Breast Cancer Foundation NZ

"I'm still here"

Insights into living – and dying – with Advanced Breast Cancer in New Zealand

Executive Summary









September 2018

Towards zero deaths: Education, research and support.

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Foreword

This year, about 300 New Zealanders will be told they have advanced breast cancer (ABC) – also called secondary, or Stage Four, or metastatic breast cancer. Breast cancer that has spread to another part of the body and is incurable.

Most of those 300 people – mainly women, but also a few men – will do everything in their power to stay alive, to stay with their families for as long as possible.

They'll become part of the constantly changing population of Kiwis living with ABC. Their struggle will take place out of the spotlight that celebrates the "success stories" of early breast cancer survival. Many of them will end up feeling unseen, forgotten, isolated. They'll feel that the health system has turned its back on them.

That's because the system focuses on cure. The Ministry of Health measures DHB performance and tracks treatment outcomes only for people diagnosed with early breast cancer (and the small percentage who have ABC at initial diagnosis). Those who can't be cured simply aren't counted.

So while each individual patient is known and cared for by her medical team, there's been an enormous gap in our collective knowledge of people with ABC.

Until now.

This report offers the first cohesive picture of the state of advanced breast cancer in New Zealand. It is the output of three studies commissioned by Breast Cancer Foundation NZ: a qualitative online panel study of medical staff treating advanced breast cancer patients; a quantitative email-based survey of people living with ABC; and the first comprehensive statistical analysis of ABC data from the Breast Cancer Foundation National Register.

We wanted to know, what kind of breast cancer do people with ABC have, and how soon after their early diagnosis did it spread? What treatments do they get, and how long do they survive with ABC? Does it make a difference if you're Maori, or if you're older or younger? Is survival improving?

We also wanted to know about the quality of life people have with ABC, and what makes it better or worse. How do our medical professionals feel about the range of treatments they can offer, and how do they handle the difficult conversations necessary in terminal disease?

How well is New Zealand doing compared with other countries? And how can we, as a caring nation, do better?

The answers to our questions surprised and disturbed us. New Zealanders with ABC die faster than people in comparable countries. Often much faster. Maori five-year survival is abysmal.

Many patients feel under-informed about treatments and uninvolved in decisions. For a variety of reasons, they may end up having fewer treatments than people overseas. They find it hard to talk with their doctors about the things that matter most to them: clinical trials, unfunded treatments and complementary therapies.

ABC patients struggle to manage their symptoms, reducing their quality of life and potentially shortening their survival. Sadly, because there's no hope of cure, they are pushed to the back of the queue when resources are stretched.

What can we do about it?

Knowing the true picture, revealed by this report, is the first step towards doing better in ABC. Next, we need a change in attitude that says ***New Zealanders with ABC are worth it*** – worth our best and most assertive treatments, worth the coordinated, multidisciplinary care that has achieved so much in early breast cancer.

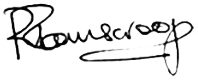
We need to examine where and when we might be giving up too easily, and how to shift the conversation to an emphasis on long-term survival, as it is overseas. We need to look at inequalities and act fast to eliminate them. And, yes, we need new drugs and wider access to existing drugs. But as our recommendations show, there are plenty of things we can do that don't cost the earth and that will make a real difference.

The title of this report – "I'm still here" – came from a conversation with Tamara Malone, a mother-of-five diagnosed with ABC in her late thirties. She told us how vastly different her experience as an ABC patient was from her first diagnosis of breast cancer; how she felt the health system had given up on her, long before she'd given up on herself.

Sadly, Tamara is not "still here" – she died in January 2018, aged 41. But her words, her feelings, are echoed by hundreds of other New Zealanders. It's time to listen, and time to change. To all those with ABC, our message is: ***You are still here, and we are here with you.***

Adèle Gautier
Research Manager
Breast Cancer Foundation NZ

Evangelia Henderson
Chief Executive
Breast Cancer Foundation NZ



Dr Reena Ramsaroop
Chair, Medical Advisory Committee
Breast Cancer Foundation NZ

1 Executive Summary

1.1 Purpose and scope of this study

Breast Cancer Foundation NZ initiated this study to address the severe deficit of information about advanced breast cancer (ABC) incidence, treatment and survival in New Zealand, which is in marked contrast to the comprehensive data available for early breast cancer.

Such information is of potential use in many areas:

- Identifying inequalities between early and advanced breast cancer care pathways, and ethnic and regional inequalities in ABC care and outcomes.
- Providing quantitative insight into ABC for use by scientific and clinical researchers, DHB planners and the Ministry of Health.
- As the quality and quantity of ABC data increases in other countries, enabling benchmarking against international practice and performance.
- Informing clinicians about patient priorities and concerns.
- Equipping patients to have more productive conversations with their medical teams.
- Informing NGOs' advocacy programmes and service provision.
- Providing a baseline for future measures of ABC care, outcomes, and patient experience.

The key questions covered by the study are:

- How many people are living with advanced breast cancer in NZ, how soon after their initial diagnosis did they relapse, and how long do they survive? What impact do tumour pathology (stage, grade, subtype) and patient demographics (age, ethnicity) have on relapse and survival? How is survival changing?
- How is advanced disease diagnosed? How many lines of treatment do patients receive, and what variations exist between regions?
- How do patients feel about their treatment and their lives? What helps, and what makes things worse?
- What about the doctors and nurses who treat them? Do they have the resources to do their best for their patients?
- Are we able to provide world-class treatment? How do New Zealand's treatment pathways and survival compare with other OECD countries?
- How can we do better?

There are two kinds of advanced breast cancer: locally advanced, which can be treated successfully, and metastatic, which is incurable. This report is about metastatic breast cancer; none of the findings or comments refer to locally advanced disease.

1.2 Methodology

This report focuses on advanced breast cancer, also called metastatic, stage four or secondary breast cancer, meaning cancer that has spread beyond the breast and lymph nodes and is incurable. The report combines input from three studies commissioned by Breast Cancer Foundation NZ (BCFNZ): a qualitative online panel study of doctors and nurses treating advanced breast cancer patients[1], conducted by Ipsos; a quantitative email-based study of patients living with advanced breast cancer[2], also by Ipsos; and a statistical analysis of data held in the Breast Cancer Foundation National Register[3].

In the qualitative study, twenty-four healthcare professionals – medical and radiation oncologists, palliative care specialists and breast cancer or oncology nurses – from around New Zealand participated in a secure online discussion over the course of ten days. The discussion focused on the challenges in treating ABC patients, gaps in treatment options, "hot topics" such as clinical trials, complementary therapies and treating oligometastases, adherence to treatment guidelines, and access to palliative care.

For the quantitative study, 102 people with ABC participated in an online survey. BCFNZ, Breast Cancer Aotearoa Coalition / Metavivors and other patient support groups shared the survey invitation through their Facebook pages and by email to group members. The aim was to understand patient perception of ABC diagnosis and treatment options, symptom management, financial impact of their disease, and quality of life.

The analysis of the Breast Cancer Foundation National Register focused on patients diagnosed with metastatic breast cancer between 2000 and 2015, across the four regions (Auckland, Waikato, Wellington and Christchurch), representing nine DHBs, that report to the Breast Cancer Foundation National Register. Currently, these regions represent around 70% of breast cancer diagnoses annually. The data analysis was performed by the Department of Statistics at the University of Auckland.

1.3 Limitations

People with advanced breast cancer were recruited into the quantitative survey through cancer support groups, as this was the most effective way to reach this audience. Their involvement with support groups means that they may be more informed and engaged than those who are not accessing this support. In addition, people who are less tech-literate or who have less access to the internet may not have participated, which could in particular have excluded some older people or those in higher deprivation quintiles.

