SWEET - Follow up Questionnaire

Trial ID: ☐☐☐☐ **Initials:** ☐☐☐

Timepoint:

☐ 6month follow-up
☐ 12month follow-up
☐ 18month follow-up

Office use only

ABOUT THESE QUESTIONS

Thank you for taking part in the SWEET study. This questionnaire asks about you, your experiences and views of breast cancer and hormone therapy and how people with breast cancer use the health and care services available to them. Please try and complete all the questions in full, even if they seem similar or repetitive as this will help us to collect the most reliable information for the study. **If questionnaires are not fully completed, it will affect the success of the study - that means it is less likely that the study will be able to help other women with breast cancer in the future.**

Once you have completed this questionnaire, please return it to your local research team, or return it directly to the SWEET trial office using the pre-paid envelope provided.

SWEET Trial Office
Warwick Clinical Trials Unit,
Warwick Medical School
University of Warwick
Coventry, CV4 7AL

There are no right or wrong answers - we just want to hear about your own views and experiences. Everything you tell us is **completely confidential –** we won't share your questionnaire with any of the doctors or nurses involved in your care, or anyone outside the research team. The questionnaire should take approximately **25-40 minutes to complete.** You may find it easier not to complete it all in one go.

If you have any questions or difficulty completing the questionnaire, please contact your local research team.

Throughout the questionnaire you will find references to **hormone therapy.** This is sometimes called endocrine therapy and refers to any of the following medications:

- tamoxifen
- anastrazole (Arimidex®)
- letrozole (Femara®)
- exemestane (Aromasin®)

Please answer the questions with regards to the hormone therapy you have been prescribed, **even if you are not currently taking it**.

SECTION A: About your hormone therapy

This section is about your experiences of, and what you think about, taking hormone therapy.

A1. Please enter today's date:

A2. Please rate the information you have received or obtained about each of the following aspects of your hormone therapy (e.g. tamoxifen, letrozole, anastrazole, exemestane).

	Too much	About right	Too little	None received	None needed
What your hormone therapy is for	☐	☐	☐	☐	☐
What it does	☐	☐	☐	☐	☐
How it works	☐	☐	☐	☐	☐
How long you will need to be on your hormone therapy	☐	☐	☐	☐	☐
How to take your hormone therapy	☐	☐	☐	☐	☐
How to get a further supply	☐	☐	☐	☐	☐
Whether the hormone therapy has any unwanted effects (side-effects)	☐	☐	☐	☐	☐
What are the risks of you getting side-effects	☐	☐	☐	☐	☐
What you should do if you experience any unwanted side-effects	☐	☐	☐	☐	☐
Whether hormone therapy interferes with other medicines	☐	☐	☐	☐	☐
Whether hormone therapy will affect your sex life	☐	☐	☐	☐	☐
What you should do if you forget to take a dose of hormone therapy	☐	☐	☐	☐	☐

A2a. How did you receive or obtain information about hormone therapy? (please tick all that apply)

☐ Breast cancer doctor
☐ Breast cancer nurse
☐ GP
☐ Attended workshop or course (please specify)
☐ Charity websites or information leaflets/booklets
☐ HT&Me Support Package
☐ Other (please specify)

A3. How frequently do you take your hormone therapy?

Daily	☐	Most days	☐	At least 3 times a week	☐	At least once a week	☐	Less than once a week	☐	Not at all	☐

A4. How many of your hormone therapy tablets have you taken *in the past 7 days*?

A5a. Since you started the SWEET study, have you switched types of hormone therapy (e.g. changing from anastrazole to letrozole)?

Yes	☐	No *If No, please go to question A6a.*	☐

A5b. If yes, what type of oral hormone therapy are you currently being prescribed?

tamoxifen	☐	anastrazole	☐	letrozole	☐	exemestane	☐	other (please specify	☐

A5c. If you have switched treatments, approximately when did you switch?

A5d. Why did you switch treatments?

A6a. Since you started the SWEET study, have you stopped taking your hormone therapy completely?

Yes	☐	No *If No, please go to question A7*	☐

A6b. If yes, approximately when did you stop taking it?

A6c. If yes, why did you stop taking it?

