

Professional Information Sheet

LIBERATE: Living Better with Advanced Breast Cancer

Quality of life interview study

We would like to invite you to take part in a study which will involve discussing your experiences of the care and supportive needs of patients living with secondary breast cancer. Before you decide whether or not you would like to take part, please read the information below. This will explain why we are performing this research and what it will involve for you.

Purpose of the study

The study is part of a PhD project funded by Breast Cancer Now. The overall aim of the project is to develop an online symptom-monitoring and self-management tool specifically tailored to the needs of those living with secondary breast cancer. Usability and feasibility of the intervention will then be assessed within this population of patients, with the aim of better addressing their care and supportive needs throughout their disease.

It is acknowledged that women living with secondary breast cancer encounter a diverse range of symptoms and quality of life concerns which are often very different to those experienced in primary breast cancer. Patients and health professionals must now make increasingly complex decisions in order to harness the potential of treatment advances, whilst maintaining quality of life over a long and varied illness trajectory. However, research into this area remains sparse and there is a recognised need for supportive resources specifically tailored to women with secondary breast cancer.

Why have I been asked to take part?

You have been approached because we would like to gain the perspective of a range of professionals involved in the care and support of women living with secondary breast cancer, in order to guide the development of more tailored support.

Do I have to take part?

No. You are not obliged to take part and you are free to take time to consider your decision before responding. Any decision you do make will be respected.

Should you agree to take part and change your mind prior to interview, you are free to withdraw from the study without giving a reason. If you take part in the interview and later decide that

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you do not want us to use any of the information you have provided, you will be able to ask for it to be removed from the study up to two weeks after your interview date. To request to be withdrawn from the study, please contact Kathleen Kane on [011320 67580](tel:01132067580) or via email at um08k2k@leeds.ac.uk

What will be involved?

If you choose to take part in the study, you will be asked to sign a consent form. The interview itself will be an informal one-off discussion between yourself and the researcher, held in your place of work or over the telephone. Interviews will be audio-recorded and transcribed data will be thematically analysed. All contributions will be anonymised.

Will my confidentiality be maintained?

Yes. Your information and the audio-recording of your interview will be stored securely and access will be restricted to those within the research team. You will be assigned an anonymous study number so that your identity cannot be linked to your contributions. As far as possible, your audio-recording will be transcribed by the researcher undertaking this research, Kathleen Kane (PhD student). Should time become limited, this may be carried out by a University of Leeds approved transcription company, who work in line with strict confidentiality and data protection practices. Your consent form and other personal information (such as name, job role and email and work postal addresses, to allow us to send you information relating to the study to you) will be held in locked filing cabinets in the research offices at St James' University Hospital, with access strictly limited to those within the LIBERATE research team.

What happens to the information I have provided?

The information you provide will be used to guide the development of an online supportive resource. Once the study ends, your personal information (such as name, postal and/or email addresses) will be securely held in a locked filing cabinet in the secure research offices of Bexley Wing, St James' University of Leeds, for six months before it is confidentially destroyed. This is in case you get in touch with us with any queries regarding the study and also allows us to send you a summary of what we have found.

The anonymous information you provide within the interview itself will be stored electronically for five years after the end of the study, within a restricted part of the University of Leeds

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computing system, for use within the three-year overall PhD project and to allow an additional two years for research findings to be shared.

Are there any benefits of taking part?

We hope that the information and experiences you share will help us to develop more effective support for women living with secondary breast cancer, both now and in the future. If you are interested, we would be happy to inform you of future research outcomes.

What happens next?

You are welcome to take as much time as you need to consider this information. We may follow-up with you to see if you would like to be involved. Alternatively, please contact Kathleen Kane via the details below to let us know if you would like to take part.

Thank you for taking the time to read this information sheet.

If you have any questions regarding the LIBERATE study, please contact:

Kathleen Kane, PhD Student. Tel: 0113 20 67580 Email: um08k2k@leeds.ac.uk

Dr Fiona Kennedy, Chief Investigator Tel: 0113 20 68939

Email: f.r.kennedy@leeds.ac.uk

If you are unhappy or dissatisfied with any aspect of this study, we would ask you to contact a member of the research team via the contact details above, so that we can try to address your concerns and find a solution.

If you are not satisfied with our response, you can make a complaint to an independent professional, Claire Skinner. Claire is the Faculty Head of Research and Innovation Support for Medicine and Health at the University of Leeds and will be able to give you independent advice about any problems you are encountering with the research.

Ms Claire Skinner Tel: 0113 343 4897 Email: governance-ethics@leeds.ac.uk