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

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SENsE STUDY

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# Foreword

The SENsE Study Report is an important study into the scope and impact of the Epilepsy Specialist Nurse (ESN) role which not only details a model of epilepsy care but provides a framework for developing and sustaining that model into the future. Epilepsy Ireland is proud to have been part of the team that funded the study, in conjunction with the Health Research Board.

Epilepsy is a common neurological disorder characterised by recurring seizures. Accurate estimates of incidence and prevalence are difficult to ascertain because identifying people who may have epilepsy is a challenge. Epilepsy has been estimated to affect over 37,000 people in Ireland and about 1 in every 20 people will have a single seizure at some time during their lives without developing epilepsy. 70% of people with active epilepsy have their epilepsy controlled satisfactorily with anti-epileptic drugs (AEDs).

Our key aim at Epilepsy Ireland is to advocate for better services for people with epilepsy in order to improve treatment and management of epilepsy; key programmes designed to achieve this aim include: the new Epilepsy Toolkit for people newly diagnosed with epilepsy; the STEPS self-management programme for people with epilepsy; and the STEPS self-management programme for parents of children with epilepsy. Our Research Funding Scheme was set up in 2009 to provide epilepsy researchers in Ireland with an avenue to access funding for work that encourage and assist people to undertake research into the causes of, cure for and management of epilepsy. In an effort to further this objective we have funded several health services research studies such as this one.

The establishment of the National Epilepsy Clinical Care Programme in 2010 was one of the most important steps in epilepsy care in the history of the state. The programme recognised the importance of developing the role of the ESN in epilepsy care as well as nurturing its leadership potential.

Given the central role of the ESN in the Irish epilepsy health service, gathering data on the role and impact of the ESN became a key research objective for Epilepsy Ireland. It is important that the role and its impact is established and outlined clearly for all stakeholders, including patients and their families, health professionals and policy makers. The feedback on the impact of ESNs has been positive in recent years and we are delighted that the evidence shows an enhancement of care and new experts in epilepsy nursing emerging. We believe that the SENsE Study established a template for the future, not only for epilepsy services in Ireland but potentially for a range of other chronic and neurological health conditions as well.

On behalf of Epilepsy Ireland I wish to thank all those who contributed to the study, especially Professor Agnes Higgins and her team at Trinity College Dublin, for their dedication over the past 4 years to this very important report.
We look forward to continuing our partnership with researchers such as Professor Higgins to work towards achieving excellence in epilepsy care in Ireland.

Peter Murphy
CEO
Epilepsy Ireland

# Acknowledgments

The research team would like to thanks all the key stakeholders (persons with epilepsy, their families and carers, and healthcare professionals) who took part in the interviews, focus groups, observations and surveys and provided invaluable insights about epilepsy specialist nursing services in Ireland.

The study would not have been possible without the assistance and support provided by the healthcare professionals who facilitated access to services and assisted with recruitment.

The team is also grateful to the Health Research Board and Epilepsy Ireland for commissioning and funding the study, and especially Mr Peter Murphy from Epilepsy Ireland for his support and wisdom throughout this research.

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| | |
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## Glossary and Acronyms

| | |
|---|---|
| ADoN | Assistant Director of Nursing |
| AEDs | Anti-Epileptic Drugs |
| ANP | Advanced Nurse Practitioner |
| APN | Advanced Practice Nursing. This is an umbrella term used to encompass the specific roles of nurses who practise at a more advanced level than that of traditional nurses. |
| Candidate ANP | Candidate Advanced Nurse Practitioner |
| CNM | Clinical Nurse Manager |
| CNS | Clinical Nurse Specialist |
| DoN | Director of Nursing |
| EBP | Evidence-based practice |
| ED | Emergency Department |
| EI | Epilepsy Ireland |
| EPR | Electronic Patient Record |
| ESN | Epilepsy Specialist Nurse |
| ESN site | Epilepsy Specialist Nurse site |
| GP | General Practitioner |
| HIPE | Hospital In-Patient Enquiry |
| HRB | Health Research Board |
| HSE | Health Services Executive |
| ICERs | Incremental Cost Effectiveness Ratios |
| ID | Intellectual Disability |
| KPIs | Key Performance Indicators |
| MDT | Multidisciplinary team |

| | |
|---|---|
| NCHD | Non-Consultant Hospital Doctor |
| NCNM | National Council for the Professional Development of Nursing and Midwifery, also referred to as ‘the National Council’ in the text. |
| NECP | The National Epilepsy Clinical Care Programme in Epilepsy. Also referred to as the Epilepsy Clinical Care Programme. |
| NICE | National Institute of Health and Clinical Excellence |
| NMBI | Nursing and Midwifery Board of Ireland |
| NMPDU | Nursing Midwifery Planning and Development Unit |
| Non-ESN site | Non-Epilepsy Specialist Nurse site |
| OPD | Out Patient Department |
| Post holding site | Clinical area where Epilepsy Nurse Specialists (Clinical Nurse Specialists, Advanced Nurse Practitioners and Clinical Nurse Managers who deliver care to PWE) are employed |
| PWE | Person/People with epilepsy |
| QoL | Quality of Life |
| RANP | Registered Advanced Practice Nurse |
| SENsE | Specialist Epilepsy Nurse(s) Evaluation |
| SHO | Senior House Officer |
| SIGN | Scottish Intercollegiate Guidelines Network |
| SUDEP | Sudden Unexplained Death in Epilepsy |
| TAL | Telephone Advice Line |
| VNS | Vagal or Vagus Nerve Stimulation |
| WHO | World Health Organisation |

# Executive Summary

## Introduction

Epilepsy is the most common neurological medical condition and is associated with particularly vulnerable groups of people including people with intellectual disabilities (ID). For the majority of people, epilepsy and its clinical manifestations are short-lived, with two-thirds entering long-term remission without any subsequent relapses. In Ireland, it is estimated that there are approximately 12,000-15,000 people with breakthrough seizures who require regular contact with secondary and tertiary hospital services. In addition to higher mortality rates among people with epilepsy (PWE) compared to the general population, uncontrolled seizures can have a significant negative impact on people's cognitive, emotional and psychosocial functioning, as well as quality of life and social and occupational aspirations.

Despite overwhelming evidence that early and accurate diagnosis and responsive care from a skilled multidisciplinary team improves health outcomes for PWE, many deficiencies in care provision have been identified. As part of a plan to improve access to expert epilepsy care and the quality of care across the healthcare environment, the National Clinical Care Programme in Epilepsy Care (NECP) recommended that all PWE in Ireland have access to the epilepsy nurse specialist (at Advanced Nurse Practitioner level).

Although the ESN role has been in existence for a number of years, there is a paucity of evidence-based research about the role and its impact on PWE, on other healthcare staff as well as service outcomes. Funded by the Health Research Board and Epilepsy Ireland, this study, the Specialist Epilepsy Nurse(s) Evaluation [SENsE] study, set out to identify the role and cost-effectiveness of the ESNs in Ireland and to evaluate their impact on patient experiences, quality of life (QoL) and satisfaction with care.

## Objectives

The objectives of the study are:

- To identify the role and scope of the ESN in the delivery of patient care within the multidisciplinary healthcare team in Ireland.

- To determine if there is a difference in patient QoL, experiences and satisfaction for those who receive care for more than 12 months from services with an ESN, compared to those receiving care from services without an ESN.
- To evaluate the impact of the ESN on patient QoL, experiences and satisfaction with care for a cohort of new patients who receive care for more than 12 months from services with an ESN, compared with a similar cohort receiving care from services without an ESN.

- To assess the costs to the health service of caring for people with epilepsy in the community in terms of use of hospital, primary and community health services and wider costs in terms of the impact on patients and their families.

## Research design and methods

The study used a mixed methods approach, with three concurrent interrelated phases. Phase one comprised a case study and gathered information from ESNs and key stakeholders. The second phase included a comparative survey design involving patients from sites where ESNs worked and sites where no ESNs were employed. The third phase included an economic component.

Data were gathered using different methods and a variety of sources:

- 61 hours of observation of 12 ESNs, interviews with 12 ESNs, and documentary evidence in 5 different sites;
- Interviews with 22 members of the multidisciplinary team with whom the ESNs had contact;
- Surveys with 505 PWE who were attending ESN and Non-ESN services for a period of over one year and 100 who had been recently diagnosed with epilepsy and were attending ESN and Non-ESN services; and
- Focus group interviews with 21 PWE and 14 family members.

## Key findings: Clinical role

Findings from this study indicate that the 12 ESNs included were experienced and well-qualified clinical practitioners. Two were registered ANPs, five were candidate ANPs, and five were CNSs. In addition to numerous clinical and academic qualifications seven were registered nurse prescribers with the NMBI.

The clinical aspect of the ESN role required a high degree of epilepsy-specific knowledge, including knowledge of local and national services and 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 ESNs were fulfilling all roles as outlined by the NECP, and were working in a range of services across the primary, secondary and tertiary care continuum and were providing care to PWE across the age continuum, including women who were pregnant, people with co-morbid physical and psychological health difficulties and challenges, and people with intellectual disability, thus, the clinical aspect of the role absorbed the vast majority of the ESN's time.

Although there were geographic differences between the services provided, collectively the ESNs provided a variety of services to people including nurse-led clinics, vagal nerve stimulation (VNS) clinics, rapid access clinics (RACs), outreach clinics and telephone advisory services.

As core members of the MDT, the ESN's clinical role included: completing an in-depth comprehensive assessment that moved beyond the disease model of care to incorporate lifestyle and psychosocial issues; education of PWE and their family on all aspects of epilepsy, including the social, safety and health aspects of epilepsy; the systematic follow-up and ongoing monitoring of the impact of care and treatment on the PWE; the co-ordination of the care pathway; and liaising with and contributing collaboratively to the decision-making of the wider MDT.

The ESNs led on patient consultations, switched on vagal nerve stimulation (VNS) devices, completed neurological assessments, ordered tests, referred PWE to allied health professionals, and prescribed or titrated medications, many tasks which might have been traditionally considered within the medical domain.

Although the psychosocial needs of PWE were being addressed, there were limits to the ESN’s ability to provide support to people with significant mental health morbidities, or who were diagnosed with non-epileptic form seizures, in terms of their own skills, and the availability of mental health services.

## Key findings: Leadership role

ESNs were involved in clinical and professional leadership, at both a strategic and patient-level, and were negotiating change across disciplinary, managerial and organisational boundaries.

Although some ESNs were more engaged than others with leadership activities, they were central to advancing the NECP’s aims of reconfiguring care away from hospital-based services, and were increasing PWEs’ access to specialist epilepsy services by expanding and developing new services, such as the telephone advisory line (TAL), VNS clinics and outreach clinics for people with ID and pregnant women.

The ESNs were improving the quality of care for PWE and influencing policy and practice by leading on the development of evidence-based clinical guidelines, protocols and care pathways; education programmes and resources for PWE, family members and the MDT; and leading and contributing to the roll-out and ongoing development of the electronic patient record (EPR).

As leaders the ESNs were self-directed and motivated individuals, who 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.

## Key findings: Evidence-based practice (EBP) & research

Findings demonstrated that the ESNs were all engaged to varying degrees in promoting EBP among MDT members, PWE, their family and the public by accumulating, applying, translating, generating and disseminating evidence.

The ESNs used multiple sources of evidence to inform decision-making within their own practice, and argue for changes at team and organisational level. They translated evidence into accessible and usable forms for PWE/family members and MDT members.

Although ESNs had limited involvement in research, all were involved in, or were leading clinical audit and service evaluations, and using the findings to drive changes at patient, team and organisational levels. Whilst all the ESNs were very active in disseminating evidence from audit within their own organisation, some were less involved in the dissemination of evidence outside of their own organisation.

Not surprisingly the clinical and leadership dimensions of their role took priority over producing research, and although all were very positive about the research dimension of the role, the challenges identified included accessing library resources, competing demands and heavy workloads, with some ESNs expressing reservations about their ability to critically appraise and interpret research findings.

## Impact of ESN role on patient and service outcomes: Stakeholder perspectives

A synthesis of the findings from all the data sources indicates that ESNs had a positive impact on outcomes for PWE /family members/significant others, for healthcare staff within and outside the ESN's organisation, and outcomes that were health service oriented.

ESNs impacted on the lives of PWE by enhancing their knowledge and confidence to self-care. PWE in ESN sites rated information provided on epilepsy-related topics, involvement in care, co-ordination of care, confidence in talking to and seeking advice from ESNs, and practical and emotional support received higher than those in Non-ESN sites.

Evidence from all participants indicated that the ESNs increased family members' and the general public's confidence to support PWE and take action in emergencies.

While there was no evidence that ESNs impacted on quality of life as measured by the QOLIE-10-P instrument, other evidence suggests that the ESNs were perceived by PWE and family members as improving overall health and well-being and impacted positively by decreasing the subjective and objective burden experienced by PWE, family and significant others.

The ESNs increased the number and range of services available to PWE, and improved accessibility to specialist epilepsy care by decentralising services, developing the TAL, VNS clinics and outreach services.

The TAL was perceived to be reducing attendance at ED departments, reducing waiting times to be seen, and improving communication between a wide range of healthcare practitioners, across disciplines, services and the care continuum.

ESNs increased knowledge of the MDT on epilepsy care, positively influenced decision-making on care issues, and promoted evidence-based practice.

ESNs were perceived by all stakeholders as being a central point of contact for the MDT for information on the person and their family.

The ESN service also impacted positively by improving the efficiency of services. By absorbing some of the roles traditionally the remit of the medical consultant, ESNs reduced the time medical consultants spent dealing with issues, enabling them to utilise time more efficiently with cost saving implications. Outreach clinics also resulted in reducing the costs associated with services providing clinical staff to accompany PWE with ID to hospital appointments.

In addition, through their work on policies, guidelines and audits, the ESNs were promoting, maintaining and monitoring the national epilepsy Standard Operating Procedures (SOPs) as well as other quality standards developed for epilepsy services. The RANPs also supported the development of less experienced ESNs and candidate ANPs in line with national policy.

## Findings from economic analysis

Overall, the economic analysis found that costs were higher among PWE in ESN sites. However, on further analysis of high cost PWE and excluding the data from Site I, there was either no difference in cost or PWE in Non-ESN sites had higher medical costs. Removing the high cost PWE (over €5,000) provided a way of controlling for case mix; and this revealed that total costs, including medical and indirect costs, were almost identical for the ESN sites (€1,098) and Non-ESN sites (€1,101). The removal of the high cost PWE shows the interaction with the complexity and case mix among patients, which is not accounted for in these data.

The lower healthcare utilisation among PWE treated at Site I and consequentially the low cost per person also required further analysis. Analysis of the data without these people means the average cost per PWE for total medical costs is higher in Non-ESN sites at €1,544 compared to €1,375 in ESN sites. The overall total per PWE, including medical and indirect costs, changed to €3,271 in ESN sites and €3,057 in Non-ESN sites. As such, controlling for case mix, with the removal of high cost PWE demonstrates that there is no difference in cost between PWE in ESN sites and Non ESN sites.

The analysis also considered whether PWE treated in an ESN site experienced better outcomes at the same cost. Although there is no evidence of difference in QoL between ESN and Non-ESN sites, a greater proportion of PWE in ESN sites either agreed or strongly agreed that ESNs made a positive difference to health and well-being. Furthermore, there is evidence from the study findings that PWE under the care of an ESN received more information on epilepsy in terms of treatment options and how to self-manage, where appropriate. In addition, statistically significant differences were found in terms of involvement in care for patients treated in ESN sites. 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.

In conclusion, based on all of the evidence, it is suggested that PWE who receive care in an ESN site have the same costs as those treated in a Non-ESN site. Sites with an ESN may be good value if they improve the PWE’s experience at no change in cost. There is evidence from this study of improved experience and better management and co-ordination of epilepsy care, suggesting an improvement at no net cost.

## Contextual and mediating factors that influence role development, integration and sustainability

Although not part of the original research objectives a number of contextual and mediating factors emerged as the study unfolded, which influenced role development, integration and sustainability. Factors supporting role development and integration included: the presence of national policies on the role, the strong support for the role among senior and junior medical and nursing personnel, the positive appraisals of ESNs' competence by all stakeholders, and the presence of formal and informal support mechanisms that facilitated the ESNs to share information and address issues that crossed discipline, service and national boundaries.

Factors that negatively influenced role enactment and ongoing sustainability included large clinical caseloads, role overload, lack of 'critical mass' of ESNs within some services, role isolation, limited access to some structural supports and resources, and the demands of achieving the competencies and other requirements to become a RANP. In addition, one factor that could be both an enabler and barrier was identified; this was the acceptance of the ESN role by PWE and families.

## Strengths and limitations

In establishing the value and significance of the findings of the study, the following strengths and limitations need to be considered. A strength of the study is that it utilised a mixed methods design and collected both qualitative and quantitative data from a variety of stakeholders in different sites and included a survey of PWE attending services with and without ESN posts. In addition, the research was undertaken by an independent team, comprised of experienced researchers with a sound understanding of mixed methods research, economic analysis, and clinical practice, and previous experience of conducting national studies of CNSs/ANPs. However, it does have certain limitations, including using a non-probability sample of PWE, convenience as opposed to random sampling of people for the focus groups, low response rates from people newly diagnosed with epilepsy and challenges in obtaining economic data.

## Recommendations

In light of the findings and limitations, recommendations are proposed under the following headings: expansion of ESN services and resources to support; model and location of ESN service; areas for future development and improvement by ESNs; ongoing professional development for ESNs and future research.

### *Expansion of ESN service and resources to support*

- This mixed methods evaluation has demonstrated very positive outcomes of the ESN role to PWE, their families, members of the MDT and the health service; therefore, it is recommended that the ESN service be expanded nationally in line with the vision outlined in the Epilepsy Clinical Care Programme, whereby all PWE have access to an ESN service (HSE 2014).
- A major factor that was considered to impact negatively on services provided and the sustainability of services provided by the ESNs was the number of ESN posts within a service. In light of the findings that indicated that ESN services had to be reduced or withdrawn in sites with low numbers of ESNs in post, due to absences including statutory leave, it is recommended that a critical mass of ESN posts (no fewer than 3) be created in all services.
- Further development and expansion of specialist ESN services in the areas of women’s health, ID, children/adolescents, mental health and older age is essential to facilitate these groups having equitable access to specialist epilepsy care and treatment, as currently access is dependent on geography. However, this needs to occur in the context of increasing numbers of ESNs in sites as there is a major risk that burgeoning caseloads will have a negative impact on the quality of service currently provided.

- A lack of structural supports was one of the key challenges to the ESNs performing their role. While some ESNs had access to administrative and IT support, others had limited access. Few had access to specialist epilepsy journals, and most were delivering care in less than ideal physical surroundings. Given the impact of lack of structural supports on the ESN's ability to enact all dimensions of their role, it is recommended that deficits in structural supports be addressed as easy accessibility to key sources of evidence is critical if ESNs are to enact the evidence-based practice dimension of their role.

### *Model and location of ESN service*

- Some people were of the view that the remit of the ESN should be redirected from tertiary services to community and primary care services to reflect the fact that a huge part of epilepsy care is chronic disease management. However, given the findings that indicate the positive benefits of the current model (access to specialist medical personnel, allied health professionals, mentorship and supervision), any change requires detailed analysis of the implications for governance, the type and quality of care provided, the workload of ESNs and other members of the MDT, and resources required, such as accommodation, administration, and financial.
- The intensive commitment required on behalf of the ESN to achieve RANP accreditation, including time and financial resources, was seen as a potential barrier to the ongoing development of future ESN roles in line with the aims of the Clinical Care Programme. Given these challenges and the likelihood that not all nurses wish to advance their career to the RANP level, it is recommended that consideration be given to including the CNS role within the SN-CNS-RANP career progression for ESNs.

### *Areas for future development and improvement by ESNs*

- Findings from the study clearly indicate that the mean scores of PWE attending ESN sites were higher than those attending Non-ESN sites for information provided; however, there are still some deficits that could be improved. In light of the findings it is recommended that ESNs give consideration to strategies for improving information provided on all aspects of epilepsy care, with specific emphasis on how to keep a seizure diary, how to explain and discuss epilepsy to others, and epilepsy and employment.
- Notwithstanding all the work that the ESNs were doing to improve the experience of PWE who attended Emergency Departments (ED) and the current crisis that all ED services are facing, given family members' negative experiences in ED there is a need for the ESNs in all services to educate staff working in ED on epilepsy and epilepsy care, and to develop care pathways for PWE who attend ED.
- Findings from this study suggest that a small minority of PWE continue to have a preference for care from medical consultants as they are more trusting of their advice, especially around medication. Although this was not a widespread issue this finding indicates a need for ESNs and services not to assume patient and family acceptance of the role, especially in the current economic climate where service changes may be interpreted as cost-cutting exercises. Therefore, it is recommended that all involved continue to profile the role and expertise of the ESN to the general public, PWE attending the service and indeed the media who are key transmitters of information to the public.
- Whilst the ESNs were providing support and education to General Practitioners (GPs), there was an absence of any visibility or mention of practice nurses. In light of this it is recommended that ESNs consider developing an education programme and protocols for practice nurses in the area of epilepsy, as practice nurses are ideally placed to provide education and support to PWE who are not in need of ongoing specialist care.

- Although the ESNs working in the area of epilepsy surgery are identified in the Epilepsy Clinical Care Programme, their role and expertise appeared to be less well integrated into the overall programme. In light of this it is recommended that the clinical lead, including the wider ESN group, consider how their role can be integrated with greater visibility.
- One of the roles of all nurses is the education and mentorship of undergraduate student nurses. Whilst the ESNs were very active in educating members of the MDT and qualified nurses, by inputting into formal and informal education programmes and by providing shadowing opportunities, undergraduate student nurses were not automatically placed with the ESNs as part of their education programme. Given the richness of such an experience in terms of learning skills in chronic disease management, it is recommended that the ESNs and third level educators explore the possibility of using ESN services as a placement for student nurse training.
- In light of the challenges that the ESNs face in completing, disseminating and acquiring funding for research, it is recommended that the ESNs forge relationships with nursing and midwifery academic schools to advance the research agenda in epilepsy nursing.

### *Ongoing professional development of ESNs*

- The majority of the ESNs observed were clearly enacting the leadership dimension of their role, however, there was limited evidence that they were being provided with education, mentorship, coaching or opportunities required to advance their leadership competencies, especially at a national or international level. It is recommended that senior nursing and medical personnel give consideration to how the ESN's leadership competencies could be enhanced and supported.
- In view of the variability of skill in relation to mental health and the challenges in accessing care, it is recommended that ESNs be provided with further education in the area of mental health, and consideration be given to developing an ESN role that incorporates advanced mental health competencies within each team, to respond to the needs of people with mental health co-morbidities and non-epileptic form seizures.

## *Further research*

- This evaluation was completed in the very early stage of the roll-out of the Epilepsy Clinical Care Programme, consequently, although experienced nurses were represented, some of the ESNs included in the study were new to the ESN role. It is therefore recommended that a further evaluation be undertaken in 5-7 years, using the outcome indicators identified in this research to measure the impact of the ESN role on PWE, their families, the MDT, and the health service.
- Evidence from this research suggests that collectively the services that the ESNs developed, such as nurse-led clinics, TAL, VNS clinics, RACs and group education programmes for PWE have a positive impact on PWEs' experience of care, satisfaction with care as well as service outcomes; however, further research needs to be undertaken to evaluate the impact and cost of each individual service.
- Further research is also needed into the needs of people with non-epileptic form seizures and, in the absence of appropriate psychological and mental health services, the time spent by ESNs supporting people with co-morbid mental health issues or non-epileptic form seizures.
- In the absence of clear information on the needs of family members, especially those who are caring for people with ID, it is recommended that epilepsy research be undertaken into their needs with a view to identifying how best to respond to the needs identified.
- Further research is needed from an economic perspective in terms of accessing data on casemix for PWE. Measuring disease severity would enable a more robust comparison of costs of patients treated in ESN sites compared to Non-ESN sites. With the ongoing development of the Epilepsy Electronic Patient Record, in the future, this repository could be interrogated and the analysis of large volumes of patient information may be possible.

## Chapter 1

# Literature

# Chapter 1: Literature

## Introduction

Funded by Epilepsy Ireland [EI] and the Health Research Board [HRB] of Ireland, the Specialist Epilepsy Nurse(s) Evaluation [**SEN**s**E**] study set out to identify the role and cost-effectiveness of the Epilepsy Specialist Nurses (ESNs) in Ireland and to evaluate their impact on patient experiences, quality of life (QoL) and satisfaction with care. To set the research study in context, this chapter discusses the international and national literature on people with epilepsy (PWE) and their experiences of care and service provision, and explores the literature on the ESN's role, including the background to the development of this role within Ireland.

## Epilepsy: Overview of incidence and prevalence

Epilepsy is the most common neurological condition after stroke, occurring equally in men and women, and is not limited by race, gender, geography, age or social class boundaries (Hadjikoutis and Smith 2005). It is estimated that at least 50 million people worldwide suffer with epilepsy, although the majority (80%) live in developing countries where the condition is likely to remain undiagnosed or untreated (ILAE/IBE/WHO 1999). The overall incidence of epilepsy (excluding febrile convulsions and single seizures) in developed societies has been reported as 50 cases per 100,000 persons per year (Engel *et al.* 2008). The figures for developing countries are generally higher, in the range of 100-190 per 100,000 per year. The most typical prevalence figure quoted for epilepsy is approximately 5-10 cases per 1,000 persons excluding febrile convulsions, single seizures and inactive cases (Engel *et al.* 2008; HSE 2014). Specific to Ireland, lifetime prevalence of epilepsy among those aged 18 years and older has been reported as 10 per 1,000 persons (n = 31,000), with 8.3-9 per 1,000 persons (approximately 33,000-37,000) aged 5 years and older having epilepsy, which is in line with other industrialised nations (Linehan *et al.* 2010). Epilepsy is also associated with particularly vulnerable groups of people including people with intellectual disabilities (ID) whose prevalence rate has been reported as being thirty times higher than the general population (Forsgren *et al.* 2005).

## Impact of epilepsy on the person and family

For the majority of people, epilepsy and its clinical manifestations can be short-lived. Two thirds will enter long-term remission and once remission has occurred, subsequent relapses are uncommon (Smithson and Hukins 2008). Of the estimated 40,000 PWE in Ireland (10,000 of whom are under 16 years), only about 70% are well controlled on medication, leaving about 12,000-15,000 PWE with breakthrough seizures, and who are in regular contact with secondary and tertiary hospital services. It is also estimated that 15% of people with highly complex epilepsy would benefit from being assessed for epilepsy surgery (HSE 2014).

Adults and children with epilepsy have an increased rate of mortality which is about 2-3 times higher than that of the general population, with a conservative estimate of 111 people dying per year due to Sudden Unexplained Death in Epilepsy (SUDEP) or the complications of prolonged uncontrolled convulsive activity, also known as Status Epilepticus (SE) (HSE 2014). In addition, the physiological, psychological and social challenges of having a chronic disease are compounded by the impact of the clinical manifestations of epilepsy on an individual’s social, cognitive and emotional functioning and well-being (Chadwick 1993). The condition can also have a significant impact on the social, vocational and occupational aspirations of the person, with uncontrolled seizures having a significant effect on the person’s quality of life due to its implications for education, employment, and psychosocial functioning (Sample *et al*. 2006; Schachter & Andermann 2008; Herman and Jacoby 2009). For example, in Ireland, PWE must be free of seizures with loss of awareness for at least one year before being permitted to drive. As a consequence there can be significant implications for the level of burden experienced by PWE, dependents and family (Zarocostas 2010). In addition to the ongoing stress of living with a chronic disease, many PWE also experience mental health problems, with an increased risk of suicide within this population (Hesdorffer *et al.* 2007). Even in the absence of an intellectual disability, the cognitive capacity of PWE may be affected due to treatments that can have a bearing on their ability to self-manage their care and/or use critical thinking skills in decision-making. The long-term effects of negative physiological responses to stress are increasingly thought to contribute significantly to health outcomes (Sample *et al*. 2006). In addition, irrespective of severity, stigma continues to be associated with epilepsy, which increases seizure worry, reduces people's levels of self-efficacy in managing their condition (Austin and Caplan 2007), and correlates significantly with poorer health-related quality of life and emotional well-being (Sample *et al*. 2006).

## Models of care and guidelines

In the last thirty years there have been remarkable scientific advancements, such as improved neuro-imaging techniques that help in making a correct and timely diagnosis, improved pharmacological interventions and the advent of neuro-surgery as a treatment modality for certain types of epilepsy (Engel *et al.* 2008). More recently, there is accelerating interest in the genetic pathways associated with seizures and epilepsy, which is driven by advancements in genetics, molecular biology, neuro-physiology and functional imaging (Kullmann 2002).

Internationally, evidence-based clinical guidelines do exist to inform clinical practice in the context of the diagnosis and management of epilepsy (Brodie *et al.* 1997; SIGN 2003; NICE 2004). The broad general principles of epilepsy care are embodied in the Commission on European Affairs' document: Appropriate Standards of Epilepsy Care Across Europe, first published in 1997 (Brodie *et al.* 1997). In addition, the NICE guideline outlines best practice in relation to the diagnosis, treatment and management of epilepsy in children, young people, adults and older people (NICE 2004, 2012) and includes timelines for referrals from primary to specialist care for all individuals with suspected epilepsy. The document is clear that the expertise of multidisciplinary teams (MDTs), which include ESNs as an integral part of the network of care, should be available to all children, young people and adults with epilepsy. The key roles of the ESNs outlined in NICE (2004, 2012) are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and well-being.

## The healthcare journey: International and Irish PWE’s perspectives and experiences

The course of the condition in its early years is an important predictor of prognosis; the longer epilepsy remains active the poorer the long-term prognosis (Engel *et al.* 2008). This illustrates the need for epilepsy care to be accurate, timely, and co-ordinated so that a diagnosis can be confirmed or excluded in order to facilitate the expeditious initiation of the most clinically effective and cost efficient treatment. Despite the evidence that supports the early and accurate diagnosis of epilepsy in the context of improved outcomes and cost-effectiveness (Langfitt & Wiebe 2002), the condition is frequently misdiagnosed and/or inappropriately treated (Montouris *et al.* 2000; Minshall and Smith 2008). In addition, despite a significant proportion of PWE (70%) having the potential to be seizure-free, in many instances PWE do not receive adequate care (Moran *et al*. 2000). International literature exploring PWE’s experiences of healthcare identify a number of problems, including delays in access to specialist services, lack of systematic follow-up, inappropriate polypharmacy, non-compliance with medication, poor patient education on epilepsy, lack of provision of information on availability or role of self-help groups, lack of psychological support and communication failures within the MDT (Ridsdale 1995; Thapar 1996; Ridsdale *et al.* 1996; Mills *et al.* 2002; Ridsdale *et al.* 2000). In addition, PWE report that doctors are too busy and have too limited time to explain diagnoses, treatments, drug interactions and side-effects, to comprehensively address the psychosocial implications of epilepsy, such as driving or alcohol, or are too busy to focus on the person’s concerns (Ridsdale *et al.* 1999b; Noble *et al.* 2013). In addition, General Practitioners (GPs) are viewed as having insufficient expertise in the area of epilepsy to be able to answer PWEs’ questions fully (Ridsdale *et al* 1999a; Mills *et al.* 2002; Ridsdale *et al.* 2002; Noble *et al.* 2013). At the same time PWE worry that asking questions is wasting specialist neurologists’ time (Ridsdale *et al*. 2002).

Within Ireland, Varley *et al*.’s (2011a) study involving 19 PWE and their carers who were attending an outpatient service in one urban hospital reported similar deficits and inadequacies in PWEs’ experiences of epilepsy care and its management. Participants in this study spoke of delays in accessing specialist services, a lack of confidence in primary care practitioners’ competence, poor integration between different healthcare sectors, and a lack of communication and information sharing between healthcare providers. Together, these deficiencies resulted in delays in diagnosis and treatment, increased anxiety and distress for PWE and their families, and a lack of awareness of peer support or advocacy organisations. In addition, deficits in care were identified for particular groups, such as pregnant women and adolescents with epilepsy. Consequently, in summarizing the findings Varley *et al*. (2011a:305) noted that the data 'creates an impression of an environment of inertia between healthcare providers and patients in which neither has a high expectation of what the health service delivers'. An audit of 374 patient records in a community setting also confirmed that a large number of people with a diagnosis of epilepsy (75%) had no evidence of having received a recent review by a specialist, and nearly 40% had not been seen by their GP in the previous 2 years (Varley *et al.* 2011b). In addition, there is evidence to suggest that there is significant variance in the manner patients presenting with seizures at the emergency interface are cared for, with many 'being admitted when often they could safely receive care and advice and rapid follow-up' at an outpatient service, while geographic variation in the availability of, and access to, epilepsy services leads to considerable inequalities for people with epilepsy and their families (HSE 2014:8).

## Family members: Roles and experience

Family members play a significant role in the lives of people with epilepsy, especially in the case a child with epilepsy or a person with significant cognitive impairment or intellectual disability (ID) (Elliott & Shneker 2008; IOM 2012). Family/carer education and support therefore is viewed as vital to ensuring effective management of epilepsy as well as positive adjustment and coping within the family unit (IOM 2012). There is evidence that educational interventions aimed at parents result in greater knowledge, greater ability to problem-solve, greater confidence in managing seizures, better emotional coping and enhanced co-ordination and partnership in managing the healthcare needs of the child (Lewis *et al.* 2010). However, research suggests that families' and carers' need for information is not always met by healthcare professionals, in relation to prognosis, accessing services and supports, first aid, Sudden Unexpected Death in Epilepsy (SUDEP), side-effects of anti-epileptic drugs (AEDs) and information on how to address the psychological and behavioural impact of epilepsy on the person, including problems at school (Kendall *et al.* 2004; Lewis *et al.* 2010; IOM 2012). Families/carers of PWE also reported receiving low levels of practical and emotional support (Kendall *et al.* 2004; McEwan *et al.* 2007; Lewis *et al.* 2010)

## The ESN role: The international perspective

It has been noted in the international literature that epilepsy specialist nursing has developed in an *ad hoc* manner owing to the lack of consistency in the role, the caseloads and service provision (Goodwin *et al.* 2004), with the development and evolution of the role being heavily influenced by factors such as the healthcare organisation's needs, consultants' views, the resources allocated to the development of a specialised role and the individual nurse's input into the role (Higgins *et al*. 2006). Although the first ESN was appointed in the UK in 1988 (Goodwin *et al*. 2004), there is a paucity of evidence-based research about the role of the ESN in clinical practice, and a lack of clarity about what functions constitute the role on a day-to-day basis (Greenhill *et al.* 2002; Higgins *et al.* 2006; Hopkins & Irvine 2012). Some writers note that as the role has evolved it has changed from being a mainly supportive role to one which has direct clinical input, incorporating prescribing and diagnostic activities as well as developing a greater therapeutic role in PWEs' care (Greenhills *et al.* 2002; Lewis 2011).

Most literature that discusses or describes the ESN role is anecdotal, originating in the UK (Foley *et al.* 2000; Greenhill *et al.* 2002; Minshall 2004; Dupras 2005; Ford 2012). Those writers who describe the role from personal or anecdotal perspectives highlight the diverse nature of the role which spans the medical, social, psychological, emotional and educational aspects of epilepsy management and treatment. A key dimension of the clinical aspect of the role is patient assessment and management, which involves a high degree of decision-making regarding 'approaches to care for individual patients' and responsibility for 'ensuring that patients are well informed and appropriately managed' (Ford 2012:391). It involves tasks such as taking detailed patient history, ordering appropriate tests, advising the PWE on drug management and other issues, monitoring any changes to medication closely, monitoring side-effects, making referrals and arranging follow-up appointments (Foley *et al.* 2000; Greenhill *et al.* 2002; Dupras 2005). Within the clinical aspect of the role, the medical aspects of epilepsy are addressed, which include explaining diagnostic tests and diagnoses in detail, providing information and advice around medication, identifying barriers to compliance, such as lifestyle habits, exploring prognosis and future plans and addressing family planning needs (Kwan *et al.* 2000).

Another key facet of the role is the provision of support, information and advice to PWE, their families and caregivers, and other healthcare professionals involved in care (Splevings 2000; Greenhill *et al*. 2002; Higgins 2008) and the documentation of care provided (Minshall 2004). The information and advice may relate to medical aspects of epilepsy, such as causes and triggers of epilepsy, seizure types, what happens during seizures, details of assessments and tests, medication, and prognosis (Foley *et al.* 2000). It may also address the social aspects of epilepsy or lifestyle implications related to home and work, safety, leisure activities, driving, employment, self-management issues, sexual issues, and access to self-help groups (Kwan *et al.* 2000). Furthermore, the ESN may adopt a therapeutic role by counselling the PWE to enable positive psychosocial adjustment to their condition, by allaying any fears, worries or misconceptions about their epilepsy (Russell 1997; Kwan *et al.* 2000; Foley *et al.* 2000). This aspect of the role has been noted as being of particular value to young people as it may help improve their coping skills and enable them to deal with issues related to peer pressure, sexuality, depression, alcohol and drugs (Dupras 2005).

For particular patient groups or those with co-morbidities, the ESN may play a particularly significant role. For example, women who are planning pregnancy can receive pre-conception counselling, advice regarding seizure control and management of epilepsy during pregnancy, and post-partum advice regarding breastfeeding and the care of the child (Foley *et al.* 2000; Greenhill *et al*. 2002). For PWE with ID, the ESN can ‘offer appropriate information and practical experience, and act as a key person in co-ordinating suitable guidelines and protocols, safeguarding the client and his or her carer’ (Loughran and O’Brien 2002:32). The ESN working in ID services can secure comprehensive care by ensuring multidisciplinary input and fast track treatment if required (Greenhill *et al.* 2002).

The ESN also plays a key role in co-ordinating multidisciplinary care for the PWE (Kwan *et al.* 2000; Minshall 2004). They may be involved in liaising between the person and primary and secondary care teams, or between the hospital, GP and other community services (Russell 1997; Foley *et al.* 2000) with the aim of consolidating epilepsy care (Greenhills *et al.* 2002). Hosking *et al.* (2002) mention an advocacy role; however, what that might entail or how it may be enacted is not described.

In addition to the clinical and co-ordination roles mentioned, the ESN may also contribute to the continuing education and training of other healthcare professionals, such as GPs, midwives, and practice nurses (Foley *et al.* 2000), as well as being a point of contact for them for advice (Greenhill *et al*. 2002). In addition, education about epilepsy and first aid responses to epileptic seizures in communities, schools, workplaces and voluntary organisations may also be performed (Russell 1997; Kwan *et al.* 2000; Splevings 2000).

Three studies were located from the UK that undertook research describing the role of the ESN (Goodwin *et al.* 2004; Higgins *et al.* 2006; Hopkins *et al.* 2010; Hopkins and Irvine 2012). In Goodwin *et al.*'s (2004) national survey, the ESNs (N= 76) reported seeing patients across the age continuum, with 31 ESNs being involved in nurse-led clinics, 57 in joint medical clinics and 27 in multidisciplinary clinics. The ESNs in the study reported that a large percentage of their time was devoted to telephone contact, drug management and teaching. The level of involvement in drug management was mainly at a monitory and advisory level. The degree of responsibility taken by the ESNs in the nurse-led clinics varied substantially, with some taking responsibility for all decisions, whilst others made what the authors called 'a small contribution to decision-making'. Higgins *et al.* (2006) also examined the role of nine clinical ESNs by requesting them to record both their clinical and non-clinical activities over a period of 20 days and be involved in interviews. Findings indicated that they were involved in leading clinics, managing caseloads, carrying out diagnostic and prescribing activities, providing education to staff and offering specialist advice to other health professionals. In contrast to Goodwin *et al.*'s (2004) study the ESNs were working at an advanced practice level in terms of assessment and evaluation, and functioning with a high degree of autonomy. Findings from Hopkins *et al.*'s (2010) and Hopkins and Irvine (2012) mixed methods study found that in addition to clinical assessment, ordering investigations, medication management, care co-ordination and running clinics, the ESNs provided a significant level of education to patients, carers, families and others around risk-assessment and emergency care. The data also revealed that much of the work of ESNs was underpinned by the core values of holistic care; proactive and responsive care, and time for patients.

The literature on the role of the ESN in relation to evidence-based practice (EBP), research and audit is sparse, with the first mention of this aspect of the role appearing in an article by Foley *et al.* (2000:39) who commented that 'through regular audit of services…. the ESN can provide evidence of cost-effectiveness, quality and access to care'. Others in discussion papers allude to the ESN's role in sharing best practice, making use of research findings, auditing services (Higgins 2008), co-ordinating epilepsy clinical trials and assisting or leading on publishing primary research (Dupras 2005:31). Findings from Good win *et al.*'s (2004:92) study suggest that ESNs spend very little time on research, with their 'research role taking the lowest priority'. Similarly, research did not feature significantly in Higgins *et al.*'s (2006) study, however, eight out of the nine ESNs who completed the diaries and interviews were involved in audit, and two were occasionally involved in clinical drug trials, although their role was not specified.

Similar to the EBP, research and audit role, the leadership role of the ESN is given scant attention within the literature. Apart from an acknowledgment of their role in building knowledge capacity among health professionals and the general public (Foley *et al.* 2000; Higgins *et al.* 2006), and a mention of their role in developing standards, policies and guidelines (Higgins *et al.* 2006), there is no exploration of their role as clinical and professional leaders.

## Evaluation and impact of the ESN role

Similar to the literature that describes the role of the ESN, the majority of studies that evaluate the impact of the role are from the UK (Taylor *et al.* 1994; Scrambler *et al.* 1996; Ridsdale *et al.* 1997; Warren 1998; Ridsdale *et al.* 1999a; Ridsdale *et al.* 1999b; Mills *et al.* 1999a; Mills *et al.* 1999b; Ridsdale *et al.* 2000; Mills *et al.* 2002; Ridsdale *et al.* 2002; Stephen *et al.* 2003; Kirton *et al.* 2012; Noble *et al.* 2013). Studies conducted elsewhere include Sarkissian & Wennberg (1999), Helde *et al.* (2005) and Kengne *et al.* (2008), which were conducted in Canada, Norway and Cameroon respectively. Studies which reported on patient feedback regarding epilepsy specialist nursing care revealed a multitude of perceived benefits and values to the ESN role from the PWE's perspective (Taylor *et al.* 1994; Sarkissian & Wennberg 1999; Ridsdale *et al.* 1999b; Ridsdale *et al*. 2002), over and above the contribution GPs and hospital specialists were perceived as making (Scrambler *et al.* 1996; Ridsdale *et al.* 1999b; Mills *et al.* 2002). ESNs were perceived by patients as making a significant contribution to continuity of care (Scrambler *et al.* 1996; Sarkissian & Wennberg 1999; Mills *et al.* 2002; Kirton *et al*. 2012) and accessibility of care in terms of the ESN's ability to fast track care and offer appropriate referrals (Taylor *et al.* 1994; Kirton *et al.* 2012; Noble *et al.* 2013). Another aspect of care with which PWE reported satisfaction was the provision of information and advice. They were of the view that the longer duration of consultations with nurses, in contrast to other health professionals (Ridsdale *et al.* 1999b; Mills *et al*. 2002; Kirton *et al.* 2012), facilitated the seeking and provision of information and advice regarding medical aspects of epilepsy, including diagnosis, symptom experiences, medication and plan of care (Taylor *et al.* 1994; Sarkissian & Wennberg 1999; Ridsdale *et al*. 2002). They were also of the view that ESNs had time to explore the social and safety aspects of epilepsy, such as regulations around driving, the impact of epilepsy on relationships, and strategies for people experiencing difficulties in schools (Taylor *et al.* 1994; Ridsdale *et al.* 1999b; Ridsdale *et al*. 2002); and practical issues, such as obtaining disability allowance and accessing funding for home improvements (Taylor *et al.* 1994).

One study that recorded the level of advice provided in nurse-run clinics compared to the standard care process, found that the provision of information on epilepsy-related issues was indeed greater (Ridsdale *et al.* 1997). Several studies also reported greater knowledge among both staff and PWE due to the ESN's input (Taylor *et al.* 1994; Ridsdale *et al.* 2000; Ridsdale *et al.* 2002), with PWE reporting feeling better equipped to self-manage their epilepsy and participate in decision-making (Kirton *et al.* 2012), as well as having greater knowledge in relation to medication issues, such as the importance of compliance, strategies to minimise non-compliance, actions to take in the event of missing dosage, side-effects and interactions of AEDs with other medications (Ridsdale *et al.* 2002; Noble *et al.* 2013). However, some studies found that an ESN intervention had no impact on social knowledge (Warren 1998; Ridsdale *et al.* 1999a) or medical knowledge (Ridsdale *et al.* 1999a). In spite of this, Mead *et al.'s* (2002:96) systematic review of specialist epilepsy services which reviewed most of the aforementioned studies concluded that 'there was good evidence that the process of care and/or patient satisfaction was improved in the epilepsy nurse groups compared to control…' while Bradley *et al.'s* (2016) recent Cochrane review found supporting evidence of the effectiveness for ESNs in terms of improving knowledge of PWE.

Studies that have explored the impact of the ESN role on clinical outcomes found that there was little evidence of reduced seizure frequency or seizure-related injuries (Warren 1998; Mills *et al.* 1999b; Meads *et al*. 2002; Bradley *et al.* 2016), or evidence of any significant improvement in the appropriateness of medication prescribed and/or compliance with medication in patients receiving ESN care compared to those receiving standard care (Warren 1998; Mills *et al.* 1999b; Bradley *et al.* 2016). In addition, poor outcomes in relation to seizure management under ESN care were identified by Stephen *et al.* (2003); a limitation of this study is the absence of a comparison group, but two other studies found a reduction in seizure frequency. Participants in Taylor et *al.*'s (1994) study of an epilepsy liaison nurse reported fewer seizures and side-effects from medication, although these were qualitative reports from a small sample size (n=20). In addition, a pre-post evaluation of a nurse-led structured management protocol for epilepsy in a rural health district in Cameroon found a reduction in the number of seizures per month at follow-up 22 months after the intervention (Kengne *et al*. 2008).

In terms of health and psychological outcomes for PWE, such as quality of life, depression and social functioning, no differences between patients receiving ESN care and those receiving usual treatment were found in several studies (Mills *et al.* 1999a; Helde *et al.* 2005). One study found what might be interpreted as a negative impact on quality of life for PWE who had accessed an ESN. Compared to those who had not accessed an ESN service, they were more likely to report that epilepsy affected their overall health, including how they felt about themselves, their social life and leisure activities (Mills *et al.* 1999b). The authors suggest that this finding may be explained by PWE gaining a greater awareness of how epilepsy may restrict and impact on one's life following consultation with an ESN. Just one study found a more positive psychological outcome among people receiving ESN care, with depression being statistically significantly lower among the group receiving ESN care compared to a control group, although the effect was mainly in a subgroup of people with no recent epilepsy attack (Ridsdale *et al.* 1999a). The two systematic reviews on ESNs concurred that there was no reliable empirical evidence of improved clinical outcomes in PWE under the care of an ESN compared to those receiving standard treatment (Meads *et al.* 2002; Bradley *et al.* 2016).

Some studies examined the organisational impact of an ESN service in terms of cost, length of stay, practitioner workload, and healthcare service utilisation. Mills *et al.* (1999a, 1999b) completed two follow-up studies, following their controlled trial that assessed the effectiveness of a primary care based specialist nurse-led service and found that the use of the ESN did not reduce use of other healthcare services. Conversely, Warren (1998) found that the introduction of an ESN case manager resulted in statistically significantly fewer GP consultations compared to patients receiving standard care as well as reduced primary care costs. Similarly, Sarkissian & Wennberg (1999) found that the introduction of the Acute Care Nurse Practitioner (ACNP) role in an Epilepsy Monitoring Unit at a tertiary health centre in Canada reduced length of stay and costs of care, with Mead *et al.'s* (2002) systematic review concluding that there was some indication that ESNs were less expensive compared to standard treatment. Whilst 84% of consultants in Hopkins *et al*.'s (2010) study felt that ESNs reduced patient demands on their time, 29% also felt there were some increased demands due to the extra throughput of patients or the greater identification of problems. In addition, almost all consultants agreed that ESNs are good value for money and disagreed that the work ESNs do could be done by less experienced staff, with many emphasising that the ESN service is more about improving quality of care than reducing costs.

## ESN roles in Ireland and The Epilepsy Clinical Care Programme

In Ireland, epilepsy specialist nursing roles developed informally and were locally regulated. More recently, however, with the development of the National Clinical Care Programme in Epilepsy Care in Ireland (2014) a more strategic and defined role for nurses in epilepsy care has emerged. The National Epilepsy Care Programme (NECP) has been charged with the task of addressing the historic deficiencies in epilepsy care in Ireland.

The three key objectives of the transformation plan are to: improve access to expert care and information, improve quality of care across the healthcare spectrum and improve value conscious care by shifting care where possible from expensive hospital care to the community (HSE 2014:7). A key innovation of the project is the creation of a cohort of advanced nurse practitioners in epilepsy (ANPs) to augment existing medical services and to help reconfigure care away from hospital based services to more appropriate, cost-effective primary care/community based services. Within the NECP it is envisioned that every PWE in Ireland will have access to the epilepsy ANP service attached to one of the adult or paediatric centres. The NECP document outlines the following roles for the epilepsy specialist nurse:

- Provide routine follow-up care to PWE attending the epilepsy outpatient services along with medical colleagues;
- Act in a consultancy capacity in reviewing patients with an established diagnosis of epilepsy who attend the Emergency Department (ED) or are admitted and provide ongoing support to inpatients, families and parents of children admitted with seizures;
- Provide rapid access clinics (RACs) in acute hospitals providing acute neurological care for ED discharges and first seizures;
- Supporting patients and families on the epilepsy surgery programme;
- Develop outreach clinics in intellectual disability services and non-acute hospitals;
- Provide General Practitioner (GP) and community practice nurse support;
- Liaise with regional physicians in hospitals without neurology services, and with pediatricians;
- Provide telephone/e-mail/web support for patients and families;
- Establish links to Epilepsy Ireland and The Irish Branch of the International League Against Epilepsy (ILAE);
- Complete accurate and up-to-date documentation of clinical encounters using an Electronic Patient Record (EPR); and
- Use of Electronic Patient Record (EPR) and Standard Operating Procedures (SOPs) and Management Operating Procedures (MOPs) (HSE 2014:26).

## Advanced and specialist nursing roles in Ireland

Advanced and specialist nursing practice roles have existed in high-income healthcare systems for over fifty years and are now established at some level in over thirty countries; although there is significant variation in terminology used to describe the role, regulation, scope of practice, competency, critical thinking, level of autonomy, educational requirements and regulatory/statutory requirements (Coster *et al.* 2006; Sheer & Wong 2008; Delamaire & Lafortune 2010; Kennedy *et al.* 2012; Kleinpell *et al.* 2012; Carney 2016). Whilst many factors, including cultural, economic, political and professional issues, continue to influence the rate of role development and their subsequent integration into the healthcare setting (Guest *et al.* 2004; DiCenso *et al.* 2010; Donald *et al.* 2011; Hourahane *et al.* 2012; Elliott *et al.* 2013; Higgins *et al.* 2014), there is also a growing body of research evidence regarding the safety, efficiency and effectiveness of the roles across all aspects of nursing (Guest *et al.* 2004; Humphreys *et al.* 2007; Department of Health (NSW) 2007; Delamaire, & Lafortune 2010; Begley *et al.* 2010, 2013). Paradoxically, the late development of advanced and specialist nursing practice roles in Ireland has allowed policy makers and legislators to avoid some of the controversial issues that have beleaguered healthcare services internationally when developing and implementing such roles for nurses (Hourahane *et al*. 2012; Elliott *et al.* 2013, 2014; Higgins *et al.* 2014).

Within Ireland advanced practice roles are differentiated into Clinical Nurse Specialist (CNS) and Advanced Nurse Practitioner (ANP) roles, with clear definitions, educational requirements, and approval and accreditation guidelines available for each role (NCNM 2008a; NCNM 2008b). The CNS is defined as a nurse who works closely with medical and para-medical colleagues in an area of specialist clinical practice, with an additional remit for education and training, patient advocacy, consultancy and improvement in the quality of patient care through audit and research (NCNM 2008a). An ANP is defined as a nurse who is an autonomous practitioner, responsible for advanced levels of decision-making, and managing a patient caseload, who demonstrates clinical and professional leadership and advances clinical practice through research (NCNM 2008b).

Internationally concern has been raised regarding the absence of universal standards for the educational preparation of nurses working at advanced level, with the education of nurses varying from diploma to masters and PhD level (Cox and Ahluwalin 2000; Daly and Carnwell 2003; Begley *et al.* 2010; Carney 2016). To register on the ANP division of the register held by the Nursing and Midwifery Board of Ireland (NMBI) the person must be a registered nurse on the active register maintained by the NMBI and hold a Master's degree in nursing or a higher degree which contains substantial modules related to advanced practice in the candidate's specific area of expertise. Currently, the NMBI has laid down a minimum of 7 years' post-registration experience of which 5 years must be in the candidate's chosen nursing specialty (Carney 2016). The NMBI has legislative responsibility for registration and re-accreditation of individuals who have met the criteria and standards set down by the National Council for the Professional Development of Nursing and Midwifery (NCNM 2008a). The professional accountability of all nurses, including nurses working at specialist and advanced level is defined by the Scope of Nursing and Midwifery Practice Framework (NMBI 2015). In addition, the professional responsibilities of nurses with prescriptive authority are outlined in the 2010 edition of the Practice Standards and Guidelines for Nurses and Midwives with Prescriptive Authority document (NMBI 2010).

From a local governance perspective the consultant epileptologist or paediatric neurologist provides clinical governance, and is responsible for CNSs' and ANPs' clinical training, with professional governance of the nurses being the remit of the Director of Nursing (DoN). Nurses working away from the regional epilepsy centre in another hospital or healthcare setting are professionally accountable to the DoN in these outreach hospital or healthcare settings. In addition, the National Epilepsy Care Programme has developed a book of Standard Operating Procedures (SOPs) and Management Operating Procedures (MOPs), which underpin the work of the ESN (HSE 2014).

## Chapter 2

# Methods

# Chapter 2: Methods

## Introduction

This chapter describes the aim and objectives of the study, together with the data collection methods used. The chapter includes information on access to study sites, sampling and recruitment strategies and a profile of participants involved. Issues relating to recruitment, data analysis, ethics, and study quality, strengths and limitations are also discussed.

## Aim and objectives

The aim of this study is to identify the role and cost-effectiveness of the Epilepsy Specialist Nurse (ESN) in Ireland and to evaluate their impact on patient experiences, quality of life (QoL) and satisfaction with care.

### *Objectives*

The objectives of the study are divided into the following three distinct areas.

#### Role of ESN: Descriptive analysis

- To identify the role and scope of the ESN in the delivery of patient care within the multidisciplinary healthcare team in Ireland.

#### Impact of role of ESN: Comparative analysis

- To determine if there is a difference in patient QoL, experiences and satisfaction for those who receive care for more than 12 months from services with an ESN, compared to those receiving care from services without an ESN.
- To evaluate the impact of the ESN on patient QoL, experiences and satisfaction with care for a cohort of new patients who receive care for more than 12 months from services with an ESN, compared with a similar cohort receiving care from services without an ESN.

### Cost of ESN role: Economic analysis

- To assess the costs to the health service of caring for people with epilepsy in the community in terms of use of hospital, primary and community health services and wider costs in terms of the impact on patients and their families.

## Research design and methods

The complex nature of healthcare organisations provides a significant methodological challenge for researchers interested in evaluating innovative programmes or initiatives (Lambert *et al.* 2006; Mills 2012). Every service has its own distinctive way of operating and delivering care, consequently it can be difficult to set up appropriate comparisons in a traditional randomized trial format (Petticrew and Roberts 2003). For the **SEN**s**E** study, we adopted a pragmatic approach (Feilzer 2010) in developing the research design to achieve the objectives. The study used a mixed methods approach, with three concurrent interrelated phases (figure 2.1). Phase one comprised a case study and gathered information from ESNs and key stakeholders (patients, family members and members of the MDT) with whom the ESNs had contact in order to i) reveal the context, scope and complexity of the nurse's role; ii) identify the perceived benefits of the role and, iii) provide insight about the impact of nurses' roles that are not easily explained or measurable (Bryant-Lukosius 2009). The second phase included a comparative survey design involving PWE from sites where ESNs worked and sites where no ESNs were employed. The third phase included an economic component that aimed to compare the costs of clinical activity and the monetary impact on PWE and their families treated in ESN and Non-ESN sites.

