

# Epilepsy Specialist Nurses The Evidence (ESPENTE): a Systematic Mapping Review

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# Foreword

Epilepsy Specialist Nurses (ESNs) have been called ‘the glue that connects services to people with epilepsy’. Guidelines, such as those produced by the National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) in the UK highlight the importance of ESNs to the care of people with epilepsy. They are in an ideal position to act as an expert resource and point of first contact for patients, carers and professionals alike. ESN roles are diverse across the three main sub-specialties: adult, paediatrics and learning disability. ESN involvement in epilepsy surgery pathways and multi-disciplinary teams has been identified as essential. Despite this, ESNs are still seen as an expensive luxury in some areas, with wide, geographical discrepancies in UK service provision.

Documents such as the ESN Competencies, developed by the Epilepsy Nurses Association (ESNA), describe the skills of nurses with different levels of knowledge and experience, in order to provide commissioners and (particularly new) ESNs with a greater understanding of the role.

The ESPENTE study creates much needed context to the argument for the development of the ESN as an integral part of the care provided to people with epilepsy, their family and carers. It provides a critical review of the available evidence and, most importantly, highlights the limitations of the current, published literature, while identifying priorities for future studies. This study provides a sound basis for nurses and academics, planning empirical studies to examine the effectiveness and impact of ESN roles in the future.

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# Executive summary

## Background:

Many UK epilepsy specialists think that effective epilepsy services depend on epilepsy specialist nurses (ESNs). Guidance from the National Institute of Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) state that specialised epilepsy services should include ESNs but despite this, many areas in the National Health Service (NHS) in the UK fall short of this standard. Commissioners do not seem to consider ESNs a high priority and initiatives such as the Epilepsy Commissioning Toolkit are impaired by the difficulty summarising the evidence in this area. We aimed to provide an overview of the international evidence relevant to ESNs.

## Methods:

We undertook a systematic mapping review in parallel with a stakeholder/ expert consensus group to describe the role of the ESN, to identify evidence that evaluates the effectiveness and impact of that role on services, patients and their families and other healthcare professionals. We completed an extensive search of electronic databases and included any published research or document that described in some way the role of the ESN. We included all research designs and also opinion or news pieces where this might be describing the ESN role. These very broad inclusion criteria were intended to allow us to identify innovations in practice that may be described but not evaluated in the literature. Retrieved papers were read and coded. Information regarding the nurse's role, the settings in which it was undertaken, how care was delivered and the different sub-roles were extracted. The study design was also recorded.

## Findings:

We included 96 published papers in the review. These included: systematic reviews (n=7), randomised controlled or controlled trials (n=9), qualitative studies (n=10), mixed methods studies (n=7), questionnaires or surveys (n=15), audits of services (n=6), case studies (n=7) describing a service, and news or opinion pieces (n=35). Different research designs offer different insights into the ESN role and its impact. It was clear from the evidence that the ESN role is varied and shaped in part by different models of practice in which the role is carried out. The different models of practice that we identified included: ESN-led services for particular groups such as children, people with refractory epilepsy, those who had attended A & E, people with epilepsy and learning disability and models of care based on the manner in which the service was delivered, such as being based in a tertiary setting, or in the community. These different models may result in some differences in the ESN role, and how it was delivered. We described the types of outcome

measures used to evaluate the ESN role in practice, with seizure frequency being used most commonly. We identified elements of the role, and outcomes of interest that have not been empirically measured. Examples include empowerment, service development and the value of the nurse as a point of contact.

We identified 14 sub-roles that collectively comprise the epilepsy specialist nurse role: advice and information, assessment, carer support roles, counselling and support, diagnosis and treatment, education and training (to other health professionals), liaison/linking services, medicines management and prescribing, monitoring, personalised care plans, point of contact, seizure and risk management, service development and coordination and specialised clinics.

For each sub-role we described and summarised the literature. We present the literature as 1) description of need for the sub-role; 2) evidence of ESNs actually performing that sub-role; and 3) the evidence of the effectiveness or impact of ESNs actually performing that sub-role. The evidence of effectiveness was categorised by study methodology (systematic reviews, RCTs, qualitative studies etc.) While comparative quantitative studies offer insights into effectiveness, we also wanted to explore impact which was achieved by including qualitative and questionnaires and mixed methods studies which explored the experiences and views of patients, their carers, ESNs, and other members of the health care team.

All 96 papers were ‘mapped’ according to the 14 sub-roles and the type of evidence. The evidence map can be seen online:

[epilepsy.org.uk/espentemap](http://epilepsy.org.uk/espentemap)

## Conclusions:

The ESN is highly valued by patients, their families and other health care professionals. Qualitative studies, mixed methods studies, and questionnaires have demonstrated the value of ESNs to patients, the range of services they provide and the perceived improvements in care. Key to their value is their specialist knowledge, their accessibility, the ability to cross boundaries, their ability to link up services and their leadership in service development and being a point of contact. RCTs and systematic reviews have demonstrated measurable benefits for patients including improvements in knowledge and quality of life. Some studies have, however, failed to demonstrate measurable improvements in outcome measures as a result of ESNs, such as reductions in seizures. There are elements of the ESN role, notably their role as a point of contact and liaising with and linking services, that are poorly recognised and inadequately evaluated in the existing evidence. There is also very limited research which reflects the very different models of practice and patient groups that they work with. Evaluation of their role in supporting children and young people with epilepsy is described but there are currently limited empirical evaluations of their impact on care. There is also a need to better understand the impact of caseload on ESNs, and workload thresholds which overstretch services and reduce their impact.

# Contents

<b>Executive Summary</b>	3
<b>Background</b>	6
<b>Methods</b>	7
Phase 1 – Descriptive phase ('development of the map')	7
Phase 2 – Locating the literature	7
Phase 3 – Analytical phase	7
<b>Findings</b>	8
1. Overview of included papers	8
2. Models of practice	18
3. Measuring outcomes of an ESN service	18
4. Sub-roles within the ESN role	20
Advice and information	22
Assessment	25
Carer support roles	27
Counselling and support	28
Diagnosis and treatment	30
Education and training	31
Liaison/linking services	32
Medicines management and prescribing	33
Monitoring	36
Personalised care plans	38
Point of contact	38
Seizure and risk management	39
Service development and coordination	40
Specialised clinics	42
<b>Discussion, conclusions and limitations</b>	44
<b>Further research</b>	48
<b>Appendix 1 – Trials included in Cochrane Review</b>	54
<b>Appendix 2 – List of included studies</b>	58
<b>References</b>	68

## Background

Many UK epilepsy specialists think that effective epilepsy services depend on epilepsy specialist nurses (ESNs) (Irvine 2010). Guidance from the National Institute of Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) state that specialised epilepsy services should include ESNs but despite this, many areas in the National Health Service (NHS) in the UK fall short of this standard (Dickson et al 2015). Commissioners do not seem to consider ESNs a high priority and initiatives such as the Epilepsy Commissioning Toolkit are impaired by the difficulty summarising the evidence in this area.

The Local Picture report into ‘Epilepsy in England’ (Epilepsy in Action) shows that 78% of responding Clinical Commissioning Groups (CCGs) had no plans to develop a joint strategic needs assessment for people with neurological conditions. In the current climate in the NHS, neurology, and epilepsy specifically, is not perceived as a priority area. There is no longer a national clinical lead for neurology and only one Strategic Clinical Network (SCN) identifies neurology as a priority area.

Little documented evidence exists on the impact of ESNs or the outcomes of the services they deliver. Commissioners are asking for published evidence on the cost-effectiveness of ESNs when commissioning new posts. In some areas, ESN posts are being down-banded and the epilepsy nurse sub-specialism is not recognised. Generic neurology/long-term condition nurses are increasing in numbers and specifically the Walton Vanguard project (with an aim to promote replication) has focussed on an advanced neurology nurses’ model rather than condition specific specialist nurses. Why are there more Parkinson’s and Multiple Sclerosis (MS) nurses for a smaller population? There are currently 245 MS nurses in the UK for a population of 100,000 people with MS (GEMSS 2015). With over 600,000 people with epilepsy, only an estimated 400 ESNs exist for paediatric, adult and learning disability services.

We undertook a systematic mapping review (James et al 2016) in parallel with a stakeholder/expert consensus group to produce a definitive paper on the evidence, the quality of the evidence and the evidence gaps for ESNs. We hope that this will provide a framework for commissioners to consider the current evidence when planning their local services and act as an agenda for further research.

### Research questions

1. What evidence exists that has proposed, described and/or evaluated the role of the ESNs?
2. What are the roles/services ESNs provide or could provide?
3. What is the overall quality of the evidence base evaluating their role?
4. What are the evidence gaps?
5. What are the research questions that need to be addressed in further primary research or systematic reviews?

## Methods

We used a mapping review methodology to examine the research evidence regarding ESNs in terms of the following: clinical effectiveness, cost effectiveness, acceptability and implementation. We also sought to describe contextual variation in the population, roles, service delivery and outcomes being achieved by ESNs. Systematic mapping reviews are a particular type of research synthesis, and can either be conducted in the process of developing a full systematic review, or serve as a research product in their own right. By collecting and thematically grouping existing research and evaluations, a systematic map provides an overview of the evidence base on the given issue or question. The systematic map can provide an overview of existing research and relevant literature that has been published to highlight quantity and quality patterns as well as gaps in the current evidence-base. Systematic maps are not designed to answer a focussed research question, but rather they provide a broad overview of the existing evidence.

### Phase 1 - Descriptive phase ('development of the map')

We used the report Best Care to create an initial conceptual framework of the component sub-roles within the ESN role (Irvine 2010). We used this framework to undertake an initial search of the literature which was presented to, and reviewed by, the stakeholder group during the first stakeholder meeting. Identified sub-roles included: Education & training (of the patient and significant others), Advice and information, Specialised clinics, Assessment, Counselling and Support, Liaison, as a Point of Contact, in Risk management and in Medicines management.

The first stakeholder group meeting took place in Sheffield on 24/04/18 and was run by AB and FC. AB and FC presented an overview of the preliminary findings from the searches as an introduction to the types of evidence and their characteristics. Key points included the broad

variation of the role and the related service and setting contexts. After the presentations, delegates were divided into 6 groups (each with a mix of stakeholders e.g. patients, neurologists, ESNs, commissioners).

Each group was given cards, with different ESN sub-roles written on each card (taken from Best Care (Irvine 2010) to provide an initial conceptual framework). In order to encourage the groups to discuss the role of the ESN they were asked to prioritise and order these different sub-roles. The groups were encouraged to add any dimensions that they felt were missing. Some sub-roles needed discussion or clarification, revealing different perceptions of what the labels meant.

### Phase 2 - Locating the literature

After the stakeholder group, the conceptual framework was finalised and 14 sub-roles were identified within the overall ESN role. Using this framework, comprehensive searches were run across numerous databases covering neurological or nursing related topics, as well as the scientific literature more broadly. Databases searched included MEDLINE, EMBASE, PsycInfo, CINAHL, British Nursing Index, Web of Science, ASSIA, HMIC etc. Citation searching from 50 studies was also utilised. As this is a mapping review, all items were screened by one reviewer, although a random sample of excludes (5-10%) were checked for false negatives by a second reviewer and procedures reviewed accordingly.

### Phase 3 - Analytical phase

A systematic mapping review differs from a systematic review. Its aim was to map and categorise a highly diverse body of evidence. In contrast to a traditional systematic review, the sources of this evidence are often methodologically heterogeneous. In the case of the ESPENTE study this included qualitative research, service evaluations, reports from charities and service providers. This may include quantitative data such as outcomes, costs and activity. Given the methodological

heterogeneity of the evidence and the diversity of the data it was not feasible to undertake a comprehensive and meaningful appraisal of the quality of the included studies within the time/financial constraints of the study. Study design was used as a surrogate for study quality (with the important proviso that studies with the same study design can be either good or poor quality). Systemic or generic flaws of the design were highlighted when summarising the evidence state.

Data was described and tabulated. Items were coded across standard descriptive variables such as year of publication, type of study, country of origin, data type, population (including paediatric / adult), and description of role. We noted aspects of the ESN role such as how referrals were received, whether they were based in primary, secondary or tertiary care, frequency of contact with patients and training required for the post. Where studies measured or recorded outcomes of care, these were noted and tabulated. For each sub-role we described and summarised the evidence. The literature was very diverse, including descriptions of the need for the role, descriptions of the ESN role and some studies evaluated the impact of the ESN role on patients and their families. We separately categorised these types of descriptions into:

- 1) the evidence of need for the sub-role as described in the included literature and
- 2) evidence where ESNs actually perform that sub-role), categorised by type of evidence (systematic reviews, RCTs, qualitative studies etc.)
- 3) the evidence of the effectiveness or impact of ESNs performing that role.

Finally, a second stakeholder event was convened. During the event the study findings and the map were described, interactive group exercises took place and feedback was invited. The feedback during and after this event was collated by the authors and the final version of the report was produced.

## Findings

The findings are presented as follows and they are summarised in the online evidence map ([epilepsy.org.uk/espentemap](http://epilepsy.org.uk/espentemap)):

1. Overview of the included papers, the study methodology, settings and where relevant the participants who were included in the research.
2. A description of the different models of practice seen in the literature.
3. Measuring outcomes of an ESN service.
4. A description of the 14 sub-roles within the ESN role, linking each sub-role to research evidence demonstrating effectiveness or impact.

### 1. Overview of included papers

Our search identified 3,831 citations. Titles and abstracts were screened and 178 papers were identified for retrieval. On further reading, 96 papers were finally included in this mapping review. We included studies if the ESN role focused on particular groups of patients such as children, people with disabilities or women of childbearing age. Papers were excluded if the nursing role was not specialised to the care of people with epilepsy (PWE).

The literature was then categorised to further map evidence of effectiveness to different aspects of the ESN role. The papers were categorised as: systematic reviews and reviews (n=7), randomised controlled trials and controlled trials (n=9), qualitative studies (n=10), mixed methods studies (n=7), audits (n=6), questionnaires and surveys (n=15), case study and descriptive papers (n=7), opinion and news pieces (n=35). Figure 1 summarises how these study types have been defined in this review and how different research designs address different types of questions and gaps in our knowledge of the ESN role, its effectiveness and impact.



The overwhelming majority of the published literature on ESNs originates from the UK. Primary studies that were geographically-based (n=88) originated in following countries: United Kingdom (n=68), Norway (n=1), Ireland (n=5), Germany (n=1), Netherlands (n=1), USA (n=10), Australia (n=1), Kenya (n=1). This

distribution may reflect cost-effectiveness pressures on a publicly-funded health system in the UK (with little epilepsy care delivered privately). In healthcare systems with more physician-led fee-paying work, there may be less incentive to find alternatives to epilepsy care delivered by doctors.

**Figure 1. Overview of research design categories used in this review**

**RCTs and controlled studies (quantitative designs):** These study designs are helpful for addressing questions of effectiveness and do so by comparing one group receiving an intervention with another which does not. When they are correctly randomised differences in outcomes between groups can be attributed to the intervention. These designs come under the umbrella of quantitative design studies.

**Qualitative studies** seek to explore and understand attitudes, values, behaviours and experiences of people. Data may be gathered in a range of ways using, for example, interviews or observations.

**Mixed Methods studies:** These study designs use a combination of approaches, usually quantitative and qualitative designs in one study. They aim to use these different approaches to add greater insights.

**Surveys and questionnaires** (can have both quantitative (numerical) and qualitative (textual) data) may also seek to collect views but also descriptive numerical data describing an existing service. The methods used are generally not seeking to gather information in as much depth as a qualitative study but will give more information from a larger sample size so may give indications of coverage, such as numbers of patients seen or referrals made.

**Audits and case studies** describe a service, without seeking to make comparisons with other services. They may be able to show improvements in services by showing changes from previously collected data, but the findings would not be considered applicable to other settings without further testing.

**Opinion pieces** though not commonly used as evidence, they can provide useful insights when there is a lack of research evidence or for descriptive purposes.

## Category of Evidence

### Systematic reviews

We identified 7 systematic reviews. Where a review was periodically updated, we only included the most recent version of that review.

The reviews were conducted between 2001–2016 and varied in their approach and the review questions that they addressed.

**Table 1: Systematic reviews**

Primary Author	Title
Bradley et al (2016)	Care delivery and self-management strategies for adults with epilepsy.
Couldridge et al (2001)	A systematic overview - a decade of research. The information and counselling needs of people with epilepsy.
Jackson et al (2015)	Neuropsychological and psychological interventions for people with newly diagnosed epilepsy.
Meads et al (2002)	Systematic reviews of specialist epilepsy services
Rajpura & Sethi (2004)	Evidence-based standards of care for adults with epilepsy-a literature review.
Ridsdale et al (2000) <sup>a</sup>	The effect of specially trained epilepsy nurses in primary care: a review.
Wiebe et al (2014)	Patient satisfaction with care in epilepsy: how much do we know?

