## LIBERATE symptom monitoring component:

## Online symptom monitoring questionnaire items

Some of the following questionnaire items have been evaluated within a previous research study of an electronic symptom monitoring intervention (eRAPID, REC 14/YH/1066). As they are applicable to women living with secondary breast cancer, and have been previously trialled, they will be used within the LIBERATE symptom monitoring questionnaire.

Further questions more specific to secondary breast cancer, its treatments and the late effects of cancer treatment have been added as an amendment and are highlighted in yellow. Two versions of the questionnaire (Questionnaire A and Questionnaire B) have been developed according to symptoms and side effects experienced by patients across two broad treatment groups. Participants will complete the questionnaire which matches their current treatment regime.

Colour coded response options relate to the action generated (either tailored selfmanagement advice or an alert message for the participant to contact their hospital for medical advice).

Кеу	
	No action.
	Self-management advice generated +/- referred to relevant section of website.
	Recommended to inform medical team, self-management advice generated +/-
	referred to relevant section of website.
	Alert message to seek medical advice immediately by contacting hospital (if this
	is a current problem) and referred to relevant support on website.

Questionnaire A: Participants treated with chemotherapy +/- monoclonal antibodies (MABs)	
Standard questions (completed by all)	
Questionnaire item	Response options
	During the last 7 days
	General
Q1. Have you had any pain or discomfort anywhere in	No
your body?	I had mild pain or discomfort.
	I had moderate pain or discomfort and I was not able to do some of the things I normally do (e.g. household chores, shopping).
	I had severe pain or discomfort and this has had a significant impact on my normal daily life.
Q2. Have you felt tired, fatigued or lacked energy?	No
	I felt tired but this was relieved by rest.
	I felt tired but this was not relieved by rest and I had difficulty doing some of the things I normally do (e.g. household chores, shopping).
	I felt tired but this was not relieved by rest and this had a significant impact on my normal daily life.

Q3. Please select from the options below the statement that best describes your level of physical ability during the past week.	I am up and about and can do everything that I could do before my illness without any difficulty. I am up and about almost all of the time. I cannot do any heavy physical work but I can do most other things (e.g. household chores, shopping). I am up and about more than half the day; I can look after myself (e.g. getting out of bed, bathing, dressing) but I cannot do much else. I am in bed or in a chair for more than half of the day and I need some help looking after myself. I am in bed or in a chair all the time and I cannot look after myself.
	Gastrointestinal
Q4. Have you felt sick (nauseous or queasy)?	No
	I felt sick but I was able to eat and drink the same amount and type of foods as usual.
	I felt sick and I ate or drank less than usual or changed what I ate or drank.
	I felt sick and was not able to eat or drink.
Q5. Have you been sick (vomited)?	No.
	I have vomited 1 - 2 times in a 24 hour period.
	I have vomited 3 - 5 times in a 24 hour period.
	I have vomited 6 or more times in a 24 hour period.
Q6. Have you had diarrhoea (loose or watery stools)?	No.
	I have had diarrhoea and opened my bowels 2 - 3 times more in a 24 hour period than is normal for me.
	I have had diarrhoea and opened my bowels 4 - 6 times more in a 24 hour period than is normal for me.
	I have had diarrhoea and opened my bowels over 7 times more in a 24 hour period than is normal for me or I have been incontinent (unable to control my bowels).
Q7. Have you been	No.
constipated?	I have had occasional constipation which was relieved by changing my diet or taking laxatives.
	I have had ongoing constipation with stomach discomfort. I was not able to do some of the things I normally do (e.g. household chores, shopping) and I have changed my diet or taken laxatives every day to relieve the constipation.
	I have had severe ongoing constipation with stomach pain, bloating or feeling sick. I was not able to care for myself (e.g. getting out of bed, bathing, dressing) and it was not relieved by regular laxatives
Q8. Have you lacked	No.
appetite or lost interest in food?	I have lacked appetite but I was able to eat and drink the same amount and type of food as usual.

