carrying out individual appraisals at all levels of ESN roles, and we will seek their views on its ease of use.

Study days

Future PENS study days will be mapped to the competencies in the framework to help members update and maintain their competence and portfolios. These will also provide opportunities to develop further insight into the impact of the framework on individual practice.

Roundtables and reports

A roundtable will be arranged to evaluate the use of the PENS competency framework. This will be followed by the publication of a report that outlines:

- The impact of the framework
- Its current usage
- Continued monitoring and evaluation of the framework
- Areas for development and how the PENS steering committee aims to address these.

The performance criteria within this PENS competency framework are specified at three levels of practice: novice, competent and expert. These are derived from Benner's five-level model of nursing competence, an evidence-based framework that can be applied at both specialist and general nurse levels. It describes and differentiates between nursing competency levels and offers useful insights into appropriate education and training for nurses at different levels of practice.

In Benner's model, competencies are divided into five stages. These progress from the novice stage, when nurses learn by instruction and closely followed guidelines and protocols, through advanced beginner, competent and proficient levels to the expert stage, when nurses have an extensive understanding of the situation and the make intuitive, fluid decisions.

This model aligns with the intention that the PENS competency framework is for all nurses working with children who have epilepsy, irrespective of whether their specified role is that of an ESN.

Stage 1 – Novice

The novice has no experience of the situations in which they find themselves at work. Actions and behaviours are guided by a context-free set of rules. The individual will be task orientated in their approach, which is limited and inflexible. Nursing students are considered as novices but have expertise in some situations. Any nurse entering a new field of nursing in a different ward/community environment can therefore be considered to re-enter the novice stage until they have built up some experience in the new situation. The new ESN will therefore be a novice in certain domains of their role when they first move into post.

Stage 2 – Advanced beginner

At the advanced beginner stage, clinical situations are seen as a set of requirements for action, or a set of tasks to perform. This stage is similar to the novice stage, although a larger number of tasks can be performed independently. Characteristics of the advanced beginner stage are:

- All tasks are perceived as equally important.
- The overriding emotion is almost constant anxiety, with concern over their own abilities/competency.
- The individual operates in the present, focusing on what needs to be done 'now'.
- The focus is the patient's physical state, technological support and equipment. The nurse is much less able to tend to patients' emotional needs and the needs of their families and does not have the 'big picture'.
- There is a reliance on nursing theory and the principles that guide practice; ordered steps are necessary.
- The nurse has no responsibility for patients' wellbeing, which gives them the freedom to learn and enables them to delight in learning.

Clinical agency is defined as the experience and understanding of one's impact on what happens to the patient and growing social integration as a member of the healthcare team. At the advanced beginner stage, work is guided by:

- The observations needed
- Charting observations and procedures
- Completing nursing notes
- Following instructions.

Nurses at this stage will strain to meet routines and schedules and be upset by individual patient needs that take up their time and alter their routine. They will seldom have the skills necessary to respond appropriately to rapidly changing situations (particularly relevant in the field of critical care) and will rely on the experience of others.

Mentorship / preceptorship is suggested as the best form of education for the advanced beginner stage. The aims of this are to:

- Help the beginner see the 'bigger picture', put together signs and symptoms and make sense of them
- Help the beginner to know what to expect and what to look out for, and remove some of the uncertainty from their experience of practice
- Provide support in the clinical setting, e.g. prioritising work. Advanced beginners are ready to apply guidelines to practice, but experience is needed before these can be applied to individual patients. Mentoring can help this learning process.

Stage 3 – Competent

General nurses tend to enter this stage after about two to three years in clinical practice. All nurses will reach this stage, which depends only on experience. The competent stage is recognised by:

- Increased clinical understanding
- Improved technical skill
- Greater organisational ability
- An ability to anticipate the likely course of events in clinical practice.

An individual at this stage will demonstrate the following:

- Marked organisational skills, fluid and coordinated actions, and better time management
- An ability to handle multiple, complex tasks
- An ability to anticipate future demands and needs, and to prepare
- Less anxiety, and greater ability to perform well in a crisis
- Less flexibility than a proficient nurse and not as quick to respond to rapidly changing needs.

A nurse at the competent stage can carry out individualised care. Emotions in practice can now act as an alerting process; as the anxiety has subsided and the nurse has settled into the role, emotions can be informative and guiding. The nurse can negotiate clinical knowledge and learning to make a case for change, for example in medication, and will become aware of the shortcomings of others and of the healthcare system. At this stage, the recommended model for education is mentorship/preceptorship by proficient or expert nurses.

Stage 4 – Proficient

This stage represents a qualitative change from the competent level. Not all nurses will make the transition from competent to proficient and some will always remain at the competent level.

Practice at the proficient level is demonstrated in six ways:

1. The development of engaged reasoning in transitions. The proficient nurse works to gain a good understanding and knowledge of the patient and can pick out what is salient in a changing situation. This requires an openness and ability to be challenged rather than needing predictability and control (in contrast with the competent nurse). Because the technical mastery of skills and tasks no longer takes so much attention, the proficient nurse is able to engage in situations and reflect upon them more readily.
2. Emotional attunement to the situation. The proficient nurse's practical grasp of the situation is increasingly accurate. If they are unable to have this grasp, a feeling of uneasiness develops, alerting them to the fact that something might be wrong. This is what is meant by 'emotional responsiveness'.

