

# The Learning Disability Epilepsy Specialist Nurse Competency Framework



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The development of the Learning Disability Epilepsy Specialist Nurse Competency Framework was led by a working party of experienced Learning Disability (LD) Epilepsy Specialist Nurses (ESNs), from Focus in Epilepsy Learning Disability (FIELD), in association with the Epilepsy Nurses Association (ESNA). The document has been accredited by the Royal College of Nursing (RCN), with the support of Epilepsy Action to ensure that the perspective of people with learning disabilities (PWLD) has been considered. The LD Steering Committee included:

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During the development of the LD ESN Competency Framework appropriate guidelines have been considered. The LD ESN Competency Framework is compliant with the following guidelines:

- RCN Diversity and Equality Standards
- Nursing and Midwifery Council Code of Conduct
- Association of British Pharmaceutical Industry Code of Conduct, Second 2012 Edition
- Association of British Healthcare Industries Code of Business Practice



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AED	Anti-epileptic drug: medication used to treat epilepsy
AFC	Agenda for Change
AHP	Allied health professionals: e.g., physiotherapists, occupational therapists, speech and language therapists
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	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 which is likely to limit the use of, or result in the person being denied access to, ordinary community facilities <sup>2</sup>
BILD	British Institute of Learning Disabilities
BNF	British National Formulary
Comorbidities	Two or more co-existing medical conditions or disease processes that are additional to an initial diagnosis. This may complicate the treatment and outcomes for the person
CPD	Continuing professional development
DoL	Deprivation of Liberty Safeguard
Epilepsy	A common chronic neurological disorder characterised by the tendency to have recurrent seizures
ESN	Epilepsy Specialist Nurse
ESNA	Epilepsy Nurses Association: the national epilepsy nursing group
FIELD	Focus in Epilepsy Learning Disability: a learning disability nurses forum, West Midlands
G-1	Learning and development
GSK	GlaxoSmithKline
HWB	Health and wellbeing
IK	Information and knowledge
ILAE	International League Against Epilepsy
IQ	Intelligence quotient
JEC	Joint Epilepsy Council
KSF	Knowledge and Skills Framework
LD	Learning Disability (also referred to as intellectual disability by the WHO and other bodies; however, LD is still more commonly used in nursing disciplines)
LD ESN	Learning Disability Epilepsy Specialist Nurse
MCA	Mental Capacity Act
MDT	Multi-disciplinary team
MHO	Mental Health Officer

NEAD	Non-epileptic attack disorder
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NMC	Nursing and Midwifery Council
PDP	Personal development plan
Polypharmacy	A term used to describe when an individual takes a number of different medications. This can be different epilepsy medications or medication used to treat other conditions
PWLD	Person/people with a learning disability
QoL	Quality of life
Rescue medication	Medication prescribed as required to help manage status epilepticus, prolonged and cluster seizures (also known as emergency rescue medication)
RNLD	Registered Nurse (Learning Difficulties). A Nurse who is registered on the NMC register and holds a first level registration for Learning Disability.
RNMH	Registered Nurse (Mental Health)
Seizures	An epileptic seizure, occasionally referred to as a fit, is defined as a transient symptom of 'abnormal excessive or synchronous neuronal activity in the brain' <sup>3</sup>
SIGN	Scottish Intercollegiate Guidelines Network
SUDEP	Sudden unexplained death in epilepsy
UK	United Kingdom
VNS	Vagal nerve stimulation
WHO	World Health Organization

## Executive Summary

Epilepsy is a common neurological condition within the general population; in people with learning disabilities (PWLD) depending upon severity of the learning disability (LD) and any co-morbid syndromes up to 50% of people could develop epilepsy at any one time.<sup>4</sup> Although there are LD nurses who specialise in epilepsy and deliver an epilepsy specialist role, it is acknowledged that a majority of clinicians look after people with epilepsy and LDs as part of their generic LD nurse role.

The key difference between an LD Epilepsy Specialist Nurse (ESN) and an LD nurse is that the latter may reach novice level in some competencies, such as risk assessment in relation to epilepsy management, and appreciating the need for emergency rescue medication for the individual, but not in others; for example, nurse-led clinics, diagnosis in epilepsy, and linking evidence-based anti-epileptic drug treatments to seizure classification.

The LD ESN Competency Framework is a key document that can be used by all LD nurses working within the field of epilepsy. The framework sets out educational and professional criteria that guide new nurses (or nurses that have changed career focus) into the role of LD ESN through to expert specialist 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 LDs, not all individuals using the document will move through all stages from novice nurse to expert specialist nurse.

The authors agree 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 as well as improving safety for PWLD and the quality of epilepsy services provided.



Learning disability (LD) is defined in many ways, but internationally the World Health Organization (WHO) defines a LD as a state of arrested or incomplete development of the mind.<sup>5</sup> Diagnosis is determined within a framework of three criteria: intellectual impairment (intelligence quotient [IQ]), social or adaptive dysfunction, and onset before the age of 18 years.<sup>6</sup> This definition is not used in isolation and the diagnosis of a LD is further categorised by severity of difficulties, and any additional behavioural impairments.<sup>7</sup>

The use of accepted and recognised terminology is varied within the medical fraternity. In a study commissioned by the WHO, the term 'mental retardation' was found to be the most commonly used term across the globe (76%), followed by 'intellectual disabilities' (56.8%), 'mental handicap' (39.7%) and 'mental disability' (39.0%).<sup>8</sup> The British Institute of Learning Disabilities (BILD) identify that the United Kingdom (UK) is unique in its utilisation of the term 'learning disabilities', stating that other terms include 'intellectual disabilities' and 'developmental disabilities', both of which are used internationally but not commonly in the UK. The term 'intellectual disability' should be considered interchangeable with the UK term 'learning disability'.<sup>9</sup> This document will use the term 'learning disabilities'.

Epilepsy is the most common neurological condition,<sup>10</sup> affecting approximately 1 in 103 people within the general population.<sup>11</sup> At any one time approximately 600,000 people within the UK will have a diagnosis of epilepsy.<sup>11</sup> There are between 602,000 and 1,204,000 people with LD (PWLD) in the UK.<sup>9</sup> Whilst figures differ slightly it is estimated that around 30% of PWLD (nearly 1 in 3) 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% of people in the general population (1 in 5) with epilepsy also have a LD.<sup>12</sup>

In PWLD, epilepsy is acknowledged as the most common co-morbidity, with approximately 26% having epilepsy.<sup>13,14</sup> PWLD who have epilepsy do less well than adults with epilepsy in the general population; the prognosis for seizure control is poorer and they have higher rates of morbidity and mortality, including sudden unexplained death in epilepsy (SUDEP).<sup>14,15,16</sup> Supporting people with a dual diagnosis of LD and epilepsy is a very important element of care, enabling the individual, their family and carers to lead a positive and inclusive quality of life (QoL).<sup>17</sup> Management of their epilepsy should be delivered from clinicians who have an 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 Clinical Excellence (NICE) guidelines recommend that all individuals with epilepsy should have access to an ESN, and this includes people with LD.<sup>18</sup>

Diagnosis can be difficult to obtain in people with LD due to a range of additional complexities, such as communication difficulties, and behavioural disorders.<sup>19</sup> It can also be hampered by the current LD pre-registration nursing curriculum, as the teaching of epilepsy and the link with LD is not widely included as a compulsory element of the curriculum. The management of epilepsy in PWLD demands high professional standards across a range of clinical domains.<sup>20</sup> One of the many roles of the LD ESN is to provide essential post-registration training to enable precise monitoring of events during the diagnostic process. Once diagnosed, joint working between a LD nurse with an interest in epilepsy and the LD ESN can be extremely beneficial as it enables regular monitoring and a rationalised management plan. It is recognised that on-going management can be difficult due to an association between LD and refractory epilepsy.<sup>20</sup>

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 realm 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 providing social care interventions to PWLD. Many LD registered nurses now work in a social care setting, for which there may be a lack of specific standards and guidelines surrounding epilepsy management and care.

The LD ESN Competency Framework is designed to fill this gap by providing aspirational guidelines that should be used to develop skills, knowledge, and inform practice, training and development, and provide a structure for appraisals. The framework will ensure that nurses working within LD deliver high-quality, safe and accountable care to PWLD and epilepsy. By utilising common frameworks within the novice section of the framework LD nurses will be able to improve their daily clinical practice, care planning and general knowledge surrounding epilepsy in PWLD.

It is suggested that LD nurses as a minimum should aim to meet novice level in the competencies listed below:

- A (II).** Assessing and Managing Seizures
- A (II) i.** Assessing, Planning, Implementing and Evaluating Care
- A (II) ii.** Emergency Medication
- B.** Assessing and Managing Risk
- D.** Capacity and Consent to Treatment
- F.** Multi-disciplinary Team Working

Epilepsy should be a core part of all LD nurse training; once registered all nurses are likely to encounter epilepsy from the clinical observation of seizures and monitoring their frequency. The authors of the framework acknowledge that within LD nursing continuing professional development (CPD), in relation to knowledge around epilepsy, is not isolated to those clinicians practising as recognised ESNs. The roles of both the community nurse and LD ESN are not exclusive, therefore an element of parallel working is essential to help reduce the impact of epilepsy on the individual, their families, and carers, due to the complexities of the person's LD and associated co-morbidities.

The LD ESN is pivotal in disseminating a greater understanding of the condition through the provision of training, information, guidance and advice, both to the PWLD, their families and paid carers. The LD ESNs are also essential in unravelling the complexities that arise during the management of patient seizures. Having in-depth knowledge of epilepsy provides LD ESNs 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. Utilising risk-assessment tools will help the LD ESN balance the management of a patient's seizures with the side effects to treatment and the effect of the seizures on their QoL. Risk assessment is recognised by NICE as holding particular importance in PWLD and epilepsy; NICE are specific in stating areas in which risk assessment should take place.<sup>18</sup>

Understanding the process of assessing capacity and working within the best practice guidelines is critical to the role of the LD ESN, especially in the provision of treatment, rescue medication guidance and to reduce the risk of diagnostic overshadowing.<sup>21</sup> The role of the LD ESN should focus on enabling a PWLD with epilepsy to lead as independent a life as possible by providing a holistic, collaborative and co-ordinative approach to effective treatment planning and risk management. This requires the LD ESN to be an expert resource to all involved in epilepsy care and results in the LD ESN becoming a consultant in evidence-based epilepsy care, education and research.

Working with PWLD takes considerable time and expertise. The added challenge of epilepsy makes time-management skills critical in the LD ESN role. For this reason, the framework provides a specific section on time management. The role of the LD ESN varies according to the local environment, the length of time an individual has been in post and their knowledge, skills and experience. This document aims to define a competency framework to support the LD ESN role.

