

Participant Information Sheet
Namaste Phase 1: Interviews and Consultation Workshops

The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review and feasibility study for a cluster randomised controlled trial: Phases 1 and 2

My name is Katherine Froggatt and I am conducting this research at Lancaster University, Lancaster, United Kingdom in collaboration with researchers from the Universities of Hertfordshire, Bristol, Liverpool and St Christopher's Hospice, London.

What is the study about?

This research study aims to research the use of a multi-sensory programme of care (Namaste Care), for people with advanced dementia living in nursing care homes. In the first phase of the study we are looking to understand how care interventions for people with advanced dementia at the end of life work in different contexts and with what outcomes. We will do this by talking to experts, reviewing the literature and holding two consultation workshops. We will use the findings from this work to inform a feasibility trial of Namaste Care for people with advanced dementia in nursing care homes.

Why have I been approached?

You are being invited to join the study because you are an expert stakeholder, i.e. already a member of an organisation that is closely involved in the provision of palliative care, dementia care or care home care for people with advanced dementia care from a policy, practice or research perspective.

Do I have to take part?

No. It is completely up to you to decide whether or not you take part. If you decide to take part you are able to withdraw up to two weeks after participation in the interview or consultation workshop, without giving a reason and without detriment to yourself.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to participate in an interview and two consensus workshops.

1. Qualitative interview

The interview will be undertaken with a researcher (either by telephone or face-to-face) of between 30 and 60 minutes length. The interview will be audio-recorded with your permission. The interview will focus on what good end of life care looks like for people with advanced dementia, in what circumstances and why and how this can be implemented. We will also collect personal information including your gender, age, occupation and organisation.

2. Consultation Workshops

We will hold two consultation workshops. Each workshop will last for a working day (including travel time), and during the day we will present findings from the research team. For Consultation Workshop 1 this will focus on findings from the scoping exercise (interviews and a preliminary literature review). For Consultation Workshop 2, the focus will be on the findings of the realist review. During the workshops you will be asked about what you think about the findings and any links you can identify between the different elements of palliative care, dementia care and care

home provision. The discussion will be tape recorded and transcribed and structured fieldnotes made during the workshop.

Will my data be identifiable?

The information you provide will be anonymised, from the interviews, but participation in the consensus workshops means that quotes may be attributable to individuals at a later date.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the final report has been submitted and accepted by the funding body.
- Hard copies of transcripts will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the research team will be able to access them) and the computer itself password protected.
- Data will be kept for ten years after the end of the study.
- At the end of the study, hard copies of interview transcripts will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, in presentations at future conferences, and for future training events and resources. Your name will not be attached to them.
- Anonymous data from this study may be shared and used by researchers for further analysis in the future.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported to the funding body (the National Institute for Health Research). The results will be used to refine the design of a feasibility trial being conducted as part of this research project. We will also aim to submit findings for publication in an academic or professional journal and also undertake conference presentations.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Professor Katherine Froggatt
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Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster LA1 4YW

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Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Steve Jones
Division of Health Research
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 593382
Email: s.jones7@lancaster.ac.uk

If you wish to speak to someone outside of the Division of Health Research you may contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
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Thank you for taking the time to read this information sheet.


***National Institute for
Health Research***

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