Evaluating the Carer Support Nurse Pilot

Final report

November 2023

[VERSION CONTROL edits from V1.0 to V1.1: (1) Figure 10 title corrected, p43; (2) added Possible Mechanisms of Action row to Appendix 2, Box 19, p121]

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Study details

Short title: Carer Support Nurse Pilot

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

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

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Ethical approval:

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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

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

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

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"So many carers, like myself, would have warmly welcomed an informed, friendly, and genuinely interested professional like the Carer Support Nurse in our often difficult lives.

We talk so much about the importance of personalised care, but digital transformation cannot always provide that personal contact or respond appropriately and confidently to sometimes very difficult feelings and concerns. Very importantly, the Carer Support Nurse can see the carers in the context of their own homes and share the reality of their daily lives.

I just hope that this project stimulates commissioners, providers and partners to understand the value of the Carer Support Nurse and replicate the model"

Dame Philippa Russell DBE
Vice-President, Carers UK

13th November 2023

1. Background

NHS England defines a carer as "anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid" [1]. NICE describes it as a "close supportive role" and notes that carers "share the illness experience of the patient" and "undertake vital care work and emotion management" [2].

Unpaid/family carers have health-related support needs due to this caring role [3]. There were up to 9.1 million carers in the UK pre-Covid; the pandemic has added 4.5 million more [4]. Carers provide unpaid care, help, or support to family members/friends with care needs [5]. The personal care, practical and emotional support [3,6-8] they provide is valued at £132 billion annually [9], reducing formal care costs. Additionally, there has been an unprecedented reliance on home care as one pillar of the health-care system during the COVID-19 pandemic [10] whilst carers' support needs have increased but care access has reduced [11].

The unpaid carer role often helps to keep some of our most vulnerable members of society out of hospital or social care and improve their quality of life. However, sustainability is threatened by economic, welfare/social trends, and negative effects on carers' health and wellbeing, including premature mortality [3,12-18]. This includes one in three NHS staff who also act as unpaid carers [19], many of whom are aged between 45-64 and so are likely to be among the most experienced and skilled staff [20]: negative impacts on their physical and mental health not only threatens this unpaid care they provide, but also affects the NHS workforce through absenteeism.

Carers experience uncertainty, lack role preparedness and confidence [7,8,15,21-24] causing anxiety and impacting their ability to ask for help [25,26]. Many lack access to services [6,8,34], remaining unnoticed or invisible [27,28] until a crisis occurs [7,8]. Carers can be ambivalent about their own needs, putting patients' needs first, neglecting their own health [6,29,30]. Time-limited healthcare professionals (HCPs) similarly prioritise patient need [31,32]. Carers' health-related support needs are exacerbated when caring is prolonged [3,33], when there is uncertainty or complexity [34], and in marginalised communities at risk of unequal healthcare access [35-38]: they need support to sustain their own health and wellbeing (i.e., support for self) and boost their skills/confidence (i.e., support to care) [39].

National calls for improved carer support [40-44] includes NHS calls for new ways to identify and support carers, especially the most vulnerable such as those with their own health needs [45]. Most carers want to continue caring, but current provision doesn't work for most carers' health-related needs. Local Authorities (LA), private care and charities do not address carer health or upskill them to care. The NHS has the remit/potential reach through strategic "carer leads", GPs and community nurses, but carer leads are not always clinicians (and not always carer-facing) and carers face barriers accessing GP support [16,46]. Changing community demographics [47] and falling District Nurse numbers [48,49] challenge increasingly task-focused community nurses [22,50]. In qualitative data from district and community nurses for modelling work for the Queen's Nursing Institute

District Nurse workforce standards the nurses reported that caring for carers was often something they no longer had time to do along with bereavement work[1].

Evidenced-based carer interventions, such as the Carer Support Needs Assessment Tool Intervention (CSNAT-I [31,32,39,51,52]), can be delivered by healthcare professionals to help identify and address carers' unmet support needs. CSNAT-I is a practical, clearly defined, and targeted intervention delivering person-centred care to carers. However, healthcare roles that are for both patients and carers will prioritise patients [31,32] and so challenge delivery of interventions like CSNAT-I, leaving carers' health-related needs largely invisible, unvalidated, and unmet [53].

A dedicated Carer Support Nurse role [54] who can support carers with complex needs and cross-skill other HCPs will address this, and could help ameliorate crises, and reduce associated patient and service impacts.

Two evidence-based role prerequisites were proposed in the development of the role:

1) that it is dedicated to carers, and
2) that it is a nurse.

Dedication to carers was identified as key due to (a) carers' reluctance to "bother" HCPs [7,24], particularly in non-emergencies [6,8], during what they see as the "patient's time", and (b) nurses' difficulty supporting carers within their patient-led roles, largely due to limited time [22,53]. Dedicating the role to carers legitimises carers' help-seeking, overcoming their reluctance, and legitimises carer support for HCPs too. Further, supporting the carer supports two people: the carer and the patient.

A nurse fulfilling the role was identified as key as nurses have the knowledge/expertise to support carers' health-related support needs, particularly when complex [51,57-60]. Most carer interventions target psychosocial/psychoeducational needs [61], not health-related needs. Any dedicated trained person could increase carer visibility and meet some carer support needs, but the holistic nature of nursing [57-59] combines need identification, physical/mental health assessment and support, self-care, and case management at expert level [61]: all would be delivered within the Carer Support Nurse role. In some areas Admiral Nurses support people living with dementia and their carers targeting complex cases: they are valued by carers (particularly for their clinical knowledge) and improve outcomes [62], but they only support those living with dementia.

Five Evidence-based Design Principles for the role were established, outlined in Box 1.

Box 1: Five Evidence-based Design Principles (EDPs) for Carer Support Nurse role
1) Community-based [63,64], within existing teams e.g., in Primary Care Home teams [65] 2) Cross-sector working e.g., across health, social, and voluntary care, and Primary Care Network/Integrated Care System aligned 3) Engaging marginalised communities [35-38] 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

[1]Personal communication: UEA Carer Support Evaluation, Prof Alison Leary, June 2023

care), through delivery of the evidence-based CSNAT-I [52] which complements local authority assessment

5) Cross-skilling other health care professionals e.g., best practice in carer support to distribute benefits for greatest impact

2. Initial Stakeholder Consultations

The idea of an evidence-based Carer Support Nurse role was endorsed by the project's national collaborators who noted its alignment to/delivery of national policy [40,43,55,56]: Jen Kenward (then lead for NHSE/I Commitment to Carers Programme [55]), Dame Philippa Russell (Vice-President Carers UK), and the Queen's Nursing Institute (QNI; represented by Sue Boran and Amanda Young).

In addition to consulting these national leads, an extensive programme of consultations on the proposed role, and the plan for its evaluation, was conducted with **70+ East of England stakeholders and groups across health, social care, and the voluntary sector, plus over 100 carers/patients (PPI: Patient & Public Involvement)**. These consultations were conducted within Farquhar's funded time within the NIHR Applied Research Collaboration East of England [66].

The level and universality of enthusiasm among these stakeholders was remarkable, with lack of provision for carers' health-related needs a repeated message. In their feedback patients emphasised their carers' vital role but were concerned over carers' lack of support from healthcare. Patients and carers helped shape the role and this study. They advised that the CSN role should be community-based and shared their thoughts on how to recruit carers to the study, giving key advice on terminology: despite its shortcomings, "carer" was preferred. They welcomed the planned continued engagement of carers and cross-sector stakeholders in the study.

These stakeholders endorsed the two evidence-based role prerequisites: (1) that it is dedicated to carers, and (2) that it is a nurse. Stakeholders (including carers, HCPs, social care practitioners, healthcare commissioners, social care leads and voluntary sector) advised a nurse for effective interprofessional working [67]. Patient and Public Involvement (PPI) consultations with carers and patients suggested that a Carer Support Nurse would increase the likelihood of carers' health-related support needs being identified and thus addressed, by giving carers "permission" to express them. These **stakeholders also endorsed the five Evidence-based Design Principles for the role** (EDPs: outlined in Box 1).

This study therefore sought to establish a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse role, explore the value and impact of the stakeholder-operationalised role, explore the feasibility of a future wider multi-site implementation study and establish stakeholder-informed recommendations for the role.

3. Funding and Support

Funding for a 12-month Band 7 Carer Support Nurse pilot role was provided by the former **Norfolk & Waveney Clinical Commissioning Group (CCG)** in 2022 prior to Integrated Care Boards (ICBs) replacing clinical commissioning groups (CCGs) in the NHS in England (from 1 July 2022) – the pilot therefore subsequently reported to Norfolk & Waveney ICB.

The study (i.e., the evaluation of the pilot role) was funded by **Health Education England (East of England)**[2] and affiliated to the **NIHR Applied Research Collaboration East of England** (ARC-EoE: supported Farquhar, Peryer, and Wagner's time) [66] where improved carer support is a key PPI/clinician-identified research priority, and carers' health-related needs a local carer-determined one [68]. The study was further supported by **UEA Health & Social Care Partners** (UEAHSCP) [69]. UEAHSCP and NIHR ARC-EoE infrastructure facilitated stakeholder engagement, communication, and dissemination.

The pilot role was located within Great Yarmouth & Waveney [70] as one of NIHR ARC-EoE's *Populations-in-Focus*: regionally deprived/high health need areas with marginalised communities which are rarely a site for applied health research. It was hosted by East Coast Community Healthcare (ECCH) within its Primary Home Care Team as a service improvement. Primary Care Home Teams are integrated community teams which include social care and are aligned to the Primary Care Network in Gt Yarmouth and Waveney (same footprint): https://www.ecch.org/our-services/primary-care-homes-pch/.

[2]Health Education England (East of England) is now NHS England – East of England Region

4. Study Team

The study was led by Professor Morag Farquhar (University of East Anglia: UEA) and delivered and managed by the Carer Support Nurse pilot study Core Team (Box 2).

Box 2: Carer Support Nurse pilot study – Core Team

- Professor Morag Farquhar (PI): Professor of Palliative Care Research – University of East Anglia (UEA); NIHR ARC EoE Palliative & End of Life Care theme *[expertise in unpaid/family carers, intervention development and evaluation, applied qualitative methods, multi method studies, CSNATv3; registered nurse]*

- Professor Alison Leary: Professor of Healthcare & Workforce Modelling – London South Bank University *[extensive experience in evaluating specialist nursing roles; activity analysis lead; registered nurse]*

- Roberta Lovick (PPI): former unpaid/family carer

- Dr Guy Peryer: Senior Research Fellow – University of East Anglia (UEA); NIHR ARC EoE Palliative & End of Life Care theme and NIHR ARC EoE Inclusive Involvement theme *[expertise in complex systems, functional interface between sectors & process evaluation]*

- Dr Jennifer Lynch: Reader in Social Care, Technology & Knowledge Mobilisation – Centre for Research in Public Health and Community Care, University of Hertfordshire; NIHR Expert Advisor—Knowledge Mobilisation *[expertise in knowledge mobilisation & implementation]*

- Dr Adam P Wagner: Associate Professor (Health economist/statistician) – University of East Anglia (UEA); NIHR ARC EoE Health Economics and Prioritisation Theme *[expertise in health economics and statistics]*

- Professor Susanne Lindqvist: Professor of Interprofessional Practice – University of East Anglia (UEA) *[expertise in interprofessional practice]*

- Dr Carole Gardener: Senior Research Associate – University of East Anglia (UEA) *[expertise in person-centred care, intervention development and evaluation, applied qualitative methods, multi method studies, PPI]*

5. Public Involvement

In addition to the pre-study PPI work with over 100 carers and patients described earlier, the study itself was supported by a lead PPI Carer Representative (a female former carer) and Carer Support Nurse Study Patient and Public Involvement Group (CSN-PPI) of three current carers (one female; two male) whose roles were advertised via NIHR ARC East of England and regional carer leads across NHS England. Study funding enabled reimbursement of PPI carers' time.

Through two online group meetings (using Zoom), plus additional individual consultations (online, via email, and by phone), they provided advice and guidance on:

- rationale for the Carer Support Nurse role and the pilot project
- likely carer acceptability of the proposed data collection methods from carers
- developing carer-facing recruitment materials
- developing carer-facing data collection materials i.e., carer survey
- identifying end of pilot questions for the Carer Support Nurse post-holder that would be important to carers
- troubleshooting operational aspects of the Carer Support Nurse role
- troubleshooting operational aspects of the evaluation
- interpretation and sense-checking qualitative carer data

6. Project Advisory Group

A Carer Support Nurse pilot study Project Advisory Group (CSN-PAG) was convened for the evaluation comprising multidisciplinary methodological experts, nursing experts, carer experts, national collaborators, and the lead PPI Carer Representative (Box 3). They were consulted through two online group meetings (via MSTeams) and individual consultations (online/via email).

Box 3: Carer Support Nurse pilot study Project Advisory Group (CSN-PAG)

- **Carer Support Nurse pilot study Core Team** – see Box 2
- **Jen Kenward**: former lead for NHS England/NHS Improvement's Commitment to Carers Programme
- **Deborah Sturdy**: Chief Nurse Adult Social Care
- **Dame Philippa Russell**: Vice-President Carers UK
- **Amanda Young**: Queen's Nursing Institute (QNI)
- **Fiona Rogers**: Queen's Nursing Institute (QNI)
- **Jodie Deards**: Carer & Patient Experience Lead, East of England, NHS England
- **Professor Mari Carmen Portillo**: Professor of Long-Term Conditions, University of Southampton
- **Professor Ruth Harris**: Professor of Healthcare for Older Adults, King's College London
- **Professor Kathryn Almack**: Professor of Family Lives and Care, University of Hertfordshire; NIHR ARC EoE Ageing & Multimorbidity Theme
- **Dr Claire Thompson**: Reader in Food Inequalities and Health, University of Hertfordshire; NIHR ARC EoE Prevention & Early Detection in Health and Social Care Theme
- **Maria Martin**: Advanced Nurse Practitioner, Charles Hicks GP surgery, Huntingdon
- **Dr Gail Ewing**: CSNAT-I developer (retired – University of Cambridge)
- **Professor Gunn Grande**: CSNAT-I developer (retired – University of Manchester)
- **Diane Gray**: Health Education England (East of England)[3]

[3] Health Education England (East of England) is now NHS England – East of England Region

7. Aims, Research Questions, and Objectives

Three overarching study aims were mapped to four research questions and seven objectives, as shown in Box 4.

Box 4: Aims mapped to the research questions and objectives		
Overarching study aims	Research Questions (RQs)	Objectives (Os)
1) To establish a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse role.	RQ1) What would a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse role look like?	O1) To establish a stakeholder-operationalised model for the pilot Carer Support Nurse role
2) To establish the value and impact of a stakeholder-optimised Carer Support Nurse role, and stakeholder-informed recommendations for the role.	RQ2) What is the value and impact of a stakeholder-optimised Carer Support Nurse role?	O2) To determine acceptability and feasibility of the Carer Support Nurse role
		O3) To establish the impact of the Carer Support Nurse role (from multi-perspectives)
		O4) To establish the resource and cost implications of the Carer Support Nurse role
		O5) To establish mechanisms of action and effect
	RQ3) What are the stakeholder-informed recommendations for the role to inform sustainability?	O6) To establish stakeholder-informed recommendations for the Carer Support Nurse role (to inform sustainability)
3) To establish the feasibility of a future wider multi-site implementation study if the role shows promise.	RQ4) If the role shows promise, what learning should inform a future grant application to further develop and evaluate the role in a multi-site study?	O7) To establish the feasibility of a future wider multi-site implementation study if the role shows promise

8. Study Plan & Methods (summary)

To achieve the study's aims, answer its four research questions and meet its seven objectives, a three-stage multi-task multi-method study was conducted.

- Stage 1: Development of a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse (CSN) – this comprised two tasks:
    a) Identifying local resources that support unpaid carers (**carer asset-mapping**: Task 1A). This involved: 1) an internet search to identify key organisations involved in supporting carers both locally and nationally, and 2) online interviews with ten professionals from the health, social and voluntary sectors about their role in supporting unpaid carers and their knowledge about other providers.
    b) **Consulting stakeholders** (local unpaid carers and cross-sector professionals) to help plan how the nurse should work (Task 1B). To do this we ran a series of online workshops and interviews involving a total of 16 unpaid carers and professionals from different sectors.
- Stage 2: Value and impact of a stakeholder-operationalised Carer Support Nurse role and feasibility of a future wider implementation study – this comprised three tasks:
    a) Carer Support Nurse role data capture (Task 2A). This involved: 1) CSN completion of a **Weekly Reflective Diary** and **CSNAT-I Activity Template** (anonymised aggregated data on carer needs identified and types of actions taken), 2) **Monthly data-generating meetings** with the CSN to monitor role delivery and identify and address any emerging barriers, 3) **activity analysis** using the Cassandra matrix [71] for specialist nursing practice (captures perceived activity e.g., types of nursing interventions, for whom, where), and 4) **Monthly anonymised aggregated process data** from the SystmOne Business Intelligence Unit.
    b) Carer outcomes and the experiences of carers and patients (Task 2B). This involved a **baseline and follow up postal survey of adult carers** who had contact with the nurse, and **interviews with carers** and a patient.
    c) Carer Support Nurse and cross-sector colleague experiences and impacts (Task 2C). This involved **end of pilot interviews with the CSN and their line manager**, plus **focus groups and interviews with key cross-sector colleagues**.

  Stage 2 was timed to allow the Carer Support Nurse to embed in the role, and for the role to embed in system – as such, most Stage 2 data relate to February-August 2023 (data generated by the Business Intelligence Unit relates to December 2022-September 2023).
- Stage 3: Establishing mechanisms of action and effect, and recommendations – this involved review of the Stage 1-2 findings by the core team, CSN-PPI, and CSN-PAG to explore the mechanism of action, optimise the CSN operational model, and refine recommendations.

Appendix 1 provides the detailed study plan and methods.

For the purposes of this report, key findings were synthesised to address eight questions considered most useful for stakeholders and are reported on the following pages.

Appendix 2 reports additional findings in relation to the feasibility of a future wider multi-site implementation study (Aim 3/Research Question 4/Objective 7).

9. Key findings for stakeholders

The key findings of the pilot were synthesised to address eight questions considered useful to a range of stakeholders:

1) What was in place to support carers before the Carer Support Nurse role?
2) How was the role set up?
3) Which types of carers did the Carer Support Nurse support?
4) What did the Carer Support Nurse do?
5) What was the impact of the Carer Support Nurse role on carers?
6) What was the key stakeholder feedback on the Carer Support Nurse role, as delivered? – Cross-sector stakeholders & national recognition
7) What was the CSN's experience of, and reflections on, delivering the role?
8) What are the resulting recommendations?

These are each reported on under sections 9.1 to 9.8 pale green header boxes.

Data sources (in terms of study stages/tasks) are given where felt helpful to provide clarity.

9.1. What was in place to support carers before the Carer Support Nurse role?

A number of carer support organisations across Norfolk, Suffolk and nationally were identified from multiple sources within Task 1A and informed the creation of a Carer Asset Map to act as an updatable resource for the incoming Carer Support Nurse (see Appendix 3).

Before the Carer Support Nurse commenced, carer support within health care fell to those providing care primarily to patients. End of pilot focus groups and interviews involving cross-sector stakeholders (across health, social care, and the voluntary sector) suggests that health care professionals' knowledge of resources, such as those on the Carer Asset Map, was limited, even when they engaged with other cross-sector colleagues to try to connect carers to support (source: Task 2C – reported in Section 9.6).

These cross-sector end of pilot focus groups and interviews also described difficulties that health, social care and voluntary sector professionals encountered in accessing support for carers' health and wellbeing before the Carer Support Nurse commenced.

Stakeholder support for the role before the Carer Support Nurse commenced was universally positive – it was described as *"the missing piece of the puzzle"*. Their only concern was that the nurse could be overwhelmed with referrals, so they advised referral criteria to help manage this.

9.2. How was the role set up?

Cross-sector stakeholder interviews were conducted before the Carer Support Nurse commenced in order to inform role set up (source: Task 1B). These stakeholders were clear that referral criteria were needed to keep the Carer Support Nurse's caseload manageable, but flexibility was key in terms of where and how long carers should be supported to meet individual needs. In order to complement existing local services, they felt the nurse should support carers with their own health needs and help them develop the skills needed to provide physical care for the cared-for person. They also felt that the nurse could enable hospital discharge teams to consider the needs of carers.

Five key points came from these stakeholder interviews to guide CSN practice:

1) The CSN role should fill gaps in the range of services currently offered to carers. This could include:
    a. directly supporting the carer with their own physical health or wellbeing needs
    b. assessing need and providing supportive input in relation to the cared-for person's health needs
    c. supporting the carer to liaise with health or social care providers for the cared-for person.
2) The CSN role should provide carer assessment and supportive input in a way that demonstrates understanding of the needs/constraints and impact of the caring role. This should involve understanding that:
    a. carers can find in very difficult to talk about their own needs or experiences, and often require a flexible response to referral, contact and discharge
    b. carers need easy access to someone at a time of 'crisis'
    c. even when carers are linked in with services their wellbeing can still be impacted by the ongoing daily pressures of the caring role.
3) When responding to carers' individual support needs, the CSN role should be a deliverer of supportive input, in addition to referring to other services, as carers expressed frustration at being signposted round in circles, being continually assessed for new services and the lack of actual input from service providers.
4) The CSN role should proactively support services and populations where there has been less focus and/or where there are existing barriers to supporting carers such as hospital discharge teams. In addition, the need to identify hidden carers and, in particular, carers from marginalised or disadvantaged groups were identified.
5) The CSN role should be promoted through provision of information, networking and training given of awareness of the new role outside the immediate network of carer support worker and organisations in the locality.

These key points mapped to, and complemented, the role's two pre-requisites (i.e., that it is a nurse and is dedicated to carers) and five Evidence-based Design Principles (EDPs: Box 1).

An ECCH Project Team was established to set up the post. This initially included ECCH Programme Lead, Project Co-ordinator, Deputy Director of Quality, Business Intelligence Team members, line manager, and administrative support, as well as the study PI (Farquhar). It met for weekly checkpoint meetings from 30/05/2022 to 14/11/2022, with identified actions and progress logged in a workbook (Excel spreadsheet). Together the ECCH Project Team developed the CSN pilot role job

description and draft policy, informed by the Task 1B findings. The post was advertised and appointed to, however the first appointee withdrew for personal circumstances. The role was readvertised and successfully appointed to. Box 5 summarises the background of the appointed nurse.

Box 5: Summary of background of the appointed Carer Support Nurse
• Five years' acute care experience in orthopaedic trauma and specialist haematology • Over four years' experience as a community nurse, clinical educator, and community sister before taking the secondment to the Carer Support Nurse role.

The CSN commenced in post on 16/10/2022 and joined the ECCH Project Team to refine the Carer Support Nurse policy[4] (including referral criteria and processes), develop a dedicated SystmOne recording unit with ECCH's Business Intelligence Team, and establish an ECCH communication strategy to promote the role and referrals (e.g., a dedicated leaflet[5] and dedicated ECCH webpage[6]).

The referral criteria established for the pilot 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.

The ECCH Project Team cycle ended with a review exercise, known as a "Retrospective", to inform future ECCH projects – this identified key learnings such as, for example:

- the need to improve the structure and presentation of the CSN job description
- the need to offer secondment opportunities for pilot roles
- the need to establish referral criteria and required documents (e.g., promotional leaflet) ready early to allow enough time for IT to build a webpage in time for launch
- acknowledgement that referred carers may be providing care 'out of area' and so the patient benefit may be realised elsewhere

In parallel, the Carer Support Nurse underwent role induction which included a Clinical Corporate Induction, meetings with key stakeholder identified by the study team, and completion of a bespoke CSNAT-I training (i.e., in addition to completing CSNAT-I's freely available online training toolkit, two bespoke support webinars with Dr Gail Ewing – one of the CSNAT-I developers). A CSNAT licence was secured for the service.

Governance meetings were held monthly online and involved the Carer Support Nurse, the line manager, ECCH's Professional Clinical Lead (Nursing & AHPs), and the study PI (Farquhar).

The first referral was received 30/11/2022: six weeks from role commencement.

[4] Available on request
[5] ECCH leaflet: https://www.ecch.org/media/0h5de2ty/carer-support-nurse-leaflet.pdf
[6] ECCH website: https://www.ecch.org/our-services/carer-support-nurse/

9.3. Which types of carers did the Carer Support Nurse support?

The Carer Support Nurse received 124 referrals during the 9-month period when the role was open to referrals (early December 2022 to late September 2023): Figure 1 shows the number of referrals and discharges by month.

Figure 1: Number of referrals and discharges by month (source: Task 2A ECCH data)

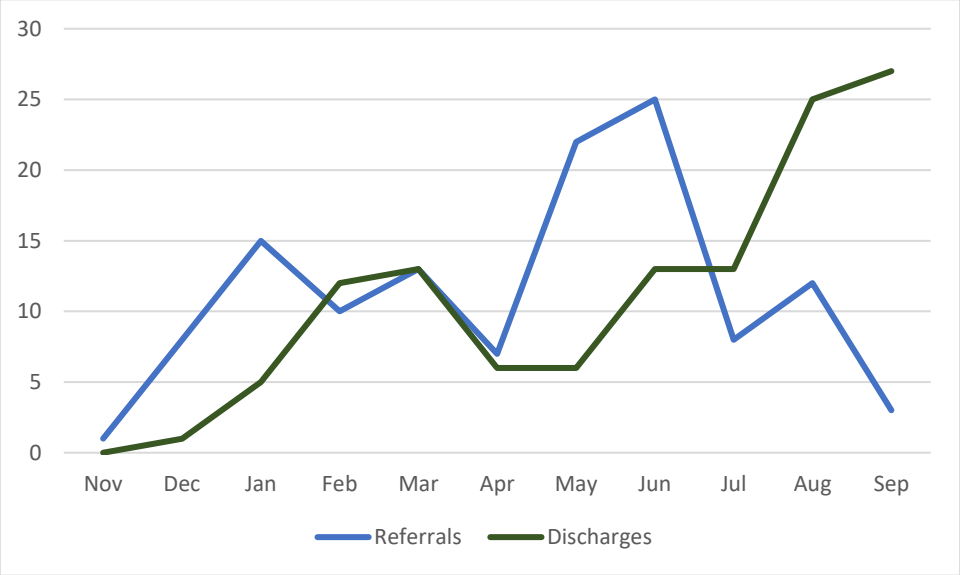


Table 1 shows the referral source and reason for discharge (source: Task 2A ECCH data).

Table 1: referral source and reason for discharge (source: Task 2A ECCH data)

Carer's GP practice:	Number of referrals (n=124)	Percentage (%)
East Norfolk Medical Practice	46	37
Coastal Partnership	35	28
The Park Surgery	15	12
Beaches Medical Centre, Sussex Road	12	10
The Nelson Medical Centre	6	5
Millwood Surgery	5	4
Cutlers Hill Surgery	2	2
Unknown	2	2
Sole Bay Health Centre	1	1
Referral source:		
ECCH – primary care home	72	58
Allied Health Professional	18	15
GP	17	14
Self-Referral	6	5
Great Yarmouth Borough Council	5	4

	Social services	3	2
	Relative / friend	2	2
	Voluntary organisation	1	1
Reason for discharge (n=121*):			
	Specialist input complete	71	59
	Advice and guidance provided	20	17
	Specialist input not required	14	12
	Internally redirected referral	5	4
	Inappropriate referral	4	3
	Carer declined	3	2
	Unable to contact	3	2
	Duplicate referral	1	1

*3 referrals in September still being seen

The CSN received referrals from across health, social care, and the voluntary sector – most referrals came from health, and predominantly from ECCH's Primary Care Home Team (source: Task 2A ECCH data), but were from a range of sources e.g., Mental Health Team, Early Discharge Stroke Team, Memory Impairment Nurse, and neurology nurses. Some self-referrals were made by carers themselves (source: Task 2A CSN report).

Over the course of the pilot there were periods where the service would receive many referrals and other times when referral numbers were low. Early stakeholder concerns that the nurse could be overwhelmed with referrals were not therefore realised (source: Task 1B interviews). Low referral periods often mapped to national holiday periods. During these low referral periods the CSN pro-actively advertised the service by, for example, joining daily 'Huddles' within ECCH, running drop-in sessions at a local voluntary organisation, putting up posters and attending carers' day events hosted by a local GP practice (source: Task 2A CSN report). These strategies were often successful in increasing referral numbers (and were supported by presentations and outputs by the study team to audiences that included potential referrers – see Appendix 4), however, cross-sector end of pilot focus groups/interviews (source: Task 2C) suggested that a more strategic approach could have been taken at an organisational level to promote the service (reported in Section 9.6). It was also recognised, however, that, as a waiting list was required at one point during the pilot, the nurse may not have had the capacity to manage additional referrals as a single-handed nurse.

Table 2 shows the characteristics of referred carers (source: Task 2A ECCH data). Most referred carers were female, and White British. Those referred included adults of all ages; no young carers (aged under 18 years) were formally referred, however there was evidence of young carers being supported e.g., quote from S-01-Health, Box 9, Section 9.6.3). This also identifies that there was direct carer support work conducted in addition to formal referrals.

Table 2: characteristics of referred carers (source: Task 2A ECCH data)

Characteristics of carers:	Number of carers (n=124)	Percentage (%)
Female*	91	73
Ethnicity:		
White British	68	55
White – any other	12	10
Asian, Asian British or any other Asian	1	1
Other ethnic groups	4	3
Ethnicity not stated	39	31
Age	**Years** (n=121 due to missingness)	**SD**
Mean	66	16
Median	70	
Minimum	20	
Maximum	95	

*source data only provided details of sex dichotomised into male and female

Figure 2 shows the number of referrals by carer age group.

Figure 2: Number of referrals by carer age group (n=121) (source: Task 2A ECCH data)

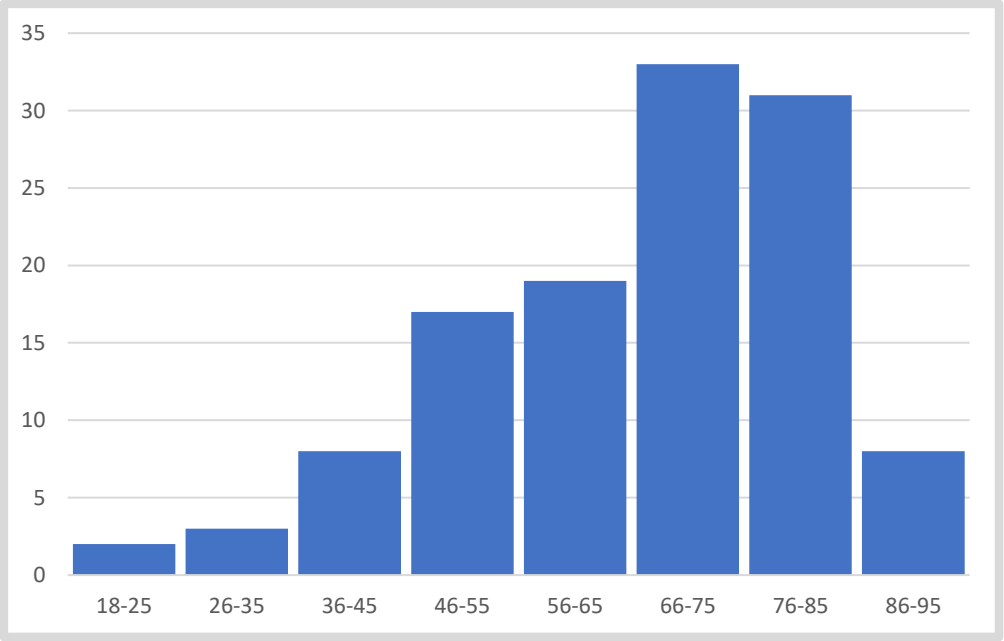


Table 3 shows the IMD Decile characteristics for the outcode section of referred carers' postcodes (the first part of the postcode).

Table 3: IMD Decile characteristics for outcode section of postcode (source: Task 2A ECCH data)

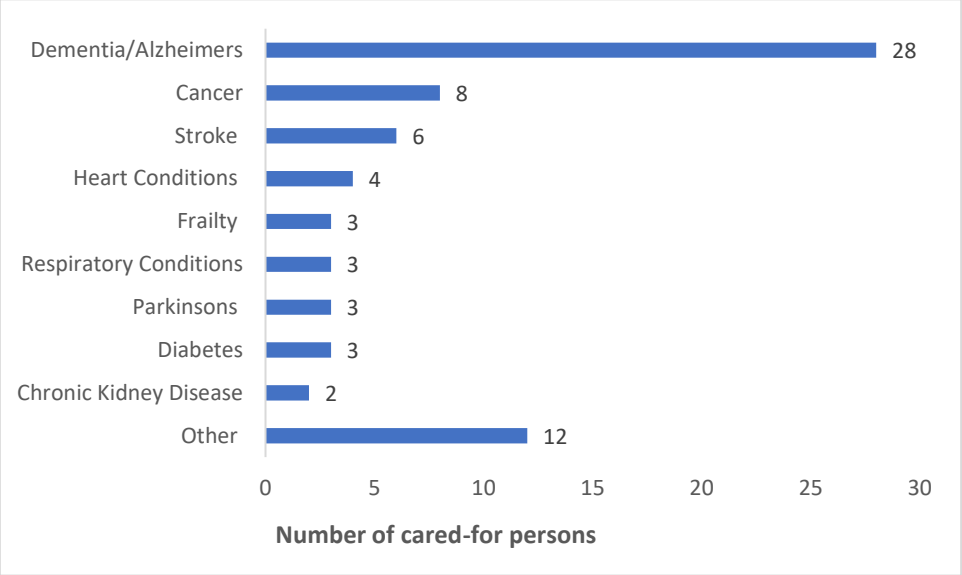
			IMD deciles of postcodes within outward code					
Outward code	No. of carers	% carers	N*	Median IMD Decile	Min IMD Decile	Max IMD Decile	Lower Quartile	Upper Quartile
NR29	26	21	791	4	1	6	4	6
NR30	64	52	1,264	1	1	7	1	2
NR31	30	24	1,359	3	1	9	2	6
NR34	1	1	115	4	4	6	4	4
IP**	2	2	1	8	8	8	8	8
UB5	1	1	1,319	4	2	6	3	4

*the number of postcodes within that outward code
**numbers redacted to preserve anonymity

The Index of Multiple Deprivation (IMD) is an official measure of relative deprivation for small areas in England. Each small area has been ranked from most to least deprived and divided into 10 equal groups or deciles. For example, if a postcode is in decile 1, it is among the 10% most deprived small areas. To maintain patient anonymity, we collected data on just the first part of the post code which is known as the outward code. We grouped the carers by outward code (Table 3) where, for example, 52% of the carers lived in a postcode that started with NR30 and among these carers there are a total of 1,264 unique postcodes where these carers could have lived. To characterise the deprivation of carers, we considered the range of IMDs that these deciles could have been. For example, amongst carers in NR30, we considered the 1,264 different decile values and report the median deprivation decile value 1, the most deprived. The majority of carers (>97%) lived in 'NR' area postcodes, in which the median decile was among the more deprived: deciles 1-4. However, it is worth noting the variability that this aggregation obscures: the 'outward' code NR31 includes postcodes that rank from decile 1, all the way to decile 9.

