

An evaluation of the role of the **Epilepsy Specialist Nurse** and the impact on care: **SENsE** study

Key Findings



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



Health
Research
Board



SENsE
STUDY

The SENsE Report

*The SENsE Report*¹ (Higgins et al. 2017) details the findings of a national study into the role, impact and cost-effectiveness of the Epilepsy Specialist Nurse (ESN) in Ireland. An ESN is a member of the multidisciplinary team (MDT), has specialist education and expertise in epilepsy, and plays a key role in the management and support of people with epilepsy across primary, secondary and tertiary care.

This 'Key Findings' report outlines some of the major findings of *The SENsE study*.



Some facts about epilepsy and epilepsy care

- Epilepsy is the most common neurological condition
- Affects all ages
- Treatable condition
- Majority of people with epilepsy are seizure free
- 37,000 people in Ireland over the age of 5 years have epilepsy
- Estimated 10,000 people in Ireland live with controlled epilepsy
- Epilepsy is not just a medical problem, but a complex condition with psychological and social challenges
- Epilepsy may impact on education and employment, and may affect social, cognitive and emotional well-being
- Early diagnosis and responsive care from a skilled multidisciplinary team improves health outcomes
- In 2014 the National Clinical Care Programme in Epilepsy Care (NECP) recommended that every Person with Epilepsy (PWE) has access to an ESN at Advanced Nurse Practitioner (ANP) level

Study Aims

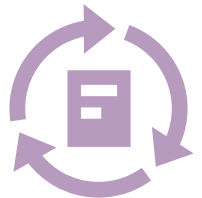
Funded by the Health Research Board and Epilepsy Ireland the study aims were to:

- evaluate the impact of the ESN on patient and family experiences, satisfaction with care and service delivery;
- identify the scope of the ESN role within the multidisciplinary healthcare team; and
- assess the cost-effectiveness of the ESN role.



Study Design

A mixed methods study that gathered data using different methods and a variety of sources:



- **Interviews** with 12 ESNs, 22 members of the multidisciplinary team, 21 PWE and 14 family members



- **Surveys** with 605 PWE who were attending ESN and Non-ESN services



- 61 hours of **observation** of 12 ESNs



- **Documentary evidence** in 5 different sites

¹ The SENsE study was conducted by a research team led by Prof. Agnes Higgins from the School of Nursing & Midwifery, Trinity College Dublin. This report was launched by the Minister for Health Mr Simon Harris, TD, in February 2017. The full report of the study is available at www.epilepsy.ie and www.nursing-midwifery.tcd.ie/

