NIHR | Applied Research Collaboration East of England

Involving carers and patients to design and try out a Carer Support Nurse Role

Carer Support Nurse Pilot Study

Changes, Benefits and Learning from Public Contributors: Public Involvement Impact Case Study

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Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning,** gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to our research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.

Public Involvement Impact Case Study: Involving carers and patients to design and try out a Carer Support Nurse role

Project Title:

Carer Support Nurse Pilot

What problem is this research addressing?

Carers provide unpaid care, help, or support to family members or friends with care needs [1]. There were up to 9.1 million carers in the UK pre-Covid; the pandemic has added 4.5 million more [2]. The personal care, practical and emotional support they provide is valued at £132 billion annually [3], reducing formal care costs. Added to this, there has been an unprecedented reliance on home care as one pillar of the health care system during the Covid-19 pandemic [4] while carers' support needs have increased but access to care was reduced [5]. However, carers can feel unprepared for the caring role and lack confidence in it [6-12]. This can cause anxiety and impact on their ability to ask for help [13,14]. This, in turn, can impact on their ability to keep 'caring' if they wish to.

Many carers lack access to services [7,12,15], remaining unnoticed or invisible [16,17] until a crisis occurs [6,7]. They can be ambivalent about their own needs, putting the patient's needs first, neglecting their own health [15,18,19]. Time-limited healthcare professionals similarly prioritise patient need [20,21]. Added to this, carers' support needs are exacerbated when caring is prolonged [22,23], when there is uncertainty or complexity [24], and in marginalised communities at risk of unequal healthcare access [25-28].

Carers need support to look after their own health and wellbeing and boost their skills and confidence to care.

National calls for improved carer support [29-33] includes NHS calls for new ways to identify and support carers, especially the most vulnerable such as those with their own health needs [34]. A dedicated Carer Support Nurse role [35] (to support carers with complex needs and enhance the skills of other healthcare professionals) could help address this, ameliorating crises, and reducing patient and service impacts. We therefore worked with carers, patients, health and social care professionals, voluntary organisations, and national and regional leaders in carer support, to develop this new role. It was designed to help carers who have their own needs, or who need extra support for their caring role, that cannot be met by their usual healthcare team. The role also works with other healthcare providers to raise their awareness of carer needs and model best practice in how to support them.

Dedicating this new nursing role to carers is key due to carers' reluctance to "bother" healthcare professionals [6,12], particularly for non-emergencies [7,15], during what they see as the "patient's time", and nurses' difficulty supporting carers within their patient-led roles (due to limited time) [10,36]. By being carer-dedicated the role could legitimise carers' help-seeking, overcoming their reluctance, and legitimise carer support for other healthcare professionals.

A registered nurse fulfilling the role is key as nurses have the knowledge and expertise required to support carers' health-related support needs, particularly when complex [37-41]. The holistic nature of nursing [38-40] combines the required skills in need identification, physical and mental health assessment and support, self-care, and case management at expert level [42].

Carers and patients have told us that a Carer Support Nurse would increase the likelihood of carers' health-related support needs being identified and therefore addressed, by giving carers "permission" to express them.

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, funded by the former Health Education England – East of England (now NHS England – East of England Region) and supported by the NIHR Applied Research Collaboration East of England and UEA Health & Social Care Partners.

How were the public involved in this research?

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: Jen Kenward (then lead for NHSE/I Commitment to Carers Programme), Dame Philippa Russell (Vice-President Carers UK), and the Queen's Nursing Institute (QNI; represented by Sue Boran and Amanda Young). This national endorsement from key figures and organisations in carer support provided a catalyst for an extensive programme of consultations on the proposed role, and the plan for its evaluation, 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) both before and during the study. The breadth of these consultations was considered a key strength, garnering cross-sector views, support, and endorsement. These consultations were conducted within funded time within the NIHR Applied Research Collaboration East of England.

Pre-study PPI work:

The pre-study PPI consultations with over 100 carers and patients (living with advanced disease) were conducted individually, in dyads and in established patient/carer support groups. In these

consultations we sought carer and patient views on the problem we wanted to address (to ensure both relevance and importance), our proposed solution to the problem (to explore the potential acceptability of the intervention), how we hoped to co-develop the intervention with carers, care professionals and commissioners (to establish that co-development was the right approach), and implement it (to identify where the role might best be located).

To facilitate this, we developed a crib sheet of topics to cover in each consultation, including points to mention in our introduction to the topic, and key questions to ask of carers and patients. This proved useful in ensuring that each consultation covered those topics and for the recording the answers we received from different consultees/groups in order to bring together their thoughts and ideas. Each session was led by a post-doctoral researcher with a background in nursing and interest in unpaid/family carers and took the form of an informal (group) discussion to generate ideas.

Within-study PPI work:

In addition to the pre-study PPI work, 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). The 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., a 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 data from carers

What were the outcomes of public involvement in this project?

Pre-study PPI work:

Both carers and patients confirmed that the topic was highly relevant. Patients emphasised the vital role their carers played and some voiced concern over carers' lack of support. Both felt that intervention was warranted for some carers and would be welcomed. They supported the idea that this should be a nursing role and advised that it would be best located in the community.