Referred carers provided care and support for spouses, elderly parents and, to a lesser extent, their children. The people these carers were caring for had a wide range of primary conditions (see Figure 3), the most common of which was some form of dementia reflecting referral sources which included a newly established Memory Impairment Nurse service. The CSN also reported that many of the cared-for people were multi-morbid (source: Task 2A CSN data).

Figure 3: Primary conditions of cared-for persons (Feb-Aug 2023) (source: Task 2A CSN)



9.4. What did the Carer Support Nurse do?

There were three key sources of data related to the Carer Support Nurse role activities:

1) Business Intelligence Unit data provided by ECCH (Task 2A)
2) activity analysis data gathered using Cassandra (Task 2A), and
3) data gathered from the CSN during Task 2A.

The CSN summarised the role as involving:

- Carer role acknowledgement and listening
- Person-centred assessment and solutions – using the evidence-based CSNAT-I to open up conversations about what is important to the carer and their unmet support needs, then enabling solutions by responding together to the carer's physical, social and emotional concerns
- Giving carers the opportunity to discuss their unmet health needs and the needs of the person they care for
- Providing carer health screening (physical and mental health) and coaching
- Upskilling carers and enabling them to provide care: giving them the skills to provide care and work with healthcare professionals.
- Supporting carers to access health services, educating as to health support available and giving carers a choice to decide what support would work for them
- Advocating on carers behalf when they feel there are not supported of misunderstood by healthcare teams
- Assessing risk of carer breakdown and providing crisis management
- Identifying and managing safeguarding concerns

This highlights the need for the role to be fulfilled and delivered by a registered nurse at a senior banding.

The CSN was described as a **"super-connector"** and **"knowledge broker"** due to her extensive interprofessional inter-sector working across health care (primary and community care, the mental health trust, and wellbeing service), social care (with Norfolk County Council and Great Yarmouth Borough Council), the voluntary sector (including carer and patient support groups), and emergency services (fire and police). Examples of services the CSN engaged with are listed n Box 6.

Box 6: Examples of cross-sector services the Carer Support Nurse engaged with
Health • GP Practices (East Norfolk Medical Practice, Nelson Medical Centre, Coastal Practice, Park Surgery), health coaching, Social Prescriber, Care coordinator) • Community ECCH (Occupational Therapy, Physiotherapy, Community Nursing, Community Matron, Wheelchair Service, Smoking Cessation, Falls and frailty, Volunteer Service, Pharmacy Technicians, Memory Impairment Nursing, Safeguarding, Health Connector, St Elizabeths Hospice, Neurology nurse, Stroke team, MSK) • School Nurse • NSFT (Community Mental Health)

• Wellbeing Service • Steam House Café • Active NoW
Great Yarmouth Borough Council • Community Hub (Community Marshall, Environmental health, Community Hub, Tenancy officer, Housing Service, Forget me not grant, Handy man service, Adaptations, Community alarm)
Norfolk County Council • Social Services (Social worker, Sensory Support, Norfolk Emergency Carers Card) • Better together Norfolk
Support Groups, Registered Charities, Social Groups • Acorn Centre • Centre 81 • Caister Parkinson's Support group • Carers Voice • Carers Matter • Caister Chatterbox Carers • Great Yarmouth Parkinson's Café • Independence Matters • DIAL • Feathers Future • Mens Shed • Age Concern • Bread Kitchen • Sallys Stores • Shrublands community Food Club • Dementia Norfolk • Age UK • Alzheimer's Society • Admiral Nurse • Great Yarmouth Allotment Association • Great Yarmouth Stoke Group • The Big C • Carers UK
Emergency Services • Fire Service • Police Service

9.4.1. Business Intelligence Unit data

Table 4 shows the type and duration of Carer Support Nurse role activities recorded on the Business Intelligence Unit (Task 2A ECCH data).

Table 4: Type and duration of activities (source: Task2A ECCH data)

Activity recorded across all time periods	Count	Minutes (total)	Mins (total with mean imputation)*	Mean (mins)*	Std dev.*	Min	Max
Activities with carer:							
Review	292	3,390	3,390	308	135	60	590
Advice & support	187	4,226	4,226	384	185	76	685
Assessment	127	10,025	10,025	911	483	60	1590
Intervention	118	2,995	*3,661	333	254	35	765
Advice & guidance	82	1,643	1,643	149	52	20	230
Access visit	76	550	550	50	60	0	173
Prescribing	2	0	*0	0	0	0	0
Relative	2	0	*0	0	0	0	0
Health coaching	1	0	*0	0	0	0	0
Administration:							
Data entry	360	2,001	2,001	182	122	16	378
Administration - clinical	220	2,168	2,168	197	125	50	505
Referrals/meetings with other services:							
Triage	231	2,752	2,752	250	148	20	487
Referral to other service	76	1,220	*1,491	136	60	25	225
Referral to social services	32	520	*635	58	44	0	115
Referral to local council	20	30	*47	4	6	0	15
Referral to GP	19	75	*138	13	15	0	55
Referral to PCH	12	105	*128	12	15	0	50
Bereavement contact	9	260	260	24	39	0	100
MDT discussion	7	30	*47	4	9	0	30
Joint professional contact	1	60	60	5	18	0	60
No access visit	2	0	0	*0	0	0	0
Finished appointments	202						

*Mean imputation was used to replace 26 observations for minutes which could not be deciphered from the pie chart data. For each activity type, where there were missing values, the mean of available values for that activity was used to fill in the missing values.

The distinction between some of the Table 4 activity categories recorded on the Business Intelligence Unit (Task 2A ECCH data) was unclear e.g., the distinction between “Advice & support” and “Advice & guidance”.

Table 5 shows the referrals and activities by time period.

Table 5: Referrals and activities by time period (source: Task2A ECCH data)			
Time period:	Number of referrals (n=124)	Total number of activities	Total number of minutes
November 2022	1	96	1,634
December 2022	8	235	3,402
January 2023	15	216	3,902
February 2023	10	216	3,644
March 2023	13	159	2,682
April 2023	7	110	2,028
May 2023	22	199	3,908
June 2023	25	245	4,372
July 2023	8	164	3,284
August 2023	12	170	3,166
September 2023	3	66	1,200
Total	**124**	**1876**	**33,222**

The table shows an initial rise in referrals, followed by a decline around the Easter holiday period, then a notable increase which followed a period of active service promotion by the CSN. Referrals notably reduced in September due to the pilot end date.

9.4.2. Activity analysis

Data recorded on Carer Support Nurse Activity using Cassandra (Task 2A) over 10 working days sampled in May and June 2023 found that face-to-face new assessments took between 90 and 120 minutes (week beginning 16/05/2023). All data recording using Cassandra is likely to be underestimated by about 40%, which is not unusual when data are collected using Cassandra initially.

Table 6 shows example daily carer contact data.

Table 6: Example daily carer contact data for the CSN (source: Task 2A Cassandra)	
Date	Carer contacts by the CSN
16/05/2023	4 carer contacts: 1 home visit + 3 triage
17/05/2023	3 carer contacts: 1 home visit + 2 triage
23/05/2023	4 carer contacts: 1 home visit + 2 triage + 1 follow up
24/05/2023	8 carer contacts: 1 home visit + 3 triage + 4 follow up/reviews
26/05/2023	6 carer contacts: 1 home visit + 4 triage + 1 follow up

There was additional unrecorded work reported such as service establishment, building networks, and establishing jurisdiction; these meetings range from 30 mins to total 3 hours per day. Examples of meeting times: Collaboration Meeting 1.0 hr, Carer Support Nurse clinical governance meeting 1.0

hr, attending Carers' Group 1.5hr, Caister Integrated Care Meeting 1.0hr, CSNAT-I Support Group 1.0hr, CSN research meeting 1.0 hr, ECCH lunch Huddle 0.5hr, meeting with Admin 0.5 hr.

Figure 4 shows that most activity took place in carers' homes (Task 2A Cassandra), although later in the pilot the CSN was also able to offer the option of meeting at ECCH: both appeared to work well (Task 2A CSN report).

Figure 4: Location of interventions (source: Task 2A Cassandra)

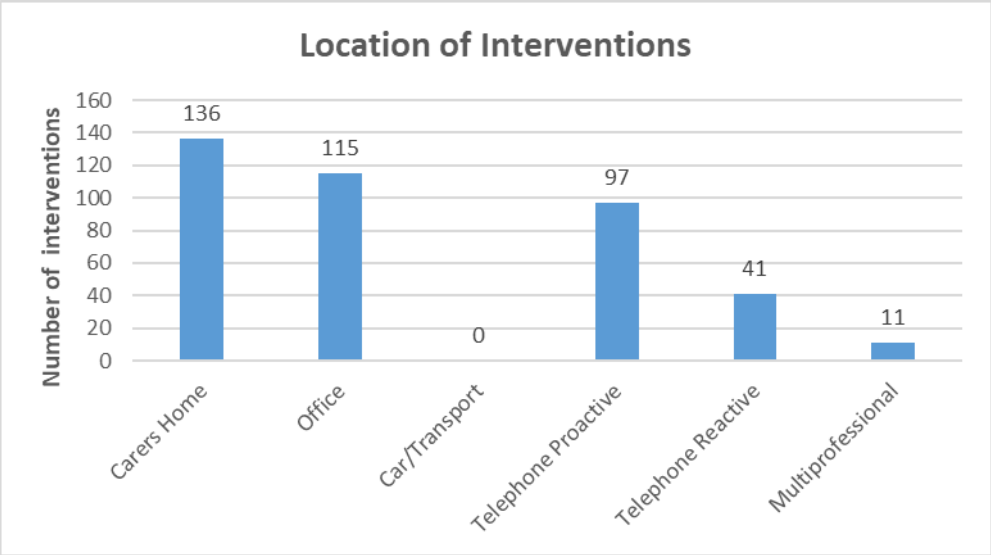


Table 7 shows the hours worked, unpaid overtime and travel time over the 10-working-days sampled. This did not include ECCH's "lunchtime Huddles" which consumed lunch breaks.

Table 7: Hours worked, unpaid overtime and travel time over the 10-working-days sampled (May and June 2023) (source: Task 2A Cassandra)

	Hours Worked	Unpaid	Travel
16th	7.5	0	1
17th	7.5	0	0.58
23rd	7.5	0	1.25
24th	7.5	2	1.2
26th	7.5	0.5	0.75
6th	7.5	0	0.75
7th	7.5	0	0.5
8th	7.5	0	0.75
9th	7.5	0	0
12th	7.5	0	0
Total	**75**	**2.5**	**6.78**

In completing the Cassandra tool, the CSN made the following observations:

- Time was spent doing general office tasks – could spend 30-60 minutes reading and actioning emails not always relating to carer support role)
- Follow up *"admin (documenting visit, onward referrals, telephone calls, discussion with other HCP's and agencies) can sometime feel like it takes forever – at least 30 mins to an hour to write up, 10-15 mins per referral, calls 5 to 30 minutes, follow up calls"*
- Time was spent triaging new referrals and providing interim advice before full assessments
- one carer contact could lead to multiple referral and signposting to other services/agencies
    - Example 1: GP, social and financial services
    - Example 2: Social services, GP, Carers Matter, Wellbeing (mental health), Carers Voice, and housing

Figures 5-7 show the extensive range of activity undertaken:

- Figure 5 presents the proportion of activity undertaken by the CSN. It shows that the work is distributed across different types of work and across the nursing process i.e., assessment, planning, intervention, and evaluation. **This confirms the benefit of an experienced registered nurse being in the role.**
- Figures 6-7 show the frequency of these activities and, in particular, the response to the psychological needs of the carers as well as physical and social needs of the carers undertaken by the CSN.

Figure 5: Proportion of activity by grouping over the 10-working-days sampled (source: Task 2A Cassandra)

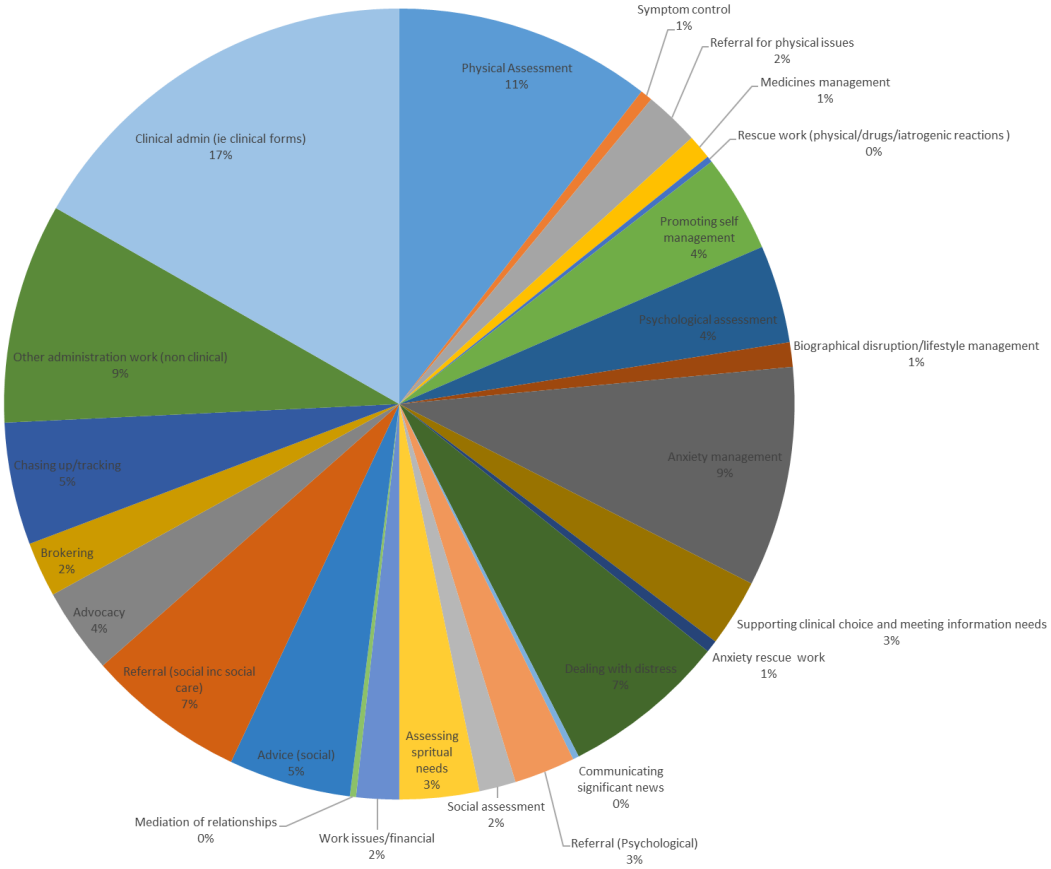


Figure 6: Detailed breakdown of cumulative activity over 75 hours over the 10-working-days sampled (source: Task 2A Cassandra)

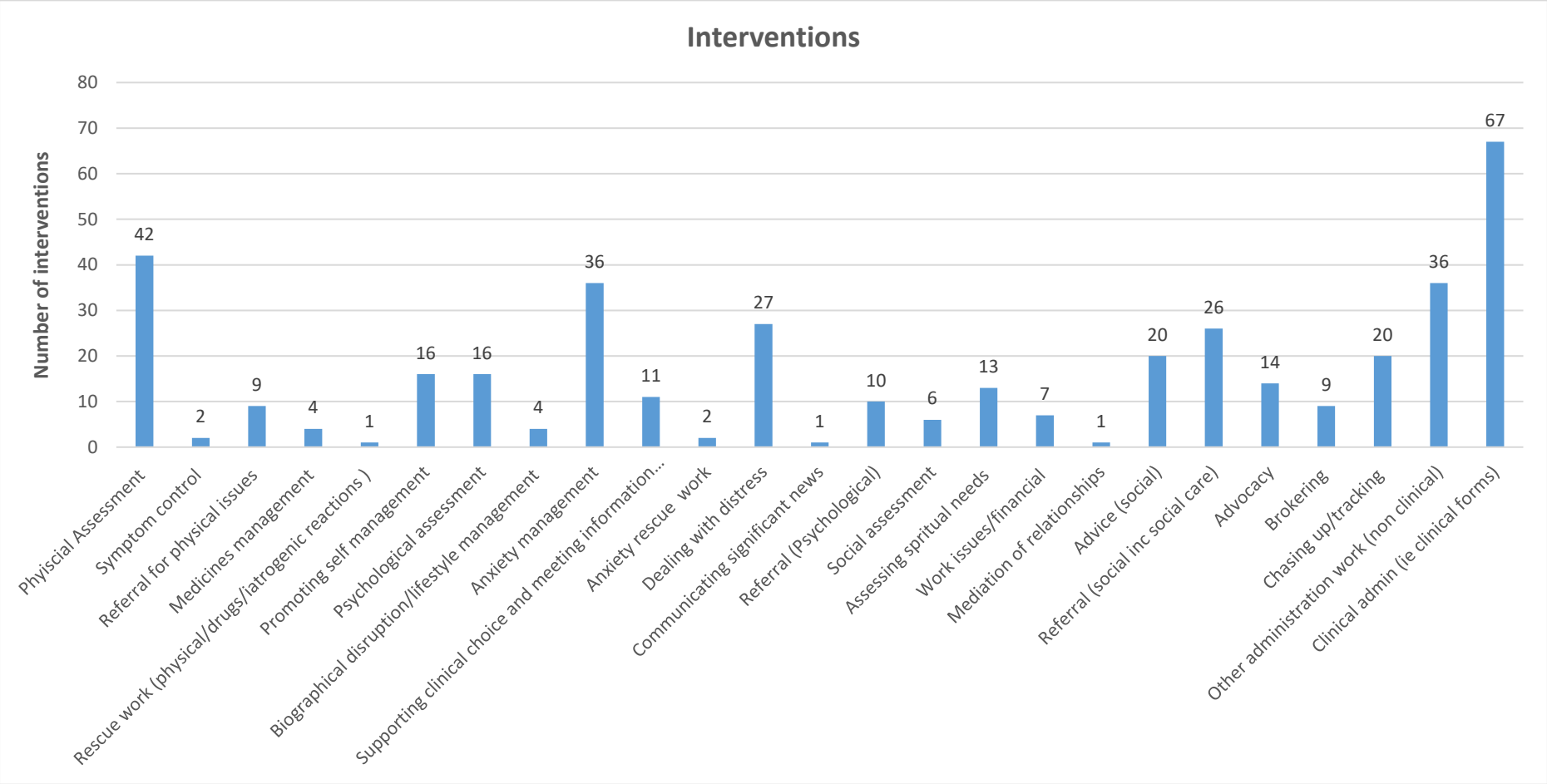
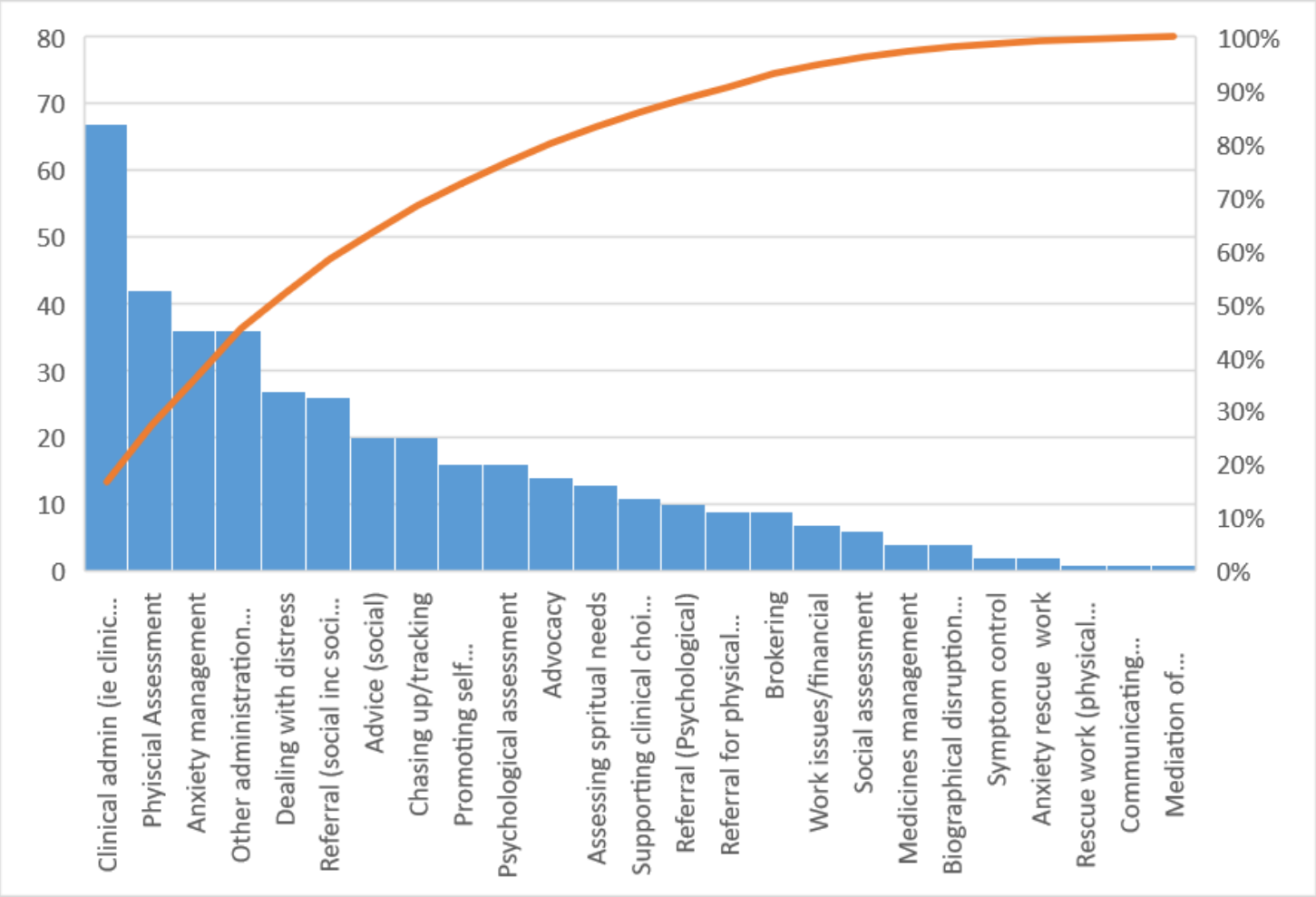


Figure 7: Interventions as a Pareto chart (to 100% of recorded work) over the 10-working-days sampled (source: Task 2A Cassandra)



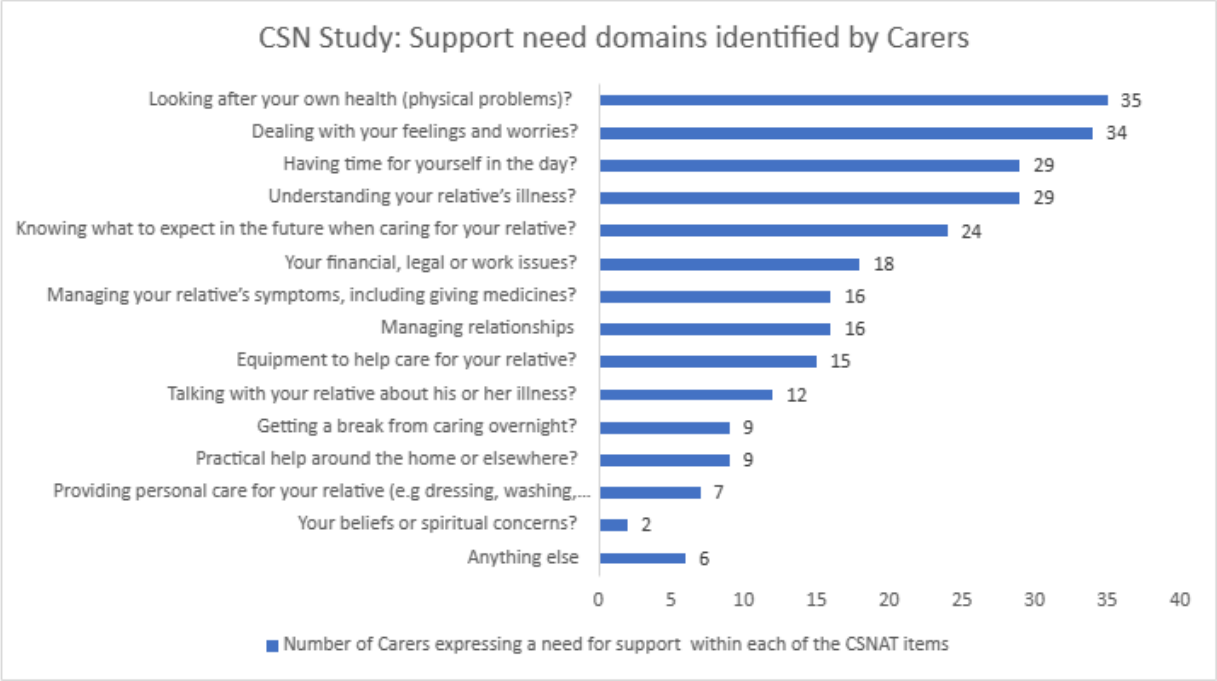
9.4.3. Working with carers

During carer consultations the CSN would assess any health concerns of the carer (using standard medical checks) and used the Carer Support Needs Assessment Tool Intervention (CSNAT-I) to enable a person-centred conversation with carers about their wider support needs.

Use of CSNAT-I involved the CSN facilitating a carer-led process involving CSNAT-I's five stages. After it was introduced to them (CSNAT-I Stage 1) each carer completed the "About you" booklet which contained the Carer Support Needs Assessment Tool (CSNAT) – this helped them identify the broad areas where they needed more support (CSNAT-I Stage 2). The CSN reported that carers were happy to do this and were able to use the tool to identify areas of support they would like to discuss.

Data collected by the CSN (source: Task 2A CSN report) about which areas of support need carers identified throughout the study showed that, as a group, carers identified needing (more) support across the full range of items on the CSNAT (see Figure 8). The most frequently identified items being 'looking after your own health (physical problems)' and 'dealing with feelings and worries', which suggests that referrals were in line with the referral criteria (i.e., carers with health and wellbeing needs) and stakeholder recommendations.

Figure 8: Areas of unmet support need identified by referred carers (source: Task 2A CSN report)



Using the completed tool, the carer and CSN were then able to explore and identify the underlying individual needs within those broad areas ticked on the tool that the carer wanted to talk about (CSNAT-I Stage 3). They then tried to work together to identify tailored support i.e., what carers felt would be helpful (CSNAT-I Stage 4). The CSN found that going through carers' responses on their completed tool enabled the carers to open-up and share their stories with her (CSNAT-I Stage 3). The conversations showed how some of the identified needs overlapped, and sometimes these

conversations moved into area of support need that had not been initially identified on the tool. As such the tool acted as a conversation starter, in line with its intended use within the wider CSNAT intervention (CSNAT-I).

Working together to identify tailored support (i.e., what carers felt would be helpful: CSNAT-I Stage 4) was more of a challenge as the carers rarely had proactive ideas about the sort of supportive input they felt would help in response to their needs. However, the CSN was able to support this process by making carers aware of the range of possible supportive inputs available and discussing with them e.g., exploring together what sorts of resources would make the biggest difference to them. Informed by these conversations, and in line with CSNAT-I, the CSN and carer would then draw up a support plan detailing what the CSN and carer would do (CSNAT-I Stage 4).

A further challenge for the CSN was deciding how much to be involved in facilitating the items on the support plan, particularly as she noted that some of the carers were already aware of available resources but often hadn't had the time or energy to connect with them. As a result, the CSN undertook many enabling activities to ensure delivery of the support plan (e.g., liaising with services, identifying funding sources etc.) but also described coming to the realisation that she would not have the capacity to do this single-handedly for every referred carer and so described being only sometimes able to provide these opportunities for carers.

Box 7 shows some examples of individual needs and tailored support put in place by the CSN using CSNAT-I (source: Task 2A CSN report).

Box 7: Examples of carers' individual needs and tailored support (using CSNAT-I)
(source: Task 2A CSN report)

Individual support needs	Support provided
Afraid of mum falling	Discussed impact on carer and referred to Falls Team
Continence issues overnight	Discussed carer feeling exhausted and arranged continence review for cared-for person
Carer's desire to take relative out but difficult due to behaviour (could be rude and abusive)	Discussed and suggested approaching organised social group, explaining concerns
Carer's own health	Referral to GP for review for low blood pressure and high heart rate which led to medication review Referral to Physio/Falls Team following fall resulting in rib and spinal fracture
Carer worried that parent had onset of memory loss	Consent gained from parent to refer to Memory Impairment Team

All the carers were followed up – either by phone or, if more appropriate, with a face-to-face appointment. Typically, the CSN would take this opportunity to review the CSNAT-I support plan to find out how far the plan has been implemented, how the carer was feeling and assess whether additional support was needed (CSNAT-I Stage 5). The CSN also asked carers to re-visit the CSNAT to help them think about whether they had on-going or additional support needs.

A further challenge faced by the CSN was when to 'step back'. It is notable that 'step back' was the term the CSN preferred to 'discharge' as she would always let the carers know that they could get back in touch if necessary. She had struggled initially with balancing carer expectations of the service and her own capacity in relation to this but, reflecting back, felt that in the majority of cases the review stage was an appropriate time to do this stepping back for most. However, as the CSN developed in the role, she began to be able to identify those carers likely to need on-going support. These included: 1) carers of people requiring palliative or end-of life care and 2) carers of people with long term conditions experiencing multiple infections and admissions.

For the CSN the workload was challenging both logistically and emotionally. Over the course of the pilot it became clear that it was feasible to plan for only one assessment visit per day as these sessions would take two to three hours each, and generated additional work both in terms of administration and on-going support e.g. liaising with other services.

Appendix 5 provides some brief case studies of the CSN's work with referred carers.

9.4.4. Other roles

In addition to directly supporting carers, the CSN also carried out other work to develop links with other organisations and promote the role within ECCH (e.g., being shadowed by other professionals from ECCH and providing advice to other professionals), to attended multi-disciplinary case conferences, to delivering training, and to complete administrative tasks (source: Task 2A CSN report).

9.4.5. Describing the Carer Support Nurse Intervention: TIDieR

The Template for Intervention Description and Replication (TIDieR [72,73]) is a 12-item checklist and guideline developed to help to improve completeness in the reporting of interventions in research studies. As such, the checklist reports an intervention's name, why it was introduced, and then addresses a series of points related to its intended delivery *(i.e., what it is [and any associated materials and procedures], who provides it, how, where, when and how often)*, and any changes that occurred on delivery *(i.e., tailoring, modifications, how well [planned], how well [actual])*. The template was therefore completed for the Carer Support Nurse role using the study background and findings across the two empirical stages of the study (Stage 1 and Stage 2). The completed template is presented in Appendix 6.

9.5. What was the impact of the Carer Support Nurse role on carers?

There were two key sources of data relating to the impact of the CSN on carers: the carer baseline and 6-week follow-up surveys (reported in Section 9.5.1) and carer feedback collected from the carer interviews (reported in Section 9.5.2). Both sets of data were collected within Task 2B.

9.5.1. Carer survey data

Eighteen carers completed a baseline survey (Task 2B). This was a 32% response rate which is considered high for a carer survey, particularly for carers experiencing complex needs[7].

The survey included the Preparedness for Caregiving Scale [74], Warwick-Edinburgh Mental Wellbeing Scale [75,76], EQ-5D-5L [77,78] (a standardised measure of health status for clinical and economic appraisal), demographic questions and questions related to their caring role and resource use (Task 2B). Ten of these carers completed the follow up survey which repeated these measures approximately six weeks later.

Table 8 summarises the characteristics of the responding carers at baseline.

