

Privacy Notice for Research Participants

This Privacy Notice provides information on how Oxford Brookes University (Oxford Brookes) collects and uses participant's personal information when you take part in one of our research projects. Please refer to the research Participant Information Sheet for further details about the study and what information will be collected about you and how it will be used.

Oxford Brookes is the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it lawfully. We will make the decisions on how your data is used and for what reasons.

Why do we need your data?

The aim of this research study is to find out the views of people who have previously been diagnosed with breast cancer, as to what they think about the signs and symptoms and the possibility of their cancer returning. This includes views regarding the information received or found regarding a recurrence, experiences of 'breast awareness' and self-checking following breast cancer treatment, experiences (if any) of seeking help for any possible signs of recurrence, as well as views about what could help patients in the future. People whose breast cancer has previously come back will also be asked for their views on this topic, as well as health professionals and charity representatives supporting people with breast cancer. Our findings will help us to design a future support resource aimed at helping people with breast cancer to help them feel more confident in being able to recognise and report any possible signs or symptoms of a breast cancer recurrence beyond their treatment.

Oxford Brookes' legal basis for collecting this data is:

Your consent is an ethical requirement. Processing is necessary for the performance of a task in the public interest such as research. Oxford Brookes University's legal basis for processing your Personal Data (or information) is as set out in Art 6 UK GDPR.

Special Category Data:

Oxford Brookes may ask you for sensitive data such as: racial or ethnic origin and data concerning health. This is defined by law as Special Category Data. If Oxford Brookes requests this data it can only be used because one of the following processing exemptions applies as set out in Art 9 UK GDPR:

Oxford Brookes needs to use this data for scientific or research purposes.

What type of personal data will Oxford Brookes use?

We will collect your name, email address and/or (postal address, if email address is not available) and telephone number in order to contact you to arrange an interview or workshop.

If you are taking part in an interview, we will ask if you are able to provide some demographic information about yourself (e.g. your age, ethnicity, marital status, type of cancer diagnosis received).

All data collected from you as part of the interview or workshop will be recorded and transcribed. Any information that could identify you will be removed during transcription. Any personal contact details collected will be stored separately to the transcripts and given password protection. Copies of transcripts will be stored securely on the Oxford Brookes University Google Drive. Once the study is completed your anonymised data (transcripts and consent forms) will be held for ten years by Oxford Brookes University in a data repository (Arkivum) and then destroyed after this time. Your contact details will be deleted once the study has been completed, and any audio files will be destroyed once the data analysis has been completed.

Who will Oxford Brookes share your data with?

Your personal data will only be accessible to the principle researcher (Lauren Matheson) at Oxford Brookes University, and will be stored in a password protected Google drive folder. Data will be stored electronically only. Research team members who are external to Oxford Brookes University (University of Stirling, Guys Cancer, Oxford University Hospitals Trust and Great Western Hospitals Trust) will be able to review anonymised transcripts but will not be able to access any personal contact data.

Will Oxford Brookes transfer my data outside of the UK?

No

What rights do I have regarding my data that Oxford Brookes holds?

- You have the right to be informed about what data will be collected and how this will be used
- You have the right of access to your data
- You have the right to correct data if it is wrong
- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold about you
- You have the right to data portability
- You have the right to object to Oxford Brookes using your data
- You have rights in relation to using your data in automated decision making and profiling.

Your rights will depend on the legal ground used to process your data.

Where did Oxford Brookes source my data from?

You may have seen an advertisement for the study through social media, a charity newsletter, support group or (if you are a health professional) through your professional body or through email invitation. You may have consented for us to contact you about this study when you spoke to your clinical team, or have been posted or emailed information about the study by your clinical team.

Are there any consequences of not providing the requested data?

There are no consequences of not providing data for this research. It is purely voluntary. If you like to withdraw part way through the research, the Participant Information Sheet includes this information. It may be that some of the data that you have provided has already been used in the research. If you would like more information about this, you should feel free to contact the research team.

Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation.

How long will Oxford Brookes keep your data?

In line with Oxford Brookes policies data generated in the course of research, data must be kept securely in paper or electronic form for a period of ten years in accordance with the research funder or University policy. Once the study is completed your anonymised data (transcripts and consent forms) will be held for ten years by Oxford Brookes University in a data repository (Arkivum) and then destroyed after this time. Your contact details will be deleted once the study has been completed, and any audio files will be destroyed once the data analysis has been completed.

Who can I contact if I have concerns?

In the event of any questions about the research study, please contact the research team in the first instance. Their contact details are listed on the Participant Information Sheet. If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee at ethics@brookes.ac.uk. For further details about information use contact the

Information Security Management team on info.sec@brookes.ac.uk or the Data Protection Officer at brookesdpo@brookes.ac.uk. You can also contact the Information Commissioner's Office via their website ico.org.uk.