Other:

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The ESPENTE study – a Mapping Review

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INTRODUCTION

Many UK epilepsy specialists think that effective epilepsy services depend on epilepsy specialist nurses (ESNs). Guidance from NICE and SIGN state that specialised epilepsy services should include ESNs but many areas in the NHS in the UK fall short. Commissioners do not seem to consider ESNs a high priority and improvement initiatives are impaired by the difficulty summarising the evidence.

METHODS

We undertook a systematic mapping review in parallel with a stakeholder/expert consensus group to describe the role of the ESN, to identify evidence that evaluates the effectiveness and impact of that role on services, patients and their families and other healthcare professionals.

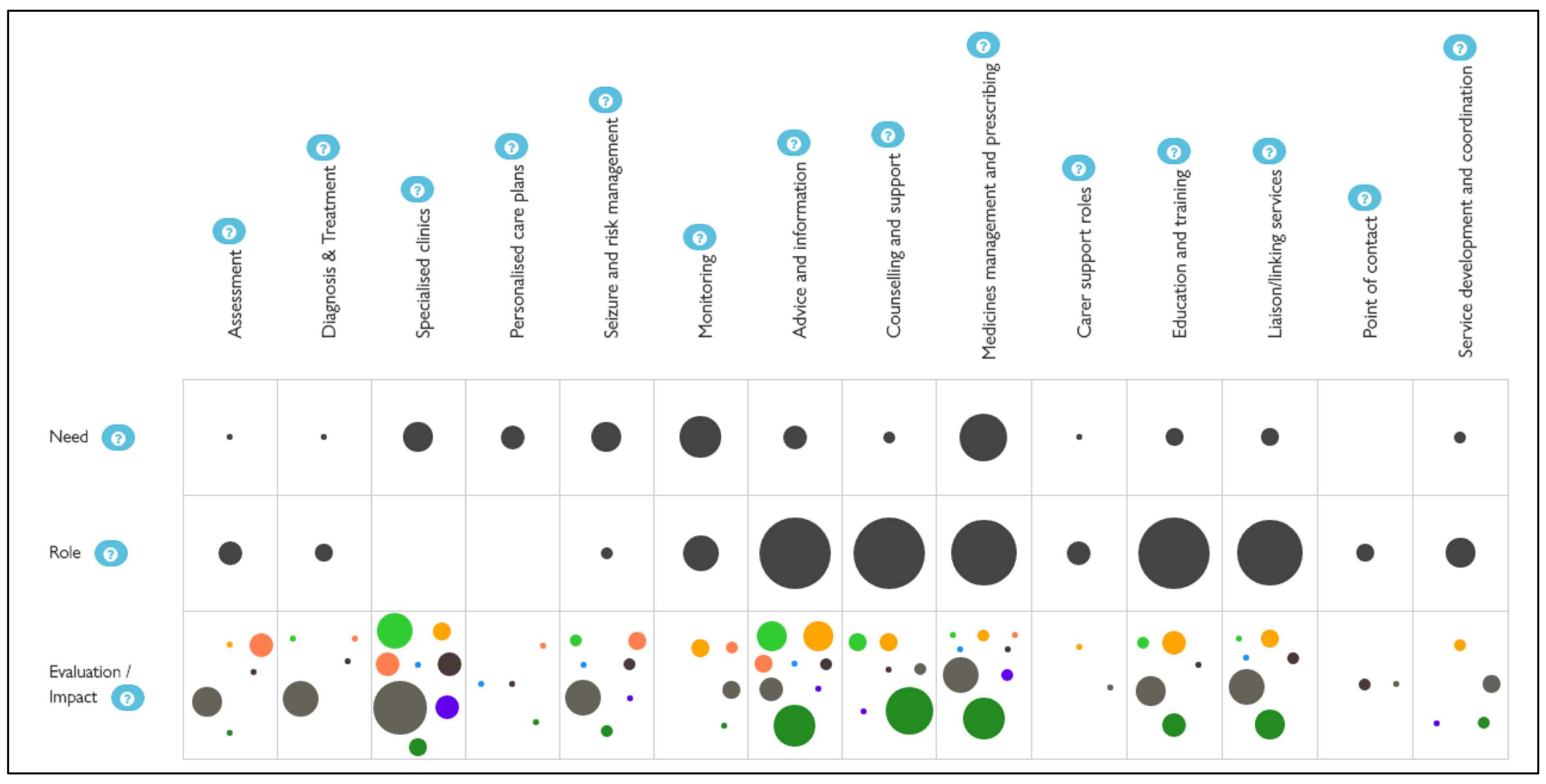
RESULTS

We included 96 published papers including:

- systematic reviews (n=7),
- RCTs or controlled trials (n=9)
- qualitative studies (n=10)
- mixed methods studies (n=7)
- questionnaires or surveys (n=15)
- audits of services (n=6)
- case studies (n=7)
- descriptive, news, opinion (n=35).

Different research designs offer different insights on the ESN role and impact. We identified 14 ESN sub-roles. Each sub-role was described and summarised as follows:

1) description of need for the sub-role
2) evidence of ESNs performing that sub-role
3) evidence of the effectiveness or impact of ESNs actually performing that sub-role.



The interactive evidence map and full report can be seen online at (or use QR code): **epilepsy.org.uk/espentemap**

(printed copies of the report are also available today at the Epilepsy Action stall)

CONCLUSIONS

The ESN is highly valued by patients, their families and other health care professionals. Qualitative studies, mixed methods studies, and questionnaires have demonstrated the value of ESNs to patients, the range of services they provide and the perceived improvements in care. RCTs and systematic reviews have demonstrated measurable benefits for patients including improvements in knowledge and quality of life. Some studies have, however, failed to demonstrate measurable improvements in outcome measures as a result of ESNs, such as reductions in seizures. There are elements of the ESN role, notably their role as a point of contact and liaising with and linking services, that are poorly recognised and inadequately evaluated in the existing evidence.