
Charles Darwin University

What factors influence the treatment decisions of women with breast cancer? Does residential location play a role?

Youl, Philippa; Morris, Bronwyn; Jenny, Anderson; Morstyn, Lisa

Published in:
Rural and Remote Health

DOI:
[10.22605/RRH4497](https://doi.org/10.22605/RRH4497)

Published: 01/05/2019

Document Version
Publisher's PDF, also known as Version of record

[Link to publication](#)

Citation for published version (APA):

Youl, P., Morris, B., Jenny, A., & Morstyn, L. (2019). What factors influence the treatment decisions of women with breast cancer? Does residential location play a role? *Rural and Remote Health*, 19(2), 1-11.
<https://doi.org/10.22605/RRH4497>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



ORIGINAL RESEARCH

What factors influence the treatment decisions of women with breast cancer? Does residential location play a role?

AUTHORS

Philippa Youl¹ PhD, Senior Research Fellow *, pyoul@usc.edu.au

Bronwyn Morris² PhD, Research Manager

Jenny Anderson³ PhD, Research and Evaluation Manager

Lisa Morstyn⁴ LLB, Policy Officer

CORRESPONDENCE

*Dr Philippa Youl pyoul@usc.edu.au

AFFILIATIONS

¹ University of the Sunshine Coast, Sippy Downs, Qld 4556, Australia; and Queensland University of Technology, Kelvin Grove, Qld 4059, Australia

² Menzies School of Health Research, Level 1, 147 Wharf Street, Spring Hill, Qld 4000, Australia

^{3,4} Breast Cancer Network Australia, 293 Camberwell Rd, Camberwell, Vic. 3124, Australia

PUBLISHED

27 May 2019 Volume 19 Issue 2

HISTORY

RECEIVED: 23 June 2017

REVISED: 4 March 2019

ACCEPTED: 4 March 2019

CITATION

Youl P, Morris B, Anderson J, Morstyn L. What factors influence the treatment decisions of women with breast cancer? Does residential location play a role? *Rural and Remote Health* 2019; 19: 4497. <https://doi.org/10.22605/RRH4497>

Except where otherwise noted, this work is licensed under a Creative Commons Attribution 4.0 International Licence

ABSTRACT:

Introduction: Inequalities in cancer outcomes continue to exist throughout the world. In Australia, rural women diagnosed with breast cancer have significantly poorer 5-year survival, with variations in clinical management additionally observed. While factors impacting clinical management have been identified, there is little understanding about the factors that influence treatment decisions of women diagnosed with breast cancer.

Methods: A mixed-methods study was conducted with women

diagnosed with either pre-invasive or invasive breast cancer in Australia. The study included qualitative interviews and an online survey utilising Breast Cancer Network Australia's membership. Semi-structured interviews were conducted with rural women focusing on topics such as decision-making and factors influencing this. The online survey amongst metropolitan and rural (including regional, remote, very remote) women examined involvement in, and preference for, decision-making, and to what degree certain

factors influenced treatment decisions. Sociodemographics included age, residential location, education and household income. Qualitative interviews were analysed using NVivo, and descriptive analyses were used to examine differences in frequency distributions across survey questions by residential location and age group for the online survey. Multivariable logistic regression analysis was conducted to examine factors associated with treatment decision-making.

Results: Nine women participated in the qualitative interviews and 815 (365 metropolitan and 450 rural) completed the online survey. Interviews found most women concurred with the recommendations of their doctor(s) and did not see this experience as 'making a decision'. In the online survey, 83.2% of women indicated at least some involvement in the decision-making with this being similar between rural and metropolitan women. Compared to women educated at an under- or postgraduate level, those educated at high school or less were about 50% less likely to be involved in treatment decision(s) (OR=0.51, 95% confidence interval=0.30–0.86). In both interviews and the online survey, factors having the strongest influence on treatment decisions centred around survival and reducing risk of progression or recurrence. Significantly more rural compared to

Keywords:

Australia, breast cancer, decisions, treatment.

FULL ARTICLE:

Introduction

It is estimated 1.67 million women worldwide were diagnosed with breast cancer in 2012¹. In Australia, breast cancer is the most common cancer diagnosed amongst women (with the exception of keratinocyte cancers) and the second leading cause of cancer death².

Inequalities in cancer outcomes continue to exist across the world with these inequalities observed at socioeconomic, racial and geographical levels³. In Australia, there are persistent survival disadvantages for those who live in rural areas compared to their urban counterparts. For example, 5-year relative survival for rural women diagnosed with breast cancer is about 2–5% lower in absolute terms compared with that of urban women⁴⁻⁸. While more recent analyses have shown survival has improved over time across all population groups, rural and disadvantaged women continue to experience poorer survival (after adjusting for age and disease stage at diagnosis)⁹.

Further, variations in the clinical management of breast cancer exist amongst rural and disadvantaged women. Rural and disadvantaged women with early breast cancer are more likely to undergo mastectomy than breast-conserving surgery (BCS), with these differentials remaining after adjustment for clinical factors¹⁰⁻¹². Similar variations have been observed in other countries¹³⁻¹⁶. While rates of mastectomy for early breast cancer have reduced over time, rural women continue to undergo mastectomy more frequently than their urban counterparts¹⁷. A

metropolitan women indicated their decision was strongly influenced by treatment service location (42.8% and 28.1%, respectively, $p < 0.001$). Rural women more frequently cited financial costs of treatment influenced their decision compared to metropolitan women (30.4% and 21.3%, respectively, $p = 0.04$). Significantly fewer rural, (16.2%) compared to metropolitan (23.6%) women, had breast reconstruction ($p = 0.009$). The option of having reconstructive surgery was less frequently cited as influencing treatment decisions for rural compared to metropolitan women (27.7% v 44.1% respectively, $p < 0.001$).

Conclusions: The treatment decisions of the majority of women were strongly influenced by the need to do everything possible to get better; however, rural women additionally indicated their decisions were also influenced by factors such as access to treatment services and the financial costs of treatment. Addressing travel and costs issues for rural women with breast cancer should be prioritised. Additionally, the finding that women with lower levels of education were significantly less likely to be involved in the decision-making process highlights the need to develop new or tailor existing resources. Further work could also examine the reasons why rural women are less likely to consider breast reconstruction important in decision-making.

number of studies have also shown lower rates of sentinel node biopsy for rural women, with authors suggesting the results may reflect difficulties in obtaining radiopharmaceuticals required for this procedure as well as a lack of trained specialists¹⁸⁻²⁰. While more recent population-based registry analysis showed an increase in the use of sentinel node biopsy overall, there remained no evidence of a reduction in the geographical disparity over time²¹.