	I have lacked appetite and I ate or drank less than usual or I have been taking supplement drinks.
	I have lacked appetite and I was not able to eat or drink.
Q9. Have you had a sore mouth or tongue?	No.
	My mouth was a bit sore.
	My mouth was quite sore but I was still able to eat soft foods and drink fluids.
	My mouth was very sore and I was not able to eat or drink.
Q10. Have you had any	No.
indigestion or heartburn?	I had some mild indigestion or heartburn which passed.
	I had some moderate indigestion or heartburn which was relieved with over the counter medications.
	I have had severe or ongoing indigestion or heartburn which has been difficult to relieve.
Q11. Have you experienced	No.
any pain, swelling or bloating (uncomfortable	I had mild pain/swelling/bloating of the tummy.
fullness) in your abdomen?	I mad moderate pain/swelling/bloating of the tummy and I was not able to do some of the things I normally do (e.g. household chores, shopping).
	I had severe pain/swelling/bloating of the tummy and this had a significant impact on my normal daily life.
	Respiratory
Q12. Have you had any	No.
difficulty breathing or shortness of breath?	I have been short of breath but only when exerting myself (e.g. climbing stairs)
	I have been short of breath when walking around the house and I was not able to do some of the things I normally do
	(e.g. household chores, shopping)
	I have been short of breath at rest and this has had a
O12 Hove you had a	significant impact on my normal daily life.
Q13. Have you had a cough?	No. Yes, it was dry.
	Yes, I coughed something up.
Q13 (a). What was the	I have a mild cough.
severity of your dry cough?	I have a cough which interferes with some of the activities I
	normally do (e.g. household chores and shopping) or
	requires regular medication.
	I have a cough which has affected my ability to care for myself or has affected my sleep.
Q13 (b). What was the severity of your cough which	I have had a cough which has occasionally brought up a small amount of phlegm/mucus which was white or clear.
caused you to cough something up?	I have had a cough which has occasionally brought up a moderate amount of phlegm/mucus and it has stopped me
	from doing some of the things I normally do (e.g.
	household chores and shopping). I have had a cough which has produced persistent
	(ongoing) or large amounts of phelgm/mucus which was

	green or yellow and it has had a significant impact on my normal daily life.	
Symptoms of infection		
Q14. Please take your temperature with a thermometer and choose the best option below.	My temperature is less than 37 °C.	
	My temperature is between 37°C and 37.5 °C.	
	My temperature is above 37.5°C but less than 38°C.	
	My temperature is 38°C or above.	
Q15. Have you had	No.	
shivering, shaking or chattering of the teeth?	I have felt a little cold with shivering and chattering of teeth.	
	I have felt very cold, with shaking all over my body but this settled very quickly.	
	I have felt very cold, with shaking all over my body for 30 minutes or more.	
	Dermatological	
Q16. Have you had soreness or redness of the	No.	
hands and feet?	My skin was a bit red but was not painful.	
	My skin was painful, red, cracked or peeling and I was not able to do some of the things I normally do (e.g. household chores, shopping).	
	My skin was very painful and this had a significant impact on my normal daily life.	
Q17. Have you noticed any	No.	
rashes on your skin?	I have noticed a raised or blistered rash covering a very small amount of skin (which may/may not have been itchy or tender).	
	I have noticed a raised or blistered rash covering quite a large area of skin (which may/may not have been itchy or tender) which has affected my daily life; I have not been able to do some of the things I normally do (e.g. household chores, shopping).	
	I have noticed a raised or blistered rash covering a very large area of skin which has been itchy and tender; this has had a significant impact on my normal daily life.	
	Neurological	
Q18. Have you experienced	No.	
any headaches?	I have had a mild headache(s) which has passed.	
	I have had some moderate headache(s) which have required pain relief and which have stopped me from doing some of the things I normally do (e.g. household chores, shopping).	
	I have had one or more severe headaches which I have woken up with or which have had a significant impact on my normal daily life.	
Q19. Have you had any new	No.	
weakness in any part of your body?	I have noticed some mild general weakness in my body.	
<u>,</u>	I have noticed some moderate weakness in a particular part of my body (e.g. face, arms, legs) and it has stopped me from doing some of the things I normally do (e.g. household chores and shopping).	

