

**Interview Participant Information Sheet**

I’m Lorraine Hansford, a researcher from the University of Exeter. I would like to invite you to take part in the research study ‘Checking Out’, which is exploring what the notion of a ‘good death’ means for people living on a low income.

To help you decide whether to take part, this sheet provides information about why the research is being done and what it would involve. I will be happy to go through this information with you and answer any questions you may have. Do ask if anything is unclear, and please feel free to talk to friends or family about the study if you wish.

**Why is this research being done?**

Living with life-limiting illness and getting the right care and support in the later stages of life can be difficult, both for the person themselves and for family and friends. National information suggests that people living on a low-income are the least likely to know about and access the different kinds of end-of-life care available.

This study is interested in finding out people’s views and feelings about talking about death and dying at different stages in their lives, their experiences of caring for others at the end-of-life, and the impact of funeral poverty. By understanding what is difficult for people in considering end-of-life, this will help to develop the right kinds of support and information to better meet people’s needs.

**Why have I been asked to take part?**

You have been asked to take part because we need to listen to people who have had experience of funeral poverty and/or caring for someone at end-of-life with limited income. As interviews are a useful way of finding out people’s views and experiences for this project, I am looking for 10 men and women aged 18 or over to take part in individual interviews.

**Do I have to take part?**

No. Taking part in this research is entirely up to you. If you agree to take part, you will be asked to give consent and sent a copy of the consent form. Also, if you do decide to take part but change your mind later, that is okay.

**What would taking part involve?**

If you agree to take part, it would involve one interview which will take the form of a fairly informal conversation. This will take about an hour, depending on what you wish to discuss, and will take place on a video call such as skype or whatsapp, or a telephone call, whichever you prefer.

The researcher will ask about your opinions and feelings about what makes it easier or more difficult for people to talk about the late stages of life, and to get the care and information that they need, and how being on a low income affects people’s experiences at the end of life and when someone has died.

**What are the possible benefits of taking part?**

* I cannot promise that the research will help you, but by taking part you will be helping researchers understand the ways people feel and think about talking about end-of-life care and support, and we hope this will help people in the future.
* You can see and comment on the written record of the interview once it is typed up if you would like to. We will share our research findings with everyone who has taken part.
* You will receive a payment of £25 to thank you for your time.

**What are the possible disadvantages of taking part?**

I hope you will enjoy taking part in the conversation. Some people may find talking about end-of-life or bereavement upsetting. If you do, you can pause or stop taking part at any point.

Should you feel you would like to talk to someone after the interview, the researcher can give you information about organisations that offer support and how to get in touch with them. You might want to consider whether you’d like to have a friend/ family member available to chat with afterwards.

**What if I** **don't want to carry on with the study?**

* You can stop taking part at any time, or say that you don’t want to answer some questions.
* You do not have to give a reason, and there will be no disadvantage to you.
* If you withdraw from the study or in the (unlikely) event that you lose capacity to consent during the study, we will erase all your personal data, and we will not retain the research information you have provided up to your withdrawal unless you are happy for us to do so. All this information would be anonymised so no-one will be able to identify you.
* You have the right to withdraw up to the point at which findings are published.

**How will my information be kept confidential?**

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the researcher, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection.

* If you agree, the interview will be audio recorded and typed up later, either by the researcher or a professional transcriber who agrees to our confidentiality statement. No-one else will listen to the recording.
* All data will be securely stored on a password-protected computer that only the researcher can access.
* Audio files will be destroyed once the project is completed (October 2021).
* Anonymised interview transcripts will be stored indefinitely to be used for research purposes only.
* All names in any report will be changed and other identifiable information will be removed in order to protect anonymity.
* The researcher will not tell anyone what you say unless they think that someone might be at risk or might be harmed. If so, they will talk to you first about what could be done to help.
* If you would like to receive updates or information about future research you can choose to let me keep your contact details by ticking the last box on the consent form. Your contact details will be stored securely so that only the researcher can access them.

**What will happen to the results of this study?**

The findings from this study will be:

* Written up for academic publications to inform other people working in this area.
* Shared at conferences, meetings with professionals and community groups and other appropriate organisations to inform those working in relevant areas.
* Information about the outcomes and a brief report will be placed on the Wellcome Centre website (<https://wcceh.org/>).
* Your name will not be used in any publication or presentation, so no-one will be able to trace the information you give back to you.

**Who is organising and funding this study?**

The study is being organised by Lorraine Hansford, Research Fellow at the Wellcome Centre for Cultures and Environments of Health at the University of Exeter, as part of a fellowship funded by the Wellcome Trust.

**Who has reviewed this study?**

This project has been reviewed by the Humanities Research Ethics Committee at the University of Exeter.

**Further information and contact details**

If you have any questions or comments about this research, would like to know more, would like to take part or wish to withdraw from the project, please contact the researcher:

**Lorraine Hansford**, Wellcome Centre for Cultures and Environments of Health, Queens Building, The Queen’s Drive, Exeter EX4 4QH

[l.j.hansford@exeter.ac.uk](mailto:l.j.hansford@exeter.ac.uk) 07766 950698

**If you have any complaints about the way in which this study has been carried out please contact**

**Dr Jana Funke**, Chair of the College of Humanities Ethics Committee, University of Exeter

Department of English & Film, Queen’s Building, The Queen’s Drive, Exeter EX4 4QH.

[j.funke@exeter.ac.uk](mailto:j.funke@exeter.ac.uk) 01392 725612

*Or*

**Gail Seymour**, University of Exeter Research Ethics and Governance Manager, University of Exeter, Lafrowda House, St Germans Rd, Exeter EX4 6TL.

[g.m.seymour@exeter.ac.uk](mailto:g.m.seymour@exeter.ac.uk) 01392 726621

**Thank you for your interest in this project**