### Randomised controlled trials (RCTs) and non-randomised controlled trials (non-RCTs)

We identified six RCTs and three non-RCTs. Six of the studies were undertaken in the UK, and one each in Ireland, Norway and Germany. They evaluated diverse interventions including: the ESN role in implementation of guideline strategies, ESN led interventions, ESN led care for people with disabilities and a psychological intervention delivered by an ESN and psychologist.

While RCTs are the best research designs for exploring questions of effectiveness, in the context of evaluating the ESN role they have some limitations. Limitations include a more limited duration of assessment which may not allow the ESN role to become well-established, for the necessary networks to be formed, or provide the nurse the opportunity to develop a leadership role within the service and influence positive change.

Arguably, the impact of the service is poorly captured by measuring patient level outcomes during a short follow-up period, and outcomes such as empowerment, self-efficacy and informal care requirements, that might arise from developing local patient support groups for example, are not recorded.

Evaluations of the ESN role using trial design include some limitations. The role of the ESN is varied, and an evaluation in one setting may have limited generalisability to another setting, for example the role of supporting carers may comprise a greater part of an ESN role where they work only with children with epilepsy and their families. An ESN based in primary care may have a greater role in educating other healthcare professionals or supporting follow-up than an ESN based in a tertiary care centre. An ESN in a tertiary care centre may be doing more to manage those with drug regimens that

require adjusting. The impact of the service may also change over time and so effectiveness and impact over time cannot be assumed. The evolving nature of the specialist service was highlighted in a description of the development of a district epilepsy service (Taylor et al, 1994); for example clinics increased to fortnightly and co-operation cards were developed to incorporate management plans.

In order to address the limitations of these approaches to evaluating a complex intervention, such as the provision of access to an ESN, we have included other research designs that are able to measure the impact of the ESN on patients' experience of care and the epilepsy service developments that result from their role. Where RCTs do provide evidence, we have included this within the review.

**Table 2: RCTs, controlled trials and comparative studies**

Author	Title	Setting	Participants
Davis et al (2004) * RCT	Implementation strategies for a Scottish national epilepsy guideline in primary care: results of the Tayside Implementation of Guidelines in Epilepsy Randomized (TIGER) trial.	UK	N=69 GP practices with 1133 patients with epilepsy treated with AEDs
Dorris et al (2017) * RCT	A randomized controlled trial of a manual-based psychosocial group intervention for young people with epilepsy [PIE].	UK	N=83 young people with epilepsy
Helde et al (2005) RCT	A structured, nurse-led intervention program improves quality of life in patients with epilepsy: a randomized, controlled trial.	Norway	N=114 adults with uncontrolled epilepsy
Higgins et al (2018) Non-RCT	Patients with epilepsy care experiences: Comparison between services with and without an epilepsy specialist nurse.	Ireland	N=305 people with epilepsy
Noble et al (2014) RCT	Clinical- and cost-effectiveness of a nurse led self-management intervention to reduce emergency visits by people with epilepsy.	UK	N=85 people with chronic epilepsy
Pfafflin et al (2016) RCT	Efficacy of the epilepsy nurse: results of a randomized controlled study.	Germany	N=187 people with epilepsy
Ring et al (2018) RCT	Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial.	UK	UK
Ring et al (2018)	Training nurses in competency framework to support adults with epilepsy and intellectual disability: the EpAID cluster RCT.	UK	N=320 adults with epilepsy and intellectual disability
Mills et al (1999)* Non-RCT	Effect of a primary care-based epilepsy specialist nurse service on quality of care from the patients' perspective: results at two-years follow-up.	UK	N=595 adults with epilepsy
Sarkissan et al (1999)* Non-RCT	Effects of the acute care nurse practitioner role on epilepsy monitoring outcomes.	UK	N= Adults with epilepsy

\*included in systematic reviews; AEDs anti-epileptic medications

### Qualitative Studies

We identified and included 10 qualitative studies. These study designs set out to empirically gather the views, attitudes, beliefs and behaviours of participants. They can provide useful insights into the acceptability of services to patients, and the barriers they face in accessing care, managing their condition and their experiences of illness and health service

provision. They also can provide insights into the experience of health professionals delivering care. Most of the qualitative studies were undertaken in the UK, with one each from Ireland and the Netherlands. The views of patients were the perspective that was most commonly explored.

**Table 3: Qualitative Studies**

Study	Title	Setting	Participants
Betts & Greenhill (2001)	The cost of everything and the value of nothing: Nursing case histories.	UK	Case histories
Goodwin et al (2011)	Do epilepsy specialist nurses use a similar history-taking process as consultant neurologists in the differential diagnosis of patients presenting with a first seizure?	UK	Observing nurse and neurology clinics
Noble et al (2013)	A nurse-led self-management intervention for people who attend emergency departments with epilepsy: the patients' view.	UK	PWE
Hopkins et al (2012)	Qualitative insights into the role and practice of Epilepsy Specialist Nurses in England: a focus group study.	UK	ESN
Mills et al (2002)a	What do patients want and get from a primary care epilepsy specialist nurse service?	UK	PWE
Mills et al (2002)b	Professional and organizational obstacles to establishing a new specialist service in primary care: Case study of an epilepsy specialist nurse.	UK	ESN
Smithson et al (2006)	How general practice can help improve care of people with neurological conditions: a qualitative study.	UK	HCPs and voluntary organisations
Vallenga et al (2006)	Decision-making about risk in people with epilepsy and intellectual disability.	The Netherlands	PWE, nurse and carer
Varley et al (2010)	Epilepsy in Ireland: Towards the primary–tertiary care continuum.	Ireland	HCP
Wallace (1999)	Quality of epilepsy treatment and services: the views of women with epilepsy.	UK	Women with epilepsy

PWE: people with epilepsy; HCP: healthcare professionals; ESN: epilepsy specialist nurse

### Mixed methods studies

Three studies (seven publications) included both qualitative and quantitative components. Studies were undertaken in the UK and the Republic of Ireland and both used methods that describe the role of the ESN.

**Table 4: Mixed methods studies**

Study	Title	Setting	Methods and data sources
Scambler et al (1996)	Towards an evaluation of the effectiveness of an epilepsy nurse in primary care.	UK	Interviews and RCT
Ridsdale et al (1997) RCT	Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial.		
Ridsdale et al (1999)	The effect of a special nurse on patients' knowledge of epilepsy and their emotional state.		
Ridsdale et al (2000)	Newly diagnosed epilepsy: can nurse specialists help? A randomized controlled trial.		
Ridsdale et al (2003)	How can a nurse intervention help people with newly diagnosed epilepsy? A qualitative study of patients' views.		
Higgins et al (2006)	Quantifying the role of nurse specialists in epilepsy: data from diaries and interviews.	UK	Diaries and interviews
Higgins et al (2018)	Rising to the challenge: Epilepsy specialist nurses as leaders of service improvements and change (SESNE study).	UK	Interviews, observation and documentary analysis

### Questionnaire and surveys

Fifteen questionnaires/surveys were included. The studies included in this category sought to gather data from more than one site or from respondents from different sites. Studies that gathered data from one service, where there were no comparator groups, were categorised

as audit or a descriptive paper. Again, most of the studies were undertaken in the UK (n=9). The studies included a range of perspectives including people with epilepsy, health professionals, carers and teachers.

**Table 5: Questionnaires and surveys**

Study	Title	Setting	Participants
Hosking et al (2002)	The epilepsy nurse specialist at a tertiary care hospital-improving the interface between primary and tertiary care.	UK	PWE
Fairgrieve et al (2000)	Population based, prospective study of the care of women with epilepsy in pregnancy.	UK	Women in pregnancy
Frost et al (2003)	Implementing good practice in epilepsy care.	USA	HCPs
Golstein et al (1997)	Are what people know about their epilepsy and what they want from an epilepsy service related?	Ireland	PWE
Goodwin et al (2004)*	The role of the clinical nurse specialist in epilepsy. A national survey.	USA	ESN
Goodwin et al (2011)	Epilepsy specialist nurse prescribing practice in the United Kingdom: a national questionnaire survey.	UK	ESN
Hill et al (2017)	Improved availability and quality of care with epilepsy nurse practitioners.	UK	PWE
Jain et al (1993)	What people with epilepsy want from a hospital clinic.	USA	PWE
Lambert et al (2001)	The assessment and management of adult patients with epilepsy – the role of general practitioners and the specialist services.	Ireland	GPs
Lewis et al (2008)	Informing patients about sudden unexpected death in epilepsy: a survey of specialist nurses.	USA	ESN
Lu et al (2005)	Where do families of children with epilepsy obtain their information?	UK	Carers of CWE
Macdonald et al (2000)	General-practice-based nurse specialists-taking a lead in improving the care of people with epilepsy.	UK	GPs
Mott et al (2013)	Knowledge of epilepsy and preferred sources of information among elementary school teachers.	USA	School teachers
Neligan et al (2006)	Management of epilepsy in the community.	Ireland	GPs
Ridsdale et al (1996)	Epilepsy monitoring and advice recorded: general practitioners' views, current practice and patients' preferences.	UK	GPs

continued...

**Table 5: Questionnaires and surveys continued**

Study	Title	Setting	Participants
Ridsdale et al (1999)	The effect of a special nurse on patients' knowledge of epilepsy and their emotional state.	UK	PWE
Terry (2016)	Barriers to Seizure Management in Schools: Perceptions of School Nurses.	USA	School nurses
Thapar (1998)	Attitudes of GPs to the care of people with epilepsy.	UK	GPs

PWE: people with epilepsy; HCP: healthcare professionals; ESN: epilepsy specialist nurse; GPs: General Practitioners; CWE: Children with epilepsy

### Audit

Six papers described an audit of records or treatment received at a particular centre of service. All the audits were undertaken in the UK.

**Table 6: Audits**

Study	Title	Setting
Hosking et al (2004)	The specialist nurse role in the treatment of refractory epilepsy.	UK, Tertiary referral centre
Irving et al (1999)	An audit of admissions of patients with epilepsy to a district general hospital.	UK, District General Hospital
Jacoby et al (1996)	A general practice records audit of the process of care for people with epilepsy.	UK, GP
Mar et al (2005)	Comparison of a dedicated children's seizure clinic to mixed general paediatric clinics.	UK, Clinic-secondary
Nitkunan et al (2017)	A hyper-acute neurology team - transforming emergency neurological care.	UK, Hyper-acute neurology team
Stephen et al (2003)	Outcomes from a nurse-led clinic for adolescents with epilepsy.	UK Secondary care

### Case study

Seven described a service, and are categorised as ‘case studies’ in this review. All, except one of the case studies describe UK based services.

**Table 7: Case studies**

Author	Title	Setting
Doller et al (1993)	Epileptologist’s assistant: a cost-effective expert system.	USA
Mantri et al (2008)	Developing a nurse-led epilepsy service for adults.	UK
Rollinson (2007)	How nurses can help epilepsy patients take control over managing their condition.	UK
Solomon et al (2012)	Supporting young people with epilepsy in school.	UK
Solomon et al (2001)	Day in the life...Nina Solomon... epilepsy nurse specialist.	UK
Taylor et al (1994)	A district epilepsy service, with community-based specialist liaison nurses and guidelines for shared care.	UK

### Opinion/news pieces

For the purposes of this review, we included editorials, news or opinion pieces that might describe the role of the ESN, or where a gap in service provision might be addressed by the

introduction of an ESN service. We identified 35 articles, not all of the identified papers yielded information used in the review.

**Table 8: News/opinion pieces**

Author	Title	Setting
Anderson (2006)	Knowledge of epilepsy in schools needs improvement.	UK
Middleton (2011)	Right by design.	UK
Austin (2015)	A career in nursing research: A personal journey.	USA
Barr (2007)	Providing more effective care for people with epilepsy.	UK
Bicknell-Royale et al (2005)	Epilepsy nurse co-ordinators make a difference.	Australia
Brown et al (2001)	Personal view: Randomized controlled trials in epilepsy specialist nursing: the seduction of content by form.	UK
Clewes et al (2010)	Epilepsy nurse specialist halves admissions.	UK
Collins et al (2009)	Developing primary care services for people with epilepsy.	UK
Davis et al (2015)	Champions needed.	UK
Davison et al (2015)	How service users are supported to understand their epilepsy.	UK
Eastwood et al (2008)	A new guide may hold the key to securing specialist nurse roles.	UK

continued...



**Table 8: News/opinion pieces continued**

Author	Title	Setting
El-Radhi et al (2015)	Management of seizures in children.	UK
Faulkner et al (2013)	National epilepsy specialist nurse role to support improvement of local services.	UK
Foley et al (2000)	Improving the epilepsy service: the role of the specialist nurse.	UK
Goodwin et al (2009)	More specialists needed to achieve NICE standards.	UK
Graydon et al (2000)	Do learning disability services need epilepsy specialist nurses?	UK
Gruenthal et al (2005)	Therapeutic options in new-onset epilepsy.	USA
Hannah and Brodie (1998)	Epilepsy and learning disabilities – a challenge for the next millennium?	UK
Hanson et al (2018)	Improving outcomes: overcoming the challenges of epilepsy in people with learning disabilities.	UK
Higgins et al (2008)	Outlining and defining the role of the epilepsy specialist nurse.	UK
Hosking et al (2006)	Epilepsy and supplementary nurse prescribing: the NHS needs advanced nurse prescribers.	UK
Hosking et al (2003)	Prescribing and the epilepsy specialist nurse.	UK
Josephs (2005)	Utilizing all opportunities in clinical practice.	UK
Kengne et al (2008)	Nurse-led care for epilepsy at primary level in a rural health district in Cameroon.	Kenya
Krishnamoorthy & Gilliam (2009)	Best clinical and research practice in adult epileptology.	International
Kwan et al (2000)	An epilepsy care package: the nurse specialist's role.	UK
Lewis et al (2011)	Advances in epilepsy management: the role of the specialist nurse.	UK
Mate et al (2012)	Too few children with epilepsy can access specialist nurses.	UK
Nordli et al (2001)	Special needs of the adolescent with epilepsy.	USA
Nothern et al (2008)	Marvellous medicine.	UK
Ridsdale et al (1995)	Matching the needs with skills in epilepsy care.	UK
Ridsdale et al (2009)	The social causes of inequality in epilepsy and developing a rehabilitation strategy: a UK-based analysis.	UK
Shafer et al (2015)	Shared decision-making in epilepsy management – Its time has come, but are we missing some concepts?	USA
Shuttleworth et al (2004)	Implementing new guidelines on epilepsy management.	UK
Thomas (2011)	Leave our nurse specialists alone!	UK

## 2. Models of Practice

The literature revealed the diverse contexts and client groups with whom ESNs might be working. These included: the setting in which the nurse worked, how referrals were made, how often the PWE were seen, features of his/her client group including different age groups, type of epilepsy, and setting. These differences may derive from the historical development of the post, the needs of the area, the interests and expertise of the ESN or those of other HCPs and other factors. The model of practice will influence the nature of the role they undertake in providing nursing care. Each model will have different purposes, may have different client groups, be based in different settings, have different working relationships with others in the healthcare team, and may require different skill sets. These different models were identified from both the literature and stakeholders. Although this list may not be exhaustive we identified ESN services developed for particular patient groups or based in particular settings including:

- ESN led service for those who had attended A & E (Noble et al 2013, Faulkner 2013)
- ESN service for newly diagnosed patients working with a neurologist in a tertiary setting (Hill et al 2017)
- ESN led fast track access for patients who have had a seizure and are not diagnosed (Greenhill 2001)
- ESN for children with epilepsy (Anderson et al 2006, Appleton & Sweeney 1995, Austin et al 2015, El-Radhi et al 2015)
- ESN for people with epilepsy and learning disabilities (Graydon et al 2011)
- ESN for people with brain tumour induced epilepsy (Campbell et al 2005)
- ESN for women of childbearing age with epilepsy (Lewis & Smith 2006)
- ESN for patients with refractory epilepsy (Hosking et al 2004)
- Primary care-based ESN (Mantri 2008, Macdonald et al 2000, Mills et al 2002)
- Tertiary care-based ESN (Helde et al 2005, Hill et al 2017, Hosking et al 2002)

- ESN for maternity services (Fairgrieve et al 2000)
- ESN in prisons (stakeholder group)
- ESN in transition services from paediatric to adult care (Chisanga et al 2009)
- ESN based in GP practices (Davis et al 2004, Bradley & Lindsay 2001)
- ESN based in neurology clinics (Bradley & Lindsay 2001, Goldstein et al 1997)

## 3. Measuring outcomes of an ESN service

In order to quantitatively evaluate the effectiveness or impact of an ESN service, different measures have been used to evaluate the outcomes of the service. Similar elements of the service may be measured using different tools or outcome measures, making comparisons between studies more challenging. They may also differ at the point at which the outcome is measured, and some outcomes may only become more evident in the longer term. ESNs also work in multi-disciplinary teams and evaluation of their impact may be hard to evaluate in isolation from the impact of the wider team. Defining what are appropriate measures of effectiveness, how and when these should be measured needs consideration. Inappropriate measures, used at inappropriate times may result in a lack of demonstrable effectiveness. Useful and accurate measures will however support the development of services, and quality improvements. We identified a wide range of outcome measures used in thirty-nine of the studies that measured quantitative outcomes. Changes in seizure frequency, quality of life and health status and knowledge of epilepsy were the most commonly measured outcomes.

