

The Role of the Epilepsy Specialist Nurse in Comprehensive Epilepsy Care

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Healthcare in the UK

- Each patient registered with a General Practitioner (primary care)
- Patient with first seizure attends GP or A+E and is referred to:
- Secondary care for initial diagnosis, assessment and treatment
- Tertiary centres for complex epilepsy/ epilepsy surgery

Secondary Care

- Diagnosis and investigation
- Commence treatment
- Review to one year seizure free - discharge to GP
- Patients re-referred for withdrawal of medication, change in seizures, pre-conceptual advice etc
- Complex epilepsy, review 3-6 monthly
- Specialist review for all paediatrics

Healthcare in the UK

- 350 neurologists in UK
- 1 neurologist per 170 000 patients
- Limited health resources
- Innovative development of service delivery

A Study of Epilepsy Service Provision in England (2009)

- 49% of acute trusts don't employ an epilepsy specialist
- 24% don't employ consultant neurologist
- 32% don't run epilepsy clinics
- 90% report longer wait for assessment than guidelines
- 1/3 patients wait longer than recommended for investigation

www.epilepsy.org.uk/timeforchange

Specialist Nurse Role

- Introduced in the UK in the 1980's to develop clinical career structure
- Encourage nurses to remain in clinical arena
- Improve standards of care
- Proliferation of new posts and titles followed

The Scope of Professional Practice

'....enables professional practice to develop naturally into areas that were once seen as delegated medical tasks'

- Make and receive direct referrals
- Admit and discharge patients
- Order diagnostic tests
- Run clinics
- Prescribe drugs

DOH (2000)

Ethical and Legal Implications

- Nurse extending role is making a statement in legal terms about knowledge/skill level
- Act as a reasonably competent Dr would
- Dr finally responsible for patients under their care (GMC 1995)
- Binds professions more closely
- Patient aware of nurse status and knowledge
- Employer vicariously liable

Advanced Practitioner Status

- NMC proposals 2010
- Advanced practice registered
- Generic domains and competencies
- Public protection and awareness
- "Masters level thinking"

Epilepsy Specialist Nurse (ESN)

- ESN role first established in 1988 - community model
- Posts followed in district general hospitals and tertiary centres
- 1995 -sapphire nurse scheme-epilepsy action pump-primed posts
- Approximately 180 posts currently

Epilepsy Specialist Nurse

NICE (2004)

'ESN should be an integral part of the network of care of individuals with epilepsy. The key rolesare to ensure access to community and multi-agency services and to provide information, training and support to the individual'

Components of Specialist Nurse Role

- Clinician/practitioner
- Consultant
- Educator
- Administrator
- Researcher

Buller (1995), Miller (1995), Dunn (1997)

Skill Acquisition-specialist nurse

Novice

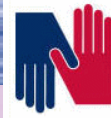
- Proficient/expert at delivering direct patient care

Competent

- Performs effectively and confidently and integrates most of the component roles

Expert

- Deep understanding of all sub-roles and able to integrate into one



Competencies:

a competency framework and
guidance for developing
paediatric
epilepsy nurse specialist
services

Nursing Role Development

Three major forces

- Professional forces
- Management forces
- Policy forces

Research Papers

- The role of the clinical nurse specialist in epilepsy. A national survey
Goodwin M, Higgins S, et al. Seizure 2004;13:87-94
- Quantifying the role of the nurse specialist in epilepsy in diaries and interviews.
Higgins S, Goodwin M et al. British journal of neuroscience nursing July 2006 Vol 2, no 5

A Survey of the role of the Epilepsy specialist nurse in the UK.

- Delphi technique
- Nine hypotheses
- Pilot questionnaire(unchanged)
- Postal questionnaire to all CNSE's
- Reminder one month later

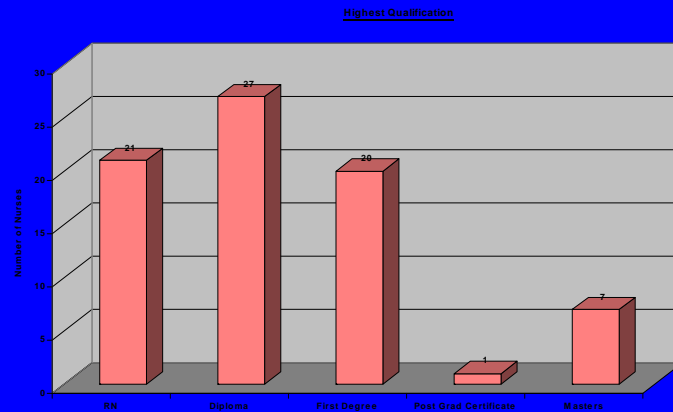
A Survey of the role of the Epilepsy specialist nurse in the UK.