<u>If you have stopped taking your hormone therapy, please answer the remaining questions thinking about how you felt when you were *last taking hormone therapy.*</u>

A7. We would like to ask you about your personal views about your hormone therapy. These are statements other people have made about their hormone therapy. Please show how much you agree or disagree with them by ticking the appropriate box.

There are no right or wrong answers, we are interested in your personal views.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Having to take hormone therapy worries me	☐	☐	☐	☐	☐
I sometimes worry about the long-term effects of taking hormone therapy	☐	☐	☐	☐	☐
Hormone therapy is a mystery to me	☐	☐	☐	☐	☐
Taking hormone therapy disrupts my life	☐	☐	☐	☐	☐
I sometimes worry about having to take hormone therapy over a long period of time	☐	☐	☐	☐	☐
My health at present depends on me taking hormone therapy	☐	☐	☐	☐	☐
Taking hormone therapy makes me feel I am taking positive steps to remain well	☐	☐	☐	☐	☐
Without taking hormone therapy I would be more likely to develop breast cancer again	☐	☐	☐	☐	☐
My health in the future will depend on me taking hormone therapy	☐	☐	☐	☐	☐
Hormone therapy protects me from becoming ill	☐	☐	☐	☐	☐
I have been supported to make the right decision for me about taking hormone therapy	☐	☐	☐	☐	☐
All my questions about hormone therapy have been answered	☐	☐	☐	☐	☐
The pros and cons of hormone therapy are clear to me	☐	☐	☐	☐	☐
I have received all the support I need around taking hormone therapy	☐	☐	☐	☐	☐
I am fully informed about my breast cancer	☐	☐	☐	☐	☐
I have many unanswered questions about hormone therapy	☐	☐	☐	☐	☐
I am clear about the benefits and risks of hormone therapy	☐	☐	☐	☐	☐

A8. Many people find a way of taking their hormone therapy tablets which suits them. This may differ from the instructions on the label or from what their doctor had said. We would like to ask you a few questions about how you use your hormone therapy.
Here are some ways in which people have said they use their hormone therapy. For each statement, please tick the box which best applies to you *in the past month.*

	Always	Often	Some-times	Rarely	Never
I forget to take my hormone therapy tablets	☐	☐	☐	☐	☐
I alter the dosage of my hormone therapy tablets	☐	☐	☐	☐	☐
I stop taking hormone therapy for a while	☐	☐	☐	☐	☐
I decide to miss out a dose	☐	☐	☐	☐	☐
I take less hormone therapy tablets than instructed	☐	☐	☐	☐	☐

A9. Please indicate the extent to which you agree or disagree with each of the following statements.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I intend to take my hormone therapy every day	☐	☐	☐	☐	☐
I have a plan regarding **when** to take my hormone therapy (e.g. morning)	☐	☐	☐	☐	☐
I have a plan for **how** to take my hormone therapy when my routine changes (e.g. holidays)	☐	☐	☐	☐	☐
I am confident that I can take my hormone therapy every day for as long as has been prescribed	☐	☐	☐	☐	☐

SECTION B: How you feel

This section is about how you feel, and any side-effects of your breast cancer and its treatment.

B1. Below is a list of statements that other women with breast cancer have said are important. Please tick one box per line to indicate your response as it applies *to the past 7 days.*

	Not at all	A little bit	Some-what	Quite a bit	Very much
I have a lack of energy	☐	☐	☐	☐	☐
I have nausea	☐	☐	☐	☐	☐
Because of my physical condition, I have trouble meeting the needs of my family	☐	☐	☐	☐	☐
I have pain	☐	☐	☐	☐	☐
I am bothered by side effects of treatment	☐	☐	☐	☐	☐
I feel ill	☐	☐	☐	☐	☐
I am forced to spend time in bed	☐	☐	☐	☐	☐
I feel close to my friends	☐	☐	☐	☐	☐
I get emotional support from my family	☐	☐	☐	☐	☐
I get support from my friends	☐	☐	☐	☐	☐
My family has accepted my illness	☐	☐	☐	☐	☐
I am satisfied with family communication about my illness	☐	☐	☐	☐	☐
I feel close to my partner (or the person who is my main support)	☐	☐	☐	☐	☐
I am satisfied with my sex life *(please answer this question regardless of your current level of sexual activity. If you prefer not to answer, please skip to the next question.)*	☐	☐	☐	☐	☐

Please continue answering the questions below:

I feel sad	☐	☐	☐	☐	☐
I am satisfied with how I am coping with my illness	☐	☐	☐	☐	☐
I am losing hope in the fight against my illness	☐	☐	☐	☐	☐
I feel nervous	☐	☐	☐	☐	☐
I worry about dying	☐	☐	☐	☐	☐

	Not at all	A little bit	Some-what	Quite a bit	Very much
I worry that my condition will get worse	☐	☐	☐	☐	☐
I am able to work (including work at home)	☐	☐	☐	☐	☐
My work (including work at home) is fulfilling	☐	☐	☐	☐	☐
I am able to enjoy life	☐	☐	☐	☐	☐
I have accepted my illness	☐	☐	☐	☐	☐
I am sleeping well	☐	☐	☐	☐	☐
I am enjoying the things I usually do for fun	☐	☐	☐	☐	☐
I am content with the quality of my life right now	☐	☐	☐	☐	☐

B2. Have you been bothered by any of these symptoms in the past four weeks? Please tick one box per line to indicate how bothered you have been in the *past 4 weeks.*

	Not at all	Slightly	Moderately	Quite a bit	Extremely
Hot flushes	☐	☐	☐	☐	☐
Night sweats	☐	☐	☐	☐	☐
Joint pain	☐	☐	☐	☐	☐
Muscle stiffness	☐	☐	☐	☐	☐
General aches and pains	☐	☐	☐	☐	☐
Vaginal dryness	☐	☐	☐	☐	☐
Pain with intercourse	☐	☐	☐	☐	☐
Forgetfulness	☐	☐	☐	☐	☐
Difficulty concentrating	☐	☐	☐	☐	☐
Easily distracted	☐	☐	☐	☐	☐
Weight gain	☐	☐	☐	☐	☐
Unhappy with appearance of my body	☐	☐	☐	☐	☐
Genital itching/irritation	☐	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐	☐
Sleep problems	☐	☐	☐	☐	☐
Irritability or mood changes	☐	☐	☐	☐	☐

B3. Please rate your confidence in your ability to cope with the following symptoms on a scale from 1 (not confident) to 10 (very confident). Please circle one number on each row. If you haven't had a specific symptom, please tick the not applicable (N/A) option.

	N/A	Not at all confident									Totally confident
Hot flushes	☐	1	2	3	4	5	6	7	8	9	10
Night sweats	☐	1	2	3	4	5	6	7	8	9	10
Joint aches and pains	☐	1	2	3	4	5	6	7	8	9	10
Sexual problems	☐	1	2	3	4	5	6	7	8	9	10
Fatigue	☐	1	2	3	4	5	6	7	8	9	10
Sleep problems	☐	1	2	3	4	5	6	7	8	9	10
Changes in mood	☐	1	2	3	4	5	6	7	8	9	10
Memory problems	☐	1	2	3	4	5	6	7	8	9	10
Weight changes	☐	1	2	3	4	5	6	7	8	9	10
Emotional problems	☐	1	2	3	4	5	6	7	8	9	10

B4. Please rate your confidence in your ability to do the following things on a scale from 1 (not at all confident) to 10 (totally confident). Please circle one number on each row.

	Not at all confident									Totally confident
Get support from friends and family if you have any problems with your hormone therapy?	1	2	3	4	5	6	7	8	9	10
Get support from health professionals if you have any problems with your hormone therapy?	1	2	3	4	5	6	7	8	9	10

SECTION C: About your breast cancer

This section asks about your beliefs about your breast cancer and hormone therapy.

C1. We are interested in views you hold currently about your breast cancer and hormone therapy. Please indicate how much you agree or disagree with the following statements about breast cancer by ticking the appropriate box.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Hormone therapy has major consequences on my life	☐	☐	☐	☐	☐
I can't function normally whilst taking hormone therapy	☐	☐	☐	☐	☐
Taking hormone therapy has had an impact on those around me	☐	☐	☐	☐	☐
My work / social life has been affected by taking hormone therapy	☐	☐	☐	☐	☐
There's a good chance my cancer will come back	☐	☐	☐	☐	☐
I expect to have a recurrence of cancer in the future	☐	☐	☐	☐	☐
I am extremely likely to have a recurrence	☐	☐	☐	☐	☐
The chance of my cancer coming back is low	☐	☐	☐	☐	☐
There are things I can do to stop the cancer coming back	☐	☐	☐	☐	☐
What I do has an influence on whether my cancer comes back	☐	☐	☐	☐	☐
There is nothing I can do to help my risk of recurrence	☐	☐	☐	☐	☐
My actions will have no effect on the risk of cancer coming back	☐	☐	☐	☐	☐
Hormone therapy can reduce my risk of recurrence	☐	☐	☐	☐	☐
There is very little that can be done to stop the cancer coming back	☐	☐	☐	☐	☐
Taking hormone therapy will help stop the cancer coming back	☐	☐	☐	☐	☐
There is nothing that can help my risk of recurrence	☐	☐	☐	☐	☐

