



SUPPORTED: IMPROVING HOME CARE AT THE END OF LIFE

Support and training for home care workers

SUPPORTED study: Public members of the study steering committee

Information sheet

What is our study about?

Our study is about supporting, enabling and sustaining home care workers to deliver end of life care.

We want to:

- understand the experiences of home care workers providing end of life care, including:
 - a. the care given,
 - b. how they work with health and council staff, their clients' family/friends, and
 - c. what everybody (including the person receiving care) considers is needed to provide best care;
- assess how local and national guidance helps – or hinders – home care workers to give best end of life care;
- produce recommendations for developing the skills of home care workers and supporting them to provide end of life care;
- develop an end of life care training resource;
- make recommendations on how to include and support home care workers in the wider care team.

When does the study begin and end?

SUPPORTED will begin on 1 October 2022 and will last for 30 months, ending in March 2025.

Who is funding this study?

We have received funding from the Health and Social Care Delivery Research programme of the National Institute for Health and Care Research (NIHR). You can read more about this funding programme here: [Health and Social Care Delivery Research | NIHR](#).

What is the role of public members of the study steering committee?

This committee will monitor, supervise and advise the study. Your role as a public member of the committee will be to:

- offer the perspective of a potential public participant in the study;
- act as a 'critical friend' when discussing what is practical and acceptable;
- offer advice on the plans for involving families and those receiving home care towards the end of life.

What experience are we looking for?

We are looking for people with personal experience of receiving home care for a family member or loved one towards the end of life.

It is helpful if you also have some experience of taking part in meetings, reading and commenting on written documents, and working as part of a team. We are looking for people who are confident and willing to speak up and ask questions.

Who will you be working with?

You will work alongside senior academics, clinicians, service providers and home care workers.

We are seeking three public members to join the committee, one each from Hull, Bradford and London.

How often will the committee meet and for how long?

The first meeting of the committee will be in February 2023. After this, the committee will meet every six months until the end of the study in March 2025. This means there will be five meetings of the steering committee in total. As we are recruiting three public members, you will be able to share the role and will not have to attend every meeting.

Where or how will meetings be held?

Our meetings will be held online using Zoom or Teams video-conferencing software. We will share simple instructions for joining each meeting and ground rules for taking part. This means that you will need access to a mobile phone or a computer with internet access.

What will the study steering committee do?

The committee will:

- monitor the progress of the study;
- monitor adherence to the study protocol;
- monitor the safety and wellbeing of participants;
- make recommendations to the Study Management Group;
- make recommendations to the study sponsor;
- consider new information as it becomes available.

What benefits are we offering?

We will reimburse your expenses for taking part in committee meetings and other activities. This will include a remote working allowance to cover your broadband/wifi costs of £5 per meeting, travel expenses if we meet in person, and the cost of arranging a replacement carer or childcare to enable you to attend meetings. More information about the expenses covered is available on request.

We will offer you a fee of **£25 per hour** to thank you for your time and contribution to the study. This will include time spent preparing for, attending and following up meetings, and time spent on separate activities.

Expenses and fees will be paid as soon as possible after each meeting or activity. Invoices or receipts will be required to claim expenses (with the exception of the remote working allowance, which is a fixed payment).

What support will you be offered?

Helen Roberts will be the main point of contact and support for the public members of the committee, with support from Liz Walker. Helen will meet with you before the first meeting to discuss your role and answer any questions. She will be available to offer one to one support outside of meetings, including support with using video-conferencing software, if you need this.

We will send the papers for each meeting at least 10 days in advance so that you have time to prepare. If you need printed copies, these can be supplied on request. We will share minutes of each meeting.

Liz is a member of the steering committee and will be available to discuss any issues with you, to help you prepare, or to reflect on a meeting afterwards. She will be able to explain any complex issues or technical language. She can also speak to the Chair on your behalf if you need support with any issues.

Any questions?

If you have any questions or are interested in volunteering for this role, please get in touch with:

Helen Roberts

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