



CARECOACH

Carer Participant Information Sheet

Developing 'Partner in Balance' (PiBUK) for UK use

Part of the CARECOACH programme: Adapting and testing an intervention for carers of people with dementia

This leaflet is an invitation to take part in a study being undertaken by researchers from the University of Exeter and the University of East Anglia (UEA). It tells you why the study is being done and what it would involve for you. Please read it and if you wish, discuss with others, so that you can decide whether or not you would like to take part. Take your time in making your decision. This information sheet is yours to keep.

The study is funded by the National Institute of Health Research

Study contact details:

Dr Jane Cross

Lead Investigator

j.cross@uea.ac.uk

01603 593315

What is the purpose of this study?

Carers of people with dementia need to have information about the disease and necessary skills to manage and support the day-to-day care they give to the person with dementia. This study aims to adapt a Dutch intervention called Partner in Balance, to implement it into the UK's NHS. The intervention is a package of resources and tips to help carers. We are interested in the experiences and views of carers of people living with dementia. It is part of a larger programme of research called CARECOACH.

Why have I been chosen?

You have been sent this invitation because you are the carer of someone recently diagnosed with dementia. You were identified as an eligible participant by a member of the local Trust because of your carer status.

Do I have to respond to this invitation?

No. You will be given as long as you need to consider the information in this leaflet. The research team who sent you this may contact you to answer any questions you may have and ask if you are interested in taking part in the study. If you say yes, they will ask you to complete and sign a consent form and send it back to them using the envelope provided or by email. Please discuss the study with your friends and/or family, and if you wish, member(s) of the dementia team. Your decision about whether to take part in the study will in no way affect the care received by the person you care for.

What will happen to me if I take part?

If you consent to take part, a researcher from the University of East Anglia (UEA) in Norwich will contact you to arrange an interview via an online video call, using Zoom or Microsoft Teams. The interview will last no longer than 2 hours (with as many breaks as you need) and will be recorded. Before the interview takes place, the researcher will introduce themselves, explain the purpose of the study and ask you to agree to the interview.

The researcher will ask you to talk about yourself and the person with dementia that you care for. You will be asked to give an insight into your caregiving experience and browse a website designed to support dementia carers. There are no right or wrong answers. We are interested in your experiences and your opinions about the website.

What are the possible risks or disadvantages in taking part?

As we are interested in your experiences, there are only minor risks. The most serious may be that you could become upset when asked about your recent experiences. This interview will take up some of your time.

What are the possible benefits of taking part?

There are no direct benefits although many people enjoy taking part in research. By participating and sharing your experiences you will be playing your part in a larger project which aims to lead to future improvements in support for dementia carers like yourself. After the interview we will offer you a £20 gift voucher as a thank you for your time.

What will happen if I don't want to carry on with the study?

If you do decide to take part in the study, you can still change your mind, even during the interview. Your decision to withdraw from the study will not affect the current or future levels of care and support you and the person you care for receive. After the interview you will have 7 days to change your mind and withdraw your contribution.

What if there's a problem?

If you have concerns about any aspect of the study, please feel free to discuss the matter with a researcher. If you have more general concerns about the way that you have been approached or treated during the study, you can access the NHS complaints mechanism via the Patient Advice and Liaison Service (PALS). If you wish to contact the PALS team please contact Norfolk and Suffolk NHS Foundation Trust PALS, email: pals@nsft.nhs.uk or Tel: 01603 421191 BT Freephone: 0800 279 7257 (calls from mobiles and other providers may charge) between 9am and 5pm Monday to Friday - outside these hours you can leave a message on the PALS voicemail which we aim to respond as soon as possible. In writing: PALS Office, Hellesdon Hospital, Drayton High Road, Norwich NR6 5BE.

If you are still unhappy, please raise a complaint to the Dean of Health Sciences, Sally Hardy (s.hardy@uea.ac.uk) or the Dean of Medicine, William Fraser (w.fraser@uea.ac.uk).

Will my taking part in the study be confidential?

Only members of the University of East Anglia (UEA) research team and your Trust's dementia team will know that you were part of the study. Your recorded interview will be stored securely in line with the Data Protection Act (1998) for 10 years and then destroyed. The only time that we would pass on information would be if you disclosed information in your interview that made us think that you, or someone else, was at risk of serious harm.

How will the results of the research study be used?

The results of this study will interest many different people and organisations. To help the research we may use quotes and clips from your interview. If we do so, we will not use your real name and your quote will be in no-way traceable back to you.

Who is organising/funding the study? Who has reviewed it?

Our study is funded by the National Institute for Health Research (NIHR). The Principal Investigator for the CARECOACH Programme is Dr Jane Cross, an allied health professional, based at UEA. This study has been reviewed and approved by a National Research Ethics Committee (REC ref:21/PR/1353).

What will happen to my data?

In 2018 regulatory changes in the way that data is processed came into force, with the EU General Data Protection

Regulation 2018 (**GDPR**) and the Data Protection Act 2018 (**DPA 2018**). Since the UK left the EU, the key principles of EU GDPR have been adopted in the **UK GDPR** (a 'UK-only' version) and the **DPA 2018** still applies.

The University of Exeter terms its lawful basis to process personal data for the purposes of carrying out research as being in the 'public interest'. The University continues to be transparent about its processing of your personal data and the participant information sheet should provide a clear explanation of how your data will be collected, processed, stored and destroyed. If you have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information can be obtained from the University of Exeter's Data Protection Officer via the link;

<https://www.exeter.ac.uk/aboutoursite/dataprotection/dpo/>

If you have any concerns about how your data is controlled and managed for this study, then please contact the Sponsor Representative: Pam Baxter, Senior Research Governance Officer.

All information collected in this study will be kept strictly confidential and stored either on an encrypted password protected computer servers, or in a locked cabinet in a secure office at the University of East Anglia, which can only be accessed by the research team. You will be allocated a unique participant number, to ensure your information will be protected and cannot be identified outside of the research team. Any personally identifiable information will be stored separately and securely from information obtained from the

research, it will only be kept for a limited time (*10 years*) and securely destroyed.

Your rights to access, to change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible

Optional future research studies

You may be contacted about future studies related to the CareCoach Programme. You would be provided with information about what the study involves and a separate consent to take part. This is optional and you are not obliged to participate.

What do I do now?

If you are interested in taking part, please fill in and sign **2** copies of the **Consent form** and return **BOTH** to the research team using the freepost envelope provided. A researcher will contact you within 1 week to answer any questions you may have and arrange a time for the interview.

Want to know more about the study?

If you have any questions about this study, please do not hesitate to contact one of the following:

Dr. Jane Cross, Lead Investigator,
School of Health Sciences, University of East Anglia

Norwich, NR4 7TJ

Email: j.cross@uea.ac.uk

Tel: 01603 593315

Or the study researchers at:

Email: carecoach@uea.ac.uk

Tel: 07599 926354

Sponsor Representative:

Ms Pam Baxter - Senior Research Governance Officer
University of Exeter, Research Ethics and Governance Office
Exeter EX4 6TL

Email: p.r.baxter2@exeter.ac.uk

Tel: 01392 723588

NSFT Research:

Prof Chris Fox -Principal Investigator
Claire Rischmiller – Lead Research Nurse

Tel: 01603 421397

Email: researchinfo@nsft.nhs.uk

**Thank-you for reading this
information sheet**



Norfolk and Suffolk
NHS Foundation Trust