

BREAST CANCER NETWORK AUSTRALIA'S

STATE OF THE NATION REPORT

Breast
Cancer
Network
Australia





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ABOUT BREAST CANCER NETWORK AUSTRALIA

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 120,000 individual members and around 300 Member Groups. BCNA supports, informs, represents and connects people affected by breast cancer. BCNA works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs. BCNA's vision is a better journey for all Australians affected by breast cancer.

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MESSAGE FROM OUR FOUNDER



Lyn Swinburne AM
Founding CEO

When I drove the establishment of BCNA 20 years ago, I was running on passion. My own experience through diagnosis and treatment five years beforehand had been frightening and depressing.

The challenges were overwhelming – from being told I had breast cancer in a brusque telephone conversation with my doctor's receptionist, to undergoing heavy-duty treatment in a fog of limited knowledge. I struggled with my young children and the fear that they would grow up without a mother.

I felt powerless and alone within a community environment where talk of cancer was still taboo, and a medical system primarily focused on the tumour and not the woman.

I was determined that things had to change, and gathered a small core group of women who felt the same. We worked hard to change attitudes and help drive a system that was supportive and empowering, so that women would not be crushed by the breast cancer experience.

The task was overwhelming, and I can wholeheartedly say that I am so proud of BCNA's achievements over the past 20 years. Women no longer feel like the faceless person on the conveyor belt that I did – they feel heard.

This *State of the Nation* report gives us strong indications of progress made, new emerging issues, and areas where far more work needs to be focused. We know this because the women themselves have shared their experiences and desire to make things better for the women who come after them, just as we did 20 years ago.

Only a consumer-driven organisation like BCNA could produce such a document, capturing the powerful voices of women who have experienced this disease first hand, ensuring this report is pure gold.

My heart sang when I read Raffaella's case study on page 49. She felt fully informed, understood her options, was connected with support services (including a breast care nurse), was treated with respect and sensitivity by her medical team, and had access to a psychologist. She felt she mattered! Raffaella's story demonstrates what is often most important to women, and shows this level of care and support can be achieved.

On the other hand, I was struck by the disparity of service often cited between the public and private sectors. While women paid private health insurance and assumed they would receive gold-standard care, the reality for many was little or no access to a breast care nurse and outrageous out-of-pocket expenses. Women do not need this worry.

The other outstanding areas requiring major attention are the services and support systems for those with metastatic disease, who face major obstacles as they strive to deal with their daily challenges and desire to live well.

Much has been achieved in 20 years and we should celebrate this – the improved survival figures are a great testament to the work of many. New technologies, diagnostic and treatment discoveries, and improved treatments are all exciting.

However, incidence rates continue to rise alarmingly, and while most women survive breast cancer, they face lifelong survivorship challenges. BCNA is needed now more than ever.

BCNA must continue its commitment to reflect the needs of ordinary women and men affected by this disease – individuals with genetic mutations, a family history of breast cancer, early disease, metastatic disease – and those close to us.

We must focus on the personal impact, use our voices strongly, do what we can as an organisation to fill gaps, and press others in power to do the same.

MESSAGE FROM OUR CEO



Kirsten Pilatti
Chief Executive Officer

In between when you woke up this morning and when you go to sleep tonight, 50 Australians will be told they have breast cancer. The same will happen tomorrow, and the next day too, making breast cancer the most common cancer affecting Australian women.

While most will survive – more than ever before – eight women die from breast cancer every day in Australia.

It is important that we also recognise the 148 men who are diagnosed each year.

The people who hear the words, ‘You have breast cancer’, aren’t just statistics. They are partners, siblings, parents, children, friends and colleagues. Their diagnosis will impact not only them, but all those around them.

For the past 20 years, BCNA has worked tirelessly to make sure that no one needs to go through a breast cancer journey alone. We exist to provide quality information and support for those who need it most. We are the trusted voice representing all Australians affected by breast cancer.

Twenty years is cause for celebration, and we have much to celebrate at BCNA. We are particularly proud that we have been able to lead the way for many others in the cancer community, delivering innovations that have benefited those with other types of tumours.

Standing beside us are key partners we work with including our Foundation Partner, Bakers Delight. We have also been generously supported by the Australian Government’s lead cancer control agency, Cancer Australia, and our generous corporate partners and donors. Particular thanks goes to Sussan for its trust and support in our organisation in assisting to fund this project.

However, despite all our successes, there are still unacceptable gaps in treatment and care. Some people are missing out and we wanted to find out, and report on, what they were missing.

In what is the biggest study of its kind, this *State of the Nation* report is informed by a survey of over 10,300 of our members and our *Financial Impact of Breast Cancer* survey that explored the out-of-pocket costs of 2,000 people.

Over the past 18 months I have met with more than 3,500 women and men to hear about the issues Australians diagnosed with breast cancer are facing. Those stories and experiences are reflected in the many quotes throughout this report.

I saw what it means to receive the best possible care, but sadly, I also saw first hand the disparity of care that exists across the country. From women who have been waiting more than five years for a breast reconstruction, to those who have never seen a breast care nurse, or people who have not had access to counsellors to deal with the emotional impact of their disease.

It has been a privilege to hear these stories and learn more about the challenges that Australians diagnosed with breast cancer are facing in 2018. While there have been significant advancements in breast cancer detection and treatment, it has become clear through the *State of the Nation* report that there is still much to be done.

Advocacy has always been at the heart of BCNA, and over the years we’ve raised many concerns because statistics do not tell the whole story. Inequities continue.

This report provides the foundation for many more years of rigorous advocacy as we strive to improve the experience of Australians affected by breast cancer. Our goal is to improve the lives of those who are missing out today, and to make sure that no one misses out tomorrow.

BCNA will not stop until every Australian, no matter who they are, or where they live, receives the very best treatment, care and support.

THE STATE OF THE NATION

In 2018 more and more people in Australia are having their lives affected by breast cancer, as incidence continues to increase due to better screening and people living longer. On today's figures, one in eight Australian women will experience a breast cancer diagnosis in their lifetime, with thousands of families, friends, colleagues and others affected by their experience. Reflecting on 20 years of consumer advocacy, Breast Cancer Network Australia (BCNA) asks in this report what does it feel like to be diagnosed with and treated for breast cancer in Australia today?

SUMMARY OF FINDINGS AND RECOMMENDATIONS

We are delighted to report that, from the patient perspective, there are many helpful factors that shape Australians' experience of breast cancer. Many of the 15,000 Australians who took part in the State of the Nation consultation recognised that there has been substantial progress in Australia over the last two decades in awareness, early detection, treatment and support services for breast cancer.

Progress is obvious. Of the 63 recommendations contained in the two landmark advocacy documents BCNA has produced – *Making a Difference* (1998) and *Still Making a Difference* (2004), about two-thirds of the recommendations have been achieved or partially achieved.



State of the Nation consultation in Parramatta

POSITIVE CHANGES



INCREASING SURVIVAL RATES

Australia has one of the best survival rates in the world. The chance of surviving at least five years following a breast cancer diagnosis in Australia is 90 per cent. In Western Australia survival is 92 per cent.¹ The lack of survival data around metastatic disease adds to the uncertainty of the diagnosis. While the number of people diagnosed continues to rise, survival rates have increased by 17 per cent since the early 1980s.² According to Cancer Council Australia, approximately 359,000 Australians will be living with or will be beyond breast cancer in 2040.³ 'Survivorship' has become an important element as more people embrace the prospect of surviving and seek to live well after breast cancer.



AN OPEN DIALOGUE

BCNA notes and celebrates the increasingly open public discussion about breast cancer. Only a few decades ago, public discussion of illness related to what were considered the 'private' parts of the human body was uncommon, and doctors sometimes hesitated to talk frankly with patients in the face of a cancer diagnosis. Today, the public discussion of breast cancer is a more open conversation, and increasingly well informed, although there are communities to whom discussion around breast cancer remains taboo.



PATIENT EMPOWERMENT

Patient rights are now a given, with the establishment of a set of codes about the right to be informed of diagnosis and prognosis and the need for informed consent to treatment. BCNA, which has advocated strongly in this area, welcomes the progress from discussing patient rights to adopting patient-centred care.



CLINICAL PRACTICE GUIDELINES DEVELOPMENT

The development of clinical practice guidelines for the management of early and metastatic breast cancer and in more recent times the optimal care pathways for breast cancer have established the benchmark for the standard of care by which all patients should be treated. The guidelines have helped to assist in decision making by women and their doctors and are based on the best available evidence at the time of writing. They are designed to reduce disparities in care and ensure all women have access to the best possible outcomes regardless of where they are treated.



NEW MODELS OF CARE

Breast cancer has led the way in the development of new models of care for cancer patients, notably through the introduction of multi-disciplinary treatment teams and dedicated breast care nurses providing practical and psychosocial support for patients.



PRACTICAL HELP

Recognition of the practical help that people with breast cancer often require has improved dramatically. BCNA has led the way, not only with extensive evidence-based information resources and community forums, but also practically with the provision of more than 150,000 post-surgery bras and temporary prostheses, generously supported by Berlei.



GENETIC TESTING

Advances in genetic testing have reshaped our ability to understand an individual's risk of developing breast cancer. This has allowed the development of new risk-reducing strategies, and has provided people with better information to help them understand their risk and make treatment decisions that are right for them.



TREATMENT ADVANCES

Advances in breast cancer research have brought about a new understanding of the biology of the breast cancer subtypes. This has allowed for development of more personalised treatments, from surgery to drug treatment, radiotherapy and supportive care.

THE GAPS



FINANCIAL BURDEN

For those having treatment in Australia's private health system, the cost of breast cancer can be an intolerable burden, with far-reaching impacts on breast cancer patients and survivors, their families, employers and communities. These costs usually run into thousands of dollars and can reach the tens of thousands if life-extending drugs that are not approved for the PBS are purchased. For women who already live close to the financial brink, breast cancer can force them to rely on family, friends, government benefits or charities for the first time in their lives.



INEQUITIES OF LOCATION

Living outside a metropolitan area has been found to be associated with poorer survival outcomes if you are diagnosed with breast cancer.⁴ The burden of travel - distance, cost and disruption to normal life - is just one aspect of this outcome. Lack of specialist breast and reconstructive surgeons in regional centres can mean women face reduced choices around the type of surgery that may be right for them. Reduced access to clinical trials and neoadjuvant chemotherapy also impact on treatment decision making for rural Australians. The burden of travel can create many other issues and disadvantages for people in rural and remote areas.



My diagnosis occurred when I was 34 years old. I chose to have a mastectomy, as we lived 600 kilometres from Adelaide, so travelling for radiotherapy treatment was not an option for me.



LACK OF ALLIED HEALTH SERVICES

A breast cancer diagnosis creates a complex set of needs. Allied health services such as psychology, physiotherapy, exercise physiologists, lymphoedema support and social workers are not located in many outpatient hospital settings, requiring people diagnosed with breast cancer to access these services in the private setting. This can further increase fragmentation of care and add to out-of-pocket costs incurred.



LACK OF INFORMATION

Despite two decades of dedication to the information needs of people with breast cancer, BCNA cannot make up for inadequacies that some individual women face as a result of poor communication and transparency by health practitioners and private health insurers, particularly related to out-of-pocket costs. In addition to information needs around costs, women who participated in our consultations also highlighted fertility treatment options, clinical trials and follow-up care as areas where they needed more information from their treating team.



SHORTAGE OF BREAST CARE NURSES

With the incidence of breast cancer rapidly increasing, the provision of breast care nurses is not keeping pace. We acknowledge the dedicated work of the McGrath Foundation, but there are still women in Australia who are not referred to a breast care nurse. Almost one in five (18 per cent) of BCNA's 2017 Member Survey respondents disagreed or strongly disagreed when asked whether they had as much contact with a breast care nurse as they needed. In addition, women with breast cancer sometimes suffer the effects of not consistently seeing the same breast care nurse, who understands their needs and history.



I would have really appreciated information and discussion with a breast care nurse. I am a private patient. I have had no contact at all with a breast care nurse.



Coming from a country area, there was no consideration for travel and travel time, money, lack of help in the area, no breast care nurses.



INCONSISTENT HEALTHCARE

While people with breast cancer acknowledge the many positive experiences they have had with dedicated healthcare practitioners and supportive institutions, there is still a worrying level of disparity in the quality of care some women receive. Lack of mandatory patient outcome reporting means patients often have no, or limited access to, information on benchmarking to help guide decision making around who they may want to have involved in their care.



PROFESSIONAL INSENSITIVITY

There will always be healthcare professionals and other staff who are not as sensitive as they should be. Some people with breast cancer are being given their diagnosis over the phone, and sometimes by medical administrative staff rather than a doctor or other healthcare professional.



