

# Geographical comparisons of information and support needs of Australian women following the primary treatment of breast cancer: a 10-year replication study

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## Abstract

**Background** In 2002, Raupach and Hiller examined the use of and satisfaction with information and support following treatment of breast cancer from a sample of participants in South Australia. In 2013 this study was replicated to include participants Australia wide and analyse comparisons based on geographical location. Statistical comparisons with the original study were also conducted.

**Design** A 10 year replication study using a cross-sectional needs analysis survey.

**Setting and participants** Women aged 18+ years diagnosed with breast cancer between 6 and 30 months ago were sourced from two national databases of women diagnosed with breast cancer.

**Results** A total of 325 participants completed the survey. The Internet was the most commonly used source of information with 70% ( $n = 229$  of 325) of women using the internet for information, a statistically significantly higher percentage compared with the 2002 study. The study found the top four information issues rated as moderately/extremely important by women in 2013 were identical in 2002. A comparison of sources of support used showed that women in outer regional, remote and very remote areas were statistically more likely to use the breast care nurse (BCN) for support ( $P = 0.044$ ).

**Conclusions** The study provides useful, up-to-date data about information and support services used by Australian women with breast cancer. Comparisons with the earlier study show some of the needs of women have changed over time, but others have remained the same. Geographic comparisons overall, demonstrate many consistent findings regardless of location, however, the important work of the breast care nurse is an area in need of further research.

## Introduction

In Australia in 2002, Raupach & Hiller<sup>1</sup> concluded women experience a heightened need for information concerning breast-cancer-related issues following primary treatment for breast cancer with many such needs largely unmet. Since then, several studies continued to find women with breast cancer have high unmet needs.<sup>2–9</sup>

In 2012, the Australian Institute of Health and Welfare (AIHW) reported breast cancer is the most common cancer among Australian women with 12 567 cases diagnosed in 2007 (AIHW<sup>10</sup>). By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with numbers of women diagnosed estimated to be around 15 409 (AIHW<sup>11</sup>). For women with a diagnosis of breast cancer, receiving adequate information is essential to make informed treatment decisions.<sup>3</sup> Additionally, adequate support is required to help women cope with their diagnosis.<sup>3</sup> There is evidence many Australian women do not have adequate information concerning their disease and treatment, nor do they receive sufficient practical and emotional support from health professionals.<sup>1,2,5,12–14</sup>

Needs of women with breast cancer vary depending on their particular circumstances. For example, those with more advanced disease report higher levels of unmet needs in the psychological and physical and daily living domains.<sup>8</sup> On the other hand, young women with breast cancer report needing more age-specific information and support.<sup>15</sup>

Similarly, those living in rural and remote areas of Australia have needs specific to their situation, and in fact, there is great regional and remote disadvantage for Australians diagnosed with cancer. Addressing the needs of Australian women in rural and remote areas has proven difficult due to rural health service provision being challenged by issues of equity, coverage and supply.<sup>16</sup> New figures reveal people in regional and remote Australia are much more likely to die from cancer than those in metropolitan areas.<sup>17</sup> A study by Underhill

and Bartel *et al.*<sup>18</sup> highlighted marked cancer service deficiencies in rural and regional Australia, leading to poorer outcomes for patients with cancer living in these areas. Many patients with cancer are geographically isolated from care facilities and therefore do not experience the same access to specialists, GPs and allied health services as those in metropolitan areas.<sup>19</sup>

Over the past decade, due to therapeutic advances and early detection initiatives such as the BreastScreen Australia Program, there have been reductions in morbidity and mortality from breast cancer in Australian women.<sup>20</sup> However, despite therapeutic advances, those living with and beyond a breast cancer diagnosis can still experience physical, functional and psychosocial morbidities impacting on their quality of life.<sup>4,21–24</sup> The primary aim of this study was to replicate a previously validated need analysis survey completed by Raupach & Hiller<sup>1</sup> and to compare the findings with those of a decade ago, with the addition of making comparisons based on geographical location of participants.

## Research questions

1. What information is currently available to Australian women with breast cancer?
2. What is the level of satisfaction with information sources used by Australian women with breast cancer?
3. What sources of support are currently available to Australian women with breast cancer?
4. What is the level of satisfaction with sources of support used by Australian women with breast cancer?
5. What are the findings compared to a decade ago?
6. Are there geographic differences with information and support sources used by Australian women with breast cancer?

## Methods

### Design

A cross-sectional replication study was undertaken using a previously validated survey

with both structured and semi-structured questions.

#### Survey instrument

Permission to replicate was obtained from researchers conducting the original survey.<sup>1</sup> The original survey was developed using interviews with women and service providers, a focus group with women with breast cancer, findings from a literature review and a report from a National Breast Cancer Conference for women. The original survey was evaluated by women and providers, before being formally pilot tested on a random sample of 25 women diagnosed with breast cancer.<sup>1</sup> For the current study, six questions were added to determine the principal place of residence of each participant so geographical differences could be analysed.