3. The ability to recognise the changing relevance of aspects of a situation. The nurse can see when to react in a different way from that initially planned. This ability involves a holistic assessment, a trust in one's own interpretation of signs and symptoms, and intuition.

4. A socially skilled sense of urgency.

5. Improved and more differentiated skills of involvement with patients and families.

6. Proficient nurses perceive and understand a situation as a whole. They have the 'big picture'.

At this level the nurse is still learning through reflection. The use of narratives/case studies discussed in small groups can be particularly valuable.

Stage 5 – Expert

Expert practice is characterised by increased intuitive links between seeing the salient issues in the situation and ways of responding to them in practice.

- The expert nurse knows what to expect and is constantly comparing what is present to their expectations (subconsciously). Anticipation is a key component of this level of practice.
- Where patterns are clear, the expert nurse knows what to do with little conscious thought involved. They run on 'autopilot' with respect to tasks, and can therefore simultaneously engage in psychological support, talking with the patient's family and others as they perform tasks.
- The expert nurse will have a strong sense of the future and how this may be influenced, as well as a good understanding of the past.
- Practice is characterised by fluid, skilled performance underpinned by judgement.
- Expert nurses have a good understanding of the patient's world and are able to put that first. They have vision and a commitment to good clinical and caring practices.

The expert nurse has much to offer in terms of guiding the service and planning curricula but might not be the appropriate person to teach a novice or advanced beginner.

AANPE	Association of Advanced Nursing Practice Educators
ABN	Association of British Neurologists
ABHI	Association of British HealthTech Industries
ABPI	Association of the British Pharmaceutical Industry
AED	Anti-epileptic drug
AfC	Agenda for Change
AHP	Allied health professional
ARAF	Annual risk acknowledgement form
ASD	Anti-seizure drug
ASM	Anti-seizure medication
BMA	British Medical Association
BNF	British National Formulary
BPNA	British Paediatric Neurology Association
Buccal (oral mucosal) Midazolam	Midazolam belongs to a group of medicines called benzodiazepines, which are used to treat a number of different conditions, including seizures.
CAMHS	Child and adolescent mental health service
CESS	Children's Epilepsy Surgery Service
Co-morbidities	Two or more co-existing medical conditions or disease processes that are additional to an initial diagnosis; this may complicate the treatment and outcome for a person.
CPD	Continuing professional development
CYP	Children and young people
DHSC	Department of Health and Social Care (replaced the Department of Health in 2018)
EBP	Evidence-based practice
Epilepsy	A common chronic neurological disorder characterised by the tendency to have recurrent seizures.
EHCP	Education, health and care plan
ESN	Epilepsy Specialist Nurse
ESNA	Epilepsy Nurses Association
GMS	General medical services (GP contract)
GP	General practitioner
HCP	Healthcare professional
HCPC	Health and Care Professions Council
HEE	Health Education England
HWB	Health and wellbeing
ICD	International Classification of Diseases
ICH	International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use
ILAE	International League Against Epilepsy
LD	Learning disability
LTC	Long-term condition

LTC-N	Long-term condition – neurological
MDT	Multidisciplinary team
MHRA	Medicines and Healthcare products Regulatory Agency
NEAD	Non-epileptic attack disorder
NES	NHS Education for Scotland
NHS KSF	NHS Knowledge and Skills Framework
NICE	National Institute for Health and Care Excellence
NIPEC	Northern Ireland Practice and Education Council for Nursing and Midwifery
NLIAH	National Leadership and Innovation Agency for Healthcare
NMAHP	Nursing, midwifery and health professionals
NMC	Nursing and Midwifery Council
NMP	Non-medical prescriber
NOS	National Occupational Standards
PDNSA	Parkinson's Disease Nurse Specialist Association
PDP	Personal development plan
PDR	Personal development review
PET	Paediatric epilepsy training
PENS	Paediatric epilepsy nurse specialist
PHE	Public Health England (replaced in October 2021 by the UK Health Security Agency and Office for Health Improvement and Disparities)
Polypharmacy	A term used to describe when an individual takes a variety of medications. This can be different epilepsy medications or medications used to treat other conditions.
PREP	Post-registration education and practice
PWE	Person / people with epilepsy
QOF	Quality and Outcomes Framework
QoL	Quality of life
Rescue medication	A medication prescribed as required to help manage status epilepticus, prolonged and cluster seizures.
RCN	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
RCPH	Royal College of Paediatrics and Child Health
RNMH	Registered nurse in mental health
SCQF	Scottish Credit and Qualifications Framework
Seizure	An epileptic seizure, occasionally referred to as a 'fit', is defined as a transient symptom of abnormal or excessive or synchronous neuronal activity in the brain.
SIGN	Scottish Intercollegiate Guidelines Network
SPESS	Scottish National Paediatric Epilepsy Surgery Service
SUDEP	Sudden unexpected death in epilepsy
VNS	Vagus nerve stimulation
WHO	World Health Organization
WWE	Woman / women with epilepsy

NICE and SIGN recommend that patients be given appropriate information. The following is a checklist that can be used to identify what information to give patients and families/carers, adapted to the needs of children and young people. Epilepsy Action produces a range of information that can be used in primary care to increase patient and carer knowledge of epilepsy. If the patient requires more detailed information on subjects included in this list, then referral to a specialist should be considered.

