

Evaluating the Carer Support Nurse Pilot

Final report – Executive Summary

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NIHR | Applied Research Collaboration
East of England



Study details

Short title: Carer Support Nurse Pilot

Principal Investigator (PI): Prof Morag Farquhar, University of East Anglia (UEA)

Study funder: Health Education England – East of England (*now NHS England – East of England Region*) (Note: the Carer Support Nurse post itself was funded by Norfolk & Waveney ICB)

Study supported by:

- NIHR Applied Research Collaboration East of England (ARC-EoE): <https://arc-eoe.nihr.ac.uk/>
- UEA Health & Social Care Partners (UEAHSCP): <https://ueahscp.com/>

Study sponsor: University of East Anglia (UEA)

Ethical approval:

Protocol	Stage title	Approval
Stage 1 protocol v1 date 10/06/2022	Establishing a stakeholder-operationalised model and implementation strategies for a pilot Carer Support Nurse role (CSN Pilot S1)	UEA FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee): ETH2122-2232
Stage 2 protocol v3 date 14/12/2022	Value and impact of a stakeholder-operationalised Carer Support Nurse role and feasibility of a future wider implementation study (CSN Pilot S2)	Wales Research Ethics Committee 4 IRAS Project ID: 322511 REC reference: 22/WA/0371

Protocol registration: ClinicalTrials.gov Identifier: NCT05753072

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This executive summary is for Carer Support Nurse pilot project funders, supporting organisations and key stakeholders.

A full final report is available on request.

A separate report for carers will be shared with carers who took part and the voluntary organisations who facilitated the study (to share with carers).

Executive summary

Background:

- Unpaid/family carers are crucial in enabling patients to be cared for, and die, in their place of choice, but have unmet health-related support and education needs that are not met by current healthcare provision.
- A 'Carer Support Nurse' role (CSN) was proposed to support carers with complex health or wellbeing needs and promote best practice in carer support among other healthcare providers.
- The idea of the role was endorsed by 70+ cross-sector stakeholders, 100+ carers and patients (Patient & Public Involvement work), and regional and national cross-sector leads in carer support.
- Funding for a one-year pilot role was provided by the former Norfolk & Waveney CCG (now Norfolk & Waveney ICB) and hosted by East Coast Community Healthcare (ECCH)
- A three-stage multi-method multi-perspective pilot and feasibility study was conducted by a multidisciplinary team.
- The pilot study was funded by the former Health Education England – East of England (now NHS England – East of England Region)
- The pilot study was further supported by the NIHR Applied Research Collaboration East of England and UEA Health & Social Care Partners
- The pilot role was operationalised with carers and cross-sector professionals.
- Referral criteria were:
 - Carers living within a defined geographical locality, who have complex support needs relating to (or impacting on) their own health/wellbeing (support for self) or their skills/confidence to care (support to care), or unresolved support needs that cannot be met by their usual health care professional team.
 - The complexity lies with/relates to the carer, rather than the patient.

Key findings of the pilot:

- The award-winning Carer Support Nurse pilot role enabled support for carers with complex health and wellbeing needs, worked across sectors and cross-skilled health care professionals in carer support.
- The Carer Support Nurse addresses the healthcare policy rhetoric on the need for carer support.
- The Carer Support Nurse role was universally well-received: by carers who both received the intervention and carers who heard about the intervention, by health and social and voluntary sector professionals, and by other regional and national stakeholders. Stakeholders were therefore clear on need for role before it commenced, and this was confirmed by their experiences in the pilot.
- 124 cross-sector carer referrals were received in the 9 months that the service was open to referrals (mean 66yrs; 73% female).
- Additional work outside of direct carer support was conducted, in line with the five Evidence-based Design Principles that underpin the role.
- There was fidelity to the intervention: the Carer Support Nurse role was delivered as intended.

- The pilot confirmed that the two stakeholder-endorsed prerequisites for the role remain essential: (1) that it is dedicated to carers and (2) that it is a registered nurse role.
- The pilot identified that the role needs to be delivered by an experienced registered nurse: activity analysis showed that the work was distributed across different types of work and across the nursing process (assessment, planning, intervention, and evaluation) and the nurse's skills created psychological safety for the carers to express distress and enabled responses to that distress based on assessment.
- The pilot identified that the role should remain a Band 7 role, but that a team model would achieve a number of identified benefits.
- The five Evidence-based Design Principles (EDPs), which were endorsed by stakeholders before the pilot role commenced, all remained important for stakeholders and were identified as delivered in the pilot, however working with marginalised communities (EDP-3) requires more than 12 months to fully achieve.
- With the caveat that the evaluation was of one nurse, who was in post for one year, with data collected over just 9 months, and on a small sample size, a small (non-statistically significant) improvement in carer quality-of-life was identified. Given the complex needs of referred carers and the trajectory of the caring role, such a small improvement or even maintenance of quality-of-life score is encouraging.
- The Carer Support Nurse pilot was nominated for and shortlisted for two national awards and was regional winner for one.
- Early positive findings were shared with ECCH, Norfolk & Waveney ICB, and cross-sector stakeholders and the wider community (see Appendix 4 of full report), however, at the time of reporting, continued funding was not available to sustain the role.
- The evaluation of the pilot was successful in answering its research questions relating both to the role itself and the feasibility of evaluating it.
- Given the success of the pilot role, its testing on a larger scale is warranted, guided by the feasibility findings.
- Possible Mechanisms of Action were identified based on the pilot findings and are reported in the full report.
- The 21 key recommendations of the pilot are summarised in the box below.