C2. We are interested in your views on possible causes of breast cancer coming back (recurrence). For each of the factors below *please indicate the extent to which you agree or disagree that it may influence your risk of recurrence. There are no right or wrong answers.*

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Stress or worry	☐	☐	☐	☐	☐
Runs in the family	☐	☐	☐	☐	☐
A germ or virus	☐	☐	☐	☐	☐
Diet or eating habits	☐	☐	☐	☐	☐
Chance or bad luck	☐	☐	☐	☐	☐
Pollution in the environment	☐	☐	☐	☐	☐
My own behaviour	☐	☐	☐	☐	☐
Exercise	☐	☐	☐	☐	☐
Family problems or worries	☐	☐	☐	☐	☐
My emotional state (e.g., feeling down, lonely, anxious, empty)	☐	☐	☐	☐	☐
Ageing	☐	☐	☐	☐	☐
Hormonal influence	☐	☐	☐	☐	☐
God's will	☐	☐	☐	☐	☐

SECTION D: About your lifestyle and your general health

This section asks about your current lifestyle, including exercise and alcohol consumption.

D1. How tall are you? *Please complete then tick one box to tell us the unit of measurement.*

	in cm/m ☐	or ft/inches ☐

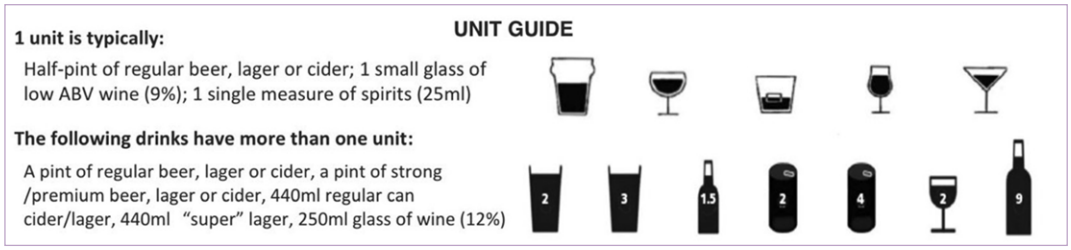
D2. How much do you weigh? *Please complete then tick one box to tell us the unit of measurement.*

	in kg ☐	or stone/lbs ☐

D3. The following questions are about how active you are. During a typical *7-day period* (a week), how many times on average do you do the following kinds of exercise for *more than 15 minutes* during your free time.

	Times per week
a. Strenuous exercise (heart beats rapidly) (e.g., running or jogging, team sports, squash, fast swimming, riding a bike fast or on hills)	
b. Moderate exercise (not exhausting) (e.g., fast walking or hiking, water aerobics, Zumba, tennis, easy bicycling, badminton, easy swimming, popular and folk dancing)	
c. Mild/light exercise (minimal effort) (e.g., yoga, bowling, golf, easy walking)	

These questions are about your alcohol intake.



D4. How often do you have a drink containing alcohol?

Never	☐
Monthly or less	☐
2-4 times a month	☐
2-3 times a week	☐
4 or more times a week	☐

D5. How many units of alcohol do you drink on a typical day when you are drinking?

Not applicable - I don't drink alcohol	☐
1 or 2	☐
3 or 4	☐
5 or 6	☐
7, 8 or 9	☐
10 or more	☐

D6. How often have you had 6 or more units on a single occasion in the last year?

Never	☐
Less than monthly	☐
Monthly	☐
Weekly	☐
Daily or almost daily	☐

D7. These questions are about smoking.

