BCNA Member Survey Report

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Social
Research
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Report prepared for:

Dr Jenny Anderson
Research and Evaluation Manager
Breast Cancer Network Australia
janderson@bcna.org.au

Report prepared by:

Anna Lethborg
Senior Research Consultant
The Social Research Centre
Level 9, 277 William Street
Melbourne VIC. 3000
Tel: (613) 9236 8500
Fax: (613) 9602 5422
Email: anna.lethborg@srcentre.com.au

www.srcentre.com.au

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Background and methodology

In 2017, Breast Cancer Network Australia (BCNA) commissioned the Social Research Centre to conduct a large-scale online survey of members. The purpose of the survey was to provide BCNA with a measure of the recent information and support needs of members and the extent to which these needs were being met. The research will be used to reveal gaps in current service delivery and identify priorities for action to assist BCNA to meet the needs of people with breast cancer. Results will be used to inform the development of the *Breast Cancer State of the Nation Report 2018*.

An invitation to participate in the online survey was distributed via SMS or email to 35,852 listed members who had provided BCNA with a mobile number or email address prior to the commencement of the survey. Additionally, a link to the survey was posted on the BCNA website and information on the survey was distributed via BCNA communication channels.

The main member survey was conducted between 3 February and 19 February 2017 during which time 8,215 responses were received. The link on the BCNA website remained open until 30 June 2017, during which time an additional 2,103 responses were achieved. Data from all 10,318 respondents has been combined for reporting purposes.

Respondent profile

The survey was open to any Australians who have had a diagnosis of breast cancer. The majority of respondents had less invasive breast cancer with two-thirds having been diagnosed with early breast cancer (75%) and a further 20% with DCIS / LCIS.

Approximately one in twenty respondents (5%) had been diagnosed with metastatic breast cancer.

Due to the large sample size, this equated to 527 respondents – more than sufficient to allow for comparison of the responses of people with different types of breast cancer throughout the report.

Other considerations when analysing results at the total sample level related to how recently respondents had received their diagnosis. Approximately a quarter of respondents (27%) had received their most recent diagnosis in the 12 months before they completed the survey. Overall, 70% had received their most recent diagnosis in the previous five years.

Over half of the respondents (57%) had received some form of treatment in the four weeks prior to completing the survey, whether this be surgery, chemotherapy, radiotherapy, or hormone treatment. Excluding those who had only received hormone treatment, the proportion in active treatment in the four weeks prior to the survey decreased to 18%. Slightly more respondents had received most of their treatment through the private rather than the public system (53% compared to 45%).

In terms of the demographic profile of respondents, males made up less than 1% of the total sample which is consistent with their representation in the population of people with breast cancer. Half (50%) of all respondents were age 60 years and over. However, younger people with breast cancer were represented in the survey with 19% of the sample being between 18 and 50 years of age.

Two-thirds of the sample (67%) resided in major cities with the remainder living in regional or rural areas (including 9% from outer regional, remote, or very remote areas). Just 2% of respondents (242 people) indicated that they mainly speak a language other than English at home.

Interpreting the results

As a key objective of the research was to understand unmet needs within subgroups of interest, an appropriate measure of informational and support gaps was required. This was measured in two stages: firstly, by identifying specific information and support needs among those with breast cancer; and, secondly, by asking those with particular needs to what extent their needs had been met in each of these areas.

The extent to which needs were met was measured on a scale that asked respondents to indicate whether all, most, some, or none of their needs were met. While it may appear that the best measure of unmet needs would be the proportion who indicated that ‘none of my needs were met’, analysis of the results revealed that too few respondents used this response to allow for valid subgroup analysis. In actuality, gaps were more evident when differentiating between the proportions of respondents who indicated that ‘all of my needs were met’ in a particular area. For example, a common result when comparing responses from people with metastatic breast cancer to those with non-metastatic breast cancer, was that people with non-metastatic breast cancer were significantly *more likely* to indicate that all of their needs had been met. Comparatively, people with metastatic breast cancer were *less likely* to report that all their needs had been met – in essence, they had more unmet needs.

When interpreting results, the reader is advised to look at the subgroups in which *fewer* respondents reported that all their needs had been met and to consider these as groups experiencing gaps in service delivery. For people in these groups, there is an opportunity to improve access to information and support and increase the proportion reporting that all their needs had been met if the research were to be replicated in future.

The following section summarises the main areas in which respondents had needs and the extent to which these were met.

Information and support needs

Approximately three quarters of respondents indicated that they had needed information (77%) or support (76%) in the 12 months prior to completing the survey. For those who had received a diagnosis of metastatic breast cancer, the proportion with needs was significantly higher. In this group, 93% needed information and 91% needed support, compared to 76% and 75% respectively for people with non-metastatic breast cancer.

Unmet information needs

When asked whether their *informational* needs had been met in the last 12 months, approximately half of all respondents (49%) indicated that *all* of their needs had been met. The proportion reporting that all of their informational needs had been met was significantly lower for people with metastatic breast cancer with just 34% reporting that all their needs had been met. This compares to 50% of those with non-metastatic breast cancer.

Other key subgroup variations related to whether the informational needs of people with breast cancer were met are shown in Table 1. This table demonstrates the subgroups in which people were *less likely* to report all their needs had been met compared to groups who were significantly *more likely* to report all their needs had been met.

Table 1 Key subgroup variations related to whether *information* needs were met in the 12 months prior to the survey

↓ Less likely to have had all needs met	More likely to have had all needs met ↑
Residents of ACT (38%) and WA (45%)	Residents of TAS (58%), VIC (50%), QLD (50%)
Live in remote areas (38%)	Reside in major cities (48%) or inner/ outer regional areas (51%)
People aged 18-39 (32%) or 40-49 (38%)	Aged 70+ years (63%) or 60-69 years (54%)
Speak a language other than English (32%)	Speak English as their main language (49%)
Diagnosed <1 (49%), 1<2 (45%), or 2<5 (48%) years prior to survey	Diagnosed 5<10 (53%) or 10+ (57%) years prior to survey
People with metastatic breast cancer (34%)	People with DCIS/LCIS (52%) or early breast cancer (49%)
Received active treatment (45%) or hormone therapy only (47%) in the last four weeks	Received no active treatment in the last four weeks (53%)

Unmet support needs

Similar trends were observed in relation to *support* needs in the last 12 months, with 47% of the total sample indicating that *all* of their needs had been met. Amongst people who had been diagnosed with metastatic breast cancer, the proportion indicating that all of their needs had been met was 34%, compared to 48% of those with non-metastatic breast cancer.

Key subgroup variations related to whether support needs were met are shown in Table 2.

Table 2 Key subgroup variations related to whether *support* needs were met in the 12 months prior to the survey

↓ Less likely to have had all needs met	More likely to have had all needs met ↑
Residents of ACT (40%), SA (43%) & WA (44%)	Residents of TAS (57%), QLD (49%), VIC (48%) & NSW (48%)
Live in remote areas (37%)	Reside in major cities (47%) or inner/ outer regional areas (50%)
People aged 18-39 (30%) or 40-49 (36%)	Aged 70+ years (63%) or 60-69 years (53%)
Speak a language other than English (34%)	Speak English as their main language (48%)
Diagnosed <1 (47%), 1<2 (44%), or 2<5 (47%) years prior to survey	Diagnosed 10+ (60%) or 5<10 (51%) years prior to survey
People with metastatic breast cancer (34%)	People with DCIS/LCIS (51%) or early breast cancer (48%)
Received active treatment (44%) or hormone therapy only (45%) in the last four weeks	Received no active treatment in the last four weeks (52%)

Needs related to specific types of information or support

In terms of specific information or support needs related to breast cancer side effects, life stage, practical help, emotional wellbeing, and treatment and survivorship, the proportion of respondents with needs ranged from approximately one third who required information related to lymphoedema (35%), fatigue (34%) and physical activity and healthy eating (33%) to around one in twenty who needed information on being a parent and caring for young children (6%) or fertility needs (3%).

However, when making subgroup comparisons, it is important to consider the groups more likely to have particular informational and support needs. For example, across all of the specific information and support needs, the proportion with needs was higher among younger respondents (aged 18 to 39 years) and decreased in each of the older age groups.

The proportion with needs was also consistently higher for people who speak a main language other than English, people with metastatic breast cancer, those who had been diagnosed more recently and those who had received active treatment in the four weeks prior to completing the survey.

Other notable subgroup differences related to specific informational or support needs included:

- Respondents who reside in remote or very remote areas were more likely to have needs related to travel assistance (47%, compared to 7% of residents of a major city) and managing the financial costs associated with breast cancer (30%, compared to 21%)
- People with non-metastatic breast cancer were more likely to need information related to breast reconstruction options (21%, compared to 16% of those with metastatic breast cancer).

Table 3 shows the proportions of respondents with needs in each of the specific topic areas who reported that *all* their information or support needs had been met. It is followed by subgroup analysis showing those in which *less* people reported that all their needs had been met when compared to their counterparts.

Table 3 Key subgroup variations related to whether *specific* needs were met in the 12 months prior to the survey

Type		ALL needs met	Groups with unmet needs (significantly lower % reported all needs were met)
Side effects	Changes in sexual function/ relationships (n=2,099)	13%	• Diagnosed 5<10 years ago (6%) • Diagnosed 2<5 years ago (8%) • No recent treatment (10%) • Hormone therapy only (12%) • Live in a major city (12%)
	Managing problems thinking clearly or concentrating (e.g. 'chemo-brain') (n=2,553)	18%	• Main language other than English (6%) • Diagnosed 2<5 years ago (11%) • Diagnosed 5<10 years ago (13%) • 18-39 years of age (13%) • 40-49 years of age (16%) • Hormone therapy only (16%) • No recent treatment (16%) • Live in a major city (17%)
	Early menopause due to cancer treatment (n=1,949)	22%	• Main language other than English (8%) • Diagnosed 5<10 years ago (16%) • Live in a major city (22%)
	Managing fatigue related to cancer treatment (n=3,544)	26%	• Diagnosed 2<5 years ago (14%) • Main language other than English (15%) • Diagnosed 5<10 years ago (17%) • People with metastatic breast cancer (17%) • 18-39 years of age (17%) • No current treatment (22%) • 40-49 years of age (23%) • Residents of NSW (23%) • Hormone therapy only (23%) • Live in a major city (24%)
	Lymphoedema (fluid retention and tissue swelling) due to cancer treatment (n=3,575)	40%	• Live in a remote/very remote area (24%) • Main language other than English (25%) • 18-39 years of age (28%) • People with metastatic breast cancer (31%) • Residents of SA (33%) • Diagnosed 2<5 years ago (34%) • 40-49 years of age (36%) • Most treatment through the private sector (38%)
Emotional wellbeing	Anxiety or depression related to cancer (n=2,853)	15%	• Main language other than English (9%) • Residents of TAS (11%) • Diagnosed 5<10 years ago (11%) • 50-59 years of age (17%) • Received no recent treatment (18%) • Received hormone therapy treatment in last 4 weeks (20%)
	Body image changes related to cancer (n=2590)	20%	• People with metastatic breast cancer (12%) • Diagnosed 2<5 years ago (12%) • 40-49 years of age (17%) • Received hormone therapy treatment only (18%) • Received no recent treatment (19%) • 50-59 years of age (19%)

Type		ALL needs met	Groups with unmet needs (significantly lower % reported all needs were met)
Life stage	Challenges for young (premenopausal) women with cancer (n=1,307)	18%	• Main language other than English (5%) • Diagnosed 2<5 years ago (12%) • Residents of NSW (15%)
	Fertility problems related to cancer treatment (n=301)	25%	• Diagnosed 2<5 years ago (8%) • Hormone therapy only (15%)
	Being a parent with cancer and caring for young children (n=649)	25%	• Received no recent treatment (18%)
Practical help	Receiving practical help around the home (e.g. programs or services available) (n=1,296)	18%	• Residents of SA (9%) • 50-59 years of age (10%) • People with metastatic breast cancer (11%) • 40-49 years of age (13%) • Received most treatment through the private sector (13%) • Live in a major city (16%) • Live in an inner regional area (20%)
	Managing the financial costs of breast cancer (n=2,178)	20%	• Diagnosed 5<10 years ago (8%) • People with metastatic breast cancer (9%) • Diagnosed 2<5 years ago (13%) • 18-39 years of age (13%) • 40-49 years of age (15%) • 50-59 years of age (16%)
	Managing your return to work or changes to work (n=1,394)	23%	• Main language other than English (7%) • People with metastatic breast cancer (13%) • 18-39 years of age (17%) • Diagnosed 2<5 years ago (17%) • Diagnosed 1<2 years ago (18%) • 50-59 years of age (21%) • Live in a major city (21%) • 40-49 years of age (22%)
	Travel assistance related to breast cancer (e.g. PATS) (n=1,300)	38%	• Main language other than English (7%) • Live in a major city (20%) • 18-39 years of age (23%) • People with metastatic breast cancer (26%) • 40-49 years of age (29%) • Received most treatment through the private sector (32%) • Received active treatment (33%) • 50-59 years of age (33%) • Residents of NSW (35%) • Residents of QLD (36%) • Residents of VIC (38%) • Hormone therapy only (38%)
Treatment / survivorship	Breast reconstruction options (n=2,165)	26%	• Residents of ACT (21%) • People with metastatic breast cancer (26%) • Diagnosed 5<10 years ago (27%) • Diagnosed 2<5 years ago (31%) • Received most treatment through the public sector (31%) • People with early breast cancer (32%) • 50-59 years of age (32%) • 40-49 years of age (33%)
	The benefits of physical activity and healthy eating (n=3,358)	32%	• Main language other than English (15%) • People with metastatic breast cancer (22%) • Diagnosed 2<5 years ago (26%) • 18-39 years of age (28%) • 40-49 years of age (28%) • 50-59 years of age (30%) • Diagnosed 1<2 years ago (29%) • Diagnosed 5<10 years ago (30%)

Recent support experiences related to State of the Nation best practices

All respondents were asked their agreement with a series of statements measuring experiences of support associated with the best practices outlined in the State of the Nation framework. The proportion who 'agreed' or 'strongly agreed' has been combined to produce a single '% agree' measure and to allow for significance testing of key groups of interest.

For the majority of the statements, agreement was quite high and outweighed disagreement. The highest levels of agreement (around four-fifths agreed) were recorded for the following statements:

- 'I was given enough information to make or understand important treatment decisions' (83% agreed while 8% disagreed)
- 'I feel I have been heard by my medical team' (81% agreed while 7% disagreed)

The lowest levels of agreement were recorded for two statements asked only of those with metastatic breast cancer:

- 'I was given opportunities to talk about clinical trials that might be relevant to me' (metastatic only) (41% agreed and 39% disagreed)
- 'I was informed that palliative care could support me at any time and not just at the end of my life' (79% agreed while 8% disagreed).

Subgroup analysis was not reported for these two groups due to the small sample sizes. For other statements, subgroup variations were apparent though these varied dependent on the nature of the statement.

Table 4 shows the proportion of respondents who provided an agreement rating for each question and agreed or strongly agreed with each statements. This is followed by the subgroups recording the lowest levels of agreement with each of the statements when compared to their counterparts.

Table 4 Key subgroup variations related to whether *State of the Nation* best practices were met in the 12 months prior to the survey

Type		Agree / strongly agree	Groups less likely to agree/strongly agree with statements ↓
Live well	I feel the people close to me are supported (n=7,006)	53%	• Residents of ACT (44%) • 18-39 years of age (49%) • 50-59 years of age (49%) • Diagnosed 1<2 years ago (49%) • Diagnosed 2<5 years ago (49%) • 40-49 years of age (50%) • Live in a major city (52%) • Received hormone therapy only (51%) • Diagnosed 5<10 years ago (52%) • Received no recent treatment (52%) • Main language English (53%)
	I was given opportunities to donate my time or money to help others with breast cancer (n=7,458)	65%	• 18-39 years of age (46%) • Diagnosed in the last year (50%) • Received active treatment in last 4 weeks (51%) • Residents of NT (55%) • 40-49 years of age (56%) • People with metastatic breast cancer (58%) • Diagnosed 1<2 years ago (59%) • Most treatment through the public sector (62%) • Residents of NSW (64%) • Residents of SA (64%) • Residents of QLD (64%) • Diagnosed 2<5 years ago (72%)
	My cultural and/or spiritual beliefs were respected (n=4,070)	66%	• Residents of TAS (54%) • 50-59 years of age (64%) • Diagnosed 5<10 years ago (64%) • Received no recent treatment (64%) • 40-49 years of age (65%) • Diagnosed 2< 5 years ago (65%) • 60-69 years of age (66%) • Main language English (66%)
Breast cancer experience	I received treatment that took my lifestyle into consideration (n=5,483)	58%	• Residents of ACT (49%) • Residents of WA (51%) • Diagnosed 2<5 years ago (54%) • 40-49 years of age (55%) • 50-59 years of age (55%) • Diagnosed 1<2 years ago (56%) • Diagnosed 5<10 years ago (56%) • Main language is English (57%) • People with early breast cancer (57%)
	I had opportunities to hear about the experiences of others who have been through the same thing (n=7,524)	64%	• People with metastatic breast cancer (49%) • Live in a remote/very remote (55%) • 18-39 years of age (57%) • 40-49 years of age (60%) • Residents of WA (61%) • Diagnosed in the last year (61%) • Diagnosed 1<2 years ago (62%) • Received active treatment in last 4 weeks (62%) • Most treatment through the public sector (63%) • 50-59 years of age (63%)

Type		Agree / strongly agree	Groups less likely to agree/strongly agree with statements ↓
Breast cancer experience (continued)	I have been treated as a whole person not just someone with cancer (n=7,750)	79%	• Residents of ACT (73%) • People with metastatic breast cancer (74%) • 40-49 years of age (75%) • 18-39 years of age (76%) • Diagnosed 2<5 years ago (76%) • 50-59 years of age (78%) • Diagnosed 1<2 years ago (78%) • Diagnosed 5<10 years ago (78%) • Received no recent treatment (78%) • Received hormone therapy only (79%)
	I feel I have been heard by my medical team (n=8,063)	81%	• Residents of NT (67%) • Residents of TAS (75%) • Residents of WA (76%) • Live in outer regional (76%) • People with metastatic breast cancer (76%) • 40-49 years of age (77%) • Most treatment through the public sector (77%) • Diagnosed 1<2 years ago (78%) • 50-59 years of age (79%) • People with DCIS/LCIS (79%) • Diagnosed 2<5 years ago (79%) • Diagnosed 5<10 years ago (79%) • Received no recent treatment (79%)
	I have had as much contact with a Breast Care Nurse as I needed (n=6,722)	70%	• People with metastatic breast cancer (56%) • Residents of ACT (62%) • Diagnosed 2<5 years ago (63%) • 40-49 years of age (64%) • Diagnosed 5<10 years ago (65%) • 18-39 years of age (68%) • 50-59 years of age (66%) • Most treatment through the private sector (68%) • Live in a major city (69%) • Received hormone therapy only in last 4 weeks (69%)
	I was given enough information to make or understand important treatment decisions (n=7,063)	83%	• Residents of NT (68%) • Live in remote/very remote (68%) • 40-49 years of age (77%) • People with metastatic breast cancer (77%) • Diagnosed more than 10 years ago (77%) • 18-39 years of age (79%) • Residents of QLD (80%) • Residents of WA (80%) • 50-59 years of age (81%) • Received no recent treatment (81%) • Most treatment through the public sector (81%)
Recovery (non-metastatic only)	I was provided with a long-term follow-up care plan after finishing treatment (n=6,098)	64%	• Received active treatment in last 4 weeks (54%) • 18-39 years of age (56%) • 40-49 years of age (57%) • Residents of WA (59%) • Diagnosed in the last year (61%) • 50-59 years of age (62%)

Information and support requirements of specific people or services

The members of the cancer treatment team that more respondents had required support from in the last 12 months included their breast cancer surgeon (63%), medical oncologist (61%), their GP (60%) and their Breast Care Nurse (48%). Those with metastatic cancer were more likely to have needed information from a medical oncologist (91%, compared to 59%), a GP (74%, compared to 59%) or a Breast Care Nurse (57% compared to 48%). Those with non-metastatic cancer were more likely to have needed support from their breast cancer surgeon (64%, compared to 43%) or breast reconstruction or plastic surgeon (20%, compared to 13%).

Respondents with metastatic breast cancer were also more likely to indicate that they had needed support from their family and friends (70%, compared to 52% of those with non-metastatic cancer) or their partner (58%, compared to 45% of those with non-metastatic cancer).

Whether information and support requirements were met by specific people or services

For those respondents who had needed information or support from their cancer treatment team in the last 12 months, the proportions reporting that all of their needs had been met were high. However, approximately one in ten respondents indicated that none of their needs had been met by their breast reconstruction or plastic surgeon (11%) or their Breast Care Nurse (10%).

Those with metastatic breast cancer were *less likely* than those with non-metastatic cancer to indicate that all of their informational and support needs had been met by particular members of their cancer treatment team. In particular, people with metastatic breast cancer were less likely to indicate that all their needs had been met by their:

- Breast Care Nurse (43%, compared to 54% of those with non-metastatic cancer).
- medical oncologist (50%, compared to 58%)
- General Practitioner (52%, compared to 58%)
- radiation oncologist (55%, compared to 64%)
- radiation treatment centre (56%, compared to 65%)

Conversely, those with metastatic breast cancer were *more likely* to report that their needs had been met by the people close to them, including their:

- family and friends (70%, compared to 52%)
- partner (58%, compared to 45%)

Whether support needs were met by BCNA

Overall, 48% of respondents indicated that they had needed information and / or support from BCNA in the 12 months prior to completing the survey. Among those with needs, 48% indicated that all their information and support needs were met by BCNA with a further 31% indicating that most of their needs had been met. Any differences in the proportion who indicated *all* needs were met within subgroups is shown in Table 5 below.

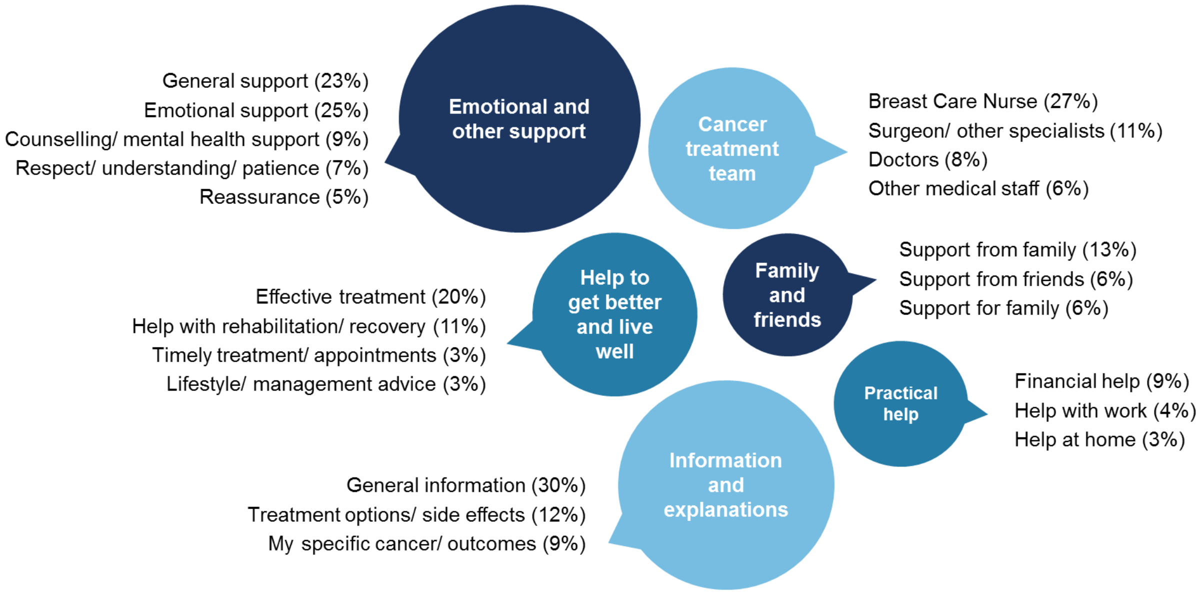
Table 5 **Key subgroup variations related to whether *BCNA* had met support needs in the 12 months prior to the survey**

↓ Less likely to have had all needs met	More likely to have had all needs met ↑
Live in a remote or very remote area (37%)	Reside in major cities (47%), inner regional (52%) or outer regional areas (49%)
People aged 18-39 (34%) or 40-49 (41%)	Aged 70+ years (62%) or 60-69 years (53%)
Diagnosed 1<2 (44%) or 2<5 (43%) years prior to survey	Diagnosed <1 (52%), 5<10 (48%) or 10+ (51%) years prior to survey
People with metastatic breast cancer (40%)	People with DCIS/LCIS (51%) or EBC (48%)
Received no active treatment in the last four weeks (28%)	Received active treatment (32%) or hormone therapy only (32%) in the last four weeks
Low engagement with BCNA (26%)	Moderate (33%) or high (35%) engagement with BCNA

Main informational and support needs (summary of verbatim responses)

To elicit further information related to the main unmet needs of people with breast cancer and to reveal any gaps that may not have been covered in previous questions, two open-ended verbatim questions were asked of all respondents. The first of these asked respondents what their main needs were during their experience of breast cancer while the follow up question asked which, if any, of these were unmet. Analysis of responses from the first question allowed us to code responses into sub-themes (refer to black text in Figure 1) and to classify these into main areas of need (shown in speech bubbles in Figure 1).

Figure 1 **Main needs during experience of breast cancer**



When asked which of their main information or support needs had *not* been met, approximately two-thirds of respondents said *all* of their main needs had been met. However, the remainder provided responses indicating which of their main needs were unmet. These fall into seven key themes shown in Table 6. Examples of the verbatim responses related to each theme are summarised under each of these headings.

Table 6 Main areas where needs were unmet

- **Information on treatment options / side effects**
  - Needed to know more about specific side effects, more information on and better understanding of my treatment options, to know how my treatment is progressing, to understand what to expect from treatment, to know what to expect after surgery, to know what my cancer means for me long term.
- **Emotional support**
  - Needed someone to talk to, someone to listen to my fears, to be asked if I was okay, support for my anxiety, help to feel less alone, needed empathy and understanding.
- **Counselling / mental health support**
  - Needed help with my self-esteem, help to cope with the shock after diagnosis, information on coping during treatment, to be referred to counsellors, needed to be encouraged to seek support even if I did not seem to need it.
- **Support for family**
  - Needed emotional support for my partner or family, support and care for my children, help at home for my family, help to keep family routines.
- **Financial help**
  - Needed financial assistance, financial support, financial planning advice, a roadmap to help manage my finances, more affordable treatment options, advice on how to minimise costs or find savings.
- **Doctors**
  - Needed more time with my doctor not just nurses, needed my doctor to know what was going on, needed more support from my doctor, for them to be more caring, needed better availability of doctors.
- **Breast Care Nurses**
  - Wanted a dedicated Breast Care Nurse, more or easier access to my Breast Care Nurse, for them to be more helpful, to answer my questions, to provide psychological and emotional support, to listen to me.

Specific examples of written responses to open-ended questions are provided in Appendix 5.

Fear of recurrence or progression

To measure the anxiety people feel at different stages following a diagnosis of breast cancer, respondents were asked to rate their agreement with two additional statements. People with metastatic breast cancer were asked to what extent they worry that their cancer may spread further (or progress). Those with non-metastatic breast cancer were asked to what extent they were worried that their cancer might come back (or recur)

For people with metastatic breast cancer, fear of progression was prevalent (81% agree that they worry their cancer may spread). Further, this concern was felt strongly by approximately half of those with metastatic breast cancer, evidenced by 44% indicating that they 'strongly agree' with the statement. For people with metastatic breast cancer, the proportion who strongly agreed with the statement was higher if they had received their most recent diagnosis in the 12 months prior to the survey (50% strongly agreed) compared to those diagnosed more than 10 years earlier (27%). Concern was also felt more strongly by those who had received active treatment in the four weeks prior to the survey (49% strongly agreed) compared to those who had not received recent treatment (34%).

Comparatively, concern about recurrence was lower (though still prominent) among those with non-metastatic breast cancer, with 67% agreeing that they worry their cancer might come back. Approximately one quarter demonstrated a high degree of concern, with 24% indicating that they 'strongly agree' with the statement. Again, people who had been diagnosed more than 10 years prior to the survey were significantly less likely to strongly agree that they are worried (12%) when compared to those diagnosed in the 12 months prior to the survey (27%). A higher proportion of those in active treatment in the four weeks prior to the survey strongly agreed (28%) compared to those who had received no treatment during this time (20%).

BCNA products, services, and activities

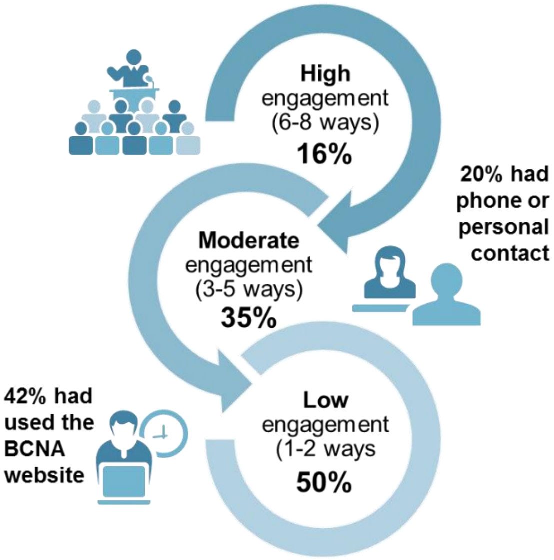
Of all BCNA products, services and activities, higher levels of awareness were recorded for BCNA's online space to chat to others with breast cancer (56%), telephone helpline people can call for information and support (55%), provision of information and opportunities to become more active and live well (63%), advocacy role to government and other organisations (63%) and connecting people to cancer support groups (63%).

Respondents were asked which of the following BCNA services they had used in the last year:

1. 73% read an email sent from BCNA
2. 42% used the website to read information
3. 23% visited the BCNA Online Network
4. 15% visited the Facebook page
5. 13% used the website to save/print items
6. 11% attended a fundraising event
7. 8% phoned BCNA
8. 6% attended an information forum

For each respondent, the number of services used was summed to create an engagement measure (refer to Figure 2).

Figure 2 Level of engagement with BCNA



Those with high levels of engagement with BCNA tended to be younger respondents, people diagnosed in the last few years and people who had recently received active treatment.

Digital preferences

When asked their preference for digital or printed publications, a higher proportion of respondents would prefer *digital* copies of *The Beacon* (53%, compared to 34%), booklets and fact sheets (45%, compared to 29%) and *The Inside Story* (29%, compared to 16%) while *printed* copies were preferred for the *My Journey Kit* (44%, compared to 16%) and *Hope & Hurdles* (20%, compared to 15%). Among those preferring printed copies, the main reasons they identified for this were that it can be taken anywhere (74%), passed on to others (51%), and filed away (43%).

BCNA funding and donations

Readership of *The Beacon* was high with 85% of respondents indicating that they had read or browsed a copy in the previous 12 months. However, when asked likelihood to pay an annual fee to receive the publication, only 31% indicated they would be 'very' or 'quite' likely to do so. Likelihood to pay a small fee was higher for those aged 60 years and over (33%), who speak English as their main language at home (32%), who live in remote or very remote areas (41%), who have metastatic breast cancer (36%) who were diagnosed more than 10 years ago (35%) and who have high engagement with BCNA (43%). Lower levels of likelihood to pay for *The Beacon* were recorded by residents of Queensland (27%) and Western Australia (29%) when compared to those from Victoria (34%), the ACT (36%) and New South Wales (33%).

When asked whether they had made any donations to charity in the past 12 months, 12% had not made any. However, 26% of respondents had donated to BCNA, 44% had donated to another cancer charity, and 23% had donated to another breast cancer charity.

Table 7 Key subgroup variations related to whether respondents had donated to BCNA

↓ Less likely to have donated to BCNA	More likely to have donated to BCNA ↑
Residents of NSW (24%), SA (25%), QLD (22%)	Residents of TAS (35%), VIC (30%), ACT (31%)
Speak a language other than English (21%)	Speak English as their main language (26%)
Diagnosed <1 (20%), 1<2 (25%) years prior to survey	Diagnosed 2<5 (29%), 5<10 (30%) or 10+ (30%) years prior to survey
People with early breast cancer (25%)	People with DCIS/LCIS (29%) or metastatic breast cancer (28%)*
Received most treatment through the public sector (23%)	Received most treatment through the private sector (29%)
Received active treatment (21%)	Received no recent treatment (53%) or hormone therapy only (27%) in the last four weeks
Got info / support from BCNA via 1-2 channels (19%)	Got info / support from BCNA using 3-5 (29%) or 6-8 (43%) channels

*Shown for comparative purposes but not a statistically significant difference.

If respondents were made aware that BCNA receives the majority of their funding through public fundraising and corporate sponsorships, 23% would be 'a lot more likely' and 38% would be 'a little more likely' to donate to BCNA in future.

Political attitudes

Three-quarters (75%) of respondents agreed that voluntary and medically assisted euthanasia should be legalised. This consisted of 54% of respondents who 'strongly agree' and a further 22% who 'agree' that euthanasia should be legalised. Agreement (% 'agree' or 'strongly agree') increased to 80% among respondents with metastatic breast cancer and 79% of those aged 40 to 59 years.

Agreement that medicinal marijuana should be made legal in Australia for people who are suffering ongoing and severe pain was also high at 83% of all respondents, increasing to 87% of those who had been diagnosed with metastatic breast cancer.

Conclusion and recommendations

Overall, the information and support needs of respondents were considerable and varied. Respondents with the greatest needs tended to be those who had received a diagnosis more recently, were receiving active treatment and those with metastatic breast cancer. In relation to demographic groups, younger respondents and those who speak a main language other than English at home also tended to have greater needs than their counterparts. In terms of overall information and support received, these groups were *less likely* to report that all of their needs had been met. That is, the subgroups of respondents with the *greatest needs* were often those who were *less likely* to report that all of these needs had been met.

Those with the most unmet information and support needs also tended to have higher levels of engagement with BCNA. When asked whether BCNA had met their support requirements, those who were more engaged were *more likely* to indicate that BCNA had met all or some of their needs. This suggests that members with the greatest unmet needs reported better outcomes if they had high levels of engagement with BCNA in the 12 months prior to the survey

Following is the full list of recommendations drawn from a thorough review of research outcomes. This includes a range of short-term solutions through which BCNA can have the most immediate impact.

1. Continue to provide core services to the current standard as these are highly valued by those who use them. This includes the provision of information and support services and playing an advocacy role. Some members noted the importance of having someone to advocate on their behalf, suggesting BCNA should also aim to communicate any advocacy efforts to increase the feeling of being supported.
2. Increase awareness of BCNA products and services overall as less than two-thirds of respondents were aware of the products, services and activities offered by BCNA (with the exception of major publications such as *The Beacon*). In particular, knowledge of BCNA partnerships and funding sources could be improved. BCNA should also consider making efforts to raise awareness amongst the general population as their knowledge of BCNA is likely to be substantially lower (and potentially non-existent) when compared to those who completed the survey.
3. Given the apparent link between the use of a range of BCNA services and the likelihood of having all needs met, ensure that those who contact BCNA via any means are made aware of, and encouraged to use, the full suite of BCNA information and support services. To do so, systems will need to be put in place to allow BCNA to identify new members at this initial point of contact.
4. As unmet needs were more prevalent among those who had been diagnosed more recently and those who had received recent treatment, it would also be beneficial to initiate contact via GPs, hospitals, treatment centres, and other relevant services to increase awareness and make services available to those in the early identification and treatment stages.

5. The following groups should be targeted through communication and support strategies as they demonstrated the greatest informational and support needs and gaps across a range of areas:
    - Younger women and men (particularly those aged under 40 years)
    - People who speak a language other than English
    - People who live in remote areas
    - People who have been diagnosed with metastatic breast cancer
    - People who have recently been diagnosed with any type of breast cancer
    - People who are currently receiving chemotherapy, radiotherapy, or surgery to treat their cancer.
6. To meet the needs of the above target groups, BCNA will need to review existing communication and support materials with the specific purpose of increasing exposure to and engagement with these among these audiences. For example, to meet the information and support needs of younger people, consideration should be made to the characteristics of people in this group. Young people tend to be more mobile (more likely to be renting than older people), more technologically savvy (though this gap is closing) and more time poor. Thus, communicating via mobile technology or internet may be more appropriate for this target group along with using briefer messages up front and allowing the option of drilling down if they require further information.
7. The type of information being provided can be used as an indicator of the types of people to target when designing or distributing information. For example, communication materials related to early menopause, challenges for premenopausal women with cancer, fertility problems or being a parent and caring for young children were more likely to be required by respondents aged under 40. Thus, information on these topics should be designed to be accessible to younger people.
8. Some sub-groups of respondents indicated that they felt isolated or lacking in support due to being part of a minority group when compared to the population of people with breast cancer. For some, they felt they could not access information relevant to their circumstances or that generic materials tailored to the masses did not meet their needs. The following minority groups require increased support and could be targeted to facilitate connections and provide reassurance that they are not alone:
    - Older people with limited support networks (family or friends)
    - Young people with a lack of access to others in a similar situation
    - Men who feel little is known about their experience or that they are not considered
    - People who live in remote areas who are unable to access all services
    - People with language barriers who are unable to easily access information and support
    - People with metastatic breast cancer who have complicated needs and greater concerns

    To reduce their feeling of isolation, these groups would also benefit from an increased focus on building support networks by connecting those in shared situations.
9. As well as considering the needs of minority groups internally, BCNA could advocate on behalf of people in these vulnerable groups by encouraging others to be inclusive in their design of support materials, in their service provision and in their general treatment of people in these groups.

    Given the number of findings related to improving support provided by cancer treatment teams, one means of advocating for breast cancer patients would be to communicate the results of this survey to cancer treatment teams and other relevant networks. This could be via an electronic fact sheets with key results, through case studies drawn from verbatim responses or by pulling out other findings of relevance to specific types of service providers. Focus on the following areas to increase understanding of the patient experience and the main needs of people with breast cancer:

- The importance of access to members of the cancer treatment team
- The importance of continuity of the cancer treatment team
- The importance of treating patients as an individual (not a patient)
- The importance of hearing and respecting the decisions of the individual
- The need to encourage take-up of support services (not to assume patients will do so)
- Increased transparency and openness regarding the patients' diagnosis and likely journey
- Increasing awareness of the issues encountered by groups with specific needs
- The need for post-treatment follow-up.

10. Of the self-perception statements respondents were asked about, the one that resonated most strongly with BCNA members was, 'I am not cancer, I am me'. This resonated especially strongly for those who had been diagnosed five or more years ago and older respondents. A positive message that resonated strongly with younger people was, 'I would like to use my experience to help others with breast cancer' while those who had been more recently diagnosed were more likely to agree that, 'I would like to use my experience to help others with breast cancer'. These sentiments could be used in relevant communications to increase engagement with particular target groups.

11. When transitioning communication materials to digital, consider the finding that respondents were more open to being provided with the following publications in a digital format: booklets or fact sheets, *The Beacon*, and *The Inside Story*. During the transition phase, be mindful of the barriers to transitioning to electronic publications among those with a preference for printed materials. For example, consider designing materials for use on mobile devices wherever possible to account for the proportion of members who prefer hard copy as they can take it anywhere or because they have a slow internet connection. Ensure the ability to share information electronically is enabled (such as via email, Facebook, and so on) for those who prefer hard copy because they can pass it on to others.