The original survey was paper based; however, the replication survey was undertaken using an online format using Qualtrics survey software. The online format was tested by five people and minor modifications to layout completed. The self-report survey consisted of 150 items (142 closed questions and 8 open questions) and was distributed to women diagnosed with breast cancer belonging to two national databases. In the years since the original survey, general Internet access across Australia has risen to 83% of households having access to the Internet in the home.<sup>25</sup> This and the availability of women with breast cancer belonging to two national databases willing to participate in online research studies influenced the decision to use an online survey in this study.

#### Participants

Participant criteria for inclusion were replicated to match the original study, with women living in Australia aged 18 years and over who had been diagnosed with breast cancer between 6 and 30 months ago targeted. No other eligibility criteria were stipulated. The original study sourced participants from a

single, urban hospital over a period of 25 months. However, due to a lack of national perspective of evidence on current unmet needs, participants from across Australia were targeted.<sup>26</sup>

Participants were sourced from two national databases of women diagnosed with breast cancer that assist with recruitment of participants through online measures: Register4 has 34 000 members Australia-wide and is open to people over 18 years old with and without cancer<sup>27,28</sup> and the BCNA Review and Survey Group containing membership of 2500 women with breast cancer across Australia.<sup>29</sup>

A total of 402 participants commenced the survey. Nineteen participants did not provide geographical information essential for allocating a geographical code enabling analysis of geographic differences, and 58 participants submitted an incomplete survey, and examination of incomplete surveys revealed random patterns of exit points in the survey. Therefore, 325 responses or 81% were analysed.

#### Procedures

Following ethical approval from Australian Catholic University Human Research Ethics Committee, members of Register4<sup>27</sup> and the Breast Cancer Network Australia Review and Survey Group<sup>29</sup> were forwarded information about the study and directed to the online survey which included a participant information letter. Participants were given the option to receive a hard copy of the survey and a stamped, self-addressed envelope if they were unable to complete the online version of the survey. One participant chose to take this option. Voluntary participation was achieved by participants completing and submitting a survey.

An Australian Bureau of Statistics (ABS) Remoteness Area (RA) code was manually allocated to the physical residential address of each participant to identify their geographical location.<sup>30</sup> These RA codes were consistent with the latest available information from the ABS and were allocated using an address

coding tool on the ABS website.<sup>31</sup> Once the RA code was allocated, all other information relating to place of residence was deleted from the database to protect the identity of participants.

A de-identified summary of results was published on the Register4 website and sent via email to BCNA Review and Survey Group members.

### Data analysis

The data were analysed using IBM SPSS software, version 20.0: IBM Corporation, Ireland, United Kingdom. Descriptive statistics were calculated for all variables to determine missing and inappropriate (out of range) values. Frequency tables for each section of the survey were generated enabling a summary of results at a glance. After checking responses were consistent, some RA codes were combined, resulting in the reduction of the number of categories from 5 to 3. Major cities and inner regional categories remain unchanged, whereas the remaining three categories were combined: outer regional, remote and very remote. Variables measured on a four-point Likert scale were collapsed into two categories. Responses in the 'not' or 'slightly' (important/useful/helpful) categories were combined, and responses in the 'moderately' and 'extremely' (important/useful/helpful) categories were combined. This latter reduction of codes was a replication of recoding undertaken prior to reporting the original survey.

Open-ended questions were analysed using content analysis to identify common themes about women's need or lack of need for information and support.

### Results

Three hundred and twenty-five women completed the survey. Table 1 describes the demographic and treatment characteristics of respondents. Respondents from major Australian cities comprised 69% of the total sample. Nineteen per cent resided in inner regional Aus-

tralia, with the remaining 12% residing in outer regional, remote or very remote Australia. Age ranged from 27 to 81 years with a mean of 54 years. The number of women in outer regional, remote and very remote areas were significantly more likely to be aged under 50 years ( $n = 18$  of 39, 45%) than women in major cities ( $n = 74$  of 224, 33%) compared to inner regional areas ( $n = 14$  of 62, 23%) ( $\chi^2 = 6.111$ ,  $P = 0.0047$ ). Two hundred and sixty-nine participants (83%) were born in the continent of Australia and Oceania, with the remaining 17% ( $n = 56$ ) being born in Europe, Asia, Africa or North America. Seventy-eight per cent ( $n = 254$ ) of women were married or committed. Just over half of respondents (53%,  $n = 173$ ) had completed a university education, however, the percentages of university graduates from major cities ( $n = 124$  of 224, 55%) and inner regional areas ( $n = 33$  of 62, 53%) were higher than those living in outer regional, remote or very remote areas ( $n = 16$  of 39, 41%).