Current evidenced-based guidelines for the management of early breast cancer state that, where clinically appropriate, women should be provided with information about mastectomy and BCS to assist them in making an informed choice^{22,23}. While both procedures have equivalent survival, BCS is associated with reduced morbidity and better quality of life²⁴. However, choice of mastectomy among women who are eligible for BCS appears dependent on a number of factors. Studies have shown these include clinical factors (stage, tumour size, grade, previous history of breast cancer or breast disease)²⁵, as well as non-clinical factors such as age, socioeconomic status and geographical location²⁶⁻²⁸. Distance to closest radiation facility has also been identified as a barrier for rural women²⁹⁻³¹.

While historically clinician and patient discussions regarding treatment options were uncommon, the shared decision-making model is increasingly being used, particularly where more than one treatment is available³². Factors that influence treatment decisions can be complex and individualistic. A key factor influencing treatment decisions is the perception of a need to do everything

possible to reduce risk of the disease recurring and to afford the best chance of long-term survival. Covelli and colleagues³³ found an overriding factor influencing treatment decisions was fear of recurrence, and a previous experience of cancer involving a family member or close friend. Access to health care has been proposed as an important factor in the treatment decision process. For example, while adjuvant radiotherapy is often used in combination with BCS, distance to the closest radiation service along with access to radiation oncologists have been reported as being a barrier for rural women in particular²⁹⁻³¹.

The aim of this present study was to examine factors that influence treatment decisions of women with breast cancer, with a particular focus on identifying whether there are differences between rural (including regional, remote and very remote) and metropolitan women.

Methods

This study used a mixed-methods approach involving qualitative interviews followed by an online survey utilising Breast Cancer Network Australia's (BCNA) membership database. BCNA is the peak national organisation for Australians affected by breast cancer, with over 120 000 members Australia-wide.

Qualitative interviews

Semi-structured interviews were conducted with nine women living in rural locations throughout Australia in September 2016 recruited via BCNA's Review & Survey Group. A semi-structured interview guide was used to ensure relevant topics were discussed including treatment decision-making and factors that may have influenced this, information received/obtained at that time, satisfaction with treatment decisions and information and support received, along with adherence to treatment regimens.

Interviews were audio-recorded (with consent), transcribed and analysed using NVivo v11.3.1 (QSR International; <https://www.qsrinternational.com/nvivo/nvivo-products>). The thematic analysis approach was based on an interpretive phenomenological framework that aims to capture the lived experience of the participant and adopts a shared understanding on the part of the researcher and the participant. Emergent themes were identified by grouping similar concepts. Data saturation was achieved during analysis and new codes were not generated with later participants.

Online survey

The online survey was developed in consultation with BCNA. Survey questions were additionally shaped by the themes that emerged from the qualitative interviews. The survey was pilot-tested among a small sample of BCNA consumer representatives. The survey was specifically aimed at women diagnosed with early stage breast cancer more than 12 months but less than 5 years ago who had completed treatment (with the exception of ongoing hormone therapy), and those diagnosed with metastatic breast cancer more than 12 months but less than 3 years ago.

The survey included sociodemographics including age, postcode at residential location, Indigenous status, education and annual household income. Participants were asked to indicate the type of breast cancer they had been diagnosed with: ductal carcinoma in-situ (DCIS), lobular carcinoma in-situ (LCIS), early stage breast cancer, metastatic breast cancer or 'don't know what type of breast cancer'. Residential postcode was coded to major city, inner regional, outer regional, remote and very remote using the Australian Bureau of Statistics Australian Statistical Geographical Standards Remoteness Structure 2011.

Involvement in treatment decision was assessed by asking participants whether they were involved in deciding what treatment(s) they would have at time of their initial diagnosis. Participants were further asked who was involved in making treatment decisions. Women not involved in the treatment discussions were additionally asked the reasons why (Figure 1 provides response categories.) Using the Control Preference Scale from Degner and Sloan³⁴, researchers asked participants how they would have preferred the treatment decision to be made with possible responses being:

- *I was satisfied with how the decision was made.*
- *I would have preferred that the decision was made by my doctor(s) with little input from me.*
- *I would have preferred that my doctor(s) made the decision, but seriously considered my opinion.*
- *I would have preferred that my doctor and I made the decision together.*
- *I would have preferred to make the decision after seriously considering my doctor's opinion.*
- *I would have preferred to have made the decision with little input from my doctor(s) with little input from my doctor(s).*

Participants were additionally asked to identify to what degree various factors influenced their treatment decisions using a Likert-type scale ('not at all', 'a little', 'moderately', 'quite a bit' or 'a lot' with the factors adapted from the work of Degner et al³⁵.

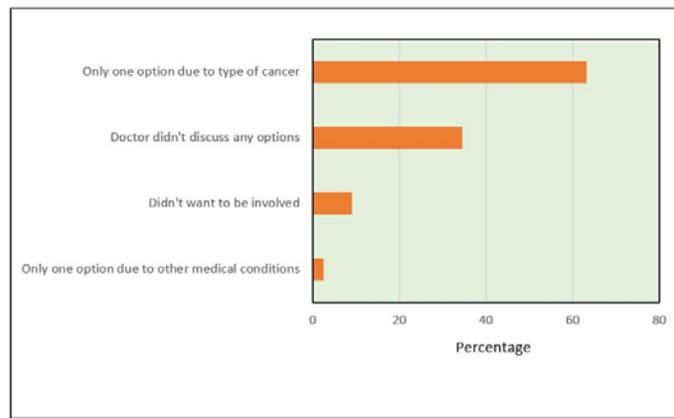


Figure 1: Most common reasons why women were not involved in treatment decision.