12. To increase donation likelihood, target long-term members (five or more years from diagnosis) and those in the private sector as these groups were more open to donating to BCNA. Communicate current funding sources, including the fact that BCNA is predominantly non-government funded, as this knowledge will increase donation likelihood.

13. For the purpose of future research, encourage collection of mobile and email contact details for all members at the time of membership and request updated details from existing members prior to undertaking any future research. Consider a mixed-mode of data collection if possible to increase sample coverage and allow completion by those who are unable or unwilling to complete an online survey. Qualitative research should be considered if any of the survey results require further exploratory work. A qualitative approach allows researchers to answer the 'why' questions that are difficult to flesh out in-depth through a quantitative research methodology.

1. Introduction

1.1. Background

Breast cancer is the most common cancer affecting Australian women. In 2017, it is estimated that 17,586 women and 144 men will be diagnosed with breast cancer. While the number of deaths from breast cancer is decreasing, the number of Australians diagnosed is expected to increase due to our ageing population. As such, the availability of information and support related to breast cancer remains critically important.

BCNA is the peak national organisation representing Australians experiencing breast cancer. Its role is to provide information and support to Australians affected by breast cancer. BCNA also takes on an advocacy role, representing the interests of Australians with breast cancer as required.

The majority of BCNA members have had a formal diagnosis of breast cancer. However, around one in ten have experienced breast cancer through a family member or friend. In order to fully understand the experience and requirements of members, BCNA sought to carry out a national survey of BCNA members.

In 2016, the Social Research Centre was commissioned to deliver the 2017 BCNA Member Survey using an online survey methodology. The 2017 Survey builds upon previous member research conducted in 2007, 2010, and 2013. The overall aim of the project was to increase BCNA's knowledge of the needs and outcomes of people with breast cancer, provide comparison to previous research, and to inform the development of the BCNA State of the Nation Report.

The specific objectives of the 2017 BCNA Survey were to:

- identify the current information and support gaps for Australians with breast cancer
- maximise the opportunity for BCNA members to share their opinions on the current information and support gaps they have experienced
- provide a set of recommendations to BCNA to aide in understanding of the current needs of people with breast cancer, priorities for action, and how BCNA may meet these needs.

1.2. Methodology

An online survey methodology was employed for the 2017 BCNA Member Survey. This approach balanced a range of design considerations and met BCNA's key requirement of collecting responses from a large number of members.

The online survey was conducted in two phases:

- Phase 1: Main survey data collection (via direct invitation and open link on BCNA website)
- Phase 2: Extended data collection (via open link on the BCNA website).

1.2.1. Sampling

The available sample frame for the main survey was the BCNA member list, specifically, members with a listed email address and / or mobile contact number. Following cleaning of the sample records, duplicate cases and those with incomplete or invalid contact details were removed. The final member sample list contained 35,852 cases. A census approach was taken to sampling meaning all listed members were invited to participate in the survey.

To increase survey coverage, an open invitation was posted on the BCNA website. This sought participation from members who had not previously provided BCNA with the contact details required for sending survey invitations (email or mobile). It also provided an opportunity for any non-members who visited the site to participate in the research.

While respondents did not need to be current BCNA members to participate in the survey, eligibility was limited to those who had previously been diagnosed with breast cancer. No further restrictions were made to the in-scope population and no quotas were applied.

1.2.2. Questionnaire design

The questionnaire was designed in close consultation with BCNA. It was developed with consideration to meeting project objectives, the potential for comparison with previous research and the sensitive nature of the topic.

The questionnaire also aimed to measure key elements of the State of the Nation Framework. Following is an overview of the Framework. Items marked with a tick were evaluated using questions developed for the questionnaire, while those marked with a cross are to be measured via other means determined by BCNA. The list of corresponding questionnaire items is included in Appendix 1.

If I have been diagnosed with early breast cancer

- ✓ I have the information that I need
- ✓ I am heard and treated with empathy and respect
- ✓ I get access to the treatment that is best for my cancer and my family
- ✗ My treatment is delivered by a multidisciplinary team and I have continuity of care
- ✓ I get the social, emotional, and practical support that I need during treatment

I am supported to live well after treatment for breast cancer

- ✓ I am provided with a long term follow up plan
- ✓ I am supported to manage long-term physical effects of treatment
- ✓ I can access treatments and support to help improve my emotional wellbeing
- ✗ I have access to the social supports that I need to live well
- ✓ I get the financial and practical supports that I need to live well
- ✓ My cultural and spiritual needs are addressed and valued
- ✓ The people around me get the support they need
- ✓ I know how I can give back

If I have been diagnosed with Metastatic breast cancer

- ✓ I benefit from access to best practice research, information, and treatment
- ✓ I have access to a Breast Care Nurse and multidisciplinary team
- ✓ I get the social, emotional, and practical support that I need
- ✗ I am supported towards the end of my life
- ✗ I have a good death

The average time taken to complete the questionnaire was 23.8 minutes. The full questionnaire is provided as Appendix 1.

1.2.3. Phase 1: Main data collection

The main survey sought participation via the member sample and the open survey link. The online survey for this phase opened on 3 February 2017 and closed on 19 February 2017.

Data collection commenced with an invitation email or SMS with a link to the questionnaire sent to the member sample. At the same time, information regarding the survey was posted on the BCNA website with a link to the survey itself. During fieldwork, a number of survey reminders were sent to BCNA members. During main survey data collection, the Social Research Centre was responsible for distributing reminder emails and SMS' to the member sample.

The details of the invitation and reminder activities conducted during the main data collection phase are provided in Table 8.

Table 8 Key dates for the main survey

Survey milestones	Members	Open link
Member invitation sent (email and SMS) / website link posted	03-Feb-17	03-Feb-17
Member reminder 1 sent (email)	07-Feb-17	-
Member reminder 2 sent (SMS)	10-Feb-17	-
Member reminder 3 sent (email)	13-Feb-17	-
Main survey closed	19-Feb-17	19-Feb-17

1.2.4. Phase 2: Extended data collection

The extended data collection period captured responses only from those who accessed the survey via the open survey link. The extended survey period ran from 20 February to 30 June 2017. Visitors to the BCNA website were able to access the survey at any point during this period.

BCNA was responsible for all invitation and reminder activity prompting completion via the open link during both phases of data collection. Table 9 provides the key dates for the extended data collection period.

Table 9 Key dates for the extended survey

Survey milestones	Open link
Survey commences (link remains available)	20-Feb-17
Member reminder 1 sent by BCNA (Article in the Beacon)	26-May-17
Member reminder 2 sent by BCNA (Emailed to 31,902 members)	16-Jun-17
Extended data collection closed (link removed from website)	30-Jun-17

1.2.5. Survey response

A total of 10,318 responses were received to the survey (8,215 during the main data collection phase). Approximately two-thirds (68%) of all responses were completed by clicking on the link provided in the members sample. The remaining one-third of respondents (32%) completed the survey via the open survey link.

Due to the different recruitment methods used, response rates could only be calculated for the invited member sample. Amongst the invited members, one-fifth (20%) went on to complete a survey.

This proportion was higher amongst those who were contacted via email (21%) than the SMS sample (17%). The response rate for the members sample is provided in Table 10.

Table 10 Member sample response rates by contact mode

	Total	Email sample	SMS sample
Total invited (n)	35,852	21,730	14,122
Total completions (n)	6,974	4,603	2,371
Response rate (%)	19.5	21.2	16.8

Note that it was possible for invited members to complete via the link available on the website rather than using the direct link provided in the invitation email and / or SMS. Further, it is likely that the majority of those who completed via the website were also BCNA members. The above response rate is therefore likely to be understated to some extent. Further information on the potential for overlap across the two samples is provided in Section 1.3.3.

1.2.6. Respondent profile

Throughout this report, all responses have been combined to provide a total figure. When analysing results, readers should be mindful of the composition of the total respondents group explained below.

The majority of respondents indicated that they had been diagnosed with non-metastatic breast cancer: 75% with early breast cancer and 20% with DCIS/LCIS. The remaining 5% of the sample had been diagnosed with metastatic breast cancer. Results from people with metastatic and non-metastatic breast cancer are split out throughout the report to illustrate differences between the two groups.

More than half of the respondents (54%) had received their most recent diagnosis in the three years prior to the survey. The remainder had been diagnosed more than three and up to five years prior (16%) or more than five years prior (30%). Approximately one in ten respondents (11%) indicated that their most recent diagnosis had not been their first.

In the four weeks prior to the survey, 18% of respondents had received ‘active treatment’ (this includes surgery, radiotherapy, chemotherapy, and hormone therapy if required), 39% had received ‘hormone therapy only’ (exclusive of active treatment) and the remaining 43% had not received any formal treatment during this time.

Responses were split between those who had received most of their treatment through the private health system (53%) or the public health system (45%) while a small portion did not provide a response to this question.

In terms of the demographic composition of respondents, less than 1% were male. Half (50%) were aged 60 years and over, 47% were aged 40 to 59 years and a small portion (3%) were aged 18 to 39 years. The majority of respondents (97%) spoke English as their main language. A small portion of respondents (1%) identified as Aboriginal or Torres Strait Islanders.

All States and Territories were represented in the sample and the proportion of respondents in each fell out roughly in line with the population. Approximately two-thirds of respondents (67%) were residents of major cities, 22% lived in inner regional areas, 8% in outer regional areas and 1% in remote or very remote areas of Australia.

Results have been analysed by respondent groups and any significant differences between subgroups are discussed throughout the report. The full demographic profile of respondents is provided in Table 11.

Table 11 Survey respondent profile

H1. Gender; H2. Age; H3. State/territory; H4. Postcode; H5. LOTE; H6. ATSI; A1. Diagnosis; A6. Health system.

Demographics	Survey respondents	
Gender	**n**	**%**
Male	24	0.2
Female	10,278	99.6
Other/unspecified	16	0.2
Total	**10,318**	**100.0**
Age	**n**	**%**
Under 40 years	331	3.2
40 to 49 years	1,577	15.3
50 to 59 years	3,237	31.4
60 to 69 years	3,337	32.3
70 years or over	1,809	17.5
Unspecified	27	0.3
Total	**10,318**	**100.0**
Language	**n**	**%**
English	10,048	97.4
LOTE	242	2.3
Unspecified	28	0.3
Total	**10,318**	**100.0**
ATSI	**n**	**%**
Yes	95	0.9
No	10,159	98.5
Unspecified	64	0.6
Total	**10,318**	**100.0**

Basic information about the population of all BCNA members (by location and breast cancer type) was provided by BCNA as an indication of the composition of this group. The final achieved sample fell out roughly in line with these population parameters (refer to Appendix 2).

1.3. Analysis

1.3.1. Throughout the report

In some tables and figures, totals shown and / or mentioned in the accompanying text may differ slightly from the apparent sum of their component elements. This is due to the effects of rounding.

Some questions required respondents to rate their level of agreement on a 5-point scale as follows:

1 = Strongly agree

2 = Agree

3 = Neither agree nor disagree

4 = Disagree

5 = Strongly disagree

For the purposes of reporting, agreement and disagreement netts were created. Where 'agree' is reported throughout, this refers to the combined estimates of 'strongly agree' and 'agree' responses. When 'disagree' is used, this combines the responses 'disagree' and 'strongly disagree'. In some instances, only the estimates from the extremities are discussed in the commentary. Where this occurs, these are clearly marked with 'strongly agree' or 'strongly disagree'.

1.3.2. Significance testing

Statistical tests were undertaken to establish whether the responses of subgroups were statistically significant. Where differences across subgroups are highlighted in the report commentary, unless otherwise noted, it implies that a statistically significant difference at a 95% confidence level has been established. In charts and tables, results marked with an asterisk denote significant differences. Significance testing was routinely conducted on the following variables of interest:

- age group
- main language spoken in the household
- State or Territory
- remoteness of location
- most recent diagnosis type
- time since most recent diagnosis
- recent treatment
- system received most treatment through
- level of engagement with BCNA services.

Refer to Appendix 3 for full details of the composition of subgroups derived for the purpose of significance testing.

1.3.3. Considerations

While an online survey methodology was considered fit-for-purpose for this research, there are some limitations to this approach that the reader should consider. In an online environment, respondents are limited to those who have internet access, a level of computer proficiency and have a sufficient level of literacy. Therefore, the final sample of respondents is not inclusive of people with breast cancer who fall outside of this scope.

The member sample were sent a unique survey link and could complete the survey once only using this approach. Comparatively, there were no controls over the group of respondents who accessed the survey via the open link on the BCNA website.

Upon survey commencement, little was known about who would complete via the open link on the BCNA website beyond the fact that they had visited the site. While respondents completing via this entry mode were likely to be BCNA members (and the majority of respondents went on to say they had received BCNA publications in the 12 months prior to the survey), this group may also contain a small number of respondents who are not BCNA members but have visited the BCNA website nonetheless. For this reason, respondents are referred to as people with breast cancer throughout this report rather than BCNA members.

The main differences between people who accessed the survey via the member survey invitation email or SMS and those who completed via the open link on the website are summarised in Table 12.

Table 12 Distinctions between the member sample and open link

Feature	Member survey	Open link
Access	Accessed the survey via a unique link provided in email or SMS Could complete survey once only (no duplicates)	Accessed the survey via an open link provided on BCNA website or in member communications Potential to complete more than once (possible duplicates)
Reminders	Member sample checked prior to reminders being sent to remove those who had completed - reminders sent to all non-respondents	Reminders distributed to the full member sample, regardless of whether a response had already been received
Duration	Survey conducted over a two-week period	Survey completions collected over a five-month period
Membership	All respondents had registered an email or mobile number with BCNA	May or may not be registered members of BCNA and could include respondents from the member sample

Upon investigation of survey responses to demographic questions, respondents who completed using the open link to the survey shared very similar characteristics to the member sample. For this reason, and for ease of analysis, all respondents have been combined and are referred to as 'total' for reporting purposes.

Note that, due to the extended survey period and later survey reminders not excluding people who have already completed, it is possible that people may have responded to the survey on more than one occasion via the open link.

1.4. Ethics and quality assurance

All data collection activities were undertaken in accordance with ISO 20252 quality standards, the Australian Market and Social Research Society code of ethics, and the Market and Social Research Privacy Principles.

2. Informational and support needs

A key objective of the research for BCNA was to understand informational and support gaps amongst people with breast cancer. This section details the extent to which respondents had needs related to breast cancer side effects, a person's life stage, emotional wellbeing, practical help requirements and other needs and the extent to which their needs had been met in these areas.

As a means of identifying support gaps, only those respondents who indicated that 'all my needs were met' were considered to have had no informational or support gaps in the associated area. Major informational or support gaps are illustrated by those who reported that 'none of my needs were met'.

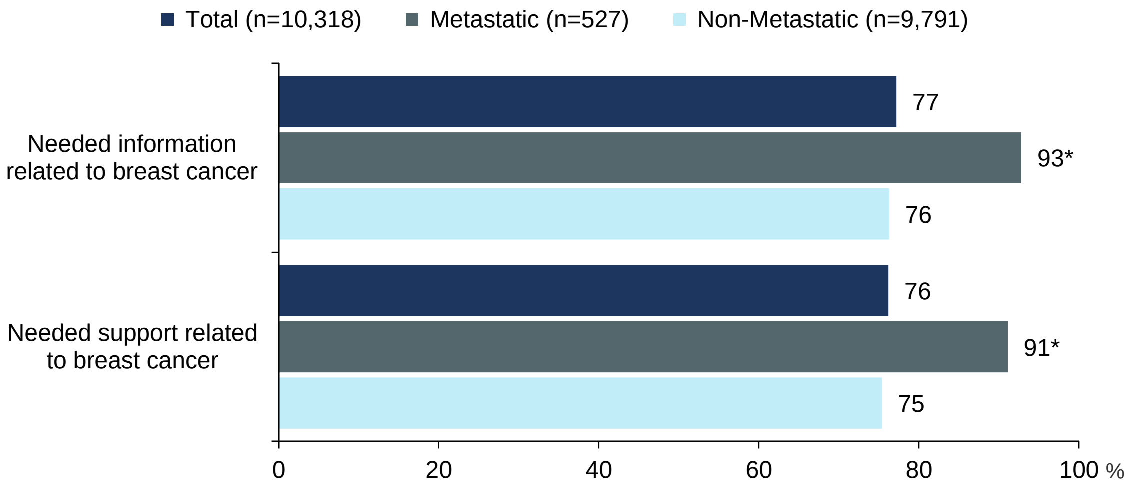
2.1. Breast cancer information and support overall

2.1.1. Proportion who had informational or support needs

Around three-quarters of all respondents indicated that they had informational or support needs related to breast cancer in the 12 months prior to the survey (77% and 76% respectively). Comparatively, respondents who had been diagnosed with metastatic breast cancer were more likely to be in need of information (93%) or support (91%) than people with non-metastatic breast cancer. Amongst the latter group (shown in light blue in Figure 3), people with early breast cancer had more informational (76%) and support (75%) needs than people with DCIS or LCIS (73% needed information and 71% needed support).

Figure 3 Overall informational or support needs

B1. In the last 12 months, to what extent did you have needs in relation to…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Decreasing informational and support requirements were associated with an increase in the age of respondents. Of the younger respondents aged 18 to 39 years, 92% needed information and 92% needed support. Needs decreased as each ten year age category increased, with 67% of those aged 70 years and over having informational needs and 65% having support needs.

No notable differences in informational or support needs were observed based on whether respondents resided in metropolitan or regional/remote areas.

Both informational and support needs were higher for those whose most recent diagnosis had been in the year prior to the survey (99% needed information; 99% needed support) or one to two years prior (92% needed information; 92% needed support). This compares to respondents who had been diagnosed more than ten years prior to the survey, amongst whom 44% needed information and 41% needed support.

People who had received active treatment (survery, radiotherapy or chamotherapy) or hormone therapy only in the month prior to the survey were more likely to have had informational (96% for active treatment and 87% for hormone treatment) and support needs (96% for active treatment and 87% for hormone treatment). This compares to 60% needing information and 59% needing support if they had not received treatment in the month prior to the survey. People receiving treatment primarily in the public sector were significantly more likely than those in the private sector to require information (79% versus 76%) or support (78% versus 75%), though the difference was not extreme.

Those with a high or moderate level of engagement with BCNA (91% and 82% respectively) had greater informational needs when compared to those with low engagement (70%). This was also true for support needs (89% with high engagement had needs, 81% of those with moderate engagement and 68% of those with low engagement).

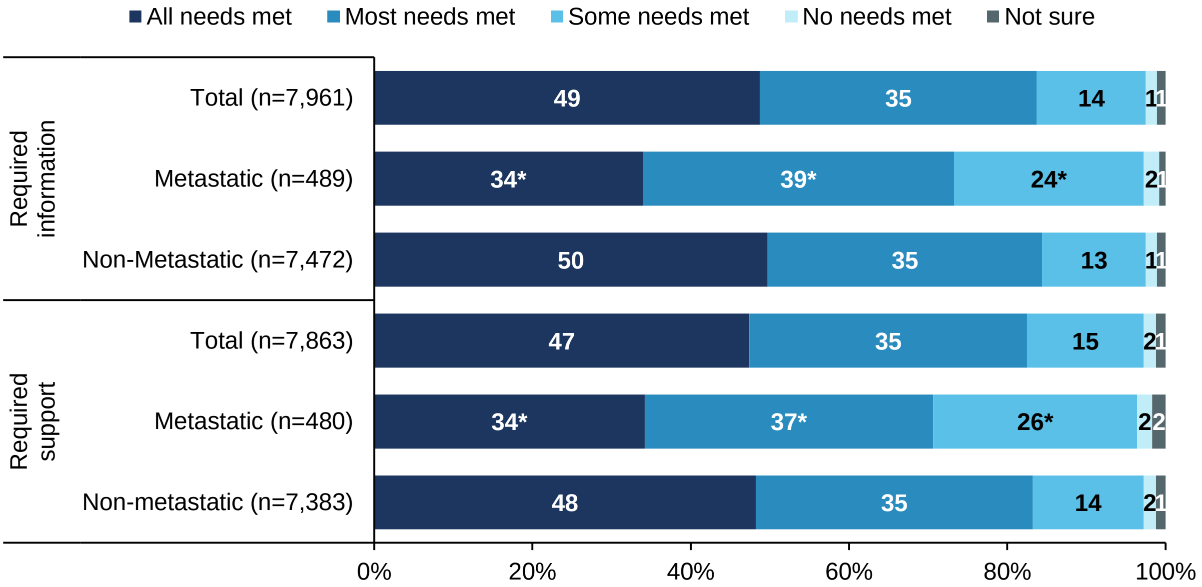
2.1.2. Whether overall informational or support needs were met

Amongst those respondents with informational needs related to breast cancer, less than half indicated that they had received all of the information (49%) they had required in the 12 months prior to completing the survey. A similar proportion of respondents with support needs (47%) indicated that they had received all the support they had needed. The remainder of respondents can be considered to have some informational and support gaps.

Informational and support gaps were more apparent amongst those with metastatic breast cancer than those with less invasive breast cancer. Amongst those with metastatic breast cancer, three quarters (74%) reported that all of their informational needs had *not* been met, while this proportion decreased to 50% amongst those with non-metastatic breast cancer. A similar proportion of those with metastatic breast cancer (66%) indicated that all of their support needs had *not* been met (52% amongst those with non-metastatic breast cancer). A full breakdown of responses is provided in Figure 4.

Figure 4 **Extent to which overall informational and support needs were met**

B1. In the last 12 months, to what extent were your needs met in relation to… a) Receiving all the breast cancer information you needed, b) Receiving all the support related to breast cancer that you needed?



Base: Respondents with informational and support needs
*Significantly different to results for those with non-metastatic breast cancer

The proportion of respondents reporting that *all* their information and support requirements had been met increased with age. A higher proportion of people aged 70 years and over indicated that *all* their needs were met (63% of this group reported their informational needs were met and 63% indicated their support needs were met) compared to younger age groups. Amongst those aged 18 to 39 years, 32% indicated *all* their informational needs had been met and 30% indicated *all* their support needs had been met.

Respondents whose main language was English were more likely to indicate that *all* their informational (49%) and support (48%) needs had been met in the past year when compared to those whose main language is not English (32% and 34% respectively).

Respondent remoteness tended to be associated with a reduced likelihood of all informational or support needs being met. Those who reside in a major city, inner or outer regional area were more likely to indicate that *all* their information (48 to 51%) and support (47 to 50%) needs had been met when compared to those who live in a remote/ very remote area (38% and 37% respectively).

In terms of time since most recent breast cancer diagnosis, people who had been diagnosed five to ten years ago (53%) or more than ten years ago (57%) were more likely to report *all* their informational needs had been met compared to those whose most recent diagnosis was made within the last five years (45 to 49%). Amongst those requiring breast cancer support, 60% of those diagnosed more than ten years ago indicated that *all* their needs had been met compared to 44 to 51% of those diagnosed in the past ten years.

Over half of those who had received no active treatment in the month prior to the survey indicated that *all* their informational (53%) and support (52%) needs had been met in the past year. This compared to 45% of those in active treatment and 47% of those receiving hormone therapy only with *all* their informational needs met and 44% of those in active treatment and 45% of those receiving hormone therapy only indicating *all* their support needs were met.

The proportions of respondents stating *all* their needs had been met in the past year was higher amongst those who reported having a low level of engagement with BCNA during this period (54% indicated their informational needs were met and 53% that their support needs had been met). This compares to 41% of those with high engagement with BCNA reporting *all* their needs were met and 39% of the same group indicating *all* their support needs were met. However, this does not necessarily mean that their needs were not met by BCNA, rather simply that high engagement with BCNA was in some cases linked to respondents having informational or support gaps.

2.2. Breast cancer side effects

2.2.1. Needs related to breast cancer side effects

Respondents were asked whether they had needed any information on the following breast cancer side effects in the 12 months prior to the survey:

- Lymphoedema (fluid retention and tissue swelling) due to cancer treatment
- Managing fatigue related to cancer treatment
- Managing problems thinking clearly or concentrating (e.g. 'chemo-brain')
- Changes in sexual function or relationships
- Early menopause due to cancer treatment.

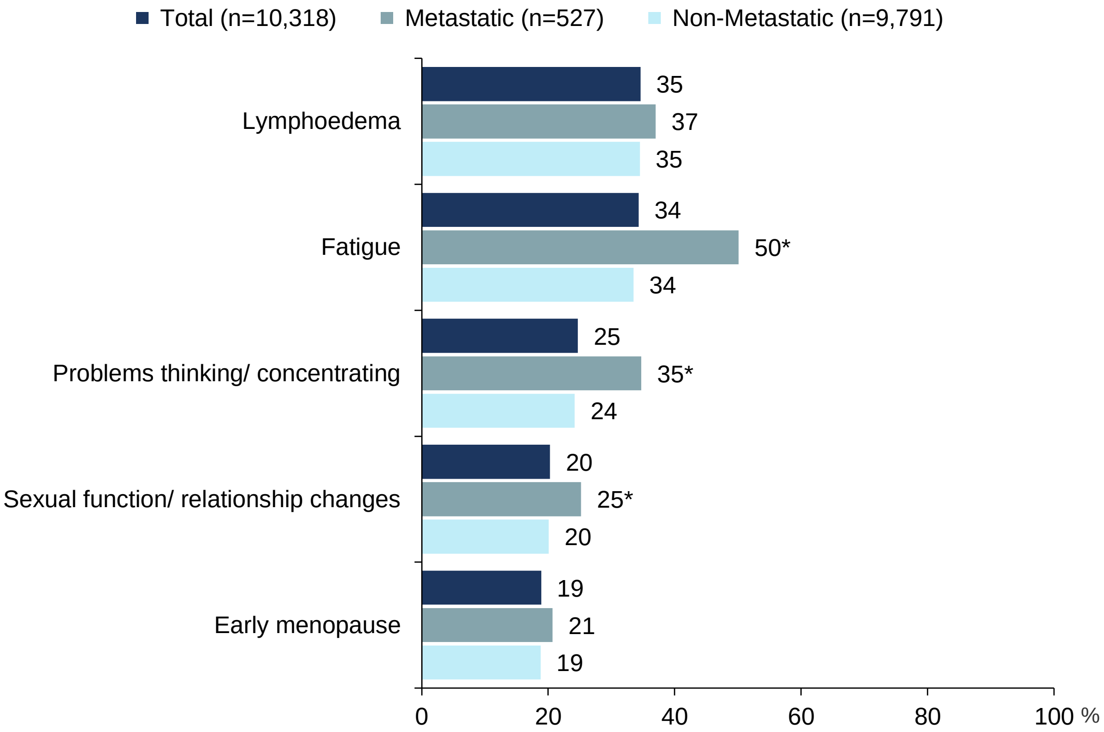
Approximately one third of respondents (35%) had needed information related to lymphoedema while a similar proportion (34%) needed information related to managing fatigue. The extent to which information on lymphoedema was required was comparable amongst those with metastatic and non-metastatic breast cancer. However, significantly more of those with metastatic breast cancer (50%) had required information regarding managing fatigue in the 12 months prior to the survey.

Compared to managing fatigue and lymphoedema, comparatively fewer respondents required information on side effects including problems thinking clearly or concentrating (25%), changes in sexual function/relationships (20%) or early menopause (19%).

As shown in Figure 5, those diagnosed with metastatic breast cancer were more likely to require information related to managing problems thinking clearly or concentrating (35%) and changes to their sexual function or relationships (25%) when compared to those with non-metastatic breast cancer (24% and 20% respectively). For those with DCIS or LCIS, the proportion with needs related to each of the side effects was lower when compared to those with early breast cancer.

Figure 5 **Proportion with needs related to breast cancer side effects**

B2_1. In the last 12 months, have you needed any information on the following topics…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Informational needs related to breast cancer side effects were lower for those who had not received treatment in the four weeks prior to the survey (ranging from 11% needing information on early menopause to 24% requiring information on lymphoedema). This compares to 28% requiring information on early menopause due to cancer treatment and 50% requiring information on lymphoedema if in active treatment. Most notably, 56% of those in active treatment required information on managing fatigue related to cancer treatment compared to 21% of those who had not required treatment in the four weeks prior to the survey.

The proportion of respondents needing information related to each of the side effects presented decreased as the age group of respondents increased. The need for information related to early menopause due to cancer treatment was considerably higher amongst those aged 18 to 39 years (64%) and 40 to 49 years (60%) and minimal amongst those aged 60 years and over (1 to 2%). A higher proportion of those aged 18 to 39 years (47%) required information on fertility problems while this proportion decreased to 6% of those aged 40 to 49 years and less than 1% of respondents aged 50 years and over. Though not as extreme, the need for information on lymphoedema, managing problems thinking clearly or concentrating and managing fatigue also decreased with age.

Informational needs related to early menopause due to cancer treatment were higher amongst those whose main language is not English (31%) compared to those whose main language is English (19%). This group of respondents were also more likely to indicate that they need information related to changes in sexual function or relationships (28% compared to 20% of those whose main language is English).

Respondents who reported having high levels of engagement with BCNA were more likely to indicate that they had informational needs related to breast cancer side effects (from 30% needing information on early menopause to 51% needing information on managing fatigue related to cancer treatment) when compared to those with lower levels of engagement (from 13% needing information on early menopause to 28% needing information on lymphoedema).

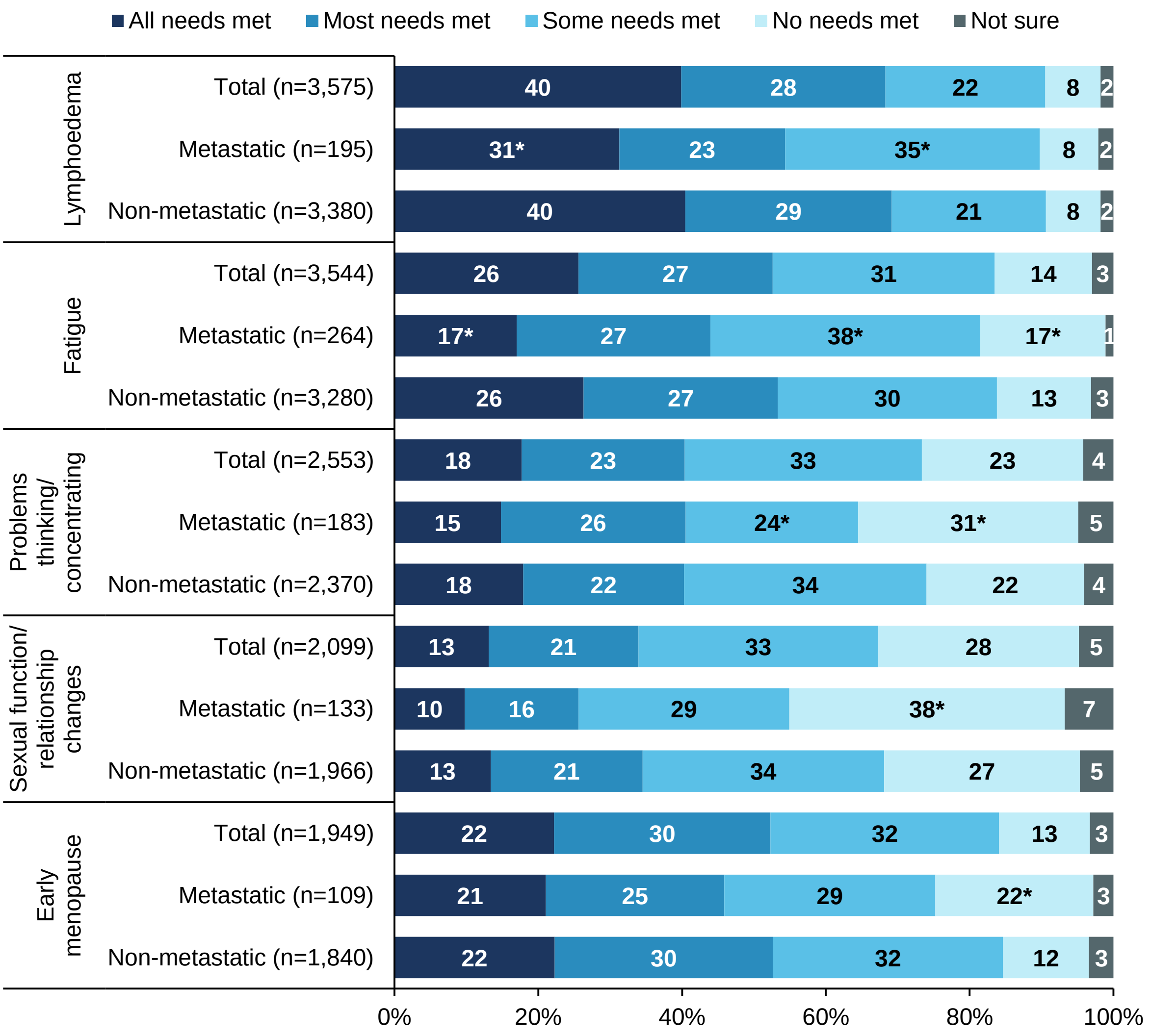
2.2.2. Whether needs related to breast cancer side effects were met

Amongst those who needed information about each of the five breast cancer side effects presented, the proportions stating that *all* their needs had been met tended to be low. At best, two-fifths (40%) indicated that *all* their lymphoedema-related informational needs were met. Comparatively, 13 to 26% of those requiring information on each of the other side effects indicated that *all* their needs had been met.

When compared to those with non-metastatic breast cancer, those with metastatic breast cancer were significantly more likely to say that none of their informational needs had been met in relation to changes in sexual functioning or relationships (38% compared to 27%), managing problems thinking clearly or concentrating (31% compared to 22%), early menopause (22% compared to 12%) or managing fatigue (17% compared to 13%).

Figure 6 Extent to which needs were met in relation to breast cancer side effects

B2_2. To what extent have your information needs been met in this area?



Base: Respondents with informational and support needs
* Significantly different to results for those with non-metastatic breast cancer

For those needing information on these topic areas, respondents were more likely to say *all* their needs had been met if they had received active treatment (chemotherapy, radiology or surgery) in the four weeks prior to the survey than those who had not received recent treatment. Notable differences were observed in the proportion saying *all* their needs had been met related to managing fatigue related to cancer treatment (32% of those in active treatment compared to 22% of those not receiving treatment), managing problems thinking clearly or concentrating (21% compared to 16%) and needing information on changes in their sexual function or relationships (20% compared to 10%).

The proportion of respondents who had needs related to each of the breast cancer side effects and indicated that *all* their needs had been met were higher for those diagnosed in the 12 months prior to the survey when compared to those diagnosed more than two years earlier. For example, the proportion indicating *all* their needs related to changes in sexual function/ relationships amongst those diagnosed in the last 12 months decreased from 22% to 6 to 9% of those who had been diagnosed more than two years prior. Amongst those with informational needs related to managing fatigue related to cancer treatment, 35% said *all* their needs had been met if diagnosed in the 12 months prior to the survey compared to 12 to 17% of those diagnosed 2 or more years prior.

A few differences were observed in the proportion of older respondents indicating *all* their needs had been met compared to those in the younger age group. The proportion indicating *all* their needs were met for lymphoedema increased from 28% of those aged 18 to 39 years to 43% of those aged 60 to 69 years and 51% of those aged 70 years and over. For managing fatigue related to cancer treatment, 17% of those aged 18 to 39 years indicated that *all* their needs had been met compared to 30% of those aged 60 to 69 years and 31% of those aged 70 years and over. While for managing problems thinking clearly or concentrating, 13% of those aged 18 to 39 years indicated that *all* their needs had been met compared to 20% of those aged 60 to 69 years and 24% of those aged 70 years and over.

2.3. Life stage specific

2.3.1. Needs related to life stage

Respondents were asked whether they had needed any information on the following life stage specific topics in the 12 months prior to the survey:

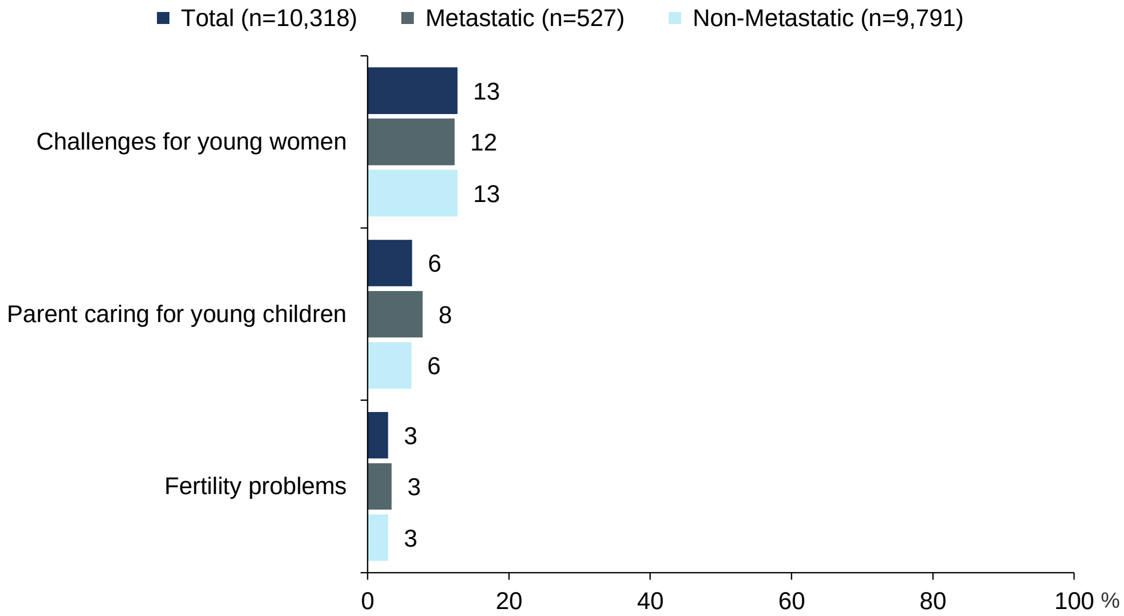
- challenges for young (premenopausal) women with cancer
- being a parent with cancer and caring for young children
- fertility problems related to cancer treatment.

Though comprising a relatively small number of respondents overall, 13% of respondents indicated that they required information regarding the challenges associated with being a young (premenopausal) woman with breast cancer, 6% of respondents required information on caring for young children as a parent with breast cancer, and 3% required information on fertility problems associated with cancer treatment.

As shown in Figure 7, informational needs specific to particular life stages did not vary significantly dependent on whether respondents had metastatic or less invasive forms of breast cancer.

Figure 7 Proportion with needs related to related to life stage

B2_1. In the last 12 months, have you needed any information on the following topics…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

The need for information related to particular life stages reduced as the age group of the respondent increased. Life stage specific needs were higher for those aged 18 to 39 years with 75% needing information on challenges for young women with breast cancer, 47% needing information on fertility problems associated with cancer treatment, and 38% needing information on being a parent with cancer and caring for young children. Comparatively, the proportion needing information on challenges for young women with cancer was 48% of those aged 40 to 49 years, 8% of those aged 50 to 59 years and less than 1% of those aged 60 years and over. The proportion needing information on associated fertility problems decreased to 6% of those aged 40 to 49 years, and less than 1% in the older age groups. The needing for information on being a parent with cancer dropped to 24% in the 40 to 49 year age group, 4% of those aged 50 to 59 years and less than 1% of those aged 60 years and over.

