

Living better with advanced breast cancer (LIBERATE):

Feasibility study of a supportive, self-management website for women living with secondary breast cancer

Additional information for participants

The General Data Protection Regulation (GDPR) came into force on the 25th May, 2018, with the aim of improving the law surrounding data protection and data privacy. This means important changes to how personal information is used for purposes such as marketing and social media, but also applies to information collected from participants involved in health research studies such as this one. Lots of information relating to how we will use and store your data is provided in your participant information sheet. The Health Research Authority (HRA) also require that all participants receive the below further information.

'Personal data' or 'personal information' refers to details about an individual from which they can be identified, either directly or indirectly.

How will we use your personal data in this research study?

The University of Leeds is the sponsor for this study, based in the UK. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 6 months after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Kathleen Kane on um08k2k@leeds.ac.uk or visiting <https://dataprotection.leeds.ac.uk/>.

Personal data you provide

Leeds Teaching Hospital Trust will use your name, date of birth and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Leeds Teaching Hospital Trust will pass these details to the University of Leeds along with the information collected from you and/or your medical records. The only people in the University of Leeds who will have access to information that identifies you will be people who need to contact you with study information, to arrange an interview or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, date of birth or contact details.

Leeds Teaching Hospital Trust will keep identifiable information about you from this study for 6 months after the study has finished.

Personal data from your medical records

If you are a patient at St James' Hospital, Leeds, the University of Leeds will collect information about you for this research study from your medical records at Leeds Teaching Hospitals Trust. This information will include details of your breast cancer diagnosis, treatment and other health conditions you are managing.

If you have any questions relating to how your data will be used, or the research study in general, please contact Kathleen Kane via the details below.

Kathleen Kane, PhD student Email: um08k2k@leeds.ac.uk Tel: 0113 2067580

Patient Centred Outcomes Research Group
Level 6, Bexley Wing
St James' Institute of Oncology
Leeds
LS9 7TF