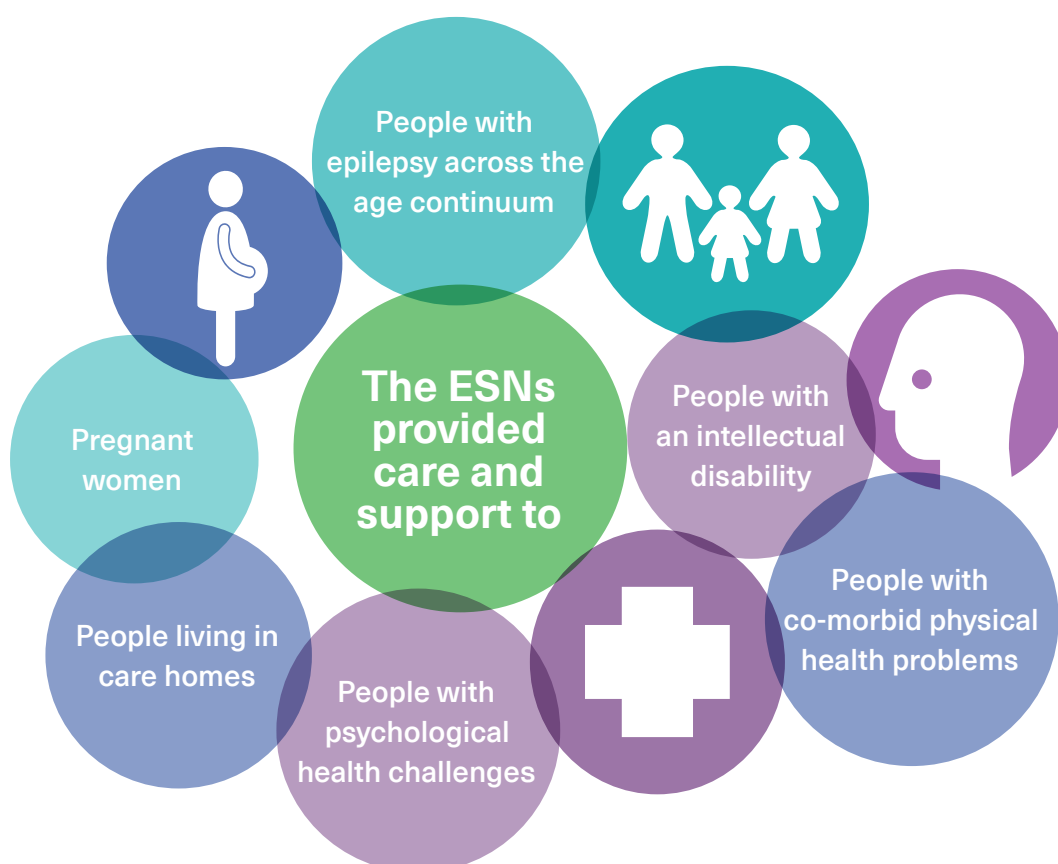
Profile of ESNs involved

The 12 ESNs included were experienced and well-qualified clinical practitioners, some of them with extensive experience in the field. They were nursing for between 12-34 years, and were working in their current role between 3 and 21 years. Two were registered as RANPs, five were candidate ANPs, and five were Clinical Nurse Specialists (CNSs). In addition to being registered general nurses, 1 was a registered midwife, 2 were registered in intellectual disability (ID) nursing, 4 were registered in children's nursing and 7 were registered nurse prescribers with the Nursing and Midwifery Board of Ireland. All ESNs had gained a number of professional and academic qualifications that directly informed their practice in epilepsy.

Services provided by ESNs

Although there were geographic differences in relation to the services provided, collectively the ESNs provided a variety of services to PWE across the care continuum including:

- **Nurse-Led Clinics**
- **Rapid Access Clinics**
- **Vagal Nerve Stimulation Clinics (VNS)**
- **Telephone Advisory Services**
- **Outreach Services**



Impact of ESN

A synthesis of the findings from all the data sources indicate that the ESNs, as part of a multidisciplinary team, impacted positively on the lives of PWE, family members and significant others, MDT and services.



Impact on PWE

- Enhanced knowledge of epilepsy and epilepsy related issues
- Enhanced confidence to self-manage
- Improved sense of involvement in care
- Improved co-ordination of care
- Improved satisfaction with care
- Enhanced preparedness for tests and investigations
- Increased prompt identification of problems
- Enhanced psychological well-being



Impact on MDT

- Increased knowledge on epilepsy and epilepsy care
- Informed decision-making on diagnosis and treatment
- Enhanced communication between healthcare practitioners, across disciplines and services
- Promoted evidence-based practice
- Supported and developed future ESNs and candidate ANPs



Impact on family members and significant others

- Increased family members' confidence to support PWE
- Decreased subjective and objective burden experienced by family
- Increased general public's confidence to support PWE



