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Briefing on Breast Cancer Issues in New Zealand

For: Hon. Tony Ryall, Minister of Health
Hon. Jo Goodhew, Associate Minister of Health

CC: Hon. Annette King, Member, Health Committee
Hon. Barbara Stewart, Member, Health Committee

From: Breast Cancer Aotearoa Coalition (BCAC)

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1. Introduction

BCAC is again grateful for the opportunity to meet with the Minister of Health and other Members of Parliament to discuss key issues for the breast cancer sector in New Zealand.

These issues are of national importance given the significant impact breast cancer has on the New Zealand community.

Breast cancer:

- is the most common form of cancer to affect women, with more than 2,800 women diagnosed annually. We note this has risen to 3,000 in the Ministry's 2012 provisional data.
- accounts for 28 per cent of all new female cancers
- affects more than 150 women under the age of 40 each year
- kills close to 650 women every year and is the second most common cause of death from cancer for women
- disproportionately affects Māori women. The Māori registration rate is 1.6 times higher than the non-Māori rate and Maori women are more likely to die from it than non- Māori women.

(All figures taken from: Cancer: New Registrations and Deaths 2010)

These statistics show that there is clearly still work to be done to improve the health outcomes for New Zealanders with breast cancer. We hope this document will highlight the areas where a real difference can be made for those diagnosed with this disease.

In this document we outline:

- our feedback on the latest Government initiatives on cancer care
- issues that need to be addressed to improve breast cancer care.

2. Government initiatives on cancer care

Since BCAC met with the Minister last year, the Government and Ministry of Health have taken further positive steps to improve the treatment pathway and outcomes for cancer patients, including those with breast cancer. These measures include:

- Convening national expert working groups to develop tumour-specific Standards of Service Provision for a range of cancers, including breast.
- Ensuring the Faster Cancer Treatment wait time indicators are a core element of each of the Standards.
- Establishing Cancer Nurse Co-ordinator (CNC) positions to ensure cancer patients receive optimal care and information; appointing a National Oncology Nurse Clinical Lead; appointing 54 CNCs across the 20 District Health Boards (DHBs).
- Progressing the Medical Oncology Models of Care project through a National Implementation Plan, to optimise provision of medical oncology services.
- Initiating a National Radiation Oncology Plan by convening an expert group to advise on workforce, costings and linear accelerator capacity.

BCAC applauds all of these initiatives. Each of them will contribute to improved, more efficient and effective treatment and care for the growing number of New Zealanders diagnosed with cancer. In

particular, the tumour-specific standards will have a positive impact in ensuring every DHB understands and strives to meet its responsibilities in providing timely, optimal treatment and care to their cancer patients.

BCAC was pleased to provide consumer representation in the development of the Breast Cancer Standards. The Chair of the Working Group, Prof. Ian Campbell, ran an extremely robust and thorough process and we are confident that the Standards, currently in draft form and awaiting Ministerial sign-off, are evidence-based and appropriate.

We note that active monitoring of service provision by the Ministry will be key to ensuring effective implementation of the Standards.

Prior to developing our 2013 Ministerial Briefing, BCAC consulted our members groups and individual patients as well as breast cancer specialists and nurses around the country. Many of the issues raised as current critical priorities were identical to those raised by our members and outlined by BCAC in last year's Ministerial Briefing. Where this is the case we have appended last year's more detailed submission to this Briefing and referred only briefly to the issue below.

It is reassuring to see that implementation of the draft Standards of Service Provision for breast cancer patients would remedy many of these problems. However, while we await implementation, patients continue to receive sub-optimal care and to suffer as a result.

3. Priority issues that directly affect the wellbeing of patients

3.1 Faster cancer treatment

Several cases have been raised with BCAC where referral of patients from one DHB to another has resulted in unacceptable delays that would not meet the Faster Cancer Treatment (FCT) requirements. Some patients being managed within single DHBs are also experiencing slow and complicated treatment pathways. This problem is particularly acute in rural areas. It is vital that the FCT timeframes are adhered to for all patients, whether their treatment is provided in a single DHB or across different DHBs.

BCAC is pleased to see that 54 nurses have been appointed to part time and full time Cancer Nurse Coordinator (CNC) positions across the 20 DHBs.