We discussed the best ways to recruit carers and patients to the study – what would be acceptable and what might work – gaining helpful advice on the most acceptable terminology to use both in our funding application and recruitment materials: "carer" was the term preferred by most. These early discussions informed the naming of the role as "Carer Support Nurse".

These patients and carers therefore helped shape both the role and the study design. They also welcomed the planned continued engagement of carers in a PPI role within the study itself.

Within-study PPI work:

Carers confirmed the need and rationale for the Carer Support Nurse role and the pilot project, as well as its design. They gave direct feedback on carer-facing recruitment and data collection materials, such as the carer survey. Examples of changes we made to the survey as a result of this feedback included clarifying wording in relation to different services that carers might have accessed, providing adequate space for carers to write in their answers, providing additional response options, and clarifying completion instructions (e.g., whether more than one answer could be ticked in response to a question).

They suggested some questions that carers would consider important to include in the end of pilot interview with the Carer Support Nurse post-holder, such as 'Which skills did the nurse feel have been priceless?' and 'Are there any skills the nurse would like to develop in the role?'. They also suggested ways the Carer Support Nurse might engage with carers from marginalised groups. They further provided valuable insight on our qualitative data collected from carers who had contact with the nurse.

How did public involvement influence the project overall?

Pre-study PPI work:

Having the endorsement of patients and carers in terms of the need for and design of the role and its evaluation was invaluable. It bolstered consultations going forward with professional stakeholders who universally echoed their views.

Within-study PPI work:

The questions they suggested we include in the end of pilot interview with the Carer Support Nurse post-holder (that they felt would be important to carers) made a significant difference as they proposed questions that the research team had not considered. These proved to be valuable for collecting data that could be triangulated with data from other sources i.e., quantitative data on the activities the nurse carried out was triangulated with qualitative data from carers (which our PPI Carers also provided valuable reflective insights on) and the Carer Support Nurse post-holder. This gave added strength to the findings and informed some of the proposed Mechanisms of Action for the intervention and final recommendations from the pilot.

What was the feedback from public contributors involved in this project?

All four of our within-study PPI carers supported the study enthusiastically and have agreed to continue to contribute to the Carer Support Nurse programme going forward (Roberta Lovick, Sue Schofield, Les Readfearn and Kevin Minier). We will be consulting with them during 2024 on the design of a larger study to gain learnings beyond the single pilot role, building on the pilot/feasibility findings.

They provided the following feedback on their experience of contributing to the study:

"My involvement with the project was remote due to distance & included email and zoom inclusively no postal info received. I felt very included in the study and found it very interesting. Zoom is an easy platform to

communicate and nice to see the people involved, the biggest impact on me was the anonymised interview study I received to review on, it proved and confirmed to me just how well this Carer Support Nurse Pilot study worked and is a much needed service, the trained nurse quickly identified a struggling carer (who obviously went unrecognised) she identified her needs and knew how to help together with the efficiency of the team all got quickly and smoothly sorted out! I can't imagine how bad this case could have been without this service. I applaud the teamwork for their, knowledge, skill and efficiency at its very best, every town could benefit and learn from you." [Sue Schofield 07/01/2024]

"Being involved with the project helped me focus on my own health. Every year gets harder and impacts on your physical and mental health. The biggest worry for a Carer is becoming unwell themselves and in my case has caused me to suffer from anxiety [...] Would love to have access to a Carer Support Nurse in my area." [Les Redfearn 09/01/2024]

"I was impressed as to how efficient the PPI was in that we covered a huge amount of material in a few short co-production workshops. The prime area of PPI that I was impressed with was evaluation and feedback. As carers we were involved in the co-production of the evaluation criteria (the questions asked of the Carers Support Nurse) and the responses and were able to assess if what we had contributed earlier had improved the quality of the service and the impact on carers. The study also highlighted the commissioning requirements to support a viable post-pilot service." [Kevin Minier 15/01/2024]

What are the reflections and learning from public involvement in this research?

We were overwhelmed by the positive reaction to the proposed Carer Support Nure role and study. The pre-study consultations were conducted in person, before the Covid pandemic. The within-study consultations were conducted online. Both modes of access worked well; remote access allowed for a wider geographic spread. We found that our carers preferred Zoom to Microsoft Teams for online meetings, and they were happy to also work via email (backed up by post for larger documents).

We worked hard to ensure that financial reimbursement for their time was processed efficiently, and this was acknowledged. We didn't experience any challenges in this but felt it was important in order to demonstrate how we valued their contribution. In a similar vein, we tried to give timely feedback to the PPI group on the impact their contributions had made e.g., sharing the valuable data gathered from the questions they had suggested we asked the nurse at the end of pilot interview (questions we would not have asked without their input, and therefore data we would not have otherwise generated).

When conducting PPI work in the future we would again use the strategies outlined here in terms of how we engaged with PPI consultees, when we engaged with them, the types of questions we asked them, and our work to demonstrate to them the value of their contribution. We would also seek to again have our own time protected and funded for this work, and be able to reimburse public contributors financially for their time.

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The case study template is informed by GRIPP 2-SF (Staniszewska et al., 2017)

For more information, visit the project webpage

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