



# "I'm still here"

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





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Advanced Breast Cancer in New Zealand**

September 2018



**Breast Cancer  
Foundation NZ**

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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.**



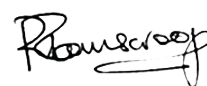
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# 1 Executive Summary

## 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:**

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- 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:**

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- 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<sup>1</sup>, conducted by Ipsos; a quantitative email-based study of patients living with advanced breast cancer<sup>2</sup>, also by Ipsos; and a statistical analysis of data held in the Breast Cancer Foundation National Register<sup>3</sup>.

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 (MBC) 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

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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<sup>4</sup>

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- 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

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- 1.4.6 Medical professionals report that access to diagnostic tests to confirm advanced breast cancer can be slow<sup>5</sup>, 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.<sup>5</sup>

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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

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- 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<sup>6</sup>.
- 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.<sup>7</sup>
- 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<sup>7</sup>.
- 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.<sup>7</sup>
- 1.4.14 While many ABC patients feel well informed, and involved in decisions about their treatment, a significant minority do not.<sup>7</sup>

## Hot Topics

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- 1.4.15 Medical professionals feel they don't have enough time with their patients, forcing them to pick and choose their conversations<sup>6</sup>. 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.<sup>7</sup>
- 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.<sup>7</sup>

## World-Class Treatment?

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- 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.

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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.<sup>8</sup> 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.<sup>9</sup>
- 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.<sup>8</sup>
- 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.<sup>8</sup>

### **The financial burden of ABC**

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- 1.4.23 People with ABC and their families face a huge financial burden<sup>10</sup>, 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

## **1.5 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

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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

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.

## Priority #1 – Medical Care

Action	When	Ref
<b>“No one should get nothing”</b> – 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
<b>Therapy beyond the second line should become the standard of care</b> , 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
<b>Equal access to chemotherapy.</b> 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	
<b>Clinical trials should be considered as a first-line treatment option for all ABC patients.</b> 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](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



<p><b>Patients to be allowed infusions of privately-funded drugs in public hospital facilities.</b> 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.</p>	Now	
<p><b>Every ABC patient to be discussed in a multi-disciplinary team (MDT) meeting</b> 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.</p>	July 2019	16 17
<p><b>NZ guidelines for ABC diagnosis and treatment to be agreed and adopted.</b> Given the urgency of improving our treatments and our current under-treatment and poor survival, these should be adapted from existing overseas guidelines.</p>	July 2019	18
<p><b>Anyone who has had early breast cancer should be fast-tracked for diagnostic imaging</b> 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).</p>	December 2019	19 20 21 22
<p><b>Biopsy of accessible metastases to be routine,</b> preferably for all patients, but particularly those whose early breast cancer was hormone receptor negative.</p>	January 2020	23 24
<p><b>Planned adoption of stereotactic and other treatments for oligometastases.</b> 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.</p>	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
<b>Offer electronic symptom reporting.</b> 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
<b>Introduce palliative care specialists into ABC care early on,</b> 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
<b>Schedule longer appointments for metastatic patients</b> to enable symptoms to be dealt with fully	Now	30
<b>Free GP visits for people with advanced breast cancer</b> will reduce the burden of symptom management costs and make treatment more accessible.	Now	
<b>Free prescriptions for people with ABC</b> will lower the cost of symptom management, reducing the need for patients to compromise for financial reasons.	Now	

## Priority #3 – Drugs

Action	When	Ref
<b>Remove prescribing restrictions on existing drugs to enable more lines of therapy.</b> 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
<b>Faster access to new and “still waiting” drugs.</b> New Zealand lags severely behind Australia and other comparable countries in access to new drugs like Kadcyra, palbociclib and ribociclib. 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](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
<b>Educate patients who are considering declining medical treatment</b> , using latest research and guidelines, to ensure an accurate understanding of risks and potential benefits.	Now	
<b>Actively include family and friends to whatever extent suits the patient in their interactions with the health system.</b> This could involve the use of technology to bring remote people into medical consultations or to record/video consultations.	Now	
<b>NGOs to help upskill family and friends to support ABC patients</b>	Now	
<b>Māori and Pacific nurses and care coordinators</b> can play a significant role in easing access. Assess whether existing resources are sufficient.	July 2019	
<b>Kinder communication:</b> Provide communications training to medical professionals who will have sensitive conversations with patients about terminal illness.		
<b>Assess how well existing Ministry of Health transportation funding meets the needs of advanced breast cancer patients.</b> Investigate new programmes to fund transportation and parking where these do not exist.		

## Priority # 5 – Investing in the Future

Action	When	Ref
<b>Surveillance strategies:</b> 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 response to early detection of metastases.	From now	32
<b>Genomic testing</b> 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	
<b>Adoptive transfer therapies</b> 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

## 2 Advanced Breast Cancer in New Zealand – Subtypes and Survival

### In brief:

- **Median survival after a diagnosis of metastatic / advanced breast cancer in New Zealand is 16 months, considerably worse than other, comparable countries. Survival varies greatly by subtype, from 27.3 months for Luminal A patients down to 6.6 months for triple negative breast cancer.**
- **One and five-year survival rates are also worse in New Zealand than overseas, with the gap widening in recent years.**
- **Median survival for Māori with ABC appears worse than non-Māori, and five-year Māori survival is significantly worse.**
- **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 much longer than people with recurrent disease; this is an area highlighted for further investigation in overseas studies, suggesting a different approach to treatment may be required for the two groups.**
- **The median metastasis-free interval (MFI) between early and advanced diagnosis is 30 months, in line with international data. However, MFI varies greatly by breast cancer subtype.**

Unless otherwise stated, the statistics in this section are from the *Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018*. Metastasis-free interval and survival data are from Auckland and Waikato, being the two regions with long-term patient data.

### 2.1 de novo and recurrent disease

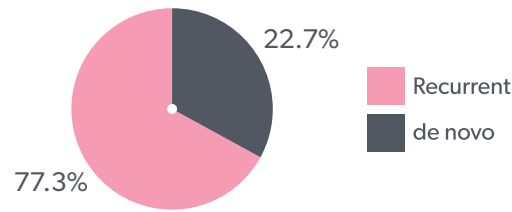
Only around 5% of all people diagnosed with breast cancer in New Zealand have de novo metastatic breast cancer<sup>34</sup>, that is, disease that has spread beyond the breast and lymph nodes at initial diagnosis.

Among patients in this study (people diagnosed with ABC), 22.7% had advanced disease at initial diagnosis (de novo metastatic)<sup>35</sup>; the remainder had a metastatic recurrence of early breast cancer (also called relapse or distant recurrence, meaning a cancer that had been confined to the breast and possibly lymph nodes at initial diagnosis has now spread elsewhere). This de novo to recurrent ratio is comparable to studies in other countries.

34 Seneviratne et al, "Stage of breast cancer at diagnosis in New Zealand: impacts of socio-demographic factors, breast cancer screening and Biology", *BMC Cancer* (2016) 16:129

35 *Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018*. De novo patients are those presenting with metastatic disease, or whose metastatic disease was detected within three months of a diagnosis of early invasive breast cancer.

**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
<b>Relapsed</b>	82%	61%	59%	82%
<b>de novo</b>	28%	39%	41%	18%

The higher proportion of de novo diagnoses in Māori and Pacific ABC patients is likely to be linked to low uptake of mammogram screening (historical and current for Māori; historic for Pacific women). In addition, Māori and, particularly, Pacific women have a higher incidence of breast cancer at a younger age<sup>36</sup>, and therefore a higher percentage of diagnoses below the screening age. The very high percentage of Asian de novo diagnoses is surprising and may be due to the small number of Asian patients in this cohort.

## 2.2 Metastasis-free interval (MFI)

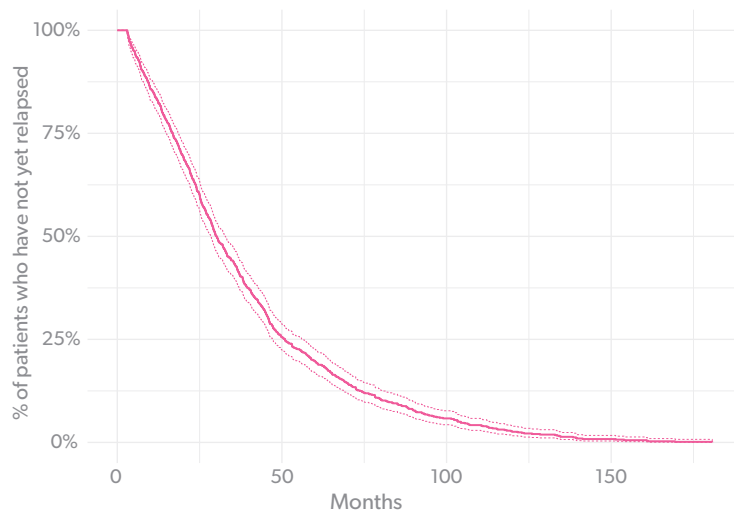
Metastasis-free interval (MFI) is the time (in months) from the date of a patient's first tissue diagnosis to MBC diagnosis. The estimated time in months is calculated as the number of days between the date of initial tissue diagnosis and the date of MBC diagnosis, and then divided by 30.5. MFI analyses in this study are limited to Auckland and Waikato due to the small number of patients and short existence of the Wellington and Christchurch registers. The MFI analyses reported here exclude de novo patients, and pertain only to people with relapsed metastatic breast cancer.

Studies show that the longer the time between early breast cancer diagnosis and relapse, the longer the patient is likely to survive with advanced breast cancer.<sup>37 38</sup> The median metastasis-free interval (MFI) in our study was 30 months, a figure comparable with overseas studies relative to the duration of the study; this is likely to increase as the register data ages.

On average, recurrent patients relapsed 30 months after their early breast cancer diagnosis.

36 Seneviratne et al, "Stage of breast cancer at diagnosis in New Zealand: impacts of socio-demographic factors, breast cancer screening and Biology", BMC Cancer (2016) 16:129  
 37 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  
 38 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

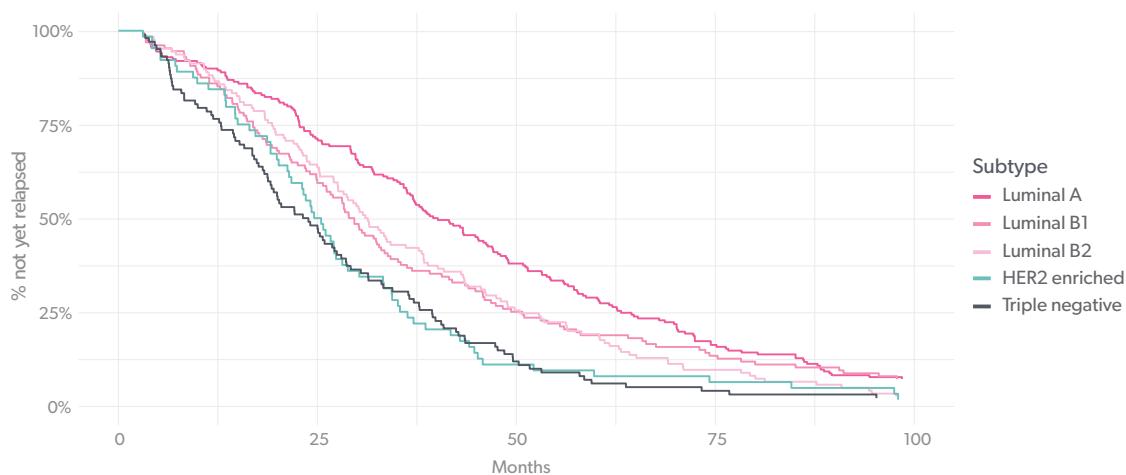
**Figure 2: Metastasis-free interval (relapsed patients)**



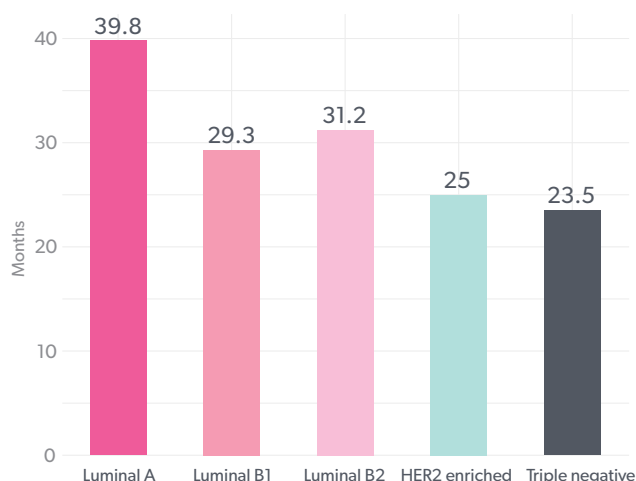
Metastasis-free interval varies greatly by subtype. Breast cancer subtyping is an advancing field, allowing more nuanced incidence, treatment and survival analysis by tumour receptor status for the hormones oestrogen and progesterone (ER/PR), and expression of the HER2 protein. The proliferation marker Ki67 can be used to refine subtype further; however, there is considerable inter-laboratory variation in Ki67 measurement, and it is not routinely tested in New Zealand. Therefore, subtype analysis in this study excludes Ki67, but classifies NZ metastatic breast cancers according to the five subtypes currently favoured by many clinicians:

- Luminal A (ER+/PR+, HER2-)
- Luminal B1 (ER+ or PR+, HER2-)
- Luminal B2 (ER+/PR+, HER2+)
- HER2-enriched (ER-/PR-, HER2+)
- Triple Negative (ER-/PR-, HER2-)

**Figure 3: Metastasis-free interval (relapsed patients by subtype)**



**Figure 4: 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)

People whose early breast cancer was ER-negative experienced significantly shorter median metastasis-free interval. Of triple negative patients who have relapsed, 24% relapsed within one year. Of Luminal A patients who have relapsed, 29% had not relapsed within five years of their initial diagnosis. Overseas studies suggest about 40% of ER+ patients who relapse do so more than five years after their initial diagnosis<sup>39</sup>; the metastasis incidence rate for patients diagnosed with early breast cancer is still 1.5% at 15 years<sup>40</sup>. It is likely that the percentage of New Zealand ABC patients whose relapse occurred more than five years after diagnosis will increase as the register data ages.

## 2.3 ABC survival

Median survival after a diagnosis of metastatic / advanced breast cancer in New Zealand is 16 months. While international data for ABC survival is scarce relative to early breast cancer, it seems New Zealand’s ABC survival is considerably worse than overseas (see **Table 7: Metastatic Breast Cancer Survival – an international snapshot**).

Median survival with advanced breast cancer is 16 months

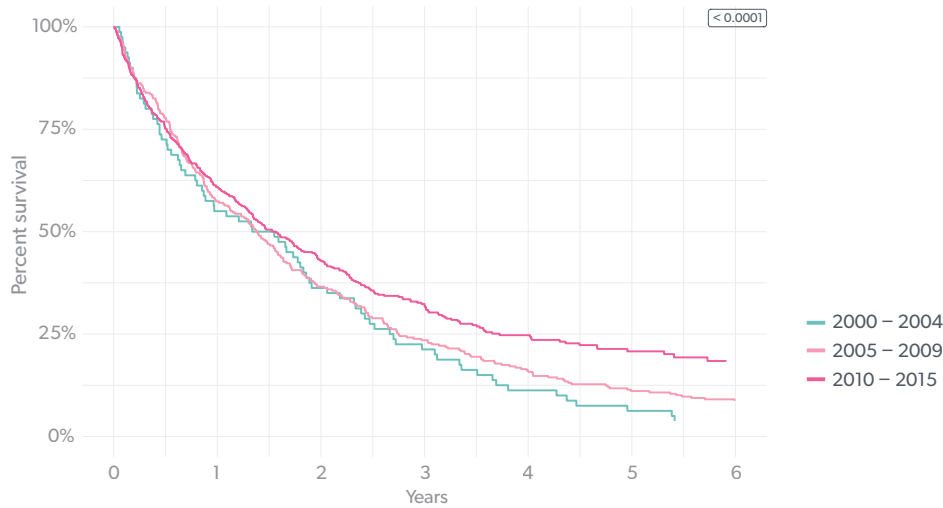
**Section 6: World-Class Treatment?** discusses some of the possible reasons for New Zealand’s substandard ABC survival, including lack of access to new medications, New Zealanders with ABC potentially having fewer lines of treatment than their counterparts overseas, and differences in approaches to treatment.

Despite poor survival for most patients, of those people currently alive with ABC in New Zealand today, 32% have lived with their advanced disease for five years or more. For these people, ABC is a chronic disease with a complex range of symptoms requiring ongoing management. These are discussed in **Section 4: Person-Centred Care and Quality of Life**.

39 Pan et al, “20-Year Risks of Breast-Cancer Recurrence after Stopping Endocrine Therapy at 5 Years”, *N Engl J Med* 2017;377:1836-46

40 A. Houze de l’Aulnoit et al, “Metastasis-free interval in breast cancer patients: Thirty-year trends and time dependency of prognostic factors. A retrospective analysis based on a single institution experience”, *The Breast* 37 (2018) 80-88

**Figure 5: Survival with 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
<b>Median survival (months)</b>	10.6 (6.8, 19.9)	14 (11.4, 16.7)	18.8 (15.9, 21.4)
<b>One-year survival</b>	46% (34, 58)	54% (48, 60)	62% (58, 67)
<b>Five-year survival</b>	12% (05, 20)	11% (08, 15)	15% (11, 19)

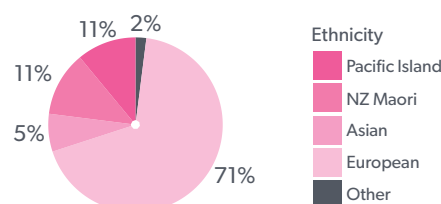
Median survival has improved, though confidence intervals for 2000-2004 and 2005-2010 overlap. People diagnosed with ABC from 2010-2015 had a median survival of 18.8 months. One-year survival has improved, though again confidence intervals for 2000-2004 and 2005-2010 overlap, and there is a trend towards improvement in five-year survival. Since there have not been major changes in surveillance for metastasis, it seems likely that survival improvements are related to new therapeutic approvals for ABC (e.g lapatinib and gemcitabine in 2012), rather than a lead-time bias resulting from metastases being detected earlier.

Median survival time from initial tissue diagnosis (with early breast cancer or de novo MBC) is 45 months.

### 2.3.1 Māori survival with ABC

Māori represent 11% of ABC diagnoses, compared with 9% of early breast cancer diagnoses. Pacific women also represent 11% of ABC diagnoses (5% of early breast cancers)

**Figure 6: Ethnicity of ABC patients**



Māori survival with ABC is worse than non-Māori, with the gap widening over time. Māori survival five years after ABC diagnosis is only 5% (15% for non-Māori). Median survival for Māori with ABC appears worse than non-Māori.

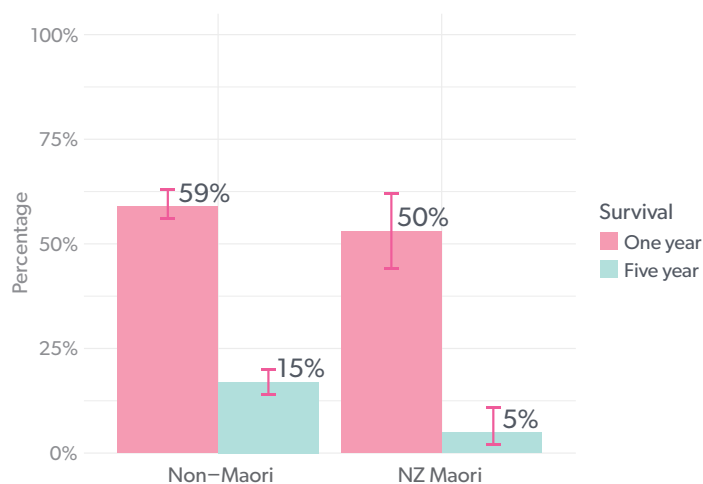
While the high proportion of Māori who develop metastatic breast cancer is mainly due to delayed diagnosis<sup>41</sup>, it is unclear why Māori survive a shorter time after ABC diagnosis. This may be related to treatment access issues.

When non-Māori numbers are broken down into key ethnicities (European, Pacific Island and Asian), the data suggests Māori survival with MBC is the worst of all ethnicities, while Asian people have the longest one and five-year survival and the highest median survival. European median survival with MBC appears 23% longer than Māori (though largely overlapping confidence intervals make this insignificant), and Europeans are three times more likely to survive five years than Māori. While the data indicates that Asian people and – unexpectedly – Pacific people fare better on all three measures than other ethnicities, the confidence intervals are large. As the number of Asian and Pacific patients in the register increases, their survival numbers may change.

**Table 4: Māori and other ethnicities' survival with ABC**

	NZ Māori	Pacific Island	Asian	European
<b>Median survival (months)</b>	12.8 (9.5, 18.6)	18.5 (12.1, 23.1)	26.8 (18.3, 36.4)	15.7 (13.7, 17.3)
<b>One-year survival</b>	50% (41, 59)	64% (52, 73)	82% (68, 90)	57% (53, 60)
<b>Five-year survival</b>	5% (2, 10)	21% (13, 31)	14% (5, 29)	15% (12, 18)

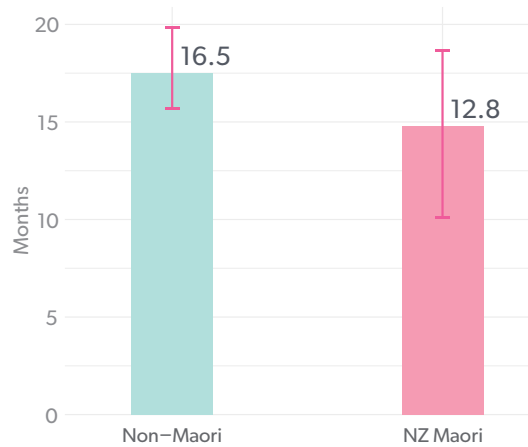
**Figure 7: One-year and five-year survival with ABC – Māori and non-Māori**



41 S Seneviratne, et al, "Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival", BMC Public Health (2015) 15:46



**Figure 8: Median survival with ABC – Māori and non-Māori**



### 2.3.2 de novo and recurrent survival

**Table 5: de novo and recurrent survival**

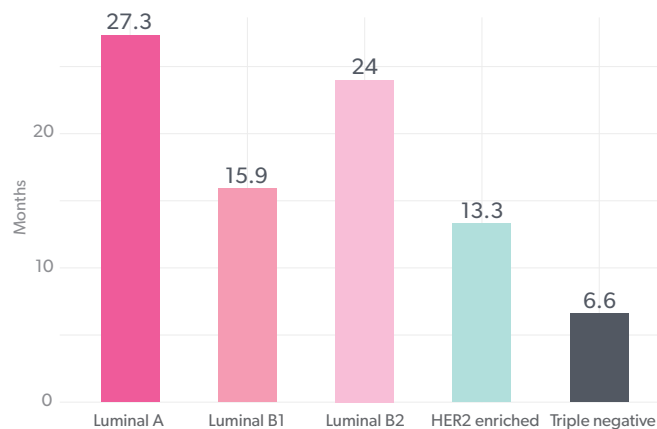
	Median survival (months)	One-year survival	Five-year survival
<b>de novo MBC</b>	29.2 (24, 36.1)	72%	23%
<b>Recurrent MBC</b>	13.9 (11.6, 16)	53%	11%

In line with studies overseas, New Zealanders with de novo ABC have significantly longer survival than patients with recurrent ABC. Overseas studies suggest this important distinction is not necessarily recognised when devising treatment plans, and that there is a need for greater understanding of the differences in outcomes between the two groups.<sup>42</sup>

### 2.3.3 Subtype and survival

Survival with ABC varies greatly by subtype, from an abysmal 6.6 months for people with triple negative breast cancer (TNBC), up to 27.3 months for those with Luminal A breast cancer. Patients in the ER- subtypes have worse survival than those in ER+ subtypes. The poor triple negative survival reflects a lack of targeted treatments for TNBC.