We suggest that CNCs be given the responsibility of ensuring the treatment delivery timeframes are met for every patient in their care.

If this role is given to CNCs, they must be empowered within the DHBs to achieve this.

Recent examples of slow provision of treatment and care are listed in *Appendix 6.1*.

3.2 Access to delayed breast reconstruction

Women in Tauranga and the Waikato are again being dropped from surgical waiting lists and referred back to their GPs after six months of receiving no breast reconstruction surgery. Many patients are waiting two years and more for this vital surgery. The problem is very likely to be more widespread and following discussions in September the Ministry is looking into this.

This issue, raised by BCAC last year with the Minister (See *Appendix 6.2*), is deeply upsetting to

women and can impact on emotional wellbeing and quality of life. It can also put pressure on women to make hasty decisions to have immediate reconstruction when this is not the best option either medically or psychologically.

We are pleased to see the provision of breast reconstruction has been established in the draft Breast Cancer Standards. Note, numbering of Standards in this document conforms to that in the draft of July 2013 and may change in the final version.

Surgery - Breast reconstruction

Standard 7.6 *Clinicians should discuss delayed or immediate breast reconstruction with all women who are due to undergo mastectomy, and offer it except where significant comorbidity precludes this option. All appropriate reconstruction options should be offered and discussed with women, irrespective of whether they are all available locally (modified National Institute for Health and Clinical Excellence 2009).*

Following a September meeting between BCAC and the Ministry, we look forward to hearing the result of their scoping the situation around the country. How wide is the problem and are there any plans to remedy this?

We request that all those awaiting delayed breast reconstruction surgery be treated in a timely way.

3.3 Access to counselling (psycho-social support)

The lack of counselling and supportive care in many places has been again raised as a critical issue affecting the welfare of patients by clinicians, breast care nurses and women around the country. The issue was outlined in BCAC's 2012 Ministerial Briefing (see Appendix 6.3). BCAC is pleased to see the provision of psychosocial support is an integral part of all the national tumour standards and we look forward to seeing this implemented.

Supportive care

Standard 8.1 *Women with breast cancer will be screened with a validated tool to identify psychological and social needs at key points of their breast cancer experience.*

Standard 8.2 *Women or their whanau/family found to have significant psychological distress or facing particularly difficult treatment decisions will be offered prompt referral to a specialist psychological service, as part of an integrated cancer service.*

We ask that the Ministry ensure the provision of counselling and psychosocial support to cancer patients as a priority.

3.4 Lymphoedema prevention, treatment and aids

The lack of provision of lymphoedema care was again raised as a top priority by breast care nurses, support groups and patients around the country. Many DHBs provide no support, while some offer slow and patchy support to some patients, often after irreversible damage has been done (see Appendix 6.4). Again we are delighted to see lymphoedema assessment and therapy will be provided once the Standards are implemented.

Follow up & Surveillance

Standard 9.3 *Women who develop lymphoedema have access to lymphoedema assessment and therapy services including complex physical therapy, fitting, provision and replacement of compression garments where indicated.*

We request the provision of resources to upskill nurses in the provision of lymphoedema massage and kinesio taping and to establish a mobile lymphoedema service for those in rural areas.

3.5 Fertility

As noted in BCAC's 2012 Ministerial Briefing, fertility assessment and treatment would make a huge difference to the lives and wellbeing of young women diagnosed with breast cancer (see Appendix 6.5). This service could be provided at a very reasonable cost. We are pleased to see that timely referral to a fertility specialist is now set out in Good Practice Points in the draft BC Standards.

Standard 7.7, Good Practice Point 3. Fertility issues and options for fertility preservation need to be discussed with premenopausal women prior to commencing chemotherapy, preferably well in advance, so that chemotherapy is not unduly delayed if women wish to undergo fertility preservation treatment. For those women that wish to preserve fertility consultation with a fertility specialist should be arranged. Women must have timely access to fertility assessment and treatment.

Standard 13, Good Practice Point under Breast Cancer in Younger Women. Effects on fertility need to be discussed and consultation with a fertility specialist must be arranged for young women that wish to preserve fertility (National Child Cancer Network 2013).