	I have had some severe weakness in a particular part of
	my body (e.g. face, arms, legs) and this has had a significant impact on my normal daily life.
Q20. Have you had any	No.
numbness, tingling or change in sensation in an area of your body (anywhere <u>other than</u> your hands and feet?)	I have had some mild numbness, tingling or change in sensation in an area of my body (NOT my hands or feet). I have had some moderate numbness, tingling or change in sensation in an area of my body (NOT my hands or feet) and this has stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have had some severe numbness, tingling or change in sensation in an area of my body (NOT my hands or feet) and this has had a significant impact on my normal daily life.
Q21. Have you experienced	No.
any changes in your vision? E.g. double vision, blurred vision.	I have noticed some mild changes in my vision but these have not interfered with my daily routine. I have noticed some moderate changes I my vision and these have stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have noticed to severe changes or disturbances in my vision and these have had a significant impact on my normal daily life.
Q22. Have you experienced	No.
any unsteadiness, dizziness or loss of balance?	I have experienced mild unsteadiness/felt off balance or had a mild sensation of moving or spinning.
	I have experienced moderate unsteadiness or had a sensation of spinning or moving and this has stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have felt severely unsteady/off balance, had strong sensations of moving or spinning and this has had a significant impact on my normal daily life.
	Psychological, sleep & sexual
Q23. Have you felt worried	No.
or anxious (e.g. feelings of dread, restlessness, panic	I have felt mildly anxious but it has not stopped me going about my day.
and tension) about your current situation or the future?	I have felt moderately anxious and it has stopped me from doing some of the things I normally do.
	I have felt severely anxious and it has had a significant impact on my normal daily life.
Q24. Have you felt low in	No.
mood? (e.g. feeling hopeless, helpless, irritable, guilty or worthless)	I have felt mildly down or low in mood but it has not stopped me going about my day. I have felt moderately down or low in mood and it has
	stopped me from doing some of the things I normally do. I have felt severely down or low in mood and it has had a significant impact on my normal daily life.
Q25. Have you experienced	No.
difficulty sleeping?	I occasionally have difficulty falling asleep, staying asleep or I wake too early.

	Later have different of the second and the line second and
	I often have difficulty falling asleep, falling asleep, staying asleep or I wake too early.
	I always have difficulty falling asleep, staying asleep or I
Q26. Have you experienced	wake too early. Not applicable/prefer not to answer.
pain or discomfort during	No.
sex?	I have experienced a little bit of discomfort or pain during
	sex which was relieved with the use of vaginal lubricants.
	I have experienced quite a bit discomfort or pain during sex
	which was only partially relieved with the use of vaginal lubricants.
	I have experienced extreme discomfort or pain during sex
	which was not relieved with the use of vaginal lubricants.
Q27. Have you experienced a loss of interest in sex?	Not applicable/prefer not to answer. No.
	I have experienced a loss of interest in having sex but this
	has not caused me distress and/or has not had a negative
	impact on my relationship with my partner.
	I have experienced a loss of interest in having sex and this has caused me distress and/or has had a negative impact
	on my relationship with my partner.
Q28. Have you been	Not applicable/prefer not to answer.
bothered by feeling unsatisfied with your sex	No.
life?	I am feeling unsatisfied with my sex life and this is bothering me slightly.
	I am feeling unsatisfied with my sex life and this is
	bothering me a lot. I am feeling unsatisfied with my sex life and this is having a
	negative impact on my relationship.
Q29. Have you had any	Diagnosis & treatment.
particular concerns or feel that you require information	Healthy living.
or support relating to any of	Complementary therapies.
the following: (provide link to	Psychological well-being.
relevant section of website).	Employment & finances.
	Relationships, sex & intimacy.
	Younger women with secondary breast cancer. Looking ahead (practicalities & planning for an uncertain
	future).
	Experiences of other women with secondary breast cancer.
	Support for others affected by your diagnosis.
	End of standard questions.
-	lown symptoms (for participant to self-select)
Problems experienced when passing water (e.g. pain,	I have had some mild discomfort when passing urine and have needed to go more often than normal.
needing to go to the toilet	
more often or more urgently,	I have had some moderate to severe discomfort or pain
cloudy or foul smelling urine): what was the severity	when passing water, have needed to go to the toilet much
of these problems?	more often than usual and/or have noticed my urine is cloudy or foul smelling.
L	and any or row entering.