- 130 questionnaires distributed
- 82 (63%) response rate
- 6 (7%) invalid
- Data statistically analyzed using percentages and cross tabulations

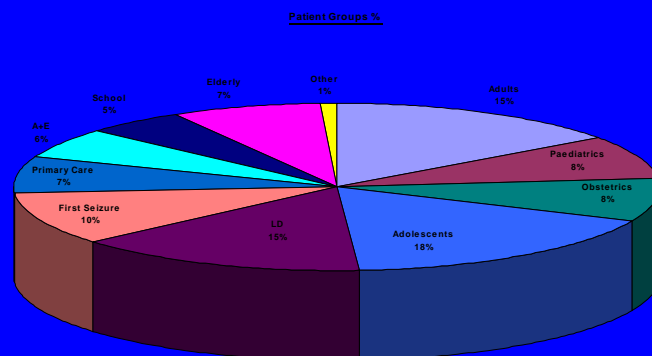
ESN Registration

- Adult 63%
- Paediatric 31%
- Both 6%
- Learning disability 16%

Highest Academic Qualification



CNSE's See Specific Patient Groups



What Type of Clinic Does the ESN Work In?

- Nurse-led 39%
- Medically led 41%
- Multi-disciplinary 19%
- Other 1%

Nurse-Led Clinics

Enables patients to see a nurse for assessment, diagnosis, treatment, investigations, monitoring and/or discharge. Nurses have their own list of patients who are not expected to see a doctor during this attendance. Cross referrals may occur.

Nurse-Led Clinics

- Ranged from 2-15 hours/week
- Average clinic 2-4 hours
- Patients seen 2-24/week
- New patient OPA 15-90 minutes
- Follow up appointments 15-60 minutes
- 23 (32%) complete responsibility for all decisions made

Nurse-led First Seizure Clinic

- All patients referred with a suspected first seizure reviewed by ESN
- History taken
- Advice- driving regulations, safety issues
- Order appropriate investigations
- Neurologist review a few weeks later with investigation results

Telemedicine Enabled Nurse-led Clinic

- ESN travels to local hospital
- Reviews patient - requires expertise of neurologist
- Telephones neurologist-still can't resolve
- Video-link established so neurologist can see patient via link
- Acceptable to patient

Nurse-Led VNS clinic

- Order device
- Co-ordinate theatre time for insertion
- Switch on device
- Clinic review to increase rate of stimulation and assess seizure control/side effects
- Teach patient/carers

Nurse-led Complex Epilepsy Clinic

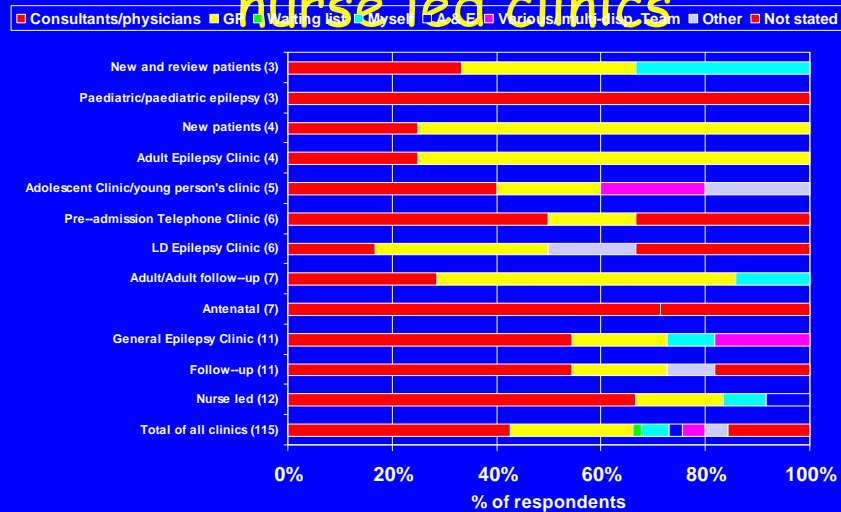
- Continuity of care
- Complex medication changes
- Social issues
- Long term case management perspective
- Therapeutic listening
- Supportive counselling and motivation

