The competency framework for registered nurses providing specialist care for those with a diagnosis of epilepsy and learning disability





Contents

1 Executive summary	4
2 Introduction	5
3 What is the role of the ESN LD?	6
4 What are nursing competencies?	7
4.1 What is a competency framework?	7
5 What is the purpose of the ESN LD competency framework?	8
5.1 Benner's five-level model of nursing competence	9
6 How to use the ESN LD competency framework	10
6.1 The NHS Knowledge and Skills Framework (NHS KSF)	11
7 The ESN LD competency framework	12
7.1 Evidencing the ESN LD competency framework	12
7.2 The ESN LD competency framework	13
Appendix 1: References and bibliography	51
Appendix 2: Evaluation and review of the ESN LD competency framework	59
Appendix 3: Benner's model of nursing competence	61
Appendix 4: Glossary	64
Appendix 5: General epilepsy checklist	67
Appendix 6: Older people with epilepsy checklist	69
Annendix 7: Example ion descriptions	70

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1 Executive summary

Epilepsy is a common neurological condition within the general population. There is a strong positive correlation between epilepsy and people with learning disabilities (PWLD). Both conditions may be caused by a wide range of pathological insults during the neurodevelopmental period (Kerr et al., 2018).

Although there are nurses who specialise in epilepsy and learning disability (LD) as an epilepsy specialist, it is acknowledged that there are nurses who support people with epilepsy and learning disabilities as part of their generic LD nurse role. This document may not always cover all nursing titles but can be adapted to your role. As noted earlier, it is named the competency framework for registered nurses providing specialist care for those with a diagnosis of epilepsy and learning disability, but it will simply be referred to here as the ESN LD competency framework.

The epilepsy specialist nurse (ESN) LD competency framework is a key document that can be used by all nurses working within the field of epilepsy who support people with LD. The framework sets out educational and professional criteria that guide nurses into the role, from novice to expert to specialist epilepsy nurse. The framework supports clinicians to agree a personal development plan (PDP) with their manager. Although this framework is relevant to all clinicians working within LD, not all individuals using the document will move through all stages from novice nurse to expert to specialist nurse.

The authors acknowledge that although epilepsy services vary depending on locality, there is still agreement that most of the role requirements can and should be standardised. This will promote the recruitment and succession planning process for nurses as well as improving safety for PWLD and the quality of epilepsy services provided.

The World Health Organization (WHO) defines LD as a state of arrested or incomplete development of the mind (WHO, 2019). Diagnosis is determined within the framework of three criteria: intellectual impairment (intelligence quotient or IQ); social or adaptive dysfunction; and onset before the age of 18 years (Mercier, 2008). This definition is not used in isolation, and the diagnosis of LD is further categorised by severity of difficulties and any additional behavioural impairments (WHO, 2019). The use of accepted and recognised terminology varies among the medical fraternity. This document will use the term 'learning disabilities'.

Epilepsy is the most common neurological condition affecting an estimated one in 100 people within the general population (Epilepsy Action, 2021). At any one time, approximately 600,000 people in the UK will have a diagnosis of epilepsy (Epilepsy Action, 2021). There are between 602,000 and 1,204,000 people with LD (PWLD) in the UK (Mencap, undated). While figures differ slightly, it is estimated that around 30 per cent of PWLD (nearly one in three) will also have epilepsy. The more severe the LD, the more likely it is that a person will have epilepsy. In addition to this, around 20 per cent of people in the general population (one in five) with epilepsy will also have LD (Robertson, 2015). People with epilepsy also have a 2-5 times increased risk of developing any psychiatric disorder, and 1 in 3 patients with epilepsy have a lifetime psychiatric diagnosis. Psychiatric comorbidities represent a poor prognostic marker as they have been associated with a poor response to treatment (drugs and surgery), increased morbidity, and mortality. (Mula et al 2021) which can also further complicate the support needs of PWLD and epilepsy's care as multidisciplinary working will be required to provide high quality care (Shanker 2020)

The ESN LD competency framework is designed to provide aspirational guidance that should be used to develop skills and knowledge and inform practice, training and development. It can provide structure for appraisals. The framework will ensure that ESN LDs can deliver high-quality, safe and accountable care to PWLD. By using common competencies ESN LDs will be able to improve their clinical practice, care planning and general knowledge surrounding epilepsy, and create a clear developmental pathway leading from novice to expert.

Since January 2019, the Nursing and Midwifery Council (NMC) has been responsible for registering and regulating nursing associates in England to address the skills gap between unregulated healthcare assistants and registered nurses. Nursing associates work to a nationally recognised code of conduct and actively contribute to the delivery of holistic care within their role, under the supervision and ultimate responsibility of both the community nurse and the ESN LD, delivering care independently in line with the individual PWLD's defined epilepsy care plan and parameters of practice of their nursing associate role, and accessing clinical and care advice within a multidisciplinary framework. They should be equipped with the specific knowledge of epilepsy and the relevant skills and capabilities required in this area to respond to the future needs of the individual.

The authors of this framework acknowledge that within LD nursing continuing professional development (CPD), in relation to knowledge around epilepsy, is not isolated to those clinicians practicing as recognised ESNs. The roles of both the community nurse and ESN LD are not exclusive; therefore, an element of parallel working is essential to help reduce the impact of epilepsy on the individual, their family and care workers due to the complexities of the person's LD and associated comorbidities.

The ESN LD competency framework 2012 was developed by a UK-wide steering group of ESN LDs 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 ESN LD?

In PWLD, epilepsy is acknowledged as the most common comorbidity, with approximately 20-30% having epilepsy (RCP 2017, Shanker et al 2020). PWLD who have epilepsy do less well than adults with epilepsy in the general population. Epilepsy tends to be more severe, chronic and causes more hospitalization and more early deaths in people with an intellectual disability than in the general population (Kerr et al 2013, Shanker 2020)

Supporting people with a dual diagnosis of LD and epilepsy is a very important element of care, enabling the individual, their family and care workers to lead a positive and inclusive quality of life (QoL) (Rich, 2009). Management of their epilepsy should be delivered by clinicians who have expertise in epilepsy and can manage this as an individual condition rather than part of the overall LD diagnosis. The National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) guidelines recommend that all individuals with epilepsy should have access to an epilepsy specialist nurse (ESN) and this includes people with LD (NICE, 2022; SIGN, 2018). This is evidenced by results of the UK, N.G.A., (2022). Effectiveness of a nurse specialist in the management of epilepsy which was the evidence review developed using the methods and process described in developing the NICE guidelines (2022). It showed 'Overall, interventions led by epilepsy specialist nurses appeared to have an important benefit over treatment as usual in terms of outcome satisfaction and emotional wellbeing' which in this very vulnerable patient group is vitally important.

Diagnosis can be difficult to obtain in people with LD due to a range of additional complexities, such as communication difficulties and behavioral disorders (Bowley, 2000). People with an intellectual disability face key challenges in receiving accurate diagnosis, full investigations, monitoring of treatment, and access to health care (Kerr 2014). A prevalence of 20% is reported among people known to learning disability services; likewise up to 30% of people with epilepsy are considered to have learning disability or difficulties. The existence of physical, mental and other developmental co-morbidities among people with a learning disability and epilepsy can present varying degrees of challenges requiring specialist approaches and collaborative working between different specialist healthcare settings (Shanker 2020). This can be one of the many roles of the ESN LD is to provide

It is acknowledged that not all nurses working within LD will be ESNs, and many work as generic community practitioners with an added interest in epilepsy. This framework has been developed to provide nurses working within the realms of epilepsy and LD with a set of competencies that can be used nationwide. Over the last few decades there have been several governmental papers and initiatives that have changed how care is provided to PWLD. Care management has been removed from the National Health Service (NHS) and transferred to social and private care providers, in turn shifting the emphasis to provide social care interventions to PWLD. Many LD registered nurses are now working in a social care setting, for which there may be a lack of specific standards and guidelines surrounding epilepsy management and care but these nurses can then become the key to ensuring good communication between all the professionals involved in the PWLD and epilepsy's care (Shanker 2020).

The ESN LD is pivotal in disseminating a greater understanding of epilepsy through the provision of training, information, guidance and advice to PWLD, their families and care workers. The ESN LD is also essential in unravelling the complexities that arise during the management of a person's seizures. Having in-depth knowledge of epilepsy provides the ESN LD with the skills to help differentiate between concerns that arise due to the individual's epilepsy and relevant treatment or due to their LD or other physical health conditions, leading to appropriate and timely signposting. Using risk assessment tools will help the ESN LD balance the management of a person's seizures with the side effects of treatment and the effect of the seizure on their QoL. NICE and SIGN recognise risk assessment as holding particular importance in PWLD and epilepsy, and they are specific in stating the areas in which risk assessment should take place (NICE, 2022; SIGN, 2018).

Understanding the process of assessing capacity and working within the best practice guidelines is critical to the role of the community nurse and ESN LD, especially in the provision of treatment and emergency medication guidance and to reduce the risk of 'diagnostic overshadowing' (Mencap, 2007). The role of the ESN LD should focus on enabling PWLD with epilepsy to lead as independent a life as possible by providing a holistic collaborative and coordinated approach to effective treatment planning and risk management. This requires the ESN LD to become and expert in epilepsy care, education and research.

Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain, cope and recover with health problems. 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 ather than the 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 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 Nursing and Midwifery Council (NMC) 2019 standards for pre-registration nursing education confirm that competence is a requirement for entry to the NMC register, with students needing to ensure the knowledge and skills for nurses responsible for general care set out in Article 31(6) and the competencies for nurses responsible for general care set out in Article 31(7) of Directive 2005/36/EC for pre-registration nursing programmes leading to registration in the adult field of practice have been met. (NMC, 2019).

4.1 What is a competency framework?

A competency framework is a "collection of competencies that are thought to be central to effective performance" (RPS, 2016). Developing and assessing nursing competence is becoming increasingly important. With concerns about fitness to practice, it has become essential to ensure nurses are competent to perform their roles as developed by the NMC. The Nursing and Midwifery Council 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 practices 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 (PWLD) and diverse populations (NMC, 2018). The NMC defines the advanced/specialist nurse as a registered nurse who has command of an expert knowledge base and clinical competence, is able to 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 practice (NES, 2012).

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

The ESN LD competency framework is a key document that can be used by all LD nurses working in the field of epilepsy. 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 PWLD and 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 LD expert level. This then enables the individual to disseminate knowledge by research and teaching practices in a safe, effective and accountable manner (Miller, 1995). The randomized trial conducted by Ring et al 2018 concluded the effectiveness of the expertise of the learning disability nurse working with people with epilepsy and LD. The outcome and conclusion of the trial was positive at advocating a nurse led epilepsy care approach to this client group as it benefitted care elements and cost to service with people with mild/moderate LD. This can be used as a starting block for future work on increasing the effectiveness of ESN LD in providing better clinical outcomes for patients..

The ESN LD competency framework can be used to:

- Provide a vehicle to facilitate knowledge and skills development for all practitioners working in LD services
- 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 ESN LDs, or nurses with a specialist interest in epilepsy
- Identify the need for educational programmes and ongoing practice development at different stages of the ESN LD's career pathway
- Support clinical supervision and personal development plans (PDPs) to identify gaps in competence
- Provide a platform for future research into how treatment by ESN LD, and the use of a competency framework can increase effectiveness of care and better clinical outcomes for patients (Ring et al 2018)
- Ensure the highest standard of care is provided by the ESN LD, in accordance with published papers and government initiatives that influence changing political and professional issues (see Appendix 1: References and bibliography).

The ESN LD 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 LD competency framework are specified at three levels of practice: novice, competent and expert (see Table 2).

Table 2: Levels of	competency
Novice nurse	Newly registered nurse, up to two years from taking post, or LD nurses who wish to develop their epilepsy knowledge base, regardless of time post-registration Working at first-degree level Suggested AfC level 6
Competent nurse	Qualified nurse who is developing expertise to use detailed theoretical and practical knowledge in the management of epilepsy for PWLD Working at first-degree level Suggested AfC level 6/7
Expert specialist nurse	Qualified nurse who has developed specialist psychosocial and clinical expertise to assess and manage epilepsy for PWLD 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 LD competency framework is for all nurses working with PWLD who have epilepsy, 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 ESN LD competency framework

This document has been written in line with the previously published adult and LD ESN competency frameworks and research trial into the value of the LD nurse working with people with LD and epilepsy (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 LD and epilepsy. However, it is recognised that LD nurses work with children, who have specific and different needs and requirements in many areas. In this case, nurses may need to use elements from both the LD and children and young people ESN competency frameworks, selecting the sections most relevant to their areas of work.

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 through the knowledge and understanding examples that nurses requirements 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.

It is recommended that the ESN LD 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 LD nursing. This allows for professionals working with individuals with epilepsy and LD 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 ESN LD competency framework is designed to be used in conjunction with the 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 ESN LD competency framework

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

The ESN LD competency framework is separated into competencies that have been linked to both the NHS KSF dimensions and the HEE pillars of practice. These are underpinned and supported by the 2019 NMC standards for pre-registration nursing education LD competence section (NMC, 2019). The ESN LD competency framework specifies competencies at a more detailed level than the published evaluation version of the NHS national service framework for long-term conditions – neurological (LTC -N) (Department of Health, 2005).

7 The ESN LD competency framework

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

7.2 The ESN LD competency framework

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

Specific KSF dimensions: HWB2; HWB4; HWB6

Pillars of practice: Clinical practice

Competency	Novice	Competent	Expert
A1 Knowledge of epilepsy	Develop knowledge of the pathology, diagnosis and treatment of epilepsy specific to PWLD.	Explain the causation theory linked to epilepsy, using ILAE classifications from 2017 and 2022	Understand the links between onset of epilepsy and the ageing population of PWLD, especially in reference to specific LD syndromes, and explain current theories regarding aetiology of epilepsy.
	Have a functional understanding of the central nervous system.	Explain the neurobiology of epilepsy in relation to PWLD.	Understand and teach the functional and neurobiology of epilepsy in relation to PWLD.
	Recognise the existence of non-epileptic attack disorder (NEAD) and be aware of conditions that are commonly associated with differential diagnosis.	Establish appropriate monitoring/recording tools to support the classification of any NEAD and differential diagnosis.	Evaluate and interpret evidence of investigations and assessments to assist in differential diagnosis and a NEAD.
	Demonstrate a good understanding of epilepsy.	Understand the common LD syndromes, epilepsy syndromes and other neurological conditions and how they influence management and long-term prognosis of a person's epilepsy.	Demonstrate a thorough knowledge of differential diagnosis, aetiology of the epilepsy and LD syndromes, and possess comprehensive knowledge of drug resistant epilepsy, and translate this knowledge into practice.
	Have a working knowledge of seizure types and be able to align these to the classification system as provided by the ILAE.	Classify seizures in accordance with the ILAE classification system.	
A1.1 Understanding seizure types	Have a working knowledge of seizure types and be able to align these to the classification system as provided by the ILAE.	Classify seizures in accordance with the ILAE classification system.	
	Identify different seizure types and understand seizure syndrome classification.		

Competency	Novice	Competent	Expert
A1.1 Understanding	Use the ILAE classification system.		
seizure types (continued)	Have an understanding of the implications of seizures and discuss issues daily with PWLD, care workers, family members, support workers and personal assistants.		
Evidence examples	 Evidence of ability to accurately describe seizures 	Evidence of correct use of current ILAE classifications	Evidence of input to local/national service debates
	 Case study review Discussion with mentor Documentation 	 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 	 Publications Evidence of input to local/national guidance and protocols Discussion with mentor regarding critical incident review
A2 Assisting and supporting diagnosis	Identify routine investigations that may be completed during diagnosis e.g. obtaining witness reports-witness videos of seizures, blood screening, ECG, CT/MRI brain scan and EEG	Identify and understand the relevance of each investigation and possible outcomes.	Identify and request appropriate investigations, interpret each investigation (within level of competency) and its outcome, and identify the need for referral to an appropriate specialist e.g. Witness reports, videos of seizures, blood screening, ECG, CT/MRI, EEG
	Gather relevant information/observation for diagnosis and differential diagnosis.	Collate observations to support diagnosis.	Be actively involved in the diagnostic decision-making within the MDT.
		Understand the clinical aspects that influence diagnosis.	Identify differential diagnosis and refer for additional tests.
	Demonstrate good listening and communication skills, including desensitisation techniques.	Advise on seizure management, possible triggers and patterns to seizure frequency.	Interpret results and outcomes of investigations and relate information to PWLD/care workers/family in an appropriate way.

Competency	Novice	Competent	Expert
A2 Assisting and supporting diagnosis (continued)	Provide leaflets, information and support in relation to epilepsy and diagnostic tests.	Adapt lifestyle and first aid advice appropriately to seizure type and individual impact on PWLD.	Provide specialist and holistic advice around risk management and promoting independent living following a diagnosis of epilepsy.
	Tailor the information provided to suit the abilities and needs of PWLD.	Use user-friendly resources (e.g. easy read materials, photos, multimedia) and communication systems.	Relay sensitive information to PWLD, care workers and families.
	Understand what information should be discussed with PWLD and their care workers once a diagnosis has been ascertained.	Tailor information to address the language needs of people whose first language is not English.	
Evidence examples	 Evidence of records Production of care plans Evidence of process of practice assessment Review of supervision notes Evidence of understanding of current epilepsy classification tools, including ILAE Evidence of use of assessment tools Evidence of review of seizure description forms/ diaries 	 Minutes of MDT meetings Evidence of development of monitoring/recording tools Evidence of development of assessment tools 	 Evidence obtained from review of clinical letters Evidence of devising complex care plans Evidence of supervising/mentoring others Literature review and critical appraisal of publications
A3 Care planning, implementation and evaluation	Liaise with prescribing physician or lead clinician.	Provide continuity of care through regular reviews, home visits or structured clinics.	Initiate investigations to support the treatment and management of the individual's epilepsy.
		Participate in nurse-led clinics.	Implement and manage nurse-led clinics.
		Initiate timely and appropriate review/investigation and seek further specialist advice.	Identify most appropriate clinician for ongoing seizure management.
		Make prompt referral for specialist intervention where appropriate.	Provide holistic management, make clinical decisions and establish treatment plans within a specialist service.

