COVID-19 Report

December 2020

Care experiences of Australians living with and beyond breast cancer during the 2020 novel Coronavirus (COVID-19) pandemic: findings from a cross sectional-survey

Breast
Cancer
Network
Australia

Acknowledgements

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The authors would like to acknowledge and thank the 2307 people affected by breast cancer who shared their breast cancer care experiences and concerns in relation to COVID-19. The study was conducted by Breast Cancer Network Australia (BCNA). The survey was adapted with permission from a survey conducted by Breastcancer.org in the United States. We would like to thank and acknowledge the work of a team of consumers who reviewed and assisted in adapting the original survey to the Australian environment. We would also like to thank the consumers who reviewed and provided comment on this report. The report is better for their input. This report was funded by BCNA.

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Background

In response to the rapid and ongoing rise in the number of people contracting the novel Coronavirus (COVID-19) across the world, the World Health Organization officially declared a pandemic on 11 March 2020. To control the spread of the virus in Australia, from March 2020 state and federal governments enacted a wide number of restrictions to limit social interactions and reduce the demands on the health system by for instance, cancelling elective/non-urgent medical procedures, moving to telehealth (video or telephone based consultations) and restricting numbers attending hospitals. People affected by cancer are at increased risk from the virus, especially those with active cancer. Much of the research into the impact of COVID-19 on cancer care has come from outside Australia. The current study addresses this situation and aims to understand the experiences of people affected by breast cancer in relation to:

- health care service changes/delays
- telehealth
- information access and
- anxiety and concerns regarding COVID-19 and breast cancer.

Method

Design: Cross-sectional online survey of members of a national breast cancer consumer based advocacy group: Breast Cancer Network Australia (BCNA). No restrictions were placed on the time since diagnosis and breast cancer stage.

Survey: The online survey was based on a survey developed by the US organisation Breastcancer.org, with BCNA adapting the original survey to the Australian context.

The timing: Survey was conducted between 22 June 2020 and 6 July 2020.

Results

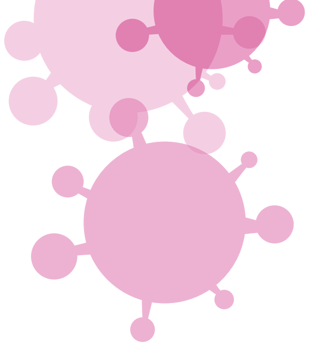
Participants: In total, 2,307 people completed the survey (5.8% response rate). The majority were female (85.6% (14% missing)), aged between 45 and 74 years (72.5%), lived in metropolitan areas (48.3%) from NSW (21.9%), Victoria (27.1%) or Queensland (15.5%). Most respondents had early breast cancer (eBC) (70%), with 22% in active treatment at the time of the survey and 40% on hormone-blocking therapy.

Changes/delays in treatment-related procedures: Respondents in or about to start active treatment; on hormone-blocking therapies or living with mBC indicated whether they had experienced changes or delays in treatment-related areas of care. The key area of changes/delays was in relation to appointments, with 37% reporting alterations instigated by the health care team. Around 13% experienced changes/delays to surgery, 13% changes/delays for radiotherapy and 10% reported changes/delays in chemotherapy. Younger women (p<.01), and those living with metastatic breast cancer (p<.01) were more likely to report health care team initiated appointment change/delay.

Changes/delays in follow-up care: Changes/delays were more common for follow-up care than treatment. Around 1 in 3 respondents in follow-up care or on hormone-blocking therapy experienced treatment team initiated alterations to their follow-up care appointments, with alterations significantly higher for those having hormone-blocking therapy (37%) than those in follow-up care only (31%) (p<.01). Changes/delays were common for allied health appointments, with 37% indicating treatment team initiated changes/delays. Only 9% of respondents indicated changes/delays in follow-up scans, which was not related to stage of care. Respondents under 65 were more likely to report treatment team initiated changes/delay in follow-up care appointments (p<.01), psychological care appointments (p<.01) and allied health appointments (p=.028).

> **My lumpectomy surgery was delayed and rescheduled twice.**

> **Radiotherapy postponed for 3 months due to COVID-19.**



Anxiety in relation to COVID-19 and breast cancer care: On average there was a slight level of anxiety about COVID-19 (mean score: 2.01) with 56% indicating some level of anxiety including 14% who were somewhat anxious and 14% who were moderately/extremely anxious. Anxiety was higher for women respondents in active treatment (mean=2.54), women living with metastatic breast cancer (mean=2.05) and women under 45 years (mean=2.32).

Experiences with telehealth: For respondents still in the health care system for their breast cancer care, telehealth appointments were common: 72% had had some type of telehealth consultation. Mostly telehealth was conducted over the telephone, with 80% reporting a telephone consultation, 6% a video consultation and 14% a mix of video and telephone consultations. GPs (45%) and medical oncologists (45%) were the health professionals most commonly consulted with via telehealth.

Of those having a telehealth appointment, 68% found it helpful, 22% thought it was helpful but had some hesitations, and 10% did not find it helpful at all. For those seeing telehealth as helpful, benefits included: convenience (reduction in travel and appointment waiting times); reducing exposure to COVID-19, and enabling questions to be answered.

Key reasons for not finding the telehealth appointments helpful were: preference for face-to-face; lack of physical examination; poor communication with the clinician; impersonal; brevity of the call; inappropriate location/form for receiving bad news; and cost and technical issues.

These problems were key contributors to the reasons why some respondents were hesitant about telehealth.

Interest in telehealth: Of those who had not had a telehealth appointment, only 13% were interested in utilising telehealth for their breast cancer care.

Access to information: For most respondents, the treatment team was the most common source of information about COVID-19 (50%), followed by television news (42%) and the Australian Government Department of Health website (41%). Approximately 32% of respondents sourced information through BCNA and state/territory health departments. 14% accessed information through social media.

> I have put off breast ultrasound, all specialist appointments, physio and counselling until further notice due to difficulty.

> Extreme psychological and emotional toll being unable to take support person to chemo treatments and specialist appointments.

> Telehealth was better than nothing, I suppose, but I felt it was inadequate and of course, there was no physical examination of the breasts.
>
> I found it more difficult to talk to the oncologist as she was so busy, I feel face-to-face I had a better chance of asking questions and voicing my concerns.

Concerns in general: While the majority of respondents did not indicate any specific concerns in relation to COVID-19 and breast cancer, 44% of respondents did have some concerns. Having concerns was inversely related to age (p<.01), breast cancer care continuum (p<.01) and breast cancer stage (p<.01).

Health-related fears due to a compromised immune system was the most common concern, mentioned by 33% of those with a concern. The next most common concerns were around restrictions placed on socialising, with comments grouped under this theme including a mix of issues such as missing social supports from family and friends, lack of access to social support services, and hospital restrictions on visitors during treatment.

Conclusion

The impact of COVID-19 pandemic and associated restrictions introduced to control the spread of the virus in Australia has broad ranging effects on people affected by breast cancer. In terms of medical care experiences, the survey found that around a third of those in treatment and follow-up care experienced changes/delays in their appointments for medical care/follow-up care and for appointments with allied health and psychological services during follow-up care. The move from face-to-face appointments to telehealth was one of the key changes experienced. While telehealth was generally acceptable and associated with many benefits including reduced travel and waiting times, a significant minority were not in favour of telehealth, with these respondents finding telehealth appointments more rushed, less reassuring and not appropriate for some types of appointments. Offering choice of appointment type will be important if telehealth is continued in Australia. While most respondents experienced either no or a slight level of anxiety around COVID-19 and breast cancer, those in active treatment, living with metastatic disease and younger respondents were more at risk for feeling anxious with concerns relating to COVID-19 infection due to low immunity and feeling socially isolated key concerns. Identifying strategies to address these issues for people with breast cancer may be important if cases of COVID-19 start to rise and social restrictions are reintroduced.

> Meant I didn't have to travel to appointments, which saved time and money. All questions answered by healthcare person.
>
> Telehealth appointments are very convenient especially for those of us living in semi-rural, rural areas. Telehealth appointments need to continue into the future!

> As my immune levels are low I am concerned with the possibility of contracting the virus.
>
> My concerns are around my potential exposure to the virus whilst in hospital or getting treatment.
>
> Found it difficult to go through surgery and start of chemo without being able to see family and friends due to lockdown restrictions.

Introduction

In response to the rapid and ongoing rise in the number of people contracting the novel Coronavirus (COVID-19) across the world, the World Health Organization officially declared a pandemic on 11 March 2020. To control the spread of the virus in Australia, during March and April 2020 state/territory and federal governments introduced a wide number of restrictions that aimed to limit the number and type of social interactions. While the specific restrictions introduced varied between states, they generally included: restrictions on travel within Australia; limits on social gathering numbers; banning large sporting, social and cultural events and local sports; the closure of education facilities; and dine-in options at cafes, restaurants and pubs. In addition, stay at home restrictions were introduced for a period of time, with residents only permitted to leave their homes for work, food, shopping, medical services, care and exercise. To ensure health systems across Australia had capacity to treat COVID-19 infections, elective and non-urgent medical procedures were cancelled or delayed, and medical appointments were postponed or moved to telehealth (video or telephone based consultations). To reduce infection risk within hospitals, restrictions were placed on visitors who could attend appointments or visit people in hospital.

While states started to relax some social, work and sporting restrictions from May/June 2020, state borders remained closed or restricted at this time and in July 2020 the state of Victoria went into a second more severe lockdown period that lasted for several months.

While much is still not known about the health effects of COVID-19, there is increasing evidence that those who are older, have comorbidities, and a weakened immune system are more likely to experience severe effects if infected.[1-3] People affected by cancer were recognised as being at increased risk from the virus, especially those with active cancer.[4, 5] The changes made to the health care system to reduce potential spread of the virus and to enable health care services to manage an increasing number of COVID-19 infections also impacted on the health outcomes of those with cancer.[6] As part of the initial phase of responses to the COVID-19 pandemic in Australia, screening and diagnostic tests and imaging for cancer were stopped or restricted, medical appointments moved to a telehealth format, and some surgery and other treatments postponed or modified.[7] In addition, for those having treatment, hospital visitor restrictions meant treatment could be a more isolated experience for many.

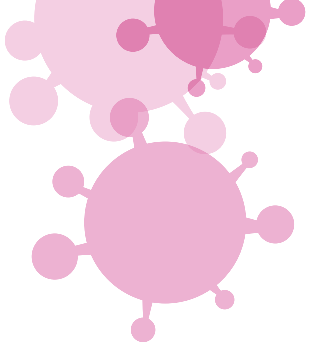
Much of the research into the impact of COVID-19 on the care experiences of people affected by breast cancer has come from outside Australia. While the type of local restrictions put in place to limit the spread and impact of COVID-19 in Australia (e.g. restrictions on social gatherings, closure of entertainment, non-essential businesses, etc.) were similar to those in many other countries, Australia tended to introduce these restrictions sooner in relation to the number of cases in the community than other countries. In addition, Australia closed its borders to international travel and required those coming into the country to go into hotel quarantine for 2 weeks. Australia has experienced a lower number of COVID-19 cases compared to many other countries. For instance, at 1 June 2020 Australia had approximately 282 COVID-19 cases per 1 million population compared to 2330 cases per 1 million population in France and 3688 cases per 1 million population in the United Kingdom.[8] This difference may have influenced perceptions of risk and experiences of the pandemic for Australian cancer patients. To this end, the current study aims to understand the experiences of health care service changes and delays, telehealth and COVID-19 concerns and anxiety in Australians with breast cancer and determine whether these experiences differ by age, breast cancer stage, current position in the cancer care continuum and residential location.

Method

Design: Cross-sectional online survey of members of a national breast cancer consumer based advocacy group: Breast Cancer Network Australia (BCNA).

Eligible participants: The survey was open to all BCNA members with a diagnosis of non-invasive breast cancer (ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS)), or invasive breast cancer (early stage breast cancer (eBC) or metastatic breast cancer (mBC)) who had provided an email address to BCNA. No restrictions were placed on time since diagnosis thus those members who were not currently receiving any treatment or follow-up care could participate in the survey.

Survey: An online survey developed by the US breast cancer charity Breastcancer.org, was the basis for the survey, with BCNA adapting the original survey to the Australian context. Three BCNA Consumer Representatives reviewed the survey tool and provided advice regarding changes needed to ensure the survey was suitable to Australian breast



cancer survivors. All suggested changes were incorporated into the survey. A copy of the survey/questionaire is shown in Appendix 1.

Survey items: Questions relevant to this report concern five closed-ended questions and three open-ended questions. Closed questions assessed respondents' experiences with changes or delay in two care areas: i) treatment-related care and ii) follow-up care. Items in the treatment-related care area included: investigative tests or scans; screening; doctor/specialists appointments; surgery; radiotherapy; chemotherapy; hormone-blocking therapy; clinical trial participation; reconstruction surgery immunotherapy; CDK4/6 inhibitor therapy; fertility treatment; and scalp cooling. In the follow-up care areas, items assessed changes/delays related to: follow-up appointments; scans or tests; psychological care and allied health services. For all questions respondents could choose one of four responses: i) change/delay instigated by health care team, ii) change/delay they instigated, iii) no alteration, and iv) not applicable. Respondents who indicated any change or delay could provide further information about the change/delay experienced in an open text box. All respondents were asked: "How anxious are you generally feeling about your breast cancer care being affected by the pandemic at this time?" and indicated their response on a five-point scale ranging from 1) not at all anxious to 5) extremely anxious. All respondents were asked about their experiences with telehealth with the question: "Have any of your medical appointments been done via telehealth (i.e. by telephone or video) during the COVID-19 pandemic?" Respondents could choose a response from: yes by telephone, yes by video; yes both video and telephone; no; and not applicable. Those having a telehealth consultation were asked what they found helpful about telehealth with respondents given a text box to allow them to write their response. Respondents who had not used telehealth were asked an open-ended question regarding whether they would like to. Participants were asked where they were accessing information to assist with making their breast cancer management decisions and could indicate multiple sources from a list including health care team, BCNA, cancer organisations, health departments' websites, news, etc. Participants were also asked another open-ended question to assess concerns they may have regarding breast cancer and COVID-19.

Demographic questions assessed age (in seven 10-year age groups with 75+ years the highest), gender, state of residence, residential location (metropolitan, regional, rural and remote), and First Nations person status. In addition to these questions, respondents self-reported the stage of breast cancer they were last/most recently diagnosed with and could choose an option from the following: DCIS; LCIS; early breast cancer (described as being contained within the breast and/or lymph nodes); or metastatic breast cancer (described as having spread to distant parts of the body; also called advanced, secondary or stage four). For analysis, DCIS and LCIS were combined.

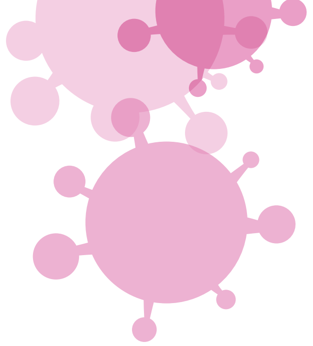
To gain an idea of where respondents were in the breast cancer care continuum they were asked: "What best describes where you are at in your breast cancer experience?" selecting one response from: i) in active treatment, ii) treatment not yet started, iii) having hormone-blocking therapy, iv) completed treatment and in follow-up care, v) living with metastatic disease, and vi) diagnosed in the past, completed treatment, and no longer in follow-up care (finished care). Formal definitions of these options were not provided, and therefore interpretation between respondents may differ. Additionally it is recognised that the response option 'living with metastatic disease' differs from the other options, as it describes the stage of breast cancer rather than specific treatment. People with metastatic disease may have a range of treatments to help manage or control their cancer and symptoms. Therefore a number of different responses to this question could accurately reflect the current care experiences of respondents with mBC (e.g. having active care; having hormone-blocking therapy, 'living with metastatic disease'). Analyses involving this question use the responses provided by respondents, as this reflects their description of their current care experience. While noting the limitations of this question, for this report this question is taken as indicating where respondents are on the 'breast cancer care continuum' and the question is referred to as 'care continuum'.

Procedure: An email was sent to BCNA members meeting the eligibility criteria, inviting them to take part in the survey. A reminder email was sent on 1 July 2020 to those members who had not opened the initial invitation.

The survey was administered online via SurveyMonkey and was open between 22 June 2020 and 6 July 2020. Completed surveys were downloaded and transferred to SPSS for data analysis via Excel.

Statistical analyses: Descriptive statistics were used to characterise participants in terms of their age, gender, residential status, breast cancer stage and care continuum. Chi-square statistics were used to examine univariate associations between demographic and breast cancer characteristics and experiences in treatment and follow-up delay. For these analyses, respondents who had finished treatment and follow-up were excluded for all questions. For questions assessing change/delay in follow-up care, all respondents regardless of breast cancer stage indicating they were currently having active treatment were excluded. Sample size for each analysis varied between questions depending on relevance of specific question to respondents, e.g. questions relating to chemotherapy changes/delay were only relevant to those having chemotherapy. Multivariate logistic regression examined factors associated with change/delay caused by the treatment team in the different treatment or follow-up areas. In these analyses, breast cancer stage, care continuum, age, residential location and state were entered simultaneously to determine their relative influence on the change/delay. Only those respondents for whom the questions were relevant are included in these multivariate analyses. Responses from all respondents are included in analyses relating to anxiety with differences in mean scores by demographic and breast cancer related factors examined using analyses of variance (ANOVA) analyses. Multivariate ANOVA analyses examined the relative influence of the demographic and breast cancer related variables (stage and care continuum).

Thematic analyses were undertaken for responses to open-ended questions. For questions relating to telehealth experiences and concerns regarding COVID-19 and breast cancer care, all responses were reviewed, and themes and subthemes developed. For telehealth-related questions, responses were coded into two initial groups indicating positive or negative experiences. Frequencies of these responses were explored in relation to the demographic and breast cancer-related factors. Themes relating to reasons for the positive or negative response to telehealth were reported. Responses regarding concerns regarding COVID-19 and breast cancer care were coded and major themes identified.



Results

Participants: In total, 2,307 members participated in the survey representing a 5.8% response rate. The demographic characteristics of the sample are shown in Table 1. The majority of respondents identified as being female (85.6%), were aged between 45 and 74 years (72.5%), lived in a metropolitan area of Australia (48.3%) and lived in NSW (21.9%), Victoria (27.1%) or Queensland (15.5%). Between 296 and 365 respondents did not provide information on at least one of these four demographic characteristics. When analyses focused on these different characteristics, non-responders were excluded. Due to their relatively small numbers, respondents from the NT were combined with those from South Australia, and those from ACT were combined with NSW.

Table 2 shows the type of breast cancer and the care continuum of respondents. Most respondents had invasive breast cancer and were on hormone-blocking therapy or in follow-up care.

Table 3 shows the proportion of respondents in the different care continuum categories by breast cancer stage. The majority of women with eBC indicated they were on hormone-blocking therapy, with around 24% in active treatment/not started treatment and 25% in follow-up care. Of those with mBC, 27% indicated they were currently having treatment, with around 40% indicating they were living with metastatic disease. Forty-one per cent of respondents with DCIS/LCIS were in follow-up care, with 31% indicating they were on hormone-blocking therapy.

Table 1: Age, sex and residential location of sample

	N	%
Total N	2,307	100
Sex		
Female	1,974	85.6
Male	4	.2
Other	4	.2
Missing	325	14.1
Age		
<=44	201	8.7
45–54	488	21.2
55-64	672	29.1
65–74	513	22.2
75+	137	5.9
Missing	296	12.8
Residential location		
Metropolitan	1,114	48.3
Regional	564	24.4
Rural	244	10.6
Remote	20	0.9
Missing	365	15.8
State		
ACT	50	2.2
NSW	505	21.9
NT	8	0.3
Queensland	358	15.5
SA	172	7.5
Tasmania	48	2.1
Victoria	626	27.1
Western Australia	206	8.9
Missing	334	14.5

Table 2: Number and proportion of respondents by breast cancer stage and breast cancer care continuum

	N	%
Total N	2,307	100
	Breast cancer stage	
Ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS)	377	16.3
Early breast cancer (eBC)	1,611	69.8
Metastatic breast cancer (mBC)	237	10.3
Missing	82	3.6
	Breast cancer care continuum^	
Not yet started treatment	20	0.9
In active treatment	496	21.5
On hormone-blocking therapy	911	39.5
Completed treatment now in follow-up care	578	25.1
Living with mBC	96	4.2
Completed both treatment and follow-up care	191	8.3
Other	5	0.2

^ Respondents could only select one response. As management of metastatic disease can involve hormone-blocking therapies, radiotherapy, chemotherapy, etc. Respondents with metastatic disease may select responses reflecting current treatment rather than selecting 'living with mBC'.