When analysing treatment characteristics, at least 98% of respondents had undergone surgery to treat their breast cancer. The percentage of respondents treated with chemotherapy (62–66%) or radiotherapy (68–72%) was comparable regardless of geographical residence. Respondents in outer regional, remote or very remote areas had much higher percentages of hormone therapy treatment ( $n = 31$  of 39, 80%) compared to those living in major cities ( $n = 161$  of 224, 72%) and inner regional areas ( $n = 38$  of 62, 61%). Breast reconstruction percentages were similar in all three geographical areas, with around one fifth of women choosing to have breast reconstruction.

Just under a quarter of respondents (24%,  $n = 78$ ) had an immediate family member diagnosed with breast cancer. However, percentages of an immediate family member being diagnosed with breast cancer were significantly higher in the outer regional, remote or very remote category 41% ( $n = 16$  of 39) compared to 22% ( $n = 49$  of 224) in the major cities and 21% ( $n = 13$  of 62) in inner regional areas ( $\chi^2 = 14.329$ ,  $P = 0.006$ ). Almost all (97%,

**Table 1** Demographic and treatment characteristics of respondents

Characteristic	Total <i>N</i> = 325		Major cities <i>n</i> = 224		Inner regional <i>n</i> = 62		Outer regional, remote or very remote <i>n</i> = 39		Chi- squared	<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Age										
≤50 years	106	33	74	33	14	23	18	46	6.111	0.047 <sup>†</sup>
More than 50 years	219	67	150	67	48	77	21	54		
Continent of birth										
Australia and Oceania	269	83	180	80	55	89	34	87	2.754	0.252
All other continents	56	17	44	20	7	11	5	13		
Marital status										
Single, separated, divorced or widowed	71	22	49	22	11	18	11	28	1.535	0.464
Married or committed	254	78	175	78	51	82	28	72		
Education completed*										
Secondary or tertiary non-university	151	46	99	44	29	47	23	59	2.836	0.242
Tertiary University	173	53	124	55	33	53	16	41		
Immediate family diagnosed with breast cancer**										
Yes	78	24	49	22	13	21	16	41	14.329	0.006 <sup>†</sup>
No	239	74	170	76	49	79	20	51		
Has a usual GP***										
Yes	315	97	216	96	62	100	37	95		
No	10	3	8	4	0	0	2	5		
Treatment undergone										
Surgery ( <i>n</i> = 322)***	320	98	219	98	62	100	39	100		
Chemotherapy ( <i>n</i> = 321)	211	65	146	65	41	66	24	62	0.348	0.840
Radiotherapy ( <i>n</i> = 321)	231	71	161	72	42	68	28	72	0.710	0.701
Treatment completed ( <i>n</i> = 321)***	299	92	205	92	57	92	37	95		
Tamoxifen/hormone therapy ( <i>n</i> = 321)	230	71	161	72	38	61	31	79	4.709	0.095
Breast reconstruction ( <i>n</i> = 321)	75	23	52	23	15	24	8	21	0.210	0.900

\*One missing (primary education only).

\*\*The remainder said they 'did not know'.

\*\*\*No statistic possible due to 0 values.

<sup>†</sup>Statistically significant findings.

*n* = 315) of respondents had a regular general practitioner (GP).

### Information about specific issues

Table 2 shows the issues for which women rated a need for information was moderately or extremely important. The number of women receiving information about these

issues in the last 6 months is also reported in the table.

In the current study for six of the 13 issues presented to women 74% or more women rated the issue as moderately or extremely important to them. The three top issues were recognizing a recurrence (*n* = 304, 94%), chances of cure (*n* = 274, 84%) and risk to family of breast cancer (*n* = 269, 83%). At

**Table 2** Need for information and extent of information received (listed in order of highest *n* to lowest *n* based on current results)

Issue	Current study <i>n</i> = 325			2002 study <i>n</i> = 217*			Current study <i>n</i> = 325			2002 study <i>n</i> = 217*		
	Rated item as moderately/extremely important			Rated item as moderately/extremely important			Received information within the previous 6 months			Received information within the previous 6 months		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Recognizing a recurrence	304	94	92–97	191	90	85–94	99	30	25–35 <sup>†</sup>	27	13	9–19
Chances of cure	274	84	80–88	167	82	76–87	121	37	32–42	66	32	26–39
Risk to family of breast cancer	269	83	79–87	167	81	75–86	82	25	20–30 <sup>†</sup>	25	12	8–17
Tamoxifen and other anti-oestrogen drugs	243	75	70–80	148	72	65–78	166	51	46–56 <sup>†</sup>	54	26	20–32
Where to go for more support	243	75	70–80	128	64	57–71	150	46	43–51 <sup>†</sup>	43	21	16–28
Effect on family of breast cancer	242	74	69–79	142	68	61–74	77	24	19–29	27	13	9–18
Physical appearance after surgery	186	57	52–62	121	58	51–65	108	33	28–38	44	21	16–28
Arm problems and lymphoedema	183	56	51–61	132	64	57–70	114	35	30–40 <sup>†</sup>	33	16	11–22
Sexuality and relationships	171	53	48–58 <sup>†</sup>	81	39	32–46	77	24	19–29 <sup>†</sup>	5	2	1–6
Menopause and hormone replacement therapy	167	51	46–56	100	50	43–57	84	26	21–31 <sup>†</sup>	17	8	5–13
Complementary and alternative therapies	161	50	45–55	105	51	44–58	100	31	26–36 <sup>†</sup>	32	15	11–21
Breast reconstruction	125	38	33–43	74	36	30–43	96	30	25–35 <sup>†</sup>	24	12	8–17
Prostheses	98	30	25–35	82	41	34–48	67	21	17–25 <sup>†</sup>	36	18	13–24