Impact on services

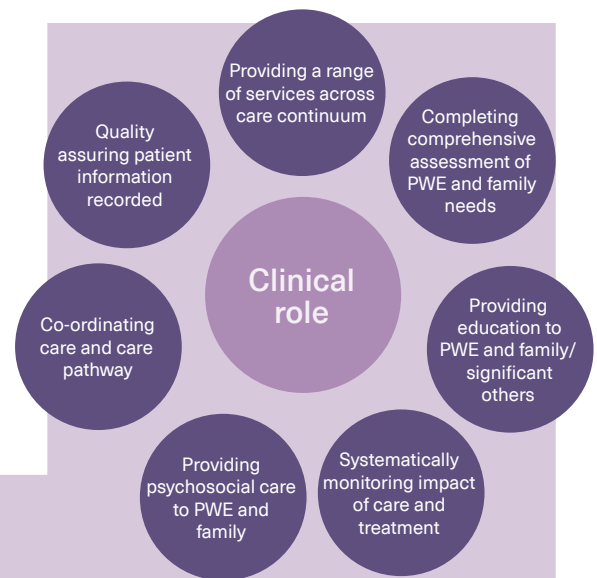
- Increased the number and range of services available to PWE
- Increased access to specialist epilepsy care by decentralising services
- Improved continuity of care and patient flow
- Reduced attendance at ED departments
- Increased use of Electronic Patient Record

Scope of ESN role

Clinical role

The clinical aspect of the ESN role was underpinned by the principles of holistic person-centred care, continuous assessment, responsive action, empowerment and collaboration with the PWE, their family members and the MDT. The clinical role required a high degree of epilepsy-specific knowledge, including knowledge of local and national services and absorbed the vast majority of the ESN's time.

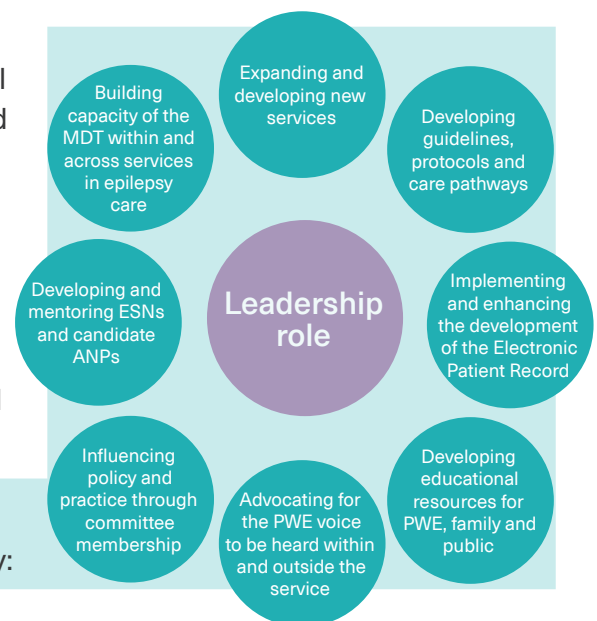
As core members of the MDT, the ESN's clinical role included:



Leadership role

The ESNs were involved in clinical and professional leadership, at both a strategic and patient-level, and negotiating change across disciplinary, managerial and organisational boundaries. As leaders they were very self-directed and motivated individuals, and were guided by beliefs in equality of access, the right to service quality, collegiality of working relationships, and the importance of mentorship and support for all members of the MDT within and outside of their service.

As leaders, the ESNs were improving the quality of care for PWE and influencing policy and practice by:



Evidence-based practice role

Whilst the clinical and leadership dimensions of the ESN role took priority over producing research, the ESNs were all engaged to varying degrees in promoting evidence-based practice (EBP) among MDT members, PWE, their family and the public.