Table 3: Breast cancer care continuum as reported by respondents with different staged disease (per cent reported)

	DCIS/LCIS#	eBC^	mBC^^	Total
	N=374	N=1601	N=237	N=2212
Active treatment/not yet started	13.9%	23.8%	27.4%	22.5%
Hormone-blocking therapy	30.5%	44.1%	27.4%	40.0%
Follow-up care	40.9%	24.5%	5.5%	25.0%
Living with mBC	na##	na##	39.7%	4.3%
Completed both treatment and follow-up care	14.4%	7.6%	na##	8.1%

DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ (non-invasive breast cancer)
^ eBC: early breast cancer ^^mBC metastatic breast cancer.
na not applicable

Breast cancer stage varied by age (p=.01) with more DCIS/LCIS in those over 75 years (22%) compared to those under 45 years (11%) and more eBC in those under 45 years (82%) compared with 55–65-year-olds (70%) and those over 75 years (70%). Breast cancer stage also varied by state (p=.02) with more mBC in WA (17%) compared to other states (approximately 10%) and more DCIS/LCIS in Queensland (21%) compared to SA/NT (14%).

Changes/delays in treatment related procedures.

The following section reports responses to questions assessing experiences of changes or changes/delays in different components of treatment. While respondents indicating they had completed treatment and all follow-up care were excluded from these analyses, those in follow-up care, on hormone-blocking therapy or with metastatic disease were included in analyses. However, as questions relating to specific aspects of treatment are not relevant to all respondents (e.g. radiotherapy questions are not relevant to those in follow-up care only), some respondents are excluded from analyses of different questions. This approach is most clearly demonstrated in relation to the question assessing change/delay in screening tests. As this question specifically asked about screening before the initial diagnosis, responses from those in follow-up care, on hormone-blocking therapy and with metastatic disease were excluded.

Overall experience of changes/delays

Overall, the majority of respondents did not experience any changes or delays to their diagnosis or treatment (Table 4). The key area where most participants experienced changes/delays was in relation to doctor/specialist appointments with 37% reporting some alterations mostly instigated by the health care team. Although applicable to a smaller number of respondents, 40% of those responding to the question asking about delays/changes to reconstruction surgery indicated there had been some change with this primarily instigated by the health care team. Additionally while the question relating to changes to clinical trial participation was relevant to a smaller number of respondents (n=102), 31% indicated there had been some change to their participation in the clinical trial with this alteration mostly instigated by the health care team.

Table 4: Proportion of respondents^ indicating changes/delays or no changes in different components of breast cancer care

	N	Change/delay-by treatment team	Change/ delay-by me	No change
Screening tests	298	13.4%	5.0%	81.5%
Doctor appointments	1,592	33.2%	4.3%	62.4%
Tests/scans	819	6.5%	2.3%	91.2%
Surgery	338	13.0%	0.9%	86.1%
Reconstruction surgery	264	33.0%	7.2%	59.5%
Radiotherapy	418	13.4%	1.2%	85.4%
Chemotherapy	366	11.7%	0.8%	87.4%
Hormone-blocking therapy	909	6.3%	3.0%	90.8%
Targeted therapy	221	8.1%	0	91.9%
Immunotherapy	73	5.5%	5.5%	89.0%
CDK4/6 inhibitor therapy	66	7.6%	1.5%	90.9%
Fertility therapy	36	5.6%	5.5%	88.9%
Clinical trial participation	102	26.5%	3.9%	69.6%

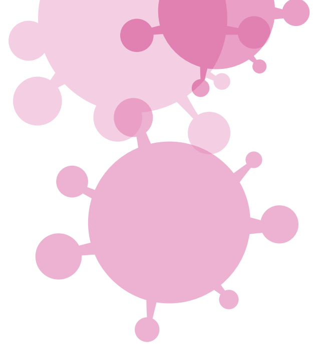
^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Four hundred and twenty-seven respondents provided further information about the alteration to their care they had experienced. Review of these open-ended text responses indicated that the most commonly reported alterations related to:

- moving face-to-face appointments to telehealth;
- changes at the hospital level regarding visitor access and access to support people during care;
- infection control processes at health services.

However, instances of more substantive changes or delays to the diagnosis and/or treatment were also reported, and these included:

- Delays to the initial diagnosis of cancer (e.g. due to the closure of screening services or delays to tests and scans investigating symptoms);
- Travel restrictions, which impacted access to routine screening, tests and scans, and in several instances, treatment itself;
- Changes to surgery to minimise time in hospital or the need for adjuvant therapy;
- Changes to surgical approach regarding the contralateral breast;
- Adjustments to radiotherapy, chemotherapy and other therapies;
- Restricted access to scalp cooling during chemotherapy;
- Medication shortages.



Illustrative comments of respondents' experiences of treatment delays and changes are shown below. Further example quotes can be found in Appendix 2.

Influence of age on changes/delays

Overall, 1526 respondents provided information about their age and answered questions about doctor appointment change/delays (Table 5). Of these, 34% indicated that their health care team had changed/delayed their appointments, 4% indicated that they had requested a change/delay and 62% indicated there had been no change/delay. There was a significant association with age and appointment delays (p<.001) with older women (those over 65 years) less likely to indicate any change/delay in their appointments. Around 40% of women aged 45-54 years and 46% of those younger than 45 years of age indicated a change/delay instigated by their health care team.

> “
>
> **Breast screen delayed due to COVID-19 causing shutdown of service.**
>
> **Delayed initial investigations due to COVID-19 lockdown.**
>
> **Various symptoms of metastatic breast cancer have arisen, but delayed investigation.**
>
> **A full mastectomy was performed to avoid radiation and additional hospital visits, however a double mastectomy was not possible during COVID-19.**
>
> **Was unable to go ahead with mastectomy due to recovery time required, lump was removed instead.**
>
> **My hospital stays with each surgery with shortened because of COVID-19. Sent home 24 hours after major surgery. Awful!!**
>
> **Radiotherapy was delayed for six months. Began hormone-blocking therapy prior to radiotherapy.**
>
> ”

Table 5: Experience of changes/delays in appointments, screening and other tests by age group^

	<44	45-54	55-65	65-74	75+	Total
	Appointments					
Changed/delayed-by treatment team	46.3%	39.8%	34.3%	21.6%	24.7%	33.6%
Changed/delayed-by me	2.3%	4.8%	4.0%	5.7%	2.5%	4.3%
No alteration	51.4%	55.5%	61.7%	72.7%	72.8%	62.1%
N	175	400	504	366	81	1,526
	Screening					
Changed/delayed-by treatment team	7.8%	11.5%	17.2%	15.2%	0.0%	13.2%
Changed/delayed-by me	5.9%	2.6%	5.7%	6.5%	0.0%	4.9%
No alteration	86.3%	85.9%	77.0%	78.3%	100.0%	81.9%
N	51	78	87	46	3	265
	Tests/scans					
Changed/delayed-by treatment team	4.9%	8.1%	7.6%	3.4%	3.6%	6.3%
Changed/delayed-by me	2.9%	3.2%	1.9%	1.7%	0.0%	2.3%
No alteration	92.2%	88.7%	90.5%	94.9%	96.4%	91.4%
N	102	222	262	177	28	791

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Questions relating to delays in screening tests and scans/tests in general were answered by 265 and 791 respondents respectively. Around 13% of people answering questions relating to screening indicated their health care team made some changes to their appointment schedule. Ninety-one percent of those answering questions on delays relating to scans/other tests did not experience any delays or changes. Age was not related to responses for either of these questions.

Table 6 provides information relating to the experience of different treatments by respondent's age. Due to small numbers, respondents over 75 years of age were combined with those aged 65-74 years.

Overall, around 13% of respondents indicated their treatment team changed/delayed their surgery or radiotherapy with 10% indicating their treatment team changed/delayed chemotherapy. Few respondents indicated that they instigated any changes in these treatment modalities. Eight per cent or respondents indicated a treatment team change/delay in targeted therapies and 6% indicated a treatment team change/delay in hormone-blocking therapies. While the experience of changes/delays in these different treatment modalities varied slightly across age groups, there was no statistically significant association with age.

Table 6: Experiences of changes/delays with different treatment modalities by age group^

	<44	45–54	55–65	65+	Total
	Surgery				
Changed/delayed–by treatment team	15.3%	13.4%	9.0%	13.3%	12.6%
Changed/delayed–by me	1.4%	2.1%	0.0%	0.0%	0.9%
No alteration	83.3%	84.5%	91.0%	86.7%	86.5%
N	72	97	89	60	318
	Reconstruction				
Changed/delayed–by treatment team	35.0%	44.9%	31.3%	14.0%	33.3%
Changed/delayed–by me	0.0%	6.4%	12.5%	9.3%	7.3%
No alteration	65.0%	48.7%	56.3%	76.7%	59.0%
N	60	78	80	43	261
	Radiotherapy				
Changed/delayed–by treatment team	9.4%	16.0%	17.7%	7.4%	13.4%
Changed/delayed–by me	1.9%	2.8%	0.0%	0.9%	1.3%
No alteration	88.7%	81.1%	82.3%	91.7%	85.4%
N	53	106	130	108	397
	Chemotherapy				
Changed/delayed–by treatment team	17.9%	11.4%	7.5%	11.1%	10.2%
Changed/delayed–by me	0.0%	1.8%	0.0%	0.0%	0.6%
No alteration	82.1%	86.8%	92.5%	88.9%	87.6%
N	78	114	93	63	348
	Targeted therapy				
Changed/delayed–by treatment team	2.3%	12.1%	9.9%	5.4%	8.1%
Changed/delayed–by me	0	0	0	0	0
No alteration	97.7%	87.9%	90.1%	94.6%	91.9%
N	43	58	71	37	209
	Hormone-blocking therapies				
Changed/delayed–by treatment team	4.4%	7.2%	4.2%	7.6%	6.0%
Changed/delayed–by me	3.3%	3.0%	2.1%	0.6%	2.4%
No alteration	92.2%	89.9%	93.7%	90.4%	91.6%
N	90	237	286	251	864
	Clinical trial				
Changed/delayed–by treatment team	28.6%	30.8%	32.3%	18.2%	28.0%
Changed/delayed–by me	0	7.7%	3.2%	4.5%	4.3%
No alteration	71.4%	61.5%	64.5%	77.3%	67.7%
N	14	26	31	22	93

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Two hundred and sixty one respondents provided a response relating to reconstruction surgery with 33% indicating they experienced a treatment team change/delay, and 7% indicating that they instigated the change/delay. Change/delay in reconstruction surgery was significantly associated with age (p=.006) with women aged over 65 years least likely to report a treatment team change/delay (14%) compared to those aged 45–54 years, where 45% indicated a treatment team change/delay. Older respondents were more likely to report self-initiated change/delay for reconstruction surgery.

Influence of residential location on changes/delays

Respondents not providing information on their residential location were excluded from the following analyses. Tables 7 and 8 show the proportion of respondents residing in metropolitan areas and regional, rural, remote areas experiencing changes/delays in the different areas of care. Changes/delays in appointments, screening tests and other tests did not differ by residential location.

While there was a slightly higher proportion of respondents from regional, rural and remote areas reporting a treatment team change/delay in surgery (16%) compared to experiences of respondents from metropolitan areas (11%), surgery changes/delays did not differ significantly by residential location (Table 7). Similarly, residential location did not influence experiences regarding changes/delays in other areas of treatment. While 41% of respondents from regional, rural and remote areas reported a treatment team change/delay in having reconstruction surgery compared with 31% of metropolitan respondents, this difference was not statistically significant.

Table 7: Experiences of changes/delays in appointments, screening tests and other tests by residential location^

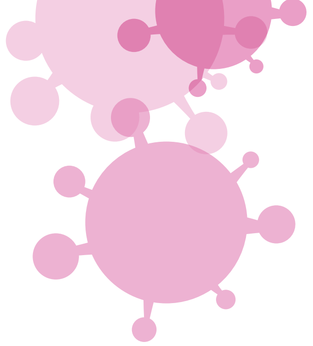
	Metropolitan	Regional, rural, remote	Total
	Appointments		
Changed/delayed–by treatment team	34.0%	33.6%	33.9%
Changed/delayed–by me	4.5%	4.3%	4.4%
No alteration	61.5%	62.2%	61.7%
N	852	444	1,296
	Screening		
Changed/delayed–by treatment team	10.0%	19.5%	13.4%
Changed/delayed–by me	5.0%	2.6%	4.1%
No alteration	85.0%	77.9%	82.5%
N	140	77	217
	Scans/tests		
Changed/delayed–by treatment team	5.6%	5.4%	5.5%
Changed/delayed–by me	3.0%	1.7%	2.5%
No alteration	91.4%	92.9%	91.9%
N	429	241	670

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Table 8: Experiences of changes/delays with different treatment modalities by residential location^

	Metropolitan	Regional, rural, remote	Total
	Surgery		
Changed/delayed-by treatment team	11.2%	15.7%	12.7%
Changed/delayed-by me	1.1%	1.1%	1.1%
No alteration	87.7%	83.1%	86.2%
N	179	89	268
	Reconstruction		
Changed/delayed-by treatment team	31.3%	40.7%	33.8%
Changed/Delayed-by me	6.9%	6.8%	6.8%
No alteration	61.9%	52.5%	59.4%
N	160	59	219
	Radiotherapy		
Changed/delayed-by treatment team	13.8%	12.8%	13.5%
Changed/delayed-by me	1.8%	0.9%	1.5%
No alteration	84.4%	86.2%	85.0%
N	225	109	334
	Chemotherapy		
Changed/delayed-by treatment team	9.9%	13.6%	11.3%
Changed/delayed-by me	1.0%	0.0%	0.7%
No alteration	89.1%	86.4%	88.1%
N	192	110	302
	Hormone-blocking therapy		
Changed/delayed-by treatment team	7.0%	4.4%	6.1%
Changed/delayed-by me	2.2%	2.0%	2.2%
No alteration	90.8%	93.5%	91.7%
N	489	248	737
	Targeted therapy		
Changed/delayed-by treatment team	7.0%	9.6%	8.0%
Changed/delayed-by me	0	0	0
No alteration	93.0%	90.4%	92.0%
N	114	73	187
	Clinical trial		
Changed/delayed-by treatment team	25.0%	26.3%	25.3%
Changed/delayed-by me	3.3%	10.5%	5.1%
No alteration	71.7%	63.2%	69.6%
N	60	19	79

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.



Influence of residential state on changes/delays

Change/delay in appointments, screening and other tests were seen in all states (Table 9), and while there were some variations in proportion of respondents indicating treatment team delays, residential state was not statistically related to changes/delays in appointments, screening or other tests. Note the small number of respondents from Tasmania suggests caution in interpreting proportions for this state.

Table 9: Experience of changes/delays in appointments, screening tests and other tests by residential state^

	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	Total
	Appointments						
Changed/delayed-by treatment team	34.0%	37.3%	31.3%	29.5%	27.3%	43.2%	33.6%
Changed/delayed-by me	2.7%	5.7%	3.1%	3.6%	5.2%	13.5%	4.4%
No alteration	63.3%	56.9%	65.6%	66.9%	67.5%	43.2%	62.1%
N	412	490	128	281	154	37	1502
	Screening						
Changed/delayed-by treatment team	9.1%	17.3%	14.3%	16.7%	6.9%	10.0%	13.4%
Changed/delayed-by me	1.5%	5.3%	4.8%	6.7%	10.3%	0.0%	5.0%
No alteration	89.4%	77.3%	81.0%	76.7%	82.8%	90.0%	81.6%
N	66	75	21	60	29	10	261
	Tests/scans						
Changed/delayed-by treatment team	4.3%	7.4%	6.3%	8.3%	5.7%	5.6%	6.4%
Changed/delayed-by me	2.4%	2.9%	3.1%	1.3%	2.3%	0.0%	2.3%
No alteration	93.3%	89.8%	90.6%	90.4%	92.0%	94.4%	91.3%
N	208	244	64	157	87	18	778

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Table 10: Experiences with delay in different treatment modalities and residential state^

	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	Total
	Surgery						
Changed/delayed-by treatment team	16.0%	17.2%	3.7%	9.4%	9.3%	11.1%	12.9%
Changed/delayed-by me	0	0	0	3.1%	2.3%	0	1.0%
No alteration	84.0%	82.8%	96.3%	87.5%	88.4%	88.9%	86.2%
N	81	87	27	64	43	9	311
	Reconstruction						
Changed/delayed-by treatment team	28.8%	40.0%	40.0%	30.6%	24.3%	57.1%	33.5%
Changed/delayed-by me	3.0%	8.0%	5.0%	8.2%	10.8%	0	6.7%
No alteration	68.2%	52.0%	55.0%	61.2%	64.9%	42.9%	59.4%
N	66	75	20	49	37	7	254
	Radiotherapy						
Changed/delayed-by treatment team	21.1%	16.4%	5.4%	8.6%	4.1%	12.5%	13.7%
Changed/delayed-by me	2.6%	0	0	2.9%	0	0	1.3%
No alteration	76.3%	83.6%	94.6%	88.6%	95.9%	87.5%	85.1%
N	114	110	37	70	49	8	388
	Chemotherapy						
Changed/delayed-by treatment team	16.8%	12.8%	6.1%	9.2%	4.8%	28.6%	12.0%
Changed/delayed-by me	0	0	0	1.5%	2.4%	0	0.6%
No alteration	83.2%	87.2%	93.9%	89.2%	92.9%	71.4%	87.4%
N	101	94	33	65	42	7	342
	Targeted therapy						
Changed/delayed-by treatment team	10.8%	11.4%	8.3%	0	6.3%	0	8.3%
Changed/delayed-by me	0	0	0	0	0	0	0
No alteration	89.2%	88.6%	91.7%	100.0%	93.8%	100.0%	91.7%
N	65	70	12	37	16	5	205

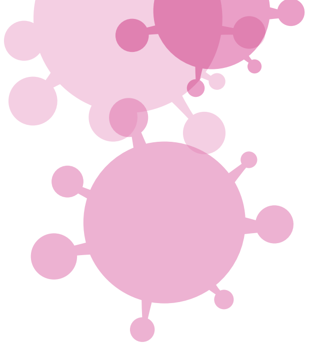


Table 10 shows the proportion of respondents in each state reporting changes/delays for the different treatment modalities. While there were small variations across states, in general changes/delays were similar across states with no significant associations found. The exception to this was radiotherapy where differences between states was statistically significant (p=.035), with a greater proportion of respondents from NSW/ACT reporting treatment team changes/delays for radiotherapy (21%) compared to respondents from WA (4%) and SA (5%). Due to the small number of respondents from Tasmania, analyses were repeated, combining data from Victoria and Tasmania. A similar pattern of results was found with only radiotherapy change/delay significantly related to state. The small number of respondents in each state answering the question assessing clinical trial changes/delays, suggests caution is needed when interpreting findings for this question.

