

Protocol

A focus group study of the experiences of women diagnosed with secondary breast cancer and their preferences regarding their needs for counselling and information.

MA in Counselling Practice. (Swansea Metropolitan University).

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Academic Supervisor: Dr Ceri Phelps

Clinical Supervisor: Ms Marianne Dillon.

Version 1 23/07/13

1. Introduction

Breast cancer survivors represent the largest population of cancer survivors in the UK, being responsible for over a quarter of the country's two million cancer survivors (Cancer Research UK, 2008). In Wales, one woman in every eight is diagnosed as having breast cancer with approximately 25,000 living in Wales having received the diagnosis in the last two decades (Wales Cancer Intelligence and Surveillance Unit, 2008). When primary breast cancer cells are found in other parts of the body such as bone, liver or lung this is known as secondary or metastatic breast cancer, this mode of transmission would be via the blood or lymphatic system. This indicates the cancer is progressive and not curable. NICE (2002) suggest between 40% - 50% of first time breast cancer survivors are living with secondary breast cancer. Johnston & Swanton (2006) estimated 5-10% of newly diagnosed patients will be metastatic at the time of diagnosis with 20-70% developing secondary breast cancer as time goes on.

NICE (2004) made recommendations regarding needs assessment, information provision and access to psychological support recognising that these guidelines should significantly improve the care of women with metastatic breast cancer. From this document came the recommendation that each patient with a cancer diagnosis should be allocated a key worker to coordinate the patient's care and whom they can contact at any time. Breast Cancer Care (2007) in their standards state this person should be a Clinical Nurse Specialist (CNS) who has knowledge regarding the disease, treatments and support needs acting as advocate and as a link between the woman and the multidisciplinary team (MDT). Ritz, et al. (2000) concluded that contact with a Clinical Nurse Specialist (CNS) reduced levels of uncertainty and reduced levels of morbidity at primary diagnosis or when facing breast surgery (Halkett, et al, 2006) .When patients had access to a CNS, high levels of patient satisfaction were reported by The Department of Health (2012).

Breast Cancer Care (2009) conducted a UK wide cross – sectional survey representing 276 CNS in breast care and revealed 57% believed specialist nursing care provision for metastatic breast cancer patients to be inadequate. In practice, therefore, it appears that there is not the same level of a seamless service of allocation of a CNS for support when a patient is diagnosed with metastatic breast cancer compared to the well established support at initial primary diagnosis (Reed et al., 2010). There have been significant advances in the treatment

and management of secondary breast cancer in particular the availability for entry into clinical trials and targeted therapies such as trastuzumab. These have resulted in the overall survival rates increasing when combined with chemotherapy (Slamon et al, 2001). This has impacted on service provision with the original role of the breast CNS being established to meet the needs of the patient with primary breast cancer. It is now acknowledged that women with secondary cancer have a chronic condition and in some health trusts no designated CNS to support them.

Women with a diagnosis of secondary breast cancer have complex needs reporting a higher level of psychological distress compared to that at receiving a primary diagnosis (Mahon et al. 1990) with themes of uncertainty and lack of control (Hanson-Frost et al. 2000). Breast Cancer Care's 'Spotlight on secondary breast cancer' (2012) have produced standards of care for people with secondary breast cancer and includes women should have their emotional well being regularly assessed and have access to the appropriate level of psychological support at need, at diagnosis, at progression or when treatment changes occur. Currently, therefore, it appears that women with a diagnosis of secondary breast cancer are not always having their information and psychological support needs met.

2. Study Aims/Objectives

The aim of the proposed qualitative study is to explore the experiences of women with secondary breast cancer in terms of their information and support needs. Two separate focus groups with a maximum of 6-8 women in each group will be conducted.

Specific research objectives are:

1. To explore the women's experiences regarding their secondary breast cancer diagnosis.
2. To gain an understanding of the women's needs for emotional support and information since their diagnosis.
3. To discover whether the women feel their needs have been met.
4. To identify the women's preferences regarding types of support.

3. Methodology

A qualitative exploratory focus group study will be carried out to explore the women's experience regarding their diagnosis of secondary breast cancer and to gain an understanding of their perceived needs from the time of their diagnosis to the present time. This study aims to discover whether their needs have been met and to identify preferences for types of support.