Informational needs related to life stages were higher for people who speak a language other than English in the household when compared to those whose main language is English. The proportion needing information related to challenges for young women was 12% amongst those whose main language was English compared to 23%. Among those whose main language was English, 6% needed information on being a parent with cancer and caring for young children (compared to 14%) and 3% of those whose main language is English needed information on fertility problems related to cancer treatment (compared to 11%).

Respondents were more likely to require life stage related information if they had been diagnosed in the 12 months prior the survey or had received active treatment in the four weeks prior to the survey. Amongst those diagnosed in the 12 months prior to the survey:

- 20% needed information on challenges for young women with cancer (compared to 6% of those diagnosed five to ten years prior and 3% of those diagnosed more than 10 years prior)
- 12% needed information on being a parent with cancer and caring for young children (compared to 2% of those diagnosed five to ten years prior and 1% of those diagnosed more than 10 years prior)

- 5% needed information on fertility problems related to cancer treatment (compared to 1% of those diagnosed more than 5 years prior).

Amongst those who had received active treatment in the four weeks prior to the survey:

- 21% needed information on challenges for young women with cancer (compared to 14% of those receiving hormone treatment only and 8% of those receiving no treatment)
- 13% needed information on being a parent with cancer and caring for young children (compared to 6% of those receiving hormone treatment only and 4% of those receiving no treatment)
- 6% needed information on fertility problems related to cancer treatment (compared to 2% of those receiving hormone treatment only and 2% of those receiving no treatment).

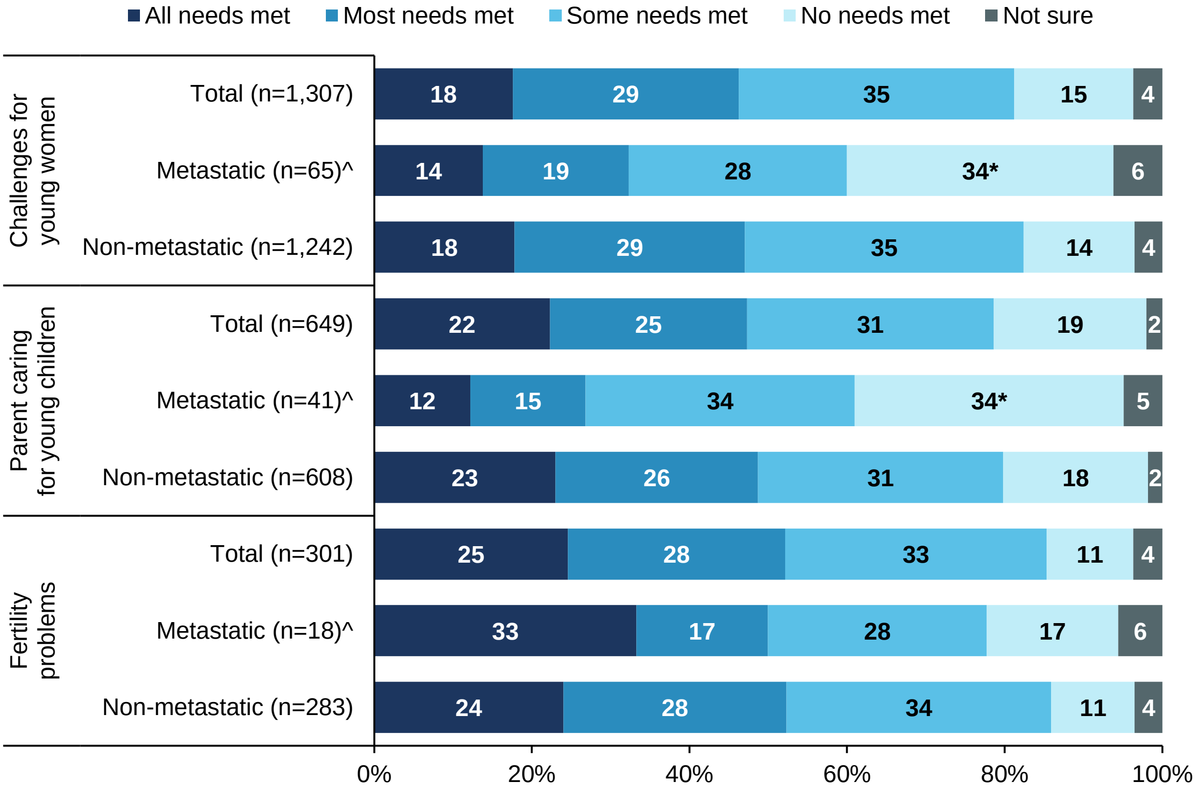
2.3.2. Whether needs related to life stage were met

Amongst those with life stage related informational needs, the proportions indicating that *all* their needs had been met did not exceed one-quarter for any of the topic areas. The proportions indicating that *all* their needs were met was 25% amongst those needing information related to fertility problems, 22% of those needing information on being a parent with cancer and caring for young children, and 18% of those needing information on the challenges associated with being a young woman with cancer. Thus, the biggest informational gap was experienced by those requiring information related to being a young woman with cancer.

For two of the topic areas, the proportion reporting that *none* of their informational needs had been met was especially high for people with metastatic breast cancer when compared to those with non-metastatic cancer types. Of those who required information on being a parent with cancer and caring for young children, approximately one-third of those with metastatic breast cancer said none of their needs had been met (34% compared to 18% of those with non-metastatic cancer) while the same proportion of those who needed information in relation to the challenges facing young women with cancer said none of these were met (34% compared to 14%).

Figure 8 Extent to which needs were met in relation to life stage

B2_2. To what extent have your information needs been met in this area?



Base: Respondents with informational and support needs ^Caution: Small sample size
* Significantly different to results for those with non-metastatic breast cancer

Due to the small number of respondents who required life stage specific information, few significant differences were observed across subgroups of respondents. The two exceptions were differences based on time since most recent breast cancer diagnosis and whether respondents had received recent treatment.

For those who required information related to challenges for young women with cancer, 21% of those diagnosed in the 12 months prior to the survey and 19% of those diagnosed more than 12 months but less than two years prior said *all* their informational needs had been met. Fewer of those diagnosed more than two years but less than ten years prior to the survey (12%) indicated that their informational needs had been met in relation to challenges for young women with cancer.

For those who required information regarding being a parent with cancer and caring for young children, 30% of those diagnosed in the 12 months prior to the survey said *all* their informational needs had been met. This compared to 9 to 17% of those diagnosed earlier. Of those who received active treatment in the four weeks prior to the survey, 28% said *all* their needs regarding being a parent with cancer had been met, compared to 18% of those not currently receiving treatment.

2.4. Emotional wellbeing

2.4.1. Needs related to emotional wellbeing

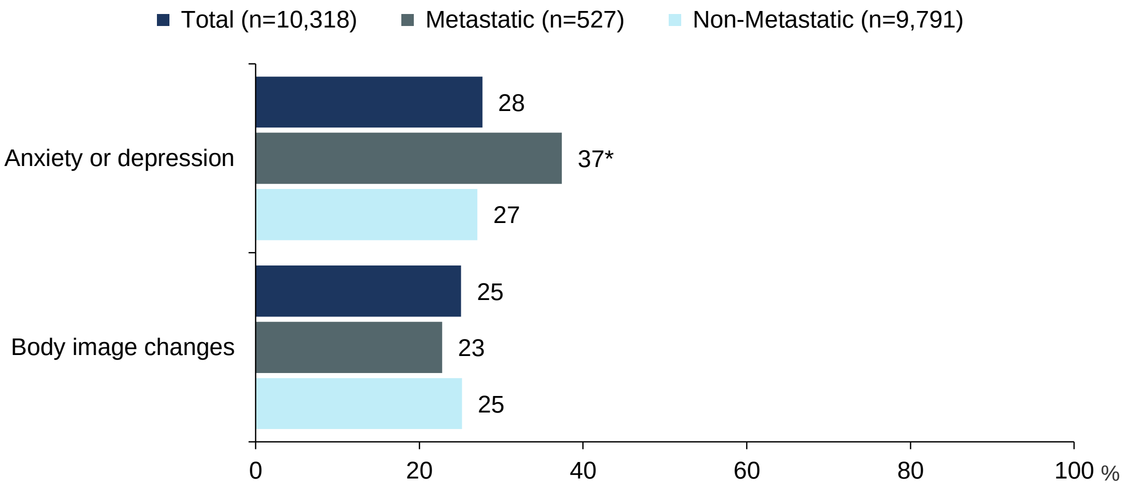
Respondents were asked whether they had needed any information on the following topics related to emotional wellbeing in the 12 months prior to the survey:

- anxiety or depression related to cancer
- body image changes related to cancer.

Approximately one-quarter of respondents indicated that they had required information on these two topics in the 12 months prior to the survey. Overall, 28% had required information on anxiety or depression related to cancer and 25% needed information on associated body image changes. Those with metastatic breast cancer were significantly more likely to need information related to anxiety or depression related to cancer (37%) compared to those with less invasive cancer types (27%). Further, within the latter group, those with early breast cancer were more likely to need information (28%) than those with DCIS or LCIS (25%).

Figure 9 Proportion with needs related to emotional wellbeing

B2_1. In the last 12 months, have you needed any information on the following topics…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

With every increase in respondent age group, the proportion requiring information related to these two topic areas decreased. Amongst respondents aged 18 to 39 years of age, 51% needed information related to anxiety or depression while 54% required information related to body image changes. This compares to 42% of those aged 40 to 49, 31% of those aged 50 to 59, 23% of those aged 60 to 69 and 13% of those aged 70 years and over who needed information on anxiety or depression related to cancer and 41% of those aged 40 to 49, 29% of those aged 50 to 59, 18% of those aged 60 to 69 and 12% of those aged 70 years and over who needed information on anxiety or depression related to cancer.

The need for information related to anxiety and depression was lower for those who speak English as their main language (27% compared to 36% of those who speak another main language) as was the need for information related to body image changes (25% compared to 36% of those who speak another main language).

Those who had received active treatment (which may or may not include hormone therapy) or hormone therapy only in the four weeks prior to the survey were more likely to have needed information about anxiety or depression in the last year (37% of those receiving active treatment; 37% of those receiving hormone treatment) or body image changes (39% of those receiving active treatment; 32% of those receiving hormone treatment). This compares to those who had not received recent treatment, of whom 21% needed information on anxiety or depression related to cancer and 19% needed information on body image changes.

Informational needs related to emotional wellbeing were higher for respondents who had received a more recent diagnosis. In terms of needing information on anxiety and depression related to cancer, needs were higher amongst those diagnosed in the 12 months prior to the survey (37%) and over 12 months and up to two years prior (37%) when compared to those diagnosed more than two but less than five years ago (27%), more than five but less than 10 years ago (16%) or more than 10 years ago (10%).

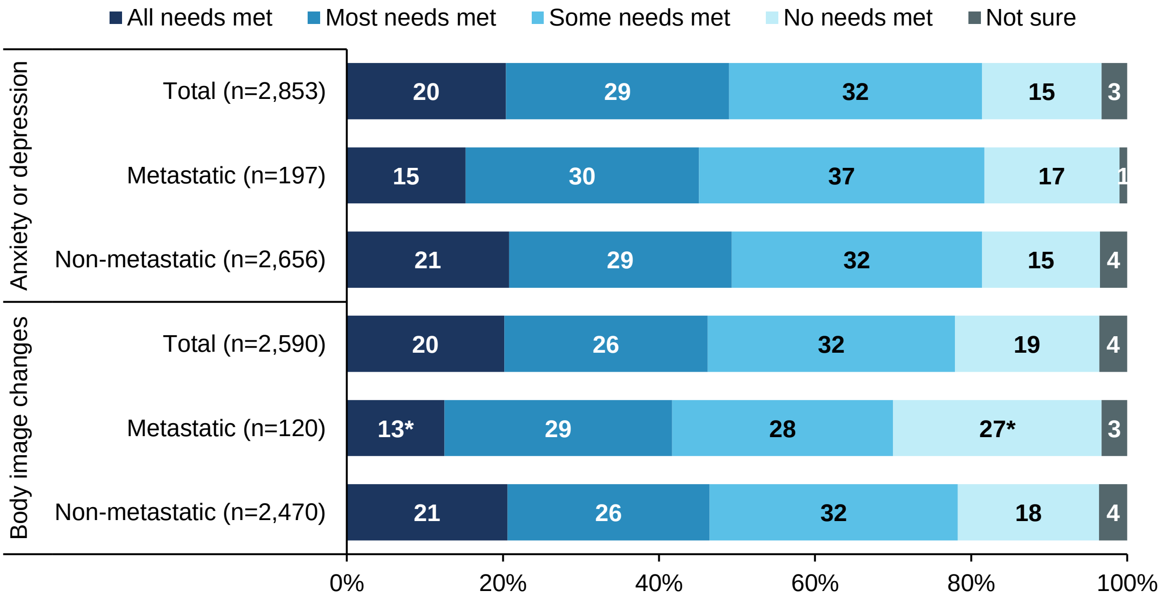
The need for information on body image changes related to cancer was also higher amongst those diagnosed in the 12 months prior to the survey (39%) and over 12 months and up to two years prior (32%) when compared to those diagnosed more than two but less than five years ago (21%), more than five but less than 10 years ago (13%) or more than 10 years ago (10%).

2.4.2. Whether needs related to emotional wellbeing were met

Overall, one in five of those who had informational needs related to their emotional wellbeing indicated that *all* of their needs had been met regarding cancer related anxiety or depression or body image changes. Few differences were observed in relation to needs being met by type of cancer diagnosis though those with metastatic breast cancer were significantly less likely to say that *all* their needs related to body image changes had been met (13%) when compared to those with non-metastatic breast cancer (21%).

Figure 10 Extent to which needs were met in relation to emotional wellbeing

B2_2. To what extent have your information needs been met in this area?



Base: Respondents with informational and support needs
* Significantly different to results for those with non-metastatic breast cancer

Few subgroup variations were observed in relation to the extent to which needs were met for the two topic areas associated with emotional wellbeing. One notable difference amongst those with informational needs related to depression and anxiety was that those who had been diagnosed in the 12 months prior to the survey were more likely to indicate that *all* their needs had been met (27%). This compared to 18% amongst those diagnosed more than 12 months but less than two years prior, 18% of those diagnosed more than two and up to five years prior and 11% of those diagnosed more than five and up to 10 years prior.

A similar observation was made amongst those who required information related to body image changes with those who had been diagnosed in the 12 months prior to the survey being more likely to indicate *all* their needs had been met (28%). This compared to 17% of those diagnosed more than 12 months but less than two years prior, 12% of those diagnosed more than two and up to five years prior and 15% of those diagnosed or more than five and up to 10 years prior.

Amongst those who needed information related to anxiety or depression, 24% of those who had received active treatment in the four weeks prior to the survey indicated that *all* their needs had been met, compared to 20% of those who had received hormone therapy only and 18% of those who had received no treatment in the four weeks prior. For those who needed information on body image changes, 25% of those who had received active treatment in the four weeks prior to the survey indicated that *all* their needs had been met, compared to 18% of those who had received hormone treatment only and 19% of those not receiving treatment.

2.5. Practical help

2.5.1. Needs related to practical help

Respondents were asked whether they had needed any information on the following topics related to practical help for people with breast cancer in the 12 months prior to the survey:

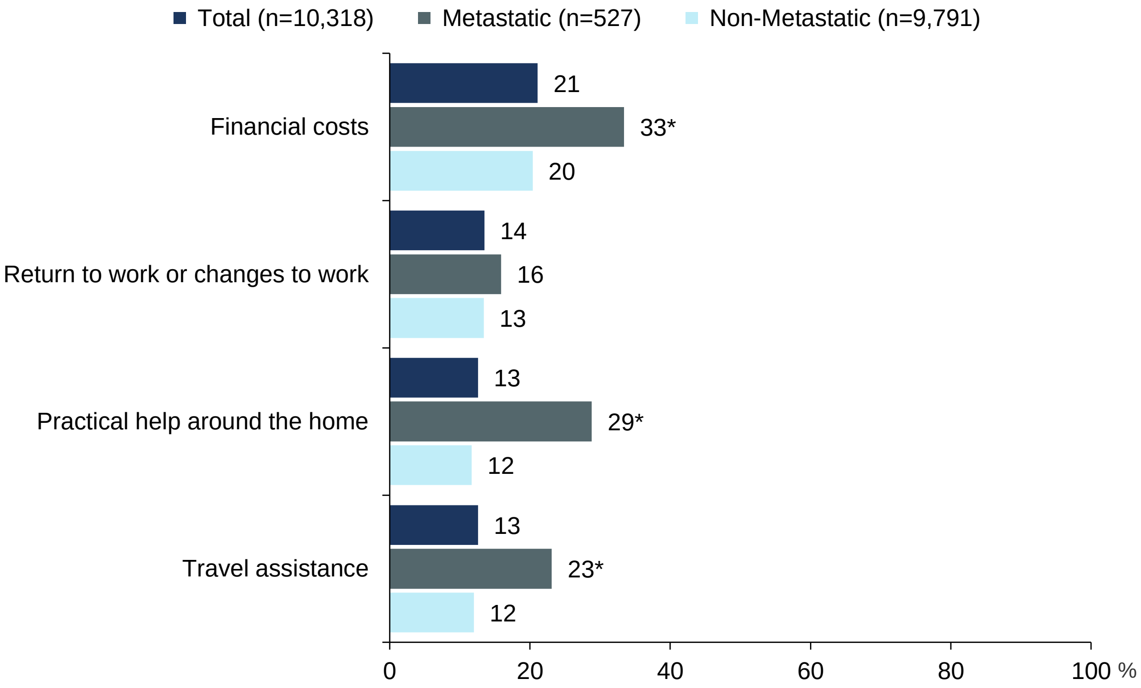
- managing the financial costs of breast cancer
- managing your return to work or changes to work
- receiving practical help around the home (e.g. programs or services available)
- travel assistance related to breast cancer (e.g. patient assisted travel schemes or PATS).

In the year prior to the survey, the main practical topic on which respondents needed information was managing the financial costs associated with breast cancer with approximately one-fifth (21%) having needed this information. Fewer respondents required information related to managing their return to work or changes to their work (14%), receiving practical help around home (13%) or travel assistance for breast cancer patients (13%).

Those with metastatic breast cancer were more likely to need information on most of these topics with 33% needing information on the associated financial costs (compared to 20% of those with non-metastatic cancer), 29% needing information on practical help around home (compared to 12%) and 23% needing information on travel assistance (compared to 12%).

Figure 11 Proportion with needs related to practical help

B2_1. In the last 12 months, have you needed any information on the following topics…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Those who reside in remote or very remote areas were more likely to require assistance related to the financial costs associated with breast cancer (30%) compared to those living in a major city (21%) or inner regional area (21%). Further, the need for information on available travel assistance related to breast cancer increased amongst those who reside in more remote areas. The proportion who indicated they need information on travel assistance was 47% amongst those who reside in remote or very remote areas compared to 7% of those in major cities, 21% of those in inner regional areas and 37% of those in outer regional areas.

For each of the topic areas related to practical help, respondents were more likely to indicate they needed information on the topic if they had been in active treatment in the four weeks prior to the survey than if they had received hormone therapy only or no recent treatment. Most notably, the proportion who sought information on managing the financial costs of breast cancer was 38% amongst those who had been in active treatment compared to 22% of those who had received hormone therapy only and 13% of those who had not received recent treatment.

Those who had received their most recent diagnosis in more recent years were more likely to require information on practical help. Of those who had been diagnosed in the 12 months prior to the survey:

- 39% had needed information on managing the financial costs of breast cancer (compared to 5 to 7% of those diagnosed more than five years prior)
- 24% had needed information on managing their return to work or changes to work (compared to 3 to 4% of those diagnosed more than five years prior)
- 21% had needed information on receiving practical help around the home (compared to 5% of those diagnosed more than five years prior)
- 22% had needed information on travel assistance related to breast cancer (compared to 5 to 6% of those diagnosed more than five years prior).

Respondents who had a high level of recent engagement with BCNA were more likely to have needed information on managing the financial costs of breast cancer in the year prior to the survey (33% needed this information) when compared to those with moderate (23%) or low (16%) engagement.

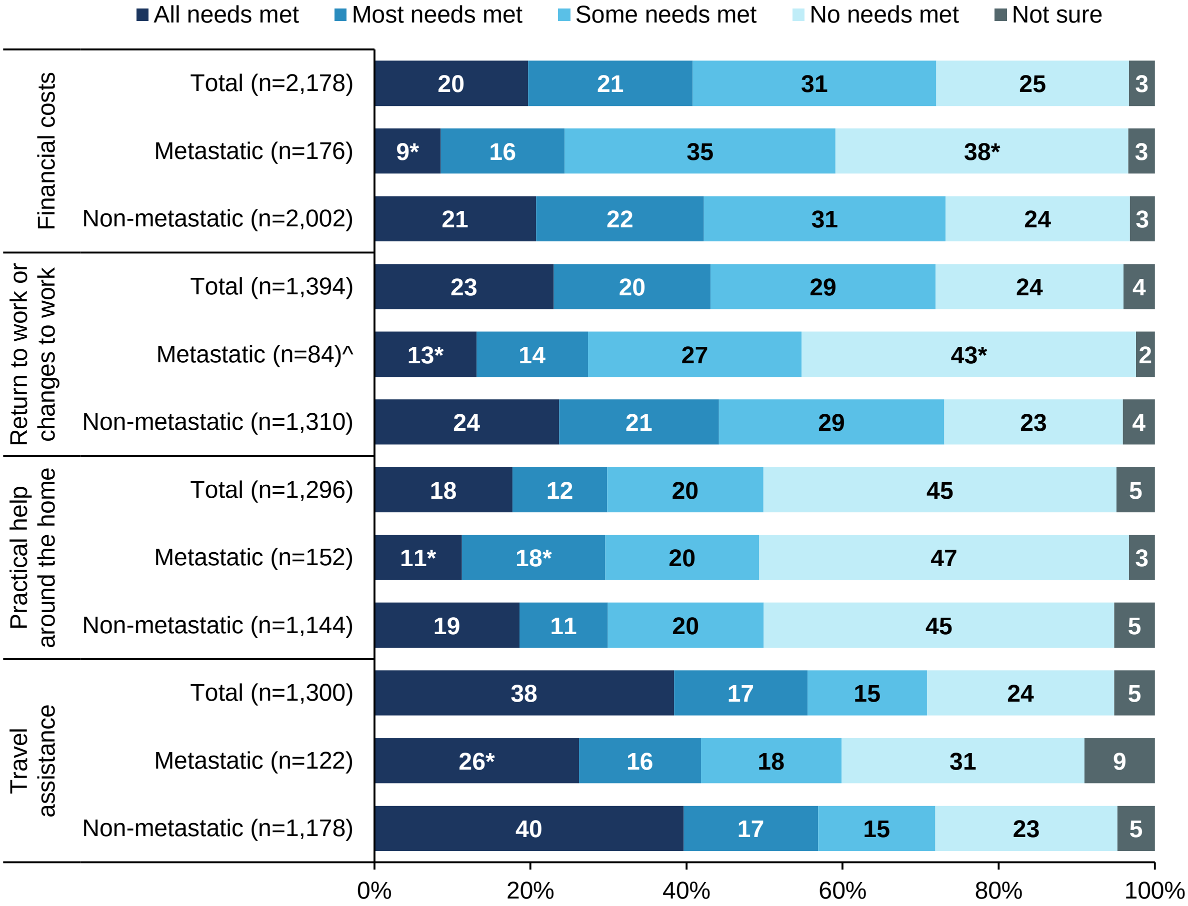
The proportion needing information related to practical assistance was higher in the 18 to 39 year age group across each of the four topic areas, and decreased in each increasing age group. For example, 36% of those aged 18 to 39 years required information related to managing the financial costs of breast cancer compared to 27% of those aged 40 to 49 years, 18% of those aged 50 to 59 years, 7% of those aged 60 to 69 years and 2% of those aged 70 years or over.

2.5.2. Whether needs related to practical help were met

For respondents who had needs related to practical help, their needs were more likely to have been met if they related to travel assistance. Approximately two-fifths (38%) of those needing information on travel assistance indicated that *all* their needs had been met. The proportion indicating *all* their needs had been met was lower for those needing information on practical help around the home (18%), managing the financial costs associated with breast cancer (20%) and managing the return to work or changes to work (23%). Those with metastatic breast cancer were less likely to indicate that *all* their informational needs had been met in each of the topic areas when compared to those with non-metastatic cancer.

Figure 12 Extent to which needs were met in relation to practical help

B2_2. To what extent have your information needs been met in this area?



Base: Respondents with informational and support needs ^Caution: Small sample size
* Significantly different to results for those with non-metastatic breast cancer

For those who needed information on managing the financial costs of breast cancer, the proportion who indicated *all* their needs were met was higher amongst those aged 70 years and over (37%) or 60 to 69 years (27%) when compared to those in the younger age groups (13% of those aged 18 to 39, 15% of those aged 40 to 49, and 16% of those aged 50 to 59). Amongst those who needed information on receiving practical help around the home, the proportion indicating *all* their needs had been met in this area was higher amongst those aged 18 to 39 years (22%) and in older age groups (24% of those aged 60 to 69 years and 30% of those aged 70 years or when compared to those aged 40 to 49 years (13%) and 50 to 59 years (10%).

Amongst respondents who needed information regarding travel assistance, the proportion indicating *all* their needs had been met was higher for those aged 70 years and over (52%) or 60 to 69 years (48%) when compared to those in the younger age groups (13% of those aged 18 to 39 years, 15% of those aged 40 to 49 years and 16% of those aged 50 to 59 years).

Amongst those who needed information related to travel assistance, respondents were more likely to indicate that *all* their needs had been met if they live in inner regional (44%), outer regional (57%) or remote/ very remote (46%) areas than those who reside in major cities (20%).

Those who had not received cancer treatment in the four weeks prior to the survey were more likely to say *all* their informational needs related to travel assistance had been met (46%) when compared to those receiving active treatment (33%) or hormone therapy only (38%).

Respondents who had been diagnosed with breast cancer in the 12 months prior to the survey were more likely to state that *all* their needs related to managing the financial costs of breast cancer had been met (25%) when compared to people whose most recent diagnosis had been over a year but less than two years prior (18%), more than two but less than five years prior (13%) or more than five but less than ten years prior (8%).

2.6. Other informational or support needs

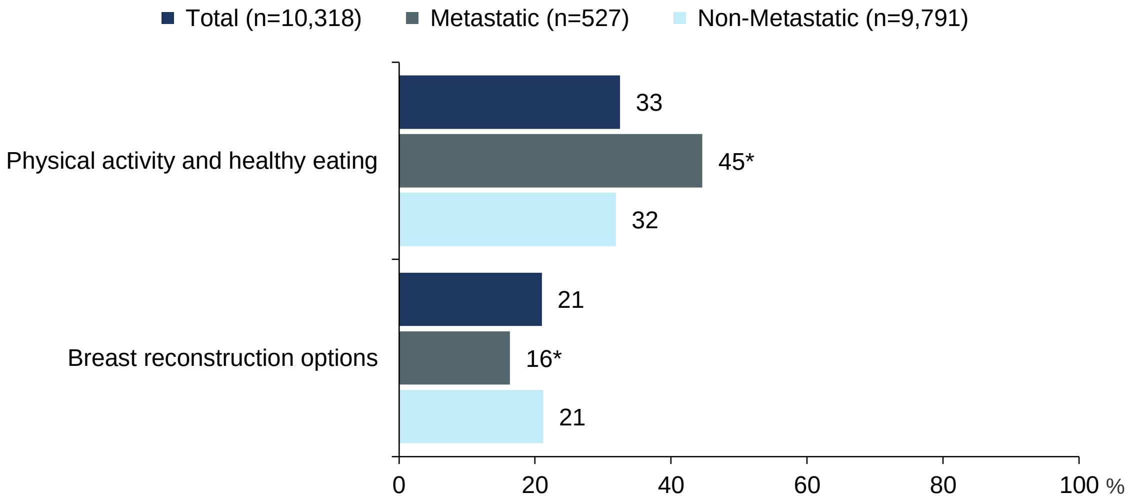
Respondents were asked whether they had needed any information on the following other topics related to breast cancer in the 12 months prior to the survey:

- the benefits of physical activity and healthy eating
- breast reconstruction options.

One-third of respondents (33%) had required information on the benefits of physical activity and healthy eating in the 12 months prior to the survey while approximately one-fifth (21%) had needed information about options for breast cancer reconstruction. Amongst those with metastatic breast cancer, the proportion requiring information on physical activity and healthy eating was higher (45%) than those with non-metastatic cancer (32%). However, as shown in Figure 13, those with metastatic cancer were less likely to require information on breast reconstruction (16%) than those with non-metastatic cancer (21%).

**Figure 13	Proportion with other informational or support needs**

B2_1. In the last 12 months, have you needed any information on the following topics…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Younger respondents were more likely to require information on breast reconstruction options with 58% of those aged 18 to 39 years needing information about the topic compared to 39% of those aged 40 to 49 years, 24% of those aged 50 to 59 years, 13% of those aged 60 to 69 years and 7% of those aged 70 years and over.

More of those aged 18 to 39 years (58%) required information related to the benefits of physical activity and healthy eating compared to those aged 40 to 49 years (45%), 50 to 59 years (37%), 60 to 69 years (238%) or 70 years and over (18%). Amongst those who speak a main language other than English, more required information on the benefits of physical activity and healthy eating (52%) than those whose main language is English (32%).

Amongst those receiving active treatment, 49% needed information on the benefits of physical activity and healthy eating and 31% needed information on breast reconstruction options. This compares to 36% of those receiving only hormone therapy treatment and 22% of those who had not received treatment in the four weeks prior to the survey who needed information on the benefits of physical activity and healthy eating and 22% of those receiving hormone therapy and 16% of those not receiving treatment who needed information on breast reconstruction options.

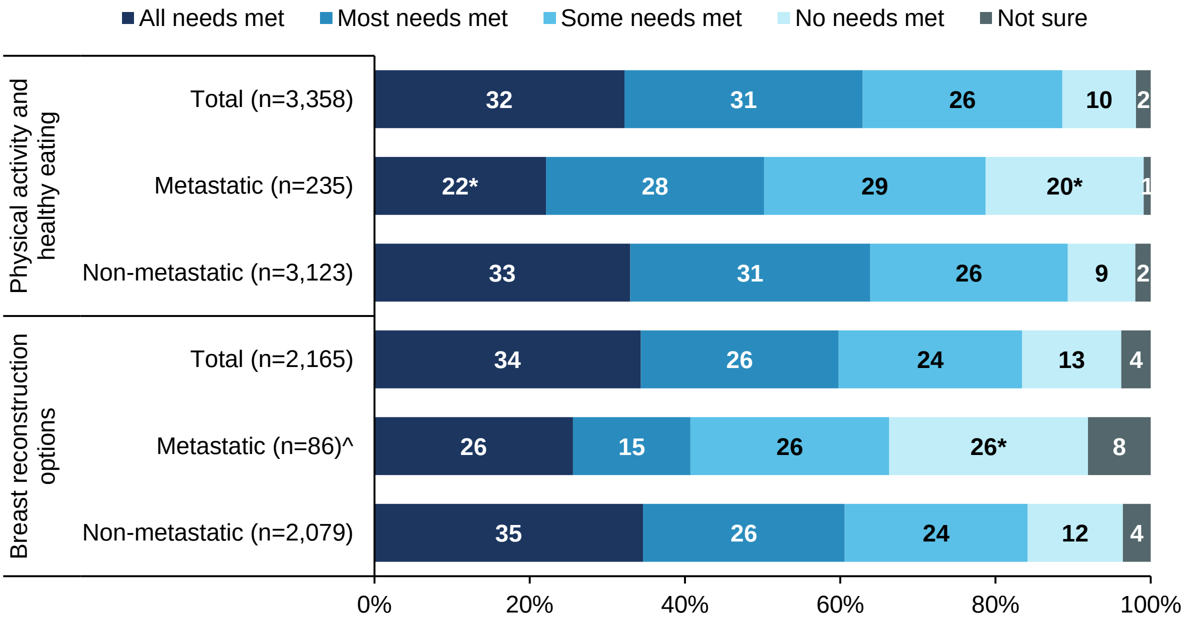
The proportion of respondents needing information on the benefits of physical activity and healthy eating was higher amongst those who had a high level of engagement with BCNA in the year prior to the survey (50%) compared to the proportion of those who had moderate (36%) or low (25%) levels of engagement.

2.6.1. Whether other informational or support needs were met

Approximately one-third of respondents indicated that *all* their informational needs had been met in relation to the benefits of physical activity and healthy eating (32%) and breast reconstruction options (34%). However, fewer of those with metastatic breast cancer indicated that all of their physical activity and healthy eating informational needs had been met (22%) compared to those with non-metastatic cancer (33%). Those with metastatic breast cancer were also more likely to indicate that none of their informational needs related to breast reconstruction had been met (26%) compared to those with non-metastatic cancer (12%).

Figure 14 Extent to which other informational or support needs were met

B2_2. To what extent have your information needs been met in this area?



Base: Respondents with informational and support needs ^Caution: Small sample size
* Significantly different to results for those with non-metastatic breast cancer

Amongst respondents who needed information regarding the benefits of physical activity and healthy eating, the proportion indicating *all* their needs had been met was higher among those aged 70 years and over (36%) and 60 to 69 years (38%) when compared to those in the younger age groups (28% of those aged 18 to 39 years, 28% of those aged 40 to 49 years and 30% of those aged 50 to 59 years). For the group needing information on physical activity and healthy eating, more of those whose main language is English (33%) said *all* their needs had been met than those whose main language is something other than English (15%).

Amongst those needing information on breast reconstruction options, those aged 18 to 39 years were more likely to indicate that *all* their needs were met in the past year (41%) compared to those aged 40 to 49 years (33%) and 50 to 59 years (32%).

For respondents who needed information on the benefits of physical activity and healthy eating, people who had been diagnosed in the 12 months prior to the survey were more likely to indicate that *all* their informational needs had been met in this area (38%) compared to those diagnosed more than 12 months but less than two years prior (29%), more than two but less than five years prior (26%) or more than five but less than 10 years prior (30%). For respondents who needed information related to breast reconstruction options, 38% of those diagnosed in the 12 months prior to the survey had needed information which was significantly higher than the 31% of those diagnosed more than two years but less than five years prior or more than five years but less than 10 years prior.

2.7. Support from cancer treatment team

2.7.1. From whom in the cancer treatment team support was required

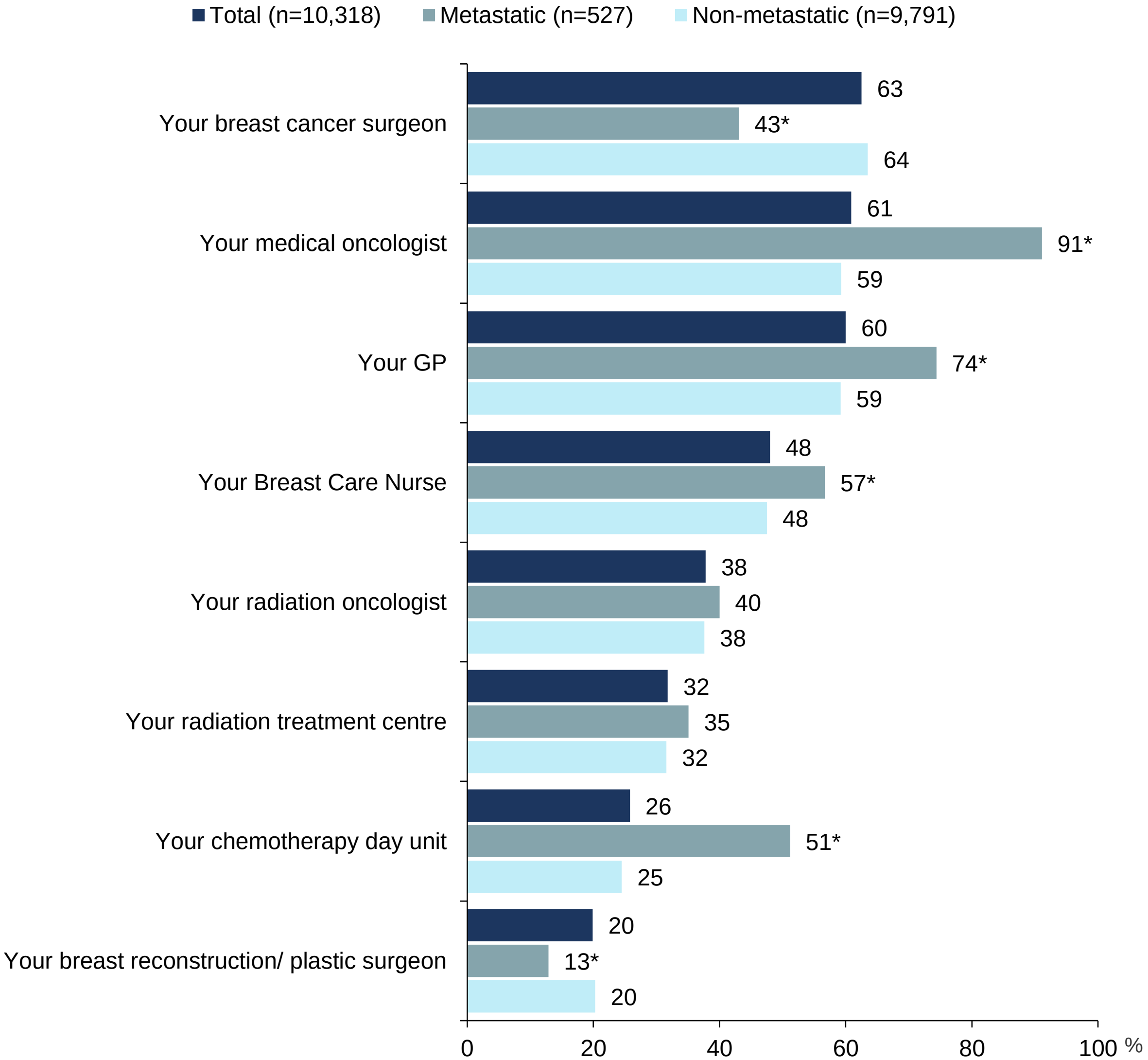
Preferred sources of information and support within the cancer support team varied dependent on whether the respondent had been diagnosed with metastatic or non-metastatic breast cancer.

The majority of those with metastatic breast cancer (91%) would have liked to receive information or support from their medical oncologist in the year prior to the survey. Other key sources of support for this group were their GP (74%), Breast Care Nurse (57%) and chemotherapy day unit (51%).

The main members of the cancer support team that people with non-metastatic breast cancer would have liked to receive information or support from were; their breast cancer surgeon (64%), their medical oncologist (59%), and their GP (59%).

Figure 15 From whom in the cancer treatment team support was required

C1_1. In the last 12 months, would you have liked to receive information and/or support from…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

In relation to subgroup variations, younger respondents (aged 18 to 39 years or 40 to 49 years), people who had been diagnosed more recently (in the 12 months prior to the survey or more than a year but less than 2 years prior) and those who had a high level of engagement with BCNA were more likely than their counterparts to indicate that they would you have liked to receive information and / or support from all members of the cancer treatment team.