We request timely implementation of the recommendations and strategies included in the National Child Cancer Network report that define the fertility services needed for adult cancer patients.

4. Other issues

4.1 Inability of NZ Health and Disability Ethics Committees to determine safety and ethical status of clinical trials

BCAC is concerned that New Zealand's Health and Disability Ethics Committees are unable to determine the safety and ethical status of clinical trials recruiting New Zealand patients. We recently raised our deep concern about the safety of participants in the SOLD clinical trial with the Northern B Ethics Committee, and asked the Committee to examine the ethical status of the trial.

Our submission was made on the basis of results from the PHARE clinical trial that were presented at ESMO and SABCS late in 2012, and were then published in The Lancet in June 2013. The PHARE trial showed that patients with early HER2 positive breast cancer who were treated for only 6 months (9 treatments) with trastuzumab were 28% more likely to experience cancer recurrence or death than those who received 12 months of treatment (18 treatments). BCAC expressed its concern to the Committee about potential grave harm to New Zealand patients who continue to be recruited to the

SOLD clinical trial in which half of the patients receive only 9 weeks of treatment (3 treatments) and their outcomes compared with those who receive 12 months (17 treatments).

BCAC presented four detailed submissions to the Northern B Ethics Committee on this matter, with supporting statements from Assoc. Prof. Chris Frampton (biomedical statistician) and Dr Chris Walsh (BCAC Deputy Chair and consumer/patient representative). The Committee received submissions in response from the trial's principal investigator.

The BCAC submissions referred to relevant elements of New Zealand's Ethical Guidelines for Intervention Studies (2012) including:

- *the greater the potential harm from a study, the closer the scrutiny that is required of the ethical issues raised (EGIS Section 3.2)*
- *the potential risks of an intervention study must be proportional to the potential benefits (EGIS Section 3.11)*
- *a study warrants greater provision for the protection of participants if they are to be exposed to more than minimal risk (EGIS Section 4.14)*

We noted that the risk for patients receiving only 3 treatments in SOLD is a higher likelihood of the recurrence of their aggressive HER2 positive breast cancer and resulting death, as was found in those who received the shortened course of 9 treatments in the PHARE study.

The Committee's response to BCAC stated:

.. whilst committees are responsible for checking that appropriate peer review of the scientific merits of the study has been carried out prior to the study being approved, it is not the role of the ethics committee to conduct peer review. If the SOLD trial were a new application, the Committee would require evidence of independent peer review of the scientific basis and methodology of the study as well as SCOTT review. The Committee does not have scope to review the scientific merits of the SOLD study.

Ethics committees do not proactively monitor approved studies. The Committee is satisfied that there is a Data Safety Monitoring Committee in place to monitor the SOLD trial. The Committee notes that the SOLD study is continuing world-wide and that it has not received notification from the Data Safety Monitoring Committee that there are safety concerns in relation to the trial. The Committee has decided that there are insufficient grounds to justify withdrawing ethical approval for the SOLD trial.

This response means that the Ethics Committee was unable to review the safety and ethical status of a trial recruiting patients in NZ, even when they had received evidence from concerned citizens suggesting that this trial is dangerous and unethical. The Committee appears to have disregarded our reports of the concern of many New Zealand oncologists regarding the safety of the trial, the low worldwide and New Zealand recruitment rate and the fact that the trial appears likely to close early without reaching its recruitment targets.

The Committee was unable to review the impact on patient safety of new data emerging from a similar trial and states that safety and ethical status will be monitored by the trial's Data Safety Monitoring Committee, an anonymous and unidentifiable group based overseas.

It is clear that the requirements of the Ethical Guidelines for Intervention Studies (EGIS 2010) cannot currently be met as:

- there is no opportunity for close scrutiny despite great potential harm
- there is no means of determining whether risks are proportional to benefits
- there is no means of protecting participants despite their being at high risk

BCAC concludes that this is a dangerous situation for New Zealand patients involved in clinical trials. We are not aware of any avenues for appealing the Committee's decision or for having this matter properly examined.

We request that the Ministry urgently review this situation and establish an independent body with the medical knowledge necessary to properly review the ongoing safety and ethical status of clinical trials.

