Participant Information Sheet: Interview

Supporting decision-making on place of death and care in mesothelioma (SDM) research study: improving the experience of people with mesothelioma and their families

Introduction

We invite you to take part in a research study looking at any experiences of end-of-life planning for a relative (or close friend) with mesothelioma, and experience of their last days.

We are conducting interviews to find out about any experiences of planning ahead and experiences of the last days within different places, (e.g. home, hospital etc.) from the perspective of bereaved families. We aim to explore factors which influenced any positive/negative experiences, and what helped and hindered patients and their families in making well-informed decisions on the place of death (and the care provided).

We are also inviting interviewees to fill out the Care of the Dying Evaluation (CODE) questionnaire. This questionnaire is frequently used to gather information about the last days from the perspective of bereaved families or friends.

Before you decide to take part, it is important to understand why this research is being done and what it will involve for you if you decide to take part. This information sheet will explain everything, so please read it carefully. It should take about 5-10 minutes to do so. Then you can discuss it with others, if you wish.

The study involves a national survey and interviews with a smaller number of bereaved families.

This information sheet is about the interview only.

1. What is the purpose of this study?

This study explores any experiences of end-of-life planning for a relative (or close friend) with mesothelioma, and experience of their last days.

We are doing this because we do not know where people with mesothelioma would prefer to die, the choices of their families, and what is important in making those decisions. We also know very little about experiences of planning ahead, and how families experience the end-of-life of a loved one within different settings (home, hospice, hospital etc).

We aim to use this research to develop resources and recommendations to improve planning for the future and informed choices about care in the last days.

2. Why have I been invited to participate in the interview?

You are invited to take part in the interview if you are: -

- Aged 18 years or above
- You are bereaved after your relative or close friend died of mesothelioma (who was either definitively diagnosed or suspected)
- You live in the UK, or your relative or friend lived in the UK.

3. What does the interview involve?

If you are interested in taking part (and have not filled out the project survey) we will invite you to fill out a short online questionnaire to give us some information about you (such as, your ethnicity, gender, age, whereabouts you live, where your relative or close friend with mesothelioma died e.g. hospital or home). **This is optional**. The purpose of the background information questionnaire is to make sure that we interview a broad range of people with different experiences. If you fill out the background information questionnaire, we will contact you within 2 months to let you know if you are invited to interview. If you are not invited to interview the background information questionnaire data will be deleted.

The interview would involve talking about (i) what helped or hindered any planning ahead; and (ii) the positive and negative aspects of the setting where your relative or close friend with mesothelioma died. The interview will last a maximum of one hour and you can choose how to take part. The interview can take place on the telephone, or via an online video call using Google Meet. We can also offer an email or paper interview whereby the questions are emailed or posted to you, and you can write or type your answers. A stamped addressed return envelope is provided for the written interview.

Interviews will be recorded and then transcribed. At no stage in the research will the identity of the person interviewed be revealed.

If you choose a Google Meet interview you can chose to have your camera on or off. Google Meet recordings will be converted to an mp4 audio format, and the video recording will be deleted as soon as possible. A backup recording will also be made using an encrypted voice recorder. This will be deleted if the Google Meet recording is successful.

Telephone interviews will be recorded by an encrypted voice recorder.

After the interview you will be invited to fill out the Care of the Dying Evaluation questionnaire (CODE). **This is optional.** If you choose to do so, you will be emailed an online link to the CODE questionnaire or if you would prefer a CODE questionnaire will be posted to you with a stamped addressed return envelope. The CODE questionnaire has 37 questions about the quality of care and support in the last days. The purpose of the CODE questionnaire is to provide further information on the quality of care within different settings for the study analysis.

If you choose to take part in an interview and have not taken part in the survey part of the study, you will be invited to complete the survey after the interview. This is optional.

4. Do I have to take part?

No. It is up to you whether you take part in this study or not, and all participation is voluntary. Discuss the study with your colleagues, family, and friends should you wish before deciding.

If you decide at any point to withdraw from the study, please let us know. You are free to withdraw from the study at any point without giving a reason. This would not have any negative consequences and will not exclude you from future studies.

- **Interview**
  If you withdraw within one month of your interview, your data will be removed from the study. If it is beyond one month, data analysis will have commenced and the data that you have provided will be included in the study (all data will be anonymised and kept without your identity being shown).

5. If I am interested in taking part, what do I do next?

Please contact the researcher, Sarah Hargreaves, by emailing (sarah.hargreaves@sheffield.ac.uk) or ringing (0114 222 2406) stating your interest in taking part. Sarah will then be in touch to talk about the study, answer any questions that you may have, and discuss the next steps.