Table 8 Characteristics of carer survey respondents and their caring role (at baseline)

	Baseline (all) n=18		Baseline (completed both baseline and follow-up) n=10	
Carer characteristics (survey respondents)	%	n	%	n
Mean age of carer	69.88	17	69.80	10
Female	71%	17	90%	10
White British	100%	17	100%	10
Supporting how many people:				
One	88%	16	100%	9
Two	13%	16	0%	9
Carer is a family member	100%	18	100%	10
Living with the person they are caring for:				
Yes	89%	18	80%	10
Mixed (living/not living)	6%	18	0%	10
No	0%	18	20%	10
Hours per week spent in caring role:				
<20	0%	15	0%	8
20-34	7%	15	0%	8
35-49	13%	15	25%	8
50-99	13%	15	25%	8

[7] Personal communication with Jen Kenward, former lead for NHSE/I Commitment to Carers Programme

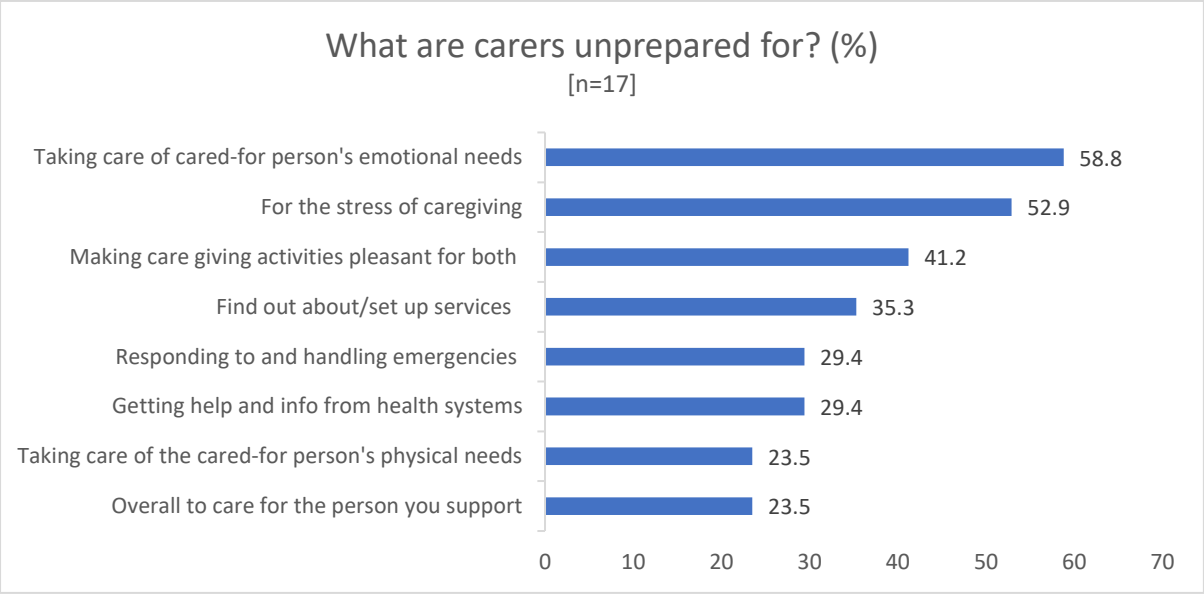
100+	67%	15	50%	8
Employment type:				
Retired	72%	18	44%	10
Unemployed	0%	18	0%	10
In full-time employment	6%	18	0%	10
In part-time employment	6%	18	0%	10
Other	17%	18	11%	10
Receiving support/professional care:				
Yes	24%	17	12%	9
No	76%	17	41%	9
Self-funded	25%	4	50%	2
Funded by social services	75%	4	50%	2

For carers who completed both the baseline survey and the follow-up survey, there were no carers supporting more than one person (Table 8). Also mean hours spent in a caring role was lower (96 hours, Table 8) than for 'all baseline' respondents (107 hours). It is possible that those carers missing in the follow-up may have been more complex/busy carers.

9.5.1.1. Preparedness to Care Scale

Seventeen of the 18 responding carers completed the Preparedness for Caregiving Scale. Figure 9 shows these carers baseline scores. Lack of preparedness to care was evidenced by carers answering 'not at all' or 'not too well' to the caring activities. Three missing data points were replaced using person-mean imputation: this scoring approach involves averaging across non-missing items for each participant, implicitly assuming that missing items have similar distributional properties (e.g., means) as non-missing items [79,80].

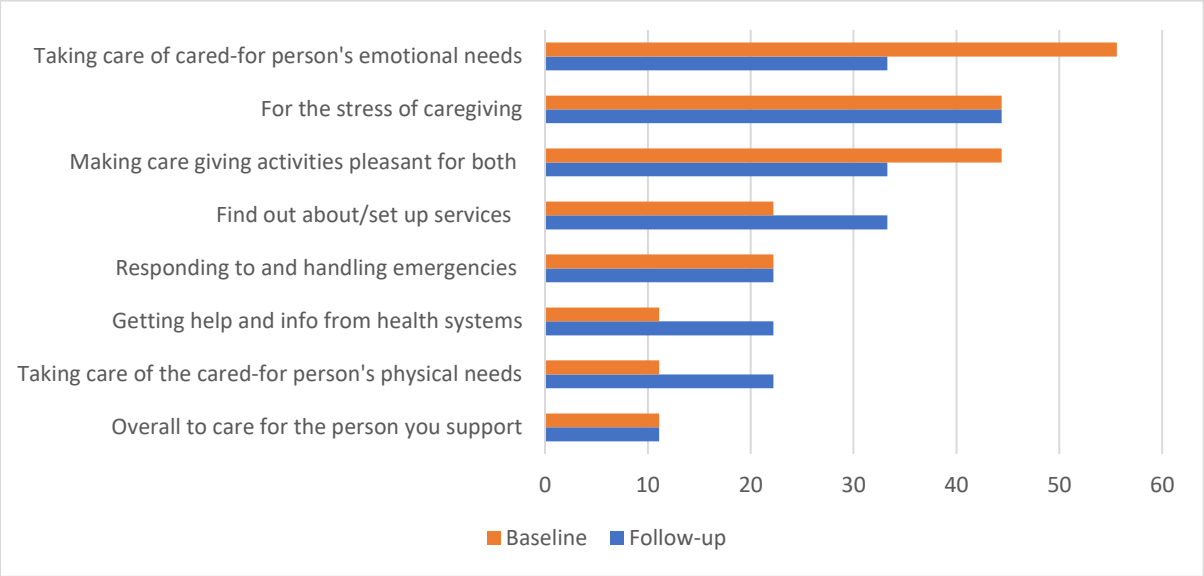
Figure 9: Baseline Preparedness for Caregiving



Carers were least prepared for taking care of the cared-for person's emotional needs prior to contact with the CSN. This likely reflects the high number of carers supporting someone with dementia within the referred carer population.

Of the 10 carers who returned a follow up survey, nine completed the Preparedness for Caregiving Scale. Due to the sample size a simple comparison of the baseline and follow-up percentage scores for those who completed this scale in both surveys was conducted (n=9): the results are shown in Figure 10. One carer only responded to 2/8 questions (25%): person-mean imputation replacement was conducted but understood to be less reliable when the number of missing items is more than 20% [79].

Figure 10: Comparison of what carers were unprepared for at baseline and follow-up: Preparedness for Caregiving (%) (n=9)



This comparison suggests an improvement in carers' sense of preparedness to take care of the cared-for person's emotional needs; other smaller changes in preparedness should be treated with caution given the small sample size.

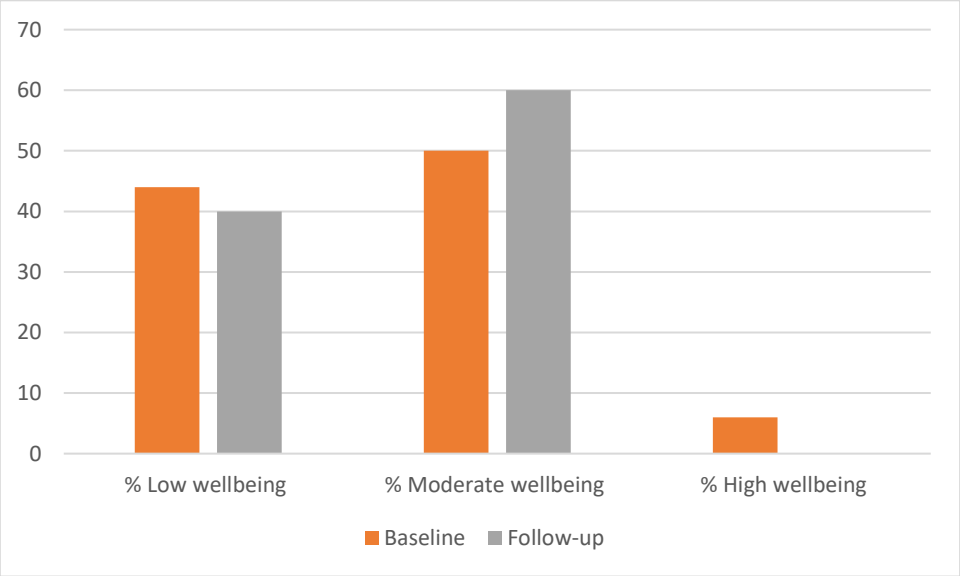
9.5.1.2. Warwick-Edinburgh Mental Wellbeing Scale

All carers who completed a baseline and follow up survey completed the Warwick-Edinburgh Mental Wellbeing Scale (n=18 and n-10 carers respectively). The results shown in Table 9 and Figure 11 were calculated using the recommended Excel spreadsheet for calculating scores; although they signal improvement, they should be treated with caution given the small sample size.

Table 9: Carer wellbeing at baseline: Warwick-Edinburgh Mental Wellbeing Scale scores

	Baseline	Follow-up	Change	Positive Change	Statistically significant change	Wilcoxon signed rank test p value
Total no. of responses	18	10				
% Low wellbeing	44%	40%				
% Moderate wellbeing	50%	60%				
% High wellbeing	6%	0%				
Mean Score	22.2	23	0.60	Yes	No	p>0.05
Standard deviation	5.4	5.2	2.6			
Number of people with a meaningful positive change =2 (20%) Number of people with a meaningful negative change =1 (10%)						

Figure 11: Comparison of carers' wellbeing at baseline and follow up: Warwick-Edinburgh Mental Wellbeing Scale scores (%) (n=10)



9.5.1.3. EQ-5D-5L

The EQ-5D-5L has five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with five response levels ranging from no problems to extreme problems (see Table 10). Carers indicated their health by ticking one of the levels for each dimension, their set of responses to the five dimensions generates a health state.

Table 10 shows the distribution of EQ-5D-5L dimension responses at baseline for all responding carers, at baseline for those carers who completed both the baseline and follow-up survey, and follow-up responses.

Table 10: Distribution of EQ-5D-5L dimension responses at baseline (all), baseline (respondents completing both baseline and follow-up) and follow-up

Dimension	Baseline (all) % (n)	Baseline (respondents completing both baseline & follow-up) % (n)	Follow-up % (n)
Mobility	n=18	n=10	n=10
No problems walking about	50 (9)	60 (6)	50 (5)
Slight Problems walking about	11 (2)	10 (1)	30 (3)
Moderate problems walking about	33 (6)	20 (2)	10 (1)
Severe problems walking about	6 (1)	10 (1)	10 (1)
Unable to walk about	0 (0)	0 (0)	0 (0)
Self-care	n=17	n=10	n=10
No problems washing or dressing	82 (14)	70 (7)	70 (7)
Slight Problems washing or dressing	6 (1)	10 (1)	20 (2)
Moderate problems washing or dressing	12 (2)	20 (2)	10 (1)
Severe problems washing or dressing	0 (0)	0 (0)	0 (0)
Unable to wash or dress	0 (0)	0 (0)	0 (0)
Usual activity	n=17	n=10	n=10
No problems doing usual activities	41 (7)	50 (5)	60 (6)
Slight Problems doing usual activities	35 (6)	20 (2)	20 (2)
Moderate problems doing usual activities	18 (3)	20 (2)	10 (1)
Severe problems doing usual activities	6 (1)	10 (1)	10 (1)
Unable to do usual activities	0 (0)	0 (0)	0 (0)
Pain/discomfort	n=18	n=10	n=10
No pain or discomfort	28 (5)	40 (4)	40 (4)
Slight pain or discomfort	22 (4)	20 (2)	20 (2)
Moderate pain or discomfort	28 (5)	20 (2)	30 (3)
Severe pain or discomfort	22 (4)	20 (2)	10 (1)
Extreme pain or discomfort	0 (0)	0 (0)	0 (0)
Anxiety/Depression	n=18	n=10	n=10
Not anxious or depressed	11 (2)	20 (2)	20 (2)
Slightly anxious or depressed	39 (7)	40 (4)	50 (5)
Moderately anxious or depressed	39 (7)	30 (3)	20 (2)
Severely anxious or depressed	6 (1)	0 (0)	0 (0)
Extremely anxious or depressed	6 (1)	10 (1)	10 (1)

Figure 12 shows the proportion of responses by level of severity for EQ-5D-5L dimensions at baseline for all responding carers.

Figure 12: Proportion of responses by level of severity for EQ-5D-5L dimensions at baseline (all) n=17-18)

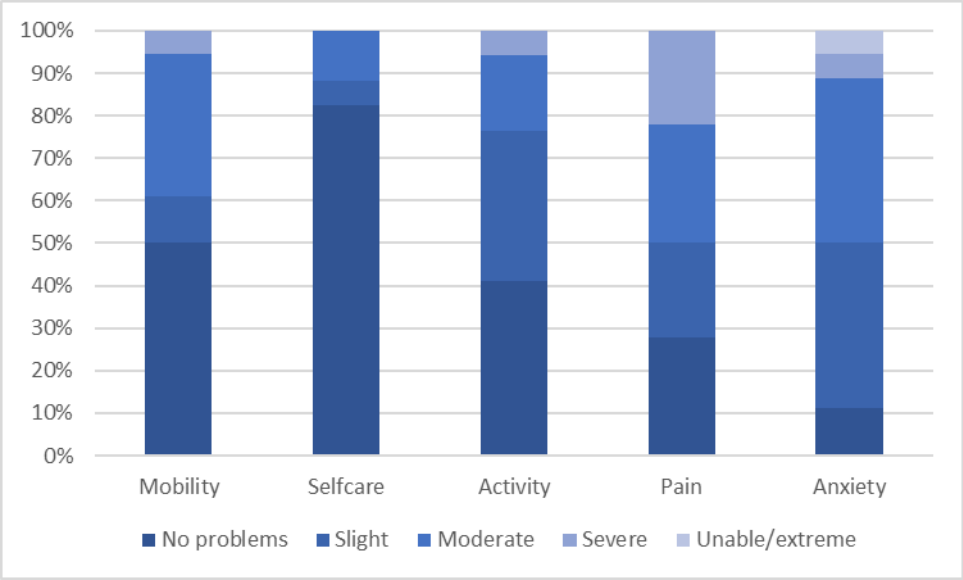
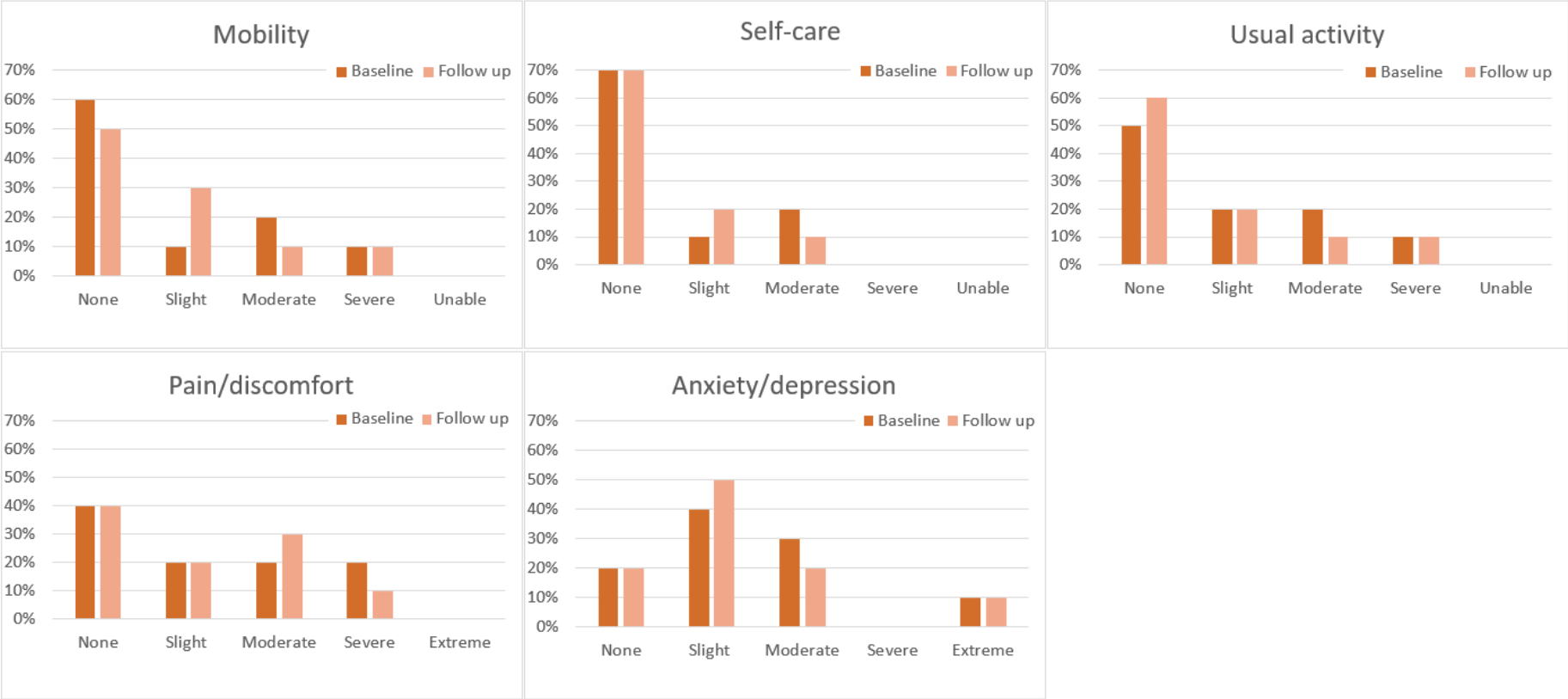


Figure 13 shows the proportion of responses by level of severity for EQ-5D-5L dimensions at baseline and at follow-up, among carers completing measure at both time points.

Figure 13: Proportion of responses by level of severity for EQ-5D-5L dimensions at baseline and at follow-up, among participants completing measure at both time points (n=10)



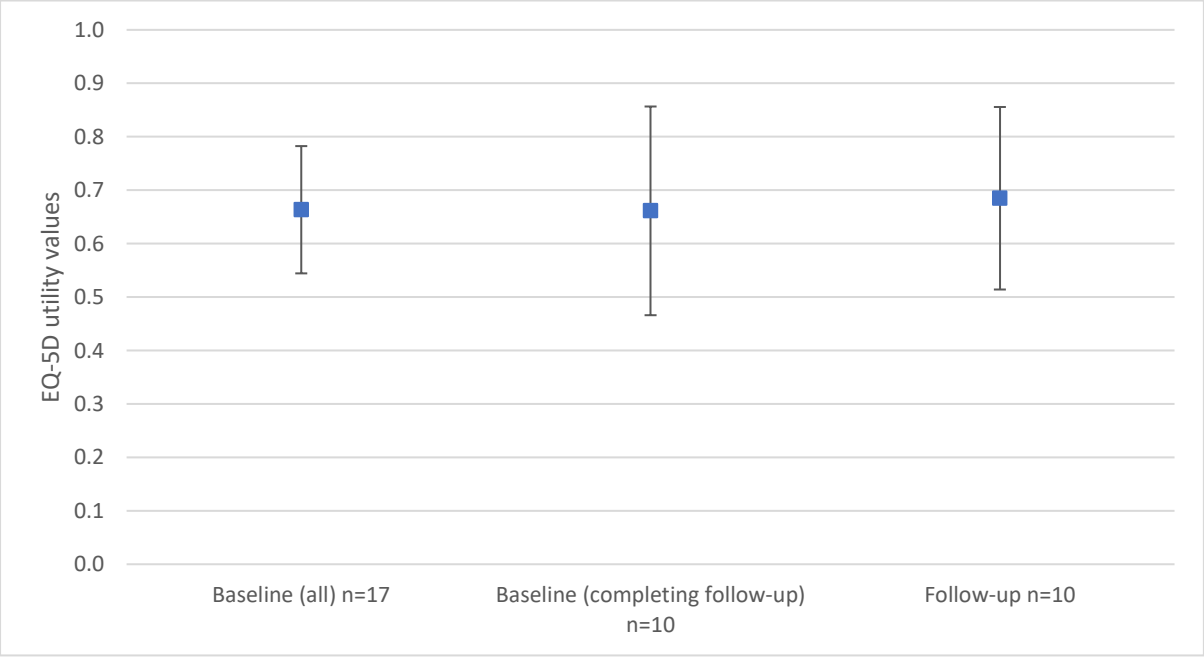
An individual's health state can be converted to a single summary index – a utility – using a country/region specific value set. Typically, value sets are generated from the general population, with the value set utilised here derived in van Hout et al (2012) [81]. A utility value typically ranges between 0 and 1, with 0 representing death, 1 representing a state of perfect health; however, negative values can occur, indicating a health state considered worse than death. Table 11 shows the EQ-5D utility values at baseline for all responding carers, at baseline for those carers who completed both the baseline and follow-up survey, and follow-up responses.

Table 11: EQ-5D utility values at baseline (all), baseline (respondents completing both baseline and follow-up) and follow-up

EQ-5D utility value	Baseline (all) n=17	Baseline (respondents completing both baseline & follow-up) n=10	Follow-up n=10
Mean	0.66	0.66	0.69
Median	0.72	0.75	0.74
Standard deviation	0.25	0.32	0.28
IQR (LQ-UQ)	0.31 (0.55-0.86)	0.39 (0.50-0.89)	0.32 (0.56-0.88)
Minimum	-0.06	-0.06	0.04
Maximum	1	1	1

Figure 14 shows the EQ-5D values at baseline for all responding carers, at baseline for those carers who completed both the baseline and follow-up survey, and follow-up responses.

Figure 14: EQ-5D values at baseline (all responses, one participant excluded due to incomplete data, n=17), baseline (respondents completing both baseline and follow-up, n=10) and follow-up (n=10): mean values and 95% confidence intervals



One participant, a female aged 80, reported a negative health state worse than death at baseline (-0.060); this carer's score had improved at follow up (0.044). A single participant reported a state of perfect health (utility=1) at both baseline and follow-up: a female aged 69. Mean baseline utility values were lower at baseline (0.663 [n=17] and 0.661 [n=10]) than at follow-up (0.685).

The EQ-5D-5L includes the EQ VAS which is a vertical Visual Analogue Scale (VAS) upon which patients report a global assessment of their own health. Values range from 100 (best imaginable health) to 0 (worst imaginable health). Table 12 shows the EQ-5D-5L visual analogue scale (VAS) at baseline for all responding carers, at baseline for those carers who completed both the baseline and follow-up survey, and follow-up responses. The mean EQ VAS score was lower at baseline (71 and 73) than at follow-up (75). Two respondents (11%) reported best imaginable health at baseline.

Table 12: EQ-5D-5L visual analogue scale (VAS) for participants at baseline (all), baseline (respondents completing both baseline and follow-up) and follow-up

EQ VAS score	Baseline all (n=18)	Baseline (respondents completing both baseline & follow-up) (n=10)	Follow-up (n=10)
Mean	71	73	75
Median	75	78	80
Standard deviation	19	24	24
IQR (LQ-UQ)	20 (60-80)	21 (63-84)	29 (65-94)
Minimum	20	20	20
Maximum	100	100	95
Participants rating 100 (best imaginable health)	2	2	0

Quality of life scores were (on average) similar at baseline and follow-up (n=17: 0.663, 95% CI 0.544-0.782; among n=10 completing both baseline and follow-up: 0.661, 95% CI 0.466-0.857; 0.685 95% CI 0.514-0.856). Among those (n=10) completing both surveys, there was a small (non-statistically significant) improvement in quality of life – though this should be interpreted with caution given the very small sample sizes. However, 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.

9.5.1.4. Resource use and costs

Carers were asked to recall health services resource use over a six-week time frame at baseline and again at follow-up. GP and nurse face to face contacts were the most frequently reported resource use by carers at both baseline and follow-up (Appendix 7 – Table 13). There were no contacts reported for 'community/district nurse' and no overnight hospital stays were reported. Overall, the mean number of primary and secondary care visits reported by carers was low and the mean visits were similar at both baseline and follow-up for each type of resource use (Appendix 7 – Table 14).

Unit costs (see Appendix 7 – Table 15) were applied to resource use and mean total costs were generated (Appendix 7 – Table 16). Assumptions were made whereby missing data was treated as zero for costing purposes (unless a 'further information' text field was completed). When a resource was reported to be used but the number of times was not reported, we have assumed one use (due to the short follow-up period).

Mean total costs at baseline (for carers completing both surveys) and follow-up were similar at £72 and £80 respectively. The higher mean total cost at baseline reported for all 18 carers (£108) was likely due to a higher number of reported outpatient appointments among those carer participants only contributing data at baseline.

9.5.2. Carer feedback

Direct carer feedback is essential to truly capture the value and impact of the role for carers themselves. Preliminary results from a forthcoming NIHR evidence synthesis on factors affecting carers' mental health notes how the narratives and qualitative data may carry more weight than quantitative or statistical data for practitioners and policy makers[8].

Six unpaid/family carers who received the Carer Support nurse intervention were interviewed (Task 2B). All were female, white, and ranged in age from 57-87 years. All described supporting a family member they lived with (five were wives and one was a daughter), and most provided between 35 hours or more of care per week. All but one of the unpaid/family carers were retired. Three of the carers experienced bereavement in relation to their caring role during the pilot.

9.5.2.1. Impact of the caring role

The participants described supporting the people they cared for across a range of activities: managing personal care, assisting with other activities of daily living, ensuring the cared for person was safe, managing medication and accompanying the cared-for-person to medical or other appointments. In addition, they had all taken on responsibility for all, or most, of the activities relating to running the household.

> *"I mean literally I just have to do everything now, for two people"* [C21]
>
> *"I just get on with everything: the banking, the shopping, the cooking, the organising, the planning, caring"* [C20]
>
> *"What don't I do?"* [C70]

The carers also highlighted the impact their caring role had on their own health and well-being. Some described being physically exhausted, but most also highlighted how the role had resulted in them feeling worried, anxious, stressed, overwhelmed, and increasingly isolated.

> *"I'm tired. I worry. I get very stressed... My way of life has changed... I would meet friends. [we] would go out. It's like I've had a bereavement, that's the only way I can explain it. Life wasn't what we thought it would be. It started slowly but it's all coming very quickly now*

[8] Personal communication with Professor Gunn Grande 30/11/2023

and, yes, I just don't do anything anymore, except care. That's what it feels like… a couple of weeks ago I just stood in the middle of the floor and screamed" [C20]

"I'm very tearful, it doesn't take much to set me off. You know, if something goes wrong, just the slightest thing, I sort of burst into tears and can't cope [...] I don't always sleep very well, because I am sort of half-awake listening to [the cared-for-person]" [C70]

9.5.2.2. Carer support received prior to CSN contact

Prior to meeting the Carer Support Nurse none of the carers reported getting any significant support for themselves outside of family, friends, and paid-for cleaning/gardening services. Despite the challenges in their caring role, they described the focus of services and professionals as always being on the cared-for-person whilst their needs, as the carer, were overlooked. One of the younger carers in the sample had also attempted, unsuccessfully, to find carer support services where she could meet people of a similar age. Support that was available to these carers typically focused on assistance with benefit claims. Only one of the cared-for people had received additional support from professional carers.

9.5.2.3. Contact with the Carer Support Nurse:

Four of the carers described how they were referred to the CSN after a significant incident, or deterioration, in the cared-for-person's health had resulted in the involvement of services on that person's behalf. On these occasions a professional had also recognised the carers' distress and referred them to the CSN service. One noted "*I was quite glad that this other lady had referred me. That she picked up that we needed help. That I needed help"* [C20]. One wasn't sure why she had been referred and the remaining carer described how the referral had come about in a roundabout way via a friend who was also a nurse.

Each of the carers met initially with the CSN in their own home and all but one were followed up by the CSN with at least one phone call. The one carer who was not followed up did not identify any support needs with the CSN and arranged that they would get in touch if things changed.

All were very positive with home being the location for the first meeting and recollected how this provided a comfortable environment in which to discuss their issues, and to let the Carer Support Nurse "see" their situation. The presence of the cared-for-person was not felt to be a limiting factor, instead, the carers generally reported that those they were caring for were happily settled somewhere else in the home, and that meeting the CSN at home also reduced carer concerns about having to be away from the cared-for-person.

9.5.2.4. Impact of the Carer Support Nurse:

Overwhelmingly, the carers were extremely positive about meeting the CSN. They described her as easy to talk to, friendly, someone who listened and someone who was extremely well informed. Some also reflected on how her experience, maturity and professional background were also important factors in enabling them to open up and share their experiences:

> *"I think had she been a younger woman I would have felt 'you don't know what I'm talking about because you're too young to understand'. But I felt that her maturity gave her some insight to what I was trying to say. Which I liked"* [C20]

> *"when you're caring for somebody, [...] liaising with healthcare professionals, [...] dealing with her needs, you become sort of a bit like a robot [...] If it hadn't been for [the CSN] coming in when she did, I don't know what I would have done [...] I was on my knees [...] She's just very kind, very natural. [...] There was no sort of 'I'm the nurse here to tell you what you've got to do & you do it'... it was, 'I'm here, what help do you need?'"* [C42]

> *"I think she seemed to be a very good choice, because she's obviously very experienced and, you know, she seemed to be able to cover everything as required"* [C80]

This was reflected in the activity analysis data presented in Figure 5 which indicated the benefit of an experienced registered nurse being in the role and how the nurse created psychological safety for these carers to express distress, and then respond to that distress.

In preparation for discussing their concerns with the CSN the carers had all been sent, and in most cases, completed CSNAT-I's 'About You' booklet. One noted how this had enabled her *"to look at and see what's happening because when you are living with it every day, you tend to just not notice little things, until I really think and look back and think 'oh yeah, that's changed'"* [C21]. Others described going through the booklet with the CSN and discussing highlighted items, although some were less sure how the booklet had contributed to their conversation.

Within these conversations the carers described discussing and developing a response to a range of their support needs with the CSN. For some this meant talking through difficult issues. For example, one carer wasn't sure where her responsibility for the cared-for-person began and ended. She recounted how the CSN helped her step back a bit and set some boundaries for herself. Another carer discussed the anger she felt towards her husband for neglecting his health and was able to work through some of these feelings with the CSN and later share them with another family member, which she hadn't previously. Others identified needing support with things like finances, identifying on-going sources of emotional support, making time for themselves, and planning for future emergencies. Here the CSN was able to make them aware of both local and national resources including the Carer Passport and Carers Handbook, and local and national voluntary organisations such as Carers Matter Norfolk and Age UK. She also linked one carer up with a range of well-being activities. In addition, carers described how the CSN was also able to identify potential health concerns and facilitate additional help for on-going health conditions. One carer was referred to the incontinence service and counselling, another to the GP with a potential diagnosis of depression, and a third was provided with help to facilitate access to an overdue scan.

In addition to the CSN linking them directly with services, carers also described being given suggestions of resources they could explore themselves. Some were able to undertake this easily, for example, one took the initiative and joined an on-line support group meeting. However, for some this was more difficult, as this carer who recounted: *"she said I could ring Age Concern and see if I'm entitled to any money… but I haven't done that yet. It sounds too complicated, and I can't take on anymore at the moment"* [C20]. Just one carer reported not identifying any support needs with the CSN but commented that the CSN had left saying *"that if I need anything, to phone her. So, you can't be fairer than that*"[C110].

One of the carers had cared for her mother for many years but, when she met the CSN, was struggling with the acute pressures of providing care at the end of life. She recounted how the CSN

quickly identified that the situation was too much for her to cope with and, rather than attempting to start a conversation about wider issues (using CSNAT-I), instead focused on identifying and addressing the immediate needs of the situation. In practice this meant arranging for professional carers to come in from that evening and sit with the cared-for person overnight:

> *"when she said 'Right, we've got somebody coming in to sit with your mum tonight', I went 'Wow!' [...] I was able to get a bit of sleep, be more with my mum, sit with my mum, & just not have to worry 'will she be alright?' all night...[...] It allowed me to be her daughter for the last three days of her life"* [C42]

She went on to describe a series of other actions the CSN took in relation to her physical and mental health and described how the CSN phoned and provided immediate post-bereavement support, enabling her to grieve and manage everything without having to re-tell her story to another professional:

> *"she made [...] a big difference to [...] my family's situation [...] if you want any more proof that this scheme works, there's your proof" [C42]*

All of these carers were content to end contact with the CSN after the first meeting and follow-up phone calls, with the reassurance that they could get in touch in the future if needed. One commented *"You know you've always got that contact then, that's the important thing I think, is knowing that there is somebody there you can ring if you need them"* [C80]. However, there was also a sense that this might not work for everyone, not because they were unhappy with the service but because they didn't want to be a bother.

When summing up their experience with the CSN, all the carers were positive and highlighted again the many ways in which the CSN had supported them:

> *"it was really helpful. It was nice to have someone actually come round to the house, because that's the first person that's really ever been round here... .it was comfortable for [the cared-for-person]... he was in his own home and I could relax and talk to [the CSN] more openly. Oh, that was really good. [She] told me a few things that I hadn't, I didn't know about... [...] that was helpful"* [C21]

> *"I was very pleased that I'm within the programme. I'm very thankful that what she did for me has happened. We have got this appointment this week with this lady to talk about our mental health. [...], I have got the incontinence programme, I have had the carers thingamabob"* [C20]

> "*[she was] very helpful, because at the end of the day if you find yourself in a situation where then you think 'Well, I do need some help', it's knowing that there's someone there. Even if she can't help herself, she can probably get the help for you from somewhere else, sort of thing. It is always good to have a contact point and someone that you can turn to, and sometimes also outside the family. You can say things to someone who's not emotionally attached, shall we say, that you can't say to your family because you hold back a lot of stuff from your family, because you don't want to upset them"* [C70]

However, it was also noted that the role of caring can be so overwhelming that even the positive impacts delivered by the service could not fully address the on-going distress that some people experience.

"It hasn't made me feel any less like a drudge or an unpaid carer. Nothing makes it go away, because you are here all the time, you can't get away from it" [C20]

9.5.2.5. Ongoing support for carers

All the carers who were interviewed thought that the provision of a CSN service would be beneficial for carers more generally. Together they highlighted the benefits to the wider carer community in terms of sourcing information, having someone to talk through issues with, and sourcing practical help.