Problems with tasting food and drink: What was the	Mild.
severity of your problems with tasting food and drink?	Moderate.
	Severe.
	Very severe.
Tingling or numbness in your fingers and/or toes:	I had a bit of tingling or numbness (perhaps when handling cold or hot objects).
What was the severity of the tingling or numbness in your fingers or toes?	I had tingling or numbness and I was not able to do some of the things I normally do (e.g. buttoning up or using cutlery).
	I had tingling or numbness and I was not able to carry out daily activities (e.g. I had difficulty walking, dropped things or stepped on things by accident).
Difficulty concentrating: What was the severity of	I have had some mild difficulty concentrating or paying attention.
your difficulty concentrating?	I have had some moderate difficulty concentrating or paying attention and this has stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have had some severe difficulty concentrating or paying attention and this has had a significant impact on my daily life.
Poor memory: What was the severity of your difficulty	I have some mild memory loss but this was only temporary/I was able to remember later on.
remembering things?	I have had some moderate memory loss, forgetting things that have happened recently and this has stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have had some severe memory loss, forgetting things that happened less recently/a long time ago and this has had a significant impact on my daily life.
Unusual bruising or bleeding: What was the	I have noticed a small amount of bruising in one area/I have had a small amount of bleeding.
severity of the unusual bruising or bleeding? (E.g. from mouth, nose, vaginal,	I have noticed a moderate amount of bruising/bruising in several areas of my body/a moderate amount of unusual bleeding.
when vomiting or when going to the toilet).	I have noticed one or more large areas of bruising on my body/have had large amounts of unusual bleeding.
Nose bleeds: What was the severity of your nose	I had a bit of blood from my nose (for example when blowing my nose).
bleeds?	I had quite a bit of nose bleeding which took a while to stop.
	My nose is bleeding and I cannot get it to stop.
Pain along the vein(s) of	Mild.
your arms: What was the severity of the pain along the veins of your arm?	Moderate.
	Severe.
	Very severe.
Pain, swelling or redness at the injection site: What was	Mild.
	Moderate.

the severity of the pain,	Severe.
swelling or redness at the	Very severe.
injection site?	
Painful or uncomfortable swelling in the arm(s): What	I have noticed some mild swelling in my arm(s), causing me mild discomfort/pain.
was the severity of the	I have developed quite a lot of swelling in my arm(s) and
painful or uncomfortable	this has caused me pain/discomfort and stopped me from
swelling in your arm(s)?	doing some of the things I normally do (e.g. household
	chores, shopping).
	I have severe swelling in my arm(s) and this has had a
Dry or flaky skin: What was	significant impact on my normal daily life. I have experienced a small amount of dry skin but it has
the severity of your dry or	not been red or itchy.
flaky skin?	I have had a quite a bit of dry skin which has been red or
	itchy and has stopped me from doing some of the things I
	normally do (e.g. household chores, shopping).
	I have had a lot of dry skin all over my body which has been itchy and has had a significant impact on my normal
	daily life.
Itching of the skin: What	I have experienced some slight/mild itching which was
was the severity of your	relieved by using a moisturiser or cream.
itching?	I have experienced itching all over which comes and goes
	and have noticed some changes in my skin after scratching (e.g. swelling, oozing, sores). This has stopped me from
	doing some of the things I normally do (e.g. household
	chores, shopping etc.)
	I have constant itching (i.e. doesn't go away) which is
Nail changes: What was the	having a significant impact on my normal daily life. Mild.
severity of your nail changes	Moderate.
(e.g. discolouration, ridges	Severe.
or bumps)?	
Distance related to bein loss	Very severe.
Distress related to hair loss or hair thinning: What was	I have noticed some hair thinning or hair loss but this is not noticeable and I am able to cover it with a different hairstyle
the severity of your distress	OR I have felt slightly distressed/concerned by hair thinning
in relation to hair loss or hair	or hair loss.
thinning?	I have noticed significant hair thinning or hair loss which is
	very noticeable and may require a wig to disguise OR I
	have felt very distressed by hair loss and it is affecting my daily life.
General muscle aching,	I have had some mild aches, pain or weakness in my
pains or weakness: What	muscles.
was the severity of the	I have had some moderate aches, pain or weakness in my
aching, pains or weakness	muscles which has stopped me from doing some of the
in your muscles?	things I normally do (e.g. household chores, shopping). I have had had some severe aches, pain or weakness
	which has had a significant impact on my normal daily life.
Aching or pains in your	I had a little pain or discomfort in my joint(s).
joints: What was the severity	I had quite a bit of pain or discomfort in my joint(s) and I
of the aching or pains in your joints?	was not able to do some of the things I normally do (e.g.
your joints?	household chores, shopping).
	I had severe pain or discomfort and this had a significant impact on my normal daily life.
L	inpact on my normal daily life.

Aching in your jaw or mouth: What was the severity of the aching or pain in your jaw or mouth?	I have experienced some mild aching or pain in my jaw which I needed to take medication for and which stopped me from doing some of the things I normally do (e.g. household chores, shopping). I have had severe pain in my mouth or jaw which had a significant impact on my normal daily life.
Hot flushes: What was the severity of the hot flushes you experienced?	I have experienced mild hot flushes which passed. I have experienced moderate hot flushes which stopped me from doing some of the things I normally do (e.g. household chores, shopping). I have experienced severe hot flushes which had a significant impact on my normal daily life.