Focus groups discussions are an ideal way of obtaining rich narrative information on the lived experiences of a group of people that share something in common and may find themselves in a minority group. The group explores through discussion of a particular topic different viewpoints and opinions and are recorded digitally. McLeod (2011, P71.) states that 'focus groups allow a group of research informants to interact with each other and generate useful qualitative data not only in response to the researcher's questions, but through spontaneous dialogue with each other'. This form of data collection will be suited to the health care environment to be a source to aid in the planning for meeting the future needs of the women with a diagnosis of secondary breast cancer (Breast Cancer Care 2008). The information gathered through focus groups can assist in decision making and planning for the implementation of a policy and care packages (Kruger & Casey, 2000). Focus group methods have been used previously to explore similar issues in patient cohorts. For example, Hughes & Phelps (2010) investigated preferences for an ongoing support network in cancer gene carriers using focus groups. The study informed the development of an appropriate support network based on a hub and spoke model to help carriers and their families adapt to living and coping with their genetic risk.

4. Sample

The study will involve women who have been diagnosed with secondary breast cancer who are under the care of the oncology department at Singleton Hospital, Swansea. The researcher will use a purposive sample of women with secondary breast cancer as this group would be the best available to provide the data for the area of study (Parahoo, 1997).

This study will run two focus groups with a maximum of six-eight women in each; the focus groups would be convened on different days in order to capture a larger sample across the

two groups while keeping the number in any one group relatively small. The aim of the small number would be to create an environment in which the women would feel comfortable and at ease to share their views regarding their experiences.

Although there are no definitive guidelines on a number of participants for a focus group, between 6 and 13 participants will work well depending upon the complexity of the topic (Carter & Thomas 1997, Bowling 2002). It is hoped the group commonality and inclusion will encourage effective interaction and in-depth discussion. It is recognised that if the members of a group are too diverse, due to a wide range of views and experiences this may potentially reduce the narrative flow and data collection (Bloor et al, 2001). The groups will take place in Maggie's Caring Centre at Singleton Hospital in Swansea following agreement with the Director of the centre.

5. Recruitment

The research student is a qualified nurse for 32 years working as a Clinical Nurse Specialist in breast cancer care. The researcher would not be directly involved in recruiting women into the study. She will not directly approach her own patients; however if her patients became aware of the study through the posters and they decided they would like to take part they will be allowed to do so providing they meet the inclusion criteria.

A poster (see appendix I) advertising the focus group study with an invitation to take part would be placed on an information board in the breast, oncology clinic and Maggie's Caring Centre by a superintendent radiographer / nurse working in each of these departments whom are not involved directly with the study. The poster will contain contact numbers for the women if they wish to obtain more information regarding possibly taking part in the study. The work contact numbers on the information sheet would be of the researcher including her student email address, the academic supervisor and a breast care nurse.

If interest is expressed then a participant information sheet (see appendix II) and consent form (see appendix III) would be posted out. The consent form explains the study would be recorded and the participant's identity would be confidential. It states the participants have the right to withdraw from the study at any time and the decision whether to take part or not would not influence their treatments. The consent form states that permission is sought to

view information in the medical notes by the clinical supervisor. The women who consent to take part in the study will be asked to retain a copy of the information sheet and to sign and return the consent form to the researcher (via the Academic Supervisor's postal address at Swansea Metropolitan University) in a pre-paid envelope within two weeks of the consent form being sent out.

Once the consent forms are returned the researcher will then make arrangements to confirm the venue of the focus groups, date and time to take place and then contact the group members to arrange a suitable date to attend the focus groups. The splitting of the participants into two focus groups would be with the help of the clinical supervisor taking age and site of metastases into account to try and balance the focus group.

The researcher has considered access for special mobility requirements and style of chairs or furniture and the use of cushions to aid positioning. This will be discussed with the staff at Maggie's Caring Centre once final participants are known.

6. Inclusion and Exclusion Criteria

Whether potential participants meet the inclusion/exclusion criteria prior to being consented into the study will be judged by the woman's oncology team and the Clinical Supervisor who is also an Oncoplastic Surgeon and the researcher.