**Figure 9: Median survival after metastatic diagnosis by subtype**

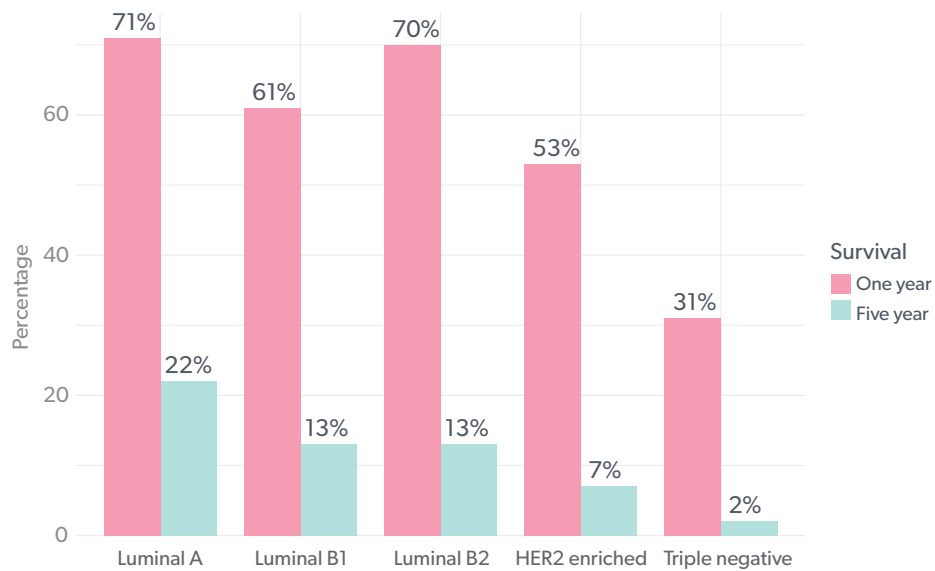


42 J Malmgren et al, "Differential presentation and survival of de novo and recurrent metastatic breast cancer over time: 1990–2010", Breast Cancer Res Treat (2017) DOI 10.1007/s10549-017-4529-5

**Table 6: 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)

**Figure 10: One-year and five-year survival by subtype**



## Where to from here?

- The health sector needs an urgent conversation about the reasons for New Zealand’s poorer survival with ABC. This should include consideration of access to new treatments, number of lines of therapy, reasons for worse survival among Māori, approaches to treatment and use of treatment guidelines. These issues are discussed further in **Section 6: World-class Treatment?**
- In planning treatment for de novo patients, clinicians should be aware of the possibility of significantly extended survival for these patients.
- Greater access to clinical trials could improve survival for some patients. Given the current poor median survival, clinical trials should be considered as a possibility for first-line treatment for all ABC patients, with equal access for patients regardless of location. Triple negative patients in particular need access to clinical trials.

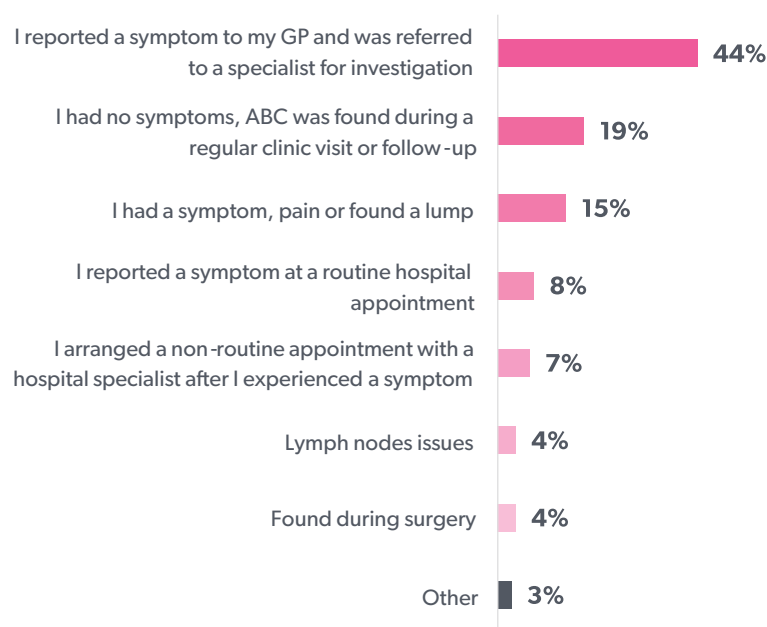
## 3 ABC Diagnosis

### In brief:

- **ABC is mostly diagnosed after the patient detects a symptom. Slow access to imaging tests to confirm diagnosis leads to treatment delays, potentially limiting clinicians' and patients' options in rapidly-progressing disease.**
- **The private sector is seen to offer more and faster diagnostic and treatment options than public.**
- **While most clinicians handle breaking the bad news of an ABC diagnosis well, a quarter of patients had a negative experience.**

### 3.1 Detection and diagnosis

Figure 11: "How was your advanced breast cancer detected?"<sup>43</sup>



Detection of advanced breast cancer mostly starts with a symptom experienced by the patient, who must often wait for a referral from their GP to be processed through the health system before they can return to a public hospital breast clinic.<sup>44</sup>

Both patients and medical professionals feel strongly that having access to treatment as soon as possible is important for ABC patients.<sup>43,44</sup> Metastatic disease is more easily managed (via drugs, radiation therapy and sometimes surgical removal) when there are fewer lesions (spots or areas of abnormal damage caused by the cancer). Clinical trial eligibility is often limited to patients with fewer metastatic lesions.

43 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

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

Slower spread of advanced disease – an important aim of medical treatment for these patients – tends to equal longer survival, with one study estimating that the risk of death increasing by 18% for each additional metastatic site.<sup>45</sup>

“ *The time for a GP referral to be acted upon with an appointment with the relevant specialist can be long.*

– Radiation oncologist

“ *What I do see is, working on the wait list for patients’ FSA (first specialist appointment), early breast cancer patients are seen slightly earlier than MBC, as (with) early we are aiming for cure.*

– Medical oncologist

Unlike early breast cancer patients, ABC patients’ access to diagnosis and treatment has not been monitored by the Government’s Faster Cancer Treatment targets – even though advanced disease is often more time-sensitive than early breast cancer.

Medical professionals acknowledge that private healthcare is seen to provide more treatment and diagnostic options for ABC than the public sector, and faster.<sup>46</sup>

Doctors believe that advanced radiation therapy techniques will allow a small percentage of ABC patients to be treated curatively, if the spread of their cancer is found when there are only a few metastatic lesions (see Section 6.4, Oligometastases). This will require metastases to be found sooner than they typically are now.

### 3.2 Communicating an ABC diagnosis

Most patients felt the way their ABC diagnosis was communicated to them was done well. However, one quarter had the bad news made even worse by the way in which it was delivered.

**Figure 12: “How do you feel about the way you were told you had ABC?”<sup>47</sup>**



“ *My GP phoned and asked to come to our house. So, I was told in the privacy of my home, which I found very thoughtful.*

“ *It was a shock, of course. The doctor who told me also immediately told me there was no cure and no hope, that they’d medicate me but I would die very soon. He also advised me to look into a hospice. It was pretty horrible.*

45 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

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

47 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

“The doctor was nearly crying! He was very careful to be clear about findings, answered all my questions and I was pleased with his sincerity and personal interest in how I was feeling about the news.”

“Very bad. I had been admitted to hospital due to my severe pain. I was by myself when a specialist came to see me. He assumed that I had already been told, but I still thought that I had DVT or something, as I had just arrived home from England. He had no empathy and even told me not to get morose about it when I showed some emotion.”

### 3.3 Where to from here?

- **Rapid access to diagnostic tests:**

ABC patients should not be lower priority than patients with early breast cancer. When people previously diagnosed with early breast cancer experience symptoms of metastasis, the system should provide rapid access to diagnostic tests in order to keep patients' range of treatment options as broad as possible. The Ministry of Health should consider setting targets for access to diagnostic tests for ABC, as there have been in early breast cancer. Suspected metastatic progression should also be prioritised for diagnostic imaging.

- **Kinder communication:**

Provide communications training to medical professionals who will have sensitive conversations with patients about terminal illness.

- **Surveillance strategies / emerging technologies:**

Existing guidelines (currently under review) do not recommend routine blood tests or imaging scans (other than mammograms) to monitor for advanced disease.<sup>48</sup> However, the guidelines acknowledge that the systematic reviews and meta-analyses underpinning those recommendations were of varying quality and had significant heterogeneity. No randomized controlled trials were considered for the guidelines, and the RCTs that have informed the debate on this topic were conducted in the 1990s<sup>49,50</sup>, before the widespread use of new targeted therapies and more sophisticated radiation therapies and imaging technologies. Recent advances in subtyping can enable better identification of at-risk patients who should be the focus of strategic surveillance.

For these reasons, existing evidence should not be considered definitive as to the effectiveness of surveillance in today's oncology environment. Emerging technologies, e.g. blood tests that monitor circulating tumour DNA (ctDNA), will potentially offer more affordable and effective means for earlier detection of metastasis, although this may present a clinical challenge in knowing how to respond to metastasis before lesions are visible. In the field of imaging, bio-engineering led advances may provide cheaper or more effective detection of metastasis in the future. In New Zealand, we should consider making pilots

48 Khatcheressian et al, "Breast Cancer Follow-Up and Management After Primary Treatment: American Society of Clinical Oncology Clinical

49 Rosselli Del Turco et al, "It is now the age to define the appropriate follow-up of primary breast cancer patients" J Clin Oncol 1994;12:1996-7

50 TG Investigators, "Impact of follow-up testing on survival and health-related quality of life in breast cancer patients. A multicenter randomized controlled trial. The GIVIO Investigators." JAMA. 1994;271:1587-92

and trials of clinically and economically effective new technologies for metastatic surveillance (both in high-risk early breast cancer patients and in ABC patients with progressive disease) a priority. Guidelines will need to be established for how patients should be treated in response to early detection of metastases.

## 4 Person-Centred Care

### In brief:

- **Person-centred care for people with ongoing disease improves patient quality of life, clinician satisfaction and health outcomes.**
- **When evaluating patient experience against the principles of person-centred care, it seems the system falls short in delivering person-centred care in some key areas of ABC management.**

### 4.1 Why person-centred care?

The Ministry of Health and most DHBs have committed to person-centred care (also called patient-centred care). Definitions vary, but one of the most widely used describes patient-centred care as espousing eight core principles<sup>51</sup>:

- **Respect for patients' values, preferences and expressed needs**
- **Coordination and integration of care**
- **Information, communication and education**
- **Physical comfort**
- **Emotional support and alleviation of fear and anxiety**
- **Involvement of family and friends**
- **Transition and continuity**
- **Access to care**

Systematic reviews show that patient-centred care in chronic disease results in increased adherence to management protocols, reduced morbidity and improved quality of life for patients<sup>52</sup>. It leads to better health outcomes, improved patient and family experience of care, better clinician and staff satisfaction, and wiser allocation of resources<sup>53</sup>. While still a terminal condition, on a day-to-day basis advanced cancer is a form of chronic disease, one with a high symptom burden.

Our research, detailed in sections 4.2. to 4.9, suggests that despite the best efforts of healthcare professionals, the system falls short in the delivery of person-centered care to people with ABC.

51 The Picker Institute's Principles of Patient-Centered Care

52 Getting it right: why bother with patient-centred care?, Bauman, A et al; Med J Aust 2003; 179 (5): 253-256.

53 Explanation of patient-centred care from the Institute of Patient- and Family-Centered Care, [www.ipfcc.org/about/pfcc.html](http://www.ipfcc.org/about/pfcc.html)

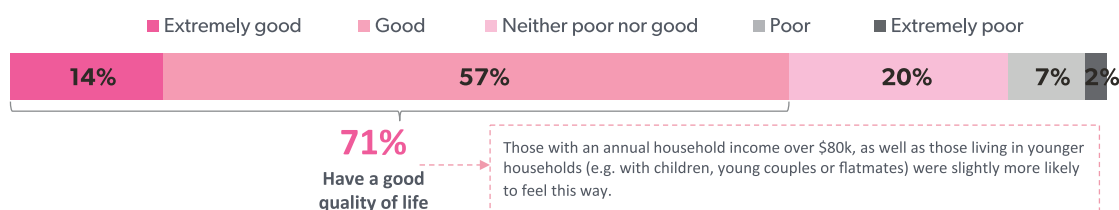
## 4.2 Quality of life

### In brief:

- Although most people with ABC consider they have a good quality of life, nearly a third do not. Support of friends and family is a major positive influence on quality of life.
- A quarter of patients do not believe their medical team is doing everything possible to extend their life and to give them a good quality of life.

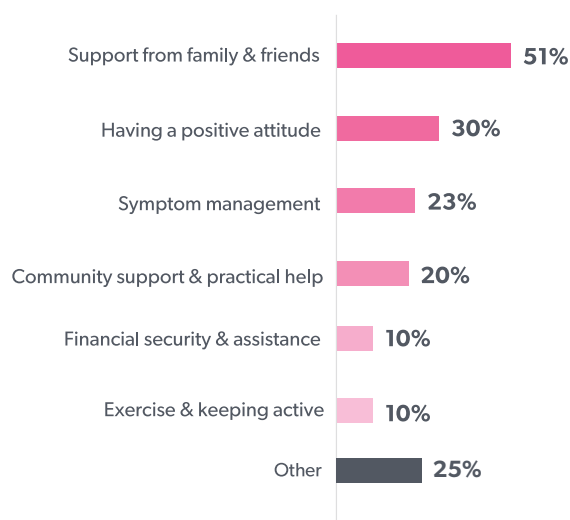
The *Understanding Advanced Breast Cancer in NZ – Patient Research study* (Ipsos) found that most New Zealanders with ABC consider they have a good quality of life.

**Figure 13: How would you rate your quality of life?**



However, nearly a third rate their quality of life as either neutral or poor. The key factors cited as **currently** having a positive effect on quality of life are **support from family and friends, community support and practical help, having a positive attitude, and symptom management** (although, as this report will discuss, this inability to manage symptoms is a major issue for many). **Exercise and financial security** are additional positive factors for some patients.

**Figure 14: Factors having the most positive impact on quality of life**

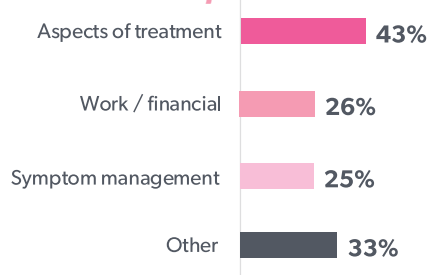


With the exception of symptom management, the factors that currently have the most positive effect on quality of life are unrelated to the disease and its treatment. But when asked **what could improve future quality of life the most**, responses were largely treatment-related, (including finding a cure, funding for new

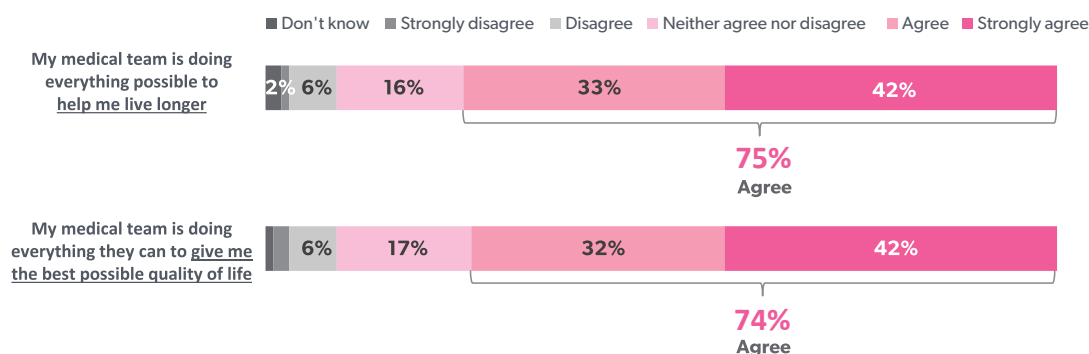


treatments, extended survival and “not being written off by specialists”), followed by financial aspects and symptom management.

**Figure 15: What would make the most positive difference to quality of life?**



**Figure 16: How do ABC patients feel about the quality of their care and the commitment of their medical teams?**



Three-quarters of patients feel their medical team is doing everything possible to extend their life and to give them a good quality of life, which is very encouraging. However, a significant one quarter of patients don't share that sentiment.

### 4.3 Respect for patients' values, preferences and expressed needs

**In brief:**

- **Healthcare professionals understand in principle that patients make the ultimate decisions surrounding treatment and support. However, doctors admit their own tendency to judge or dismiss patients' opinions can have a negative effect on the dialogue between patient and clinician.**

The qualitative study commissioned by Breast Cancer Foundation NZ found that healthcare professionals understand in principle that, ultimately, patients make the decisions surrounding treatment and support, and as medical professionals, they must respect patients' decisions. This understanding does not prevent some of them from at times disagreeing with the decisions their patients make.

The expertise of medical professionals can become an implicit barrier for ABC

patients, when their doctors come across as judgemental or apathetic towards patients who lack medical expertise, or whose values and opinions conflict with theirs.<sup>54</sup>

Medical professionals' intolerance around the values and opinions of their patients can also explicitly impede access to the "right" healthcare as determined by individual patients.

## 4.4 Coordination and integration of care

### In brief:

- **It appears many ABC patients miss out on the benefits of multidisciplinary meetings (MDT), widely regarded as the gold standard in cancer care.**
- **One third of patients have used private medical care in search of faster or unfunded treatments, but this can entail a sacrifice of continuity of care and has potential to jeopardise patient safety. Patients in the public sector who choose to pay for unfunded medicines that require infusions are forced to pay for private infusions, adding sometimes thousands of dollars per month to the already high cost of the medicine and disrupting the care they have been receiving from the public hospital team.**

The **multidisciplinary meeting** (MDT or MDM) is the gold standard for ensuring coordination and integration of cancer care in New Zealand, enabling medical experts to agree on the most appropriate treatment and care for an individual patient. The meetings are an opportunity to get a range of expert opinions and learn from best practice across multiple specialties.

MDT meetings are standard in early breast cancer, and medical professionals see them as an important part of providing continuity of care for their patients.

The Ministry of Health says, "MDMs have been shown to improve equality of outcomes for patients, improve continuity of care and avoid duplication of services."<sup>55</sup> The international ABC4 consensus guidelines state that every ABC patient should be treated by a specialised multidisciplinary team, including specialised side effects management and a nurse experienced in the treatment of ABC."<sup>56</sup> and this practice is increasingly a part of ABC treatment specifications within individual centres overseas<sup>57</sup>.

However, NZ clinicians say their MBC patients are generally not discussed at MDT meetings.<sup>54</sup> This seems primarily to be because breast cancer MDTs are surgery-led,

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

55 [www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-programme/multidisciplinary-meetings](http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-programme/multidisciplinary-meetings) accessed 17 January 2018

56 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

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

whereas ABC treatment is oncology-led. Patients with de novo metastatic disease are more likely to be discussed in the MDT than those with recurrent disease.

Doctors say<sup>58</sup>:

“ *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

“ *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

Some medical professionals said they are siloed in their departments and are unable to collaborate with colleagues in other departments to provide better options for patients. MDTs may also help to alleviate this issue.

“ *I think we need to work more cross collegially, maybe with combined clinics etc rather than being siloed in our depts.*

– Radiation oncologist

“ *The gaps are the lack of integration between the multidisciplinary teams and the time it takes to transfer care across different specialities.*

– Palliative care specialist

Coordination and integration of care also become issues when patients mix private and public treatment for advanced breast cancer, sometimes with the aim of faster treatment, or for access to treatments not available in the public sector.

The New Zealand Health & Disability Commissioner's *Code of Rights* is clear that care must be coordinated between the two sectors:

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***“Every consumer has the right to co-operation among providers to ensure quality and continuity of services.”<sup>59</sup>***

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One third of patients have accessed private care for their ABC treatment<sup>60</sup>, but our research suggests the level of quality and continuity of service often falls short.

Patients in the public sector who choose to pay for unfunded medicines that require infusions are forced to pay for private infusions, adding sometimes thousands of dollars per month to the already high cost of the medicine and disrupting the care they have been receiving from the public hospital team.

