

The competency framework for adult epilepsy specialist nurses (adult ESN)



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Acknowledgements

This document is the second edition of the epilepsy specialist nurse (ESN) competency framework. It has been formally renamed the competency framework for registered nurses providing specialist care for those with a diagnosis of epilepsy to appeal to all nurses working in the field of epilepsy, but throughout this document it will be referred to as the ESN competency framework for simplicity.

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Following publication of the first adult competence framework questionnaires were completed by ESN's from the ESNA membership followed by a small in-person focus group convened in Sep 2017. The outcomes of this focus group have been used to update and amend the original adult epilepsy specialist nurse competency framework.

Focus group members included:

- Alison Carr Bradford and Airedale
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The focus group comprised novice, competent and expert ESNs as well as patient representatives. This looked at;

- How they were using the adult competency framework
- Use of competency framework to support professional development
- Did it support ESN in the mentoring/supervision process?
- Whether it was missing any areas

During the development of the adult ESN competency framework, appropriate guidelines were considered to ensure it is compliant with the:

- Royal College of Nursing equality, diversity and inclusion standards (RCN, undated)
- Nursing and Midwifery Council code of conduct (NMC, 2018)
- Association of the British Pharmaceutical Industry code of conduct (ABPI, 2021)
- Association of British HealthTech Industries code of business practice (ABHI, 2021)



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1 Executive summary

Epilepsy is a common neurological condition that can have effects that reach far into the lives of the person/people with epilepsy (PWE). Since 1988, adult epilepsy specialist nurses (ESNs) have been involved in managing and supporting PWE. However, despite this long association, it was not until 2012 and the first publication of the epilepsy specialist competencies that agreed guidelines for recruiting and training an ESN came into force. This guidance also agreed the clinical experience and educational attainment the nurse should have prior to moving into the field of specialist nursing.

The adult ESN competency framework sets out the educational and professional criteria for nurses wishing to undertake the adult ESN role. Additionally, the adult ESN competency framework provides the opportunity for the ESN and their employer to agree a professional development plan (PDP). This plan will assist and evidence the ESN's passage from specialist novice nurse to competent ESN and finally to expert specialist nurse safely. It is envisaged that the adult ESN competency framework will be used across the UK by healthcare providers in England, Scotland, Wales and Northern Ireland, and be embedded in national appraisal systems.

Epilepsy services vary, depending on locality, but there is agreement that the role requirements can and should be standardised. This should support the recruitment and succession-planning process as well as improving patient safety and the quality of epilepsy services provided.

Epilepsy is one of the most common neurological conditions and affects people of all ages, races, social class, and geographical location. It is characterised by the recurrence of seizures. “The underlying cause and the adverse effects of treatment have neurologic, cognitive, psychological, and social consequences that significantly affect the quality of life of the affected individuals” (Beghi 2020). Approximately 600,000 people in the UK will have a diagnosis of epilepsy (Epilepsy Action, 2021). The prevalence rate of epilepsy in the UK is approximately 0.97 per cent (Epilepsy Research UK, undated). The prognosis of epilepsy is generally favourable. However, long-term remission rates vary and are dependent on the syndromic categorisation as well as whether or not seizures continue despite trialling two antiepileptic drugs (Giussani 2016). Appropriate management and support for PWE can help to minimise social and financial deprivation, stigmatisation, and misunderstandings, and promote independence and employability.

The ESN competency framework is designed to provide aspirational guidance that can be used to develop skills and knowledge and inform practice, training, and development. It can provide structure and objectivity for appraisals. The framework aims to ensure that ESNs can deliver high-quality, safe and accountable care to PWE in line with the Health Education England (HEE) Quality Framework (2021). The competencies aim to follow the HEE by providing a structured way to learn, develop and support a sustainable workforce. The objective of using this competency framework is to optimise clinical practice and to generate a pathway leading from novice epilepsy specialist nurse to expert epilepsy specialist nurse.

The adult ESN competency framework reflects the need for all practitioners working in advanced clinical roles to be able to demonstrate and evidence their competence and capability across the four pillars of clinical practice, leadership and management, education and research as laid out in the multi-professional framework for advanced clinical practice in England (2017). This builds on previous work undertaken in Scotland, England, Wales, and Northern Ireland.

The adult ESN competency framework 2012 was developed by a UK-wide steering group of ESNs with a variety of experience and reviewed by academics and researchers. This work has been led by the Epilepsy Specialist Nurses Association (ESNA) and accredited by the Royal College of Nursing (RCN), with the support of Epilepsy Action. This new/revised framework builds on the original document.

3 What is the role of the adult ESN?

The role of the adult ESN should focus on empowering those affected by epilepsy by providing timely information, support, and advice. This should take place at the point of diagnosis and throughout the trajectory of the person's epilepsy. The ESN should assist PWE to reach the goal of self-management and independence. The ESN is pivotal in providing a greater understanding of the condition and adopting a holistic, collaborative, and coordinated approach that can help reduce the impact of epilepsy on the individual and their family. There may be specific and changing information needs at times such as during transition from paediatric to adult services.

The role requires the ESN to be an expert resource for all those involved in epilepsy care. The role of the ESN varies according to the local environment, the length of time an individual has been in post, their clinical skills and education. Knowledge and expertise are developed through the process of caring for PWE, their families and community, learning from peers, developing clinical skills, reviewing, interpreting and involvement in research, teaching and education, regular professional development, reflection, and reflexivity.

Evidence identifies that ESNs improve patient satisfaction and emotional wellbeing and are more likely to provide consistency of care. 'The involvement of an epilepsy specialist nurse is likely to result in cost savings by reducing the overall use of healthcare services especially in terms of reduced emergency department visits and the subsequent length of hospital stay' (NICE 2022).

It is expected that anyone undertaking a specialist nursing role for adults with epilepsy will be a registered nurse on the adult or learning disability (LD) NMC register. Nurses applying for ESN roles may have many of the essential management, teaching, education, and research skills to enable them to work at a specialist level, but they might lack specific epilepsy knowledge.

4 What are nursing competencies?

Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain, cope, and recover with health problems. The outcome is to achieve the best possible quality of life (QoL), whatever their disease or disability, until death (Scott H 2002). Provision of care needs to be bound by the competence to provide and maintain the highest standard of clinical care. Competence is defined by Roach 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” (RCN, 2009), whereas a competency is more than just knowledge and skills. It involves the ability to meet complex demands by drawing on and mobilising psychosocial resources (including skills and attitudes) in a particular context (Analytic Quality Glossary, 2012).

It is the duty of registered nurses to maintain competence in their field of practice. This can be achieved through post-registration courses, self-directed study and continuing professional development (CPD); however, it is acknowledged that linking educational development to clinical practice does not always imply that the practitioner has a sound level of competence. This has therefore brought into question the assessment of clinical competence. The government agreement on pay and conditions of service for NHS staff, the Agenda for Change (AfC) (Department of Health, 2004a), partly addressed these issues by developing and introducing the NHS Knowledge and Skills Framework (NHS KSF), linked to pay banding. However, this has not been the ultimate answer and the future holds the possibility of ‘competency passports’ to aid career progression and movement between specialties and a practitioner’s career path (Murrells, 2009).

The NMC 2018 Standards of proficiency for registered nurses state the knowledge and skills that the registered nurse must be able to demonstrate when caring for people of all ages and across all care settings. It lays out what the public can expect from nurses to deliver safe, compassionate, and effective nursing care.

4.1 What is a competency framework?

A competency framework is central to effective performance and assessing nursing competence is increasingly important (RPS 2021). With concerns about fitness to practise, it has become essential to ensure nurses are competent to perform their roles as developed by the NMC. The NMC 2018 code of professional practice states that a nurse is a safe, caring, and competent decision-maker willing to accept personal and professional accountability for their actions and continuous learning. The nurse practises within a statutory framework and code of ethics, delivering nursing practice (care) that is appropriately based on research, evidence and critical thinking that effectively responds to the needs of individual clients and diverse populations (NMC, 2018). The NMC has developed competencies for different post-registration specialties within documented standards for competence for registered nurses (2014). The NMC defines the advanced/specialist nurse as a registered nurse who has command of an expert knowledge base and clinical competence, can make complex clinical decisions using expert clinical judgement, is an essential member of an independent healthcare team and whose role is determined by the context in which they practise (NES, 2012).

5 What is the purpose of the adult ESN competency framework?

The ESN competency framework is a key document that can be used by all ESNs. It is recognised that certain domains in the novice elements are essential to the clinical development of nurses to advance their knowledge and skills in relation to the management of epilepsy. It is expected that the novice elements within the framework will be the minimum accepted standards of knowledge for all nurses working with epilepsy. The competency framework can be exited at that level, although the national framework will enable nurses to work through skills development towards clinical expertise to achieve the ESN expert level. This then enables the individual to disseminate knowledge by research and teaching practices in a safe, effective, and accountable manner (Higgins 2019)

The ESN competency framework can be used to:

- Provide a vehicle to facilitate knowledge and skills development for all practitioners
- Increase the focus on lifelong, self-directed, and work-based learning
- Provide standards and expertise to demonstrate advanced/national practice
- Facilitate and provide guidance for professional development for ESNs or nurses with a specialist interest in epilepsy
- Identify the need for educational programmes and ongoing practice development at different stages of the ESN career pathway
- Support clinical supervision and personal development plans (PDPs) to identify gaps in competence
- Ensure the highest standard of care is provided by the ESN, in accordance with published papers and government initiatives that influence changing political and professional issues (**see Appendix 1: References and bibliography**).

The ESN competencies are also structured around the four 'pillars' of advanced clinical practice set out by Health Education England (HEE, 2017). These are shown in Table 1.

Table 1: Four pillars of practice

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

5.1 Benner's five-level model of nursing competence

The performance criteria within this ESN competency framework are specified at three levels of practice: novice, competent and expert (see Table 2). Timescales for progression may vary depending on prior clinical experience.

Table 2: Levels of competency	
Novice nurse	2 years post registration on the LD/Adult NMC register and in first two years of epilepsy specialist nurse post Working at first-degree level Suggested AfC level 6
Competent nurse	Qualified nurse who has worked in the area of epilepsy specialist nursing for a minimum of nine months and who is developing expertise to use detailed theoretical and practical knowledge in the management of epilepsy for PWE Working at first-degree level Suggested AfC level 6/7
Expert specialist nurse	Qualified nurse who has developed specialist clinical and psychosocial expertise to autonomously assess and manage epilepsy psychosocial Hold, or working towards, a master's degree Suggested AfC level 7 or above

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 (Benner, 1984; Benner et al., 1996; Gobet and Chassy, 2008).

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 they make intuitive, fluid decisions.

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

For further detail of Benner's five-level model of nursing competence, please refer to Appendix 3.