2.7.2. Whether needs from the cancer treatment team support were met

For those respondents who needed support from their cancer treatment team, the proportions reporting *all* their needs had been met by the specific people or services relevant to them were high. Less than one in twenty respondents reported that none of their needs had been met by their chemotherapy day unit, breast cancer surgeon, radiation treatment centre, radiation oncologist, medical oncologist, or GP. This was true of respondents who had been diagnosed with metastatic or with non-metastatic breast cancer.

However, the proportions stating that none of their needs had been met increased to approximately one in ten respondents who had needed information or support from their Breast Care Nurse (10%) or breast reconstruction/ plastic surgeon (11%). For respondents with metastatic breast cancer, the proportion stating that none of their needs had been met by their Breast Care Nurse was 24% while the proportion indicating none of their needs had been met by their breast reconstruction/ plastic surgeon was higher at 34%.

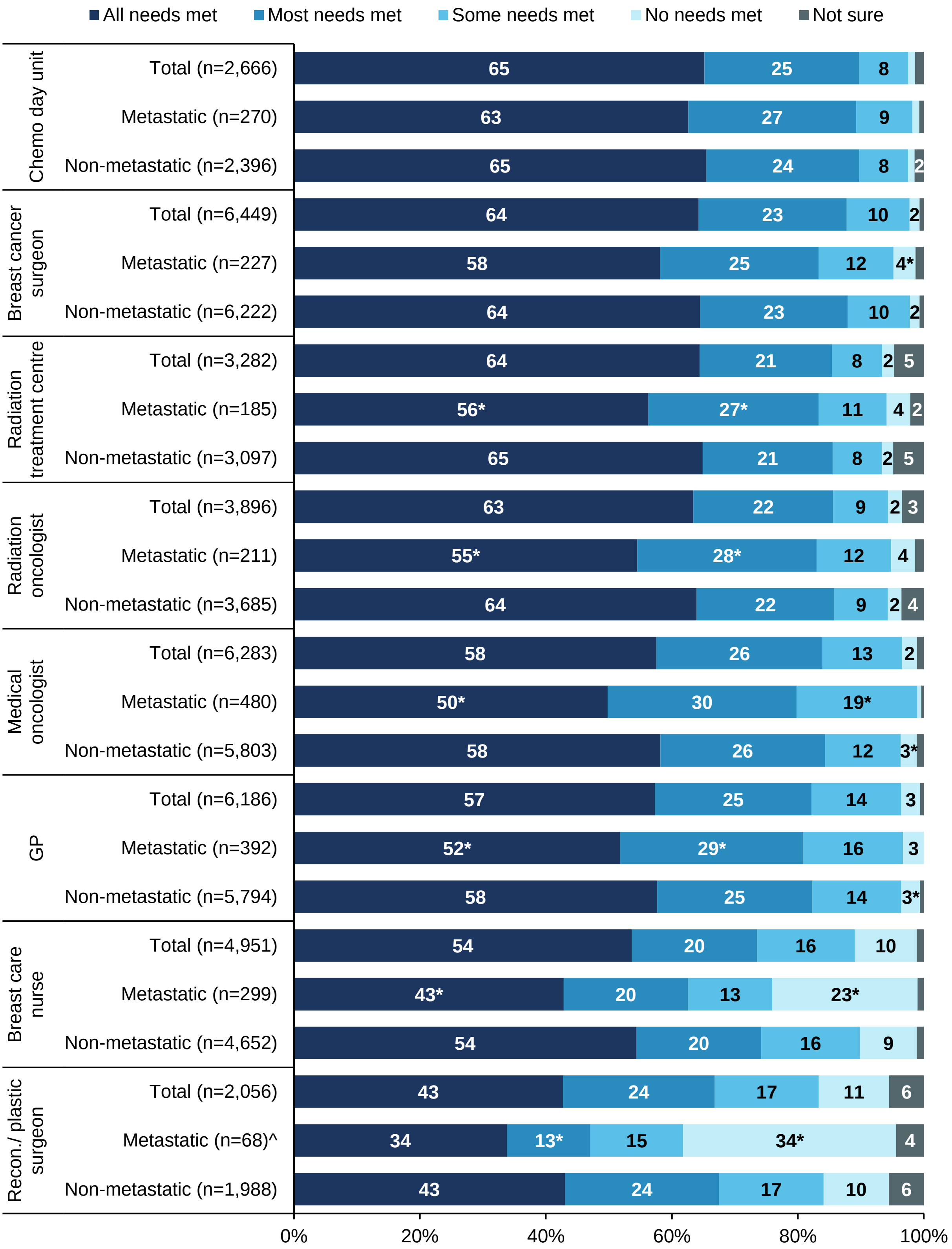
In addition, people with metastatic breast cancer were less likely than those with non-metastatic cancer to indicate that all of their informational and support needs had been met by particular members of their cancer treatment team. For those metastatic breast cancer patients who needed information or support from the following people or services in the last 12 months the proportions stating *all* their needs had been met were:

- 34% of those with needs from their breast reconstruction/ plastic surgeon (compared to 47% amongst those with DCIS/LCIS and 42% of those with EBC)
- 43% of those with needs from their Breast Care Nurse (compared to 56% amongst those with DCIS/LCIS and 54% of those with EBC)
- 50% of those with needs from their medical oncologist (compared to 57% amongst those with DCIS/LCIS and 58% of those with EBC)
- 55% of those with needs from their radiation oncologist (compared to 66% amongst those with DCIS/LCIS and 64% of those with EBC)
- 56% of those with needs from their radiation treatment centre (compared to 68% amongst those with DCIS/LCIS and 64% of those with EBC)
- 52% of those with needs from their GP (compared to 59% amongst those with DCIS/LCIS and 57% of those with EBC).

The full distribution of responses is provided in Figure 16.

**Figure 16	Extent to which needs from the cancer treatment team support were met**

C1_2. If you would have liked to receive information and/or support from the following people or services in the past 12 months, to what extent have these needs been met?



Base: Respondents with informational and support needs ^Caution: Small sample size
* Significantly different to results for those with non-metastatic breast cancer

Amongst those who needed information or support from their cancer treatment team, older respondents (aged 70 years or over) were more likely than younger respondents to report that all of their needs had been met by their:

- Medical oncologist (72% compared to 49% aged 18 to 39, 50% aged 40 to 49 years and 54% aged 50 to 59 years)
- Radiation oncologist (76% compared to 53% aged 18 to 39 and 54% aged 40 to 49 years)
- Radiation treatment centre (76% compared to 55% aged 18 to 39, 57% aged 40 to 49 years and 60% aged 50 to 59 years)
- Breast cancer surgeon (76% compared to 56% aged 18 to 39, 55% aged 40 to 49 years and 63% aged 50 to 59 years)
- Breast cancer nurse (65% compared to 49% aged 18 to 39, 49% aged 40 to 49 years and 51% aged 50 to 59 years)
- GP (68% compared to 46% aged 18 to 39, 52% aged 40 to 49 years and 54% aged 50 to 59 years).

Respondents who speak English as their main language were more likely than those who speak another main language to say *all* their needs were met by their breast cancer surgeon (65% compared to 49%), medical oncologist (58% compared to 45%), radiation oncologist (64% compared to 47%), radiation treatment centre (65% compared to 49%) and their GP (58% compared to 45%).

For those who needed information or support in the 12 months prior to the survey, respondents who had received most of their treatment in the private sector were more likely than those who had gone through the public sector to say *all* their needs had been met by their breast cancer surgeon (68% compared to 60%), breast reconstruction/ plastic surgeon (48% compared to 36%) and their medical oncologist (61% compared to 54%). Those who had mainly used the public section were more likely to report *all* their needs had been met by their radiation treatment centre (67% compared to 62%) and their Breast Care Nurse (56% compared to 52%).

Respondents who needed information or support from their GP in the year prior to the survey were more likely to report that *all* their needs had been met if they reside in a major city (58%) or inner regional area (59%) than those in remote or very remote areas (49%). Those with needs from a breast reconstruction or plastic surgeon more often indicated that all their needs were met if they reside in a major city (45%) than those in an outer regional (34%) or rural/ very remote area (36%).

The proportions reporting *all* their needs had been met by their cancer treatment team were higher amongst those diagnosed more than five years prior to the survey for those who needed information or support from a:

- breast cancer surgeon (*all* needs met for 72% of those diagnosed more than 10 years prior and 68% of those diagnosed more than five but less than 10 years prior compared to 62 to 64% of those with a more recent diagnosis)
- medical oncologist (*all* needs met for 65% of those diagnosed more than 10 years prior and 63% of those diagnosed more than five but less than 10 years prior compared to 54 to 57% of those with a more recent diagnosis).

Those with a more recent diagnosis were more likely to have had *all* their needs met by their:

- GP (*all* needs met for 62% of those diagnosed in the year prior to the survey compared to 55% of those diagnosed one but less than two years prior, 54% of those diagnosed more than two but less than five years prior and 55% of those diagnosed more than 5 but less than 10 years prior)

- Breast Care Nurse (*all* needs met for 58% of those diagnosed in the year prior to the survey compared to 52% of those diagnosed one but less than two years prior, 47% of those diagnosed more than two but less than five years prior and 48% of those diagnosed more than 5 but less than 10 years prior).

2.8. Support from other support services

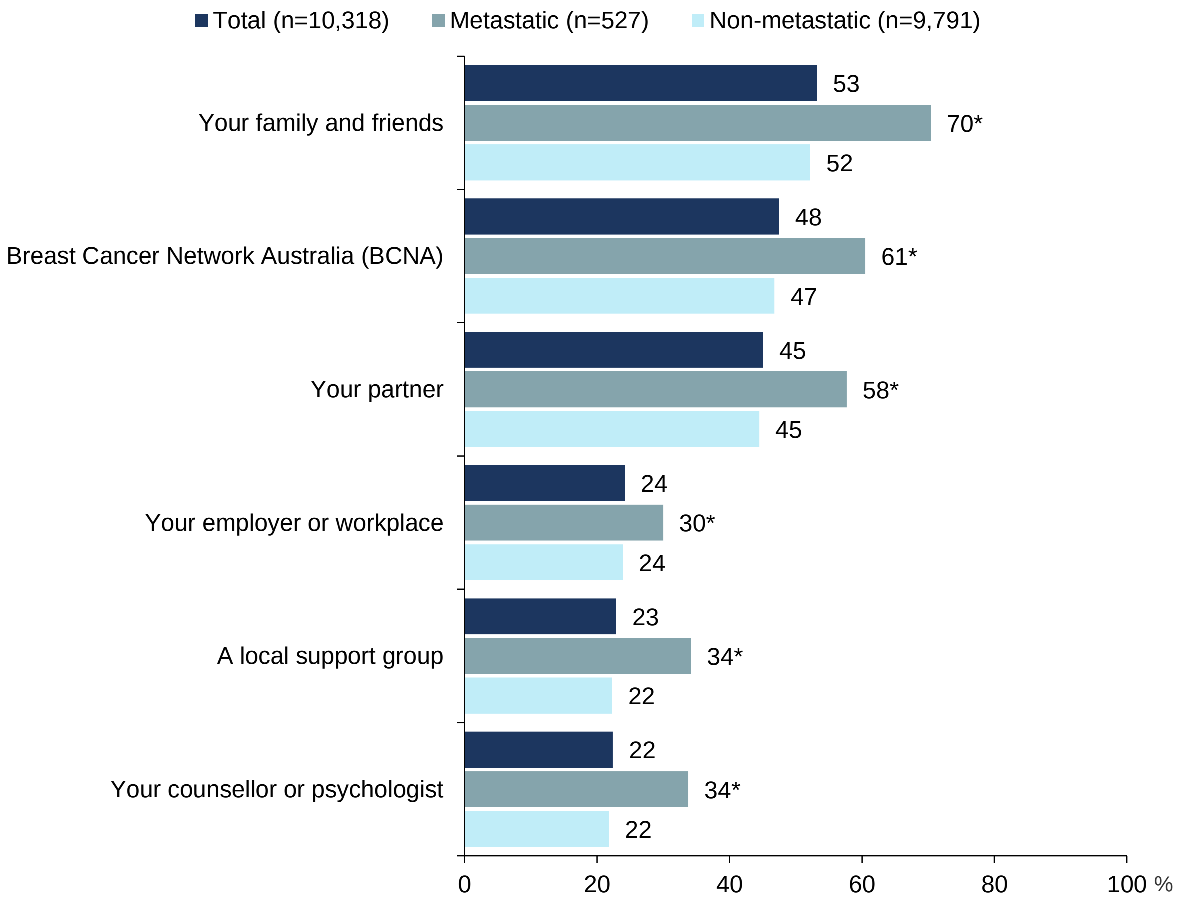
2.8.1. From whom other support was required

In the year prior to the survey, approximately half of all respondents had needed support from outside of their cancer treatment team, with 53% indicating they needed information or support from family and friends, 45% from their partner and 48% from BCNA. Comparatively, approximately one-quarter of respondents had needed information or support from their employer or workplace (24%), a local support group (23%), a counsellor or psychologist (22%).

Respondents with metastatic breast cancer were more likely than those with non-metastatic cancer to have needed information or support from each of the sources presented.

Figure 17 From which other sources support was required

C1_2. If you would have liked to receive information and/or support from the following people or services in the past 12 months, to what extent have these needs been met?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Across different sources of information or support, subgroup variations were consistent. Younger respondents (aged 18 to 39 years or 40 to 49 years), people who had been diagnosed more recently (in the 12 months prior to the survey or more than a year but less than 2 years prior) and those who had a high level of engagement with BCNA were more likely than their counterparts to indicate that they would you have liked to receive information and / or support from all members of the cancer treatment team.

Respondents were more likely to report they had needed information or support from BCNA in the year prior to the survey if they:

- had been diagnosed in the 12 months prior to the survey (74%) or more than 12 months but less than two years prior (61%) (compared to 38% of those diagnosed two to five years prior, 26% of those diagnosed five to 10 years prior and 22% of those diagnosed more than 10 years prior)
- were receiving active treatment (70%) or hormone therapy only (52%) (compared to 34% of those who had not received treatment in the four weeks prior to the survey)
- were aged 18 to 39 years (65%) or 40 to 49 years (60%) compared to those aged 50 to 59 years (49%), 60 to 69 years (45%) or 70 years of age or over (35%)
- speak a main language other than English (57%) compared to those whose main language is English (47%).

2.8.2. Whether needs from other support services were met

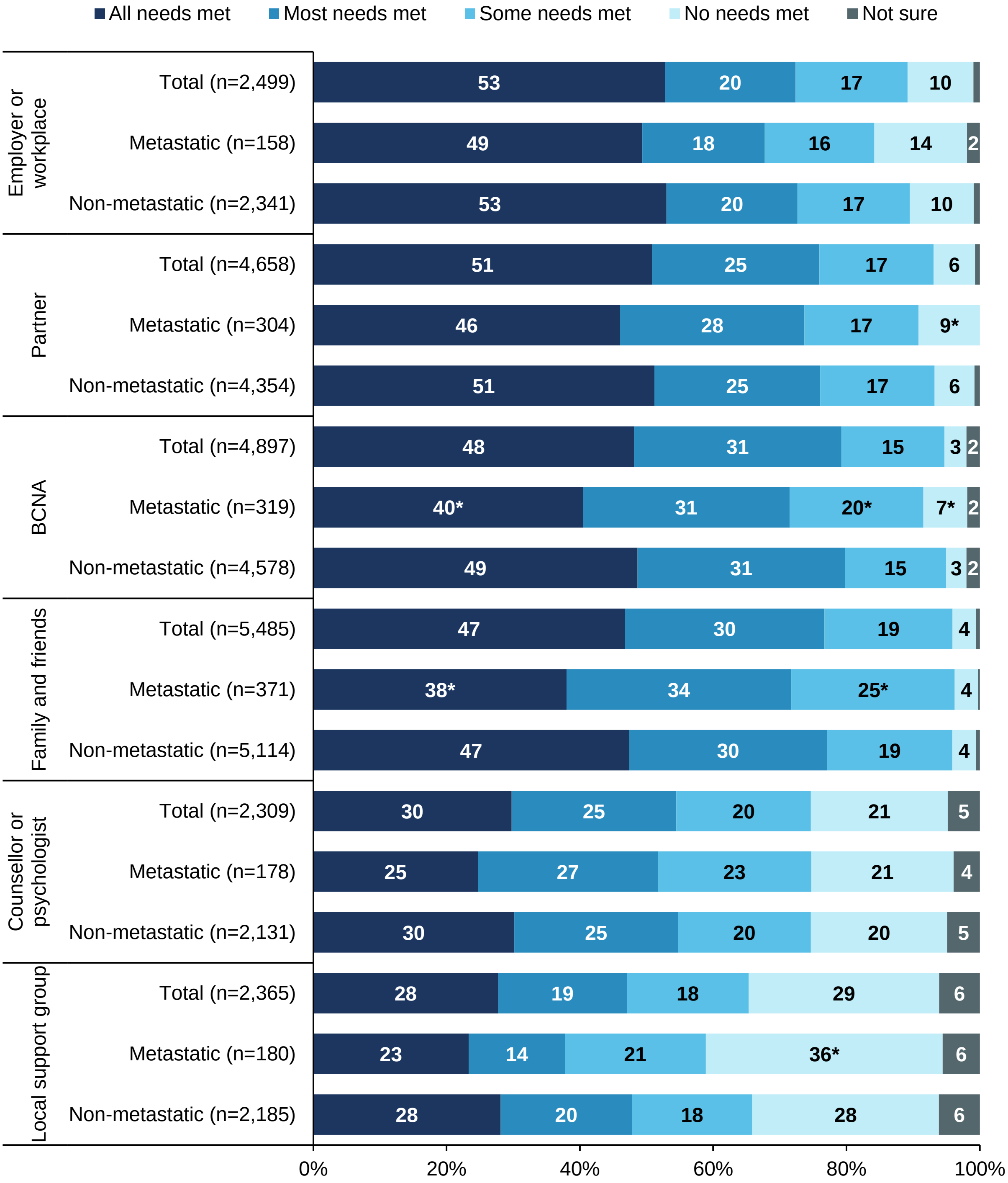
Amongst those who had needed information or support from other services in the 12 months prior to the survey, approximately half indicated that *all* their needs had been met by their employer or workplace (53%), their partner (51%), BCNA (48%) or their family or friends (47%). For those needing support from these sources, no more than one in ten indicated that none of their needs had been met.

The proportions indicating that *all* their needs had been met were lower for those needing this from a local support group (28%) or a counsellor or psychologist (30%). Respondents were also more likely to indicate that *none* of their informational or support needs had been met by a local support group (29%) or a counsellor or psychologist (21%).

Amongst metastatic breast cancer patients who had needed information or support from BCNA in the 12 months prior to the survey, the proportion indicating *all* their needs were met was lower (40%) when compared to those with non-metastatic cancer (49%). Respondents with metastatic breast cancer were also more likely to indicate that BCNA had met none of their needs (7%) than those with non-metastatic cancer (3%).

Figure 18 Extent to which needs from the cancer treatment team support were met

C1_2. If you would have liked to receive information and/or support from the following people or services in the past 12 months, to what extent have these needs been met?



Base: Respondents with informational and support needs ^Caution: Small sample size
* Significantly different to results for those with non-metastatic breast cancer

Amongst those who had needed information or support from BCNA in the year prior to the survey, the proportion who indicated that *all* their needs had been met was higher amongst:

- those who had been diagnosed in the 12 months prior to the survey (52%), more than ten years prior (51%) or more than five but less than ten years prior (48%) compared of those diagnosed more than one but less than two years prior (44%) or two to five years prior (43%)
- those aged 70 years of age or over (62%) or 60 to 69 years (53%) compared to 34% of respondents aged 18 to 39 years, 41% of those aged 40 to 49 years and 44% of those aged 50 to 59 years
- those who speak a main language other than English (57%) compared to those whose main language is English (47%)
- those who live in a major city (47%), inner regional (52%) or outer regional area (49%) compared to those who live in remote or very remote areas (37%).

Of those in the workforce, the proportion that felt *all* their needs had been met by their employer or workplace were higher amongst workers aged 60 to 69 years (60%) or 70 years and over (62%) than younger employees (43% of those aged 18 to 40 years). People who had been diagnosed more recently were more likely to have had all of their information or support needs met by their work place (60% of those diagnosed in the 12 months prior to the survey compared to 50% of those diagnosed more than one but less than two years prior, 47% of those diagnosed more than two but less than 5 years prior, 42% of those diagnosed more than 5 abut up to 10 years prior and 46% of those diagnosed more than 10 years prior). The proportion indicating *all* their needs had been met by their employer or workplace was also higher for those who had received active treatment in the four weeks prior to the survey (57%) compared to those receiving hormone therapy only (51%) or no recent treatment (50%).

People who reside in inner regional (34%) and outer regional areas (32%) were more likely to indicate that all of their needs had been met by a local support group for those with breast cancer compared to residents of major cities (25%) or remote / very remote areas (27%). Amongst those who needed information or support from a local support group in the year prior to the survey, 58% indicated *all* their needs had been met if they had received their diagnosis more than 10 years earlier compared to 34% of those diagnosed more than five but less than 10 years prior and 23 to 28% of those diagnosed in the five years prior to the survey.

Older respondents were more likely to indicate that *all* their informational and support needs had been met by their partner (62% of those aged 70 years and over and 56% of those aged 60 to 69 years) or family and friends (60% of those aged 70 years and over and 52% of those aged 60 to 69 years) compared to 45 to 48% of those aged 18 to 59 years indicating their partner had met *all* their needs and 38 to 42% of those aged 18 to 59 years indicating their family and friends had done so.

3. Recent support experiences related to *State of the Nation* best practices

This section measures respondent experience against key best practices outlined within the State of the Nation Framework. For this purpose, respondents were asked to rate their agreement with statements aligned with the best practices within the Framework. Where respondents have agreed with a statement, this indicates that the best practice associated with that element of the Framework had been achieved. Where respondents have disagreed, this points to areas in the Framework that may require work to ensure best practices are achieved.

Respondents were also asked what support they had received during their treatment, from whom they had received support, and whether their support needs had been met. Dependent upon their breast cancer type and the progression of the disease, respondents were either asked about the support they had received following a more advanced diagnosis or during their recovery.

3.1. Support received during treatment

All respondents were asked their agreement with the following statements related to their experience during treatment:

- I was given enough information to make or understand important treatment decisions
- I have had as much contact with a Breast Care Nurse as I needed
- I feel I have been heard by my medical team
- I received treatment that took my lifestyle into consideration
- I have been treated as a whole person not just someone with cancer
- I had opportunities to hear about the experiences of others who have been through the same thing.

Those who determined that the statement was not relevant them could select ‘does not apply’ to continue to the next statement without provide an agreement rating. Thus, responses reflect those of people who felt the statements were applicable to their treatment experience.

For each of the statements, agreement (proportion who ‘strongly agree’ or ‘agree’) was quite high and outweighed disagreement (proportion who ‘disagree’ or ‘strongly disagree’).

As demonstrated in Figure 19, highest agreement was recorded for the following statements:

- ‘I was given enough information to make or understand important treatment decisions’ (83% agreed while 8% disagreed)
- ‘I feel I have been heard by my medical team’ (81% agreed while 7% disagreed)
- ‘I have been treated as a whole person not just someone with cancer’ (79% agreed while 8% disagreed).

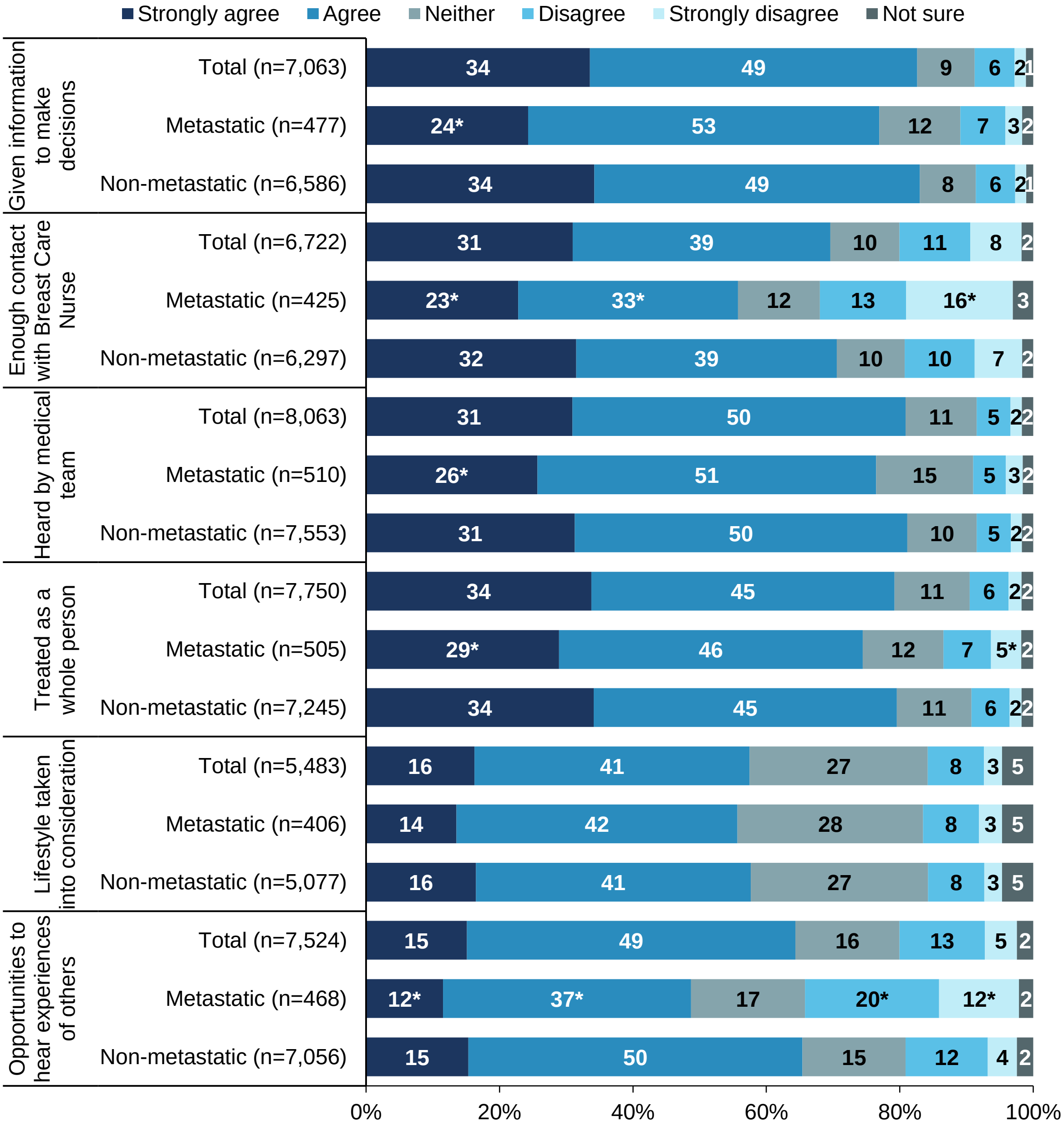
However, for each of these statements, the proportion who ‘strongly agreed’ was lower amongst respondents with metastatic breast cancer when compared to those with non-metastatic cancer.

The most notable differences between people with metastatic and non-metastatic breast cancer were the higher proportion who disagreed with the remaining statements:

- ‘I had opportunities to hear about the experiences of others who have been through the same thing’ (32% with metastatic cancer disagreed, compared to 17% of those with non-metastatic cancer)
- ‘I have had as much contact with a Breast Care Nurse as I needed’ (29% with metastatic cancer disagreed, compared to 18% of those with non-metastatic cancer)
- ‘I have been treated as a whole person not just someone with cancer’ (12% with metastatic cancer disagreed, compared to 7% of those with non-metastatic cancer).

Figure 19 Level of agreement that support was received during treatment

B3. Based on your experience over the last 12 months, to what extent do you agree or disagree with the following statements…?



Base: Respondents indicating the statement was relevant to their situation

The most consistent subgroup variations in agreement with statements related to receiving support during cancer treatment were observed by age of respondent and time since diagnosis. Subgroup variations in other areas such as state of residence and the system through which most treatment was received varied across the statements.

Respondents from the 60 to 69 year and 70 years and over age groups were more likely to agree with each of the statements when compared to those aged 50 to 59, 40 to 49 and, for some statements, also those aged 18 to 39 years. For example, amongst those who rated their agreement that, ‘I have been treated as a whole person not just someone with cancer’, the proportion who agreed was 85% amongst those aged 70 years and over, and 81% of those aged 60 to 69 years of age. This compared to 76% of those aged 18 to 39 years, 75% of those aged 49 to 50 years and 78% of those aged 50 to 59 years.

Those who had received their most recent diagnosis in the 12 months prior to the survey were significantly more likely than those who had been diagnosed more than one year prior to agree with all but one of the statements. Agreement with the statement, ‘I had opportunities to hear about the experiences of others who have been through the same thing’ was higher amongst those diagnosed more than 10 years prior to the survey (79%, compared to 61% of those diagnosed in the 12 months prior to the survey).

For two of the statements, agreement reduced with remoteness. Agreement was higher amongst those in major cities for the following statements when compared to those in remote or very remote areas:

- ‘I was given enough information to make or understand important treatment decisions’ (84% compared to 68%)
- ‘I feel I have been heard by my medical team’ (82% compared to 76%).

The proportion of respondents who agreed with the statement, ‘I feel I have been heard by my medical team’ was also higher in some of the larger States and Territories. A significantly higher proportion of residents from Victoria (84%), New South Wales (81%), South Australia (82%), and Queensland (79%) agreed with the statement when compared to those in the Northern Territory (67%).

People who had received the majority of their treatment through the public sector were more likely to agree that, ‘I have had as much contact with a Breast Care Nurse as I needed’ (72% compared to 68%). Those who had received most of their treatment through the private system were more likely to agree with the following statements:

- ‘I feel I have been heard by my medical team’ (84%, compared to 77%)
- ‘I was given enough information to make or understand important treatment decisions’ (84%, compared to 81%)
- ‘I had opportunities to hear about the experiences of others who have been through the same thing’ (66%, compared to 63%).

Respondents who speak another main language other than English were more likely to agree that, ‘I received treatment that took my lifestyle into consideration’ (67%) compared to those whose main language is English (57%).

The proportion reporting, ‘I had opportunities to hear about the experiences of others who have been through the same thing’ was significantly higher amongst those who had a high (73%) or moderate (66%) level of engagement with BCNA in the year prior to the survey than amongst those with low engagement (59%).

3.2. Support received to live well

All respondents were asked their agreement with the following statements regarding whether they had received support to live well during their experience of breast cancer:

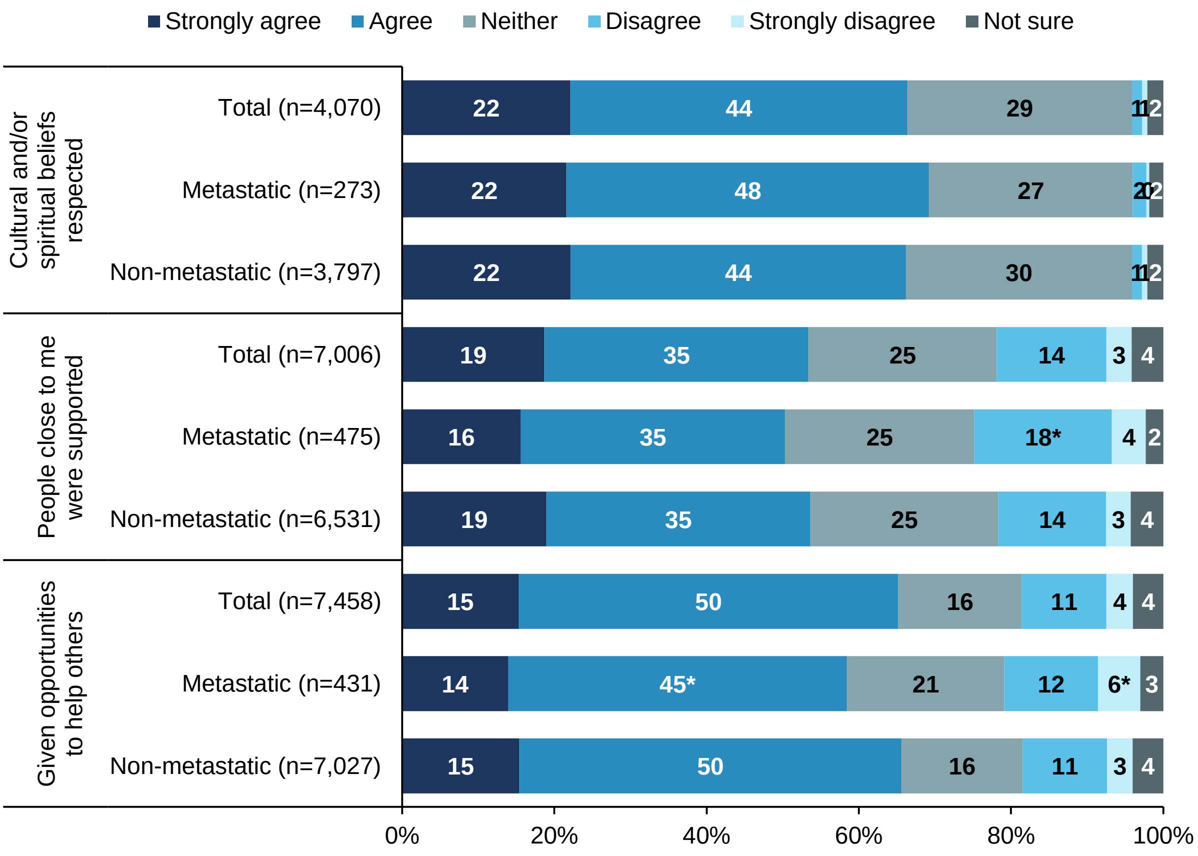
- I was given opportunities to donate my time or money to help others with breast cancer
- My cultural and/or spiritual beliefs were respected
- I feel the people close to me are supported.

As shown in Figure 20, amongst those who indicated the statement applied to them, very few disagreed (‘disagree’ or ‘strongly disagree’) that, ‘My cultural and/or spiritual beliefs were respected’ was relevant to them (2% disagreed, 66% agreed and the remainder neither agreed nor disagreed or were unsure).

Comparatively, the proportion who disagreed was higher for the other two statements. However, more agreed than disagreed that, ‘I was given opportunities to donate my time or money to help others with breast cancer’ (65% compared to 15%) and, ‘I feel the people close to me are supported’ (53% compared to 18%). The proportion who disagreed that the people close to them are supported was higher amongst those who had been diagnosed with metastatic breast cancer (23%) than those with non-metastatic cancer (17%).

Figure 20 Level of agreement that support was received to live well

B3. Based on your experience over the last 12 months, to what extent do you agree or disagree with the following statements…?



Base: Respondents indicating the statement was relevant to their situation
* Significantly different to results for those with non-metastatic breast cancer

For two of the statements, older respondents recorded higher levels of agreement than those in the youngest three age groups. More specifically:

- 75% of those aged 70 years and over and 70% of those aged 60 to 69 years agreed that, ‘I was given opportunities to donate my time or money to help others with breast cancer’ compared to 46% of those aged 18 to 39 years, 56% of those aged 40 to 49 and 63% of those aged 50 to 59 years
- 62% of those aged 70 years and over and 57% of those aged 60 to 69 years agreed that, ‘I was given opportunities to donate my time or money to help others with breast cancer’ compared to 49% of those aged 18 to 39 years, 50% of those aged 40 to 49 and 49% of those aged 50 to 59 years.

However, agreement that, ‘My cultural and/or spiritual beliefs were respected’ was higher amongst respondents in the age groups at the extremities with 78% of those aged 18 to 39 and 72% of those aged 70 years and over agreeing with this statement. This compares to 65% of those aged 40 to 49, 64% of those aged 50 to 59 years and 66% of those aged 60 to 69 years.

Agreement was higher amongst those whose main language is something other than English that their cultural and / or spiritual beliefs (85%) and the people close to them had been supported (74%) when compared to those whose main language is English (66% and 53% respectively). The proportion who agreed, ‘I feel the people close to me are supported’ was higher amongst those who had received active treatment in the four weeks prior to the survey (60%) compared to those who had only received hormone therapy (51%) or had no recent treatment (52%).

In terms of the time since their diagnosis, respondents were more likely to agree that people close to them had been supported if they had been diagnosed within 12 months of completing the survey (59% agreed) or more than 10 years prior (61%) than those who had been diagnosed in between these two extremities (49 to 52%).

Agreement that, ‘I was given opportunities to donate my time or money to help others with breast cancer’ increased the longer it has been since most recent diagnosis: 50% of those diagnosed within the 12 months prior to the survey agreed with the statement compared to 59% of those diagnosed more than a year but less than two years prior, 72% of those diagnosed more than 2 years but less than five years prior, 76% of those diagnosed more than five but less than 10 years prior and 83% of those diagnosed more than 10 years prior to the survey. Agreement with this statement was also higher for those who had received their treatment mainly through the private sector (68%) compared to those in the public system (62%).

The proportion of respondents who agreed that they had been given opportunities to donate their time or money to help others was significantly higher amongst those who had a high (72%) or moderate (67%) level of engagement with BCNA in the year prior to the survey than amongst those with low engagement (61%).

3.3. Support in follow up

Respondents who had been diagnosed with early breast cancer or DCIS/LCIS (referred to here as non-metastatic breast cancer) were asked to rate their agreement with the following statements:

- I was provided with a long-term follow-up care plan after finishing treatment
- I am worried that my cancer might come back (or recur).

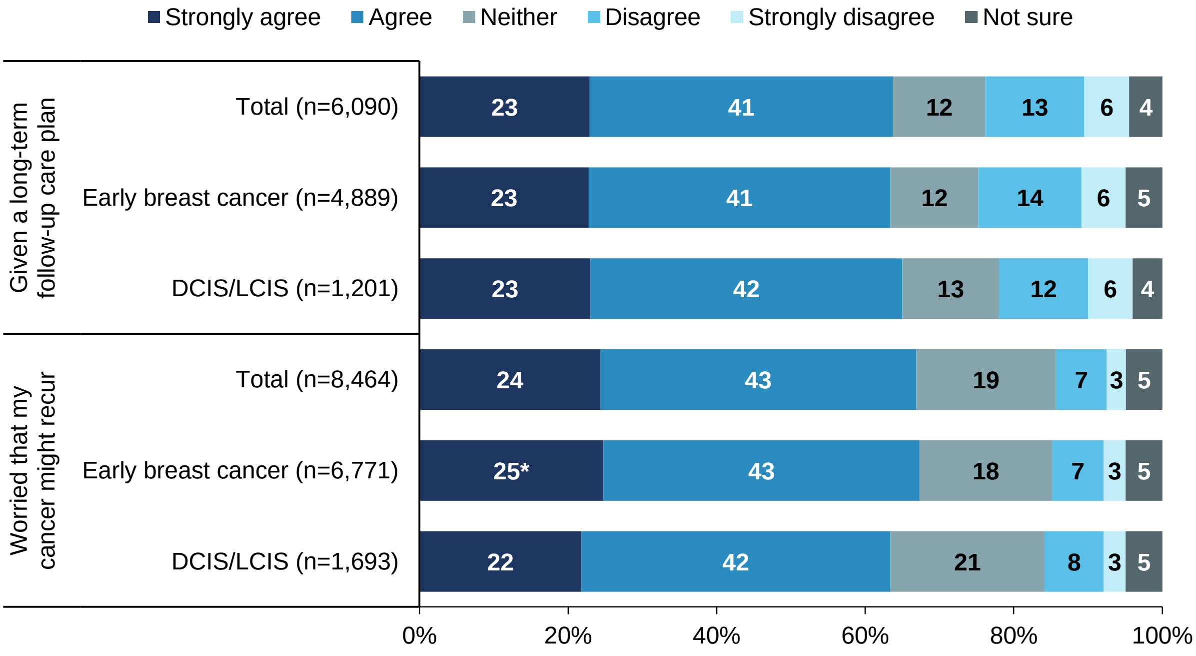
Throughout this section, concern about whether their cancer might recur was relevant to all those with non-metastatic breast cancer. However, discussion related to being provided with a long-term follow-up care plan excludes respondents who thought this was not relevant to their situation.

