Living better with advanced breast cancer (LIBERATE):

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

Health Professional Interviews

Participant information sheet

As part of the LIBERATE feasibility study, we would like to invite you to take part in a short interview to share your experiences of the LIBERATE intervention in your consultations and to offer your perspective as a health professional.

Before you decide whether or not you would like to take part, please read this information sheet to find out why we are carrying out this research and what it would involve for you.

Background

As you may now be aware, this study is part of the LIBERATE (*'Living better with advanced breast cancer'*) three year PhD project, funded by Breast Cancer Now and supported by Breast Cancer Care. The overall aim of the project is to better understand the needs of women living with secondary breast cancer and to develop and test out an online resource designed to support and address these needs.

Guided by evidence of current online resources supporting patients in the advanced stages of cancer, as well as interviews with secondary breast cancer patients and health and charity professionals, we designed a tailored, interactive website, which you may have come across in your interactions with patients. This comprises a number of features:

- **Holistic health information**: evidence based information on lots of different health and lifestyle topics relevant to secondary breast cancer, brought together in one place.
- **Virtual 'waiting room' of case studies**: a wide variety of cases based on the real life experiences of secondary breast cancer patients, promoting learning through shared experience.
- **Support for others**: a range of information for family, friends, loved ones, colleagues and others affected by the diagnosis of secondary breast cancer, gathered in one place.
- **Signposting support**: a list of websites, resources and support services for women and families coping with secondary breast cancer, alongside guidance on how to search for appropriate support using the internet.
- **Symptom monitoring**: link to an online questionnaire system, developed within our research group, where patients can report on a range of symptoms and issues and receive tailored self-management advice.

You may have encountered the symptom monitoring component through the questionnaire results which are available in participating patients' electronic medical records. Your patients may have also discussed the other self-management, information and signposting components with you, or you may have explored these yourself.

Why have I been invited to take part?

We are interested in speaking to the health professionals whose patients have participated in our study, and who have therefore had the opportunity to view and discuss the results of the symptom monitoring questionnaires which form part of the LIBERATE intervention.

We are also interested to hear your thoughts on the intervention as a whole and whether you have any suggestion for improvements to the intervention or to the study itself.

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 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 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 a private clinic room or over the telephone. Interviews will last for approximately 30 minutes. They will be audio-recorded and transcribed data will later 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 address, to allow us to send you information relating to the study) 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 analysed alongside our other results to determine the feasibility of the LIBERATE intervention and to guide potential further development and evaluation. Once the study ends, your personal information (such as name and email address) will be securely held in a locked filing cabinet in the secure research offices of Bexley Wing, St James's University Hospital, 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 anonymised 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 computing system, for use within the PhD project and potentially within other projects in the research group. With your permission, it may also be shared with other researchers for educational and research purposes. It will not be possible to identify you from this information.

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 Integrity and Governance 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