6 How to use the adult ESN competency framework

This document has been written in line with the previously published adult and LD ESN competency frameworks (ESNA, 2012; ESNA, 2013). To allow for consistency and easy movement between all three documents, the framework has followed an identical process. This competency framework is aimed at all nurses supporting people with epilepsy, who may on occasion also need to use elements from both the LD and paediatric ESN competency frameworks.

For each competency, the authors of the framework have identified examples of knowledge and understanding that can be used to demonstrate the level of practice the individual is operating at. The competencies have been written as cumulative statements; therefore, statements at expert specialist level build on those outlined for novice and competent nurses. It is recognised that the knowledge and understanding examples that nurses require are specific to each one's role, service provision and local commissioning; a nurse may not necessarily become expert in all domains. Therefore, the knowledge and understanding examples have been written as examples rather than definitions of competence. The general requirement for the role is to be operating at a competent level, though some nurses may become expert in some aspects of care.

The competencies should facilitate and provide a structure for:

- Revalidation
- Self and 360° appraisals
- Personal development plans (PDPs)
- Development of an individual's professional portfolio
- Mentorship/preceptorship
- Continuing professional development (CPD) and study days.
- Commissioning ESN roles

It is recommended that the ESN competency framework is reviewed between the individual nurse/ESN and their manager (providing they have knowledge of epilepsy) at least once annually to facilitate and ensure developmental planning and training. However, the framework should be used more frequently for nurses/ESNs 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 service delivered – should flag the need for a review of the post. It is also acknowledged that parts of the competency framework may be used in isolation, within an overall NHS KSF or PDP outline, due to the varying role of epilepsy management in the holistic approach to nursing. This allows for professionals working with individuals with epilepsy as part of their extended role to use appropriate elements of the document to enhance overall caregiving and educational understanding.

6.1 The NHS Knowledge and Skills Framework (NHS KSF)

The adult ESN competency framework is 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, 2004b).

The following dimensions are relevant to the ESN role: health and wellbeing (HWB); information and knowledge (IK); and learning and development (G1) (see Figure 1). 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.

Figure 1: Core and specific dimensions of the KSF relating to the adult ESN competency framework

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

7 The adult ESN competency framework

The ESN competency framework has been developed as a cumulative document. It is assumed that nurses 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.

7.1 Evidencing the ESN competency framework

Multiple types of evidence can be used to support practice, from formal qualitative assessment through to less formal qualitative review or direct observation. The 'best' level of evidence will be determined by what is possible and appropriate for the situation. It is assumed that all competencies will be evidenced with:

- Discussions between mentor and ESN
- Evidence-based guidelines
- Review of documentation and audits
- Reflective practice
- Direct observation
- Feedback from PWE, families and care workers on the role of the ESN
- Minutes from relevant meetings
- Documented evidence of adhering to the Mental Capacity Act (MCA).

A: Diagnosis and management of epilepsy

7.2 The adult ESN competency framework

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

Specific KSF dimensions: HWB2; HWB4; HWB6 IK1 G1

Pillars of practice: Clinical practice

Competency	Novice	Competent	Expert
A1 Knowledge of epilepsy	Demonstrate a good understanding of the definitions of epilepsy and seizures.	Understand epilepsy syndromes and other neurological conditions and how they influence management and long-term prognosis of epilepsy.	Have a thorough knowledge of the anatomy, physiology, neurophysiology and pathology of the nervous system in relation to epilepsy, seizures and treatments.
	Be able to simply explain structure of the nervous system, including the hemispheres and lobes of the brain and their functions.	Understand typical and atypical brain development.	
	Have a basic understanding of the architecture of neurons and how electrical impulses are transmitted.	Understand the neurophysiology of the brain in relation to epilepsy.	
A1 Knowledge of epilepsy – Aetiology	Develop knowledge of diagnosis and treatment of epilepsy.	Undertake file reviews for medical history, investigation results and medication history.	Be able to consult with PWE, to evaluate information, request further investigations and consult with MDT colleagues as required to ensure a safe diagnosis of epilepsy.
A1 Knowledge of epilepsy – Diagnosis: Investigations	Develop knowledge of diagnosis and treatment of epilepsy.	Undertake file reviews for medical history, investigation results and medication history.	Be able to consult with PWE, to evaluate information, request further investigations and consult with MDT colleagues as required to ensure a safe diagnosis of epilepsy.
	Understand the information required to make a diagnosis of epilepsy, including investigations.	Understand the investigations required to help diagnose epilepsy.	
		Be able to identify the barriers to investigations and challenges in diagnosis and ways of addressing these.	Re-evaluate diagnosis of epilepsy in drug-resistant epilepsy, exacerbations of seizures, changes in presentation etc.

Competency	Novice	Competent	Expert
A1 Knowledge of epilepsy – Diagnosis: Investigations (continued)		Understand the limitations of the investigations within different client groups	
A1 Knowledge of epilepsy – Differential diagnosis	Develop knowledge of differential diagnosis commonly mistaken for epilepsy.	Establish appropriate monitoring and recording tools to identify possible differential diagnosis.	Evaluate and interpret evidence of investigations and assessments to assist in differential diagnosis as part of the MDT.
A1.1 Understanding seizure types – ILAE seizure classification	Demonstrate an understanding of the current ILAE classification for seizures.	Understand and classify the types of seizure and possible syndromes and how they affect treatment plans and risk.	Recognise the limitations of the classification system.
			Recognise atypical seizure presentations.
			Take opportunities to participate in local and national discussions around seizure classifications and syndromes.
			Be part of educational programmes to teach other professionals.
A1.1 Understanding seizure types – Seizure descriptions	Understand the relevant information required to accurately document different seizure descriptions from patient and witness assessment.	Understand the barriers to obtaining good seizure descriptions and develop tools to assist in gathering the information.	Interpret information provided by PWE and carers to stratify risk and propose appropriate treatments based on seizure type or syndrome.
A1.1 Understanding seizure types – Dissociative seizures	Recognise the different names for dissociative seizures/non-epileptic attack disorder (NEAD)/ psychogenic seizures etc	Recognise some of the clinical features of dissociative seizures and how they might be distinguished from epileptic seizures.	Be able to expertly discuss with MDT colleagues and diagnose accurately dissociative seizures, if necessary, referring to appropriate services.
	Be sensitive to attitudes and stigma around this diagnosis.	Establish appropriate monitoring and recording tools to support differential diagnosis and be able to provide appropriate information.	Be able to confidently explain the diagnosis of dissociative seizures to patients.
		Be aware of management approaches locally and nationally for dissociative seizures.	Develop/contribute to resources and services, locally and nationally for the support of people with dissociative seizures.

Competency	Novice	Competent	Expert
Evidence examples	<ul style="list-style-type: none"> Evidence of use of current ILAE classification Case study review Discussion with mentor Documentation 	<ul style="list-style-type: none"> Literature reviews/critical appraisal of publications Care plans Seizure charts Protocol development for seizure management Case study review Evidence of reflective practice Discussion with mentor 	<ul style="list-style-type: none"> Evidence of input to local/national service debates Publications Evidence of input to local/national guidance and protocols Discussion with mentor regarding critical incident review
A1.2 Understand and recognise the cognitive impact of seizures and treatments	Be aware of possible cognitive impairments and their potential effect on PWE, their families and carers.	Recognise the common cognitive difficulties experienced by PWE.	Be aware of other comorbidities that may also affect cognition, such as polypharmacy.
		Explain to PWE why and how cognition may be affected by epilepsy and ASMs.	Have knowledge of other medications that may affect cognition.
		Understand the appropriate referral pathways to address cognitive concerns.	Recommend and implement treatment changes to improve cognition as required.
		Have knowledge of and recommend strategies to reduce the cognitive impact on PWE.	Have expertise in the recognition of subtle cognitive impairment and the implications for PWE on their work and personal life.
Evidence examples	<ul style="list-style-type: none"> Discuss and review with team members and other agencies that may be able to offer help Peer review with mentor 	<ul style="list-style-type: none"> Evidence of use of assessment tools Evidence of use of strategies to help PWE to deal with common cognitive problems faced Case study review 	<ul style="list-style-type: none"> Evidence of professional collaboration, design of care pathways and networks for patient support Evidence of strong MDT links in the community and/or hospital settings Evidence of appropriate referrals
A2 Assisting and supporting diagnosis according to individual needs and circumstances	Understand that PWE, families and carers require knowledge of the basics of epilepsy and risks.	Be able to discuss confidently epilepsy and epilepsy risk with PWE their families and carers	Develop local and national resources to help PWE their families and carers understand their epilepsy and the inherent risks and daily management.

Competency	Novice	Competent	Expert
A2 Assisting and supporting diagnosis according to individual needs and circumstances (continued)	Be able to identify the resources currently available.	Answer questions and respond appropriately to differing emotional responses and to personalise answers to the individual.	
		Identify and review additional written/audio resources to help the PWE better understand and cope with their epilepsy.	
Evidence examples	<ul style="list-style-type: none"> • Observed clinical reviews • Evidence of using a variety of written resources to educate and reinforce information for PWE • E-counselling checklist or information needs assessment tool • Case study review 	<ul style="list-style-type: none"> • Testimony from PWE and their family/carers • Evidence of continuous assessment and review of PWE and information needs of their families/carers 	
A3 Care planning, implementation and evaluation	Be able to write a basic epilepsy care plan, including reference to epilepsy risk and basic first aid, and to be able to identify sources of advice.	Be able to write a detailed epilepsy shared care plan with the person/family/carer, including intervention with emergency medications if required.	Develop treatment pathways, taking into consideration a holistic approach.
	Identify signs that may illustrate the need for increased patient and family support or intervention.	Have up-to-date, evidence-based knowledge of epilepsy risks and interventions to reduce risk.	Develop appropriate tools to evaluate pathways, including the need to escalate.
		Complete appropriate assessments to support referral onwards for increased support/assessment.	Develop complex epilepsy treatment plans/care plans for people with drug resistant epilepsy and multimorbidity.
		Provide practical assistance through signposting or providing direct assistance to resolve problems/concerns.	Develop networks of professional contacts that can provide ongoing support to PWE, their families and carers.

Competency	Novice	Competent	Expert
A3 Care planning, implementation and evaluation (continued)		Use expertise, communication and coordination skills to enable professional meetings, and ensure continuity of complex care needs between hospital and the community care setting.	Develop local and contribute to national care pathways that can improve the outcomes for PWE.
Evidence examples	<ul style="list-style-type: none"> • Evidence of referrals and intervention • Case conference notes • MDT links/professional relationships • Case study review • Evidence of reflective practice 	<ul style="list-style-type: none"> • Shared care guidelines • Evidence of referral on for support from other agencies, including the voluntary sector (with prior agreement from the PWE) 	<ul style="list-style-type: none"> • Patient satisfaction surveys • Evidence of pathways/protocols developed • Observed chairing of complex case conferences/MDT reviews • Evidence of provision of ongoing patient support through patient groups, self-management programmes and patient education meetings
A4 Medicine and treatment management	Have knowledge of the treatment options and be aware of common side effects and drug interactions.	Make recommendations for PWE's drug treatment, monitoring and evaluation.	Prescribe, monitor, and evaluate drug treatment in accordance with NICE/SIGN guidelines and other national studies.
	Understand the importance of adherence to medication and treatment to PWE, families and carers.	Ensure PWE, their families and carers are made fully aware of potential side effects and actions to be taken.	Recognise the effects and problems associated with polypharmacy of ASMs as well as other commonly used medication and be able to support and advise PWE, families, carers, and MDT.
		Assess the efficacy of current epilepsy treatment and consider when to refer the patient on for further specialist review.	Request and interpret relevant investigations required to inform treatment options
		Recognise the barriers to adherence and promote effective strategies for adherence.	