General epilepsy information	
Mandatory	**Optional**
Explanation of what epilepsy is	Probable cause
Prognosis	Explanation of investigative procedures
Sudden unexpected death in epilepsy	Classification of seizures
Choice of drug	Syndrome
Efficacy	Epidemiology
Side effects	Genetics
Concordance and adherence	Recurrence risks
Drug interactions	ASMs
Free prescriptions	Missed doses
Lack of sleep	Seizure triggers
Alcohol and recreational	Photosensitivity
Stress	Status epilepticus
General guidelines	Support organisations
First aid	Addresses and telephone numbers of national and local epilepsy organisations

Lifestyle	
Mandatory	**Optional**
Driving regulations	Employment
Safety in the home	Education (e.g. guidance for teachers)
Parenting	Leisure
	Relationships
	Safety and appropriate restrictions for children and young people
	Alarms, apps and monitors
	Identity bracelets
	Free prescriptions
	Financial allowances
	Multi-agency support for family (education, social work, voluntary sector etc)
	Organisations to support those experiencing parenting difficulties e.g. Family Lives, Children 1st, Parentline (Scotland) and Parentline NI

Possible psychological consequences	
Mandatory	**Optional**
Perceived stigma	Hormones and sexual health
Memory loss	Behavioural problems in children and young people
Self-esteem	
Depression & Anxiety	
Maintaining mental well being	
Signature:	**Date:**

These generic ESN job descriptions (levels 6 and 7) are included in the framework to offer a template for what an ESN job description might cover. They can be adapted by individual organisations and departments to suit their own epilepsy services and ESN provision, including PENS roles. Text in red specifically indicates where individual organisations can tailor some details to their own circumstances.

Example level 6 ESN job description

The level 6 job description below is an example, and roles may vary across posts and depending on environment e.g. district hospital, primary care.

Job identification	**Job title:** Paediatric epilepsy nurse **Responsible to:** **Department:** Neurology **Directorate:** Neurosciences **Operating division:** **Number of job holders:**
Job purpose	This service takes referrals for adults and adolescents as well as people with LD and psychiatric comorbidity. The aim is to ensure the highest standard of personalised epilepsy nursing care is delivered to patients and their families in partnership with all members of the MDT. The remit of this post is to: • Be responsible for a caseload of patients allocated to the specialist service within the relevant health board/trust/CCG area and the regional or wider service. This includes delivering epilepsy nurse-led services and can take place in a community and acute hospital setting. • Ensure all care delivered is in accordance with national guidelines for epilepsy practice. • Motivate staff to provide high standards of care by acting as a role model. • Provide professional and clinical care advice to patients, carers and the MDT. • Contribute to the provision of specialist education and training programmes for healthcare professionals and other professional groups. • Contribute to research activities ensuring evidence-based practice in the specialist area. • Ensure any care gaps are noted in epilepsy care provision are communicated to senior ESN and/or ward charge nurse.
Dimensions	• The post holder contributes to the clinical responsibility for the regional and wider epilepsy service. • The post holder may participate in nurse-led clinics within the overall service provision for patients in the epilepsy specialty. • The post holder will interact with other staff, including: medical practitioners, therapists, support services, education facilitators, health and safety, risk management, community health practitioners, higher education institutions, social work services and voluntary agencies.

Organisational position	Structural diagram showing who post holder reports to/who reports to them
Role of department/ service	The Department of Neurosciences provides a comprehensive regional neurology service to [number] people [children and young people] and a supra-regional service to [number] people [children and young people]. The epilepsy service potentially serves [number] people [children and young people] locally and [number] people [children and young people] in the wider regional areas. The epilepsy service provides specialist inpatient and outpatient epilepsy care to patients in [appropriate population and health board/CCG/trust]. Its role covers: • Providing high-quality epilepsy care to all patients within a supportive and safe environment • Ensuring epilepsy care in the acute care area and in the community meets nationally agreed guidelines. This involves assessing the care provided by medical staff, nursing and all other healthcare staff who may come into contact with the patient • Contributing to and participating in developments in the epilepsy service in partnership with the acute services division and the health board/CCG.
Outcomes	**Professional (100%)** • Practise at all times within the Nursing and Midwifery Council code of professional conduct • Develop the role by using evidence-based practice and continuously improve own knowledge, following PREP guidelines • Deliver clinical evidence-based practice in accordance with national NICE/ SIGN guidelines and clinical standards for epilepsy nursing • Act as a role model for specialist nursing services
	Leadership and management (100%) • Provide advice and support to the nursing staff within the epilepsy service, ensuring that patient needs are assessed and care is planned, implemented and evaluated, and that there is consultation with, and the involvement of, patients and families/carers • Contribute to epilepsy-specific initiatives within the MDT, and to the development, implementation and maintenance of the epilepsy service policies, procedures, standards and protocols throughout the health board/ CCG locality • In conjunction with the senior clinical nurse specialist, ensure that all nursing staff and members of the MDT are aware of, and work within, local, directorate and division policies and procedures to ensure that safe working practices are maintained for both patients and staff

Clinical (70%)