\*Varying levels of non-response in each category.

<sup>†</sup>Statistically significant findings.

least 50% of women rated 11 of the 13 issues as moderately or extremely important to them. The lowest need was expressed for information about breast reconstruction (*n* = 125, 38%) and prostheses (*n* = 98, 30%).

To enable comparisons, the results of the 2002 study are also provided in the table. The top four issues for women in 2002 are the same top four issues rated for women in the current study (recognizing a recurrence, chances of cure, risk to family of breast cancer, Tamoxifen and other anti-oestrogen drugs). Ninety-five per cent confidence intervals comparing the two studies reveal that women in the current study were statistically more likely to rate information about sexuality and relationships (*n* = 171, 54%, 95% CI = 48–58) as moderately or extremely important compared with the 2002 study (*n* = 81, 39%, 95% CI = 32–46).

Despite rating these issues as important, for many of the issues, information received in the past 6 months was reported on average by only 30% of women. In this study, the three top

issues that women received information about in the past 6 months included tamoxifen and other anti-oestrogen drugs (*n* = 166, 51%), where to go for more support (*n* = 150, 46%) and chance of cure (*n* = 121, 37%). It is important to note, however, that the percentages of women actually receiving information in the previous 6 months are statistically significantly higher in this study in ten of the 13 information areas listed.

### Sources of information

Women used a variety of sources of information, and Table 3 shows the use of and extent of satisfaction with these sources of information. In this study, the most frequently used source of information was the Internet (70%, *n* = 229). Other frequently used sources of information include the surgeon (58%, *n* = 190), the cancer specialist (56%, *n* = 181) and the television (53%, *n* = 172).

A comparison with 2002 data revealed statistically significant differences for the receipt of

information from the Internet (CI: 2013 = 65–75%, 2002 = 2–8%), the cancer specialist (CI: 2013 = 51–61%, 2002 = 19–32%), the breast cancer support group (CI: 2013 = 32–42%, 2002 = 2–9%) and the breast cancer support service volunteer (2013 = 14–21%, 2002 = 2–8%).

In the free text, many women indicated there were difficulties experienced in obtaining information such as having to self-source information, receiving too little information after completion of treatment or receiving confusing or conflicting information (Box 1).

**Box 1** Difficulties encountered in seeking out and obtaining information and support

Difficult to obtain reliable, credible information.  
 After treatment is completed, not much information is available.  
 I am 20 months post breast cancer. I don't receive any information.  
 I feel there is very little ongoing support.  
 I have had to source all information myself on anything I need.  
 Little support available outside the city.  
 Little information is offered unless specifically asked for.  
 Not given written information. Have found extra on www.  
 There is no central place to find good information.  
 Have not received any information and I have been discharged.  
 I have sourced all information myself.  
 Information has been confusing and contradictory.  
 Little information has been received.  
 Information is not always useful – vague at times.  
 Information is not easily available in my area.

### Satisfaction with information sources

The highest levels of satisfaction with information sources were for information received from the Cancer Help Line ( $n = 10$  of 11, 91%), the breast care nurse ( $n = 75$  of 84, 89%), the surgeon ( $n = 161$  of 190, 85%), the complementary or alternative therapist ( $n = 46$  of 54, 85%) and cancer specialist ( $n = 154$  of 181, 85%). There were six other sources of information where at least 74% of women rated the information received as moderately or extremely useful. The lowest levels of satisfaction were for information

received from television ( $n = 65$  of 172, 38%), newspapers ( $n = 48$  of 129, 37%) and magazines ( $n = 30$  of 90, 33%).

Comparisons with 2002 data show statistically significant differences for satisfaction of information found in brochures (CI: 2013 = 69–79%, 2002 = 81–99), magazines (CI: 2013 = 28–38%, 2002 = 47–68%) and through friends (CI: 2013 = 47–57%, 2002 = 64–89%) and family (CI: 2013 = 49–59%, 2002 = 73–99%).

In the free text, many women indicated that the medical team (surgeon, oncologist, radiologist, BCN and GP) and cancer organizations and support groups were very useful sources of information. However, a strong theme emerged where women felt that if they needed additional information, they had to search for it themselves, usually turning to the Internet. In terms of using the Internet, women's experiences were both negative and positive (Box 2).