Competency	Novice	Competent	Expert
Evidence examples	Evidence of using risk assessment Evidence of producing care plans Review of clinical notes Seizure diaries Evidence of using QoL tools Evidence of using generic assessment tools Evidence of producing user-friendly records Evidence of using current classification tools Service user/carer feedback	 Evidence of appropriate referral to other services Evidence of developing user-friendly records Testimony from PWLD/care workers Observed clinical reviews Evidence of the production of management/treatment plans Review of specific LD publications Production of MDT meeting minutes 	 Expert Evidence of using recognised seizure type and syndrome classification Case presentation Evidence of development of documentation Evidence of investigation requests Evidence of assessments undertaken Evidence of creating individualised monitoring tools Evidence of service development Production of treatment plans Development of protocol for managing seizures
A3.1 Using personalised care plans	Develop care plan in collaboration with care workers to reflect the specific needs of the PWLD and include core information surrounding the PWLD's epilepsy: Seizure description Management guidelines Record of seizures First aid	Assess, plan, and implement PWLD-specific care plan that reflects current needs, highlights relevant treatment information, and includes an assessment in relation to the management of prolonged seizures and any appropriate protocols.	Complete comprehensive care plan that includes a holistic approach to the person's management of epilepsy, to include QoL assessment and risk management.

Competency	Novice	Competent	Expert
A3.1 Using personalised care plans (continued)	Be aware of appropriate measurement and recording methods, including interviews and individual epilepsy care plans.	Use appropriate measurement and recording methods, including interviews and individual epilepsy care plans.	Formulate and review epilepsy management plans and protocols.
	Demonstrate knowledge of governmental, national and local guidelines that may influence the content of a care plan.	Have an understanding of governmental, national and local guidelines that may influence the content of a care plan.	Influence governmental, national and local guidelines that may influence the content of a care plan.
	Be aware of the long- term implications of epilepsy even when the PWLD's seizures are well managed.	Recognise the need for, and refer for consideration, medication withdrawal.	Initiate baseline investigations prior to discussing appropriate drug withdrawal.
Evidence examples	 Evidence of completed care plan Evidence of completed seizure records 	Evidence of assessment, data collection and completed care plans	 Evidence of professional collaboration and design of care plans/protocols Supervision records
A4 Medicine and treatment management	Have an understanding of the relationship between epilepsy and LD diagnosis, and how this may determine treatment choice and prognosis.	Review evidence-based treatment options and demonstrate the ability to triage, refer and liaise appropriately in a timely manner.	Initiate, monitor and evaluate evidence-based treatment options, to include medical and non-medical treatment available to the person.
	Undertake a full treatment history of previous medications taken and reasons for discontinuation.	Interpret a treatment history and consider the implications of aetiology when decision- making and treatment planning.	Monitor and evaluate decision-making and treatment planning to ensure the correct course of action is taken.
	Record current ASM therapy, monitor seizure frequency and report concerns regarding treatment plan.	Assess the efficacy of prescribed medication and impact on side effects and QoL.	Review and evaluate treatment in relation to ASM response, to initiate treatment changes based on ease of use, seizure frequency and side effects of ASMs.

Competency	Novice	Competent	Expert
A4 Medicine and treatment management (continued)	Review medical and nursing notes and care plans to establish previous treatments prescribed.	Be able to explain seizure frequency and poor outcome balanced against dosage and side effects of ASMs.	Recommend alternative treatment and therapies that could complement ASM therapy, while acknowledging potential -interactions (e.g. between ASM and non-ASM treatment).
	Provide information and advice on medicines to PWLD, their families and care workers, and have knowledge of current MHRA/NICE guidance on ASM and pregnancy.	Recommend and identify appropriate formulation of medication acceptable to the PWLD.	Demonstrate a comprehensive knowledge of the limitations of alternative treatments, and review and evaluate these alternative treatments.
	Assess the use and storage of ASMs in a variety of care settings, and document and report findings to the appropriate organisation/prescribing manager.	Assess the appropriate administration and adherence of ASMs in a variety of care settings.	Assist external organisations with the development of protocols, guidance for best practice, research and other outputs.
	Explain the range of ASMs available, understand how to check for common side effects and basic interactions, and undertake an initial review of medicines and their side effects, using the BNF.	Make the correct links between signs and symptoms, failure to respond to treatment, and drug side effects.	Ensure timely, appropriate monitoring for drug effects and side effects and ensure the PWLD and their care workers are educated regarding these.
	Be aware of signs and symptoms of treatment failure.	Recognise potential complications of polypharmacy, side effects and frequent clinic appointments, unscheduled emergency hospital attendance and develop appropriate management strategies.	Recognise when biomedical investigations are appropriate, request blood tests, be aware of pharmacodynamic and pharmacokinetic interactions of drugs and make changes to treatment.

Competency	Novice	Competent	Expert
and treatment effect management individual responsible and h with L differed and b	Understand the effect of LD on how individuals may respond to medication and how individuals with LD may respond differently to treatment and be unable to articulate side effects.	Identify and observe potential side effect profiles and understand how to take a case history from PWLD and their care workers to preempt side effects.	Manage and lead review of treatment, recommending treatment options and taking into consideration appropriate formulation of medication acceptable for the individual, and be aware of reasons for and limitations of biomedical investigation.
	Identify potential concordance and adherence issues.	Demonstrate an ability to evaluate adherence with medication regimens.	Review concordance and adherence of medication, develop treatment plans accordingly, and develop adherence strategies for prescribed medication.
	Be aware of current NICE/SIGN guidance in relation to drug treatment, including the most recent MHRA guidance.	Use NICE/SIGN and MHRA guidance to influence practice and be aware of latest knowledge and practice in relation to Valproate and Topiramate prescribing and other ASMs, including the risk and incidence of fetal anticonvulsant syndrome and also in relation to LD and physical disability.	Prescribe and monitor the correct ASM as per current NICE/SIGN and MHRA guidance for the epilepsy diagnosed, complete appropriate risk assessments in line with MHRA guidance, and educate and support primary care, pharmacists and the wider MDT in relation to formulations and prescription by brand issues.
Evidence examples	 Demonstrate use of BNF via drug assessment Mentor supervision notes Seizure diaries Evidence of provision of care plans Evidence of review of clinical notes 	 Evidence of shared care protocols Evidence of referral to other agencies Evidence of review of clinical guidelines 	 Publications Patient satisfaction surveys Evidence of pathway, protocol and policy development Production of relevant audits Knowledge of and adherence to the RPS competency framework for all prescribers (RPS, 2016) Clinical case review Production of individualised treatment plans

Competency	Novice	Competent	Expert
A4.1 Emergency medication	Identify potential need for the use of emergency medication for assessment of seizure frequencies/severity.	Be able to analyze records of emergency medication administration and outcome of episodes of prolonged and cluster seizures and review effectiveness.	Initiate the use of emergency medication and treatment for PWLD.
	Observe local policies for emergency medications.	Assist in the development of local policies for emergency medication.	Develop, evaluate and review local policies for emergency medication.
	Understand principles and basic action of treatment used.	Understand the individual's need and diagnosis, and take account of the needs of PWLD e.g. capacity to consent issues.	
	Explain the criteria for, and understand the risk associated with, prolonged seizures.		
	Collect and collate records of emergency medication usage and outcomes appropriately.	Assist the prescriber in the formulation of a treatment plan.	Review and evaluate records of emergency treatment administration, and consider the appropriate merits and uses of available rescue treatments, including efficacy and the practical considerations, to meet the PWLD's needs.
	Refer to the relevant specialist for review and modification of treatment plan.		Review, evaluate and recommend changes to individualised emergency medication protocols and treatment plans.
	Provide information and support regarding emergency medication including checking expiry dates	Support and educate families and care staff and others in emergency medication treatment principles and techniques.	Make appropriate modifications to management plans in partnership with the PWLD, care workers and other professionals, and advise appropriately in situations that arise where the epilepsy management plan is complex or the unexpected arises.

Competency	Novice	Competent	Expert
A4.1 Emergency medication (continued)	Signpost to and support professionals and care workers with training.	Deliver training sessions to care workers and family members, and the PWLD if possible, for the administration of emergency medication, following published ESNA guidance (2019).	Develop and review training materials used during training sessions.
	Demonstrate an awareness of emergency medication and controlled drug constraints.	Develop skills to undertake training/health education for appropriate professionals and care workers within the context of the individual epilepsy care plan, using ESNA carer competencies and guidance (2021).	Provide expert training/ education to staff groups and other professionals in the use of emergency treatment in epilepsy.
	Keep up to date with new treatments or techniques.	Understand potential implications when changes are made to local policy and guidance.	Use current research and guidance to inform the development of policies and procedures regarding emergency medication.
	Have an awareness of recognised guidance in the use of, and training for, emergency treatment.		Act as an expert adviser to ensure local changes to policy reflect national guidance and ensure that they are evidence based.
Evidence examples	 Evidence of assessment process of need for emergency medication Evidence of treatment review Evidence of use of person's information Evidence of use of relevant clinical guidelines 	 Evidence of CPD and relevant teaching qualifications Review of training evaluation sheets Evidence of review of treatment protocols Portfolio of training delivery 	 Evidence of training records Production of new training material Evidence of training material review Evidence of development of treatment protocols Evidence of prescribing audit
A5 Epilepsy surgery and VNS			Consider those individuals who may benefit from surgical assessments, resective or non-resective surgery e.g. VNS.