The clinician report is purely qualitative and cannot be said to be a statistical representation of the views of breast cancer clinicians in New Zealand. However, it does identify issues that are top-of-mind for some clinicians and gives a range of perspectives on those issues.

The *Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018* is an analysis of data from the Auckland, Waikato, Wellington and Christchurch regions, and includes patients from nine of NZ's 20 District Health

1 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos
2 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos
3 Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018

Boards. While the data is not technically national (this will change as the Register expands in years to come), the Register currently collects data relating to 70% of New Zealand's breast cancer diagnoses, giving a statistically robust insight into New Zealand breast cancer treatment and outcomes.

The Christchurch and Wellington registers are newer than Auckland and Waikato, having started in 2009 and 2010 respectively. Data from these registers is not mature enough to use in survival and metastasis-free interval measures, so those measures are based on the longer term data held in Auckland and Waikato. In the next few years, Christchurch and Wellington will be able to make a meaningful contribution to the full spectrum of insights in to ABC in New Zealand. Data collection in the Auckland register lags behind the other regions; we have indicated the sections in this document where this limitation affects the data reported.

The lack of robust comparator statistical data about advanced breast cancer internationally means that international comparisons are imperfect.

1.4 Key findings

ABC in New Zealand – subtypes and survival[4]

1.4.1 Median survival after a diagnosis of metastatic / advanced breast cancer in New Zealand is 16 months, considerably worse than overseas. Survival varies greatly by subtype, from 27.3 months for Luminal A patients down to 6.6 months for triple negative breast cancer.

1.4.2 One and five-year survival rates are also worse in New Zealand than overseas, with the gap widening in recent years.

1.4.3 Median survival for Māori with ABC appears worse than non-Māori, and Māori five-year survival is significantly worse.

1.4.4 23% of people with ABC had advanced disease at initial diagnosis (de novo metastatic), while the remainder had a metastatic recurrence of an earlier breast cancer. People with de novo metastatic breast cancer survive on average much longer than people with recurrent disease.

1.4.5 The median metastasis-free interval between early and advanced diagnosis is 30 months, in line with international data. However, time to relapse varies greatly by breast cancer subtype.

ABC Diagnosis

1.4.6 Medical professionals report that access to diagnostic tests to confirm advanced breast cancer can be slow[5], potentially limiting treatment options and reducing length of survival.

1.4.7 Patients having private treatment get faster access to diagnosis and care, but don't receive the same level of wraparound support.[5]

4 Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018

5 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos

Person-Centred Care

1.4.8 For many people with advanced breast cancer, the system is falling short on delivering on the person-centred care principles that the Ministry of Health and DHBs espouse.

1.4.9 Chemo suites often assign ABC patients a lower priority for chemotherapy than early breast cancer patients, despite the fact that, in many cases, ABC will progress faster than early disease.

1.4.10 The multidisciplinary meetings (MDT) that have improved outcomes in early breast cancer often do not include discussion of ABC patients[6].

1.4.11 Overall, people with ABC consider they have a good quality of life – the main contributing factors are around family and friends, and having a positive attitude. The factors that could **improve** their quality of life are treatment-related and financial.[7]

1.4.12 Inability to manage ongoing physical and emotional symptoms is the number one negative impact on quality of life for people with ABC – only a third have good control over their symptoms[7].

1.4.13 One quarter of patients do not believe their medical team is doing all they can to help keep them alive and give them a good quality of life.[7]

1.4.14 While many ABC patients feel well informed, and involved in decisions about their treatment, a significant minority do not.[7]

Hot Topics

1.4.15 Medical professionals feel they don't have enough time with their patients, forcing them to pick and choose their conversations[6]. This means the full range of treatment options may not be discussed – and it's up to the patient to initiate conversations on topics that matter to them, such as clinical trials and unfunded treatments.[7]

1.4.16 The topic of complementary therapies is a difficult one for doctors and patients, but given that many patients use them at a significant personal cost and potentially (though rarely) with negative effect on their medical treatment, it's a conversation that needs to happen.[7]

World-Class Treatment?

1.4.17 New Zealand is a world leader in the collection of near-national data about ABC diagnosis, treatment and outcomes.

1.4.18 New Zealand's ABC survival appears considerably shorter than that of comparable countries. While survival has increased since 2010, the five-year survival gap may be widening.

6 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos
7 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

1.4.19 New drugs play a vital role in extending the lives of people with ABC. Our healthcare professionals feel keenly the lack of publicly funded access to the latest medicines.[8] There is also increasing emphasis overseas on continued therapy after disease progression, or re-trying a previously failed treatment, either after another treatment or in combination with another medicine. These options are often not available under NZ's current prescribing restrictions.

1.4.20 While there is limited international data about the number of lines of systemic therapy given to ABC patients, studies suggest many patients can benefit from more than three lines of therapy. In New Zealand, only about 15% of patients have more than three systemic treatments. Few patients have metastatic biopsies that could suggest additional treatment options. Too many patients in New Zealand receive no systemic treatments at all.[9]

1.4.21 Healthcare professionals expressed a lack of awareness of or adherence to guidelines for treatment of ABC. This could potentially allow for suboptimal care or less ambitious treatment plans.[8]

1.4.22 The potential for treating oligometastases with intent to cure is currently underexplored, yet many oncologists believe it will play a significant role in future.[8]

The financial burden of ABC

1.4.23 People with ABC and their families face a huge financial burden[10], which is with them for the rest of their lives. Three-quarters of people with ABC have had a decline in household finances; nearly half say their situation is "a lot worse".

1.4.24 The stresses of living with terminal disease and struggling to manage symptoms are compounded by financial difficulties, which in turn limit patients' ability to manage symptoms. The cost of GP visits becomes a major financial burden when patients no longer have regular hospital appointments; inability to afford appointments means patients don't get the symptom relief they need

8 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos
9 Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018
10 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

1.5 Key Findings - Illustrated

1.5.1 Advanced Breast Cancer in New Zealand - subtypes and survival

Figure 1: ABC Patients with de novo or recurrent disease

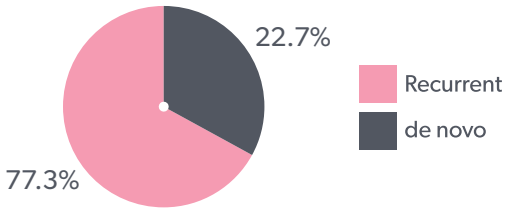


Table 1: de novo and recurrent disease by ABC patients' ethnicity

	NZ Māori	Pacific Islands	Asian	European
Relapsed	82%	61%	59%	82%
de novo	28%	39%	41%	18%

Figure 2: Median metastasis-free interval by subtype

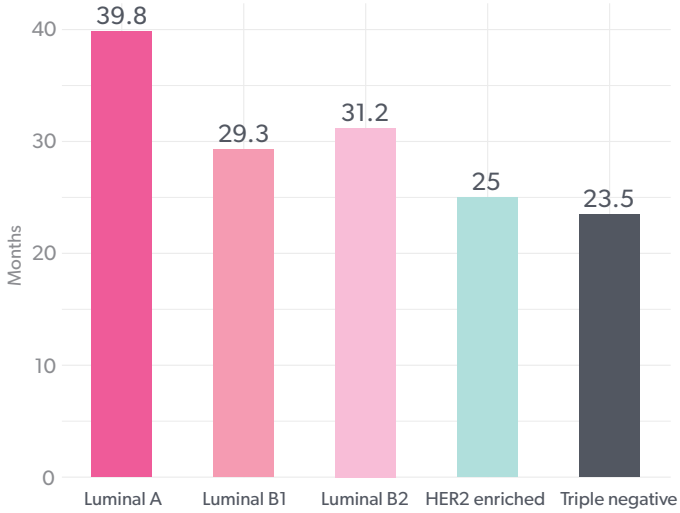


Table 2: Median metastasis-free interval by subtype

Luminal A	Luminal B1	Luminal B2	HER2 enriched	Triple Negative
39.8 (36.2, 46.2)	29.3 (25.7, 33)	31.2 (27.5, 37.7)	25 (21.2, 28.1)	23.5 (18.8, 27.4)