**Box 2** Positive and negative comments about the use of the Internet as an information source

Positive:

I received a lot of my information from the internet - pretty useful.  
 I would be lost without the internet.  
 If I need information, I generally search online.  
 Much of my information was helpful and came via the internet.  
 Internet is most helpful as you can look up what you want.  
 Some internet sites are extremely good.

Negative:

The internet has been helpful, but may not be accurate.  
 Internet information can be overwhelming.  
 I received information mainly from the internet.  
 Usefulness varied.  
 The internet often has conflicting information.  
 Internet has too much information and it is difficult to know what is accurate.

### Sources of support

The frequency of use and extent of satisfaction with sources of support are reported in

**Table 3** Sources of information used and satisfaction with those sources (ranked by frequency of use based on current results)

Source of information	Current study <i>n</i> = 325			2002 study <i>n</i> = 217			Current study <i>n</i> = 325			2002 study <i>n</i> = 217		
	Received information within the previous 6 months						Satisfaction with information*					
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Internet	229	70	65–75 <sup>‡</sup>	9	4	2–8	183	80	76–84	8	89	52–100
Surgeon	190	58	53–63	125	60	53–67	161	85	81–89	111	92	85–96
Cancer specialist	181	56	51–61 <sup>‡</sup>	49	25	19–32	154	85	81–89	40	83	70–93
Television	172	53	48–58	114	56	49–63	65	38	33–43	52	46	37–56
Newspapers	129	40	35–45	66	32	26–39	48	37	32–42	34	52	40–65
General practitioner	122	38	33–43	65	32	25–38	98	80	76–84	57	89	79–95
Breast cancer support group	120	37	32–42 <sup>‡</sup>	10	5	2–9	94	78	73–83	10	100	69–100 <sup>†</sup>
Brochures	107	33	28–38	44	22	17–29	79	74	69–79 <sup>‡</sup>	40	93	81–99
Books	97	30	25–35	64	32	25–39	81	84	80–88	48	77	65–87
Magazines	90	28	23–33	91	45	26–39	30	33	28–38 <sup>‡</sup>	52	58	47–68
Friends	90	28	23–33	46	23	17–29	47	52	47–57 <sup>‡</sup>	34	78	64–89
Breast care nurse	84	26	21–31	37	18	13–24	75	89	86–92	30	83	67–94
Breast cancer support service volunteer	57	18	14–21 <sup>‡</sup>	9	4	2–8	46	81	77–85	6	75	35–97
Complementary or alternative practitioner	54	17	13–21	19	9	6–14	46	85	81–89	17	89	67–99
Radio	54	17	13–21	44	22	16–28	25	46	43–51	25	60	43–74
Family	28	9	6–12	24	12	8–17	15	54	49–59 <sup>‡</sup>	21	92	73–99
Cancer Help Line	11	3	1–5	10	5	2–9	10	91	88–94	8	73	39–94

\*Satisfaction = (number of women who rated information received from that source as moderately or extremely useful/total number of women who received information from that source) expressed as a percentage.

<sup>†</sup>One-sided 97.5% CI.

<sup>‡</sup>Statistically significant findings.

Table 4. The most frequently used sources of support in the past 6 months were friends ( $n = 263$ , 81%) and family ( $n = 261$ , 80%), followed by the GP and surgeon (both 61%). The least frequently used sources of support were the psychiatrist or psychologist ( $n = 54$ , 17%), the breast cancer support service volunteer ( $n = 31$ , 10%) and the Cancer Help Line ( $n = 10$ , 3%).

Comparisons with 2002 data revealed significant differences were found in the support received with the previous 6 months from the cancer specialist (CI: 2013 = 54–64%, 2002 = 23–36%), the Internet (CI: 2013 = 45–55%, 2002 = 1–6%), the breast cancer support group (CI: 2013 = 27–37%, 2002 = 2–9%), the psychiatrist or psychologist (CI: 2013 = 13–21%, 2002 = 3–10%) and the breast cancer support service volunteer (CI: 2013 = 7–13%, 2002 = 1–6%).

### Satisfaction with support sources

In terms of satisfaction with support, women were generally very satisfied with the support they had received. All 12 sources of support were rated as moderately or extremely helpful by at least 76% of women (See Table 4). The highest levels of satisfaction were for the complementary or alternative therapist ( $n = 63$  of 71, 89%), the breast cancer support group ( $n = 90$  of 105, 86%), the psychiatrist or psychologist ( $n = 46$  of 54, 85%), and the breast care nurse ( $n = 69$  of 83, 83%). The lowest levels of satisfaction were reported for the support received from the Internet ( $n = 125$  of 164, 76%).

