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Participant information sheet: Version 1, 4.8.2020

Study title:	Barriers and facilitators to engaging with health services for patients with breast cancer symptoms or a breast cancer diagnosis during the COVID-19 pandemic.
Chief investigator	Heather Drury-Smith
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I am sorry if you have experienced upsetting or worrying symptoms or if you have received a breast cancer diagnosis during the current pandemic. We are concerned about the drop in the number of people attending their General Practitioner (GP) with potential symptoms of breast cancer during the pandemic and lower referrals to cancer services during this period. Our research study wants to investigate patient's experiences of arranging an appointment with a GP or accessing cancer services for a suspected breast cancer during the pandemic. Before you decide, it is important to understand what involvement in the project will mean for you and why the study is being done. If you wish, you may discuss the study with others. Ask us if you need more information or if you are not clear about anything and take time to decide whether you want to take part or not.

The aim of this study is to understand the experiences of people who have noticed or developed a potential breast cancer symptom during the COVID-19 pandemic as well as those people who were diagnosed with breast cancer just before the lockdown in March 2020.

1. What is the purpose of the study?

The purpose of the study is to investigate the reasons why people with potential breast cancer symptoms may not make contact with their General Practitioner, or may find it difficult to make contact with the General Practitioner during the COVID-19 pandemic. We want to identify what barriers and challenges people have faced in seeking an appointment with a General Practitioner (GP) or accessing cancer services for breast cancer treatment during the COVID-19 pandemic.

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2. **Why have I been invited?**

We would like to recruit individuals that have experienced breast cancer symptoms or received a breast cancer diagnosis during the COVID-19 pandemic.

3. **Do I have to take part?**

Your decision to participate in the study is entirely voluntary. A copy of the information provided here is yours to keep, along with the consent form if you do decide to take part. You may refuse to participate, you can withdraw from the study at any time or you can refuse to answer any particular questions asked of you.

4. **What will happen to me if I take part?**

The researcher will contact you to arrange a convenient time for an interview. You will be required to participate in a 1 to 1 interview with the researcher. This will be via a telephone or it may be undertaken electronically via a computer, laptop or tablet depending on your preference. The interview may last up to one hour and will be recorded using an audio recorder. You will be invited to read the data generated by the research after your interview in order to check if the interpretation made by the researcher represents the opinion you offered during the interview; this will likely take 30 minutes of your time. All you have to do is make yourself available at a mutually convenient time and be prepared to discuss your ideas and thoughts, within the interview, as guided by the researcher.

5. **Expenses and payments**

You will not be paid for taking part in this study.

6. **Any possible disadvantages and risks of taking part?**

We do not anticipate that there will be any risks in taking part. We understand that there is a demand on your time and there is some inconvenience in taking part in the interview. You are free at any stage to withdraw from the interview or take time out if you wish. Your wellbeing is of utmost importance during the interview and beyond.

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It is possible that reflecting upon your experiences may bring up emotions and you may become upset. If this does happen the researcher will pause the interview and offer support. If you feel unable to carry on the researcher will stop the discussion. With your permission the researcher will offer to contact someone on your behalf or signpost you to some sources of support which may be able to assist. If you felt able to continue, the discussion would continue. The researcher will respect your wishes and act in accordance with your wishes at all times. You will be reminded that your participation in the interview and the research is voluntary and you can withdraw at any point.

7. Any possible benefits of taking part?

There is no intended benefit to you from taking part in this study. However, the information we get from this study will help us to prepare appropriate information for future patients; G.Ps. and cancer services that will help future patients where they suspect they may have a breast lump or a suspicion they may have breast cancer. You will be contributing to research and education.

8. How will you use what is recorded and reported about me?

The University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of public tasks that are in the public interest. A full statement of your rights can be found at: https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notices/privacy-notice-forresearch

All information that is collected from you during the course of the research will be kept strictly confidential but the project supervisor and other responsible people at Sheffield Hallam will be able to see that you have been interviewed and may read the transcripts of the interviews as part of any audit process.

Direct quotations from the interview may be used when writing up the research however identifying details will be taken out of any final report and any publication so people reading these will not be able to identify you.

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

It is anticipated that the results of the study will be submitted for publication in a high quality research journal as well as being presented at a relevant professional conference. You may receive a summary of the results if you wish. Simply let us know that you would like to receive a summary of the results and we shall email you, once the project is complete.

10. What will happen to the information when this study is over?

All information in the study will be kept confidential. The study documents will be stored electronically on a secure University drive. The researcher will be responsible for the secure archiving of study documents. The study database will also be kept electronically on the secure Sheffield Hallam University database for a minimum of ten years.

11. Who is sponsoring the study?

In this study, the sponsor is Sheffield Hallam University. It is unfunded research.

12. Who has reviewed this study?

All University research is reviewed to ensure that participants are treated appropriately and their rights respected. This study was approved by the Sheffield Hallam University Research Ethics Committee.

If you have any queries or questions please contact:

Principal investigator: *Heather Drury-Smith*
Email: h.drury-smith@shu.ac.uk
Alternatively, you can contact my supervisor: *Professor Heidi Probst*
Email: h.probst@shu.ac.uk

Below are details of who to contact if you have any concerns or if you want to speak with someone after the study:

You should contact the Data Protection Officer if:

- you have a query about how your data is used by the University
- you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately)
- you would like to complain about how the University has used your personal data

Email for Data Protection Officer: DPO@shu.ac.uk
Postal address: Sheffield Hallam University, Howard Street, Sheffield S1 1WBT.
Telephone: 0114 225 5555

You should contact the Head of Research Ethics (Professor Ann Macaskill) if:

- you have concerns with how the research was undertaken or how you were treated

Email for Head of Research Ethics: a.macaskill@shu.ac.uk