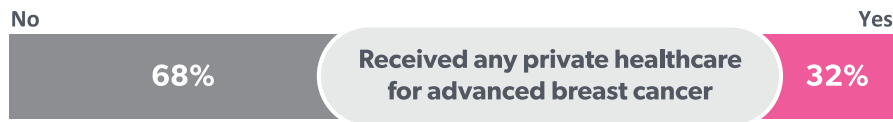
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58 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos

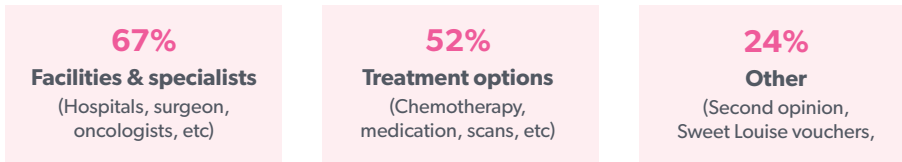
59 The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996

60 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

**Figure 18: “Have you received private healthcare for your advanced breast cancer?”**



**Types of private healthcare received (n=33)\***



However, while medical professionals see great benefit in quick access to treatment, some are sceptical that the private sector is delivering the best quality of care for its patients, and believe patients are forced to make a trade-off between the speed and access offered privately, and the more “wrap-around” supportive care patients receive in the public system.<sup>61</sup>

“ *The public system has a lot more resources for supporting the patient than the private system.*

– Medical oncologist

“ *We see no evidence of patient support services coming from the private sector and the public sector is expected to pick this up entirely.*

– Medical oncologist

“ *In our area I believe the public system provides a more comprehensive support system. We have access to an onsite psychologist and counsellor and patients can be referred to them.*

– Nurse

“ *Private system allows potentially quicker and direct access to be seen initially, but also the potential to continue on a treatment way beyond therapeutic benefit as long as the patient can continue to pay, can also create false expectations as all sorts of novel treatments with minimal survival benefits can be pursued at huge cost.*

– Nurse

In some instances, clinicians say, faster access to treatment can come at the cost of toxicity and associated side effects. When patients experience these effects, or become too unwell while undergoing treatment, medical professionals consider the public sector to have a responsibility to care for them – while some in the public sector resent having to “clean up” after their private colleagues. When patients are deemed to have suffered from decisions made in the private sector, some clinicians view the switch from private to public care with hostility. This is at best unfair on the patient, and at worst a potential risk to patient safety if this attitude were allowed to compromise clinical responsiveness.

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

“ Public system is often forced to manage toxicities of treatment delivered in private. And when we consider the “cost / benefit” ratio of some drugs this does seem inequitable. E.g. if there is a very high cost palliative drug treatment with a significant side effect profile. Patient is willing to pay for it in private despite narrow therapeutic index but costs of toxicity will be met within the public sector – this does not seem a fair use of public resource.

– Medical oncologist ”

Other things can impact on continuity. Whether entirely in public or private care, or mixing the two, patients commonly receive care from several specialists at different clinics, offering an inherent barrier to continuity.<sup>62</sup>

“ Continuity of care for patients with metastatic cancer is essential but not always available with multiple providers.

– Medical oncologist ”

“ Often it’s about continuity. Due to rotation of junior staff the patient does see a lot of different doctors.

– Medical oncologist ”

“ I think patients may struggle to have an overall picture of their cancer as they are seeing numerous doctors and they may see the registrar one month and another doctor then next time which may make it hard on them to get a good picture of what the plan is. I’m not entirely sure how they struggle to navigate the system as they don’t tell me and I don’t ask.

– Radiation oncologist ”

Patients themselves are aware of the value of coordinated services in easing their journey and providing better care.<sup>63</sup>

“ In the UK you are assigned one nurse (specialist) and she does everything. She organises and coordinates your care, trust funds, support groups, counselling, gives you website info and sends you copies of everything current... She sees you and rings you regularly feeding the information through at the rate she thinks relevant. It was an awesome service and diagnosis through the diagnostic centre is in 24 hours, it was incredible. My GP nurse rings me regularly, most weeks to check on me. Maybe GP nurses could be trained in this role, but would need frequent training and loads of info as things change constantly.

“ My dream is a one-stop-shop holistic wellbeing centre where all support services are interconnected and complementary. You have to work very hard to pull these strands together. ”

## Where to from here?

- Consider facilitating ABC-specific MDTs as having potential to generate greater continuity and a higher standard of care.

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

63 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

- Allow public hospital patients who are paying for unfunded medicines that are FDA-approved for their breast cancer to have the medicine infused free of charge in a public hospital. This would preserve continuity and reduce the financial burden on the patient.
- Being truly person-centred means ensuring private sector patients are not made to feel unwelcome or “a problem” when they seek emergency or other care in the public sector.
- Public and private providers must live up to the standard set by The Code of Rights. Safety concerns should not be an excuse to deny patients access to one system or the other, or to share care, but should be recognised and addressed to ensure patients can safely access the best possible care in either environment. Private providers should consider adding a greater level of wraparound support to patients within their existing pricing.

## 4.5 Information, communication and education

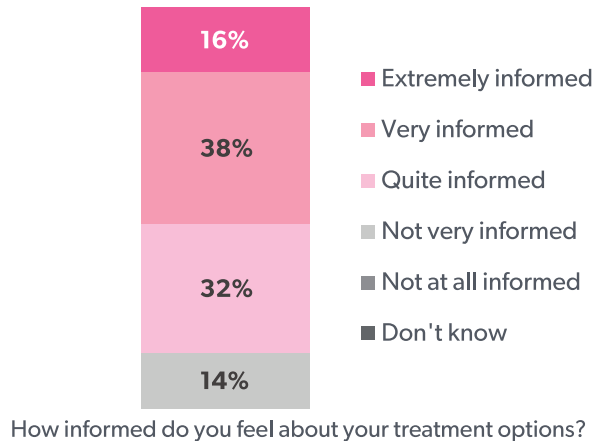
### In brief:

- **Despite a requirement to present all viable treatment options to patients (including unfunded treatments), time constraints and clinicians’ assumptions about patient circumstances mean that in reality, patients receive a version of their options that could be seen as “curated” but is in fact incomplete.**
- **Nearly half of patients feel “not very” informed or only “quite informed” about their treatment options. Only half of patients understand their actual treatment very well or better. One quarter say they are not or not very involved in decision-making.**
- **ABC patients with low health literacy struggle to navigate the healthcare system and need additional support to truly understand treatment options and make informed decisions.**

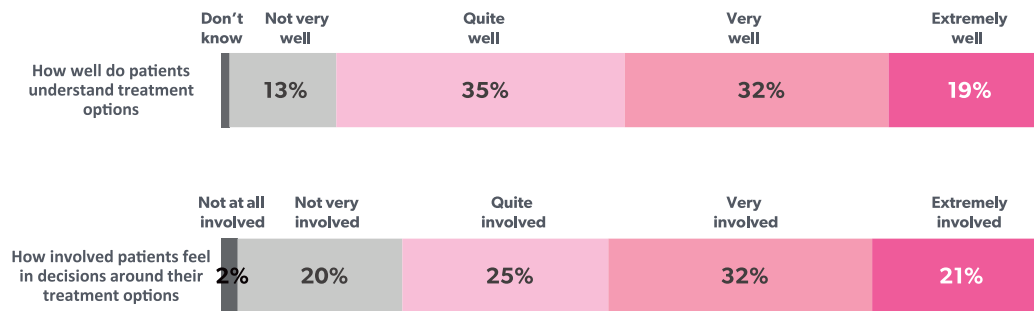
Treatment decisions for people with ABC have direct and major impact on their quality of life and on the time they have left. It is essential for patients to have as wide a range of options and as full an understanding of treatment decisions as they want. The research showed that just over half of patients feel highly informed about their options for treatment.<sup>64</sup> But nearly half feel “not very” or only “quite” informed. When it comes to their actual treatment, half of patients feel they understand their treatment very well or better. But more than a third only understand their options quite well and 13% not very well. **Is “quite well” good enough?** Half feel they are very or extremely involved in treatment decisions. A quarter are “quite involved”, but nearly a quarter of patients feel they are not very involved in these.

64 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

**Figure 19: “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 20: Understanding of and involvement in treatment options**



Patients’ sense of being under-informed is not just their imagination. Medical professionals are aware that different options exist for different people, and make their recommendations with this in mind. Combined with time constraints, this means that ABC patients are not always provided with all the options. Instead, sometimes, those options have been filtered and selected by medical professionals on the basis of assumptions about patients’ understanding, cultural factors, what the patient can or can’t afford, and what the doctor sees as “worth” spending money on. These assumptions may or may not be correct.<sup>65</sup>

On the positive side, most patients feel at least as informed as they were during their treatment for early breast cancer, with a substantial number feeling more informed. However, arguably, the stakes are higher now.

**Informing and obtaining consent**

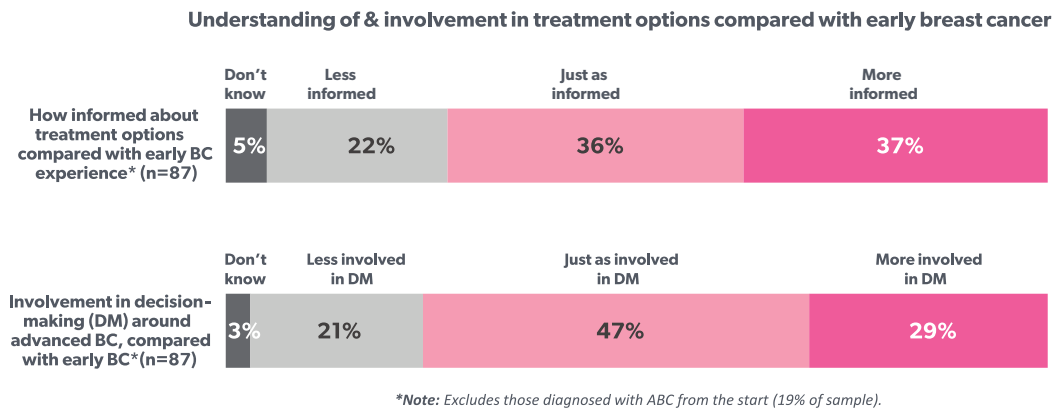
Informed consent is more than getting a patient to sign a consent form. The consent form is merely the written acknowledgment of a process that provides the patient with sufficient information in order to make an informed decision about their treatment. It is a two way communication process between a doctor and patient which results in the patient feeling confident that they have enough information to agree to undergo a specific medical intervention. It is also more than a one off action. It is a process throughout all stages of treatment or procedure....

In addition to discussing the risks and benefits of any proposed treatment, the patient has the right to know of alternative treatments and their risks and benefits. This does not mean that a doctor must know of every single possible alternative treatment, but they should know about a range of treatments that their colleagues would judge to be reasonably known by a doctor in their position. This includes informing the patient of treatment options that might be available outside of the publically funded health service.

**COLE’S MEDICAL PRACTICE  
IN NEW ZEALAND 2013, NZ  
Medical Council**

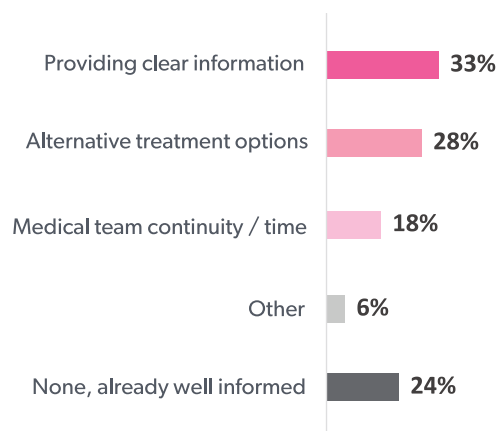
65 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos

**Figure 21: “How does that compare with your treatment for early breast cancer?”<sup>66</sup>**



While most feel informed on treatment options, patients reported they would still like more information about a range of alternative options, including other funded treatments, unfunded treatments and clinical trials. They also want information presented more clearly. Given that cancer treatments can have negative effects on cognition and memory, clarity should be a priority.

**Figure 22: “How could you be better informed about treatment options?”<sup>66</sup>**



“ Knowing more about the drugs available and what is potentially available in the not too distant future so I can make informed decisions re risk and reward; minimising side effects and having good quality of life for the longest time. ”

“ Take longer time with specialists around expectations of the treatment, what they are hoping to achieve with treatment. Be available for research programmes even if it means shifting to where the research is undertaken. Be listened to - I was put on hormone treatment. After 3-4 months I advised it wasn't helping, didn't get changed until 6 months, therefore extra 9 months more after diagnosis that cancer was unchecked. ”

“ It would be great to have doctors, researchers and other treatment providers in one holistic space to advise all kinds of potential treatment. ”



Medical professionals say that ABC patients with low health literacy struggle to navigate the healthcare system and need additional support to truly understand the treatment options with which they are presented to make informed decisions.

“ Literacy is vitally important in understanding a cancer diagnosis and the corresponding implications of both the illness and the treatment. I have accompanied several patients to clinic appointments to assist them with translation of medical jargon into something they could process and understand for themselves.

– Nurse

”

Knowing that patients are aware of how limited their doctors are for time, many doctors do go out of their way to make themselves contactable by doing things like giving out their personal phone numbers and saying they are available outside of working hours.<sup>67</sup>

“ I give out my cellphone number to all my patients so that progress through the system, whether ED, referral with a new pain or whatever, can be expedited. Even so, some are reluctant to bother me.

– Radiation oncologist

”

## 4.6 Physical comfort / emotional support and alleviation of fear and anxiety

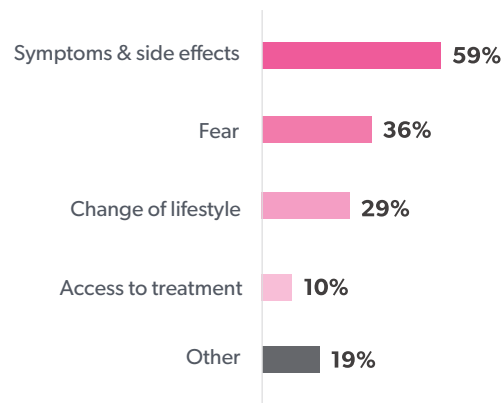
### In brief:

- **People with ABC live with many different emotional and physical side-effects, which are often underestimated and/or undertreated. These symptoms have a more negative impact than anything else on patients' quality of life.**
- **Although most patients feel they communicate well with their doctors, few feel they have good control over their symptoms.**

For people with ABC, ongoing physical and emotional symptoms and side effects – such as pain, fear, fatigue, depression – have a major impact on quality of life, with 59% rating symptoms and side effects as having the greatest negative impact. Fear, which is arguably also a side effect of an ABC diagnosis, is rated second highest.

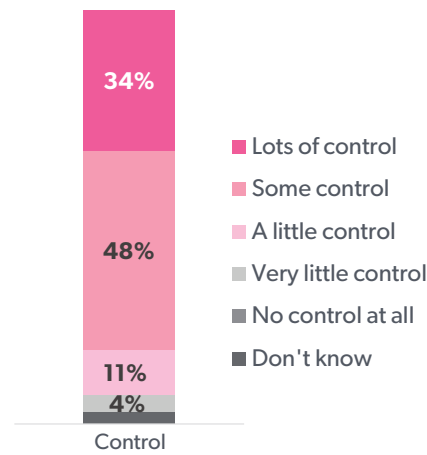
67 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos

**Figure 23: “What is having the most negative impact on your quality of life?”**



Unfortunately, only a third of patients are able to control their symptoms very well. The rest struggle to varying degrees.<sup>68</sup>

**Figure 24: Control over managing symptoms**



“ I’m on high doses of opiates for pain and this makes me very tired. So, I’m either in pain or sleepy. There doesn’t seem to be a balance. ”

“ I have to go to GP if I am having problems, who will then refer me to hospital. I don’t feel able to go directly to hospital. ”

“ I have been given a range of pain medicines and I am experimenting myself to find the best combination. I have been given very little advice about what / when to take various combinations. ”

Their experience is not unique to New Zealand ABC patients. International studies show cancer-related pain is notoriously under-reported and under-treated.<sup>69</sup> Despite improvements in the quality of cancer pain management over the last two decades, approximately one-third of patients still do not receive appropriate pain medication.<sup>70</sup>

68 Understanding the needs of healthcare professionals to optimise advanced breast cancer care, Ipsos  
 69 Roger Von Moos et al., “Improving quality of life in patients with advanced cancer: Targeting metastatic bone pain”, European Journal of Cancer 71 (2017): 80e94  
 70 M.T. Greco et al. “Quality of cancer pain management: an update of a systematic review of undertreatment of patients with cancer”, J Clin Oncol, 32 (2014): 4149-4154

Clinical focus on side effects can tend to be on more urgent or severe reactions, with less attention paid to grade 2 adverse events, such as persistent moderate fatigue, or nausea. These conditions can be quite debilitating, negatively affecting quality of life and potentially limiting patients' ability to continue with a treatment. Studies suggest that ABC patients experience an average of 14 symptoms, and that a focus on only acute grade 3 or 4 adverse events may lead clinicians to underestimate the impact of treatment on a patient's quality of life.<sup>71</sup>

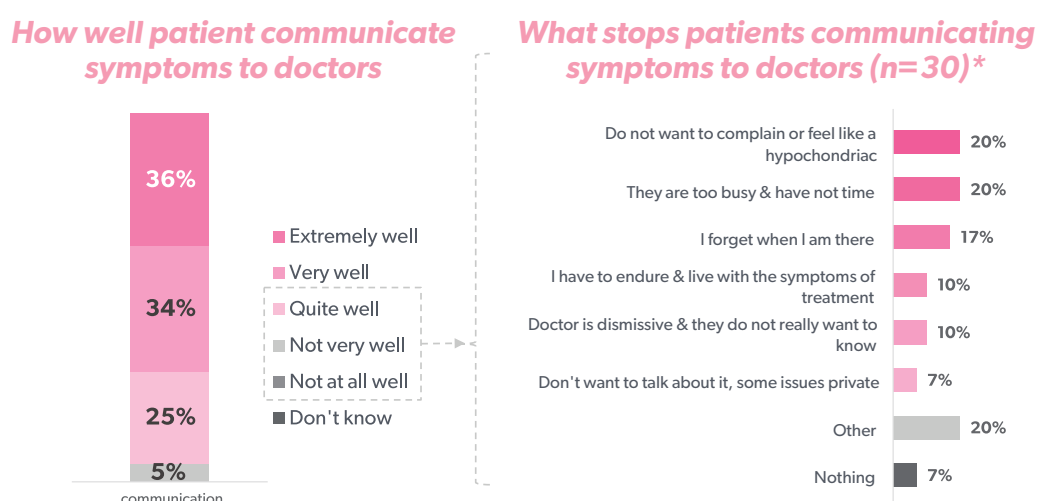
Good communication between patients and their medical team is a likely prerequisite for resolving symptoms. However, because people with ABC may have many months between specialist appointments or clinic visits, they may have limited opportunities for such communication. And although 70% of people with ABC believe they communicate well with their doctors<sup>72</sup>, patients and families may struggle to identify, assess, and classify pain in a way that leads to optimal treatment.<sup>71</sup>

Communication about symptoms is perhaps more important than doctors and patients realise. An important USA study showed that electronic reporting of symptoms by advanced cancer patients to a nurse in between clinic appointments not only improved quality of life, reduced hospital admissions and increased treatment adherence<sup>73</sup> but also extended overall survival by five months<sup>74</sup>, a greater survival benefit than offered by some new drug therapies.

1. Trust is a vital element in the patient-doctor relationship and for trust to exist, patients and doctors must believe that the other party is honest and willing to provide all necessary information that may influence the treatment or advice. The doctor needs to inform the patient about the potential risks and benefits of the options available and support the patient to make an informed choice.
2. Informed consent is an interactive process between a doctor and patient where the patient gains an understanding of his or her condition and receives an explanation of the options available including an assessment of the expected risks, side effects, benefits and costs of each option and thus is able to make an informed choice and give their informed consent

**Information, choice of treatment and informed consent, NZ Medical Council**

**Figure 25: Communication between doctors and patients**



Patients who feel they communicate symptoms effectively attribute that to having **a good relationship with their doctor and being direct.**<sup>72</sup> Others feel their doctor doesn't encourage either a level of connection or directness that would facilitate effective communication.

“ I write down my notes for each meeting, but the last two times I only saw a registrar. My pain this time around is severe and feel they have not taken as seriously as I would like - looking to speak to doctor about pain meds so I can sleep. I also always take my partner and we plan out and discuss what we will need to review. ”

71 Christopher Twelves, William J Gradishar, Joyce A O'Shaughnessy. "Clinical Roundtable Monograph: Effective Management of Quality of Life in Metastatic Breast Cancer", Clinical Advances in Hematology & Oncology, Vol 12, Iss 2, Suppl 4. Feb 2014

72 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

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

74 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

“ I am by nature an open person and my oncologist respects my need to understand what is happening (both my illness and treatment) and allows me to report fully. I feel included in the process as far as time allows. ”

“ I have a very open communication relationship with my oncologist. I feel free to email her if necessary. She is supportive to my husband attending all appointments - two heads are better than one. I have learnt to mention anything that I consider insignificant - and recognise her skill and training, as in every case she has found a problem and cure for the side effects I have mentioned. Never made me feel silly and in most cases has endorsed my feelings. ”

“ I tend to downplay things or think that they are not worth mentioning and will go away on their own. Taking my sister to appointments helps, as she says all the things that I've mentioned to her. ”

“ My oncologist has a rather abrupt manner and does not communicate in an empathetic or manner or make one feel that talking about my symptoms is encouraged. ”

“ My GP just doesn't want to hear it and blows me off. He's quite dismissive. His nurse asked me how my health was and I told her I have Stage IV cancer. She said 'but no high blood pressure, etc' and I told her that was correct. She said 'Ok. We'll mark your health as excellent!' My oncologist is just time-limited but happy to listen. ”

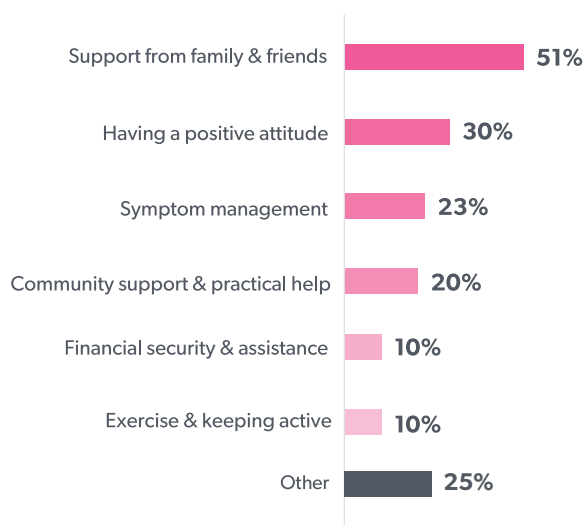
## Where to from here?

- Although patients believe they communicate well with their medical team, there is room for improvement on both sides. Patients need to put aside their fear of being considered a hypochondriac and the assumption that symptoms are something they just have to accept. They should consider writing down their symptoms, or taking someone with them to appointments to make sure symptoms are not forgotten. Patients and caregivers may benefit from training in how to identify, assess, classify, and treat pain; this could be the focus of a pilot.
- Medical professionals – specialists, GPs and nurses – may make some of the same assumptions about “having to live with” symptoms, and may need to be more proactive in enquiring about symptoms and referring patients for further support.
- There is a need for systems that facilitate easy (electronic) reporting of symptoms between clinic appointments, and access to nursing support to manage referrals (currently, many ABC patients do not have access to specialist nurse support).
- Earlier involvement of palliative care specialists in the treatment of ABC may help improve symptom management.