Of those who felt the statement applied to their situation, approximately two-thirds of those with early breast cancer (64%) and those with LCIS/DCIS (64%) agreed that they were provided with a long-term follow-up care plan after finishing treatment.

Similar proportions of those with early breast cancer (68%) or LCIS/DCIS (64%) agreed that they were worried about the possibility of their cancer recurring.

Figure 21 Level of agreement that support was received during recovery

B3. Based on your experience over the last 12 months, to what extent do you agree or disagree with the following statements…?



Base: Respondents with non-metastatic breast cancer
* Significantly different to results for those with DCIS/LCIS

For respondents with non-metastatic cancer, the proportion who agreed that they had been provided with a long-term follow-up care plan after finishing treatment increased with every increase in the age group of respondents. Approximately three-quarters of those aged 70 years and over (74%) indicated they had been given a long-term care plan compared to 56% of those aged 18 to 39 years, 57% of those aged 40 to 49 years, 62% of those aged 50 to 59 years and 67% of those aged 60 to 69 years.

Amongst those non-metastatic breast cancer patients, agreement with the statement, ‘I am worried that my cancer might come back (or recur)’ was higher for younger respondents aged 18 to 39 years (81%), 40 to 49 years (79%), or 50 to 59 years (72%), than for older respondents aged 60 to 69 years

(63%) or 70 years and over (48%). Concern about their cancer recurring was lower for those whose most recent diagnosis had been ten years prior to them completing the survey (54% agreed) compared to those who had been diagnosed in the last five years (68 to 69%).

Across states, there was some variation in whether respondents had been provided with a long-term follow-up care plan. Residents of Victoria and New South Wales were more likely to agree that they had been provided with a long-term follow-up care plan than residents of some of the other States and Territories: 67% of those in Victoria and 65% of those in New South Wales agreed compared to 57% of those in the Australian Capital Territory, 60% of those in South Australia, and 63% of those in Queensland.

Those with higher levels of engagement with BCNA services were more likely to agree that they were worried their cancer may come back (76% amongst highly engaged and 71% amongst moderately engaged compared to 61% of those who had low engagement with BCNA).

3.4. Support specific to those with metastatic breast cancer

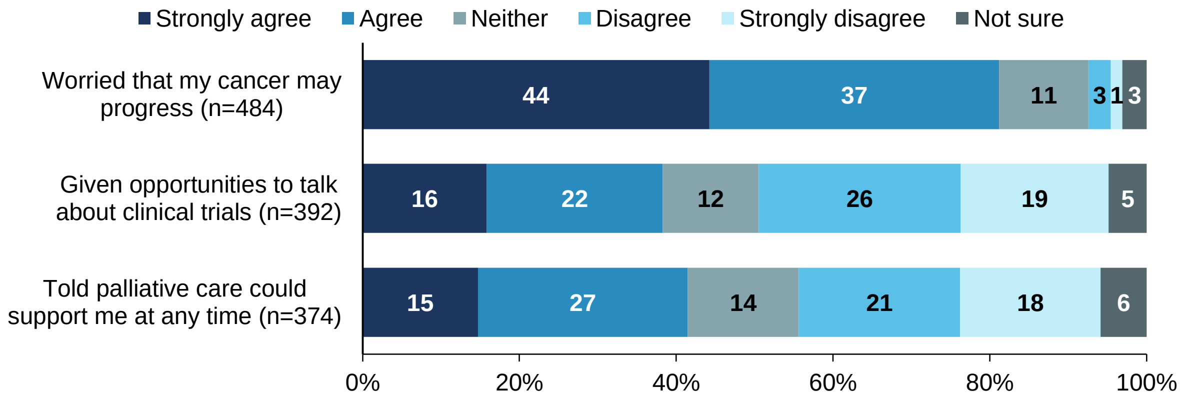
Respondents who indicated that they had been diagnosed with metastatic breast cancer were asked their agreement with the following statements:

- ‘I was informed that palliative care could support me at any time and not just at the end of my life’
- ‘I was given opportunities to talk about clinical trials that might be relevant to me’
- ‘I am worried that my cancer may spread further (or progress)’.

Amongst those with metastatic breast cancer, a high proportion agreed that they were worried their cancer would spread further or progress (81% agreed and 4% disagreed). Comparatively, amongst those who felt the question was appropriate to their situation, similar proportions of respondents agreed (41%) and disagreed (39%) that they were informed about the availability of palliative care while more disagreed (45%) than agreed (38%) that they were given opportunities to talk about potentially relevant clinical trials. The full breakdown of responses is provided in Figure 22.

Figure 22 Level of agreement that support was received during later stages

B3. Based on your experience over the last 12 months, to what extent do you agree or disagree with the following statements…?



Base: Respondents with metastatic breast cancer

Due to the small number of respondents who rated their agreement with each statement, significant differences were not observed across subgroups.

3.5. How BCNA can help

An open-ended verbatim question was asked of all respondents to determine what their main needs were during their experience of breast cancer. Overall, respondent's informational and support needs were varied. However, some themes were observed across responses. In terms of general support requirements, most related to emotional support or support specifically from the treatment team or during treatment. Also common was a need for practical help or support during rehabilitation while some wanted more support for their partner or family. Informational needs were common and tended to relate to increasing the understanding of their specific cancer type and progression, treatment options, lifestyle impact, and managing change or side effects.

Due to the quantity of responses received (n=8,907) and available budget, a sample of verbatim responses (approximately 16%, n=1,466) were coded to develop key themes demonstrating respondent's main needs. These are provided in Figure 23 (over page). Examples of verbatim responses to each open-ended question are provided in Appendix 5 to add context to the following summary information.

Figure 23 Main needs during experience of breast cancer

B4. Overall, thinking about your experiences of breast cancer, what were your main needs?

Emotional and other support

General support (23%)
Emotional support (25%)
Counselling / mental health support (9%)
Respect / understanding / patience (7%)
Reassurance (5%)

Practical help

Financial help (9%)
Help with work (4%)
Help at home (3%)

Information and explanations

General information (30%)
Information on treatment options/ side effects (12%)
Understanding my specific cancer / outcomes (9%)

Cancer treatment team

Breast Care Nurse (27%)
Surgeon/ other specialists (11%)
Doctors (8%)
Other medical staff (6%)

Help to get better and live well

Effective treatment (20%)
Assistance with rehabilitation / recovery (11%)
Timely access to treatment / appointment times (3%)
Lifestyle / management recommendations (3%)

Family and friends

Support from family (13%)
Support from friends (6%)
Support for family (6%)

A follow up verbatim question asked respondents which if any of these needs had not been met. Following coding of a sample of responses (approximately 17%, n=1,091), approximately two-thirds indicated that all their stated needs had been met during their experience of breast cancer. However, the remainder recorded gaps that spanned the six main themes. The main areas where respondents felt their needs had not been met were in the provision of emotional support and, less so, financial support.

Key areas where gaps were identified, and examples of the reasons respondents gave for their needs not being met, include:

Emotional support: Needed someone to talk to, someone to listen to my fears, to be asked if I was okay, support for my anxiety, empathy and understanding, wanted to feel less alone.

Financial help: Needed financial assistance, financial support, financial planning advice, a financial roadmap, more affordable treatment options, advice on how to minimise cost.

Information on treatment options / side effects: Needed to know more about specific side effects, more details on my treatment options, to understand my options, to know how my treatment is progressing, to understand what to expect from treatment, to know what to expect after surgery, to know what my cancer mean for me long term.

Doctors: Needed more time with doctor not just nurses, more support from my doctor, for my doctor to be more caring, better availability of doctors, for my doctor to know what was going on.

Breast Care Nurses: Needed more or better access to a Breast Care Nurse, wanted them to answer my questions, to be more helpful, to provide psychological support, to listen to me, wanted a dedicated/consistent Breast Care Nurse.

Counselling / mental health support: Needed help with my self-esteem, with coping with the shock after diagnosis, with coping during treatment, with managing my anxiety, with referrals to counsellors, should have been encouraged to seek support.

Support for family: Emotional support for my partner or family, support and care for my children, help at home for my family, support to keep household routines.

4. BCNA products and services

4.1. Product and service awareness

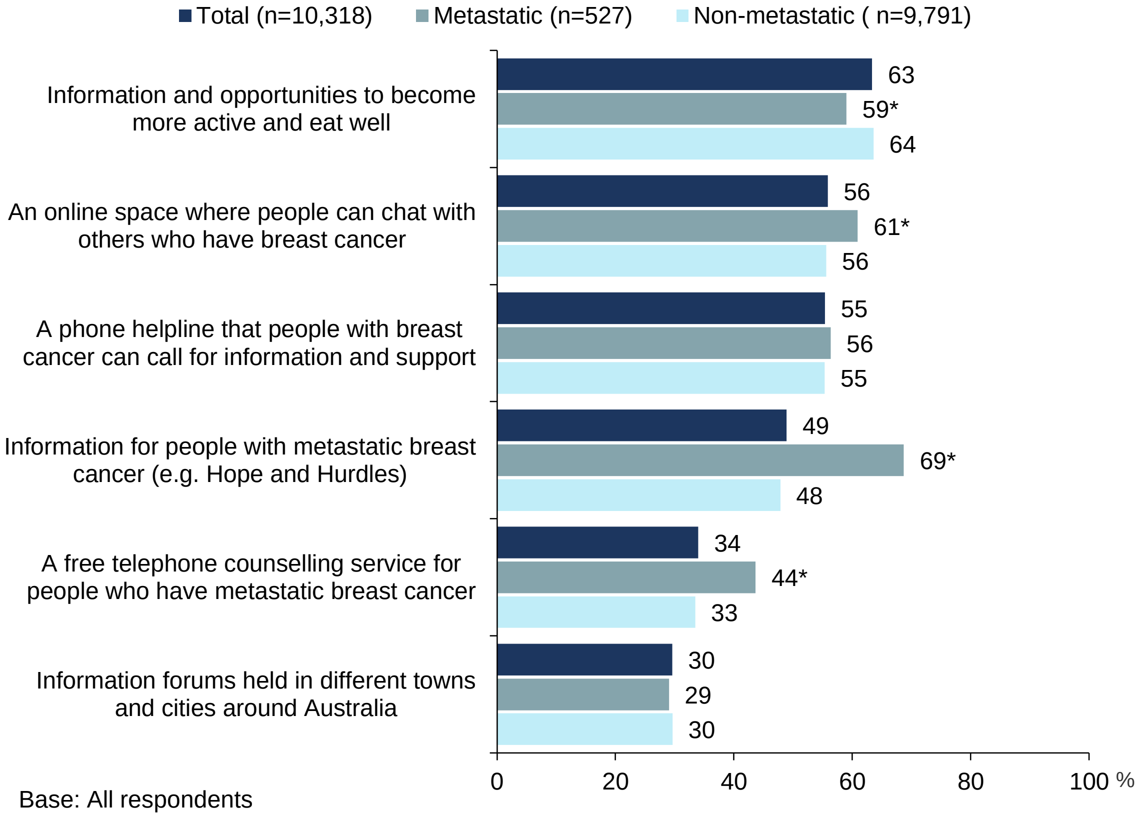
Respondents were presented with a list of BCNA products and services and asked which they had been aware of prior to the survey. These included:

- information and opportunities to become more active and eat well
- an online space where people can chat with others who have breast cancer
- a phone helpline that people with breast cancer can call for information and support
- information for people with metastatic breast cancer (e.g. Hope & Hurdles)
- a free telephone counselling service for people who have metastatic breast cancer
- information forums held in different towns and cities around Australia.

As shown in Figure 24, most of BCNA's products or services were known to at least half of all respondents. The exceptions were the telephone counselling service for people with metastatic breast cancer (34% were aware) and information forums held around Australia (30%). Respondents with metastatic breast cancer recorded higher levels of awareness than those with non-metastatic breast cancer, with 69% reporting awareness of information tailored to people with metastatic breast cancer (compared to 48%), 44% aware of the telephone service for metastatic breast cancer patients (compared to 33%).

Figure 24 Awareness of BCNA products and services

C2. Breast Cancer Network Australia (which we will refer to as BCNA) provides a range of products and services. Before today, were you *aware* that BCNA provides…?



Base: All respondents

* Significantly different to results for those with non-metastatic breast cancer

Younger respondents aged 18 to 39 years reported lower levels of awareness of all but one of the products and services (Online Network) presented to them compared to older respondents:

- 24% were aware of the free telephone counselling service for people who have metastatic breast cancer (compared to 36% of those aged 60 to 69 years and 37% of those aged 70 years and over)
- 41% were aware of the phone helpline that people with breast cancer can call for information and support (compared to 58% of those aged 60 to 69 years and 59% of those aged 70 years and over)
- 44% were aware of the information for people with metastatic breast cancer (compared to 50% of those aged 60 to 69 years and 48% of those aged 70 years and over)
- 47% were aware of the information forums held in different towns and cities around Australia (compared to 66% of those aged 60 to 69 years and 67% of those aged 70 years and over)
- 48% were aware of the information and opportunities to become more active and eat well (compared to 68% of those aged 60 to 69 years and 68% of those aged 70 years and over).

The one exception was awareness of BCNA’s online space where people can chat with others who have breast cancer. Those aged 18 to 39 years had lower awareness of this service (52%) however, so did people aged 70 years and over (49%). Awareness was higher amongst those aged 40 to 49 (59%), 50 to 59 years of age (58%) or 60 to 69 years (56%).

Those whose main language is English were more likely than people who speak a main language other than English to be aware of information and opportunities to become more active and eat well (64% compared to 54%), information forums held in different towns and cities around Australia (62% compared to 52%), an online space where people can chat with others who have breast cancer (56% compared to 48%) and information for people with metastatic breast cancer (49% compared to 40%).

Awareness of BCNA products and services was also lower for those who had received active treatment (surgery, radiotherapy, or chemotherapy) in the four weeks prior to the survey compared to those who had received hormone therapy only or no treatment in the four weeks prior. Amongst those who had recently received active treatment:

- 51% were aware of the information and opportunities to become more active and eat well (compared to 67% of those receiving no treatment)
- 49% were aware of BCNA’s online space where people can chat with others who have breast cancer (compared to 56% of those receiving no treatment)
- 50% were aware of the phone helpline that people with breast cancer can call for information and support (compared to 58% of those receiving no treatment)
- 39% were aware of the information for people with metastatic breast cancer (compared to 52% of those receiving no treatment)
- 30% were aware of the free telephone counselling service for people who have metastatic breast cancer (compared to 37% of those receiving no treatment)
- 47% were aware of the information forums held in different towns and cities around Australia (compared to 68% of those receiving no treatment).

For all six of the products and services presented, awareness was lower for those who had received their most recent diagnosis in the two years prior to the survey, with the proportion of respondents who were aware increasing with their time since diagnosis. For example, 45% of those diagnosed in the year prior to the survey and 56% of those diagnosed one but less than two years prior reported being aware of information forums held in different towns and cities around Australia, compared to 66% of those diagnosed two but less than five years prior, 76% of those diagnosed five to ten years prior and 80% of those diagnosed more than 10 years prior to the survey.

The proportions aware of the information for people with metastatic breast cancer were 35% of those diagnosed in the year prior to the survey and 45% of those diagnosed one but less than two years prior, compared to 52% of those diagnosed two but less than five years prior, 58% of those diagnosed five to ten years prior and 69% of those diagnosed more than 10 years prior to the survey.

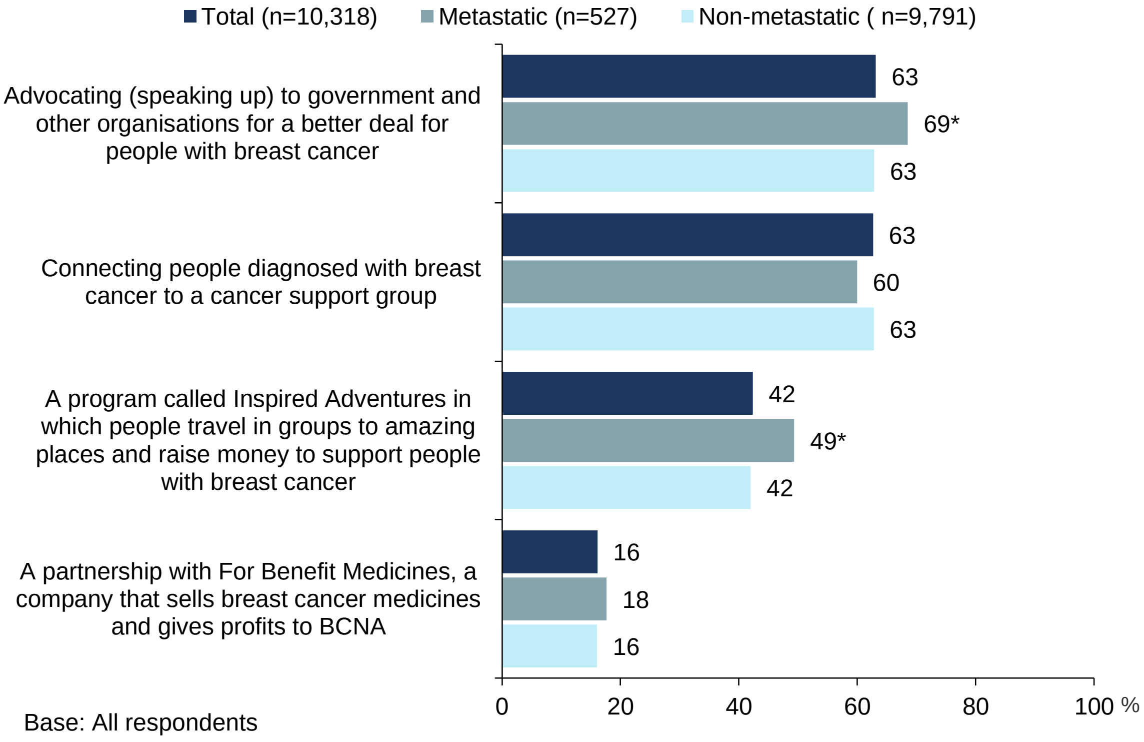
4.2. Awareness of activities

Awareness of BCNA's programs and partnerships to support or advocate for people with breast cancer were varied. Few (16%) indicated they had been aware of BCNA's partnership with For Benefit Medicines while approximately two-thirds of respondents were aware of BCNA's advocacy role (63%) or their ability to connect people with cancer to support groups (63%). Approximately two-fifths of respondents were aware of the Inspired Adventures program.

Figure 25 shows that few variations in awareness were noted between those with metastatic breast cancer and those with non-metastatic cancer, though those with metastatic cancer were more aware of BCNA's advocacy role (69% compared to 63%) and the Inspired Adventures program (49% compared to 42%).

Figure 25 Awareness of BCNA activities

C3. BCNA is also involved in a number of activities. Before today, were you *aware* that BCNA is involved in…?



Base: All respondents

Awareness of BCNA activities were lower amongst those who had been more recently diagnosed. Compared to those diagnosed more than 10 years prior to the survey, the proportions with awareness amongst those diagnosed in the 12 months prior to the survey were:

- 50% were aware of BCNA's advocacy role (compared to 84% of those diagnosed more than 10 years prior)
- 52% of those aware that BCNA connects people to cancer support groups (compared to 76% of those diagnosed more than 10 years prior)
- 21% were aware of the Inspired Adventures program (compared to 52% of those diagnosed more than 10 years prior)
- 14% were aware of the partnership with For Benefit medicines (compared to 19% of those diagnosed more than 10 years earlier).

Amongst those who had received active treatment in the four weeks prior to the survey, respondents were less likely to have heard of the Inspired Adventures program (26%) compared to those receiving hormone therapy only (44%) or no recent treatment (47%).

Awareness of each of the activities was also consistently higher for those aged 50 years and over compared to younger respondents aged 18 to 49 years. For example, awareness of BCNA's advocacy role was 48% of those aged 18 to 39 years and 55% of those aged 40 to 49 years compared to 62% of those aged 50 to 59, 67% of those aged 60 to 69 and 69% of those aged 70 years and over.

Amongst those who speak English as their main language, awareness was higher for BCNA's advocacy role (63% compared to 52% of those who speak another main language), their role in connecting people to cancer support services (63% compared to 57%) and the Inspired Adventures program (43% compared to 35%).

4.3. Service or activity use

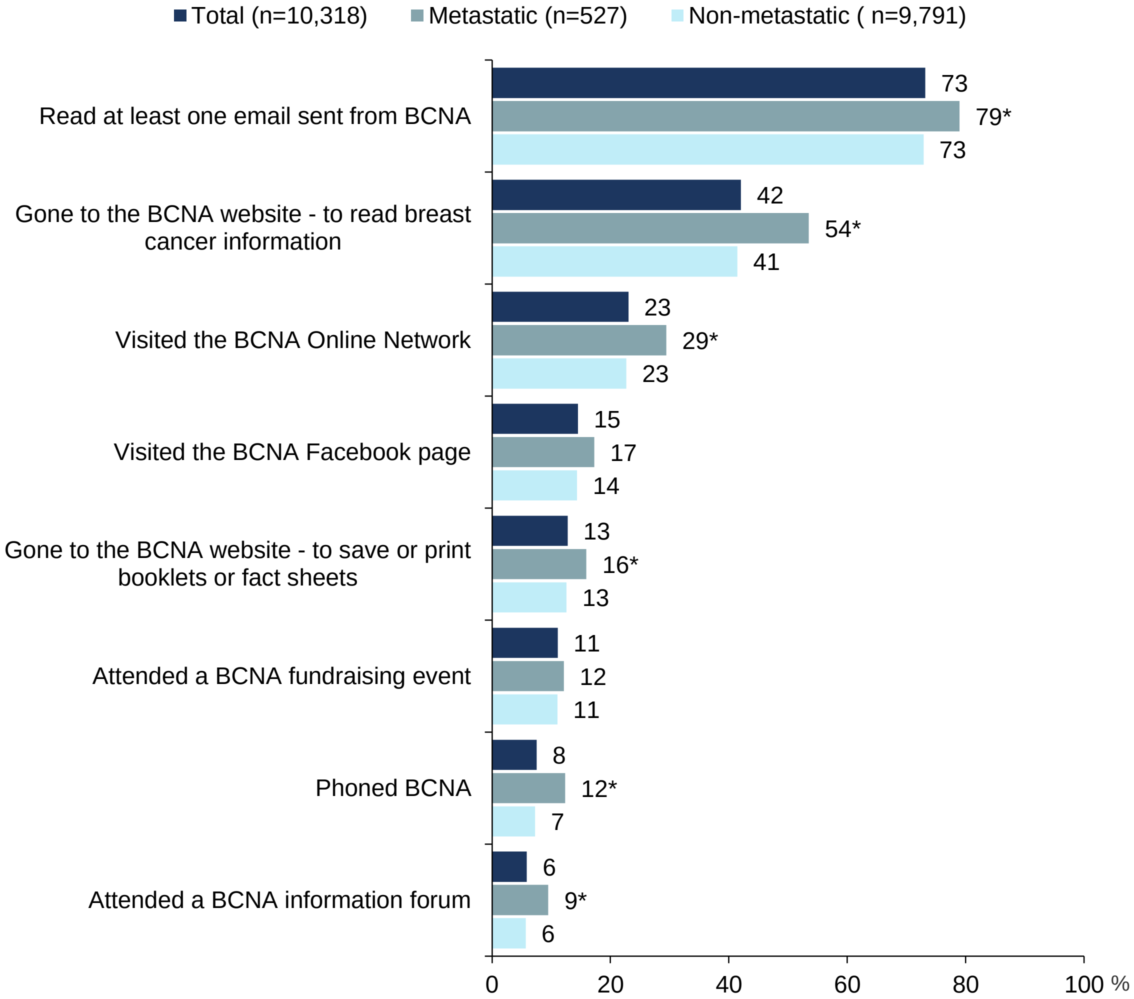
Respondents were asked which, if any of BCNA's key services or activities they had accessed in the 12 months prior to the survey. The number of touch points for respondents was used to derive a variable measuring level of engagement with BCNA. Respondents who had used six to eight of BCNA's key services made up 16% of all respondents and formed the 'high engagement' group. Those who had engaged with three to five services contributed 35% of the sample and were considered to have 'moderate engagement' with BCNA. Approximately half (49%) of all respondents used two or less services or activities and were therefore assigned to a 'low engagement' group.

The most common interaction that respondents had with BCNA in the 12 months prior to the survey was to have read or browsed an email sent by BCNA. Approximately two-thirds had done so (73%) compared to 42% who had visited the BCNA website to read or browse information while around one-quarter (23%) had visited the BCNA online network. Fewer had done any of the other activities presented to respondents.

Figure 26 shows that people with metastatic breast cancer were more likely than those with non-metastatic cancer to have read at least one BCNA email (79% compared to 73%), read or browsed the website (54% compared to 41%), visited BCNA's online network (29% compared to 23%), phoned BCNA (12% compared to 7%) or attended a BCNA forum (9% compared to 6%).

Figure 26 Use of BCNA services or activities

D2. Thinking about *other services* provided by the BCNA, in the last 12 months *have you*…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

In terms of age group variations, more of those aged 18 to 59 years had used BCNA's online services than those in older age groups. In the younger age groups:

- 59% of those aged 18 to 39, 55% of those aged 40 to 49 and 47% of those aged 50 to 59 had gone to the BCNA website to read breast cancer information (compared to 39% aged 60 to 69 years and 24% aged 70 years and over)
- 37% of those aged 18 to 39, 27% of those aged 40 to 49 and 17% of those aged 50 to 59 had visited the BCNA Facebook page (compared to 9% aged 60 to 69 years and 6% aged 70 years and over)
- 28% of those aged 18 to 39, 30% of those aged 40 to 49 and 26% of those aged 50 to 59 had visited the BCNA online network (compared to 21% aged 60 to 69 years and 14% aged 70 years and over)
- 17% of those aged 18 to 39, 17% of those aged 40 to 49 and 15% of those aged 50 to 59 had gone to the BCNA website to save a copy to their computer or print one or more booklets or fact sheets on a breast cancer topic (compared to 11% aged 60 to 69 years and 6% aged 70 years and over).

Respondents who had been diagnosed in the five years prior to the survey were more likely to have used BCNA's online services than those diagnosed three or more years prior. As an example, the proportion of those diagnosed in the 12 months prior to the survey who had gone to the BCNA website to read information was 57%, decreasing to 47% of those who had visited more than one but less than two years prior and 37% of those who had visited more than two but less than five years prior. This compares to 29% who had visited more than five but less than 10 years prior and 32% who had been diagnosed more than 10 years prior.

People who had received active treatment in the four weeks prior to the survey were also more likely to have used BCNA's online services compared to those who were not receiving current treatment. The proportion who had gone to the BCNA website to read information was 55% for those in active treatment, 46% of those who had received hormone therapy only compared to 33% of those not in treatment. Respondents were more likely to have visited BCNA's online network if they had received active treatment (27%) or hormone therapy (26%) in the four weeks prior to the survey compared to those who had not received recent treatment (19%).

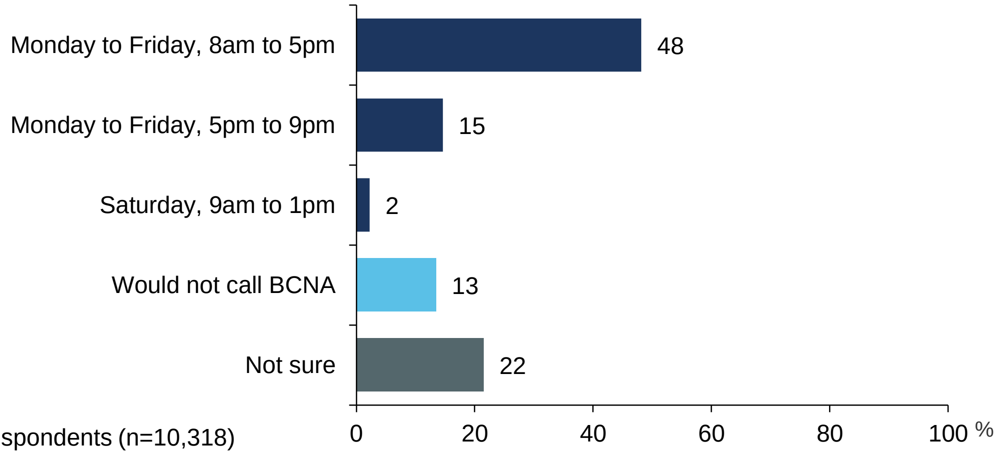
Tasmanian residents were significantly more likely to have attended a BCNA fundraising event (26%) than residents of all other States and Territories (ranging from 6 to 15%). The proportion of residents who had attended a fundraising event was higher amongst those who reside in inner (14%) or outer (15%) regional areas compared to those residing in major cities (10%). Attendance at fundraising events was higher for those whose most recent diagnosis had been more than 10 years prior to the survey (16%) compared to those who had been diagnoses in the 12 months before the survey (7%) or one but less than two years prior (11%).

4.4. Preferences for extended call centre hours

If respondents had to choose, they would prefer the call centre operate from 8am to 5pm on weekdays (48% would prefer this option), rather than being available from 5pm to 9pm on weekdays (15%). Just 2% gave a preference for Saturday 9am to 1pm as shown in Figure 27.

Figure 27 Preferences for call centre contact times

D6. If you wanted or needed to call BCNA, what time of day would you be most likely to call?



Base: All respondents (n=10,318)

Amongst respondents who had phoned BCNA in the 12 months prior to the survey, the proportion stating that they would prefer the call centre opening hours to be Monday to Friday 8am to 5pm was higher at 66% compared to 47% amongst those who had not phoned BCNA. There were no other notable differences in preferences between those who had or had not contacted BCNA's call centre.

Compared to those in the older age groups, a higher proportion of respondents aged 18 to 39 years would prefer later weekday opening hours (30%), even so, more would prefer the earlier weekday hours (36%). This compares to 56% showing a preference for earlier weekday hours and 4% for later weekday hours amongst those aged 70 years and over.

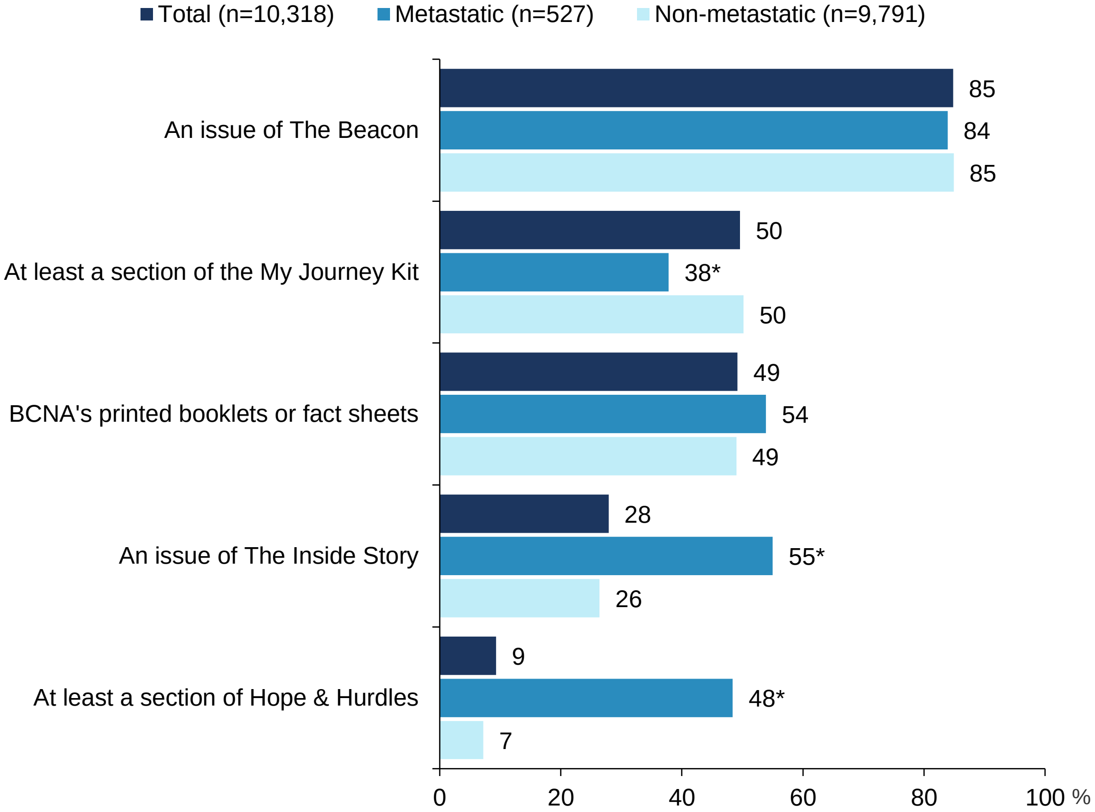
4.5. Use of publications

All respondents were asked which of the following BCNA publications they had read or browsed in the 12 months prior to the survey. Most respondents had read or browsed an issue of BCNA's quarterly newsletter The Beacon (85%), while approximately half had read at least a section of the My Journey Kit (50%) or read BCNA's printed booklets or fact sheets (49%).

Though fewer had read an issue of Inside Story (28%), this proportion was higher amongst those with metastatic breast cancer (55%) compared to those with non-metastatic cancer (26%). At least one section of Hope & Hurdles, BCNA's information pack for people with metastatic breast cancer, had been read by 48% of those with metastatic breast cancer compared to 7% of those with non-metastatic cancer.

Figure 28 Proportion of respondents who have read or browsed BCNA publications

D1. In the last 12 months have you *read or browsed* any of the following BCNA publications…?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Likelihood of having read or browsed BCNA's publications varied dependent on the age of the respondent. People aged 18 to 39 years were less likely to have read The Beacon (75%) compared to those aged 40 years and over (85 to 87%). However, younger respondents were more likely to have read or browsed at least one section of the My Journey Kit (66% of those aged 18 to 39 had done so) compared to those aged 60 to 69 years (54%) or 70 years of age and over (49%). They were also more likely to have read or browsed one or more of BCNA's printed booklets or fact sheets (58% had done this) compared to 51% of those aged 60 to 69 years and 49% of those aged 70 years and over.

People who speak English as their main language were more likely to have read The Beacon (87%) compared to those who speak another main language (72%). However, those who speak another main language were more likely to have read or browsed the My Journey Kit (66% compared to 56%) or Hope & Hurdles (20% compared to 14%).

Those who had been diagnosed more than 10 years prior to the survey were more likely to have read or browsed The Beacon (92% compared to 75% of those diagnosed in the last 12 months) and The Inside Story (49% compared to 28%). However, those who had been most recently diagnosed in the 12 months before the survey were more likely to have recently read or browsed the My Journey Kit (84% compared to 34% of those diagnosed more than 10 years prior) or one or more of BCNA's printed booklets or fact sheets (74% compared to 43%).

4.6. Digital vs printed publications

The preference for digital (online) or printed publications varied dependent upon which of BCNA's publications were referenced. Amongst all respondents more would prefer digital rather than printed copies of The Beacon (53% online compared to 34% printed), The Inside Story (29% compared to 16%) and booklets or fact sheets (45% compared to 29%). This compares to a preference for printed versions of the My Journey Kit (16% compared to 44%) and Hope & Hurdles (15% compared to 20%).

The proportions indicating that they would prefer not to receive the publications regardless of how they were printed were higher amongst non-metastatic breast cancer patients for:

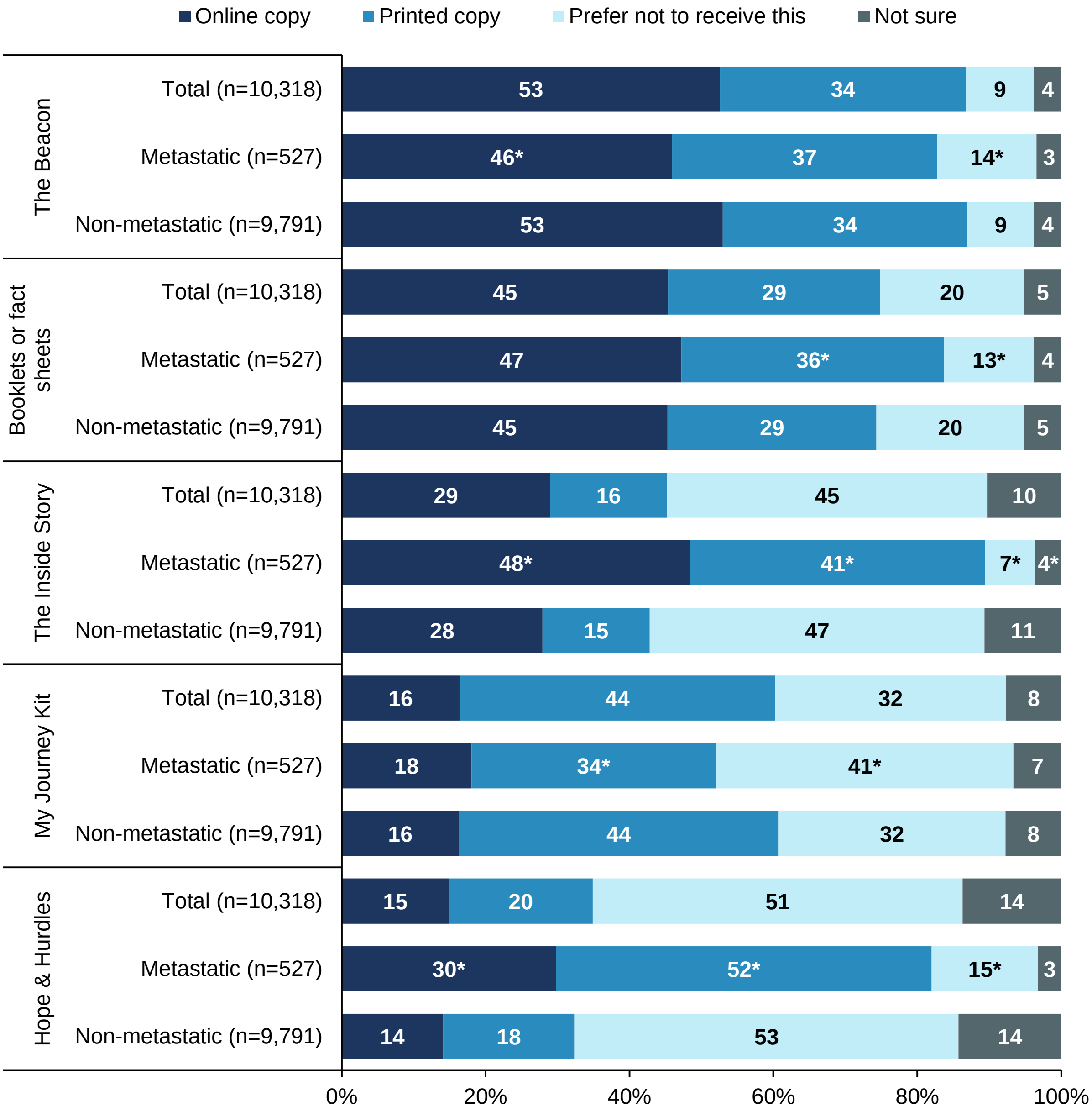
- Hope & Hurdles (53% non-metastatic would prefer not to receive this compared to 15% of those with metastatic cancer)
- The Inside Story (47% non-metastatic would prefer not to receive this compared to 7% of those with metastatic cancer)
- Booklets or fact sheets (20% non-metastatic would prefer not to receive this compared to 13% of those with metastatic cancer).