"I think it's a brilliant idea. I mean, obviously I know that that's no substitute for having the physical help from, you know, people to come in and help you with the person that's not well, but I think that is correct that you do need support. And for years and years and years now people have been doing this without anybody to turn to, some people with no relatives at all, no support whatsoever. So, I think, especially for these people... I think it's an essential role" [C80]

"If I had her phone number, I'd be passing it round. Totally! Anything the NHS can do to help carers then that's all to the good. You really are very much on your own when you're a carer. You've got lots of support for the person you're taking care of. You've got the district nurses. You've got the occupational therapists, physiotherapists, phlebotomists. You've got doctors, nurses. You've got specialists in the different fields, like diabetic, heart, all that sort of stuff. So, you've got lots of people helping you with the person, but there's nobody really to help you help the person... helping you. When you're not sure of something you can't necessarily pick up the phone and say 'I'm feeling a bit low today, is there somebody I can talk to?'" And I would assume that that's possibly something that the Carer Support [nurse] will [be able to do]" [C42]

"having that contact with somebody who is a little bit more in the know of what is out there and what you can get help with, I think it's just nice to have that contact. Because like I said, really right in the beginning, you are literally just out on a limb and having to find all these things out by yourself" [C21]

In terms of how other health care services could improve their support for carers, these carers would welcome easier access to healthcare appointments and a greater understanding by these services that the carer and cared-for person are a partnership.

9.6. What was the key stakeholder feedback on the Carer Support Nurse role, as delivered? – Cross-sector stakeholders & national recognition

Data relating to key stakeholder feedback on the Carer Support Nurse role, as delivered came from the end-of-pilot cross-sector stakeholder focus groups and interviews (Task 2C), the unsolicited feedback from a GP practice, and – as an award-winning role – the **national recognition** achieved.

Box 8, below, provides some unsolicited feedback about the Carer Support Nurse role and its positive impact from East Norfolk Medical Practice.

Box 8: Unsolicited feedback from East Norfolk Medical Practice
"We have been very fortunate to work with [the Carer Support Nurse] and so far, the difference she is making to our patients is incredible. In fact, since December last year, [she] has seen 45 carers via various referral routes which is the highest number of engagements for carer support over all the GYNV practice areas, so this is very positive that we are going in the right direction to ensure that unpaid carers are supported" [Sept 2023]

Cross-sector stakeholder feedback was formally collected within Task 2C. It is notable that 12 of the 16 cross-sector stakeholders invited to provide feedback (including the CSN's line manager) agreed to take part (75% agreement rate). The four that did not respond had had limited direct contact with the CSN. Eleven stakeholders were then able to provide feedback (one was unable to due to their diary) and, of these, seven had personally referred carers to the CSN. Three had had personal experience of being in an unpaid/family carer role.

Extensive quotes are provided to illustrate the key findings, using the stakeholder voice. The sector of the stakeholder is indicated in the anonymised identifier following each quote i.e., health, social, voluntary sector and a patient organisation representative.

9.6.1 Response to the pilot ending

Their feedback was captured in the final two weeks of the pilot and, although all understood there was no guarantee of onward funding, there was clear dismay and bewilderment as to why the role was not continuing. The direct negative impact of this on cross sector stakeholders was emphatically stated:

> *I'm really disappointed that we're not keeping her. [...] I refer a lot of patients to [CSN name]... I don't.... she's just been invaluable to our patients [...], for the carers. It's just a shame that it's shown how good it is with the awards that she's won. It's just amazing!* [S-05-Health]

I'm here not because I know of anything, it's what happened when she stopped [...] Huge numbers of people were disappointed. [...] we had an amazing woman... we had a service that worked and was needed. We had two major awards.... two major awards! We had all that and it's still finished! [...] How far do you have to go? [...] Parliamentary awards! I think there is something really wrong with the way we are asking people to look at stuff. You know what I mean? I'm here with you today because what is the point in me [supporting] pilots, or bidding for things, or doing something new [...]. This is not patient-centred... and it makes me frustrated [...] Your "baby"[9] *is fab! Absolutely fab! [...] How much do you have to do? How much do you really have to do?* [S-03-Health]

I recently tried to refer somebody through to [CSN name] and I was told 'no... that the service is no longer available... and I was gutted! Because there's very little else out there for the carers... [name of voluntary organisation], yeah, I get that, but... this was specific for the carers and to look at the carers needs – do you know what I mean? – to look at their physical and mental health needs and to offer education and support and how best to support their loved one at home. So I found that was a really effective job, or role, and I'm quite lost without it to tell you the truth [S-09-Health]

You don't know you need it till you need it. You know? [It] worked really well and, yeah, missed already! [S-07-Social]

When we found out that the pilot had ended [a colleague] was really sort of not happy about it – let's put it that way! – because she thought it was so good! So yeah, it was really valued [S-04-Health]

9.6.2. The need for the role

All but two of the stakeholders felt there was a strong need for the CSN role prior to the role being introduced based on their professional experience and also, for some, their personal experience. They spoke of carers putting their own health and wellbeing second to the detriment of their own health, thereby creating vulnerability in the caring role, and spoke emphatically using terms such as "definitely", "absolutely", "massively important", and "100%":

I knew the role was ***so needed****. Carers [...] don't put their health first; it's all about the person they're caring for. They don't have time to think about their own health and their own needs. So having a dedicated person to do that for them is* ***absolutely crucial****. [...] [someone] for carers that solely focuses on their, their health and well-being [..] carers need to be supported and I think this is such a huge step in the right direction [...] the health element is really important****. Really, really, important****. [...]Knowing they've got a dedicated person that's focusing on them... and their needs and their well-being and their health [...], I think* ***it should be national... it should be a mandatory thing for all carers*** *to have access to a Carer Support Nurse and, I hope, hope one day it will be* [S-06-Voluntary]

[I find] that the cared-for is actually being well and truly cared for and the carer isn't [...] it's just where the priority sometimes appears to be and it's actually explaining to the carer that

[9] "baby" refers to the idea of the Carer Support Nurse role

[...] by them looking after themselves, they can care as well as, or better, for the cared-for. So yes, ***absolutely*** *[...] they are so in the background* [S-04-Health]

Definitely, definitely *[...] If you are sitting on the Safeguarding Board and [...] whether it be a husband caring for a wife, that can have such a dramatic impact on everything [...] because they get to the end of their tether and they do things that perhaps they shouldn't, or they'll end up taking them to A&E because they're at the end of their tether. Now that is a terrible thing for... on both sides of the coin, you know, because for someone to be that low. [...] when people are caring for somebody, they don't think about their own health and well-being but [...] if they weren't there because they were poorly [...] who's going to pick up that mantle and run with it then?* [S-08-Voluntary]

Absolutely 100%. *And not only from my work experience, but also from personal experience as well. [...] we're talking about the carer's well-being and health as a result. [...] I just... I don't feel that anybody who isn't currently a carer or are involved with organizations who are, necessarily understands the burden. [...] Yes, there is a need:* ***100%.*** *[...] somebody who is skilled to recognise certain responses to becoming a carer* [S-07-Social]

we also have older people who have a diagnosis of dementia but also have mental health problems as well, so there's very complex presentations and, bless them, the carers that are involved or are supporting these service users are swamped. They're absolutely swamped. [...] everybody knows it's a 24 hour a day role and that can really have a massive impact on somebody's ability to care [...] there's very little else out there for the carers [...] specific [...] to look at their physical and mental health needs and to offer education and support and how best to support their loved one at home. [...] if the carer's not looked after then that has a knock-on effect on to the service user... ***absolutely... 100%...*** *and especially in our role, in the area of work that we are in [MENTAL HEALTH], that is* ***massively important, massively important*** [S-09-Health]

Some described it as "obvious", a "no-brainer", or "not rocket science":

Yeah, I think ***that's obvious, if I'm honest*** *[laughter]! It's been obvious for many years [...] it's a* ***no-brainer*** *to say that it was obvious that there was a demand. [...] when she first arrived we thought, [laughter] "do you know what, we definitely needed this – this is what we want!"* [S-03-Health]

...you sort of think "well ***that's really obvious****, isn't it?" really. It's a bit of a* ***no-brainer****. [...] [Carers] just have so much to do with so little support. [...] if they're not getting the support they need they get ill, then they can't care for the people they need to care for, and then their more stressed and then it's just like... people's lives can fall apart so quickly* [XS-15-PatientOrganisation]

We know the need is there. [...] ***it's not rocket science****. We need to morally be looking after these people and making sure they're supported and looked after – if not morally, economically, we need we need to be doing it because what they do is invaluable, and we need to ensure that they are looked after so that they are able to continue with their caring role. [...] The ICB [...] very much made it clear [to me] that their commitment to carers was a number one priority and will remain on their agenda. [...] I think this very much falls into that promise*. [XS-14-Voluntary]

The two stakeholder who were initially unsure about the need for the role reported realising its necessity and value once the role commenced (both of these stakeholders were nurses):

> *I didn't actually think there was a need for the role until we got [CSN name]. And then **I can't believe how much of a need there was for the role** [...] [and] my referrals didn't stop going in! [...] I thought, actually naively, that I just covered everything [...] until [CSN name] come along* [S-05-Health]

> *I think at the beginning it wasn't 100% sure what the role... really.... the nitty gritty of the role. But as the role sort of presented itself and it's grown, I think, yeah, **there is a need** for that. I think it's really supported some patients, well, relatives [...] Going through it with my own family, I think my mum could have done with [more] support* [S-16-Health]

Stakeholders also commented on the financial savings carers make to the NHS:

> *if all of our unpaid carers down tools tomorrow and said "you know what, I can't do this" or "I don't want to do this anymore" and the government had to replace the care that they provide, it would cost £164 billion. [...] give or take 2 billion, they are providing a whole national NHS service budget. [...] **that's what it would cost to replace [carers] – a whole NHS budget** [...] in an ideal world [the CSN] would be a standard practice across the whole county or the whole country* [XS-14-Voluntary]

> *we really need to put some [...] care in the direction of carers is, you know, **the amount of money they save on hospital admissions and formal care savings**, you know?* [S-01-Health]

> *there's such a strong business case for it. [...] **carers save the NHS just a crazy amount of money** [...] They're unpaid, especially people that are caring for someone that's end-of-life that otherwise would have to be in a hospital or hospice. [...] And then it's also just saving tons of money, and you could fund 10 carer nurses and it would still be a... just... to my mind, it would be a justified expense. [...] [carers] must save so much money and they can only be doing that if they're getting the adequate support. [...] it's one of these things where you it doesn't seem like a sunk cost to me* [XS-15-PatientOrganisation]

9.6.3. <u>What advantages did the CSN role have compared to what happened before?</u>

All of the cross-sector stakeholders highly valued the Carer Support Nurse role. They identified a range of advantages – across each of the sectors – compared to the support available for carers' health and wellbeing prior to the role commencing.

> *We just didn't have her! [...] over the last 18 months, carers has been in [the QOF] agenda, you know, when you come for flu... "Are you a carer?" So, we already had the group function of looking for [carers], but we always built it knowing that if we said "are you a carer?" it was only ever going to be a tick box if we didn't have something with it [...] [with the CSN] we had a lead. You know, we had one person whose main aim... role was to have that in their head, so their conversation was [...] "This is your problem that I'm here for. I don't have to think about anything else [and] because I'm a nurse, and you tell me you've got a bit of chest pain or your foot hurts, I can direct you to the appropriate space without having to book an appointment with a GP, or anybody!" [...] [But] we're now back to square one. We are [only]*

seeing the person who gets on the phone, who comes to the door... because we don't have time to review the whole situation [S-03-Health]

I think "not supported" is the right answer. Yeah, you'd call... I would call a matron to say "can you get...?", "We're too busy". And they'd have waiting lists and waiting lists... to go on, or "we'll just try our best" and... they'd be unsupported and [...] failed packages of care... they'd bounce back into hospital, or their crisis would happen. [...] [There were carers] who have not come into the system yet but are struggling out there that she's picked up, and that would have broke down eventually [...] been nipped in the bud before it's even got to crisis point [...] it's perfect. She] had more time to spend with patients [S-05-Health)

So yeah, I do think [...] we've seen a benefit [...] we've gained care... our patients have had better care. So we've probably prevented them admitting to hospital, you know, maybe increased visits for the district nursing service [...] she's probably kept people at home where they could have ended up... maybe a reduction in social care as well because they're doing the role... there's not that carer breakdown as much because they've got that support. So yeah, I think... [...] it's probably supported some of our patients that have been in real need [S-16-Health]

So we would look to referring them on like [carer voluntary organisation name] or social services [...] but it was just nice to know that there was another resource available, you know? [...] we're dealing with an ageing population in our group, right. So a lot of the carers are significantly [...] and yet the caring responsibilities that were placed on them were way above sometimes what they were able to do. [...] We're finding a lot of our carers also may have underlying dementia or cognitive problems. Physically frail. Don't have access to the Internet, so even making appointments with the GPs for their loved ones to be seen was an absolute nightmare! ...because everything is online now. You can't even phone a surgery and ask for an appointment [...] and accessing appointments for themselves as well [although] everything is put towards the [patient]... they don't tend to think about their own physical well-being until it's too late when they think "I just can't cope anymore. I was supposed to have a blood test two years ago and I've still not followed that up" – do you know what I mean? And "I'm depressed" or "I'm anxious" or, you know, "I'm exhausted"... all of them things [...] have a knock-on effect on their ability to care. [...] We were having quite a lot of calls from carers who were at burnout, who were at absolute burnout, who were at the point where they felt they couldn't cope anymore... and as such, they were looking for emergency respite for their loved one and feeling so guilty about it, or they [...] didn't fully comprehend what the diagnosis might mean and how to best support their loved one... so in that instance that's when we were definitely using the referral process to the Carers' Nurse because we felt that would be really, really helpful [S-09-Health]

Nothing would have happened before. It relied on the carer to present themselves to a GP or a... a healthcare professional for their own physical health. [...] carers very often park their own healthcare needs because they're putting their the cared-for person in front of their own and we know that carers often present much later with illnesses and, you know, if it's a serious illness that that can be very worrying that they're parking something and putting something off that needs addressing and then present that much later stage. Whereas, obviously, if the nurse is on the ground there, there's is that early intervention and prevention to make sure that they are addressing their own healthcare needs early [XS-14-Voluntary]

Existing services for carers, largely in the voluntary sector, were valued but the direct, local, individualised support that the Carer Support Nurse provided was addressing previously unmet needs:

> [S-07-Social]: *a VCSE[10] kind of support request [is] a signposting rather than an expectation of a guaranteed service and, you know, some of these groups might not necessarily be as empowered to act or advocate... they are more, perhaps on a global rather than an individual level. [...] it's just knowing that somebody who is skilled to recognise certain responses to becoming a carer [...] before it's too late [...] I feel that we'll go backwards [laugh/shrug], [...] like you were making a referral and now it just like we're going back to signposting. [...] The problem with the voluntary sector is that each [is] probably project based... there are limitations to how they can act as well within the scope of the certain projects, [..] to help with a specific need [...]. And the thing, obviously, about having, you know, the Carer Support Nurse role and [...] that single point of contact, you know, 'Make Every Contact Count'.... the [carers are] only telling one person it once, and then [she] can then go and get that support across all of the partnerships. [...] I just feel like that's what we're gonna have to go back to interfere[ing] with that person's life whilst they're trying to be a carer [...] you've got to then give the space and obviously having one person, rather than many, gives that additional space*.
> FACILITATOR: *I haven't thought about it from that point of view, so it reduces the number of people that the carer has to engage with.* [S-07-Social]
>
> *It's so valuable. I really hope that it can continue to be honest [...] So much gets put on the voluntary sector [...] we still we do an awful lot of signposting and often for assorted things. There is just nowhere to send people, and especially if, you know, people's issues aren't in neat little packages where it's just one thing and everything else in their life is fine. It's usually lots of interconnected things. [...] it would feel like a backward step once you've got something like this in place that... it really plugs the gap, doesn't it. Yeah, I think that's the thing. And it's currently filling in area, I suppose, because you are asking how were things dealt with before? [...] the answer probably would be... they probably weren't! Really. You know, not in the same way that they would have been able to be dealt with now. It might be OK for voluntary sector organizations trying to take a little bit of the strain off so that the carer can just attend more regular healthcare settings, but... I'm just guessing here, but I would have thought that a lot of health needs would go missed because that carer, even with those additional voluntary sector support things in place [...] would make the decision not to go to those healthcare settings because there's always 101 other things that [...] they're thinking about themselves last really, aren't they... on these things* [XS-15-PatientOrganisation]

These cross-sector stakeholders were passionate about the value and impact of the role:

> *For [carers] to know that there's a service there and someone there that's there for them, it's quite mind-blowing for some people. It hasn't occurred to them that that's there for them* [S-04-Health]
>
> *Priceless... because you can't put a value on how that has, you know, the work that [CSN name]'s done has helped change some of these people's lives [...] what they think they want to start with and what they end up with at the end is a skill that [CSN name] had in actually*

[10] voluntary, community or social enterprise organisation

> *uncovering all of that [...] ...you don't know what you don't know until you need to know it, if that makes sense? [...] Definitely I thought she was brilliant [...] I can remember one person in particular [...] who came back in and said 'thank you very much for putting us in touch with her' because that help that she'd given and the support was... you know, she didn't realise that that that was out there and having someone who was listening to her... was, you know, invaluable* [S-08-Voluntary]

> *I had a friend who was struggling with her mum and dad... her mum's the main carer for her dad with Alzheimer's, and [CSN name] took that on as a referral [...] and went and supported the mum, dad and the whole family through that, and got them through a tricky time [...] And that would have broke down eventually* [S-05-Health]

> *[CSN name]'s the link to the things that [carers] need. I think if you're a carer you can't... you haven't got time to be looking out for what... what support networks you need as a carer [...] You don't always see how hard you're actually caring until it's there in front of you. You know what I mean? I think until somebody points it out. I think, yes, she has helped massively [...] just made it improved, I suppose. Give us that link to support people who were in crisis, maybe, you know, patient's relatives that needed, or carers that needed, support* [S-16-Health]

> *I think the role was excellent [...] I think the fact that [CSN name], you know, was... was doing such a good job, you know, she'd won awards as well! [...] how much money [CSN name] probably is saving by empowering people to, you know, be able to manage* [S-01-Health]

One stakeholder described how this would now mean that certain types of questions, that had begun to be asked of carers by social care colleagues, would not now be:

> *if you don't have an outlet or have something within your toolbox, that sticking plaster or something, you are less inclined to ask the question that would lead to the response that says you need that plaster. And... and I just felt more and more confident that we were getting there [WITH THE INTRODUCTION OF THE CSN ROLE]... that when we send out our front-facing staff, or somebody comes to our customer service team, or our housing options team, that I make them aware of what's available... so that they can say "it's fine", you know, and they can with confidence go a little bit deeper with the questions, not just say "oh, sorry, that's not my job", [...] "we've got somebody there to go to" and, you know, it's just thoroughly important* [S-07-Social]

These cross-sector stakeholders' narratives highlight not only how the Carer Support Nurse supported individual carers but also how, in doing so, she supported those who had referred them to her: she was supporting cross-sector professional need as well as carer need, enabling those cross-sector professionals to support carers – Box 9 shows some examples.

Box 9: Examples of cross-sector stakeholder narratives highlighting the CSN's support of both carer and cross-professional needs
I've got a Romanian family [...] reaching out to food banks on a weekly basis... because they didn't know what to do. I've been using a translator in there to work out what's going wrong, and it was [CSN name] that then said to me [...] "I'm not gonna get in for a few weeks", but she signposted me into the right directions of where to go and [...] they managed to get benefits sorted with translators and got all their finances sorted and they're [now] not using food banks. They just weren't getting the right money. And what a huge difference that's made [...]. The gentleman had had a car accident, so the wife had become the sole carer of this man who's a paraplegic... literally in food banks day in day out, their life had changed, they had no family here... what a struggle for them ...and [CSN name] had changed that because I didn't know where to turn. [...] I thought I knew what to do but if it weren't for her, that family would still be using food banks. [...] And I could have gone probably on Google and found all that out, but that would have took me some time... but I had had a call with the social worker regarding this man. She had not mentioned once to me... about these places [S-05-Health]
there's loads of mine have been supported by her [...] lots of safeguarding. Lots of issues around capacity and power of attorney, as well, especially for carers that just don't understand, [...], there's quite a few examples of how [CSN name]'s gone in and helped. We had a gentleman who had a head injury, a younger gentleman, and he had a daughter of 13 or 14 that he was bringing up and [...] I was concerned because I was feeling that she was probably a young carer. So [CSN name] came and sat in clinic with me[11], with the gentleman [and daughter], and she'd been self-harming, and I think we were able to give some, you know, good tips and advice and get in touch with the schools. So that was a good example [S-01-Health]
We had a lady who had her bin stolen. So, she didn't have the money to buy a new bin and when I went to do her leg dressings [...] she had lots of rubbish and [...] there was maggots and flies and it was going into her house. And when I spoke to [CSN name] about this lady, I'd referred her son who was supporting his mum at the house. [CSN name] never did gain access there, because they then refused all their calls, but what she did manage to do she had linked to someone at the council who, because of their hardship, she was able to get them a bin that didn't cost them any money [...] I would never have known that link. I wouldn't have even known where to start [S-05-Health]
for me, I think it's the speed of response because I would phone someone and I would be able to see on the notes that [CSN name] had been in touch, or I would ask the question, and whenever I phoned, they'd had that contact within a couple of weeks and that was really helpful because so often people just have to wait so long for anything from anywhere. So to get that immediate response, even if they weren't seen at that time, but to get that contact was always really valued [S-04-Health]
the team has benefited from that because then when they've gone into patients' houses and they've come upon sort of carer breakdown, things like that, it has helped. They've got somebody to turn to... that can manage all that for them and they've got all the links and things. So yeah, I do think, from a team point of view, we've seen a benefit [S-16-Health]

[11] Not, therefore, a formal referral

9.6.4. Confirming that the CSN is a nursing role

These cross-sector stakeholders valued that the role was a nursing role:

> S-04-Health: *it's been nice for me to be able to say to someone, you know, to get someone clinical because [...] I have no clinical training [and] it's not always appropriate to go to the surgery, or they've got reasons not to go to surgery as they go to surgery and actually the cared-for takes over... so actually having [CSN name] contacting that person and having that clinical background, [...] just getting that contact without having to go "well you've got to ring the surgery..." or "you've got to do this or the other", it just cuts down, hopefully, on, you know, some of the rubbish that people have to go through to access what they should be able to access more easily*
> FACILITATOR: [...] Does it need to be a clinician?
> S-04-Health: I think so because you've got other people doing some of the other stuff.
>
> *It might be OK for voluntary sector organizations trying to take a little bit of the strain off so that the carer can just attend more regular healthcare settings, but [...] a lot of health needs would go missed because that carer, even with those additional voluntary sector support things in place [...] [may] make the decision not to go to those healthcare settings because there's always 101 other things that [and] they're thinking about themselves last* [XS-15-PatientOrganisation]
>
> *I think that's where being a nurse is very much involved. I don't mean that other people are not caring or have that insight, but I think that's where the nursing element actually did well in the fact that, you know, yeah that carer may [be impacted] [...] in medical terms and they've not actually recognised that they need to see someone, and that would be something [CSN name], would be able to take forward [...] I definitely feel that, 100%, she was able to do that* [S-01-Health]
>
> *When we're looking at carers own healthcare needs, or complex healthcare needs, a nurse is probably best place to do that because they've got medical knowledge also* [XS-14-Voluntary]

A couple of stakeholders did explore whether, as a nursing role, it was really possible, or appropriate, for the role to be dedicated to the carer, or whether it should also support the patient:

> *it's solely for the carer, but [...] given that she's a nurse [...] a whole family approach [could be taken] because [...] we know if the cared-for is actually receiving all the support they need that instantly takes pressure off the carer. [...] when you are in that home, and you are a nurse, she would be able to, you know, the carer will be able to raise her own concerns and that [...] is gonna in turn have a positive impact on the carer. [...] and in a community-based role, when you're presumably going to the homes of people, how do you draw the line and say: "I'm sorry, I'm not here for you, I'm here for you". It's not gonna work, and I don't think that would be well received by a carer either* [XS-14-Voluntary]
>
> *The only downside is trying to keep the distance, the separation, between the patient and the carer. It's that going in and you're looking at the carer and not the patient... [...] 'cause, to me, that carer wouldn't be there if it weren't for the patient, so do they come hand in hand. [...] it's the difficulty of [...] support[ing] the carer, and not the patient [...] I suppose maybe just being allowed to have an input with the patient as well [...]. Say [CSN name] was going to go in and [...] if there were something highlighted they could deal with [then deal with it and] not be "It's not my.... I'm not here for that" [...] because people don't care who is doing*

> *it, they just want it done. So if they're saying "I've got an issue with this" and if you've got the skills to do it, then so be it. Do you know? I'm not saying she has to dress the legs or whatever, but maybe that voice if they say "oh, well, I'm having trouble with my medication", just being able to say "actually, well I can sort that out"* [S-16-Health]

The evidence the underpins the role would not support a dual patient-carer role, but there may be instances when attending to a patient need actually addresses a carer need. This could also be addressed if the Carer Support Nurse role was integrated into team which also supported the patient and took a family approach.

A number of the stakeholders also noted that, in addition to her clinical skills, the individual who fulfilled the role brought some particular skills, and had some particular characteristics, that were highly valued. Their views reflected those of the carers we interviewed and reported earlier.

> *I think it's been as successful as it is because it was [CSN name] that did it. [...] when you're only a year's pilot, it takes a long time to actually build up that trust and bits and pieces like that, and some people would not hit the ground running [...] so, for me, I think it's that she came in and just got on with it and her personality has helped make a success. How successful it would have been with someone else? I don't know* [S-04-Health]

> *I think that in this particular case, as a pilot, you actually had the ideal person – you had an experienced, mature, logical person who was neither worried by mental, nor physical health... so huge amounts of experience* [S-03-Health]

> *It's all of those qualities rolled into one [...] [you] have to be a special person to be able to do the work that she's done, and she certainly had all of those qualities. [...] she was calm, you know, listened... and that's what people want. [...] she hit the ground running with that and she made it her own* [S-08-Voluntary]

9.6.5. Role delivery & activity

We asked the stakeholders whether the CSN role had been implemented according to each of the five Evidence-based Design Principles (EDPs, outlined in Box 1) and whether each remained relevant or important following the pilot and should be retained as principles. The stakeholders were unanimous with regard to both the successful delivery and continued relevance of all five principles.

9.6.5.1. EDP-1: The need to be community-based

The community base was achieved as the role was located within ECCH. Being community-based was felt to be important *"because of the local knowledge, the local links"* [S-06-Voluntary], and *"having a local face is really important for these people as well [as regional support organisations]"* [S-08-Voluntary].

There was a feeling that *"most things do better when they're rooted in communities"* [XS-15-PatientOrganisation]. Community was felt to facilitate a *"collaborative approach"* and was accessible: it enabled the CSN *"to be able to go to them, not for other people to present somewhere else"* [S-07-Social] and may enable person-centred care (which relates to EDP-3). This view was endorsed by others:

completely agree [...] having someone that can reach out to those people and not the other way around... it's yeah, definitely [XS-15-PatientOrganisation]

Definitely [community]. If you refer into primary care or secondary care, you remove the ability for people to have choice and you remove that confidence that you can gain something from your community [S-03-Health]

real one-on-one [...], somebody in the community out there on their doorstep. [...] [name of voluntary organisation] are brilliant [but] they are covering such a vast area and you don't get that person-centred one-to-one support and if you have got carers they do have complex healthcare needs, having somebody local in your community I think is this is much better [XS-14-Voluntary]

A community-base was felt to be particularly valuable for rural communities:

particularly those that particularly isolated or live somewhere quite rural. And particularly because that's always a problem. Yes, there are services of support, but if you're in a rural area then you'll... your transport and all that kind of stuff and of course leaving your cared-for as well in some situations is not always an option [XS-14-Voluntary]

And could also benefit the post-holder:

I think yeah, a local community-based because then you know you're patch well [...] and the carers within your patch. [...] [XS-14-Voluntary]

One stakeholder agreed with the community-base but also felt there was potential for the role to work in the acute setting to:

It's a well-regarded role and is much needed in community and in acute care really... because you've got a whole other selection of people there that worry about their relative, worry about their care and who they're caring for [S-01-Health]

9.6.5.2. EDP-2: Cross-sector working

The stakeholders reported that cross-sector working had been achieved and was valued by them. Many spontaneously gave examples of this cross-sector working, how she made and received cross-sector referrals and how they had welcomed this for the carers they all supported.

[CSN name] was a very good sign poster [and] she did coordinate [S-01-Health]

sometimes [CSN name] and I would have a discussion... so, if it's something that we've been jointly been supporting, or she was pulling out and what have you, we would sort of have a discussion about how we would proceed and what could happen and that always seemed to work well [S-04-Health]

we would make referrals to [CSN name] and they were like from [carers] that we were working with [...] where we'd identified that [...] her service would be very, very beneficial to them. [And] we've had a couple back that have come through... through a different route, because she was then more aware of what we were able to do, the services that we provide [...]: I can remember that there was one where there was a debt issue, so that came back to us, you know, and we can help and support that person to manage their debt [...] so it is a two-way street [S-08-Voluntary]

Yes, I think crossway referral is as it should be. Absolutely [XS-14-Voluntary]

Some spoke of the networks the Carer Support Nurse had developed (developed very quickly), and how she shared these connections with other professionals in order to improve carer support:

> S-05-Health: *She had better networks than what we ever had, so she knew more than what we did. She'd opened up doors in places we hadn't. [...] I don't know how she got these links [laughter]! [...]*
> FACILITATOR: *somebody described her as a "super connector" [...]*
> S-05-Health*: Yeah, that's perfect word for her! [...] I've been here 18, nearly 19 years... I've never found these links but, in the year, she found them!*

> *[She was] a link between the other organisations. We always hear from carers about the fragmentation of services, they don't know who to contact, they don't know what organisations coming in. There's so many people that are often involved, and it's quite overwhelming. So having a person that can support with that is absolutely essential* [S-06-Voluntary]

Stakeholders from both within her own sector and from other sectors valued the access to the particular clinical skills of the Carer Support Nurse and how that complemented their own provision, meeting a need they could not meet:

> *The beauty of her was she worked in a [different] space [...] when she first arrived we thought, [laughter] "do you know what, we definitely needed this – this is what we want!". We put in myself, our Caldicott Guardian, our team lead... we put in a whole load of advertising. We introduced straight into social prescribing [...] We started to ring around – in our own time – because we knew there was need... there was need. We needed to make sure she was on the ground running* [S-03-Health]

> *As soon as we heard about [the role]: "OK, we'll have this!" [laughter]* [...] *my perception is around the non-clinical side of things, obviously, but that's where we come in to support. But that's how it's worked really, really well [...] As a result of this project and similar, we are able, as non-clinical, to feel that we're offering a preventative proactive support... and so we're in the right place, it's drawn us into the right place. It's not just about health being in the right place, it's drawn us into health and so that collaborative approach and working together in... in partnerships is helping us* [S-07-Social]

> *I've referred on numerous occasions and I do line management for my team, and I know when we're talking through [...] any complex issues, again, I've recommended that the clinician referred on to the Carers' Nurse [...] which we have utilised it quite a lot* [S-09-Health]

There were also descriptions of cross-sector interprofessional working that enabled shared learning and enhanced the carer support landscape through partnership:

> *I was with one of our carer involvement meetings when [CSN name] was able to come and also share feedback about different experiences that the carers that she was working with had... so we could take that back and report back to the relevant organisations or feed it up to our Partnership Board, which is more... where more strategic decisions get made. So having that two-way link where she's able to come in to say what she does, but also feedback from other carers and be their... their voice as well* [S-06-Voluntary]

> *We have a clear boundary, we're not clinical, but there's a fuzzy line, yeah. We have members of staff working in [hospital A] for discharge... [...] but that's where those transitional roles have worked so well... and this felt like one of those, as well as to bridge across, fully recognizing the area specialism where she came from, but then there's that level of respect in there. I don't feel in any way it was her downgrading herself into the land of the common people, the non-clinical support [laughter]... it is partnership. It's about that partnership side of things. [...] And whilst we're looking forward about integrated neighbourhood teams and the likes, you know, this fits in perfectly with it* [S-07-Social]

They spoke of how the CSN had attended, presented at, and participated in meetings with other sectors:

> *It's been [...] partnership and collaboration, and she did present obviously to the collaboration meeting [...] [she]* was successfully professional, came forward and presented in a very clear, obviously ambitious, way what was available. *[...] and just being present and ready to put your expertise in is a safety net for everybody involved and so that's where it worked... [...] any kind of level of clinical support and partnership work [...] only helps us as well. So there's more than just [...] the sum of the parts with the job and the project... it's having that level of access [...] and [her] regular attendance at the collaboration meetings [worked] very well – she didn't just turn up because she had a case to bring, you know, that's important thing about collaboration for us, it's not just being there because you've got to get something out of it [laughter] [...] it wasn't like that with [CSN name]... she was there... she gave assistance around [...] what else was available within ECCH... and so, yes, worked really well and, yeah, missed already!* [S-07-Social]

They also spoke of how they valued the CSN's attendance at carer sessions run by other sectors and the accessibility that enabled:

> *I know the days that [CSN name] was in here [...] to be able, when we've got a carer with us, [to] say "would you like to have a chat with..." – that was just a seamless, warm handover and [...] I do know that [for] some of those people... [that] contact was invaluable* [S-08-Voluntary]
>
> *She went for lots of like family events and things like that and networked, you know, things that were on a weekend. Yeah, lots of stuff that around in the community. She definitely networked* [S-16-Health]
>
> *[CSN name] came to a morning meeting we ran for carers and there was [carer voluntary organisation name] there... so they are probably very much aware of her* [S-03-Health]

A social care stakeholder particularly valued the CSN's uptake of a data-sharing agreement that enabled cross-sector working with multiple partners, not just social care:

> *our data-sharing agreement technically gives all of the partners access to the other partners... not, not necessarily through us. They could have actually gone directly to [CSN name], and vice versa [...] it was great because ECCH are signed up, [CSN name] was able to act as a conduit as well for that as well* [S-07-Social]

9.6.5.3. EDP-3: Engaging marginalised communities

When asked about the whether the CSN had managed to deliver on the EDP related to engaging marginalised communities, and whether this remained an important principle, many started by commenting that carers themselves are marginalised communities:

> *Just by the very nature of being a carer you're immediately marginalized! [...] you lose access and time, resources, finances to do anything that we take for granted. So, you know, that's immediate marginalisation for me* [S-07-Social]

> *Carers in themselves are... are silent, aren't they?* [S-03-Health]

They went on to describe how carers from ethnic minority communities, migrant communities with language barriers, the traveller community, or carers from other minoritized groups such as those with adult literacy difficulties, and those living in rural areas were at an additional disadvantage:

> *"marginalized" is pretty broad [...] we've got like really large migrant community, a lot of those community are like first generation migrants, so they don't have and maybe any English at all? We've also got fairly substantial traveller community as well – there's a couple of sites in the area. [...] large sections of the of the population in Yarmouth that I would say have so many additional factors to consider. If you're a carer, on top of all of that and... and maybe you you're not aware of any of the entitlements... [...] there's like massive, massive levels of adult literacy problems* [XS-15-PatientOrganisation]

> *you need to keep it as diverse as you can [...]... there is the temptation to become, not ageist, but maybe, you know, the older clientele, but obviously there is young mothers, you know, young... young children, being carers as well so...* [S-01-Health]

> *I would say, from her time here, we gave her [...] some of our marginalised community. But I think there's probably... depending where else she goes, the accessibility [...] is very difficult [...] you've got a real diverse population in Great Yarmouth... the language barrier is probably one of the barriers that she... would be a big one... and because... that their views on caring for people are totally different* [S-08-Voluntary]

> *Great Yarmouth and Northern Villages is very... quite different areas [in] Great Yarmouth [there are more] ethnic minorities [whereas] in the villages you've got more the social isolation. So she's been able to [...] get them support because they're out in the sticks [...]... she's worked across a massive section of patients and different social backgrounds and things* [S-16-Health]

They described how the CSN had begun to engage with these communities, but also commented on the challenges of doing so. The noted that it required the building of trust and often working through other organisations (particularly initially). Several noted that the time it took to do this effectively would extend well beyond the single year of the pilot.