Competency	Novice	Competent	Expert
Evidence examples			<ul style="list-style-type: none"> Evidence of strong links with other agencies Evidence of assessments undertaken Knowledge of and adherence to non-medical prescribing standards (RPS framework for all prescribers).
A5 Epilepsy surgery – For general nurses, including VNS management	Describe the epilepsy surgical assessment process to PWE.	Discuss the implications of epilepsy surgery.	Use clinical assessment guidelines to identify PWE who may be suitable for epilepsy surgery assessment.
	Have knowledge of the investigations required when considering epilepsy surgery.	Understand the implications of investigation findings for surgery.	Oversee the surgical assessment process.
	Understand the roles of the epilepsy surgical MDT team and follow guidelines for patient management following epilepsy surgery.	Liaise with all members of the epilepsy surgery MDT team.	Explain individual investigation outcomes and implications for potential epilepsy surgery.
A5 Epilepsy surgery – For general nurses, including VNS management (continued)	Make the patient aware of follow-up plans.	Ensure appropriate timely review of post-surgical outcomes and undertake assessment of patient's follow-up needs.	Actively participate in discussion with the MDT epilepsy surgery team.
	Teach PWE/carers how to use the VNS magnet in response to seizure activity.	Programme and titrate the VNS device and ensure patient understanding.	Ensure long-term assessment and measurement of surgical outcomes using appropriate tools.
Evidence examples	<ul style="list-style-type: none"> Evidence of critical incident reflection Knowledge of surgical pathway Testimony from families/carers 	<ul style="list-style-type: none"> Testimony from other members of the MDT Evidence of the use of appropriate evidence-based assessment tools Evidence of referrals and intervention 	<ul style="list-style-type: none"> Service review Publications

B: Assessing and managing risk

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 The patient perspectives	Understand the impact that epilepsy can have on the individual, families, and carers.	Be able to provide effective knowledge and understanding of epilepsy and the impact it has on life, including work, education, and relationships.	Develop, research and educate about the risk and impact epilepsy has on people both individual, local and national.
	Be aware of local and national support of PWE and be able to signpost as required.	Advise on real and potential risks around epilepsy.	
	Develop communication skills to be able to effectively listen and communicate with PWE, families and carers		
Evidence examples	<ul style="list-style-type: none"> Observed clinical reviews Patient satisfaction survey Case study review Testimonies of PWE Evidence of ability to build positive patient/nurse relationships 	<ul style="list-style-type: none"> Case study review 	<ul style="list-style-type: none"> Evidence of the development of epilepsy services
B2 Using risk assessment tools	Be aware of local and national risk assessment tools and how they can be used	Use local and national risk assessment tools and provide the appropriate risk assessments for PWE, families, carers, and MDT.	Research and develop and audit local and national risk assessment tools for the improvement of the management of PWE and their associated risks.
Evidence examples		<ul style="list-style-type: none"> MDT discussions Risk assessment forms Protocols 	<ul style="list-style-type: none"> Risk assessment policies and strategies MDT member testimonies

C: The impact of epilepsy

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 PWE, families and carers	Be aware of the psychosocial impact of epilepsy on PWE, families and carers.	Discuss the psychosocial impact of epilepsy in relation to an individual's community, culture and beliefs and ways to modify the impact.	Develop resources locally and nationally to help support PWE from differing communities.
	Understand the implications of cultural and social issues that may compound feelings of stigma following a diagnosis of epilepsy.	Identify and review resources to help the PWE better understand and cope with the wider effect epilepsy may have on psychosocial health.	Engage with different diverse communities and cultures to reduce the psychosocial impact of epilepsy on PWE, families and carers.
	Be aware of other resources of information that can help to support PWE, families and carers from differing communities, cultures and beliefs.		
C2 Self-management and independent living	Acknowledge people may require support to manage some or all aspects of their epilepsy.	Assist and develop strategies to promote self-management where possible for shared decisions and informing choices	Develop research and audit local and national self-management tools, including for special patient groups, communities and diverse cultures.
	Understand the tools available to support an individual's epilepsy and signpost.	Understand the barriers to self-management for all patient groups.	
Evidence examples	<ul style="list-style-type: none"> • Testimonies from PWE • Observed ESN and patient interactions 	<ul style="list-style-type: none"> • Case study review 	<ul style="list-style-type: none"> • Delivering self-management protocols • Evaluation of patient and carer satisfaction surveys • Management plans • Clinical letters
C3 Advocacy	Recognise the need for advocacy in a PWE and act as an advocate as required.	Refer for advocacy services as required.	Influence at a strategic, trust, CCG, health board or commissioning level on behalf of all PWE at a local and national level.
	Be aware of different advocacy services.	Promote participation of PWE at local and national level to influence local and national services.	

Competency	Novice	Competent	Expert
Evidence examples		<ul style="list-style-type: none"> • Minutes of meetings, including evidence of patient/public involvement • Patient forums • Patient satisfaction surveys from user groups 	<ul style="list-style-type: none"> • Use of evidence based QoL scores • Presence of patient support groups • Involvement or partnerships with the voluntary sector • Minutes of meetings, including evidence of patient/public involvement
C4 Capacity to consent to treatment	Identify the need and gather information for the assessment of capacity.	Carry out review/assessment of capacity.	Fully adhere to the MCA and give balanced opinions based on knowledge of treatment.
	Understand the principles of the MCA and 'best interest' and seek advice and support when required.	Gather information to inform and support 'best interest' meetings.	Coordinate, chair and facilitate decision-making process under the MCA and act as a decision-maker where appropriate.
	Be familiar with legislation in relation to capacity of the individual.	Have in-depth knowledge of how to approach PWE for consent.	Have extensive knowledge of MCA capacity assessments, consent and Deprivation of Liberty Safeguards (DoLS)/Liberty Protection Safeguards (LPS).
	Demonstrate knowledge of when to involve advocacy services and signpost to appropriate service if level of understanding is deficient.	Refer to other services for added support and work with advocates, including independent mental capacity and health advocates.	Act as an expert coordinator, ensuring all requirements applicable to consent and capacity, best interest meetings and DoLS/LPS are fulfilled and documented.
	Understand and adhere to the MCA and the principles of capacity to consent to treatment (including the importance of accessible and appropriate information for PWE to achieve this).	Provide accessible and appropriate information to PWE and their care workers and families, to enable them to give informed consent to treatment.	Advocate for capacity to consent to treatment and ensure that the MCA is adhered to.

Competency	Novice	Competent	Expert
C4.1 Capacity to consent to treatment	Understand the fundamental principles of consent to treatment.	Demonstrate a detailed knowledge and understanding of the Adults with Incapacity (Scotland) Act 2000 and Mental Capacity Act 2005 and amendment 2019	Advise peer group and senior staff on the ethical issues surrounding informed consent.
	Understand the definition of incapacity and adhere to the principles of the Adults with Incapacity (Scotland) Act 2000.	Understand the link between the Act and the Mental Health (Care and Treatment) (Scotland) Act 2003 and statutory bodies with responsibility under the Act.	Advocate on behalf of PWE and ensure they can make informed choices when they are able to do so.
	Have a basic understanding of Part 5 of the Act, including Section 47.		Advise on and implement complex care and treatment plans.
	Be familiar with the provisions of the Act (e.g., powers of attorney and guardianship).		Contribute to local and national consultations.
Evidence examples	<ul style="list-style-type: none"> Evidence that relevant principles of the Adults with Incapacity (Scotland) Act are applied Evidence that the person's views have been taken into consideration when using accessible information, where appropriate Documentary evidence of completion of Section 47 of Part 5 of the Adults with Incapacity (Scotland) Act 2000 Evidence that relevant professional advice and onward referral have been considered 	<ul style="list-style-type: none"> Evidence of MDT working with relevant health and social care professionals, including mental health officer (MHO) Evidence of consultation with welfare guardian to develop the person's epilepsy care plan 	<ul style="list-style-type: none"> Production of minutes outlining the principles of the Adults with Incapacity (Scotland) Act Evidence of MDT consultation regarding complex care and treatment plans Participate in appropriate national guidelines and framework development (e.g., SIGN)

Competency	Novice	Competent	Expert
Further information	Implementation of the Mental Capacity Act (Northern Ireland) 2016 and related legislation including Mental Capacity Act 2005 and amendment 2019 (See Refs for links to legislation)		

D: Personal planning and organisation

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	Manage and prioritise allocated caseload and identify when appropriate to seek support by considering: <ul style="list-style-type: none"> Clinical activity Professional responsibilities. 	Manage own caseload and prioritise workload in response to service demands.	Prioritise and allocate caseload within service demands.
		Understand and apply the dynamic process of goal setting.	Balance resources to changing service needs.
		Initiate database development for caseload management if required.	Interpret the data available for service to ensure safe service delivery.
		Evaluate own capacity to workload.	
Evidence examples	<ul style="list-style-type: none"> Review of diary or Outlook calendar Data collection logs Evidence of clinical and managerial supervision 	<ul style="list-style-type: none"> Evaluation of critical incidents Review of time self-management Review of waiting lists Evidence of goal setting 	<ul style="list-style-type: none"> Evidence of team building Clinical and peer supervision notes Case study review Business plan/cases
D1.1 Managing phone/multimedia relationships	Take a sound, clear history of current problems faced by the PWE.	Have a sound method of documenting calls and advice given alongside any plans for treatment changes.	Develop, audit and research the use of telephone and multimedia with the intention of improving services locally and nationally.
	Demonstrate effective listening and questioning skills appropriate to telephone communication, ensuring the caller feels confident that their needs have been understood.	Use active questioning skills and recognise limitations of telephone contact and when to arrange a face-to-face follow-up.	
		Confidently manage distraught and unexpected calls.	