## 4.7 Involvement of family and friends

Family and friends play a vital role in quality of life for people with ABC, being overwhelmingly the most positive factor in determining quality of life.

Figure 26: "What is having the most positive impact on your quality of life?"<sup>75</sup>



### Where to from here?

- 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.
- Is there a role for NGOs in helping to upskill family and friends to support ABC patients?

## 4.8 Transition and continuity

### In brief:

- **Conversations around the decision to stop active treatment are difficult to time, challenging and stressful for clinicians and often not welcomed by patients.**
- **There do not appear to be any guidelines applied around stopping active treatment, and access to palliative care varies regionally. Clinicians agree that it generally comes too late.**

Unlike early breast cancer patients, who have a mostly linear progression through the healthcare system until they are discharged from treatment, ABC patients go in and out of the system, looping between oncology, GP and palliative care as their disease progresses.

75 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

Patients are sometimes, but not always, discharged from the hospital system when<sup>76</sup> there are no more treatment options.

“ We also follow patients with MBC for the rest of their life (well, until they are too unwell for further treatment).

– Medical oncologist

“ We do not have resource to keep seeing patients if they are not on treatment. Once they stop treatment they are discharged to hospice and GP.”

– Medical oncologist

This transition to GP care can be hard for medical professionals and ABC patients alike, with the medical team feeling helpless to prolong life, and patients distressed that they have limited treatment options. Patients often feel their GP or practice nurse isn't equipped to help.<sup>77</sup>

The palliative care transition is more complex.

Palliative care “focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.”<sup>78</sup>

Generally, clinicians consider all treatment for MBC to be palliative, in that it cannot be curative (this may change for a very small percentage of patients as treatment for oligometastases with stereotactic radiotherapy increases, see Section 6.4 Oligometastases). Rather than aiming for cure, palliative treatment (including surgery, chemotherapy, radiotherapy and others) has the dual goals of prolonging survival and maintaining or improving quality of life.

For patients, on the other hand, the word “palliative” is associated with a cessation of active treatment, and the beginning of end-of-life care. No patients in the Ipsos quantitative patient study mentioned palliative care as something that might improve their quality of life, or as a service they had any experience with.<sup>77</sup>

“ Unfortunately palliative care is seen as end stage and I believe if patients and families are introduced to the concept and associated supports from palliative care earlier there is improved outcomes for families... I think there needs to be a more integrated approach between treatment centres, primary care and palliative care team.

– Nurse

The Government's (yet to be ratified) Standards of Service Provision for Breast Cancer Patients in New Zealand make it clear that palliative care in ABC is not intended to be end-of-life only.

#### Standard 8.11

Women with advanced breast cancer are offered early access to palliative care services. This is especially important when there are complex symptom control issues, when breast cancer treatment cannot be offered or if such treatment is declined.

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

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

77 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

78 Center to Advance Palliative Care, [www.capc.org/about/palliative-care/](http://www.capc.org/about/palliative-care/) accessed 17/01/2017

However, DHBs around New Zealand vary in the stage at which they offer palliative care. In at least one region, access to palliative care requires a life expectancy of only six weeks.<sup>79</sup> Whether this is an officially stated time, or becomes the actual service delivery due to resource constraints, this falls well short of the Standards of Service Provision. Other regions have similar challenges.

“ *The palliative care funding is too little and requires a life expectancy of 6 weeks or less. It is ridiculous to expect that to be realistically estimated.*

– Radiation oncologist

“ *A main challenge is also achieving a more effective integration with palliative care while the patient is still on active treatment with an expected prognosis greater than 12 months. These patients can often greatly benefit from the specialist palliative care input running parallel with oncology at an earlier point in the patient journey, but this can be difficult to achieve due to referral and resource / budgeting restraints of palliative care services.*

– Nurse

Resource constraints are not the only factor preventing timely uptake of palliative care. Optimism (whether unrealistic or not) on the part of both patient and doctor is another contributor to delays.

“ *Oncologists have a very hard job, balancing the maintenance of hope whilst being honest, especially when many palliative [chemo] treatments work well, so patients are lured into thinking there will always be another therapy to work, when the last one has failed.*

– Palliative care specialist

“ *An overly optimistic physician (or patient) can result in delays and there are oncologists who are widely known for accepting the inevitable much later than others. This can be a problem.*

– Nurse

“ *One of the most common reasons for our department to refer a case to our in-house mortality and morbidity meetings is due to a MBC patient dying while on obviously futile treatment. We frequently review why a decision to stop wasn't reached despite a clear situation that we were doing harm. More formalised decision-making tools around MBC treatments would be a huge benefit in this regard.*

– Palliative care specialist

Research shows that palliative care can improve the patient and family experience in dealing with advanced disease<sup>80</sup>, and a landmark study of advanced lung cancer patients found that palliative care, delivered concurrently with oncologic palliative treatments such as chemotherapy, resulted in improvements in quality of life and mood, less aggressive care at the end of life, and prolonged survival.<sup>81</sup>

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

80 K. Ramchandran, and JH Von Roenn, “Palliative care always”, *Oncology*. 27(1) (2013):13-6, 27-30, 32-4 passim.

81 JS Temel et al, “Early palliative care for patients with metastatic non-small-cell lung cancer”, *N Engl J Med*. 363 (2010):733-42

Regardless of when palliative care starts, there will be a point at which active treatment for ABC stops. Understandably, this is a difficult conversation for healthcare professionals<sup>82</sup>, with some feeling they lack the time or the communications skills to hold these conversations well. The conversation is often not welcomed by patients, and is difficult to time, due to frequently changing patient pathways and an apparent lack of guidelines applied around stopping active treatment.

As a result, these transitional conversations appear to not always be happening smoothly or at the right time – at worst, they appear to be avoided and put off until the last possible moment.

“ *I do worry that access to specialist pall care happens much later in private practice than public.*

– Palliative care specialist

”

Medical professionals agree in theory that palliative care should be introduced much earlier in the healthcare pathway for ABC patients.<sup>82</sup>

“ *Many of the people we look after have felt disempowered by the medical machinery and part of their “wellbeing” is feeling in control again. This sort of control / respect regained is often more important than a longer life.*

– Palliative care specialist

”

“ *A palliative approach with providers working alongside each other during the trajectory of illness would maximise better outcomes for all patients.*

– Nurse specialist

”

## Where to from here?

- Introduce palliative care specialists into ABC care at the time of diagnosis, in line with the Standards of Service Provision for Breast Cancer, to help reduce negative associations and educate patients about the value of palliative care. Palliative specialists should be present in the MDT when ABC patients are discussed.
- If necessary, provide support and training to medical professionals in how to have difficult conversations.
- Investigate variations in palliative care access, and discrepancies between stated and delivered access, around the country.
- Consider developing guidelines or a decision support tool to help doctors and patients work together to determine when active treatment should cease.

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



## 4.9 Access to care

### In brief:

- **Sudden or rapid disease progression requires quick access to appropriate specialists, to relieve pain and prolong life. Healthcare professionals feel the frustration of not always being able to meet patients' needs in a timely manner.**
- **Oncology 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.**

Accessibility of specialists and specialty services, ease of scheduling appointments, and availability of appointments when needed are all issues for ABC patients, whose disease status can change suddenly.<sup>83</sup>

“ *The challenges faced are having a system that can respond to changes in a patient's clinical course in a timely fashion and having all treatment modalities with quick response times. If a patient has to wait 4 weeks to see a rad onc for some palliative radiotherapy to a bony met this is not providing timely care. They (sic) same is true if a patient with liver mets needs to wait 4 weeks to see a med onc to have systemic therapy initiated. In some patients the pace of the disease is too fast for these long wait times.*

– Radiation oncologist

”

Medical professionals are trying their best to get the most out of the healthcare system for their patients; but the system in which they are operating has limitations and constraints – time, funding and support – within which they must work. These parameters manifest in aspects such as opening hours, funded treatments, and prioritised patient lists. At present, it seems medical professionals do not feel they have all they need to provide the best quality of care for their ABC patients; some are struggling and feel they are stretched too thinly to meet their patients' needs.<sup>83</sup>

Some aspects of the system actively thwart timely treatment for ABC patients. Chemo suites often assign ABC patients a lower priority for chemotherapy than early breast cancer, despite the fact that in many cases, ABC will progress faster than early disease. Given that, for example, triple negative patients have an average ABC survival of 6.6 months, any delay is unacceptable. And while ER+ patients are a longer-surviving patient group, they are typically offered chemo at times of rapid progression, or when other options are exhausted, again making it difficult to justify delaying chemo.

Medical professionals perceive that people with ABC face more challenges navigating the healthcare system than early breast cancer patients, with these challenges the result of differences in disease rather than various socioeconomic or cultural factors. However, within the subset of ABC patients, difficulties with transportation and language can be particularly challenging.<sup>83</sup>

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

“ A diagnosis of breast cancer can be a very lonely journey and someone whose command of English is poor is disadvantaged from the outset.

– Nurse

“ Many (Māori and Pacific peoples) are mistrustful of our organisations and systems, some believe their cancer diagnosis is payback for the way they have lived their lives, others just do not have the language, support systems or access to our conventional services to make more appropriate choices.

– Nurse

Healthcare professionals suggest access issues mean Māori and Pacific people are more likely to miss appointments.<sup>84</sup> While there are health initiatives designed to support socioeconomically vulnerable groups, e.g. with coordinated transport and health literacy support, these services are not seen as being available to all who require them.

Geography also affects access, with patients in provincial areas sometimes having fewer options presented to them than urban patients, or struggling to take up recommended treatments.<sup>84</sup>

“ Rural patients are less likely to take up radiation therapy compared with patients in cities that have a radiation therapy department.

– Radiation oncologist

“ As I work in a tertiary centre we have more available for the patients than in a rural setting. Such as medical oncology consultants, hospice. Due to the location I work in MBC patients also have access to community cancer nurses and palliative care coordinators which enhances their care.

– Nurse

“ Due to our geography, I cannot offer treatment at a local centre if they live a long way from our regional service and I also may not be able to see them locally in a clinic in a timely way as our clinics are often 2-3 weekly at the regional clinics if they are having a lot of symptoms we offer them an appointment at our main centre but this means travelling to discuss a treatment they may or may not want and they may prefer to wait to be seen in their local clinic. To me this is not equitable. Our local patients will often be seen in 1 or 2 weeks of referral but regional patients could wait 4 weeks.

– Radiation oncologist

## Where to from here?

- Māori and Pacific nurses and care coordinators can play a significant role in easing access. Assess whether existing resources are sufficient.
- Prioritise ABC patients for appointments related to suspected change in disease and for chemotherapy appointments.
- Quantify regional access issues and identify strategies to ensure equity. In the light of regional variations, consider if there is a need for a national approach to ABC.

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

## 5 Hot Topics

### In brief:

- **Workload constraints limit the time clinicians have to talk with patients. Patients must initiate conversations on the topics that really matter to them – clinical trials, new or unfunded treatments, complementary medicines – and sometimes doubt their medical team’s receptiveness.**
- **Clinicians fall short of their own standards in their ability and willingness to discuss complementary therapies with patients.**
- **Clinical trials offer a chance for ABC patients to access potentially life-extending treatments that are not funded by Pharmac; they also ensure a level of care and monitoring that patients may not otherwise be experiencing. There are not enough drug trials in NZ; those that are established sometimes fail to recruit patients. This can be due to refusal of DHBs to admit patients from other areas, or to clinicians’ reluctance to refer patients. However, anecdotally, we observe increased interest in clinical trials in some centres over the past year.**

### 5.1 Opportunities to converse

Time restrictions force healthcare professionals to prioritise which topics to discuss with their patients, and consequently they are not always able to have conversations about everything they would like to.<sup>85</sup>

“ *There is very limited opportunity to sit and talk, due to constraints of time and workload. We work in an area with a “factory-like” approach to treatment. Training focusses on the safe delivery of care, trying to minimise harm. There is little, or limited, focus on communication & equipping nurses for meaningful communication when we collectively, as a discipline, spend the most time with patients. ...A focus on communication training may allow health workers (to) use tools & strategies to enable more meaningful conversations... There is sometimes an issue of the fear of saying the wrong thing... we are not all equipped to start, maintain, or conclude these conversations whilst at the same time staying safe within ourselves.*

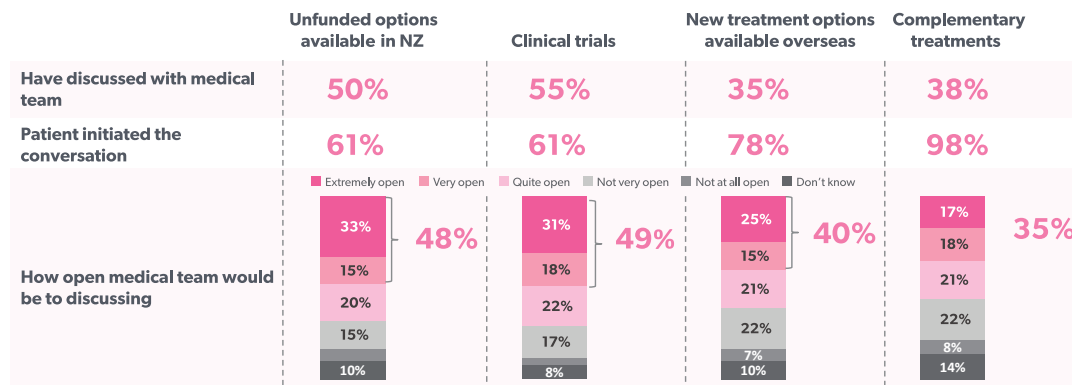
– Nurse

On the flipside, patients don’t get to talk about what concerns them, either. Patients want to talk about clinical trials, about unfunded medicines, about new treatments overseas, and about complementary medicines. But more often than not, they have to initiate the conversation, and they sometimes doubt their medical team’s receptiveness.<sup>86</sup>

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

86 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

**Figure 27: “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?”**



## 5.2 Clinical Trials

Clinical trials are seen by ABC patients as a way to access new or unfunded medications, and as offering hope when existing medication options have been exhausted. Clinical trials typically offer a level of monitoring and care that ABC patients may not otherwise receive on an ongoing basis. Despite patients’ strong interest in clinical trials, we estimate that less than 5% of breast cancer patients in New Zealand participate in clinical trials.

“ I think trials are critical for NZ to be at the cutting edge, providing modern care, but there is not a focus on this. I don’t see a future for trials in MBC for much longer in NZ. They are expensive to set up, and with the increasing fragmentation of breast cancer subtypes, hard to recruit to.

– Palliative care specialist

“ In NZ we are also struggling to be offered trials funded by industry as they feel that their drugs will not be funded in this country in the future. I do however feel that enrolling patients in clinical trials is vitally important.

– Medical oncologist

Medical professionals reported they are interested in clinical trials and believe trials are essential for oncology as a discipline<sup>87</sup>. But some have little faith in how trials are currently operating and say there are many barriers preventing them from being involved in good clinical trials. For medical professionals to take on an investigator role in clinical trials requires large amounts of time and funding, which they struggle to access, and they also perceive challenges in recruiting patients to participate in trials. These factors can deter them personally from being involved in running trials.

“ I am supportive of clinical trials but it is increasingly difficult and frustrating to open / run them due to the costs associated with e.g. data management.

– Radiation oncologist

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

At the same time, some doctors are reluctant to suggest their patients become involved in clinical trials run by others. For some, this may stem from a belief that trials are not conducted optimally, with the right purpose, and a suspicion that other medical professionals undertake trials to fulfil economic or career interests. Note, this was a minority view among respondents, with no substantiation offered.<sup>88</sup>

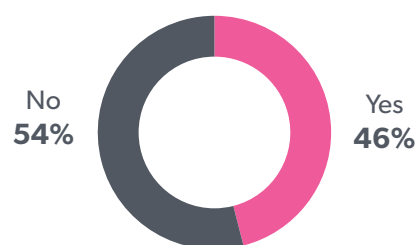
ABC patient participation in clinical trials is considered challenging, especially if patients must travel long distances. Doctors believe that travel for many ABC patients is not an option as they are either too unwell or cannot afford travel and accommodation costs; this is contrary to the expressed level of interest that patients themselves have in trials and their willingness to make a financial contribution to their treatment.<sup>89</sup> It is also contrary to an expert report commissioned by the Health Select Committee, which noted that a national patient referral network is essential for an effective clinical trial environment.<sup>90</sup> In reality, patients encounter bureaucratic barriers when they wish to access a trial outside their region.

Medical professionals perceive patients as interested in participating in clinical trials for a variety of reasons, including seeing trials as the last option (“they have nothing left to lose”) and an altruistic motive of helping to make a difference for future patients.<sup>88</sup> This contrasts with the doctors’ understanding of a trial as having a specific investigative purpose, which may not provide a positive result for the individual patient. Doctors are therefore conscious to ensure their patients have realistic expectations around what they will get out of the trial and any potential side effects.

Anecdotally, Breast Cancer Foundation NZ has observed increased interest in clinical trials among clinicians over the past year.

### 5.3 Complementary medicines

**Figure 28: Used any complementary therapies for advanced breast cancer**



Around half of patients have used complementary treatments, but this can be a difficult conversation with their medical team.<sup>89</sup> Only 35% of patients who haven’t discussed complementary treatment with their medical team think their doctors would be open to the conversation, and of those who have discussed it, the patient initiated the conversation in 98% of cases.

Yet most medical professionals claim they are happy to speak with their patients about complementary and alternative medicines (CAMs) – even though they may disagree about the value of such treatment – and indeed are sometimes anxious

“Patients sometimes raise the possibility of a treatment that the doctor does not agree with or does not know about. This is especially true of “alternative therapies”. In these circumstances the doctor should advise the patient of the evidence base for the respective treatments as far as they know them, and give the patient clear reasons why they recommend one treatment over another.”

**Coles Medical Practice in NZ, 2013 – NZ Medical Council**

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

89 Understanding Advanced Breast Cancer in NZ – Patient Research, Ipsos

90 “Improving New Zealand’s Environment to Support Innovation Through Clinical Trials”, Report to Health Select Committee by Cranleigh Health, 2010

to know what supplements patients are taking.<sup>91</sup> Some see that complementary therapies can play an important role in the wellbeing of patients and are critical of the healthcare system that appears to discredit CAMs, while others are critical of CAMs for their lack of scientific support.

“ *I prefer patients not to take complementary therapies while on chemotherapy as I have concerns regarding safety, toxicity and possible interaction with the efficacy of chemo.*

– Medical oncologist

“ *Due to time constraints I have in managing my ‘standard’ radiation related issues related to the treatment of MBC patients on a day to day basis, I do not have the time available to explore this in detail with the patients or to increase significantly my in depth knowledge of these areas of CAM.*

– Radiation oncologist

“ *I am interested in complementary therapies as I think they can enhance the wellbeing of the patient.*

– Medical oncologist

There is limited scientific evidence related to most complementary therapies in cancer. However, studies suggest this is an area where many medical professionals may know less than their patients, and for that reason, recent years have seen the publication of scientific papers discussing the benefits and harms of nutritional supplements in cancer, along with the production of guidelines rating supplements and other therapies according to their proven efficacy in breast cancer.<sup>92,93</sup>

Despite these resources, with many healthcare professionals pressed for time, if they are forced to be selective about the topics they discuss with their patients, CAMs are likely to not be discussed. Because some complementary therapies may lessen the effectiveness of medical treatments, it is important for patients to feel comfortable discussing these therapies with their medical team.

## 5.4 Where to from here?

- All patients with advanced breast cancer should have a conversation about clinical trials at the point where their advanced disease is diagnosed, and the subject should be revisited when relevant trials arise. Doctors should not assume patients are not interested, not well enough, or unable to fund travel costs, and should be willing to refer their patients for eligibility assessment.
- National recruitment for trials is a way to counter recruitment challenges, and should be the default for trials, with exceptions for made 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.

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

92 Moshe Frenkel and Victor Sierpina, “The Use of Dietary Supplements in Oncology”. *Curr Oncol Rep* (2014) 16:411

93 Heather Greenlee et al, “Clinical Practice Guidelines on the Evidence-Based Use of Integrative Therapies During and After Breast Cancer Treatment”, *CA Cancer J Clin* (2017);67:194–232

- For safety's sake, doctors should proactively ask their patients if they are using any complementary therapies. It will be easier to come across as respectful of patients' decisions if they avoid lumping all complementary therapies into one "rubbish" basket. It may be useful for doctors to familiarise themselves with the more popular therapies and ensure they are up-to-date with latest thinking and research, so they can give patients an informed assessment of possible harms and benefits.
- Medical professionals could ask patients the extent to which they want to be informed on topics, such as the full range of treatment options (funded and unfunded). They should avoid making assumptions based on perceived socio-economic and cultural factors. Could ABC patients be allocated longer appointments, given the weight of conversations about balancing of quality of life and extended survival?

## 6 World-Class Treatment?

### In brief:

- **New Zealand is a world leader in the collection of near-national data about ABC diagnosis, treatment and outcomes.**
- **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.**
- **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. 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.**
- **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.**
- **Healthcare professionals expressed a lack of awareness of or adherence to international guidelines for treatment of ABC and suggested that local guidelines may vary between centres. This could potentially allow for suboptimal care or less ambitious treatment plans.**
- **The potential for treating oligometastases with intent to cure is currently under-explored worldwide, yet many oncologists believe it will play a significant role in future.**

### 6.1 ABC epidemiology, treatment and outcomes data

New Zealand is ahead of most other countries in our collection of data about advanced breast cancer. The Breast Cancer Foundation National Register currently records c. 70% of all breast cancer diagnoses (>99% of diagnoses across the four regions currently represented), and this will rise to almost 100% nationwide as additional DHBs join the Register over the next few years. With the exception of de novo cases, The Ministry of Health does not collect data about metastatic breast cancer, so the Breast Cancer Foundation National Register is the only repository of such data.

The Register enables: an understanding of the epidemiology of de novo and relapsed metastatic breast cancer; audit of individual clinicians' practice; insights into pathology, treatment and survival; national treatment and outcome analysis; and comparison of treatments and outcomes between regions. It also provides data that can be used for international benchmarking.



Currently, the primary limitation on international benchmarking is lack of data from other countries. The European Society of Medical Oncology notes there is “a major lack of accurate data on this prevalence [of metastatic breast cancer] in the great majority of countries since most cancer registries do not capture relapses.”<sup>94</sup> In the USA, the Surveillance, Epidemiology and End Results (SEER) Program collects data from population-based cancer registries covering c.34.6% of the US population and is comparable to the general US population with regard to measures of poverty and education. SEER offers insight into de novo metastatic breast cancer, but there are no nationally representative data on recurrence / relapse, and most registries do not routinely collect relapse data.<sup>95</sup> The Australian state cancer registers also capture only de novo data.

