

Carer Support Nurse project **- helping us think about how the nurse might work with carers**

PARTICIPANT INFORMATION SHEET

(1) What is this study about?

You are invited to take part in a research study about a new nursing role, the Carer Support Nurse, that is dedicated to supporting carers in the Great Yarmouth and northern villages area. You have been invited to participate in this study because we want to ask carers for their views on how this new role might work here to support those carers in greatest need.

This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.
- ✓ You have received a copy of this Participant Information Sheet to keep.

(2) Who is running the study?

The study is being carried out by the following researcher(s): Prof Morag Farquhar, Dr Guy Peryer, and Dr Carole Gardener from the School of Health Sciences at University of East Anglia (UEA), Dr Adam Wagner and Prof Susanne Lindqvist from Norwich Medical School at UEA, Prof Alison Leary (London South Bank University), and Dr Jennifer Lynch (University of Hertfordshire).

This study is being funded by Health Education England (NHS HEE).

(3) What will the study involve for me?

We are inviting you to help us by taking part in a one-hour workshop (group discussion), with two or three other carers, online (using your computer, laptop or iPad). However, if you want to take part but would prefer not to join an online workshop, the researcher may be able to speak to you individually either by phone or online.

We will gather your views on whether this new nursing role is needed, how the nurse could work day-to-day, how it might benefit carers, whether there might be any difficulties for carers in getting help

from this new nursing role, and how we can find out whether this new role is useful. An audio/video recording will be taken.

(4) How much of my time will the study take?

The workshop will last about one-hour.

(5) Do I have to be in the study? Can I withdraw from the study once I have started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of East Anglia or East Coast Community Healthcare (ECCH) now or in the future.

If you decide to take part in the study, you can withdraw your consent up to the point that your data is fully anonymised. You can do this by notifying the study researcher (Carole Gardener) or study lead (Morag Farquhar). You do not need to give a reason.

(6) What are the consequences if I withdraw from the study?

If you take part in the workshop (group discussion), you are free to stop participating at any stage or to refuse to answer any of the questions. However, it will not be possible to withdraw your individual comments from our records once the group has started, as it is a group discussion.

(7) Are there any risks or costs associated with being in the study?

Taking part may uncover concerns you have and how you are managing. If you want to talk someone about how you feel after the study, please get in contact with us.

(8) Are there any benefits associated with being in the study?

Although we cannot guarantee any specific benefits to you, you may gain from discussing how we can improve support for carers. By taking part you will help to develop this new nursing role for carers, and help those carers who benefit from the new nursing role.

(9) What will happen to information provided by me and data collected during the study?

The discussion will be audio recorded, with your permission, then typed up by a professional transcription company and analysed by the research team. All information about you will be treated in the strictest confidence and used for research purposes only. Information recorded will have your name and address removed so you cannot be recognised. With your permission, we may use quotations from recordings in publications, but all identifiable details will be removed.

All data will be stored in a project-specific UEA One Drive folder accessible only to the project team. Project work will use password protected University computers and laptops. No identifiable data will be stored locally on computers or laptops. Data storage/handling will comply with University policies on data security. Paper data will be stored in a locked filing cabinet in a locked room at the University, separately from any related data.

Information that has been anonymised (that is where identifiable data has been removed e.g. your name) may be used after the study by other health care researchers: this is called secondary analysis. To do this they would apply for permission from the research team.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's [Research Data Management Policy](#).

The information you provide will be stored securely and your identity will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be identified in these publications if you decide to participate in this study.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include your name or any identifiable information about you.

(10) What if I would like further information about the study?

When you have read this information, the study researcher (Carole Gardener: CSN.project@uea.ac.uk, 01603 597057) will be available to discuss it with you further and answer any questions you may have.

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one page lay summary, provided at end of study.

(12) What if I have a complaint or any concerns about the study?

If there is a problem, please let me know. You can contact me via the University of East Anglia at the following address:

Prof Morag Farquhar
School of Health Sciences
University of East Anglia
NORWICH NR4 7TJ
M.Farquhar@uea.ac.uk
01603 597649

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of School of Health Sciences: Professor Sally Hardy (s.hardy@uea.ac.uk, 01603 593940).

(13) How do I know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

(14) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your data protection rights at the [Information Commissioner's Office \(ICO\)](#).

- If you are unhappy with how your personal data has been used, please contact the University's Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(15) OK, I want to take part – what do I do next?

You can let us know that you are interested in taking part by either emailing us at CSN.project@uea.ac.uk or, if you have been given a paper-based pack, you can complete the paper reply slip and return that to us instead (a stamped-addressed envelope is provided). We will then get in touch to answer any questions you may have and to make arrangements for the workshop. Please keep the letter and information sheet for your information. If you agree to take part and sign a consent form we will give you a copy of it to keep.

(16) Further information

This information was last updated on 01 July 2022.

If there are changes to the information provided, you will be notified by email or post.

This information sheet is for you to keep