21 Key recommendations of the Carer Support Nurse pilot evaluation

Pivotal recommendations

- 1) **The Carer Support Nurse role is a mechanism for delivery on NHS pledges to support carers.**
- 2) **The Carer Support Nurse role should continue** to prevent loss of the opportunity to move to a sustainable role, prevent loss of developed skills, and prevent loss of established networks.
- 3) **A team model** would maximise reach and should be led by a Band 7 registered nurse, supported by Band 6 registered nurses.
- 4) The two evidence-based prerequisites for the **Carer Support Nurse role should remain: (i) that it is dedicated to carers, and (ii) that it is a registered nurse.**

- 5) **An experienced registered nurse is recommended for the Carer Support Nurse role** as the work required is distributed across different types of nursing work and across the nursing process (i.e., assessment, planning, intervention, and evaluation) as seen both in the activity analysis, and in carer and stakeholder feedback. Consideration should also be given to the relatability of the post-holder, or team members, to the target carer population(s).
- 6) **The five Evidence-based Design Principles (EDPs) for the Carer Support Nurse role should remain**, including the Carer Support Needs Assessment Tool Intervention (CSNAT-I) as a core component of the role:
 - EDP-1) Community-based, within existing teams
 - EDP-2) Cross-sector working e.g., across health, social, and voluntary care, and Primary Care Network/Integrated Care System aligned
 - EDP-3) Engaging marginalised communities
 - EDP-4) Providing person-centred care to carers (prioritising complex cases), identifying, and addressing their health-related needs (e.g., carer health/wellbeing and upskilling them to care), through delivery of the evidence-based CSNAT-I (<https://csnat.org/>) which complements local authority assessment
 - EDP-5) Cross-skilling other health care professionals e.g., best practice in carer support to distribute benefits for greatest impact

Recommendations related to establishing and delivering the role in practice

- 7) **Senior management team/high-level support is required** for the introduction of a Carer Support Nurse role or service, informed by a dedicated monitoring and reporting mechanism that collects and evaluates data relating to the five Evidence-based Design Principles for the role.
- 8) The **time to initially build, then maintain and grow the networks** required to deliver the Carer Support Nurse role **should be acknowledged and planned within the service model**, including the establishment of trusted relationships with marginalised communities.
- 9) **Formal clinical supervision should be provided for the Carer Support Nurse role** to ensure support for the emotional demands of the role – the proposed team model (Recommendation 3) would provide further support for this.
- 10) The **first in-person contact with the Carer Support Nurse** should happen in a **location most relevant to assessment of the carer's needs and where the carer feels comfortable** – requiring the time and ability to travel and is most likely to (but not exclusively) be the carer's home.
- 11) **Carer resources** identified for, and through, the Carer Support Nurse role **should be promoted to healthcare colleagues and shared with other sector colleagues.**

Recommendations related to organisational support for the role

- 12) The Carer Support Nurse service would benefit from **administrative support and dedicated contact routes** e.g., a dedicated telephone number (potentially a mobile number supporting text messages) and email address.
- 13) **A carer e-record system that meets the needs of the Carer Support Nurse role is required** and should be in place ahead of service initiation to enable ease of data entry by the CSN and access for those professionals requiring it.
- 14) Where possible (acknowledging GDPR/consent/confidentiality requirements), **the Carer Support Nurse should have access to the cared-for person's notes** where it enables timely

responses to those carers' needs that are directly linked to their care of the patient, whilst ensuring that the Carer Support Nurse role remains dedicated to carers and their needs.

- 15) Where possible (acknowledging GDPR/consent/confidentiality requirements), **other health care staff should have access to the carer's notes created by the Carer Support Nurse**
- 16) **Data sharing agreements should be in place with relevant organisations** be they statutory bodies, local authorities, housing providers, or voluntary, community or social enterprise (VCSE) sector providers and as appropriate.

Recommendations related to enablement of the role

- 17) **The Carer Support Nurse job description would benefit from improved structuring and presentational refinement.**
- 18) The Carer Support Nurse service should be **promoted to carers and cross-sector referrers via a strategic early and continued promotional campaign** both within and beyond the host organisation – this could include early and regular features in staff communications (e.g., e-newsletters and webinars internally, with similar opportunities sought externally) and early and regular inclusion of the Carer Support Nurse in relevant clinical and organisational staff meetings.

Recommendations related to future directions

- 19) The Carer Support Nurse service could **seek opportunities to support young carers' health and wellbeing** by working with young carers' groups, education settings, and other relevant organisations in the locality (in collaboration with existing services e.g., school nurses) – the identification of, and response to, young carers' support needs will require appropriate training and resources which could be delivered through the young carer version of CSNAT-I, and its related training, currently in development.
- 20) **A future larger research and implementation study to explore the Carer Support Nurse role/service in varying localities is warranted** and should be designed to provide evidence of how, when and for whom the role/service works (and its impact), guided by the pilot's feasibility findings.
- 21) Where establishment of a Carer Support Nurse post/service is associated with a research study, the **inclusion of a lead researcher from the study team in role set up, and recruitment is beneficial** to the host organisation, post holder, and study team.