

Understanding the offer and uptake of support for lifestyle behaviour change following breast cancer treatment

Participant Information Sheet: Healthcare provider survey

The research team from the University of Birmingham and Shrewsbury and Telford Hospital NHS Trust would like to invite you to take part in a research study. Before you decide, we would like to explain why we are doing this research and what it will involve. Please take time to read this information sheet and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information before deciding whether or not to take part. Our contact details are at the end of this information sheet.

What is the study about?

More than half of people who have breast cancer are overweight or obese at diagnosis, and 50-80% gain weight afterwards. People living with excess weight at or after breast cancer diagnosis have poorer outcomes than those with a normal weight. They may also have poorer response to treatment; greater risk of cancer recurrence or secondary cancers and increased overall and cancer-specific mortality. Activities which help people lose weight can improve quality of life and mental health, and maintaining a healthy lifestyle may improve disease prognosis and outcomes. Examples of these activities are eating healthily, exercising and accessing psychological (therapy) support. However, there is no clear way to help people with breast cancer do this, and different activities are provided in different places. This research project aims to describe what lifestyle and behaviour change support is currently offered to breast cancer survivors following diagnosis or during treatment, to identify good practice and to understand some of the challenges. We are asking you to complete a survey about your experiences of providing lifestyle and behaviour change support for people with breast cancer.

Why have I been chosen?

You have been invited to take part because you are a Breast Care Nurse or Cancer Navigator currently working in the NHS in England, whose role includes providing care and support to people who have been diagnosed with breast cancer.

Do I have to take part?

The decision about whether you choose to take part in this survey is entirely up to you. Whether you decide to take part or not will have no effect on your job or legal rights, and you can leave

the study at any time by not submitting a survey response, without giving a reason. However, once your survey response has been submitted, you will not be able to withdraw your data from the study.

What will happen to me if I take part?

If you choose to take part in this study, participation involves completing an online survey that includes closed and free text questions about lifestyle and behaviour change support for people with breast cancer at the NHS Trust where you work. You can contribute as much or as little detail as you like. The survey will take up to 20 minutes to complete. If you wish to save your responses at any time and complete the survey later, you will be able to do so. The survey questions ask about a number of aspects of lifestyle and behaviour change support, such as healthy eating, wellbeing support and advice about physical activity. Questions cover what lifestyle and behaviour change support is offered by your Trust, when in the patient pathway it is offered (e.g. at diagnosis or during treatment), who it is offered to, how it is offered and how it is delivered. We are interested in identifying examples of good practice, but if your Trust does not offer lifestyle and behaviour change support to people with breast cancer or does so in a limited way, we are still interested in hearing from you because an important aim of the survey is to understand how practice varies in different areas.

We also ask whether you would like to take part in an interview in a few months' time to discuss your experiences in more detail with a researcher from the study, and you are free to say yes or no to this and can change your mind about participating in an interview at any time.

Expenses and payments

You will receive a £20 Amazon voucher in recognition of the time you would be giving up in order to complete the survey.

What are the possible benefits of taking part?

Although there is no direct benefit to you if you complete the survey, the surveys we receive will give us important information about the type of lifestyle and behaviour change support that is offered to people with breast cancer and how this varies across England. It will also help us to identify good practice that can help services to improve in the future.

What are the possible risks and disadvantages of taking part?

There are no potential risks associated with completing the survey. The main disadvantage is that it will take some of your time. However, you can complete the survey at a time that suits you, and you can save your responses and come back to them later if you do not have the time to complete the survey in a single session.

What if there is a problem?

If you have any concerns, please get in touch with us using the contact details at the end of this information sheet. If your concerns are not addressed and you wish to make a formal

complaint, you can refer to an independent representative of Shrewsbury and Telford Hospital NHS Trust by using the contact details at the end of this information sheet.

How will we use information about you?

We will need to use information from you for this research project. This information will include your job role and the NHS Trust that you work for, and some basic information about you (sex, age group and ethnic group). If you choose to complete the survey, your responses will be kept strictly confidential and this information will never be used to identify you. The online survey platform (JISC Online Surveys) does not store any cookies, your IP address or any personal information about you. We will ask you to provide your name and preferred email address so that we can send you the £20 Amazon voucher if you would like to receive this. If you provide these details, they will only be used to send you the voucher and will subsequently be deleted. People who do not need to know who you are will not be able to see your name or contact details.

The survey database will be password-protected and stored electronically within a secure folder on the IT network at the Institute for Applied Health Research (IAHR) at the University of Birmingham, using the University's research drive which provides secure, backed up storage of research data. No survey data will be shared outside of University of Birmingham, and anonymised data will be archived under the University of Birmingham's regulations on the management of research data and retained for 10 years. If you choose to provide us with your name and contact details so that we can contact you about participating in an interview, these will be removed from the survey database and stored in a separate, password-protected document and stored securely on the IT network for IAHR at the University of Birmingham. These details will be kept until the interview phase of the research is complete, then they will be deleted. All data collected will be accessible only by members of the core research team involved in the management and analysis of the survey data.

In the survey data analysis, there will be no identifying information. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

Your participation is completely voluntary. You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you have already submitted your survey response, it will not be possible to remove your data from the analysis. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Limits to confidentiality

Your confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. For example, if evidence of a serious crime or professional misconduct

was disclosed, we may have a duty to disclose this to legal or other authorities. If this was the case, we would inform you of any decisions that may limit your confidentiality.

What will happen to the results of the research study?

The information we collect will be analysed and the results will be presented in several ways. We will share our results with professional networks, patient groups, at conferences and in academic journals. We will also make available a short written summary of the results which you can request from University of Birmingham using the contact details at the end of this information sheet.

Who is organising and funding the research?

The research is funded by the National Institute for Health and Care Research (NIHR) Research for Patient Benefit (RfPB) programme. The study leads are based at the Institute for Applied Health Research, University of Birmingham. The research is a collaboration between University of Birmingham and Shrewsbury and Telford Hospital NHS Trust.

Who has reviewed the study?

Ethical approval for the study has been obtained from the Wales5 NHS Research Ethics Committee (REC) (Ref 24/WA/0201; IRAS ID: 332207).

Study sponsorship

The study is sponsored and insured Shrewsbury and Telford Hospital NHS Trust who will act as data controller for this study. Where relevant, representatives of the research sponsor and regulatory bodies will have access to study data for the purposes of monitoring and audit.

Where can you find out more about how your information is used?

You can find out more about how we use your information by asking one of the research team (details below) or by sending an email to Information Governance Support Officer Kellyanne Harrison at Shrewsbury and Telford Hospital NHS Trust (kellyanne.harrison@nhs.net). You can also contact Data Protection Officer Mick Hillman at Shrewsbury and Telford Hospital NHS Trust (michael.hillman@nhs.net).

Contact details for complaints:

If you wish to make a complaint, please contact Research and Innovation Manager Joanne Sawyer at Shrewsbury and Telford Hospital NHS Trust (joanne.sawyer1@nhs.net).

What happens next?

If you wish to complete a survey, please do so using the link provided. If you would like to contact the research team to find out more about the study or to request a summary of the survey results, please use the details below:

The research team:

Dr Sarah Damery (Joint chief investigator and survey lead) (s.i.damery@bham.ac.uk)

Mrs Blossom Lake (Joint chief investigator) (blossom.lake@nhs.net)

Address for the research team: Institute of Applied Health Research, Murray Learning Centre,
University of Birmingham, Birmingham, B15 2TT.