4.2 Screening age

Australia has raised their maximum breast screening age to 74 and so should New Zealand. Our population is ageing and breast cancer incidence is increasing. We need to detect and treat as early as possible for the benefit of New Zealand women and the health system. Evidence for the benefits of later age screening is presented in Australia's Dept of Health and Ageing BreastScreen Australia Evaluation (2009). Australia will now invite women from 50 – 74 for screening. They also screen women 40 - 49 and 75 + who want screening.

BCAC is pleased to learn that the National Screening Unit and BreastScreen Aotearoa (BSA) are reviewing this evidence and communicating with the National Health Committee on the matter. Jane McEntee of the National Screening Unit has agreed to keep BCAC informed of developments.

We strongly encourage adoption of older age screening by BreastScreen Aotearoa.

4.3 Screening high-risk women

The Breast Cancer Standards make it evident that women at high risk of breast cancer occurrence should be screened within the health system, but do not specify whether this should be undertaken by DHBs or BSA. Currently neither group is taking responsibility for this important function. BCAC suggests it may be best to allocate money to BSA and get them to do this in a uniform way across the country. We understand BSA normally doesn't operate on a one year cycle and that this would initially create logistical challenges. However we do trust, given the necessary funding and MRI capacity, that BSA would be a reliable provider capable of delivering national uniformity.

Screening women at high risk of breast cancer

Standard 1.2 Women who are known to carry a breast cancer susceptibility gene mutation (BRCA)

should have annual breast magnetic resonance imaging (MRI) and consider annual mammography from ten years prior to the age of onset for the youngest affected family relative. Mammography is not recommended before 30 years of age.

Standard 1.3 Women at high risk of developing breast cancer should be considered for annual breast magnetic resonance imaging (MRI) in addition to mammography (over age of 30 years) and clinical examination.

We recommend that BreastScreen Aotearoa be provided with the resources necessary to undertake the screening of women at high risk of getting breast cancer.

4.4 Ensuring optimal treatment and care for elderly patients

Recent reports from the UK Department of Health (*The Impact of Patient Age on Clinical Decision-Making in Oncology*, 2012 and *Cancer Services Coming of Age: Learning from the Improving Cancer Treatment, Assessment and Support for Older People Project*, 2012) have shown that effective cancer treatments have not been provided equitably to elderly patients and that this neglect has led to higher rates of morbidity and mortality in aged patients. We have provided the Ministry with a particular New Zealand example where we question whether optimal treatment was offered and its benefits adequately explained.

We ask that the Ministry review the provision of care in elderly cancer patients and report on their findings.

4.5 Consumer/patient representation

We note the many serious problems identified in the UK health system revealed in the Francis Report on the activities of the Mid-Staffordshire Health Board. No doubt the Ministry is aware of this and seeks to ensure there is proper patient focus and voice within the New Zealand health system to avoid similar disasters. DHBs are aware of this report and its implications. We are interested to hear of any work under way to ensure such problems don't happen in NZ.

The fact that the Cancer Control still has no patient/consumer representative on its Board sets a poor example in the Cancer sector.

We continue to encourage the Ministry to ensure effective consumer representation at all levels of cancer policy making and care.

4.6 PHARMAC's OPP

A consultation is currently underway on PHARMAC's Operating Policies and Procedures. We strongly believe that PHARMAC must respond to input with significant reforms. There is a need for input into decision processes from independent expert clinicians and consumers along with greater transparency and timeliness.

It may be necessary to deal with the evaluation and funding of high-cost medicines outside PHARMAC. More funding is desperately needed as new medicines improving length and quality of life are increasingly developed. New Zealand needs to meet this challenge and provide good access for our people. Horizon-scanning to identify and prepare for new and improved treatments would diffuse tensions and lead to more timely access.

Breakthrough breast cancer drugs include pertuzumab (Perjeta), T-DM1 (Kadcyla) and on the near horizon Entinostat (an HDAC inhibitor).

We encourage the Ministry to guide PHARMAC in significantly reforming its policies and procedures in response to input received during the OPP consultation.