Figure 3: Survival time for metastatic breast cancer

Changes in survival through time

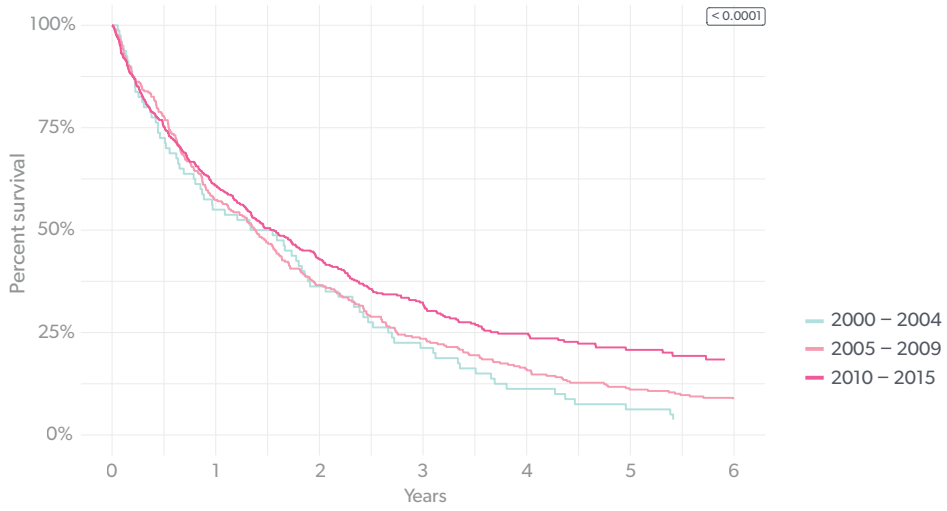


Table 3: Median, one and five-year survival after MBC diagnosis, for people diagnosed in each period

	2000-2004	2005-2009	2010-2015
Median survival (months)	10.6 (6.8, 19.9)	14 (11.4, 16.7)	18.8 (15.9, 21.4)
One-year survival	46% (34, 58)	54% (48, 60)	62% (58, 67)
Five-year survival	12% (05, 20)	11% (08, 15)	15% (11, 19)

Figure 4: One year and five-year survival with ABC – Māori and non-Māori

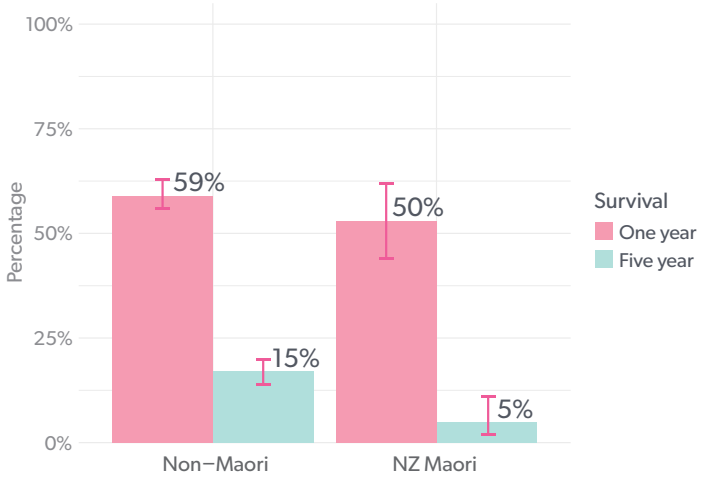


Figure 5: Median survival after metastatic diagnosis by subtype

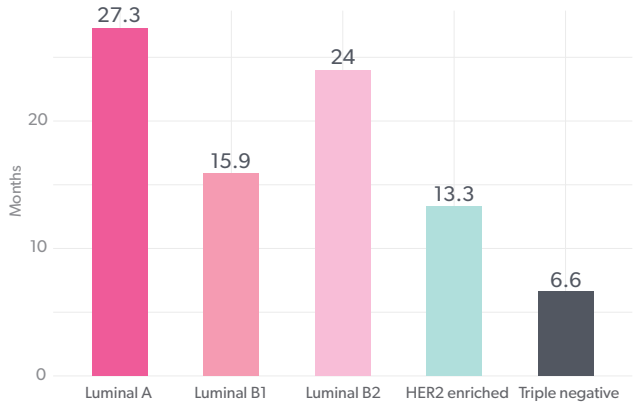
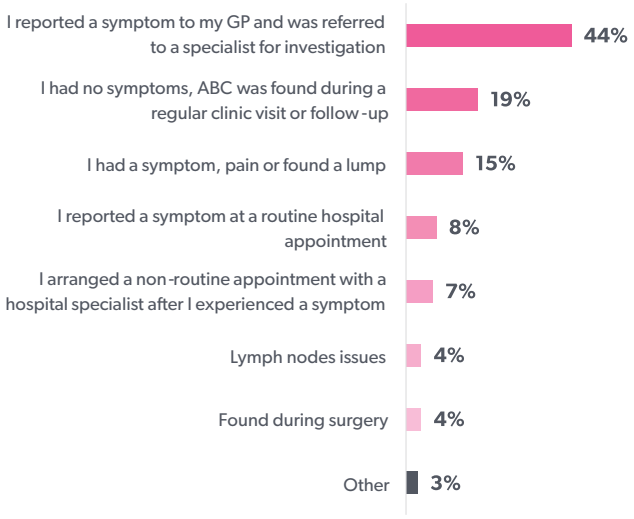


Table 4: Median survival after metastatic diagnosis by subtype

Luminal A	Luminal B1	Luminal B2	HER2 enriched	Triple Negative
27.3 (21.4, 30.6)	15.9 (13, 20.8)	24 (18.3, 28)	13.3 (10, 17.7)	6.6 (5.8, 8.7)

1.5.2 ABC Diagnosis

Figure 6: "How was your advanced breast cancer detected?"



1.5.3 Person-Centred Care

Figure 7: "How informed do you feel about your treatment options? How well do you understand those options, and how involved are you in treatment decision-making?"

