

Participant Study ID: _____

Living better with advanced breast cancer (LIBERATE):

Feasibility study of a supportive, self-management website for women living with secondary breast cancer

12 WEEK QUESTIONNAIRE BOOKLET

We would be very grateful if you could complete these questionnaires to give us an understanding of the impact of secondary breast cancer on your life and how confident you feel in being able to manage its effects.

All of the questions have a range of answers for you to choose from. There are no right or wrong answers; you should choose a response that best reflects you or your situation.

If, after answering any of the questions, you realise that you have made a mistake (for example, ticking the wrong box) please cross out your answer clearly and then select the answer that you meant to choose.

If you have any questions, please feel free to speak to one of our researchers in clinic or contact Kathleen Kane via the contact details below.

Once you have completed the questionnaire booklet, it can be handed back to a member of the LIBERATE research team.

If you have received this questionnaire in the post, please return the completed questionnaire using the stamped addressed envelope provided.

Thank you very much for your time and valuable contributions to the LIBERATE study.

LIBERATE Project

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FACT-B (Version 4)

Below is a list of statements that other people with your illness have said are important.

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

PHYSICAL WELL-BEING	Not at all	A little bit	Some -what	Quite a bit	Very Much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some -what	Quite a bit	Very Much
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4

Regardless of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section

I am satisfied with my sex life	0	1	2	3	4
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By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

EMOTIONAL WELL-BEING	Not at all	A little bit	Some -what	Quite a bit	Very Much
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry about dying	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4
 FUNCTIONAL WELL-BEING					
	Not at all	A little bit	Some -what	Quite a bit	Very Much
I am able to work (include work at home)	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

ADDITIONAL CONCERNS	Not at all	A little bit	Some -what	Quite a bit	Very Much
I have been short of breath	0	1	2	3	4
I am self-conscious about the way I dress	0	1	2	3	4
One or both of my arms are swollen and tender	0	1	2	3	4
I feel sexually attractive	0	1	2	3	4
I am bothered by hair loss	0	1	2	3	4
I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
I worry about the effect of stress on my illness	0	1	2	3	4
I am bothered by a change in weight	0	1	2	3	4
I am able to feel like a woman	0	1	2	3	4
I have certain parts of my body where I experience pain	0	1	2	3	4

Health Questionnaire

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

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

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

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

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

ANXIETY / DEPRESSION

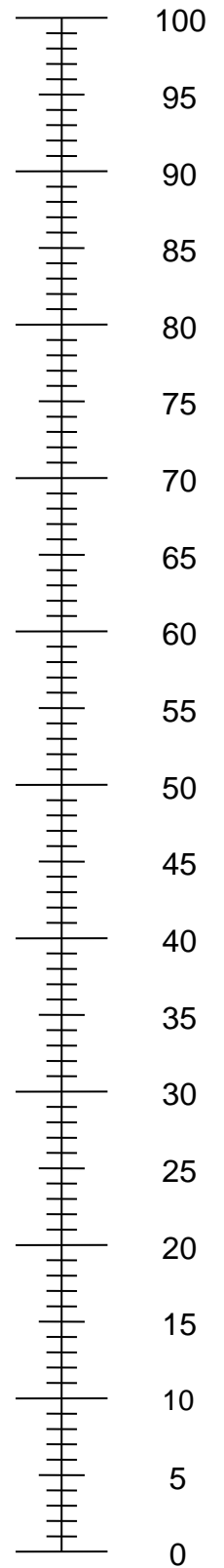
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

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- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

Cancer Behaviour Inventory (CBI-B)

This questionnaire contains many things that a person might do when receiving treatment for cancer. We are interested in your judgment of how confident you are that you can accomplish those things.

Please read each numbered item. Then rate that item on how confident you are that you can accomplish that behaviour. Circle a number on the scale. If you circle a "1" you would be stating that you are not at all confident that you can accomplish that behaviour. If you circle a "9" you would be stating that you are totally confident that you can accomplish that behaviour. Numbers in the middle of the scale indicate that you are moderately confident that you can accomplish that behaviour.

Please rate all items. If you are not sure about an item please rate it as best you can

		NOT AT ALL CONFIDENT			MODERATELY CONFIDENT			TOTALLY CONFIDENT		
		1	2	3	4	5	6	7	8	9
1.	Maintaining Independence.	1	2	3	4	5	6	7	8	9
2.	Maintaining a positive attitude.	1	2	3	4	5	6	7	8	9
3.	Maintaining a sense of humour.	1	2	3	4	5	6	7	8	9
4.	Expressing feelings about cancer.	1	2	3	4	5	6	7	8	9
5.	Putting things out of my mind at times.	1	2	3	4	5	6	7	8	9
6.	Maintaining activities (work, home, hobbies, social).	1	2	3	4	5	6	7	8	9
7.	Trying to be calm throughout treatments and not allowing scary thoughts to upset me.	1	2	3	4	5	6	7	8	9

		NOT AT ALL CONFIDENT			MODERATELY CONFIDENT			TOTALLY CONFIDENT		
8.	Actively participating in treatment decisions.	1	2	3	4	5	6	7	8	9
9.	Asking physicians' questions.	1	2	3	4	5	6	7	8	9
10.	Seeking social support.	1	2	3	4	5	6	7	8	9
11.	Sharing my worries or concerns with others.	1	2	3	4	5	6	7	8	9
12.	Managing nausea and vomiting (whether or not I have had these problems in the past).	1	2	3	4	5	6	7	8	9
13.	Coping with physical changes.	1	2	3	4	5	6	7	8	9
14.	Trying to be calm while waiting at least one hour for my appointment.	1	2	3	4	5	6	7	8	9

Self –Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can keep the fatigue caused by your disease from interfering with your life?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

END OF QUESTIONNAIRES