> *I know [CSN name]'s been out to some community events [...] – that's a good way to connect with people because I was particularly... there's quite a lot online, so actually getting out in the community, I think, it's important [...]. [She's]s also been to a couple of our carer involvement meetings in the East where she's been able to describe the role and like build that trust really with carers [...] and promote what she's able to do* [S-06-Voluntary]

a lot, you know, is word of mouth... and trust... so if she serviced one family in that position and then the next one found out that that was available to them... [S-07-Social]

that is a big thing. I don't know how successful [CSN name] was in that, and I don't think I was particularly successful in helping her! [...] when you're only a year's pilot, it takes a long time to actually build up that trust [S-04-Health]

a year is not very long to reach those communities [...] it takes years to earn the trust of people that are consistently failed [...] ...if she hasn't managed to reach those people in the year, it wouldn't surprise me. I don't think that's like any fault of her own, but I would say that like focusing on trying to support marginalised communities is something that should be kept just with a recognition that... that really takes a lot of time and maybe more than one person [...] [and] it really makes like a really big difference when you've got someone that's like inside those communities already [XS-15-PatientOrganisation]

you're talking of a different ethnicity, or non-English speaking... if I'm honest, you need a non-English speaking ethnic person because people relate to the same people. I don't think it matters after a while, but [...] you'd need those right experience people [S-03-Health]

that's a much bigger piece of work [...] depending on what communities are you're talking about, whether it's ethnic communities or the [traveller] community or the whatever, they all have their own cultural barriers... particularly in the world of being a carer [...] different religions don't acknowledge the carer, but [...] it is important, absolutely, but I think it's a much bigger piece of work [XS-14-Voluntary]

They confirmed the continued importance of this principle, and that it should be retained, but were also clear that this would be seen as a longer terms goal and that expectations around delivering on this should be managed.

9.6.5.4. EDP-4: Delivering person-centred care to carers with complex needs

When asked about the whether the CSN had managed to deliver person-centred care to carers with complex needs, and whether this remained an important principle, stakeholders considered this a fundamental aspect of the role – one that was delivered and one that should remain:

Absolutely. That would, to me, [be a] fundamental part of the role [S-16-Health]

Definitely person-centred... [...] it needs to be person-centred because it needs... you need to look into the impact of being a carer has been for that person [S-01-Health]

That's a very important principle and, certainly from the feedback and that I'm aware of, yes, absolutely [CSN name] met those [S-04-Health]

Definitely, I think that that principle needs to stay, and I think with [CSN name]'s personality... she's very calm and, you know, very approachable. And I think, you know, she gave... from what I've saw when she was in here, 110% of her time and her attention to working with that individual. So yeah, definitely, person-centred. Definitely [S-08-Voluntary]

That is possibly the most important principle to tell you the truth, because it has to be focused on the carers' needs, not the [patient's] needs, and they need to feel that they are

> *valued and that they're being looked after 100%. So yeah, I believe 100% that that needs to be a real priority* [S-09-Health]

> *That real one-to-one person-centred support on the ground in the community is needed [...] I'd be surprised if anyone in your focus groups have said that that's not important! Person-centred care, regardless of whether you're talking about carer support, or dementia support, or whatever it is, person-centred care is best practice and that absolutely should be a priority* [XS-14-Voluntary]

In observing the CSN's delivery of that person-centred process, one stakeholder noted how carers' needs, or initial thoughts on ways to address those needs, sometimes changed through that process – or were uncovered in a truly person-centred way to enable individualised responses to address them:

> *What they think they want to start with and what they end up with at the end is a skill that [CSN name] had in actually uncovering all of that [...]. And that is a skill to be able to do this. [...] it's one of those things, isn't it, you don't know what you don't know until you need to know it, if that makes sense? [...] Definitely. I thought she was brilliant!* [S-08-Voluntary]

9.6.5.5. EDP-5: Cross-skilling other health care professionals

When asked about the whether the CSN had managed to cross-skill other health care professionals and whether this remained an important principle, stakeholders confirmed that this was delivered and should be retained as an underlying principle for the role:

> *She's like the source of information for both staff and carers isn't she... like all the health and social contacts [and voluntary sector], having links with all of that.... it's really important for both staff and carers* [S-06-Voluntary]

> *Absolutely. [...] it's the toolkit thing, [...] and it helps you to provide* [S-07-Social]

> *[CSN name] came in and sort of talked... discussed her role in our MDT meeting and which was really, really, informative, and helpful* [S-09-Health]

> *if you're upskilling [...] you're spreading your net wider for carers to receive support. If the professionals engaging with them have the awareness to check in and ask about how the carer is as well as the cared-for [...], signposting to services of support [...], that's an absolute golden priority* [XS-14-Voluntary]

> *Yeah, 100% she did that* [S-01-Health]

Although they supported the inclusion of this principle, one health care professional added some expectation management around what that cross-skilling might achieve:

> *there is hundreds of hours of people who think that by upskilling other people in their role they will get better. We can't continue to think that one person, by learning a little bit more, can become responsible for another area. There is only so many hours in the day [...]. You can share information, but the idea that you can give someone a two-hour training and that they are then capable of initiating change in that field, has become vastly overused now. You know? We... we don't have anybody spare to learn someone else's job* [S-03-Health]

However other health care professional stakeholders who had directly experienced this cross-skilling by the CSN, described how they had gained from it and were able to use it in small ways to change their practice:

> *Yeah... she attends our lunchtime huddle every day [and] the thing that it has helped is [...] she's given us an idea of what is actually out there in our community: voluntary sector, different things that are going on, different like say cafes or groups. So she's give us that bit more [...] understanding what is in our area. I think nurses [...] we struggle to find what's going on because we're so busy focused on that patient [...] Having that link has enabled us to then say "actually, I've got Joe Bloggs here who needs extra this or extra that... actually I know where it is". You know? "I can go and get it straight away". And so yeah, it has helped* [S-16-Health]

> *Yeah, I guess I was more inquisitive about the carer in themselves and [...] probably took more notice, really... and I did consciously ask if they needed any support, or, you know, would they like to be referred? Some people didn't because they didn't like to think that they were carers and that they felt... thought they coped and, you know, it was... got to a crisis point when sort of anything went forward. But yeah... Definitely* [S-01-Health]

> *I'm a bit old school and I spend a lot of time in the patient's house. So I thought that we covered everything. [...] I was quite surprised that actually I don't do the jobs that I thought I did until [CSN name] come along. [CSN name] has taught me so much about things. [...] she's just teaching me so much. And now I ring her for advice... "[CSN name], I've got this. What can I do?" And she's like "oh, I've learned this" and she helps me with things. ...and [she has] changed [my knowledge] because I didn't know where to turn* [...] *She's positively impacted me on how much she's embraced the job. I think that she's taken it all on board for what she's learned and developed in this year, I think has been amazing. How she shared that knowledge with us as a team. I just think it's been really positive* [S-05-Health]

9.6.6. Could operationalisation of the role be improved?

In terms of the day-to-day operational aspects of the role, the referral criteria and referral process had been straightforward for all but one stakeholder:

> *it's easy enough [...] the referral's like a quick five minute job, it's probably one of the easiest referrals we've got on our system* [S-05-Health]

> *The referral process was quite easy. It was a form [and] [CSN name] sent it through to us all so we saved on our database and we were able to access that. Yeah, it was quite easy to complete* [S-09-Health]

For one stakeholder referral was more of a challenge where they were tasked to carry out the referral on behalf of GPs:

> *getting tasks sent on SystmOne [was difficult]. So, for example [...] a GP who was absolutely wanting to refer to [CSN name] but couldn't send a task for some reason...]...] so then she would then task me, I would then have to go into the patient record to try and extrapolate what information I could to fill in a referral form to send to [CSN name], for her to be able to do that. And it was just.... I was beside myself that, by the end of a pilot, that we still couldn't get on top of that, we couldn't get our IT people to... [...]. So that actually had quite a*

> *negative impact on my work [laughing] because, you know, finding time for that was not the best use of my time... we got there, and it's important that people got that access, but [...] this shouldn't be that difficult and [...] if we would do anything like that again, we need to get over that* [S-04-Health]

Cross-sector stakeholders also spoke of engaging with the CSN by email or phone:

> *and also how to get advice and guidance from [CSN name] anyway via email so... and yeah, it just worked well* [S-07-Social]

> *we would make the referrals in line with what the process was and [CSN name] was always very... approachable. We'd pick up the phone if... if we were unsure of something* [S-08-Voluntary]

> *[she'd sometimes ring to say] that she'd picked up somebody and that, you know, she was aware of it, and could I give her some more information* [S-09-Health]

Some referring stakeholders noted the challenge of accessing both patient and carer records. The CSN had the carer record and the referrer the patient record, but neither could access the other:

> *the thing I couldn't get my head round [laughter] – sounds really silly really – but, because [CSN name] was seeing the carer, she would be on the carer's notes on SystmOne and I would be on the patient's notes on SystmOne so I could never see what she'd done and she couldn't see what I'd done* [S-01-Health]

> *she'd have to come back to me to say "well, I can't go into the cared-for's notes", so then I'd have to do that. And yeah, that was a bit frustrating at times. Yeah, absolutely. [...] we need to find... if anything like this goes on... a better way of managing that* [S-04-Health]

This patient/carer split was also identified by one referrer, who was in a triage role, who wondered if this was a reason for limited feedback on the outcome of referrals:

> *I don't think [CSN name] [...] reported back on any carers she was supporting, and I imagine that's because the confidential issues? I mean, it's about the carer and it's not about the service user. So I wonder if that was a problem, but never really got any formal feedback back from [CSN name] in regards to who she was supporting and why or how she was supporting that person. [...] I don't know if that was because of confidentiality [...] because it's about the carer... it's not so much about the patient* [S-09-Health]

Health care professional stakeholders who worked very closely with the CSN commented on the challenge she faced with ending episodes of care or discharging carers:

> *I think on a couple of people, she's... it's been difficult to... when to discharge... because ultimately they need support. I mean some of them it's been fine because some of them that I've sent on to her, she's then handed over to, like, community matrons or she's done their bit. But she's just given them an open referral. So when she's done what she needs to do... so, like the Romanian family, she's sorted out their benefits [...] and it's perfect. She's done what she needed to do for them and then that's ended. So it's quite good there. But I think for some of the carers she's... it's hard for them to let go because she's been so helpful to them.* [S-05-Health]

> *I don't know really 'cause getting the referrals, I think, she found difficult at first because it was getting everybody... we were getting people to refer in, and then I think they came in*

> *quite thick and fast [laughter]! At the end I think she needed more support! [laughter] So, I suppose, it's getting the discharges correct. She did have quite a few when she had to wind down the service that she had to discharge, and I don't think she felt [...] ready to discharge them. And I think there's no sort of one-size-fits-all [...] because everybody's needs are different. So some people probably need a little bit longer than others. [..] I think with any nursing [...] you've got to be able to be fluid [...] it's not that straight and cut* [S-16-Health]

Stakeholders from other sectors also commented on this challenge:

> *'cause caring could be like a lifelong role... if it's like for a parent carer, I think it's really difficult because it's going to... that it might fluctuate when they need support throughout that time and [...] there's no end to it...* [S-06-Voluntary]

Another stakeholder was less clear on whether carers were formally discharged:

> *we've never had a discharge per se [...] you create an opportunity, and the decision is made between the individual and the professional when the end is [...]... it's just like the end of a conversation, it's not a discharge [...], you know "you can come back" [...] I haven't had any discharge summaries that I'm aware of* [S-03-Health]

9.6.7. Impact of CSN on stakeholders

We asked stakeholders about the impact of the CSN on themselves and other professionals in their setting. A repeated message was the value of the role to these stakeholders and how the ability to refer to the CSN helped them to deliver their own role alongside the positive impacts on carers themselves. In supporting carers the CSN supported three inter-linked people: the carer, the patient and the professionals:

> *the team has benefited [...] because then when they've gone into patients' houses and they've come upon sort of carer breakdown, things like that, it has helped. They've got somebody to turn to... that can manage all that for them and they've got all the links and things* [S-16-Health]

> *it's been nice for me to be able to say to someone, you know, to get someone clinical because [...] I have no clinical training – I'm very upfront about that all the time – but it's not always appropriate to go to the surgery, or they've got reasons not to go to surgery, as they go to surgery and actually the cared-for takes over... so actually having [CSN name] contacting that person and having that clinical background [...] getting that contact without having to go "well you've got to ring the surgery..." or "you've got to do this or the other", it just cuts down, hopefully, on, you know, some of the rubbish that people have to go through to access what they should be able to access more easily* [S-04-Health]

> *some patients struggle with their catheter bags - how to connect it - and the carer, the wife or someone, will say "oh, I can't remember how quite to connect that bag", but who more perfect to do that than [CSN name] to go in and teach them how to do it. So actually, let's remind the whole team of who [CSN name] is and what [CSN name] can do because actually [CSN name] can save us a job* [S-05-Health]

> *It was reassuring to know that there was somebody there just for them, doing all of the stuff that we [haven't time for], you know, as a holistic way of thinking* [S-03-Health]

> *I've literally got a case come in half an hour [ago] that [CSN name] came straight to my mind to give support to, which is somebody who's newly in the position to give palliative care to their father and... and what's quite sad is that they're already looking forward to the time of which their father dies so that it doesn't have this impact on them [...] so, without a shadow of a doubt, once [the role] came I thought "this is brilliant!" [...] All I know is the case that came in half an hour ago would definitely have been going to [CSN name]! [...] now I know I'm gonna be spending probably three hours additional work with this case that's come in myself* [S-07-Social]

> *All the team found that [...] so helpful because we are not commissioned to offer support to our carers [...] Informal support, yeah [...], but we don't have the time to be spending with carers. [And] of course it's gonna help, because if we know that our service users are being cared effectively for, and that the carer's coping, then it makes life much, much easier for everybody... everybody! You know? So the fact that it's not there anymore... and I really did notice it when I had a complex case recently and I was like "I'm going to... I will definitely refer you to the Carer's Nurse". And I felt it was really important to go to the Carers' Nurse for somebody that was experiencing real burnout, real burnout to the point where they were going to leave the house... they just couldn't cope with it anymore [...] and then I found out that there was no Carers' Nurse and I had to go back to this person and say "I'm so sorry for building your hopes up", you know, "but that that facility is not available at the moment"... yeah* [S-09-Health]

This disappointment at the ending of the role, which was also noted earlier, was palpable – there was even anger that the pilot and the role had ended:

> *I haven't seen any negative in it at all, except that it's come to an end [...] I'm <u>really</u> disappointed that we're not keeping her [...] I just think it's been really positive. I haven't seen any negative in it at all, except that it's come to an end. [...] I'm counting down the days thinking "until she leaves us". I just think it's a loss for our patients. It's a loss for the community. Huge. I feel sad [...] I think it's just so valuable that we need it in place for the patients, for the carers. It's just a shame that it's shown how good it is with the awards that she's won. It's just amazing! [...] if she can do it in a year, what can she do over the next five years?* [S-05-Health]

> *you don't really realise what you've had until you've lost it. [...], because I know something's gone [that] worked really well and, yeah, missed already!* [S-07-Social]

> *anything that's going to help us to provide care and support for our service users in the community is always an advantage... and to have that, and then as a taster, and then be taken away, you kind of think "oh, it's not fair! It's not fair!" [...] we've got very limited resources, so when another one's taken away, you think "oh!"* [S-09-Health]

One stakeholder noted an increase in their own receipt of referrals from the CSN, but welcomed this:

> *I mean I got more referrals, which was good [...] probably of people that I wouldn't have normally been able to see because obviously she was seeing the carers of the people with the cognitive issues, or [cognitive issues in] the carers themselves* [S-01-Health]

We asked stakeholders whether the CSN role had impacted on their own, or team member's awareness of, or attitudes to, or engagement with carers. The biggest impact here was on health

care professional stakeholders: social and voluntary care were already highly aware of, and engaged with, carers and one of the drivers behind the Carer Support Nurse role was the limited engagement of health care professionals in carer identification, acknowledgement and support. The introduction of the role increased their awareness and engagement:

> *I guess I was more inquisitive about the carer in themselves and so probably took more notice [...], you know, I did consciously ask if they needed any support or, you know, would they like to be referred* [S-01-Health]

> *It's been an eye opener! It's interesting to know... you forget about the carers, so it has highlighted what actually that... caring is a tough, tough job to do [...] it's good to highlight that [...]... [staff] have thought more about carers because she's been there. They've sort of like gone "Oh, actually, yeah, I've got..." [and] we I have noticed in Huddle, nurses bring up patients and carers that if she hadn't been there... or if we hadn't had [her] [...] would have never been raised* [S-16-Health]

9.6.8. Fit with existing work processes and practices

Stakeholders were asked how well the CSN role had fitted with existing work processes and practices, or whether they'd had to make any changes or alterations because of the introduction of the CSN role.

Other than managing the challenge around patient and carer record access, and the additional work created for one stakeholder in supporting GPs to make referrals, the only other "work" the role created for others was reported by one stakeholder who described helping to get the role initially established with their setting:

> S-03-Health: *we did a lot right at the beginning, in our own time, because we thought it was important and logical, but after that, because of what we did and the way we functioned, you know, working closely with [CSN name], it just went smoothly. There was no need to do anything more and it changed nothing.*
> INTERVIEWER: *So it sounded like it was a relatively good fit?*
> S-03-Health: *Yeah, definitely*

By far the majority of stakeholders similarly reported the good "fit" and reported no other changes to their processes and practices:

> *No, nothing at all. [...] we just carried on with our role and then just refer the stuff... she just worked alongside* [S-05-Health]

> *We didn't change anything at all* [S-09-Health]

> *No [changes], just made it improved [...]. Give us that link to support people who were in crisis [...] patient's relatives that needed, or carers that needed, support* [S-16-Health]

> *[It's] become something that's part of that toolbox* [S-07-Social]

Some also highlighted the fit with their services and with the cross-sector carer support landscape:

> *It really plugs the gap, doesn't it* [XS-15-PatientOrganisation]

> *Whilst we're looking forward about integrated neighbourhood teams and the likes, you know, this fits in perfectly with it [...] Literally jigsaw piece fit. Absolutely* [S-07-Social]

9.6.9. Promoting the CSN role

A number of cross-sector stakeholders described how the CSN (and the research team) had promoted the role – for example:

> *[CSN name]'s also been to a couple of our carer involvement meetings in the East where she's been able to describe the role and like build that trust really with carers.... and, yeah, and promote... promote what she's able to do* [S-06-Voluntary]

> *my colleague [had] been somewhere where you've done a presentation [...] so she knew about it because of the presentation* [XS-14-Voluntary]

The time and effort that promotional activity takes was also noted:

> *I think the best thing was [...] getting out there, networking, attending things, attending social gatherings, or going to coffee meetings or whatever [...], but it's like a continuous... you've got to keep it going. You can't just put a poster up [...] you've got to keep reiterating it until it's embedded. [...] I think she did well with website, leaflet and then obviously she's selling it face to face* [S-16-Health]

Others described helping to promote the role:

> *When [CSN name] first approached us, we reached out because we knew that the way in which she was going to start functioning as quickly as possible was to have a network built with her as quickly as possible* [S-03-Health]

Some felt that the role could have been better promoted so that more carers (and patients) could have benefitted, both at the start of the pilot and throughout the pilot year. Some were surprised that others weren't aware of it:

> *I think referrals seemed to be quite slow for [CSN name] coming in. And then I don't think it was advertised as well as it could have been originally, but once word got out... my referrals didn't stop going in. And I think it should have been on our initial assessment page that we have this amazing person out there... who could help people [...] she's come to our Huddles loads to say to us, actually, "this is what we do". And she tells our nurses all the time "Refer to me. Refer to me"... and people don't refer to her enough [...].I refer a lot of patients to [CSN name] [...] [Our] weekly communication letter [has] a section about a member of staff almost weekly. I think they should have put [CSN name] in it [earlier]. They do a webinar – I think they should have invited [CSN name] on it to talk about herself. I think they should have made her talk constantly about herself. Put her out there. I think she should have been in every Huddle, boring us about herself [laughter], until everyone knew what she was doing. [...] So she might come into a Huddle once... bring her back! Bring her back! Keep... repeating who she is, 'cause she... she was so important... what her role is... they need... Don't do it once! Do it again! Do it again! Keep putting it out there. So I just think we have loads of communication... we have loads of Huddles... we have loads of webinars. Put her out there! [...] We want to know about what's out there for the patients* [S-05-Health]

> *I'm not sure whether she got many referrals from [name of voluntary organisation] or not, but I think it takes time, doesn't it, which is annoying for one year project, but to like to get that trust and recognition. But I think [...] a short video [...] like 5 minutes about what she can do, areas she can cover [...]... an example of where she's helped... [...] 'cause it is such a great role* [S-06-Voluntary]

> *I think you missed a trick by not having a meeting with [name of voluntary organisation], or at least saying "look, I'm here, put me on your list of services – if you get calls from people within this area, you know I'm here..."... you know, from their perspective, they want as many resources to be able to sign post carers to as possible*[12]*. [...] I think a bit more communication would have would have been better. Yeah, not that's... that's a two-way thing [...] not a criticism of you at all* [XS-14-Voluntary]

> *if we're successful in getting it put in place, I think promoting it, if the service is able to continue* [S-07-Social]

Stakeholders also discussed further promotion of the role directly to carers:

> *an element of outreach [...] should be incorporated. You know, we've got groups like Centre 81 [where] people are being dropped off and collected and then that could be a good time to work in with them to actually... then you don't have the individual requiring care in the house and you can go and have a quiet time. They might say "no, sod off, I'm going down the pub [laughter] – this is my time!"...[...] just being somewhere where some of these are, you know? [There's a] bereavement charity and [...] what worked really well was that you couldn't physically get out the building without walking through a room [laughter] where there were some people there to help deal with, you know, the parents' aspects of dealing with child bereavement and... you could go if you wanted – don't get me wrong – but there was nice couches and a cup of tea and whatever to have a chat and do whatever, you know. So that kind of thing works [...] an element of outreach to get the voice out there that it is available* [S-07-Social]

> *I didn't see [CSN name] do that other than that first presentation that she done. So that was maybe an area that she could have developed [...] especially as we've got the People Participation Lead Group [...] for people who are carers for service users in the community.* [S-09-Health]

However, they also recognised that greater promotion of the role would have led to more referrals which would have been beyond the capacity of one nurse:

> *I think we didn't advertise her enough, although [CSN name] will think she had too much work anyway, I think let's give her more work! [laughter] [...] I guess the more advertised she is, the more people would come in and then she would get bombarded because... in the beginning she was seeing people quicker, but then there it gets a waiting list, doesn't there? And then it gets harder and there is literally just one of her, one of her for Yarmouth in the villages. But you need to reach out and you need to start spreading to Gorleston and further afield, and then you need a team* [S-05-Health]

> *I encouraged [referral] at all times. At one point, actually I thought I don't know how [CSN name]'s actually going to be coping with the demand [laughter]!* [S-09-Health]

[12] The voluntary organisation was engaged with by both the CSN and the study team

9.6.10. Endorsement and support for the CSN role

Although they themselves had welcomed and embraced the CSN role, the stakeholders were less aware of endorsement or support for the intervention from leaders in their sectors, other than initially.

> *I only know at the start, when it was presented, that our Head of People was made aware of it and endorsed it at that point and said: "this is great!". And said: "long may it continue!". I've got an email that says that in it [laughter]!* [S-07-Social]

> *Senior management [...] certainly recognise, you know, what she was doing and was quite often talked about in, you know, meetings... when they were taken forward by leadership... [...] I certainly think it's a well-regarded role* [S-01-Health]

> *I know that [senior leader] did want.... was interested [...] about the role going forward, but it all lies down to finances, doesn't it? [...] it's where the money comes from. [...] we've got the virtual ward coming, which is a big thing from the ICB. So that's the big thing. Got the IV antibiotics in the community. Got the ACPs, which are the advanced clinical practitioners' role. So that's all being looked at. So they're quite big... it's about preventing hospital admissions, so they're taking a big chunk of time and finances, I presume, to get that all running* [S-16-Health]

> *I've not had anything directly, but I can only imagine that it's been [well] received. I mean, why wouldn't it be? You know?* [XS-15-PatientOrganisation]

Endorsement and support these stakeholders had come across for the role rather came from those who had had direct experience of it i.e., their own team members and colleagues, and carers themselves.

> *I just hear from carers that she's reached out to have been saying stuff... a couple of GPs say about it... what a good role it is to have* [S-05-Health]

> *Any meeting that we attend or anywhere that is mentioned, carers are just saying, "Wow! What a great idea this is!". I mean, you heard yesterday the young carer who was chairing the conference yesterday... he was just like "this is amazing!". That's all we've heard from carers... that it's... it's just a brilliant idea. And that they want it across the county* [S-06-Voluntary]

> *I think the fact that [CSN name], you know, was doing such a good job, you know, she'd won awards as well! [...] I'm not 100% [that] most people know [the role has ended] yet [...] when I told [mental health trust name] [...] they were questioning, you know, why... "where's the service gone? It's such a useful service!"* [S-01-Health]

That success of the role in two national awards was noted by several cross-sector stakeholders.

9.6.11. Next steps for the Carer Support Nurse role

Across the sectors there was a call for the role, if rolled out, to be a team model rather than a single nurse:

> *There is literally just one of her, one of her for Yarmouth in the villages. But you need to reach out and you need to start spreading to Gorleston and further afield, and then you need*

> *a team [...] I would just like to see it go and develop forward with a team around her [...] create a team with [CSN name] leading it. [...] Look what she can do to our area... what difference she can make! She and a team. I just think it's incredible [...] and it's exciting... to see what we what can happen!* [S-05-Health]

> *I think [...] the best way to support this would be as a team. [...] It is never going to be done by one person* [S-03-Health]

> *If it was going to be a team [...] you would need a Band 7 nurse there in order to sort of advise, and... just having that one person was not enough* [S-09-Health]

> *I think a team, and in each practice, would be ideal! Whether you'd ever get funding anywhere near that... how great would that be?! [...] you haven't had one nurse in the GP practice, you've had one nurse covering quite a vast area!* [XS-14-Voluntary]

Stakeholders simply wanted more of her:

> *So [CSN name] is an individual... [laughter] but you are obviously looking at a job role for other people... to genetically have lots of [CSN name]s! That's what we're after! [...] I was really surprised that [CSN name] was the only one in the whole of the country!* [S-07-Social]

> *Just more, more [CSN name] across the county, yeah [laughter]!* [S-06-Voluntary]

> *at the very least, what [CSN name] has been doing should be replicated in other areas. I think more than one [CSN name] would have would be ideal, but yeah, yeah... more! [...] it should be so, so much more* [XS-14-Voluntary]

> *It comes down to that capacity and would one per PCN be enough? Looking at social prescribers... each medical practice has got one. [...] guess it comes down to how many... [...] there are hundreds of young carers in our... and they're registered ones! ...we aren't just talking adults... and elderly care... so it comes down to numbers, I guess... uh, I think a minimum of one per PCN.... I think that might work [...] it would need to have some kind of automatically identifiable geography* [S-07-Social]

> *Minimum of one per PCN [...] with the ability to scale it up* [XS-15-PatientOrganisation]

The stakeholders explored different ways an extended service or future model could work that would protect the role and its delivery:

> *[You could take] the model forward by having people maybe co-located? I mean if you had staff attached to surgeries, you'd just need so many staff. [...] if someone is attached to somewhere and goes off sick, then you've got to pull someone from somewhere to cover that. I think if you just co-locate it to an area... then, yeah, that area is covered* [S-01-Health]

> *If they're assigned to a surgery, they could then be pulled in to doing, you know...surgery [work]. [Whereas] co-located [sorts out] ownership [...]... "it's not your member of staff, it's a collective"* [S-08-Voluntary]

As well as extending the geographical reach, it was felt that a team model could enable more proactive support:

> *I know [CSN name] probably doesn't have the capacity, but carers say they would really appreciate having someone that got in contact with them every so often, like every six*

> *months or something, just to say: "how are you doing?". And pick up those really early things that might be going on before they become big things and people don't know where to go for them. So having that semi-regular... knowing someone's going to call, and someone actually cares... would be really, really helpful. [...] Just to see how they're doing. Have a conversation. Let them know someone is thinking and cares about them. And yeah, the opportunity to just to share anything that might just be starting off to... to catch it before it becomes into a crisis situation. But obviously [CSN name]'s one person! [laughter] And there's a lot of carers! [...] If there was a bigger team, maybe they could do the more regular sort of six-monthly check-ins just to make sure carers are OK, they're coping, or whether they have got any anything that they can be supported with. Just have that regular contact* [S-06-Voluntary]

> *Yeah, [proactive is] perfect. Yeah, let's get it before it breaks down* [S-05-Health]

And help identify carers:

> *...identifying carers as well, because there's so many people... they don't even know they're carers even and... and whether there's something else to sit alongside that role to kind of support in that function and I'm not sure what that would look like and it might be that that already exists in different teams [...] and maybe it's just a case of making sure things are really tightly working together. But it might be that there's some sort of part time function and that... that's there almost purely existing just to identify people?* [XS-15-PatientOrganisation]

And target different categories of carers:

> *[It could] look at the different categories of carers [...] not just the elderly care, but the young carers* [S-07-Social]

The potential skill mix of a team was also explored:

> *I think also the model of care that [...] would probably work [is] looking at different... mixed levels of staff[...] the Kaiser Permanente self-management model? [...] it gives you that triangle of care where you've got people... self-management at the bottom, you've got people that need to be supported in the middle and then you've got complex patients, or carers, at the top that need more help and that's how they go up and down the triangle... [...] But then if you had a skill mix [...] then they might not be discharged straight away... they could be, like, led down a path to self-management, you know, and being fully educated in, you know, what they needed... to a support group maybe?* [S-01-Health]

A final benefit of team working that was identified was the potential for support of the CSN role itself:

> *I think the only thing that I'd say about the role [...] is that I think it's quite a lonely role [...] [and] making sure that [CSN name] had peer support. [...] you know, if she's dealing with people with safeguarding issues and things like that, it's not all rosy, is it? [...] if this was to continue, I think there'd have to be some sort of peer support [or] clinical supervision or... just somebody to sound off to if she needed it. [...] it's quite a standalone position and whether it would be that she'd have some more in the team [...] maybe an HCA to support her or an admin..., but I think [...] it could be quite a lonely role* [S-16-Health]

National recognition

As the stakeholders noted, the Carer Support Nurse was recognised in two national awards.

Firstly, the Carer Support Nurse nominated by MP Brandon Lewis for an **NHS Parliamentary Award 2023** in the Nursing & Midwifery category and was the **regional winner for the East of England**: https://nhsparliamentaryawards.co.uk/shortlist/. The team attended an awards ceremony at Westminster in July 2023.

Second, the role was shortlisted for **Royal College of Nursing RCNi Award 2023** in the Innovations category, as **one of 75 finalists from over 900 applications**, leading to an invitation to attend the award ceremony in Liverpool Cathedral on 10th November 2023: https://rcni.com/nurse-awards/finalists-2023.

9.7. What was the CSN's experience of, and reflections on, delivering the role?

There were multiple sources of data on the CSN's experience of, and reflections on, fulfilling the role both during the pilot (Task 2A) and at the end of (Task 2C) the pilot.