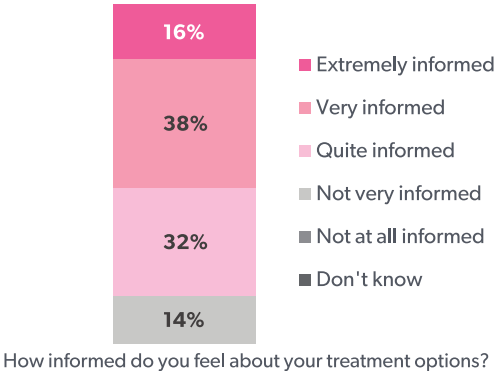
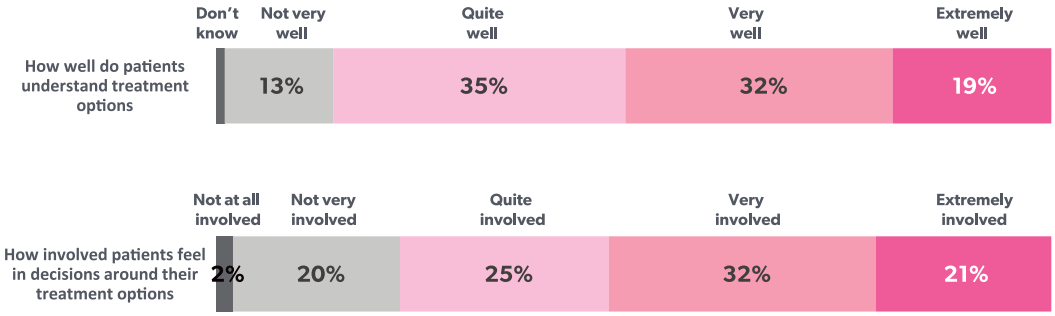


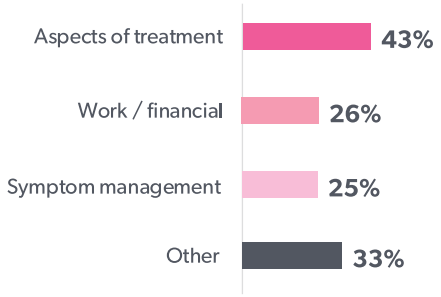
Figure 8: Understanding of and involvement in treatment options



> *MDMs are very helpful in this way but most MBC cases are not discussed in MDMs only early cancers so a specific MBC MDM might be a way forward although this does have its own issues of time availability for clinicians to attend this.*
>
> – Radiation oncologist

> *Many newly diagnosed MBC patients are not discussed at an MDM prior to referral to medical oncology, as the MDMs predominantly focus on early breast cancer.*
>
> – Medical oncologist

Figure 9: "What would make the most positive difference to quality of life?"



("Aspects of treatment" included finding a cure, funding for new treatments, extended survival and "not being written off by specialists")

Figure 10: "What is having the most negative impact on your quality of life?"

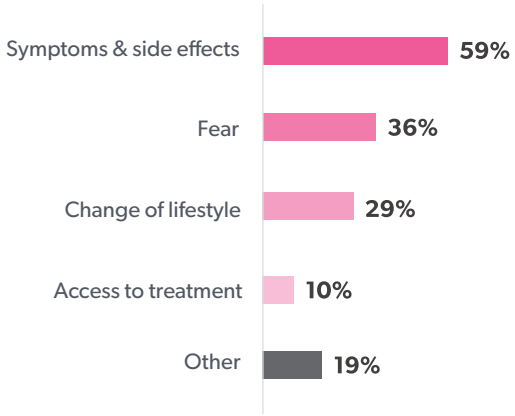
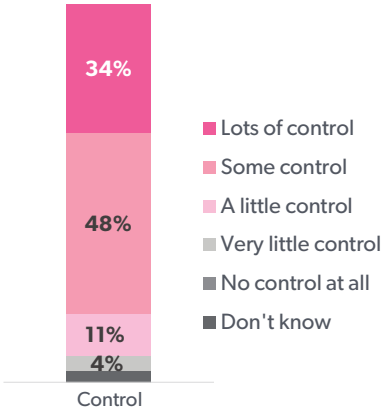
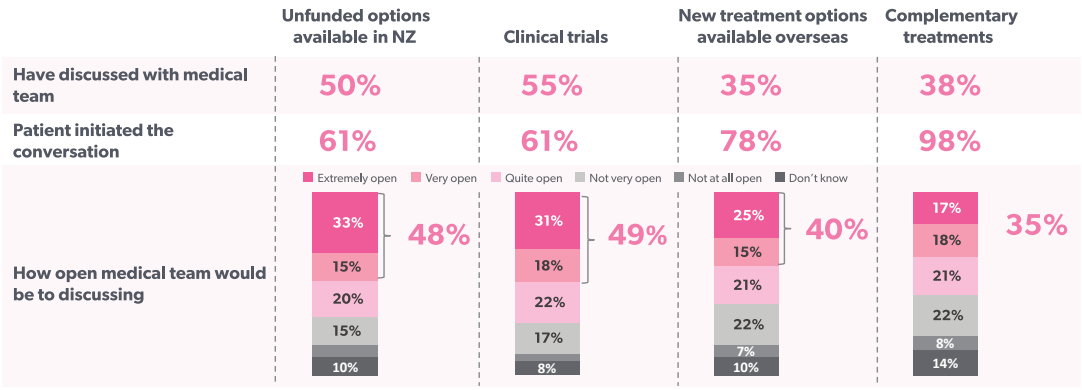


Figure 11: Control over managing symptoms



1.5.4 Hot Topics

Figure 12: "Have you ever talked with your medical team about the following things? Who initiated the conversation? Even if you haven't talked with your medical team about these things, how open do you think your medical team would be to talking about them?"



1.5.5 World-Class Treatment?

1.5.5.1 International Survival Comparison Chart

Table 5: Metastatic Breast Cancer Survival – an international snapshot

dnMBC = de novo metastatic breast cancer rMBC = recurrent metastatic breast cancer

Publ'n date	Country	# of MBC patients	Study period	Median survival with MBC (months)	1-year survival	5-year survival	Study limitations / considerations
2018	Breast Cancer Foundation National Register (NZ)	950 (long term data only)	2000-2015	16 (29 dnMBC) (14 rMBC)	58% 53% rMBC 72% dnMBC	14% 11% rMBC 23% dnMBC	Long-term register (Auckland / Waikato) data only. Auckland region length of follow-up varies. Disease-specific survival.
				(27 Lum A, 16 Lum B1, 24 Lum B2, 7 TNBC, 13 HER2 enriched)	(71% Lum A, 61% Lum B1, 70% Lum B2, 31% TNBC, 53% HER2 enriched)	(22% Lum A, 13% Lum B1, 13% Lum B2, 2% TNBC, 7% HER2 enriched)	
			2000-2004 2005-2009 2010-2015	10.6 14 18.8	46% 54% 62%	12% 11% 15%	
2015[i]	New Zealand	1920	1994-2011		51.8%	17.6% 10-yr survival: 13%	de novo MBC only. Relative survival (likely to be slightly higher than overall survival).
2016[ii]	Australia	N/A	1995-2009	N/A	73.9%	43.9%	de novo patients only; NSW only; follow-up to Dec 2013; figures are age-standardised relative survival.
2017[iii]	Germany	7559	1998-2015		67% (all pts) 72% dnMBC	20% (all pts) 23% dnMBC	Munich Cancer Registry, observed survival.
			1988-1997 1998-2006 2007+		67% 68% 68%	17.6% 19.7% 21.2% 10-yr survival: 10%	
2015[iv]	Netherlands	815	2007-2009	29.4 (dnMBC) 21.1 (rMBC)			Consecutive MBC diagnoses. Median follow-up 37.1mo.
2014[v]	Germany	716	1995-2013	36.8 (37 ER+, 34 HER2+, 13 TNBC)		34% 10-yr survival: 12%	Single-centre study, disease-specific survival.
2017[vi]	USA	12762	2005-2012	25.2 38.4 for patients <50 at metastatic diagnosis		26% 36% for patients aged <50 at MBC diagnosis 10-yr survival: 10%	de novo MBC only; 5-year survival is relative survival (likely to be slightly higher than overall survival).
2010[vii]	USA	3524	1992-2007	39.2 (dnMBC) 27.2 (rMBC)	N/A	N/A	Single-centre study (MD Anderson Cancer Center); median follow-up 19mo.
2015[viii]	USA	189	1996-2006	33 (39 ER+, 23 ER-, 54 HR+/HER2+, 34 HR+/HER2-, 25 HR-/HER2+, 16 TNBC)	80%	18.5% 10-year survival: 4.7%	Recurrent patients only; single-centre study (University of Miami).