Handling what is almost always life altering news in a sensitive way is something that has improved significantly in the last 20 years, but there are still some cases in which people are not being treated with the sensitivity and with the care that they need.



UNDERSTANDING AND SUPPORTING METASTATIC BREAST CANCER

Metastatic breast cancer continues to be poorly understood by the community and under-reported in Australian breast cancer statistics in terms of incidence, survival and mortality. People with metastatic breast cancer often report that although they have a much more serious diagnosis, with an uncertain future, they receive less support than those diagnosed with early breast cancer. Many are not supported by a breast care nurse and many do not have the support of a cancer care coordinator to help them navigate their care. When asked whether they had as much contact with a breast care nurse as needed, 29 per cent of respondents with metastatic breast cancer disagreed or strongly disagreed, compared with 18 per cent of respondents with early breast cancer.

Other gaps include support for families and carers, provision of palliative care services and, crucially, the expense of non-PBS drugs that have proven effective in extending the progression-free survival of people with metastatic breast cancer in clinical trials. It is disheartening for Australians to learn there are new drugs available in other countries that are not yet available here.

DIFFICULTIES EXPERIENCED BY SPECIFIC DEMOGRAPHIC GROUPS

YOUNG WOMEN

The average age of diagnosis of breast cancer in Australia is 61.⁵ However, every year approximately 840 women under 40 will hear the news that they have breast cancer.⁶ Disturbingly some young women report delays in diagnosis, having been assured by their primary health practitioners that their symptoms are not cancer. In addition to challenges around diagnosis they face concerns related to their age and life stage including financial, employment and emotional issues and grief or fears about infertility. Young women are often under-supported to deal with their situation, and childcare support for young mothers facing illness is insufficient.

MEN

Breast cancer in men is a rare cancer and, as a result, little information specific to the needs of men is available to the 148 men expected to be diagnosed with breast cancer in Australia this year. While they deal with many of the same gaps as women, men also face delayed diagnosis, reduced research investment and ineligibility for clinical trials, and stigma in daily life.

ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN

Aboriginal and Torres Strait Islander women are less likely to be diagnosed with breast cancer but, once diagnosed, are more likely to die of breast cancer than other Australians.⁷ Aboriginal and Torres Strait Islander women are less likely to participate in breast screening⁸ and highly likely to feel culturally isolated in hospitals and clinics. Culturally, they need to access more support and information from Aboriginal and Torres Strait Islander breast cancer survivors and more assistance to access treatments closer to family.



While I received immediate treatment, many Aboriginal people do not. I have seen too many friends, women and men, suffer and die because they were diagnosed too late and because they live in very deprived circumstances in their remote community.

WHAT HAS TO CHANGE?

Best practice care is the only way all Australians diagnosed with breast cancer can have access to the best possible outcomes. Reducing national disparities is critical to easing the physical, emotional and financial impact of breast cancer. Anyone diagnosed with, or at risk of, the disease should have confidence in the healthcare system to meet their needs and expectations - whether it be for prevention, treatment, psychosocial or palliative care.

Patient priority must form the basis of every decision made in healthcare reform. The detailed experiences of more than 15,000 women and men who participated in the research that informs this report should be utilised to bring positive change. Breast cancer survival rates reflect many advances and improvements but they are no mask for the disparities of care reflected in the *State of the Nation* report.

Breast Cancer Network Australia (BCNA) is calling on federal and state governments, health professionals, researchers and health providers to action the recommended changes in this report.

PRIORITIES FOR URGENT ACTION



01

Reduce 'bill shock' by establishing a government portal to help consumers compare fees for common breast cancer tests and treatments against Medicare rebates.

02

Reduce out-of-pocket costs for tests and scans by:

a

abolishing the multiple service rule for breast imaging.

b

extending the Medicare rebate for breast MRI for diagnosis and treatment planning.

c

resolving the lack of public mammography diagnostic services in Tasmania and other states and territories.

d

ensuring Medicare rebates are aligned with the true cost of service provision.

03

Improve Australia's breast reconstruction rate to meet international standards and find a solution to the unacceptable delays for women in Far North Queensland.

04

Improve access to allied health by:

a

funding allied health outpatient services in public hospitals.

b

increasing the Medicare rebate for allied health for cancer patients through the GP Chronic Disease Management Plan from five visits per year to 10.

05

Establish specialist lymphoedema clinics in all metropolitan and regional cancer centres and fund a National Lymphoedema Compression Garment Scheme.

06

Increase the number of metastatic breast care nurses in major metropolitan and regional cancer centres and establish cancer care coordinator roles to support people with metastatic disease living in rural and regional Australia.

07

Mandate and fund communication training for healthcare professionals working with cancer patients.

08

Provide a national framework for Patient Assisted Transport Scheme (PATS) funding to improve access to specialist services and clinical trials for people in rural, regional and remote areas.

INTRO- DUCTION

WHY WE NEED THIS REPORT

Many people point to high public awareness, earlier diagnosis, improvements in survival rates and effective fundraising to argue that breast cancer does not warrant the level of attention it has today. Yet breast cancer is still the most common cancer in Australian women. In 2018, an estimated 18,235 Australians will be diagnosed with breast cancer, an average of 50 people per day. Approximately 3,000 Australians will die from breast cancer in 2018.⁹

Any Australian who has had to undergo treatment for breast cancer, or any Australian who has been an intimate onlooker as a loved one has endured the experience of surgery, chemotherapy radiotherapy and hormone therapy for breast cancer, will know just how demanding it is. It calls upon all of the diagnosed person's reserves of courage and resilience. It leaves many breast cancer survivors with long-term physical, psychological and financial issues.

In its 20-year life, Breast Cancer Network Australia (BCNA) has worked to fulfil the two-pronged vision of our founder Lyn Swinburne:

- no one should feel alone through their experience of breast cancer
- Australians diagnosed with breast cancer get the best possible treatment and care appropriate to their needs.

Today BCNA is a supportive network of more than 120,000 members and around 300 affiliated breast cancer support groups that reaches over 80 per cent of Australians newly diagnosed with breast cancer. We support, inform, connect and represent them in a journey that nobody wants to take.

This *State of the Nation* report tracks how far BCNA has come in two decades of breast cancer activism. In this report, our practical achievements are underscored by the real-life experiences of our members.

Importantly, the report also tracks how far the Australian community - health professionals, workplaces, government and support services of all kinds - has come in ensuring that Australian women and men with breast cancer have the best possible treatment and experience at what is often the most challenging time in their lives.

The report also looks at life after diagnosis and initial treatment for breast cancer, and asks the questions:

- How well equipped are Australian breast cancer survivors to make the best of life after breast cancer?
- How well supported are those who receive the devastating diagnosis of metastatic breast cancer?

METHODOLOGY

VIEWS AND VOICES

This report is largely informed by the views and voices of Australians who have been diagnosed with breast cancer. It includes the outcomes of:

- Face-to-face individual and group consultations with 3,500 Australians from all states and territories affected by breast cancer, primarily women, during 2016/17.
- BCNA's 2017 Member Survey completed by over 10,300 breast cancer survivors during the first half of 2017. This ground-breaking survey is the largest general survey of Australian breast cancer survivors ever completed, and is one of the largest surveys of breast cancer survivors in the world. It was funded by the Sussan Group and conducted on behalf of BCNA by the Social Research Centre.
- A survey completed by almost 2,000 Australians diagnosed with breast cancer as part of BCNA's 2017 Financial Impact of Breast Cancer report.
- BCNA's Aboriginal and Torres Strait Islander Think Tank attended by 48 women from all states and territories, held in March 2017.
- Previous research and consultations undertaken by BCNA.
- Examination of national and international best practice in breast cancer treatment and care and a range of relevant clinical guidelines.
- Consultations with breast cancer health professionals.
- Roundtables held in late 2017 and early 2018 in four capital cities to present the findings of the survey and consultations with a range of stakeholders, and to garner further feedback.

This report reflects the voices, perspectives and experiences more than 15,000 women and men affected by breast cancer across Australia.

Throughout this report, the quotes used are from BCNA's 2017 Member Survey and the stories and experiences that arose through the face-to-face consultations held around the nation. Unless otherwise specified, all statistics come from BCNA's 2017 Member Survey of 10,318 participants.

LIMITATIONS

The women and men who participated in the face-to-face consultations self-selected to participate. The people who attended were interested and motivated to have their voices heard. All 2017 Member Survey responses were voluntary.

Due to issues of scope, the consultations and surveys focused on the lived experiences of women and men diagnosed with breast cancer. No research was conducted with carers for this project. We acknowledge that the needs of carers are significant and are often under-considered, and we will explore options to better understand the needs of carers in future work.

OVERSIGHT

An Expert Advisory Group oversaw this project, with members including breast cancer survivors, a BCNA Board member, and a number of clinicians and academics with relevant expertise.

PRINCIPLES

The principles that have informed the State of the Nation project are:

CONSUMER VOICES

This report is primarily driven by the voices of people affected by breast cancer. All too often, the consumer voice is missing or not given enough attention in the shaping and delivery of health policy and models of care.

NO VOICE UNHEARD

A consultative and inclusive approach was taken to ensure representation of the concerns of the whole range of people with breast cancer across Australia, including people with metastatic breast cancer, young women, men, Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse backgrounds.

BEST PRACTICE

Existing and emerging evidence of best practice informed the project, including Cancer Australia guidelines and the *Cancer Australia Statement – Influencing best practice in breast cancer*. We also talked to a number of health authorities, particularly after women consistently reported positive experiences.

GAPS EXIST

For some issues, knowledge is incomplete and there is no general consensus on how to proceed. Breast density is an example. BCNA continues to participate in these ongoing conversations ensuring that the right to be informed underpins all of our advocacy positioning.

IMMEDIATE ACTION

Where clear deficiencies in practice existed, action was taken immediately. The issue of access to breast reconstruction in the Far North Queensland region is one such issue.

AVOID SURPRISES

We have progressively kept decision makers informed, to encourage transparency and to avoid surprises at the end of the project for governments and hardworking health professionals and administrators.

PRAGMATIC

All advocacy measures and recommendations are designed to address the specific difficulties experienced by Australians affected by breast cancer.

FRAMEWORK

This report is structured around the stated needs and expectations of people living with breast cancer in Australia today - a set of 'I' statements. In capturing the views of consumers, we have sought input from health professionals and researchers to validate these statements and we have drawn on the experience and knowledge of BCNA's extensive consumer network.

STATE OF THE NATION

BREAST CANCER TODAY

When Australians are faced with the prospect or the reality of breast cancer, what do they want, expect and need?

01

I want to **understand** my risk of developing breast cancer and how to reduce it.

02

If I have breast cancer, I want it found **early**.

03

I expect to get the **information** I need to understand my diagnosis.

04

I expect to get the information I need to make important **decisions** about my treatment, including information about the costs of my care.

05

I want to be treated by a **team** of experts, including a breast care nurse and/or a cancer coordinator, and receive the best possible treatment.

06

I want to be **heard**, and treated with empathy, care and respect by health professionals.

07

I expect to be offered **clinical trials** that might be helpful to me.

08

I want to get the social, emotional, financial and practical **support** that I need during treatment.

09

I want to be supported to **live well** after treatment and helped to manage my side effects.

10

I expect to have a **follow-up** care plan which meets my needs.

For Australians diagnosed with metastatic breast cancer, what else is needed?

11

I expect to have one **key contact** in my multi-disciplinary treatment team to coordinate my care, including palliative care.

12

I want the people around me to recognise the **serious nature** of my diagnosis and give me the support needed to live well for as long as possible.

13

I do not want to experience **discrimination** or stigma at work or in the community.

14

I need to be supported towards the end of my life to have **a good death**.

These key expectations - our 'I' statements - are grouped into seven themes:

01

Risk

02

Early diagnosis

03

Information

04

Care

05

Support

06

Surviving

07

Living with metastatic breast cancer

THEME 01: RISK

THE STATE OF THE NATION:

UNDERSTANDING AND ACTING ON BREAST CANCER RISK

*'I want to
understand
my breast
cancer risk
and how
to reduce it.'*

PRE-DIAGNOSIS ISSUES

MISSING THE BREASTSCREEN BUS

While BreastScreen Australia services are provided for women in remote areas of every state and territory, services are delivered from a mobile centre. If women are away when the bus visits, they are less likely to participate and are generally unaware of what they should do to start or catch up with the two-year BreastScreen cycle. For Aboriginal and Torres Strait Islander women, there is an added difficulty if BreastScreen buses provide clinics during 'men's business', when women are not able to leave their community to participate, or clinics are set up on men's land.