4.7 Funding issue for patients receiving care in private v public health system

BCAC has been informed that currently in some cancer treatment centres, e.g. Auckland, if a patient receives any element of their chemotherapy in a private clinic, they are forced to pay for chemotherapy agents that are normally publicly funded. Comment from the Ministry suggests that there is no policy in place that would dictate such a stance. BCAC is further investigating this and if it is correct, patients who choose or who need to receive some of their treatment in a private setting are being unfairly disadvantaged, particularly those who seek private care in order to access an unfunded medicine. All our citizens are taxpayers and funding for chemotherapy medicines should be available wherever the patient is treated. Those who choose a private setting, thus taking some pressure off the public system, should not be penalised.

We foresee a big issue for patients with advanced HER2 positive breast cancer wanting to increase their progression-free survival by using pertuzumab (Perjeta). It is likely that, as with other innovative medicines, it will take some years for this medicine to be publicly funded in New Zealand, so patients needing it will have to receive this agent in the private system. As Perjeta is given with Herceptin in the first line metastatic setting these women would lose their funded access to Herceptin and be required pay the list price of around \$60,000 in addition to the considerable cost of Perjeta. This will in effect prevent women from accessing a very effective treatment that will extend their lives.

We strongly request that funded access to medicines be provided whether the patient is treated in the public or private system.

4.8 Cancer workforce issues

There is on-going evidence of workforce shortages and this will intensify as numbers diagnosed increase. The Cranleigh Report and subsequent work on Models of Care, initially developed for medical oncology, provide a pathway for optimal use of existing resources. We are pleased to hear similar analysis is under way for radiation oncology. However, the cancer workforce also needs to be increased in number and we propose that specialist cancer consultant roles be prioritised for recruitment and training. This would no doubt involve Health Workforce NZ.

We suggest the Ministry prioritise specialist cancer consultant roles in medical and radiation oncology and surgery for recruitment and training in order to increase the numbers in these vital professions.

5. Information on BCAC

5.1 What BCAC does

The Breast Cancer Aotearoa Coalition (BCAC) is an incorporated charitable society established in 2004 to provide a unified, evidence-based voice for the New Zealand breast cancer sector. Our membership comprises more than 30 breast cancer-related groups from around New Zealand, as well as many individual members.

BCAC is run by a committee of women, most of whom have experienced breast cancer. We work as volunteers to make world class detection, treatment and care accessible to all those affected by breast cancer in New Zealand. By virtue of our experience and knowledge of this disease, as well as our networks across breast cancer patients, groups and clinicians around the country we are able to provide unique insights into improvements that can be made in the provision of breast cancer services.

BCAC provides direct support to those diagnosed with breast cancer through provision of our *Step by Step* resource pack, our informative website www.breastcancer.org.nz and our web videos at <http://www.breastcancer.org.nz/share-your-story/web-videos>

5.2 BCAC member groups

- Age Concern
- Alleviate
- Ascot Radiology Pink Dragons
- Boobops Dragon Boat Team
- Breast Cancer Action Trust
- Breast Cancer Network
- Breast Cancer Research Trust
- Breast Cancer Support Inc
- Breast Cancer Support Northland Trust
- Breast Cancer Support Tauranga Trust
- Breast Health NZ
- Busting With Life
- HER2 Heroes
- Inflammatory Breast Cancer Australasia
- Kenzie's Gift
- Look Good Feel Better
- Lymphoedema Support Network
- The Gift of Knowledge
- The Mamazon Club
- The New Zealand Breast Cancer Foundation
- Pink Pilates
- Rotorua Breast Cancer Trust
- Sweet Louise
- Shocking Pink
- Taranaki Dragons
- Te Ha o te Oranga o Ngati Whatua
- Terrier Race Against Time
- Waikato Breast Cancer Trust
- Waikato Treasure Chests
- Well Women and Family Trust (formerly WONS)
- YWCA Encore

5.3 BCAC representatives who will visit the Minister



Chairperson: Elisabeth (Libby) Burgess (MNZM). Ms Burgess is a scientist living in Auckland. She is currently on the National Breast Cancer Working Group providing consumer input into the development of *Standards of Service Provision for Breast Cancer Patients in New Zealand*. She has participated as a consumer representative in the development of the best practice *Guideline for the Management of Early Breast Cancer* and contributes to the Northern Region Cancer Network. She had breast cancer in 1998. Libby became a Member of the New Zealand Order of Merit in the 2011 New Year's Honour list for her breast cancer work.