	Yes	No
a. Have you ever smoked cigarettes regularly – that is at least one cigarette per day for 6 months or more? (not including e-cigarettes)	☐	☐
b. Do you smoke cigarettes now? (not including e-cigarettes)	☐	☐

D8. Under each heading, please tick the ONE box that best describes your health TODAY

a. MOBILITY

I have no problems in walking about	☐
I have slight problems in walking about	☐
I have moderate problems in walking about	☐
I have severe problems in walking about	☐
I am unable to walk about	☐

b. SELF-CARE

I have no problems washing or dressing myself	☐
I have slight problems washing or dressing myself	☐
I have moderate problems washing or dressing myself	☐
I have severe problems washing or dressing myself	☐
I am unable to wash or dress myself	☐

c. USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐
I have slight problems doing my usual activities	☐
I have moderate problems doing my usual activities	☐
I have severe problems doing my usual activities	☐
I am unable to do my usual activities	☐

d. PAIN / DISCOMFORT

I have no pain or discomfort	☐
I have slight pain or discomfort	☐
I have moderate pain or discomfort	☐
I have severe pain or discomfort	☐
I have extreme pain or discomfort	☐

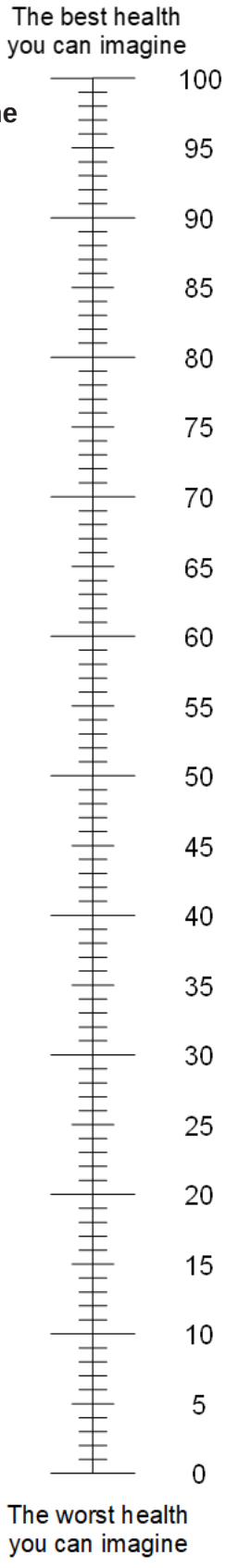
e. ANXIETY / DEPRESSION

I am not anxious or depressed	☐
I am slightly anxious or depressed	☐
I am moderately anxious or depressed	☐
I am severely anxious or depressed	☐
I am extremely anxious or depressed	☐

D9. We would like to know how good or bad your health is today. The scale is numbered from 0 to 100, 100 means the best health you can imagine and 0 means the worst health you can imagine.

- Please mark an X on the scale to indicate how your health is **TODAY**.
- Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



IF YOU DID NOT RECEIVE ACCESS TO THE HT&Me SUPPORT PACKAGE AS PART OF THE STUDY, PLEASE SKIP TO SECTION F BELOW.

If you did receive access, please continue to answer the questions below.

SECTION E: HT&Me support package feedback

This part of the questionnaire pack asks you some questions about your thoughts and experiences with the HT&Me support package. Some of these questions refer to the overall HT&Me support package (that is, the package as a whole), and others refer to some of the specific features within it (e.g., nurse/practitioner appointments, website and email/text contacts).

E1. Please rate how helpful you found specific parts of the HT&Me support package, by ticking the box that applies to you. If you have not looked at or used parts of the HT&Me support package, or if you do not think the question is relevant to you, please select the 'Not Applicable' option (N/A):

	Not Applicable (N/A)	Very unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Very helpful
a. HT&Me website	☐	☐	☐	☐	☐	☐
b. Receiving text / email messages to remind me to take my hormone therapy	☐	☐	☐	☐	☐	☐
c. Receiving text / email messages to remind me to collect my prescription	☐	☐	☐	☐	☐	☐
d. Receiving text/email messages to remind me about the HT&Me website	☐	☐	☐	☐	☐	☐
e. Receiving text/email messages to remind me why taking hormone therapy is important	☐	☐	☐	☐	☐	☐
f. Overall HT&Me support package (e.g., the nurse/practitioner appointments, the website and text/email messages)	☐	☐	☐	☐	☐	☐