Table 10: Experiences with delay in different treatment modalities and residential state^, continued

	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	Total
	Hormone-blocking therapies						
Changed/delayed-by treatment team	5.8%	6.6%	8.9%	4.2%	4.2%	4.8%	5.9%
Changed/delayed-by me	2.7%	2.1%	0.0%	2.8%	3.1%	9.5%	2.5%
No alteration	91.6%	91.3%	91.1%	93.0%	92.7%	85.7%	91.7%
N	225	288	79	143	96	21	852
	Clinical trial						
Changed/delayed-by treatment team	19.0%	35.1%	20.0%	12.5%	41.7%	na	28.0%
Changed/delayed-by me	4.8%	5.4%	0	6.3%	0	na	4.3%
No alteration	76.2%	59.5%	80.0%	81.3%	58.3%	na	67.7%
N	21	37	5	16	12	na	93

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Influence of breast cancer stage on changes/delays

Table 11 shows the proportion of respondents with DCIS/LCIS, early breast cancer (eBC) and metastatic breast cancer (mBC) reporting changes/delays in doctor/specialist appointments, screening tests and other tests. As the question in relation to screening was not relevant to respondents with metastatic disease or those in follow-up care or having hormone-blocking therapy, these respondents were excluded from analyses of this question. While slightly more respondents with mBC reported treatment team instigated changes/delays in doctor appointments, these differences were not statistically significant. However, the proportion of mBC respondents reporting changes/delays in other tests (13%) was significantly higher than the proportion of respondents with DCIS/LCIS (4%) or eBC (5%) reporting changes/delays in this area of care (p=.022).

There was little difference in the experiences of change/delay in different areas of care by breast cancer stage (Table 12). The only statistically significant difference was found for hormone-blocking therapies where a greater proportion of respondents with DCIS/LCIS changed/delayed this treatment (7%) compared with respondents with eBC (2%) or mBC (2%) (p=.033). However, the small number of mBC respondents providing a response to the question assessing surgery and reconstruction change/delay and the small number of DCIS/LCIS respondents answering questions about chemotherapy and targeted therapy changes/delays suggests caution is needed when interpreting findings for these questions for these two breast cancer types.

Table 11: Experience with changes/delays in doctor appointments, screening tests and scans/other tests by breast cancer stage^

	DCIS/LCIS#	eBC##	mBC###	Total
	Doctor/Specialists appointment			
Changed/delayed-by treatment team	29.8%	33.1%	39.6%	33.4%
Changed/delayed-by me	4.3%	4.4%	4.8%	4.4%
No alteration	66.0%	62.5%	55.6%	62.2%
N	235	1,117	187	1,539
	Screening			
Changed/delayed-by treatment team	12.5%	13.3%	na^^	13.2
Changed/delayed-by me	3.1%	5.2%	na	4.9%
No alteration	84.4%	81.5%	na	81.9 %
N	32	233	na	265
	Scans/tests			
Changed/delayed-by treatment team	3.8%	5.4%	13.2%	6.2%
Changed/delayed-by me	2.3%	2.4%	0.9%	2.2%
No alteration	93.9%	92.2%	85.8%	91.6%
N	132	552	106	790

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.
# DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ
eBC: early breast cancer ###mBC metastatic breast cancer.
na: not applicable

Table 12: Experience of changes/delays with different treatment modalities by breast cancer stage

	DCIS/LCIS#	eBC##	mBC###	Total
	Surgery			
Changed/delayed-by treatment team	29.8%	33.1%	39.6%	33.4%
Changed/delayed-by me	4.3%	4.4%	4.8%	4.4%
No alteration	66.0%	62.5%	55.6%	62.2%
N	235	1,117	187	1,539
	Reconstruction			
Changed/delayed-by treatment team	12.5%	13.3%	na^^	13.2
Changed/delayed-by me	3.1%	5.2%	na	4.9%
No alteration	84.4%	81.5%	na	81.9 %
N	32	233	na	265
	Radiotherapy			
Changed/delayed-by treatment team	3.8%	5.4%	13.2%	6.2%
Changed/delayed-by me	2.3%	2.4%	0.9%	2.2%
No alteration	93.9%	92.2%	85.8%	91.6%
N	132	552	106	790
	Chemotherapy			
Changed/delayed-by treatment team	3.8%	5.4%	13.2%	6.2%
Changed/delayed-by me	2.3%	2.4%	0.9%	2.2%
No alteration	93.9%	92.2%	85.8%	91.6%
N	132	552	106	790
	Targeted therapies			
Changed/delayed-by treatment team	3.8%	5.4%	13.2%	6.2%
Changed/delayed-by me	2.3%	2.4%	0.9%	2.2%
No alteration	93.9%	92.2%	85.8%	91.6%
N	132	552	106	790
	Hormone-blocking therapies			
Changed/delayed-by treatment team	3.8%	5.4%	13.2%	6.2%
Changed/delayed-by me	2.3%	2.4%	0.9%	2.2%
No alteration	93.9%	92.2%	85.8%	91.6%
N	132	552	106	790

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.
# DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ
eBC: early breast cancer ###mBC metastatic breast cancer.

Influence of breast cancer care continuum on changes/delays

Table 13 shows the relationship between the breast cancer care continuum (not started, in active care, on hormone-blocking therapy, follow-up and mBC) and experiences of changes/delays in appointments, screening tests and other tests. Regardless of where respondents were in the care continuum, the majority did not experience any changes/delays in these aspects of care. However, there was some difference in appointment change/delay by care continuum position, with those living with mBC most likely to report change/delay initiated by their health care team (46%) compared to only 6% of those who hadn't started treatment, 29% of those in active treatment and 28% of those in follow-up care (p<.001).

Table 14 shows the proportion of respondents with treatment changes/delays by care continuum. Only respondents in active treatment, having hormone therapy or living with mBC are included in analyses, as treatment-related questions were most relevant to these respondents. There was no significant association between position in the care continuum and changes/delays in any treatment. The small number of respondents with mBC suggest caution is needed for interpreting responses to questions.

Table 13: Experience of changes/delays in doctor appointments, screening tests and scans/other tests by breast cancer care continuum^

	Treatment not started	Active treatment	On hormone-blocking therapy	In follow-up	Living with mBC#	Total
	Doctor/Specialist appointment					
Changed/delayed-by treatment team	5.9%	29.2%	38.0%	28.3%	45.7%	33.2%
Changed/delayed-by me	5.9%	2.5%	5.8%	4.0%	2.9%	4.3%
No alteration	88.2%	68.3%	56.2%	67.7%	51.4%	62.4%
N	17	445	685	375	70	1,592
	Screening					
Changed/delayed-by treatment team	16.7%	13.0%	na^^	na	na	13.1%
Changed/delayed-by me	16.7%	4.2%	na	na	na	4.7%
No alteration	66.7%	82.8%	na	na	na	82.2%
N	12	262	na	na	na	274
	Scans/tests					
Changed/delayed-by treatment team	7.1%	4.9%	7.2%	7.5%	10.3%	6.5%
Changed/delayed-by me	7.1%	1.8%	2.5%	2.9%	0.0%	2.3%
No alteration	85.7%	93.3%	90.3%	89.6%	89.7%	91.2%
N	14	326	277	173	29	819

NB: As noted previously, people with mBC can receive multiple types of treatment and may be included in active treatment, on hormone-blocking therapy, in follow-up care or living with metastatic disease.
^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.
#mBC metastatic breast cancer
^^ na not applicable.

Table 14: Experiences of changes/delays with different treatment modalities by breast cancer care continuum

	In active treatment	On hormone-blocking therapies	Living with mBC#	Total
	Surgery			
Changed/delayed-by treatment team	11.9%	na	na	11.9%
Changed/delayed-by me	1.0%	na	na	1.0%
No alteration	87.1%	na	na	87.1%
N	311	na	na	311
	Radiotherapy			
Changed/delayed-by treatment team	9.2%	18.6%	16.7%	13.1%
Changed/delayed-by me	0.4%	2.4%	0	1.2%
No alteration	90.4%	79.0%	83.3%	85.7%
N	229	167	12	413
	Chemotherapy			
Changed/delayed-by treatment team	12.6%	na	0	11.8%
Changed/delayed-by me	0.6%	na	5.9%	0.8%
No alteration	86.8%	na	94.1%	87.3%
N	342	na	17	359
	Targeted therapy			
Changed/delayed-by treatment team	8.5%	7.9%	8.0%	8.2%
Changed/delayed-by me	0	0	0	0
No alteration	91.5%	92.1%	92.0%	91.8%
N	129	63	25	219
	Hormone-blocking therapies			
Changed/delayed-by treatment team	7.0%	5.7%	5.6%	5.9%
Changed/delayed-by me	2.3%	2.2%	3.7%	2.3%
No alteration	90.7%	92.0%	90.7%	91.8%
N	129	714	54	899
	Clinical trial			
Changed/delayed-by treatment team	14.7%	34.4%	na	26.8%
Changed/delayed-by me	0	6.6%	na	4.1%
No alteration	85.3%	59.0%	na	69.1%
N	34	61	na	95

#mBC metastatic breast cancer

Influence of multiple factors on delay (multivariate analyses)

Multivariable analyses (logistic regression) examined the relative influence of the three demographic factors along with breast cancer stage and care continuum on determining health care team change/delay as outlined in Tables 13 and 14. As participant initiated change/delay was minimal, health care team change/delay was focused on. Consequently, respondents indicating they initiated change/delay in their treatment were excluded from these analyses.

Only health care team initiated appointment change/delay was associated with multiple factors. Age (p<.01), state (p=.027) and care continuum (p<.01) were associated with health care team initiated appointment change/delay.

In multivariate analyses, health care team initiated changes/delays in tests were only significantly associated with breast cancer stage (p<.001).

For radiotherapy, only state (p=.03) was significantly associated with health care team initiated change/delay in multivariate analyses.

Reconstruction was only associated with age (p<.01) in multivariate analyses with younger respondents more likely to report treatment team initiated change/delay.

Age, state, breast cancer stage and breast cancer care continuum were not related to changes/delays in screening tests, surgery, chemotherapy, targeted therapy, hormone-blocking therapy or clinical trial participation in multivariate analyses.

Changes/delays in follow-up care

Experiences of delay in follow-up care was explored for those respondents indicating they were having follow-up care or having hormone-blocking therapy, which could include respondents with DCIS/LCIS, early breast cancer and metastatic breast cancer.

Table 15 shows the proportion of respondents having changes/delays in their follow-up care according to whether they were in follow-up care only or having follow-up care while on hormone-blocking therapy. Around 35% of respondents experienced treatment team initiation changes/delays in follow-up care appointments, with this significantly higher for those having hormone-blocking therapy (37%) compared to those having follow-up care only (31%) (p<.01). Changes/delays were most common for allied health appointments with 37% of respondents indicating health care provider instigated changes/delays that did not differ by care continuum. Twenty-nine per cent of respondents indicated treatment team initiated changes/delays for psychological care, which was similar for those in follow-up care and those having hormone-blocking therapy. Only 9% of respondents indicated changes/delays in follow-up scans, which was not related to the care continuum.

Table 15: Experience of follow-up care changes/delays for those in follow-up care only and those on hormone-blocking therapy^

	In follow-up care	On hormone-blocking therapy	Total
	Doctor appointments		
Changed/delayed-by treatment team	30.5%	37.0%	34.5%
Changed/delayed-by me	3.7%	5.8%	5.0%
No alteration	65.8%	57.2%	60.5%
N	456	741	1,197
	Scans/tests		
Changed/delayed-by treatment team	9.2%	9.3%	9.3%
Changed/delayed-by me	5.7%	5.6%	5.6%
No alteration	85.1%	85.2%	85.1%
N	336	539	875
	Psychological care		
Changed/delayed-by treatment team	29.7%	27.8%	28.5%
Changed/delayed-by me	7.6%	11.8%	10.2%
No alteration	62.7%	60.4%	61.3%
N	118	187	305
	Allied health		
Changed/delayed-by treatment team	31.9%	40.3%	37.2%
Changed/delayed-by me	18.6%	16.1%	17.1%
No alteration	49.5%	43.5%	45.8%
N	210	347	557

^ Base: respondents in: active treatment; not yet started treatment; on hormone-blocking therapies; living with mBC.

Table 16 shows the proportion of respondents in follow-up care or on hormone-blocking therapy experiencing changes/delays in follow-up in different age groups. There was a significant effect of age on experiences of change/delay for all items except follow-up scans/tests. For appointments, a greater proportion of younger respondents reported treatment team initiated changes/delays (51%) compared to respondents aged 65–74 years (24%) or those aged 75 and over (28%) (p<.01). A greater proportion of respondents aged under 65 years reported changes/delays in psychological care than did older respondents (65–74 years: 10%; 75+ years: 12%) (p<.01). For allied health appointments, younger respondents were more likely to report treatment team initiated changes/delays, than respondents over 65 years (p<.01).

Table 16: Experience of changes/delays in different aspects of follow-up care by age group^

	<44	45-54	55-65	65-74	75+	Total
	Doctor/Specialist appointments					
Changed/delayed-by treatment team	50.5%	39.0%	39.3%	23.9%	28.2%	35.2%
Changed/delayed-by me	4.4%	4.9%	4.3%	5.7%	7.0%	5.0%
No alteration	45.1%	56.1%	56.3%	70.4%	64.8%	59.8%
N	91	264	394	314	71	1,134
	Scans/tests					
Changed/delayed-by treatment team	17.5%	11.8%	7.3%	7.9%	11.5%	9.5%
Changed/delayed-by me	5.3%	5.3%	5.9%	5.0%	5.8%	5.5%
No alteration	77.2%	82.9%	86.7%	87.2%	82.7%	85.1%
N	57	187	286	242	52	824
	Psychological care					
Changed/delayed-by treatment team	37.8%	35.3%	35.5%	9.8%	21.4%	29.7%
Changed/delayed-by me	16.2%	9.4%	10.8%	6.6%	7.1%	10.0%
No alteration	45.9%	55.3%	53.8%	83.6%	71.4%	60.3%
N	37	85	93	61	14	290
	Allied health					
Changed/delayed-by treatment team	50.0%	37.4%	41.6%	31.1%	24.2%	37.6%
Changed/delayed-by me	18.0%	23.7%	12.9%	11.1%	24.2%	16.4%
No alteration	32.0%	38.8%	45.5%	57.8%	51.5%	46.0%
N	50	139	178	135	33	535

^ Base respondents having follow-up care or having hormone-blocking therapy only

Table 17 shows the proportion of respondents reporting treatment-initiated or self-initiated change/delay in the different follow-up care appointments by state. Changes/delays were fairly similar across the different states. Only responses to questions relating to delay in scans/tests showed some statistically significant differences in change/delay across the states (p=.043) with a greater proportion of respondents from Tasmania (16%) indicating they initiated changes/delays for scans. This is compared to respondents from other states where 7% or fewer respondents initiated changes/delays in scans.

Experiences of follow-up care changes/delays did not differ significantly for those residing in metropolitan and regional/rural/remote areas of Australia (see Table 17).

Table 17: Experiences of changes/delays in different aspects of follow-up care by residential state^

	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	Total
	Doctor appointments						
Changed/delayed-by treatment team	35.4%	37.2%	31.4%	32.5%	34.0%	35.7%	35.0%
Changed/delayed-by me	4.5%	7.5%	2.9%	2.0%	5.2%	7.1%	5.0%
No alteration	60.2%	55.3%	65.7%	65.5%	60.8%	57.1%	60.0%
N	314	371	102	203	97	28	1,115
	Scans/tests						
Changed/delayed-by treatment team	5.4%	12.4%	10.5%	8.8%	12.2%	5.3%	9.5%
Changed/delayed-by me	6.8%	6.0%	2.6%	1.5%	4.1%	15.8%	5.2%
No alteration	87.8%	81.6%	86.8%	89.8%	83.8%	78.9%	85.3%
N	221	283	76	137	74	19	810
	Psychological care						
Changed/delayed-by treatment team	28.2%	28.1%	33.3%	28.3%	26.7%	50.0%	29.3%
Changed/delayed-by me	9.9%	14.6%	7.4%	3.8%	10.0%	10.0%	10.0%
No alteration	62.0%	57.3%	59.3%	67.9%	63.3%	40.0%	60.7%
N	71	89	27	53	30	10	280
	Allied health						
Changed/delayed-by treatment team	34.5%	42.4%	35.4%	29.6%	40.8%	55.6%	37.5%
Changed/delayed-by me	19.7%	16.5%	16.7%	12.2%	16.3%	22.2%	16.8%
No alteration	45.8%	41.2%	47.9%	58.2%	42.9%	22.2%	45.7%
N	142	170	48	98	49	18	525

^ Base respondents having follow-up care or having hormone-blocking therapy only

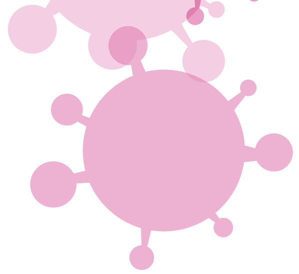


Table 19 shows the experiences of changes/delays in follow-up care by breast cancer stage. Differences in the experiences of changes/delays in different aspects of follow-up care by breast cancer stage were of borderline significance for psychological care (p=.048) and allied health appointments (p=.053). For both types of appointments, eBC respondents were least likely to indicate there had been no change/delay, with 57% of eBC respondents indicating no change/delay in psychological care appointments compared to 76% of DCIS/LCIS and 74% of mBC respondents. For allied health appointments, 40% of eBC respondents to this question indicated treatment team initiated change/delay compared to 29% of DCIS/LCIS respondents and 17% of mBC respondents.

Table 18: Experience of changes/delays in different aspects of follow-up care by residential location^

	Metropolitan	Regional, rural, remote	Total
	Doctor appointments		
Changed/delayed-by treatment team	36.2%	34.4%	35.6%
Changed/delayed-by me	5.3%	4.0%	4.8%
No alteration	58.6%	61.6%	59.6%
N	647	323	970
	Scans/tests		
Changed/delayed-by treatment team	9.8	8.6	9.4
Changed/delayed-by me	4.8%	7.4%	5.6%
No alteration	85.4%	84.0%	85.0%
N	481	231	712
	Psychological care		
Changed/delayed-by treatment team	35.2%	26.7%	32.7%
Changed/delayed-by me	10.8%	8.0%	10.0%
No alteration	54.0%	65.3%	57.4%
N	176	75	251
	Allied health		
Changed/delayed-by treatment team	35.1%	37.4%	35.8%
Changed/delayed-by me	20.5%	15.0%	18.7%
No alteration	44.5%	47.6%	45.5%
N	308	147	455

^ Base respondents having follow-up care or having hormone-blocking therapy only.

Table 19: Experiences of changes/delays in different aspects of follow-up care by breast cancer stage^

	DCIS/LCIS#	eBC##	mBC###	Total
	Doctor appointments			
Changed/delayed-by treatment team	27.6%	36.8%	23.3%	34.4%
Changed/delayed-by me	6.0%	4.7%	8.3%	5.2%
No alteration	66.4%	58.5%	68.3%	60.4%
N	217	886	60	1,163
	Scans/tests			
Changed/delayed-by treatment team	6.3%	9.1%	14.8%	9.0%
Changed/delayed-by me	8.3%	4.9%	5.6%	5.6%
No alteration	85.4%	85.9%	79.6%	85.4%
N	144	647	54	845
	Psychological care			
Changed/delayed-by treatment team	18.6%	30.9%	21.7%	27.8%
Changed/delayed-by me	5.1%	12.4%	4.3%	10.4%
No alteration	76.3%	56.7%	73.9%	61.9%
N	59	217	23	299
	Allied health			
Changed/delayed-by treatment team	28.7%	40.0%	17.4%	37.3%
Changed/delayed-by me	14.9%	16.7%	21.7%	16.6%
No alteration	56.3%	43.3%	60.9%	46.1%
N	87	432	23	542

^ Base respondents having follow-up care or having hormone-blocking therapy only.
# DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ.
eBC: early breast cancer ###mBC metastatic breast cancer.

Five hundred and twenty-eight respondents provided free text comments, discussing the change or delay they experienced in their follow-up care. A full summary of these comments are provided in Appendix 3. Examples of comments regarding Appendix 3 says alterations in follow-up care are provided below.