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	Liaise with care workers about potential difficulties with the management of the PWLD's epilepsy, for example drug adherence, and signpost to other professionals/services as required.		
	Identify any common links between LD diagnosis and epilepsy prognosis.	Demonstrate an understanding of the risk factors of developing epilepsy depending on the person's LD syndromic classification e.g. Down's syndrome.	Interpret and influence practice, adjusting care as required for the PWLD (PHE, 2014).
	Carry out a basic health assessment, including developing health action plans.	Discuss the link between seizure control and physical ill health, and take a written history that includes aetiology of LD, epilepsy syndrome, seizure diagnosis and treatment of neurological conditions.	Assess the impact of epilepsy and its treatment on the individual's mental health status and/or behaviour.
	Discuss recognised LD conditions and syndromes linked to epilepsy.	Discuss recognised epilepsy syndromes and potential impact on learning and development.	Assess and record the impact of syndrome-specific features, and assess and respond to the relationship between epilepsy and concomitant conditions.
	Demonstrate a basic understanding of the relationship between aetiology, diagnosis and prognosis.	Confidently discuss with others the evidence-based relationship between aetiology and diagnosis, with seizure presentation and treatment prognosis.	Assess the relationship between epilepsy and concomitant conditions, in particular chest infection, dysphasia, sleep disorder and diabetes.
B1.1 Managing linked health conditions	Complete health assessments.	Understand the potential link between physical ill health, seizure frequency and ASMs.	Consider the overall impact of epilepsy in relation to specific conditions, which may be exacerbated by seizure and/or treatment and vice versa, and the health and wellbeing of the individual.

Competency	Novice	Competent	Expert
B1.1 Managing linked health conditions (continued)	Signpost the PWLD to their GP for an annual health check within an individual epilepsy management plan.		Manage potential ill health implications of long-term medication administration e.g. bone health and hyponatremia.
Evidence examples	 Evidence of appropriate referrals Evidence of using generic health assessment forms Evidence of developing health action plans Reviewing evidence from publications 	 Evidence of completing relevant continued healthcare assessments Critical analysis and appraisal (published evidence) 	 Use of audit to assess prescribing patterns Development of clinical care pathways/protocols Clinical observation Participation in advanced literature review
B2 Using risk assessment tools	Use appropriate assessment tools to gather information on: Seizure type/class Triggers for seizure Severity (type of seizure, pre/post ictal Seizure frequency Seizure pattern Injuries.	Use formal assessment tools to interpret information, including: Triggers for seizure Severity (type of seizure, pre/post ictal Seizure frequency Seizure pattern Injuries Management plans	Use formal assessment tools to allow for the development of individualised complex management plans and protocols.
		Understand the range of assessment tools relevant to people with LD.	Create individualised monitoring tools to obtain specific information surrounding more complex issues.
			Initiate use of video monitoring to support seizure and syndrome classification.
			Use assessment tools appropriately in the context of known aetiology.
B2.1 Identifying and reducing risks to PWLD	Identify common risk factors associated with epilepsy and seizures.	Identify and record discussion of high-risk areas, including SUDEP, bathing and acute seizure management, and treatment risk (as per the NICE/SIGN guidelines on epilepsy).	Complete risk assessments and formulate effective responses in complex situations.

Competency	Novice	Competent	Expert
B2.1 Identifying and reducing risks to PWLD (continued)	Identify risks that may require further intervention.	Advise on environmental risk and the range and availability of safety equipment, assistive technology and seizure alert technology, and know the evidence base and signpost as necessary (Shankar, 2013).	Have a high level of expert knowledge of specialist equipment and actively engage in research and development of guidelines that influence practice.
	Identify issues surrounding vulnerable adults and raise safeguarding applications where appropriate.	Demonstrate knowledge surrounding the evidence base for reducing risks including seizure management, alarms and alerts, and environmental factors.	Work with other organisations in accordance with safeguarding applications and offer expert knowledge.
	Be aware of specific risks associated with epilepsy and LD in special populations: Multiple disabilities Transition Gender Age related Mental health.	Interpret the risk and develop risk management strategies.	Hold specialist clinics.
	Collect data for specific risk assessments.	Work within the wider MDT.	Develop specialist risk assessments, using evidence-based practice.
	_		Refer to wider MDT.
Evidence examples	 Production of completed risk assessment forms and risk-management documentation Attend safeguarding adults training (and get certificate) Treatment plans Evidence of care worker support training QoL management plan Completed referral forms 	 Review of clinical papers Evidence of complex risk assessments Evidence of requests for aids/equipment Minutes of risk strategy meetings 	 Evidence of policy development Prescribing records Clinical management notes Evidence of clinics

Competency	Novice	Competent	Expert
B3 Controlling seizures	Understand the difference between generalised seizures and focal seizures.	Use epilepsy-specific expertise to obtain a clinical history and assess seizure frequency and severity.	Be aware of all treatment options.
	Implement and evaluate seizure description forms.	Document and communicate a clear and holistic epilepsy history, while understanding the difficulty of receiving information from a third party.	Lead an innovative approach to practice in epilepsy and behaviour and differential diagnosis.
	Monitor the management of seizures through regular visits and provide continuity of review.	Understand how diagnosis of syndrome and seizure type can lead to specific medicine management.	

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	Recognise the potential impact epilepsy may have on the person's psychosocial wellbeing.	Assess the degree to which epilepsy affects individuals' lives, specifically psychosocial wellbeing and lifestyle areas.	Refer to wider members of the MDT, including psychologists, to develop holistic lifestyle plan.
	Help reduce the impact on a PWLD's lifestyle, specifically in the areas of: Health Psychosocial effects (balance of risk and QoL) Mental health Memory Balance between treatment and seizures Behaviour Autism Sexual health	Provide support and reduce risk to the PWLD's lifestyle, specifically in the areas of mental health, psychosocial, behaviour and autism.	Provide comprehensive support and monitoring around the impact epilepsy can have on an individual, using recognised assessment tools.
			Assess and evaluate data and implement appropriate strategies to improve QoL.
C2 Impact on families and carers	Assess and note the level of carer concern and burden including epilepsy related death	Identify specific gaps in the PWLD and their care workers' knowledge and understanding and identify how this may impact on the individual's care.	Assess and identify needs and produce a plan to develop care workers' skills and knowledge.

Competency	Novice	Competent	Expert
Competency C2 Impact on families and carers (continued)	Assess and note the effect of knowledge, understanding and ability of care workers to: Recognise and manage seizure and risk Record seizures Differentiate behaviour from epilepsy Recognise treatment effects and managed treatment and care plan Understand and describe potential barriers to learning.	Involve the care worker in the provision of a plan to address deficiencies in understanding, and where appropriate, use accessible information to aid the retention of information.	Develop innovative materials to support learning and to minimise potential barriers to learning.
			Evaluate the effectiveness of care workers' increased knowledge and skill in the level of care for the individual.
	Encourage PWLD and their care workers to participate in service development.	Aid the person and their care workers to be involved in PWLD group meetings in relation to service provision.	Engage PWLD to be instrumental in modelling service frameworks and to encourage engagement in initiatives such as the expert PWLD programme.
	Be familiar with local provision of support services.	Negotiate with families and care workers regarding accessible and acceptable recording methods.	Recognise the limitations and constraints of the service and how this may impact on the level of care.
Evidence examples	 PWLD/care workers' testimony Diary of training opportunities Case studies Observed clinical review 	 Engagement with established user groups Meetings of service user forums Evidence of assessment of care workers' knowledge 	 Evidence of specific training packages for care workers Reviews of effectiveness of training provided Evidence of development of care worker networks Minutes from specific care worker/service user forums

Competency	Novice	Competent	Expert
C3 Independent living	Encourage PWLD to access leisure, social and employment opportunities.	Initiate risk assessments and management plans to reduce risk where appropriate.	Provide specialist resources based on risk assessment to encourage independent living and community participation.
	Support the PWLD's access to mainstream services as appropriate.	Liaise with mainstream services and ensure appropriate management and monitoring.	Work with mainstream services to ensure that reasonable adjustments are made to allow access to generic epilepsy services.
		Disseminate and discuss reasonable adjustment guidance (Mencap, 2007).	Actively contribute to the development of local and national guidance.
	Demonstrate an understanding of how to maintain QoL, including independence.	Use evidence-based tools appropriate to PWLD to assess QoL.	Evaluate data and implement strategies to improve QoL.
Evidence examples	Completed QoL assessment	Evidence of regular review and evaluation of QoL assessments	Evidence of creating individualised QoL assessments
		Evidence of referrals to MDT	Evidence of implementing reasonable adjustments
			Emergency protocolsEvidence of development of referral pathways
C4 Self- management	Understand that seizure freedom is not always achievable and identify signs that may indicate increased support is required.	Assess the fine balance between seizure frequency, severity and effective treatment on the person's QoL.	Work with the PWLD and care workers to be responsive to the changing needs of the person and the trajectory of their epilepsy diagnosis.
		Use evidence-based assessment tools when appropriate.	Devise an individualised epilepsy care plan to help ensure that relevant information is available on review.
		Make referrals for increased support where appropriate.	Where appropriate, provide advice on emergency protocols, and make recommendations on the use of emergency medication.
C5 Advocacy	Recognise equality and diversity issues that may impact on the diagnosis of epilepsy.	Recognise and address equality and diversity issues to provide a non-discriminatory service.	Evaluate the balance between equality and diversity beliefs and treatments, early intervention and support.