- Act as a specialist resource in epilepsy nursing by promoting the service and increasing awareness of the condition in hospital and community settings to enhance standards of care
- Ensure the quality of patient care is reviewed, assessed, implemented and monitored to maintain standards of care given to patients and their families/carers
- Participate in clinical audit of specialist nursing services for epilepsy to ensure evidence-based practice
- Participate in monitoring standards of care within the defined policies, procedures and protocols of the service, ward, directorate and division, to ensure adherence to, and delivery of, a high-quality service
- Be responsible for the provision of support and specialist advice to patients with epilepsy, their families and carers, ensuring that this is in line with nationally agreed practice
- Assess patients' clinical condition and, following discussion with senior medical and nursing colleagues, alter or initiate treatment of the patient with epilepsy, ensuring a high degree of epilepsy-specific expertise and care that is in line with nationally agreed guidelines
- Provide a responsive email and telephone helpline for patients, that is staffed [five] days a week. The post holder is responsible for dealing with calls/queries and, following discussion and consultation with senior colleagues, for communicating plans to the patient/carer and all other members of the care team
- Monitor standards of care within the defined policies, procedures and protocols of the service, ward, directorate and division to ensure adherence to, and delivery of, a high-quality epilepsy service
- Develop and provide specialist programmes for care/care packages for patients in the epilepsy service
- Be responsible for improving and streamlining the process of care for patients throughout their pathway in primary and secondary care

Research (10%)

- Contribute to research and clinical audit programmes to support best practice that is research and evidence based and leads to continuous improvements in care
- Interpret epilepsy research and ensure all practice has a nationally accepted evidence base
- Maintain an evidence-based knowledge base through reading, networking and attending local and national epilepsy meetings

	Education (20%) • Contribute to multidisciplinary specialist education and training programmes to promote a wider understanding of epilepsy in primary and secondary healthcare settings • Promote and advise on health and lifestyle activities for patients, carers, healthcare professionals and the general public • Teach, advise and coach patients and carers with regard to the condition and treatment options • Promote a normal life philosophy of care, promoting empowerment of the patient • Contribute to the provision of clinical practice for pre-registration and post-registration learners, to fulfil curriculum requirements and ensure that appropriate educational opportunities are provided • Ensure educational material is provided for all patients, ensuring that this is in an appropriate format and taking into consideration cognitive decline, ethnic group and presence of LD • Ensure that ongoing personal development, professional education and research needs are identified and met
Equipment and machinery	The post holder is expected to have the knowledge and ability to use all relevant equipment, although they might not have daily clinical involvement. Such equipment could include the following [include specific makes/models as appropriate/necessary]: Generic: television bedside unit; hoists; cardiac monitor; fridge; bath hoist; pulse oximeter; ice machine; nurse call system; blood pressure machine; database/computers Specialised: glucometer; compartment monitor; fire equipment; suction equipment; pneumatic tube system; pressure mattress; pat slides; electroencephalograph; water boiler; electrocardiograph; walking aids (frames, crutches, walking sticks); humidified therapy Very specialised: vagus nerve stimulator; oxygen cylinders; standing and turning aids; transfer boards; raised toilet seats; pat slides; glide sheets; X-ray boxes; electrically controlled chair; wheelchairs; trolleys; video camera; voice recorder
Systems	• Specialist databases – collect and input patient data that allows post holder to determine workload and activity • Local patient administration system – as above • Human resources administration system • Incident reporting system • Laboratory information system – specimen results • Internet and intranet – personal and business • PowerPoint/Excel • Access database • Vagus nerve stimulator • Telecommunications

Assignment and review of work	The post is largely self-directed but work maybe assigned by the direct supervisor in response to the needs of patients in the epilepsy service.

Referrals to epilepsy nurse-led service are generated from the health board/ CCG locality and caseload will be allocated by Grade 6/7 ESN colleagues.

Work is reviewed by the Grade 6/7 clinical nurse specialists and [assistant general manager of the neuroscience division].

The post holder will have a professional personal development plan that is reviewed every six months by the delegated line manager. |
| **Decisions and judgements** | The post holder might be expected to:
- Make autonomous clinical and professional decisions on a daily basis, including the provision of advice to the MDT, patients and carers
- Inform clinical decision making with regard to patients' healthcare through stringent monitoring of the patient's condition and acting on clinical judgements
- Act as the patient's advocate to ensure their rights are upheld at all times.

Their freedom to act is guided by precedent and clearly defined divisional policies, protocols, procedures and codes of conduct in accordance with NMC regulations, clinical and staff governance frameworks and the MHRA UK clinical trial legislation. |

Most challenging parts of the job	Epilepsy is a highly prevalent disease, which historically has always been managed within the secondary care setting. National guidelines now advise more primary care input but relevant expertise in both primary and secondary care could be insufficient.
	The post holder is likely to face the following challenges:
	• Improving and streamlining the process of care for patients with epilepsy across regions and boundaries
	• Communicating this care using various communication systems in both primary and secondary care
	• Continued development and promotion of the service
	• Improving communication between the professions involved in the care and treatment of patients with epilepsy
	• Unexpected patient activity and demand resulting from the open access nature of the role (email/telephone/pager etc.)
	• Limited funding and resources, which affects delivery of a high-quality service, because epilepsy is a low priority of care within national and local health plans
	• Complexity of patient problems – many patients have associated comorbidity or neurological handicap, and the condition is more prevalent in socially deprived areas
	• Addressing the equality and diversity needs of patients and staff
	• Dealing with multi-faceted organisations
	• Implementing change effectively in a multidisciplinary environment
	• Time management
	• Discharging patients from caseload

