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# WHAT MATTERS MOST TO BREAST CANCER SURVIVORS? DEVELOPMENT OF A NEEDS ASSESSMENT TOOL FOR CLINICAL USE

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Presented by



Australian  
Cancer  
Survivorship  
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# WHAT MATTERS MOST TO BREAST CANCER SURVIVORS?

DEVELOPMENT OF A NEEDS ASSESSMENT TOOL FOR  
CLINICAL USE

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# BACKGROUND

- Breast cancer survivors may **experience a range of issues and unmet needs** for many years post-treatment
- **Needs assessment is important** in identifying patient issues and unmet needs.
- There is **no appropriate needs assessment tool** for clinical use sensitive and specific to the needs of breast cancer survivors

# AIMS

1. Investigate the physical, psychosocial and practical issues experienced by breast cancer survivors
2. Explore survivors' preferences about needs assessment and care
3. Develop a needs assessment tool for clinical use with breast cancer survivors



# METHODS

## **Study design**

Cross-sectional study involving online and paper-based questionnaires

## **Inclusion criteria**

- Prior diagnosis of stage I, II, or IIIa breast cancer
- Over 18y at diagnosis
- Completed treatment with curative intent, no evidence of active disease

## **Recruitment**

- Peter Mac breast clinics (July-October, 2018)
- Breast Cancer Network Australia (BCNA) Review and Survey Group

## **Data collection**

- Medical and demographic data via patient report and medical records
- Study-specific survey (based on a systematic review)



**Peter Mac**  
Peter MacCallum Cancer Centre  
Victoria Australia

# STUDY-SPECIFIC SURVEY

	A. Do you think this should be routinely asked about?		B. Has this been an issue for you?			C. If you have experienced this issue, how would you like to receive help?		
	Yes	No	No	Yes and it is resolved	Yes and it is ongoing	I would not like help	I would like help from the hospital	I would like help from a community provider
<b>Symptom issues</b>								
Fear of cancer returning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling worried or anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down or depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue or always feeling tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the spaces provided below, please list up to 5 of the most important issues that you have experienced relating to your diagnosis and treatment of breast cancer and believe should be routinely asked about. You can list these in any order.

- 1 \_\_\_\_\_
- 2 \_\_\_\_\_
- 3 \_\_\_\_\_
- 4 \_\_\_\_\_
- 5 \_\_\_\_\_

### 3. Further comments

If you have any other feedback related to your experience since completion of treatment for breast cancer, please use the space below

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Thank you for completing this survey!

<b>Information, support, and practical issues</b>								
Accessing information for myself	<input type="checkbox"/>							
Accessing information for family, friends, or carers	<input type="checkbox"/>							

<b>Other issues not covered (please specify)</b>								
	<input type="checkbox"/>							
	<input type="checkbox"/>							



# RESULTS

Response rates:

- 93% (122/131) for Peter Mac participants
- 11% (159/1475) for BCNA participants

Participant characteristics	n=281
Sex (n)	
Female	280
Male	1
Mean age (SD)	51.6 years ( $\pm 9.6$ )
Mean time since treatment (SD)	6.1 years ( $\pm 5.3$ )
Treatment type (n):	
Surgery	254
Radiation therapy	209
Hormonal therapy	187
Chemotherapy	176
Antibody therapy	41
Current medication for breast cancer (n)	
Yes	154
No	127