Online survey participants

The BCNA database contained 14 762 members who met the inclusion criteria (ie individuals with an email address who were diagnosed with early stage breast cancer between December 2011 and December 2017 or those diagnosed with metastatic breast cancer between December 2013 and December 2015). As there were significantly more members living in metropolitan compared to rural locations, the researchers elected to contact a random sample of 4000 metropolitan members and all 2311 rural members. The random sample of metropolitan members was representative of the whole group. Recruitment was supplemented through contact with BCNA member group facilitators ($n=351$), BCNA's Facebook and their online network. Potential participants were contacted by email and provided with a brief summary of the aims of the study along with a website address they could access to complete the survey after first giving online consent. There were no significant differences across sociodemographics according to recruitment method.

Analyses

Descriptive analyses were used to examine frequency distributions across survey questions. The statistical significance of bivariate comparisons between various survey questions and residential location, age group and education was estimated using χ^2 test. Analyses additionally included separate logistic regression models to examine factors independently associated with treatment decision-making. For the purposes of this analysis participants living in major city locations were classified as 'metropolitan' and those living in inner or outer regional, or remote and very remote locations were collapsed into the broader category of 'rural'. However, when analysing factors associated with treatment decision making, we included three categories (metropolitan, inner regional and outer regional/remote/very remote). All online survey analyses were conducted using Stata v14.2 (Stata Corp, <https://www.stata.com>).

Ethics approval

Ethics approval for the study was obtained from the University of the Sunshine Coast (approval #A16/168).

Results

Description of participants

Nine rural women agreed to take part in the qualitative interviews (24% response rate). Mean age was 55 years with half having dependent children living at home and all participants, with the exception of one, with a current partner/husband. All interview participants had received surgery, seven radiotherapy and six chemotherapy. Most were diagnosed with early stage breast cancer and two with metastatic breast cancer.

In all, 6662 women were emailed regarding the online survey, with 1046 (15.7%) initially consenting to participate. Of those, 815 (77.9%) completed all survey items. Table 1 provides an overview of survey participants. Mean age was 57 years (range 29–83 years) and 1.4% identified as Aboriginal or Torres Strait Islander (hereafter referred to respectfully as 'Indigenous'). Approximately 45% lived in a metropolitan location. Of those living in rural areas, just under one-third (31.9%) were from an inner regional area, 20.1% from outer regional areas and 3.2% ($n=26$) were from remote or very remote locations. Just over one-third were educated at an undergraduate or postgraduate level (39.0%) and 32.8% had a diploma or certificate. Education at an under- or postgraduate level was more common amongst metropolitan women ($p=0.002$). About one-third (31.8%) of all women reported an annual household income of less than \$65,000 per annum, with this being more frequently observed for rural women ($p<0.001$). In relation to breast cancer diagnosis, the majority of women reported being diagnosed with early stage breast cancer (69.9%), about 1 in 5 reported a diagnosis of DCIS or LCIS and 5.8% had metastatic breast cancer with these proportions being similar amongst rural and metropolitan women. Nearly all women reported having some form of surgery (98.8%), with just under three-quarters reporting they had radiotherapy; 61.6% had chemotherapy and 73.7% had or were currently receiving hormone therapy. There were no significant differences observed according to residential location. Overall, just under 1 in 5 women (19.5%) indicated they had undergone breast reconstruction, with this being significantly more common amongst metropolitan compared to rural women ($p=0.009$).

Table 1: Description of 815 participants completing the online survey

Characteristic	Metropolitan (n=365) (%)	Rural (n=450) (%)	p-value
Age group (years)			0.36
<50	24.6	20.4	
50–69	64.7	68.4	
≥70	10.7	11.1	
Indigenous status			0.24
Indigenous	0.8	1.8	
Non-Indigenous	99.2	98.2	
Education			0.002
High school or less	24.0	29.6	
Certificate/diploma	29.6	38.4	
Undergraduate/postgraduate	46.4	34.1	
Household income			<0.001
\$0–64,999	25.7	36.7	
\$65,000–129,000	30.7	36.0	
≥\$130,000	26.8	11.8	
Unknown/prefer not to say	16.7	15.6	
Type of breast cancer			0.23
DCIS/LCIS†	19.7	22.0	
Early stage breast cancer	73.1	67.3	
Metastatic breast cancer	4.4	6.9	
Don't know/prefer not to say	2.7	3.8	
Received surgery	99.4	98.2	0.11
Had breast conserving surgery	48.2	48.1	0.99
Had breast reconstruction	23.6	16.2	0.009
Received radiotherapy	72.3	71.8	0.86
Received chemotherapy	62.5	60.9	0.64
Received/receiving hormone therapy	75.9	72.0	0.21

DCIS, ductal carcinoma in situ and LCIS, lobular carcinoma in situ.

Involvement in decision treatment decision-making process

In qualitative interviews, most women concurred with the recommendations of their treating doctor(s) and did not see this experience as ‘making a decision’. However, two participants reported disagreeing with the recommended treatment options presented, and ‘making their own decision’ based on their career experience/knowledge and research.

In the online survey the majority of women (83.2%) indicated they had at least some involvement in deciding what treatment(s) they would have (Table 2). At a bivariate level, while no significant differences were observed according to residential location, fewer women educated at certificate/diploma level or high school or lower level indicated they were involved in the decision-making process ($p=0.007$). In multivariable logistic regression analysis,

compared to women educated at an under- or postgraduate level, those whose education was high school or less, and those at a level of diploma/certificate, were both about 50% less likely to indicate they were involved in the treatment decision process (odds ratio (OR)=0.51, 95% confidence interval (CI)=0.30–0.86 and OR=0.48, 95%CI=0.29–0.78, respectively, $p=0.008$). When the analysis was restricted to those diagnosed with early breast cancer, the strength of the association between not being involved in the treatment decision-making process and lower levels of education was even more pronounced. Further, compared to women diagnosed with metastatic breast cancer, those with DCIS/LCIS or early breast cancer were significantly more likely to report being involved in the treatment decision-making process (OR=2.29, 95%CI=1.32–5.10 and OR=3.32, 95%CI=1.51–7.31, respectively, $p=0.02$) (Table 2).