> **I see a specialist every 3 months for follow up care (scans and getting results). Nearly all of these sessions in the past 4 months have either not happened or were on the phone. I only had to go into hospital for the scan and then results on zoom or on the phone.**
>
> **I have put off breast ultrasound, all specialist appointments, physio and counselling until further notice due to difficulty being able to safely travel (as I'm avoiding public transit) to and from appointments.**
>
> **Psychology by phone, not convinced it's as good.**
>
> **Psychology was over the phone which was OK but too tiring for an hour appointment.**
>
> **Physiotherapy delayed due to concerns around COVID-19. Plans to see exercise physiologist and re-engage with breast cancer rehab program delayed as program was ceased during COVID-19. Plans to utilise gym/class/pool membership delayed due to centre closure and restrictions during COVID-19.**

Influence of multiple factor's on follow-up care change/delay (multivariate analyses)

Multivariate analyses examined the relative role of age, breast cancer stage, state and breast cancer care continuum on changes/delays in follow-up care. Age was the most consistently related factor, with significant associations found for changes/delays in follow-up care appointments ($p<.01$), psychological care appointments ($p<.01$) and allied health appointments ($p=.028$). Breast cancer stage had a marginally significant association with changes/delays in allied health appointment changes/delays ($p=.04$) and marginally non-significant for follow-up appointment changes/delays ($p=.07$) and changes/delays in scans ($p=.09$).

First Nations people

Of the 10 respondents identifying as First Nations people (Aboriginal, Torres Strait Islander or both), eight had eBC and two had DCIS/LCIS. Of First Nations respondents, five were in follow-up care and five were having hormone-blocking therapy. Five First Nations people reported that they had treatment team instigated appointment delays. Only three First Nations people responded to questions relating to changes/delays in follow-up care scans, allied health appointments and psychological care appointments. One person reported health care team instigated changes/delays in psychological and allied health care appointments. None of those on hormone-blocking therapy reported changes/delays in this area of care.

Factors influencing impact of COVID-19 on care

In addition to providing comments on the changes/delays caused by the COVID-19 pandemic on treatment and follow-up care, respondents were asked: "If your treatment or follow-up care was impacted in some way by coronavirus (COVID-19), which of the following factors (if any) influenced the change?" with a list of eight factors and a no-impact response provided. For these analyses, respondents indicating no impact were excluded, enabling an understanding for the most common factors influencing care alterations for those experiencing change.

For respondents reporting their care was impacted by COVID-19 pandemic the key factor in this were changes to the health services because of COVID-19 in the community (46%), followed by use of telehealth (26%) and the inability to take a support person to appointments/lack of hospital visitors (20%) (Table 20). There were some differences in responses by the breast cancer care continuum with respondents indicating they were in active treatment/treatment not yet started more likely to report health care team concerns regarding susceptibility ($p=0.014$), inability to have a support person/visitors ($p<.01$) and financial concerns ($p<.01$) than others along the care continuum.

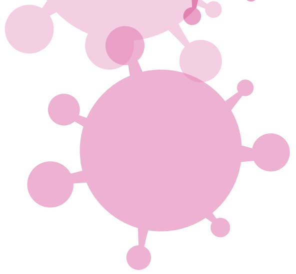


Table 20: For respondents having their care impacted by COVID-19 pandemic, factors perceived as influencing alterations in care by breast cancer care continuum (n=1330)

	Active treatment/not yet started	On hormone-blocking therapies	Living with mBC^	In follow-up care	Total
Changes to the health services because of COVID-19 in the community	46.0%	48.1%	44.4%	41.7%	45.8%
Access to and/or ability to use telehealth	25.4%	26.1%	36.1%	24.6%	26.1%
Unable to take support person to appointments or have hospital visitors	40.3%	12.0%	26.4%	13.2%	20.2%
My treating team was concerned about the effects of treatment on my susceptibility to COVID-19 infection	15.2%	8.8%	9.7%	9.0%	10.5%
Travel restrictions	11.0%	8.6%	11.1%	9.0%	9.5%
Financial concerns	10.4%	5.6%	2.8%	4.8%	6.5%
My family's/friends' advice	1.2%	1.7%	2.8%	3.0%	2.0%

^ mBC: metastatic breast cancer.

Experiences of anxiety in relation to COVID-19 and breast cancer care

Respondents were asked to indicate how anxious they were feeling in relation to their breast cancer care being affected by the COVID-19 pandemic using a 5-point scale ranging from not at all (1) to extremely (5). One hundred and twenty-four respondents did not answer this question and were excluded from the analyses. When looking at the distribution of responses to this question, 44% indicated they were not at all anxious, 28% were slightly anxious, 14% were somewhat anxious, 9% were moderately anxious and 5% were extremely anxious. However, the average anxiety score was 2.01 (SD=1.16) indicating that on average respondents felt slightly anxious. Mean anxiety scores for respondents at different breast cancer stages and at different points in the care continuum can be seen in Table 21. There was a statistically significant effect of breast cancer stage on anxiety levels (p<.001), with mBC respondents having a higher mean score (mean=2.19) than DCIS/LCIS (mean=1.96) or eBC (mean=2.00) respondents.

To examine the unique effect of the different cancer-related and demographic factors on anxiety levels, a multivariate analysis of variance was conducted to examine the significance of associations between each of these variables on anxiety, after adjusting for the influence of all other factors. In this analysis, the significant effects of care continuum (p<.01), age (p<.01) and state were maintained while associations with breast cancer stage and residential location were not statistically significant. Examining the effect size of the three significant variables (partial eta square (η^2)) indicated that the care continuum variable had the greatest effect (η^2=0.057; indicating a medium effect size) on anxiety, with age (eta η^2=0.017) and state (η^2=0.004) both having small effects on anxiety.

A free text box allowed respondents to provide further information about their anxiety relating to breast cancer and COVID-19, with 474 respondents taking this opportunity. Details of responses made in this section of the survey are shown in Appendix 4.

Among respondents who indicated little anxiety, many expressed a sense of trust in their treating team and in the coronavirus-related precautions being taken by health services more generally.

> **“I did feel anxious about having radiation at the hospital but in the end I felt safer going there each day than I did going to the supermarket! Lots of processes were in place to protect staff and patients.”**

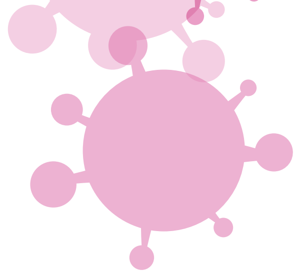


Table 21: Mean scores and standard deviations (SD) on anxiety measure by cancer type, care continuum and demographic characteristics

Breast cancer factors

Breast cancer stage

	Total	DCIS/LCIS#	eBC^	mBC^^	p-value
Mean	2.02	1.96	2.00	2.19	
SD	(1.16)	(1.19)	(1.13)	(1.27)	
N	1,889	314	1,374	201	.029

Breast Cancer Care Continuum

	Total	Active treatment/ not yet started	On hormone-blocking therapies	In follow-up care	Living with mBC	Finished treatment and follow-up	p-value
Mean	2.02	2.54	1.94	1.80	2.05	1.46	
(SD)	(1.16)	(1.32)	(1.08)	(1.04)	(1.19)	(0.81)	
N	1,881	438	771	461	77	134	<.001

Demographic factors

Age group

	Total	<45 years	45–54	55-64	65–74	75+	p-value
Mean	2.01	2.32	2.29	1.95	1.83	1.52	
SD	(1.16)	(1.16)	(1.20)	(1.14)	(1.11)	(0.96)	
N	1,988	200	486	669	499	134	<.001

State

	Total	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	p-value
Mean	2.01	1.99	2.16	1.88	1.97	1.90	1.77	
SD	(1.16)	(1.15)	(1.22)	(1.05)	(1.17)	(1.12)	(1.08)	
N	1947	543	617	179	356	204	48	.006

Residential location

	Total	Metro	Regional/rural/remote	p-value
Mean	2.01	2.00	2.04	
SD	(1.15)	(1.12)	(1.19)	
N	1,675	1,095	580	.44

DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ.
^ eBC: early breast cancer ^^mBC metastatic breast cancer.

Others noted low numbers of COVID-19 cases in their state or precautions they were taking to reduce their risk of coronavirus infection, such as self-isolating, social distancing and handwashing.

> **“I was extremely anxious during initial time of pandemic; then later very cautious & careful; however now, still careful about social distancing but not anxious at all.”**

Several respondents noted that, while they had initial concerns about the potential impact of the pandemic on their treatment, their fears had been allayed by treatment proceeding as planned.

> **“Initially I was concerned whether my treatment could continue, but as it has progressed as planned and I'm almost at the end of treatment I am no longer concerned.”**

However, other respondents expressed significant fear and concern about a range of issues, with the key ones including:

- increased susceptibility to coronavirus infection due compromised immune system;
- Fear of potential changes/delays to treatment, scans or tests or fears these may be cancelled due to changes to health services generally or if they were to contract COVID-19;
- Fear of contracting COVID-19;
- Anxiety about having fewer options for services and supports to help with physical and emotional wellbeing;
- Concerns about not being physically examined by health professionals due to the shift to telehealth;
- Fear of contact with others and not being able to socially distance, as well as anxiety that not all people appear to be complying with public health guidelines;
- Fears due to social isolation as a result of government restrictions on socialising, travel and hospital restrictions on access by visitors/support persons.

Many of these fears and concerns were reiterated in other sections of the survey that asked for respondents to describe their concerns in relation to COVID-19 and breast cancer. Responses to these other questions are described in detail below.

> **“Just concerned if I contract COVID-19 it will delay targeted treatment.**
>
> **I had many infections after my mastectomy. So I was petrified of any people coming near me, due to my low immune system.**
>
> **As soon as restrictions were lifted many people stopped respecting social distancing. Trips to the supermarket were scary because of my low immunity.**
>
> **It has been a difficult experience finding out that I have cancer and is compounded by the fact that I live on my own. My family, friends and I have all been in isolation.”**

Experiences with telehealth

First Nations people

Mean anxiety scores were calculated for the 10 respondents identifying as First Nations people. The mean anxiety level was 2.0 (SD=1.25) similar to the mean score found for the entire sample.

Experiences with telehealth

The survey asked a number of questions relating to experiences of telehealth, which many health services and doctors introduced as part of the response to the COVID-19 pandemic. Respondents indicated whether they had had any medical appointments via telehealth (response: yes or no). Those who had a telehealth appointment were asked for their comments on these types of appointments, while those that had no telehealth appointments were asked if they were interested in having telehealth appointments in the future. Responses to these questions were reviewed and major themes emerging from the comments are reported here.

Excluding respondents indicating that they had finished all treatment and follow-up, 72% had some type of telehealth consultation. Of those having a telehealth appointment, 80% reported a telephone telehealth consultation, 6% a video consultation and 14% a mix of video and telephone consultations.

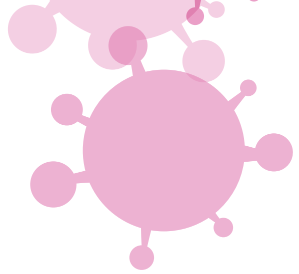
Table 22: Most common health professionals seen via telehealth (multiple responses allowed) (n=1391).

	N	%
GP	631	45.4%
Medical oncologist	624	44.9%
Radiation oncologist	323	23.2%
Breast surgeon	258	18.5%
Breast care nurse	245	17.6%
Psychologist or counsellor	204	14.7%
Allied health professional (e.g. physiotherapist)	158	11.4%

The most common doctors seen by telehealth were GPs and medical oncologists (around 45% each) (Table 22). Around 15% of respondents indicated they had spoken with a psychologist or counsellor by telehealth and 11% had seen an allied health professional. A telephone based appointment was most common for those seeing a surgeon (83%), medical oncologist (77%), radiation oncologist (78%) and GP (80%).

Multivariate analyses examined whether breast cancer stage, breast cancer care continuum, age and residential state were associated with consulting the different health professionals via telehealth. State (p<.01) and breast cancer stage (p<.01) were significantly associated with consulting a breast surgeon via telehealth, with this least likely for mBC respondents and most likely for those residing in Victoria. Consulting a radiation oncologist was only significantly associated with breast cancer stage (p<.01) and was least likely for those with mBC. Consulting a medical oncologist via telehealth was significantly associated with breast cancer stage (most likely for mBC) (p<.01), care continuum (least likely for those in follow-up) (p<.01) and state (least likely in Queensland and most likely in Victoria and Tasmania) (p<.01). Consulting a Breast Care Nurse via telehealth was significantly associated with breast cancer stage (p=.039) and care continuum (p<.05) and was most likely for those in active treatment and those with DCIS/LCIS or eBC. Consulting a psychologist was only associated with age (p<.01) and was most likely for younger rather than older respondents. Only state was associated with consulting an allied health professional via telehealth and was most likely in WA and least likely in SA/NT.

Reporting a telehealth consultation with a GP was not related to any of the demographic or breast cancer factors in multivariate or bivariate analyses.



While reporting a telehealth consultation did not differ across state or by residential location (metropolitan, regional/rural/remote), it did differ by age (p<.01), breast cancer stage (p<.01) and care continuum (p<.01). Younger respondents, those with metastatic breast cancer and those currently in active treatment were most likely to report having telehealth appointments (Table 23).

Table 23: Proportion of respondents indicating they had any type of telehealth consultations by age, breast cancer stage and breast cancer care continuum

What is your age? (years)							
	25-34	**35-44**	**45-54**	**55-64**	**65-74**	**75+**	**Total**
Any telehealth	85.2%	82.0%	75.8%	73.4%	68.6%	66.3%	73.4%

Breast cancer stage				
	DCIS or LCIS#	**eBC^**	**mBC^^**	**Total**
Any telehealth	63.5%	74.1%	83.8%	73.7%

Breast cancer care continuum					
	Active/not yet started	**On hormone-blocking therapies**	**In follow-up care**	**Living with mBC^^**	**Total**
Any telehealth	78.4%	73.7%	65.2%	85.0%	73.2%

DCIS or LCIS: ductal carcinoma in situ or lobular carcinoma in situ.
^ eBC: early breast cancer ^^mBC metastatic breast cancer.

Of those having a telehealth appointment 1,153 provided a response regarding whether they found this helpful. Of these, 68% indicated it was helpful, 22% indicated it was helpful but had some hesitations and 10% did not find it helpful.

Of the 10 First Nations people participating in the study, 7 indicated they had a telephone based telehealth consultation, one indicated they had used both telephone and video, and two indicated they had not had a telehealth consultation. Two noted that the telehealth consultations were helpful and two noted they would have preferred face-to-face consultations. The two people who indicated they had not had a telehealth consultation were not interested in having this type of appointment.

Around half of those indicating that their telehealth appointments were helpful did not provide further comment. Of those providing comments, respondents indicated a number of reasons for finding telehealth helpful, including convenience (reduction in travel and appointment waiting times) as well as reducing their exposure to COVID-19 by not having to travel or attend clinics or doctor's rooms.

> **“Yes. I prefer them because I didn’t have to travel and I was waiting in my own environment, not in a hospital waiting room with many others.”**

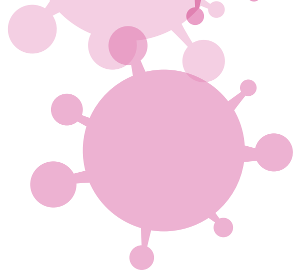
> **“Yes. These are just quick appointments and more time is spent in the waiting room. These should be ongoing in certain circumstances.**
>
> **Yes, was a 5 minute phone call. Avoided 60 minutes of return travel to the hospital and more time off work.**
>
> **Meant I didn’t have to travel to appointments, which saved time and money. All questions answered by health care person.**
>
> **Yes. I got the information needed without a 6 hour return journey!**
>
> **Yes I did as it eased my anxiety of going to the doctor’s office or hospital and waiting in waiting room and being in close proximity to people. I got same information over the phone as if I would going there in person.**
>
> **Yes, at the height of the epidemic I felt safer than going to GP’s rooms.**
>
> **Yes, very supportive and most importantly I felt that I was not alone and could access help if needed.**
>
> **I really liked that the consultants all did telehealth. There was no travel and wait time, the appointments were all really quick and got to the point. I would like to continue to do it this way.”**

Many respondents indicated that the telehealth consultation was helpful, as their questions were answered.

> **“Yes, and able to ask questions as easily as face-to-face appointment.**
>
> **Yes helpful and all questions were answered.”**

People from regional and rural areas reported telehealth was helpful due to the reduced need to travel to medical appointments, making telehealth a convenient way to access health care.

> **“Yes, telehealth appointments are very convenient especially for those of us living in semi-rural and rural areas. Telehealth appointments need to continue into the future!**
>
> **Yes, very helpful. Also, I live in a regional centre and it means that I haven’t needed to travel 4 hrs to attend the appointments. Face-to-face appointments are the most ideal but Tele and Video appointments are very helpful.**
>
> **It was fine. Due to being regional, no flights to get to this appointment.”**



As indicated, 22% of people who had a telehealth appointment had some hesitation about their helpfulness. These comments generally started with a ‘Helpful but … ’ or ‘Yes but … ’. Reasons for the hesitation could be grouped into several themes: preference for face-to-face; better than nothing; useful for some appointment types but not others (e.g. useful for GP appointments but not specialists). Other comments reflected a fear that something could be missed due to the remote nature of the consultation and absence of a physical examination. There was also a feeling that telehealth appointments were impersonal and more rushed than face-to-face appointments.

> **“I didn’t have any issue with the phone consult, however, you can’t beat the reassurance of having your oncologist doing a physical check.**
>
> **The phone appointments were adequate but I would have preferred face-to-face appointments so I could be physically examined.**
>
> **I think they’re better than nothing but I find it frustrating as I much prefer face-to-face.**
>
> **Ok, but not very personal, felt a little alone.**
>
> **Better than no appointment at all but far inferior to in person consultation which allows for the doctor to physically examine the breast and face-to-face interaction with specialist.”**

> **“Helpful enough, but definitely not the same as a face-to-face appointment during this very difficult and stressful time of my mBC diagnosis.**
>
> **It was better than nothing I suppose, but I felt it was inadequate and of course, there was no physical examination of the breasts.**
>
> **Yes and no – great didn’t have to go out or to hospital for appointment so wasn’t at risk of COVID infection but also made it feel as your treatment wasn’t as important to enable a face-to-face – also harder to put on a brave face in person if things aren’t going well, and Dr can’t observe that you appear in pain or not walking well or short of breath, etc. You can hide via a phone call.”**

While some respondents in all care continuum groups considered telehealth to be unhelpful, a greater proportion of those reporting this were in follow-up care or on hormone-blocking therapy.

Key reasons for not finding the telehealth appointments helpful were categorised into eight themes: preference for face-to-face; lack of physical examination; poor communication with the clinician; impersonal; brevity of the call; inappropriate location/form for receiving bad news; and cost and technical issues. While some of these issues were similar to the reasons some respondents expressed a hesitation with telehealth (e.g. preference for face-to-face and physical examination), for this group of respondents no positives were associated with telehealth.

> **“I found sitting out on the footpath of a local shopping centre adjacent to where I work, a cold and lonely experience which risked confidentiality.**
>
> **No one wants to be told you have cancer over the phone.**
>
> **I found it more difficult to talk to the oncologist as she was so busy, I feel face-to-face I had a better chance of asking questions and voicing my concerns. With face-to-face I also usually see the registrars first so again can ask questions and voice concerns.**
>
> **They are brief and seem distant.**
>
> **Not really, as I felt rushed and the personal element wasn’t there.**
>
> **No I hated them, I felt very alone.**
>
> **Not as good as a personal meeting. They tended to be shorter and I felt more superficial.”**

Some respondents who did not find telehealth helpful noted that they felt less certain of the outcomes of their consultation.

> **“This appointment was to be the first chance I have had to speak to the specialist in person as my previous appointments were with different doctors. I felt the phone conversation was very vague and of very little help as the specialist had no idea of how my health/recovery was progressing and did not have reports from my oncologist and surgeon.**
>
> **Telehealth appointments were not as reassuring or did not feel as supportive as face-to-face appointments.”**

Others noted difficulties with scheduling, with some noticing both delays and early appointments. Early appointments were problematic, as people felt unprepared for the consultation.

> **“Not really. They were running ahead of time and twice I was called hours early and asked to speak now. I said yes but should have said no. I wasn’t prepared mentally or organisationally. Both the major ones seemed scripted and like they just read from a template.”**

> I was driving when I was contacted, two days earlier than my appointment time, by my radiation oncologist and had to pull over to talk, so it made me stressed. And my surgeon can't check my wound over the phone.