Competency	Novice	Competent	Expert
C5 Advocacy (continued)	Recognise the individual's aspirations, using a person-centred approach and shared decision-making.	Work with care workers and families to facilitate appropriate strategies to meet the person's aspirations.	Use advocacy skills and endorse frameworks and policies to ensure that the person's aspirations are met.
			Advocate at trust/ strategic commissioning level on behalf of PWLD and epilepsy.
C6 Capacity to consent to treatment (England and	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.
Wales) Given the political hiatus in Northern Ireland that has disrupted revisions to the relevant legislative framework (nb. Assisted Decision-Making (Capacity) Bill 2022) for the sake of parity across the UK, the same guidance and competency statements as for England and Wales, under country-specific mental capacity legislation is to be considered.	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 PWLD 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 PWLD to achieve this).	Provide accessible and appropriate information to PWLD, 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
Evidence examples	 Evidence of documenting concerns in a person's notes and seeking professional advice in regards to this Evidence of using accessible information 	 Evidence of developing accessible information Production of capacity assessment documentation Evidence of appropriate referrals 	Production of 'best interest' meeting minutes
C6.1 Capacity to consent to treatment (Scotland)	Understand the fundamental principles of consent to treatment.	Demonstrate a detailed knowledge and understanding of the Adults with Incapacity (Scotland) Act 2000 and other related legislation.	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 PWLD and ensure they have the opportunity to 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.

Competency	Novice	Competent	Expert
Evidence examples	 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 	 Evidence of multidisciplinary 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 	 Production of minutes outlining the principles of the Adults with Incapacity (Scotland) Act Evidence of multidisciplinary consultation in regard to complex care and treatment plans Participate in appropriate national guidelines and framework development (e.g. SIGN)
Further information	Implementation of the Mental Capacity Act (Northern Ireland) 2016 and related legislation https://www.health-ni.gov.uk/mca		

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 allocated caseload and identify when appropriate to seek support.	Manage own caseload and Prioritise workload in response to service demands.	Prioritise and allocate caseload within service capacity.
	Prioritise work to make the most effective use of time and resources appropriately by considering:	Demonstrate setting own priorities and respond to unplanned workload and changing service needs.	Balance resources to changing service needs.
	Clinical activityProfessional responsibilities.		
		Make any reasonable adjustments to provide an equitable service for PWLD and their families and care workers.	Manage others' time.
	Demonstrate a considered and professional approach to practice by ensuring sound diary planning.	Understand and apply the dynamic process of goal setting.	Develop services to ensure appropriate numbers of PWLD-to-nurse caseload ratio.
		Initiate database development for caseload management.	
	Demonstrate an awareness of the urgency and completion of tasks in an appropriate time frame.	Demonstrate awareness of professional limitations and be aware of the need to prioritise time based on the level of clinical urgency.	Demonstrate awareness of time constraints and pre- emptively manage these.
		Demonstrate appropriate allocation of clinical time.	
	Input data into collection systems in timely way.	Measure own capacity to workload.	Interpret the data available for service development and work allocation and use this to challenge and advocate for appropriate services to meet PWLD needs and ensure safe service delivery.

Competency	Novice	Competent	Expert
Evidence examples	 Review of diary or Outlook calendar Data collection logs Evidence of clinical and managerial supervision 	 Evaluation of critical incidents Review of time self-management Review of waiting lists Evidence of goal setting 	 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 PWLD.	Have a sound method of documenting calls and advice given alongside any plans for treatment changes.	Confidently manage distraught and unexpected calls.
	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.	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.
	Understand that conversation is likely to be taking place via a third party and this could lead to interpretation difficulties.	Understand the difficulty when communicating with a third party and take appropriate action to clarify concerns.	Efficiently manage potential interpretation problems that arise in relation to 'by proxy management'.
	Encourage participation of PWLD.		
	Work within regional guidance in relation to confidentiality in NHS England, Wales, Scotland or NI confidentiality policies.		
	Provide a timely and responsive method of communication according to individual needs (e.g. via a telephone service, faceto-face communication or other media).	Effectively assess and prioritise need based on telephone communication and agree realistic expectations with caller.	Use audit to assess effectiveness of telephone management.
Evidence examples	 Evidence of documentation relating to call Production of telephone records Carer testimonial 	 Testimony of care workers Case study review Evidence of clinical visits Development of telephone call template sheets 	 PWLD/carer satisfaction surveys Development of care pathways/protocols Clinical observations

Competency	Novice	Competent	Expert
D2 Knowledge development	Work to best practice guidelines (e.g. NICE/SIGN).	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 and attend sessions on a regular basis.	Improve service quality through reflection on positive and negative clinical experience.	Initiate and provide skilled supervision for members of the team.
	Use reflection to prioritise areas for PDP with line manager and mentor.	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 PWLD and epilepsy.	Participate in educational programmes at first-degree level in relevant subjects.	
	Develop skills in working with PWLD in partnership with families and care workers.		
Evidence examples	Read articles from relevant journals as part of CPDPDP		
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.

Competency	Novice	Competent	Expert
D3 Accountability and autonomy (continued)	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.
D4 Recognising professional	Identify own professional limitations.		
and personal development needs	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.		

Competency	Novice	Competent	Expert
	 Attendance at local and national meetings or conferences Contact sheets/PDP 	 Certificate/diploma in epilepsy RN with post-qualification experience and evidence working towards a first-level degree Recognised teaching qualifications Evidence of working with PWLD who have complex epilepsy, through production of case study 	 Postgraduate diploma with extensive experience of working with PWLD 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 PWLD may be referred to other services to aid diagnostic process.	Collaborate with other agencies as required to provide a seamless service.	Work across other services providing joint specialist clinics to provide high-quality specialist input for PWLD.
	Identify other epilepsy services provided by health, social care and voluntary sectors.	Establish links with wider epilepsy services to understand and appreciate differing roles, while effectively promoting own role within the MDT.	Be aware of the scope of other professional roles, 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 an independent practitioner within the MDT.
		Mediate between services and facilitate complex and ethical decision-making.	May be approached by other professionals for advice and support in managing epilepsy in PWLD.
	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 PWLD may receive.	Acknowledge the influence of driving factors around service delivery, such as local or national policies.
	Explain different models of care and how they can be interlinked to benefit people with epilepsy and LD.	Communicate, promote and develop the role of the ESN LD as a pivotal member of the MDT.	
		Identify limitations within the service/team.	Address the limitations within the service/team.
			Devise and deliver generic and specific in-service training packages to a range of professionals.

Competency	Novice	Competent	Expert
E1 Being part of a multidisciplinary team (continued)			Work as independent practitioner within the MDT, with the role to be renegotiated as experiences are gained.
E2 Professional networking	Foster good working partnerships with care providers.		
	Establish working relationship between health and social care, voluntary and statutory sectors.	Act as a link for advice and support within established working relationships.	
	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	 Evidence of networking opportunities 	 Documented attendance at networking opportunities Evidence of review of benefits of networking and how this has influenced practice through reflection 	Documented evidence of planning or hosting networking opportunities/ meetings
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.

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	 Testimony from care workers Production of networking minutes/attendance certificates Peer supervision Review of relevant literature Evidence of referrals to other MDT members 	 Testimony from professionals Evidence of MDT working Review service objectives Evidence of PWLD and public consultation 	 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 PWLD, families and carers about epilepsy in a clinical setting.	Use appropriate information to discuss and teach PWLD, families and carers about epilepsy risks and management.	Develop, research and audit materials to support learning for PWLD, families and carers and minimise potential barriers to learning.
	Identify opportunities for patient education.		Incorporate the concept of the expert patient.
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.
	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.	