2008[ix]	France	1038	1975-2005 1980-1984 1985-1989 1990-1994 1995-1999 2000 - 1/1/05	23.1 (27 ER+, 9 ER-, 36 HER2-, 29 ER+) 16 22 24 26 30.9		Recurrent patients only. Consecutive MBC diagnoses in a single centre, patients followed up for 5 years.
2016[x]	Germany	886	1992-2008	27 (38 Lum A, 26 Lum B1, 31 Lum B2, 10 TNBC, 19 HER2 enriched)		Median follow-up with MBC 27mo.
2013[xi]	USA	113	1999-2005	3.5 years		HER2+ patients with ≥1 dose of trastuzumab (Herceptin) for recurrent disease; single-centre study; median follow-up 3.6 yrs.
2017[xii]	Sweden	784	1985-2016 <1990 1990-1994 1995-1999 2000-2004 2005-2009 ≥2010	18 13 16 16 20 23 33	14% 10% 13% 9% 15% 17% 27%	Single-county study.
2017[xiii]	USA	1158	1990-2010 1990-1998 2005-2010	47 (dnMBC) 22 (rMBC)	44% (dnMBC) 20% (rMBC) 28% (dnMBC) 23% (rMBC) 55% (dnMBC) 13% (rMBC) (p=.065)	This single-centre study, with unusual results showing decreased 5-yr rMBC survival (p value = 0.065), has been widely reported and we have therefore included it in this summary.
2017[xiv]	Canada	2796	2001-2009	29 (dnMBC) 17 (rMBC) Luminal A / B1: 34 (dnMBC) 23 (rMBC) TNBC: 11 (dnMBC) 8 (rMBC) HER2+: 29 (dnMBC) 15 (rMBC) ER-: 23 (dnMBC) 12 (rMBC)		Only 17% of HER2+ pts were treated with trastuzumab. Median follow-up 91mo.
2015[xv]	Italy	514	1990-2009 1990-1993 1994-1997 1998-2001 2002-2005 2006-2009		 11% 15% 12% 20% 29%	Modena Cancer Register, de novo patients only, a relatively small number of patients given the length of study.
2009[xvi]	France	558	1973-2006	28		Patients selected in alphabetical order from database of MBC patients.
2018[xvii]	France	16,680	2008-2014	37 (42 HR+/HER2-, 45 HER2+, 14.5 HR-/HER2-)		Consecutive MBC patients treated in the 18 French Comprehensive Cancer Centers.

i Cancer Patients Survival 1994-2011, Ministry of Health, 2015

ii Cancer survival in New South Wales 1995–2009, Table 5: Summary of relative survival from breast (female) cancer, adults (15–100 years), NSW, 1995–2009 followed up to 31 Dec 2013 (cohort approach), released May 2016

iii Munich Cancer Registry, "ICD-10 C50: Breast cancer (women) Survival", August 22, 2017

iv D JA Lobbezoo et al, Prognosis of metastatic breast cancer: are there differences between patients with de novo and recurrent metastatic breast cancer?, British Journal of Cancer (2015) 112, 1445–1451 | doi: 10.1038/bjc.2015.127

v Weide et al. "Metastatic breast cancer: prolongation of survival in routine care is restricted to hormone-receptor and Her2-positive tumors", SpringerPlus 2014, 3:535

vi Mariotto, et al, "Estimation of the Number of Women Living with Metastatic Breast Cancer in the United States", Cancer Epidemiol Biomarkers Prev; (2017) 26(6)

vii S Dawood et al, "Survival differences among women with de novo stage IV and relapsed breast cancer", Annals of Oncology (2010) 21: 2169–2174

viii S Zeichner et al. Defining the Survival Benchmark for Breast Cancer Patients with Systemic Relapse. Breast Cancer: Basic and Clinical Research 2015:9 9–17 doi:10.4137/BCBCR.S23794

ix R. Largillier et al, "Prognostic factors in 1038 women with metastatic breast cancer", Annals of Oncology (2008) 19: 2012–2019, doi:10.1093/annonc/mdn424

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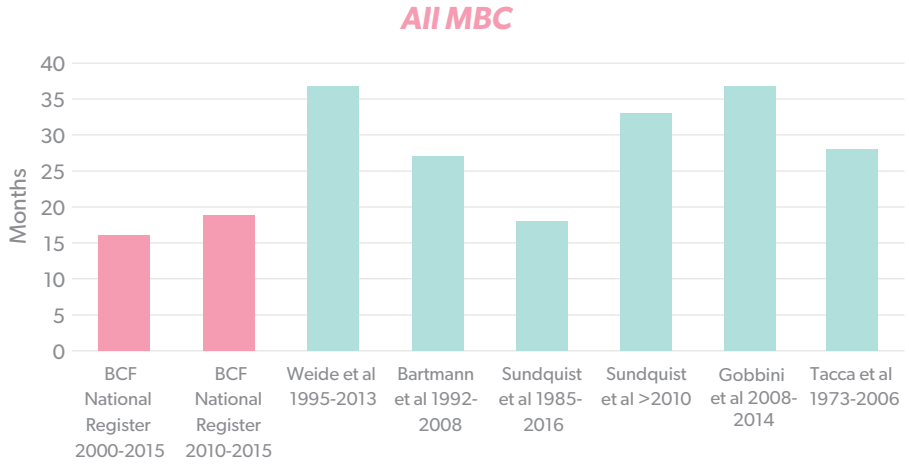
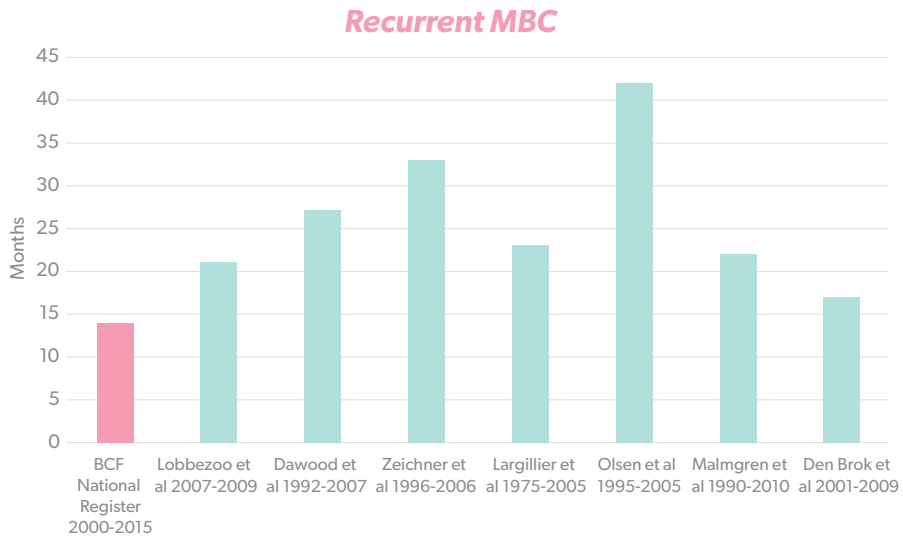
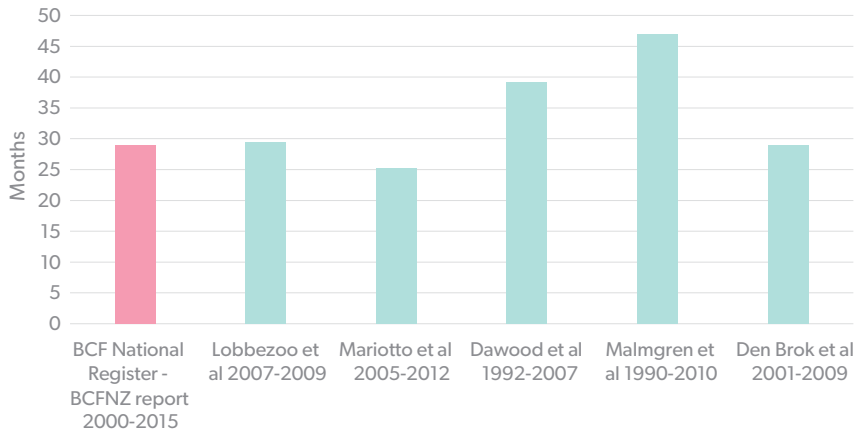
Median metastatic survival by study