“ *I live in a remote town of 6,000 people in WA. The mammogram bus only comes about once every two years. This is not often enough, and there have been some poor outcomes with breast cancer in this region, especially with younger women.*

BREAST DENSITY

Women are not routinely told about their breast density, and most do not understand that breast density can be a risk factor for breast cancer. Western Australia is the only state where women are advised if they have dense breasts. They are advised that their screening mammogram is less sensitive to breast cancer than those who do not have dense breasts, and that they may need additional screening tests and encouragement to be vigilant to the signs and symptoms of breast cancer.

As the debate around how to assess and manage breast density continues among health professionals and researchers, women who were found to have an interval breast cancer (a cancer diagnosed between regular screening mammograms), who were then advised they had dense breasts, reported feeling angry they were not informed about their risk.

“ *I wasn't informed that I had dense breast tissue and that a mammogram or ultrasound could therefore miss an invasive cancer. I was originally treated for a stage 0 grade 2 cancer. Further cancer in the contralateral breast was missed at further screenings.*

POST-DIAGNOSIS ISSUES

Most women who have experienced breast cancer understand at least some of their options for acting on their own risk of recurrence. However, when there are practical barriers or information gaps, they are less confident that they can keep on top of their own risk profile.

Sixty-seven per cent of Member Survey respondents were worried that their cancer may recur.

“ *Many years down the track it is fear of recurrence, it's with me all the time.*

FEAR OF RECURRENCE

Women who have had breast cancer often experience anxiety prior to follow-up screening. They worry that screening will detect a new or recurrent cancer. They reported that their anxiety impacted the whole family. They are also prone to experience fear and anxiety whenever they have pain in other areas of the body, and want to know how to access quality information to deal with this anxiety, including advice on when not to worry. They do not understand the evidence around why additional tests and scans are not included in routine follow-up care, or why early detection of asymptomatic systemic recurrence does not improve survival.

“ *I need follow-up that doesn't leave me feeling like diagnosing a recurrence rests solely with me recognising symptoms in a body I no longer know because of treatment.*

DIET AND EXERCISE INFORMATION

Thirty-six per cent of Member Survey respondents who reported needing information about physical activity and healthy eating said only some or none of their information needs had been met. In the consultations, some women reported that they didn't understand what they were 'allowed' to do, and therefore hadn't changed their behaviour. Exercise was rarely a topic of discussion with their treatment team. This is a disappointing finding considering the volume of emerging evidence that highlights how regular

exercise before, during and after treatment reduces the severity of side effects and the risk of new and recurrent cancers.¹⁰

“ *How much exercise to do after four weeks and how heavy can your weights be?*

ALCOHOL

Research is increasingly exploring the role alcohol may play in increasing the risk of a breast cancer diagnosis or recurrence.¹¹ A number of women who participated in the Member Survey expressed uncertainty about the recommendations around alcohol consumption and how alcohol may impact breast cancer risk.

“ *Should you drink alcohol or completely abstain?*

FEAR FOR DAUGHTERS

Even if women do not have a strong family history, many reported that they were fearful for their daughters following their own diagnosis.

Daughters who attended consultations were also worried about their risk, with many taking up screening much earlier at their own cost.

“ *I was diagnosed 15 years ago, but recently my daughter has been asking a lot of questions. I think she is very worried about being diagnosed – what should I be saying to her?*

FEAR FOR MEN

Men with breast cancer expressed their concern that there was significant anxiety among other men who understood that they could be diagnosed with breast cancer, but are not included in screening programs.

“ *I've met 13 male breast cancer survivors [around the world], and with these 13 guys, the story is the same. You know, you have those types of conversations initially where you have to tell your employee or your employer, or you have to tell your family and your friends, and it's like, 'Really! You've got breast cancer? You've got a woman's disease! You must be less of a male!'*

ADDRESSING THE ISSUES

BCNA IS:

Advocating for the development of clinical guidelines for breast density, and ensuring women have accurate and reliable information on the current breast density debate.

Advocating for the national implementation of BreastScreen Western Australia's policy to inform women with dense breasts that mammography is a less sensitive screening tool for them.

Continuing to produce and provide targeted resources to help women deal with their fear of recurrence and raise awareness around the importance of good communication to help people manage this fear.

Working with young women to better understand their experience and ways we can support and connect them.

Building awareness of men's breast cancer through media and promotional campaigns, including through acknowledging Male Breast Cancer Awareness Day on 20 October.

ACTION IS REQUIRED TO:

Improve data collection (including incidence and prevalence of metastatic disease and patient-reported outcomes).

Develop clinical practice guidelines around assessment and management of breast density.

Improve referral pathways for psychological interventions and promote awareness of GP mental healthcare plans to help manage the emotional impact of breast cancer.

THEME 02: EARLY DIAGNO- SIS

THE STATE OF THE NATION:

GETTING AN
EARLY DIAGNOSIS
OF BREAST
CANCER AND
ENSURING IT
IS ACTED ON
QUICKLY

*'If I have
breast cancer,
I want it
found **early**.'*

The good news is that the BreastScreen message around benefits of screening and early detection is getting through. Most people's breast cancer is being diagnosed at an early stage. Ninety-five per cent of Member Survey respondents were diagnosed while their cancer was still considered early breast cancer. Of this group, 21 per cent were diagnosed with ductal carcinoma in situ (DCIS) and 79 per cent were diagnosed with early breast cancer.

Five per cent of survey respondents were living with metastatic disease, meaning that breast cancer had spread to other parts of the body such as the bones, liver or lungs. This is consistent with data from Cancer Australia's Stage, Treatment and Recurrence (STaR) project, which found that approximately 5 per cent of breast cancer cases diagnosed are metastatic.¹²

BARRIERS TO AN EARLY DIAGNOSIS

BEING 'TOO YOUNG'

Young women reported being frustrated when they presented with symptoms and were told 'You are too young to have breast cancer'. This was a common theme for women under 40 years who are not eligible for regular screening through the BreastScreen Australia screening program.



I had to go to my GP three times before they agreed to investigate my lump.

COST

Many women reported significant out-of-pocket costs for mammography. Diagnostic mammography has one of the lowest bulk billing rates of all imaging procedures in Australia (around 50 per cent), making it very difficult for patients to access this service if they cannot afford to pay a sometimes significant gap.¹³ BCNA was astounded to discover that there are no mammogram machines in public health in Tasmania*. This means that Tasmanian women must rely on being bulk billed to avoid out-of-pocket costs associated with their breast cancer diagnosis. As an alternative, some Tasmanian women symptomatic for breast cancer try to access BreastScreen services or choose to delay diagnosis because they are unable to afford the costs of tests.

Women with private health insurance reported that out-of-pocket costs for diagnostic testing and the options for less expensive referral pathways through the public system were often not discussed at diagnosis. Additional screening and diagnostic work-up (notably breast MRI) not

*Further to our consultations BCNA has established Northern Territory and Australian Capital Territory also do not have with no public mammography diagnostic services.



KEIRA, NSW

YOUNG DIAGNOSIS

I was 31 and living in Newcastle with my young family. I had not long finished breastfeeding my son, when I noticed my breast was painful and had a hard spot. Initially I thought it must be something to do with a blocked milk duct, but my family suggested I get it checked out.

The GP said not to worry, but I wanted to get more checks, including an ultrasound and a biopsy. These were inconclusive and my GP said to come back in 12 months. I really wanted to know what this was, so I insisted on having more tests, including a core biopsy and a mammogram. I had to push at every point for further investigations because of my age and the fact that I had just finished breastfeeding.

When the GP told me I had breast cancer, I was absolutely devastated. I had a two-week wait between being told, 'You have breast cancer' and my first surgeon's appointment. I was so stressed that I was physically sick. It was an awful waiting game.

Thankfully my oncologist was very supportive during my treatment and I had access to a fantastic breast care nurse, who I saw every day when I was in hospital for my mastectomy.

Looking back on my experience two years down the track, I definitely needed to be taken seriously as a young woman with breast symptoms. I know there would have been many women who would have walked away from the GP and gone back in 12 months.

I hate to think what would have happened had I listened to my GP's advice. I also needed support when I was dealing with the stress of hearing those words, 'You have breast cancer'.

available in public health meant women who needed to undergo tests in the private setting incurred significant out-of-pocket costs. For women who required 3-D mammography, costs were inconsistent, with some women reporting that they paid \$150 and some as much as \$600. BCNA hopes that the new Medicare item number for 3-D mammography will reduce cost discrepancies associated with this test and that more women who require testing in the private system will have the option of being bulk billed.

It was pleasing to note that for women under 50 deemed to be 'high risk' the rebate for MRI as well as access to free genetic counselling services has helped reduce the costs of risk assessment. For other women, the out-of-pocket cost of an MRI as part of breast cancer diagnostic work-up can be a significant and unexpected burden. Lack of affordability for this test creates significant disparity, with the benefits of breast MRI as an important diagnostic tool seemingly reserved for those who can pay.

“ Having access to MRI as a starting point would have gotten us there [to diagnosis] sooner. The MRI is optional and the cost would be solely borne by me – being so important, this is crazy.

“ MRI scans were not subsidised by Medicare or my private health fund, which was surprising and very disappointing.

ISSUES WITH THE PROCESS

FROM DIAGNOSIS TO SURGEON

Women reported being relieved to learn that there was no significant time gap between diagnosis and their appointment with a surgeon; however, some were concerned that there was a gap in support services during this important early period.

“ Having emotional support from the medical staff from the very moment that I was given the diagnosis. This was lacking.

MULTIPLE SERVICES BILLING RULE

When patients present for a diagnostic ultrasound at a practice with a radiologist on site, it may be beneficial to conduct the core biopsy or fine needle aspiration (FNA) on the same day (when indicated by the results of the ultrasound, or when the patient has had to travel a long distance for the service). Even when the facility and the radiologist are available to perform this service following the diagnostic ultrasound appointment, Medicare does not fund the ultrasound-guided core biopsy or fine needle aspiration (FNA) due to the multiple services billing rule. Having to return on a separate day causes significant and unnecessary fragmentation in clinical care in addition to stress and inconvenience, particularly for rural women who need to travel for this test.

“ I needed timely appointments for further tests after being diagnosed, timely appointments that allowed me to get back to work, not waiting days and days for appointments.

ADDRESSING THE ISSUES

BCNA IS:

Empowering women on how to have financial conversations following their diagnosis, including both public and private referral options.

Working with women aged under 40 to raise awareness that young women can get breast cancer too and about the need for prompt investigation of breast symptoms by primary healthcare providers.

Supporting a current application to the Medical Services Advisory Committee (MSAC) to extend the Medicare rebate for breast MRI.

Advocating to remove the multiple service billing rule for breast imaging currently before the Federal Government's MBS Review Taskforce.

ACTION IS REQUIRED TO:

Fund BCNA to develop a decision tree to empower patients to help navigate the complex financial system post a breast cancer diagnosis.

Extend bulk billing options for women who require additional tests only available in the private sector.

Resolve the issue of no public mammography in Tasmania and other states and territories.

Improve bulk billing rates for mammography.

Extended the Medicare rebate for breast MRI:

when ultrasound, mammography, and physical examination are inconclusive for the presence of breast cancer

in women newly diagnosed with cancer to help with treatment planning when conventional imaging with mammography and ultrasound may not show the extent of disease.



State of the Nation consultation in Alice Springs

THEME 03: INFORMATION

THE STATE OF THE NATION:

GETTING
THE RIGHT
INFORMATION
AT THE RIGHT
TIME

*'I expect to get the **information** I need to make important **decisions** about my treatment, including information about the costs of my care.'*

Having access to high-quality, evidence-based information is vital for people diagnosed with breast cancer. Of the more than 10,300 people surveyed, 69 per cent agreed or strongly agreed with the statement, 'I need to find out as much as I can about my cancer.'

Seventy-seven per cent of Member Survey respondents said they had information needs in the previous 12 months. When asked whether their information needs had been met, only 49 per cent of those surveyed said they had received all of the information they needed.

“

The treatment options were not explained. Surgery was seen as urgent and as the only option. In fact, my GP referred me to a general surgeon, and I thought I was seeing a cancer specialist (until I arrived). In hindsight, more review of options would have been sensible.

HEARING YOUR DIAGNOSIS

INSENSITIVE COMMUNICATIONS

One of the most disheartening experiences that women with breast cancer report is an insensitive delivery of diagnosis. It is of great concern to BCNA that the most life-changing piece of information is still sometimes delivered by a medical receptionist or a doctor over the phone with no regard to whether the person is in a position to receive this sort of information. Women have reported being told of their diagnosis while on speaker phone, with their children or colleagues listening in.

“

I was called by BreastScreen at 4.45 pm on a Friday to be told I have breast cancer. My appointment wasn't until the following Wednesday and they offered me no support services to call. I found BCNA by searching Google.

“

At the BreastScreen recall appointment I was lying on the bed having a biopsy done and an insensitive doctor asked me where I'd be having treatment because I 'would be having treatment'. I had no support with me that day and I walked away completely numb as I then knew I had breast cancer, without officially being diagnosed.