Competency	Novice	Competent	Expert
D1.1 Managing phone/multimedia relationships (continued)		Ensure methods for swift and effective communication of all plans made following telephone consultation and ensure these are communicated to all relevant personnel involved in the individual's care.	
	Work within regional guidance in relation to confidentiality in NHS England, Wales, Scotland or NI confidentiality policies.		
Evidence examples	<ul style="list-style-type: none"> • Evidence of documentation relating to call • Production of telephone records • Patient/carer testimonials 	<ul style="list-style-type: none"> • Testimony of care workers • Case study review • Evidence of clinical visits • Development of telephone call template sheets 	<ul style="list-style-type: none"> • PWE/carer satisfaction surveys • Development of care pathways/protocols • Clinical observations
D2 Knowledge development	Be aware of national best practice guidelines and the importance of working within guidelines for patient safety and professional accountability.	Use evidence-based practice to influence service development.	Use clinical governance frameworks to identify service/evidence-based gaps and use framework to address these.
	Recognise the importance of clinical supervision with other epilepsy professionals	Improve service quality through reflection on positive and negative clinical experience.	Initiate and provide skilled supervision for members of the team.
	Use reflection to identify areas for personal and professional development.	Maintain professional development through access to appropriate study days and courses.	Maintain advanced professional development through literature, self-directed study and networking.
	Participate in educational programmes e.g., recognised CPD programmes for the management of people with epilepsy.	Participate and contribute to educational programmes in epilepsy.	

Competency	Novice	Competent	Expert
Evidence examples	<ul style="list-style-type: none"> • Demonstrate evidence of working towards a qualification in epilepsy or the neurosciences at level 4 or above • Evidence of clinical visits 	<ul style="list-style-type: none"> • Demonstrate evidence of working towards an epilepsy or neurosciences qualification at first-degree level • Patient satisfaction surveys 	<ul style="list-style-type: none"> • Provide evidence of working towards MSc or PhD in a relevant subject area
D3 Accountability and autonomy	Demonstrate ability to work within the NMC code of professional standards of practice and behaviour for nurses and midwives (NMC, updated 2018).	Demonstrate ability to work flexibly within the scope of professional practice and challenge boundaries to develop new ways of working.	Demonstrate involvement in the development of best practice guidelines, ensuring national policy and guidance are considered.
	Be aware of how own personal and cultural beliefs can influence clinical judgements.	Be aware of professional boundaries and scopes of practice and adopt changes in approach to accommodate these.	Offer advice to other health professionals in the statutory and voluntary sectors and challenge if professional and personal boundaries become blurred.
	Maintain accurate records and understand the principles of data protection and confidentiality.	Share relevant information with the MDT and complete complex reports.	Audit records and manage breaches of data protection.
	Work within the framework of information governance.	Ensure others are aware of and work within the realm of information governance.	Contribute to the ongoing development and review of information governance.
	Understand policy and procedures that may impact on service delivery e.g., 'lone working' policy.	Implement regional and national guidance.	Take strategic overview of service and be accountable for developing new services and implementing local/national guidance.
			Act as an expert/advocate at local and national level to help with challenges and develop epilepsy services.
	Demonstrate access to current NICE/SIGN/MHRA and other relevant guidelines.	Interpret guidelines within own clinical practice.	Influence service delivery in line with guidelines at local and national level.

Competency	Novice	Competent	Expert
Evidence examples	<ul style="list-style-type: none"> Discuss lone working policy, highlighting risks Incident analysis 	<ul style="list-style-type: none"> Show risk assessment forms and compliance with policies Adherence to local lone working policy Anticipate any potential associated personal risks Clinic templates Clinical observation 	<ul style="list-style-type: none"> Testimony from MDT members Evidence of service adaptation Development of clinical pathways and protocols
D4 Recognising professional and personal development needs	Identify own professional limitations.		
	Work under a high degree of support and supervision.	Work independently with minimal supervision.	Recognise if NMC standards and clinical governance are not met and offer peer supervision as needed.
	Work within clinical governance and NMC standards and begin to develop skills for leadership and innovation.	Develop skills for leadership and innovation, including clinical governance and working to NMC standards.	Drive leadership and innovation, including clinical governance and working to NMC standards.
	Understand the importance of CPD.	Understand the theory behind education.	Act as a role model at local and national level, promoting best practice to aid service and professional development.
	Identify and effectively use a mentor or gain support.		
Evidence examples	<ul style="list-style-type: none"> Attendance at local and national meetings or conferences Contact sheets/PDP 	<ul style="list-style-type: none"> Certificate/diploma in epilepsy RN with post-qualification experience and evidence working towards a first-level degree Recognised teaching qualifications Evidence of working with PWE who have complex epilepsy, through production of case study 	<ul style="list-style-type: none"> Postgraduate diploma with extensive experience of working with PWE who have complex epilepsy Evidence of working towards an MSc or PhD Non-medical prescriber (NMP)

E: Joint working and professional relationships

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 the MDT works and when PWE may be referred to other services to aid diagnostic process.	Collaborate with the MDT as required to provide a seamless service and understand the potential limitations within the service/team.	Work across other services providing joint specialist clinics to provide high-quality specialist input for PWE.
	Identify and promote relationships with other epilepsy services provided by health, social care and voluntary sectors.	Establish links with wider epilepsy services to understand and appreciate differing roles including your own.	Be aware of the scope of other professional roles and ensure all aspects of care are met through agreed roles and responsibilities.
	Establish relationships that promote partnership working and work in conjunction with other professionals to enhance the management of a person's epilepsy.	Develop interprofessional services through cooperative working between own and other services.	Work as independent practitioner within the MDT, with the role to be renegotiated as experiences are gained.
		Mediate between services and facilitate complex and ethical decision-making.	
	Communicate effectively with other professionals to enhance service delivery By demonstrating how the role impacts on service delivery.	Understand the scope of own professional role and how that will enhance wider services and the services PWE may receive.	Acknowledge the influence of driving factors around service delivery, such as local or national policies.
		Identify limitations within the service/team.	Address any limitations within the service/team.
			Devise and deliver generic and specific in-service training packages to a range of professionals.
E2 Professional networking	Foster good working partnerships with care providers.		
	Establish working relationships between health and social care, voluntary and statutory sectors.	Act as a link for advice and support within established working relationships.	

Competency	Novice	Competent	Expert
E2 Professional networking (continued)	Recognise the importance of, and participate in, networking opportunities.	Seek opportunities to network at wider level, accessing specialist groups and training opportunities.	Initiate and foster networking opportunities.
	Be aware of regulations that apply to conduct between nurses and drug representatives and pharmaceutical companies.		
Evidence examples	<ul style="list-style-type: none"> • Evidence of networking opportunities • Development of contact list • Documentation of minutes from networking groups • Maintain a register of interests 	<ul style="list-style-type: none"> • Documented attendance at networking opportunities • Evidence of review of benefits of networking and how this has influenced practice through reflection 	<ul style="list-style-type: none"> • Documented evidence of planning or hosting networking opportunities/meetings • Evidence of development of networks, including in linked areas • Terms of reference and membership lists for new networking groups
E3 Integration and development of services			Contribute to development of policies and services through nurse leadership (e.g. transitional care, joint generic neurology clinic and emergency care).
			Identify and work with key people to support the introduction of service developments.
			Work jointly with professionals across different organisations to enable enhanced provision of care.
Evidence examples	<ul style="list-style-type: none"> • Demonstrate links with other departments and providers of services • 360-degree appraisal with other team members and services 	<ul style="list-style-type: none"> • Contact log • Provide evidence of advocacy through meetings and referrals • Evidence of service development • Demonstrate range of referrals made to/from adult ESN • Evidence of use of care pathways • Testimonies from HCPs 	<ul style="list-style-type: none"> • Business plans • Minutes of meetings with action points • Policy and protocol development • Development of new care pathways • Development of shared care guidelines

Competency	Novice	Competent	Expert
E4 Negotiation, influencing and leading innovation			Recognise gaps in services and influence local provision by developing epilepsy nursing leadership and innovation.
			Influence policy at local and national level.
Evidence examples	<ul style="list-style-type: none"> • Testimony from care workers • Production of networking minutes/attendance certificates • Peer supervision • Review of relevant literature • Evidence of referrals to other MDT members 	<ul style="list-style-type: none"> • Testimony from professionals • Evidence of MDT working • Review service objectives • Evidence of PWE and public consultation 	<ul style="list-style-type: none"> • Development of shared care protocols • Publication of articles • Evidence of service evaluation/review • Evidence of business plans

F: Creating an effective learning environment

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	Understand and describe the potential barriers to learning in teaching PWE, families and carers about epilepsy in a clinical setting.	Use appropriate information to discuss and teach PWE, families and carers about epilepsy risks and management.	Develop, research and audit materials to support learning for PWE, families and carers, and minimise potential barriers to learning.
	Identify opportunities for patient education.		Incorporate the concept of the expert patient.
Evidence examples	<ul style="list-style-type: none"> • Observed clinical reviews and teaching • Diary of teaching opportunities • Case studies • Patient/mentor witness statements 	<ul style="list-style-type: none"> • Portfolio of teaching evaluation • Documentation of information giving • Evaluation from PWE, families and carers 	<ul style="list-style-type: none"> • Teaching evaluation • Discussion of the use and limitations of different teaching tools • New educational materials • Demonstrate use of a wide variety of information tools
F2 Sharing knowledge and skills with MDT members and other colleagues		Work with other service providers, such as local authority and education, to develop their knowledge and understanding of epilepsy.	
	Share knowledge with nursing colleagues and provide mutual peer support.	Share knowledge and best practice with other professionals, using clinical expertise and best practice guidance.	Participate in knowledge dissemination at regional, national, and international level.
	Teach within own limitations, providing education as a mentor and at local level via in-house training, either face to face or using multimedia as appropriate.	Deliver teaching sessions in pre-registration programmes, and work towards delivering higher education.	Demonstrate delivery of pre- and post-registration training programmes.
		Act as a supervisor and/or assessor for student nurses, associate nurses and AHPs.	Provide advice and education to other professionals (e.g. pharmacists and GPs) through CPD workshops.