Communications and relationships	The post holder will be expected to:
	• Communicate with the patient, their family and/or carers on the delivery of patient care
	• Manage patients through chronic illness, terminal illness and acute illness as epilepsy presents in all ages and in many acute and chronic disease processes, and is often lifelong
	• Frequently communicate a difficult and stigmatising diagnosis, which may lead to very immediate and drastic alterations to the individual's lifestyle (including driving and employment) and can often result in the patient and/or their family being verbally abusive
	• Liaise with the MDT on service needs and requirements.
	Other relevant lines of communication will encompass the following internal and external groups to ensure the gathering and dissemination of information as appropriate:
	Internal communication: operational services; director of nursing; general manager/assistant general manager; principal nurse; clinical director; managed clinical network (manager and lead clinician); LD service; physicians; ward nurses; psychiatric services; psychology services; paediatric services; laboratory services; obstetric services; multidisciplinary leads; finance; procurement; support services; human resources; health and safety; risk management; palliative care team; critical care teams; bed managers; radiology; pathology; IT; research and development (R&D) department
	External communication: other health boards/CCGs/hospitals; professional links developed locally and nationally; GPs; specialist support groups; voluntary agencies; ambulance service; community health practitioners; social services; housing services; benefits agencies; child protection agencies; patients; carers; general public; educational institutions; staff organisations
Physical, mental, emotional and environmental demands of the job	**Physical skills required** • 12-lead ECGs • Intravenous cannulae/venepuncture • Blood glucose monitoring • Advanced maintenance of patient's airway (using bag valve mask manual resuscitator) • Driving
	Physical demands • Moving patients with mechanical aids • Manoeuvring patients • Pushing trolleys and wheelchairs • Standing/walking for the majority of shift • Activities of daily living • Ergonomics

Mental demands

- Concentration required due to the nature of the epilepsy nurse role, with possibility of frequent direct and indirect interruptions from patients, families/carers and MDT members
- Maintenance of precise and accurate research records
- Recognising and responding to ethical issues that may arise
- Concentration required when observing patient behaviours that may be unpredictable
- Time management
- Communication difficulties (number of professionals the post holder communicates with; patients from different ethnic groups; patients with cognitive, speech, hearing or visual problems)
- Keeping up to date with research/developments in specialist area
- Developed responsibility skills
- Service changes
- Organisational changes
- Political agendas
- Workforce planning
- Challenging inappropriate/poor clinical practice

Emotional demands

- Communicating with distressed, anxious or worried patients and/or families
- Communicating complex issues to the MDT
- Balancing the demands of maximising recruitment with respect for patients and other ethical dimensions
- Caring for patients and supporting families following receipt of bad news
- Caring for patients and families who may project anger and frustration towards professionals due to the distressing nature of the condition
- Dealing with issues surrounding epilepsy management (i.e. associated mental, physical and psychosocial problems including depression, social deprivation, physical and sexual abuse and living with chronic condition)
- Personal/interpersonal stressors
- Spiritual

Environmental demands (working conditions)

- Exposure to body fluids several times each shift
- Exposure to verbal aggression (high frequency)
- Temperature/air quality of working environment
- Ergonomics
- Exposure to risk when working on one-to-one basis with patients (while adhering to lone working guidelines)

Knowledge, training and experience required to do the job	Minimum requirement to undertake the role: first-level registered nurse with five years post registration and relevant experience demonstrating the appropriate competencies and skills for the job. These include: • Educated to degree level or evidence of working towards this – desirable • Evidence of further education, including postgraduate certification, diploma or continuing professional development in neuroscience and/or epilepsy • Evidence of management, education and training – desirable • Effective listening and interpersonal skills • Time management skills/ability to prioritise workload • Excellent teamworking skills plus ability to work on own initiative • Evidence of effective problem-solving skills • IT skills • Expert clinical practice
Job description agreement	A separate job description will need to be signed off by each post holder to whom the job description applies. Post holder's signature: .... Date: .... Head of department's signature: .... Date: ....

Example level 7 ESN job description

The level 7 job description below is an example, and roles may vary across posts and depending on environment e.g. district hospital, primary care.

Job identification	**Job title:** Epilepsy clinical nurse specialist **Responsible to:** Directorate nurse manager **Department:** **Directorate:** Emergency care **Operating division:** **Number of job holders:**
Job purpose	This service takes referrals for adults and adolescents as well as people with LD and psychiatric comorbidity. The remit of this post is to: • Be professionally and managerially responsible for the delivery and ongoing development of the epilepsy nurse service • Ensure the highest standard of personalised nursing care is delivered to patients and their families in partnership with all members of the MDT • Supervise the assessment of care needs and the delivery and maintenance of optimal care outcomes • Motivate staff to provide high standards of care by acting as a role model • Provide professional and clinical care advice to patients, carers and the MDT • Ensure all care delivered is in accordance with national guidelines for epilepsy practice • Be responsible for providing specialist education and training programmes for healthcare professionals and other professional groups
Dimensions	• The post holder has lead clinical and management responsibility for adult epilepsy patients within the health board/CCG/trust etc. • The post holder has clinical and management responsibility for the team providing epilepsy care and for delivering care that is of a high standard and is within national agreed practice guidance (SIGN/NICE guidelines). • The post holder is responsible for developing and writing protocols and policies to promote good practice locally and division-wide, while ensuring there are adequate safeguards in place for patients. • The post holder has direct responsibility for developing and implementing nurse-led adult epilepsy services across the health board/CCG/trust etc. • The post holder is a signatory for their specific area of responsibility.
Organisational position	Structural diagram showing who post holder reports to/who reports to them