Respondents with metastatic breast cancer were more likely to indicate they would prefer not to receive The Beacon (14% compared to 9% of those with non-metastatic cancer) and the My Journey Kit (41% compared to 32%).

The full distribution of preferences is provided in Figure 29.

Figure 29 Preferred format for receiving BCNA publications

D3. For each of the following, please indicate whether you would prefer to receive the information in printed or online format?



Base: All respondents
* Significantly different to results for those with non-metastatic breast cancer

Respondents aged 60 years and over were more likely than younger respondents aged 18 to 59 years to prefer not to receive each of the publications. The preference for online materials decreased with age. For example, the proportion of respondents who would prefer to receive The Beacon online was 62% of those aged 18 to 40 years, 57% of those aged 40 to 49 and 57% of those aged 50 to 59 years compared to 51% of those aged 60 to 69 years and 42% of those aged 70 years and over.

Those who indicated a preference for receiving information in a printed format gave the following main reasons (multiple responses possible):

- ‘I can take it anywhere I want to read it’ (74%)
- ‘I can pass it on to other people’ (51%)
- ‘I like to file it with other information’ (43%)
- ‘My internet connection is too slow / unreliable’ (10%)
- ‘I don't feel confident using the internet’ (7%)
- ‘I don't have easy access to the internet’ (5%).

4.7. Preparedness to pay for publications

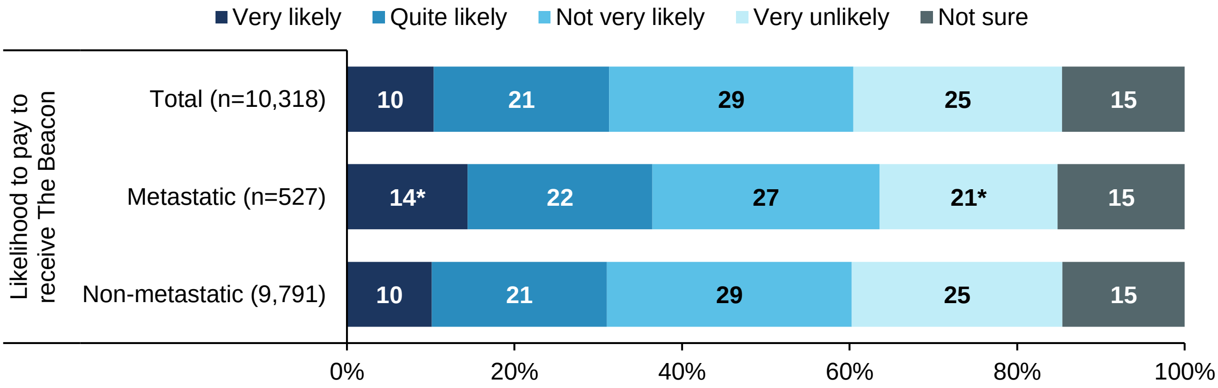
For BCNA there is a cost associated with continuing to provide printed materials. As other services are increasingly switching to online publications, survey respondents were asked how likely they would be to consider paying a fee to continue to receive printed publications.

As shown in Figure 30, likelihood to pay a small yearly fee (approximately $20) for four issues of The Beacon was low. Around three in ten respondents would be ‘very likely’ (10%) or ‘quite likely’ (21%) to consider paying a fee while over half would be ‘not very likely’ (29%) or ‘very unlikely’ (25%). The remainder (15%) were unable to answer.

Likelihood to pay was higher amongst people with metastatic breast cancer with 14% indicating they would be ‘very likely’ to pay a yearly fee compared to 10% of those with non-metastatic breast cancer.

Figure 30 Likelihood to pay an annual fee for The Beacon

D5. How likely would you be to pay a small yearly fee (say $20) to receive four printed issues of The Beacon (BCNA’s quarterly newsletter) sent out each year?



Base: Respondents with informational and support needs

Preparedness to pay for printed publications was higher amongst respondents who live in remote or very remote areas (16% were ‘very likely’ and 25% were ‘quite likely’ to pay a fee) than those who live in major cities (10% were ‘very likely’ and 21% were ‘quite likely’).

Respondents who reported having a high level of engagement with BCNA were also more likely to consider paying a small yearly fee (16% were ‘very likely’ and 27% were ‘quite likely’) compared to those with low engagement (8% were ‘very likely’ and 17% were ‘quite likely’).

5. BCNA funding and donations

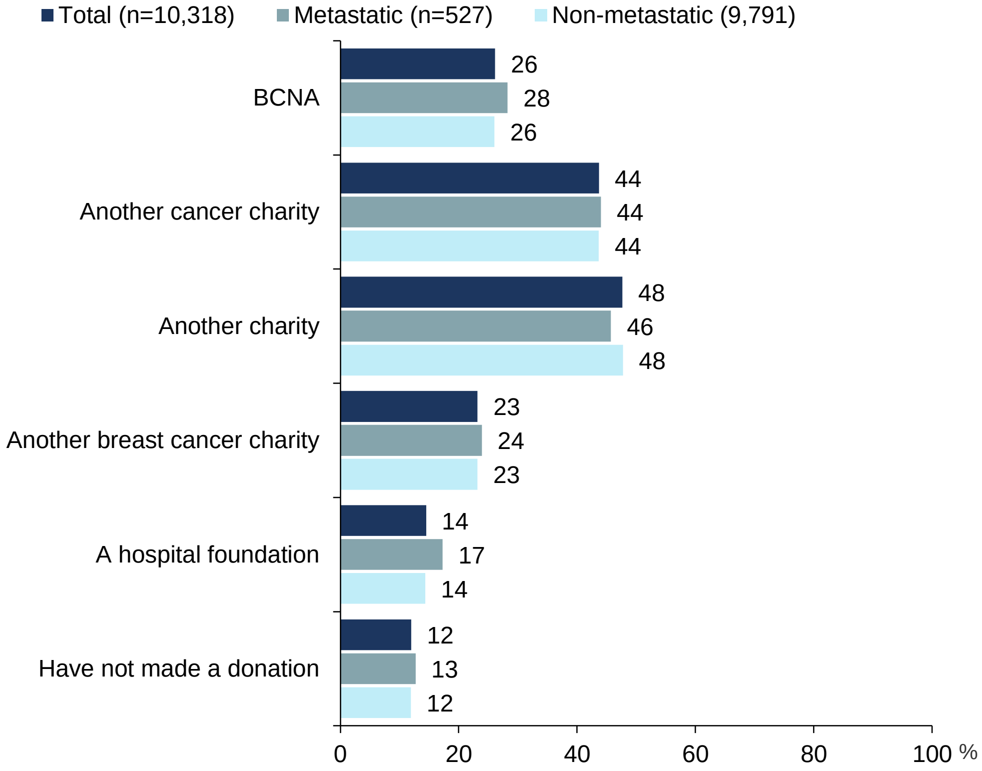
5.1. Donation activity

Overall, approximately one in ten respondents (12%) indicated they had not donated to any charities in the 12 months prior to the survey. Most common were donations to charities other than cancer charities (48% had donated to these) and general cancer charities not including BCNA (44% had donated to these). Approximately one-quarter (26%) indicated that they had made a monetary donation to BCNA in the year prior to the survey.

As shown in Figure 31, no differences were observed between the proportion of metastatic breast cancer patients and those with non-metastatic cancer who had made charitable donations.

Figure 31 Charitable donations in the past 12 months

E1. In the last 12 months, have you given a donation of money to any of the following charities…?



Base: All respondents

Respondents in the following subgroups were more likely to say they had not made any donations to any charity, including BCNA, in the 12 months prior to the survey:

- People aged 18 to 39 years (16%) compared to 11 to 12% of those aged 40 years and over
- Those who speak a main language other than English (22%) compared to those whose main language is English (12%)
- People diagnosed in the 12 months prior to the survey (14%) compared to those diagnosed more than two years prior (10 to 11%)
- People who had received active treatment in the four weeks prior to the survey (14%) compared to those who had received hormone therapy only (11%) or no recent treatment (12%)

- People who had mainly been treated through the public sector (14%) compared to those who had been through the private sector (10%)
- People who reported low levels of engagement with BCNA in the 12 months prior to the survey (14%) compared to those with high engagement (8%).

Those who were more likely to have donated to BCNA in the 12 months prior to the survey were residents of Tasmania (35%), Victoria (30%) and the Australian Capital Territory (31%) when compared to residents of Queensland (22%), New South Wales (24%), and South Australia (25%).

People who had received their most recent diagnosis more than five years prior to the survey were more likely to have recently donated to BCNA (30%) than those who had been diagnosed in the last 12 months (20%). Respondents who had received most of their treatment through the private sector were more likely to have donated to BCNA in the previous 12 months (29%) than those who had gone through the public sector (23%).

Those respondents whose main language is English were more likely to have donated to BCNA in the previous 12 months (26%) compared to those whose main language is a language other than English (21%).

The proportion who had donated to BCNA in the previous 12 months was higher among those who had received hormone therapy only (27%) or no active treatment (27%) than those who had received active treatment in the last 4 weeks (21%).

5.2. Funding awareness

Prior to asking respondents whether they had been aware of how BCNA was funded, all respondents were informed that:

> *BCNA is a not for profit organisation that provides free breast cancer information and services. BCNA receives about 85% of its funding from public fundraising and corporate sponsorship. This includes individual donations, gifts from wills, fundraising events and corporate donations. Most of the remaining funding (around 15%) is provided by the government.*

Overall, 48% of respondents indicated that they had been aware of how BCNA was funded prior to the survey. The proportion aware of how BCNA was funded did not differ significantly between those diagnosed with metastatic or non-metastatic cancer.

Awareness was also higher amongst those who had received their diagnosis two or more years prior to the survey (54% amongst those diagnosed more than two but less than five years prior, 57% of those diagnosed more than five but less than 10 years prior and 66% amongst those diagnosed more than 10 years prior) compared to 33% of those diagnosed in the 12 months prior to the survey and 45% of those diagnosed more than one and up to two years prior.

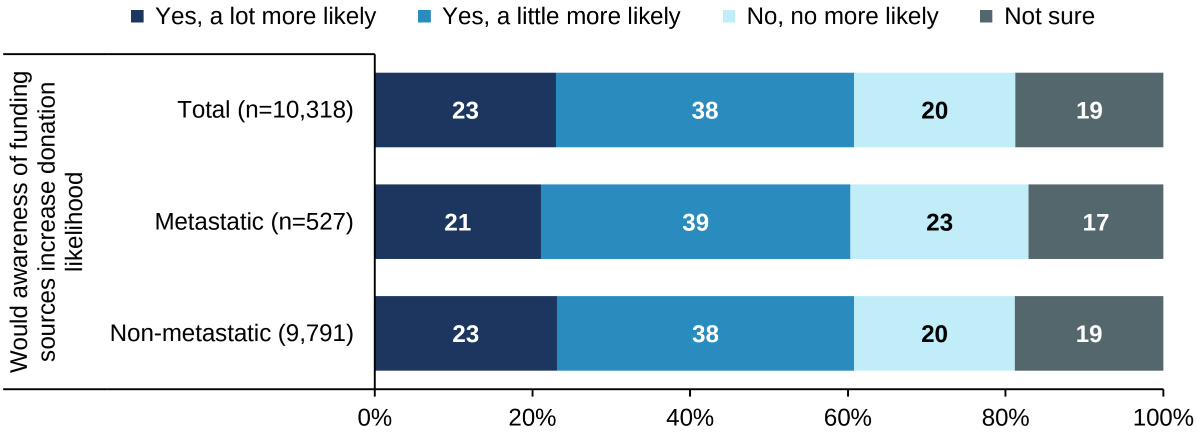
Awareness was higher amongst those aged 60 to 69 years (50%) and 70 years and over (54%) when compared to younger respondents aged 18 to 39 years (39%).

Regardless of whether they had been previously aware of how BCNA is funded, all respondents were asked whether knowing the source of funding would make them any more likely to donate to BCNA in the future. Overall, approximately three-fifths of respondents (61%) indicated that knowing BCNA's funding sources would make it at least a little more likely that they would donate to BCNA in future. This compares to one-fifth who indicated that it would not increase their likelihood of donation (20%) and a further one-fifth who were unsure (19%).

As shown in Figure 32, there were no differences in whether donation likelihood would increase in funding sources were known by respondents with metastatic or non-metastatic breast cancer.

Figure 32 Whether knowledge of funding sources would increase donation likelihood

E3. Would knowing that BCNA receives most of its funding from non-government sources make it any more likely that you would make a donation to BCNA in the future?



Base: Respondents indicating the statement was relevant to their situation
* Significantly different to results for those with non-metastatic breast cancer

Knowing that BCNA receives most of its funding from public sources would be more effective at increasing the likelihood the following subgroups of respondents would donate to BCNA:

- Younger people aged 18 to 39 years (31% would be ‘a lot’ and 42% would be ‘a little’ more likely to donate) compared to those aged 70 years and over (18% would be ‘a lot’ and 35% would be ‘a little’ more likely to donate)
- Those diagnosed in the 12 months prior to the survey (30% would be “a lot” and 38% would be “a little” more likely to donate) compared to those diagnosed more than 10 years prior (18% would be “a lot” and 36% would be “a little” more likely to donate)
- People who had received active treatment in the four weeks prior to the survey (30% would be ‘a lot’ and 38% would be ‘a little’ more likely to donate) compared to those who had received no treatment during that time (20% would be ‘a lot’ and 36% would be ‘a little’ more likely to donate)
- Respondents who have a high level of engagement with BCNA (33% would be ‘a lot’ and 37% would be ‘a little’ more likely to donate) compared to those with a low level of engagement (18% would be ‘a lot’ and 37% would be ‘a little’ more likely to donate).

Past donation activity was related to increased likelihood to donate in future if BCNA’s funding sources were known. The proportion of respondents who were more likely to donate to BCNA in future if they knew how BCNA receives their funding was higher amongst respondents who had donated to BCNA (69%) or to another charity (62%) in the 12 months prior to the survey. This compares to 42% amongst those who had not made any charitable donations in the 12 months prior to the survey.

The proportion of respondents who would be more likely to donate to BCNA in future if they were made aware that BCNA was largely publicly funded was higher amongst respondents who had not known how BCNA was funded prior to the survey (67%) compared to those who had been aware of how BCNA is funded (58%).

6. Political attitudes

Figure 33 shows that respondents demonstrated high levels of agreement with the following statements regarding health-related political issues:

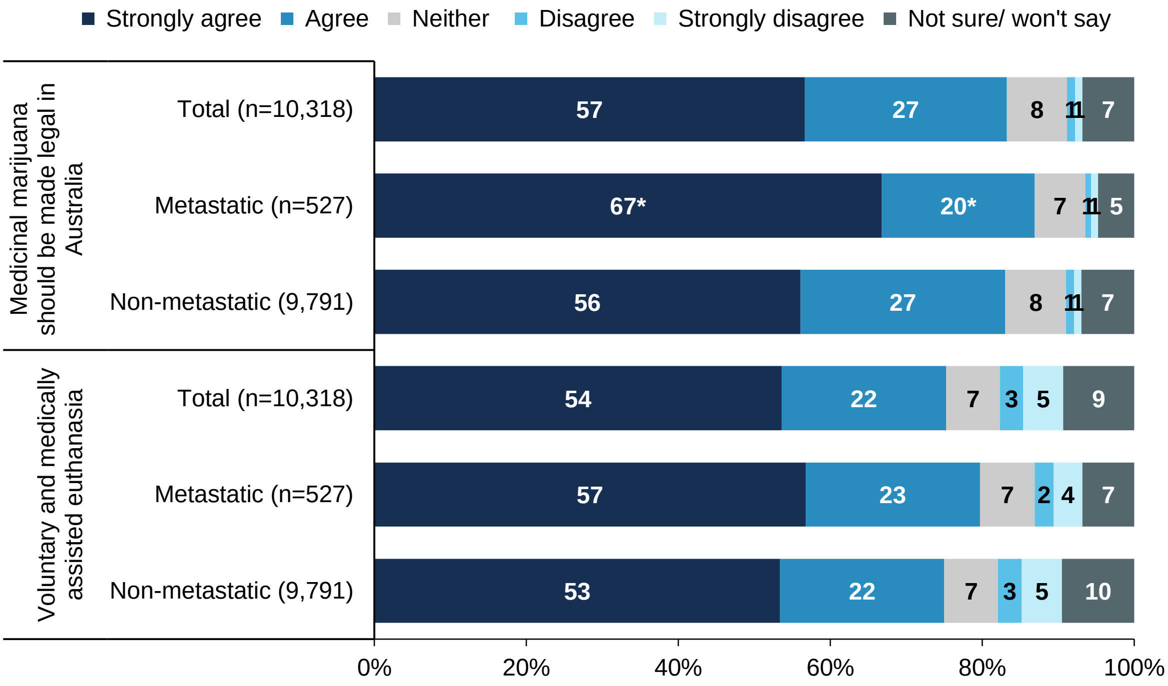
- medicinal marijuana should be made legal in Australia for people who are suffering ongoing and severe pain
- voluntary and medically assisted euthanasia (allowing people to end their lives with their own consent and the help of doctors) should be made legal in Australia for people who are near the end of their life and who are suffering.

Amongst those with metastatic breast cancer, agreement that medical marijuana should be legalised for people who are suffering (87% ‘strongly agree’ or ‘agree’) outweighed disagreement (2% ‘strongly disagree’ or ‘disagree’). While the proportion who agree was lower amongst those with non-metastatic cancer (83%), a small proportion (2%) disagreed with the statement.

A similarly high proportion of respondents agreed that voluntary and medically assisted euthanasia should be legalised (80% of those with metastatic breast cancer patients compared to 75% of those with non-metastatic cancer). Disagreement with the legalisation of voluntary euthanasia was 6% amongst those with metastatic breast cancer and 8% for those with non-metastatic cancer.

Figure 33 Level of agreement with health related political issues

F1. Recently, state parliaments have discussed a range of laws that affect people who have serious medical conditions. In your opinion, to what extent do you agree or disagree that…?



Base: Respondents indicating the statement was relevant to their situation

Agreement that medical marijuana should be legalised in Australia was significantly higher for respondents from New South Wales (86%) than respondents from Victoria (83%), South Australia (82%) and Queensland (83%). Agreement was higher in these states and, additionally, Tasmanian residents (86%) when compared to residents of Western Australia (79%), amongst whom lower levels of agreement were recorded.

The only significant difference in agreement with legalising voluntary euthanasia when comparing respondents from different States and Territories was higher agreement amongst Victorians (77%) than Queensland residents (74%).

Agreement with both statements was lowest for those aged 70 years and over compared to respondents in the younger age groups. Amongst those aged 70 years and over:

- 80% agreed medicinal marijuana should be made legal in Australia for people who are suffering ongoing and severe pain (compared to 84% of those aged40 to 49 years, 85% of those aged 50 to 59 years, and 83% of those aged 60 to 69 years)
- 67% agreed that voluntary and medically assisted euthanasia (allowing people to end their lives with their own consent and the help of doctors) should be made legal in Australia (compared to 76% of those aged 18 to 39 years, 79% of those aged 40 to 49 years, 79% of those aged 50 to 59 years, and 75% of those aged 60 to 69 years).

Agreement was higher amongst those whose main language is English (84% agreed marijuana should be legalised; 76% agreed euthanasia should be legalised) compared to those who speak a main language other than English amongst whom 63% agreed medicinal marijuana should be legalised and 55% agreed voluntary euthanasia should be made legal in Australia.

7. Cancer diagnosis and treatment

7.1. Relationship with cancer

Respondents were asked their agreement with the following statements to assist with understanding their relationship with cancer:

- ‘I am feeling angry, fearful, or sad a lot of the time about having cancer’
- ‘I would like to use my experience to help others with breast cancer’
- ‘I need to find out as much as I can about my cancer’
- ‘I see myself as a breast cancer survivor’
- ‘I am not cancer, I am me’
- ‘I want to move on with my life and not think about cancer anymore’ (non-metastatic only).

The majority of respondents agreed with the statement ‘I am not cancer, I am me’ (90% agreed; 2% disagreed). This proportion was higher amongst those who had been diagnosed with non-metastatic breast cancer (90%) compared to those with metastatic cancer (84%).

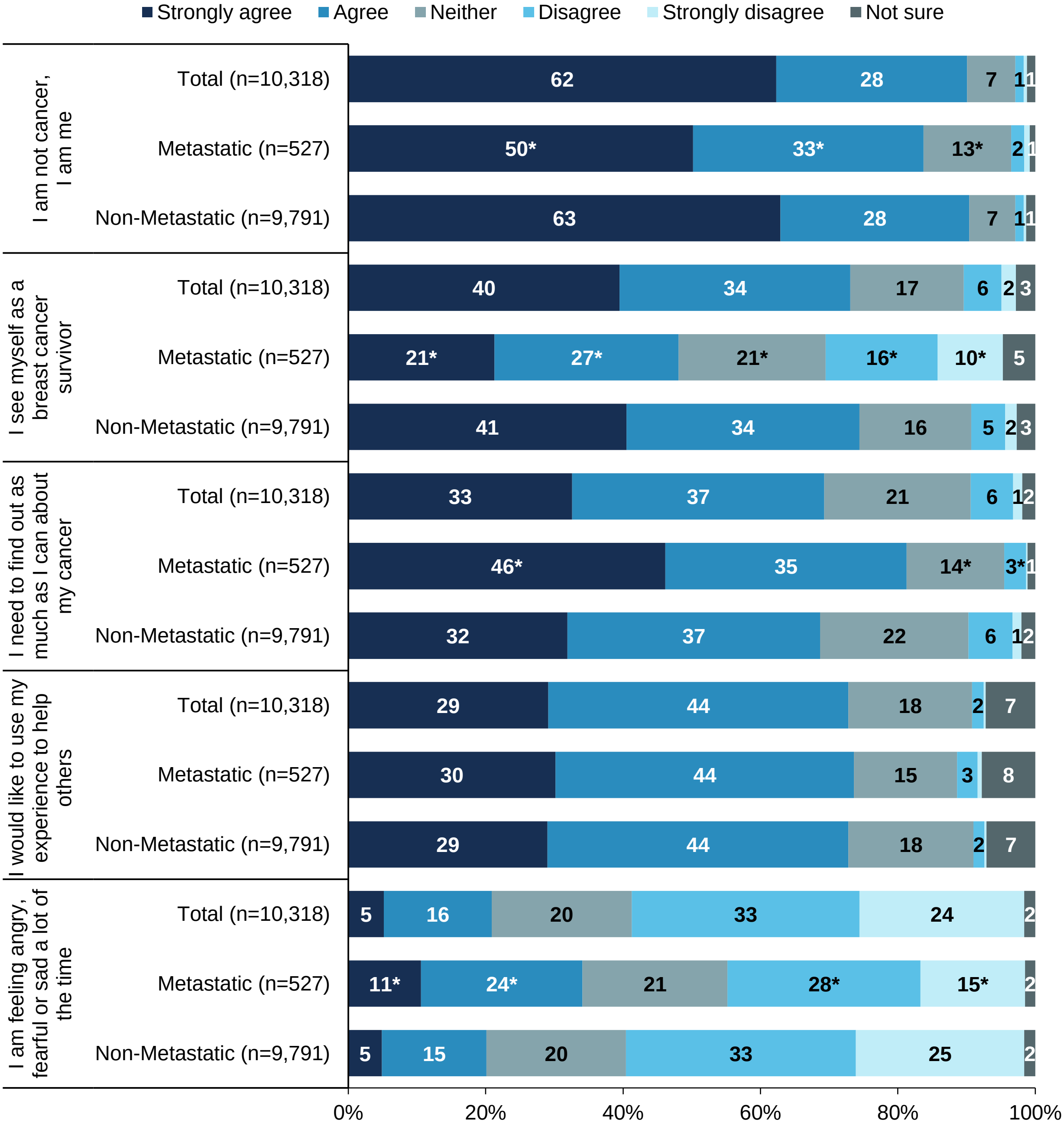
Approximately three-quarters of respondents agreed with the statements, ‘I would like to use my experience to help others with breast cancer’ (73% agreed; 2% disagreed) and ‘I see myself as a breast cancer survivor’ (73% agreed; 8% disagreed). Agreement was also high that, ‘I need to find out as much as I can about my cancer’ (69% agreed; 7% disagreed). Agreement with this statement was higher amongst those with metastatic breast cancer (81%) than those with non-metastatic cancer (69%).

Amongst those with non-metastatic breast cancer, agreement was high that, ‘I want to move on with my life and not think about cancer anymore’. (70% agreed; 8% disagreed). As this statement was not asked of respondents with metastatic breast cancer, it has not been shown in Figure 34.

Agreement with the statement, ‘I am feeling angry, fearful or sad a lot of the time about having cancer’ was low overall (21%). However, the proportion of those with metastatic breast cancer who agreed with the statement (34%) was higher than amongst those with non-metastatic breast cancer (20%).

Figure 34 Perception of self in relation to breast cancer

A7. Thinking about how you currently see yourself in relation to breast cancer, to what extent do you agree or disagree with the following statements?



Base: Respondents indicating the statement was relevant to their situation
* Significantly different to results for those with non-metastatic breast cancer

Agreement with the statement, ‘I am not cancer, I am me’ was higher amongst respondents whose most recent breast cancer diagnosis had been five but less than 10 years prior to the survey (92%) or more than 10 years prior (92%) compared to those who had been diagnosed in the 12 months prior to the survey (89%). Older respondents aged 60 to 69 years (91%) or 70 years and over (92%) were also more likely to agree with this statement than those aged 18 to 39 years (86%), 40 to 49 years (89%) or 50 to 59 years (89%).

Respondents were more likely to agree that, ‘I want to move on with my life and not think about cancer anymore’ if they had not received formal treatment in the four weeks prior to the survey (89%) when compared to those who had received active treatment (66%) or hormone therapy only (72%). The proportion who agreed with the statement was 68% amongst those diagnosed in the 12 months leading up to the survey, 70% amongst those diagnosed more than one and up to two years prior and 72% of those diagnosed more than two and up to five years prior. This compares to 84% amongst those diagnosed more than 10 years prior to the survey and 79% of those diagnosed more than five and up to ten years prior. Older respondents aged 60 to 69 years (76%) or 70 years and over (82%) were also more likely to agree that, ‘I want to move on with my life and not think about cancer anymore’ than those aged 18 to 39 years (62%), 40 to 49 years (67%) or 50 to 59 years (70%).

Younger respondents were more likely to agree that, ‘I would like to use my experience to help others with breast cancer’ with 85% of those aged 18 to 40 years and 83% of those aged 40 to 49 years recording agreement with the statement compared to 76% of those aged 50 to 59 years, 69% of those aged 60 to 69 years and 64% of those aged 70 years and over. Agreement with this statement was higher amongst residents of New South Wales (76%) and the Australian Capital Territory (77%) when compared to agreement amongst those from Victoria (71%), South Australia (71%) and Queensland (71%). Respondents who live in remote or very remote areas (80%) and outer regional areas were also more likely to agree with that they would like to use their experience to help others compared to those in major cities (72%) or inner regional areas (73%).

Agreement that, ‘I would like to use my experience to help others with breast cancer’ was higher amongst those who had received active treatment (75%) or hormone therapy only (75%) in the four weeks prior to the survey than amongst those who had not received recent treatment (70%). Agreement with the statement was also higher amongst people who recorded a high level of engagement with BCNA in the 12 months prior to the survey (86%) compared to those with a lower level of engagement (67%).

8. Conclusion

Overall, the 2017 BCNA Member Survey was a comprehensive piece of survey research, with participation from 10,318 people with breast cancer across Australia. This large sample size provides significant analytical power and enabled results to be analysed at the subgroup level even within groups that represent a small proportion of the population of people with breast cancer. For example, responses were received from 527 people with metastatic breast cancer, more than enough to allow for comparisons to be made between the unmet needs of people in this group and those with non-metastatic breast cancer.

For BCNA, this work provides a valuable insight into the experiences, needs and support gaps of Australians who have received a diagnosis of breast cancer. This report has identified a range of actionable recommendations that will assist BCNA to meet the needs of people with breast cancer (refer to the conclusions and recommendations section of the Executive Summary). The research will inform the strategic direction of the BCNA and will feed into the development of the *Breast Cancer State of the Nation Report 2018*. It also provides a benchmark against which future needs can be measured.

Appendix 1 Questionnaire

Breast
Cancer
Network
Australia

Breast Cancer Network Australia (BCNA) Survey 2017

Questionnaire

1 February 2017

Version 16 – FINAL

Contents

*OUTCOMES AND RR1

*USE STANDARD DIMENSIONS ONLINE SURVEY OUTCOMES AND RR1
*INCLUDE FLAG FOR ACCESS MODE (I.E. UNIQUE OR GENERIC LINK)

*SAMPLE VARIABLES

*USE STANDARD BUT ALSO ADD:

Variable name	Variable label	Full description
SRCID	Unique ID	SRC assigned Unique ID
LINK	Survey Link	Unique survey link (using SRC ID & SAMTYP)
MLINK	Masked Link	Shorter survey link (masking LINK)
FNAME	First name	Sample member's given name
EMAIL	Email Address	Email address provided with sample
MOBILE	Mobile number	Mobile number provided with sample
STATE	State from sample	State provided with sample
SAMTYP	Electronic or mobile	Flag for SMS or email approach
BCTYPE	Diagnosis from sample	Breast cancer diagnosis from sample

*WELCOME SCREEN

Welcome to the Breast Cancer Network Australia (BCNA) Survey 2017. BCNA is interested in finding out more about the needs of people who have had a breast cancer diagnosis. Your help in completing this survey will provide BCNA with important information regarding the future direction of the organisation and how it can best support people who experience breast cancer.

The survey will take 15 to 20 minutes to complete.

The survey is being conducted on behalf of BCNA by the Social Research Centre which is owned by the Australian National University (ANU). Your responses will remain entirely confidential and no identifying information will be provided to BCNA.

This research is carried out in compliance with the Privacy Act and the Australian Privacy Principles, and the information you have provided will only be used for research purposes. The Social Research Centre's Privacy Policy is available by visiting www.srcentre.com.au and clicking on the Privacy Policy in the right hand menu. BCNA's Privacy Policy is available at https://www.bcna.org.au/legal-information/privacy-policy/.

BCNA would like to thank Sussan for its generous contribution that helped make this survey possible.
[PROGRAMMER NOTE: INSERT LOGO – SEE BELOW]

sussan

Click "Next" to continue.

*INTRODUCTION SCREEN

How to complete the survey

For most questions you just need to click on the circle that corresponds to your answer. In some instances you will be asked to type in your answer.

Please use the ‘Next’ and ‘Previous’ buttons to navigate through the survey. [ONLY DISPLAY FOR 1768: You may ‘Pause’ and save your responses at any time. You can re-enter using your unique link to return to the place you left off.]

Your responses are entirely confidential and you will not be identified in any way. Your participation is voluntary – you can opt out at any time or choose to skip questions using the ‘Not sure’, ‘Not applicable’, or ‘Prefer not to say’.

Technical support

If you experience any technical difficulties completing the survey, please call The Social Research Centre on 1800 023 040 (free call).

*(TIMESTAMP1)

*PROGRAMMER NOTE: ALL QUESTIONS ARE MANDATORY UNLESS SPECIFIED. ALL CODEFRAMES TO BE DISPLAYED AS VERTICAL LISTED OPTIONS RATHER THAN CAROUSEL.

*STANDARD DISPLAY AT BOTTOM OF EACH SCREEN FROM SECTION A ONWARDS:
For information or support related to breast cancer, contact the BCNA helpline on 1800 500 258. If you have any questions or concerns about the survey, please contact The Social Research Centre on 1800 023 040 (free call).
Privacy: http://www.srcentre.com.au/about-us/privacy
FAQ’s: http://www.srcentre.com.au/taking-part-in-research/survey-participants/faqs
Email: bcna@srcentre.com.au

SECTION A: BREAST CANCER EXPERIENCES

*(ALL)
Firstly, we would appreciate it if you could tell us about your experience of breast cancer.

A1. What was your most recent diagnosis of breast cancer?

1. Ductal cancer in situ (DCIS) or lobular cancer in situ (LCIS) (both pre-cancers)
2. Early breast cancer (where the breast cancer is contained within the breast and/or lymph nodes)
3. Metastatic breast cancer (breast cancer that has spread to distant parts of the body, such as the bones, liver and lungs; also called advanced, secondary or stage four)
4. Other type of breast cancer (SPECIFY)
5. I have not been diagnosed with breast cancer [GO TO TERM1, ONLY DISPLAY FOR 1768o]

*(ALL)

*PROGRAMMER NOTE: SET UP DUMMY VARIABLE FOR RESPONDENTS WITH NON-METASTATIC CANCER AND METASTATIC CANCER

A1DUM. BREAST CANCER DIAGNOSIS

1. Non-metastatic (A1≠3)
2. Metastatic (A1=3)

*(ALL)

A2. Was this your first breast cancer diagnosis?

1. Yes
2. No

*(ALL)

*PROGRAMMER NOTE: INCLUDE “MOST RECENT” ONLY IF A2=2

A3. How long ago was your [*most recent*] diagnosis of breast cancer?

1. Up to 6 months ago
2. More than 6 months, up to 1 year ago
3. More than 1 year, up to 2 years ago
4. More than 2 years, up to 3 years ago
5. More than 3 years, up to 4 years ago
6. More than 4 years, up to 5 years ago
7. More than 5 years, up to 10 years ago
8. More than 10 years, up to 20 years ago
9. More than 20 years ago

*(A2=2, MULTIPLE DIAGNOSES OF BREAST CANCER)

A4. How long ago was your *first* diagnosis of breast cancer?

*PROGRAMMER NOTE: RESPONSE TO A4 CAN NOT BE LESS THAN RESPONSE TO A3.

1. Up to 6 months ago
2. More than 6 months, up to 1 year ago
3. More than 1 year, up to 2 years ago
4. More than 2 years, up to 3 years ago
5. More than 3 years, up to 4 years ago
6. More than 4 years, up to 5 years ago
7. More than 5 years, up to 10 years ago
8. More than 10 years, up to 20 years ago
9. More than 20 years ago

*(ALL)

A5. Within the last 4 weeks, have you received any of the following types of treatment?

(PLEASE SELECT ALL THAT APPLY)

(PROGRAMMER NOTE: MULTIPLE RESPONSES POSSIBLE EXCEPT 7 IS AN EXCLUSIVE ANSWER)

1. Surgery
2. Radiotherapy
3. Chemotherapy
4. Hormone treatment (e.g. tamoxifen, anastrozole, letrozole, exemestane)
5. Targeted therapy (e.g. Herceptin, Perjeta, Kadcyla or Tykerb)
6. Other (please specify)
7. Not currently receiving treatment

*(ALL)

A6. Have you received *most* of your breast cancer treatment through the public or private health system?

1. Public health system
2. Private health system
3. Not sure

*(ALL)

A7. Thinking about how you CURRENTLY see yourself in relation to breast cancer, to what extent do you agree or disagree with the following statements?

*PROGRAMMER NOTE: FROM STATEMENT B, CHANGE LEAD IN TEXT TO:

To what extent do you agree or disagree…?

*(PROGRAMMER NOTE: ROTATE ORDER MENTIONED)

*(STATEMENTS)

a. I need to find out as much as I can about my cancer
b. I am feeling angry, fearful or sad a lot of the time about having cancer
c. I see myself as a breast cancer survivor
d. I am not cancer, I am me
e. I would like to use my experience to help others with breast cancer
f. I want to move on with my life and not think about cancer anymore [NON-METS ONLY]

*(RESPONSE FRAME)

1. Strongly agree
2. Agree
3. Neither agree nor disagree
4. Disagree
5. Strongly disagree
6. Not sure

*(TIMESTAMP2)

SECTION B: BREAST CANCER NEEDS

*(ALL)

B1. We're interested in your information and support needs related to your most recent breast cancer diagnosis. By support, we mean emotional support, practical support, or being referred to other services you need.

In the last 12 months, to what extent were your needs met in relation to…?

*(STATEMENTS)
a) Receiving all the breast cancer information you needed
b) Receiving all the support related to breast cancer that you needed

*(RESPONSE FRAME)
1. All my needs were met
2. Most of my needs were met
3. Some of my needs were met
4. None of my needs were met
5. Not sure
6. Did not need this in the last 12 months

(PROGRAMMER NOTE: DISPLAY RESPONSE FRAME 1 AND 2 ON THE SAME SCREEN FOR EACH STATEMENT – SHOW RESPONSE FRAME 2 ONLY IF RESPONSE FRAME 1=1)

*(IFNOT (A7f=1 AND B1a=6 AND B1b=6)), NOT THINKING ABOUT CANCER AND DID NOT NEED CANCER INFO/SUPPORT IN LAST 12 MONTHS)

B2_1. In the last 12 months, have you needed any information on the following topics…?

B2_2. If so, to what extent have your information needs been met in this area?

*PROGRAMMER NOTE: FROM SECOND STATEMENT, CHANGE LEAD IN TEXT TO:
B2_1. In the last 12 months, did you need information on…?
B2_2. If so, to what extent were your needs met in this area?

*PROGRAMMER NOTE: ROTATE ORDER MENTIONED.
*(STATEMENTS)
a) Lymphoedema (fluid retention and tissue swelling) due to cancer treatment
b) Early menopause due to cancer treatment
c) Managing problems thinking clearly or concentrating (e.g. 'chemo-brain')
d) Fertility problems related to cancer treatment
e) Changes in sexual function/relationships
f) Managing fatigue related to cancer treatment
g) Managing the financial costs of breast cancer
h) Travel assistance related to breast cancer (e.g. patient assisted travel schemes or PATS)
i) Receiving practical help around the home (e.g. programs or services available)
j) Anxiety or depression related to cancer
k) Body image changes related to cancer
l) The benefits of physical activity and healthy eating
m) Breast reconstruction options
n) Managing your return to work or changes to work
o) Being a parent with cancer and caring for young children
p) Challenges for young (premenopausal) women with cancer

*(RESPONSE FRAME 1)

1. Needed information on this **(*provide response below*)**
2. Did not need information on this **(*click next to continue*)**

*(RESPONSE FRAME 2)

1. All my needs were met
2. Most of my needs were met
3. Some of my needs were met
4. None of my needs were met
5. Not sure

*(IFNOT(A7f=1 AND B1a=6 AND B1b=6)), NOT THINKING ABOUT CANCER AND DID NOT NEED CANCER INFO/SUPPORT IN LAST 12 MONTHS)

B3. And, based on your experience over the last 12 months, to what extent do you agree or disagree with the following statements…?