**Table 9: Quantitative Outcomes identified in the included papers**

Outcome	N of studies (%)
Seizures	N=13
Quality of life/Health status scores	N=11
Knowledge of epilepsy	N=10
Attitudes to health services	N=8
Monitoring role	N=7
Appropriate medicine/ Changes to drug management /Medication management	N=7
Cost-effectiveness	N=7
Anxiety	N=6
Hospital admissions	N=5
Depression	N=5
Recorded advice given	N=5
Patient satisfaction	N=5
Mastery over illness	N=4
Feel stigmatized	N=4
Adverse drug effects	N=3
Seen GP	N=2
Deaths and accidents	N=2
Outpatient care utilisation	N=2
Reduced misdiagnosis	N=2
Injuries from seizures	N=1
Cognitive function	N=1
Physical role Limitations	N=1
Improved transitional preparedness	N=0

### Sub-roles within the ESN role

Fourteen different sub-roles within the ESN role were identified and are shown in Figure 2. These were identified both from within the literature and also at our stakeholder events. As categories they have limitations, for example they may not be present in every model of ESN practice. There is also a lack of clear distinction between some of the roles, for example medicines management will incorporate considerable skill in assessment and patient education. However, they allowed us to explore the many dimensions of the ESN role and to consider the extent to which this is considered and evaluated in the literature. It also allowed us to consider what elements of the role may be overlooked in health services research and in commissioning. During our stakeholder events the 'point of contact' and 'liaison and linking services' were prioritised as key sub-roles. However, it was these roles which were poorly represented in the literature and may be associated with outcomes that are not measured in evaluation studies.

We have mapped findings from the literature to ESN sub-roles and categorised these as:

#### 1) Need for that sub-role

Literature describing the ESN role and referring to the need for each sub-role, was noted here. Literature describing how the ESN addresses a need was differentiated from literature that described the role or sought to evaluate it. This often emerged from opinion pieces.

2) A description of how that sub-role is delivered within the ESN role, and where the literature describes the ESN role, for example a survey of ESN clinic records, this was differentiated from literature evaluating the effectiveness of the role. It was purely descriptive and typically includes surveys or case study designs.

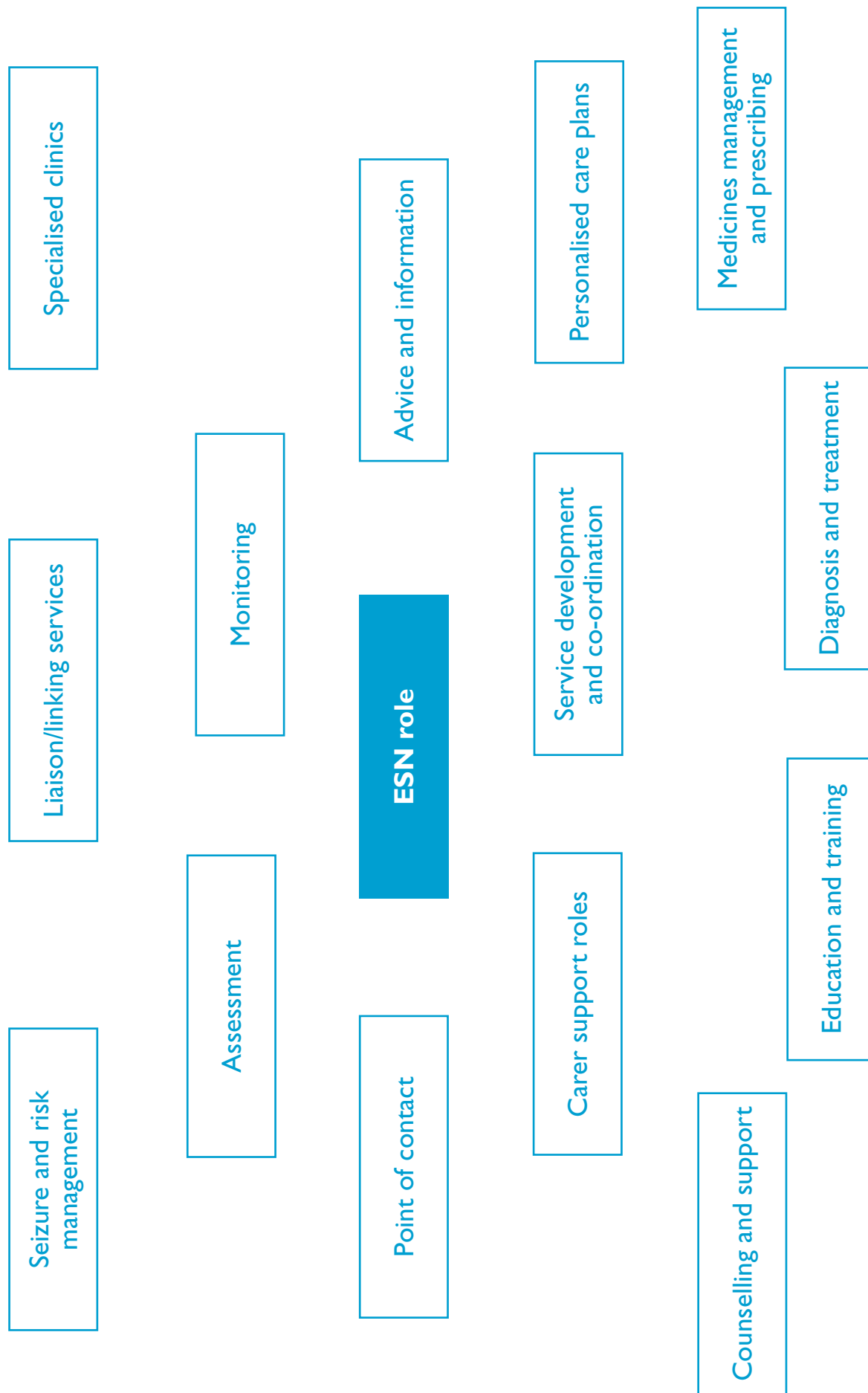
3) Evidence of impact or effectiveness for that sub-role.

Literature that described efforts to evaluate the ESN role were noted here. These included studies using a comparison group so that the impact of the ESN could be measured on particular outcomes of care. It also included non-empirical descriptions of benefits of the ESN role.

This section of the report corresponds with the online evidence map which accompanies this report. One purpose of the map is to locate gaps in the existing evidence base. As a result, some sub-roles appear to be supported by less literature than others. The description of the existing literature for each sub-role should not be considered exhaustive. Mapping the literature to different sub-roles was not based on line-by-line analysis of included papers, and how the literature is mapped necessarily reflects subjective coding by the reviewers.

Furthermore, a mapping review does not seek to be comprehensive; literature is typically described within the section for which it holds most resonance and not within every relevant section. Thus, each section of the report represents a commentary and not an exhaustive description of each included paper.

Figure 2 – Fourteen sub-roles within the ESN role



- Advice and information (page 22)
- Assessment (page 25)
- Carer support roles (page 27)
- Counselling and support (page 28)
- Diagnosis and treatment (page 30)
- Education and training (page 31)
- Liaison/linking services (page 32)
- Medicines management and prescribing (page 33)
- Monitoring (page 36)
- Personalised care plans (page 38)
- Point of contact (page 38)
- Seizure and risk management (page 39)
- Service development and coordination (page 40)
- Specialised clinics (page 42)

## Advice and Information

### Need

Two surveys (Jain et al 1993, Goldstein et al 1997) of patients attending clinics of consultant neurologists (tertiary care) investigated the level of knowledge that PWE have in relation to their own condition and their needs and preferences for receiving information. Many were found to have poor knowledge of their own condition and in particular of their drug regimens. Information giving at diagnosis was often poor. The results indicated that in particular there is a high demand for the services of a specialist nurse with expertise in epilepsy, despite relatively few patients having been referred to an ESN. Where they had been referred to an ESN, 23% had received useful advice (Goldstein et al 1997). It is evident that patient information needs change and the information needed and the manner in which it is given also varies between patients. Particular needs include more information at diagnosis, and more information for young people at transition to adult services (Northern et al 2008), certain groups such as older people, those with learning difficulties or poor levels of education or who lack support (Ridsdale et al 1999).

Jain et al sent a questionnaire to 511 patients with epilepsy who were being reviewed at the clinics of two consultant neurologists, to ask

about counselling and preference for hospital care. Over 90% of respondents wanted more information about the condition, and 60% wanted to talk to someone other than a consultant about epilepsy, the most frequent person requested being a specialist nurse.

### Role of the ESN

It is clear from the literature that giving information and advice about the clinical and social aspects of epilepsy is a key aspect of the ESN role. Not only does it require an advanced level of specialist knowledge, but requires skills in assessing what information is needed, how that should be delivered and reinforced, adapting to the patients changing circumstances and responding to new needs for information and advice. Information and advice must be tailored according to individual need for advice and covers diverse topics including clinical issues such as: knowledge of epilepsy, its causes, types of seizure, what happens during a seizure and how to get help, self-management, treatment options, prognosis, anti-epileptic drugs, side-effects. Importance of adherence, seizure first aid, seizure triggers, safety in the home and workplace or school. Advice may be required on lifestyle issues such as sleep, diet, alcohol, contraception, pregnancy, accident prevention, regulations concerning driving, legal rights and benefits, concessionary travel, prescription exemption, national and local support organisations and self-help groups. The ESN will use a range of resources of support materials including leaflets, booklets, video recordings, websites. (Ridsdale et al 1995, 2001, 200b, 2007, Dorris et al 2017, Noble et al 2014, Phaffin et al 2016, Ring et al 2016, Lu et al 2005, Hosking et al 2004, MacDonald et al 2000, Mantri et al 2008, Foley et al 2000, Stewart et al 1997, Taylor et al 1994). Some ESN services include providing a telephone advice line and email advice services (Middleton et al 2007). For certain groups, particularly children (Appleton and Sweeney 1993) and people with learning disability (Axon et al 2007, Davison et al 2015), the families need for information is critical and the ESN must incorporate their information and advice needs also). Women with epilepsy need relevant information regarding contraception and

pregnancy (Lewis and Smith et al 2006), labour, breastfeeding, caring for the infant and minimising risk from seizures (Hosking et al 2003). Adolescents need tailored advice on lifestyle matters (Chisanga et al 2007). PWE represent a diverse group and their information needs will also vary, and vary over time. Different models of ESN role mean that some ESNs work with particular groups of PWE and are therefore able to tailor the information and advice they give to the specific information needs of that particular group.

### **Evidence of effectiveness and impact of their role**

#### *Systematic Reviews*

An overview of research of the information and counselling needs of people with epilepsy concluded that specialist epilepsy clinics and specialist nurses can improve patient knowledge and communication and provide an effective and high quality service for people with epilepsy (Couldridge et al, 2001).

The Cochrane systematic review looking at different care delivery and self-management strategies for adults with epilepsy (Bradley et al 2016) included five trials that examined the effectiveness of the ESN service (Mills 1999a, 1999b, Ridsdale 1997, 1999, Ridsdale et al 2000, Warren et al 1998, Holde et al 2005). The summary of benefit for patients receiving care from an ESN concluded:

*‘There is some evidence of effectiveness for specialist nurse practitioners in terms of improving participants’ reported knowledge of information and advice received from professionals, with four of eight studies reporting improvement in at least one category compared to controls (Mills 1999a; Mills 1999b; Ridsdale 2000; Warren 1998).’*  
(Bradley et al, 2016)

They considered multiple outcomes including reported knowledge of information and advice received from professionals, concluding:

*‘There were few significant differences between groups for any of the other outcomes considered by this review with the exception of Mills 1999a*

*reporting that individuals in the intervention group were significantly more likely than those in the control group to report never missing a dose of their antiepileptic drugs. This study and the follow-up by Mills 1999b also reported significant differences between groups for 3 out of 10 measures of self reported quality of life. Primary care costs were reported to be significantly reduced in the intervention arm of Warren 1998, in which participants received the intervention in a regional epilepsy clinic.’* (Bradley et al, 2016)

#### *RCT evidence*

A comparative study (Higgins et al 2018) compared the experiences of care, satisfaction with care and quality of life between those who were in receipt of care from a service with an ESN and those who were receiving care from a service that did not include an ESN. Findings from the study suggest that ESNs make a difference to some, but not all, aspects of epilepsy. Participants attending services with an ESN had statistically significant higher mean scores in terms of information provided on the following: the nature of epilepsy, social aspects of epilepsy, safety aspects of epilepsy and medical aspects of epilepsy.

While the overall findings support the belief that ESNs make a difference to education on medical aspects of epilepsy, there was little or no difference between ESN and non-ESN sites in relation to information provided on why specific tests or scans are needed, the results of tests/scans, the purpose of anti-epileptic medication, how often medications need to be taken, and the implications of not taking anti-epileptic medications.

An evaluation of a primary care-based specialist epilepsy nurse (Mills, 1999a) found that at one year, participants in the intervention group were significantly more likely to have discussed 4 out of 11 topics with primary care staff (P = 0.004 to P = 0.048) and 2 out of 11 topics with hospital staff (P = 0.020 to P = 0.048). The study investigators adjusted these results for baseline value of outcome variable and gender in a multiple regression model. However, as only 50.9% of participants responded to both

baseline and follow-up questionnaires, these results should be interpreted with caution. At one and two year follow-up (Mills, 1999a, Mills, 1999b), participants who had access to the ESN were significantly more likely to have discussed more topics that were important and relevant to their condition than those who did not receive care from the ESN. Indeed, all results of this evaluation from both studies should be interpreted with caution because of the weak study design and the large number of comparisons made, which increase the likelihood of a significant finding occurring by chance.

An evaluation of an epilepsy nurse based in general practice measured knowledge using the Knowledge of Epilepsy questionnaire (Ridsdale et al 1999). Authors stated that overall, there were no significant differences in knowledge scores between groups at six months, but they do not provide further information (e.g. scores or statistical tests). At six months, the evaluation of a hospital-based specialist nurse by (Ridsdale et al 2000) found that of nine topics, participants in the intervention group were significantly more likely to have received enough advice on eight topics with primary care staff ( $p < 0.01$   $p = 0.05$ ). This study also found no difference in epilepsy knowledge scores between control and intervention groups (P values ranged from 0.49 to 0.73), except in those whose score lay in the lowest quartile at the start of the study. In this group, knowledge scores did improve (median in intervention group from 38.2 to 42.7, median in control group from 36.0 to 37.2,  $p < 0.01$ ). Neither Helde et al 2005 nor Ridsdale et al 1997 evaluated reported knowledge of information and advice received from professionals in their studies of specialist nurse interventions.

Pfaffin et al (2016) investigated the efficacy of epilepsy nurses on a measure of satisfaction with counselling about epilepsy in a randomized, controlled, prospective trial conducted in Germany. Satisfaction with information and support improved significantly in the ESN group compared to the control group ( $p = 0.001$ ). In addition, Epilepsy Knowledge ( $p = 0.014$ ) and Coping (subscale Information Seeking)

( $p = 0.023$ ) improved. Epilepsy nurses therefore improve the satisfaction of patients with counselling and information about epilepsy and concomitant problems.

#### *Qualitative evidence*

Qualitative studies found that patients rated information given by ESNs highly, and this was the main reason for seeing a specialist nurse (Mills et al 2002a, Ridsdale et al 2003.) They also felt that they had more time to ask questions and there was more time for the ESNs to deliver information compared with doctors (Hopkins et al 2012, Ridsdale et al 2003). The specialist nurses were described as the most knowledgeable and approachable health professional by patients and their carers, however it was a service that was perceived to be overstretched and access to it was difficult (Smithson et al 2006).

#### *Non-randomised studies and audits*

In a non-randomised study comparing the information received by women with epilepsy of childbearing age about gender-specific issues the introduction of a nurse-led clinic for women led to an increase in the amount of information given. There was a 30% increase in advice given about contraception, 89.7% of those on enzyme-inducing anti-epileptic drugs were informed of the risk of failure of the oral contraceptive pill compared to 53.2% before the intervention. Information given about the risks associated with experiencing generalized tonic-clonic seizures during pregnancy, as well as the need for compliance, increased by 40%. The introduction of a nurse-led clinic resulted in an increase in the amount of information given, and has also provided a better basis for evaluating that information (Lewis and Smith 2006).