6. Are there any risks to me in taking part in this study?

There are no direct risks to you taking part in this study. The interview aims to explore your experiences of the end-of-life of your relative or close friend with mesothelioma. There is a risk that you may find it upsetting at times to talk about or share your experiences. We have put in place steps to help you feel more comfortable: for example, you will be able to skip any interview questions that you would rather not answer. You can take a break at any time, or you can stop the interview altogether.

There are no right or wrong answers to the interview questions. We are only interested in what you think and what you have to say. We want to hear your views and learn from your unique experience.

The CODE questionnaire aims to find out about the last days of your relative or close friend with mesothelioma and may raise difficult emotions. The CODE questionnaire is optional, and if you choose to take part all questions are optional apart from the opening consent questions. If you feel upset or distressed, you can stop filling out the questionnaire at any time.

7. What are the benefits of taking part for me?

There will be no direct benefits from taking part in this study. However, in the longer-term, results may help us understand more about how people with mesothelioma and their families can be more informed on choosing the place of death and the care which is best for them.

The purpose of the interview is to capture experiences of mesothelioma end-of-life from the perspective of bereaved families or close friends, and people taking part will not receive any additional support. However, all participants will have access to a support sheet with sources of support.

8. What will happen to the results?

Once we have collected all your information on your perspectives of end-of-life due to mesothelioma, we will remove any details that could identify you. We will publish the results in a scientific journal and report.

If you would like us to tell you when we publish findings from the research, please let us know.

9. Will my taking part in the study be kept confidential?

Yes. All data collected will comply with the General Data Protection Regulations (GDPR). This means that we will remove any details that could identify you so that no one will be able to connect you with the data collected. If you did mention any names or locations in the interview that could identify you, or anybody else, these will be replaced with different names/alternative locations.

The only exception to this is if you tell the researcher that you are at risk of serious harm to yourself or others. In this situation, the researcher would discuss this with a relevant professional to ensure that you get any help that you require. If needed, immediate action will be taken, but you would be told about this first.

According to data protection legislation, we are required to inform you that the legal basis we are applying to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.
As we will be collecting some data that is defined in the legislation as more sensitive (information about mental or physical health), we also need to let you know that we are applying the following condition in law: that the use of your data is necessary 'for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

For more guidance on the additional conditions that apply to 'Special Category' personal data, refer to the University's Research Ethics Policy Note no.4 'Principles of Anonymity, Confidentiality and Data Protection and the associated Specialist Research Ethics Guidance Paper.

10. What personal data will be collected about me, and how will it be used?

In addition to your experiences of bereavement, we will collect data about your age, gender, ethnicity, postcode etc. The University of Sheffield research team will have access to this information. The University of Sheffield research team will also have access to your interview. This research data will be used to answer the project research questions.

If you choose to receive information about the later online workshop to develop resources to improve informed decision making on place of death, we will hold your contact details (email) to send this out. **This is optional.**

11. Where will the data be stored?

During the study, the data will be stored securely in The University of Sheffield Google Drive. This is password-protected and has multi-factor authentication. Only the researchers involved in this study will have access to the data. Any paper data will be kept in a secure cabinet that is only accessible by the research team.

When the study has finished and all data is analysed, it will be archived for 10 years in the securely restricted storage provided by The University of Sheffield.

Anonymised data will be stored for 10 years on the University of Sheffield's repository ORDA, and it will be destroyed after this time.

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

You can find out more about how we use your information:

- by asking one of the research team (sarah.hargreaves@sheffield.ac.uk)
- by sending an email to the data protection officer at: dataprotection@sheffield.ac.uk

13. What if there is a problem?

If taking part in this study raises any issues regarding your emotional or support needs, please contact the Mesothelioma UK Support Line on 0800 169 2409, email: info@mesothelioma.uk.com.

If you have any concerns about any research conduct, please do not hesitate to speak to the researcher, Sarah Hargreaves. If you would like to speak to somebody outside of the study, please contact Prof. Judy Clegg.

14. Who is organising and funding the research?

The study has been organised by the University of Sheffield. The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

The study is funded by Yorkshire Cancer Research.

15. Who has reviewed the study?

This study has been reviewed by the University of Sheffield Research Ethics Committee on 27/11/2025. Thank you for taking the time to read this information sheet and considering whether to take part in this study.

Contact details

Thank you for reading this information sheet. Please retain it for reference.

If you have questions or concerns regarding the study, please contact:

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If you would like to speak to someone outside of the study, please contact:

Professor Judy Clegg

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