The NHS in the UK mandated in 2013 that NHS Trusts must collect data about secondary breast cancer. However, no data have yet been published, and there is no accurate information about the number of people diagnosed and living with ABC, the treatment they receive, or their survival.<sup>96</sup>

## 6.1.1 International survival comparisons

The comparative data in **Table 7: Metastatic Breast Cancer Survival – an international snapshot** is a compilation of studies from registers and cancer centres around the world. Some are de novo-only or recurrent-only, while others combine the two patient groups. We note that none of these studies refer to UK data, which could be expected to offer a useful comparison with NZ. The varying dates, sizes and emphases of the different studies make direct comparisons difficult. However, the following points should be of interest and concern to anyone involved in care of people with ABC:

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

This study does not definitively answer the question as to why our survival is worse, but opens up areas for discussion and further investigation.

The possibility of lead-time bias affecting our survival statistics must be considered. Do other countries detect metastatic disease earlier than we do in New Zealand, and thus appear to have a longer survival after metastatic diagnosis? Given that no guidelines recommend routine imaging surveillance of asymptomatic people after treatment for early breast cancer (with the exception of mammograms), it seems unlikely that lead-time bias plays a major role in improved survival figures. It is likely that in the USA, at least, patients receive more active follow-up after early breast cancer, which could result in early detection of metastases; however, NZ’s survival compares poorly across a range of countries. Most of the studies that evaluate survival across different time periods show significant improvements in survival in more recent periods; those studies do not attribute extended survival to lead-time bias resulting from improvements in detection.

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94 F. Cardoso et al, “Locally recurrent or metastatic breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up”, *Annals of Oncology* 23 (2012) (Supplement 7): vii11–vii19 doi:10.1093/annonc/mds232

95 A. 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)

96 “The Case for Change”, report produced by Breast Cancer Care UK, October 2017

With regard to de novo diagnoses, there is no evidence to suggest New Zealand's de novo diagnoses occur later than de novo cases in other countries. New Zealand's overall high uptake of mammogram screening and an incidence of de novo diagnoses comparable to or lower than other countries do not suggest delays in initial diagnosis. While some high-deprivation groups tend to have later diagnosis of breast cancer (leading to worse outcomes), these represent only a small percentage of patients.

On balance, we do not believe there is evidence to suggest that lead-time bias plays an important role in our poor survival figures.

The possibility was also raised that some "good" metastatic breast cancers (slow-growing bone metastases likely to have a longer survival) are not being entered in the Breast Cancer Foundation National Register, thus potentially skewing the survival data. At this stage, we do not have any evidence to suggest this is the case, but this could be investigated further. We assume the de novo data represent the full spectrum of "good" and "bad" metastatic cancers, as these would all be classified metastatic at initial diagnosis, regardless of the extent of metastatic spread.

Possible contributors to poor survival discussed below include access to new medicines and the number of systemic therapies given to metastatic patients, as well as treatment conversations and approaches.

### 6.1.1.1 Median survival

Studies routinely use phrases like "two to three years" to describe median survival after diagnosis of metastatic breast cancer, well ahead of New Zealand's median survival (16 months). A more detailed investigation of a range of high quality studies in OECD countries reveals only one other study with a median under 20 months: a single-centre Swedish study<sup>97</sup> showed a median MBC survival of 18 months. However, the Swedish data goes back to 1985, an era when survival was considerably worse than it is today. In the same study, MBC median survival since 2010 is 33 months (compared with 18.8 months in NZ from 2010-2015). Median survival in the other studies cited ranges from 22 to 42 months for recurrent or mixed recurrent-de novo metastatic breast cancer.

As in New Zealand, all the overseas studies that separated out recurrent and de novo survival showed better survival for de novo patients. One USA study<sup>98</sup> put median de novo survival 1990-2010 at 3.92 years (47 months), but this was an outlier; New Zealand's 29 months' median de novo survival was similar to medians observed in Dutch and Canadian studies.

### 6.1.1.2 One-year and five-year survival

New Zealand had worse one-year and five-year survival with ABC than other countries. The nearest to our combined de novo and recurrent one-year survival of 58% is the Munich Cancer Registry, with 67% one-year survival. One USA study of recurrent patients reported 80% one-year survival, compared with 53% in New Zealand.

97 M Sundquist et al, "Improved survival in metastatic breast cancer 1985-2016", *The Breast* 31 (2017) 46e50

98 J Malmgren et al, "Differential presentation and survival of de novo and recurrent metastatic breast cancer over time: 1990-2010", *Breast Cancer Res Treat* (2017) DOI 10.1007/s10549-017-4529-5

On a more positive note, New Zealand's de novo one-year survival of 72% was the same as the Munich Registry<sup>99</sup>, and similar to the New South Wales Cancer Register in Australia<sup>100</sup> (73.9%).

New Zealand's five-year survival (14%) was again the worst of the studies reviewed. While a single-centre Swedish study<sup>101</sup> also had 14% five-year survival, that study showed 27% five-year survival since 2010, compared with 15% in New Zealand from 2010-2015.

The most "apples-for-apples" comparison in Table 7, and one of the most challenging statistics in this report, is the five year survival for de novo patients in the New Zealand register 2000-2015 (23%) compared with de novo patients in the New South Wales Cancer Register 1995-2009 (44%).

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

100 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

101 M Sundquist et al, "Improved survival in metastatic breast cancer 1985-2016", *The Breast* 31 (2017) 46e50

**Table 7: 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)
2018	Breast Cancer Foundation National Register (NZ)	950 (long term data only)	2000-2015	16 (29 dnMBC) (14 rMBC)  (27 Lum A, 16 Lum B1, 24 Lum B2, 7 TNBC, 13 HER2 enriched)
			2000-2004	10.6
			2005-2009	14
			2010-2015	18.8
2015 <sup>i</sup>	New Zealand	1920	1994-2011	
2016 <sup>ii</sup>	Australia	N/A	1995-2009	N/A
2017 <sup>iii</sup>	Germany	7559	1998-2015	
			1988-1997	
			1998-2006	
			2007+	
2015 <sup>iv</sup>	Netherlands	815	2007-2009	29.4 (dnMBC) 21.1 (rMBC)
2014 <sup>v</sup>	Germany	716	1995-2013	36.8 (37 ER+, 34 HER2+, 13 TNBC)
2017 <sup>vi</sup>	USA	12762	2005-2012	25.2 38.4 for patients <50 at metastatic diagnosis
2010 <sup>vii</sup>	USA	3524	1992-2007	39.2 (dnMBC) 27.2 (rMBC)
2015 <sup>viii</sup>	USA	189	1996-2006	33 (39 ER+, 23 ER-, 54 HR+/HER2+, 34 HR+/HER2-, 25 HR-/HER2+, 16 TNBC)

1-year survival	5-year survival	Study limitations / considerations
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.
(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)	
46% 54% 62%	12% 11% 15%	
51.8%	17.6% 10-yr survival: 13%	de novo MBC only. Relative survival (likely to be slightly higher than overall survival).
73.9%	43.9%	de novo patients only; NSW only; follow-up to Dec 2013; figures are age-standardised relative survival.
67% (all pts) 72% dnMBC	20% (all pts) 23% dnMBC	Munich Cancer Registry, observed survival.
67% 68% 68%	17.6% 19.7% 21.2% 10-yr survival: 10%	
		Consecutive MBC diagnoses. Median follow-up 37.1mo.
	34% 10-yr survival: 12%	Single-centre study, disease-specific survival.
	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).
N/A	N/A	Single-centre study (MD Anderson Cancer Center); median follow-up 19mo.
80%	18.5% 10-year survival: 4.7%	Recurrent patients only; single-centre study (University of Miami).

2008 <sup>ix</sup>	France	1038	1975-2005	23.1 (27 ER+, 9 ER-, 36 HER2-, 29 ER+)
			1980-1984	16
			1985-1989	22
			1990-1994	24
			1995-1999	26
			2000 - 1/1/05	30.9
2016 <sup>x</sup>	Germany	886	1992-2008	27 (38 Lum A, 26 Lum B1, 31 Lum B2, 10 TNBC, 19 HER2 enriched)
2013 <sup>xi</sup>	USA	113	1999-2005	3.5 years
2017 <sup>xii</sup>	Sweden	784	1985-2016	18
			<1990	13
			1990-1994	16
			1995-1999	16
			2000-2004	20
			2005-2009	23
			≥2010	33
2017 <sup>xiii</sup>	USA	1158	1990-2010	47 (dnMBC) 22 (rMBC)
			1990-1998	
			2005-2010	
2017 <sup>xiv</sup>	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)
2015 <sup>xv</sup>	Italy	514	1990-2009	
			1990-1993	
			1994-1997	
			1998-2001	
			2002-2005	
			2006-2009	
2009 <sup>xvi</sup>	France	558	1973-2006	28
2018 <sup>xvii</sup>	France	16,680	2008-2014	37 (42 HR+/HER2-, 45 HER2+, 14.5 HR-/HER2-)

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Recurrent patients only. Consecutive MBC diagnoses in a single centre, patients followed up for 5 years.

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Median follow-up with MBC 27mo.

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HER2+ patients with  $\geq 1$  dose of trastuzumab (Herceptin) for recurrent disease; single-centre study; median follow-up 3.6 yrs.

---

14%

Single-county study.

10%

13%

9%

15%

17%

27%

---

44% (dnMBC)

20% (rMBC)

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.

28% (dnMBC)

23% (rMBC)

55% (dnMBC)

13% (rMBC) ( $p=.065$ )

---

Only 17% of HER2+ pts were treated with trastuzumab. Median follow-up 91mo.

---

11%

Modena Cancer Register, de novo patients only, a relatively small number of patients given the length of study.

15%

12%

20%

29%

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Patients selected in alphabetical order from database of MBC patients.

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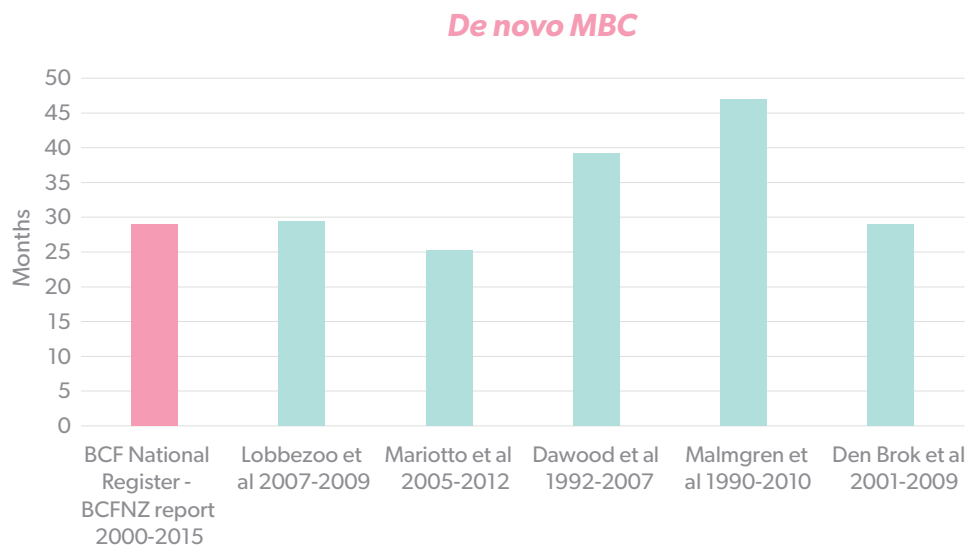
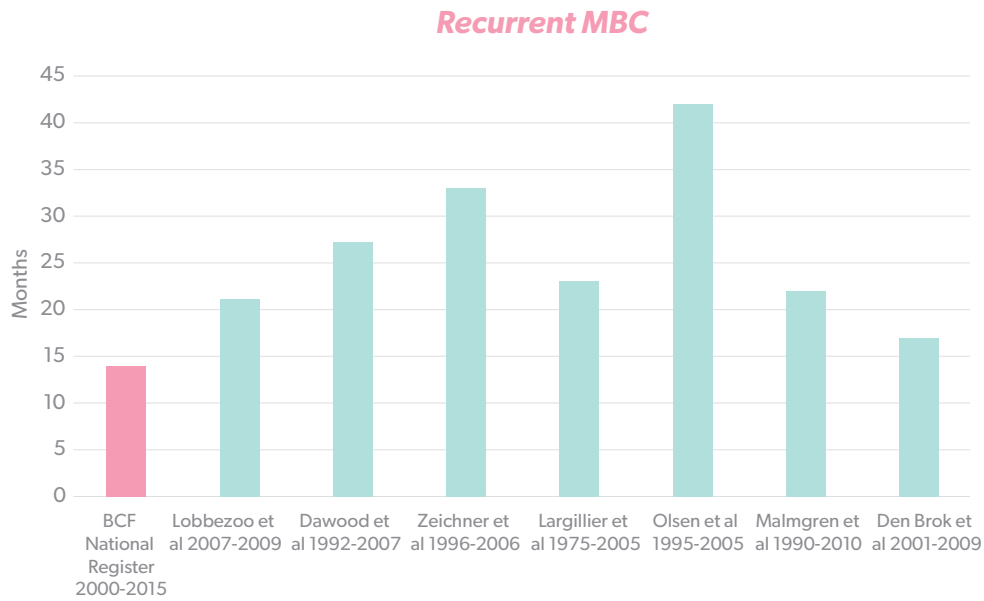
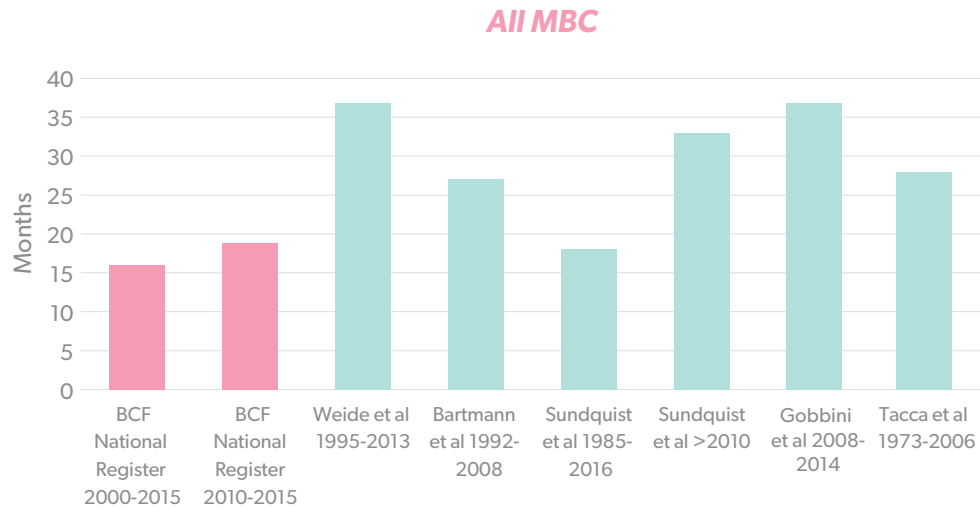
Consecutive MBC patients treated in the 18 French Comprehensive Cancer Centers.

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- 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
- x C Bartmann et al, “Pattern of metastatic spread and subcategories of breast cancer”, *Arch Gynecol Obstet* (2017) 295:211–223 DOI 10.1007/s00404-016-4225-4
- xi 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
- xii M Sundquist et al, “Improved survival in metastatic breast cancer 1985-2016”, *The Breast* 31 (2017) 46e50
- xiii J Malmgren et al, “Differential presentation and survival of de novo and recurrent metastatic breast cancer over time: 1990–2010”, *Breast Cancer Res Treat* (2017) DOI 10.1007/s10549-017-4529-5
- xiv W Den Brok et al, “Survival with metastatic breast cancer based on initial presentation, de novo versus relapsed”, *Breast Cancer Res Treat* (2017) 161:549–556
- xv L Cortesi et al, “Twenty-years experience with de novo metastatic breast cancer”, 2015, *Int. J. Cancer*: 137, 1417–1426
- xvi O. Tacca et al. “Metastatic Breast Cancer: Overall Survival Related to Successive Chemotherapies. What Do We Gain After the Third Line?” *Cancer Investigation*, 27:81–85, 2009
- xvii E Gobbini et al, “Time trends of overall survival among metastatic breast cancer patients in the real-life ESME cohort”, *European Journal of Cancer* (2018) Volume 96, 17-24



**Figure 29: Median metastatic survival by study**



## 6.2 Number of systemic treatments

Data about the number of therapies offered to people with ABC internationally is patchy, but it appears New Zealanders may receive less treatment than people overseas.

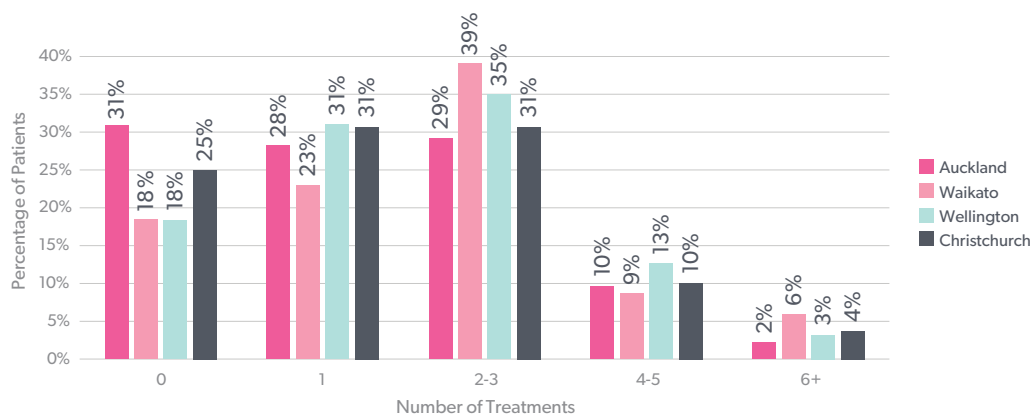
We looked at the total number of systemic therapies given to patients for their metastatic disease, including lines of chemotherapy, hormone therapies and biologic therapies. (Biologic therapies include anti-HER2 medicines such as Herceptin). Note that the data in this section refers to the number of individual therapies. Therefore, Herceptin and docetaxel have been counted as two therapies, even though they are given in combination as one line of therapy. Lines of chemotherapy and number of hormone therapies are reported in more detail below.

For patients who received any systemic therapies, the median number of systemic therapies in all regions was two.

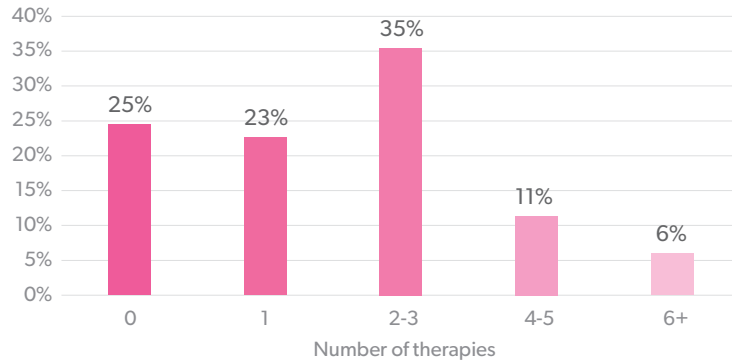
**Table 8: Median systemic therapies by age (for patients receiving 1 or more systemic therapies)**

	<45	45 - 69	70+
<b>Auckland</b>	2	2	1
<b>Waikato</b>	4	2	2
<b>Wellington</b>	3	2	1
<b>Christchurch</b>	2	2	1

**Figure 30: Number of systemic therapies by region**



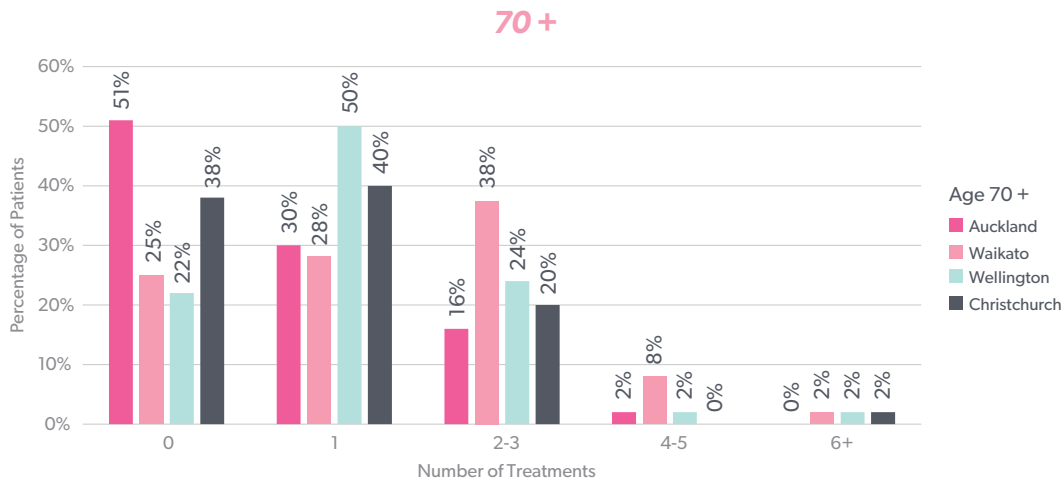
**Figure 31: Number of systemic therapies for Māori**



A significant proportion of patients received no systemic therapy. Who are these patients? Our data suggests that while many patients with zero or one treatments are older, a substantial number of patients aged <70 may also be missing out.

**Figure 32: Number of systemic treatments by age**





Why do so many patients receive 0 or 1 treatment? A small number of patients die within a few weeks of metastatic diagnosis, but oncologists suggested, where death is not clearly imminent, patients should be offered treatment. On initial viewing of this data, clinicians have expressed surprise, on the basis of their own practice and experience, that so many patients have so few treatments. Anecdotally, talking to patients, one hears of multiple lines of therapy, and not of specific refusal to treat.