Role of department	• Provide a high quality of epilepsy care to all adult patients within a supportive and safe environment
	• Ensure all adult patients with epilepsy receive high-quality care provided in the acute care area and in the community. This involves assessing the care provided by medical staff, nursing and all other healthcare staff who may come into contact with the patient
	• Lead developments in the epilepsy service in partnership with the operational division and across the health board/CCG/trust etc
	• Be responsible for collecting and collating clinical and non-clinical information for inclusion in business and healthcare planning for the next financial year
	• Lead in the development and implementation of a robust audit programme to develop and improve the service to best meet the needs of patients and carers
	• Act as an educational resource for staff and patients in all aspects of the management of epilepsy
	• Provide an environment for staff to maximise learning opportunities
	• Lead in the provision of telephone contact for patients and carers during office hours, ensuring there is a support mechanism there if required

Outcomes	Clinical
	• Practise at all times within the Nursing and Midwifery Council code of professional conduct, acting as an exemplary professional role model for leading specialist nursing services
	• Lead in the development of the role by using evidence-based practice and continuously improving own knowledge, following PREP guidelines
	• Lead in the implementation of clinical evidence-based practice in accordance with national NICE/SIGN guidelines and clinical standards
	• Act as a role model by managing self, their own practice and that of others within an ethical and legal framework that ensures the primacy of patient interests
	• Discuss potential management options for all patients with sensitivity, using experience and knowledge to support them, maintaining confidentiality and privacy at all times
	• Ensure prompt and accurate feedback of management plans for individual patients to primary care
	• Lead and act as a specialist resource for epilepsy services and epilepsy nursing by promoting the service and increasing the awareness of the disease in hospital and primary care setting to enhance standards of care
	• Use expert knowledge of epilepsy to develop highly specialist programmes for care/care packages for patients within the epilepsy service
	• Be responsible for the provision of support and specialist advice to patients with epilepsy, their families and carers, ensuring that this is in line with nationally agreed practice, and monitor and develop written protocols to guide staff in the care of the patient with seizures and epilepsy
	• Act independently in the assessment of patients' clinical condition, with the authority to alter or initiate treatment of the patient with epilepsy, ensuring a high degree of epilepsy-specific expertise and care in line with nationally agreed guidelines
	• Develop nurse prescribing within epilepsy nurse-led service by completion of nurse prescribing course
	• Develop and establish a responsive email and telephone helpline for patients that is staffed [five] days a week. The post holder is responsible for evaluating the quality of advice given and ensuring it is responsive to patients and professionals
	• Be responsible for autonomous review of patients referred by GPs into the nurse service
	• Be responsible for triaging referrals of epilepsy patients into service and prioritising their input (urgent/soon/routine) and for expediting these appointments

Education and research

- Provide comprehensive statistics to inform the audit process associated with the service
- Promote and develop research and clinical audit programmes to support best practice that is research and evidence based and leads to continuous improvements in care
- Contribute to, and take an active role in, key clinical research projects for epilepsy services
- Identify, develop and lead on research programmes within the epilepsy specialist area across the primary and secondary care interface that are nurse-led, and disseminate findings locally, nationally and internally to influence best practice
- Interpret epilepsy research and ensure all practice has a nationally accepted evidence base
- Be responsible for maintaining and updating personal epilepsy research knowledge through conference attendance, networking and reading
- Develop, provide and support appropriate multidisciplinary specialist education and training programmes to promote a wider understanding of epilepsy in primary and secondary healthcare settings
- Lead in the provision of a rolling programmes of education to GPs and practice nurses in response to the General Medical Service (GMS) contract, with the aim of improving primary care awareness and education on care of the patient with epilepsy
- Promote and advise on health and lifestyle activities for patients, carers, healthcare professionals and the general public
- Lead in teaching, advising and coaching patients and carers with regard to the condition and treatment options, encouraging a 'normal' life philosophy of care and promoting empowerment of the patient
- Be responsible for the educational material that is provided for all patients, ensuring that this is an appropriate format and taking into consideration cognitive decline, ethnic group, presence of LD etc
- Direct and support the provision of clinical practice for pre-registration and post-registration learners to fulfil curriculum requirements, and ensure that appropriate educational opportunities are provided
- Ensure that the ongoing personal development, professional education and research needs are identified and met
- Review and provide expert opinion on literature provided by voluntary agencies