# What are Nursing Competencies?

Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain, cope, and recover with health problems. The outcome is to achieve the best possible QoL, whatever their disease or disability, until death.<sup>22</sup> Provision of care needs to be bound by competencies in order to provide and maintain the highest standard of clinical care. Competence is defined by Roach as 'the state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's professional responsibilities,<sup>23</sup> 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.<sup>24</sup>

It is the duty of registered nurses to maintain their 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, Agenda for Change (AFC)<sup>25</sup>, partly addressed these issues by developing and introducing NHS Knowledge and Skills Framework (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 specialities and career paths.<sup>26</sup>

The Nursing and Midwifery Council (NMC) states that 'a nurse is a safe, caring, and competent decision maker willing to accept personal and professional accountability for his/her actions and continuous learning. The nurse practises within a statutory framework and code of ethics delivering nursing practice (care) that is appropriately based on research, evidence and critical thinking that effectively responds to the needs of individual clients (PWLD) and diverse populations.<sup>27</sup>

## What is a Competency Framework?

A competency framework is a 'collection of competencies that are thought to be central to effective performance'.<sup>28</sup> 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.<sup>29</sup> To this end, the NMC has developed pre-registration competencies and efforts are underway to further develop competencies for different post-registration specialities.<sup>30</sup> 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 s/he practises'.<sup>31</sup>

# What is the Purpose of the LD ESN Competency Framework?

The LD ESN competency framework, which is aligned with the Epilepsy Nurses Association (ESNA) strategic plan, is a key document that can be used by all LD nurses working within the field of epilepsy. It is recognised that certain domains within the novice elements are essential to the clinical development of newly qualified LD 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 LD nurses to work through skills development towards clinical expertise to achieve the LD ESN expert level, this then enables the person to disseminate knowledge via research and teaching practices,<sup>32</sup> in a safe, effective and accountable manner.

In the UK, there is currently no definitive register for LD ESNs; there are 31 LD ESNs registered with ESNA and 22 are members of Epilepsy Action. This indicates that there is a need for, and interest in, guidance developed specifically for LD and epilepsy.

The LD ESN competency framework can be used to:

- Provide a vehicle to facilitate knowledge and skill development for all practitioners working within LD services
- Increase the focus on lifelong, self-directed and work-based learning
- Provide standards and expertise to demonstrate advanced/specialist practice
- Facilitate and provide guidance for professional development for LD ESNs, or nurses with specialist interest in epilepsy
- Identify the need for educational programmes, and ongoing practice development at differing stages of the LD ESNs career pathway
- Support clinical supervision and personal development plans (PDPs) in order to identify gaps in their competencies
- Ensure the highest standard of care is provided by the LD ESN, in accordance with published papers and governmental initiatives that influence changing political and professional issues including:
  - ‘Agenda for Change’, Department of Health<sup>25</sup>
  - ‘The NHS KSF’, Department of Health<sup>33</sup>
  - ‘The NHS Plan 2000’, Department of Health<sup>34</sup>
  - ‘The Epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care’, NICE guidelines<sup>18</sup>
  - Scottish Intercollegiate Guidelines Network (SIGN)<sup>35</sup>
  - ‘The National Service Framework for Long-term Conditions’, Department of Health<sup>36</sup>
  - ‘Death by indifference: 74 deaths and counting’, Mencap<sup>37</sup>
  - ‘Valuing people – new strategy for LD for the 21st century’, Department of Health<sup>38</sup>
  - ‘Signposts for success in commissioning and providing health service for people with LD’, Department of Health<sup>39</sup>
  - ‘Once a day’, Department of Health<sup>40</sup>
  - ‘Six lives: the provision of public services to people with LD’, Parliamentary and Health Service Ombudsman<sup>41</sup>
  - ‘Good practice in LD nursing’, Department of Health<sup>42</sup>
  - Mental Capacity Act (MCA)<sup>43</sup>
  - ‘Healthcare for all’, Sir Jonathan Michael<sup>44</sup>
  - ‘Modernising Nursing Careers Framework Initiative’, Department of Health<sup>45</sup>
  - ‘Post Registration Career Framework for Nurses in Wales’, Llywodraeth Cymru Welsh Government<sup>46</sup>
  - ‘The Framework for Developing Nursing Roles’, The Scottish Government<sup>47</sup>
  - ‘Key Elements of the Career Framework’, Skills for Health<sup>48</sup>
  - ‘The Framework’, The Scottish Credit and Qualifications Framework<sup>49</sup>
  - National Occupational Standards<sup>50</sup>
  - ‘Advanced Nursing Practice Toolkit’, Scottish Government Health Department<sup>51</sup>
  - ‘Guidance on the Career Framework for Health’, The Scottish Government<sup>52</sup>

- ‘Epilepsy in England: Time for Change’, Epilepsy Action<sup>53</sup>
- ‘The Human and Economic Cost of Epilepsy in England – Wasted Money, Wasted Lives’, All Party Parliamentary Group on Epilepsy<sup>54</sup>
- ‘National Sentinel Clinical Audit of Epilepsy-Related Death’, Epilepsy Bereaved<sup>55</sup>
- ‘Consensus Guidelines into the Management of Epilepsy in Adults with an Intellectual Disability’, Working group of the International Association of the Scientific Study of Intellectual Disability<sup>56</sup>
- ‘Clinical Guidelines for the Management of Epilepsy in Adults with an Intellectual Disability’<sup>120</sup>
- ‘Qualifications and Credit Framework for Employers’, Skills for Care<sup>57</sup>
- ‘Designed for People with Chronic Conditions — Service Development Directive: Epilepsy’, NHS Wales<sup>58</sup>

### Benner’s Five-Level Model of Nursing Competence

In line with the competency frameworks for Paediatric ESNs<sup>59</sup> and Adult ESNs (2012)<sup>1</sup>, the competency performance criteria are specified at three levels of practice, namely, novice, competent and expert. These levels are derived from the work of Benner (1984)<sup>60</sup>, which identifies a pathway of nursing practice that describes and differentiates between competency levels. As illustrated in Table 1, the pathway starts at the novice stage, where nurses learn through instruction and closely follow guidelines and protocols; and moves through to the expert stage, where there is extensive understanding of a situation, and the decisions made are intuitive and fluid.<sup>61</sup> It must be remembered that the framework is intended for all nurses working with PWLD and with epilepsy, irrespective of whether they work under the job specification of an ESN.

**TABLE 1: Levels of Competency**

<b>NOVICE NURSE</b>	<p>Newly registered nurse. Up to 2 years from taking up post, or LD nurses who wish to develop their epilepsy knowledge base, regardless of time post registration</p> <p>Working at first degree level</p> <p>Authors suggest AFC level 5/6</p>
<b>COMPETENT NURSE</b>	<p>Qualified nurse who is developing expertise to use detailed theoretical and practical knowledge in the management of epilepsy for PWLD</p> <p>Working at first degree level</p> <p>Authors suggest AFC level 6</p>
<b>EXPERT SPECIALIST NURSE</b>	<p>Qualified nurse who has developed specialist psychosocial and clinical expertise to assess and manage epilepsy for PWLD</p> <p>Hold, or working towards, a masters degree</p> <p>Authors suggest AFC level 7 or above</p>

This document has been written in line with the already published Paediatric and Adult ESN Competency Framework.<sup>59</sup> To allow for consistency and easy movement between all three documents, the framework has followed an identical process. This competency framework is aimed at nurses with a LD qualification working with LD services. 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 Paediatric ESN Competency Frameworks, picking out the sections most relevant to their areas of work. The framework is designed so that sections can be used independently. Many general adult and paediatric epilepsy nurses also have patients who have a LD and may wish to use relevant sections in this way.

As an autonomous practitioner the LD nurse should, firstly, work within the sphere of their job profile and adhere to NMC guidance in order to prevent potential risks to the care of PWLD. The LD nurse must also understand their professional capabilities, recognising limitations and seeking guidance when encountering situations beyond their own knowledge, competence or scope of practice. In order to remain fully and accurately informed the LD nurse should ensure that their CPD is updated and a PDP is in place, which includes an opportunity to receive clinical supervision.

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

The competencies should facilitate and provide a structure for:

- Self and 360-degree appraisals
- PDPs
- Development of an individual's professional portfolio
- Mentorship/preceptorship
- CPD and study days

It is recommended that the LD ESN Competency Framework is reviewed between the individual nurse/ESN and their manager (provided 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 who are new in post. Any variance in the role of the job as related to the competency set, for example significant strategic changes which may alter the services 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 KSF or PDP outline due to the varying role of epilepsy management within 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 care giving, and educational understanding.

## The NHS Knowledge and Skills Framework (NHS KSF)

The LD ESN Competency Framework for LD 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; giving every member of staff the same opportunities for learning and development open to them whilst having the same structured approach to learning, development and review.<sup>62</sup>

The NHS KSF comprises six core dimensions and 24 specific dimensions that apply to some, but not all, roles within the NHS.<sup>62</sup> The Adult ESN Steering Group highlighted the following dimensions as relevant to the ESN role; health and wellbeing (HWB), information and knowledge (IK), and learning and development (G1) (Figure 1). The novice, competent and expert specialist nurse should be working towards or already be working at level 3/4 respectively 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 LD ESN Competency Framework**

Core Dimensions	Specific Dimensions
1. Communication	1. HWB2 – Assessment and care planning to meet health and wellbeing needs
2. Personal and people development	2. HWB4 – Enablement to address health and wellbeing needs
3. Health, safety and security	3. HWB6 – Assessment and treatment planning
4. Service improvement	4. IK1 – Information processing
5. Quality	5. G1 – Learning and development
6. Equality and diversity	

The LD ESN Competency Framework is separated into 10 competencies that have been linked to the NHS KSF dimensions as shown in Table 2. These are underpinned and supported by the NMC Standards for Competence (for learning disabilities).<sup>63</sup> The LD ESN 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).<sup>64</sup> The LD ESN Competency Framework dimensions remain as outlined in the Adult ESN Competency Framework but have been added to and adjusted by the LD ESN Competency Framework Steering Group. They are:

#### **A. Clinical Diagnosis and Management of Epilepsy**

- I. Diagnosis of Epilepsy – Tests, investigations, history/information gathering all pertinent to assisting the diagnosis of epilepsy.
- II. Assessing and Managing Seizures – Using assessment tools to enable effective management of an individual's seizures, understanding seizure types/syndromes.
  - (i) *Assessing, Planning, Implementing and Evaluating Care* – Use, development and review of personalised care plans.
- III. Assessing and Managing Medicines
  - (i) *Anti-epileptic Drugs*
  - (ii) *Emergency Medication*
- IV. Assessing and Managing Linked Health Conditions

#### **B. Assessing and Managing Risk**

Use of recognised validated tools, and understanding the special needs of PWLD.

#### **C. Impact of Epilepsy**

- I. Assessing and Managing the Impact of Epilepsy – Recognising the importance of understanding social impact epilepsy can have on an individual's QoL.
- II. PWLD, Families and Carers

#### **D. Capacity and Consent to Treatment**

Understanding the impact of the MCA and best interests when managing epilepsy this section should underpin interventions in relation to all other sections.

- I. Capacity and Consent to Treatment (England and Wales)
- II. Capacity and Consent to Treatment (Scotland)



### **E. Personal Planning and Organisation**

- I. Autonomy, Accountability and Management – Recognising one's realm of professionalism.
- II. Telephone Management Relationships – Recognising the importance and limitations of telephone consultations.
- III. Time Management – Prioritising work, and able to demonstrate the use of data collection systems.

### **F. Multi-disciplinary Team Working**

Recognising how the multi-disciplinary team (MDT) works, and establishing professional relationships.

### **G. Personal and Professional Development**

PDP, clinical supervision and regular review. Recognising personal development needs.

### **H. Evidence-based Practice**

Understanding the important of evidence-based practice, and how audit and research fits into the nurse's role, allowing for critical appraisal of practice.

### **I. Development of Educational Programmes, Higher Education and Teaching**

Using skills to develop other member of the MDT, carers and patients to recognise their early warning signs.