# RESULTS

Issue	Asked about?		Issue for you?		Where would you like help?					
	Yes		Yes		Would not like help		Hospital		Community provider	
	n	%	n	%	n	%	n	%	n	%
Trouble sleeping	236	86.8	168	63.4	65	39.4	15	9.1	47	28.5
Pain/discomfort	232	85.0	143	53.8	37	26.8	27	19.6	37	26.8
Fatigue/always feeling tired	231	84.3	169	63.3	56	34.8	22	13.7	45	28.0
Feeling down/depressed	230	84.2	129	48.0	41	32.5	14	11.1	45	35.7
Feeling worried/anxious	226	82.8	167	62.1	62	38.8	17	10.6	49	30.6
Menopausal symptoms	227	82.5	159	59.1	50	32.7	26	17.0	46	30.1
Fear of cancer returning	222	80.7	181	67.3	58	33.1	35	20.0	44	25.1
Returning to work	199	75.4	71	27.8	24	34.8	4	5.8	28	40.6
Financial difficulties	200	74.9	79	30.7	27	35.5	7	9.2	22	28.9
Access to support groups	199	74.8	69	26.8	16	24.2	8	12.1	19	28.8
Accomplishing daily tasks	198	73.9	58	22.8	18	32.7	5	9.1	21	38.2
Issues with sexual functioning	191	71.8	123	47.9	39	32.5	19	15.8	36	30.0
Difficulty concentrating	193	71.0	137	51.7	49	37.1	21	15.9	35	26.5
Accessing information for myself	186	68.9	52	20.2	15	30.6	9	18.4	12	24.5
Issues with appearance/body image	187	68.5	130	48.5	58	46.4	17	13.6	28	22.4
Fertility concerns	173	65.5	19	7.5	4	23.5	7	41.2	1	5.9
Transport issues	171	64.3	30	11.9	6	22.2	5	18.5	7	25.9
Maintaining relationships with family & friends	169	62.8	47	18.4	12	27.3	6	13.6	17	38.6
Accessing information for family, friends & carers	161	59.6	38	15.0	9	25.0	5	13.9	8	22.2



# RESULTS

## Open-ended responses

Themes	Findings
<b>Physical</b>	arm problems, fatigue, lymphedema, menopause, pain/discomfort/numbness, dyspareunia, skin issues, weakness
<b>Psychosocial</b>	anxiety, depression, coping, social support/relationships, emotional burden and support, fear of recurrence, feeling alone, relationship strain, libido
<b>Practical</b>	access to information and services, employment, financial burden, prosthesis issues, performing normal tasks, remoteness of residential area
<b>Living well after cancer</b>	moving on, exercise, nutrition, understanding what's normal, what to expect
<b>Preferences and quality of care</b>	continuity and coordination of care, care plans, access to own medical info, being understood, communication, knowledge of BC issues, holistic care

*"Dealing with all the ongoing joys of menopause and not knowing what to expect which has been difficult"*

*"The fear of it returning is always there"*

*"I find it hard to explain to my husband that even though I've finished treatment, my side effects are real and I've changed"*

*"It is very difficult to make Centrelink understand chronic fatigue and how it affects your ability to find employment"*

*"I didn't want to have to feel as though I was 'sick' and have all aspects of my life revolve around this"*

*"I received an ongoing care plan for after treatment which is great as I feel I have not been forgotten about"*



# KEY MESSAGES AND NEXT STEPS

## Breast cancer survivor pre-appointment questionnaire Do you have any issues you would like to discuss today?

The following table lists a range of issues commonly experienced by survivors of breast cancer. For each issue please respond to the questions by circling the appropriate answer. *The first column asks whether you have experienced the issue. The second column asks whether you would like to discuss this issue during your appointment.*

	Is this an issue for you? (please circle)		Would you like to talk about this in your consultation today? (please circle)	
	Yes	No	Yes	No
<b>Symptom issues</b>				
Trouble sleeping	Yes	No	Yes	No
Aches, pain, or discomfort	Yes	No	Yes	No
Fatigue or always feeling tired	Yes	No	Yes	No
Feeling down or depressed	Yes	No	Yes	No
Feeling worried or anxious	Yes	No	Yes	No
Menopausal symptoms	Yes	No	Yes	No
Fear of cancer returning	Yes	No	Yes	No
Difficulty concentrating	Yes	No	Yes	No
Other side effects	Yes	No	Yes	No
<b>Information and practical issues</b>				
Need for more information	Yes	No	Yes	No
Accessing services	Yes	No	Yes	No
Financial issues	Yes	No	Yes	No
Adjusting to life after cancer	Yes	No	Yes	No
Changes to relationships	Yes	No	Yes	No
Do you have any other issues you would like to talk about that are not listed here? (please specify)				
In case there isn't time to cover all issues, what are the 3 most pressing issues for you at the moment?				

- We need to understand not only which issues breast cancer survivors experience, but also if they would like help for these issues
- Major role for **primary care** in addressing breast cancer survivorship needs
- Based on findings, **we propose a preliminary needs assessment tool** designed for routine use in clinical settings
- Future directions should include **pilot testing, validation, and implementation** in clinical settings.
- Further research is also warranted into the needs of specific groups within the breast survivorship population (eg. men, rural survivors)





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