Support from family (CI: 2013 = 78–86%, 2002 = 87–96%), the surgeon (CI: 2013 = 77–85%, 2002 = 87–96%) and the cancer specialist



**Table 4** Sources of support used and satisfaction with those sources (ranked by frequency of use based on current study)

Source of support	Current study <i>n</i> = 325			2002 study <i>n</i> = 217			Current study <i>n</i> = 325			2002 study <i>n</i> = 217		
	Received support within previous 6 months						Satisfaction with support*					
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Friends	263	81	77–85	145	71	64–77	207	79	75–83	117	84	77–90
Family	261	80	76–84	164	81	75–86	215	82	78–86 <sup>†</sup>	143	92	87–96
General practitioner	198	61	56–66	107	52	45–59	162	82	78–86	94	91	84–96
Surgeon	197	61	56–66	145	70	63–76	160	81	77–85 <sup>†</sup>	128	93	87–96
Cancer specialist	191	59	54–64 <sup>†</sup>	57	29	23–36	157	82	78–86 <sup>†</sup>	52	98	90–100
Internet	164	50	45–55 <sup>†</sup>	5	2	1–6	125	76	71–81	4	80	28–100
Breast cancer support group	105	32	27–37 <sup>†</sup>	9	5	2–9	90	86	82–90	7	70	35–93
Breast care nurse	83	26	21–31	47	24	18–30	69	83	79–87	40	87	74–95
Complementary or alternative practitioner	71	22	17–21	29	14	10–20	63	89	86–92	26	90	73–98
Psychiatrist or psychologist	54	17	13–21 <sup>†</sup>	9	5	3–10	46	85	81–89	10	91	59–100
Breast cancer support service volunteer	31	10	7–13 <sup>†</sup>	6	3	1–6	24	77	72–82	5	83	36–100
Cancer Help Line	10	3	1–5	9	4	2–8	8	80	76–84	6	67	30–93

\*Satisfaction = (number of women who rated support received from that source as moderately or extremely helpful/number of women who received support from that source) expressed as a percentage.

<sup>†</sup>Statistically significant findings.

(CI: 2013 = 78–86%, 2002 = 90–100%) revealed significant differences in 2013 compared with 2002.

In the free text, women also regarded friends, family (including husband/partner), the oncologist, surgeon, GP and breast cancer organizations such as the Breast Cancer Network Australia (BCNA) and The Cancer Council highly in terms of being most helpful sources of support.

### Comparisons by geographical location

Table 5 shows percentages of women in each of the geographical areas reporting having received information or support about specific issues or from specific sources within the previous 6 months. The table also reports the satisfaction with information and support sources in each of the geographical areas. There were a number of items measured in each of the categories; however, only the top four issues in each of the three categories measured are displayed in this table. Statistically significant findings for each of the categories are also displayed.

### Information issues received

Of the 13 issues where information had been received by women in the previous 6 months (see Table 2), only one issue recorded a percentage above 50% (tamoxifen and other anti-oestrogen drugs, *n* = 166, 51%). In the remaining 12 information areas, a range of between 21 and 46% of women reported receiving information about these issues in the previous 6 months. There are no statistically significant differences found based on geographic location (see Table 4 for a summary of these). However, there were lower percentages of women receiving information in outer regional, remote and very remote areas in seven of the 13 information areas measured (see Table 2).

### Sources of information used

Percentages across all geographic areas were consistent for the top four sources of information. However, percentages of women using the newspaper as an information source are statistically significantly lower ( $\chi^2 = 8.033$ , *P* = 0.018) in outer regional, remote and very

**Table 5** Comparisons based on geographical location

Information or support received/used within the previous 6 months	Total <i>n</i> = 325		Major cities <i>n</i> = 224		Inner regional <i>n</i> = 62		Outer regional, remote and very remote <i>n</i> = 39		Chi-square	<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Information issues received										
Tamoxifen and other anti-oestrogen drugs	166	51	122	54	28	45	16	41	3.474	0.176
Where to go for more support	150	46	106	47	26	42	18	46	0.567	0.753
Chances of cure	121	37	86	38	24	39	11	28	1.547	0.461
Arm problems and lymphoedema	114	35	77	34	24	39	13	33	0.46	0.795
Sources of information used										
Internet	229	70	158	71	44	71	27	69	0.037	0.982
Surgeon	190	58	132	59	39	63	19	49	2.049	0.359
Cancer specialist	181	56	128	57	32	52	21	54	0.663	0.718
Television	172	53	118	53	30	48	24	62	1.679	0.432
Newspapers	129	40	91	41	30	48	8	21	8.033	0.018*
Satisfaction with information received										
Cancer Help Line ( <i>n</i> = 11)	10	91	9	90	1	100	0	0	†	
Breast care nurse ( <i>n</i> = 84)	75	89	46	90	17	90	12	86	†	
Surgeon ( <i>n</i> = 190)	161	85	112	85	32	82	17	90	†	
Cancer specialist ( <i>n</i> = 181)	154	85	112	88	25	78	17	81	†	
Complementary or alternative practitioner ( <i>n</i> = 54)	46	85	34	87	9	100	3	50	†	
Breast cancer support group ( <i>n</i> = 120)	94	78	69	85	16	67	9	60	†	
Sources of support used										
Friends	263	81	175	78	54	87	34	87	3.656	0.161
Family	261	80	174	78	56	90	31	79	4.928	0.085
General practitioner	198	61	140	63	36	58	22	56	0.780	0.677
Surgeon	197	61	135	60	36	58	26	67	0.779	0.678
Breast care nurse	83	26	50	22	17	27	16	41	6.253	0.044*
Satisfaction with sources of support received										
Complementary or alternative practitioner ( <i>n</i> = 71)	63	89	44	86	12	100	7	88	†	
Breast cancer support group ( <i>n</i> = 105)	90	86	63	88	16	84	11	79	†	
Psychiatrist or psychologist ( <i>n</i> = 54)	46	85	37	90	7	88	2	40	†	
Breast care nurse ( <i>n</i> = 83)	69	83	44	88	13	77	12	75	†	
Cancer specialist ( <i>n</i> = 191)	157	82	108	83	33	92	16	64	†	