9.7.1. The need for the role – the CSN's view

Like the two nurse stakeholders who were initially unsure about the need for the role, the CSN herself had not been aware of the need for the role until it was advertised:

> *Not until I'd seen the position advertised. [...] Then had think about it and then obviously looked a little bit further into it [and] it was like "Actually, yes, we are missing the carer support element. We think that we're providing that holistic approach, and that integrated approach, but we've got a whole network of carers out there that are doing a massive, massive job and we don't really engage with them." And I think that's what prompted me to do it [...] Because there wasn't a lot of literature out there [for nurses] – there was a lot of stuff obviously for cancer and [...] palliative but not for anybody out there that does this caring day in and day out just for general things [...], you know, just looking after loved ones that are just getting older and losing their independence. And I think that that's what struck me, is [...] unless it's got a label they didn't fit, so unless they were like supporting somebody with cancer so they could go to like the cancer organisations or [...] particularly on a palliative journey obviously everything's thrown in in that last twelve months on the palliative journey and everyone's looked after then, but without a label...* [CSN: Task 2C]

Like the other nurses, she had had a sense that she was providing this support in her district nursing role but came to realise that she wasn't:

> *I'd go in and I'd deal with the patient, whatever reason I was there to interact with the patient, and some of the carers would come and chat to you while you were doing it, and other carers would just stay out of the way. And you didn't think that, you know, they needed to be engaged with necessarily unless they tried to engage with you. [And they didn't] until everything starts to unravel. They tend to step back, [...] they don't want to be perceived to be interfering. And obviously I've learnt on this journey that we need to, you know, engage with them and encourage them and support them and they could really be a massive asset.* [CSN: Task 2C]

9.7.2. What advantages did the CSN role have compared to what happened before? – the CSN's view:

The CSN felt that the service addressed a clear need to support unpaid/family carers based on her experiences in the role and the positive feedback she received from carers [CSN: Task 2A]. More specifically she felt that the CSN role, combined with use of the CSNAT-I, worked well in supporting carers to identify and discuss their needs and, in particular, to focus on themselves rather than the

cared-for person. In addition, she noted that this role had made her reflect on and challenge the medically driven approach that had previously informed her practice in other roles. She recognised how initially she had had a desire to "fix" everything and make sure that there was a future proof plan in place. However, over the course of the pilot, she described coming to the understanding that this approach could be at the expense of enabling carers to make choices about the support they needed. She also described how over the course of the pilot she had come to embrace the empowering nature of her role [CSN: Task 2A].

Like the cross-sector stakeholders, at the end of the pilot the CSN identified clear advantages of the role being in place compared to the support available for carers' health and wellbeing prior to the role commencing:

> *Most of the carers that I've seen weren't supported at all. [...] the issue there is that any support they might have engaged with they themselves are still putting their loved one at the centre of.* [CSN: Task 2C]

The CSN went on to describe how health care professionals often do this too – so even where carer support was available within health care (e.g., carer meetings and workshops) most of this activity was focused on how the carer could support the patient rather than on the carers' own health and wellbeing, or how they were managing:

> *And that's what we've tried to overcome, is actually "No, we're looking after you and by looking after you indirectly we're looking after the person that you're caring for"* [CSN: Task 2C]

She described how cross-sector professionals she worked with could see the benefits of the role and, interestingly, noted that personal experience of the caring role (or caring within professionals' families) also played a part in realising its value:

> *[professionals] that have engaged with it have found it beneficial [...] once they could see the results, so [...] they'd go in themselves for different elements or I requested their supported with different things as well, then, yeah, they could definitely see the benefits, yeah. [...] and people do relate it to what's happened in their own lives* [CSN: Task 2C]

She described a series of cases where referral to the Carer Support Nurse role had made a considerable difference to carer and patient outcomes – Box 10 summarises two of these, in the CSN's own words.

Box 10: Examples of CSN narratives highlighting the impact of the CSN on both carer and patient outcomes
[There was] a lovely couple [...] both retired. She's got early onset dementia and she's got other issues - osteoarthritis and [...] continence issues as well - and because of the continence issues and like the urgency side of things they don't tend to go out at all. He does tend to do the lifting and manually handling her and [...] had a poorly back [...]. But we had quite a positive outcome with them because I spoke to the wife… it was short term memory so it was a case of having to repeat things, but we got the continence nurses are onboard, and they were revisiting just to try and look to try and get her out of the house. We discussed with the GP who was also really supportive about the possibility of, although it wasn't ideal, having a long-term catheter just for the quality of life so she hasn't got to worry about weeing. I know it's not something that we'd choose to do but it's about weighing up the balance. Got him [...] a couple of physio appointments as well. But we also managed to get a befriender through [voluntary organisation] which gives him the opportunity to spend a bit of time with a neighbour he's friendly with, they tend to go for a walk to the pub once a week, but we've managed to get a befriender in just to come and give the wife some company. So two twofold really: she's got someone there to come and see her, her friend, and he can have some man-time to himself as well. I know that they only moved to the area twelve months ago, I think, before there was a rapid health decline so they hadn't really got that social aspect themselves, so they'd left all their friends and everything because they wanted to have a bungalow towards the seaside and it's backfired really because all the friends and family they've left behind from living in the same area for fifty-odd years. So yeah, that was quite a positive outcome, because he had health needs, so they've been addressed, and obviously with his physical health as well. She's obviously had support emotionally as well as physically as well. And then there was real collaborative working with continence, the GP and myself, and physiotherapy as well. So that was one little story which was quite a nice outcome [CSN: Task 2C]
Another couple that I worked with [...] the lady who was the carer… the husband had had a stroke. She had quite poorly oedematous leaky legs, she's got quite bad leg ulcers on both her legs as well as doing the caring responsibilities for her husband [so] obviously she's got her own issues with mobility and things [...]. But we managed to get her some short-term care put into place where they were coming round and helping the husband with his personal care. Supervision really more than hands-on. [...] The six-week what they were offered free has finished but they're actually continuing to fund that privately for twice a week. But there's also been a package of care put in for her who'd perceived herself as independent [...], but she recognised that actually she could do with some help as well just for things like pegging out the laundry; she couldn't reach up properly or she couldn't stand for any length of time. We had OTs go in and put perching stools in there. She's had the Fire Service round to put fire alarms up. And then the nurses who go round and do her legs for her [...] also managed to source for her a mobile hairdresser (laughs) because neither of them had had a haircut. So one of the nurses actually lived in the village and could recommend one so obviously we had that bit of peace of mind that she didn't have a stranger going in as well. [...]. Oh, podiatry as well! Yeah, he needed his toenails cut, they were all curled and starting to dig into his feet and he's also diabetic. Yeah, so they felt like "new people", they said, after all this [...] so they had pretty much everything. But they embraced it. [...] once she'd had the conversation with me she actually recognised that she did need some support [...] and so there is a huge part of this role is actually getting people to open up to getting that additional support as well. Because there have been numerous occasions where I've opened lots of doors and no one's gone through them and you can't keep pursuing that apart from letting people know that there is help out there, should they want to engage. [CSN: Task 2C]

9.7.3. Confirming that the CSN is a nursing role – the CSN's view

Like the cross-sector stakeholders, the CSN confirmed that the role was a nursing role. She felt the label 'Carer Support Nurse' was important to the carers themselves:

> *Yes [...] it's the package of having a nurse [...] it's the label of a nurse. [...] The nursing profession I think is still viewed with quite a bit of respect and I think that they felt that they were getting the support that they needed because it was a nurse.*

She felt that being a clinician was also important when engaging with other healthcare professionals:

> *Once the penny drops as to what you can give from a clinical perspective [...] to actually alleviate some pressures off other areas, then they want to grab hold of you with both hands and not let go [...] I think it's because you're a trusted profession [...]. I mean we might just call them, from a professional point of view, 'basic observations' but we learn so much from those basic observations, and I think if you're dealing with other healthcare professionals, and even the social sector, [...] and you can clinically evidence and you're a trusted profession then that is taken. [...] I wouldn't go to a GP and say, "My patient's got low blood pressure" and they'll go, "I don't believe you, [CSN name], we're going to go out and do it again", you know? They'll take that from you and then they'll work with that, but they might come back to me and say, "Well can you do some bloods?". "Well, yes, of course I can," so I'd go out and do a blood test for them off the back of that or follow it up. [...] it is having that accountability because you've got the professional registration.*

9.7.4. Role delivery & activity – the CSN's view

As with the stakeholders, we asked the CSN whether the role had been implemented according to each of the five Evidence-based Design Principles (EDPs, outlined in Box 1) and whether each remained relevant or important following the pilot and should be retained as principles.

Box 11 shows how her views mirrored those of the stakeholders in terms of the successful delivery and continued relevance of all five principles. Her views also mirrored stakeholders' views in terms of the work that these required, particularly in relation to cross-sector working (EDP-2), engaging marginalised communities (EDP-3) and delivering person-centred care to carers with complex needs (EDP-4).

Box 11: CSN views on the delivery and importance of the five Evidence-based Design Principles (EDPs)
EDP-1: The need to be community-based**:** *Absolutely* [CSN: Task 2C]
EDP-2: Cross-sector working**:** *...engagement with all the other services, and also being able to offer carer support to all the other services, I think has been a huge part of it. If I hadn't have put myself out there and tried to connect with all these other services, it wouldn't have happened* [CSN: Task 2C]
EDP-3: Engaging marginalised communities**:** *I have had a Romanian family and I had a Spanish family which we muddled through [...], but through speaking with our local GP practices there is a real need for marginalised communities, we just need to tap in and access them but we haven't had the time [...] to then go that step up [...]. [I met somebody] speaking on behalf of the Romany community and we have actually got quite a large Romany community around here. [...] she said, but it's just the way that they're communicated with, not necessarily that they don't want the support, it's just the communication's wrong. [...] she said that they do expect to be respected and approached respectfully but it's with their standards, which obviously we don't know what their standards are until you go in with them in there. So yeah, there's still a huge opportunity to grow.[...] I think that you need to engage with those minority groups through charitable organisations maybe, which this lady was, you know, and then take it from that approach, so come through the long way round rather than trying to approach people directly or through referral of people but you need to maybe take a different approach where you actually go through somebody who they already know and trust* [CSN: Task 2C]
EDP-4: Delivering person-centred care to carers with complex needs**:** *I spent a lot of time with them, an hour and a half, two hours with them [...] We used CSNAT-I. And I did try to unpick during assessments whether or not they've actually got any health-related needs themselves. [CSNAT-I] was not always appropriate [if] things were really quite tense in the house, you know, so you knew that needed to take immediate action on whatever they were throwing at you straightaway, but you did have a chance to then [use CSNAT-I] and have that conversation [...] So I think it is really valuable, yeah, a really valuable tool. [If the role] was rolled out in general terms then you'd lose a lot of opportunity to identify unmet needs if you didn't have it in place. [It is a core part of the role] because if not then we go back to when we've got the professionals making assumptions as to what the unmet needs are and running with it rather than actually picking apart what's important to the carer* [CSN: Task 2C]
EDP-5: Cross-skilling other health care professionals**:** *Yeah, I did work closely with other healthcare professionals, particularly therapy, particularly district nurses and the GPs. Social prescribers as well. I did a lot of work with the Community Mental Health team. So yeah, [...] with the Admiral Nurses.* *I think the people that have engaged with it have found it beneficial because they've come to me [...] because they didn't know what to do and I've been able to take the carer support approach and find solutions. And you've got the education element there as well: "I didn't realise we could do that, I didn't realise that was out there". So [...] I would give them the information and they could take it forwards, [...] they just needed to know where to go* [CSN: Task 2C]

9.7.5. Could operationalisation of the role be improved? – the CSN's view

Like the cross-sector stakeholders, the CSN felt the referral process worked:

> *[The referral process] worked because it was built into the way that, operationally, we always work really. [...] you couldn't really change it, you couldn't really enhance it to make it any different with what you've got to work with.* [CSN: Task 2C]

However additional work was needed to ensure that referrals were appropriate:

> *The problem with the referral criteria [...] is that you couldn't always identify complex needs without putting eyes on the person. Because [...] they may not have had complex needs as such, you know, they might have had well-managed diabetes, for example... I wouldn't necessarily, if that was well managed, class that as a complex need. However, once I've done the assessment and found that they can't afford to put food on the table so they're not eating a well-balanced diet in line with what their needs are for the diabetes, you've potentially got something snowballing then and getting bigger and bigger where they then become unwell because they're not eating a proper diet, which is then affecting their insulin levels and their blood sugars, etc. So they would then become a potential complex need, in my eyes. [...] what really struck me as well is the mental wellbeing... people's mental health, and that's probably what you see quite often when things hit crisis point, is that they can't cope mentally anymore. But I'd also started to look at that quite differently in the second half really of what we've been doing, is the emotional wellbeing... you know, and it's actually getting that emotional support in place because the wellbeing service for mental health issues wasn't always appropriate. And it was about having that conversation [around the] emotional support they need [...] in order to put them in touch with the right people so they don't end up with anxiety and depression and everything else and then things start to unravel.* [CSN: Task 2C]

> *...the more established the role got, you needed to be a little bit smarter about what was being referred through to you. [Some had to be] nipped in the bud. [...] somebody might say, "Oh they can be referred to a Carer Support Nurse", "Well, no, hang on a minute, that's not really appropriate, it's not what they're here for". But it's because they didn't fit in with anything else.... a lot of them probably, in my opinion, that I had those sorts of conversations with could have been taken on by a Community Matron because it was around a patient that was already known in the community, and obviously making sure that they had their family support in there because there were complex health issues with the individual [...] with the patient [not the carer].* [CSN: Task 2C]

And, as noted (and welcomed) by some stakeholders, some carers were not formally referred but support was still given:

> *I did speak to some carers, you know, and they just wanted to have a chat and be pointed in the right direction, there was no need for that specific intervention.* [CSN: Task 2C]

The challenge of 'discharging' carers, which was noted by the cross-sector stakeholders, was similarly described on by the CSN:

> *I think because the conversations that I had [...] right from the first phone call when I triaged, when I was introducing it, it was "This is a pilot, it's twelve months and it's short-term support" so the expectation was set right from the beginning, and I think everyone was quite*

happy with that. Now, there were some people that I did hold onto pretty much all the way through (laughs)... because the person that they were looking after was quite poorly or they came out of hospital and their needs had changed, it was just one thing after the other, so they were having a little bit of a rollercoaster and they had that hand-holding really in the support going through and the adjustments to the support that they needed as their journey changed. But mostly, you know, the fact that it was a case of being introduced to services, obviously looking at their own health and wellbeing, making sure that they were being well supported and that they were looking after their own health is enough for most of them and I did manage to discharge after six weeks. But yeah, I think there's always going to be the complex ones. [...] I spoke to the Admiral Nurses and they said they often speak to carers who don't need them at the time or they just need initial direction, and then that's it, so they don't end the referrals, they just like close them down, you know, so they're still there on the books and then they could be reactivated. And I think that's the sort of thing that we'd potentially need to have, that they are known to the service, they can reengage with the service and [...] that support is there. But then I think we'd need to be quite careful that those carers are the ones that have got their own complex needs. [CSN: Task 2C]

9.7.6. What was the impact of the role on the CSN? – the CSN's view

There were both positive and negative impacts of the role on the CSN herself. She spoke positively of her own professional development and the opportunity the role had given her, but also the emotional load of the role and how she managed this:

I've learnt loads and I think it's really opened my eyes to what we could do in day-to-day [district nursing] practice that we don't potentially do at the moment. [...] so we could do those referrals, we could apply for carers' passports, so we could do all those little things just to help the carers feel more valued. [...] And it is signposting. I think that my toolkit is huge now because of all the connections that I've made! It's about that joined-up approach, which is where the ten-year plan and integrated care is all going, isn't it? [...] I've thoroughly enjoyed it. It's been exhausting... at times [...] from the point of to start off with you felt like you weren't getting anywhere and then the emotional load from the carers who actually unburden everything.[...] sometimes you'd come out of an assessment – well frequently, to be honest with you – you'd come out of an assessment thinking, "What happened?" or "How am I going to sort this out?" because they're looking to you for answers really. [...] I mean, I've had the conversations where they've wanted to know where… the loved ones have said, "When the time comes I want you to help me end it" you know, we've had those conversations. I've had, you know, they're going to end it together, you know? So we've had like a potentially double suicide. Childhood abuse, you know, abusive relationships, physical, sexual abuse, you know, everything. They open up... they're at that point where everything tumbles out [...] because you're asking the right questions. [CSN: Task 2C]

I did have the supervision and support available. I obviously work quite closely with our safeguarding lead who is there, and if he wasn't around then I'd turn to one of our senior nurses [...] so I engaged with her if I was ever up against a brick wall as to "I can't go to bed and not have a conversation with somebody about this!" (laughing) [...] And obviously [name of colleague] who I share an office with [...] I've offloaded onto her quite a lot [...] used her as my clinical supervision really. But because the role is so different, there isn't that support networking for you. I mean, you build one around you [...] but it is quite a lot to take on. [...] I

> *think you'd need to have a debrief, yeah, even if it was just like a weekly opportunity to discuss what's happened, you know, and what was put in place or where you went and went with it or what support might be needed, you know, and an opportunity to learn really. But I think that that debrief is really important, which is something that obviously I didn't have. Just whoever would listen to me at the time. [...] And my dog's a brilliant listener!* [CSN: Task 2C]

> *I've really enjoyed it. [...]. And for me it was to [...] develop myself as well. [...] I feel that I really have [...] been an ambassador really for what we've been trying to do. [...] from a professional perspective [...] there's been value in it for me from that perspective. [And] it's been interesting to understand why we do the research and making your idea come to life really. [...] I've enjoyed it [...], thank you for the opportunity.* [CSN: Task 2C]

9.7.7. <u>What were the challenges? – the CSN's view</u>

During the pilot, the CSN identified some of the challenges of delivering the role [CSN: Task 2A], many of which were reflected in the feedback from cross-sector stakeholders reported earlier:

- Some carers don't recognise themselves as carers.
- Some carers were difficult to contact, and frequently cancelled, making it difficult to respond to all referrals.
- Working holistically was a new way of working for the CSN and she found it hard, initially, to understand the boundaries within this approach.
- The inability to respond directly to any immediate clinical needs experience by the cared-for person which would in turn help the carer – this was due to the inability of the CSN to access the cared-for person's notes.
- Obtaining feedback from other organisations regarding whether or how referrals she had made were picked up was sometimes difficult.
- Managing the administrative load around making appointments and follow-up calls was difficult due to a lack of specific administrative support or a dedicated telephone number for the service – this resulted in some referrals not progressing.
- Being the sole clinician within a service was difficult due to the lack of someone else in a similar role with whom she could divide the role to address the differing demands of the service (e.g., responding to versus pro-actively seeking out referrals) and discuss the emotional demands of the role [CSN: Task 2A].

At the end of the pilot the CSN reflected on the challenges around some carers' reluctance to engage with other services, not feeling able to fix things, but also being able to see forthcoming problems that the carer themselves could not recognise:

> *A lot of them were completely overwhelmed and exhausted and just didn't know what to do and couldn't be bothered to try and engage with some people sometimes because, you know, it's just something else for them to think about, another phone call to take. [If I referred them to external organisations carers were sometimes concerned that they'd be] doing another assessment [...] they'd have to repeat everything. [...] it's something that I think we'd have to think about [if the service came back again].* [CSN: Task 2C]

> *...you haven't got all the answers and some people just want to have somebody to go in with a magic wand and a crystal ball and say, "Okay, everything's going to be okay," but you can't*

> *do that. And you can see from a healthcare professional how things are going to play out in the future. You know, but without holding that person's hand all the way through and trying to encourage them and nurture them and push them in the right direction to get the support they needed when they're saying, "I'm going to be fine," you know, [...] sometimes it's hard to step away when you can see [what's going] to happen in the future – but if they can't see it then what can you do? [...] it's absolutely their choice. And then obviously you've got the carers who just want you to go in and take over and do everything and you can't do that either!* [CSN: Task 2C]

9.7.8. Fit with organisational goals – the CSN's view

We asked the CSN whether the role aligned with the host organisations goals:

> *Absolutely. Because at the end of the day we're looking to provide a joined-up approach, aren't we, to be able to deliver the best service that we possibly can and for better patient outcomes. [...] we filled a gap that currently isn't filled. We didn't put a barrier in the way, we offered something more [...] So it definitely [aligned] with their values and objectives [...] 100%.* [CSN: Task 2C]

9.7.9. Promoting the CSN role – the CSN's view

There were limitations on the amount and type of promotional work the CSN could do due to the pilot nature of the project, particularly initially. Early promotional work targeted other professionals:

> *I did lots of engagement and continued plugging [...] which was a big part of that role throughout the whole period really, and still people were like, "Don't really know what you do," you know? So it's getting that understanding is a huge thing. But once you've got them onboard [...] they then can't get enough of you!* [CSN: Task 2C]

Later promotional work, a few months into the pilot, was able to target carers themselves to encourage self-referrals:

> *...once we got the nod… And it just goes to show that there were people out there, you know, from putting posters up in shops and things like that they do [self-refer]* [CSN: Task 2C]

9.7.10. Implementing the service – the CSN's view

During the pilot the CSN reflected on the process and experience of implementing the new service, describing how:

- Setting up and delivering a service was lot for one person to take on.
- The CSN felt the weight of expectations in relation to making the service work.
- The CSN was concerned about how others within the host organisation perceived her role – for example, was she doing as much work as them and was she doing the right things?
- It took a long time to make meaningful connections with other professionals outside of the host organisation, and up until the end of the pilot she was still coming across professionals and organisations that were new to her.

- Initially there was some confusion with the voluntary sector over how their roles differed which needed to be addressed and clarified.
- Service implementation may have been easier if there had been more specific administrative support from the host organisation, such as a dedicated phone number and support to arrange appointments.
- Although she experienced good support from within the host organisation, including monthly governance meetings, the CSN would have benefitted from having a colleague in a similar role to discuss issues with as they arose [CSN: Task 2A].

9.7.11. Assessing the pilot – the CSN's view

We asked the CSN, with the benefit having been in the role, how she would assess the pilot. She drew on carer and stakeholder feedback and recognised that, as a pilot, the project was not on a scale to enable the measurement of traditional quantitative outcomes related to crisis prevention:

> *Well I'd be looking at the feedback, I think, really because it's not been big enough in order to actually say that we've prevented hospital admissions and that we've prevented crises happening and things like that [...] I'm not sure how you measure what doesn't happen, you know! [...] I think the carer feedback would be massive and obviously the feedback from other services that I've engaged with, you know, if they've recognised the value and hopefully would like to see the service continue as well.* [CSN: Task 2C]

9.7.12. Next steps for the Carer Support Nurse role – the CSN's view

The CSN spoke of how being in the role had raised her awareness of carers and how that might impact on her going forward:

> *You can't turn off the button once it's been switched on, can you, that's the thing. [...] I mean, originally, I came from an acute background and my acute button's still definitely there as well. So yeah, you're not going to lose it; I still will try and offer that carer support [as I return to district nursing]. The thing is you've got the pressures of the service, haven't you, and the pressures of the service might not always allow you to do as good a job as you think you'd like to. [...] I do hope that this might come back in some shape or form [...] I'm hoping...* [CSN: Task 2C]

We asked the CSN what further training she felt she would benefit from if the role continued:

> *some sort of wellbeing training [...] specific to people's wellbeing needs, and so mental health, emotional health, and then maybe some sort of bereavement support as well, because I've had a few bereavements that I've continued support obviously after the person's passed... and then tried to let go of that because they become quite reliant [...] yeah [...] that mental health side and bereavement.* [CSN: Task 2C]

In terms of how she felt the service could develop if it continued, her views reflected those of the stakeholders in that it should continue, should be protected and should be a team model:

> *I think it needs to be quite a protected role because if not you'll get scooped up with everything else – a bit like the Community Matrons [...] their role is evolving and becoming*

> *less and less Community Matron [...] I think with any role in any organisation there is always that chance that extra is put onto you all the time and then all of a sudden you realise that you're not actually delivering the service you intended to deliver [...] you've just got a big pot, a big soup.* [CSN: Task 2C]

> *I would like to work more on the lines of a more specialist team that work out in the community - like tissue viability, you've got the heart failure team, etc – so, although they do cover all the localities, they're still under one manager and classed as a team in their own right. So we would be based somewhere but we would be obviously going out to all the different localities* [CSN: Task 2C]

Like one of the nursing stakeholders, she identified one of the benefits of a team approach as being a source of support for role holders: "*that would be built in with the team really, I think"* [CSN: Task 2C]. She also shared her thoughts on the team's composition:

> *[To lead the team] you're definitely looking at a senior… You need the experience, people value the experience. I don't think that we would've had loads of people opening up, as they have done with me, with somebody who's fresh out of nursing school; you've got to be realistic, haven't you, at the end of the day. So I do think that you do need that life experience, that maturity, you need to have that… You need to be relatable. And so I do think it sits at a Band 6 role. The delivery of the service I'd say would sit at a Band 6 role. Obviously the management of the service would sit at the Band 7.* [CSN: Task 2C]

This need for seniority and experience with a key skill set was a repeated message reflected in multiple sources of data across the pilot:

- The Activity Analysis indicated the benefit of an experienced registered nurse being in the role – the data collected reflected the nursing process i.e., the work that was done by the CSN was not just a "chat and signpost" but a full assessment, then a plan and intervention. The CSN created psychological safety for the carers to express distress and she responded to the distress and created actions based on assessment such as referrals which are seen in both the Activity Analysis and Business Intelligence Unit data.
- Carers we interviewed valued her particular skills in enabling conversations, reflecting on how the CSN's experience, maturity and professional background were important factors in enabling them to open up and share their experiences.
- Cross-sector stakeholders had described how, in addition to her clinical skills, the individual who fulfilled the role brought some particular skills, and had some particular characteristics, that were highly valued, noting her maturity and experience.

9.8. What are the resulting recommendations?

This final section (1) provides a summing up statement, (2) outlines possible Mechanisms of Action for the Carer Support Nurse pilot role, and (3) presents the key recommendations of the Carer Support Nurse pilot evaluation.

9.8.1. Summing up statement

Norfolk and Waveney ICS strategy has a carer-dedicated section which notes that *"Needs are becoming increasingly complex and so our service improvements must be more co-ordinated and effective for the service user and their carer"* [82]. The Norfolk and Waveney ICS website has a carer-dedicated page which acknowledges the "vital" role of unpaid carers in keeping people safe and well at home who would otherwise need ongoing care, and that local and national data consistently show significant negative impacts on carers' own health & wellbeing [83]. Carers within Norfolk and Waveney ICS have higher than national average long-term conditions, have higher rates of arthritis, back and joint conditions and mental health conditions [84]. The ICS website lists the Carer Support Nurse at ECCH as one of the ways it's providing carer support [83].

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. It addresses the healthcare policy rhetoric on the need for carer support, however funding for the Carer Support Nurse pilot role ended mid-October 2023.

Given the success of the pilot, the Carer Support Nurse role warrants testing on a larger scale.

9.8.2. Possible Mechanisms of Action for the Carer Support Nurse pilot role

Possible Mechanisms of Action for the CSN pilot role were developed through review of the pilot findings by the CSN Pilot Core Team, CSN-PPI group, and CSN-PAG. These possible Mechanisms of Action could inform an initial logic model for a programme theory and are summarised in Box 12 below:

Box 12: Possible Mechanisms of Action for the Carer Support Nurse pilot role
• The CSN as a direct care intervention for unpaid/family carers with complex needs • The CSN as a means to raise healthcare professionals' awareness of unpaid/family carers and their support needs, and the importance of acknowledging and addressing them • The CSN as a means to raise carers awareness of their own support needs and the importance of attending to their own health and wellbeing to both support themselves and sustain the caring role • The CSN as a means to prioritise the identification and addressing of carer needs related to their health and wellbeing

- The CSN as a means to facilitate carer access to healthcare for their own health and wellbeing needs
- The CSN as a conduit for implementing CSNAT-I
- The CSN as a provider of psychological safety
- The CSN as an absorber, or container, for some of the challenges and difficulties of the caring role
- The CSN as a super-connector and navigator for carers
- The CSN as a super-connector for cross-sector professionals
- The CSN as a system designer/improver

These possible Mechanisms of Action require testing and may evolve for an established Carer Support Nurse role or within a Carer Support Nurse Team model.

9.8.3. Key recommendations of the Carer Support Nurse pilot evaluation

Box 13 presents the 21 key recommendations of the evaluation of the pilot Carer Support Nurse, developed in collaboration with the CSN-PPI Group and CSN Project Advisory Group (CSN-PAG) based on the evaluation findings.

Box 13: 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

10. Conclusion and future work

The award-winning 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. Early positive findings were shared with ECCH, the ICB, and cross-sector stakeholders and the wider community (see Appendix 4), 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 and provided valuable feasibility data for a future multi-site study for which funding will be sought.

11. Dissemination and outputs

Appendix 4 summarise key dissemination activities and outputs of the pilot e.g., presentations, blogs, press coverage and web entries. Going forward, the findings and recommendations will be presented to the Cross-sector Consultative Community in a webinar. A separate report for carers will be shared with carers who took part and the voluntary organisations who facilitated the study (so that they can share it with their carer community). We aim to publish papers for academic and professional audiences in relevant journals. Alternative modes of sharing the findings will also be explored, informed by feedback from cross-sector stakeholders (Task 2C), such as via UEA's YouTube channel and a podcast.

The study team will continue to harness established relationships with national and regional leads and use NIHR ARC-EoE infrastructure and the CSN-PAG's credentials in carer innovation [52,85-88], to identify and leverage national opportunities (e.g., Carers Week) and organisations (e.g., Carers UK) to promote the CSN as a mechanism for delivery of the NHS commitment to carers.

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[13] Written permission to name received

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APPENDICES

APPENDIX 1: Detailed Study Plan & Methods

APPENDIX 2: Feasibility of a future wider multi-site implementation study

APPENDIX 3: Carer Asset Map

APPENDIX 4: Dissemination and outputs log

APPENDIX 5: Brief case studies of CSN work with referred carers

APPENDIX 6: Template for Intervention Description and Replication (TIDieR)

APPENDIX 7: Resource use and cost data from Carer Survey

APPENDIX 1
Detailed Study Plan & Methods

To achieve the study's aims, answer its four research questions and meet its seven objectives, a three-stage multi-task multi-method study was conducted.

- Stage 1: Development of a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse (CSN)
- Stage 2: Value and impact of a stakeholder-operationalised Carer Support Nurse role and feasibility of a future wider implementation study
- Stage 3: Establishing mechanisms of action and effect, and recommendations

Given the innovative nature of the role, implementation theory was applied throughout the study. The Consolidated Framework for Implementation Research (CFIR) [89,90] guided aspects of data collection and analyses. This conceptual framework (of 39 constructs over five domains) enables systematic assessment of multi-level implementation contexts and factors influencing implementation and scale-up.

This study predominantly took a Contribution Analysis approach [91-93]:

- qualitative data were audio-recorded (with permission), transcribed and anonymised, then analysed using framework analysis [94] incorporating the CFIR codebook (enabling both inductive and deductive approaches);
- quantitative data were analysed using descriptive statistics; and
- the multiple data sources and types were synthesised.

Indicative sample sizes were pre-determined and stated in the two protocols. Given Covid-19, our PPI carers advised that in-person data collection might not appeal therefore data collection was predominantly remote; remote data collection can also improve diversity [95].

Stage 1: Development of a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse (CSN)

Within Stage 1, two data tasks were undertaken to support the development of a stakeholder-operationalised model and implementation strategies for the pilot Carer Support Nurse (CSN) role:

- Task 1A) Asset-Based Mapping
- Task 1B) Stakeholder operationalisation of the pilot CSN role

Task 1A) Asset-Based Mapping

Asset-Based Mapping [96-98] was undertaken to identify current local carer support activity within and across sectors. First, an internet search was undertaken to identify key organisations working with carers both locally and nationally. Second, key stakeholders (n=10) were recruited from/via project work-up consultees from the health, social and voluntary sectors, and interviewed online about the role of their organisation in supporting carers, and their intelligence on the roles played by other local and national organisations who worked with carers. A locally relevant Carer Support Assets document was produced from the findings for use by the CSN.

Task 1B) Stakeholder operationalisation of CSN role

A Person-Based Approach to intervention operationalisation [99] was used ensure engagement with representatives of those who would access, work with, and enable the role (carers and care/support providers, managers, and commissioners). Carer workshops (n=2, plus one carer interview), cross-sector provider workshops (n=2), and a commissioner interview were undertaken to inform the CSN operational model. All data collection was conducted remotely: using an online platform (MSTeams or Zoom) or by phone. In total 15 participants with experience and knowledge of the locality took part: seven carers recruited via the voluntary sector; seven health/social care practitioners, managers and voluntary sector professionals; and one commissioner.

The workshops and interviews were guided by the Template for Intervention Description and Replication (TIDieR) [72,73] and Consolidated Framework for Implementation Research (CFIR) [89,90] i.e., CFIR-framed questions and prompts were included to identify upstream barriers and potential solutions. The findings were analysed within the participant groups and synthesised across the participant groups. The findings were used to produce a description of the stakeholder optimised CSN role (reported on the TIDieR template) and map implementation strategies to identified barriers and enablers.

In parallel, an ECCH Project Team was established to set up the post. The process, outcome and timeline were logged to provide feasibility data.

Stage 2: Value and impact of a stakeholder-operationalised Carer Support Nurse role and feasibility of a future wider implementation study

Within Stage 2, three tasks were undertaken to capture the value and impact of the stakeholder-operationalised pilot Carer Support Nurse role and feasibility of a future wider implementation study:

- Task 2A) CSN role data capture
- Task 2B) Carer outcomes and experiences of carers and patients
- Task 2C) Carer Support Nurse and cross-sector colleague experiences and impacts

Task 2A) CSN role data capture

The CSN was given a recruitment pack comprising an invitation letter, participant information sheet, and with reply by email (12/01/2023). The CSN job description informed candidates of the research being conducted alongside the role, and it was discussed at interview. The nurse had an opportunity to ask any further questions before informed consent was taken. See Box 14 for Task 2A inclusion and exclusion criteria.

Box 14: Task 2A Carer Support Nurse inclusion and exclusion criteria
Carer Support Nurse Inclusion Criterion: • The Carer Support Nurse
Carer Support Nurse Exclusion Criteria: • None

The CSN completed a very brief templated **Weekly Reflective Diary** [100,101] (what was done, what worked, what didn't) and **CSNAT-I Activity Template** (anonymised aggregated data on carer needs identified and types of actions taken) initially via Microsoft Forms but then reformatted as a Word document. **Monthly data-generating meetings** (informed by the data collected weekly) monitored role delivery and identified/addressed emerging barriers (first Monthly Meeting 06/02/2023). Data collected through the meetings included:

- referral numbers and sources (and repeat referrals)
- CSN's use of time (e.g., working hours, carer-/non-carer-facing activities)
- CSN enactment/modification of the five Evidence-based Design Principles
- actions in response to carers' needs
- potential impacts (costs and benefits) on the CSN/carers/patients/other services.