Deputy Chair: Dr Chris Walsh (MNZM). Dr Walsh is Director of HER Solutions (Health, Education and Research Solutions). Her breast cancer diagnosis in 2006 prompted her involvement in the campaign to get Herceptin fully funded for 12-months and she led the Judicial Review of Pharmac's decision-making on Herceptin funding. She represented consumers in the development of the *Guideline for the Management of Early Breast Cancer* and attends meetings of the Breast Cancer Special Interest Group as a consumer. Dr Walsh is currently contracted to the Health Quality Safety Commission as senior advisor – consumer engagement. She is also chair of the National Cancer Consumer Representative Advisory group and the newly appointed consumer representative on the Cancer Treatment Advisory Group. Also, she is a co-investigator in cancer survivorship research through Otago University. Dr Walsh was awarded Membership of the New Zealand Order of Merit in the 2010 New Year Honours for her work in women's health.



Secretary: Rowena Mortimer. Ms Mortimer is a lawyer who was diagnosed with breast cancer in 2005. She lives in Auckland, is married and has two children. She believes that consumers can play an important role in the planning and delivery of health services. She is a former member of the National Cancer Consumer Regional Advisory Group, represents consumers on the Northern Cancer Network Collaborative and chairs their Consumer Reference Group. Rowena is also a member of the Northern Cancer Network Breast Cancer Tumour Stream Steering Group, and a former member of the Clinical Guidance committee of Pro Care Health Limited. She is the Consumer Representative on the newly formed Northern Cancer Network Governance Board.

6. Appendices

Appendix 6.1

Faster cancer treatment

Examples of slow treatment and care

A Rotorua patient who had a lumpectomy for breast cancer two years ago noticed a new lump and visited her GP. She was given an appointment with her surgeon at the Lakes DHB six weeks later. Breast cancer recurrence was diagnosed and the surgeon discussed with the patient the possibility of breast reconstruction during surgery to remove the tumour. The patient was interested in this option and was then referred to Waikato DHB where reconstruction could be undertaken. It took a further six weeks to be given an appointment there. A week after discussing this option with the Waikato surgeon the patient decided not to have reconstruction and so was referred back to Lakes DHB. Again it took six weeks to get an appointment. In short the woman was diagnosed with breast cancer in April and did not receive surgery until August.

A Rotorua patient with pelvic tumours from metastatic breast cancer was in severe pain and had no pain management strategy in place. She was given an appointment at the Waikato DHB eight weeks hence. In desperation her friend drove her to the Waikato Hospital and demanded an appointment to provide pain relief. She was seen and treated on that day.

A patient in rural northern Hawke's Bay under annual surveillance with a history of LCIS discovered a breast lump in April. She outlined to BCAC the confusing and contradictory information she received when attempting to organise appointments with multiple elements of the Hawke's Bay DHB, her GP and surgeons in Hawke's Bay and then the Hutt Valley DHB. She was required to navigate a complicated pathway to be assessed and diagnosed with breast cancer and eventually to receive surgery in July. A less persistent patient would have waited much longer.

A 77 year old Northland patient has waited ten months for a follow-up appointment after her double mastectomy. She had originally been told she would be seen in four months but was then repeatedly told the DHB did not have the capacity to see her.

Appendix 6.2

Access to delayed reconstruction – information taken from *Briefing on Breast Cancer Issues in New Zealand* by BCAC, 2012

Breast Reconstruction

The Government has recognised that breast reconstruction, either at the time of breast cancer surgery or at a later time, is an important element of any breast cancer treatment programme. While not all women decide to have breast reconstruction, it's important that women have the choice to pursue this option.

Many women who have a mastectomy choose to have immediate breast reconstruction, but a large proportion of women require delayed reconstruction. This may be because they need further surgery, radiation therapy or other treatment that is incompatible with immediate reconstruction, or because they are simply not yet emotionally ready to undergo a reconstruction operation.