The results of an audit of the admission of epilepsy sufferers in a UK District General Hospital over a 1-year period found that most admissions of PWE were due to potentially mutable problems including poor compliance with medication rather than to difficult epilepsy per se. A change in this behaviour is most likely to result from access to consistent and informed advice, education and support. When this



provision has been made available in the primary care setting from nurse specialists in epilepsy, the amount of advice given to patients is increased and patients have expressed a higher level of satisfaction with the service. The authors suggest that similar provision in a hospital setting might well prevent a significant number of admissions following seizures in patients known to have epilepsy: a reduction of 60 days in hospital, resulting from about 12% of admissions with known epilepsy (Irving et al 1999).

Other audits have found that ESNs are the professionals patients value, being able to ask questions in an unhurried atmosphere with the ESN, that by improving patients understanding of epilepsy and its treatment that quality of life is improved (Appleton & Sweeney 1993, Kwan et al 2000).

## Assessment

### Need

As well as accurate diagnosis, PWE require ongoing follow-up and assessment as treatment effects are monitored and adjusted. Assessment of risk, and assessments of changing risk are a requirement of care.

It has been shown that risk assessment for people with epilepsy and learning disabilities is often neglected (Sheehan et al 2016). Epilepsy and convulsions are leading causes of death in people with learning disability and clinical guidelines for management in this group stress the importance of epilepsy risk assessment in mitigating the risk of harm from the condition.

### Role

Assessing the health needs of patients is one of four main activities of advanced nursing roles that distinguish it from other nursing roles (UKCC 2002). The four roles include:

- Providing education/training to staff.
- Providing specialist advice/consultancy to other healthcare professionals.
- Assessing the healthcare needs of patients.
- Making professional autonomous decisions/practice.

The ESN is often integrally involved in both the initial assessment of the patient and subsequent monitoring. In order to provide continuity of care, the ESN will review the patient's condition, treatment and individual circumstances on a regular basis and make recommendations for improvements to care (Foley et al 2000).

The key roles identified as advanced nursing practice for the ESN (Higgins 2008) include:

- Ordering diagnostic investigations, thorough pre-assessment and continuing assessment of patient diagnosis and treatment such as blood tests, electroencephalogram, electrocardiogram, scanning and history taking.
- Triaging of patients through fast-track services to improve patient access particularly through nurse-led clinics and referral pathways such as from accident and emergency or maternity services.

Assessment might involve referral of the patient to another member of the care team. Regular patient review by the ESN gives GPs and consultants more time to see new patients or existing patients with complications. In circumstances where a switch in drug therapy is indicated, nurses are able to supervise these changes in medication, and thereby reduce the need for patients to see a neurologist or GP. The nurse can also identify and advise on ways in which drug management may be improved. In addition to providing continuity of care, this regular patient contact may allow a greater understanding of the patient and their epilepsy. Completing in-depth comprehensive assessment that moved beyond the disease model of care to incorporate lifestyle and psychosocial issues was another component of the ESN's clinical role identified in a mixed methods study (Ring et al 2018).

The ESN role in assessment may vary and be influenced by the client group the ESN works with. For example, in caring for adults with epilepsy and intellectual disability, where patients may have limitations in communication. Ring et al (2016) explored the lead role of ESNs in caring for adults with epilepsy and intellectual

disability in a trial (EpAID). The role involved the regular collection of clinical information including seizure frequency, side-effects, behavioural symptoms and effects of seizures on daily life from patient and carers. ESNs also assess patients on a regular basis at a frequency determined by clinical need. This was achieved through home visits, telephone clinics and visits to the local primary care or Intellectual Disability team base. Specialist nurses can undertake screening for behavioural health disorders (Hill et al 2017).

### **Evaluation/Impact**

Assessment is key within the ESN role as a feature of clinical practice that is tailored and responsive to the particular needs of the patient. Evaluation of the ESN role, which includes broad and diverse sub-roles such as 'assessment', requires diverse research designs that explore different types of outcomes. Neither is it possible to isolate the impact of the ESN role, or of a sub-role from within the role as a whole, or from the contribution of the wider multi-disciplinary team, or indeed the health system within which ESNs are working.

ESNs work in diverse contexts; evaluation and indication of effective care in one setting cannot be assumed for the service as a whole. Isolating those factors within clinical practice that contribute to greater effectiveness, such as caseload size, background training, ongoing training needs, use of clinical assessment tools to facilitate diagnosis and assessment, supportive technologies, frequency of patient contact, structure of the MDT team, characteristics of the nurse continues to prove challenging. Research that seeks to explore what factors that can contribute to effectiveness and are transferable across settings would be valuable.

The EpAID study (Ring et al 2018) evaluated the impact of a 'Learning Disability Epilepsy Specialist nurse Competency Framework'. The competencies included assessment of seizures, medicines, linked health conditions, managing risk, impact of epilepsy. The trial found that while some clinical outcomes (seizure frequency and associated injuries) showed no

improvement in the group of patients receiving care from nurses with additional specialist epilepsy training, the intervention was however cost-effective. The competency framework was associated with a reduction in monthly costs compared to the 'treatment as usual' group.

A mixed methods study in Ireland (Higgins et al 2018) found that PWE receiving a service with an ESN reported receiving a greater amount of information, were more involved in their care, perceived care to be better coordinated and had a greater confidence in the information provided and greater comfort in discussing issues with an ESN. The study also reported higher rates of satisfaction with the emotional and practical supporter offered. These positive outcomes can only have been possible if effective assessment was part of the process of care.

Taylor et al (1994) described the development of a district epilepsy service with specialist nurses and guidelines for shared care in Doncaster. Data was gathered from a small survey and interviews. The contribution of the specialist nurse represented an important advance in epilepsy care, and enabled the supervision of complicated changes in medication successfully at home, with a reduction in the need to attend clinic or visit the GP. In the first 12 months of the service, unrecognised problems of clinical management were identified and, in many cases, resolved (compliance, unreported seizures, misunderstanding of treatment) and of coping (at school, work etc).

A US-based study undertook a cost-effectiveness analysis of a shared assessment clinic with a physician working alongside a nurse specialist. The nurse specialist gathered patient histories, and generated progress notes and a patient information sheet (Doller et al 1994). The evaluation found that physician time was reduced by 66% and the cost of a clinic visit was reduced by 39% by using the expert nurses. In addition, the progress notes were more legible, and contained more information, and there was better recording of information. Faulkner (2013) examined the ESN role in the

improvement of local services and establishment of models of good practice. He described the role of two specialist epilepsy nurses at University Hospital Cardiff, where patients suspected of having an epileptic seizure are seen by one of two specialist epilepsy nurses within 4 hours of arriving at the accident and emergency department. Patients received a review before being referred to an enhanced first seizure clinic. It is a system that has already saved £45,000 in its first year, according to unpublished data.

## Carer support

### Need

Most of the literature we identified that mentioned the ESN support of carers was in relation to parents of children and teenagers. Families often had little information and parents of children with epilepsy often experience fear and worry about their children. They may perceive a loss of their 'normal' healthy child. Many parents react by overprotecting the child. Stigma or shame is often associated with epilepsy and can lead to the child having lower self-esteem, anxiety and depression (El-Radhi 2015). With the right support parents can be instrumental in supporting their child with epilepsy, particularly if they get the necessary knowledge about epilepsy, including first-aid measures to be used if seizure occurs. One of the best ways in which parents can support children is by talking to them about their epilepsy in an age-appropriate way. Overprotection should be avoided and stigma reduced (El-Radhi et al 2015). The ESN also addresses any adverse family dynamics, misinformation or stigmatisation. The ESN helps to manage a patient's risk of sudden unexpected death in epilepsy.

### Role

The ESN also plays a lead role in educating carers in the home setting and is responsible for ensuring that they are aware of their responsibilities with regard to recording, compliance and adherence to prescribed treatment. This is particularly important for voluntary sector carers who may not fully understand the implications of epilepsy in people with learning disabilities. An additional responsibility of the ESN is to ensure that patients, carers and other healthcare professionals are kept up to date with any new and relevant findings, which could have implications for future therapy (Foley 2001).

Supporting the families and carers is a time-consuming but valuable aspect of the role of an epilepsy nurse specialist. A telephone contact point and time to talk through a crisis help people being cared for in the community. It is necessary to be an advocate for the client in some circumstances (Graydon et al 2000).

Parents need to be given information and support so they can in turn support the child with epilepsy. The ESN can also address any adverse family dynamics, misinformation or stigmatisation. The ESN also helps manage a patient's risk of sudden unexpected death in epilepsy (El-Radhi et al 2015). ESNs play a vital role supporting parents of teenagers with severe and intractable epilepsy in managing concerns and expectations (Chisanga et al 2009). Also, families wanted to be supported and taught about how to care for their child with epilepsy in their own home (Norther et al 2008).

### Evidence of impact or effectiveness

A systematic review of care delivery and self-management strategies for children with epilepsy (Fleeman & Bradley et al 2018) did not identify any ESN led interventions evaluated in an RCT.

## Counselling and support

For the life events and difficulties that are a consequence of the condition, with aim of the prevention and management of psychological illness (Ridsdale 2000).

### Need

Counselling refers to the psychological support that ESN nurses offer PWE as they come to terms with and manage a life-changing condition. Patients may potentially face lifelong medications with side-effects. Having epilepsy will impact social activities, relationships, independence, school and work places. PWE may experience a sense of stigma, feel isolated and fearful. Fear was a major theme expressed by PWE in interactions with an ESN. The fear of recurrence of seizures was common, especially for drivers and those worried about losing their job. By far the most frequent comment was being 'afraid to go out alone', expressed by over 50% of those who felt their epilepsy limited their activities. (MacDonald et al 2000). A survey of parents of children with epilepsy has been carried out by Epilepsy Action (cited by Anderson et al 2006) found that about half of the parents surveyed said that their children were having difficulties at school, but seizures were only the fourth most common reason. The top three reasons given for the problems were: difficulty concentrating, working more slowly than others, being too tired (Anderson 2006).

### Role

The ESN is a crucial source of social and emotional support as well as educational support. (Campbell et al 2005, Rollinson et al 2007). They are well placed to do so, and ESN working in primary care, going to the local general practice is a setting in which a patient has a rapport and would feel comfortable to talk about their condition (Chisanga et al 2007). The emotional repercussions of epilepsy take a toll on relationships and psychological wellbeing, requiring sympathetic understanding and practical support, which the nurse can often provide (Kwan et al 2000), aiming to prevent and manage psychological illness (Ridsdale et al

2000). ESNs may support patients by facilitating a psychosocial group intervention, so patients can share experiences of having epilepsy (Dorris et al 2017, Steward et al 1997). ESNs need a supportive attitude (Helde et al 2005) and skills in active listening (Kwan et al 2000) in order to offer tailored support for individual need, reducing psychosocial handicap and improving quality of life.

Particular support may be needed in helping patients adjust to news of their diagnosis (Ridsdale et al 2000a) and the ESN must establish a relationship and rapport with carers, fostered by regular contact in order to provide the necessary support (Ring et al 2016). Support is needed to encourage children to participate socially and access the full curriculum (Solomon et al 2012). They must monitor anxiety, signs for psychosis, assess coping mechanisms, assess for deterioration in wellbeing and screen for co-morbid depression (Mantri et al 2008).

Certain groups may have particular psychological and social challenges to overcome, for example teenagers. Identifying issues and providing appropriate support and counselling may mean seeing them independently from their parents (Nordli et al 2001).

What does an individual with a learning disability and epilepsy understand about the condition themselves? Are they frightened by their seizures? How do they feel post- and inter-ictally? These are questions which may be addressed by a specialist nurse, either individually or in small groups. Unfortunately, few existing resources are suitable to help people with learning disabilities explain their feelings or to understand the condition (Graydon et al 2000).

### Evaluation

#### RCT

A recently published study (Higgins et al 2018) set out to determine whether there were differences in experiences of care, satisfaction with care and quality of life between those who were in receipt of care from a service with an

epilepsy specialist nurse (ESN) and those who were receiving care from a service that did not include an ESN. A comparative design was used, which involved the completion of a confidential, self-completed survey. The survey was administered to a nonprobability convenience sample of patients with epilepsy who were attending services with an ESN ( $n = 244$ ) and services where the treatment team did not include an ESN ( $n = 261$ ) from each of the four health areas in Ireland. People with epilepsy from ESN sites reported higher satisfaction with the practical and emotional support provided ( $M = 8.05$ ;  $SD = 2.13$ ;  $M = 7.39$ ,  $SD = 2.47$ ) compared to PWE attending non-ESN sites ( $M = 7.41$ ;  $SD = 2.39$ ;  $M = 6.65$ ,  $SD = 2.73$ ), and this was statistically significant for both items.

In evaluations of a primary case-based specialist epilepsy nurse at one year (Mills 1999a) and two years (Mills 1999b), investigators assessed perceived quality of life primarily from 10 questions about the effects of epilepsy and its treatment on daily living. At one year, Mills 1999a reported that those in the intervention group were significantly more likely than those in the control group to report that epilepsy affected their future plans and ambitions (OR 6.19, 95% CI 2.07 to 18.50), overall health (OR 4.28, 95% CI 1.77 to 10.34) and standard of living (OR 2.74, 95% CI 1.05 to 7.16), to a large, moderate or small extent. The reported odds ratios for self-reported effects on other areas of everyday life, while greater than one, were not statistically significant. There were no significant interactions between having seen the epilepsy nurse and time since last epilepsy attack on reported quality of life variables. At two years (Mills 1999b), authors reported significant differences between the group of participants who had accessed the specialist epilepsy nurse and those who had not for the impact of epilepsy on overall health (OR 2.50, CI 1.23 to 5.08). Significant differences existed between groups with regard to how individuals felt about themselves (OR 2.09, CI 1.01 to 4.33) and the impact on their social life/activities (OR 2.28, CI 1.08 to 4.82). Investigators measured effects by controlling for the same variable at baseline, seizure in the previous year and other long-

term illness. Reported odds ratios for self-reported effects on seven other areas of everyday life were greater than one, but not significantly so. Mills (1999a, 1999b) also reported two additional questions relating to quality of life in tables (i.e. 'feel stigmatised due to epilepsy' and 'feel unhappy about life as a whole'). At neither point in time did investigators report differences between the intervention and control groups or between the participants who had accessed the specialist epilepsy nurse and those who had not. All results of this evaluation from both studies should be interpreted with caution because of the weak study design and the large number of comparisons made, which increase the likelihood of a significant finding occurring by chance.

An evaluation of an epilepsy nurse based in general practice found no significant changes over time in depression scores at six months if participants had a seizure in this period ( $P = 0.44$ ) (Ridsdale 1999). For those participants who had had no seizure, investigators did observe a significant difference in depression ( $P = 0.03$ ).

At six months, an evaluation of a hospital-based epilepsy nurse in outpatients found no significant difference between control and intervention groups in either anxiety ( $P = 0.41$ ) or depression ( $P = 0.27$ ) (Ridsdale et al 2000).

At two years, Helde et al 2005 evaluated a hospital-based specialist epilepsy nurse, showing that there were no significant differences between groups for the Quality of Life in Epilepsy Inventory (QOLIE-89) ( $P = 0.58$ ). However, intervention group participants were significantly more likely to have an improved score compared to baseline ( $P = 0.019$ ). There were also significant improvements from baseline for 3 of 17 sub-items on the QOLIE-89 scale in the intervention group. These were: role limitations - physical (intervention  $P = 0.05$ , control  $P = 0.59$ ), health discouragement (intervention  $P = 0.01$ , control  $P = 0.15$ ) and medication effects (intervention  $p = 0.04$ , control  $p = 0.36$ ). Conversely, significant improvements were reported from baseline for

1 of 17 sub-items on the QOLIE-89 scale in the control group, namely pain (intervention  $P = 0.41$ , control  $P = 0.04$ ). The earliest evaluation of an epilepsy nurse based in general practice by (Ridsdale 1997) did not report any quality of life measures.

### *Non-randomised findings*

Patients reported how they valued support e.g. dedicated phone line to ESN, “It is very reassuring to know I can just pick up the phone and get expert advice and support from this service. In particular (the ESN) enabled me to feel less stigmatised by my condition.” They also valued high levels of communication (Hosking et al 2002).

One paper reporting patient case histories (Betts & Greenhill 2001) described how the ESN built a relationship of trust with a patient experiencing poorly controlled epilepsy, side-effects from her medications and lack of confidence in doctors. Over time and with weekly contact, the ESN was able to support her in the gradual changes she needed to make in her medications. The development of the therapeutic relationship was necessary to manage the positive change needed.

