

Epilepsy Specialist Nurses: The Evidence (ESPENTE)



A summary of the Systematic Mapping Review
Published in October 2019

Background

Epilepsy specialist nurses (ESNs) are incredibly valued members of the epilepsy care team, liaising and linking with other professionals to ensure the needs of people with epilepsy are met. Many UK epilepsy specialists agree that effective epilepsy services depend on ESNs. Guidance from the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) state that specialised epilepsy services should include ESNs.

However, in many areas the UK is falling short of this standard and commissioners do not consider

ESNs a high priority. There is only around an estimated 400 ESNs for an epilepsy population of 600,000. This compares poorly to multiple sclerosis, for which there are 245 nurses for a population of 100,000.

It is commonly accepted that ESNs are vital in epilepsy healthcare teams. However, there is little clear evidence of their effectiveness and the measurable outcomes they bring for patients. This could be part of the reason why there seems to be little interest among commissioners in creating more posts.

Method

Epilepsy Action commissioned researchers at the University of Sheffield to investigate the role of ESNs. The researchers undertook a systematic mapping review (James et al 2016) in parallel with a stakeholder and expert consensus group. They produced a definitive paper looking at the evidence available to support the value of ESN roles. The review describes the role(s) of ESNs and identifies

evidence that evaluates the effectiveness and impact of ESNs on patient outcomes. It also considers the quality of this evidence and any gaps in the existing literature that may need to be filled in order to draw accurate conclusions about the effectiveness of ESNs.

A total of 96 published papers were included in the review.

Figure 1. Published papers reviewed, by research design

Systematic review	(n=7)
Random controlled trials (RCT) or controlled trials	(n=9)
Qualitative studies	(n=10)
Mixed method studies	(n=7)
Questionnaires or surveys	(n=15)
Audits of services	(n=6)
Case studies	(n=7)
Descriptive, news, opinion	(n=35)

Different research designs offered different insight on the ESN role and its impact. Both research and opinion pieces were included to ensure researchers were able to identify any innovative practices that may not have been formally evaluated.

Other study designs were valuable in allowing insight into the scope of the role (surveys, questionnaires, observational studies) and the experience of patients using those services (qualitative designs).

A series of research questions were considered when reviewing each paper.

Figure 2. Research questions answered

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?

Findings

The findings suggest that the role of the ESN has been largely pioneered in the UK. It was apparent from the literature that it is not a single ‘one size fits all’ role, providing the same service for one type of patient. It has evolved in different places, in different ways to meet the demands of particular populations. There is no consistent level of provision for patients.

There is strong evidence from the UK to suggest that the ESN role is cost-effective and valued among other health professionals. The ESN role is unique within the specialist epilepsy team. ESNs 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 value of the service is further indicated by the suggestion within some opinion pieces that ESN services quickly become overburdened with excessively large caseloads.

It is also clear from the evidence that the ESN role is varied and shaped in part by different models of practice. A total of 14 different sub-roles within the ESN role were identified and then described and summarised using the available literature. (All sub-roles may not be present in all models of practice.) Several different models of care were also identified. These different models may result in differences in the ESN role and how it is carried out.

Figure 3. 14 different sub-roles

Advice and information	Medicines management and prescribing
Assessment	Monitoring
Carer support roles	Personalised care plan
Counselling and support	Point of contact
Diagnosis and treatment	Seizure and risk management
Education and training	Service development and coordination
Liaison/linking services	Specialised clinics

Figure 4. Identified models of care

ESN-led services for particular groups	ESN-led services based on mode of delivery
Children	Community setting
People with refractory epilepsy	Secondary care
People who present at A&E	Tertiary care
People with epilepsy and learning disability	

Evidence map

Evidence from all 96 papers was 'mapped' according to the 14 identified sub-roles and types of evidence. The map provides an overview of existing research and relevant literature. It highlights quantity and quality patterns as well as gaps in the current evidence base.

The ESN evidence map includes:

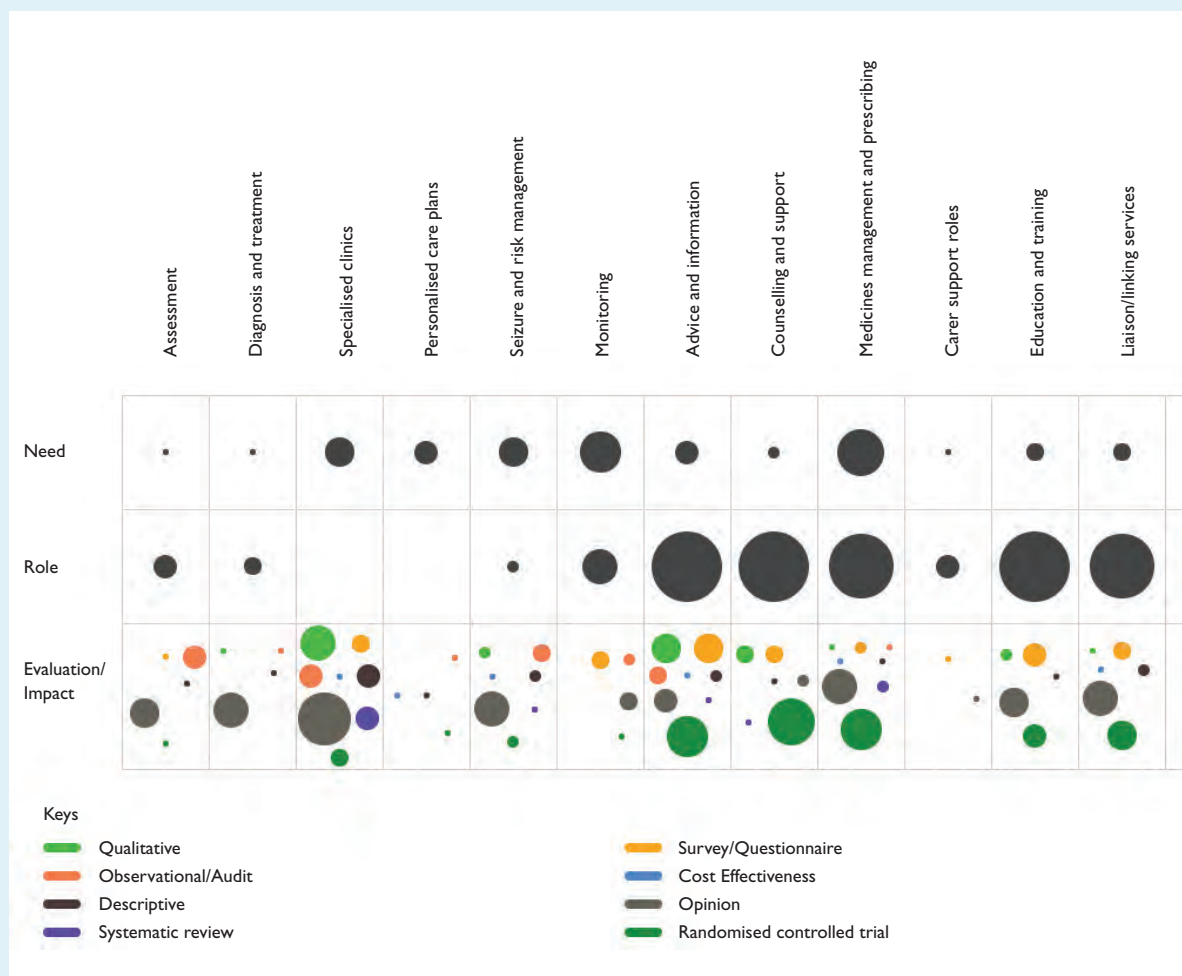
1. An overview of the included papers, the study methodology, settings and where relevant, the participants who were included in the research
2. A description of the different models of practice seen in the literature
3. Impact measures for ESN services

4. A description of the 14 sub-roles within the ESN role, linking each sub-role to research evidence demonstrating effectiveness and impact

The map should be used to help commissioners and health professionals in planning services and building business cases for ESNs in their locale. It can also be used to demonstrate the effectiveness of ESN roles and highlight the need for more research in this area in order to secure the future of ESN roles and ultimately provide an effective ESN service to all people with epilepsy.

Visit epilepsy.org.uk/espentemap to use the map.

Figure 5. Evidence map



Conclusion

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.

ESN-themed 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. Evidence supports a greater role for the ESN in liaising with GPs.

Further research focusing on which elements contribute to effective delivery of effective care should be undertaken. Future researchers in this area should consider investigating any links between seizure freedom rates among patients and access to ESN provision.



Further information

We hope that this review will provide a useful tool for commissioners in planning local epilepsy health services or making a case for more ESN resource, as well act as an agenda for further research.

To read the full report or access evidence maps, visit epilepsy.org.uk/espente

Epilepsy Action is interested to hear about any innovative service developments or examples of best practice.

For more information or to discuss any aspect of this project, please contact Peri O'Connor at poconnor@epilepsy.org.uk or 0113 210 8800.

Disclaimer

This short report is based on findings of the following research report, funded by Epilepsy Action and carried out by researchers at the University of Sheffield.

Epilepsy Specialist Nurses The Evidence (ESPENTE): A Systematic Mapping Review, Fiona Campbell, Katie Sworn, Andrew Booth, Markus Reuber, Richard Grünewald, Carina Mack, Jon M Dickson, University of Sheffield, 2019.

Epilepsy Action is the leading organisation working with and for people affected by epilepsy.

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