Inclusion criteria.

- The women would have a definite diagnosis of metastatic breast cancer made by either cytology or tissue biopsy or by radiological investigation to allow entry into the study.
- Women with bone, brain, liver and lung metastases would be included in the study.

Exclusion criteria.

- The woman becomes an oncological emergency (may develop spinal cord compression, hypercalcaemia, cerebral oedema or neutropenia warranting urgent hospital admission for appropriate treatment. This would apply if the focus group date was during the woman being an inpatient in hospital.

- Any patient considered too psychologically vulnerable by the clinical team to participate in the study (e.g., recognised mental health or other problems causing significant distress).

7. Data Collection

Following receipt of the consent forms, the participants will be invited by telephone or email to one of the two focus groups. The focus groups would be organised so they would not take place on the same day. Each focus group will last between 60 – 90 minutes and will be held at Maggie's Caring Centre, Sketty Lane, Swansea. The student Ann Baker will facilitate the groups, with the help of a co-moderator and experienced focus group moderator. (Dr Ceri Phelps – Chief Investigator).

A semi structured topic guide based around open-ended questions and follow-up prompts where necessary (see appendix IV) developed from earlier literature and discussions with colleagues will be used to guide the focus group discussions. The discussions will be recorded following informed consent. Regular summaries of the key issues emerging in each focus group will be fed back to participants during the course of the meetings in order to validate the issues identified by the moderator with the participants. Each participant will also be given a report after the focus groups have been completed in order for them to confirm that it is an accurate representation of their views and thus ensure respondent validation.

8. Data Analysis

The researcher will transcribe the recordings of the focus groups and analyse the transcript using interpretative phenomenological analysis (Smith et al, 2009). Using interpretative phenomenological analysis (IPA) framework to analyse the life experiences of the women with a diagnosis of secondary breast cancer will aid understanding of their making sense of their situation. Smith et al (p79, 2009) 'the essence of IPA lies in its analytical focus' enabling the focus on 'how people perceive an experience, or rather what an experience means for them: a focus on the life world' (Langdridge, 2007).

Each line of the transcript will be numbered and the page layout will accommodate wider left and right margins. Stage 1 - the transcript will be read and re-read and initial notes will be made in the left hand margin. The researcher in stage 2 will make notes in the right hand margin of emerging themes and from this will attempt to list themes on a separate paper identifying some common themes or clusters. The researcher will continue to work through the text becoming more familiar reordering and restructuring the themes, returning to the text to check the meaning or emerging analysis has not been lost. The researcher is aware of needing to bracket her own experience and knowledge of being a Clinical Nurse Specialist in breast care and her encounters of women with secondary breast cancer as this would possibly give an expectation of outcome themes. The researcher would produce a table of themes and link theme to line numbers. The themes are presented in the presentation of findings by marrying up the theme to relevant line number and quote to support.

9. Project Management

The proposed study will form a student dissertation for the MA in Counselling Practice. Dr Ceri Phelps will be the academic supervisor for the student researcher and Ms Marianne Dillon Consultant Oncoplastic Breast Surgeon will provide clinical support and monitor breast/cancer services. For the purpose of this study Ms Dillon would view the medical notes and radiology reports (permission taken on the consent form) confirming the participants' eligibility into the study. She would also help to split the final number of participants into two groups, age and site of secondaries will be considered to try and balance the focus groups if possible.

10. Ethical considerations.

Confidentiality:

All information gathered during the focus groups will remain confidential and this will be highlighted as part of the informed consent procedure. Written consent will have already been obtained, the consent forms will have been returned in the post to Dr Ceri Phelps co-moderator.) Ethical approval will be sought from the NHS and the School of Psychology and Counselling Ethics Committee bound by BPS/BACP. The participants will have given written consent to take part in the study which included the transcribing of the digital

recording and permission for Ms Dillion and the researcher to have access to medical notes and radiology reports to confirm eligibility into the study. During the focus group discussions, the participants will only be identified by their first name and names or other potentially identifying information on the completed written transcripts (e.g. mention of specific events or individuals) will be removed or modified. The participants will be informed their names will be changed so to protect their identity and to give them anonymity. Confidentiality is paramount because the participants will be discussing their experiences (BACP, 2010). Any published data will be anonymised in accordance with the Data Protection Act 1998. The participants name will be allocated a code; the codes will be kept in a safe this will be in a different room from the transcript. The discussions will be audio recorded and transcribed. Only the researcher will have access to the tape and transcriptions, which will be kept in a secure place. The tapes will be destroyed within 48 hours of the focus group taking place once they have been uploaded to the computer. The computer is password protected.