	Managerial
	• Be responsible for ensuring specialist epilepsy equipment is ordered and maintained, taking into consideration the financial constraints for that year
	• Lead, direct and develop, in conjunction with key stakeholders, the future service provision and planning for epilepsy services
	• Act promptly in resolving complaints effectively through investigating and responding at local level and escalating as appropriate
	• Work as an independent practitioner, demonstrating the ability to work effectively and flexibly in a changing environment, with a high degree of autonomy
	• Establish and maintain collaborative working relationships with the public, healthcare workers and other agencies
	• Maintain safe environment for patients, public and staff, using quality assurance, risk-management strategies and local and national policies, standards and guidelines
	• Participate in the management and evaluation of change to improve quality of care
	• Motivate self and others to achieve team and organisational goals
	• Represent the service at appropriate professional forums
	• Maintain accurate, timely and complete nursing records, ensuring safety and confidentiality of information at all times
	• Effectively communicate within the organisation at all times, maintaining good interpersonal relationships
	• Manage written and verbal information, taking account of local and national policies
	• Participate in the clinical risk management system by investigating, reporting and taking appropriate action on clinical incidents
	• Actively participate in strategic planning of future epilepsy services across the health board/CCG/trust area
Equipment and machinery	The post holder is expected to have the knowledge and ability to use all relevant equipment, although they might not have daily clinical involvement. Such equipment could include the following [include specific makes/models as appropriate/necessary]:
	Generic: nurse call system; vagus nerve stimulators; personal computer; infusion devices; office equipment; pulse oximeter; resuscitation equipment
	Specialised: fridge; fire equipment; syringe drivers; oxygen systems; observation equipment; vacutainer systems; voice recorder
	Very specialised: photocopier and fax; presentation equipment; laboratory specimen; syringes, needles and scalpels; sharps boxes, wheelchairs and trollies; appropriate manual handling equipment

Systems	• Ensure accurate recording of own duty roster, including annual/study leave
	• Maintain accurate, timely and complete patient records, ensuring safety and confidentiality of information at all times
	• Computer literate
	• Conversant with patient administration system
	• Internet and intranet – personal and business
	• Incident reporting system
	• Voice recorder/digital voice recorder
	• Vagus nerve stimulator
	• Video camera
	• Telecommunications

| Assignment and review of work | **Accountability**
• The post is largely self-directed and self-generated in response to the needs of patients in the epilepsy service.
• The post holder will lead in the provision of an open-access service that accepts referrals to the epilepsy nurse-led service from primary care and across all areas of the secondary care facility.
• The post holder will have a professional and personal development plan that is reviewed annually by the delegated line manager.
• The post holder will provide an annual report to the directorate nurse manager for the epilepsy nurse service.
• The post holder will lead in the production of reports from audit data regarding the performance of the service, including national targets around management of patients with epilepsy.
• The post holder will develop and implement a specific evidence-based service to ensure this group of patients is managed appropriately.
• The post holder will work closely with consultant neurologists, physicians and all members of the MDT who are involved with this group of patients.
• Referrals come primarily from on-call medical teams, GPs and consultant physicians. However, any member of the MDT involved with patients with a diagnosis or suspected diagnosis of epilepsy, in secondary or primary care, can refer to the nurse-led service.
• The post holder will be responsible to the consultant neurologists for clinical guidance.

Work allocation
• Patient referrals are made directly to the post holder by all healthcare professionals involved with patients with epilepsy.
• Referrals may be made from both secondary and primary care.
• Workload is determined by the needs of the service.

Job autonomy
• The post holder has a high degree of autonomy.
• The post holder can arrange appropriate investigations.
• The post holder can make referrals to healthcare professionals and other agencies as required. |

Decisions and judgements	The post holder will work autonomously, making advanced clinical decisions and judgements on individual patients using proven clinical expertise and knowledge. The post holder will take a detailed history and assessment before making any decision regarding each patient. These decisions and judgements include: choice and referral for investigations for appropriate patients; using initiative and making independent advanced clinical decisions, such as patient diagnosis then management plans after history taking, examination and interpreting results from relevant investigations.
	Following expert clinical assessment, the post holder will make autonomous decisions regarding the triage of patients, including: referral and review by a neurologist; referral for further medical management e.g. ordering specific investigations; autonomous decisions regarding alteration of settings on VNS and for communicating this to all personnel involved in the patient's care.
	The post holder will be accountable for all aspects of the ESN across the health board/CCG/trust area, such as:
	• Leading nurse input in multidisciplinary decision-making
	• Leading in the development of health board/CCG/trust wide multidisciplinary and clinically effective standards of care guidelines for the management of patients with suspected cardiac chest pain.
	The assessment of comorbidities such as LD and psychiatric conditions (such as depression or psychotic illness) will also be conducted autonomously by the post holder, and appropriate referrals made.
	The post holder is expected to make operational judgements within the epilepsy service, including:
	• Informing clinical decision making with regard to patients' healthcare, through stringent monitoring of the patient's condition and acting on clinical judgements
	• Acting as the patient's advocate to ensure their rights are upheld when identifying, screening and recruiting subjects into clinical research studies.
	The post holder's freedom to act is guided by precedent and clearly defined divisional policies, protocols, procedures and codes of conduct in accordance with NMC regulations, clinical and staff governance frameworks and the and the MHRA UK clinical trial legislation.

Most challenging parts of the job	The post holder is likely to face the following challenges:
	• Being pivotal in improving and streamlining care for patients with epilepsy across the health board/CCG/trust area
	• Continued development and promotion of the service through promotional work locally and nationally
	• Improving communication between the professions involved in the care and treatment of patients with epilepsy
	• Unexpected patient activity and demand due to the open access nature of the role (email/telephone/mobile phone etc.)
	• Complexity of patient problems – many patients have associated comorbidity or neurological handicap, and the condition is more prevalent in socially deprived areas
	• Dealing with multi-faceted organisations and complex liaison with many professional groups
	• Being able to function in the roles of clinical nurse specialist, manager and professional leader
	• Implementing change effectively in a multidisciplinary environment
	• Time management and meeting service demands within allocated time
	• Discharging patients from caseload

| **Communications and relationships** | The post holder will be expected to:

• Communicate with the patient, their family and/or carers on the delivery of patient care
• Manage patients through chronic illness, terminal illness and acute illness as epilepsy presents in all ages and in many acute and chronic disease processes, and is often lifelong
• Frequently communicate a difficult and stigmatising diagnosis, which may lead to very immediate and drastic alterations to the individual's lifestyle (including driving and employment)
• Liaise with the epilepsy MDT on service needs and requirements
• In consultation with staff, discuss complex personal performance development and appraisal matters in a constructive manner
• Represent the organisation at local and national meetings regarding nurse management of patients with epilepsy.