Competency	Novice	Competent	Expert
F2 Sharing knowledge and skills with MDT members and other colleagues (continued)	Provide education to voluntary and non-professional groups.	Deliver specialist epilepsy educational sessions in a variety of settings.	Work both locally and nationally within the epilepsy circuit, speaking at local and national conferences and writing for publication.
		Use varied communication techniques to enhance the learning experience.	
Evidence examples	<ul style="list-style-type: none"> • Participation feedback • Evidence of teaching packs • PDP • Diary of teaching opportunities • Review of evaluation sheets 		<ul style="list-style-type: none"> • Submit and review articles for publication • Feedback from the MDT • Teaching plans
F3 Develop, facilitate and evaluate educational programmes	Actively seek feedback/evaluation from training programmes.	Use a range of educational evaluation tools.	Provide curriculum advice for developing accredited courses.
		Be able to evidence how feedback is used in future programmes.	Engage in assessments of post-registration and postgraduate students.
		Evaluate training/teaching sessions.	Act as a 'university link' for postgraduate study for nursing, medicine and AHPs.
			Incorporate feedback and evaluation in future training packs.
Evidence examples		<ul style="list-style-type: none"> • Critically analyse published research and incorporate in teaching sessions • Evidence of training plans • Attendance certificates • Review of training evaluation forms • Assessment of learning outcomes • Evidence of review of training and production of new material 	<ul style="list-style-type: none"> • Use knowledge to develop educational programmes • Appraisal • Evidence of development and assessment of educational programmes • Demonstrate links to higher education • Publish articles, posters and presentations

Competency	Novice	Competent	Expert
F4 Mentorship	Identify and effectively use a mentor to gain support, explore ideas and devise a personal development plan.	Provide mentorship to less experienced nurses.	Support and guide other nurse mentors.
		Act as mentor to other healthcare professionals.	Act as a mentor at local, national and international levels.
Evidence examples	<ul style="list-style-type: none"> • PDP 	<ul style="list-style-type: none"> • Witness statements from novice ESNs • Evidence from meetings • Diary 	<ul style="list-style-type: none"> • Set up and maintain robust professional support • Speaker/poster presentation at local and national meetings or conferences

G: Research and audit

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	Be aware of and able to access common databases of research evidence relevant to epilepsy practice.	Differentiate between research that will improve practice and research that will promote change.	Use research findings to influence policy and/or service developments locally and nationally.
	Use research that has been published by others to support ESN role.	Identify research that is pertinent to improving practice and promoting change.	Be able to critically appraise published research.
Evidence examples	<ul style="list-style-type: none"> Provide examples of what is meant by evidence-based practice Complete a literature search 	<ul style="list-style-type: none"> Critical appraisal of publications Read an epilepsy journal monthly to keep up to date with research developments Journal clubs 	<ul style="list-style-type: none"> Publication Critically evaluate research papers
G2 Critical appraisal of practice	Understand the importance of critically analysing practice.	Develop critical appraisal skills in relation to clinical practice.	Use critical appraisal skills to transport high-quality evidence-based research into clinical practice to support practice and service developments.
Evidence examples			Evidence of research use in service delivery and development.
G3 Clinical trials	Understand and explain to patients the concept and need for clinical trials.	Actively recruit patients for a clinical trial. Understand the impact a clinical trial may have on patients and services.	Work within the MDT to coordinate a clinical trial and collate data.
Evidence examples	<ul style="list-style-type: none"> Be aware of ABPI code of practice guidelines 	<ul style="list-style-type: none"> Work within NMC and RCN scope of professional practice 	<ul style="list-style-type: none"> Study report Abstract/poster presentation Evidence of working within clinical trial protocol
G4 Patient survey	Understand the need for patient feedback.	Undertake patient satisfaction surveys, using accessible information.	Use the audit cycle to evidence how a person's feedback is incorporated into service development/change.
Evidence examples	<ul style="list-style-type: none"> Evidence of the person's feedback involvement 	<ul style="list-style-type: none"> Review of PWE and care worker satisfaction surveys 	

Competency	Novice	Competent	Expert
G5 Carrying out research	Identify those carrying out MDT epilepsy research in the local area.	Contribute to the design and practical implementation of local MDT epilepsy research projects.	Demonstrate an in-depth knowledge of the ethical implications of research, and an understanding of the ethical approval pathway.
		Explain the importance of local research and understand the difference between research and audit.	Identify nursing research questions and take the lead in research design data collection and dissemination of findings.
Evidence examples	<ul style="list-style-type: none"> • Knowledge of protocols and contacts for local MDT epilepsy research group • Knowledge of patients recruited to projects 	<ul style="list-style-type: none"> • Participate in MDT epilepsy research projects • Attendance at research planning meetings • Evidence that research is used to improve patient care 	<ul style="list-style-type: none"> • Research proposals • Grant applications • Publication and presentation of research projects • Participation in multi-centre research
G6 Carrying out audit and service evaluation	Explain the audit cycle.	Use audit to promote effectiveness of role and support key service outcomes.	Engage in multi-centre audit studies.
	Understand how the use of audit influences NHS care.	Lead the development of an audit and use a wide range of tools.	Be responsible for presentation of audit findings at local, directorate, organisational and national level.
	Contribute to an audit that has a direct link to the ESN role.	Engage in service evaluation that has a person focus.	Take the lead in the publication of local audits/ research outcomes.
	Explain the role of audit as part of the wider element of clinical governance.	Be involved in publication of local audit findings.	
	Use audit in a local capacity to enhance service frameworks and development role to identify which components of the role are appropriate to audit.		

Competency	Novice	Competent	Expert
Evidence examples	<ul style="list-style-type: none"> • Evidence of agreed audit plan • Data collection for research and audit 	<ul style="list-style-type: none"> • Evidence of audit data from own service • Production of annual reports/review of service delivery • Evidence of personal satisfaction audit in an accessible format • Production of application forms for local audit committee • Evidence of review of audit findings and implementation of recommendations 	<ul style="list-style-type: none"> • Evidence of presenting in local or national arena • Poster presentations • Evidence of service development • Publications • Contribution to guidelines surrounding epilepsy care

H: Supporting specific patient groups

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 Women with epilepsy (WWE)	Be aware of the impact of hormones, menstrual health and contraception for women with epilepsy.	Be able to discuss available contraceptive options for women taking ASMs.	Be able to advise women and the MDT on hormones, menstrual health appropriate and effective contraception for women taking different ASMs.
	Understand the pre-conceptual issues for WWE planning pregnancy. Discuss in a timely manner to support women to plan a safe pregnancy	Discuss and plan with women their pregnancy plans and develop care plans to monitor/adjust ASMs. Discuss and support to manage labour and delivery plans	Sensitively discuss available data surrounding epilepsy risks and treatment during pregnancy including teratogenic data and risk of death and how to minimise risks. Be aware of the limitations in teratogenic data for all antiseizure medications and be able to discuss confidently.
	Be familiar with restrictions in use of sodium valproate in WWE of childbearing age.	Discuss specific teratogenic risks of sodium Valproate and options for alternative treatment. Discuss valproate pregnancy prevention programme and completion of ARAF and databases.	Develop shared care agreement/database and standard operating procedure (SOP) for prescription of valproate.
	Be aware of the need to support WWE following the birth of their baby	Advice and plan with WWE how to parent effectively and safely. Review ASM post nately	Develop collaborative relationships with obstetric medicine and epilepsy services.
	Be aware of health issues specific to WWE throughout their lifespan.	Be able to discuss the differing impact of hormonal changes for WWE including impact on seizures, fertility, libido, bone density and psychological health Have a sound method of ensuring information pertaining to women is provided in a timely/patient appropriate manner	Provide expert advice and education to professionals and WWE around measures to help reduce the impact of hormonal changes on seizures, bone density and psychological health Pre-empt the need for appropriate advice throughout lifespan and the impact of ASMs and epilepsy in the peri/menopausal years.

Competency	Novice	Competent	Expert
H2 Men with epilepsy (MWE)	<p>Be aware of the impact of epilepsy and ASM's on men across the lifespan .Be aware of the specific risks associated with sodium valproate for men</p> <p>Be familiar with current MHRA recommendations for the prescribing of sodium valproate in men under the age of 55 years. (https://www.gov.uk/government/news/update-on-mhra-review-into-safe-use-of-valproate)</p>	<p>Be able to discuss the issues faced by men across the lifespan of their epilepsy including parenting, libido, sexuality, contraception, fertility and bone health.</p> <p>Be able to discuss ASM options for men and be aware of the requirements for prescribing sodium valproate in men under 55.</p>	<p>Be able to discuss the current data on sodium valproate use in men and the potential impact on fertility in line with current MHRA advice.</p> <p>Lead on a robust, responsive pathway for the decision-making process around ASM's and men under the age of 55.</p> <p>Ensure that MWE 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.</p>
Evidence examples	<ul style="list-style-type: none"> • Telephone log • Patient satisfaction surveys • Discussion with mentor • Documentation 	<ul style="list-style-type: none"> • Testimony from WWE • Case study review • Evidence of reflective practice • Discussion with mentor • Annual risk acknowledgment risk forms (ARAFs) 	<ul style="list-style-type: none"> • 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	
H3 Epilepsy in older people	<p>Describe the causes and risk factors for epilepsy in the older person and the potential diagnostic pitfalls.</p> <p>Be aware of dementia in new onset epilepsy.</p>	<p>Understand the alternative diagnosis in the older person who has seizures and be able to discuss.</p> <p>Recognise the signs and symptoms of dementia and appropriately refer to specialist clinics for support and assessment.</p>	<p>Confidently be able to discuss the common links between the most common co-morbidities in the older person with epilepsy, and to implement appropriate care plans.</p> <p>Diagnose and treat epilepsy in older people with dementia and consider the impact of treatment on their mood/cognition/compliance /safety.</p>

Competency	Novice	Competent	Expert
H3 Epilepsy in older people (continued)	Be aware of the ASM's which may be prescribed for the older person with epilepsy.	Understand pharmacokinetic differences of ASMs in the older person and be able recommend treatments and make appropriate adjustments. Recognise the problems associated with polypharmacy in this age group and the impact this may have on concordance.	Confidently advise on potential interactions of ASMs with commonly prescribed concomitant medications in the older person with epilepsy and suggest/implement measures to ameliorate these risks.
	Be aware of the increased risks associated with seizures in the older person with epilepsy.	Understand and be able to discuss risk and impact of epilepsy specific to this age group.	Develop and implement strong links with local services to support independence and safeguard the older person with epilepsy.
	Describe the potential impact on quality of life/ psychological well-being for the older person with epilepsy.	Be able to offer appropriate advice and support to minimise physical and mental health risks and promote quality of life in the older person with epilepsy.	Identify when to refer an older person with epilepsy for further assessments (dementia/Alzheimers/ mental health as appropriate).
Evidence examples	<ul style="list-style-type: none"> • Observed clinics • Evidence of ability to build positive patient/nurse relationships • Evidence of reflective practice 	<ul style="list-style-type: none"> • Case study review • Evidence of reflective practice • Evidence of advocacy and risk assessment 	<ul style="list-style-type: none"> • Evaluation of patient and carer satisfaction surveys • Business plans • Policy and protocol development • Integrated care pathways • Safeguarding protocols and assessments
H4 Patients with psychiatric comorbidities	Be aware of the increased rates of comorbid psychiatric disorders in adults and young people with epilepsy.	Be able to discuss the risks of psychiatric disorders with the adult or young person with epilepsy.	Confidently be able to educate non-specialists in the bidirectional relationship between psychiatric disorders and epilepsy and explain the benefits of treating both.
	Be aware of the presence of some psychiatric disorders and their temporal relationship to seizures.	Be able to confidently discuss the range of psychiatric disorders that may occur before, or after seizures and be able to discuss with adults and young people with epilepsy.	Ensure expert advice for non-specialist staff managing seizure-related psychiatric disturbance in the adult or young person with epilepsy.