**TABLE 2: The NHS KSF Linked to the LD ESN Competency Framework Dimensions**

LD ESN Dimension	KSF Dimensions												
	All core dimensions	HWB1	HWB2	HWB3	HWB4	HWB5	HWB6	HWB7	HWB8	HWB9	HWB10	IK1	G1
<b>A. Clinical Diagnosis and Management of Epilepsy</b>													
I. Diagnosis of Epilepsy	●								●			●	●
II. Assessing and Managing Seizures	●		●	●	●	●	●	●	●	●		●	●
<i>(i) Assessing, planning, implementing and evaluating care</i>	●	●	●	●	●	●	●	●	●	●		●	●
III. Assessing and Managing Medicines													
<i>(i) Anti-epileptic Drugs</i>	●	●	●	●	●	●	●	●	●	●		●	●
<i>(ii) Emergency Medication</i>	●	●	●	●	●	●	●	●	●	●		●	●
IV. Assessing and Managing Linked Health Conditions	●	●	●	●	●	●	●	●	●	●		●	●
B. Assessing and Managing Risk	●	●	●	●	●	●	●	●	●	●		●	●
C. Impact of Epilepsy													
I. Assessing and Managing the Impact of Epilepsy	●	●	●	●	●	●	●	●	●	●		●	●
II. PwLD, Families and Carers	●	●	●	●	●	●	●	●	●	●		●	●
D. Capacity and Consent to Treatment	●	●	●	●	●	●	●	●	●	●		●	●
E. Personal Planning and Organisation													
I. Autonomy, Accountability and Management	●	●	●	●	●	●	●	●	●	●		●	●
II. Telephone Management Relationships	●											●	●
III. Time Management	●												●
F. Multi-disciplinary Team Working	●	●	●	●	●	●	●	●	●	●		●	●
G. Personal and Professional Development	●	●	●	●	●	●	●	●	●	●		●	●
H. Evidence-based Practice	●	●	●	●	●	●	●	●	●	●		●	●
I. Development of Educational Programmes, Higher Education and Teaching	●											●	●

The LD Steering Committee would welcome feedback from nurses at all levels who use the framework; this will allow the LD ESN Competency Framework to be updated and amended for the publication of a second version (republication due 2015). If you have any feedback on the LD ESN Competency Framework please contact the Chair of ESNA who will lead this work (contact details found on <http://www.esna-online.org.uk/>).

Evaluation of the LD ESN Competency Framework will begin 2 years post-launch. This framework will be evaluated using the following methods:

- 1. Feedback requests:** At launch, publications will announce the release of the LD ESN Competency Framework. These will request LD ESNs to feedback their initial interpretation of the LD ESN Competency Framework. Sessions will be held at conferences, training meetings and forums to gather feedback from LDs using the LD Competency Framework, e.g., ESNA conference, Epilepsy Alliance conference, FIELD. Feedback on evidence used in portfolios will also be requested to help assess the LD ESN Competency Framework.
- 2. Evaluation form:** The LD ESN Competency Framework will be assessed via the feedback from evaluation forms received with the framework.
- 3. FIELD group:** Members of FIELD will be asked to evaluate the framework if they have used it themselves or mentored a novice LD ESN in post. The LD ESNs or Registered Nurse (Learning Difficulties) (RNLD) will be requested to address the following questions:

#### *Use of the LD ESN Competency Framework*

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

#### *Improvements to the LD ESN Competency Framework*

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

#### *Impact of the LD ESN Competency Framework*

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

- 4. Portfolio evidence:** Evidence used in portfolios will be assessed against the LD ESN Competency Framework.
- 5. LD ESN roundtable:** An LD ESN roundtable will be arranged to evaluate the use of the LD ESN Competency Framework. Following the roundtable a report will be published outlining:
  - Success of the LD ESN Competency Framework
  - Current usage of the LD ESN Competency Framework
  - Continued monitoring and evaluation of the LD ESN Competency Framework
  - Areas for development, in addition to how the LD Steering Committee aim to overcome these
- 6. Appraisals:** The LD ESN Competency Framework will be used by a variety of managers and mentors who are carrying out appraisals of all level of LD ESNs and its ease of use will be sought.
- 7. LD ESN Competency Framework study days:** Future ESN study days will be mapped to the competencies to assist members to update and maintain competence and portfolios.

## Using the LD ESN Competency Framework

The LD ESN Competency Framework has been developed as a cumulative document. It is assumed that nurses working from novice nurse to expert specialist nurse should not only work on the competencies listed within their column, they should also fulfil the competencies within the level(s) below.

The competencies captured within the LD ESN Competency Framework have been cross referenced to each other. **Where this cross reference occurs, a note (green box) will direct you to other areas of the framework for further information.**

e.g., maps to the Evidence-based practice competency. **H. EVIDENCE-BASED PRACTICE**

## Evidencing the LD ESN Competency Framework

Multiple types of evidence can be used to support practice, from formal quantitative 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 LD ESN
- evidence-based guidelines
- review of documentation and audits **H. EVIDENCE-BASED PRACTICE**
- reflective practice
- direct observation
- feedback from patients, families and carers on the role of the LD ESN
- minutes from relevant meetings
- documented evidence of adhering to the MCA.

# A. Clinical Diagnosis and Management of Epilepsy

## I. Diagnosis of Epilepsy

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB8, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To identify routine investigations that may be completed during diagnosis.	To identify and understand the relevance of each investigation and possible outcomes.	To identify and request appropriate investigations, interpret each investigation and its outcome, and identify the need for referral to an appropriate specialist. Is actively involved in the diagnostic decision making within the MDT.
	To gather relevant information/ observation for diagnosis and differential diagnosis. Completes appropriate documentation with accuracy and understanding.	To collate observations to support diagnosis. To initiate assessment process to support theory of differential diagnosis. Understands the clinical aspects that influence diagnosis.	To interpret/evaluate observations/ recordings to ensure appropriate diagnosis. Can identify differential diagnosis and refer for additional tests.
	To demonstrate good listening and communication skills, including desensitisation techniques. Provides leaflets, information and support in relation to epilepsy and diagnostic tests. <b>C II. PWLD</b> <b>C I. ASSESSING &amp; MANAGING THE IMPACT OF EPILEPSY</b>	To advise on seizure management, possible triggers and patterns to seizure frequency. Able to adapt lifestyle and first aid advice appropriately to seizure type and individual impact on PWLD.	To interpret results and outcomes of investigations, and relay information to PWLD/carers/family in an appropriate way. To provide specialist and holistic advice around risk management, and promoting independent living following a diagnosis of epilepsy. <b>B. ASSESSING &amp; MANAGING RISK</b>
	To tailor the information provided to suit the abilities and needs of the PWLD. Understands what information should be discussed with PWLD and their carers once a diagnosis has been ascertained. <b>C II. PWLD</b>	To use user-friendly resources (e.g., easy-read materials, photos, multimedia) and communication systems. To tailor information to address the language needs of people whose first language is not English.	To relay sensitive information to PWLD, carers and families.
	To develop knowledge of the pathology, diagnosis and treatment of epilepsy specific to PWLD. Has a functional understanding of the central nervous system, and an understanding of the genetic links to epilepsy.	To explain the causation theory linked to epilepsy including idiopathic, symptomatic, and probably symptomatic. Understands the specific needs of PWLD, including recognising that each PWLD is unique.	To assess links between onset of epilepsy and the ageing population of PWLD, especially in reference to specific LD syndromes. Understands the complexities of epilepsy and LD.

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To recognise the existence of non-epileptic attack disorder (NEAD), and is aware of conditions that are commonly associated with differential diagnosis.	To establish appropriate monitoring/recording tools to support the classification of NEAD and differential diagnosis.	To evaluate and interpret evidence of investigations and assessment to assist in differential diagnosis and NEAD.  To contribute to evidence-based practice relating to the diagnosis and understanding of epilepsy.  To make referral to specialist tertiary services as required.  <b>C 1. ASSESSING &amp; MANAGING THE IMPACT OF EPILEPSY</b>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	Evidence of records. Production of care plans. Evidence of process of practice assessment. Review of supervision notes. Evidence of use of current epilepsy classification tools, including International League Against Epilepsy (ILAE). Evidence of utility 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 tool.	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.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## II. Assessing and Managing Seizures

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB2, HWB3, HWB5, HWB6, HWB7, HWB8, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To utilise appropriate assessment tools to gather information on:</p> <ul style="list-style-type: none"> <li>Seizure type/class</li> <li>Triggers for seizure</li> <li>Severity (type of seizure, pre-/postictal)</li> <li>Seizure frequency</li> <li>Seizure pattern</li> <li>Injuries.</li> </ul>	<p>To use formal assessment tools to interpret information including:</p> <ul style="list-style-type: none"> <li>Triggers for seizure</li> <li>Severity (type of seizure, pre-/postictal)</li> <li>Seizure frequency</li> <li>Seizure pattern</li> <li>Injuries</li> <li>Management plans.</li> </ul>	<p>To utilise formal assessment tools to allow for the development of individualised complex management plans and protocols.</p> <p>To create individualised monitoring tools to obtain specific information surrounding more complex issues.</p> <p>May initiate use of video monitoring to support seizure and syndrome classification.</p> <p><b>D. CONSENT &amp; CAPACITY TO TREATMENT</b></p>
	<p>To have a working knowledge of seizure types, and be able to align these to the classification system as provided by the ILAE.</p> <p>To identify different seizure types, and understands seizure syndrome classification. Utilises the ILAE classification system.</p>	<p>To classify seizures in accordance with ILAE classification system.</p> <p>To understand the range of assessment tools relevant to people with LD.</p>	<p>Using assessment tools appropriately in the context of known aetiology.</p>
	<p>To understand the difference between generalised seizures and focal (partial) seizures.</p> <p>To implement and evaluate seizure description forms.</p>	<p>To use epilepsy-specific expertise to obtain a clinical history and assess seizure frequency and severity.</p> <p>To document and communicate a clear and holistic epilepsy history, whilst understanding the difficulty of receiving information from a third party.</p> <p>To understand how diagnosis of syndrome, and seizure type can lead to specific medicine management.</p>	<p>To be aware of all treatment options and can consider those individuals who may benefit from vagal nerve stimulation (VNS) or surgical assessments.</p> <p>To lead an innovative approach to practice in epilepsy and behaviour, and differential diagnosis.</p>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To demonstrate a good understanding of epilepsy. Has an understanding of the implications of seizures and discusses issues with PWLD, carers, family members, support workers and/or personal assistants. <b>C II. PWLD</b>	To understand the common LD syndromes, and how they influence the management and long-term prognosis of a patient's epilepsy.	To demonstrate a thorough knowledge of differential diagnosis, aetiology of the epilepsy, LD syndromes, and possess comprehensive knowledge of intractable epilepsy, and to translate this knowledge into practice.
	To monitor the management of seizures through regular visits. Provides continuity of review.	To provide continuity of care through regular reviews, home visits or structured clinics. Participates in nurse-led clinics. To initiate timely and appropriate review/investigation and seek further specialist advice.	To initiate investigations to support the treatment and management of the individual's epilepsy. Implements and manages nurse-led clinics. Identifies most appropriate clinician for on-going seizure management.
	To liaise with prescribing physician, or lead clinician.	To make prompt referral for specialist intervention where appropriate.	To provide holistic management, make clinical decisions and, establish treatment plans within a specialist service.
	To liaise with carers around potential difficulties with the management of PWLD's epilepsy for example, drug adherence and will signpost to other professionals/services as required. <b>C II. PWLD</b>	To identify potential management difficulties and communicate with PWLD, carer and wider MDT. <b>C II. PWLD</b>	To evaluate risk/benefits of various treatment and management strategies, and discuss options with carers and professionals. <b>C II. PWLD</b>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	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/carers. Observed clinical reviews. Evidence of the production of management/treatment plans. Review of specific LD publications. Production of MDT meeting minutes.	Evidence of using recognised seizure type and syndromic 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.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria



**(j) Assessing, planning, implementing and evaluating care**

<b>KSF ELEMENTS</b>	<b>CORE</b>	1, 2, 3, 4, 5, 6
	<b>SPECIFIC</b>	HWB1, HWB2, HWB3, HWB4, HWB5, HWB6, HWB7, IK1, G1

	<b>NOVICE NURSE</b>	<b>COMPETENT NURSE *</b>	<b>EXPERT SPECIALIST NURSE †</b>
<b>PERFORMANCE CRITERIA</b>	To be aware of the core elements to include within an epilepsy care plan.  To develop the care plan in collaboration with formal and informal carers to reflect the specific needs of the PWLD and include core information surrounding the PWLD's epilepsy: <ul style="list-style-type: none"><li>• Seizure description</li><li>• Management guidelines</li><li>• Record of seizures</li><li>• First aid.</li></ul>	To 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.	To complete a comprehensive care plan that includes a holistic approach to the individual's management of epilepsy. To include QoL assessment and risk management.
	To be aware of appropriate measurement and recording methods including interviews and individual epilepsy care plans.	To use appropriate measurement and recording methods including interviews and individual epilepsy care plans.	To formulate and review epilepsy management plans and protocols.
	To demonstrate knowledge of governmental, national or local guidelines that may influence the content of a care plan.	To have an understanding of governmental, national or local guidelines that may influence the content of a care plan.	To influence governmental, national or local guidelines that may influence the content of a care plan.
	To be aware of the long-term implications of epilepsy even when the PWLD's seizures are well managed.	To recognise the need for and refer for consideration of medication withdrawal.	To initiate baseline investigations prior to discussing appropriate drug withdrawal.
<b>KNOWLEDGE AND UNDERSTANDING EXAMPLE</b>	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.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

### III. Assessing and Managing Medicines

#### (i) Anti-epileptic Drugs

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB6, HWB7, HWB8, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To have an understanding of the relationship between epilepsy and LD diagnosis, and how this may determine treatment choice and prognosis.	To review evidence-based treatment options. To demonstrate the ability to triage, refer and liaise appropriately in a timely manner.	To initiate, monitor and evaluate evidence-based treatment options, to include medical and non-medical treatment available to the patient.
	To undertake a full treatment history of previous medications taken and reasons for discontinuation.	To interpret a treatment history. To consider the implications of aetiology when decision making and treatment planning.	To monitor and evaluate decision making and treatment planning to ensure the correct course of action is taken.
	To record current anti-epileptic drug (AED) therapy, monitor seizure frequency and report concerns regarding treatment plan. Review medical/nursing notes/care plans to establish previous treatments prescribed. To provide information and advice on medicines to PWLD, their families and carers. <b>C II. PWLD</b>	To assess the efficacy of prescribed medication and impact on side effects and QoL. Ability to explain seizure frequency and poor outcome balanced against dosage and side effects of AEDs. Recommends and identifies appropriate formulation of medication acceptable to the PWLD.	To review and evaluate treatment in relation to AED response, to initiate treatment changes based on ease of use, seizure frequency and side effects of AEDs. To recommend alternative treatment and therapies that could complement AED therapy, while acknowledging potential contraindications (e.g., between AED and non-AED treatment). To demonstrate a comprehensive knowledge of the limitations of alternative treatments, and to review and evaluate these alternative treatments.
	To assess the use and storage of AEDs in a variety of care settings. Document and report findings to the appropriate organisation/prescribing manager.	To assess the appropriate administration and compliance of AEDs in a variety of care settings.	To assist external organisations with the development of protocols, guidance for best practice, research, and other outputs.

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To explain the range of AEDs available, understand how to check for common side effects and basic interactions. To undertake an initial review of medicines and their side effects – using the British National Formulary (BNF).</p> <p>To be aware of signs and symptoms of treatment failure.</p>	<p>To make the correct links between signs and symptoms, failure to respond to treatment, and drug side effects. Recognise potential complications of polypharmacy, side effects and frequent clinic appointments and develop appropriate management strategies.</p>	<p>To ensure timely, appropriate monitoring for drug effects and side effects. To ensure the PWLD and their carers are educated regarding these. To recognise when biomedical investigations are appropriate. To request blood tests.</p> <p>Is aware of pharmacodynamic and pharmacokinetic interactions of drugs and make changes to treatment.</p>
	<p>To understand the effect of LD on how individuals may respond to medication.</p> <p>To demonstrate an understanding of how individuals with LD may respond differently to treatment and may be unable to articulate side effects.</p>	<p>To identify and observe potential side effect profiles, and understand how to take a case history from PWLD and their carers to pre-empt side effects.</p>	<p>To manage and lead the review of treatment, recommending treatment options and taking into consideration appropriate formulation of medication acceptable for the individual.</p> <p>Is aware of reasons and limitations of biomedical investigation.</p>
	<p>To identify potential concordance and adherence issues.</p>	<p>To demonstrate an ability to evaluate adherence with medication regime.</p>	<p>To review concordance and adherence of medication and develop treatment plans accordingly.</p> <p>To develop adherence strategies for prescribed medication.</p>
	<p>To be aware of current NICE guidance in relation to drug treatment.</p>	<p>To use NICE guidance to influence practice.</p>	<p>To prescribe and monitor the correct AED as per current NICE guidance for the epilepsy diagnosed.</p> <p>To educate and support primary care, pharmacists and the wider MDT in relation to formulations and prescription by brand issues.</p>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Demonstrates use of BNF via drug assessment.</p> <p>Mentor supervision notes.</p> <p>Seizure diaries.</p> <p>Evidence of provision of care plans.</p> <p>Evidence of review of clinical notes.</p>	<p>Evidence of shared care protocols.</p> <p>Evidence of referral to other agencies.</p> <p>Evidence of review of clinical guidelines.</p>	<p>Publications.</p> <p>Patient satisfaction survey.</p> <p>Evidence of pathway/protocol/policy development.</p> <p>Production of relevant audits.</p> <p>Assess for knowledge and adherence to the NMC non-medical prescribing standards.</p> <p>Clinical case review.</p> <p>Production of individualised treatment plans.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

**(ii) Emergency Medication**

<b>KSF ELEMENTS</b>	<b>CORE</b>	1, 2, 3, 4, 5, 6
	<b>SPECIFIC</b>	HWB1, HWB2, HWB3, HWB6, HWB7, HWB10, IK1, G1

	<b>NOVICE NURSE</b>	<b>COMPETENT NURSE *</b>	<b>EXPERT SPECIALIST NURSE †</b>
<b>PERFORMANCE CRITERIA</b>	<p>To identify potential need for the use of rescue medication through assessment of seizure frequency/severity.</p> <p>To observe local policies for rescue medications.</p> <p>To understand principles and basic action of treatment used.</p> <p>To explain the criteria for and understand the risk associated with prolonged seizures.</p>	<p>To demonstrate an ability to analyse records of rescue medication administration and outcomes of episodes of prolonged and cluster seizures and review effectiveness.</p> <p>To assist in the development of local policies for rescue medications.</p> <p>To understand the individual's needs and condition and take account of the needs of PWLD e.g., consent issues.</p>	<p>To initiate the use of rescue medication treatment for PWLDs.</p> <p>To develop, evaluate and review local policies for rescue medications.</p>
	<p>To collect and collate records of rescue medication usage and outcomes appropriately. Refer to relevant specialist for review and modification of treatment plan.</p>	<p>To assist the prescriber in the formulation of a treatment plan.</p>	<p>To review and evaluate records of rescue treatment administration, consider the appropriate merits and uses of available rescue treatments, including efficacy and the practical considerations, to meet the PWLD's needs.</p> <p>To review, evaluate and recommend changes to individualised rescue medication protocols and treatment plans.</p>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To provide information and support regarding rescue medication.</p> <p>To signpost and support professionals, formal and informal carers with training.</p> <p>To demonstrate an awareness of emergency rescue medication and controlled drug constraints.</p>	<p>To support and educate families and care staff and others in rescue medication treatment principles and techniques.</p> <p>To deliver training sessions to carers and family members, and the PWLD if possible, for the administration of rescue medication, following published guidance by the Joint Epilepsy Council (JEC).</p> <p>To develop skills to undertake training/health education to appropriate professionals, formal and informal carers within the context of the individual epilepsy care plan.</p>	<p>To make appropriate modifications to management plans in partnership with the PWLD, carers and other professionals.</p> <p>To advise appropriately in situations that arise where the epilepsy management plan is complex or the unexpected arises.</p> <p>To develop and review training material used during training sessions.</p> <p>To provide expert training/education to staff groups and other professionals in the use of rescue treatment in epilepsy.</p>
	<p>To keep up to date with new treatments or techniques. To have an awareness of recognised guidance in the use of and training for rescue treatment.</p>	<p>To understand potential implications when changes are made to local policy and guidance.</p>	<p>To use current research and guidance to inform the development of policies and procedures around rescue medication.</p> <p>To act as an expert advisor to ensure local changes to policy reflect national guidance, and ensure that they are evidence-based.</p>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Evidence of assessment process of need for rescue medication.</p> <p>Evidence of treatment review.</p> <p>Evidence of use of patient information.</p> <p>Evidence of use of relevant clinical guidelines.</p>	<p>Evidence of CPD and relevant teaching qualifications.</p> <p>Review of training evaluation sheets.</p> <p>Evidence of review of treatment protocols.</p> <p>Portfolio of training delivery.</p>	<p>Evidence of training records.</p> <p>Production of new training material.</p> <p>Evidence of training material review.</p> <p>Evidence of development of treatment protocols.</p> <p>Evidence of prescribing audit.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

#### IV. Assessing and Managing Linked Health Conditions

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB4, HWB5, HWB6, HWB7, HWB8, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To identify any common links between LD diagnosis and epilepsy prognosis. <b>A II. DIAGNOSIS</b>	To demonstrate an understanding of the risk factors of developing epilepsy depending on the patient's LD syndromic classification; for example, Down's Syndrome.	To interpret and influence practice.
	To carry out a basic health assessment, including developing health action plans.	To discuss the link between seizure control and physical ill-health.  To take a written history which includes aetiology of LD, epilepsy syndrome, seizure diagnosis and treatment neurological conditions.	To assess the relationship between epilepsy and concomitant conditions, in particular chest infection, dysphagia, sleep disorder, diabetes. To assess the impact of epilepsy on the individual's mental health status and/or behaviour.
	To discuss recognised LD conditions and syndromes linked to epilepsy.	To discuss recognised epilepsy syndromes and potential impact on learning and development.	To assess and record the impact of syndrome-specific features.  To assess and respond to the relationship between epilepsy and concomitant conditions.
	To demonstrate a basic understanding of the relationship between aetiology, diagnosis and prognosis.	To confidently discuss with others the evidence-based relationship between aetiology and diagnosis with seizure presentation and treatment prognosis.	To consider the overall impact of epilepsy in relation to specific conditions, which may be exacerbated by seizures and or treatment and vice versa, and the health and wellbeing of the individual.
	To complete health assessments.  To signpost the patient to their GP for an annual health check within an individual's epilepsy management plan.	To understand the potential link between physical ill health, seizure frequency, and AEDs.	To manage potential ill-health implications of long-term medication administration.  <b>A III. ASSESSING AND MANAGING MEDICINES</b>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Evidence of appropriate referrals.</p> <p>Evidence of using generic health assessment forms.</p> <p>Evidence of developing health action plans.</p> <p>Reviewing evidence from publications.</p>	<p>Evidence of completing relevant continued healthcare assessments.</p> <p>Critical analysis and appraisal of published evidence.</p>	<p>Use of audit to assess prescribing patterns.</p> <p>Development of clinical care pathways/protocols.</p> <p>Clinical observation.</p> <p>Participation in advanced literature reviews.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## B. Assessing and Managing Risk