Questionnaire B: Participants treated with hormone therapy +/- targeted therapy	
Standard questions (completed by all)	
Questionnaire item	Response options
During the last 7 days	
	General
Q1. Have you had any pain or discomfort anywhere in	No
your body?	I had mild pain or discomfort.
	I had moderate pain or discomfort and I was not able to do some of the things I normally do (e.g. household chores, shopping).
	I had severe pain or discomfort and this has had a
	significant impact on my normal daily life.
Q2. Have you felt tired, fatigued or lacked energy?	No
	I felt tired but this was relieved by rest.
	I felt tired but this was not relieved by rest and I had
	difficulty doing some of the things I normally do (e.g.
	household chores, shopping).
	I felt tired but this was not relieved by rest and this had a significant impact on my normal daily life.
Q3. Please select from the options below the statement	I am up and about and can do everything that I could do before my illness without any difficulty.
that best describes your level of physical ability during the past week.	I am up and about almost all of the time. I cannot do any heavy physical work but I can do most other things (e.g. household chores, shopping).
	I am up and about more than half the day; I can look after myself (e.g. getting out of bed, bathing, dressing) but I cannot do much else.
	I am in bed or in a chair for more than half of the day and I need some help looking after myself.

	I am in bed or in a chair all the time and I cannot look after myself.	
	Gynaecological/menopausal	
Q4. Have you experienced	No.	
any aching, pains or stiffness in your joints?	I had a little pain or discomfort in my joint(s).	
	I had quite a bit of pain or discomfort in my joint(s) and I	
	was not able to do some of the things I normally do (e.g.	
	household chores, shopping).	
	I had severe pain or discomfort which had a significant impact on my daily life.	
Q5. Have you experienced	No.	
any vaginal dryness?	I have had some mild vaginal dryness or discomfort (which	
	has not affected me having sex).	
	I have had moderate vaginal dryness which has caused me	
	frequent discomfort (or has affected me having sex). I have had severe vaginal dryness which has caused	
	severe discomfort and pain when passing urine.	
Q6. Have you experienced	No.	
any hot flushes?	I have experienced mild hot flushes which passed.	
	I have experienced moderate hot flushes which stopped	
	me from doing some of the things I normally do (e.g.	
	household chores, shopping).	
	I have experienced severe hot flushes which had a significant impact on my daily life.	
Q7. Have you experienced	No.	
sweating during the night?	I have experienced a small amount/occasional sweating	
	during the night and was able to manage this myself e.g.	
	by using a fan or sleeping without a duvet.	
	I have experienced quite a lot of sweating during the night	
	(and/or soaked through clothing or bed sheets) and this has impacted on my sleep and daily life.	
Q8. Have you had the	No.	
sensation of your heart	I have occasionally experienced a mild sensation of my	
beating quickly or irregularly	heart beating quickly which only last for a short period of	
in your chest (heart	time.	
palpitations)?	I have frequently experienced a moderate sensation of my	
	heart beating quickly which lasts for a longer period of time (and/or I needed to seek medical help).	
Gastrointestinal		
Q9. Have you had a sore	No.	
mouth or tongue?	My mouth was a bit sore.	
	My mouth was quite sore but I was still able to eat soft	
	foods and drink fluids.	
	My mouth was very sore and I was not able to eat or drink.	
Q10. Have you felt sick	No	
(nauseous or queasy)?	I folt sick but I was able to get and drink the same amount	
	I felt sick but I was able to eat and drink the same amount and type of foods as usual.	