Table 2: Factors associated with treatment decision-making amongst a sample of women with breast cancer in Australia

Characteristic	Involved in decision making versus not involved†					
	Unadjusted		p-value	Adjusted		
	% Yes (n=678)	% No (n=122)		OR	95% CI	p-value
Age group (years)			0.34			0.22
<50	81.5	18.5		0.69	0.44–1.09	
50–69	85.4	14.6		ref		
≥70	87.5	14.5		1.16	0.58–2.32	
Residential location			0.23			0.47
Metropolitan	87.0	13.0		ref		
Inner regional	83.7	16.3		0.82	0.52–1.30	
Outer regional/remote/very remote	81.7	18.3		0.74	0.45–1.22	
Education			0.007			0.007
High school or less	82.1	17.9		0.51	0.30–0.86	
Certificate/diploma	80.8	19.2		0.48	0.29–0.78	
Undergraduate/postgraduate	89.6	10.4		ref		
Household income			0.62			
\$0–20,799	79.8	20.4				
\$20,00–41,599	85.0	15.0				
\$41,600–64,999	86.8	13.2		N/A	N/A	
\$65,000–77,999	81.9	18.1				
\$78,000–129,000	82.2	17.8				
≥\$130,000	86.6	13.4				
Unknown/prefer not to say	88.3	11.7				
Type of breast cancer			0.009			0.02
DCIS/LCIS	87.4	12.6		3.32	1.51–7.31	
Early stage breast cancer	85.5	14.4		2.59	1.32–5.10	
Metastatic breast cancer	68.1	13.9		ref		
Don't know/prefer not to say	81.5	18.5		2.07	0.64–6.72	

† Totals vary due to missing values. CI, confidence interval. DCIS, ductal carcinoma in situ. LCIS, lobular carcinoma in situ. N/A, not included in final model. OR, odds ratio. Ref, reference value.

Who was involved in making treatment decisions?

Table 3 provides the frequency of responses when asking participating women who was involved in making the treatment decision (includes only those women who indicated some

involvement in the decision-making process ($n=678$)). The most common response was that both the woman and her doctor(s) made the decision together (40.0%) with a further 25.0% of women indicating they made the decision after seriously considering their

doctor's opinion. The researchers found no significant differences in the frequency of responses according to residential location ($p=0.13$). This was similar when only women with DCIS/LCIS or early breast cancer were included. However, when researchers examined the frequency of responses for women with either early breast cancer or DCIS/LCIS who did not have BCS ($n=315$), a

significantly higher proportion of rural compared to metropolitan women was found, indicating they decided on their treatment(s) after seriously considering their doctor's opinion (37.3% and 21.5%, respectively) ($p=0.01$). No such pattern was found for women who had BCS (Table 3).

Table 3: Who was involved in making treatment decision(s) amongst metropolitan and rural women diagnosed with breast cancer

Person involved	Metropolitan ($n=315$) %	Rural ($n=363$) %	p-value	Did not have BCS ¹		p-value
				Metropolitan ($n=160$) %	Rural ($n=166$) %	
Doctor(s) made decision with little input from me	15.6	17.6	0.13	14.1	14.5	0.01
Doctor(s) made decision, but seriously considered my opinion	18.7	16.0		21.5	13.3	
Doctor(s) and I made decision together	43.2	37.2		42.9	34.9	
I made decision after seriously considering my doctor(s) opinion	21.6	26.4		21.5	37.3	
I made the decision with little input from my doctor(s)	0.9	2.7		0.0	0.0	

¹ Includes only women with DCIS/LCIS or early breast cancer.
BCS, breast conserving surgery. DCIS, ductal carcinoma in situ and LCIS, lobular carcinoma in situ.

Why some women were not involved in treatment decisions

Approximately 15% of women indicated they were not involved in deciding what treatments they would have. The most common responses for why they were not involved was that they did not have options due to their type of breast cancer (63.1%) or that their doctor did not discuss any options with them (34.4%) (Fig1). Responses were similar for rural and metropolitan women and across age groups.

Factors influencing treatment decisions and options

Table 4 shows the component themes identified in the qualitative interviews. Many participants discussed wanting to do all treatment available in order to give themselves the best chance of surviving their breast cancer and reducing any risk of the disease recurring in the future. Some participants indicated that their experiences with cancer, either within the family or as a health professional, influenced their decision-making. Participants also identified the need to have treatment locally to avoid time away from family. This was particularly a concern for participants who were the main caregiver. One participant, rather than have treatment locally, elected to have treatment away from her community due to concerns about her own privacy.

Similarly, in the online survey, the vast majority of women indicated their treatment decision was strongly influenced by 'minimising the chance the cancer will come back' and 'the need to do everything possible to get better', with no significant differences in the frequency of responses according to residential location (Table 5). However, a significantly higher proportion of rural (42.8%), compared to metropolitan women (28.1%), indicated their treatment decision was influenced 'quite a bit/a lot' by the 'location of treatment services and facilities' ($p<0.001$). Similarly, nearly one in three rural, compared to one in five metropolitan women, said their decision was strongly influenced by the 'financial

costs of treatment' ($p=0.04$). Having 'reconstructive surgery as an option' appeared to be of more importance to metropolitan women with 44.1% of them indicating this option strongly influenced their treatment decision compared to 27.7% of rural women ($p<0.001$). Overall, the researchers found about one in five women indicated their treatment decision was strongly influenced by the wishes of family/friends, with these results being similar for both metropolitan and rural women (Table 5).

Additionally, the researchers found some significant differences in responses for a number of factors across age groups (Table 5). For example, over 80% of women aged less than 70 years, and just under 60% (58.7%) of those aged ≥ 70 years, indicated their treatment decision was influenced 'quite a bit/a lot' by 'wanting to have every possible treatment to get better' ($p<0.001$). Similarly, for older women (≥ 70 years), having reconstructive surgery as an option did not appear to have influenced treatment decisions to the same degree than for those aged less than 50 years (14.6% and 48.5%, respectively, $p<0.001$). Further, about one in four women (28.3%) aged less than 50 years indicated their treatment decisions were strongly influenced by 'the financial costs of treatment', compared to only about 1 in 10 women aged $\geq 70+$ years (9.1%, $p<0.001$). Body image appeared of more importance to younger women, with about one-third (31.3%) saying their decision was influenced 'quite a bit/a lot' by 'how their body would look after treatment', compared to 22.0% of women aged 50–69 years and 11.5% of those aged ≥ 70 years ($p=0.005$). About one in two women aged ≥ 70 years (46.3%) indicated their treatment decision was strongly influenced by 'wanting to avoid having chemotherapy' compared to 21.8% of those aged under 50 years and 30.6% for women aged 50–69 years ($p=0.004$). Just over half (51.5%) of women indicated their treatment decision was not at all influenced by the wishes of their family or friends, with these results being similar across age groups.