De novo MBC



1.5.5.2 Systemic Treatments

Figure 13: Number of systemic therapies by region

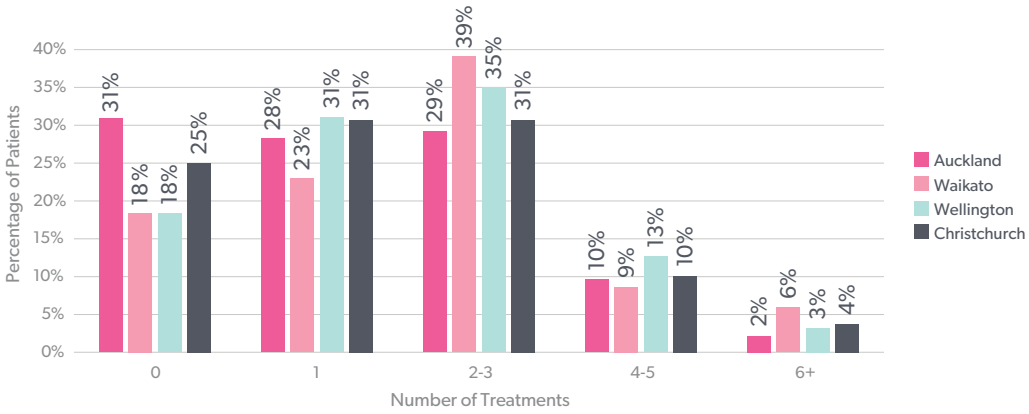


Figure 14: Number of systemic therapies for Māori

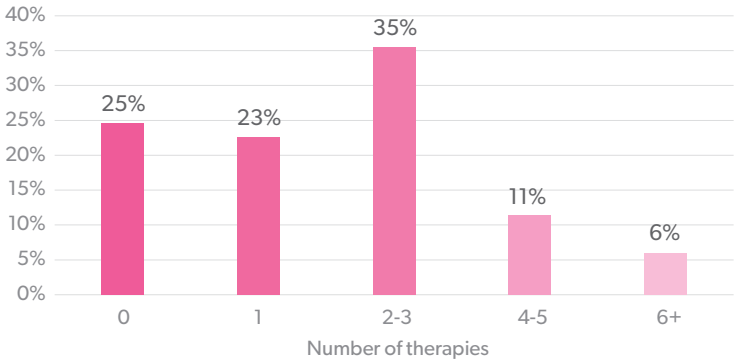
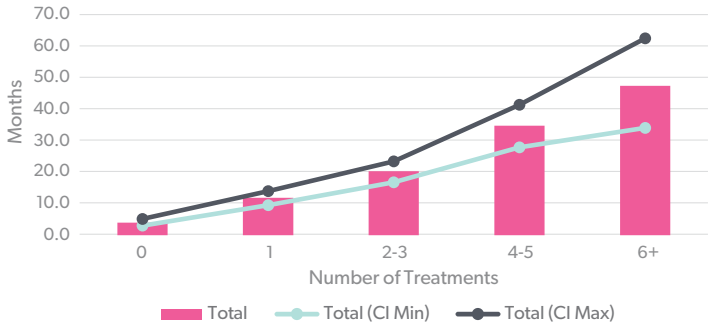


Figure 15: Median survival by number of systemic therapies (with 95% confidence intervals)