**Figure 2.1: Study design**

### *Sampling of sites and participants*

Sampling methods included a combination of purposive sampling and convenience sampling, both forms of non-probability sampling. Purposive sampling is a form of sampling in which decisions concerning the selection of sites and individuals are taken by the researcher, based upon a variety of criteria, and may include specialist knowledge of the research issue or research field (Polit and Beck 2012). Convenience sampling is a sampling technique where participants are selected because of ease of access or proximity (Robson 2002).

Sites: The study was conducted in sites where ESNs worked and sites where no ESNs were employed. Purposive sampling was used to select the sites, based on information-oriented sampling, which allowed for sites with and without ESNs to be compared for size and geographic spread. Initially 10 sites (5 ESN and 5 Non-ESN) were recruited to the study. Nine of the sites were adult services and one was a children's service with ESNs. As the study unfolded one Non-ESN site became an ESN site and data collection in that site had to stop. In addition, a number of other issues emerged that impacted on data collection. These will be discussed later in the section on factors impacting data collection.

Participants: Participants in the study included ESNs, Directors/Assistant Directors of Nursing (DoN/ADoN), members of the MDT, patients, and family members/carers. Selection of the ESNs, DoN/ADoN, and members of the MDT was based on a purposive sample of people who could inform the research question as opposed to random sampling (Polit and Beck 2012). Convenience sampling was used to select patients and family members/carers and focused on those present in clinics at the time of data collection or who were willing to attend an interview on a particular day.

### *Access to sites*

DoNs and relevant medical consultants in all sites targeted for inclusion were contacted to seek support for the study. Written information on the aim, objectives and proposed methodology of the study was sent to the DoNs and medical consultants, which was followed up with a telephone conversation. Once permission for access was granted and ethical approval was received from the University's ethics committee and the relevant site's ethics committee, recruitment of participants commenced.

### *Recruitment of participants*

All participants were invited to take part through an informed consent process. Formal study invitations, including information leaflets tailored to each group, were given to potential participants. In addition, members of the research team visited each site and made formal and informal presentations to potential ESN participants and medical consultants.

Recruitment of ESN: Contact details for all relevant ESNs were given, with ESN permission, to the research team by the DoN in the five participating sites. Written information about the study was then provided to all ESNs and in some sites an oral presentation was made to the relevant medical consultant and ESNs. Once the ESNs had a minimum of one week to consider the information given, recruitment was undertaken in person by members of the research team.

Recruitment of key stakeholders: Written information about the study was given to all DoNs at the beginning of the study. Once they had a minimum of one week to consider the information, recruitment for interview was undertaken in person by members of the research team. To identify other potential key stakeholders, each ESN was asked to provide a list of people they interacted with on a daily, weekly, monthly and less frequent basis. They were also asked to seek permission to pass on the names and contact details of those listed to the research team. Similar to recruitment of other participants, written information about the study was then sent to a selection of people and once they had a minimum of one week to consider the information provided, recruitment for interview was undertaken in person by members of the research team.

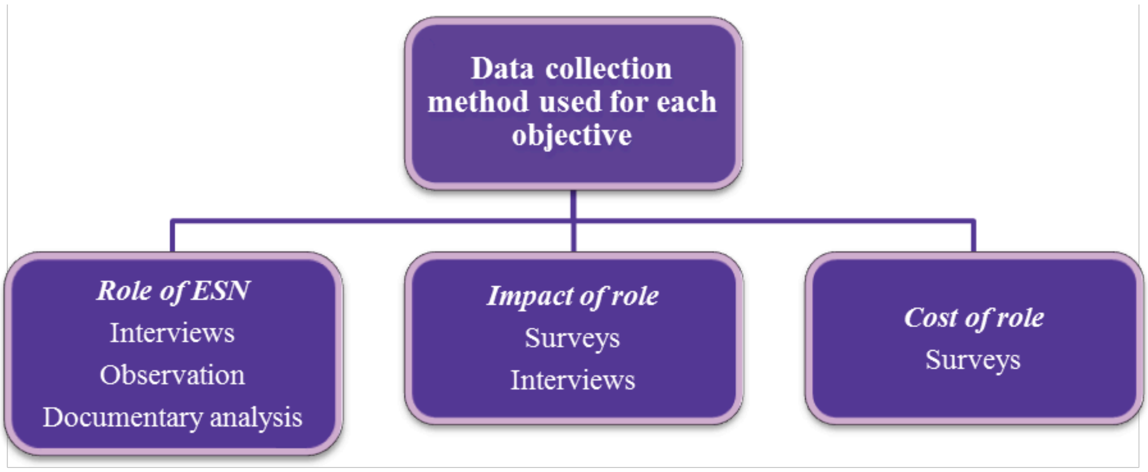
Recruitment of PWE for the survey: To recruit PWE for the survey aspect of the study, packs containing surveys and information about the study were initially given to PWE by members of the MDT when they attended Outpatient Department (OPD) services. Return of surveys using this method was extremely poor. After consultation with the MDT this recruitment strategy was added to and modified by the attendance of researchers at the relevant outpatient clinics within each site. Potential participants who were identified by a MDT member as meeting the inclusion criteria were given a survey pack, by the researcher, on their arrival to the clinic and a verbal explanation about the study was provided. They were also informed that they could take the surveys away and return them by post, or complete them while they were waiting. As one survey was a follow-up postal survey, PWE were requested to provide contact information (postal address) for the follow-up survey. To protect confidentiality, the form, giving permission for follow-up and containing the postal address, was returned to the researchers in a separate envelope from the survey.

Recruitment of PWE & family members/carers to focus groups: To recruit patients/carers for focus groups, information packs containing details of the aim and objectives of the study were distributed by the ESN to people who, they considered, met the inclusion criteria, inviting their participation. The information leaflet contained a date, time and venue for the focus group and potential participants were asked to contact the research team if interested in participating.

## Overview of data collection and profile of participants

Data were collected using a mixed methods approach, consisting of i) interviews (individual and focus group) ii) non-participant observation of ESNs; iii) documentary analysis and iv) surveys (prospective and retrospective). Figure 2.2 provides an overview of the method used to achieve each study objective.

**Figure 2.2: Data collection method**



### *Interviews*

As a means of data collection, the interview is a conversation that has a structure and purpose, the purpose being the discovery of participants' thoughts, feelings and behaviours (Kvale 1996; Gubrium & Holstein 1997; Rubin & Rubin 2005). Interviews were therefore particularly suited for this study, given the aim and objectives. Interviewing in research comprises many different formats and can involve one participant or a group of participants and may vary from highly structured to completely unstructured (Holloway & Wheeler 2002; Parahoo 2006). In this study both individual and group interviews were used to collect data. All interviews were semi-structured in nature, guided by an interview schedule developed by the research team, and audio recorded with permission. Individual interviews were used to collect data from ESNs, DoNs/ADoNs and members of the MDT. Focus groups were deemed particularly appropriate to collect data from PWE and carers as they provided an opportunity for participants to explore the subject matter under discussion through dialogue with others who have similar experiences (Ryan *et al.* 2014). Individual interviews were conducted with ESNs in order to:

- Explore their perceptions of their role and contribution to patient care, service delivery, support for staff, evidence-based practice and other outcomes; and
- Develop an understanding of the context within which care is delivered.

The initial target number for recruitment was 10 ESNs from the 5 sites involved in the study; however, to ensure maximum involvement this was increased to 12 ESNs. Five ESNs worked in one of the participating sites, one site was a single post-holder site, and 2 ESNs were recruited from each of the remaining three sites. A more detailed profile of the ESNs who participated is found in tables 2.1 and 2.2.

**Table 2.1: Profile of ESNs**

| Gender | Current title of ESNs | Employment status |
|---|---|---|
| Female n=12 | RANP n= 2<br>Candidate ANP n=5<br>CNS n= 5 | Full time n=10<br>Part time n=2 |
| **Time in current post** | **Time working in epilepsy** | **Length of time since qualifying as nurse** |
| Mean=5.42 years (SD=5.69)<br>Range= 3-21 years | Mean= 10.42 years (SD=6.02)<br>Range= 3-21 years | Mean = 20.92 years (SD=6.92)<br>Range = 12-34 years |

**Table 2.2: Participants' qualifications**

| Epilepsy-specific qualifications | Academic qualifications other than epilepsy-specific | Professional qualifications |
|---|---|---|
| MSc Epilepsy/advanced practice (epilepsy) n= 5<br>Diploma/Postgraduate Diploma in epilepsy care/advanced practice epilepsy care n= 6<br>Certificate in Epilepsy n=2<br>Currently completing MSc in Epilepsy/Advanced Practice (Epilepsy ) n=3 | Masters in Nursing<br>BSc in Nursing Studies<br>Post graduate/higher diploma/diploma in: Neuroscience Nursing; Critical Care; Women's Health; Management; Intensive Care<br>BSc in Nursing Management<br>Certificate in: Intensive Care; Anaesthetic room recovery; Infection Control | Registered General Nurse n =12<br>Registered Children's Nurse n=4<br>Registered Nurse in Intellectual Disability n=2<br>Registered Midwife n=1<br>Registered prescriber of medicinal products n=7<br>Registered prescriber of ionizing radiation n=1 |

Individual interviews were also conducted with key stakeholders working with ESNs to:

- Explore perceptions of the impact of the role on patient care, service delivery, support for staff, evidence-based practice and other relevant outcomes; and
- Develop an understanding of the context within which care is delivered.

Information-oriented sampling, as opposed to random sampling, was used to select key clinical stakeholders, ensuring that professions, disciplines, roles and sites were represented. Initially, it was intended to interview 10 people, however as the study unfolded it became clear that ESNs had contact with multiple stakeholders from a variety of disciplines. In order to get a comprehensive view from all perspectives this number was expanded. In total, 22 clinical team members were interviewed, one by telephone and 11 in face to face interviews. Five DoNs/ADoNs were included to provide a management perspective. Table 2.3 provides a role profile of the participants interviewed and table 2.4 outlines the spread of interviews across the sites.

**Table 2.3: Profile of the key clinical stakeholders**

| Role | N |
|---|---|
| DoNs/ADoNs | 5 |
| Medical consultants or other medical personnel (epilepsy, epilepsy surgery, obstetrics) | 6 |
| Allied health professional (psychologist, physiologist, social worker, administrators) | 6 |
| Other nurses at Clinical Nurse Manager (CNM) level | 2 |
| Administrative (Manager of intellectual disability service, administrator, secretary in epilepsy clinic) | 3 |
| **Total** | **22** |

**Table 2.4: Spread of key stakeholder interviews across the sites**

| Site | A | B | C | D | E |
|---|---|---|---|---|---|
| **No. of interviews** | 4 | 6 | 4 | 3 | 5 |

Five focus groups were conducted with PWE/family members/carers to:

- Explore PWE/family member perspectives on the impact of ESNs on care received, service delivery, support and education, continuity of care, access/management of epilepsy and other relevant outcomes.

PWE were not included if they were considered by a member of the MDT as being too ill to take part, lacking in ability to give informed consent, or unable to hold a conversation in the English language. In total 35 PWE/family members (21 PWE who received care from ESNs and 14 family members) were involved in five focus groups. The average duration of each of the focus groups was 75 minutes. Table 2.5 provides an overview of the participants in each focus group.

**Table 2.5: Focus group participants**

| Site | A | B | C | D | E |
|---|---|---|---|---|---|
| **Number of participants** | 7 | 8 | 8 | 5 | 7 |
| **Gender of participants** | F=6<br>M=1 | F=4<br>M=4 | F=4<br>M=4 | F = 3<br>M =2 | F= 6<br>M=1 |
| **Relationship** | 7 PWE | 8 PWE | 6 PWE<br>1 spouse<br>1 mother | 3 mothers<br>2 fathers | 6 mothers<br>1 father |

### *Non-participant observation of ESNs*

Observation is used extensively in case study research and involves the researcher entering a social system to observe activities, interactions and other events in order to gain an in-depth understanding of the phenomenon in a natural context (Baker 2006). Walshe *et al.* (2012) suggest that observational research techniques have advantages over other qualitative data collection methods when the focus of the research is on understanding actions, roles and behaviour. Within observation, the role of the researcher can vary from participant-as-observer to non-participant observer. As a non-participant the researcher does not participate in the activities being observed, but their status as a researcher is known to the participant (Robson 2002; Liu and Maitlis 2013).

Non-participant observation of ESNs working in the healthcare setting was undertaken to: i) identify the role, scope and practices of the ESN; and ii) discover the context in which care is given. Each of the 12 ESNs were shadowed by a member of the research team for a two-hour session on at least two occasions as they delivered care and interacted with PWE, family and members of the multidisciplinary team (MDT). In total, 61 hours of observation were completed in a variety of contexts, including the ESN working in hospital and outreach clinics, participating in the telephone advice line (TAL), visiting in-patients in wards, attending MDT and other meetings and providing formal educational inputs. Similar to interviewing, data may be collected using a highly structured or a more open and less prescriptive approach (Polit and Beck 2012). Within this study a semi-open approach to data collection was used. Guided by Robson's (2002) dimensions of descriptive observation, the researcher made a written record (fieldnote) of space and objects (layout of settings, decor), actors (relevant details of those involved), activities (various actions of actors, including ESNs, PWE and members of MDT), factors influencing actions (care pathways and relevant policies or guidelines followed), events (particular occasions e.g. meetings, education sessions), timing (sequence of events), goals (what actor was attempting to accomplish), and resources (IT, library resources available to support the ESN role). To assist the researcher to give form and accuracy to the data collected, the researcher often asked questions of the ESN on observations made. This was important in terms of assisting with identifying factors influencing activities, goals and resources.

### *Documentary data*

Documentary data have been widely used and are an important source of information in healthcare research (Atkinson and Coffey 2004). Bowen (2009:29) suggests that documentary analysis 'is particularly applicable to qualitative case studies'. Compared to other data collection, documentary analysis is what Bryman (2012) calls a relatively 'non-reactive' methodology. In other words, the data that are contained within documents are constructed independently of any research study; consequently, there is little risk of the data collection process intruding upon or influencing the quality of the data in question (Robson 2002). Documents also provide supplementary data that can be used to contextualise or clarify other methods of data collection, or provide data that gives 'witness to past events' (Bowen 2009:29). Despite being secondary sources of data, the primary advantage of analysing documents in this study is that it enabled the team to capture data on the ESN role in education, policy development and audit/research, areas that were not particularly evident during interview and observation. They also provided an opportunity for the triangulation of other data captured during interview, observation and survey (Bryman 2012), thus reducing the impact of potential bias of a single method (Bowen 2009). Participating ESNs were asked to provide the research team with any documentary evidence of role activity such as: continuing professional development, committee membership, education or curriculum activity, guideline development, research/audit activity, and publication or conference presentation activity.

### *Retrospective survey: Patient experience and quality of life (QoL)*

Data were also collected from PWE who were attending sites where ESNs worked and sites where no ESNs were employed, using two different self-completed surveys.

To determine if there was a difference in patient experiences and satisfaction with care, including patient QoL, a retrospective survey was administered to patients attending a service with an ESN and a cohort of patients who attended a service without an ESN, who met the following inclusion criteria:

- Have a diagnosis of epilepsy and be aware of diagnosis;
- Be attending a service with or without or without an ESN for 1 year or more;
- Be over 18 years of age; and

- Not have an ID or dementia to the level that they would not be able to self-complete the survey.

Patients who transferred between different ESN services could be included.

The survey, a 38-item questionnaire, included sections on demographics, information provided on epilepsy (20 items), continuity of care (7 items), involvement in care (6 items), views on the healthcare team (8 items), and satisfaction with emotional and practical support. One of the statements related to pregnancy and was therefore only applicable to females. Some questions within the survey were adapted from the the modified Picker patient survey (Picker Institute Europe 2011) used within the SCAPE study (Begley *et al.* 2010). Responses ranged from 1 ('strongly disagree") to 5 ("strongly agree") with higher scores reflecting higher levels of agreement. The survey also assessed PWEs' quality of life using the QOLIE-10-P, an adaptation of the QOLIE-10. It asked participants to rate the degree to which a number of epilepsy-related issues had impaired their quality of life over the past 4 weeks (Somerville *et al.* 2007). In addition, the survey gathered information for the economic aspect of the evaluation. The majority of the questions posed for the economic arm used a combination of Likert scales and yes/no responses; however, where specific information on service utilisation was required, participants were permitted to write-in answers. In addition, an open-ended question was included at the end of each survey which allowed for comments on any aspect of service or care. Each survey was designed to take approximately 15-20 minutes to complete. Permission to use QOLIE copyright questionnaires and the modified Picker Patient questionnaire were obtained before use.

The target sample for this survey was 500 returned surveys (250 in ESN and 250 in Non-ESN sites). This assumed an alpha level of 0.05, and sufficient power (≥0.80) to detect differences in proportions between care given by the two groups, in primary outcome measures of:

- Communication (explaining tests, providing information on danger signals regarding illness or treatment, and giving information to families): a difference of at least 15% (45% increased to 60%) - required 186 in each group.

- Physical care and practical advice: a difference of at least 12% (62% increased to 74%) – required 252 in each group.
- Psycho-social care (patients have sufficient time to discuss problems, patients treated with respect, clinicians not speaking about patients to others in front of them): a difference of at least 12% (70% increased to 82%) – required 214 in each group.

The above rates were based on achieved results in the SCAPE study (Begley *et al.* 2010).

### Response rate and profile of participants

In total 515 surveys were returned from participants over 18 years of age, with a total of 505 usable (244 ESN and 261 Non-ESN sites) (table 2.6).

**Table 2.6: Response rate from Non-ESN and ESN sites**

| Site | N | % |
|---|---|---|
| Non-ESN | 261 | 51.7 |
| ESN | 244 | 48.3 |
| **Total** | **505** | **100** |

Five of the hospitals were Non-ESN sites and the remaining three hospitals were ESN sites (see appendix 1a for breakdown of response per site).

**Demographic profile:** There were more female than male participants from both the Non-ESN (54.9% vs. 45.1%) and ESN (56.8% vs. 43.2%) sites. Most participants from the Non-ESN sites were either single (35%) or married (36.2%), similar to the ESN sites in which 39.9% of participants were single and 30% were married. Higher numbers of participants were between the ages 31 and 40 for both the Non-ESN (25.2%) and ESN (34.2%) sites. The age group with the lowest number of participants was 71-80 with only 3.6% in the Non-ESN sites and 0.8% at the ESN sites. The vast majority of participants for both sites lived at home with family (approximately 78%). As expected, a very low number of participants lived in supported accommodation or residential care (1.3% from Non-ESN sites and 2.2% from ESN sites). There were no statistically significant differences between Non-ESN and ESN sites on gender, relationship status or living arrangements. There was a statistically significant difference in age according to age group classification between the two sites ($x^2$ (6) = 16.418, p=0.012). The differences between the two sites appear to be most pronounced among the 21-30, 31-40 and 41-50 age groups (see appendix 1b for more detail).

The majority of participants were white Irish representing approximately 90% from both sites. The highest level of education reported by participants was secondary school education, with approximately 40% for both sites, followed by third level education, with approximately 36% for both sites. Three participants reported having no formal education in both ESN sites and Non-ESN sites while 11.9% of participants from Non-ESN sites reported having primary school education as the highest level of education attained compared to 6.9% from ESN sites. Most participants reported their current work status as ‘working for payment or profit’ (Non-ESN sites: 33.6%; ESN sites: 35.5%). Approximately a fifth of participants from both sites reported being unable to work. There were no statistically significant differences between Non-ESN and ESN sites on ethnicity, highest educational level or current work status (see appendix 1b for information on ethnicity, level of education and work status by site).

**Epilepsy profile:** Most participants had epilepsy for more than five years (77.4% from Non-ESN sites and 77.8% from ESN sites). More than 95% of participants from both sites reported being on an AED, while very few participants stated having a vagal nerve stimulator (VNS) (Non-ESN sites: 4.5%; ESN sites: 6.5%). The highest frequency of seizures reported was a ‘few times a year’ (Non-ESN sites: 22%; ESN sites: 20.6%). A majority of participants indicated that they were seizure free for both Non-ESN (39.2%, n=106) and ESN sites (33.6%, n=80), with similar percentages of participants in both sites indicating that they rarely/never missed medication (Non-ESN sites: 71.3%; ESN sites 73.7%). There were no significant differences between Non-ESN and ESN sites in terms of their epilepsy profile or for AED and VNS treatments. However, higher proportions of participants from ESN sites (12.8%) reported having had surgery for epilepsy compared to Non-ESN sites (5.4%). This difference was found to be statistically significant ($x^2$ (1) = 8.226, p=0.004) (see appendix 1c for the epilepsy profile of participants in relation to length of time of having epilepsy, AED treatment, VNS, epilepsy surgery and frequency of seizures).

The vast majority of participants (approximately 50% for both sites) stated that the duration of seizures was between 1 and 10 minutes, followed by 10-59 second seizures for approximately 30% of participants in both sites. A higher proportion of those in Non-ESN sites reported experiencing seizures of over thirty minutes duration (7.9%) compared to those in ESN sites (2%). Overall there were a small number of participants who experienced very brief seizures of less than 10 seconds and long-lasting seizures of over thirty minutes. For most participants recovery time after a seizure took between 1-10 minutes of which 24.4% were from Non-ESN sites and 22.6% were from ESN sites. There were no statistically significant differences in duration of seizure and recovery time after a seizure between the sites (see appendix 1c for further information on the duration of seizures, and recovery time after seizures for participants from both Non-ESN and ESN sites).

Participants were asked about eleven types of symptoms experienced during seizures, including loss of awareness, auras, confusion, drop/spill objects, falling, injury, tongue biting, incontinence, automatism, convulsions, and staring. The most common types of symptoms reported were: loss of awareness (Non-ESN: 71.2%, n=111; ESN: 78.1%, n=125) and confusion or agitation (Non-ESN: 69.8%, n=109; ESN: 68.8%, n=110). Incontinence was the lowest reported symptom experienced during a seizure by participants from both Non-ESN sites (28.8%, n=45) and ESN sites (24.4%, n=39). A statistically significant difference was found for the symptom of warning or aura with a higher proportion of people from ESN sites (64.4%) reporting having experienced warning or aura compared to Non-ESN sites (51.3%) ($x^2$ (1) = 5.555, p=0.018) (see appendix 1c for more detail on symptoms experienced).

Table 2.7 indicates that a higher proportion of both Non-ESN participants (31.4%) and ESN participants (25.4%) reported attending the hospital service for 3 to 5 years. A higher number of Non-ESN participants were attending the service for over 26 years compared to ESN participants (n=24 compared to n=3).

**Table 2.7: Number of years attending service**

| Years | Non-ESN (n, %) (n= 236) | ESN (n, %) (n= 229) |
|---|---|---|
| 0 – 1 year | 26, 11% | 29, 12.7% |
| 2 years | 27, 11.4% | 33, 14.4% |
| 3 – 5 years | 74, 31.4% | 60, 26.2% |
| 6 – 9 years | 37, 15.7% | 32, 14% |
| 10 – 15 years | 32, 13.6% | 44, 19.2% |
| 16 – 20 years | 12, 5.1% | 19, 8.3% |
| 21 – 25 years | 5, 2.1% | 9, 3.9% |
| 26 – 30 years | 11, 4.7% | 1, 0.4% |
| + 31 years | 13, 5.4% | 2, 0.9% |

### *Prospective survey: Effect of ESN on patient knowledge, attitudes and QoL*

To evaluate the effect of the ESN on patient knowledge, attitudes and QoL, a survey was administered to a cohort of newly diagnosed patients in services with and without an ESN (time point 1) and followed up 12-14 months later (time point 2). To be included patients needed to meet the following inclusion criteria:

- Be aware of diagnosis and have accepted diagnosis;
- Be over 18 years of age;
- Not be too distressed, at the time of data collection, to participate or give informed consent or assent;
- Not have an ID or dementia to an extent that it would inhibit them from completing the surveys.

The survey included a section on demographics and three sub questionnaires: Knowledge of own epilepsy (19 items reflected the items included in the retrospective survey on information provided); Knowledge of Epilepsy Scale (May & Pfafflin 2002); and the QOLIE-10-P questionnaire (Somerville *et al.* 2007).

The target for the sample was 154 (77 in ESN and 77 in Non-ESN sites). Despite repeated efforts to recruit, the targets set were not achieved.

### Response rate and profile of participants

At point one, 72 new patients in ESN services and 13 in Non-ESN services completed the survey (see appendix 2a & 2b for demographic and epilepsy profile of all survey 1 participants). At time point two, there was there was nearly a 50% drop-off in completion, with 38 patients in ESN services and 6 in Non-ESN services completing the survey (see table 2.8). Matched data (i.e. survey filled out by participants at two time points of data collection) was available for 45 participants, 38 in ESN sites and 6 in Non-ESN sites.

**Table 2.8: Response rates from ESN and Non-ESN sites**

| | Non-ESN sites | ESN sites |
|---|---|---|
| **Time 1** | 13 | 72 |
| **Time 2** | 6 | 38 |

Among the ESN sample, the majority were female (59%), white Irish (89.7%), educated to second level (56.4%), married/civil partnered or in a relationship (61.5%), and living with family (79.5%). The average age of the ESN sample was 42 years with a range of 18 to 77 and just over two-fifths were working for payment or profit (41%). Four of the six Non-ESN participants were female, all were white Irish and living with family, and the average age among them was 30 years of age, with a range of 16 to 47 (see appendix 2c). There was no difference in terms of demographics between non-participants and participants to the follow-up survey (see appendix 2d). The highest frequency of seizures reported by ESN participants was a ‘few times a year’ (31.6%), followed by once a year (15.8%), with duration of seizures most commonly lasting between 1-10 minutes (44.7%) and recovery time taking more than 3 hours for nearly a third of ESN participants. Half of Non-ESN participants (n=3/6) reported seizures lasting between 1-10 minutes and taking 3 hours to recover from seizures (see appendix 2e for more detailed information).

Participants were also asked about eleven types of symptoms experienced during seizures, including loss of awareness, auras, confusion, drop/spill objects, falling, injury, tongue biting, incontinence, automatism, convulsions, and staring. Among the ESN sample, the most common symptoms experienced by the majority of participants included loss of awareness, falling to the ground, tongue biting, convulsion and confusion (appendix 2e provides the full list of symptoms experienced by site).

## Economic data

Initially, this study aimed to collect cost data at the hospital level. Hence, data including pay and non-pay costs for 2013 for the epilepsy service were requested from relevant personnel in each hospital. However, this proved difficult to capture for the hospitals, as budgets in some hospitals were not allocated specifically to neurology or specifically to the epilepsy service. Casemix data, which involves the comparison of activity and costs between hospitals by classifying hospital data into a manageable number of discrete groups, called DRGs (Diagnosis Related Groups), which are clinically similar and consume similar resources was not deemed to be applicable for the **SENsE** study. In particular, the aim of the economic analysis was to compare the differences in resource use among PWE who attended a hospital with an ESN with PWE who attended a hospital without access to an ESN to manage their epilepsy.

Considering this issue, it was decided to collect utilisation data at the patient level by adding relevant questions to the retrospective survey for return patients. The data collected included the number of Emergency Department attendances, the number of nights spent in hospital for epilepsy, outpatient visits, GP visits and the number of days spent off work/school/college for patients and their carers (relative/friend) for epilepsy over the previous 12 months.

## Factors impacting on data collection

As the study unfolded a number of issues emerged which impacted on the survey aspect of data collection: i) one Non-ESN site became an ESN site after the project began and data collection in that site had to stop; ii) data collection in one of the ESN sites, which was a single post-holder site, was impacted on as the ESN went on extended leave for a significant portion of time. Hence, this site could not be included for phase 2 and 3, and there was no other site within the country with ESN posts that would meet the criteria for inclusion in the study; and iii) survey recruitment from another Non-ESN site was very low.

Recruiting people newly diagnosed with epilepsy to the study was very challenging in both ESN and Non-ESN sites but most problematic in Non-ESN sites, and the target set was not achieved. The main issues were: an epilepsy diagnoses frequently takes a long time to reach and, despite the researcher presence in clinics, there were many days when no PWE meeting the inclusion criteria were present. In addition, even when patients were present they were still distressed about their diagnosis or not at the stage of acknowledging to themselves their diagnosis, hence it would have been unethical for a member of the research team or the MDT team to attempt to recruit the person at that time. In the Non-ESN sites some newly diagnosed PWE were transferred to specialist services for investigation and diagnosis, hence they could no longer be included within the Non-ESN sites. Despite putting in a number of measures, including making repeated visits to clinics, gaining the assistance of members of the MDT to identify potential participants and extending the time line, the researchers did not manage to recruit the numbers required. In addition, despite two reminders (postal of new surveys and email/text reminder to those who had provided contact details) a percentage of participants were also lost to follow-up.

Originally, it was anticipated that cost data & Hospital In-Patient Enquiry Scheme (HIPE) data relating to inpatient and outpatient treatment would be collected at the hospital-level as part of the economic data. However, following extensive follow-up with the neurology department in each site (ESN & Non-ESN), it became clear that the level of cost information required was not readily available as budgets are allocated in a block grant. Patient-level costing is not yet developed in Ireland. Considering this issue, as previously highlighted, it was decided to collect utilisation data at the patient-level by adding relevant questions to the main **SEN**s**E** survey for return patients.

## Data analysis

The analysis of data collected through mixed methods is a complex process (Greene 2007). Data interpretation and analysis involves making sense out of what is observed, said, and measured, looking for patterns and integrating multiple sources and findings into a coherent explanation of the phenomenon (Streubert Speziale & Carpenter 2007). Within this study, different approaches were taken to each dataset.

### *Qualitative data*

Template analysis was undertaken on data that contributed to answering objective one (see table 2.9). The focus of objective one was on the role and scope of the ESN in the delivery of patient care.

**Table 2.9: Overview of the data and sources that contributed to answering objective one**

| Data collection method | Sites with ESN |
|---|---|
| Individual interviews (N= 34) | 12 ESNs<br>5 DoNs/ADoN<br>17 other MDT members |
| Observation | 12 ESNs (61 hours of observation) |
| Documentation | For 12 ESNs |
| Focus groups | 21 PWE/ 14 family members (5 focus groups) |
| Qualitative data from open-ended questions on survey with new and return patients | 505 retrospective surveys<br>44 prospective matched surveys |

Template analysis is a well-embedded analytical method in healthcare research and has been used within a range of epistemological positions (King 1998; King 2012). It is a style of thematic analysis that ‘balances a relatively high degree of structure in the process of analysing textual data with the flexibility to adapt it to the needs of a particular study’ (King 2012:426). Within the template approaches, the researcher ‘produces a list of codes or ‘*a priori* codes’ (their template) based on a hierarchical structure that forms the basis for the analysis (King 2012). King (2012) advocates one of three approaches towards the development of a template: the researcher develops template codes based: i) on a subset of the data; ii) on a predefined theoretical position or other predefined frameworks; and iii) on a ‘half way approach’, using either of the previous two approaches (some initial codes) with an openness to refinement and the addition of codes as the analysis unfolds. Within this study the third option was used, namely the combination of a deductive approach using ‘*a priori* codes’, with new codes being added as and when they emerged from the data. The ‘*a priori* codes’ identified were informed by a number of sources, and involved the development of codes at three different hierarchical levels.

The first level, or higher order codes, consisted of the following four codes: clinical practice, leadership, research/audit and context of service delivery. The codes ‘clinical practice’, ‘leadership’ and ‘research/audit’ were codes that emerged from the evaluation of the clinical nurse and midwife specialists, and advanced nurse and midwifery practitioner roles in Ireland (SCAPE study) (Begley *et al.* 2010). These codes also corresponded well with international role descriptions for nurses working in advanced and specialist roles (International Council of Nurses 2009; Kilpatrick *et al.* 2012; Royal College of Nursing 2012), and to the concepts identified by the National Council for Professional Development of Nursing and Midwifery in Ireland for clinical nurse specialists and advanced nurse practitioners (NCNM 2008 a, b). The fourth code 'context of service delivery' was added to capture data on the scope of the ESN role and other issues influencing the role.

The second level codes used to populate the four higher level codes were also drawn from a number of sources. The 'clinical practice' code was populated based on a review of the literature on the role of the nurse working in the area of epilepsy (Ridsdale *et al.* 1997, 1999a; Foley *et al.* 2000; Goodwin *et al.* 2004; Goodwin *et al.* 2011). The 'leadership' code was populated using frameworks emerging from the SCAPE study (Elliott *et al*. 2013; Elliott *et al.* 2014; Higgins *et al.* 2014), while the 'research/audit' code was informed by the work of Gerrish *et al.* (2007a) into evidence-based practice, and results from the research and audit section of the SCAPE study (Begley *et al.* 2015). The 'context of service delivery' code was populated based on advanced practice literature and the researchers' expertise in advanced practice role evaluation research (see appendix 3 for list of first and second level codes).

All the interviews were transcribed prior to analysis. In addition, all data (interviews, field notes, qualitative comments from surveys and interviews) were cleaned prior to uploading into NVivo, which was used to assist in the management and analysis of the datasets. Documentary data were initially analysed using the four higher order codes and the outcome of that analysis was uploaded into NVivo for further analysis. Once uploaded, all data were analysed by two members of the research team (AH and NE) using the complete template as a guide. In some situations, units of data were coded using more than one code. As the analysis unfolded, further second and third level codes were added to the template as they emerged from the data, the titles of which were agreed by consensus between the two researchers coding the data. In other situations, especially in the final phase of analysis and write-up, some codes were merged and others were renamed to reflect more accurately the data being described. For example, the research/audit code was renamed Evidence-based practice.

### *Survey data*

Quantitative data from the surveys were entered into an SPSS database. Prior to analysis, an audit of the quality of data entry was undertaken. The data were analysed using descriptive and inferential statistics to see if there were any differences in outcomes between the groups that had an ESN and those that did not. The majority of data were categorical, and chi-squared tests (or equivalent) were used to test for a relationship between the categorical outcome variable and site (ESN vs. Non-ESN site). Independent t-tests (or equivalent for non-parametric data) were used to test differences in means between ESN and Non-ESN sites. Paired sample t-tests (or equivalent for non-parametric data) were also conducted to determine if there were statistically significant differences in new patients' outcomes across time.

To analyse the Knowledge of Epilepsy Scale, correct answers were assigned a score of 1 while incorrect answers or don't know answers were assigned a score of zero. Where the person had complete 80% of the survey, missing data was given the mean score achieved for the questions answered and the mean was recalculated. Results are reported regardless of their statistical significance.

### *Economic data*

Where possible, the study adopts a bottom-up approach to generating the cost estimates whereby utilisation of specific services (e.g. number of GP visits in the last 12 months) is multiplied by relevant unit costs (e.g. cost per GP visit). Unit costs were calculated for each of these services and multiplied by the utilisation data in order to generate a total cost per patient and an average cost per patient in ESN sites and Non-ESN sites. Data were initially analysed in SPSS, but were later transferred to Microsoft Excel to allow analysis of the costs for each type of healthcare utilisation and indirect costs. While accepting that this exercise can be at best indicative given the small number of sites and the limitations of routine data, it was expected that any major difference in costs would be identified.

## Methodological rigour and quality in mixed methods research

Measures to assure the quality of mixed methods research go beyond that of assuring the quality of its component quantitative and qualitative parts (O’Cathain 2010). O’Cathain (2010) devised a comprehensive framework with eight domains of quality criteria that can be used at each stage of the research process; starting with domain 1, which address the planning of the study as a mixed methods design and finishing with domain 8, which considers the utility of the study after it is completed. Within the **SEN**s**E** study, the measures taken to assure quality are outlined.

### *Data quality*

Criteria under the domain of data quality include data transparency, data rigour, and sampling and analytic adequacy, which require that the methods used in data collection and analysis, and their role within the study, are described. In the **SEN**s**E** study, triangulation was used, whereby different methods of data collection (interview, observation and documents) and different sources of data (PWE, parents/carers, MDT members, DoNs/ADoNs and ESNs) were used to aid comparative analysis across the datasets, and within-case and across-case analysis.

Prior to any analyses on the survey data, four main processes were used to ensure data accuracy: screening, entering, checking and auditing. The data were firstly screened by the research fieldworker before being entered, checked and audited by the data administrator. Every questionnaire entered was checked thoroughly, similar to double entry. Once the data were checked, a random sample of 63 questionnaires was selected for audit, representing approximately 10% of the sample. The audit involved a complete check of each question in the 63 questionnaires. The error rate was 0.17% (12 errors from 7,056 data points). Generally, a 5% error rate is allowed and accounted for in statistical analyses. Qualitative data from survey and interview transcripts were also checked for data accuracy prior to entering into NVivo 10 (QSR International 2012) for analysis.

Another factor that influences data quality is the use of valid and reliable tools. Within the **SEN**s**E** study, quality of life was measured using the QOLIE-10-P, which is an adaptation of the QOLIE-10 (Somerville *et al.* 2007). The shorter versions were empirically selected from the 89-item QOLIE, using psychometrically founded item reduction approaches (Pfäfflin *et al.* 2001). Several patient-focused surveys have validated the face validity of the QOLIE instrument items and domains (Cramer *et al.* 2003). Ensuring the face validity of survey items involved an iterative process, with a great deal of communication and collaboration between the TCD research team and specialists in epilepsy care.

Internal consistency, as measured by Cronbach's Alpha, emphasises the extent to which all aspects of the tool measure the same overall principle (Cronbach and Shavelson 2004). While the researchers are conscious that caution is required in the indiscriminate use of this type of reliability measure (Cho and Kim 2015), nonetheless, the Cronbach's alpha value for the 20-item scale designed to measure information provided in the retrospective survey was $\alpha = .94$, indicating high levels of internal consistency in the responses on the scale. Similarly the Cronbach's alpha for the 5-item questionnaire devised to assess participants' views on the extent to which they were consulted and involved in decision-making around their care and treatment was high, ($\alpha = .89$), indicating high levels of internal consistency in the responses on this scale. The Cronbach's alpha value for knowledge of own epilepsy was .95, indicating a high level of internal consistency in this measure.

### *Interpretative rigour*

For the qualitative data analysis, a coding framework or template specifically developed for the **SENsE** study was used to aid transparency and reduce inter-rater variability across the data analysis of interview, observation and documentary evidence (see appendix 3). Using the **SENsE** coding framework, two researchers independently completed analysis of all interview, observation and documentary data. Any discrepancies were discussed and resolved by consensus, and interpretative agreement was reached prior to coding into NVivo.

### *Inference transferability and reporting quality*

A comprehensive account of the role and scope of the ESN, and of the health service context in which the ESN works is provided in order to allow for inference transferability; that is to enable readers to consider the extent to which the findings are applicable in other settings in Ireland or in other countries. Furthermore, the write-up and reporting of this mixed methods study followed the GRAMMS (Good Reporting of a Mixed Methods Study) guidelines to provide transparency and credibility of findings (O'Cathain *et al.* 2008).

## Ethics

Ethical approval was granted from the Research Ethics Committees of the Faculty of Health Sciences in Trinity College Dublin, and from participating clinical sites. Written information about the study and the nature of the individual's involvement in the study was given to nurses, clinicians, PWE and family members/carers. All PWE and family/carer participants were informed of their right to refuse to participate and their right to withdraw from the study at any time. They were informed that neither refusal nor withdrawal would result in any negative consequences to themselves or the care they received. Employees/staff members were made aware that should they choose not to participate in the research or if they withdrew from the study, this would not have any impact on their role within the hospital and that this would not be reported by the research team to anyone outside of the team. A contact number and email was provided to potential participants to enable them to request any additional information or clarification of the study details.

As one of the sites was a paediatric site, children also received written information that was appropriate to their age. This information was written in a clear and jargon-free manner to facilitate understanding. Participants under 18 years of age had a parent or guardian present during any communications regarding the study. The child/adolescent's assent and parental consent was sought. If the child/adolescent indicated any desire not to be involved their wish was respected irrespective of parental consent. All research team members were advised of the Children First National Guidelines for the Protection and Welfare of Children (DOHC 2011) and were advised to follow relevant protocol should they discover that a child was at risk during the course of this study. Persons with ID or an acquired brain injury and their advocates were also consulted prior to observation and facilitated in arriving at an informed decision regarding participation.

The study details and information about the nature of the participant's involvement was also reiterated when the interviews were being arranged and again at the beginning of the interview, as well as prior to any observation. In addition to using process consent at each encounter, the researchers gained verbal consent from all potential participants who were likely to be present during observation periods [PWE (adults; adolescents; children), family members and other clinicians] and recorded it in their field notes. If any person requested that their interaction not be observed, this request was respected. All participants signed a written consent form prior to the interview. For PWE participating in the survey, consent was assumed by return of the questionnaire.

All data files were anonymised, password protected and stored in accordance with the Data Protection (Amendment) Act 2003. All hard copy data were stored securely in a locked cabinet, to which only the research team had access. Surveys were anonymous and participants were advised not to write their name on the survey. Opt-in forms were returned separately to surveys to ensure anonymity. Study sites were also anonymised, using numeric identifiers. Participants' identities or any other personal information given during the interviews was anonymised through the use of pseudonyms or by removing identifying information. Data from the interviews were transcribed by an external company, the company of choice for the School of Nursing and Midwifery, Trinity College Dublin. The company was familiar with the process of dealing with confidential information and executed a confidentiality agreement.

## Strengths and limitations of the study

When interpreting the findings, the following study limitations require consideration. Firstly, the survey findings are based on a non-probability sample of PWE. Therefore, it is impossible to determine how statistically representative the survey sample is of the patients attending ESN and Non-ESN services in Ireland. Secondly, the response rate from people newly diagnosed with epilepsy attending Non-ESN sites was low for survey two, minimizing the level of comparison that could be made between ESN and Non-ESN sites. Thirdly, as the surveys were distributed at clinics and there was a near zero response rate from PWE who took them away to complete, this potentially biases the sample towards people who were more satisfied or more secure in providing an opinion. Indeed, over a third of participants in both the retrospective and prospective survey had a third level education. The PWE and family members who participated in the focus groups were not randomly selected but were sent recruitment information by the ESNs, thus there is a risk that people who were perceived to be articulate and positive about the service received the invitations. Within the economic evaluation aspect of the study, initially it was intended to collect cost data at the hospital-level, including pay and non-pay costs for 2013 for the epilepsy service; however, this proved difficult to capture for the hospitals, and other types of data were limited or unavailable. Finally, the findings from the study need to be interpreted in the context of the fact that some ESN participants were in the very early stage of role development and integration within the MDT.

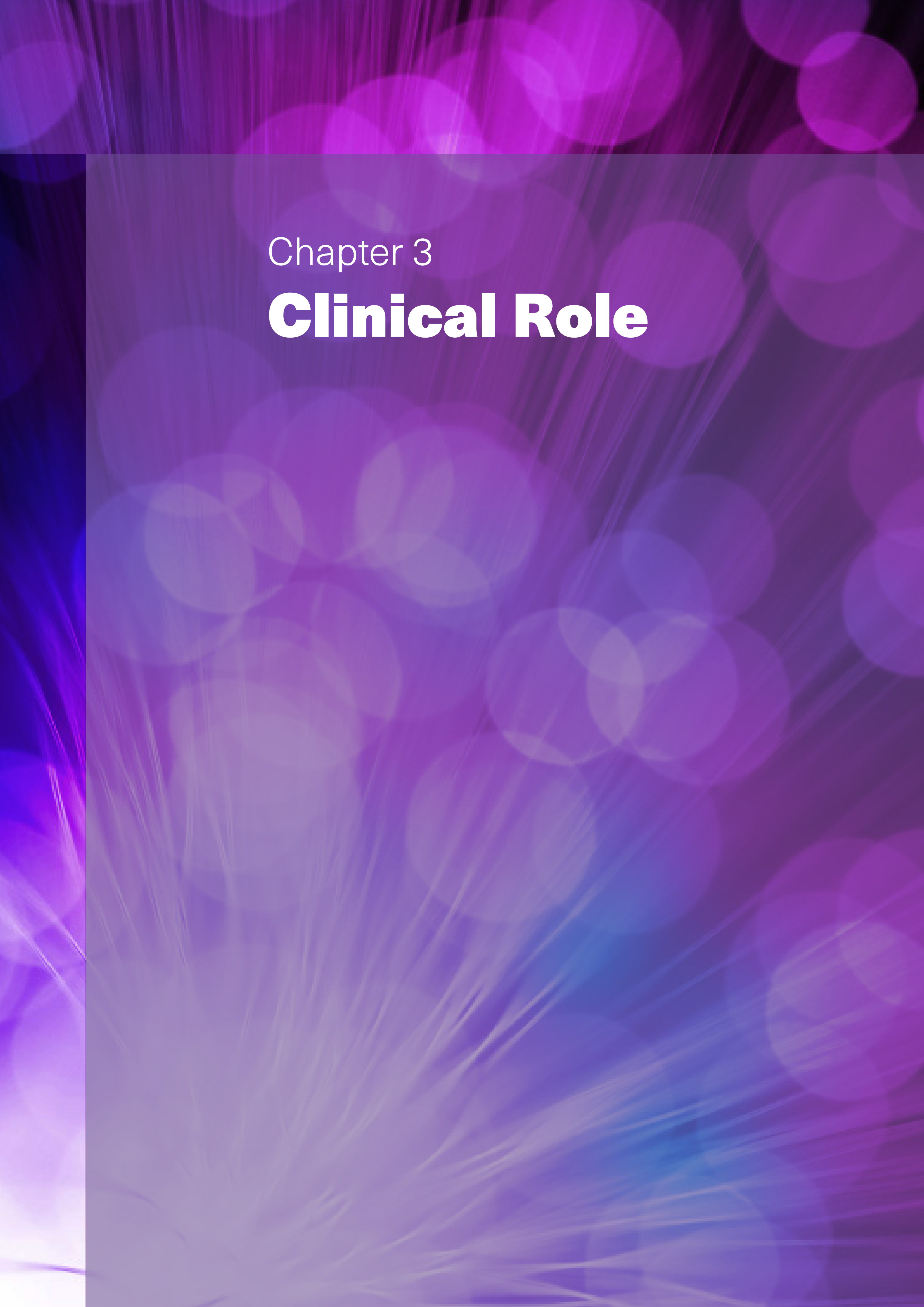
One of the strengths of the study is that it utilised a mixed methods design and collected both qualitative and quantitative from a variety of stakeholders, thus enhancing the integrity, reliability and robustness of the findings, as procedures for cross-checking across data sources were utilised during the analysis. Secondly, there is very little or no statistical difference in the profile of PWE from the ESN and Non-ESN sites who completed the surveys, thus minimizing the possibility that differences in outcomes are patient-related. There is also very little difference between those newly diagnosed with epilepsy who completed the survey at time point two and the non-responders. In addition, the research study was undertaken by an independent team of researchers from Trinity College Dublin. The team comprised experienced researchers with a sound understanding of mixed methods research and economic analysis, and data were collected by experienced researchers who also had clinical backgrounds.

## Overview of chapters

Findings from the study are presented in line with the objectives of describing the role of the ESN and evaluating the impact and cost of the role. Chapters 3, 4 and 5 report the findings in relation to the clinical, leadership and evidence-based practice aspect of the ESN role. Chapter 6 addresses the impact of the role on patient knowledge, satisfaction and QoL.  Chapter 7 reports the findings from the economic analysis. Chapter 8, the final chapter of findings, reports the contextual and mediating factors influencing role development, integration and sustainability. Chapter 9, the final chapter of the report, draws together the key findings and makes recommendations.

## Chapter 3

# Clinical Role



# Chapter 3: Clinical Role

The effective management of chronic illness, such as epilepsy, requires timely, appropriate and supportive clinical care for optimal outcomes (Cumbie *et al.* 2004). Today there is increasing recognition that for optimal outcomes to be achieved, care needs to shift its focus away from the traditional 'authoritarian' model of care where power resides in the clinician or knowledgeable expert, to a more collaborative partnership model that promotes and enhances the person's ability to meet their own needs, solve their own problems and mobilise the necessary resources to self-manage their epilepsy (Kirton *et al.* 2012). Within this framework, emphasis also moves from a disease model of care, to one that incorporates the wider psychosocial context of a person's life. Evidence suggests that when people living with a chronic condition, such as epilepsy are provided with education, support, and monitoring in partnership, self-management is enhanced (Kirton *et al.* 2012).

Research into the clinical role of the ESN in the United Kingdom suggests that in addition to their role in assessment, education and psychological support of PWE, key dimensions of their role include caseload management, co-ordination of care and the running of nurse-led clinics (Goodwin *et al.* 2004; Higgins *et al.* 2006; Hopkins *et al.* 2010; Hopkins and Irvine 2012). Within Ireland the NECP outlined a number of clinical roles for the ESN, including the provision of routine care to PWE attending services, the provision of education to patients and family members, the completion of routine follow-up, and liaising with MDT members within and external to the epilepsy service (HSE 2014). This chapter presents the findings from the **SEN**s**E** study on the clinical role of the ESN in order to provide a greater insight and understanding into the processes and complexities involved in this aspect of the ESN role. Findings in relation to the clinical role are presented under the following headings:

- Provides a range of services across the care continuum;
- Completes comprehensive assessment to inform care and treatment;
- Provides person-centred education to empower patients towards self-management;

- Systematic monitoring of impact of care and treatment;
- Provides education to family members and significant others to promote confidence;
- Provides psychosocial care to optimise psychological wellness of person and family;
- Co-ordinates care and care-pathways to enhance patients' journey; and
- Quality assurances of patient information recorded.

## Provides a range of services across the care continuum

In conjunction with other members of the MDT the ESNs involved in the **SEN**s**E** study provided a range of services to children, adolescents and adults with epilepsy attending neurology or dedicated epilepsy services. The ESN caseload included: pre-diagnosis and long-term patients; people who were seizure–free; people who had complex refractory epilepsy; people with physical and mental co-morbidities; people with varying degrees of intellectual disability and cognitive impairment; pre and post neurosurgery patients; women who were considering pregnancy and women who were pregnant; and people with non-epilepsy type seizures. To meet the needs of this wide ranging group the ESNs provided a number of ESN- led services across the primary, secondary and tertiary healthcare continuum. The specific services provided included nurse-led clinics and outreach services. In nurse-led clinics ESNs assessed, monitored and made appropriate interventions and changes to care, including referral for diagnostics test, referral to other members of the team and discharge**.** PWE attending these clinics did not always see a doctor, although the opportunity to speak to the medical consultant was frequently offered. Although the number and type of clinics provided varied geographically, they generally included: general epilepsy clinic; RACs; and VNS clinics.

In the **general epilepsy clinics** the ESNs have their own cohort of PWE to be seen for assessment, treatment and ongoing care and monitoring. The nurse-led clinic ran concurrently and adjacent to the neurologist-led clinics which facilitated consultation with the neurologist and cross-referral when required.

The **rapid access clinic (RAC)** enabled patients presenting with seizures to the Emergency Department or GP to be fast-tracked to the ESN and therefore managed in a timely manner in the appropriate part of acute neurological services.

The **vagal nerve stimulator (VNS) clinic** provided a specialist service for patients' post-insertion of a VNS, a treatment modality for certain types of epilepsy. The ESN switched on the device, programmed the settings and reviewed patient response to the device as well as monitoring any potential negative outcomes or side-effects.

In some areas the ESNs provided **outreach services** to meet the specialist needs of patients, such as pregnant women with epilepsy and outreach clinics for people with intellectual disability living in residential settings.

In some sites the ESNs operated a **telephone advice line [TAL]**. The TAL is a help-line primarily for PWE and families (some healthcare professionals also engage the TAL e.g. GPs) who are at home and who have queries about their medication, seizure activity and epilepsy management. It is service-specific in so far as it is only available to PWE who are attending the service where the TAL is offered, as the ESNs have access to the patient's healthcare records. Phone calls that are not dealt with immediately are returned within 24 hours. While this is not an emergency service, it enables a timely response which may prevent problems escalating and offers PWE reassurance. In addition, the ESNs occasionally provided advice to PWE through email.

## Completes comprehensive assessment of needs to inform care and treatment

The ESNs were very aware that effective care and management of PWE required care that was person-centred and took account of the person's biography, interests, goals and wishes. To achieve this, there was extensive evidence within the data that a core function of the ESN role involved completing and recording a comprehensive physical, psychological and social assessment, in collaboration with the PWE and/or family/carers. Whilst the ESNs had different levels of confidence in completing different aspects of the assessment, they all emphasised the importance and significance of having accurate and reliable information to inform their own and other members of the MDT's decision-making around care and treatment. Having information on the wider context of the person's life and 'knowing the whole' person was not just critical in terms of informing initial diagnosis, but was central to ensuring that shared expectations were established and interventions and advice were tailored to the person's unique needs, lifestyle and context. As the following quotes suggest, assessment and 'getting to know' the person was considered a central and iterative process that continued throughout the lifetime of the PWE's attendance at the service, irrespective of whether the encounter was face to face or over the telephone/email.

> *"Taking a history and getting to know the person is a big part of our role; you're kind of quizzing and questioning… going into the nitty-gritty of why, when, how…assessment and history is a big part of diagnosis, you might have all the investigations, EEGs, MRIs might be normal and it comes down to the patient's description of what is happening or a collateral history and that's what makes the diagnosis, so history and getting patients' view is vital in epilepsy and in deciding the care." (Candidate ANP interview)*

> *"Well the first thing, the first thing I do either on the phone or in clinic, I also look at their scans and their history, what is their diagnosis, then I look at when they were last seen and see how they were at that time. Then I get the history from them and I try to decide … have they deteriorated, are they better, have they plateaued, are they about the same , you do that every time you see them." (Candidate ANP interview)*

The epilepsy-specific Electronic Patient Record (EPR), a web-based IT system, was the primary tool used by the ESNs to structure assessment and assimilate healthcare information collected from PWE during the consultation process. Whilst the ESNs used a systematic approach and followed the EPR as their guide, their questioning style was conversational in nature which allowed the person to tell their story in their own way. In the vast majority of consultations observed the ESN usually commenced by asking the person about their current state or most recent event and worked retrospectively. Eliciting and recording accurately and succinctly the person's seizure history was core to the assessment role. The seizure history undertaken by the ESN addressed a number of areas and included a detailed history of onset, triggers, auras, seizure types, impact on awareness/consciousness, injury, recovery, headache, potential triggers etc. In completing a detailed seizure history the ESN was not only getting a detailed insight into the uniqueness of each person's seizure story, but developing an in-depth understanding of the context of the person's life and any factors that might positively or negatively influence seizure management, as the following indicates.

> *Does a detailed seizure history of last seizure, presence of warning, duration, time (night/day), feeling, photosensitivity; to help patient answer on triggers give examples of possibilities e.g. tiredness, stress. (Candidate ANP observation)*

> *"I [ESN] use the tools we have like the EPR [epilepsy-specific Electronic Patient Record] as my guide when I'm going through it (assessment) because it's [EPR] very encompassing… then move through their epilepsy history, how they're [PWE] doing, how frequent their [PWE] seizures are…We [ESNs] also look at anything else going on, provoking factors in their life that might make their seizures worse…" (Candidate ANP interview)*

> *ESN introduced herself as this was her first time meeting the patient in person. ESN confirmed a number of details including, GP, medication regime, recent seizure activity, epilepsy history, family history, childhood illness history, trauma history, birth history. (Candidate ANP observation)*

Whilst the ESNs were very skilled in eliciting information about the person's seizure history, they also took a holistic view of the person's physical health, enquiring about other aspects of physical health, especially if the person was being treated for a co-morbid physical health problem that might impact on the person's epilepsy.

> *"You'd also talk about sleep, exercise, diet, a bit about diet as well like, just go through different things about their lifestyle." (Candidate ANP interview)*

> *"It's also important to do all their weights and heights because of obesity and that's something that we all, I think every specialist in the hospital are quite aware at the moment." (CNS interview)*

> *Asks about general health history including asthma, hypertension, sleep. (Candidate ANP observation)*

There was clear evidence in the data that the ESNs were aware that to achieve effective self-management they needed to move beyond the disease model of care and include the wider psychosocial context of the person's life. Thus, a significant part of the ESN's assessment involved getting to know the wider social context of the person's life, through the inclusion of a discussion on family, relationships, education, work etc.

> *"Generally what they're doing with themselves, are they living on their own, are they in college or are they working, driving, talk about them, making sure you've kind of discussed those issues with them." (CNS interview)*

> *"Who's at home, who lives with you, you're getting in the whole social end of things… where are your supports.." (RANP interview)*

> *"…that holistic background behind the patient, they [ESNs] know the formal support networks, the informal support networks …they might know about family stressors…other dynamics happening in a family that might be having an impact on their epilepsy and until you get to know a patient you're not going to know those things…" (Allied health professional interview)*

The ESNs were also very aware of the need to assess and explore the impact of the diagnosis on the person and the resultant subjective (stigma, depression and anxiety) and objective (impact on employment and driving) burden experienced as a result of their epilepsy.

