HEARSAY (Have you ever said that?)
EDUCATIONAL E-LEARNING PROGRAMME
DATA COLLECTION

PARTICIPANT INFORMATION SHEET

Managing patients with metastatic breast cancer (MBC) can be challenging. Dynamics within clinical settings are affected by a multitude of issues that can influence communication both positively and negatively. Pitching the dialogue correctly in terms of content or tone is not always easy. What one patient might view as empathic and reassuring, another may find patronising and less than candid. Health Care Professionals can experience quite powerful emotional reactions themselves; having built up relationships with their patients over several years, from primary to advanced disease, means that they too may be affected by clinical outcomes and the messaging they relay.

The e-learning programme comprises filmed patient quotes, a panel discussion, group message board discussions and data presentations. The modules explore how patients react to conversations about diagnosis, prognosis and management options. We consider why some words and phrases help and why others are viewed as contradictory or unhelpful.

We wish to collect participant data to evaluate the efficacy of this HEARSAY e-learning programme before making it available nationally and internationally.

1. Why have I received this information sheet?

You are a healthcare professional working in the metastatic breast cancer setting who has shown interest in the HEARSAY e-learning programme. The content of this sheet provides information about the data we want to collect to evaluate the efficacy of the e-learning programme compared with results from the in-person workshops.

2. What research data will be collected from the e-learning programme?

The research data collected will evaluate the efficacy of the educational e-learning programme on improving communication with patients who have metastatic breast cancer.

There are six mandatory questionnaires to complete, two at the start, two in the middle of the programme and two at the end.

These are: -

- 10-item confidence when communicating with patients who have MBC questionnaire
- 12-item General Health Questionnaire (GHQ-12)
- 16-item Standford Professional Fulfilment Index
- 38-item Navigating Professional Boundaries
- 10-item confidence when communicating with patients who have MBC questionnaire
- 10-item participant feedback on the content of the e-learning programme

3. Do I have to take part?

It is up to you to decide whether or not you wish to take part in this pilot e-learning programme. However if you do participate you will need to complete the mandatory questionnaires as the evaluation of the programme forms part of the research grant.

4. What do I do if I want to participate?

If you decide to take part, please contact adminshore-c@sussex.ac.uk, who will send a link to the online consent form and once completed you will gain access to the e-learning programme.

5. What are the possible benefits of taking part?

We hope participants will have a better understanding of the sorts of words and phrases that are helpful and not so helpful when discussing challenging issues in the MBC setting. Participants will receive CPD points upon completion of the modules.

6. Are there any possible disadvantages or risks of taking part?

The disadvantage to you may be taking time away from clinical responsibilities, however we hope the training experience will improve your confidence in managing challenging conversations better in the future.

7. What about confidentiality?

Research data (completed questionnaire responses) will be stored securely in a password protected database on the University of Sussex MySQL server and identified with a study ID.

Personally identifying information (name, email) used to contact you about the programme and research will be securely stored separately from your research data and will be destroyed at the end of the project. Any published results will feature aggregate responses and anonymous feedback. At the end of the study anonymised questionnaire response data will be deposited on Figshare, the University of Sussex open research data repository, so that it can be used for future research and learning.

8. What will happen to my data if I don't want to carry on with the study?

You can ask to withdraw any of your research data up until 7 days after the programme end date, after which data analysis begins. Please contact the lead researcher if you no longer wish to join or wish to withdraw from the project.

9. What will happen to the results of the research study?

The evaluation of the training materials and impact of the e-learning programme will be published. You can request a copy of the publication by indicating this on the consent form.

10. Who is organising and funding the research?

The HEARSAY e-learning programme is managed by the SHORE-C team at the Brighton and Sussex Medical School, under the direction of Professor Dame Lesley Fallowfield, and funded by the Breast Cancer Research Foundation.

11. Who has approved this study?

The Science, Engineering and Medicine Faculty Research Ethics Committee: Brighton & Sussex Medical School (BSMS) has reviewed and approved this study (Ref:).

12. What if there is a problem?

If you have any concerns or complaints about the conduct of the study or about the way you have been approached or treated during the study, or if you wish to speak to someone outside of the research team, please contact the University of Sussex Research Governance Office via rgoffice@sussex.ac.uk.

13. Contact for further information?

If you would like further information, please contact Professors Dame Lesley Fallowfield / Valerie Jenkins and the SHORE-C team via 01273 873 019.

14. Insurance

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

Thank you for reading this information