1.5.5.3 Chemotherapy

Figure 16: Number of lines of chemotherapy given by region

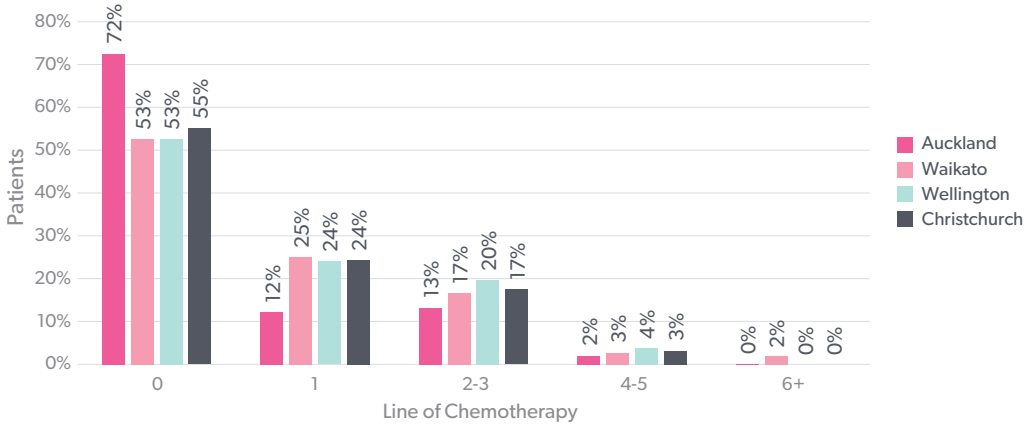


Figure 17: Lines of chemotherapy for Māori

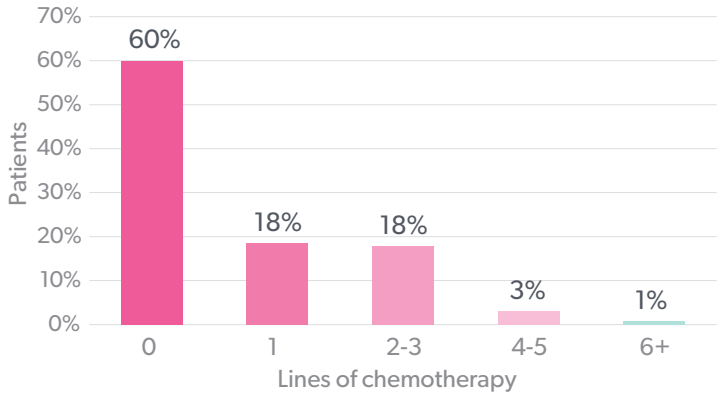


Figure 18: Lines of Chemotherapy by Age

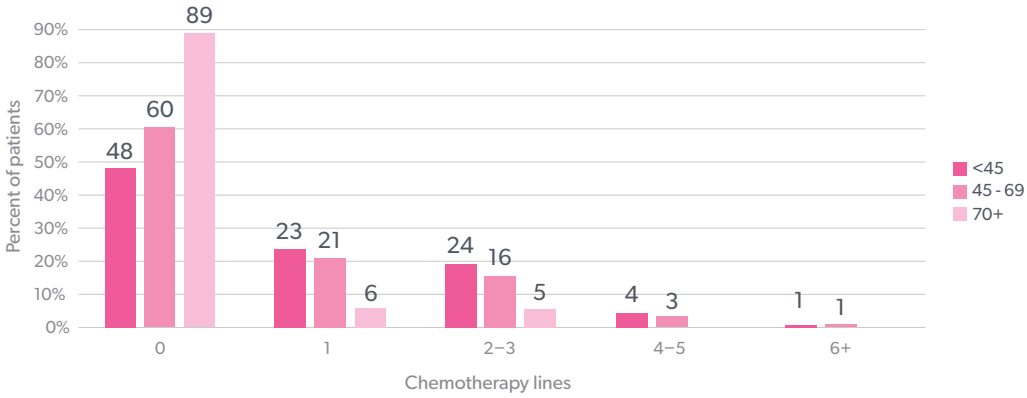
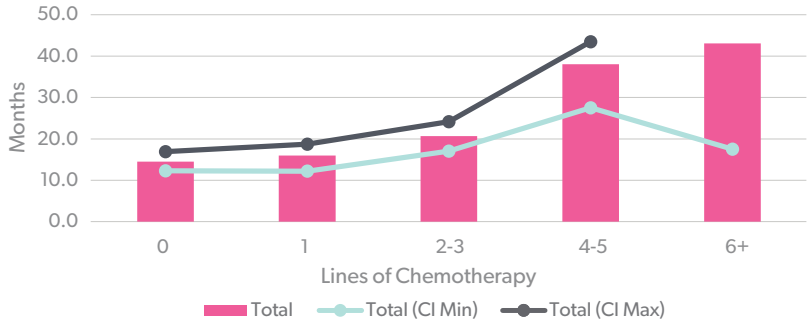


Figure 19: Median survival by number of lines of chemotherapy (with 95% confidence intervals)



1.5.5.4 Hormone Therapies

Table 6: Survival by number of hormone therapies (ER+/PR+ patients)

	0	1	>1
Median survival	10.4 (6.8, 13.9)	17.3 (14.1, 21.3)	36.4 (30.2, 40)
One-year survival	45% (37, 53)	61% (54, 67)	85% (80, 89)
Five-year survival	10% (6, 16)	17% (12, 23)	29% (23, 35)

1.6 Where to from here? – A call to action

New Zealand's poor metastatic breast cancer survival needs urgent action.

This study identifies five areas of focus for change: medical care, symptom management, drugs, support, and investing in the future.

However, none of the necessary changes will be possible without a change in attitude towards metastatic breast cancer within our health system.

In 2016, the ABC Global Charter, an initiative of the European School of Oncology developed to address the most urgent and actionable gaps in treatment and care of patients with advanced breast cancer, set a goal of doubling ABC median overall survival by 2025. The Charter notes that collecting accurate data about ABC treatment and outcomes is an essential first step; with publication of this report, New Zealand has taken that step. The remainder of the Global Charter's focus is similar to the recommendations we have outlined below: a multidisciplinary approach to care, improved access to treatments and removal of inequities, a proactive approach to quality of life issues such as symptom management.

We believe our recommendations are on the right track. In most of the areas for change, some practical steps can be taken immediately, while other changes will require a longer term commitment, planning and investment. But we know from overseas experience that metastatic breast cancer survival can be improved, that

there is every reason to prioritise patients for diagnosis and to treat their disease assertively. We are a caring nation of people. We are not asking for New Zealand to be better than the rest of the world; we just want to catch up.

Let's do it.

Priority #1 – Medical Care

Action	When	Ref
"No one should get nothing" – all patients, with the exception of a few individuals who are very ill at metastatic diagnosis, should be offered systemic therapy for MBC, as the recognised standard therapeutic approach.	Now	11 12 15
Therapy beyond the second line should become the standard of care, with deviations from this standard to be discussed in a multidisciplinary setting and to represent no more than an agreed low percentage of patients.	Now	13 14 15
Equal access to chemotherapy. The current DHB practice of de-prioritising metastatic patients for chemotherapy should be abandoned. Chemotherapy is the only treatment available to triple negative patients, whose median metastatic survival of 6.6 months means their need is always urgent. For hormone receptor positive patients, chemotherapy is used in times of rapid progression, or when the patient has few options left, so again should be prioritised. To address resource constraints, consider contracting private facilities or using other in-hospital facilities (e.g. children's hospital chemo facilities).	Now	
Clinical trials should be considered as a first-line treatment option for all ABC patients. All eligible patients should be offered access to clinical trials, and the subject of trials should be revisited when relevant trials arise. ER-negative patients in particular need access to clinical trials. Doctors should not assume patients are not interested, not well enough, or unable to fund travel costs, and should refer their patients for eligibility assessment. National recruitment should be the default for metastatic trials (with exceptions for patient safety issues). This will require DHBs to commit to developing plans for patient safety and for transfer of costs where needed, and to be open to patients meeting some or all of the cost of travelling to trials themselves if necessary.	Now	15

11 Dr Fatima Cardoso, ESMO Board of Directors & Chair of National Representatives Committee, ESO Breast Cancer Program Coordinator & Chair ABC Global Alliance, Past Chair EORTC-Breast Group – email comment, February 2018

12 Weide et al. "Metastatic breast cancer: prolongation of survival in routine care is restricted to hormone-receptor and Her2-positive tumors", SpringerPlus 2014, 3:535

13 E Olsen et al, "Clinical outcomes and treatment practice patterns of patients with HER2-positive metastatic breast cancer in the posttrastuzumab era", Breast. (2013) August ; 22(4): 525–531. doi:10.1016/j.breast.2012.12.006

14 Elsevier Practice Update video, "Metastatic Breast Cancer: Later Lines of Therapy" https://www.practiceupdate.com/c/65993/68/1/?elsca1=emc_coll_2018MidYear&elsca2=email&elsca3=practiceupdate_onc&elsca4=2018MidYear&elsca5=collection&rid=NzE2MTM1NzA4NTES1&lid=10332481 accessed July 10, 2018

15 J Gavila et al, "SEOM clinical guidelines in metastatic breast cancer 2015", Clin Transl Oncol (2015) 17:946–955 DOI 10.1007/s12094-015-1476-7

Patients to be allowed infusions of privately-funded drugs in public hospital facilities. Patients who choose to pay for drugs that are considered standard of care in ABC guidelines overseas but are unfunded in NZ should be entitled to have the privately funded drug infused free of charge in the public hospital setting. This enables patients to continue under the care of their existing medical teams and reduces the enormous financial burden they experience.	Now	
Every ABC patient to be discussed in a multi-disciplinary team (MDT) meeting at metastatic diagnosis and at progression. ABC patients should be discussed preferably in dedicated MDT meetings, or alternatively in a dedicated portion of a regular MDT. Personnel involved should include medical and radiation oncologists, diagnostic radiologists, oncology nurses and research nurses as core members, supplemented as needed by surgeons, palliative specialists, interventional radiologists, psychologists.	July 2019	16 17
NZ guidelines for ABC diagnosis and treatment to be agreed and adopted. Given the urgency of improving our treatments and our current under-treatment and poor survival, these should be adapted from existing overseas guidelines.	July 2019	18
Anyone who has had early breast cancer should be fast-tracked for diagnostic imaging when presenting symptoms of metastasis, on the basis that treatment is more effective when there is low volume disease or only one metastatic site, and that each additional metastatic site increases the chance of death by 18%. With oligometastases, there is a chance of curative treatment and complete or long-lasting remission. In addition, long-surviving metastatic patients under less active surveillance should be fast-tracked for imaging at signs of progression. If regular facilities cannot meet demand, DHBs could consider contracting private services or using other in-hospital or regional facilities that may be currently under-utilised (e.g. children's hospital CT service).	December 2019	19 20 21 22
Biopsy of accessible metastases to be routine, preferably for all patients, but particularly those whose early breast cancer was hormone receptor negative.	January 2020	23 24
Planned adoption of stereotactic and other treatments for oligometastases. The ability to treat a small subset of metastatic patients curatively requires access to appropriate equipment and trained personnel. Interventional radiology treatments may be deliverable right now in the public sector, whereas stereotactic options are limited. Until the public health system can offer stereotactic treatment, treatment for patients identified as oligometastatic could be outsourced to private providers. Equipping public hospitals to offer an expanding range of stereotactic techniques should be a priority.	January 2020	16 25