“ You might think that we have come a long way in 20 years but just as Lyn [Swinburne] was given her diagnosis over the phone, I was driving with my children in the back, the doctor on speaker phone, when I was told I had breast cancer. What did they think I was going to do?

The impact of this impersonal communication, combined with a lost opportunity to provide important information and support, can have a profound impact on women and reduce their trust in the healthcare system they are about to enter.

“ Competency in diagnosis from my first breast surgeon – not met! He was arrogant, patronising and extremely difficult to talk to, as he was irritated by my questions.

UNDERSTANDING THE DIFFERENCE BETWEEN DCIS AND INVASIVE DISEASE

Ductal carcinoma in situ (DCIS) is non-invasive breast cancer in which abnormal cells are contained in the milk ducts of the breast.

The messages that health professionals need to convey in relation to in-situ disease are complex, i.e. that DCIS is not just one disease, but a ‘spectrum’ of disease, where the treatment approach will differ from person to person, and even in one person, may differ over time.

Research has found that women diagnosed with DCIS can experience significant confusion about what DCIS is and what treatments to have, and women often overestimate the likelihood that DCIS will progress to invasive breast cancer or even metastatic disease.¹⁴

Survey respondents diagnosed with DCIS were less likely to agree or strongly agree with the statement; ‘I feel I have been heard by my medical team’ than women with early breast cancer.

“ Support from a breast care nurse was not there at all. It was difficult to access counselling through the hospital. I had DCIS and did not feel emotional support was taken seriously, as the cancer was not invasive.

“ I was rushed into making decisions and the doctors questioned and pressured me to get a mastectomy.

A high proportion of women with DCIS were also concerned about a recurrence and did not understand their risk. Sixty-four per cent of respondents with DCIS either agreed or strongly agreed with the statement, ‘I am worried that my cancer might come back (or recur)’.

“ I needed to understand the likelihood of recurrence.

FINDING OUT ABOUT METASTATIC DISEASE

Metastatic breast cancer represents about 5–10 per cent of breast cancer diagnoses,¹⁵ has a poor prognosis and is not well recorded in Australia’s breast cancer statistics. People with metastatic breast cancer are less likely to have received all of the breast cancer information they needed. Twenty-six per cent of Member Survey respondents with metastatic disease indicated that they had significant gaps in the information they received. In addition, 9 per cent of respondents with metastatic breast cancer did not feel they had enough information to make or understand important treatment decisions.

Respondents with metastatic breast cancer were also less likely to feel the people close to them were supported – 23 per cent of respondents with metastatic breast cancer felt that people close to them were not supported compared to 18 per cent of respondents with early breast cancer.

“ More information for those with metastatic breast cancer and general information about it for anyone, as most people think you can be cured, they don’t understand what it means.

“ In the past 12 months my main needs were for information about clinical trials and how to access palbociclib, which is still not available in Australia through the PBS. I had to find it myself. I also am still looking for customised support for end-of-life decisions as my family and friends have no experience in it (e.g. funeral) and don’t want to discuss it.

“ I need information on new treatments for metastatic breast cancer and earlier referral to palliative care as I am worried about my care when actively dying. I needed a referral for support immediately after I was given my diagnosis (which was over the phone on a Friday afternoon). ”

“ What did I need? To be treated well and to be well informed about what was happening and why. To know that there were many options available despite being diagnosed with metastatic breast cancer. To receive emotional support. To make the treatment as least intrusive on my daily life as possible for the benefit of my family. To feel respected and comfortable with my treatment team and able to ask questions and to not feel intimidated by the whole process. To feel that I still had some control over my life and that I could still achieve small goals. ”

THE FERTILITY QUESTION

Young women report that there is sometimes an inconsistent approach to fertility discussions and referrals, with information difficult to obtain, particularly in regional areas. Grief over loss of fertility and anger at inadequate and timely referral for a discussion around options was a theme for some young women. Costs of fertility options such as IVF were also prohibitive for some.

According to the Member Survey, of the respondents who had a need for information about fertility, a significant proportion (44 per cent) reported that they did not have the information they required. Consultations indicate that unmet needs relating to fertility information vary by state and territory. BCNA is consulting further with young women to explore this issue in more detail.

“ When I went through treatment as a woman in my early 30s, no one really engaged at all with the likelihood of post-chemo infertility, and in fact I felt actively discouraged from talking about it. Professionals were often very dismissive of my concerns if I did raise them. ”

“ I wanted more information on fertility and getting pregnant after breast cancer treatment. I took two years to get pregnant after the IVF clinic told me my fertility was at its lowest 2 years ago. I now have a beautiful 1 month old daughter. ”

THE ROLE OF GENETICS

When someone is diagnosed with breast cancer, it is common for them to worry that they carry a genetic mutation that puts them – and their families – at greater risk of breast cancer or other cancers.

A significant development in breast cancer care in the last 20 years is testing for genetic mutations BRCA1 and BRCA2. These gene mutations are associated with an increased risk of breast and ovarian cancer and can be carried by both men and women. Approximately 5 to 10 per cent of breast cancers are due to inherited genetic mutations.

New Medicare rebates announced in 2017 have assisted to address high costs of genetic testing for women diagnosed with breast cancer thought to be at risk of carrying a breast cancer gene mutation. However, barriers such as distance from specialist genetic clinics and delays in referral for women in rural areas continue to cause disparity around timely access to genetic testing. Lack of timely access to breast reconstruction options for rural women further complicates decision making for this group of women.

“ As a BRCA1 carrier, the rules need to change regarding preventative surgery in the public system. It should not be classed as elective surgery. ”

“ I needed support through the process from diagnosis to treatment. The process left me feeling very isolated. Between my radiologist and GP I navigated my way through. However the genetic counselling provided no support or guidance. The costs of the treatment and tests required are unreasonable. Patients are left with having to travel away from family members and support networks or pay the private fees. ”

ISSUES WITH THE PROCESS

DECIDING WHAT TO DO

Informed decision making is essential to help women feel in control of their disease. Seventeen per cent of survey respondents did not agree that they had enough information to make treatment decisions. This indicates that there are significant variations in the needs and confidence of people communicating with their treatment team.

“When I got the My Journey Kit I was desperately looking for information on triple negative breast cancer and it was not covered in the info sheets or book, just briefly mentioned. Very alienating at that time as a triple negative breast cancer warrior.”

CHOOSING CHEMOTHERAPY

Tumour profiling testing such as Oncotype DX is now available to help people with low or moderate risk of recurrence understand whether chemotherapy is right for them. Australian studies show that tumour profiling tests are effective in helping patients to make decisions about treatment for low-risk breast cancer, and whether chemotherapy or less invasive treatments will be most effective. We note the findings of the TAILORx study that indicate that women diagnosed with hormone receptor positive, HER2-negative, node-negative early breast cancer who receive a low- or mid-range score via the Oncotype DX test may be able to avoid chemotherapy, especially women over 50 years. However, Australians have to pay between about \$3,000 and \$7,000 to access a tumour profile test. This cost is out of reach for the majority of women.

It is of great concern to BCNA that this test and others like it are not available through Medicare. Until reimbursement is granted, many Australian women will miss out on learning whether or not they can avoid chemotherapy and all of the toxicities it entails.

“I had my breast tissue sent to America for a test, my results came back 4/100 so I didn't need to have chemo. It cost us \$4,500. I think this test should be available in Australia and either free or less expensive so others in my situation don't have to have chemo either.”

KNOWING WHAT YOU HAVE TO PAY

'Bill shock' associated with high out-of-pocket fees for breast cancer treatment and diagnostic tests is a very real issue for people diagnosed with breast cancer. This can be addressed by full disclosure of likely costs by health professionals and private health insurance providers. People with breast cancer need to be provided with comprehensive written information about the costs of procedures, tests and treatments prior to them taking place.

“Even though you may have top hospital cover, the gap is still very expensive for most patients who have to deal with it at their most vulnerable time.”

DISAPPOINTMENT OF PRIVATE HEALTH COVER

It is unacceptable for patients to be expected to provide item numbers to their private health insurers to establish whether they are covered by their policy for the cancer treatments they have been recommended to have. Women describe the shock of learning that, despite paying private health insurance premiums for years and years, their level of cover excludes some of the cancer treatments they are recommended to have. Radiotherapy is one of the most common treatments for cancer. In breast cancer it is primarily delivered as an outpatient procedure, meaning gap fees are not covered by private health. This needs to change so radiotherapy is covered for all outpatients who take out private health cover.

BEING PROACTIVE

CONNECTING WITH OTHERS

Sharing and obtaining information from others is important for women with breast cancer. From connecting emotionally with their healthcare team to joining a network of other women like BCNA, human connection is important to both manage stress and stay informed, and to lay the groundwork for emotional recovery from breast cancer.

“I needed contact with others in all aspects of the journey rather than having to rely on leaflets on different subjects.”

Too often women are not offered opportunities to connect with peers, leaving them feeling socially isolated by their diagnosis. Almost one in five respondents reported that they did not have opportunities to hear about the experiences of others who have been through the same thing.

ADDRESSING THE ISSUES

BCNA IS:

Developing tools to help women communicate their issues or concerns to their healthcare team.

Advocating for Medicare rebates for tumour profile testing to guide chemotherapy treatment decision making.

Developing new information resources specific to women with DCIS.

Working with other consumer organisations, including Consumers Health Forum, Cancer Council Australia and Prostate Cancer Foundation to raise awareness around 'bill shock' for people with cancer.

Calling on health service providers to provide written, full financial disclosure of out-of-pocket expenses prior to tests, treatments and procedures.

Advocating for greater transparency from private health funds around level of cover.

Promoting the *Cancer Australia Statement – Influencing best practice in breast cancer*, to ensure women have timely access to fertility preservation options and genetic testing.

Developing a digital version of our key resources to facilitate information provision at the time of diagnosis and better assist women to make informed treatment decisions.

Strengthening our peer support programs, including our Online Network and programs to support young women connect with one another.

ACTION IS REQUIRED TO:

Approve the current applications before the Federal Government's Medical Services Advisory Committee (MSAC) to ensure Australians diagnosed with breast cancer have access to subsidised tumour profile testing and fast track any new application for the Oncotype DX test.

Reduce 'bill shock' by establishing a government portal to help consumers compare fees for common breast cancer tests and treatments against Medicare rebates.

Regulate for health service providers to provide full financial disclosure for breast cancer patients prior to treatment commencement.

Include outpatient delivery of radiotherapy services as standard cover in private health insurance policies.

Improve data collection on the incidence, treatment and experience of metastatic breast cancer.

Ensure access for young women with breast cancer to government fertility clinics either through face-to-face consultations or telehealth, particularly those being treated in rural and regional settings.

Improve access to genetic testing to assist in treatment decision making and family risk assessment.

Assist women with metastatic breast cancer to access germline genetic testing to determine whether they may benefit from a PARP inhibitor.

THEME 04: CARE

THE STATE OF THE NATION:

TACKLING BREAST CANCER AS PART OF A TEAM

*'I want to be **heard**, and I am treated with empathy, care and respect by health professionals.'*

MULTIDISCIPLINARY CARE

Treatment for breast cancer requires a coordinated approach from a whole team, with the patient at the centre. Access to multidisciplinary care using a team approach with a range of experts is considered gold standard of care. This includes case discussion by a multidisciplinary team to help guide recommendations around treatment decision making. However, not all women are aware of whether this was part of their care.

BCNA's 2017 project exploring multidisciplinary care found that over a quarter of respondents (27 per cent) diagnosed with early breast cancer did not know whether their case had been discussed by a multidisciplinary team. Of respondents with metastatic disease, 31 per cent were unsure if their case had been discussed by a multidisciplinary team when they were first diagnosed with metastatic breast cancer.

“*It would be nice to know if there was a team discussing my treatments. I feel like I'm flying blind with little to no advice or 'options' for treatment. It feels like it's just a 'show up and do as you're told' kind of show.*”

THE CARE TEAM

THE ALL-IMPORTANT BREAST CARE NURSE

The breast care nurse is viewed by women as the pivotal member of the care team, responsible for coordinating care. It is disappointing that 30 per cent of participants did not agree they had as much contact with their breast care nurse as they needed.

Neoadjuvant patients (receiving pre-operative treatment) consistently reported not seeing a breast care nurse until they had completed their chemotherapy. As the attention of a breast care nurse is a critical part of the treatment process, this is challenging for women in the early stages of their treatment.

“*As I had my surgery out of area my breast care nurse was also out of area, the local breast care nurse did not have me on her list.*”

I wish I had a breast care nurse to help explain the process to me before my operation. I was in need of advice.