Table 4: Component themes influencing treatment decisions identified in qualitative interviews

Theme	Examples
Wanting to do everything possible	<i>Give me best chance of surviving cancer Reducing risk of recurrence or progression</i>
Previous experience with cancer	<i>Sister had breast cancer Working in palliative care Clinical experience</i>
Making treatment decisions based on family	<i>Couldn't travel to city due to family commitments Treatment completed as soon as possible Caregiver role</i>
Lack of privacy	<i>Difficulties in being treated in small community and being a local health professional</i>

Table 5: Factors influencing treatment decisions amongst metropolitan and rural women with breast cancer in Australia

Factor	Percentage indicating factor influenced treatment decision 'quite a bit/a lot' [†]						
	Metropolitan	Rural	p-value [‡]	<50 years	50-69 years	≥70 years	p-value [‡]
Minimising the chance the cancer will come back (n=787)	90.1	88.9	0.32	90.3	91.3	75.9	<0.001***
Wanting to have every treatment possible to get better (n=785)	78.9	79.0	0.14	82.7	80.8	58.7	<0.001***
Doing what my doctor thought was best (n=805)	77.3	73.9	0.47	81.8	75.0	64.4	0.02*
Wanting to remove the breast for peace of mind (n=641)	47.1	47.4	0.89	46.1	49.1	38.8	0.09
Location of treatment services and facilities (n=788)	28.1	42.8	<0.001***	33.0	37.8	32.5	0.07
Having reconstructive surgery as an option (n=534)	44.1	27.7	<0.001***	48.5	32.9	14.6	<0.001***
Being able to keep my breast (n=887)	29.7	26.5	0.60	35.8	25.3	26.5	0.17
Time associated with treatment and recovery (n=787)	23.9	26.0	0.36	29.1	26.1	20.9	0.74
Disruption to lifestyle during treatment (n=796)	23.7	27.7	0.28	28.6	26.4	16.7	0.13
Financial costs associated with treatment (n=755)	21.3	30.4	0.04*	28.3	25.3	9.1	<0.001***
How my body would look after treatment (n=778)	26.4	20.4	0.14	31.3	22.0	11.5	0.005**
Having to wear a breast prosthesis after treatment (n=511)	23.3	21.6	0.17	25.6	22.8	12.3	0.35
Wishes of family/close friends (n=767)	15.9	21.6	0.14	20.8	19.1	14.8	0.23
Wanting to avoid having chemotherapy (n=692)	28.6	31.0	0.81	21.8	30.6	46.3	0.004**
Wanting to avoid having radiotherapy (n=726)	18.6	18.6	0.21	14.8	19.6	20.8	0.49
Wanting to avoid having hormone therapy (n=861)	17.7	16.9	0.54	14.4	17.4	22.2	0.17
Religious or cultural beliefs	1.4	1.2	0.20	2.0	1.2	0.0	0.86

^{*}p<0.05, ^{**}p<0.01, ^{***}p<0.001

[†] Unknown or not applicable responses were excluded.

[‡] p-value based on Pearson's χ^2 examining differences in proportions of responses ('not a lot', 'a little bit', 'moderately' and 'quite a bit/a lot').

Were women satisfied with their treatment decision?

In the qualitative interviews, most participants reported being satisfied with their treatment decisions, with many stating they felt they had done everything they could to give themselves the best chance. For example, one participant said 'So the decisions I made were to I suppose, survive and get myself the best options available'. Another participant reported doubts and anxiety about whether they should have had chemotherapy and a few also discussed fears about their cancer returning.

In the online survey the majority of women strongly agreed (58.0%) or agreed (31.9%) that they were satisfied with their treatment decision. Similarly, the majority strongly agreed (54.3%) or agreed (34.0%) that they felt they had made an informed choice; the vast majority (90.0%) agreed/strongly agreed they felt confident the treatment they received would achieve a good result for them. Responses were similar for metropolitan and rural women and across age groups (data not shown).

Discussion

This study examined the treatment decisions, and the factors influencing those decisions, of metropolitan and rural women in Australia treated for breast cancer.

It was found that the majority of women in this study were involved in the treatment decision process and this was similar for rural and metropolitan women. Only about 15% of women indicated no involvement in the process and the vast majority of those women said this was because they had no options due to the type of breast cancer they had. Overall, women did not necessarily see the experience of discussing treatments as 'making a decision', with most concurring with the recommendations of

their doctor. This for a large part was driven by the need to do everything to live. While, rural and metropolitan women appeared to be equally involved in the decision-making process, the researchers did find significant differences in the degree of involvement according to education level. The finding that women educated at a high school level (compared to those with an undergraduate or postgraduate qualification) were significantly less likely to indicate involvement in treatment decisions is concerning. Similar findings have been reported elsewhere³⁶. The reason for this is to a large extent unknown. Communicating what is often complex information is an important part of the consultation process, and needs at the time of diagnosis have been shown to be greatest³⁷. It has been reported that women with lower levels of education do not necessarily want to be involved in discussing treatment options³⁶, and women with a higher level of education prefer to be more involved and have more control over the decision-making process³⁸. Taking into account health literacy when delivering information about breast cancer and treatment during consultations may help to empower women with lower levels of education and enable them to take part in the decision-making process.