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB3, HWB4, HWB6, HWB9, HWB10, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To identify common risk factors associated with epilepsy and seizures.	To identify and record the discussion of high-risk areas, including SUDEP, bathing and acute seizure management and treatment risk (as per the NICE guidelines for epilepsy). <sup>18</sup>	To complete specialised risk assessments. Have in-depth knowledge and understanding of risks and latest relevant research findings.
	To identify when more comprehensive risk assessment is needed.	To select appropriate risk identification methods and assessment strategies including checklists, recording charts and care plans.	To complete risk assessments and formulate effective responses in complex situations.
	To identify risk issues that may require further intervention.	To advise on environmental risk and the range and availability of safety equipment and seizure alert technology.	To be aware of specialist aids and equipment and assist in provision and funding.
	To identify issues surrounding vulnerable adults, and raise safe guarding application when appropriate.	To demonstrate knowledge surrounding the evidence base for reducing risks including, seizure management, alarms and alerts and environmental factors.	To work with other organisations in accordance with safeguarding applications and offer expert knowledge.
	To be aware of specific risks associated with epilepsy and LD in special populations: <ul style="list-style-type: none"> <li>• Multiple disabilities</li> <li>• Transition</li> <li>• Gender</li> <li>• Age related</li> <li>• Mental health.</li> </ul> To collect data for specialist risk assessments.	To interpret the risks and develops risk management strategies. To work with the wider MDT.	To hold specialist clinics. To develop specialist risk assessments, utilising evidence-based practice. To refer to wider MDT.



	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<ul style="list-style-type: none"> <li>Production of completed risk-assessment forms and risk-management documentation.</li> <li>Attendance certificate for safeguarding adults training.</li> <li>Treatment plans.</li> <li>Evidence of carer support training.</li> <li>QoL management plans.</li> <li>Completed referral forms.</li> </ul>	<ul style="list-style-type: none"> <li>Review of clinical papers.</li> <li>Evidence of complex risk assessments.</li> <li>Evidence of requests for aids/equipment.</li> <li>Minutes of risk strategy meetings.</li> </ul>	<ul style="list-style-type: none"> <li>Evidence of policy development.</li> <li>Prescribing records.</li> <li>Clinical management notes.</li> <li>Evidence of clinics.</li> </ul>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## C. Impact of Epilepsy

### I. Assessing and Managing the Impact of Epilepsy

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB5, HWB6, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To understand that seizure freedom is not always achievable.</p> <p>To identify signs that may indicate increased support is required.</p>	<p>To assess the fine balance between seizure frequency, severity and effect of treatment on patients' QoL. To use evidence-based assessment tools when appropriate.</p> <p>To make referrals for increased support where appropriate.</p>	<p>To work with the PWLD and carer to be responsive to the changing needs of the patient and the trajectory of their epilepsy diagnosis.</p> <p>To devise an individualised epilepsy care plan to help ensure that relevant information is available on review.</p> <p>Where appropriate, to provide advice on emergency protocols, and to make recommendations on the use of rescue medication.</p>
	<p>To recognise the potential impact epilepsy may have on the patient's psychosocial wellbeing.</p>	<p>To assess the degree to which epilepsy affects individuals' lives, specifically psychosocial wellbeing and lifestyle areas.</p>	<p>To refer to wider members of the MDT, including psychologists, to develop holistic lifestyle plan.</p>
	<p>To encourage PWLD to access leisure, social and employment opportunities.</p>	<p>To initiate risk assessments and management plans to reduce risk where appropriate.</p>	<p>To provide specialist resources based on risk assessment, to encourage independent living and community participation.</p>
	<p>To help reduce the impact on a PWLD's lifestyle, specifically in the areas of:</p> <ul style="list-style-type: none"> <li>• Health</li> <li>• Psychosocial effects (balance of risk and QoL)</li> <li>• Mental health</li> <li>• Balance between treatment and seizures</li> <li>• Behaviour</li> <li>• Autism.</li> </ul>	<p>To provide support and reduce risk to the PWLD's lifestyle specifically in the areas of mental health, psychosocial, behaviour and autism.</p>	<p>To provide comprehensive support and monitoring around the impact epilepsy can have on an individual, using recognised assessment tools.</p> <p>To assess and evaluate data, and implement appropriate strategies to improve QoL.</p>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To recognise equality and diversity issues that may impact on the diagnosis of epilepsy.	To recognise and address equality and diversity issues to provide a non-discriminatory service.	To evaluate the balance between equality and diversity beliefs and treatments, early intervention and support.
	To support PWLD's access to mainstream epilepsy services.	To liaise with mainstream services and ensure appropriate management and monitoring.	To work with mainstream services to ensure that reasonable adjustments are met to allow access to generic epilepsy services.
	To demonstrate an understanding of how to maintain QoL, including independence.	To use evidence-based tools appropriate to people with LD to assess QoL.	To evaluate data and implement strategies to improve QoL.
	To recognise the individual's aspirations utilising a person-centred approach.	To work with carers and families to facilitate appropriate strategies to meet aspirations of the patient.	To use advocacy skills and endorse frameworks and policies to ensure that the person's aspirations are met.
KNOWLEDGE AND UNDERSTANDING EXAMPLE	Completed QoL assessment.	Evidence of regular review and evaluation of QoL assessments. Evidence of referrals to MDT.	Evidence of creating individualised QoL assessments. Evidence of implementing reasonable adjustments. Emergency protocols. Evidence of development of referral pathways.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

‡ Specific tools are liable to change; please source and use the most up-to-date version

## II. PWLD, Families and Carers

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB9, HWB10, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To assess and note the level of carer concerns and burden.</p> <p>To assess and note the effect of knowledge, understanding and ability of carers to:</p> <ul style="list-style-type: none"> <li>Recognise and manage seizures and risk</li> <li>Record seizures</li> <li>Differentiate behaviour from epilepsy</li> <li>Recognise treatment effects and manage treatment and care plan</li> <li>Understand and describe potential barriers to learning.</li> </ul>	<p>To identify specific gaps in carers' knowledge and understanding, and to identify how this may impact on individuals' care.</p> <p>To involve the carer in the provision of a plan to address deficiencies in understanding.</p> <p>Where appropriate, to use accessible information to aid the retention of information.</p>	<p>To assess, identify needs and produce a plan to develop carers' skills and knowledge.</p> <p>To develop innovative materials to support learning and to minimise potential barriers to learning.</p> <p>To evaluate the effectiveness of carer's increased knowledge and skill in the level of care for the individual.</p> <p>To engage PWLD to be instrumental in modelling service frameworks, and to encourage engagement in initiatives such as the Expert PWLD programme.</p>
	<p>To use simple patient feedback.</p> <p><b>H. EVIDENCE-BASED PRACTICE</b></p>	<p>To undertake patient satisfaction surveys, using accessible information.</p>	<p>To use the audit cycle to evidence how patient feedback is incorporated into service development/change.</p>
	<p>To encourage PWLD and their carers to participate in service development. Is familiar with local provision of support services.</p>	<p>To aid patients and their carers to be involved in PWLD group meetings in relation to service provision. Can negotiate with families and carers regarding accessible and acceptable recording methods.</p>	<p>To advocate at trust/strategic commissioning level on behalf of PWLD and epilepsy. Recognise the limitations and constraints in the service and how this may impact on the level of care.</p>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>PWLD/carer testimony.</p> <p>Evidence of patient feedback involvement.</p> <p>Diary of training opportunities.</p> <p>Case studies.</p> <p>Observed clinical review.</p>	<p>Review of PWLD's and carers' satisfaction surveys.</p> <p>Engage with established user groups.</p> <p>Meetings of service user forums.</p> <p>Evidence of assessment of paid carer knowledge.</p> <p>Portfolio of teaching evaluation.</p> <p>Documentation of information sharing.</p>	<p>Evidence of specific training packages for carers.</p> <p>Reviews effectiveness of training provided.</p> <p>Evidence of development of carer and patient networks.</p> <p>Minutes from specific carer/service user forums.</p> <p>New educational material.</p> <p>Demonstrates use of various educational methods.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## D. Capacity and Consent to Treatment

### I. Capacity and Consent to Treatment (England and Wales)

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB3, HWB4, HWB6, HWB7, HWB8, IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To identify the need and gather information for assessment of capacity.	To carry out review/assessment of capacity.	To fully adhere to the MCA and give balanced opinions based on knowledge of treatment.
	To understand the principles of the MCA, best interest and seek advice and support when required.	To gather information to inform and support best-interest meetings.	To co-ordinate, chair and facilitate decision-making process under the MCA and act as a decision-maker when appropriate.
	To be familiar with legislation in relation to capacity of individual.	To have in-depth knowledge of how to approach people with a LD for consent.	To have extensive knowledge of MCA, capacity assessments, consent and Deprivation of Liberty Safeguards (DoLS).
	To demonstrate knowledge of when to involve advocacy services, signposts to appropriate service if level of understanding is deficient.	To refer to other services for added support. To work with advocates, including independent mental capacity and health advocates.	To act as an expert co-ordinator ensuring all requirements applicable to consent and capacity, best-interest meetings and DoLS are fulfilled and documented.
	To understand and adhere to the MCA, and the principles of consent and capacity to treatment (including the importance of accessible and appropriate information for PWLD to achieve this).	To provide accessible and appropriate information to PWLD, and their carers and families, to enable them to give informed consent and capacity to treatment.	To advocate for consent and capacity to treatment, and to ensure that the MCA is adhered to.
KNOWLEDGE AND UNDERSTANDING EXAMPLE	Evidence of documenting concerns in patient notes. 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.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## II. Capacity and Consent to Treatment (Scotland)

English and Scottish Law are separate as a general rule and are only applicable within the respective jurisdiction of each country.

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To understand the fundamental principles of consent to treatment.</p> <p>To understand the definition of incapacity and adhere to the principles of the 'Adults with Incapacity (Scotland) Act'.<sup>65</sup></p> <p>To have a basic understanding of Part 5 of the Act including Section 47.</p> <p>To be familiar with the provisions of the Act (e.g., powers of attorney and guardianship).</p>	<p>To demonstrate a more detailed knowledge and understanding of the 'Adults with Incapacity (Scotland) Act' and other related legislation.<sup>65</sup></p> <p>To understand the link between the Act and the 'Mental Health (Care and Treatment) (Scotland) Act' and statutory bodies with responsibilities under the Act.<sup>66</sup></p>	<p>To advise peer group and senior staff on the ethical issues surrounding informed consent. To advocate on behalf of the PWLD and ensure that they have the opportunity to make informed choices when they are able to so.</p> <p>To advise on and implement complex care and treatment plans.</p> <p>To contribute to local and national consultations.</p>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Evidence that relevant principles of the 'Adults with Incapacity (Scotland) Act' are applied.</p> <p>Evidence that the patient's views have been taken into consideration using accessible information where appropriate.</p> <p>Documentary evidence of completion of Section 47 of Part 5 of the 'Adults with Incapacity (Scotland) Act' (2000).<sup>65</sup></p> <p>Evidence that relevant professional advice and onward referral has been considered.</p>	<p>Evidence of multi-disciplinary working with relevant health and social care professionals including Mental Health Officer (MHO).</p> <p>Evidence of consultation with Welfare Guardian to develop the patient epilepsy care plan.</p>	<p>Production of minutes outlining the principles of the 'Adults with Incapacity (Scotland) Act'.<sup>65</sup></p> <p>Evidence of multi-disciplinary consultation in regards to complex care and treatment plans.</p> <p>Participate in appropriate national guidelines/frameworks/developments, e.g., SIGN.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria  
(Interim entry – to be reviewed 2015)

Note: The Mental Capacity (Health, Welfare & Finance) Bill for Northern Ireland is currently under development.