While breast care nurses are more available in public hospitals and cancer centres, where they are a standard feature of care, access in private hospitals can be inadequate and often only focuses on the surgical pathway, meaning women miss out on support during adjuvant treatment such as chemotherapy and radiotherapy. Member Survey respondents treated in the private health system were less satisfied with the level of contact they had with breast care nurses than respondents treated in the public health system. Twenty per cent of respondents treated in the private health system disagreed or strongly disagreed when asked whether they had as much contact with a breast care nurse as they needed compared to 16 per cent treated in the public health system.

I did my treatment (except radiation) in the private system where there were no breast care nurses or anyone or anything to help with follow-up care.

Gaps in support from a breast care nurses for patients with metastatic breast cancer is discussed in Theme 7.

HAVING A VOICE

Feeling heard and acknowledged by the medical team is something that is very important to people undergoing breast cancer treatment. Eighty-one per cent of respondents agreed that they felt heard in the discussion about their treatment. While this is an encouraging statistic, the fact remains that in 2018 there are people who do not feel heard by their medical team who are therefore less likely to participate fully in treatment decisions and less likely to feel some level of control over their breast cancer journey.

We should be able to change oncologist, but at my treatment centre there's an unofficial policy where you're given the impression that there's little choice.

COORDINATION OF CARE

While all people with breast cancer have to cope with the stressful task of managing multiple medical and related appointments, some are more supported than others. Coordination of care can be particularly challenging for women in regional areas who have to travel further distances for care. Respondents described a range of difficulties, from appointments not being scheduled on the same day to results not being received by other healthcare team members in time for appointments. While 58 per cent of people agreed that they received treatment that took into consideration their lifestyle, this figure dropped slightly for people living in outer regional (53 per cent) and remote or very remote areas (55 per cent). They also identified that if they travelled to cities for treatment, the system of referring them to a local regional nurse for ongoing support did not always work well.

I had surgery, chemo and radiation at three different hospitals – I did not know who was in charge of my care – I felt like I had to be the project manager.

Women living in border towns who may need to travel between states for treatment face additional complexities in care coordination. This includes different systems for travel reimbursement through state-run Patient Transport Assistance Schemes (PTAS). Women in Albury-Wodonga described a lack of public medical oncology services in the region – with most local services operated by private providers.

We need services that acknowledge the distance rural people need to travel to get assistance.

CULTURAL BARRIERS

For women from culturally and linguistically diverse communities, finding the right breast cancer specialist can be difficult, with cultural and language barriers preventing them from receiving optimal care.

Encouragingly, 85 per cent of respondents who speak a language other than English at home agreed that their cultural and/or spiritual beliefs were respected in their treatment. Due to Australia's cultural diversity it is important that cultural barriers are considered by all health services.

An issue facing Aboriginal and Torres Strait Islander women is cultural safety in hospitals, with many reporting that visiting hospital is a distressing experience and not all health professionals are sensitive to their needs.

“Approach of health professionals is too medical, especially in the experience of local Aboriginal women.

“We need open, honest and holistic communication from health professionals, for the whole woman, not just the cancer, and for the whole family as well as the woman.

Some Aboriginal and Torres Strait Islander women reported they are frustrated that the healthcare system forces their care to be delivered by an Aboriginal liaison officer, rather than providing them with the option of seeing a breast care nurse for clinical discussions.

“Language barriers and lack of communication was a big thing for me, feeling like my feelings and emotions were being undermined.

ACCESS TO BEST-PRACTICE CARE

CLINICAL TRIALS

Many people found that they did not have opportunities to talk about clinical trials that might be relevant to them. Without a conversation, there was no opportunity to consider whether there may be a clinical trial that could allow them to access a new and/or better cancer treatment that may otherwise be out of reach. While we tend to think of trials in terms of new drugs, radiotherapy, surgical, physical and emotional wellbeing and allied health trials are also important research studies that women should have an opportunity to participate in. Lack of opportunity to hear about current studies, including those offered at different health services, represents a significant lost opportunity for women to participate in trials and perhaps one factor in Australia's low clinical trial participation rates for people with cancer.

“I was lucky to be involved in a clinical trial for decision making and my reward for being involved was a package of really meaningful data pertaining to my situation.

FASTER ACCESS TO NEW TREATMENTS

One of the expectations that people have of an effective breast cancer care team is that new and innovative treatments will be offered. However, Australia has moved more slowly than many other countries to make some of the most effective therapies affordable. Over its 20 years of advocacy, BCNA has been involved in advocating for a number of new breast cancer treatments, including treatments for HER2-positive disease (Herceptin, Perjeta, Kadcyla and Tykerb) and more recent treatments such as the CDK inhibitors palbociclib (Ibrance) and ribociclib (Kisqali), where Australia has lagged behind other countries in having these drugs subsidised by government.

“The first problem, finding access to palbociclib, I handled myself, with the help of a friend of a friend who knows the pharma world. In the past 12 months my main needs were for information about trials, and how to access palbociclib, which is still not available in Australia.

ADDRESSING THE ISSUES

BCNA IS:

Contributing to the McGrath Foundation review of the breast care nurse treatment pathway to ensure patients receiving neoadjuvant chemotherapy and those with metastatic disease are supported by breast care nurses.

Advocating to government for increased funding for breast care nurses, including metastatic breast care nurses.

Educating people with breast cancer about their rights and what they should expect from their healthcare team, as well as providing a forum for BCNA members to share and discuss their experiences.

Working with regional, culturally linguistically and diverse and Aboriginal and Torres Strait Islander communities to ensure that their concerns are heard and barriers to effective care are minimised.

Educating people with breast cancer about clinical trials, where they can find information about trials available and what they need to do to get involved.

Continuing to campaign for new and innovative drug treatments to be made available more quickly on the Pharmaceutical Benefits Scheme (PBS).

ACTION IS REQUIRED TO:

Incorporate findings from the McGrath Foundation breast care nurse pathway review into clinical practice to ensure adequate coverage and consistent care across the treatment continuum.

Fund more breast care nurses, in line with increases in the incidence of breast cancer.

Fund training for breast care nurses in treatment pathways for people with metastatic breast cancer.

Improve timely access to innovative tests and therapies (drugs and diagnostics).

Extend the Patient Assistance Travel Scheme (PATS) to include travel for clinical trials.

Develop online portals for health professionals and patients to learn which compassionate access schemes are available for drugs not funded through the PBS.

Ensure all women diagnosed with breast cancer are discussed by a multidisciplinary team (MDT) and receive a written copy of the MDT's treatment recommendations.

THEME 05: SUPPORT

THE STATE OF THE NATION:

MANAGING AN EXPERIENCE THAT IS MORE COMPLEX THAN IT SEEMS

'I want to get the social, emotional, financial and practical support that I need during treatment.'

A diagnosis of breast cancer is often devastating. Beyond the diagnosis and the medical response, there is a complex journey to be travelled, which may present many unexpected challenges and issues. Survey respondents pointed to a range of gaps in meeting the social, emotional, financial and practical needs that arise for them on this journey.

FINANCIAL, MEDICAL AND PRACTICAL

TREATMENT SIDE EFFECTS

Changes in sexual function, exercise capability and energy levels are some of the many side effects of treatment that make life difficult for people with breast cancer. Other reported side effects associated with treatment drugs are fatigue, anxiety and depression, cognitive dysfunction (sometimes known as 'chemo brain' or 'brain fog'), early menopause, lymphoedema (fluid retention and tissue swelling) and peripheral neuropathy. Overall, 34 per cent of respondents needed information on fatigue, 28 per cent needed information on anxiety or depression related to cancer and 20 per cent needed information about changes in sexual function and relationships in the past 12 months.

“ *Emotional support for personal relationships. I needed proper follow-up and information. The ability to talk about things that change like how I feel about myself and how I live – like the effect on my body image, effect on my libido and sexuality, feeling really tired and a lack of energy. I also needed support for my partner.*

Lymphoedema was also an area of need. Of those surveyed, 35 per cent of respondents needed information about lymphoedema in the past 12 months. This may include information about how to reduce their risk and how to seek help if symptoms occur.

“ *Having gone private means I am on my own to deal with lymphoedema, which I find very distressing and depressing. The treatment I require is hard to find and very expensive. I find lymphoedema more depressing than cancer.*

The use of compression garments is a key part of the management of breast-cancer-related lymphoedema. Compression garment subsidy schemes are currently run by state and territory governments. The schemes cover some, or all, of the cost of compression garments. For example, under the Victorian Lymphoedema Compression Garment Program, eligible Victorians can purchase up to six compression garments each year and 40 to 60 per cent of the garment cost is subsidised. In the ACT, eligible residents can purchase a limit of two garments per six month period. Under the ACT scheme, 100 per cent of these garment costs are subsidised. It is of great concern that there is no state compression garment subsidy scheme in South Australia.



ALYSIA, WA

A REGIONAL DIAGNOSIS

When I was diagnosed with breast cancer aged 33, I was living on a farm in a small rural community about two hours from Perth. I loved living on the farm – the peace and tranquillity, and feeling part of a caring community.

Soon after my diagnosis my relationship fell apart. I was facing this part of my life as a single mother to my two boys, aged six and 10.

In the initial phase after my diagnosis, I tried to remain living at the farm, and travelled to Perth for appointments. However, the separation from my children was too much to bear. After a double mastectomy and emergency surgery soon after, coupled with

my ex-partner working in another country, I felt there was no other decision but to move to Perth and live with my parents.

I was fortunate to have a place to stay – unable to work, there was absolutely no way I could afford a rental, nor care for myself and my family without help.

Being young, I needed to be around people of similar age and experience for support. The young women's support group I joined was essential to my wellbeing. It was invaluable to walk into a room and feel understood. Services such as the wig library, Solaris Centre, Look Good Feel Better program, and specialised psychology programs were fantastic.

In the year after my diagnosis, I moved out of my parents house and into a rental in the same street. I felt it was impossible to move back to the country – I suffered extreme anxiety and unpredictable panic attacks, and needed to be reassured that health services were nearby.

Small communities are incredibly resilient and cohesive, and are well placed to assist in the healing of their people, provided they are given guidance and opportunity. Targeted support for young, rural women experiencing breast cancer could help alleviate some of the feelings of hopelessness and disconnect.

A person's prognosis should not be influenced by their postcode.

LACK OF FINANCIAL SUPPORT

Breast cancer can be an expensive disease. Twenty-one per cent of respondents needed information on managing the financial costs of breast cancer in the past 12 months.

In 2016, a BCNA survey of almost 2,000 people with breast cancer revealed that while the financial burden of breast cancer varies considerably, many people face significant out-of-pocket costs. This is especially the case for people who have their treatment in the private health system, with one quarter of privately insured women reporting out-of-pocket costs greater than \$21,000 in their first five years after diagnosis. The figure across their lifespan may be much higher. This is a staggering statistic.

“

The high cost of various regular annual tests - pathology, bone density checks and more expensive scans especially MRIs, etc. are also areas that impact heavily on finances.

This research also found that Centrelink sickness benefits are insufficient and leave many people with breast cancer facing financial distress. The process of navigating through Centrelink and claiming the correct payments is often complex and confusing at a time when people are already dealing with the stress of a serious illness.

“

As a single parent this was an extremely trying time. As I am the sole provider for my family this was financially crippling. Centrelink provided Newstart, which didn't come close to covering our rent in a tiny two-bed apartment. Living below the poverty line is hard. Especially when you are sick.

FINDING SERVICES

Many people commented on the difficulty of finding local services that provided practical or social support for people with breast cancer. In total 12 per cent of respondents needed information on receiving practical help around the home from programs and services in the past 12 months. Some reported that it was challenging to find these services at the time they were needed, and frustrating to hear about them later when the need had passed. Centrelink can be an important hub for people with breast cancer, but many say there is no easy pathway or special consideration for people with cancer and no designated support workers who understand the complexities of a cancer diagnosis, including impact on capacity to work.

“

I needed much more support once I got home in the country and much more information about local services that are available.

TRANSPORT

People with breast cancer are on the move – between home and medical professionals, pathology and screening services, allied health services, hospitals and clinical trial locations, as well as travelling to place children in childcare or with family, or visit pharmacists and other suppliers of medicines and therapeutic needs. Twelve per cent of respondents needed information about travel assistance in the past 12 months. For people with metastatic breast cancer, the need was even greater, with nearly one-quarter of respondents (23 per cent) needing information about travel assistance. Transportation continues to be an issue, from car running costs to negotiating the difficult and complex Patient Assistance Travel Scheme (PATS), to the high cost of parking in some hospital car parks.

“

Transport was the biggest problem, as the clinic appointments were from 9.00 am to 11.00 am and as I had a two and a half hour drive that made it hard.