Each of the two groups would be allocated a code and each participant would be identified by a coded number. The codes would be kept in a 'safe' that would be locked with a key kept in a separate room to the transcript and computer.

Potential for Distress:

In order to minimise any potential distress during the course of the focus groups:

- Participants will be reminded at the start of each session that participation is entirely voluntary and that they are not obliged to answer any of the questions;
- It will be emphasised to participants that they are free to take a break or leave the session at any time without providing any explanation;
- During the discussions, if participants find any of the topics raised distressing, they will be given the opportunity to discuss their concerns with the researchers in private.
- The researcher (a qualified nurse specialising in breast cancer) will be present for both focus groups as will the co-moderator Dr Ceri Phelps Health Psychologist. The researcher will be present to deal with any highly sensitive questions or concerns that may arise during the course of the discussions;

- If, at any time during the course of the focus group, the researcher (Ann Baker) or co-moderator (Dr Phelps) perceives that the conversation is beginning to create distress or stress for one or more of the participants involved, Ann Baker or Dr Ceri Phelps will stop the discussion and introduce a small break in the proceedings, before returning to a more general topic of discussion.
- The women would be informed that if during the focus group they feel upset or wish to have a break they can do so.
- They also have the opportunity to withdraw from the study during the focus group.
- The co-moderator would be present to monitor any triggers that may create vulnerability.
- The participants would be in Maggie's Caring Centre and there would be the availability for them to make an appointment with the psychologist based in Maggie's.
- A Secondary Breast Cancer Care Resource pack which contains the contact number to professional Secondary Breast Specialist Nurses would be offered.
- The participants would be offered refreshments at the end of the focus group and a toilet break.
- While it is hoped that participants will welcome the opportunity to talk about their experiences and their needs of living with metastatic breast cancer there is a need to be aware that some women may find the sensitive nature of the topic under discussion distressing.
- The work contact number of student researcher would be given in case the women had any queries and also the contact numbers on an information sheet would be handed out for Maggie's and Breast Cancer Care if the women needed help and advice

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Have you been diagnosed with secondary (metastatic) breast cancer?

Would you will be willing to attend a discussion group and talk about the support and information you have received?

I am a Clinical Nurse Specialist in Breast Care studying for MA in Counselling Practice. As part of my study I am undertaking a small research project.

The project wishes to gain an understanding of the experiences of women diagnosed with secondary (metastatic) breast cancer and their preferences regarding their needs for counselling support and information. I am hoping to hold two discussion groups with women who have been diagnosed with secondary (metastatic) breast cancer. These discussion groups will be held at the Maggie's Cancer Caring Centre, Singleton Hospital.

If you are interested in taking part and would like to find out more about the study please contact me.

Ann Baker. Work 01792 285265. Or email me:

mbaker.013102@students.smu.ac.uk

Or alternatively contact the academic supervisor Dr Ceri Phelps:

01792 482084 or email ceri.phelps@smu.ac.uk

You may also seek independent information regarding taking part in the study from Breast Care Sisters Heidi Handley and Alison Marks who are not part of the study. Please call the Breast Care Centre on 01792 285265.

Thank you for your time.



SWANSEA METROPOLITAN UNIVERSITY
PRIFYSGOL FETROPOLITAN ABERTAWE

Participant Information Sheet Version 1 (23/07/2013)

Part one.

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

- The aim of the study is to hold a discussion group with women, who have secondary (metastatic) breast cancer.
- These discussions will explore your experiences of the support you have received.
- These discussions will try and identify any additional support you feel you may require.

Why have I been invited?