Although many items were measured, only the top four results in each category are listed, as well as statistically significant results found for each category.

\*Statistically significant finding.

†No statistic possible due to values <5.

remote areas (*n* = 8, 21%) compared with major cities (*n* = 91, 41%) and inner regional areas (*n* = 30, 48%).

### Satisfaction with information received

The percentage of women in outer regional, remote and very remote areas satisfied with the informa-

tion they received from the complementary or alternative practitioner (*n* = 3, 50%) was much lower compared with women in major cities (*n* = 34, 87%) and inner regional areas (*n* = 9, 100%). Furthermore, the percentages of women in major cities who were satisfied with information received from breast cancer support groups (*n* = 69, 85%) outweighed women in inner

regional ( $n = 16$ , 67%) and outer regional, remote and very remote areas ( $n = 9$ , 60%). The remainder of information areas assessed for satisfaction revealed no major differences based on geographical location.

### Sources of support used

Percentages across all geographical areas were consistent for the top four sources of support. However, notable is the statistically significant difference found with the breast care nurse as a source of support ( $\chi^2 = 6.253$ ,  $P = 0.044$ ) at a much higher percentage in the outer regional, remote and very remote areas ( $n = 16$  of 39, 41%) compared with the major cities ( $n = 50$  of 224, 22%) and inner regional areas ( $n = 17$  of 62, 27%).

### Satisfaction with sources of support received

The percentage of women in outer regional, remote and very remote areas satisfied with the support received from the psychiatrist or psychologist ( $n = 2$ , 40%), as well as the cancer specialist ( $n = 16$ , 64%), were much lower than that reported by women in major cities ( $n = 37$ , 90% and  $n = 108$ , 83%, respectively) and inner regional areas ( $n = 7$ , 88% and  $n = 33$ , 92%, respectively). The percentage of women from inner regional areas satisfied with support received from a complementary or alternative practitioner ( $n = 12$  100%) outweighed the satisfaction reported by women in major cities ( $n = 44$ , 86%) and outer regional, remote and very remote areas ( $n = 7$ , 88%). No other major differences were found; however, in eight of the 12 sources of support measured, women from outer regional, remote and very remote areas were less satisfied than women in the major cities and inner regional areas.

### Discussion

Women facing a diagnosis of breast cancer need information and support to help them

make informed treatment decisions and cope with their diagnosis. Over a decade ago, Raupach and Hiller<sup>1</sup> identified the lack of information and support available to women following treatment for breast cancer. Replicating this study enabled comparisons over time. The study findings overall reveal that some of the needs of women with breast cancer have changed, but many have remained the same.

#### Information issues important to women

Raupach and Hiller<sup>1</sup> found issues such as recognizing a recurrence, chances of cure, risk to family of breast cancer, and tamoxifen and other anti-oestrogen drugs were the most important information issues for women. This study found these four issues were also the most important issues proving women diagnosed with breast cancer have some of the same information needs as 10 years ago. Furthermore, the study shows in most cases, only one-third of women are receiving information they report is important to them, and therefore, the majority have unmet information needs. Therefore, the findings add to the volume of Australian and international literature reporting that despite advances in cancer care, women continue to have high unmet information and support needs.<sup>1,3,4,8,9,32-34</sup>

#### Internet information sources vs. face-to-face information sources

Perhaps, not surprisingly, this study confirms the Internet as an information source has become more popular. Having access to information and support when the need arises, despite location, is important for patients.<sup>35</sup> Significantly, however, both qualitative and quantitative findings demonstrated satisfaction with information retrieved from the Internet is not as high as information received through face-to-face delivery. As was found in previous studies,<sup>1,34</sup> women were most satisfied with the information they received from members of the health-care team, including the surgeon, the cancer specialist, the breast care nurse and the complementary or alternative ther-

apist, confirming that delivery of information through face-to-face sources continues to be highly valued.