SOCIAL AND EMOTIONAL

EMOTIONAL CHALLENGES

Breast cancer is emotionally challenging from the moment of diagnosis. Fear, sadness and grief can be exacerbated by insensitive treatment, dealing with an overwhelming number of medical professionals and making difficult treatment decisions. While a large majority – 79 per cent of respondents – agreed that they had been treated as a whole person and not just someone with cancer, respondents in the Australian Capital Territory, Northern Territory, and who are living with metastatic disease, were less likely to feel as though they have been treated as a whole person and not just a person with cancer. Anxiety and/or depression are commonly reported by those diagnosed with cancer. Of those reporting a need, about half – 49 per cent – have either all or most of their needs met. This leaves a significant group who only reported some of their needs met, or none met at all.

Consultation participants discussed the strain on partners, families and colleagues, and the struggle to maintain a sense of normality at home and work while undergoing treatment and thinking about a future that looks different to how they imagined it would.

“Taking into consideration the phenomenal work doctors and nurses do every day, I have been surprised that counselling is not a routine part of treatment. The emotional aspect of treatment needs to be addressed. As a younger woman who had a diagnosis, our emotional needs differ from older ladies. Also, we are only briefly informed of sexual changes when in fact changes to our emotional and physical relationships differ significantly.”

FAMILY/PARTNER/CARER SUPPORT

There is not enough recognition of the burden that breast cancer places on families, partners and carers. Relationship strain, marriage breakdown, mental distress, distressed or worried children and exhausted carers are experiences that many deal with. Support for carers is often difficult to access, afford or, for some people, justify while they focus their attention on the person they love who is ill. However, ensuring the wellbeing of those around people with breast cancer has a powerful effect on all aspects of a breast cancer journey, from diagnosis to recovery. Only just over half – 53 per cent – of respondents agreed that they feel the people close to them are supported. This indicates that there is a significant gap in meeting the support needs of people supporting someone with breast cancer.

“I didn't have a partner but had my parents by my side throughout treatment. They were unable to find information/support on how to deal with an adult child with cancer. Could only find information to support partners and children.”

“I would have liked support for my family members to talk to someone freely about it all.”



ADDRESSING THE ISSUES

BCNA IS:

Calling on health service providers to commit to written, full financial disclosure of out-of-pocket expenses prior to tests, treatments and procedures.

Providing information and resources for partners, families and carers.

Providing information and support for people dealing with emotional challenges and treatment side effects.

ACTION IS REQUIRED TO:

Provide cancer liaison officers at Centrelink.

Simplify and standardise state and territory Patient Assisted Travel Schemes (PATS) paperwork.

Ensure health services providers commit to full financial disclosure for breast cancer patients prior to tests, treatments and procedures.

Prevent erosion of access to breast cancer specialists and treatments through the private system by ensuring MBS rebates reflect the realities of care.

Provide subsidised or waived hospital parking for cancer patients.

THEME 06: SURVIV- ING

THE STATE OF THE NATION:
APPRECIATING
THAT
'SURVIVORSHIP'
TAKES CARE
AND PLANNING

'I want to be supported to live well after treatment and helped to manage my side effects.'

After active treatment has finished, people with breast cancer usually describe themselves as changed in some way. They move forward carrying a number of concerns, needs and requirements that are not always fully appreciated as they adapt to a 'new normal'. Best practice is plenty of support, a follow-up care plan and clear recognition of the ways in which they have changed or may change as longer term side effects occur.

However, many people with breast cancer discover that the road to 'survivorship' lacks coordination and is challenging on many fronts.

“ *You are diagnosed, you have treatment ... surgery, maybe chemo, maybe radiotherapy. Then the doctors say your treatment is finished ... but if your cancer is hormone receptor positive it is very confusing when they say treatment is finished, cause they then go on to prescribe ten years of endocrine therapy. So is this treatment or not treatment?*

EARLY EXPERIENCES

BREAST RECONSTRUCTION

The *Cancer Australia Statement Influencing best practice in breast cancer* emphasises that all women recommended for a mastectomy should be offered the opportunity to discuss options for breast reconstruction prior to surgery.¹⁶ However, our research shows that many women are not being offered this option as part of standard care. Twenty-one per cent of respondents needed information about breast reconstruction in the past 12 months. Of these respondents, 13 per cent said none of their needs had been met. Research has found that Australia's breast reconstruction rates are among the lowest recorded in developed countries.

Lack of access to both immediate and delayed breast reconstruction in the public health system is a widespread concern for women, particularly for those living in Queensland.

Of great concern to BCNA are the excessive delays in reconstructive surgery for women in Far North Queensland, where some women have been waiting for many years for breast reconstruction surgery. The despairing stories of women who feel disfigured by mastectomy surgery who are waiting for five years and longer for reconstruction highlights significant flaws in service provision and referral pathways, particularly affecting regional and remote areas. It is insufficient to blame geographical distance from specialist services as a reason why women cannot be referred for surgery to metropolitan hospitals. More must be done to

recognise that the option of reconstruction surgery is a vital aspect of breast cancer care and should not be restricted to those living close to specialist cancer centres.

“ I am disappointed that I have now been on a waiting list for six years for breast reconstruction and have not had any contact whatsoever by anyone. So I guess I just keep waiting - maybe one day I will be put back together.

There are also many issues related to reconstruction surgery in the private system. High out-of-pocket costs for women requiring breast reconstruction in the private system was reported as a financial burden for many with some women reporting excessive fees and limited opportunities to seek a second opinion.

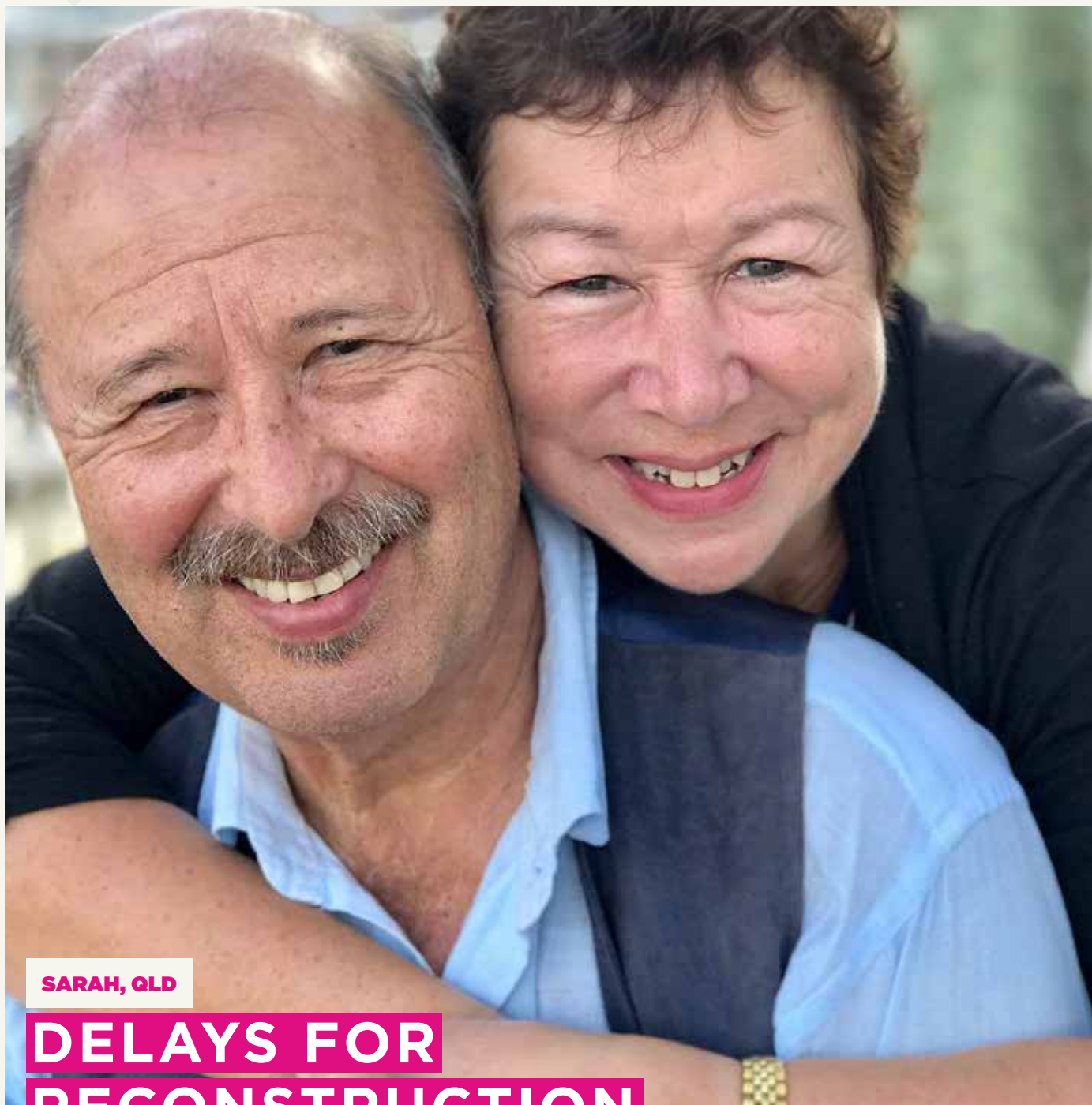
“ My quote for a bilateral mastectomy with a reconstruction is \$26,000 out-of-pocket. This does not include the anaesthetist fees. I was 38 when diagnosed and I'm 39 now. While I know I could go without reconstruction at my age I can't face that option. I don't want a daily reminder of this nightmare for 40-50 years!

Others described their shock at learning that their private health insurance provider deemed their reconstruction surgery to be cosmetic, refusing to cover the costs. This is unacceptable - reconstruction surgery after mastectomy is not cosmetic and women should not have to fight their providers, to whom they have often paid years of premiums, to claim the cost of their private hospital admission.

“ We need to lobby government to address the huge expense many breast cancer survivors bear through breast reconstruction as a direct result of a breast cancer diagnosis. This is not elective surgery, it is life-saving surgery. We wouldn't have such surgery if we weren't diagnosed with cancer. This huge (financial) cost is outrageous and offensive.



State of the Nation consultation in Port Lincoln



SARAH, QLD

DELAYS FOR RECONSTRUCTION SURGERY

I was living in Brisbane when I was diagnosed with early breast cancer in 2010 at the age of 51. I had a mastectomy, chemo and radiotherapy. My GP suggested the possibility of breast reconstruction in April 2011.

It took 18 months to get an outpatient appointment. At my second appointment I decided reconstruction was the right choice for me, and was placed on the waiting list as a non-urgent patient.

Twelve months later I got called up to the pre-admissions clinic. I had all of my pre-operative preparation done, thinking my surgery was imminent. And then ... nothing happened!

I finally had my reconstruction in December 2014 – more than three years since my GP had sent my referral.

Reconstruction should be offered as part of the standard treatment plan, and be available to all women.

It's not fair that in other parts of Australia, women can have their reconstructions done within a year, rather than wait for three years (or longer) like so many Queensland women have to.

FOLLOW-UP CARE PLANS

This was a contentious subject for most people surveyed or interviewed. Almost one in five people - 19 per cent - disagreed or strongly disagreed that they were provided with a long-term follow-up care plan after finishing treatment. People who were the least likely to have been provided with a follow-up care plan were aged under 50 and lived in South Australia, Queensland or Western Australia.

Of those who had received this critically important plan, many noted that it contained nothing more than check-up appointment dates for their medical oncologist and surgeon. If information was provided, it was often inconsistent with advice and information they had already received. In addition, the advent of super-clinics with large groups of GPs was identified as a barrier to people sharing their follow-up plans with a GP, since they were less likely to see one doctor regularly.

“Very little follow-up care was provided. Once chemo was finished and I returned to work I felt like I was cut adrift and left to fend for myself.”

HEALTH NEEDS

ALLIED HEALTH SERVICES

The need for allied health services for those with breast cancer is not always adequately provided or recognised. Funding for allied health services for out-patients is inadequate outside of specialist cancer centres. Not all women diagnosed with breast cancer are advised that a GP Chronic Disease Management Plan can assist them to access allied health services through Medicare. Those who do have a Chronic Disease Management Plan report inadequacies around the plan restricting them to five Medicare rebatable allied health visits per year. Newly diagnosed women may require five visits in the first month alone.

Once women move into the survivorship phase, these services become even more difficult to access or find, and don't always appear in follow-up care plans. Long-term treatment side effects such as lymphoedema management, sexual dysfunction, anxiety and depression, require ongoing and regular visits to allied health specialists who are an essential, yet often unfunded component of follow-up care.

“Post-surgery I needed physio to correct cording under my arm. My GP put me on a care plan where I have been able to access a physio and also an exercise physiologist on Medicare (which I would not have been able to afford otherwise) to help correct the start of osteoporosis from my drug treatment. It would be helpful to know how I can continue to pay for these visits long term.”