- You have been invited to take part because you have secondary (metastatic) breast cancer and
- You have been sent this information as you have expressed interest in taking part in a discussion group.

Do I have to take part in the study?

- The study is voluntary; it is up to you to decide to join the study.
- If you decide to take part in the study you are still free to withdraw at any time, without giving a reason.
- The decision to take part or not will not affect the standard of care you receive.

What will happen in the group discussion?

- The discussion group will be relaxed and will be conducted at a time and date convenient to all participants at Maggie's Caring Centre, Singleton, Swansea.
- The group discussion will last between 60 – 90 minutes. There will be refreshments and toilet facilities.
- Although the discussion group will be digitally recorded, the interviewer will take notes of the most relevant points.
- Only the researcher will hear the recording and have sight of the notes. Recorded and written material will be kept securely and destroyed once research is finalised.
- Involvement in the study will be confidential, data collected will be made anonymous and no comment or circumstance which could be directly connected to any participant will be identifiable

What do you I need to do if I wish to take part?

- Please read this information sheet and feel free to contact the numbers if you feel you would like more information.
- If you agree to take part please sign and return the consent form within two weeks in the stamped addressed envelope.

Part two.

What if there is a problem?

- If participation brings up upsetting material please speak to the researcher or if you have left the group please contact her as soon as possible. She will provide you with details of Breast Cancer Care Services / Maggie's Caring Centre where you will have the opportunity to speak to a nurse, counsellor, or psychologist.
- If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Ann Baker. Work 01792 285265. Or email me - mbaker.013102@students.smu.ac.uk).
- Should you have any problem with the research process or wish to complain formally Please contact Dr Ceri Phelps (01792 482084 or email ceri.phelps@smu.ac.uk)

Who has reviewed the study?

- All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests.

Will my taking part in the study be kept confidential?

- You will be identified by your first name only during the group discussions and any published data will be anonymised in accordance with the Data Protection Act 1998. Your name will be allocated a code. The codes will be kept in a safe this will be in a different room from the transcript.
- The discussions will be audio recorded and transcribed. Only the researcher will have access to the tape and transcriptions, which will be kept in a secure place. The tapes will be destroyed within 48 hours of the focus group taking place once they have been uploaded to the computer. The computer is password protected.

What will happen to the results of the research study?

- The results will form part of an MA student dissertation, and may also be published in a relevant journal. They may be presented at relevant conferences.
- The results of the study may be used to inform the development of the services for supporting women with secondary breast cancer.

Who is organising and funding the research?

- This study will contribute to an MA in Counselling Practice at Swansea Metropolitan University.
- The Breast Care Fund of the Breast Care Centre Singleton Hospital will cover the cost of petrol for the journey and would also cover the cost for refreshments pre and post focus group study.

What if I have any other questions?

Please do not hesitate to contact me by telephone. On 01792 285265 (work) or email mbaker.013102@students.smu.ac.uk

If you feel you would like to talk to someone for support Breast Cancer Care 0845 0771894 or cym@breastcancercare.org.uk

A resource pack is also available from The Secondary Breast Cancer Care which contains the contact number to professional Secondary Breast Specialist Nurses.

Thank you for taking time to read this information sheet.

Ann Baker.



SWANSEA METROPOLITAN UNIVERSITY
PRIFYSGOL FETROPOLITAN ABERTAWE

Title of Project: A focus group study of the experiences of women diagnosed with secondary (metastatic) breast cancer and their preferences regarding their needs for counselling support and information.

Name of Researchers:
Ann Baker /Dr Ceri Phelps

Participant identification code :

1. I confirm that I have read and understand the information sheet dated 23/07/13 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes to ensure that I fulfil the criteria for entry into the study and the data collected during the study may be looked at by responsible individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
4. I agree to the discussions being tape-recorded, and agree that any words I may say during the discussions can be used anonymously, in the presentation of the research	☐
5. I agree to take part in the above study.	☐

Name of Participant

Signature

Date

Contact telephone

Contact email address

Please return this form via post within 2 weeks.

I would like to have sight of the research findings when these are produced

Yes/No

FOCUS GROUP – INTERVIEW SCHEDULE

Welcome and introductions with refreshments and toilet facilities.