## E. Personal Planning and Organisation

### I. Autonomy, Accountability and Management

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB3, HWB4, HWB5, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To demonstrate an ability to work within the NMC 'Standards of conduct, performance and ethics for nurses and midwives', <sup>29</sup> Adopts professional behaviour.	To demonstrate an ability to work flexibly within the scope of professional practice and challenge boundaries to develop new ways of working.	To demonstrate involvement in the development of best practice guidelines, ensuring national policy and guidance are considered.
	To be aware of how own personal and cultural beliefs can influence clinical judgments.	To be aware of professional boundaries and scopes of practice and adopt changes in approach to accommodate.	To offer advice to other health professions, local and voluntary sector and challenges if professional and personal boundaries become blurred.
	To maintain accurate records and understand the principles of data protection and confidentiality.  To work within the framework of information governance.	To share relevant information with the MDT and complete complex reports.  To ensure others are aware of and work within the realm of information governance.	To audit records and manage breaches of data protection.  To contribute to the on-going development and review of information governance.
	To understand policy and procedures that may impact on service delivery, for example the lone working policy.	To implement regional and national guidance.	To take strategic overview of service. Is accountable for developing new services and implementing local/national guidance.  To act as an expert/advocate at local and national level to help challenge and develop epilepsy services.
	To manage allocated caseload. Identifies when appropriate to seek support.  <b>E III. TIME MANAGEMENT</b>	To manage own caseload and prioritise workload in response to service demands.	To prioritise and allocate caseload within service capacity.
	To demonstrate access to current NICE, SIGN and other relevant guidelines.	To interpret guidelines within own clinical practice.	To influence service delivery in line with guidelines at local and national level.



	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Discusses scope of practice within current role.</p> <p>Discusses lone working policy, highlighting risk.</p> <p>Reviews PDP.</p> <p>Shows evidence of discussion with MDT.</p>	<p>Records of limitations to practice and how they were overcome.</p> <p>Shows evidence of using risk assessment forms and compliance with policies.</p> <p>Identifies when it is appropriate to share assessment of risk with others.</p> <p>Produces attendance certificates to relevant epilepsy/LD groups, forums and networking opportunities.</p> <p>Undertakes case study review.</p>	<p>Evidence of influence on service delivery in line with guidelines at local and national level.</p> <p>Keeps abreast of relevant drivers and publications.</p> <p>Develops policy and protocol to reduce risk.</p> <p>Use of 360° MDT review.</p> <p>Shows evidence of audit.</p> <p>Shows evidence of implementing reasonable adjustments.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## II. Telephone Management Relationships

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	IK1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To take a sound, clear history of the current problems faced by the PWLD.</p> <p>To demonstrate effective listening and questioning skills appropriate to telephone communication, ensuring the caller feels confident that their needs have been understood.</p>	<p>To have a sound method of documenting calls and advice given alongside any plans for treatment changes.</p> <p>To use active questioning skills.</p> <p>To recognise limitations of telephone contact and when to arrange a face-to-face follow up.</p>	<p>To confidently manage distraught and unexpected calls.</p> <p>To ensure methods for swift and effective communication of all plans made following telephone consultation and ensure this is communicated to all relevant personnel involved in the individual's care.</p>
	<p>To understand that conversation is likely to be taking place via a third party and this could lead to interpretation difficulties.</p> <p>To work within the NHS Confidentiality Code of Practice.<sup>67</sup></p>	<p>To understand the difficulty when communicating with a third party and take appropriate action to clarify concerns.</p>	<p>To efficiently manage potential interpretation problems that arise in relation to 'by proxy management'.</p>
	<p>To provide a timely and responsive method of communication according to individual needs (e.g., via a telephone service, face-to-face communication, or other media).</p>	<p>To effectively assess and prioritise need based on telephone communication. Agree realistic expectations with caller.</p>	<p>To use audit to assess effectiveness of telephone management.</p>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Evidence of documentation relating to call.</p> <p>Production of telephone records.</p> <p>Carer testimonial.</p>	<p>Testimony of carers.</p> <p>Case-study review.</p> <p>Evidence of clinical visits.</p> <p>Development of telephone call template sheets.</p>	<p>Patient/carers satisfaction surveys.</p> <p>Development of care pathways/ protocols.</p> <p>Clinical observations.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

### III. Time Management

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To prioritise work to make the most effective use of time and resources appropriately by considering: <ul style="list-style-type: none"> <li>Clinical activity</li> <li>Professional responsibilities.</li> </ul>	To demonstrate setting own priorities and respond to unplanned workload and changing service needs.  To make any reasonable adjustments to provide an equitable service for PWLD, and their families and carers.	To balance resources to changing service needs. To manage others' time.
	To demonstrate a considered and professional approach to practice by ensuring sound diary planning.	To understand and apply the dynamic process of goal setting.  To initiate database development for caseload management.	To develop services to ensure appropriate numbers of PWLD to nurse caseload ratio.
	To demonstrate an awareness of the urgency and completion of tasks in an appropriate timeframe.	To demonstrate awareness of professional limitations and be aware of the need to prioritise time based on level of clinical urgency.  To demonstrate appropriate allocation of clinical time.	To demonstrate awareness of time constraints and pre-emptively manage these.
	To timely input data collection systems.	To measure own capacity to workload.	To interpret the data available for service development and work allocation.
KNOWLEDGE AND UNDERSTANDING EXAMPLE	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 plans/cases.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## F. Multi-disciplinary Team Working

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To understand how the MDT works, and when PWLD may be referred to other services to aid diagnostic process.	To collaborate with other agencies as required to provide a seamless service.	To work across generic services, providing joint specialist clinics to provide high-quality specialist input for PWLD.
	To identify other epilepsy services provided by health, social and voluntary sectors.	To establish links with wider epilepsy services to understand and appreciate differing roles, whilst effectively prompting own role within the MDT.	To be aware of the scope of other professional roles, ensure all aspects of care are met through agreed roles and responsibilities.
	To establish relationships that promote partnership working and work in conjunction with other professionals to enhance the management of a person's epilepsy.	To develop inter-professional services, by co-operative working between own and other services. To mediate between services and facilitate complex and ethical decision making.	To work as an independent practitioner within the MDT. May be approached by other professionals for advice and support in managing epilepsy in people with LD.
	To communicate effectively with other professionals to enhance service delivery. To demonstrate how own role impacts on service delivery. To explain different models of care and how they can be interlinked to benefit people with epilepsy and LD.	To understand the scope of own professional role and how that will enhance wider services and the services PWLD may receive. To communicate, promote and develop the role of the LD ESN as a pivotal member of the MDT.	To acknowledge the influence of driving factors around service delivery, such as local or national policies. To recognise gaps in services and influence local provision by developing epilepsy nursing leadership and innovation. To contribute to development of policies and services through nurse leadership (e.g., transitional care, joint generic neurology clinic). To identify and work with key people to support the introduction of service developments.
	To identify own professional limitations. To foster good working partnerships with care providers.	To identify limitations within the service/team.	To address the limitations within the service/team. To work jointly with professionals across different organisations to enable an enhanced provision of care.

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To establish working relationship between health and social care, the voluntary and independent sectors.	To act as a link for advice and support within those established working relationships.	To devise and deliver generic and specific in-service training packages to a range of professionals.  To work as independent practitioners within the MDT, with the role to be renegotiated as experiences are gained.
KNOWLEDGE AND UNDERSTANDING EXAMPLE	Testimony from carers. 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 patient and public consultation.	Development of shared-care protocols. Publication of articles. Evidence of service evaluation/review. Evidence of business plans.

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## G. Personal and Professional Development

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB3, HWB4, HWB5, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To work to best standard guidelines (e.g., NICE/SIGN).	To use evidence-based practice to influence service development.	To use clinical governance framework to identify service/evidence-based gaps, and utilise framework to address these.
	To recognise the importance of, and participate in, networking opportunities.	To seek opportunities to network at wider level, accessing specialist groups and training opportunities.	To initiate and foster networking opportunities.
	To recognise the importance of clinical supervision and attend on a regular basis.	To improve service quality through reflection on positive and negative clinical experience.	To initiate and provide a skilled supervision for members of the team.
	To use reflection to prioritise areas for PDP with line manager and mentor.	To maintain professional development through access to appropriate study days and courses.  To work with other service providers such as local authority, education to develop their knowledge and understanding of epilepsy.	To maintain advanced professional development through literature, self-directed study and networking.
	To ensure own supervision needs are met at an appropriate level with identified mentor.  To work under a high degree of support and supervision.	To provide mentorship to less experienced nurses.  To work independently with minimal supervision.	To support and guide other nurse mentors.  To recognise if NMC standards and clinical governance are not met, and to offer peer supervision as needed.
	To work within clinical governance and NMC standards, and to begin to develop skills for leadership and innovation.	To develop skills for leadership and innovation, including clinical governance and working to NMC standards.	To drive leadership and innovation, including clinical governance and working to NMC standards.
	To share knowledge with nursing colleagues and provide mutual peer support.	To share knowledge and best practice with other professionals, using clinical expertise and best practice guidance.	To participate in knowledge dissemination at regional, national and international level. Influence policy at local and national level.

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To participate in educational programmes, e.g., recognised CPD programmes for the management of PWLD and epilepsy.</p> <p>To develop skills in working with PWLD, in partnership with families and carers.</p>	<p>To deliver generic epilepsy training to nurses and care providers.</p> <p>To participate in educational programmes at first-degree level in relevant subjects.</p>	<p>To act as a role model at local and national level, promoting best practice to aid service and professional development.</p>
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Attendance at local and national meetings or conferences.</p> <p>Evidence of networking opportunities.</p> <p>Contact sheets/PDP.</p>	<p>Certificate/diploma in epilepsy.</p> <p>RNLD with post-qualification experience and evidence is working towards a first-degree level.</p> <p>Recognised teaching qualification.</p> <p>Documented attendance at networking opportunities.</p> <p>Evidence of review of benefit of networking and how this has influenced practice through reflection.</p> <p>Evidence of working with PWLD who have complex epilepsy, through production of case study.</p>	<p>Post-graduate diploma with extensive experience of working with PWLD who have complex epilepsy. Evidence of working towards an MSc or PhD.</p> <p>Nurse prescriber (see <i>Strengthening the Commitment: The report of the UK Modernising Learning Disabilities Nursing Review</i>).<sup>68</sup></p> <p>Set up and maintain robust professional support.</p> <p>Documented evidence of planning or hosting networking opportunities/meetings.</p> <p>Speaker/poster presentation at local and national meetings or conferences.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

## H. Evidence-based Practice

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB1, HWB2, HWB3, HWB4, HWB5, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	To explain the audit cycle. Understand how the use of audit influences NHS care. Contribute to an audit that has a direct link to the role.	To use audit to promote effectiveness of role and support key service outcomes. Lead the development of the audit tool and utilise a wide range of tools.	To engage in multi-centred audit studies.
	To understand the role of PWLD consent. Can explain the role of audit as part of the wider element of clinical governance.	To understand the ethical implications in relation to developing research in services that work with people with LD.	To understand study ethics, and is able to communicate the ethical consideration of clinical studies.  To demonstrate an in-depth knowledge of the ethical implications of research, and an understanding of the ethical approval pathway.
	To use audit in a local capacity to enhance service frameworks and develop role.  To identify which components of the role are appropriate to audit.	To engage in service evaluation that has a patient focus. Will be involved in publication of local audit findings. To recognise the importance of critical appraisal both for individual and organisational change.	To be responsible for presentation of audit findings at local, directorate, organisational and national level.  To take the lead in the publication of local audit/research outcomes.
	To understand meaning of evidence-based practice.	To identify and differentiate between research that will improve practice and promote change.  To contribute to the design and practical implementation of local research projects.  To explain the importance of local research, and understand the difference between research and audit.	To identify nursing research questions, and take the lead in research design, data collection and dissemination of findings.
	To use research that has been published by others to support role.	To identify research that is pertinent to improving practice and prompting change.	To use research findings to influence policy and/or service developments locally and nationally. Can critically appraise published research.