Nurse-led Clinic Summary

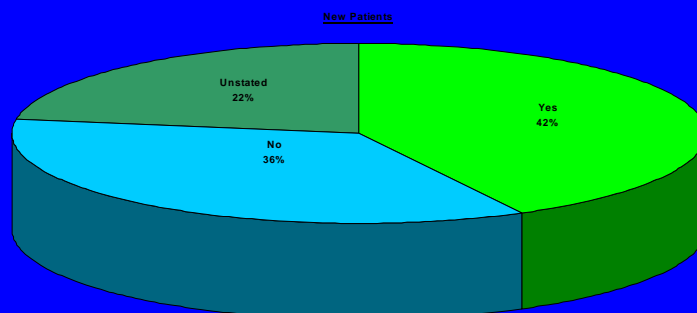
- Own case-load
- Accept direct referrals - GP, A+E, consultants etc.
- Order investigations
- Commence/change treatment
- Refer to other health care professionals, tertiary centre etc
- Individual patient centred teaching
- Discharge

Referral routes into main nurse led clinics

Consultants and GPs are the main sources of patient referral

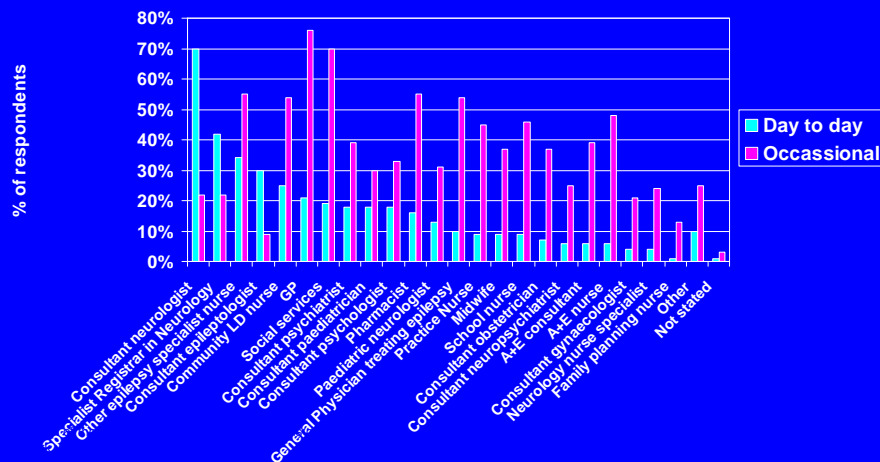


Are New Patients Reviewed By the CNSE?



Interaction Health Professionals

ESNs work primarily with Neurologists on a day to day basis, but interact with a wide range of healthcare professionals, including primary care and support services, on a more infrequent basis



ESN Caseload

- 47 (61%) caseload of less than 500 patients
- 18 (24%) caseload of 500 - 1000 patients
- 8 (11%) caseload of 1000+ patients

Specific Roles

- Order bloods, EEG, ECG and scans
- Inform patient of results
- ESN refers patients for further assessments ie. psychology, social services
- Telephone contact to monitor patients
- ESN teach individuals and groups
- Develop policies and guidelines

Telephone Help-Line

- Disease specific telephone advice part of specialist nurse service
- Quick and relevant access to expertise
- Improves continuity of care
- Report seizures and side effects
Flynn et al 2004 (if help-line unavailable)
- 57% contact hospital Dr, 27% attend GP, 6% A+E, 7% OPA sooner

Telephone Clinic

- Designated clinic time
- Patient list and hospital notes
- Less expensive, although telephone costs, secretarial support
- Patients prefer (no impact on employment)
- No travel
- Large geographical area covered

CNSE's Have Varying Degrees of Responsibility in Drug Management?

- Most CNSE's moderate to high involvement in drug management
- Mainly involvement with titration withdrawal , efficacy and side effect monitoring
- A small number of CNSE's are covertly prescribing

Nurse Prescribing

Prescribing by Nurse's Act (1992)

- Initially prescribe limited range of drugs

Supplementary nurse prescribing

- A partnership between an independent prescriber (Dr or dentist) and a qualified supplementary prescriber to implement a patient specific Clinical Management Plan (DOH 2005)

Clinical Management Plan

'Agreed, defined plan of treatment for a named patient which sets the legal boundaries of the medication and the parameters of prescribing responsibility for the supplementary prescriber'

- Occurs after patient assessment and diagnosis by independent prescriber (Dr)