Competency	Novice	Competent	Expert
H4 Patients with psychiatric comorbidities (continued)	Acknowledge that adults and young people with epilepsy may suffer increased rates of social limitation, exclusion and this may result in psychiatric disorder.	Develop close working relationships across acute and community services to ensure adults and young people with epilepsy and comorbid psychiatric disorders can access appropriate and timely support.	Enhance and develop services that are responsive to PWE with psychiatric comorbidities. Audit support services for adults and young people with epilepsy who may also have comorbid psychiatric disorders.
	Be aware that some antiseizure medication can cause psychiatric symptoms.	Be able to discuss the range of psychiatric symptoms/ side-effects that are common to each antiseizure medication.	Provide expert advice and education to non-specialists regarding management of adults and young people experiencing psychiatric side-effects secondary to antiseizure medications.
Evidence examples	<ul style="list-style-type: none"> • Observed clinics • Evidence of ability to build positive patient/nurse relationships • Evidence of reflective practice 	<ul style="list-style-type: none"> • Case study review • Evidence of reflective practice • Evidence of advocacy • Understanding of relevant, validated assessment tools 	<ul style="list-style-type: none"> • Evaluation of patient and carer satisfaction surveys • Business plans • Policy and protocol development • Attendance at conferences and speaker engagements • Poster presentations
H5 Transition between child and adult services	<p>Understand the principles of transition services and involve young people in the planning for their transition to adult services in-line with the NICE guideline on transition from children's to adults epilepsy services.</p> <p>Be aware of the risks of stigma and social exclusion for the young person with epilepsy.</p>	<p>Achieve cooperative working with MDT's across children's services and adults 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.</p> <p>Provide education and information at appropriate points in the young person's journey and ensure it is provided in an accessible format to enable them to make decisions about their lives and living with epilepsy.</p>	<p>Recognise gaps in transition services and influence local provision.</p> <p>Acknowledge rates of disengagement after transition to adult care and demonstrate a flexible and person-centred care pathway which meets the need of the young person and their families/carers.</p> <p>Incorporate opportunities for young people and their families/carers to feedback on transition to adult services which is anonymous and confidential and utilise this feedback to demonstrate improvement in services.</p>

Competency	Novice	Competent	Expert
H5 Transition between child and adult services (continued)	Be able to describe the differences between child-centred and adult oriented healthcare systems.		Audit services and use findings to develop/improve services.
Evidence examples	<ul style="list-style-type: none"> • Observed clinics • Evidence of ability to build positive patient/nurse relationship • Evidence of reflective practice 	<ul style="list-style-type: none"> • Case study review • Evidence of reflective practice • Evidence of advocacy 	<ul style="list-style-type: none"> • Evaluation of patient and carer satisfaction surveys • Analysis of attrition rates during transition to adult services • Business plans • Policy and protocol development
H6 Neuro-oncology/ Patients with brain tumours	Understand that people with brain tumours are at increased risk of developing seizures.	Ensure collaborative working relationships with oncology services to meet the needs of 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 support PWE who have brain tumours.	Develop a responsive service for PWE who have brain tumours in close collaboration with oncology services and patients.
	Recognise the clinical features of seizures associated with brain tumours.		Complete audit/patient satisfaction surveys and use to improve services provided for PWE who have brain tumours.
Evidence examples	<ul style="list-style-type: none"> • Observed clinics • Evidence of understanding of the WHO classification of tumours of the central nervous system • Evidence of reflective practice 	<ul style="list-style-type: none"> • Case study review • Evidence of reflective practice • Evidence of links between epilepsy and neuro-oncology services e.g., referral pathways/joint clinics 	<ul style="list-style-type: none"> • Evaluation of patient and carer satisfaction surveys • Business plans to enhance service provision • Policy and protocol development • Presentation at neuro-oncology meetings/conferences

Competency	Novice	Competent	Expert
H7 Vulnerable groups at higher risk of Sudden Unexpected Death in Epilepsy (SUDEP)	<p>To be aware of the risk factors that make some people at higher risk of SUDEP.</p> <p>To signpost carers and families to specific resources.</p> <p>To be able to suggest ways to reduce risks.</p>	<p>To be able to discuss risk factors of SUDEP with PWE in a proportionate way.</p> <p>To be able to discuss current thinking on the mechanisms and causes of SUDEP.</p> <p>To be aware of and use risk assessment tools such as the SUDEP and Seizure safety Check List and the specialist Apps.</p> <p>To report any SUDEP or suspected SUDEP on the Epilepsy Deaths Register.</p>	<p>To participate in national research and audits to increase knowledge of SUDEP.</p> <p>To counsel families and carers bereaved by a SUDEP Death.</p> <p>To represent your service at any coroner's enquiry or serious case review into a SUDEP death.</p>
Evidence Examples	<ul style="list-style-type: none"> • Reflective discussion • Evidence of reflective practice • Observation 	<ul style="list-style-type: none"> • Evidence of reflective practice • Evidence of use of appropriate risk assessment tools 	<ul style="list-style-type: none"> • Published audits research and papers • Evidence of reflective practice • Presentations at national meetings

Appendix 1: References and bibliography


1. **All Party Parliamentary Group on Epilepsy (2007)**. The human and economic cost of epilepsy in England. https://www.epilepsy.org.uk/sites/epilepsy/files/images/campaigns/arygrouponepilepsy_wasted_money_wasted_lives.pdf Accessed [15/09/2021].
2. **Analytic Quality Glossary (2012)**. Competence. <http://qualityresearchinternational.com/glossary/competence.htm> Accessed [11/07/2021].
3. **Association of British HealthTech Industries (ABHI) (2021)**. Code of ethical business practice. <https://www.abhi.org.uk/code-of-ethical-business-practice/> Accessed [09/03/2020].
4. **Association of the British Pharmaceutical Industry (ABPI) (2021)**. Code of practice for the pharmaceutical industry 2021. <https://www.abpi.org.uk/our-ethics/abpi-code-of-practice/> Accessed [09/03/2020].
5. **Benner P (1984)**. From novice to expert: excellence and power in clinical nursing practice. California: Addison-Wesley Publishing Company. <https://nursing-theory.org/theories-and-models/from-novice-to-expert.php>
6. **Benner P, Tanner CA and Chesla CA (1996)**. Expertise in nursing practice: caring, clinical judgement and ethics. New York: Springer Publishing.
7. **Beghi E, (2020)**. The Epidemiology of epilepsy, *Neuroepidemiology* 2020;54:185–191 <https://www.karger.com/article/Pdf/503831>. Accessed (01/11/22).
8. **Beghi, E., Giussani, G. and Sander, J.W. (2015)**. The natural history and prognosis of epilepsy. *Epileptic Disorders*, 17: 243-253. <https://doi.org/10.1684/epd.2015.0751>. Accessed (1/11/22)
9. **British Medical Association (updated 2022)**. GMS contract Wales 2020/21. <https://www.bma.org.uk/pay-and-contracts/contracts/gp-contract/gp-contract-wales-202021>. Accessed [18/01/2022].
10. **Campbell F, Sworn K, Booth A, Reuber M, Grünwald R, Mack C and Dickson JM (2019)**. Epilepsy Specialist Nurses the Evidence (ESPENTE): a systematic mapping review. *Epilepsy Action*. <https://www.ilae.org/files/dmfile/The-ESPENTE-Study---Epilepsy-Specialist-Nurses.pdf> Accessed [27/09/2021].
11. **Department of Health (2000)**. The NHS Plan: A plan for investment, a plan for reform. https://webarchive.nationalarchives.gov.uk/20130124064356/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118522.pdf Accessed [09/03/2020].
12. **Department of Health (2001a)**. National service framework: Older people. <https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people> Accessed [09/03/2020].
13. **Department of Health (2003)**. Confidentiality: NHS code of practice. <https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice> Accessed [10/07/2021].
14. **Department of Health (2004a)**. Agenda for Change – Final agreement. https://webarchive.nationalarchives.gov.uk/20130103042008/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4099423.pdf Accessed [09/03/2020].
15. **Department of Health (2004b)**. The NHS Knowledge and Skills Framework (NHS KSF) and the development review process. https://webarchive.nationalarchives.gov.uk/20130124065244/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090861.pdf Accessed [09/03/2020].
16. **Department of Health (2005)**. National service framework: long term conditions. <https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions> Accessed [09/03/2020].
17. **Department of Health (Northern Ireland) (undated)**. About the GP contract. <https://www.health-ni.gov.uk/articles/gp-contract>. Accessed [09/03/2020]

18. **Epilepsy Action (undated)**. Resources for GPs and health professionals. <https://www.epilepsy.org.uk/professional/primary-care/resource-pack> Accessed [23/11/2021].
19. **Epilepsy Action (undated 1)**. Contraception and epilepsy. <https://www.epilepsy.org.uk/info/daily-life/sex/contraception> Accessed [09/03/2020].
20. **Epilepsy Action (undated 2)**. Keeping a seizure diary. <https://www.epilepsy.org.uk/info/diagnosis/seizure-diary> Accessed [09/03/2020].
21. **Epilepsy Action (2009)**. Epilepsy in England: time for change. <https://www.epilepsy.org.uk/involved/campaigns/previous-surveys/2009/time-for-change> Accessed [15/09/2021].
22. **Epilepsy Action (2021)**. Epilepsy facts and terminology. <https://www.epilepsy.org.uk/press/facts> Accessed [11/07/2021].
23. **Epilepsy Bereaved (2002)**. National Sentinel Clinical Audit of Epilepsy-Related Death. <https://sudep.org/sites/default/files/national-sentinel-clinical-audit-of-epilepsy-related-death-2002-summary.pdf> Accessed [15/09/2021].
24. **Epilepsy Research UK (undated)**. Epilepsy statistics. <https://epilepsyresearch.org.uk/about-epilepsy/epilepsy-statistics/> Accessed [23/11/2021].
25. **Epilepsy Specialist Nurses Association (ESNA) (2012)**. The Adult Epilepsy Specialist Nurse Competency Framework. https://www.epilepsy.org.uk/sites/epilepsy/files/professionals/competency_frameworks/ESN_Adult_Competency_Framework.pdf Accessed [27/09/2021].
26. **Epilepsy Specialist Nurses Association (ESNA) (2013)**. The Learning Disability Epilepsy Specialist Nurse Competency Framework. https://www.epilepsy.org.uk/sites/epilepsy/files/professionals/LD%20ESN%20Competency%20Framework_v0%203_20Feb13.pdf Accessed [27/09/2021].
27. **Epilepsy Specialist Nurses Association (ESNA) (2019)**. Best practice guidelines for training professional carers in the administration of Buccal (Oromucosal) Midazolam for the treatment of prolonged and/or clusters of epileptic seizures in the community. <https://www.esna-online.org/> Accessed [11/07/2021].
28. **Epilepsy Specialist Nurses Association (ESNA) (2021)**. Competency checklist for the administration of Buccal (Oromucosal) Midazolam. https://www.epistatus.co.uk/downloads/Competency_Checklist_for_Oromucosal_Midazolam_Administration.pdf Accessed [11/07/2021].
29. **Fisher R, Acevedo C, Arzimanoglou A et al. (2014)**. ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia* 55(4):475–82. [https://onlinelibrary.wiley.com/doi/full/10.1111/epi.12550/](https://onlinelibrary.wiley.com/doi/full/10.1111/epi.12550)
30. **G. Giussani , V. Canelli , E. Bianchi , G. Erba , C. Franchi , A. Nobilii , J. W. Sande, E. Beghi and the EPIRES Group (2016)** Long-term prognosis of epilepsy, prognostic patterns and drug resistance: a population-based study *European Journal of Neurology* , 23: 1218– 122 <https://doi.org/10.1111/ene.13005> Accessed [11/07/2021].
31. **Gilliam FG, Barry JJ, Hermann BP, Meador KJ, Vahle V and Kanner AM (2006)**. Rapid detection of major depression in epilepsy: a multicentre study. *Lancet Neurology* 5(5):399-405. [https://doi.org/10.1016/S1474-4422\(06\)70415-X](https://doi.org/10.1016/S1474-4422(06)70415-X)
32. **Gobet F and Chassy P (2008)**. Towards an alternative to Benner’s theory of expert intuition in nursing: A discussion paper. *International Journal of Nursing Studies* 45(1):129–39. <https://www.sciencedirect.com/science/article/abs/pii/S0020748907000302?via%3Dihub>
33. **Greenhalgh J, Weston J, Dunder Y, Nevitt SJ and Marson AG (2020)**. Antiepileptic drugs as prophylaxis for postcraniotomy seizures. <https://doi.org/10.1002/14651858.CD007286.pub5>