> *"What I find is that some people, not so much struggle on the diagnosis but they struggle with how they developed epilepsy…it's kind of like a post-traumatic disorder, or post-traumatic stress… some people find it very hard or some people are maybe just in denial so it depends, but you would ask and talk about coping strategies." (Candidate ANP interview)*

> *"So like when someone comes to clinic you would always say, because sometimes people don't offer it so if you just say, you know, how's your mood, is everything okay, is your form good, and they might feel comfortable enough to tell you." (Candidate ANP interview)*

> *"How are they getting on with that… psychological issues, how are they getting on, any issues like if they've memory problems, all of those sort of aspects you have to consider every time you have that clinical encounter.." (CNS interview)*

In addition, ESNs asked about and explored lifestyle behaviours that may negatively impact on seizure control or put the person at risk, such as alcohol intake or use of other substances.

> *"It depends on the particular patient… like one guy I had he was in college and he found it very difficult… he hadn't really told his friends about his epilepsy and then he's out and he didn't want to be not drinking because everyone would be going, 'why aren't you drinking'. So he was kind of trying to hold a pint for ages and then kind of pretend he had another pint. So like you're talking about that… on the other hand you have somebody who's drinking too much, or you've someone that's taking drugs that would affect their seizures." (Candidate ANP interview)*

> *"I find particularly teenagers, young adults, drug abuse, they'll tend to admit it more as we [ESNs] tease things out … often people [other healthcare professionals] don't ask about things like that, and then it's missed… you have to ask about that." (Candidate ANP interview)*

The very nature of epilepsy and the fact that the person themselves cannot see the seizure required the ESN to engage with family members, carers, and guardians to elicit a collateral history. Getting a collateral history from parents of children and from family and carers of people with intellectual disability or cognitive impairment was also part of the ESN role.

> *Does a detailed seizure history with parents (son has ID) as he is having multiple types of seizures. Asks about seizure types, medication dosage, compliance, side-effects. Also explores with family outcome of a new antiepileptic medication prescribed, asks about changes in seizure frequency, side-effects, quality of life (alertness, communication). ESN asks focused questions and translates technical terms into lay terms with examples to help family identify seizure type. (Candidate ANP observation)*

> *"Well you're taking two histories at times, you're taking a history from the parents, the parents might say we see the child doing this, but we also need to know what the child feels during the seizure or before or what they remember, so you are getting two clinical histories essentially." (Candidate ANP interview)*

A significant part of the ESN's assessment time in relation to seizures and other health issues was spent slowly 'teasing out' patterns and organising information to inform problem formulation and subsequent advice or care and treatment.

> *"… [You ask] what happened you [PWE], how did you fall down the stairs, did you trip, did you fall, did you get dizzy …why are you dizzy.. are you on too many medications… or did you fall down the stairs from a seizure related problem...if you did, I need to increase your seizure medication…. But if you'd an accidental fall, how can we avoid that risk in the home..." (RANP interview)*

> *Does detailed history of when symptoms appeared (drowsiness, drooling) as she [ESN] is trying to get a picture if some of the patient's symptoms is related to the medication prescribed, related to seizure activity or something else. To help she names each drug and the side-effects and questions about each drug's side-effects separately. (CNS observation)*

> *"[When person rings the TAL] we …go into the nitty gritty of why this [increase in seizures] is happening, is it something new, how long, have they missed medications, are they good at taking medications, have they any infections or any other reasons for causing increased seizure activity." (RANP interview)*

Also linked to assessment and problem formulation was the ESN's role in making a decision on the urgency of need and triaging care. As the ESN was the first point of contact for PWE and family through the TAL or the rapid access seizure clinic for new referrals, the ESN's role also involved conducting a preliminary assessment with the PWE, in order to prioritise when to schedule appointments, arrange investigations or make referrals.

> *"When you get a call, you have to triage that phone call, you have to make sure that this person doesn't need to be dealt with immediately. Can you wait for the GP? Can they wait to come in for an appointment? Do they need to go to casualty? So you are constantly making sure you don't miss something." (CNS interview)*

There was also evidence that the ESN's skill in eliciting information and 'teasing out' information that was necessary to inform subsequent decision-making was valued by other members of the MDT, particularly the medical personnel.

> *"… we would see a lot of the patients [PWE] who have learning disabilities, severe learning disability, maybe associated behavioural disorders, and it can be very tricky trying to tease out was it the medication, or is it seizures, or something else in their life that is making that difficult for them [PWE]… and the nurses [ESNs] are particularly good at teasing those things out…" (Medical personnel interview)*

> *"She [ESN] spends time with the patient, the patient is made comfortable and sometimes she is able to bring out a lot more information that I have…either the patient has been intimidated or the time has been too short…she's listening and listening carefully, she's asking the right questions and getting to the core of the problem. Sometimes it is not the seizures and it's not the medication, it's other things and they don't come wrapped up, so listening, communicating, connecting is hugely important." (Medical personnel interview)*

> *"…she [ESN] was much more attuned to the little things that were happening to patients [pregnant women with epilepsy] that probably were going over my head… but as she [ESN] directed questions to them, one could see that she [ESN] was much more able to identify important symptoms of auras and so we were much more able*

> *to fine tune these patients' treatment, and to minimise their difficulties with looking after themselves through pregnancy and with their care as obstetric patients…" (Medical personnel interview)*

## Provides person-centered education to empower PWE towards self-management

A key aspect of the ESN role was the provision of education to PWE that was tailored to meet the individual's needs and context, and aimed at empowering the person to self-manage their condition and minimise the potential negative impact epilepsy had on their life. The education carried out by the ESNs included the provision of information on: epilepsy (causes, seizure types), interventions (medication, VNS, ketogenic diet, surgery), side-effects of interventions, lifestyle changes, strategies to promote personal safety, and resources available within and outside the health service.

The provision of information and education was not done in an abstract, theoretical manner, but applied in a very person-centred manner, as the ESN was focused on enabling the person to get an understanding of their own unique experience of epilepsy and note subtle and not-so subtle changes in their condition. Consequently, the ESNs spent time facilitating PWE to get an in-depth understanding of their seizures, including types, triggers, warning signs, the role of medication and the importance of compliance. In this context, promoting safety and minimising risk was one of the priorities of education, whether the risks were from a seizure, side-effects of medication or non-compliance.

> *"You are there to enhance their information… to improve their knowledge of their own condition and how to manage it…Our [ESN] responsibility is ensuring that they first of all know the risks about seizures, how to identify seizures, what is the first stage, what's the response, things like medication, so all about their medication, so when to take them, how to take them, possible side-effects, the importance of compliance, rescue medication." (Candidate ANP interview)*

> *"… if they have a side-effect not to jump straightaway and stop taking the medications because that could cause rebound seizures." (Candidate ANP interview)*

While the ESNs endeavoured to facilitate PWE to live as normal and unrestricted lives as possible and to pursue interests and hobbies, they were very aware of the need to educate PWE about potential lifestyle implications and changes that they may need to make to avoid dangers and comply with legal requirements.

> *"You'd talk through talk through lifestyle issues. You want people to lead as normal a life as possible but there is some changes that they'll have to make, like to say driving or there might be occupational changes…..So you'd talk about that, alcohol, or just say swimming, … mothers with babies, you know, if a new seizure onset, new baby, how to protect baby, like change nappy with baby on mat on the floor." (Candidate ANP interview)*

> *Patient asks about driving, [ESN] informs him of regulation re seizures and need to be one year free, also discusses impact of his recent stroke on motor ability. ESN explains that he will need to get a driving assessment done with the Irish wheelchair association as it is not just the epilepsy that is the issue but also the physical weakness and motor ability. (Candidate ANP observation)*

> *ESN discusses safety precautions with the patient, who is 82 years old very active man [accompanied by his wife]. The advice focuses on baths, ladders and garden safety. (Candidate ANP observation)*

> *ESN educates the patient about lifestyle implications, socialising and alcohol, the importance of sleep and how to manage stress. (Candidate ANP observation)*

The ESNs were constantly aware that changes in life circumstances had potential implications for self-management. Thus, a significant aspect of their role involved being aware of each PWE's changing context, so they could provide appropriate education and information in a timely manner, be it at times of transition from childhood to adolescence, sitting examinations, going to college, changing employment, deciding to become pregnant (pre and post conceptual care) or going on holiday.

> *"Then when she [her daughter] came to be a teenager, education was about alcohol and about school, about if she'd a seizure, about who to tell, who not to tell, the whole advice around really living with epilepsy as a teenager, that actually is the invaluable piece." (MDT, nurse manager interview)*

> *"ESN rang me recently and said, do you want me to have a chat with [names daughter] about contraception. I said, yes you do it. …I know if I mention anything [about contraception] she's, 'uh, please!'. Whereas, [names ESN] there is no bother she'd [daughter] come in and chat to her [ESN] you know" (Family focus group)*

> *"For the woman who, who's getting pregnant… a lot of the concern would be the medicines…and what's the potential harm for that baby… as some of the medications can be teratogenic to the unborn… one of the big questions is 'will I have a seizure in labour?' so education in pregnancy is a big thing, we go through everything it might take an hour the first time you discuss with a woman…the next time they come back it's about 15 minutes … you give them written information to read as well." (Candidate ANP interview)*

> *ESN discusses how work is going as woman recently commenced a job after long period of unemployment, patient is anxious about the impact of medication on her memory. ESN discusses this and also discusses how stress and anxiety can exacerbate memory issues. ESN also discusses contraception as woman is currently in a relationship, they discuss the option of an IUD and ESN gives information on the pros and cons of having IUD inserted, procedure for insertion, and local woman's clinic. (CNS observation)*

In addition to providing education on the medical and psychosocial implications of epilepsy, the ESNs provided education on the role of various tests and procedures that were associated with each person's ongoing care and treatment.

> *"I have had surgery. Before I had it I went through loads of tests. The girls [ESNs] that look after you explained all the tests and gave you confidence." (PWE focus group)*

> *"Part of our role is being there for the patient, making them understand maybe why all of a sudden they're getting more regular blood tests, just helping them to understand." (Candidate ANP interview)*

While all the ESNs were involved in educating PWE about all aspects of epilepsy and treatment, including VNS, the ESNs working in surgery had developed a particular expertise around epilepsy surgery and were central to the provision of information to patients about this aspect of treatment. Education in the preoperative phase was focused on helping patients make informed decisions about surgery while postoperative education was about giving patients confidence that they could manage and cope in the initial postoperative period and post discharge.

> *"[ESNs]… understand the surgery, they understand the benefit of surgery, they understand how the surgery happens, ….so when the decision for surgery is made at the conference [MDT discussion]… she [the ESN] takes over, and communicates that with the patients… also explains about surgery, help with that decision-making process… puts the things in process whereby the patient is prepared for surgery. But it is deeper than that, she creates the mental and psychological environment in the patient to accept that decision and go forward for surgery." (Medical personnel interview)*

> *ESN visits patient in ward who is post-surgery. Checks her level of discomfort and talks to the woman about swelling around wound and the fact that some swelling is normal, gets her to gently feel the swelling that is currently present and note what it feels like when touched, suggesting that it feels spongy to touch. She explains to the woman that she doesn't want her to worry when dressing is removed and wants her to be aware that swelling will be present, and what it feels like to the touch. Also talks to her about what the colour of the scar will look like and what to expect in the next few days. Gives her time to ask questions and answers questions slowly checking that the woman understands. Sits closely, touching her arm gently, reassuring her continually. Says will revisit again that evening to explain more. Also leaves written information leaflet about postoperative experience that she and colleague has developed. (CNS observation)*

> *ESN visits another woman who is post-operative, they recap information that they spoke about the previous day. ESN discusses what to expect in terms of pain, swelling, the importance of rest and what she terms 'listening to your body'. ESN informs her if on discharge she has a seizure to contact her, as they may need to review medication, but also that it may be her body telling her that she is overdoing it, hence the need to take plenty of rest and not push herself. Gives the woman time to ask questions and spends time reassuring that if she has any worries not to hesitate to phone her, says 'don't worry that when you are discharged we will not want to know, we want you to ring us if worried, as we can do an assessment over the phone, and if you need anything we can prescribe or get you a quick appointment to come back'. Informs her that they will call her back for follow-up in 6-8 weeks, but reassures her that she can phone at any time. Reassures her that the booklet has everything written down and also gives her contact details. Tells her she will see her in the morning again before she goes home and if she has other questions when she has time to think she will answer them again when she visits. (CNS observation)*

Other areas in which ESNs provided education and information were the EPR, and information on support services that were specific to epilepsy, such as Epilepsy Ireland, and more general support services that may be relevant to people at other times in their life.

> *ESN explains the role and function of the EPR to patient and his wife. ESN also gives them an information leaflet on the EPR to take home and read. (Candidate ANP observation)*

> *"You [ESN] tell them about Epilepsy Ireland, linking them in to brain injury services, depending on what their particular need is, it's constant education, there's a new Epilepsy Ireland toolkit available to people, engage them with that and the local services." (Candidate ANP interview)*

> *ESN is a source of information for community supports other than epilepsy. ESN provides advice re accessing the community OT and physiotherapy as patient [who is in a wheelchair] would like to get a wheelchair that is easily transported in the car. (Candidate ANP observation)*

Education of patients was not a once-off event, but was incorporated on an ongoing basis into each patient encounter, irrespective of the duration of time the person was attending the service. The ESNs were very cognisant of the impact of distress, medication and other factors on the person's ability to process, retain and recall information, thus they provided patients with both verbal and written information, revisited and repeated information, and continually checked understanding, while not overloading patients with information. While the ESNs always provided PWE with an open invitation to contact them, they were mindful that there was a fine balance to be sought between providing reassurance and promoting independency.

> *"Sometimes there is a risk that patients … become dependent on the phone service so instead of making a decision themselves or planning themselves they run absolutely everything by the epilepsy nurse. So that's a balance. On the whole I think self-management is really important … I think epilepsy nurses encourage people to be self-managing, to manage their own disease but there is a risk that we can encourage patients to become very dependent." (RANP interview)*

The ESNs delivered education to patients, during face to face encounters in clinics, over the TAL, on wards and through hospital-based group education sessions or as part of community outreach work, such as conducting information evenings for both PWE and their family/carers. While teaching styles varied, ESNs were very aware of the need to speak in a language that patients understood, while at the same time introducing PWE to the medical language associated with epilepsy.

Not all ESNs had the same level of expertise in providing education, with the more experienced ESNs adopting a coaching more than a didactic style, constantly seeking to understand the PWE's perspective and their priorities for learning before engaging in education. Irrespective, patients, carers and MDT members affirmed the importance and value of the education provided by the ESNs.

> *"So they [ESNs] are a huge knowledge reservoir, and I think a huge support to people with epilepsy and their families." (Medical personnel interview)*

> *"She [ESN] is very confident you know giving direction, giving advice regarding certain drugs, or lifestyle, and very very much to the point, and very compassionate with them [patients and family]." (CNM interview)*

> *"I think that the quality of the information that is given to the patient is good from all sources within the neurology service, but some patients may be more receptive to hearing it from nurses, or may be more receptive to hearing it for a second time from a nurse, if it was repeated from what the doctor said, or vice versa …" (Medical personnel interview)*

## Systematic monitoring of impact of care and treatment

Another dimension of the ESN's clinical role involved the systematic follow-up and monitoring of the impact of treatment on the person's seizure pattern and quality of life, as well as all aspects of care and treatment provided. Whilst the ESNs monitored the impact of treatments, including VNS and surgery, they played a key role in monitoring the impact of antiepileptic drug (AED) therapy. Whilst the goal of care is always complete seizure control with no side-effects, the ESNs had a heightened awareness that all the medical interventions could have both positive and negative effects on the person's quality of life. Thus to ensure the early detection of adverse effects, problems in compliance, failure to respond to treatment and/or change in seizure activity, ESNs were continually monitoring and assessing the person's response to, compliance with, and any negative impacts of, the medication prescribed.

> *"You need to know the seizure frequency since they've last been to the clinic or since the last medication change, has the frequency changed, if so how many seizures, the duration, the intensity, so you need to get a clear seizure history…." (RANP interview)*

> *"They're [PWE] coming back to you maybe once a year if their seizures are stable…,… long-term issues with medications [AEDs], medication side-effects would be another thing we'd [ESNs] look at…" (Candidate ANP interview)*

> *"[names ESN] is full-time checking, ringing me up, checking is that medication suiting me, listening to me and then literally taking down notes. Making sure my diary is perfect I'm happy that she's there and understands me, knows me, but also there to help me make them decisions on medication." (PWE focus group)*

To assist in monitoring potential side-effects of medication, in addition to history-taking and observation, the ESNs undertook a neurological assessment.

> *"A big thing I would do is a neuro assessment for the side-effect profile of the medication so I'd go through like any tremor, check their gait, check their pupils, any nystagmus." (Candidate ANP interview)*

> *Completes a neurological assessment (hand tremor, heel to toe walking), explains reason that it is to check for toxicity of medication and minimise risk of missing toxicity. Returns to chart to check if liver function tests have been done recently. Bloods not done recently so gives choice of return to GP or have done in hospital today, patient ops to go to GP. (Candidate ANP observation)*

A core aspect of monitoring medications included referring PWE for blood tests to measure the therapeutic levels of AED therapy or monitor other effects.

> *"You'd be watching for the side-effect profiles so just say [names AED] may cause liver impairments so you'd be checking their liver profile, six months, yearly. [names another AED] might cause a drop in sodium so you'd be checking their sodium level regularly. Someone has a change in their seizure control, they might have increase in seizures, you're unsure about their compliance or you just need to check a level so it's to check serum drug levels as well. So they'd be the most common blood tests but you do a full set of bloods every so often, probably yearly just to double-check everything, but it depends on the medication." (Candidate ANP interview)*

> *ESN discuses blood serum levels of AED and discusses with the patient the notion of increasing her AED dose. Gives the rationale for increasing. The patient agrees with this and they have a discussion of how, when and why the patient should get a blood serum level done. (RANP observation)*

> *ESN explains to patient that her tremor may be a side-effect of her medication, suggests that they do a blood test to check blood levels of the drug. ESN explains to patient the reason for the test and what it may tell her. (Candidate ANP observation)*

For the seven ESNs who were registered as nurse prescribers on the Nurse Prescriber Division of the NMBI register, they were in a position as part of their medication management role to increase, decrease, stop or prescribe medication under agreed organisational prescribing protocols. Those ESNs without prescribing authority sometimes provided advice to patients on increasing, decreasing or stopping medication, under the direction and guidance of the medical consultant.

### Provides education to family members and significant others to promote confidence to self-manage

The ESNs were very aware that family members were key supporters and critical in enabling the person to self-manage, thus a large component of the ESN role involved educating family members, carers, and significant others. Family education focused on enabling them to feel confident to support the PWE both psychologically and practically, skilled and confident to intervene in the event of an emergency, and confident about when to seek help or advice from others. Similar to the information provided to PWE the ESNs educated family members on all aspects of epilepsy, including medical aspects (tests and diagnosis, medication, prognosis), social, psychological and safety implications of epilepsy, and resources and services available.  While safety was part of patient education, for family members, specific emphasis was placed on first aid seizure care, rescue medication and who and how to summon help.

> *"A lot of the education around say rescue medication is done with the carers or the families more so than the patient." (DoN interview)*

> *"I now know from talking to the nurse specialist that it's OK to manage [names daughter] at home if she gets a seizure, give her some buccal medication and leave her, obviously if it continues bring her into hospital…but they have reassured me about that" (MDT interview individual interview designation withheld for confidentiality)*

> *"My mother was shown how to give [names rescue medication] to me" (PWE focus group)*

> *ESN goes through procedure for giving rescue medication with husband (patient post- surgery), so he knows what to do if required in an emergency (CNS observation)*

In addition, as family members were often key informants around seizure type and duration, the ESNs spent time educating family members on what they should observe and how to keep accurate and up to-date records whether in the form of a seizure diary or through taking a video using phone technology.

> *"Because they need to know what a seizure looks like, they keep their records, they do all the things that you've put all the effort into doing, teaching them about, that makes life easier." (Candidate ANP interview)*

> *"And sometimes when there is an uncertain diagnosis, the advice that [ESN] gives is if the partner or the sister or the mother, because often it is the sister or the mother that sees something, to video it on their phone so that if there is something going on, and it is uncertain, to actually video it, and that is advice she will give quite often give… the_partners are very very involved, because if something happens they need to know what to do* **…** *they need to know what are the kind of things to be watching out for, that could lead to an intervention, that prevents something significant." (Medical personnel interview)*

Whilst the provision of education was important for all families, it took on particular significance for parents of children with epilepsy who all spoke of their anxiety and fear when their child experienced a seizure, and also about needing skills to support their children psychologically.

> *"So she's [ESN] giving me tools, to deal with my child…she enables you to cope with your child's condition on a more personal level, gives you the confidence and the reassurance that you can help your child [when he has seizure]. Whereas, your consultant will tell you he should be on X, Y, Z drugs. These might be the side-effects, we'll see how they work that might keep the seizures away. So very medically based. The nurse has possibly a dual affect there, she does have the knowledge medically but she also helps you cope." (Family member focus group)*

> *"It's key that they [ESN] educate parents… spend the time focusing on the lifestyle issues, like obviously they're the person that reassures if the child has a seizure and they're the point of contact for the child, … like they're going to spend an hour talking about the child having problems in school because he's had two seizures recently and counselling the parents is critical." (DoN interview)*

The important role of the ESN in educating parents so that they were willing to 'let go' and support their children to develop the skills and confidence to self-manage their own epilepsy as they progressed through adolescence was an important dimension of the ESN's interaction with parents.

> *"Like the relationship they've built up with the child and the parent, they are well placed to be able to start influencing the parent maybe to start letting go a little bit, start giving the child more responsibility around managing their epilepsy in the context of normal adolescence." (DoN interview)*

Engaging and educating family members of people with ID or other family members of PWE that had significant cognitive impairments was central to their education role, as in many of these situations it was family members who were supporting the person to maintain independence, manage their medications or access other interventions, such as the VNS**.** Family members, as discussed in the section on assessment, were also key providers of collateral information about changes in the person's physical and psychological health status in response to epilepsy-specific interventions or other treatments.

> *Patient (young man with ID) had VNS inserted recently. ESN explains in detail what this is and how it works, involving patient and giving time to family (parents of the young man) to ask questions. Explains to parents and patient the procedure she is going to use to activate the device. Ensures they have understanding before proceeding, …goes through the 'dos and don'ts' of using the device and explores with them when they think is the best time to give a 'booster dose' based on seizure times. Reassures family that if anxious to ring the TAL and reassures she or a colleague will ring back and go through any concerns they have on the phone so don't have to travel if at all possible. Reassures she will be in a position from phone conversation to identify if they need to visit clinic. Given choice if they would like to see consultant and family happy not to see him. ESN suggests to the family that they go for coffee and something to eat and comeback in about one hour, to give them time to get confident with the VNS and allow them time to think of any questions they may have. When they return the parents have some questions which she answers, gives them a card with phone details, as well as written information on VNS. Also makes an appointment for them to return in six weeks for mid-morning appointment as this time suits them from a travel perspective and from the patient's perspective in terms of sleep pattern. (Candidate ANP observation)*

> *The patient's (person with ID) mother answers the telephone. The consultation is a follow-up on a recent OPD visit to review the response of the patient to AED therapy. The patient has been on multiple medications and the team are making some changes to AEDs. ESN has a conversation with the mother about AED therapy and specifically about the impact of recent changes. The change has reduced seizure activity but the mother tells the ESN that the patient has developed gastrointestinal upset. However, as the conversation progresses and ESN explores and asks questions it becomes apparent that the gastrointestinal upset has pre-dated the change. The patient's mum asks about stopping the medication. The ESN goes into detail about the objectives of the treatment and long-term goals, and need to conduct a risk versus benefit examination in respect of 'side-effects versus seizures'.*

> *Explains potential treatment options to the patient based on her knowledge of the patient, her knowledge of AED therapy and advises the patient's mum in this respect and informs her that a letter will be sent to the patient's GP to make suggestions. (Candidate ANP observation)*

## Provides psychosocial care to optimise psychological wellness of person and family

The psychological and social burden of epilepsy can be significant, not just because of stigma but because of its potential to impact on the vocational, educational and recreational aspects of the person's life. Consequently, optimising psychological wellness and adaptation was also a critical goal for the ESNs involved in this study. Psychosocial care and support was not something that was separated out as a discrete intervention but occurred simultaneously in the context of assessment, education and the provision of other treatments. In the vast majority of situations psychosocial care was about listening, reassuring, providing information and bolstering the person's or the family member's motivation and confidence in self-management.

> *"…the nurses [ESNs] are the people who pick up initially, a lot of the psychological difficulties… I mean, they're [ESNs] the ones who are on the phone on a very regular basis. They [ESNs] would tend to be the ones at the coal face. That would actually be a primary really in identifying any behavioural, emotional, or cognitive difficulties in talking, their [ESNs] talking to the parents [of children with epilepsy] on a very regular basis…they [ESNs] know the patients [PWE] really well…" (Allied health professional interview)*

> *"… I thought my child was going to die... so I needed to speak to someone that was going to tell me my child's not going to die… somebody who's got that knowledge and can calm you down… the most important thing for me was getting to speak with [names ESN]…" (Family member focus group)*

> *[On TAL to a male patient] discusses medication and seizure history, which leads into a discussion about him commencing third level education in the next week. Asks about his fears and explores anxieties, and reassures him that he can contact her to talk at any time. (CNS observation)*

> *"They [ESNs] also see patients [PWE] where it may be more important to discuss with the patient [PWE] or with the relative issues that are not maybe to do with the diagnosis [of epilepsy] or to do with the specific treatment, but revolve around psycho-social issues which I think the nurses are fantastic with…" (Medical personnel interview)*

When it came to the more significant mental health morbidities, such as depression, anxiety, substance misuse, thoughts of suicide or self-harm and working with people who had non-epileptic form seizures, there was significant variability in the ESN's skill level around assessment and response, which was not surprising as these patients frequently required specialist interventions from psychological and mental health services. Despite the challenges the ESNs encountered in accessing specialist mental health or psychological services within the public healthcare system, they were all endeavouring to engage with various members of the MDT to ensure optimum care and management of individuals experiencing significant psychological distress, and were advising and/or arranging referrals for patients.

> *"…she sent me to counselling to try and help me through [crisis in life and suicide thoughts]…but also she helped me to come to terms with being diagnosed [with epilepsy] … because I was in the middle of college and then being diagnosed, just in exam period time…" (PWE focus group)*

> *"[ESNs] we would do a lot with psychiatry. There is a big over-lay with psychiatry in epilepsy …so we would get onto the GP, arrange for urgent psychiatric involvement, while we don't directly refer …we have often typed letters, got [neurology consultant] to sign it and faxed it to the [psychiatric] consultant or the GP or the child and adolescent mental health services." (Candidate ANP interview)*

In the absence of timely access to specialist mental health or psychological services within the public healthcare system, the ESNs were spending significant amounts of their clinical time trying to support people and in some situations were involved in efforts to locate voluntary or private services for people.

## Co-ordinates care and care-pathways to enhance patients' journey

A key function of the ESN role was the co-ordination of care pathways for PWE across complex primary, secondary and tertiary services and across a diverse range of professional groups. The ESNs were valued by patients, family and members of the MDT for being '*the branch between you and the consultant', 'the go-between', 'the glue that holds the service together', 'the link person', 'the conduit for multidisciplinary care', 'the go-to person', 'the gatekeeper in keeping people in their homes', 'the point of contact*', and the person who *'takes the patient on their epilepsy journey'.* Without the ESN there was a view that '*[care] would be chaotic for me [neurologist], for the medical team, for patients'*.

The success of the ESN's co-ordination role stemmed from their extensive knowledge both of the epilepsy services and of their patients, which meant that they were able to match appropriate services to the individual patient's needs. Because of their years of clinical experience, ESNs have high levels of organisational knowledge not only of the neurology team and hospital structures but also of the diverse range of services that are available in the community and nationally. Because in the majority of situations, ESNs have continuity of care for patients attending epilepsy services, they have high levels of knowledge about individual PWE, so were able to recognise early changes or problems and to advise/refer PWE to services that were most appropriate to their specific needs, as these members of the MDT explained.

> *"The epilepsy nurses have that kind of almost trans-disciplinary function, of knowing enough about what everybody else does to know what they can contribute, what they themselves can contribute, what everybody else can contribute." (Allied health professional interview)*

> *"Because of her knowledge of how the epilepsy system worked, and of all of the nurses, not just from [hospital name] but from [hospital name] and from [hospital name], that you know she was able to, much more than I could, ease the pathway of information between us and the primary epilepsy carer and vice versa. So if there was an issue you know she [ESN] had the phone numbers, she had the contacts, she was meeting these people on an ongoing basis, so any of the really problem cases, she was able to provide a conduit for multidisciplinary care." (Medical personnel interview)*

> *"The way she [ESN] co-ordinates the whole outpatient visit is different…it is deeper than just arranging, making a phone call, and seeing [PWE] in the clinic – it's a deeper thing, it's a professional thing, there is an insight into the whole epileptology and epilepsy surgery, there is a human thing, it's a nursing thing as well, it's a professional thing." (Medical personnel interview)*

There was clear evidence in the data that ESNs have a pivotal role in co-ordinating care across the MDT, within the hospital organisation and externally, co-ordinating care across different healthcare organisations and services (e.g. intellectual disability, mental health and maternity), and across GP and primary care services.

ESN's co-ordination of patient care within the hospital organisation involved working across different healthcare professions and services to provide a streamlined care pathway for PWE through the epilepsy services.

> *[ESN] opens a case presentation document on the PC as she is presenting three [patient] cases to the MDT team on Friday for review. She sends a number of e-mails to the MDT team. (CNS observation)*

> *Patient is due in for a scan – [ESN] organises blood test and ECG forms and leaves at reception for [patient] to collect so can have them done all on the one day and prevents patient having to return to hospital on another occasion. Ensures [tests] are done when [patient] comes to next consultation. [ESN] phones patient to tell her about leaving forms for blood test, ECG, tells her that [ESN] will leave [her contact] phone number at reception, and to contact [ESN] if she has a problem. (CNS observation)*

> *" … so it's a phone call or an email or a letter saying so-and-so's battery is gone, he'll need to get it changed. We co-ordinate that waiting list. Officially it's done by date but you get an email from [consultant] saying the [patient's] battery is flat and their seizures are [severe] so they're prioritised, so we co-ordinate the battery changes." (Candidate ANP interview)*

Because the ESN's caseload included patients with complex epilepsy or with co-morbidities, they co-ordinated care and referred patients to an extensive range of services, resources and support organisations in the community.

> *"The ESNs liaise with us [intellectual disability service manager] in relation to tracking different people's seizures, and then liaising with the neurologist with regard to the medications…[ESNs] were able to tell us from their information that we would give them, whether they felt they needed a sooner appointment, whether they were able to liaise with the registrars or the consultants so as they could change medications, and actually fax us, or send us down prescriptions, to try medications, so that we could actually see does the change help, before we actually got to the neurologist for their next appointment." (Allied health professional interview)*

> *[ESN] wrote letter to the patient’s GP using EPR to ask that he/she organise a Dexascan locally, so patient did not have to travel. Monitoring bone health is part of [ESN] role as some ‘old’ antiepileptic medication impact on calcium absorption. Results of Dexascan will be returned to consultant who will pass on to the ESN. Depending on result the ESN may advise GP to prescribe calcium supplements. ESN may also refer patient to rheumatologist if other issues are of concern. (Candidate ANP observation)*

> *“[ESN] dealing with people with very complex issues … trying to see which way you can signpost them, which way you can direct them…refer them back to either their GP or the right services, directing people because they come with all sorts of problems clinically that might not be related to epilepsy… the wider issues, [refer patients to] Epilepsy Ireland, the voluntary organisations, linking them in to brain injury services.” (Candidate ANP interview)*

Importantly, ESNs were central to the co-ordination of care for PWE and family members who were managing their epilepsy at home. ESNs are the first point of contact for PWE when problems arise and they co-ordinate the care delivery between the hospital and the primary care services (e.g. GP, pharmacy), so that PWE are enabled to stay at home, go to school or work with minimum disruption to their everyday life.

> *“I rang [ESN] - [name of child] had a seizure in school. Within an hour, there was a new prescription being faxed to the pharmacy.” (Family member focus group)*

> *[ESN] is speaking on the telephone with the parent of a young teenage boy with epilepsy… [ESN] discusses the type and duration of the patient’s symptoms. There is a discussion around serum levels of [AED] drug, when and why the levels need to be checked. [ESN] reiterates the increasing dose rate from the patient’s chart and when the patient needs follow-up regarding a serum level. [ESN] informs the parent that s/he will send a copy of the new prescription to the patient’s local pharmacy. (CNS observation)*

> *"… when problems arise from a patient's perspective they have that person [ESN] they can pick up the phone and speak to, who can then interact on their behalf with the neurologist, so patient care, or changes say in medication regimes, or any changing seizure behaviour is brought to the neurologist's attention sooner and then it can be acted upon." (DoN interview)*

In addition, the ESN's role extended to improving the co-ordination of services in order to improve patient flow and journey through hospital services, and consequently, they were central to quality improvements within the epilepsy services.

> *"We work alongside the secretaries quite closely in trying to make sure that things flow…when there's patients who come in through ED with the presentation of a seizure … [ED staff] know that they can call us, we'll come down and liaise with the registrar, they're not sitting there waiting …it helps the flow of the patient maybe either way, that they are admitted or hopefully discharged." (Candidate ANP interview)*

> *"[ESNs] they've started to get more involved with the smoother transition of children from paediatric services into adult services and that's starting now but I would see that being very much nurse-led." (DoN interview)*

There was some evidence of variation across the different healthcare organisations regarding the ESN's role in patient referrals which impacted on their ability to fulfil their co-ordination role. In some organisations the ESN could refer and accept referrals. However, in other organisations, referral had to be made by medical colleagues.

> *"[ESNs] we do have some capacity to liaise with social work. They don't accept direct referrals from nurses or ANPs, not here anyway." (Candidate ANP interview)*

> *Sixty year-old female was referred to RANP by a neurologist from another hospital. Developed epilepsy post RTA as a teenager. (RANP observation)*

> *RANP suggests a neuro-psychology referral to a specialist neurology centre [for a patient who had developed epilepsy following head trauma from fall]. Patient had linked with this service previously following his accident. RANP will prepare the letter for referral following the consultation. (RANP observation)*

## Quality assurances of healthcare information recorded

An important aspect of the ESN role was the quality assurance of information recorded. This aspect of the role was carried out in conjunction with their assessment function. Checking the accuracy of information recorded both in hard copy and the EPR information was seen as critical in the reduction of adverse events, including adverse drug events, as well as ensuring that information was sent in a timely manner to the correct member of the MDT.

> *Explains to patient about EPR and reassures patient about confidentiality. Checks that information on the record is correct as GP detail on record appears to differ from hard copy. Also checks hospital database to see if GP details are correct, explains to patient that she needs to double check to make sure the letters are going to the GP's correct address. Reviews patient's seizure history on EPR to make sure that this information is also correct. (Candidate ANP observation)*

> *"Even simple things like I want to make sure the patient is still at the same address, that this is still their phone number, making sure that I have all those details, you're still with that GP." (Candidate ANP interview)*

> *"It's important that you go through the chart, the investigations, is there any outstanding tests, has any standard test been missed, so you go through that… go through the medications to make sure that there's no mistakes [in recording], because you can find mistakes or things missed." (Candidate ANP interview)*

## Discussion

Despite the ESN role being in existence in the UK since 1988 (Goodwin *et al*. 2004), there is a paucity of research-based evidence about the clinical aspect of the role with only three studies attempting to capture the role ESNs play in patient care on a day-to-day basis (Goodwin *et al.* 2004; Higgins *et al.* 2006; Hopkins *et al.* 2010; Hopkins and Irvine 2012). Given the newness of the role within the Irish context and the aspiration for the role, including the clinical dimension of the role, as outlined in the NECP (HSE 2014), findings from the **SEN**s**E** study are important in making explicit the essential part the ESN plays in providing care to PWE and their families/carers within the MDT.

Findings clearly indicate that the ESNs involved in the **SEN**s**E** study spent the vast majority of their time on the clinical dimension of their role and provided a wide range of services and interventions to PWE across the primary, secondary and tertiary healthcare continuum. In conjunction with other members of the MDT the ESNs provided services in a variety of settings to children, adolescents and adults, and to people with complex needs that according to Hopkins *et al.* (2010) are 'generally neglected', such as pregnant women, people with ID and PWE living in care homes.

Findings suggest that a key dimension of the role was continuous assessment and ongoing monitoring of the PWE, which was underpinned by the principles of holistic person-centred care, respect for the voice of the patient, and empowerment. The research revealed that the ESNs considered comprehensive history taking including eliciting the person's seizure history, physical health status and social context as the foundation to collaborative working. It was through time spent 'getting to know the person' and the meaning they attached to their epilepsy and treatment, that ESNs were enabled to integrate individual biographical differences, beliefs, goals, resources and interests into the plan of care, and deliver care in a person-centred and flexible manner. This aspect of the role required a high of degree of epilepsy-specific knowledge as not only did the information obtained inform their own decision-making but influenced the decision-making of other members of the MDT. Although some of the ESNs were in post for shorter periods of time than others, their communication, relationship-building, empathy, caring and assessment skills, skills core to nursing, were valued by their medical colleagues who perceived these skills as essential to quality epilepsy care and management. When there was an existing diagnosis of epilepsy, the evidence suggested that ESNs felt more clinically competent to manage the PWE actively.

Similar to ESNs in other studies (Goodwin *et al.* 2004; Higgins *et al.* 2006; Hopkins *et al.* 2010) a key part of the ESN role included the ongoing monitoring of treatments provided, including medication and the side-effects of medication to ensure optimal seizure management, with minimal side-effects. This is critical for the epilepsy care team and the PWE as treatment regimes may often require trials of AEDs which have significant side-effects and toxicity complications, thereby negatively impacting on the physical, psychological and social well-being of the PWE. Over 50% of the ESNs included in this study were registered with the NMBI as medical prescribers, thus they were very aware of their professional obligations to monitor carefully, act promptly and communicate with their medical colleagues about medication management.

It is increasingly recognised that epilepsy is not simply a medical problem, but a complex problem with psychological and social challenges. The association of epilepsy with stigma, fear and discrimination and other mental health co-morbidities, such as depression and psychosis, can directly impact compliance with treatment, and control of seizures, thus increasing the negative impact of the disease on quality of life and clinical outcomes (Kanner 2003; Clancy *et al.* 2014). Therefore, effective management of psychosocial issues is essential. Existing evidence generally concludes that this aspect of assessment, care and treatment is not always prioritised for people with epilepsy, as physical assessment and disease management is often given priority (Ridsdale *et al*. 1999b; Varley *et al.* 2011a; Noble *et al.* 2013). Whilst the ESNs in this study were, on their own admission, more skilled in the physical and medical aspects of care and treatment, findings from this study do suggest that they were addressing the psychosocial dimensions of care within the limits of their knowledge and skills, and were conscious of the mental health morbidities associated with epilepsy. The ESNs repeated engagement with PWE no doubt facilitated them to develop an open and trusting professional relationship, which in turn enabled them to get an in-depth understanding of the lives of the PWE and their families, and to provide on-going psychological support. However, findings also indicated that the ESN experienced challenges in accessing timely supports for people with more significant mental health morbidities, or who were diagnosed with non-epileptic form seizures.

Education of PWE and families has been noted as an important function of all clinical specialist and advanced nurse practitioners (NCNM, 2004, 2005; Gerrish *et al.* 2007b; Begley *et al.* 2010). In the context of chronic disease management and management of epilepsy, education of the PWE is considered critical if self-management is to be achieved (Helde *et al.* 2003; Doughty *et al*. 2003). Knowledge of epilepsy is an essential tool to enable PWE to improve compliance with treatment and aid self-management of their condition, to reduce fear associated with seizures, to cope better with the emotional and psychological impact of the condition and its treatment, and ultimately to attain a good quality of life (Helde *et al.* 2003; Doughty *et al*. 2003). The provision of accurate information can empower people with epilepsy to deal with their diagnosis, make informed decisions regarding treatment, educate others about epilepsy and adapt positively to their condition (Couldridge *et al*. 2001; Helde *et al.* 2003). Conversely, a lack of knowledge or misinformed and incorrect beliefs among PWE can impair their ability to self-manage effectively (Ridsdale *et al.* 1999b) and can have negative psychosocial and medical consequences, including incorrect use of anti-epileptic medication, non-compliance with treatment and advice, or a withdrawal from social life and increased risk of depression (May & Pfäfflin 2005). Findings from this study clearly indicate that the ESNs considered education as central to their clinical role. For the ESNs involved, education was not just about providing information and instruction on epilepsy and the various treatments and resources available, but also about building the person’s confidence and motivation to use their own skills and knowledge to take effective control over their life with epilepsy and enable self-care and self-management.

In addition to educating PWE, another key facet of the clinical role included the education of family members and carers. Within the literature families/carers of PWE are reported as receiving low levels of practical and emotional support, and lacking the critical information needed to support their family member with epilepsy, including information on first aid seizure management and side-effects of AEDs (Kendall *et al.* 2004; McEwan *et al.* 2007; Lewis *et al.* 2010). Findings from this study suggest that the ESNs all provided an advanced level of education to all families and carers, and were central to the education of parents of children with epilepsy and carers of people with ID or cognitive impairment.

A core element of the ESN role was the co-ordination of care. Literature on PWEs' experience of service provision within Ireland reports delays in accessing specialist services,  poor integration between different healthcare sectors, and a lack of communication and information sharing between healthcare providers which resulted in delays in diagnosis and treatment (Varley *et al*. 2011a). Findings from the **SENsE** study clearly demonstrate that the ESNs were not just crucial in the co-ordination of care within the epilepsy specialist service, but were co-ordinating care across the primary, secondary and tertiary interface, ensuring that PWE, in the majority of situations, experienced a seamless provision of care and did not fall through the 'cracks' of a busy and stretched service. Similar to ESNs in other studies, the ESNs were frequently the first point of contact and were not only matching PWE with the appropriate services, but they were triaging PWE and improving continuity of care and transition within and across services (Scrambler *et al.* 1996; Sarkissian & Wennberg 1999; Mills *et al.* 2002; Kirton *et al*. 2012).

The ESNs in this study not only provided care in an orthodox healthcare environment, such as the epilepsy outpatient clinics, or in-patient wards in the hospital, but a significant part of the interaction occurred over the TAL. While the name might suggest that the telephone consultation is merely about advice and one might underestimate the knowledge and skill required for this aspect of the role, in fact the phone consultation required greater levels of skill in history-taking, discussing aspects of epilepsy care and interpreting the response to treatment, as the ability to use observation of the person's physical state and monitor their response to questions is absent.

Finally, the ESN role description provided by the NECP for those working at ANP-level outlined a number of clinical roles including the provision of routine care and follow-up to PWE, liaising with MDT members within and outside epilepsy services, and educating patients and families (HSE 2014). It is clear that the ESNs involved in this study were fulfilling the role requirement outlined and in all cases were contributing to the clinical aspect of the service beyond what was described in the role description as documented in chapter one of this report. For example, one of the roles identified, is the completion of 'accurate and up-to-date information of clinical encounters using the EPR' (HSE 2014:16) and findings from this study suggest that not only were the ESNs using the EPR to record their clinical encounters but they were constantly quality-controlling the accuracy of information recorded by themselves, and other members of the MDT, thus reducing the likelihood of an adverse event occurring due to inaccuracy of information.

Chapter 4

# Leadership Role of ESN

# Chapter 4: Leadership Role of ESN

Whilst all nurses participate in leadership activities, there is a growing recognition that nurses working at advanced levels are ideally positioned within the clinical team and organisation to lead on the healthcare reform agenda and influence policy and practice (Kilpatrick *et al*. 2010; Higgins *et al.* 2014). Nursing leadership is considered an important factor in the provision of improved access to services, improved patient outcomes, enhanced patient care and safety, enhanced teamwork and productive working environments (American Association of Colleges of Nurses 2007; Gifford *et al.* 2007; Murphy *et al.* 2009; Begley *et al.* 2010; Higgins *et al.* 2014; Elliott *et al.* 2016). Although leadership activities of nurses at advanced level vary across countries and organisational context leadership domains usually include professional and clinical leadership (Elliott *et al.* 2016). Fealy *et al.* (2011) describe clinical leadership as influencing and directing patient care at individual, team, departmental and organisational levels, whereas professional leadership refers to 'activities supporting developments outside of the service at national and international level' (Elliott *et al.* 2013:1039).

Within the epilepsy-specific literature the leadership role of the epilepsy specialist nurses is given scant attention, except for some brief discussions on their role as educators of MDT members (Foley *et al.* 2000; Higgins *et al.* 2006), and a mention of their role in developing standards and guidelines (Higgins *et al.* 2006). However, within the broader literature on nursing at specialist and advanced practitioner level there is general consensus that leadership is a core component of the role (Elliott *et al.* 2016). In the context of nurses working at advanced practice level the NCNM framework clearly outlines an expectation that advanced practitioners take on a professional and clinical leadership role, identifying them as 'pioneers and clinical leaders in that they…initiate and implement changes in healthcare service in response to patient/client need and service demand' (NCNM 2008a:7). Although leadership is not specifically identified as part of the clinical specialist role it is included within the defining concepts of: patient advocacy; education and training; and consultancy (NCNM 2008b). In addition, there is a tacit expectation within the National Clinical Care Programme in Epilepsy Care in Ireland (HSE 2014:19), that ESNs take a leadership role in achieving the overall aims of the programme, which include the 'delivery of improved quality of care and improved access to specialist care, whilst … delivering value for money through the best use of healthcare resources'.

This chapter reports the findings relating to the leadership dimension of the ESN role. Not all of the ESNs involved were functioning at the same level of clinical and professional leadership, with the leadership dimension emerging as they became more established within the role and progressed to the ANP level. Analysis of the data demonstrates that they enacted their leadership role by engaging in the following:

- Initiating new clinical practice developments;
- Developing education programmes and resources for PWE, family and the public;
- Being an active member of multidisciplinary committees with responsibility for policy and practice development;
- Building capability within the MDT to increase the quality of service provision in epilepsy care;
- Advocating for the voice of the PWE to be represented; and
- Advancing the ESN role through site preparation and mentoring of candidate ANPs.

## Initiating new clinical practice developments

It was evident from the interview, observation and documentary data gathered that the ESNs were instrumental in initiating, implementing and reviewing a number of new practice developments namely: they established new nurse-led clinics, developed new guidelines/ protocols/ care pathways, designed epilepsy education programmes and resources for PWE, family and members of the MDT, and led the implementation of the national strategy on the EPR (Electronic Patient Record).

There was clear evidence that ESNs were actively involved in developing new services for PWE within and outside their own organisations. ESNs led on a wide range of service initiatives. There were three areas of service development evident in the data: firstly, ESNs expanded nurse-led VNS clinics to a wider geographic area; secondly, they developed new nurse-led clinics for specific patient groups e.g. people with intellectual disability and pregnant women; and thirdly, they created new services e.g. TALs and RACs to reduce the waiting times for patients and the need for hospital visits. The following data profiles the ranges of ESN initiatives.

> *"…clinics that would be led specifically by nurses that doctors really don't have any involvement in. There's a new process in place in terms of VNS clinic…that's done purely and solely by the nurses and led out by the nurses and it's a great success. There would be other rapid access clinics that … the nurses facilitate, and that's all in terms of the patient who's in crisis or that there's a problem in terms of their controlling of their symptoms and the rapid access clinic most certainly enables and facilitates that. There are off-site nurse-led clinics … they are very successful … telephone triaging, looking at the type of patients and the cohort of patients that are in the emergency department and trying to avoid the admissions if the … clinical nurse specialist is involved at a very early stage …satellite clinics and the role of the nurse in satellite clinics." (DoN interview)*

> *Evidence of collaboration with intellectual disability services to develop an "outreach clinic" at a specific long care ID service that targets specifically the care and management of people with epilepsy with ID. (RANP documentary evidence)*

> *"Currently doing rapid access here in [name of hospital]. I have been doing that over the last few years with [name of epilepsy consultant]. And obviously the OPD clinic too. But I would like to develop the rapid access out in [name of hospital]. Because just to reduce the number of bed days that people are in with seizures. When they could be seen basically quickly, hopefully by myself when we set up a rapid access in [name of hospital]. And so it will be less cost and more efficient and all the rest for the patient." (Candidate ANP interview)*

> *"…they've [ESNs] shown particular initiative for the VNS…because we didn't have a VNS clinic here there was people going…to Dublin to have that done, which is very inconvenient... So the nurses… in the last two years, on their own initiative, have led on the setting up the VNS clinic here… So now we have about twenty patients coming…it's a real addition to the service that we can provide."(Medical personnel interview)*

There was evidence in the data that ESNs were active in developing clinical practice guidelines and protocols to improve specific clinical interventions (e.g. VNS, buccal midazolam administrations, ketogenic diet), and patient care pathways (e.g. referral pathway to neurology services, pathway for transition from child to adult services).

> *"…care pathways for your ED patient presenting with a seizure… was developed by the ANPs. So I would comfortably say that any pathway we have was developed by the ANPs." (DoN interview)*

> *Led the development of a protocol for administration of buccal midazolam liquid for patients going home or ID patients in care settings so family or clinicians can follow procedure correctly and administer medication safely. (Candidate ANP documentary evidence)*

> *Developed Standard Operating Procedure (SOP) for nursing care of VNS patient in association with colleagues in UK. This SOP currently used in UK & Ireland. Developed SOP telephone advisory service, and one for discharge planning. (RANP documentary evidence)*

> *Identified issues with triage of patient who come to AE with collapse, as outcome identified need for MDT to explore this issue, spoke to senior consultant in AE and both have commenced process of setting up steering group to look at pathway for 'collapse query'. (RANP documentary evidence)*

The ESN had a major role in leading on the implementation of the EPR (Electronic Patient Record) which is a key initiative within the National Clinical Care Programme for Epilepsy to improve communication across the MDT and ensure continuity of care. In addition to consenting PWE, entering data, verifying accuracy with patient and family, corroborating information with paper record and updating information, the ESNs were championing the EPR with other members of the MDT to ensure usage. In addition, they were collecting data about its use to inform changes to the EPR and using data from the EPR to inform MDT discussion. The ESNs were also working with EPR developers when enhancements to modules were being developed and performing user acceptance testing before new modules and enhancements were released.

> *"I think from the time that the ANP started with us, it was then that the EPR was rolled out, she [ANP] literally ran with it, you know there was an advisory team but she has run with it." (Medical personnel interview)*

> *"We use the Electronic Patient Record, and the nurses really champion that, and run that, and they are instrumental in also making sure that the NCHDs* [*Non-consultant hospital doctors] use it properly...the nurses here have embraced that very strongly… I think we would be using it a lot less if the nurses hadn't advocated for it." (Medical personnel interview)*

> *She is what is called a Super user of EPR: She runs statistics to inform team and also collates issues from team on EPR and presents issues at teleconference once a month on EPR. (Candidate ANP documentary evidence)*

Furthermore, there was evidence that ESNs led on other initiatives that enhanced documentation and record-keeping within the health service.

> *Development of an Epilepsy Nurse Phone Triage Form. An 8 page document that captures both epilepsy and non-epilepsy information at the initial contact with the patient. (Candidate ANP documentary evidence)*

> *"I changed all their documentation within the service so for recording seizures, there are epilepsy charts, introduced a new care plan." (Candidate ANP interview)*

## Developing education programmes and resources for PWE and the public

A key aspect of the ESN leadership role was the design of epilepsy education programmes and resources for PWE and families that impact on PWEs' knowledge of their own condition and ability for self-care management. ESNs demonstrated their leadership by identifying educational gaps and by designing new programmes of education and educational resources. The development of a range of education resources (see table 4.1) was carried out in conjunction with Epilepsy Ireland, and members of the MDT, including the pharmacy services within their organisation. To help disseminate information, ESNs used multiple strategies, including the display case for patient information in the clinics, dissemination during patient consultations and through the Epilepsy Ireland website. In addition, in response to an identified deficit in the education of newly diagnosed people, ESNs led the development of a group education programme, which they subsequently piloted and evaluated.

Table 4.1: Educational resources developed by ESNs for patients and family

| | |
|---|---|
| **Patient information explaining procedures or interventions** | • VNS<br>• Wada test<br>• Video EEG/Epilepsy monitoring unit (EMU)<br>• Epilepsy surgery<br>• SUDEP |
| **Patient information on services available and how to access services** | • Epilepsy nurse TAL<br>• Nurse triage service |
| **Patient information on self-management of epilepsy** | • Anti-epileptic medication<br>• How to administer buccal midazolam<br>• Pharmacological information relating to pregnancy and anti-epilepsy drugs (AEDs), breastfeeding and AED therapy and side-effects of AED therapy in the new born.<br>• Pharmacological information for teenagers and young adults.<br>• Self-care plan post – epilepsy surgery<br>• Coping with seizures: Information for patients with an oral tumour<br>• Living well with epilepsy<br>• Ketogenic diet<br>• Folic Acid administration |
| **Patient self-monitoring record** | • Brain tumour patient passport<br>• Seizure diary |
| **Family/ friends & other information** | • What to do in the event of a seizure<br>• Teachers pack developed in conjunction with Epilepsy Ireland |

In addition, ESNs were involved in educating the wider public by contributing to information events organised in conjunction with Epilepsy Ireland and local support groups. There was evidence of giving talks to community groups organised by Epilepsy Ireland and local brain tumour support groups.

> *Evidence of delivering epilepsy-specific information sessions regionally at the request of Epilepsy Ireland to patients, families, and schools. (Candidate ANP documentary evidence)*

> *"We're creating an information pack for teachers in primary schools.." (RANP interview)*

> *"I was at an Epilepsy Ireland night recently and it was just specifically aimed at young people. And it was nurse [ESN] who came in giving us a talk…she was discussing employment for us… the legalities around finding employment …how to come around that aspect …you don't have to discuss personal, your personal epilepsy story and history." (PWE focus group)*

### Being an active member of multidisciplinary team committees with responsibility for policy and practice development

There was evidence that ESNs were involved in influencing policy and practice through membership of local and national committees (see table 4.2). The committees had responsibility for strategic issues (National Epilepsy Care Programme, Epilepsy Steering Group), quality assurance (EPR National Governance, Standard Operational Procedures committees, Clinical Governance), multidisciplinary practice issues (Electronic Patient Record, Transitional Care Framework Development), and professional development (Irish Epilepsy Nurses' Group, ANP Regional/National Association). Some of the committees were involved in reviewing and ensuring that local developments were aligned to the National Epilepsy Care Programme.

**Table 4.2: Membership of local and national committees**

| | Epilepsy-specific | Non-epilepsy-related |
|---|---|---|
| **Committee membership (Local)** | • Epilepsy Steering Group<br>• Epilepsy EPR Group<br>• Transitional Care Framework Development Committee. | • Healthcare Records Committee<br>• Nurse Advisory Committee (Advancing Nurses' Development Committee)<br>• Clinical Governance Committee<br>• CNS Committee<br>• Conference Committee |
| **Committee membership (National/Regional)** | • Lead Nurse on the National Care Programme<br>• Irish Epilepsy Nurses' Group<br>• National Epilepsy EPR Steering Board<br>• EPR National Governance Board<br>• ESNs from all regions involved in SOP Development Working Groups<br>• Regional Epilepsy groups (Mid-West, Mid Leinster Dublin North East, South) | • ANP National Association ANP Regional Committee<br>• West/North West Hospital Group (WNWHG) which meet quarterly to discuss matters/challenges arising in clinical nurse/midwife specialist roles |
| **Committee membership (International)** | • UK Epilepsy Specialist Nurses Association | |

There was also evidence that ESNs were actively involved in developing guidelines for clinical practice at local level and, in some instances, at international level. The guidelines developed spanned the practitioners' clinical specialties and also included more generic issues, such as drug administration and admission protocols. In the process of developing these guidelines, the ESNs collaborated with other specialist nursing and midwifery practitioners, and with other healthcare professionals.

Data indicated that ESNs were recognised by people within and outside of the discipline as experts in their area of clinical practice. Consequently, they were invited onto national fora to guide the development of epilepsy services, onto curriculum groups for the development of MSc Programmes for future epilepsy nurse specialists, and onto accreditation review committees.

- Invited to join 2011 curriculum group who developed M.Sc. in Epilepsy in RCSI;
- Invited by NMBI onto Accreditation Committee as clinical expert for ANP epilepsy and ANP neurodegenerative disorders/ motor disorders; and
- Invited to expert round table discussions with pharmaceutical companies – to comment on different medications
- Reviewer of all SOPs developed as part of the strategic reform of epilepsy services in Ireland via the National Epilepsy Programme.