Other relevant lines of communication will encompass the following internal and external groups to ensure the gathering and dissemination of information as appropriate:

Internal communication: operational services; director of nursing; directorate nurse manager; other clinical nurse specialists; clinical director; multidisciplinary leads; regional planning group; LD service; physicians; ward nurses; psychiatric services; psychology services; paediatric services; laboratory services; obstetric services; chaplaincy; finance; procurement; support services; human resources; health and safety; risk management; palliative care team; critical care teams; bed managers; radiology; pathology; IT; research and development (R&D) department

External communication: other health boards/CCGs/hospitals; professional links developed locally and nationally; GPs; specialist support groups; voluntary agencies; ambulance service; community health practitioners; social services; housing services; benefits agencies; child protection agencies; patients; carers; general public; educational institutions; staff organisations |

Physical, mental, emotional and environmental demands of the job	**Physical skills required** • Intravenous cannulae/venepuncture • Blood glucose monitoring • Advanced maintenance of patient's airway (using bag valve mask manual resuscitator) • Neurological assessment • Adjusting VNS settings • The ability to operate machinery and equipment as listed above **Physical demands** • Pushing trolleys and wheelchairs • Standing/walking for the majority of shift • Moving equipment • Working in cramped or restricted conditions
	Mental demands • Concentration required at all times due to the nature of the epilepsy nurse role, with possibility during daily practice of frequent direct and indirect interruptions from patients, families/carers and MDT members • Maintenance of precise and accurate research records • Recognising and responding to ethical issues that may arise • Concentration required when observing patient behaviours that may be unpredictable • Time management • Communication difficulties (number of professionals the post holder communicates with; patients from different ethnic groups; patients with cognitive, speech, hearing or visual problems) • Developed leadership skills • Responsibility of working in an autonomous advanced practitioner role • Keeping up to date with research/developments in specialist area • Service changes • Retention and communication of knowledge and information • Unpredictable workload • Working independently and making daily decisions about patient diagnosis and management plans • Articulating the perceived clinical needs of patients and advocating best practice • Organisational changes • Political agendas • Workforce planning • Challenging inappropriate/poor clinical practice with different professional groups

Emotional demands

- Communicating with distressed, anxious or worried patients and/or families
- Communicating complex issues to the MDT, patients and families/carers
- Balancing the demands of maximising recruitment with respect for patients and other ethical dimensions
- Caring for patients and supporting families following receipt of bad news
- Caring for patients and families who may project anger and frustration towards professionals due to the distressing nature of the condition
- Dealing with issues surrounding epilepsy management (i.e. associated mental, physical and psychosocial problems including depression, social deprivation and living with a chronic condition)
- Personal/interpersonal stressors
- Communicating complex issues to all healthcare professionals and other relevant agencies
- Liaison with tertiary referral centres for patients
- Recognising and managing conflict

Environmental demands (working conditions)

- Exposure to body fluids
- Exposure to verbal aggression (high frequency)
- Temperature/air quality of working environment
- Ergonomics
- Exposure to risk when working on one-to-one basis with patients (while adhering to lone working guidelines)
- Working in a wide variety of wards and departments on a daily basis

Knowledge, training and experience required to do the job	• First-level registered nurse with experience equivalent to seven years post registration, two years at band 6 or relevant experience demonstrating the appropriate competencies and skills for the job • Post-registration qualification relevant to neurosciences and/or management of epilepsy • Educated to master's level or working towards this – desirable • Effective listening and interpersonal skills – essential • Excellent written and communication skills with proven ability to compile reports – essential • Proven experience in developing, implementing and managing change within the specialty • Proven experience in monitoring and auditing a service, and changing and influencing clinical practice accordingly – essential • Proven experience in innovation in nursing practice and motivation and development of professional staff – essential • Time management skills/ability to prioritise workload, demonstrating ability to work autonomously and manage own workload – essential • Excellent teamworking skills, with the ability to work using own initiative • An imaginative approach to problem solving that is rooted in reality and effective personal leadership within an MDT • Expert knowledge of national agendas and targets for neurology services • Working knowledge of common IT software packages to facilitate communication and audit • Research experience, including working knowledge of relevant Research experience and working knowledge of relevant MHRA clinical trial regulation. • Community experience – desirable • Nurse prescribing qualification – desirable • Possession of extended roles (venepuncture, intravenous cannulation defibrillation) developed within the scope of practice – essential
Job description agreement	A separate job description will need to be signed off by each post holder to whom the job description applies. Post holder's signature: .... Date: .... Head of department's signature: .... Date: ....

For further information on the paediatric ESN competency framework please contact ESNA

(https://esna-online.org/)