Note that some topics may not apply to you. If this is the case please select “Not applicable” to move to the next statement.

*PROGRAMMER NOTE: FROM SECOND STATEMENT, CHANGE LEAD IN TEXT TO:
B3. In the last 12 months, to what extent do you agree or disagree…?

*PROGRAMMER NOTE: ROTATE ORDER MENTIONED; ASK “j and k” FOR NON-METASTATIC RESPONDENTS ONLY (A1DUM=1) AND “l, m and n” FOR METASTATIC RESPONDENTS (A1DUM=2)
*(STATEMENTS)

a) I had opportunities to hear about the experiences of others who have been through the same thing
b) I was given opportunities to donate my time or money to help others with breast cancer
c) My cultural and/or spiritual beliefs were respected
d) I received treatment that took my lifestyle into consideration
e) I have been treated as a whole person not just someone with cancer
f) I feel the people close to me are supported
g) I feel I have been heard by my medical team
h) I have had as much contact with a Breast Care Nurse as I needed
i) I was given enough information to make or understand important treatment decisions
j) I was provided with a long-term follow-up care plan after finishing treatment [NON-METS]
k) I am worried that my cancer might come back (or recur) [NON-METS]
l) I was informed that palliative care could support me at any time and not just at the end of my life [METS]
m) I was given opportunities to talk about clinical trials that might be relevant to me [METS]
n) I am worried that my cancer may spread further (or progress) [METS]

*(RESPONSE FRAME)

1. Strongly agree
2. Agree
3. Neither agree nor disagree
4. Disagree
5. Strongly disagree
6. Not sure
7. Not applicable / not relevant to my situation

*(ALL) (PROGRAMMER NOTE: NON-MANDATORY)

B4. Overall, thinking about your experiences of breast cancer, what were your main needs?

(PLEASE LIST ALL THAT WERE IMPORTANT TO YOU)

(RECORD VERBATIM)

*(ALL) (PROGRAMMER NOTE: NON-MANDATORY)

B5. Which, if any, of these needs were NOT met?

(RECORD VERBATIM)

*(TIMESTAMP3)

SECTION C: SUPPORT RECEIVED

*(IFNOT (A7f=1 AND B1a=6 AND B1b=6)), NOT THINKING ABOUT CANCER AND DID NOT NEED CANCER INFO/SUPPORT IN LAST 12 MONTHS)

C1_1. We are now interested to learn about the people or services that have provided you with information and/or support. By support, we mean emotional support, practical support and being referred to other services if needed. In the last 12 months, would you have liked to receive information and/or support from…?

C1_2. If so, to what extent have your support/information needs been met?

*PROGRAMMER NOTE: FROM SECOND STATEMENT, CHANGE LEAD IN TEXT TO:
C1_1. In the last 12 months, would you have liked to receive information and/or support from…?
C1_2. If so, to what extent were your needs met by…?

*PROGRAMMER NOTE: ROTATE ORDER MENTIONED.
*(STATEMENTS)
a. Breast Cancer Network Australia (BCNA)
b. Your breast cancer surgeon
c. Your breast reconstruction/ plastic surgeon
d. Your medical oncologist
e. Your chemotherapy day unit
f. Your radiation oncologist
g. Your radiation treatment centre
h. Your Breast Care Nurse
i. Your GP
j. Your counsellor or psychologist
k. Your employer or workplace
l. A local support group for those with breast cancer
m. Your partner
n. Your family and friends

*(RESPONSE FRAME 1)
1. Needed information and/or support from them **(*provide response below*)**
2. Did not need information and/or support from them **(*click next to continue*)**

*(RESPONSE FRAME 2)

1. All my needs were met
2. Most of my needs were met
3. Some of my needs were met
4. None of my needs were met
5. Not sure

*(ALL)

C2. Breast Cancer Network Australia (which we will refer to as BCNA) provides a range of products and services. Before today, were you *aware* that BCNA provides…?

*PROGRAMMER NOTE: FROM STATEMENT B, CHANGE LEAD IN TEXT TO:

Were you *aware* BCNA provides …?

*(PROGRAMMER NOTE: ROTATE ORDER MENTIONED)
*(STATEMENTS)

a) Information for people with metastatic breast cancer (e.g. the *Hope & Hurdles* information pack)
b) A free telephone counselling service for people who have metastatic breast cancer
c) A phone helpline that people with breast cancer can call for information and support
d) Information and opportunities to become more active and eat well
e) An online space where people can chat with others who have breast cancer
f) Information forums held in different towns and cities around Australia

*(RESPONSE FRAME)

1. Yes
2. No
3. Not sure

*(ALL)

C3. BCNA is also involved in a number of activities. Before today, were you *aware* that BCNA is involved in…?

*PROGRAMMER NOTE: FROM STATEMENT B, CHANGE LEAD IN TEXT TO:

Were you *aware* BCNA is involved in…?

*(PROGRAMMER NOTE: ROTATE ORDER MENTIONED)
*(STATEMENTS)

a. A partnership with For Benefit Medicines, a company that sells breast cancer medicines and gives profits to BCNA
b. Advocating (speaking up) to government and other organisations for a better deal for people with breast cancer
c. A program called Inspired Adventures in which people travel in groups to amazing places and raise money to support people with breast cancer
d. Connecting people diagnosed with breast cancer to a cancer support group

*(RESPONSE FRAME)

1. Yes
2. No
3. Not sure

*(TIMESTAMP4)

SECTION D: MEMBER COMMUNICATIONS

*(ALL)

D1. In the last 12 months have you *read or browsed* any of the following BCNA publications…?

*PROGRAMMER NOTE: FROM SECOND STATEMENT, CHANGE LEAD IN TEXT TO: In the last 12 months, have you read or browsed…?

*(STATEMENTS)

a) An issue of The Beacon (BCNA's quarterly newsletter for people with early breast cancer)
b) An issue of The Inside Story (BCNA's quarterly newsletter for people with metastatic breast cancer)
c) At least a section of My Journey Kit (BCNA's information kit for people with early breast cancer)
d) At least a section of Hope & Hurdles (BCNA's information pack for people with metastatic breast cancer)
e) One or more of BCNA's printed booklets or fact sheets on a range of breast cancer topics

*(RESPONSE FRAME)

1. Yes
2. No
3. Not sure
4. Not relevant to me/ my diagnosis

D2. And, thinking about *other services* provided by the BCNA, in the last 12 months *have you*…?

*PROGRAMMER NOTE: FROM SECOND STATEMENT, CHANGE LEAD IN TEXT TO: In the last 12 months have you…?

*(STATEMENTS)

a) Gone to the BCNA website to read breast cancer information
b) Gone to the BCNA website to save a copy onto your computer or print one or more booklets or fact sheets on a breast cancer topic
c) Phoned BCNA
d) Attended a BCNA fundraising event
e) Attended a BCNA information forum
f) Visited the BCNA Online Network
g) Visited the BCNA Facebook page
h) Read at least one email sent from BCNA

*(RESPONSE FRAME)

1. Yes
2. No
3. Not sure

*(ALL)

D3. In line with other organisations, and to cut down costs, BCNA is interested in providing some of its publications in an online format. These would be on BCNA's website and a link would be sent out via email. Before doing this, BCNA wants to know what members would prefer.

For each of the following, please indicate whether you would prefer to receive the information in printed or online format?

*PROGRAMMER NOTE: FROM STATEMENT B, CHANGE LEAD IN TEXT TO:

Would you prefer to receive this in a…?

*(STATEMENTS)

a. The Beacon (BCNA's quarterly newsletter for people with early breast cancer)
b. The Inside Story (BCNA's quarterly newsletter for people with metastatic breast cancer)
c. My Journey Kit (BCNA's information kit for people with early breast cancer)
d. Hope & Hurdles (BCNA's information pack for people with metastatic breast cancer)
e. Booklets or fact sheets on a range of breast cancer topics

*(RESPONSE FRAME)

1. Printed copy
2. Online copy via email or website
3. Prefer not to receive this
4. Not sure

*(ASK IF ANY OF D3a-e=1, PREFER PRINTED COPY FOR ONE OR MORE PUBLICATIONS)

D4. Why would you prefer to receive printed information for some or all publications?

(PLEASE SELECT ALL THAT APPLY)

*PROGRAMMER NOTE: MULTIPLE RESPONSES POSSIBLE EXCEPT 8 IS AN EXCLUSIVE ANSWER

1. I can take it anywhere I want to read it
2. I can pass it on to other people
3. I like to file it with other information
4. I don't have easy access to the internet
5. I don't feel confident using the internet
6. My internet connection is too slow / unreliable
7. Other (please specify)
8. Not sure

*(ALL)

D5. How likely would you be to pay a small yearly fee (say $20) to receive four printed issues of The Beacon (BCNA's quarterly newsletter) sent out each year?

1. Very likely
2. Quite likely
3. Not very likely
4. Very unlikely
5. Not sure

*(ALL)

D6. If you wanted or needed to call BCNA, what time of day would you be MOST likely to call?

1. Monday to Friday, 8am to 5pm
2. Monday to Friday, 5pm to 9pm
3. Saturday, 9am to 1pm
4. Would not call BCNA
5. Not sure

*(TIMESTAMP5)

SECTION E: BCNA FUNDING AND DONATIONS

*(ALL)

E1. Next we have two questions about how charitable organisations are funded.

In the last 12 months, have you given a donation of money to any of the following charities…?

(PLEASE SELECT ALL THAT APPLY)

(PROGRAMMER NOTE: MULTIPLE RESPONSES POSSIBLE EXCEPT 6-7 ARE EXCLUSIVE ANSWERS)

1. BCNA
2. Another breast cancer charity
3. Another cancer charity (e.g. Cancer Council)
4. A hospital foundation
5. Another charity
6. Have not made a donation
7. Not sure

*(ALL)

E2. BCNA is a not for profit organisation that provides free breast cancer information and services.

BCNA receives about 85% of its funding from public fundraising and corporate sponsorship. This includes individual donations, gifts from wills, fundraising events and corporate donations. Most of the remaining funding (around 15%) is provided by the government.

Before today, were you aware this was how BCNA was funded to provide its free breast cancer information and services?

1. Yes
2. No
3. Not sure

*(ALL)

E3. Would knowing that BCNA receives most of its funding from non-government sources make it any more likely that you would *make a donation* to BCNA in the future?

1. Yes, a lot more likely
2. Yes, a little more likely
3. No, no more likely
4. Not sure

*(TIMESTAMP6)

SECTION F: YOUR PERSONAL VIEW

*(ALL)

F1. Recently, state parliaments have discussed a range of laws that affect people who have serious medical conditions. In your opinion, to what extent do you agree or disagree that…?

*PROGRAMMER NOTE: FROM STATEMENT B, CHANGE LEAD IN TEXT TO:

To what extent do you agree or disagree that…?

(*PROGRAMMER NOTE: ROTATE ORDER MENTIONED)
*(STATEMENTS)

a) Medicinal marijuana should be made legal in Australia for people who are suffering ongoing and severe pain
b) Voluntary and medically assisted euthanasia (allowing people to end their lives with their own consent and the help of doctors) should be made legal in Australia for people who are near the end of their life and who are suffering

*(RESPONSE FRAME)

1. Strongly agree
2. Agree
3. Neither agree nor disagree
4. Disagree
5. Strongly disagree
6. Not sure
7. Prefer not to say

*(TIMESTAMP7)

SECTION G: YOUR FINAL COMMENTS

*(ALL) (PROGRAMMER NOTE: NON-MANDATORY)

G1. What more do you think BCNA could do to help Australians affected by breast cancer (including their family and friends) in the future?

(RECORD VERBATIM)

*(TIMESTAMP8)

SECTION H: DEMOGRAPHICS

*(ALL)

H1. Finally, a few questions to help us with our analysis.

What is your gender?

1. Male
2. Female
3. Other
4. Prefer not to answer

*(ALL)

H2. What is your age group…?

1. 18 to 29 years
2. 30 to 39 years
3. 40 to 49 years
4. 50 to 59 years
5. 60 to 69 years
6. 70 to 79 years
7. 80 years or over
8. Prefer not to answer

*(ALL)

H3. In which state/territory do you live?

1. Victoria
2. New South Wales
3. South Australia
4. Tasmania
5. Queensland
6. Western Australia
7. Australian Capital Territory
8. Northern Territory
9. Prefer not to answer

*(ALL)

H4. What is your postcode?

1. Enter postcode ____ (PROGRAMMER NOTE: LOOKUP WITH POSTCODE LIST)
2. I don't know my postcode
3. Prefer not to answer

*(H4=2)

H4a. What is your suburb?

1. Enter suburb____
2. Prefer not to answer

*(ALL)

H5. What is the main language you speak at home?

1. English
2. Arabic
3. Cantonese
4. Greek
5. Italian
6. Mandarin
7. Vietnamese
8. Other (please specify)
9. Prefer not to answer

*(ALL)

H6. Do you identify as an Aboriginal or Torres Strait Islander?

1. No
2. Yes, Aboriginal
3. Yes, Torres Strait Islander
4. Yes, both Aboriginal and Torres Strait Islander
5. Prefer not to answer

*(ALL)

PRIZE1. To thank you for your participation, BCNA is giving away eight $100 Sussan gift vouchers. Would you like to enter the prize draw?

1. Yes
2. No

*(PRIZE1=1, WISH TO ENTER PRIZE DRAW)

PRIZE2. To allow BCNA to contact winners, we will need to pass on the details we used to send you the survey. These details will NOT be linked to your survey responses and will be used only for the purpose of the prize draw.

Can we provide BCNA with your contact details for the purpose of notifying winners?

1. Yes
2. No

*(PRIZE2=1, WISH TO ENTER PRIZE DRAW) [ONLY DISPLAY FOR 1768o]

PRIZE3 So we are able to get in contact, can you please provide your preferred contact details?

1. Name:_______
2. Phone:_______
3. Email:_________
4. I don't wish to provide details *(you will not be entered in the prize draw)*

*(TIMESTAMP9)

CLOSE

[PROGRAMMER NOTE: Please remove ‘PAUSE’ button from this screen and change ‘Next’ button text to ‘Submit’]

Thank you for your participation and time. Breast Cancer Network Australia will be supplied with a summary of the key findings from the research. Please be assured that you will not be identified in any way, and your responses to closed questions (ones you click) will be merged with those of all other participants.

This research is carried out in compliance with the Privacy Act and the Australian Privacy Principles, and the information you have provided will only be used for research purposes. The Social Research Centre’s Privacy Policy is available by visiting www.srcentre.com.au and clicking on the Privacy Policy in the right hand menu.

Please click ‘Submit’ to complete the survey.

*(ALL)

FINAL SCREEN

Thanks for your time, your responses have been submitted. Good luck in the prize draw! You may now close your browser or go to the BCNA homepage: https://www.bcna.org.au/

*(TIMESTAMP10)

TERM1 Thanks for your interest, but this survey is only for people experiencing breast cancer.

Appendix 2 Respondent profile vs BCNA Member profile

When compared to the available 2016 profile data of BCNA members, survey respondents displayed similar characteristics on two key variables. A comparison of the profiles of each population are provided in Table 13. Note that the member data was collected at a different point in time to survey data. The comparison is provided only to indicate that the achieved response was spread across member characteristics.

Table 13 Sample profiles of BCNA members and survey respondents

Demographics	BCNA members		Survey respondents	
Diagnosis Type	n=	%	n=	%
Early breast cancer (incl. DCIS / LCIS)	108,113	91.1	9,791	94.9
Metastatic	3,957	3.3	527	5.1
Unspecified	6,607	5.6	-	-
Total	118,677	100	10,318	100
State	n=	%	n=	%
NSW	36,974	31.4	3,066	29.7
VIC	32,166	27.3	2,675	25.9
QLD	23,121	19.6	2,120	20.5
SA	9,032	7.7	795	7.7
WA	10,641	9.0	1,044	10.1
NT	587	0.5	58	0.6
TAS	3,307	2.8	275	2.7
ACT	1,932	1.6	251	2.4
Unspecified	131	0.1	34	0.3
Total	117,891	100	10,318	100

* Membership numbers are not identical due to differences in the data collection periods (Jul-Dec 2016).

Appendix 3 Subgroup derivations

Note that level of engagement was derived from question D2 on the basis of how many of the eight key BCNA services had been accessed by respondents (see Appendix 1 for question details).

Significance testing was conducted across the subgroups detailed in Table 14.

Table 14 Subgroups used for cross-tabulations

Variable	Values	Derivation rules
ARIA	1=Major city 2=Inner regional 3=Outer regional 4=Remote 5=Very remote 6=Unknown	Derived from postcode
Source	1=Direct link 2=Open link	1=Email and SMS list 2=All open link on website
Survey	1=Main survey 2=Extra time	1=completed in main survey period (3/2/17 – 20/2/17) 2=completed after main survey closed (20/2/17 – 30/6/27)
Gender	1=Female 2=Male / Other 3=Unspecified	Grouped from H1: -98=3 1=2 2=1 3=2
Age	1=Under 40 years of age 2=40-49 years 3=50-59 years 4=60-69 years 5=70 years of age or over 6=Unspecified	Grouped from H2: -98=6 1 and 2=1 3=2 4=3 5=4 6 and 7=5
LOTE	1=English 2=Other 3=Unspecified	Derived from H5: -98=3 1=1 else=2
Region	1=Metro 2=Regional or rural 3=Unknown	Derived from ARIA: 1=1 2-5=2 6=3
BCTYPE	1=DCIS / LCIS 2=Early 3=Metastatic	Grouped from A1: 1=1 2=2 3=3 4=2
METS	1= Metastatic 2= Non-metastatic	Grouped from BCTYPE: 3=1 else=2

Variable	Values	Derivation rules
Recent	1= < 12 months 2= 12 months < 2 years 3= 2 years < 5 years 4= 5 years < 10 years 5= More than 10 years	Grouped from A3: 1 and 2=1 3=2 4,5,6=3 7=4 8 and 9=5
Treated	1=Active treatment 2=Hormone therapy 3=No current treatment	Derived from A5 (following backcoding of codes 5 and 6): 1, 2, 3=1 4=2 7=3
Contact	1=Contacted via phone or in person 2=No in person contact with BCNA	Derived from D2_c, D2_d, D2_e; If any =1, then Contact=1 Else Contact=2
Online	1=Used 2=Have not used / not sure	Derived from D2_f; 1=1 Else=2
Donate	1=Donated to BCNA 2=Donated to other charity 3=Not made any donations	Derived from E1 (multi response): 1=1 2, 3, 4, 5=2 (excludes 1=1 or 6,7=3) 6 and 7=3
Website	1=Used 2=Have not used / not sure	Derived from D2_a; 1=1 Else=2
engage_factor	0=Least engaged 8=Most engaged	Derived as a count of D2_a – D2_h that were =1
engage_factor_group	1=Not engaged 2=Moderately engaged 3=Very engaged	Derived from engage_factor; 0-2=1 3-5=2 6-8=3

Appendix 4 Significance testing

Significance testing was conducted across the subgroups detailed in Table 15.

Table 15 Subgroups used for significance testing

Main Group	Subgroups
ARIA	Major city; Inner regional; Outer regional; Remote; Very remote; Unknown
Gender	Female; Male / Other; Unspecified
Age	Under 40; 40-49 years; 50-59 years; 60-69 years; 70 years or over; Unspecified
LOTE	English; Other; Unspecified
State	VIC; NSW; SA; TAS; QLD; WA; ACT; NT; Prefer not to answer
Region	Metro; Regional or rural; Unknown
BCTYPE	DCIS / LCIS; Early; Metastatic
METS	Metastatic; Non-metastatic
Recent	Up to 12 months; 1-2 years; 2-5 years; 5-10 years; More than 10 years
Treated	Active; Hormone; No current treatment
System	Public; Private; Not specified
Contact	Contacted BCNA by phone or in person; No phone or in person contact with BCNA
Online	Used BCNA Online Network; Haven’t used Network
Donate	Donated to BCNA; Donated to other charity; Not made any donations
Website	Have used BCNA website; Haven’t used BCNA website
engage_factor_group	Not engaged with BCNA; Moderately engaged with BCNA; Very engaged with BCNA

Appendix 5 Verbatim examples

This section provides examples of responses received in response to each of the open-ended questions asked of respondents. For each questions, examples are included under the main themes that emerged from the comments.

B4. Overall, thinking about your experiences of breast cancer, what were your main needs?

Support from Breast Care Nurse

"More time with Breast Care Nurse." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Support from a nurse would have been nice." (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

"Better Breast Care Nurses." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"The Breast Care Nurses where amazing." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"A useful Breast Care Nurse. The ones I had gave a new definition to useless." (Female, Australian Capital Territory, Early Breast Cancer)

"Breast cancer nurse was very supportive." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Was given treatment by caring nurses/doctors." (Female, 60 to 69 years, Victoria, DCIS / LCIS)

"Getting to see a Breast Care Nurse!" (Female, 60 to 69 years, New South Wales, DCIS / LCIS)

"Support from Breast Care Nurses." (Female, 60 to 69 years, Queensland, DCIS / LCIS)

"I did chemo first for six months privately and had no contact at all with a Breast Care Nurse." (Female, 40 to 49 years, Australian Capital Territory, DCIS / LCIS)

"Breast care nurses and the packs they provided." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Public Breast Care Nurses never seen, private one saw me only with my 2 breast surgeon reviews, but had nothing to offer except wig lady details. No contact or support when metastatic as a 37 year old." (Female, 30 to 39 years, Queensland, Metastatic Breast Cancer)

"Breast care nurse was invaluable, couldn't have done it without her." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"The care provided by the Breast Care Nurses in surgery and oncology was the best care I have ever had." (Female, 18 to 29 years, Queensland, Early Breast Cancer)

Support from doctors

"Support anytime from doctors." (Female, 40 to 49 years, Victoria, Early Breast Cancer)

"Doctors support. Follow up." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Was given treatment by caring nurses/doctors." (Female, 60 to 69 years, Victoria, DCIS / LCIS)

"Ease of treatment, quality and knowledge of doctor." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Help, support, and a great Doctor who cared.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“Feel comfortable with my doctors, which I am, so my experience has been positive and successful.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Open communication with my doctors.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Doctors that cared.” (Female, 60 to 69 years, Queensland, DCIS / LCIS)

“It was wonderful to experience such a switched on and caring surgical team from the initial breast specialist doctor, receptionist, Breast Care Nurse, anaesthetist, physiotherapist and surgeon.” (Female, 60 to 69 years, Western Australia, DCIS / LCIS)

Support from other medical professionals

“Kind medical staff, all were fantastic.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“Caring, thoughtful treatment by experienced professions who took into account my individual needs.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“I was a working single mum. The chemo did not stop me working, the double mastectomy did. I looked into all available to help me at home, and I spoke to social workers when having chemo. all they offered was churches, family or clubs to help out a bit at home after the surgery. I have none of these, I felt let down by the disassociation the social workers gave me, they were not interested.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Caring, medical staff, after hospital care. Great follow up visits.” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

Honesty, inclusion and respect for the individual

“To be heard by my medical team (which I was after changing breast surgeons) and to be supported.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Honest answers to questions that concerned me.” (Female, 70 to 79 years, Queensland, Early Breast Cancer)

“To do it my way.” (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

“To have my choices respected.” (Female, 40 to 49 years, Queensland, Early Breast Cancer)

“I needed to know that my feelings as a person were respected and I was not treated as cancer person.” (Female, 18 to 29 years, Queensland, Early Breast Cancer)

“Being called by my name… Friendly supportive specialists who patiently answered questions, even when they'd already done so. Privacy.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“To not be in so much pain. To not feel like a moaner/hypochondriac.” (Female, 50 to 59 years, Tasmania, Metastatic Breast Cancer)

“Being heard. Having information explained and repeated. Being called by my name and developing a rapport with the admin staff, nurses, doctors.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“I received plenty of information from my doctor and oncologist but no one informed me that today, 14 months later, I would still be going through related complications. I have gone through

instant menopause, symptoms are severe, have lymphedema/cording complications, have had infection, so had to remove expanding bag. I thought 6 months it would be over, not sure if it would have been better knowing though." (Female, 40 to 49 years, Queensland, Early Breast Cancer)

Counselling / mental health support

"Efficient friendly therapy. Being listened to." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"For my anxiety, needs to be considered too." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Emotional and mental support." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Psychological information." (Female, 50 to 59 years, Tasmania, Early Breast Cancer)

"That what I was feeling was normal." (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

"Mainly someone else in the same boat to talk to." (Female, 70 to 79 years, Queensland, Early Breast Cancer)

"Dealing with anxiety." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Understanding why I was fearful." (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"Just coping with the diagnosis." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Telephone counselling." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"Dealing with anxiety, fatigue and a bunch of complications after chemo whacked my body." (Male, 40 to 49 years, Victoria, Early Breast Cancer)

"Psychological." (Male, 60 to 69 years, Queensland, Early Breast Cancer)

"Competent, compassionate clinical care." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Looking back, I realise that I needed a social worker, I navigated everything on my own and subsequently suffered for lack of this wingman. I was referred to a health dept. psychologist who concluded that I needed to change jobs!!! What a stressful thing to suggest in the middle of treatment. Only a public servant could be so blind as to what the real world is like." (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

"Social worker (from palliative care) visits at home." (Female, 40 to 49 years, Victoria, Metastatic Breast Cancer)

"Being treated privately I didn't have access to a social worker as they do in the public sector to coordinate my accommodation and travel arrangements for radium treatment away from home. That was very upsetting and I don't believe is fair." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"The offer of a counsellor for my rehabilitation and wellbeing." (Female, 60 to 69 years, New South Wales, DCIS / LCIS)

Emotional support

"To be understood, how I felt..." (Female, 60 to 69 years, Queensland, DCIS / LCIS)

"Emotional support." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"Knowing someone would be there when needed." (Female, 70 to 79 years, Queensland, Early Breast Cancer)

"Talking to others not medical people." (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"At the time of diagnosis, opportunity to talk to someone who'd had a similar operation would have been great. I was already seeing a psychologist for other reasons and that was very helpful." (Female, 70 to 79 years, Early Breast Cancer), New South Wales

"Having someone to listen to concerns." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Understanding and time from all involved." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Talking to others who know how you feel." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Someone to talk to." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"To have all my questions and fears answered." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

Reassurance

"Reassurance that all was done to help me." (Female, 60 to 69 years, Victoria, DCIS / LCIS)

"Knowing I would survive." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"I needed to be reassured that I was taking the right path. I needed someone to listen to my fears/concerns however trivial they might have seemed." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"I was 26 years old when I was diagnosed. I appreciate that statistically there are less of us in my age group, however I often felt like there was no one else in the same situation as me. I needed to hear stories of experiences and survivors my age." (Female, 18 to 29 years, Australian Capital Territory, DCIS / LCIS)

Understanding my specific cancer / outcomes

"Long term effects of surgery and consequences." (Female, 60 to 69 years, Western Australia, DCIS / LCIS)

"Being listened to as a young person with breast cancer. I was diagnosed at 22 years old and it was very difficult to get my opinion/thoughts/questions/worries heard!" (Female, 18 to 29 years, Western Australia, Early Breast Cancer)

"Understanding likely prognosis, with a view that there was reasonable hope given it was a stage 4 diagnosis." (Male, 60 to 69 years, Victoria, Metastatic Breast Cancer)

"Information about triple negative breast cancer." (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

"Awareness, post treatment services, sexual/relationship changes, physical body changes." (Male, Queensland, Early Breast Cancer)

"Knowing what is happening and what will happen long term." Other, 50 to 59 years, Victoria, Early Breast Cancer)

“Clear and concise information regarding the stages of my treatment and future care and time with my surgeon.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Clear and factual information. A little more information on how to minimise cost of treatment and the options available. I chose to have a private richter for surgery and continued follow up care but at the time was unaware that radiation treatment was available through the public sector. It was an acquaintance of mine who had been through breast cancer treatment who suggested an option was available to me.” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

“Receiving honest, easy to understand explanations and support during my treatment.” (Male, 60 to 69 years, New South Wales, Early Breast Cancer)

“Information on and time to research the recommended treatment.” Other, 60 to 69 years, New South Wales, Early Breast Cancer)

“Understanding the cancer and treatment and effects upon my body.” (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

“Information on what to expect.” (Male, 40 to 49 years, Victoria, Early Breast Cancer)

Effective treatment leading to recovery

“To ensure the surgery removed all the cancer.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“To beat it and live long enough to raise my children.” (Female, 18 to 29 years, Western Australia, Early Breast Cancer)

“Competency from my medical team.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“That all the cancer was removed.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Medication issues.” (Female, 80 years or over, New South Wales, Early Breast Cancer)

“Post-operative ongoing drug decisions.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Being given the best treatment for me.” (Female, 30 to 39 years, Victoria, Early Breast Cancer)

“Getting the medical treatment I needed.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“Get treatment over with and start to recover.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Help determining if problems experienced are side effects of treatment and how to deal with them, and if not, a suggested course of action e.g. GP, counselling, physio etc. I often have to resort to my own research to work out what to do next. Not always easy.” (Female, 50 to 59 years, Metastatic Breast Cancer)

“Getting the right treatment and understanding it.” (Female, 50 to 59 years, Western *Australia, Early Breast Cancer)*

Assistance during treatment

“Needing support so much, as in so much pain, fatigue, numbness, rashes, lack of appetite, etc. and in general total un wellness and weakness. Constantly needing rest.” (Female, 60 to 69 years, Victoria, Metastatic Breast Cancer)

“Breast Massage. Being heard about problems with soreness and my being diligent about getting the problem fixed. Importance of hirudoid cream on chemo arm to calm veins.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“Rehabilitation, managing side effects.” (Female, 40 to 49 years, Australian Capital Territory, Early Breast Cancer)

“Information on treatment and side-affects and advice/support on rehabilitation and recovery. information on progression of metastatic cancer particularly in relation to spread to pelvic area.” (Female, 60 to 69 years, Victoria, Metastatic Breast Cancer)

Support to live well / recover

“General information around wellness and nutrition.” (Female, 50 to 59 years, South Australia, DCIS / LCIS)

“Lifestyle. Getting back to normal.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

“To look after myself with normal lifestyle.” (Female, 40 to 49 years, Victoria, Early Breast Cancer)

“131120 being staffed by cancer nurses. Receiving support material, e.g. diet, exercise, support groups in the area, psychologist etc. Information about my options/medical treatment/drugs/side effects.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“Information what could I do to mitigate against the cancer returning. Did not feel that things such as diet and exercise were emphasised enough.”

“Understanding reconstruction options.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“More communication on hormonal and body changes.” (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

“Correctly informed of treatment options.” (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

“It would have helped to have had more information about possible side effects of various treatments before they happened, though I realise this is hard because every patient reacts differently to the treatments.” (Female, 60 to 69 years, Victoria, Metastatic Breast Cancer)

“Bring told exactly what to expect especially ongoing pain from surgery. Arm issues. Weight gain and side effects from Arimidex.” (Female, 50 to 59 years, Victoria, DCIS / LCIS)

“Wish someone had talked to me re more options.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Statistics on if cancer will come back.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“More information about Natural Remedies.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“Help to regain fitness.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

Financial advice and support

“Financial support.” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"Financial options of treatment would be most convenient to people who can simply not afford all the treatment through the private sector and at the time of diagnosis when your brain is exposed to information overload, this would be a welcome addition to ease the financial burden." (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"Ongoing financial cost of treatment." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Financial needs." (Female, 70 to 79 years, Victoria, Early Breast Cancer)

"Understanding the costs - I paid $20k for 3 surgeries and all the diagnostics and pathology." (Female, 30 to 39 years, Queensland, DCIS / LCIS)

"I'm a single parent and have found it hard to be the main income earner and dealing with metastatic cancer and not being able to take time for myself. Financially it has been very stressful and some of the scans I cannot afford, so that is worrying" (Female, 50 to 59 years, New South Wales, Metastatic Breast Cancer)

"I also needed help in the house when I first had ray treatment however due to isolation and the fact I was under 65. I was not given any assistance. The cost of scans every couple of months and the cost of medications such as injections every 4 weeks and fuel costs to travel to appointments." (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

Help at home

"I was worried that I couldn't look after my dog." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Help at home." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Help with child all aspects." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"I continued to work and to this day continue to work because I'm not well enough to work out other options and I'm a sole parent with a mortgage. I'm too tired to sort it. I work, sleep and fail. The house is a mess. Just managing to keep my head above water." (Female, 40 to 49 years, Australian Capital Territory, DCIS / LCIS)

"Throughout my journey I have struggled with childcare, finances (due to work issues and added medical/travel costs etc.) and emotional support." (Female, 30 to 39 years, Western Australia, Metastatic Breast Cancer)

Help with work

"Getting back to work. Information." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Time off work." (Female, 60 to 69 years, Western Australia, DCIS / LCIS)

"Needed to take some time off until I got better." (Female, 30 to 39 years, Victoria, Early Breast Cancer)

"I have taken sick leave on advice of oncologist, I'm a kinder assistant and children attend sick all the time. My sick leave long service has run out. My husband taken long service leave for four months of my seven month treatment… may take holiday for radiation. Maybe some Centrelink advice. Can you get sickness benefits or health care card whilst on sick leave? Would help working families. I normally work 42 hour week during school term." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“Ability to have 'down time' - financial assistance regardless of employment status (as a full-time employed individual, I was not eligible for sickness allowances although others in casual/student positions were). Meant I had to continue to work and went into significant negative annual leave in order to get by.” (Female, 18 to 29 years, New South Wales, Early Breast Cancer)

“Working throughout my treatment to keep me busy!” (Female, 18 to 29 years, Queensland, Early Breast Cancer)

More information

“I would also have liked to automatically receive a copy of the pathology reports and operation report. In some places overseas this information is automatically available. I find it intimidating to have to ask for it. The more information the better.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Information!!” (Female, 40 to 49 years, Queensland, Metastatic Breast Cancer)

“Having facts to enable decisions.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

“Information on pain relief.” (Male, 70 to 79 years, Victoria, Early Breast Cancer)

“To trust experts, not be overwhelmed by information and then be told, it's your choice!" how do I know what is right?” (Female, 50 to 59 years, Queensland, Metastatic Breast Cancer)

“Lots of info.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“General information.” (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“Correct and up to date information.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Being fully informed as needed” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Information I could understand.” (Female, 40 to 49 years, New South Wales, DCIS / LCIS)

“As a male there is no support information.” (Male, 50 to 59 years, New South Wales, Early Breast Cancer)

Support from family

“Support from family and friends.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“The love and support I receive from my husband.” (Female, 70 to 79 years, Victoria, Early Breast Cancer)

“My family.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“To have the support from family and friends.” (Female, 30 to 39 years, Victoria, Early Breast Cancer)

“Having my family there for me no matter what.” (Female, 50 to 59 years, South Australia, Metastatic Breast Cancer)

“Family family family.” (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

Support from friends

“Immediate mentoring from a close friend.” (Male, 60 to 69 years, South Australia, DCIS / LCIS)

“Support and friendship.” (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“I had great support from family and friends, but they just did not fully understand how I felt and that changed daily.” (Female, 40 to 49 years, Queensland, Early Breast Cancer)

Support for family

"Support for family around me." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Support for family and friends." (Female, 18 to 29 years, Western Australia, Early Breast Cancer)

"Support from family. Support for family" (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"I did know there was help out there, but failed to contact anyone, we coped the best we could. We came together as a family. I met women at clinic going through chemo with me, we became friends, and we all have been supporting each other, still are to this day. Probably more support for family would be a good improvement." (Female, 40 to 49 years, Queensland, Early Breast Cancer)

General Support

"Support, from all around me." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"Support person and friendly chats." (Female, 18 to 29 years, New South Wales, Early Breast Cancer)

"Someone I could call, go and visit when needed." (Female, 50 to 59 years, Victoria, Metastatic Breast Cancer)

"Help." (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

"I think because I went private, no breast cancer organisations contacted me. I should have reached out for help." (Female, 40 to 49 years, Queensland, Early Breast Cancer)

"Physical and emotional support." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Assistance when things went wrong." (Female, 50 to 59 years, Western Australia, DCIS / LCIS)

"To feel cared for." (Female, 70 to 79 years, Victoria, Early Breast Cancer)

Surgeon / other specialists

"Straight forward and honest medical team and surgeon." (Female, 18 to 29 years, New South Wales, Early Breast Cancer)

"Would like doctors to explain the results of tests to me not just that they are worse or stable. Explain why things are sore (feet and hands), feet and tips of fingers get very sore. I am a person that likes to know why things are happening to me and not being treated like everyone else as everyone is different. I feel my GP is more concerned about me than the specialist. He is concerned about me as a person. I know I am very lucky to have such an excellent GP." (Female, 70 to 79 years, New South Wales, Metastatic Breast Cancer)

Timely access of medical treatment / appointment times

"Confidence in my medical personnel and quick access to appointments with these people as required. Not having to wait and worry." (Female, 50 to 59 years, South Australia, Metastatic Breast Cancer)

"Appointment for specialist - waiting." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Local support

"I would have liked access to a heated pool locally as I was aware of the benefits of exercise and water therapy but this wasn't available in my town. Because I couldn't swim in winter I then had to find a trainer who understood my physical abilities having to regain my strength after chemo and radium. I know of other ladies who were cancer survivors struggled also trying to

find support for a fitness program to suit us 50+ year olds." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"Travelling costs is an issue and an ongoing problem as we have to pay a minimum of $550 every 3 weeks for airfares which I have had to beg pats for urgent refunds. This only happened because I had to contact my local MP I was forwarded to a social worker at our local hospital by my… nurse and have an advocate involved… due to us not receiving our refund promptly. Not being able to work and therefore left with a huge mortgage still plus a car rental of $140 of which is not refunded has caused a massive stress in our lives. Really I would like to have my treatment in my hometown city." (Female, 50 to 59 years, South Australia, Metastatic Breast Cancer)

Support for men with cancer

"Firstly, I am a man. Any questions I asked were answered with, "we don't know you are a man". Oncologist insisted no connection between diabetes 2 and tamoxifen. Not enough information given on side effects for men. I stopped tamoxifen against oncologists advice but my wife says I am almost human again. I changed my diet and have lost all the weight + more that I put on when on tamoxifen. I now have normal blood sugar levels." (Male, 70 to 79 years, Victoria, DCIS / LCIS)

"As I am male and use a wheelchair my needs where not met. Need mobility, financial assistance, health options, needed information for men. Most services are only for women, felt left out alone. Needed a waiting room and change room they were not an option for men." (Male, 40 to 49 years, Western Australia, Early Breast Cancer)

"To give men a voice to improve early detection and better outcomes." (Male, 50 to 59 years, New South Wales, Metastatic Breast Cancer)

Not to be defined by cancer

"I have had so much contact with hospitals, pathology, and other doctors that in my 'spare' time, I like to be 'normal' and pretend that I don't have cancer. Apart from friends who like to have an update, I avoid the topic, and I hate getting the BCNA newsletter, as it is just another reminder that I have cancer. I have sent an email to be taken off the list, but the newsletters have just kept coming. Having been a nurse for around 30 years, I don't need much educating, and if I have any queries, I ask the consultants that I see. Sometimes people with breast cancer become their cancer, and use their diagnosis to feel special and gain attention from others. I am not one of them." (Female, 50 to 59 years, Victoria, Metastatic Breast Cancer)

"I needed not to be defined by my cancer. I do not want to think about myself as a survivor. I knew from the outset that my treatment would be successful because my cancer was caught so early and so I feel it diminishes the experience of those who travel a much tougher road, if women in my position jump on the 'breast cancer survivor' bandwagon. It also serves to increase the perception (one that I had) that 'survivors' can fall back into the mire at anytime." (Female, 60 to 69 years, Tasmania, Early Breast Cancer)

Other

"Support and advice from people who had have cancer. I had all the support from family and friends, but no from people who had the same." Other, 70 to 79 years, New South Wales, Early Breast Cancer)

"The cancer council tells you to stay away from eating meat and dairy yet the hospital cannot provide meat free or dairy free meals." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"My family are in the United Kingdom but my daughter has been raised in Australia and has just finished year 12 so feel quite conflicted about missing my family but leaving my daughter behind so cancer has very much turned my life upside down." (Female, 50 to 59 years, New South Wales, Metastatic Breast Cancer)

"I found support everywhere. Thankyou Berlei - after the operation your bra made my life so comfortable. The wonderful ladies who sew the cushion, the drainage bag gave me comfort and privacy." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Knowing how to be dealing with family and friends who were avoiding me." (Female, 40 to 49 years, Queensland, Early Breast Cancer)

B5. Which, if any, of these needs were NOT met?