BCAC has learned that many women in New Zealand are once again being removed from surgery waiting lists while awaiting delayed breast reconstruction surgery. We are told that delayed breast reconstruction is not available at all within the public sector in the Bay of Plenty or Auckland regions and this may well be more widespread than we are aware.

This situation causes high levels of stress and can impact on a woman's emotional wellbeing and quality of life. It can also put pressure on women to make hasty decisions to have immediate reconstruction when this is not the best option for them either medically or psychologically.

We ask that DHBs be instructed that delayed breast reconstruction surgery is deemed by the Government to be a high priority service that must be provided as an integral part of the breast cancer treatment programme.

Action point:

- Instruct District Health Boards that delayed breast reconstruction surgery must be provided as an integral part of the breast cancer treatment programme.

Appendix 6.3

Access to counselling (psycho-social support) - information taken from *Briefing on Breast Cancer Issues in New Zealand* by BCAC, 2012

Psychosocial Support

Psychological and social support during breast cancer diagnosis, treatment and recovery is crucial as many women and their families struggle to deal with the mental and emotional stress of cancer and its associated invasive treatments.

It's estimated that up to 25 per cent of all cancer patients will suffer from clinical depression ¹. Further research has shown that major depression is frequent among breast cancer patients, but is often unrecognised and untreated and can amplify physical symptoms and result in poor treatment adherence ².

Counselling, cognitive behavioural therapy, and/or support groups can help women to overcome stress and depression in a healthy way, ultimately leading to better physical and emotional outcomes. In recognition of this point, the *New Zealand Guidelines on the Management of Early Breast Cancer* recommend that psychosocial support should be available to all women with early breast cancer. In addition, one of the six goals of the New Zealand Cancer Control Strategy is to "improve the quality of life for those with cancer, their family and whanau through support, rehabilitation and palliative care". This goal includes an objective to ensure that those with cancer have access to appropriate resources for support.

However, BCAC is aware that psychosocial support is not offered as a matter of course in every DHB. In some areas, such as Waikato, there is no psychosocial support offered through the DHB at all. In other areas, such as Auckland, a psychologist may be available, but has such limited resource that he or she cannot meet the demand from breast and other cancer patients. In Christchurch, access to a psychologist is free for those who have received private treatment at the Cancer Care Centre, but this service is not available to those treated in the public system. For some patients counselling may be available through the Cancer Society of New Zealand, but the number of sessions they receive is limited and variable throughout the country.

BCAC believes breast and other cancer patients should be offered psychosocial support to optimise their quality of life and potential health outcomes. Clearly patients should be able to access such

support equitably wherever they live in New Zealand. Counselling should also be available for couples and families given that the stresses of cancer diagnosis and treatment can impact negatively on relationships.

We are aware that Don Bevan of Psychosocial Oncology New Zealand and Susan Sutcliffe of the Cancer Society are drafting standards for supportive care for the National Breast Cancer Tumour Stream Working Group (NBCTSWG) to consider. We would expect this group to include the availability of psychosocial support as a standard of care within the breast cancer pathway.

Action Point:

- Include provision of psychosocial support for cancer patients as a necessary element of service provision by DHBs

1 Henriksson MM, Isometsä ET, Hietanen PS, et al.: Mental disorders in cancer suicides. *J Affect Disord* 36 (1-2): 11-20, 1995.

2 Fann JR, Thomas-Rich AM, Katon WJ, Cowley D, Pepping M, McGregor BA, Galow J.: Major depression after breast cancer: a review of epidemiology and treatment.

Appendix 6.4

Lymphoedema prevention, treatment and aids - information taken from *Briefing on Breast Cancer Issues in New Zealand* by BCAC, 2012

Lymphoedema Treatment

Lymphoedema is a common side effect of breast cancer surgery, particularly when women have lymph nodes removed as part of their treatment. Around 13 per cent of those who have axillary node dissection during breast cancer surgery will develop significant lymphoedema that requires treatment³. Lymphoedema often occurs in the arm or hand on the side of breast surgery, but it can also occur in the breast, underarm, torso, or back. The condition results in an excessive build-up of fluid in one or more of these areas and requires specialist and on-going care. If women do not receive treatment, swelling can worsen and result in permanent changes to the tissue.

Lymphoedema can be a debilitating condition that can severely impact on quality of life.

