Participant Information Sheet: Survey

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 would like to invite you to take part in a survey about planning for the future when you are living with mesothelioma, or supporting a relative or close friend living with mesothelioma

We are conducting a survey to find out about your thoughts about planning for the future, what has helped or hindered any planning, and any preferences for care in the last days

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

Data collection will take place through a national survey.

1. What is the purpose of this study?

This study explores experiences of planning for the future and any preferences for care in the last days in people with mesothelioma and their families (or close friends). We are doing this because we know little about this topic.

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. What does this study involve?

This would involve filling out a consent form to record your consent to take part, and whether you agree to how your information will be managed during and after the study. This will be followed by a short survey. There are questions about you, any planning for the future, what has helped or hindered any planning, and any preferences for care in the last days.

It will take about 10 minutes to complete. The survey can be accessed on-line or, or if you would prefer we can send you a paper copy and a stamped addressed envelope (please email sarah.hargreaves@sheffield.ac.uk or ring 0114 222 2406).

At the end of the survey, everyone will be asked if they wish to sign up to receive information about the later online workshop to develop resources.

You will also be invited to forward the link to the survey to any other people you know who have relevant experiences might like to take part in the survey. This will be done to increase the uptake to the survey.

3. Why have I been invited to participate in this study?

You are invited to take part in this study if you are: -

1. **Living with mesothelioma**

- Aged 18 years or above
- Living in the UK

Or 2. **Supporting a relative or close friend living with mesothelioma**

- Aged 18 years or above
- Living in the UK, or living abroad and the person with mesothelioma lives in the UK

If you are not sure if this applies to you, just ask (email: sarah.hargreaves@sheffield.ac.uk; phone: 0114 222 2406).

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. Both before and after beginning to take part in the survey, you are free to withdraw from the study, without giving a reason. If you do choose to drop out there will be no negative consequences and it would not exclude you from future studies. If you have already started or completed the survey, we will be unable to remove your data from the study (however, you will be unidentifiable in any subsequent publications).

5. What are the possible disadvantages and risks of taking part in this study?

We hope that you will have a positive experience if you choose to take part. However we recognise that this is a very sensitive topic, and questions might raise difficult emotions or experiences. We have put in place steps to help you feel more comfortable, for example, you will be able to skip questions that you do not wish to answer. We have also provided information about support services.

There are no right or wrong answers and we are interested in what you think, and have to say, and want to hear your views.

6. 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 future planning experiences and preferences for care in the last days. We aim to develop resources to help people in planning for the future and making informed choices about the last days.

7. What will happen to the results?

Once we have collected the survey data, we will remove any details that might 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.

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

Yes. All data collected will comply with the General Data Protection Regulation (GDPR). This means that we will remove any details that could identify you and that no one will be able to connect you with the research data collected. If you did mention any names or locations in the survey that could identify you, this will be disguised making them unidentifiable or locatable. Data will be presented as an aggregate, for example, we will present age as an age-band.

The only exception is if you disclose in the survey that you are at risk of serious harm to yourself (or others) and have chosen to provide contact details (to take part in the workshop to develop resources). The researcher would then discuss this with a relevant professional to ensure you get any help that you require. If needed, immediate action will be taken, but you would be told about this first. **In most instances this further action will not be possible as we are not routinely collecting participants' full contact details.**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order 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 (about end-of-life choices or experiences), 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.

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

In addition to your experiences of future planning, we will collect data about your age (which will be grouped into an age-band), your gender, ethnicity, etc. We will collect your postcode which will be used to link to national data about geographical areas. The University of Sheffield research team will have access to this information. This research data will be used to answer the project research questions.

10. Where will the data be stored?

During the study the data will be stored securely in The University of Sheffield secure Google drive. This is password protected and has multi-factor authentication. Only the researchers involved in this study will have access to the data.

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

Anonymised data will be stored for 5 years on the University of Sheffield's repository ORDA. It will be destroyed after this time.

11. 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

12. 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 (j.clegg@sheffield.ac.uk)

13. 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.

14. Who has reviewed the study?

This study has been reviewed by the University of Sheffield 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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Email: sarah.hargreaves@sheffield.ac.uk

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

Professor Judy Clegg

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Here are the links to take part in the surveys

1) **Links to the survey for people living with mesothelioma**:
https://shef.qualtrics.com/jfe/form/SV_8GExTHnqLOdcstM

2) **Links to the survey for people supporting a relative (or close friend) living with mesothelioma:**

https://shef.qualtrics.com/jfe/form/SV_4JdAfQbEDi2Y6rQ