Cost was often mentioned in relation to the brevity of the meeting or that it wasn't covered by private health.

> An absolute waste of time. Mine was done by a person who I had never met who was more interested in getting off the phone rather than answering my concerns. They then had the hide to want $90 for the gap fee for a 60 second phone call. It was absolutely terrible and a waste of my time.

Interest in telehealth

Five hundred and forty-four respondents indicated that they hadn't used telehealth and of these 228 (42%) responded to a question asking if they had any interested in using this form of consultation. Most people responding to this question were not interested in telehealth, 69 (13%) were interested and 13 (2%) were not sure. Interest in telehealth differed depending on breast cancer stage: respondents with DCIS/LCIS were more likely to indicate interest in telehealth (22%) than respondents with eBC (11%) or mBC (3%) ($p<.01$). Reflecting this, a greater proportion of respondents with eBC (45%) and mBC (47%) than DCIS/LCIS (29%) indicated they were not interested in telehealth consultations ($p<.01$).

Age, but not care continuum or location was also related to interest in having a telehealth consultation. Respondents under 45 years of age (27%) were more likely to indicate interest in telehealth than respondents over 65 years (8%) ($p=.011$).

While many respondents simply indicated 'no' or 'not really' to this question, the more detailed comments were reviewed and themes determined. The key reasons for not wanting this form of consultation concerned a preference for face-to-face appointments and the need for a physical examination. The preference for a face-to-face appointment was often mentioned in relation to the need for a physical examination with respondents often commenting that without this aspect of the consultation, the health care team could not really assess their condition or provide reassurance that all was well.

> No as everything revolves around a physical check.
>
> Prefer face-to-face appointments with health personnel where safe to do so.
>
> It would not have been practical, physical examination required.
>
> Probably not in this situation. I needed the confidence of speaking to the specialists for advice to help me to decide which option to go with.
>
> I like having face-to-face consult with my medical team as I understand better what is happening with me.
>
> With my breast surgeon last week I refused a telehealth consultation as I can't see how you can examine a breast over the phone, so I saw him in person.
>
> I was first offered telehealth & made the appointment then became very anxious as I've had bilateral mastectomies & (r) axillary node dissection. An examination lessens my anxiety about recurrence.

A small number of respondents noted technology issues, lack of privacy and insurance issues as a reason for not wanting a telehealth appointment.

Access to COVID-19 information

Respondents were asked where they had sourced information about COVID-19 to assist them make decisions about their management of risks and breast cancer care. Four hundred and forty-eight respondents indicating that information was not needed, as they were not making any treatment-related decisions, were excluded from analyses of responses to this question as were people indicating they had finished all treatment and follow-up.

Table 24 shows the proportion of respondents accessing information through different sources by age group, residential state and location. Across all respondents, the treating team was the most common source of information (50%), followed by television news (42%) and the Australian Government Department of Health's website (41%). Approximately 32% of respondents sourced information through BCNA and state health departments. While 26% of respondents accessed information through news websites, 14% accessed information through social media. Demographic factors were only related to a few information sources. Age was inversely associated with accessing information through the treatment team ($p<.01$) but positively associated with accessing information through television news ($p<.01$). Fewer respondents in Victoria accessed information from the state health department, with residents in Tasmania and SA/NT most likely to get information through this source ($p=.024$).

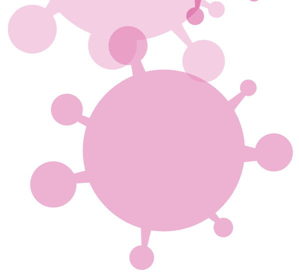


Table 24: The proportions of respondents accessing information sources by age group, residential state and residential location

	Age group					
	<44	45-54	55-64	65-74	75+	Total
Treating team	63.8%	58.8%	47.8%	35.1%	21.7%	47.9%
Television news	25.3%	36.9%	40.8%	46.0%	54.2%	40.0%
Australian Government Department of Health	41.4%	40.2%	40.4%	37.8%	25.3%	39.0%
BCNA	36.2%	34.8%	28.5%	29.6%	26.5%	31.2%
State health departments	34.5%	28.1%	32.3%	29.6%	26.5%	30.5%
News websites	27.6%	23.5%	25.2%	28.2%	24.1%	25.7%
Other cancer organisations	18.4%	20.9%	16.7%	17.8%	9.6%	17.9%
Social media	16.7%	16.2%	13.5%	12.3%	4.8%	13.8%
Hard to find information	2.3%	3.6%	1.5%	1.6%	1.2%	2.2%

	Residential state						
	NSW/ACT	Vic	SA/NT	Qld	WA	Tas	Total
Treating team	49.8%	47.9%	37.5%	50.8%	50.7%	41.7%	48.1%
Television news	39.8%	43.0%	37.5%	36.4%	38.2%	47.2%	40.0%
Australian Government Department of Health	41.3%	38.4%	43.4%	36.4%	36.2%	36.1%	39.0%
BCNA	30.3%	31.9%	36.0%	29.1%	30.9%	36.1%	31.3%
State health departments	32.8%	25.7%	39.0%	29.5%	31.6%	41.7%	30.6%
News websites	28.3%	28.1%	23.5%	21.3%	23.0%	25.0%	25.9%
Other cancer organisations	15.5%	17.1%	22.1%	16.7%	23.7%	22.2%	17.9%
Social media	15.3%	13.3%	15.4%	10.9%	16.4%	5.6%	13.7%
Hard to find information	1.8%	3.0%	0.7%	1.9%	2.6%	0.0%	2.1%

	Residential location		
	Metropolitan	Regional, rural, remote	Total
Treating team	49.1%	48.0%	48.7%
Television news	39.1%	38.9%	39.0%
Australian Government Department of Health	38.6%	41.8%	39.7%
BCNA	30.9%	31.5%	31.1%
State health departments	31.7%	30.3%	31.3%
News websites	25.2%	23.6%	24.7%
Other cancer organisations	16.8%	18.9%	17.5%
Social media	12.8%	14.8%	13.5%
Hard to find information	2.5%	2.1%	2.4%

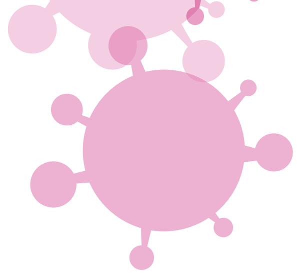


Table 25: The proportions of respondents accessing information sources by breast cancer stage and breast cancer care continuum

	Breast cancer stage			
	DCIS/LCIS#	eBC^	mBC^^	Total
Treating team	34.5%	41.6%	52.6%	41.9%
Television news	37.5%	32.5%	37.2%	33.9%
Australian Government Department of Health	37.9%	33.6%	34.9%	34.4%
BCNA	24.9%	28.8%	23.3%	27.5%
State health departments	25.3%	26.7%	27.4%	26.6%
News websites	25.3%	21.5%	22.8%	22.3%
Other cancer organisations	15.7%	16.2%	13.5%	15.8%
Social media	13.8%	11.4%	12.6%	11.9%
Hard to find information	0.8%	1.9%	2.3%	1.8%

	Breast cancer care continuum				
	Active Treatment or not started	On hormone-blocking therapy	In follow-up care	Living with mBC	Total
Treating team	58.8%	36.4%	29.1%	49.4%	41.4%
Television news	31.6%	33.8%	35.9%	33.7%	33.7%
Australian Government Department of Health	33.1%	36.6%	33.4%	31.5%	34.5%
BCNA	29.9%	29.0%	21.7%	22.5%	27.1%
State health departments	26.0%	27.7%	23.8%	29.2%	26.3%
News websites	19.5%	23.7%	22.2%	22.5%	22.1%
Other cancer organisations	16.6%	17.1%	12.1%	12.4%	15.4%
Social media	12.3%	12.9%	10.3%	10.1%	11.9%
Hard to find information	0.8%	2.0%	2.2%	4.5%	1.8%

Table 25 shows sources of information by stage of breast cancer and care continuum. Breast cancer stage was generally not associated with information source. The exception to this was treatment team (p<.01) with respondents with mBC more likely to report accessing information through this source than respondents with DCIS/LCIS. Current location in the breast cancer care continuum was only related to accessing information through the treatment team (p<.01) and BCNA (p=.01). For this last association, respondents in follow-up care were less likely to access information through BCNA than those in active treatment.

Information sources for respondents identifying as First Nations people were similar to those described above, although TV news was the most common source followed then by the treatment team, Australian Commonwealth Government and state health departments.

Concerns in general

All respondents were asked to if they had any concerns in relation to COVID-19 pandemic and their breast cancer. Approximately 44% of respondents indicated some type of concern. Having concerns was related to age (p<.01), breast cancer care continuum (p<.01) and breast cancer stage (p<.01) but was not related to state or residential location. Respondents over the age of 65–74 years were less likely to have concerns compared to those aged 44 years and under and those over 75 years (Table 26). Respondents with mBC were more likely to have concerns than those with DCIS/LCIS or eBC. Additionally, those living with mBC were more likely to have concerns than those in follow-up care or those who had finished all their treatment (Table 26). In multivariate analyses age and care continuum were the key factors associated with having concerns.

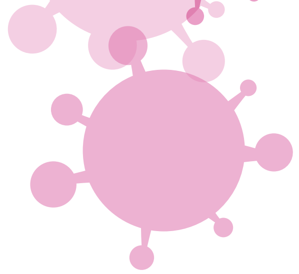
Table 26: Proportion of respondents indicating concerns relating to COVID-19 by age, breast cancer stage and breast cancer care continuum

	Age						
	25–34	35–44	45–54	55–64	65–74	75+	Total
Any COVID-19 related concerns	57.2%	57.0%	53.1%	40.2%	36.5%	50.0%	57.2%

	Breast cancer stage			
	DCIS or LCIS	eBC^	mBC^^	Total
Any COVID-19 related concerns	40.1%	43.8%	54.4%	44.3%

	Breast cancer care continuum					
	Active treatment/not yet started	On hormone-blocking therapies	In follow-up care	Living with mBC^^	Finished care	Total
Any COVID-19 related concerns	55.8%	42.9%	39.1%	52.1%	26.2%	43.8%

^ eBC: early breast cancer; ^^mBC: metastatic breast cancer.



The concerns reported by respondents were reviewed and a number of themes emerged. Health-related fears due to a compromised immune system was the most common concern, mentioned by around 33% of those indicating a concern. Respondents expressed an understanding that a weakened immune system due to cancer increased their risk to COVID-19, with this exacerbated by age and/or other health conditions. Comments reflecting this theme were:

> “I am currently on chemotherapy and my immune system is suppressed, which makes me highly vulnerable to COVID-19 and the consequences of catching it would be fatal for myself.
>
> Extra cautious as I doubt my ability to fight off Covid19 due to a compromised immune system.
>
> As my immune levels are low I am concerned with the possibility of contracting the virus.
>
> The higher chance of being infected with the virus, immune suppressed because of medication, keeping myself and my family safe.
>
> I’m concerned about my treatment lowering my immunity, making the effects likely to be more severe if I was to contract COVID-19.”

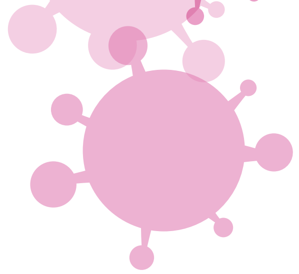
The next most common concerns related to fears of contracting the virus (n=187) and potential exposure to the virus (n=133). While both of these concerns were often mentioned in relation to a weakened immune system, they were also mentioned in relation to being exposed to potential risk. Comments regarding potential exposure to the virus were associated with attending hospital for treatment, and the potential exposure from family/friends/others. Concerns about lack of social distancing at shops, clinics and hospitals were also related to concerns about exposure and contracting the virus. Comments reflecting these themes were:

> “Immunity issues – my children were at school and my husband worked during the at risk period. Even though I was self-isolating – they could have contracted COVID-19 from exposure.
>
> When attending my routine Breast Clinic (MBH) receptionists followed COVID-19 guidelines & the waiting room was set up appropriately. During the consultation with the Specialist’s Registrar our chairs were only a metre apart & the doctor didn’t wear a mask when conducting the breast examination – I was shocked & disappointed that protocols were not followed & challenged him of this breach. ‘The risk is low in this area’ was the response!!!”

> “When I visited my GP and the chemist I found people in these surroundings not keeping 1.5m distance and are very abrupt when I try to keep them at a distance especially when I have a wig on as they think I am over cautious.
>
> Any effect of medication in increasing my risk of contracting the virus. Upcoming travel to Melbourne for regular scans and appointments, with risk of exposure.
>
> Contracting it as I have to attend the hospital for treatment.
>
> My concerns were around my potential exposure to the virus whilst in hospital or getting treatment.”

Treatment delays, including delayed surgery were mentioned by around 120 respondents. Comments in this area were a mix of concerns for possible delays in treatment if the number of COVID-19 cases increased, concerns relating to own or postponed other’s appointments or surgeries and concerns regarding surgery delays (particularly reconstruction). Respondents also expressed concern for the community who were not able to access mammograms and other tests during this time, potentially delaying breast cancer diagnoses. For some, the concern related to the possibility of contracting COVID-19 and having their breast cancer treatment delayed because of this. Comments reflecting these themes were:

> “I was emotionally geared up to have my reconstruction this year and did not expect the delay. I guess I just had to shift my mind-set around timeframe.
>
> Treatments not offered or ceased.
>
> That I will be able to proceed with my desired mastectomy within a reasonable time (say 12 months) as I’m sure there will be a backlog of surgeries.
>
> Catching COVID-19 and then not being able to get treatment because of lock down.
>
> Possible longer waiting list for reconstruction surgery
>
> Having to wait such a long time for breast reconstruction and whether it could be risky to have surgery.
>
> I’m concerned that if I need further scans or treatments they could be delayed. At the same time I’m confident that my care team would deal with this if it became a problem.
>
> That BreastScreen has stopped and for a lot of people that is how they find the cancer early. And that a lot of people are too scared to go to the doctor for things, so if they found a lump they would put it off and we all know that early detection makes all the difference in survival rates.”



The next most commonly mentioned concerns were around the restrictions of social support. Comments grouped under this theme included a mix of issues such as missing social supports from family and friends due to the need to remain isolated, lack of access to social support services, and hospital restrictions on visitors and support people during treatment. Comments indicated that while many understood the reason for different restrictions, the lack of social support and feeling isolated made it more difficult to go through treatment.

> **“Isolation is hard without being able to see people in general. Also unable to participate in breast cancer support group as this is done through zoom and I have babies at home.**
>
> **Found it difficult to go through surgery and start of chemo without being able to see family and friends due to lockdown restrictions.**
>
> **Disappointed for not having the ability to have personal family member as a support person at appointment (ie operation/chemo treatment), it is a difficult time to have to face on own without family – I do also understand that we need to protect the health of other people at the same time however it just doesn’t seem fair when you see the protestors being so selfish.”**

> **“My family and close friends were remote to me while having treatment. I needed to relocate to have treatment. Isolated in an isolated time.”**

Heightened levels of anxiety, distress and depression were also mentioned by a number of respondents. These concerns were grouped together and reflected the impact of isolation and reduced levels of social support as a result of the pandemic restrictions. Concerns regarding reduced immunity, risk of contracting COVID-19 and possible effects on treatment also contributed to increased levels of distress.

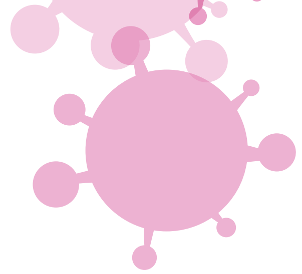
> **“Living alone I became very isolated during shut down and found the lack of normal affection very hard to deal with as I was quite distressed at times.**
>
> **Isolation. I’d already distanced myself from others for the 12 months after my diagnosis. I was just about to start an Art Therapy course - which was a huge step for me to take. Cancelled.”**

In addition to concerns about potential exposure to COVID-19 virus, there were also comments specifically relating to concerns about people in the general community not following social distancing protocols properly. While this theme is related to the potential exposure theme mentioned above, these comments talked specifically about lack of social distancing and the concerns about the response of others in the community.

> **“I have been very isolated by choice, and for about 10 weeks my only outing was for medical reasons. I have been to the shopping centre about three times in the last two weeks and find myself very anxious with regard to lack of consideration and behaviour of others.**
>
> **Although I’m not receiving treatment other than Letrozole, I’m still immunocompromised, and there are plenty of people who don’t/won’t follow physical distancing guidelines. Sure, they’re invincible, but I’m not!**
>
> **People not maintaining safe distancing rules when shopping and therefore increasing my risk of contracting COVID-19**
>
> **Feeling a bit weary to go out. I’m doing my own shopping now but still feel a bit anxious about the people around me.”**

Around 40 respondents indicated a concern related to work. Concerns in this area were mixed and covered issues relating to concerns about attending work due to lack of appropriate COVID-19 precautions, concern because the workplace has identified them as being at elevated risk and requesting them not to return to work, concerns over stress of working from home, concerns relating to working in a high-risk environment (aged care, hospital) and concerns about losing work.

> **“My concern is about returning to the workplace (the organisation is planning for this to happen in the next few months) or going somewhere essential and contracting COVID-19. I don’t want to contract any disease, especially not after going through cancer and surgeries.**
>
> **I have started going to work once a week, am now slightly worried.**
>
> **Working as a nurse with health impacts from breast cancer and potentially being exposed to COVID-19.**
>
> **Now I’m back at work after being home for 3 months, what am I exposed to?**
>
> **At the moment I am worried because it has been stated we can all go back to work. Nothing has been said about the immune compromised (as I am with heart disease – my bloods show not compromise from completed chemo). I have no idea of where I stand and what my rights are.**
>
> **I am managing well with COVID but I do get stressed with my work. I am worried about increased stress levels and any likely increase in breast cancer recurrence. I have had to work from home and using the remote software on the computer makes the job harder to achieve.”**



Around 20 people also commented on the interruption to activities they engaged in to assist their wellbeing and physical recovery from their breast cancer. Comments reflected a lack of access to yoga, exercise programs, support programs, services like wig libraries and Look Good Feel Better, Wellness Centres as well as weight gain due to staying at home restrictions.

> **“Reduced access to support services, including Otis Foundation holiday stay accommodation for family time away, but also all other face-to-face support via Solaris Care, Cancer Council, etc.**
>
> **I am anxious that, with the recent increase in cases in Victoria, that the Wellness Centre will remain closed for an extended period and it will be a long time before I am able to go back to the sessions.**
>
> **Balancing need to exercise to minimise side effects of treatment with need to be isolated.**
>
> **I was finally losing the weight I gained during treatment but now working from home and not exercising, all the weight is coming back and I can concerned that this will impact on my cancer coming back.”**

A number of other concerns were also mentioned including concerns relating to travel, financial concerns, and concerns relating to a fear of increasing COVID-19 cases and the impact this may have on health services and risk for them.

While the key themes relating to COVID-19 and breast cancer concerns are discussed individually, in many cases more than one theme was mentioned in a comment and many themes were interrelated. The connections between themes were evidenced in comments connecting reduced immunity to a need to stay isolated from others and the impact this may have on social activities, access to support and mental health. The comments below depict the interconnection between themes, reflecting the wide-ranging impact COVID-19 had on some people with breast cancer.

> **“Difficult to get support from friends and relatives while apart. Difficult to help recovery with exercise. Stuck at home, mental health drops.**
>
> **For me it was hugely important to have a support person. During the chemo when you are sitting in the chair it was so important to have one of my family with me.**
> **I did not know what it would be like having poison injected into me and for 7.5 hours. The nursing staff were great, really great but it was overwhelming and they really tell you to take care of yourself so you don’t get the virus. It makes you so terribly anxious. And if I was to contract it, my treatment would stop and then what. Do I just go home and die. I don’t want to die.”**

> **“I am concerned that my current treatment and lymphoedema as well as past chemo and radio make me susceptible to severe disease should I become infected. I fear that I will end up in hospital again. I have changed the way I live because of my fears.”**

Concerns of people identifying as First Nations people

Of the 15 people identifying as First Nations people, seven provided comments regarding their concerns in relation to COVID-19. There was a mix of concerns, and these generally reflected the concerns mentioned by all respondents. Four people mentioned concerns about contacting the virus due to having treatment and/or low immunity. Two people mentioned being concerned about the risks of contracting the virus by going out in public, two mentioned contracting the virus and then spreading it to others and one mentioned that not being about to have a support person during treatment was stressful.

