PARTICIPANT INFORMATION SHEET FOR Modified e-Delphi Participants

Title of Study The PALLUP Study- Equipping community services to meet the palliative care needs of older people with frailty approaching the end of life; a mixed methods study

IRAS ref: 277171

PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

Section: Taking Part

We would like to invite you to take part in our research project. Participation is voluntary. Before you decide whether you want to take part, it is important that you understand why the research is being carried out and what your participation will involve. Take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is a Modified-e-Delphi survey?

The Delphi technique is a method of building consensus amongst a group of experts through a series of questionnaires. The responses to each questionnaire are summarised and sent back to the experts for further feedback. In this study the e- survey will be followed by a consensus meeting of selected participants. This meeting will seek to understand the opinions of differing stakeholders and finalise agreement on the core palliative care needs of community dwelling older people with severe frailty.

What is the study's purpose?

The larger study aims to identify and understand the Palliative Care needs of severely frail elders, develop a Service Framework on the key service features of community palliative care and produce resources and recommendations that best support delivery of this care. The purpose of the Modified Delphi is to establish consensus on the core palliative care needs of severely frail elders living at home and gain insight into the shared and distinctive features of agreed Palliative care needs. Older people will also be given the option to participate though interviews

Why have I been invited to take part?

You have been identified as someone with an interest in, knowledge and/or experience of providing home-based care for older people with severe frailty. Your input will help develop an understanding and agreement on the core palliative care needs of severely frail elders. This is central to ensuring that subsequent stages of the study are aligned to the needs and priorities of older people with severe frailty in the last phase of their lives. We hope to recruit at least 80 multidisciplinary experts, across health, social and voluntary/charitable organisations and policy/research perspectives to take part in the online questionnaire, of which up to 30 will take part in the consensus meeting.

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Do I have to take part?

No, you should only take part voluntarily. Choosing not to take part will in no way disadvantage you. Please read this information sheet and contact us if you have any questions.

What will happen to me if I take part?

Participation involves completing two online questionnaires and consenting to receive an invitation to be part of a Zoom video-conference consensus meeting.

Questionnaires

The first questionnaire will be based on a series of statements of need, identified through a literature review. You will be asked to rate statements. Your feedback, alongside that of the other experts, will be used accordingly to revise the statements of need. You will then be sent the revised framework and asked again for your ratings and feedback, as well as to indicate the priority you place on each statement from your professional perspective. We believe each questionnaire will take no more than 30 minutes to complete, and that consensus will be achieved in 2 rounds over three months. Study consent is assumed if you complete a survey. Once a questionnaire has been submitted, the data within it cannot be withdrawn. This is because at the point of submission your data is combined with that of other participants and will therefore no longer be identifiable. However, you are free to withdraw between rounds without giving a reason.

Consensus Meeting (additional component – by invitation only)

The 3-hour consensus meeting will bring together up to 30 people to finalise the core palliative care needs of older people with severe frailty. Participants will be selected to represent the differing types of organisations and perspectives gathered in the survey.

Results from the e-questionnaires will be reviewed to understand areas of agreement/disagreement across differing stakeholder groups. The composite film of older peoples' views on their palliative care needs will be used to stimulate discussion.

Involvement in the consensus meeting is three-fold- 1) a one to one zoom introductory meeting with the facilitator to introduce the consensus exercise 2) a 3 hour zoom meeting with other participants which will be audio and video recorded and transcribed verbatim 3) a short online evaluation

Consenting to be approached for the consensus meeting does not mean there is any obligation to take part nor that you will be approached to do so. There will be the need for variation of stakeholders within the consensus meeting. Therefore, not everyone who agrees to be approached for the consensus meeting will be invited to attend. If you agree to be part

If you do attend, you will be asked to sign a consent form before the meeting. You are free to withdraw or leave the consensus meeting at any time without giving any reason. However, you will not be able to withdraw any data you contribute to the Group before leaving due to the nature of discussions and the inability of the researcher to ignore what has been said by Group members.

Those who are invited to participate in the Consensus Meeting will be offered a £20.00 voucher to thank-you for your participation in the consensus meeting once the study is completed.

What happens if I do not want to take part or if I change my mind?

You are free to withdraw from the study at any time, without giving a reason.

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What are the possible benefits and risks of taking part?

The Delphi will determine the first consensus on the most important palliative care needs of older people with severe frailty. This will both inform subsequent stages of the PALLUP study and be a resource for further evidence building. You can request a summary describing the main findings. There are no foreseeable participation risks.

Will my taking part be kept confidential?

Yes. Your details (name, email address, profession, experience in role) will remain confidential, and will not be shared with anyone who is not on the research team. We will only use your personal details to contact you about this study. We are responsible for making sure that any data is kept secure and used only in the way described in this information sheet. Your information may be subject to review for monitoring and audit purposes, by individuals from the University of Surrey and/or regulators who will treat your data in confidence.

How is the project being funded?

The study is funded by HEE/NIHR as part of a senior clinical fellowship and has been approved by London- Brent research ethics committee.

What will happen to the results of the study?

The results of the Delphi will underpin subsequent stages of the study to characterize current palliative care provision, understand the needs and experiences of care for older people with severe frailty in real time and create a service framework to inform care delivery. The study findings will also be disseminated through relevant publications and conferences.

Section: Your personal data

What is personal data?

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to the study and this section gives information on that. This personal data collected will include name, email address, profession, experience in role which is regarded as 'personal data'

Who is handling my personal data?

The University of Surrey, has the legal responsibility for your study, will act as the 'Data Controller'. The research team will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. We will use this information as explained in the 'What is the purpose of the study' section above.

What will happen to my personal data?

As a publicly-funded organisation, we have to ensure that when we use identifiable personal information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the public interest and special category data is processed on an additional condition necessary for research purposes. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep

identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

You can find out more about how we use your information https://www.surrey.ac.uk/information-management/data-protection and/or by contacting dataprotection@surrey.ac.uk .

How will we use information about you?

We will need to use information from you for this research project. This information will include a patient identification number held by site and/or sponsor for the research. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are, will not be able to see your name or contact details. Your data will have a code number instead.
We will keep all information about you safe and secure.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients, by asking one of the research team or by contacting our data protection officer Suzie Mereweather (dataprotection@surrey.ac.uk). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) (https://ico.org.uk/).

Section: Further information

What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)
Research and Innovation Services
University of Surrey
Senate House, Guildford, Surrey, GU2 7XH
Phone: +44 (0)1483 689110
Email: rigo@surrey.ac.uk

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

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Who should I contact for further information?

If you have any questions or require more information about this study, please contact the PALLUP Research Team using the following contact details:

Phone: 07815919559
Email: c.nicholson@surrey.ac.uk or richard.green@surrey.ac.uk
Post: School of Health Sciences,
Kate Granger Building,
Priestley Road,
Guilford, GU27YH

Thank you for reading this information sheet and for considering taking part in this research.

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