	I felt sick and I ate or drank less than usual or changed
	what I ate or drank. I felt sick and was not able to eat or drink.
Q11. Have you been sick (vomited)?	No.
	I have vomited 1 - 2 times in a 24 hour period.
	I have vomited 3 - 5 times in a 24 hour period.
	I have vomited 6 or more times in a 24 hour period.
Q12. Have you had diarrhoea (loose or watery	No.
stools)?	I have had diarrhoea and opened my bowels 2 - 3 times more in a 24 hour period than is normal for me.
	I have had diarrhoea and opened my bowels 4 - 6 times more in a 24 hour period than is normal for me.
	I have had diarrhoea and opened my bowels over 7 times
	more in a 24 hour period than is normal for me or I have
	been incontinent (unable to control my bowels).
Q13. Have you been	No.
constipated?	I have had occasional constipation which was relieved by changing my diet or taking laxatives.
	I have had ongoing constipation with stomach discomfort. I was not able to do some of the things I normally do (e.g. household chores, shopping) and I have changed my diet or taken laxatives every day to relieve the constipation.
	I have had severe ongoing constipation with stomach pain, bloating or feeling sick. I was not able to care for myself (e.g. getting out of bed, bathing, dressing) and it was not relieved by regular laxatives
Q14. Have you had any	No.
indigestion or heartburn?	I had some mild indigestion or heartburn which passed.
	I had some moderate indigestion or heartburn which was relieved with over the counter medications.
	I have had severe or ongoing indigestion or heartburn which has been difficult to relieve.
Q15. Have you experienced	No.
any pain, swelling or bloating (uncomfortable	I had mild pain/swelling/bloating of the tummy.
bloating (uncomfortable fullness) in your abdomen?	I mad moderate pain/swelling/bloating of the tummy and I was not able to do some of the things I normally do (e.g. household chores, shopping).
	I had severe pain/swelling/bloating of the tummy and this
	had a significant impact on my normal daily life. Respiratory
Q16. Have you had any	No.
difficulty breathing or	I have been short of breath but only when exerting myself
shortness of breath?	(e.g. climbing stairs)

	I have been short of breath when walking around the house
	and I was not able to do some of the things I normally do
	(e.g. household chores, shopping)
	I have been short of breath at rest and this has had a
Q17. Have you had a	significant impact on my normal daily life.
cough?	Yes, it was dry.
	Yes, I coughed something up.
Q17 (a). What was the severity of your dry cough?	I have a mild cough.
	I have a cough which interferes with some of the activities I normally do (e.g. household chores and shopping) or
	requires regular medication.
	1 5
	I have a cough which has affected my ability to care for myself or has affected my sleep.
Q17 (b). What was the	I have had a cough which has occasionally brought up a
severity of your cough which	small amount of phlegm/mucus which was white or clear.
caused you to cough something up?	I have had a cough which has occasionally brought up a moderate amount of phlegm/mucus and it has stopped me
	from doing some of the things I normally do (e.g.
	household chores and shopping).
	I have had a cough which has produced persistent
	(ongoing) or large amounts of phlegm/mucus which was
	green or yellow and it has had a significant impact on my normal daily life.
	Symptoms of infection
Q18. Please take your temperature with a	My temperature is less than 37 °C.
thermometer and choose	My temperature is between 37°C and 37.5 °C.
the best option below.	My temperature is above 37.5°C but less than 38°C.
	My temperature is 38°C or above.
Q19. Have you had	No.
shivering, shaking or chattering of the teeth?	I have felt a little cold with shivering and chattering of teeth.
Ŭ	I have felt very cold, with shaking all over my body but this settled very quickly.
	I have felt very cold, with shaking all over my body for 30
	minutes or more.
	Dermatological
Q20. Have you noticed any rashes on your skin?	No.
	I have noticed a raised or blistered rash covering a very
	small amount of skin (which may/may not have been itchy or tender).
	I have noticed a raised or blistered rash covering quite a large area of skin (which may/may not have been itchy or tender) which has affected my daily life; I have not been able to do some of the things I normally do (e.g. household chores, shopping).

	I have noticed a raised or blistered rash covering a very large area of skin which has been itchy and tender; this has had a significant impact on my normal daily life.
Musculoskeletal	
Q21. Have you had any general muscle aching, pains or weakness?	No. I have had some mild aches, pain or weakness in my muscles.
	I have had some moderate aches, pain or weakness in my muscles which has stopped me from doing some of the things I normally do (e.g. household chores, shopping). I have had had some severe aches, pain or weakness
	which has had a significant impact on my normal daily life.
	Neurological
Q22. Have you experienced	No.
any headaches?	I have had mild headache(s) which has passed.
	I have had some moderate headache(s) which have required pain relief and which have stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have had one or more severe headaches which I have woken up with or which have had a significant impact on my normal daily life.
Q23. Have you had any new	No.
weakness in any part of your body?	I have noticed some mild general weakness in my body. I have noticed some moderate weakness in a particular part of my body (e.g. face, arms, legs) and it has stopped me from doing some of the things I normally do (e.g. household chores and shopping). I have had some severe weakness in a particular part of my body (e.g. face, arms, legs) and this has had a significant impact on my normal daily life.
Q24. Have you had any	No.
numbness, tingling or change in sensation in an area of your body (anywhere <u>other than</u> your hands and feet?)	<ul> <li>I have had some mild numbness, tingling or change in sensation in an area of my body (NOT my hands or feet).</li> <li>I have had some moderate numbness, tingling or change in sensation in an area of my body (NOT my hands or feet) and this has stopped me from doing some of the things I normally do (e.g. household chores, shopping).</li> <li>I have had some severe numbness, tingling or change in sensation in an area of my body (NOT my hands or feet) and this has had a significant impact on my normal daily life.</li> </ul>
Q25. Have you experienced	No.
any changes in your vision? E.g. double vision, blurred vision.	I have noticed some mild changes in my vision but these have not interfered with my daily routine. I have noticed some moderate changes I my vision and these have stopped me from doing some of the things I
	normally do (e.g. household chores, shopping). I have noticed to severe changes or disturbances in my vision and these have had a significant impact on my normal daily life.