Opening: Thank you all for coming today.

- The reason you are all here is because we want to explore experiences of women diagnosed with secondary (metastatic) breast cancer and their preferences regarding their needs for counselling support and information.
- I (The student researcher) have a few house keeping rules to mention before we can start.
- I need to inform you where the fire exit and toilet area are and to explain if anyone wishes to stand or change their seating during the discussion they could feel free to do so.
- I would also say if at any point anyone wishes to leave or to use the toilet to feel free to do so.
- Before starting the audio recording I will explain you have all agreed and consented to the discussion being audio recorded and agreed that any words said during the discussions can be used anonymously, in the presentation of the research. Are there any questions?
- Also I will confirm that everything we talk about will only be listened to by the researcher, me, Ann Baker.
- I will need to make some notes during the discussion to help supplement the audio recording and these would be transcribed and the hand written notes would be shredded.
- I wish you to know you are free to withdraw from the study at any time and do not have to give a reason and your travel expenses will still be refunded,
- I would also say that today is for research purposes and although some of you will know me in my capacity as a Breast Care Nurse, this discussion group is for my dissertation for my MA in Counselling Practice. Therefore if you do have any clinical issues or if following our discussions you wish to discuss anything which is not relevant to today then please do not hesitate to talk to me after or phone me.
- In order to get all of your views and opinions, please don't be offended if we need to move on at any point. And it would be really helpful if you could talk clearly and try not to talk over each.
- I would just also like to check that everyone is happy with what certain terms mean e.g. secondary or metastatic. Please let me know if I say anything that you aren't familiar with or don't understand and I will explain.
- So if everyone is happy for me to move on and has no questions (pause)...

Introductory Question

- Lets start by going round and introducing ourselves just saying our name and where we have travelled from today, I will go first.

Key question 1:

- What type of support was offered to you at the time of your diagnosis of secondary breast cancer?

Prompt:

- information from professionals/psychological support/peer support etc.

Transition – Thank you that was really helpful.

Key question 2 :

- Can you say what you found most helpful since your diagnosis?

Prompt:

- coping strategies used eg relaxation techniques, counselling and or distraction techniques.

Transition – Thank you. That was very informative. I would like you to take some time and think about your needs regarding what you were offered versus what you wanted?

Key question 3:

- At the time of your secondary diagnosis were you given the information you needed?

Prompt – Secondary Breast Cancer Resource Pack? Offered benefits advice? Counselling?

Key question 4:

- What information would you like made available to you?

Prompt:

- Information on groups, one to one support? What format would you prefer ?

Transition – thank you that is really useful to know. I wonder if it is possible to think a little about your feelings.

Key question 5:

- Do you feel your emotional well being is regularly assessed?

Prompt- by whom? A nurse, support group, counselling service.

Transition – Can you think about whom you would choose to see regarding your emotional well being.

Key question. 6:

- Can you tell me about someone you can contact if you need to discuss how you are feeling? If you have any concerns?

- Prompt – Have you asked for advice about any symptoms example pain fatigue, breathlessness or coping with your diagnosis. A nurse, GP, Support service ?

Key question 7:

- Have you been informed about any counselling services, support groups or centres in your area?

Prompt – can you tell me a little more on how you came to be aware of the services?

Key question 8:

- How would you feel if you were offered counselling?

Prompt – are there any factors that would influence you accepting an offer for counselling?

For example distance, transport, child care, timing of appointment?

Ending

Thank you for sharing and being so open with your responses. I would like to close the group discussion but before I do would any of you like to add anything.

Close focus group – State that if any of the women would like to speak individually or have concerns to let the student researcher know now.

Invite the women for refreshments and toilet facilities.

It would be vital to have a debriefing to monitor any triggers that may create vulnerability. The women need to feel they are in a safe environment and the student researcher and clinical psychologist need to be sure the women are emotionally safe to leave the facility of study to return home.

The contact number of student researcher would be given also the contact numbers on an information sheet would be handed out for Maggie's and Breast Cancer Care if the women needed help and advice.

Offer 'The Secondary Breast Cancer Care' resource pack which contains the contact number to professional Secondary Breast Specialist Nurses.