(RANP documentary evidence)

> *"… [ESNs]..would be involved in…nursing practice guidelines…contribute to general guidelines…around hand hygiene or around…medication managements, certainly nurse prescribing, they'd be involved in…the writing up the guidelines..." (DoN interview)*

> *"I was involved in the development of Standard Operating Procedures for the National Epilepsy Care Programme." (Candidate ANP interview)*

> *"[Name of ESN] was instrumental in developing the guideline and care pathway for care of women with epilepsy. In fact she wrote the guideline and I had very little to add when she gave it to me, again she know what was needed and is working at national level so she is very informed. We then sent the guideline to the obstetrician group for approval. That guideline will be used nationally, so she had a big input into that." (Medical personnel interview)*

## Building capability within the MDT to increase the quality of service provision in epilepsy care

All ESNs were involved in building capability within nursing, the MDT and the public through formal and informal education programmes and consultancy. The data provide evidence that ESNs were involved in the education of a wide range of practitioners including undergraduate and post-graduate student nurses and midwives, junior and senior doctors, and allied health practitioners such as social workers and care assistants. Although ESNs were primarily hospital-based, their educational reach extended beyond their own organisation to primary care services and the wider community including GPs, intellectual disability services and nursing homes (see table 4.3).

There is evidence in the data that ESNs as an educational resource have a positive impact on epilepsy care provision by enhancing the clinical decision-making of the MDT.

> *"So [ESN] can give another perspective on what the patient might be going through, what the best approach to managing the patient is. And they can give their opinions on that which actually are very, very helpful…Tends to steer my decision quite a bit anyway." (Medical personnel interview)*

> *"If I hadn't had [ESN] I don't know whether by now I would have cottoned on to some of those subtle nuances in relation to the questions to ask a patient with epilepsy. Would I have cottoned on to those unless I had gone and done some neurology for a while, I don't know!...I might have been missing some of those subtle clinical questions to ask." (Medical personnel interview)*

> *"The man [ID person] had severe kidney issues… he was having lots of seizures, so I [manager of ID service] rang [ESNs] about the seizures, they were able to access [records], and come back and give us the other angle, which helped prevent his seizures, didn't change his medication, but got him treated for something else as well that was adding to the seizures…It is also hugely educational…the [ESNs] are fantastic because they are able to advise, they are able to liaise. And also in relation to talking to GPs, it is fantastic to be able to say to the GP "I've been on to the [ESNs], they are saying this". Because often GPs can be very set in their ways." (Allied health professional interview)*

The ESNs were active in providing a wide range of educational interventions to increase the knowledge and upskill the MDT and nurses/midwives in epilepsy care (see table 4.3). ESNs led the development of short educational programmes on various aspects of epilepsy care as well as being invited as experts to continuing professional development events for MDT members held at local, regional and national level. In some instances, ESNs secured accreditation and approval from the relevant professional body for the formal educational events organised by them. Furthermore, ESNs during their clinical work were constantly consulted by individual nurses and MDT members for their expert advice on patient care management. This ongoing day-to-day mentoring and consultancy formed a significant part of their contribution to building capability and upskilling of healthcare staff.

> *“A new SHO or registrar that comes on the service…the nurse practitioners teach the SHOs and the registrars, and there is discussion back and forth about patients…if you have a reg, the neurology reg, or SHO on a ward, they would go to the nurse practitioners for advice about epilepsy and epilepsy management. Also as you know we use the…Electronic Patient Record, and the nurses really champion that, and run that, and they are instrumental in also making sure that the NCHDs use it properly, you know, so… But, yea, I mean absolutely the nurses learn from the medics, and the medics should learn from the nurses.” (Medical personnel interview)*

> *“The SHOs and the interns in particular might ask the epilepsy nurse specialist things about patients and patient care that they wouldn’t necessarily ask me [consultant], because they would be afraid to think that I don’t think they’re very good by asking that question…I think they are very grateful to have the help of the epilepsy nurse specialists…to educate them.” (Medical personnel interview)*

> *ESN interrupted by SHO to discuss a person who wants to reduce medication and is seizure free for a number of years. ESN advises the SHO on the importance of patient making an informed decision as if get a seizure this will have implications for driving/insurance, which is important to her as she [PWE] has small children. ESN goes through in detail with the SHO explaining that it is patient’s choice once information is presented clearly and the importance of the SHO ensuring patient understands implications. (Candidate ANP observation)*

> *“The [ESNs] have shown great initiative, so there has been new driving regulations in relation to epilepsy...and the epilepsy nurse specialists here had a session where they…discussed the driving regulations … they summarised the driving regulations for us and that was very helpful to be able to discuss them.” (Medical personnel interview)*

Two service areas, namely, GPs and intellectual disability services were heavy users in seeking ESN advice regarding the management of epilepsy patient care.

> *"GPs and the ID services, we do a huge amount… we have gone out to give talks to the ID sector…But GPs, absolutely, some of my calls [telephone advisory line] during the week, GPs ring us directly querying medications…Especially in pregnancy, they deal with us, they liaise with us a lot." (Candidate ANP interview)*

> *ESN rings GP who has left a voice message saying she was called to the care home and would be visiting later. ESN asks GP about her prescribing and reason for her deciding to increase certain medications. ESN cautions about increasing without adequate assessment and monitoring effect of increase before making further changes and additions. (Candidate ANP observation)*

Table 4.3: Educational interventions to increase the knowledge of MDT

| Strategy | Topic area | Target audience |
|---|---|---|
| **Written information** | • Shedding light on epilepsy<br>• Anti-epileptic medication.<br>• Epilepsy surgery & referral process.<br>• Epilepsy competency pack | • Nurses<br>• Junior doctors<br>• Neurologists and ESNs<br>• Staff in nursing homes |
| **In-service seminar** | • Epilepsy awareness<br>• Medication and side-effects<br>• Management of epilepsy and ID<br>• Documenting seizure activity.<br>• Ketogenic diet<br>• Buccal midazolam<br>• Epilepsy first aid<br>• New driving regulations | • Nurses<br>• MDT<br>• Healthcare workers<br>• ID services |
| **Teaching undergraduate & post-graduate education programmes** | • Epilepsy-related care (e.g. pregnancy & epilepsy) | • Nurses and midwives<br>• Candidate ANPs<br>• NCHD/ SPR training day |
| **One day course** | • Range of topics including buccal midazolam<br>• Epilepsy and acute seizure management | • Nurses<br>• MDT |
| **Education session** | • Epilepsy awareness & administration of buccal midazolam | • Staff in ID residential care services |
| **Journal club presentation** | • New epilepsy information | • MDT members |
| **Ward-based session** | • Epilepsy first aid<br>• Care of patient during seizure<br>• Recording seizure activity.<br>• Epilepsy surgery and post-operative care | • Nurses & MDT |
| **Continuing education forum within hospital** | • Epilepsy-related care<br>• EPR | • GPs<br>• MDT |
| **Presentation at conferences and seminar events** | • Epilepsy<br>• Glasgow coma scale and neurological assessment | • MDT |
| **Facilitating clinical learning through being 'shadowed'** | • Epilepsy care and service delivery<br>• Role of ESN | • Candidate ANPs<br>• Medical students<br>• Erasmus students |

## Advocating for the voice of the PWE to be represented

A further dimension of the leadership role was advocacy, which took the form of developing opportunities and processes for the voices of PWE to be represented, including lobbying at national and local levels for enhanced benefits or services for PWE and families.

> *Development of a patient council to feed into the development of information leaflets and other developments in relation to epilepsy. (Candidate ANP documentary evidence)*

> *[ANP has] written to Departments of Education and Health to advocate for support for people being put off road for hardship funding. (Candidate ANP documentary evidence)*

> *"…they always speak about the patient needs, it very much is their focus you know, and it is about I suppose that safer care being delivered to the patient." (DoN interview)*

> *"I couldn't put a price on the help that they have given in the last while. Cos I'm due to go to Dublin, I had my video EEG done. And it was, well, with the help of Dr. X, they got it put forward for me. And got it done and I'm up to see Dr. Y on Monday, to have a Wada test done. And that was thanks to [ANP] and [ANP] again, because they kept pushing the girls up in B, in the epilepsy section." (PWE focus group)*

## Advancing the ESN role through site preparation and mentoring candidate ANPs

Epilepsy specialist nurses who were at ANP-level were actively involved in building capacity and had a key role in advancing the ESN role in Ireland. In the context of this evaluation, building capacity is part of the national strategy to improve access to epilepsy care in Ireland (HSE 2014). The goal is that 'every patient with epilepsy in Ireland will have access to the epilepsy ANP service attached to one of the adult or paediatric centres' (HSE 2014:25). To achieve this, one of the strategy's aims is to increase the number of

ANPs from 10 to approximately 30 ANPs in the adult and paediatric epilepsy services across the healthcare regions.

As part of building capacity, ANP-level ESNs, who had completed their Master's Degree in Epilepsy Care in the UK, were involved in setting up the first Master's level educational Programme in Epilepsy in Ireland. These ANPs were responsible for curriculum development, lecturing, assessment of clinical competency and involved with the NMBI in the process of accreditation of new ANPs.

> *Development of the curriculum for Advanced Nursing Practice in Epilepsy delivered in the RCSI (2013). The evidence supports her role in initiating and developing the course and developing the stand alone epilepsy module (Level 9) in collaboration with epileptologists/neurologists throughout Ireland. (Candidate ANP documentary evidence)*

> *Member of curriculum development group for MSc in Advanced Nursing Practice in Epilepsy care. Teaches and is responsible for setting the final assessment in clinical competency for epilepsy care module. (Candidate ANP documentary evidence)*

> *"We came back here to Ireland and set a Masters up in Dublin…we set up the curriculum." (RANP interview)*

In addition to formal lecturing, ANP-level ESNs were involved in mentoring candidate ANPs in the clinical area and supporting the development of clinical competencies which they required to register as ANPs with the NMBI.

> *"Mentoring, you're asking [ANP candidates] the questions…to assess their knowledge. You're looking for what they may not have asked [the PWE] and you're listening for what they did ask. You're looking at the clinical notes and making sure that they've interpreted and analysed everything. You're then helping them make their own decision while…at times, saying, 'have you considered X,Y and Z?' To make sure that they are making the correct decisions, learning the right way... Creating a culture of knowledge, creating a culture of decision-making, because they're novices on this pathway." (RANP interview)*

> *"I would be involved in the training and the mentoring of those [candidate ANPs] on a daily basis, you know, you're constantly mentoring them, supporting them."*
> *(RANP interview)*

> *Candidate ANP seeks advice from RANP on patient case involving substance misuse and epilepsy. RANP is familiar with patient case. Candidate ANP discusses with RANP non-epileptic conversion disorder and patient pathology. RANP advises candidate ANP to contact [name drug addiction service] to discuss the issue of a particular drug in urine and get their perspective as if she is taking [names a drug] that may cause the traces in urine, RANP advises [candidate ANP] to link in with the psychology team who is currently working with this patient, also to ring local pharmacy to check exactly what the prescription says, advised not to increase medications until a full review with MDT team including psychology and psychiatry. (Candidate ANP observation)*

RANPs were also involved in supporting candidate ANPs across the different healthcare regions, helping them to develop new nurse-led services, and implement national epilepsy policies including the EPR.

> *Candidate ANP went to [name of hospital] to work and shadow RANP before setting up own VNS clinic. Staff from [name of hospital] and manufacturing company also visited [name of hospital] to follow-up with [candidate ANP] and ensure competence. (Candidate ANP observation)*

> *Evidence of acting as a consultant to epilepsy services outside of [own organisation] to assist and advise in setting up nurse-led outreach clinics. (RANP documentary evidence)*

> *"We've had to bring the [RANPs] from Dublin down over the EPR … we've received a lot of support." (Candidate ANP interview)*

At a strategic level, the RANP-level ESNs were instrumental in ensuring that future new ESNs were educationally prepared to the level that supported them in their roles as clinical leaders.

> *"So I had to fight for a year… for that [Masters level education]… they need the Masters, they need the prescribing, they need the authority, if they're ever going to lead out. And you can't do that as a staff nurse." (RANP interview)*

They were also instrumental in ensuring new ESNs were integrated into existing epilepsy services through providing information workshops for the healthcare organisations on the role.

> *Evidence of presenting workshops on the ESN role nationally. (RANP documentary evidence)*

## Discussion

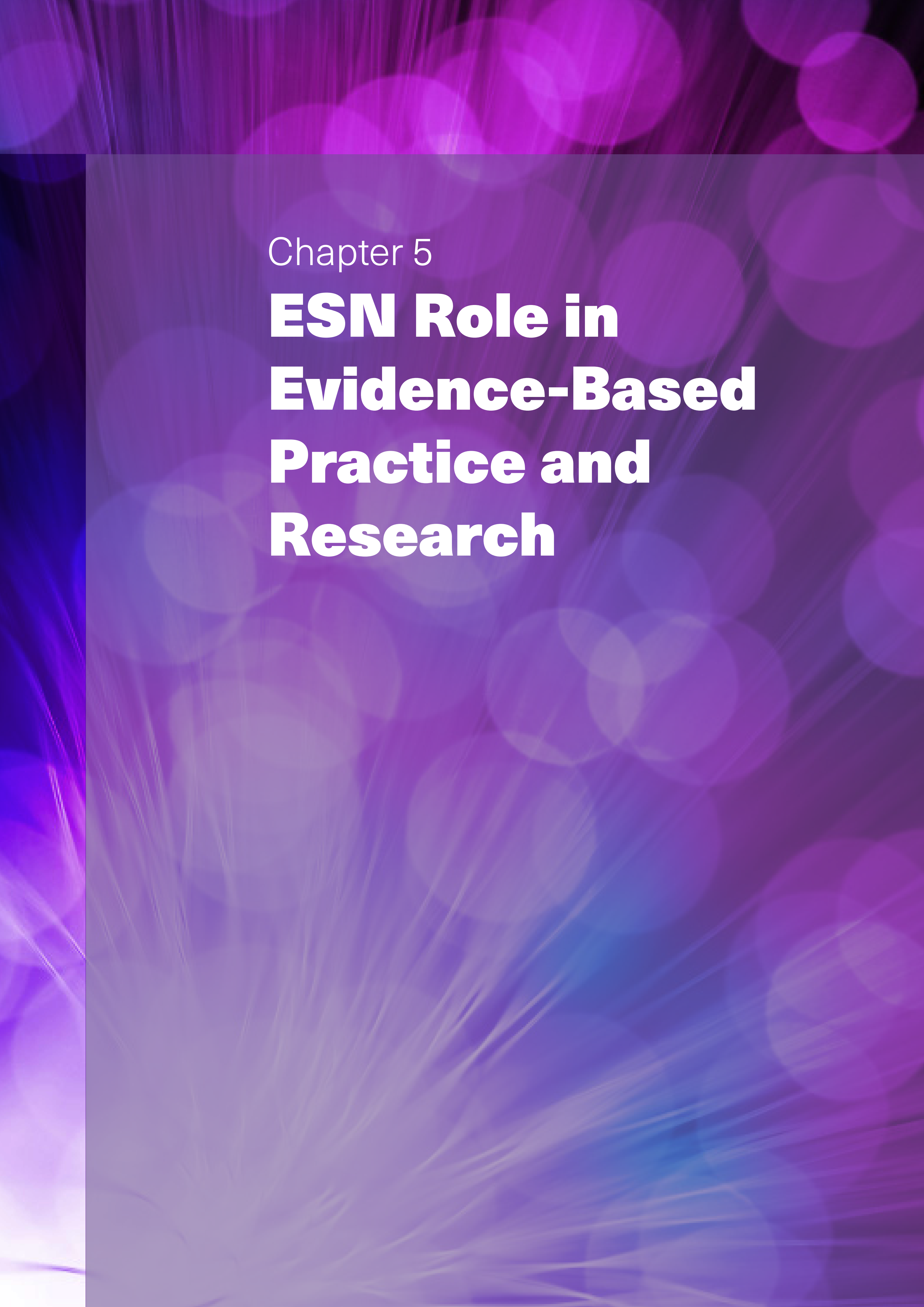
The few studies available on the role of the ESN have focused on the clinical practice component of the ESN role (Goodwin *et al.* 2004; Higgins *et al.* 2006), with a significant dearth of literature on the leadership component. This chapter addresses this neglected area and demonstrates the important ways in which the ESNs enact their leadership role at the patient, service, national, professional and cross boundary levels to advance the aims of the National Clinical Care Programme and the HSE agenda of providing an integrated model of care that is 'national, population based, multidisciplinary, collaborative and predominately nurse-led' (HSE 2014:19). The findings offer many examples of how the ESNs improved quality of care and enhanced quality of the patient's journey by developing and expanding nurse-led clinics and services. By so doing the ESNs also helped advance the aim of equitable access to services across the country, a principle which underpins many national healthcare policy documents (DOH 2006; HSE 2014).

The ESNs took a lead role in the roll-out of the Electronic Patient Record (EPR), which is a key objective within Irish healthcare policy, as the sharing of clinical information in a timely manner, within and across organisations, is viewed as key to achieving effective disease management (DOH 2013; HSE 2014). Fitzsimons *et al.* (2012:5) suggest that in addition to improving standardised vocabulary and record keeping the EPR has the potential to enhance healthcare co-ordination, improve integration of services, facilitate clinical research data mining and enable the monitoring of service performance. Despite the existence of the EPR the adoption into clinical practice is often slow to materialise as it involves an inter-relatedness of human, organisational and technological systems (McQuaid *et al.* 2010; Fitzsimons *et al.* 2012). Whilst use of the EPR is identified as one dimension of the epilepsy ANP role within the National Clinical Programme document (HSE 2014:25), findings from this study clearly indicate that the ESNs were far more than users of the system (consenting patients, entering data, verifying accuracy, corroborating information with paper record, updating information); they were also early adopters and key champions in ensuring adoption and population of the system by other members of the MDT. In some cases the ESNs took a lead role in co-ordinating feedback on its use, thus enabling the person responsible for its development and national roll-out to improve the efficiency and effectiveness of the system.

The ESNs not only contributed to the development of a comprehensive epilepsy service through their leadership in service development and the EPR, they were also leading on the development of guidelines, protocols and care pathways, and educational capacity building initiatives involving the wider healthcare workforce, both within and outside their own organisation. Part of this involved the RANPs specifically supporting the development of candidate ANPs so that the aim of every patient with epilepsy in Ireland having access to an ANP service (HSE 2014) could be realised.

Whilst patient education is viewed as key to self-management (Varley *et al*. 2011a; Fitzsimons *et al*. 2012) and a central part of the clinical dimension of the role of the ESN (see chapter three), improving PWEs' knowledge and enabling them to take an active role in their own care requires the development of educational resources. Findings from this study suggest that in striving to enhance services for PWE the ESNs were not just using educational resources developed by others, but were in many cases leading the design of epilepsy education programmes and resources for patients, family, public and members of the multidisciplinary team.

In conclusion, the integrated data from multiple sources provides empirical evidence that the ESNs were involved in clinical and professional leadership, albeit some were engaging in a wider range of leadership activities than other. The data also indicate that, to ensure that change programmes were sustainable and were systematically planned and implemented, the ESN identified gaps in services, developed business cases, sourced resources, collaborated with the key stakeholders (e.g. senior nursing management, hospital administration, information technology), encouraged and incentivised staff to participate in change processes, sought approval through relevant governance structures and piloted and evaluated initiatives.



Chapter 5

# ESN Role in Evidence-Based Practice and Research

# Chapter 5: ESN Role in Evidence-Based Practice and Research

Evidence-based practice which originated in the field of medicine, is now central to the practice and vocabulary of all nurses (Veeramah 2016; Jansson and Forsberg 2016), irrespective of position or role. Whilst some debate exists on what constitutes evidence, there is general consensus that it incorporates the most valid and current findings from primary research, systematic reviews, clinical guidelines, clinical expertise, and patient preferences (Sackett *et al.* 1996; Reynolds 2000). The application of best evidence is central to quality care and enhanced outcomes for patients, with the regulatory board for the nursing profession in Ireland making it very explicit that nurses are expected to 'use evidence-based knowledge and apply best practice standards in their work…and value research … [as] research informs standards of care and ensures…the highest quality and most cost-effective services to society' (Nursing and Midwifery Board of Ireland (NMBI) 2014:20). Furthermore, the importance of delivering evidence-based care to people experiencing epilepsy is reiterated in the guidelines published by the National Institute of Health and Clinical Excellence (NICE 2012) and the Scottish Intercollegiate Guidelines Network (SIGN 2015).

Although the literature on epilepsy nurse specialists tends to focus on the clinical dimension of the role, with little reference to the ESN role in evidence-based practice or evidence-based nursing, research and audit, international literature on specialist and advanced practice roles identify the need for nurses in such roles to base their practice on research evidence, and through their clinical leadership role to promote evidence-based nursing among other nursing staff (Gerrish *et al.* 2007b, 2011a, 2011b). They are also expected to be 'knowledge brokers' linking evidence to practice (Gerrish *et al.* 2011a), 'opinion leaders' influencing front-line nursing staffs' views on evidence (Kleinpell and Gawlinski 2005; Davies *et al*. 2006), as well as be involved in the generation and dissemination of evidence (Begley *et al.* 2010, 2015; Gerrish 2011b). Begley *et al.* (2010:262) suggest that 'with support, nurses in specialist or advanced practice posts can be extremely influential in their specialist area of practice locally, nationally and internationally'.

Within Ireland, nurses at clinical specialist level are expected to:

- Identify, critically analyse, disseminate and integrate nursing/midwifery and other evidence into the area of specialist practice;
- Initiate, participate in and use the outcomes of audit to improve service provision; and
- Contribute to service planning and budgetary processes through use of audit data and specialist knowledge (NCNM 2008a:8)

In addition to the application of evidence-based practice and audit, nurses at advanced practice level 'are required to carry out nursing/midwifery research which contributes to quality patient/client care and which advances nursing/midwifery and health policy development, implementation and evaluation…. and thus contribute to the professional body of nursing/midwifery knowledge both nationally and internationally' (NCNM 2008b:7).

Using Gerrish *et al.*'s (2007a) five dimensions of 'evidence brokering', namely: accumulating, applying, translating, generating and disseminating, this chapter reports the findings relating to the role of the ESN in advancing evidence-based practice and research. Analysis of data demonstrates that ESNs were actively involved in advancing quality epilepsy patient care by engaging in the following:

- Accumulating evidence
- Applying evidence
- Translating evidence
- Generating evidence
- Disseminating evidence

## Accumulating evidence to inform practice

Gerrish *et al*. (2007a:ix) define accumulating evidence as the active 'searching out, networking and acting as a conduit for organizational evidence'. Analysis of the data clearly indicated that all ESNs were involved in actively searching out evidence to inform their own and others' practice. The ESNs used multiple sources of evidence to ensure that practice was based on up-to-date evidence and international best practice. They gained knowledge through completing degree programmes (Masters in Nursing with epilepsy modules), attending conferences/study days with a specific focus on epilepsy, and attending journal clubs and other educational meetings and fora within their organisation and abroad that were designed to advance their knowledge in epilepsy care (see table 5.1 on example of educational initiatives).

**Table 5.1: Educational initiatives undertaken by the ESNs**

| **Formal Education** |
|---|
| MSc in Advanced Practice in Epilepsy |
| Certificate in Nurse Prescribing |
| PG Certificate in Advanced Practice (Epilepsy) |
| Higher Diploma in Epilepsy Practice |
| Higher Diploma in Neuroscience Nursing |
| **Study days and short programmes** |
| Epilepsy and rescue medication - train the trainer |
| Epilepsy Master classes (2011) University of Cambridge |
| Introduction to Cochrane systematic reviews |
| Pediatric epilepsy training course |
| Global symposium on dietary treatment of epilepsy |
| Expert day on epilepsy |
| Epilepsy day |
| Epilepsy in people with intellectual disability |
| Annual Epilepsy Nurses Study Day |
| Developing telephone skills |
| Public speaking workshop for ANPs |
| **In-service education (mandatory)** |
| Data protection training |
| Hand hygiene |
| CPR |
| Child protection awareness |
| Handling and moving |
| Fire safety |

In addition, the evidence indicates that ESNs accumulate evidence experientially through their day-to-day interactions with members of the multidisciplinary team, especially consultant epileptologists who are research active in the field of epilepsy and have a clinical reporting and mentoring relationship with the ESNs. In some sites ESNs presented case studies of patients to the MDT team and acquired knowledge from the interdisciplinary discussion.

> *“It's [presenting case studies] good for us because we get to research around this particular condition or seizure type or some complication and then we present it and then there's the whole team then, the neurology team are there and we'd discuss this patient.” (CNS interview)*

> *“I do clinics in [name of consultant epileptologist’s] clinic…I really enjoy doing that because…it enhances my education every week…to be surrounded by my peers.” (Candidate ANP interview)*

> *“Over the years we have met fairly frequently…[candidate ANPs] have presented patients to me …They sometimes go on rounds with me, they go to the monitoring unit, they are seeing the interaction in clinic…, seeing how I deal with things in clinic…” (Medical personnel interview)*

More junior ESNs, those who are candidate ANPs or CNSs, source knowledge from RANPs, particularly those in post for a significant length of time. These RANPs not only pass on knowledge to candidate ANPs within their own service but they are also a source of evidence for other candidate ANPs around the country.

The ESNs also access information from a range of published materials including scientific journals tailored to their specialty, epilepsy-focused websites, and information generated by Epilepsy Ireland. In addition to pharmaceutical representatives, the online database[1] http://www.medicines.ie is an important source of medicine information, with some ESNs using it during patient consultations, in order to ensure they are interpreting patient accounts of potential side-effects of medication accurately and giving accurate information about medication prescribed.

> *ESN does assessment to explore possibility of link between new drug prescribed and weight loss experienced by patient. She also checks Medscape to see side-effect profile, as drug not listed on Medscape she checks medicines.ie database. (Candidate ANP observation)*

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[1] This database may be accessed as a link from the EPR medication module and information leaflets printed and given to PWE and family members.

> *ESN consults the BNF [British National Formulary] specific to side-effects of the AED [Anti-Epileptic Drugs] that have been prescribed. (Candidate ANP observation)*

> *"Through the internet…the libraries and e-journals, all the different databases, clinical summaries, Cochrane Library… reading the literature, anything new on the drugs or meeting the [pharmaceutical] representatives about the drugs." (Candidate ANP interview)*

In addition to above, other sources of evidence that ESNs relied on included international guidelines and protocols on epilepsy care.

> *"Well we would go with the recommended guidelines …NICE guidelines or the SIGN guidelines but sometimes those drugs don't work and you've gone through all the recommendations so then, we would go with what the consultants would say but would always address what have they been tried on before." (Candidate ANP interview)*

> *Evidence of epilepsy-specific NICE guidelines underpinning local epilepsy care at site. (Candidate ANP documentary evidence)*

> *"You might have someone whose seizure control just isn't working, they're on a high level of this particular drug, we're not getting anywhere you know, working within NICE guidelines and what's recommended for their particular epilepsy, okay come up with a plan, this is maybe what we could start. And then liaise, talk with the consultant or the doctors and decide what medication, what new medication." (Candidate ANP interview)*

Accessing online library resources was easy for those who were registered on third level education programmes or who worked in services where they had access to online resources through their linked third level institution; however, a number of ESNs did mention the challenge they were experiencing in accessing online journals and other library databases once they completed their education programme as they were no longer entitled to library access and, in particular, access to the specialist epilepsy journals they required. To overcome the problem of access some ESNs mentioned networking with colleagues in other organisations both in Ireland and UK, who would pass on key literature.

## Applying evidence to clinical practice

Gerrish *et al.* (2007a:ix) define application as the use of 'different types of evidence directly, persuasively or conceptually in their own practice and in promoting the use of evidence among front-line staff'. Although the direct use of evidence within practice is difficult to capture, observation and interview data provide some insights into how ESNs apply evidence within practice. Frequently ESNs cite research evidence in the course of explaining to patients and families aspects of care, such as choice of medication, decisions to increase/decrease medication, and rationale for performing certain tests. In addition, patients or family members frequently brought concerns and questions arising from information they sourced on the internet and the ESNs responded to these questions by citing current best evidence.

> *ESN explains potential treatment options to the patient based on her knowledge of the patient and her knowledge of research on the AED therapy. ESN also references research a number of times during the consultation. (Candidate ANP observation)*
>
> *Patient's mother has concerns around vaccinations (childhood) and epilepsy and the ESN goes over the research evidence specific to this with the mother. (Candidate ANP observation)*
>
> *Patient suggests that she be prescribed some treatment [sourced on the internet]. ESN goes through the research evidence for both treatment suggestions with the woman, and discusses when both options would be used, including the pros and cons of each option given her type of epilepsy. (Candidate ANP observation)*

> *"Some of the medicines can be extremely teratogenic to the unborn child…have long term cognitive affects, on the unborn child as well. So for that reason, we meet with the women prior to them planning a pregnancy, so we can give them all this information. I suppose the gold standard is to have the woman seizure-free on one medicine, with no seizures and no side-effects prior to becoming pregnant …women with epilepsy, who are pregnant are ten times more at risk of dying during pregnancy, than outside pregnancy…again, this is why these are a special cohort and need to be minded closer in pregnancy." (Candidate ANP interview)*

Although ESNs differ in the amount of contact they had with front-line staff, there were examples of ESNs promoting evidence when educating front-line staff, including GPs and practice nurses, and using evidence to defend their clinical decision-making.

> *ESN receives a telephone call from a medical colleague working in another department. A patient currently being reviewed in the department and known to the epilepsy service is exhibiting signs of acute psychosis. ESN suggests possible causes of psychosis secondary to recent increase in AED therapy using evidence from research and previous experiences with this particular AED. (RANP observation)*

> *"We would still have a high number of patients coming from Eastern Europe who are on [names a particular AED]… the evidence now supports changing during pregnancy to minimise the effect of, on IQ, and autism. …she [ESN] is very good at being very clear about that evidence…" (Medical personnel interview)*

> *As consultant is not in clinic, [ESN] discusses decision [regarding medication] with Medical Register, explains the rationale supporting her decision with reference to research (has a hard copy of research study in her hand); he is not familiar with the study but affirms her decision. (Candidate ANP observation)*

There are a number of examples where ESNs were using outcomes from audit or small scale research studies to inform changes in their own and others' practice, and as one DoN stated they *"certainly don't audit or do research for the sake of it, they certainly implement any changes that come out of it."* The following are just some examples of how the ESNs were using evidence from their audits and research projects.

> *"The other audit, which was on depression, I find that I ask a lot about mood now, which maybe I probably didn't before it [doing audit] …But I would, invariably ask, now 90% of the time, 95% maybe, I would ask about mood, yeah, because it's really heightened my awareness." (Candidate ANP interview)*
>
> *There are a number of KPI's available in relation to epilepsy set by National Clinical Care programme. One of these relate specifically to the % of newly referred patients who have been contacted within 10 days by ESN; Evidence that ESN led the audit of the % of people contacted by phone within 10 days. As an outcome of this audit the ESN modified the letter going out to new referrals by advising on core information required on first visit, so that the first appointment was more streamlined and effective. (RANP observation)*

There were also examples of how ESNs used evidence persuasively to argue for the need for changes, for more resources and service development.

> *"Audited in a systematic way sort of how many epilepsy referrals come in per month, the epilepsy patients are coming in to the ED, so [ESN] is, in a very systematic manner, trying to establish information systems and gather information and ask questions. To give us answers that will lead to service development. ESN has been the driver." (Medical personnel interview)*
>
> *"Audit is constant. In order to justify the establishment of the services we've developed, when I commenced the post initially I did an audit of all A&E admissions, their length of stay, their follow-up, and I did an audit of all the out-patient referrals that the consultants receive, the timelines, the details, and we presented that to [names senior clinical committee] and then it was presented to business management to get support for the services that we want developed, in order to get clinic space for example… we just needed solid proof and an audit was the only way to do that." (Candidate ANP interview)*

## Translating evidence

Translating evidence involves a number of processes including ‘evaluating, distilling and interpreting evidence to make it understandable to different audiences, including front-line staff, patients and family members (Gerrish *et al*. 2007a:ix). Evaluating, appraising and synthesising evidence for guideline development requires knowledge of research methods, especially quantitative research and statistics to a level that many of the ESNs did not believe they had, consequently most of the evidence used by the ESNs had already been distilled into evidence-based guidelines, SOPs, and protocols. At a local level a number of ESNs identified areas where they took action, either individually or as part of a group, to improve care to patients by translating often complex information into understandable protocols and policies for local use, targeted at nursing colleagues or junior doctors (Chapter four). ESNs were also involved in translating information into an accessible form for patients and family members. To assist this, the ESN used both verbal and written information.

> *ESN discusses with patient the implication of driving as she has been informed by doctor she cannot drive and is upset. Patient is calmer and reporting that she understands why she cannot drive. ESN explores why she needs to be able to drive and potential other solutions. Patient is given opportunity to ask questions and asks about her dose of AED during pregnancy. ESN answers the question, citing research evidence to support her opinion, demonstrating a high level of expertise in this area and communicating this simply and effectively to the patient. Refers to literature and research evidence when highlighting the increased metabolism of this particular AED during pregnancy. (RANP observation)*

> *Arrives on ward and meets a female patient who is 5 days post-surgery. The woman is being prepared for discharge. ESN goes through pre discharge information and uses a booklet prepared by the ESNs to explain issues, draws a picture, gives time for questions and explains what to expect in terms of symptoms and what not to expect in the next days. Reassures that headache is normal post-surgery for a period, talks about facial swelling using very simple and easy to understand terms… later during discussion with the consultant he says 'with most of the patients we see, the nurse stays afterwards to, in a sort of a relaxed way, discuss and explain to the patient what we said on the round. (CNS observation)*

> *Opens discussion with patient and family (patient has ID) with general conversation, explains that she would like to go through history and update the EPR record, does a detailed seizure history. Patient appears to be experiencing multiple types of seizures. ESN asks very focused questions and translates technical terms into lay terms with examples to help the family and patient identify seizure type. ESN classifies seizures into ABCD and writes a simple explanation of each type into the patient's seizure diary and goes through each with family and patient until they are confident they know the difference and how to record in the diary. (Candidate ANP observation)*

In cases where PWE were specifically challenged due to cognitive impairment, the ESNs were constantly trying out strategies to enhance their understanding, as in this case where a man with a brain trauma was attending the clinical unaccompanied.

> *Patient is unaccompanied to the clinic, although his wife normally comes with him. He developed epilepsy post a fall and has residual symptoms of brain trauma. He is having his AED therapy adjusted. Patient is explaining his medication but finding this act difficult. ESN uses a colour co-ordinated chart of AEDs to assist the patient recall his medication. ESN goes through information a few times slowly and respectfully, until both are happy. (RANP observation)*

The sensitivity of the ESNs and their willingness to take time to translate information was valued and appreciated by PWE and family members.

> *I have received emotional support as well as informative meetings where all the irrelevant, oversaturated and incorrect information from the internet has been put aside. This is something I feel is difficult to do, and ESNs explain that epilepsy varies dramatically from person to person. (PWE survey)*

> *I was recently with the ESN in [names service] and she made me feel so relaxed about my meds [medication] and why I had to take certain ones… The nurse was lovely, so caring and helped me…and for the first time since being diagnosed 2 years I was given an explanation to why my epilepsy may have started out of nowhere. So grateful for my time there. (PWE survey)*

> *"Sometimes higher up [medical staff], they talk too technical for people. That they might not understand that you don't understand…even when my parents are in on the consultations, they do not understand and [names ESN] discusses them [medication action and side-effects] in an easier terminology." (PWE focus group)*

In addition to translating evidence for other healthcare professionals, PWE and families, family members also mentioned the role some ESNs played in translating evidence to other groups, such as school teachers and the general public.

> *"…because children go to school, it's very important that their teachers are also educated around how to manage a child with epilepsy if they have a seizure, so we run programmes for school teachers." (DoN interview)*

> *"I go around the country to each community resource officer, at least once a year…we do information evenings for people with epilepsy, evenings for carers, general public…train people in how to give [names recue medication]… whatever the community resource officer wants covered, it could be epilepsy in adolescents, epilepsy and intellectual disability, epilepsy and sexuality, that's a big part of my role." (Candidate ANP interview)*

## Generating evidence

In relation to the generation of evidence, all ESNs were involved in clinical audit. The majority of audits measured the National SOPs for epilepsy practice, thus providing an opportunity to measure practice against the national agreed standard. Others focused on auditing nursing activity, service development and staff education, which were then used as a benchmark for evaluating any subsequent changes made (see table 5.2 for range of audits).

> *"An example of audits would be: one of the KPIs of the HSE is to capture nursing activity, so that's something that I'm doing. So all my clinical encounters are captured every day also the HSE drug prescribing database[2] has to be entered daily, any prescriptions and there have been other audits like triaging of new patients."(Candidate ANP interview)*

Some ESNs collaborated with the multi-disciplinary team in generating evidence from audits that informed future service development.

> *"I have done audits in conjunction with the epilepsy nurse specialists, and one of the areas that we are very keen to explore is the telephone service… I think for the nurses to get over-burdened with the phone calls is easy….When they [ESN] talk to somebody on the phone they log each phone call, so we can get an idea of the activity…one of the things we are working at the moment is trying to look at that and decide a strategy for what percentage of the time we'd like them to be on the phone call…it is very important for budgetary allocations and that is something that is one of our major audits for the future." (Medical personnel interview)*

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[2] Nurse prescribers must enter data into a national database that monitors activity of nurse and midwifery prescribers.

**Table 5.2: Range of audits from documentary evidence**

- TAL activity (type of call, interaction required and outcome achieved)
- Time taken to triage into ESN service
- Type of education given within 10 days
- Information given to patients regarding driving
- First Seizure Service
- EPR generated discharge letter using an amended Sheffield Assessment Instrument or Letters (SAIL) assessing the readability, safety and quality of the letter content
- Reliability and accuracy of data inputted into the epilepsy-specific Electronic Patient Record (EPR)
- Waiting times for patients in nurse-led clinic
- Percentage of new referrals contacted by ESN within 10 days of receipt of referral to the epilepsy service
- All epilepsy A&E admissions, their length of stay, their follow-up
- All the out-patient referrals that the consultants receive, the timelines, the details
- Outcomes of VNS
- Adverse effects of new anti-epileptic medication
- Impact of group education sessions for patients
- Needs of staff for in-service education on epilepsy

In relation to research and the production of new knowledge the majority of ESNs considered themselves novices in research. While research is a key aspect of the role description of ANPs, as outlined by the NCNM, and one that the ESNs were committed to developing, the level and degree of research involvement varied across individuals and organisations. Some ESNs were involved at the level of recruiting participants while others collected data on larger MDT research studies. ESNs accredited at RANP level were involved as collaborators and co-applicants on funded research.

> *"A new anti-epileptic drug…we did the data collection, it's part of a bigger research piece… it's feeding into, well I think it's UK run, it could be European… the majority of the hospitals, the main epilepsy centres we'll call them in the UK will be involved and a number of centres in Ireland." (Candidate ANP interview)*

> *"We have a lot of genetics research here and the ANPs will help recruit patients in clinic for example, even though there is no obviously personal gain to them even in terms of publications, but they know they are expected to do that, and I think that is reasonable in a busy programme." (Medical personnel interview)*

Where the ESNs were leading on and completing their own research the majority of projects were small scale, unfunded, undertaken in response to local clinical need or linked to academic programmes (e.g Masters). These projects led the ESNs to take action to change practice.

> *"My thesis was on [Names a medication] I had identified that there's a gap in…what we deliver, how we deliver it [education], our care plans…the leaflets that we give out…so, there's a lot of work to be done…I was in [names another hospital] recently,…I'm working in conjunction with them [on medication], trying to lead out on an education package…and…guidelines, looking at a standard operational procedure…what education to deliver and for a national service more than just [names own service]." (Candidate ANP interview)*

> *"I did a research into the knowledge of student midwives to deal with epilepsy. Student midwives did know about the higher dose of Folic Acid but yet, they didn't know that the women with epilepsy were supposed to continue on their medicines. They didn't know that women with epilepsy could breastfeed. As a result of that, I actually go into the midwives, the student midwives now and I give a lecture in [names 3 third-level institutions]." (Candidate ANP interview)*

Some ESNs accredited at RANP level were making applications for funded research as Principal Investigator, co-applicant or collaborator.

- Application made to the NMPDU (Nursing Midwifery Planning and Development Unit) with colleague in centre of nurse education for funding for e-learning package on seizure response for nursing and allied health professionals. Awaiting outcome.
- Submitted application for research on driving regulations and epilepsy- shortlisted in the last six.
- Evidence of collaborating with grant applications e.g. HRB.

(RANP documentary evidence)

All the ESNs were positive about their role in generating evidence through audit and research. However, ESNs found the research aspect of the role difficult to maintain due to competing demands of clinical practice, service development and, site and role accreditation.

> *"In relation to research, I'm very interested, very excited about the future but I feel that the site preparation, has consumed everything, and at the moment there is no time for me to do research." (Candidate ANP interview)*

> *"Hopefully. I don't know but, I suppose, I would like to (be doing research)… but the time constraints at the moment, you know, it's very difficult for one person to run all these services and incorporate everything." (Candidate ANP interview)*

> *"Well, to be truthful that (research) is an area that she [ESN] hasn't been involved with that much, she has been very busy with her prescribing and now that she has it complete we certainly will be looking at research." (Medical personnel interview)*

> *"But if research is the discovery of new things, we haven't done a lot of that…When there is a busy clinical service, it [doing research] is difficult…this would be a potential criticism say of my own service… it is hard for the ESNs I think to develop a significant research component to their work, when we're not doing it either." (Medical personnel interview)*

## Disseminating evidence

ESNs use a range of formal and informal strategies to disseminate evidence to PWE, family members, healthcare practitioners and the wider public. Both within and outside their services the ESNs disseminate evidence to practitioners using a variety of forms; such as, MDT meetings, ward meetings, impromptu encounters with staff, in-service staff education days, formal education programmes on epilepsy and epilepsy literature.

> *ESN is providing feedback to the epilepsy MDT Team regarding the implementation of pilot group educational sessions for newly diagnosed PWE, its content, progress to date and the organizational issues associated with the initiative. Discusses with the group the findings of an evaluation she performed with the group. She administered a survey to participants pre and post the session regarding their knowledge and attitude to epilepsy, medication management, lifestyle issues and*

> *psycho-social issues…. highlights the saving of "nurses time" from such group educational sessions. (Candidate ANP observation)*

ESNs also disseminate evidence from their audits to senior management personnel through different forums, such as a monthly or annual report or during attendance at meetings with senior management.

> *"[ESNs] are looking at trends… numbers of patients they're seeing, are they [numbers] going up, are they going down... They prepare an annual report and…will have these figures… how many patients they saw, how long they spent on the telephone etc." (DoN interview)*

> *"I've seen how powerful it (presenting finding of audit to managers) can be. We audit our service quite a bit… keep data of our activity, of patient outcomes, patient satisfaction, and we also report that data on a monthly basis (to management personnel), so we're constantly looking at the service." (Candidate ANP interview)*

> *"She [ESN] does an audit of her service and inputs it into the annual report of the service." (Medical personnel interview)*

In terms of dissemination of evidence produced by themselves, ESNs presented at conferences and other study days. Although presentation of research was mainly at national conferences, some presented at international conferences and had won awards for posters at international conferences.

> *Received award from American Epilepsy Society for "A multi-centred audit of nurse-led epilepsy telephone advice service" at the 63rd American Epilepsy Society conference in 2009. (RANP documentary evidence)*

> *Evidence of presenting a poster at the International Epilepsy Congress 2011 in Rome and presented a poster American Academy of Neurology conference. (Candidate ANP documentary evidence)*

> *Midwifery Conference RCSI; 2014 Presented Impact of telemedicine on epilepsy outcomes at 2nd Annual Research Seminar Temple Street. (Candidate ANP documentary evidence)*

> *Number of posters on walls around the clinical rooms that have been presented at conferences, the posters are of audits completed and two of the posters have the ESN named. (Candidate ANP observation)*

Documentary evidence also indicated that some ESNs had commenced dissemination through publication on Epilepsy Ireland's website and in their newsletter, and professional magazines.

> *First author on a number of articles related to specialised epilepsy care available online on the Epilepsy Ireland website and/or printed in the quarterly newsletter. Contributed as a co-author to an article relating to leadership in nursing. (Candidate ANP documentary evidence)*

> *Named as co-author on an information pack entitled "Shedding Light on Epilepsy" which is available through Epilepsy Ireland 2008. (Candidate ANP documentary evidence)*

## Discussion

The importance of ESNs delivering evidence-based care to people experiencing epilepsy is without question and there is a growing consensus within the literature that nurses at speciality and advanced practice level have a responsibility to provide leadership in the area of evidence-based practice and evidence-based nursing (Kleinpell and Gawlinski 2005). Despite many being in the early stage of role development, findings clearly demonstrate that the ESNs are engaging with, and embracing, the EBP dimension of their role. The findings from a number of data sources suggest that the ESNs within the **SENsE** study were all active to varying degrees as 'knowledge brokers' and 'knowledge managers' (Gerrish *et al.* 2011a, b) by accumulating, translating, applying, generating and disseminating evidence. In contrast to nurses in many other studies who tended to privilege evidence derived from work-based activities, such as clinical experience or from interaction with senior nursing or medical colleagues (Thompson *et al.* 2001; Gerrish *et al*. 2008; Spenceley *et al*. 2008; Jansson and Forsberg 2016), the ESNs in the **SENsE** study drew on a variety of sources of evidence (see table 5.3 for summary).

**Table 5.3: ESN role in EBP**

| Accumulating evidence | Applying/using evidence | Translating evidence | Generating evidence | Disseminating evidence |
|---|---|---|---|---|
| Formal education<br>Study days/ education meetings/ conferences<br>Interactions with senior medical colleagues and RANPs<br>Published literature in journals/websites<br>International and local guidelines/protocols | Education of other members of MDT across primary, secondary and tertiary care<br>Education of patients and family<br>Informing and defending own practice and decision-making<br>Using evidence from audit to argue for the need for change | Guideline, protocol and policy development<br>Presenting evidence in an accessible way to patients, family and members of the care team<br>Presenting evidence in an accessible way to teachers, community groups and members of the public | Completing audit<br>Completing small scale research and evaluation projects<br>Data collection and inputting into larger scale research projects led by others | Through MDT meetings<br>Informal encounters<br>Annual reports<br>Meetings with management<br>Conference presentations<br>Publications |

Formal educational programmes and continuing professional development opportunities (study days/conferences) were key sources of evidence for the ESN in this study. In line with the findings on ANPs in other studies (Profetto-McGrath *et al*. 2007; Gerrish *et al*. 2011b; Begley *et al*. 2015), the ESNs also used evidence from literature specifically tailored to their speciality that was published in peer reviewed journals and other sources, and used evidence synthesised by others, such as NICE and SIGN guidelines. In addition, medical consultants with an expertise in epilepsy were key sources of up-to-date evidence for all of the ESNs, with the RANPs being a source of information for more junior nursing and medical colleagues and for candidate ANPs, within and outside their own organisation.

In addition to accumulating and synthesising information from a variety of sources to inform their own practice, ESNs were all facilitating, to varying degrees, the translation of evidence to practice, by others, through role modelling, guideline/protocol development, and formal and informal education. Whilst ESNs in the **SEN**s**E** study had varying degrees of contact with front-line clinical nurses, those that had contact used every opportunity to translate and disseminate information and, depending on the context of their role, were involved in the translation and dissemination of evidence to others including, clinicians within the MDT, PWE, family members and the general public. Those that were involved in outreach services, such as clinics within the ID service, were using every face to face contact as an opportunity to translate and disseminate evidence to clinicians within those organisations.

Whilst all of the ESNs were very positive about their research role, in terms of evidence generation, their research activity was limited and mainly consisted of small scale unfunded research projects, with some involved in recruitment or data collection on larger MDT research studies. This finding is similar to findings from other studies involving advanced practitioners (Gerrish *et al*. 2011a, b; Begley *et al.* 2015). Positively, however, all the ESNs were actively involved in, or were leading clinical audit and service evaluations and most importantly were using findings from the audits to improve the patient experience by arguing for, and leading changes at patient, team and organisational level. All were acting as 'conduits' for disseminating evidence (Thompson *et al*. 2001) to other clinical nurses and members of the MDT; however, the limited degree to which they were involved in formal dissemination of knowledge generated by themselves, outside of their own organisation, reflected the stage of development of each individual ESN. Having said this, formal dissemination was certainly beginning to flourish, as it appeared that each year more ESNs were disseminating at national and international fora, with some receiving awards for poster presentations.

Within the literature, irrespective of country, nurses report various factors that hinder their ability to implement EBP, including lack of knowledge and skills, lack of autonomy to change practice, inadequate supports from managers, lack of time, and insufficient resources (Parahoo 2000; Glacken and Chaney 2004; Kuuppelomäki and Toumi 2005; Hutchinson and Johnston 2006; Rycroft-Malone 2008; Veeramah 2016). In one study involving ANPs,  40% cited heavy workload, 31% lack of resources, 25% lack of time and 10% lack of supportive medical staff as barriers to promoting EBP (Gerrish *et al.* 20011b). Whilst some ESNs did  mention difficulties in accessing library resources and all mentioned the challenges of competing demands and workloads, lack of autonomy or lack of support from managers or medical colleagues were not barriers identified. In fact the ESNs were very positive about the support they received from nursing management and medical consultants in relation to education, research and audit. In addition, they were all very positive about the level of autonomy they had to lead and implement changes as evidenced in the previous chapter on the leadership dimension of their role (Chapter four). There is no doubt that their position as specialists, their level of knowledge of epilepsy, their clinical credibility, and support from senior nursing personnel as well as their interpersonal skills enabled them to exert a positive influence on the behaviour and practice of others in relation to EBP.

Similar to other studies involving nurses (Rycroft-Malone 2008; Veeramah 2016), including nurses practising at an advanced level (Gerrish *et al*. 2011b; Begley *et al.* 2015), the ESNs in the **SEN**s**E** study did have some reservations about their skills to critically appraise and interrogate research findings, especially statistical information and language used in quantitative research. Indeed, some writers question the expectation that nurses engaged in clinical practice should have the expertise to appraise, interpret and translate research findings into clinical guidelines and protocols given the substantial expertise and time required to complete a systematic review (Parkes *et al*. 2001; Gerrish *et al*. 2008).

In conclusion, the findings in this chapter support the international view that nurses at specialist and advanced level are well placed to promote EBP among other nurses, junior members of the MDT, patients and families. Whilst some writers allude to the role of the ESN in relation to research and audit (Foley *et al*. 2000; Dupras 2005; Higgins 2008), to our knowledge, this is the first study that comprehensively documents how ESNs, and more specifically how ESNs in Ireland, enact the evidence-based practice, research and audit dimensions of their role.

## Chapter 6

# Impact of ESN Role on Patient and Service Outcomes: Stakeholder Perspectives

# Chapter 6: Impact of ESN Role on Patient and Service Outcomes: Stakeholder Perspectives

## Introduction

International and Irish research, as highlighted in chapter one, indicate many deficits in epilepsy care provision including difficulty accessing specialist services, poor co-ordination of care, lack of systematic follow-up, poor communication between clinicians across services, poor patient education, and lack of psychological support (Ridsdale 1995; Thapar 1996; Ridsdale *et al.* 1996; Ridsdale *et al.* 2000; Varley *et al.* 2011 a, b; Mills *et al. 2002).*

International studies that report on feedback from PWE, regarding the impact of the ESN role, suggest that they have the potential to respond to both the knowledge and care deficits (Scrambler *et al.* 1996; Ridsdale *et al.* 1999b; Mills *et al.* 2002). In addition to their contribution to PWE's self-management through the provision of information and advice (Ridsdale *et al.* 1999b; Mills *et al*. 2002; Kirton *et al.* 2012), ESNs are perceived as making a significant contribution to continuity of care (Scrambler *et al.* 1996; Sarkissian & Wennberg 1999; Mills *et al.* 2002; Kirton *et al*. 2012), co-ordination of care (Taylor *et al.* 1994; Kirton *et al.* 2012; Noble *et al.* 2013), the reduction of GP consultations (Warren 1998) as well as reducing  demands on medical consultants' time (Hopkins *et al.* 2010).

While the previous three chapters of findings outlined the role of the ESN in respect to their clinical, leadership and evidence-based practice roles, this chapter, drawing on both qualitative and quantitative data and the perspectives of PWE and their family members, reports on the impact of the ESN role. The chapter addresses their impact in relation to i) differences in experience of PWE who were attending an epilepsy service for more than 12 months; ii) differences in experience of PWE who were newly diagnosed; and iii) reported impact on health service outcomes.

## Difference in experiences of PWE who were attending an epilepsy service for more than 12 months

To explore the experiences of PWE attending an epilepsy service for more than 12 months, a survey was completed by 244 PWE attending a service with an ESN and 261 PWE attending a service without an ESN. The aim was to ascertain if PWE experienced differences in the care they received from the two types of service. PWE were asked to rate their experience of care provided by an ESN, or in the case of the non-ESN sites, the provision of care from a healthcare professional. In the majority of questions response categories ranged from 1 ('strongly disagree') to 5 ('strongly agree'), with the exception of the two questions on practical and emotional support where a ten point scale was used. This section addresses differences under the following headings: information provided; confidence and comfort; dignity and respect; involvement in care; co-ordination of care; practical and emotional support; and QoL.

### *Difference in information provided*

To identify differences in information provided, PWE were asked to rate their experience on 20-items. In addition, female respondents were asked an additional question about the provision of information on anti-epileptic medication and pregnancy. On the 21 items included, the ESN sites had higher mean scores than Non-ESN sites on all items, with the exception of 'how often I need to take my anti-epileptic medication' (figure 6.1).

The 20 items were grouped into four categories as follows: nature of epilepsy and own epilepsy; medical aspects of epilepsy; social aspects of epilepsy; and safety aspects of epilepsy. Total mean scores for each category were calculated and a comparison between ESN and Non-ESN sites scores was conducted using independent t-tests. Findings indicated statistically significant differences between ESN and Non-ESN sites in relation to information provided on: the nature of epilepsy [t(470) = -5.337,p= .000]; medical aspects of epilepsy [t(464)= -3.008, p=.003]; social aspects of epilepsy [t(458)= -4.582, p=0.000]; and safety aspects of epilepsy [t(471)= -5.091, p=0.000], with ESN sites having higher mean scores than Non-ESN sites in each category (see table 6.1). In terms of the mean score for the provision of information in pregnancy, there was a statistically significant difference between the ESN sites (M=3.92, SD=1.20) compared to the Non-ESN sites

(M=3.52, SD=1.3) [t(241)= -2.497, p=0.013], with a higher mean score in ESN sites (table 6.1).