## Diagnosis and treatment planning

### **Need**

A misdiagnosis of epilepsy occurs in 20-31% of adults (Stokes et al 2004), highlighting the importance of implementing best practice guidelines which recommend that diagnosis should be made by medical practitioners specializing in epilepsy (NICE 2012, 2018). A detailed history should be obtained, supported by an eyewitness account of the seizure and appropriate investigations are needed to support the diagnosis, its classification and plan treatment. Lewis (2011) highlights the specialist knowledge of the ESN means they should be involved to reduce misdiagnosis.

Diagnosing epilepsy and classifying syndromes in patients with learning disabilities can be very difficult (Hannah & Bodie 1998). The diagnosis of epilepsy relies heavily upon an accurate description of events and the presence of a witness. The individual is often unable to describe the symptoms and sensations which are experienced during an aura or post-ictally. Professional carers attending a clinic with such a patient often vary, and there may be a lack of continuity in information sharing. All this adds to the unease about the accuracy of diagnosis compared to other patient groups.

### **Role**

While the role of diagnosis and plans for treatment lie typically within the domain of medical practice, there is some evidence that the ESN role has blurred the boundaries between medicine and nursing. ESNs are involved with diagnosis and treatment planning in some settings, and there are recommendations that they should be involved in supporting this aspect of patient care (Lewis 2011). Close working with medical colleagues is evident in joint clinics, where the ESN is involved with supporting history-taking details to aid diagnosis or in Rapid Access Clinics following a first seizure. ESNs also have roles in diagnosis and beginning treatment in triage clinics (Greenhill et al 2002). Patients with well-controlled epilepsy should be reviewed periodically in a primary care setting, preferably by a GP or ESN. The ESN role in ensuring accurate and up-to-date record keeping can assist liaison between primary and secondary care.

The specialist nurse may also triage undiagnosed or newly referred patients following a first seizure, take a medical history, consider the differential diagnoses, initiate and interpret diagnostic investigations, diagnose seizure types and syndromes and recommend first line treatment in consultation with consultant colleagues (Hosking 2003).

## Evaluation/Impact

A national survey (Goodwin et al 2004) exploring the role of the ESN found that 41% (n=57) of respondents (n=64) were involved in joint medical clinics. A cohort study undertaken in the United States comparing the quality of care delivered by ESN and physician teams to physician teams only found that the ESN-physician team care model increased the availability of care and could also improve the quality of care delivered. However, diagnostic investigation and treatment escalation during the study period showed little difference between the two cohorts (Hill et al 2017).

Goodwin (2011) examined the structure of the ESN and consultant neurologist (CN) clinical interviews at first seizure presentation and opinion on diagnosis. Audio-recordings of clinical reviews with an ESN and a CN were recorded. The clinical interviews of CN and the ESN were similar in structure. Differences demonstrated CNs concentrated on the prodrome to events and expressed less diagnostic uncertainty. ESNs concentrated on post-ictal recovery and used more investigations. Complete disagreement on diagnosis occurred in 25% of patients. The Kappa score (0.510) demonstrated a moderate level of inter-rater agreement. Both missed important information at times. It was apparent that information obtained differed between the reviews, which would support that a diagnosis of epilepsy should be made using a team approach.

## Education and training

### Need

As well as providing information support to PWE and their families. The ESN role also frequently involves supporting the learning needs of others caring for PWE. Need for educational support have been expressed by GPs (Lambert et al 2001), teachers (Mott et al 2012), health professionals working in A&E and wards which may admit people with epilepsy and a learning disability (Graydon et al 2000). The inclusion of routine monitoring of epilepsy in the QOF framework (Quality and Outcomes

Framework) incentivised GPs and practice nurses to seek support in increasing their competence and confidence in managing epilepsy (Ridsdale et al 2009) although epilepsy has subsequently been removed from QOF (except the requirement for GPs to keep a register of people with epilepsy).

### Role

It is evident from the literature that the ESN is often involved in education and training of other professionals. This includes training general practices to establish epilepsy review programmes, promoting the use of guidelines in epilepsy management, providing information on epilepsy management and relevant clinical development (Davis et al 2004, Mills et al 2002a, Mills 2002b, Hosking et al 2006, Foley et al 2000, Helde et al 2005, El-Radhi et al 2015). Paediatric ESNs spend time in the community, educating school staff and families on epilepsy, seizure management and use of rescue medications (Higgins et al 2008, Stewart et al 1997, Nordil et al 2001, Ring et al 2016, Appleton & Sweeney 1993).

### Impact/Effectiveness

While the literature supports the importance of the ESN role in education and training, few papers explore the impact or effectiveness of the ESN role in educating other professionals in epilepsy and its management.

Davis et al (2004) explored the effectiveness of two dissemination and implementation strategies to implement a national guideline for epilepsy management in primary care settings included and intervention arm which included an ESN who supported and educated practice in the establishment of epilepsy review clinics. None of the intervention groups showed any change in the primary or secondary outcome measures or process of care measures. None of the intervention strategies led to improved patient quality of life or quality of epilepsy care. The authors suggest that one reason for this finding is that primary care practitioners do not see epilepsy care as their responsibility and therefore see no need to prioritize its care. They recommend further qualitative research in

order to better identify barriers to implementation strategies.

Evidence from a recently published mixed methods study (Higgins et al 2018), gathering data using interviews with ESNs, observation of their practice and documentary analysis, showed that their role in leadership developed as they became more established in their roles. One of the themes that emerged from the study was the role of the ESN in building capability within the multi-disciplinary team (MDT). To enhance the quality of service provision the ESNs increased the capability of nurses, MDT members and other practitioners both within and outside of their organisation, through the development and implementation of a range of formal and informal educational initiatives. This included short educational programmes on various aspects of epilepsy care, providing consultancy on patient care issues to MDT members, GPs and staff from the intellectual disability services.

In a survey of 750 health professionals, the ESN was also identified by other HPs as playing a key role in the promotion and successful adoption and application of good practice guidelines in epilepsy care (Frost et al 2003). GPs felt that education provided by the nurse improved awareness of the issues involved during pregnancy and in initiating and terminating AED treatment (Lambert et al 2001).

## Liaison linking services (and team working)

### Need

Audits of epilepsy-related deaths, demonstrate fragmented provision of services in the UK, to people with epilepsy (Lewis et al 2011). Certain groups of patients with epilepsy are particularly vulnerable to services which fail to adequately link up. Young people, as they transition from child to adult services, and enter adulthood, often get insufficient help (Davis 2015). Services are described as being poorly linked on a broader level (Varley et al 2010).

### Role

Quite unique to the ESN is their role in liaising with and linking services, patients, families, health providers. Different models of ESN practice work differently in this respect, but no other provider of care to PWE crosses boundaries to the same extent. These boundaries include; primary and secondary care, hospital and home, school/work and health providers, GP and neurologist, childhood to adolescence and adulthood, pregnancy which are all boundaries that patients themselves must navigate, but which no other professional navigates with them. The ESN uniquely, does cross those boundaries and it is critical to the effectiveness of their role.

This linking and liaising role will include making referrals, tailored to the patients' requirements, to other services (e.g. counselling, social services, emergency rescue medication clinics). Advice and actions taken communicated to the patients GP (Noble et al 2014, Mills et al 1999) include detailing and communicating all medication changes promptly (Mantri et al 2008) and ensuring links and good communication between GPs and consultant neurologists (Hosking et al 2002). Liaison is also needed between primary, secondary and tertiary care to enable seamless delivery of care (Graydon et al 2000). They coordinate multi-disciplinary service need of PWE, linking support groups and coordinating between different agencies and groups (Kwan et al 2000), communicating with the GP (Mills et al 1999, scheduling medical appointments (Helde et al 2005).

The ESN role in coordinating services for children seems to feature prominently in the literature. liaising for example, between the medication team and the family, creating a treatment plan that meets the needs of the child (Greenhill et al 2002). Central to the role of the nurse specialist is the need to establish a link between hospital and community and specifically between the hospital and school health services (for children) (Appleton and Sweeney 1993). They establish and ensure close links between the doctor, families and visit the



child at home (El-Radhi 2015) and later supporting young people at transition into adult life (Davis et al 2004).

### Impact/Effectiveness

A study comparing the experiences of patients receiving care from an ESN with those of patients who did not found there was greater continuity of care experienced by patients in receipt of the ESN service. A higher proportion of participants in non-ESN sites strongly agreed/agreed that they meet the same practitioner each time (58.7%) compared with those in ESN sites (40.6%) [ $\chi^2(4) = 20.44, p = 0.001$ ]. There were no statistically significant differences between non-ESN sites and ESN sites on their views in relation to whether they had to explain their epilepsy repeatedly to different healthcare professionals [ $\chi^2(4) = 0.230, p = 0.124$ ] and whether there was consistency in the information they received [ $\chi^2(4) = 0.035, p = 0.134$ ] (Higgins et al 2018).

A study comparing the experiences of care between a cohort of patients in receipt of care from a service with an ESN (n=244) and those who were receiving care from a service that did not include an ESN (n=261), were asked to rate four items that addressed coordination of care: care delivered in a planned and coordinated manner, easy to make appointments, good follow-up care, and reasonable waiting times. Participants from ESN sites had higher mean scores on all four items compared to non-ESN participants. The total mean score for coordination of care was higher in ESN sites (M = 3.77; SD = 0.78) compared to non-ESN sites (M = 3.57; SD = 0.88) [ $t(475) = -2.597, p = 0.01$ ] (Higgins et al 2018).

A questionnaire based survey (Frost et al 2003) demonstrated that achieving good practice in integrating care and linking patients to appropriate services was credited to the role of the ESN.

GPs report that they are unhappy about the levels of access they have to neurologists but 95% felt that the provision of an ESN would help alleviate this problem (Neligan et al 2005).

## Medicines management and prescribing

### Need

There is evidence that patients feel they lack information about AEDs, and their side-effects. They value being able to talk to someone other than a consultant about epilepsy and the most frequent persons requested is the specialist nurse (Jain et al 1993). Patients describe experiencing inappropriate drug management by both neurologists and general physicians (Wallace & Solomon 1999). An audit (Hanna et al 2002) of epilepsy-related deaths shows that service provision continues to be fragmented in the UK. This audit identified that 77% of children and 54% of adults with epilepsy received inadequate care pre-mortem, and that 59% of children's deaths and 39% of adults' deaths could potentially or probably have been avoided. Major deficiencies were identified in both primary and secondary care, and included inadequate access to specialist care, inadequate AED management and inadequate or lack of appropriate investigations (Hanna et al 2002).

Particular groups of patients have different needs in respect to medicines management. Carers need written information about epilepsy and drug side-effects (Steward et al 1997).

Managing the medicines of people with learning disabilities and epilepsy requires additional skill and knowledge of individual needs. The issue of care plans for giving medication in emergency situations may require liaison, to ensure appropriate action by all carers. As most medical care is supplied by the general practitioner, it is important to have good communication channels, particularly at times of drug changes, when seizure control and side-effects can be unpredictable (Graydon et al 2000). Compliance is a major issue in treating children and may require extra support. In addition, schools needed support in ensuring there was a seizure rescue plan and policies in place over medication to be used and delivered by whom. School staff express fears of liability in regard to seizure management of children (Terry et al 2016).

## Role

Supporting medication management may be considered a significant component of the ESN role. How such support is delivered depends on the model within which the ESN service is delivered and on whether the ESN is a NISP (Nurse Independent and Supplementary Prescriber). Medication management support includes; discussing with patients how they are managing their medicines, assessing issues of adherence, reviewing dosages, side-effects and plasma concentrations. They may monitor effects of changes and supervise commencing new medications, switching medicines, oversee titration of medicines or withdrawal protocols. They might initiate adjustments in medication, organise tests, EEGs and ambulatory monitoring. Advice given is recorded and correspondence made with GPs regarding changes in medicines. Advice might be available over the phone (Bingham et al 2009), and the ESN could work more proactively than under a system where a patient has to wait for a six-month review (Hopkins et al 2012).

Although mainly monitoring and advising, some ESNs hold much greater responsibility (Goodwin 2004). Some ESNs can also assess, diagnose and independently prescribe any licensed medicine within their area of competence. A questionnaire completed by ESNs (n=29) working as independent prescribers, exploring their role found that 21 (72%) signed prescriptions, 28 (97%) made recommendations to other prescribers, 14 (48%) prescribed or amended ward/in patient drug prescriptions and 10 (34%) used clinical management plans. The medications prescribed by ESNs included anti-epilepsy medication, folic acid, vitamin K, antidepressants, steroids, rescue medication and the contraceptive pill. Most ESNs wrote a prescription for a new drug at least once a week whilst most nurses titrated medication daily. In other situations, the ESN may be consulted prior to the prescription of AEDs by a physician.

In general, epilepsy nurse specialists who undertake this role work in secondary or tertiary care settings and make

recommendations to patients' GPs who do the actual prescribing. In this way, their role is analogous to the hospital doctors who make treatment recommendations to GPs. In recommending treatment changes, patients have more rapid access to improved management. This was previously the function of only medically trained staff. Patients with refractory epilepsy are monitored for AED efficacy and side-effects and some specialist nurses advise patients on medication changes to improve treatment (Hosking et al 2003).

Compliance is a major issue that ESNs treating children address. The nurse specialist has a role in monitoring treatment compliance and, in consultation with the child, addressing any associated problems. Issues such as school, exams and lifestyle choices, particularly for adolescents, need to be considered when planning treatment. The nurse specialist liaises with all members of the medical and nursing team, and co-ordinates all aspects of patient care, both in hospital and at home (Greenhill et al 2002).

The ESN also identifies and responds to situations where additional advice regarding AEDs is required, for example on family planning or, after four or more years' remission, about the possibility of reducing drug treatment Ridsdale (1995) or on interactions of AEDs (Ridsdale 2000a).

### Impact / Effectiveness

Bradley et al (2016) reviewed care delivery and self-management strategies for adults with epilepsy. They included seven RCTs that evaluated the ESN as a service model for delivering epilepsy care. The findings could not be pooled in a meta-analysis but were described narratively. They concluded that there was evidence of benefit of the ESN. The studies measured a range of outcomes, those that relate to medicine management roles are summarised below.

Quantitative studies have sought to evaluate this aspect of the ESN role using different measurement tools including: medication

management skills (Noble et al 2014), self-reported non-compliance with medication, 'taking one type of antiepileptic drug', 'feel very well controlled by drug', 'report very important to take tablets exactly as prescribed' and 'reporting side-effects from drugs' (Mills 1999a), appropriateness of medication supplied (Ridsdale et al 1997).

The evaluation of a hospital-based epilepsy nurse by Warren 1998 (cited in Bradley et al 2016), which included a minority of participants with learning disabilities, found that there was no difference between study and intervention groups with respect to self-management, as measured by self-reported non-compliance with medication (intervention 46%, control 35%,  $p = 0.130$ ) and attendance at epilepsy clinic (intervention 84%, control 92%,  $p = 0.085$ ). At both one year (Mills 1999a) and two years (Mills 1999b), an evaluation of a primary care-based specialist epilepsy nurse reported five outcomes relating to the appropriateness of medication. For four of these ('taking one type of anti-epileptic drug', 'feel very well controlled by drug', 'report very important to take tablets exactly as prescribed' and 'reporting side-effects from drugs'), there were no significant differences between intervention and control groups at one year (Mills 1999a) or between those who had accessed the specialist epilepsy nurse and those who had not at two years (Mills 1999b). Intervention participants were, however, significantly less likely than controls to have reported never missing taking their anti-epileptic medications (OR 0.48, 95% CI 0.24 to 0.94,  $P = 0.032$ ) at two years. There was no significant difference for this outcome between those who had accessed the specialist epilepsy nurse and those who had not (Mills 1999b). This also raises questions about the duration of the effect of ESN support and whether the intervention should be sustained. All results of this evaluation from both studies should be interpreted with caution because of the weak study design and the large number of comparisons made, which increase the likelihood of a significant finding occurring by chance.

At six months, the evaluation of a general practice-based epilepsy nurse reported on the 'appropriateness of medication supplied' (Ridsdale et al 1997). This outcome was in fact a measure of the number of occasions when the specialist nurse felt that medication plans could be improved and noted this in the patient record. The trial reported that the epilepsy nurse found that 11.1% of participants required medication management changes. However, authors did not give any information on whether these proposed changes were or were not appropriate, and there was no control group comparison.

Three RCTs did not report on the appropriateness and volume of medication prescribed (Helde et al 2005; Ridsdale et al 1999; Ridsdale et al 2000).