The following questions refer to sections within the HT&Me website:

g. 'Taking Hormone Therapy' section	☐	☐	☐	☐	☐	☐
h. Animation video (cartoon film) about hormone therapy	☐	☐	☐	☐	☐	☐
i. 'Dealing with Side Effects' section	☐	☐	☐	☐	☐	☐
j. 'Healthy living, Healthy mind' section	☐	☐	☐	☐	☐	☐
k. 'Help and Support' section	☐	☐	☐	☐	☐	☐
l. 'My Hormone Therapy Diary' section	☐	☐	☐	☐	☐	☐
m. 'My Goals and Plans' tool	☐	☐	☐	☐	☐	☐
n. 'My Personal Support' tool	☐	☐	☐	☐	☐	☐

E2. Please tell us whether you agree or disagree with the following statements:

The overall HT&Me support package:	Not Applicable (N/A)	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree
a. Increased my knowledge about hormone therapy	☐	☐	☐	☐	☐	☐
b. Increased my understanding of why taking hormone therapy is important	☐	☐	☐	☐	☐	☐
c. Motivated me to keep taking my hormone therapy	☐	☐	☐	☐	☐	☐
d. Helped me talk to my doctor about hormone therapy	☐	☐	☐	☐	☐	☐
e. Helped me with any emotional concerns about hormone therapy	☐	☐	☐	☐	☐	☐
f. Made me feel more anxious	☐	☐	☐	☐	☐	☐
g. Helped me to manage any side effects	☐	☐	☐	☐	☐	☐
h. Was relevant for me	☐	☐	☐	☐	☐	☐
i. Was overwhelming	☐	☐	☐	☐	☐	☐
j. Was trustworthy	☐	☐	☐	☐	☐	☐
k. Was an unwelcome reminder of cancer	☐	☐	☐	☐	☐	☐
l. Was easy to understand	☐	☐	☐	☐	☐	☐
m. Was easy to use	☐	☐	☐	☐	☐	☐
n. Took too much effort	☐	☐	☐	☐	☐	☐

E3. We would like to ask you about the timing of receiving the HT&Me support package. In relation to when you first started taking your hormone therapy, do you feel that the timing of receiving the HT&Me support package was:

Too early	☐	Just about right	☐	Too late	☐

SECTION F: Health care use

We would like to know whether you have used health and care services over the past 6 months for anything that is (in your opinion) related to your breast cancer or any related side-effects and complications. **Please give your best guess if you don't know the exact number.** Please answer every question if you can, even if the answer is 0.

Section F1: Contact with NHS primary and community health care and charity providers

1. **Have you had any contact with health professionals in an NHS primary health care or *community*-based setting or *charity* services (i.e. outside the hospital setting, e.g. GP, counsellor, practice or district nurse) for anything which, in your opinion, was related to your breast cancer or any related side-effects and complications during the *past 6 months*?**

Yes ☐ No ☐

If you ticked 'yes', please complete the table below:

If you ticked 'no', please go to question 2 in Section F2

Please don't include in this table any contacts that were in a hospital or that you paid for privately, we will ask you about these later.

Type of health care provider	Have you used the service during the past 6 months?	Total number of face-to-face contacts (in person, video conference, or 'online') during the past 6 months	Total number of contacts by telephone or email during the past 6 months
GP	Yes ☐ No ☐		
GP practice nurse	Yes ☐ No ☐		
Macmillan nurse (or other charitable care provider)	Yes ☐ No ☐		
District nurse or community health team	Yes ☐ No ☐		
Paid carer (to help with healthcare, personal or household tasks in your home)	Yes ☐ No ☐		
Counselling, or mental health support	Yes ☐ No ☐		
Community Pharmacist	Yes ☐ No ☐		
Family or patient support or information, or courses/workshops provided by cancer charities e.g. Breast Cancer Now, Maggie's Centre	Yes ☐ No ☐		
NHS direct (111)	Yes ☐ No ☐	Not applicable	
Other *(please specify)*:	Yes ☐ No ☐		
Other *(please specify)*:	Yes ☐ No ☐		

Section F2: Contact with NHS hospital-based services

2. Have you used any NHS hospital-based services during the past 6 months (e.g. outpatient hospital visits, inpatient stay, A&E) for anything which in your opinion was related to your breast cancer or any related side-effects and complications?