	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>Provides examples of what is meant by evidence-based practice.</p> <p>Completes a literature search.</p> <p>Evidence of agreed audit plan.</p>	<p>Evidence of audit data from own service.</p> <p>Production of annual report/review of service delivery.</p> <p>Evidence of patient satisfaction audit in an accessible format.</p> <p>Production of application forms for local audit committee.</p> <p>Evidence of review of audit findings and implementation of recommendations.</p>	<p>Evidence of presenting at local or national arena.</p> <p>Poster presentations.</p> <p>Evidence of service development.</p> <p>Publications.</p> <p>Contribution to guidelines surrounding epilepsy care.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

# I. Development of Educational Programmes, Higher Education and Teaching

KSF ELEMENTS	CORE	1, 2, 3, 4, 5, 6
	SPECIFIC	HWB10, G1

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
PERFORMANCE CRITERIA	<p>To understand the importance of CPD.</p> <p>To identify and effectively use a mentor to gain support.</p> <p>To teach within own limitations, providing education as a mentor and at a local level, via in-house training.</p>	<p>To understand the theory behind education.</p> <p>To act as a mentor to novice nurses and other healthcare professionals.</p> <p>To deliver teaching sessions in pre-registration programmes, and to work towards delivering higher education.</p>	<p>To demonstrate delivering pre- and post-registration training programmes.</p> <p>To provide curriculum advice for developing accredited courses.</p> <p>To act as a mentor and role model at local, national and international levels.</p> <p>To engage in assessment of post-registration and postgraduate students.</p> <p>To act as university link for postgraduate study for nursing medicine and allied health professionals (AHPs).</p>
	<p>To provide education to voluntary and non-professional groups.</p>	<p>To deliver specialist epilepsy educational sessions within a variety of settings.</p>	<p>To provide advice and education to other professionals, e.g., pharmacists and GPs through CPD workshops.</p> <p>To work both locally and nationally within the epilepsy circuit, speaking at local and national conferences, and writing for publication.</p>
	<p>To actively seek feedback/evaluation from training programmes.</p>	<p>To use a range of educational evaluation tools. Is able to evidence how feedback is used into future programmes.</p> <p>To evaluate training/teaching sessions.</p> <p>To use varied communication techniques to enhance the learning experience.</p>	<p>To use feedback to influence training.</p> <p>To incorporate feedback and evaluation into future training packs.</p>

	NOVICE NURSE	COMPETENT NURSE *	EXPERT SPECIALIST NURSE †
KNOWLEDGE AND UNDERSTANDING EXAMPLE	<p>To read articles from relevant journals as part of CPD.</p> <p>Participation feedback.</p> <p>Evidence of teaching packs.</p> <p>PDP.</p> <p>Data collection for research and audit.</p> <p>Diary of teaching opportunities.</p> <p>Review of evaluation sheets.</p>	<p>To critically analyse published research and incorporate into teaching sessions.</p> <p>Evidence of training plans.</p> <p>Attendance certificates.</p> <p>Review of training evaluation forms.</p> <p>Assessment of learning outcomes.</p> <p>Evidence of review of training, and production of new material.</p>	<p>To submit and review articles for publication.</p> <p>To utilise knowledge to develop educational programmes.</p> <p>Appraisal.</p> <p>Feedback from the MDT team.</p> <p>Evidence of development and assessment of educational programmes.</p> <p>Teaching plans.</p> <p>Demonstrate links to higher education.</p> <p>Published articles, posters and presentations.</p>

\* In addition to novice nurse criteria

† In addition to novice/competent nurse criteria

### Stage 1 – Novice

The novice has no experience of the situations in which they find themselves at work. Actions are guided by a context-free set of rules, which guides their behaviour. The individual will be task oriented in their approach, which is limited and inflexible. Nursing students are considered as novice 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 some experience is built 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 PWLD's physical state, technological support and equipment. The nurse is much less able to tend to the PWLD's emotional needs and the needs of their families, and does not have the 'big picture'
- A reliance on nursing theory and the principles that guide practice; ordered steps are necessary
- No responsibility for the PWLD's well-being, which gives them a freedom to learn and an ability to delight in learning. Clinical Agency is defined as the experience and understanding of one's impact on what happens to the PWLD 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 PWLD 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 this stage. The aims of this are:

- To help the beginner to see the 'bigger picture', to put together signs and symptoms and make sense of them
- To 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
- To 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 PWLD. Again mentoring can help this learning process

### Stage 3 – Competent

General Nurses tend to enter this stage after about 2–3 years in clinical practice. All nurses will reach this stage, which is dependent only upon 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 within clinical practice, an individual at this stage will demonstrate the following:
  - Marked organisational skills. Fluid, co-ordinated actions. Better time management

- An ability to handle multiple, complex tasks
- An ability to anticipate future demands and needs, therefore able to prepare
  - Less anxious, therefore more able to perform well in a crisis
  - Less flexibility than a proficient nurse and not as quick to respond to rapidly changing needs

The nurse at this stage can carry out individualised care. Emotions in practice can now act as an alerting process and 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 6 ways:

1. The development of engaged reasoning in transitions. The proficient nurse works to gain a good understanding and knowledge of the PWLD and is able to pick out what is salient in a changing situation. This requires an openness and ability to be challenged rather than needing predictability and control (contrast with 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 nurse's practical grasp of the situation is increasingly accurate. If she is unable to have this grasp, a feeling of uneasiness develops which alerts her to the fact that something may 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 way that is different 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 PWLD 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 her expectations (subconsciously). Anticipation is a key component of this level of practice.
- Where patterns are clear the nurse knows what to do with little conscious thought involved. The expert runs on 'autopilot' with respect to tasks and can therefore simultaneously engage in psychological support, talking with the PWLD's family etc. as she performs tasks.
- The nurse will have a strong sense of the future and a good understanding of the past and how it might influence both.
- Practice is characterised by fluid, skilled performance underpinned by judgment.
- Expert nurses have a good understanding of the PWLD's world and are able to put that first.
- A vision and commitment to good clinical and caring practices.
- The expert practitioner has much to offer in terms of guiding the service and planning curricula. They may not be the appropriate person to teach a novice or advanced beginner.

## Appendix 2: Epilepsy Action Patient and Carer Survey

A short survey was developed by Epilepsy Action and the LD ESN Competency Framework Steering Committee, with assistance from a speech and language therapist, to enable PWLD and their carers to comment on what they considered to be important aspects of the LD ESN role. The survey was designed to be easy to read and complete, with visuals for each question. Epilepsy Action distributed the survey to ESNs and promoted it on their website in November 2012. Eighteen responses were received.

Respondents were asked if they currently had a LD ESN, with 12 out of 18 answering yes, 4 answering no and 2 stating that they used to have one but didn't anymore. Overall, it was felt that explaining hospital admissions, talking to other people about how to respond to a seizure and explaining epilepsy to other professionals were the most important part of a LD ESN's role. Aspects of the role, ranked in importance, are summarised below mapped to dimensions A-I of the LD ESN Competency Framework:

- Outlining hospital admission and the epilepsy care pathway – **C. Impact of Epilepsy**
- Educating families/carers on managing seizures – **A II. Assessing and Managing Seizures**
- Promoting epilepsy care to other healthcare professionals – **F. Multi-disciplinary Team Working**
- Providing a forum for people with epilepsy to talk about their epilepsy – **A I. Diagnosis of Epilepsy**
- Informing patients on the impact of epilepsy and safely managing day-to-day situations – **B. Assessing and Managing Risk**
- Assisting people with epilepsy with care-plan development – **A IV. Assessing and Managing Linked Health Conditions**
- Providing information on epilepsy, seizure management and triggers – **A II. Assessing and Managing Seizures**
- Explaining the role of epilepsy medicine – **A III. Assessing and Managing Medicines**
- Discussing seizures with family and carers – **C II. PWLD, Families and Carers**