Q26. Have you experienced	No.
any unsteadiness, dizziness	I have experienced mild unsteadiness/felt off balance or
or loss of balance?	had a mild sensation of moving or spinning.
	I have experienced moderate unsteadiness or had a
	sensation of spinning or moving and this has stopped me
	from doing some of the things I normally do (e.g.
	household chores, shopping).
	I have felt severely unsteady/off balance, had strong
	sensations of moving or spinning and this has had a
Deveh	significant impact on my normal daily life.
	ological, sleep and sexual questions
Q27. Have you felt worried	No.
or anxious (e.g. feelings of dread, restlessness, panic	I have felt mildly anxious, but it has not stopped me going
and tension) about your	about my day.
current situation or the	I have felt moderately anxious and it has stopped me from
future?	doing some of the things I normally do.
	I have felt severely anxious and it has had a significant impact on my normal daily life.
Q28. Have you felt low in	No.
mood? (e.g. feeling	
hopeless, helpless, irritable,	I have felt mildly down or low in mood but it has not
guilty or worthless)	stopped me going about my day. I have felt moderately down or low in mood and it has
	stopped me from doing some of the things I normally do.
	I have felt severely down or low in mood and it has had a
	significant impact on my normal daily life.
Q29. Have you experienced	No.
difficulty sleeping?	I occasionally have difficulty falling asleep, staying asleep
	or I wake too early.
	I often have difficulty falling asleep, falling asleep, staying
	asleep or I wake too early.
	I always have difficulty falling asleep, staying asleep or I
	wake too early.
Q30. Have you experienced	Not applicable/prefer not to answer.
pain or discomfort during	No.
sex?	I have experienced a little bit of discomfort or pain during
	sex which was relieved with the use of vaginal lubricants.
	I have experienced quite a bit discomfort or pain during sex
	which was only partially relieved with the use of vaginal
	lubricants.
	I have experienced extreme discomfort or pain during sex
Q31. Have you experienced	which was not relieved with the use of vaginal lubricants. Not applicable/prefer not to answer.
a loss of interest in sex?	
	No.
	I have experienced a loss of interest in having sex but this
	has not caused me distress and/or has not had a negative
	impact on my relationship with my partner.
	I have experienced a loss of interest in having sex and this has caused me distress and/or has had a negative impact
	on my relationship with my partner.
Q32. Have you been	Not applicable/prefer not to answer.
bothered by feeling	No.
	INU.

upportiofied with your pov	I am fooling upporticfied with my pay life and this is
unsatisfied with your sex life?	I am feeling unsatisfied with my sex life and this is bothering me slightly.
	I am feeling unsatisfied with my sex life and this is
	bothering me a lot.
	I am feeling unsatisfied with my sex life and this is having a
Q33. Have you had any	negative impact on my relationship. Diagnosis & treatment.
particular concerns or feel	Healthy living.
that you require information	Complementary therapies.
or support relating to any of	Psychological well-being.
the following: (provide link to relevant section of website).	Employment & finances.
	Relationships, sex & intimacy.
	• •
	Younger women with secondary breast cancer.
	Looking ahead (practicalities & planning for an uncertain future).
	Experiences of other women with secondary breast cancer.
	Support for others affected by your diagnosis.
End of standard questions.	
-	down symptoms (for participant to self-select)
Problems experienced when	I have had some mild discomfort when passing urine and
passing water (e.g. pain, needing to go to the toilet	have needed to go more often than normal.
more often or more urgently,	I have had some moderate to severe discomfort or pain
<mark>cloudy or foul smelling</mark>	when passing water, have needed to go to the toilet much
urine): what was the severity of these problems?	more often than usual and/or have noticed my urine is
· · · · · · · · · · · · · · · · · · ·	cloudy or foul smelling.
Lack of appetite or loss of interest in food: How severe	I have lacked appetite, but I was able to eat and drink the same amount and type of food as usual.
was your poor appetite?	I have lacked appetite and I ate or drank less than usual or
	I have been taking supplement drinks.
	I have lacked appetite and I was not able to eat or drink.
Distress related to hair loss	I have noticed some hair thinning or hair loss but this is not
<mark>or hair thinning: What was</mark>	noticeable and I am able to cover it with a different hairstyle
the severity of your distress	OR I have felt slightly distressed/concerned by hair thinning
in relation to hair loss or hair thinning?	or hair loss. I have noticed significant hair thinning or hair loss which is
	very noticeable and may require a wig to disguise OR I
	have felt very distressed by hair loss and it is affecting my
	daily life.
Dry or flaky skin: What was	I have experienced a small amount of dry skin but it has
the severity of your dry or flaky skin?	not been red or itchy. I have had a quite a bit of dry skin which has been red or
	itchy and has stopped me from doing some of the things I
	normally do (e.g. household chores, shopping). I have had a lot of dry skin all over my body which has
	been itchy and has had a significant impact on my normal
	daily life.