Yes ☐ No ☐

If you ticked 'yes', please complete the questions below.

If you responded 'no', please go to Section F3.

a) Type of hospital service	**Have you used this service during the past 6 months for your breast cancer?**	**Total number of *face-to-face* (in person or video-conference/ online) contacts during the past 6 months**	**Total number of contacts by *telephone* or *email* during the past 6 months**
Hospital outpatient clinic: cancer/oncology (eg follow-up appointment with breast cancer team)	Yes ☐ No ☐		
Hospital physiotherapy	Yes ☐ No ☐		
Hospital counselling	Yes ☐ No ☐		
Hospital dietitian	Yes ☐ No ☐		
Hospital occupational therapy	Yes ☐ No ☐		
Hospital lymphoedema clinic	Yes ☐ No ☐		
Other hospital outpatient appointment	Yes ☐ No ☐		
If other, please state:			

b) Were any procedures or scans undertaken at a hospital outpatient clinic? *(Please include everything you have had in the past 6 months excluding those done during an inpatient stay)*

	Number of times you have had this scan/procedure in the last 6 months
Mammogram	
Ultrasound	
CT scan	
MRI scan	
X-ray	
Needle biopsy	
Needle aspiration	
Bone scan	
Radiotherapy	
Chemotherapy	
Other	
(please specify)	

c) Have you had any hospital day case visits in the last 6 months for anything which in your opinion was related to your breast cancer or any related side-effects and complications? (e.g. for cancer, infection or

mental health) A day case is an admission to hospital where you are given a hospital bed but do not stay overnight.

Yes ☐ No ☐

If yes:

i) How many day case visits? _____

ii) Why did you have the day case(s)? _____

_____

iii) If you had any procedures or scans, please write them here _____

_____

d) Have you been to the hospital A&E department in the last 6 months for anything which in your opinion was related to your breast cancer or any related side-effects and complications?

Yes ☐ No ☐

If yes:

i. How many times did you visit A&E? _____

e) Have you stayed overnight in hospital in the last 6 months for anything which in your opinion was related to your breast cancer or any related side-effects and complications? (e.g. for cancer, infection or mental health)

Yes ☐ No ☐

If yes:

i) How many times did you stay overnight in hospital? _____

ii) For each hospital inpatient stay related to your breast cancer, please fill in the following information:

Stay	Number of nights spent in hospital	Why were you admitted to hospital? Please select the main reason using numbers 1-8 below	If other, what?	If you had an operation, what type? *(free text)*	If you were in intensive care, please tell us how many days
Stay 1					
Stay 2					
Stay 3					
Stay 4					
Stay 5					
Stay 6					
Stay 7					
Stay 8					

1 Cancer
2 Infection
3 DVT or clot
4 Breast surgery
5 Problem with a breast implant
6 Fracture/broken bone
7 Mental health
8 Other (please state)

Section F3: Medication use

3. **Have you taken any <u>prescribed</u> medications <u>over the past 6 months</u> for anything which in your opinion was related to your breast cancer or any related side-effects and complications?** You should tick "no" if the only medication you are prescribed is your hormone treatment. Please include ongoing medications as well as new prescriptions.

   Yes ☐ No ☐

   If you responded 'no' please go to section F4.

   If you responded 'yes', please complete the following table:

   Please only include medication prescribed by a doctor or nurse in this table: if you bought any medication over the counter please include this in section F4.

Prescribed Medication	**Have you used this medication during the past 6 months?**	**Date started** dd/mm/yy	**Date completed** dd/mm/yy	**Please tick if you are still using this medication**
Bisphosphonates (medication for osteoporosis eg alendronic acid, ibandronic acid, risedronate, zoledronic acid)	Yes ☐ No ☐			☐
Anti-depressants (eg fluoxetine, sertraline, citalopram)	Yes ☐ No ☐			☐
Calcium supplements (for osteoporosis)	Yes ☐ No ☐			☐
Vitamin D supplements (for osteoporosis)	Yes ☐ No ☐			☐
Medications for hot flushes (eg gabapentin, venaflaxine, citalopram).	Yes ☐ No ☐			☐
Progesterone-based medications (e.g. Megace)	Yes ☐ No ☐			☐
Chemotherapy (either tablets or injections) *Please state drugs if known:*	Yes ☐ No ☐			☐
Vaginal gels and moisturisers	Yes ☐ No ☐			☐
Vaginal oestrogen	Yes ☐ No ☐			☐
Homeopathic remedies	Yes ☐ No ☐			☐
Other: *Please specify:*	Yes ☐ No ☐			☐
Other: *Please specify:*	Yes ☐ No ☐			☐
Other: *Please specify:*	Yes ☐ No ☐			☐