Pfaffin et al (2014) investigated the efficacy of epilepsy nurses on satisfaction with counselling about epilepsy in an RCT. The ESN group received counselling according to their needs and this was assessed using a questionnaire. The questionnaire covered a range of topics including the therapeutic issues, risks and adverse effects of medication and other therapies. The nurses provided leaflets and other written information. The effects on satisfaction with information and advice, coping and epilepsy knowledge were also statistically significantly improved in the intervention group.

However, another RCT Noble et al (2014) found no improvement in medication management skills in patients receiving a nurse led self-management intervention compared to those in a treatment-as-usual group. The intervention consisted of 2 one-to-one sessions with an ESN plus treatment as usual which may have been too brief to lead to measurable changes within the 12 month follow-up period.

A survey of GPs found that those with access to the nurse specialist services tended (75%) to ask advice as to the most appropriate drug (Lambert et al 2001). An analysis of case notes of 100 women of child bearing age found that the introduction of a nurse-led clinic for women

demonstrated an increase in the amount of information given and has also provided a better basis for evaluating that information. There was a 30% increase in advice given about contraception, 89.7% of those on enzyme-inducing anti-epileptic drugs were informed of the risk of failure of the oral contraceptive pill compared to 53.2% before the intervention. Information given about the risks associated with experiencing generalized tonic clonic seizures during pregnancy, as well as the need for compliance, increased by 40% (Lewis et al 2006).

Patients with refractory epilepsy were asked their views of an ESN service at a tertiary care hospital. 59% of contacts with the ESN were for medication advice and about side-effects. Patients described the support for themselves and for their GP who also contacted the service for advice about the patients' medication regimen as "immeasurable" (Hosking et al 2002). Patients also described feeling more confident with their medicines and trying different regimes (Hoskin et al 2002).

## Monitoring (ongoing assessment, review of treatment, symptoms, needs, adjusted provision of clinical support)

### Need

Adults with epilepsy should have a review at least once a year by their GP or specialist. (Josephs 2005, NICE 2012). However, monitoring and ongoing support may need to change depending on life stages that PWE encounter. For example, women with epilepsy may need to be seen pre-conceptually and more frequently during pregnancy. A prospective study of 300 pregnant women with epilepsy, carried out in the north of England, found that, when epilepsy management was supervised by their general practitioner, control of seizures was poor, compliance with medication was

variable, and methods of pre-conceptual counselling were ineffective (Faigrieve et al 2000). There is evidence in primary care contexts that most women wanted advice about pre-conceptual counselling and by implication were not receiving it (Lambert et al 2001). Successive general practice audits have illustrated the lack of organized care for PWE with follow-up and monitoring for patients has been shown to be poor (MacDonald 2000). Some argue that there are insufficient numbers of ESNs to provide the level of monitoring that is needed and some groups, such as young people moving into adult service, may receive insufficient help (Davis et al 2015).

### Role

Continuity of care is a key concept for epilepsy nurses and the way they monitor and deliver care. Patients were monitored for AED efficacy and side-effects. The manner in which monitoring is undertaken and what is monitored will vary and be informed by patient need. It may be necessary for specialist nurses to undertake monthly monitoring of the effects and compliance with medications (Axon 2007). ESNs monitor a wide variety of patient symptoms, treatments or events - seizure-related hospital admission, seizure-related injury, improvement in seizures (Hosking 2004).

These are all aspects of ESN monitoring given in the context of the treatment of refractory epilepsy. Each week the ESN responds to a large number of calls (see above – Hosking 2002). Monitoring may relate to tasks across contexts and service boundaries. ESNs might be regularly engaged in conducting assessments and care plans; receiving referrals from primary and secondary care; assessing in nurse-led clinics or in patients' homes or workplace and planning care in partnership with the patient (Mantri 2008).

Another key aspect of monitoring was to make contact with the patient between appointments with specialist services (Chisanga 2007). Chisanga (2007) points out how nurses working in general practice have a fundamental role to play in ensuring that women with epilepsy are

supported between appointments in specialist services, for example women who have epilepsy and are going through the menopause.

The systematic follow-up and ongoing monitoring of the impact of care and treatment on the PWE was another clinical aspect of the ESN role requiring knowledge of local and national services and a high degree of epilepsy specific knowledge. Different models of care had different means of monitoring and the frequency of monitoring PWE. A combination of outpatient, inpatient and phone contact with consultations recorded into medical records (Hosking et al 2002). The monitoring role will include screening for behavioural health disorders and side-effects of treatment (Hill et al 2017), ordering and interpreting investigations (Ring et al 2016). Monitoring of patient progress includes providing continuity of care and possible referrals (Lambert et al 2001, DeVries-Rizzo et al 2016, Kwan et al 2002). ESNs monitor patients between appointments with specialists (Chisanga 2007). Patients with refractory epilepsy are monitored for AED efficacy and side-effects efficacy and side-effects and some specialist nurses advise patients on medication changes to improve treatment (Hosking 2003, Hosking 2004).

It is also possible that nurses take on other roles such as therapeutic psychosocial intervention for young people for instance. This may have a monitoring function. In an RCT of such an intervention (Dorris et al 2017) the study concluded, “Improvements in participants’ sense of confidence, inclusion, and may indicate that group therapies may be important in preventing or moderating the development of more serious later mental health disorders”.

The ESN undertakes monitoring through phone calls and ordering and interpreting investigations (Hosking et al 2016, Ring 2016). Hosking et al (2002) described the role of the ESN at a large tertiary referral epilepsy centre. Each week the ESN responds to up to 70 telephone calls and provides an average of eight out-patient and three inpatient consultations and telephone consultations are documented onto a

standardised form, which is reviewed by the Consultant before being copied and filed in the patient medical records (p. 495, Hosking et al 2002).

Nurses used telephone contact as an assessment tool and encouraged patients to call for monitoring during complex medication changes to discuss progress (Higgins 2006). The same study remarked ESNs would telephone those patients who had previously proven less motivated to access the service. Telephone calls were usually returned within 24-48 hours. The nurses can then follow-up by querying for side-effects. In practical terms this means documentation of query of side-effects or offer of intervention for side-effects according to the quoted American Academy of Neurology updated quality measures (Hill 2017). These were all classified as clinical management tasks. ESN telephone contact was due to: AED side-effects, ongoing seizures, recurrence or exacerbation of seizures, an improvement in seizures, a seizure-related injury, AED overdose, new seizure presentation and prolonged post-ictal aggression.

### **Evaluation/Impact**

A qualitative study (Higgins et al 2006) found that most used the telephone as an assessment tool and encouraged patients to call for monitoring during complex medication changes to discuss progress.

Greater acceptability of follow-up and attendance for monitoring was improved with the introduction of an epilepsy nurse specialist based in general practice. A survey of patients receiving monitoring by an ESN based in primary care found that there was a 71% attendance rate at the check-up and review. 92% of those who responded indicated that they would return for an annual appointment with a nurse. Given that 70% of people with epilepsy are not managed by hospital-based specialists, and therefore rely on the general practitioner for epilepsy care, general practitioners and practice nurses are best placed to regularly review these patients (MacDonald et al 2000).

A survey of GPs found that they routinely reviewed their patients annually, however, those in the practices with a specialist nurse believed they assessed them every 6 months (Lambert 2001). As well as improving existing service provision, the role of the ESN may also reduce waiting times for people with epilepsy to see a specialist or general neurological consultant (NHS, 2008), and help to reduce A&E admissions (NHS, 2008) cited in Eastwood et al 2008.

One commentary summarises issues arising from the International League Against Epilepsy (ILAE) symposium (UK branch). Core aspects of the role of the nurse included “working across professional and organisational boundaries, the perceived objective of the nurse specialist is to consolidate epilepsy care by liaising with multi-disciplinary health professionals and coordinating patient care, in addition to informing and supporting patients”. The authors also comment on how the role of the nurse was expanding as some nurses started to fulfil a diagnostic and therapeutic role.

## Personalised care plans

### Need

We identified no literature in respect of the need for personalised care plans, though there is overlap in the sections looking at the ESN role in liaison and coordinating services and providing access to specialised care.

### Role

The role of the ESN in developing personalised care plans did not feature a great deal within the literature. However, PWE need ongoing rehabilitation with personalised, comprehensive care plans including information about diagnosis, investigation, prognosis, medications, efficacy, side-effects, adherence, drug interactions, free prescriptions, epilepsy triggers, lack of sleep, alcohol, drugs, stress, first aid management, women’s issues if applicable, safety in the home, driving, stigma, anxiety, depression and support organizations (Ridsdale 2008, NICE 2012, 2018).

In the RCT evaluating the ESN role in following up PWE who had attended an emergency department, the role of the ESN included developing personalised care plans with the patient, helping them set goals (e.g. to socialise more, be comfortable talking about epilepsy, and less fearful about seizures), evaluating progress and providing the patient with the opportunity to ask questions (Noble 2014). The ESN, specialised in caring for children with epilepsy, liaises with other health professionals and the family to ensure a treatment plan meets the needs of the child (Greenhill et al 2002).

Developing personalised epilepsy safety education plans were also part of the nurses role in the model of care described in the evaluation by (Hill et al 2017) where nurses worked in joint nurse practitioner and physician teams in a specialist tertiary centre in the United States.

Development of care plans was also described within ESN clinical management (Mantri 2008). This activity featured within the community-based specialist liaison nurse service, developed in Doncaster (Taylor et al 1994).

### Evaluation/Impact

The use of, and effect of, developing care plans for patients has not been formally evaluated in the existing literature. “Care plans” may mean different things to different health and social care professionals, as well as varying across different models of ESN working.

## Point of contact

### Need

Epilepsy nurses are frequently the first point of contact for patients, and it is this ready access to a specialised professional, which is highly valued by patients. Provision of 250 ESNs across the UK fell far short of the identified need for over a thousand in 2015 (El-Radhi et al 2015) suggesting that many patients are not able to access specialist support, and that existing services are spread too thinly, potentially limiting their effectiveness and increasing work stress for health professionals.

## Role

The ESN appears to adopt a role as a first point of contact on issues relating to epilepsy and some describe offering a telephone helpline providing crisis prevention and management. (Greenhill et al 2002, Appleton & Sweeney 1993, Higgins et al 2008). They may also act as a point of contact for healthcare professionals looking for specialist support.

## Effectiveness/Impact

A questionnaire to GPs to determine their referral practices for adult patients with epilepsy suggested that the introduction of such and ESN can help increase awareness of the difficult issues involved in the treatment of epilepsy and reduced their need to get further advice (Lambert et al (2001). However, the number of questionnaires from the practices with input from the ESN was too small to draw firm conclusions.

## Seizure and risk of seizure management

### Need

The 'epilepsy treatment gap' described by the Joint Epilepsy Council (2005) refers to the 48% of people with epilepsy who are not seizure free, when 70% of people with epilepsy could be seizure free with optimal treatment (APPG 2007). Each year approximately 1,200 people die from epilepsy and it is estimated that about 500 of these deaths could be prevented. The best way to prevent SUDEP is to bring seizures under control. (Josephs 2005).

Seizures are a great concern to patients and can have a negative impact on physical, psychological and social functioning, disrupting family life and adversely affecting the quality of an already compromised life (Campbell 2005).

A survey of school nurses in the USA, to assess perceptions of barriers to optimal management of seizures in schools, identified a need for a specific seizure plan for each child and education on intranasal midazolam and vagus

nerve stimulator magnet use as needed (Terry 2016).

### Role

ESNs have various roles in the monitoring of seizures and addressing the risks PWE face that may differ within different models of care. These include working with caregivers, ensuring they know first aid actions and when to seek medical help (Kwan et al 2000). They also include working on safety precautions within the home and work environment. Accurate monitoring of seizures is also important for appropriate treatment planning. NICE guideline for the treatment and management of epilepsy (2004) states that anyone with epilepsy should be fully involved in all discussions about the benefits and risks of any treatment programme. This should include a care plan, which should explain what other options are available if the first drug does not stop the seizures (Josephs 2005).

The aims of epilepsy management are: (1) To reduce seizure-related morbidity, such as head injuries, burns and scalds, helping cut the number of A & E admissions. This may be improved by education on safety, risk taking and first aid. (2) To reduce seizure-related mortality, such as drownings and accidents, and to raise the awareness of SUDEP. (3) To reduce treatment-related morbidity, by monitoring side-effects. (4) To reduce psycho-social morbidity and enhance quality of life in the community (Graydon 2000).

Seizure risk aversion may be enhanced by the ESN, who plays a pivotal role in providing a close link with children with epilepsy and their families. El-Radhi et al (2015) provides several examples of how this bond manifests, for example: the ESN has an important role in ensuring better compliance with AEDs and addressing any adverse family dynamics, misinformation or stigmatisation.

Personalised epilepsy safety education, with documentation of discussion of injury prevention, potential seizure precipitants (Hill et al 2017). Provision of information about safety precautions, with attention to specific risks such

as stairs, glass doors, furniture, trailing electrical leads, cookers and bathtubs (Kwan et al 2000) are key aspects of the ESN role.

The ESN informed patients about the names of their seizures and syndrome and having reviewed their existing medical records, probable cause. In terms of advice concerning seizure first aid, the ESN informed the patient what should and should not be done when a seizure occurs and, as a permanent record, provided the patient with an information pamphlet on first aid management of seizures developed by the UK's National Society for Epilepsy (Noble et al 2014, Ridsdale et al 2000b, Hill et al 2017). The nurse asked about the frequency of epilepsy attacks and how patients managed their drugs (Ridsdale 1997). Monitoring seizures and helping patients to use systems of recording seizures was also described as part of the ESN role (Taylor et al 1994, Matri et al 2008b, Hosking 2004).

### **Evidence of effectiveness/impact**

Evidence from systematic reviews (see appendix 2) does not suggest that those models of ESN service measured reduced incidence or severity of injury in patients receiving the ESN service. Audit results suggest, however, that the ESN service enhances the management of patients with refractory epilepsy, patients understanding of epilepsy issues, confidence and ability to make decisions about treatment (Hosking 2004).

In an audit of contacts made to an ESN by patients (the majority of whom had refractory epilepsy) 60 % were for urgent advice. Ongoing seizures and seizure worsening, which occurred both in relation to and in the absence of recent AED changes were the most frequent causes for contact (Hosking et al 2004). Advice about seizure management also a feature of a telehealth service provided to PWE in remote rural and island locations (Bingham 2009). Again this supports the evidence of the role of the ESN as an important point of contact for PWE.

### **Qualitative Evidence**

Campbell (2005) provides a commentary written from the perspective of an ESN. The

discussion looks at patients in Scotland with brain tumours and epilepsy managed through a nurse-led seizure clinic in a cancer centre. Seizures have a negative impact on physical, psychological and social functioning. The risk of a seizure can affect an already compromised life.

Graydon (2000) points out the general aims of epilepsy management policy include an aim to reduce seizure-related morbidity, such as head injuries, burns and scalds, which will help to cut the number of A&E admissions; and an aim to reduce seizure-related mortality. Specialist nurses can talk with people with learning disabilities and understand if they are frightened by their seizures and how they feel before and after a seizure. Josephs (2005) argues that nurses can help encourage patients back into the system. For example, nurses can review anti-epileptic medication and level (which may not have been reviewed for years). Nurses can also help to identify more suitable medication, or combination of medicines that would improve seizure control.

## **Service delivery/ coordination/development**

### **Need**

The literature shows a historical and current deficit in ESN and a lack of recognition of the impact of this on the provision and the development of local epilepsy services (Collins et al 2009). Opinion and news pieces highlight the demands on the service with ESNs carrying excessively large caseloads (Northern 2008) (although the optimal number of patients per full-time equivalent nurse has not been established).

### **Role**

Coordination of services is closely linked to an ESN liaison role, but also suggests a leadership role in service delivery. ESNs may take a lead in the way local healthcare services are organised and run, providing a patient-focused link both within and between primary and secondary care, as well as with other agencies, so are able



to take the lead to develop services (Higgins 2008). They can help to optimise the skill mix for care (Kwan et al 2000). Examples of nurses developing services include creating registers of patients with active epilepsy to facilitate monitoring and recall systems and establishing primary care based clinics (Ridsdale et al 2000a, Ridsdale et al 1997, Kwan et al 2000, Mantri et al 2008a).

### **Evaluation/Impact**

A mixed methods study (Higgins et al 2018), including data derived from interviews, observation and documentary analysis, identified key themes in relation to the ESN role in leadership. This included a role in initiating new services and practice developments. ESNs identified gaps in services, developed business cases, sourced resources, collaborated with the key stakeholders and sought approval through relevant governance structures to initiate and implement new services, both within and outside their organisation. The ESNs contributed to the development of a comprehensive epilepsy service through developing and expanding nurse-led clinics, such as Vagal Nerve Stimulation clinics, and Rapid Access Clinics, new services such as the Telephone Advisory Line and outreach clinics for specific patient groups such as people with intellectual disabilities and pregnant women. They also found that the ESNs were active in initiating collaboration with other practitioners and leading the development and evaluation of care pathways, clinical guidelines and standard operating procedures. Guidelines for care of PWE in emergency departments, as well as Rapid Access Clinics and the provision of telephone advice, was viewed by members of the multi-disciplinary team (MDT) and family as an important strategy in reducing hospital admissions and family burden. The ESN was also instrumental in the collection of data to aid development of services.