Itching of the skin: What	I have experienced some slight/mild itching which was
was the severity of your	relieved by using a moisturiser or cream.
itching?	I have experienced itching all over which comes and goes
	and have noticed some changes in my skin after scratching
	(e.g. swelling, oozing, sores). This has stopped me from
	doing some of the things I normally do (e.g. household
	chores, shopping etc.) I have constant itching (i.e. doesn't go away) which is
Unusual bruising or	having a significant impact on my normal daily life. I have noticed a small amount of bruising in one area/I
bleeding: What was the	have had a small amount of bleeding.
severity of the unusual	I have noticed a moderate amount of bruising/bruising in
bruising or bleeding? (E.g.	several areas of my body/a moderate amount of unusual
from mouth, nose, vaginal,	bleeding.
when vomiting or when	I have noticed one or more large areas of bruising on my
going to the toilet).	body/have had large amounts of unusual bleeding.
Tingling or numbness in	I had a bit of tingling or numbress (perhaps when handling
your fingers and/or toes:	cold or hot objects).
What was the severity of the	I had tingling or numbness and I was not able to do some
tingling or numbness in your	of the things I normally do (e.g. buttoning up or using
fingers or toes?	cutlery).
0	I had tingling or numbness and I was not able to carry out
	daily activities (e.g. I had difficulty walking, dropped things
	or stepped on things by accident).
Difficulty concentrating:	I have had some mild difficulty concentrating or paying
What was the severity of	attention.
your difficulty concentrating?	I have had some moderate difficulty concentrating or
	paying attention and this has stopped me from doing some
	of the things I normally do (e.g. household chores,
	shopping).
	I have had some severe difficulty concentrating or paying
	attention and this has had a significant impact on my daily
	life.
Poor memory: What was the	I have some mild memory loss but this was only
severity of your difficulty	temporary/I was able to remember later on.
remembering things?	I have had some moderate memory loss, forgetting things that have happened recently and this has stopped me from
	doing some of the things I normally do (e.g. household
	chores, shopping).
	I have had some severe memory loss, forgetting things that
	happened less recently/a long time ago and this has had a
	significant impact on my daily life.
Watery eyes: What was the	I have had some mild eye watering but this has not
severity of your watery	affected my ability to see.
eyes?	I have had quite a lot of eye watering and it has affected
	my ability to see.
	I have had severe eye watering and this has significantly
	affected my ability to see.
Dry eyes: What was the	I have had some mildly dry eyes but this has not caused
severity of your dry eyes?	me discomfort.
	I have some moderately dry eyes which have caused me
	some discomfort that was relieved by eye drops.

	I have had severely dry eyes which have caused me pain and discomfort and had a significant impact on my daily life.
Aching in your jaw or mouth: What was the severity of the aching or pain in your jaw or mouth?	I have experienced some mild aching or pain in my jaw which I needed to take medication for and which stopped me from doing some of the things I normally do (e.g. household chores, shopping).
	I have had severe pain in my mouth or jaw which had a significant impact on my normal daily life.
Weight gain: How much weight gain have you	I have noticed that I have gained a small amount of weight but my clothes still fit the same.
noticed?	I have noticed that I have gained a moderate amount of weight and my clothes feel tighter than they used to.
	I have noticed that I have gained quite a lot of weight and some of my clothes no longer fit me.