Section F4: Personal costs

4. **<u>Over the past 6 months</u>, have you or your family/carers incurred any personal costs (e.g. over the counter medications, travel and childcare expenses, private health care) which in your opinion is related to your breast cancer or any related side-effects and complications? We are asking this as we would like to find out about the impact of your breast cancer and treatment on your personal finances.**

   Yes ☐ No ☐

   If you ticked 'yes', please complete the following table:

   If you ticked 'no' please go to question 5 in section F5.

		Approximate total cost to you or your family/friends
Have you spent any money on travelling to medical appointments over the past 6 months for ***your breast cancer or any related side-effects and complications***? (medical appointments may include visits to your GP surgery, hospital or any other health care setting e.g. GP walk-in centres). Travel costs may include bus fares, train fares, fuel costs and parking charges.	Yes ☐ No ☐	£_____
Have you paid for private practitioners over the past 6 months for ***your breast cancer or any related side-effects and complications?*** (such as private hospital care, acupuncturists, physiotherapists, counselling or lymphoedema services).	Yes ☐ No ☐	£_____
Have you had to pay for child care over the past 6 months as a result of ***your breast cancer or any related side-effects and complications?***	Yes ☐ No ☐	£_____
Have you paid for, or had to buy, anything else over the past 6 months for ***your breast cancer or any related side-effects and complications***? If yes, please tell us what this was:	Yes ☐ No ☐	£_____

Section F5: Time off work and usual activities

5. We would like to find out the impact on your work and usual activities from your breast cancer and treatment over the <u>over the past 6 months</u>.

Which of these best describes your current employment status?
(If you are employed or self-employed but are currently on sick leave or working reduced hours due DA illness, please select the option that best describes your usual work status)

In paid work (including self-employed) full-time or part-time	☐	Unemployed	☐
Homemaker	☐	Retired	☐
Unable to work because of long-term disability or ill health	☐	In full-time education, training or work experience	☐
Other (*please tell us more*)			

Time off work and usual activities		**Please complete as Hours or Days**	
In the past 6 months have you had any **time off paid work** as a result of your breast cancer or related conditions or problems caused by your cancer (This may include time off because you were feeling ill, were attending medical appointments or in hospital etc).	Yes ☐ No ☐	Approximate number of hours **OR** days off paid work:	_____hours _____days
In the past 6 months, have you had to **change your other usual activities** (excluding any changes to your paid work) because of your breast cancer, or related conditions or problems caused by your cancer. (This may include changes to your usual activities because were feeling ill, attending medical appointments or in hospital etc). *Usual activities* may include social arrangements, housework, shopping, child care, study, exercise, or other hobbies.	Yes ☐ No ☐	Approximate number of hours **OR** days off other usual activities:	_____hours _____days

5b) Have you received help or support from family or friends <u>over the past 6 months</u>, which in your opinion was related to your breast cancer or any related side-effects and complications?

Yes ☐ No ☐

If yes, approximately how much time have they spent helping you over the past 6 months?	_____hours
Did they have to take any time off paid work to help or support you?	Yes ☐ No ☐
Approximately how much time in total did they take off paid work over the past 6 months?	_____hours

Thank you for completing this questionnaire.

If you have questions about your breast cancer care, please contact your clinical team. If you have questions about general health, you can contact your GP. If you would like more information, advice or support about living with breast cancer and hormone therapy in general you could contact the following charities:

Breast Cancer Now: 0808 800 6000 or breastcancernow.org
Macmillan Cancer Support: 0808 808 0000 or macmillan.org.uk
Maggie's cancer support centres: https://www.maggies.org/

Should you be experiencing any difficult emotions or feelings and wish to speak to someone, please contact Mind for advice (website: https://www.mind.org.uk/).

Thank you.