



# **Public Member Role Description**

## Name of project

A realist evaluation of the Kent and Medway Dementia Care Coordinator service in primary care and across care pathways

## Summary of project

Dementia is a progressive syndrome that has huge individual, family, societal and economic impact. Navigating the health and care system both pre and post diagnosis can be particularly challenging for those living with dementia and those caring for them. Diagnosis rates remain low, meaning early interventions are not instigated, and community support is lacking for people living with the disease often resulting in hospital admissions that could be avoided.

This study aims to work with Kent and Medway Integrated Care System (ICS) to evaluate a new role, - that of Dementia Care Coordinator (DCC). For two years, from April 2022, the ICS is funding one DCC post in each of its 42 Primary Care Networks (collections of general practices serving 30,000 to 50,000 people) to improve care for people with dementia and their families. This is a new and novel role within the care system.

Findings from this study will provide evidence to the ICS that will inform decisions about the continuation of investment in the DCC role and how the service can be successfully delivered.

## Description of role or activity required

We are seeking a patient/ public representative with lived experience of caring for someone with dementia to form a specific stakeholder group. Being a member of the project stakeholder group would mean helping the study team to sense-make findings and advise on other aspects of the project such as engagement with people with dementia. You will be part of a small group of individuals (maximum of four) who share similar experiences to you.

#### **Anticipated commitment**

The study duration is 24 months running Oct'22-Oct'24. Being a stakeholder member will include attending three meetings of approximately 2 hours long each (6 hours) spread across the 24 months.

Time will be allocated for document reviewing where appropriate (maximum 1 day across the 24 month project).

#### Support to be offered

All activities will be planned and led by the PI, Dr Ruth Abrams. Activities will be supported by the recruited research fellow (TBC and dependent upon funding success), who will coordinate communications and act as a sole point of contact for all individuals. Additionally we will have a patient and public representative chair to facilitate all meetings.





We recognise that not every member will be able to attend every meeting and will encourage non-attenders to send a nominee and/or to contribute their insights by another means (e.g., email and/or telephone conversation). We will also provide opportunities for those stakeholders who may have some inhibition or tension of discussing views in a larger group, to discuss the topic with the research team between meetings. We will also convene 'briefing meetings' as required before the 'full' stakeholder meeting - to better prepare those who may be inhibited.

#### Remuneration

Budget has been allocated for the following:

Meeting attendance costed at £75 per person per meeting.

Document reviewing costed at £150 per person, for one day maximum.

All meetings will be conducted remotely. Therefore no reimbursement will be made for travel/subsistence expenses.

The University of Surrey will make these payments and will require the completion of a PPI claim form. This will be paid in monetary form.

# Matters for consideration by public contributor:

As a public member contributing to this research project you are asked not to share confidential information you may have received as a result of your position. This should be discussed with the project group and/or contact person.

For any questions concerning this position please contact Dr Ruth Abrams, project lead, in the first instance: r.abrams@surrey.ac.uk