34. **Health Education England (HEE) (2017).** Multi-professional framework for advanced clinical practice in England. <https://www.hee.nhs.uk/sites/default/files/documents/multi-professionalframeworkforadvancedclinicalpracticeinengland.pdf> Accessed [27/09/2021].
35. **Higgins A, Downes C, Varley J, Doherty CP, Begley C and Elliot N (2018).** Rising to the challenge: Epilepsy specialist nurses as leaders of service improvements and change (SENSE Study). *Seizure* 63:40–7. [https://www.seizure-journal.com/article/S1059-1311\(18\)30505-3/fulltext](https://www.seizure-journal.com/article/S1059-1311(18)30505-3/fulltext)
36. **Higgins A, Downes C, Varley J, Doherty CP, Begley C and Elliott N (2019).** Supporting and empowering people with epilepsy: Contribution of the Epilepsy Specialist Nurses (SENSE study). *Seizure* 71:42–9. <https://doi.org/10.1016/j.seizure.2019.06.008>
37. **Louis DN, Perry A, Reifenberger G, von Deimling A et al. (2016).** The 2016 World Health Organization Classification of Tumors of the Central Nervous System: a summary. *Acta Neuropathologica* 131:803–20. <https://braintumor.org/wp-content/assets/WHO-Central-Nervous-System-Tumor-Classification.pdf>
38. **Medicines and Healthcare Regulatory Agency (MHRA) (2023)** <https://www.gov.uk/government/news/update-on-mhra-review-into-safe-use-of-valproate> Accessed [08/03/23].
39. **Mula M, McGonigal A, Micoulaud-Franchi J-A, May TW, Labudda K and Christian Brandt C (2016).** Validation of rapid suicidality screening in epilepsy using the NDDIE. *Epilepsia* 57(6):949–55. <https://doi.org/10.1111/epi.13373>
40. **Mula, M., Kanner, A.M., Jetté, N. and Sander, J.W., 2021.** Psychiatric comorbidities in people with epilepsy. *Neurology: Clinical Practice*, 11(2), pp.e112–e120.
41. **Murrells T, Robinson S and Griffiths P (2009).** Assessing competence in nursing. *Nursing Management* 16(4):18–9. https://www.researchgate.net/publication/26702780_Assessing_competence_in_nursing
42. **National Guideline Centre (UK).** Evidence review: Transition from paediatric to adult epilepsy services: Epilepsies in children, young people and adults: diagnosis and management: Evidence review 20. London: National Institute for Health and Care Excellence (NICE); 2022 Apr. PMID: 35700298.
43. **National Institute for Health and Care Excellence (NICE) (2022).** Epilepsies in children, young people and adults. NICE guideline 217. <https://www.nice.org.uk/guidance/ng217> Accessed [25/06/2022].
44. **National Occupational Standards database (undated).** <http://www.ukstandards.co.uk/Pages/index.aspx> Accessed [09/03/2020].
45. **NHS Education for Scotland (NES) (undated).** Nursing, midwifery and allied health professionals (NMAHP) development framework. <https://www.nmahpdevelopmentframework.nes.scot.nhs.uk/> Accessed [23/11/2021].
46. **NHS Education for Scotland (NES) (2008, updated 2012).** Advanced nursing practice toolkit. <http://www.advancedpractice.scot.nhs.uk/> Accessed [09/03/2020].
47. **NHS Education for Scotland (NES) (2012).** Post-registration career development framework for nurses, midwives and allied health professionals. <https://www.careerframework.nes.scot.nhs.uk/post-reg-framework/> Accessed [27/09/2021].
48. **NHS Employers (undated).** NHS terms and conditions of service (Agenda for Change). <https://www.nhsemployers.org/topics-networks/pay-pensions-and-reward/nhs-terms-and-conditions-service-agenda-change> Accessed [20/01/2022].
49. **NHS England (undated).** GP contract. <https://www.england.nhs.uk/gp/investment/gp-contract/> Accessed [23/11/2021].

50. **NHS Scotland (2005).** Framework for developing nursing roles. <https://www.webarchive.org.uk/wayback/archive/20150221102352/http://www.gov.scot/Publications/2005/07/08144857/49036> Accessed [21/03/2022].
51. **NHS Wales and National Leadership and Innovation Agency for Healthcare (NLIAH) (2011).** Framework for advanced nursing, midwifery and allied health professional practice in Wales. www.wales.nhs.uk/sitesplus/documents/829/NLIAH%20Advanced%20Practice%20Framework.pdf Accessed [09/03/2020].
52. **Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC) (2016).** Advanced nursing practice framework. <https://www.health-ni.gov.uk/publications/advanced-nursing-practice-framework> Accessed [27/09/2021].
53. **Nursing and Midwifery Council (NMC 2018)** Standards of proficiency for registered nurses <https://www.nmc.org.uk/globalassets/sitedocuments/standards-of-proficiency/nurses/future-nurse-proficiencies.pdf> Accessed [Accessed 6.11.22]
54. **Nursing and Midwifery Council (NMC) (2014).** Standards for competence for registered nurses. <https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-competence-for-registered-nurses.pdf/> Accessed [10/07/2021].
55. **Nursing and Midwifery Council (NMC) (2015).** Revalidation. www.nmc.org.uk/standards/revalidation Accessed [27/09/2021].
56. **Nursing and Midwifery Council (NMC) (2016).** Modernising fitness to practise – Changes to the Fitness to Practise Rules 2004. <https://www.nmc.org.uk/about-us/consultations/past-consultations/2016-consultations/modernising-fitness-to-practise---changes-to-the-fitness-to-practise-rules-2004/> Accessed [09/03/2020].
57. **Nursing and Midwifery Council (NMC) (updated 2018).** The Code: Professional standards of conduct, performance and ethics for nurses, midwives and nursing associates. <https://www.nmc.org.uk/standards/code/> Accessed [09/03/2020].
58. **Nursing and Midwifery Council (NMC) (2018).** Standards of proficiency for registered nursing associates. <https://www.nmc.org.uk/standards/standards-for-nursing-associates/> Accessed [11/07/2021].
59. **Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009).** Six lives: the provision of public services to people with learning disabilities. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250750/0203.pdf Accessed [15/09/2021].
60. **Public Health England (PHE) (2014).** Making reasonable adjustments to epilepsy services for people with learning disabilities. https://www.ndti.org.uk/assets/files/Epilepsy_services.pdf Accessed [15/09/2021].
61. **Rampling J, Mitchell AJ, Von Oertzen T, Docker J, Jackson J, Cock H et al. (2012).** Screening for depression in epilepsy clinics. A comparison of conventional and visual-analog methods. *Epilepsia* 53(10):1713-21. <https://doi.org/10.1111/j.1528-1167.2012.03571.x>
62. **Roach MS (1992).** The human act of caring: a blueprint for the health professions. Ottawa: Canadian Hospital Association Press.
63. **Royal College of Nursing (RCN) (2009).** Integrated core career and competence framework for registered nurses. <https://nipec.hscni.net/download/217/reading/1019/rcn-core-career-and-competence-framework-rn.pdf> Accessed [09/03/2020].
64. **Royal College of Nursing (RCN) (2018).** Advanced practice standards. <https://www.rcn.org.uk/professional-development/advanced-practice-standards> Accessed [21/03/2022].

65. **Royal College of Nursing (RCN) (undated).** Advanced level nursing practice credentialing. <https://www.rcn.org.uk/professional-development/professional-services/credentialing> Accessed [20/02/2022].
66. **Royal College of Nursing (RCN) (undated).** Diversity and inclusion. <https://www.rcn.org.uk/about-us/diversity-and-inclusion> Accessed [21/03/2022].
67. **Royal College of Obstetricians and Gynaecologists (2016).** Epilepsy in pregnancy: Green Top Guideline No 68. https://www.rcog.org.uk/globalassets/documents/guidelines/green-top-guidelines/gtg68_epilepsy.pdf Accessed [09/03/2020].
68. **Royal Pharmaceutical Society (RPS) (2016).** A competency framework for all prescribers. <https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Professional%20standards/Prescribing%20competency%20framework/prescribing-competency-framework.pdf> Accessed [11/07/2021].
69. **Scheffer IE, Berkovic S, Capovilla G, Connolly MB, French J, Guilhoto L, Hirsch E, Jain S, Mathern GW, Moshé SL, Nordli DR, Perucca E, Tomson T, Wiebe S, Zhang YH and Zuberi SM (2017).** ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology, *Epilepsia* 58(4):512–21. <https://onlinelibrary.wiley.com/doi/10.1111/epi.13709>
70. **Scott H, (2002)** RCN's definition of nursing: what makes nursing unique? <https://doi.org/10.12968/bjon.2002.11.21.10922> Accessed 06/07/2022
71. **Scottish Government (2006).** Modernising nursing careers: Setting the direction. <http://www.scotland.gov.uk/Resource/Doc/146433/0038313.pdf> Accessed [09/03/2020].
72. **Scottish Government (2008).** Supporting the development of advanced nursing practice: A toolkit approach. <https://www.advancedpractice.scot.nhs.uk/media/1371/supporting%20the%20development%20of%20advanced%20nursing%20practice.pdf> Accessed [09/03/2020].
73. **Scottish Government (2017).** GMS contract 2018. <https://www.gov.scot/publications/gms-contract-scotland/>. Accessed [09/03/2020].
74. **Scottish Government (2021).** Transforming nursing, midwifery and health profession (NMaHP) roles: review of clinical nurse specialist and nurse practitioner roles within Scotland. <https://www.gov.scot/publications/transforming-nursing-midwifery-health-profession-nmahp-roles-review-clinical-nurse-specialist-nurse-practitioner-roles-within-scotland/> Accessed [23/11/2021].
75. **Scottish Intercollegiate Guidelines Network (SIGN) and Health Improvement Scotland (2015, updated 2018).** Diagnosis and management of epilepsy in adults: SIGN 143. <https://www.sign.ac.uk/our-guidelines/diagnosis-and-management-of-epilepsy-in-adults/> Accessed [09/03/2020].
76. **SCQF Partnership (undated).** The Scottish Credit and Qualifications Framework. <http://www.scqf.org.uk/> Accessed [09/03/2020].
77. **Sen A, Jette, N., Husain, M. and Sander, J.W., 2020.** Epilepsy in older people. *The Lancet*, 395(10225), pp.735–748.
78. **Shankar R, Tripp M, Jory C, Hagenow K and Cox DA (2013).** The use of movement infra-red sensors as assistance technology for nocturnal seizure monitoring in vulnerable patients. *Learning Disability Practice* 16(9):36–8. https://www.researchgate.net/publication/256475527_The_use_of_movement_infra-red_sensors_as_assistive_technology_for_nocturnal_seizure_monitoring_in_vulnerable_patients
79. **Skills for Health (undated).** Customised Career Frameworks service. <https://skillsforhealth.org.uk/integrated-solutions/framework-development/customised-career-frameworks/> Accessed [09/03/2020].