New research also tells us that increasing exercise and maintaining a healthy weight after breast cancer may reduce the risk of a breast cancer recurrence.¹⁷ However, many women are unsure how to start an effective and personalised diet and exercise program. As these services are an outpatient activity and may attract significant out-of-pocket expenses, many women are unable to afford the expertise of an exercise physiologist or dietitian who could assist them to adopt risk-reducing behaviours that would benefit their overall health and wellbeing.

“I needed an exercise regimen provided by a cancer exercise physiologist to help get me started on a plan that could work for me.”

LONG-TERM SIDE EFFECTS

Lymphoedema is a side effect which can occur as a result of some breast cancer treatments and is a life-long condition. Lymphoedema was the top information need identified in this report closely followed by fatigue. Approximately one-third of respondents (35 per cent) needed information related to lymphoedema and a similar proportion (34 per cent) needed information on managing fatigue. These statistics show that more needs to be done to educate women around lymphoedema to address fears and concerns and to also help those who do go on to develop lymphoedema.

Research shows that around 20 per cent of all breast cancer patients will develop lymphoedema.¹⁸ Public health options for assessment and management of lymphoedema are limited and vary between states. Services in states such as Victoria and New South Wales have reduced over time. This can dramatically increase waiting times for treatment. The cost of treatment by private physicians, exacerbated by inadequate or no Medicare rebates, has created a significant barrier to ongoing treatment. The absence

of a Medicare rebate for compression garments necessary to help manage this condition means women must rely on state-run programs which are inconsistent and often do not cover the costs of made to measure garments, including sleeves and gloves which need regular replacement over a woman's lifetime.

Other long-term side effects are also often under-resourced and under-supported, including early menopause and sexual side effects of treatment.

I struggled with the early menopause (without children) and my sexual changes. I was referred by a breast care nurse to a counsellor who was terrible, which put me off seeking any more help.

Get vaginal atrophy products and treatments such as the Mona Lisa touch laser therapy funded by Medicare. Our sex lives are even more important after breast cancer!

RISK SURVEILLANCE

Some women in the consultations said that they are shocked by what they feel is a low level of surveillance following breast cancer treatment, including testing for the recurrence of breast cancer or the appearance of metastatic breast cancer. It appears there is a need to better communicate the research around why additional tests and body scans do not improve outcomes for women who are asymptomatic for metastatic breast cancer. Women also commented that it was 'unbelievable' and discriminatory that they could access a free mammogram through BreastScreen prior to diagnosis, but that free screening mammograms are not routinely available to them during follow-up care.

On my last mammogram I was told how much it would be, for one side only. Then told if I need further scans it would cost extra. Is that okay? No it's not okay. I don't have hundreds of dollars to spend every time I do this. I felt like saying I'll just walk away and hope I don't have more cancer, \$400 later.

I don't understand why blood tests and scans are not compulsory. Isn't that important to find new cancers?

LIVING WELL

PEER SUPPORT AND CONNECTION

Survey data showed that 64 per cent of respondents felt that they had opportunities to hear about the experiences of others who had been through a similar experience. However, people living with metastatic breast cancer, those living in remote or very remote areas, women in same-sex relationships and those who were under 50 reported fewer opportunities for peer support and connection. This reflects the isolation of some groups of survivors.

I felt my breast care nurse was judgemental, and the lymphoedema therapist was very unhelpful and unprofessional, I did not feel she really helped me with the things I needed help with. I would have liked to have been given access to alternative narratives, instead of just the 'pink' ones, but instead I had to find these for myself, which was frustrating and tiring, when I was already tired enough. I felt very alone because I didn't feel represented.



State of the Nation consultation Hobart

ADDRESSING THE ISSUES

BCNA IS:

Working with the Queensland Government on behalf of the women of Far North Queensland to address delays in access to breast reconstructive surgery.

Undertaking a project to further explore the breast reconstruction experiences of BCNA members Australia-wide, with the aim of improving access to this surgery for all women who are recommended or choose mastectomy.

Advocating to the Federal Government to ensure any changes to levels of private health insurance do not impact on women's capacity to have breast reconstruction in the private system.

Advocating to private health providers to not deem breast reconstruction surgery, including symmetry surgery, to be cosmetic.

Working with Cancer Australia and health professionals to advise on and address shortcomings in follow-up care planning.

Calling for improved state and territory government funding for lymphoedema education and management.

Advocating for the extension of the Medicare rebate for cancer patients under the Chronic Disease Management Plan to be increased from five to 10 sessions per year.

Providing extensive opportunities for breast cancer survivors to connect with and support each other through the BCNA Online Network, face-to-face community forums and other channels.

ACTION IS REQUIRED TO:

Resolve long waiting times for access to breast reconstruction in Queensland and other states and territories.

Improve access to breast reconstruction surgery for all women who choose mastectomy.

Increase health industry and government focus on follow-up care pathways and plans.

Fund early menopause clinics for survivors of breast and other cancers.

Provide funding for research into new programs to target and mitigate long-term side effects.

Lift the level of state and territory government funding for lymphoedema services in all states, particularly Victoria, New South Wales and Queensland.

Establish specialist lymphoedema clinics in all metropolitan and regional cancer centres and fund a National Lymphoedema Compression Garment Scheme.

Double the Chronic Disease Management Plan provisions for allied health services, including lymphoedema management.

THEME 07: LIVING WITH META- STATIC BREAST CANCER

THE STATE OF THE NATION:

MBC PATIENTS FEEL MISUNDERSTOOD AND UNDER- INFORMED

*'I need to
be supported
towards the
end of my
life to have
a good death.'*

Metastatic breast cancer, or breast cancer which has spread from the breast to more distant parts of the body (bones, liver, lungs, brain), is one of the most challenging diagnoses to receive. Although people with metastatic breast cancer are now living longer, the combined burden of continuing ill health and the awareness that metastatic disease will eventually claim their lives is a heavy one. It is exacerbated by the lack of community understanding of metastatic breast cancer and what it means for those who live with the diagnosis. Gaps in information and services that are frustrating for people with early breast cancer can seem overwhelming to people with metastatic disease.

On nearly every measure, the State of the Nation research reveals gaps and insufficiencies that make living with metastatic breast cancer even more difficult than it has to be. The lives of those with metastatic breast cancer are often shaped by the need for support, information and access to treatment. Our members report significant frustration and disappointment about the gaps that exist in meeting those needs.

TREATMENT GAPS

FASTER ACCESS TO NEW THERAPIES

The most important requirement for people with metastatic breast cancer is access to new and innovative therapies that have been shown to slow down the progress of their disease and improve their quality of life as well as their length of life. As discussed elsewhere in this report, Australia often lags behind other countries in making new drugs affordable by listing them on the Pharmaceutical Benefits Scheme (PBS). While overall survival remains the gold standard, progression-free survival (the time before the cancer progresses) is vital to people living with metastatic disease and needs to be considered in Pharmaceutical Benefits Advisory Committee (PBAC) decision making.

The long-running campaign to have the CDK inhibitors listed has now resulted in Kisquali (ribociclib) being publicly subsidised for use as a first-line therapy in treating metastatic breast cancer. This is wonderful news and means no newly diagnosed woman who could benefit from a CDK inhibitor will have to face the huge financial burden of paying upwards of \$5,000 per month. However, women who have already had treatment for metastatic breast cancer will continue to miss out on access to a CDK inhibitor unless the pharmaceutical companies apply for approval for second-line therapy or extend their access schemes to offer the drugs to women on compassionate grounds. This is often a heartbreaking and uncertain process for women who grapple with decision making around whether to pay for a treatment not otherwise available to them. While they feel comforted that those coming after them may benefit from

new treatments as clinical trial data matures, for those diagnosed now, delays in adding new drugs to the PBS are a bitter pill to swallow.

“ I needed support regarding anxiety (financial stress) related to paying for drugs not available on the PBS.

BREAST CARE NURSES AND CANCER COORDINATORS

A multi disciplinary care team led by a single coordinator - a ‘patient navigator’ - is important for all people with breast cancer. However, the model is not always successfully applied. For people with metastatic breast cancer, this is even more important, as they are often overwhelmed with difficult decisions about complex treatment options.

Despite the complexity of treatment and the lifelong involvement with the treatment team, women report that they commonly receive less support once they are diagnosed with metastatic breast cancer than they did with their initial diagnosis of early breast cancer. Twenty-nine per cent of people with metastatic breast cancer said that they did not have as much contact with a breast care nurse as they needed. Sixteen per cent of people with metastatic breast cancer said that access to a breast care nurse was one of their main unmet needs compared with only 4 per cent of women diagnosed with early breast cancer. Unless they are treated through a specialist cancer centre, many will not receive support from a specialist breast care nurse or cancer care coordinator.

For those with de novo disease (where the first diagnosis of breast cancer is metastatic) who may have limited understanding of the healthcare system and how to navigate through it, the first time they hear about a breast care nurse is often through their peers when they attend community forums or participate in online discussions. Even then they often struggle to understand how they can access the support of a specialist nurse.

“ I have metastatic breast cancer and have never met a breast care nurse, maybe because I am in the private system.

INFORMATION GAPS

CLINICAL TRIALS

Elsewhere in this report we have discussed the importance of clinical trials. Clinical trials are particularly important to people with metastatic breast cancer to test innovative therapies that might extend or improve their lives. It is disappointing that only 38 per cent of those surveyed with metastatic breast cancer (150 women) in our Member Survey said they had been given an opportunity to discuss participating in a clinical trial. This adds pressure on women who have to try to navigate through the minefield of finding out about compassionate access schemes for new drugs recommended to them or consider paying the high cost of purchasing them privately.

“ I had nothing to lose and a lifetime to gain. Being on a clinical trial meant I had access to leading-edge treatments.

PALLIATIVE CARE

Statistics show that Australians who die of breast cancer use palliative care at a very low rate.¹⁹ However, people with metastatic breast cancer have an obvious need for care that will support them to have ‘a good death’. The survey reveals that the nature and benefits of palliative care are not well understood. Thirty-nine per cent of respondents with metastatic breast cancer said they had not been informed that palliative care could support them at any time, rather than just at the end of their lives. Considering recent research findings that palliative care can extend life for people living with lung cancer,²⁰ this is of particular concern.

“ I am still confused about palliative care and the role it can play in my care.



CLAIRE, QLD

NOT ENOUGH SUPPORT FOR PEOPLE WITH METASTATIC BREAST CANCER

When I was first diagnosed with early breast cancer, the services were great – parking vouchers, money towards a wig and my electricity bill, and a breast care nurse to help me navigate cancer.

But when I was diagnosed with metastatic breast cancer at 48, my world fell apart. The support just wasn't there. There was no contact with a breast care nurse to be my source of information as I was processing this diagnosis and its implications. It was a confusing and scary time.

I saw the palliative care team, which was really confronting. It made me think, 'Am I dying?' – I didn't realise that palliative care can actually be helpful at all stages of metastatic breast cancer.

Financially, the support is just not there, even though my needs are greater. There's no money to cover parking costs and time off work, even though I have to go to hospital every three weeks. I had chemo and lost my hair for a second time, but there was no money for a wig this time.

My oncologist looks after me, but otherwise I feel on my own. I found dragon boating, which is fabulous for exercise and support from other women, and I heard about a service through the hospital in Brisbane, where someone interviews you and captures memories for your children. These are great things, but I had to be proactive and find them myself, at a time when I was feeling so vulnerable, and learning to live with an awful diagnosis.

Women with metastatic breast cancer desperately need extra support. I would love to have a breast care nurse to help me through, but it hasn't happened.

AWARENESS OF METASTATIC BREAST CANCER

Metastatic breast cancer continues to be poorly understood within the community. With breast cancer survival rates now at 90 per cent, often people do not understand that people still die from breast cancer despite the advances. While metastatic breast cancer is still considered an incurable disease, new understanding of breast cancer biology and new targeted treatments have meant that, for some people, metastatic breast cancer can be treated more like a chronic disease, with cyclic periods of wellness and illness.

Regardless of how well people respond to treatment the reality is that treatment will continue until the end of a person's life. As a result, people living with metastatic breast cancer experience uncertainty about their prognosis, difficulty in communicating it to others, discrimination in the workplace and limited access to supportive care services and programs that can meet their needs.