In this study around 40% of women indicated they shared the decision-making with their doctor, with a further one-quarter saying they made the decision after seriously considering the opinion of their doctor, with this being similar amongst rural and metropolitan women. The present study did however find some differences in treatment decision-making according to residential location for women with early breast cancer who did not have BCS. Over one-third of rural women with early breast cancer who did not have BCS made their own treatment decision (after considering their doctor's opinion) compared to only about one-

quarter of metropolitan women. This finding was not replicated for women who had undergone BCS. While the present study could find no significant differences overall in the proportion of metropolitan and rural women who had received BCS, a number of studies report lower rates of BCS amongst rural women^{10,12}. It is possible that rural women who did not have BCS were more likely to have made the treatment decision themselves due to factors such as the need to have follow-up radiotherapy, coupled with travel issues. Katz and colleagues reported more patient involvement in decision making when undergoing mastectomy with patient attitudes being significantly associated with surgical procedure³⁹. As radiotherapy often follows BCS, travel distance to radiation services can be problematic for women living in rural locations²⁶⁻²⁸. Thus distance to closest radiation centre may mean that where rural women are given treatment options, it plays a more significant role in the decision-making process.

In the present study three factors strongly influenced the treatment decisions for both rural and metropolitan women equally. These were the need to do everything possible to get better, minimising the chances of recurrence and doing what the doctor thought best. These factors are in line with other research. A number of studies have shown the overriding factors influencing treatment decisions have been fear of the cancer returning or progressing, and having all possible treatments to survive the disease^{33,40}. Further work has shown that women cite the recommendation of the surgeon as being an important influence in their treatment decision⁴¹.

The present study found significant differences in responses for three other factors amongst rural and metropolitan women. Rural women were more likely to indicate the location of treatment services and facilities had a strong influence over their treatment decision. Similar findings have been observed in a number of studies where travel distance, particularly for radiation therapy and other specialist cancer services, plays a significant role in treatment decisions²⁹⁻³¹. While the present study did not find any differences in the proportion of metropolitan and rural women indicating their treatment decision was strongly influenced by wanting to avoid having radiotherapy, Australia is a geographically large country, where most health services are concentrated in major cities. Therefore, rural patients are more likely to rate issues with distance and access more highly than those living in metropolitan areas.

A significantly greater number of rural compared to metropolitan women indicated their treatment decisions were strongly influenced by the financial costs associated with treatment. It is likely the concern about costs includes the costs of travelling for treatment, being away from home and the financial burden associated with not working. Similar findings have been reported elsewhere where the need to stay in accommodation away from home and the potential costs of travelling have been reported as playing a significant role in deciding what treatments to undergo²⁸. Further, Australian research has noted potential loss of income and travel costs are associated with patient choice of treatment⁴². While patient-assisted travel schemes are available for patients in Australia who reside more than 100 km from a

treatment centre, these schemes vary from state to state in how they are accessed and managed, and reimbursement amounts. State-based cancer councils in Australia can also assist with transport and accommodation costs and, in some cases, can provide accommodation for patients and their carers travelling a long distance for treatment. While such schemes do not cover costs associated with loss of income, knowledge about the availability of the scheme at the time of treatment discussions may help patients when deciding on a course of treatment.

This study additionally found about double the number of metropolitan compared to rural women indicated their treatment decision was strongly influenced by having reconstructive surgery as an option. In Australia, rates of reconstructive surgery decline with increasing remoteness. A recent Queensland study found about 14% of women living in highly accessible areas had breast reconstruction compared to about 4% of those living in less accessible areas. While the disparity had reduced over time, after adjustment for a number of factors it remained that women in less accessible areas were about 70% less likely to have breast reconstruction¹⁷.

The present study additionally found some differences in factors that influence treatment decisions across age groups. By and large, younger women were more likely to place more emphasis on the need to reduce risk of recurrence and doing what the doctor thought best. A significantly higher proportion of younger compared to older (≥ 70 years) women, indicated their treatment decision was influenced by factors associated with body image. These factors included having reconstructive surgery as an option and how their body would look after treatment. Again, these results are in keeping with other findings that body image plays an important role in treatment decisions of younger women^{42,43}.

Limitations

There are limitations to this study that need to be acknowledged. The main limitation was the use of the BCNA member database as the primary recruitment method. While BCNA represents the peak national organisation for those diagnosed with breast cancer, it is possible the participant sample was biased. The study examined participant interactions with BCNA in the 12 months prior to the survey being undertaken and found nearly three-quarters had at least some interaction with BCNA during that time (mostly through BCNA's regular newsletters or through their website). Thus, it may be the case that participants were more engaged and have already had access to numerous information resources focusing on breast cancer in general and breast cancer treatments. That said, BCNA's member network includes over 120 000 members and the sample of metropolitan and rural women who participated was reflective of the whole group. Further, the mean age of participants, the proportion living in metropolitan or rural areas, and levels of education were similar to those observed in a recent population-based study of women diagnosed with breast cancer⁴⁴. Finally, the researchers elected to collapse participants from inner regional, outer regional, remote and very remote areas into one group (rural). While it could be argued that participants from inner

regional areas have better access to treatment services and therefore they may more closely reflect the results of those living in major cities, it was actually found in this study that they were more reflective of those living in outer regional areas.

Conclusions

While the treatment decisions of the majority of women were strongly influenced by the need to do everything possible to get better and reduce the risk that their breast cancer would progress

or recur, rural women indicated their decisions were influenced by additional factors. These primarily focused around access to treatment services and the financial costs associated with treatment. Addressing the issues around travel and costs for rural women with breast cancer should be prioritised. Additionally, the finding that women with lower levels of education were significantly less likely to be involved in the decision-making process highlights the need to develop new or tailor existing resources for this group in particular.

REFERENCES:

- 1 Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, et al. *GLOBOCAN 2012 v1.0, Cancer incidence and mortality worldwide: IARC CancerBase No. 11*. 2013. Available: <http://globocan.iarc.fr> (Accessed 20 June 2016).
- 2 Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre. *Breast cancer in Australia: an overview, 2009*. Cancer series no 50 Cat no CAN 46. Canberra: Australian Institute of Health and Welfare, 2009.
- 3 Singh GK, Williams SD, Siahpush M, Mulhollen A. Socioeconomic, rural-urban, and racial inequalities in us cancer mortality: part i-all cancers and lung cancer and part ii-colorectal, prostate, breast, and cervical cancers. *Journal of Cancer Epidemiology* 2011; **2011**: 107497. <https://doi.org/10.1155/2011/107497> PMID:22496688
- 4 Roder D, Webster F, Zorbas H, Sinclair S. Breast screening and breast cancer survival in Aboriginal and Torres Strait Islander women of Australia. *Asian Pacific Journal of Cancer Prevention* 2012; **13(1)**: 147-155. <https://doi.org/10.7314/APJCP.2012.13.1.147> PMID:22502658
- 5 Clayforth C, Fritschi L, McEvoy SP, Byrne MJ, Ingram D, Sterrett G, et al. Five-year survival from breast cancer in Western Australia over a decade. *Breast* 2007; **16(4)**: 375-381. <https://doi.org/10.1016/j.breast.2007.01.010> PMID:17448661
- 6 Mitchell KJ, Fritschi L, Reid A, McEvoy SP, Ingram DM, Jamrozik K, et al. Rural-urban differences in the presentation, management and survival of breast cancer in Western Australia. *Breast* 2006; **15(6)**: 769-776. <https://doi.org/10.1016/j.breast.2006.04.001> PMID:16765049
- 7 Cramb SM, Mengersen KL, Turrell G, Baade PD. Spatial inequalities in colorectal and breast cancer survival: premature deaths and associated factors. *Health & Place* 2012; **18(6)**: 1412-1421. <https://doi.org/10.1016/j.healthplace.2012.07.006> PMID:22906754
- 8 Dasgupta P, Baade PD, Aitken JF, Turrell G. Multilevel determinants of breast cancer survival: association with geographic remoteness and area-level socioeconomic disadvantage. *Breast Cancer Research and Treatment* 2012; **132(2)**: 701-710. <https://doi.org/10.1007/s10549-011-1899-y> PMID:22160639
- 9 Yu XQ, Luo Q, Kahn C, O'Connell DL, Houssami N. Temporal trends show improved breast cancer survival in Australia but widening urban-rural differences. *Breast* 2015; **24(4)**: 524-527. <https://doi.org/10.1016/j.breast.2015.03.006> PMID:25843905
- 10 Azzopardi J, Walsh D, Chong C, Taylor C. Impact of geographic location on surgical outcomes of women with breast cancer. *Australian and New Zealand Journal of Surgery* 2014; **84(10)**: 735-739. <https://doi.org/10.1111/ans.12514> PMID:24438049
- 11 Azzopardi J, Walsh D, Chong C, Taylor C. Surgical treatment for women with breast cancer in relation to socioeconomic and insurance status. *Breast* 2014; **20(1)**: 3-8. <https://doi.org/10.1111/tbj.12203> PMID:24164659
- 12 Roder D, Zorbas H, Kollias J, Pyke C, Walters D, Campbell I, et al. Factors predictive of treatment by Australian breast surgeons of invasive female breast cancer by mastectomy rather than breast conserving surgery. *Asian Pacific Journal of Cancer Prevention* 2013; **14(1)**: 539-545. <https://doi.org/10.7314/APJCP.2013.14.1.539> PMID:23534791
- 13 Aarts MJ, Hamelinck VC, Bastiaannet E, Coebergh JW, Liefers GJ, Voogd AC, et al. Small but significant socioeconomic inequalities in axillary staging and treatment of breast cancer in the Netherlands. *British Journal of Cancer* 2012; **107(1)**: 12-17. <https://doi.org/10.1038/bjc.2012.205> PMID:22596236
- 14 Fisher S, Gao H, Yasui Y, Dabbs K, Winget M. Treatment variation in patients diagnosed with early stage breast cancer in Alberta from 2002 to 2010: a population-based study. *BMC Health Services Research* 2015; **15**: 35. <https://doi.org/10.1186/s12913-015-0680-z> PMID:25609420
- 15 Freeman AB, Huang B, Dragun AE. Patterns of care with regard to surgical choice and application of adjuvant radiation therapy for preinvasive and early stage breast cancer in rural Appalachia. *American Journal of Clinical Oncology* 2012; **35(4)**: 358-363. <https://doi.org/10.1097/COC.0b013e3182118d27> PMID:21422902
- 16 Lautner M, Lin H, Shen Y, Parker C, Kuerer H, Shaitelman S, et al. Disparities in the use of breast-conserving therapy among patients with early-stage breast cancer. *JAMA Surgery* 2015; **150(8)**: 778-786. <https://doi.org/10.1001/jamasurg.2015.1102> PMID:26083835
- 17 Dasgupta P, Youl PH, Pyke C, Aitken JF, Baade PD. Geographical disparity in breast reconstruction following mastectomy has reduced over time. *Australian and New Zealand Journal of Surgery*. 2016; **87(11)**: E183-E178.
- 18 Morris T, Wetzig N, Sinclair S, Kollias J, Zorbas H. Evaluation of implementation of sentinel node biopsy in Australia. *Australian and New Zealand Journal of Surgery* 2012; **82(7-8)**: 541-547.

<https://doi.org/10.1111/j.1445-2197.2012.06111.x> PMID:22776424

19 Arrington AK, Kruper L, Vito C, Yim J, Kim J, Chen SL. Rural and urban disparities in the evolution of sentinel lymph node utilization in breast cancer. *American Journal of Surgery* 2013; **206(5)**: 674-681. <https://doi.org/10.1016/j.amjsurg.2013.07.007> PMID:24035212

20 Chen AY, Halpern MT, Schrag NM, Stewart A, Leitch M, Ward E. Disparities and trends in sentinel lymph node biopsy among early-stage breast cancer patients (1998-2005). *Journal of the National Cancer Institute* 2008; **100(7)**: 462-474. <https://doi.org/10.1093/jnci/djn057> PMID:18364506

21 Dasgupta P, Youl P, Pyke C, Aitken J, Baade PD. Sentinel node biopsy for early breast cancer, Queensland, Australia 2008-2012. *Australian and New Zealand Journal of Surgery* 2018; **88(5)**: E400-E405.

22 National Health and Medical Research Council. *Clinical practice guidelines for the management of early breast cancer*. Available: <https://cancer australia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed> (Accessed 12 April 2019).