- 
80. **Skills for Health (2010)**. Key elements of the career framework. http://www.skillsforhealth.org.uk/images/stories/Resource-Library/PDF/Career_framework_key_elements.pdf Accessed [09/03/2020].
 81. **Watson R, Stimpson A, Topping A and Porock D (2002)**. Clinical competence assessment in nursing: a systematic review of the literature. *Journal of Advanced Nursing* 39(5):421–31. <https://onlinelibrary.wiley.com/doi/abs/10.1046/j.1365-2648.2002.02307.x>
 82. **Welsh Government (2009)**. Post registration career framework for nurses in Wales. <https://gov.wales/post-registration-career-framework-nurses> Accessed [09/03/2020].
 83. **Welsh Government (updated 2021)**. General medical services contract (Quality Assurance and Improvement Framework). <https://gov.wales/general-medical-services-contract-quality-assurance-and-improvement-framework>. Accessed [18/01/2022]
 84. **World Health Organization (WHO) (2019)**. International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Chapter V Mental and behavioural disorders. <https://icd.who.int/browse10/2019/en#/V> Accessed [24/01/2021].

Legislation

1. **Adults with Incapacity (Scotland) Act 2000**. www.legislation.gov.uk/asp/2000/4/contents Accessed [10/07/2021].
2. **Mental Health (Care and Treatment) (Scotland) Act 2003**. www.legislation.gov.uk/asp/2003/13/contents Accessed [10/07/2021].
3. **Mental Capacity Act 2005 (MCA)**. <https://www.legislation.gov.uk/ukpga/2005/9/contents> Accessed [15/09/2021].
4. **Mental Capacity Act (Northern Ireland) 2016**. <https://www.legislation.gov.uk/nia/2016/18>. Accessed [15/09/2021].
5. **Mental Capacity (amendment) Act 2019**. <https://www.legislation.gov.uk/ukpga/2019/18/enacted> Accessed 15/09/2

Appendix 2: Evaluation and review of the adult ESN competency framework

The ESNA adult 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 adult ESN 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 adult ESN competency framework?
- Did the adult ESN competency framework support your professional development?
- Did the process of using the adult ESN 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 adult ESN competency framework?

Possible improvements:

- Were any of the dimensions included in the adult ESN 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 adult ESN competency framework?

The impact on ESN practice

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

Evaluation and review methods

This framework will be evaluated using the following methods.

Feedback requests

Following the launch of this new adult ESN competency framework, we will ask ESNs for feedback on their initial interpretation of it. There will also be sessions to gather the views of 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 adult ESN competency framework.

Evaluation forms

The adult ESN 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 adult ESN 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 adult ESN competency framework. This will be followed by the publication of a report that outlines:

- Impact of the framework
- Its current usage
- Continued monitoring and evaluation of the framework
- Areas for development and how the adult ESN steering committee aims to address these.

Research

A study to assess and embed this specialist competency framework into ESN appraisal will be developed.

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.

Appendix 4: Glossary

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
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
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.
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
DHSC	Department of Health and Social Care (replaced the Department of Health in 2018)
DoLS	Deprivation of Liberty Safeguards (due to be replaced by Liberty Protection Safeguards under the Mental Capacity (Amendment) Act 2019)
EBP	Evidence-based practice
Epilepsy	A common chronic neurological disorder characterised by the tendency to have recurrent seizures.
ESN	Epilepsy Specialist Nurse
ESNA	Epilepsy Nurses Association
ESN LD	Epilepsy Specialist Nurse Learning Disability
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. Also referred to as intellectual disability by WHO and other bodies; however, LD is still more commonly used in nursing disciplines.
LPS	Liberty Protection Safeguards (replaced DoLS under the Mental Capacity (Amendment) Act 2019 and due to be implemented in 2022)
LTC	Long-term condition
LTC-N	Long-term condition – neurological
MCA	Mental Capacity Act 2005

MDT	Multidisciplinary team
MHO	Mental Health Officer
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 Professional
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
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
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
SOP	Standard operating procedure
SUDEP	Sudden unexpected death in epilepsy
VNS	Vagus nerve stimulation
WHO	World Health Organization
WWE	Woman/women with epilepsy

Appendix 5: General epilepsy checklist

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 carers. 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	Depression
Memory loss	Anxiety
Self-esteem	Maintaining mental wellbeing
	Sexual difficulties
	Behaviour problems in children and young people
Signature:	Date:

Appendix 6: Older people with epilepsy checklist

The specialist who manages their epilepsy should also have the expertise to manage other comorbid conditions affecting older people. The NICE guidance recommends that the choice of treatment, access to investigations, and the importance of regular monitoring of effectiveness and tolerability are the same for older people as for the general population (NICE, 2022). This is supported by the emphasis in the national service framework for older people on tackling age discrimination (Department of Health, 2001a).

Older people with epilepsy

Referral to an ESN is desirable to ensure the patient has access to ongoing support. In the absence of an ESN, a referral to a district liaison nurse or a community matron is required. Practice nurses can also be a good source of support.

Epilepsy in older people may pose several additional problems for the provision of services compared with the rest of the population:

Diagnostic difficulties

- Due to comorbidity, cognitive impairment, and polypharmacy.

Unclear patient and witness accounts

- The older patient may live alone (absence of an eyewitness).

Susceptibility to ASM side effects and toxicity

- ASM therapeutic blood levels were established on younger populations and might not apply to older people. For this reason, toxicity may occur with levels within or below the traditional therapeutic range.

Polypharmacy and drug interaction

- Some older people will take medication for other conditions. This poses two potential problems:
 1. The person may struggle to remember what tablets to take, how many to take and when.
 2. There is an increased likelihood of interaction with medication for other conditions.

Psychosocial and generational difficulties

- Increased feeling of stigma; impact on ability to drive and possible loss of confidence; can lead to social isolation.

Physical restrictions to lifestyle

- Seizures that cause falls are more likely to cause injury in older people.

Multidisciplinary service

- May be needed in the community, such as a liaison nurse, social worker, falls specialist and occupational therapist.

Pharmacokinetics

- Special attention should be paid to pharmacokinetics (the movement of drugs within the body) and pharmacokinetic issues with polypharmacy; consider using lower doses of ASMs and/or controlled-release formulations (Epilepsy Action, undated 2).

Appendix 7: Example job descriptions

These generic ESN job descriptions (levels 6 and 7) are included in the framework to offer a template for what an adult ESN job description might cover. They can be adapted by individual organisations and departments to suit their own epilepsy services and ESN provision. 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: Epilepsy specialist nurse Responsible to: Epilepsy specialist nurse Department: Neurology Directorate: Neurosciences Operating division: Number of job holders:
Job purpose	<p>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:</p> <ul style="list-style-type: none"> • 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 and communicated to senior ESN and/or ward charge nurse.
Dimensions	<ul style="list-style-type: none"> • 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	<p>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.</p> <p>The epilepsy service provides specialist inpatient and outpatient epilepsy care to patients in [appropriate population and health board/CCG/trust]. Its role covers:</p> <ul style="list-style-type: none"> • 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	<p>Professional (100%)</p> <ul style="list-style-type: none"> • 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
	<p>Leadership and management (100%)</p> <ul style="list-style-type: none"> • 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 • Contribute to the development of future service provision and planning for epilepsy nursing

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

<p>Assignment and review of work</p>	<p>The post is largely self-directed but work may be assigned by the direct supervisor in response to the needs of patients in the epilepsy service.</p> <p>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.</p> <p>Work is reviewed by the Grade 6/7 clinical nurse specialists and [assistant general manager of the neuroscience division].</p> <p>The post holder will have a professional personal development plan that is reviewed every six months by the delegated line manager.</p>
<p>Decisions and judgements</p>	<p>The post holder might be expected to:</p> <ul style="list-style-type: none"> • 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. <p>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.</p>

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

	<p>Emotional demands</p> <ul style="list-style-type: none"> • 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
	<p>Environmental demands (working conditions)</p> <ul style="list-style-type: none"> • 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)
<p>Knowledge, training and experience required to do the job</p>	<p>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:</p> <ul style="list-style-type: none"> • 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

- Author of the job description will need to adapt the red points for their service.

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	<p>Job title: Epilepsy specialist nurse</p> <p>Responsible to: Directorate nurse manager</p> <p>Department:</p> <p>Directorate: Emergency care</p> <p>Operating division:</p> <p>Number of job holders:</p>
Job purpose	<p>This service takes referrals for adults and adolescents as well as people with LD and psychiatric comorbidity. The remit of this post is to:</p> <ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<p>Structural diagram showing who post holder reports to/who reports to them</p>

Role of department/ service

- 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 a 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

<p>Systems</p>	<ul style="list-style-type: none"> • 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
<p>Assignment and review of work</p>	<p>Accountability</p> <ul style="list-style-type: none"> • 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. <p>Work allocation</p> <ul style="list-style-type: none"> • 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. <p>Job autonomy</p> <ul style="list-style-type: none"> • 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 adult 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](#) 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 patient 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 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

	<p>Environmental demands (working conditions)</p> <ul style="list-style-type: none"> • 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
<p>Knowledge, training and experience required to do the job</p>	<ul style="list-style-type: none"> • 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 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/>)