The data-generating meetings were not audio-recorded – instead data were transcribed by a study researcher directly onto a template used successfully in similar activities in other studies. The first was conducted in person, with most of the follow up meetings conducted via MSTeams.

Two additional meetings facilitated captured of the CSN's perceived activity. The method used was activity analysis using the Cassandra matrix [71] designed for specialist nursing practice. The Cassandra matrix captures perceived activity (e.g., types of nursing interventions, for whom, where) and is based on the a priori dataset of approximately 17,000 clinical nurse specialists and case managing nurses, such as District Nurses. It contains around 64,000 weighted interventions within a parse tree. Iterations of Cassandra since 2010, and its forerunner Pandora, have allowed a sampling of work (capturing most of the work, most of the time) to be developed which can then sample the activity of complex work [102]. In this current study we worked with the Carer Support Nurse to conduct a feasibility study to explore if Cassandra would be valid in this type of work, to understand its strengths and limitations.

Monthly anonymised aggregated process data were provided by the site at a group/system level (rather than for individual carers) from the SystmOne Business Intelligence Unit e.g., number of carers seen by the nurse, number of repeat contacts. A data sharing agreement was in place with the host site.

Task 2A data therefore sought to begin to evidence the value and cost of the role and help commissioners understand what activities are undertaken to achieve outcomes and the complexity of the work. It was collected to generate knowledge to facilitate future planning (e.g., population description, carer needs identified, actions taken to meet carer needs, costs, capacity, cost-per-carer) and inform the design of a future multi-site study.

<u>Task 2B) Carer outcomes and experiences of carers and patients</u>

Once the Carer Support Nurse was established in post with an optimal caseload (estimated as three months into post), carers who had had contact with the nurse were invited to participate in the study. Task 2B therefore overlapped temporally with Task 2A.

Carer baseline and outcome data were collected from adult carers who had contact with the nurse through a baseline and follow up postal survey, and interviews with a sub-sample of carers. Patients were also invited to take part in interviews.

Using the Task 2B inclusion and exclusion criteria (see Box 15), the Carer Support Nurse provided eligible carers with a recruitment pack for the study. This occurred through various routes e.g., by post (e.g., when sending an initial contact or appointment letter) or by hand – whichever was the earlier.

Box 15: Task 2B Carer inclusion and exclusion criteria
Carer Inclusion Criterion: • Adult unpaid carers who have been referred to, or who have contacted (self-referral), the Carer Support Nurse *Note: Although the CSN could see young carers as part of the role, the study only collected data from adult carers due to resource limitations. However, the number of young carers seen was recorded and will inform the design of a future multi-site study.*
Carer Exclusion Criteria: • Unable to understand or communicate in English • Serious mental health problem • Unable to give informed consent *Note: Although the Carer Support Nurse could see carers unable to understand or communicate in English as part of the role, the study sought only to collect data from those able to communicate in English due to resource limitations. However, the number of carers unable to understand or communicate in English seen by the nurse was recorded and will inform the design of a future multi-site study.*

The carer recruitment pack for the study include an invitation letter, participant information sheet, consent form and the baseline Carer Postal Survey Booklet. The participant information sheet included contact details for the research team should the carer have any questions. The invitation letter and participant information sheet invited carers to complete the baseline postal survey, a follow up postal survey, and potentially be contacted for interview: those willing to receive a follow-up postal survey, and/or potentially be contacted for interview, were asked to provide their contact details on a reply form. Carers could opt not to complete the follow-up postal survey but still to take part in the interview. No reminders were sent.

The **Baseline Carer Postal Survey Booklet** included:

- Preparedness for Caregiving Scale (8 items) [74]
- Warwick-Edinburgh Mental Wellbeing Scale (7 items) [75,76]
- EQ-5D-5L (6 items) [77,78] [EQ-5D registration ID: 52830]
- background questions: age, sex, ethnic group, number of people carer is supporting, living situation (i.e., with patient(s)/distance from patient(s)), relationship to patient(s), patient's(s') primary diagnosis, caregiving hours, employment status, funding status (receipt of funded care)

- resource use questions (in last 6 weeks) e.g., primary care, secondary care, social care, respite care
- a question asking whether they had already had contact with the CSN (as this could occur) and planned appointments.

The **Follow-up Carer Postal Survey Booklet** was mailed out (to those who had consented) to arrive approximately six weeks from the carer's first contact with the CSN. It included the Preparedness for Caregiving Scale, Warwick-Edinburgh Mental Wellbeing Scale, EQ-5D-5L and the resource use questions only (not the background questions). No reminders were sent.

Interviews with carers (and the patients they supported) who had received the CSN intervention explored their experiences of the CSN, ideally within two weeks [103] of their main CSN contact (approx. n=12 for information power [104]). Purposive sampling was proposed to seek maximum variation in carer sex, age, and ethnic group if a high number of responses were received. Data on the timing of interviews (in relation to contacts with the nurse) was collected to inform the design of a future multi-site study. Carers who earlier agreed to be contacted for interview, and who met the purposive sampling criteria, were contacted by letter, email, or phone (depending on their indicated preference) to invite them to be interviewed. No reminders were sent.

Patients were also invited to be interviewed (separately), via the carer. If the contact with the carer about the interview was by letter, then the patient recruitment pack was included with it to optionally share with the patient; if the contact with the carer was only by email or phone, the patient recruitment pack was sent to the carer to share with the patient if the carer agreed to this. The patient recruitment pack included an invitation letter, participant information sheet, with reply-options by email, post, or to give their reply at the start or end of the carer interview (if they were co-habiting). Patient inclusion/exclusion criteria are outlined in Box 16).

Box 16: Task 2B Patient inclusion and exclusion criteria
Patient Inclusion Criterion: • An adult identified by a Task 2B carer as the person they support in their caring role *Note: Although the Carer Support Nurse could see carers of children as part of the role, the study only collected data from adult patients due to resource limitations. However, the number of carers seen who supported children was recorded and will inform the design of a future multi-site study.*
Patient Exclusion Criteria: • Unable to understand or communicate in English • Serious mental health problem • Unable to give informed consent. *Note: Although the Carer Support Nurse could see carers of patients unable to understand or communicate in English as part of the role, the study only collected data from those able to communicate in English due to resource limitations. However, the number of carers of patients unable to understand or communicate in English seen by the nurse was recorded and will inform the design of a future multi-site study.*

Carers and patients had an opportunity to ask any questions before informed consent was taken (online or by post). The topic-guided interviews were conducted online or by phone, audio-recorded (with permission), transcribed, anonymised, then analysed using framework analysis [94]. The carer interview topic guide covered their caring role, support they may have had before contact with the Carer Support Nurse, their contact with the Carer Support Nurse, and what was helpful or unhelpful about it. The patient interview topic guide explored whether patients felt the Carer Support Nurse was helpful, or if anything was unhelpful, and any impact it had on them as the patient. The interviews will also help inform the design of a future multi-site study.

Task 2C) Carer Support Nurse and cross-sector colleague experiences and impacts

End of study interviews with the CSN and their line manager (interviewed separately) and focus groups with key cross-sector colleagues explored:

- the role (experiences of delivering it/working with it)
- role activity (e.g., carer-facing versus colleague-facing activity)
- enactment/modification of the five Evidence-based Design Principles
- perceived impacts (positive/negative)
- mechanisms of action for refinement of CSN model
- CFIR-framed questions and prompts to identify experienced multi-level barriers, enablers and strategies influencing implementation
- learnings for the design of a future multi-site study.

The line manager interview and cross-sector colleague focus groups *additionally* explored:

- impacts on own (or team members') awareness of/attitudes to/engagement with carers, subsequent to the CSN starting in post.

For Task 2C, the Carer Support Nurse was already recruited at Task 2A. The Carer Support Nurse's line manager was invited to take part in Task 2C via an emailed recruitment pack from the study team (see Box 17 for inclusion/exclusion criteria). The line manager was already in contact with the research team. The recruitment pack included an invitation letter and participant information sheet, with reply by email (directly back to the study team). An opportunity was provided to ask any questions before informed consent was taken. Both interviews were topic guided and audio-recorded (with permission): the Carer Support Nurse interview was conducted in person, and the line manager interview conducted online (via MSTeams).

Two focus groups were planned to involve key health, social and voluntary sector working partners (approximately n=9 participants in total; see Box 17 for inclusion/exclusion criteria). Fifteen key cross-sector colleagues were purposefully identified primarily from the CSN's role activity in the preceding months and supplemented through our Cross-sector Consultative Community (i.e., those stakeholders consulted during study work-up from across health settings, social care, voluntary sector, and HealthWatch). These cross-sector colleagues were invited to participate via an emailed recruitment pack (an invitation letter and participant information sheet) with reply by email. Eleven of the 15 stakeholders approached agreed to take part. Reminder emails were sent.

Due to the challenges of professional diaries, six smaller data collection events were conducted rather than the planned two focus groups: three focus groups (of 2-3 participants) and three one-to-

one interviews involving n=10 participants in total across the three sectors (a suitable date could not be found for one stakeholder within the data collection window). Data collection events for more than one stakeholder involved different stakeholder types i.e., a mix of health, social and voluntary sector professionals. They had an opportunity to ask any questions before informed consent was taken. The focus groups and interviews were topic guided and audio-recorded (with permission) and conducted online via MSTeams.

Box 17: Task 2C Inclusion and exclusion criteria
Carer Support Nurse Inclusion Criterion: • The Carer Support Nurse
Carer Support Nurse's Line Manager Inclusion Criterion: • The Carer Support Nurse's Line Manager or similar
Key colleagues from health, social care and the voluntary sector Inclusion Criterion: • Identified as a key colleague of the Carer Support Nurse from either health, social care or the voluntary sector, or a stakeholder (from health, social care, the voluntary sector or HealthWatch) who helped develop the role.
Task 2C Exclusion Criterion: • None

The interview and focus group audio-recordings were transcribed, anonymised, then analysed using framework analysis [94] incorporating the CFIR codebook (enables both inductive/deductive approaches).

Stage 3: Establishing mechanisms of action and effect and recommendations

The core team, CSN-PPI and CSN-PAG reviewed and synthesised Stage 2 learnings and CFIR actionable findings [89,90] to:

- explore mechanism of action and effect e.g., the CSN as (1) a direct care intervention, (2) a conduit for implementing CSNAT-I, and/or (3) a system designer/improver [105],
- develop and refine study recommendations
- inform any suggestions for optimising the CSN operational model reported on the Template for Intervention Description and Replication (TIDieR) [72,73].

The mechanisms of action and effect, and the recommendations, will also inform the design of a future multi-site study.

The study was registered on ClinicalTrials.gov (ClinicalTrials.gov Identifier: NCT05753072).

Ethical approvals

Ethical approval was sought separately for the two empirical stages: Stage 1 and Stage 2. Stage 1 did not recruit carers or patients via the NHS therefore NHS ethics was not required; ethical approval

was secured from University of East Anglia. Stage 2 involved recruitment of carers and patients via the NHS, therefore NHS ethics was required and secured.

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

For ethical approval purposes, the end of the study was the date of the final data collection activity outlined the relevant protocols. Completion of data analysis or publication of results was not considered the end of the study.

APPENDIX 2
Feasibility of a future wider multi-site implementation study

The third aim of the Carer Support Nurse pilot was to establish the feasibility of a future wider multi-site implementation study if the role showed promise. Box 18 shows the research question and objective related to the aim.

Box 18: Feasibility aim, research question and objective		
Aim 3)	Research Question 4)	Objective 7)
To establish the feasibility of a future wider multi-site implementation study if the role shows promise.	If the role shows promise, what learning should inform a future grant application to further develop and evaluate the role in a multi-site study?	To establish the feasibility of a future wider multi-site implementation study if the role shows promise.

Feasibility data were collected throughout Stages 1-2 and were reviewed by the Core Team, CSN-PPI, and CSN-PAG to develop recommendations for a future wider multi-site implementation study. The findings and recommendations are summarised in Box 19 below.

Box 19: Feasibility findings and recommendations		
Aspect/Task	**Finding/commentary**	**Recommendation**
Role set up time	ECCH Project Team convened between 30/05/2022 to 14/11/2022. CSN post first advertised 27/06/2022 – then required readvertising. CSN came into post 16/10/2022. First referral received 30/11/2022: six weeks from role commencement. First referral received 30/11/2022: six weeks from role commencement.	A future study should ensure adequate time for host organisation's set up time: job description, role advertising and appointment, then policy development.

Inclusion of study PI (Farquhar) in ECCH Project Team, CSN interview panel and CSN governance meetings	Enabled development of the CSN post in line with its intended design and embedding of research processes	A future study should follow this model and seek inclusion of senior research team member in host organisation's project team, interview panel and CSN governance meetings
Ethics and approvals timelines	Stage 1 submitted to UEA FMH ethics 02/07/2022 – green light to start given 09/08/2022 (5 weeks). Stage 2 submitted to NHS ethics 24/11/2022 – green light to start given 23/01/2023 (8.5 weeks – included Christmas period).	Ensure adequate time for NHS ethics and approvals – ideally funded time within a project
Stage 1 data collection	Task 1A aimed for n=10 cross-sector professional online interviews: all completed as planned.	No revisions required.
	Task1B aimed for n=2 online carer workshops (3-4 carers/workshop), n=2 online cross-sector professional (3-4 professionals/workshop), one online commissioner interview: all completed as planned, but with an additional individual online carer interview.	A future study should similarly allow for interviews as an alternative option to workshops to enable participation.
Stage 2 data collection	We estimated the Carer Support Nurse would be established in post with an optimal caseload by three months into post and used this as a guide to plan commencement of Stage 2A data collection from the nurse.	No revisions required.

	Collection of Stage 2A data from the Carer Support Nurse began 02/02/2023 with the first CSNAT-I Activity Template (first Monthly Data-Generating Meeting conducted in person 06/02/2023): 15 weeks from commencement in post (16/10/2022) and 10 weeks from first referral (30/11/2022).	
	The CSNAT-I Activity Template developed for Stage 2A was modified 14/02/2023 to remove duplicate questions (answered from other sources). In addition, the format was changed from MSForms to a Word version to enable repeated use by one nurse; this was emailed to the Carer Support Nurse every Thursday with a request for return by the following Wednesday.	A future study should use the modified CSNAT-I Activity Template and ways of enabling repeated use of an MSForms version by the same nurse could be explored, although the emailed Word version was acceptable.
	The study site was able to provide monthly aggregated activity outputs to the study team from the Business Intelligence Unit (Task 2A ECCH data), however the distinction between some of the categories in the data was unclear (e.g., the distinction between “Advice & support” and “Advice & guidance” in the activity categories reported in Table 4 was unclear). This data was entered by the Carer Support Nurse.	A future study should seek clarity, at an early stage, on the distinction between categories in any site-provided aggregated activity data to enable accurate completion by the CSN and interpretation by the study team.

	Data were sought to monitor reach to marginalised communities, but this was limited to IMD characteristics and ethnicity due to the small-scale pilot nature of the evaluation. No data were collected on other aspects of marginalisation e.g., physical/mental/learning disability, sexual orientation.	A future study should explore collecting a broader range of data to enable more comprehensive monitoring of reach to marginalised communities.
	Task 2A Cassandra data (Activity Analysis): the study exposed areas of congruence with the model, and also areas in which different levels of the parse tree would need to be used – for example more interventions in the social domain.	A future study should make the suggested modifications.
	CSN feedback on completion of the Task 2A Cassandra data collection (Activity Analysis) identified the challenge of doing this within the first 6 months of the pilot role, and for one person.	A future study should consider the optimum timing of Activity Analysis data collection to capture the role when more optimally established. A future study should ideally collect Activity Analysis data from more than one CSN.
	Carer eligibility criteria for the evaluation excluded young carers and any carers who were unable to communicate in English due to resource limits (although the CSN took referrals for carers with these characteristics).	A future study should seek to work with eligibility criteria that reflect the full range of potential CSN referrals.
	We estimated the Carer Support Nurse would be established in post with an optimal caseload by three months in post and used this as a	No revisions required.

	guide to plan commencement of Stage 2B data collection directly from carers who had had contact with the nurse. The first mail out to carers was 10/02/2023, 16 weeks from commencement in post (16/10/2022) and 11 weeks from first referral (30/11/2022).	
	We estimated that the Carer Support Nurse would see approximately n=120 carers during the planned 6-month data collection period for Task 2B (based on the community matron model) – the CSN saw approximately two thirds of the estimate during this 6-month period.	A future study should work on an evidence-based estimate of 80 carers per 6-month period (within the first year and with the CSN pilot model of one nurse for a similar locality).
	The Carer Support Nurse needed to mail out the carer recruitment packs separately to carer appointment letter as the letters were sent out on a rota by varying PCH admin teams and so may not have been sent out by her base where the carer recruitment packs were located. To help with this she printed batch of cover letters then wrote in carer name and date.	A future study should seek to clarify the process of appointment letter mail out and could explore including the carer recruitment pack within this.
	A 32% response rate was achieved for the carer baseline survey. Commentary from others working in carer research and carer support suggest this was a high response rate	A future study could offer an online survey option in addition to postal. A future study could revise the eligibility criteria to include the additional reasons for non-mail out and could explore ways to collect carer outcome/impact data for referrals where the CSN was able to provide the needed advice or support during the initial phone call.

	for these carers, given their circumstances. Working with the eligibility criteria, the number of carer recruitment packs the CSN mailed out was n=57, and 18 baseline surveys were returned (postal). In addition to the eligibility criteria, packs were not sent out to carers who were out of area, where the reason for referral was resolved prior to CSN input, for referrals where the CSN was able to provide the needed advice or support during the initial phone call. No reminders were sent for the baseline survey.	A future study could explore with a Carer PPI group the acceptability of reminders being sent for the baseline survey.
	Completion of baseline surveys sometimes occurred after the carer was first seen by the CSN (due to logistics). In addition, some carers (Task 2B) and stakeholders (Task 2C) identified that very existence of the CSN, and process of referral to the CSN, had a positive impact even before their first contact. Therefore, the carer baseline survey was not a true baseline for some carers.	A future study design should seek to optimise ways to achieve, or get closer to, the true baseline for as many carers as possible.

	Of the 18 carers who returned baseline surveys, 15 carers agreed to be sent a follow up survey and 11 agreed to be sent an invitation to interview. Some carers were therefore willing to complete a survey but not to be interviewed. It is not known whether some would have been willing to be interviewed who did not complete the survey.	A future study could reduce respondent burden could by offering the carer interview as an alternative to the follow up survey but including follow survey questions within the interview if timings allow.
	Of the 15 carers who agreed to be sent a follow up survey, n=9 were returned. No reminders were sent for the follow up survey.	A future study could explore with a Carer PPI group the acceptability of reminders being sent for the follow up survey.
	The survey data demonstrate it was feasible to collect Preparedness for Caregiving Scale data from carers at baseline and follow-up.	A future study could continue to include the Preparedness for Caregiving Scale if the outcome, and outcome measure, remain relevant.
	The survey data demonstrate it was feasible to collect Warwick-Edinburgh Mental Wellbeing Scale data from carers at baseline and follow-up.	A future study could continue to include the Warwick-Edinburgh Mental Wellbeing Scale if the outcome, and outcome measure, remain relevant.
	The survey data demonstrate it was feasible to collect EQ-5D-5L data from carers, with a complete utility value generated for 9/10 follow-up respondents.	A future study could continue to include the EQ-5D-5L if the outcome, and outcome measure, remain relevant.
	The survey data demonstrate it was feasible to collect resource use data from carers.	A future study could continue to include resource use questions if this baseline descriptive data and outcome data remains relevant. A future study could reduce participant survey burden by removing ‘community/district’ nurse contacts (as none were reported), relying on participants to use the ‘other healthcare

	A high proportion of carers completed the questions concerning GP and practice nurse contacts, with a completion rate ≥83% (Appendix 7 – Table 13). For baseline carers (all and those responding to both surveys), fewer carers completed the remaining primary care contact questions (50-72%). Secondary care contacts had a 100% completion rate for both baseline (all carer participants and those responding to both surveys) and follow-up surveys (Appendix 7 – Table 13). No one reported overnight hospital stays. It is possible 'hospital day cases' were included by carers within 'outpatient clinics' – it may be best to extend the label (e.g., "Outpatient clinic or day case"), or add a further category in the surveys (Q.4).	contacts' to report this. 'Other healthcare' and 'other social services' had the lowest completion rates; these two categories could be grouped together to further reduce participant burden. A future study could extend the "Outpatient clinic" label (e.g., "Outpatient clinic or day case"), or add a further category in the surveys (Q.4).
	The health economic data collected were limited due to the pilot nature of the project, but key learning was achieved in relation to collecting and processing this data which will inform future study designs.	In line with wider considerations, a future economic evaluation would need to address the identification of a suitable comparator, and how to go about recruiting the related participants – this will be challenging in this setting, as one of the issues is carers not coming forward for support and the lack of a dedicated alternative. Beyond on this key consideration, subject to considerations of participant burden, it would be valuable to: - Collect some wider resource use information e.g., use of non-NHS and Personal Social Service services (such as respite care and other charity support) and also capture the impact on prescription use;

		- Increase the time horizon (the period of follow-up) as the six-week follow-up may not capture all the impact (both costs and benefits) of the CSN role, particularly as the CSN supported some patients beyond six weeks; - Investigate the use of routinely collected patient data (e.g., GP records or hospital episode statistics data sets) to help reduce participant burden; - Consider using a quality-of-life measure beyond the EQ-5D-5L, such as the ICECAP https://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/index.aspx
	Of the 11 carers who agreed to be sent an invitation to interview, n=7 were interviewed (one interview yielded minimal data). No reminders were sent for the carer interviews.	A future study could explore with a Carer PPI group the acceptability of reminders being sent for the carer interviews.
	Purposive sampling was proposed for the carer interview sample to seek maximum variation in carer sex, age, and ethnic group should a high number of responses be received: n=7 carers agreed to interview (n=6 interviews were conducted) therefore purposive sampling was not possible. Recently bereaved carers (whose bereaved status was not known to the study team until arranging the interview) volunteered to be interviewed – they wanted to share their experience of seeing the CSN.	A future study should retain the purposive sampling plan but acknowledge that it may not be possible. It should be aware that the sample may include recently bereaved carers.
	Only one patient agreed to be interviewed. It is not known how many carers passed a recruitment pack onto the person they cared for (in hindsight we could have asked this question at the carer interview,	A future study should consider not seeking patient interviews. Not seeking these would streamline the carer recruitment pack and may, as a result, increase the carer response rate.

	although three carers reported that the person they supported had recently died). The one patient interview generated limited data. The Carer PPI Group were asked for their thoughts on this low uptake and advised that it may be the carer preference or may reflect patients' ability to participate.	
	Task 2C aimed for two stakeholder focus groups (of approximately n=9 participants in total). Sixteen recruitment packs were emailed out and 12 agreed to take part (75% agreement rate): 11 participated (one was unable to due to their diary) – a high response rate was therefore achieved. Those that did not respond had had limited direct contact with the CSN. Due to busy diaries, it proved impossible to group these 10 participants into two focus groups, therefore six data collection "events" were conducted: n=3 one-to-one interviews, and three small focus groups (with n=2-3 participants in each, with a mix of sectors in each group). This approach worked very well, enabling coverage of a number of topics and time for exploration and discussion. The duration of the data collection element of each interview/focus group (i.e., the	A future study should aim for small focus groups and include interviews as an option. The duration of the data collection element of each interview/focus group reported should inform transcription costs.

	transcribed portion) was: 19:58, 25:26 and 26:32 for the interviews and 38:17 (two person focus group), 47:22 (three person focus group), and 49:30 (two person focus group). Reminders were sent and positive responses received. Cross-sector representation was achieved.	
Intervention fidelity	Intervention fidelity was not directly observed but assessed via the multiple sources of data.	A future study could consider audio-recording a sample of Carer Support Nurse consultations.
Possible Mechanisms of Action	A set of possible Mechanisms of Action were proposed based on the pilot findings to inform an initial logic model for a programme theory.	A future study should seek to test and refine the proposed Mechanisms of Action and logic model for a programme theory.
Outputs	A range of outputs were delivered during the pilot which helped to raise the profile of the role, and further are planned for post-pilot. Task 2C stakeholders were asked how they would like to receive the findings of the evaluation in addition to a standard report – suggestions to boost engagement and accessibility included an executive summary at the front of the report, a short narrated PowerPoint, short video (potentially including the Carer Support Nurse), a podcast, and animation. They also noted the need to pitch to different audiences with different needs, and that some carers might also be interested in the	A future study should seek to deliver the range of outputs and methods of dissemination identified in the pilot but ensure that funded time and budget for their effective delivery secured.

	findings. The timeline for report preparation was very tight for the study team, however the team aims to deliver some of these additional outputs as time and budget allows.	
Study team	The study team benefitted from a range of skills, experience and methodological expertise.	A future study should form a similar study team profile but should ensure inclusion of skills related to any new methodologies used.
CSN PPI group	There was a good balance of men and women in the group but no further diversity (in terms of age, ethnicity). The model used for PPI engagement worked well (combining telephone, email, and online consultations). Zoom was preferred over MSTeams.	A future study should seek a larger carer PPI group to enable greater diversity. It should also follow the model of asking carers' preferences regarding the online platform used and note that a Zoom licence may be required (cost implication).
CSN Project Advisory Group	The project benefitted from a diverse (in terms of roles and expertise) membership across health, social care and the voluntary sector as well as academia, with some members holding regionally or nationally facing roles.	A future study should seek similar PAG membership.

APPENDIX 3
Carer Asset Map

Asset Map of organisations providing support for carers in Norfolk, Suffolk and nationally Resource for Carer Support Nurse (for nurse to update) (Not definitive[14] – informed by stakeholder consultations [Sept-Oct 2022] for Carer Support Nurse pilot)	
Organisation – Norfolk	**Services**
Carers Matter Norfolk (a network partner of carers trust, and a one stop umbrella for a number of organisations that includes Carers Voice, Caring Together, Voluntary Norfolk which together provide the services outlined) https://*carersmatternorfolk*.org.uk *Self-referral/referral from agencies* *Via phone 0344 800 8020 or online form* • Caring Together https://www.caringtogether.org/about-us • Carers Voice https://www.carersvoice.org • Voluntary Norfolk https://www.voluntarynorfolk.org.uk	• Advice Line – information & advice, listening support, peer support, form filling, emergency planning • Community support – a team of Family Carer Practitioners, based in Early Help Hubs (District Council offices) and in Norfolk County Council Adult Social Services offices, who deliver one-to-one support in the community and carry out Statutory Carers Assessments/ assist in completing Part B of the Carer's Assessment including creating an Action Plan • Carer training including access to the Carer Self-Help Hub • Health and well-being fund • Carers Matter Norfolk Handbook • Specialist support for young carers • Domiciliary/respite care • Carer Friendly Tick – scheme to encourage employers (health and community organisations) • Carer involvement in service design • Digital inclusion – training/tablet loan/funding to support purchase of equipment • Carer Ambassadors linked to Carers Voice who offer advice and support to other carers (rights, finance, services)

[14] Note: web-links and contact phone numbers may be subject to change

	• Carers Voice facilitates carer involvement in campaigns/projects/volunteering/service design
Norfolk County Council https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone *Self-referral/referral from agencies* 0344 800 8020 (main number including Adult Social Care)	• Norfolk Carers Charter • Carers Emergency card: https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/prepare-for-emergencies/emergency-carers-card • Swift (emergency response for example if carer needs to go into hospital) • Carer Assessment (Adult Social Care) • Information on website about other useful services (e.g., fire safety, meal providers, emergency social services, trusted trader) • Welfare rights unit (advice but also heal with appeals and tribunals etc)
Norfolk Family Carers (a network partner of carers trust) https://www.norfolkfamilycarers.org/ Self-referral/referral from agencies via phone 01603 219924 or info@norfolkfamilycarers.org	• Offers support to carers of all ages but with a particular focus on young carers • Telephone advice and support • Access to carers funds and grants • Supporting young people/carers • Provision of information for those caring at a distance • Supporting commissioners and funders

Carer Support Groups (or groups for carers and the people they support)	• Up to date information on current nature/location of various groups via Carers Matter and Carers Voice
	  ○ Golden Threads (bereavement group)
	  ○ Bradwell and Gorleston Carers group
	  ○ Carers Headspace (for people who care for those who have had a stroke)
	  ○ Chatterbox carers (Caister)
	  ○ Crafty Quackers Carers group
	  ○ Yarmouth Carers Group
	  ○ MS support Group
	  ○ Great Yarmouth Stroke Group
	  ○ Great Yarmouth Parkinson's Disease Support Group
	  ○ Shrubland Carers Group
	  ○ Music Makers (Christ Church in Yarmouth) – singing group for people with dementia and carers, or those who feel lonely and anxious

Care for Carers https://www.careforcarers.org.uk Self-referral Online form Peter and Christine Rowley 0300 777 8880 info@careforcarers.co.uk	• Charitable organisation that aims to support carers, carer support groups and carer organisations • Norfolk based but also seems to have a national outlook • Information and advice • Mutual help, co-operation and friendship • Carer information days
Alzheimer's Association (Norfolk) - specialist dementia support service in Norfolk for patients and carers https://communitydirectory.norfolk.gov.uk/Services/4242/Alzheimers-Society Self or agency referral 01603 736556 or norfolk@alzheimers.org.uk	• Specialist information and signposting • Bespoke specialist non-clinical support • Clinical support nurses for more complex needs • Dementia cafes and activities

GP surgeries
 	
Key Social Prescribing contact for carers (Alison Begley: alison.begley@nhs.net)
Referrals via primary health care professionals /self-referral/ other agencies, but only available to patients of Great Yarmouth and Northern Villages practices
	• Carers champions (in some surgeries)
	• Identification/coding of carers to enable easier access to some services (e.g., vaccinations) via carer register (in some surgeries) Social prescribing (Northern villages)
	• Social Prescribing
	  • Social Prescribing/Care Co-ordinators (based in GP surgeries in Great Yarmouth and Northern Villages)
	  • Signpost to support
	  • Supporting self-help
	  • Able to get back in contact after discharge if further help is required

Age Concern Norfolk https://www.ageuk.org.uk/norfolk/about-us/contact-us/ 01603 787111 advice@ageuknorfolk.org.uk	• Home visiting service to help claims with benefits including Attendance Allowance and carers allowance
Norfolk and Waveney MIND https://www.norfolkandwaveneymind.org.uk/	• Carer specific support worker – for people with mental health issues (Sarah Knight)

Self-referral/ referral via other agencies 0300 330 5488	• Support and signposting for carers of people with mental health issues • Carers groups
Norfolk and Suffolk NHS Mental Health Foundation Trust Referrals via clinicians, MIND and other carer organisations. Technically focused around working-aged adults but there is some flexibility Contact: Senior Carers Lead for people who care for people with mental health issues Howard Tidman (howard.tidman@nsft.nhs.uk)	• Individual support for carers • Carers group • Socio/educational groups • Residential for young carers • Supporting other HCPs to develop support for carers
Centre 81 https://www.centre81.co.uk/ 01493 852573 reception@centre81.com	• Supports people with disabilities and their carers • Provides opportunities for carers to have space and activities for themselves
West Norfolk Carers http://www.westnorfolkcarers.org.uk/ info@westnorfolkcarers.org.uk 01553 768155	• Carer Support Groups for people caring for people with dementia in Kings Lynn and Hunstanton
Great Yarmouth and Gorleston Young Carers Group Carers up to 18yrs old https://gygyc.co.uk/ 01493 650056	• Age specific peer groups • One-to-one mentoring
The Big C https://www.big-c.co.uk/ Self-referral 0800 092 7640	• Support for people with cancer and their carers • Listening ear for carers and family members and space for carers to go to for time on their own
Louise Hamilton Centre	• Palliative Care centre

Gorleston https://www.jpaget.nhs.uk/media/294456/bi-fold-services.pdf Self and agency referral 01493 453100	• Carer Lead whose role is to support family carers • Peer support group for carers
Great Yarmouth Borough Council – Independent Living Services www.great-*yarmouth*.gov.uk/independentliving Self-referral or via other agencies (Hospital discharge is via professionals only) 01493 856100	• Provides indirect support for carers through the provision of adaptations in the home (private and social sector) to help them remain living independently and well at home • Hospital discharge service providing fast track adaptations for people being discharged or at risk of being admitted • Community alarm (pendent) and monitoring service
Great Yarmouth Borough Council – Community Hub Self-referral or via other agencies Community Hub Helpline 0808 196 2238	• Collaboration between local voluntary and statutory services within the hub • Opportunities to raise individual carers who need support in order to develop a joint response • Community Champions (volunteers) informal route for identifying and referring people within the community for people in need of assistance
Organisation – Suffolk	**Services**
Suffolk Family Carers https://*suffolk*family*carers*.org Self/agency referral for a statutory carer assessment is via Suffolk County Council portal 01473 835477	• Information hub • Adult statutory carer assessment provider for Suffolk County Council • Emotional support e.g., one-to-one sessions, regular phone calls, workshops online coffee breaks • Practical help – respite, help at home, help with personal care • Access to training for the caring role • Access to wider social prescribing • Support for young carers
Suffolk Carers Matter *https://suffolkcarersmatter.org.uk* 01449 707030 info@communitiestogether-ea.org	• Carers' card • Tailored information, advice and guidance, emotional support, signposting • Counselling

Pear Tree Fund (based in Halesworth) Self-referral (for people living in north east Suffolk and south Norfolk) 01986 899655 infro@peartreefund.org https://peartreefund.org/	• Supports people with chronic conditions, mental health issues and at end of life, and their carers • Support and counselling • Provide advice and information on benefits, housing • Well-being activities/complimentary therapy • Physical care for people living in Halesworth • Pear Tree Centre (one stop centre for advice and support) in Halesworth
Suffolk County Council https://www.suffolk.gov.uk/care-and-support-for-adults/caring-for-someone/help-for-carers/	• Adult Carer assessments (starting point) • Carers' Strategy 2022-27 • Website with information about emergency planning, finances, respite, and generic support services (lunch clubs etc.)
Alzheimer's Association Suffolk 01473 237301 suffolk@alzheimers.org.uk	• Information and emotional support over the phone • Dementia cafes
Halesworth Dementia Carers Fund https://halesworthdementia-cf.com/ information.hdcf@btinternet.com	• Provide respite care for families who look after people with dementia • Carer Support group
Organisation – National (Carer Specific)	**Services**
Carers UK https://www.carersuk.org Helpline 0808 808 7777 advice@carersuk.org	• Helpline • Factsheets • Opportunity to take part in campaigning • Online forum
Carers Trust https://carers.org	• Online information for carers (e.g., benefits, caring for someone with a specific condition, working and learning etc.)