The data from the Higgins et al (2018) study also demonstrated the influence of the ESN on issues related to epilepsy service provision, clinical policy, practice and professional development through membership of national and international committees, and also through

advocacy work, lobbying and empowering patients and their families to lobby at local and national levels for better services.

A questionnaire sent to randomly selected health professionals working in primary and secondary care in England. Respondents felt that the role of a nurse specialist was key to the successful implementation of good practice guidelines (Frost et al 2003). The role of the ESN in promoting joint working and coordinated care was indicated in questionnaire responses sent to GPs (Lambert et al 2001).

In terms of cost-effectiveness there is RCT evidence and anecdotal evidence that the ESN is a cost effective intervention and therefore improves resource use. When an ESN service was started at a large tertiary referral epilepsy centre, it received approximately 300 patients who were referred in the first 6 months, freeing up scarce medical time (Hosking et al 2002). Much of the success of emerging models of care is credited in part to the implementation of ESNs who are key players in developing and coordinating the service (Foley et al 2000). Noble et al (2014) also evaluated the effectiveness of an ESN intervention in a nonrandomised controlled trial. Consistent with the findings of the Bradley et al (2014) review, no significant effect of the intervention on emergency department visits at 12 months was identified. However, the average service cost for intervention participants over follow-up was less than for patients receiving usual care (on average £558 less), in part due to the shorter duration of hospital admission. The ESN role in this study consisted only of two one-to-one sessions with an ESN. It may be that a more extensive intervention would have reduced the cost-effectiveness, but may also have led to measurable improvements in other outcomes.

An article in the Nursing Times (Clewes et al 2010) reports an audit of data collected by the Sherwood Hospitals Foundation Trust showing that the appointment of an ESN to work with children with epilepsy and their families has halved hospital admissions for children with epilepsy. The data showed that the ESN

involvement with patients increased dramatically in her second year in post, with more than twice as many home visits, ad hoc outpatient clinics and crucially telephone consultations. The ESN also provided education for schools and other childcare facilities so they were better able to support children with epilepsy more effectively.

## Specialised clinics and access to specialised help

### Need

Healthcare professionals, PWE and the carers and families of PWE have described a lack of access to specialised services. A lack of access to consultant neurologists and specialist care was described as a limitation of service provision in a survey of GPs, 95% of whom felt that the provision of an Epilepsy Clinical Nurse Specialist would help alleviate the problem (Neligan et al 2006). Parents of children with epilepsy also expressed a need for specialist community children's nurses and a need for children with epilepsy to be seen in a specialist clinic in an evaluation of existing service provision in South Tees (Stewart et al 1998).

However, provision of the ESN service can also become difficult to access if it too is inadequately resourced. A qualitative study (Smithson et al 2006) exploring the experiences and needs of patients and carers affected by neurological conditions, including epilepsy, found that specialist nurses are highly valued by patients and their families but that the service is overstretched and access is difficult.

### Role

A theme that runs consistently through the literature is the value of the ESN role in interfacing and traversing many of the settings in which PWE have to receive care (primary secondary, secondary and tertiary care, and home) and also in their day-to-day lives (school, work, recreation, and home). One of the very valuable aspects of the ESN role, is that they can liaise and work across traditional boundaries and seek to prevent some of the problems in

communication and continuity of care plans, changes in treatment, consistency in care, conveying of information that occur when patients are at points of transition or change. Through the provision of specialist clinics, telephone access and often home, school, or work place visits, PWE and their families are able to access expertise that is both local and provided more rapidly.

### Evaluation/Impact

Bradley et al (2016) undertook a systematic review of care delivery and self-management strategies for adults with epilepsy. The interventions included a specialised or dedicated team or individual for the care of epilepsy patients. The ESN might be based in general practice, or part of a specialist epilepsy clinic in hospital or in general practice. The review included seven RCTs that had evaluated the effects of specialist nurse practitioners (Helde et al 2005, Mills 1999a; Mills 1999b, Ridsdale et al 1997, Ridsdale 1999, Ridsdale et al 2000, Warren 1998). Details of the included studies that evaluate the ESN role are summarised in table 2. They found mixed results for some outcomes, but concluded that there is evidence to support the role of the ESN.

There is evidence that patients express high levels of satisfaction with the ESN service. A systematic review of studies measuring satisfaction with epilepsy care (SEC) (Wiebe et al 2014), including 25 primary studies, found that attending a nurse-led epilepsy clinic gave high ratings of satisfaction with information and communication. Where newly diagnosed patients are offered appointments with a specialist nurse they are likely to accept the offer (81% attendance) (Ridsdale et al 2000).

Provision of nurse-led specialist services requires investment in training. Mills et al (2002b) explored the experiences, feelings and perceived problems of providing new specialist nurse services from the nurse's perspectives. The responses highlight the additional training needs ESNs expressed, including improved preparation for working in a primary care setting. Making these improvements would

impact the outcomes of care and highlights again the risk of assuming that evaluations at one point in time would be an accurate reflection of the care provided at other times.

Particular groups were shown to experience benefits from nurse-led epilepsy clinics. One study (Lewis & Smith 2006) found improvements in the information received by women with epilepsy of childbearing age about gender-specific issues following attending the ESN clinic. Case notes of 100 women attending epilepsy clinics were examined before and after the introduction of specialist nurse-led clinics. The introduction of a nurse-led clinic for women demonstrated an increase in the amount of information given. There was a 30% increase in advice given about contraception, 89.7% of those on enzyme-inducing anti-epileptic drugs were informed of the risk of failure of the oral contraceptive pill compared to 53.2% before the intervention. Information given about the risks associated with experiencing generalised tonic-clonic seizures during pregnancy, as well as the need for compliance, increased by 40%.

Several papers describing evaluations and audits of local initiatives described various benefits of introducing a specialist epilepsy nurse service including; families seen in a time-efficient manner without the need for extra hospital or clinic visits (Mar et al 2005), rapid access to evaluation following a blackout (Petkar et al 2011), higher quality of service, reduced waiting times, improved continuity of care, ready accessibility to support and the identification of compliance problems and AED side-effects (Stephen 2003), unrestricted access to an ESN based in a tertiary centre for patients with refractory epilepsy (Hosking et al 2004), nurse run clinics were feasible and well attended (Foley et al 2000), and the development of ESN-led specialist clinics has been met with a high degree of acceptability and patient satisfaction (2000).

Qualitative evidence also supports the finding that patients want treatment from health professionals with a specialised knowledge of their condition and that specialist nurses'

knowledge was highly regarded by patients. Indeed, many patients expressed a preference for seeing the ESN over any other clinician (Smithson 2006, p.206). Findings suggested participants thought much of the follow-up epilepsy management at primary care could be taken on by general practice nurses with support from their epilepsy specialist nurse colleagues in the specialist centres. Participants wanted rapid access clinics (patients currently encounter poor access) (Varley et al 2010).

Descriptions of services and their impact demonstrate how the role of the ESN, and their role as a first point of contact, providing a dedicated telephone line, and being available to see patients who are in hospital as well as those attending out-patient clinics (with hour-long appointment times given to patients) had led to improved access to services for patients (Hosking et al 2002).

Hosking et al (2002) described the role of the ESN at a large tertiary referral epilepsy centre (the National Hospital for Neurology and Neurosurgery, London). The ESN had considerable prior experience and training including an MSc in Epileptology. Patients accessed the ESN by telephone, as inpatients or in outpatient clinics, which had hour-long appointment times. Inpatients were seen during their hospital stay and the ESN was the first point of contact for postsurgical patients after discharge. A dedicated telephone line was also available. Approximately 300 patients were referred to the ESN in the first six months of the service. Sixty per cent of patients contacted the ESN for urgent medical advice. A questionnaire was posted to 193 patients (69% responded). Important aspects of the service were access by telephone to medication advice, information, support and adequate time to discuss issues. The ESN improved continuity of, and accessibility to, care for patients. The ESN also freed up scarce medical time.

For PWE, access to services can present particular barriers as they are more restricted in terms of transport, physical disability or significant intellectual disability. By localising

services, and providing specialist support in nurse-led clinics, the ESNs improved access to specialist service and also reduced the geographic variation in the availability of, and access to services which leads to considerable inequality for PWE and their families (Higgins et al 2018 - mixed methods study).

A national survey of UK ESNs (n=76) to identify their perceptions of roles and contribution to care (Goodwin et al 2003) indicated that 31 (39%) held nurse-led clinics. Nurse led clinics were defined as ‘an independent organised clinic setting providing on-site and off-site services with the administration, supervision and coordination of care by registered nurses and with formal protocols ensuring the arrangement of consultation or referral as needed’. (Goodwin et al 2004). ESNs working in the paediatric field were less likely to manage a nurse-led clinic. Nurse-led clinics were mainly managed by those nurses employed on a G or H grade, although length of service did not appear to be a factor. The degree of autonomy of the ESN within the nurse-led clinic also varied considerably, with some nurses taking responsibility for all decisions made, whilst others only made a small contribution to decision making.

Attendance at a nurse-led clinic is valued by most patients (Ridsdale 2000), improves compliance and provides high-quality, cost-effective care. The models of nurse led clinics are varied in the literature. Hill et al (2017) evaluates a clinic run for patients with newly diagnosed epilepsy jointly between the specialist nurse practitioner and the physician. The nurse practitioner - physician team care model saw, on average, 3 more patients per clinic session. They also were more likely to gather more information about side-effects, safety, education and screening for behavioural disorders when compared to the physician only model. The two care models performed similarly in all clinical outcomes. Greenhill et al (2001) also describes different models of care that exist and highlights how the ESN supports the specialist physician in epilepsy care, the non-specialist physician and the primary care physician in patient communication.

The description of the development of a district level epilepsy service (Taylor et al 1994) found that as the service developed, a model of epilepsy care based on a special clinic was improved by developing a community-based specialist nurse model and locally agreed guidelines. The ability of the nurse to move freely, visit homes, schools, workplace and general practice is key to their effectiveness. It is clear that current RCT evaluations have not explored the effectiveness or different models of specialist nurse care delivery. In other models the specialist clinic is multi-disciplinary, with the ESN a key part of the team, but not working within the community also (El-Radhi et al 2011).

Innovations described within the literature include an ESN using telemedicine to reach PWE in rural or island communities (Bingham et al 2009), and a nurse specialist-led seizure clinic for patients with brain tumour related epilepsy and their carers (Campbell 2000). Service innovations developed in response to unmet local need, to improve access to care, to improve continuity and provide support.

## Discussion, conclusions and limitations

We undertook a systematic mapping review to explore the evidence related to ESNs as described and evaluated within the literature. The published literature we identified for this review spanned just over three decades from 1986 to 2018. The findings suggest that the role of the ESN has largely been innovated and pioneered in the UK. It is also apparent that it is not a single role, providing the same services for one type of patient but has evolved in different places in different ways. This has meant that different ESN roles may be further specialised in fields such as child health, community nursing, diagnosis and prescribing, which will shape how the ESN service is delivered.

We included both research and opinion pieces in order to ensure we were able to identify innovations in practice that may not have been formally evaluated. We included a range of study

designs, recognising that RCT evaluations have limitations in determining the effectiveness of the ESN role. Other study designs are valuable for allowing insights into the scope of the role (surveys, questionnaires, observational studies) and also the experiences of patients using those services (qualitative designs). Qualitative research also allows exploration of the views of health professionals and families so is useful for gaining insights into the acceptability and satisfaction of a service, but also ways it might be improved and how that might be achieved.

Although a small number of RCTs have been carried out to evaluate the role of the ESN, they have only evaluated a small range of ESN services and models of service delivered over relatively short intervention periods and using a limited number of possible outcome measures. It is apparent from the literature that there is some considerable heterogeneity in the role. The role within the multi-disciplinary team (MDT), the settings in which they work, the client group that is the focus of their practice, caseload size, previous training, prescribing permission, existing neurology services will all vary. The ESN role has clearly evolved and developed differently to respond to local needs and the expertise of the nurse themselves, meaning that there is currently no consistent level of provision for patients. Different types of patients clearly have different needs, and particular groups have been identified in this review including:

- People with epilepsy and learning disabilities
- Children, young people with epilepsy and their families
- Women with epilepsy
- People in prison with epilepsy
- People with poorly controlled epilepsy

It is perhaps unhelpful to think of the ESN role independent of the type of patients with which they are working. This is important for planning services, as it will also identify key groups whose needs are not being met. The provision of an ESN may not mean that all the needs of the range of groups of patients with epilepsy are being addressed.

The most frequently used quantitative outcome measure in quantitative evaluations of epilepsy services is seizure frequency. When measured in studies evaluating the ESN role it consistently fails to show any significant improvement among patients receiving care from a service that includes an ESN. (Mills 1999, Warren et al 1998, Ridsdale et al 1997, 1999, Ridsdale et al 2000, Stephon et al 2003, Ring et al 2018). While acknowledging that narrow medical outcomes, measured at specific time points, fail accurately to assess the impact of the ESN role this finding does raise the question why reductions in seizure frequency were not observed. It is worth considering research that explores why this is the case and how might the ESN role be developed to address the morbidity and mortality associated with poorly controlled epilepsy.

There is strong evidence from the UK suggesting that the ESN role is cost-effective. There is also strong evidence derived from qualitative studies that consistently demonstrate how highly valued the service is to patients who benefit from ready access to a specialist who they regard as highly knowledgeable. Their role is also unique within the specialist epilepsy team as they are the only professionals who work across the boundaries that patients themselves must navigate, such as community and hospital-based services, home and school, as well as the transition from childhood to adulthood. The ESN is able to offer access to their services to ensure access to specialist care is made as easy as possible by utilising telephone access, rapid access clinics, and specialist clinics in primary and secondary care for example. The value of the service is perhaps further indicated by the suggestion within some of the opinion pieces, that the service quickly becomes overburdened and ESNs carry excessively large caseloads. The role is clearly valued by other health professionals who also benefit from their expert knowledge of epilepsy and good understanding of individual patients.

The evidence supports a greater role for the ESN in liaising with GP's. Clinical nurse specialists in epilepsy could have direct links with primary health care (PHC) teams and

allowance could be made for their attendance at GP surgeries for this purpose. The use of clinical nurse specialists is probably the most cost-effective method of improving quality of care if they can develop effective liaison with PHC teams (Brown et al 1993). One of the very valuable aspects of the ESN role, is that they can liaise and work across these settings and seek to prevent some of the problems in communication and continuity of care plans, changes in treatment, consistency in care, conveying of information that occur when patients are at points of transition or change.

Throughout the review, we sought to identify gaps in knowledge and to identify areas for further research. Advice and information giving to patients featured frequently within the ESN role. However, there was little aligning how this information is given, reinforcement of information, frequency of contact, training needs of the ESN to the effective self-management by patients. The goals of patient education in epilepsy and the use of structured approaches to information giving was an area that appeared to be lacking within the literature. There is also mixed evidence in respect of its effectiveness in leading to improved self-management. Exploring what patients need and the barriers they face in terms of using information also appears to be inadequately addressed in the literature. The needs of patients in terms of self-management and the extent to which the models of ESN service delivery maximise opportunities to reinforce self-management behaviours is not clear. The optimal frequency of contact, and what approaches might best reinforce what has been learnt, would be useful. Also, the role of peers and promoting group support networks and community teaching is little explored in the literature.

Persistent gaps in understanding relate to which features of the ESN model of practice, background skills and training, and the working arrangements in which they must practice (such as caseload) contribute to effectiveness of the role. Further research focusing on which elements contribute to effective delivery of effective care should be undertaken.

There appear to be features of the role that are unique but are rarely described within the literature and the effects of which are not readily measured. This includes their role in ensuring support for PWE, their families across the many barriers to services where care often becomes fragmented (such as between hospital and home, child to adulthood, home and school and workplace). It is also unclear what the learning needs of ESNs are in respect of delivering effective patient education. ESNs' own educational needs, and resource support to continue to be effective, and increase in effectiveness as patient educators and supporting self-management needs to be explored. This is particularly the case as caseload size may influence the effectiveness of their role as educators.

There is little published evidence on outcome measures as opposed to process measures. Trials with adequate sample size and long-term follow-up are necessary to identify whether nurse monitoring with advice and counselling can benefit patients in terms of epilepsy self-management in the long run (Ridsdale 2000).

It is notable that the majority of the literature includes research and descriptions of the ESN role within the UK context. There is much less published work describing the impact of this service in other countries. The reasons for the evolution of the role in the UK and the opportunities to make comparisons with other health systems may be an opportunity to explore the effectiveness of the role.