Support from Breast Care Nurse

"Access to a Breast Care Nurse." (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

"Breast care nurse in my area." (Female, 70 to 79 years, Western Australia, Early Breast Cancer)

"Getting to see a Breast Care Nurse was almost impossible and I had a lot of questions." (Female, 60 to 69 years, New South Wales, DCIS / LCIS)

"No Breast Care Nurses in my day." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Access to a Breast Care Nurse advocate when needed. Too little access available." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Was often difficult to contact hospital Breast Care Nurse." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Reassurance aspect in terms of hospital stay before and after surgery. The Breast Care Nurses did not spend enough time with you to talk to you about what was happening to you or after surgery care. Everything was rushed." (Female, 50 to 59 years, South Australia, Early Breast Cancer)

"Breast care nurses. Hopeless." (Female, Australian Capital Territory, Early Breast Cancer)

Support from doctors

"More contact with doctor not just nurses." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Good supportive first doctor." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"They were all met while going through treatment, it was after treatment that I felt a little let down. The day of my last chemo was the last day I saw my oncologist. I was referred to my GP but my GP didn't know a lot of what was going on or had gone on. I felt I wasn't giving a lot of information on what would happen when I finished treatment." (Female, 40 to 49 years, South Australia, Early Breast Cancer)

"Getting doctors to respond to my story. Needing advice on how to pursue malpractice."

"Sometimes feeling like doctors care." (Female, 70 to 79 years, Victoria, Early Breast Cancer)

“Some doctors were better at listening and explaining or treating me as a person than others.” (Female, 70 to 79 years, South Australia, Early Breast Cancer)

“I was not notified by my GP of my core results, I had to make the call and insist I see a doctor after the receptionist told me I never had cancer. My sister has had it twice and when you know you know. Not happy. To make matters worse, the clinic I (use to go to) train young doctors. I'm really scared for other cancer people who would've just walked away elated that the receptionist told them they never had cancer. Or has this already happened and how many times?” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

“Primary care plan was not suggested or offered to me at hospital, a friend told me about it. Then had to push my doctor to do one for me that covered my physio.” (Female, 60 to 69 years, Tasmania, Early Breast Cancer)

“Follow up from hospital.” (Female, 70 to 79 years, Victoria, Early Breast Cancer)

Surgeon / other specialists

“I did not get a second opinion.” (Female, 60 to 69 years, South Australia, Early Breast Cancer)

“Not enough access to Specialist.” (Female, 80 years or over, New South Wales, Metastatic Breast Cancer)

“No support from my surgeon.” (Female, 70 to 79 years, South Australia, Early Breast Cancer)

“I had a private specialist and a private hospital specialising in Brisbane with breast cancer. If the Cancer Council had not rescued me by placing me under the oncology department and doctor of a local public hospital, I believe I would have been dead now!” (Female, 70 to 79 years, Early Breast Cancer), Queensland

“My first oncologist (in the very expensive private sector) was very disrespectful of my choices and told me (after a 6 hour wait in his offices, where I had to leave before my appointment to go home to the babysitter because it was 10pm at night and many patients were all still waiting) that I, 'was going to die if I did not listen to him and that I had to come back for my appointment'... I have heard several horror stories about him since that experience and I feel sorry for the fact he is still treating in our area patients who prefer the private sector of cancer care. Lucky for me I have a brilliant and caring GP who (after this terrifying experience) then referred me to the public system and I now have a second oncologist and a brilliant cancer care support team. Those guys make the world of difference to my health, my mind set and respecting my personal treatment choices. and guess what. I'm still here xx.” (Female, 40 to 49 years, Queensland, Early Breast Cancer)

“Information from the surgeon was non-existent. The Breast Care Nurses were cheerful, professional and full of good advice.” (Female, 70 to 79 years, Australian Capital Territory, DCIS / LCIS)

“Surgeon was not sympathetic, did not hear anxiousness, made light of fears coming from mother's treatment.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“Difficult surgeon put me through hell.” (Female, 70 to 79 years, Victoria, Early Breast Cancer)

“I find that if I mention reconstruction during my review visits that I am fobbed off and it makes me feel as if I am being vain, apart from that the surgery cannot be done on the Sunshine Coast and I would have to go to Brisbane. There is a shortage of surgeons in Queensland who perform reconstructions.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Communication with my first surgeon was very poor even after I asked for clearer explanations." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

Support from other medical staff

"The main problem I have had is in the continuity of care. The staff treating me have changed so often that I have had to repeat myself many times. Feeling like a stranger at many appointments, peripheral to the story rather than the main character in the story. I found that quite odd." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Help with expenses and support from allied health (not my doctor or nurses, but other groups)." (Female, 70 to 79 years, South Australia, Early Breast Cancer)

Counselling / mental health support

"I did not pursue counselling for emotional issues but should have." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Mental support." (Female, 30 to 39 years, Queensland, Early Breast Cancer)

"Depression." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"Coping skills." (Female, 30 to 39 years, South Australia, Early Breast Cancer)

"They were all met to an extent, more psychological help at an affordable rate would have been good. There were no support groups for breast cancer in Melbourne that accepted men, I understand the reasons and accept them but I believe that being a part of a group would have been great help." (Male, 40 to 49 years, Victoria, Early Breast Cancer)

"Coping with the shock of the diagnosis. Coping with Where to From Here after Treatment finished." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Emotional and psychological support, family support and counselling was not offered or suggested. I was 43 years old with a husband, 2 teenage daughters and a job. Menopause and depression were not discussed. It was very difficult. We live in a small town." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Ongoing care, especially mentally. I was diagnosed with severe depression after the second breast had a lump in it as well as battling other health issues at the same time. There seemed to be no ongoing care. I felt I was left alone with my concerns and that of my partners." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"None were met hardly. No counselling, I went for anxiety depression fear still going through community welfare pay. Self-image not discussed. If cancer comes back, help me cope? No one from breast Cancer Council has ever helped me." (Female, 60 to 69 years, South Australia, Early Breast Cancer)

"Help towards medication as I suffer from depression and anxiety and Letrozole and other health problems medication cost a lot and I can't just stop it, this takes a big chuck out of the budget and this start to affect me, my husband and children daily." (Female, 40 to 49 years, Western Australia, DCIS / LCIS)

"Support for depression - some was provided for depression arising from cancer but did not cater for depression arising from a series of life events and exacerbated by cancer treatment (tamoxifen)." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Emotional Support

"Emotional support was lacking as I sometimes felt that I was just a number in treatment. My outward stoicism probably made me appear as though I was handling the experience better than I actually did handle it." (Female, 60 to 69 years, Victoria, DCIS / LCIS)

"Emotional support." (Female, 40 to 49 years, South Australia, Early Breast Cancer)

"Feeling of isolation." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Emotional needs." (Female, 50 to 59 years, Victoria, Metastatic Breast Cancer)

"I felt alone in my journey." (Female, 70 to 79 years, South Australia, Early Breast Cancer)

"Support after treatment was finished." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"The need for psychological support." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"I did not find a support group." (Female, 40 to 49 years, Western Australia, Early Breast Cancer)

"Finding a support group. Felt alone at times." (Female, 40 to 49 years, Victoria, DCIS / LCIS)

"It was up to me to try and conquer my fear. Being older had a mastectomy instead of cancer removal for this reason. No regrets." (Female, 80 years or over, Queensland, Early Breast Cancer)

"I received three counselling appointments during radiotherapy but I have received nothing since then about any programs offered to breast cancer survivors. I keep thinking I should make enquiries of the cancer care centre but my memory isn't good. I would prefer regular updates of programs offered to the many patients rather than me having to do all the enquiring over and over again." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"It was sometimes hard to find someone to talk to." (Female, 70 to 79 years, Victoria, Early Breast Cancer)

"I feel rather alone living in a regional area and having a metastatic diagnosis." (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

"As I had early stage diagnosis and treatment am expected to just be over it and back to normal (doctor and husband) which I want, but am struggling, with unexpected emotional impacts and anger which has only hit me 12 months after treatment completed." (Female, 50 to 59 years, Tasmania, Early Breast Cancer)

Reassurance

"Reassurance it was ok to not be ok." (Female, 40 to 49 years, Queensland, Early Breast Cancer)

"Proper support following treatment and remission. I really needed to still talk out my cancer journey and the futures fears and anxiety of the cancer coming back. I didn't want to continue to burden family and friends but I really needed constant reassurance. Being able to see a counsellor or psychologist after the treatment had finished would have made my emotional recovery better." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"I received reassurance from medical practitioners but only after searching out by myself. My surgeon had died and I was left stranded for a time - a compassionate oncologist took me in and did my five year check-ups even though I did not need chemo." (Female, 60 to 69 years, Australian Capital Territory, DCIS / LCIS)

"Continued reassurance that all would be well." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

Honesty, inclusion and respect for the individual

"Being respected as a young breast cancer patient." (Female, 18 to 29 years, Western Australia, Early Breast Cancer)

"Respect, empathy." (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

"Respect and confidentiality." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Respect for the right to choose treatment options other than chemotherapy and radiation." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"Understanding/respect from some people whom I thought would do so. Respect and understanding mean a great deal to me, especially at a time like this." (Female, 60 to 69 years, Queensland, DCIS / LCIS)

"Being heard and having my decisions respected by the doctors." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Sometimes I feel like a clinical trial and I am not respected as a person by my oncologist. my side effects are huge and overshadow my life but I am still alive and functioning so that is all that matters to my oncologist even though I am unable to work or function as I did before." (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

Information on treatments options / side effects

"More open discussion needs to take place regarding treatment using cannabinols. Stigmas should be removed and doctors should receive more education on the subject." (Female, 40 to 49 years, Tasmania, Early Breast Cancer)

"Information around all aspects of reconstructive surgery." (Female, 40 to 49 years, Western Australia, Early Breast Cancer)

"Side effects of hormonal therapy." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Information on reconstruction." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"My doctors were unable to clearly define the chances of cancer returning but I understand that those figures are constantly changing. also, my reconstruction surgery has not been a success. I felt it would be more pleasing than it has turned out to be, leaving me disappointed and self-conscious." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"As the doctor keeps your records, or the relevant medical facility, often with more complex detail than I would need to keep, I have nothing that summarises my treatment for my personal record." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"Reliable Oncarta information." (Female, 50 to 59 years, Tasmania, Early Breast Cancer)

"Honesty, lymphoedema info lacking." (Female, 60 to 69 years, South Australia, Early Breast Cancer)

"I wish I had a better understanding of the side effects of anastrozole." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Indepth conversation regarding surgeries." (Female, 50 to 59 years, South Australia, Metastatic Breast Cancer)

“Not being fully informed.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“Understanding why certain medication was given and the effects of them. Not getting all the answers from my list of questions to my oncologist. Not having explained what can happen to your body inside and out when treatment is finished.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“The only thing that I have found since I have late onset of a shrinking breast is that I was given so much information in the beginning of each stage that I only remember that this was spoken of when I was about to begin radiotherapy, and not much more, and now because my breasts are so different, I feel a little concerned.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Follow up by surgeon. They operate and disappear. I didn't understand pain that is normal or not. No one tells you about bandage changes etc. Left hospital feeling vague.” (Female, 60 to 69 years, Northern Territory, Early Breast Cancer)

“Future prognosis. Radiation side effects not explained or even referred to. Depression.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“*Information, and clear pictures of what to expect in a reconstruction, or just a tidy up of scars. Also information about how to remove 'dog ears.' I do not want these ugly things for the rest of my life. surgeons seem reluctant to do anything about them.”* (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

“The treatment options were not explained. Surgery was seen as urgent and as the only option. In fact, my GP referred me to a surgeon, and I thought I was seeing a cancer specialist (until I arrived). In hindsight, more review of options would have been sensible.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Some conflicting ideas on what was making me feel so bad during chemo treatment.” (Female, 70 to 79 years, Queensland, Early Breast Cancer)

“Not enough information on all aspects of the post operation/radiation recovery.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

Understanding my specific cancer / outcomes

“Probably didn't have a clear understanding of long term prognosis.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“What to expect, i.e. what is normal.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“No one has any information on male breast cancer.” (Male, 50 to 59 years, New South Wales, Early Breast Cancer)

“Most needs were met. I wanted to have genetic testing which was denied me, so was disappointed and that has left me with some fears about my daughters' risk levels and also the likelihood that I could be at risk of ovarian cancer. We have a family history of breast cancer, but it was not considered to be strong enough for testing. It is too expensive to pay for the test myself.” (Female, 60 to 69 years, South Australia, Early Breast Cancer)

Effective treatment

"The oncology department at the Frankston hospital not listening to me regarding the size of the tumour that was growing. Was only going by the treatment by other patients and not personalised treatment." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"The private hospital system and specialist I had exposed me as a high risk patient to day surgery patients and I got golden staph during the operation. After the specialist and hospital finally discharged me, I was told there would not be any need for follow up cancer treatment and only needed to attend appointments with the infectious disease specialist. Thank god for the Australian Cancer Council. I believe very strongly that the public hospital I attend who keep the female hormones under control these days with the treatment and the follow up of side effects. this was my 4th dose of cancer in 15 years - all related to being 98% positive to female hormones." (Female, 70 to 79 years, Queensland, Early Breast Cancer)

"Results and research from previous diagnosis, mammograms and doctors reports from 20 years previously. That recent surgery and treatments could have been prevented." (Female, 70 to 79 years, Queensland, Early Breast Cancer)

"I don't think my concerns about lymphedema were fully met. I had 5 or 6 sentinel nodes removed and found that my arm seemed to take a while to get back to normal after surgery. I've never been able to fully raise the arm since, although it was only a problem if I was trying to lift my arms when trying to take clothing on and off sometimes. that was just over 5 years ago. I am now diagnosed with mild lymphedema but back then I was told it would be extremely unlikely that I would have lymphedema as I only had sentinel nodes removed and lymphedema was a condition associated with lymph node removal. I think I'd like more awareness of lymphedema. I am due for my first appointment to the clinic next month." (Female, 40 to 49 years, Victoria, Early Breast Cancer)

"Unable to have pet scan." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

Assistance with rehabilitation / recovery

"Recovery support." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Post treatment support." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"Post-surgery physio for lymphedema." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"To recover and get on with my life!!!! Seek as much information as possible about my treatments and then trust that I was receiving the best possible advice, care and treatment." (Female, 70 to 79 years, Early Breast Cancer), New South Wales

"I feel that there needs to be a lot more information and support for women concerning body image. And learning to live with looking in the mirror." (Female, 30 to 39 years, Queensland, Early Breast Cancer)

"Physical rehabilitation I had to pursue myself." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

Financial help

"I needed an MRI to get a conclusive opinion but the cost involved at the recommended / referred provider was prohibitive for me. Consequently, I have not been able to have the breast MRI." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Funding for a family with young kids." (Female, 40 to 49 years, Victoria, Early Breast Cancer)

"Having to pay for reconstruction." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Financial support." (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"All were met, apart from finances for radiotherapy." (Female, 70 to 79 years, Victoria, DCIS / LCIS)

"Out of pocket expenses." (Female, 60 to 69 years, Queensland, DCIS / LCIS)

"I found it very difficult to not worry about everything concerning my/our financial situation. I was the only wage earner as my husband is disabled. Centrelink made it extremely hard for us with the constant barrage of paperwork to be filled in. My doctor said she was going to charge them by the hour because of the ridiculous amount of questions re my condition. All the angst I was already feeling was magnified by Centrelink. They eventually gave in and awarded me a short-term benefit of $360 per fortnight. wow." (Female, 50 to 59 years, DCIS / LCIS), Victoria

"Financial assistance." (Female, 18 to 29 years, New South Wales, Early Breast Cancer)

"I had no idea I was going to be out of pocket $20k." (Female, 30 to 39 years, Queensland, DCIS / LCIS)

"Financial needs were challenging, we needed government support half way through my treatment requiring sitting in Centrelink going through a long meeting so I could get financial support. This was done and had to be done at a time when I could hardly walk and talk due to the debilitating effects of chemo, let alone the risk of infection. Regular logging in to receive your payments or phone calls to services was stressful at times. That's just one of the stories. This was 6 years ago, I'm not sure what it's like now." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Finances. As a result, I had to return to my job earlier than my body was ready for." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Financially, by the time sickness benefits were approved and paid I was back at work having struggled to feed my children and having accumulated a substantial credit debt. The stress involved was incredible." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

Help at home

"Physical assistance with small children." (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

"The need to care for my family (I have 2 young children) has only ever been considered by a Breast Care Nurse, never by a doctor. they have been disinterested in factoring my life into treatment." (Female, 30 to 39 years, Victoria, Early Breast Cancer)

"Help with meal preparation. Only some help with housework and gardening." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Housework - all family are interstate and friends are the other side of town. I'm still sorting out the house where I was too tired to put things away and they've just sat on the ironing board or dining table for the past 18 months." (Female, 50 to 59 years, Queensland, DCIS / LCIS)

Help with work

"My employer didn't really understand and in fact, I was basically bullied in the workplace, so I threatened to go to the industrial relations. My employer paid me off and I left. Horrible experience which pushed me backwards in my recovery." (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

“I needed support around coping with return to work and the doctor downplayed the physical impact of a mastectomy and me doing fulltime demanding work.” (Female, 60 to 69 years, New South Wales, DCIS / LCIS)

“Time off work after treatment.” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

“Returning to work - very unsupportive boss.” (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“Sufficient time off work to recover.” (Male, 30 to 39 years, New South Wales, Metastatic Breast Cancer)

Help to live well / recover

“*What genetic implications, if any, on my family.”* (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“*Fertility, diet and exercise. I did receive a little information but would have liked more information.”* (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“Items needed to help with side effects of tamoxifen (compression stockings) they only supply to women. Diet. Option of gym. I have not had any physio given.” (Male, 40 to 49 years, Western Australia, Early Breast Cancer)

“Post treatment - no exercise physiology recommended nor a dietary recommendation.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“*Natural therapies, juicing, alternative vitamins that aid in cancer prevention, I did my own research while off work, many people don't have the time and we are all sheep in a way doing what the medical world tell us to do.”* (Female, 50 to 59 years, Tasmania, DCIS / LCIS)

Information

“In some areas I needed more detailed, specific information.” (Female, 30 to 39 years, South Australia, Early Breast Cancer)

“Information on any changes in diet / lifestyle/ medications that might reduce risk of cancer returning.” (Female, 40 to 49 years, New South Wales, DCIS / LCIS)

“Often had to search out the information myself, little assistance from medical team to do so.” (Female, 50 to 59 years, Australian Capital Territory, Early Breast Cancer)

Support from family and friends

“My family support situation could have been better.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“My partner left me after treatment and that has been the hardest to deal with. Moving house, finances, going back to work earlier because the need for money. I am only 10 weeks into separation.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Husband left me after a 25 year marriage. met someone else. Devastating.” (Female, 50 to 59 years, South Australia, Early Breast Cancer)

“Maybe could have done with more family support, emotionally.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"Support of family perhaps less so. And the head tilt when saying, "how are you?" was pretty <expletive removed> annoying." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"I did not get the help at home from my husband that I needed while having treatment. I was exhausted." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"My friends backed off a lot when they found out." (Female, 18 to 29 years, Queensland, Early Breast Caner)

"All but family support." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"My husband attitude - his words "why me"!!!" (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"I found I pulled away from some friends and family who were overly negative about the diagnosis or would tell you worse case scenarios all the time instead of listening to the information I was receiving from my treating professionals. Also had a case (6 months after treatment) where, when I stood up for my rights at work and dared to question current workplace policies where it was put to me that I, "should have counselling due to my cancer"." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"The need for family support was huge and was partially met." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Support for family

"Looking after family needs." (Female, 40 to 49 years, Victoria, Early Breast Cancer)

"All but family support." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Home help and parenting support." (Female, 40 to 49 years, Victoria, Metastatic Breast Cancer)

"Emotional support for husband." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"There was no help at all offered to my loved ones during my treatment. While this has not been of huge need, my partner suffers from depression so we have had to seek our own counselling support outside the cancer care system. Apart from a booklet on caring for a loved one with breast cancer, he received nothing." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Support for the children via a nanny - we needed more support from school teachers especially - kids missed a lot of school, my eldest at age 14 went into depression and had difficulty switching schools. My youngest are behind still now." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

Timely access of medical treatment / appointment times

"Oncologist delayed start of chemo - she was going away to conference. Day chemo staff stressed and understaffed, no contact with Breast Care Nurse - she kept saying "I'll call you", never did. When I called her in midst of emergency, no answer on mobile. Asked for referral to psychologist, took 2 months till available and no longer needed." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Timely access to lymphedema treatment." (Male, 30 to 39 years, New South Wales, Metastatic Breast Cancer)

"Scar treatment still not met." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Still waiting for surgery.” (Female, 60 to 69 years, Queensland, DCIS / LCIS)

“I would have preferred (if possible) to wait less time between procedures.” (Female, 80 years or over, Victoria, Early Breast Cancer)

“Waiting for surgery for a long time, especially having cancer diagnosis. I had never been afraid of surgery before but don't think you'll see me anywhere near a hospital again!!!!!!!” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

Support for men with breast cancer

“Information on side effects for men. The men's website in my opinion does not help as it recommends you go to a professional for advice. They don't know. Seeing the oncologist once a year for ten minutes is not worth anything. I have yearly mammograms and scans.” (Male, 70 to 79 years, Victoria, DCIS / LCIS)

Support for young people with breast cancer

“Services/products for young women - everything is designed for older women.” (Female, 18 to 29 years, South Australia, Early Breast Cancer)

“Being a young 26 year old woman.” (Female, 18 to 29 years, Australian Capital Territory, DCIS / LCIS)

Other unmet needs

“Closest hospital is 80 km away.” (Female, 60 to 69 years, New South Wales, Metastatic Breast Cancer)

“Still to see if the hospital will arrange to pick me up for chemo treatments.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“I have been well supported by clinicians around the depression. There needs to be greater public awareness of the impact of cancer and the ongoing treatment.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

“My only complaint has nothing to do with radiation, but to do with the incessant noise of a tv. In most hospital waiting rooms.” (Female, 70 to 79 years, Western Australia, Early Breast Cancer)

“Access to holistic approach to identifying cause for cancer, including mapping of biological and environmental factors. Only follow up offered was through pharmaceutical prescription drugs or no action (apart from regular screening, which is not proactive).” (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

“I did not realise that I needed support from BCNA and did not reach out for that help. I had received their support kit when I came home from my surgery but I did not have the awareness or time to follow-through with contacting the organisation. I had decided to move interstate and my family had offered to support me through my chemotherapy and radiation treatment. It was no "fault" on anyone's part that some of my needs were not met. I had been through many changes and in hindsight everything got on top of me. Now I am able to reach out and seek the support that I require. I wrote to a friend and said, "cancer is like a road with no signposts". It is just that, unless you speak to people travelling the same "road", then they become the "signposts".” (Female, 60 to 69 years, Western Australia, Early Breast Cancer)

All needs were met

“All these needs were met.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"Everything was met ☺" (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"None, I found BCNA information a great help." (Female, 60 to 69 years, Australian Capital Territory, DCIS / LCIS)

"My experience was exceptional in my case. So very happy with how I was treated and my outcome." (Female, 50 to 59 years, Tasmania, DCIS / LCIS)

"All were met." (Male, 60 to 69 years, Victoria, Metastatic Breast Cancer)

"Everyone was lovely at hospital, pre op tests were very thorough, additional diagnosis re heart defect also made, I cannot see where my needs weren't met." (Female, 60 to 69 years, Victoria, Early Breast Cancer)

"All these needs were met by wonderful, caring and inspiring people." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"I was lucky - my breast cancer was diagnosed at a very early stage following a routine BreastScreen, So I did not have any major problems with my treatment and follow-up." (Female, 70 to 79 years, Victoria, Early Breast Cancer)

"All were met. and continues with my check-ups as they are still ongoing." (Female, 70 to 79 years, Australian Capital Territory, Early Breast Cancer)

G1. What more do you think BCNA could do to help Australians affected by breast cancer (including their family and friends) in the future?

Already doing a great job

"I think that you are doing a marvellous job in what you are doing now and hope that you keep up the good work." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"Continue to do the wonderful work you do." (Female, 40 to 49 years, South Australia, Early Breast Cancer)

"I think u do an amazing job" (Female, 50 to 59 years, Queensland, DCIS / LCIS)

"Keep on keeping on!" (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Think they are doing a fine job." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"I was amazed by the information I received and the helpfulness of that information." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"I think that BCNA do any incredible job so I don't think that they could do anything else." (Female, 30 to 39 years, Western Australia, Early Breast Cancer)

"I can't think of anything more as I found there was plenty of information and support for me and my family already." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Doing a fabulous job of providing information, personally did not access lots of your services but glad they are available." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"The support I received was great and I couldn't have asked for more help. I believe you are doing all you can." (Female, 40 to 49 years, Queensland, DCIS / LCIS)

"To continue providing the level of support and care that has always been there." (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

“I think as Australia we have great support for breast cancer. Until my diagnosis I had no idea how valuable the BCNA would be.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

Counselling / emotional support

“More support for partners who aren't likely to open up to their friends or family.” (Female, 30 to 39 years, Queensland, Early Breast Cancer)

“Counselling for young children in the family at their level of understanding (if this is not already available).” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Phone services or counselling out of hours (e.g. when panic strikes during the night).” (Female, 40 to 49 years, Victoria, Early Breast Cancer)

“Maybe more support for families of loved ones. Especially children and husbands?” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

“Instigate a network to work with newly diagnosed patients to oversee a holistic approach on the journey they will be travelling.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Have someone visit the hospital after any operations to let them know there is life after diagnosis and removal of your breasts.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“My husband didn't cope - ended up in us splitting up, losing friends and now my life frankly is not happy, this is 6 years on.” (Female, 40 to 49 years, Western Australia, Early Breast Cancer)

“Family support counselling services, somehow compulsory?? As they needed support to help me but reluctant to seek it.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Make contact directly with newly diagnosed people. A more personable approach.... human contact is what I craved.” (Female, 50 to 59 years, Queensland, DCIS / LCIS)

Support to live well

“Now that treatment options are enabling those diagnosed with breast cancer to live longer, healthier lives, there needs to be more information on the effects treatment and cancer can have long term. Effects not only on the medical health of those diagnosed but on their mental, spiritual and sexual health. It does not seem to be easy to find information on sexual health, relationships and management of menopause.” (Female, 40 to 49 years, South Australia, Early Breast Cancer)

“I think I would have liked the routine of having an annual appointment with someone to talk generally about lifestyle, mental health and wellbeing related to cancer and my ongoing treatment.” (Female, 60 to 69 years, South Australia, Early Breast Cancer)

“Increase awareness, benefit and opportunity for healthy lifestyle activities e.g. Exercise, yoga, meditation.” (Female, 40 to 49 years, Victoria, Early Breast Cancer)

“I find most of the information and support from BCNA suitable for my needs. I would like to see more support in hospital for women and more support for changing lifestyle and dealing with coping after the end of treatment and getting back to life.” (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Support for men

“I would like men to be aware that they too can be diagnosed with breast cancer.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Advising woman and men if they are worried of the importance on having mammograms especially at 50+.” (Female, 50 to 59 years, Victoria, DCIS / LCIS)

Advocate for more research

“I’m not real sure..... I understand people need help but I personally believe more funding into finding a cure would be better.” (Female, 40 to 49 years, South Australia, Metastatic Breast Cancer)

“Maybe look into health benefits of other natural remedies as well.” (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“Find an easy cure!! Without going through all the treatments!!” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“Find a cure.” (Female, 40 to 49 years, Australian Capital Territory, Early Breast Cancer)

“More cancer research.” (Female, 40 to 49 years, Victoria, Early Breast Cancer)

“Lobby for increased research support, lobbying for rights of the terminally ill.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“Funding research.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“I think most of the money raised should be put towards researching a cure for metastatic breast cancer.” (Female, 40 to 49 years, Western Australia, Early Breast Cancer)

“Find a cure. Sorry know that's' a biggie.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“I prefer more research to find a cure rather than funds going to awareness. support is important but a cure would make support a minor issue.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“Funding research - a cure is the only way forward!” (Female, 40 to 49 years, Victoria, Metastatic Breast Cancer)

“Keep pushing for more research to find a cure.” (Female, 50 to 59 years, South Australia, Early Breast Cancer)

Education and awareness-raising

“Just give younger or middle aged women more information about the risks of breast cancer and early detection is essential.” (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

“Raising more awareness of range of services. Higher visibility through media.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

“More awareness of your existence especially online forums which I used a lot when first diagnosed. Thank you!” (Female, 70 to 79 years, Western Australia, Early Breast Cancer)

“Provide information on what professions offer by way of therapy and treatments.” (Female, 60 to 69 years, Australian Capital Territory, Early Breast Cancer)

“Get out there so people know about you I’m metastatic and never heard of you ‘til this survey. Have been suffering in silence.” (Female, 50 to 59 years, South Australia, Metastatic Breast Cancer)

“Keep building on messages that breast cancer doesn't discriminate... It's more than 1 in 8.” (Male, 50 to 59 years, New South Wales, Metastatic Breast Cancer)

“*More education for early detection and awareness of any kind of cancer not only breast cancer.”* (Female, 60 to 69 years, New South Wales, DCIS / LCIS)

“More awareness about breast cancer in young people.” (Female, 70 to 79 years, Queensland, Early Breast Cancer)

“Maybe increase the awareness at our workplace. Sometimes they are very strict especially with my medical appointments. More lenient on our leave. Last year I end up leave without pay because my manager didn't let me use my pro rata leave.” (Female, 50 to 59 years, New South Wales, Metastatic Breast Cancer)

“Support and raise awareness of the need for cancer prevention and most importantly early detection especially in young, pre-menopausal women 40-50.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

Advocate for financial assistance

“Provide funded counselling services within local area to people going through treatment.” (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“Help cut costs for patients.” (Female, 30 to 39 years, New South Wales, DCIS / LCIS)

“Subsidy on meds especially if needed to take for 5-10 years.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

“Radiotherapy is very expensive. Should be free for everyone.” (Female, 60 to 69 years, South Australia, Early Breast Cancer)

“Offer free or heavily subsidised follow up mammograms and ultrasounds.” (Female, 40 to 49 years, Tasmania, Early Breast Cancer)

“The big issue is the ongoing cost of follow up checks. There needs to be access to a free or less costly follow up option.” (Female, 50 to 59 years, Victoria, DCIS / LCIS)

“Fund education on healthy eating and independent research that proves the kinds of foods and lifestyle choices that dramatically reduce risks of cancer. Educate doctors on the vital role of nutrition and lifestyle changes. Stop putting funds into glossy promotional papers and put it into spreading the word that we can all reduce cancer causing effects in a significant way.” (Female, 50 to 59 years, Queensland, Early Breast Cancer)

Advocate for follow up

“Maybe get in contact with people who have gone through it to see how they are going.” (Female, 40 to 49 years, Victoria, DCIS / LCIS)

“In my own experience, I would have liked more information on the follow up help e.g. Lymphatic massage, physiotherapy etc and where to go/who to contact.” (Female, 30 to 39 years, Australian Capital Territory, Early Breast Cancer)

“Follow up on patients.” (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

“Maybe a bit more follow up after chemo and radiation treatments.” (Female, 60 to 69 years, Victoria, Early Breast Cancer)

“A follow up phone call to rural patients after surgery to answer questions and reassure rather than patients having to initiate a conversation to the wonderful nurses available. I had a

mastectomy and fortunately didn't require chemo or radiotherapy and thought that I fully may not fully qualify for the service." (Female, 50 to 59 years, Western Australia, DCIS / LCIS)

"Offer free or heavily subsidised follow up mammograms and ultrasounds." (Female, 40 to 49 years, Tasmania, Early Breast Cancer)

"Some sort of follow up afterwards." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Follow up on support groups and make sure that they are actively supportive!" (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Advocate for more services

"Home visit service." (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

"Support in home." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"For patients to have exclusive access to after treatment services such as gym, tai chi, yoga and Pilates. I'm not comfortable to go to a public gym as I get self conscious and anxious about my medical condition." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

Help for regional areas

"I know it is difficult, but people in small country areas still miss out on a lot of support." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"I live in a regional city and found treatment occasionally problematic. My friends in Sydney seemed to have an easier time getting treatment and support. My friends in the country had real difficulties getting the support they needed. Often, they were quite desperate. It is unfair for them. I believe BCNA is trying to correct this imbalance. I would like that to increase." (Female, 60 to 69 years, New South Wales, Early Breast Cancer)

"Offer seminars in rural Victoria, there has never been any in [my area]." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Need more staff in rural areas." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"More help for country patients." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"People who live in cities and large regional cities can access any number of services and medical facilities (private and public) etc. Unfortunately many of these services don't extend to smaller and remote regional centres, which leaves people very isolated sometimes. Anything BCNA can do in this space would be invaluable." (Female, 50 to 59 years, Queensland, Early Breast Cancer)

"Help set up young people support group in regional areas, or use the online network to connect similar ages people living in the same area." (Female, 40 to 49 years, Queensland, Metastatic Breast Cancer)

"Look at the spread of services across the states and in particular for regional areas." (Female, 50 to 59 years, Western Australia, DCIS / LCIS)

"One on one, face to face, discussions with women who have had breast cancer and who live in a similar or same area as myself. Rural and regional breast cancer patients have very different lifestyles and issues to those in city and suburban areas. Geographic location, lifestyle and climate issues are not taken into account with much of BCNA's advice and assistance. I found

much of the advice irrelevant to me which left me floundering on my own." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

Provide more information

"Offer as much information as possible including where to go to get assistance." (Female, 50 to 59 years, South Australia, DCIS / LCIS)

"More information made available for help, never knew it existed until too late." (Female, 40 to 49 years, Queensland, DCIS / LCIS)

"Keep information feeds going, act more like a cancer commons where we share information not just our narratives." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

"Targeted information addressing people particular issues. Rather than lengthy brochures and booklets." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"More local forums. Information is knowledge." (Female, 60 to 69 years, Queensland, Early Breast Cancer)

"Directory of support services, like early treatment for Children with Autism." (Female, 40 to 49 years, Queensland, DCIS / LCIS)

More support for families / partners

"More support/information made available to partners." (Female, 40 to 49 years, Western Australia, Early Breast Cancer)

"Partners and family need more information and support." (Female, 50 to 59 years, Victoria, DCIS / LCIS)

"Support group for partners. Wifi in chemo wards." (Female, 30 to 39 years, Western Australia, Early Breast Cancer)

"Support the cost of childcare and provide housekeeper who has young children." (Female, 40 to 49 years, Victoria, Early Breast Cancer)

"More counselling services for families after treatment from breast cancer." (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

Information on natural / alternative therapies

"I should like to see more emphasis on non-pharmaceutical methods of coping with side effects of chemo and radiation." (Female, 70 to 79 years, New South Wales, Early Breast Cancer)

"Talk about the problem with mammograms causing cancer and the possible use of thermography and ultrasound in its place." (Female, 50 to 59 years, Western Australia, Early Breast Cancer)

"Provide more information regarding alternative treatments other than chemo and radiation." (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

"Be able to look outside of surgery, chemo, radiation and pharmaceutical hormonal therapies for treatment options." (Female, 50 to 59 years, Victoria, Early Breast Cancer)

"Maybe look into health benefits of other natural remedies as well." (Female, 30 to 39 years, New South Wales, Early Breast Cancer)

“It would be nice to have information around specific symptoms (say for chemo) and what are some natural therapies to use instead of constantly pumping our bodies with drugs. E.g. Indigestion = have bi-carb soda in water, sleep = take magnesium and Gabba.” (Female, 40 to 49 years, Victoria, Early Breast Cancer)

“Support other ways of treatment as well i.e. natural remedies through change of diets and natural treatments. Not all people react well to the recommended treatment like chemotherapy or radiation.” (Female, 40 to 49 years, New South Wales, Early Breast Cancer)

Support meetings

“Monitor the availability and suitability of support groups. Re-evaluate the training of group facilitators.” (Female, 70 to 79 years, Victoria, Early Breast Cancer)

“A support group in my area would be useful to know about.” (Female, 60 to 69 years, Queensland, DCIS / LCIS)

“Have meetings at smaller local groups.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“More meetings for those people who are past 5 years since treatment.” (Female, 60 to 69 years, Queensland, Early Breast Cancer)

“Have meetings that are gold coin donation. People can't afford meetings when they are sick and off of work.” (Female, 50 to 59 years, South Australia, Early Breast Cancer)

“Support meetings.” (Female, 40 to 49 years, Queensland, Early Breast Cancer)

Other

“Perhaps some sort of transport help to be able to get to appointments post-surgery.” (Female, 50 to 59 years, New South Wales, DCIS / LCIS)

“Keep the phone lines and web going for people to access should they require information or help.” (Female, 60 to 69 years, Western Australia, DCIS / LCIS)

“Concentrate on what you are doing well rather than dispersing efforts too much.” (Female, 40 to 49 years, South Australia, Early Breast Cancer)

“Beware of Overloaded with too much information. Good news stories are not helpful to me.” (Female, 50 to 59 years, New South Wales, Early Breast Cancer)

“You do a great job in many areas. I think it necessary to understand if patient wants support or not.” (Female, 80 years or over, Victoria, Early Breast Cancer)

“Offer a companion service to those undergoing chemo or radiation therapy who have no significant family in their lives. Transport to and from appointments. Warn people before you post information on you Facebook page which could be traumatic for cancer sufferers. I have read stories which pop on my feed which unexpectedly cause stress and emotion because of the content. Remember that too much information at early stage of diagnosis can be detrimental, it can give false hope, cause unnecessary fear and confusion.” (Female, 30 to 39 years, South Australia, Early Breast Cancer)