	• Partners with a network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes and raise awareness and influence policy. • Information about more local services
Mobilise https://www.mobiliseonline.co.uk/mobilise-community	• Online Facebook page/chat for carers • Information about finances/caring role
Sibs https://www.sibs.org.uk/about-sibs/	• Supports young and adult siblings in a caring role • Provides information, support, and training on sibling issues for adult siblings, young siblings, parents, and professionals
Organisation – National (Condition Specific)	**Services**
Silverline Helpline 0800 470 8090	• 24-hour telephone service for older people across the UK offering support, friendship and conversation for older people
Age UK https://www.ageuk.org.uk/	• Telephone Befriending Service • Advice and information • Links to local Age UK services
Stroke Association https://www.stroke.org.uk/finding-support Helpline 0303 303 3100	• Information for people caring for stroke survivors
Alzheimer's Association (national) https://www.alz.org/ 0800 272 3900	• Information for carers • Educational programmes for carers
British Lung Foundation https://www.blf.org.uk/search/site/carers 0300 222 5800	• Information for carers
British Heart Foundation https://www.bhf.org.uk/informationsupport	• Advice and information • Local groups for patients and carers

0300 330 3322 heretohelp@bhf.org.uk	
MIND https://www.mind.org.uk/	• Online advice and information on supporting someone with a mental health issues • Carer mental health • Advice for carers re. specific issues relating to mental health (e.g., anger problems or anxiety attacks)
Other Support Organisations	**Services**
Gorleston MESH – neighbourhood support https://carenav.co.uk/norfolkandwaveney/mesh-gorleston/ Self-referral	• Support with wide range of community issues (e.g., parking and befriending)
Access Community Trust (Lowestoft) https://www.accessct.org/ 01502 527200 Self-referral	• Access provides a range of services for young people and adults including housing related support, helping with learning, development and employment, and providing support with mental health and well-being
Local libraries	• Drop-in groups/Just a cuppa
Acorn Centre (Great Yarmouth) https://www.acgy.org.uk/ Self-referral 01493 262052 or online form	• Lots of social activities/lunch clubs • Haircuts, foot help, health advice • Legal services
DIAL (Great Yarmouth) https://www.dial-greatyarmouth.org.uk Self-referral or via another agency	• Benefit, debt, work advice and support

01493 859900 info@dial-greatyarmouth.org.uk	
Halesworth Volunteer Centre https://www.halesworthvc.co.uk Self-referral 01986 875600	• Access to volunteer provided transport for carers
Age UK (Norfolk) https://www.ageuk.org.uk/norfolk/ 01603 787111	• Befriending • Information and advice • Digital inclusions
Active Norfolk https://www.activenorfolk.org/public/get-active/active-disability/	• Accessible exercise and activities (including people with disabilities/carers etc.)
Monument project https://www.norfolk.gov.uk/out-and-about-in-norfolk/monument-project	• Opening up outdoor spaces for people including those with disabilities and their carers

APPENDIX 4
Dissemination and outputs log

Box 20: Carer Support Nurse pilot evaluation outputs			
Type	Details	Audience	Notes
Talk	Great Yarmouth Health & Well-being Partnership (online via MSTeams) 14/11/2022	33 cross-sector	Carer Support Nurse concept very positively received and those present keen to hear more as the pilot progresses.
Talk	Carers' Rights Day (Kings' Centre, Norwich) 24/11/2022	4+ vol sector 3+ health care 1 social care 1 carer	Carer Support Nurse concept very positively received and those present keen to hear more as the pilot progresses.
Blog	UEA Health & Social Care Partners UEAHSCP – invited blog https://t.co/Ebh9LukvGY 14/12/2022	UEAHSCP's audience	Promoted by UEAHSCP via Twitter: https://twitter.com/UEAHSCP/status/1603027297958764546
Talk	Carers' Voice: Carer Involvement Meeting (online via Zoom) East locality meeting 08/02/2023	4 vol sector 1 social care 1 carer	Used opportunity to encourage carer self-referrals. Shared handout version of slides afterwards. Carer Support Nurse concept very positively received. Keen to hear more as the pilot progresses.
Talk	Carers' Voice: Carer Involvement Meeting (online via Zoom) North locality meeting 01/03/2023	4 vol sector 1 social care 8 carers	Led by Sharon Brookes Used opportunity to encourage carer self-referrals. Shared handout version of slides afterwards. Carer Support Nurse concept very positively received. Keen to hear more as the pilot progresses. Keen for it to be introduced in North Norfolk.
Web piece	UEA School of Health Sciences' Success Highlights website	UEA website users	https://www.uea.ac.uk/web/about/school-of-health-sciences/business-innovation-and-skills/success-highlights

	May 2023		
Award & press coverage	NHS Parliamentary Award – Nursing & Midwifery category April 2023 submission	Politicians NHS staff General public	Won the regional award for the East of England (June 2023): https://nhsparliamentaryawards.co.uk/shortlist/ ECCH press release (14/06/2023) led to local press coverage e.g., https://www.edp24.co.uk/news/23589532.norfolk-carer-support-service-nominated-national-award/ Norfolk carer support service nominated for national award | Eastern Daily Press (edp24.co.uk) UEA coverage: https://my.uea.ac.uk/news/-/article/award-winning-carer-support-nurse-role-developed-by-uea-led-team
Award	Royal College of Nursing RCNi Award – Innovations category April 2023 submission	Nursing profession	Shortlisted for the RCNi award in the "Innovations" category as one of 75 finalists from 900+ applications – July 2023: https://rcni.com/nurse-awards/finalists-2023 Attended award ceremony in Liverpool Cathedral 10th November 2023
Recognition	NIHR ARC East of England (EoE) Added Value Example	NIHR	One of just three Added Value Examples (AVEs) included in NIHR ARC East of England's annual report to NIHR 2022-23 (April 2023)
Recognition	NIHR ARC East of England (EoE) Bite May 2023	NIHR ARC EoE audiences	Bites are short promotional pieces about key projects within the NIHR ARC EoE portfolio that are used at conferences, ARC EoE Impact Showcases and on the ARC EoE website.
Blog	NIHR ARC East of England (EoE) blog for Carers' Week 2023	NIHR ARC EoE audiences	Developing a new nursing role to support carer's health needs | ARC East of England (nihr.ac.uk)
Talk & poster	NICHE (Norfolk Initiative for Coastal and rural Health Equalities) & Norfolk & Waveney ICS national conference 14th September 2023	110+ delegates – health & social care professionals, researchers	Abstract submitted June 2023 – accepted for oral and poster presentation John Innes Centre, Norwich https://www.uea.ac.uk/groups-and-centres/projects/niche/events/ics-conference-2023
Talk	Norfolk & Norwich University Hospital 34th Palliative Care Conference 24/05/2023	150 delegates – health & social care professionals, researchers	Invited presentation on "Supporting unpaid/family carers using evidence-based interventions" included the Carer Support Nurse pilot. John Innes Centre, Norwich
Talk	Lancashire and South Cumbria Stroke and Neurorehabilitation Patient and Carer Group	N=10: mainly carers + Stroke Association Engagement Lead, Change Transformation	Very positive response from carers and professionals

	14th July 2023	Lead for ICS, Programme Manager for Networks	
WEDPage entry	NIHR ARC East of England (EoE) wEDPage	NIHR ARC EoE audiences	https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/palliative-and-end-life-care/carer-support-nurse-pilot
Talk	Norfolk & Waveney ICS Carers' Conference 2023 (online via Zoom) 27th September 2023	N=40 – mainly carers & voluntary orgs	Very positive response from carers and voluntary organisations
Feature	NIHR ARC East of England (EoE) annual report 2022-23 September 2023	NIHR ARC EoE audiences	Listed as a highlight on page 5 Full page feature on page 17 See link below[15]
Feature	NIHR ARC East of England (EoE) example of project in an ARC EoE populations-in-focus areas September 2023	NIHR ARC EoE audiences	Shared on the ARC EoE website and within their populations-in-focus review
Talk	NIHR ARC East of England (EoE) showcase 20th September 2023	NIHR ARC EoE audiences	Co-presented with the Carer Support Nurse
Talk	Norfolk & Waveney ICB Patient experience meeting 3rd October 2023	N=11 patient & carer experience leads	Co-presented with the Carer Support Nurse
FORTHCOMING			
Talk	ICS National Carers Leads Catch Up Call 14th Dec 2023	ICS National Carers Leads	Invited to present pilot findings
Abstract submitted	Marie Curie 2024 conference	National charity, health care professionals, researchers, PPI	Awaiting outcome

[15] https://arc-eoe.nihr.ac.uk/sites/default/files/documents/ARC%20East%20of%20England%20Annual%20Report%202022%202023.pdf

Abstract submitted	European Association for Palliative Care 2024 conference	International health care professionals, researchers, and organisations	Awaiting outcome

APPENDIX 5
Brief case studies of CSN work with referred carers

Case Study 1 (source: Task 2A CSN)
CSN saw a lady caring for her adult son who is profoundly deaf and now losing his vision. The carer indicated to the CSN that she would like help with knowing what to expect in the future. She highlighted how prior to the problems with his sight the son was able to lead a fully independent life but is now increasingly dependent on his mother to help with cooking, medication etc. The carer was worried that when she is no longer able to support him there could be a 'crisis' response that didn't take account of his many strengths. She was also worried that he was potentially at risk of losing the home (and neighbourhood) with which he was familiar. As a result she was wanting to set up some kind of advance planning. She had previously been in contact with services but had not been able to access the support she needed. CSN was able to link her up with the Sensory Support Team who could help them put together an advance care plan based around the son being able to live independently in his home. The CSN was also involved in negotiating consent issues.

Case Study 2 (source: Task 2B carer interview 12)
Carer was a young woman whose partner has early onset dementia. She described how since the diagnosis she has increasingly taken on all roles managing their day-to-day life (cooking, driving finances) as well as helping her partner with personal care. She is also working. Overall, she described feeling very overwhelmed and receiving very little practical or emotional support since her partners diagnosis. In addition, she feels increasingly isolated from her friends and there are few people her age who are in a similar position. A friend suggested she see one of the memory impairment nurses who in turn introduced her to the CSN. She described highlighting her social isolation (via CSNAT-I) and the value the CSN brought in terms of 1) being listened to and having someone understand her situation, 2) being given information about a range of support services (including emergency planning), 3) being enabled to access some well-being services for herself and 4) facilitating gym sessions for her partner via the social prescribing services (enabling her to have some time for herself). Reflecting back, she felt that she would have benefited from a service like this from the point that she began to become concerned about her partners health, in order to help her make sense of what was happening and access appropriate services for both of them. In terms of her current support needs she described how the CSNAT booklet prompted her to think about how her needs had changed and she felt this would be a useful exercise to repeat in the future. *"It was nice to have someone actually come round to the house, because that's the first person that's really ever been round here. It was nice for someone to come to the home and see if there was more [support needed].*

Case Study 3 (source: Task 2B carer interview 08)
The carer and cared for person were a retired couple. The husband had diabetes and vascular dementia, and as result had frequent falls, was forgetful, incontinent, had a high number of infections and poor mobility. The carer recounted how her carer role involved sorting out his medication, assisting with his personal care, driving him to appointments and monitoring him at night in case of falls. She has also had to take on full responsibility for the day-to-day management of the household. Despite this she talked about having no support (other than family) for either

herself or her husband prior to meeting the CSN, resulting in her feeling tearful and sleep deprived.

She was referred to the CSN by a psychiatrist who was involved in her husband's dementia care. During her initial meeting the CSN identified that she was probably depressed and facilitated contact with the GP who was subsequently able to prescribe medication and signpost her to counselling services. In addition, she talked about how the CSN provided her with information about a range of support groups and services which she didn't feel able to access right away but which she was pleased to know about. A key value however was also the opportunity to talk to the CSN about what she was experiencing and in particular the anger she felt towards her husband for having neglected his health – feelings which she found difficult to share with anyone else. She was pleased that she could have on-going contact with the CSN if needed.

"No, I thought that she [the CSN] was very patient and just worked through her things that she needed to do and listened, and we chatted, and I think she understood where I was coming from and what the situation was. So I would say very helpful, because at the end of the day if you find yourself in a situation where then you think, "Well, I do need some help," it's knowing that there's someone there. Even if she can't help herself, she can probably get the help for you from somewhere else, sort of thing. It is always good to have a contact point and someone that you can turn to, and sometimes also outside the family. You can say things to someone who's not emotionally attached, shall we say, that you can't say to your family because you hold back a lot of stuff from your family, because you don't want to upset them and you don't want to worry them."

Case Study 4 (source: Task 2A CSN)

A referral to the Carer Support Nurse was received from Community Neurology Team. Mrs X was the unpaid Carer for her husband Mr x who has Parkinson's disease and his condition is beginning to deteriorate. Both were worried that Mr X may not be able to stay at home as he has fallen recently. Mrs X had her own long term health conditions including high blood pressure and she was awaiting a knee replacement which she was putting off due to caring responsibilities. As a result of this she was experiencing continuous pain and was finding it was affecting her mobility and ability to drive.

She identified her unmet needs as both her and her husband are feeling socially isolated, she was worried about the suitability of their home, she wanted to have her operation as she was feeling unwell, but Mr X did not want to go into respite. They are both worried about the future.

Together, the CSN and Mrs X discussed her unmet health needs. She was taking more pain relief and felt it was making her 'wobbly and tired'. Blood pressure check was conducted and was low, although Mrs X reported being well hydrated, so the CSN escalated to the GP to review the blood pressure prescription.

They explored options available for support when Mrs X has her operation. Mr & Mrs X did not realise they would have a choice of support in the home; it was also likely that family would be happy to stay with Mr X overnight. They both felt that this would be less of a burden for their daughter who works full time.

Mrs X was introduced to Parkinson support groups in the local area for both carers and the cared for person, along with a local organisation who would provide prebooked transport with adapted vehicles at a travel cost only (which is considerable cheaper than a taxi). Mr X would then also be

able to travel with his motorised chair. Mrs X did not realise that this local service existed and felt it would do them both good to get out.

Adaptations to the property were also discussed and it was agreed that a referral to Occupational Therapy would be of value. Mrs X was reassured that all Healthcare professionals will support to keep Mr X at home unless he was at risk.

Mrs X was referred to Carers Matter who complete Carers' Assessments on behalf of social services. This would help her plan for future and arrange support while she has her operation and recovery.

Following this, her GP requested daily monitoring of her blood pressure and reduced her prescribed medication (under ongoing review) and she is feeling much better. They are considering joining a support group after her operation and are awaiting an appointment with the community OT.

APPENDIX 6

Completed Template for Intervention Description and Replication (TIDieR[72,73]) for the Carer Support Nurse role

Key elements of the Carer Support Nurse role and its delivery summarised according to TIDieR	
TIDieR guideline item	**The Carer Support Nurse** [v1.0 28/11/2023]
1. Brief description:	The Carer Support Nurse is a specialist nursing role with advanced assessment skills to support unpaid carers with complex needs and cross-skill other healthcare professionals in carer identification and support.
2. Why: Rationale, theory and goal of the elements essential to the intervention	**Rationale:** Unpaid carers provide unpaid care, help, or support to family members or friends with support needs. They help to keep some of our most vulnerable members of society out of hospital, provide health and social care for them, and improve their quality of life. The personal care, practical and emotional support they provide reduces formal care costs and is valued at £132 billion annually (close to the NHS annual budget). However, sustainability is threatened by economic, welfare or social trends, and negative effects on carers' health, including premature mortality. Carers can experience uncertainty, and lack role preparedness and confidence, leading to anxiety and impacting their ability to ask for help. Many lack access to services remaining unnoticed or invisible until a crisis occurs. Carers can be ambivalent about their own needs, putting patients' needs first, neglecting their own health and well-being. Time-limited healthcare professionals similarly prioritise patient need. Carers' health-related support needs are exacerbated when caring is prolonged, when there is uncertainty or complexity, and in marginalised communities at risk of unequal healthcare access. Carers need support to sustain their own health and well-being (support for self) and boost their skills/confidence (support to care). A dedicated Carer Support Nurse role (a specialist community nursing role with advanced assessment skills to support carers with complex needs and cross-skill other healthcare professionals) could address carers' support needs (support for self and support to care), help ameliorate crises, and reduce associated patient and service impacts. **Theory:** The Carer Support Nurse role is underpinned by two key pre-requisites: 1) that it is dedicated to carers, and (2) that it is a registered nurse. Dedication to carers is key due to (a) carers' reluctance to "bother" healthcare professionals particularly in non-

	emergencies during what they see as the "patient's time", and (b) nurses' difficulty supporting carers within their patient-led roles (due to limited time). Dedicating the role to carers legitimises carers' help-seeking, overcoming their reluctance to seek support, and legitimises engaging in carer support for healthcare professionals too. A registered nurse fulfilling the role is key as nurses have the knowledge and expertise to support carers' health-related support needs, particularly when complex. Most carer interventions only target psychosocial or psychoeducational needs, not health-related needs. Whilst any dedicated trained person could increase carer visibility and meet some carer support needs, the holistic nature of nursing combines need-identification, physical and mental health assessment and support, self-care and case management at the expert level. Further, the Carer Support Nurse role is underpinned by Five Evidence-based Design Principles (EDPs): EDP-1) Community-based (within existing teams) EDP-2) Cross-sector working (health/social/voluntary; 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 (carer health and upskilling them to care), through delivery of the evidence-based CSNAT-I (complements local authority assessment) EDP-5) Cross-skilling other HCPs e.g., best practice in carer support (distributes benefits for greatest impact) **Goals:** The goals are (1) to provide person-centred care to carers (prioritising complex cases), identifying and addressing their health-related needs (carer health and wellbeing, and upskilling them to care where needed), and (2) to cross-skill other healthcare professionals in best practice in carer support (to distribute benefits for greatest impact).
3. What – intervention materials:	The Carer Support Nurse provides person-centred care to carers, identifying and addressing their health-related needs (carer health and wellbeing, and upskilling them to care where needed). To achieve this, all appropriately referred carers (unless immediate crisis management required) should be offered the opportunity to participate in the evidence-based Carer Support Needs Assessment Intervention (CSNAT-I: https://csnat.org/) which complements Local Authority carers' assessment. CSNAT-I is delivered through a five-stage person-centred process of assessment and support (the five stages are described at https://csnat.org/). CSNAT-I uses an evidence-based, comprehensive tool (the CSNAT) comprising 15 domains (broad areas of support need) presented to carers as a set of questions within a booklet called the 'About you' booklet. The booklet (the CSNAT) enables carers to identify, express and prioritise domains where they need more support. A needs-led conversation, informed by the carer-completed booklet, then explores the carer's individual needs and what they feel would be helpful, enabling the delivery of tailored support. Essential materials for Carer Support Nurse therefore include: • CSNAT-I training:

	All practitioners who deliver CSNAT-I must complete CSNAT-I training. Training is available online via the CSNAT-I website at https://csnat.org/training-for-use-in-practice/ (no cost) • Carer Support Needs Assessment Tool (CSNAT)/'About you' booklet: The CSNAT is a designed-for-purpose, validated tool comprising 15 evidence-based questions (each relating to a broad domain of support need) to help carers consider and prioritise areas where they may need more support in preparation for the CSNAT-I needs-led conversation. It is presented to carers as the "'About you' booklet". • CSNAT Licence: The CSNAT is protected by copyright, and a licence required for its use (free for not-for-profit organisations). This can be requested via the CSNAT-I website at https://csnat.org/licensing/ once CSNAT-I training has been completed. • CSNAT-I Support Plan: The CSNAT-I Support Plan is a document or framework used for recording the outcomes of the CSNAT-I needs-led conversation. The Support Plan documents the actual support needs of the individual carer and the supportive input (to be) provided. The CSNAT-I Support Plan is provided to CSNAT-I trained practitioners, with the CSNAT, once a licence is in place. • Other appropriate evidence-based tools can be used by the Carer Support Nurse with the carer on an individual basis such as for wellbeing assessment if indicated e.g., Depression scale PHQ-9, Anxiety GAD-7 (this not an exhaustive list of assessments, but examples of what can be used). • Referral process: A referral process (including a referral form) is required that enables self-referral by carers and referrals from health, social care and the voluntary sector. • Records system: A records system is required to record assessments and outcomes. A "carer unit" was set up in SystmOne (electronic health record system) which included (1) an Initial Generic Assessment template and (2) the fields of the CSNAT-I Support Plan (through an alternative functionality questionnaire in SystmOne). • Transport: The Carer Support Nurse requires mileage or travel reimbursement/access to transport, in order to conduct home visits. A mobile phone, laptop for offsite working, risk assessment and lone-worker policy should therefore also be in place. • Clinic base for clinic-based appointments. • Standard clinical equipment for health screening as required e.g., sphygmomanometer. Optional materials for Carer Support Nurse: • Updatable information sheet for the Carer Support Nurse listing local and national agencies and resources that offer support for carers that could be signposted to or referred to.

4. What – intervention procedures:	1. Referral: • Referrals can come from anywhere: health care, social care, the voluntary sector, or self-referral. • A referral mechanism was established and was outlined on the service's website: https://www.ecch.org/our-services/carer-support-nurse/ • Referral criteria: 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. • Following referral, the carer was triaged. If the referral was deemed inappropriate the referral was be returned to the referrer identifying reasons for the rejection. 2. The Carer Support Nurse carer-facing aspect of the role: • The Carer Support Nurse should work with the carer to complete all five stages of the person-centred Carer Support Needs Assessment Tool Intervention (CSNAT-I: https://csnat.org/), in addition to other assessments (including using validated assessment tools) as required, resulting in the co-creation (with the carer) and actioning of a CSNAT-I Support Plan. • The Carer Support Nurse may also directly deliver supportive or clinical input – where this occurs it is likely to include (but not be restricted to) clinical assessment of carer, active listening, reassurance, providing information, giving advice and guidance, and upskilling the carer to provide direct care where needed. • The Carer Support Nurse may also signpost the carer to other agencies, refer the carer on, and/or liaise with the cared-for person's clinical or care team. • The Carer Support Nurse should have follow-up contact with the carer to assess outcomes. • The Carer Support Nurse should liaise with the referrer regarding outcomes. • The Carer Support Nurse should discharge from the service where possible, ensuring the carer either has their current support needs met or has a plan in place to help meet those needs (which may include referral on as appropriate, subject to consent). Carers can be re-referred (including through self-referral). 3. Within the role, the Carer Support Nurse should also works to cross-skill other healthcare professionals in carer identification (increasing their awareness and acknowledgement of carers) and support.
5. Who provided:	The Carer Support Nurse is the intervention: a Band 7 specialist community nursing role with advanced assessment skills who has completed CSNAT-I training and works under a CSNAT clinical practice licence.

	The Carer Support Nurse also needs a knowledge of local resources, holds clinical skills, an awareness of mental health issues and skills in needs assessment.
6. How:	**In terms of the direct carer-facing aspects of the role**, the Carer Support Nurse is designed to support carers with complex needs (the complexity relates to the carer and not the cared-for person). It is a role that works across sectors (i.e., taking referrals from and referring to the health, social care and voluntary sectors as required) and seeks to engage with marginalised communities. There are no age restrictions on either the carers or the cared-for person (e.g., they can be a young person caring for an adult, or an adult caring for a child). At the time of the pilot two alternative versions of CSNAT-I adapted for (1) young carers and (2) carers of children were in development and not yet available for clinical use: in these scenarios the Carer Support Nurse worked with the original CSNAT-I. The mode of delivery of the direct carer-facing aspects of the role is not prescribed in terms of when or where carers are in contact with the Carer Support Nurse, however delivery of CSNAT-I should follow the five-stages outlined in the CSNAT-I training (although there is flexibility within these five-stages in terms of their delivery mode and timing). **In terms of the indirect aspect of the role (cross-skilling healthcare professionals in care identification and support)**, how this is delivered is not prescribed and is likely to occur through multiple processes (e.g., formal teaching/presentations, formal feedback via letters to referrers, informal feedback/guidance) and using multiple methods (e.g., in person, online, by phone and in writing) as opportunities arise or are sought.
7. Where:	The role is located in health care and is community-based but is a role that works across sectors (i.e., taking referrals from and referring to the health, social care and voluntary sectors as required); it is aligned to the Primary Care Network and Integrated Care System. **In terms of the direct carer-facing aspects of the role**, place of delivery is not prescribed. Instead, the location should be guided by the needs/preferences of the carer, being mindful of privacy and the potential impact of the presence of the cared-for person. This could therefore be in a healthcare clinic, at the carers' home, or the home of the person they support (with consent), on-line or by telephone. The agreed location may change in response to changing carer circumstances. **In terms of the indirect aspect of the role (cross-skilling healthcare professionals in care identification and support)**, place of delivery is not prescribed and is likely to occur in multiple locations and using multiple methods (e.g., in person, online, by phone and in writing) as opportunities arise or are sought.
8. When and how much:	**In terms of the direct carer-facing aspects of the role**, this is initiated on receipt of a referral either from the carer (self-referral) or from healthcare, social care or voluntary sector agencies.

	The timing of the intervention is not prescribed either in terms of frequency or duration. Instead, timings should be guided by the needs/preferences of the individual carer e.g., to fit around the carers work commitments or caring role and as appropriate for that carer's individual support needs. There is therefore a need for flexibility over appointment times offered, and an understanding that any agreed appointment times may change in response to changing carer circumstances. The amount of contact/support offered by the Carer Support Nurse should be determined by the needs of the individual carer, in agreement with the carer. The aim will be for short-term support, but re-referral is possible if the carer's circumstances change. The carer could be held on an open caseload and provided with a clear route back to the Carer Support Nurse if required. Where the Carer Support Nurse feels it is appropriate to limit or withdraw support a clear explanation should be provided to the carer and referrer. **In terms of the <u>indirect aspect of the role</u> (cross-skilling healthcare professionals in care identification and support)** this will vary as opportunities arise or are sought.
9. Tailoring: If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	As a person-centred intervention, the Carer Support Nurse role is designed to be flexible. **In terms of the <u>direct carer-facing aspects of the role</u>** it is flexible for the carer, the practitioner, and the service context. There are core delivery elements relating to the need to deliver CSNAT-I and the delivery of CSNAT-I itself (as specified in the CSNAT-I training), but other elements of the Carer Support Nurse role can (and should) be tailored as described above e.g., the location and timing of delivery, the length of contact and the nature of supportive in-put delivered by the Carer Support Nurse. **In terms of the <u>indirect aspect of the role</u> (cross-skilling healthcare professionals in care identification and support)** this will be tailored as opportunities arise or are sought.
10. Modifications: If the intervention was modified during the course of the study, describe the changes (what, why, when, and how)	The intervention was not modified during the course of the study however it was not possible to "discharge" all carers from the service due to their changing needs. For some carers, episodes of care were "closed" in order to manage situations where a carer's needs had been supported (at that point in time) but where they were likely to need more support at some time in the future.
11. How well – planned: If intervention	Intervention fidelity was not directly observed (e.g., Carer Support Nurse consultations were not audio recorded), however fidelity was assessed via multiple sources of data:

adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them	• monthly anonymised aggregated process data from the SystmOne Business Intelligence Unit (providing data on referrals and Carer Support Nurse activities) provided by the host site • Activity Analysis of data collected using the Cassandra matrix for specialist nursing practice (https://www.apollonursingresource.com/showing-how-i-spend-my-time/) • a templated Weekly Reflective Diary and CSNAT-I Activity Template completed by the Carer Support Nurse • monthly data-generating meetings with the Carer Support Nurse to monitor role delivery • baseline and follow up postal survey and interviews with adult carers who had contact with the Carer Support Nurse • end of pilot interview with the Carer Support Nurse's line manager • end of pilot focus groups and interviews with key cross-sector colleagues and stakeholders • end of pilot interview with the Carer Support Nurse. All interviews and focus groups were conducted by researchers from the study team. Three actions may have helped maintain fidelity to the Carer Support Nurse intervention: (1) two follow-on support webinars to consolidate the CSNAT-I training, (2) monthly data collection by the study team from the Carer Support Nurse requiring spoken interactions, and (3) involvement of the study PI in the Carer Support Nurse monthly governance meetings.
12. How well – actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	The multiple sources of data suggest that intervention fidelity was achieved. The five Evidence-based Design Principles were all adhered to, although it was acknowledged by multiple cross-sector stakeholders that attending to marginalised communities (EDP-3) requires longer than a one-year pilot to be truly effective.

APPENDIX 7

Resource use and cost data from Carer Survey (Source: Task 2B)

- 18 carers returned a baseline survey
- 10 of these carers returned a six-week follow-up survey

Table 13: Numbers of participants reporting any healthcare contacts at baseline (all), baseline (completing both baseline and follow-up) and follow up.

		Responded	Yes	No	Missing
Baseline (n=18)	**Primary care contacts**				
	GP	**18**	6	12	0
	Practice nurse	**15**	4	11	3
	Community nurse	**13**	0	13	5
	Other healthcare	***11**	0	11	*7
	Other social services	**12**	1	11	6
	Secondary care contacts				
	Hospital overnight	**18**	0	0	0
	Emergency care attendances	**18**	1	17	0
	Outpatient clinic	**18**	3	15	0
Baseline (n=10, completing both)	**Primary care contacts**				
	GP	**10**	3	7	0
	Practice nurse	**9**	4	5	1
	Community nurse	**7**	0	7	3
	Other healthcare	***5**	0	5	*5
	Other social services	**6**	0	6	4
	Secondary care contacts				
	Hospital overnight	**10**	0	10	0
	Emergency care attendances	**10**	1	9	0
	Outpatient clinic	**10**	1	9	0
Follow-up (n=10)	**Primary care contacts**				
	GP	**8**	5	3	2
	Practice nurse	**9**	4	5	1
	Community nurse	**8**	0	8	2
	Other healthcare	****9**	**1	8	1
	Other social services	**9**	0	9	1
	Secondary care contacts				
	Hospital overnight	**10**	0	10	0
	Emergency care attendances	**10**	0	10	0
	Outpatient clinic	**10**	2	8	0

*One person with a missing response completed the text box with '40 yo medical review' and was therefore included in the costing analysis.
**One person reporting a resource use completed the text box with 'pharmacy', this was not included in costing analysis (we assumed this to be a visit to a community pharmacist, for which the NHS would not incur a direct cost; we had no information about the use of pharmaceuticals).

Table 14: Mean number of visits to healthcare services reported by participants at baseline, baseline (those who completed both baseline and follow-up) and follow-up.

Face to face visits	Baseline (n=15)	Baseline (completed both baseline and follow-up) (n=10)	Follow-up (n=10)
Primary care contacts			
GP	0.61	0.4	0.7
Practice nurse	0.22	0.4	0.5
Community / district nurse	0	0	0
Other healthcare	0.06	0.1	0
Other social services	0.06	0	0
Secondary care contacts			
Hospital overnight stays	0	0	0
Emergency care attendances	0.06	0.1	0
Outpatient clinic	0.28	0.1	0.2

Table 15: Unit costs of health services resource use

Health service contact	Cost £ per visit / attendance 2021/22	Reference	Assumptions
GP face to face visit	37	PSSRU 2022	p.70 Table 9.4.2: Unit costs for a GP, PSSRU 2022. Per surgery consultation lasting 9.22 minutes, excluding direct care staff costs, with qualification costs.
Practice nurse face to face visit	13	PSSRU 2022	p.68 Table 9.3.1: Costs and unit estimations for nurses working in a GP practice nurse (Band 5), PSSRU 2022. Assuming a 15.5-minute consultation duration based on a GP practice nurse (p.180, PSSRU 2012).
Health check	39	Review of NHS Health Check 2021: Annex E: health economic modelling	Appendix A: Cost £ per completed health check (37.70) and cost per invitation (£1.34).
Adult social services	31	PSSRU 2022	p.81 Table 10.1: social worker (adult services), cost including qualifications (£50), PSSRU 2022. Assuming 37 minutes of activity, incorporating a 25-minute consultation (p.181, PSSRU 2012) and 12-minute travel time (as per GP home visit p.176 PSSRU 2015).
Emergency Care attendance	242	National Cost Collection: National Schedule of NHS Costs 2021/2022	Weighted average of non-admitted Emergency Care attendances.

Outpatient attendance	235	PSSRU 2022	p.40 Table 6.1.1: Unit costs for hospital services. Weighted average of all outpatient attendances. Derived from National Cost Collection 2020/2021 and uprated to 2021/22 prices using the NHS Cost Inflation Index.

Table 16: Mean costs (£, 2021/22) for each resource and overall mean total cost associated with healthcare contacts for baseline (all), baseline (those who completed both baseline and follow-up) and follow-up

Face to face contacts	Baseline (n=18)	Baseline (completed both baseline and follow-up) (n=10)	Follow-up (n=10)
Primary care			
GP	£23	£15	£26
Practice nurse	£3	£5	£7
Community / district nurse	£0	£0	£0
Other healthcare	£2	£4	£0
Other social services	£2	£0	£0
Secondary care			
Hospital overnight stays	£0	£0	£0
Emergency care attendances	£13	£24	£0
Outpatient clinic	£65	£24	£47
Mean total cost	**£108**	**£72**	**£80**