The ESN role in medicines management is very varied. We don't know which model is most effective. Different models of working may mean that some liaising and linking elements need to be strengthened. How adequately are nurses equipped and trained to reach their potential in this role? Is this part of their role well enough recognised and facilitated? Are the requirements for 'integrated care' met?

Debate needs to focus on the level of skills, education and knowledge that the ESN requires to take on a diagnostic role. Objective outcome

measures and continuous monitoring of practice are also required. Patient outcomes need to be measured over a longer period of time in order to assess the impact of a nurse led service on long term attitude to treatment, care and diagnosis if continuous care was given by the ESN. There appears to be differences in the extent to which ESN are involved in joint working with clinical neurologists and their role in contributing to the process of diagnosis and treatment planning.

### **Review limitations**

The aim of this mapping review was to undertake a broad overview of the existing published literature rather than to perform a close analysis of a smaller body of work addressing a specific question. This mapping review therefore carries several limitations. While we endeavoured to identify and locate all relevant literature, resource constraints limited the extent to which we could fully explore evidence that was not published in journals and the extent of our search of the 'grey literature'. Our analysis of the identified literature did not include detailed, double blind data extraction. We relied on single data extraction for a limited number of features from the paper allowing us to identify the type of research that had been undertaken, the setting of the study and features of the ESN role.

We did not undertake line by line coding of the papers and hence we may have missed elements of the ESN role. We hope that stakeholder involvement throughout the project has minimised the risk that key sub-roles within the overall ESN role were omitted.

Creating the evidence map and seeking to map evidence to the roles was iterative and relied on subjective decision making by the reviewers. Many of the outcomes measured do not precisely align with specific sub-roles.

Indeed, outcomes such as cost-effectiveness, or patient satisfaction cut across many areas of the ESN role and the EGM is unable to reflect their pervasive nature. The mapping review offers guidance and suggestions, highlights gaps in existing knowledge and research evidence as well as where evidence of the ESN role is effective and where the role has a positive impact on the health and well-being of people with epilepsy

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## Further research

### The ESPENTE report - Evidence gaps and possible next steps

Role	Possible gap identified	Potential areas of future research
<p><b>Models of practice</b></p>	<p>ESN operate within different models of practice but no strong evidence of which is best, or leads to better patient outcomes. There may also be patient groups who do not have access to nurse specialist provision.</p>	<p>Establishing a clear picture of the different groups of PWE and which groups might be missed even if ESN provision is made would be valuable. Exploring the different training needs of ESN working in these different contexts, particularly ensuring that ESN who have developed expertise in secondary care settings are equipped for working in community settings.</p>
<p><b>Advice and information</b></p>	<p>Can ESN input help improve compliance with medication?</p>	<p>While patients receiving ESN input appear to have better knowledge of their condition and medicines, there is a lack of robust evidence that this translates to improved compliance with medication (see appendix 2) or reductions in seizure frequency. There needs to be research exploring ways in which the ESN can provide information but also support self-management. Developing theory based self-management programmes that ESNs can deliver with appropriate follow up and comparing its impact would be a valuable development to the services. Examples of nurses delivering these initiatives can be seen in the development of self-management programmes in diabetes types 1 (See for example DAPHNE) Campbell, F, Lawton, J, Rankin, D, Clowes, M, Coates, E, Heller, S, &amp; Breckenridge, J P (2018). Follow-Up Support for Effective type 1 Diabetes self-management (The FUSED Model): A systematic review and meta-ethnography of the barriers, facilitators and recommendations for sustaining self-management skills after attending a structured education programme. BMC health services research, 18(1), 898. <a href="https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3655-z">https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3655-z</a></p>



Role	Possible gap identified	Potential areas of future research
<p><b>Assessment</b></p>	<p>Use of nursing competency frameworks being more cost-effective than services that don't use these frameworks. Is this a promising area for research? How could we research the most cost-effective sub roles for nurses?</p>	<p>How do you go about identifying relevant outcomes to measure the ESN role? Assessment has many purposes and so measuring its impact is very hard. It also may have different purposes for different PWE and at different times.                      Outcome measures include                      A realist review of 'what works in what context' might be helpful approach to identifying the factors that contribute to effectiveness.                      Also work on exploring why 'seizure frequency' fails to capture changes is worth asking.                      Can the competency framework be applied to other types of patients with epilepsy and provide a guide for training needs.                      ESN role in assessment in different contexts, such as in A and E which is linked to their role in assessment appears to be cost-effective but this has not been subject to a rigorous evaluation.</p>
<p><b>Carer support</b></p>	<p>There is very little research on this aspect of the role.</p>	<p>Research shows the importance of working with families if self-management is to be maintained. Looking to develop the ESN role so that there is more structured support that includes carers will build on the support that is already delivered.                      Mixed methods approaches to any research of this topic will ensure that both the question of 'does it work' and 'why does it work' can be addressed.                      What are the learning needs of ESNs? Do they have the necessary skill set to provide the carer support needs? How do they support a family at risk of SUDEP. Surveys and qualitative research could be undertaken with ESNs to better understand the varying contexts in which they work.</p>

Role	Possible gap identified	Potential areas of future research
<b>Diagnosis</b>	This is an area where there is very little research to date.	<p>Do team approaches to diagnosis and treatment planning improve accuracy of diagnosis, improved treatment, and better patient experience? As this is typically the domain of the medical team what is the acceptability of a shared approach?</p> <p>People with learning disabilities present particular challenges in the diagnosis of epilepsy. Does the involvement of an ESN improve care for this group in improved diagnosis and treatment?</p> <p>59% of ESNs are not involved in running 'joint clinics'</p> <p>Some ESNs are 'aligned' with specialist services and others based in primary care. How do the roles differ?</p>
<b>Education and training</b>	ESNs train other professionals. Is this cost effective? Does it lead to better patient experience when those trained support epilepsy patients?	ESNs role in this respect is likely to vary from context to context. One of the criticisms of many evaluations of their role is that they fail to take into account the whole culture of a service and how they impact on service quality which may go beyond that of their individual patient contact. It also takes time to develop the networks to positively influence a culture, often services are evaluated as they start. Evaluation studies need to measure these aspects of the role either quantitatively or qualitatively.

Role	Possible gap identified	Potential areas of future research
<b>Liaison linking services (and team working)</b>	Little emphasis appears to be made on the role of the ESN in supporting patients at transition points, or in their ability to cross boundaries between settings.	<p>The feature of the ESN role that appeared quite unique in the HCP team was there role in supporting patients in different settings: primary, secondary, home, school, work.</p> <p>Potential research questions might be:</p> <p>Is this an actual feature of their role or does it depend on the context in which they are working?</p> <p>What is its impact on patient care?</p> <p>This could be investigated in surveys or direct observation of practice. Its impact could be evaluated using a mixed methods approach with combined gathering patients' and carers' views, as well as data looking at outcomes that indicate effective transmission of patient information between care settings.</p>
<b>Medicines management and prescribing</b>	There is a lack of evidence of the greater impact of nurse-led clinics.	<p>The ESN role in supporting medicines management is one where there is much literature. There is a lack of appropriate outcome measures that assess their impact on this aspect of care. Existing outcome measures (seizures, compliance with medication) fail to show impact of the service. Research needs to focus on ways that ESN can more effectively support medicines management and a Delphi approach to selecting appropriate outcome measures.</p>
<b>Monitoring</b>	Possible impact on reducing admissions was identified in one study. How could this be researched?	<p>Establishing whether routine monitoring provided by and ESN reduces admissions could be explored by using observational case control studies or cohort studies comparing patients receiving care from an ESN with those not receiving care.</p> <p>Another question is what should be the components of 'routine monitoring'. To what extent do these reviews include risk assessment and SUDEP? Observational studies or qualitative studies would allow exploration of the most important components of routine monitoring.</p>

Role	Possible gap identified	Potential areas of future research
<b>Point of contact</b>	This was one of the most important elements of the ESN role identified at the stakeholder events but appears to have been poorly evaluated in the research evidence	Outcomes that measure this aspect of the ESN role and how it directly impacts on patient and carer experience, including the value of reassurance as a patient experience.
<b>Seizure and risk of seizure management</b>	Seizure frequency is the most commonly used outcome measure in evaluation studies. Why do evaluation studies find no effect of the ESN role on this outcome?	While the evidence suggests that the ESN increases patient satisfaction with the information they are given, they may not be able to 'know what they don't know'. There is no clear link in the literature that shows that the ESN reduces the risk of injury or SUDEP. While this may be a poor marker of effectiveness, requiring studies of large sizes and long duration to rigorously measure an impact, it should not prevent ESN examining the quality of the support patients are given to reduce seizures and prevent ensuing injury.

Role	Possible gap identified	Potential areas of future research
<p><b>Specialised clinics and access to specialised help</b></p>	<p>There is a gap in evidence demonstrating benefits for women of child-bearing age of having nurse input. Which professional is best placed to address managing risks around contraception and conception?            What further research could be done to support this?</p>	<p>Qualitative data exploring WVVE experience of their needs for specialist advice and support regarding contraception, conception and pregnancy is lacking. During pregnancy women transition to obstetric care, how is continuity of care ensured for WVVE?</p> <p>It is difficult to establish why only a small number of ESNs manage nurse-led clinics and hold little responsibility for decision making. Reasons may include the employment of ESNs to roles they are not adequately prepared for, or medical staff who are unaware of, or unwilling to allow ESNs to take on such roles. This highlights the need for specific and targeted job descriptions, appropriate recruitment procedures and support and mentoring of nurses new to the role (McCreadie &amp; Hutchinson 2001, cited in Goodwin et al 2004).</p> <p>Current research that is underway includes a cluster randomised controlled trial (Ring et al 2016) exploring the effect of an epilepsy nurse-led care service for adults with epilepsy and a learning disability. The majority of previous research into the use of ESNs has been in the general population and have excluded adults. Therefore this research is of particular value in addressing current gaps in the research evidence. The ESNs in this intervention regularly collect clinical information including seizure frequency, side-effects, behavioural symptoms and effects of seizures on daily life from patient and carers. ESNs also assess the patient on a regular basis at a frequency determined by clinical need, through home visits, telephone clinics and visits to the local primary care or learning disability base as appropriate.</p>

## Appendix I

RCTs included in Cochrane Review of models of care for adults with epilepsy showing effects on each measured outcome (red text showing where there was no difference or a negative result, and green where an improvement was found with the ESN intervention)

Setting	Participants	ESN Intervention	Outcomes
Mills (1999 & 1999) HIGH risk of bias	n=574 n=394 (at 2 year follow-up)	Intervention group members received information, advice and support from the epilepsy nurse, who also liaised with other professionals and provided education for staff.  Vs  Usual care	<ul style="list-style-type: none"> <li>Seizure frequency (at 1 and 2 years) <b>No difference</b></li> <li>AED use</li> <li>Feel well controlled by drug <b>No difference</b></li> <li>Report very important to take AED as prescribed <b>No difference</b></li> <li>Report never missing taking AEDs <b>Improvement with intervention at yr 1. No difference at yr 2</b></li> <li>Side effects from AEDs <b>No difference</b></li> <li>Taking one type of AED <b>No difference</b></li> <li>Information provision</li> <li>Discussed epilepsy topics <b>Patients More likely to have discussed more topics with ESN than with hospital doctors (year 1 and 2)</b></li> <li>Effect of epilepsy and treatment on everyday life</li> <li>10 questions about quality of life Intervention group statistically significantly more likely to report an effect for three items: Epilepsy affects future plans and ambitions, Epilepsy affects overall health, Epilepsy affects standard of living</li> <li>Feel stigmatised due to epilepsy <b>No difference</b></li> <li>Feel unhappy about life as a whole <b>No difference</b></li> <li>Attitudes to care</li> <li>Patient preferences</li> <li>Long term health problems <b>No difference</b></li> <li>Injury as a result of epilepsy attack <b>No difference</b></li> <li>Costs</li> <li>Seen GP for any reason <b>No difference</b></li> <li>Seen GP for epilepsy <b>No difference</b></li> <li>Seen hospital doctor for epilepsy <b>No difference</b></li> </ul>

	Setting	Participants	ESN Intervention	Outcomes
Ridsdale (1997 & 1999) HIGH risk of bias	Primary care 6 general practices in southern England	N=251 Adults with epilepsy Excluded those with other severe illness, mental illness or learning disability.	Specialist nurse based in GP  Vs  'usual care'	Admitted to hospital for epilepsy <b>No difference</b> Attended A&E department for epilepsy <b>No difference</b> Regular arrangement to see GP for epilepsy <b>No difference</b> <ul style="list-style-type: none"> <li>• Appropriateness of medical management <b>11.1% of intervention patients required changes; no data reported for control. Statistically significant increase in serum monitoring over time in intervention group compared with control group</b></li> <li>• Knowledge of epilepsy <b>No difference</b></li> <li>• Depression <b>No statistically significant differences</b> between groups in patients who had had a seizure but statistically significantly reduced risk of depression in patients reporting no seizures</li> <li>• Anxiety scores <b>No difference</b></li> <li>• Reported on patient attendance rate</li> <li>• Perceptions of level of advice</li> </ul>
Ridsdale (2000) HIGH risk of bias	Hospital setting 5 hospitals in SE England	N=102	ESN providing two consultations, three months apart	<ul style="list-style-type: none"> <li>• Seizure frequency (at 6 m) <b>No difference</b></li> <li>• Information provision <b>patients in the intervention group were statistically significantly more likely to have received enough advice</b></li> <li>• Measured knowledge of epilepsy <b>No difference</b></li> <li>• Depression <b>No difference</b></li> <li>• Anxiety scores. <b>No difference</b></li> </ul>

Setting	Participants	ESN Intervention	Outcomes
<p>Warren (1998)</p> <p>MODERATE risk of bias</p>	<p>N=322</p> <p>Included patients with learning disabilities</p>	<p>ESN case manager. The nurse complemented the work of the clinic doctors and replaced them in some aspects of care.</p>	<ul style="list-style-type: none"> <li>• Seizure frequency (at 6 m) <b>No difference</b></li> <li>• Impact on medical management</li> <li>• Self-reported non-compliance with medication <b>No difference</b></li> <li>• Attendance at epilepsy clinic <b>No difference</b></li> <li>• Anxiety and depression <b>No difference</b></li> <li>• Impact of epilepsy (functioning) <b>No difference</b></li> <li>• Number of days absent from work <b>No difference</b></li> <li>• Knowledge of epilepsy <b>Improved level of medical knowledge in intervention group. No difference for social knowledge of epilepsy</b></li> <li>• Psychosocial outcomes for patients and caregivers</li> <li>• Patient and general practitioner satisfaction with clinic care</li> <li>• Use of other hospital services at six months</li> <li>• Costs of treatment.                         <ul style="list-style-type: none"> <li>≥ 1 GP consultations <b>A smaller proportion of intervention patients saw their GP once or more than did control patients but this difference was not statistically significant</b></li> </ul> </li> <li>• Number of GP consultations <b>Intervention patients had statistically significantly fewer consultations than the control group</b></li> <li>• Visits to general practice nurse <b>No difference</b></li> <li>• Visits made by district nurse <b>No difference</b></li> <li>• Visits made by health visitor <b>No difference</b></li> <li>• Visits made by CPN <b>No difference</b></li> <li>• Visits to outpatient clinic doctor <b>Intervention patients made statistically significantly fewer visits</b></li> <li>• Specialist inpatient admission <b>No difference</b></li> <li>• EEG <b>No difference</b></li> <li>• MR scan <b>No difference</b></li> </ul>



	Setting	Participants	ESN Intervention	Outcomes
<p>Helde (2005)</p> <p>MODERATE risk of bias</p>	<p>Neurology clinic at a hospital in Trondheim, Norway</p>	<p>N=144 adults with epilepsy who attended a neurology clinic</p>	<p>Counselling and teaching from an ESN</p>	<p>Other outpatient consultation <b>No difference</b></p> <p>Other inpatient admission <b>No difference</b></p> <p>Other day-patient visit <b>No difference</b></p> <p>Visit to A&amp;E <b>No difference</b></p> <p>Primary healthcare cost per patient <b>Primary care costs were statistically significantly reduced in intervention group</b></p> <p>Secondary healthcare cost per patient <b>No difference</b></p> <p>Total healthcare cost per patient <b>No difference</b></p> <p>Blood level estimation for antiepileptic drugs <b>No difference</b></p> <ul style="list-style-type: none"> <li>Injury from seizures <b>No difference</b></li> <li>Quality of Life QOLIE-89 <b>No statistically significant differences between groups overall but some statistically significant improvements reported for individual domains over time in both groups</b></li> </ul>

## Appendix 2 – List of Included Studies

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