> **“I was scared of contracting COVID-19 during treatment, I found not being allowed to have a loved one with me during infusion very stressful.”**

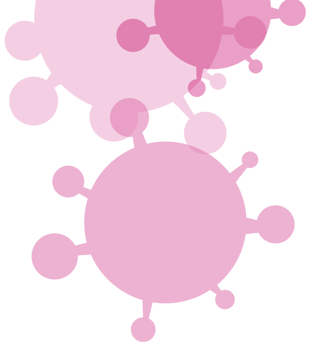
Discussion

The relatively sudden onset world wide of the COVID-19 pandemic and the response of national governments to control the spread of the novel virus has caused significant concern to many groups including those with cancer. Internationally, the pandemic has influenced cancer screening participation, access to tests, scans, treatment and follow-up care.[9] This survey provides information on the experiences of Australians affected by breast cancer in relation to medical care delays, experiences of telehealth, and their concerns and anxiety with relation to COVID-19. The large sample size and representation from across the country, meant the study provides information on the experiences of the COVID-19 pandemic across a broad range of people whose experiences of restrictions were likely to differ as was the number of diagnosed COVID-19 cases in their residential state.

COVID-19 related changes and delays to care: A key concern relating to the impact of COVID-19 on breast cancer care was the potential for treatment delay or changes, either through hospitals postponing or altering care to assist in the management of COVID-19 cases or patients delaying hospital attendance to reduce their risk of contracting the virus. Reports have shown that the onset of the pandemic in Australia resulted in reductions in the number of breast cancer diagnostic tests and surgery being undertaken in April/May 2020 compared to the same period in 2019.[7] The current study found that a significant minority of people affected by breast cancer experienced some care changes/delays, with changes/delay in doctor appointments during active care and follow-up care a key area for alteration. Additionally about a third of respondents for who breast cancer reconstruction was relevant indicated a change or delay in reconstruction surgery. Most commonly, change or delay in care was instigated by the treatment-team, with few respondents indicating they delayed or changed elements of their care. The level of change/delay reported here is lower than that found in the United States in the early days of the pandemic, where up to 50% of breast cancer survivors reported some care delays.[10]

In general, the current study found that experiences of changes or delays were relatively consistent across demographic groups, breast cancer stage and current breast cancer care continuum, although some exceptions to this were found. For instance, regardless of breast cancer stage, younger respondents were more likely to report appointment changes/delays during both treatment and follow-up care, and younger respondents were also more likely than older respondents to report reconstruction surgery changes/delay. This pattern of results is consistent with the study from the US that also found younger survivors were more likely to report delay in appointments.[10] The current study found state differences in radiotherapy changes/delays which were most common in NSW/ACT and Victoria and least common for residents in WA and South Australia. These differences may reflect differences in each state's pandemic response policies. Treatment-related appointment changes or delays more common for those with mBC than those with eBC or DCIS/LCIS.

Telehealth experiences: To reduce the need for patients to attend face-to-face medical appointments during the COVID-19 pandemic, in late March 2020, the Australian Government temporarily expanded the telehealth scheme to all residential locations enabling subsidised healthcare services to be accessed via telephone or videoconferencing.[7, 11] In the current study around 70% of respondents in active care or follow-up had a telehealth appointment with the majority conducted via the telephone. The large proportion of respondents having a telephone based appointment is similar to findings from another Australian study of general population consumers of health care, that reported 72% of people reporting telehealth appointments had these by telephone.[11] A review of Medicare service data produced by Cancer Australia also found that most telehealth appointments conducted between April and May 2020 were via the telephone.[7] Most people in the current study who participated in a telehealth appointment found it helpful, although around 20% experienced some hesitations with this type of consultation and 10% did not find them useful. A key benefit of telehealth was enabling people to stay connected with their health care team, with reduced travel, and waiting times also highlighted as benefits. Key reasons for being hesitant regarding the benefits of telehealth (or not wanting this type of appointment) included a preference for face-to-face appointments, the desire to have a physical examination, and a belief that communication is less effective over the phone, resulting in uncertainty around the outcomes of the appointment. Several barriers to using telehealth were also noted, such as the potential for being in an inappropriate environment for the consultation, a lack of privacy during the appointment, the impersonal nature of the contact (and being told bad news) and physical problems such as hearing difficulties making the call more problematic. While some people appreciated that a phone call was appropriate for what is normally a brief appointment, others disliked the brevity of the consultation, which was considered a result of the telehealth format. Similar barriers to telehealth have been noted in previous studies of consumers' experiences with this form of medical appointment.[11] Most trials demonstrating the positive impact of telehealth have utilised a form of video conferencing. This form of telehealth was used much less frequently than telephone based consultations in response to the COVID-19 pandemic. As many respondents noted the telehealth appointment was 'better than nothing', ensuring greater opportunities for people to use videoconferencing facilities may reduce some of the hesitancy in this form of health care and ensure it can be utilised effectively for both health professionals and consumers.



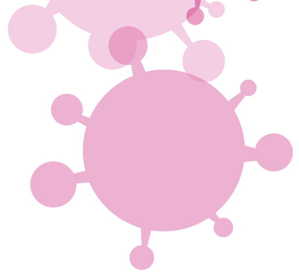
Anxiety and Concerns: A study from the UK exploring the effect of the COVID-19 pandemic on anxiety levels in women with breast cancer, found those whose care was disrupted due to COVID-19 had higher levels of anxiety and were more at risk of experiencing elevated anxiety.[12] In the current study, anxiety levels were in general only slightly elevated with the mean score indicating that on average respondents were feeling "slightly anxious". A key factor influencing anxiety levels was where people where in the treatment continuum, with those currently in active treatment and those living with metastatic disease having higher mean scores than those who were in follow-up or who had finished treatment altogether. The higher levels of anxiety found in the UK sample may reflect the greater number of COVID-19 cases in the UK compared to Australia and the public awareness of the strain the UK's health system was experiencing as a result of COVID-19. In the current study the higher level of anxiety in respondents living with mBC and those undergoing active treatment may reflect an increased likelihood of being immune compromised as a consequence of some breast cancer treatment they maybe are having or have recently had.

Just under half of the sample in the current study indicated some level of unease associated with their breast cancer and COVID-19. The key factors associated with feeling unease were younger age and current location in the care continuum with those living with mBC more likely to feel unease. While a range of concerns were noted by survey respondents, the most commonly mentioned issues were related to compromised health outcomes and increased risk of contracting COVID-19 (e.g. weakened immune system). These concerns related to fears about being exposed to the virus in the community, at hospital and inadvertently through family. Respondents also expressed concerns regarding treatment delays, lack of social support (due to lockdown restrictions and hospital visitor limitations), the impact of COVID-19 for themselves and others and the uncertainty associated with the virus on mental health outcomes. While some of the respondents expressed concern with work, this concern was complex. Some people felt stressed that they were increasing their risk of contracting the virus by attending work, while others were concerned that they were unable to go to work as they were identified by their employer as high risk. Others noted the stress of working from home and other work-related stressors as potentially having a detrimental impact on their overall health. Concerns expressed were generally multifaceted, with the impact of one concern (e.g. compromised immune system) associated with another concern (e.g. contracting the virus, poor health outcomes, need for increased isolation). The interconnection of the different concerns on health and mental health were noted by respondents, with the impact of the social interaction restrictions on mental health a concern for some respondents. Strategies to provide social support remotely while people undergo chemotherapy or other cancer treatments may assist people to feel connected and supported during their care.

Information sources: Information about COVID-19 was most commonly sourced through health care teams, the Australian Government Department of Health and television news. In general, demographic factors were not related to information sources, although twice as many older respondents accessed information through television news than did respondents under 45 years. The health care team was more likely to be utilised as an information source for those with mBC compared to those with DCIS/LCIS.

Study limitations: Several limitations of this study need to be noted. First, the questionnaire did not distinguish between changes or delays, thus responses may be indicated a change to telehealth appointment (from face-to-face), a change in timing of different treatment modalities or a delay in starting/having a treatment/test/scan. While comments from respondents provided some insights into the alterations in their management, the quantitative data can only report on the percentage of respondents indicating change or delay. Second, the question assessing treatment experience used to determine current position in the care continuum used response options that were not defined in the survey and options used were a mix of treatments (e.g. on hormone-blocking therapy), breast cancer stage (living with metastatic disease) and description of care continuum (e.g. in active treatment). Additionally respondents could only select one response, and responses may not have provided an adequate description of current care (e.g. many people with breast cancer may be on hormone-blocking therapy and have follow-up appointments with their surgeon). Results showed that while many respondents with mBC selected 'living with mBC' as their descriptive of current care experiences, others selected active treatment or on hormone-blocking therapies. This situation reflects the ongoing nature of the management of metastatic breast cancer that can involve multiple treatment modalities, including hormone-blocking therapy, radiotherapy and chemotherapy. For this reason we did not recode responses for respondents with mBC to indicate 'living with metastatic disease' but we note that respondents in this group will also be having some ongoing management of their disease. Despite the large sample size, the number of respondents from some states in Australia and from rural and remote areas of Australia were small. While the small numbers in these areas reflect the distribution of Australia's population, the lack of separate findings for these groups limit this study's ability to speak about the experiences of people with breast cancer residing in rural or remote locations and even in the Northern Territory.

Conclusion: Despite these limitations, this study provides information regarding the impact of COVID-19 pandemic on the care experiences of Australians with breast cancer and highlights their concerns in relation to the virus. The study found that around a third of people in treatment and follow-up care experienced changes/delays with general appointments and for allied health and psychological services in follow-up care. While between 10% and 13% of people having treatment experienced changes/delays with surgery, chemotherapy or radiotherapy, a third of those waiting for reconstruction surgery reported treatment team changes or delay. While telehealth was generally acceptable and helpful for respondents, greater use of video technology for these consultations may help to further increase its acceptability. The information provided here highlights the challenges people affected by breast cancer faced in the first wave of the COVID-19 pandemic in Australia.

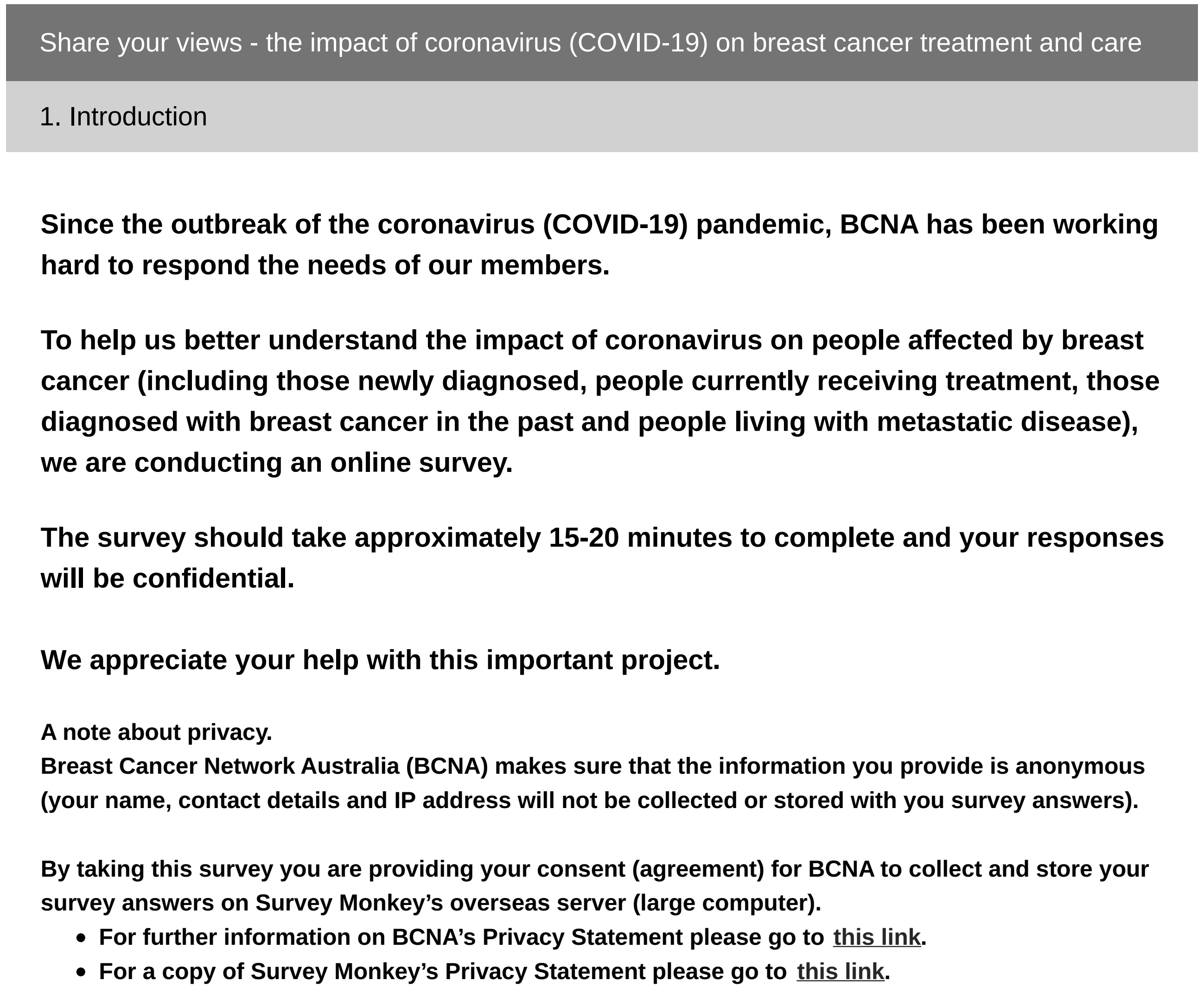


References

1. King JT, Jr., Yoon JS, Rentsch CT, et al. Development and validation of a 30-day mortality index based on pre-existing medical administrative data from 13,323 COVID-19 patients: The Veterans Health Administration COVID-19 (VACO) Index. PloS One. 2020;15: e0241825.
2. Ioannou GN, Locke E, Green P, et al. Risk Factors for Hospitalization, Mechanical Ventilation, or Death Among 10 131 US Veterans With SARS-CoV-2 Infection. JAMA Netw Open. 2020;3: e2022310.
3. Suleyman G, Fadel RA, Malette KM, et al. Clinical Characteristics and Morbidity Associated With Coronavirus Disease 2019 in a Series of Patients in Metropolitan Detroit. JAMA Netw Open. 2020;3: e2012270.
4. de Joode K, Dumoulin DW, Tol J, et al. Dutch Oncology COVID-19 consortium: Outcome of COVID-19 in patients with cancer in a nationwide cohort study. Eur J Cancer. 2020;141: 171-184.
5. Kuderer NM, Choueiri TK, Shah DP, et al. Clinical impact of COVID-19 on patients with cancer (CCC19): a cohort study. Lancet. 2020;395: 1907-1918.
6. Maringe C, Spicer J, Morris M, et al. The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. Lancet Oncol. 2020;21: 1023-1034.
7. Cancer Australia. Review of the impact of COVID-19 on medical services and procedures in Australia utilising MBS data: Skin, breast and colorectal cancers, and telehealth services. In: Cancer Australia, editor. Surrey Hills, NSW: Cancer Australia, 2020.
8. Worldometer. Available from URL: (https://www.worldometers.info/coronavirus/?utm_campaign=homeAdvegas1?%22%20%5Cl%20%22countries#countries [accessed 12 November 2020].
9. Gasparri ML, Gentilini OD, Lueftner D, Kuehn T, Kaidar-Person O, Poortmans P. Changes in breast cancer management during the Corona Virus Disease 19 pandemic: An international survey of the European Breast Cancer Research Association of Surgical Trialists (EUBREAST). Breast. 2020;52: 110-115.
10. Papautsky EL, Hamlish T. Patient-reported treatment delays in breast cancer care during the COVID-19 pandemic. Breast Cancer Res Treat. 2020;184: 249-254.
11. Isautier JM, Copp T, Ayre J, et al. Lessons from the COVID-19 pandemic: People's experiences and satisfaction with telehealth during the COVID-19 pandemic in Australia. J Med Internet Res. 2020.
12. Swainston J, Chapman B, Grunfeld EA, Derakshan N. COVID-19 Lockdown and Its adverse impact on psychological health in breast cancer. Front Psychol. 2020;11: 2033.

Appendix 1

Questionnaire



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

1. Introduction

Since the outbreak of the coronavirus (COVID-19) pandemic, BCNA has been working hard to respond the needs of our members.

To help us better understand the impact of coronavirus on people affected by breast cancer (including those newly diagnosed, people currently receiving treatment, those diagnosed with breast cancer in the past and people living with metastatic disease), we are conducting an online survey.

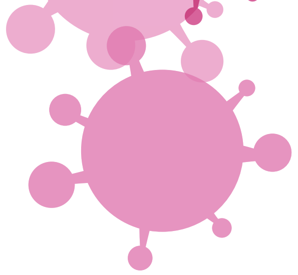
The survey should take approximately 15-20 minutes to complete and your responses will be confidential.

We appreciate your help with this important project.

A note about privacy.
Breast Cancer Network Australia (BCNA) makes sure that the information you provide is anonymous (your name, contact details and IP address will not be collected or stored with you survey answers).

By taking this survey you are providing your consent (agreement) for BCNA to collect and store your survey answers on Survey Monkey's overseas server (large computer).

- **For further information on BCNA's Privacy Statement please go to this link.**
- **For a copy of Survey Monkey's Privacy Statement please go to this link.**



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

2. Impact on your treatment and care

* What was your most recent/last diagnosis of breast cancer?

- ○ DCIS - Ductal cancer in situ (pre- cancer)
- ○ LCIS - Lobular cancer in situ (pre-cancer)
- ○ EBC - Early breast cancer (contained within the breast and/or lymph nodes)
- ○ MBC - Metastatic breast cancer (breast cancer that has spread to distant parts of the body; also called advanced, secondary or stage four)
- ○ Unsure
- ○ Other (Please comment)

What best describes where you are at in your breast cancer experience?

- ○ Not yet started treatment
- ○ Receiving active treatment (i.e. surgery, chemotherapy and/or radiotherapy)
- ○ On hormone-blocking therapy (e.g. tamoxifen, letrozole, anastrozole, exemestane)
- ○ Completed treatment and in follow-up care
- ○ Diagnosed in the past, completed treatment and no longer in follow-up care
- ○ Living with metastatic breast cancer
- ○ Other (please comment)

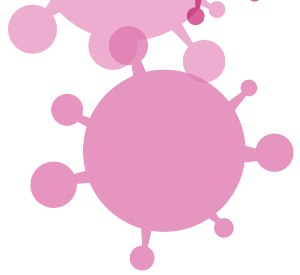
- ○ I had symptoms, but tested negative for COVID-19
- ○ I had symptoms, but decided not to get tested for COVID-19
- ○ I have not had symptoms and have not been tested
- ○ Other (please specify)

Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

3. The impact of COVID-19 on treatment and follow-up care

	Changed/delayed by my treating team	Changed/delayed by myself	No alterations or delays	Not applicable
Routine screening for breast cancer before my diagnosis (if recently diagnosed)	○	○	○	○
Tests and scans investigating signs of breast cancer (e.g. lump, reddening of the skin)	○	○	○	○
Doctor or specialist appointment	○	○	○	○
Breast surgery (i.e. lumpectomy, mastectomy)	○	○	○	○
Breast reconstruction	○	○	○	○
Radiotherapy	○	○	○	○
Chemotherapy	○	○	○	○
Targeted therapy (Herceptin, Perjeta, Kadcyla, Tykerb)	○	○	○	○
Hormone-blocking therapy (e.g. tamoxifen, letrozole, anastrozole, exemestane)	○	○	○	○
CDK4/6 inhibitor therapy	○	○	○	○
Immunotherapy	○	○	○	○
Clinical trials participation	○	○	○	○
Fertility treatment	○	○	○	○
Scalp cooling	○	○	○	○

Please explain



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

3. The impact of COVID-19 on treatment and follow-up care

Have any aspects of your **follow-up care** been **delayed** or **changed** by your treating team or by yourself because of COVID-19?