Independent Nurse Prescribing

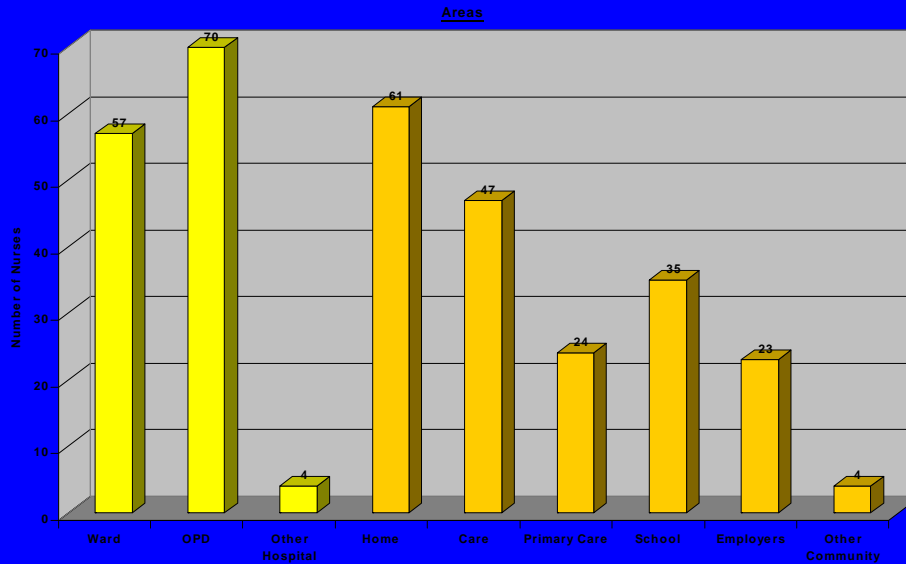
- Prescribing by a practitioner (Dr, dentist, nurse etc.) Responsible and accountable for the assessment of patients with undiagnosed or diagnosed conditions and for decisions about the clinical management required.
- Any licensed medicine within the nurse's competence

Other Clinical Roles

Specific clinics

- Pre-conceptual/pregnancy review
- Transition clinics
- Psychology clinics
- Hospital in-patient review/discharge
- Teaching schools/employers
- Development of guidelines/protocols

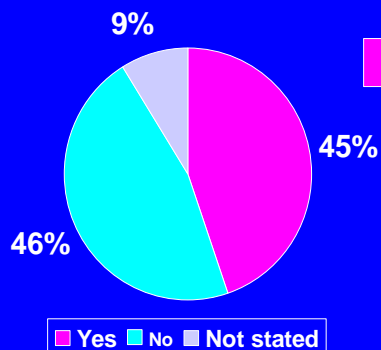
Which settings do ESN's work in?



ESNs and Research

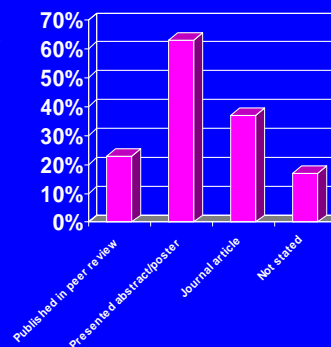
Those ESN's who have been involved in clinical research (45%) are most likely to have presented an abstract or poster at a congress/meeting

Have you ever been involved in clinical research?



YES

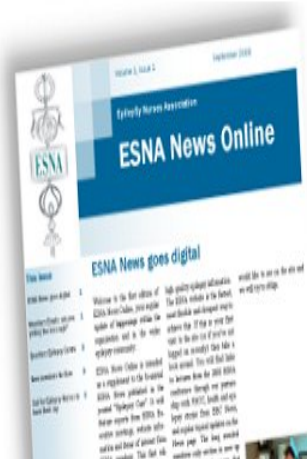
Which of the following have you done?



EPILEPSY NURSES ASSOCIATION

[NEWS](#)[RESOURCES](#)[LOCALITY GROUPS](#)[EVENTS](#)[MEMBERS](#)[LINKS](#)

ESNA - Epilepsy Nurses Association is a professional organisation whose membership consists of nurses and other health professionals working to support people with epilepsy in the fields of adults, learning disabilities and paediatrics. We work with our membership to raise the profile of epilepsy and to encourage a holistic and co-ordinated approach to care to enable our patients to reach the goal of self-management.



ESN Role

- Cost effective
- Reduces length of hospital stay
- Increases patient satisfaction through continuity of care
- Reduces waiting times
- Provides an explanation that the patient understands and remembers

(JEC 2002, Sarkisson 1999, Bradley and Lindsay 2001, Ridsdale et al 2002)

Conclusions

- Role of the ESN is diverse due to rapid and unchecked increase of posts
- Requires a structured pathway to enable progress from novice to expert
- Variations in role dependent on setting
- Competencies www.esna-online.org.uk