



Scans and scanxiety experiences of adults with mesothelioma, pancreatic, brain and liver cancer. Participant information sheet: survey

Introduction

We would like to invite you to take part in a research study on scans and scanxiety experiences in adults with primary mesothelioma, pancreatic, brain and liver cancer.

Undergoing scans as part of cancer treatment and surveillance can cause scan anxiety (the worry people may experience due to scans) for people undergoing the scans. Scan anxiety can occur at any part of the scanning pathway either before, during, or after the scan.

We are conducting a survey to find out the scan and scanxiety experiences of people who have scans and also the care and support needs of people undergoing scans experiencing scanxiety. We are interested in the views of those with or without scanxiety.

Please take time to read this information sheet and discuss with others if you wish. **This Information Sheet is about the survey only.**

What is the purpose of this study?

This study explores the scan and scanxiety experience of adults with primary cancers; mesothelioma, pancreatic, brain and liver. It also explores the care and support needs that are needed when having scans and experiencing scanxiety. This research is being undertaken as there is currently very little known about scanxiety for the cancers mesothelioma, pancreatic, brain and liver. We also have limited understanding of the care and support needs for people experiencing scanxiety.

We aim to use this research to develop the knowledge of scanxiety. It will also be used to understand the care and support needs and an intervention to help manage and prevent scanxiety.

What does this study involve?

It involves filling out a short survey that will take around 10 minutes to complete. There are questions about experiences of scanxiety and what care and support needs are needed to cope and manage scanxiety.

The survey can be accessed online, or if preferred we can send you a paper copy and a stamped addressed envelope (please email clusted1@sheffield.ac.uk).

At the end of the survey everyone will be asked if they wish to take part in the next stage of the study which will involve an interview with a researcher. **This is optional.**

Why have I been invited to participate?

You are invited to take part if you are:

- Living with primary mesothelioma, pancreatic, brain (malignant) and liver cancer and undergoing scans as part of your cancer care.
- Aged 18 years or above.

Do I have to take part?

No. It is your choice whether you take part in the study or not, all participation is voluntary. You may wish to discuss the study with your family and friends before deciding to take part. Both before and after taking part in the survey, you are free to withdraw from the study without giving a reason. If you choose to withdraw from the study there will be no negative consequences. If you choose to withdraw the data that has already been anonymised will be kept.

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 participate in this study. However, we recognise that the questions being asked to explore your experiences of scanxiety could raise sensitive issues or experiences. We have put steps into place to help you feel more comfortable. For example, you will be able to skip questions if you do not want to answer them.

What are the benefits of taking part for me?

There are no direct benefits in taking part in the study. However, the study results could assist in understanding scanxiety experiences of adults with mesothelioma, pancreatic, brain and liver cancer. It will also help to understand and improve the care and support needs of adults with mesothelioma, pancreatic, brain and liver cancer experiencing scanxiety.

What will happen to the results?

When the survey of your experiences has been collected any identifying information will be removed. The results will then be published in an academic journal or report. If you would like us to tell you when we publish findings, please let us know.

Will my taking part be kept confidential?

Yes. All that data collected will comply with 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.

The only exception 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 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 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 (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 legal bases, including the additional conditions that apply to 'Special Category' personal data, refer to the University's Research Ethics Policy Note, and Specialist Research Ethics Guidance paper, on 'Anonymity, Confidentiality and Data Protection': <https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage>.

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

In addition to your experiences of scans, scanxiety and care and support needs, we will collect data about your age band, gender, ethnicity, etc. The University of Sheffield research team will have access to this information. The research data will be used to answer the project research questions.

We will use your name and email to contact you if you decide that you would like to take part in the interview stage of the study. **This is optional.**

Where will the data be stored?

During the study your data will be stored on the University of Sheffield secure restricted storage. 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 10 years on the University of Sheffield's repository ORDA. It will be destroyed after this time.

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 supported by funding from the London Asbestos Support Awareness Group.

Who has reviewed the study?

This study has been reviewed by the University of Sheffield Ethic Committee on: 11/12/25. Thank you for reading this information sheet and considering taking part in this study. Please keep this for future reference.

Where can I get support ?

Mesothelioma UK: <https://www.mesothelioma.uk.com/>

Pancreatic cancer UK: <https://www.pancreaticcancer.org.uk/>

The Brain Tumour charity: <https://www.thebraintumourcharity.org/>

Liver cancer UK: <https://livercanceruk.org/>

If you have any questions or concerns, please contact:

Researcher - Caitlin Lusted

Email: clusted1@sheffield.ac.uk

Supervisor: Dr Rachel King

Email: rachel.king@sheffield.ac.uk

School of Allied Health, Pharmacy,

Nursing and Midwifery

Room 206A

362 Mushroom Lane

Sheffield

S10 2TS

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

Professor Judy Clegg

Email: j.clegg@sheffield.ac.uk

School of Allied Health, Pharmacy,

Nursing and Midwifery

Room 209

362 Mushroom Lane

Sheffield

S10 2TS