	Changed/delayed by my treating team	Changed/delayed by myself	No changes or delays	Not applicable
Follow-up care appointments	○	○	○	○
Follow-up scans and tests (e.g. follow up mammography)	○	○	○	○
Appointments with psychologist or counsellor	○	○	○	○
Allied health services (e.g. physiotherapy, lymphoedema therapy, exercise physiology)	○	○	○	○

Please explain

If your treatment or follow-up care was impacted in some way by coronavirus (COVID-19), which of the following factors (if any) influenced the change. Please select all that apply.

☐ I contracted COVID-19

☐ My treating team was concerned about the effects of treatment on my susceptibility to COVID-19 infection

☐ Changes to the health services because of COVID-19 in the community

☐ Access to and/or ability to use telehealth

☐ Unable to take support person to appointments or have hospital visitors

☐ Travel restrictions

☐ Financial concerns

☐ My family's/friends' advice

☐ Not applicable

☐ Other (please specify)

Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

3. The impact of COVID-19 on treatment and follow-up care

How anxious are you generally feeling about your breast cancer care being affected by the pandemic at this time?

○ Not at all anxious

○ Slightly

○ Somewhat

○ Moderately

○ Extremely

Please explain

* Have any of your medical appointments been done via telehealth (i.e. by telephone or video) during the COVID-19 pandemic?

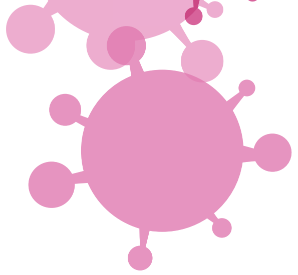
○ Yes, by telephone

○ Yes, by video

○ A combination of both video and telephone

○ No

○ Not applicable



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

4. Telehealth

If yes, did you find the telehealth appointment/s helpful?

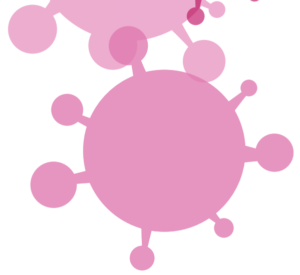
* If one or more of your appointments was done via telehealth, which of your healthcare providers was this with? Please select all that apply.

☐ Breast surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Breast care nurse
☐ GP
☐ Psychologist or counsellor
☐ Allied health professional (e.g. physiotherapist)
☐ Other (please specify)

Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

5. Use of telehealth

If no, would you have liked to use telehealth?



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

6. Information and concerns about COVID-19

Where are you getting information about COVID-19 to help make your breast cancer care decisions? Please select all that apply

- ☐ My treating team
- ☐ BCNA (e.g. the Helpline, the online network, the My Journey online tool)
- ☐ Other cancer organisation (e.g. Cancer Council, National Breast Cancer Foundation, the McGrath Foundation)
- ☐ Australian Department of Health website
- ☐ State and territory governments health websites
- ☐ TV News
- ☐ News websites
- ☐ Social media
- ☐ I am struggling to find the information I require
- ☐ I am not making any care decisions
- ☐ Other (please specify)

What (if any) are your key concerns regarding COVID-19 and breast cancer during this time?

Is there any other information you would like to provide?

Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

7. Tell us a bit about yourself

What is your age? (years)

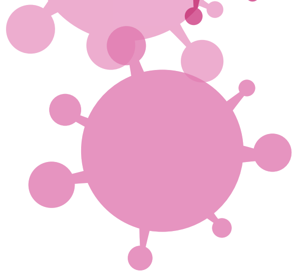
- ○ 18-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65-74
- ○ 75+

What is your gender?

- ○ Female
- ○ Male
- ○ Other

What state or territory do you live in?

- ○ Australia Capital Territory (ACT)
- ○ New South Wales (NSW)
- ○ Norther Territory (NT)
- ○ South Australia (SA)
- ○ Tasmania (TAS)
- ○ Victoria (VIC)
- ○ Western Australia (WA)
- ○ Queensland (QLD)



Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

7. Tell us a bit about yourself

How would you describe where you live?

○ Metropolitan
○ Regional
○ Rural
○ Remote

Do you identify as an Aboriginal or Torres Strait Islander?

○ Yes, Aboriginal
○ Yes, Torres Straight Islander
○ Yes, both Aboriginal and Torres Strait Islander
○ No
○ Prefer not to say

What is the main language you speak at home?

○ English
○ Arabic
○ Cantonese
○ Greek
○ Italian
○ Mandarin
○ Vietnamese
○ Prefer not to say
○ Other (please specify)

Share your views - the impact of coronavirus (COVID-19) on breast cancer treatment and care

8. Opportunity to share your story (optional)

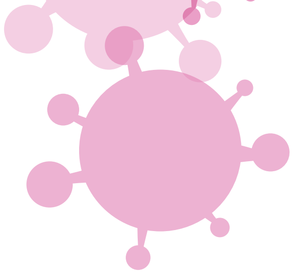
Over the coming months, BCNA will be working with governments, health professionals and other stakeholders to ensure that people diagnosed with breast cancer continue to receive optimal treatment and care during this difficult time. We may also get media requests about how the coronavirus is affecting people with breast cancer.

If you are interested in **sharing your story with media** to assist with BCNA's advocacy efforts, please provide your name and contact details.

If you prefer to remain anonymous for this survey, you can email your contact details to policy@bcna.org.au.

Name

Email Address



Appendix 2

Summary of themes arising from free text comments relating to alterations in treatment

The summary reported here was completed by Ms Lisa Morstyn and Ms Vicki Dunstan from BCNA and was first presented in: "BCNA Research Report: The impact of coronavirus (COVID-19) on breast cancer treatment and care."

After completing questions relating to changes/delays in different aspects of treatment, participants were asked if they want to provide any comments in relation to their response.

456 respondents provided free text comments discussing how their care had been impacted by the COVID-19 pandemic.

The majority of respondents reported no changes or delays to their diagnosis or treatment or changes/delays which related primarily to the process by which care was delivered. Changes commonly reported included:

- The use of telehealth for consultations with GPs, cancer specialists and breast care nurses
- Restrictions on support persons and changes to hospital policies regarding visitors.
- Processes for Infection control at health services

However, instances of more substantive changes or delays to the diagnosis and/or treatment of breast cancer were reported. These included:

- Delays to the initial diagnosis of cancer (e.g. due to the closure of screening services or delays to tests and scans investigating symptoms)
- Travel restrictions, which impacted access to routine screening, tests and scans, and in several instances, treatment itself.
- Changes to surgery at minimising a patient's time in hospital or the need for adjuvant therapy
- Changes to surgical approach regarding the contralateral breast
- Adjustments to radiotherapy, chemotherapy and other therapies.
- Delays to breast reconstruction
- Delays and alterations to clinical trials participation
- Restricted access to scalp cooling during chemotherapy
- Medication shortages

Quotes illustrating these changes are included below.

Delays to screening, the investigation of symptoms and diagnosis

Reasons cited for changes or delays to routine screening included:

- service closures

> **"Breast screen delayed due to COVID-19 causing shutdown of service."**

- the impact of travel restrictions

> **"My routine scanning is held in another state as I live in remote Australia and I am unable to travel."**

- a desire to delay routine screening due to concern about potential coronavirus infection or changes to health services.

> **"I delayed a review with my surgeon and delayed 12-monthly mammogram by three months as I felt overwhelmed by the local doctors doing tele-consultations with patients on the footpath in local shopping area."**

However, of concern, several instances of delayed cancer diagnosis were reported.

> **"... BreastScreen bus not coming to perform routine tests which delayed my findings.**
>
> **My 2 yearly breast screen was delayed due to COVID-19 and thus my diagnosis of early breast cancer."**

Regarding changes/delays to tests and scans, reasons cited included:

- changes to health services

> **"... Had to get scans done at different hospital due to limited services during COVID.**
>
> **[ultrasound] and mammogram scheduled for April postponed to July by [name of health service]**
>
> **At end of treatment, 1 week before going back to work, I found another lump. Difficult to get scans. Breast screen closed so private companies overbooked. Had to use another company rather than my usual, so comparisons more difficult."**

- Hospital processes for infection control

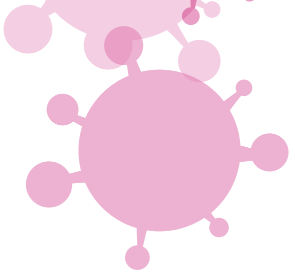
> **"A fever delayed an investigation.**
>
> **Yesterday I went to [name of hospital] for a mammogram and ultrasound prior to appointment with oncologist surgeon on 23rd July. At the door I had my temperature taken It was normal and when asked if I had a runny nose I said yes because it was a very cold day. They say I will not be let in with a runny nose, but they will check with radiology. Radiology will not admit me with a runny nose. I had to turn around and drive another expensive 150 km back home and also go back next week for the same appointment."**

- changes/delays caused by travel restrictions

> **"Due to covid no flights for tests far away. Extremely long drives to go for tests. Over 14hours driving ...**
>
> **Pre-covid appointment, seen and needed further investigation, but no follow-up due to lack of access to doctor and travel to clinic."**

Of particular note, several respondents reported delays to the investigation of symptoms, which may have also resulted in delays to the diagnosis of breast cancer.

> **"Delayed initial investigations due to COVID-19 lockdown.**
>
> **Various symptoms of metastatic breast cancer have arisen, but delayed investigation**
>
> **The initial mammogram, ultrasound and biopsy may have been delayed slightly due to less staff being able to be in the practice at the same time due to COVID-19 restrictions.**
>
> **Doctors delayed from Sydney to test my lumps."**



Delays and changes to appointments with treating team

The use of telehealth was a commonly cited change to doctors or specialists' appointments and appears to have been widely used by members of respondents' treating teams as well as by GPs.

> “Some consultations were by phone with my Doctor and Specialist. Breast Cancer Care Nurse did not see me while in hospital only by phone due to working from home.”

The use of telehealth will be discussed in detail later in the report. However, a number of respondents discussed difficulties with telehealth, such for situations where they believed a physical examination was needed, where they had questions about treatment options or where they were not familiar with their treating team.

> “My diagnosis occurred prior to COVID-19 (October 2019). Breast surgery and most of my radiotherapy were also completed prior to COVID-19. My follow-up with the oncology team scheduled after I had completed radiation therapy to discuss hormone therapy was changed to a phone consultation. I wasn't confident with this consult and would have preferred a face-to-face consult. I needed the oncology team to examine my breast as I had experienced severe bruising which was not healing to the extent I expected – I still have very dark colouring and thickness where I was operated.
>
> No real delays but delivery of information changed because most appointments had to be via telehealth/video link which, for the first consultation with the surgeon, was very confronting.
>
> I was diagnosed at the end of March. I had a brief appointment with the oncologist followed by Telehealth calls … My face-to-face appointment with the oncologist a month ago was so much better. The doctor seemed less stressed and we had a much better conversation about what was happening for me.”

Delays and changes to breast surgery

While some respondents discussed the use of telehealth for surgical consultations, several respondents reported instances in which their primarily cancer surgery was delayed, or where the surgical approach was altered to minimise a patient's time spent in hospital or avoid the need for adjuvant therapy.

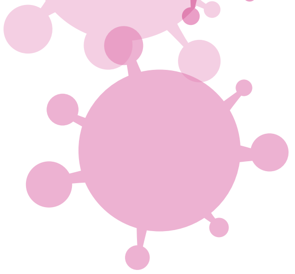
> “‘ … my lumpectomy surgery was delayed and rescheduled twice'.
>
> Didn't meet face-to-face most of my team, medical oncologist, plastic (reconstruction) surgeon due to COVID-19. Had phone calls & sent photos. I was booked in for surgery 3 times, but it was delayed twice due to COVID-19.
>
> A full mastectomy was performed to avoid radiation and additional hospital visits, however a double mastectomy was not possible during COVID.
>
> Was unable to go ahead with mastectomy due to recovery time required, lump was removed instead.
>
> My hospital stays with each surgery with shortened because of Covid. sent home 24 hours after major surgery. Awful!!
>
> Second surgery 'postponed' went to chemo instead.”

A number of respondents discussed changes to surgery regarding the contralateral (non-affected) breast due to restrictions on elective surgery. The restrictions on what surgery was available to these respondents appear to have caused significant anxiety and distress, especially where it meant respondents could not have the surgery they had planned for or would need subsequent surgery.

> “I had lumpectomy which would normally include reduction of other side to match. Other side classes as “elective” surgery so now delayed for year. This was pure red tape and only affects me as theatre and PPE same. Very upset by this.
>
> 5 mths of preparing for a bilat mastectomy 3wks before surg was told I can't have it & that I will be getting a L sided lumpectomy with Node removal end of story & as a consolation a bilat reduction/mammoplasty I was told when I asked for my mastectomy (regardless of info, research, journals & peoples experiences) “Nup” you're getting this & that, breast conservation & that's it because having an implant was deemed “non-essential” & to have a spacer they couldn't allow me to come back to the hospital every 2wks due to Covid restrictions! I was so disappointed, angry, alone, felt not one bit of my concerns were listened to, & 'patient focused care' was non existing.
>
> No option of mastectomy to unaffected breast. Took a week longer to get operation date. Results from surgery took 17 days. Diagnosed 3/4/20. Surgery 4/5/20. Chemotherapy start 15/6/20.
>
> I wanted a double mastectomy as other breast shoes changes. They won't remove the second as it isn't a category 1 surgery. Means I'll need a second operation. Also wanted lymph nodes removed the same time as mastectomy, they'd only remove the sentinel node for testing initially as it wasn't category one surgery unless cancer proven in it. Meant two separate operations and a 4 week delay. Caused so much stress and anxiety at already such a difficult time.”

Several respondents also discussed feelings of uncertainty and worry regarding what the changes to health services and cancellation of elective surgeries might mean for them.

> “I was diagnosed about a week prior to elective surgeries being cancelled. I was panicked that I would not get my testing, surgery and treatment completed before everything shut down - nobody knew what the future held at that time. I elected to self-fund for my surgery through the private system and am thousands of dollars out of pocket. Surgeries were cancelled on the eve of my lumpectomy. When I had the surgery most of the patients at the private hospital were free of charge as they had been moved over from the public to the private hospital. I was one of the unfortunate patients who had to pay their own way.”



> Asked for mastectomy before chemo as I was unsure if hospitals would be able to do that during COVID-19 outbreak. This was in March before measures were in place.

Delays and changes to radiotherapy

A number of respondents discussed changes to radiotherapy due to health services' infection control processes.

> Reschedule radiation sessions to limit the number of staff that I came into contact with ...
>
> I found it a bit surreal to be going through this journey of breast cancer at this time of COVID-19, going through the radiation therapy without ever meeting my Radiologist face-to-face.
>
> Radio therapy continued with less contact with nursing staff, i.e. wound dressing, etc. Radiotherapy doctor's appointments done via Telehealth.
>
> Covid changes in the hospital meant radiation was on different machines to allow for immunosuppressed patients to be safer. Radiation appoints were moved around. Partner was unable to come in a support.
>
> Due to covid the oncologists and radiotherapists divided into separate hospitals, so I had radiotherapy and preparation including 2 masks and 2 MRIs done at 3 hospitals over 3 weeks ...

Several respondents noted instances of delays or changes to the provision of radiotherapy. Two respondents discussed hypofractionated radiotherapy.

> Radiotherapy was delayed for six months. Began hormone-blocking therapy prior to radiotherapy.
>
> Radiotherapy postponed for 3 months due to COVID19. Now started.
>
> I had my radiation cut short by 2 sessions and had 2 on the same day (my last day) as my daughter was coming home from the USA and the centre did not want to take any risks. This was even though she was going to be isolated in a different part of the house and I was not going to be in contact with her.
>
> Two radiotherapy consults were done using telehealth. The number of treatment days (20) which I had originally been told were the best way to treat me were shortened to 15 with a higher dose. This was a little concerning, but all went okay in terms of no skin issues arising
>
> Slight delay and slight modification to my radiotherapy – used a different and therefore shorter protocol.

Of concern, one respondent discussed an instance in which a complication from radiotherapy, pneumonitis, was missed due to an inability to see her specialist.

> Finished radiation but got not (sic) call back. I went and asked, to be told next appointment was 6 months. Eventually went. Had been in hospital getting antibiotics because the x-ray reported I had pneumonia, but it wasn't. A physician took over they found I had pneumonitis (burning of the lungs) described my GP as very dramatic. Been on prednisone and still far from well. Could not go from [name of regional location] back to see either the surgeon or anyone in [name of major city] because of COVID.

One respondent noted that the fear of potential coronavirus infection impacted her decision making about whether or not to have radiotherapy.

> As a result of Covid-19, I chose not to undergo RT or CT. I considered it far too risky for the potential very small benefit.

Delays and changes to chemotherapy

While the majority of respondents (87.8%, n = 439) indicated no changes or delays to chemotherapy, a number of respondents reported instances in which chemotherapy was either delayed or forgone.

> Post-surgery I was given all the facts by my surgeon and oncologist and due to COVID 19 we all agreed that chemotherapy was more of a risk for very little gain.
>
> On the night before my first chemo, my housemate informed me he was waiting for COVID-19 test results. On the day of chemo, I reported this to the hospital. The oncologist spoke to me and suggested there is evidence of poorer survival rate if I were to get COVID-19 while on chemo. So we decided to cancel chemo (it was already 13 weeks after surgery), and go with Zoladex + hormone therapy immediately.
>
> Chemotherapy treatment was delayed on one occasion due to less flights into the NT impacting on chemo treatment arriving on time to meet scheduled appointments.
>
> Our local hospital was shutdown and so all follow-up appointments were cancelled. Consequently, chemo was late starting, and radiation is further down the track.

Several instances of changes to chemotherapy drug or schedule were also noted.

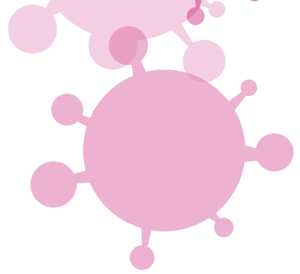
> My chemotherapy treatment changed as we added in an extra chemo drug & moved by cycle to every 3 weeks instead of weekly. This was because there was a new drug made available which offset side effects of that new drug. This was a benefit as I spent less time in the hospital and meant I could recover more from the chemo.
>
> I ended chemo after 2 rounds instead of 4 due to the concern about increased risk of Covid19 and its consequences compared to the very small long term benefit of chemo in my case.
>
> Xegeva went from monthly to 3 monthly and specialist appointment went to zoom.

One respondent also noted a shift to oral chemotherapy.

> Chemotherapy changed from infusion to oral (at home).

A number of respondents were unable to access scalp cooling due to COVID-19 crisis.

> Was told scalp cooling wasn't being done because of the pandemic.



> “Was initially offered scalp cooling by my breast care nurse at [name of hospital], but [name of second hospital] withdrew the offer explaining that they needed to reduce face-to-face time spent at hospital during treatment due to covid.
>
> Was unable to use cooling cap for the last session of my chemotherapy due to covid19. Hospital wanted me in and fast.”

Other therapies

Responses below relate to targeted therapy, hormone-blocking therapy, immunotherapy and fertility treatment.

> “Of note, several respondents reported difficulties obtaining hormone-blocking therapies.
>
> Tamoxifen was delayed as I could not access it (all pharmacies in my locality was out of stock). Did eventually track it down but side effects too severe so after consultation ceased.
>
> There has been shortages of Tamoxifen in pharmacies, which started before the pandemic but worsened during the pandemic. I often have an extra bottle, so I have not missed a dose.
>
> Wasn’t able to source tamoxifen when I was supposed to start hormone therapy delayed till my treating team could find some!”