“ *This is no longer a personal battle! It's one that now affects families and communities because more and more people living with cancer are chronic, not dying. Our society needs to acknowledge this phenomenon, and start a conversation. Technology is keeping us alive and well, so the challenge is how to keep us involved and connected and not a drain on society.*

GAPS IN SUPPORT

AT HOME

Metastatic breast cancer places enormous pressure on partners and families. They must not only deal with their feelings about their loved one's declining health and eventual death, but also carry a heavy burden of practical, emotional and sometimes financial care for the affected person. As people with metastatic breast cancer live longer, new challenges are emerging, including ongoing side effects for the person with cancer, exhaustion of financial resources, and carers needing to look after their own emotional and physical health over a long period of supporting the person they love. People who are on their own require carer support, and people with very young children often need childcare support. Nearly one-quarter (23 per cent) of people with metastatic breast cancer felt those close to them did not receive the support they needed. In research consultations for this report, people with metastatic breast cancer expressed their strong concerns about getting sufficient support for those who support them.

“ *My husband and son are very helpful but they do not access any services for themselves.*

IN THE WORKPLACE

People with metastatic breast cancer identified gaps in getting the information they need to navigate their workplaces and working lives. Of those who needed information about work, 43 per cent of respondents said that none of their needs were met. This indicates that people with metastatic breast cancer face difficulties with work due to their diagnosis. This may include discrimination or stigma in the workplace. Feedback to BCNA indicates that many people with metastatic disease want and need to work, but find it difficult to assert their rights in the workplace. They also report needing to work flexibly during periods where their health needs are greater. However, this is not always possible because their disease is poorly understood.

“ *I have advanced breast cancer, therefore I have a chronic condition which is not going away. That is what my employer grappled with. I could no longer work full-time. It was this reality that was a game changer with me and my employer. This is when relationship and communication problems with my employer became a big issue.*

ADDRESSING THE ISSUES

WHAT BCNA IS DOING:

Joining the international advocacy efforts of the Advanced Breast Cancer Global Alliance to call for improving and extending the lives of women and men living with advanced breast cancer in all countries worldwide and fighting for a cure.

Continuing to advocate for new drugs to be added to the PBS in a timely manner.

Continuing to advocate about the importance of progression-free survival and quality of life - not just length of life - in PBS decision-making.

Advocating to government for increased funding for metastatic breast care nurses.

Educating people with metastatic breast cancer about their rights and what they should expect from their care team, as well as providing forums for BCNA members to share and discuss their experiences of their healthcare teams.

Educating people with metastatic breast cancer about clinical trials and how they can decide whether a clinical trial might be a good option for them.

Working with Palliative Care Australia to demystify palliative care and reduce the fear many women feel about what take-up of palliative care services says about their life expectancy.

Distributing the *Hope & Hurdles* information pack to people with metastatic breast cancer.

Providing information for carers, employers and others about the realities of living with metastatic breast cancer and ways to provide support.

ACTION IS REQUIRED TO:

Improve data collection on the incidence, treatment and experience of metastatic breast cancer.

Improve timely access to innovative tests and therapies (diagnostics and drugs).

Develop portals for health professionals and patients that provide details of access schemes for new drug therapies not yet available on the PBS.

Fund training for breast care nurses in treatment pathways for people with metastatic breast cancer.

Commit to funding for metastatic breast care nurses positions in all major metropolitan and regional cancer centres.

Investigate a more effective and sensitive pathway to palliative care for people with metastatic breast cancer.

Improve funding of palliative care for metastatic cancer patients to ensure adequate access to services, including for symptom management support not just end of life care.

Fund an initiative to educate nursing, allied health professionals and primary healthcare providers working with metastatic cancer patients.

Review adequacy of carer supports available for people supporting others with metastatic breast cancer.

Provide cancer liaison officers at Centrelink.

CONCLUSION

WHEN LYN
SWINBURNE
FOUNDED BCNA
HER VISION WAS
FOR NO ONE
TO FEEL ALONE
THROUGH THEIR
EXPERIENCE OF
BREAST CANCER.
IN 2018 THAT
VISION STILL
REMAINS.



RAFFAELLA, VIC

GREAT PRACTICAL SUPPORT FROM COMMUNITY

I was concerned about money when I was diagnosed with breast cancer. I was 57 and living alone in Melbourne. My two adult sons were living overseas. My mum was in Israel with my sister, who was dying of thyroid cancer.

My specialist explained my options for treatment in the public and private systems and offered to see me as a public patient, which really helped ease my money worries.

I was put in touch with community groups, Jewish charities and the local council. They helped me with many of my practical and financial difficulties – travel to and from the hospital, groceries, rent, and cleaning the house. It was also great to have the support of peers who knew what I was going through so I felt less alone.

I had a really great team of people around me through my breast cancer journey. My breast care nurse was my saviour. She really knew what she

was talking about and explained everything that was going to happen. She listened too and connected me with community supports.

I was put in touch with people in my community who had been through breast cancer. Friends would visit me, take me out for walks and stay with me when I was having night terrors.

Volunteers even sat with me while I was having chemo. Some of them were cancer survivors themselves, which was great, as I sometimes didn't want my friends to see me that way.

Seeing a psychologist through the hospital made a big difference too, especially when my older sister passed away while I was facing my own treatment.

Having these sorts of supportive care services makes me feel like I matter to someone, and that's a great feeling.

This report shines a light on the experience of people living with breast cancer in Australia today.

We are a very fortunate country in so many ways, and the dramatic improvement in survival rates for breast cancer is just one indicator of the quality of our health system. The people whose voices fill this report are facing one of life's biggest challenges, as they deal with the experience of breast cancer and potentially face their own mortality. Yet they too recognise that they are fortunate to live in Australia today and that they have a much improved chance of surviving and living well after breast cancer than in the past.

In recent years, there have begun to be voices questioning why we continue to focus so strongly on breast cancer, given the improved outcomes for the disease and the poorer outcomes of some rarer cancers. Statistically, there is a simple answer - while survival rates have increased, more women than ever are being diagnosed with breast cancer. One in eight Australian women will be diagnosed with breast cancer in their life time yet more than 3,000 still die every year. Breast cancer was the fourth-highest cause of cancer deaths in 2017, and the second most likely cause of cancer death in Australian women.²¹

But statistics do not tell the whole story. The voices in this report tell a more compelling story of why we must not only continue to do all that we can to eradicate breast cancer, but also to address the impact of breast cancer on the lives of Australian women, men, families, friends and community. In celebrating the improved outcomes for people with breast cancer, we can't lose sight of the gaps in care this report highlights:

METASTATIC BREAST CANCER

The incurable diagnosis of metastatic breast cancer, which will eventually lead to death and generally requires years of physical, financial and emotional support, including palliative care. People with metastatic breast cancer will continue to be a major focus for BCNA as we seek to address gaps in individualised care, data collection, provision of clinical trial opportunities and access to new therapies and government services. Around 5-10 per cent of people diagnosed with breast cancer will be diagnosed with metastatic breast cancer,²² yet our research shows they are often given less access to a whole range of supports compared to people with early breast cancer.

BREAST CARE NURSES

The continuing and growing problem of insufficient breast care nurses and cancer care coordinators, which undermines the quality of care that people with breast cancer can receive from their care teams. The coordination role played by breast care nurses is critical to the outcomes of medical care, access to support services of all kinds, stress reduction and quality of life for people with breast cancer.

ACCESS TO CARE

The sobering fact that living away from a metropolitan centre is associated with poorer survival outcomes following a breast cancer diagnosis.²³ Listening to the voices in this *State of the Nation* report, you hear some of the reasons - from Aboriginal and Torres Strait Islander people struggling with cultural barriers, to difficulties accessing medical services locally or affording the cost of transport to the cities where those services are available.

COST

The impact of the financial cost of breast cancer, the expense of treatments, tests and drugs, travel costs, and essential allied health services not covered by Medicare to mitigate debilitating symptoms such as lymphoedema. There is a need for extra investment in childcare, carer support and other supports for people and their families already struggling with the experience of breast cancer. Combined with the impact of breast cancer on people's ability to earn a living, this is an overwhelming situation for many of the people who spoke to us for this report.

These experiences exist alongside a whole range of other issues people with breast cancer face. Some are big and some are small, but they all add up to a serious threat to the wellbeing of any person. Many of these issues will change people's lives forever, regardless of whether they survive breast cancer or are trying to live as well as possible with the life-threatening diagnosis of metastatic breast cancer.

BCNA will continue to work on two fronts to address these issues.

Our work with our members will continue to be fundamental. We will continue to seek the support of our funders, donors and sponsors to enable us to work with and for our members to address issues, provide information and support, and empower people with the tools they need to help them support each other.

At the same time, we will continue to advocate strongly for people with breast cancer. We will be taking the recommendations of this report to governments at both state and federal levels, health insurance providers, health professionals, cancer treatment centres, community groups and service providers of all kinds who can drive change on the issues we have identified. We will engage with experts and breast cancer peer groups globally to bring new information and ideas back to the table for decision makers to consider.

As we at BCNA move into our third decade, we recognise that now, more than ever, our work is needed to guarantee that the voices of people with breast cancer are heard. We will draw on the strength of our membership to ensure their voices are heard and acted on. Breast cancer is not 'off the table', cured or adequately provided for. Breast cancer is a part of life for more people than ever in Australia. There is much to do to help them on this journey.

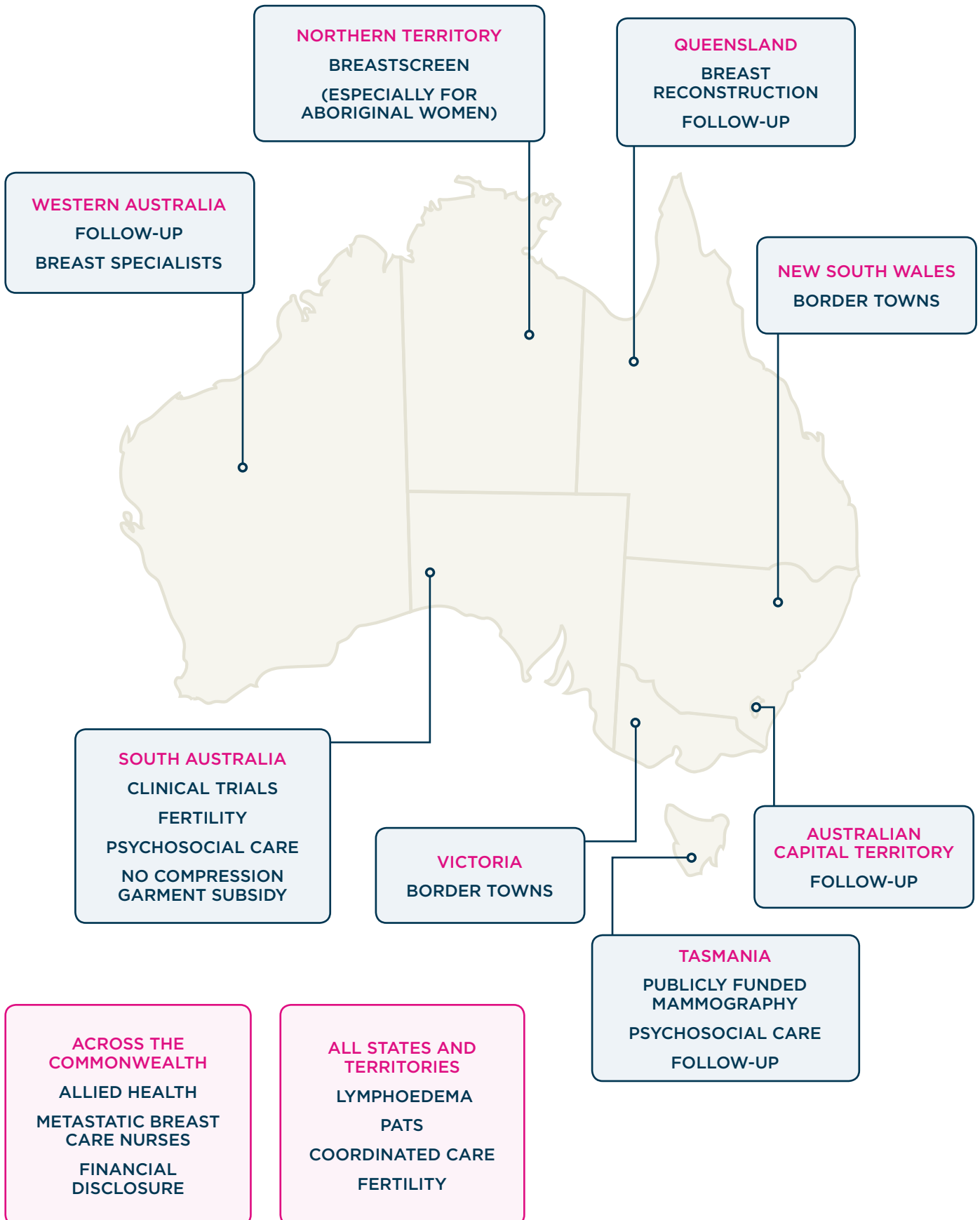


State of the Nation consultation Canberra



State of the Nation consultation Mildura

STATE BY STATE ISSUES



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