Currently, the Ministry of Health does not require DHBs to provide a lymphoedema service for breast cancer patients so many women are not getting the care they need. The service levels provided throughout the country are patchy. In some areas women receiving breast cancer treatment through a public hospital have no access to lymphoedema services and women in many rural areas have poor access to lymphoedema practitioners.

Lymphoedema is a common side-effect of breast cancer surgery and treatment should be provided within any comprehensive breast cancer treatment programme. We'd like to see the Ministry of Health direct DHBs to include this as part of breast cancer service coverage.

A cost-effective way to address this issue would be to offer training to breast care nurses to provide some of the lymphoedema treatment required by women. To address service inequalities in rural areas we suggest the establishment of a mobile lymphoedema service in which a trained breast care nurse or lymphoedema practitioner could travel to rural areas to provide treatment on a regular basis for women who need it.

Action points:

- Ministry of Health to include lymphoedema treatment as part of breast cancer service provision by District Health Boards.
- Provide a training budget to upskill breast care nurses in lymphoedema massage and kinesiо taping so that they can provide treatment for women with lymphoedema.
- Establish a mobile lymphoedema service so that women in rural areas can access this treatment if they need it.

³ Muhammad Asim, Alvin Cham, Sharmana Banerjee, Rachael Nancekivell, Gaelle Dutu, Catherine McBride, Shelley Cavanagh, Ross Lawrenson, Ian Campbell, 2012. Difficulties with defining lymphoedema after axillary dissection for breast cancer. *NZ Medical Journal* 125 No 1351, pgs. 29-39.

Appendix 6.5

Fertility - information taken from *Briefing on Breast Cancer Issues in New Zealand* by BCAC, 2012

Fertility Preservation

Around 150 New Zealand women under the age of 40 will be diagnosed with breast cancer every year. Many of these women will either have not started their families or have not completed them. Younger women are frequently diagnosed with a more aggressive form of breast cancer and this is more likely to require chemotherapy treatment. The chemotherapy agents used to treat breast cancer can have a detrimental effect on the ovaries, with 20 to 70 per cent of women becoming menopausal as a result of treatment. Women are also usually advised to delay conception for a number of years after a breast cancer diagnosis which can further impact on fertility.

In order to preserve their fertility options, younger women who are about to undergo chemotherapy need to consider either oocyte (egg) or embryo cryopreservation, in which eggs or embryos are frozen for potential future use. For some, ovarian tissue cryopreservation may be an option. When these women are ready to become pregnant the frozen egg or ovarian tissue is thawed, fertilised and transferred to the uterus as an embryo.

However, cryopreservation of oocytes, ovarian tissue and embryos is not currently publicly funded for women who become menopausal as a result of chemotherapy treatment.

We believe women should have choices about their future fertility options and that women who have been treated for breast cancer should have access to publicly funded fertility treatment, just as other women who have been identified as infertile do.

We would like to see New Zealand women affected by breast cancer receive a funded first assessment with a fertility specialist to discuss their options. Where the woman is medically fit, has sufficient time and is informed of the potential risks of hormonal treatment, she should be offered a publicly funded cycle of oocyte or embryo cryopreservation.

We estimate that around half of the 150 women aged 40 or less diagnosed with breast cancer each year would wish to access a specialist assessment and approximately half of these women may wish to undergo either oocyte or embryo cryopreservation. The cost of subsidising this service for around 75 women a year at a cost of \$7,500 per treatment would be approximately \$550,000. We believe this spending would be well received by the general public and would make a dramatic difference for young women with breast cancer for whom the prospect of losing their fertility can be extremely distressing.

We are aware that the current providers of fertility treatments in New Zealand have the capacity and the willingness to provide a comprehensive fertility preservation service. The National Child Cancer Network has recently established a Fertility Preservation Working Group. This group is currently working on nationally agreed guidelines for fertility preservation that will include recommendations for adult cancer patients.

Action Points:

- Provide funding for women with breast cancer under the age of 40 to have an initial assessment with a fertility specialist to discuss treatment options.
- Publicly fund oocyte, ovarian tissue and embryo cryopreservation treatment for women under the age of 40 with breast cancer.