Two respondents noted changes or delays to treatment with one of the CDK 4/6 inhibitors, and one respondent decided to stop treatment with a CDK inhibitor due to the potential impact of the drug on her immune system.

> “Ribociclib reduced to help increase white blood cell count over this period.
>
> … There was a delay obtaining Ribocliclib due to supply probelms due to COVID19. Had 1 week on the tablets and developed severe abdominal pain, and had my gall bladder removed end of May. Just waiting for incisions, etc, to heal to start Ribocliclib again, hopefully more successfully.
>
> I stopped taking CDK inhibitor due it reducing my immunity levels.”

One respondent reported a change in relation to fertility treatment, with telehealth used for appointments prior to egg retrieval.

> “Changes to no support people and telehealth appointments. I only saw the fertility doctor in person on the day of egg retrieval.”

Delays to breast reconstruction

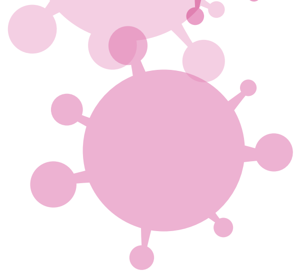
Over one-third of respondents (39.3%, n=110) indicated a change or delay to breast reconstruction, due in a large part to the ban on elective surgeries, but also to travel restrictions.

> “I was originally told I’d have reconstruction surgery in May but Covid-19 meant it was delayed until at least November, as it must be done interstate (I live in NT).
>
> Reconstruction surgery to be undertaken in Brisbane. Has been put on hold due to travel restrictions.
>
> Unable to offer immediate reconstruction due to covid19.
>
> I was promised an immediate recon during skin sparing mastectomy during consult on 26.3.20 but surgeon forgot to order my implants for surgery on 1.5.20. I think because generally no recons were being done due to their ‘elective’ status under COVID. She forgot, but instead of informing me and sending me home she put one in from the stock cupboard, which was way too big. It was the only one there. She then had to do an exchange surgery 4 weeks later as it was unacceptable. I was distressed and stressed about this and it then delayed the start of my chemo because you have to allow for a recovery period.”

Alterations to clinical trials

A number of respondents commented on the postponement or cancellation of clinical trials they were either part of, or interested in.

> “I was to participate in a trial of a drug to lessen the symptoms of menopause caused by Letrozole.
>
> A global trial I was due to participate in has been postponed because of the situation in the US with COVID 19 even though we could safely run it in Australia. If it doesn’t start by April next year I won’t be eligible.
>
> The clinical trial that I want to be involved has been put on hold.
>
> One clinical trial I am part of looking at neuropathy following Docetaxel has testing delayed because of COVID19.
>
> The clinical trial I was to be a part of was cancelled.
>
> Trial recruitment stopped at the time I finished chemo/radiation so I was unable to access relevant clinical trial.”



Appendix 3

Summary of themes arising from free text comments relating to alterations in follow-up care

The summary reported here was completed by Ms Lisa Morstyn and Ms Vicki Dunstan from BCNA and was first presented in: “BCNA Research Report: The impact of coronavirus (COVID-19) on breast cancer treatment and care.”

After proving information regarding whether aspects of follow-up care had been delayed or changed by either their treating team or themselves because of COVID-19, respondents were provided with an opportunity to detail the changes/delays experienced.

528 respondents provided free text comments, discussing the change or delay they experienced and/or the impact of the change.

Delays or changes to the provision of follow-up care

The use of telehealth was a commonly cited change to follow-up care appointments

> “Telephone follow-up instead of face-to-face.
>
> Initial appointment for the treatment of cording was done through telehealth which was kind of pointless as it’s difficult to receive physiotherapy over the phone.
>
> I see a specialist every 3 months for follow up care (scans and getting results). Nearly all of these sessions in the past 4 months have either not happened or were on the phone. I only had to go into hospital for the scan and then results on zoom or on the phone. I only had 1 in person appt, with my oncologist ...”

A number of respondents reported delays or cancellations to follow-up appointments or tests or scans by health services, while several respondents decided to postpone follow-up care due to concern about potential coronavirus infection or changes to health services.

> “CT Scan was due at the end of May now being done in July but other clinical signs were stable.
>
> Telehealth consults for my 6 monthly checks with breast surgeon and oncologist (which also includes clinical trial) - therefore no physical examination and now moving to annual checks for both. This will mean 18 months between physical examination by specialists.
>
> Was due for 12 mthly follow up ultrasound & mammogram in April but this year I didn’t complete it then. I had heard that breast screen Qld was closed due to covid19 and then I really didn’t want to be out in public and especially in a medical facility (e.g other imaging facility or breastscreen when it was opened) with the pandemic happening. I’m looking at scheduling it soon but it seems a secondary concern to covid whereas in previous years it has been a high priority.
>
> I have put off breast ultrasound, all specialist appointments, physio and counselling until further notice due to difficulty being able to safely travel (as I’m avoiding public transit) to and from appointments.
>
> After coming through the 2019 bushfires and the now living with the worry of the pandemic, the distance and rural locality of where I live, and the nature of my employment (nurse) and hours I work, I feel like there’s no good time for me to make an appointment.”

Appointments with psychologists or counsellor (n=551)

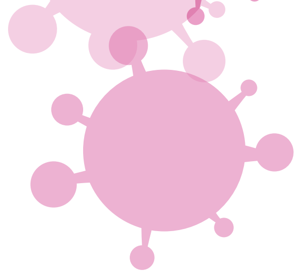
The use of telehealth was a commonly reported change to appointments with psychologists or counsellors.

While several respondents noted the support has been helpful, others discussed difficulties (e.g. lack of privacy) or a sense that telehealth was not as effective.

> “My psychologist follow–up appointments have been over the phone but they have continued which has been incredibly helpful post treatment.
>
> I still see my psychologist but it has either been on zoom, postponed or have gone in a couple of times but have had to catch a tram which was fine during lock down as no-one was on the tram!
>
> I cancelled counselling because it’s hard to talk at home. Not good for my mental health or that of others.
>
> Psychology by phone, not convinced it's as good.
>
> [Counsellor] was available over the phone ... but I didn’t want to do this.
>
> Psychology was over the phone which was OK but too tiring for an hour app[ointment].
>
> With my Counsellor at the Cancer Centre, we felt it would be best for my health to have the calls via phone, this does not make it easy for them to see your feelings, emotions and body language, although she is very supportive and helpful.
>
> Initially the psychologist at the cancer centre was only providing telephone appointments. I had one but I didn’t like interacting with her this way. I postponed my next appointment until we could have a video-link appointment. I still don’t find this as satisfactory but it’s better than the phone.”

Several respondents indicated they had experienced difficulty accessing support from a psychologist or counsellor.

> “I was not able to get an appointment with a psychologist for around 6 weeks as there were just no appointments available. Everyone I spoke to was fully booked.
>
> Due to the increase pressure on the psychologist, I was asked if I was comfortable to sort counselling closer to home. I said I was but I’m yet to sort it closer to time. I’m having a terrible time during to get a hold of face-to-face time with my GP to do a mental plan in person so have currently put this on hold
>
> Online psychology treatment didn’t occur.
>
> The psychologist i was due to see would not take face-to-face appointments, hence we have not had our initial appointment as yet. I was due to see her in March 2020.”



Allied health services

In total, 51% of respondents (n=456) reported a delay or change in their access to allied health services due to the COVID-19 crisis.

A commonly cited change was the use of telehealth for the provision of allied health services, including information and support. A number of respondents spoke about the difficulties receiving allied health support via the phone.

> “Exercise physiology done via Zoom.
>
> Physiotherapy changed to telephone check up with reassurance if I felt any changes I could call back.
>
> … no physical access to lymphoedema clinic but spoke to them on phone which helped a little with my questions.
>
> My appointment with the lymphoedema clinic was changed to a telehealth appointment then restrictions lifted a little and luckily I was able to change back to face-to-face appointments.
>
> Pilates classes now via Zoom at home.
>
> Appointments are by telehealth. Which is really, really challenging as I can't see my lymphoedema physio to help with my lymphoedema management. It's all done by phone.”

Many respondents discussed services closures and/or difficulties accessing allied health services due to the COVID-19 crisis. Physiotherapy, exercise physiology and lymphoedema were frequently mentioned.

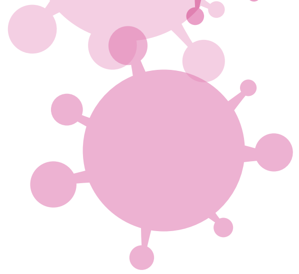
> “The clinic that was doing exercise physiology was shut down and the massage and exercise classes not available.
>
> Regular lymphatic drainage massage stopped for several months, started back up about 6 weeks ago.
>
> Masseuse (specialised in oncology) not treating due to the virus.
>
> Physiotherapy was not open after surgery due to Covid.
>
> Physiotherapy for Lymphoedema cancelled for 2 months during COVID-19.
>
> Physiotherapy delayed due to concerns around COVID-19. Plans to see exercise physiologist and re-engage with breast cancer rehab program delayed as program was ceased during COVID-19. Plans to utilise gym/class/pool membership delayed due to centre closure and restrictions during COVID-19
>
> I live in a rural area with only 2 individuals trained in manual lymphatic drainage massage at the nearest major centre 50 kms away. My OT was unable to continue her practice on 27/3/20 due to Covid-19 restrictions. I was having treatment every 2-3 weeks up to this time. I contacted the other practitioner and she was not able to work either due to the restrictions. I was able to start having treatment again in mid-May.
>
> I could not access lymphatic massage as the therapist, (small massage business in a regional town) was unable to continue trading due to restrictions. I then had to travel two hours to our nearest town with a therapist but due to travel restrictions felt uncomfortable doing this.
>
> Was due to start reconditioning program, put on hold, now have appointment with psychologist, dietician and physiotherapist on July 1st.
>
> I couldn't get a lymphoedema therapist that remained working, called numerous times with no response. Physios also have not returned calls, I think now that they are beginning to reopen I will be able to get appointments.”

Several respondents spoke about the negative impact that the closure of these programs and services have had on their physical and emotional wellbeing, as they no longer have access to the support, connection and physical benefits of these programs/services.

> “My fortnightly gym group for women recovering from cancer and my weekly yoga class for the same were both cancelled at the beginning of restrictions and have not yet resumed. The [name of group] group in particular I miss very much, it was very good for me physically and mentally (great group). No word yet on when or whether it will resume.
>
> Pool program postponed. Counsellors never followed up. Groups stopped. Yoga stopped Gym program stopped. All my supports stopped and left to own devices …
>
> I did zoom for psychology and physio. Delayed acupuncture and lymphatic massage which impacted my energy and pain in arm during chemo.
>
> Exercise physiology classes were cancelled due to COVID-19 which has impacted my stress levels, i.e. I am less able to control my stress around my bc.

In some cases, respondents indicated the decision to cancel or postpone was their own.

> Allied health service I have delayed as its not urgent and I don't want to be at medical centres if I don't need to be.
>
> I didn't arrange to go see physiology for arm stiffness as it was in middle of lockdown.
>
> I cancelled physio and occupational therapy to avoid going to the hospital.
>
> I am reluctant to go to exercise physiology during the pandemic.
>
> Haven't been to lymphoedema clinic but badly need to!
>
> My follow up scans aren't due until September, but other appointments have been by telehealth or phone call (Oncologist), or cancelled by me (psychologist and exercise physiologist – I couldn't do the zoom meetings while home schooling three children).”



Appendix 4

Summary of themes arising from free text comments relating to experience of anxiety in relation to COVID-19 and breast cancer care.

The summary reported here was completed by Ms Lisa Morstyn and Ms Vicki Dunstan from BCNA and was first presented in: 'BCNA Research Report: The impact of coronavirus (COVID-19) on breast cancer treatment and care.'

A total of 474 respondents provided free text comments after indicating their level of anxiety in relation to COVID-19 and breast cancer care.

Among respondents who indicated little anxiety, many expressed a sense of trust in their treating team and in the coronavirus-related precautions being taken by health services more generally.

> **“I trust my medical team are taking the precautions required.**
>
> **Because I am retired and self-isolating I am not particularly anxious about catching the virus. I am concerned about the possibility that if any of the team at the cancer centre are infected there would have to be quarantine which would slow things down. They have taken steps to have two separate treatment areas so this is not a huge concern.**
>
> **I did feel anxious about having radiation at the hospital but in the end I felt safer going there each day than I did going to the supermarket! Lots of processes were in place to protect staff and patients.”**

Others noted low numbers of COVID-19 cases in their state or precautions they were taking to reduce their risk of coronavirus infection, such as self-isolating, social distancing and handwashing.

> **“As time has gone on and we don’t have any community spread in WA I feel much more comfortable to try and get back to a routine of getting out and about more.**
>
> **I am only slightly concerned as I have been careful with self-isolation and family and friends have been supportive.**
>
> **I was extremely anxious during initial time of pandemic; then later very cautious & careful; however now, still careful about social distancing but not anxious at all.”**

Several respondents noted that, while they had initial concerns about the potential impact of the pandemic on their treatment, their fears had been allayed by treatment proceeding as planned.

> **“Initially I was concerned whether my treatment could continue, but as it has progressed as planned and I’m almost at the end of treatment I am no longer concerned.**
>
> **I was anxious when receiving radiotherapy at height of outbreak but once that finished all Ok.”**

However, many respondents expressed significant fear and concern about a range of issues. These included:

- The fear of increased susceptibility to coronavirus infection due to the impact of treatments on the immune system. Several respondents also spoke about having multiple vulnerabilities that would be likely to put them at greater risk of infection.

> **“I have been concerned about contacting COVID-19 as being immunocompromised and having had pneumonia 3 time in the past year I have lung scarring. I was frightened when I had to leave the house for essential reasons that I might come into contact with someone who was infected.**
>
> **I am unsure if my immune system has recovered sufficiently after chemotherapy.**
>
> **Even though I’m on Femara and in follow up stage, I wonder how my immune system would handle COVID-19 if I contracted it due to me having endured chemo and radio.”**

- Fear of potential delays to treatment or fear of cancellation of treatment due to changes to health services generally or if they were to contract COVID-19. Treatments discussed included surgery, breast reconstruction, chemotherapy and radiotherapy.

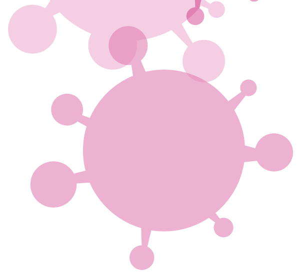
> **“I worry I won’t get surgery, I worry I will get covid and have chemo delayed or that I will die from it.**
>
> **The breast reconstruction surgery was already on the never-never and to be told there are now even further delays is doing my head in. I really wish I had chosen to have breast implants after my mastectomy so things can be back to “normal”. If I had known there would be such delays I would have chosen very differently and now it is too late to change my mind given my radiation treatment now makes breast implants an impossibility. It’s been over 3 and a half years now of feeling self-conscious of how I look in my clothes and how I feel about myself and there appears to be no end in sight.**
>
> **Was originally quite concerned that patients with advanced mets would be given low priority care if the pandemic became extensive. Now less concerned.**
>
> **I’m nervous I may contract COVID and radiotherapy may be delayed.**
>
> **Just concerned if I contract COVID it will delay targeted treatment.**
>
> **Nervous that contracting COVID-19 may delay my treatment.”**

- Anxiety about the impact of delays to tests and scans or treatment, which have occurred as a result of the COVID-19 crisis.

> **“Of course I’m worried about the potential longer term effects of cancelling chemo.**
>
> **I was due for a mammogram 2 months ago but has been delayed until I see my Specialist again as she said she to Covid it has to be delayed. I’m worried sick.”**

- Fear about contracting COVID-19 while attending health services for scans, tests or treatment.

> **“Was extremely concerned about contracting COVID-19 during hospital or scan visits.”**



> **“I feel anxious prior to chemo, as I am exposing myself & loved ones to the possibility of contracting Covid-19 while I'm in the facility.**
>
> **I have been more anxious about having to get to the hospital complex and also contact with other people in waiting rooms.”**

- Anxiety about having fewer options for services and supports to help with physical and emotional wellbeing

> **“Side effects of chemotherapy/ surgery present a huge impact on my health and mobility and not being able to get physio, massage, hydrotherapy and take anti-inflammatory medicine with new COVID risks caused stress and excessive pain during this period.**
>
> **Would like to access More support groups but not sure how with [name of cancer centre] closed.”**

- Fear of future access to treatment and follow-up care due to the impact of the COVID-19 crisis.

> **“If there is a recurrence or complications I worry hospital system may strain to cope because of increase in virus in Victoria.**
>
> **If I develop symptoms of metastatic cancer, I'm concerned that there may be delays in having it diagnosed and treated.”**

- Concerns about not being physically examined by health professionals due to the shift to telehealth

> **“I still have catch up appointments with my oncologist by telehealth, but I do miss the reassurance of them doing a clinical exam. I do my own breast checks but as I did not notice that I had cancer the first time, I don't feel 100% reassured by my own checks.**
>
> **I can still feel lumpiness in my breast - it's likely just scar tissue, but if I was having in-person appointments the oncologist could check. Not possible with telehealth.”**

- Fear of contact with others and not being able to socially distance, as well as anxiety that not all people appear to be complying with public health guidelines

> **“I had many infections after my mastectomy. So I was petrified of any people coming near me, due to my low immune system**
>
> **I was also very anxious as I live in Bondi and before there were clusters found in Bondi I was worried walking down the street as there are many overseas travellers in Bondi and it was people who were returning/ coming from overseas that were bringing the virus. I was lucky that I was able to move to my parent's house in the country during this time and felt much safer.**
>
> **As soon as restrictions were lifted many people stopped respecting social distancing. Trips to the supermarket were scary because of my low immunity; But deliveries left out many items ordered.”**

- Anxiety due to social isolation, lack of contact with family and friends and not being able to utilise strategies to help with their feelings of wellbeing.

> **“I'm not seeing family and friends as I would normally due to their concerns so it has made me feel lonely.**
>
> **It has been a difficult experience finding out that I have cancer and is compounded by the fact that I live on my own, my family, friends and I have all been in isolation. Distractions with social engagements, shopping etc have not been happening and even food shopping for myself initially was somewhat challenging.”**

- Anxiety at not being able to have a family member's, friends, or other support people with them when attending appoints or undergoing treatment. This elevated respondents' sense of isolation.

> **“Extreme psychological and emotional toll being unable to take support person to chemo treatments and specialist appointments. Extreme isolation at home when at one stage no visitors allowed in the home.”**

- Feelings of general anxiety regarding the COVID-19 crisis and high levels of stress at this time

> **“Some days I did not want to get out of bed, and found the situation completely hopeless, every time I turned on the news and saw the case count I would suffer extreme anxiety and was not able to function properly.**
>
> **Tiredness makes me scared although with DCIS I am told does not compromise my immunity. However, psychologically I am still weary.”**

- Fears around using public transport

> **“As I am dependent on public transport it concerns me as I travel to and from appointments that I may come into contact with someone who shows signs or has coronavirus.**
>
> **I don't feel safe using public transport and am concerned about hygiene measures at appointments.”**

- Several respondents spoke of practical difficulties at this time, such as shopping

> **“Despite restrictions being eased, I cannot afford to contract COVID-19, so still avoiding places like restaurants, shopping centres, groceries or crowded settings, including some aspects of my job, until I finish chemotherapy.”**

- Several respondents mentioned financial concerns or fears about contracting COVID-19 infection when returning to work.

> **“On the advice of my Oncologist, it is not advisable for me to return to my working environment because of COVID. My job involves me working closely with children and adults in a school environment. I have been able to work from home for the past few months, but my employer called me last week to say that they would have to drop my paid working hours from 37 to 14 as part of my duties require me to be supervising and working closely with the children … This has caused extreme financial and emotional stress to me as I don't know how I will survive on this amount of money as I am the only person with an income in my household. I feel very down and saddened that I am in this position because of a combination of my recent cancer treatments, and COVID starting around the same time.”**

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