Yet anecdotally, patients also express a sense that they are being “written off” by the system, and the numbers show that many patients in actuality receive limited treatments. This study cannot answer the question as to why that is and the number of treatments may have increased in recent years, but conversations with clinicians have suggested the following possibilities:

- **Omissions in register data.** This data has been reviewed and rechecked against oncology letters with a specific focus on treatment information, and discovered omissions have been corrected. There may still be omissions, but we do not have reason to believe they will substantially change the overall picture. However, we welcome further investigation in this area, and suggested improvements for ensuring ongoing accuracy of metastatic treatment data.
- **Patients may decline treatment in favour of alternative medicines.** Oncologists report their frustration when patients decline treatments the oncologist believes would help, in favour of alternative therapies.
- **Patients may feel discouraged from pursuing further treatment.** Is the conversation about treatment unintentionally biasing patients against treatment? There is no evidence that patients are refused treatment when they ask for it. But what is intended to be a two-way discussion, in which doctors express their honest opinions, may in fact discourage treatment. “You could have more chemo, but I don’t think it will do much”. There is a world of difference implicit in phrases such as, “You could get up to five more months”, compared with, “You could get as much as five more months”.
- **Are we too chemo-conservative?** One oncologist noted that New Zealand is a “chemo-conservative” country compared with others, and there is a suggestion that under-use may occur locally in other tumour streams, too<sup>102</sup>. Yet studies suggest that each additional line of chemo confers benefit, and some patients do very well on later lines. We note also that in New Zealand, patients have tended to

102 C Jackson et al, “The PIPER Project: An Internal Examination of Colorectal Cancer Management in New Zealand”, final report, 7 August 2015

have a fixed duration of chemotherapy rather than continuing on chemotherapy until disease progression (probably for resource and toxicity reasons). A meta-analysis<sup>103</sup> demonstrated improved survival for longer duration of chemotherapy; while this is unrelated to the number of lines of therapy given, it could have an impact on our metastatic survival. Are we too conservative with our chemo?

- **Are individual doctors setting the threshold for what they believe to be worthwhile treatment gains at different levels?** Are we getting the right balance in consideration of toxicity concerns v. extended survival? Is our thinking with regard to older people and chemo up-to-date? Do we need a guideline to help raise the bar?
- **Are our doctors running out of options?** In recent years, doctors have felt that NZ patients are being left behind, as other countries approve new drugs or have more flexible prescribing options. These are discussed further below.

Does it matter that New Zealanders are on average apparently receiving few lines of therapy for ABC?

The optimum number of treatments for metastatic breast cancer is the subject of much debate. But it seems very few patients in overseas studies receive no systemic therapy. One German study showed that 86% of patients with ER+ metastatic disease received endocrine therapy and 83% received chemotherapy<sup>104</sup>; while a Canadian study showed that 13% of patients had no systemic treatment.<sup>105</sup>

Overseas studies reporting total systemic therapies given are hard to find; however, studies suggest a substantial number of patients receive systemic treatment beyond the third line.

We did not find any published data in Australia; however, anecdotally, Australian clinicians report an average of “4-5” and up to “7-10” lines of therapy for ABC patients, with an average life expectancy of “at least 5 years (could be shorter for a minority)”<sup>106</sup>; we note that anecdotal recall tends to reflect only the best performance. A US study showed patients receiving an average of five lines of systemic therapy for metastatic HER2-positive breast cancer<sup>107</sup> and a recent Elsevier clinician update noted that five to eight lines of systemic therapy are not uncommon in metastatic breast cancer.<sup>107</sup> We note that the US healthcare system is significantly different from New Zealand’s, and it is possible that the numbers of lines of therapy is insurance-driven or the result of fear of litigation.

However, European guidelines and studies also suggest a higher number of systemic therapies offered to metastatic patients.

Spanish guidelines for treating metastatic disease recommend that patients with advanced HER2-positive breast cancer, who have been treated with two or more lines

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- 103 A Gennari et al, “Duration of chemotherapy in metastatic breast cancer: a systematic review and meta-analysis of RCTs”, *J Clin Oncol*. 2011 Jun 1;29(16):2144-9
- 104 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
- 105 W Den Brok et al, “Survival with metastatic breast cancer based on initial presentation, de novo versus relapsed”, *Breast Cancer Res Treat* (2017) 161:549–556
- 106 Anecdotal comments made by Australian clinicians via email in response to a question about a typical number of therapies for MBC patients.
- 107 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
- 108 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](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

of anti-HER2 therapy, may benefit from a third or further line of anti-HER2 treatment, noting that, “The optimal number of lines of anti-HER2 therapy for metastatic breast cancer is currently unknown.”<sup>109</sup> The same guidelines note that, “There is no limit to the number of therapy lines to be proposed to metastatic TNBC patients, as long as a good quality of life is maintained.”

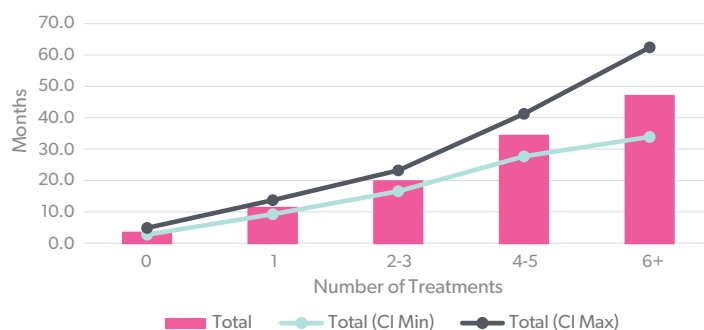
The lack of availability of multiple therapies, whether a lack of new medications, the inability to continue treatment after progression, or restricted indications for existing medications, may be a factor in the number of lines of treatment given in New Zealand. For example, pertuzumab (Perjeta), an important addition to the range of therapies for HER2+ breast cancer, has only been publicly funded in NZ since 1/1/17, so would not have been used by many patients in our study population. These issues are discussed further below.

One opportunity to identify new lines of therapy is through biopsy of metastatic lesions before treatment commences, to re-evaluate the HR and HER2 status. Estimates of discordance (variations in receptor expression between early breast lesions and metastatic lesions) vary. One study suggests discordance may occur in up to 45% of patients<sup>110</sup>; a meta-analysis quotes a mean discordance of 14% for ER, 21% for PR and 10% for HER2<sup>111</sup>. Discordance may have an impact on choice of systemic treatment<sup>110</sup>. Which is why international guidelines recommend that metastatic lesions should be biopsied<sup>112</sup>; however, anecdotal evidence suggests this practice is at best inconsistent in New Zealand.

Studies show that MBC survival increases in line with the number of systemic therapies given. There is an argument to suggest this is in part due to the fact that “healthier” patients, who would have been expected to survive longer anyway, can tolerate more therapies. Patients with more aggressive metastatic disease might die before there is a chance for multiple lines of therapy to be given.

However, the studies of the benefits of later lines of therapy conclude that each line does confer a survival benefit. These studies vary in reported levels of additional toxicity from later lines. Some studies conclude that cumulative lines of therapy lead to cumulative toxicity, while others report toxicity being no more severe in later lines. It appears there is at least a subset of patients who do very well on later lines of therapy; identifying and treating those patients to the full extent should be a priority.

**Figure 33: Median survival by number of systemic therapies (with 95% confidence intervals)**



109 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

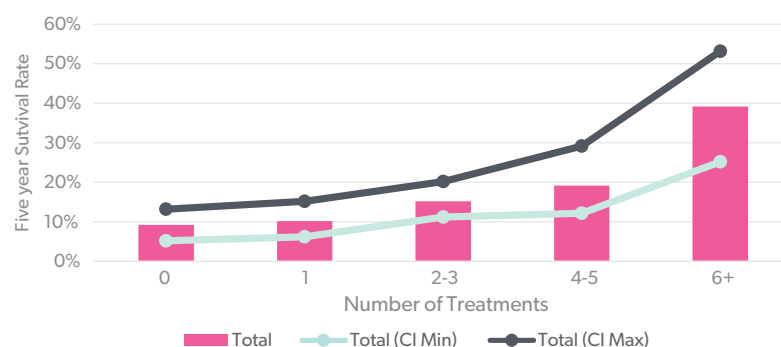
110 M Thill et al, “AGO Recommendations Advanced and Metastatic Breast Cancer: Update 2017”, Breast Care 2017;12:184–191

111 C Yeung et al, “Estrogen, progesterone, and HER2/neu receptor discordance between primary and metastatic breast tumours—a review”, Cancer Metastasis Rev. 2016 Sep;35(3):427-37

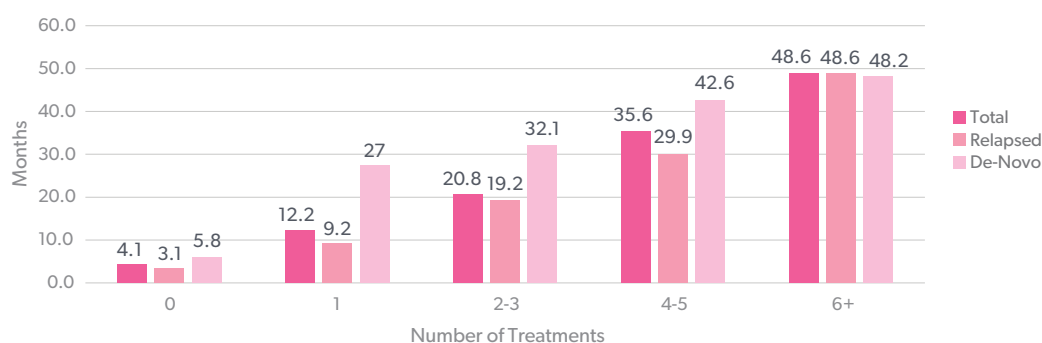
112 F. Cardoso et al, “3rd ESO–ESMO International Consensus Guidelines for Advanced Breast Cancer (ABC 3)”, Annals of Oncology (2017) 28: 16–33

In the New Zealand data, both median and five-year survival gains were attained with more systemic therapies. The confidence intervals widen with more treatments as patient numbers decline; very few patients received six or more therapies.

**Figure 34: Five-year survival by number of systemic therapies (with 95% confidence intervals)**



**Figure 35: Median survival time after systemic post-MBC treatments (AKL-WAI)**



## 6.2.1 Chemotherapy

While some chemotherapy studies overseas have not demonstrated benefit from third and subsequent lines, recent studies suggest that multiple lines of chemotherapy play a major role in determining overall survival (OS) in advanced breast cancer for at least a sizable subset of patients. One review of studies of chemotherapy beyond the second line showing that ABC patients can benefit from chemotherapy in the fifth line and beyond<sup>113</sup>. Another showed that while half of patients did not benefit from more than three lines of chemotherapy, 30-40% of patients did experience a clinical benefit (stable disease or partial response) between the fourth and seventh chemotherapy lines<sup>114</sup>. The investigators suggested that some patients always respond beyond the third line and that therefore an individualised approach should always be taken.

A French study reported that patients receiving more than three chemotherapy lines achieved a median OS benefit of 11 months for each line<sup>115</sup> It also found that

113 R. Palumbo et al. "Which patients with metastatic breast cancer benefit from subsequent lines of treatment? An update for clinicians", *The Breast* 20 (2011) 574e578

114 O. Tacca et al. "Metastatic Breast Cancer: Overall Survival Related to Successive Chemotherapies. What Do We Gain After the Third Line?" *Cancer Investigation*, 27:81-85, 2009

115 E. Planchat et al, "Late lines of treatment benefit survival in metastatic breast cancer in current practice?" *The Breast* 20 (2011) 574e578

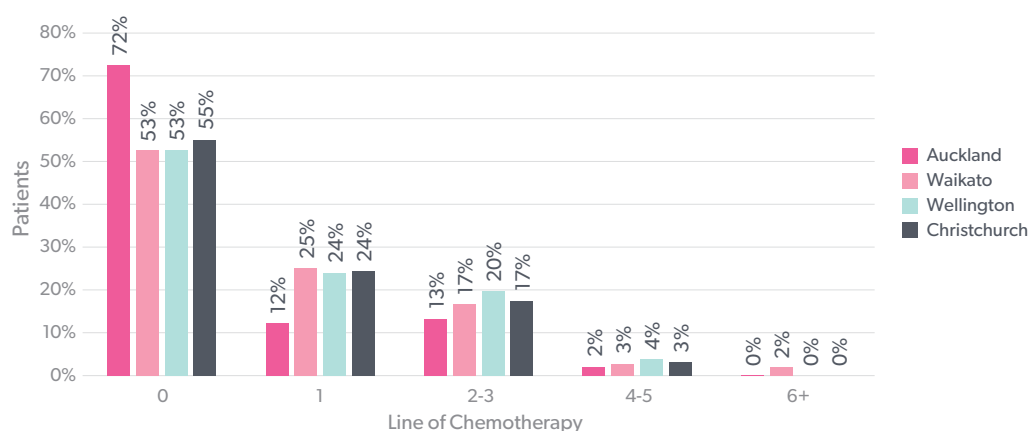
late lines of chemo had additional clinical benefits in the form of fewer metastatic disease complications, with a lower rate of bone fractures, hypercalcemia, orthopedic interventions, prolonged jaundice, ascitis (an accumulation of excess fluid in the peritoneal cavity) and pleural effusions.

**Table 9: Median number of chemotherapies by region (for patients who had 1 or more lines of chemotherapy)**

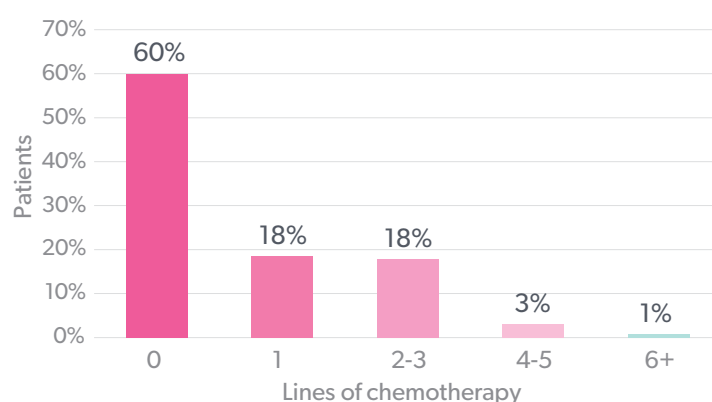
Region	Median
Auckland	2
Waikato	1
Wellington	1
Christchurch	1

In the current treatment era, almost all ABC patients in some countries will end up receiving chemotherapy<sup>116</sup>. In New Zealand, over half of patients did not have chemo for metastatic disease in the 2000-2015 period.

**Figure 36: Number of lines of chemotherapy given by region**



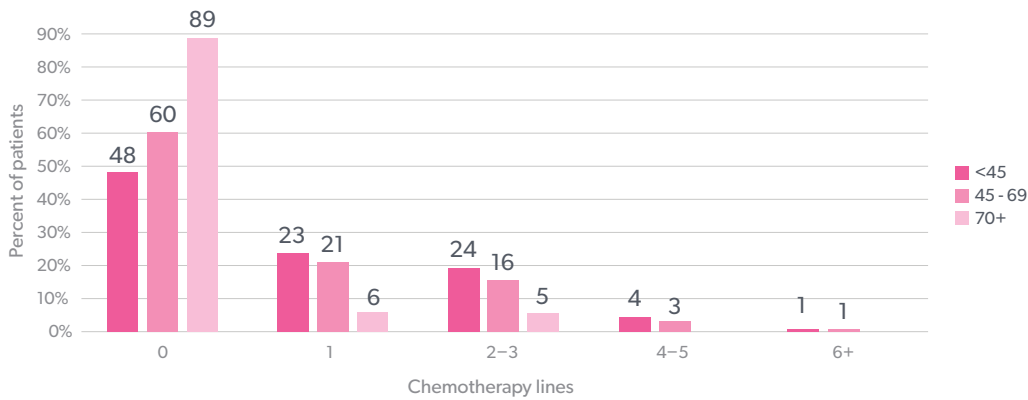
**Figure 37: Lines of chemotherapy for Māori**



116 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

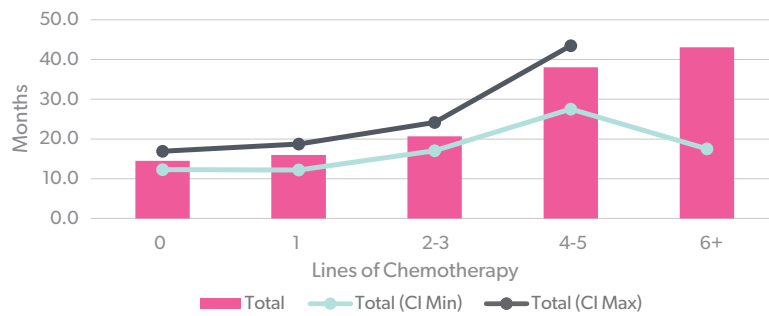


**Figure 38: Lines of Chemotherapy by Age**



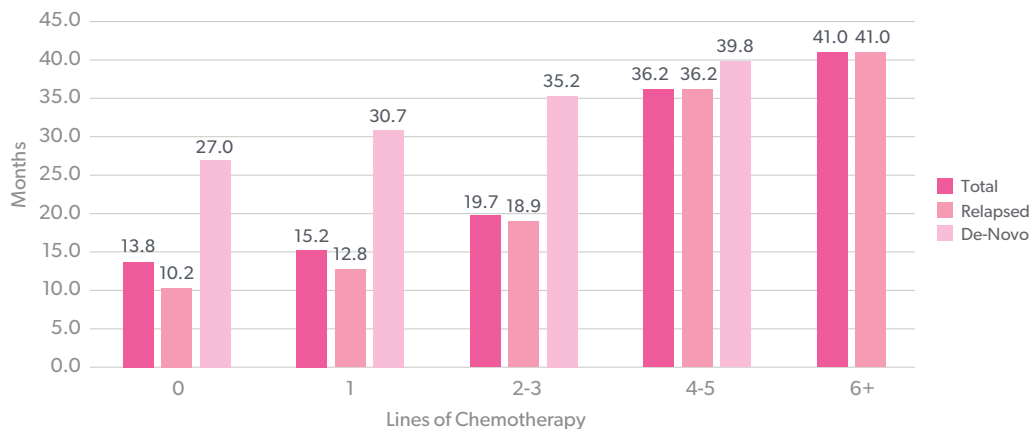
Older patients have significantly less chemotherapy, as might be expected. However, views around the tolerability of chemotherapy by older women are changing (though perhaps particularly in adjuvant treatment), and there may be scope to reconsider the thresholds for chemotherapy being offered to New Zealanders with ABC.<sup>117</sup>

**Figure 39: Median survival by number of lines of chemotherapy (with 95% confidence intervals)**



As in the overseas studies, New Zealand patients (long-term Auckland/Waikato data only) showed improved survival with more lines of chemotherapy. While the small number of patients having more lines of treatment widens the confidence intervals, there is a clear trend towards survival benefit.

**Figure 40: Median survival time after chemotherapy**

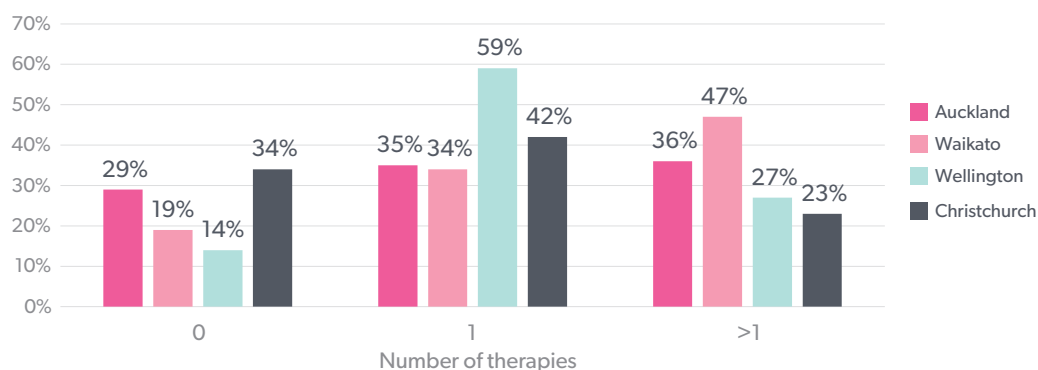


117 O Le Saux et al, "Optimal management of breast cancer in the elderly patient: current perspectives; Clinical Interventions", Aging; 6 January 2015 Volume 2015:10 157-174

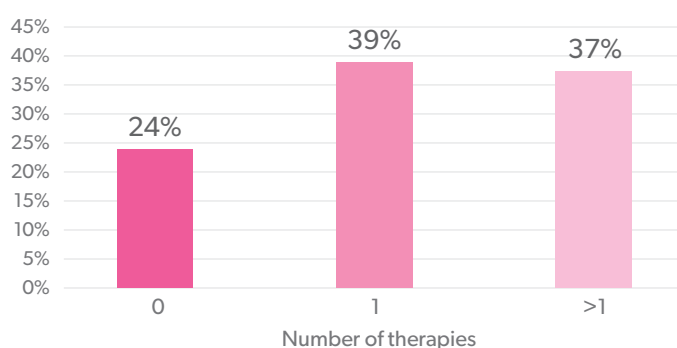
## 6.2.2 Endocrine (hormone) therapies

We looked at the number of hormone therapies given to ER+/PR+ patients. Of the patients who received any hormone therapy for metastatic disease, 55% received one therapy, and 45% received more than one.

**Figure 41: Number of hormone therapies (ER+/PR+ patients)**



**Figure 42: Number of hormone therapies for Māori (ER+/PR+ patients)**



**Table 10: Survival by number of hormone therapies (ER+/PR+ patients)**

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

## 6.3 Access to new treatments

Medical professionals would like to be able to provide their patients with the best possible treatment options but feel that, due to lack of funding or selective funding of some treatments in the public healthcare system, this is not always possible.

Medical professionals expressed concern about lack of access to the range of funded drugs available in other countries.<sup>118</sup> Even where drugs are Pharmac-funded,

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

restricted eligibility can be a source of frustration to those treating ABC patients. This frustration could increase if the combination therapies that are currently the focus of many clinical trials overseas become accepted clinical practice.

As discussed earlier, access to clinical trials, one way of accessing new medicines for some patients, is already suboptimal.

Right now, drugs loom large in the minds of clinicians as an area where New Zealand falls notably short, but other emerging tools and technologies, such as new radiotherapy technologies and genomic testing, will face the same funding hurdles. It is worth noting that new drugs often target specific genes; only patients whose tumours express that gene will respond to treatment with the drug. Genomic tests relating to gene expression are in the early stage of clinical use around the world, but could soon enable more effective use of funds (not wasting money on treatments that won't work for an individual's cancer) and prevent patients wasting valuable time on treatments that won't help.

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.

“ *I think the main issue affecting MBC patients is lack of access to state of the art drugs .... We have fallen behind Australia in this regard. The problem is that these drugs are not funded and most patients cannot afford to access them in private. These drugs would need to be funded by Pharmac.*

– Medical oncologist

”

“ *Drug funding is less comprehensive than in many other developed countries... Even aside from drug funding, the registration process is slow, as pharmaceutical companies unkeen [sic] on submitting to Medsafe if unlikely to be reimbursed). If drug not registered, insurers will not fund. Suboptimal drug funding puts many pharmaceutical companies off doing trials in NZ.*

– Medical oncologist

”

Patients are acutely aware of the potential for new drugs to prolong life, but see access to them as a distant dream. Patients say:

“ *Treatment options are not always discussed, as the price tags that come with the drugs required are too high, so I think oncologists just talk about the current treatments, as it is likely stressful for them too, knowing there are drugs that can keep us alive, but without a lottery win these drugs are out of reach for most.*

”

## 6.4 Oligometastases

Advanced (metastatic) breast cancer is currently incurable for nearly all patients. However, a small but very important subset of patients with ABC, for example those with oligo-metastatic disease (a very small number of small metastatic lesions in other parts of the body) or low volume metastatic disease that is highly sensitive to systemic therapy, can achieve complete remission and a long survival.<sup>119 120 121</sup>

Current treatment options for oligometastases, in addition to systemic therapies, mainly involve stereotactic radiotherapy / radiosurgery, surgical resection (removal), or interventional radiology treatments such as cryoablation.

There is currently little agreement on the definition of oligometastases – some experts allow just one or two lesions, others up to five. The ABC3 consensus guidelines define oligometastatic as “low volume metastatic disease with limited number and size of metastatic lesions (up to five and not necessarily in the same organ)”. This has made it hard to define eligible patients, and there are no agreed treatment guidelines. Breast cancer specialists in NZ have great interest in treating oligometastases but appear to be careful when discussing treatment options with their patients and are conscientious to consider treating oligometastases in the wider context of the patient’s disease.<sup>122</sup>

“ Sometimes, in our rush to find a solution to a particular clinical problem we forget to consider the overall context of a patient’s metastatic disease.

– Medical oncologist

“ I do feel offering treatment can be helpful for a patient psychologically, as it makes them feel something is being done, that the medical team are trying their best for them. But radiation, even very localised treatment, can have side effects, so we must be sure we are not causing significant problems for our patients because we can do something, rather than we should do something.

– Radiation oncologist

Treatment of oligometastases is a new area that, because of its applicability to only a small number of patients, will not be supported by evidence from large randomised clinical trials. This means some medical professionals are sceptical about its value.<sup>122</sup>

“ I think we are still in a relatively evidence-free zone with regards to treating oligometastatic breast in metastatic breast cancer.

– Radiation oncologist

“ The data is early for the treatment of oligometastases. However, it is very promising.

– Radiation oncologist

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

120 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>

121 G Sledge, “Curing Metastatic Breast Cancer”, *Journal of Oncology Practice*, Volume 12 / Issue 1 / January 2016

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Current treatment for oligometastases in NZ is ad hoc and mostly performed through the private setting; therefore access is highly unequal<sup>123</sup> (with the exception of stereotactic radiotherapy for breast cancer that has spread to the brain, which is available in several public hospitals).

“ *There is a potential that privately funded treatments make surgery more available, and there is a risk that this could not be in the patient’s best interest (though it could also be) we need to separate can from should at all times.*

– Palliative care specialist

“ *I think private providers are potentially more aggressive in treating oligomets, particularly in the brain. With the equipment we have at our centre we would not be able to treat more than 4 brain mets with stereotactic treatment due to the limitations of our equipment, but at a private centre with cyberknife they can treat over 10 brain mets. But the patient has to pay a lot of money for this.*

– Radiation oncologist

## 6.5 Treatment Guidelines

In early breast cancer, treatment is largely in accordance with national and international standards and guidelines, with decision support tools such as PREDICT and Adjuvant! Online available to oncologists to determine the need for more or less extensive treatment.

Treatment for advanced breast cancer is less regimented, due to wide variations in disease progression, and possibly due to the historically short survival in this patient group. However, there is a growing body of standards and guidelines for metastatic breast cancer, including the influential ABC international consensus meeting, held in Lisbon every two years since its inception in 2011.

New Zealand clinicians have been notable for their absence from the ABC conferences (whereas the equivalent in early breast cancer, the St Gallen consensus meeting, has been attended by several NZ medical professionals). None of the doctors participating in the research for this report used the ABC1/2/3/4 guidelines, or other international guidelines.<sup>123</sup>

In our qualitative study, clinicians who were aware of the international ABC guidelines did not see them having a large place in the NZ ABC landscape, due to lack of funding of or restrictions on prescribing of key drugs. Some said their places of work had their own guidelines which they felt are more appropriate for the NZ context. This implies likely variation in the guidelines being followed at different facilities around the country. Some doctors questioned the applicability of guidelines for ABC and advocated that treatment decisions for ABC patients are always unique to individuals.<sup>123</sup>

“ *I am not aware of this [international MBC guidelines] – it is news to me.*

– Radiation oncologist

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“ I am not overly aware of international mbc guidelines. It’s not something that’s routinely referred to or discussed in my dept. We mostly utilise local or national standards.

– Nurse

”

“ I am fully aware of such guidelines. Some have limited applicability given our suboptimal drug funding. The treatment decisions for MBC pts need to be INDIVIDUALISED based on disease, temporal and patient factors (such as willingness to be proactive and comorbid health issues).

– Medical oncologist

”

The Government’s draft Standards of Service Provision for Breast Cancer Patients in New Zealand, developed to “promote nationally coordinated and consistent standards of service provision...[and]...to ensure efficient and sustainable best-practice management of tumours, with a focus on equity”, include high-level guidelines for treating metastatic breast cancer. However, these stop short of recommending specific therapies or numbers of therapies, and have never been officially ratified as standards.

New Zealand has a much smaller population of ABC patients than other countries; one could argue that many of the quantifiable insights into best practice treatments and outcomes will be demonstrated earlier in larger populations. Standards based on experience in larger populations may therefore be of value.

## Where to from here?

- 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.
- 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).
- 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.

- NZ guidelines for ABC diagnosis and treatment to be agreed and adopted. Given the urgency of improving our treatments, these should be adapted from existing overseas guidelines.
- Biopsy of accessible metastases to be routine, preferably for all patients, but particularly in those whose early breast cancer was hormone receptor negative.
- Use the Breast Cancer Foundation National Register to actively benchmark against international data, with the ability to do this increasing as more comprehensive data is tracked overseas.
- Faster access to new drugs, and restrictions on existing drugs to be lifted to enable combination therapies plus more options for patients whose disease progresses. Metastatic patients to have funded access to drugs that are Pharmac-funded but not indicated for breast cancer, where their oncologist believes the evidence suggests the patient may benefit.
- Pharmac should in future consider funding medications by genomic indications rather than by tumour type. In tandem, we will need publicly funded genomic tests to predict treatment efficacy for metastatic patients.
- Establish guidelines for identifying and treating oligometastases, along with a planned implementation of equipment in strategic locations, accessible by all clinically eligible patients. This will require access to appropriate equipment and trained personnel.
- 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.

## 7 The financial burden of Advanced Breast Cancer

### In brief:

- **Three-quarters of people with ABC have had a decline in household finances; nearly half say their situation is “a lot worse”. Patients are forced to quit work or reduce hours, and they and/or family members take unpaid leave to attend appointments.**
- **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.**
- **About a third of patients have accessed private healthcare. While most fund this through health insurance, some use household or retirement savings.**
- **Geography matters. Patients who live out of main cancer centres incur higher costs related to ABC treatment.**
- **Unlike early breast cancer, where the main impact of treatment is felt over a relatively short period of up to a year, the negative impact that ABC has on finances will likely continue for the rest of the patient’s life.**

### 7.1 Impact on household finances and employment

Advanced breast cancer costs patients money, even in New Zealand’s “free” public healthcare system.

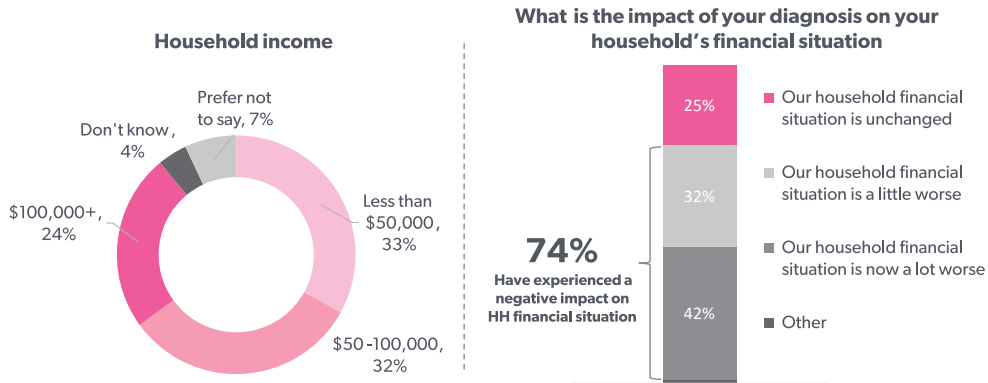
Three-quarters of patients reported a decline in their household finances after their ABC diagnosis, and 42% say it’s a lot worse.<sup>124</sup> Many patients who worked full-time prior to diagnosis with ABC either cut down their working hours or are unable to work. Only 38% remain in full-time employment.

Similarly, **part-time** workers often find themselves unable to work, or they move into volunteer work.

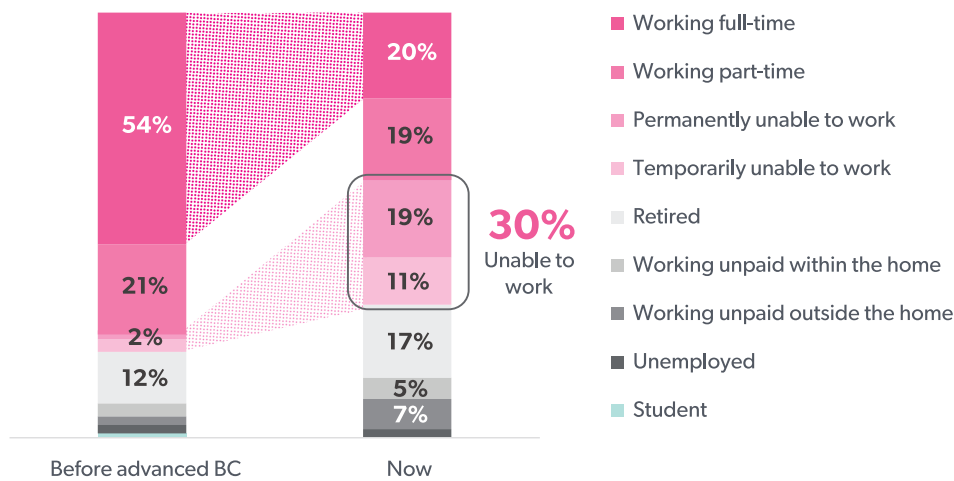
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**Figure 43: Impact of ABC on household income**

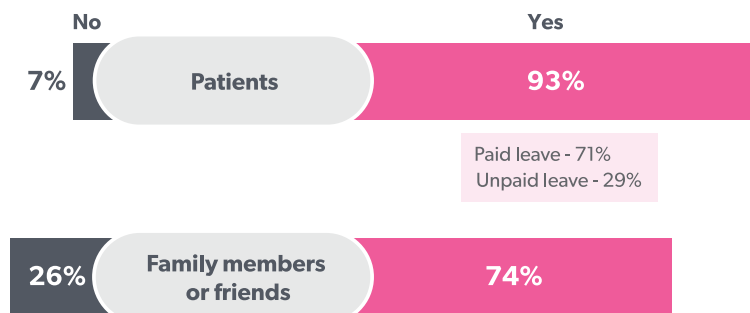


**Figure 44: Working Situation**



At the same time as their income decreases, people with ABC face expenses not incurred to the same extent in early breast cancer. Leaving aside the question of paying for unfunded drug treatments, the amalgamation of many comparatively smaller financial costs add up to a significant burden and prevent access to care.<sup>125</sup> These include parking and transport to clinics, and the patient or family members taking time off work to attend appointments over a potentially much longer period than in the early breast cancer treatment journey.

**Figure 45: Taken time off work to attend medical appointments or get treatment**



“ Lower socio economic status is associated with difficulties coming for appointments and treatments costs to family for transport / parking (!!!) / family members’ time off work.

– Radiation oncologist

”

## 7.2 Increased primary care costs

ABC patients who have been discharged by their oncologist rely on their GP for their healthcare needs; the cost of regular GP visits presents a significant barrier to receiving the treatment and support they require.<sup>126</sup> Almost all patients pay for over-the-counter medications, a significant cost over a long period for people dealing with multiple symptoms. This is quite different from early breast cancer, where the public system picks up the tab throughout treatment.

“ Metastatic breast cancer is more difficult with more reliance on the GP which brings a cost. There are some who cannot afford their proper care. We have pressure on us not to see follow up patients but to delegate to the GPs who I am sure would do a great job, but the cost is a problem for some people... This is a tough country in which to be chronically ill. The benefit is meagre. Poverty is part of metastatic cancer for many... Travelling to see doctors is expensive with the need of a family member or friend to take a day off work and travel. GP fees are a big part of the budget for someone on a benefit.

– Radiation oncologist

”

“ Early breast cancer patients are mainly cared for in the hospital system which is free.

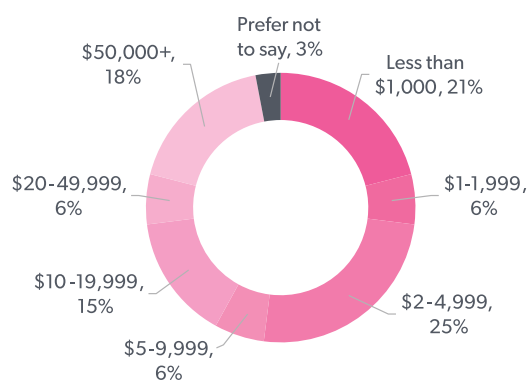
– Radiation oncologist

”

## 7.3 Private healthcare

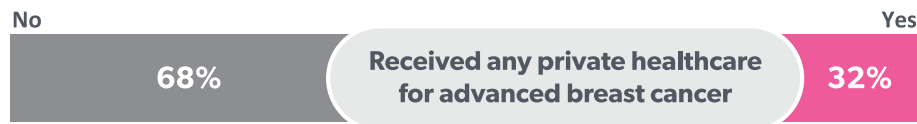
A third of patients have sought private treatment for their ABC.<sup>127</sup> Most have funded this through health insurance, but one-fifth have used retirement savings, and 15% have used household savings.

**Figure 46: Total spent on private healthcare**

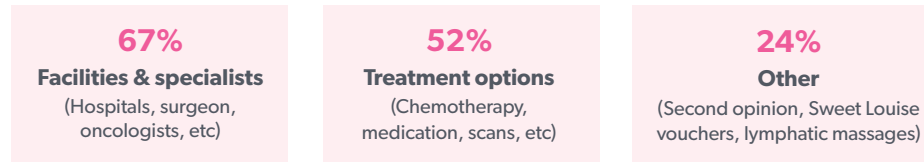


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### Types of private healthcare received (n=33)\*



## 7.4 Geography and the financial burden

The cost of ABC is further impacted by where the patient lives.

Socioeconomic status and geography are tightly intertwined<sup>128</sup>; in more rural areas of New Zealand, there tends to be a greater proportion of people with a lower socioeconomic status. Further, in more rural areas there is little opportunity to access private healthcare and a full range of free treatment options. Geographic location also impacts the distances patients are required to travel in order to receive some treatments; patients reported having to pay travel and accommodation costs for treatment.

To overcome geographic obstacles is challenging. ABC patients' treatment needs continue over an extended period; they don't fit with a healthcare system designed to treat a defined pathway for early breast cancer over a relatively short period in a limited number of specialist treatment centres.

Unlike early breast cancer, where the main impact of treatment is felt over a relatively short period of up to a year, the negative impact that ABC has on finances will likely continue for the rest of the patient's life. As more people live longer with ABC, we can expect the financial burden will become greater, lowering quality of life and having a long-term impact on the family.

## 7.5 Where to from here?

- Consider free GP visits for people with advanced breast cancer.
- Consider scrapping prescription charges for people with ABC.
- 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.
- Consider making more out-of-hours clinic appointments available to patients, to reduce unpaid leave.
- Better symptom management, as discussed earlier in this report, will enable people to continue working and will reduce the financial impact of disease while improving quality of life. Explore flexible and / or low-cost means of managing symptoms in a distributed patient population.

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# Appendix

This Appendix includes additional data from the *Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018*. Topics covered include: additional survival data by histological factors such as receptor status, grade and stage; more detailed age breakdowns; screened vs symptomatic ABC survival; and comparisons of early breast cancer and advanced breast cancer populations.

## A1. Statistical analysis – notes and assumptions

The analysis in the *Metastatic Breast Cancer – Breast Cancer Foundation National Register Data Analysis 2018* only includes patients who were diagnosed with metastatic breast cancer on or before December 31, 2015.

**Table 11: Study dates**

Region	Start of study	End of study
Auckland	02-06-2000	01-06-2017
Waikato	21-06-2000	01-04-2017
Wellington	11-01-2010	01-04-2017
Christchurch	15-06-2009	01-04-2017

Only Auckland and Waikato patients were included in the metastasis-free survival, survival from initial tissue diagnosis and survival with MBC calculations. To ensure that Auckland does not dominate the combined calculations, the combined Auckland-Waikato results use all 475 Waikato patients, plus a random sample of 475 patients from the Auckland data set. This gives each region an equal number of observations in the analysis and therefore equal 'weight'. The Wellington and Christchurch registers did not have enough patients or sufficient longevity for robust analyses.

**Table 12: Total number of patients included in survival analyses**

	N
<b>AKL-WAI – all patients</b>	<b>950</b>
AKL-WAI - Relapsed	734
AKL-WAI - De-novo	216

Survival time is the time from the date of MBC diagnosis to death. If the cause of death was unknown or missing, we assumed the patient died from breast cancer.

## A2. Incidence and prevalence

**Table 13: ABC Diagnoses per year, 2010-2015**

	Auckland	Waikato	Wellington	Christchurch	Total
<b>2010</b>	143	40	7*	18	208
<b>2011</b>	136	38	20	23	217
<b>2012</b>	154	48	30	31	263
<b>2013</b>	126**	46	35	42	249**
<b>2014</b>	108**	42	36	38	224**
<b>2015</b>	93**	32	39	30	194**

\* The Wellington Breast Cancer Register began operations in 2010, so this will not include all patients diagnosed with ABC in that year.

\*\*The Auckland Register is lagging in long term follow-up of some patients, so these numbers are expected to rise

Between 200 and 300 people per year are diagnosed with ABC across the four regions that represent 70% of all diagnoses. This suggests that nationally, 286-430 are diagnosed with ABC each year.

Our study reported 389 people who had been diagnosed with metastatic breast cancer before 31/12/15 were still alive when data was collected in April 2017 (including five men). Nearly a third (32%) had been alive for five years or more with their advanced disease.

To assume this represented 70% of national data would suggest that c. 556 people are currently alive in NZ with ABC (prevalence). However, the study total of 389 may not include most patients diagnosed with metastatic disease in Auckland in 2014-2015. Estimates from NGOs and pharmaceutical companies suggest there are about 700-1000 people currently alive with Advanced Breast Cancer in New Zealand.

## A3. ABC survival by age

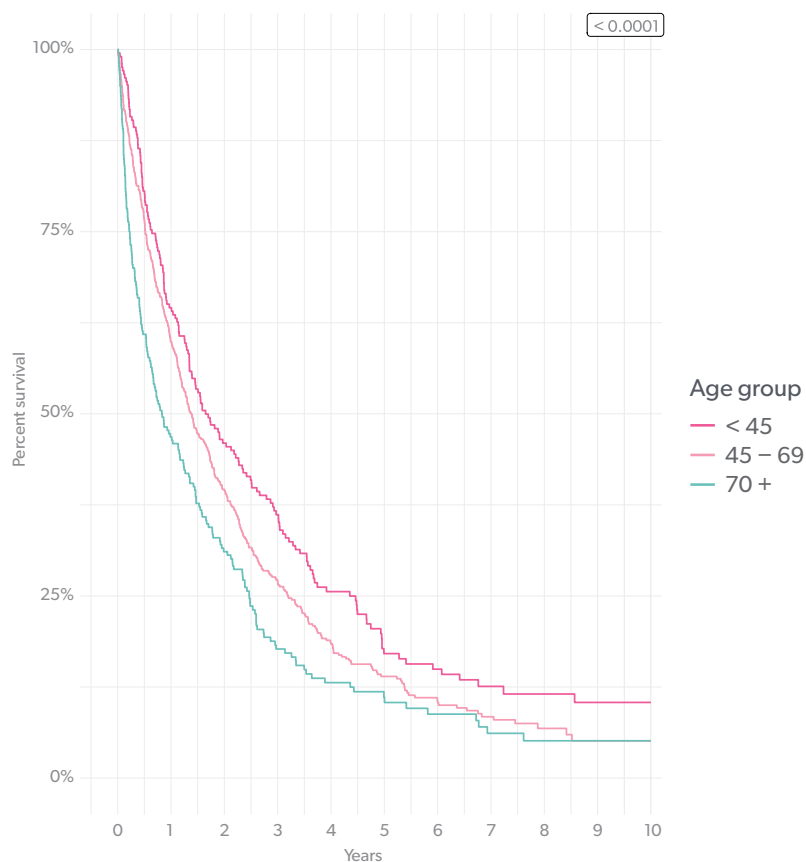
**Table 14: Median, one- and five-year ABC survival by age at initial diagnosis**

	Median (months)		One-year		Five-year	
	<50	≥50	<50	≥50	<50	≥50
<b>All patients</b>	20.7 (16.7, 24.4)	38 (11.8, 16.1)	66% (61, 71)	54% (50, 57)	17% (13, 22)	12% (10, 15)
<b>de novo MBC</b>	42.8 (32.6, 51)	24.7 (17.5, 31.1)	80% (68, 88)	69% (61, 76)	20% (10, 32)	24% (17, 31)
<b>Recurrent MBC</b>	13.9 (9.4, 19.7)	11.8 (8.3, 15.6)	59% (53, 65)	49% (45, 54)	15% (11, 20)	9% (6, 12)

New Zealand survival patterns reflect those overseas, with younger women having longer survival with metastatic disease. Note that some of the confidence intervals in this table are strongly overlapping.

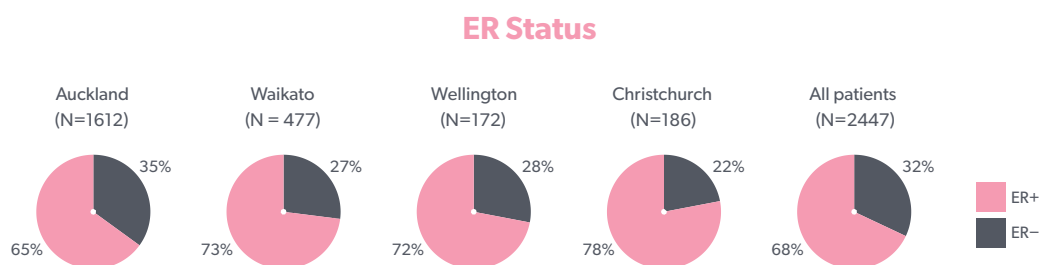
**Figure 47: ABC Survival for screening and non-screening age at initial tissue diagnosis**

(Age bands align with the current BreastScreen Aotearoa screening age range, 45-69)

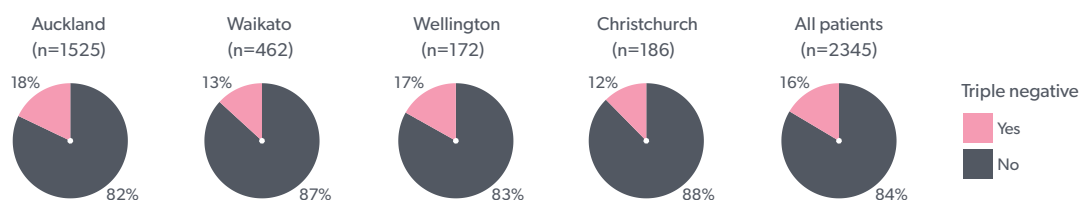


#### A4. Incidence and survival of metastatic breast cancer by receptor status at initial tissue diagnosis

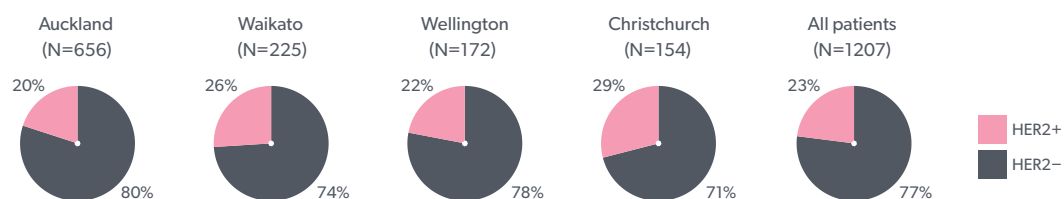
**Figure 48: Regional variations in incidence by receptor status (ABC patients)**



### Triple Negative status



### HER2 Status



This figure comprises only patients with an initial tissue diagnosis from 2010 onwards, hence the smaller cohort (N=1207)

### The changing picture of HER2+ metastasis

Herceptin was initially funded for metastatic breast cancer in 2002. In 2007, funding was extended to patients with early breast cancer for 9 weeks. That was extended to 12 months early in 2009.

Use of Herceptin as adjuvant therapy in early breast cancer should be expected to decrease the proportion of HER2+ metastatic breast cancer diagnoses.

An analysis of Breast Cancer Foundation National Register patients before and after 1/1/2010 enables a comparison of HER2+ metastasis rates before and after the funding of 12 months' adjuvant Herceptin.

**Table 15: HER2+ metastasis pre and post 2010**

Region	Pre_Post 1/1/2010	HER2+	Total	Proportion
<b>Auckland</b>	Post	133	653	0.20
<b>Auckland</b>	Pre	185	600	0.31
<b>Waikato</b>	Post	57	223	0.26
<b>Waikato</b>	Pre	69	189	0.37
<b>Wellington</b>	Post	36	165	0.22
<b>Christchurch</b>	Post	44	153	0.29
<b>Christchurch</b>	Pre	2	8	0.33

Using these numbers, we can use a Chi-Square test to test for a significant change in the proportion of patients who had HER2+ cancers at initial diagnosis being diagnosed with MBC before and after 2010.

From this analysis we can see that the proportion of patients diagnosed as HER2-positive decreased from 31% to 20% of the population in Auckland. This is significant at the 95% confidence level (p-value < 0.001). There is weak / no evidence to suggest a decrease in the proportions in Waikato from 37% to 26% (p-value  $\approx$  0.1).

Overall, we have very strong evidence (p-value < 0.001) to suggest that after 1st Jan 2010, the proportion of patients diagnosed as HER2-positive decreased.

Wellington and Christchurch have insufficient numbers before 2010 to do a formal comparison for each of these regions separately. The overall Chi-square test combines all the available data in all the regions.

### One-year and five-year ABC survival by receptor status

Figure 49: HER2 status

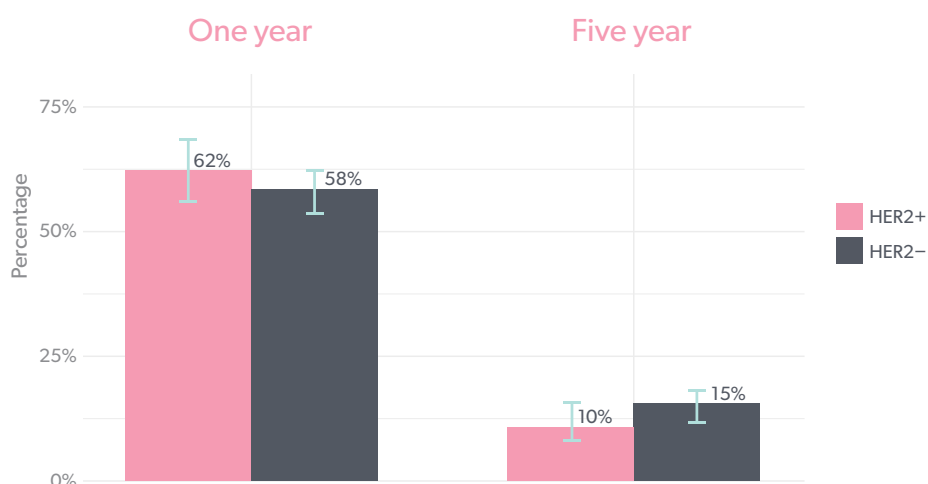
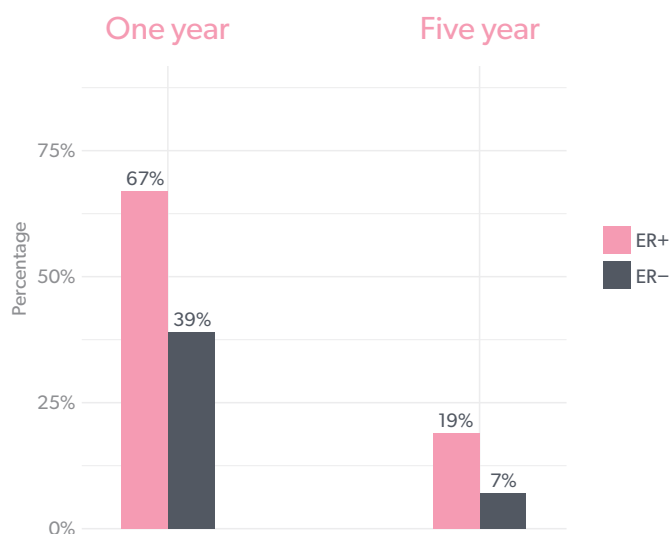


Figure 50: ER Status





## A5. ABC survival by grade at initial diagnosis

**Table 16: Survival by grade at initial diagnosis**

	Grade 2	Grade 3
<b>Median (months)</b>	24.2 (20.4, 28)	11 (9.3, 12.9)
<b>One-year survival</b>	67% (63, 71)	47% (42, 52)
<b>Five-year survival</b>	23% (19,27)	9% (4,9)

Survival after ABC diagnosis was significantly longer for people whose initial cancer had been a histological grade 2, than for grade 3. (Numbers of metastatic patients with a grade 1 initial diagnosis were insufficient to obtain a meaningful result)

## A6. ABC survival by T Stage at initial diagnosis

**Table 17: Survival by T stage at initial diagnosis**

	Stage 1	Stage 2	Stage 3
<b>Median survival (months)</b>	23.1 (17, 26.1)	14.4 (11.7, 17.8)	15.5 (11.7, 17.9)

Confidence intervals are strongly overlapping for stage 2 and 3 cancers, but people whose initial diagnosis was a stage 1 cancer appear to have significantly improved median survival after ABC diagnosis.

One-year and five-year survival differences were insignificant across all stages.

## A7. Survival by initial detection method

### Early breast cancer detection and ABC

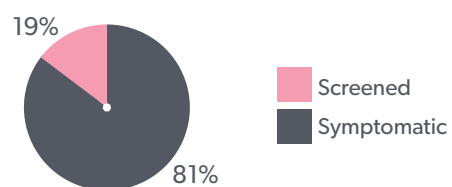
Free mammogram screening through BreastScreen Aotearoa has been offered to New Zealand women aged 50–64 years since December 1998. In 2004, the eligible age range was extended to 45–69 years. In the Auckland Breast Cancer Register, over 60% of breast cancers in New Zealand women aged 50-69 and 29% of breast cancers in women aged 45-49 were found on a mammogram (screen-detected)<sup>129</sup>. Most other diagnoses are symptomatic – the patient finds a lump or other symptom.

Among NZ ABC patients, only 19% had their early breast cancer detected by screening mammogram. This is in line with statistics showing that ten-year breast cancer survival for mammogram-detected cancers is significantly higher than symptomatic cancers (92.2% vs 75.2%)<sup>129</sup> and that New Zealand women whose cancer is detected by screening have a substantially lower mortality from breast cancer compared to those women whose breast cancers were not screen-detected.<sup>130</sup>

129 Auckland Breast Cancer Register – 12 Year Data, Auckland Breast Cancer Study Group, 2015

130 "Summary of the BreastScreen Aotearoa Mortality Evaluation 1999–2011", BreastScreen Aotearoa, 2015

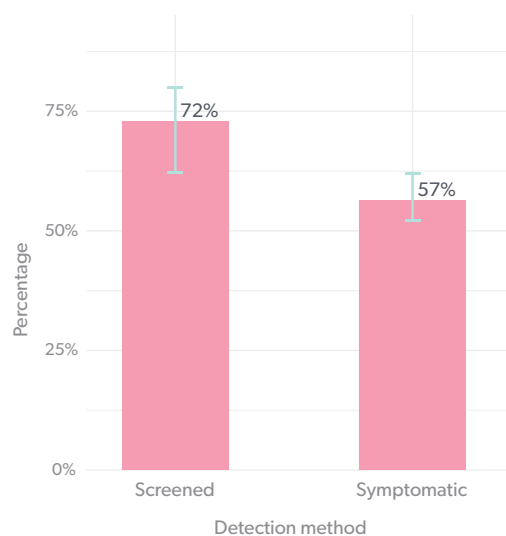
**Figure 51: Detection of initial early breast cancer among people with ABC aged 45-69**



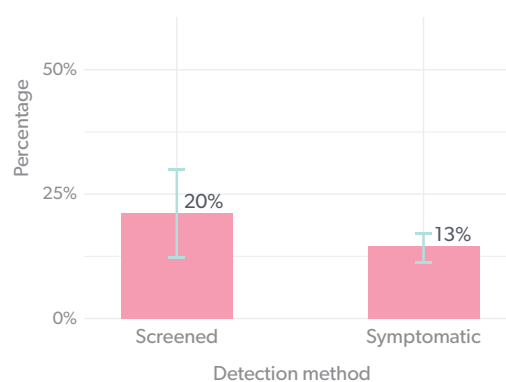
**Table 18: Median ABC survival by detection method at initial diagnosis (women aged 45-69)**

	Screened	Symptomatic
Median survival (months)	20 (15.3, 24.7)	15.7 (13.4, 19.2)

**Figure 52: One-year ABC survival by detection method at initial diagnosis (women aged 45-69)**

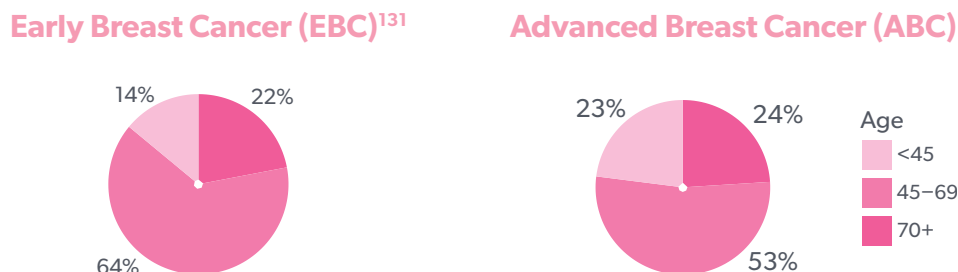


**Figure 53: Five-year ABC survival by detection method at initial diagnosis (women aged 45-69)**



## A8. Early breast cancer (EBC) and ABC patient profiles

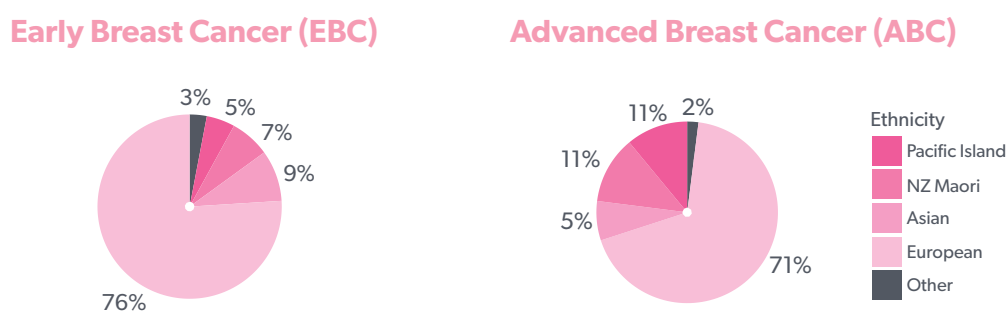
Figure 54: Age at diagnosis



ABC patients are typically younger at their initial breast cancer diagnosis than the wider EBC patient group. ABC patients had a median age of 55 at initial diagnosis; 22% were diagnosed with breast cancer under age 45, compared with 14% of all breast cancer patients. The higher metastasis rate among women with a younger initial diagnosis could be due to several factors. Younger women’s cancers are often found at a more advanced stage, as the result of a lump or other symptom (free mammogram screening is not available before age 45), and younger women have a higher percentage of more aggressive cancer subtypes that are harder to treat.

People aged 70+ at initial diagnosis make up a slightly higher percentage of ABC patients than of early breast cancers. Since older women are generally regarded to have less aggressive cancers, this could be due to the fact that their cancers are less likely to have been detected on a mammogram (free screening currently stops at age 69), or they may have received less assertive treatment for their early cancer due to comorbidities or, historically, clinician concern about the effect of treatment-related toxicities on older patients (recent studies have shown this concern has proven to be generally not an acceptable reason to withhold treatment<sup>132</sup>).

Figure 55: Ethnicity



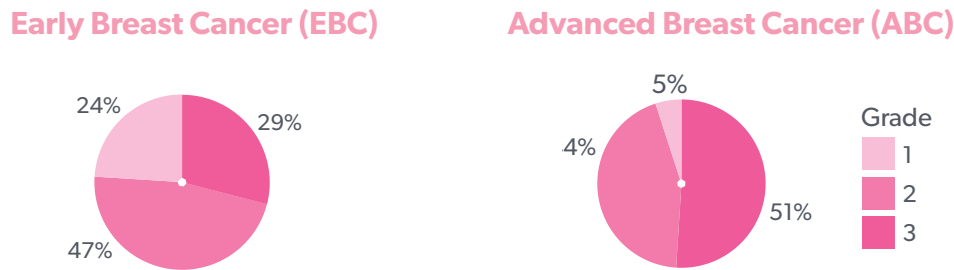
Māori and Pacific women are represented in greater proportion among ABC patients than EBC (11% v 9% for Māori, and 11% v 5% for Pacific). A Waikato study showed that for Māori, breast cancer survival is equal to non-Māori survival for screen-detected cancers, suggesting the higher rate of metastasis in Māori is due to delays in detection

131 EBC data is from the New Zealand Breast Cancer Register, and pertains to all recorded patients diagnosed with early invasive breast cancer from 2000-2015.

132 O Le Saux et al, “Optimal management of breast cancer in the elderly patient: current perspectives; Clinical Interventions”, Aging; 6 January 2015 Volume 2015:10 157-174

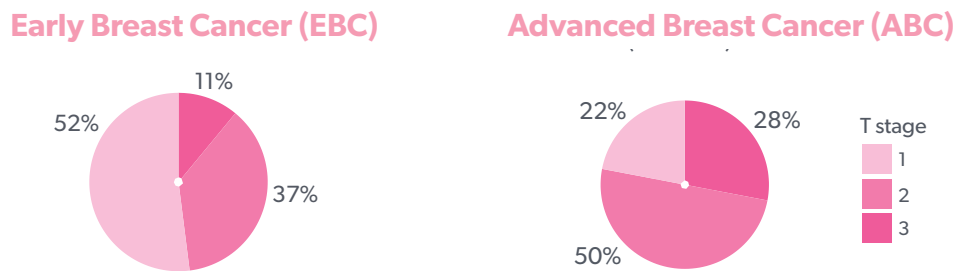
of early cancer<sup>133</sup>. The reasons why Pacific women have higher levels of metastasis are unclear, but may historically be related to lower screening levels and / or to higher levels of HER2+ breast cancer in this group<sup>134</sup>.

**Figure 56: Cancer grade at early diagnosis**



Very few people with advanced breast cancer had a grade 1 cancer at initial diagnosis (grade is a measure of the cancer's biological aggressiveness and is not related to early or late detection).

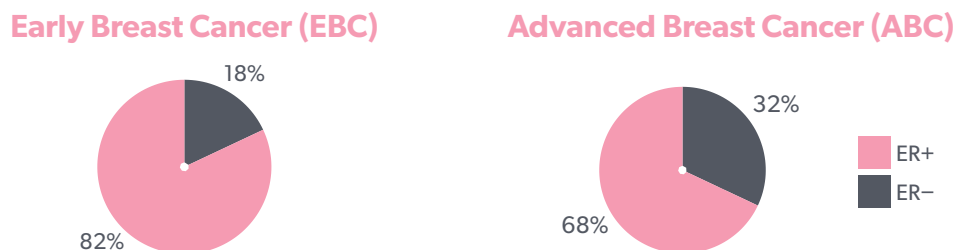
**Figure 57: Cancer T Stage at early diagnosis**



People whose tumours are Stage 3<sup>135</sup>, also called locally advanced, at their early breast cancer diagnosis are more likely to develop advanced or metastatic breast cancer. T Stage is time and location related: the earlier a cancer is detected, the earlier its T Stage is likely to be (although some tumours grow faster than others).

## A9. Type of breast cancer (receptor status) at initial diagnosis

**Figure 58: ER status**



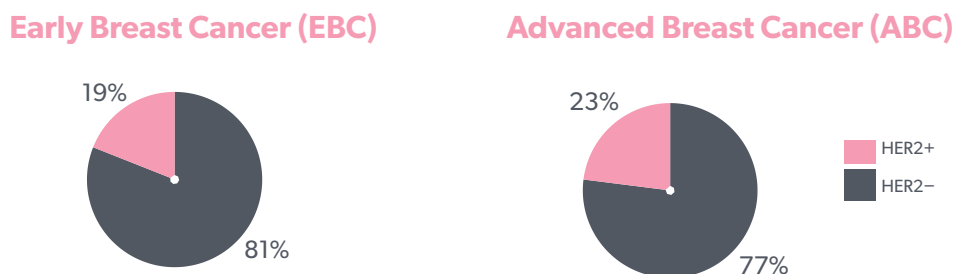
133 S Seneviratne, et al, "Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival", BMC Public Health (2015) 15:46

134 R Ramsaroop, "Ethnicity and Breast Cancer in the Greater Auckland Region: 2000-2011

135 Stage 3 means the tumour is larger than 5cm, or the tumour is any size and has spread to lymph nodes or the chest wall or skin of the breast

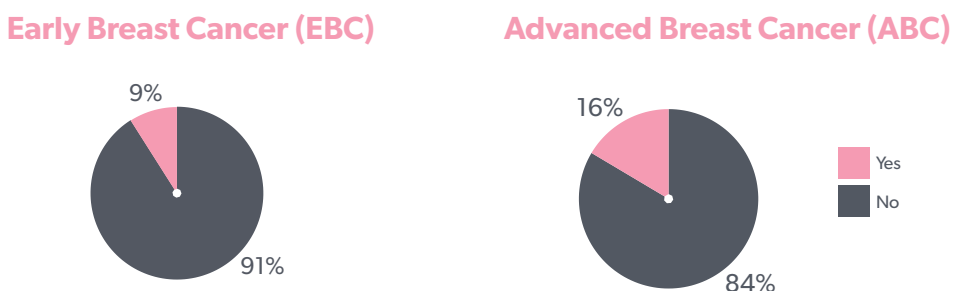
Only 18% of early breast cancers are ER-negative, but for advanced cancers, that number rises to 32%. This is because ER-negative tumours are more difficult to treat than ER-positive, being nonresponsive to the hormone treatments that work well in ER-positive breast cancer. ER-negative patients are therefore more likely to relapse with advanced disease.

**Figure 59: HER2 status**



HER2-positive cancers are historically more likely to metastasise than HER2-negative, giving a higher percentage of ABC patients with HER2-positive disease. However, anti-HER2 targeted treatments in early breast cancer (e.g. Herceptin) are reducing the percentage of HER2-positive patients whose cancers relapse, so this proportion is likely to change over time.

**Figure 60: Triple Negative Breast Cancer (TNBC)**



Triple negative cancers make up a larger proportion of advanced breast cancers. People with TNBC are often younger, and this cancer is often aggressive. There are no established targeted therapies for TNBC.

## Acknowledgements

Breast Cancer Foundation NZ gratefully acknowledges the contributions of the following individuals and groups

*Assistance with recruitment of patients into the patient survey*

**Breast Cancer Aotearoa Coalition**

**Metavivors NZ**

**Look Good Feel Better**

**All the New Zealanders living with Advanced Breast Cancer who shared their views**

*Data extraction, analysis and review*

**Data managers at the Auckland, Waikato, Wellington and Christchurch breast cancer registers**

**Dr Blake Seers, PhD, Data analyst | Department of Statistics Consultant, Statistical Consulting Centre, University of Auckland**

*Report review and comment*

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