16 F Cardoso et al, "4th ESO–ESMO International Consensus Guidelines for Advanced Breast Cancer (ABC 4)", Annals of Oncology 0: 1–24, 2018, doi:10.1093/annonc/mdy192

17 Metastatic Breast Model Service Specification, London Cancer Alliance, February 2016, accessed on July 23, 2018 at http://www.londoncanceralliance.nhs.uk/media/121058/lca-metastatic-breast-service-specification-feb-2016-revised-march-2016-.pdf

18 J Gavila et al, "SEOM clinical guidelines in metastatic breast cancer 2015", Clin Transl Oncol (2015) 17:946–955 DOI 10.1007/s12094-015-1476-7

19 Weide et al. "Metastatic breast cancer: prolongation of survival in routine care is restricted to hormone-receptor and Her2-positive tumors", SpringerPlus 2014, 3:535

20 M-T Chen et al, "Comparison of patterns and prognosis among distant metastatic breast cancer patients by age groups: a SEER population based analysis" Sci Rep. 2017; 7: 9254.

21 S Dawood et al, "Survival differences among women with de novo stage IV and relapsed breast cancer", Annals of Oncology 21: 2169–2174, 2010

22 G Sledge, "Curing Metastatic Breast Cancer", Journal of Oncology Practice, Volume 12 / Issue 1 / January 2016

23 M Thill et al, "AGO Recommendations Advanced and Metastatic Breast Cancer: Update 2017", Breast Care 2017;12:184–191

24 F. Cardoso et al, "3rd ESO–ESMO International Consensus Guidelines for Advanced Breast Cancer (ABC 3)", Annals of Oncology (2017) 28: 16–33

25 T Koboyashi et al, Possible clinical cure of metastatic breast cancer: lessons from our 30-year experience with oligometastatic breast cancer patients and literature review", Breast Cancer (2012) 19: 218. https://doi.org/10.1007/s12282-012-0347-0

Priority #2 – Symptom Management

Action	When	Ref
Offer electronic symptom reporting. A key study showed that electronic reporting of symptoms to nurses improved metastatic cancer patient quality of life significantly and improved survival by an average of 5 months. An electronic solution is particularly relevant for NZ ABC patients, given the lack of metastatic nursing support in hospitals, and given our distributed ABC population who report symptom management as having the most negative impact on their quality of life.	January 2019	26 27 28
Introduce palliative care specialists into ABC care early on, in line with the NZ Standards of Service Provision for Breast Cancer and international guidelines, to help reduce negative associations and educate patients about the value of palliative care.	Now	28 29
Schedule longer appointments for metastatic patients to enable symptoms to be dealt with fully	Now	30
Free GP visits for people with advanced breast cancer will reduce the burden of symptom management costs and make treatment more accessible.	Now	
Free prescriptions for people with ABC will lower the cost of symptom management, reducing the need for patients to compromise for financial reasons.	Now	

Priority #3 – Drugs

Action	When	Ref
Remove prescribing restrictions on existing drugs to enable more lines of therapy. Removal of restricted indications for some drugs (e.g. lapatinib) and the ability for therapy to be continued or restarted after progression (e.g. Herceptin) would give oncologists more treatment options for later-line therapy combinations. This would go some way towards bringing New Zealand in line with overseas practice.	January 2019	31
Faster access to new and "still waiting" drugs. New Zealand lags severely behind Australia and other comparable countries in access to new drugs like Kadcyla, palbociclib and riboclib. Other drugs on the "still-waiting" list with proven ability to delay breast cancer progression include everolimus, nab-paclitaxel, eribulin.		

26 E Basch et al, "Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment", J Clin Oncol, 2015, 34:557-565

27 E Basch et al, "Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment", JAMA Research Letter, published online June 4, 2017. doi:10.1001/jama.2017.7156

28 F Cardoso et al, "4th ESO–ESMO International Consensus Guidelines for Advanced Breast Cancer (ABC 4)", Annals of Oncology 0: 1–24, 2018, doi:10.1093/annonc/mdy192

29 Standards of Service Provision for Breast Cancer Patients in New Zealand, 2013

30 Metastatic Breast Model Service Specification, London Cancer Alliance, February 2016, accessed on July 23, 2018 at http://www.londoncanceralliance.nhs.uk/media/121058/lca-metastatic-breast-service-specification-feb-2016-revised-march-2016-.pdf

31 Elsevier Practice Update video, "Metastatic Breast Cancer: Later Lines of Therapy" https://www.practiceupdate.com/c/65993/68/1/?elsca1=emc_coll_2018MidYear&elsca2=email&elsca3=practiceupdate_onc&elsca4=2018MidYear&elsca5=collection&rid=NzE2MTM1NzA4NTES1&lid=10332481 accessed July 10, 2018

Priority #4 – Support

Action	When	Ref
Educate patients who are considering declining medical treatment, using latest research and guidelines, to ensure an accurate understanding of risks and potential benefits.	Now	
Actively include family and friends to whatever extent suits the patient in their interactions with the health system. This could involve the use of technology to bring remote people into medical consultations or to record/video consultations.	Now	
NGOs to help upskill family and friends to support ABC patients	Now	
Māori and Pacific nurses and care coordinators can play a significant role in easing access. Assess whether existing resources are sufficient.	July 2019	
Kinder communication: Provide communications training to medical professionals who will have sensitive conversations with patients about terminal illness.		
Assess how well existing Ministry of Health transportation funding meets the needs of advanced breast cancer patients. Investigate new programmes to fund transportation and parking where these do not exist.		

Priority # 5 – Investing in the Future

Action	When	Ref
Surveillance strategies: Emerging technologies, e.g. blood tests that monitor circulating tumour DNA (ctDNA) and bioengineering-led advances in imaging, will potentially offer more affordable and effective means for earlier detection of metastasis. While these are not yet clinic-ready, NZ should embrace opportunities for pilots and trials of clinically and economically effective new technologies for metastatic surveillance. Guidelines will need to be established for how patients should be treated in reponse to early detection of metastases.	From now	[32]
Genomic testing to establish biomarkers for treatment efficacy will move into routine clinical use in treatment of metastatic breast cancer. NZ will require publicly funded genomic tests to enable more precise targeting of tumours. Clinical use of genomic testing will require PHARMAC to consider new funding indications, based on genomic indicators rather than by tumour stream. NZ needs to upskill now in genomic analysis. Trials and pilots will have an important role to play in building local skills and experience.	From now	
Adoptive transfer therapies such as CAR-T and TILs-based therapies are highly experimental in metastatic breast cancer, but as the technology develops and as some patients achieve complete enduring remission, we would hope that clinical trials will be available in New Zealand.	2020	[33]

32 G Sledge, "Curing Metastatic Breast Cancer", Journal of Oncology Practice, Volume 12 / Issue 1 / January 2016

33 N Zacharakis et al, "Immune recognition of somatic mutations leading to complete durable regression in metastatic breast cancer", Nature Medicine June 2018 Vol 24 724–730

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Report review and comment

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