Although satisfaction was rated highest from face-to-face medical sources, patients in the present day rely heavily on non-medical information sources such as the Internet. The information presented via the Internet is under no guidance or regulation and therefore can be of questionable reliability and quality.<sup>34</sup> O'Grady<sup>36</sup> explains despite calls for research into the credibility of health-care websites for a number of years, little has been undertaken. Consistent with other research, our study found the Internet to be widely used as a health information source, highlighting a need for providing patients with the details of high-quality websites to access for information.<sup>34</sup>

#### Sources of support for women

The findings also reveal the highest sources of support came from friends and family, with the general practitioner and the surgeon also offering high levels of support. Interestingly, these top four sources of support were also the top four sources of support in the original study. These findings once again highlight the importance that women place on receiving information in a supportive and caring context where information and support can be tailored to meet individual needs.<sup>1</sup>

A new finding was that women in outer regional, remote and very remote areas were more likely to use a breast care nurse as a source of support. It is not clear why this is so, but it may be that BCNs are more accessible to those in rural and remote areas; however, no national comparative data exist about the geographical distribution of BCNs. It is well publicized that patients in rural and remote Australia experience limited access to health professionals including cancer specialists, GPs or allied health services,<sup>19,37–39</sup> and perhaps, BCNs are more accessible. The value of BCNs has been reported in several Australian and international studies.<sup>9,40–48</sup> However, a review of contemporary Australian literature has

revealed little is known about the role of the Australian BCN,<sup>26</sup> indicating a need for more research in this area.

Importantly, our study revealed overall women in outer regional, remote and very remote areas have lower levels of satisfaction with sources of support they receive, compared with women in major cities and inner regional areas. This adds to the volume of evidence reporting on the geographical disadvantage that exists in health-care services and support available in Australia.

#### Policy and research implications

As the Internet is so widely used, the opportunity exists for health professionals when interacting face-to-face to educate women on the appropriate use of only reputable and credible Internet sites. Research in the United States has revealed when using the Internet, patients have trouble knowing what information is relevant and what is reliable, and it is the health-care provider that patients turn to for consistent, reliable information and answers.<sup>49</sup> Australian BCNs could take on the role of educating women about the appropriate use of the Internet for attaining health information and provide a list of appropriate Internet sites. BCNs in Australia may already do this; however, as limited research exists about the BCN role, this is not known.

Previous research suggests increasing health literacy, and access to good targeted information can improve patient compliance and satisfaction with treatment options.<sup>50</sup> Prolific use of the Internet to access health information is irreversible, and therefore, there is a high need for further research to investigate the characteristics of reputable and informative breast cancer Internet sites and inform policymakers about the potential regulation of such Internet sites.

The study found that patients value the information and support they receive from their BCN. Perhaps, BCNs could be further utilized to improve patient education and care through the use of e-health solutions. The use of such initiatives has the potential to not only

improve health outcomes for patients, but save time and resources for health professionals and patients alike. Therefore, further research is recommended to investigate interventions whereby additional BCNs could be employed to specialize in offering e-health solutions enabling the delivery of health services to all women with breast cancer, but particularly those in rural and medically underserved populations on a more regular basis, for example video-linked appointments. Such services enable health-care providers to educate their patients within the confines and time constraints of today's medical system,<sup>51</sup> and these targeted services may also address the levels of low satisfaction experienced by women in outer regional, remote and very remote Australia.

#### Strengths and limitations

A particular strength of this study was that comparisons of the demographic data with Australian Bureau of Statistics demographic data indicated that in terms of numbers, the sample was representative of women living in metropolitan, regional and rural and remote areas. Furthermore, the sample size was adequate to provide ample data about the information and support needs of women in each of the geographical areas and perform comparisons between the different geographical areas.

There are a number of limitations of this study. First, we did not know exactly where women were in the participant treatment trajectory and therefore could not report on differences experienced due to time since diagnosis. Second, participants in this study belonged to one of two national databases of women diagnosed with cancer, and participants self-selected their involvement in the study. Using a convenience sample such as this meant, it was not possible to clearly identify the population from which the sample was derived. Third, it is also recognized that using online recruiting methods may potentially exclude those who do not have Internet access. Finally, non-completion of surveys may have been due to respondent burden.

#### Conclusion

This study has provided quantitative findings about the information and support services that are currently available to and used by women with breast cancer. Importantly, the respondents were a geographically representative sample enabling comparison of those living in metropolitan areas, with those living in inner regional, outer regional, remote and very remote areas. The methods provide a platform which further studies can emulate to attain data based on a national perspective. It is suggested that the findings from this study be used to drive further targeted research to improve information and support services available to women with breast cancer, thereby improving outcomes for the many Australian women diagnosed with cancer each year.

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#### Conflict of interest

There is no conflict of interest declared.

#### Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Appendix S1:** Sample Survey Questions.

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