



CareCoach Service User Advisory Group (SUAG) Information Sheet

Who would we like to be members of our Service User Advisory Group (SUAG)?

We are looking for people living with dementia, and carers who have experience of providing support for people living with dementia to join our Service User Advisory Group (SUAG).

What role do members of our SUAG play?

SUAG members have a key role as expert advisors to the research team, providing their lived experience and insights to ensure the CareCoach programme is addressing key issues and concerns which will be relevant to people living with dementia, their family carers and professionals who support these groups.

How will SUAG members be involved in running the CareCoach programme?

We are looking to form a group made up of people living with dementia, people caring for those with dementia, and dementia experts to work with us as part of a Service User Advisory Group (SUAG). Members of the SUAG will work with us on a research programme which aims to adapt an online programme called 'Partner in Balance' (PiB). This is an online supportive resource to provide information and advice which carers can access along with input from a coach. This PiB resource was developed in the Netherlands and the CareCoach study aims to understand how to translate the PiB resource from Dutch language and adapt it for the UK setting, to examine if it can be acceptable and useable.

The study will involve service providers and carers through discussions and meeting to co-produce ways the PiB can be integrated into current services for carers in the UK. The CareCoach programme will run over a period of five years and will use a range of methods. After early qualitative studies we will run a feasibility trial to test how it can be implemented and to select and apply outcome measures to inform a larger randomised control trial of the intervention. SUAG members will continuously advise on the relevance and acceptability of a wide range of aspects of the CareCoach research design, intervention and sharing findings.

What time will SUAG members be expected to commit?

SUAG members will regularly attend a maximum of 4 meetings per year (with potentially some additional sub-group meetings). The project runs for about 5 years. SUAG members can choose to be involved for the entire duration of the study or less. We would expect a minimum of 12 months involvement.

What is the CareCoach programme?

CareCoach is a research study using mixed methods to adapt and test the PiB programme across four work packages (WP).

WP1 uses co-production to collaboratively adapt the PiB to the UK-setting (with carers/clinicians)

WP2 will focus on implementation using Normalisation Process Theory” with clinicians/wider system service providers to understand how to fit new practices to existing ways of doing things.

WP3 will be a feasibility trial to compare the adapted PiBUK intervention (as developed in WP1) with “treatment as usual” (NICE guidelines) as a control. We will test whether the PiBUK intervention is accessible and what outcomes are important for carers (eg. perceived stress, burden, mood, quality of life) and care recipients (behaviour problems, quality of life), within a small sample group of participants (approximately 45 carers). We aim to carry out a qualitative evaluation of their experiences of the intervention with carers and coaches

WP4 will be a “randomised controlled trial” comparing the PiBUK intervention with treatment as usual (NICE guidelines) as a control. A larger number of carer participants would be enrolled in the study to test the outcomes of the intervention for carers and people with dementia and to measure whether the PiBUK programme is cost-effective.

Role description: Carers supporting people living with dementia expert Service User Advisory

Group (SUAG) members

- Members will contribute to the design and progress of the overall research programme from their perspective as a person caring for someone living with dementia.
- Members will work with academics to improve public accessibility of written information (for example, invitation letters, participant information sheets, advertisement materials, social media posts)
- We would like members to advise on recruitment stages.

- Members will attend SUAG meetings which will take place at three monthly intervals throughout the 5-year programme.
- The CareCoach research team will update on the programme through regular emails, meetings and contact with the SUAG members.
- Members will be offered appropriate training, development, and support activities to support their active involvement.
- Members will help produce useable, accessible research and contribute where appropriate to dissemination papers and/or events.
- Each member will bring their own experience and knowledge to contribute to discussions and decision-making during SUAG meetings. We request that members are courteous and respectful to each other and the research team, as it is important that we can all learn from each other's different contributions.
- We request that all personal information, study documentation and research data discussed between SUAG members is kept confidential.

Format of SUAG meetings

Meetings will start by using an online Zoom format. However, we hope to move to face-to-face meetings in the future. These will be half-day meetings at the University of East Anglia, Norwich. Members of the research team and PPI leads will jointly facilitate these meetings.

Terms and conditions of SUAG membership

Duration of role: The maximum duration is when the project ends in December 2027. Due to the nature of the role (which requires training and familiarisation with details of the study topic) there is a desired minimum commitment of 12 months, but the ideal term of membership is for the full 5 years of the programme.

Payment

In recognition of their contribution and time, SUAG members will be offered an attendance fee for attending the half day SUAG meetings. If extra work is requested, for example reviewing additional documents, an hourly fee will be paid. This is in line with PPI payment guidance as set out in the UK Standards for Public Involvement in Research, part of the NIHR Centre for Engagement and Dissemination (previously the INVOLVE guidelines)

<https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372>

Expenses

SUAG members can claim reasonable expenses for standard class travel in connection with their attendance at SUAG meetings.

Meeting attendance

If SUAG members cannot attend a meeting due to illness or unforeseen personal circumstances they should contact CareCoach via email at carecoach@uea.ac.uk.

Declarations of interests

All members of SUAGs are required to declare if they have any interest that might be in conflict with independently contributing to its work, for example, if you know someone in a research team personally.

Application process

To apply please email a cover letter to carecoach@uea.ac.uk.

Alternatively, please send a cover letter to CareCoach, NCTU, Norwich Medical School, University of East Anglia, Earlham Road, Norwich, NR4 7TL.