The ESNs were promoting EBP by:



Stakeholders' views of the ESN

"The [ESN] is ringing me up, checking medication, listening to me, making sure my [seizure] diary is perfect. She understands me, knows me, there to help me make decisions." (PWE)

"The patient needs is their focus, and it is about safer care being delivered to the patient." (Director of Nursing)

"They're like another family that you never knew you had, and they're always there." (PWE)

"[ESNs] have their own cohort of PWE, so there's continuity in your care... that's invaluable." (Medical personnel)

Amazing
Link person
Empathetic **Reassuring**
Trust **Comforting**
Safe care
Fantastic **Experienced**
Change champions
Incredible **Systematic** **Confidence**
Knowledgeable
Invaluable **Know you**
Supportive
Like Family

"She's [ESN] giving me tools, ... gives the confidence and reassurance that you can help your child [when he has seizure]... helps you cope." (Family member)

They [ESNs] are a huge knowledge reservoir, and a huge support to PWE and their families." (Medical personnel)

"Because of her knowledge of how the epilepsy system worked, she is able to ease the pathway of information between us and primary care and vice versa... she provides a conduit for multidisciplinary care." (Medical personnel)

"The [ESNs] are the people who pick up a lot of the psychological difficulties..., they're the ones who are on the phone...at the coal face...they know the patients [PWE] really well..." (Allied health professional)

"We use the Electronic Patient Record, and the nurses really champion that... they are instrumental in making sure that it is used properly...we would be using it a lot less if the nurses hadn't advocated for it." (Medical personnel)

Cost and Contextual Factors

Cost-effectiveness

PWE included in this study who received care from an ESN, had the same costs as those treated in a Non-ESN site but experienced better outcomes in terms of their knowledge and the management and treatment of their epilepsy. This would suggest that sites with an ESN are good value if they improve the patient experience at no change in cost. In addition, a change in skill mix was observed for ESNs as they took on some of the roles traditionally under the remit of the medical consultant. As

such, the ESN role reduced the time medical consultants spent dealing with issues, enabling them to utilise their time more efficiently, with potential cost saving implications.



Contextual factors influencing role



Supporting role

- presence of national policies on role
- strong support for the role among medical and nursing personnel
- positive appraisals of ESNs' competence by all stakeholders
- presence of formal and informal support mechanisms
- acceptance of the ESN role by PWE and families

Challenges to role

- large clinical caseloads/role overload
- lack of 'critical mass' of ESNs within some services
- role isolation
- limited access to structural supports and resources
- demands of achieving the competencies and other requirements to become a registered ANP
- lack of acceptance of the ESN role by PWE and families

Recommendations

This mixed methods evaluation has demonstrated very positive outcomes of the ESN role for PWE, their families, members of the MDT and the health service; therefore, it is recommended that:

- the ESN service be expanded nationally;
- a critical mass of ESN posts (no fewer than 3) be created in all services;
- specialist ESN services in the areas of women's health, ID, children/adolescents, mental health and older age be expanded;

- deficits in structural and professional supports be addressed and;
- further evaluation be undertaken in 5-7 years, using the outcome indicators identified in this research to measure the impact of the ESN role.

The full list of recommendations is available in the SENsE report.

Acknowledgment:

The research team thanks all the stakeholders (persons with epilepsy, their families and carers, and healthcare professionals) who took part in or provided support with the study.

All data, including this key findings, should be referenced to:

Higgins A; Elliott N; Varley J; Tyrrell E; Downes C; Begley C; Normand C; Doherty C; Clarke M (2017) An evaluation of the role of the Epilepsy Specialist Nurse and the impact on care: SENsE study: Key findings. Dublin: Epilepsy Ireland.



The full SENsE report is available at www.epilepsy.ie and www.nursing-midwifery.tcd.ie



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The School of Nursing and Midwifery Trinity College Dublin is the largest and leading School of Nursing and Midwifery in the country. The school offers a range of undergraduate and postgraduate programmes in all Nursing disciplines (Mental Health, Children's, General and Intellectual Disability Nursing) and in Midwifery.
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Epilepsy Ireland (previously Brainwave - The Irish Epilepsy Association) was established in 1966 by a group of individuals concerned to improve the quality of life of people with epilepsy in Ireland. Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy. Epilepsy Ireland is committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers.
www.epilepsy.ie