Competency	Novice	Competent	Expert
Evidence examples	 Participation feedback Evidence of teaching packs PDP Diary of teaching opportunities Review of evaluation sheets 		 Submit and review articles for publication Feedback from the MDT Teaching plans
F3 Developing, facilitating, and evaluating	Actively seek feedback/ evaluation from training programmes.	Use a range of educational evaluation tools.	Provide curriculum advice for developing accredited courses.
educational programmes		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.
			Use feedback to influence training.
			Incorporate feedback and evaluation in future training packs.
Evidence examples		 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 	 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
F4 Mentorship	Ensure own supervision needs are met at an appropriate level with an identified mentor.	Provide mentorship to less experienced nurses.	Support and guide other nurse mentors.
		Act as mentor to other healthcare professionals.	Act as mentor and role model at local, national and international levels.

Competency	Novice	Competent	Expert
Evidence examples			 Set up and maintain robust professional support Speaker/poster presentation at local and national meetings or conferences

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	Understand the meaning of evidence-based 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 LD role.	Identify research that is pertinent to improving practice and promoting change.	Be able to critically appraise published research.
Evidence examples	 Provide examples of what is meant by evidence-based practice Complete a literature search 		
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.
G3 Clinical trials	Understand and explain to patients the concept and need for clinical trials.	Actively recruit patients for a clinical trial.	Understand and study ethics and be able to communicate the ethical consideration of clinical studies.
		Understand the impact a clinical trial may have on patients and services.	Work within the MDT to coordinate a clinical trial and collate data.
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	Evidence of the person's feedback involvement	 Review of PWLD and care worker satisfaction surveys 	
G5 Carrying out research	Understand the role of PWLD's capacity to consent.	Understand the ethical implications in relation to developing research in services that work with PWLD.	Demonstrate an in-depth knowledge of the ethical implications of research, and an understanding of the ethical approval pathway.
		Contribute to the design and practical implementation of local research projects.	Identify nursing research questions and take the lead in research design data collection and dissemination of findings.

Competency	Novice	Competent	Expert
G5 Carrying out research (continued)		Explain the importance of local research and understand the difference between research and audit.	
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 LD 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.		
Evidence examples	 Evidence of agreed audit plan 	Evidence of audit data from own service	Evidence of presenting in local or national arena
Cxamples	Data collection for research and audit	 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 	 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) and mild, moderate, severe or profound LD https:// phescreening. blog.gov. uk/2018/09/13/ easy-guidesfor-pregnant-women-with-learning-disabilities-well-received/	Be aware of the issues of contraception for women with LD and epilepsy and the impact of epilepsy, ASM and LD on hormones and menstrual health	Be able to discuss available contraceptive options for women with LD taking ASMs.	Be able to advise women and the MDT on appropriate and effective contraception for women taking different ASMs.
	Understand the pre- conceptual issues for WWE planning pregnancy including advice regarding folic acid 5mg if risk of pregnancy.	Discuss and plan with women their contraception, pregnancy and support through labour and delivery, and appropriate monitoring/adjustment of ASMs. MDT referral early pregnancy to health and social care in order individualised support can be targeted to optimise outcome for the woman and her baby.	Sensitively discuss available data surrounding epilepsy risks and treatment during pregnancy including teratogenic data and risk of death.
	Be familiar with restrictions in use of sodium valproate and Topiramate in WWE of childbearing age.	Discuss risks to women during pregnancy and how parenting potential risks can be minimized or averted.	Develop shared care agreement/database and standard operating procedure (SOP) for prescription of valproate or Topiramate.
	Be aware of the need to support WWE following the birth of their baby including the possible need for someone to have to stay with the WWE whilst in hospital.	Discuss valproate pregnancy prevention programme and completion of ARAF and databases.	Develop collaborative relationships with obstetric medicine and epilepsy services.
	Be aware of health issues specific to WWE throughout their lifespan and the potential need for longer appointments to discuss these.	Ensure WWE are informed of measures to safeguard their babies while carrying out their care.	Pre-empt the need for appropriate advice throughout life and the impact of ASMs on bone health, effect of ASMs during peri and menopausal years.
	Have a sound method of ensuring information pertaining to women is provided in a timely and understandable manner.		

Competency	Novice	Competent	Expert
Evidence examples	 Telephone log Patient satisfaction surveys Discussion with mentor Documentation 	 Testimony from WWE Case study review Evidence of reflective practice Discussion with mentor Annual risk acknowledgment forms (ARAFs) 	 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	https://www.rcpch. ac.uk/sites/default/ files/2021-01/Pan_ College_Guidance_ Document_on_ Valproate_Use%20 V2.1.pdf	ARAF template	
H2 Epilepsy in older people with LD	Describe the causes and risk factors for epilepsy in older people with LD (epilepsy is the third most common neurological disorder in the over 65s after stroke and dementia (Sen 2020).	Understand pharmacokinetic differences of ASMs in older patients.	Confidently advise on potential interactions of ASMs with commonly prescribed concomitant medications in older patients e.g blood thinning medication.
	Describe the potential diagnostic pitfalls in older people and potential differential diagnoses.	Be able to appropriately recommend and adjust treatments given most new onset epilepsy in over 65s is focal in origin (Sen 2020).	Develop and implement services that meet the needs of this patient group.
	Awareness of increased risk of side effects in the older population	Be familiar with the problems of polypharmacy and potential concordance issues.	Support non-specialist staff working with older people to develop and implement appropriate care plans.
		Discuss risk and impact of epilepsy specific to this age group.	Identify when to refer older people with epilepsy for dementia assessment or to mental health services as appropriate.
		Be able to offer appropriate advice and support to minimise physical and mental health risks.	

Competency	Novice	Competent	Expert
Evidence examples	 Observed clinics Evidence of ability to build positive patient/nurse relationships Evidence of reflective practice 	 Case study review Evidence of reflective practice Evidence of advocacy and risk assessment 	 Evaluation of patient and carer satisfaction surveys Business plans Policy and protocol development Integrated care pathways Safeguarding protocols and assessments
H3 Patients with LD with psychiatric comorbidities	Be aware of the increased rates of anxiety and depression in PWLD and epilepsy.	Use available validated screening tools to identify PWLD at risk of psychiatric comorbidities.	Develop referral pathways for PWLD and psychiatric comorbidities.
	Be aware of potential diagnostic issues in PWLD, psychiatric co-morbidities and epilepsy	Be able to advise on potential peri-ictal symptoms, side effects of ASM in relation to concurrent psychiatric medications	Be able to understand the classification of psychiatric symptoms according to temporal relation to seizures
	Be aware that the symptoms of anxiety and depression can differ in PWLD and epilepsy.	Develop collaborative working relationships with psychological and psychiatric services.	Audit services for PWLD and psychiatric comorbidities.
	Acknowledge the need to refer patients onward for appropriate support.	Ensure strong advocacy for patients with epilepsy and psychiatric comorbidities.	Enhance and develop services that are responsive to PWLD with psychiatric comorbidities.
	Be aware of how peri-ictal symptoms, side effects of drugs, comorbid psychiatric symptoms can affect the PWLD and epilepsy	Be aware of relevant, validated assessment tools associated with psychiatric disorders in management of people with epilepsy including peri-ictal and temporal /frontal relation to seizures	Understanding of comorbidies of epilepsy and psychiatric disorders and its differentiation from seizure disorders
Evidence examples	 Observed clinics Evidence of ability to build positive patient/nurse relationships Evidence of reflective practice 	 Case study review Evidence of reflective practice Evidence of advocacy Understanding of relevant, validated assessment tools 	 Evaluation of patient and carer satisfaction surveys Business plans Policy and protocol development Attendance at conferences and speaker engagements Poster presentations

Competency	Novice	Competent	Expert
H4 Transition between children and young peoples services and adult services recognising the special potential challenges relating to individuals with	Understand the principles of transition services and how these are different when supporting children and young people with LD	Achieve cooperative working with children and young people's 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 including advice on life style choices, quality of life issues, and understanding of epilepsy.	Recognise gaps in transition services and influence local provision. How to mitigate risks around safety, lifestyle choices including contraception advice, epilepsy, ASMs adherence
mild, moderate, severe or profound learning disabilities	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	 Observed clinics Evidence of ability to build positive patient/nurse relationship Evidence of reflective practice 	 Case study review Evidence of reflective practice Evidence of advocacy 	 Evaluation of patient and carer satisfaction and outcome surveys Business plans Policy and protocol development
H5 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 PWLD and epilepsy who have brain tumours.	Develop a responsive service for PWLD with epilepsy and 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 PWLD with epilepsy and brain tumours.
Evidence examples	 Observed clinics Evidence of understanding of the WHO classification of tumours of the central nervous system Evidence of reflective practice 	 Case study review Evidence of reflective practice Evidence of links between epilepsy and neuro-oncology services e.g. referral pathways/joint clinics 	 Evaluation of patient and carer satisfaction surveys Business plans to enhance service provision Policy and protocol development Presentation at neuro-oncology meetings/conferences