23 Senkus E, Kyriakides S, Ohno S, Penault-Llorca F, Poortmans P, Rutgers E, et al. Primary breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology* 2015; **26(Suppl.5)**: 8-30. <https://doi.org/10.1093/annonc/mdv298> PMID:26314782

24 Fisher B, Anderson S, Bryant J, Margolese RG, Deutsch M, Fisher ER, et al. Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. *New England Journal of Medicine* 2002; **347(16)**: 1233-1241. <https://doi.org/10.1056/NEJMoa022152> PMID:12393820

25 Morrow M, White J, Moughan J, Owen J, Pajack T, Sylvester J, et al. Factors predicting the use of breast-conserving therapy in stage I and II breast carcinoma. *Journal of Clinical Oncology* 2001; **19(8)**: 2254-2262. <https://doi.org/10.1200/JCO.2001.19.8.2254> PMID:16783613

26 Celaya MO, Rees JR, Gibson JJ, Riddle BL, Greenberg ER. Travel distance and season of diagnosis affect treatment choices for women with early-stage breast cancer in a predominantly rural population (United States). *Cancer Causes Control* 2006; **17(6)**: 851-856. <https://doi.org/10.1007/s10552-006-0025-7> PMID:16783613

27 Onega T, Cook A, Kirlin B, Shi X, Alford-Teaster J, Tuzzio L, et al. The influence of travel time on breast cancer characteristics, receipt of primary therapy, and surveillance mammography. *Breast Cancer Research and Treatment* 2011; **129(1)**: 269-275. <https://doi.org/10.1007/s10549-011-1549-4> PMID:21553117

28 Shearer R, Rashid M, Hubbard G, Abbott N, Daltrey I, Mullen R. Factors associated with patients in the Scottish Highlands who chose mastectomy when suitable for breast conservation. *Glandular Surgery* 2016; **5(4)**: 385-390. <https://doi.org/10.21037/g.s.2016.03.02> PMID:27563559

29 Athas WF, Adams-Cameron M, Hunt WC, Amir-Fazli A, Key CR. Travel distance to radiation therapy and receipt of radiotherapy following breast-conserving surgery. *Journal of the National Cancer Institute* 2000; **92(3)**: 269-271. <https://doi.org/10.1093/jnci/92.3.269> PMID:10655446

30 Churilla TM, Donnelly PE, Leatherman ER, Adonizio CS, Peters CA. Total mastectomy or breast conservation therapy? How radiation oncologist accessibility determines treatment choice and quality: a SEER data-base analysis. *Breast Journal* 2015; **21(5)**: 473-480. <https://doi.org/10.1111/tbj.12449> PMID:26133235

31 Nattinger AB, Kneusel RT, Hoffmann RG, Gilligan MA. Relationship of distance from a radiotherapy facility and initial breast cancer treatment. *Journal of the National Cancer Institute* 2001; **93(17)**: 1344-1346. <https://doi.org/10.1093/jnci/93.17.1344> PMID:11535710

32 Pope TM, Hexum M. Legal briefing: shared decision making and patient decision aids. *Journal of Clinical Ethics* 2013; **24(1)**: 70-80. PMID:23631339

33 Covelli AM, Baxter NN, Fitch MI, McCready DR, Wright FC. 'Taking control of cancer': understanding women's choice for mastectomy. *Annals of Surgical Oncology* 2015; **22(2)**: 383-391. <https://doi.org/10.1245/s10434-014-4033-7> PMID:25190120

34 Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiology* 1992; **45(9)**: 941-950. [https://doi.org/10.1016/0895-4356\(92\)90110-9](https://doi.org/10.1016/0895-4356(92)90110-9)

35 Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, et al. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997; **277(18)**: 1485-1492. <https://doi.org/10.1001/jama.1997.03540420081039> PMID:9145723

36 Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing* 1996; **19(1)**: 8-19. <https://doi.org/10.1097/00002820-199602000-00002> PMID:8904382

37 Halkett GK, Kristjanson LJ, Lobb E, O'Driscoll C, Taylor M, Spry N. Meeting breast cancer patients' information needs during radiotherapy: what can we do to improve the information and support that is currently provided? *European Journal of Cancer Care (Engl)* 2010; **19(4)**: 538-547. <https://doi.org/10.1111/j.1365-2354.2009.01090.x> PMID:19708930

38 Janz NK, Wren PA, Copeland LA, Lowery JC, Goldfarb SL, Wilkins EG. Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *Journal of Clinical Oncology* 2004; **22(15)**: 3091-3098. <https://doi.org/10.1200/JCO.2004.09.069> PMID:15284259

39 Katz SJ, Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, et al. Patient involvement in surgery treatment decisions for breast cancer. *Journal of Clinical Oncology* 2005; **23(24)**: 5526-5533. <https://doi.org/10.1200/JCO.2005.06.217> PMID:16110013

40 Mercieca-Bebber R, King MT, Boxer MM, Spillane A, Winters ZE, Butow PN, et al. What quality-of-life issues do women with ductal carcinoma in situ (DCIS) consider important when making

treatment decisions? *Breast Cancer* 2017; **24(5)**: 720-729.
<https://doi.org/10.1007/s12282-017-0765-0> PMID:28247220

41 Nold RJ, Beamer RL, Helmer SD, McBoyle MF. Factors influencing a woman's choice to undergo breast-conserving surgery versus modified radical mastectomy. *American Journal of Surgery* 2000; **180(6)**: 413-418. [https://doi.org/10.1016/S0002-9610\(00\)00501-8](https://doi.org/10.1016/S0002-9610(00)00501-8)

42 Rippey EE, Ainsworth R, Sathanathan D, Kollias J, Bochner M, Whitfield R. Influences on decision for mastectomy in patients eligible for breast conserving surgery. *Breast* 2014; **23(3)**: 273-278. <https://doi.org/10.1016/j.breast.2013.12.009> PMID:24456967

43 Bellavance EC, Kesmodel SB. Decision-making in the surgical treatment of breast cancer: factors influencing women's choices for mastectomy and breast conserving surgery. *Frontiers in Oncology* 2016; **6**: 74. <https://doi.org/10.3389/fonc.2016.00074> PMID:27066455

44 Youl PH, Aitken JF, Turrell G, Chambers SK, Dunn J, Pyke C, et al. The impact of rurality and disadvantage on the diagnostic interval for breast cancer in a large population-based study of 3202 women in Queensland, Australia. *International Journal of Environmental Research and Public Health* 2016; **13(11)**. <https://doi.org/10.3390/ijerph13111156>

This PDF has been produced for your convenience. Always refer to the live site <https://www.rrh.org.au/journal/article/4497> for the Version of Record.