Figure 6.1: Information provided on epilepsy

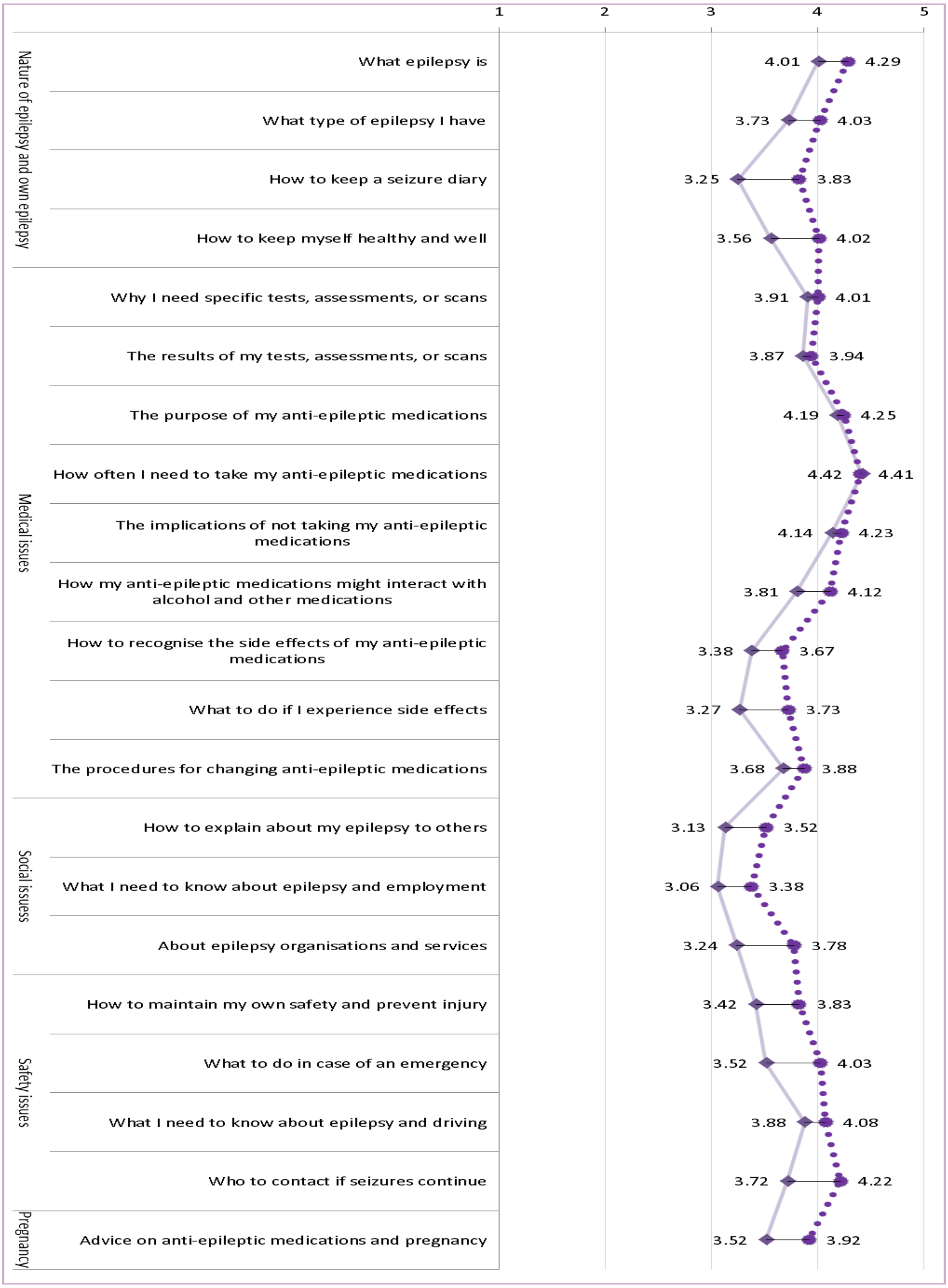


Table 6.1: Information provided on epilepsy by ESN/healthcare professional

| Provided information on…. | Non-ESN Mean (SD) | ESN Mean (SD) |
|---|---|---|
| **The nature of epilepsy and own epilepsy** | | |
| What epilepsy is | 4.01 (.985) | 4.29 (.828) |
| What type of epilepsy I have | 3.73 (1.074) | 4.03 (1.021) |
| How to keep a seizure diary | 3.25 (1.243) | 3.83 (1.076) |
| How to keep myself healthy and well | 3.56 (1.148) | 4.02 (1.009) |
| *Total mean score* | *3.65 (.841)* | *4.06 (.798)* |
| **Medical aspects of epilepsy** | | |
| Why I need specific tests, assessments, or scans | 3.91 (1.039) | 4.01 (.995) |
| The results of my tests, assessments, or scans | 3.87 (1.022) | 3.94 (1.008) |
| The purpose of my anti-epileptic medications | 4.19 (.891) | 4.25 (.753) |
| How often I need to take my anti-epileptic medications | 4.42 (.707) | 4.41 (.749) |
| The implications of not taking my anti-epileptic medications | 4.14 (.926) | 4.23 (.877) |
| How my anti-epileptic medications might interact with alcohol and other medications | 3.81 (1.068) | 4.12 (.912) |
| How to recognise the side-effects of my anti-epileptic medications | 3.38 (1.192) | 3.67 (1.093) |
| What to do if I experience side-effects | 3.27 (1.241) | 3.73 (1.039) |
| The procedures for changing anti-epileptic medications | 3.68 (1.171) | 3.88 (1.079) |
| *Total mean score* | *3.85 (.739)* | *4.05 (.717)* |
| **Social aspects of epilepsy** | | |
| How to explain about my epilepsy to others | 3.13 (1.248) | 3.52 (1.182) |
| What I need to know about epilepsy and employment | 3.06 (1.228) | 3.38 (1.220) |
| Epilepsy organisations and services | 3.24 (1.207) | 3.78 (1.030) |
| *Total mean score* | *3.16 (1.068)* | *3.60 (1.011)* |
| **Safety aspects of epilepsy** | | |
| How to maintain my own safety and prevent injury | 3.42 (1.191) | 3.83 (1.110) |
| What to do in case of an emergency | 3.52 (1.179) | 4.03 (1.025) |
| What I need to know about epilepsy and driving | 3.88 (1.063) | 4.08 (.973) |
| Who to contact if seizures continue | 3.72 (1.137) | 4.22 (.837) |
| *Total mean score* | *3.65 (.927)* | *4.06 (.806)* |
| **Pregnancy related information** | | |
| Advice on anti-epileptic medications and pregnancy | 3.52 (1.300) | 3.92 (1.201) |

Pearson chi-square/fisher's exact tests were also conducted to see if there were any statistically significant differences in information provided depending on whether the site was an ESN site or a Non-ESN site. No statistically significant differences were found in five of the nine items coded as medically related, namely: why specific tests, assessments, or scans are needed; the results of tests, assessments, or scans; the purpose of anti-epileptic medication; how often medications need to be taken; and the implications of not taking anti-epileptic medications. All other items showed statistically significant results (see table 6.2).

Greater proportions of PWE from ESN sites strongly agreed that they received information on what epilepsy is (48.1%) and on what type of epilepsy they have (40.2%) compared to those from Non-ESN sites (35.4% and 25.7% respectively). Higher proportions of PWE from ESN sites strongly agreed that they were informed about how to keep a seizure diary (33.8%), maintain their own safety and prevent injury (33.7%) and maintain their health and well-being (38.4%) compared to respondents from Non-ESN sites (19.6%, 21.2% and 22.5% respectively). More PWE from ESN sites also strongly agreed that they were provided with information about epilepsy organisations and services (30.2%), who to contact if seizure continues (44.3%) and about epilepsy and driving (42%) compared to respondents from Non-ESN sites (17.4%, 27.3% & 30.8% respectively). A higher proportion of female PWE in ESN sites reported receiving advice on anti-epileptic medications and pregnancy (67.7%) compared to female PWE in Non-ESN sites (56.6%).

More PWE from Non-ESN sites disagreed that they received information about how anti-epileptic medications might interact with alcohol and other medications (12.1%), how to recognise the side-effects (25.1%) and what to do in the event of side-effects (26.3%) or an emergency (16.9%) compared to ESN sites (5.2%, 11.4%, 8.2% and 5.6% respectively). More PWE from Non-ESN sites also disagreed that they were informed about the procedures for changing anti-epileptic medications (15.1%) and how to explain epilepsy to others (21.7%) compared to PWE from ESN sites (6.7% and 16.1% respectively).

**Table 6.2: Information provided by ESN/healthcare professional**

| Information provided on…. | | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|---|
| **Nature of epilepsy and own epilepsy** | | | | | | | |
| **What epilepsy is** | Non-ESN (240) | 2.5 (6) | 5.8 (14) | 15.4 (37) | 40.8 (98) | 35.4 (85) | 10.869(4), p=0.025$^{*}$ |
| | ESN (210) | 0.5 (1) | 3.3 (7) | 11 (23) | 37.1 (78) | 48.1 (101) | |
| **What type of epilepsy I have** | Non-ESN (237) | 3.8 (9) | 10.5 (25) | 19.8(47) | 40.1 (95) | 25.7 (61) | 11.452(4), p=0.021* |
| | ESN (209) | 1.9 (4) | 7.7 (16) | 15.8 (33) | 34.4 (72) | 40.2 (84) | |
| **How to keep a seizure diary** | Non-ESN (235) | 9.8 (23) | 18.7 (44) | 28.1 (66) | 23.8 (56) | 19.6 (46) | 31.370(4),p =0.000$^{***}$ |
| | ESN (210) | 3.8 (8) | 5.2 (11) | 29 (61) | 28.1 (59) | 33.8 (71) | |
| **How to keep myself healthy and well** | Non-ESN (240) | 5.0 (11) | 15.8 (38) | 20.0 (48) | 36.7 (88) | 22.5 (54) | 20.799(4),p =0.000$^{***}$ |
| | ESN (216) | 1.4 (3) | 7.9 (17) | 16.7 (36) | 35.6 (77) | 38.4 (83) | |
| **Medical aspects of epilepsy** | | | | | | | |
| **Why I need specific tests/assessments/scans** | Non-ESN (238) | 2.5 (6) | 9.2 (22) | 16.0 (38) | 39.5 (94) | 32.8 (78) | 3.902 (4), p=.424$^{ns}$ |
| | ESN (212) | 1.4 (3) | 7.1 (15) | 18.9 (40) | 34 (72) | 38.7 (82) | |
| **The results of my tests/assessments/scans** | Non-ESN (238) | 2.6 (6) | 8.6 (20) | 18 (42) | 40.8 (95) | 30.0 (70) | 1.257 (4) p=.872$^{ns}$ |
| | ESN (208) | 2.4 (5) | 6.7 (14) | 19.2 (40) | 38 (79) | 33.7 (70) | |
| **The purpose of my AEDs** | Non-ESN (241) | 1.7 (4) | 4.1 (10) | 9.5 (23) | 43.2 (104) | 41.5 (100) | 5.191 (4), p=.275$^{ns}$ |
| | ESN (211) | 0 | 2.4 (5) | 11.8 (25) | 44.5 (94) | 41.2 (87) | |
| **How often I need to take my medications?** | Non-ESN (237) | 0.8 (2) | 0.8 (2) | 5 (12) | 41.8 (99) | 51.5 (122) | Fisher's exact test: p=.581$^{ns}$ |
| | ESN (215) | 0.5 (1) | 1.9 (4) | 7.4 (16) | 36.7 (79) | 53.5 (115) | |
| **The implications of not taking my AEDs** | Non-ESN (228) | 0.4 (1) | 7.0 (16) | 13.2 (30) | 37.3 (85) | 42.1 (96) | 3.013(4), p=.556$^{ns}$ |
| | ESN (208) | 1.0 (2) | 3.8 (8) | 13 (27) | 35.6 (74) | 46.6 (97) | |
| **How my AEDs might interact with alcohol.** | Non-ESN (240) | 2.1 (5) | 12.1 (29) | 19.2 (46) | 35.8 (86) | 30.8 (74) | 11.744(4), p=0.019$^{*}$ |
| | ESN (210) | 0.5 (1) | 5.2 (11) | 17.6 (37) | 35.2 (74) | 41.4 (87) | |
| **How to recognise the side-effects of my AEDs** | Non-ESN (239) | 3.8 (9) | 25.1 (60) | 23.4 (56) | 25.1 (60) | 22.6 (54) | 15.272(4), p=.004$^{**}$ |
| | ESN (211) | 2.8 (6) | 11.4 (24) | 30.3 (64) | 27 (57) | 28.4 (60) | |
| **What to do if I experience side-effects** | Non-ESN (236) | 6.8 (16) | 26.3 (62) | 20.8 (49) | 25.8 (61) | 20.3 (48) | 33.695(4),p =0.000$^{***}$ |
| | ESN (208) | 2.4 (5) | 8.2 (17) | 32.2 (67) | 28.8 (60) | 28.4 (59) | |
| **The procedures for changing AEDs** | Non-ESN (239) | 4.2 (10) | 15.1 (36) | 19.2 (46) | 31.8 (76) | 29.7 (71) | 10.033(4), p=0.040$^{*}$ |
| | ESN (209) | 3.3 (7) | 6.7 (14) | 24.4 (51) | 29.7 (62) | 35.9 (75) | |
| **Social aspects of epilepsy** | | | | | | | |
| **How to explain my epilepsy to others** | Non-ESN (235) | 11.1 (26) | 21.7 (51) | 27.7 (65) | 22.6 (53) | 17.0 (40) | 11.625(4), p=0.020$^{*}$ |
| | ESN (205) | 4.9 (10) | 16.1 (33) | 27.8 (57) | 24.9 (51) | 26.3 (54) | |
| **What I need to know about epilepsy and employment** | Non-ESN (237) | 10.5 (25) | 24.5 (58) | 29.1 (69) | 19.8 (47) | 16.0 (38) | 7.859(4),p= 0.097$^{ns}$ |
| | ESN (209) | 6.2 (13) | 19.1 (40) | 29.2 (61) | 21.1 (44) | 24.4 (51) | |
| **Epilepsy organisations and services** | Non-ESN (235) | 8.1 (19) | 21.7 (51) | 25.5 (60) | 27.2 (64) | 17.4 (41) | 29.531(4),p =0.000$^{***}$ |
| | ESN (212) | 1.9 (4) | 8.5 (18) | 29.2 (62) | 30.2 (64) | 30.2 (64) | |
| **Safety aspects of epilepsy** | | | | | | | |
| **How to maintain own safety and prevent injury** | Non-ESN (236) | 5.9 (14) | 19.5 (46) | 22.9 (54) | 30.5 (72) | 21.2 (50) | 14.578(4), p=0.006$^{**}$ |
| | ESN (208) | 3.4 (7) | 10.6 (22) | 19.2 (40) | 33.2 (69) | 33.7 (70) | |

| Information provided on…. | | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|---|
| **What to do in case of an emergency** | Non-ESN (241) | 5.5 (13) | 16.9 (40) | 21.2 (50) | 33.1 (78) | 23.3 (55) | 25.117(4),p =0.000$^{***}$ |
| | ESN (214) | 2.8 (6) | 5.6 (12) | 17.3 (37) | 34.6 (74) | 39.7 (85) | |
| **Epilepsy and driving** | Non-ESN (234) | 3.4 (8) | 9.8 (23) | 13.2 (31) | 42.7 (100) | 30.8 (72) | 12.467(4), p=0.014$^{*}$ |
| | ESN (219) | 0.5 (1) | 8.2 (18) | 16 (35) | 33.3 (73) | 42 (92) | |
| **Who to contact if seizures continue** | Non-ESN (238) | 4.6 (11) | 13 (31) | 15.5 (37) | 39.5 (94) | 27.3 (65) | 30.406(4),p =0.000$^{***}$ |
| | ESN (221) | 0 | 4.1 (9) | 14 (31) | 37.6 (83) | 44.3 (98) | |
| **Pregnancy related information** | | | | | | | |
| **Advice on AEDs and pregnancy** | Non-ESN (122) | 9 (11) | 15.6 (19) | 18.9 (23) | 27.9 (34) | 28.7 (35) | 10.104(4), p=0.039$^{*}$ |
| | ESN (121) | 2.5 (3) | 15.7 (19) | 14 (17) | 23.1 (28) | 44.6 (54) | |

*ns not significant * significant at p<.05 **significant at p<.01 ***significant at p< 0.001*

### *Difference in experiences of involvement in care*

To explore differences in PWEs' experience of involvement in care, PWE were asked to rate 4 items that addressed the extent to which they were given an opportunity to ask questions, discuss concerns, have their wishes heard and be involved in decision-making around their care and treatment, and one question that asked about family involvement. The ESN sites had higher mean scores for the 5 items compared to Non-ESN sites. There was a statistically significant difference in the overall mean score for involvement in care between ESN and Non-ESN sites [t(477)= -4.068, p=.000], with ESN sites having a higher mean score (M=4.23, SD=.73) compared to Non-ESN sites (M=3.95, SD=.82) (Table 6.3).

**Table 6.3: Involvement in care**

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| I am given opportunity to ask questions | 4.20 (.88) | 4.44 (.72) |
| I am given enough time to discuss my worries | 3.91 (1.03) | 4.24 (.93) |
| I am involved in all decisions made about my care and treatment | 3.86 (1.03) | 4.14 (.94) |
| My wishes and needs are taken into account when my care is planned | 3.89 (.93) | 4.16 (.91) |
| If my family or someone else close to me wants to talk to the ESN/healthcare professional, they have the opportunity to do so | 3.84 (.98) | 4.21 (.83) |
| **Total Mean Score** | **3.95 (.82)** | **4.23 (.73)** |

These differences are further highlighted in table 6.4, which reports on the results of Pearson chi-square tests performed to examine whether there were any statistically significant differences in involvement in care depending on the type of site. Statistically significant results were found for all five items. Compared to Non-ESN sites, higher proportions of those in ESN sites strongly agreed that they and their families are given the opportunity to ask questions (54.3%, 44.1% versus 41.1%, 27.3%), are afforded enough time to discuss worries (47.8% versus 32.4%), that they are involved in decisions (42.5% versus 30%) and have their wishes taken into account (41.8% versus 27.3%) (Table 6.4)

Table 6.4: Involvement in care

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **I am given opportunity to ask questions** | | | | | | |
| **Non-ESN (246)** | 2.0 (5) | 3.3 (8) | 8.9 (22) | 44.7 (110) | 41.1 (101) | 14.210(4), |
| **ESN (229)** | 0 | 2.9 (7) | 4.1 (10) | 38.7 (93) | 54.3 (128) | p=0.007** |
| **I am given enough time to discuss my worries** | | | | | | |
| **Non-ESN (244)** | 2.9 (7) | 7.8 (18) | 16.8 (41) | 40.2 (98) | 32.4 (79) | 15.321(4), |
| **ESN (224)** | 2.2 (5) | 3.1 (7) | 10.7 (24) | 36.2 (81) | 47.8 (107) | p=0.004** |
| **I am involved in all decisions made about my care and treatment** | | | | | | |
| **Non-ESN (243)** | 3.3 (8) | 7.0 (17) | 19.8 (48) | 39.9 (97) | 30.0 (73) | 10.011(4), |
| **ESN (221)** | 1.8 (4) | 4.5 (10) | 13.6 (30) | 37.6 (83) | 42.5 (94) | p=0.040* |
| **My wishes and needs are taken into account when my care is planned** | | | | | | |
| **Non-ESN (242)** | 2.1 (5) | 5 (12) | 22.3 (54) | 43.4 (105) | 27.3 (66) | 13.876(4), |
| **ESN (220)** | 1.4 (3) | 4.5 (10) | 12.7 (28) | 39.5 (87) | 41.8 (92) | p=0.008** |
| **If my family or someone else close to me wants to talk to the ESN/healthcare professional, they have the opportunity to do so** | | | | | | |
| **Non-ESN (245)** | 2.0 (5) | 7.8 (19) | 22 (54) | 40.8 (100) | 27.3 (67) | 20.678(4), |
| **ESN (222)** | 0 | 3.2 (7) | 16.7 (37) | 36 (80) | 44.1 (98) | p=0.000*** |

*ns not significant * significant at p<.05 **significant at p<.01 ***significant at p< 0.001*

A sixth question relating to participants' desire to be more involved in care was also asked. Slightly more PWE from Non-ESN sites reported wanting to be more involved in decisions about their care and treatment (67.2%) compared to ESN respondents (61.9%), though this difference was not statistically significant (See table 6.5). There was also no statistically significant difference in the mean score on this item between ESN (M=2.14, SD=.963) and Non-ESN sites (M=2.14, SD=1.06) [t(445.357)= -.387, p=.699].

Table 6.5: Desire for greater involvement in decision making and care

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **I want to be more involved in decisions made about my care and treatment** | | | | | | |
| **Non-ESN (246)** | 1.7 (4) | 5.4 (13) | 25.7 (62) | 36.1 (87) | 31.1 (75) | 5.478(4), $p=.242^{ns}$ |
| **ESN (230)** | 2.3 (5) | 7.2 (16) | 28.5 (63) | 26.2 (58) | 35.7 (79) | |

*ns not significant*

These positive findings on involvement in care in relation to sites with ESNs were reiterated in the qualitative data from interviews and surveys. The majority of the comments made by PWE suggested that they felt very involved in their care and had an opportunity to ask questions and discuss any issues of concern with the ESN.

> *"She [the ESN] actually came over to the house. Spent a couple of hours there answering all my questions and informing me, what was normal and what wasn't. I found that very helpful." (PWE focus group)*

> *"Having them [ESNs] there is fantastic…they can answer an awful lot of questions for you… particularly when you've forgotten what questions to ask when you're in with the consultant and you go back and go 'oh I should have asked' … very, very useful." (PWE focus group)*

Satisfaction was also expressed in relation to family involvement in care. This is reflected in the following interaction between two parents within a focus group where they discussed how the ESNs listen, respect and facilitate involvement in their child's care.

> *"I just think they [ESNs] totally respect the mother's input and they involve you every bit of the way." (Family member focus group)*

> *"Yes, it was the same with [names son]…, wanting to go off medication like one of the times. I said, look he's going crazy, he says 'none of this is working, none of it is working'. He'd be on many different tablets at this stage… and like he's sixteen. I said, look he's getting really to the stage he wants to stop everything. And she [ESN] listened and said, I'll talk to him, bring him in and we'll change it another way … They [ESNs] talked him through." (Family member focus group)*

### *Difference in experience of co-ordination of care*

To explore differences in co-ordination of care, PWE were asked four questions that addressed the delivery of care in a planned and co-ordinated manner, ease of making appointment, follow-up care after appointments and waiting times. The individual item mean scores were higher in ESN sites compared to Non-ESN sites, and the total mean score was higher for ESN sites (M=3.77; SD=.78) compared to Non-ESN sites (M=3.57; SD=.88), a difference which was statistically significant [t(475) = -2.597, p=0.01] (table 6.6).

**Table 6.6: Co-ordination of care (mean results)**

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| My care is delivered in a planned and co-ordinated manner | 3.91 (.884) | 3.98 (.93) |
| I find it easy to make an appointment or arrange tests | 3.36 (1.27) | 3.73 (1.06) |
| There is good follow-up after my appointment | 3.45 (1.24) | 3.68 (1.09) |
| I wait a reasonable amount of time before being seen on each visit | 3.52 (1.30) | 3.66 (1.09) |
| **Total mean score** | **3.57 (.88)** | **3.77 (.78)** |

Pearson chi-square tests were performed to establish whether there were any statistically significant differences in the strength of views about co-ordination of care depending on type of site. Whilst there was no statistically significant difference between ESN sites and Non-ESN sites on whether care is delivered in a planned and co-ordinated manner or whether there is good follow-up, statistically significant associations were found between type of site and the amount of time waiting to be seen and the ease with which an appointment or test could be arranged. Higher proportions of Non-ESN site respondents strongly disagreed that they had to wait a ‘reasonable amount of time’ to be seen and that appointments could be easily made (12.8% & 13.1% respectively) compared to respondents from ESN sites (4.9% & 3.2% respectively) (table 6.7).

Table 6.7: Co-ordination of care

|  | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **My care is delivered in a planned and co-ordinated manner** |  |  |  |  |  |  |
| **Non-ESN (244)** | 2.5 (6) | 2.9 (7) | 20.5 (50) | 49.6 (121) | 24.6 (60) | 4.942(4), |
| **ESN (227)** | 1.8 (4) | 4.8 (11) | 18.9 (43) | 42.7 (97) | 31.7 (72) | p=0.293$^{ns}$ |
| **I find it easy to make an appointment or arrange tests** |  |  |  |  |  |  |
| **Non-ESN (244)** | 13.1 (32) | 10.2 (25) | 23.0 (56) | 35.2 (86) | 18.4 (45) | 16.717(4), |
| **ESN (220)** | 3.2 (7) | 10.5 (23) | 22.7 (50) | 37.7 (83) | 25.9 (57) | p=0.002$^{**}$ |
| **There is good follow-up after my appointment** |  |  |  |  |  |  |
| **Non-ESN (240)** | 10.4 (25) | 10.4 (25) | 24.6 (59) | 32.5 (78) | 22.1 (53) | 8.978(4), |
| **ESN (224)** | 4.0 (9) | 11.6 (26) | 21 (47) | 39.3 (88) | 24.1 (54) | p=0.062$^{ns}$ |
| **I wait a reasonable amount of time before being seen on each visit** |  |  |  |  |  |  |
| **Non-ESN (247)** | 12.8 (31) | 9.1 (22) | 14.9 (36) | 39.3 (95) | 24 (58) | 10.397(4), |
| **ESN (236)** | 4.9 (11) | 11.5 (26) | 18.6 (42) | 42.9 (97) | 22.1 (50) | p=0.034$^{*}$ |

*ns not significant * significant at p<.05 **significant at p<.01*

Although there was no significant difference between ESN and Non-ESN sites in relation to whether care was delivered in a planned and co-ordinated manner, participants' comments suggested that ESNs were viewed as contributing to co-ordinated care through their close liaison with the neurologist. Several PWE and family members commented that ESNs provided a vital link between them and the medical consultant, facilitating rapid access to medical expertise and circumnavigating the problem of lack of direct face-to-face contact with the neurologist.

> *"They kind of liaise between you and the consultant because not all the time you get too long to talk to the consultant." (PWE focus group)*

> *"And if you're having trouble with your…medication and you're upping and downing, you're dealing with her [ESN] but she's actually not making the full decision. She's going back to your specialist you know." (PWE focus group)*

> *"All you've got to do is ring, she'll ask all the right questions and she'll get back to you, either that afternoon with word from the neurologist…You feel at ease that you're not disturbing the neurologist and taking his time. Whereas, they [ESNs] have immediate contact with him." (Family member focus group)*

Also apparent from participants' comments, was the degree to which the telephone added an important dimension to the ESN's ability to provide good follow-up care, particularly in the intervening period between consultations. An important aspect of this was the responsiveness of the ESNs as most participants described the ESNs as very responsive with telephone messages being returned almost immediately or within reasonable time frames.

> *"When I had surgery and came home, they [ESNs] were ringing me afterwards, constantly, looking to see how you are, how are things…the support is unreal." (PWE focus group)*
>
> *"In all the 9 years [name of son] has attended [names site]. The epilepsy nurses' [telephone] line was our life line. We could not have done without it. It was an invaluable part of our life. Although I'd speak to an answering machine one of the epilepsy nurses would always return the call." (Family member focus group)*
>
> *"Without them [ESNs] the whole system would fall apart. They are my first port of call if I need anything. I can always get a fast response." (PWE focus group)*
>
> *My nurse has called me 3 or 4 times. I found these conversations very rewarding, as the period in between appointments were sometimes difficult. It was great to be able to share some of my concerns with a specialist. (PWE survey)*
>
> *"I find [ESN] brilliant. If I ring her, I had to get my dose [of AED] increased as I felt something coming on. I was pregnant at the time and she said we're going to have to do something and increase it because you don't want anything to happen. She's just brilliant. Anytime I ring her up she's straight back on. If I give her a wee text or that, if she can't answer it or if she's busy or whatever, she'll ring me within the hour and she'd always sort me out." (PWE focus group)*

### Difference in experience of continuity of care

To explore differences in PWEs' experience of continuity of care, survey participants were asked three questions: number of practitioners encountered; frequency of having to recount their personal story; and consistency of the information provided. For the purpose of this analysis, two of the negatively worded items were reverse coded. The mean scores for meeting the same ESN/healthcare practitioner and repeating epilepsy information to different members of the team were higher for Non-ESN sites compared to ESN sites, indicating that PWE from Non-ESN sites rated continuity of care higher compared to PWE in ESN sites. There was little mean difference in scores on receiving conflicting information from the healthcare team (table 6.8).

**Table 6.8: Continuity of care**

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| I meet the same ESN/healthcare practitioner(s) on each visit | 3.45 (1.25) | 3.10 (1.35) |
| *I have to tell about my epilepsy repeatedly to different members of the healthcare team | 2.78 (1.25) | 2.53 (1.26) |
| *I get conflicting information [mixed messages] from the healthcare team | 3.46 (1.09) | 3.51 (1.06) |

**Reverse coded for purpose of analysis*

Pearson chi-square tests were conducted to determine whether there were any statistically significant differences in continuity of care depending on the type of site. A statistically significant result between Non-ESN sites and ESN sites was found for meeting the same practitioner, with a higher proportion of respondents in Non-ESN sites agreeing that they meet the same practitioner (58.7%) compared to those in ESN sites (40.6%) (table 6.9). 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 and the consistency of the information they received from their healthcare team.

Table 6.9: Continuity of care

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **I meet the same ESN/healthcare practitioner(s) on each visit** | | | | | | |
| **Non-ESN (242)** | 7.4 (18) | 24.0 (58) | 9.9 (24) | 33.9 (82) | 24.8 (60) | 20.447(4), |
| **ESN (229)** | 11.4 (26) | 29.7 (68) | 18.3 (42) | 18.3 (42) | 22.3 (51) | p=0.000$^{***}$ |
| **I have to tell about my epilepsy repeatedly to different members of the healthcare team** | | | | | | |
| **Non-ESN (242)** | 10.3 (25) | 22.3 (54) | 18.2 (44) | 33.5 (81) | 15.7 (38) | 7.230(4), |
| **ESN (224)** | 8.5 (19) | 16.5 (37) | 19.2 (43) | 31.3 (70) | 24.6 (55) | p=0.124$^{ns}$ |
| **I get conflicting information [mixed messages] from the ESN/healthcare team** | | | | | | |
| **Non-ESN (239)** | 17.2 (41) | 35.6 (85) | 30.1 (72) | 10.9 (26) | 6.3 (15) | 7.035(4), |
| **ESN (225)** | 16.4 (37) | 40.9 (92) | 23.1 (52) | 16.0 (36) | 3.6 (8) | p=0.134$^{ns}$ |

*ns not significant ***significant at p< 0.001*

Although PWE in Non-ESN sites were more likely than those in ESN sites to report seeing the same person on each visit, the importance of the ESN being a constant presence within a revolving medical team in order to create continuity of care and instil confidence in care was underlined by PWE within the focus groups.

> *"The team is changing, there'd be a different registrar, and there'll be a different SHO… so [by having the ESN] you're not talking to somebody different all the time. Because that will not fill you with confidence." (PWE focus group)*

> *"Like I…see the same one [ESN] all the time and she's very personal, and she is a lovely lady and easy to talk to." (PWE focus group)*

> *"…the last few times I've seen, I've come here, I've seen the same person and that really is important for me…" (PWE focus group)*

The presence of the ESN and their impact on continuity of care was also evident from the comments on the close and positive relationships they had developed with ESNs.

> *"..the one on one [relationship] and…the familiarity and the continuity between you know, with a nurse and yourself, you know, they get to know you." (PWE focus group)*

> *"[Name of ESN] is a very unique person. Where we all got to know her and she got to know our children very well." (PWE focus group)*

As a result of the continuity in care, PWE and family members were of the view that the ESNs had an intimate and comprehensive knowledge of their life history with epilepsy, which meant that they and their families could often avoid repetitive explanations and were not over burdened with the responsibility of remembering and explaining all the details of past care and treatment.

> *"She [ESN] knows exactly what she's talking about. And she can say, 'oh now I remember such and such a time'. I could barely remember but she can remember, 'oh and he [son] doesn't usually take them [medication] like that now'. I don't know where they [ESNs] store the information but I feel like it's her little child that she's speaking about." (Family member focus group)*

> *"But she's an amazing girl [ESN] you know … each time we go, we don't have to repeat the whole lot. How will I remember what happened in the last seizure. [Name of ESN] always knows, always; always knows." (Family member focus group)*

> *"[ESNs] have their own cohort of PWE, so there's continuity in your care… that's invaluable, a patient is not repeating themselves to a brand new clinician on each visit. I hear the feedback from the PWE, I've seen this doctor and you know he's gone now or he's on a different rotation. They have to start from square 1 again, and when you open up to a clinician on your visit, you don't want to tell the same story again on your next visit in 3 to 6 months' time." (Medical personnel interview)*

Also apparent, from PWE and family comments, was the ease of accessibility to the ESNs through the TAL. The phone service offered PWE and their families a measure of comfort that if they ran into any problems, they would not have to wait until they got an appointment to seek advice and support; instead they could address the problems much more quickly using the telephone.

> *"Well, what I know about the nurse is that any time I ring her she will ring me. She is, I find her fantastic." (PWE focus group)*

> *"Having that port of call [TAL], being able to ring them up and if you've a bad weekend or a Wednesday or a Thursday night, you have someone to ring, you know there's somebody who knows their [PWE] form." (Family member focus group)*

> *"And I only have to lift the phone even though, thank God I don't have to. But…it's great to know that…if you have any fears. You don't have to make an appointment with the doctor, you can just lift the phone and ask to talk to somebody, you know." (Focus group family member)*

Although participants were generally satisfied with services where ESNs were employed a few participants did identify deficits in relation to continuity of care, namely long waiting times to access care, lack of monitoring following surgery and having to repeat information to clinicians.

> *"I think that nurses and doctors are very helpful in this hospital. Only thing that worried me was I had no contact after my surgery for 10 weeks. I probably should have contacted the nurses myself. I think they do their best." (PWE focus group)*

> *Wait times could be less. (PWE survey)*

> *I have to go over all my symptoms repeatedly which I find quite annoying and time wasting. (PWE survey)*

### *Difference in perception of being treated with dignity and respect*

To explore differences in PWEs' experience of being treated with dignity and respect, two questions were asked (table 6.10). For the purpose of this analysis, the negatively worded item on the ESN/healthcare practitioner talking in front of PWE as if they were not present was reverse coded. Higher mean scores were found for ESN sites compared to Non-ESN sites, indicating that respondents from ESN sites rated their treatment more highly than those from Non-ESN sites.

Table 6.10: Views about the ESN/healthcare professional

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| I feel like I am treated with respect and dignity by the ESN/healthcare professional | 4.29 (.78) | 4.50 (.66) |
| *The ESN/healthcare professional talks in front of me as if I was not there | 3.77 (1.16) | 3.93 (1.14) |

**Item reversed coded*

Pearson chi-square/fisher's exact tests were performed to establish whether there were any statistically significant differences in views about dignity and respect depending on type of site. There was no statistically significant difference between ESN sites and Non-ESN sites in relation to ESNs/healthcare professionals talking in front of them, with approximately 13-16% of respondents in both sites reporting that the ESN/healthcare professional talked about them as if they were not present. There was a statistically significant difference between ESN sites and Non-ESN sites in relation to whether the ESN/healthcare professional treated them with respect and dignity, with respondents from ESN sites more likely to agree strongly with this statement (58%) compared to respondents from Non-ESN sites (43%). However, high proportions of PWE from both ESN (93.3%) and Non-ESN sites (90.5%) felt that they were treated with dignity and respect by the ESN/healthcare professional (table 6.11)

Table 6.11: Views about the ESN/healthcare professional

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **I feel like I am treated with respect and dignity by the ESN/healthcare professional** | | | | | | |
| **Non-ESN (244)** | 1.2 (3) | 2.0 (5) | 6.1 (15) | 47.5 (116) | 43 (105) | Fisher's exact test: p=0.003** |
| **ESN (224)** | 0.4 (1) | 0 | 6.3 (14) | 35.3 (79) | 58 (130) | |
| **The ESN/healthcare professional talks in front of me as if I was not there** | | | | | | |
| **Non-ESN (240)** | 28.3 (68) | 43.8 (105) | 11.7 (28) | 9.2 (22) | 7.1 (17) | 6.492(4), p=0.166$^{ns}$ |
| **ESN (213)** | 38 (81) | 35.2 (75) | 13.6 (29) | 8.0 (17) | 5.2 (11) | |

*ns not significant **significant at p<.01*

### *Difference in reported confidence in advice and comfort in talking*

To explore differences in PWEs' willingness to discuss issues and their confidence in advice given, four questions were asked. Two questions focused on comfort in talking about concerns and two focused on how confident they felt in the practitioner to provide the care needed and to take the advice given. The individual item mean scores were higher in ESN sites compared to Non-ESN sites, as was the total mean score (M=4.21; SD=.658) compared to Non-ESN sites (M=3.97; SD=.73), a difference which was statistically significant [t (467) = -3.641, p=0.000] (table 6.12).

**Table 6.12: Views about the ESN/healthcare professional: comfort and confidence**

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| I feel comfortable talking to the ESN/healthcare professional about my concerns | 4.24 (.863) | 4.42 (.686) |
| I feel comfortable talking with the ESN/healthcare professional about sexual issues | 3.21 (1.031) | 3.54 (1.035) |
| I have confidence in the ESN/healthcare professional to provide the care I need | 4.15 (.932) | 4.39 (.733) |
| I trust the advice given to me by the ESN/healthcare professional | 4.25 (.802) | 4.42 (.692) |
| **Total mean score** | **3.97 (.730)** | **4.21 (.658)** |

These differences are further highlighted in table 6.13, which reports on the results of Pearson chi-square tests performed to examine whether there were any statistically significant differences in views around comfort with and confidence in the ESN/healthcare professional depending on type of site. Statistically significant differences between ESN sites and Non-ESN sites were found in relation to three of the four items: comfortable talking to the ESN/healthcare professional about concerns; comfortable talking with the ESN/healthcare professional about sexual issues; and confidence in the ESN/healthcare professional to provide the care needed. No PWE from ESN sites reported not feeling comfortable talking to the ESN compared to 11 PWE from Non-ESN sites who reported discomfort talking to the healthcare professional.

In relation to sexual issues, twice as many respondents from ESN sites reported feeling comfortable discussing issues of sexuality with the ESN (23.9%) compared to PWE from Non-ESN sites discussing sexuality with their healthcare professional (11.6%). With regard to confidence in the ESN/healthcare professional to provide the care required, a slightly greater number of PWE from ESN sites reported that they had confidence in the ESN to provide the required care (87.9%) compared to Non-ESN sites (83.5%). Overall there was a high level of trust in advice given among PWE in the ESN and Non-ESN sites, with no significant differences between the sites emerging.

Table 6.13: Comfort and confidence

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **I feel comfortable talking to the ESN/ healthcare professional about my concerns** | | | | | | |
| **Non-ESN (242)** | 1.7 (4) | 2.9 (7) | 9.5 (23) | 42.1 (102) | 43.8 (106) | 14.004(4), |
| **ESN (223)** | 0 | 0 | 11.2 (25) | 35.4 (79) | 53.4 (119) | p=0.005** |
| **I feel comfortable talking with the ESN/healthcare professional about sexual issues** | | | | | | |
| **Non-ESN (233)** | 6.9 (16) | 12.4 (29) | 45.1 (105) | 24.0 (56) | 11.6 (27) | 15.847(4), |
| **ESN (213)** | 2.8 (6) | 8.5 (18) | 44.6 (95) | 20.2 (43) | 23.9 (51) | p=0.003** |
| **I have confidence in the ESN/healthcare professional to provide the care I need** | | | | | | |
| **Non-ESN (242)** | 2.1 (5) | 5.0 (12) | 9.5 (23) | 42.6 (103) | 40.9 (99) | 14.786(4), |
| **ESN (223)** | 0 | 1.3 (3) | 10.8 (24) | 35.0 (78) | 52.9 (118) | p=0.004** |
| **I trust the advice given to me by the ESN /healthcare professional** | | | | | | |
| **Non-ESN (246)** | 0.8 (2) | 2.9 (7) | 9.1 (22) | 45.0 (109) | 42.1 (102) | 7.217(4), |
| **ESN (232)** | 0 | 1.3 (3) | 7.6 (17) | 38.6 (86) | 52.5 (117) | p=0.110ns |

*ns not significant **significant at p<.01*

The interview data from PWE and their families also supported the findings. The following word cloud represents the terms most frequently used within the interview data (figure 6.2).

Figure 6.2: PWE and family members' views of ESNs

The ESNs were viewed by PWE and family participants as immensely experienced and knowledgeable, and consequently were deemed well equipped to deal effectively with a whole wide range of people and situations. It was their combination of specialist expertise in epilepsy, combined with clinical experience, interpersonal skills and person-centred focus that appeared to instil confidence and trust among PWE and their families, as these comments illustrate.

> *"They reassure you…and their knowledge comes across so strongly that that gives you that sense of confidence in them." (Family member focus group)*
>
> *"Yeah, I mean, they have the information, they specialise, they specialise in epilepsy. So you feel more confident ringing them." (Family member focus group)*
>
> *"For me, it's I know medically, they know what they're doing. You know, I really believe that they know what they're doing." (PWE focus group)*

The personal and empathetic approach to care adopted by ESNs was regarded as providing a counterbalance to the doctors' and consultants' approach to care, which participants viewed as being more medical and medication-orientated and lacking the time to dedicate the same attention to personal care that the ESNs provided. This exchange of views between PWE within one of the focus groups illustrates this point.

> *"There is like a kind of difference in their approach, you know." (PWE focus group)*
>
> *"Mmm, it's more personal." (PWE focus group)*
>
> *"The doctors are much more yeah, medication-minded and we do this, this and this and but em, you know, so if the two of them could meet in the middle and create a person that you could see, it would be great you know." (PWE focus group)*

A natural ability to empathise with PWE and their families' situation, as well as having an intuitive sense of their needs and an ability to respond appropriately were cited as some of the ESN's distinct skills.

> *"For me, I think that coming back to their [ESNs] empathy, I think for me that would be, would've been important." (PWE focus group)*

> *"Where I feel like the nurses, not that they've more time to listen but they're kind of a nice ear to listen." (PWE focus group)*

Several participants felt that the treatment they received from the ESNs was akin to that which a family member might bestow and had a vocational quality.

> *"As for the nurses who look after you before during and after [surgery], you couldn't get better. They're like another family that you never knew you had and they're always there." (PWE focus group)*

> *"And I think they're never off duty, you're right [names another focus group member], no matter when you meet them they are friendly. But I think ultimately they're human and they don't see it as a job, they see it as a bit of a vocation." (PWE focus group)*

### *Difference in practical support offered*

To explore the difference in practical support offered, PWE were asked to indicate on a scale of 0 to 10 how satisfied they were with the practical advice received from the ESN/healthcare professional, with higher scores reflecting higher levels of satisfaction. PWE from ESN sites reported higher satisfaction with practical support (M=8.05; SD=2.13) compared to PWE attending Non-ESN sites (M=7.41; SD=2.39) and this difference was statistically significant [t(467.022)= -3.080, p<.002] (table 6.14).

**Table 6.14: Practical support by site**

| | Non-ESN | | ESN | | Independent samples t-test (two-tailed) | | |
|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | t | df | p |
| **Practical support** | 7.41 | 2.39 | 8.05 | 2.13 | -3.080 | 467.022 | 0.002** |

***significant at p<.01*

In terms of practical support, PWE were of the view that the ESNs offered practical strategies and solutions to deal with epilepsy-related issues on a daily basis, thereby facilitating better coping.

> *"But it's the nurses [ESNs] who give you more practical advice…. they come up with different solutions, 'get a big bowl of porridge in you, then try taking it [medication]'. And I mean it's unbelievable you know, just the little simple tip." (PWE focus group)*

> *"I found some of the practical things they told you, like when I started to have my seizures it was contact the Epilepsy Society, buy a special pillow, you need to do this, you need to do that. Mine [seizures] were nocturnal, and it was all those extra little things that probably made the difference." (PWE focus group)*

### *Difference in emotional support offered*

To explore the difference in emotional support offered, PWE were asked to indicate on a scale of 0 to 10 how satisfied they were with the emotional support received from the ESN/healthcare professional, with higher scores reflecting higher levels of satisfaction. PWE from ESN sites reported significantly higher satisfaction with emotional support (M=7.39, SD=2.47) compared to respondents from Non-ESN sites (M=6.65, SD=2.73), [t(461.315)= -3.056, p<.002] (table 6.15).

**Table 6.15: Emotional support by site**

| | Non-ESN | | ESN | | Independent samples t-test (two-tailed) | | |
|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | t | df | p |
| **Emotional support** | 6.65 | 2.73 | 7.39 | 2.47 | -3.056 | 461.315 | 0.002** |

***significant at p<.01*

In addition, the qualitative data from focus groups and open-ended survey data from PWE offered numerous examples of the emotional support provided by the ESN to PWE and their families.

> *"But definitely with [name of ESN] it's been always positive and she's always been there. Which does make a difference because sometimes you can feel very isolated and it's a frightening place to be when you don't have anyone who understands." (PWE focus group)*

> *"Yea, the worry, that's why the nurses are valuable like. My mother's a worrier, so if I brought up that I had some sort of an aura she'd, she'd fret for days. But at least with the nurse, you know, you can just, it's just reassurance for yourself." (PWE focus group)*

> *"At times I've been on the phone nearly, not hysterical, but when I just needed to be calmed. You know, just to be reassured and they were just, it's amazing, I don't know how they do it. It's just amazing." (Family member focus group)*

> *"For me, it's just knowing that they're at the end of a phone… because at the end of the day, it's me that's on my own at home, with my partner. I'm on my own at home with a child that's having difficulty with epilepsy. That I have somebody that I can talk to and that can just reassure me. They mightn't have the answer but they can just help me cope better with my child." (Family member focus group)*

> *"For me, it's just being able to pick up the phone and my husband, he just the biggest 'scaredy cat' you've ever…so when I pick up the phone and I'll get [name of ESN]. It's just such a relief, it means everything. You know because when you're going through those really, really dark days it's just nice to get that bit of sunlight from them. And that's, that's what I feel; you know it means everything to me." (PWE focus group)*

> *"I suppose what we'd have found with the specialist nurse… in a selfish way you could say they're there for me, for my wife, they're there for us. They're there supporting us, they're supporting us whereas the consultant is more or less dealing with the medication point of view." (PWE focus group)*

Several satisfactory comments in relation to support received from the ESN were also evident in the surveys.

> *The level of support I have received from the epilepsy clinic nurses has been beyond all expectations (PWE survey)*

> *Over the last 7 years since diagnosis, the support has been absolutely tremendous from the specialist nurses and is much appreciated (PWE survey)*

### *Difference in contribution to health, well-being and quality of life*

To explore the difference in contribution to health and well-being, PWE were asked a question on whether the ESN/healthcare professional made a positive difference to their health and well-being. Responses ranged from 1 (‘strongly disagree’) to 5 (‘strongly agree’). PWE from ESN sites gave a higher mean rating than those in Non-ESN sites, reflecting higher levels of agreement that the ESN made a positive difference to the person’s health and well-being (table 6.16).

**Table 6.16: Views about the ESN/healthcare professional and health and well-being**

| | Non-ESN M (SD) | ESN M (SD) |
|---|---|---|
| The ESN/healthcare professional makes a positive difference to my health and well-being | 4.08 (.963) | 4.22 (.817) |

A Pearson chi-square test was conducted to see if there was any statistically significant difference in the strength of the view that ESNs/healthcare practitioners made a positive difference to health and well-being depending on whether the site was an ESN or Non-ESN site. There was a statistically significant association between views on whether the ESN/healthcare practitioner had a positive impact on health and well-being depending on site type. PWE from Non-ESN sites were more likely to disagree (4.2%) or strongly disagree (2.9%) with this statement compared to PWE from ESN sites (2.8% & 0% respectively) (table 6.17).

**Table 6.17: Views about the ESN/healthcare professional and health and well-being**

| | Strongly Disagree % (n) | Disagree % (n) | Neither % (n) | Agree % (n) | Strongly Agree % (n) | $X^2$ test |
|---|---|---|---|---|---|---|
| **The ESN /healthcare professional makes a positive difference to my health & well-being** | | | | | | |
| **Non-ESN (240)** | 2.9 (7) | 4.2 (10) | 12.5 (30) | 42.9 (103) | 37.5 (90) | 10.019(4), |
| **ESN (215)** | 0 | 2.8 (6) | 16.3 (35) | 37.2 (80) | 43.7 (94) | p=0.040* |

** significant at p<.05*

The positive endorsement of the contribution the ESN made to health and well-being was reflected in several comments made by participants about the impact of ESN on improving health.

> *"And they've [ESNs] been like a piece into a jigsaw puzzle in my child's life, in our child's lives and it's been a huge piece. It's not a little small piece; it's had a huge impact on her life." (Family member focus group)*
>
> *Since attending the epilepsy clinic and ESN my quality of life has dramatically improved, given concise information, staff always available to answer concerns and by far the best treatment I've received. Being spoken to in a less formal manner also really helps. (PWE survey)*
>
> *I have found the ESN service invaluable and it greatly enhanced my care when it became available. (PWE survey)*

In addition to the above question on health and well-being, impact was also measured using the Quality Of Life In Epilepsy (QOLIE-10-P) instrument (Cramer *et al.* 1996). Respondents were asked a series of questions regarding their feelings and the types of problems they experienced in the previous three weeks. Scores ranged from 0 to 100 with higher scores indicating better quality of life. Overall there was huge variation in the scores with a range of 0.28-100. (SD=27.53). Three quarters of the total sample who responded to the quality of life question (n=447) scored under 55 on the QOLIE-10-P scale. The average QOLIE-10-P score was similar for PWE from both Non-ESN sites (M=39.15, SD=28.53) and ESN sites (M=37.34, SD= 26.46) with no statistical difference observed [t (439) =.690, p=.491].

There were also no differences between ESN and Non-ESN sites on the total mean score (questions 1-10) (table 6.18) or on the epilepsy-related QOL item (question 11) (table 6.19).

Table 6.18: QOLIE-10-P (Questions 1-10)

| | Non-ESN | | | ESN | | |
|---|---|---|---|---|---|---|
| | N | Mean | SD | N | Mean | SD |
| Have a lot of energy? | 241 | 49.05 | 25.62 | 233 | 51.67 | 26.15 |
| Felt downhearted & low | 241 | 60.91 | 26.91 | 232 | 61.72 | 27.36 |
| Trouble driving | 195 | 78.33 | 37.33 | 196 | 65.94 | 42.41 |
| Work limitations | 217 | 69.24 | 36.34 | 216 | 64.35 | 38.61 |
| Social limitations | 234 | 61.32 | 37.99 | 228 | 58.88 | 39.76 |
| Memory difficulties | 234 | 46.90 | 37.54 | 228 | 45.61 | 35.24 |
| Physical effects of medication | 236 | 51.38 | 37.20 | 230 | 52.17 | 34.59 |
| Psychological effects of meds | 237 | 51.90 | 36.19 | 226 | 53.54 | 36.34 |
| Afraid of having fit | 238 | 59.52 | 34.11 | 232 | 59.19 | 34.99 |
| Quality of life | 238 | 59.14 | 26.14 | 232 | 60.45 | 26.44 |
| **Total mean score** | **230** | **58.56** | **22.03** | **228** | **57.20** | **21.28** |

Table 6.19: Epilepsy-related QOL (Question 11)

| | Non-ESN | ESN |
|---|---|---|
| **N** | 236 | 228 |
| **Mean** | 2.72 | 2.71 |
| **SD** | 1.22 | 1.19 |

## Difference in newly diagnosed patient experiences

To explore if there was a difference in newly diagnosed patients' knowledge of epilepsy and quality of life a  survey was administered to a cohort of patients in services with and without an ESN (time point 1) and followed up 12-14 months later (time point 2). The survey included the knowledge of own epilepsy scale [19 items rated on an 11 point scale, 0= no knowledge; 10 = very knowledgeable (May & Pfafflin 2002)], Knowledge of Epilepsy Scale and the QOLIE-10-P instrument (Somerville *et al.* 2007).

### *Knowledge of own epilepsy over time*

Matched data (survey completed by participants at two time points of data collection) was available for 45 participants, 39 in ESN sites and 6 in Non-ESN sites. A paired sample t-test was conducted to determine if there was a statistically significant difference in the score for PWEs' 'knowledge of their own epilepsy' across time.

The items were grouped into four categories as follows: *nature of epilepsy and my epilepsy; medical aspects of epilepsy*; *social aspects of epilepsy* and *safety aspects of epilepsy*. Scores at time point one in all categories were above a mean of 5 indicating some level of knowledge. Findings indicate that PWE attending an ESN service improved their knowledge to some extent in each area; however, statistically significant improvements were only found in relation to medical and social aspects of epilepsy but not in relation to the nature of epilepsy or safety aspects of epilepsy.

Overall knowledge score on the scale rose from time point (M=6.4, SD=2.19) to the follow-up survey (M=7.3; SD= 2.07) and this was statistically significantly [t (38) = -2.79, p=0.008] (table 6.20); however, caution must be used when interpreting these results as the sample size is not large.

Table 6.20: PWE knowledge of own epilepsy in ESN sites over time (n=38/39) (matched surveys)

| | Point 1 M (SD) | Follow-up M (SD) | Paired Sample T-test |
|---|---|---|---|
| **Nature of epilepsy and my epilepsy** | 6.06 (2.48) | 6.78 (2.48) | t (38)= -1.787,p=0.082$^{ns}$ |
| **Medical aspects of epilepsy** | 6.87 (2.38) | 7.79 (2.08) | t (38)= -2.565 p=.014$^{*}$ |
| **Social aspects of epilepsy** | 5.13 (2.53) | 6.57 (2.57) | t (37)= -3.153, p=0.003$^{**}$ |
| **Safety aspects of epilepsy** | 6.81 (2.37) | 7.42 (2.51) | t(38)= -1.728, p=.092$^{ns}$ |
| **Total mean knowledge score** | **6.4 (2.19)** | **7.3 (2.07)** | **t (38)= -2.79, p=0.008**$^{**}$ |

*ns not significant * significant at p<.05 **significant at p<.01*

As there were only 6 PWE in the Non-ESN sites, their knowledge of their own epilepsy over time was not assessed statistically as the power of the test would have been too low.

The Mann-Whitney U test was performed to examine whether there was a statistically significant difference between PWE attending ESN services and those attending Non-ESN services in respect of knowledge of own epilepsy over time. The results indicated that there was no statistically significant difference in mean knowledge scores between the ESN and Non-ESN respondents at point 1, and this remained the case at the follow-up point, as table 6.21 shows.

Table 6.21: ESN vs Non-ESN PWE knowledge of own epilepsy

| | Point 1 | | Follow-up | |
|---|---|---|---|---|
| | Non-ESN N=13 M(SD) | ESN N=71 M(SD) | Non-ESN N=6 M(SD) | ESN N=39 M(SD) |
| **Knowledge of own epilepsy** | 6.26 (2.36) | 6.54 (2.31) | 7.42 (2.61) | 7.30 (2.07) |
| **Mann Whitney U Test** | U= 406.500, p=.496 | | U=100.500, p=.582 | |

### *Knowledge of Epilepsy Scale*

The knowledge of epilepsy scale, developed by May & Pfafflin (2002), was used to assess newly diagnosed PWEs' knowledge of epilepsy. The scale comprised 19 items with three response categories (Yes/No/Don't know). Correct answers were assigned a score of 1 while incorrect answers or don't know answers were assigned a score of zero. Any missing values were replaced by mean imputation. The sum of correct answers was then calculated and expressed as percentage of all answers (0-100%). The mean score for the whole sample was 58.23 (SD=19.13) at point 1 and 60.49 (SD=19.29) at follow-up. Scores at both time points for matched participants ranged from a minimum of 10.53 to a maximum of 94.74. A paired sample t-test was conducted to determine if there was a statistically significant difference in PWE attending ESN service knowledge of epilepsy across time. There was a slight increase in the mean score from point 1 to follow-up; however, this difference was not statistically significant (table 6.22).

**Table 6.22: Knowledge of epilepsy among PWE in ESN sites over time (n=38) (matched surveys)**

| | Point 1 M (SD) | Follow-up M (SD) | Paired Sample T-test |
|---|---|---|---|
| **Knowledge of epilepsy scale** | 58.34 (20.21) | 59.65 (19.98) | t (37)= -.593, p=.557 |

As there were only 6 PWE in the Non-ESN sites, their knowledge of epilepsy over time was not assessed statistically as the power of the test would have been too low. The rates for overall knowledge score on the scale were M=57.5 (SD=11.08) at the first time point and M=65.79 (SD= 14.41) at the follow-up survey.

The Mann-Whitney U test was performed to examine whether there was a statistically significant difference between PWE under ESN care and those under Non-ESN care in respect of knowledge of epilepsy over time. The results indicated that there was no statistically significant difference in knowledge scores between the ESN and Non-ESN respondents at time point one, and this remained the case at the follow-up point, as table 6.23 shows.

Table 6.23: ESN vs Non-ESN PWE knowledge of epilepsy

| | Point 1 | | Follow-up | |
|---|---|---|---|---|
| | Non-ESN N=13 M(SD) | ESN N=72 M(SD) | Non-ESN N=6 M(SD) | ESN N=38 M(SD) |
| **Knowledge of epilepsy** | 56.09 (15.98) | 56.41 (18.72) | 65.79 (14.41) | 59.65 (19.98) |
| **Mann Whitney U Test** | U= 454.500, p=.869 | | U=98.500, p=.593 | |

### *Quality of life over time*

Quality of life was measured using the Quality Of Life In Epilepsy (QOLIE-10-P) instrument (Cramer *et al.* 1996). A paired sample t-test was conducted to determine if there was a statistically significant difference in the QOLIE-10-P scores over time. The results indicated that there was a statistically significant improvement in quality of life among PWE receiving ESN care from time point 1 to follow-up at time point 2 (table 6.24); however, caution must be used when interpreting these results as the sample size is not large.