Competency	Novice	Competent	Expert
H6 Vulnerable groups at higher risk of Sudden Unexpected Death in Epilepsy (SUDEP)	 To be aware of the risk factors that make some people at higher risk of SUDEP. To signpost carers and families to specific resources To be able to suggest ways to reduce risks. 	 To be able to discuss risk factors of SUDEP with PWE in a proportionate way. To be able to discuss current thinking on the mechanisms and causes of SUDEP To be aware of and use risk assessment tools such as the SUDEP and Seizure safety Check List and the specialist Apps To report any SUDEP or suspected SUDEP on the Epilepsy Deaths Register 	 To participate in national research and audits to increase knowledge of SUDEP To counsel families and carers bereaved by a SUDEP Death, To represent your service at any coroner's enquiry or serious case review into a SUDEP death
Evidence Examples	Reflective discussionEvidence of reflective practiceObservation	Evidence of reflective practice Evidence of use of appropriate risk assessment tools	 Published audits research and papers Evidence of reflective practice Presentations at national meetings
H7 Men with epilepsy (MWE)	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 Be familiar with current MHRA recommendations for the prescribing of sodium valproate in men under the age of 55 years. (MHRA 2023)	Be able to discuss the issues faced by men across the lifespan of their epilepsy including parenting, libido, sexuality, contraception, fertility and bone health. Be able to discuss ASM options for men and be aware of the requirements for prescribing sodium valproate in men under 55	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. Lead on a robust, responsive pathway for the decision making process around ASM's and men under the age of 55 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

Competency	Novice	Competent	Expert
Evidence examples	 Telephone log Patient satisfaction surveys Discussion with mentor Documentation 	 Testimony from WWE Case study review Evidence of reflective practice Discussion with mentor Annual risk acknowledgment risk forms (ARAFs) 	 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	

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The ESNA learning disability 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 ESN LD 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 ESN LD competency framework?
- How did using the ESN LD competency framework support your professional development?
- Did the process of using the ESN LD 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 ESN LD competency framework?
- Potential cost savings/stream lining of services when using framework, offering the potential of improved outcomes (Ring et al 2018)

Possible improvements:

- Were any of the dimensions included in the ESN LD 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 ESN LD competency framework?
- Consider developing FAQs, appropriate Forums and support mechanisms for those managers/ appraisers who will sign-off competencies for candidates.
 - It was considered how to involve patients in the review of this document (they were involved in the original document) and ways to involve these patients will be sought for the next review
 - To conduct research to explore the specific value of using the framework for those with a mild to moderate LD (Ring et al 2018).
 - Research the potential for long-term benefits arising from application of the continuing professional development element of the framework (Ring et al 2018)'

The impact on ESN practice:

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

Evaluation and review methods

This framework will be evaluated using the following methods.

Feedback requests

Following the launch of this new ESN LD 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. There will be a working party to evaluate feedback forms from ESNA.

Portfolio evidence

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

Evaluation forms

The ESN LD competency framework will be further assessed on an ongoing basis via the feedback from evaluation forms received within the framework itself. These will be collated and reviewed by an ESNA representative.

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

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

Appendix 3: Benner's model of nursing competence

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:

- The development of engaged reasoning in transitions. The proficient nurse works to gain a good understanding and knowledge of the patient and can pick out what is salient in a changing situation. This requires an openness and ability to be challenged rather than needing predictability and control (in contrast with the competent nurse). Because the technical mastery of skills and tasks no longer takes so much attention, the proficient nurse is able to engage in situations and reflect upon them more readily.
- 2. Emotional attunement to the situation. The proficient nurse's practical grasp of the situation is increasingly accurate. If they are unable to have this grasp, a feeling of uneasiness develops, alerting them to the fact that something might be wrong. This is what is meant by 'emotional responsiveness'.
- 3. The ability to recognise the changing relevance of aspects of a situation. The nurse can see when to react in a different way from that initially planned. This ability involves a holistic assessment, a trust in one's own interpretation of signs and symptoms, and intuition.
- 4. A socially skilled sense of urgency.
- 5. Improved and more differentiated skills of involvement with patients and families.
- 6. Proficient nurses perceive and understand a situation as a whole. They have the 'big picture'.

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

Stage 5 - Expert

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

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

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

AANPE	Association of Advanced Nursing Practice Educators		
ABN	Association of British Neurologists		
ABHI	Association of British HealthTech Industries		
ABPI	Association of Entism realitmeet industries Association of the British Pharmaceutical Industry		
AfC	Agenda for Change		
AHP	Allied Health Professional		
ARAF	Annual risk acknowledgement form		
ASM	Anti-seizure medication		
Autism	A lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.		
Behaviour disorder	Culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be put in jeopardy, or behaviour that is likely to limit the use of, or result in the person being denied access to, ordinary community facilities (Chadwick, 1994).		
BILD	British Institute of Learning Disabilities		
ВМА	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.		
Comorbidities	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		
Emergency medication	A medication prescribed as required to help manage status epilepticus, prolonged and cluster seizures.		
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		
НСР	Healthcare professional		
НСРС	Health and Care Professions Council		
HEE	Health Education England		
HWB	Health and wellbeing		
IASID	International Association of the Scientific Study of Intellectual Disability		
ICD	International Classification of Diseases		
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ICH	International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use	
ILAE	International League Against Epilepsy	
Intellectual disability	A significant reduced ability to understand new or complex information and apply new skills (impaired intelligence) that results in a reduced ability to cope independently (impaired social function) and begins before adulthood, with lasting effect on development.	
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	
МНО	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 professionals	
NMC	Nursing and Midwifery Council	
NMP	Non-medical prescriber	
NOS	National Occupational Standards	
PDNSA	Parkinson's Disease Nurse Specialist Association	
PDP	Personal development plan	
PDR	Personal development review	
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	
PWLD	Person/people with a learning disability	
QOF	Quality and Outcomes Framework	
QoL	Quality of life	
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
SUDEP	Sudden unexpected death in epilepsy
VNS	Vagus nerve stimulation
WHO	World Health Organization
WWE	Woman/women with epilepsy

NICE and SIGN recommend that patients be given appropriate information. The following is a checklist that can be used to identify what information to give patients and 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

Optional
Sexual health and impact on hormones
Behaviour problems in children and young people
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 including older people with LD. 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 LD is desirable to ensure the patient has access to ongoing support. In the absence of an ESN LD, 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 ESN job description might cover. They can be adapted by individual organisations and departments to suit their own epilepsy services and ESN provision, including specific services for PWLD. 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 liaison nurse
	Responsible to: Epilepsy specialist nurse
	Department: Neurology
	Directorate: Neurosciences
	Operating division:
	Number of job holders:
Job purpose	This service takes referrals for adults and adolescents as well as people with LD and psychiatric comorbidity. The aim is to ensure the highest standard of personalised epilepsy nursing care is delivered to patients and their families in partnership with all members of the MDT. The remit of this post is to:
	Be responsible for a caseload of patients allocated to the specialist service within the relevant health board/trust/CCG area and the regional or wider service. This includes delivering epilepsy nurse-led services and can take place in a community and acute hospital setting.
	Ensure all care delivered is in accordance with national guidelines for epilepsy practice.
	Motivate staff to provide high standards of care by acting as a role model.
	 Provide professional and clinical care advice to patients, carers and the MDT.
	Contribute to the provision of specialist education and training programmes for healthcare professionals and other professional groups.
	 Contribute to research activities ensuring evidence-based practice in the specialist area.
	Ensure any care gaps are noted in epilepsy care provision are communicated to senior ESNs and/or ward charge nurse.
Dimensions	The post holder contributes to the clinical responsibility for the regional and wider epilepsy service.
	The post holder may participate in nurse-led clinics within the overall service provision for patients in the epilepsy specialty.
	The post holder will interact with other staff, including: medical practitioners, therapists, support services, education facilitators, health and safety, risk management, community health practitioners, higher education institutions, social work services and voluntary agencies.

Organisational Structural diagram showing who post holder reports to/who reports to them position Role of department/ The Department of Neurosciences provides a comprehensive regional service neurology service to [number] people [PWLD] and a supra-regional service to [number] people [PWLD]. The epilepsy service potentially serves [number] people [PWLD] locally and [number] people [PWLD] in the wider regional areas. The epilepsy service provides specialist inpatient and outpatient epilepsy care to patients in [appropriate population and health board/CCG/trust]. Its role covers: Providing high-quality epilepsy care to all patients within a supportive and safe environment Ensuring epilepsy care in the acute care area and in the community meets nationally agreed guidelines. This involves assessing the care provided by medical staff, nursing and all other healthcare staff who may come into contact with the patient Contributing to and participating in developments in the epilepsy service in partnership with the acute services division and the health board/CCG. **Outcomes** Professional (100%) Practice at all times within the Nursing and Midwifery Council code of professional conduct Develop the role by using evidence-based practice and continuously improve own knowledge, following PREP guidelines Deliver clinical evidence-based practice in accordance with national NICE/ SIGN guidelines and clinical standards for epilepsy nursing Act as a role model for specialist nursing services Leadership and management (100%) Provide advice and support to the nursing staff within the epilepsy service, ensuring that patient needs are assessed and care is planned, implemented and evaluated, and that there is consultation with, and the involvement of, patients and families/carers Contribute to epilepsy-specific initiatives within the MDT, and to the development, implementation and maintenance of the epilepsy service policies, procedures, standards and protocols throughout the health board/ **CCG** locality • In conjunction with the senior clinical nurse specialist, ensure that all nursing staff and members of the MDT are aware of, and work within, local, directorate and division policies and procedures to ensure that safe working practices are maintained for both patients and staff 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 a learning disability with epilepsy, their families and carers, ensuring that this is in line with nationally agreed practice
- Assess patients' clinical condition and, following discussion with senior medical and nursing colleagues, alter or initiate treatment of the patient with epilepsy, ensuring a high degree of epilepsy-specific expertise and care that is in line with nationally agreed guidelines
- Provide a responsive email and telephone helpline for patients, that is staffed [five] days a week. The post holder is responsible for dealing with calls/queries and, following discussion and consultation with senior colleagues, for communicating plans to the patient/carer and all other members of the care team
- Monitor standards of care within the defined policies, procedures and protocols of the service, ward, directorate and division to ensure adherence to, and delivery of, a high-quality epilepsy service
- Develop and provide specialist programmes for care/care packages for patients in the epilepsy service
- Be responsible for improving and streamlining the process of care for patients throughout their pathway in primary and secondary care