1. Epilepsy Nurses Association (ESNA). [Internet]. The Adult Specialist Nurse Competency Framework 2012. [cited June 2012]. Available from: <http://www.esna-online.org.uk/index.asp>
2. Emerson, E. Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties. Cambridge: Cambridge University Press; 1995
3. Fisher R. Epileptic seizures and Epilepsy: Definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005; **46**: 470-72
4. Tunstall.co.uk [Internet]. Learning Disabilities Guide [cited June 2012]. Available from: [http://www.tunstall.co.uk/assets/Literature/Guides/learning\\_disabilities\\_guide\\_03.10.pdf](http://www.tunstall.co.uk/assets/Literature/Guides/learning_disabilities_guide_03.10.pdf)
5. WHO.int/classifications/icd/ [Internet]. International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version 2010 Chapter V Mental and behavioural disorders (F00-F99) [cited June 2012]. Available from: <http://apps.who.int/classifications/icd10/browse/2010/en#/F70-F79>
6. Mercier C, S Saxena, J Lecomte, M Cumbreira, G Harnois. Atlas: Global Resources for Persons with Intellectual Disabilities 2007. Geneva: WHO; 2007
7. WHO.int/classifications/icd/ [Internet]. International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version 2010 Chapter V Mental and behavioural disorders (F00-F99) Mental retardation (F70-F79) [cited June 2012]. Available from: <http://apps.who.int/classifications/icd10/browse/2010/en#/F70-F79>
8. WHO.int/mental\_health/evidence/atlas\_id\_2007.pdf [Internet]. Atlas: global resources for persons with intellectual disabilities: 2007 [cited August 2012]. Available from: [http://www.who.int/mental\\_health/evidence/atlas\\_id\\_2007.pdf](http://www.who.int/mental_health/evidence/atlas_id_2007.pdf)
9. Bild.org.uk [Internet]. Factsheet: Learning Disabilities [cited June 2012]. Available from: [http://www.bild.org.uk/pdfs/05faqs/Learning\\_Disabilities\\_11.pdf](http://www.bild.org.uk/pdfs/05faqs/Learning_Disabilities_11.pdf) accessed Jan 2011
10. Chadwick D. Epilepsy. *Journal of Neurology, Neurosurgery, and Psychiatry* 1994; **57**: 264-77
11. Jointepilepsycouncil.org.uk [Internet]. Joint Epilepsy Council: Epilepsy prevalence, incidence and other statistics 2011 [cited June 2012]. Available from: <http://www.jointepilepsycouncil.org.uk/resources/publications.html>
12. Epilepsysociety.org.uk [Internet]. Epilepsy and learning disability [cited September 2012]. Available from: <http://www.epilepsysociety.org.uk/AboutEpilepsy/Epilepsyandyou/Epilepsyandlearningdisability-1>
13. Lhatoos S & Sander J. The Epidemiology of Epilepsy and Learning Disability. *Epilepsia* 2001; **42**(Suppl 1): 6-9
14. McGrother C, Bhaumik S, Thorp C, Hauck A, Branford D, et al. Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications. *Seizure* 2006; **15**(6): 376-86
15. Silanp M. Learning disability: occurrence and long term consequences in childhood onset epilepsy. *Epilepsy and Behaviour* 2004; **5**: 937-44
16. Ring H, Zia A, Bateman N, Williams E, Lindeman S, et al. How is epilepsy treated in people with a learning disability? A retrospective observational study of 183 individuals. *Seizure* 2009; **18**: 264-8
17. Rich F, Doherty C. Epilepsy and specialist learning disability practice. In: Jukes M, editors. *Learning Disability Nursing Practice: Origins, perspectives and practice*. London: Quay books; 2009. pp 243-84
18. NICE.org.uk [Internet]. Epilepsy: The Diagnosis and Management of the Epilepsy in Children and Adults [cited June 2012] Available from: <http://guidance.nice.org.uk/CG137>
19. Bowley C & Kerr M Epilepsy and intellectual disability – a review. *Journal of Intellectual Disability Research* 2000; **44**: 1-15
20. Kerr M; Guidelines Working Group, Scheepers M, Arvio M, Beavis J, Brandt C, Brown S, Huber B, Iivanainen M, Louise AC, Martin P, Marson AG, Prasher V, Singh BK, Veendrick M, Wallace RA. Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *Journal of Intellectual Disability Research* 2009; **53**(8): 687-94
21. NMC-uk.org [Internet]. Death by indifference-Following up the Treat me right! Report [cited June 2012]. Available from: <http://www.nmc-uk.org/Documents/Safeguarding/England/Death%20by%20Indifference.pdf>
22. RCN.org.uk [Internet]. Learning from the past –setting out the future: Developing learning disability nursing in the United Kingdom [cited June 2012] Available from: [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0007/359359/003871.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0007/359359/003871.pdf)
23. RCN.org.uk [Internet]. Integrated Core career and competence framework for registered nurses 2009 [cited June 2012]. Available from: [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0005/276449/003053.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0005/276449/003053.pdf)
24. Qualityresearchinternational.com [Internet]. Analytic Quality Glossary [cited June 2012]. Available from: <http://www.qualityresearchinternational.com/glossary/competence.htm>
25. DH.gov.uk [Internet]. Agenda for Change – Final Agreement 2004 [cited in October 2011]. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4099423.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4099423.pdf)
26. Murrells T, Robinson S, Griffiths P. Assessing competence in nursing. *Nursing Management* 2009; **16**(4): 18-9
27. NMC-uk.org [Internet]. Standards for preregistration nursing education; 2010 [cited June 2012]. Available from: <http://standards.nmcuk.org/PublishedDocuments/Standards%20for%20preregistration%20nursing%20education%2016082010.pdf>
28. NPC.nhs.uk [Internet]. A single competency framework for all prescribers; 2012 [cited June 2012]. Available from: [http://www.npc.nhs.uk/improving\\_safety/improving\\_quality/resources/single\\_comp\\_framework.pdf](http://www.npc.nhs.uk/improving_safety/improving_quality/resources/single_comp_framework.pdf)
29. NMC-org.uk [Internet]. Guidance on professional conduct [cited June 2012] Available from: <http://www.nmc-uk.org/Documents/Guidance/Guidance-on-professional-conduct-for-nursing-and-midwifery-students-September-2010.PDF>
30. National Nursing Research Unit. Nursing Competence: What are we accessing and how should it be measured? [Internet]. Policy + 2009; 18 [cited June 2012] Available from: <http://www.kcl.ac.uk/content/1/c6/05/68/69/PolicyIssue18.pdf>
31. Advancepractice.scot.nhs.uk [Internet]. Advanced Nursing Practice Toolkit. [cited June 2012]. Available from: <http://www.advancedpractice.scot.nhs.uk/definitions/defining-advanced-practice.aspx>
32. Miller L. The clinical nurse specialist: a way forward? *Journal of Advanced Nursing* 1995. **22**: 494-501
33. DH.gov.uk [Internet]. The NHS Knowledge and Skills Framework (NHS KSF) and the Development Review Process 2004 [cited in October 2011]. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4090861.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090861.pdf)
34. DH.gov.uk [Internet]. The NHS plan 2000 [cited October 2011]. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_118522.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118522.pdf)
35. SIGN.ac.uk [Internet]. Scottish Intercollegiate Guidelines Network [cited June 2012]. Available from: [www.sign.ac.uk/](http://www.sign.ac.uk/)

36. DH.gov.uk [Internet]. The National Service Framework for Long Term Conditions [cited June 2012] Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4105369.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4105369.pdf)
37. MENCAP.org.uk [Internet]. Death by indifference: 74 deaths and counting [cited June 2012] Available from: <http://www.vodg.org.uk/uploads/pdfs/Death%20by%20Indifference.pdf>
38. DH.gov.uk [Internet]. Valuing people – a new strategy for LD for the 21st century – a white paper [cited June 2012]. Available from: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4009153](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153)
39. DH.gov.uk [Internet]. Signposts for success in commissioning and providing health service for people with learning disabilities (1998) [cited June 2012]. Available from: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4008585](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008585)
40. DH.gov.uk [Internet]. Once a day [cited June 2012] Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4042779.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4042779.pdf)
41. ombudsman.org.uk [Internet]. Six lives: the provision of public services to people with LD [cited June 2012]. Available from: <http://www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities>
42. DH.gov.uk [Internet]. Good practice in Learning Disability nursing [cited June 2012]. Available from: [http://www.hscbusiness.hscni.net/pdf/DH\\_Good\\_practice\\_in\\_learning\\_disability\\_nursing-2007.pdf](http://www.hscbusiness.hscni.net/pdf/DH_Good_practice_in_learning_disability_nursing-2007.pdf)
43. Legislation.gov.uk [Internet]. Mental Capacity Act [cited June 2012] Available from: <http://www.legislation.gov.uk/ukpga/2005/9/contents>
44. Leeds.nhs.uk [Internet]. Healthcare for all (2008) [cited June 2012]. Available from: <http://www.leeds.nhs.uk/Downloads/Public%20Health/Learning%20disabilities/Healthcare%20for%20all%20independent%20enquiry%20report.pdf>
45. DH.gov.uk [Internet]. Modernising Nursing Careers Framework Initiative [cited June 2012]. Available from: <http://www.scotland.gov.uk/Resource/Doc/146433/0038313.pdf>
46. Wales.gov.uk [Internet]. Post Registration Career Framework for Nurses in Wales [cited June 2012]. Available from: <http://wales.gov.uk/topics/health/ocmo/professionals/officechiefnursing/cnopublications/career/?lang=en>
47. Scotland.gov.uk [Internet]. The Framework for Developing Nursing Roles [cited June 2012]. Available from: <http://www.scotland.gov.uk/Publications/2005/07/08144857/48584>
48. Skillsforhealth.org [Internet]. Key Elements of The Career Framework [cited June 2012]. Available from: <http://www.skillsforhealth.org.uk/workforce-transformation/customised-career-frameworks-services/>
49. Scqf.org.uk [Internet]. The Scottish Credit and Qualifications Framework [cited June 2012]. Available from: <http://www.scqf.org.uk/The%20Framework/>
50. Ukstandards.org.uk [Internet]. National Occupational Standards [cited June 2012] Available from: [www.ukstandards.org.uk/](http://www.ukstandards.org.uk/)
51. Advancedpractice.scot.nhs.uk [Internet]. NHS Scotland Advanced Nursing Toolkit [cited June 2012]. Available from: <http://www.advancedpractice.scot.nhs.uk/toolkit-concept.aspx>
52. Scotland.gov.uk [Internet]. NHS Scotland Guidance on Career Framework for Health [cited June 2012]. Available from: <http://www.scotland.gov.uk/Resource/Doc/1093/0083002.pdf>
53. Epilepsy.org.uk [Internet]. Epilepsy in England: Time for Change (2009) [cited June 2012]. Available from: <http://www.epilepsy.org.uk/campaigns/timeforchange>
54. Booksjop.rcplondon.ac.uk [Internet]. The human and economic cost of epilepsy in England [cited June 2012] Available from: <http://bookshop.rcplondon.ac.uk/contents/pub354-4c9a756c-bdfa-43ad-9f2a-ef91cfeafdf.pdf>
55. Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy–death in the shadows. Available from: <http://www.sudep.org/wp-content/uploads/2009/10/National-Sentinel-Audit-2002.pdf>
56. Working group of the International Association of the Scientific Study of Intellectual Disability. Clinical guidelines for the management of epilepsy in adults with an intellectual disability. *Seizure* 2001; **10(6)**: 401–9
57. Skills for Care [Internet]. Qualifications and Credit Framework [cited August 2012]. Available from <http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?ID=1139&SID=104>.
58. Welsh Assembly Government. [Internet]. Designed for People with Chronic Conditions — Service Development Directive: Epilepsy [cited 3 August 2012]. Available from: <http://www.nliah.com/portal/microsites/Uploads/Resources/MgTvSejsv.pdf>.
59. RCN.org.uk [Internet]. Competencies: a Competency Framework and Guidance for Developing Paediatric Epilepsy Nurse Specialist Services 2005 [cited June 2012]. Available from: [www.rcn.org.uk/\\_data/assets/pdf\\_file/0004/78673/002792.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0004/78673/002792.pdf)
60. Benner, P. From novice to expert: Excellence and power in clinical nursing practice. California: Addison-Wesley; 1884
61. Gobet F, Chassy P. Towards an alternative to Benner's theory of expert intuition in nursing: A discussion paper. *International Journal of Nursing Studies* 2008; **45(1)**: 129–39
62. DH.gov.uk [Internet]. The NHS Knowledge and Skills Framework (NHS KSF) and the development review process [cited June 2012]. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4090861.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090861.pdf)
63. NMC-uk.org [Internet]. Standards for pre-registration nursing education (competencies for learning disabilities), 2010 [cited October 2012]. Available from: <http://standards.nmc-uk.org/PreRegNursing/statutory/competencies/Pages/Competencies.aspx>
64. DH.gov.uk [Internet]. The National Service Framework for Long-term conditions; 2005 [cited October 2011]. Available from: [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4105369.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4105369.pdf)
65. [legislation.gov.uk/asp/2000/4/contents](http://www.legislation.gov.uk/asp/2000/4/contents) [Internet]. Adults with Incapacity (Scotland) Act (2000) [cited October 2012]. Available from: <http://www.legislation.gov.uk/asp/2000/4/contents>
66. [legislation.gov.uk/asp/2003/13/contents](http://www.legislation.gov.uk/asp/2003/13/contents) [Internet]. Mental Health (Care and Treatment) (Scotland) Act (2003) [cited October 2012]. Available from: <http://www.legislation.gov.uk/asp/2003/13/contents>
67. DH.gov.uk [Internet]. Confidentiality: NHS Code of Practice [cited October 2012]. Available from: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4069253](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253)
68. Scottish Government [Internet]. Strengthening the Commitment: The report of the UK Modernising Learning Disabilities Nursing Review [cited 3 August 2012]. Available from <http://www.scotland.gov.uk/Resource/0039/00391946.pdf>.









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