Table 6.24: Quality of Life among PWE in ESN sites over time (n=36) (matched surveys)

| | Point 1 M (SD) | Follow-up M (SD) | Paired Sample T-test |
|---|---|---|---|
| **QOLIE-10-P** | 31.86 (22.64) | 42.05 (31.46) | t (35)= -2.069, p=0.046 |

As there were only 6 PWE in the non-ESN sites, their Quality of Life was not assessed statistically as the power of the test would have been too low. The rates for overall QOLIE-10-P were M=17.09 (SD=12.79) at the first time point and M=36.37 (SD= 21.18) at the follow-up survey.

The Mann-Whitney U test was performed to examine whether there was a statistically significant difference between PWE attending ESN services and those attending Non-ESN services in respect of quality of life over time. The results indicated that there was no statistically significant difference in mean QOLIE-10-P scores between the ESN and Non-ESN respondents at time point 1 and this remained the case at follow-up (time point 2), as table 6.25 shows.

Table 6.25: ESN vs Non-ESN quality of life

| | Point 1 | | Follow-up | |
|---|---|---|---|---|
| | Non-ESN N=13 M (SD) | ESN N=68 M (SD) | Non-ESN N=6 M (SD) | ESN N=38 M (SD) |
| **QOLIE-10-P** | 33.25 (25.70) | 37.84 (27.51) | 36.37 (21.18) | 43.11 (30.99) |
| **Mann Whitney U Test** | U=399.000, P=.580 | | U=108.000, P=.837 | |

## Impact of ESN role on healthcare service outcomes

In addition to above results, the service providers interviewed and ESNs also identified a number of key healthcare service outcomes that they attributed to the ESN role. In addition to making more specialist epilepsy services available and accessible, the service providers were of the view that RACs, TALs and conducting triage work in the ED, reduced hospital admissions by making available RACs, TALs and conducting triage work in the ED.

> *"It is sometimes just the patient wanting to talk. And that may escalate to a level where the patient ends up in the ED. But that's prevented by the [TAL] telephone call." (Medical personnel interview)*

> *"There are a certain cohort of PWE that avoid ED by having the nurse specialist, they might have come in [to ED] because they're not feeling well, they've a headache and it's to do with their epilepsy, that can be managed over the phone or managed through their clinic, they [ESNs] fit them in there [rapid access clinic], so they're not admitted." (DoN interview)*

> *"If a kid came into A&E with bad seizures, [ESN] will go down, and she will sort them out, it's sorted. So the neurology registrar, or the neurology SHO, doesn't necessarily have to go down and manage that patient. [ESN] can go down and she will take all of their history, go through everything, make a plan for those PWE, avoid them being admitted, if feasible." (MDT Clinical nurse manager interview)*

> *"Patients who come in through A&E with the presentation of a seizure and maybe if they're an established diagnosis they know that they can call us and we'll liaise then with the registrar, they're not sitting there waiting to see....so it helps the process,*

> *helps the flow, the moving of the patient maybe either way, that they are admitted or hopefully discharged." (Candidate ANP interview)*

> *"People realize that, oh just because I've had a seizure today doesn't mean I have to come to clinic or ED, especially if I live down in [names a town 60 KM away] or somewhere like that, I can ring [TAL]. If a medication needs to be increased we [ESN] can get that arranged over the phone, can monitor them over the phone and then they can come to clinic and we evaluate their progress. So I think it's definitely made neurology very accessible." (Candidate ANP interview)*

The ESNs were of the view that in addition to the TAL and attendance in EDs their prescribing authority and follow-up on PWE admitted to hospital also assisted in reducing number of visits to ED and length of hospital stay.

> *"The service that the epilepsy nurses offer, like the telephone service, the immediate access to the EPR and the fact that you can make medication changes, discuss medication changes with them [PWE] and send them a prescription or get their GP to give them a prescription and provide advice, to GPs and other health care professionals, I think that definitely reduces the amount of attendances at the Emergency Department." (RANP interview)*

> *"When PWE are admitted that there's an epilepsy nurse that can go up [to the ward] and speed them through the hospital that reduces length of [hospital] admission." (RANP interview)*

The speedy access to nurses with specialist knowledge of epilepsy and prescribing authority was also perceived to make a significant contribution to reducing adverse events, such as drug-related events or medication errors.

> *"The information that she has given some of the PWE [pregnant women] within the clinic and subsequently in occasional cases seen them in the home environment in relation to the need to continuing treatment, and to perhaps changing treatment, has prevented some PWE deaths, and has almost certainly prevented some of the babies being on inappropriate medication, well the mum being on inappropriate*

> *medication in pregnancy…So I think [ESN] has prevented death in some PWE who wanted to just stop their medications because they were pregnant, and you know I mean she has made a real impact on this type of risk, getting these women of these medications [sodium valproate] and on to more suitable medications." (Medical personnel interview)*

> *"The core strengths of the role, certainly clients have much more ready access to a clinician [ESN] who can make appropriate treatment decisions for them, if there is a crisis and they [ESNs] are unable to get hold of the consultant. In the bad old days nothing would be done until their next appointment came up, and the epilepsy nurse bridges that gap because that is unacceptable really, that's not safe or appropriate for clients who may have had an exacerbation of seizures, or any of a number of things may have happened, and they need some involvement, some interaction quickly." (Medical personnel interview)*

> *"Becoming a nurse prescriber, being able to adjust these medications, prior to me doing the nurse prescribing, it was a matter of deciding what you wanted to do with a patient and asking a junior doctor to do this, so I always felt it was an extremely unsafe practice…you've one person making a decision and another person writing a script, it's never a good success." (RANP interview)*

> *"[PWE are] getting side-effects from medication, they don't have to sit there in the community waiting for their appointment... They can actually ring the epilepsy nurse, I can actually see the patient an awful lot sooner. And they don't have to suffer with unnecessary side-effects." (Candidate ANP interview)*

Another key outcome identified was the reduction of burden on patients and families. By decentralising services and localising VNS clinics and TALs, as well as having outreach services, many PWE and their families did not have to travel large distances to services. This was especially important for PWE who were restricted in terms of transport, physical disability or significant intellectual disability.

> *"We are able to access information over the phone and have contact with the doctors, through nurses that know what they are talking about [it] means we have*

> *less trips to the hospital. Yes, we do go at least once, if not twice, a year with most people…they would fast-track it for us, and there is very little waiting time." (Allied health professional interview)*
>
> *"[The VNS clinic] is a great service, it has made a difference for families and PWE as well, travelling, so it's local and they don't have the big journeys… because PWE used to have to travel to Dublin before this.." (Candidate ANP interview)*
>
> *"[The Outreach service] has been extremely positive for the residents [ID], particularly for some of our residents who may find it difficult to travel for one reason or another. Or to sit in an outpatients department for two hours, remember we are a little bit outside of Dublin. So by the time you get there, you're probably looking at, you're looking an hour, an hour and a half. Both ways and then an extended waiting period in an outpatients department." (Medical personnel interview)*
>
> *"[Telephone advice line] reduced the amount of people needing to come to out-PWE…they don't have to travel…a lot of epilepsy PWE that can't drive so it's a lot of hassle for them, they need to get somebody to come with them, they need to have a day off work, they need to, safety, travelling, if they're having increased seizures and stuff, they're on a bus on their own, so it saves that. The [ESN] will go through the problem on the phone if they can and certainly won't put an unnecessary journey on the patient if they can avoid it." (DoN interview)*

In addition, ESNs were also observed to be reducing burden through the prioritisation of people with ID when they visited clinics. As these PWE and their families were well known to the ESNs they were in a position to ensure that they were provided with an appointment time at the beginning of the clinic, or in the case of surgery for VNS insertion they were put first on the surgery list.

> *[ESNs] decide to have the VNS clinic for people with ID at the beginning of the general epilepsy clinic to minimize travel for PWE. As a consultant is present for the epilepsy clinic and if patient coming to the VNS clinic require a medication review that requires consultant input it can happen on same visit. Thus PWE and families*

> *are saved from having to have 2 separate visits, and having to take extra time off [work]. (CNS observation)*

The final service outcome identified was greater efficiency in the use of resources. The ESNs were of the view that they contributed in no small way to making it a more efficient service and reducing cost.

> *"Well I think, your NCHDs at this hospital would be working a whole lot harder and that wouldn't be in keeping with the European directive. And I think the organisation would have to pay our NCHDs a whole lot more money, to stay within the European directorate. So really the big thing would be cost implications, that's the biggest thing, our salary is cheap." (RANP interview)*

> *"With the clinic, generally we've estimated that I've slashed the day by an hour and half because I'm seeing patients and letting them go. So if you're seeing five patients that's five less that need to go in to see the consultant, so you are reducing the overall day. When you do see patients and the consultant needs to see them you are shortening the consultant's time to come in because you've done a lot of the background, an extensive clinical exam, clinical history, you've done education with the parents, you've done the questions and answers." (Candidate ANP interview)*

> *"By bringing one patient up [from ID service outside Dublin], I think it costs them something like, in around 500 euros for one outpatient clinic visit… from a hospital perspective it means that it [outreach clinic] freed up more slots… I save the hospital these slots, a new hospital slot is 45 minutes, a return visit is 30 minutes, so I've saved all those slots every time, so 16 slots, 4 times a year. And that's just for the outreach clinic in [name of ID services]." (Candidate ANP interview)*

> *"Epilepsy nurses are very prudent and, what's the word, you know, they know what investigations need to be ordered. There's a much less risk that inappropriate investigations are going to be ordered by the epilepsy nurses because it's very specific what investigations you'd order." (RANP interview)*

These qualitative comments on the efficient use of resources were also reflected in the survey data on first point of contact for information. The first contact person for most participants from the Non-ESN sites was a doctor (n= 152, 65%), either the doctor or neurologist at the hospital (n= 77, 32.9%) or the GP (n=75, 32.1%), whereas the first point of contact for most PWE attending ESN sites was the ESN (n= 111, 51.2%). Table 6.26 provides information on the first person of contact.

**Table 6.26: The first contact person for information**

| | Non-ESN (n=259) n (%) | ESN (n=222) n (%) |
|---|---|---|
| Epilepsy Specialist Nurse | 0 (0%) | 111 (51.2%) |
| Another type of nurse | 28 (12%) | 1 (0.5%) |
| Doctor/ Neurologist at hospital / clinic | 77 (32.9%) | 30 (13.8%) |
| GP | 75 (32.1%) | 46 (21.2%) |
| Pharmacist | 5 (2.1%) | 0 (0%) |
| Epilepsy Ireland | 18 (7.7%) | 2 (0.9%) |
| Internet | 19 (8.1%) | 18 (8.3%) |
| Other | 12 (5.2%) | 9 (4.2%) |

## Discussion

Despite research which demonstrates that effective education is central to empowering people to deal with their diagnosis, improve compliance, make informed decisions, self-manage their own condition as well as improving psychosocial outcomes and quality of life (Helde *et al.* 2003; Doughty *et al*. 2003), several studies have found that knowledge of epilepsy is lacking among people with epilepsy (Goldstein *et al*. 1997; Long *et al.* 2000; Meads *et al.* 2002; Helde *et al.* 2003; May & Pfäfflin 2005). Whilst there is no convincing evidence that specialist epilepsy nurses can improve overall outcomes for PWE (Bradley and Lindsay 2008), it is accepted that such roles can support and improve patient knowledge (Kendall *et al.* 2004). Ridsdale *et al.* (1997) reported higher levels of information on epilepsy-related issues being given by ESNs in nurse-run clinics compared to the standard care process, with other studies reporting positive impact on knowledge in relation to medical, social and safety aspects of epilepsy (Ridsdale *et al.* 2002; Noble *et al.* 2013). Data from the **SEN**s**E** study does not support the belief that ESNs make a difference to education on all medical aspects of epilepsy, as no difference was found 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. These findings are not surprising as irrespective of whether PWE are attending a site with or without an ESN they are under the care of a neurologist with expertise in the medical aspects of epilepsy. The added value of the ESN role appears to be in the contribution they make to the information provided on the social, safety and health aspects of epilepsy, including how to recognize and manage side-effects of medication, areas reported by other researchers as part of the ESN role (Taylor *et al.* 1994; Ridsdale *et al.* 1999a; Ridsdale *et al*. 2002) and areas that are central to self-management. Indeed, ESNs were regarded by PWE, their families and members of the MDT as being very knowledgeable sources of information, with well-honed educational skills and the ability to bring clarity to aspects of diagnosis and treatment as well as dispel misconceptions and misinformation. However, it must be noted that the mean scores within the ESN sites for all items on information provided ranged between 3.5 and 4.5 out of a total of 5, indicating that there is still room for improvement, particularly in relation to information provided on issues such as disclosure to others, employment, and seizure diaries. The impact of the information provided by the ESNs on knowledge outcomes is harder to assert, due to the small sample size that completed the survey designed to measure changes in knowledge over time. Although there is some evidence that PWE attending ESN sites improved their knowledge of epilepsy across time, statistically significant differences in knowledge scores between PWE attending ESN and Non-ESN sites were not observed.

In addition to ESNs impacting on the type of information provided, findings indicate that PWE who attend sites with ESNs report a greater sense of involvement in care, with a greater proportion of PWE who attended an ESN site agreeing or strongly agreeing that they were given the opportunity to ask questions; given enough time to discuss worries; were involved in decision-making; and had their wishes and needs taken into account. These outcomes on PWEs' sense of involvement are important, as studies indicate that people with chronic medical conditions who are involved in their own care and included in decision-making feel better equipped to self-manage their condition (Kirton *et al.* 2012). While the finding in relation to involvement in care possibly reflects the longer duration of consultations with the ESNs, a finding reported previously (Ridsdale *et al.* 1999b; Mills *et al*. 2002; Kirton *et al.* 2012), it is without doubt also related to the ESNs' communication, caring and empathy skills. While there was a high level of trust among PWE in the ESN and Non-ESN sites in relation to advice given, a greater proportion of PWE reported comfort in talking to the ESN about their concerns, including sexual concerns, and confidence in the ESN to provide the care they needed. The qualitative data suggest that it is a combination of the ESNs' clinical expertise in epilepsy, and their interpersonal competence and compassion, combined with their genuine interest in the person's biography and life context that instilled confidence and trust among PWE and their families.

Previous studies into the role of the ESN also reported benefits to continuity of care (Scrambler *et al.* 1996; Sarkissian & Wennberg 1999; Mills *et al.* 2002; Kirton *et al*. 2012) and co-ordination of care (Taylor *et al.* 1994; Kirton *et al.* 2012; Noble *et al.* 2013). In relation to continuity of care there were no statistically significant differences between Non-ESN sites and ESN sites in relation to whether PWE had to explain their epilepsy repeatedly, or in the consistency of the information received from their healthcare team. However, a higher proportion of PWE attending Non-ESN sites agreed that they meet the same practitioner on each visit, a finding that is not surprising given that the teams in the Non-ESN site mainly consist of the medical consultant. In relation to co-ordination of care, whilst there was no statistically significant difference between ESN sites and Non-ESN sites on whether care was delivered in a planned and co-ordinated manner or whether there was good follow-up after appointments, however, a greater proportion of PWE attending ESN sites agreed that waiting times were reasonable and making appointments was easy, findings which were statistically significant.

Whilst the findings from the study did not reveal any difference in QoL scores between the ESN and Non-ESN sites, findings did indicate that PWE who attend sites with ESNs reported higher satisfaction with the practical support and emotional support offered. While ESNs did not impact on quality of life as measured by the QOLIE-10-P instrument, qualitative data did indicate that by decentralising services, the ESNs impacted positively on PWE and family burden. Not only did the TAL provide PWE and families with efficient and easy access to support and information, the service also reduces the number of people that may have accessed emergency or other face to face services. In addition, by localising VNS clinics as well as having outreach services, both travel time and distance was reduced, which was especially important for PWE who were dependent on others in terms of transport.

Similar to other studies (Warren 1998; Hopkins *et al.* 2010) findings from the **SEN**s**E** study also indicate that ESNs impact on other service outcomes, such as the efficient use of resources including demands on medical time. First, ESNs absorb some of the roles that were traditionally the remit of the medical consultant, such as completing clinical assessments, medication management (reviewing, titrating, or changing medication), ordering tests and investigations, and reviewing patients at clinics and in A&E, with potential for cost savings. Second, in addition to freeing up consultants' time by assuming these roles and improving patient flow, they are also the first point of contact within the service for PWE and family members, again reducing the time medical personnel spend on dealing with issues. Third, by decentralising services and developing outreach services for people with ID they are reducing the financial cost (travel and pay) incurred by ID services' associate staff taking time away to accompany the person to a hospital appointment. In addition, and similar to Hopkins *et al.* (2010) and Hopkins and Irvine (2012) findings, the proactive and responsive style of the ESNs means that they are constantly seeking to prevent problems developing or exacerbating by intervening in a timely and prompt manner, thus reducing long-term problems.

## Chapter 7

# Findings from Economic Analysis

# Chapter 7: Findings from Economic Analysis

## Introduction

This chapter provides an economic analysis of data from the **SENsE** study. The aim of this analysis was to compare the costs of clinical activity and the monetary impact on patients with epilepsy and their families. The chapter begins by discussing the overall methodology adopted for this analysis and follows with a discussion on the calculation of unit costs. Cost and utilisation data are presented based on the original dataset with patterns of service use analysed. An analysis of high cost patients and their impact on the difference in cost between ESN and Non-ESN sites is examined.

## Methodology

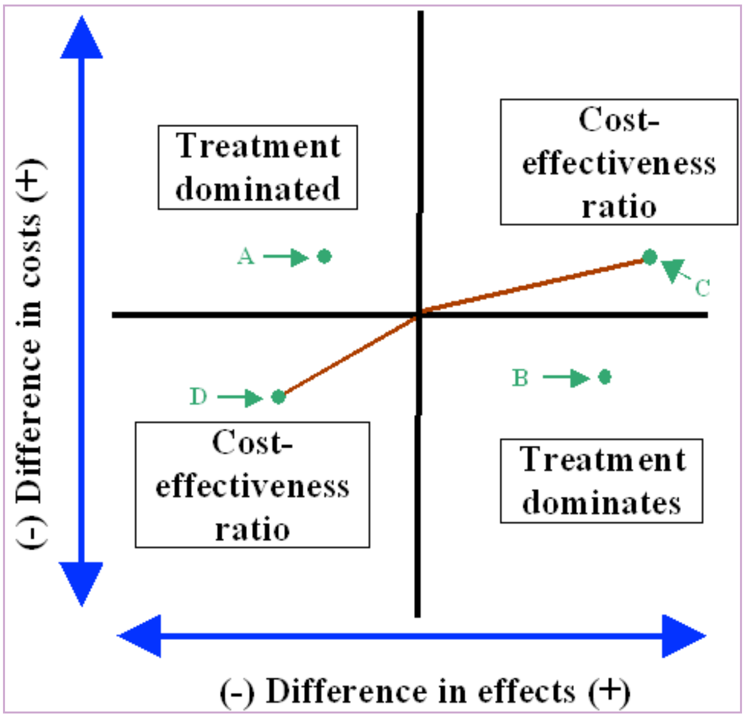
Initially, this study aimed to collect cost data based on budgets and expenditure at different hospitals. However, it was not possible to capture financial data on epilepsy services from individual hospitals, as budgets in some hospitals were not allocated specifically to Neurology or to the epilepsy service. In particular, the aim of the economic analysis was to compare the differences in resource use among patients who attended a hospital with an ESN with patients who attended a hospital without access to an ESN to manage their epilepsy.

Considering this issue, it was decided to collect utilisation data at the patient level by adding relevant questions to the main **SENsE** survey for return patients. Questions related to Emergency Department attendance, nights spent in hospital for epilepsy, outpatient visits and GP visits, as well as time spent off work by patients and their carers.

Where possible, the study adopted a bottom-up approach to generating the cost estimates whereby utilisation of specific services (e.g., number of GP visits in the last 12 months) was multiplied by relevant unit costs (e.g., cost per GP visit). Unit costs were multiplied by the utilisation data in order to generate an average cost per patient and a total cost per patient in ESN sites and Non-ESN sites.

Cost-effectiveness derives from the analysis of economic efficiency, where one alternative is preferred to another if it provides greater benefit at the same or lower cost, or lower cost for the same or greater benefit. The concept of cost-effectiveness is illustrated graphically on the cost-effectiveness plane in Figure 7.1. Strategies are represented according to their effectiveness (e) and cost (c) relative to those of some reference standard (Black 1990). Incremental Cost Effectiveness Ratios (ICERs) are presented graphically as a combination of the costs and the effects of a health intervention, described in the diagram below as a treatment, compared to some alternative. Costs are conventionally placed on the north-south axis and effects on the east-west axis. In both cases, these effects can be negative, zero or positive.

**Figure 7.1: Cost-effectiveness plane (Black, 1990)**



Although this study did not seek to generate an efficiency frontier or ICERs on the cost-effectiveness plane (see figure 7.1), it considered, based on all of the evidence from the research study, whether the addition of ESNs in each service provided additional benefit taking into account the investment of the ESN posts by the National Clinical Programme for Epilepsy.

## Data analysis

For each patient who answered the return patient **SENsE** survey, utilisation of services was multiplied by the unit cost for each service.

Equation 1 illustrates the method, taking the example of GP costs:

GP cost, i, = GP unit x GP use, i, (1)

Where GP cost, i, 3 refers to the total cost of GP care for patient *i* in the last 12 months, GP unit refers to the unit cost per GP visit and GP use, i, 3 refers to the number of GP visits for the patient *i*. This method is repeated for utilisation of other services and time spent off work/college/study related to epilepsy as a patient or their carer.

The total cost of care for each individual was obtained using equation 2:

Total cost, i, = GP cost, i, + ED cost, i, + ... + Informal cost, i, (2)

Where Total cost, i, 3 refers to the total cost of direct and indirect care received by patient *i* in the last 12 months, ED refers to Emergency Department attendances, and so on to include all services.

Data were initially analysed in SPSS, but later transferred to Microsoft Excel to allow analysis of the costs for each type of healthcare utilisation and indirect costs. Total costs per site and per patient for each type of utilisation were calculated and a cost per patient was estimated.

The following section outlines the unit cost estimates for each service. The methodology for calculating each unit cost is discussed in detail[3].

### *Emergency Department attendances*

The unit cost of a public emergency department (ED) attendance was calculated by dividing total public hospital ED expenditure for non-admitted ED attendances by the total number of non-admitted ED attendances in the Republic of Ireland in 2011. These data were available from the HSE National Case-mix Programme Ready Reckoner 2013[4]. The unit cost was calculated at €268 per attendance.

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[3] Unit cost data and methodology from the Economic Evaluation of Palliative Care in Ireland study was utilised in this study.

[4] Health Service Executive (2013) Ready Reckoner of Acute Hospital Inpatient and Day Case Activity & Costs (Summarised by DRG) Relating to 2011 Costs and Activity. National Casemix Programme.

### *Admissions to hospital*

Aggregate national HIPE data on In-patient admissions to hospital for epilepsy-related cases was requested from HIPE. The average cost per epilepsy-related case was €4,636. A cost per bed night of €467 was calculated based on the average length of stay across all epilepsy-related cases. Data on the number of nights spent in hospital in the last year was requested in the survey.

### *Outpatient visits*

The unit cost for a public outpatient department (OPD) specialist visit was first calculated by dividing the total public hospital OPD expenditure by the total number of OPD attendances in 2011. These data were available from the HSE. This resulted in a cost of €130 per visit. However, following discussion with consultant neurologists regarding the intensive treatment provided at an epilepsy outpatient appointment, it was decided that this cost may underestimate the true cost of providing the service.

The cost of an outpatient visit to manage a patient with epilepsy was provided by Site C at €149 based on 1,640 OPD attendances in 2013 and a total cost of running the outpatient clinics of €244,360.

### *GP visits*

GP costs were calculated for public (medical card) patients[5]. Utilisation data were obtained from the Quarterly National Household Survey (2010), a large-scale, nationwide survey of households. The average number of GP consultations for medical card holders was 5.4 for those over 18 years in the last 12 months. Using the PCRS (2012) average payment to GPs per eligible person of €257.93, a unit cost of €48 per GP visit by a medical card holder was calculated.

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[5] It is noted, however, that not all patients with epilepsy qualify for a medical card in Ireland, which entitles holders to free GP visits among other entitlements. A price survey was conducted in 2008 by The Competition Authority, which revealed the cost of GP visits at approximately €50-€55 in urban areas, with slightly lower charges in rural areas. This survey was based on fees charged by 51 GPs in rural and urban locations throughout Ireland. Another report suggests that the charge for a visit ranges from €45-€60 (DOHC 2010). It is acknowledged that the cost of €48 utilised in this study may be slightly lower than other estimates for private GP visits.

### *Indirect costs*

Indirect costs for both patients and informal carers such as relatives or friends were calculated based on the CSO average weekly earnings of €689.88 in Q1 2014[6]. Based on an average of 220 working days per year, the cost per day was calculated as €163 per day. The 220 working days is based on the total number of working days per year of 260 minus nine public bank holidays and minus 22 days annual leave and nine sick days (based on 3.5% sick leave rate).

## Sample

In total, there were three hospital sites with an ESN (Hospital A, Hospital B and Hospital C) and five hospital sites without an ESN (Hospital F, Hospital G, Hospital H, Hospital I, and Hospital J) included in this analysis.

The overall sample of 505 participants included 16 responses with entirely missing data from all cost questions; these were removed from the database. This left a total number of participants in the ESN sites of 242 and 247 in Non-ESN sites. The breakdown for each site of missing responses removed from the data is shown in table 7.1.

**Table 7.1: Sample**

| Site Code | Total Participants | No. Missing | Total excl. missing |
|---|---|---|---|
| **ESN Sites** | | | |
| A | 85 | 2 | 83 |
| B | 96 | 0 | 96 |
| C | 63 | 0 | 63 |
| **Total** | **244** | **2** | **242** |
| **Non-ESN Sites** | | | |
| F | 26 | 4 | 22 |
| G | 96 | 3 | 93 |
| H | 28 | 3 | 25 |
| I | 103 | 3 | 100 |
| J | 8 | 1 | 7 |
| **Total** | **261** | **14** | **247** |

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[6] http://www.cso.ie/en/releasesandpublications/er/elcq/earningsandlabourcostsq42013finalq12014preliminaryestimates/

## Finding from data analysis

The following section describes the utilisation and costs associated with Emergency Department attendances, admissions to hospital – planned and unplanned nights spent in hospital, Outpatient visits, GP visits and time spent off work/college/school for patients with epilepsy for a period of 12 months. For each site, the frequency for each type of healthcare utilisation is outlined and the total cost per patient is displayed.

### *Emergency Department utilisation and costs*

The number of Emergency Department attendances is largely similar between the ESN sites, average of 0.8 per patient (range: 0.7-0.9), and the Non-ESN sites with an average 0.6 attendances (range: 0.2-1.3); the cost per patient is €215 in ESN sites compared to €166 in the Non-ESN sites (table 7.2). At this point, we note that cost per patient in Site I is comparatively lower than both other Non-ESN sites and average costs in ESN sites.

**Table 7.2: Emergency Department (ED) utilisation & costs by site**

| Site Code | Participants | Avg no. per patient | ED cost per patient |
|---|---|---|---|
| A | 83 | 0.8 | €223 |
| B | 96 | 0.9 | €232 |
| C | 63 | 0.7 | €179 |
| **Total ESN** | **242** | **0.8** | **€215** |
| F | 22 | 1.0 | €256 |
| G | 93 | 0.8 | €219 |
| H | 25 | 1.3 | €343 |
| I | 100 | 0.2 | €48 |
| J | 7 | 0.9 | €230 |
| **Total Non-ESN** | **247** | **0.6** | **€166** |

A t-test shows that these differences in Emergency Department costs are not statistically significant between ESN and Non-ESN sites (table 7.3).

**Table 7.3**: **Emergency Department cost t-test: Two-sample assuming unequal variances**

| | ESN | Non-ESN |
|---|---|---|
| Mean | 214.843 | 166.0081 |
| Variance | 380422.6 | 177582.4 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 | |
| df | 425 | |
| t Stat | 1.020287 | |
| P(T<=t) one-tail | 0.154087 | |
| t Critical one-tail | 1.648447 | |
| P(T<=t) two-tail | 0.308173 | |
| t Critical two-tail | 1.965561 | |

## *Number of nights spent in hospital and costs*

### Unplanned nights in hospital

This section outlines the number of unplanned and planned nights spent in hospital related to epilepsy in the last 12 months per patient and the associated costs. In terms of unplanned nights, the average number per patient in ESN sites was 1.1 (range: 0.5-1.6) with the average cost per patient over the 12 months of €523 in ESN sites (range: €252-€748) and lower at 0.7 nights (range: 0.2-1.9) per patient in Non-ESN sites with a cost of €316 (range €75-€867) (table 7.4).

### Planned nights in hospital

The total number of planned nights was largely similar between the ESN sites (107 nights, 0.4 nights per patient) and the Non-ESN sites (119 nights – 0.5 nights per patient), with a slightly greater number of nights per patient in Non-ESN sites. Likewise, the average cost per patient was €206 (range: €56-€379) for the ESN sites and €225 (range: €0-€542) for the Non-ESN sites.

Overall, the total cost for nights spent in hospital is higher in ESN sites at €729 (range: €393-€885) compared with Non-ESN sites at €541 (range: €122-€1,069) (table 7.4).

We note that the utilisation in Site I is comparatively lower for unplanned nights in hospital which may reflect a lower complexity of patients.

**Table 7.4: No. of nights spent in hospital & costs**

| Site Code | No. unplanned per patient | Un/p cost per patient | No. planned per patient | Planned cost per patient | Total cost nights in hospital |
|---|---|---|---|---|---|
| A | 1.6 | €748 | 0.1 | €56 | €804 |
| B | 1.1 | €506 | 0.8 | €379 | €885 |
| C | 0.5 | €252 | 0.3 | €141 | €393 |
| **Total ESN** | **1.1** | **€523** | **0.4** | **€206** | **€729** |
| F | 0.8 | €382 | 0 | €21 | €403 |
| G | 1.1 | €527 | 1.2 | €542 | €1,069 |
| H | 0.6 | €280 | 0 | €0 | €280 |
| I | 0.2 | €75 | 0.1 | €47 | €122 |
| J | 1.9 | €867 | 0 | €0 | €867 |
| **Total Non-ESN** | **0.7** | **€316** | **0.5** | **€225** | **€541** |

Tables 7.5 & 7.6 outline the results of the t-test, showing that the differences in cost for both unplanned and planned nights are not statistically significant.

**Table 7.5: Unplanned nights in hospital cost t-test: Two-sample assuming unequal variances**

|  | ESN | Non-ESN |
|---|---|---|
| Mean | 522.9628 | 315.7449 |
| Variance | 3094443 | 1959334 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 |  |
| df | 460 |  |
| t Stat | 1.439587 |  |
| P(T<=t) one-tail | 0.075332 |  |
| t Critical one-tail | 1.648173 |  |
| P(T<=t) two-tail | 0.150665 |  |
| t Critical two-tail | 1.965134 |  |

**Table 7.6: Planned nights in hospital cost t-test: Two-sample assuming unequal variances**

|  | ESN | Non-ESN |
|---|---|---|
| Mean | 206.4835 | 224.9919 |
| Variance | 676609.9 | 3824242 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 |  |
| df | 332 |  |
| t Stat | -0.1369 |  |
| P(T<=t) one-tail | 0.445597 |  |
| t Critical one-tail | 1.649456 |  |
| P(T<=t) two-tail | 0.891194 |  |
| t Critical two-tail | 1.967135 |  |

### *Outpatient utilisation and costs*

Outpatient attendances were higher in ESN sites (average 2.1 attendances per patient) compared to Non-ESN sites (averages 1.7 attendances per patient), which is not surprising considering the extra management of epilepsy patients which is provided by ESNs in the extended model of care. The average cost per patient was €307 (range: €262-354) in the ESN sites versus €256 (range: €106-357) in Non-ESN sites (table 7.7).

**Table 7.7: Outpatient utilisation & costs**

| Site Code | Participants | Avg. OPD attendances per patient | OPD cost per patient |
|---|---|---|---|
| A | 83 | 2.4 | €354 |
| B | 96 | 1.8 | €262 |
| C | 63 | 2.1 | €315 |
| **Total ESN** | **242** | **2.1** | **€307** |
| F | 22 | 2.0 | €305 |
| G | 93 | 2.4 | €357 |
| H | 25 | 1.4 | €203 |
| I | 100 | 1.2 | €176 |
| J | 7 | 0.7 | €106 |
| **Total Non-ESN** | **247** | **1.7** | **€256** |

The results of the t-test (see table 7.8) show that the differences in cost are statistically different (p=0.03).

**Table 7.8: Outpatient cost t-test: Two-sample assuming unequal variances**

| | ESN | Non-ESN |
|---|---|---|
| Mean | 307.2355 | 256.3765 |
| Variance | 85125.66 | 54665.42 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 | |
| df | 461 | |
| t Stat | 2.124524 | |
| P(T<=t) one-tail | 0.017079 | |
| t Critical one-tail | 1.648166 | |
| P(T<=t) two-tail | 0.034158 | |
| t Critical two-tail | 1.965123 | |

### *GP utilisation and costs*

There were fewer GP visits for PWE treated with an ESN for their epilepsy, with an average of 2.6 visits per year (range: 1.5-4.1 visits), compared to 3.1 visits (range: 0.6-3.9

visits) for patients in the Non-ESN sites. Likewise, the average cost per PWE is lower in the ESN sites at €123 (range: €73-€196) versus €149 (range: €77-€189) in the Non-ESN sites (table 7.9).

**Table 7.9: GP utilisation & costs**

| Site | Participants | Avg. GP visits per patient | GP cost per patient |
|---|---|---|---|
| A | 83 | 1.5 | €73 |
| B | 96 | 2.5 | €119 |
| C | 63 | 4.1 | €196 |
| **Total ESN** | **242** | **2.6** | **€123** |
| F | 22 | 3.6 | €175 |
| G | 93 | 3.9 | €189 |
| H | 25 | 1.6 | €77 |
| I | 100 | 2.7 | €132 |
| J | 7 | 0.6 | €27 |
| **Total Non-ESN** | **247** | **3.1** | **€149** |

Table 7.10 shows that the differences in costs for GP visits are not statistically significant.

**Table 7.10: GP cost t-test: Two-sample assuming unequal variances**

| | ESN | Non-ESN |
|---|---|---|
| Mean | 123.1736 | 148.664 |
| Variance | 73302.02 | 96128.01 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 | |
| df | 481 | |
| t Stat | -0.96894 | |
| P(T<=t) one-tail | 0.166531 | |
| t Critical one-tail | 1.648028 | |
| P(T<=t) two-tail | 0.333061 | |
| t Critical two-tail | 1.964908 | |

### *Indirect costs*

This section analyses the indirect costs associated with having a diagnosis of epilepsy in terms of time spent off work/school/college due to the illness, both by the patient and by any relative or friend that cared for them in the last 12 months.

In terms of the number of days PWE spent off work/school/college related to their epilepsy, the results are the same at 7 days per patient, with similar associated costs at €1,109 in ESN sites (range: €424 - €1,759) and Non-ESN sites at €1,110 (range: €652-

€3,793). Although it is noted that the range for Non-ESN sites is higher as the per patient cost for one site is €3,793, which is driven by one PWE who was off work every day for the full 12 months.

The largest differential is observed for the time spent off work by relatives/friends, with ESN sites showing higher costs, with an average of €787 per PWE (range: €572 to €927) compared to €203 in the Non-ESN sites (range: €0 to €354). However, it must be noted that much of this difference is driven by a very small number of PWE, who are off work for an extended period relative to other PWE.

**Table 7.11: Indirect costs**

| Site Code | Avg. days off per patient | Per patient indirect cost | Avg. days off per relative/friend | Relative indirect per patient | Total indirect cost |
|---|---|---|---|---|---|
| A | 3 | €424 | 6 | €927 | €1,351 |
| B | 8 | €1,273 | 5 | €808 | €2,081 |
| C | 11 | €1,759 | 4 | €572 | €2,331 |
| **Total ESN** | **7** | **€1,109** | **5** | **€787** | **€1,896** |
| F | 23 | €3,793 | 2 | €259 | €4,052 |
| G | 5 | €797 | 2 | €354 | €1,151 |
| H | 5 | €835 | 0 | €0 | €835 |
| I | 6 | €911 | 1 | €106 | €1,017 |
| J | 4 | €652 | 1 | €116 | €768 |
| **Total Non-ESN** | **7** | **€1,110** | **1** | **€203** | **€1,313** |

The following tables outline the results of the t-tests for the differences in indirect costs for patients and their relatives, showing that the differences in costs are not statistically significant (tables 7.12 & 7.13).

Table 7.12: Indirect patient cost t-test: Two-sample assuming unequal variances

| | ESN | Non-ESN |
|---|---|---|
| Mean | 1108.669 | 1109.984 |
| Variance | 34468535 | 35011252 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 | |
| df | 487 | |
| t Stat | -0.00247 | |
| P(T<=t) one-tail | 0.499017 | |
| t Critical one-tail | 1.647989 | |
| P(T<=t) two-tail | 0.998034 | |
| t Critical two-tail | 1.964847 | |

Table 7.13: Relative indirect cost t-test: Two-sample assuming unequal variances

| | ESN | Non-ESN |
|---|---|---|
| Mean | 787.3843 | 202.5951 |
| Variance | 24706310 | 590072.1 |
| Observations | 242 | 247 |
| Hypothesized Mean Difference | 0 | |
| df | 252 | |
| t Stat | 1.809174 | |
| P(T<=t) one-tail | 0.035808 | |
| t Critical one-tail | 1.650923 | |
| P(T<=t) two-tail | 0.071616 | |
| t Critical two-tail | 1.969422 | |

### *Healthcare cost per patient*

The following table outlines the cost per patient for each type of healthcare utilisation collected as part of the economic analysis including Emergency Department (ED) visits, Unplanned and Planned nights in hospital, OPD attendance, and GP visits. Overall, the total healthcare utilisation cost per patient is higher in ESN sites at €1,375, compared to Non-ESN sites at €1,112 per patient. In particular, the ED cost per patient is €215 in ESN sites, while it is €166 in Non-ESN sites. The cost per patient for unplanned nights spent in hospital is higher in ESN sites at €523 compared to Non-ESN sites at €316 (tables 7.14 & 7.15).

Table 7.14: Hospital cost per patient

| | ED cost per patient | Un/p cost | Plan cost per patient | OPD cost per patient | GP cost per patient | Total medical cost |
|---|---|---|---|---|---|---|
| **Total ESN** | €215 | €523 | €206 | €307 | €123 | €1,375 |
| **Total Non-ESN** | €166 | €316 | €225 | €256 | €149 | €1,112 |

### *Total medical and indirect costs per patient*

This section analyses the total medical and indirect costs and per patient costs for each site. Overall, the average cost per patient for both medical costs and indirect costs in ESN sites is €3,271 (range: €2,806-€3,580), while it is €2,424 (range: €1,494-€5,191) in Non-ESN sites.

The average medical cost per patient is €1,375 (range: €1,082-1,498) in ESN sites and €1,112 (€477-€1,835) in Non-ESN sites. It is noted that Site I's medical costs are substantially lower than the other Non-ESN sites – the impact of removing Site I patients from the dataset in terms of overall average costs will be discussed in a later section. In terms of indirect costs, the total indirect cost per patient cost is higher in ESN sites at €1,896 (range: €1,351-€2,331) compared to €1,313 in Non-ESN sites (range: €768-€4,053).

Table 7.15: Total medical and indirect costs per patient by site

| | Total per patient | Medical per patient | Indirect per patient |
|---|---|---|---|
| A | €2,805 | €1,454 | €1,351 |
| B | €3,580 | €1,498 | €2,082 |
| C | €3,413 | €1,082 | €2,331 |
| **Total ESN** | **€3,271** | **€1,375** | **€1,896** |
| F | €5,191 | €1,138 | €4,053 |
| G | €2,987 | €1,835 | €1,152 |
| H | €1,738 | €903 | €835 |
| I | €1,494 | €477 | €1,017 |
| J | €1,999 | €1,231 | €768 |
| **Total Non-ESN** | **€2,425** | **€1,112** | **€1,313** |

In relation to the total per patient indirect costs, the average indirect cost associated with time spent off work/school/college for patients was the same at €1,109 in ESN sites and €1,110 in Non-ESN sites. However, the difference was evident for the relative indirect cost per patient at €787 in ESN sites and €203 in Non-ESN sites. Overall, the total cost per patient (patient + relative) was €1,896 in ESN sites and €1,313 in Non-ESN sites (table 7.16).

Table 7.16: Total indirect cost per patient by site

| | Per patient indirect cost | Relative indirect per patient | Total indirect cost |
|---|---|---|---|
| **Total ESN** | €1,109 | €787 | €1,896 |
| **Total Non-ESN** | €1,110 | €203 | €1,313 |

Taken together, the overall average cost per patient for ESN and Non-ESN sites is shown in table 7.17. Adding the total medical per patient cost to the total indirect cost results in a figure of €3,271 for patients in ESN sites compared to €2,424 in Non-ESN sites.

Table 7.17: Total direct and indirect costs by site

| | Total medical cost | Total indirect cost | Total direct & indirect costs |
|---|---|---|---|
| **Total ESN** | €1,375 | €1,896 | €3,271 |
| **Total Non-ESN** | €1,112 | €1,313 | €2,424 |

### *Analysis of high cost epilepsy patients*

The removal of the high cost patients shows the interaction with the complexity and case mix among patients, which is not accounted for in this data. The following section describes an analysis of the data with high cost patients removed, beginning with those patients whose total direct and indirect cost totalled over €5,000; over €10,000; over €15,000; and over €20,000. It is evident from table 7.18 that the greatest number of high cost epilepsy patients (over €5,000) are predominately in the ESN sites (N=30) compared to the Non-ESN sites (N=19), which was anticipated as the patterns of service use and associated costs in the previous results are in line with this finding.

Table 7.18: High cost patients

| | Over €20,000 | Over €15,000 | Over €10,000 | Over €5,000 |
|---|---|---|---|---|
| A | 1 | 2 | 4 | 11 |
| B | 2 | 6 | 8 | 13 |
| C | 3 | 3 | 3 | 6 |
| **Total ESN** | **6** | **11** | **15** | **30** |
| F | 1 | 2 | 2 | 4 |
| G | 3 | 3 | 3 | 8 |
| H | 0 | 1 | 1 | 2 |
| I | 1 | 1 | 1 | 4 |
| J | 0 | 0 | 0 | 1 |
| **Total Non-ESN** | **5** | **7** | **7** | **19** |

### Costs with patients over €20,000 removed

Once patients whose total costs are €20,000 or over are removed from the dataset, who represent the most complex patients in terms of cost, the medical costs per patient are higher in ESN sites (€1,651) than Non-ESN (€981) sites. All healthcare costs are higher in the ESN sites with the exception of costs associated with GP visits (table 7.19)

Table 7.19: Total healthcare costs with patients over €20,000 removed

| | ED cost | Un/p cost | Plan cost | OPD cost | GP cost | Total healthcare cost |
|---|---|---|---|---|---|---|
| **ESN** | €231 | €625 | €252 | €401 | €142 | €1,651 |
| **Non-ESN** | €185 | €279 | €60 | €287 | €170 | €981 |

The indirect costs per patient for the ESN group are lower (€942) than the Non-ESN group (€1,052) (table 7.20)

Table 7.20: Total indirect costs with patients over €20,000 removed

| | Patient indirect cost | Relative indirect cost | Total indirect cost |
|---|---|---|---|
| **ESN** | €612 | €330 | €942 |
| **Non-ESN** | €863 | €189 | €1,052 |

The total costs per patient for the ESN sites were €2,593 and €2,033 for the Non-ESN sites (table 7.21).

**Table 7.21: Total costs per patient with patients over €20,000 removed**

| | Total medical | Total indirect | Total per patient |
|---|---|---|---|
| **ESN** | €1,651 | €942 | €2,593 |
| **Non-ESN** | €981 | €1052 | €2,033 |

### Costs with patients over €15,000 removed

Once all the patients whose total costs are over €15,000 are removed from the dataset, the medical costs per patient are higher in ESN sites (€1,416) than Non-ESN (€946) sites (table 7.22). While the indirect costs for the ESN group are largely the same (€612) as the Non-ESN group (€609), although patients in the ESN sites had more care provided by relatives/friends (table 7.23).

**Table 7.22: Total healthcare costs with patients over €15,000 removed**

| | ED cost | Un/p cost | Plan cost | OPD cost | GP cost | Total healthcare costs |
|---|---|---|---|---|---|---|
| **ESN** | €215 | €515 | €183 | €370 | €133 | €1,416 |
| **Non-ESN** | €174 | €273 | €59 | €278 | €162 | €946 |

**Table 7.23: Total indirect costs with patients over €15,000 removed**

| | Patient indirect cost | Relative indirect cost | Total per patient |
|---|---|---|---|
| **ESN** | €386 | €226 | €612 |
| **Non-ESN** | €428 | €181 | €609 |

The total costs per patient in the ESN sites were €2,027 and €1,555 for the Non-ESN sites (table 7.24)

**Table 7.24: Total costs per patient with patients over €15,000 removed**

| | Total medical | Total indirect | Total per patient |
|---|---|---|---|
| **ESN** | €1,416 | €612 | €2,027 |
| **Non-ESN** | €946 | €609 | €1,555 |

### Costs with patients over €10,000 removed

Once all the patients whose total costs are over €10,000 are removed from the dataset, the medical costs per patient are slightly higher in ESN sites (€1,124) than Non-ESN (€916) sites (table 7.25) Again, this is related to the proportion of high cost patients being higher in ESN sites. The indirect costs for the ESN group are still lower (€542) than the

Non-ESN group (€590). The planned cost of inpatient treatment in hospital for epilepsy is higher in the ESN sites at €149 per patient compared to €57 in Non-ESN sites (table 7.26).

**Table 7.25: Total healthcare costs with patients over €10,000 removed**

| | ED cost | Un/p cost | Plan cost | OPD cost | GP cost | Total healthcare cost |
|---|---|---|---|---|---|---|
| **ESN** | €182 | €330 | €149 | €342 | €121 | €1,124 |
| **Non-ESN** | €169 | €264 | €57 | €269 | €157 | €916 |

**Table 7.26: Total indirect costs with patients over €10,000 removed**

| | Patient indirect cost | Relative indirect cost | Total indirect cost |
|---|---|---|---|
| **ESN** | €345 | €197 | €542 |
| **Non-ESN** | €415 | €176 | €590 |

The total costs per patient for healthcare and indirect costs for the ESN sites was €1,666 compared to €1,506 for patients in the Non-ESN sites (table 7.27).

**Table 7.27**: **Total costs per patient with patients over €10,000 removed**

| | Total medical | Total indirect | Total per patient |
|---|---|---|---|
| **ESN** | €1,124 | €542 | €1,666 |
| **Non-ESN** | €916 | €590 | €1,506 |

### Costs with patients over €5,000 removed

The medical costs are largely similar between the ESN (€778 per patient) and Non-ESN (€704 per patient) sites when all the high cost patients (patients whose total direct and indirect costs amount to over €5,000 per year) are removed from the dataset. Indeed, it is clear that the cost of unplanned nights in hospital is the same per patient in the ESN (€174) and Non-ESN sites (€174) when all high cost patients are removed, while planned nights in hospital are higher in ESN sites (€108 vs. €43) (table 7.28).

**Table 7.28: Total healthcare costs with patients over €5,000 removed**

| | ED cost | Un/p cost | Plan cost | OPD cost | GP cost | Total healthcare cost per patient |
|---|---|---|---|---|---|---|
| **ESN** | €133 | €174 | €108 | €277 | €86 | €778 |
| **Non-ESN** | €115 | €174 | €43 | €230 | €141 | €704 |

The indirect costs for the ESN group are lower (€320) than the Non-ESN group (€397) (table 7.29)

Table 7.29: Total indirect costs with patients over €5,000 removed

| | Patient indirect cost | Relative indirect cost | Total indirect cost |
|---|---|---|---|
| **ESN** | €228 | €91 | €319 |
| **Non-ESN** | €272 | €125 | €397 |

Total costs, including medical and indirect costs, were almost identical for the ESN sites at €1,098 and €1,101 for the Non-ESN sites (table 7.30).

Table 7.30: Total costs per patient with patients over €5,000 removed

| | Total medical costs | Total indirect costs | Total per patient |
|---|---|---|---|
| **ESN** | €778 | €320 | €1,098 |
| **Non-ESN** | €704 | €397 | €1,101 |

### *Analysis of low cost epilepsy patients*

As we decided to do an analysis of the effect of removing high cost patients from the dataset to see the effect on the difference in cost between the ESN and Non-ESN sites, it was also deemed important to analyse low cost patients. 'Low cost patients' in this analysis are categorised as those patients whose total medical and indirect costs is €149 or lower. The reason for this assumption is that the cost of one outpatient visit was estimated at €149, and this was deemed as the lowest maintenance possible for patients with well-controlled epilepsy. Table 7.31 highlights the number of patients whose total costs met this assumption and were, therefore, excluded from this analysis. We can see that the number of patients in ESN (N=41) and Non-ESN sites (N=42) whose costs were either zero or €149 and under are almost identical. From this table, we can see that the numbers of low cost patients did not differ between ESN and Non-ESN sites, so this analysis did not provide any additional insight into the patterns of service use.

Of interest though, is the higher numbers of low cost patients treated in Site I relative to other sites, amounting to 29/100 or 29%. This finding will be discussed in the next section.

Table 7.31: Low cost patients

| Participants removed | €0 | €149 or under | Total | Including low cost | Excluding low cost |
|---|---|---|---|---|---|
| A | 7 | 3 | 10 | 83 | 73 |
| B | 11 | 8 | 19 | 96 | 77 |
| C | 2 | 10 | 12 | 63 | 51 |
| **Total ESN** | **20** | **21** | **41** | **242** | **201** |
| F | 1 | 1 | 2 | 22 | 20 |
| G | 1 | 3 | 4 | 93 | 89 |
| H | 3 | 2 | 5 | 25 | 20 |
| I | 14 | 15 | 29 | 100 | 71 |
| J | 1 | 1 | 2 | 7 | 5 |
| **Total Non-ESN** | **20** | **22** | **42** | **247** | **205** |
| **Total ESN + Non-ESN** | **40** | **43** | **83** | **489** | **406** |

### *Analysis of Site I patients*

As previously highlighted, the low number of visits and consequentially the low cost per patient for patients treated at Site I hospital required further analysis. On further analysis, we found there is no overall difference in quality of life scores between ESN and Non-ESN sites when the Site I data are excluded. However, there is a higher quality of life score among patients of Site I and more controlled epilepsy (defined as having fewer seizures and being diagnosed with epilepsy for longer) in comparison to the Non-ESN sites.

If patients of Site I hospital were excluded from the analysis, the average ED cost for the Non-ESN sites would be higher at €246 per patient (versus €166), with an average of one visit per patient and may reflect a predominately outpatient service for people with very stable and well controlled epilepsy. In terms of total medical costs per patient, this would change from €1,112 with Site I to €1,544 once these data are removed. In this case, this would mean the average cost per patient for total medical costs would be higher in Non-ESN sites at €1,544 compared to €1,375 in ESN sites. In terms of indirect costs, with Site I data removed the cost associated with patients and their relatives would increase from €1,313 to €1,514. The overall total per patient, including medical and indirect costs, would change to €3,271 in ESN sites and €3,057 in Non-ESN sites.

## Discussion

This chapter has provided an economic analysis of data from the **SEN**s**E** study. The aim of this analysis was to compare the costs of clinical activity and the monetary impact on patients with epilepsy and their families.

### *Utilisation of health services*

Utilisation of health services was analysed for Emergency Department attendance, nights spent in hospital for epilepsy, outpatient visits and GP visits. Findings show that the number of Emergency Department attendances is largely similar between the ESN and Non-ESN sites, although there are a slightly higher average number of attendances in ESN sites.

In terms of nights spent in hospital, planned nights in hospital were largely similar between ESN and Non-ESN, while unplanned nights were higher in ESN sites suggesting that patients at Non-ESN sites may have more well-controlled disease. As anticipated, outpatient visits were higher among patients in ESN sites compared to Non-ESN sites and this difference was statistically significant.

In relation to GP visits, there were slightly fewer visits per patient in ESN sites compared to Non-ESN sites. This could be related to the more intensive management of patients by ESNs, meaning they require fewer visits to their GP for the treatment and maintenance of their epilepsy or that the outpatient visits are substituting for visits to the GP.

### *Difference in medical and indirect costs*

Overall, the data presented have shown that costs were higher among patients in ESN sites (€3,271) when compared to patients treated in Non-ESN sites (€2,424). In terms of total medical costs, it was higher in ESN sites at €1,375 compared to €1,112 in Non-ESN sites.  In relation to the total per patient indirect cost, the average indirect cost associated with time spent off work/school/college for patients was the same in ESN and Non-ESN sites at seven days per year. However, the difference was evident for the relative indirect cost per patient, which was higher among patients in ESN sites; much of this difference is driven by a very small number of patients, who were off work for an extended period relative to other patients. Overall, the total cost per patient for indirect costs was €1,896 in ESN sites and €1,313 in Non-ESN sites.

### *Site I hospital patients*

The lower healthcare utilisation among PWE treated at Site I and consequentially the low cost per person also required further analysis. Analysis of the data excluding Site I means the average cost per PWE for total medical costs is higher in Non-ESN sites at €1,544 compared to €1,375 in ESN sites. The overall total per PWE, including medical and indirect costs, changed to €3,271 in ESN sites and €3,057 in Non-ESN sites. As such, controlling for case mix, with the removal of high cost PWE, demonstrates that there is no difference in cost between PWE in ESN sites and Non ESN sites.

### *High cost patient analysis*

The greatest number of high cost epilepsy patients (costs over €5,000) are predominately in the ESN sites. Medical costs are largely similar between the ESN (€778) and Non-ESN (€704) sites when all the high cost patients (patients whose total direct and indirect costs amount to over €5,000 per year) are removed from the dataset. The indirect cost is €320 per patient in ESN sites compared to €397 in Non-ESN sites, bringing the total cost per patient in ESN sites to €1,098 and €1,100 in Non-ESN sites. The removal of the high cost patients shows the interaction with the complexity and case mix among patients, which is not accounted for in these data.

## Conclusion

Overall, the economic analysis found that costs were higher among PWE in ESN sites. However, on further analysis of high cost PWE and excluding the data from Site I, there was either no difference in cost or PWE in Non-ESN sites had higher medical costs. Removing the high cost PWE (over €5,000) provided a way of controlling for case mix; and this revealed that total costs, including medical and indirect costs, were almost identical for the ESN sites at €1,098 and €1,101 for the Non-ESN sites. The removal of the high cost PWE demonstrates the cost per PWE is the same in ESN and Non ESN sites, highlighting that the costs are not fully accounting for differences in case severity.

The next question then is whether PWE treated in an ESN site experienced better outcomes at the same cost. Although there is no evidence of difference in QoL between ESN and Non-ESN sites, a greater proportion of PWE in ESN sites either agreed or strongly agreed that ESNs made a positive difference to health and well-being. Furthermore, there is evidence from the study findings that PWE under the care of an ESN have received more information on epilepsy in terms of treatment options and how to self-manage, where appropriate. In addition, statistically significant differences were found in terms of involvement in care for PWE treated in ESN sites. In addition, a change in skill mix was observed for ESNs as they could take 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.

In conclusion, based on all of this evidence, it is suggested that PWE included in this study who received care from an ESN, have 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 place the treatment of PWE with an ESN in the North East quadrant of the cost-effectiveness plane, suggesting that sites with an ESN may be good value if they improve the patient experience at no change in cost. There is evidence of improved experience and better management and co-ordination of epilepsy care, so the data from this section show that there is an improvement at no net cost.

Further studies should aim to measure disease severity to allow more robust comparisons of costs of patients treated in ESN sites compared to Non-ESN sites.

## Limitations

There are a number of limitations associated with this economic analysis, which need to be considered in the context of the results. Firstly, as we did not have a precise measurement of disease severity for epilepsy patients included in the study, some observed differences in healthcare utilisation and time spent off work may relate to case complexity and this was not adjusted for in the data. Indeed, as we have seen with the data from Site I, patients treated in this site had much lower utilisation of services relative to other Non-ESN sites, as well as relative to ESN sites. As the methodology for this analysis used average costs, it did not take into account differences in outpatients visits provided by ESNs, as the cost was an average of all epilepsy outpatient visits. Finally, the large differences in cost for certain healthcare utilisation and indirect costs was related to a small number of patients, which brings up the average cost per patient. This was analysed further with the removal of high cost patients.

## Chapter 8

# Contextual and Mediating Factors that Influence Role Development, Integration and Sustainability

# Chapter 8: Contextual and Mediating Factors that Influence Role Development, Integration and Sustainability

Specialist and advanced practice nursing roles have been developed in many specialist areas of nursing both in Ireland and internationally. In many cases, these posts have been hailed as the panacea to the challenges facing healthcare organisations, especially in relation to health education, health promotion and the meeting of patient needs in an efficient and timely manner (Plager and Conger 2007; Lowe *et al*. 2012). However, the process of introducing new roles such as ESNs within established healthcare systems is both complex and challenging, as development and integration often challenges traditional disciplinary boundaries, requiring inter-professional teamwork and collaboration (Kilpatrick *et al.* 2013).

Despite ESN roles being in existence in the UK since 1988 (Goodwin *et al.* 2004), very little research has systematically documented or identified contextual and mediating factors that influence role development, role integration and the ESN's ability to enact their role. While Higgins *et al.* (2006:239) noted a lack of clarity around ESNs' role definition, with potential for confusion, they also viewed that ambiguity as a strength, providing individual nurses with the freedom to develop a 'service without a defined role model or set of parameters'. Hopkins *et al.* (2010) in their UK study into the ESN role found that, although there was a high level of support for the ESN role, there were mixed reactions among medical colleagues to ESNs prescribing. Where ESNs were working in 'isolation', prescribing authority was seen as a necessary requirement of the role; however, in environments where doctors and nurses worked in close partnership and proximity, there was some opposition to the prescribing role. In addition, they found that in resource depleted environments, ESNs were required to move into non-specialist roles, such as helping on busy wards or taking on administrative tasks due to staff shortages. In addition, the generic advertising of posts, which in some cases were filled by non-nurses (e.g. pharmacists), was viewed as limiting the scope of services provided to PWE, with the potential to erode the status and professional identity of the ESN.

International and Irish research has reported on factors influencing the development and integration of clinical specialist and advanced practice roles in other areas of nursing. The presence or absence of national policies and local frameworks, support for the role among medical and nursing colleagues, structural, clinical, educational and mentoring supports, as well as personal attributes of the clinical nurse specialist or advanced practitioner were some of the factors identified (Griffin and Melby 2006; Norris and Melby 2006; Thrasher & Purc-Stephenson 2007; Delamaire and Lafortune 2010; DiCenso *et al.* 2010; Keating *et al*. 2010; Lindblad *et al.* 2010; Pulcini *et al.* 2010; Begley *et al*. 2010; Kilpatrick *et al.* 2012; Kilpatrick *et al*. 2013; Higgins *et al.* 2014; Elliott *et al*. 2016).

This chapter explores the contextual and mediating factors that influence the ESN role, and discusses both the enablers and barriers to role development, role integration and role enactment. It also includes findings on factors that participants considered could impact on ongoing development and sustainability of the ESN service.

## Contextual factors that support role development and integration

The following enablers to ESN role development and integration were identified within the **SEN**s**E** data:

- Presence of the National Clinical Care Programme in Epilepsy and other funding sources;
- Medical consultant and multi-disciplinary team support;
- DoN and senior management support;
- Process of site preparation and accreditation of new RANPs in epilepsy;
- Network supports;
- Structural supports and resources;
- Personal attributes of ESN; and
- Acceptance of ESN role by patients and families.

### *National Clinical Care Programme in Epilepsy and other funding sources*

The National Epilepsy Care Programme was essential to the development of the ESN role as it provided a cohesive programme which incorporated funding for new ESN posts, Standard Operating Procedures and guidelines for epilepsy care, and medical and nursing champions who provided leadership and influenced the development of epilepsy services at national and regional level.

> *"We met [National Clinical Lead], they want ANPs in epilepsy across the country… if those posts are available elsewhere… And then obviously, if it's gonna benefit the patient and they're going to feel that by having somebody who is immersed 200% in epilepsy it is going to have improved outcomes…we got funding and we had an interested candidate and there's a care programme that says this is the best model of care for patients with epilepsy so you can kind of say, oh right, okay, thanks very much, we'll have all of that." (DoN interview)*

> *"The clinical care programme, we were employed as candidate nurse practitioners and we signed up for that, that's the commitment we've made." (Candidate ANP interview)*

> *"Great support, like for study leave, I've got my study leave, I've got funding as part of the National Care Programme as well, so, like we're very lucky to get that so that, it's facilitating my education for my role as well. At the start … we were part of the National Care Programme so there was all the SOPs and KPIs, which were great guidelines and were an aim for us at the start." (Candidate ANP interview)*

> *"[National Clinical Lead person] has done a great job on the National Care Programme, in terms of increasing the number of nurse practitioners and nurse practitioners to be, as in nurse practitioners in training." (Allied health professional interview)*

Other sources of funding that were used to support the development of specific ESN roles included Epilepsy Ireland and a neurosurgical departmental budget.

> *"The situation within the home environment as to how supported or otherwise [people with epilepsy] were… That part of [ESN] work is supported by Epilepsy Ireland – and that aspect, I think has been inordinately helpful." (Medical personnel interview)*

> *"[ESN in surgery] position was funded and brought into being, not by the Programme, but actually by the Neurosurgical Department." (Medical personnel interview)*

### *Medical consultant and multi-disciplinary team support*

At organisational level, support from medical consultants in epilepsy and neurology was essential to the successful introduction and integration of the ESN posts. At governance level, medical consultants were involved in the development of local protocols and guidelines, so that the ESN's extended scope of practice was recognised by other disciplines and departments. This collaboration helped minimise any potential resistance to the ESNs extending their scope of practice in the care of PWE. Medical consultants were also essential insofar as they provided mentorship and clinical supervision, supported the ESNs to develop advanced competencies in epilepsy care, and gave them the confidence to become more autonomous clinical practitioners. Medical consultants who had worked overseas and had first-hand experience of nurse practitioners were highly supportive of the introduction of the role within the epilepsy services in Ireland.

> *"We have a supportive neurologist [name of consultant], we have a supportive neurology team of consultants, who very much value the role." (DoN interview)*

> *"… we have [name of nurse] who was the epilepsy nurse specialist, is a nurse prescriber now, she'll be an RANP hopefully at the end of the year and that is really down to the consultants pushing, pushing, pushing, you know, mentoring, teaching, really good teamwork has gone on there." (DoN interview)*

> *"[The]… consultants have, have never seen…the CNSs as a threat to anything, you know,…unfortunately that is how some doctors see them, so they [neurology consultants] would see them as a valuable part of the team,…they give them the autonomy so then they blossom and they stand out." (DoN interview)*

> *"[Name of consultant] for example came from the [names country], he was very keen to develop a whole lot of things, one of them being the epilepsy nurse role, I could see that he was very, very much behind the development of that role. And also gave the nurses who were in those roles a huge amount of freedom …which has allowed [them] to make decisions and grow things… So I think that was another contributing factor." (Allied health professional interview)*

> *"Very open, you can talk to them [epilepsy consultants], they're very approachable. If you have any issues with patients it's no problem, emailing them, ringing them…a good team to work with, like approachable consultants, we can ask them questions. You might present a patient and talk about a patient that you're worried about but you've the facility to say I don't understand, can you explain this to me, what does this mean, what type of seizure is this, this is what I think it is…" (RANP interview)*

> *[Name of consultant] is also the clinical mentor for [candidate ANP]. [Name of consultant] is concurrently running a neurology clinic in OPD as is available to [candidate ANP] if required. (Candidate ANP observation)*

### *Director of Nursing and senior management support*

Support from the DoN and senior nursing management was equally essential to the introduction and integration of new ESN posts. As executive managers of the nursing services within the organisation, DoNs had a key role to play in providing resources (study leave/ protected time for Master's degree study) and brokering support from local NMPDUs and nurses at different grades (ADoN to staff nurse) to support and to help new ESNs become established.

> *"I think the biggest… it would be our nurse divisional manager, which is our ADoN…she would have been the biggest driver." (Candidate ANP interview)*

> *"Our nurse administration was on-board from day one. It was welcomed and it was embraced." (Allied health professional interview)*

> *"The Director of nursing has been very supportive in terms of study days, we don't go to very many but any of the few that are in the country we apply for study leave and we get it.  She's very good that way, so when I did my Advance Practice module, there was no problem, I could attend and had my time off, the same with nurse prescribing." (Candidate ANP interview)*

### Process of site preparation and accreditation of new RANPs in epilepsy

The National Council's site preparation and approval process was instrumental in ensuring that candidate ANPs were working towards meeting the national education and practice requirements. The process for the approval of posts required local policy and scope of practice guidelines to be developed collaboratively with medical consultants and senior nurse managers (NCNM 2008b). Consequently, barriers to role development and integration into the organisation and healthcare team were minimised. Although the ESNs found the process of site preparation personally and professionally challenging, in their view, it provided role clarity and a structured process to prepare them academically and clinically for the advanced practice role.

> *"[Candidate ANP] I would link up with NMBI, also practice development in the hospital…they help people who are going through advanced nurse practitioner documentation… the NMBI, came out and did a meeting in the hospital and I found that very beneficial because it sort of puts you on the right road instead of going off the wrong track." (Candidate ANP interview)*

> *"The good thing about the site preparation, it does give you clarity, it gives your role clarity, I mean at times you don't know your own role throughout the journey and it does bring clarity and it does bring buy-in and it is a blueprint for the future." (Candidate ANP interview)*

### Network supports

Network supports within the ANP community were an important factor in providing ESNs with advice and peer-support for the development of the ANP role. Current RANPs in epilepsy were supporting and mentoring candidate ANPs in role and service development. In addition, other non-epilepsy RANPs provided professional advice and support specifically around site preparation.

> *"We have an email kind of, I'll call it a forum… well just say if I come across something I can email [name of ESN] who is the head of the forum and she will pass on my query to everybody else. She'll say can you help, and then if you can help people reply…you get emails every so often or if something comes out, if there's kind of new trends in something." (Candidate ANP interview)*

> *"We have great support, even for developing the role as an ANP. There's a group here as well within the hospital and the other ANPs are very supportive as well so we've plenty of places we can go to ask for help." (Candidate ANP interview)*

> *"I'm very heavily involved with the Irish Epilepsy Nurses' Group… it was initially established by Epilepsy Ireland… our [Irish Epilepsy Nurses' Group] main aim there, is to continue to support nurses who work with patients with epilepsy, in whatever sector that is, be it intellectual disability, paediatrics, psychiatric. And we have meetings…and we have educational meetings that we get outside speakers in. And we have a national conference once a year as well, so I'd be involved in that as well." (Candidate ANP interview)*

Networking with national and international epilepsy interest groups or at epilepsy conferences also supported role development as they provided the ESNs with opportunities to identify future trends and developments in epilepsy care.

- Attended Irish Chapter of ILAE – Expert Epilepsy Study Day;
- Attended Epilepsy Nurses Study Day;
- Attended the 10th European Congress on Epilepsy UK;
- Attended the European Forum on Epilepsy Research 2013; and
- Attendance at Annual Irish Epilepsy Nurses' Group meetings

(Documentary evidence)

### *Structural supports and resources*

The availability of infrastructural resources had a positive impact on the ESNs' ability to enact their clinical role, including administration/ secretarial support, physical space, and IT (EPR/ mobile technology/ bleep). Having administration/ secretarial and IT support, where available, meant that more time was available for the ESNs to focus on direct patient contact and to engage in other aspects of their role.

> *"I would be the administrative support to them regarding the clerical side of their roles. And that would be booking patients, organising templates, patient correspondence and other admin duties. I suppose I'd be their go-to person as regards any administration tasks." (Allied health professional interview)*

> *"I work remotely, so I have a laptop and I have access remotely to the Electronic Patient Record. So I don't go out to anybody's house now, where I don't have some record on the Electronic Patient Record, that I can make reference to it, if I need it." (Candidate ANP interview)*

> *[Candidate ANP] has a dedicated clinical room where she can review her caseload of patients. The room is large and well light and ventilated and contains the necessary equipment to conduct a physical examination. There is a PC open on the desk and has a version of the epilepsy EPR open on a laptop. (Candidate ANP observation)*

### *Personal attributes of ESNs*

The personal attributes of the ESNs were considered by all stakeholders as important factors influencing success. Personal attributes, such as being innovative, creative and committed to developing quality epilepsy services and to their own professional development were considered essential.

> *"Their keenness to learn is a very significant addition to the service because I think if people are willing to learn, they provide a better service in general." (Medical personnel interview)*

> *"Then the people who were actually in the roles themselves are very clearly innovators and people who want to continuously improve things." (Allied health professional interview)*

> *"[ESNs] were very heavily involved in kind of coming up with new ideas "let's do this", "let's try that", "how about doing a bit of this", "how about we have a…", you know.  So they were very much innovators…" (Medical personnel interview)*

The importance of having interpersonal skills and patient-centeredness was commented on by MDT members, which was validated within the patient and family focus-group interviews, and comments on surveys.

> *"I think it's their personality.  I think why are they nurses in the first place!  They have an aptitude for it.  And I think the second thing is they are very professional, and I think I have highlighted some of that with my previous response.  I think the third thing is and that's just I think spending time with patients, and being interested in them is just another facet of that." (Medical personnel interview)*

> *"I think they're never off duty …no matter when you meet them. But I think ultimately they're human and they don't see it as a job, they see it as a bit of a vocation." (PWE focus group)*

> *The service provided by (names ESN) has been second to none. She is personal, friendly, and helpful and it feels as if she genuinely cares. She… is a constant comfort. (PWE survey)*

> *I have the highest respect for epilepsy nurse (names ESN). She has helped me immensely during this difficult period. Wonderful personality, bedside manner and always listens. (PWE survey)*

In addition, other key attributes that were perceived by others as essential to enabling ESNs to be successful in their role included being knowledgeable about epilepsy and issues specific to particular groups (e.g. pregnancy, intellectual disability, paediatrics, surgery), having confidence in their clinical decision-making, and knowing how to navigate healthcare systems to the benefit of the patient and their family.

> *"I think it's important for the candidate to know when, I think knowing when to escalate is an important concept. But also the opposite of that is a lack of confidence where you are escalating everything." (Medical personnel interview)*

> *"[Name of ESN]'s perseverance and, and her approach and her manner and she's very confident in what she does. But she's also extremely respectful of any concerns that people might have." (Allied health professional interview)*

> *"[ESN] level of knowledge and expertise in terms of epilepsy is far superior than a regular staff nurse and I suppose especially in the current climate where we've got staff nurses who are quite junior, but when you've got somebody in a standalone position they work at a very, very high level and they are deemed and considered clinically expert at what they do and when you look at the jobs and the roles that they fulfil they most certainly demonstrate that they'd be far superior to any staff nurse." (DoN interview)*

### *Acceptance of the ESN role by patients and families*

The final factor that influenced the ESN role was the degree of acceptance of the ESN role by patients and families. Overall the data indicated that the majority of patients and families accepted and valued the ESN as a member of the MDT as previously discussed in chapter six. It is perhaps unsurprising that in the early stages of introducing the ESNs as service providers, some patients and families took time to adjust to and have confidence in this new model of service delivery. As the following candidate ANPs explained.

> *"I think as time goes on they're beginning to see you as clinicians. Initially it was like 'I want to see the doctor,' but as time has progressed, I've noticed they're more happier to come and see me because I'm the same person they'll see each time. They say 'we class you as our doctor' …they know that if I have any issues or any queries I can also link up with the team, because we all work together, you know, as a team." (Candidate ANP interview)*

> *"The medical consultant at the moment sees all new patients, and I see a lot of return patients. Some of the patients are quite happy to see a nurse but some aren't, they don't expect to see a nurse… they go 'oh but we haven't seen the Doctor you know' …it takes time [to shift culture]." (Candidate ANP interview)*

Despite service providers' belief that reservations about the ESN role was a transient phase, some PWE in one focus group continued to express reservations about ESNs prescribing medications, and were concerned that the role was becoming overly focused on seizure control and in some situations questioned whether the ESN service was a cost-saving initiative.

> *"Every time I go into the epilepsy nurse she says 'oh I'll just up it [medication]' and that's it…I don't even see the reg [medical registar], it's just the nurse, all she does is up it. And I was like 'no that's too painful.' She says 'oh it will be fine, it will be fine.' It's all about the seizure control …. when you ask her can you see someone, see [name of consultant], 'oh no it's, he's not here.' She says 'I'm in charge now'." (PWE focus group)*

> *"I'm a cynic, I'm a real cynic here and the reason that they want more clinical nurse specialists is because, in my opinion, is the HSE are on cut backs, cut back, cut back. And why have a doctor when you can put in a nurse?" (PWE focus group)*

Some PWE within that focus group had built relationships with their medical consultant, which they valued, and appeared to be more trusting of their advice; hence they were of a view that certain decisions would always require input from the medical consultant.

> *"It was only when I came to [names consultant] that he did tell me go on this [medication], you're not supposed to be on that [medication]. So he was very effective in that way and I guess that's why I like seeing him, maybe because he can tell me more about medications and I trust him maybe." (PWE focus group)*

> *"When the nurse wrote that I was to go through with labour [birth], and I knew I was having thirty seizures a day, I wasn't going to be able for it. …she should have ran that by [name of consultant]. But when I seen [name of consultant] on my next visit, he [consultant] spoke to the Dictaphone for it to be typed out that I wasn't to go through natural labour. Important decisions like that should be sent through the neurologist." (PWE focus group)*

## Barriers to role development and integration

A number of barriers to the development and integration of the ESN role were also identified. These included:

- Factors associated with implementation of a new role;
- Workload and case management;
- Lack of sufficient structural supports; and
- Number of ESNs in epilepsy team.

### *Factors associated with implementation of a new role*

The demands to achieve accreditation and site preparation were experienced by the candidate ANPs as resource intensive. Not only had the ESNs, who were candidate ANPs, a clinical caseload, but many were simultaneously completing education programmes to Master degree level, preparing documentation for the NMBI for the accreditation of the site and the post, and contributing to the development of new epilepsy services and related guidelines and policies for practice (as discussed in chapter four on leadership).

> *"A huge time, chunk of my time in the last year has been taken up with site preparation…, I don't think anything prepared you for it, just the time consuming nature of it, that it takes you away from your patient clinical outcomes, it's a lot of paperwork… it's a massive undertaking, from an academic, clinical, trying to adjust to a new role, trying to…develop a new role and then the site preparation." (Candidate ANP interview)*

Lack of understanding of the ESN role by some members of the MDT and nursing profession gave rise, in the early stage of implementation, to various levels of resistance to the role at advanced practice level. Concerns expressed included that ESNs would encroach on other professionals' roles, would de-skill other members of the nursing profession or would become 'mini-doctors'.

> *"Consultant buy-in, consultants who don't understand the role of advanced practice, who see the nurses perhaps as clinical nurse specialists and will be slow to allow them become advanced nurse practitioners with a caseload and become autonomous…we have met resistance in some sites and have been told that some of the nurses have had unpleasant experience in some of the hospitals from some of the senior nursing management…they don't understand the role and I think they're scared and they feel perhaps threatened. I think the grading of advanced nurse practitioners at an assistant director of nursing level is threatening to some directors of nursing who feel that clinical nurses perhaps shouldn't have that level." (RANP interview)*

> *"Some nurses see nurse specialists as having an easier life and 'I wish I was one of them and she's doing nothing'…the unfortunate down side for me is that you meet a lot of young nurses…who don't know how to deal with certain things because they're used to handing it over to a nurse specialist, which is an issue." (DoN interview)*

> *"I've heard countless times the comment of, what's the point in ANPs, it's only a yellow pack doctor… definitely from nursing colleagues." (Candidate ANP interview)*

The ESNs and others were also challenged in differentiating between the CNS and ANP roles, and articulating how they differ in the epilepsy context.

> *"I think those posts from an ANP perspective are slightly harder to define and describe to get them accredited because you're saying well what's the differential between the CNS in neurology, CNS in epilepsy versus the ANP… that is a barrier, being able to describe the differential between the roles and the NMBI were really, really, really sticky on that…" (DoN interview)*

A particular challenge associated with some ESN roles was that they were employed by one organisation yet were developing and delivering services across different organisations and across different primary care and hospital services.

> *"The greatest obstacle is being employed by [name] Hospital…managed by my nursing management…at the end of the week I have to send off my [off-duty] to [name] Hospital…but yet the [epilepsy] service is here… both hospitals run very differently." (Candidate ANP interview)*

Another challenge associated with the building of ESN capacity within the MDT was the need for epilepsy specialists, especially neurologists, to carve out sufficient time to supervise and monitor candidate ANPs in their clinical skill development, whilst at the same time maintaining their own clinical caseload. This had implications where multiple candidate ANPs were being developed concurrently in the same epilepsy service.

> *"Even things like the neurological examination in clinic for a new patient, it's great to say that an experienced nurse practitioner can see new patients in a clinical environment, but they also need to be trained up on the physical and neurological exam, which we are doing, but it takes time." (Medical personnel interview)*

### *Workload and case management*

Whilst the ESNs were achieving considerable success in meeting the objectives of the National Epilepsy Care Programme by increasing access to epilepsy services and by increasing the number and types of epilepsy services available, this resulted in an ever-expanding clinical caseload for ESNs along with an increasing complex patient profile, and complex inter-agency case management. The prioritisation of meeting the clinical demands meant that the research, audit and leadership dimensions of the role were made secondary. Both members of the multi-disciplinary team and ESNs acknowledged that one of the greatest barriers to the research, audit and leadership dimensions was carving out the time required to meet the demands of heavy clinical workloads and the demands of developing and implementing new epilepsy services.

> *"The concern I would have is that they've taken on far too much…they don't have time to do the other parts of their roles, whether it be analysis of information data, doing the research side of what they're supposed to be doing, that they're so totally focused on the patient, and that's very important, but to fulfil their other roles and responsibilities, whether it be leadership, whether it be focusing on advancing practice even further, whether it be the whole audit and research agenda." (DoN interview)*

> *"The case load is huge. We have up to now not developed satellite clinics because we felt like are we out growing our supply and are we just doing too much." (Medical personnel interview)*

> *"That there's only two of them and just from talking to everyone here. They seem to have so much work on, there must be a phone ringing every half hour." (PWE focus group)*

The demand of a heavy clinical workload was further exacerbated by the fact that complex cases required input from services outside of the ESN's remit (e.g. securing emergency hospital-bed admission, cognitive behaviour therapy or other mental health services), and these weren't always available in a timely manner. In addition, in some situations there was a reported resistance to accepting referrals from ESNs by some services.

> *"It's a really tough thing for anybody to deal with, and expecting an epilepsy nurse who has an enormous caseload of clients to be able to support somebody appropriately with that, or even expecting a generic mental health service, I think they also would be really at sea in meeting the needs of somebody in that situation." (Allied health professional interview)*

> *RANP is trying to arrange admission for the patient. However the bed manager informs RANP by telephone that no bed is available. RANP also speaks by telephone with the psychiatry team on call and with the neurology registrar in person who has come into the room. There is a protracted debate and discussion in respect of who should admit the patient (i.e. which team) and where to keep the patient until a bed*

> *for admission becomes available. The neurology registrar on call suggests that the patient should be transferred to the ED until a bed becomes available. RANP challenges respectfully this suggestion and feels this is an inappropriate solution (i.e. "ED is not a suitable place for this patient"). However from their discussion it appears there is no alternative to this solution. The patient is transferred to the ED. (RANP observation)*

> *"I think that's a local thing as much now to be honest, any of them [allied health professionals], not just social work, any of them at the moment don't accept referrals from anybody only medicine but I believe they're addressing it…" (Candidate ANP interview)*

Concerns were raised regarding the heavy clinical workload and its impact on the ESN's ability to sustain the quality of the service provided and the pace of expansion of new epilepsy services.

> *"One concern is that the [ESNs] who are so good at this will try and spread themselves too thinly and therefore the quality of the service, or their own personal well-being, will suffer because they are trying to do too much." (Medical personnel interview)*

> *"The concern I would have is that, ultimately people will tip over the edge when they've done too much and they've taken on far too much… there's a burnout risk there." (DoN interview)*

> *"I do think they're under a lot of pressure, for the amount of people that they're dealing with." (PWE focus group)*

> *"It may be a double-edged sword, the telephone advisory line is invaluable to patients, but it is a huge work commitment for the nurse specialists." (Medical personnel interview)*

### *Lack of sufficient structural supports*

A number of infrastructural resource issues had a negative impact on some of the ESN's ability to enact their role, including administration/secretarial support, physical space, information technology and access to online library resources. The lack of administration or secretarial support meant that ESNs' time was taken up with retrieving patients' charts from the hospital records department (if a patient's information wasn't previously on the EPR), internal delivery of patient forms to relevant departments within the hospital, sending out appointment letters and filing patient information. In addition, populating the EPR was also very time consuming.

> *"So every patient, we have to go through the whole chart and put this patient onto the EPR, it's very time consuming, you might have a patient who has a history, thirty year history of epilepsy, and you're going through what medications they were on before, why they were stopped, when they were stopped, what dose they got to. So you're literally, that could take an hour to go through that chart, it could take more for some." (Candidate ANP interview)*

> *"I organise, I do all my own administrative work, so I send out appointment letters and everything, I do the whole lot, so I don't get really any support, I do everything you know. I do the whole lot." (Candidate ANP interview)*

> *CNS uses lunch break to deliver referral form for an admission of patient to a central administration location in hospital. This is a good walk away, she also delivers other referral sheets into a post box along the way. ESN does not have administrative support. (CNS observation)*

In addition, the ESNs often lacked suitable physical accommodation to enable them to deliver patient care. In the absence of an assigned office-space, they shared offices with numerous colleagues, delivered services in cramped and over-crowded conditions, and at times had to spend time trying to locate a private or comfortable space for PWE and family consultations.

> *The room is small, narrow, not a clinical room and does not have obvious resuscitation equipment which is necessary given the type and complexity of patient being reviewed. [Candidate ANP] states 'we have big problems with space' and 'sometimes rooms are not the best'. (Candidate ANP observation)*

> *"One of the big barriers was, well there's no space for you to sit down, we don't have a room for you, and that was a big, you know, that was a problem. So kind of once we got into seeing patients clinically, that was the biggest transition." (RANP interview)*

> *Met ESN in office that is shared by 3-4 other nurse specialists. (CNS observation)*

The third structural issue that impacted on the ESN role was the lack of Information Technology (IT) support, the lack of integration and harmonisation of the EPR within the IT systems and, in some situations, the lack of access to online library resources, thereby limiting ESNs' ability to source evidence-based information from specialist epilepsy publications.

> *"Most of our hiccups have not been clinical. They have been in terms of the actual running of the clinic and information technology and support that has been extremely challenging." (Allied health professional interview)*

> *"We have a slight problem in the sense that [EPR] not fully rolled out, we can't use these computers because there is internet explorer and when it was put on these computers there was a clash and things were sort of wiped out and computers were non-functioning. So it's only on laptop. So our candidate ANP here has her own laptop which is EPR enabled in the interim; they have ordered laptops for us which we hope will come very soon." (Medical personnel interview)*

> *[ESN] notes that the EPR is a great system for keeping track of MDT communication and interventions etc., but that it does take time to complete and you can't complete a draft and save, so you must complete immediately and within a 20 minute timeframe, so need to be very organised and not get distracted by other things, as could lose the data entered. (Candidate ANP observation)*

> *"I have access to the [names university] library until October and I'm dreading it then, I don't know what I'll do, I'm going to lose my access in October [finishing her course]  so, it's going to be a huge loss to me." (Candidate ANP interview)*

### *Number of ESNs in epilepsy team*

The number of ESNs in the MDT had an impact on their ability to enact all aspects of their role. In situations where the ESNs were working as lone practitioners, large clinical caseloads coupled with a lack of time limited their opportunities to develop clinical services, and carry out leadership, research and audit functions. Furthermore, clinical services that were dependent on lone practitioners were at risk of having gaps in service delivery due to no replacements for leave (e.g. annual leave, sick or maternity leave).

> *"There's one person who provides a very, very specialised service and is highly skilled within that service. If… that person is on leave, for whatever reason, that can be a huge shortfall for the service that they provide…if somebody has to take leave, then they might have to cram all their caseload for a given week into, you know, say if they're working five days, they might have to cram it into four days. I'm not sure that is a great way to run a service…. if they are one person alone, then I think in their absence, there is a huge…it results in an enormous gap in the service…I think that there needs to be a plan B." (DoN interview)*

> *"We learned an expensive lesson when our nurse practitioner went on maternity leave. There was no backfill, you could see the impact of the lack of, hugely. Even the number of consults increased, the epilepsy attendances in ED increased. Now while this is anecdotal we felt the pinch of the absence." (Medical personnel interview)*

> *"I think the policy makers should be sensitive to the fact that they [ESNs] will have families and they will have family issues, maternity leave will occur, in places like here where there was one advanced nurse practitioner it created an enormous problem. The fact that we had to discontinue clinics, discontinue the help line. This caused a huge problem and this is because there was no back fill of." (Medical personnel interview)*

> *"As much as we wish them every happiness I think I'd have a heart attack if I saw one of them pregnant. (Laughs) No, one of you gone for six months." (PWE focus group)*

Single post-holders who were also candidate ANPs spoke of feeling isolated within their own organisation as they were the 'trail-blazers' creating a new epilepsy-specific advanced practice role.

> *"It has been a very isolating journey, you know, from the start…because I suppose you have to break away from what you were doing and then you're trying to evolve a service, evolve your role and there's so much for you to do within that pathway or within that journey during your candidacy …I would be envious of other centres that would have ANP candidates because they can bounce off each other." (Candidate ANP interview)*

## Recommendations for future developments

The stakeholders made a number of recommendations for the future development of the ESN service. There was general agreement by all that the ESN services needed to be expanded nationally in line with the vision outlined in the Epilepsy Clinical Care Programme (HSE 2014). It was also recommended that the remit of the ESN be redirected from tertiary services to community and primary care services to reflect the fact that a huge part of epilepsy care is chronic disease management. Community epilepsy specialist nurses were identified as vital resources in establishing supports, resources and activities for PWE and their families with the aim of improving education and enabling better coping. The continuing development of outreach work in the area of ID services, maternity care as well as greater ESN involvement within older age services, and mental health services was seen as important. Several specialist type nurse-led clinics were identified as being required for particular cohorts of patients (i.e. adolescent clinic to deal with adolescent issues pertaining to epilepsy, pre conception clinics for women, greater supports for patients transitioning from paediatric to adolescent services and for people with brain tumours or brain injuries and epilepsy).

Several PWE and family members encountered negative experiences in the Emergency Department [ED], including staff not being able to identify the person's seizure as epileptic and inappropriate waiting times combined with inappropriate conditions for PWE in the ED environment. Thus, stakeholders identified a need for better understanding and more timely and appropriate responses to PWE in ED, including greater input by ESNs in terms of educating staff working in ED on epilepsy and having a nurse who is specialised and knowledgeable in epilepsy care working in the ED, especially in relation to PWE with ID.

The telephone advisory line (TAL) was regarded as a vital resource by all stakeholders as it facilitated rapid access to advice and information at crisis points and was identified as being particularly valuable in the early stages of a diagnosis. However, there were mixed recommendations on its operation and sustainability. Though PWE and their families/carers expressed a desire for a 24/7 service to be available and the allocation of a dedicated person to staff the line, professionals were aware of the workload burden involved in managing TAL.

With regard to the EPR, it was recommended that this be rolled-out nationally to improve continuity in care and consistency in the information available to professionals.

Stakeholders also identified a continuing need to promote the ESN service in order to garner greater understanding, support and acceptance of the ESN role among nursing colleagues, GPs, PWE and management.

Finally, as a means of meeting increased demand for the ESN service and ensuring its sustainability, it was recommended that the number of specialist nurses be increased, including increasing the number of nurses with prescribing authority. It was also recommended that there be a commensurate increase in the number of senior medical personnel to meet the need for clinical supervision that would inevitably arise.

## Barriers to sustainability of ESN role

A number of issues emerged from the stakeholders, which they believed were potential barriers to the ongoing sustainability of the ESN service. The intensive commitment required on behalf of the ESN to achieve RANP accreditation, including time and financial resources, was seen as a potential barrier to the ongoing development of future ESN roles in line with the aims of the Clinical Care Programme. In addition, the lack of transferability of the RANP (as per NCNM policy (NCNM 2008b) across organisations should the person seek employment in a new organisation, and the reluctance of experienced nurses to take on the responsibility associated with RANP were identified as other potential factors impacting on sustainability.

> *"…a certain element of fear as well, you know that's a huge responsibility**…**To take on…to diagnose epilepsy, and to decide on treatments,…use the information…what if I made a mess of something?...[that has] serious implications for my patients**…**That's a big responsibility to take on board**…**it was just the sheer volume of academic work she [candidate RANP] had to put in, and that was huge…they are not always transferrable if you do want to move outside of a hospital**…**Start from scratch again with your accreditation." (MDT nurse manager interview)*

> *"I think they view it as a positive thing but I also think some people think it's a lot of unnecessary stress…because some of my colleagues can see what exactly I've had to go through and it's like one obstacle after another…they wonder like why. Then they say 'I'm not going down that road, absolutely not', and nearly the majority of them have said that, because candidate ANPs, they're very out on their own and it is a very stressful time…" (Candidate ANP interview)*

Some reservations were expressed about a model of career pathway that omits the CNS role within the SN-CNS-RANP career progression.

> *"Don't only have ANPs … I don't think is good [not to have CNSs] and then how do you then ensure that there's enough differential for people to be able to see their value and their piece in the care pathway." (DoN interview)*

Other areas of concern included recognition that, although the ESNs working in the area of epilepsy surgery are identified in the Clinical Care Programme, there needed to be greater integration of these roles into the overall ESN service and in the preparation of future ESNs. At the same time there was a fear that the Clinical Care Programme was becoming overly focused on the ESNs and nursing, and the role of other disciplines within the MDT would be forgotten.

> *"…I think they [ESNs not working in surgery] need to see the [ESN] surgical role, and I think it might be good if they were kind of linked, seconded, or annexed or whatever the expression is – to an epilepsy surgery nurse, for a few months…" (Medical personnel interview)*

> *"The nursing thing has been so huge in the development of the national clinical care programme, and it's very, very, very good, but it's almost like the nurses, and everything else… I think this is an accidental and unintended consequence of that focus, but the multidisciplinary team approach and other disciplines possibly have been lost at the moment." (Allied health professional interview)*

Finally, a major factor considered to impact on sustainability was that ESNs were reaching a critical tipping-point where the service demand was out-stripping the available resources. A major concern was that ESNs would become victims of their own success unless the parameters of their clinical workload and service development were defined at national level. Linked to all these issues was a concern that the increasing clinical workload was leaving little time available for developing a long-term plan and vision for services and was risking staff burnout of both nursing and medical personnel.

> *" I was looking at figures today…and you look at the outpatient activity alone and it's just skyrocketed over the last couple of years…I suppose the question is well, how in the name of XXX are you going to, you know, enable all of that work." (DoN interview)*

> *"Our cohort of patients is growing all the time, staff levels aren't growing with the cohort of patients. Yeah and the thing is at the end of the day my role and … the nurses' [role] have expanded over the last 2 years greatly. You can see that in the statistics, the amount of patients, the data that I pull yearly, you can see our cohorts are getting bigger, and bigger, and bigger but our staffing levels aren't." (Allied health professional interview)*

> *"There is no body, or no group of people, or no whatever, able to take a kind of a longer view into that [future vision], … the number of patient encounters isn't a determinant, or doesn't sort of give me a measure of how successful a service is, for me it's more quality than quantity…there is an overhead to managing people – I'm not talking about how much I pay them, I'm talking about day to day – "have you got the tools to do your job?" "How did that work out for you today?" "What's the next thing you want to do?" (Allied health professional interview)*

> *"I think we are at a critical point, I don't think we can stretch the services provided by the nurses too much more…we are already struggling. … the nurse practitioners are working extremely hard,…they put a lot of energy into their work…, which is fantastic but I don't think they can do much more… we are actually at breaking point … if you provide a good service you start becoming a victim of your success, demand increases, expectations increase and we can't stretch without more resources… but you also need to make sure there is adequate medical supervision … even though they [ESNs] provide great services and do valuable clinical work, they still need to be mentored and supervised..." (Medical personnel interview)*

## Discussion

The findings of the **SENsE** study clearly identify a number of enablers and barriers to the development and integration of the ESN role. These enablers and barriers can be categorised using Elliott *et al.*'s four levels, developed from a systematic scoping review of barriers and enablers influencing the advanced practitioner's leadership role (Elliott *et al.* 2016), namely: healthcare systems level, organisational level, team level and practitioner level. In this study, the existence of one factor at patient level was identified, that could be both an enabler and a barrier; this was the acceptance or otherwise of the ESN role by patients and families. In addition, factors that have the potential to impact on future sustainability were identified (see table 8.1 for summary).

Although little research exists on ESNs and the factors that support or mediate role development and integration, barriers and enablers to the introduction of new clinical specialist and advanced practice posts in other areas of nursing have been identified (Begley *et al.* 2010; Higgins *et al.* 2014; Elliott *et al.* 2016). Interprofessional tensions and medical opposition due to concerns about malpractice cases and their legal liability are key barriers to role development and integration reported in the international literature (Norris and Melby 2006; McIntosh and Tolsen 2009; DiCenso *et al.* 2010; Gerrish *et al*. 2011b; Hourahane *et al*. 2012; Elliott *et al.* 2016). While some ESNs in the SENsE study reported experiencing resistance from some junior medical and nurse colleagues in the early phase of development, in contrast to international experiences, senior and junior medical and nursing personnel were clearly very supportive of the ESN role, in keeping with findings of the SCAPE study, another Irish study that evaluated specialist and advanced practice roles, albeit not ESNs (Begley *et al.* 2010). The strong support for the ESN role within the SENsE study no doubt reflects the inclusion of both a role description and outcomes for the ESN within the national policy document on epilepsy care (HSE 2014). The NCNM documents on specialist and advanced practice acted as enablers as they provided a framework for role development, accreditation and site preparation (NCNM 2008 a, b). In addition, the presence of advanced practice roles in other areas of nursing within the sites also helped minimise potential resistance, as they were viewed as making a significant contribution to quality patient care.

Table 8.1: Contextual and mediating factors influencing ESN role

| | Healthcare systems level | Organisational level | Team level | Practitioner level |
|---|---|---|---|---|
| **Enablers to development and integration** | • National Clinical Care Programme in Epilepsy and other funding sources<br>• Presence of guidelines on accreditation of new RANPs in epilepsy and the process of site preparation | • Director of nursing and senior management support<br>• Structural supports and resources | • Medical consultant and MDT support | • Network supports<br>• Personal attributes of ESN |
| **Barriers to development and integration** | | • Lack of understanding of role<br>• Lack of sufficient structural supports<br>• Developing and delivering services across organisations | • Number of ESNs in epilepsy team<br>• Demands on medical consultant time to mentor and supervise | • Workload and case management<br>• Demands of role and site preparation to register as ANP |
| **Potential barriers to future sustainability** | • Lack of clear parameters on clinical workload capacity and service development capacity<br>• Model of career pathways that omits CNS level | • Lack of resources to sustain expansion of services<br>• Lack of time to envision and plan future development | • Workload outstripping current resources leading to frustration and burnout | • Availability of a cohort of nurses willing to assume level of responsibility and engage with the demands of achieving RANP status.<br>• ESN in surgery currently not well integrated into the overall ESN services |

Another factor that appears to beleaguer healthcare services internationally when developing and implementing specialist roles was concerns about nurses' competence to expand their role into areas traditionally considered the domain of other disciplines, especially prescribing (Wilson *et al.* 2005; Griffin and Melby 2006; Thrasher & Purc-Stephenson 2007; Delamaire and Lafortune 2010; Keating *et al.* 2010; Lindblad *et al.* 2010; Pulcini *et al.* 2010). Again, these concerns were not evident within **SENsE**, with all disciplines involved in the interviews commenting on the knowledge, competence, and personal attributes of the ESN. This positive appraisal of competence no doubt stemmed from their experience of working alongside the ESNs and an appreciation of their commitment to continuing professional development, as evidenced by the number of academic programmes and other educational opportunities they had availed of, especially in their speciality area of epilepsy. Medical consultants, in particular, were very supportive of the prescribing role, and were active in their encouragement, support and mentoring of ESNs to expand their scope of practice.

While a lack of formal support mechanisms has been identified as a barrier in other studies (Booth *et al.* 2006; Norris and Melby 2006; Elliott *et al*. 2016), this again did not emerge as a major issue in this study. Data suggested that the ESN had created many formal and informal support mechanisms for sharing and addressing issues that crossed discipline, service and national boundaries. When support was an issue, it related to role isolation in single post holding sites, a factor that has been identified previously in Begley *et al.*'s (2010) Irish study.

Similar to other studies that explored barriers to the development of nurse specialist posts, large clinical caseloads, and role overload were some of the most significant mediating factors influencing role enactment. The demands of large clinical caseloads, coupled with the demands of developing services, while also achieving the competencies and other requirements to become a RANP, left little time for research and audit. The challenge of carving out time for audit and research is not new. Many studies that explored how specialist and advanced practitioners spend their time highlight how service demands take priority, with most time being spent on clinical and administrative activities (Ridley *et al.* 2000; Guest *et al*. 2004; Mullen and Gavin-Daley 2010; Kilpatrick *et al.* 2012). Linked to role isolation and the number of ESNs within a service, was a concern that a lack of 'critical mass' of ESNs left patient services extremely vulnerable should an ESN be absent for any length of time. There were also concerns about the long-term sustainability of the ESN service, and whether the ESNs could continue service expansion at the same pace, without risking quality of service provision and burnout.

Other challenges encountered in the implementation and integration of the role were associated with structural supports and resources. While some ESNs had access to administrative and IT support, others had limited access to such resources, delivering care in less than ideal physical surroundings and, in some cases, lacking the essential requirement of library access, especially to specialist epilepsy journals. Similar deficiencies in structural resources have been reported in other Irish (NCNM 2005; Begley *et al*. 2010; Higgins *et al*. 2014) and international (Donald *et al.* 2011; Gerrish *et al.* 2011b) studies evaluating specialist and advanced practice roles. In addition, despite previous research, which suggests that patients who received care from an ESN are more likely at follow-up not to mind who provides their epilepsy care (Mills *et al.* 1999a), findings from this study suggest that some patients continue to have a preference for care from medical consultants as they are more trusting of their advice, especially around medication. Although this was not a widespread issue among the patients interviewed, this finding indicates a need for ESNs and services not to assume patient and family acceptance of the role, especially in the current economic climate where service changes may be interpreted as cost-cutting exercises.

Finally, some of the barriers influencing the ESN role were related to the stage of development associated with the implementation of new roles within multi-professional and multi-layered healthcare organisations and there was overwhelming support for the role among all disciplines and across all levels of the healthcare system. However, the findings also clearly indicate a need to consider the capacity of the ESN workload, the long term impact of further expansion of services on the quality of service provision, and the innovator and research dimensions of the ESN role. In addition, there is a need to develop a strategy to identify nurses who are willing to assume the challenge of an ANP role and one that addresses the other issues identified, including the implications on medical consultants' clinical, mentoring and supervision workload should the numbers of ESNs be expanded within the MDT.

## Chapter 9

# Synthesis of findings and recommendations

# Chapter 9: Synthesis of findings and recommendations

## Introduction

Up to the time of the development of the National Clinical Care Programme in Epilepsy in Ireland (HSE 2014), ESN roles had developed informally. However, with this development a cohort of ESNs were appointed, with a view to augmenting existing ESN and medical services so that every PWE in Ireland would have access to the epilepsy ANP service.

This study, the Specialist Epilepsy Nurse (s) Evaluation [**SEN**s**E**], set out to identify the role and cost-effectiveness of the ESNs in Ireland and to evaluate their impact on patient experiences, quality of life (QoL) and satisfaction with care. The study used a mixed methods approach, with three concurrent interrelated phases. Phase one comprised a case study and gathered information from ESNs and key stakeholders. The second phase included a comparative survey design involving patients from sites where ESNs worked and sites where no ESNs were employed. The third phase included an economic assessment.

Data were gathered using different methods and a variety of sources:

- 61 hours of observation of 12 ESNs, interviews with 12 ESNs, and documentary evidence in 5 different sites;
- Interviews with 22 members of the multidisciplinary team with whom the ESNs had contact;
- Surveys with 505 PWE who were attending ESN and Non-ESN services for a period of over one year and 100 who had been recently diagnosed with epilepsy and were attending ESN and Non-ESN services; and
- Focus group interviews with 21 PWE and 14 family members.

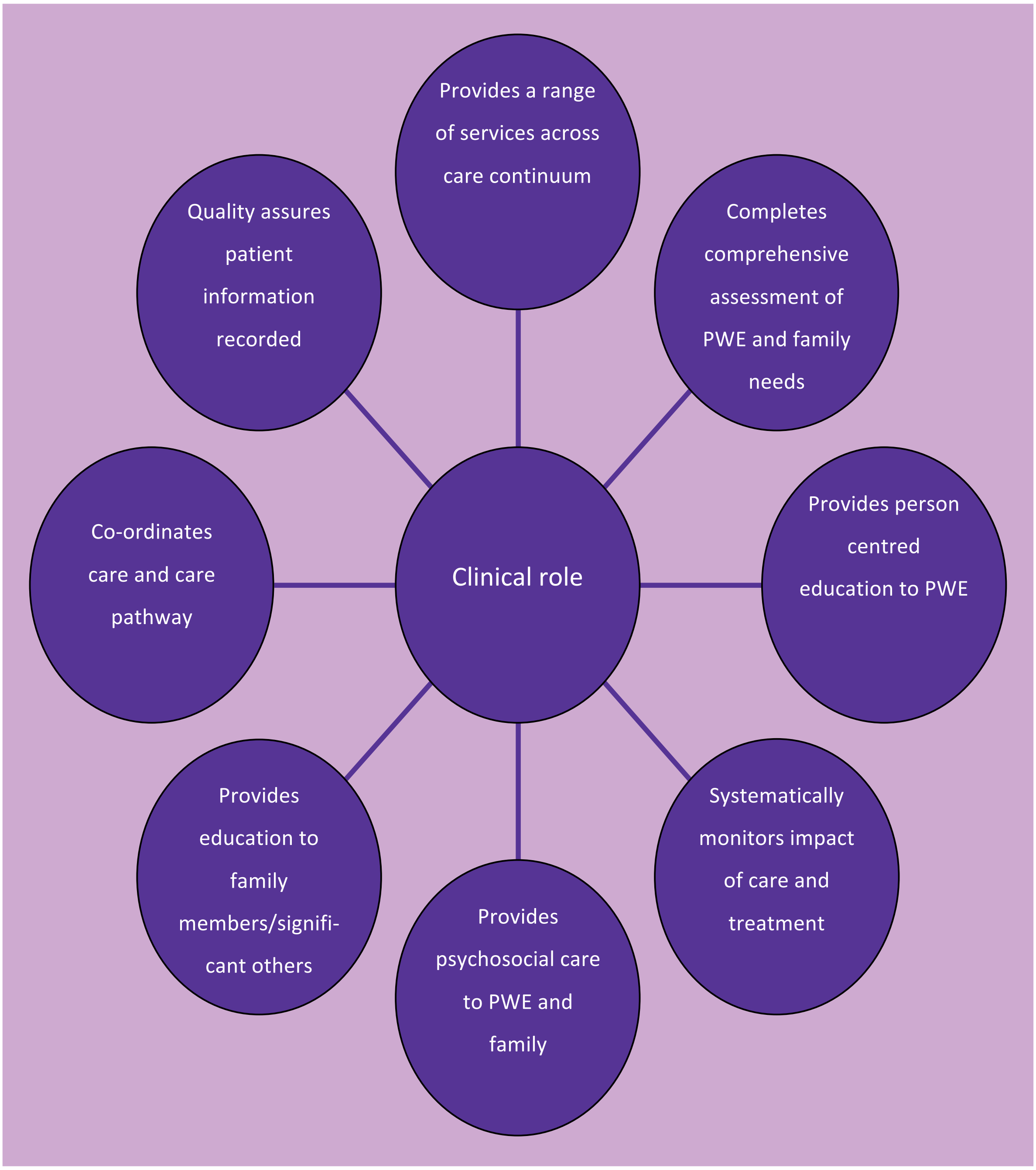
This chapter briefly summarises the findings in relation to the clinical, leadership and EBP dimensions of the ESN role. Following this, and drawing on a synthesis of findings from the various data sources, the impact of the ESN role on outcomes related to PWE, family members/significant others, the multidisciplinary team within and outside of the ESN’s organisation, and the health service are presented. Although contextual and mediating factors that influence role development and sustainability were not part of the original research objectives, a summary of these outcomes are included as they emerged as the study unfolded. The chapter concludes with a number of key recommendations that arise from this mixed methods study.

## Clinical role of the ESN

Findings from this study indicate that 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. They all had gained a significant number of professional and academic qualifications (see chapter 2). Seventy five percent of the ESNs (n=8) had completed or were completing Master degrees, and all had completed some form of education that directly informed their practice in epilepsy. Two of the ESNs were registered ANPs, 5 were candidate ANPs, and 5 were at CNS level. In addition to being registered general nurses, 1 was a registered midwife, 2 were registered in intellectual disability nursing, 4 were registered in children's nursing and 7 were registered nurse prescribers with the NMBI.

As part of the clinical dimension of their practice the ESNs were working in a range of services across the primary, secondary and tertiary care continuum and were providing care to PWE across the age continuum and who were experiencing various degrees of co-morbid physical and psychological health difficulties and challenges, including intellectual disability. Whilst the ESNs were working as core members of the MDT, the focus of their clinical role was on ensuring optimal seizure management and psychosocial well-being for PWE, providing prompt and timely interventions, which included education to address changing life circumstances and contexts, enabling the PWE and their family to self-manage their care, enhancing PWEs' journey through the healthcare system, and contributing collaboratively to the decision-making of the wider MDT. Thus, the clinical dimension of the 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 aspect of the role incorporated a number of functions, including in-depth comprehensive assessments that moved beyond the disease model of care to incorporate lifestyle and psychosocial issues, the education of the person and their family on all aspects of epilepsy, including the social, safety and health aspects of epilepsy, the systematic follow-up and ongoing monitoring of the impact of care and treatment on the PWE as well as co-ordinating the care provided, liaising with other members of the MDT  and ensuring the quality of information recorded (see figure 9.1). In addition, the ESNs led on patient consultations, switched on VNS devices, completed neurological assessments, ordered tests, referred PWE to allied health professionals, and prescribed or titrated medications, many tasks which might have been traditionally considered as being within the medical domain. The clinical aspect of the ESN 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.

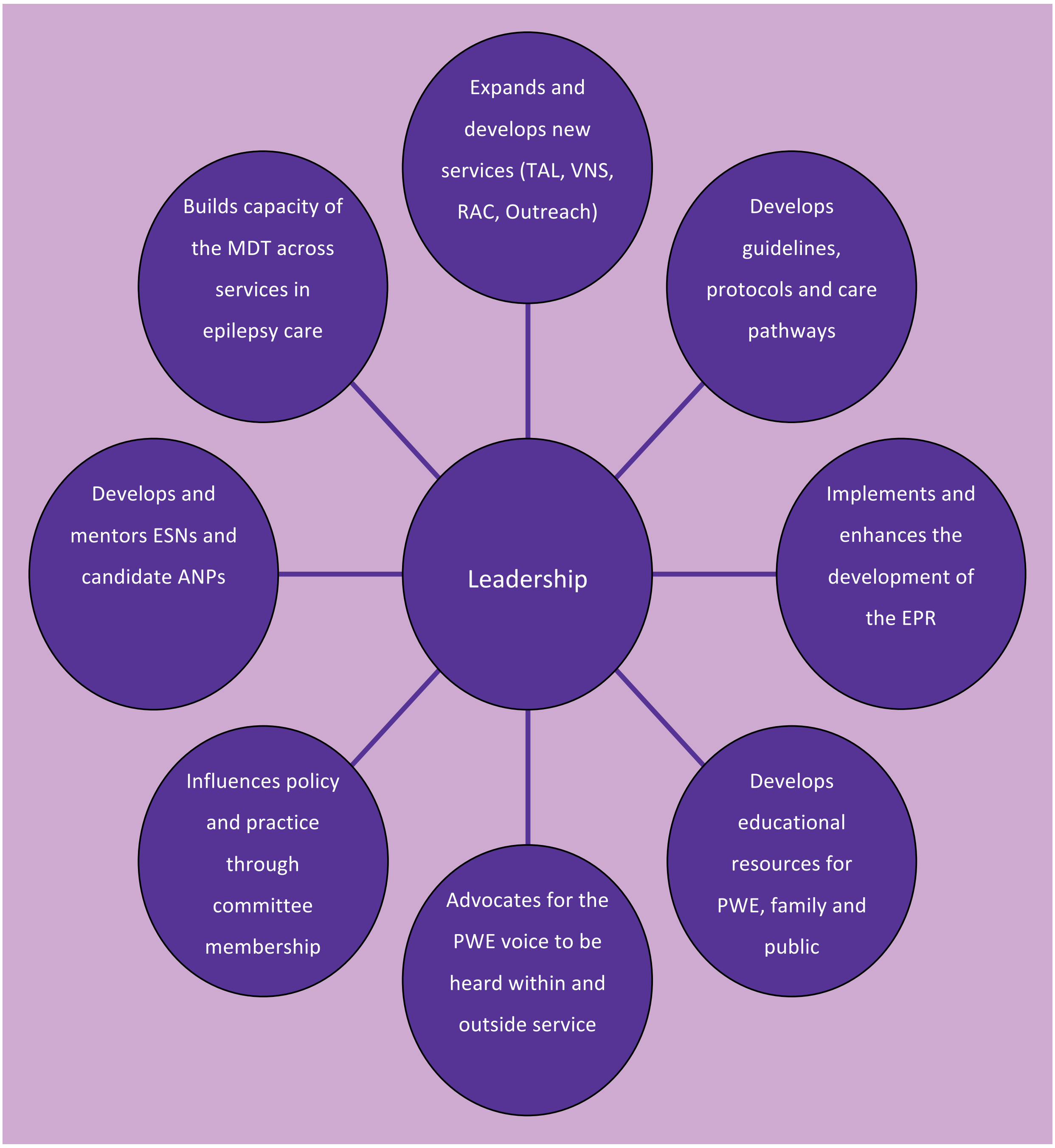
Figure 9.1: Clinical role of the ESN



## Leadership role of the ESN

The ESNs were enacting their clinical and professional leadership role at an organisational and strategic level (see figure 9.2) and were central to advancing the NECP's aims of reconfiguring care away from hospital-based services and providing an epilepsy ANP service  to all PWE (HSE 2014). As leaders they were not only increasing PWEs' access to specialist epilepsy services by expanding and developing new services, such as TAL, VNS clinics and outreach clinics for people with ID and pregnant women, but they were also improving the quality of care for PWE by leading on the development of clinical guidelines, protocols and care pathways, and advocating for the voices of PWE to be heard at local and national level. They were also building and enhancing the competencies of PWE, family members, the general public and members of the MDT in relation to epilepsy care by leading on the design and development of evidence-based educational programmes and materials. In addition, as part of the leadership dimension of the role, they were influencing policy and practice, and were advancing the ongoing development and implementation of the EPR, as well as the development and support of candidate ANPs, both core national policy initiatives. To ensure sustainability and smooth implementation of change, they were proactive in identifying gaps in services, sourced resources, and piloted and evaluated new initiatives. 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.

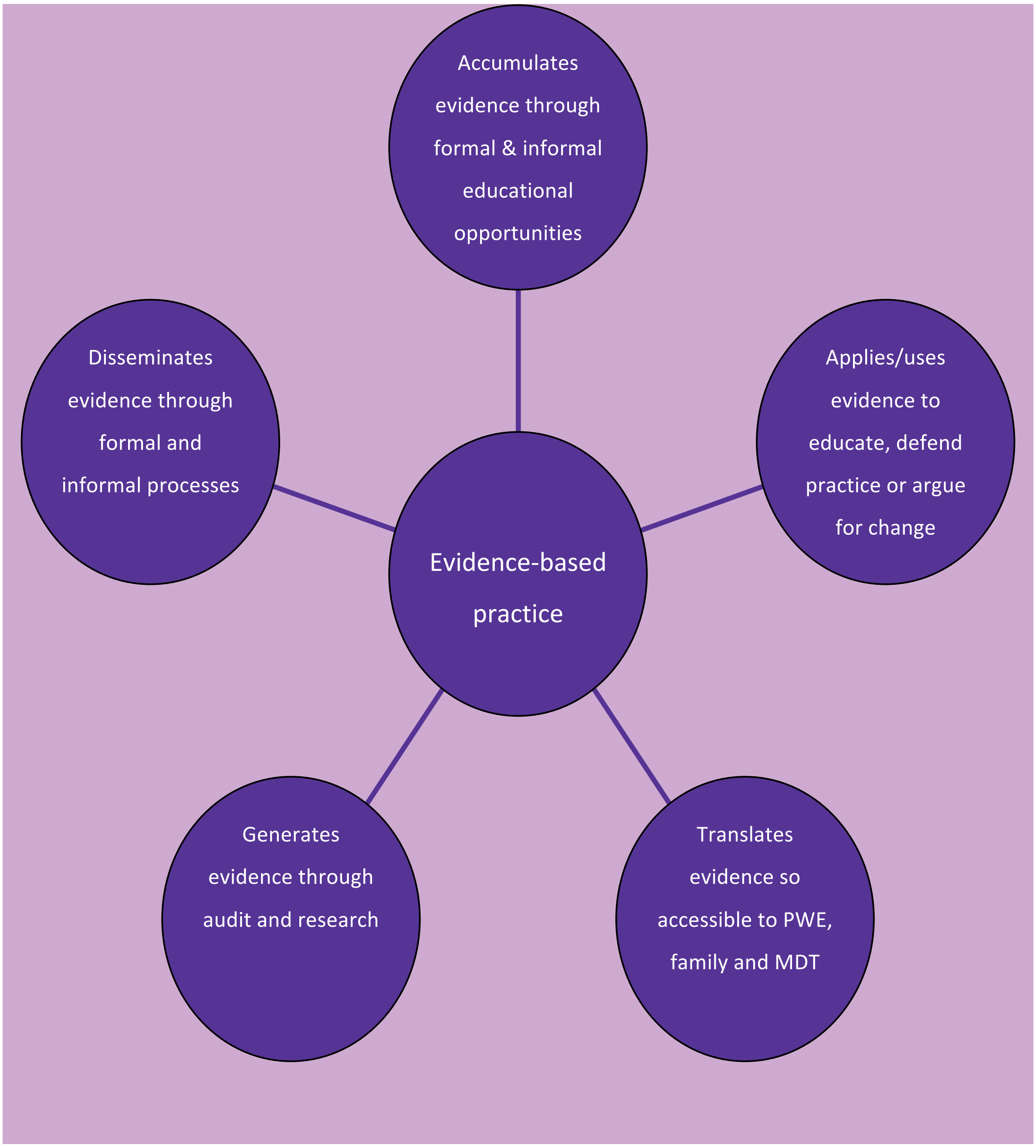
Figure 9.2: Leadership role of the ESN



## Evidence-based practice role of the ESN

Findings demonstrated that the ESNs were all engaged to varying degrees in promoting EBP among MDT members, PWE, their family and the public by accumulating, applying, translating, generating and disseminating evidence (see figure 9.3). The ESNs accumulated evidence from multiple sources to inform decision-making within their own practice, and to argue for changes at team and organisational level. They also had an important role in translating evidence into accessible and usable forms for PWE/family members and MDT members through the development of protocols and guidelines. Whilst the ESNs were very active in generating and disseminating evidence from audit within their own organisation they were less involved in the generation of evidence through research and in dissemination of evidence outside of their own organisation. Not surprisingly the clinical and leadership dimensions of their role took priority over producing research, and although the skills and supports required for this aspect of the EBP role varied between individuals and across sites, all ESNs were very positive about getting involved in research in the future.

**Figure 9.3: Evidence-based practice role of the ESN**



## Impact of ESN role on outcomes

A synthesis of the findings from all the data sources indicates that ESNs had an impact on outcomes for PWE and their family members/significant others, for healthcare staff within and outside the ESN's organisation, and outcomes that were health service oriented. Findings from the **SEN**s**E** study clearly indicate that the ESNs were not only working in line with the role description as identified in the NECP but, in many situations, were working beyond the expectations of the role (HSE 2014:26).

### *Outcomes related to PWE and their family members/significant others*

In total 13 PWE and family member outcomes were identified. For all of the outcomes, between three and five data sources supported the impact of the ESN on these outcomes (see table 9.1). Whilst there is limited evidence that ESNs alone improve overall clinical outcomes for PWE, findings from the **SEN**s**E** study indicate that the ESN, as part of a multidisciplinary team, impacted on the lives of PWE by enhancing their: knowledge about epilepsy; safety issues; seizure management and AEDs, as well as enhancing understanding of and preparedness for tests and investigations. In addition to increasing the prompt identification of problems, they improved PWEs' sense of involvement in care, co-ordination of care, and satisfaction with care. Notwithstanding the challenges ESNs encountered in responding to the needs of people with co-morbid mental health problems, they did enhance psychological well-being and PWEs' confidence to self-manage their own epilepsy. While there was no evidence that ESNs impacted on quality of life as measured by the QOLIE-10-P instrument, other evidence suggests that the ESNs were perceived by PWE and family members as improving overall health and well-being. In addition, evidence from all people involved indicated that the ESN increased family members' and the  general public's (e.g., teachers') confidence to support PWE and take action in emergencies, as well as decreasing the subjective and objective burden experienced by family and significant others.

Table 9.1: Outcomes related to PWE, family members/significant others

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| **1** | Enhanced PWE knowledge about epilepsy and own epilepsy | ESNs were observed to be educating PWE during every clinical encounter.  Examples of education provided included: medical, social and safety aspects. ESNs tailored education to specific needs and context of the PWE and their family. | Information booklets designed by ESNs and others were available in sites. | Greater proportions of PWE in ESN sites reported receiving information on all aspects of epilepsy compared to Non-ESN sites. In particular a greater proportion of PWE reported receiving information on social, safety and health aspects of epilepsy in comparison to PWE attending Non-ESN sites. There was also an increase in the knowledge score among PWE in ESN sites over time. | PWE provided examples of how the ESN educated them about all aspects of epilepsy and helped translate evidence, especially medical language, into an understandable form. | All stakeholders and in particular the medical personnel spoke of the ESNs' skill in educating PWE. |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| **2** | Enhanced PWEs' knowledge of and preparedness for interventions/tests/procedures | ESNs were observed explaining tests and interventions so that PWE understood the reasons for tests/surgery, could anticipate what to expect and understand the results of tests and investigations. | Information booklets designed by ESNs to explain procedures and tests (WADA test, Video EEG, Epilepsy surgery VNS) were evident. | PWE in ESN sites had higher mean scores on receiving information on the reason for tests/procedures and the results of tests/procedures than participants in Non-ESN sites. | PWE spoke of ESNs providing explanations for tests, thereby enhancing confidence in care and treatment. They also spoke of ESNs providing support and monitoring interventions (e.g., VNS insertion, brain surgery), which reduced anxiety especially for PWE who were undergoing surgery. | Medical personnel reported that ESNs were key providers of information on tests and investigations and assisted with decision-making around surgery through skilled communication, thus increasing PWEs' mental preparedness. |
| **3** | Enhanced PWEs' confidence to self-manage epilepsy | ESNs observed to be teaching and coaching towards self-management, and tailoring information to each person's context. ESNs also monitoring changing contexts in order to provide relevant and timely information, including information on epilepsy | Information leaflets designed by ESNs to promote self-management (e.g., Living Well with Epilepsy) and self-monitoring (e.g., seizure record diary) were available. | PWE in ESN sites had higher mean scores on receiving information on how to manage their own epilepsy, what to do in an emergency and about epilepsy organisations. | PWE spoke of increase in personal agency and confidence to self-manage. This increase appeared to be related to PWEs' increased knowledge, and the ease of accessibility of ESNs through TAL. | All stakeholders spoke of the ESN providing information that was relevant to age, lifestyle etc. and aimed at promoting the person's ability to live with epilepsy. |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| | | organisations and resources. | | | | |
| **4** | Enhanced seizure management without side-effects of medication | ESNs observed working to ensure optimal seizure management by ascertaining reasons for seizure activity, impact of lifestyle, side-effects of the medication prescribed, compliance issues, non-response to treatment etc. ESNs also took actions to remedy issues identified, such as altering medications, and devising plans to minimise risk associated with seizures. | Information booklets designed by ESNs on medication and medication side-effects. | PWE in ESN sites had higher mean scores on receiving information on how to recognise side-effects of medication, what to do if side-effects experienced and procedures for changing AEDs than participants in Non-ESN sites. | PWE reported that ESNs gave them practical strategies to self-manage their epilepsy optimally. | Medical and allied health professional interviews indicated that the ESNs were vigilant in their attention to medication compliance and side-effects. |
| **5** | Enhanced identification of problems and minimising of exacerbation by prompt referral and treatment | ESN observed to be i) continually enquiring about potential negative outcomes from treatments; ii) conducting a holistic assessment beyond | ESNs had i) developed an Epilepsy Nurse Phone Triage Form; ii) documented education of the MDT to ensure early identification of problems. | Those in ESN sites were significantly more likely to agree that they had to wait a ‘reasonable amount of time’ to be seen and that appointments could be | PWE gave examples of ESNs i) identifying problems quickly; ii) responding promptly to TAL queries; iii) solving problems in relation to access to services; and | Rapid access clinics and telephone triaging service provided by the ESNs was recognised as facilitating prompt attention for those in crisis. Medical |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
|  |  | epilepsy; iii) following up on tests and investigations; iv) engaging with others to get a collateral history, especially for children, people with ID or cognitive impairments; v) triage and refer promptly; vi) getting prescriptions to PWE in an efficient way and minimising waiting time. Interview data: education given on observing seizures and how to keep accurate and up to-date records. |  | easily made compared to those in Non-ESN sites. | iii) directing them to appropriate services. | personnel reported that the telephone contact ESNs maintained with PWE and family resulted in problems being solved by the ESN or being brought to attention of the MDT promptly. |
| **6** | Increased satisfaction among PWE with care provided | Observational (Thank you card displayed) and interview evidence support the view that PWE were satisfied with the information, advice and support received from ESNs, with no PWE |  | PWE in ESN sites were significantly more satisfied with practical and emotional aspects of support provided than participants in Non-ESN sites. Numerous qualitative | PWE were very satisfied with involvement in care and support received from ESNs, and provided numerous examples of positive experiences. They were also of the view that the | None of the stakeholders interviewed indicated that they had heard any negative feedback or complaints from PWE about the ESN. |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| | | requesting to see the medical consultant, although this opportunity was offered. | | comments in surveys to support satisfaction with care received from ESN. | ESN provided a more person-oriented approach. | |
| **7** | Enhanced psychological well-being of PWE | ESNs were observed including psychological well-being as part of their holistic assessment. Interview and observation data highlight ESN efforts to alleviate psychological stressors by talking them through, by reassuring PWE and, in the case of more significant mental health morbidities, endeavouring to refer promptly to specialist services. | | PWE attending ESN sites in comparison to Non-ESN sites reported significantly higher satisfaction with emotional and practical support offered, plus open-ended comments in survey data provided examples of emotional support offered. | PWE reported feeling able to share concerns with ESNs in person and over the telephone thus reducing sense of isolation and anxiety. PWE were more willing to discuss sensitive issues with the ESNs than those in the Non-ESN sites. They also reported that the ESN helped them to access psychological services. | MDT members reported that ESNs, through regular contact with patients, were well positioned to identify any behavioural, emotional, or cognitive difficulties requiring attention. Also a recognition among MDT that the ESNs' communication and empathy skills enhanced psychological well-being of PWE and their family. |
| **8** | Increased PWE and family members' sense of involvement in | ESNs observed to be involving PWE during consultations. ESNs advocated for PWE so | | PWE attending ESN sites in comparison to Non-ESN sites had higher mean scores for all five | PWE and family members felt involved in care and had opportunities to ask | |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| | care | wishes were heard and respected. | | questions on involvement in care, and four were statistically significant. | questions and receive answers. Evidence that PWE and family members felt their concerns and needs were listened to. | |
| **9** | Enhanced health and well-being and enhanced quality of life | Observed to ask about quality of life issues as part of assessment. | | No evidence of difference in QoL between ESN and Non-ESN sites. However, a greater proportion in ESN sites agreed/strongly agreed that ESNs made a positive difference to health and well-being. | PWE reported that the practical strategies offered by ESNs made a difference to their health and quality of life. | |
| **10** | Enhanced safety for PWE | ESN observed to be i) constantly enquiring about medication side-effects; ii) checking potential drug interactions; iii) quality assuring information on EPR; iv) following up on PWE who missed appointments; v) | ESNs were involved in educating the MDT, family and public on epilepsy, epilepsy first aid, and care of person during a seizure. Evidence that ESNs audit adverse events of new AEDs and of information given to | PWE in ESN sites had higher mean scores on receiving information on how to recognise side-effects of medication and who to contact if the seizure continued than participants in Non-ESN sites. | | MDT members stated that the education and monitoring of patients by ESNs had reduced iatrogenic risks and prevented death in some circumstances. In addition ESNs accessibility was highlighted as |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| | | referring PWE for tests to monitor negative impacts of AED; vi) educating PWE, family and general public about risks and safety in home, sport and other aspects of life, such as driving, pregnancy. | PWE on driving. | | | contributing to risk reduction. |
| **11** | Enhanced co-ordination of care | Observed referring or co-ordinating referrals to other MDT members or services e.g., mental health. | | Higher mean scores in ESN sites for 4 co-ordination of care items and also statistically significantly higher overall compared to Non-ESN sites. | PWE and family members reported ESNs liaising with consultant on their behalf. | MDT members reported that ESNs were conduit for multidisciplinary care due to their knowledge of epilepsy services, hospital structures, neurology teams and community resources. |

| No | Outcome | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interviews with other stakeholders |
|---|---|---|---|---|---|---|
| **12** | Increased family members' and general public's (e.g., teachers) confidence to support PWE and take action in emergencies | Education and support given to family/carers focuses on enhancing their ability to support their family member to cope with epilepsy in day-to-day life and support them to self-manage. Interview data also highlighted the emphasis on first aid seizure care, rescue medication and who and how to summon help. | ESNs educated family members on epilepsy and seizure first aid, including administration of rescue medication. | Data not collected | Family members spoke of importance of the ESN providing education and giving them confidence to support the PWE. This was especially true for parents of children/ adolescents with epilepsy and parents of PWE with ID. | All stakeholders spoke of the ESN's role in educating PWE. |
| **13** | Reduced burden on family members/ significant others | ESNs gave reassurance to family members of their availability through TAL if support was required. Also observed reducing family burden by prioritising PWE with ID during visits to clinic and by reducing their waiting time in clinics. |  | Data not collected | Family members reported feeling better able to cope as a result of ESN service and in particular the reassurance they received. The TAL was mentioned as facilitating access to ESNs and reducing burden. | MDT members stated that decentralising of services and localising of VNS clinics and TALs, as well as having outreach services, reduced cost and personal burden associated with travelling distances to access services. |

### *Outcomes specific to the multidisciplinary team within and outside of ESNs' organisation*

In total, four outcomes specific to the multidisciplinary team within and outside of the ESN service were identified. Data supporting the impact of the ESN is available from four data sources (see table 9.2), as the survey was only administered to PWE. Findings from the **SEN**s**E** study clearly indicate that ESNs increased the knowledge of the MDT on epilepsy and epilepsy care within and outside their own service, positively influenced their decision-making on care provided and promoted evidence-based practice. In addition, the RANPs were supporting and developing candidate ANPs in line with the NECP's aim of making an ESN service available to all PWE (HSE 2014).

**Table 9.2: Outcomes specific to the multidisciplinary team within and outside of ESN organisation**

| | | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|
| **1** | Increased MDT members' knowledge of epilepsy and epilepsy care | ESNs demonstrated educating, mentoring and role modelling for members of MDT within and outside their service, including GPs. ESNs were also presenting at journal clubs, organising seminars and conferences, and facilitating learning through being shadowed. | A range of educational resources were developed, and formal and informal education was provided to members of the MDT within and outside service on epilepsy and epilepsy care, including lecturing on undergraduate and postgraduate programmes. | Data not collected | All stakeholders spoke of the important role of the ESN in building MDT members' expertise in epilepsy and epilepsy care. Medical personnel also spoke of their role in educating medical colleagues. |
| **2** | Informed decision-making of MDT around diagnosis and treatment | Evidence of ESNs conducting comprehensive holistic assessments which informs MDT problem formulation, diagnosis and treatment. ESNs document consent from PWE so in a position to input information into EPR database and ensure information recorded is accurate. | | PWE and family members state that ESNs communicated information to other members of the MDT to influence decisions made and represent views of PWE and their families/carers. | ESNs viewed as skilled at eliciting information which elucidates on the source of the problems being experienced by PWE, making it easier for medical and other colleagues to provide appropriate care and treatment. |
| **3** | Promoted evidence-based practice among | Accumulated and used evidence to underpin own practice and translated, | ESNs led the development of guidelines and protocols to inform their own and others' | PWE and family members reported that ESNs translated evidence into an | ESNs viewed by stakeholders as basing their practice on best evidence for other |

| | | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|
| | MDT members | generated and disseminated research evidence to inform others' practice. | practice. | understandable form and used research to support education and challenge misinformation provided to PWE and family members. | members of the MDT, including junior nursing and medical colleagues. |
| **4** | Supported development of more junior ESN and candidate ANPs in line with the aims of Clinical Care Programme | The RANPs mentored and supported more junior ESNs at CNS and candidate-ANP level, within and outside their own service. They assisted them to develop and expand services, develop guidelines and policies, and achieve clinical competencies required for registration with the NMBI. | ESNs were networking across services with other ESNs and through email forums. They were teaching on epilepsy and prescribing modules that were part of candidate ANPs' preparation. | Data not collected. | DoN/ADoNs commented on the role of the RANP in mentoring and supporting candidate ANPs. |

### *Outcomes specific to the health service*

In total nine outcomes specific to the health service were identified, with between three and five data sources supporting the impact of the ESN on these outcomes (table 9.3). In addition to increasing the number and range of services available to PWE, the ESN also increased accessibility to specialist epilepsy care by decentralising services, and developing the TAL and outreach service. The presence of the TAL was perceived to reduce attendance at ED departments, with some evidence that the ESN improved continuity of care and patient flow, as well as reduced waiting times to be seen. The ESN improved communication between a wide range of healthcare practitioners, across disciplines, services and the care continuum, and were perceived by PWE, family and all stakeholders as being a central point of contact for information on the person and family. In addition, through their work on policies, guidelines and audits, the ESNs were central in promoting, maintaining and monitoring the national epilepsy SOPs as well as other quality standards developed for epilepsy services.

In relation to the economic outcomes, utilisation of health services was analysed for PWE treated with an ESN and those without an ESN. In terms of nights spent in hospital, planned nights in hospital were largely similar between ESN and Non-ESN sites, while unplanned nights were higher in ESN sites suggesting that patients at Non-ESN sites may have more well-controlled disease. As anticipated, outpatient visits are higher among patients in ESN sites compared to Non-ESN sites and this difference is statistically significant.

In relation to GP visits, there were slightly fewer visits per patient in ESN sites compared to Non-ESN sites. This could be related to the more intensive management of patients by ESNs, meaning they require fewer visits to their GP for the treatment and maintenance of their epilepsy or that the outpatient visits are substituting for visits to the GP.

Overall, the economic analysis found that costs were higher among PWE in ESN sites. However, on further analysis of high cost PWE and excluding the data from Site I, there was either no difference in cost or PWE in Non-ESN sites had higher medical costs.

Although the economic component of the study found no difference in cost between ESN and Non-ESN sites, the ESN service did improve the efficiency of services. By absorbing some of the roles traditionally the remit of the medical consultant, ESNs reduced the time medical consultants spent dealing with issues, enabling them to utilise time more efficiently with potential cost saving implications. Outreach clinics also resulted in reducing the time and potential costs associated with services providing clinical staff to accompany PWE with ID to hospital appointments.

In conclusion, based on all of the evidence, it is suggested that patients who receive care with an ESN have the same costs as those treated in a Non ESN site. Sites with an ESN may be good value if they improve the patient experience at no change in cost.  There is evidence from this study of improved experience and better management and coordination of Epilepsy care, and the data show that there is an improvement at no net cost.

**Table 9.3: Outcomes specific to the health service**

| | | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|---|
| **1** | Increased epilepsy services available to PWE | ESNs expanded the range of services available and led on the development of new services, including TAL, VNS clinics, rapid access clinics and outreach clinics. | Evidence of ESNs developing and expanding services within their own sites. Evidence of RANPs supporting ESNs to develop services in other sites, such as VNS clinics. | Data not collected. | Family members of PWE spoke of difference in having VNS clinic locally as it prevented them having to travel long distances with the PWE to avail of services. | Key stakeholders identified the range of services that the ESNs expanded and developed, and acknowledged their role in making available specialist epilepsy to a greater number of people, particularly to people with ID. |
| **2** | Increased accessibility of service | Evidence that RACs, TAL and local VNS clinics, facilitated rapid access and increased accessibility. | ESNs collaborated with other services to develop an outreach clinic in an ID service and a clinic in a maternity service. | Those in ESN sites were significantly more likely to agree that they had to wait a 'reasonable amount of time' to be seen and that appointments could be easily made compared to those in Non-ESN sites. Survey comments highlighted the accessibility of ESNs through TAL and their responsiveness to | PWE indicated that the provision of the TAL also increased accessibility of the service. The liaison and co-ordinating role of the ESN also helped them access services of allied health professionals. | Stakeholders felt that access was improved through the availability of ESNs with specialist knowledge and prescribing authority. |

| | | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|---|
| | | | | peoples' needs. | | |
| **3** | Reduced errors in written and electronic records | ESNs conducted a comprehensive quality assurance process of information recorded in EPR which was then used to inform MDT decision-making. Some ESNs were leading on collecting information on changes required to EPR and communicating to the EPR team with responsibility for changes. | Evidence of auditing the accuracy of information recorded on EPR and the readability, safety and quality of letters generated through the EPR. | Data not collected. | | Medical personnel identified that the ESNs were central to the roll-out of the EPR, including consenting PWE and populating the database with the information required. |
| **4** | Reduced waiting times for PWE | ESNs worked to improve patient flow through the system. ESNs prioritised people with ID during clinical visits. The ESN's prescribing powers also contributed to reducing waiting times. | Evidence of ESNs completing audits on time taken to triage into ESN services, waiting times for PWE in nurse-led clinics, and outpatient referral times. | Those in ESN sites were significantly more likely to agree that they had to wait a 'reasonable amount of time' to be seen and that appointments could be easily made compared to those in Non-ESN sites. | While responsiveness was generally considered good and waiting times less, a small number of participants in one focus group did cite examples of long waiting times. | Evidence that those presenting at A&E are quickly attended to by ESNs, and that both TAL and the outreach services provided by ESNs reduced waiting times. |

|  |  | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|---|
| **5** | Reduced admissions and attendance at ED | TAL, rapid access clinics, and ESNs conducting triage work in the ED identified as impacting positively on hospital attendance and hospital admissions. | ESNs developed admission protocols. Also evidence of audit of A&E admissions to support case for more service expansion. |  |  | Identified the TAL and the RAC as instrumental in avoiding ED visits and that ESNs try to avoid admission if possible. |
| **6** | Improved continuity of care | Evidence from observation data indicated that the ESNs were using the TAL to follow-up on PWE after consultations, and identifying and following-up on PWE who missed appointments. | Evidence of ESN developing care pathway and auditing percentage of new referrals contacted by ESN within 10 days of receipt of referral. | Not statistically significantly better in ESN sites compared to Non-ESN sites. Nevertheless open-ended comments at end of surveys indicated that PWE valued seeing the same ESN on each visit. | PWE expressed satisfaction with continuity of care and reported that the ESN's familiarity with and knowledge of their situations avoided their need to repeat information. The TAL enabled ESN to follow-up and respond promptly. | MDT stakeholders reported better continuity of care due to presence of ESN. |
| **7** | Improved communication across MDT and services. | ESNs communicated with a wide range of healthcare practitioners, across disciplines, services and the care continuum. Also evidence that the |  |  | Focus group participants commented on the close liaison ESNs had with the medical team and how this contributed to better | MDT stakeholders identified ESNs as central point of contact for information about PWE as they were perceived as having a detailed knowledge of |

| | | Evidence from ESN interviews and observation | Evidence from ESN documentary data | Evidence from survey data from PWE | Evidence from focus groups with PWE and family members | Evidence from interview with other stakeholders |
|---|---|---|---|---|---|---|
| | | EPR facilitated prompt tracking of MDT communication and interventions. | | | co-ordination and communication regarding their care. | seizure history and psychosocial context. |
| **8** | Efficient use of resources | ESNs identified the efficient use of resources as an outcome. By carrying out roles that are traditionally within the domain of medical personnel, such as patient assessment, prescribing and running clinics, ESNs reduced the time required by a neurologist or other medical personnel for patient consultation with potential to reduce costs. Outreach clinics also resulted in reducing the costs associated with services providing clinical staff to | | Although the economic analysis did not find evidence of reduced costs, ESNs were the first point of contact for 51% of PWE in ESN sites, whereas medical doctor or pharmacist was first point of contact for 67% of PWE in Non-ESN sites. | | |

| | | **Evidence from ESN interviews and observation** | **Evidence from ESN documentary data** | **Evidence from survey data from PWE** | **Evidence from focus groups with PWE and family members** | **Evidence from interview with other stakeholders** |
|---|---|---|---|---|---|---|
| | | accompany PWE with ID to hospital appointments. | | | | |
| **9** | Promoted quality improvement | ESNs were completing audits and small-scale research projects that informed ongoing quality improvements. Some ESNs were collaborators or co-applicants on funded research. | Evidence of i) completing audits of the SOPs and KPIs developed by the NECP and small scale research; ii) using findings to improve services; and iii) dissemination of evidence to MDT within and outside service. | Data not collected. | | DoNs spoke of the ESNs presenting findings from audits to senior management and using information from audits to inform changes in practice. Medical personnel completing audits in conjunction with ESNs, using the information to argue for resources and service developments. |

## Contextual and mediating factors that impact on role development and future sustainability

While many factors positively supported the role, role development and integration was not without its challenges. Contextual and mediating factors that both supported and challenged role development were identified at a healthcare systems level, organisational level, team level, practitioner level and patient level. Positively, many of the barriers to the development and integration of the ESN role identified in international literature were not evident in this study. In addition to the NECP in epilepsy acting as a driver, there was strong support for the role among medical and nursing personnel, positive appraisals of ESNs' competence, and by and large ESNs had established formal and informal support mechanisms for sharing and addressing issues that crossed discipline, service and national boundaries.

Mediating factors that were barriers to role development and possibly future sustainability included large clinical caseloads, role overload, limited access to structural supports and resources, as well as the demands of achieving the requirements to become a RANP. Together, these conditions challenged ESNs in the performance of all aspects of their role, but had particular impact on the research dimension of the role, as in a time pressured context the ESNs prioritised the clinical and developmental aspects of their role. A lack of 'critical mass' of ESNs within services was also a challenge to the provision of a consistent service to PWE, with some services, particularly in sites where one or two ESNs were employed, having to reduce the services offered if ESNs were on extended leave for any reason. Some reservations were also expressed about a model of career pathway that omits the CNS role within the SN-CNS-RANP career progression. In addition, one factor at patient level was identified, that could be both an enabler and a barrier; this was the acceptance or otherwise of the ESN role by PWE and families.

## Strengths and limitations

In establishing the value and significance of the findings of the study, the following strengths and limitations need to be considered. A strength of the study is that it utilised a mixed methods design and collected both qualitative and quantitative data from a variety of stakeholders in different sites and included a survey of PWE attending services with and without ESN posts. In addition, the research was undertaken by an independent team, comprised of experienced researchers with a sound understanding of mixed methods research, economic analysis, and clinical practice, and previous experience of conducting national studies of CNSs/ANPs. However, it does have certain limitations, including using a non-probability sample of PWE, convenience as opposed to random sampling of people for the focus groups, low response rates from people newly diagnosed with epilepsy and challenges in obtaining economic data. Difficulties accessing relevant HIPE records for each site meant that comparison based on service records could not be obtained, so utilisation data had to be collected at the patient-level with questions added to the main **SEN**s**E** patient survey. Consequently, a precise measurement of disease severity for PWE was not possible within the study. Some observed differences in healthcare utilisation and time spent off work may relate to case complexity and this is not adjusted for in the economic data.

## Recommendations

In light of the findings and limitations, recommendations are proposed under the following headings: expansion of ESN services and resources to support; model and location of ESN service; areas for future development and improvement by ESNs; ongoing professional development for ESNs and future research.

### *Expansion of ESN service and resources to support*

- This mixed methods evaluation has demonstrated very positive outcomes of the ESN role to PWE, their families, members of the MDT and the health service; therefore, it is recommended that the ESN service be expanded nationally in line with the vision outlined in the Epilepsy Clinical Care Programme, whereby all PWE have access to an ESN service (HSE 2014).
- A major factor that was considered to impact negatively on services provided and the sustainability of services provided by the ESNs was the number of ESN posts within a service. In light of the findings that indicated that ESN services had to be reduced or withdrawn in sites with low numbers of ESNs in post, due to absences including statutory leave, it is recommended that a critical mass of ESN posts (no fewer than 3) be created in all services.

- Further development and expansion of specialist ESN services in the areas of women's health, ID, children/adolescents, mental health and older age is essential to facilitate these groups having equitable access to specialist epilepsy care and treatment, as currently access is dependent on geography. However, this needs to occur in the context of increasing numbers of ESNs in sites as there is a major risk that burgeoning caseloads will have a negative impact on the quality of service currently provided.
- A lack of structural supports was one of the key challenges to the ESNs performing their role. While some ESNs had access to administrative and IT support, others had limited access. Few had access to specialist epilepsy journals, and most were delivering care in less than ideal physical surroundings. Given the impact of lack of structural supports on the ESN's ability to enact all dimensions of their role, it is recommended that deficits in structural supports be addressed as easy accessibility to key sources of evidence is critical if ESNs are to enact the evidence-based practice dimension of their role.

### *Model and location of ESN service*

- Some people were of the view that the remit of the ESN should be redirected from tertiary services to community and primary care services to reflect the fact that a huge part of epilepsy care is chronic disease management. However, given the findings that indicate the positive benefits of the current model (access to specialist medical personnel, allied health professionals, mentorship and supervision), any change requires detailed analysis of the implications for governance, the type and quality of care provided, the workload of ESNs and other members of the MDT, and resources required, such as accommodation, administration, and financial.

- The intensive commitment required on behalf of the ESN to achieve RANP accreditation, including time and financial resources, was seen as a potential barrier to the ongoing development of future ESN roles in line with the aims of the Clinical Care Programme. Given these challenges and the likelihood that not all nurses wish to advance their career to the RANP level, it is recommended that consideration be given to including the CNS role within the SN-CNS-RANP career progression for ESNs.

### *Areas for future development and improvement by ESNs*

- Findings from the study clearly indicate that the mean scores of PWE attending ESN sites were higher than those attending Non-ESN sites for information provided; however, there are still some deficits that could be improved. In light of the findings it is recommended that ESNs give consideration to strategies for improving information provided on all aspects of epilepsy care, with specific emphasis on how to keep a seizure diary, how to explain and discuss epilepsy to others, and epilepsy and employment.
- Notwithstanding all the work that the ESNs were doing to improve the experience of PWE who attended ED services and the current crisis that all ED services are facing, given family members' negative experiences in ED there is a need for the ESNs in all services to educate staff working in ED on epilepsy and epilepsy care, and to develop care pathways for PWE who attend ED.
- Findings from this study suggest that a small minority of PWE continue to have a preference for care from medical consultants as they are more trusting of their advice, especially around medication. Although this was not a widespread issue this finding indicates a need for ESNs and services not to assume patient and family acceptance of the role, especially in the current economic climate where service changes may be interpreted as cost-cutting exercises. Therefore it is recommended that all involved continue to profile the role and expertise of the ESN to the general public, PWE attending the service and indeed the media who are key transmitters of information to the public.

- Whilst the ESNs were providing support and education to General Practitioners, there was an absence of any visibility or mention of practice nurses, in light of this it is recommended that ESNs consider developing an education programme and protocols for practice nurses in the area of epilepsy, as practice nurses are ideally placed to provide education and support to PWE who are not in need of ongoing specialist care.
- Although the ESNs working in the area of epilepsy surgery are identified in the epilepsy Clinical Care Programme, their role and expertise appeared to be less well integrated into the overall programme. In light of this it is recommended that the clinical lead, including the wider ESN group consider how their role can be integrated with greater visibility, including as a dimension of the educational preparation of future ESNs.
- One of the roles of all nurses is the education and mentorship of undergraduate student nurses. Whilst the ESNs were very active in educating members of the MDT and qualified nurses, by inputting into formal and informal education programmes and by providing shadowing opportunities, undergraduate student nurses were not automatically placed with the ESNs as part of their education programme. Given the richness of such an experience in terms of learning skills in chronic disease management, it is recommended that the ESNs and third level educators explore the possibility of using ESN services as a placement for student nurse training.
- In light of the challenges that the ESNs face in completing, disseminating and acquiring funding for research, it is recommended that the ESNs forge relationships with nursing and midwifery academic schools to advance the research agenda in epilepsy nursing.

### *Ongoing professional development of ESNs*

- The majority of the ESNs observed were clearly enacting the leadership dimension of their role, however, there was limited evidence that they were being provided with education, mentorship, coaching or opportunities required to advance their leadership competencies, especially at a national or international level. It is recommended that senior nursing and medical personnel give consideration to how the ESN's leadership competencies could be enhanced and supported.
- In view of the variability of skill in relation to mental health and the challenges in accessing care, it is recommended that ESNs be provided with further education in the area of mental health, and consideration be given to developing an ESN role that incorporates advanced mental health competencies within each team, to respond to the needs of people with mental health co-morbidities and non-epileptic form seizures.

### *Further research*

- This evaluation was completed in the very early stage of the roll-out of the Epilepsy Clinical Care Programme, consequently, although experienced nurses were represented, some of the ESNs included in the study were new to the ESN role. It is therefore recommended that a further evaluation be undertaken in 5-7 years, using the outcome indicators identified to measure the impact of the ESN role on PWE, their families, the MDT, and the health service.
- Evidence from this research suggests that collectively the services that the ESNs developed, such as nurse-led clinics, TAL, VNS clinics, RACs and group education programmes for PWE have a positive impact on PWEs' experience of care, satisfaction with care as well as service outcomes; however, further research needs to be undertaken to evaluate the impact and cost of each individual service.
- Further research is also needed into the needs of people with non-epileptic form seizures and, in the absence of appropriate psychological and mental health services, the time spent by ESNs supporting people with co-morbid mental health issues or non-epileptic form seizures.
- In the absence of clear information on the needs of family members, especially those who are caring for people with ID, it is recommended that epilepsy research

- In the absence of clear information on the needs of family members, especially those who are caring for people with ID, it is recommended that epilepsy research be undertaken into their needs with a view to identifying how best to respond to the needs identified.
- Further research is needed from an economic perspective in terms of accessing data on casemix for PWE. Measuring disease severity would enable a more robust comparison of costs of patients treated in ESN sites compared to Non-ESN sites. With the ongoing development of the Epilepsy Electronic Patient Record, in the future, this repository could be interrogated and the analysis of large volumes of patient information may be possible.

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# Appendices

## Appendix 1a: Response rate to retrospective survey (retrospective survey)

### Response rate by site

|  | Non-ESN (n, %) | ESN (n, %) |
|---|---|---|
| **Site** | (n= 261) | (n= 244) |
| **A** | - | 85, 34.8% |
| **B** | - | 96, 39.3% |
| **C** | - | 63, 25.8% |
| **F** | 26, 10% | - |
| **G** | 96, 36.8% | - |
| **H** | 28, 10.7% | - |
| **I** | 103, 39.5% | - |
| **J** | 8, 3.1% | - |

## Appendix 1b: Demographic profile of survey participants (retrospective survey)

| | Non-ESN (n, %) | ESN (n, %) | $X^2$ | P |
|---|---|---|---|---|
| **Gender** | (n= 257) | (n= 243) | .188 | .366$^{ns}$ |
| Male | 116, 45.1% | 105, 43.2% | | |
| Female | 141, 54.9% | 138, 56.8% | | |
| **Age Group** | (n= 260) | (n= 248) | 16.418 | .012$^{*}$ |
| 18-20 | 23, 9.2% | 17, 7.2% | | |
| 21-30 | 57, 22.8% | 69, 29.1% | | |
| 31-40 | 63, 25.2% | 81, 34.2% | | |
| 41-50 | 47, 18.8% | 27, 11.4% | | |
| 51-60 | 35, 14% | 23, 9.7% | | |
| 61-70 | 16, 6.4% | 18, 7.6% | | |
| 71-80 | 9, 3.6% | 2, .8% | | |
| **Relationship Status** | (n= 240) | (n= 233) | 3.89 | .421$^{ns}$ |
| Single | 84, 35% | 93, 39.9% | | |
| In a relationship | 56, 22.8% | 59, 25.3% | | |
| Married/ Civil Partnership | 89, 36.2% | 70, 30% | | |
| Separated/ Divorced | 13, 5.3% | 7, 3% | | |
| Widowed | 3, 1.2% | 4, 1.7% | | |
| **Living Arrangements** | (n= 239) | (n= 231) | 6.020 | .198$^{ns}$ |
| Live alone | 30, 12.6% | 21, 9.1% | | |
| Live with family | 185, 77.4% | 179, 77.5% | | |
| Live with flatmates/ friends | 8, 3.3% | 17, 7.4% | | |
| Supported accommodation/ | 3, 1.3% | 5, 2.2% | | |
| Residential Care | 13, 5.4% | 9, 3.9% | | |
| Other | - | - | | |
| **Ethnicity** | (n= 239) | (n= 233) | 6.260 | .282$^{ns}$ |
| White Irish | 214, 89.5% | 215, 92.3% | | |
| White Irish Traveler | 3, 1.3% | 2, 0.9% | | |
| White Non Irish | 19, 7.9% | 11, 4.7% | | |
| Black or Black Irish | 0, 0.0% | 3, 1.3% | | |
| Asian or Asian Irish | 1, 0.4% | 0, 0.0% | | |
| Other Including Mixed | 2, 0.8% | 2, 0.9% | | |
| **Highest Level of Education** | (n= 243) | (n= 232) | 5.803 | 0.214$^{ns}$ |
| No Formal Education | 3, 1.2% | 3, 1.3% | | |
| Primary Education | 29, 11.9% | 16, 6.9% | | |
| Secondary Education | 103, 42.4% | 92, 39.7% | | |
| Technical / Vocational Education | 21, 8.6% | 30, 12.9% | | |
| Third Level Education | 87, 35.8% | 91, 39.2% | | |

| | **Non-ESN (n, %)** | **ESN (n, %)** | **$X^2$** | **P** |
|---|---|---|---|---|
| **Current Work Status** | (n= 241) | (n= 231) | 3.901 | .690$^{ns}$ |
| Working for payment or profit | 81, 33.6% | 82, 35.5% | | |
| Unemployed looking for work | 26, 10.8% | 37, 16.0% | | |
| Student or pupil | 24, 10.0% | 20, 8.7% | | |
| Looking after home or family | 22, 9.1% | 20, 8.7% | | |
| Retired from employment | 17, 7.1% | 13, 5.6% | | |
| Unable to work | 58, 24.1% | 47, 20.3% | | |
| Other | 13, 5.4% | 12, 5.2% | | |

*ns not significant *significant at $p < 0.05$*

## Appendix 1c: Epilepsy profile of survey participants by site (retrospective survey)

| | Non-ESN (n, %) | ESN (n, %) | $X^2$ | P |
|---|---|---|---|---|
| **Length of time of having epilepsy** | (n= 257) | (n= 243) | .966 | $0.915^{ns}$ |
| Less Than A Month | 3, 1.2% | 1, .4% | | |
| Less Than A Year | 7, 2.7% | 7, 2.9% | | |
| 1-2 Years | 21, 8.2% | 19, 7.8% | | |
| 3-4 Years | 27, 10.5% | 27, 11.1% | | |
| 5+ Years | 199, 77.4% | 189, 77.8% | | |
| **Currently taking AEDs** | (n= 250) | (n= 238) | 3.349 | $0.67^{ns}$ |
| Yes | 250, 96.2% | 238, 98.8% | | |
| No | 10, 3.8% | 3, 1.2% | | |
| **Frequency of missed dose** | (n= 244) | (n= 232) | .763 | $0.858^{ns}$ |
| Once a week | 13, 5.3% | 13, 5.6% | | |
| Few times a month | 23, 9.4% | 17, 7.3% | | |
| Few times a year | 34, 13.9% | 31, 13.4% | | |
| Rarely/ Never | 174, 71.3% | 171, 73.7% | | |
| **Have vagal nerve stimulator (VNS)** | (n= 247) | (n= 230) | .989 | $0.32^{ns}$ |
| Yes | 11, 4.5% | 15, 6.5% | | |
| No | 236, 95.5% | 215, 93.5% | | |
| **Have had surgery for epilepsy** | (n= 258) | (n= 243) | 8.226 | $0.004^{**}$ |
| Yes | 14, 5.4 | 31, 12.8% | | |
| No | 244, 94.6% | 212, 87.2% | | |
| **Frequency of seizures** | (n= 255) | (n= 238) | 4.282 | $0.510^{ns}$ |
| Daily | 7, 2.7% | 13, 5.5% | | |
| Few Times a Week | 18, 7.1% | 18, 7.6% | | |
| Few Times a Month | 42, 16.5% | 41, 17.2% | | |
| Few Times a Year | 56, 22% | 49, 20.6% | | |
| Seizure Free | 106, 39.2% | 80, 33.6% | | |
| Other | 32, 12.5% | 37, 15.5% | | |
| **Duration of seizures** | (n= 139) | (n= 147) | 6.573 | $0.160^{ns}$ |
| Less than 10 second | 10, 7.2% | 17, 11.6% | | |
| 10 – 59 seconds | 40, 28.8% | 45, 30.6% | | |
| 1 – 10 minutes | 70, 50.4% | 74, 50.3% | | |
| 11 – 30 minutes | 8, 5.8 % | 8, 5.4% | | |
| > 30 minutes | 11, 7.9% | 3, 2% | | |
| **Recovery time after a seizure** | (n= 156) | (n= 159) | 2.889 | $0.717^{ns}$ |
| Less than 1 minute | 24, 15.4% | 23, 14.5% | | |
| 1 – 10 minutes | 38, 24.4% | 36, 22.6% | | |
| 11 – 30 minutes | 19, 12.2% | 30, 18.9% | | |
| 31 – 59 minutes | 14, 9% | 15, 9.4% | | |

| | Non-ESN (n, %) | ESN (n, %) | $X^2$ | P |
|---|---|---|---|---|
| 1 – 3 hours | 29, 18.6% | 27, 17.0% | | |
| More than 3 hours | 32, 20.5% | 28, 17.6% | | |

*ns not significant **significant at* $p < 0.01$

### Types of symptoms experienced during seizures by site

| Types of Symptoms | Non-ESN (n, %) | ESN (n, %) | $X^2$ | P |
|---|---|---|---|---|
| **Loss of awareness** | | | | |
| Yes | 111, 71.2% | 125, 78.1% | 2.030 | $0.154^{ns}$ |
| No | 45, 28.8% | 35, 21.9% | | |
| **Warning or Aura** | | | | |
| Yes | 80, 51.3% | 103, 64.4% | 5.555 | $0.018^{*}$ |
| No | 76, 48.7% | 57, 35.6% | | |
| **Drop/ Spill Object** | | | | |
| Yes | 60, 38.5% | 56, 35% | .407 | $0.523^{ns}$ |
| No | 96, 61.5% | 104, 65% | | |
| **Fall to Ground** | | | | |
| Yes | 88, 56.4% | 85, 53.1% | .557 | $.344^{ns}$ |
| No | 68, 43.3% | 75, 46.9% | | |
| **Injury** | | | | |
| Yes | 70, 44.9% | 68, 42.5% | .181 | $.671^{ns}$ |
| No | 86, 55.1% | 92, 57.5% | | |
| **Tongue Biting** | | | | |
| Yes | 65, 41.7% | 75, 46.9% | .868 | $.351^{ns}$ |
| No | 91, 58.3% | 85, 53.1% | | |
| **Incontinent** | | | | |
| Yes | 45, 28.8% | 39, 24.4% | .809 | $.368^{ns}$ |
| No | 111, 71.2% | 121, 75.6% | | |
| **Automatism** | | | | |
| Yes | 65, 41.7% | 58, 36.3% | .975 | $.323^{ns}$ |
| No | 91, 58.3% | 102, 63.8% | | |
| **Convulsion** | | | | |
| Yes | 92, 59% | 98, 61.3% | .171 | $.680^{ns}$ |
| No | 64, 41% | 62, 38.8% | | |
| **Staring** | | | | |
| Yes | 84, 53.8% | 101, 63.1% | 2.802 | $.094^{ns}$ |
| No | 72, 46.2% | 59, 36.9% | | |
| **Confusion, Agitation** | | | | |
| Yes | 109, 69.8% | 110, 68.8% | 0.047 | $.829^{ns}$ |
| No | 47, 30.1% | 50, 31.3% | | |

*ns not significant *significant at* $p < 0.05$

# Appendix 2a: Demographic profile of participants (Prospective survey: newly diagnosed patients at time point 1)

## Demographic information of survey 1 participants

| | Total<br>%(n)/ M(SD) | Non-ESN<br>%(n)/ M(SD) | ESN<br>%(n)/ M(SD) |
|---|---|---|---|
| **Gender** | | | |
| Male | 58.3 (49) | 38.5 (5) | 42.3 (30) |
| Female | 41.7 (35) | 61.5 (8) | 57.7 (41) |
| **Average Age** | | | |
| | 36.93 (15.15) | | |
| **Highest Level of Education** | | | |
| Primary | 6.0 (5) | 23.1 (3) | 2.8 (2) |
| Secondary | 47.6 (40) | 23.1 (3) | 52.1 (37) |
| Technical/Vocational | 9.5 (8) | 23.1 (3) | 7 (5) |
| Third Level | 36.9 (31) | 30.8 (4) | 38 (27) |
| **Ethnicity** | | | |
| White Irish | 92.9 (79) | 100 (13) | 91.7 (6) |
| White non Irish | 4.7 (4) | - | 5.6 (4) |
| Asian or Asian Irish | 1.2 (1) | - | 1.4 (1) |
| Other including mixed | 1.2 (1) | - | 1.4 (1) |
| **Relationship status** | | | |
| Single | 37.6 (32) | 53.8 (7) | 34.7 (25) |
| In a relationship | 30.6 (26) | 23.1 (3) | 31.9 (23) |
| Married/ Civil Partnership | 24.7 (21) | 15.4 (2) | 26.4 (19) |
| Separated / divorced | 5.9 (5) | 7.7 (1) | 5.6 (4) |
| Widowed | 1.2 (1) | - | 1.4 (1) |
| **Living arrangements** | | | |
| Live alone | 7.1 (6) | - | 8.3 (6) |
| Live with family | 77.6 (66) | 100 (13) | 73.6 (53) |
| Live with flatmates / friends | 5.9 (5) | - | 6.9 (5) |
| Other | 9.4 (8) | - | 11.1 (8) |
| **Work status** | | | |
| Working for payment or profit | 38.1 (32) | 23.1 (3) | 40.8 (29) |
| Unemployed looking for work | 16.7 (14) | 23.1 (3) | 15.5 (11) |
| Student or pupil | 11.9 (10) | 23.1 (3) | 9.9 (7) |
| Looking after home or family | 3.6 (3) | - | 4.2 (3) |
| Retired from employment | 6.0 (5) | - | 7 (5) |
| Unable to work | 17.9 (15) | 30.8 (4) | 15.5 (11) |
| Other | 6.0 (5) | - | 7 (5) |

## Appendix 2b: Epilepsy profile of participants (Prospective survey: newly diagnosed patients at time point 1)

| | Point 1 survey participants %(n) |
|---|---|
| **Seizure frequency within past year** | |
| Daily | 2.4 (2) |
| Few times a week | 9.8 (8) |
| Few times a month | 13.4 (11) |
| Few times a year | 39.0 (32) |
| Few times in total | 7.3 (6) |
| Once | 8.8 (8) |
| None (Seizure free) | 8.5 (7) |
| Don’t know | 1.2 (1) |
| Other | 8.5 (7) |
| **Seizure duration** | |
| Less than 10s | 6.3 (5) |
| 10 – 59 seconds | 25.0 (20) |
| 1 - 10 mins | 42.5 (34) |
| 11 - 30 mins | 8.8 (7) |
| More than 30 mins | 2.5 (2) |
| I don't know | 15.0 (12) |
| **Seizure recovery time** | |
| Less than 1 Min | 13.6 (11) |
| 1 - 10 mins | 21.0 (17) |
| 11 - 30 mins | 13.6 (11) |
| 31 - 59 mins | 13.6 (11) |
| 1 - 3 hrs | 12.3 (10) |
| More than 3 hrs | 25.9 (21) |

## Appendix 2c: Demographic profile of matched survey participants (Prospective survey: newly diagnosed patients)

| | Non-ESN<br>%(n)/ M(SD) | ESN<br>% (n)/ M(SD) |
|---|---|---|
| **Gender** | | |
| Male | 33.3 (2) | 38.5 (15) |
| Female | 66.7 (4) | 59.0 (23) |
| **Average Age** | | |
| | 30 (11.96) | 42 (14.82) |
| **Highest Level of Education** | | |
| Primary | 33.3 (2) | 2.6 (1) |
| Secondary | 16.7 (1) | 56.4 (22) |
| Technical/Vocational | 33.3 (2) | 5.1 (2) |
| Third Level | 16.7 (1) | 35.9 (14) |
| **Ethnicity** | | |
| White Irish | 100 (6) | 89.7 (35) |
| White non Irish | - | 7.7 (3) |
| Asian or Asian Irish | - | - |
| Other including mixed | - | 2.6 (1) |
| **Relationship Status** | | |
| Single | 16.7 (1) | 30.8 (12) |
| In a relationship | 50.0 (3) | 33.3 (13) |
| Married/ Civil Partnership | 16.7 (1) | 28.2 (11) |
| Separated / divorced | 16.7 (1) | 5.1 (2) |
| Widowed | - | 2.6 (1) |
| **Living arrangements** | | |
| Live alone | - | 7.7 (3) |
| Live with family | 100 (6) | 79.5 (31) |
| Live with flatmates / friends | - | 5.1 (2) |
| Other | - | 7.7 (3) |
| **Work Status** | | |
| Working for payment or profit | 33.3 (2) | 41.0 (16) |
| Unemployed looking for work | 33.3 (2) | 15.4 (6) |
| Student or pupil | 16.7 (1) | 7.7 (3) |
| Looking after home or family | - | 2.6 (1) |
| Retired from employment | - | 5.1 (2) |
| Unable to work | 16.7 (1) | 15.4 (6) |
| Other | - | 12.8 (5) |

## Appendix 2d: Demographics of non-participants vs. participants to follow-up survey (newly diagnosed patients)

| | Non-participants to follow-up %(n)/ M(SD) | Participants to follow-up % (n)/ M(SD) |
|---|---|---|
| **Gender** | | |
| Male | 45 (18) | 38.6% 917) |
| Female | 55 (22) | 61.4 (27) |
| **Average Age** | 33.41 (14.85) | 40.12 (14.87) |
| **Highest Level of Education** | | |
| Primary | 5.1 (2) | 6.7 (3) |
| Secondary | 43.6 (17) | 51.1 (23) |
| Technical/Vocational | 10.3 (4) | 8.9 (4) |
| Third Level | 41.0 (16) | 33.3 (15) |
| **Ethnicity** | | |
| White Irish | 95.0 (38) | 91.1 (41) |
| White non Irish | 2.5 (1) | 6.7 (3) |
| Asian or Asian Irish | 2.5 (1) | - |
| Other including mixed | | 2.2 (1) |
| **Relationship Status** | | |
| Single | 47.5 (19) | 28.9 (13) |
| In a relationship | 25.0 (10) | 35.6 (16) |
| Married/ Civil Partnership | 22.5 (9) | 26.7 (12) |
| Separated / divorced | 5.0 (2) | 6.7 (3) |
| Widowed | - | 2.2 (1) |
| **Living arrangements** | | |
| Live alone | 7.5 (3) | 6.7 (3) |
| Live with family | 72.5 (29) | 82.2 (37) |
| Live with flatmates / friends | 7.5 (3) | 4.4 (2) |
| Other | 12.5 (5) | 6.7 (3) |
| **Work Status** | | |
| Working for payment or profit | 35.9 (14) | 40.0 (18) |
| Unemployed looking for work | 15.4 (6) | 17.8 (8) |
| Student or pupil | 15.4 (6) | 8.9 (4) |
| Looking after home or family | 5.1 (2) | 2.2 (1) |
| Retired from employment | 7.7 (3) | 4.4 (2) |
| Unable to work | 20.5 (8) | 15.6 (7) |
| Other | - | 11.1 (5) |

## Appendix 2e: Seizure profile of matched participants (new patients)

| | Non-ESN %(n) | ESN % (n) |
|---|---|---|
| **Seizure Frequency within past year** | | |
| Daily | - | - |
| Few times a week | 16.7 (1) | 5.3 (2) |
| Few times a month | 33.3 (2) | 10.5 (4) |
| Few times a year | 16.7 (1) | 31.6 (12) |
| Few times in total | | 13.2 (5) |
| Once | 16.7 (1) | 15.8 (6) |
| None (Seizure free) | 16.7 (1) | 7.9 (3) |
| Don’t know | - | 2.6 (1) |
| Other | - | 13.2 (5) |
| **Seizure duration** | | |
| Less than 10s | - | 5.3 (2) |
| 10 – 59 seconds | 16.7 (1) | 18.4 (7) |
| 1 - 10 mins | 50.0 (3) | 44.7 (17) |
| 11 - 30 mins | 16.7 (1) | 5.3 (2) |
| More than 30 mins | - | 2.6 (1) |
| I don't know | 16.7 (1) | 23.7 (9) |
| **Seizure recovery time** | | |
| Less than 1 Min | - | 8.1 (3) |
| 1 - 10 mins | 33.3 (2) | 24.3 (9) |
| 11 - 30 mins | - | 2.7 (1) |
| 31 - 59 mins | - | 18.9 (7) |
| 1 - 3 hrs | 16.7 (1) | 13.5 (5) |
| More than 3 hrs | 50 (3) | 32.4 (12) |

### Types of symptoms experienced during seizures by site

| Types of Symptoms | Non -ESN<br>%(n) | ESN<br>% (n) |
|---|---|---|
| **Loss of awareness** | | |
| Yes | 66.7 (4) | 74.4 (29) |
| No | 16.7 (1) | 25.6 (10) |
| **Warning or Aura** | | |
| Yes | 66.7 (4) | 43.6 (17) |
| No | 16.7 (1) | 56.4 (22) |
| **Drop/ Spill Object** | | |
| Yes | 40 (2) | 20.5 (8) |
| No | 60 (3) | 79.5 (31) |
| **Fall to Ground** | | |
| Yes | 60 (3) | 51.3 (20) |
| No | 40 (2) | 48.7 (19) |
| **Injury** | | |
| Yes | 40 (2) | 28.2 (11) |
| No | 60 (3) | 71.8 (28) |
| **Tongue Biting** | | |
| Yes | 40 (2) | 51.3 (20) |
| No | 60 (3) | 48.7 (19) |
| **Incontinent** | | |
| Yes | 60.0 (3) | 12.8 (5) |
| No | 40.0 (2) | 87.2 (34) |
| **Automatism** | | |
| Yes | 40 (2) | 28.2 (11) |
| No | 60 (3) | 71.8 (28) |
| **Convulsion** | | |
| Yes | 60 (3) | 79.5 (31) |
| No | 40 (2) | 20.5 (8) |
| **Staring** | | |
| Yes | 40 (2) | 35.9 (14) |
| No | 60 (3) | 64.1 (25) |
| **Confusion, Agitation** | | |
| Yes | 80 (4) | 61.5 (24) |
| No | 20 (1) | 38.5 915) |

## Appendix 3: First and second level codes

**Clinical practice**

- Completes comprehensive assessment of patient needs to inform care and treatment
- Provides patient-centered information to empower patients towards self-management
- Develops collaborative working relationship to empower patients to self-manage
- Co-ordinates care and care pathway to enhance patient journey
- Where appropriate, provides information to empower family
- Reduces burden on patients and family
- Manages caseload

**Research**

- Accumulates evidence
- Applies evidence
- Translates evidence
- Produces/generates evidence
- Disseminates evidence

**Leadership**

- Builds capacity and capability of people
- Leads on new clinical initiatives
- Influences practice and policy development

**Context of service delivery**

- Services provided
- Nature of caseload
- MDT and governance
- Process of maintaining accountbaility
- Factors present to support role