Research (10%)

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

Education (20%)

- Contribute to multidisciplinary specialist education and training programmes to promote a wider understanding of epilepsy in primary and secondary healthcare settings
- Promote and advise on health and lifestyle activities for patients, carers, healthcare professionals and the general public
- Teach, advise and coach patients and carers with regard to the condition and treatment options
- Promote a normal life philosophy of care, promoting empowerment of the patient
- Contribute to the provision of clinical practice for pre-registration and post-registration learners, to fulfil curriculum requirements and ensure that appropriate educational opportunities are provided
- Ensure educational material is provided for all patients, ensuring that this
 is in an appropriate format and taking into consideration cognitive decline,
 ethnic group and presence of LD
- Ensure that ongoing personal development, professional education and research needs are identified and met

Equipment and machinery

The post holder is expected to have the knowledge and ability to use all relevant equipment, although they might not have daily clinical involvement. Such equipment could include the following [include specific makes/models as appropriate/necessary]:

Generic: television bedside unit; hoists; cardiac monitor; fridge; bath hoist; pulse oximeter; ice machine; nurse call system; blood pressure machine; database/computers

Specialised: glucometer; compartment monitor; fire equipment; suction equipment; pneumatic tube system; pressure mattress; pat slides; electroencephalograph; water boiler; electrocardiograph; walking aids (frames, crutches, walking sticks); humidified therapy

Very specialised: vagus nerve stimulator; oxygen cylinders; standing and turning aids; transfer boards; raised toilet seats; pat slides; glide sheets; X-ray boxes; electrically controlled chair; wheelchairs; trolleys; video camera; voice recorder

Systems

- Specialist databases collect and input patient data that allows post holder to determine workload and activity
- Local patient administration system as above
- Human resources administration system
- Incident reporting system
- Laboratory information system specimen results
- Internet and intranet personal and business
- PowerPoint/Excel
- Access database
- Vagus nerve stimulator
- Telecommunications

Assignment and review of work

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

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

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

The post holder will have a professional personal development plan that is reviewed every six months by the delegated line manager.

Decisions and judgements

The post holder might be expected to:

- Make autonomous clinical and professional decisions on a daily basis, including the provision of advice to the MDT, patients and carers
- Inform clinical decision-making with regard to patient healthcare through stringent monitoring of the patient's condition and acting on clinical judgements
- Act as the patient's advocate to ensure their rights are upheld at all times.

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

Most challenging parts of the job

Epilepsy is a highly prevalent disease, which historically has always been managed within the secondary care setting. National guidelines now advise more primary care input but relevant expertise in both primary and secondary care could be insufficient.

The post holder is likely to face the following challenges:

- Improving and streamlining the process of care for patients with epilepsy across regions and boundaries
- Communicating this care using various communication systems in both primary and secondary care
- Continued development and promotion of the service
- Improving communication between the professions involved in the care and treatment of patients with epilepsy
- Unexpected patient activity and demand resulting from the open access nature of the role (email/telephone/pager etc.)
- Limited funding and resources, which affects delivery of a high-quality service, because epilepsy is a low priority of care within national and local health plans
- Complexity of patient problems many patients have associated comorbidity or neurological handicap, and the condition is more prevalent in socially deprived areas
- · Addressing the equality and diversity needs of patients and staff
- Dealing with multi-faceted organisations
- Implementing change effectively in a multidisciplinary environment
- Time management
- Discharging patients from caseload

Communications and relationships

The post holder will be expected to:

- Communicate with the patient, their family and/or carers on the delivery of patient care
- Manage patients through chronic illness, terminal illness and acute illness as epilepsy presents in all ages and in many acute and chronic disease processes, and is often lifelong
- Frequently communicate a difficult and stigmatising diagnosis, which may lead to very immediate and drastic alterations to the individual's lifestyle (including driving and employment) and can often result in the patient and/ or their family being verbally abusive
- Liaise with the MDT on service needs and requirements.

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

Internal communication: operational services; director of nursing; general manager/assistant general manager; principal nurse; clinical director; managed clinical network (manager and lead clinician); LD service; physicians; ward nurses; psychiatric services; psychology services; paediatric services; laboratory services; obstetric services; multidisciplinary leads; finance; procurement; support services; human resources; health and safety; risk management; palliative care team; critical care teams; bed managers; radiology; pathology; IT; research and development (R&D) department

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

Physical, mental, emotional and environmental demands of the job

Physical skills required

- 12-lead ECGs
- Intravenous cannulae/venepuncture
- Blood glucose monitoring
- Advanced maintenance of patient's airway (using bag valve mask manual resuscitator)
- Driving

Physical demands

- Moving patients with mechanical aids
- Manoeuvring patients
- Pushing trolleys and wheelchairs
- · Standing/walking for the majority of shift
- Activities of daily living
- Ergonomics

Mental demands

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

Emotional demands

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

Environmental demands (working conditions)

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

Knowledge, training and experience required to do the job

Minimum requirement to undertake the role: first-level registered nurse with five years post registration or relevant experience demonstrating the appropriate competencies and skills for the job. These include:

- Educated to degree level or evidence of working towards this desirable
- Evidence of further education, including postgraduate certification, diploma or continuing professional development in neuroscience and/or epilepsy
- Evidence of management, education and training desirable
- Effective listening and interpersonal skills
- Time management skills/ability to prioritise workload
- Excellent teamworking skills plus ability to work on own initiative
- Evidence of effective problem-solving skills
- IT skills
- Expert clinical practice

Job d	lescri	iption
agree	men	t

A separate	job description	n will need	to be	signed	off by	each	post	holder	to
whom the jo	ob description	applies.							

Post holder's signature:
Date:
Head of department's signature:
Date:

Example level 7 ESN job description

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

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

Role of department/ 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

Systems

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

Assignment and review of work

Accountability

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

Work allocation

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

Job autonomy

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

Decisions and judgements

The post holder will work autonomously, making advanced clinical decisions and judgements on individual patients using proven clinical expertise and knowledge. The post holder will take a detailed history and assessment before making any decision regarding each patient. These decisions and judgements include: choice and referral for investigations for appropriate patients; using initiative and making independent advanced clinical decisions, such as patient diagnosis then management plans after history taking, examination and interpreting results from relevant investigations.

Following expert clinical assessment, the post holder will make autonomous decisions regarding the triage of patients, including: referral and review by a neurologist; referral for further medical management e.g. ordering specific investigations; autonomous decisions regarding alteration of settings on VNS and for communicating this to all personnel involved in the patient's care.

The post holder will be accountable for all aspects of the ESN across the health board/CCG/trust area, such as:

- Leading nurse input in multidisciplinary decision-making
- Leading in the development of health board/CCG/trust wide multidisciplinary and clinically effective standards of care guidelines for the management of patients with suspected cardiac chest pain.

The assessment of comorbidities such as LD and psychiatric conditions (such as depression or psychotic illness) will also be conducted autonomously by the post holder, and appropriate referrals made.

The post holder is expected to make operational judgements within the epilepsy service, including:

- Informing clinical decision-making with regard to 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

Environmental demands (working conditions)

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

Knowledge, training and experience required to do the job

- First-level registered nurse with experience equivalent to seven years post registration, two years at band 6 or relevant experience demonstrating the appropriate competencies and skills for the job
- Post-registration qualification relevant to neurosciences and/or management of epilepsy
- Educated to master's level or working towards this desirable
- Effective listening and interpersonal skills essential
- Excellent written and communication skills with proven ability to compile reports essential
- Proven experience in developing, implementing and managing change within the specialty
- Proven experience in monitoring and auditing a service, and changing and influencing clinical practice accordingly – essential
- Proven experience in innovation in nursing practice and motivation and development of professional staff – essential
- Time management skills/ability to prioritise workload, demonstrating ability to work autonomously and manage own workload essential
- Excellent teamworking skills, with the ability to work using own initiative
- An imaginative approach to problem solving that is rooted in reality and effective personal leadership within an MDT
- Expert knowledge of national agendas and targets for neurology services
- Working knowledge of common IT software packages to facilitate communication and audit
- Research experience, including working knowledge of relevant 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:

