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BCAC Submission on Women's Health Strategy for New Zealand

For: Women's Health Strategy Team
Manatū Hauora, Ministry of Health
Wellington

From: Breast Cancer Aotearoa Coalition Incorporated (BCAC)

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Breast Cancer and Women's Health in Aotearoa New Zealand

On behalf of the thousands of New Zealand women diagnosed with breast cancer every year, the Breast Cancer Aotearoa Coalition (BCAC) is grateful to have the opportunity to make submissions on the contents of a Women's Health Strategy for Aotearoa. BCAC is a patient-based organisation that supports, informs and represents New Zealanders diagnosed with breast cancer. Our membership includes over 30 breast cancer groups as well as individual members across Aotearoa.

We recognise that despite improvements in our healthcare, women continue to have unique healthcare needs that are not being addressed. We suggest this is because we tend to treat everyone as uniform, with a 'one size fits all' approach. However, if we are to bring about improvements then we need to implement more tailored and precise care.

Therefore, developing a comprehensive Women's Health Strategy is crucial to ensure that women across the country receive the care they need and deserve to live long and healthy lives.

Breast cancer is an important consideration in a Women's Health Strategy as it is one of the most common types of cancer that affect women. It is influenced by the hormonal and reproductive differences that impact women across their lives and the therapy required to treat women in turn impacts women and their whānau in many ways.

Improving access to healthcare services is important for women in rural and remote areas who face significant barriers to accessing healthcare services due to distance, transportation and financial constraints. There is a need to continue to invest in mobile clinics and telehealth services to bring healthcare services closer to women living rurally. Allied to this is the need to address the unique health needs of different populations of women. For example, Māori and Pacific women face unique health challenges. It is also important to better understand the social determinants of health including provision of culturally sensitive healthcare information and services to address ethnic and cultural differences. Similarly, women with disabilities may require specialised care to address their unique health needs.

Another critical component of a Women's Health Strategy is the promotion of preventive healthcare. Women should have access to optimal, timely risk assessment as well as tailored screening and health check-ups to detect and prevent diseases early. Our current screening programmes for breast cancer, cervical cancer, and other common health conditions that women may face are suited to the general population and fail to recognise that some people are at higher risk at an earlier or later age. Additionally, providing culturally appropriate education and resources to help women maintain a healthy lifestyle, including nutrition and exercise, is important, particularly where social determinants of health may make this more difficult.

Mental health conditions such as depression and anxiety disproportionately affect women, and it is essential to provide adequate support and resources to women who are struggling with these issues.

In conclusion, developing a comprehensive Women's Health Strategy is crucial to ensuring that women across Aotearoa receive the care they need and deserve. By improving access to healthcare services, promoting preventive healthcare, addressing mental health issues, and addressing the unique health needs of different populations of women, all women in Aotearoa will have the opportunity to lead healthy and fulfilling lives.

We will address these issues in relation to breast cancer and explain why there should be a focus on this health condition in Aotearoa's Women's Health Strategy.

Key facts about breast cancer in New Zealand

- Breast cancer is the most common cancer to affect women.
- In New Zealand 3477 breast cancers are diagnosed each year with 685 people dying (1,2).
- New Zealand has one of the highest rates of incidence of breast cancer at 93.1 per 100,000 women (3).
- Breast cancer accounts for 27% of all new female cancers (1).
- After adjusting for age, wāhine Māori are 33%, and Pacific 52% more likely to die from breast cancer (4).
- Late stage at diagnosis is the single biggest contributor to worse outcomes for Māori and Pacific women (4, 5).
- Breast cancer is the biggest cause of death for New Zealand women under 65 years of age (4).
- Fewer than half of women have their breast cancer detected by screening mammogram, their cancer is instead detected symptomatically (4).
- The current screening age (45-69 years) does not incorporate those with early and late onset disease (396 women diagnosed under the age of 44 in 2020 (1)) and an estimated 743 women over the age of 69 years are diagnosed with breast cancer each year (4).
- Breast cancer has an overall survival of 86% at 10 years, but around 685 women die each year from breast cancer. The most common breast cancer subtype (hormone receptor positive) sees women relapse and die 10 to 20 years following diagnosis (4).
- Deprivation affects breast cancer survival and access to care is an issue. Median survival for advanced breast cancer patients in New Zealand is 16 months compared to 32+ months globally (6).
- New Zealanders are more likely to die from breast cancer than Australians (2, 3, 7, 8).
- Breast cancer risk is affected by many aspects of women's genetics, biology, health, life events and choices, including:
 - Age at menarche
 - Age at menopause
 - Parity
 - Age at first live birth
 - Oral contraceptive use
 - Menopause hormone therapy combining oestrogen and progesterone
 - Mammographic density
 - Tubal ligation
 - Endometriosis
 - Body mass index
 - Height
 - Mutations in a number of specific cancer genes
 - Alcohol use.

Breast cancer impacts other health conditions that are specific to women

- Pregnancy and cancer treatment
- Breast feeding ability
- Fertility / infertility and chemotherapy
- Genetic factors and gene mutations

- Sexuality and self-image
- Hair loss
- Early menopause with oestrogen suppression
- Bone health and osteoporosis
- Fear of recurrence and uncertainty
- Loss of identity
- Mental health
- Lack of social support.

A Women's Health Strategy needs to span the whole lifetime of our women, from girls to older age and end of life. It should include health literacy including education on breast health in language that is easy to understand. Girls should be breast aware, know if they have dense breasts, and learn about their family history of the disease. Even with a BRCA mutation only some will know as fathers often silently carry this and other genes related to the disease.

The incidence and mortality rates for Māori and Pacific women demonstrate that current means of educating, diagnosing and treating women are sub-optimal and need rapid improvement. As mentioned, a 'one size fits all' approach is clearly not adequate.

Significant work is needed to improve health outcomes for New Zealand wāhine with breast cancer. Inclusion of breast cancer in a Women's Health Strategy is essential, given the massive impacts of this disease on individual women, their whānau and communities.

Elements of the breast cancer pathway that impact on the health and wellbeing of women and their whānau

Breast cancer is a significant health challenge and mortality factor for the women of Aotearoa and their whānau. A Women's Health Strategy should prioritise prevention, detection, diagnosis and treatment of breast cancer as well as supportive care. It should also deal with the longer-term effects of breast cancer as, with modern methods and treatments women are surviving longer, but continue to have health needs that relate back to their diagnosis and treatment. It should also address the fact that breast cancer is a disease that is driven by hormonal, reproductive, lifestyle and genetic factors along with mammographic density.

Prevention comes in two forms: *reducing incidence* and *reducing late diagnosis* to ensure that the cancer is less likely to recur. Precise diagnosis and appropriately targeted treatment, along with an understanding of genetic elements driving the cancer, is critical to achieving optimal outcomes. It is also important to recognise breast cancer is a disease that often occurs spontaneously, simply as a result of mutations or random accumulated damage to DNA.

What needs to change?

Better screening coverage for earlier detection, risk-based screening, extend screening age to 74, and to 40 for high-risk groups (family history/genetics, Māori and Pacific).

Increased resource allocation to BreastScreen Aotearoa (BSA) is vital in enabling screening targets to be met. BSA fell well behind 70% targets across ethnicities and age groups as a result of Covid lockdowns

and delays. There remain a large number of women whose **screening is delayed** and some of these will have undetected cancers that are advancing. BSA urgently requires resource to build and retain its **workforce** at effective levels and to ensure staff are well trained. Further resource is needed to acquire **modern technology** and to implement **work programmes** such as an Information, Communications Technology project, the extension of screening age and an increased focus on Māori and Pacific peoples.

Validate, publicly fund and **integrate breast cancer risk assessment tools** into our pathways; most tests are validated on populations not as ethnically diverse as ours.

Measure and report breast density and provide supplementary screening. Breast density both masks cancer on mammograms and is an independent risk factor. Māori women have higher volumetric breast density (9). On 9 March 2023 the US FDA announced that it now requires mammography facilities to notify patients about the density of their breasts (10).

Women require information about the impact that breast density and other factors can have on the risk for developing breast cancer, and this **education** is an important element of a comprehensive breast health strategy.

Screening programmes today are suboptimal for those diagnosed symptomatically while those who do not develop cancer perceive little benefit from a 'one size fits all' screening programme over their lifetime.

More precise diagnosis is needed, by using genomic testing and precision diagnostic and prognostic tests. This allows better targeting of treatments as well as identification of low-risk early cancers where harsh chemotherapy may be safely avoided.

More effective treatment with medicines targeted precisely to mutation/subtype/receptors.

Improved treatment regimens with a greater range of treatment options for those with early and advanced breast cancer.

Better support services including better health education for girls and women that is age and ethnicity appropriate.

Better information for those diagnosed to empower better treatment decision-making and treatment adherence.

Wrap around health services for women would mean that symptomatic women might be identified earlier and treated at an early stage.

Our big wish for the next generation – Precision Health

Inclusion of breast cancer in a Women's Health Strategy is vital in addressing this life-threatening cancer that has a massive impact on so many of Aotearoa's women.

Our wish is that Aotearoa adopts a **Precision Health** approach to more effectively and precisely assess breast cancer risk, to detect, accurately diagnose and treat breast cancer, including greater access to clinical trials, as well as ongoing support and care for breast cancer patients.

Better support includes cancer service navigation, appropriate culturally diverse information for patient, counselling, lymphoedema treatment, ongoing psychosocial support and monitoring. This includes monitoring of treatment side-effects and clinical responsiveness to these to ensure adherence to therapy and optimal outcomes as well as ongoing monitoring of health and potential symptoms of recurrence.

The equity impact of breast cancer

Early breast cancer is a curable disease when treated with the appropriate medicines for the subtype and stage, an approach which is the current global standard of care, but New Zealand falls short of that standard. **Māori and Pasifika women currently have their breast cancers detected later and receive less treatment than those of other ethnicities. This results in poorer outcomes and higher death rates.** This is unacceptable in Aotearoa and requires targeted information and education as well as health services designed to deliver culturally appropriate and acceptable care, from risk assessment, screening, detection, treatment and supportive care and follow-up.

Globally, metastatic breast cancer is fast becoming a chronic, treatable illness that can be lived with over many years. This is possible when clinicians can rapidly and accurately determine the nature of the disease, apply timely treatments precisely targeted to the identified subtype and switch to other treatments as needed, depending on individual response and tolerance.

Without adequate **investment into new medicines** and allowing swift and early access for patients, New Zealand's cancer mortality statistics will not improve and will fall further behind those of similar countries. BCAC hopes that a Women's Health Strategy will include a strategy to fund new medicines and innovative treatments earlier to improve the lives of all women, particularly Māori and Pasifika.

Key issues and solutions

Adoption of a precision health approach to all aspects of breast cancer would reap huge benefits in the health and wellbeing on the women of Aotearoa. Below we list three key areas in which a real difference can and should be made in the lives of the thousands of New Zealanders who either have breast cancer or are at risk of developing breast cancer. BCAC considers that these need urgent attention and we offer meaningful solutions that should be adopted immediately. These could be included in the Women's Health Strategy:

1. **Assess, stratify and manage risk and improve screening so that breast cancers are detected earlier and treatments are less invasive and more effective. This involves resourcing BreastScreen Aotearoa to allow increased participation in the current screening programme**

and also modernising the programme it so that it better targets particular groups based on their breast cancer risk.

2. Ensure greater access to new medicines so that oncologists have a ‘full toolkit’ and can give patients optimal treatments, targeted to their particular breast cancer subtype and stage.
3. Increase precision by using germline testing, genomic sequencing and gene expression profiling to improve breast cancer diagnosis, appropriately target treatments, optimise health outcomes, reduce inequity and ensure efficient use of resources.

Key Issue One: Improved screening with risk assessment

Breast density

Breast density is one risk factor that could be easily incorporated into the current screening system. Up to 50% of women aged 45 to 69 have varying proportions of fibro-glandular tissue, or “dense” breasts, which masks tumours from the view of radiologists reading the mammogram film. Those with dense breasts also have an intrinsically higher risk of breast cancer. As of March 2023 the FDA requires all providers of mammograms across the USA to measure and report breast density.

Currently, New Zealand policy dictates that women are not informed of the density of their breasts. When no evidence of disease is picked up in mammograms performed by Breastscreen Aotearoa, that information is provided without any caveat informing the women that they have dense breasts, and that this raises the chances of receiving a false negative test result. This results in later diagnosis, more invasive treatment (e.g., full mastectomy, chemotherapy, radiotherapy) and more advanced cancers. Earlier diagnosis would lead to less invasive treatment and reduced cost to the health system and societal burden.

Women who have dense breasts benefit from additional forms of screening such as ultrasound and MRI. Women in New Zealand’s private healthcare system are more likely to be informed of their breast density and advised to have more frequent checks and supplemental screening in addition to mammography. This creates another inequity between those who can afford private screening and those who rely on the public screening programme. This disproportionately impacts Māori women, as this population has a higher incidence of dense breasts (9) and is less likely to have health insurance.

This is an inequity that can be swiftly and simply remedied by mandating that women are informed of the density of their breasts and offered additional forms of screening.

Risk assessment tools

There are now a number of breast cancer risk assessment tools available that could be used alongside screening by primary care providers to assess an individual’s risk and ensure that they receive appropriate surveillance and advice. These tools take into account not only genetic and medical history risk factors (e.g. dense breasts, early menarche, late menopause, late or no childbearing, high polygenic risk scores), but also some modifiable behavioural factors (e.g. HRT use, high BMI after menopause, excessive alcohol consumption). Examples of breast cancer risk assessment tools are BOADICEA (12),

CanRisk (11) and CRA (13). (For more information on Precision Health and Breast Cancer, please visit [this link](#).)

Actions

- Effectively resource BreastScreen Aotearoa and accelerate the roll-out of mammographic screening for 70-74 year-olds followed by reduction of the screening age to 40 for those at above average risk.
- Notify all screened women of their breast density and provide appropriate supplemental screening (e.g., ultrasound, contrast enhanced mammography, abbreviated MRI) for those at above average risk of breast cancer.
- Better resource the Genetic Health Service of New Zealand and genetic counselling services to improve access and broaden the testing criteria for germline breast cancer mutations.
- Introduce risk assessment tools at primary care so that at-risk patients may be identified and given appropriate advice and access to strategies such as modified screening and surveillance, lifestyle/behaviour changes, and/or prophylactic surgery.

Key Issue Two: Improved access to medicines

New Zealand is not only slow to adopt a Women's Health Strategy but slow to approve and fund medicines which will assist in the treatment of women with breast cancer including extending their lives. BCAC's website lists breast cancer medicines that remain unfunded as well as medicines for which strong evidence is emerging (<https://www.breastcancer.org.nz/content/striving-better-care>).

New Zealand women continue to have insufficient and slow access to effective medicines. This is impacting quality and length of life for New Zealanders diagnosed with breast cancer and other cancers as well as other treatable diseases. New Zealand ranks last of 20 OECD countries compared for market access to modern medicines (14). New Zealand no longer reports per capita expenditure on medicines to the OECD, but Pharmac annual report data for 2018/19 suggests funding for all medicines and medical devices is only \$US138 per capita, which was only 5.4% of Government spending on health at the time (14). There is direct correlation between our poor medicines access, poorer outcomes, and the lack of money invested by successive governments into medicines.

Advances in medicine

Around 25,000 New Zealanders are diagnosed with cancer each year and this number will increase in the coming years as our population grows and ages. Globally, personalised treatment has seen an overall drop of 29% in cancer deaths between 1991 and 2017; approximately 2.9 million fewer cancer deaths. Treatment breakthroughs such as immunotherapies and targeted therapies have contributed significantly to this decline (15). Providing New Zealanders with access to the most effective treatment for their cancer subtype is a smart investment that will result in savings long term as more precisely targeted medicines are used to treat smaller subgroups of patients and people suffer less morbidity and mortality and are better able to contribute to their whānau and society.

The current narrative

New Zealanders are missing out on effective treatments and any aspiration to do better. Generally, modern targeted therapies are less toxic and the side effects more tolerable than those of traditional cytotoxic chemotherapy. The scientific advances validated through clinical trials and published in peer reviewed journals are well documented in breast cancer, and frontiers of treatment are moving rapidly. Other countries, such as Australia, Canada and the United Kingdom, adopt this science by funding newer medicines many years earlier than New Zealand. Interestingly, these countries do have Women's Health Strategies and therefore a greater commitment to women's health.

To ensure the long term economic and societal benefits of effectively treating cancer, clinicians need to have a suite of medicines available to optimally treat their patients. While better medicines remain unfunded for many treatable diseases in New Zealand, our knowledge of breast cancer allows us to identify a range of medicines available for use across early and metastatic breast cancer.

Simply put, to provide access to modern, effective treatments, New Zealand's medicines budget must substantially increase. To reach the OECD average, the budget would need to increase to two to three times its current allocation. This would result in many benefits to patients and our health system.

Key Issue Three: Increase precision by using gene-based tests and tools

Germline testing at the time of diagnosis can also play a role in precisely identifying targeted medicines that will be effective. Private providers and their patients are embracing these technologies, as their use can achieve better risk assessment, more precise diagnosis, better prognosis and in some instances better prediction and active surveillance. These benefits result from patients and clinicians having the genomic and molecular evidence needed to determine which therapies will or will not bring benefit, in what sequence and to assess the risk of a cancer occurring or recurring. The information provided may also determine whether a particular treatment can be avoided and how light or aggressive treatment may need to be. Clearly, patients want to be given only treatments that they know will work for them and avoid those that will not.

Within New Zealand's public system such initiatives are not funded and there is a tendency to treat people as if they are the same when it is clear they are not. We urge the Government to develop the infrastructure and processes for routine DNA/RNA sequencing of patient's tumours and blood samples just as we did in our response to COVID 19, when we understood that an upfront cost would bring a downstream benefit. Adoption of advanced testing technologies will provide our health system with the opportunity to break away from being a reactive 'late follower' and ensure that we take advantage of the cost savings and societal benefits that well selected modern cancer treatments can confer.

Actions

- Include the screening, diagnosis and treatment of breast cancer in a Women's Health Strategy.
- Include breast cancer in sections dealing with health literacy so that women are informed about the disease and can make decisions about their health.
- Include breast cancer in sections of the strategy that deal with pregnancy, lactation, fertility and menopause.

- Include breast cancer in the section dealing with older women along with the treatment of osteoporosis and maintenance of bone health.
- Increase funding for the medicines budget to the OECD average to achieve better disease treatment and outcomes, i.e. longer, healthier lives.
- Explore options to facilitate access to new and innovative medicines, including Early Access Schemes and Cancer Drug Funds.
- Include breast cancer in the strategy relating to genetic testing.
- Explore options to improve screening and diagnosis by incorporating risk assessment, measuring and reporting density, and utilising new tools and technologies to assist with this, e.g. CanRisk (11), supplemental screening etc.
- Ensure that PHARMAC's decisions take into account their impact on the efficient functioning of other parts of the health system, e.g. an injectable version of a drug that would reduce pressure on infusion services, or drugs that improve survival and reduce palliative care costs.
- Recognise the importance of education about breast cancer for girls and women.

References

1. <https://www.tewhatauora.govt.nz/assets/Our-health-system/Data-and-statistics/new-cancer-registrations-2020.xlsx>
2. <https://www.tewhatauora.govt.nz/our-health-system/data-and-statistics/historical-cancer/>
3. <https://www.wcrf.org/cancer-trends/breast-cancer-statistics/>
4. 30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand. <https://www.breastcancerfoundation.org.nz/what-we-do/advocacy/2022-register-report-launch>
5. Seneviratne S, Campbell I, Scott N, Shirley R, Peni T, Lawrenson R. Ethnic differences in breast cancer survival in New Zealand: contributions of differences in screening, treatment, tumor biology, demographics and comorbidities. *Cancer Causes Control*. 2015 Dec;26(12):1813-24. doi: 10.1007/s10552-015-0674-5. Epub 2015 Sep 25. PMID: 26407955.
6. I'm Still Here. Insights into living – and dying – with Advanced Breast Cancer in New Zealand. BCFNZ 2018. <https://www.breastcancerfoundation.org.nz/images/assets/22648/1/bcfnz-abc-report-2018-reprint-10.2018.pdf>
7. <https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release>
8. <https://www.stats.govt.nz/topics/population>
9. Ellison-Loschmann L, McKenzie F, Highnam R, Cave A, Walker J, Jeffreys M. Age and ethnic differences in volumetric breast density in new zealand women: a cross-sectional study. *PLoS One*. 2013 Jul 31;8(7):e70217. doi: 10.1371/journal.pone.0070217. PMID: 23936166; PMCID: PMC3729838.
10. <https://www.fda.gov/news-events/press-announcements/fda-updates-mammography-regulations-require-reporting-breast-density-information-and-enhance>
11. Carver T, Hartley S, Lee A, Cunningham AP, Archer S, Babb de Villiers C, Roberts J, Ruston R, Walter FM, Tischkowitz M, Easton DF, Antoniou AC. CanRisk Tool-A Web Interface for the Prediction of Breast and Ovarian Cancer Risk and the Likelihood of Carrying Genetic Pathogenic Variants. *Cancer Epidemiol Biomarkers Prev*. 2021 Mar;30(3):469-473. doi: 10.1158/1055-9965.EPI-20-1319. Epub 2020 Dec 17. PMID: 33335023; PMCID: PMC7611188.
12. BOADICEA <https://ccge.medschl.cam.ac.uk/boadicea/>
13. CRA <https://crahealth.com/welcome/>

14. https://www.medicinesnz.co.nz/fileadmin/user_upload/Publications/NZ_Medicines_Landscape_2021-22.pdf
15. https://www.medicinesnz.co.nz/fileadmin/user_upload/New_Zealand_Medicines_Landscape_2019-2020_FINAL.pdf

Breast cancer issues identified by BCAC's members in recent consultation

Breast Cancer Aotearoa Coalition (BCAC) is an umbrella organisation representing more than 30 breast cancer-related groups as well as individual members across Aotearoa. We regularly consult with:

- patients with breast cancer
- our membership groups
- cancer clinicians and researchers.

Issues identified by our members following recent consultation are listed below. These provide insights into the day-to-day challenges faced by New Zealanders with breast cancer. They offer many opportunities to improve the care provided within our health system.

1. Medicines funding:

- a. Request for increased funding to the medicines budget. Members comment “we do not choose to have cancer and it’s ridiculous that some women have to worry about the extra cost of a crucial and possibly life-saving non-Pharmac funded drug”.

2. Continuity of care:

- a. At many large teaching hospitals, members report they can go for months without seeing their oncologist and are seen by a revolving door of other doctors. This is unsettling for the patient, and results in a much lower standard of care as the doctors do not have a sense of the patient and are just working from previous notes which can be inaccurate – they also do not appear to have time to prepare thoroughly for each patient.
- b. Request that women see their dedicated oncologist at least every other appointment (this may require more oncologists in the bigger centres).

3. Risk assessment, stratification, screening and diagnosis:

- a. There are unacceptable delays between receiving concerning screening results and being seen at the hospital.
- b. There is a reluctance within DHBs to biopsy cancer patients.
- c. Younger women are having to pay for a mammogram when a lump is found. Many young women cannot afford to do this.

- d. Breast Screen Aotearoa has guidelines that outline very strict reporting timeframes to those who are eligible. Younger women fall outside of the eligibility, and can often wait extended periods for the results. The reporting timeframes should be the same – if not with more priority as younger women usually get more aggressive forms of cancer.
- e. Members noted that post mastectomy surveillance mammograms are untaken on the remaining breast. No surveillance is undertaken on the mastectomy/reconstructed side, despite 3-5% risk of recurrence showing up on the mastectomy/reconstructed side. The mastectomy/reconstructed side should also receive ultrasound (private patients routinely have this as part of post cancer follow ups).

4. Follow-up care:

- a. Request that surveillance in the public system includes routine MRI, particularly for women with dense breasts. This is standard surveillance for a high risk patient in the private system.

5. Breast density:

- a. Women should be informed of their breast density as high density can mask breast cancer. A member required a bilateral mastectomy in 2018 due to advanced and aggressive cancer that was not seen by a radiologist on a screening mammogram before it became a palpable lump. Subsequently, the member paid for a private ultrasound and was then told that she had extreme density.

6. Genetic testing:

- a. Adopted women are not receiving genetic testing services because they are unable to access family medical history. This results in many “at risk” women not being tested for gene mutations.
- b. There is an unacceptable delay between women being informed they have a genetic mutation and receiving (recommended) prophylactic surgery, e.g., hysterectomy, mastectomy. There is a points system that identifies risk factors, which in turn places a patient on a priority list, but this is not being communicated to women at the point of learning of the mutation.

7. Travelling to receive treatment:

- a. Members have noted the difficulties they face in the regions because of centralised use of resources, e.g., having to travel from Napier to Wanganui for chemotherapy and radiotherapy. This results in financial concerns, family worries and additional stress on health from the additional travel.

8. Post code lottery cancer care:

- a. Currently some DHBs offer a secondary mastectomy as an equal option to reconstruction. The option to “go flat” should be available to women throughout the country.
- b. Request that cancer care is the same regardless of DHB, e.g., creams and Mepitel (second skin) to reduce skin burns from radiation should be funded in all centres for patients receiving radiation treatment.
- c. Members report issues regarding waiting times for reconstructions in different DHBs, e.g. Hutt Hospital is reported by members as being a number of years. The delays cause mental stress and anxiety.
- d. Women have reported they are offered different levels of testing, scanning, radiation and medical treatments as well as different amounts of nursing and supportive care, depending on which DHB is managing their cancer.

9. Financial support during treatment:

- a. Request for a cancer support scheme to financially help those who are too ill to continue to work (for a period of time), and don't have the sick leave or annual leave to cover it (similar to ACC). These women **DO NOT** want to resign their employment and apply for a sickness benefit.
- b. Request for free GP visits and prescriptions for patients with advanced breast cancer. Many women are struggling financially and “save up” their pain for one GP visit, rather than going each time they have a singular issue. This is dangerous.

10. Patient communication and consultation:

- a. Members note that DHBs are not adhering to the legal requirement to ensure women are given ALL the information they require to understand their treatment options and give informed consent.
- b. Members note that their right to question what treatments are available are ignored, and that their specialists have refused to compromise on treatments offered.
- c. Members note that some GPs do not take patients' concerns seriously when presenting with symptoms (of cancer and treatment). Members feel brushed off by their GPs.
- d. Request that GPs are provided with more education to recognise signs of cancer.
- e. Request that complementary treatments are made more available, and/or that more information is provided.
- f. Request that better nutritional advice or direction on where to obtain good advice on this during and after treatments.

11. Post-treatment care and support:

- a. Request for more “after care” support for when treatment is finished, e.g.:
 - i. Mental health services;
 - ii. Dental care post chemotherapy;
 - iii. Eye care;
 - iv. Physio care for rehabilitation after surgeries and assistance with post treatment exercise programmes
 - v. Proper care and guidelines for patients with lymphedema
 - vi. Request for funding of lymphedema garments. Some women are paying \$650 per sleeve out of their own pocket.

- b. Members noted that they are left dealing with the mental and physical scars with no support. They note that if they had been in a car crash, they would be covered by ACC, but there appears to be no Government support available for those who request assistance after receiving cancer treatment.